

Health Informatics

J.A. Magnuson  
Paul C. Fu, Jr. *Editors*

# Public Health Informatics and Information Systems

*2nd Edition*

 Springer

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Editors

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# Foreword

As a medical student in the early 1980s, I was rather scandalized to discover that my required textbook of medicine did not provide standard treatment protocols for even the most common of medical conditions. What good is a textbook, I asked myself, if it does not provide even this most basic treatment information? The textbook in question was the (then) current edition of the *Principles and Practices of Medicine*, originally published by William Osler in 1892 and continually updated by Johns Hopkins University School of Medicine faculty in many editions to this day. In succeeding years, of course, I came to realize that field-encompassing textbooks cannot and should not be concerned with the specific treatments and protocols of the day, but rather – as Osler understood – the principles and practices that perennially define the field from generation to generation. This is similarly the essence and focus of this, the second edition of this public health informatics textbook: the principles and practices that define and shape this growing and exciting discipline.

Having said that, there is a reason why Osler’s venerable textbook has been updated through dozens of editions and an ever-changing cast of editors: the challenges and context for a discipline, whether medicine or public health informatics, are ever-changing, and textbooks that seek to guide, inform, and inspire new students of a given discipline must change likewise.

The first edition of *Public Health Informatics and Information Systems* [1] was begun as a straightforward compendium of key public health–relevant information systems: mortality and natality data systems, survey-based systems (like the Behavioral Risk Factor Surveillance System), and so forth. But the editors quickly came to feel that a more comprehensive focus on *informatics* was needed, for two primary reasons: (1) the burgeoning information age presented the field of public health with extraordinary and unprecedented opportunities to improve its efficiency and effectiveness, and even to revolutionize the ways in which public health itself was practiced; and (2) an absence of familiarity with the basic tenets of informatics had led, and would inevitably lead in the future, to costly (and sadly predictable) failures to develop effective, integrated, and sustainable new information system applications for public health.

With this in mind, the project evolved into what would become the first American public health informatics textbook, and its first edition was expanded to include a broad presentation of the principals and practices, as well as the context and basic science, of

public health informatics. To be sure, the major information systems in general use by public health professionals were described and explained. But two concluding parts of the book were included, to describe then-emerging information systems and challenges; and to illustrate through a diverse series of case studies the kinds of value that were being accrued through public health information system development, as well as the special challenges that the development of these systems often entailed. Through these case studies, undergirded by the material that preceded them, the essential principles and practices of public health informatics were illustrated in real-world terms.

This second edition, developed by JA Magnuson and Paul Fu, Jr., continues this focus and tradition. The basic sections of the original textbook have been preserved, providing the student with the context and science of public health informatics; descriptions of key public health information systems; overviews of new challenges and emerging systems; and a series of illustrative case studies. The material in every section has been enormously updated, however, to reflect astonishingly rapid advances in information technology as well as profound changes in the societal and legislative context for both healthcare and public health.

By way of illustration, consider that when the first edition was published in 2003, social media and social networking applications were essentially unknown. Facebook<sup>®</sup>, for example, was not launched until 2004. Yet as of September 2012, Facebook<sup>®</sup> had over one billion active users—roughly one-seventh of the entire global population (and a much higher proportion in developed countries). Consider also that the US Patient Protection and Affordable Care Act was only signed into law in March 2010 (roughly 3 years ago at this writing), and will not take full effect until 2014. Yet this game-changing legislation is already altering the landscape for healthcare in ways that powerfully promote truly health-oriented (as opposed to procedure-oriented) healthcare. By highlighting the importance of prevention—in financial as well as ethical terms—the Act also promotes closer connections and collaboration between the healthcare and public health sectors.

These and many other rapid technological and societal developments present today's informatics professionals with enormous, unprecedented opportunities to apply information science and technology in innovative ways to promote the public's health. There has never been a better time to exert passionate and creative leadership to improve existing systems of prevention and public health, and to invent new and yet-undreamt-of approaches to promote human health and well-being.

With that, let me invite the student of public health informatics to take full advantage of the information and guidance in this textbook to ignite your passion and develop your creative informatics leadership; and let me congratulate the editors on this much-improved second edition.

Seattle, WA, USA

Patrick W. O'Carroll, MD, MPH, FACPM, FACMI

## Reference

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# Preface

When the first edition of *Public Health Informatics and Information Systems* was published in 2002, Public Health Informatics was a relatively young field. That first edition was invaluable in helping to establish the field of study and provide structure for the emerging discipline. A decade later, great progress has been made, but Public Health Informatics is still an emerging field that needs continued focus in order to grow into its full potential.

This edition builds upon the foundation established by the first edition. We have expanded into new areas that have become important due to changing technologies and needs, as well as updating and augmenting many of the original core tenets. The breadth of material included in this work makes it suitable for both undergraduate and graduate coursework in Public Health Informatics, enabling instructors to select chapters that best fit their students' needs.

## Structure and Objective of This Book

The template for the chapters in this book contains learning objectives, an abstract or overview, the chapter content, review questions, and references. The book itself is organized into five parts:

- Part I. *Context for Public Health Informatics* provides a background for the textbook. This part begins with an introduction to the subject of Public Health Informatics and a review of the history and significance of information systems and public health. The context of biomedical informatics is discussed and the governmental and legislative context of informatics is reviewed.
- Part II. *The Science of Public Health Informatics* reviews the technology and science behind the field of informatics. Informatics infrastructure and information architecture are discussed. This part examines data sources and tools, and the critical issue of information standards. The topics of privacy, confidentiality, security, and ethics are explored. Electronic health records are examined, as well as project management and system evaluation.



- Part III. *Key Public Health Information Systems* are studied in this part. The areas of disease prevention and epidemiology, and environmental health, are reviewed. Specific systems and instances for public health laboratories, risk factor information systems, the National Vital Statistics System, and immunization information systems are discussed.
- Part IV. *New Challenges and Emerging Solutions* addresses some of the newest challenges facing Public Health Informatics, as well as emerging solutions. Included are new means of data collection and accessibility, geographic information systems, health information exchange, decision support and expert systems, delivery of preventive medicine, and case-based learning.
- Part V. *Case Studies: Information Systems and the Strata of Public Health* highlights informatics case studies from the different strata of public health. The case studies begin with local and regional public health, progressing to state examples for both high population and low population states. Then, national perspectives are represented by examples from the USA, Canada, and a collaborative chapter illustrating informatics experiences in Malawi and Rwanda.

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# Acknowledgements

This book reflects the hard work and dedication of many people.

As editors, we want to acknowledge the contributions of our chapter authors, who generously managed to find the time to share their wealth of knowledge and experience. Their contribution was absolutely critical to this effort, and we are grateful that so many leaders in the field of Public Health Informatics were willing to participate in this project.

We are also grateful to the editors of the previous edition, whose hard work and inspiration pioneered a path for Public Health Informatics. The enthusiasm and encouragement given to us by that edition's senior editor, Patrick O'Carroll, is especially appreciated.

Finally, we would like to acknowledge the skill and support of our editor at Springer, Grant Weston, and our developmental editor Connie Walsh. Their encouragement, guidance, and skills were invaluable.

J.A. Magnuson, PhD  
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**Part I**  
**Context for Public Health Informatics**

# Chapter 1

## Introduction to Public Health Informatics

J.A. Magnuson and Patrick W. O'Carroll

**Abstract** The transformation of public health by informatics is still in the nascent stages. Thus far, informatics in public health generally has been relegated to “pushing the broom” at the end of the parade: public health has tended to bring in informaticists to help resolve systemic issues such as non-interoperability, rather than realizing the full potential benefits that would accrue from their involvement at the outset.

To facilitate the understanding of Public Health Informatics, this chapter includes a brief review of public health, discussing the purpose, history, structural organization, and challenges of public health. Once the context of public health has been reviewed, the principles of Public Health Informatics are described, including some history and background, and the challenges encountered, as well as the drivers for change.

Although the discipline of public health informatics has much in common with other informatics specialty areas, it differs from them in several ways. These include (a) a focus on applications of information science and technology that promote the health of populations, rather than of individuals, (b) a focus on disease prevention, rather than treatment, (c) a focus on preventive intervention at all vulnerable points in the causal chains leading to disease, injury, or disability, and (d) operation within a governmental, rather than a private, context.

Drivers of change forcing public health professionals to be conversant with the development, use, and strategic importance of computerized health information

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systems include health reform, advances in information technology, the advent of Big Data, and continuation of disruptive innovation.

**Keywords** Big Data • Disruptive innovation • Electronic Health Record • Gene patenting • Healthy People • Informatician • Informaticist • Informatik • Informatique • Infrastructure • Meaningful use • Mobile technology • Open access • Personal health record • Personalized medicine • Prevalence • Preventability • Severity • Software as a Service • SaaS • Telehealth • Value • Variety • Velocity • Volume

### Learning Objectives

1. Define the concept of public health informatics and explain the aspects that it has in common with medical informatics.
2. Understand the four principles that define, guide, and provide the context for the types of activities and challenges that comprise public health informatics and differentiate it from medical informatics.
3. Describe the history, organization, purpose, and challenges of public health in the US.
4. Explain how the four main drivers of change are affecting the future of public health informatics.
5. Discuss the major developments that have increased the importance and immediate relevance of informatics to public health.

## Introducing Public Health Informatics

Karl Steinbuch (1917–2005) is often credited with creating the term *informatik* [1], for automatic information processing, a term which came to denote computer science in German. In 1962, Philippe Dreyfus [2] devised the French term *informatique*, and in 1966 Alexander Mikhailov et al. [3] promoted the Russian term *informatika* for the theory of scientific information. In the US, a public health *informaticist* or *informatician* (both are correct) is a professional in the “systematic application of information and computer science and technology to public health practice, research, and learning” [4], illustrating the relation but clear distinction between computer science and informatics in this usage.

The scope of public health informatics includes the conceptualization, design, development, deployment, refinement, maintenance, and evaluation of communication, surveillance, information, and learning systems relevant to public health. Public health informatics requires the application of knowledge from numerous disciplines, particularly information science, computer science, management, organizational theory, psychology, communications, political science, and law. Its practice must also incorporate knowledge from the other fields that contribute to public health, including epidemiology, microbiology, toxicology, and statistics.

Although public health informatics draws from multiple scientific and practical domains, computer science and informatics science are its primary underlying disciplines. Computer science, the theory and application of automatic data processing machines, includes hardware and software design, algorithm development, computational complexity, networking and telecommunications, pattern recognition, and artificial intelligence. Informatics science encompasses the analysis of the structure, properties, and organization of information, information storage and retrieval, information system and database architecture and design, library science, project management, and organizational issues such as change management and business process reengineering.

An important distinction between medical and public health informatics is illuminated by the difference between medicine and public health. Public health is concerned with the health of populations, whereas clinical medicine involves the health of the individual. The World Health Organization perspective of health as a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [5] can be extrapolated to population health as well. Public health includes not only the often-spotlighted communicable disease programs, but also chronic disease control, health and wellness promotion, environmental health, mental health, and other program areas.

Public health informatics differs from other informatics specialties in that it involves:

1. A focus on applications of information science and technology that promote the health of populations, rather than of individuals;
2. A focus on disease prevention, rather than treatment;
3. A focus on preventive intervention at all vulnerable points in the causal chains leading to disease, injury, or disability; and
4. Operation typically within a governmental, rather than a private, context.

## **Principles of Public Health**

In order to understand public health informatics, it is necessary to have a good introduction to public health. As referenced earlier in this chapter, public health is concerned with the health of populations. The key characteristics of public health as contrasted with medicine are presented in Table 1.1.

### ***History of Public Health***

Data forms the foundation of public health, and has very early roots in that area. Some of the earliest known examples of public health data involve the pneumonic plague surveillance conducted by the Venetian Republic in the fourteenth century, and the recording of vital events in the sixteenth century in the London Bills of

**Table 1.1** Some critical differences between public health and medicine

Attribute	Medicine	Public health
Source	Clinicians, health practitioners	Agencies and organizations
Primary focus	Persons with disease, injuries, other health problems	Populations (in communities, states, the nation)
Primary strategy	Treatment of persons with disease, injury, or disability; secondary emphasis on prevention	Prevention of disease, injury, and disability
Timing of action	Usually taken after illness/injury occurs	Both before illness/injury (e.g., prevention) and after (e.g., surveillance)
Intervention context	Clinical and surgical encounters and treatment	Any vulnerable points in the causal chain. Modes include education, policy, research, monitoring, assurance
Operational context	Private practices, clinics, hospitals	Governmental context, requiring responsiveness to legislative, regulatory, policy directives, and political context

Mortality [6]. As time passed, these rich sources of data came to be increasingly analyzed and studied for public health reasons. In the US, Massachusetts developed a postcard-based reporting system in 1874, which marks the beginning of US infectious disease reporting [7].

The Communicable Disease Center, precursor of the Centers for Disease Control and Prevention (CDC), was established in 1946 [8]. The new center was an extension of the wartime agency MCWA (Malaria Control in War Areas), developed to combat malaria through mosquito control. From those DDT-drenched roots grew today's CDC, with its emphases on working with states and other partners to monitor and prevent outbreaks; maintain national health statistics; and, as included in its very name (Disease Control and Prevention), to prevent and control infectious and chronic diseases, injuries, and environmental health hazards.

### ***Public Health Strata in the United States***

Public health in the US is a composite of agencies/responsibilities. Although some regions differ in their public health composition or have entirely different structures such as tribal health agencies, in *general*, public health agencies in the US are arranged into three strata – federal, state, and local.

- Federal level – There are numerous so-called “operating divisions” within the US Department of Health and Human Services (HHS) that comprise the federal public health family: CDC, US Food and Drug Administration (FDA), National Institutes of Health (NIH), Indian Health Service (IHS), Substance Abuse and Mental Health Services Administration (SAMHSA), and Health Resources and Services Administration (HRSA) foremost among them. However, as regards the day-to-day practice of public health, the CDC [9] may be considered HHS's



primary federal public health agency. It has many important responsibilities, including but not limited to:

- Development and dissemination of prevention guidelines and policies.
  - Distribution of federal funds to states (and, to a lesser degree, directly to local health departments) for specific public health programs (e.g., immunization, HIV-AIDS, preparedness). Many state initiatives and program areas rely almost exclusively on federal funding.
  - Collaboration, representation, and leadership in the public health arena
  - Assistance to other public health organizations, at their request. In 2011, for example, CDC sent Epi-Aid assistance (Epi-Aids are requests to the CDC for epidemiological assistance) to US states (Wisconsin, Arkansas, Louisiana, and Georgia), and Ethiopia [10].
- State and Territory level – State health departments coordinate public health at the state level. Responsibilities include:
    - Assisting local health departments (LHDs) with investigations such as outbreak investigations
    - Coordinating statewide initiatives and programs, such as statewide electronic laboratory reporting, vital statistics, immunization registries, etc.
    - Setting state policy and legislation, such as state notifiable conditions. The Council of State and Territorial Epidemiologists (CSTE) maintains a State Reportable Conditions Assessment (SRCA) that represents an annual assessment of reporting requirements by state and territory [11].
    - Distributing funds (often federal funds) to LHDs.
  - Local level – The local level includes county health departments, metropolitan area health organizations, tribal public health, and regional collaboration organizations.
    - LHDs often have the primary responsibility for investigating cases and outbreaks.
    - Not all states have LHDs; some may perform all investigations at a state level.
    - Many large metropolitan areas have health organizations that function at the level of an LHD. For example, the New York City Department of Health and Mental Hygiene gathers data and provides information on residents of New York City [12].
    - The National Indian Health Board (NIHB) works with a variety of partners, including the Indian Health Service (IHS) and CDC, on public health projects such as the recent Traditional Foods Project and the Methamphetamine and Suicide Prevention Initiative (MSPI) [13].
    - Regional public health initiatives may adhere to the ten HHS-designated regions of the US [14] or may constitute a response to local needs, such as Alaska's public health centers [15].

In addition to governmental structure, public health is arranged into program areas based on activity and purpose. The Public Health Accreditation Board (PHAB) offers public health department accreditation options to tribal, state, local, and

territorial public health departments in the US. The core public health programs and activities covered under PHAB [16] include:

- Access to clinical services
- Chronic disease prevention and control
- Communicable disease
- Community health
- Environmental public health
- Governance
- Health education
- Health promotion
- Injury prevention
- Management/administration of public health programs and activities
- Maternal and child health
- Public health emergency preparedness
- Public health laboratory services

The CDC is arranged into centers, institutes, and offices that reflect focus on different public health concerns [17]. These include such examples as the Office of Infectious Diseases, National Institute for Occupational Safety and Health (NIOSH), National Center for Environmental Health/Agency for Toxic Substances and Disease Registry, and Office of Surveillance, Epidemiology, and Laboratory Services.

### ***The Purpose of Public Health***

The Institute of Medicine's 1988 report on public specifies that the "core functions of public health agencies at all levels of government are assessment, policy development, and assurance" [18]. The CDC National Public Health Performance Standards Program (NPHPSP) determined ten Essential Public Health Services [19] essential to all communities, listed as:

1. Monitor health status to identify and solve community health problems.
2. Diagnose and investigate health problems and health hazards in the community.
3. Inform, educate, and empower people about health issues.
4. Mobilize community partnerships and action to identify and solve health problems.
5. Develop policies and plans that support individual and community health efforts.
6. Enforce laws and regulations that protect health and ensure safety.
7. Link people to needed personal health services and assure the provision of healthcare when otherwise unavailable.
8. Assure competent public and personal healthcare workforce.
9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
10. Research for new insights and innovative solutions to health problems.

These ten essential services of public health harmonize well with the IOM's three core functions (assessment, policy development, and assurance), and all are improved by the application of informatics. Assessment includes collection and analysis of health data, as well as the critical step of distribution of information gained to the community: informatics can advance the accuracy and security of health data collection, and increase the value of knowledge distribution. In addition, informatics-enhanced data improves the efficacy of both policy development and assurance, including enactment of regulations or provision of services.

Public Health has achieved tremendous accomplishments in the twentieth century. From the *Morbidity and Mortality Weekly Report* (MMWR) list of ten highly-significant public health achievements in the US, it is easy to see that the principles of PHI must have been involved [20]. The unordered list below includes some selected highlights of those achievements:

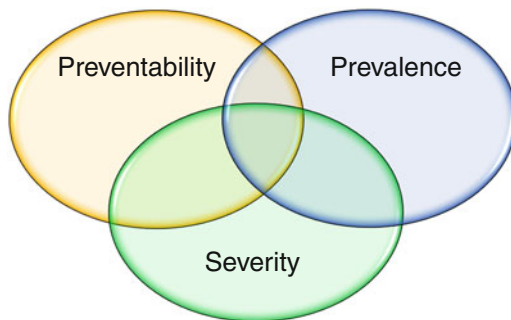
- *Vaccination* – worldwide eradication of smallpox, and elimination of poliomyelitis in the US
- *Motor-vehicle safety* – such as seat belt implementation, reduction in drunk driving
- *Safer workplaces* – reduction in occupational injuries and unsafe working conditions
- *Control of infectious diseases* – improved sanitation, improved therapies
- *Decrease in coronary heart disease/stroke deaths* – smoking cessation programs, improved treatment and detection
- *Safer and healthier foods* – food fortification, reduction in contamination
- *Healthier mothers and babies* – improvements in nutrition and healthcare access
- *Family planning* – contraception, STD prevention, and treatment
- *Fluoridation of drinking water* – reduced tooth decay
- *Recognition of tobacco as health hazard* – antismoking campaigns

Public health has significantly increased life expectancy. Since 1900, the average life expectancy in the US has increased 30 years, and a startling 25 of those years are attributed to public health initiatives. In the twentieth century alone, smallpox killed around 300 million people [21]. In 1977, a dedicated public health initiative brought about worldwide eradication of this disease [22]. And in the 1970s, a huge majority (88 %) of US children had elevated levels of blood lead, but by 1994, public health had reduced that percentage to only 4.4 % [23].

### ***Public Health's Unique Challenges and the Promise of Public Health Informatics***

Public health usually operates in a resource-scarce environment, dependent upon inconstant but always inadequate public funding. Additionally, the public health workforce is impacted by detrimental factors including: between 1980 and 2000, the number of public health workers per 100,000 Americans declined from 220 to

**Fig. 1.1** Diagram illustrating the intersection of qualifying conditions for a public health response



158; around half of the public health workforce is nearing retirement age; and four out of five public health employees lack formal public health training [24]. Given these and other challenges, public health must be cautious about committing resources to a program. In order for a condition to realistically be of interest to public health, it usually needs to match some degree of each of the following criteria: *severity* – the condition/disease must be severe enough in its effects to warrant some type of intervention/monitoring; *preventability* – the condition must be preventable or at least able to be mitigated by health interventions, behavioral modifications, etc.; and *prevalence* – the condition must be prevalent enough in the population to warrant some type of intervention/monitoring (Fig. 1.1). In this environment of scarcity, public health is beginning to realize the benefits that can accrue from application of informatics.

## Principles of Public Health Informatics

### *History and Background*

Public health informatics is related to medical informatics in several respects [25]. Both disciplines seek to use information science and technology to improve human health, and there are subject matter areas of common concern (e.g., standards for vocabulary and information exchange). Moreover, lessons learned in medical informatics often apply to public health informatics. Further, there are informatics applications for which there is no real distinction between public health and medical informatics. Examples of such applications include systems for accessing public health data from electronic medical record systems or for providing patient-specific prevention guidance at the clinical encounter.

Nevertheless, we believe that public health informatics is a distinct specialty area within the broader discipline of informatics, a specialty area defined by a specific set of principles and challenges.

Our view is that the various informatics specialty areas – for instance, nursing informatics and medical informatics – are distinguished from one another by

the principles underlying their respective application domains (i.e., nursing and medicine), as well as by the differing nature and challenges of their informatics applications. In the case of public health informatics, there are four such principles, flowing directly from the scope and nature of public health, that distinguish it from other informatics specialty areas. These four principles define, guide, and provide the context for the types of activities and challenges that comprise this field:

1. The focus of public health informatics is on applications of information science and technology that promote the health of populations as opposed to the health of specific individuals.
2. Another focus of public health informatics is on applications of informatics science and technology that prevent disease and injury by altering the conditions or the environment that put populations of individuals at risk. Although notable exceptions exist, traditional healthcare largely treats individuals who already have a disease or high-risk condition, whereas public health practice seeks to avoid the conditions that led to the disease in the first place. This difference in focus has direct implications for the ways in which informatics technology might be deployed.
3. Public health informatics applications explore the potential for prevention at all vulnerable points in the causal chains leading to disease, injury, or disability; applications are not restricted to particular social, behavioral, or environmental contexts. In public health, the nature of a given preventive intervention is not predetermined by professional discipline, but rather by the effectiveness, expediency, cost, and social acceptability of intervening at various potentially vulnerable points in a causal chain. Public health interventions have included, for example, legislatively mandated housing and building codes, solid waste disposal and wastewater treatment systems, smoke alarms, fluoridation of municipal water supplies, redesign of automobiles, development of inspection systems to ensure food safety, and removal of lead from gasoline. Contrast this approach with the approach of the modern healthcare system, which generally accomplishes its mission through direct patient care services such as clinical and surgical encounters. Although some of these healthcare system encounters can properly be considered public health measures (e.g., vaccination), public health action is not limited to the clinical encounter.
4. As a discipline, public health informatics reflects the governmental context in which public health is practiced. Much of public health operates through government agencies that require direct responsiveness to legislative, regulatory, and policy directives; careful balancing of competing priorities; and open disclosure of all activities. In addition, some public health actions involve authority to take specific (sometimes coercive) measures to protect the community in an emergency. Examples include medication or food recalls, closing down a restaurant or a contaminated pool or lake, and making changes to immunization policy.

## ***Challenges of Public Health Informatics***

In addition to these principles, the nature of public health also defines a special set of informatics challenges. For example, in order for public health practitioners to assess a population's health and risk status, they must obtain data from multiple disparate sources, such as hospitals, social service agencies, police departments, departments of labor and industry, population surveys, on-site inspections, etc. Data from these various sources about particular individuals must be accurately combined. Then, individual-level data must be compiled into usable, aggregate form at the population level. This information must be presented in clear and compelling ways to legislators and other policymakers, scientists, advocacy groups, and the general public. At the same time, the public health practitioner must insure that the confidentiality of the health information about specific individuals is not compromised.

Together with the four principles that distinguish public health informatics from other informatics specialty areas, then, these and other special challenges define public health informatics as a distinct specialty area.

## **Change Is a Constant: The Future of Public Health Informatics**

There are many drivers mediating the rapid advances and changes in Public Health Informatics. The escalating power and speed of these factors make it increasingly critical that public health professionals be conversant with the development, use, and strategic importance of computerized health information systems and resources. Some of these drivers are discussed briefly in this chapter; many will be covered in detail in the following chapters.

### ***Driver for Change: Health Reform***

Both clinical care and public health are undergoing massive changes. The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 was enacted as part of the American Recovery and Reinvestment Act (ARRA) to foster the adoption and meaningful use of health information technology. In 2010, the Patient Protection and Affordable Care Act (PPACA, or commonly, ACA) was signed; it seeks to change the very nature of clinical practice, in part by changing financial incentives that promote health and wellness versus pay-for-procedure reimbursement. In this new context, healthcare entities can potentially increase reimbursement by keeping their patients healthier – potentiating a new focus on prevention and new partnerships with public health agencies.

Public health is (still) eagerly anticipating the bonanza of information it expects to accrue from the HITECH Act [26]. *Electronic Health Records (EHRs)* have traditionally elicited an almost Pavlovian response from public health workers as they anticipate a cornucopia of surveillance and research data, but in truth, public health is only just starting to realize the full extent of the confidentiality and data access problems involved.

The HITECH Act incentivizes adoption of EHR technology by offering Medicare and Medicaid payment to healthcare providers and hospitals that use certified EHR systems to achieve *meaningful use*, a set of standards specified by the Centers for Medicare & Medicaid Services (CMS) [27]. And the incentives are at an unprecedented level – a total of US\$27 billion over 10 years, on a per clinician basis of up to US\$44,000 (Medicare) and US\$63,750 (Medicaid) per clinician. Now at the beginning of 2013, US Healthcare IT News reports that “Medicare and Medicaid electronic health record payments are estimated to have blasted through [US]\$10.3 billion to a total of 180,200 physicians and hospitals through December [2012] since the program’s inception” [28].

Meaningful Use is planned to develop in three stages, as described on the HealthIT.gov site referenced above:

- Stage 1, 2011–2012: Data capture and sharing. This stage concentrates on capturing data electronically and in standardized format and reporting clinical quality measures and public health information.
- Stage 2, 2014: Advance clinical processes. This stage emphasizes increased health information exchange (HIE) and e-prescribing, and incorporation of laboratory results.
- Stage 3, 2016: Improved outcomes. This stage is planned to lead to better outcomes through elevated quality, safety, and efficiency, and to improved population health.

EHRs are expected or hoped to produce three general benefits for patients, and to a lesser degree, to public health. First, more complete and accurate information should lead to better patient care. Second, providers will have better access to information. Third, patients will be empowered by increased access to their medical information, including the ability to download and share (if desired) their medical records.

Realizing the benefits of EHRs is not an easy task. Many of the factors needed for effectiveness of an EHR system, such as acceptance by partners (including the public), interoperability, implementation of coding systems and standard formats, and utilization of a unique health identifier (UHI), are also *barriers* to implementation.

### ***Driver for Change: Advances in Information Technology***

The information technology revolution continues unabated. Today’s computer systems are both faster and less expensive than ever before, and prices are continuing

to decrease rapidly. In fact, computer hardware is no longer the major cost it once was in information system development projects.

More important, the Internet has emerged as both a universal communications medium and the source of a universal graphical user interface – the World Wide Web, accessed with Internet browser software. In fact, the growth in use of the Internet has been little short of phenomenal in recent years.

The broad deployment of the Web has provided a powerful paradigm for standardized implementation of the communication capabilities that are central to all information systems. A Web browser interface allows broad access without the necessity for development or deployment of specific software or communications protocols for potential users. Updating information systems is greatly simplified, since new versions of Web-based applications are immediately available to users without distribution of new end-user-installed software. Most system development has utilized this paradigm, with the resultant creation of many new and powerful tools to streamline and simplify the process. Consequently, information system development is now faster and easier than ever before, with collaborative development, interactive Web experiences, and explosive growth of social media continuing to unlock new opportunities. In this environment, the benefits of public health information systems are more obvious and more easily achievable, and thus much more compelling.

However, along with advances in capabilities come parallel advances in system hacking, identity theft, and other malicious intent. The goals of privacy, confidentiality, and security have never before been so challenging or so critical. While public health is accustomed to handling sensitive data, handling those data in electronic form introduces new and continually evolving spheres of ethical and security concerns.

### ***Driver for Change: Big Data***

Advances in medicine and public health, such as the explosion of genomic data and the implementation of EHR systems, are rapidly bringing attention to the topic of *Big Data* in health fields. As noted by IBM recently, “Every day, we create 2.5 quintillion bytes of data – so much that 90 % of the data in the world today has been created in the last 2 years alone” [29].

Health data is rapidly exceeding conventional database capacities. The overwhelming volume of data and its rapid accumulation are further complicated by the inherent variability of the data; health data can be structured, such as data from monitoring equipment and laboratory results, or unstructured, such as medical transcription and imaging. The traditional Three V's of Big Data – volume, velocity, and variety – can and should be supplemented by a fourth V, *value* [30]. This applies to any kind of data, and especially to public health data – the resources invested in accumulating and analyzing data must be offset by the value to the population. The ultimate goals for all health data sources and



tools, both public and private, should be to improve cost, increase efficiency, and improve health.

### ***Driver: Disruptive Innovation***

Disruptive innovation, which creates new markets/fields and displaces existing technologies, has become the norm for technological advances. For example, today's (2013) smart phones have more computing power than was used for the NASA moon landing in 1969 [31].

Public Health Informatics, undergirded as it is by information technology, will experience the same disruptive changes. Ten years into the future, today's public health informatics students will be working at jobs that are not even visualized yet. Therefore, it is absolutely critical that public health today embrace rather than resist (futilely) the turbulence of disruptive innovation.

Many of the disruptive innovations taking place in healthcare also will affect public health. A few examples of these innovations include:

- *Mobile technology*: increasingly utilized by private health clinicians for purposes such as data access and entry during hospital rounds, mobile technology can similarly be used by public health professionals in clinics or for surveillance and tracking purposes, such as mapping wells or disease outbreaks using GPS.
- *Telehealth*: both public and private health consultation and diagnostic services can be provided to remote districts using telecommunication technologies or *telehealth*.
- *Personalized medicine*: private health can provide treatment that is customized or tailored to an individual being, based on detailed knowledge gained from specialized testing such as genetic screening. Genetic data are just beginning to be used by public health, usually for purposes such as HIV genotype research and tracking, but these usages are destined to expand greatly as genetic screening technologies simultaneously expand in value and decrease in price.
- *Personal health record (PHR)*: a PHR is maintained by the patient, as opposed to an electronic health record (EHR) that is maintained by an institution. Public health should work to develop ways to add value to PHRs, in order to increase engagement with the public and foster prevention of adverse health conditions.
- *Open Access (OA)*: OA publishing offers the potential to enable greater access to research articles, which would benefit both private and public health researchers.
- *Gene patenting*: fully as controversial as the patenting of genetically modified organisms, gene patenting is (currently) allowed in the US. Although gene patents do not apply to naturally-occurring genes, the repercussions and legal issues are guaranteed to affect medical research and testing, making them important to both private and public health.
- *Software as a Service (SaaS)*: software delivery over a network, rather than through individually purchased installations, has the potential to greatly reduce IT support costs for both private and public health.

## Conclusion

Informatics has become something of a buzzword, which has the potential damage of diluting the power of the field. When a popular term is co-opted, there is a danger of devaluation. Currently, examples of this incorrect usage include IT professionals and web designers often self-identifying as informaticists. While many of the skills held by these professions can and indeed should be part of an informaticist's toolbox, the possession of those skills does not automatically bestow the title of informaticist.

In the context of the challenges discussed in this chapter, familiarity with at least the basic principles and practices of informatics is becoming essential. This may not be a welcome development for many public health practitioners, who already must be conversant with such wide-ranging fields as epidemiology and statistics, risk communication, community organization, legislative development, behavioral modification, emergency response, and of course program management. Nevertheless, facility in at least the use of key information technologies for public health (e.g., the Web, social media tools, web conferencing, secure communications, and epidemiologic databases) is already a requirement for state-of-the-art public health practice. And more advanced informatics expertise is undeniably critical for the development of future information systems such as immunization registries, improved disease and epidemic surveillance, and so forth. Like it or not, informatics has already joined the long list of disciplines with which public health practitioners must be conversant.

Public health informatics has often found itself in the position of "pushing the broom" at the end of the parade, being brought in to solve problems such as non-interoperability or poor data quality. But as informatics continues to grow as a field, public health will begin to realize the full potential benefits of public health informatics when it becomes routine to involve informaticists at the outset or ground level of project planning and system improvement.

### Review Questions

1. What are the main differences between public health informatics and other informatics fields?
2. Discuss the history of public health in the US. What do you think has been the most important factor in developing today's public health infrastructure?
3. Of the top achievements of public health in the US, which do you think is most closely dependent upon informatics, and why?
4. Compare and contrast the functions performed by public health professionals and practitioners of traditional healthcare. How do they differ in their approach to (1) the individual, and (2) the community? To what parties are these two categories of professionals accountable for their actions, and how?
5. Discuss the drivers of change in public health informatics. Which do you think will have the greatest impact, and why?

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# Chapter 2

## History and Significance of Information Systems and Public Health

John R. Lumpkin and J.A. Magnuson

**Abstract** From the earliest development of counting and counting machines to today's sophisticated public health systems, a fundamental problem of public health practice has been the development of systems that can collect and analyze data, then convert it to useful forms. The development of modern mechanical measuring devices was a quantum leap toward solving the problem, but even after the invention of the computer in the twentieth century, there was a continuing need for systems that would maximize integration of system components and minimize duplication of data entry. A review of the three waves of modern federal-state public health system development reveals the progression toward the optimization goal. In general, today's systems to manage public health data and information have evolved in step with the scientific basis underlying public health practice, a practice that integrates findings in the biomedical field with the sciences of epidemiology and biostatistics.

**Keywords** Data • Information • Knowledge • Age of observation • Age of analysis • Software reuse • Public health data collection • Federal-state system development • Public health information system development

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### **Learning Objectives**

1. Clearly differentiate among the terms data, information, and knowledge, and provide an example of each.
2. Briefly trace the evolution of information systems, from the development of counting and counting machines to the development of computers.
3. Explain and distinguish between the three stages in development of public health information management systems.
4. List and discuss the nineteenth century developments in Europe and the United States that contributed to the development of modern public health data collection and analysis.
5. List and describe the characteristics of the three waves of federal-state public health information system development.

## **Introduction**

Today's systems to manage public health data and information have evolved in step with the evolution of the scientific basis underlying public health practice. Public health practice now integrates findings in the biomedical field with the sciences of epidemiology and biostatistics. As the need for knowledge integration has become more complex, so has the nature of the information systems necessary for acquisition and understanding of larger amounts of data, along with the analytical systems necessary for processing those data. Technological advances have allowed the automation of the systems that are now required for the practice of public health.

In this chapter, we will trace the history and evolution of the science of public health informatics. We will begin by tracing the development of counting and counting machines in the human experience. In a brief examination of public health information management in the pre-computer era, we will discuss the developments that created the need for increasingly complex data collection and analysis systems. The chapter concludes with a review of the three waves of federal-state public health systems development, beginning with the first wave in the late 1960s and closing with an examination of the third wave now underway.

## **Data, Information, and Knowledge**

The terms data, information, and knowledge are often misused in discussions of public health informatics. This misuse can lead to confusion, so our first task is to define these terms in the context of public health informatics. The term *data* is used to designate a measurement or characteristic of the entities (such as persons, things, measurements) that are the focus of a public health information system. The term

‘data’ can be used as a singular noun (as for an abstract mass, such as “public health data is complex”) or as a plural noun (as in, “these data are lacking standards”), and both usages are correct and standard. This term can encompass clinical measurements, laboratory values, medication dosages, clinical or diagnostic findings, and treatment options, to name only a few examples. In isolation, data have little meaning. Consider, for example, the components of data in a vital records system used as part of a mission to monitor the health status of a nation. Each record in the system includes a notation of the deceased individual’s age, race, and other demographic features. It also typically includes a description of the cause of death by a physician, a medical examiner, or a coroner. All of these data are the raw material of the vital records system. However, without context or analysis, these isolated bits do not convey much meaning.

In contrast, *information* refers to data placed in context with analysis. Extending our previous example of the vital records system, the data element indicating cause of death may lack meaning in isolation. But if a public health official correlates this data element and generates a table categorizing the frequency of numerous causes of death, then context has been applied and this has led to the creation of information. A user of the public health table can identify the leading causes of death, as well as the distribution of those causes in the jurisdiction under study.

Finally, *knowledge* in a public health system is the application of information by the use of rules. In our vital records system example, suppose that one leading cause of death identified in a locality is lead poisoning. In that locality, a toxicologist can review results of blood lead tests administered to the population and compare the outcomes to areas with normal blood lead values. This process in itself yields information. At the same time, the toxicologist has access to action levels developed by experts working with the CDC. These action levels represent rules for action for managing blood lead levels in the affected population. The action levels, then, are an example of knowledge; they prescribe the rules to be used in the application of information. Table 2.1 summarizes the distinction among these three terms.

**Table 2.1** Data information and knowledge

Term	Definition	Example
Data	A measurement or characteristic of the person or the thing that is the focus of an information system	A public health assessor records the levels of thallium at various locations at a toxic waste site.
Information	Data placed in context with analysis	A public health assessor creates a table showing the proportion of the locations exceeding the appropriate maximum contaminant level for thallium at the site.
Knowledge	The application of information by the use of rules	The public health assessor consults the action levels for thallium as published by CDC/ATSDR and determines the appropriate remedial actions to be taken at the contaminated site.

## The Development of Counting and Counting Machines

As the scientist William Thomson, Lord Kelvin, stated in the late 1800s, “When you can measure what you are speaking about and express it in numbers, you know something about it, but when you cannot measure it, when you cannot express it in number, your knowledge is of a meagre and unsatisfactory kind” [1]. Indeed, the history of information systems is in one sense a history of measurement. From the earliest known artifact associated with counting – a fibula of a baboon, with 29 clearly defined notches, dated approximately 35,000 BCE and found in a cave in the Lebombo Mountains in southern Africa [2] – to the present day, information systems have concentrated on measurement. In addition, of course, they now perform sophisticated analytical work on large sets of data.

The earliest counting systems reflect the fact that the human brain has inherent limitations in its ability to comprehend quantity. The eye is not a very precise counting tool, particularly in comprehending quantities above four or five. Societies that entered the twentieth century isolated from the rest of the world rarely had words for numbers greater than four. You can verify the limitations of the eye in counting with a simple experiment: Look at a number of marbles in a bowl very briefly, starting with one or two marbles and then adding a few marbles to the bowl. As you add marbles, try to determine the number without counting. If your visual limits are typical, you will have difficulty in determining the exact number of marbles without counting them once the actual number exceeds four or five.

That limitation of the human brain to readily accommodate larger numbers led to the use of objects to implement one-to-one correspondence in measurement, and to reliance on the property of mapping. We can see this human tendency to grasp the principle of one-to-one correspondence and to utilize the property of mapping in an infant who, at 15 or 16 months, has gone beyond simple observation of the environment. If we give such a child an equal number of dolls and little chairs, the infant will probably try to fit a doll on each seat. This kind of play is nothing other than mapping the elements of one set (dolls) onto the elements of a second set (chairs). But if we set out more dolls than chairs (or more chairs than dolls), after a time the child will begin to fret: it will realize that the mapping is not working [3].

Application of the principle of one-to-one correspondence led early humankind to the use of objects to record the association of one thing to another. We have already mentioned the fibula of the baboon dated to approximately 35,000 BCE; it is marked with 29 clearly defined notches, and it resembles calendar sticks still in use by Bushmen clans in Namibia [4]. In a similar fashion, cave drawings with clear counting marks beneath the depicted animals may have represented an account of success at a hunt. One-to-one correspondence is also demonstrated by the earliest tally sticks used for counting and for accounting, and other historic devices,



including counting pebbles and molded, unbaked clay tokens. Another example is an early form of an abacus used in Sumer (lower Mesopotamia).

It is believed that the earliest counting tool was the human body, and specifically the hand. In fact, the earliest device used for calculation was the fingers of the hand. This counting system would seem to have led to the development of numbering systems with a base of five in many locations throughout the world. Funerary paintings from an Egyptian tomb at Beni Hassan dating from the Middle Kingdom (2,100–1,600 BCE) depict people playing the game of *morra*, a game that uses finger-based calculations to determine the winner [5].

The Egyptians were noted for their early adoption of a written numerical system. A document carved on the Palermo Stone (circa 2,925–2,325 BCE) listed the current census of livestock, as well as a 600-year history of the cycle of flooding of the Nile [6]. The Egyptian civilization was dependent upon the water from the Nile River that fertilized the fields when it flooded once per year. However, if the flooding was too great, the damage to irrigation systems (and homes) would lead to poor crops. The government stored grain to abate any shortfall of grain production. By measuring the height of the flood, they were able to calculate the expected size of the crop and project any shortfalls [7]. The Egyptians of the Middle Kingdom were early users of numbers and counting to do more than just document their environment; they also used counting to predict and plan for the future.

### ***Development of Mechanical Counting Devices***

The success of the abacus, finger-based calculation, and other similar methods predominated until the 1600s CE. These counting methods were used primarily in commerce. It was the measurement of time, of the motion of stars, and of distance that sparked the development of mechanical calculating devices. Egyptians were among the first to use mechanical devices to measure the passage of time. They invented the water clock to mark the hours of the night (early fourteenth century BCE). The water clock used the passage of water from a carefully designed vessel to divide the night into 12 equal hours. This device had adjustments for the seasons, when the length of night and day varied. This water clock is one of the earliest known mechanical calculation devices [8]. In approximately 150 BCE, Hipparchus developed a device, called an astrolabe, to calculate the position of the stars [9]. Other Greek mechanical artifacts from the time indicated the use of gears and wheels to calculate the positions of the planets and stars [8]. In the same period, Roman documents indicated the development of a geared device to measure distance [8]. Such devices were also developed in China in the third century CE. In 723 CE, I-Hsing, a Buddhist monk and mathematician, developed a water-driven mechanical clock [8].

## *The Development of Modern Mechanical Measuring Devices*

Mechanical devices for arithmetic or other mathematical calculations were not developed until 1622 CE, when English mathematician William Oughtred invented the rectilinear logarithmic slide rule. His student Richard Delamain developed the circular slide rule in 1630 CE [10]. These devices used logarithmic theory to approximate complex mathematical calculations. Slide rules were used until the 1970s, when they were replaced by electronic calculators.

The first truly mechanical calculating device was developed in 1623, when German scientist Wilhelm Schickard developed a machine that used sprocket wheels to add numbers. Multiplication and division was possible with the use of logarithm tables [11]. In 1642, Blaise Pascal developed the first adding and subtracting device; it was able to carry or borrow digits from column to column automatically [3, 10]. Over the next 240 years, the fundamental principles developed by Oughtred, Schickard, and Pascal formed the basis of calculation machines (calculators).

Although these calculating machines and their increasingly sophisticated descendants were able to perform basic arithmetic functions accurately, they were unable to perform more sophisticated analytical work on large sets of data. In 1820, British mathematician Charles Babbage began construction of a machine for calculating mathematical tables. He secured aid from the Royal Society and the British government to continue his work, but ran out of funding in 1856 without completing his device [10]. However, many of his concepts have formed the foundation of electronic computers in use today [12].

Early mechanical calculators were effective for accounting purposes in the business setting, but as mentioned, they were less effective when working with large data sets. It was the 1880 United States (US) census that served as a catalyst for the development of the first machine capable of performing analysis of such large data sets. By 1880, the increased population of the US created significant obstacles for the decennial census, and in fact, it took 8 years to complete. Under direction of Dr. John Shaw Billings, from the US Surgeon General's office, Herman Hollerith borrowed technology from Joseph-Marie Jacquard, the developer of the automated loom. Jacquard's loom was controlled by a series of cards with holes punched in them, corresponding to the weave pattern. Hollerith developed a system that read holes punched into a card. Each dollar bill-sized card was able to hold a large amount of data. The card was read in a rapid fashion by a machine designed by Hollerith. The 1890 census was completed in half the time required for the 1880 census, with savings of US\$500,000 (US 1890 dollars) [13]. This innovation was the basis of many electric business and scientific machines, well into the second half of the twentieth century.

The military challenges of World War I led to a greater focus on automated calculation. To hit the faster targets on the mechanized battlefield, gunnery officers had to make quick adjustments for speed of the target, weight of the shell, and wind speed and direction. To assist the gunnery officers, the US Army sought to prepare

firing tables. Those tables allowed the gunnery office to determine quickly the angulation and direction for the guns. However, the time-consuming computations necessary for developing the tables completely overwhelmed the Ballistic Research Laboratory. Through a contract with the University of Pennsylvania, more than 100 students began working on the project, but failed to eliminate the backlog [14].

In response to the need to speed up this process, the Army funded the creation of ENIAC (Electronic Numerical Integrator and Computer). The project was started in 1943 and completed in 1945. When completed, it weighed 30 tons, contained 18,000 vacuum tubes, and was capable of 360 multiplications per second [13, 15]. The ENIAC, along with the Mark I, developed by Howard Aiken, were the first modern programmable computers [11].

Although ENIAC was not the only computer of its time – the British computer Colossus, for example, had been designed to crack Nazi codes – it was the first multipurpose computer. It could be programmed to perform different functions, and it was also fast (at the time). For example, it could add 5,000 numbers or do 14 10-digit multiplications in a second. Although these feats are slow by modern standards, they were incredible for the 1940s. ENIAC was the brainchild of Professor John Mauchly, a physics teacher, and graduate student J. Presper Eckert, both of the University of Pennsylvania. Although the purpose of the design of ENIAC was to assist the army in performing the calculations necessary for gunnery charts, it was completed too late to be of use for that purpose during WWII. In fact, ENIAC began its first task even before it was dedicated in 1945: performing millions of calculations associated with top-secret studies of nuclear chain reactions in connection with the eventual development of the hydrogen bomb.

Later, Dr. John von Neumann, of the Institute for Advanced Study in Princeton, contributed an enhancement to ENIAC. Before his work with ENIAC, reprogramming the computer involved manually rewiring it. Dr. von Neumann suggested that code selection be made with switches, so that cable connections could remain fixed. This innovation saved considerable time in reprogramming ENIAC [15].

## **Stages in Development of Public Health Information Management Systems**

Public health information management systems have their roots in antiquity. The first phase of these systems reflected public health observations according to individual experience (Age of Observation). A second phase reflected a movement beyond observation to analysis of the root causes of public health disturbances (Age of Analysis). Finally, a third phase, leading to the rise of modern public health informatics, featured advanced methods of data collection and analysis in public health practice (Modern Public Health Informatics).<sup>1</sup>

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<sup>1</sup>Melnick D. Building Robust Statistical Systems for Health. Report to the National Committee on Vital and Health Statistics; 1999. Unpublished. Available from author: danmelnick1008@gmail.com.

## *The Age of Observation*

Observations based upon individual experience marked the first phase of data-based public health practice. Observations by the great physicians of their times in China, Egypt, India, Greece, and Rome provided the foundations for preventive and curative practice; the practice of vaccination is known to have existed as early as the first century BCE in China [16]. Of course, one of the most famous pre-computer era public health practitioners was Hippocrates, whose teachings reflect the way early health practitioners used observation to understand the relationship of health to living conditions. The observations of such practitioners led to the development and implementation of public health interventions. For example, the public health importance of sanitation was discovered early in the rise of civilization. Eventually, the age of observation in public health gave way to the age of analysis.

## *The Age of Analysis*

The fall of the Roman Empire, during the late 400s of the Common Era, marked the end of an exchange of scientific learning between the hemispheres. For the next 1,000 years, social and political forces led to the isolation of Europe from many of the cultural and scientific developments in Africa, Asia, and other parts of the world. Many of the writings and knowledge acquired during the Observation Era were lost. However, the Arab cultures of the Mediterranean preserved it to some extent, and reintroduced it to the peoples of Europe during trade and the Moorish occupation. The European rediscovery of the Americas and the subsequent colonization resulted in a Eurocentric New World scientific community. The scientific and health systems that developed in the colonial and nineteenth century US was dependent on the state of the art in Europe.

Certain events occurring during the Age of Analysis had profound implications for public health practice. These events and developments included:

- *Plague epidemics.* The breakout of bubonic plague in Messina, Sicily, in October 1347, with the subsequent spread of the deadly disease to other parts of Europe, resulted in social upheaval.
- *The Renaissance.* A great explosion in knowledge and learning accompanied the Renaissance in Europe. An important resulting enhancement to the evolution of public health practice was the adoption of the scientific method, a systematic approach that laid the foundation for collection and analysis of health-related data.
- *Concept of population health.* General recognition of the importance of a healthy population to the national wealth and power was established. The philosopher William Perry, who invented the term *political arithmetic*, argued that the analysis of data could throw light on matters of national interest and policy. He suggested that the control of communicable disease and the reduction of infant

mortality would contribute the most to preventing impairment of the population. Perry was one of the first to calculate the economic loss caused by disease [17].

- *Concept of Data analysis.* The basic principles for analysis of data and determination of data reliability were established by John Graunt, who in 1662 analyzed over 30 years of vital statistics and social data. Graunt's work demonstrated a method of developing useful information through the careful and logical interpretation of imperfect data.
- *Mortality tables precursor.* Huygens developed a precursor to mortality tables, work that was based on the findings of Graunt and his own earlier work on probability.
- *First mortality tables.* Edmond Haley merged these concepts and developed the first mortality tables to predict life expectancy in 1693. Haley's merger of data collection and probabilistic analysis established modern principles for the management and analysis of public health data.
- *Roots of epidemiology.* Scientists such as Laplace and Bernoulli applied mathematical principles to public health issues, work that set the stage for the major advances in data and information management that led to the development of the modern epidemiological approach.

### ***The Origin of Modern Public Health Informatics***

During the nineteenth century and the first half of the twentieth century, developments in both England and the US created the necessity for advanced methods of data collection and analysis in public health practice. Some of these developments are discussed in detail in the following sections.

#### **The Cholera Outbreaks in England**

In England, the nineteenth century cholera epidemics led to major changes in the practice of public health. The cholera epidemics of 1831 and 1832 highlighted the role of neglected sanitation among the poor in imperiling the health of all. The Poor Law was passed in 1834 [18] and the Poor Law Commission was formed in response. Dr. Edwin Chadwick was appointed the secretary of the commission and became one of the leading forces in the sanitation movement. He proposed the formation of the Bureau of Medical Statistics in the Poor Law Office. Under his leadership, Dr. William Farr began to use data that became available under the 1836 Births and Deaths Act. Chadwick proposed that this act would lead to registration of the causes of disease, with a view to devising remedies or means of prevention [19]. A vast amount of data was collected under these two acts. Analysis of these data by Farr led to a better understanding of the role of sanitation and health. Farr's analysis represented one of the earliest examples of the presentation of a plausible epidemiological theory to fit known facts and collected data.

In 1859, Florence Nightingale, working with William Farr, confirmed the connection between sanitation and mortality by studying the horrendous death rate in the British Army in the Crimea. Not only did these public health workers compare death rates for non-combat-related illness in the army to rates in a reference population, they also published one of the first uses of graphics to present public health data. Also at this time, Adolphe Quetelet consolidated current statistical developments and applied them to the analysis of community health data compiled by observation and enumeration. He noted that variation was a characteristic of biological and social phenomenon, and that such variation occurred around a mean of a number of observations. Further, he demonstrated that the distribution of observations around a mean corresponded to the distribution of probabilities on a probability curve. This work helped form the foundation of biostatistics as applied to the health of the public.

In 1854, cholera again struck London. Dr. John Snow conducted an investigation of this outbreak in the Soho section of London. He carefully mapped the location of each of the victims, which revealed a pattern centered on the Broad Street pump. He then proceeded to convince local authorities to remove the handle from the pump, thereby stopping the outbreak. He continued the analysis of the outbreak and was able to associate the location of the water intake that supplied the Broad Street pump with other water companies and sewage outflows in the Thames River. His work led to future regulation of water supply intakes. The methodology that he used has become the foundation of all modern epidemiological investigations of disease outbreaks. He also was one of the first to use a rudimentary manual geographical information system (GIS), his tools basically consisting of a map and a pencil [20, 21]. Thus, the application of scientific learning began to have a positive impact on the health of the English population. In 1866, it was noted that cities without a system for monitoring and combating cholera fared far worse in the epidemic of that year [22].

## **Public Health Data Collection in the United States**

In the US, independence fostered the development of strong state and local governments. These organizations began to incorporate current scientific knowledge into protecting the health of their populations. The first local health department was formed in 1798 in Baltimore, Maryland [23]. In the early 1800s, local health departments collected health data only sporadically. In Illinois, for example, sporadic data were collected in the City of Chicago starting in 1833, with the formation of the Chicago Department of Health.

Data collection problems in the seventh decennial census in 1850, however, inspired more comprehensive public health data collection and analysis in the US. The seventh census included gross death and birth rates that many considered inaccurate, due to defects in the collection of this data. Changes in the methods of data collection were implemented for the eighth decennial census in 1860, and more reliable data were collected [24].

One of the most profoundly influential nineteenth century data collection developments in the US was the publication in 1850 of Lemuel Shattuck's *Report of the Sanitary Commission of Massachusetts*. This report provided the basic blueprint for the development of a public health system in the US. It outlined many elements of the modern public health infrastructure, including a recommendation for establishing state and local health boards [25].

By 1900, many state and local health departments had formed in the US. An important role of these departments was the collection and analysis of reports of communicable diseases and vital statistics. In the early 1900s, the vital records system was still struggling. The Census Bureau worked with many states to encourage the recording and reporting of birth and death data. During the Depression and the Second World War, the importance of enumerating and documenting births became evident as more people needed to prove citizenship, for eligibility for relief and other programs. In fact, during World War II, laws prohibited the employment of noncitizens in essential defense projects; for many job seekers, proof of citizenship through birth or naturalization became essential.

In 1933, Texas became the last state to begin reporting vital statistics to the federal government. Even so, in 1940, it was estimated that as many as 55 million native-born persons did not have birth records [26]. In response, the US Bureau of the Budget recommended moving the vital statistics office to the Public Health Service. In the 1960s, the vital statistics function became a part of the new National Center for Health Statistics, and the current cooperative system with states was put into place [27, 28].

In the first part of the twentieth century, the system for collecting birth and death records was being established and standardized. However, data about nonfatal illnesses was difficult to obtain and therefore sparsely available. An early attempt at a survey-based assessment of the health status of the US population was conducted by the US Public Health Service in the 1930s, using Work Projects Administration funds. The survey incorporated data from 750,000 households in 84 cities and several rural areas. It was conducted with the time's accepted methodology, which did not include probability sampling or standardized questionnaires. These data became the reference for policy development until the National Health Interview Survey (NHIS) reported its first results in 1957 [27]. The design of the NHIS was one of the early tasks of the National Committee on Vital and Health Statistics (NCVHS) in 1953 [28].

The scientific discoveries of the nineteenth century laid the basis for substantial progress in the control of infectious disease. The nature of public health challenges changed as the importance of data in policy and program decision-making became better understood, both by organized public health agencies and researchers. Advances in immunizations, sanitation, and nutrition led to substantial improvements in the health of the public. By the middle of the twentieth century, the leading causes of death had changed to heart disease, cancer, and stroke. The increasing importance of these chronic illnesses in public health practice mandated a disease model capable of handling numerous factors, including longer intervals between cause and effect. As interventions became more complex and long-term, new

approaches had to be developed that involved data collected about individuals over time and space. In turn, the need to analyze data in different locations and times led to the concept of data linkage [29]. Initially, attempts were made to develop a paper-based cross-index, but the complexity of such a task became daunting and led to frustration and failure.

Better surveillance systems and enhancements to national and local vital statistics systems increased the amount of data available to public health agencies, enabling programmatic decisions for the prevention and treatment of disease to be driven by data and information. The increasing volumes of data, along with the increasing need to analyze that data, created conditions that were ripe for technological advancement. In fact, many tasks, including record linkage on a large scale, were impossible, given the state of technology in the mid-twentieth century. The newly emerging automated information systems were a perfectly-timed match with the need for public health entities to manage large volumes of data and information.

## **The Three Waves of Federal-State System Development**

At the beginning of this chapter, we pointed out that many of today's public health information systems are products of a partnership between state and federal public health officials. The evolution of this partnership occurred in three waves, representing (a) independent systems development, often with federal systems imposed on the states; (b) federal funding of state-level systems; and (c) integration of the benefits of state-level system development with the tools of software reuse.

### ***The First Wave: Independent Systems Development***

In the early days of system development, states and the federal government developed information systems independently, although there were many instances of significant collaboration. Standards developed through the cooperative system in vital statistics assured that data that were delivered to the National Center for Health Statistics (NCHS) were comparable from one state to another. The NCHS developed the cooperative system in vital statistics in cooperation with state registrars. Any changes made to this system occurred according to a process of agreement among the many partners.

Similarly, the CDC and the Council of State and Territorial Epidemiologists (CSTE) collaboratively developed standards for reports of communicable diseases. States actively developed stand-alone systems to manage their own programs. Federal systems were also developed and made available to states. Some federal systems used standardized data definitions, whereas others did not. However, as is common in public health, resources for system development were hard to come by,



therefore states considered these federal systems as major enhancements to their own capacity to meet their missions.

Early state systems included those for newborn metabolic disease screening. Screening newborns for phenylketonuria began in 1969; severe mental retardation can be avoided if a child is diagnosed soon after birth and placed on a diet low in phenylalanine. Often, laboratories were the earliest users of computers to track newborn screening test results. The challenge was to assure that every positive laboratory test was followed up, and that the baby was put on the low phenylalanine diet. The earliest newborn screening systems were developed in California, Illinois, Oregon, and Texas [30–32]. By 2012, every US state and the District of Columbia had such systems in place [33, 34]. These systems were developed separately in each state.

In this same time frame, the CDC and other federal agencies were developing information systems for use in states. One example is the automated medical information management system developed in the 1980s by the CDC and other partners to automate data collection for sexually-transmitted disease registries; the system was designed to read completed surveillance forms with an optical scanner, which converted pencil marks on a specially designed document into an electronic database [35]. On a monthly basis, state data were transferred to the CDC for use in national surveillance programs. Although the system worked very well for the purpose for which it was designed, state health agencies needed to modify their operational systems in order to use it. Clerical staff had to review each form by hand for completeness before the forms were inserted into the scanner; if the data were incomplete, the form could not be scanned. State health department staff had to contact the local health departments to complete the form. Organizationally, state health department staff would be able to work more efficiently if the system could be modified to read the form and discard the records with incomplete data. But because CDC designed the turnkey system, modifications could not be made at the state level. Essentially, the system was designed to meet the needs of the program at CDC, not the needs of those who would be collecting the data. Despite the frustrations felt by state health agency staff, this arrangement had a clear ability to be cost effective. Because the CDC developed the program and then provided it to the states, the development costs were paid only once.

### ***The Second Wave: Federal Funding of State-Level Systems***

Over time, state agencies became concerned about the increasing number of systems existing in each program. Additionally, the systems were unable to communicate with each other (non-interoperability). What had initially been a blessing became a curse as state and local health agency staff had to enter the same data into multiple systems.

During this time frame, data standards for health care were under development. For example, the College of American Pathologists developed a standard

nomenclature for pathology in 1965 [36, 37]. Similarly, the NCVHS proposed standards for a Uniform Hospital Discharge Data Set in 1979 that were eventually published in 1985 and became effective in 1986 [38]. Systems that were independently developed by CDC centers, institutes, or offices each used the data definition they deemed best for their own purposes; those definitions frequently were different from those selected by other units of the CDC, by the Health Resources and Services Administration (HRSA), by the Health Care Financing Administration, or by other federal agencies. States also developed their own definitions and scoring systems. Consequently, most of these numerous systems were unable to share data. As an example, at one point in the HIV/AIDS program at the Illinois Department of Public Health, there were eight different information systems that transferred and monitored laboratory data, operated the AIDS registry and the HIV registry, provided AIDS service delivery under the Ryan White program and state-funded programs, delivered data to the CDC, and operated the AIDS Drug Assistance Program. Because each system was independent, data had to be entered separately into each system, and individual data elements had to be entered multiple times. It is noteworthy that this same situation often existed (or exists, even today) at the local health department level, where agencies frequently had (or have) multiple data-entry systems imposed upon them by both state and federal agencies.

In the early 1990s, state and local health departments, the Association of State and Territorial Health Officials (ASTHO), and the National Association of County and City Health Officials (NACCHO) opened a discussion of their system problems with Phil Lee, the Assistant Secretary for Health, US Department of Health and Human Services. Dr. Lee was noted to comment, "I knew that data was a four letter word. I just never knew it was spelled T-U-R-F." State and local health departments were looking for the ability to build more integrated information systems, such as the Illinois Cornerstone and the Georgia Information Network for Public Health Officials and Host systems [39]. In response, CDC and HRSA began allowing state and local health departments to use categorical funding to implement information systems that were integrated across programs. Additionally, funding became available for the development of information systems at the state and local level. Using a combination of state and federal funding, many states created state-based information systems, such as those for immunization registry programs.

With federal agencies funding development of information systems by states, the systems could be developed with a focus on state and local operations. The automated processes could reflect the nature of the public health environment in each state. The adoption of standards for health information, developed by national standards development organizations, allowed the exchange of data between states. This was (and is) a crucial issue, because of the highly mobile nature of the US population. This wave of state-federal development had the clear advantage of assuring that information systems could be developed to fit the needs of each individual state. The disadvantages were that the cost of development had to be paid 50 times – each time one of the states developed a specific system. In addition, there was no assurance that each state would build the system to be consistent with national standards.

### ***The Third Wave: Integration of the Benefits of State-Level System Development with the Tools of Software Reuse***

The third wave of system development integrates the benefits of state-level system development with the tools of software reuse. System development began to use tools such as object-oriented software development and Web-enabled environments. Further, an axiom of third-wave system development is that each new system must be standards-based.

In the third-wave approach, federal funds may be granted to a limited number of states to develop prototype systems. Those systems are designed in a modular fashion to facilitate easy modification for use in other states. After the prototype systems are completed and validated, the federal government makes funding available only for the costs of modifying the prototype system to meet the unique needs of each state. This type of resource sharing is a continuing trend in public health, fueled by advances in open source development and cloud computing.

The third wave of state-federal system development is also dependent upon development and implementation of standards for public health data. Historically, the CDC has played a leading role in this process, beginning with the formation of the Health Information and Surveillance Systems Board (HISSB) in 1993 [40]. Working with other federal agencies – ASTHO, NACCHO, and the National Association of Local Boards of Health – the CDC developed a conceptual model for public health data [41]. This wave continues to advance, recently augmented with CDC's Public Health Information Network (PHIN) initiative, which was intended to enhance the ability of public health agencies to exchange data and information electronically across organizations (including both private and public health organizations) and jurisdictions. The PHIN initiative includes funding for states and jurisdictions; increasingly, it requires use of standards and other technical requirements [42], and facilitates standards implementations by providing resources such as the PHIN Vocabulary Access and Distribution System (VADS), a standards lookup utility [43].

## **Conclusion**

Public health information management has been an important aspect of protecting the health of the public since prehistoric times. Public health practice has used currently available science in mathematics, chemistry, and biology to carry out its mission, making dramatic advances in the last 200 years. Building on discoveries in other fields, public health has constructed a unique science base with the development of biostatistics and epidemiology. This science base facilitates the analysis of large sets of data to describe and understand health problems. Through analysis, data are converted into information to drive effective interventions. The advent of computer technology and automated information systems has led to a dramatic

increase in the effectiveness of public health analysis. Leveraging all of these advances, public health interventions have accounted for the bulk of the spectacular increases in life expectancy experienced in the US in the twentieth century, and it is anticipated that this remarkable progress will continue in the twenty-first century.

### Review Questions

1. What factors account for the fact that early public health information systems developed as stand-alone products?
2. What are the main distinctions between the three stages in development of public health information management systems?
3. What characteristic distinguished the computer ENIAC from all the other computers developed during World War II?
4. In what sense did the cholera epidemics in nineteenth century England serve as a watershed in public health practice and public health information systems?
5. To what extent can it be said that the needs of the US Bureau of the Census laid the foundation for the development of modern state public health information systems?
6. Summarize the main characteristics of the three waves of federal-state system development.
7. To what extent is the third wave of state-level public health system development a continuation of the second wave? In what respect does federal funding for the third wave differ from the federal funding for the second wave?

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# Chapter 3

## Context and Value of Biomedical and Health Informatics

William R. Hersh

**Abstract** Public health informatics (PHI) is one branch of the larger field of *biomedical and health informatics* (BMHI) (Hersh, BMC Med Inform Decis Mak 9:24, 2009). In this chapter, we will define the terminology of BMHI and identify where other branches of the field can inform the science and practice of PHI. We will also discuss the value of BMHI in all health-related disciplines.

**Keywords** Teleradiology • Telepathology • eHealth • Informatics • Biomedical informatics • Health informatics • Imaging • Consumer health • Translational research • Health information management • Management information systems • Electronic medical record • Electronic health record • Personal health record • Health information exchange • Secondary use • Telemedicine • Evidence-based medicine • Evidence-based practice • Clinical epidemiology • Comparative effectiveness research

### Learning Objectives

1. Define biomedical and health informatics and its sub-disciplines.
2. Distinguish informatics from other disciplines.
3. Describe evidence supporting the value of biomedical and health informatics.

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## Definition and Context of Informatics

Before delving into the various sub-disciplines of BMHI, let us first define the word *informatics*. This word has been around for several decades and its usage is not limited to biomedical and health disciplines. But certainly in the United States, the most prominent usage of it comes from the biomedical and health disciplines. This author has defined informatics as the field concerned with optimal use of information, often aided by the use of technology, to improve individual health, health care, public health, and biomedical research [1].

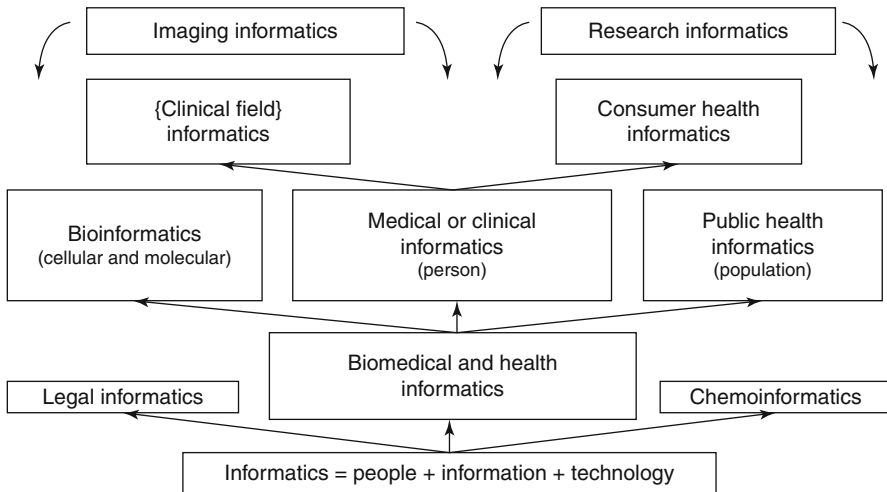
Informatics is more about information than technology, with the latter being a tool, albeit an important one, to make best use of information. The former School of Informatics at the State University of New York Buffalo defined informatics as a Venn diagram showing the intersection of people, information, and technology. Friedman has defined a “fundamental theorem” of informatics, which states that informatics is more about using technology to help people do cognitive tasks better than about building systems to mimic or replace human expertise [2]. He has also described informatics as “cross-training,” bridging an application domain (such as public health or medicine) with basic information sciences [3]. In effect, he characterized informatics by what it is not, including analyzing large data sets, employment in circumscribed information technology (IT) roles, or routine work using a computer [3].

Collen penned in the 1990s a history of the early usage of the term in medicine, from its origination in Europe as somewhat synonymous to computer science to its more recent usage to imply computer science or IT applied to a specific domain [4]. Another early seminal document attempting to define it in the US came from Greenes and Shortliffe, who described it as “the rapidly developing scientific field that deals with the storage, retrieval, and optimal use of biomedical information, data, and knowledge for problem solving and decision making” [5]. This author has further elaborated about the field [6], its practitioners [7], and its career opportunities [8]. Detmer et al. recently defined the discipline of clinical informatics in preparation for efforts at professional certification, somewhat similarly noting that the field transforms health care by “analyzing, designing, implementing, and evaluating information and communication systems that enhance individual and population health outcomes, improve patient care, and strengthen the clinician-patient relationship” [9].

## The Sub-Disciplines of Informatics

If we consider BMHI to be the over-arching phrase to name the overall field (defined above), we can then properly define its sub-disciplines. Shortliffe has proposed that informatics proceeds along a continuum from the cellular and molecular (bioinformatics) to the person (medical or clinical informatics) to the population





**Fig. 3.1** An overview of biomedical and health informatics and its sub-disciplines (From Hersh [1] Biomed Open Access)

(public health informatics) [10]. But there are other sub-disciplines of BMHI that do not fit neatly into this continuum:

- *Imaging informatics* – informatics with a focus on imaging, including the use of picture archiving systems (PACS) to store and retrieve images in health care settings [11]
- The application of informatics focused on specific health care disciplines, such as nursing (*nursing informatics*) [12], dentistry (*dental informatics*) [13], pathology (*pathology informatics*) [14], etc.
- *Consumer health informatics* – the field devoted to health informatics from a consumer view, which focused on applications such as personal health records (PHRs) [15]
- *Clinical research informatics* – the use of informatics to facilitate clinical research, with increasing emphasis on *translational research* that aims to accelerate research findings into clinical practice [16] Fig. 3.1.

## Related Terminology of Informatics

There are a number of other terms related to BMHI that are important for students to understand. One of these terms, *health information management* (HIM), refers to the discipline that has historically focused on the management of medical records [17]. As the medical record has become electronic, the HIM field has been in transition and increasingly overlaps with informatics. One major difference between HIM and informatics is the educational path of practitioners: HIM professionals

have historically been educated at the associate or baccalaureate level, whereas informaticians often come from clinical backgrounds, including those with doctoral degrees, such as MD, PharmD, etc.

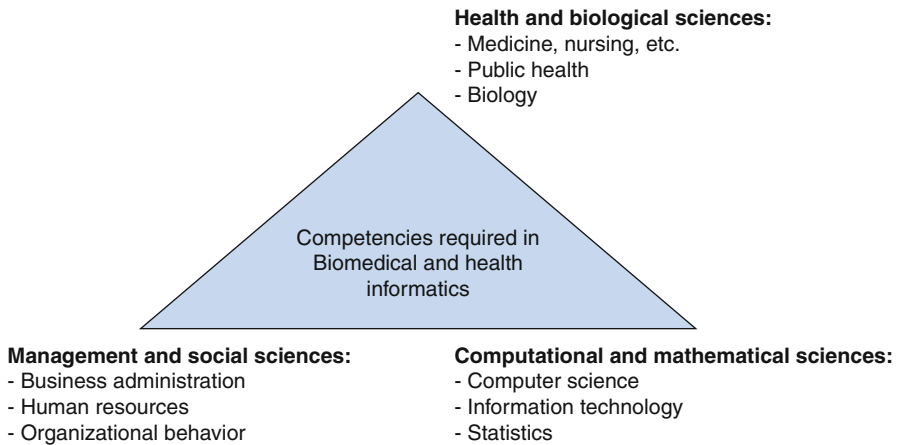
Another term, *information technology* (IT), is generally used to describe computers and related technologies in operational settings. The academic discipline that underlies IT is *computer science*, which is often housed academically in engineering schools [18]. However, IT professionals also come from other backgrounds, including fields such as *management information systems* (MIS), a field whose programs are usually in business schools. Within IT and computer science are a heterogeneous array of people with varying skills, including *developers, programmers, engineers, architects, and support personnel*. Although focused on clinical research informatics, a paper by Bernstam et al. describes how BMHI differs from IT academically and operationally in that setting, with BMHI more focused on data and information of the field and IT more concerned with the underlying technology and its operations [19].

Another source of diverse terminology concerns the health record of the individual. When these records were first computerized, the term *electronic medical record* (EMR) was most commonly used. However, this has mostly been supplanted by the term *electronic health record* (EHR), which implies a broader and more longitudinal collection of information about the patient. There is increasing interest in the *personal health record* (PHR), which usually refers to the patient-controlled aspect of the health record, which may or may not be tethered to one or more EHRs from health care delivery organizations.

There has been major investment in EHRs in the US since 2009, when the Health Information Technology for Clinical and Economic Health (HITECH) Act was included as part of the American Recovery and Reinvestment Act (ARRA, also known as the economic stimulus bill) [20, 21]. HITECH allocates up to \$30 billion in incentives for the adoption of EHRs by physicians and other professionals as well as by hospitals in the US. The HITECH program is administered by the Office of National Coordinator for Health IT (ONC), an agency within the US Department of Health and Human Services.

Related to EHR growth is interest in *health information exchange* (HIE), which is the exchange of health information for patient care across traditional business boundaries in health care and was also funded through the HITECH Act [22]. Even many health care organizations that have exemplary health information technology (HIT) systems have difficulty providing patient information to other entities where the patient may receive care, but an increasingly mobile population needs to have “data following the patient.” HIE is actually but one example of what is sometimes called *secondary use* or *re-use* of clinical data, where data from clinical settings is used for other applications such as quality assurance, clinical research, and public health [23].

Another broad set of terms important to BMHI are the “tele-” terms. The two most widely used terms are *telemedicine*, which refers to the delivery of health care when the participants are separated by time or distance, and *telehealth*, which has more of a focus on direct interaction with health on information and communications technology (ICT) [24]. As with informatics, the “tele-” terms sometimes



**Fig. 3.2** The competencies required for biomedical and health informatics practitioners (From Hersh [1] Biomed Open Access)

reflect medical specialties in which they are applied, e.g., *teleradiology* and *telepathology*. A somewhat related term is *eHealth*. An entire systematic review has been carried out around definitions of eHealth, which is defined as centering around two broad themes (health and technology) and six narrower ones (commerce, activities, stakeholders, outcomes, place, and perspectives) [25].

Another area important to BMHI is *evidence-based medicine* (EBM) [26]. Some use the term *evidence-based practice* (EBP), which advocates that health care decisions be made using the best available scientific evidence with those who receive care, informed by the knowledge of those who provide care, and within the context of available resources for that care [27]. EBM and EBP are usually described to be part of the larger discipline of *clinical epidemiology* [28]. A new term to emerge related to EBM is *comparative effectiveness research* (CER), which has been defined as “research studies that compare one or more diagnostic or treatment options to evaluate effectiveness, safety or outcomes” [29]. There is an emerging consensus of methodologies for CER that focuses on research that is patient-centered and has practical and actionable clinical outcomes [30].

An additional perspective on BMHI can be seen from the competencies that emanate from its practitioners, as shown in Fig. 3.2 [1]. These fit into three broad categories of health and life sciences, computing and information sciences, and management and social sciences.

## The Value of Informatics

All of these nuanced definitions of informatics and its sub-disciplines would be moot if informatics did not provide value to health. A great deal of research does show that informatics, when properly applied, can contribute to the “triple aim” of

improved health, improved health care, and reduced health care costs [31]. Most studies of the value of informatics have come from the health care setting, which makes it challenging for PHI and other sub-disciplines to demonstrate value scientifically in their settings. A good deal of the evidence for the value of BMHI is summarized in three successive systematic reviews.

The first systematic review to critically analyze all informatics evaluation studies to date was published in 2006 [32]. A total of 257 studies met the inclusion criteria. Most studies addressed decision support systems or EHRs. One concern was that approximately 25 % of the studies were from four academic institutions that had implemented internally-developed systems; only nine studies evaluated multifunctional, commercially-developed systems. The review concluded that evidence for the value of BMHI was demonstrated most prominently in three areas: increased adherence to guideline-based care, enhanced surveillance and monitoring, and decreased medication errors. The primary clinical domain of these improvements was preventive health. The major efficiency benefit shown in the studies was decreased utilization of care. Data on another efficiency measure, time utilization, were mixed. There was limited empirical cost data in the identified research.

A second systematic review was published in 2009 [33]. In this review, 179 studies met the inclusion criteria. This review found comparable benefits to the previous systematic review that came from both EHRs and HIT systems designed to run independently from EHRs, but little formal evaluation of other types of applications. There were somewhat fewer relevant studies from the health IT leader organizations.

These two previous reviews were updated using the same methodology in 2011 [34]. These authors reviewed the literature in a similar manner to the previous reviews and found that 92 % of the recent articles on health IT reached conclusions that were overall positive. These authors also found that the benefits of health IT were beginning to emerge in smaller practices and organizations, as well as in large organizations that had been early adopters. However, they also noted that dissatisfaction with EHRs among some providers was still high and a barrier to achieving value. They concluded that the need for studies documenting the challenging aspects of implementing health IT and how those challenges might be addressed were critically needed.

Another important component of the value of BMHI is its workforce [35]. The HITECH Act also stipulated the development of short-term training programs and related activities to match the needs generated by the incentives for EHR adoption. ONC developed its Workforce Development Program by surveying the research literature and convening a workshop of experts in 2009. Based on the research literature, it was estimated that a workforce of approximately 51,000 professionals would be required to help eligible hospitals and professionals achieve meaningful use of the EHR. Adding the opinions of experts, ONC determined that professionals in 12 workforce roles would be required (Table 3.1). They believed that these roles could be grouped into three categories. The first category would be a wave of personnel who would be mobile in nature, moving from site-to-site implementing EHR

**Table 3.1** ONC workforce categories and roles

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Category 1: Mobile Adoption Support Roles
Implementation support specialist*
Practice workflow and information management redesign specialist*
Clinician consultant*
Implementation manager*
Category 2: Permanent Staff of Health Care Delivery and Public Health Sites
Technical/software support staff*
Trainer*
Clinician/public health leader†
Health information management and exchange specialist†
Health information privacy and security specialist†
Category 3: Health Care and Public Health Informaticians
Research and development scientist†
Programmers and software engineer†
Health IT sub-specialist†

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Accessed at: <http://www.healthit.gov/policy-researchers-implementers/workforce-development-program>

Those with an asterisk (\*) were slated to have training take place in community colleges, while those with a dagger (†) would have training occur in university-based settings. These roles were not meant to be so much job descriptions as they were meant to be job categories

systems. They would be followed by more permanent staff that would maintain and support the implemented EHR systems. A third category would consist of clinical and public health informatics experts who would manage, evaluate, educate, and perform further research and development of these systems. Half of these workforce roles were designated for training in 6-month certificate programs in community colleges, while the other half would require 1–2 years in university-based programs.

The ONC Workforce Development Program rolled out in late 2009 consisted of four specific programs to train the workforce roles from Table 3.1:

1. Community College Consortia – 82 community colleges, grouped into five regional consortia, funded to offer 6-month certificate programs in the first six workforce roles listed in Table 3.1.
2. Curriculum Development Centers – Because the community colleges did not have curricula for these programs, five universities received awards to develop curricular components that were to be developed into courses by the community colleges. One university was additionally designated the National Training and Dissemination Center (NTDC), tasked with developing the Web site for dissemination of the materials and carrying out training activities for community colleges.
3. Competency Examinations – Examinations to test the competencies gained by graduates of the community college programs for the six workforce roles trained in their programs are available.

4. University-based Training (UBT) programs – Additional training funds were awarded to nine universities for longer-term university-based training in the latter six workforce roles listed in Table 3.1.

Although the focus of the HITECH Act is on clinical informatics, there are parts that are relevant to PHI. The curriculum being developed by the CDCs does include materials that cover aspects of PHI. In addition, the UBT program includes a workforce role that is devoted to PHI leaders.

Education in BMHI did not begin with the HITECH Act, nor will it end when its funding ends. One shortcoming of many educational programs in BMHI has been their lack of development in PHI. Recent efforts to define and close this gap should contribute to improving the PHI workforce specifically [36], especially if they are based on known PHI workforce competencies [37, 38]. Another means for ramping up the workforce is through shorter courses, more akin to continuing education than formal degree programs. One approach has been the 10×10 (“ten by ten”) program of the American Medical Informatics Association (AMIA) [39]. Although somewhat more focused on clinical informatics, one offering of the program has specifically focused on PHI.

## Conclusions

It is critical that an understanding of PHI include the perspective of the larger BMHI. This chapter has provided an overview of the field of BMHI and where sub-disciplines such as PHI fit into the larger field. It also describes the value of BMHI that has been demonstrated in studies and summarized in systematic reviews, as well as the human capacity developed via educational programs.

### Review Questions

1. Choose a health-related problem to apply biomedical and health informatics and describe what sub-discipline(s) of informatics is/are involved.
2. Select an information system application in a health-related discipline and distinguish the application of informatics from other aspects of the health-related problem.
3. Choose an application of informatics and find or describe the evidence supporting the answer to the question being studied.
4. Select a public health problem that requires data and/or information from information systems outside the public health system and describe how that/those applications would interact with the public health information systems.
5. How might public health informatics leverage the large investment in HIT workforce to more efficiently and effectively train public health informaticians?

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# Chapter 4

## Governmental and Legislative Context of Informatics

Margo Edmunds

**Abstract** The Institute of Medicine has identified three core functions of public health that recognize the importance of timely and accurate information and are central to contemporary public health practice: assessment of population health, policy development, and assurance of the availability of high-quality public health services [1]. Others have noted that an information infrastructure is considered to be central to those functions [2]. Historically, federal funding for public health information systems was both limited and categorical, leading to non-standardized, non-interoperable, disease-specific applications that were difficult for state and local health departments to support and maintain. However, the terrorist events of 2001 led to the largest federal investment in public health infrastructure since World War II [3].

Over the past two decades, the term *public health informatics* has been used to describe the intersection of public health and information technology [4]. The purpose of this chapter is to describe the emergence and evolution of public health informatics policy, which began to develop in the mid to late 1990s, accelerated after the terrorist events of 2001, and came into new prominence when the public health objectives in Stage 2 meaningful use rules were released in September 2012. The chapter begins with a review of the fundamentals of the public policy process and the government, legal, and regulatory framework for public health informatics. It then describes the policy environment for public health informatics, showing how large-scale public events and public-private collaboration and leadership from professional organizations helped to move the policy process forward by increasing transparency and investments in public health information infrastructure. The chapter closes with a look forward to future policy issues at the national level.

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**Keywords** Health policy • Health information technology policy • Public health informatics • Policy development • Population health • Regulatory framework • Funding • Congress • Public health funding • HIPAA • NEDSS • HAN • ONC • HITECH • Meaningful use • PCAST

### Learning Objectives

1. Describe the policy development process for public health informatics and its relationship to health IT policy.
2. Become familiar with the main legal and regulatory frameworks that apply to and influence public health informatics.
3. Be able to identify at least three key future policy challenges for the field of public health informatics and a strategy for how each might be addressed.

## Overview

The Institute of Medicine has identified three core functions of public health that recognize the importance of timely and accurate information and are central to contemporary public health practice: assessment of population health, policy development, and assurance of the availability of high-quality public health services [1]. Others have noted that an information infrastructure is considered to be central to those functions [2]. Historically, federal funding for public health information systems was both limited and categorical, leading to non-standardized, non-interoperable, disease-specific applications that were difficult for state and local health departments to support and maintain. However, the terrorist events of 2001 led to the largest federal investment in public health infrastructure since World War II [3].

Over the past two decades, the term *public health informatics* has been used to describe the intersection of public health and information technology (IT) [4]. The purpose of this chapter is to describe the emergence and evolution of public health informatics policy, which began to develop in the mid to late 1990s, accelerated after the terrorist events of 2001, and came into new prominence when the public health objectives in Stage 2 meaningful use rules were released in September 2012. The chapter begins with a review of the fundamentals of the public policy process and the government, legal, and regulatory framework for public health informatics. It then describes the policy environment for public health informatics, showing how large-scale public events and public-private collaboration and leadership from professional organizations helped to move the policy process forward by increasing transparency and investments in public health information infrastructure. The chapter closes with a look forward to future policy issues at the national level.

## Introduction

The landmark Institute of Medicine report on the *Future of Public Health* identified three core functions of public health: assessment of population health, policy development, and assurance of the availability of high-quality public health services [1]. These core functions, derived from the base science of epidemiology, acknowledged the importance of timely, accurate information from a variety of sources and led one expert to describe information infrastructure as the “nerve center” of public health practice [2]. By 2001, the term *public health informatics* had been coined to describe the intersection of public health and information technology [4], with a primary focus on population health and prevention.

While some members of the public health community were early adopters of computer systems for assessment activities such as disease tracking, surveillance, and registries, pre-Internet funding from the Centers for Disease Control and Prevention (CDC) was both limited and categorical, leading to dozens of disease-specific applications that were not standardized or interoperable. These standalone systems were particularly difficult for state and local health departments to support and maintain, and few members of the public health workforce were sufficiently trained to use them. In response, the CDC launched an initiative called the National Electronic Disease Surveillance System (NEDSS), a standards-based approach to improve the timeliness, quality, and security of health data and create a shared vision of a national system to exchange and integrate electronic data [5, 6].

The terrorist events of September 11, 2001, and the anthrax attacks of October 2001 created a sense of urgency about increasing the capacity of the public health information technology and communications infrastructure to handle catastrophic events. In November 2001, the National Committee on Vital and Health Statistics (NCVHS) released its report *Information for Health: A Strategy for Building the National Health Information Infrastructure*, which had taken 18 months to develop and now took on new meaning in light of a national recognition of the need for “an effective, comprehensive health information infrastructure that links all health decision makers, including the public” [3]. In January 2002, Congress made its largest investment in public health infrastructure since World War II, allocating US\$1.1 billion to enhance surveillance, epidemiology, and laboratory capacity; communications and information technology, including training in risk communication for public health officials; and additional workforce and training to enhance preparedness [2, 7, 8].

By its very nature and definition, public health informatics is practiced in a governmental context in which public events, legislative and regulatory directives, and public perceptions require transparent and accountable responses. But public health policy in general, and informatics policy in particular, have also been influenced by policy recommendations made by private sector organizations such as the Institute of Medicine, American Medical Informatics Association (AMIA), the Association of State and Territorial Health Officials (ASTHO), the National Association of County and City Health Officials (NACCHO), and by private funding from the

Robert Wood Johnson Foundation, the W. K. Kellogg Foundation, the Markle Foundation, the Pew Charitable Trusts, and others whose policy priorities included the development of public health information and communications infrastructure and health information exchange.

## **Legal and Regulatory Framework for Public Health Informatics**

### *Fundamentals of the Policy Process in the United States*

The fundamental purpose of government is to act in the public interest and provide for the public good through such activities as maintaining roads and other physical infrastructure; providing for public safety, defense, and foreign diplomacy; maintaining systems for education, voting, environmental protection, consumer protection and product safety; and maintaining a public health system. Public policies are statements, positions, and courses of action that reflect governmental goals and values and may be expressed through legislation; budgets and program priorities; statements and writings of public officials; executive orders; and other means.

The United States Constitution does not mention the word “health” and does not explicitly grant the federal government authority over health [8], although the Department of Health and Human Services is the largest source of funding for state and local public health programs and infrastructure, and provided US\$2.25 billion between FY 2010 and FY 2012 [9]. The states bear the majority of statutory responsibility for health, insurance regulation, professional licensure and credentialing, and other activities related to the health and well-being of their populations.

Thus, public health law in the United States includes a federal system and 50 separate state legal systems, all of which have their own structure for organizing and funding local health agencies. In short, the US public health system is a three-tiered network of state and local agencies that work in partnership with the federal government [1]. This complex and often confusing arrangement is not without tensions, and it helps to explain why developing and implementing national standards for public health is so challenging. Lacking statutory authority, CDC relies on cooperative agreements, stakeholder engagement with states and professional associations representing state and local officials, and voluntary standards and frameworks such as Healthy People 2020.

A complete discussion of the balance of powers doctrine would be beyond the scope of this chapter; further resources, such as Teitelbaum and Wilensky [10] should be consulted. However, a fundamental premise of government in the United States is that the Constitution grants Congress with the authority to make laws (legislative authority), the President is commander in chief and head of the executive branch of government, which implements and administers the laws by developing budgets, regulations, and guidelines and providing program

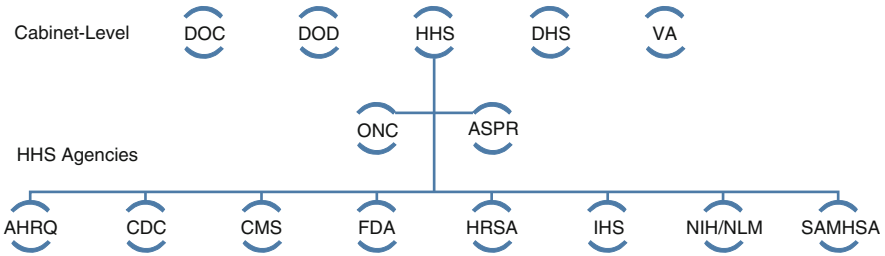
oversight; and the judicial branch (courts) interprets the laws. This chapter focuses primarily on the policy agendas promoted by the legislative and executive branches of government.

## **Organization and Authority of the Legislative Branch**

The US Congress has two chambers: The Senate, whose 100 members serve 6-year terms; and the House of Representatives, whose 435 members serve 2-year terms. Each branch does its legislative work through committees, and the committee and subcommittee chairs have the most influence in the legislative process – particularly those that deal with appropriating money. There are 21 standing committees in the Senate and 20 in the House, some with special oversight responsibilities for programs and issues that cut across committee jurisdictions. For health care and public health, the key Senate committees are Finance; Health, Education, Labor, and Pensions (HELP); and Appropriations. Key Congressional committees are Ways and Means; Energy and Commerce; and Appropriations. The Senate Finance and House Ways and Means Committees have jurisdiction over Medicare, Medicaid, and the Children’s Health Insurance Program (CHIP); The Senate and House Appropriations Committees have authority for HHS agencies (e.g., AHRQ, CDC, HRSA, NIH). The Senate HELP Subcommittee on Public Health oversees bioterrorism and public health preparedness in HHS, as well as other HHS programs [10].

In its simplest form, the legislative process begins with individual members introducing bills, with as many co-sponsors as possible. The Constitution requires all appropriations bills to originate in the House, but all other bills may be introduced in either chamber (i.e., either the House or the Senate). Within each legislative body or chamber, a bill will be sent to the committee of jurisdiction for consideration, and the committee may send it to a subcommittee, hold public hearings, “mark up” the bill by making additions and deletions, and then vote on whether to send the bill to the floor for debate and further consideration by the full chamber, i.e. the originating legislative body (either the House or Senate). If the bill is brought to a vote and passes one chamber, it will be sent to the other chamber. After a similar bill is developed in the other chamber and voted on, the two versions are reconciled in conference and another vote is held. If the bill cannot be reconciled in conference, it dies. When the conference version is passed in both chambers, it goes to the President for signature or veto.

Members of committees often develop expertise in the areas they cover, and their expertise may be recognized and relied on by their colleagues. However, many issues require more in-depth research and policy analysis than they may have time to undertake, and Members and professional staff may seek information from other sources, such as reports by the Institute of Medicine, The Government Accountability Office (GAO), the Congressional Research Service, or professional associations such as AMIA, APHA, ASTHO, and others. The value of providing reports, issue briefs, fact sheets, and other reader-friendly material on complex policy issues to professional staff and members cannot be underestimated, when legislation is being developed, researched, and written.



**Fig. 4.1** Federal Agencies whose jurisdictions affect informatics and Health IT [12, 13] (Sources: ONC Strategic Plan, 2011; DHS Healthcare and Public Health Sector Overview, 2013)

## Organization and Authority of the Executive Branch

The President heads the executive branch of government, which is organized into 15 Cabinet-level departments such as the Departments of Health and Human Services, Agriculture, and Homeland Security, and several other executive level agencies such as the Office of Management and Budget, Government Accountability Office, and many others. The US spent almost US\$2.5 trillion on health in 2009, with 3.1 % or US\$76.2 billion of the total being devoted to government-administered public health programs and US\$11.6 billion from the federal government [9, 11]. That means an investment of only US\$251 is made per person per year on public health, compared with US\$8,086 per person on medical care. The IOM recently recommended a doubling of the public health investment to approximately US\$24 billion/year in order to meet the needs of public health departments [11].

As shown in Fig. 4.1, there are several Cabinet-level departments whose jurisdictions or activities impact the fields of public health informatics and health IT. Within the Department of Commerce (DOC), the National Institute for Standards and Technology (NIST) has a Health IT Standards and Testing program that collaborates with ONC on test procedures for certification of health IT, as well as developing and certifying standards. The National Telecommunications and Information Administration (NTIA) has provided funding for broadband investments to improve adoption and use of Internet-based applications in health care, education, public safety, and other sectors. The Department of Veterans Affairs (VA) is a major provider of health care services through the Veterans Health Administration (VHA), which is the largest integrated healthcare system in the US and provides veterans with health benefits at more than 1,700 sites of care, including many telehealth sites. The VHA developed an enterprise-wide EHR known as Veterans Health Information Systems and Technology Architecture (Vista) and the Blue Button web portal, which is used for veterans as well as Medicare beneficiaries. The Blue Button web portal was the foundation for the Blue Button Initiative, a federal initiative to provide web-based portals that allow for downloading of personal health information and sharing the information with providers. The Department of Defense (DOD) also provides a high volume of health care to all active duty military personnel and is supported by a well-developed EHR system, AHLTA. It also supports the Blue

Button Initiative. The size of the VHA and DOD healthcare delivery systems and the relative maturity of VISTA and AHLTA have incentivized their participation in a wide range of informatics activities, from standards development to interoperability testbeds. The Healthcare and Public Health sector within the Department of Homeland Security (DHS) protects the public in the event of bioterrorism, infectious disease outbreaks, and natural disasters and takes an important role in coordinating information sharing during events, which directly influences the promulgation of data standards. Also, the National Incident Management System (NIMS) defines the responsibilities of DHS and the Department of Health and Human Services (HHS) in terms of critical assets and infrastructure protection.

HHS is the principal agency for protecting the health of all Americans. Virtually every major operating division of the Department of Health and Human Services has responsibilities that affect or interface with informatics. The Office of the National Coordinator for Health IT (ONC) is located administratively within the Office of the Secretary of HHS and holds the responsibility for coordinating all health IT activities across the government. It supports the nation's efforts to adopt health IT and to promote health information exchange to improve health care. The Assistant Secretary for Preparedness and Response (ASPR) is the HHS Secretary's main advisor on emergency preparedness and the position was created after Hurricane Katrina under the Pandemic and All Hazards Preparedness Act (PAHPA) to lead public health emergency preparedness efforts, which rely on field communications and public health communications infrastructure. ASPR uses health IT extensively during emergency mobilization of providers (e.g., mobile response units).

Since 2004, the Agency for Healthcare Research and Quality (AHRQ) has provided guidance and technical assistance tools for health care organizations seeking to plan for, adopt, and evaluate health IT. It is the lead federal agency for improving the quality of health care for all Americans. AHRQ grants and contracts have been foundational in developing an evidence base for the best approaches to health IT implementation. Specifically, AHRQ has given out demonstration grants, funded evaluations, and provided technical assistance and training on EHR implementations. For example, in primary care, there was a recent paper on promoting practice-based population health to help anticipate reporting requirements under meaningful use [14]. These are the kinds of forward-thinking guidance documents that will help clinical practitioners develop technical capacity that allows them to focus on population health reporting.

CDC (Centers for Disease Control and Prevention) is the nation's lead federal public health agency, with responsibilities for working with state and local health departments on health promotion, disease prevention, and emergency preparedness. It has had the highest concentration of interest and expertise in public health informatics throughout the federal government, and from 2005 to 2008, CDC also had a National Center for Public Health Informatics (NCPHI) [15, 16], to help coordinate federal, state, and local public health informatics practice activities. At this writing, public health informatics activities are currently undertaken in several parts of the Public Health Surveillance and Informatics Program Office (PHSIPO).

The Centers for Medicare and Medicaid Services (CMS) oversees the Medicare and Medicaid incentive programs for meaningful use of EHRs. The Food and Drug Administration (FDA) protects the public health by assuring the safety and security of human and veterinary drugs, medical devices (including mobile medical applications), and the food supply. The Health Resources and Services Administration (HRSA) improves access to care for low-income and uninsured individuals and uses health IT to improve access to care through telehealth and community health centers. Like the DOD and VHA, Indian Health Service (IHS) is a major provider of health care services and provides comprehensive health care for 1.9 million Native Americans, and leverages health IT and web portals to improve access to care. It uses an established EHR called the Resource and Patient Management System (RPMS) that is based upon a fork of the VHA VISTA EHR code base, but has been extensively developed.

At NIH (National Institutes of Health), the NLM (National Library of Medicine) and all of the NIH institutes work with electronic health data, and the NLM plays the lead federal role in developing clinical terminology standards for health IT. The NLM also provides support for informatics fellowships, both at NLM and through sponsored university-based training programs. SAMHSA (Substance Abuse and Mental Health Services Administration) is the lead behavioral health agency for service integration and plays a major role in disaster response.

## **Private Sector Role in Policy Development and Implementation**

The role of independent advisory committees in policy development should not be underestimated. Notably, the National Committee on Vital and Health Statistics (NCVHS) has served as a statutory advisory body to the Secretary of Health and Human Services since 1949 and has been responsible for some of the major national recommendations about health information infrastructure and informatics. The Institute of Medicine (IOM), founded in 1970 as part of the National Academy of Sciences, has provided independent advice to Congress and the executive branch on many health and healthcare issues, including public health infrastructure, health care quality, and patient safety including the unintended consequences of implementing health IT. The Commission on Systemic Interoperability, created by the Medicare Modernization Act, and the Health IT Policy Committee, created by the Affordable Care Act, are two more examples of advisory bodies created by Congress to address complex and/or contentious technical and policy issues.

Table 4.1 provides a timeline of public health informatics policy development that reflects legislative, executive, and private sector leadership over the course of the past 25 years. It demonstrates the variety of influences on policy development and implementation, including the roles of convening stakeholders, developing consensus recommendations and reports, passing legislation, developing regulatory frameworks, and providing oversight.



**Table 4.1** Timeline: key events in public health informatics policy

January 1988	Institute of Medicine (IOM) report on <i>The Future of Public Health</i> defines the core functions of public health as assessment of population health through data collection and analysis; policy development in the public interest; and assurance about availability of services [1]
April 1995	National Library of Medicine (NLM) convenes first national meeting on public health's role in national information infrastructure [17]
August 1996	Health Insurance Portability and Accountability Act (HIPAA) includes administrative simplification provisions requiring national standards for electronic exchange of health information [18]
October 1998	Local, state, and federal public health officials (CDC) begin to define requirements for a nationwide emergency communications network, later named the Health Alert Network (HAN) [5, 19]
September 1999	Senate Appropriations Committee requests a CDC report on the current state of public health infrastructure [20]
September 2000	CDC launches National Electronic Disease Surveillance System (NEDSS) with a US\$9.8 million investment to promote the development of interoperable surveillance systems at federal, state, and local levels [21, 22]
April 2001	IOM <i>Quality Chasm</i> report calls for national commitment to an electronic infrastructure to support sharing of personal health information [23]
March 2001	CDC reports that less than half of public health agencies have continuous, high-speed Internet access and 70 % need training in use of information technology [20]
November 2001	National Committee on Vital and Health Statistics proposes a strategy for building the National Health Information Infrastructure (NHII) [3]
December 2001	AMIA develops national agenda for public health informatics with 74 recommendations to facilitate large-scale adoption and implementation of interoperable information systems [24]
January 2002	Congress allocates US\$1.1 billion for public health infrastructure and specifies investments in information and communications technology and training [7]
April 2003	New guidance on HIPAA privacy rule allows sharing of personal health information for public health purposes without individual authorization [25]
April 2004	Office of the National Coordinator for Health IT (ONC) is created by Executive Order to coordinate Health IT activities and nationwide health information exchange [26]
September 2004	Agency for Healthcare Research and Quality (AHRQ) Health IT Portfolio provides US\$139 million in funding for implementation projects to improve patient safety and population health [26]
November 2005	HHS provides post-Katrina support for regional electronic health record (EHR) adoption in four Gulf Coast states, but legal barriers later prevent implementation [27]
February 2009	Congress passes the American Reinvestment and Recovery Act (ARRA), with US\$45 billion in provider incentives for meaningful use of electronic health records (EHRs) to help improve population and public health [28]
February 2010	ONC funds state Health Information Exchanges to support the development of infrastructure for exchanging health information [29]

(continued)

**Table 4.1** (continued)

March 2010	Patient Protection and Affordable Care Act (ACA) is passed by Congress, with provisions to support prevention and public health programs [30]
March 2010	As required by ARRA, Federal Communications Commission releases national plan to extend broadband services nationwide and help build Health IT and telehealth infrastructure [31]
March 2011	ONC releases a 5-year strategic plan for Health IT to increase adoption of EHRs, promote health information exchange, improve quality, and promote individual access to health information [12]
September 2012	Stage 2 of Meaningful Use includes 3 core measures with public health objectives: submitting electronic data for immunizations, reportable laboratory results, and syndromic surveillance [32]
January 2013	HHS releases final changes to HIPAA Privacy and Security Rules based on statutory changes under HITECH; changes are effective March 26, 2013 [33]

### *The Policy Environment for Public Health Informatics*

Public health informatics is different from other informatics specialties for many reasons, including its focus on population health and prevention, use of a wide range of interventions and data streams, and the constraints of limited funding within a governmental framework [4]. But it is also different because the principles of social justice underlie the public health enterprise and tend to unify the public health workforce in a shared sense of purpose [8]. Compared with the competitive health care marketplace, which has significant geographic variations in local markets, the unity of purpose in public health tends to increase collaboration in the public interest. The public health community supports the shared vision of a nationwide, standards-based health information infrastructure that assures that health care data can be collected, shared, aggregated, analyzed quickly, and made actionable.

### **Health Insurance Portability and Accountability Act (HIPAA)**

A landmark legislative event for health and health care was passage of the Health Insurance Portability and Accountability Act (HIPAA) of 1996. While its main purpose was to ensure health insurance coverage after leaving an employer, HIPAA's administrative simplification provisions foresaw the need to standardize health data so they could be exchanged electronically, thereby increasing efficiency and reducing administrative costs. HIPAA directed HHS to adopt health care data standards and prohibited the Centers for Medicare and Medicaid Services (CMS) from paying claims after October 16, 2003, unless they were submitted electronically. HIPAA also directed NCVHS to study uniform data standards for electronic medical records and clinical data exchange. In a 1998 letter to then Secretary Donna Shalala, then NCVHS Chair Don Detmer described an overarching vision of the national health information infrastructure as being a "set of technologies, standards, applications, systems, values, and laws," not a database of individual information [7].

The subsequent November 2001 NCVHS report to then Secretary Tommy Thompson, *Information for Health: A Strategy for Building the National Health Information Infrastructure*, identified public health as one of three operational dimensions for health data, along with personal health and health care providers [3]. These dimensions were seen as a means for “conceptualizing the capture, storage, communication, processing, and presentation of information for each group of information users” [3]. While NCVHS acknowledged that the health care dimension was the most highly developed at the time, and that the three dimensions were interdependent, it also made the case that the population health dimension “makes it possible for public health officials and other data users at local, state, and national levels to identify and track health threats, assess population health, create and monitor programs and services including health education campaigns, and conduct research” [3]. Among its many recommendations, the report called for federal leadership and the establishment of a new position to “oversee and coordinate a broad range of health information policy, research, and program activities in different sectors, both public and private.” In 2004, that position was created by executive order as the head of the Office of the National Coordinator for Health Information Technology (ONCHIT, later shortened to ONC).

HIPAA also required HHS to develop regulations to protect the privacy of personal health information (PHI), while exempting public health reporting from the authorization and consent requirements that are required for health care providers [7]. The public health exemption was based on years of experience on the part of public health agencies handling sensitive personal information; the existence of federal and state laws governing the protection of personal health information; and the need for public health authorities to accomplish mandated activities such as disease surveillance, outbreak investigation, and other public health objectives [25]. CDC issued specific requirements and guidance for public health when the HIPAA Privacy Rule was issued [25].

### **National Electronic Disease Surveillance System (NEDSS) and the Health Alert Network (HAN)**

While the national health policy community was focused on the all-consuming task of HIPAA implementation and electronic health records, the public health community was exploring web-based applications that would allow local, state, and national officials to develop “new and improved” information systems for public health [24]. After years of pilot programs to create core data elements, in the late 1990s, CDC launched the National Electronic Disease Surveillance System (NEDSS), an architecture and base system to overcome the existing “stovepiped” single applications and allow the web-based transfer and integration of public health, laboratory, and clinical data at federal, state and local levels [6, 7].

Also in the late 1990s, CDC launched the Health Alert Network (HAN), a “communication, information, and training system” that would support an early warning and response network against bioterrorism and other public health threats [19]. At the time, according to a survey by the National Association of County and City Health Officials (NACCHO), fewer than half of local health departments had high-speed

continuous Internet access, and 20% did not have e-mail [20]. Through NACCHO's efforts, the Senate Appropriations Committee requested a report from CDC to assess the "current state of the nation's public health infrastructure and make recommendations on possible actions that could be taken to strengthen key components" [34, 35].

On September 11, 2001, CDC issued an alert to all 50 states by e-mail and fax to heighten surveillance for any unusual diseases that might be associated with the terrorist attacks, and 24 states used their own statewide HANs to cascade the message to their local health departments [19]. With NEDSS, the HAN eventually became the backbone of connectivity for local health departments and both remain a core part of the information and communications infrastructure for public health [36]. If not for the terrorist events of 2001, and the truism "Funding Follows Fear" [34], infrastructure investments might have taken much longer. The direct personal experiences of anthrax attacks on Congressional members and staff also contributed to the acceleration of infrastructure funding, which began as funding for bioterrorism preparedness and then broadened to cover all-hazards public health preparedness [37].

### **National Agenda for Public Health Informatics**

The first national agenda for public health informatics was developed at the AMIA Spring Congress in 2001 and was co-sponsored by CDC, the Health Resources and Services Administration (HRSA), and the National Library of Medicine (NLM). It included 74 consensus recommendations developed by more than 500 people from the medical and public health informatics communities [24]. These 74 recommendations provided a broad and inclusive framework for the public health informatics enterprise, and addressed six areas: funding and governance; architecture and infrastructure; standards and vocabulary; research, evaluation, and best practices; privacy, confidentiality, and security; and training and workforce.

After the agenda was published in *JAMIA* in December 2001, it provided the overarching public health informatics framework for more than a decade, until the Robert Wood Johnson Foundation provided support for an AMIA Public Health Informatics conference in November 2011 to revisit the previous national agenda [38]. Participants found that many of the previous recommendations had already been implemented, but there were still significant needs to enhance communication and information sharing within the PHI community; unify the field through standard vocabulary, rigorous evaluation, and competency-based training; and promote effective coordination and leadership. As in the previous agenda, participants called for coordinated national leadership "to advocate and align research and evaluation priorities with public health problems and priorities" [38].

Informatics infrastructure investments spurred by the terrorist events continued through Public Health Emergency Preparedness Cooperative Agreements from CDC to state health departments, at a level of approximately US\$1 billion a year [8]. Focus Area E, Health Alert Network/Communications and Information Technology, explicitly called for electronic exchange of clinical, laboratory, environmental, and other public health information in standard formats "between the computer systems of public health partners."

## **Office of the National Coordinator for Health Information Technology (ONC)**

Another milestone was the establishment of the Office of the National Coordinator for Health Information Technology (ONC) in the Office of the Secretary of Health and Human Services, created by executive order in 2004. ONC is the principal federal entity charged with coordinating nationwide efforts to implement and use health information technology and the electronic exchange of health information to improve the quality of health care delivery and the patient experience.

The following year saw the worst natural disaster in US history hit the Gulf Coast, with a devastating loss of life and evacuation of more than one million individuals from Louisiana, Mississippi, and Texas. Much has been written about the failures of emergency preparedness and response to Hurricanes Katrina and Rita, but a triumph of informatics expertise and leadership from ONC and national health IT experts ensured that prescription data from any source (Medicaid, Veterans Health Administration, commercial payers, and community pharmacies) could be retrieved from a single, secure web portal.

This way, evacuees and others whose pharmacy records were lost or irretrievable could work with physicians and pharmacists to gain access to their own electronic prescription medication records, providing a continuity of care despite dislocation. The Markle Foundation, American Medical Association, Gold Standard, RxHub, SureScripts, ONC, the VA, and ultimately a total of 150 academic organizations, health systems, PBMs, professional organizations, and other volunteers leveraged their own resources to provide a single solution at a pace and scale that had never been attempted before [39, 40].

KatrinaHealth may have been a once in a lifetime event, but it provided proof of concept of how technical and proprietary barriers to clinical data integration and clinical information flow can be overcome by a larger vision to benefit patients. The leadership shown by Mark Frisse, Carol Diamond, and others who had worked together on the Markle Foundation's Connecting for Health Project showed the importance of a trust fabric in connecting stakeholders to address a common concern.

## **Current Policy Context for Public Health Informatics**

### ***HITECH: Infrastructure as a Down Payment on Healthcare Reform***

When it became law in February 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act created an exciting new environment for health IT. After years of claims by providers that the cost of software was the main barrier to adoption of EHRs, there was now a US\$2 billion investment in the Office of the National Coordinator of Health IT (ONC) for innovative programs such as state health information exchanges, demonstration projects, and training to increase

adoption of health IT. Up to US\$38 billion was also committed to providing direct incentives to Medicare and Medicaid providers to use EHRs in clinically meaningful ways to coordinate care and promote secure access to health information.

By the end of 2009, ONC had awarded almost US\$800 million in grants for the following key programs [41, 42]:

- Regional Extension Centers (RECs) across the country to support local clinical practitioners in using EHRs (US\$643 million);
- State programs for health information exchange (US\$564 million);
- Workforce training programs to train up to 45,000 new informatics experts (US\$118 million);
- Demonstration projects (Beacon Communities) to develop strategies to improve quality of care and health outcomes in defined geographic areas (US\$235 million); and
- Advanced research projects to fund breakthrough advances (SHARP) (US\$60 million).

In addition, ONC has been working on a standards and certification framework to develop technical specifications and standards for interoperability and the National Health Information Network (NwHIN) as a common platform for health information exchange across the country.

HITECH also created a new technology policy and standards framework to promote health information exchange, with two Federal Advisory Committees, the HIT Policy Committee (HITPC) and the HIT Standards Committee (HITSC), to advise ONC on the development of a nationwide health information infrastructure [35]. Through hearings, testimony, and extensive periods for public comment, stakeholders such as states, clinicians, vendors, consumers, and other entities have provided their perspectives on implementation, reporting, governance, privacy and security, and best practices in health information exchange. Seasoned public health professionals have served on both FACA committees, ensuring that the population health perspective has been represented.

## Meaningful Use

HITECH also authorized HHS to develop standards for the incentive payments to eligible providers and hospitals, which became known as “meaningful use” standards to emphasize their role in achieving certain objectives rather than focusing on technology for its own sake. In collaboration with ONC and other HHS entities, the Centers for Medicare and Medicaid Services (CMS) developed meaningful use requirements that are designed to foster adoption and meaningful use of electronic medical records through staged financial incentives. The Stage 1 final rule and requirements were released in July 2010 after an extensive public comment period, and implementation began in early 2011. Stage 2 meaningful use rules were published in the *Federal Register* on September 4, 2012, and will go into effect January 2014. Stage 3 is scheduled to begin after 2016 [12].

Of note for public health informatics and population health, the Stage 2 rules require eligible providers to be able to submit electronic data for immunizations, and eligible hospitals must be able to submit electronic data for immunizations, reportable laboratory results, and syndromic surveillance [12]. Two new public health objectives have been added to the available options known as the “menu set.” These include the ability to identify and report cancer cases to a cancer registry and the ability to report to another specialized registry. While some public health agencies are concerned about the capacity to accept electronic data from providers, moving this capability to a core requirement is an endorsement of population health objectives [12].

### **President’s Council of Advisors on Science and Technology (PCAST) Report**

In December 2010, the President’s Council of Advisors on Science and Technology (PCAST) released a report entitled *Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: The Path Forward* [43]. The PCAST report brought renewed attention to infrastructure and a sense of urgency about information-sharing in health care by proposing new technological innovations to solve long-standing barriers, calling for a faster and more comprehensive approach to achieve the nation’s goals for health information exchange by adopting a common language to exchange data between EHR systems. While the infrastructure investment is a necessary first step toward exchanging clinical information to coordinate care, it is not sufficient to create an ecosystem in which health information flows easily and securely among providers. While these concerns center on clinical practice, they are necessary but not sufficient for population health reporting. As the PCAST report noted, there are many reasons why health IT adoption has lagged, including these;

- Most health IT is embedded in legacy systems that focus on payment and administrative functions, not clinical information;
- Most current systems are proprietary applications that are not easily adapted into clinical workflow and use data formats that are not easily exchangeable;
- Most healthcare organizations focus on internal exchange of information and have no incentives to share information with outside organizations;
- Most patients have concerns about the privacy and security of their information.

In mid-April 2011, ONC released the Federal Health IT Strategic Plan and opened it to public comments. Building on meaningful use, the Plan notes that EHRs, telehealth devices, remote monitoring devices, and mobile health applications are “remarkably underutilized” and lays out a framework for widespread adoption and information exchange that will gradually begin to focus on health outcomes, population health, and reduced health care costs. The final version was released on November 10, 2011, and the second of five national goals reads

“Improve Care, Improve Population Health, and Reduce Health Care Costs through the Use of Health IT” [12]. Three of the four objectives address improvements in population health through EHR-generated reporting measures and being able to demonstrate and support new approaches to population health management [12], and the role of CDC is specified in investing in public health infrastructure to build core capacity and support the National Prevention and Health Promotion Strategy.

While these goals and objectives are high-level, they allow a degree of flexibility in their implementation to accommodate variations in state and local infrastructure. The ONC Strategic Plan acknowledges and integrates the role of public health information exchange and informatics in new ways and offers opportunities for health information exchange to help improve the population’s health.

## Future Policy Challenges

Together, the development, implementation, and stewardship of health data systems are arguably the dominant public health informatics policy issue we face in this decade. For the first time since 9/11, public health infrastructure investments are a national priority as part of the HITECH investments under the American Recovery and Reinvestment Act of 2009. While it is true that the majority of the HITECH funding is focused on provider adoption and meaningful use of electronic health records (EHRs), it is also true that the core requirements for meaningful use include using EHRs for public health reporting of immunization data, certain laboratory data, and syndromic surveillance data. Funding is also provided to states to help build infrastructure to support Health Information Exchanges that will allow the transmission of clinical data within their boundaries. The massive overhaul of the nation’s information infrastructure, requiring changes in workflow at hospitals, clinics, private offices, and health departments also necessitates new training in new ways of thinking about how information flows across settings.

The complexity of this national effort is stunning. Because we are immersed in the process, it is difficult to see how long it will take to have a fully interoperable health data system for clinical, research, and public health reporting. While expressing concern about some of the details of implementation and funding levels, most expert observers believe that the efforts to shape the HITECH investments are sound, and represent the full array of investments that will be required to encourage stakeholders to make the major changes envisioned by the legislation [44].

When we look back on this time, we will see that public health informatics continued to strengthen its capabilities to advance and enhance public health surveillance, a core function of public health [45]. But collecting and sharing population health data, a goal for decades, is now almost within reach and it is important to keep learning from our experiences and trying new things if we are going to be successful [46]. For example, centralized data collection and analysis is beginning to be replaced by new federated data models [47] and “big data” approaches that could greatly accelerate biosurveillance capabilities [48]. While these leading-edge



technologies hold great promise, they are still beyond the capacity of most clinical providers and health departments unless they develop new partnerships with academic centers and health systems who share their interest in community and population health.

Even if the nation achieves its adoption goals for electronic health records within the next few years, does that mean that we will also build a robust public health infrastructure for receiving clinical data from health care providers? The imperative for the future is to build systems that want to talk to each other, starting today.

### Review Questions

1. Describe three aspects of the policy process and policy making.
2. Explain the role of federal, state, and local government in public health policy development.
3. What is the role of the private sector in public health informatics policy development?
4. How are public health informatics responsibilities organized at federal, state, and local levels?
5. Describe at least three characteristics of the relationship between Health IT/Health care policy development and public health informatics policy.
6. How have biosurveillance and emergency preparedness (e.g., Katrina) pushed the healthcare agenda around the adoption of electronic health records?
7. Describe three ways to better integrate the information infrastructure for public health and health care.
8. What factors limit our ability to use the array of data and informatics tools that are currently available? How can those be overcome?

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**Part II**  
**The Science of Public Health Informatics**

# Chapter 5

## Public Health Informatics Infrastructure

Brian E. Dixon and Shaun J. Grannis

**Abstract** To monitor and protect communities, societies create public health infrastructures. A capable, prepared public health infrastructure possesses a skilled public health workforce, robust information and communications technologies (ICT), and effective organizations. Yet there are numerous challenges facing public health agencies that seek to update and evolve the public health infrastructure, including budget constraints, rapidly changing ICT, and increased demands on public health workers. To meet the challenges facing public health, organizations must implement a technical architecture that enables integration across information siloes in public health. Organizations must also redesign work processes and system interfaces to support changing work patterns in public health. Finally, public health informaticians must emerge as leaders who can build and support the evolving public health infrastructure. This chapter defines the public health infrastructure, the challenges facing its implementation, and the core components that will help drive public health organizations to meet current and future information needs.

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**Keywords** Public health infrastructure • Information architecture • Immunization information system • Electronic laboratory reporting • Syndromic surveillance • Bidirectional communication • Business process analysis • Usability • Health information exchange • Accountable care organization • Electronic health record system • Public health informatician • Service-oriented architecture

### **Learning Objectives**

1. List and describe the three components of the public health infrastructure.
2. List and describe four dimensions of health care data.
3. List and describe seven components of a health information infrastructure.
4. Discuss twenty-first century policies affecting the collection, management, and use of patient data effecting public health organizations and functions.
5. Define the role of a public health informatician.
6. Identify the challenges facing integration of health data across multiple information systems such as electronic health records.

## **Overview**

To monitor and protect communities, societies create public health infrastructures. A capable, prepared public health infrastructure possesses a skilled public health workforce, robust information and communications technologies (ICT), and effective organizations. Yet there are numerous challenges facing public health agencies that seek to update and evolve the public health infrastructure, including budget constraints, rapidly changing ICT, and increased demands on public health workers. To meet the challenges facing public health, organizations must implement a technical architecture that enables integration across information siloes in public health. Organizations must also redesign work processes and system interfaces to support changing work patterns in public health. Finally, public health informaticians must emerge as leaders who can build and support the evolving public health infrastructure. This chapter defines the public health infrastructure, the challenges facing its implementation, and the core components that will help drive public health organizations to meet current and future information needs.

## **Introduction**

Every nation, state, and local community faces threats to its health from disease, environmental, and human (e.g., war, bioterrorism) agents. To monitor and protect the community, societies create public health infrastructures. A public health

infrastructure can be envisioned as a framework composed of three interconnected *systems*:

1. *Organizations* – Governmental and non-governmental entities with interrelationships that create and enforce policies to protect, monitor, and improve population health.
2. *Information and communications technologies (ICT)* – Hardware, software, and devices that capture, store, manage, exchange, and create data and information used by public health organizations and its workforce.
3. *People* – The public health workforce, which contains both personal and professional interrelationships within and between organizations.

A capable, prepared public health infrastructure possesses a skilled public health workforce, robust ICT, and effective organizations [1]. Since the start of the twenty-first century, the need for an improved public health infrastructure has been a recurring theme in reports at local, state, and national levels around the world. These reports highlight that the existing infrastructure for public health is underprepared for events like the September 11, 2001 and subsequent anthrax attacks in the United States [2–4].

Following events in the early twenty-first century, public health invested heavily to increase its capacity for syndromic surveillance, or the detection of initial manifestations of disease before diagnoses are established [5–7]. This capacity is crucial for national security, and use at the 2002 Winter Olympics, the Indianapolis 500, and other high profile events showed that a contemporary public health infrastructure can provide effective surveillance [8, 9]. While funding for preparedness has been important for updating the public health infrastructure, the focus on syndromic surveillance has diverted attention away from other areas of population health, including communicable diseases as well as the rising epidemic of chronic illness [10]. Going forward, public health agencies are challenged to develop infrastructures that are flexible, with capacity for addressing outbreaks due to terrorism, the food supply chain, migration, and chronic illness. Major shifts in health care financing, the growth of electronic health record (EHR) systems in health care delivery, and a widening array of data sources necessary for population health necessitate further investment in and upgrades to the public health infrastructure.

The Affordable Care Act of 2010 authorized a number of payment reforms to clinical health, including the creation of accountable care organizations in which providers are charged with managing defined populations [11]. Accountable care organizations (ACOs) are further required to conduct community health assessments and report population level metrics to payers, including the US Centers for Medicare and Medicaid Services (CMS). Such changes in the health system challenge traditional roles for public health agencies. Armed with sophisticated electronic information systems, ACOs and payers seek to collect, manage, analyze and report data on chronic diseases, the communities where their populations reside, and the health of their respective populations. Public health agencies must, in turn, evolve from being the only entities capable of assessing and monitoring population health to strategic and enabling partners involved in population health practice.



Health care information management is also experiencing rapid transformation with its shift from paper to electronic records. The adoption and use of information technologies to capture, store and analyze health information began in earnest in the late 1990s. However, the Health Information Technology for Economic and Clinical Health (HITECH) provisions of the American Recovery and Reinvestment Act of 2009 have accelerated adoption by providing incentives to hospitals and physicians to become meaningful users of electronic health record (EHR) systems [12]. To qualify for the incentives, hospitals and providers must comply with a set of administrative rules from CMS [13]. These rules include a set of public health reporting objectives, including the submission of electronic laboratory reports to public health departments for notifiable conditions, submission of information for syndromic surveillance programs, and increased exchange of information with immunization registries. The increasing adoption of EHR systems by hospitals and providers has prompted the Centers for Disease Control and Prevention (CDC), Council of State and Territorial Epidemiologists (CSTE), the Association of State and Territorial Health Officials (ASTHO), and National Association of City and County Health Officials (NACCHO), among others, to urge state and local health departments to prepare for a sharp increase in electronic reporting of data [14, 15].

A sharp increase in electronic reporting of information is ushering in a new era in public health where agencies are increasingly moving from hunter-gatherers of data silos to agrarian cultivators of shared information farms. Historically, public health workers were dispatched into the field to collect data directly from a variety of sources including but not limited to patients, nurses, physicians, allied health professionals. The rise of EHR systems and health information exchange [16] has resulted in more data and information being electronically reported from health care providers to public health agencies. In addition, electronic surveying and crowdsourcing technologies enable public health agencies to capture increasing amounts of information on health behaviors directly from consumers [17]. Current trends suggest that in the future, public health agencies will spend less time gathering the data they need to monitor the health of populations. Public health workers will instead focus their time and energy on analysis and application of the information received. The exploding use of ICT in health care providers and other health-related organizations has also increased the number of potential sources of data for use in public health processes. The shift from hunter-gatherer to data agrarian will also mean that public health agencies will no longer control the entire information chain, becoming collaborators and secondary users of data collected for other, typically clinical, purposes [10, 14].

In this chapter we describe the key elements for a successful, capable public health infrastructure that can address these challenges. We begin by describing core technologies necessary to support existing and evolving needs of public health organizations. Next we discuss the role of public health organizations in designing and managing the public health infrastructure. Finally, we discuss the critical role that people play in supporting and evolving the public health infrastructure.

## A Technical Architecture for Public Health

Historically, public health agencies have created and maintained information system silos that served individual divisions aligned with specific business and regulatory processes (e.g., HIV/AIDS, immunization registry, environmental monitoring). Such a model makes it difficult for program areas to share information with one another, and it requires agencies to gather and store the same data in multiple places. Furthermore, multiple silos increase health agency costs for hardware and software licenses, as well as for personnel costs required to manage multiple systems. Given a changing ICT landscape in which data is cheap, an increasingly ubiquitous cloud for processing and storage, and agencies' need to integrate data and information from a growing list of electronic sources, thought leaders in public health informatics now recommend a standardized approach to collecting data once and using it for multiple business processes within a public health organizations [10, 18]. So called *Write Once, Read Many (WORM) strategies* require that data be normalized – or standardized – to enable each application or data user to share the same understanding of what the data and information mean.

The technical infrastructure in public health, depicted in Fig. 5.1, must seek to normalize data and information across four fundamental dimensions:

1. *Who received health services?*

The infrastructure must capture information about individual(s) who have diseases, receive vaccinations, and/or are exposed to environmental hazards.

2. *Who provided the health services?*

The infrastructure must capture information regarding provider(s) who diagnose a person with a disease/condition/exposure and/or provide treatment to a patient.

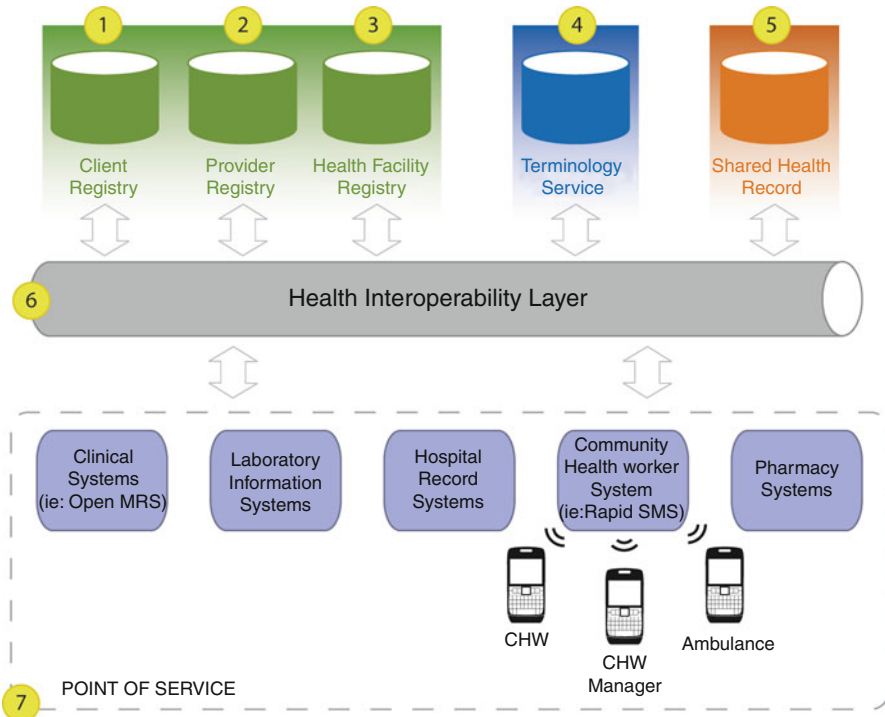
3. *Where were health services received?*

In a fragmented health care delivery system, patients are treated at numerous locations. The infrastructure must capture information describing the location where diagnosis occurred, treatment was performed, and/or the individual was exposed.

4. *What specific care was provided?*

The infrastructure must capture information on what happened during an encounter. What vaccine was given? What was the laboratory result that confirmed a suspected diagnosis? How was the environmental exposure identified?

The architecture in Fig. 5.1 depicts several technical components that enable a public health organization to capture, store, manage, and share information across the four key dimensions. The architecture is based on the *service-oriented architecture (SOA)* concept in which discrete, interoperable services function together as an information system. Each component of the architecture can be a different software application or Web-based service. While each component plays a critical role, the sum of the system is greater than its individual parts.



**Fig. 5.1** A technical infrastructure for public health (Copyright © 2013 OpenHIE. All Rights Reserved. Used with permission)

We now describe each component and how it relates to the other parts of the architecture.

1. An *enterprise master patient index (EMPI)*, or *Client Registry* manages the unique identity of people receiving health services or diagnosed with disease – “For whom”
2. A *Provider Registry* is the central authority for maintaining the unique identities of health providers– “By whom”
3. A *Health Facility Registry* serves as a central authority to uniquely identify all places where health services are administered – “Where?”
4. A *Terminology Service* serves as a central authority to uniquely identify the clinical activities that occur within the care delivery process by maintaining a terminology set mapped to international standards – “What?”
5. A *Shared Health Record (SHR)* is a repository containing the normalized version of content created within the community, after being validated against each of the previous registries. It is a collection of person-centric records for patients with information captured by the health agency.

6. A *Health Interoperability Layer* receives all communications from point of service applications within a specified population, and orchestrates message processing among the point of service application and the hosted infrastructure elements. Other industries refer to this as an enterprise systems bus (ESB).
7. *Point of service applications*, such as an electronic health record (EHR), laboratory information systems, and mHealth applications, are used by clinicians and by other clinical workers to access and update person-centric shared health information and record healthcare transactions.

Furthermore, this architecture is flexible, allowing health departments to add other point of service applications, such as a syndromic surveillance system, or a different kind of data store, such as a de-identified repository of survey data, to the architecture. The SOA approach enables many kinds of applications, services, and repositories to co-exist, provided they are integrated in a manner that allows them to leverage and be leveraged by the rest of the architecture. A health department may have use for multiple kinds of repositories for various legacy (e.g., vital records system) and new (e.g., social media) data types. As long as the repositories are exposed through the interoperability layer to apps and services, an infinite number of options are available for deployment. We now illustrate how the technical architecture supports selected public health functions.

### ***Immunization Records***

An immunization information system (IIS, also known as immunization registry) is a classic example of a public health informatics application. An IIS maintains a longitudinal, person-centric record of immunizations given to an individual over his or her lifetime and supports providers in delivering age-appropriate immunizations, leading to improved vaccination coverage. The main functions of IISs are to:

1. Consolidate immunization data from disparate sources;
2. Provide patient-specific vaccine forecasting/decision support based on known immunization history and patient age;
3. Support the creation of reminder and recall notices;
4. Support proper vaccine inventory management; and
5. Generate vaccination coverage assessments.

IISs exist in most states, and, as of 2011, 84 % of US children aged <6 had two or more immunizations recorded in an IIS [19]. IISs are adept at receiving both batch and real-time information from clinical information systems, in a variety of formats, but rarely provide two-way, real-time information exchange and synchronization between EHRs and the IIS [20]. For example, clinicians often access IISs through standalone applications, independent of their EHR systems, in order to view patient immunization histories and vaccine forecasts. Stage 2 Meaningful Use

regulations issued in 2012 from CMS require EHR systems to exchange immunization data with IISs starting in 2014. These new regulations may result in more bidirectional exchange between EHR systems and IISs.

Bidirectional exchange requires that the public health technical infrastructure be capable of receiving and sending messages with clinical and other health information systems. When a message arrives at the health department, it must pass through the health interoperability layer (#6 on Fig. 5.1) and match to a patient record in the shared health record (#5 on Fig. 5.1). This is facilitated by a call to the client registry (#1 on Fig. 5.1), which attempts to link the incoming message to an existing patient. If no match is found, then a new patient record can be created. Next, the health interoperability layer matches information in the immunization message to data in the provider (#2 on Fig. 5.1) and facilities registries (#3 on Fig. 5.1), respectively. Here the system seeks to ensure that the provider administering the immunization and the facility in which the immunization was given match to known providers and facilities in the jurisdiction. Finally the system calls the terminology service (#4 on Fig. 5.1) to match the information about which immunization(s) were administered to the patient or the reason(s) for refusal. Standardized vaccine data, such as CVX codes developed and maintained by the CDC, provide the name of the vaccine along with the manufacturer name and lot number [21]. Once the various parts of the incoming message have been matched to client, provider, facility, and terminology data, the information in the message can be stored in the shared health record. The infrastructure now supports storing millions of immunization events in the shared health record along with other existing information about the individuals – such as birth certificate records.

The other function of an IIS is to provide decision support to providers, informing nurses and physicians when a patient is overdue for certain immunizations (e.g., pneumovax for adults over 65). A shared public health infrastructure can support this through an interface with the IIS [19]. A physician can use the IIS to query the infrastructure to receive an immunization history and recommendations on overdue items. The IIS calls the health interoperability layer, which uses the client registry to locate all immunization records in the shared health record for the selected patient. The raw immunization records are then passed back to the IIS, which can deliver them to the requesting physician along with recommendations derived from the shared health record. The IIS and infrastructure work together to manage person-centric immunization data.

### ***Electronic Laboratory Reporting***

Electronic laboratory reporting (ELR) involves the transmission of laboratory data, following the confirmation of a reportable disease, to a public health agency. ELR has been used successfully in a number of cities, states, and nations to improve public health surveillance [22, 24]. Public health agencies that have implemented and used ELR report a number of benefits. First, notifiable disease reports that

arrive electronically arrive faster than the previously used paper-based reports [22, 24, 25]. Second, ELR has been shown to increase completeness or the proportion of reportable disease reports that are transmitted to public health [22–25]. Thus ELR addresses the problem of underreporting of reportable disease cases [26, 27].

Currently, more than 40 states in the US have some capacity to receive electronic reports from laboratories [28]. Given previously variable adoption rates, routine ELR was made a requirement under Stage 2 Meaningful Use regulations. Laboratory information systems are required to electronically submit laboratory results to EHR systems for delivery to clinicians, and hospitals must electronically report laboratory results for notifiable disease cases to public health departments [13]. The CDC and other public health organizations anticipate the regulations will significantly increase ELR adoption [14].

ELR can leverage a common public health infrastructure by connecting lab information systems to the health interoperability layer. As lab messages arrive, the patient, provider, and facility information can be matched to respective records in the client, provider, and facility registries. The vocabulary service interprets the Logical Observation Identifiers Names and Codes (LOINC<sup>®</sup>) codes, which identify the test performed by the laboratory [29], and the Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT<sup>®</sup>) codes, which identify organisms, substances, diseases, and other findings from the lab test [30]. Data from the ELR messages could then be stored in the shared health record, linking multiple tests performed on the same individual to aid in case investigation procedures. The shared health record would also link ELR information to immunization history and other clinical observations known by the health department about an individual. Other information systems in the health department could query or extract data from the shared health record to aggregate counts of reported disease or examine relationships between immunization history and diagnoses for vaccine-preventable disease.

## *Syndromic Surveillance*

Syndromic surveillance detects initial manifestations of disease before diagnoses (clinical or laboratory) are established [5–7]. Data and information in syndromic surveillance systems come from a variety of sources, including hospital emergency department visits, ambulatory clinic visits, school absenteeism, poison control centers, and over-the-counter medication sales [26]. Data are usually reported as de-identified lists or aggregate counts of cases due to laws that prohibit sharing identified data (e.g., Family Educational Rights and Privacy Act [FERPA] does not allow schools to provide identified child records).

According to a survey conducted by the International Society for Disease Surveillance, around 80 % of state and territorial health departments in the US performed some form of syndromic surveillance as of 2007–2008 [31]. The United Kingdom [32], Armenia [33], Taiwan [34], and New Zealand [35] have also

implemented syndromic surveillance systems, and there is growing interest in these systems in low and middle-income nations [36].

Syndromic surveillance, like ELR, poses several challenges for public health agencies. A primary challenge is coordination and integration of syndromic surveillance systems. A report by the US Government Accounting Office describes 19 surveillance systems, as of 2004, in use at the state and federal levels [37]. These systems have a need to talk with one another [26], either to exchange information between levels of government or integrate multiple syndromic indicators into a single “view” of a community or region. These systems, however, do not all use a single messaging platform that enables easy integration, and data standards that enable semantic interoperability remain a challenge.

Use of a common infrastructure within a health agency may be a solution to some of these challenges. Incoming messages could be passed to the health interoperability layer, which could resolve provider and facility identifiers in the messages using the respective registries. The client registry would not be used when syndromic information is de-identified. The vocabulary service can support grouping messages – which typically contain open-ended text – into syndrome categories for use by the surveillance system. Syndromic data could also be passed directly to the syndromic surveillance system, or stored in a separate repository.

Storing data in the shared health record would be suboptimal given that patient identities are obfuscated or absent. A constrained shared repository for managing de-identified surveillance data could enable the data to be utilized by multiple applications within the health department instead of just a surveillance system designed specifically for syndromic information. For example, population health assessments or surveys, like the Behavioral Risk Factor Surveillance System (BRFSS), which capture de-identified data on populations, would be supported by the constrained data repository. Co-located population data could be combined by point of service applications to explore social determinants of health [38] or multi-source surveillance activities [39, 40].

### ***Bidirectional Communication***

Public health has a responsibility to both monitor disease and inform the community on events involving disease spread and management. Thus the public health infrastructure requires the capacity to both receive data from health care information systems and deliver information to clinical systems. In other words, the public health infrastructure needs to support bidirectional communication with EHR and other health information systems. Informing front line clinical staff about population health outcomes and events using a common infrastructure is form of public health decision support [41].

Currently health departments often communicate community-level information or statistics to physician offices and hospitals using postal mail or electronic newsletters [42]. As the public health infrastructure becomes more

interoperable, bidirectional communication from public to clinical health information systems is likely to increase [41]. The common infrastructure we describe supports bi-directional communication in a variety of scenarios, such as:

1. *Public health alerts*, used to raise a clinician's index of suspicion for known or as of yet unidentified disease or condition emerging in the community. For example, one study utilized a common clinical infrastructure outside the EHR to deliver guidance and information on vaccine supply management to primary care clinicians during the H1N1 outbreak [43]. Other studies have examined methods for pushing alerts directly into EHR systems based on increased reports of shigellosis or another reportable disease [44, 45].
2. *Routine population health statistics* to support healthcare organizations and their increasing responsibilities for patient population health management. By making health statistics and research results more readily available to support clinical decision-making, both the clinician and the patient are enabled to make better-informed decisions about a course of treatment.
3. *Person-specific case management* or other information to support coordinated care management between clinical and public health.

A common infrastructure in public health can support knowledge repositories and applications that push alerts and information out to providers using the health interoperability layer. Provider and facility registries can contain electronic addresses for providers that enable routing of messages both to and from clinical information systems.

## **The Indiana Network for Patient Care: A Real-World Instantiation of a Robust Information Infrastructure Supporting Public Health Processes**

The Indiana Network for Patient Care (INPC) is the nation's longest-tenured and most comprehensive health information exchange (HIE). Researchers at the Regenstrief Institute created the INPC in 1995 with the goal of providing clinical information at the point of care for the treatment of patients [46, 47]. The architecture of the INPC inspired the technical architecture described in this chapter, and the INPC remains an active technology laboratory influencing the evolution of the public health infrastructure given the examples below where the HIE is used to support a wide range of public health functions.

The INPC includes clinical data from more than 49 hospitals; local and state health departments; local and national laboratories; a national pharmacy benefit manager (PBM) consortium; long term post-acute care (LTPAC) facilities; free standing radiology centers; emergency management services (EMS); and several large-group practices closely tied to hospital systems. The INPC data repository



carries over 4.3 billion pieces of clinical data, including over 79 million text reports, for approximately 25 million different patient registrations totaling approximately 12 million unique patients.

The primary use of the INPC is to improve communication and decision-making in the context of individual patient care. However, because the INPC standardizes incoming clinical and administrative data, the HIE enables a wide range of secondary uses, including public health reporting and syndromic surveillance [46, 48]. For example, clinical laboratory test results are mapped to a set of common test codes (e.g., LOINC<sup>®</sup>) with standard units of measure for use in patient care (e.g., displaying all blood lead level measurements chronologically in a table or chart for clinician review), public health (e.g., identifying elevated blood lead levels in pediatric patients reportable to public health), and research (e.g., extracting address data for patients with elevated lead levels and integrating such information with the geographical locations from environmental studies identifying elevated soil lead levels). These are similar activities to those in health departments around the world, and the INPC often partners with local and state health departments to facilitate access to data they need to support the core functions of public health.

Since 1998, the Regenstrief Institute has maintained an operational, automated electronic laboratory reporting (ELR) system [49] called the Notifiable Condition Detector (NCD) as a service provided by the INPC. The NCD identifies clinical results that are positive for reportable conditions and automatically reports them to both local and state health departments in near real-time, as well as providing daily aggregate counts for all reportable conditions found. Data sources (hospital, state health, and referral laboratories) transmit results to the INPC in electronic format. The NCD processes incoming ELR messages using Logical Observation Identifiers Names and Codes (LOINC<sup>®</sup>) codes [29], ICD-9 diagnoses, and natural language processing [50] to determine if a test is potentially reportable, and the NCD uses the CDC reportable condition mapping table [51] to verify reportable conditions. Final results are shared with health agencies in a variety of formats including Health Level 7 (HL7<sup>®</sup>) and comma delimited files (CSV), based on the jurisdiction's technical capacity. The NCD is a freely available component of Regenstrief's Open Medical Record System (OpenMRS) platform, which enables implementation and use by health care providers in over 100 nations around the world [52–54].

The INPC has further supported efforts to increase infection preventionists' (IP) awareness of patients' MRSA infection history and reduce the spread of healthcare acquired infections (HAIs) in INPC facilities. Over the course of 1 year, we found that 286 unique patients generated 587 admissions accounting for 4,335 inpatient days where the receiving hospital was not aware of the prior history of methicillin-resistant *Staphylococcus aureus* (MRSA) [55]. These patients accounted for an additional 10 % of MRSA admissions received by study hospitals over 1 year and over 3,600 inpatient days without contact isolation. To improve physician and IP awareness of patients who should be in contact isolation given a history with MRSA or vancomycin-resistant *enterococcus* (VRE), we first developed and implemented a clinical reminder to alert physicians when a patient on the contact isolation list did

not have a standing order for contact isolation [56]. Then, we expanded this innovation to the INPC, alerting IPs when patients who had a history of MRSA or VRE were admitted to their facilities [57, 58]. In the first year, the INPC delivered 2,698 admission alerts for patients with a history of MRSA, one-fifth of which (19 %) were based on data from a different institution.

## **Managing the Public Health Infrastructure: The Role of Organizations**

Public health organizations manage the public health infrastructure. They carry out their duties in three ways:

1. By *creating and enforcing policies*, public health organizations define the scope of the public health infrastructure.
2. By *organizing work*, public health organizations define the business processes that drive the public health infrastructure.
3. By *managing people*, public health organizations define how and when the workforce can access and use public health data and information.

The work performed by public health agencies is diverse and expansive in nature. The Institute of Medicine [59] defines three core functions of public health:

1. Assessment and monitoring of the health of communities and populations at risk to identify health problems and priorities;
2. Formation of public policies to solve identified local and national health problems and priorities; and
3. Assurance that all populations have access to appropriate and cost-effective care, including health promotion and disease prevention services, and evaluation of the effectiveness of that care.

The nature of public health is shifting in the twenty-first century. Whereas public health activities have largely focused on monitoring and intervening in the spread of communicable diseases (e.g., polio, tuberculosis, HIV/AIDS), chronic and environmental threats are increasing in prevalence. Therefore while agencies must continue to record data on the spread of infection and fight emerging diseases that spread quickly, efforts at many public health organizations are expanding into community-based interventions to improve self-management of chronic illness and complex physical/social/behavioral interventions to prevent environmental and chronic disease in healthy populations. Furthermore, the Patient Protection and Affordable Care Act (PPACA) of 2010 requires private ACOs to conduct annual population health assessments, blurring the traditional line between private and public health organizations [11].

Therefore the technical infrastructure described here is a suggested core designed to support a wide range of public health functions. However, unique laws, regulations, and requirements of a given public health organization may necessitate

amendments or additions. As new policies are enacted that change the nature of public health work, the infrastructure that supports public health will need to be amended.

This point is illustrated in the National Institute of Standards and Technology's Enterprise Architecture Model, which emphasizes that an organization's business processes should drive its infrastructure [60]. Effective management of the public health infrastructure will require organizations to understand its business processes and the needs of public health workers. Otherwise, health departments will suffer the same fate as the one in New Jersey, where the introduction of ELR led to a significant increase in the completeness of disease reports, but it "exceeded local investigative capacity" [61].

### ***Business Process Analysis and Redesign***

A business process describes a set of activities and tasks that logically group together to accomplish a goal or produce something of value for the benefit of the organization, a stakeholder, or a customer [62]. In the context of public health, a business process is intended to support the needs of the health agency, community, or a target population. Because information technology and services facilitate business processes, a clear understanding of these processes is needed to ensure that public health informatics strategies will result in maximally effective and efficient support of public health needs.

Documenting business processes and re-designing them to meet the challenges associated with (a) the shift from acute to chronic disease surveillance and (b) increasing electronic data flows from clinical health, can be achieved using business process analysis (BPA). BPA gathers information from stakeholders about existing processes with an eye towards redesigning them to improve efficiency or enhance the value they produce. This technique has been utilized by the Public Health Informatics Institute (PHII) to redesign and enhance multiple business processes in the context of public health. For example, PHII has defined functional requirements for immunization information systems [20, 63] and public health surveillance [64]. BPA is further recognized and recommended as a best practice for achieving the Public Health Informatics agenda [18].

### ***User-Centered Approach***

In addition to analyzing and redesigning business processes, public health organizations need to understand end users' (public health workers') information needs [65]. Asking and involving users in the design, development, and implementation of the infrastructure will maximize the likelihood that ICT in agencies meets not only the business needs but also the context of use.

User-centered approaches require early and frequent involvement of frontline public health workers. When designing a system or process, workers should be asked about their needs. Low fidelity prototypes or wireframes can be used to elicit and identify user needs before any system engineering work has been done [66], reducing cost to make changes after implementation. If purchasing a commercial system, users can review screenshots, process diagrams, and interact with demo systems to provide feedback to the group in the organization making purchasing decisions. Usability testing can also be performed where end users attempt to complete certain tasks using an information system [67]. Vendors can be asked to make a test or demo system available to the organization for such testing during the evaluation process if specified in request for proposal documentation.

## **Managing the Public Health Infrastructure: The Public Health Workforce**

People are the third critical component of the public health infrastructure. Managing the infrastructure requires public health organizations to ensure their workforces are knowledgeable and capable. In the modern era, the public health workforce requires competencies in informatics. Organizations must train and prepare two types of staff: end users and public health informaticians. End users are epidemiologists, communicable disease nurses, food safety inspectors, and others on the front lines of public health who *interact with information systems*. Public health informaticians are those who help organizations *design, manage, and evaluate information systems and work processes*.

### ***Public Health Informaticians***

The role of a public health informatician is defined by consensus-based competencies [68, 69] from the CDC, Association of Schools of Public Health (ASPH), and American Medical Informatics Association (AMIA). Public health organizations must hire or train informaticians to meet their informatics needs. An emerging, increasingly necessary role within a public health organization is a Chief Public Health Informatics Officer. This management or executive position bridges the gap between public health program areas, the ICT department, and the senior health officer.

Currently there is a paucity of these officers in local and state health departments. Consequently, there is great need to train and mentor epidemiologists and other senior program officials into informatician roles. The CDC and public health professional organizations are currently working to identify and prepare

epidemiologists and other senior program officers to become informaticians. In the future, it will be critical for these and other existing public health informaticians to mentor junior informatics-trained individuals in their region or across jurisdictions. ASTHO and CDC have created public health informatics internship programs to provide experiential learning opportunities for individuals with training in informatics. It is likely the US will need many of these types of programs. Furthermore, model job descriptions are needed to ensure consistency in the role of public health informatician across jurisdictions.

### ***Public Health End Users***

The growing need for public health informatics competencies will further require schools of public health to produce available candidates for positions that will work to modernize information systems and strategically align information needs with work processes. Faculty in public health schools will either need to create informatics concentrations or specializations within epidemiology degree programs, or they may collaborate with schools of information, computing, or informatics to offer joint majors or minors in public health informatics. These programs will provide modern competencies to emerging public health professionals, which can be leveraged by departments to train existing personnel.

Public health professionals across the infrastructure will need some understanding of informatics, ICT, and how information is central to work processes. Such core knowledge as a component of training in public health will help the workforce collaboratively work towards improving public health systems and population outcomes.

### **Conclusions**

The public health infrastructure requires a skilled public health workforce, robust ICT, and effective organizations. In this chapter we have reviewed a model ICT architecture, examples where information systems are supporting effective public health practice, key informatics factors for managing organizations, and important informatics aspects of the workforce. These dimensions of the public health infrastructure are complex and evolving. One thing that is clear is the public health infrastructure will change as health reform is implemented and additional information systems are adopted in both clinical and public health. The principles and lessons in this chapter, however, should help guide informaticians seeking to design, implement, evaluate and evolve ICT across the public health infrastructure.

### Review Questions

1. Describe the three components of the public health infrastructure. How do the interconnected systems that define the public health infrastructure work together to support public health practice?
2. What challenges does the public health infrastructure face, and how can public health organizations respond to these challenges?
3. Describe four dimensions of health data. How can a technical infrastructure supporting these dimensions be leveraged across public health use cases, such as immunization registries and communicable disease case reporting?
4. Describe how population health assessment data could be integrated into a common public health infrastructure operating in a county health department. What new data sources, repositories, or applications would be involved in the integration?
5. How can public health agencies leverage community-based health information exchange initiatives to support their mission of population health monitoring and improvement?
6. Describe how a public health organization might redesign its communicable disease reporting processes to manage a significant increase in electronic laboratory reports.
7. What are the roles of a public health informatician in building and enhancing the public health infrastructure?
8. Define business process analysis and its role in supporting public health infrastructure.
9. How has growth in EHR systems and health information exchange impacted the nature and volume of information, and how has this growth impacted public health data gathering processes?

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# Chapter 6

## Information Architecture

Dina Dickerson and Patricia Yao

**Abstract** Public health information today is spread across many programs, most with their own method for identifying people and related data elements, a program-level data model, nonstandard vocabulary, program specific vertical workflow, and customized reports. A single office may use multiple processes to manage workflow information, including paper, fax, spreadsheets, electronic documents, and proprietary databases. If needed data resides in another database silo, the process may include a custom interface that then must be maintained as another step in the process to capture and manage public health information.

These disparate data silos translate to fragmented and redundant public health data and workflow and the inability to present a complete picture of an individual or population, further distancing care coordination and the achievement of best outcomes. An effective information architecture must address the issue of interoperability between data silos and serve as a guide for transitioning to shared data and optimized workflow. A shared data model using standards-based metadata tags and attributes is the best option for public health to begin this transition.

Adopting a shared metadata model enables exchange of information with other standards-based systems, such as electronic health records, without redundant data entry. It enables care to be coordinated across programs and agencies according to best practice evidence and reinforced with alerts and reminders to individuals and providers. A shared metadata model is extensible to other disciplines in the public

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sector, such as education and child welfare, by populating the model with content from those domains. Standard terminology practices are facilitated and the model becomes scalable to large populations. Given public health funding and workload realities, moving toward a shared metadata model will occur in a phased approach with programs joining the process over time, and according to priority assigned by a governance body of stakeholders.

**Keywords** Interoperability • Information architecture • Syntax • Semantics • Logical data model • Vocabulary • Metadata • Value sets • Clinical Document Architecture • Continuity of Care Document • Data governance

### Learning Objectives

1. Define the concept of information silos and understand their impact on the practice of public health.
2. Define the concept of a public health shared standards-based data and services model and explain how it can be used to coordinate care according to best practice evidence across individuals, providers and organizations to improve health outcomes for the population.
3. Explain how public health information architecture is simplified through the use of common identifiers and metadata standards, and how the model extends to other public sector domains, such as education and child welfare.
4. Summarize two strategies for moving public health programs from data silos to a shared data and services model.

## Overview

Public health information today is spread across many programs, most with their own method for identifying people and related data elements, a program-level data model, nonstandard vocabulary [1], program specific vertical workflow, and customized reports. A single office may use multiple processes to manage workflow information, including paper, fax, spreadsheets, electronic documents, and proprietary databases. If needed data resides in another database silo [2, 3], the process may include a custom interface that then must be maintained as another step in the process to capture and manage public health information.

These disparate data silos translate to fragmented and redundant public health data and workflow and the inability to present a complete picture of an individual or population, further distancing care coordination [4] and the achievement of best outcomes. An effective information architecture must address the issue of interoperability between data silos and serve as a guide for transitioning to shared

data [5] and optimized workflow. A shared data model using standards-based metadata [6] tags and attributes is the best option for public health to begin this transition.

Adopting a shared metadata model enables exchange of information with other standards-based systems, such as electronic health records, without redundant data entry. It enables care to be coordinated across programs and agencies [7] according to best practice evidence and reinforced with alerts and reminders to individuals and providers. A shared metadata model is extensible to other disciplines in the public sector, such as education and child welfare, by populating the model with content from those domains. Standard terminology practices are facilitated and the model becomes scalable to large populations. Given public health funding and workload realities, moving toward a shared metadata model will occur in a phased approach with programs joining the process over time, and according to priority assigned by a governance body of stakeholders.

## Background

Healthy People 2020 [8], which establishes national public health goals for this decade, calls out the role of health information technology (HIT) in building and integrating the HIT infrastructure in alignment with national standards-based initiatives and models to support public health measures and interventions, health literacy, and health communication efforts. In the case of public health, the enterprise is the population of patients and providers; the standardized services address the essential functions and roles of public health as first described by the Institute of Medicine (IOM) [9], and later detailed and expanded to include governance by the Public Health Accreditation Board (PHAB) standards and measures [10].

The essential functions and roles of public health are summarized as follows:

- Monitor health
- Diagnose and investigate
- Inform, educate and empower
- Mobilize community partnerships
- Develop policies
- Enforce public health laws
- Link to and provide care
- Assure competent workforce
- Evaluate
- Research
- System management
- Governance

These functions and roles are supported today by myriad information silos. Lacking data standards, information silos are incapable of reciprocal exchange with related information systems [11]. Typically, they are vertical information management systems that were developed to address a single problem or program

workflow, without regard to sharing information with other programs. Silos are a barrier to obtaining a comprehensive view of a client's service needs and interventions, a provider's participation, or coordinating care across providers. Moreover, information silos are burdensome to the frontline users who must enter the same data into multiple programs, often with different interfaces and data formats. It is expensive to create and maintain parallel information systems and the data are difficult to combine to serve the needs of public health or for research and policy analysts to analyze and interpret data.

## Interoperability and Information Architectures

Interoperability is defined as the ability of diverse systems and organizations to work together (inter-operate) [12]. Information architecture supplies the standard definitions and protocols for data within the business architecture; the business architecture supports standardized services that address the goals and objectives of the enterprise [13].

Information architecture is akin to the data schema for the enterprise. It describes the relationships between entities, including patients, providers, programs, organizations, and evidence-based practice protocols, to achieve the goals of public health. The information architecture needs to be scalable to the population and extensible across public health knowledge domains in support of those essential public health functions, including communicable diseases, immunizations, maternal and child health, environmental health, and chronic diseases, because a single individual can be served by any and all of those domains. However, there is no universally-accepted information architecture in place today for public health, although work has been done to address public health reporting needs in other models, such as the Federal Health Information Model [14], Public Health Data Standards Consortium [15], the HL7® Clinical Document Architecture (CDA) [16], National Information Exchange Model (NIEM) [17], and the National Human Services Information Architecture (NHSIA) [18]. In general, there are thousands of heterogeneous and geographically diverse databases that are limited in scope, have proprietary content and structure, and are not designed to share data. This makes it challenging to obtain a comprehensive view of risks and other determinants of health, services and interventions provided to patients, outcomes of those interventions, or to coordinate care across providers and programs. The core of the HIT infrastructure to address this problem is the information architecture.

## Interoperability and the Problem of Information Silos

Interoperability enables information to be shared across systems based on common representation (*syntax*) and meaning (*semantics*) [19]. The information architecture needs to support, integrate and organize the work of public health so data sharing is



Fig. 6.1 Public health shared services model aligned with IOM and PHAB models

fundamental to the process. For public health to function effectively, common standards-based data and validated workflow tools need to be shared across programs. The essential functions and roles of public health described above identify the major categories of work that need to be addressed.

To document the extent of data silos and then to align and systematize the public health program-level work with the IOM and PHAB models, qualitative research was conducted in Oregon in which 142 database silos for 41 state programs were analyzed for content and functionality, and key informants were interviewed concerning the purpose of the system and goals of the State programs [12]. From that analysis, 36 common services were derived that support programmatic functions. Those common core services were aligned with the IOM and PHAB models to create the Public Health Shared Services Model depicted in Fig. 6.1.

Each of the 36 services referenced in the outer and inner rings of Fig. 6.1 are comprised of data and workflow that can be represented in a standardized way that the information architecture aligns and supports. The identified public health services and data that can be shared across programs are grouped below according to the categories of *assessment*, *policy development*, and *assurance*. System management and governance underlie all of the services. While data from different services can be structured in a consistent and simplified format using metadata tags, attributes of

the data elements will vary across services but remain consistent within a service, so the information architecture should organize each service into its own object or module.

## Assessment

- Identification and Demographics: Every child, adult, and family served, and every provider of services, organization, and site, needs a unique master identifier [20] that is used to link their records across systems. An identity resolution tool would make that link by comparing multiple data elements, such as name, address, date of birth, and gender. Demographics are metadata classes that are used to stratify individuals, such as race and ethnicity, and establish risk groups, such as zip code, gender, and age. The information architecture needs a module or object that contains the cross-sectional data about an individual, such as date of birth and death, and a companion object that contains data elements that occur in a many to one relationship, such as race and contact information.
- Screening: Standardized screening tools are used to identify potential health, mental health, developmental delays, or problem areas for a target population. The screening tools are typically used according to a standardized schedule, but can also be administered at any time if a provider suspects a potential problem or has a concern. The information architecture needs to address both the screening tool elements, such as result of *positive* or *negative*, and the administration schedule, such as *at 6 months and 12 months*, to enable the data to be used for care coordination.
- Registries: A registry is a system for tracking a cohort of individuals who share some common characteristic. Registries typically have considerable domain-specific data that is not a candidate for sharing, but membership in the registry and a status indicator such as up-to-date with immunizations is important to share. The registry identifier, date of enrollment, diagnosis, procedure, birth, death or other relevant date together with other defining data that marks the individual as a member of the cohort can represent membership in a registry. Designation of membership in a registry permits a simplified representation of the data in the information architecture and the identifier enables linkage back to the registry if more information about the individual is required.
- Surveillance: Surveillance is the practice of continuously gathering, analyzing, interpreting and disseminating data about diseases or conditions, such as developmental disorders like autism, communicable diseases like Hepatitis C or visits to emergency rooms for influenza-like illness. It also includes periodic surveys such as the Perinatal Risk Assessment Monitoring Survey of the CDC that are monitored over time for trends. Surveillance is related to screening but focuses more on the distribution and possible causes of diseases in a population so requires a different set of attributes in the information architecture model.

- **Testing:** Testing for a health problem or hazard is a method for measuring, detecting and diagnosing markers for diseases, conditions or agents. In general, tests can be represented by CPT or LOINC<sup>®</sup> codes, diagnoses by ICD-9 or ICD-10 or SNOMED-CT<sup>®</sup> codes, and other agents by other relevant data standards. A positive result for a test may include a trigger for other testing or follow-up and needs to be addressed in the model.
- **Conduct Investigations and Compliance Reviews:** A systematic method for reviewing processes and procedures for an entity that are measured against a standard. Compliance investigations and reviews involve a comparison of standards-based practice protocols with the actual practice of service delivery. As such, the information architecture needs to accommodate the elements of the practice protocol, including service delivery schedules, and findings of the investigation. If deficiencies are detected, practitioners, and facilities may be placed on probation with specific issues to remedy within a designated time frame. The existence of deficiencies in the data can be used to trigger the capture of additional data elements to track progress on the measures.
- **Response and Mitigation:** Conduct investigations or implement measures to enable an adequate response to health hazards. If health hazards are detected, such as an outbreak of norovirus at a restaurant, public health officials can require the facility or provider to undertake corrective actions. The information architecture for this module or object needs to allow multiple corrective actions for each hazard identified as well as subsequent follow-up for each action to determine if the problem is resolved.

## Policy Development

- **Health Promotion and Disease/Injury Prevention:** Population-based educational prevention-related activities designed to reduce disease and injury. Health promotion and disease/injury prevention activities involve the creation, organization, distribution, and presentation of evidence-based or best practice educational materials and interventions. It also involves scheduling and tracking of the distribution of these materials and presentations including the audience targeted, all of which must be accommodated in the information architecture module or object.
- **Advise and Consult:** Provide information to the governing entity, health providers and public to identify and address health problems. Public health practitioners engage with health providers, the public and governing bodies through a variety of means including steering committees, advisory committees, workgroups, expert presentations, and other methods. Data associated with advising and consulting is comprised of membership rosters for committees and workgroups, identification of practitioners and consultants who are expert in the field, materials to support advice and consultation, event scheduling and outcome tracking.



- **Business Continuity:** Develop advance arrangements & procedures to continue critical business functions. If a disaster occurs, such as an earthquake or flood, public health needs to be able to continue its critical functions. Business continuity involves planning, simulations and testing to assure that the business does continue. Plans are created for switching to redundant information systems for critical services, such as the immunization registry, and other procedural steps to keep critical services operational. The information architecture needs to accommodate the creation, testing, and maintenance of these plans.
- **Emergency Response Planning:** Conduct planning and maintain an All Hazards/ Emergency Response plan. Emergency response planning is similar to business continuity but extends to procedural data that identifies the mitigation steps in the emergency response plan, and the resources to marshal in addressing health-related threats associated with the emergency. Those resources include providers who can be called upon to assist in and materiel that can be employed in the emergency. Data about provider specialty, geography, and availability require tracking, along with inventories of supplies such as vaccines and procedures for each program are included.
- **Health Improvement Planning:** Comprehensive planning that includes population assessment resulting in a health improvement plan. For example, population assessment data for a jurisdiction may indicate a high rate of sexually transmitted diseases (STDs) among the young adult population compared with similar jurisdictions. A health improvement plan could target that cohort with a health promotion campaign or intervention delivered in the schools and other places where young adults congregate. Data might include baseline and follow-up STD rates for the jurisdiction, data about the intervention, and data about the cohort targeted. It also includes process data about stakeholder meetings and schedules.
- **Strategic Planning:** A process for organizing resources to appropriately direct them toward meeting goals and objectives. Strategic planning involves stakeholders working together to establish goals and objectives and to identify participants, materials and activities necessary to achieve those goals.

## Assurance

- **Licensing and Permits:** Grant, give permission or authorize a health-related or health care activity. Public health licenses restaurants, swimming pools, providers, ambulances, medical equipment, and many other entities that have the potential to impact the public's health. Typically, an entity must meet specified criteria to be eligible for licensure and then be subject to periodic review of compliance for continued licensure.
- **Rules and Regulations Enforcement:** Draft, administer, and enforce administrative rules. Public health has the authority to set standards for entities that impact the public's health, such as restaurant sanitation criteria, and to shut down entities

that are not in compliance with those standards. This data would involve the set of standards that must be followed by a class of entities, and the data that tracks inspections, violations, and mitigations of those standards.

- **Health Service Delivery:** A program or entity that assures health care services meet standards or provides essential services. Public health provides health care services for populations that otherwise would not have access to those services. For example, nurse home visiting services are provided to pregnant women who are at risk for a poor birth outcome because they are teenagers, homeless, substance abusers, in abusive relationships or have other risk factors. This data is focused on the clinical and nonclinical encounter, and as such involves information about the client's problems, diagnoses, care plans, compliance with the care plans, interventions, and information about the provider and facility responsible for the client's care.
- **Referral:** A referral occurs when a provider identifies the need for a specialist to evaluate an individual. For example, if an infant fails a hearing screening test, that child would require a referral to an audiologist for diagnostic testing. If hearing loss or problems are confirmed, a second referral is made to Early Intervention services. Evidence-based protocols need to guide the referral process to prevent loss to follow-up. Also, the referring provider needs to be notified of the outcome of each of these referrals. The information architecture needs to address all of these components.
- **Eligibility:** To meet qualifications to gain access to services. Every public health program has eligibility criteria as a condition of enrollment for its services, such as pregnant, income at 185 % of Federal Poverty Level, geographic area, or HIV positive status. Eligibility criteria for an individual are the same as risk factors or demographics. The information architecture needs to include an object or module that designates which criteria belong to which program so that those criteria can be compared to an individual's risk or other factors to determine eligibility to receive services for any program.
- **Enrollment:** To enter a register, list or meet qualifications to gain access to services. Enrollment into a program can occur for those individuals whose risk and other factors align with the program eligibility criteria. Enrollment includes a start and end date for the individual's participation in the program along with the client and program identifier. As the client may be enrolled in more than one program at any time, the information architecture needs to permit multiple simultaneous enrollments.
- **Care Coordination:** Every program has a set of services that it offers to eligible clients. Clients may be eligible for and enrolled in more than one program and may be receiving services from multiple providers. Those services are delivered over time according to a schedule set by the program. Care coordination, or case management, could help families align and navigate multiple providers and schedules, and could help providers keep track of their client caseload and document client encounters, risks assessed, services provided, and outcomes derived from interventions. The information architecture needs to include the care plan that is made up of a set of service identifiers and target timeframes and

acceptable variances on those timeframes for service delivery, such as Month1, Month2, Month3, and so on. It also needs to include a separate object for identifying the client's calculated schedule for the program's services based on the enrollment date or whatever other trigger is defined for the program, such as estimated due date for a pregnancy, and an actual service delivery date. The actual date can be compared with the variance defined in the care plan to determine compliance with the program.

- **Providers:** Qualified workforce that delivers care to the patient population. Providers require a unique identifier, such as UPIN or NPI, so that a comprehensive view of the clients they serve and the services they deliver can be obtained. Similar to clients, the information architecture needs to accommodate both cross-sectional and longitudinal data about the provider including contact information, specialty, affiliations with organizations, care delivery sites and clients.
- **Training:** Assess staff competencies and provide organizational and individual training and development opportunities to achieve workforce competency. Public health provides training and testing for some disciplines with public health impact, such as emergency management technicians or organizations using radiologic equipment. Data needed for the training function focuses on the library of the training classes and materials available for the discipline, schedules for those training classes, rosters of individuals who attend the training class, and a designation for pass or fail for the training class.
- **Certification:** Provide, assure or obtain professional certification of knowledge or competencies. The certification function draws on historical data for the provider along with data obtained through the training function to determine competency. The certification data includes criteria that defines competency such as the set of training classes that must be passed or other factors that must be present within a given time frame. This data can be compared with an individual provider or organization records to determine eligibility for certification. Certification eligibility may also involve disciplinary actions or revocation of certification until corrective measures are taken. The object or module needs to address each of these data needs.
- **Performance Measures and Outcomes:** Evaluate and improve public health processes, programs, interventions, and quality assurance. Every program has a set of performance measures and outcomes, which are used to assess how well it meets its intended goals, and objectives and where it might do better. The data associated with performance measures and outcomes often takes the form of constructs or benchmarks that are made up of other data elements. For example, a program performance measure might be the percent of pregnant women who stopped smoking during their pregnancy. This construct examines the cohort of women who are both pregnant and smoking at the time of enrollment into the program and compares that baseline data with the assessment of smoking throughout the pregnancy to determine the outcome. Research analysts who need a systematic way to create their constructs typically perform this work to evaluate benchmarks based on the services provided by a program and then compare those constructs against client and service data collected over time for the program.

- Service Quality and Best Practices: Conduct and promote the understanding and use of research, evaluation and evidence-based practices. Public health researchers evaluate interventions and conduct research to determine which practices yield the optimum results for the population. Those practices are termed *evidence-based practices* and public health promotes their use throughout the population and within the provider community. Data for this service involves both a roster of evidence-based practices for a discipline as well as data examining individual providers, programs, and organizations for their fidelity in using evidence-based practices.
- Governance: Assemble stakeholders in steering committees, professionals in advisory committees, and stakeholders in data sharing committees to guide the work of public health. This data includes the governance model that has been adopted for use by the entity, membership rosters for committees, meeting schedules with associated attendance, and documentation of committee goals and outcomes.
- System Management: System management relates to the work performed to create, maintain and retire databases that are used to capture, use and analyze program data.

## Information Architecture Components

### *Logical Data Model*

The information architecture includes a logical data model or diagrammatic representation of an organization's data, which defines relationships between entities that link cross-sectional and longitudinal data tagged with metadata classifications to establish a coherent context for public health. Metadata is defined as data about data and in the case of the public health logical data model it is referring to structural classes of data, such as demographics or referrals that are used to organize the main data objects needed by public health. The purpose of the logical data model is to create a comprehensive view of clients/consumers, providers, programs, and practices that can be easily understood by users so that they can find prompt answers to questions or quickly and easily perform workflow functions.

### *Identifiers*

Linking an individual's data across programs and organizations requires a methodology for uniquely identifying the individual. At present, clients, providers and organizations have identifiers that are specific to a program or organization and are not readily sharable, such as a medical record number in the electronic health record,

**Table 6.1** Example of using metadata classes to store disparate data elements in a common framework

Class	Subclass	Data element	Standard	Data element code
Laboratory	Screening	Lead in capillary blood	LOINC®	10368-9
Procedure	Screening	Ages & stages questionnaire	SNOMED CT®	443222000
Advance Directive	Physician orders for life sustaining Treatment	Do not resuscitate	SNOMED CT®	304253006
Problems	Conditions	Hepatitis B	ICD-9	70.3

person identifier in the birth registry, or physician identifier in the immunization registry. Cross-organization identity resolution and management will simplify data entry, enable data sharing and care coordination, and facilitate reporting and analysis by public health programs, agencies, and stakeholders. However, there are concerns that unique identifiers for the population undermine an individual's right to privacy of their information. To address this concern from a technical standpoint, the information architecture needs to include permissions for every data element that specifies who has the right to view that identifiable information based on their role as a user and audit trails to monitor access and report violations. However, privacy issues need to be addressed through governance by stakeholders including patients and providers.

## *Knowledge Representation*

There is a lack of standardized representation for data elements or evidence-based practice that contributes to public health knowledge today. Additionally lacking is a common minimum data set that must be collected and shared to enable public health to function effectively. Stakeholders need to agree upon a common set of data elements to be shared and then agree on a mandatory standards-based representation for those data elements. Reaching agreement on a common minimum data set will require stakeholders to work together to harmonize their program data and workflow processes. The resulting vocabulary, metadata, and value sets will comprise the knowledge base that serves to standardize, classify, and describe the meaning, scope, and context of the data.

*Vocabulary* refers to the standards-based terminology that will be used to express common data elements. *Metadata* is used to describe the attributes and classify data elements so that they can be grouped, retrieved, and used to trigger alerts and reminders according to evidence-based practice [21]. Metadata tags enable disparate data elements to be stored in a common framework and can be used to address issues of interoperability. Table 6.1 demonstrates the use of metadata tags to create a standards-based data dictionary that integrates different types of data into a

common structure. Additional attributes can be added to designate acceptable value sets, syntax, normal ranges or other qualifiers for a data element. The metadata tags can be indexed and filtered as needed for a particular workflow, and they provide a mechanism for linking nonstandard public health data to the standardized representation so that the data can be shared. For example, a provider could look up all screening tools to select the appropriate one, Ages and Stages Questionnaire, to use with parents of a child who she suspects is developmentally delayed. The metadata subclass *Screening* simplifies that search and demonstrates the value of data about data to quickly find the needed information based on how the data element has been classified. Table 6.1 shows how metadata enables many types of data to be stored in and accessed from a common framework for a data dictionary.

*Value sets* relate to the allowable codes and syntax for those codes for a data element. Much work has been done to develop standards-based vocabularies, metadata, and value sets, including Public Health Information Network (PHIN) Vocabulary Metadata Standards([22], PHIN Vocabulary Access and Distribution System (PHIN VADS) [23], and the National Library of Medicine Unified Medical Language System (UMLS) Metathesaurus® [24]. However, widespread adoption of those vocabularies has not been achieved at the program level in public health.

## Applying Information Architecture

### *Public Health Reporting*

At present, reporting to public health is *ad hoc* and outside the workflow of local health departments and other providers, such as reporting for a communicable disease. With integrated information architecture, public health reporting could leverage data that is created at the point of care, such as information stored in electronic health records (EHRs). Public health has an opportunity to obtain data from EHRs as a result of the HITECH Act of 2009 [25] that was designed to encourage health-care providers to adopt and meaningfully use EHR technology. Meaningful use criteria [26], for obtaining incentive payments by providers who adopt electronic health records, include objectives around public health reporting. Those criteria open the door for decision support tools to automatically initiate public health reporting for mandated and other conditions.

### *Leveraging National Platform Independent Models*

Work at the national level has been underway for some time to develop platform-independent models for information architecture that will enable health information exchange and data sharing. Examples of those models follow.

*Clinical Document Architecture (CDA)* was created using the HL7® Development Framework and is intended to be a national standard for sharing clinical information about patients between providers. The content of the CDA is the *Continuity of Care Document (CCD)* that includes both mandatory textual patient summaries and structured data. The Federal Health Information Model (FHIM) [27] is focused on establishing EHR standards for partners and vendors at the national level, especially concerning information and terminology. Models for public health programs, such as immunizations and newborn hearing screening, have been included in the FHIM.

The National Information Exchange Model (NIEM) [28] is intended to be a foundation for information exchange. It is based on a common vocabulary and provides a data model, governance, methodologies, training, technical assistance, and an active community to assist users in adopting a standards-based approach to exchanging information. The National Human Services Interoperability Architecture (NHSIA) [29] focuses on sharing eligibility and enrollment information across public health and social welfare agencies and improving service delivery and outcomes for children and families. The Medicaid Information Technology Architecture (MITA) [30] is focused on modularizing services and adopting data standards to enable data sharing [31].

The Office of the National Coordinator for Health IT, Standards and Interoperability Framework, Public Health Reporting Initiative (PHRI), Data Harmonization Workgroup [32] identified the recommended data elements that EHR vendors will need to provide to public health as part of the Stage 3 meaningful use criteria for obtaining incentive payments for adopting electronic health records [33]. To define the common core of data elements, the PHRI and participating stakeholders harmonized user stories and the required data that were submitted by practitioners from different knowledge domains, such as child health and adverse events reporting, to describe how data from EHRs could be used by public health programs. The resulting standards-based Data Harmonization Profile was included in the FHIM for each of the domains analyzed and is available for any public health department to use for its own data harmonization work [34].

## **Strategies for Adopting a Shared Standards-Based Data and Modular Services Model**

An information architecture based on a shared, standards-based data model used by modular services would enable public health data to be integrated and shared across agencies and jurisdictions. Evidence-based practices could be implemented and population outcomes improved. Figure 6.2, the Public Health Combined Data and Services Model, is an entity relationship model developed by the authors that diagrams how shared data and services can be represented in an integrated metadata model in support of public health functions.

Transitioning from data silos will require a commitment to align related initiatives and governance across disciplines. Governance over the process relies on the participation of stakeholders at every level to be successful which requires

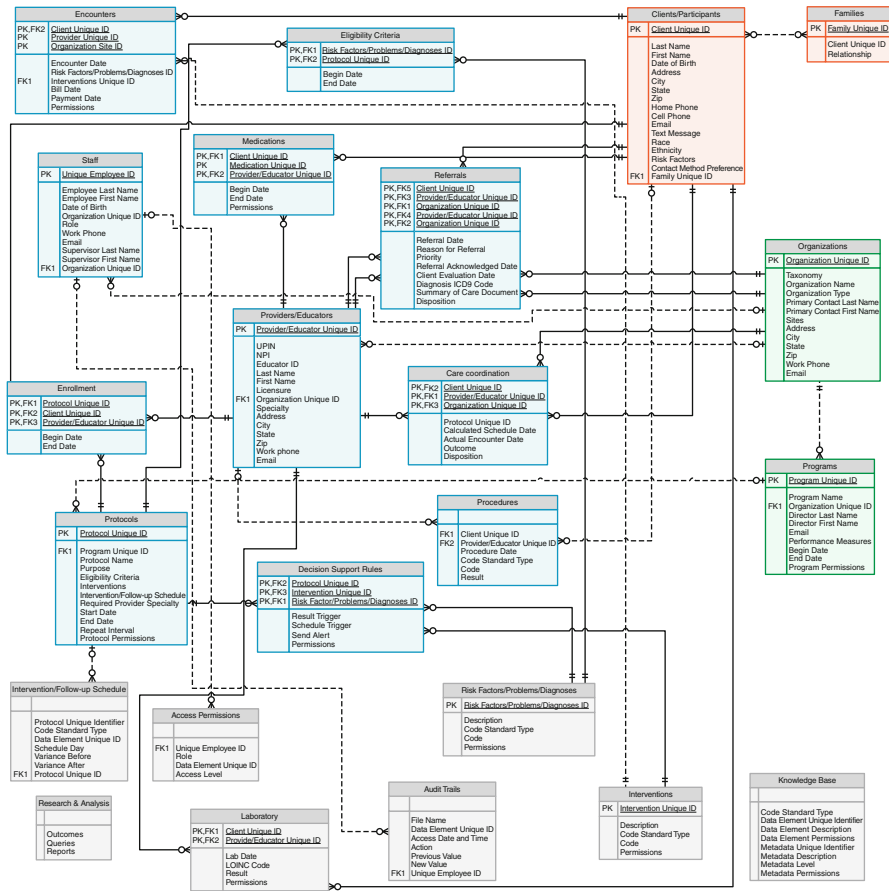


Fig. 6.2 Public health combined data and services model

educating the stakeholders that they need to participate in the process that will organize and articulate their work and that this is not an IT staff function. There are barriers to success that must be addressed by effective governance such as data privacy and ownership. For example, who owns the data entered into a state public health data system? A common complaint from local health departments is that they enter data into state systems and then cannot get it back out for their own uses. Another example relates to the nature of federal funding which supports many public health programs and that specifies that the money can only be used to create and manage a limited purpose database management system. An effective governance process would include informatics professionals who could work with programs to articulate their incremental data needs using the shared metadata model to avoid creation of another database silo.

The process of harmonization will need to be undertaken to identify common core, program specific, and jurisdiction specific data elements and value sets.



Modularizing functionality for common services that can be shared across programs and agencies, such as referral management, will have to be phased in over time and according to the priorities of the programs and availability of funding. As modularized functionality and standardized data becomes available, silos can be phased out. The task is nontrivial but the focus on health information exchange and the recognition that the current practice of a nonstandard data silo for every program is not working has created an opportunity for change.

### Review Questions

1. How can metadata be used to simplify the information architecture for public health?
2. What role do stakeholders and data governance play in adopting an information architecture that is based on a shared data and services model?
3. Describe the process for selecting the standards-based vocabulary that will be shared by public health stakeholders.

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# Chapter 7

## Data Sources and Data Tools

Edward Mensah and Johanna L. Goderre

**Abstract** *Data Sources and Data Tools* offers an introduction to the basic concepts of strategically finding and evaluating publically available data for health analysis. Leading data providers and sources, at the local, state, and national levels, are introduced and reviewed as exemplars. In the evolving and dynamic universe of available health data, a variety of statistical tools and techniques as well as methods to organize complex work schemes are necessary for data acquisition, management, and interpretation.

**Keywords** Data • Information • Big data • Qualitative data • Quantitative data • Open data • White hat testing • Application programming interfaces • Health information exchange • Data sources • Data science

### Learning Objectives

1. List and discuss the five characteristics of good data.
2. List and discuss principles to strategically evaluate data sources and data.
3. Describe publicly available datasets and tools at different levels of granularity.
4. Describe the process of preparing a data set for *ad hoc* analysis.

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## Introduction

Thanks to technological advances, public health organizations can collect, manage, store, and use data about programs, clients, and systems more easily. As organizations are increasingly called upon to deliver measurable and effective services, qualitative and quantitative facts and statistics - *data* - have become a high priority in every office. When meaningfully aggregated, contextualized, and prioritized, these data form the building blocks of important messages - *information* - about the public health system. *Information Systems (IS)* constitute the physical, human, and electronic infrastructures that support the use of data in the service of discovery.

As data floods in from local and global initiatives, perhaps doubling in quantity every few months, many industries struggle to find tools that will produce insight and develop focus to improve individual and population health and quality of life. This problem exists, in part, because not all data is high quality - it may not be timely, accurate, sufficient, relevant, or cost-effective. *Big Data* is data that exceeds the limits of human or computing capacity when released in great quantities with rapid turnover and increasing complexity, and requires novel processing methods.

Legal, ethical, and regulatory responsibilities are also attached to data at all stages, from collection through management and application. Federal, state, and local governments must adhere to a variety of potentially conflicting mandates as they navigate the demands that data and information become both public and secure.

Data providers have grown more diverse. Historically, governments provided almost all available basic surveillance and assessment data. Recently, universities, companies, foundations, and individuals have become active partners in releasing data. Many more entities now provide infrastructure to support re-use and extension of health data such as indicators, disease rates, and healthcare utilization data. As governments build the culture and technology to share and link data in novel ways these datasets have added value for public health agencies and other healthcare enterprises that improve the quality of health service delivery. Infrastructure data, such as water and transit usage or the enumeration of factors in the built environment, can be incorporated into analysis and contextualization of health issues. Mobile technologies are being developed for use in the home to monitor environmental as well as physiologic states of a patient. In a world of social media, people self-report geocoded information about their health state; these online venues can be important methods of engaging a community. All of these data providers - as well as informed individuals - help develop novel applications of data with the goal of improving the US health system.

## Definition of Data and Information

Data and information, while related and often used interchangeably, describe different concepts. *Data* are facts and statistics held in varying forms, often numerical or categorized variables stored in tabular or electronic format, without context.

*Information* is the collection, aggregation, analysis, and presentation of data that provides understanding. For example, specific data about medical errors may be gathered and maintained electronically, but reports providing an understanding of the context of those errors, which allow the hospital environment to benefit the public, would be considered information.

Data are also typically classified as qualitative or quantitative. *Qualitative data* are nonnumeric and capture concepts with words or labels and can often be summarized using distinct categories. For example, key informant interview transcripts about locally available resources can be analyzed for thematic content and provided to a health officer in a report about community challenges. *Quantitative data* consists of numbers and can be categorized based on the range of potential values. In 1946, S. S. Stevens developed four classifications, or levels of measurement, for quantitative data based on its inherent values: nominal, ordinal, interval, and ratio scales. *Nominal data* are discrete categories without quantitative distinctions at the lowest level of measurement. For example, a community assessment could classify each block within a neighborhood as primarily dedicated to residential, civic, or commercial purposes. *Ordinal data* have a natural ordering scheme, although the numerical values themselves do not have quantitative meaning. Data on an *interval* scale allow the measurement of the difference between items, but not the ratios between them, and have the same characteristics of the lower orders of measurement. If an interval scale has a zero point it is not an absolute 0. Typical examples include year, elevation, IQ score, or longitude. A *ratio* level of measurement does have a natural zero-point, such as degrees in Kelvin, a quantity of time, or length in meters. Examples of ratios used in health research include: the distance from a park for some neighborhood blocks that may be twice as long as others, thus limiting options to enhance community cohesion and fitness [1], an index of social cohesion [2], or a measure of income inequality (the Gini coefficient) at the state and county level made available in the Health Indicators Warehouse [3], the aggregated database that informs Healthy People 2020 goals.

When the size of a dataset is so unwieldy that it exceeds the current capacity for an information system to capture, curate, manage, and process within a reasonable time period, it is called *Big Data* [4]. Participants in the 2013 NIH Bioinformatics Festival agreed the factors that create such large datasets include high volume, variety, velocity, variability, as well as complex vocabularies, validation, and verification, and these issues continue to be subject to intense research and discussion.

The reformed core functions of public health (assessment, policy development, and assurance) require data; while IS infrastructure vastly improved through the 1990s, access to public health data expanded only in the first decade of the twenty-first century. In 2002, the updated *The Future of the Public's Health in the Twenty-first Century* highlighted how little technical progress had been made throughout health systems in the US. The quality of services and care at the individual, community, and population levels continues to suffer due to a lack of efficient coordination that can only be supported by appropriate, integrated, and interoperable data use. Applying the lens of the core functions of public health to data use, *assessment* requires collecting data to know what programs are needed, *policy development* is best when informed by timely data in understandable format, and *assurance* involves

correct implementation and monitoring of programs. A knowledgeable public health practitioner is an “information broker” between data, the public, business, and traditional health fields. These core functions will be enhanced by truly open data [5] allowing novel applications to achieve efficient and effective health improvements.

### ***Definition of an Information System***

An *Information System (IS)* is the combination of physical, electronic, and procedural elements - the database, hardware, network, people, processes and software - that help manage and present data for meaningful use [6–8]. Developing information systems requires training in the theory and application of hardware systems, understanding user behavior and needs, application development, programming platforms and languages, database architecture, system performance, data analysis and reporting, as well as systems integration and deployment. In the process of developing an application, software engineers must begin with requirements analysis that considers system performance and reach out to the fields of psychology, communications, and the law to ensure that systems are designed in an intuitive and secure manner.

### ***Value of Data***

Not all data is created equal, and data can be inappropriately applied. Public health and healthcare professionals must increasingly discriminate between data that will or will not prove useful to their projects and organizations. One framework calls for evaluating the value of data based on *timeliness, accuracy, sufficiency, relevance, and cost-effectiveness*.

#### **Timeliness**

Data may need to be refreshed frequently and accessed rapidly. An emergency response system must process and transmit data during incident response coordination, but healthcare providers’ quality metrics may enjoy a long lag in reporting. In many situations, data updates can occur on weekly, quarterly, or longer intervals. The periodicity of updates should be considered carefully as an organization’s infrastructure and budget can wither under an excessively demanding update schedule. If a school is converted to a community center, failure to update records can hinder emergency preparedness plans or decisions made in a crisis as responders enter and navigate the buildings.

## Accuracy

Accuracy is a key feature of high quality data and must be achieved at the data definition, collection, management, and analysis stages. Specific data elements may be inaccurate, for example, feet or meters may be converted incorrectly, or race and ethnicity may be captured using a method noncompliant with federally mandated standards [9]. Alternatively, a data collection system could have been inappropriately designed or inappropriately used, yielding inaccurate data such as an incorrect timestamp for specimen retrieval and processing. Clinical alert and monitoring systems can be crippled by inadequate data capture of patient encounters [10]. Ensuring that the data and system being used has the right functionality and is appropriate to the intended purpose is essential to accurate data analysis.

## Sufficiency

Data must be collected with enough granularity and provided in a useable format so that it can sufficiently answer the health problem and facilitate later merging with other data sources. If program data is captured at an aggregate level of service providers, it may be difficult to breakdown and identify specific patient populations who have common needs but see different service providers. For example, a health record may not contain the patients' race and ethnicity and it may not be linked to other datasets with this information, which limits reporting by this common socio-demographic variable. Neuropsychological batteries consist of multiple cognitive tests that require data collection about the participant and interviewer to ensure correct administration of key results. If the database is designed so that variable names and structures do not clearly refer to any of the data elements captured during the interview, it may be impossible to align the variables in the database to their original meaning, delaying analysis for database revision and additional data entry effort.

## Relevance

In many organizations, data can be both abundant and lacking at the same time. Historical processes may have led to collecting and reporting data that is no longer relevant to contemporary needs and uses. Data should be evaluated based on its applicability to the question at hand. Data gathered at the national level may be useful for comparisons to county-level measures, but without additional county level detail, individual counties will not be able to evaluate progress over time. Data collection and use by public health entities is most relevant when used to answer questions raised during the three core functions of public health: assessment, policy development, and assurance [11].

## Cost-Effectiveness

Balancing the costs and benefits of data enters into most discussions about developing, expanding, or redesigning information systems. There are also varied and multiple factors that play into this balancing act—a single factor rarely weights the decision in one direction or another. If data collection, reporting, or maintenance is burdensome and will not effectively improve a situation or provide valuable insight, then less-intensive tiers of data management may be warranted. For example, a reduced scale infrastructure can be developed immediately with limited funding, and then expanded to deliver more comprehensive services later when additional resources are available. Sometimes a system with limited functionality developed sooner is better than a comprehensive system developed later.

Stakeholders must also consider what data systems are already in place that may provide related data. Individual health entities as well as local, state, and federal health systems often provide a descriptive catalogue of available datasets, which can help offset the cost of new data collection. The website [Data.gov](https://data.gov) is the main resource for federal data with varying degrees of geographic granularity. Other governmental agencies and academic groups also catalog available datasets, sometimes to highlight the application of particular data such as the social determinants of health [12, 13], health services research [14], and small-area research [15]. The federal government has set the standard for release of data in easily managed formats [16], which often serves as a guide for lower levels of government as well as academia, private health, and community-based organizations. While comprehensive and often initially overwhelming, baseline strategic planning inherent to the community health assessment process [17] is familiar to public health practitioners and can be applied to information systems and change management, leading to a cost-effective data strategy that incorporates an understanding of relationships, infrastructure, external forces, capacity, and tiered solutions.

## Data Sources

A public health practitioner, community group, or researcher will inevitably face the problem of finding the right kinds of data when they conduct an assessment, apply for funding, or analyze the need for a health service. The cost of collecting new data can be restrictively high, especially when attempting to supply an answer quickly or to demonstrate need. Three paradigms are particularly helpful in outlining an efficient process to identify source data: requirements analysis, strategic planning, and the scientific method.

- *Requirements analysis* is a user-oriented method used in systems and software engineering to reduce the adverse effects of unanticipated needs downstream that increase the costs and time of a project [18]. Identifying requirements before design and development significantly reduces project cost and significantly increases the likelihood of project success. When applied to finding data sources,



requirements analysis includes gathering information about what data elements are required to answer the question, determining if the requirements are clear and resolving inconsistencies among data elements or requirements, and then documenting the expected procedures and goals of the data identification process.

- *Strategic planning* models such as MAPP [19] have various phases but a search for data would involve organizing an outline of possible data partners, clearly describing project goals, evaluating data quality, prioritizing goals and requirements, addressing problems and defining clear action steps, and then compiling the data resources. A state-level health improvement process may start with identifying health issues prioritized by disease prevalence and incidence [20–22] followed by the discovery of data to frame causal and descriptive hypothesis for health problems, for example, the accessibility of health care resources in a county [23, 24]. It would also be necessary to obtain sample data sets and review their data collection instruments and data dictionaries to determine how data elements could be logically combined. This situational analysis would also inform the design of health improvement interventions by fully characterizing the population [25, 26] and health impacts [27]. The strategic planning approach is also important for the selection of data management tools; adhering to pre-defined principles and goals must always be placed ahead of the desire to use any particular technology.
- *Scientific method or stages of research* [28] can also be applied to the problem of data identification. The question that will be solved by data must be clearly defined and then it is possible to develop a framework for finding the appropriate data. The datasets must be characterized and well understood, especially with the complications of longitudinal data analysis, to link them to research goals and to evaluate the quality of the data and its units of analysis. Once specific datasets are deemed responsive to the project, compilation, processing, analysis, and interpretation can take place. Visualizations of changes in health metrics on maps, charts, or tables can maximize the data's impact and drive policy discussions [29]. An expert panel convened by the Institute of Medicine evaluated HIV care systems nationwide using this type of framework. The panel's report described the process by which data systems were identified and the capture of metadata that enabled them to assess how data sources complemented each other in the service of surveillance, treatment, and outcomes across healthcare delivery and research models [30].

The National Library of Medicine remains an authoritative gateway to find and become proficient at using health data [31–34]. As data sources grow, resources will evolve to organize data products and the knowledge to use them. Data products will continue to grow and change, therefore, a static compendium of data resources would be of little use. State-of-the-art data collections, storage, analysis, and distribution can be strategically sourced from the portals of trusted authorities. Ultimately, using a structured approach to outlining data needs and defining the principles of quality data sources will result in efficient, comprehensive, and appropriate resolution of data-driven answers to health analysis.

## ***Regulatory, Ethical, and Legal Responsibilities and Authority***

Many data providers collect data as part of their legal mandate, such as preparedness [35–38] or as part of operational responsibility [39, 40]. Where data is collected, there is often no plan for comprehensive data release until further legislation or rulings [41, 42]. Ownership and privacy are matters that inform the provision and use of data and can be refined after successive legislative changes [43]. Ethical issues associated with data will continue to evolve, partly in response to innovation [44], and must incorporate relevant stakeholders at the start of the initial design phase. Individuals can also contribute their data to citizen scientist [45], patient-to-patient [46], research, consumer efforts, or even inadvertently [47] but the newness of these possibilities means that ethical implications of these relationships are not well understood. Methods include mobile devices or biological samples [48], although permitted use should be clearly defined in data sharing agreements. Data that was collected for a defined use can afford powerful insights when linked with complementary data [49, 50], but this begins with discussions about ethical and appropriate use in a new context. Data sharing acknowledges that people described by data are fundamental actors in the planning, use, and extension of data, not just those who collect and manage data.

## ***Finding Data***

Data can be provided in many ways: as a downloadable file in a standardized format for defined geographic boundaries, indicators and rates with a defined unit of analysis, as part of a web-based analysis platform, or within an aggregator application that combines many data sources. If data is not available openly, information is often available to contact data providers about access and appropriate uses [51, 52]. If an entity gathers data but does not release it, interested parties can enter into an agreement to share data for specific purposes. For example, major health insurers and public health officials in a region could partner with regional food retailers to confidentially report aggregated food purchase data. In an effort to promote awareness and encourage data usage, many organizations hold development contests where datasets are released that can be used to solve a specific problem by those willing to take up the challenge [53].

As the number of publicly available datasets and resources continue to grow, public health practitioners will be challenged with finding the right datasets on the Internet, a needle in a haystack problem, and applying principles from data science to use the most appropriate management and analysis tools. In many situations, finding data or the institutions, research articles, and general information must begin with a basic query of trusted sources on the Internet. The first step is to devise a short but specific list of keywords that lead to entities that make data available as well as the actual data files. This process leads to discovery of additional keywords

specific to the line of inquiry. A data provider may make a searchable online catalog of data or it may be necessary to use search operators or an advanced search page to find specific file types or search within a domain. For example, [“health insurance” file type: xls] will return results for Excel files that contain the words *health* and *insurance*, while [“injury data” site: [hhs.gov](http://hhs.gov)] will return all files and web pages that use the phrase “injury data” within the [HHS.gov](http://HHS.gov) domain. Search engine companies generally provide instructions on how to use operators, especially Boolean logic, to conduct targeted searches. To stay current on new topics, create a search engine alert that will send an email about new web pages that include your search terms, for example, an alert for “local health data” will return new postings about those topics. Peer-reviewed literature is generally found through MEDLINE/PubMed, which uses the Medical Subject Headings, MeSH, controlled vocabulary to categorize the content of journal articles and filters to facilitate searches; in emergencies the National Library of Medicine provides free access to full text articles through the Emergency Access Initiative. Research in military populations can be found through the Defense Technical Information Center (DTIC). While these are simple first steps, professional libraries and their staff can provide up-to-date methods that make searching less time-intensive and more fruitful. Informaticians should be familiar with the latest search algorithm and ranking methods as well as recommended search methods from search engines and peer-reviewed literature portals.

### *Open Data Movement*

The *Open Data* movement arose from the convergence of technological advances and public expectations facilitated by a loose confederacy of people with the skills and knowledge to promote and employ data in novel applications. The birth of open data is frequently credited to the release of geographic information systems through the World Data Systems [54] in the 1950s and then satellite GPS technology for civilian use in the 1980s. This has served as a model for public-private partnerships in the decades-long struggle to retrieve healthcare and government data out of closed or impractical systems.

Ideas of data ownership have also evolved over time. In 2009, President Obama issued the Memorandum on Transparency in Government to direct the federal government on the principles of open government to “strengthen our democracy and promote efficiency and effectiveness in Government” [55]. Shortly thereafter, [Data.gov](http://Data.gov) became the model for an accessible repository of datasets and tools. Later that year, the Office of Management and Budget [56] issued a directive that mandated a timeline for agencies to publish data online, establish an infrastructure of technical expertise, change the culture of data management, and create a policy framework for open access. As federal data became available, it encouraged profit-seeking commercial as well as non-profit and government initiatives. The federal effort created a legal and procedural template for state and local governments implementing their own open government initiatives. In 2013, the federal government directed

agencies with research and development budgets exceeding US\$100 million to develop concrete data release plans [16]. In a complementary effort, the US Congress introduced the FASTR (Fair Access to Science and Technology Research) bill which directs agencies funding US\$100 million or more of extramural research to provide public data access. During the same time period, international bodies [57] and various scientific disciplines pushed for infrastructures that improve the quality and consistency of sharing data.

## Federal Data Sources

The federal government is perhaps the largest provider of health, economic, and social data in the US. Different agencies, such as the Department of Health and Human Services, collect and provide data under the auspices of their legal and regulatory framework. Some data centers for these agencies are located at universities. Reviewing organizational charts and regulatory mandates can help determine who produces what kinds of data sets and public release files. Entities responsible for basic surveillance and assessment of public health and health services offer focused tools and statistical reports, such as WISQARS from the CDC [58], NCHS surveys [59], the Census Bureau [60], HRSA's data warehouse [61], AHRQ quality indicators [62], the Office on Women's Health data aggregator [63], the NIH's cancer, specimen, and genetic databases [64–66], EPA's data finder [67], BLS employment-related surveys [68], HUD data sets [69], DOJ crime statistics [70, 71], USDA data and statistical tools [72], and the NCES educational data [73]. Data portals provide a large catalogue of data systems and files, such as those from the National Library of Medicine [33], [HealthData.gov](#), Nature Publishing Group's *Scientific Data*, and [Data.gov](#). Portals also tend to provide tools for developers to automatically download data for innovative applications. Federal grant recipients often have dataset transmission and archive requirements permitting others to use public datasets in addition to information from peer-reviewed journals.

Healthcare providers are also required to provide data to regulatory bodies; these data may be aggregated and provided to the public in reports, such as with Medicare and Medicaid data, or licensure information may be available directly. In general though, private and non-profit healthcare providers do not release information except for a legal obligation or by public demand. Private insurers are realizing the potential for providing supportive tools for their clients [74] as well as reimbursement strategies [75].

Joining research consortia or submitting an application for governmental data has been a burdensome model; the Open Government movement is a welcome catalyst of the rapid release of important data. This is, however, ultimately arbitrated data that has been sanitized and intentionally released. It is also costly to collect and subject to discontinuation due to cost cutting or political restructuring [76]. Filing a Freedom of Information Act (FOIA) request can provide access to publicly acquired data [77], but can take years and initiate an antagonistic relationship. Combining multiple data sources is also a novel way to answer pressing public health questions,

such as using natality data from CDC Vital Statistics, the National Survey of Family Growth, the Youth Risk Behavioral Surveillance Study, and the Family and Fertility Survey to analyze teen birth rates nationally and by states [78].

Effective analysis does not always require raw data. Health indicators and calculated statistics can be valuable data elements. Indicators are important tools to prioritize health issues, create goals, and characterize health impacts. Availability of data varies widely among agencies and is partly dependent on the nature of the data. Public use files, stripped of personally-identifiable information, may be downloaded or ordered but some datasets may require a formal process of application, and some public use files are restricted to on-site restricted use. Access to federally funded research data is typically gained by joining a consortium and submitting research proposals, especially for data provided by work funded through the NIH [79]. Public data files from health research studies, anonymized and made HIPAA-compliant, are available through the NTIS library [80].

### **International Data Sources**

The health and public sectors of the United States are not alone in their efforts to make more data available to inform efforts to improve the public's welfare. The World Bank [81], United Nations [82–84], IMF [85], OECD [86], WHO [87, 88], and PAHO [89] all release data about their programs and organizational activities. Some non-governmental entities facilitate making data available and even advocate for improved access such as The Open Knowledge Foundation, Google Public Data Explorer [90], Guttmacher Institute International Data Finder [91], and GapMinder [92]. Numerous countries have developed accessible platforms with a range of datasets including the Australian Institute for Health and Welfare, Public Health Agency of Canada [93], and the United Kingdom [94].

### **State Data Sources**

State and local governments may have a select menu of data sources and tools readily available in a distributed fashion. Coordinated release of health-related data typically does not happen until after the passage of laws that specifically require this type of broad transparency. However, some states, counties, or cities pursue coordinated open data policies based on citizen demand and initiative. States that have led these efforts include California, Colorado, Georgia, Illinois, Louisiana, Maryland, and New York. In some cases, individual departments release their own datasets, in others a broad catalogue is made available through a process of internal negotiation, legal review, and subsequent integrated platform [95].

Localized data is often prepared as neighborhood profiles or a community dashboard. As GIS researchers have found for decades, small-area data can be incredibly powerful to identify and better characterize target populations and services [96], ensure that interventions occur only in areas of need, redefine health assessment by

meaningful geographic boundaries, and present complex layers of data in easily interpretable format for public distribution. However, small-area data requires a high degree of statistical expertise to ensure confidentiality, does not necessarily reflect a causal relationship, and may require costly analysis to adjust values extrapolated from very small samples at fine geographic granularity, or labor-intensive geocoding and data management [97, 98]. Confidentiality is a major concern; analysts must carefully plan how datasets are merged together and also identify when the number of individuals reported for any area is so small that identifying individuals may be possible. In general though, there are no automated solutions to ensuring confidentiality, so this responsibility rests with skilled experts at institutions that can ensure appropriate use of data [99]. Ideally, well-funded efforts to analyze local-area data should involve a form of “*white hat*” testing in which an independent analyst is tasked with re-deriving the identity of individuals. Their failure helps confirm that confidentiality has been secured. Accidental privacy violation through release of personally identifiable information has the potential to ruin public support for future GIS projects. Additionally, GIS investigators must ensure the security of stored data and that data being transmitted cannot be intercepted and used to identify individuals. For these reasons, GIS analyses often involve highly trained analysts, even though a range of personnel can competently prepare community assessments using a variety of data sources.

When data is made available, it may not always be readily accessible. For example, a PDF or scanned table of statistics is far less useful than providing the same report with access to a direct download of the dataset. Several states and cities have adopted the approach of a comprehensive data portal that allows for access to many types of data from different departmental sources, as well as development tools required to use the data like a directory of *APIs* or *Application Programming Interfaces* [100]. These portals are not necessarily health-specific but are often helpful for characterizing the health of a state [101–106].

## Local Data Sources

Local data sets have traditionally evolved in silos so that it remains a challenge to pull across a variety of datasets to form a comprehensive understanding of local health issues. Local health departments, businesses, community organizations, universities, and even individuals increasingly need data germane to small geographic areas within traditional boundaries of municipalities or within novel boundaries that encompass several of these traditionally defined communities in a region. Academic and non-governmental organizations are important data providers, especially for topically-focused or richly contextualized data. Community profiles are proving more important as grant opportunities focus on health impacts and assessments; organizations conduct what are essentially market surveys of communities to provide greater FQHC services and insurance products described by the Affordable

Care Act. These profiles often use a range of publicly available datasets, but they are aggregated into reports to facilitate comparisons and comprehensive assessment. As place has become a recognized determinant of health, data outside the health focus is an important component of characterizing health challenges and successes [107]. Unfortunately, security and privacy issues related to large survey sampling and health datasets mean that data often cannot be provided at a county or city level. Solutions for de-identification are slowly developing [108, 109] and will facilitate making data accessible to a wider audience.

Applying the techniques of business analysis of a market base can assist governments, businesses, and community leaders in identifying needed resources. An application to become a Federally Qualified Healthcare Center (FQHC) [110] must be bracketed by a marketing analysis using datasets that drill down to at least the county level, such as those from the Census Bureau [25, 111], the National Center for Education Statistics [73], Health Resources and Services Agency [24, 112], the National Center for Health Statistics [113–115], Centers for Disease Control [116, 117], the Agency for Healthcare Research and Quality [118], and others [23, 26, 119, 120]. Health departments often commission their own population surveys and may have clinical and service delivery data as a resource for healthcare and promotion, but they may also have assessments of the infrastructure and resources available to a community. Ancillary supportive services like housing quality and occupancy can also inform a situational analysis of health barriers. Other local governmental bodies may hold rich datasets on code enforcement related to environmental and housing issues as well as the types of emergency calls and response times.

Local municipalities, research institutions, and non-profit agencies collect and provide access to data. As of March 2013, [Data.gov](http://Data.gov) counted 34 cities and counties offering open data portals, including Chicago [121, 122], New York City [123], Palo Alto [124], San Jose [125] and San Francisco [126], Seattle [127], Somerville MA [128], Austin TX [129], Albuquerque [130], Baltimore [131], New Orleans [132], Raleigh [133], Cook County IL [134], Mecklenburg County NC [135], Sonoma County CA [136], and Gwinnett County GA [137]. Universities and research companies serve as data centers and provide access to those data when the culture of the study investigators or the funding agency has made open access a requirement, such as The Universities of Michigan [138–140], North Carolina [141], Chicago [142], and Maryland [143], as well as Harvard [144, 145], Pennsylvania State [146], and the Urban Institute [147]. An advantage of many of these data centers is that the characterization of a local area is designed to afford statistically valid findings and can be very specific to a particular area or group. Community profiles are frequently developed by collaborative efforts coordinated by health departments, universities, or non-profits. These efforts include the Baltimore Neighborhood Alliance Indicators [148], Patchwork Nation [149], CUNY and Brooklyn Community Foundation Brooklyn neighborhood reports [150], City of Madison Neighborhood Indicators Project [151–156].

## Health Information Exchanges

A *Health Information Exchange (HIE)* is the interoperable and flexible infrastructure by which personal health information can be shared across providers and platforms in a manner that preserves confidentiality, privacy, and accountability. Passage of the Patient Protection and Affordable Care Act of 2010 formalized state-level HIEs while early HIEs, and the Health Information Organizations that govern them, were developed under the HITECH section of the American Reinvestment and Recovery Act of 2009. Predefined and adjudicated standards for data exchange and transmission are critical when a diversity of potential data providers participate in an HIE across local, state, and regional jurisdictions. HIEs can eliminate the need for duplicative testing or vaccinations and enable providers to reference comprehensive medical records. The most commonly requested data on displaced individuals after Hurricane Katrina included demographics, discharge diagnoses, and immunizations [157]. When considering HIEs as a data source for population analysis, it is crucial to recognize that HIEs without broad population data are inherently biased. Early adopters are likely to be different from those who never participate in the exchange. Entrance must be consent-driven, but development of an HIE requires years of investment in policy and data ownership issues. The consent provided by participants must be broad but descriptive so that they understand, for example, that their child's immunization data at a clinic will be accessible to a wide range of other exchange participants [158]. Additionally, early data providers like hospitals, health departments, laboratories, and insurers will have inherently biased data as their own populations will not necessarily represent the entire market nor typical population-level utilization. Clinical data in HIEs has also proven of insufficient quality, as it is typically collected for reimbursement purposes and may inadequately and inconsistently collect data on sub populations [159].

## Data Tools

The production and widespread use of publicly available data is a rapidly evolving field that defies comprehensive characterization. Through effective data practices, public health practitioners can use modern tools to achieve their objectives in ways only recently made possible by technological advances.

## Introduction

Analysis is a key step in research and health service; without it there would be no method to measure progress, evaluate the effectiveness and efficacy of treatments or programs, or improve systems. There are a variety of tools that improve the quality, efficiency, and impactful visualization of analysis.



## ***Public Health Informatics Competencies***

Informatics has been described as the application of data science to a particular discipline [4]. Public health informatics focuses on the methodologies of systematically applying information and computer science and technology to public health issues [160], rather than specific software or technologies. Informaticians respond to a variety of demands to organize data, ensure an information system's operational efficiency, and deliver knowledge through complex analysis and reporting. Specialization in particular software and technologies would not afford the flexibility to select the best tools to deliver extensive public health information [6].

Public health practitioners must have informatics competencies for managing resources, information, projects, and change and skills to support public health information systems. They must be aware of public health requirements for a range of disciplines and be able to guide informatics development and innovation. They do not necessarily need high-level knowledge in the tools of information systems design, structure, and processing - but they must know how public health inputs and demands should effectively and efficiently interact with information systems [161–163]. Core competencies are periodically reviewed and updated as dictated by changes to technical and health infrastructure. However, these competencies are categorized by the broad skills of analytics, assessment, policy and program development, communication, cultural competency, as well as the ability to develop applications of technology and systems that address public priorities by analyzing information organization and contribution and recommending complex, agency-wide IT projects. The informatician is tasked with not just holding specific skills and serving as a knowledge base for developing information systems, but knowing how technology can support public health decision-making. Critical informatics competencies for public health informaticians are similar but have different priorities. Their knowledge and skill in managing resources, projects, and change should be founded in computer science and technology. They must have advanced training in the implementation of technical and well-designed information systems that manage the broader network of dynamic public health activities.

## ***Cost-Effective “ad hoc” Analyses***

The availability of data can result in synergistic requests for its use. Those who are responsible for data will find that simply having data generates need in ways not originally anticipated. Data providers as well as analysts eventually find the need for an organized and systemized method for data storage, backups, processing, and reporting that helps them achieve operational efficiencies in analysis and in making findings available to other users. Data elements or variables, files, metadata, and the storage scheme in which these resources are placed should be named using a logical schema or naming convention. With longitudinal collection of data, version control becomes a critical tool in ensuring that data are managed properly and the correct

version can be referenced when validating findings. Preferably, files should be stored in standardized, interoperable formats so that they are accessible by the most appropriate software application. Efficient, repeated use of data usually necessitates the creation of standard variables and documentation of their creation. For example, raw flow cytometry data may need to be summarized into CD4 counts for clinical reporting. Data that has been used for analysis should be archived in non-proprietary formats to facilitate later analysis and organized with the programs that created the files as well as the associated documentation and metadata. If an informatician is responsible for data updates, an appropriate framework to pause updates and complete analysis is necessary otherwise the perpetual cycle of appending new records can supersede understanding what the data can report through analysis.

Archiving, documenting, and adherence to data use protocols becomes increasingly important when many individuals share files and as a rich, longitudinal data catalog grows over time. Designing specific *ad hoc* analyses, especially from a variety of sources, should follow the principles of requirements analysis, strategic planning, and the scientific method where the question dictates data sources, the analyst develops a deep understanding of the data, key fields are identified by which sources can be compared and merged appropriately, and all documentation is archived in a way that allows others to clearly understand and review the code, data files, and intent. Various data audit and management assessments are available and periodically improved for specific disciplines [164].

Several basic statistical tools and techniques are necessary to effectively describe and plan the progress of later stages in an analysis. Basic frequency tabulations and measures of dispersion (e.g., mean, standard deviation, range, variance) as well as compilation of *z*-scores and graphical depictions of normality inform how data should be analyzed with more sophisticated techniques. Informaticians should master basic coursework in these methods and can build on their knowledge by teaching themselves new techniques guided by textbooks, open courseware, training classes, and higher level methodological courses. As catalogs of open data resources become more common, finding data will be easier and informaticians can devote more resources to online and in-person training for data management and analysis [165–167]. Software and scripting-based user communities, online and locally, are also important learning options.

## Commonly Used Software Tools

The most common software tools for data management, analysis, and visualization can be offered at enterprise (owned by the organization) or desktop (software licensed for individuals) levels, and may be commercial products or open source. Data storage and management has been a quickly evolving technical field dominated by several well-known software companies; proprietary licenses can be prohibitively expensive. Open source software is often a reasonable option but may require more troubleshooting and problem resolution from the user. Some textbooks come with specialized analytical tools with short-term licenses, such as ArcGIS

texts, or downloadable applications that can construct analytic or visualization products [168]. With data freely available, and as finding the right data becomes more efficient, mastering powerful technical skills is simply an investment of time by a public health informatician.

The workhorses of data management and analysis include SAS, SUDAAN, S-PLUS, SPSS, STATA, CALC, Refine, Data Wrangler, Shiny, ScaleR and R. Classical tools include MiniTab, Crystal Reports, or Microsoft Excel. Geographic analyses rely on experience in programming languages like Python and database tools as well as integrated systems like ArcGIS, BatchGeo, Quantum GIS, GeoVISTA suite[169], or GeoNetwork. Specific analyses may require specialized software such as Atlas.ti for qualitative analysis. Emerging fields of social network analysis and data mining rely on tools like Pajek, Netdraw, UCINET, and Gephi or WEKA, respectively. Advanced and specialized packages can facilitate workflow and development like Mathematica. Specific disciplines such as survey research and epidemiology have resulted in development of tailored software like WesVar, VNLX, or Integrated Microcomputer Processing System (IMPS) and Epi Info. Data can be made available in spreadsheets or published in web-based platforms like Socrata, CKAN, RedHat, OpenGov, Community Commons, GapMinder, Google tools (Insight for Search, Fusion Tables). If data are made available on the Internet, it may be necessary to analyze web traffic (Google Analytics, Clicky, GoSquared, Woopra, and Webalizer) and use these results to demonstrate that providing the service is worthwhile. While PDFs are the least useful method of distributing data, ePUB is one alternative to a portable document format and less proprietary. Sharing programs and code templates are important aspects of functional technical communities, repositories like Github serve anyone able to manipulate software source code.

Finally, communication software and organizing groups for collaborative analysis cannot be overlooked. Hackpad, Slideshare, Google products, and wikis are commonly used to organize and prioritize work flow. Communities of people using particular software or analyzing particular issues [120, 170] naturally arise and are an important knowledge base to novice and advanced informaticians.

### Review Questions

1. Discuss the concept of data being “worth its cost” in terms of the factors that add to the cost of collecting and maintaining data and developing information. List factors that contribute to the high cost of data and high return on information in order of importance. Does the relative contribution of factors contributing to your answer depend on the type of information system that the organization uses?
2. Assume that you are a manager of a public health agency. How would you develop and expand the informatics competencies of the staff at your agency? It may help to frame your response in terms of the specific issue, such as the importance of developing an organizational capacity to create *ad hoc* reports.

3. Compare and contrast enterprise-level tools for data analysis and reporting versus desktop tools for data analysis and reporting. What are the advantages and disadvantages of each?
4. Select a research or policy issue. Frame the issue using a curated set of health indicators that demonstrate its importance. Describe how to assess data requirements and availability, potential data sources, benchmarks, and indicators. For example, reducing child injuries would entail the formation of cause- or issue-specific planning groups that would conduct situational analysis. Data resource may include the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, CDC Wonder, Defense Medical Epidemiology Database, WISQARS, a state data center, the National Highway Traffic Safety Administration, and local data sources to identify high-risk groups and the potential for behavioral modification. Describe evaluation measures to determine that systems are integrated and working.
5. Find and download a dataset from a government source. Describe how the search keywords, operators, and refinement of your search led to a dataset. Describe how the data were originally collected and their recommended use. Prepare the dataset for use in analytic software and create a basic summary tabulation of a few key variables.
6. Identify a public health issue of interest to you. Describe how silo data systems currently prevent health improvement and write a brief proposal that would highlight the expected benefits and challenges of a collaborative data sharing agreement.
7. You are a local health official responsible for managing data on reportable diseases. Describe a plan to confidentially report this information to the public and how presentation of data would involve community and stakeholder engagement to reduce disease prevalence.
8. As a non-governmental health service provider you are seeking to expand your organization. Describe what data would be necessary and the basic components of your market analysis that will be presented to the board.
9. You have been tasked with convening a task force on improving a health information system. Describe the organization, issues involved in improvement, and what players should be present at the table and their areas of expertise.

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# Chapter 8

## Public Health Information Standards

J.A. Magnuson, Riki Merrick, and James T. Case

**Abstract** Standards are one of the most efficient ways to prevent data silos, achieve system interoperability, and promote the value of data. Public health's growing use of electronic data interchange lends increasing urgency to the need to adopt and promote standards, and to participate in standards development as a fully-engaged partner.

However, public health and its many partners must agree upon both the selection and value of standards in order to overcome the significant barriers and challenges to standards adoption. Implementation of standards is complex and resource-intensive, sometimes unevenly more so for one of the partners involved in data interchange.

In this chapter, standards are categorized into process standards and data or content standards. After reviewing a number of the most common standards utilized in public health, we focus in more depth upon three of the most important – HL7®, LOINC®, and SNOMED CT®.

**Keywords** Electronic data interchange • Clinical decision support • Clinical Document Architecture • Code systems • Confidentiality • Continuity of Care

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Document • Data standards • Electronic laboratory reporting • Fully specified name • Functional interoperability • Granular • Implementation guide • Integrity • Interoperability • Laboratory Information Management System • Laboratory Information System • Optional • Privacy • Process standards • Required • Semantic interoperability • Standards development organization • Structure • Syntax • Vocabulary • HL7® • LOINC® • SNOMED CT®

### **Learning Objectives**

1. Learn about standards categories, including the two main categories of standards used in this chapter, process standards and data or content standards.
2. Evaluate the anticipated benefits of standards use and the obstacles to adoption of standards.
3. Identify some of the main standards used in public health.
4. Describe the general process for standards development.
5. Review details about three of the commonly-used standards in public health, HL7®, LOINC®, and SNOMED CT®.

## **Overview**

Standards are one of the most efficient ways to prevent data silos, achieve system interoperability, and promote the value of data. Public health's growing use of electronic data interchange lends increasing urgency to the need to adopt and promote standards, and to participate in standards development as a fully-engaged partner.

However, public health and its many partners must agree upon both the selection and value of standards in order to overcome the significant barriers and challenges to standards adoption. Implementation of standards is complex and resource-intensive, sometimes unevenly more so for one of the partners involved in data interchange.

In this chapter, standards are categorized into process standards and data or content standards. After reviewing a number of the most common standards utilized in public health, we focus in more depth upon three of the most important – HL7®, LOINC®, and SNOMED CT®.

## **Introduction**

With a little imagination, one can picture many systems that must communicate over distances, “speak” different languages, and coordinate time-sensitive materials and actions, and that are often critical to the health and safety of individuals or

populations; examples might include systems for air traffic controllers, police, and hospitals. Public health systems may not seem as obvious a choice, but they also fit into this category.

As public health continues its enthusiastic rush into the arena of *electronic data interchange (EDI)*, interoperability, or the capacity to exchange and utilize data between systems, becomes increasingly critical. Examples of EDI in public health are many and varied, such as:

- *Communicable disease reporting* from laboratories (Electronic Laboratory Reporting or ELR)
- *Wide-ranging surveillance* of sources such as emergency department (ED), emergency medical services (EMS), pharmacy, over-the-counter (OTC), poison control, and absenteeism data
- *Meaningful Use (MU) objectives* (identified by the Centers for Medicare & Medicaid Services as part of Incentive Programs to promote the adoption of Electronic Health Record Systems), including public health choices for immunizations, syndromic surveillance, and ELR for Stage 1 MU [1].
- *Data sharing* within-state and between state partners such as other states, local or regional health departments, and federal agencies

Jernigan et al. [2] list three main causes of non-communicating or silo-ed public health systems:

- *Functional requirements*: design differences may be based on function, for example the function of case management vs. the function of population surveillance.
- *Policy requirements*: policy restrictions upon systems, such as those that could restrict choices of software
- *External restrictions* imposed by federal funding. Many of the silo-ed systems in wide use today are actually required. One such current example is the Enhanced HIV/AIDS Reporting System (eHARS), a browser-based HIV surveillance system used by state and local health departments to submit de-identified data electronically to the Centers for Disease Control and Prevention (CDC) national database [3].

In this chapter, we are adding two additional causes of public health silos, both closely tied to standards:

- *System architecture* or more specifically, lack of system architecture. If the importance of system integration and architecture is either unknown or discounted when building a new system, then the outcome will be an isolated, non-integrated system. Harmonization, or at least accommodation, of standards is a critical factor in system integration.
- *Exchange partner variations*. There is a wide variety of exchange partners inherent in public health matters, and the corresponding barrier of asking all these partners to agree upon and incorporate any chosen standard can be formidable. Public health exchange partners include local, regional, state, and federal public health agencies; the public and its personal health records; laboratories;

hospitals; and other data generating entities. In the future, these partners should expand to include new data *receiving* entities, such as bi-directional exchange with laboratories or with clinical Electronic Health Record systems, as public health becomes more adept at sharing its wealth of data and information.

## The Value of Standards

One of the most efficient ways to prevent data silos, achieve system interoperability, and promote the value of data is through the utilization of standards. Establishing and gaining consensus for standards is not an easy task, however, and to date public health has lagged industry (though not healthcare in general) in agreeing upon and utilizing standards. But to keep perspective on the difficulty of such an endeavor, we need only consider that although the metric system was introduced in France in 1799, the United States is today the only industrialized country that does not utilize it as its official standard of measurement (the metric system is certainly accepted in the US, but it is not yet the official standard). In a nutshell – standards are hard.

## Obstacles to Adoption

In order for a standard to be both useful and accepted by the community, there must be agreement among the affected industries or groups on the goals to be accomplished through adoption of standards. This agreement may be a challenging objective in itself, especially if the industries and groups are fragmented. Additionally, even the experts often disagree on details. The difficulties and costs inherent in the implementation of standards within any organization must be justified by stated objectives for the exchange of data or the utilization of aggregate data from multiple institutions.

Ideally, standards are developed by a panel of experts and formally approved by a *standards development organization (SDO)* such as the International Organization for Standardization (ISO) [4] or the American National Standards Institute (ANSI) [5]. In practice, many “standards” are the product of legacy use within an industry or group. Such *de facto* standards can be extremely useful when no formal standards are available.

The process of developing a standard differs somewhat between SDOs, but there remains a basic similarity, illustrated here by the ISO process. The International Organization for Standardization follows a six-step process [6] when developing a standard. The process begins with (step 1) a proposal to the appropriate technical committee (TC), and then (step 2) a working draft is developed by a group of experts and (step 3) shared with the TC. Next, the draft is (step 4) released for comment by all ISO national members and (step 5) the final draft, after reconciliation of comments, is sent to all ISO members for a vote. If approved by the vote, the draft finally becomes (step 6) an official ISO International Standard.

Agreeing upon a standard is only the beginning. Despite the critical advantages and benefits of standards, it is important to remember that not all partners in a data exchange may share equally in those benefits. The implementation and utilization of standards is often resource-intensive, and many times the essential costs of standards implementations are borne by partners who may not share in the benefits. A good illustration of this situation involves *electronic laboratory reporting* or *ELR*. Around 2000, public health began asking the laboratories legally required to send reportable condition data to public health (including hospital, private, and public health laboratories) to report electronically through the new institution of ELR. Implementation of ELR systems creates a potential for faster disease reporting [7]. This new reporting path, however, requires that the data submitted be standardized in both format and content. These new requirements for standardization often create significant expense for laboratories, especially those with multi-jurisdictional clients requiring multi-jurisdictional reporting. The laboratory must be able to retrieve, format, and transmit data from the *Laboratory Information System (LIS)* or *Laboratory Information Management System (LIMS)*, originally signaling industrial settings, though that distinction is fading and the terms are becoming interchangeable), as well as apply standard codes for laboratory tests and results. This resulting standardization is highly valuable to public health, but confers little practical return on investment for the submitting laboratory. Some funding has been made available to assist laboratories, either directly by public health entities or tangentially by measures such as the Meaningful Use incentives. Nevertheless, in most cases the efforts have been funded largely by the laboratories themselves.

As demonstrated in the previous example, decisions to develop, select, implement, or require standards should not be reached without careful consideration. Figure 8.1 illustrates a decision process flow that represents effective contemplation of such standards issues.

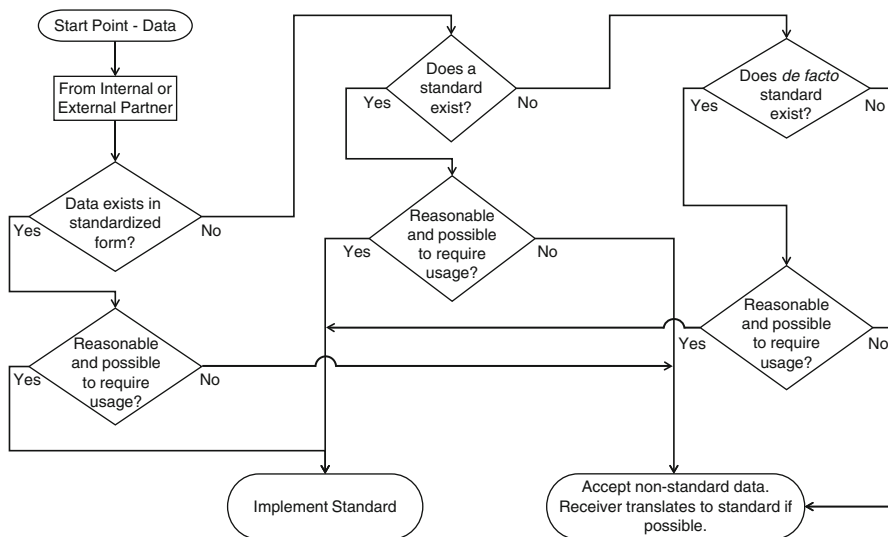


Fig. 8.1 Sample decision process flow for standards utilization



## Standards Categories

Categorization of public health standards can help to simplify the subject, but there are a number of different categorical schemas from which to choose. For example, in February 2006, the Health Information Technology Standards Panel (HITSP) [8] separated health information technology standards into the categories and corresponding examples shown in Table 8.1.

For this chapter, we will use a slightly different categorization, and divide public health informatics standards into two fundamental categories, *process* standards and *data or content* standards. *Process standards* include procedure and policy standards. Examples of process standards include security policies, data use agreements, workflow, architectural, and metadata standards (creating some overlap with data standards). *Data (or content) standards* address common terms and methods, and increase the ability to share data between systems, i.e., interoperability and integration. The theoretical components of data standards are (a) vocabulary, (b) format, and (c) transmission. Transmission standards include privacy and confidentiality components, and so tend to overlap somewhat with process standards.

## Process Standards

As mentioned earlier, transmission standards and process standards have some degree of overlap in the areas of privacy and confidentiality. *Privacy* generally refers to a ‘people’ context, a state of being free from unauthorized intrusion or invasion. This concept is as applicable to medical records as it is to your own house. *Confidentiality* is viewed more in the context of information, usually dealing with accessing and sharing information or data.

## Security Policies

Data *integrity* (freedom from errors or flaws) and confidentiality are often the prime focus of security concerns. Data integrity must be maintained during any

**Table 8.1** One example of Public Health Standards Categorization, based on work done by Public Health Data Standards Consortium [9]

Standards categories	Examples
Data standards	Vocabularies and terminologies
Information content standards	Reference information models (RIM)
Information exchange standards	Message-based and structured document-based
Identifier standards	Identifiers, such as the National Provider Identifier (NPI) [10]
Privacy and security standards	Access control, audit, electronic consent
Functional standards	Work processes, workflow and dataflow models
Other standards	Internet standards, transport mechanisms

transaction; for example, when reporting data, the data received must be exactly the same as the data that were sent. Data confidentiality is a critical concern in public health, which frequently requires the exchange of clinical or laboratory data containing patient identifiable information. Almost all public health agencies are concerned with confidentiality, since they routinely deal with sensitive data that are their legal responsibility to safeguard. A breach in security that allowed patient identifiable data to be made public would jeopardize the ability of a public health agency to perform its data gathering duties, as well as damaging its public reputation as a trustworthy government agency.

The confidentiality of an institution's data depends in large part upon enterprise security – the administrative, physical, and technical security measures enacted by the institution to safeguard its systems. Physical security measures (e.g., locked doors and security patrols), administrative measures (e.g., limiting access rights of employees, providing management and financial support for security policies, prohibiting downloading/playing of music on computers), and technical measures (e.g., firewalls, encryption, digital certificates) – all must be part of an effective enterprise security solution. Effective security policies will address these issues, and may be authored locally or involve collaboration between entities or jurisdictions. HIPAA, the Health Insurance Portability and Accountability Act of 1996 [11], includes efforts to improve health data security nationally; HIPAA is discussed in detail in other parts of this book.

### ***Data Use Agreements (DUA)***

Data use agreements are legal agreements between entities that are intended to ensure appropriate safeguarding and use of shared information or data. DUAs will include details of the agreed-upon security measures and confidentiality requirements, such as the conditions under which data may be accessed and disclosed. An effective DUA will also include measures to ensure tracking of data and data use, to enforce compliance with the DUA and provide evidence in the case of a security breach or unauthorized use.

### ***Metadata***

Metadata is often described as “Data about Data,” and entails structured information that facilitates usage and management of an information resource [12]. Metadata not only makes it easier to generate value from a resource, it enables continued usage of the resource by providing vital descriptive and identifying information for future users. For this discussion, we will review three important divisions of metadata:

- *Descriptive metadata* – generally used for discovery and identification, e.g., title, abstract, author, and keywords

- *Structural metadata* – describes the parts of compound objects, e.g., sections of a document
- *Administrative metadata* – information for resource management, e.g., a database creation date and development platform. May be considered to contain the concepts of rights management metadata (intellectual property rights) and preservation metadata (archival information).

## Data or Content Standards

As discussed earlier in this chapter, data or content standards are divided into three categories, (a) vocabulary, (b) format, and (c) transmission. In the following sections, we will discuss the vocabulary and format standards in greater detail. In order for systems to successfully communicate or interface, there must be both functional and semantic interoperability. *Functional interoperability* occurs when systems are able to physically communicate or share data, whereas *semantic interoperability* involves interpretation of data via a common language or *vocabulary*. Interoperability is facilitated by standards of all categories.

### *Data Format Standards*

Information exchange standards define *structure* (parts) and *syntax* (arrangement), including to some extent the vocabulary, of the electronic communication and are referred to as the standard ways of sending and receiving information [13]. These standards can be compared to the grammar requirements in a language.

Health Level Seven (HL7<sup>®</sup>) [14] is an international standard that is the most widely used formatting standard for health data. Created by developers in the 1980s, it is present in most hospital systems and has been adopted by public health as a data format standard. The term ‘Health Level Seven’ refers to the Open Systems Interconnection (OSI) standard developed by the International Organization for Standardization (ISO) [15] in 1984. The OSI Reference Model defines the different stages that data must go through to travel over a network, and the seventh level (level 7) is the Application Level, which includes definition and structure of data.

HL7<sup>®</sup> is a complex and flexible set of format protocols that can encompass a staggering array of data requirements. The flexibility of HL7<sup>®</sup> can be a ‘good news/bad news’ attribute – while it can accommodate an enormous variety of data situations (definitely good), users can also create an astonishing number of variations upon the standard, which may lead to confusion and extra effort.

HL7<sup>®</sup> defines two major ways to exchange data – message-based (sent as a message) and document-based (sent as a structured document). HL7<sup>®</sup>, like many standards, was developed over time based on additional requirements for different settings, so there are many versions of HL7<sup>®</sup> – notably the group of Version 2

messages (also referred to as v2.x), developed first and initially growing in an *ad hoc* or needs-based fashion. There are multiple versions of the international HL7®v2.x standards in use, the latest, v2.8 was balloted in 2012. These versions are backwards compatible with each other, i.e., a system updated to a newer version can still receive data from systems using any previous version [16]. After some experience was gained with v2.x, HL7® developed a formal data model, the Reference Information Model (RIM), that forms the core for all Version 3 (v3) artifacts, to explicitly retain the context in which the exchanged information is used; they can be message- or document-based exchange standards.

HL7®version 2.x messages are identified by message type and trigger event code. For example, a commonly used message for public health laboratory reporting is the ORU^R01 message, which is identified as message type ORU (Observation result unsolicited), and trigger event R01, signifying unsolicited transmission of an observation message. There are many other commonly used message types and trigger events. HL7® tables 0076 and 0003 contain, respectively, 84 message types and 184 event types. A few examples of HL7® message types are: ACK, General acknowledgement, used to let the sender know when the message was received, either successfully or unsuccessfully; ADT, Admit discharge transfer, used in the hospital setting, for example, to exchange information about the patient with the different systems inside a hospital; OSQ, Order status query, used to find out what's going on with an ordered diagnostic test; RAS, Pharmacy administration message, used to report when a specific medication has been given to the patient; VXQ, Query for vaccination record, used to find out if a patient has been immunized against a specific disease.

Think of the messages as information vehicles – put together from a library of building blocks that define information about specific topics. Some of these building blocks (segments) are used in every message, while others are only used when their information needs to be part of the message. Every message has an MSH segment – the message header, which establishes the foundation information. It contains metadata about the message that systems need in order to properly understand the content. Other commonly used segments are PID, patient information; PV1, patient visit; NTE, notes, containing additional information in unstructured text format for clarification; OBR, detailed order request information; and OBX, result information.

A version 3 artifact that has been adopted by several clinical and public health programs in the US is the *Clinical Document Architecture (CDA)*. The CDA was derived from the HL7® Reference Information Model (RIM) to enable semantic consistency across platforms for the purpose of exchange and re-use of clinical documents [17]. CDA allows representation of clinical or public health information in a structured format, using CDA templates that are similar or identical to the formats of the paper forms [18]. Thus, the CDA standard closely mirrors traditional paper-based reporting workflows, and information is exchanged as documents instead of repackaged into discrete data elements (as is done in messages). The HL7® CDA standard incorporates the concepts of human readability, persistence, stewardship, and wholeness; it allows for authentication and ensures semantic

interoperability through use of the RIM structure and associated controlled vocabulary. It is implemented in Extensible Markup Language (XML). A CDA document has a header and a two-part body, containing the human readable part and the structured data part. The header contains information about the patient, the encounter, and document authors. The body contains the respective clinical content [19].

## ***Vocabulary Standards***

Vocabulary standards are often explained using the metaphor of language. If people are speaking different languages, it will be difficult for them to communicate effectively. Similarly, if systems are using different vocabularies to refer to data content, it will be difficult for them to interoperate. Vocabulary standards can be considered to be either local or ‘universal’, depending upon the partners involved and how widely accepted the standard in question may be. It should be remembered that there are both advantages and disadvantages for local or universal standards. For example, local code sets may be more easily updated or changed by the source institution, but may make sharing data with other institutions much more difficult. ‘Universal’ codes enhance data sharing between systems and across regions, but may require specialized training to use, and may not be as flexible as local codes in adapting to local circumstances. As with different languages, one can also translate between the local and the universal codes.

One of the most important components of data standards is the consistent representation of clinical concepts or terms through the use of unique codes or identifiers. These are commonly referred to as *code systems*. Some of the areas where code systems are used in public health EDI include:

- Laboratory Tests
- Laboratory Results
- Other subjects, such as diagnoses and clinical findings, administration, or demographics

## ***Laboratory Test and Result Code Standards***

### **Logical Observation Identifiers Names and Codes (LOINC®)**

The most widely adopted code system for laboratory observation coding is the Logical Observation Identifier Names and Codes (LOINC®) system [20]; LOINC® can be used to represent the name of both ordered and related performed tests. This code system is owned and maintained by the Regenstrief Institute. Current LOINC®

codes are 3–7 characters in length, and will expand as the code set continues to increase in content. LOINC<sup>®</sup> codes are constructed as the combination of a simple integer sequence number (beginning with “1”), a “dash” delimiter, followed by a Mod-10 check digit. LOINC<sup>®</sup> terms are composed of six major parts:

- Component/analyte – The substance or entity that is being measured or observed.
- Kind of property – The kinds of quantities or qualities relating to the same substance.
- Time aspect – measurement relates to either a point in time or a specified time interval. The vast majority of laboratory measurements are “point in time”.
- System type – For laboratory observations, this is equivalent to the sample type being analyzed.
- Scale – Specifies the scale of measurement. The most common scales used in laboratory analyses are quantitative (QN), qualitative (QL), nominal (NOM), ordinal (ORD), and narrative (NAR).
- Method – This reflects the technique or procedure used to obtain the result.

Of these LOINC<sup>®</sup> parts, the code, analyte, property, timing, and scale are required. Both system and method are able to be specified in other parts of an HL7<sup>®</sup> message, which is the primary vehicle for using LOINC<sup>®</sup> coded terms.

An example of a fully specified LOINC<sup>®</sup> term and its component parts is shown below:

13203-5: *Borrelia burgdorferi* AB.IGM:ACNC:PT:CSF:ORD:IB

- COMPONENT – *Borrelia burgdorferi* AB.IGM. The specific immunoglobulin subclass IgM stimulated in response to the presence of *Borrelia burgdorferi* (the organism that causes Lyme disease) antigen.
- PROPERTY – ACNC. Arbitrary Concentration, or an arbitrary number of units in a volume.
- TIME ASPECT – PT. Point or moment in time, i.e., the time the sample was collected.
- SYSTEM – CSF. Sample type, cerebrospinal fluid.
- SCALE – ORD. Ordinal, a qualitative ordered list of values such as “Detected,” “Not detected,” “Positive,” or “Negative.”
- METHOD – IB. Measurement method, “Immune blot.”

### **Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT<sup>®</sup>)**

Standardized laboratory result coding for non-numeric values is increasingly being represented using SNOMED CT<sup>®</sup>. SNOMED CT<sup>®</sup> was initially produced by the College of American Pathologists (CAP), which entered into an agreement with the US National Library of Medicine (NLM), funded by the Department of Health and

Human Services, to offer open access to the US for the International release content of SNOMED CT®. Since 2007, the code system has been owned and managed by International Health Terminology Standards Development Organisation (IHTSDO®) in Denmark [21].

### ***Other Data Content Coding Standards***

Laboratory test and result standards are of course not the only coding standards of importance to public health informatics. A sampling of other important code systems includes:

- *Procedural codes*: – The Current Procedural Terminology (CPT) code system contains content developed (and copyrighted) by the American Medical Association. CPT codes are five-digit alphanumerics that classify medical service and are used for insurance billing [22]. As an example, the 2013 CPT codes and Medicare payment information show that “Application of short leg cast (below knee to toes)” has the assigned CPT code of 29405, and a cost (facility: in hospital) of US\$68.65. It is of note that fee-based code systems, especially those that are generally accepted for reimbursement, are often far more advanced in their acceptance, adoption, and implementations. This reflects the popular adage, “Money talks and people listen.”
- *Geographic codes*: In 2006, the Geographic Names Information System (GNIS) Feature ID became the official federal reference to named geographic entities [23]. Using this system in 2013, the White House in Washington DC has an ID of 531723. However, public health often uses the legacy standard, the Federal Information Processing Standards (FIPS), to identify geographic areas such as states and counties [24]. Using FIPS, the Washington, DC code is 11001. Another option for geographic coding is the US Census Bureau coding INCITS 38:200x, “Codes for the Identification of the States, the District of Columbia, Puerto Rico, and the Insular Areas of the United States” [25]. Using this resource, the District of Columbia is identified as ANSI State Code “11”; Official United States Postal Service (USPS) Code “DC”; Name “District of Columbia”; and Geographic Names Information System Identifier (GNISID) “01702382.”
- *Industry and Occupation codes*: These code systems may be used by public health programs, such as programs tracking environmental issues like lead exposure. The Standard Occupational Classification (SOC) system, Bureau of Labor Statistics, classifies workers into occupational categories [26]. The 2010 dataset includes 840 detailed occupations, which are also grouped into broader categories. For example, Carpenters Assistant is classified as 47-3012 Helpers – Carpenters; Broad Occupation is 47-3010 Helpers, Construction Trades; Minor Group is 47-3000 Helpers, Construction Trades; and Major Group is 47-0000 Construction and Extraction Occupations. The North American Industry Classification System (NAICS) is the standard used by Federal statistical

agencies in classifying business establishments for the purpose of collecting, analyzing, and publishing statistical data [27]. As an example, the 2012 NAICS Definition assigns code 238350 to “Finish Carpentry Contractors.”

- *Demographic codes:* Information on demographic or population variables, such as gender, race, ethnicity, and age, are crucial to public health. Demographic codes used for public health data include the Race Value Set developed by HITSP [28]. As an example, this value set assigns a code of 2010-7 to the concept “Aleutian Islander.”

## Format Standards Paradigm – HL7®

### *HL7® Version 2.x Artifacts*

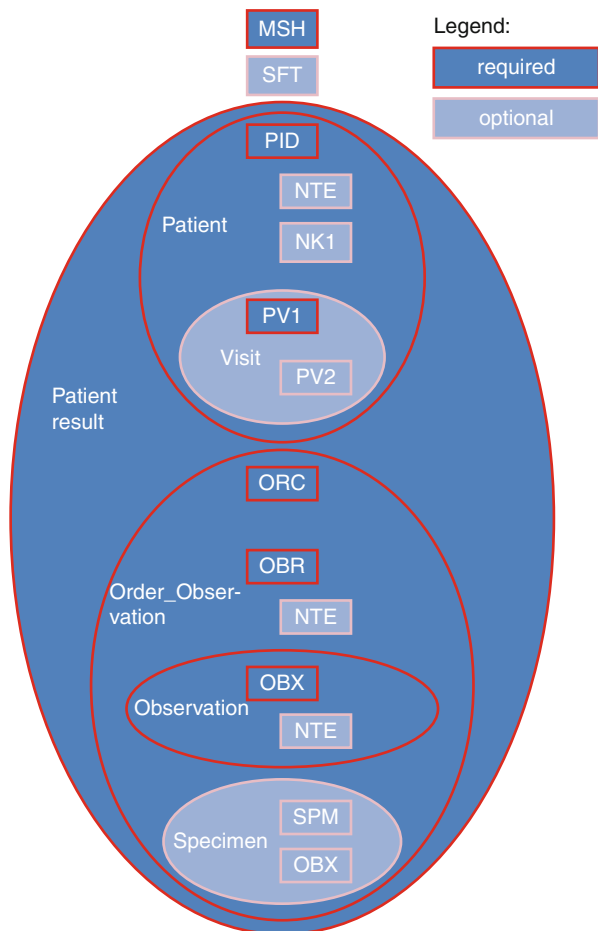
#### Reporting Observations (ORU)

Let’s look in detail at the contents of a v2.x HL7® message using the Observation message – for instance, to report a laboratory result. The way the segments are arranged within a message creates a hierarchy of information. There are two types of observation messages used in laboratory reports, (a) the ORU, which is patient centric, meaning the information about the patient comes before anything else, and (b) the OUL, which is sample centric, allowing for grouping under the sample rather than a patient. As an example, the OUL could be used because you want to report a result from testing a water sample for contamination; water usually is not considered a patient. For this illustration, we want to look at the ORU because in health-care we most often are interested in patient-related observations. The ORU message structure in the standard is defined by its required and optional segments, assembled in a specific order. *Required* means the segment must be sent, while *optional* means that you don’t have to send it – but if you send it, it has to follow the rules of the standard. The standard also specifies (in an *implementation guide*, a document that contains the specifications for the message) whether a segment or a group of segments can be repeated. The underlying segment order must be maintained, but changes can be made in the optionality (whether segments are required or optional) or the number of times a segment or a group of segments can repeat.

Each segment has a specified number of fields that carry specific information related to the general topic of the segment (Fig. 8.2). For example the PID or patient information segment will have fields for name, date of birth, birthplace, address, gender, etc. Each field has a specific format called a data type; data types can be a *string of characters* (*ST, string*), while in other cases the format can be more complex and have several components. One such complex data type is *Extended Person Name (XPN)*, which can contain last name, first name, other given names, suffix, etc. Data types follow a precise order that has meaning, such as in the *Date/Time (DTM)* data type, used for values like date of birth; DTM values are listed as



**Fig. 8.2** Generic ORU message structure with the most commonly used segments (Published with kind permission of © Riki Merrick 2013. All Rights Reserved)

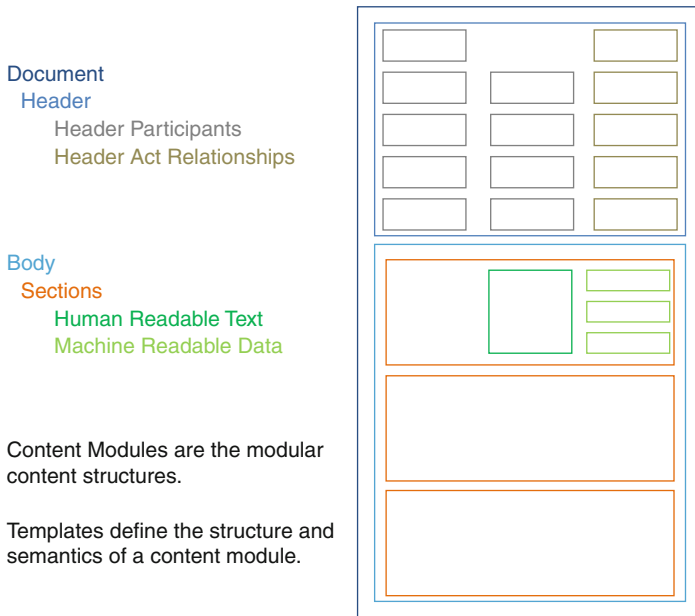


four-digit year, two-digit month, two-digit day, and, if available, two-digit hours, etc. Another complex datatype very important for reporting observations is the *Coded with Exceptions (CWE)* datatype, which is used to carry the codes describing the ordered tests, performed tests, sample types, and results.

### **HL7® Version 3 Artifacts**

#### **Clinical Document Architecture (CDA)**

Along with several HL7® v2.x artifacts, the Health IT Standards Federal Advisory Committee, in their September 2011 rule about Meaningful Use, named the HL7® *Clinical Document Architecture (CDA)* standard for use in data exchanges between



**Fig. 8.3** CDA building blocks (© 2012 Lisa R. Nelson, used with permission)

clinical *Electronic Health Record systems (EHRs)*, as well as from EHRs to public health information systems [29]. In the US, Meaningful Use requires EHRs to create, transmit, receive, and display the *Continuity of Care Document (CCD)* [30], which uses the CDA as a framework. CDA serves as the basis for the creation of closely-related documents within a document-based health information exchange. CDA defines templates at different levels; documents, which have a header and a body, which in turn has its human readable and structured part, comprised of template-based sections and entries. This structure is illustrated in Fig. 8.3, and can also be organized to construct valid public health reports.

MU requires the use of CCD for exchange of discharge information from hospitals to the patient’s primary care provider, for example, core clinical information about the hospital stay and instructions on what to do next. It must also be used to summarize clinical information when a specialist needs to be involved in the patient care. The CCD described in MU is a collection of CDA templates, which will be combined in a specific order for each specific purpose, but the core information in each template is pre-defined [31].

An example of a CDA-based PH report is that sent for the group of reports about Healthcare-Associated Infections, such as bloodstream infections, surgical site infections, urinary tract infections, etc., to the National Healthcare Safety Network at the CDC. CDA parts and specific vocabulary (LOINC®, SNOMED CT®, demographic standards, etc.) are defined in the implementation guide to ensure all

required data for this reporting purpose are included. A different implementation guide, also CDA-based, is used to report about cancer patients to cancer registries in the US. Both the way the sections are put together and the vocabulary that is required are specialized to the needs of cancer reporting. In order to reduce the many variations imposed on the data providers (i.e., the EHR systems) the Public Health Reporting Initiative (PHRI) has convened many public health programs at the local, state, and federal level to collaborate and harmonize the format and vocabulary used for data that is needed across many different programs. These harmonized “Common Core” data elements have been incorporated into another information model to retain the context, by defining format and vocabulary binding in the Federal Health Information Model (FHIM) [32], which is also linked to the underlying HL7<sup>®</sup> RIM. PHRI has also created the Reference Implementation Framework document, intended to be a “one-stop shop” to access all currently available standards for public health reporting, regardless of the format used for exchange (can be HL7<sup>®</sup> v2.x messages or HL7<sup>®</sup> v3 messages or CDA based) [33].

## Vocabulary Standards – SNOMED CT<sup>®</sup>

As mentioned earlier in this chapter, SNOMED CT<sup>®</sup> is a comprehensive reference terminology that encompasses all areas of healthcare. Its primary use is within EHRs, for the purposes of both meaning-based retrieval and use in *clinical decision support* (assistance to health professionals in making choices). The by-product of consistent representation of clinical data is the ability to perform broad-ranging data aggregation, reporting, and analysis. SNOMED CT<sup>®</sup>, at its highest level, is based on three primary structures - concepts, descriptions, and relationships. A brief outline of the content and structure of SNOMED CT<sup>®</sup> is provided below.

### *Concepts*

Within the SNOMED<sup>®</sup> terminology, a concept is a unit of content that is assigned a unique “meaningless” identifier in numeric format. These identifiers are meaningless in that it is not possible by simply looking at the identifier to deduce any meaning of the associated term or its position within the SNOMED CT<sup>®</sup> hierarchy. Each concept is represented by a description called the *fully specified name* (FSN) that uniquely represents the concept; this is accomplished through the combination of the description string and a semantic tag, which represents the top-level category to which the concept belongs. To illustrate this, let’s examine the term “swab,” which has multiple meanings within the healthcare environment. It may represent a physical object, a unit of a product, or a specimen type. Within SNOMED CT<sup>®</sup>, these are represented by uniquely identified concepts: 408098004 identifies swab

as a physical object; 420401004, as a unit of product usage (qualifier value); and 257261003, as a specimen.

Concepts are arranged hierarchically within SNOMED CT®, such that less granular (more general) concepts are assigned as “parents” to more granular (more detailed) “children” through explicitly defined “is a” relationships (i.e., a granular concept “is a” child to the more general parent concept). In some cases, concepts may have many parents depending on the types of defining relationships assigned to them. There are a number of important considerations when assessing these parent–child relationships:

1. For a concept to be a child of another concept, all of the defining attributes for the purported parent must be always and necessarily true for the child.
2. One cannot, by looking at the children of a concept, deduce the meaning of a parent concept: i.e., a parent defines the children, children do not define the parent.
3. Not all levels of intermediate granularity of meaning are represented by the terminology: i.e., there may be perceived “gaps” in the hierarchies.
4. It may not be possible to ascertain the full meaning of a concept without looking at all of the parents.

What this means in practice is that in some cases it may be difficult to ascertain the full meaning of the “words” in the concept description without looking at the surrounding content in SNOMED CT® to gain the full context of the term.

## ***Concept Identifiers***

Concept identifiers are assigned permanently to any concept that is incorporated into the terminology. This means that once an identifier is assigned, it is never reused. Local extensions to SNOMED CT® are assigned namespace identifiers that allow for the unique assignment of extension concepts, descriptions, or relationships that augment the content of the International Release in order to meet specific needs of the extension owner. In the US, the National Library of Medicine has been assigned the extension namespace identifier for the official US extension to SNOMED CT®. This extension is designed to support the specific needs of US healthcare as designated by legislative mandates such as Meaningful Use. In general, SNOMED CT® identifiers have the general structure demonstrated below.

- SNOMED CT® Identifier (SCTID): 101291009, is comprised of an item identifier [101291], a partition identifier [00], and a check digit [9].
- SCTID: 430261000124101, is comprised of an extension item identifier [43026], a namespace identifier [1000124], a partition identifier [10], and a check digit [4].

SNOMED CT® differs from most other clinical terminologies in that it provides a multi-hierarchical representation of distinct clinical concepts as well as a set of

defining relationships that allow systems to perform reasoning against the terminology. For example, a disease concept in SNOMED CT® may have assigned relationships to a causative agent (e.g., a particular species of bacteria) and a finding site (a specific anatomic structure). This would allow a reasoning system to classify the concept as a bacterial disease, an infectious disease, a disease affecting a particular part of the body, etc. This allows one to analyze SNOMED CT® encoded content from a variety of perspectives, based on the associated defining relationships attached to a concept.

### ***SNOMED CT® Descriptions***

In addition to fully specified names, SNOMED CT® allows for a variety of alternative descriptions to represent the intended meaning of the concept. The primary purpose of these alternative descriptions, contrary to the general perception, is not to provide different display terms for the concept but to provide users with assistance in searching the terminology for the proper concept that meets their particular need. While these alternative descriptions have historically been called “synonyms,” in many cases they are not true synonyms; the meaning of these terms could be more general, or in some cases, ambiguous. Looking back at the example provided at the beginning of this section, all three of the concepts related to “swabs” have alternate descriptions of “swab.” Without the knowledge of the concept’s fully specified name, one could not determine the full meaning of the descriptive term “swab.” Thus, it might be possible for the term to be used incorrectly if a user did not have access both to the descriptive term and the associated FSN.

This lack of true synonymy, and confusion as to the purpose of SNOMED CT® descriptions, often causes users some frustration because SNOMED CT® “does not have my words.” Because the ways in which users might want to have terms displayed by their own EHRs is nearly limitless, SNOMED CT® does not attempt to provide an exhaustive list of potential alternative descriptions.

### ***SNOMED CT® Relationships***

The relationships defined by SNOMED CT® are at the heart of the true value of the terminology, to provide enhanced usefulness for a variety of analytical needs. Through the explicit relationships, it is possible to easily select concepts based on particular attributes such as infectious disease, neoplastic disease, location on the body, or clinical manifestation. Because all concepts are related to one or more “parents,” it is possible to computationally aggregate highly specific terms into more general categories for trend reporting and analysis. This value allows data recorders to be as specific as possible with their entries, without having to worry about how their entries will be categorized during analysis.

## ***SNOMED CT® Browsers***

Generally, users will first become familiar with the content of SNOMED CT® through exposure to one of a growing population of SNOMED CT® specific “browsers.” These tools, whether stand-alone or web-based, provide mechanisms to search for specific concept, descriptions, or identifiers within the entire SNOMED CT® terminology and then traverse associated hierarchies to view the terms located within the same “vicinity” of the searched term. Currently, the US National Library of Medicine maintains a listing of available SNOMED CT® browsers [34]. These browsers include the NLM SNOMED CT® Browser, which differs from all the others in that it leverages the NLM Unified Medical Language System (UMLS) to find terms within SNOMED CT®. As mentioned above, SNOMED CT® does not attempt to include all possible descriptions that might be applicable for a particular SNOMED CT® concept. The NLM browser, by utilizing the power of the UMLS® Metathesaurus® (a multi-lingual collection of biomedical and health-related concepts, synonyms, and relationships), can use descriptions that originate from any of its over 150 source terminologies. Of these sources, 15–20 are updated annually. Thus, the NLM SNOMED CT® browser allows users to search for concepts in SNOMED CT® using descriptions that do not actually exist in the full SNOMED CT® terminology. This additional power provides more comprehensive retrieval of concepts than can be accomplished through the use of SNOMED-only browsers.

## **Summary**

There is a well-worn saying among standards aficionados, to the effect that the nice thing about standards is that there are so many from which to choose. Entertaining as that phrasing may (or may not) be, it actually may be true that the variety of standards really is a positive development. The incredible complexity of situations and data inherent in public health and healthcare EDI demands a similar complexity in standards.

### **Review Questions**

1. Discuss the two categories of standards used in this chapter, process standards and data or content standards. What are some examples of these standards that are used in public health?
2. Describe the general process for standards development. How can public health participate in standards development, and why should it do so?
3. Select two of the standards reviewed in this chapter and describe in detail (a) the benefits accrued to public health from use of the standard, and (b) the barriers to implementing this standard in public health.

4. If you had to choose between process standards and data or content standards, which category do you think is most important for public health to utilize?
5. Based on the two standards presented in depth in this chapter, HL7® and SNOMED CT®, compare and contrast their role in public health and their importance to population health as a whole. Use examples to strengthen your key points.

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# Chapter 9

## Privacy, Confidentiality, and Security of Public Health Information

William A. Yasnoff

**Abstract** Public health organizations need to protect the confidentiality of sensitive, identifying information about individuals to maintain the willingness of individuals to disclose such information and to adhere to laws affecting the handling of health information. Safeguarding the privacy, confidentiality, and security of such information is an important undertaking. A public health organization needs to adhere to the basic principles of fair information practices, as incorporated into the Privacy Act of 1974, and to develop and enforce confidentiality policies that govern the handling and release of public health data. Among security measures that an organization can institute to protect the integrity of information and guard against unauthorized access to it are passwords, smart cards, biometrics, and cryptography. In addition, a public health organization needs to be especially vigilant about potential intrusions into its computer systems, and particularly of those systems that rely or reside on the Internet. The use of proxy servers, session password mechanisms, and firewalls can help guard against mischievous attacks from the Internet, while intrusion detection measures can help an organization detect efforts to compromise systems.

**Keywords** Authentication • Biometrics • Capacity for correction • Confidentiality • Consent • Covered entities • Cryptography • Data availability • Data integrity • Denial of service • Disclosure • Fair information practices • Firewalls • HIPAA • Identifying information • Integrity • Intrusion detection • k-anonymity • Key • Need-to-know access • Passwords • Privacy • Protected health information • Proxy servers • Public health exception • Re-disclosure • Relevance • Security • Session password mechanisms • Smart cards • Written purpose

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### **Learning Objectives**

1. Explain why it is important both practically and legally for public health organizations to maintain the confidentiality of information about individuals and to avoid releasing aggregate data that could identify an individual or cohort.
2. List and briefly describe the six principles of fair information practices.
3. Describe the key provisions of the HIPAA Privacy and Security rules.
4. Describe a rule of thumb that can be used in determining the adequacy of a denominator in the release of aggregate public health data.
5. List and describe the steps that a public health organization should take in establishing confidentiality agreements regarding health information.
6. Describe at least four characteristics that a good password system should have.
7. Describe the features of (1) smart cards, (2) biometrics, and (3) cryptography as computer security devices.
8. Explain ways that public health organizations can prevent unauthorized access to their Internet-based systems and guard against attacks by intruders.
9. List and describe two ways by which a public health organization can detect potential intruders of their systems.

## **Introduction**

The practice of public health requires that we have access to very sensitive, identifying information about individuals. This type of information is essential if we are to perform our tasks of preventing and controlling the spread of disease. Access to this information, however, requires a careful balancing of the rights of individuals and the needs of the community. With rare exceptions, public health practice has an excellent record of protecting the confidentiality of information obtained from and about individuals. This record helps maintain the confidence of the community and insures the continued willingness of individuals to disclose sensitive information to public health officials. Often, our ability to protect this information depends on statutory authority that prohibits any access or use of such information by individuals or groups who are outside the realm of public health.

We also have an obligation to disclose information about the health status of the community and trends of disease. In meeting this obligation, we must not compromise any individual's identity in releasing statistical information about the community. Avoiding indirect identification of individuals from the use of aggregate statistics is a continuing challenge.

Finally, as information systems are more widely applied in public health, the difficulties of protecting information increase. The public correctly perceives that all information systems that provide improved access to data for worthwhile and

laudable purposes simultaneously increase opportunities for misuse of information. However, there are many tools and techniques available to insure that the electronic information is used only for appropriate purposes. Developers of public health Information systems must be familiar with the application of these techniques.

In this chapter, we will define and discuss the concepts of privacy, confidentiality, and security as they relate to handling information about individuals in the practice of public health. We will briefly discuss fair information practices, legal requirements for public health officials when handling confidential information, and the policies and procedures that public health organizations need to follow in this regard. We will conclude the chapter with a discussion of security arrangements that public health organizations need to make in order to prevent unauthorized access to information.

## Definitions

Terms such as *privacy*, *confidentiality*, and *security* often are subject to varying interpretations. In fact, they are often confused with one another. Before proceeding further, we will define these key terms.

*Privacy* may be defined as the right of individuals to hold information about themselves in secret, free from the knowledge of others. This definition implies that private information has not been disclosed to any third party.

*Confidentiality* is the assurance that information about identifiable persons, the release of which would constitute an invasion of privacy for any individual, will not be disclosed without consent (except as allowed by law). The exception for legal release of confidential data without an individual's consent may cause some concern until we realize that this exception implies "community" consent. Confidential data should never be released without consent – but community consent implies that the consent itself takes the form of legal requirements. In this context, *identifying information* represents any information, including but not limited to demographic information, which will identify or may reasonably lead to the identification of one or more specific individuals.

*Security* relates to the mechanisms by which confidentiality policies are implemented in computer systems, including provisions for access control, integrity of data, and availability of systems. Because security is, in this definition, dependent on and derived from confidentiality, it makes no sense to ask information technology personnel to develop a security plan until and unless the organization already has confidentiality policies in place.

A good analogy to the relationship between confidentiality and security is an access control system for a large building. A locksmith can provide security via excellent locks of various types to prevent and control entry to areas throughout the building. However, it is the confidentiality policy that tells the locksmith who gets the keys to which room. Without good confidentiality policies, security cannot be effective.

## **Fair Information Practices**

The basis for confidentiality policy in public health is “fair information practices,” a set of ideas defined in a 1973 study [1] and incorporated into the federal Privacy Act of 1974. They represent a set of principles that define the responsibilities of an organization that holds confidential, identifying information about individuals. Although the Privacy Act applies only to federal agencies, the principles of fair information practices form an excellent basis for the confidentiality policy of any public health agency. The concept of fair information practices is built on the foundation that confidential, identifying information collected by a public health organization should possess the qualities of (1) *relevance*, (2) *integrity*, (3) *written purpose*, (4) *need-to-know access*, (5) *capacity for correction*, and (6) *consent* of the individual or the community from which the information was obtained.

### ***Relevance***

Information collected about individuals should be necessary and relevant to public health or be otherwise required by law. It is always tempting to collect all the information that is easily collected, under the assumption that it may be useful someday for something. However, the relevance principle requires us to avoid gathering information under such an assumption. The relevance principle recognizes that individuals are entitled to privacy; the benefits of information collection must therefore outweigh any individual privacy concerns. Another important aspect of information relevancy is that the collection of information should not be overly burdensome, intrusive, or coercive.

### ***Integrity***

Once information is collected, its integrity must be protected. The concept of integrity therefore means we must take reasonable measures to prevent loss, interception, or misuse of the information. No unauthorized alteration or destruction of information may be permitted.

### ***Written Purpose***

All information collected should be consistent with written public health purposes and/or required by law. In practice, this concept means that every database must have a written purpose or purposes, and the usage of information in the database must be restricted to the stated purpose(s). A linkage of multiple databases should be considered a new database requiring a new written purpose.

### ***“Need-to-Know” Access***

All confidential Information should be accessible only on a need-to-know basis, both internally and externally. Public health organizations should require that all personnel sign confidentiality agreements at least annually. Moreover, an employee’s access to confidential information should be terminated when duties change and the employee no longer has a job-related need to view the information. A public health organization should also prohibit an employee’s *re-disclosure* of confidential information to someone who does not have the need to know it. Such a *re-disclosure* policy is essential to prevent loss of control of confidential information. After all, if such information is disclosed to an appropriate person who is allowed to re-disclose it to someone else, it is no longer possible for the organization to enforce a confidentiality policy. Finally, a public health organization should submit any information it plans to disclose to an external entity for research purposes to an institutional review board (IRB) – for both practical and legal reasons.

### ***Opportunity to Correct Errors***

Individuals should have access to information about themselves and the ability to correct this information to the extent allowed by law. Implicit in such provisions is the requirement that a public health organization maintain a public list of all databases so that individuals are aware that information about them may be in use. In fact, a key principle of fair information practice is that there must not be any secret databases. A public list of databases should contain the name of the database, a description of the information included, and a list of the information sources, excluding confidential sources. A system must be in place to respond to inquiries regarding information held about an individual, and this system must allow the individual to correct such information. As with credit reporting data, disputed data must be marked to indicate that the individual in question does not agree that the information is correct.

### ***Consent***

All information must be collected with the consent of the individual or else the community to whom it pertains. As we have indicated, community consent implies a legal basis that overrides the privacy interest of an individual. The consent must be informed (i.e., made in full understanding of the risks, benefits, and alternatives). In the absence of community consent, a public health organization must disclose to an individual the purpose of the information collection, the data protections in place, and the consequences of withholding information, if any.

## Legal Requirements for Privacy and Confidentiality

Because of the importance of privacy, confidentiality, and security of health care information, numerous federal, state, and local laws and regulations address how such information may or may not be used, including for public health purposes. A complete review of all these legal restrictions is beyond the scope of this chapter. However, the federal Health Insurance Portability and Accountability Act (HIPAA) of 1996 sets national minimum requirements that are relevant to public health practice throughout the US. Therefore, HIPAA will be covered here in some detail. Information about the highly variable state laws related to privacy of public health information, including details about some of their inconsistencies and inadequacies, was summarized recently [2]. Another recent report describes the interactions between HIPAA, the Common Rule that governs the use of information for medical research, and public health law [3].

### ***HIPAA***

The HIPAA Privacy Rule was finalized in 2002, while the Security Rule became final in 2003 [4]. The HIPAA Privacy Rule requires patient consent for disclosure of identifiable records of medical care (“*protected health information*” or *PHI*) with certain exceptions. Among those exceptions is the provision of *PHI* for the purposes of treatment, payment, or healthcare operations (“*TPO*”). There is also a “*public health exception*,” allowing release of *PHI* without consent to “public health authorities and their authorized agents for public health purposes including but not limited to surveillance.” The Privacy Rule applies to “*covered entities*” including health care providers, health plans, health care information clearinghouses, and their “business associates” that handle medical information on their behalf. HIPAA does not pre-empt stricter state or local regulations, so it represents a minimum set of rules for *PHI*. Public health officials should also be aware of additional state and local health privacy laws and regulations.

Despite the public health exception, the practical impact of HIPAA on the ability of public health agencies to collect needed information has been somewhat negative. While HIPAA says that covered entities “may” provide information to public health, it does not require them to do so. This has, ironically, led some providers to be reluctant about supplying information to public health even when it is required by state and local regulations. The Institute of Medicine observed that the Privacy Rule “impedes the conduct of important health research” [5]. In many cases these negative impacts are due to misunderstanding of HIPAA by providers, but the effects are real nevertheless. Therefore, public health officials must be prepared to educate providers about HIPAA to help overcome inappropriate reluctance to share needed data for public health purposes.

Adding to the issues of provider reluctance to share data with public health, many public health agencies themselves are actually HIPAA covered entities

because of their direct health care delivery activities. In a 2004 survey by the Association of State and Territorial Health Officials (ASTHO) [6], 14 state health departments reported that they were HIPAA covered entities. An additional 32 state health agencies reported themselves to be “hybrids,” with only some of their activities covered by HIPAA (the remaining four were classified as “other”). To fully understand their obligations with respect to privacy, it is essential for public health officials to be aware of the HIPAA status of their organization and, if it is a “hybrid,” the HIPAA status of the various parts of the organization within which they operate. In that same ASTHO survey, several states reported additional, stricter state legislation that affected their operations. Many states also indicated that they have HIPAA compliance officers and/or internal HIPAA educational programs.

The HIPAA Security Rule requires that effective, state-of-the-art computer security procedures be used to protect electronic PHI from alteration or improper release. This includes regular risk assessments with remedial action, encryption of data in transit, and use of physically and technically secure computer facilities with appropriate backup copies and disaster plans for continuity of operations. Personnel with access to PHI must be trained in security policies and procedures, and sanctioned for violations. Larger organizations, such as public health agencies, may find the services of a commercial HIPAA security auditing firm helpful in meeting and maintaining compliance with these requirements.

## ***HITECH***

The Health Information Technology for Economic and Clinical Health (“HITECH”) Act of 2009 [7] provided substantial financial incentives to individual providers and hospitals for adopting and demonstrating “meaningful use” of electronic health record systems (EHRs). It also provided funds to the states for development of health information exchanges (HIEs) designed to aggregate the distributed information of individuals from various EHRs into coherent comprehensive records. The resultant increase in adoption and use of EHRs is creating new and exciting opportunities for public health information collection and use, and even the potential for individualized population interventions.

HITECH also added new requirements to the HIPAA Privacy Rule. It extended all the Privacy Rule requirements, e.g., for disclosure of records to patients, to business associates as well as covered entities (previously, business associates did not need to directly meet some of these requirements). It also makes covered entities responsible for any HIPAA violations of their business associates.

HITECH also added a new requirement for “audit trails” of TPO disclosures, which were not necessary under the original Privacy Rule. The original omission of audit trails made it nearly impossible to discern improper TPO disclosures (e.g., a disclosure for marketing purposes that a covered entity mischaracterized as “TPO”), since no records needed to be kept. Under the new provision, 3 years of audit trail records showing TPO disclosures must be available on request to patients. To

maintain compliance, all HIPAA-covered systems must include this expanded audit trail capability. These new HITECH requirements may further increase the reluctance of providers to share PHI with public health agencies.

## **Privacy Policy and Public Health**

There is a natural ongoing tension between individual privacy and the need for information to be available to public health agencies to enable monitoring and tracking of the health of the population. There are also ongoing challenges in clearly delineating and differentiating public health research from surveillance from outbreak investigation, each of which require different levels of oversight and regulation. The increasing availability of electronic information about individuals both enables more effective public health activities and heightens the sensitivity of the public to privacy issues. Since public health officials must maintain the trust of the people they serve in order to be effective, transparency is essential in dealing with these issues on day-to-day basis. Consistent application of the Fair Information Practices is a useful starting point, but public health officials must also realize that there are no quick and easy answers and thoughtful, evolving policies will be needed.

## **Organizational Policies and Procedures to Ensure Confidentiality of Information**

It is essential for public health organizations to have appropriate confidentiality policies and procedures in place. These policies must be sufficiently comprehensive to encompass electronic information systems.

Confidentiality policies for restricting release of data are essential to prevent the inadvertent identification of individuals in the course of a release of data. All data releases by a public health organization should be reviewed, either manually or through use of an automatic computer-based approach. To control the potential for indirect identification, an organization should give special attention to the denominator of any count. For example, disclosing that one person in a population of one million has a particular health condition is not likely to result in the identification of that person. However, as the denominator decreases, the possibility that a released statistic will allow identification through the use of other available information increases. There is no absolutely secure cutoff for the size of the denominator. However, one rule of thumb that has proved to be useful is that the denominator must be greater than 50 in a population, or greater than 10 for a cohort. Table 9.1 provides examples of this rule of thumb in action.



**Table 9.1** Examples of statistical denominators that are usually either adequate or inadequate to prevent inadvertent identification of an individual or a cohort: rule of thumb method

Example	Adequate or Inadequate?
A public health assessment presents data showing that one person in a population of 50,000 has been diagnosed with metallic mercury poisoning	Adequate
A study of eight families living in a remote Alaskan village presents data showing that one of the families has a head of household with a sexually transmitted disease	Inadequate
A study presents data showing that one person in a population of 500,000 has a rare blood disorder	Adequate
A table in a public health consultation presents data showing that of 30 different groups using water from 40 community wells, two groups have members with elevated levels of lead in the blood	Adequate

More sophisticated measures of the potential for re-identification are available, such as the commonly used *k-anonymity*. A table provides *k-anonymity* if all attempts to link explicitly identifying information to its contents ambiguously map the information to at least *k* entities [8]. There are algorithms available for selectively altering, or perturbing, datasets to ensure *k-anonymity* with a high degree of certainty [9]. Recently, algorithms providing more flexible privacy protection have been described, which include the ability to add privacy-protective, yet minimal, changes to geolocation data [10]. It should be recognized, however, that computational approaches to privacy protection in the release of data must be utilized intelligently in the context of the purpose for which the data is to be used and other policy considerations.

Ensuring that all personnel are familiar with confidentiality policies is essential. Confidentiality agreements signed upon employment, and at least annually thereafter, should include the definition of confidential information and indicate that such information is available on a need-to-know basis only and should not be re-disclosed. The agreement should direct the employee to ask his or her supervisor about any questions related to confidentiality. It should also indicate that confidentiality breaches will result in disciplinary action and that confidentiality must be maintained indefinitely.

Confidentiality agreements signed by data system administrators should contain special provisions, inasmuch as data system administrators have access to extensive confidential information because of their computer system responsibilities. Such provisions should indicate that information is to be used only as needed for administration of the computer systems, and that access granted to others should only be in accordance with established policies and procedures. If possible, listed disciplinary actions for violations of the agreement by the data system administrators should include the possibility of termination on the first offense. If these individuals are not extremely sensitive to the issues of confidentiality, the entire organization will be at risk.

## Security

Once appropriate confidentiality policies are in place, security mechanisms to ensure the enforcement of those policies must be established. These may be divided into *authentication*, ensuring that the identity of the user is confirmed; *data integrity*, protecting information from unauthorized alteration; and *availability*, preventing interference with system access by authorized users.

Authentication is at the heart of any security system. The choices regarding what access is provided or denied depend entirely on correct identification of the user. There are three basic methods to determine the identity of a computer user: (1) what the user knows (e.g., *password*); (2) what the user has (e.g., *smart card*); and (3) what the user is (e.g., *biometrics*).

### *Passwords*

Passwords are by far the most common form of user authentication. Each user has a specific (usually self-chosen) combination of characters known to him or her and the system for use as a password. Entering this (hopefully secret) combination of characters identifies the user.

However, passwords have many practical drawbacks. First, most people choose very short dictionary words as passwords. A potential intruder may easily guess such passwords. The length of a password is important because it determines the number of possible combinations. For example, a combination lock that opens with a single number is not nearly as secure as one with three numbers. Just so, a longer password is more secure from such guessing or the use of a trial-and-error method to determine a user's password. It is also very undesirable to use any single dictionary word as a password, since many software packages exist that will simply try a dictionary's words in an attempt to gain unauthorized access.

Good passwords should be at least eight characters in length. They should also have more than one dictionary word connected with one or more digits or special characters. A good working model for passwords is two dictionary words connected with a special character, e.g., "word1;word2." Passwords should not contain any familiar numbers, names, or words; for example, they should not consist of telephone numbers, birth dates, anniversary dates, Social Security or driver's license numbers, parts of a user's name or names of family members, or parts of a user's address, city, home town, etc. Passwords should never be written down anywhere – there is no security in an excellent password written on a Post-It™ note attached to a computer screen.

It is also important for a user to remember that if a password is entered over a network, particularly on the Internet, that password will travel "in the clear" unless it is entered on a secure page (e.g., a web page with a designation of "https:" before the address instead of the normal "http:"). Passwords sent in the clear can easily be intercepted and used by hackers for unauthorized entry.

Finally, a password should have a short life. A user needs to change a password every 3–4 months. After all, the longer a password is in existence, the greater is the time frame during which a potential intruder can attempt to guess it or otherwise discover its nature. However, changing passwords too often is also detrimental to security. If passwords change very frequently, users are more likely to write down or otherwise record them for reference, which defeats the purpose of them being “secret.” A careful balance is necessary in choosing the timeframe for required password changes.

Listed below are some of the password requirements that have been imposed by the Centers for Disease Control and Prevention (CDC) on users of its systems:

1. A password is required to be created to gain access to all agency information technology systems.
2. The minimum allowable length for reusable passwords is eight characters.
3. Passwords may not contain the individual’s name and must have a mix of at least three of the following: upper case letters, lower case letters, numerals, and punctuation marks (one suggestion is to include the first letters from a phrase that is easily remembered).
4. Reusable passwords must be changed at least every 90 days.
5. Repeated unsuccessful attempts to login result in account suspension (this is the most effective means to prevent automated attacks at guessing passwords for accounts).
6. Password sharing is prohibited.
7. Passwords must be protected from disclosure to others and may not be displayed on the screen or displayed at the desk environment where they might be viewed.
8. Creating shortcuts for automatic entering of a password is prohibited.

### ***Smart Cards***

*Smart cards* are increasingly being used to improve the security of the authentication process. A smart card is a small device, the size of a credit card or even smaller, with an embedded microchip that can be loaded with data, including unique identifying information, to be input via special readers (that may be a short distance away from the card). Some smart cards also can display a random number that changes periodically (usually every 60 s). The number displayed is typically included as part of the user’s password. Therefore, even in the absence of a smart card reader, user login can require entry of the displayed number to gain access to a system (in addition to a memorized password). Even if this combined password is intercepted, it is not helpful to a potential intruder, because its validity lasts no more than 1 min. This type of improved authentication is strongly recommended for system administration personnel, because improper access to such an account typically provides total access to both the system in question and perhaps the entire network. Similarly, if a smart card reader is available, authentication via possession of the smart card adds

to (or even substitutes for) the security of a password. Authentication with a smart card and a password is known as “two-factor” authentication, since the user is required to have two separate ways to prove identity.

The major disadvantages of smart cards are the possible inconvenience of having them always available, their cost (from less than US\$1 to several dollars each depending on quantity ordered and features), and the overhead of administration – keeping track of who has which smart card. Also, it is necessary for the clocks of the central computer and the smart cards to be synchronized to be sure both sides generate the same password. These challenges are not terribly difficult to overcome and, as a result, smart cards are rapidly increasing in popularity. Such cards can be used by public health agencies to provide secure remote access to internal systems.

## ***Biometrics***

Probably the ultimate authentication is through biometrics, such as retinal scanning, iris scanning, fingerprint scanning, voice identification, or hand geometry. For practical use, both the sensitivity and specificity of authentication with biometrics must be extremely high to both exclude unauthorized users and avoid creating obstacles to legitimate access. Fingerprint scanning in particular is now commercially available; it uses inexpensive devices (under US\$25) and provides reliable and repeatable results. Eventually, as such fingerprint scanning devices are built into computer keyboards, tablets, and smartphones, the use of this technique for authentication is likely to become much more widespread.

## ***Cryptography***

Protecting data integrity goes beyond authentication. Information must also be secure while in transit. Accomplishing this goal involves the use of *cryptography* – encoding messages so that they are intelligible only to the proper recipient. On a practical level, cryptography involves converting messages composed of “plain text” into new messages readable only with a key possessed by a user. Cryptography is a substantial discipline in its own right, and a complete description of it is beyond the scope of this chapter. Luckily, a working knowledge of very basic cryptography is more than adequate for its application in information systems.

The two basic elements of cryptography are the key and the algorithm. The *key*, analogous to a physical key used to open a lock, is a group of characters or numbers used to encode or transform a message into a form designed to be unreadable. The use of larger keys provides more security by making it difficult for a potential code breaker to test every possible combination of characters or numbers. At present, a key length of 128 bits (which provides  $2^{128}$  or about  $3.4 \times 10^{38}$  possible combinations) is considered sufficient to provide a very high level of security. However, as computer power increases, key lengths will need to expand to ensure that a potential intruder’s testing every possible combination remains impractical.

The *algorithm* is the method or steps used to apply the key to the message, producing an encoded result. Modern cryptography typically uses algorithms that have been fully disclosed and are well known. This use of algorithms allows standard devices and software to be available to perform encryption at very low cost.

One cryptographic technique growing in popularity is public key cryptography. With this technique, each user has both a public and private key. The public key is typically published in widely available directories, much like phone books. Anyone who desires to send a message to a person can encode it by use of the public key. Decoding the message, however, requires use of the private key, which is known only to the recipient. Therefore, anyone can send a message that can be read only by the desired receiver.

This technique is widely used with the RSA cryptography algorithm. The RSA algorithm was invented in 1978 by Ron Rivest, Adi Shamir, and Leonard Adleman (RSA being an acronym comprised of the first letter from the three last names) [11]. This cryptographic method, which is in the public domain, requires a public key that is the product of multiplying two very large numbers, while the private key consists of the two factors. The security of the method depends on the difficulty of determining the factors of an extremely large number. A user may increase the security of an encrypted message by utilizing larger key sizes.

More recently, a more complex algorithm has been adopted for use as a US federal standard. Called the Advanced Encryption Standard (AES) [12], it uses a substitution-permutation network with key sizes between 128 and 256 bits. The details of the operation of the algorithm are publicly available, and it is approved for use in federal computer systems that handle classified information.

When transmitting information over a network, especially a public network like the Internet, a user should employ encryption to prevent interception or alteration of the data. Note that using a secure browser connection (“https:”) typically ensures at least 128-bit encryption, which is currently sufficient to meet this requirement.

## **Systems Availability and Computer Security**

Availability of systems is another important aspect of computer security. Simply denying access to unauthorized users is not sufficient. Information systems must also be available to those users who need them. Making the systems available can be a difficult and challenging task, especially in the case of systems on the Internet.

### ***Web Site Security***

There have been a number of high-profile attacks on Web sites conducted by presenting an overwhelming number of requests for service. Known as “denial of service attacks,” they are very difficult to defend against, especially if the attack comes from a large number of different sources at the same time (“distributed”). Because even unauthorized users can attempt to gain access to a system, a large number of such attempts can effectively preclude usage by everyone.

In public health, this same type of scenario could easily occur in an emergency situation without any malicious intent. A public health crisis might result in an overwhelming number of legitimate public requests for service to public health web sites. Such crisis-level usage could effectively prevent use of the sites by public health officials and other emergency responders.

To address this problem, public health agencies must have a backup emergency Internet connection through an alternate Internet service provider. Such an arrangement allows emergency traffic to utilize this alternate channel. Only official personnel should be informed of this backup address.

The overall solution to “distributed denial of service” attacks is likely to require some changes to the Internet itself. Mechanisms will need to be developed to disconnect users who are rapidly generating huge numbers of repeated requests for service. Because these attacks represent a major problem for all Internet sites, efforts to develop effective preventive and defensive strategies are continuing. Meanwhile, designers of public health information systems must provide alternate access paths that can be activated in emergencies.

### *Internet User Security*

The Internet has been a boon to the development of public health information systems because it provides a common user interface and a communications protocol accessible with Internet browser software. Information system developers, however, must understand the basic principles of Internet security to utilize this tool properly.

The first of these principles is that a computer is not necessarily protected from malicious websites during the use of browser software. In particular, the Java language can run programs that may potentially have harmful consequences for a user’s computer. To deal with this potential problem, some organizations have implemented *proxy servers* for Web browsing. The use of a proxy server means that the browser software does not run on a user’s machine, but rather on another, “proxy” machine. The user’s screen simply duplicates the view of the screen of the proxy machine. In this configuration, only the proxy machine is at risk from potentially harmful Java programs.

In the absence of a proxy server, the best strategy for gaining protection from potential damage from Web sites is to be sure that key files have been backed up to a secure location. Of course, file backup is an essential part of computer usage in any case, and it should be a regular habit. If a file contains information that is important to a user or to an organization, then it is worth taking the time to create a backup regularly. Ideally, such backups should be done every day. Many software packages are available to automate the backup process.

A second principle is that a user should employ one of two basic mechanisms currently in use to transmit and receive information in a secure fashion from a Web site. Both mechanisms involve the establishment of a “session password” used to

encrypt information traveling back and forth between the user and the web site. The first of these mechanisms, S-HTTP or “secure http,” creates secure envelopes for messages that are then transmitted to and from the web site. The other mechanism, “secure sockets layer” or SSL, creates a secure “pipe” between the user’s machine and the Web server; SSL is transparent to any application, not just to a Web browser. Either of these security mechanisms will result in a high level of resistance to message interception or alteration. It is unwise to enter any sensitive information into a web site unless the page into which the information will be entered is secure.

A third principle to follow in insuring the integrity of computer systems connected to the Internet is to use a firewall. In this context, firewalls have nothing to do with preventing the spread of flames or smoke, but rather with protecting computer systems from inappropriate access. A *firewall* is a separate, dedicated computer system that filters the packets of information from the Internet. Each packet of information has an indication of its source; therefore a firewall can be programmed to intercept and discard packets from inappropriate sources. This filtering process provides substantial protection against access from inappropriate users. However, it is far from foolproof, because it is possible for a hacker to create Internet packets that appear to originate from a source other than the true sender.

A firewall can also limit the types of access provided to Internet users. It is possible, for example, to remotely log on to another system on the Internet and have access to some or all of the commands and information on that system. A firewall can prevent requests for log-on from reaching any of the systems inside the firewall. By configuring the firewall to allow only Web access, an organization can attain a significant degree of protection.

To minimize the potential for attack on the firewall system itself, an organization should take certain precautions. These precautions include mounting all disks as read only so that a potential intruder cannot alter any information. Eliminating all unnecessary commands and services and allowing only a very small number of user accounts (that have very long and complex passwords) also is helpful. Although the percentage of Internet users trying to break into systems is quite small, the number of Internet users is so large (billions of people) that it is inevitable that attempts to inappropriately access your systems will be made.

### ***Intrusion Detection***

Another important element in a security plan is *intrusion detection*. After all, without a system in place to detect potential intruders, an organization will never find any. It is important to look for unusual access patterns or activities. There are two major types of evaluation techniques to permit an organization to detect unusual access patterns and activities: statistical and rule-based. *Statistical techniques* look at patterns of usage. For example, most systems have peaks of usage in mid-morning and mid-afternoon. A sudden surge of user activity in the middle of the night would therefore be highly suspicious and would require investigation.

*Rule-based intrusion detection* involves the assessment of certain conditions, the violation of which would indicate a possible problem. For example, if seven users try to log in simultaneously under the same user account, such an event would be highly likely to represent an organized attack. Most systems utilize the rule that a user account is locked after three failed attempts to enter a password. This is a good example of rule-based intrusion detection. Application of this rule makes it very difficult for a potential attacker to try thousands of possible passwords to gain illicit entry into the system.

In short, it is wise to assume that all systems are subject to attempted unauthorized use. An organization should plan accordingly. After all, an organization should not make the mistake of thinking that its systems are too unimportant or uninteresting to potential hackers.

## Conclusion

Privacy, confidentiality, and security of computer systems and the information they contain requires serious attention from knowledgeable personnel. It is important to back up key files on a daily basis and to use strong encryption for transmitting or receiving sensitive data. Users should be required to employ long passwords that are not single dictionary words or other easy-to-guess information. Computer network security in particular requires expertise in authentication techniques, in encryption, and in deploying firewalls. Once comprehensive confidentiality policies are in place, it is possible to develop a security system to enforce those policies effectively. While computer systems and increasing quantities of electronic medical information provide unprecedented opportunities for public health, they also require a greater degree of protection to assure that information is used only for its intended purposes.

### Review Questions

1. Briefly explain why community consent to release of public health information overrides individual consent.
2. Differentiate between *privacy*, *confidentiality*, and *security*, as those terms relate to public health informatics.
3. Assume that a public health employee has signed a confidentiality agreement that incorporates a need-to-know provision and prohibits re-disclosure of any information to which she gains access within her public health organization's systems. The agreement's term of enforcement is indefinite.



Discuss the applicability of this agreement with regard to the following situations, assuming the information she has accessed is relevant to a project on which she is working:

- (a) The employee discusses individual information she obtains with a colleague working on the same project.
  - (b) At lunch, the employee reveals the individual information to a friend working in a commercial enterprise not affiliated with the public health organization.
  - (c) During a weekend trip, the employee discusses the individual information with her husband.
  - (d) After the employee leaves this job, she begins self-employment and discusses the individual information with her best customers.
4. Robert Jameson, an epidemiologist for the Department of Public Health in state X, was born on May 5, 1965. His wife Mary works for the department as a sexually transmitted disease specialist. Mr. Jamison is about to change the password he uses to access the department's databases. Examine all the password possibilities below and determine whether each is suitable for use as a secure password. If the password is not suitable, explain why.
- (a) Bob65
  - (b) Schlerx342
  - (c) 050565
  - (d) MarySTD
  - (e) Rjameson0565
  - (f) RJ1965
5. List the advantages and disadvantages of (1) smart cards and (2) biometrics as authentication devices for users of public health information systems.
6. Differentiate between a *key* and an *algorithm* in an encryption system, and explain the basic features of public-key cryptography.
7. You are the principal data administrator in a public health department. Your department operates systems on the Internet. Explain how you can (1) guard against denial of service attacks, (2) protect computers from malicious websites while organization employees are browsing the Web, (3) ensure the integrity of your organization's information systems from external attack, and (4) detect efforts of intruders to gain access to your organization's systems.

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# Chapter 10

## Electronic Health Records

Stephen P. Julien

**Abstract** The Electronic Health Record (EHR) represents the evolution and convergence of medicine and technology. Its advent has significantly changed the landscape in which medical policy and process shall be created. From its origins as simple billing and accounting systems, to the full-fledged interactive records of today, the wills of the medical community, public health, and government have been at odds to ensure their concerns and requirements are adequately represented in implementations around the world. Governments around the world have passed legislation to foster the adoption of unified health records capable of recording and reporting health data in a standardized, structured format, with surprising and varying results.

The United States (US) also has ventured down the path of creating a national system of electronic health records that is able to exchange patient data seamlessly and securely. Extensive emphasis has been paid to the standardization of data, and to transmission structures and methodologies to ensure the extensibility of the system as a whole. After witnessing the difficulty encountered by other nations that mandated a singular solution for all providers, programs have been created that provide paths for software vendors to have their applications certified as compliant with the program's standards. This approach allows providers to have the ability to choose EHR packages that meet the needs of their practices and facilities. Additional measures provide incentives for adoption and still others call for improved reporting to public health and evidence-based medicine repositories.

All of these forces are moving the medical community ever closer to the ultimate goal of EHR technology providing clearer pictures of the conditions affecting individuals and the effects of these conditions upon the population as a whole. Globally or more narrowly, in various geographic or socioeconomic sectors the impact of the EHR and its myriad uses are only beginning to be discovered.

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**Keywords** Acknowledgement logic • Computerized Provider Order Entry • Continuity of care • Electronic Data Interchange • Electronic Health Record • Health Insurance Portability and Accountability Act • Health Level 7 • Healthcare Information Technology • Hospital Information System • Integration Engines • Interface • Laboratory Information Systems • Meaningful Use • Picture Archiving and Communications Systems • Protected Health Information • Public Health Informatics • e-Prescribing

### **Learning Objectives**

1. Learn the Goals and Origins of the Electronic Health Record.
2. Understand the importance of standards in the creation, organization, and maintenance of an effective Electronic Health Record.
3. Learn about the positive and negative impacts legislation has had on the success and failure of national Electronic Health Record implementation efforts around the world.
4. Understand the concept of Meaningful Use and its importance to the success of current efforts in the United States toward implementing a national Electronic Health Record system.

## **Overview**

The Electronic Health Record (EHR) represents the evolution and convergence of medicine and technology. Its advent has significantly changed the landscape in which medical policy and process shall be created. From its origins as simple billing and accounting systems, to the full-fledged interactive records of today, the wills of the medical community, public health, and government have been at odds to ensure their concerns and requirements are adequately represented in implementations around the world. Governments around the world have passed legislation to foster the adoption of unified health records capable of recording and reporting health data in a standardized, structured format, with surprising and varying results.

The United States (US) also has ventured down the path of creating a national system of electronic health records that is able to exchange patient data seamlessly and securely. Extensive emphasis has been paid to the standardization of data, and to transmission structures and methodologies to ensure the extensibility of the system as a whole. After witnessing the difficulty encountered by other nations that mandated a singular solution for all providers, programs have been created that provide paths for software vendors to have their applications certified as compliant with the programs standards. This approach allows providers to have the ability to choose EHR packages that meet the needs of their practices and facilities. Additional measures provide incentives for adoption and still others call for improved reporting to public health and evidence-based medicine repositories.

**Table 10.1** Core functionalities and uses of an EHR system [1, 2]

Core functionalities for an Electronic Health Record system
Health information and data
Results management
Order entry/management
Decision support
Electronic communication and connectivity
Patient support
Administrative processes
Reporting & population health management
Primary and secondary uses of an Electronic Health Record system
Primary uses
Patient Care Delivery
Patient Care Management
Patient Care Support Processes
Financial and Other Administrative Processes
Patient Self-Management
Secondary uses
Education
Regulation
Research
Public Health and Homeland Security
Policy Support

All of these forces are moving the medical community ever closer to the ultimate goal of EHR technology, providing clearer pictures of the conditions affecting individuals and the effects of these conditions upon the population as a whole. Globally or more narrowly, in various geographic or socioeconomic sectors the impact of the EHR and its myriad uses are only beginning to be discovered.

## The Goals of an Electronic Health Record

In 2003, the Department of Health and Human Services called on the Institute of Medicine (IOM), part of the National Academy of Sciences, to define the Core Functionalities for an EHR System. In doing so they also considered the potential uses of EHR systems and identified a list of ten Primary and secondary uses of an Electronic Health Record System (Table 10.1).

### *Continuity of Care*

As shown in the table, the primary goals of the electronic health record [EHR] center around the patient, the delivery of care to the patient, management of that care,

and the financial, administrative, and support processes that enable it. Also included as a goal is the vital component of education of the patient for the facilitation of patient self-management. The resultant effect is the provision of a comprehensive record of care for the lifetime of every patient, and a higher level of ongoing health-care quality- or more simply stated, *Continuity of Care*. The existence of such comprehensive records creates the vehicle by which this continuity of care is imparted, both for the individual and for the population as a whole. In practice, this record would include every element of medical data obtained on a single individual, from prenatal genetic testing all the way through to postmortem autopsy results. Laboratory tests and their results, imaging, surgical reports, current medication listings, dental screenings, eye exams, high school physicals, and vaccinations would all be collected and included in the record; every single patient encounter in a medical setting throughout a patient's lifetime would be captured, cataloged, and made available to the patient and their authorized health care providers.

### ***Access and Security***

Access to such continuous records by those who might require it (including patients, health care providers, public health surveillance, employers, payers, and insurers), and a means of controlling such access are fundamental to the success of the EHR. Without widespread availability, all that is accomplished is a localized, digital copy of patient data, with little more functionality than the paper chart it replaced. Standardization and organization are additional fundamentals, fostered by this digitization, which further build upon the foundation provided by the EHR.

### ***Reduction of Medical Errors***

By eliminating handwritten ordering and documentation, the EHR removes concerns about legibility and misinterpretation of provider orders. Electronic prescribing (e-Prescribing) and *computerized provider order entry (CPOE)* functionalities ensure accurate and timely delivery of physician orders. The addition of drug-drug interaction validation and cross-referencing of drug allergies and the patients vital statistics further reduces risk to the patient, closing the loop on dosage and prescribing errors previously attributable to manual processes.

### ***Increased Patient Access and Awareness***

The inclusion of patient access portals in a comprehensive EHR implementation brings an unprecedented level of access for patients to their medical records' data.

This access generates a heightened awareness for patients of their health, the medical conditions for which they are being treated, the treatments they are receiving, results of those treatments, and the patient's overall progress as they undergo treatment. This will create a new type of patient in the marketplace, one who is aware of and connected to their treatment, and who is educated about their conditions and outcomes, adding a finer level of scrutiny to the practice of medicine.

### ***Evidence-Based Medicine***

An increased level of scrutiny from patients and providers alike is one of the ultimate benefits of the EHR as it pertains to the health of the population. Additionally, the collection of EHR data aids in the development of new and more effective techniques and methods of treatment. By developing connected databases of patient medical data for increasingly large portions of the global population, medical practitioners and researchers will be able to track symptoms, conditions, treatments, and outcomes over long periods of time. This data resource will result in enormous gains; the gathering of evidence-based treatment data will provide doctors and the medical community at large with a more comprehensive perspective on patient medical histories.

### ***Public Health Reporting***

All of this data – structured, cataloged, and maintained in a responsible fashion – equates to the most accurate and efficient support for public health surveillance of communicable illnesses and chronic conditions. The EHR is infinitely useful in the identification and tracking of outbreaks and public health trends, from electronic reporting of laboratory results to identifying environmental factors affecting individuals, families, neighborhoods, or countries, or studying related chronic or communicable conditions in specific geographic or demographic divisions of the population. Notification and sharing of treatments and outcomes elevates the practices of public health to an unprecedented level of efficiency and effectiveness, and can provide valuable decision support to the patients and healthcare providers.

### **Achieving Portability**

In order for an electronic health record to truly be effective, the portability of the data contained within must be established. Unless there exists a means to accurately and securely transfer the health data of a patient from one health care provider or facility to another in a timely and efficient manner, reversion to manual and

printed methods is inevitable. And while it is important to maintain many manual and printed processes for mitigation of periods where electronic systems may be unavailable, the main focus of electronic health record technologies for the foreseeable future will be standardization and connectivity.

### ***The Ideal Scenario***

The ideal end state for a global use of the EHR would be a scenario where all data for every patient is collected, shared, protected, and maintained seamlessly. All measurable points across the spectrum would be recorded, analyzed, and utilized to truly identify outbreaks, trends, and anomalies in every aspect of the world population's health. This prospect is one the healthcare community at large has chosen to undertake. In the US, as of 2011, 54 % of physicians had adopted EHR technologies; in physicians under 50 years old, that number jumps to 65 % [3]. Nations around the globe have embraced this goal with an unprecedented fervor and are scrambling to achieve a universal health record for their populations. Progress is visible as, component-by-component, portions of the community gradually implement records that collect subsets of available data and make them available in increasingly useful ways.

### ***Barriers to Success***

However, it is not a road without significant obstacles; the barriers to the success of the EHR are many. It is often thought of as a road hopelessly intertwined with controversy from all directions. Legislation and negotiation, at the highest levels of national and international government and policy, have been vital in helping EHR adoption and advancement to overcome these hurdles. Equal and greater efforts of this kind will continue to be necessary if the process is to provide its greatest rewards.

### ***Integration, the evolution of the EHR***

Integration within and outside the confines of the health care facility constitutes the core of successful EHR deployment. Seamless connectivity between the disparate systems that make up the health care continuum, (i.e., registration, radiology, laboratory systems, etc.), is the cornerstone of delivering a complete and accurate picture of the patient, their condition, the treatment they receive, and their subsequent outcomes. This problem has been approached from a number of directions throughout the computerization of the world's health care operations.



## Origins of the EHR

The evolution of the EHR begins a few decades ago, with the development of computerized billing systems designed solely to generate paper claim forms to be adjudicated by insurance carriers around the globe. As insurance carriers and their information systems grew and became more robust, the inclusion of methods of capturing supporting claims documentation evolved from scanning of the printed forms to regular *electronic data interchange (EDI)* transactions. The EDI format was developed originally by the steamship and railroad industries in order to better exchange data about their transportation businesses within their respective companies, but across great distances. It evolved over decades to become several standards used in varying industries, and not entirely compatible. To combat this, the United Nations created a committee to identify and standardize EDI transmissions globally, which developed the Electronic Data Interchange for Administration, Commerce and Transport (EDIFACT) [4]. During the same timeframe, the introduction of computerization to the medical billing realm also led to advances in clinical systems and their ability to read, analyze, store, and report vital clinical data for the treatment of patients. Market forces and competition led to a best-of-breed marketplace, where systems designed for each medical specialty and sub-specialty battled for market share in niche markets, catering to the needs and desires of their chosen specialized audience. Laboratory processes once performed by hand were now integrated into instruments that were designed to focus on aspects of the analysis of blood, urine, and other facets of human physiology.

The sheer volume of data available in laboratories necessitated the creation of *Laboratory Information Systems (LIS)* to connect with instruments for the aggregation and reporting of results. Magnetic Resonance Imagers (MRI), Computerized Tomography Scanners (CT), X-ray machines, mammography suites, and all forms of ultrasonic and radiographic imagers were now connected to *Picture Archiving and Communications Systems (PACS)* for image storage and generation of patient reports. An endless array of medical technologies, each generating their own sea of reports, came into being (and often, still remains). Without the means to connect these systems, and a centralized repository for aggregating patient data, each system had to generate a printed report to be shared with other facilities, healthcare providers, and the patient. These reports then needed to be stored in patient records in every hospital, physician office, or diagnostic facility the patient happened to visit.

## *Interoperability*

The lack of connectivity described above led to development of the integration engine. The evolution of *Healthcare Information Technology (HIT)* was in full swing, and the demand for more specialized documentation to support medical claims grew to include diagnostic data as well. With almost every department of the

hospital maintaining and operating its own specialized information system, it was necessary to devise means of transporting and, more importantly, translating the data from ancillary systems into the *Hospital Information System (HIS)*. *Interface* or *Integration Engines* provided this capacity, building upon the foundation of the newly formed (in 1987) *Health Level 7 (HL7<sup>®</sup>)* messaging standard for EDI transport and delivery of health care data between systems [5]. Along with the PACS standard of Digital Imaging and Communications in Medicine (DICOM), developed in 1983 by the American College of Radiology and the National Electronics Manufacturers Association [6], and updates to the United Nations Electronic Data Interchange for Administration, Commerce and Transport (EDIFACT or X12) for eligibility and insurance claims transactions, integration engines began the task of integrating the health care enterprise and creating true interoperability between systems and health care organizations.

In an effort to gain further market share, and to diversify their offerings from billing solutions, the larger vendors of the hospital billing and physician practice management software systems began to acquire and/or develop their own clinical software solutions. These were obvious extensions of their functionality, inasmuch as even the most novel of procedures must ultimately be billed, and thus these previously clinical-based systems began the process of becoming electronic health records. The collections of applications that each vendor now possessed were eventually assimilated. Through continued development and acquisition, these collections grew into suite offerings that arose as competition to the traditional best-of-breed market. By offering these suites of applications, large vendors were able to market turnkey hospital and integrated delivery system solutions by incorporating integration engines of their own, or rebranding third party interface solutions.

Integration engines provided the solution to a series of issues that had plagued information systems in the past. As previously stated, they fundamentally establish and ensure reliable and secure standards-based communication between disparate systems. Standards regulations control conformity to particular versions or specifications of a standard, but adoption of standards in the absence of regulations allows for interpretation beyond the letter of the specification. Fortunately, integration engines not only establish, monitor, and maintain standards-based communications between disparate systems, they incorporate data transformation, translation, or manipulation to adjust for the variations that can occur in the interpretation of the standard specification from one software vendor to the next.

Another issue that all hospital information technology departments find themselves dealing with on a fairly regular basis is downtime. From time to time, all computer systems need to be brought offline for various forms of maintenance. These can be planned events for upgrading of software or hardware, or, at times, catastrophic in nature, due either to failure or some other outside force. Either way, the integration engine provides handling for the event of a planned or unplanned temporary system downtime by incorporating *queuing* and *acknowledgement logic*. Successfully-sent messages are acknowledged by the receiving application during normal operation. If an acknowledgement is not received, the message is queued, along with subsequent messages. These messages remain in sequence in the queue,

to ensure that updates and revisions to orders and results remain in appropriate order to safeguard proper message delivery and patient safety.

### ***Privacy and Security***

Messaging security is the cornerstone for extension of the EHR beyond the confines of the enterprise. Without the ability to adequately ensure that the data contained within each message is encrypted during transmission and uniformly unreadable by any but the intended recipients, sharing patient information would be unrealistic. The integration engine again provides the solutions necessary to accomplish this. The mechanisms necessary to transform, queue, and secure messages to ensure proper delivery also provide multiple monitoring points; sophisticated monitoring systems have been created to ensure the overall health of the enterprise and, subsequently, the extended network of the electronic health record.

### **Legislation, Regulation, & the Importance of Standards**

The *Health Insurance Portability and Accountability Act (HIPAA)* [2] of 1996 focused on the regulation of developments surrounding the exchange of *Protected Health Information (PHI)*. PHI is essentially any information that can positively identify an individual or connect them to a particular medical condition, health record, or billing related to the provision of health care. PHI can be found in explanation of benefits statements, and prescription medication records, as well as lists, charts, or room/bed assignment rosters or diagrams that could be viewed by persons not directly related to the individual's care or approved to do so by the individual. Whereas previously most patient data resided within the confines of the facilities or providers that the patient visited, advances in technology now made data ubiquitous and vulnerable. As a result of these advances, it became necessary to create legislation to codify a definition of PHI in order to provide penalties for its misuse as well as for negligence surrounding the handling of PHI. HIPAA provided such protections and added civil and criminal penalties for their violation, with fines of up to US\$250,000 and up to 10 years in prison per instance for various types of egregious offenses.

### ***Standardization***

The act also adopted established national standards surrounding EDI transactions for claims, benefits, and eligibility. The National Council for Prescription Drug Programs (NCPDP) [2] standard for pharmacy transactions and the

National Drug Codes (NDC) [2] listings were adopted as well. HIPAA also mandated that the Centers for Medicare and Medicaid Services (CMS) [2] oversee the identification and maintenance of standard code sets to be utilized for the codification and description of medical procedures. CMS revised the Healthcare Common Procedure Coding System (HCPCS), [2] identifying two major areas of concentration:

- HCPCS Level I – comprised of the Current Procedural Terminology (CPT-4) [2] maintained by the American Medical Association (AMA) for physician procedures and services.
- HCPCS Level II – intended for products, supplies, and services generally provided by suppliers other than physicians and their staff.

Additional provisions were also made to officially mandate the codification of diagnoses and hospital inpatient procedures according to the World Health Organization's (WHO) International Classification of Disease (ICD) Revision 9 (ICD-9), with a deadline for conversion to Revision 10 (ICD-10) by October 1, 2013 [2]. Subsequent changes to this ruling have postponed this date until October 1, 2014, a year before ICD-11 is to be released by WHO. Additionally, HIPAA also identifies the code on Dental Procedures and Nomenclature (CDT) [2], maintained by the American Dental Association (ADA), to be used for identification of dental procedures on all dental claims submitted for payment.

### ***Provider Access & Identification***

The final aspect HIPAA required was the standardization of employer and provider identification. It called for employers to be nationally identified by their IRS issued Employer Identification Number (EIN) and for the creation of a National Provider Identifier (NPI). The NPI number is not to contain any other identifying information about the provider, but is merely a ten-digit identifier uniquely identifying the individual as a recognized medical provider [2].

The focus of all administrative changes enacted by HIPAA were for the purposes of standardization of insurance billing regulation. However, the resultant effect was to lay the necessary foundation to create true interoperability within the healthcare system, and ultimately, the creation of true electronic health records.

### ***Executive Order***

During the final year of his first term in office, President George W. Bush executed Executive Order: Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology

Coordinator. As the subtitle suggests, the order called for the establishment of the Office of the National Health Information Technology Coordinator (ONC). It further defined the position as one appointed by the Secretary of Health and Human Services [7].

### ***Office of the National Health Information Technology Coordinator (ONC)***

As mentioned above, the Executive Order: Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator delineated the new position of coordinator. The order defined the role and expectations of the office as follows [7]:

Sec. 2. Policy. In fulfilling its responsibilities, the work of the National Coordinator shall be consistent with a vision of developing a nationwide interoperable health information technology infrastructure that:

- (a) Ensures that appropriate information to guide medical decisions is available at the time and place of care;
- (b) Improves health care quality, reduces medical errors, and advances the delivery of appropriate, evidence-based medical care;
- (c) Reduces health care costs resulting from inefficiency, medical errors, inappropriate care, and incomplete information;
- (d) Promotes a more effective marketplace, greater competition, and increased choice through the wider availability of accurate information on health care costs, quality, and outcomes;
- (e) Improves the coordination of care and information among hospitals, laboratories, physician offices, and other ambulatory care providers through an effective infrastructure for the secure and authorized exchange of health care information; and
- (f) Ensures that patients' individually identifiable health information is secure and protected.

### ***Health Information Technology for Economic and Clinical Health (HITECH)***

The Health Information Technology for Economic and Clinical Health (HITECH) Act was enacted as part of the American Recovery and Reinvestment Act of 2009 [8], during President Barack Obama's first term in office. Its mandates built upon the previous executive order, by amending the existing Social Security and Public Health Service Acts to provide the ONC with US\$1.2 billion in incentive programs

for Medicare and Medicaid providers and hospitals, for the adoption of and *Meaningful Use (MU)* of certified electronic health records. It further goes on to provide a definition of a Qualified HER [8]:

**QUALIFIED ELECTRONIC HEALTH RECORD.**—The term ‘qualified electronic health record’ means an electronic record of health-related information on an individual that—

- (a) includes patient demographic and clinical health information, such as medical history and problem lists; and
- (b) has the capacity—
  - (i) to provide clinical decision support;
  - (ii) to support physician order entry;
  - (iii) to capture and query information relevant to health care quality; and
  - (iv) to exchange electronic health information with, and integrate such information from other sources.

The Act additionally calls for the formation of federally-matched educational grants in the field of medicine involving the safe and effective use of EHR technology. These grants address clinical environments as well as the fields of nursing and information technology, and focus on the effective use, implementation, and maintenance of EHR systems and their infrastructure.

## **Meaningful Use (MU)**

The single greatest measure to support the implementation and effective use of EHR technology is the Meaningful Use of Certified EHR Technology clause, in Subtitle A: Medicare Incentives: Incentives for Eligible Professionals, of the HITECH Act. This clause details the method by which eligibility, certification, and subsequent compensation for participation in the incentive program are achieved. In doing so, it outlines very clearly how providers can receive up to US\$44,000 [8] worth of incentives over a period of 5 years, and makes additional provision for incentives under the Medicaid program as well. More importantly, the clause explains what will constitute the meaningful use of the EHR, providing distinct guidelines for the recording, storage, and exchange of medical data with particular attention paid to the operations of systems within and between hospital systems. Additional incentives are provided by the measure to foster adoption and expansion within hospital organizations; compensation can be obtained by institutions to defray the costs of implementation of qualified EHR systems, the amount dependent upon the size and patient volumes of the respective institutions. Incentive funds set aside by HITECH total US\$1.045 billion for Medicare and Medicaid combined, and these will be made available until expended by the reimbursement schedule outlined in the Act for incentive distribution [8].

## ***Incentives for Adoption of EHRs***

The incentive payment structure for adoption of EHRs is appropriately tiered to promote early adoption, with the early adopters garnering the majority of the funds. The implementation strategy is structured in stages, which provides incremental incentives to encourage the growth necessary to achieve the Act's goals. To combat delays in executing the mandated policies, the Act includes tiered reduction of incentive payments for late adopters. Upon the expiration of the 5-year tier incentive program, measures have been included to reverse the cycle to impose significant penalties upon those providers failing to comply with the electronic filing and reporting standards set forth by MU.

## ***Maintenance***

Understanding that technology and its progression are not a one-time expense, the Act also implemented a structure to ensure that the infrastructure and the technologies supported by the ONC are maintained. The Act mandated the creation of two committees designed to review and suggest the best policies and methods of standardization for Health Information Technology (HIT). The Act gave power to the HIT Policy Committee to determine when standards, implementation specifications, and certification criteria are necessary for the accurate and secure exchange and use of health information [8].

## **Extensibility**

The second committee required by HITECH is the HIT Standards Committee. The Act states the committee shall develop, harmonize, and recommend standards, implementation specifications, and certification criteria to the National Coordinator, as requested by the HIT Policy Committee [8].

As a result of the creation of the HIT Standards Committee, final rulings have been filed amending HITECH with the initially recognized standards designated for certification for MU. These approved standard code sets centered on everything from transaction security to person authentication. The standards included:

- HL7<sup>®</sup> version 2.5.1
- Logical Observation Identifiers Names and Codes (LOINC<sup>®</sup>) version 2.38
- SNOMED-CT<sup>®</sup> International Release January 2012
- NDDP version 10.6
- ICD-10-CM
- HCPCS
- CPT-4

To ensure that the ability for health information to be gathered and shared is maintained appropriately throughout the nation, additional wording specifies that a Nationwide Health Information Network (NwHIN) will be recommended. The committee is tasked with ensuring that the standards utilized by the NwHIN are in tune with the current technologies employed by the industry, and are updated accordingly to exist within that environment. This includes advancements in the formatting of future versions of existing coding and standards bodies (such as HL7<sup>®</sup>, ICD, LOINC<sup>®</sup>, SNOMED<sup>®</sup>), and the inclusion of new standards as the market adopts them [8].

## **Security**

Data security is the foundation from which the network itself must grow. As such, HITECH addresses the security of EHR systems in general, including user authentication, positive patient identification, patient records, and the transactions that are used to exchange data between providers, facilities, insurance carriers, and systems within the enterprise. Along with the standardization of security protocols and transactions are attached severe penalties and protections for privacy and confidentiality violations, built upon those set out in HIPAA for individuals and institutions that knowingly and willfully misuse PHI.

## **Public Health**

Public health will benefit when standardized, secure medical data are able to be transmitted instantly between local, state, and federal agencies. The data can then be aggregated and analyzed by public health, based upon any number of environmental or demographic factors. The public health community has often been mired in the unstructured world of manual processes or incompatible systems, so receipt of standardized data is highly valued.

## **The Future**

### *Lessons Learned*

Recent legislation like HIPAA and HITECH have laid the groundwork for the US to join a global movement of national EHR adoption that has been in motion for quite some time, as evidenced by the international community's continued development and adoption of the latest versions of global standards. Countries around the world have been racing to achieve a state of readiness where health information can be easily exchanged and studied. There are successful examples of this in Denmark, Sweden, and New Zealand, where EHR adoption and use by practitioners is at or



approaching 100 % [9]. There are also several examples where efforts at the introduction of a national EHR system struggled to succeed. From those struggles, both the nations directly involved and other nations have gleaned valuable insights into implementation of a national EHR system.

Great Britain's National Programme for Information Technology (NPfIT), originally dubbed "the world's biggest civil information technology program," began in 2002. With over £6 billion (roughly, US\$11 billion) in initial funding, the program continued for the next 9 years through many stops, starts, and challenges. The British government's ambitious goal of identifying, procuring, configuring, customizing, and implementing a set of systems for all health providers and facilities in the country was a difficult challenge [10].

A similar attempt took place in Victoria, Australia, Australia's smallest and most densely populated state. This state began the process of implementing a statewide EHR, modeling it closely after the British effort in its top-down structure. The process of selecting and defining the system began in the confines of administrative offices, far removed from the clinicians it would serve. In 2012, after 40 % completion, 5 years, hundreds of millions of dollars in overruns, and similar outrage from the medical community as expressed in England, the Victorian government ended the effort [11].

Unfortunately, in both of the above instances the importance of physician involvement and acceptance was not understood early enough in the process to enfranchise the physician community on the benefits of the measure, even as they continued to point out areas where patient safety and quality of care were of concern. In addition, the practice of dictating the configuration and usage of EHR systems by national governing groups proved to be controversial, due to the varied operating procedures that existed from facility to facility.

The overwhelming consensus is that clinician engagement at the onset is vital to the success of EHR implementation. Efforts focused on the administrative functions of the system, prior to the clinical aspects, will affect the usability and adoption of the product. Medical procedures and functions are far too specialized and precise in their design to have change dictated by functions as mundane and arbitrary as billing and personnel management. Solutions are far easier defined and implemented when overlaid upon logically defined, codified, clinical processes which constitute clinical workflows, evidence-based medical guidelines, and exchange of clinical data in a manner that maintains focus upon patient outcomes.

### *The Good News*

Implementation of EHRs is a commonplace activity in the world today. Nations, states, counties, hospitals, clinics, and single physician medical practices are all increasingly utilizing EHR technologies. The infrastructures and standards required to support the free exchange of PHI are now in place and being modified, updated, and maintained regularly to keep up with the burgeoning growth of information technology worldwide. The barriers to an integrated health record for all individuals are no longer fully technological or clinical. The hurdles to be faced lie mainly in humans' abilities to fully understand the nature of the processes.

Adoption of EHRs will continue to gain acceptance as people's lives everywhere become increasingly infused with a myriad of technologies. Information technology departments now struggle with such; they are forced to understand the concerns of their employees and customers, all accessing their information network with an unending array of computerized devices. The prevalence of these devices in the day-to-day lives of individuals will affect the directions taken for recording and accessing EHR data. The ubiquitous nature of concepts such as social media and electronic banking have changed, and will continue to change, expectations of how information and services are delivered, evoking advances in the ways electronic health records are consumed and utilized.

### Review Questions

1. Describe some of the positive and negative effects legislation can have on the success of EHR implementation for the establishment of a National Electronic Health Record. Provide examples of effective and ineffective legislation described. What are the primary factors that determine the success of legislation surrounding EHR technology implementation?
2. Discuss the importance of utilizing widespread standards for health data in the interoperability of Electronic Health Records.
3. What effect does the standardization of health data have upon the effectiveness of public health surveillance? What are the benefits?
4. What is meant by the term, 'Meaningful Use'? How does the concept of Meaningful Use differ from other EHR implementation strategies?
5. What are some of the measures that HIPAA, HITECH, and the ONC have in place to ensure EHR policies, standards, and technologies are modified, maintained, and updated in accordance with the progression of technology and the market?

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# Chapter 11

## Ethics, Information Technology, and Public Health: Duties and Challenges in Computational Epidemiology

Kenneth W. Goodman and Eric M. Meslin

**Abstract** The use of powerful information technology tools in the practice of public health poses many interesting, difficult, and important ethical challenges. Under a modern, electronic standard of care, it can be as blameworthy not to apply such tools as it is to apply them inappropriately. Ethical guidelines can help public health scientists make sound decisions about what users and uses of IT are appropriate in public health. Even with these guidelines, however, there remain some gray areas, particularly with respect to maintaining the privacy and confidentiality of public health information.

The power of modern IT tools renders obsolete some previously sacrosanct guidelines about maintaining privacy and confidentiality. Indeed, it may blur these distinctions to the point of complete conflation. It is therefore necessary for public health practitioners to exercise “progressive caution” in applying information technology to the practice of public health. Developments such as bioinformatics pose acute challenges to maintaining privacy and confidentiality, as does the use of powerful computing technology as support for decisions about interventions.

Moreover, the completion of the map and sequence of the genome of humans (and other organisms) is a technological accelerant for public health ethics. New genetic technologies have spawned an emerging field – public health genomics—engaging the nature vs. nurture debate in new ways. Finally, the interests of ethics and sound public health practice collide in the application of such modern tools as meta-analysis and data mining to public health problems. Even the time-honored

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practice of using and publishing case studies in public health research presents challenges to maintaining confidentiality of information as the World Wide Web and other communication and education tools make it increasingly possible for readers to identify the individual(s) discussed in a case.

**Keywords** Decision support systems • Bioethics • Data synthesis • Privacy • Confidentiality • Security • Group confidentiality • Standard of care

### **Learning Objectives**

1. Differentiate between appropriate and inappropriate uses and users of information technology in public health under an electronic “standard of care.”
2. Explain why there is an ethical imperative to use appropriate IT tools under an electronic “standard of care” in public health, and why failure to use appropriate IT tools can be as blameworthy as inappropriately using such tools.
3. Explain the concept of “progressive caution” in the ethical application of information technology to public health.
4. Explain the ethical tension inherent in attempting to maintain confidentiality of individual information while using modern IT tools to store and use group data.
5. Explain why ethical considerations will not permit scientists to entrust decisions about public health interventions to computers alone.
6. Identify meta-analysis and data mining as tools in public health research, and explain why such tools can themselves pose ethical challenges for scientists in making public health decisions.

## **Overview**

The use of powerful information technology tools in the practice of public health poses many interesting, difficult, and important ethical challenges. Under a modern, electronic standard of care, it can be as blameworthy not to apply such tools as it is to apply them inappropriately. Ethical guidelines can help public health scientists make sound decisions about what users and uses of IT are appropriate in public health. Even with these guidelines, however, there remain some gray areas, particularly with respect to maintaining the privacy and confidentiality of public health information.

The power of modern IT tools renders obsolete some previously sacrosanct guidelines about maintaining privacy and confidentiality. Indeed, it may blur these distinctions to the point of complete conflation. It is therefore necessary for public health practitioners to exercise “progressive caution” in applying

information technology to the practice of public health. Developments such as bioinformatics pose acute challenges to maintaining privacy and confidentiality, as does the use of powerful computing technology as support for decisions about interventions.

Moreover, the completion of the map and sequence of the genome of humans (and other organisms) is a technological accelerant for public health ethics. New genetic technologies have spawned an emerging field – public health genomics—engaging the nature vs. nurture debate in new ways. Finally, the interests of ethics and sound public health practice collide in the application of such modern tools as meta-analysis and data mining to public health problems. Even the time-honored practice of using and publishing case studies in public health research presents challenges to maintaining confidentiality of information as the World Wide Web and other communication and education tools make it increasingly possible for readers to identify the individual(s) discussed in a case.

## Introduction

At least as much as any other domain in the health professions and sciences, epidemiology and public health are information-intensive. Public health is at ground, albeit not at heart, the collection, sharing, and analysis of data; precious little of this effort uses 3-by-5 cards. The ancient, or at least traditional, thrust of public health informatics is best appreciated by picturing Aristotle, Paracelsus, John Graunt, and others building databases, sending e-mail, and surfing the Web – perhaps even tweeting – in search of more and better information. We have digitized the Broad Street pump—along with its handle, its dirty water and, increasingly through social media, the very people who drink from it. With technological improvements have also come advances in speed, accuracy, storage capacity, and ease of dissemination. On balance, this is good news. But attention to the intersection of ethics and public health informatics requires us to look more closely and with greater precision at the ways information technology (IT) is used and the issues it raises. Some of these issues are not especially novel – there has long been an interest in the security of personal information. Among the developments we discuss below are the technological and policy changes that have transformed issues of personal privacy and confidentiality from matters of personal or immediate family concern to those affecting vast swaths of society.

To begin, it is noteworthy that we are dealing with three broad areas of human inquiry: ethics, computing, and public health. Previous related work has explored the marriage of (a) ethics in epidemiology and public health [1–3], (b) ethics, computing, and health care [4], and (c) ethics, genetics and public health [5–7]. So we have a number of tools (or at least predecessors) to guide us; this is good, given that the three-way intersection we are about to traverse is one formed by high stakes, the need for practical guidance, and the existence of principled disagreement.

## Toward an Electronic Standard of Care

In science and in particular the health care professions, standards evolve or are stipulated for a number of reasons. These include: the need for a public (that is, an accountable and transparent) evaluation metric, a system of professionally-accepted goals and objectives, and a calculus for assigning blame. Failure to agree on which criterion is being used has led to disputes in public health research – such as occurred when a controversial placebo controlled trial for HIV prevention was critiqued for using a standard of care that was local rather than international [8, 9]. In this debate the term “standard” was used to describe a level to be reached as an aspirational ceiling. Yet at the same time, especially in law, ethical standards are also seen as a floor below which practitioners may not fall without being found negligent. When ethics functions in both of these ways – describing aspirational goals and minimal conditions of professionalism – it can lead to some confounding consequences. For example, contrary to what many people expect when ethics is given a seat at the policy assessment table, the result is not always nay-saying and handwringing; sometimes, perhaps often, ethics will *require* use of a new technology if it will promote or achieve independently scrutinized goals (e.g., better patient care, improved public health, etc.). Such situations imply that ethical commentary can serve to both set floors and propose ceilings. This was clear at the dawn of interest in the intersection of ethics and health informatics when it was noted that failure to use a computational tool might itself be blameworthy [10]. This argument has also been made recently, especially as large electronic databases are being used for health care evaluation [11] and research using biomaterials [12]. Common to both uses is the recognition that promotion or protection of the public’s health is a social value of importance—so important that taking actions that promote the public’s health may outweigh those actions that promote the health of an individual person. It is but a short step, ethically, to take the view (as we do) that if an institution (for example, a state health department) is committed to promoting the public’s health, is authorized to exercise its legal authority to do so, and has the tools available to do so, then it would be acting *unethically* if it failed to take appropriate steps and use the legal and technical tools at its disposal. But we should be cautious about moving too quickly from “a commitment to promoting public health” to “it is unethical not to use available health information technology.” The context, details, and ethical justification are jointly important.

The idea of a standard of care for public health informatics therefore consists of several considerations: (a) what constitutes a standard for public health practice, (b) what constitutes a standard for public health research, and (c) what constitutes a standard for the use of informatics technology? Such a standard will help make clear which uses and users of information systems are appropriate, why failure to use appropriate tools can be as blameworthy as inappropriate use, and why system evaluation is essential for an ethically optimized IT system. Throughout this tour, we will attend to a critical tension between the need for science to progress and the demands of a reasoned and robust ethics; we call this “progressive caution” [13].

## Appropriate Uses and Users of IT in Public Health

It is reasonable to hypothesize that there is a broad social consensus that state health departments should maintain databases and use them to “promote the public’s health.” We further surmise that there would be substantial agreement (though perhaps not as much as with the prior statement) that a state health department should maintain a public database to track the incidence of illness caused by tainted food, including, say, infant formula [14], but it should not maintain a database to *market* or sell infant formula. What’s the difference? What makes the one use appropriate and the other inappropriate? While we consider these questions in some detail in what follows, we can lay out here some general strategies for answering them.

First and perhaps most obviously, not all uses or users are equal. We can begin to sort them out by looking at intentions, consequences, and values. So, for example, a database created with public funds to improve public health and promote public welfare is, well, a *public* database. This means that such a database is available for use by authorized public representatives for public purposes. Indeed, very little generally needs to be added to the idea of “public welfare” in order to understand this first criterion. *Anything* that is funded with taxpayer money and used without prejudice to help all will qualify as an ethical use. We are (of course intentionally) forgoing a robust and formal discussion of what “to help all” means. For instance, free reproductive counseling may be seen by some as “helping the community,” while others would strongly disagree. A potentially inappropriate use of the public database would therefore be for some sort of private gain or benefit. This is not a comment on or criticism of free enterprise or the free-market system. It is only to observe that public resources should not generally be used to benefit private interests. On the other hand, even private entities have moral obligations to the public: One would expect, perhaps even demand, of a company that makes infant formula that it inform the public about a tainted product; that is both good business and good business ethics. Indeed, such a company might be considered morally praiseworthy if it prospectively established a database to track tainted food.

In addition, even the most ardent libertarian would agree that if data are collected for proprietary purposes, the needs for transparency and the free flow of information require that the fact of the data collection be disclosed in advance, if for no other reason than to allow the sources of the data to negotiate for their share of the profit. But then, of course, if (i) a person were told that his or her personal information were to be stored for proprietary purposes, (ii) failed to reach an agreement over profit sharing, and (iii) that person then refused to allow the information to be used, then such a database would be less valuable, less useful, and less accurate as a *public health* resource. Not all databases are of equal utility.

So far, however, we have merely stipulated that when a database is publically constructed and funded, a good moral case can be made for its use in the service of promoting the public’s health. More importantly and powerfully, we assign moral weight to the *intention* guiding the creation and maintenance of the database to benefit the public. Intentions matter in ethics because they can aim for good or ill.



In this case, the intention (creating a public database to reduce infant mortality) was a good one, and so hewing to it will constitute an appropriate use. We also assigned moral weight to the idea that the status of the organization (perhaps we can refer to it as its moral status) is a morally relevant consideration. This is why we emphatically did not say that proprietary uses are somehow inherently ill-intentioned – indeed they conceivably might be very well intentioned – only that the use of public health information for public health should be regarded as more praiseworthy by virtue of the greater benefits that will accrue. Indeed, a private company wishing to develop a database for marketing its infant formula would not be acting *unethically* if it made its intentions clear, and the public were aware of the purpose of the database. But it might be acting unethically if it misrepresented the database as principally meeting a public health need.

But suppose an evil database designer set about creating a computational resource for marketing untested home remedies, discriminating against minorities, or spreading panic? Surely this intention should not enjoy the same status as the other. Put differently, intentions (like information technology uses and users) are not created equal. They are distinguished by, among other things, the consequences of their realization and the value we attach to the intention (whether realized or not). In part because the evil database designer, if successful, will cause great harm, we judge her intentions to be morally inferior. Likewise, we value health over illness, stability over chaos, justice over discrimination.

Looking at matters in this way, we can also see why failure to use appropriate tools can be as blameworthy as inappropriate use – though this, of course, is true only when there is reason to believe the tools will have a positive or valued effect. Health IT tools require comprehensive and even systematic evaluation, and this evaluation must occur in the context of actual use. Indeed, it has been convincingly argued that there is an ethical imperative to conduct such evaluation [15]. We can here explicitly extend this insight to public health informatics, at least provisionally, as we sort out the idea of an “electronic standard of care.” This is because system evaluation also helps us make sense of particular uses and users of public health IT systems, at least to the extent that we need to determine for individual uses and users their efficacy and thereby part of their propriety.

We can now look at particular uses and users and see if our intentions-consequences-values metric does any good. For the sake of discussion, let’s identify registry maintenance and querying, decision support and data analysis as uses; government officials, students, and corporate investors as users. To be sure, there are many other actual and potential uses and users, and they might be combined in many ways. Indeed, with the lists just presented, we have nine possible scenarios (i.e., three potential uses multiplied by three potential users). We will not review them all; the idea is rather to give a sense of how the process might work. We can do this with two easy hypothetical cases (or one case with two variants):

*Case 1.* A tumor registry is funded by a federal appropriation from the U.S. Occupational Safety and Health Administration (OSHA). As part of a periodic monitoring program, a government scientist working for OSHA wants to query

the registry to identify the incidence and prevalence of a certain neoplasm in a particular population living near a toxic waste site. The registry was built with public funds, and patients with cancer had agreed to contribute to the bank. The scientist's *intention* is to obtain epidemiologic data that will be used to help determine whether there are empirical grounds for closing the site. One of the possible *consequences* of the query is closing the toxic waste site, thereby reducing correlated morbidity and mortality in future populations in that area. Assuming that we accept that the user was appropriate, the *intentions* were appropriate, the *consequences* of the actions were appropriate and – perhaps most importantly, the *value* we place on reduced morbidity and mortality was appropriate — then we have identified an appropriate use and user.

*Case 2.* Suppose now that the same registry is queried by a biopharmaceutical investor with the stated goal of identifying biomarkers in those same neoplasms that have especially unusual properties. While it is very likely that his instrumental *intention* is to identify markers that will be used to design better anti-cancer drugs (reducing morbidity and mortality from cancer), it is also clearly the case that he is immediately and directly keen to predict for the sake of financial gain which anti-cancer agents will enjoy the greatest markets in coming years. Let us assume his principal intent is commercial. Using the public database for private commercial gain has many *consequences*, not the least of which is eroded public confidence in database security. The *value* is entrepreneurship. The question of whether this was an appropriate use by an appropriate user should be easy to answer: this use (querying a public database for private gain) by this user (a private entrepreneur) is not ethically equivalent to the use in Case 1 (querying a public database for preventing mortality and morbidity) by the user (a government-supported epidemiologist).

Make no mistake: many or most cases are vastly more complex than these. Indeed, developments in translational science already suggest that the once-bright lines between public and private funding, and basic and applied research, are blurring (and that such blurring is being encouraged) [16]. Rarely are data – or intentions! – as unambiguous as implied in our examples. In Case 1, what about the problem of communicating health risks and the likelihood of engendering fear or even panic? What about people who lose their jobs if a factory is closed? In the revised version, is there nothing to be said about the virtues of data sharing? What would we think if the entrepreneurial investor's query led more quickly than expected to a medical breakthrough that actually reduced the impact of a devastating cancer?

As a general starting point, it makes sense to say that ethics can help guide thinking towards optimal solutions and away from sub-optimal ones. Of course, in the same way that it is simplistic to explain genetics using only a basic Mendelian example of two types of pea plants – smooth and wrinkly – so too is it simplistic to explain the ethics of database use using only virtuous government epidemiologists and profit-focused business people (indeed, one can imagine examples in which the moral attributes are reversed). Issues raised later in this chapter will give examples

of these nuanced differences. In fact, ethical issues related to the use of IT should be seen as a subset of the ethical issues that arise in several domains of human activity including epidemiology, public health, and health research, as well as national security, economic development, and social networking.

Such refinement, it is worth emphasizing, is precisely the task of applied ethics. The model is reasonably well evolved in clinical ethics (where patients, families and health care providers wrestle with difficult care decisions) and in research ethics (where researchers, research subjects and oversight bodies confront difficult choices). Applied ethics is a growing area of disciplinary expertise with rigorous peer-reviewed methods that must pass public and professional scrutiny. It is not, however, the mere rote application of existing rules and regulations. The growing interest in codes of ethics is positive and noteworthy—but codes, guidelines, and lists of best practices are no substitute for robust and ongoing ethics education and analysis.

### “Progressive Caution”

Ethics thrives on new science and technology. This is no less true in epidemiology and public health than in any other science. In the health professions, where the stakes are consistently high, the role of ethics is complex. When it comes to new technology, what role do we want ethical analysis to have? Should we be stomping our feet, shaking our heads, and clucking our tongues at the new technology, Luddites at the gates of progress? Or should we prefer facile boosterism, cheering each new gadget independent of its utility or consequences, cheerleaders at the edge of the abyss? The answer, of course, is straightforward: Neither. We want thoughtful analyses and practical guidance. We want science to progress, but not at any cost. We want to minimize risk but not to the point of unreasonably restricting liberty. But we also emphasize that each of these paired goals is understood differently when the practice is about social institutions promoting the public health than when it is about physicians providing excellent patient care or researchers conducting meritorious experiments.

That is, we want a kind of “*progressive caution*” whereby we move forward, and that progress is tempered or leavened by attention to the kinds of details being scrutinized here. To be fair, we recognize that some nuance is at work here, but it is worth emphasizing: it is the difference between prohibiting an action but allowing certain exceptions, and enthusiastically encouraging an action but placing certain restrictions. The path that ethics has trod in health care and research is littered with such nuanced distinctions. More than 60 years ago the Nuremberg Code laid out the first modern set of ethical principles for medical research, strictly prohibiting all research involving humans *unless* they could give voluntary informed consent. Over time, this protectionist stance relaxed to the point where research on humans is widely permitted, even on children and those who cannot give fully informed consent themselves because of diminished capacity to consent, so long as certain

restrictions and procedures are followed. There has been, in other words, a progressive caution exercised about research involving human subjects. Indeed, this is seen in many areas of biotechnology assessment, from stem cell research and reproductive health to gene therapy.

In a slightly different context, the idea of progressive caution was introduced thus: “Medical informatics is, happily, here to stay, but users and society have extensive responsibilities to ensure that we use our tools appropriately. This might cause us to move more deliberately or slowly than some would like. Ethically speaking, that is just too bad” [13].

The idea of progressive caution is perhaps best or most productively put in the form of a question: How should we arrange things so that we enjoy the benefits of new technology while reducing, minimizing, or mitigating the (potential) harms? Given that both the use and the failure to use information technology raise ethical issues, the concept of progressive caution will help guide us as we consider the specific ethical issues that arise when information technology is used in epidemiology and public health.

## Privacy, Confidentiality and Security

The technical issues associated with privacy, confidentiality, and security in health informatics are discussed in other chapters. Here, we will discuss privacy, confidentiality, and security with an emphasis on ethics.

The intersection of ethics and health informatics almost immediately brings to mind the challenges of privacy and confidentiality. These issues are indeed what most people, scientists and lay people included, worry about. We suspect that most people have a reasonably well-developed idea about what these topics concern and why they are important.

We begin by recalling the general difference between privacy and confidentiality. *Privacy* is best thought of as relating to *people* and their expectation, hope, goal, or right to be left alone and free of intrusion by others; you might, for instance, intrude in my private life by peering in my window to study my behavior. Privacy is intruded upon when someone gains access (especially physical access) to you without your permission. *Confidentiality* relates to the status of *information* about people, the “holy secrets” of Hippocrates; you might violate my confidentiality by looking at my medical chart, or by querying the database that contains some or all of that information, without my permission or knowledge. Indeed, one of the intriguing developments in bioethics has been the way privacy intrusion and confidentiality violation have traded places as the more worrisome ethical transgression: unauthorized access to a person (privacy intrusion) may have been worse than unauthorized access to information about a person when the harms of the former are seen as more damaging than the latter. Once medical charts became more widely available to more people with a “need to know,” confidentiality may have become the more worrisome. Indeed, one of the landmark ethics reports which documented

the large number of health care providers in a hospital with access to a patient's medical chart referred to confidentiality as a "decrepit concept" [17]. And now that genome science has progressed to the point where tiny bits of DNA can identify individuals without ever having to physically interact with a person, it may be time to revisit the entire analysis.

So too will public health informatics require that we think about privacy and confidentiality in ways somewhat different than we might be accustomed to in clinical medicine, nursing, or psychology. The core problem with confidentiality and electronic health media is this: We want simultaneously to make information easily accessible to appropriate users and inaccessible to inappropriate users. This is a problem, because the means for accomplishing the one are often in conflict with the means for accomplishing the other. But this air of dilemma is resolvable in at least three ways [18, 19]:

- Technology, including security measures
- Institutional policies and procedures
- Education programs addressing the foundations and importance of confidentiality

These practical steps may be regarded as moral imperatives, measures to take as part of a comprehensive program to protect individuals' health information. But such protections cannot—and should not—be absolute. That is, there may be credible challenges to confidentiality, and many of the most interesting and important ones arise in public health.

## **Information, Consent, and Stigma**

The most obvious way one might ethically set aside concerns about confidentiality breaches is with the consent of those about whom the information pertains. This is often the case in research contexts: Investigators need to have access to personal health information, and subjects/participants must agree to this access. Patients also routinely consent to release of information to third parties—e.g., insurers—for the sake of reimbursement of health professionals (though because they must provide such consent to be treated in the first place, one might plausibly wonder how voluntary such consent really is.) We also note the apparent ease with which individuals routinely "consent" to allow information to be used, collected, and shared to facilitate social networking, downloading of "apps" and website content. This gives rise to a new public health informatics reality arising from social media. For example, by relying on search queries alone, Google Flu Trends is able to measure influenza outbreaks faster and, some scientists argue, more accurately, than by relying on traditional health care system reports [20]. The key point is that if individuals voluntarily permit others to obtain and use information about them, then the information that has been shared is no longer confidential. It may have an impact if it is

shared, it may cause embarrassment, remorse, guilt, pain, or befuddlement, but the act of giving permission (and the assumption that one understood what one was giving permission for) renders the status of that information no longer confidential and thus outside the range of violation. This is why, for example, there is considerable interest in the world of biobanking to de-emphasize privacy and confidentiality protections to those being asked to donate samples and allow access to information, and to focus instead on providing clear information about possible uses.

Public health IT poses special challenges to the traditional clinical/research model, in part because there are many cases in which it would be logistically or practically impossible for epidemiologists or public health officials to obtain consent from all those whose information they want to collect or analyze. In other contexts, such as collecting information about transmission of various diseases, rates of vaccination, and so forth, society has set aside the notion of absolute confidentiality in exchange for the benefits of better health surveillance, monitoring, and analysis. Indeed, a great deal of personal health information is collected, stored, and processed by governments, universities, and other entities without any individual consent whatsoever. Institutional Review Boards (IRBs) oversee some of these efforts, but they do not oversee all public health surveillance, in part because some of these activities do not fall under standard definitions of research involving human subjects.

This is not as far-fetched as one might think. In environments where the public is confident that government officials will use previously collected health information in a trustworthy manner, consent is not always required [11, 21]. But that willingness is not to be presumed come what may: It is, we might surmise, a gift from citizens in open societies. They trust health authorities to make sound decisions and recommendations based on the best available evidence, and they trust those authorities to acquire the evidence in the least intrusive ways possible. One of the ways to accomplish this is to render the data anonymous in salient respects. For instance, many public health surveillance efforts do not require the collection or storage of unique identifiers such as name, address, or Social Security Number; all that is needed is case information, context, and so forth. Another way is to make explicit efforts to engage the community [22].

But the balance of the “special challenge” of public health IT is that health data achieve a distinctive synergy when they are stored in computers. For example, it might not matter that you do not know an individual’s name if you know her disease, race, postal code, and sexual orientation [23, 24], or perhaps have a sample of her blood [25]. Either you will be able to identify this person – to pick her out of the crowd – anyway by virtue of these surrogate data ensembles, or your surveillance or research will come to associate her social, racial, ethnic, or other group with a malady or behavior in ways she would have objected to had she been given the opportunity to dissent.

Even in open societies, most people are ignorant of the ability of geographic information systems to characterize neighborhoods and draw inferences about ever-narrower social groups. Would people consent to these characterizations or inferences? Indeed, would they ever have agreed in the first place to allow their personal

information to be digitized if they knew the kinds of inferences that might be drawn? What we have come to call “group confidentiality,” or the idea that population subgroups have privacy and confidentiality interests [25], has acquired increased currency, especially in genetics principally because genetic information is ultimately about the information that is shared by communities, be they families or persons who share a similar disease. In the case of families, knowing the genetic test results of a parent immediately conveys information about their biological children; testing an individual for the presence of a genetic mutation that is more prevalent in a racial or ethnic group will immediately convey information about that group.

## The Case of Bioinformatics

Completion of the project to map and sequence the human genome is ushering in what many hope to be a golden age of molecular epidemiology. It is therefore important to provide a brief excursus on computational genomics or bioinformatics [26, 27]. For a variety of clinical and research purposes, including drug discovery, clinicians and scientists are increasingly able to digitize genetic information and store it in databases. Three key questions emerge from this effort, and they will continue to challenge our ability to get an ethical grip on this new technology:

1. Does it make any real sense to talk about confidentiality when computers processing genomic data (perhaps in conjunction with other information) provide a high-powered way of identifying individuals whose idea of confidentiality was a piece of paper in a locked desk?
2. Consent to acquire information increasingly needs to take into account the idea that people might—or might not—want to learn the results of aggregate genetic analysis. In other words, if I agree to let you store and analyze my genetic data, does that mean you will later let me know what you learn? Will you have an unanticipated duty to disclose risks and other incidental findings to people who might not want to hear of them?
3. What standards or assurances are available that error reduction is being addressed by the new technology? Complex databases and gene annotation protocols are ripe for both error and error-reduction strategies. With genomes as email attachments and digitized genetic information being included in very large databases, the job of valid consent will be as difficult as in any other aspect of biomedical research. There are several reasons for this. Some are independent of the role of information technology and some are greater because of computers.

As already noted, genetic information is not about one person; it is also information, in 1 degree or another, about others. These relatives might be identified in research (usually pedigree studies) without having consented to be subjects in the research. Genetic information is to some extent also about members of one’s racial or ethnic group, increasing the risk of bias and stigma – even as we might make use of the information for standard epidemiologic purposes. And of course genetic

information is about people who share common genetic mutations that raise their level of risk of disease. Genetic information increases in scientific (and other) value over time. This is due to the fact that while we have sequenced the human genome, we are still mostly ignorant of the *functions* of most genes—what genes actually do when they make the proteins that form the parts of our human selves. As functional genomics progresses, we will acquire tomorrow the ability to conduct research that is not possible today. This increase in research potential is independent of the stored genetic information or tissue samples themselves. In other words, today's genetic database will increase in value tomorrow even if it is not changed or augmented.

Can valid consent rise to these challenges? There is every reason to believe it can, especially as we ensure that the concept of valid consent as a process and not an event does not collapse into platitude and cliché. Indeed, the idea that consent is a process which might, in fact, never end offers a way to ethically optimize the epidemiologic use of digitized genetic and, indeed, other information. Consider the potentially great value in special newsletters for subjects (and even communities) whose genetic information has been digitized and stored in an electronic database. Such newsletters can inform individuals, relatives, and communities of new and potential uses, including research, planned for the database. The database, if appropriately constructed, could provide the means for individual subjects to opt out of specific studies. For instance, suppose I am willing to consent to research in cancer genetics but not research on Alzheimer's disease. Once my genome is in your database you will be able to let me know of the contemplated use for Alzheimer's studies, and if I dissent you will be able to ensure that my genetic information is not included in your study.

Such a newsletter might also provide a much better way of including subjects in the broad sweep of the research in general by informing them of study results, related research, and even ethical issues raised by the research. Furthermore, imagine that not only would a newsletter or blog be available to patients, but that physicians received up-to-the-minute information about the relevance of these findings, with reminders, warnings, and special considerations, as they now often do when they write a prescription in a computerized physician order entry system. The positive potential for using genetics in the service of public health is only now starting to be explored. Among the most obvious targets for applying genomic science to population health is the focus on predictive, diagnostic, and therapeutic benefits for stratified populations and subpopulations rather than individuals. The benefits of population screening for familial hypercholesterolemia or inherited colorectal cancer are good examples of genetics helping public health. But many implementation and infrastructure challenges remain [28].

## Decision Support

Our discussion of appropriate uses and users of IT systems will be of no small utility as we consider the issue of computational decision support in epidemiology and public health. In one sense, all computers used in epidemiology and public health are decision support systems—computers that help us navigate among the shoals of probabilistic data.



In clinical medicine and nursing, there are generally thought to be at least three kinds of decision support systems: *reminder* systems, *consultation* systems, and *educational* systems. Their functions are easily inferable from their names. Apart from seasonal reminders to “get your flu shot,” it is not clear if decision support in epidemiology and public health runs parallel to these three uses—what constitutes a reminder in clinical medicine, for instance, has no ready analog in the public health sciences. We can however identify two functions of ethical interest in decision support in epidemiology and public health; they are (1) *interventions* and (2) *data synthesis*, including meta-analysis and data mining.

## ***Interventions***

A decision support system might be used to help decide whether and when to begin an intervention program and what kind of intervention would be best or most efficacious. Why is there an ethical issue here? To answer this question, let’s turn to clinical medicine.

What has come to be called the “standard view” of decision support in diagnosis suggests that humans are better than machines at functions as complicated as diagnosis [29]. Humans *understand* data better than machines (even if computers might be able to *process* it better and faster. The answers to questions about whether to close a toxic waste site, commence an education program, or call for a quarantine are decisions that require more than digital firepower. They are decisions that require vast background knowledge, a scientific as well as an intuitive understanding of risk, and a more or less clear sense of how best to balance and trade off among competing goals. Computers cannot meet these criteria, and are unlikely to be able to for some time.

It follows that while we might have a duty to use computers to help in making tough calls, we must not let the computers make the tough calls. This stance is appropriate whether we are contemplating needle exchange programs or anthrax attack countermeasures, vaccination protocols or mutant flu quarantines. Another way of putting this is that public health decisions are rarely if ever exclusively scientific, statistical, or empirical. Public health scientists and officials are faced with a difficult array of decision points such that the correct or best answer will rarely be arrived at with more information or more computing power. Rather, scientists and officials need to analyze their intentions or the goals they hope to achieve, the consequences of various decisions they might make or actions they might take, and the values that guide them.

The question of whether to intervene and which intervention to commend is in part an ethical one precisely for these reasons. It is possible that a decision support system might one day be able to analyze human values as well as data sets—but it is very unlikely and, in any case, it will be quite a long time before that happens. The lesson in public health is the same as in clinical medicine and nursing: Computers should not be allowed to trump people [29].

## *Data Synthesis and Computer-Based Research*

Ever-increasing demands for data and evidence to inform guidelines and best practices have made it clear that we need computers to help us sort out all our information. Indeed, we now turn with increasing frequency to various forms of research synthesis to make sense of the data. The computational tools of meta-analysis and data mining will give us our best examples; they provide ways of eliciting conclusions, answers, or even mere suggestions from the apparent mess of data. They provide us with many case studies about whether and when to use a computer in making scientific decisions. Debates over meta-analysis, which often turn on its methods and reliability, remain important for any discussion of ethics in epidemiology in general, and ethics-computing-and-epidemiology in particular [30].

Consider the important historic case of meta-analytic studies of the effects of environmental tobacco smoke. In 1993, the US Environmental Protection Agency, relying on a meta-analysis of 11 studies of smokers' spouses, classified environmental or "second-hand" tobacco smoke as a Group A carcinogen along with radon, asbestos, and benzene [31]. No problem so far—tobacco smoke is bad, people agree tobacco smoke is bad, a study shows that tobacco smoke is bad. The problem is that meta-analysis continues to engender intense debate about its accuracy and reliability. It might be, in other words and just for the sake of discussion, that we (in 1993) actually lacked adequate scientific warrant to rank environmental tobacco smoke as a Group A carcinogen. At any rate, the debate elicited the following remark: "Yes, it's rotten science, but it's in a worthy cause. It will help us to get rid of cigarettes and to become a smoke-free society" [32]. This quote is two-sided: on the one hand the self-righteous among us are prepared to accept a certain amount of scientific uncertainty so long as the public health policy goal is achieved – how sure do we have to be, scientifically, to recommend an anti-smoking policy for city restaurants? On the other hand, uncertain science is precisely the basis for the pushback by opponents of anti-smoking regulation. And what tobacco science was to the 1990s, climate change science is to the early part of the twenty-first century. How much certainty is required (and what counts as good data) that the planet is warming and that humans bear some responsibility before public health policy to restrict carbon emissions takes place?

The ethics-computing-public health tension has been described as follows:

In one respect, the very idea is incoherent: If one believes the science to be flawed, then how can it support a worthy cause? How even can the cause become worthy in the absence of credible evidence? (If environmental smoke does not harm children, then there is no reason to protect them from it, and so protecting them cannot be worthy.) But granting for the sake of discussion that the cause is worthy, it is nevertheless a severe form of ethical shortsightedness to suggest that the credibility of scientists, government institutions, and policy makers is a fair trade for a victory on one policy issue. Even the most craven utilitarian would recognize this to be a bad bet [27].

Note that while the intention might be praiseworthy (to reduce environmental tobacco smoke) and the consequence a positive one (fewer people suffering the effects of second-hand smoke), the value we place on scientific method and credibility may sometimes outweigh the other considerations. It is also important to underscore that it can be very difficult to calculate future consequences – including future negative consequences.

Think of meta-analysis and data mining as secondary or *n*-ary uses of data. Such use matters, as it did with bioinformatics, because subjects or communities might have consented to the primary use but not necessarily the secondary or *n*-ary one. Now, this might matter little or not at all to research subjects, especially if the risks of such research are minimal or absent and if (as is usually the case with meta-analysis) individuals cannot be identified from or in the data. With data mining, also sometimes called “knowledge discovery” or “machine learning,” we have the *n*-ary analysis of databases in search of patterns, trends, associations, and so on. Employed to great profit in science and business, data mining is emerging as a potentially valuable resource in health care.

Our concern is with valid consent in computational public health practice and research – specifically, the use of personal information for purposes other than originally intended (advocates for public health surveillance observe that if data are collected for public health, their use for public health is primary, not secondary). Data mining technology promises public health trend-spotting, quality assessment, and outcomes research of depth and breadth unimagined a few years ago. Since this information is *personal* information, we need to ask whether those people the information is about would agree to such use. We need to look at three key considerations:

1. Is the database analysis something that was disclosed and consented to when the information was obtained?
2. Is the purpose of the data mining scientific, commercial or both?
3. Are individuals identifiable in the database or as a result of the research?

The answer to question 1 is rarely “yes”; for question 2, the use might be commercial; the answer to question 3 will often be “generally” or “in principle.” The feature of data mining that distinguishes it from more garden-variety forms of database research is the facility with which scientists (and others) can look through vast amounts of personal, identifiable information — again and again and again (it is, therefore, a question at least of degree and perhaps of kind). Each analysis is a further “experiment” for which we may generally presume that no consent has been obtained. Besides, tools such as newsletters are more useful for focused research programs in which the goals of the research can be itemized. In data mining, one might perform an analysis with all the effort and forethought that go into a PubMed search, for instance.

As with bioinformatics, more research is needed to clarify the ethical issues surrounding data mining. We include it here to give a sense of exciting new challenges to the standard model of valid consent (how best, for instance, might one describe data mining in lay language to prospective subjects?). For now, the best consent for data mining research is likely to be obtained in advance, for non-commercial research, and for studies where individual identifiers are either not available or can be readily hidden and secured.

## Conclusion

The computational turn in epidemiology and public health offers extraordinarily powerful and intelligent tools to collect, analyze, and transmit the personal health information of millions of people. We have seen that it would be ethically irresponsible not to continue to develop and use these tools for the improvement of public health. As important, we have learned that the ordinary people who are the sources of that information have warrant to expect that its collectors, analyzers, and transmitters will safeguard it and ensure its appropriate use.

What counts as an appropriate use and who should be regarded as an appropriate user are questions whose answers will guide practitioners and policy makers as they balance the needs of public health and the rights of individuals. This balancing effort can be difficult and nuanced: the information at issue includes both the familiar and quotidian (on vaccinations and vital statistics) and the novel and complex (genetic data about individuals and groups).

Moreover, what is in some domains a comfortable demarcation between practice and research becomes fraught and controversial in epidemiology and public health. This is unavoidable, but it presents us with splendid opportunities to apply and evaluate the tools of applied ethics. This will be especially true as ever-grander computers and data networks link scientists and officials from around the world. We will judge them by how well they use the networks in the service of public health, and by how well they attend to the concerns of individuals who, in a flash (or a click), may find themselves and their genes and maladies and behaviors out there for all to see.

### Review Questions

1. Many people think of ethics as prohibitive. What does it mean to say that use of a technology might be obligatory?
2. Explain why the concepts of “appropriate use” and “appropriate user” are given so much emphasis.
3. What is the point of “progressive caution” and why does it matter in public health informatics?
4. Differentiate among *privacy*, *confidentiality*, and *security*, as those terms relate to public health information.
5. Review the ways electronic health data might be made easily accessible to appropriate users and inaccessible to inappropriate users.
6. Say why “group confidentiality” is important in public health informatics.
7. Review some of the leading challenges that arise in bioinformatics.
8. In their discussion of decision support, the authors conclude that “Computers should not be allowed to trump people.” Why do they say this? Do you agree? Why or why not?

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# Chapter 12

## Project Management and Public Health Informatics

James Aspevig

**Abstract** The chapter provides a high-level overview of the discipline of project management, serving as a brief introduction to the Project Management Institute's widely used methodology as it is often practiced in the field of public health informatics. The use of the project management process groups is described and explored from the perspective of the management of public health informatics projects. Key issues in the management of public health informatics projects are also highlighted in the project context. Specific tools and techniques likely to improve opportunities for public health informatics project success are identified and discussed. An understanding of project management techniques is essential for the public health manager, as informatics activities are often implemented as projects.

**Keywords** Project Management • Information Systems • Competencies • Project Management Institute • Project Management Body of Knowledge • Process Group • Public Health Informatics Institute

### Learning Objectives

1. Discuss the importance of project management in context of public health informatics.
2. List the Project Process Groups and place the project process groups in order.
3. Understand examples of project management activities, and project management tools and techniques.
4. Judge whether or not a proposed project needs to be broken down into sub-projects or phases.

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## Overview

The chapter provides a high-level overview of the discipline of project management, serving as a brief introduction to the Project Management Institute's widely used methodology as it is often practiced in the field of public health informatics. The use of the project management process groups is described and explored from the perspective of the management of public health informatics projects. Key issues in the management of public health informatics projects are also highlighted in the project context. Specific tools and techniques likely to improve opportunities for public health informatics project success are identified and discussed. An understanding of project management techniques is essential for the public health manager, as informatics activities are often implemented as projects.

## The Importance of Project Management in Public Health Informatics

The use of information systems (IS) to collect data and support the delivery patient and public health client services is exploding across all sectors of the health care system and these trends are only accelerating. The federal support available for Health IT through the American Recovery and Reinvestment Act of 2009 (ARRA) will exceed US\$49 Billion. Resources made available at this level will almost inevitably have a substantial impact on the health care delivery system, including public health [4].

This chapter is, therefore, intended to serve as a general introduction to the major aspects and domains of project management in the public health informatics context. While project management, which may be defined generically as the process of meeting project requirements through the application of specialized knowledge, skills and techniques, makes a distinctive contribution to the field of public health informatics, it is also a unique discipline in its own right. The purpose of this chapter is to introduce some of the basic concepts associated with project management and provide a brief overview of the major aspects of project management in the public health informatics context. As such, a complete treatment of the discipline of project management is beyond the scope of this chapter. However, additional references to supplementary materials are provided at the end of this chapter. Project management is an increasingly important field and competent project managers are in high demand across virtually all industries [11].

We will use two terms in this chapter to describe the types of projects that public health informaticists are engaged in. The term public health "informatics projects" will be used as a broader term to describe the full range of projects that a public health informaticist might engage in. These can include projects involving data analysis and epidemiology or population health research. The term public health "information systems" project or "Public Health IS project" will refer to the smaller



subset of informatics projects dealing expressly with the implementation or support of a public health information system (i.e., a public health software application).

## **Project Management Competencies in Public Health Informatics**

In 2009, a working group sponsored by the US Department of Health and Human Services detailed a total of 13 domains of competency for senior public health informaticists [5]. Five of these 13 domains contained a substantial emphasis on the various aspects of project management, including project planning, project communication, and the management of the human and financial resources associated with projects [5]. This provides direct validation of the importance of project management to the practice of public health informatics.

However, in realistic terms many public health agencies simply don't have access to the services of trained public health informaticists or certified project managers in the number that are needed. As a result, many public health informatics projects will likely be managed by traditional public health managers and program coordinators for the foreseeable future. This creates a situation where public health managers need to develop an understanding of public health informatics project management and how it differs from the management of traditional program operations. Review of this chapter alone will not permit the reader to go out and manage a large, multi-faceted, public health IS project. This chapter is intended to serve as an introduction that will hopefully stimulate both the discussion of, and a desire for, further study in the reader. Project management is an active and growing discipline. Both students of public health and practitioners would do well to study the tools and techniques of project management.

## **Project Management and the Prevention of Information Systems Project Failure**

In the area of IS, project management has assumed an increasingly important role because the methods, tools, and techniques of project management have largely been developed with the goal of reducing the risk of project failure and making the outcomes of a project more predictable. The significant risks and challenges associated with the development and implementation of information systems are not unique to the practice of public health informatics. One of the ways to illustrate the importance of project management to public health IS implementation includes measures of the general rate of IS project failure across all industries.

One of the more widely recognized efforts to quantify the ratio of success to failure for IS projects is provided by the Standish Group, whose biannual CHAOS

report has consistently shown a relatively high failure rate for IS projects across all sectors [29]. While it is noted that the CHAOS methodology for reporting IS project failure is subject to some limitations, the fact that the Standish Group has performed the CHAOS survey for more than a decade may still provide a level of relative internal validity [9]. When initiated in 1994, the CHAOS report concluded that only 16 % of IS projects were successful, meaning that only 16 % of IS projects met the three basic requirements of having been delivered on-time, within budget, and with the features and functions required by the users [9]. In contrast, the 2006 report stated that approximately 35 % of IT projects were successful. While this does indicate improvement in the success rate for IS projects, in 2006 it was also reported that, even 12 years after the initial 1994 report, 19 % of IS projects were still classified as failures and 46 % were still being evaluated as “challenged.” A designation indicating that these projects had either experienced cost overruns, delays, or had not fully meet user needs [6]. In other words, even though there were indications of improvement in the rate of project failure, as of 2006, approximately two-thirds of IS projects evaluated in the report were still either failing or facing significant challenges.

Whatever the limitations of the CHAOS report’s measures, there is little doubt among many healthcare and public health practitioners that IS projects are often perceived as costly, frustrating and somewhat risky [13]. The tools and techniques of project management have emerged as the primary means of reducing the risks and frustrations associated with implementing IS projects in the public health and healthcare environments.

## **Project Management Methodologies**

A large number of methodologies are available to assist in the management of IS projects. For learners relatively new to the discipline, the sheer number of methods available may be confusing. Some methodologies are very specific to the creation of a particular type of product. These highly specialized methodologies are often referred to as “product methodologies,” and using them successfully requires knowledge of the methodology itself and also a match between the methodology and the particular product the organization wants to create. For example, the Systems Development Life Cycle (SDLC) methodology is a software development methodology oriented toward the development of complex software applications for large organizations [27]. If a health department engages to develop a large, complex software application, then SDLC would likely represent a good choice of method. However, if a health department wants to quickly create a small software application for temporary use, or just wants to train users on how to work more proficiently with an existing system, then SDLC would not be a good choice of method. The weakness of product methodologies is that they are highly specialized to a particular type of output (i.e., product) and are not very adaptable to the wide range of projects that public health agencies often need to engage in and complete.

Other project management methodologies are more general and not specific to a certain type of product. For example, CompTIA, a professional organization actively involved in educating and certifying IT professionals, sponsors its own project management certificate program and provides training materials oriented toward the specific concerns of IT professionals involved in implementing information technology and maintaining IS [7]. The general project management methodologies are more adaptable and may be regarded as providing a framework for the implementation of a wide variety of projects. This chapter will draw most principally from the general methodology for project management championed by the Project Management Institute (PMI). PMI is a large organization that advocates for the use of formalized project management techniques across many different industries, including healthcare and public health [8, 21].

It is worth noting that most of the more widely-accepted project management methodologies hold a substantial number of their most prominent features in common, such as a substantial emphasis on planning, and the use of specific project phases. As a result, while each particular methodology may have its more ardent proponents; it might also be said that the use of any methodology is better than attempting to conduct a project unsupported by any method. The PMI methodology will serve to illustrate the utility of project management techniques across a wide range of public health informatics activities. A list of materials and resources to support independent study is provided at the end of the chapter.

## The Project Management Context: Definition of a Project

There is often a fundamental misunderstanding of the meaning of the term *project*. When used in casual conversation, “project” is applied, often incorrectly, to a wide range of activities; which may include writing an annual application for a continuation of funding to support of a given public health program or ordering more toner for the photocopier. However, project management, like all disciplines, uses some very precise definitions for its key terms. Among public health informatics professionals, a widely accepted definition of a *project* is “a temporary endeavor undertaken to provide a unique product, service or result” [22]. From the perspective of a public health manager, the attributes of this definition are the key to the understanding of the true nature of those activities that actually constitute a project. Using the given definition, the *temporary* nature of projects points to the fact that projects are focused, *time-limited* efforts intended to create something of unique value to the public health agency. The concept that projects are *one-time* and *unique* points to the fact that projects do not represent the typical, ongoing work performed by the public health agency. A true project calls for the creation of something that has not existed in the public health agency prior to the project endeavor. In the public health IS context, it therefore follows that projects usually involve the development, selection or implementation of a new IS as a way to fundamentally transform certain aspects of the way the public health agency operates and also, most likely, the way it collects and maintains the data needed to serve their clients and generate the information necessary to support the agency.

## Project Management vs. Operations Management

The formal definition given for the term *project* also serves to contrast it with the activities associated with *operations management*. The management of operations is intended to direct the routine, day-to-day functions of the public health agency. In a public health agency, operations management may include managing the routine delivery of client exams and screening services. From this example, we may also see that the process of setting up new public health programs and services that the agency has not delivered before likely represents a project; increasingly, it is also associated with the simultaneous implementation of an electronic IS or the altering of an existing IS to accommodate the new public health program. However, as soon as these changes are made and the processes incorporated into the organization's routine operations, then a transition has been made to operations management. The idea that setting up a new public health program and associated set of services represents a project, and then transitioning this new set of services into routine operations, is a concept important to public health IS project management. After the implementation of any new public health IS, the use of that IS must be transitioned into the normal day-to-day operations of the agency in support of the agency's programs.

An example of this type of program implementation occurred when a new role for public health in emergency preparedness was defined in 2000, with the launch of the Health Alert Network (HAN) initiative. One of the major objectives of HAN was to establish an electronic communications infrastructure in all local public health agencies. When the HAN program was first initiated, many staff working in local city and county health departments did not have routine, reliable access to high-speed Internet or e-mail [1]. The HAN program first began as a project, but over time public health's role in emergency preparedness has been routinized, and virtually all local public health agencies now have transitioned to a point where the use of electronic communications and Internet technologies has been integrated into everyday operations [18]. Today, few of us could even imagine a work environment in public health that did not include the routine use of e-mail and other Web-based communications, but a project was required to put that infrastructure in place across the nation [2]. The HAN program is an excellent example of how the adoption of new technologies may begin as a project, accelerated by the provision of additional resources as occurred following the terrorists attacks of 2001, and is then transitioned into routine use in a way that provides additional technological capacity to the public health organization and all the programs it supports [16].

## The Project Management Knowledge Areas

The PMI methodology divides the discipline of project management into nine major knowledge areas. This section will constitute a very brief introduction to the knowledge areas; whole chapters of formal project management texts are frequently dedicated to each knowledge area. Examples of issues commonly faced by public health

informaticists in the management of projects and key aspects of select knowledge areas will be explored later in the chapter, as we look more directly at the process of public health informatics project management itself. A concise definition of a *knowledge area* is “An identified area of project management defined by its knowledge requirements and described in terms of its component processes, practices, inputs, outputs, tools and techniques” [20]. The key to understanding this somewhat generic definition lies in an understanding of the term “*knowledge requirements*,” which indicates an area of specialized managerial expertise where the public health informatics project manager is aware of, and correctly applies, certain practices, tools and techniques toward the management processes and creation of the deliverables important to each phase of the informatics project. The nine major knowledge areas of project management are:

- Project Integration Management
- Project Scope Management
- Project Time Management
- Project Cost Management
- Project Quality Management
- Project Human Resource Management
- Project Communications Management
- Project Risk Management
- Project Procurement Management

The list above names several knowledge areas that are relatively unique to the discipline of project management such as “Scope,” and “Integration Management.” However, the majority of the knowledge areas listed above are likely familiar to most public health managers, as they also pertain to similar areas of expertise important in the management of a public health agency’s routine operations. These would include areas such as Cost, Procurement, and Human Resource management. The project context, where the informatics project is defined as a time-limited endeavor that will create a unique product, drives the differences in how these tools and techniques are applied on a project as opposed to how they are applied during routine operations. Project Human Resource management will be later presented as an example of how staff are managed differently in the project context, when compared to how they might be managed during the course of routine public health program operations.

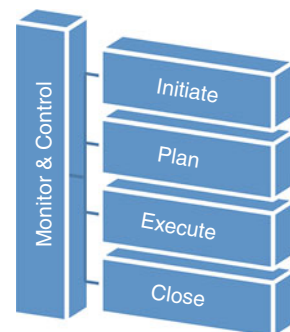
## **The PMI Project Management Process Groups**

Under the PMI methodology, the phases of managing a project are divided into “process groups.” The five process groups are:

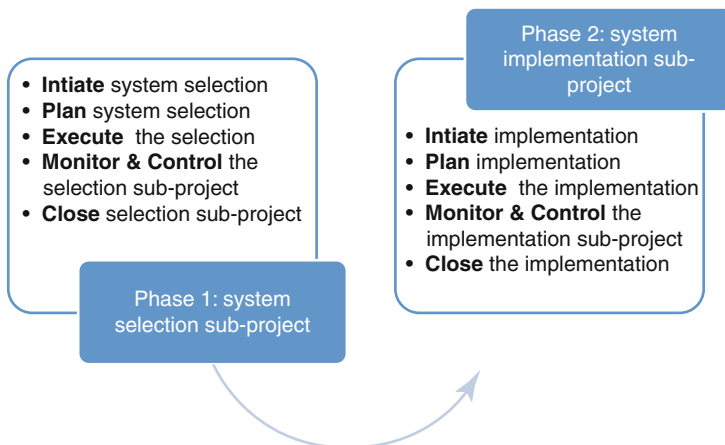
- Initiating
- Planning
- Executing
- Monitoring and Controlling
- Closing

In simple terms, these process groups are sometimes thought of as the phases of a project that are meant to be carried out sequentially. However, there are two major reasons the process groups are not simply referred to as project phases. First, each group is comprised of specific sets of activities or processes. For example, the planning process group consists of activities that would include (1) collecting the information system's requirements; (2) developing the project management plan, and; (3) completing the estimate of project costs. Moreover, the *Monitoring and Controlling* group consists of different activities applied during all of a project's phases in order to make sure the project is moving forward.

The second major reason that these sets of activities are not simply referred to as project phases is that relatively complex projects may inherently consist of multiple phases. For example, if a public health agency wants to implement a new client management system but has not yet selected the software it will use, then the overall public health IS project may consist of two distinct phases, the first phase being the selection of a software application from a range of options and the second phase comprised of the installation and implementation of the application that was chosen in the first phase. Even though the overall goal is known for this project (i.e., implementing a new public health client management system) it is necessary to break the project down further into additional phases or sub-projects as it is not possible to plan the details of a software implementation without first knowing what software the organization will be using. Therefore, it is necessary to complete the entire set of process groups for each phase or sub-project. In other words, the selection of the software application would be initiated, planned, executed, monitored, and closed. The final result of the first project phase would be the selection of a software application. The subsequent phase or subproject would then be initiated to install and implement the newly selected application, and the process groups (initiating, planning, executing, monitoring and controlling, and closing) would be repeated in order once again, with the end result being that the application selected in the first phase would be fully implemented and in operation following the second phase. Figure 12.1 shows the relationship of the process groups to one another and Fig. 12.2 shows the relationship of the process groups during the two phases of our hypothetical "public health systems selection and implementation project."



**Fig. 12.1** The relationship of the PMI process groups (Adapted from Project Management Institute [22])



**Fig. 12.2** The relationship of the PMI process groups to an informatics project's phases (Adapted from Project Management Institute [22])

In order to provide an introduction to the project management processes most directly related to the practice of public health informatics, the following sections will describe a project management process group while highlighting the tools and techniques of specific knowledge areas that are used to manage those process groups during a public health informatics project.

### *Initiating the Public Health Informatics Project*

Commissioning the development of a customized software application to serve the specific needs of a single public health agency is becoming increasingly rare at the state and local levels. Public health agencies are increasingly pooling their resources and convening much more innovative project approaches, where applications are shared and their further development overseen by a governing board of stakeholders. For example, Wisconsin manages their immunization registry software as an open-source project, where the application is shared with 24 other entities as part of an Immunization Information System consortium [3]. Moreover, the increasing abundance of commercially available electronic health record software solutions, coupled with the development of mature public health software applications and the availability of a significant number of standards-based open source software systems, have had the effect of significantly reducing the need for public health agencies to engage in the development of customized software applications to meet their needs [19, 28, 30, 31].

The outcome of this change to the public health IS environment means that emphasis in public health IS project management may be moving away from the management of pure software development projects. The two most common types

of IS projects in the broader healthcare system have become (1) software selection projects and (2) systems implementation projects [12]. Public health informatics may be going through a similar evolution, with some IS project management focus shifting from the management of software development efforts and over to an emphasis on helping stakeholders select a software application from a number of available options and then working to implement the system that has been chosen.

### *The Project Charter*

Once the need for a system has been established, the initiation of a systems selection and implementation project should be undertaken in a very formal manner. The PMI methodology calls for the development of a document known as a *project charter*. At a minimum, the project charter provides the authorization, from the appropriate level of management, for a project to move forward.

Other organizations with an interest in public health informatics project management are also strong advocates of the use of a project charter. The Public Health Informatics Institute (PHII) published a case study in 2004 which emphasized the importance of creating a clear and highly detailed project charter [23]. In their case study, PHII expands the role of the project charter into that of a more comprehensive planning document which included the following sections:

- A statement of the project's purpose
- A list of the project's principle deliverables
- A governance plan for the project detailing where decision making authority was placed and under what circumstances it would be exercised
- A thorough project plan
- An analysis of the all the stakeholders who would be involved in, or otherwise affected by, the project
- A communications plan
- A risk analysis and corresponding mitigation plan [17, 24]

Under the PMI methodology, many of these documents, such as the communications plan, would not be created until the project formally completed the initiation process group and entered the planning process group. However, the goal of this chapter is not to indoctrinate the reader into some form of project management orthodoxy. In its 2004 case study, PHII illustrated the use of the project charter as a tool to define the project and gain consensus among a diverse group of stakeholders at a relatively early phase in the project cycle [23]. This approach may offer substantial advantages to public health agencies undertaking informatics projects that involve external stakeholders. By their very nature, most public health informatics projects are collaborative and tend to cross organizational lines. Foundations, non-profits, and non-governmental organizations, like PHII, work with federal agencies, federal agencies work with state health agencies, and state health departments



coordinate activities with local public health agencies, which collaborate with the primary care providers in their communities.

To illustrate this point, local public health departments may collaborate with hospitals and major clinics in conducting a community health assessment. These assessments require some measure of data collection and data sharing in order to help quantify the various risks to health that a community may face [25]. As more data becomes held in electronic systems, obtaining and effectively evaluating this data will increasingly become an informatics function [26]. However, some external partners in a community health needs assessment may be reluctant to share certain data. As an example, a hospital may fear a loss of competitive advantage if it reveals too much information about certain attributes of its patient base. Engaging the stakeholders involved in a collaborative project, such as a community health needs assessment, early in the process offers substantial advantages. It provides an early opportunity to establish decision-making structures and identify areas where consensus may be readily achieved as well as areas of potential conflict. Moving rapidly into the planning process on a project that involves many independent stakeholders gives the stakeholders and project team an opportunity to address issues and assess the viability of the project very shortly after its initiation.

As a general rule, as projects grown larger and more complex, the scale and extent of the project charter also increases. In any case, a project charter, authorizing the project to move forward, is an essential element of effectively initiating a multi-stakeholder public health informatics project.

### ***Planning the Public Health Informatics Project***

The PMI definition of the planning process group states that it consists of “Those processes performed to define and mature the project scope, develop the project management plan, and identify and schedule the project activities...” [20]. Establishing the scope of the informatics project and identifying all of the activities that will need to be performed in order to complete the project are essential elements of creating the project schedule. The project schedule is one of the main outputs of the project planning process. The schedule represents a key document that will be referenced continually in order to help assure that the project is moving forward in an orderly and timely fashion.

### ***Developing the Project Schedule***

Even public health managers may often assume that proficiency in the use of expensive, proprietary project management software is required of all project managers, and that such software is also needed to create a project schedule. However, the most common representation of a project schedule is a Gantt chart which was popularized

by Henry Gantt in the early years of the twentieth century [10]. While it may be true that project management software is useful and helps to automate certain aspects of developing a complex project schedule, the basic steps involved in creating a project schedule are actually quite simple and straightforward, as outlined below:

1. Pick the time-scale for your project planning.
  - 1.1. Days or weeks represent the most common time-scales used to plan most projects.
2. List the tasks needed to complete the project.
3. Place the tasks in order of precedence.
  - 3.1. Determining precedence involves deciding which tasks must be completed first and which tasks must follow others.
4. Determine the resources available for each task
  - 4.1. Resources for a public health informatics project usually include staff, contractors, vendors and technology.
  - 4.2. The resources available will tend to determine the time required to complete a task.
5. Set the duration of each task based on the resources available for that task.
6. Place the schedule on a calendar.

It is the author's experience that sometimes a low-tech approach to drafting the project schedule is less frustrating for the new, or occasional, public health informatics project manager. The excessive cognitive load created by attempting to juggle the some of the less familiar concepts associated with project management and informatics while simultaneously attempting to master a complex and unfamiliar software application can be very frustrating. Project schedules have been laid out manually for many years and there is nothing wrong with "going old-school" and creating the project schedule by hand.

## **Factors in Scheduling the Public Health Informatics Project**

One of the most common ways to schedule a public health informatics project is to *schedule backward* based on a hard end date by which the project must be completed. Two scenarios are outlined in the review questions at the end of the chapter. Please review Scenario 2 titled, "Is this my Job?" as an aid to understanding the following example of backward scheduling based on a hard end date. The public health program manager in scenario 2 faces a situation that requires users to be trained and the software be installed and ready to use within 90 days. In these cases the IS project manager must look at the delivery date for the final product and bring together sufficient resources to meet that deadline.

A second way to plan a project schedule is to *schedule forward* based on the resources available. A project manager has a great deal of flexibility if it is possible to use this option. Under this scheduling method, a project manager simply places the necessary tasks in order, determines how long each task will take, and the final date the project will be finished simply emerges from the process. In other words, the project is allowed to “take as long as it takes.” Public health informatics project managers rarely have this luxury, as many of their projects are governed by time-lines set by federal agencies, cooperative agreements, grantors and other funders, and their local, state and federal fiscal calendars.

### ***Executing the Public Health Informatics Project***

The execution of a well-planned informatics project will likely proceed much more smoothly than a less thoroughly planned project. The ideal in project planning, though probably rarely achieved on all but the simplest projects, is that the project unfolds almost exactly according to the plan and schedule. However, public health informatics project execution is not simply “planning the work and working the plan.” Managing staff on a public health project is one of the key elements of informatics project execution.

### **Human Resource Management and Informatics Project Execution**

Human resource management in the context of day-to-day operations usually involves building a team that will work together smoothly for an extended period of time under a single supervisor. Because of the temporary nature of projects, human resource management in the project context usually involves rapidly assembling a group of individuals, often from different departments within the organization or from several different organizations; they will often report to both the project manager and the operational manager who has control over their routine day-to-day work. We sometimes see this in public health IS implementations, where representatives of various work units in a public health agency (such as Epidemiology, Immunization Services, and Maternal & Child Health), may be assigned to a project team tasked with implementing a new information system that will be used jointly by all of these units within the agency. As with an operational work unit, these individuals must work well together, but they will not have a long-term relationship with the project manager, as, once again, due to the temporary nature of projects, the project team is generally disbanded at the conclusion of the project with each member returning to their original department.

The previous example illustrates how the project context has a profound effect on the practice of human resource management. The project manager may not have complete authority to direct the work of the members of her team as they often still, at least in part, report to the operational manager of their primary work unit. And the project manager certainly does not enjoy the luxury of having years to build her team and refine the various aspects of how they will work together. In a joint informatics project, the public health project manager will be relying on the expertise and availability of staff from a variety of work units at key times in the project cycle. This requires the public health informatics project manager to negotiate their authority and the availability of staff for the project with senior and line managers, and other key project partners, well in advance of the actual execution of the project and, preferably, as part of the project initiation process group in the earliest days of the project [14]. A lack of availability of key staff during a public health project's execution can have devastating effects on the ability of the project to move forward. Operational public health managers at lower levels in the organizational structure must clearly understand that senior management supports the informatics project and that coordination with the project manager, in terms of making key members of their staff available to support the project, is expected.

## **Communication and Informatics Project Execution**

If we understand the difference between the requirements for effective management practices in the project context versus a routine operational context, then we may also understand that the public health context will impose additional requirements on the way that a public health agency will manage the projects that it undertakes. For example, a private clinic may undertake a project to install an Electronic Medical Record (EMR) software application and require only the approval of the partners in the practice to proceed with the implementation. In this situation, the decision to implement an EMR is largely internal. In contrast, a city-county health department may want to use an EMR software application to improve their delivery of various health services, but before they proceed, the city-county public health agency will likely need the approval of local elected officials. Additionally, strict policies regarding the governmental purchase of information technology services, such as the requirement to issue a formal Request for Proposal (RFP), may also have to be followed. The approval of the agencies at the state or federal levels responsible for funding the local programs affected may also need to be sought. Further, in this example, it would not be inconceivable that the clients of the local public health agency might have confidentiality concerns that they may publicly express as citizens of the jurisdiction. This example illustrates the increased complexity that the governmental aspect of the public health context may impose on the management of a public health informatics project. In other words, the nature of public health activities tends to expand the number of stakeholders with an interest

**Table 12.1** Sample communications matrix

Stakeholder role	Document name	Document format	Contact person	Due date
Senior Managers	Monthly Status Update	Hard Copy	Rita Jones	First of month
State Health Dept Contact	Monthly Status Update	e-Mail	Charlean Smith	First of month
Agency Manager (Project Sponsor)	Schedule/Milestone Review	Hard Copy and Meeting	Irene Spear	15th of month

*Source:* Adapted from Schwalbe [27], Copyright 2010 by Cengage Learning

in an IS project beyond the public health organization itself, into the entire local community and beyond.

The abundance of stakeholders in a public health informatics project often creates a need for robust and timely communications as a way to keep all stakeholders informed and involved at the appropriate level. Executing a project communications plan can ensure that the right stakeholders receive the information they require at the right time. Using a simple project communications matrix, as outlined in Table 12.1, will serve to keep communications on track [27].

## Monitoring and Controlling the Informatics Project

Informatics projects are rarely completed without requiring some changes to the IS design or the project approach. Methodical planning reduces the number of changes required during the execution of a project, but it rarely eliminates them. Uncontrolled changes to the project, sometimes referred to as scope or “feature creep” when applied to an informatics project, will almost inevitably increase the project’s costs and/or delay its scheduled completion [15].

## Managing the Triple Constraint

While virtually all projects are unique in their execution, a common feature of a well-managed project is the active management of the relationship between a project’s scope, time, and cost. The public health project’s *scope* may be understood broadly as the attributes or extent of the informatics product desired. Often, this simply comes down to the features and functions that users desire, as determined by a requirements analysis. The *cost* constraint may be viewed more broadly as the sum total of all the resources available to the project. The project manager works to avoid a situation where the resources required to achieve the desired product actually exceed the resources available to the project. The *time* constraint consists of any deadlines by which certain products must be delivered. Taken together, project *scope*, *cost*, and *time* are often referred to as the *triple constraint* of project management.

**Table 12.2** Effects of the triple constraint

Constraint	Effect of an increase	Effect of a decrease
Scope	Increase Time	Decreased Time
	Increased Cost	Decreased Cost
Time	Decreased Cost	Increased Cost
	Increased Scope	Decreased Scope
Cost	Decrease Scope	Increase Scope

Monitoring and controlling changes to an informatics project depends on understanding the importance of actively managing this “triple constraint” and understanding how the three factors of the triple constraint are inter-related. With this understanding, the project manager can reasonably anticipate the effect that altering one parameter of the triple constraint is likely to have on the other two. Table 12.2 shows the inter-relationship of these three parameters of a project.

Let’s use an example as an aid to interpreting Table 12.2. If we are working on a reporting project where the goal is to extract useful data from a public health information system and, mid-way through the project, the users decide they want to double the number of reports generated by the system (Increased Scope), then it will likely increase the time required to develop the specifications for those reports (Increased Time) and the consultants being paid to develop those reports will bill more hours to the project (Increased Cost). However, if we find that the time available to complete the project has been extended (Increased Time), then the project manager will have the opportunity to make adjustments to the project. She may be able to assign the creation of some of the reports to less experienced staff paid at a much lower hourly rate as compared to a more highly compensated consultant. Even though the less experienced staff member takes longer to create each report, their lower rate of pay results in cost savings to the project (Decreased Cost). Having more time available to complete the project, may also make it possible for the project manager to arrange for the addition of extra features to the reporting system (Increased Scope). In any case, both the project and operations manager need to understand that the elements of the triple constraint are interdependent and that, when one is altered, there is an inevitable change in the other two.

A further exploration of Scenario 2 (available at the end of the chapter under *Review Questions*) might also give us a good idea of how a project manager would handle a decrease in the time allotted to complete a project. Assume that the program manager had to assure that the software was installed and users were trained in the 50 local health departments of her state, and that she had estimated it would take one installation team an average of two working days to install the software application and train the staff in each health department. At that rate, it would take 100 working days for a single team to complete the project. However, if the federal agency set new requirements for the start date of the system, mandating that the state-level program have the software installed in all 50 health departments 35 working days from now, then one of the most obvious solutions is to increase the number of installation teams working on the project. Adding two additional teams, for a total of three teams on the project, would permit the installations to be completed in approximately 33 working days with each team installing the software and training the staff at approximately 17 sites. Of course, adding teams to compress the

schedule in this way would also increase the overall cost of the project. In this example, the scope of the project remained the same (i.e., 50 health departments to be installed); and the time was shortened. This means that the only parameter of the triple constraint that the program manager was able to adjust was cost (i.e., the number of resources made available to the project). This example illustrates a key point in the management of the triple constraint; as a general rule, as time allotted to complete a project is reduced, then either costs or resources must be increased or scope must be reduced, or some combination of both must be achieved.

### ***Closing the Informatics Project***

The closing process group consists of all those activities that formally conclude the project or an individual phase of the project [20]. These activities include formally releasing members of the project team who may have been “borrowed” from other units of the public health agency to work on the project. After verifying that all required deliverables have been provided, the project manager will oversee the closing of any contracts that may have been established with consultants or vendors. The project manager will also generally verify that the informatics product delivered has met users’ requirements, and will obtain a sign-off from senior management confirming that the project has met its objectives and is being formally concluded. Closing the project also marks the transition from the project phase to the operations phase, where an IS or other informatics product must be integrated into the routine operations of the organization.

As public health agencies plan and scope IS and informatics projects, they must also plan for their ability to support any system once the project phase is concluded. This is particularly important for those informatics projects initiated with special “one-time” funding from grants or external sources. It is possible, when resources appear to be abundant, that a public health agency might scope a system so large or complex that they are unable to maintain it without extensive external support when the resources are reduced or return to a more usual level. The public health informaticist must ensure that the resources needed to maintain the system during routine operations will be available following the conclusion of the project. A prudent public health manager also takes these factors into consideration during the earliest phases of project planning, knowing that one of the keys to a successful transition from the project phase to the operations phase is planning for sustainability.

## **Summary and Conclusions**

This chapter has provided a brief introduction to the discipline of project management in the public health informatics context. Project management is formally divided into five process groups; (1) initiating, (2) planning, (3) executing, (4) monitoring and controlling, and (5) closing. These process groups are supported by the tools and techniques

available from nine knowledge areas. The overall purpose of project management is to reduce risk and uncertainty and to increase the opportunities for project success.

Due to the shortage of trained and experienced public health informaticists, it is very likely that many informatics projects will be managed by project coordinators and the managers of other public health programs for the foreseeable future. However, the management of an informatics project in public health is not an impossibly complex endeavor. With a bit of additional study, the tools and techniques of project management may be applied to many different public health projects. Moreover, the best person to manage a public health informatics project is rarely the expert in information technology (IT). Subject matter experts in the area of information technology may often be better utilized as technical managers of specific aspects of a project, and IT staff and consultants can be brought in to contribute their specific technical expertise on an as-needed basis. The day-to-day responsibilities of the public health project manager actually include substantial amounts of stakeholder communication, financial management, and project staff management. It is, therefore, much more important that the public health project manager understand population health and the public health organization's workflows, goals, and strategic objectives, and be competent to apply the tools and techniques of project management to a project effort.

## **Recommended Resources for the Study of Informatics Project Management**

The following resources are provided to those learners who want to know more about project management in the informatics context.

### *Introductory-Level Resources*

1. *Project Management: Absolute Beginner's Guide*  
Edition: 3 [Paperback] Gregory M. Horine (Author)  
Publication Date: October 26, 2012
2. *Project Management for Healthcare Informatics (Springer Health Informatics Series)*  
Edition: 1 [Hardcover] Susan Houston and Lisa Anne Bove (Authors)  
Publication Date: November 30, 2007

### *Intermediate-Level Resources*

3. *Project Management for Healthcare Information Technology*  
Edition: 1 [Paperback] Scott Coplan and David Masuda (Authors)  
Publication Date: February 1, 2011
4. *Information Technology Project Management [Paperback]*  
Edition: 6 [Paperback] Kathy Schwalbe (Author)  
Publication Date: March 24, 2009



*Advanced-Level Resources*

5. *A Guide to the Project Management Body of Knowledge: PMBOK Guide*  
Edition: 5 [Paperback] Project Management Institute (Author)  
Publication Date: January 1, 2013
6. *Project Management: A Systems Approach to Planning, Scheduling, and Controlling*  
Edition: 10 [Hardcover] Harold Kerzner (Author)  
Publication Date: March 23, 2009

**Review Questions****Scenario 1. Tag! You're it!**

You are a newly hired MPH at a state public health agency. Your supervisor is very excited to have a young professional with an MPH on staff. As a younger person you are also thought of as belonging to the generation of “digital natives” who have been using technology all of their lives. You have just settled into your office when your supervisor approaches you with your first assignment; informing you that she is receiving complaints from local health departments regarding a new information system that has been implemented in county health departments across the state. Your supervisor has received many conflicting opinions about what the problem with this system may actually be and tells you that your first project is “to find out what the problem is and fix it.” What are your next steps?

**Scenario 2. Is this my job?**

You are a seasoned public health program manager. The federal agency overseeing your program has just negotiated a major increase in funding for distribution to the state and local levels to address an urgent public health crisis that affects your program area. Policy-makers at the federal level are very concerned that this funding be used effectively and for the purposes for which it was appropriated. The result is that the lead federal agency supporting your program has commissioned the creation of a new information system to support timely reporting of important program metrics to both the state and federal levels. One of the system's objectives is to enable the federal agency to share these measures with policy-makers and demonstrate the rapid progress the program is making. You receive an e-mail with the subject line “Good News! You will soon be able to add the term *public health IS project manager* to your resume.” The e-mail informs you that software developers at Health and Human Services, in coordination with private contractors, have been working very hard to develop a new reporting application for the past 4 months and should be delivering the first version of the software in approximately 30 days. You have been instructed to prepare your program for the delivery, installation, and use of the software within 90 days. It is your responsibility to integrate the use of the software into your program's operations and ensure that local health departments across the State receive the training they

need to use the software application appropriately. How do you plan to meet the deadlines set for the installation and use of the software?

1. List the five “project management process groups” and describe each process group in your own words.
2. List the three elements of the “triple constraint” and describe how altering each of the attributes is likely to impact the other two. Use examples.
3. Do you believe that a person must be a technology expert in order to effectively manage a public health informatics project? Why or why not? How familiar should a project manager be with the technologies that are being used in the project they are managing? To develop a satisfactory response to this question you will likely have to perform some additional research.
4. A state public health agency has experienced several failed informatics projects. As a result, senior management mandated that all IS projects will now use the PMI methodology. However, as a new project manager in this public health agency, several mid-level managers are now criticizing you for “...spending too much planning and not getting anything done.” Senior management has made you aware of these concerns and has requested a response. Write out a justification for the increased amount of time spent in planning public health IS projects.
5. This question is based on *Scenario #1: Tag! You're it!* Review the first scenario presented at the start of this section. The supervisor is presenting the employee with a project that involves “...finding out what the problem is...” and fixing it. Does this scenario actually represent a project that is comprised of two or more sub-projects? Yes or no? If yes, list and describe, at a very high level, the main sub-projects that you believe would be required to solve the problem. If no, describe, at a high level, how you would solve the problem without breaking it down into two or more sub-projects.

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# Chapter 13

## Evaluation for Public Health Informatics

Paul C. Fu, Jr., Herman Tolentino, and Laura H. Franzke

**Abstract** Evaluation is the application of specific criteria to determine the value or merit of the object of the study. Ensuring that public health information systems (ISs) and programs are managed wisely is essential. Evaluation answers the question of “why” a system is necessary, by collecting the data and performing the analysis needed to make determinations of efficiency and effectiveness and is a critical component to any public health informatics (PHI) project. Evaluation should occur at all stages of a PHI project. By using a combination of formative and summative evaluation, a well-designed plan provides key data to stakeholders that allow for informed decision-making about continuing, replacing, enhancing or retiring a public health IS. The design of the evaluation plan begins with identifying a mental model (e.g., information value cycle or data-information system-context-rings) from which to view the project and the evaluation objectives and determine what to evaluate. Conceptual frameworks, evaluation strategies, and methodology toolkits help define how the evaluation plan is developed and executed. A comprehensive program (e.g., the Centers for Disease Control and Prevention’s six-step evaluation framework) provides an example of an evaluation template.

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**Keywords** Evaluation • Formative evaluation • Summative evaluation • Mental models • Evaluation frameworks • Evaluation strategies • Information value cycle • Data-information-system-context rings • Mental models • Information Value Cycle • Data-Information System-Context Rings • CDC Six-Step Evaluation Framework

### **Learning Objectives**

1. Explain the purposes of an evaluation of a public health information system (IS).
2. Differentiate between formative and summative evaluation.
3. Describe how mental models and frameworks help to support evaluation of public health informatics programs and services.
4. Articulate steps in conducting a public health informatics evaluation using the Centers for Disease Control and Prevention framework as a guide.
5. Illustrate how project management is essential to effective evaluation design and implementation.
6. Contrast three challenges in conducting evaluations in public health informatics.

## **Overview**

Evaluation is the application of specific criteria to determine the value or merit of the object of the study. In an era of resource constraints, it is essential that public health information systems and programs are managed wisely. Evaluation answers the question of “why” a system is necessary, by collecting the data and performing the analysis needed to make determinations of efficiency and effectiveness; it is a critical component to any public health informatics project. Evaluation should occur at all stages of a public health informatics project. Using a combination of formative and summative evaluation, a well-designed evaluation plan provides critical data to stakeholders that allows for informed decision-making. The design of the evaluation plan begins with identifying an appropriate mental model, such as the Information Value Cycle (IVC) or the Data-Information System-Context (DISC) Rings, from which to view the project and the evaluation objectives and determine “what” to evaluate. Conceptual frameworks, evaluation strategies, and methodology toolkits help define “how” the evaluation plan is developed and executed. A comprehensive program such as the CDC Six-Step Evaluation Framework provides an example of an evaluation template.

## Introduction

Evaluation is the application of specific criteria or measures to determine the value or merit of the object of the evaluation. That value can be measured in terms of quality, utility, effectiveness, or impact, using quantitative or qualitative approaches or a combination of both [1]. Evaluation of a public health IS, at its simplest, should determine compliance with standards, assess data collection methods, and the efficiency of applying standards to that data. The level of rigor in evaluation has changed significantly over time. During the Hundred Years' War, both France and England used evaluation methods, albeit informal ones, to assess the utility of the longbow. The French determined that the shaft velocity of the crossbow was of greater importance than rate of fire; the English concluded the opposite. The Battle of Agincourt was the result of a successful English evaluation [2]. Today, we need to design and perform informatics evaluations on complex health IS, which are the tools we use to wage battles for improving population health.

Three questions should be addressed for a successful public health informatics (PHI) evaluation. The first question is why an evaluation is necessary. Managing the development and implementation of a public health IS project, as well as measuring its ongoing effectiveness, is essential. Evaluation can and should occur at all stages of a PHI project, and an evaluation plan should be developed before project initiation. A well-designed evaluation provides key data to stakeholders that allow for informed decision-making and can help stakeholders gain more knowledge about a public health IS, make a judgment of its value, or determine areas for improvement. Evaluation of an existing public health IS can facilitate a decision regarding whether it needs to be continued, enhanced, replaced or retired. Evaluation of health interventions and outcomes can help the public to make more informed health care decisions.

The second question asks what to evaluate. When the system or process in question is complex, either in architecture or workflow or both, difficulty in sufficiently focusing the scope of the evaluation to obtain meaningful data can be encountered. This might involve using different *mental models* (i.e., a representation of an idea) to understand the interactions between stakeholders or entities using the system and to guide design of different evaluation components. The last question asks "how" to evaluate. Conceptual frameworks, strategies, methods, and metrics are all crucial components of the informatics evaluation. They provide guidance on how to define the evaluation standards used. Multiple evaluation methods may be required.

This chapter will describe the concept of evaluation as applied to PHI, by examining the why, what and how. The Center for Disease Control and Prevention's (CDC) six-step Evaluation Framework will be used to illustrate the stepwise procedure associated with an evaluation in PHI [3].



**Fig. 13.1** Fundamental theorem of biomedical informatics (From Friedman [4]. Used with permission from BMJ Publishing Group Ltd)

## Evaluation in PHI – Why Evaluate?

### *The Fundamental Theorem of Biomedical Informatics*

During 2009, Friedman articulated a key concept that not only explains what informatics is and what it is not, but also highlights that “the ultimate unit of evaluation should be whether the user plus the system is better than the unaided user with respect to a specified task or problem.” The fundamental theorem of biomedical informatics (Fig. 13.1) thus proposes: “A person (e.g., information resource users) working in partnership with an information resource (e.g., computer, information system, smart phone, health information exchange, paper forms) is ‘better’ than that same person unassisted” [4]. Viewed from this theorem, PHI practice can involve designing, developing, and implementing information resources that make this inequality true. The “greater than” sign represents an inequality that can be methodologically demonstrated in various ways, through quantitative, qualitative, or mixed methods. PHI evaluation can help elucidate why this inequality holds true or not in an evaluation setting, and describe and recommend a course of action that will make it true. For example, a software developer who developed a smart phone application (“app”) to collect data about a disease condition may expect that the app improves data collection, as the theorem suggests. However, a PH informatician conducting an informatics evaluation of the same app in terms of its usefulness for data collection may learn that it actually impedes data collection, rendering the inequality false.

### *Why Embed Evaluation into PHI Projects*

Public health information systems are implemented with the goal of improving an underlying process; it is unlikely that anyone would choose to introduce an expensive technology with malice. Early health IT project assessments focused upon project execution and did not conduct what would be considered today to be a thorough evaluation. In part, that was due to the relative immaturity of the conceptualization of evaluation of health and public health information systems. The evaluations that

were done were focused upon project management milestones: was the project on-time, on-budget, and in-scope? This focus was driven by the non-trivial cost of technology. IT often comprised a significant portion of the project budget and stakeholders, whether local, state, or federal, wanted to know whether there was value in the investment. Because of the limitations behind this type of evaluation, often conducted after the project was completed, there was little attention on the impact upon people, processes, and outcomes.

Increasing processing power and decreasing technology costs have helped to evolve the concept of value. Although technology costs remain considerable, they no longer represent a substantial capital expenditure for certain initiatives. This has allowed the concept of value to change. As a field, PHI evaluation is moving away from anecdote and limited experiences and toward more rigorous methodologies that take a precise and measured approach to determining what is measured and why it is measured, and that can be used across multiple settings. Our more sophisticated approaches now allow us to:

- validate our predictions about the system;
- understand what worked and what did not;
- generate lessons from which others can learn; and
- examine the subsequent influence of the public health IS on the improvement of population health.

More powerful processors, higher capacity disk storage, and better user interfaces have allowed a more granular level of data collection. This facilitated the move from a project management perspective to a project outcomes perspective. Along with that change was recognition that different evaluations were necessary for different phases of the IS life cycle. The first differentiation was in understanding the role that formative and summative evaluation play.

## Formative and Summative Evaluation

In 1967, Scriven distinguished between *formative* and *summative* evaluation for the purposes of educational program assessment [5]. Since then, the concepts have been generalized for use in non-education settings. Formative evaluation is an assessment process designed to “identify potential and actual influences on the progress and effectiveness of implementation efforts” with the aim of providing feedback that can be used to improve operations [6]. The audience for formative evaluation is typically internal, such as program or project staff. Examples of formative questions include such specific topics as the following:

- Does the current system meet program requirements? If not, is a change justified?
- Do proposed system modifications meet end-user workflow needs?



- What are end-user expectations?
- Are costs in line with budget expectations?
- What barriers have been encountered? How and to what extent have they been overcome?

Summative evaluation focuses upon measurement of the effectiveness of the system or program, but as opposed to formative evaluation, is not done with the intent of causing change. The audience for summative evaluation is typically external, such as funding agencies, consumers, or others stakeholders. Examples of summative questions include:

- Did the system produce the expected results? Did it meet its overall goals?
- Was the system effective for all participants?
- Was the system cost-effective?
- How did the system impact service delivery?
- Were there any unintended consequences? Why did they occur?
- Is the project replicable and transportable?

## Evaluation or Research?

Evaluation and research are not the same. The difference lies in destination, not in the journey. In fact, the journey may be remarkably similar. Evaluation projects and research studies may use the same qualitative and quantitative methodologies and can be equally rigorous and systematic in data collection. The generation and analysis of data is also not unique to research; public health surveillance programs generate and analyze large amounts of data, but those program activities would not be described as research.

The paths diverge near the destination. Traditional research is “conclusion-oriented” whereas evaluation could be described as “decision-oriented” [7]. The Global AIDS Monitoring and Evaluation Team (World Bank Global HIV/AIDS Program) uses *primary intent* as the major distinguishing factor [8]. Research strives to generate new knowledge with the aim of advancing what is known in a field of study, (e.g., public health) using carefully considered methods and tools in order to ensure the validity and generalizability of what has been learned. The generation of new knowledge is the endpoint, and might not be actionable. Evaluation examines a specific program or process, gathering data necessary to draw conclusions that will support decision-making. The conclusions might not be generalizable to other settings because of the context-specific focus. Guba describes the evaluator as creating and testing solutions to an operating problem, with the ability to use the results to adjust the process continuously [9]. Evaluation may be continuous, or it may have a finite span, but the endpoint is reaction to data, not the data itself.

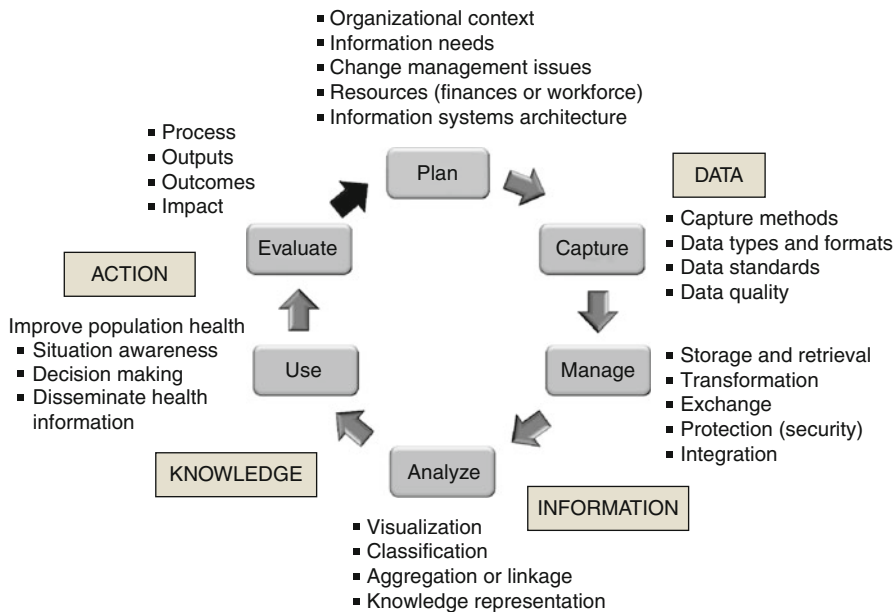


Fig. 13.2 The information value cycle

## What to Evaluate? Using Mental Models to Guide Evaluation

*Mental models* are structures of knowledge about things and their relationships with each other in a potentially changeable world [10]. Mental models can be used to provide PH informaticians with insights regarding “*what to evaluate*” (evaluation objects) in IS used in public health (PH). Evaluation objects can be any component of an IS (e.g., people, process, or technology) and can range from the simple to complex [11].

## The Information Value Cycle

The IVC consists of steps in information management that result in the creation of value and the transformation of data to information, and to knowledge that facilitates public health action [12–14]. Failure to create value may lead to informatics problems in subsequent steps. The topics listed in the IVC steps in Fig. 13.2 can be used to develop evaluation questions and identify evaluation objects.

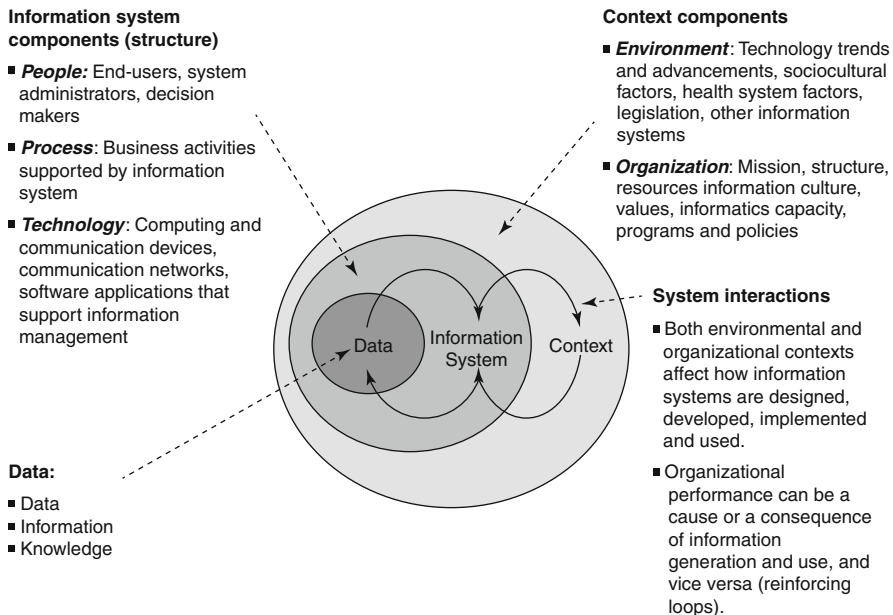
These value creation steps in the IVC contribute to the transformation of data to information and to knowledge that supports policies and programs that consequently facilitate actions to improve population health. The IVC steps point to opportunities for performing public health IS evaluations. For example, in the Manage step, the data

protection activity might involve performing an evaluation of information security threats during storage and retrieval or transmission of data during information exchange.

Different sets of IVC steps become critical depending on the phase of development of ISs. An evaluation of IS may occur at any phase, including design, development, implementation, or maintenance. During the design or development phases, the *planning* and *evaluation* steps of the IVC can help identify opportunities for preventing subsequent problems, including wasted time, money, and effort, through careful attention to planning and evaluation. Performing formative evaluations can be extremely valuable during these early phases of IS development, by ensuring maximum creation of value in each step as data is collected and transformed through the cycle. During the implementation or maintenance phase, the *capture*, *manage*, *analyze*, and *use* steps of the IVC can reveal opportunities for system improvement. These latter phases may also provide opportunities to rethink or reframe attendant problems within an IS, as its organizational and environmental context might already have shifted. Yesterday's solutions could become today's problems.

## Data-Information System-Context Rings

Environmental and organizational contexts can affect how systems are designed, developed, implemented, and used [15]. IS goals determine what data are collected and how it is structured (e.g., format) and represented (e.g., data standards). The "data" in this model collectively represents data, information, and knowledge. A "chicken or the egg" cyclic relationship exists between technological change and organizational change [16], and organizational performance can be a cause or a consequence of information generation and use, and vice versa (reinforcing loops) [17]. In addition, how IS are developed, implemented, and used can affect both the organization and its context. When this happens, evaluators may observe phenomena related to unintended consequences from use. Unintended consequences include deviations from intended digital workflows (i.e., sequence of electronic steps) or system protocols by doing workarounds, inadvertent creation of new information security risks (e.g., system passwords are posted in notes on computer screens), generation of new types of errors continued of paper form use after electronic versions are in place, or disregarding important alerts when excessive alerts to process are received (e.g., alert fatigue) [18]. This view places IS and the data they manage within the organization and its environment. Components of an IS and its context (organization and its environment), represented as concentric rings, characterize a complex set of factors that can affect its eventual success or failure [19]. To make this complex representation easy to remember, the chapter authors used the acronym "DISC" plus "rings," with "Data" at the center, followed by the "IS," and the IS "Context" (Fig. 13.3). Each ring represents a system with its components and their interactions. A characteristic of systems is that they can be further broken down into their component subsystems. This rich inventory of systems and their interactions help identify potential evaluation objects.



**Fig. 13.3** Data-Information System-Context (DISC) rings – the information system and its context

## Combining the DISC Rings and the IVC Steps to Support Evaluation Design

From an evaluation perspective, the IVC steps and DISC rings can be combined to form a matrix of cells that can be used in multiple ways to plan an evaluation project, as follows:

1. To serve as an organizing framework for developing an inventory of evaluation objects before designing an evaluation project. What can be evaluated?
2. After developing an inventory of evaluation objects, the matrix can also be used to develop an inventory of evaluation questions. What evaluation questions can we ask?
3. After evaluation questions have been identified, the matrix can then be used to identify methods that can be used to answer evaluation questions. How do we obtain the answers to the evaluation questions? What evaluation tools are available to help obtain answers and measurements to the evaluation questions?

Table 13.1 shows an abbreviated example of how this matrix can be applied in a real-life evaluation situation. Let us use the following example to describe how this matrix is used.

**Table 13.1** Use of a matrix of DISC rings and IVC steps to create an inventory of potential evaluation topics (some boxes left blank)

		<b>The information system (IS) and its context</b>	
		<b>Information system</b>	<b>Context</b>
<b>Information value cycle</b>	<b>Plan</b>	<b>Data</b>	<b>Environment</b>
			Workforce capacity
		Project resources	Diversity of training needs
		Feasibility	Awareness about One Health concept
		Business process	System of systems issues
		Fit with NPS enterprise information system architecture	
		Data collection procedures	One Health data providers within organization
		Data collection technology (e.g., mobile phones, information kiosks)	One Health data providers outside organization
		Information technology architecture – centralized or distributed	Data sharing/use agreements with other organizations
		Ontology of One Health concepts (concept dictionary)	One Health data consumers outside organization
		Data transformations	
		Health indicators and measurements	Information needs of other stakeholders within organization
		Data for decision support	Workforce capacity to analyze data
		Data for situation awareness	Analysis and visualization tools (e.g., geographic information systems (GIS)), dashboards
		Data for reporting and dissemination	Decision support tools
		Data quality of One Health system	Situation awareness tools
		Data access	Usability
		Data and information security	Metrics for service quality
			Outcomes and impact
			Other users outside organization
			Information needs

*Example.* The US National Park Service (NPS), an agency popular with the public for its health and recreational value, is uniquely poised as a One Health [20] leader. NPS's mission is to protect the health of animals, ecosystems, employees, and visitors. The U.S. national parks have >280 million visitors per year. Within the NPS, each of the 394 ecologically-diverse units has its own internal subject matter experts and divisions. The Public Health Informatics Fellowship Program (PHIFP) at CDC is a 2-year applied, competency-based training program for professionals with background and experience in health and information technology. PHIFP fellows respond to short-term technical assistance (Info-Aid) requests from public health agencies. During 2010, the NPS Office of Public Health requested an InfoAid from PHIFP for the implementation of a pilot integrated NPS One Health Surveillance System at Mt. Zion and Yellowstone National Parks. The goal of the NPS was to enable sharing of data from diverse sources that can facilitate interdisciplinary communication and serve as a tool to put One Health concepts to a real-life test. PHIFP developed a set of recommendations to support the NPS goal. Included in the recommendations was an inventory of evaluation-related topics that the NPS could work on to enable better planning and IS design.

The mental models presented here can help answer the "what to evaluate" question by providing a view of the depth and breadth of evaluation objects. When mental models are used to represent an evaluation problem and shared with others, they enable evaluators to bring diverse stakeholders to a shared understanding of the evaluation to be designed and implemented.

## **How to Evaluate? – By Using Frameworks, Strategies, and Toolkits**

### ***Conceptual Frameworks***

Kaufman defines a *framework* as a general set of assumptions, constructs, or ideas that guides research and theoretical development. Evaluation frameworks provide value through established principles to answer the how-to-evaluate question and to guide formulation of evaluation questions, selection of methods, and interpretation of results. These rules can be tailored to evaluation needs both during and after system development [21]. Frameworks based on a philosophy, theory, or set of assumptions may have very limited and specific areas of application [22]. The chapter authors provide several categories of frameworks derived from Currie [23] and Yusof et al. [24], some with examples.

*Generic evaluation frameworks.* These are frameworks that do not specifically refer to socio-technical, software development life cycle or logic model principles as a guide. An example is the modified CDC evaluation framework [3], presented in

this chapter. The chapter also briefly describes evaluation strategies developed by Cronholm and Goldkuhl [25]. The reader can learn more about evaluation approaches in medical informatics, which can also be applied to public health informatics, by reading the classic textbook regarding evaluation in medical informatics by Friedman and Wyatt [26].

*System development life cycle-based frameworks.* These frameworks adapt the evaluation approach to the system development life cycle phase of the IS being evaluated. Westbrook described a multi-method evaluation framework that examines an IS across three stages, as follows (1) pre-system implementation, (2) at 6 months post-implementation, and (3) at 18 months to 2 years post-implementation [27]. This framework also falls under the socio-technical evaluation frameworks that follow because it assesses the influence of IS regarding organizational processes and outcomes. Kaufman described five case studies [21] using an evaluation framework developed by Stead and colleagues that mapped an evaluation level to each of five stages of IS development [22]. The following are the five evaluation levels with example descriptors:

1. *Definition studies:* assessing information needs, stakeholder analysis
2. *Bench or laboratory studies:* testing algorithms, prototyping user interfaces
3. *Field studies:* controlled software testing, randomized controlled trials

The fourth and fifth levels do not closely involve the developers of the information system.

4. *Validation studies* similar to Level 3 but developers excluded from evaluation team; and
5. *Efficacy studies* IS studied during routine use, including randomized trials, cohort studies, influence studies, critical incident techniques

*Behavioral and socio-technical evaluation frameworks.* These frameworks consider behavioral aspects of an IS (e.g., user-to-user, or user-to-machine interactions). Anderson described the use of network analysis to discover patterns of relationships that affect adoption, diffusion, and use of informatics applications at the individual and organization levels [28]. Merrill used organizational network analysis to describe the structure of information flow in a public health department's communication networks and provide insights into organizational processes, which informed managers' strategies for addressing problems and leveraging network strengths [29].

*Logic model frameworks.* These frameworks consider approaches that map evaluation questions to various components of the logic model (input, process, output, outcome, impact). Donabedian described evaluation frameworks for assessing the quality of care by examining the structure, process, and outcome of a care system [30]. The *structure* framework describes the components of the system (e.g., human, financial, physical, and other inputs). The *process* framework describes what is done within that system (e.g., activities that transform inputs using the components of the system). The *outcome* framework describes results or changes attributable to the preceding processes. Delone and McLean's *IS success model* synthesized

knowledge from theoretical and empirical IS research in the 1970s and 1980s, and developed a taxonomy and an interactive model as frameworks for conceptualizing IS factors that contribute to IS success [31, 32]. The Public Health Informatics Institute developed a logic model-based framework that uses similar constructs as the Delone and McLean IS Success Model to support the assessment of the value of integrating newborn screening laboratory information management systems with child health ISs [33]. It may be necessary to combine different frameworks to describe different aspects of a complex system. For example, Hebert described a framework to evaluate telehealth success through a combination of the Donabedian structure-process-outcome framework combined with the Delone and McLean IS success model [34].

As the above does not constitute an exhaustive, detailed list of frameworks, the reader should review the references on the framework examples provided.

## Evaluation Strategies

Evaluation strategies can help address the “how to evaluate” question. Cronholm and Goldkuhl identified three general strategies for evaluation of information systems [35]. These strategies can be adapted for evaluation of information systems used in public health.

1. *Goal-based*. This deductive approach measures whether or not predefined organizational goals have been achieved, and if achieved, to what extent and how they were achieved within the context of the organization. The metrics used depend on whether goals require quantitative or qualitative measures.
2. *Goal-free*. This interpretive, inductive approach enables both deeper understanding and generation of knowledge about the evaluation object, including its qualities and measurable effects and outcomes. A goal-free framework also helps to generate motivation and commitment through its nonjudgmental approach and the removal of the negative connotation related to discovery of unintended consequences. This can be used for evaluating prototypes in development or testing, or pilot implementations of IS, to provide background knowledge for designing other evaluations. Examples include clarifying IS processes, determining how to measure outcomes, and developing an inventory of interactions within the IS.
3. *Criteria-based*. This approach uses checklists or experience-based methods (heuristics), as evaluation measurement and typically involves study of interactions between the user and technology. The criteria or heuristics are usually based on one or more perspectives or theories, and are not tied to the organizational context as in goal-based evaluations. The criteria could change, be refined over time or be affected by new insights into the evaluation situation. Hence the evaluator needs to be sensitive to these insights. For example, the performance of certain aspects of the IS (e.g., user interface, data entry, improving situation awareness) can be evaluated using this strategy.



## Evaluation Toolkits and Methods

The word “tool” was first used around 1000 AD to refer to a thing, either concrete or abstract, that was used to perform an operation [36]. The “tool-box” appeared in the early nineteenth century to refer to a container that held tools. The concept of a software “toolkit” evolved from that concept in the early 1980s, to describe a set of software building blocks and programming frameworks that could be shared among programmers, therefore saving time and avoiding redundant effort [36]. Since then, the concept has spread into many other domains to reflect a collection of resources focused upon a narrow topic, and is typically collated by experts in the field.

Using an evaluation toolkit has many benefits that can span the why, what, and how of a PHI evaluation. Simple toolkits typically provide static lists of information (e.g., Health Resource and Services Administration’s Health IT Adoption Toolbox) [37]. Others, including the Agency for Healthcare Research and Quality (AHRQ)’s Health Information Technology Evaluation toolkit [38], are more focused and provide highly specific guidance on how to develop an evaluation plan, including listing measures used in other evaluations. Standardized measures help for controlled comparisons across complex settings and, when applied across multiple smaller programs, can be used to assess for overall program effect. Toolkits like the CDC’s six-step evaluation framework (described in a following section) are richly detailed and complex, and provide a roadmap for a comprehensive program evaluation [39].

Varied and multiple evaluation tools are available for use. The data generated by the evaluation is either *quantitative* (expressed in numerical form) or *qualitative* data (captured in narrative), or both. Quantitative techniques have the advantage of breadth and generalizability; examples include questionnaires, surveys, and tests. Qualitative techniques have the advantage of depth and the ability to target specific groups; examples include direct observations, interviews, focus groups, and literature review. Typically, an evaluation strategy will involve the use of both quantitative and qualitative techniques, and may be used in different areas of evaluation. A more complex strategy involves the use of *mixed methods* design, where quantitative and qualitative questions are posed on the same topic in order to generate complementary data that can converge on a result. A review of mixed methods design is beyond the scope of this chapter.

## Designing PHI Evaluations

### *The Modified CDC Six-Step Evaluation Framework*

The CDC six-step evaluation framework is a generic framework originally developed for program evaluation but it also can be applied as a high-level framework for informatics evaluation projects [3]. The CDC Framework has the following steps that the authors modified and adapted for use in evaluation of IS in public health:

*Step 1 – Engage stakeholders.* ISs typically involve many kinds of stakeholders that play different roles in relation to an IS and its evaluation. Stakeholders might belong to any of these groups: system sponsors, system developers, funders, purchasers, users or those served by the IS, operations staff, managers, senior officials and administrators, consumers of the evaluation report, and other groups potentially impacted by evaluation results. Engaging IS project stakeholders enables the evaluator to take into account perspectives and value systems, and plan coordination of inputs and communication. This helps to avoid potential misunderstandings, criticism, or resistance to the recommendations and evaluation outcomes. The evaluator, however, should try to avoid excessive stakeholder identification, because this might cause unnecessary delays in the evaluation.

*Step 2 – Describe the IS and its context.* DISC rings and the IVC steps can serve as a guide to describe IS structure, context, and function. For example, using the DISC rings, the IS context description can include information about its host organization and its mission; while the IS description can include the goals for its development, the users and their information needs being met, and the resources and workforce used to operate it. The system description can also include data sources, types, formats, and methods of data capture, and how data is stored, protected, and transformed.

*Step 3 – Focus the evaluation design.* Evaluation design is an iterative process. The project management triple constraint of scope, time, and resources is important to consider in designing the evaluation. Oftentimes, a faulty assumption is to assume the evaluator works in isolation during the design step; however, the evaluator should be both consulting and working collaboratively with the stakeholder in selecting the “best” method for the problem. Evaluation questions drive evaluations and a potentially infinite number of questions can be asked in an evaluation object [40]. An evaluation question can be answered by more than one method, and the best method chosen must also be feasible in a given environment. The refinement of the design continues until a focused set of evaluation methods have been identified that will provide answers to the evaluation questions in a feasible, useful, ethical, and accurate way. This step ensures that the evaluation project is practical, politically viable, and cost-effective. The activities in this step include:

- meeting with stakeholders to clarify real purpose and intent of evaluation and evaluation questions;
- learning who will use the findings, how they will use the material, and orienting the evaluation to meet their decision making needs;
- describing and documenting methods for sampling (if required), data collection, analysis, interpretation, presentation of results, and judgment; also ensuring the necessary approvals are acquired (e.g., for federal government level informatics evaluations, the White House Office of Management and Budget must approve use of a survey form on more than nine subjects); and
- revising the evaluation plan when circumstances require change and communicating this to stakeholders

In functional terms, *methodology* refers to the knowledge of how to prepare and use methods, while in structural terms it consists of a coherent set of methods

regarding the subtasks necessary for the evaluation. In practical terms, it also includes a strategy for splitting up tasks into subtasks and choosing and constructing a combination of methods that, in their entirety, comprise a coherent whole. A *methodology* can appear similar to a *framework*. A *methodology* is a prescriptive tool to carry out a given task, whereas a *framework* describes the inter-relationships (i.e., structure) among concepts. A *method* is a formal description of a procedure or approach to implement an actual task. It is based on well-defined principles and theories, and includes a consistent set of tools, techniques, and their descriptions applicable to a certain task. A framework, through the concepts it contains, helps in the selection of methods to use in an informatics evaluation. A *metric*, on the other hand, is a concrete measurement technique or tool, which can be a formula or a device. *Measures* are actual, concrete values derived from applying a metric [41]. For example, in the evaluation of an automated surveillance system, we would need a performance measurement method to measure the effectiveness of software algorithms to detect disease conditions from free-text diagnosis fields in electronic medical records. If the disease detection system uses natural language processing, we can use positive predictive value (PPV or precision rate) as a metric that can reveal the proportion of disease detected that is a true positive. The resulting measure would be the actual values derived from applying the formula for computing PPV.

*Step 4 – Gather credible evidence.* The evidence consists of measurements that can be performed on IS components (people, process, and technology) and their interactions. The goal of this step is to perform these measurements in such a way that stakeholders perceive the data collected as trustworthy. The evidence should also provide relevant answers to evaluation questions. The evidence can be experimental or observational. It can also be quantitative or qualitative (or both). Credibility depends on data sources, data collection conditions, reliability and validity of measurements, manner of interpretation, and steps taken to assure quality of data. Reliability can often be increased through triangulation, or collecting data about the same subject from multiple sources.

Critical activities in this step include:

- selecting standardized measures that can address evaluation questions;
- describing data sources and reason for their selection;
- developing repeatable and clear procedures that can be shared with members of an evaluation team;
- ensuring quality through monitoring and data quality checks; and
- protecting evaluation data from unauthorized access.

Frequently measuring components of complex IS and abstract metrics might have to be developed. Common methods used to gather evidence include: interview, performing observations, examining documents, exploration and testing of system properties, and performing measurements on directly observable system phenomena [42].

*Step 5. Justify conclusions.* For the evaluator to render judgments or make claims regarding the IS, the conclusions must be supported by the evidence gathered. The

conclusions developed must be useful to the stakeholders, consist of accurate statements related to the quantitative or qualitative analyses performed, demonstrate systematic interpretation, and describe comparisons against relative standards or norms for judgment. The evaluator performs the following activities to arrive at a credible conclusion:

- uses relevant and rigorous methods for analysis and synthesis;
- Interprets significance of results and deciding what they mean;
- makes judgments about measurements and their interpretations;
- considers methods of comparing results and alternative explanations for findings to address differing perspectives;
- recommends actions consistent with findings and conclusions; and
- limits conclusions to evaluation settings for which lessons can be applied.

*Step 6. Ensure use and share lessons learned.* By performing IS evaluations and sharing lessons learned in a timely manner, more fully informed decisions can be made about the IS under study. To enable use of findings and recommendations in decision making, the IS evaluation must address three things:

- stakeholders should receive continuous feedback on evaluation procedures, findings, and interpretations that might affect its use;
- evaluator should assist the intended users of findings and conclusions in translating the findings and recommendations into decisions or actions that will positively impact the information system; and
- evaluation participants should be able to use knowledge generated from the evaluation in other similar settings (e.g., practice-based evidence)

Additional important lessons can be learned after the evaluation project is completed. Once evaluation recommendations are implemented, changes introduced to an IS will have long-term effects and consequences that can be considered as outcomes and effects of the evaluation. Because these effects and consequences unravel over a period of time, the evaluator must continue to track and monitor the outcomes and effects of the evaluation recommendations as they unfold. By a deliberate process to implement this extra step, the evaluator can obtain valuable feedback and lessons that enable further refinement or improvement of original approaches and methods used in the evaluation. This cycle of application and improvement increases the evaluator's level of expertise [43].

The steps in the CDC's evaluation framework are similar to milestones on a roadmap to a destination. The traveler can choose from multiple routes to that destination. Likewise, no single method for implementing an evaluation is applicable to all situations. The traveler will learn about certain things, both good and bad, about the trip and the things viewed while on the road to the destination. Through this experience, the traveler will also likely learn how to carry out a similar trip better next time. Like the trip, an evaluation is not just the application of methods, tools, and techniques, but also a process to be understood, with its benefits, insights, lessons learned, limitations, and problems.

## Challenges in Implementing PHI Evaluations

Common challenges encountered during IS evaluations stem from certain reasons, including complexity of the evaluation object, complexity of the evaluation project, and motivation for evaluation [11].

*Complexity of evaluation object.* Certain public health information systems are large and complex. This complexity arises from several observed phenomena. First, the design, development, implementation, and maintenance of IS take time. When an IS is introduced into a particular setting, its users have to go through an adjustment period to learn its functions before fully achieving the intended benefits. Over time, the IS can be altered by factors that develop within the organization, or by the organization itself as a response to an external stimulus that can threaten its survival; this creates a moving target for evaluation. Preventing changes to the environment might not be possible or acceptable, leading to a situation where the evaluation object might substantially change from the original baseline. However, strategies to address the complexity of the evaluation object under investigation are available. First, given a changing and unpredictable environment for an ongoing IS evaluation, detailed documentation can serve as both a reference and data source [44]. Second, evaluation questions can be mapped to each phase of the IS development life cycle. This allows incorporation of evaluation perspectives native to each phase of system development. Documentation and life cycle-based approaches will not completely address issues related to complexity of the evaluation object, but will allow for a more manageable approach.

*Complexity of the evaluation project.* The public health environment consists of professionals from diverse disciplines working to fulfill the three core functions of public health (i.e., assessment, policy development, and assurance). These professionals are characterized by different training and experience backgrounds as they implement various public health interventions (e.g., surveillance, policy development, or education) to improve population health. Stakeholders in an evaluation project can present different views of the IS and the concept of successful IS operation. These professionals often have different information needs that might result in competing requirements for the design and evaluation of an IS. Understanding multiple stakeholders' needs when defining a problem is both critical and challenging [45]. The consequences of a complex evaluation project might include excessive evaluation questions from multiple stakeholders, leading to risk of not having enough resources to answer all the questions, or too few questions from few stakeholders, and alienating other stakeholders or not accurately representing context. In addition, the evaluation questions and design might change during the study as context unfolds [11]. Although certain project challenges are unpredictable and unavoidable, using project management to develop a timetable of measurable deliverables helps minimize the influence of unknowns. The tracking of an evaluation project allows one to identify interdependencies, define time-bound outcomes, and generate reports and updates to disseminate to stakeholders.

*Motivation for evaluation.* The initiation of an IS evaluation requires financial support, motivation from stakeholders to perform the evaluation, and willing participants [11]. Factors that lead to low motivation to conduct an evaluation include a

fear of the unknown, potential financial or personnel implications from evaluation results, or anxiety over a perceived negative outcome or revealed deficiency [46]. Additionally, without a vested stakeholder, challenges in obtaining financial support might be encountered. Even if key stakeholders are supportive in conducting an evaluation, recruiting participants because of time burden (e.g., answering questions), lack of benefits (e.g., often unpaid), and perceived risks (e.g., organization opposes certain views) are common challenges. Recruiting participants often presents the challenge of representativeness, including whether those who agree to participate represent various IS end users. Evaluators should emphasize to potential participants the direct (e.g., financial) and indirect (e.g., change agent within a participant's environment, chance to influence decisions, and change) benefits of evaluation participation and strive to involve representative participants.

Although multiple challenges in conducting IS evaluations in public health are known, knowledge gained is a benefit that allows organizations to make informed decisions and better investments. A systematic and planned approach is imperative for minimizing the complexity of challenges highlighted, and also utilize tools (e.g., project management), mental models (e.g., IVC or DISC ) and frameworks (e.g., CDC Six-step Framework) to better plan and implement an IS evaluation.

## Summary

The era of siloed or disconnected and duplicative public health IS and programs is ending. Contemporary information architectures and process workflows incorporate interoperability, shared services, and open data as core tenets. These developments mean bringing a more varied array of stakeholders into IS projects that serve a wide array of information needs from public health and non-public health perspectives. These changes in the IS landscape not only broaden the stakeholder community interested in any individual system but also increase the complexity of evaluations to be performed. PHI evaluations result in an increased level of understanding of ISs at all phases of development. When combined with the internal program need to steward limited resources carefully, evaluations enable public health agencies to reap maximum value from IS investments. They also provide the data and information necessary to meet elevated expectations for operational transparency and program effectiveness.

The well-designed evaluation plan takes into account this modern complexity. Mental models, such as the Information Value Cycle or the Data-Information System-Context Rings model, help to provide the perspectives on *what* to evaluate, and to discover where in the process to ask the questions that will return the data necessary to perform both formative and summative evaluations. Conceptual frameworks, evaluation strategies, and toolkits provide the detail on *how* to examine the system; they help define the questions and shape the measures and instruments that will be used to gather data.

Evidence-based evaluation of public health IS is still not a standard practice across the domain, largely because of shifting funding streams and limitations in

time and personnel expertise. Nevertheless, in a landscape of evolving technologies, changing programmatic priorities, and limited resources, evaluation has become an essential component to every new initiative.

### Review Questions

Case: A network of small rural clinics located across two counties in State X has requested help from the state health department to address the healthcare needs of their patients with diabetes. The community clinics use a combination of nurse practitioners and physician assistants to provide care, with telemedicine consultation to the endocrinologists at the university medical center in the state capital when necessary. Each clinic has a separate, stand-alone electronic health record. Lab data is provided directly to each EHR through phone connections from the regional laboratory. The state health department has been awarded funding through a federal grant program to use health IT to *improve the health* of rural residents with diabetes, and has proposed using a single hosted EHR for all clinics and using the state health information exchange to support communicable disease notifications and immunization registry updates. You have been asked to provide evaluation support.

1. Identify the current and potential sources of data and stakeholders.
2. Using a mental model, identify what you will need to evaluate by developing an inventory of potential evaluation topics.
3. What type of conceptual framework is appropriate for this state project that has a goal of improving health outcomes?
4. What are the benefits and disadvantages of using goal-based, goal-free, or criteria-based evaluation strategies for this program? Which would you choose?
5. Describe how the CDC framework is or is not applicable.
6. What types of evaluation questions would you ask? Are they formative or summative?

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**Part III**  
**Key Public Health Information Systems**

# Chapter 14

## Informatics in Disease Prevention and Epidemiology

Richard S. Hopkins and J.A. Magnuson

**Abstract** This chapter provides a description of the components of disease prevention and control programs, and then focuses on information systems designed to support public health surveillance, epidemiologic investigation of cases and outbreaks, and case management. For each such system, we describe sources used to acquire necessary data for use by public health agencies, and the technology used to clean, manage, organize, and display the information. We discuss challenges and successes in sharing information among these various systems, and opportunities presented by emerging technologies.

Systems to support public health surveillance may support traditional passive case-reporting, as enhanced by electronic laboratory reporting and (emerging) direct reporting from electronic health records, and also a wide variety of different surveillance systems. We address syndromic surveillance and other novel approaches including registries for reporting and follow-up of cases of cancer, birth defects, lead poisoning, hepatitis B, etc., and population-based surveys (such as BRFSS or PRAMS).

Systems to support epidemiologic investigation of outbreaks and clusters include generic tools such as Excel, SAS, SPSS, and R, and specialized tool-kits for epidemiologic analysis such as Epi-Info. In addition to supporting outbreak investigation,

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agencies also need systems to collect and manage summary information about outbreaks, investigations, and responses.

Systems to support case management, contact tracing, and case-based disease control interventions are often integrated to some degree with surveillance systems. We focus on opportunities and choices in the design and implementation of these systems.

**Keywords** Case reports • Shared services • Unified systems • Positive predictive value • Syndrome • Incidence • Outbreak • Cluster • Reportable • Notifiable • Registry • Surveillance system

### Learning Objectives

1. Describe the range of information systems in current use to support public health surveillance, epidemiologic investigations, and disease prevention.
2. Identify opportunities for more effective epidemiology and disease prevention through implementation of emerging technologies.
3. Describe the challenges and opportunities presented by integration of information systems for epidemiology and disease prevention.

## Overview

This chapter provides a description of the components of disease prevention and control programs, and then focuses on information systems designed to support public health surveillance, epidemiologic investigation of cases and outbreaks, and case management. For each such system, we describe sources used to acquire necessary data for use by public health agencies, and the technology used to clean, manage, organize, and display the information. We discuss challenges and successes in sharing information among these various systems, and opportunities presented by emerging technologies.

Systems to support public health surveillance may support traditional passive case-reporting, as enhanced by electronic laboratory reporting and (emerging) direct reporting from electronic health records, and also a wide variety of different surveillance systems. We address syndromic surveillance and other novel approaches including registries for reporting and follow-up of cases of cancer, birth defects, lead poisoning, hepatitis B, etc., and population-based surveys (such as BRFSS or PRAMS).

Systems to support epidemiologic investigation of outbreaks and clusters include generic tools such as Excel, SAS, SPSS, and R, and specialized tool-kits for epidemiologic analysis such as Epi-Info. In addition to supporting outbreak investigation, agencies also need systems to collect and manage summary information about outbreaks, investigations, and responses.

Systems to support case management, contact tracing, and case-based disease control interventions are often integrated to some degree with surveillance systems. We focus on opportunities and choices in the design and implementation of these systems.

## The Main Components of a Disease Prevention Program

Public health programs to prevent disease typically have been designed and implemented one disease at a time. Each disease has its own patterns of distribution in populations, risk factors, and optimal and practical intervention strategies that are effective in controlling, preventing, or even eliminating cases of the disease. For example, an important strategy to prevent measles is vaccination, the main strategy to prevent gonorrhea is antibiotic treatment of case contacts before they become ill themselves, an important strategy to prevent cervical cancer is screening with Pap smears and treatment of preclinical disease, and the main strategy for prevention of neural tube defects is folic acid supplementation of selected foods. Still, each disease prevention program's components are drawn from a relatively short list:

- Planning and evaluation
- Public health surveillance
- Outbreak or cluster recognition and response
- Policy and guidance development
- Clinical services
  - Screening
  - Immunization
  - Prophylaxis
  - Treatment
- Laboratory services
- Case-contact identification and interventions
- Education and training for clinicians
- Public education
- Regulation (for example, of food services, drinking water, child-care centers, hospitals, etc.)
- Administration and financial management

Ideally, program managers choose the most effective combination of these program components to prevent or control the disease or diseases they are charged with addressing. However, as this must be done within the constraints imposed by the available funds, cost-effectiveness is the usual criterion for choosing the preferred combination of program components.

Public health agencies typically are organized both by disease and by function. For example, each disease-specific program usually does not have its own

laboratory, and a single public health clinical facility and its staff may provide varied services such as immunizations for well children, treatment of people with tuberculosis (TB) and their contacts, and Pap smear services. To variable degrees, they may even combine activities in a single patient encounter, for example, testing women for gonorrhea and *Chlamydia trachomatis* infections at the same visit where they get a Pap smear, or offering hepatitis B vaccination during a visit for sexually transmitted diseases (STD) treatment.

As information technology has become more widely used in public health and replaced paper-based systems, it has typically been implemented program area by program area, as resources became available. This has led to the creation of information ‘silos.’ For example, laboratory information systems usually have developed in isolation from those to support clinical care or public health surveillance.

Information systems to support clinical operations of public health departments (for example, clinical services for STDs, childhood immunizations, HIV/AIDS, TB, or family planning services) have characteristics similar to those of other electronic health record systems in ambulatory care. However, in some health departments, clinical information systems have been separated by disease or clinic.

If one were to design information systems from scratch for a set of disease prevention programs, there would be potential savings and efficiencies from identifying the ways that one program component depends on information from another, or can serve multiple programs, and then designing the system to provide that information seamlessly. One can identify potential efficiencies from two perspectives:

1. *Shared Services*: Information systems can provide the same services for multiple disease programs. For example, electronic reporting of selected laboratory results for surveillance purposes can be implemented only once for any given public health agency, and the same reporting system can receive reportable results related to numerous infectious diseases and acute poisonings, screening tests like Pap smears, and abnormal pathology reports for cancer surveillance.
2. *Unified Systems*: Information systems supporting different program components can be unified, often using a master person index. For example, this would allow clinicians treating people with TB to have ready access to any HIV testing results on their patients, and allow HIV/AIDS clinicians similar access to information about results of tests indicating TB infection.

In reality, it is rare to have an opportunity to design such extensive information systems as a single project. One is dealing with numerous legacy systems that were designed to support program-specific workflows. So a key challenge for the public health informaticist is to help their agency make decisions about where information system ‘integration’ will yield substantial benefits and where it will not.

For example, if it is desired to know (one time) how many people in the jurisdiction have been reported during a particular time interval with both syphilis and hepatitis B, one could do an *ad hoc* match of information in two independent surveillance information systems. This task might take an analyst a few days or weeks to accomplish – which is almost certainly inexpensive compared to the cost of building a new information system that could do this task almost immediately. For

many purposes, it may be useful and sufficient to be able to display multiple streams of surveillance or programmatic data in the same environment, on the same screen or even in the same chart. In Florida, de-identified reportable disease case information and death certificate information are imported into the ESSENCE analytic environment that was originally designed for syndromic surveillance [1], so that trends for similar conditions by age, sex, and geographic area in the two data streams can be easily compared. On the other hand, if it is desired to have real-time information available to the STD clinic staff about past diagnoses of hepatitis B, or about past receipt of hepatitis B vaccine, then information systems need to be designed to support this kind of look-up; the usual solution is a shared person index between the two systems. Alternatively, a common data repository can be designed in which all information about each person is permanently linked.

As mentioned earlier, there are a number of components common to disease control and prevention programs. In this chapter, we will address information systems designed to support the following:

- Public health surveillance
- Outbreak or cluster recognition and response
- Acquisition of laboratory information
- Case-contact identification and intervention

### ***Public Health Surveillance***

CDC defines public health surveillance as “the ongoing, systematic collection, analysis, and interpretation of health data, essential to the planning, implementation, and evaluation of public health practice, closely integrated with the dissemination of these data to those who need to know and linked to prevention and control” [2]. Each word of this definition is carefully chosen, and has implications for the design of surveillance information systems. A one-time data collection activity is not surveillance. Data collection for research purposes is not surveillance. Surveillance data are collected to support public health action, and analyses and recommendations based on these data must be shared with those who provided the data and with others who need to know.

Objectives of surveillance systems differ at the local, state, and federal levels [3]. At the local level, immediate response to individual cases is relatively more important, while at the federal level the analysis of larger-scale patterns is the most important function of surveillance. For state health departments, both uses of surveillance data may be important, depending on the disease and the size of the state.

Public health surveillance systems may be based on data capture from a variety of sources, including case reports, population-based surveys, sentinel providers, electronic health records (including laboratory information management systems for ELR and emergency department records for syndromic surveillance), or administrative data (like hospital or physician claims for reimbursement). For some non-infectious diseases, surveillance is carried out through registries (see below).

Information systems to support reportable disease surveillance contain records representing *case reports* that currently are, for the most part, entered manually into an application by public health staff, based on information received from doctors, infection control practitioners, hospitals, and laboratories. Increasingly, the laboratory information in these records comes from electronic records transmitted by the public health laboratory, hospital laboratories, and commercial laboratories, when there is a positive result meeting certain reporting criteria (like a positive IgM antibody test for hepatitis A). These records typically contain a combination of clinical, laboratory, and epidemiologic information about each case.

In future, increasing proportions of these case reports will be entered directly into a website by the practitioner creating the case report, or be transmitted electronically from the practitioner's electronic health record (EHR) system. Currently almost half the states in the US use the CDC-provided NEDSS Base System (NBS) as their platform for managing case reports. The remainder use either a system developed in-house or one of several commercially-available solutions [4].

In case-based surveillance practice, there is usually a relatively short list of required elements in the initial case report. For some diseases this is the only information received on all cases. For other diseases, usually of more importance and with lower case numbers, an additional data collection form is initiated by the receiving health department, which gathers information as appropriate from the ill person, the treating physician, and health records. The optimum amount of information to collect in the initial case report, as opposed to the disease-specific case report form, is a matter of judgment and may change as technology changes. In a largely manual system, health departments typically desire to minimize barriers to reporting of cases, so the incentive is to keep the initial case report form short. If much of the information desired for the disease-specific case report form can in fact be extracted from an electronic medical record with no additional effort by the person making an electronic case report, then the balance changes. Careful decisions are needed: for which cases of which diseases are follow-up interviews necessary [5]?

Until very recently, virtually all of the case-based surveillance information used at the federal level was collected initially at the local (or sometimes state) level, where it was used in the first instance for local response. As the case report information passes from the local to the state to the federal level, it is subjected to validation and cleaning: cases not meeting the surveillance case definition have been removed from the data submitted to the federal level, missing data have been filled in to the extent possible, and cases have been classified as to whether they are confirmed, probable, or suspected using standard national surveillance case definitions (these case definitions are developed by the Council of State and Territorial Epidemiologists in consultation with CDC) [6].

More recently, advances in technology have allowed case reports, and the information on which they are based, to move almost instantaneously from electronic health record systems, maintained by doctors, hospitals, and laboratories, to public health authorities. There are no technical barriers to these data being available at the federal level essentially as early as they are at the local and state levels. This ready availability of unfiltered clinical information may allow more rapid awareness by



public health officials at all levels of individual cases of high-priority diseases (like botulism or hemorrhagic fevers like Ebola virus infection), and thus lead to more rapid detection and characterization of likely outbreaks.

The simultaneous availability of raw data to multiple agencies at different levels of government also presents certain challenges. The user at the local level will have ready access to information from many sources about local conditions and events, and can use this information to interpret local observations. They will be in a position to understand when an apparent anomaly in their surveillance data is due to an artifact or to local conditions that are not a cause for alarm. They will also know whether a problem is already under investigation. A user at a state or federal level will be able to see patterns over a larger area, and thus may be able to identify multi-jurisdictional outbreaks, patterns, or trends that are not evident at a local level.

The fact that several users may be examining the same raw data at the same time requires that these multiple users be in frequent communication about what they are seeing in their data and which apparent anomalies are already explained or need further investigation. There is a danger that users at a higher level may prematurely disseminate or act on information that, while based on facts, is incomplete or misleading. Similarly, users at a local level may not realize that what they are seeing is part of a larger phenomenon. In the syndromic surveillance domain, the BioSense 2.0 Governance Group [7] has adopted a set of etiquette principles which participating jurisdictions will be required to agree to, that spell out the mutual obligations of analysts at each level of the system (Scott Gordon, Association of State and Territorial Health Officials, 2013, personal communication).

From an information management perspective, an important question is where to put human review of case reports in this information flow. For example, it is becoming technically possible for likely cases of reportable diseases to be recognized automatically in health care electronic record systems. Some of these could be passed on to public health authorities without human review, in the same way that reportable laboratory results are already passed on in Electronic Laboratory Reporting (ELR). For which constellations of findings in the electronic health record would this be appropriate? Should some electronic case reports generated by electronic health record systems be passed to state or even federal public health officials before they are reviewed and validated at the local or state levels? If so, which ones? As always, there is a tension between the speed of information flow and its quality and completeness. There is a need for research to determine which constellations of findings in electronic health records have adequate specificity and sensitivity to warrant automated identification of a person as being likely to have a case of a reportable disease. The acceptable sensitivity and specificity will vary by disease.

In 2001, CDC published the Updated Guidelines for Evaluating Public Health Surveillance Systems [8]. This document identifies a set of key attributes of surveillance systems to be assessed during a surveillance system evaluation, including simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness, and stability. These are also useful attributes to consider when designing a surveillance information system [9]. The relative importance of these attributes will vary depending on the condition under

surveillance and the main purposes for surveillance. For example, a surveillance system to detect cases of botulism for immediate public health response puts a high premium on timeliness, and its operators are likely to be willing to accept a modest number of false-positive reports (a lower *positive predictive value*) in order to assure that reports are received very quickly. On the other hand, surveillance to support planning of cancer prevention programs and treatment services is less time-sensitive, given the quite long incubation periods for most cancers, and therefore more concerned with diagnostic accuracy of every case report than with speed of reporting. Timeliness, positive predictive value, and sensitivity of a public health surveillance system are always in tension with each other; increasing two of these always compromises the third.

In systems based on case-reporting from doctors, hospitals, and laboratories, and receipt of electronic health records from these same organizations, records for an individual can in principle be linked with records for that same individual in numerous public health information systems, including those supporting clinical service, immunization registries, case investigation, partner or contact identification, partner or contact notification, and provision of interventions to partners or contacts. Sometimes this will be done best by automated messaging of structured data from one system to another, sometimes by supporting real-time look-up capabilities, and sometimes by development of a master person index to underlie some or all of these applications. One key decision is which application to consider as the hub for this information sharing, for example, the surveillance application itself or a clinical application.

Surveillance systems that are based on sample surveys (such as the Behavioral Risk Factor Surveillance System, BRFSS [10]), on sentinel practices (such as ILI-Net for surveillance of influenza-like illness [11]) or on syndromic surveillance do not have individual patient identifiers, and so intrinsically cannot be linked at the individual level to information systems supporting other disease control program components. Their data are typically managed in systems built on standard statistical software packages, or other independent systems.

Syndromic surveillance systems are based on rapid acquisition of unfiltered, real-time, electronic records without individual identifiers from hospital emergency rooms [12] and urgent care centers, and also, increasingly, from outpatient physicians' offices and from hospital admissions [13]. The primary purpose of these systems is to support detection and characterization of community disease outbreaks, as they are reflected in care received at emergency departments, physicians' offices, or hospitals. Each visit to an emergency department is assigned to a category or *syndrome*, based on words and strings contained in the patient's chief complaint and/or the triage nurse's notes. As the records received by the health department do not have individual identifiers, they cannot be linked to records in other information systems. However, records received by the syndromic surveillance system should contain unique identifiers that could allow the epidemiologist analyzing the data to work back through the sending facility to an identified clinical record. This traceback might become necessary if the person appeared to have a case of a reportable disease or to be part of a significant outbreak. Adding outpatient visits and hospital admissions to the scope of syndromic surveillance is opening up additional

uses for this technology, especially in the areas of real-time non-infectious disease surveillance.

Surveillance for cancers [14], stroke [15], birth defects [16], and some other chronic diseases like amyotrophic lateral sclerosis (ALS) is carried out through registries. *Registries* are usually established by specific legislation, and typically relate to a single topic – for example a registry of records for a disease, or of immunization records. Registries may be restricted to a geographic region.

A distinctive feature of registries is that individual case reports are kept open for long periods of time, up to several or many years, allowing additional information about treatment, hospitalization, and death or other outcomes to be added. Registries thus serve as systems to monitor type, duration, and outcome of treatment for these diseases, in addition to the occurrence of new cases of disease (disease *incidence*). They may also support outreach efforts to patients or their families, as a way to document that appropriate steps have been taken to link patients to needed types and sources of care.

Most cases recorded in state-level cancer registries are acquired from hospital-level registries, using an electronic case report in a standardized format [17]. Some case abstracts are obtained directly by registry personnel or contractors, when hospitals do not have suitable registries of their own. Case reports require extensive review and abstraction of medical records by trained workers. Birth defect registries may also be built by active search for cases in hospital and other medical records, and abstraction of those records to make case reports. They also may be built by electronically linking records from vital statistics (birth and death records), centralized hospital discharge record systems, and clinical service providers for children with birth defects (such as state programs for children with special medical needs) [18]. The latter are much less expensive to develop but cannot be assumed to have captured all cases of the disease under surveillance, or captured them correctly [19].

## ***Disease Outbreaks and Clusters***

A disease *outbreak* is defined as a number of cases greater than the number expected during a particular time interval in a geographic area or population. This term usually is used for events due to infectious diseases, and sometimes for those of toxic origin. A similar increase above expected numbers for a non-infectious disease, such as birth defects or cancer, is usually called a *cluster*. Outbreaks and clusters may be due to diseases for which individual cases are reportable (like shigellosis or breast cancer), or diseases for which they are not (like food poisoning due to staphylococcal or *Clostridium perfringens* toxins in most states, SARS when it was new, or multiple sclerosis).

Surveillance systems are designed to facilitate recognition of outbreaks or clusters by frequent examination of the most current information available. The design of the user interface is particularly important. The interface should allow users to: flexibly display line lists, bar charts by date of event (epidemic curves), and maps of location

of cases; flexibly select subsets of cases for display; apply appropriate statistical tests to detect improbable increases in case counts; and display multiple streams of data on the same chart. For example, users may want to display the epidemic curve of an influenza outbreak for several different regions of a state or for several different age groups, or to display counts of positive influenza tests and emergency department visits for influenza-like illness on the same graph with different scales for each.

Syndromic surveillance systems have been leaders in developing and evaluating statistical algorithms for automated detection of anomalies which may, on investigation, turn out to be outbreaks. Such algorithms have less frequently been applied for automated detection of possible outbreaks or clusters in reportable disease data streams.

Most outbreaks and clusters are in fact not recognized by examination of regularly-collected surveillance system data. Instead, they are recognized by private citizens (such as the organizer of a social event, a teacher or school nurse, the manager of a child care center, the manager of a food service facility, an employer, or the ill people themselves) or by practicing doctors, and brought to public health attention via a phone call or e-mail or entry on a web site established for the purpose [20]. Public health workers assess the information and make the decision whether or not to do a formal investigation of the outbreak. One part of such an assessment is to look at available streams of surveillance data and determine whether there is information supporting the occurrence of an outbreak. For example, a report of a possible influenza outbreak in a high school might prompt closer examination of syndromic surveillance data from nearby hospital emergency departments to determine whether there is a more general increase in visits for influenza-like illness. A report of a neighborhood cluster of brain cancers would prompt closer examination of available cancer registry information, which might or might not support an interim conclusion that such a cluster is real and statistically significant.

In order to be accountable for the effectiveness of their work, local and state health departments need to track the occurrence of outbreaks and the public health response to those outbreaks. Since outbreaks can be due to reportable or non-reportable diseases, this cannot be done only by actions such as identifying some cases in the reportable disease data system as being part of an outbreak. Systems to track the occurrence of outbreaks need to document the following:

- time and date the first and last cases occurred
- total (estimated or counted) number of cases
- population group most affected (by age, sex, location)
- setting of the outbreak (school, workplace, restaurant, wedding, etc.)
- suspected or confirmed agent
- most common clinical presentation
- suspected or confirmed source and mode of spread
- methods used to investigate agent, source and mode of spread
- control measures recommended
- control measures implemented
- lessons learned for prevention of future outbreaks and improved investigation and response in future events

This information about outbreaks should be stored for ready retrieval, and to serve as a basis for quality improvement efforts. For quality improvement purposes, it is also helpful to document the content of the summary report written about each outbreak. When the outbreak is due to a reportable disease, individual cases in the reportable disease surveillance information system can be linked to the outbreak, for example by having an outbreak identifier attached to their records.

If preliminary information about outbreaks in a jurisdiction is entered into the outbreak information system in real time, as the investigation is proceeding, and if the outbreak database is readily searchable by all communicable disease investigators in the jurisdiction, then local investigators can use the outbreak database to help them with investigations of new illness or outbreak complaints [21]. For example, if they receive a complaint that illness has occurred in people who consumed a particular food product, they can look in the database and determine whether other recent or current complaints or outbreaks mention the same food product. If they receive a report about a gastroenteritis outbreak in a childcare center, they can determine what agents have been found to be responsible for recent or current similar outbreaks in nearby communities; this can help focus their laboratory testing and initial control strategies.

Some US states have had long-standing systems to document all outbreaks investigated by local or state personnel, but others have not. A major variable in the design of such systems is the state-local division of responsibilities in each state, including the degree of state oversight of ‘routine’ local outbreak investigations.

The actual investigation of an outbreak or cluster may involve enhanced “active” case-finding, use of case-report forms, group surveys, and formal epidemiologic studies. Active case-finding involves regular solicitation of case reports from doctors, hospitals, and laboratories. Managing the reports of possible, probable, and confirmed cases that are part of the outbreak is an important task. For a reportable disease, the jurisdiction’s reportable disease surveillance system may be adequate to manage reported cases. It may be necessary, however, to create a continuously-updated line list of possible cases and their current status, which is outside the scope of the standard reportable disease application.

Outbreak investigation surveys will typically involve interviewing everyone with a possible exposure (like all attendees of a wedding reception), whether they were ill or not. Formal studies may involve interviewing selected non-ill people, for example, as part of a case-control study. The investigation may also involve obtaining and sending to a laboratory a large number of specimens from ill persons, and sometimes from exposed non-ill persons and from environmental sources (food, water, air, soil, etc.). Managing these disparate types of information is a challenge, especially in a large outbreak or one involving multiple jurisdictions. There is currently no one widely-accepted and satisfactory way to manage data in such settings. Each investigation team typically uses the tools it is most familiar with, including some combination of data management tools like MS Excel, MS Access, or EpiInfo [22], and standard statistical packages. Many health departments maintain libraries of standard questionnaires with associated empty data bases, for use during outbreak investigations.

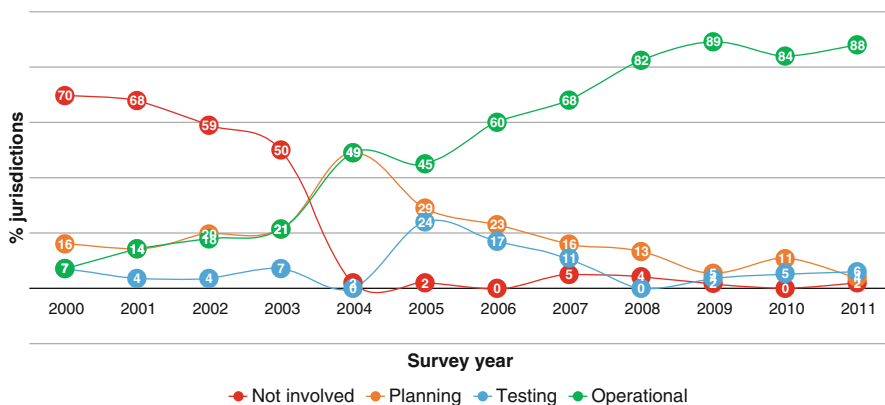
When CDC is involved in a multistate outbreak, the investigation team at the local or state level needs to be able to produce and transmit timely case report and other information in the format desired by CDC. The services of an experienced public health informaticist can be extremely helpful to the investigation team when outbreaks are large and multifocal. An ongoing challenge for CDC and the states is how to make the transition from specialized case reporting during an outbreak of a new disease, such as West Nile Virus encephalitis or SARS, to routine case-based surveillance. If this transition is not well-managed, it is likely to result in the creation of a permanent stand-alone surveillance information system (or silo) for that disease. If the new disease is of national importance, cases should be made nationally notifiable and its surveillance should be incorporated into existing systems.

### ***Laboratory Information***

Laboratory information is a critical component of disease surveillance and prevention. Laboratory data form the foundation of many surveillance systems. There are different types of laboratories involved in the public health data stream. Laboratories providing data to public health fall into the general categories of commercial or private industry, hospital or clinical, and public health laboratories.

Public health laboratory information systems (LIS) contain information about test results on specimens submitted for primary diagnosis, for confirmation of a commercial or hospital laboratory's results, for identification of unusual organisms, or for further characterization of organisms into subgroupings (like serotypes) that are of epidemiologic importance. In some states, all clinical laboratories must submit all isolates of certain organisms to the public health laboratory. Many of the results obtained in a public health laboratory turn out to be for diseases that are not reportable and not targets of specific prevention programs. Some of those results may, however, be for cases of non-reportable diseases that are historically rare in the jurisdiction but of great public health importance, or are new or newly-recognized.

The main business of clinical laboratories (located both inside and outside hospitals) is to test specimens for pathogens or groups of pathogens specified by the ordering physician, and return the results to the person who ordered the test. Public health agencies have, since the early 1990s, asked or required such laboratories to also identify results meeting certain criteria (indicating the presence of a case of a reportable disease) and send a copy of the results to the public health agency for public health surveillance. Initially, case reporting by laboratories was accomplished on paper forms, which were mailed or faxed to public health departments. Some laboratories very soon moved to mailing printouts of relevant laboratory results, then to sending diskettes, then to transferring computerized files containing laboratory results by direct modem-to-modem transfer, and eventually to transferring such files via the Internet using standard formats and vocabularies. In some states, public clinics (for example, STD clinics) have used contract laboratories for their testing needs. In this situation, the outside laboratory supplies both positive



**Fig. 14.1** Trends in ELR adoption; stages of development by percentage of US jurisdictions

and negative results to the public health agency, increasingly by transfer of electronic results in standard formats.

Laboratories provide data on *reportable* conditions to their local or state public health authority. Reportable diseases are determined by each state; clinicians, hospitals, and/or laboratories must report to public health when these conditions are identified. Some reportable conditions are also nationally notifiable. Deidentified cases of these are voluntarily notified by states and territories to CDC, which, in collaboration with the Council of State and Territorial Epidemiologists, maintains a listing of nationally notifiable conditions that includes both infectious (e.g., rabies, TB) and non-infectious (e.g., blood lead, cancer) conditions [23].

The public health partnership with laboratories has led to the very successful and still increasing implementation of electronic laboratory reporting (ELR) in the US. ELR refers to the secure, electronic, standards-based reporting of laboratory data to public health. ELR implementation has been steadily escalating since its inception around the year 2000, replacing previous reporting systems that relied on slower, more labor-intensive paper reporting. The ELR National Working Group conducted annual surveys from 2004 to 2011 [24] which gathered data from all 50 states as well as from several territories and large metropolitan areas. These data were supplemented with data for years 2000–2004, retroactively gathered in the 2010 survey. The tracked growth of ELR (Fig. 14.1) illustrates its rapid rise in the US, from the start of early stage planning to fully operational ELR [25].

The expected benefits of ELR include more rapid reporting of reportable cases to public health departments, allowing faster recognition of priority cases and outbreaks for investigation and response, and thus more effective prevention and control [26]. ELR also is expected to reduce the number of missed cases, as automated systems do not require laboratory staff to actively remember to make case reports, and to improve the item-level completeness and quality of case reports. Although experience shows that the expected improvements in timeliness, sensitivity, completeness, and accuracy are generally being realized [27], timeliness may not be

improved substantially for those diseases where clinicians routinely report based on clinical suspicion without waiting for laboratory confirmation (for example, meningococcal disease) [28]. In addition, laboratories (especially referral laboratories) often do not have access in their own information systems to home addresses for people whose specimens they are testing, and have struggled with providing complete demographic information to public health agencies.

Implementation of an operational ELR system is not a trivial undertaking. Laboratories must configure data into an acceptable message format, most commonly Health Level Seven (HL7<sup>®</sup>) [29]. Laboratory tests and results should be reported with correlated vocabulary or content codes. Two of the most common code systems used for laboratory tests and their associated results are Logical Observations Identifiers Names and Codes (LOINC<sup>®</sup>) [30] and Systematized Nomenclature of Medicine (SNOMED CT<sup>®</sup>) [31]. Neither of these systems is sufficient by itself to encode all the information needed for public health surveillance.

Public health jurisdictions have introduced ELR to their partner laboratories using one or more of the following approaches:

- The “charm” approach – relies on establishing goodwill and collaboration with laboratory partners. While this collegial approach is very appealing, it may be unable to overcome significant barriers such as lack of laboratory funding or resources, and some facilities will supply data only in methods specifically required by law.
- The incentive approach – involves offering either financial or technical assistance to laboratory partners, assisting them in the startup process of ELR. While this approach may be preferred by many laboratories, relatively few jurisdictions have the discretionary funds (or are able to receive federal assistance funds) to implement the approach.
- The enforcement or legislative approach – requires reporting rules or legislation that requires laboratories to participate in ELR. The most successful enforcement approach will include low-cost options for smaller laboratories, such as web data entry, so that they may benefit from an ELR –“lite” implementation [32].

The mainstreaming of ELR systems in the US has pioneered a clear path forward for public health to begin maximizing its presence in the domain of electronic data interchange.

### ***Field Investigation Information Systems***

At a local level, case reports for communicable diseases prompt action. Although the specific action varies by disease, the general approach is the same. It starts with an interview of the ill person (or that person’s parents or other surrogates) to determine who or what the person was in contact with in ways that facilitate transmission, both to determine a likely source of infection and to identify other people who may be at risk from exposure to this person.



Information systems to support contact tracing, partner notification, and post-exposure prophylaxis (for STDs or TB, for example) contain records about all elicited contacts (exposed persons) for each reported case of the disease in question. These records contain information about each contact, such as whether they were located, whether they received post-exposure prophylaxis, and the results of any additional partner-elicitation interviews or clinical testing that were completed.

Information systems to support surveillance for other reportable diseases also increasingly contain information about what disease-appropriate action was taken in response to each case; such actions may include identification of contacts, education of household members, vaccination or antibiotic prophylaxis of contacts, isolation of the case (including staying home from work or school), or quarantine of exposed people.

STD and TB information systems typically capture full locating information for contacts, and can be used both to support field work and to generate statistics on effectiveness of partner notification activities worker by worker and in the aggregate. Systems for other reportable diseases may capture only the fact that various interventions were done, and the date that these were initiated. Information about the timeliness of initiation of recommended control measures is now required as a performance measure for selected diseases by CDC's Public Health Emergency Preparedness Cooperative Agreement [33].

In the investigation of a case of meningococcal disease, contacts are people who had very close contact with the original person, for example a household member, boyfriend, or regular playmate. Health department staff determines who the close contacts are. Each will then be offered specific antibiotic treatment to prevent illness. For syphilis, contacts are people who have had sex with the original case. Contacts will be examined by a clinician and assessed serologically to see if they are already infected, and offered appropriate prophylactic or curative antibiotic treatment. For measles, contacts may include anyone who spent even a few minutes in the same room as a case. Contacts whose exposure was recent enough, and who are not fully immunized already, will receive a dose of measles-containing vaccine, and all contacts will be asked to self-isolate immediately if they develop symptoms of measles. In investigating a common-source outbreak of legionellosis, histoplasmosis, or anthrax, the local health department may want to locate everyone who had a specified exposure to the apparent source of the infection. These exposed people may need antibiotic prophylaxis or may be advised to seek medical care promptly if they become ill.

Information systems to support this type of work typically have three purposes:

1. Serve as a place for workers to record and look up information about people who are or may be contacts, and to track which contacts have and have not yet received needed interventions.
2. Serve as a source of information for calculating indices of program or worker timeliness and performance, such as the average number of sexual contacts elicited per syphilis patient interviewed, or the percentage of measles contacts who were identified in a timely way and who received post-exposure measles vaccine prophylaxis.
3. Document the workload and effort put in by epidemiology and disease control field staff

It seems logical that the surveillance information system should serve as the basis for a system to support field investigation, and this is often the case. The fact that the recommended interventions vary by disease makes designing a single system more complex. Existing systems that track field worker activities in detail are much more common for STD and TB programs than for others. For general communicable disease fieldwork, it is currently more common that the system simply documents which interventions were done and when, rather than use the application to track specific named contacts or exposed people.

The Public Health Informatics Institute has published a detailed analysis [34] of the typical workflow involved in surveillance, investigation, and intervention for reportable diseases, and the corresponding information system requirements. The work group that PHII convened had representatives of nine different state and local health departments, who were able to identify a large number of processes that were common to all nine jurisdictions, such as case-finding, case investigation, data analysis and visualization, monitoring and reporting, case/contact specific intervention, and others. These common processes can then serve as a basis for designing information systems to support case-reporting, surveillance, and case-based intervention work that are useable in multiple jurisdictions.

### ***Interoperability and Integration in Disease Control Information Systems***

Consider existing or planned surveillance systems for multiple diseases and conditions. Broadly, there are three functions in each of these systems – acquiring the raw data, cleaning and managing the data, and making the data available to users. Each of these functions potentially can be integrated, to varying degrees. For example, multiple surveillance systems may benefit from receiving electronic laboratory reports with a result indicating the presence of a case of a reportable disease. Laboratories appreciate having a single set of instructions and a single destination for all their required reports, as this simplifies their work. The laboratories then benefit from the ability of the recipient health department to route the reports internally to the right surveillance information system.

At the other end of the data pathway, users appreciate having a single interface with which to examine data about multiple conditions or diseases, using the same commands and definitions. The users do not have to understand how different surveillance information systems may internally code the same concept in different ways. They also appreciate being able to directly compare information that originally was submitted for the use of different program areas – for example, hepatitis B and gonorrhea in the same chart or table.

In the short to medium term, it is not necessary to build a single integrated data repository or a master person index to achieve these goals, even if that is what one would have designed if one were starting from the beginning. However, if one

wants to be able to see information about the same person that originates and is stored in multiple systems – for example, so that TB clinicians can see HIV data on their patients and vice versa – then an integrated data repository, or a master person index, or a query system that is extremely accurate in finding data on the right person, is needed. Modifying existing systems to be able to carry out these functions is time consuming and expensive, so the business case and requirements need to be especially clear.

### Review Questions

1. What are some of the methods for surveillance besides case-reporting?
2. How are registries different from other surveillance information systems?
3. What are the advantages and disadvantages of building a master person index across surveillance information systems for multiple diseases?
4. What are the expected benefits of electronic laboratory reporting as a method to enhance surveillance?
5. What are the advantages and disadvantages of building a system to manage information about case contacts as part of the surveillance information system?
6. Who determines for which diseases cases are nationally notifiable?

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# Chapter 15

## Informatics in Toxicology and Environmental Public Health

Edwin M. Kilbourne

**Abstract** Computerized information systems are especially important in supporting the areas of toxicology and environmental public health because of the sheer number of toxic agents that may be involved, the widely differing ways in which those conditions may be prevented or treated, and the many pathophysiological processes by which toxins and toxicants may affect health. This chapter will review the major outline of the history and continuing development of informatics in this area and describe major needs and uses of computers in this field, including selected individual systems of special importance.

**Keywords** Etiological • Toxicology • Toxin • Toxicant • Toxicokinetics • Chemical exposure • Pharmacokinetics • Quantitative structure-activity relationship • Congeners • Drug development • Poisoning • Toxicity • Computational toxicology • NIEHS • National Toxicology Program • Environmental Protection Agency • TOXNET • MEDLINE • TOXLINE • ChemIDplus • HSDB • Regulation • Regulatory • Poison centers • Poison control • Public health surveillance • POISINDEX

### Learning Objectives

1. Understand the distinct origins and gradual convergence of clinical toxicology and environmental public health.
2. Understand the reasons why informatics is particularly important in the practice of clinical toxicology and environmental public health.

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3. Begin to develop an understanding of the informatics resources available to these fields and the distinct utility of each.
4. Understand the extent to which computational toxicological techniques can currently supplant animal toxicity testing for regulatory purposes.

## Overview

Computerized information systems are especially important in supporting the areas of toxicology and environmental public health because of the sheer number of toxic agents that may be involved, the widely differing ways in which those conditions may be prevented or treated, and the many pathophysiological processes by which toxins and toxicants may affect health. This chapter will review the major outline of the history and continuing development of informatics in this area and describe major needs and uses of computers in this field, including selected individual systems of special importance.

## Introduction

This chapter will address the need for information processing and informatics solutions by toxicology (the science dealing with poisons and their effects) and environmental health professionals. Clinical toxicologists are physicians or other health professionals who deal with problems of toxicity (referring to the degree to which a substance causes harm) in individual patients. Practitioners of environmental public health deal with the health impact from toxic exposures in a population or group of individuals, and do not necessarily have clinical training. Conversely, clinical toxicologists may not be conversant with the principles of population health that underlie public health decision-making. Although the two sets of professionals are separated by differences in the history of their respective fields, training, and the techniques used to arrive at professional judgments, they require similar information resources and informatics support in order to function effectively. Increasingly, the two groups of professionals find themselves addressing similar or identical situations, especially in emergencies.

## History

### *Convergence of Movements with Distinct Origins*

The information services and systems currently available to toxicology and environmental public health arise from two distinct movements affecting US medicine and public health: the poison control movement of the early 1950s and the

environmental protection movement that began to exert a substantial effect on US public policy in the late 1960s and the early 1970s. The information systems that have their roots in these two movements are still somewhat separable and distinct. However, with increasing recognition of the common aims of clinical (medical) toxicology and environmental public health, such distinctions have begun to blur.

### *Information to Support the Clinical Encounter*

During World War II and the post-war period, there were dramatic advances in chemical technology, and an increasing number of new and diverse drugs and chemical products became widely available for use in the home. In 1952, a study done by the American Academy of Pediatrics showed that almost half of unintentional injuries to children were due to the ingestion of poisons (toxins or toxicants) [1]. Here, the reader should note a nuance of terminology: The word *toxin* refers to a toxic substance produced by a living organism (e.g., staphylococcal enterotoxin). *Toxicant* most correctly refers to a toxic substance arising naturally or from the activities of human beings but *not* from living cells. Together, toxins and toxicants comprise all toxic substances.

The first poison control center in the United States (US) opened in Chicago in 1953, under the leadership of Dr. Edward Press [2, 3]. At that time, the principal goal of US poison control centers had been to provide timely information helpful in the acute care and management of individuals exposed to potentially harmful chemical substances.

As the number of poison centers grew, the need for comprehensive authoritative information on potential *toxicants* also grew. In 1957, the US Public Health Service (USPHS) became involved in the collection, dissemination, and updating of information on toxicants. The Surgeon General established the National Clearinghouse for Poison Control Centers (NCHPCC), then located within the US Food and Drug Administration (FDA). States were asked to designate poison control centers, and the NCHPCC provided them with periodically updated sets of 5-by-8 inch index cards with information useful in the acute care of patients affected by specific toxicants. Also, poison exposures were tracked through NCHPCC [2].

This system served the country from the late 1950s through the early 1970s. Physicians who practiced bedside medical toxicology during this era identified problems with the index card system. For example, prior to official updates, cards frequently were updated locally with handwritten information of uncertain quality. In addition, because of the emergent nature of many poisonings, cards often made their way out of the card set by being taken to the bedside, and frequently lost. These aspects of the system made it unreliable.

Another weakness was the fact that the system addressed principally the toxicity and treatment of generic chemical substances. Understandably, patients rarely reported exposure to scientifically-named generic compounds. Rather, the typical patient or poison center client described exposure to one or more brand-named commercial products (which frequently are mixtures) rather than to the generic



substances catalogued in the card set. There was no comprehensive, centralized source of information on the precise chemical formulations of the non-pharmaceutical commercial products.

The old system took a quantum leap forward in the early 1970s, when Dr. Barry Rumack undertook a comprehensive survey of companies marketing commercial products, asking for information on their precise chemical formulations. The response rate to this survey was unexpectedly high. The study effort required so much time, effort, and space that Dr. Rumack moved it out of the hospital and continued it independently. He formed a company that produced a microfiche product including both (a) clinical information on specific toxicants and (b) commercial product formulation information, including type and concentration of toxicants.

This combination of these two types of information had tremendous clinical utility, and the microfiche product was extremely well received. This was the original POISINDEX<sup>®</sup>, which rapidly became the principal information source for most US and Canadian poison centers. In the late 1980s, the product was made available in CD-ROM format for computers and computer networks, further facilitating rapid access to the most clinically relevant parts of the database. This information source has continued to develop in ways that are consonant with the increasing use of computer networks in healthcare, although the company ownership of POISINDEX<sup>®</sup> has changed a number of times. It nevertheless remains in widespread use, retaining its original market of US and Canadian poison control centers.

### ***Information to Support Environmental Public Health***

The National Library of Medicine (NLM) has had a central role in providing access to information supporting environmental public health activities. NLM traces its origins back to the US Army Surgeon General's office, which, in 1836, budgeted US\$150 for “medical books” for officers [4]. The Library expanded greatly within the Department of the Army during the nineteenth and twentieth centuries. In 1955, Congress passed a law sponsored by Senators Lister Hill and John F. Kennedy and signed by President Dwight D. Eisenhower, which gave the NLM its current name and placed it within the Department of Health, Education, and Welfare [5]. NLM was charged by Congress with improving health in the US by facilitating access to the world's biomedical literature.

NLM began computerizing data in earnest in 1965 with the creation of the Medical Literature Analysis and Retrieval System (MEDLARS). MEDLARS was initially developed primarily for the purpose of managing data required to produce and publish the Index Medicus, a periodically-updated index of biomedical publications. However, additional functionality was added and MEDLARS became able to support literature searches for health professionals.

In 1966, increasing public concern regarding the potential adverse health consequences of pollutants and other chemicals in the environment led the President's Science Advisory Committee to evaluate the availability of toxicologic data. The Committee concluded that “there exists an urgent need for a much more

coordinated and more complete computer-based file of toxicological information than any currently available and, further, that access to this file must be more generally available to all those legitimately needing such information” [2]. This finding led to the creation in 1967 of NLM’s Toxicology Information Program (TIP) [6]. The objectives of TIP were to create automated toxicology data banks to provide toxicology information and data services.

TIP predated even the creation of the US Environmental Protection Agency (EPA) in 1970. During the remainder of the 1970s, awareness of environmental issues increased in the US. Concern about the environment grew as a result of the extensive publicity surrounding such shocking examples of environmental contamination as that found at the Love Canal, where Hooker Chemical disposed of a wide variety of chemical industrial wastes for years, then sold the land to the City of Niagara Falls Board of Education (although with disclosure of this prior use in the legal documentation of land transfer) at a price of only a single dollar [7]. In 1980, Congress passed the Comprehensive Environmental Response, Compensation, and Liability Act (CERCLA), also known as “Superfund.” Although the lion’s share of Superfund monies was directed to the EPA to deal with the problem of abandoned sites with hazardous wastes, significant new funding was made available to NLM to continue and intensify its programs to organize and enhance access to toxicologic data.

In 1994, TIP was renamed TEHIP (Toxicology and Environmental Health Information Program), a name that more accurately reflects the mission and content of the databases offered. TEHIP is overseen by NLM’s Division of Specialized Information Services (SIS). Although SIS covers other specialized areas, the bulk of the databases offered cover toxicology and environmental health. TEHIP is now a major function of SIS, and offers a broad array of databases containing a wide range of toxicologic and environmental health information. The mission of TEHIP is broader than TIP in that TEHIP (a) provides selected core information resources and services; (b) facilitates access to national and international information resources; and (c) strengthens the information network of toxicology and environmental health [6].

## **Underlying Needs**

### ***Scope of Information Required***

In the health disciplines, practitioners of environmental health and clinical toxicology are among those that benefit most from computerized information systems. These systems enable practitioners to deal effectively with the extraordinarily large number of potential etiological (toxic) agents that pose potential health threats to patients and populations, and about which these professionals may need to form a professional opinion.

The Chemical Abstracts Service (CAS) and other sources of toxicologic information make use of CAS numbers for unambiguous identification of the chemicals discussed in literature citation and factual databases. NLM’s

ChemIDplus service (available over the Web) has an extensive list of synonyms that can be related to the basic compounds [8]. For almost 100,000 entries, each compound can be displayed graphically, showing its two- or three-dimensional structure.

The scope of the field may be judged on the basis of statistics from the Chemical Abstracts Service or CAS, a Division of the American Chemical Society (ACS). CAS has developed a registry, in essence, a comprehensive database identifying specific chemical structures and associating them with a CAS “registry number” (CAS RN or “CAS number”). When this chapter was first written in 2001, the most comprehensive database of chemical entities, the CAS Registry<sup>SM</sup>, contained specific identifying information for some 18 million unique organic and inorganic substances [9], including alloys, coordination compounds, minerals, mixtures, polymers, and salts. As of this writing (2013), there are now 71 million unique organic and inorganic chemical substances, and more than 64 million sequences [10]. Although it is maintained commercially, the CAS Registry Number (RN) is a *de facto* standard and serves as a universally recognized unique identifier for chemical substances, whether referred to in the context of science, government, or private industry. Even the US National Library of Medicine (NLM) uses the CAS RN as a search field to identify chemicals in its MEDLINE and other biomedical databases [11].

Although the numbers of chemicals with significant potential for human exposure are far fewer than the many tens of millions of registry entries, a 1984 National Research Council report nevertheless estimated that they number at least in the tens of thousands [12]. There are thousands of compounds approved for use as medicines, and there are hundreds to thousands more in quasi-medicinal use (health foods, herbal tonics and remedies, vitamins, and nutritional supplements). Identifying the human consequences of chemical exposure is further complicated by the frequent interactions among chemicals to which humans may be exposed. Indeed, even diet—the foods one chooses to eat—may substantially influence one’s response to a chemical exposure [13]. Moreover, as of this writing, CAS has identified over 296,000 substances subject to regulation in one or another jurisdiction [14].

Toxicologists and those working in environmental public health naturally and necessarily gain familiarity with some of the most common environmental and clinical problems involving toxins and toxicants as they gain professional experience over time. Nevertheless, both in poison centers and in the field of environmental public health, the need to deal with unfamiliar exposures is still an almost daily occurrence. For this reason, computerized databases became essential to the practice of clinical toxicology and environmental public health.

A number of government, commercial, and non-profit organizations provide information that may be useful in dealing with toxic exposures. Some of the most important of these information sources for US practitioners—as well as for practitioners in many other countries—are mentioned below in the section labeled “Systems, Applications, and Databases.”

## ***Modeling in Toxicology and Environmental Public Health***

Over the past two decades, toxicologists and environmental health professionals have increasingly recognized the importance of using pattern recognition and knowledge derived from other fields (e.g., chemistry) to extend the utility of existing toxicological data. Although there may be 296,000 substances regulated, as mentioned above, comprehensive animal toxicological information is available on far fewer compounds. And comprehensive human toxicological information is limited to a very small group of substances. Accordingly, reasonable conjectures based on existing knowledge may guide us toward conclusions in situations that are similar—but not identical—to those about which we know. Such conjecture should be done systematically, by means of mathematical modeling, most frequently done on computers. Models useful in toxicology and environmental health are of several types. The most important model classes include:

### **Acute Exposure Models**

Such models are used to predict the geographic and human extents of exposure and possible health consequences following an acute release of a toxic substance into the environment or other environmental event (e.g., tsunami or earthquake) with potential adverse impacts on human health.

One aspect of exposure modeling involves predicting dispersion of environmental toxins/toxicants into the environment. Such models frequently employ Lagrangian estimation techniques. Lagrangian model estimates are based on the predicted dispersion of particles of sizes with a defined distribution, based on their original states of motion, size, and other parameters, as well as a variety of physicochemical parameters (e.g., vapor pressure, particle size, surface tension, sensitivity to photolysis, etc.) that will necessarily vary not only by substance, but also depending on the circumstances surrounding the dispersion.

### **Chronic Exposure Models**

This class of model is perhaps best exemplified by General Circulation Models (GCMs). Such models are four-dimensional (that is, time and space) models developed to characterize changes in the atmosphere and oceans. Together with additional data and/or modeled inputs on other important variables (e.g., information on ice cap sizes and carbon dioxide emissions), GCMs can be used in forecasts of global climate change. The profound changes predicted by the most highly

developed GCMs suggest large impacts by climate change on human health in the coming decades.

## **Computational Toxicology Models**

These models focus on the sub-set of problems and informatics solutions developed within the larger field of computational biology. Based on the actions of similar chemical substances, such models may be used to attempt to identify the types of human adverse effects likely to result from a chemical about which little is known, and/or the toxicokinetics (compartmentalization, metabolism, and elimination kinetics) of an unfamiliar compound.

## **Systems, Applications, and Databases of Special Interest**

### ***HPAC—Hazard Prediction and Assessment Capability***

A particularly useful set of models, mostly Lagrangian in type, is known as HPAC (Hazard Prediction and Assessment Capability) and was developed by and is used within the US Department of Defense (DoD). An unclassified version is available for use by civilian agencies and authorities involved in environmental public health. HPAC evaluates the extent of dispersion and threat resulting from releases of harmful substances related to the use of nuclear, biological, chemical, and radiological weapons and from attacks on facilities involved in work with nuclear, biological, chemical, and radiological materials. HPAC is capable of modeling with “typical” weather, actual (current) weather, or near-term weather predictions. Casualty estimates are based on worldwide local population estimates developed using Oak Ridge National Laboratory’s LandScan™ methodology (worldwide satellite-based estimates of day-time and night-time populations of small areas). HPAC accounts for dynamic plume rise and dense gas effects. Perhaps the most useful feature of HPAC is its ability to predict the concentrations of an agent within relevant areas of three-dimensional space and to do so as a function of time. In addition, it models the impact on dispersion and deposition of agents resulting from flow over complex terrain.

For purposes of assessing hazard, there are components permitting the calculation of two-dimensional chemical concentration isopleths marking areas of particularly high inhaled dose and surface deposition. These isopleths may be calculated in such a way as to include some of the uncertainty involved in the model conclusions.

Data defining boundaries of areas of concern are available as geographic coordinates (latitude and longitude) and can be exported as ESRI Shapefiles [15].

Boundary information can be imported into the popular Geographic Information System (GIS) software products available from ESRI (the Environmental Systems Research Institute), which can then be used to display the findings from HPAC modeling. Because the ESRI Shapefile definition has been published [11], many other systems for GIS analysis and map displays can also be used to display HPAC output.

### ***Authoritative Information on Individual Substances and Products***

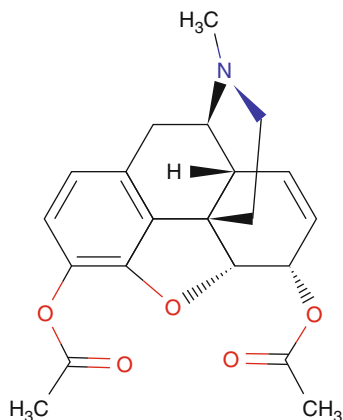
Databases containing facts or authoritative opinions can be particularly useful in situations in which rapid action is required. In environmental public health emergencies (e.g., significant chemical spills and releases) and in medical toxicologic emergencies (e.g., overdoses), authoritative facts and pre-developed peer-reviewed conclusions have great utility because they can form the basis for rapid rational action at a time of emergency. In these situations, bibliographic databases are less useful because of the time and effort required to locate, review, and draw conclusions from appropriate literature citations. A variety of authoritative and factual databases are available either as part of NLM's TOXNET website [16] or from other governmental and private information services.

### ***ChemIDplus***

The purpose of ChemIDplus, one of NLM's TOXNET family of databases, is unambiguous chemical identification. This function has grown increasingly difficult as the number of known chemical substances has become extremely large and continues to grow at an astonishing rate. By 1984, some five million chemical substances had been synthesized. As of this writing in April 2013, that number now exceeds 71 million. Many of these new substances are complex chemical molecules, which can only be fully and unambiguously identified with reference to their three-dimensional molecular structure.

Although there are internationally accepted conventions for naming complex molecules, the use of alternative schemes, including systematic, "generic," proprietary, incomplete, or trivial names, is frequent, even in the peer-reviewed scientific literature. Thus, the unambiguous identification of the precise chemicals to which toxicologic information refers is problematic. In particular, common chemicals and drugs of abuse frequently have large numbers of alternative names (synonyms). For example, the illegally marketed euphoriant, "heroin" is associated with many names. When entered into ChemIDplus "heroin" resolves to "heroin" (CAS number 561-27-3). However, both street names and scientific synonyms all resolve

**Fig. 15.1** Two dimensional structure of “heroin” (RN 561-27-2) as obtained from ChemIDplus (Source: National Library of Medicine, ChemIDplus)



similarly. Thus, such diverse terms as “horse,” “smack,” “junk,” and “diacetylmorphine” are all identified as “heroin” by ChemIDplus, and important basic information about the chemical is displayed (Fig. 15.1).

Other NLM databases support the identification-by-synonym feature. For example, the Hazardous Substance Data Bank (HSDB) contains an extensive list of synonyms and is capable of resolving synonyms into unique (CAS-identified) chemicals in many instances, independently of the ChemIDplus service. However, the synonym function is not as robust as that of ChemIDplus.

Ultimately, there are limits to synonym resolution by any chemical identification service. It is impossible to link one term unambiguously to a specific chemical entity if that term is itself used ambiguously—that is, if the term is used to refer to more than one compound. For example, the acronym “MDA” is linked in ChemIDplus both to the industrial curing agent and azo dye intermediate methylenedianiline and to the altogether chemically dissimilar 3,4-methylenedioxyamphetamine or “ecstasy,” a drug of abuse. The user would have to interpret from the context of his/her query which compound was meant.

### *The Hazardous Substances Data Bank*

Because of its broad and comprehensive coverage, the Hazardous Substances Data Bank (HSDB) was labeled by an Institute of Medicine committee as the “default” database among NLM’s TOXNET group of on-line authoritative and factual databases [17]. HSDB is tremendously useful, particularly for public health officials, as a source of quick and authoritative information on subject chemicals. Like all of NLM’s TOXNET databases, it is organized into records, each covering an individual chemical substance and associated with one or more specific CAS numbers. Some 4,500 of the most commonly encountered chemical substances are covered.

**Table 15.1** Categories of information in National Library of Medicine's Hazardous Substance Data Bank (HSDB)

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Human health effects
Emergency medical treatment
Animal toxicity studies
Metabolism/pharmacokinetics
Pharmacology
Environmental fate/exposure
Environmental standards & regulations
Chemical/physical properties
Chemical safety & handling
Occupational exposure standards
Manufacturing/use information
Laboratory methods
Special references
Synonyms and identifiers
Administrative information

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*Source:* National Library of Medicine, Hazardous Substances Data Bank

HSDB has potential value to a wide array of health professionals because of the comprehensive nature of its coverage of individual substances. Each chemical record contains a large number of standardized fields, and these fields cover a number of different categories of information (Table 15.1) required by the broad array of health professionals likely to be involved in an exposure situation. For example, public health and emergency medical personnel can be guided by the human health effects and emergency medical treatment sections of the record. Additional data helpful to both clinical and research personnel may be found in the animal toxicity studies, metabolism/pharmacokinetics, and pharmacology field groups. Personnel charged with clean-up and prevention of further exposure will be interested in the environmental fate and exposure and the environmental standards and regulations sections. Those entrusted with prevention planning and the safety of occupationally-exposed persons will likely use the chemical safety and handling, manufacturing/use information, and occupational exposure standards information categories. Chemists and analytical toxicologists will benefit from both the chemical/physical properties and laboratory methods sections. All will benefit from the special references sections, a list of review documents particularly relevant to the specific chemical. An administrative information section lists changes and updates made to the record.

## ***POISINDEX***<sup>®</sup>

The POISINDEX<sup>®</sup> system is a widely used factual database that is a proprietary product (available on CD-ROM) from Micromedex, Inc., a company that is a major developer of toxicologic and pharmacologic information. POISINDEX<sup>®</sup> is particularly focused toward providing the information needed by clinical care



providers, particularly in emergency circumstances. It serves two important functions: (a) linking the common or trade names of products with their constituent generic substance or substances and (b) identifying the toxicity of the individual generic component or components and discussing appropriate treatment. Hundreds of thousands of industrial, commercial, pharmaceutical, and biological substances are covered, and each of these is linked to one or more of over 900 management documents providing information on clinical effects, range of toxicity, and treatment protocols for exposures.

Specific types of information available from POISINDEX® include substance identification and pseudonyms, clinical effects, lab tests for monitoring and diagnosis, therapeutic maneuvers, pharmaceutical treatment, antidotes, complications, and prognosis. POISINDEX® has made great use of hypertext linking to enhance user mobility around the database. Moreover, patient management systems used by poison centers to document and record patient information may smoothly integrate access to POISINDEX® so that the center personnel can easily alternate between giving and receiving information, thus facilitating the work flow in what can be a very high-pressure, busy environment.

### ***Toxics Release Inventory***

The Toxics Release Inventory (TRI), published by the US EPA, informs citizens about toxic chemicals that are being used, manufactured, treated, transported, or released into the environment. It contains information concerning waste management activities and release of toxic chemicals by facilities that manufacture, process, or otherwise use these substances. The list of currently reportable substances includes over 600 individual chemicals and chemical categories.

The data are compiled by EPA and made available to the public. Access to the information was initially quite cumbersome. However, EPA's current interface operates over the Web and is user-friendly [18]. Users may indicate their geographic area of interest or may focus the output in other ways (e.g., all sites dealing with a particular substance). They are able to see the amounts of environmental releases organized by chemical and area of interest. "Drilling down" into the database permits the identification of commercial enterprises that may be the source of environmental releases of chemicals, identifying them by name and address. Thus, one may identify the reported environmental chemical releases of any particular company itemized by year, by chemical substance, by quantity emitted, and even by the environmental route of pollution (i.e., to air, surface water, injection well, or land).

Such information is of great help to those trying to identify the types of pollution problems in a community and identify the sources. Moreover, because remedies may differ substantially by chemical type, these data may help identify solutions to environmental contamination problems.

## ***Bibliographic Databases***

Because of its pioneering and longstanding investment in developing and providing computerized access to citations of the literature of health and medicine, NLM dominates the area of bibliographic databases that are relevant to toxicology and environmental health. Derivative products exist and are marketed commercially; they may have added-value features related to advanced methods of indexing and retrieval. Nevertheless, the initial data source is NLM.

NLM has two named bibliographic databases of substantial importance for toxicology. These are TOXLINE and MEDLINE (both available over the Web). Both databases have evolved greatly over the years. TOXLINE's usefulness has historically centered on its coverage of publications and technical and governmental reports not covered in MEDLINE. In addition to MEDLINE journals, TOXLINE covers special journal and other research literature including that found in the database Developmental and Reproductive Toxicology (DART<sup>®</sup>) and publications of the International Labour Office (CIS). It also includes information on the technical reports and research projects, including Federal Research in Progress (FEDRIP), Toxic Substances Control Act Test Submissions (TSCATS), Toxicology Document and Data Depository (NTIS), and Toxicology Research Projects (CRISP) [19]. Accordingly, for detailed recovery of information on research, TOXLINE is complementary to MEDLINE. However, using PubMed for MEDLINE access provides toxicology information seekers with the advantages of PubMed searching, including related records, MeSH term selection document delivery, and linking out features.

Bibliographic searching is a particularly useful exercise when one is involved in toxicological research or in toxicological or environmental health practice in situations that are not urgent or emergent. Putting together a cogent search strategy may take time, as does the selection and finding of the individual articles to which MEDLINE or another source has guided one. To this must be added the time required to digest the literature and arrive at useful conclusions.

## ***Poisoning Case Management***

Patients, their friends and family members, and/or their healthcare providers seek expert advice about the evaluation and treatment of toxic or potentially toxic human exposures to chemical substances over two million times per year. Despite their large numbers the cases are distributed throughout the population. It is not feasible to have substantive clinical toxicologic expertise at every healthcare facility to which poisoned patients might come for evaluation and treatment. Accordingly, over 55 regional poison control centers (poison centers) located around the country share their toxicologic expertise with callers who may be healthcare providers or members of the public.

Because of the many potential clients of poison centers, the call volume may be high. At any given moment, the specialists in poison information (SPIs) may have several active cases, all of which need further follow-up. While dealing with these cases, they intermittently need to access computerized sources of data. Moreover, SPI's pass on active cases to others at the end of a shift.

Electronic medical record systems specific to poison centers have been developed and deployed at poison centers around the country. These systems perform the following functions:

- Record and display information on:
  - Patient identification and demographics
  - Exposure: toxicant, dose, context
  - Symptoms, signs, laboratory findings
  - Information obtained on follow-up calls
  - Eventual outcome
- Operate with sufficient efficiency and ease to allow the SPI to record and read information while continuing to carry on the telephone conversation
- Change rapidly between patients
- Provide a legible and easily understandable account of the case to an SPI who takes over at shift change
- Allow (or facilitate) consultation of computerized data sources (especially POISINDEX<sup>®</sup>) during a call
- Hold data and produce reports providing data for:
  - Improved case management
  - Administrative reports
  - Regular reports of summary call information to the American Association of Poison Control Centers to update its surveillance system (required for poison center accreditation)

## *Surveillance*

The National Poison Data System (NPDS) is maintained by the American Association of Poison Control Centers and contains a standardized set of information from the more than two million calls made annually to US poison centers across the country. NPDS is notable for the frequency of its updates, continually uploading new and updated data records from each of the more than 55 US poison centers about every 19 minutes [20].

Data from the NPDS can provide the basis for research on poisonings. It may alert public health authorities to new or emerging threats from drugs, household products, or other chemical products. It may be useful in identification and tracking of outbreaks of food-borne illness. Where difficulties appear unusually prevalent with a

medication or pharmaceutical product, analyses of NPDS data may prompt product recalls, warnings, or reformulations. Under certain circumstances, NPDS may provide the first indication of a covert biological or chemical terrorist attack [14].

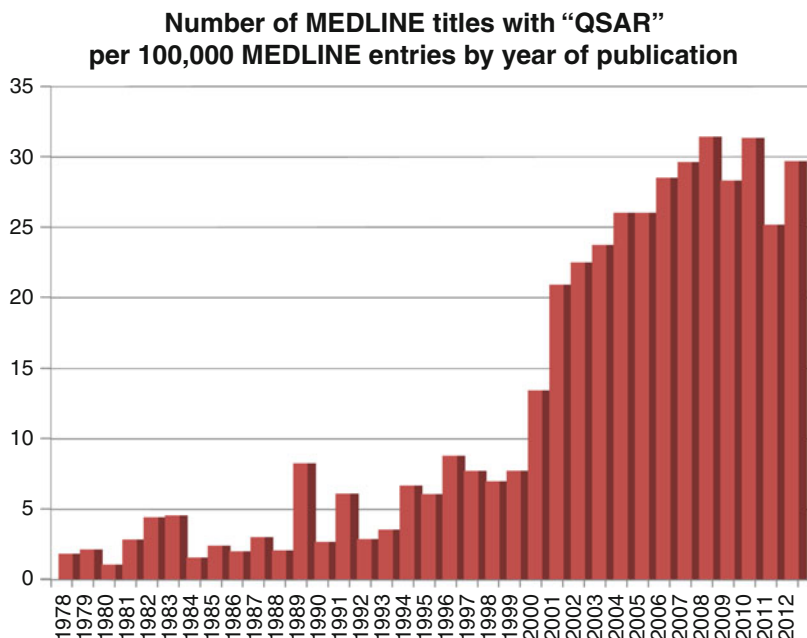
## The Future

Long dependent on the findings of animal testing to evaluate the toxicity of new chemical compounds, the National Institute of Environmental Health Sciences (NIEHS) established the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM) in 1997 [21]. For NIEHS and partner research and regulatory agencies, the guiding principle has been to reduce, to refine, and where possible to replace animal studies for safety testing with other methods. Accordingly, ICCVAM in collaboration with NIEHS and partner agencies has evaluated and promoted methods for shifting from *in vivo* animal studies to *in vitro* assays, from *in vivo* assays in higher organisms to *in vitro* assays in lower organisms, and of particular interest for readers of this chapter, development of computational modeling for toxicity assessments.

A primary guiding concept for the development and use of computational models in toxicity testing has been that of *quantitative structure-activity relationships* (QSAR). QSAR refers to the tendency of similarly structured compounds in the body to behave pharmacologically and toxicologically in similar ways.

Especially since the year 2000, QSAR-based models have seen increasingly widespread use (Fig. 15.2). Such models are widely used in drug discovery and development and may greatly improve the odds of developing more active variants of chemicals with potentially therapeutic biological activity. QSAR models may accelerate the drug discovery process by identifying the congeners (molecular variants) most likely to have high activity of the type desired. Identifying candidate drugs prior to expensive *in vitro* and *in vivo* testing greatly decreases the cost of drug discovery and development. Because QSAR relationships may also predict toxicity, these models are used to eliminate drug candidates with a high likelihood of having unacceptable adverse effects. As a result of these incentives, many QSAR modeling packages are now available [22].

Because QSAR models cannot predict toxicity with certainty, their use in environmental regulation is more problematic. These models are not yet sufficiently well developed to serve as the sole source of information for predicting toxic effects. Moreover, in order to have impact on human exposures, the techniques must be embraced by regulatory agencies. But regulatory agencies must perform their regulatory functions according to law and associated regulations. Despite their utility in identifying probably toxicity, in the next few years the effective use of QSAR-based modeling techniques as environmental regulatory tools will depend as much on a compatible legal framework as on advances in the technology of the models themselves [23].



**Fig. 15.2** Occurrence of term “QSAR” in MEDLINE-indexed publications by year, 1978–2012

### Review Questions

1. Why were poison centers developed? What is their purpose?
2. What sorts of information systems are available to support the work performed by poison centers?
3. What do environmental health professionals do? How does informatics support their work?
4. Name at least four systems designed to assist toxicologists and environmental health professionals in protecting the public. Describe the function of each.
5. What is/are the likely role(s) of computational toxicology in the future protection of individuals and public health?

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# Chapter 16

## Public Health Laboratories

Riki Merrick, Steven H. Hinrichs, and Michelle Meigs

**Abstract** This chapter will review the multiple functions of Public Health Laboratories (PHLs), including their differences to commercial clinical laboratories. For example, the types of samples submitted to PHLs differ from those submitted to commercial clinical laboratories. PHLs are critically important to population based healthcare; playing an essential role in the detection of disease outbreaks.

This chapter will describe the hierarchical organization of the PHL system in the United States, as well as the networks that have been created to support diverse PHL functions such as food safety testing and emergency response to terrorism or natural disaster. It will briefly describe the standards used by PHLs and how the implementation of standards should further improve patient safety as a whole.

In this chapter the reader will be introduced to PHL informatics in the context of the laboratories operational workflow – from test ordering, interfacing with diagnostic instruments, quality control and result reporting and analysis. The reader will also understand the impact of PHL informatics collaboration efforts and its effect on ongoing policy development.

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**Keywords** Laboratory information management systems • Sentinel sites • Surge capacity • Continuity of care • Laboratory Response Network • LRN-Biological • LRN-Chemical • Data Exchange Template • Electronic Laboratory Exchange Network • Electronic Data Deliverables • Laboratory Information Management System

### **Learning Objectives**

1. Illustrate how Public Health Laboratory (PHL) functions differ from clinical labs, either at hospitals or national commercial laboratories.
2. Examine the full environment of the PH informatics domain; from the long term sustainability of an enterprise Laboratory Information Management System (LIMS) to the universe of data exchange partners and networks.
3. Demonstrate how the evolution of informatics has enhanced the PHL workplace and its practice.

## **Overview**

This chapter will review the multiple functions of Public Health Laboratories (PHLs), including their differences to commercial clinical laboratories. For example, the types of samples submitted to PHLs differ from those submitted to commercial clinical laboratories. PHLs are critically important to population based healthcare; playing an essential role in the detection of disease outbreaks.

This chapter will describe the hierarchical organization of the PHL system in the United States, as well as the networks that have been created to support diverse PHL functions such as food safety testing and emergency response to terrorism or natural disaster. It will briefly describe the standards used by PHLs and how the implementation of standards should further improve patient safety as a whole.

In this chapter the reader will be introduced to PHL informatics in the context of the laboratories operational workflow – from test ordering, interfacing with diagnostic instruments, quality control and result reporting and analysis. The reader will also understand the impact of PHL informatics collaboration efforts and its effect on ongoing policy development.

## **Functions of a Public Health Laboratory**

Public Health Laboratories (PHLs) play a vital role in protecting the public from health hazards. PHLs offer diagnostic testing for humans and animals as well as testing of environmental samples and products. These laboratories also provide laboratory confirmation for special organisms, and are part of public health's (PH) disease surveillance enterprise, conferring accurate, timely identification of infectious organisms or toxins during disease outbreaks. They are also critical components in disaster response and bioterrorism preparedness. PHLs often perform tests that are not commonly available



elsewhere. The catalog of available tests at a PHL varies almost as much as their organizational structures. Some PHLs are multi-branch operations; others are university-affiliated laboratories, while others are an integrated part of a Public Health Department [1].

The Association of State and Territorial Health Officials (ASTHO) and the Association of Public Health Laboratories (APHL), in their publication “A Practical Guide to Public Health Laboratories for State Health Officials,” summarize these 11 core functions of the PHL [2]:

1. *Enable disease prevention, control and surveillance* by providing diagnostic and analytical services to assess and monitor infectious, communicable, genetic, and chronic diseases as well as exposure to environmental toxicants.
2. *Provide integrated data management* to capture, maintain, and communicate data essential to public health analysis and decision-making.
3. *Deliver reference and specialized testing* to identify unusual pathogens, confirm atypical or uncommon laboratory results, verify results of other laboratory tests, and perform tests not typically performed by private sector laboratories.
4. *Support environmental health and protection*, including analysis of environmental samples and biological specimens, to identify and monitor potential threats. Part of the monitoring also ensures regulatory compliance.
5. *Deliver testing for food safety assurance* by analyzing specimens from people, food or beverages implicated in foodborne illnesses. Monitor for radioactive contamination of foods and water.
6. *Promote and enforce laboratory improvement and regulation*, including training and quality assurance.
7. *Assist in policy development*, including developing standards and providing leadership.
8. *Ensure emergency preparedness and response* by making rapid, high-volume laboratory support available as part of state and national disaster preparedness programs.
9. *Encourage public health related research* to improve the practice of laboratory science and foster development of new testing methods.
10. *Champion training and education* for laboratory staff in the private and public sectors in the US and abroad.
11. *Foster partnerships and communication* with public health colleagues at all levels, and with managed care organizations, academia, private industry, legislators, public safety officials, and others, to participate in state policy planning and to support the aforementioned core functions.

## Levels of PHLs

PHLs exist at all levels of government – from local to state to federal, and even internationally. There are approximately 300 public health laboratories in the US [3]. Local PHLs are an intrinsic part of the safety network in underserved populations – they are highly integrated with Public Health Departments (PHDs) clinics to provide routine diagnostic testing as well as screening tests for disease prevention. Lead

abatement programs and monitoring of sexually transmitted diseases are other examples of community support functions of a local PHL. Local PHLs may serve metropolitan areas, counties, or regions within a state. In 2012, 40 local PHLs are listed as members of the Association of Public Health Laboratories (APHL).

There are 54 State PHLs [4]; they are found in every US state and territory as well as the District of Columbia. State PHLs often offer and perform tests that no other labs perform – be it for clinical practice (e.g., a regional reference lab for *Salmonella* serotyping) or environmental surveillance (e.g., well water testing). Their work informs public health officials in state government, allowing for targeted disease surveillance, quicker response to disease outbreak and provides population based data that may lead to new guidelines or policies to protect their residents. Where local PHLs are not available, the state PHL supports locally-needed public health activities. State PHLs also have the power to regulate private medical laboratories [5] and operate quality assurance programs (e.g., air quality or clean water act). During surveillance activities, the state PHL takes a leadership role through active collaboration with federal agencies, state epidemiologists, first responders, and environmental professionals.

Within the US, the federal government operates several PHLs that act as reference labs for their state and local counterparts; they manage centers for public health program areas, and are liaisons to international organizations like the World Health Organization (WHO). These federal reference laboratories are located at the Centers for Disease Control and Prevention (CDC), the United States Department of Agriculture (USDA), the Food and Drug Administration (FDA), and the Environmental Protection Agency (EPA). Just like their state counterparts, they provide the federal government with information to help protect Americans everywhere, and through global outreach they ensure laboratory capacity around the world [6].

## **Differences Between PHLs and Clinical and Commercial Laboratories**

At the typical clinical lab, human biological samples are sent in for routine testing, such as blood sugar level, presence of bacteria, or screening for cancers. At a PHL, in addition to human samples, PHLs also perform testing on non-human samples and even inanimate objects. Animal samples are received at the PHL for a number of reasons including: rabies testing, West Nile virus surveillance, as well as ensuring the safety of our food animals through feed testing. Water samples are also tested at the PHL for a variety of reasons, but most importantly the PHL monitors both well water and public water systems. Food, be it peanut butter or spinach, is tested on a daily basis to detect pathogenic bacteria. Our soil, building materials and even cups and plates are tested to protect citizens from high levels of toxic chemicals such as lead. And finally; our PHLs work closely with first responders and the federal government to test for agents of bioterrorism; these samples can range from “white powder” to human based samples.

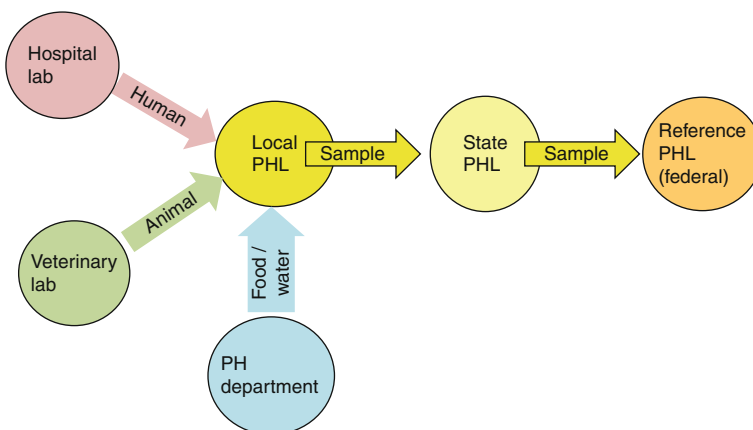
PHLs also perform regularly scheduled tests on samples collected from designated sentinel (guard) sites. Samples come from animals that are more susceptible to a disease, are living in close proximity to people and are being tested regularly to gauge when a

new disease can be expected. The monthly testing of samples from a chicken population for West Nile Virus is one example. Chickens are more susceptible to West Nile Virus infections than people. When West Nile Virus is detected in the chicken population, it is a good indicator that human cases can be expected soon in the same area.

While commercial laboratories do report the detection of certain infectious diseases to their respective public health departments, it is the PHLs that are at the frontline when an infectious disease outbreak occurs. PHLs provide support to the public health department in identifying the cause of the latest foodborne outbreak that may have been first detected at a clinical laboratory. PHLs also spend a significant amount of time developing new test procedures for emerging new diseases; such as the detection of the newest influenza virus strain that may cause the next epidemic or even a pandemic, as we experienced in 2009. Because of their efficacy, some of these newly developed tests are adopted by commercial laboratories and offered to their customers at a later point in time.

Not all human samples arriving at a PHL come from sick people. For example, every newborn is screened for a panel of genetic disorders to ensure early detection of issues that can sometimes save a child's life. These tests are almost exclusively performed at the PHLs [5]. Clinical labs perform mostly diagnostic testing, but they also offer some screening tests for example the pap smear testing to screen for cervical cancer.

PHLs have *surge capacity* agreements with partner laboratories to cover the increase in testing volumes during outbreaks: if one PHL is overwhelmed by the volume of samples received during an outbreak, they can send some of the samples to a neighboring PHL with whom they have such an agreement. These surge capacity partners will have to have identical, or at least similar, testing capabilities, hence they are mainly other PHLs. Because PHLs are critical to the health of a population, they also have *continuity of care* agreements to ensure that, in the event one PHL is affected by a natural disaster, the other partner will perform their duties. Hurricane Katrina put these agreements to the test, especially in the areas of newborn screening, where test requests were successfully transferred to partner PHLs, because babies don't wait to be born because of a disaster (Fig. 16.1).



**Fig. 16.1** Levels of PHLs in the US and their sample flow

## Informatics in the Public Health Lab

Since the advent of computers, the laboratory, with its capacity to produce and manage important data, has been at the forefront of health informatics. What initially began as a database for local results, over time developed into a Laboratory Information Management System (LIMS) that provides capacity for improved workflow management, inventory tracking, and most importantly, patient management. Testing is often performed on stand-alone instruments. These results need to be incorporated into the LIMS, in order to be included in the final result sent to the submitter. In the beginning the LIMS was capturing only those results that needed to be printed to be sent back to the submitter. With the improvement of informatics knowledge in the PHLs more and more of the instruments are being interfaced, using industry developed standards, improving the quality of data and making the workflow more efficient. Informatics practice certainly has transformed several laboratory workflows as organizations migrate from paper-based to electronic system-based tracking. Being able to draw data from a database in an electronic format facilitates secondary use of this information for forecasting or event detection. This information can then be shared with partners in the Public Health Laboratory system (e.g., the public health department, a regional taskforce, preparedness coordinators, policy makers and federal agencies). The capability of the laboratory and its public health partners to share data in the same format, through an electronic data interchange (EDI), can greatly reduce communication delays between partners; resulting in faster, better outcomes for both patient and population based responses. All these functions are covered by informatics principles – from database design to queries as well as application of format and content standards. Table 16.1 illustrates examples of laboratory data at the center of public health events. Figure 16.2 depicts other situations in which the PHL needs to exchange data with a partner as part of normal PHL operations, used with permission from Zarcone et al. [1].

The LIMS Functional Requirement Document [8], developed by APHL and the Public Health Informatics Institute (PHII), lists 16 core business processes for every Laboratory Information system:

1. Laboratory test processing – this business process includes four segments:
  - (a) Test request and sample receiving
  - (b) Test preparation
  - (c) Testing, result recording and result verification
  - (d) Test result report preparation and exchange
2. Test scheduling – includes assignment of resources and prioritizing of the order of testing
3. Sample collection logistics and workload projections – this includes distribution of sample collection kits and order forms to partners
4. Chain of custody tracking for samples
5. Manufacturing of media, reagents and other test related supplies

**Table 16.1** Events where critical PHL data enabled response [7]

Disease outbreak	Year	Natural disaster/bioterrorism
Severs Acute Respiratory Syndrome (SARS)	<b>2001</b>	Anthrax letters
West Nile Virus		
Several foodborne outbreaks	<b>2002</b>	
Worst Hepatitis A outbreak in US	<b>2003</b>	
	<b>2004</b>	
	<b>2005</b>	Hurricane Katrina Hurricane Rita
E coli outbreak in spinach	<b>2006</b>	
several foodborne outbreaks	<b>2007</b>	
Salmonella in salsa	<b>2008</b>	Floods in IA
Pandemic Influenza (H1N1)	<b>2009</b>	
Salmonella in eggs	<b>2010</b>	Tornado in Joplin, MO
Multiple foodborne outbreaks including the second deadliest on record due to Listeriosis in cantaloupe	<b>2011</b>	
Salmonella outbreak in Salmon	<b>2012</b>	Hurricane Sandy

Use case	Diagram	Business need	Example
Unsolicited laboratory results	<pre> graph LR     PHL((PHL)) -- Result --&gt; PHD-Epi((PHD-Epi))     PHL -- Result --&gt; CDC-Epi((CDC-Epi))             </pre>	Laboratory surveillance	Reportable condition to PHD influenza positive test results to CDC influenza division
PHL to PHL; PHL to CDC; clinical lab to PHL	<pre> graph LR     PHL1((PHL1)) -- Order --&gt; PHL2((PHL2))     PHL2 -- Result --&gt; PHL1     PHL((PHL)) -- Order --&gt; CDC-Lab((CDC-Lab))     CDC-Lab -- Result --&gt; PHL     ClinLab((Clin. lab)) -- Order --&gt; PHL3((PHL))     PHL3 -- Result --&gt; ClinLab             </pre>	Service requests	Routine testing such as measles IgM; salmonella PFGE; hantavirus PCR
PHL to PHL	<pre> graph LR     PHL1((PHL1)) -- Order --&gt; PHL2((PHL2))     PHL2 -- Result --&gt; PHL1             </pre>	Surge capacity	West Nile virus outbreak – state must divert sample surge to neighboring state
PHL to PHL	<pre> graph LR     PHL1((PHL1)) -- Order --&gt; PHL2((PHL2))     PHL2 -- Result --&gt; PHL1             </pre>	Continuity of operations	State declares "state of emergency" i.e. Louisiana post Katrina

**Fig. 16.2** Public health laboratories: data exchange scenarios (use cases) (Originally published in Public Health Reports, Copyright 2010 Association of Schools of Public Health)

6. Inventory and forms management
7. General Laboratory Reporting – is part of the general systems requirements – all electronic data management systems need to be able to create reports
8. Statistical analysis and surveillance – provides value added to the test results to both the submitters of the sample as well as public health partners
9. Billing for services
10. Contract and Grant management – unlike clinical laboratories, PHLs often are funded through grants to provide services free of charge to the submitter of the sample, so tracking funding amounts and requirements is important
11. Training, education and resource management – to comply with regulations and to document capacity of laboratory personnel and equipment
12. Lab certifications and licensing – PHLs, mostly at the state level, are responsible to ensure compliance in laboratories operating in their jurisdiction, which includes inspections of those laboratories
13. Customer feedback tracking
14. Quality Control (QC) and Quality Assurance (QA) management – both involve audit functionality about the tests performed – QC tracks the parameters for each method and instrument at the test level and allows for over time analysis of the control parameters, while QA defines specific measures across all the tests performed to ensure accurate testing
15. Laboratory safety and accident investigation
16. Laboratory mutual assistance and disaster recovery to support surge capacity and continuity of care operations

Not all business processes apply to every lab, but across the spectrum of laboratories all of these business processes are relevant. This document describes interdependencies between the lab and outside partners and following informatics protocol decomposes each of the core business processes into their individual steps with related functional requirements for the system, based on detailed laboratory workflow analysis [8]. The publication of this requirements document has created a functional standard vendors can utilize to build more useful systems that are conformant with these requirements. Although much variability between information systems still exists, this requirement document has provided a solid basis to better identify and pin-point these variations.

The PHLs use several kinds of codes in their daily operations: codes for the tests they offer and perform, codes for pre-defined results, and codes for patient demographics. In order to make data comparable across locations, the PHLs map their local codes to national data standards. These data standards include the Logical Identifiers Names and Codes (LOINC<sup>®</sup>) [9] for the tests they perform, Systematized Nomenclature of Medicine (SNOMED<sup>®</sup>) [10] to identify organisms and ordinal results, and codes from Health Level Seven (HL7<sup>®</sup>) [11] for patient demographics like gender, race, and ethnicity. To exchange standardized data between PHLs and their partners, the order and format of the data to be exchanged needs to be defined. For individual point to point exchanges, simpler formats can be agreed upon; for example, comma-separated files (CSV) or excel spreadsheets can be exchanged, but in order to accommodate larger scale data exchange with multiple partners across

multiple information systems standards such as HL7® messages (in version 2.x) or the XML-based clinical document architecture (CDA) formats should always be considered as part of the normal business process. In addition to utilizing these standards, transport mechanisms need to be defined and agreed upon by electronic data interchange (EDI) partners [12].

In order to support these critical public health functions, PHLs create support networks among themselves. These networks help group laboratories together that perform the same kinds of tests and exchange results within the same networks, usually under the guidance of a federal program. Utilization of the requirements document among PHLs has advanced the application of informatics in the PHL realm, and has made several of these networks quite successful. Examples of functional PHL networks in the US are summarized in Table 16.2.

Unfortunately, at this stage each of these networks is using different data exchange methods. LRN and NAHLN use HL7® v2.x messages as data exchange standard, FERN and ERLN use XML-based Electronic Data Deliverables (EDDs). This forces the PHL to support a variety of formats and vocabularies in order to properly report to the respective partners during an investigation. A significant obstacle to the development of consistent data exchange deliverables is the sheer number of networks and reporting requirements. Table 16.3 shows what a laboratory must do, after discovery of a food-borne illness outbreak due to consumption of tainted hamburgers.

## Issues with Interoperability

The following barriers to effective electronic laboratory information exchange were identified in the APHL-PHDSC White Paper, “Assure Health IT Standards for Public Health, Part 1: Health IT Standards in Public Health Laboratory Domain,” [12]:

- Barrier I – The *incomplete and inconsistent adoption of existing standards* by the wide array of laboratories responsible for reporting laboratory results as well as by the Electronic Health Record systems (EHR-S) and public health information systems they report to.
- Barrier II – The *lack of adoption of EHR-S* [18] in clinical settings (i.e., test order senders and result receivers) preventing electronic communication between providers and LIMS.
- Barrier III – The *use of proprietary, non-standardized information systems* in public health preventing electronic communication between LIMS and public health programs (i.e., receivers of test results on public health threat conditions).
- Barrier IV – The *absence of a sustainable approach and funding* to support the development of laboratory standards and their testing; and of certification and adoption of standards-based IT products in clinical, laboratory and public health settings.
- Barrier V – The *need for informatics-savvy personnel in PHLs* to operate in a new HIT and information communication environment.

**Table 16.2** Examples of laboratory networks in the United States [7]

Network	Description
LRN [13]	The CDC manages the Laboratory Response Network (LRN). This includes the CDC LRN-Biological (LRN-B) and CDC LRN-Chemical (LRN-C). The mission of the LRN is “to maintain an integrated national and international network of laboratories that are fully equipped to respond quickly to acts of chemical and biological terrorism, emerging infectious diseases, and other public health threats and emergencies.” Due to the sensitive nature of CDC’s bioterrorism preparedness activities, details of LRN-B operations are protected against general public access and distribution. These details, designated as “Sensitive But Unclassified,” are maintained at CDC, and require coordination with the LRN LIMS Integration team to obtain. The LRN provides specifications about the message format (HL7 <sup>®</sup> v2.x) and data content, including standardized vocabulary (for example LOINC <sup>®</sup> and SNOMED CT <sup>®</sup> )
ERLN [14]	The Environmental Response Laboratory Network (ERLN) is managed by EPA. The ERLN consists of federal, state, and commercial laboratories that focus on responding quickly to an environmental chemical, biological, or radiological terrorist attack, as well as natural disasters affecting human health and the environment. The ERLN provides an <i>Electronic Data Deliverable</i> (EDD), which can be either a spreadsheet or the recommended XML format and a Data Exchange Template (DET) with data element definitions and groupings. The ERLN also provides a Web-based Electronic Data Review tool that automates the assessment of EDDs by providing web access for upload by the laboratory and review by project personnel
FERN [15]	The Food Emergency Response Network (FERN) is managed by United States Department of Agriculture (USDA)’s Food Safety and Inspection Service and the Food and Drug Administration (FDA). The primary objectives of FERN are to help prevent attacks on the food supply through utilization of targeted food surveillance; prepare for emergencies by strengthening laboratory capabilities to respond to threats, attacks, and emergencies in the food supply; and to assist in recovery from such an incident. FERN uses the Electronic Laboratory Exchange Network (eLEXNET) that allows multiple government agencies engaged in food safety activities to compare, communicate, and coordinate findings of laboratory analyses
NAHLN [16]	The National Animal Health Laboratory Network’s (NAHLN) purpose is to enhance the nation’s early detection of, response to, and recovery from animal health emergencies. Such emergencies might include bioterrorist incidents, newly emerging diseases, and foreign animal disease agents that threaten the nation’s food supply and public health
GISN [17]	The WHO Global Influenza Surveillance Network (GISN) receives result reports and samples of isolates from participating state and municipal PHLs to monitor influenza disease burden, detect potential novel pandemic strains, and obtain suitable virus isolates for vaccine development

## Public Health Laboratories’ Influence on Informatics Standards

The Association of Public Health Laboratories (APHL) is a national non-profit, member-based organization representing governmental laboratories of all levels in all aspects of operation. APHL is especially active as the primary advocate for PHLs



**Table 16.3** Food outbreak investigations and the PHL: the Saga of a Hamburger [7]

Reason for data exchange	Receiver of the data	Data format
Contamination related to food (lettuce, ketchup, mayo, bun), but NOT the meat	Food and Drug Administration (FDA)	HL7 <sup>®</sup> v3 messages or XML based EDD
Contamination related to meat	U.S. Department of Agriculture (USDA)	XML based EDD
A person became ill	Centers for Disease Control and Prevention (CDC)	HL7 <sup>®</sup> v2.x message
	Local and/or state public health department based on patient's residence	HL7 <sup>®</sup> v2.x message
	Local or state public health department based on lab's location, if different from patient's residence	HL7 <sup>®</sup> v2.x message
Offending contaminant is biologic, i.e. a bacteria or virus or organism created toxin	Centers for Disease Control and Prevention (CDC) – biological network	HL7 <sup>®</sup> v2.x message
Offending contaminant is chemical, i.e. a fertilizer, other chemical toxin	Centers for Disease Control and Prevention (CDC) – chemical network	HL7 <sup>®</sup> v2.x message
Contamination is related to environmental reasons, i.e. flooding	Environmental Protection Agency (EPA) – several networks for water, air, waste or response mitigation	XML based EDD
Follow-up testing of food animals	National Animal Health Laboratory Network (NAHLN)	HL7 <sup>®</sup> v2.x message

by promoting workflow improvements and refining laboratory science operations within the laboratory. It provides a forum for member collaboration, education, and workforce development [19]. The fruits of this collaboration are evident in the success of APHL's Informatics Committee in identifying and subsequently improving many of the functions required of LIMS and in the domain of laboratory informatics in general. One such example is the effort to standardize LIMS functionality across vendors. APHL LIMS user groups provide ways to prioritize and consolidate development efforts among customers of a specific vendor, which in turn can be easily compared to overall standardization approach. In partnership with other PH organizations, under the umbrella of the Joint Public Health Informatics Taskforce (JPHIT), APHL also influences national e-health policy.

Internationally, APHL helps to build laboratory capacity in developing countries, including the selection and implementation of information systems.

As part of every implementation, validation testing according to test cases also employs informatics principles. Having identified the need to harmonize the adoption of standards across federal programs and PHL functional areas, APHL is actively involved in national standards harmonization activities for laboratory-related use cases (information exchange standards for laboratory orders and results, reporting in clinical and public health settings, as well as functional standards for

Electronic Health Record System (EHR-S) interactions with PHLs). Due to limited informatics funding at PHLs and the ongoing struggle for these laboratories to support informatics trained specialists, APHL provides hands on informatics technical assistance to PHLs and their partners. These services include project management, national standards implementation and technical architecture support.

PHLs are continually providing expertise to support the standards development process. They were instrumental in creating an implementation guide for newborn screening; working alongside Standards Development Organizations (SDOs) like the Regenstrief Institute to develop the required vocabulary and to make sure the HL7<sup>®</sup> message contained all the data elements needed for proper newborn screening result reporting. APHL provides leadership for the Laboratory and Messaging Community of Practice (LabMCoP), assisting PHLs and partners in harmonizing terminology and related standardized vocabulary to properly describe the specimen submitted for testing.

On a national scale, when the Office of the National Coordinator for Health Information Technology (ONC)'s certification process for commercial Electronic Health Record products was announced, PHL expertise was utilized by providing real-world testing scenarios to ensure that specific result formats are properly represented in this information exchange paradigm. By ensuring a basis in reality, this effort will ensure greater patient safety, and improve public health's response to emerging diseases, terrorism, and natural disasters.

In summary, PHLs are a critical public health resource and service. They detect, identify and monitor infectious disease outbreaks, chemical or biological contamination in people, animals, food and the environment. They provide testing that other labs cannot provide and screen for diseases that haven't even shown symptoms yet (i.e. newborn screening). PHL testing supports food and environmental safety law enforcement and their data contributes vital information to support local, state and federal health policies. PHLs are at the forefront of population based health threats due to bioterrorism, newly emerging disease and natural disasters and they continue to ensure quality service by inspecting and certifying other laboratories in their jurisdiction.

Information systems enable PHLs, or any laboratory for that matter, to more predictably forecast testing demand and assist with human resource utilization during an outbreak or response. Auditing functionality help to monitor the quality of testing and this analysis can be used to improve laboratory workflow over time. Data derived from these systems can assist with both state and federal efforts to forecast disease, help with outbreak management as well as health policy development.

But to ensure the long term operational capacity of our PHLs to provide these services and remain relevant in patient and population care, informatics must be considered a pivotal core business function.

The use of electronic test orders, communicating between disparate systems about order statuses and specimen results as well as contributions to both electronic health records and personal health records submitters all require use and continual development of national data exchange standards. The work in this field has barely

begun, yet the continual evolution of standards will drive greater collaboration and cooperation between all levels of PHLs – local, state and federal as well as their commercial partners.

### Review Questions

1. List at least 6 of the 11 core PHL functions and discuss how each of them can be supported by informatics.
2. How does the workflow in a PHL change when an emergency arises – for example a disease outbreak, a bioterrorism event or a natural disaster?
3. List the different partners of a PHL and their importance for Public Health.
4. Contrast the differences and similarities between a PHL and a commercial clinical lab.

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# Chapter 17

## The National Vital Statistics System

Charles J. Rothwell, Mary Anne Freedman, and James A. Weed

**Abstract** The vital statistics system in the United States has always recognized the importance of collecting information about public health. Today, the national vital statistics system in the US is a major cooperative effort between the states and federal agencies. The Vital Statistics Cooperative Program provides for collection of records of births, deaths, marriages, and other events on a national level. Moreover, increasing adoption of modern technology for record keeping and data exchange has resulted in faster and more accurate vital statistics reports. State data, supplemented by surveys administered by the National Center for Health Statistics within the Centers for Disease Control and Prevention, provide fundamental information for use in the arena of public policy and public health practice.

In this chapter, we will describe the history of vital statistics in the United States, and examine what data is collected and how collection methods have changed over time. In addition, we will examine the complex relationship between the collection of data at the local and state levels and the aggregation and analysis of the data by the National Center for Health Statistics. This will set the stage for a discussion of the components and uses of the present National Vital Statistics System, including an assessment of the challenges and solutions that the twenty first century presents.

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**Keywords** Vital statistics • National Vital Statistics System • Model State Vital Statistics Act • International Classification of Disease • Vital Statistics Cooperative Program • National Center for Health Statistics • National Association for Public Health Statistics and Information Systems • US Standard Certificates • US Standard Reports • Interstate record exchange • Electronic birth registration • Electronic death registration • Mortality surveillance • State and Territorial Exchange of Vital Events • Electronic Verification of Vital Events

### Learning Objectives

1. Describe the origins of the vital statistics system in the United States and explain the areas of responsibility of the states and federal agencies in maintaining the system.
2. Explain the operation of the national vital statistics system with respect to the collection of data regarding births and deaths.
3. Define the nature and the purpose of the Model State Vital Statistics Act.
4. Describe how the International Classification of Diseases can be a tool for uniform standards in listing causes of morbidity and death.
5. Analyze contemporary challenges to timely collection of vital statistics data and how recent innovations enhance the vital statistics system.
6. Summarize why a comprehensive vital statistics system is important to the practice of public health.

## Overview

The vital statistics system in the United States has always recognized the importance of collecting information about public health. Today, the national vital statistics system in the US is a major cooperative effort between the states and federal agencies. The Vital Statistics Cooperative Program provides for collection of records of births, deaths, marriages, and other events on a national level. Moreover, increasing adoption of modern technology for record keeping and data exchange has resulted in faster and more accurate vital statistics reports. State data, supplemented by surveys administered by the National Center for Health Statistics within the Centers for Disease Control and Prevention, provide fundamental information for use in the arena of public policy and public health practice.

In this chapter, we will describe the history of vital statistics in the United States, and examine what data is collected and how collection methods have changed over time. In addition, we will examine the complex relationship between the collection of data at the local and state levels and the aggregation and analysis of the data by the National Center for Health Statistics. This will set the stage for a discussion of

the components and uses of the present National Vital Statistics System, including an assessment of the challenges and solutions that the twenty first century presents.

## Introduction

The inception, development, and maintenance of a system to produce national vital statistics based on the local registration of vital events have been a major accomplishment of the United States during the twentieth century. In this country, legal authority for the registration of births, deaths, marriages, divorces, fetal deaths, and induced terminations of pregnancy (abortions) resides individually with the states (as well as with cities in the case of New York City and Washington, DC, and with territories in the case of Puerto Rico, the Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands). In effect, the states are the full legal proprietors of the records and the information contained therein and are responsible for maintaining registries according to state law and for issuing copies of birth, marriage, divorce, and death certificates.

As a result of this state authority, the collection of registration-based vital statistics at the national level has come to depend on a cooperative relationship between the states and the federal government. This relationship has evolved over many decades, with its initial beginnings in the early development of the public health movement and the creation of the American federal system.

## Milestones in National Vital Statistics [1]

The registration of births, marriages, and deaths has a long history in the United States, beginning with a registration law enacted by the Grand Assembly of Virginia in 1632 and a modification of this law enacted by the General Court of the Massachusetts Bay Colony in 1639. In enacting this legislation, the early settlers, who were predominantly English, were following English customs in the new country. They were accustomed to the registration of christenings, marriages, and burials. In England, this kind of registration dated back to 1538, when the clergy in all parishes were first required to keep a weekly record of such events. In those early days, there was little or no statistical use made of such records, and certainly there was no thought of using them for health purposes. In the beginning, these records, along with wills and property inventories, were regarded primarily as statements of fact essential to the protection of individual rights, especially those relating to the ownership and distribution of property.

Although the Massachusetts law was based on English precedent, it differed in two important respects: (1) responsibility for registration of vital events was placed on government officers rather than on the clergy, and (2) the law called for the

recording of vital events—births, deaths, and marriages—rather than church-related ceremonies. Connecticut and Plymouth, and eventually other colonies, followed a similar pattern.

Thus, at the basis of the vital registration system was the principle that the records are legal documents that help assure the rights of individuals. This principle was not sufficient, however, to create a fully effective registration system in the highly migratory American population during the seventeenth and eighteenth centuries, despite efforts to strengthen the registration laws. The impetus for a truly effective system came from the realization by some very astute statisticians and physicians, both here and abroad, that records of births and deaths, particularly records of deaths by cause, were needed for the control of epidemics and the conservation of human life through sanitary reform.

During the seventeenth century, parish lists of interments, usually including cause of death and age of deceased, were published in London as Bills of Mortality during epidemics of plague. The origin of vital statistics in the modern sense can be traced to an analysis of the English Bills of Mortality published by John Graunt in 1662. Similarly, death records of some sort were apparently kept by American settlements from the earliest days. Disease ranked with starvation as a threat to the existence of many of the colonies; clergy compiled various lists of parish dead, and cemetery sextons made burial returns to town officers. For example, the clergyman Cotton Mather noted in 1721, during a severe smallpox epidemic in Boston, that more than one in six of the natural cases died, but only one in 60 of the inoculated cases did so [1].

In the eighteenth and nineteenth centuries, the Industrial Revolution was associated not only with rapid urbanization and overcrowding of cities, but also with the deterioration of social and living conditions for large sectors of the population in Europe. Slums, crime, poverty, filth, polluted water, and epidemics of old and new diseases severely challenged the existing social order. As Lumpkin notes in Chap. 2, in England, as on the European and American continents, public health reformers became acutely conscious of the need for general sanitary reform as a means of controlling epidemics of disease—particularly cholera, but also typhoid, typhus, yellow fever, and smallpox. These early used the crude death statistics of the time to arouse public awareness of the need for improved sanitation, and in the process they pressed for more precise statistics through effective registration practices and laws. The work of Edwin Chadwick (1800–1890) and William Farr (1807–1883) in England and of Lemuel Shattuck (1793–1859) in Massachusetts was instrumental in the development of public health organization and practice, including registration and vital statistics, during the nineteenth century. Thus, the history of public health is essentially the history of vital registration and statistics.

When the US Constitution was framed in the aftermath of the American Revolution, provision was made for a decennial census, but not for a national vital registration system. To obtain national data on births, marriages, and deaths, the decennial censuses in the latter half of the nineteenth century—1850 to 1900—included questions about vital events, such as: “Born within the year”; “Married within the year”; “Disease, if died within the year.” These census items were introduced with the help of Shattuck, against his better judgment. Indeed, the method



came to be recognized as inefficient and the results as deficient, but the census questions were not abandoned until 1910, when the developing registration area was large enough to provide better national statistics.

The US Bureau of the Census was made a permanent agency of the federal government in 1902, and the enabling legislation authorized the Director of the Bureau to obtain annually copies of records filed in the vital statistics offices of those states and cities having adequate death registration systems and to publish data from these records. A few years earlier, the Bureau had issued a recommended death reporting form (the first "US Standard Certificate of Death") and requested each independent registration area to adopt it as of January 1, 1900. Those areas that adopted the form and whose death registration was 90 % complete were to be included in a national death-registration area that had been established in 1880. In 1915, the national birth-registration area was established, and, by 1933, all states were registering live births and deaths with acceptable event coverage and providing the required data to the Bureau for the production of national birth and death statistics.

In 1946, responsibility for collecting and publishing vital statistics at the federal level was transferred from the Census Bureau to the US Public Health Service, first in the National Office of Vital Statistics and in 1960 to the National Center for Health Statistics (NCHS). In 1987, NCHS became part of the Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services.

## **Operation of the National Vital Statistics System**

Vital records and reports originate with private citizens—members of the families affected by the events, their physicians, funeral directors, and others. The responsibilities of these individuals are defined in states' laws. Birth registration is the direct responsibility of the hospital of birth or the attendant at the birth (generally a physician or midwife.) In the absence of an attendant, the parents of the child are responsible for registering the birth. Although procedures vary from hospital to hospital, usually the personal information is obtained from the mother; medical information may be obtained from the chart or from a worksheet filled out by the birth attendant.

Death registration is the direct responsibility of the funeral director or person acting as such. The funeral director obtains the data required, other than the cause of death, from the decedent's family or other informant. The attending physician provides the cause and manner of death. If no physician was in attendance or if the death was due to other than natural causes, the medical examiner or coroner will investigate the death and provide the cause and manner.

Reporting requirements vary from state to state. In general, the completed birth certificate must be filed with the state or local registrar within 10 days of the birth; death certificates must be filed within 3–5 days of the death.

Because the federal government has no constitutional authority to enact national vital statistics legislation, it depends upon the states to enact laws and regulations

that provide for registration and data collection comparable from state to state. To achieve the needed uniformity for combining data from all states into national statistics, the federal agency responsible for national vital statistics recommends standards for use by state registration offices. The two primary standards are the Model State Vital Statistics Act and the US Standard Certificates and Reports.

The states are collectively represented in their dealings with the federal government by the National Association for Public Health Statistics and Information Systems (NAPHSIS). NAPHSIS is a professional organization whose members include primarily, but not exclusively, the vital statistics executives and other employees of state registration offices. In addition to providing the states with a common point of contact with the federal government and numerous other professional organizations, NAPHSIS facilitates interstate exchange of ideas, methods, and technology for the registration of vital events and dissemination of vital and other public health statistics. NAPHSIS's progenitors date back to 1933, when it was organized as the American Association of Registration Executives [2].

## **US Standard Certificates and Reports**

The standard certificates are the principal means of promoting uniformity in the data collected by the states. They are intended both to meet the legal needs of the system and to provide the data needed to be responsive to emerging public health issues. The standards are reviewed and revised approximately every 10 years through a process that includes broad input from data providers and users, including recognized experts in epidemiology and public health.

There have been 12 issues of the US Standard Certificates of Live Birth; 11 of the US Standard Certificate of Death (in 1915, only the birth certificate was revised); seven of the US Standard Report of Fetal Death (formerly stillbirth); four of the US Standard Certificate of Marriage and the US Standard Certificate of Divorce, Dissolution of Marriage, or Annulment; and two of the US Standard Report of Induced Termination of Pregnancy [3].

The 1989 US Standard Certificate of Marriage and Certificate of Divorce, Dissolution of Marriage, or Annulment and the 1997 US Standard Report of Induced Termination of Pregnancy are the current versions. The 2003 US Standard Certificates of Live Birth and Death, and Report of Fetal Death represent a revision of the previous edition in order to focus upon data collection procedures in an electronic era [4].

## **Model State Vital Statistics Act and Regulations**

A model act (or model bill) is proposed legislation drafted in a form that can be enacted into law by a state legislature. A model act is not a law itself. The revision process for the Model State Vital Statistics Act and Regulations mirrors that of the

**Table 17.1** Some key provisions in the 1992 Model State Vital Statistics Act

Act category	Provisions
Authorization	Provides for the establishment of an Office of Vital Statistics and a statewide system of vital statistics within a designated state agency and a naming of a state registrar with specified duties.
Birth registration	Provides for the Office of Vital Statistics to register and certify each live birth in a specified manner and compels physicians and others to comply with the act. Other provisions specify the manner in which infants of unknown parentage, adopted children, and establishment of facts of a birth are to be handled.
Death registration	Provides for filing of a certificate of death for each death occurring in the state, and places duties on funeral directors and physicians to comply with the act. Also requires a report on each fetal death if the fetus weighs 350 g or more, or if weight is unknown and the fetus dies after 20 completed weeks of gestation or more. Establishes requirements for final disposition of a body.
Marriage registration	Requires a record of each marriage performed in the state to be filed with the vital statistics office in a specified manner.
Divorce, marriage dissolution, annulment	Establishes provisions for recording these events.
Amendment and disclosure of vital records	Establishes procedures by which vital records may be amended and disclosed.
Enforcement	Imposes duties on institutional heads, funeral directors, physicians, and others to comply with the act, and imposes penalties for failure to comply.
Technology	The model legislation explicitly permits vital statistics offices to incorporate technological advances in records and information management.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, Model State Vital Statistics Act and Regulations, 1992 Revision. <http://www.cdc.gov/nchs/data/misc/mvsact92b.pdf>

standard certificates, although the model law is revised less frequently. The Bureau of the Census submitted the first model bill to the states in 1907, covering both birth and death registration. There have been several revisions over the century. The 1942 revision was the first to provide a statutory definition of vital statistics, defining them as “the registration, preparation, transcription, collection, compilation, and preservation of data pertaining to the dynamics of the population, in particular data pertaining to births, deaths, marital status, and the data and facts incidental thereto” [1].

The most recent full revision of the Model Act that has been adopted by HHS occurred in 1992 and is the current Model Act [5]. Key provisions of the 1992 Model Act are shown in Table 17.1.

The 2003 standard certificate revision panel recommended that the Model Act be modified to accommodate the use of electronic signatures, standardized work sheets for data collection, and electronic transmission of source documents from the provider to the state registrar [6]. In 2009, the CDC convened a working group to

evaluate and revise the 1992 Model State Vital Statistics Act and Regulations. The major goal of this revision, as with the 2003 revision of the Standard Certificates, was to provide “guidance for vital event registration, issuance, security and fraud prevention, and protection of confidential information in an electronic environment” [7]. References to paper records were changed to allow for either paper or electronic formats, such as substituting “certified copy” with “certification.” The proposed revision of the Model Law was endorsed by NAPHSIS in June 2011 and, as of publication, is still in DHHS review [8].

## **The Vital Statistics Cooperative Program**

In the early part of the twentieth century, the Bureau of the Census and subsequent federal agencies responsible for the vital statistics system received unit record data from the states in hard copy or microfilm. States were reimbursed for copying efforts at four cents per record. Data were transcribed (later key entered) at both the national and state levels as both states and federal government produced statistics. In 1971, NCHS began an experiment with the state of Florida to receive data on computer tape. This effort expanded rapidly and evolved into the Vital Statistics Cooperative Program (VSCP). Under the VSCP, NCHS partially supports state costs of producing vital statistics through a contract with each state. NCHS works with states to implement standards for data elements, editing and coding specifications, quality control procedures, and data transmission schedules.

### ***Federal Activities in Training State and Local Personnel***

The NCHS training and technical assistance program for state and local vital statistics staff incorporates a number of activities aimed at developing expertise in all aspects of vital registration and vital statistics. These include a complement of courses for registration staff, statisticians, and coding specialists; telephone and e-mail hotlines; periodic meetings; and on-site assistance. The on-site assistance program is designed to send a team of federal and state vital statistics specialists into states requesting assistance. In addition to focusing on the areas of most concern to the requesting state, the teams review the entire operation of the office and offer suggestions for improvements.

### ***The Interstate Record Exchange Program***

Prior to 1937, the federal government published birth and death statistics by place of occurrence. Starting in 1937, subnational statistics were published primarily by

place of residence. Subsequently, states also began publishing their statistics by place of residence. Because residents of one state may be born or may die in a different state, a mechanism was needed to enable states to obtain records of vital events that occurred to their residents in other states. Thus, the Interstate Record Exchange Program was initiated. It is an agreement among the states to exchange records of out-of-state occurrences with the state of residence. The exchange agreements are negotiated and administered by NAPHSIS [2]. NCHS supports the arrangement by periodically providing states with lists of out-of-state occurrences.

### ***Vital Statistics Data Files***

One of the strengths of the vital statistics system is that it is a census rather than a survey. Thus, it includes a record of each vital event that occurs in the United States. Because all events are included, vital statistics can be used to examine data for small geographic areas, detailed demographic subgroups, specific causes of death, and rare events. The level of detail contained in each of the major vital statistics data files is described below.

The *nativity* file contains demographic and health information recorded on certificates of all live births that occur in the United States. Demographic and health characteristics of the mother include age, race, Hispanic origin, education, birthplace, residence, marital status, medical risk factors of pregnancy, month that pregnancy prenatal care began, number of prenatal visits, tobacco use, alcohol use, weight gain during pregnancy, and obstetric procedures. Characteristics of the birth include birth weight, length of gestation, birth order, sex, plurality, method of delivery, Apgar score, complications of labor and delivery, abnormal conditions of the newborn, congenital anomalies, and attendant at delivery.

The *mortality* file includes demographic and medical information recorded on death certificates of all deaths that occur in the United States. Variables include residence, place of occurrence, month of death, age, race, Hispanic origin, birthplace, sex, educational attainment, occupation and industry of decedent (selected states), injury at work, marital status, type of place of death, and underlying and multiple causes of death.

The *fetal death* file includes demographic and health information recorded on reports of all fetal deaths of 20 weeks or more gestation that occur in the United States. The demographic and health characteristics of the mother and fetal death are similar to those for natality, but also include the fetal or maternal conditions causing death.

The *linked birth/infant death* data system contains records of all live births and infant deaths that occur in the United States. Three separate files are included in the system. One is a numerator file with linked birth-infant death records for each of the approximately 25,000 infants who die in the United States each year. The denominator file contains birth certificate information for each of the approximately four million live births. An additional file contains the relatively few infant death records

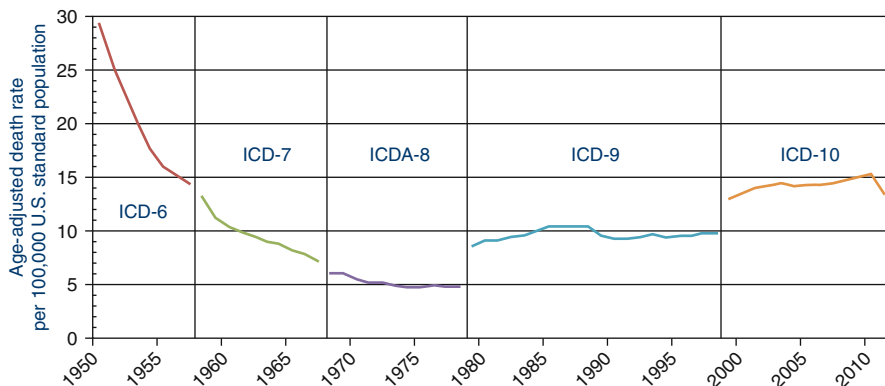
that were not linked to birth certificates. The match rate is about 97–98%. Data are available for each of the birth cohorts from 1983 through 1991. Beginning with data year 1995, the data are organized by calendar year rather than by birth cohort to expedite data release.

## *International Classification of Diseases*

Causes of death are classified for purposes of statistical tabulation according to the International Classification of Diseases (ICD) published by the World Health Organization (WHO) [9]. The classification originated as the “Bertillon Classification of Causes of Death” prepared in the late 1800s by Dr. Jacques Bertillon, chairman of the committee charged with development of a classification of causes of death for international use. In 1898, the American Public Health Association recommended that the classification be adopted by the United States and that it be revised every 10 years to keep abreast of advances in medicine [1]. The ICD is maintained collaboratively by WHO and 10 international centers, one of which is the WHO Collaborating Center for the Classification of Diseases in North America. To date, there have been 11 editions of the ICD, the most recent being the 10th revision (ICD-10), implemented in the United States in 1999. The 11th revision (ICD-11) is projected for completion in 2015 [10].

Traditionally, a single cause of death has been selected for statistical tabulations. When the certifying physician indicates that more than one cause contributed to death, a procedure is required for selecting the cause to be tabulated. The ICD provides the basic ground rules used to code and classify causes of death, to identify the underlying cause of death, and to compensate for certifier errors in the cause of death statement. It also includes definitions of terms such as “underlying cause of death,” “live birth,” and “maternal death,” as well as tabulation lists that define the cause of death groupings to be used for international comparisons. The ICD also delineates the format of the medical certification of death and specific regulations regarding the compilation and publication of statistics on diseases and causes of death.

The introduction of a new ICD revision can create major discontinuities in statistical trend data [11, 12]. Discontinuities are measured through the use of “comparability ratios.” These are obtained by coding a large sample of death records by both the previous and the current revisions and by calculating the ratio of deaths from a given cause as coded by the later revision to deaths from the same cause as classified by the earlier revision. As an example of the use of comparability ratios, Fig. 17.1 shows the age-adjusted death rates for nephritis, nephrosis, and nephrotic syndrome in the United States during the period 1951–2011 which encompasses four changes in ICD versions. A comparability ratio of 1.74 for nephritis, nephrosis, and nephrotic syndrome between ICD-8 and ICD-9 indicated that 74 % more deaths were classified to this cause in 1979 compared with 1978 solely because of the introduction of ICD-9.



**Fig. 17.1** Age-adjusted death rates for nephritis, nephrosis, and nephrotic syndrome across ICD revisions: United States, 1951–2011 (Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System)

## Challenges Confronting the Vital Statistics System at the beginning of the Twenty First Century

For more than a hundred years, the United States has operated a decentralized vital statistics system as an essential component of public health. Statistics based on births and deaths registered in the United States continue to be a primary source of data used to track health status, to plan, implement, and evaluate health and social services, and to set health policy. The national vital statistics system provides nearly complete, continuous, and comparable federal, state, and local data. That being said, the system going into the twenty first century was based on outmoded vital registration practices and structures, raising concerns about data quality, timeliness, security and the lack of real-time data linkage capabilities with electronic medical records. Timeliness of vital statistics reporting continued to deteriorate to the point that reports were more of historical interest of where we were and not where we are as a nation. In order to make vital statistics vital again, more complete automation at the level of primary data collection was needed as well as changes in the relationships among the providers of source records, the state registration offices, and NCHS.

For example, for more than 20 years, states have been using electronic birth certificate systems and while this has been a significant step forward, some states continue to operate dual paper and electronic systems. To compound these problems, the current electronic registration systems at the state level have been difficult to modify, causing many states to delay implementation of the 2003 revision to the US standard certificate of birth, which would provide a wealth of new information on mothers and infants. Collection of death information in most states continues to be primarily a paper-based process for cause of death reporting, unchanged at the local and state levels for the last half century. Funeral directors are responsible for collecting demographic information

on the decedent from the next of kin and that portion of the death registration system is automated in most states. Yet most attending physicians, medical examiners and coroners provide and certify medical information on cause of death on paper. The lack of complete automation of vital statistics at the source precludes timely follow-back to improve data quality and does not take advantage of the growing utilization of hospital and physician-based electronic medical records systems.

Complicating matters even further, states have not used efficient electronic systems to transfer data among each other and with Federal partners. States also have not provided appropriate security for their systems and procedures that would make it almost impossible to the use of vital records for fraudulent purposes, including identity theft much more difficult to accomplish. At the Federal end, NCHS had not changed its internal systems to take advantage of faster state reporting from states that had automated at the source and had not changed its philosophy of only annual reporting after the records for the last events were received and processed rather than reporting incomplete but highly useful data for surveillance and health planning purposes.

### ***Strategies Undertaken to Meet the Challenges of Timeliness, Quality and Security of the Vital Statistics System***

To address these problems, NAPHSIS, NCHS, the Social Security Administration (SSA), and other Federal agencies developed partnerships to improve the responsiveness of state vital registration and statistics systems. The objective has been to improve the timeliness, quality, security and sustainability of these systems by adopting national, consensus-based standards and guidelines. The resulting reengineered state systems would use the 2003 version of the US standard certificates of live birth, death, and fetal death. Reengineered systems would also include efficient methods for capturing data obtained from the implementation of standardized data-collection instruments, coding specifications, query guidelines, and definitions, as well as Health Level-7 (HL7<sup>®</sup>)-based standardized messaging for future sharing of data with electronic medical records. The development of these functional requirements for reengineering birth and death registration systems has served as the foundation for the design, development, and implementation of reengineered, internet-based vital records and statistics systems for the states.

## **Achievements in Meeting Twenty First Century Challenges**

### ***Electronic Death Registration Systems (EDRs)***

Real time reporting of death information is critical for timely public health planning, detecting and defining pandemic and other calamitous events and showing shifts in



causes of death by age, race and sex. Yet, timely death reporting has been a major challenge. Using grant funding from SSA, with assistance from NAPHSIS and NCHS, states began implementing electronic death registration systems (EDRs) in 2002 to improve the timeliness of fact-of-death reporting. As a result of the SSA financial stimulus, 31 of the 57 registration jurisdictions implemented fact-of-death EDRs. Of the states operating an EDR for 1 year or more, 99 % of deaths are submitted to SSA through their EDR systems and over 70 % of these states are submitting fact-of-death reports within 6 days with many even more current. Also, at least one state is using its EDR system as input for its reporting responsibilities for the CDC 122 Cities Mortality Surveillance System. As of January 2013, 36 states have EDR reporting to some extent.

Despite these successes, many of the jurisdictions with operational EDRs have not achieved statewide coverage and/or full participation of physicians and medical examiners, preventing the use of EDRs as a real-time surveillance system for public health. NCHS along with NAPHSIS and the states have initiated a “good to great” effort to improve vital statistics timeliness and quality. Out of this effort, NCHS has entered into a 5-year contract with states to obtain vital records that require states to improve timeliness throughout the contract period. The contract also has a special projects section that can be used to target funds to the specific needs of states including the development or improvement in coverage of EDRs. As a result of these new contracts, a cooperative agreement with NAPHSIS targeted at improving data timeliness, and a growing number of states adopting automated systems as well as improved processing systems internal to NCHS, NCHS has seen significant improvement in reporting timeliness. In 2012, for the first time, NCHS published preliminary reports (for over 90 % births and deaths) within 9 months of the close-out of the 2011 data year and will soon be publishing preliminary reports 6 months after the close of the data year. With full EDRs coverage there is the potential for reporting mortality statistics 1 month after the end of the data year.

For mortality surveillance, NCHS has entered into a pilot activity with CDC partners, NAPHSIS and the states to quickly report vaccine-preventable deaths to assure accurate cause of death reporting as well as for mortality surveillance. If successful, this activity could lead to a nationwide mortality surveillance system for all causes of death of immediate public health importance. To help with data quality, NYC, NCHS and NAPHSIS have developed a generic web-based tutorial for physicians using EDRs to help improve responsiveness and data quality and this system is now available to all states.

### ***Electronic Birth Registration Systems (EBRs) and the 2003 Revision of the US Standard Birth Certificate***

As of April 2012, 46 jurisdictions have an electronic birth registration system (EBRs) in production based on the 2003 Revision of the Model US Standard Birth Certificate. These systems were developed and financially supported by the states. States with EBRs that are significantly different from the 2003 revision are in the

process of making changes to be in compliance and NCHS has provided funding for system development in some of the remaining jurisdictions without EBRs. The “good to great” goal is to have all jurisdictions using EBRs providing data in compliance with the 2003 revision by 2014. For states that revised quickly, a variety of data quality studies on the 2003 Revision have been conducted. In Florida, Kansas, Washington and Vermont, birth clerk interviews were conducted. In Kansas and South Carolina birth certificate data were compared with information from hospital medical records. Although the findings from these studies have been useful in comparing variation in data quality by hospital, more data quality studies are needed to implement effective strategies for improved data reporting and future quality studies of the new data items are planned.

### ***Electronic Transfer and Access to Vital Statistics Data to Improve Timeliness and Security***

The slow, or in some instances non-existent, inter-state data sharing of vital events has caused states to delay their own reporting of vital statistics in their state as they wait for the receipt of out-of-state events. This has also precluded states from linking out-of state death records with their birth certificates to protect against the inappropriate issuance of copies of birth certificates for those who have died. The reason for this delay in vital event data sharing between states is that the process has been paper based and in some instances records are not shared at all due to lack of staff time to manually select and mail birth certificates for residents of other states back to the state of residence or death certificates to the state of birth of the decedent. To resolve this situation, the State and Territorial Exchange of Vital Events (STEVE) System was developed by NAPHSIS for the electronic exchange of vital event data between jurisdictions. By the end of 2012, STEVE had been installed in over 30 states and in 2014, STEVE will be used by all states to provide data electronically to NCHS.

Many agencies rely on birth certificates for proof of age, proof of citizenship, identification for employment purposes, to issue benefits or other documents (e.g. driver’s licenses, Social Security cards, and passports) and to assist in determining eligibility for public programs or benefits. To expedite this process, NAPHSIS has developed and implemented an electronic system called Electronic Verification of Vital Events (EVVE) that allows immediate confirmation of the information on a birth certificate presented by an applicant to a government office anywhere in the nation irrespective of the place or date of issuance. Authorized Federal and State agency users via a single interface can generate an electronic query to any participating vital records jurisdiction throughout the country to verify the contents of a paper birth certificate or to request an electronic certification (in lieu of the paper birth certificate). An electronic response from the participating vital records jurisdiction either verifies or denies the match with official state or jurisdiction records. Queries can be generated and matched against over 250 million

birth records located in databases in the registration jurisdictions. The EVVE system is also capable of supporting the electronic verification and/or electronic certification of death records for agencies wishing to delete recent decedents from their eligibility files.

### ***Re-Engineering Internal NCHS Vital Statistics Systems***

At the turn of the twenty first century, the IT systems supporting the NCHS vital statistics activities and the jurisdictions were a collection of many separate main-frame and PC systems utilizing different technologies. The systems initiated quality control edits for jurisdictions primarily at the end of the year. NCHS has re-engineered these systems so that real time monitoring of data quality can be done including requesting additional information from states when needed soon after the records are received [13]. Examples of such edits include unusual causes of death by sex or age, unusual birth outcomes, unusual medical history of the mother and survivorship of extremely low weight births. This makes information available for real time public health surveillance purposes and timelier and better quality data for year-to-date reporting. The first phase of this re-engineered system is now operational. Automated cause of death coding systems were also re-engineered to be web-based and all medical coding was centralized in NCHS to speed the availability of cause of death information at the state and national level for quality control and surveillance purposes.

### ***Secure Vital Registration Systems and Practices***

Birth certificates are proof that a birth occurred and was officially recorded. However, the use of birth certificates has evolved to where they are recognized as proof of age, place of birth, and identity, and used extensively for employment purposes and to obtain benefits and other documents such as driver's licenses, Social Security cards, US passports, and State identification documents. Birth certificates have become the "path of least resistance" for fraud as the security features in other documents, such as driver's licenses, SSA cards, and immigration documents, have increased in sophistication. As such, birth certificates continue to be used as breeder documents from which other supporting documents can be secured to alter identities and fraudulently obtain services and benefits. Fraud usually begins with a purchased, stolen, counterfeit, or altered birth certificate. The birth certificate is then used as the basis of age, citizenship, and identity to obtain other documents and seek benefits.

Many birth certificate security problems existed in the beginning of the twenty first century. Some states allowed open access to birth certificates at the State and/or local level. In these States, if a person can identify a birth certificate, he or she then

can purchase a copy of it. There are over 2,000 locations in which birth certificates are issued and issuance methods include requests made by mail, telephone, and the Internet. Proof of identity is not always required to purchase a certified copy of a birth certificate.

The Internet poses a significant security risk to the integrity of birth certificates for several reasons. Not only are birth certificates available through the Internet, but in some States, birth certificate information necessary to request certified copies of birth certificates has been found using the Internet. For example, some vital records offices had posted indexes containing the names and birth dates of people for whom they have registered births. The problem of identifying fraudulent birth certificates is compounded by the fact that there are more than 14,000 different versions of certified copies of birth certificates in circulation and most birth certificate fraud involves genuine certified copies of birth certificates that are held by imposters, which is very difficult to detect.

After 9/11, the States and NAPHSIS moved to improve security for vital registration. NAPHSIS and the States have drafted an update to the Vital Registration Model Law, which now provides appropriate legislative language for states to implement secure electronic registration and issuance systems and procedures. This update was also used to develop a security manual for states to use to implement more secure systems and procedures and that manual has been used to improve security procedures of many states. The quick matching of birth and death records is an excellent method of insuring that birth certificates are not inappropriately issued. STEVE and EVVE were developed to quickly share data with partners and EDRs and EBRs have been implemented in many states to allow for quick sharing of records with other jurisdictions.

### ***Electronic Health Records (EHR) and Vital Statistics***

The collection of medical information on EBRs and EDRs is drawn from a variety of sources. In the future, electronic health records could provide standardized clinical information needed for the EBRs and EDRs. For example, hospital medical records serve as the source for more than half of all data items collected on the 2003 US Standard Certificate of Live Birth. Standardization of data needed in vital records within the electronic health record would reduce the redundancy of data entry and improve the timeliness and accuracy of vital statistics. A long-term vision for the use of EHR systems should include functionalities to facilitate the collection of vital records data at the point of primary care. To test this vision, the vital statistics community is currently pilot testing the electronic exchange of birth and death data using the available HL7<sup>®</sup> and Integrating the Healthcare Enterprise (IHE) standards, which should be ready for nationwide adoption by 2016. What remains to be seen will be whether the data standards used for electronic health records will contain the information necessary for valid comparisons of vital statistics at the local state and national level.

## Challenges Remain

Although many organizations have begun working together to address issues of data quality, timeliness and security and many notable achievements have been made, significant problems remain [14]. Efforts to rejuvenate the nation's vital statistics system will need to expand dramatically to provide public health with a timely, high-quality, secure and flexible system to monitor vital health outcomes at the local, state, and national levels. The most daunting challenges still to be overcome are: the development, implementation and maintenance of state electronic registration systems; expanding the use of electronic death registration systems by physicians; implementing secure systems and procedures; and real time electronic data sharing with electronic health records.

## Vital Statistics and the Practice of Public Health

Over several centuries of development, the nation's vital registration systems have evolved into the primary source of the most fundamental public health information. From the early beginnings of the movement to improve sanitation and to control disease, the data on deaths, especially causes of death, have been critical for identifying, tracking, and eventually understanding and controlling epidemics of communicable diseases. Today, mortality data are used more generally to study trends and differentials in all kinds of causes of death, both chronic and communicable, as well as those due to homicide, suicide, and unintentional injuries. In addition, infant mortality has traditionally served as a key indicator of general health conditions in a given population. The availability of mortality statistics for small geographic units, such as counties, has contributed uniquely to the value of these data for epidemiologic investigations and surveillance.

Statistics obtained from birth certificates, fetal death reports, and the linked birth/infant death file provides a wealth of information about infant health. Of current interest to the public health community are statistics on teenage and unmarried childbearing, birth weight, length of gestation, smoking during pregnancy, access to prenatal care, complications of labor and/or delivery, abnormal conditions of the newborn, and obstetric procedures. Healthcare providers and epidemiologists specializing in infant and child health monitor trends in these and other natality statistics.

Vital statistics also provide fundamental information in the arena of public policy. For example, out-of-wedlock childbearing is a topic of continuing high interest among national welfare policymakers. Similarly, national health policy is very much concerned with the problem of health disparities among various race and ethnic groups in the US population. In these and many other important policy issues, the vital statistics system constitutes a frontline source of information that leads to action programs, yields indicators of effectiveness, and generally guides the practice of public health. Achievements to this point indicate that a re-vitalized vital statistics system for the twenty first century is feasible, practical and necessary.

### Review Questions

1. Explain why development and maintenance of a vital records system is a state responsibility, rather than a mandated federal responsibility.
2. Explain the role of the National Association for Public Health Statistics and Information Systems (NAPHSIS) in the relationship between state vital records systems and the federal government.
3. Under the existing vital records system, who is typically responsible for providing information for the registration of (1) deaths and (2) births and what challenges does this present to the collection of real-time birth and death data?
4. What is the purpose of US standard certificates? How are they periodically revised?
5. Define a model act and explain the origin and purpose of the Model State Vital Statistics Act? List the provisions of the 1992 Model State Vital Statistics Act with regard to (1) authorization for a state Office of Vital Statistics, (2) provisions for birth registration, (3) provisions for death registration, and (4) provisions for marriage registration. Why is the Model Act not adopted in its entirety by all states?
6. Explain the purpose and the nature of the Vital Statistics Cooperative Program. What is the role of the National Center for Health Statistics (NCHS) in this program?
7. In what sense is the vital statistics system a census, rather than a survey? Explain the nature of (a) a natality file, (b) a mortality file, (c) a fetal death file, and (d) a linked birth/infant data system.
8. Why is the World Health Organization's International Classification of Diseases an important resource for use in the national vital records system?
9. Why is the development of electronic birth and death registration a critical element in a redesigned national vital statistics system?
10. Explain the importance of a national vital registration system to the practice of public health. What public health-related uses are being made of vital statistics?

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# Chapter 18

## Risk Factor Information Systems

Alan Tomines

**Abstract** Risk factor information systems monitor the prevalence of specific antecedents of premature disease and death. These systems focus on tracking behaviors, conditions, and exposures to increase awareness of the burden of disease in a community, support prioritization of public health resources, and allow measurement of the effectiveness of prevention programs. There are a variety of important risk factor information systems in use at the present time, both in the United States and internationally: some systems are designed to produce national or regional estimates, while others have a more local, community focus; some systems cover a broad range of health risk factors across all demographic groups, while others focus on a small number of disease-specific exposures in special populations; some systems require only subjective responses, while others collect additional measurements of the body and biological assays. There are numerous efforts underway that use information technology to make risk factor information more accessible and useful through integration and innovative presentation, and the future uses of new information technologies to augment risk factor surveillance are explored.

**Keywords** Risk factors • Risk behaviors • Surveillance systems • Data collection • Data dissemination • Disease prevalence • Chronic disease • Risk transition • Causal chain

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### Learning Objectives

1. Define “risk factor information system” and explain how such systems complement primary scientific research and vital statistics systems.
2. Describe specific data collection methods employed by various risk factor information systems.
3. Describe similarities and differences among national-level risk factor surveillance systems, and explain the rationale for specific risk factor information systems focused on special populations.
4. Identify repositories that enhance the dissemination of risk factor data through consolidation or integration, and identify technologies that may change risk factor data collection.

## Overview

Risk factor information systems monitor the prevalence of specific antecedents of premature disease and death. These systems focus on tracking behaviors, conditions, and exposures to increase awareness of the burden of disease in a community, support prioritization of public health resources, and allow measurement of the effectiveness of prevention programs. There are a variety of important risk factor information systems in use at the present time, both in the United States and internationally: some systems are designed to produce national or regional estimates, while others have a more local, community focus; some systems cover a broad range of health risk factors across all demographic groups, while others focus on a small number of disease-specific exposures in special populations; some systems require only subjective responses, while others collect additional measurements of the body and biological assays. There are numerous efforts underway that use information technology to make risk factor information more accessible and useful through integration and innovative presentation, and the future uses of new information technologies to augment risk factor surveillance are explored.

## Introduction

For centuries, scientists have used vital statistics systems as primary data sources to study trends in morbidity and mortality. In the early 1500s, as a means of warning the public about local plagues, parish clerks in London began weekly postings of deaths and their causes, which came to be known as the *Bills of Mortality* [1]. In the 1600s, John Graunt (a haberdasher by trade) became fascinated with demographic patterns in these “lists of the dead,” and published his *Natural and Political Observations Made upon the Bills of Mortality*. His work was notable for a number of innovations, including the creation of “life tables” (charts of survivorship based

on age) and frequency summaries by cause of death—spurring greater interest in the systematic capture and use of these data [2].

The practice of public health continued to evolve, driven in part by the effective use of vital statistics and other mortality data to characterize and prevent premature death [3]. Over time, public health practitioners developed important health indicators from these data, such as mortality rates and years of potential life lost (YPLL), that continue to be used to communicate and assess the severity of important public health problems in the modern era [4].

By the start of the twentieth century, the public health community had recognized that vital statistics and other mortality data lacked the breadth, depth, and timeliness to effectively detect, describe, and respond to modern threats to the public's health, as increasing focus was placed on mitigating the antecedent behaviors, conditions, and exposures (hereafter referred to as *risk factors*) that strongly influence future disease, disability, and death [5]. From this need for richer and more current risk factor information, public health agencies developed specialized surveillance procedures and systems to support them.

This chapter introduces the concept of risk factor information systems, including the rationale for their use, and their role in preventing premature morbidity and mortality. Specific examples will be presented to acquaint the reader with: the breadth of conditions and populations under surveillance; the variety of methods that are employed to gather data and disseminate results; and some examples of the use of the data to improve public health. The chapter will then review examples of informatics innovations that may contribute to more efficient and effective use of risk factor information in the future.

## Risk Transition in the Twentieth Century

The twentieth century saw a significant change in the nature of premature mortality worldwide. In 1900, the leading causes of death in the United States were infectious in origin—pneumonia and influenza, tuberculosis, and gastrointestinal infections; by the end of the century, the leading causes of death had taken a decidedly non-communicable turn—heart disease, cancer, noninfectious airway diseases, cerebrovascular disease, and accidents [6]. A similar shift occurred worldwide, with nearly two-thirds of deaths now attributable to chronic illnesses—mainly cardiovascular diseases, cancers, diabetes, and chronic lung diseases [7].

This *risk transition* from infectious to non-communicable causes of death was due in large part to important scientific advances: public health interventions, such as vaccinations and improved sanitation that reduced the incidence of infectious diseases; and improvements in medical care that prevented premature death. In addition, extended longevity has led to an aging population (with older adults having the highest rates of chronic diseases) [8]. The world's population was expanding, and people were living longer with diseases that took a slower toll on their beings.

One important consequence of this risk transition was the recognition that measures of mortality were not sufficient to convey all outcomes of chronic disease. For example, the multi-systemic sequelae of Type 2 diabetes mellitus debilitate the individual long before death. This recognition led to increased interest in the *quality*, not simply the length, of life lost [9]. The past four decades have seen the advent of additional health indicators, such as quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs), to provide public health with additional tools to communicate and assess the effect of chronic diseases on the health of populations [10].

Public health placed great focus on identifying the causative factors that increased the risk of living with, and dying of, chronic disease. Scientific research in the latter half of the twentieth century revealed many of these underlying risk factors. For example, the Framingham Heart Study has provided generations of information regarding specific conditions or exposures that contribute to cardiovascular disease and premature death, including obesity [11], type 2 diabetes mellitus [12], smoking [13], and genetic associations [14], as well as risk factors for stroke and dementia [15]; in addition, the protective properties of healthful behaviors, such as proper diet [16] and exercise [17] were identified. Early studies linking tobacco smoking to bronchiogenic carcinoma set the stage for future work revealing the risk factors for lung and other cancers [18]. In addition, industrialization brought to prominence new risk factors for premature death and disability, including environmental contaminants, occupational hazards, and injuries and violence. A common thread among many unhealthful risk factors was that their effects accumulated over years, even decades, and the key was to identify these risk factors in individuals as early as possible.

## The Nature of Risk Factors and the Causal Chain

In the United States [19] and worldwide [7], the leading risk factors for chronic diseases are tobacco, poor diet and physical inactivity, and alcohol consumption. These risk factors are all *external* (and, therefore, avoidable) exposures or behaviors that directly cause chronic disease, or create antecedent *internal* states (such as elevated cholesterol and hypertension) that cause chronic disease and death. Further, all of these identified risk factors contribute to *one or more* of the leading chronic diseases (heart disease, cancer, noninfectious airway diseases, cerebrovascular disease); conversely, these leading chronic diseases have one or more of these antecedent risk factors [20]. Risk factors represent the start of a *causal chain* of events that lead to disease, disability, and untimely death.

While tertiary prevention (the treatment of symptoms and complications of disease to prolong life and forestall death) and secondary prevention (the detection and treatment of disease before it becomes symptomatic) are important health activities, primary prevention (the identification or mitigation of the risk factors for disease before they cause disease) is the mainstay goal in public health. To effectively

prevent a disease, it is important to have specific and timely information about the prevalence of its risk factors, and this information must be reliable and comparable in order to plan, manage, and evaluate appropriate interventions [21].

Risk factor information systems provide much of the information used to monitor the prevalence and trends of specific risk factors at the local, national, and international level. Public health leaders use these systems to prioritize those health problems that are relevant in their communities, and to concentrate resources on evidence-based prevention programs. Further, where standardized measurement of risk factors is employed in ongoing surveillance, comparisons can be made over time (supporting evaluation of prevention programs that have been implemented) and across geographies (where communities may forecast regional trends or assess interventions that have been effective in comparable locales). Some risk factor information systems, particularly those that are incorporated into vital statistics or otherwise report on acute causes of death and injury, may also augment scientific research by identifying new dangers to the public's health.

The next sections of this chapter will provide specific examples of risk factor information systems, including the breadth of conditions and populations under surveillance, the variety of methods that are employed to gather data and disseminate results, and some examples of their effective use.

## National (United States) Risk Factor Systems

In the United States, there are a number of important risk factor surveillance activities that have national scope, and collect information on the breadth of risk factors that lead to injury, disability, disease, and death. Three prominent systems are presented and compared (Table 18.1).

**Table 18.1** Some national (United States) risk factor systems

System	Annual # of participants	Method	Representativeness of data
The National Health Interview Survey (NHIS)	89,976 persons 34,239 households (2010)	Computer-assisted interview	National-level
The National Health and Nutrition Examination Survey (NHANES)	5,000 (approximate)	Computer-assisted interview, plus physical exam and laboratory testing	National-level
The Behavioral Risk Factor Surveillance System (BRFSS)	400,000 (approximate)	Telephone-based survey	National-level, state-level, specific metropolitan and micropolitan statistical areas (MMSAs)

## *The National Health Interview Survey (NHIS)*

The National Health Interview Survey (NHIS) is a cross-sectional, multi-purpose survey of households that monitors the health of the civilian, non-institutionalized population of the United States. Established by the National Health Survey Act of 1956, and initiated in 1957, the survey has been administered by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) since 1960 [22].

Employees of the US Bureau of the Census conduct the annual survey throughout the year, following interview procedures defined by NCHS. The NHIS uses computer-assisted personal interviewing (CAPI) technology, allowing interviewers to enter responses directly into a computer as the survey is conducted, and promoting the efficient and accurate capture of data. The NHIS uses computer-assisted personal interviewing (CAPI) technology, allowing interviewers to enter responses directly into a computer as the survey is conducted, and promoting the efficient and accurate capture of data.

The NHIS sampling plan is intended to select participants in households that are statistically representative of the population of the United States, excluding those persons in long-term care facilities, active duty members of the Armed Services, the incarcerated, and US nationals living abroad. The sampling plan is multi-staged, and redesigned following every decennial census. The first stage identifies primary sampling units (PSUs) covering the 50 states and the District of Columbia; a PSU may be a county, a small group of contiguous counties, or a metropolitan statistical area. A PSU is further subdivided into area segments (containing 8–16 addresses) and permit segments (containing approximately 4 addresses from housing units built after the most recent census. To correct for statistical bias of under-represented populations, the NHIS *oversamples* (selects more) persons of black, Asian, and Hispanic heritage. Participation in the survey is voluntary and uncompensated, and the responses of participants remain confidential. In the 2010 survey, household interviews were completed for 89,976 persons in 34,329 households with a household response rate of 79.5 % [23].

The survey itself has two main parts: a Core questionnaire and Supplements. The Core questionnaire collects socio-demographic and basic health information, including important risk factors such as physical activity, tobacco use, and injuries and poisoning. The Core questionnaire has four components:

- Household (basic demographic information about all members of the household);
- Family (additional information about health-related issues and socio-demographic factors);
- Sample Adult (additional health questions specific to one adult in the household); and
- Sample Child (additional health questions specific to a child in the household—if any).

The Core questionnaire has remained relatively stable following a significant redesign in 1997, allowing for analysis of trends over time, but limiting comparability with prior years [24]. The Supplements portion of the NHIS includes questions on specific public health topics of interest, including cancer screening,

complementary and alternative medicine, children's mental health, and Healthy People 2010 objectives. Health information can be trended for specific socio-demographic groups and the country as a whole, but the sample size is not large enough for precise state-specific estimates. The survey questionnaires and the survey data can be accessed on links at the NHIS website. The data are also summarized in reports from NCHS and by researchers using the datasets.

NHIS data are generally used to monitor national trends in disease and disability, to track national health objectives (such as Healthy People 2020), and to evaluate Federal health programs. The data may also be used for public health research to describe the status of specific conditions in particular socio-demographic groups, or to identify new associations—such as linkages [25] between occupation and lung cancer, or to create or evaluate policy. Since the data are intended to be nationally representative, their utility for state and local public health monitoring of risk factors may be limited.

### ***The National Health and Nutrition Examination Survey (NHANES)***

The National Health and Nutrition Examination Survey (NHANES) is a multi-component survey designed to assess the health and nutritional status of adults and children in the United States. NHANES began in the early 1960s and, like the NHIS, is administered by the National Center for Health Statistics [26].

The NHANES sample is intended to be nationally representative. The sampling plan for NHANES is multi-staged, and includes PSUs (roughly corresponding to single counties) and secondary sampling units (SSUs) that are progressively divided from segments (generally equivalent to city blocks) to households and then individuals. Each annual sample selects from approximately 15 counties nationwide. The NHANES oversamples for persons age 60 and over, and also for persons of black or Hispanic heritage. The annual sample size is approximately 5,000 participants, who receive monetary compensation. The number of persons sampled for NHANES in the years 2009–2010 was 10,253 [27].

NHANES has two major components: an interview and a physical examination. The NHANES interview is administered using CAPI technology, and includes socio-demographic and health-related questions; categories of risk factors elicited include smoking, alcohol consumption, sexual practices, drug use, physical fitness and activity, and dietary intake. The NHANES examination is conducted by medical personnel, and includes medical, dental, and physiological measurements, as well as laboratory tests.

NHANES questionnaires and survey data can be accessed on links at the NHANES website. The data are also summarized in reports from NCHS and by researchers using the datasets. NHANES findings have been used to: assess nutritional status risk factors; establish national standards for measurements such as height, weight, and blood pressure; and even link chemical exposures to chronic diseases [28].

## ***The Behavioral Risk Factor Surveillance System (BRFSS)***

The Behavioral Risk Factor Surveillance System is a cross-sectional, telephone-based survey that collects state-level data about health-related risk behaviors, chronic conditions, and the use of preventive services by residents of the United States. The survey is conducted in and by all 50 states, plus the District of Columbia and three US territories, with technical assistance from the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) of the CDC [29].

Each state administers its survey continuously throughout the year, using its own employees or contractors. Approximately 350,000–400,000 participants nationwide are selected annually using random digit dialing (RDD) techniques to both landlines and cellular phones—a recent change to accommodate cell-phone only households [30]. Participants are adults 18 years or older; participation is voluntary, and there is no monetary compensation.

Each state's BRFSS has three components: a standardized set of core questions that are asked every year (fixed core) or every other year (rotating core); optional modules that states may elect to use; and state-specific questions. The core categories of risk factors on the BRFSS include alcohol consumption, asthma, cardiovascular disease, diabetes, disabilities, exercise, and tobacco use, among other areas of interest. The use of standardized core questions allows for comparisons to be made across and within states over time.

Unlike the NHIS and NHANES, the BRFSS does not employ a sampling plan, as participants are selected at random. The BRFSS employs a methodology that weights collected survey data based on age, race/ethnicity, sex, geography, marital status, education level, home ownership, and type of phone. As part of the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) project, data may be analyzed for specific metropolitan and micropolitan statistical areas (MMSAs) with 500 or more respondents.

BRFSS data and documentation can be found on the BRFSS Annual Survey Data webpage. BRFSS data are used in all states to establish and track state and local health objectives, support and evaluate health policies, develop and plan health programs, public education, create new laws or regulations, implement disease prevention and health promotion activities, and monitor trends [31]. Some state-level uses include monitoring of diabetes trends [32], assessment of state smoking prevalence [33] and evaluation of smoking cessation programs [34], as well as tracking exposures [35].

Some common barriers to more widespread state and community use of BRFSS data include limited availability of regional and subgroup data, lack of data analysis skills, and inadequate staff resources [36]. For these reasons, CDC has used information technology to facilitate greater use of the data, including a web-based, menu-driven query system to create summary tables and graphs. In addition, CDC developed BRFSS Maps—a web-based application that uses geographic information system (GIS) technology to create interactive maps that display behavioral risk factor prevalence data at the state and MMSA level.

Although the survey is telephone-based, there has been much research done to validate the reliability of the responses [37–39]. Concerns about decreasing response

rates on landline phones prompted recommendations to include cellular phones in the random digit dialing methodology [40]. The use of dual-frame survey for landlines and cell phone numbers has been a recent update to the methodology to continue to get valid, reliable, and representative data [41].

### ***Comparing the Systems***

While the NHIS, NHANES, and BRFSS are all similar in terms of monitoring health status in the United States, including the prevalence of important health risk factors, there are important differences to consider.

In terms of statistical comparability, national estimates on the prevalence of specific risk factors are generally comparable [42], although estimates may differ when further stratifying by demographic subgroup [43]. These variances in estimates may be due to differences in methods of data collection and analysis [44]. Following a decline in BRFSS response rates (from 72 % in 1993 to 51 % in 2006) some differences in comparability have been observed on selected measures between BRFSS and NHIS, and between BRFSS and NHANES [45].

The NHIS and NHANES are limited to national-level estimates, while the BRFSS by design can produce state-level (and in some instances, city-level) results. Further, these data may not be directly comparable with data in other national systems such as HEDIS [46]. Consequently, where a similar risk factor is measured in more than one system, all relevant systems should be considered before making important public health assessments of prevalence or outcome.

### **Risk Factors in Special Populations**

While large risk factor information systems may effectively monitor the health of specific demographic groups, geographic regions, or the nation as a whole, they may not be appropriate to monitor the prevalence of risk factors or the outcomes of targeted interventions in specific, high-risk populations. Specialized risk factor information systems have been developed to address this need, and the selected examples are intended to demonstrate the breadth of populations studied and the variety of methods employed (Table 18.2).

#### ***The Youth Risk Behavior Surveillance System (YRBSS)***

The Youth Risk Behavior Surveillance System (YRBSS) uses a school-based survey to monitor the prevalence and trends of risk behaviors that place youth in the United States at most risk for premature morbidity, mortality, and social problems.



**Table 18.2** Some risk factor surveillance systems for special populations (United States)

System	Eligible subjects	Participation	Method	Sampling method
Youth Risk Behavior Surveillance System (YRBSS)	US Youth (grades 9–12) in public schools	15,503 (2011, National YRBS)	Paper-based survey	Two-stage: probability of school selection proportional to school size; random selection of classroom
Pregnancy Risk Assessment Monitoring System (PRAMS)	Women with a recent live birth	77,000 (annually across all participating states)	Mailed survey with telephone follow-up (if necessary); linkage to birth certificate data; indirect linkage to additional data sources	Monthly sampling of women with a recent live birth using birth certificate information
National HIV Behavioral Surveillance (NHBS)	Men who have sex with men (MSM); Injecting drug users (IDUs); High-risk heterosexuals (HET)	10,073 IDUs (2009) 18,377 HET (2007) ~10,000 MSM (2005)	Handheld computer based survey	Venue-based (MSM); Respondent-driven peer-referral (IDUs, HET)

The survey is conducted by state, local, and territorial education agencies as well as tribal governments, with technical assistance provided by the Division of Adolescent and School Health (DASH) of the CDC. Each survey is intended to be representative of the state or local educational jurisdiction that conducts it; the CDC conducts a separate national school-based survey that is intended to be representative of students across the United States. YRBSS data are used primarily by state and local education agencies to describe risk behaviors, create awareness, supplement staff development, set and monitor program goals, develop health education programs, support health-related legislation, and seek funding [47].

The Youth Risk Behavior Survey (YRBS) is the specific data collection instrument for the YRBSS. The YRBS is conducted biennially during odd-numbered years. The survey is self-administered and comprises 87 core multiple-choice questions across six categories of priority health-risk behaviors: behaviors that contribute to violence and unintentional injuries; tobacco use; alcohol and other drug use; sexual behaviors that contribute to pregnancy and sexually transmitted diseases; unhealthy dietary behaviors; and inadequate physical activity. To preserve anonymity, the survey does not collect personal identifiers, and participants are not compensated. The survey uses paper-and-pencil with results scanned in electronically for processing and analysis.

For each state or local education agency, a two-stage cluster sample design is used to produce samples representative of 95 % of students in grades 9–12. The first stage selects for schools with probability proportional to school enrollment; the second stage randomly selects appropriate classes within the identified schools. If the overall response rate for a survey is greater than 60 %, it is considered to be “weighted” and representative of the students attending public school in that state or local jurisdiction. The survey design specifically excludes certain groups of youth, including absentees and dropouts, and students that attend private school, alternative schools, or who are home-schooled [48].

The YRBSS has conducted other special national surveys in the past, specifically capturing populations not present in public schools, grades 9–12. In 1992, a Youth Risk Behavior Supplement was added to the 1992 NHIS, and included youth who were attending and not attending school (this group was oversampled) [49]. In 1995, a mail-based National College Health Risk Behavior Survey was used to determine the prevalence of health-risk behaviors among college students [50]. In 1998, a school-based National Alternative High School Youth Risk Behavior Survey was administered to measure priority health-risk behaviors among students attending alternative high schools who are at high risk for failing or dropping out of regular high school, or who have been expelled from regular high school because of illegal activity or behavioral problems [51].

YRBSS data and documentation can be found on the YRBSS Data Files & Methods webpage. As education agencies have historically lacked the resources to conduct statistical analyses on complex survey data, DASH has used innovative information technology to make survey data more usable for its constituents. In the 1990s, DASH developed and distributed a CD-ROM based application that allowed users to query data. In 2001, DASH developed Youth Online, a web-based, menu-driven system created using user-centered design principles; the user experience was informed by the most common data requests of YRBSS stakeholders. Youth Online allows users to generate summary tables and graphs, and conduct *ad hoc* trend-analyses and comparisons with real-time evaluation of statistical significance. The utility of YRBSS is limited by the need for an appropriate response rate in order to provide comparable (weighted) data, and by the paucity of measures to demonstrate changes in prevalence or trends that result from monitoring these behaviors.

### ***Pregnancy Risk Assessment Monitoring System (PRAMS)***

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a nationwide surveillance system that collects state-level information to monitor changes in specific maternal and child health indicators. The PRAMS is conducted by participating states, with technical assistance provided by the CDC’s Division of Reproductive Health [52].

The PRAMS is administered annually. For each participating state, the PRAMS sample is selected from all women who have had a recent live birth. Each state samples 100–300 women each month (approximately 1,300–3,400 each year). Low-weight births are usually oversampled, as are some high-risk populations, and some states oversample by race/ethnicity. All states currently use either a participation incentive (sent to all mothers in a sample) or reward (sent only to respondents) to enhance response rate [53].

PRAMS has two initial data collection methods: the primary method is a mailed survey questionnaire, with frequent follow-up mailings made to non-responders; the second method is a telephone survey, in the event of repeated non-response to the mailed survey [54]. The survey is standardized to permit comparisons among states, although some customizations are permitted. Specific risk factors monitored by PRAMS include barriers to and content of prenatal care, obstetric history, maternal use of alcohol and cigarettes, physical abuse, contraception, economic status, maternal stress, and early infant development and health status.

Mothers' responses are linked to birth certificate data for subsequent analysis [55], and may be further linked to other available data sources, including: newborn screening; Medicaid; birth defects data; Women, Infants, and Children program (WIC); hospital discharge data; Sudden Infant Death Syndrome (SIDS) data, and Assisted Reproductive Technology (ART) data.

PRAMS data may be queried using CDC's PRAMS Online Data for Epidemiologic Research (CPONDER) system. PRAMS data are used by researchers and for state program evaluation, and have been used to gain support for program initiatives directed at unintended pregnancy, to promote policies aimed at monitoring or reducing unintended pregnancy, to acquire additional funds for related programs (such as family planning), and to evaluate psychosocial risk and prenatal counseling [56–58].

### ***National HIV Behavioral Surveillance System (NHBS)***

The National HIV Behavioral Surveillance System (NHBS) tracks behaviors and care access among persons at high risk for HIV infection. The NHBS was created in 2003, and is administered by the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) at CDC [59].

The survey is conducted by public health staff and administered using a handheld personal computer device that facilitates the efficient collection of data. A standard survey instrument is used, to collect core demographic information and information about specific risk factors, including sexual behavior, injection and non-injection drug use, HIV testing and results, and access and use of prevention services. In addition to the core questions, local jurisdictions may add questions to help evaluate local HIV prevention programs. The survey is anonymous, and participants receive monetary compensation [60].

The NHBS samples are intended to be specific to the 20 participating jurisdictions, with a separate sample selected to be nationally representative. The survey focuses on

the three populations at highest risk for HIV: men who have sex with men (MSM), injecting drug users (IDUs), and high-risk heterosexuals (HET). To recruit MSM, venues that are highly frequented by MSM are selected; for IDUs and HET, respondent-driven sampling (where participants recruit additional participants) is employed. Within each jurisdiction, 450–500 eligible persons are recruited from the at-risk population of interest, and participate in interviews and testing [61]. Data collected from NHBS are used to describe trends in key behavioral risk indicators and to evaluate HIV prevention programs; the data also further characterize the at-risk populations, identify gaps in prevention services, and identify new prevention opportunities.

## International Systems

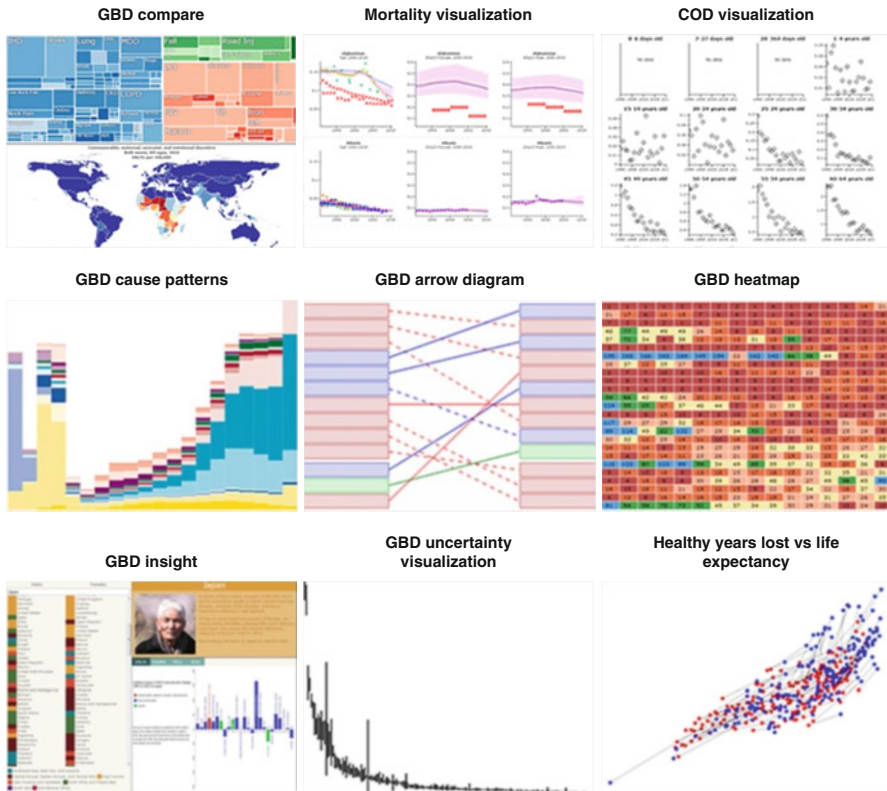
There are a number of CDC-supported risk factor information systems used internationally, including the Global School-Based Health Survey (GSHS), the Global Adult Tobacco Survey (GATS), and the Global Youth Tobacco Survey (GYTS). However, the focus of this section will be on three separate international efforts to provide prevalence information on major health risk factors, particularly in developing countries where the determinants of premature mortality are divergent for children vs. young adults vs. older adults, acknowledging the ongoing effects of poverty and infectious disease (see Table 18.3) [62].

### *Global Burden of Disease, Injuries, and Risk Factors Study*

The Global Burden of Diseases, Injuries, and Risk Factors Study (GBD) was commissioned in the early 1990s by the World Bank as the Global Burden of Disease Study, and is now led by the Institute for Health Metrics and Evaluation (IHME) at the University of Washington, in collaboration with Harvard University, Imperial College London, Johns Hopkins University, University of Queensland, University of Tokyo, and the World Health Organization (WHO) [63]. The GBD collects information on 291 diseases and injuries, 67 risk factors, and 1,160 disease sequelae, across 21 regions on all continents except Antarctica, and 20 age groups—using

**Table 18.3** Some international risk factor surveillance efforts

System	Sponsoring agency	Method
Global Burden of Diseases, Injuries, and Risk Factors Study (GBD)	WHO	Interview
STEPwise approach to Surveillance (STEPS)	WHO	Interview, optional physical measurements and lab tests
MEASURE Demographic and Health Survey (DHS)	USAID	Interview



**Fig. 18.1** Examples from GBD Visualizations (*Source:* The Institute for Health Metrics and Evaluation at the University of Washington, 2013. Used with permission)

DALYs as a common metric to account for premature mortality as well as the prevalence, duration, and severity of premature morbidity and injury. The GBD was designed to support rapid implementation of a cost-effective data collection system in developing countries, and has been adapted to meet a diverse set of cultural, demographic, and linguistic contexts; categories of risk factors cover a range of public health problems, including: communicable disease, newborn and maternal health, nutrition, non-communicable diseases, and injuries [64].

The IHME hosts innovative applications to encourage the dissemination and use of GBD data: GHDx, a web-based data query system; and GBD Visualizations, a web-based data presentation and analysis tool. GHDx allows users to access links to datasets for international and US risk factor information systems, and allows users to directly query GBD data by country and topic [65]. GBD Visualizations utilizes a wide variety of interactive charts (Fig. 18.1) to allow the user to easily understand and communicate data [66]. The GBD has been used by governments, and non-governmental organizations, to inform priorities for research, development, policies, and funding [67].

## ***STEPS***

The WHO STEPwise approach to Surveillance (STEPS) is a multi-component survey designed to assess health and nutritional status in WHO member countries. STEPS has standardized questions and protocols to support monitoring trends over time, as well as across-country comparisons [68].

STEPS is a three “step” assessment: (1) Questionnaire; (2) Physical Measurements; (3) Lab tests. The first step is required; the second and third steps are subject to the availability of local resources. The questionnaire includes: a required set of questions related to important risk factors (socio-economic conditions, tobacco and alcohol use, and nutritional status and physical inactivity); an “expanded” set of recommended questions (socio-cultural factors, hypertension, and diabetes topics); and an “optional” set of questions (covering mental health, intentional and unintentional injury and violence, and oral health). The physical measurements include: required measurements (height, weight, waist circumference, and blood pressure), “expanded” measurements (hip circumference and heart rate) and “optional” measurements (skin fold thickness, and a physical fitness assessment). The laboratory tests include: required tests (fasting blood sugar and total cholesterol), “expanded” tests (Fasting HDL and triglycerides), and “optional” tests (Oral glucose tolerance, urine exam, salivary nicotine metabolites).

STEPS data are disseminated via the WHO Global InfoBase, which is a data warehouse that collects, stores and displays health information on chronic diseases and their risk factors for all WHO member states [69].

## ***MEASURE Demographic and Health Surveys (DHS)***

The MEASURE Demographic and Health Surveys (DHS) is a project to collect and disseminate nationally representative data on health and population in developing countries. DHS is primarily funded by the United States Agency for International Development (USAID), which has conducted 230 surveys in more than 80 countries since 1984; donors and host countries provide additional funding [70].

There are two main types of DHS Surveys: Standard and Interim. The Standard DHS Surveys are conducted approximately every 5 years, and typically sample between 5,000 and 30,000 households. The Interim DHS Surveys focus on key performance monitoring indicators but may not include data for all impact evaluation measures (such as mortality rates). Interim surveys are conducted between cycles of the Standard survey, and the sample size is typically smaller.

The core questionnaires collect basic demographic and health information. There is inter-nation variation in questions and methods: most surveys include women of reproductive age (15–49) and men age 15–59, whereas in some countries only women are interviewed. Other required questionnaires focus on marriage, fertility,

family planning, reproductive health, child health, and HIV/AIDS; some optional questionnaires have focused on domestic violence and maternal mortality [71]. DHS datasets are available on the MEASURE DHS website.

## **Opportunities in Information Technology**

There are numerous efforts underway that use information technology to support the dissemination and use of risk factor data, and there are emerging opportunities for other innovative uses of information technology to augment the capture of risk factor data, and the identification and evaluation of new risk factors.

### ***Integrated Data Dissemination***

Examples from the BRFSS, YRBSS/Youth Online, WHO STEPS/Global Infobase and GBD/IHME systems have been previously identified for their innovative use of informatics principles to assist in the dissemination and analysis of risk factor data. Presented here are additional noteworthy examples of consolidation or integration of risk factor data from multiple sources.

#### **CDC WONDER**

CDC's Wide-ranging OnLine Data for Epidemiologic Research (WONDER) system is a menu-driven, web-based system that provides access to risk factor information on births, deaths, cancer, HIV/AIDS, tuberculosis, census, and other data that have been collected from other surveillance activities. Users may generate tables, maps, and other data extracts, as well as access relevant publications electronically. An application programming interface (API) has been developed to support automated web service data queries using XML.

#### **CDC WISQARS**

CDC's Web-based Injury Statistics Query and Reporting System (WISQARS) is a menu-driven, web-based system that provides access to information on risk factors for unintentional and violence-related injury in the United States. Fatal and nonfatal injury, violent death, and cost of injury data have been consolidated from several different information systems, including the National Vital Statistics System (NVSS), the National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP), and the National Violent Death Reporting System (NVDRS). Users may generate tables, maps, summary reports, and other data extracts by filtering on

a number of variables, including intent of injury, mechanism, affected body region, injury type, geographic location, sex, race/ethnicity, and age.

### **Health Data Interactive**

CDC/NCHS Health Data Interactive is a web-based system that provides users with access to summarized data on a number of different health topics, including risk factors and disease prevention such as cholesterol level, hypertension, overweight/obesity, physical activity, smoking, and vaccinations for influenza and pneumonia. The data are presented as tabular summaries, and the user may filter the tables by several variables, including age, gender, race/ethnicity, and geographic location. Data may also be downloaded directly for external use.

### **Vital Stats**

CDC/NCHS Vital Stats is a web-based system that provides users with access to summarized vital statistics risk factor data for deaths, births, and perinatal mortality. The data are presented as tabular summaries, which may be filtered by several variables; users may also generate graphs and maps, or download files for external analysis.

### **NCHS Data Linkage Activities**

NCHS has an ongoing effort to more fully explore risk factors by linking its population-based health surveys (such as NHIS and NHANES), to other important data sources such as air monitoring data from the Environmental Protection Agency (EPA) and death certificate records from the National Death Index (NDI). Although no user-driven query system is available, NCHS provides access to public-use and restricted-use data sets for analysis.

### **Health Indicators Warehouse**

The Health Indicators Warehouse is a collaborative effort of agencies of the US Department of Health and Human Services to consolidate access to national, state, and community risk factors and other health indicators. The user may initiate searches by a specific topic (e.g., demographics, disease, disabilities, specific health risk factors), geography, or initiative (e.g., Healthy People 2020, County Health Rankings). The user may also select directly from more than 1,000 specific indicators (such as “Cigarette Smoking: Adults” or “Cholesterol Level: Adults”). The user may access the definition and rationale for the indicators, information about the data source, links to evidence-based interventions, as well as data summarized as tables,



graphs, or maps (where appropriate). The warehouse also includes an API to support automated web service data queries using REST and SOAP services.

## Emerging Opportunities

Web-based surveys, geographic information systems, and electronic health records are technologies that may have a future role in the capture of risk factor data, the identification of new risk factors, the evaluation of the effectiveness of intervention strategies, and the augmentation of existing data.

### *Web-Based Surveys*

The use of Internet-detached electronic devices to capture risk factor survey data (interviewer-driven CAPI for NHIS and NHANES, and participant use of handheld computing devices for NHBS) has been previously described in this chapter, and noted for the benefits on efficiency of data capture and data validity. However, there is not widespread use of web-based surveys to capture risk factor data.

Web-based surveys have a number of benefits over conventional paper or in-person methods, including: electronic data capture; interactivity (including error checking and skip patterns); and rapid updating of survey content to address emerging needs. However, web-based surveys may not be appropriate where Internet connectivity is unavailable, a physical examination or laboratory testing (e.g., NHANES) is required, or the identity of the responder must be confirmed. There are other concerns regarding response rate and the validity of responses in web-based surveys [72].

The YRBSS has traditionally administered surveys with paper-and-pencil, with forms being collected and stored for electronic scanning in bulk, and edit checks applied during analysis. In a study comparing administration of the YRBS survey as paper-and-pencil vs. web-based mode, results indicated that prevalence estimates from paper-and-pencil and web-based surveys are generally equivalent [73]. Although this has the potential to streamline data collection, and enforce data validation at the time of the survey, additional study is required to determine the effect of technology-specific issues such as screen size and resolution before web-based surveys can be used in unmonitored settings.

The effect of web-based surveys on response rates appears to be mixed. Generally, web-based survey response rates are lower than with paper-based surveys [74, 75]. However, in the specific case of assessing the risk behaviors in a college population, the response rates did not differ and students were more likely to answer socially-threatening items on a web-based survey [76]. Further study is required to determine whether this effect on response rate is specific to participant age, or the subject

matter, or is an effect that will extinguish over time as the aging demographic becomes more technology-savvy.

## ***Geographic Information Systems***

Geographic information system (GIS) technology is a well-established tool for public health communication and analysis. The use of maps to present risk factor surveillance data has been highlighted in selected systems in this chapter, although the presentation of results at small geographic levels may be limited by the specificity of the geographic data collected (if any) or the representativeness of the smaller corresponding sample size.

GIS may also be a valuable tool for identifying and evaluating risk factors for disease (particularly those related to environmental exposures), and targeting interventions or public health policy. For example, GIS is commonly used to assess risk for lead exposure, and to evaluate screening programs. Lead screening programs have typically targeted high-risk populations by risk markers such as older housing and poverty. Detailed capture of geographic information as part of household surveillance can further refine targeted screening and validate risk-factor-based prediction rules [77], while also identifying unexpected clusters and potential new sources [78]; policies to remediate lead hazards can then be implemented and their outcomes evaluated [79]. GIS was used in another study to establish that living in a residence with more nearby traffic increased the risk of childhood asthma; this has potential implications for targeting asthma screening and education programs, as well as issues of vehicular emissions and urban planning [80].

## ***Electronic Health Records***

With the increasing adoption of electronic health records (EHRs) [81], and the collection of specific clinical quality measures (CQMs) that support the “meaningful use” of EHRs, there is a new opportunity to conduct surveillance of risk factors in populations. Although the future use of risk factor data from EHRs is not well understood, the potential availability of these data may facilitate determination of prevalence rates, and help evaluate the outcomes of individually-targeted interventions for specific risk factors, such as tobacco use and cessation [82]. In addition, the use of data mining and analytic techniques on EHR data has the potential to permit inferences about new risk factors that have not previously been identified [83].

In an example from the University of Wisconsin, EHR data were linked with community-level data to describe asthma and diabetes prevalence and health care quality, for individual patients and the community at-large, suggesting potential future use in assessing health status and outcomes [84]. There are a number of current limitations, including few instances of direct access to EHR data for public

health use, and the quality and representativeness of EHR data; however, once available, the sheer volume of clinical data may allow for selective sampling and may make risk factor estimates reliable for smaller geographic levels than is possible using traditional survey methods [85]. Further investigation will be needed to determine the reliability and validity of objective physical measures (such as height and weight) in addition to the degree of standardization of responses about risk behaviors (such as smoking and exercise) across many EHR vendors.

There are two BRFSS demonstration projects underway to evaluate the potential use of EHRs to conduct behavioral risk factor surveillance. In the first project, consenting patients will be surveyed and their responses will be linked to their respective electronic health records, to create an anonymized data set containing patient survey data. Researchers will then compare individual survey responses to the corresponding EHR data to evaluate their validity and reliability for monitoring population health. The second project will use simulated patient data to test analytic tools that summarize self-reported data collected from web-based surveys and compare them statistically with EHR data. These demonstration projects are expected to complete by the end of 2013 [86].

## Conclusion

Risk factor information systems are a relatively new tool used in the prevention of premature injury, disability, disease and death. They are used on a national and international scale, as well as at the community level and in special populations. Recent efforts in data dissemination (e.g., Health Indicators Warehouse) and presentation (e.g., GBD Visualizations) should facilitate the analysis, understanding, and use of risk factor data. Innovative use of geographic information systems has been effective in identifying risk factors in communities, and in evaluating outcomes of disease programs, and the use of clinical data from electronic health records may increase the efficiency with which interventions can be targeted and evaluated.

### Review Questions

1. Explain how risk factor information systems complement vital statistics systems and primary scientific research. What has driven the need for risk factor information systems in the last century?
2. What are the basic components of a risk factor information system? Why do the methods of data collection vary for different risk factor information systems?
3. What are some similarities and differences among the following behavioral risk factor surveillance systems: the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES), and the Behavioral Risk Factor Surveillance System (BRFSS)?

4. Why are separate risk factor information systems needed for special populations?
5. What are some similarities and differences among prominent international risk factor information systems?
6. Explain how innovations in information technology may affect the use of risk factor data and knowledge. How may electronic health records and other information technologies augment the collection of risk factor data?

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# Chapter 19

## Setting National Policies and Standards for Immunization Information Systems

Nedra Y. Garrett

**Abstract** Immunization Information Systems (IIS) are confidential, computerized, population-based systems that collect and consolidate vaccination data from vaccination providers and provide important tools for designing and sustaining effective immunization strategies (National Center for Immunization and Respiratory Diseases, Immunization information systems [Internet]. Atlanta: Centers for Disease Control and Prevention, 2013). At the *point of clinical care*, an IIS can provide consolidated immunization histories for use by a vaccination provider in determining appropriate client vaccinations. The Centers for Disease Control and Prevention (CDC), in collaboration with key stakeholders, works to ensure IIS are responsive to the needs of the Immunization programs at all levels of government and that these systems take advantage of advances in technology and are aligned with national data and exchange standards. CDC's Immunization program publishes IIS Minimum Functional Standards that provides a framework for the development of IIS through 2017 that describes specific standards that address the IIS programmatic goals, and operational and technical capacities that all IIS should achieve by the end of 2017. These standards were developed through a consensus process from a variety of IIS managers and technical experts from across the US. Several examples of data, standards and systems are provided for each functional standard. This chapter also will examine various policy and technology drivers such as the Centers for Medicare & Medicaid Services (CMS) EHR Incentive Programs' Meaningful Use criteria.

**Keywords** Immunization information systems • Standards • National • Policies • Vaccines • Decision support • Adverse events • Point of clinical care

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### Learning Objectives

1. Describe how national policies influence the development and implementation of Immunization Information Systems (IIS).
2. Identify the Meaningful Use standards required to support IIS.
3. Describe the minimum functional standards of Immunization Information Systems and provide examples of each.
4. Describe key considerations in maintaining the quality, integrity, and security of IIS data.

## Overview

Immunization Information Systems (IIS) are confidential, computerized, population-based systems that collect and consolidate vaccination data from vaccination providers and provide important tools for designing and sustaining effective immunization strategies [1]. At the *point of clinical care*, an IIS can provide consolidated immunization histories for use by a vaccination provider in determining appropriate client vaccinations. The Centers for Disease Control and Prevention (CDC), in collaboration with key stakeholders, works to ensure IIS are responsive to the needs of the Immunization programs at all levels of government and that these systems take advantage of advances in technology and are aligned with national data and exchange standards. CDC's Immunization program publishes IIS Minimum Functional Standards that provides a framework for the development of IIS through 2017 that describes specific standards that address the IIS programmatic goals, and operational and technical capacities that all IIS should achieve by the end of 2017. These standards were developed through a consensus process from a variety of IIS managers and technical experts from across the US. Several examples of data, standards and systems are provided for each functional standard. This chapter also will examine various policy and technology drivers such as the Centers for Medicare & Medicaid Services (CMS) EHR Incentive Programs' Meaningful Use criteria.

## Introduction to Immunization Information Systems (IIS)

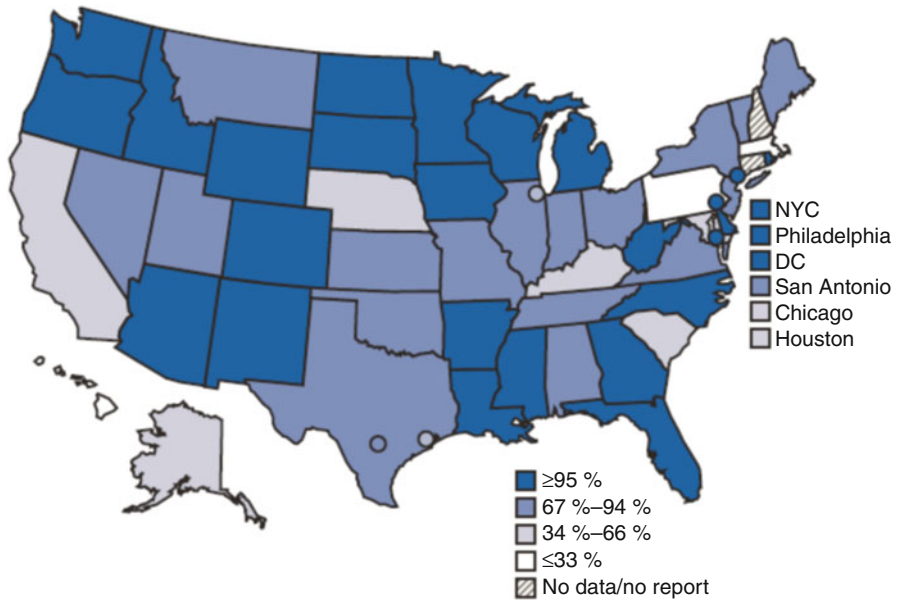
Public Health Informatics is a multi- and inter-disciplinary field that relies on information technology as the cornerstone. Information is the underlying commodity to any public health information system and successful utilization requires a systematic approach to how information is collected, managed, analyzed and used. Some of the principles around how information is captured, managed, and used will be examined in context of a national network of systems – Immunization Information Systems (IIS), also referred to as immunization registries. However, it is important

to note there are other domains that directly influence how these systems are used and implemented in practice to improve public health outcomes in their respective program areas. Additionally we will highlight information technology drivers, policies that affect implementation, and opportunities to leverage emerging health information technology and standards.

Immunization Information Systems are confidential, computerized, population-based systems that collect and consolidate vaccination data from vaccination providers and provide important tools for designing and sustaining effective immunization strategies [1]. At the *point of clinical care*, an IIS can provide consolidated immunization histories for use by a vaccination provider in determining appropriate client vaccinations [1]. At the *population level*, an IIS provides aggregate data on vaccinations for use in surveillance and program operations, and in guiding public health action with the goals of improving vaccination rates and reducing vaccine-preventable disease [1]. IIS were originally intended to record vaccination data for the residents of a geographic area [2]. However, over the last 8 years their functionality has been extended to include sending caregiver reminders, forecasting recommended immunizations, running reports, assessing coverage, managing inventory, and generating immunization certificates [2].

The CDC National Center for Immunization and Respiratory Diseases (NCIRD) program is responsible for providing funding, leadership, and technical assistance to states to implement state-based IIS [3]. In this chapter, this program will be referred to as the CDC Immunization Program. CDC monitors the 64 immunization program grantees that receive funding under section 317b of the Public Health Service Act [4]. The CDC Immunization Program received additional funding through the American Recovery and Reinvestment Act (ARRA) in 2010, to enhance interoperability of IIS with electronic health record systems [4, 5]. The grantees include the 50 states, five cities, the District of Columbia (DC) and eight territories [5]. The CDC Immunization Program also conducts an annual assessment – the Immunization Information Systems Annual Report (IISAR) to monitor progress of the grantees and uses this report to develop strategies for these systems [6].

As a result of the implementation of IIS across the states, there have been many positive strides in vaccination coverage for children. In the CDC Morbidity and Mortality Weekly Report (MMWR), *Progress of Immunization Information Systems in 2013* (2013), results of the IISAR show that 84 % (19.2 million) of US children aged <6 years participated in IIS, as defined by having at least two recorded vaccinations [7]. This was an increase from 82 % (18.8 million) in 2010 (Fig. 19.1) [7]. Grantees reported that an average of 63 % of vaccination records for these children contained data in the field for vaccine manufacturer and 60 % contained data in the field for lot number [7]. The Community Preventive Services Task Force has recommended IIS as an effective intervention in increasing vaccination rates [8]. The Task Force considered a large body of evidence demonstrating the capabilities and effectiveness of IIS to generate or directly support interventions known to increase vaccination rates: (1) client reminder and recall systems (20 papers); (2) provider assessment and feedback (12 papers); and (3) provider reminders (1 paper) [7].



**Fig. 19.1** Percentage of children aged <6 years participating in an Immunization Information System — United States, five cities, and the District of Columbia, 2013 [6]. Abbreviations: *NYC* New York City, *DC* District of Columbia

The implementation of IIS is an important part of increasing immunization coverage and sustaining effective immunization strategies [7]. A *Healthy People 2020* objective (IID-18) is to increase to 95 % the proportion of children aged <6 years whose immunization records are in fully operational, population-based IIS [6]. The National Vaccine Advisory Committee (NVAC) has published goals for IIS, including required and optional core data elements for which IIS should collect information [7].

## IIS and Electronic Health Records Meaningful Use Standards

Electronic health records (EHRs) provide an opportunity to increase the utilization of IIS by healthcare providers and hospitals, as well as to increase the data collected by these systems. The Center for Medicare and Medicaid Services (CMS), through the HITECH EHR Incentive Program (Meaningful Use), made provisions for IIS by including immunization registries as an objective to incentivize providers and hospitals to adopt EHRs [9]. Meaningful Use (MU) specified in Stage One the option for eligible professionals and eligible hospitals to select IIS as one of three population health objectives by choosing to test the submission of electronic immunization data from certified EHR technologies. Stage 2 built upon this requirement by requiring eligible professionals and hospitals to submit immunization data to public health

on an ongoing basis [9, 10]. The start date for Stage One was October 1, 2010 for eligible hospitals and critical access hospitals, and January 1, 2013 for eligible professionals [9]. The start date for Stage 2 was October 1, 2013 for eligible hospitals and critical access hospitals, and January 1, 2014 for eligible professionals [9, 10]. The timeframe for Stage 3 has not been determined at the time of this writing.

Standardized information exchange is critical to achieving interoperability between EHRs and IIS. In Stage One, MU allowed healthcare providers to send immunization data to public health jurisdictions using either Health Level Seven (HL7<sup>®</sup>) version 2.3.1 or 2.5.1 [11], allowing some flexibility for providers. However, state and local health departments encountered a few issues with the provision allowing multiple formats. For example, some state and local health departments were only able to accept HL7<sup>®</sup> 2.5.1 but the provider elected to send immunization data to the IIS using HL7<sup>®</sup> 2.3.1, creating compatibility issues. This was later rectified in Stage 2, which allowed only one standard version (HL7<sup>®</sup> 2.5.1). Additionally, HL7<sup>®</sup> 2.3.1 allowed a great deal of variation in how data were captured and sent, creating some confusion and disagreement on what constituted successful transmission in many jurisdictions. In this instance, testing for certification becomes almost meaningless to achieve true interoperability between healthcare providers EHRs and IIS, since systems could be considered certified with either standard. The 2.5.1 standard was subsequently updated and constrained many of the issues by ensuring that the HL7<sup>®</sup> 2.5.1 Implementation Guide (IG) was specific enough for both the EHR and IIS developers, and that the MU certification procedures accurately reflected the needs of IIS [11]. The IIS taskforce included vendors, CDC, Office of National Coordinator (ONC) and the American Immunization Registry Association (AIRA) and helped to identify ways to improve both the IG and the certification testing process. Finally, simply having a national IG helped to ensure that the business needs of different jurisdictions' IIS were addressed. For example, some state IIS can receive adult vaccines, others cannot. The CDC Immunization Program has created a format for communicating how jurisdictions' IG might vary locally from the national IG. The clinicians and their EHR vendors seeking to connect with IIS need clear and current guidance and policies to address jurisdictional variations. Obviously, providers and EHR vendors would prefer a one-size-fits-all standard, so public health jurisdictions would do well to harmonize business and interoperability requirements still further in the future.

MU Stage 3 is expected to increase the exchange of immunization data between providers, hospitals, and public health, both by allowing submission of immunization data and by sending information from the IIS back to the provider. Information sent to the provider will likely include both a patient's vaccine history from the IIS and guidance ("decision support") regarding those immunizations which are due [9]. The enhanced capability will give providers and hospitals the ability to receive feedback from the EHRs on a patient's immunizations. Underlying this capability is the utilization of standardized information exchange. The ONC, in collaboration with the CMS, has established transmission standards to support exchange of immunization data between EHR systems and IIS, as well as vocabulary standards to support how immunization data are coded in the EHR system. The standards specified are listed in Table 19.1.

**Table 19.1** Immunization registries & IIS meaningful use standards

Immunization registries (IIS) meaningful use standards		
	Exchange standards	Vocabulary standards
Meaningful use stage 1	Standard – HL7® 2.3.1 Implementation guide for immunization data transactions using version 2.3.1 of the health level seven (HL7®) standard protocol implementation guide version 2.2 HL7® 2.5.1 implementation guide for immunization messaging release 1.0	HL7® standard code set CVX – vaccines administered, July 30, 2009 version
Meaningful use stage 2	HL7® 2.5.1 implementation guide for immunization messaging release 1.4	HL7® standard code set CVX – vaccines administered, July 30, 2009 version HL7® standard code set CVX – vaccines administered, updates through July 13, 2012
Meaningful use stage 3	Undetermined at the time of the writing	Undetermined at the time of the writing

CMS has also established clinical quality measures (CQMs) that providers and hospitals can select to demonstrate meaningful use of EHR technologies. One of the measures that may be selected is childhood immunization status [12].

The increased adoption of EHRs will increase provider and patient access to immunization records as stipulated in the MU rule. CDC conducted a telephone survey of state immunization information system-related legislation with the survey audience composed of Immunization Program Managers and/or other state health department personnel in 50 states and the District of Columbia (DC). The Survey of State IIS Legislation summarizes for each state [13]:

- If a state has laws authorizing IIS; and if so, if it mandates reporting
- If a state has laws addressing sharing of immunization information
- If a state has laws addressing sharing of healthcare information
- Type of consent: required, implied, or not yet addressed
- If implied consent, whether there are provisions to opt out or limit access
- Whether notice is given to patient of inclusion in the IIS

The study showed that 31 states had laws authorizing IIS and 16 of these states mandated reporting [13]. In a 2012 study examining childhood **immunization** reporting laws in the United States, the results showed that the IIS grantees generally have more than one law addressing immunization records reporting, exchange, and privacy protections [14]. Not all of these laws are in alignment, but there is a trend toward increased authorizing laws, mandated reporting, and implied consent provisions [14]. Of the 56 grantees, 37 (66 %) had IIS authorizing laws, and 46 (82 %) had laws addressing healthcare provider and vital statistics reporting [14]. Though there is inconsistency in laws addressing sharing of data across states, there

is a trend toward laws that encourage sharing [14]. States are advised to consult their state policies to determine how and if sharing and reporting are allowed.

## **IIS Minimum Functional Standards**

CDC's Immunization program published IIS Minimum Functional Standards that provides a framework for the development of IIS through 2017 [15]. These standards were developed through a consensus process, from a variety of IIS managers and technical experts from across the US. The standards supersede an earlier version of "Minimum Functional Standards for Registries," adopted by the National Vaccine Advisory Committee (NVAC) in 2001 in recognition of the growing importance of IIS to the broader health information technology landscape [15]. The IIS Minimum Functional Standards describe specific standards that address the IIS programmatic goals, and operational and technical capacities that all IIS should achieve by the end of 2017 [15]. Some standards can only be implemented in conjunction with the broader department of health or state/local infrastructure [15]. State, local, and tribal policies on information sharing as well as technical capabilities may influence the implementation of functions outlined in the Minimum Functional Standards [15]. The standards reflect necessary functions, whether those functions are implemented by the IIS program or others [15]. In some cases, current law or policy may preempt full implementation unless changed. In these instances, an unmet standard may serve as a suggestion for possible revisions to such law or policy [15]. The IIS Minimum Functional Standards are discussed below, along with several examples and applied informatics principles:

### ***IIS Should Support the Delivery of Clinical Immunization Services at the Point of Immunization Administration, Regardless of Setting [13]***

The purpose of all immunization activities, including the IIS, is to ensure the appropriate delivery of immunization services to all members of a population. Quality of care in immunization services requires age-appropriate administration of vaccines to the individual patient in a clinical setting. To accomplish this end, the IIS must provide access to quality, complete immunization data and clinical decision support information, in a location and at a time where it can affect patient care [15]:

1. The IIS provides individual immunization records accessible to authorized users at the point and time where immunization services are being delivered.
2. The IIS has an automated function that determines vaccines due, past due, or coming due ("vaccine forecast") in a manner consistent with current ACIP recommendations; any deficiency is visible to the clinical user each time an individual's record is viewed;

3. The IIS automatically identifies individuals due/past due for immunization(s), to enable the production of reminder/recall notifications from within the IIS itself or from interoperable systems.
4. When the IIS receives queries from other health information systems, it can generate an automatic response in accordance with interoperability standards endorsed by CDC for message content/format and transport.
5. The IIS can receive submissions in accordance with interoperability standards endorsed by CDC for message content/format and transport.

In this functional standard, the setting where the immunizations are being administered and the systems interacting with the IIS are both important factors. The setting may be a health department with users interacting directly with the system, a clinical setting with users remotely interacting with IIS through an EHR or web interface, or a clinical setting with users interacting with the IIS through an intermediary such as a regional Health Information Exchange (HIE). However, according to MU Stage 2, a public health jurisdiction must identify and designate an HIE to receive the immunization data on behalf of the state or jurisdiction before HIE submission can be considered sufficient to attest to the MU objective. It is the intent of the MU rules to address information exchange from the designated sender to the intended receiver. In some instances, it was found that HIEs were collecting information that did not get transmitted to the IIS. However, the functionality outlined will ensure that clinical users have timely and accessible information on requisite immunizations at the point of care at the time of need.

### ***Vaccine Forecasting & Scheduling***

Vaccine forecasting and scheduling – key components of this functional standard – are complex functions requiring multiple decision points to determine the appropriate set of vaccines to administer. These decision points include the child's date of birth, vaccine history, and current vaccination schedule. There are some instances where decision support systems and services to address the complexity of the decisions have been successfully implemented in EHRs interacting with IIS. In a study focused on children 6-years or younger at the Wishard Memorial Hospital pediatric clinic, clinical decision support systems were used to provide recommendations on vaccine schedule based on the child's date of birth and vaccine history [16]. The study showed that childhood immunization clinical decision support systems (CDS) can assist providers in delivering accurate, appropriate, and timely childhood vaccines [16].

The CDC Immunization Program Office has developed a logic specification for the Advisory Committee on Immunization Practice (ACIP) recommendations on vaccine administration, number of doses, dosing interval, and precautions and contraindications [17]. A group of technical and clinical subject matter experts interpreted and translated the recommendations into technical logic that can be



implemented in CDS engines. CDS engines also can accommodate logic for evaluation and forecasting of vaccine [17, 18]. An example of an evaluation and forecasting engine is a tool an IIS might use to alert a physician that a presenting child is overdue for a Measles, Mumps, and Rubella (MMR) vaccination [18]. The translation of that clinical language into technical logic that is processed within evaluation and forecasting engines is a time-consuming and complex process that happens, mostly independently, within different health information systems including IIS, EHRs, and Health Information Exchanges [17]. Due to the challenge of interpreting clinically-written ACIP recommendations, CDS engine outputs often vary and do not always match the expectations of clinical subject matter experts [17].

The Open CDS consortium is an example of a group of organizations focused on using open source standards-based clinical decision support to improve patient outcomes [19]. OpenCDS is a multi-institutional, collaborative effort to develop such (CDS) tools and resources that can be widely adopted to enable CDS at scale [19]. One of the efforts of the Open CDS Consortium includes an Immunization Calculation Engine (ICE), which is a state-of-the-art immunization forecasting software system that evaluates a patient's immunization history and provides appropriate recommendations to providers [20]. ICE also provides a tool for subject matter experts to manage the immunization algorithms through a web-based interface [20]. Thus, technology and policy drivers have tremendous influence on the development of IIS and their integration with EHRs and other health information systems.

### ***Reminder and Recall Systems***

Reminder and recall systems have been shown to be effective in increasing vaccination coverage in pediatric and adult populations for universally recommended vaccines and targeted vaccines, when conducted by a health-care provider, an academic center, or a health department, and when carried out using postcards, mailed letters, or telephone calls [21]. The systems provide parents of children who are due or overdue on vaccinations with recall letters, with the aim of increasing vaccination coverage [21]. However, there have been studies of reminder and recall systems that returned varying results. In an evaluation of a recall letter system for Medicaid-enrolled children aged 19–23 months, the system-generated recall letters during a 3-month period did not significantly increase the completion of the scheduled vaccine series [22]; specific reminder and recall systems and methods are not effective in every setting. For example, among urban adolescent populations, automated text message reminders have been shown to significantly increase vaccination coverage [21]. Recall and reminder functionality in IIS needs to be flexible in order to adapt to variety of delivery modes [21]. Under MU Stage 2, healthcare providers have to provide patients the capability to electronically view, download, and transmit relevant information securely from their EHRs [10]. The information may be made available via email, web service, personal health record, or other secure means.

### ***IIS Should Support the Activities and Requirements for Publicly-purchased Vaccine, Including the Vaccines for Children (VFC) and State Purchase Programs [15]***

An IIS can assist providers and health departments with the reporting and monitoring requirements of the federal VFC entitlement program [15]. The VFC is federally funded and provides vaccines at no cost to children who might not otherwise be vaccinated because of the inability to pay. Children who are eligible for VFC vaccines are entitled to receive those vaccines recommended by the Advisory Committee on Immunization Practices (ACIP) [23].

1. The IIS has a vaccine inventory function that tracks and decrements inventory at the provider site level according to VFC program requirements.
2. The IIS vaccine inventory function is available to direct data entry users and can interoperate with EHR or other inventory systems.
3. The IIS vaccine inventory function automatically decrements as vaccine doses are recorded.
4. Eligibility is tracked at the dose level for all doses administered.
5. The IIS interfaces with the national vaccine ordering, inventory, and distribution system.
6. The IIS can provide data and/or produce management reports for VFC and other public vaccine programs [15].

### ***Vaccine Tracking System***

CDC require states to use the Vaccine Tracking System (VTrckS) – a vaccine tracking system that allows provider practices to place, track, and manage publicly-funded vaccine orders on-line [24]. The system, which supports integration with IIS, improves tracking from ordering to delivery by automating order approval and processing; this allows for near real-time inventory visibility [24]. The system supports grantees, providers, and CDC program staff, provides one-stop access to order and provider data, and manages the vaccine budget [24]. VTrckS consolidated the functionality of other legacy systems to include VACMAN, NIPVAC, and VOFA which are all obsolete [24].

### ***IIS Should Maintain Data Quality (Accurate, Complete, Timely Data) on all Immunization and Demographic Information in the IIS [15]***

Ensuring that individuals receive all vaccines due, but no duplicative or unnecessary doses, requires that complete immunization data be available to the vaccine provider [15]. Likewise complete, non-duplicative demographic information is vital to several IIS functions, including vaccine accountability and client follow-up

activities [15]. Finally, locating such information in a comprehensive IIS enables the analysis necessary to achieve population-wide protection against vaccine-preventable diseases [15]. These requirements are summarized below, as shown in the IIS Minimum Functional Requirements:

1. The IIS provides consolidated demographic and immunization records for persons of all ages in its geopolitical area, except where prohibited by law, regulation, or policy.
2. The IIS can regularly evaluate incoming and existing patient records to identify, prevent, and resolve duplicate and fragmented records.
3. The IIS can regularly evaluate incoming and existing immunization information to identify, prevent, and resolve duplicate vaccination events.
4. The IIS can store all IIS Core Data Elements
5. The IIS can establish a record in a timely manner from sources such as Vital Records for each newborn child born and residing at the date of birth in its geopolitical area.
6. The IIS records and makes available all submitted vaccination and/or demographic information in a timely manner.
7. The IIS documents active/inactive status of individuals at both the provider organization/site and geographic levels.

Data quality is essential to fully realizing the benefit of immunization registries, to make sure that individuals receive all needed vaccines with no duplicative or unnecessary doses and that complete immunization data are made available to the vaccine provider [2]. Likewise, complete, de-duplicated demographic information is vital to several IIS functions, including vaccine accountability and client follow-up activities [2]. Finally, locating such information in a comprehensive IIS enables the analysis necessary to achieve population-wide protection against vaccine-preventable diseases [2].

To ensure data quality, it is important to consider the methods with which data are exchanged. The HL7<sup>®</sup> 2.5.1 message transmission from health care systems to IIS has been shown to improve timeliness and completeness of immunization data over manual entry [2]. Standardized information exchange between EHRs and IIS creates opportunities for IIS to capture patient data, validate demographic data of the patient and parents, and avoid creation of duplicate records [2].

CDC Immunization Program, with input from a variety of IIS managers and technical experts from across the US, established a core set of data elements for IIS for the 2013–2017 timeframe. EHRs, vital records, and practice management or billing systems are expected to store and send a required core set of data elements to IIS. The purpose of the core data element is to facilitate record exchange between IIS. It is imperative that, at a minimum, each IIS include in its database schema a method to receive and store all of the required core data elements, even if the IIS does not routinely collect the information [25]. Thus, if an IIS receives a record from one system and subsequently transfers it to another, no required core data elements will be lost in the process. It is strongly recommended that IIS also collect data on all of the required core data elements for their own patients [25]. Prospective implementation should begin on or before January 1, 2009 to enhance completeness and value of IIS data [25]. The core data elements include the patient's and mother's

demographic data, information on the vaccine and administration of the vaccine, information on the provider, history of vaccine preventable diseases, and other related data. Where appropriate, IIS may infer or auto populate distinct values; actual architectural solutions will differ among systems [15].

### ***IIS Should Preserve the Integrity, Security, Availability and Privacy of all Personally-identifiable Health and Demographic Data in the IIS***

As more individuals and programs depend on the IIS for critical information, the security and reliability of the data, and the availability of the system itself, are vital [15]. People who entrust their own information, and that of their children, to an IIS need to be confident that data will be kept secure and private [15]. Both law and basic ethics mandate the IIS to maintain the highest standards of privacy and accountability relating to the storage and release of sensitive personal information [15]. This intent is detailed as follows [15]:

1. The IIS program has written confidentiality and privacy practices and policies based on applicable law or regulation that protect all individuals whose data are contained in the system.
2. The IIS has user access controls and logging, including distinct credentials for each user, least-privilege access, and routine maintenance of access privileges.
3. The IIS is operated or hosted on secure hardware and software in accordance with industry standards for protected health information, including standards for security/encryption, uptime and disaster recovery.

Access and control of immunization records are facilitated through various security measures, to ensure that the person accessing the immunization record is who they say they are, and to provide patients with control over sharing and exchanging their records with authorized persons. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy and Security Rule sets national standards for the security of electronic protected health information; the confidentiality provisions of the Patient Safety Rule protect identifiable information being used to analyze patient safety events and improve patient safety [26].

### ***Provide Immunization Information to all Authorized Stakeholders [15]***

IIS provide information to a wide range of stakeholders, including public and private care providers, public health programs, emergency responders, and many others. The specifics of which entities or users are authorized vary somewhat from state to state, and are regulated in large measure by state and local law or policy [15]. This concept is specified as follows [15]:

1. The IIS can provide immunization data access to healthcare providers, public health, and other authorized stakeholders (e.g., schools, public programs, payers) according to law, regulation or policy.
2. The IIS can generate predefined and/or ad hoc reports (e.g., immunization coverage, vaccine usage, and other important indicators by geographic, demographic, provider, or provider groups) for authorized users without assistance from IIS personnel.
3. With appropriate levels of authentication, IIS can provide copies of immunization records to individuals or parents/guardians with custodial rights.
4. The IIS can produce an immunization record acceptable for official purposes (e.g., school, child care, camp).

### ***IIS Should Promote Vaccine Safety in Public and Private Provider Settings***

Maintaining the safety of administered vaccine involves two major activities: detailed monitoring of vaccine administration, and adverse event reporting. Although it is rare, occasionally a problem is identified with a specific manufacturer or lot of vaccine [15]. Such problems may include the administration of sub-potent vaccine (requiring re-immunization), or association of a specific vaccine with adverse outcomes [15]. In either case, the detailed administration records in an IIS can greatly facilitate identifying all recipients of that vaccine so that proper follow-up can be initiated [15]:

1. Provide the necessary reports and/or functionality to facilitate vaccine recalls when necessary, including the identification of recipients by vaccine lot, manufacturer, provider, and/or time frame.
2. Facilitate reporting and/or investigation of adverse events following immunization.

The detailed data in IIS can greatly streamline the process of adverse event report [15]. The National Childhood Vaccine Injury Act of 1986 (Public Law 99-660) created the National Vaccine Injury Compensation Program (VICP) and the Vaccine Adverse Events Reporting System (VAERS), which require the monitoring and reporting of adverse events possibly associated with vaccine administration [15]. CDC and the Food and Drug Administration (FDA) sponsor and support the Vaccine Adverse Event Reporting System (VAERS) – a national passive reporting system that collects information from the public on adverse events (side effects) associated with vaccines licensed in the United States [27, 28].

## **Conclusion**

CDC develops policies and standards to enable the implementation of IIS in state and local public health departments, ensuring systems are aligned with national standards and policy efforts to include ONC standards. For example, CDC works with partner organizations like the American Immunization Registry Association to

develop policies and recommendations on IIS development; these include identifying needs of jurisdictions, identifying standards to support the exchange of immunization data with EHRs, developing policies on how data are collected and managed, advancing immunization registries, and identifying best practices. CDC also works closely with ONC and CMS, as well as the Health Information Technology Policy Committee, on the development of policies and standards that impact public health information systems, including IIS. The HITECH Act under ARRA provided a tremendous opportunity to enhance interoperability of EHRs with IIS, allowing public health to exchange vaccination records and reduce the need for duplicate data entry by providers. The use of standards such as HL7<sup>®</sup> will help to improve the quality of data available to public health systems, by ensuring data are uniformly structured when exchanged between systems. New York City is an example of a site that has successfully implemented HL7<sup>®</sup> for reporting from an EHR system to the IIS to support meaningful use. Implementation of the service eliminated double data entry and provided the ability for providers to query and import patient immunization data into their EHR [29]. Clinical Decision Support (CDS), which is embedded in EHRs or called from an IIS, offers tremendous opportunities to support immunization scheduling and forecasting. Decision support within IIS helps providers and parents determine when immunizations are due and helps ensure that children get only the vaccinations they need. Clinical decision support tools within EHRs are used to provide patient-specific recommendations on vaccines to providers at the point-of-care during the patient encounter. Essentially this requires guidelines or recommendation to be made ‘computable,’ or sometimes called ‘machine readable,’ in order to implement in EHRs. One key component of a CDS implementation is the development of the rules or logic necessary to guide a specific recommendation.

As technology and policies continue to evolve and the adoption of EHRs increases, policies and standards governing immunization data and the exchange of data will need to evolve. Equally important is the development of evaluation strategies to address the efficiency and effectiveness of IIS. These systems, services, and tools will need to be flexible to support the varied requirements across the public health enterprise. State and local participation in national standards efforts are critical to ensure that the business needs of public health are incorporated in policies that have a direct impact on the IIS that states and locals are responsible for purchasing (in some cases developing), maintaining, and most importantly, using.

### **Review Questions**

1. Define an Immunization Information System.
2. What role does the federal government have in the development and implementation of Immunization Information Systems?
3. What are some of the requirements specified in Meaningful Use for providers, e.g., hospitals and eligible professionals, for Stage One and Stage Two? What is the difference?

4. What standards are specified in Meaningful Use for Immunization Information Systems?
5. What role does Clinical Decision Support have in Immunization Information Systems?
6. What is the purpose of the minimum functional standards for Immunization Information Systems?
7. Describe the functional standard that addresses data quality.
8. Describe the functional standard that addresses the security and privacy of personally identifiable information.
9. What is the purpose of reminder and recall systems?
10. Identify three key stakeholders responsible for developing policies and standards for Immunization Information Systems.

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**Part IV**  
**New Challenges and Emerging Solutions**

# Chapter 20

## New Means of Data Collection and Accessibility

I. Charie Faught, James Aspevig, and Rita Spear

**Abstract** This chapter discusses data needs within the public health enterprise and provides an overview of current and future methods and systems supporting data collection. The foundations of public health's need to deploy information systems for data collection, based in the essential services of public health, are examined. Openings for the development of partnerships between the primary care and public health sectors are explored in the context of the expansion of the use of Health IT across the healthcare delivery system. New tools and technologies are coming to the fore that may fundamentally transform the management of data and information in public health. While barriers to the effective use of current and future technologies, in support of data collection and access to data, exist, rather than dread the rapid expansion of the use of Health IT, readers are encouraged to look for opportunities. Several options that may move the public health system forward are proposed.

**Keywords** Data collection • Public health data • Individual data • Aggregate data • Community-level data • Primary data • Secondary data • Secondary data use • Data type • Data standard • Registry • Database management system • HL7® • Messaging • Electronic data interchange • mHealth • Cloud computing • Meaningful use • EHR

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### Learning Objectives

1. Describe three different public health surveillance systems typically implemented at the state level.
2. Offer an independent and informed definition of the term *public health data*.
3. List and describe the four distinct Cloud service models.
4. List and describe at least three new tools supporting the collection of public health data.
5. List and describe the benefits of mHealth.
6. Discuss the advantages and disadvantages of the traditional methods of public health data collection.

## Overview

This chapter discusses data needs within the public health enterprise and provides an overview of current and future methods and systems supporting data collection. This chapter examines the need to deploy information systems for data collection based on the ten essential services of public health. Openings for the development of partnerships between the primary care and public health sectors are explored in the context of the expansion of the use of Health IT across the healthcare delivery system. New tools and technologies are coming to the fore that may fundamentally transform the management of data and information in public health. While barriers to the effective use of current and future technologies, in support of data collection and access to data, exist, rather than dread the rapid expansion of the use of Health IT, readers are encouraged to look for opportunities. Several options that may move the public health system forward are proposed.

## Introduction

The consumerization of information technology (IT) has increased the demand for easier means of data collection and also raised expectations for the accessibility of both data and information systems. This chapter explores public health data collection and accessibility in light of the new technologies and systems available to public health, both internally and externally. The chapter starts with an overview of the ten essential public health services, which provides the context justifying public health's need for data. Obtaining and using data is essential to the practice of public health informatics. The second section provides an overview of methods for data collection, and the third section discusses new technologies enabling improved accessibility to data.

## What Is Public Health Data?

Understood in the broadest possible terms, *public health data* may be thought of as *any data pertaining to the health of populations*. This is a very broad interpretation of the concept of public health data and it encompasses several classes of data. Public health data has (1) individual; (2) aggregate; and (3) community-level attributes. The *individual* component of public health data is frequently based on the clinical encounter in the primary care sector, or represents data that has been obtained from the delivery of preventive healthcare services to clients by programs operated by local health departments. Individual data is identifiable data and is considered Protected Health Information (PHI) under the HIPAA rule.

*Aggregate* data is typically information on individuals that has already been processed in some fashion to derive additional information. This information may become a data input to another research or analytical process. This occurs, for example, when data on the prevalence of malignant neoplasm in a county is combined with injury data and other information to contribute to a composite score or ranking of the comparative “health” of a county [1].

Lastly, *community-level data* in public health is related to *ambient conditions* that may influence health. An example would include data on lead levels in the soil at various sites within a community. However, community-level data is not simply limited to data associated with the ecosystem and the natural world. In the context of our broad definition of public health data, it may also be used to describe data that may have an effect on the entire community, including social and economic factors such as the median income of individuals or groups in a population. It also commonly includes data related to the quality or availability of medical services in a community, such as the number of physicians in family practice that are available to serve the community. Community-level data may also describe factors likely to impact the accessibility of healthcare services, such as the proportion of uninsured and under-insured within a population.

### *Types of Public Health Data*

The prior section provided a definition of public health data based largely on the attributes of the data itself. Another common way to classify public health data, particularly among informaticists involved in research and epidemiological investigation, is by the data’s source relative to the user of the data. From this perspective, *primary data* is defined as data that is generated within the organization itself. The organization that generates the primary data controls the data and bears responsibility for its completeness, accuracy, and security. Data related to an individual patient’s record and entered into the organization’s own Practice Management System (PMS) or Electronic Health Record (EHR) to support the delivery of services to that patient is an example of primary data.

*Secondary data* is information collected and provided by another organization [2]. An example of this type of data would be data produced by an external organization, such as a primary care clinic furnishing data to a state-level public health diabetes control program for the purpose of assessing the clinic's performance in their management of patients with Type II Diabetes. In this case, the clinic's quality assurance manager would regard the data they submitted as primary data because their clinic had generated the data. However, an informaticist at the state health agency would regard that same data as secondary data. Public health informaticists frequently work with secondary data from a relatively large number of external sources.

The term *secondary data* is sometimes confused with the term *secondary data use*. "Secondary data use" occurs when primary data, such as data that originally supported the delivery of client care or preventive health services, is put to additional subsequent uses by the organization [3]. For example, data on influenza vaccine administered to individual older adult patients may be aggregated and assessed for quality reporting purposes, such as those measures associated with the Healthcare Effectiveness Data and Information Set (HEDIS) [4]. This illustrates the idea that the healthcare or public health organization may use the data it generates from the delivery of services for other purposes, such as assessing the quality of preventive services delivered, or reviewing the records of current clients to determine if they may be eligible to participate in other public health programs.

### ***The Need to Collect and Access Data Is Built-In to the Ten Essential Services of Public Health***

According to the American Public Health Association (APHA), the ten essential public health services [5] are:

1. Monitor health status to identify community health problems.
2. Diagnose and investigate health problems and health hazards in the community.
3. Inform, educate, and empower people about health issues.
4. Mobilize community partnerships to identify and solve health problems.
5. Develop policies and plans that support individual and community health efforts.
6. Enforce laws and regulations that protect health and ensure safety.
7. Link people to needed personal health services and assure the provision of healthcare when otherwise unavailable.
8. Assure a competent public health and personal healthcare workforce.
9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
10. Research for new insights and innovative solutions to health problems.

While each essential service requires data, the essential services that most require data collection (as opposed to data interpretation, analysis, or connectivity) are 1, 4, 5, 9 and 10. As such, each of these is discussed individually.

The first essential service is *monitoring the health of the population*, which includes the ability to track, assess, and modify. The University of Kansas explains that “public health surveillance—the ongoing, systematic collection, analysis, and interpretation of health related data—is at the core of this Essential Service” [6]. The fourth essential service is the “*comprehensive approach to community health*, in which professionals and even entire sectors of a community collaborate to plan, implement, monitor, evaluate, and subsequently modify activities,” all of which requires data to “guide the development of programs” [6].

The fifth essential service encompasses the following activities [6]:

- Leadership development at all levels of public health;
- Systematic community-level and state-level planning for health improvement in all jurisdictions;
- Development and tracking of measurable health objectives as a part of continuous quality improvement strategies;
- Joint evaluation with the medical health care system to define consistent policy regarding prevention and treatment services; and
- Development of codes, regulations, and legislation to guide the practice of public health.

The data required for the fifth service includes data needed to evaluate, track, and trend quality measures in health. Data is also required in order to present the value and effectiveness of programs to key stakeholders such as policymakers [6]. The ninth essential service requires activities such as “*ongoing evaluation of health programs* based on analysis of health status and service utilization data, to assess program effectiveness and to provide information necessary for allocating resources and reshaping programs” [7]. Lastly, the tenth essential health service involves *research*, which by its very nature requires the analysis of complex data [6].

In summary, data is needed for accomplishing the ten essential health services. Without accurate and comparable data, particularly from a variety of sources, activities such as monitoring, evaluating, planning, and research cannot occur. While all of the essential services require data, individual essential services require data collection and accessibility.

One of the challenges of public health informatics practice is to determine what data is needed, where that data is located, and how to collect or access that data. The next subsection provides an overview of what data is needed, by reviewing categories of data elements that are mandated for collection by state legal statutes and regulations.

### ***Categories of Data Elements Mandated for Collection***

A single set of required “public health” data elements does not exist. The United States largely follows a federal model in the administration of its public health programs. While federal agencies may provide overall direction and guidance, the responsibility for the actual collection of the data and maintenance of the systems to

store the data is largely the responsibility of the states. Most states support the collection of many similar data sets, and use similar data systems to support the collection of this information. Federal health agencies often provide leadership in order to promote uniformity and comparability between systems. There is a need not only to assess the health status of public health jurisdictions at the state and local levels, but also at the national level.

For example, vital statistics are collected by every US state and territory. These are data associated with marriages, divorces, births, deaths, fetal mortality, and induced abortions [8]. Vital statistics data consists of several data sets and each data set consists of multiple data fields. The National Vital Statistics System has taken the lead in standardizing the core *data elements* collected by the states. Virtually all state vital statistics systems have standardized the coding system used for causes of death on the International Classification of Diseases version 10 (ICD-10) coding standard [9]. The use of common coding standards and data domains permits data to be readily compared between public health jurisdictions. A *data domain* may be thought of as a list of permissible values that may be used to populate a data field. For example, the ICD-10 codes provide a list of all the values that are acceptable for populating a “cause of death” field in the mortality data set. This is an excellent example of the use of a standard to ensure that all vital statistics systems generate data that is comparable between states. The National Center for Health Statistics (NCHS) also receives aggregate counts on the numbers of marriages and divorces from each state, an example of aggregate reporting in public health.

Other data sets of importance to public health include:

1. The National Hospital Discharge Survey, which includes the data elements defined in the UHDDS (Universal Hospital Discharge Data Set). The National Hospital Discharge Survey is a census capturing the demographics of patients, diagnoses, major procedures, and dates of admission and discharge, which permit length of stay to be calculated [8].
2. The National Hospital Ambulatory Care Survey is a source of data similar to the UHDDS, but it is a survey targeting the population of patients who are seen in a hospital’s ambulatory care centers (e.g., same-day surgery) or emergency departments, but who are not admitted for an overnight stay [8].
3. The Behavior Risk Factor Surveillance Survey (BRFSS) is a relatively unique survey, funded in every state by the Centers for Disease Control and Prevention (CDC) to assess the prevalence of behaviors impacting individual health. BRFSS includes questions designed to assess risk factors related to smoking, alcohol use patterns, health screenings, and other health behaviors [10].

### ***Data Elements and Surveillance Systems***

In addition to the data elements recommended to the states from the federal level, each state may mandate the collection of its own set data elements related to health or environmental conditions of interest. For instance, the state of Michigan



mandates the collection of information directly related to the state public health's department's "duty to prevent disease and promote the public health through public health programs, health statistics, and health-related research" [11]. The data includes communicable diseases and other diseases and hazards that can threaten the health of the public [11].

## Data Systems

Certain systems for data collection are also common to the various states, especially registries associated with a specific class of diseases or health risks. Common systems of data capture include:

- Immunization registries implemented with the goals of achieving and maintaining high rates of immunization, by ensuring that infants and children receive appropriate vaccinations at the recommended intervals.
- Cancer registries used to collect and organize data on neoplasms and follow-up cancer patients.
- Trauma registries consist of a database(s) on patients who have received severe injuries.
- Birth defect registries collect information on newborns with birth defects.
- Diabetes registries collect data about patients with diabetes, to assist in the management of their care as well as research. Much of this data is collected from outpatient clinics.
- Implant registries track the performance of implants, including complications, deaths, and defects resulting from implants, as well as longevity.
- Transplant registries maintain databases of patients who need organs.

For illustrative purposes, several examples of data collection systems are provided covering the categories of immunization, cancer, and trauma registries.

## New York Immunization Information System (NYIIS) Requirements

New York has listed the data elements pertaining to its immunization registries on the New York State Department of Health website as follows: "the patient's name (first, middle and last); date of birth; gender; address, including ZIP code; mother's maiden name; mother's or other responsible party's name (first, middle and last); and vaccine administration date, type, lot number and manufacturer" [12]. These data elements are considered by the State of New York to fulfill the minimum required elements as recommended by the CDC.

The website also provides information about regulations relevant to NYIIS, describing those required to report, which includes any provider ordering an immunization. The methods of reporting are: (1) direct online entry of immunization information into the statewide system; (2) use of existing electronic information systems compatible with NYSIIS; and (3) historical immunization information

previously submitted to a regional registry. The state also requires the information be submitted to the correct registry, which is based on practice location rather than patient location [12].

### **Oregon Cancer Registry Requirements**

Since 1995, the state of Oregon considers cancer to be a reportable disease. The Oregon State Cancer Registry (OSCaR) is used to collect and analyze cancer cases in the state. The goal of the registry is to develop ways to prevent and control cancer [13].

Because cancer covers a broad category of illnesses, case definitions of specific diagnoses, such as all invasive malignant neoplasms or juvenile astrocytoma, are required to describe how the registry is to be populated. The supporting demographic information collected includes patient information such as name, address, age, and sex, and diagnosis and treatment information including the types and characteristics of the cancer, details of the diagnosis, and treatment given. Lastly, reporters include hospitals, clinics, and physician's offices diagnosing or treating Oregon residents [13].

### **Florida Trauma Registry Requirements**

Florida is one many states collecting data on cases of trauma: "The Florida Department of Health (FDOH) Trauma Program collects patient-level data from all verified and provisional Trauma Centers quarterly. Each Trauma Center has its own unique software system that collects data in varying formats and then generates files submitted to the statewide Trauma Registry" [14]. Further, the state collects information from trauma centers includes activities such "as performance improvement, outcomes research, and resource utilization" [14]. The goal of the program is to provide "necessary data for statewide planning and injury prevention initiatives" [15].

Florida has outlined the data elements for trauma registries on the Florida Department of Health website, which include 224 data elements [14]. Of the 224 data elements, 115 are required, and include patient demographic information (patient identifier, age, birth date, ZIP code), health information (pulse, blood pressure, drugs given), and diagnosis and treatment data [14].

### **Summary of State Examples**

While each state has its own data collection, reporting, regulations, and requirements, some categories of data elements are common to the states. These include demographic information on individuals, and diagnosis and treatment information. Most states also have regulations which require providers to collect and report a

minimum set of data elements relative to each health issue or population of interest. Lastly, however, methods for collection of data may vary depending on the state's technology infrastructure.

## *Technical Data Types*

The public health informaticist must take a more technical view of public health data. This is especially so when the public health informaticist is called on to combine data from different sources for the purposes of assessing a public health issue. When data is stored in a database it is usually classified by its data type. Most database management systems (i.e., the software “engine” that manages and controls a database) have powerful built-in tools that permit the protection, management, query, and manipulation of the data in the database. Common types of data that may be stored in database are listed in Table 20.1.

**Table 20.1** Common data types

Data type	Description
Text	Probably the most common data type. The data in a text field will consist of a mix of characters (i.e., letters and numbers). A street address, such as “123 Main Street” is an example of text data.
Numeric data	Another very common data type. Numeric data consists of numbers and may include whole numbers (i.e., integers), positive numbers, negative numbers, and also decimal numbers defined to a certain degree of precision (i.e., the database administrator may generally set the number of places following the decimal). Database management systems (DBMS) frequently have special classifications for each sub-type of numeric data their DBMS may be configured to manage. These sub-types of numeric data are created for efficiency. Theoretically, numbers may be both infinitely large and infinitely subdivided. Setting up every numeric data field to hold “infinite” numbers would sap a lot of a databases’ processing power. This is why, when database administrators set up a database, they tend to use the simplest numeric sub-type that will fulfill the purpose of the field. For example, the number of children in the household will likely be reported as a whole number, so, in a database, this field would be given one of the “integer” numeric data sub-types.
Date/time	The Date/Time data type ensures that valid data on the date and/or time of events may be collected. Most DBMS also incorporate sophisticated functions that permit the use of dates in calculations, such as finding the number of days between two dates (e.g., a hospital admission date and a hospital discharge date).
Boolean	Boolean data may be thought of as a “yes/no” or “true/false” data type. It is a very efficient way to store data for fields where there is only an <i>either/or</i> option with regard to the condition's state, such as “living or deceased.”
BLOB	BLOB is an acronym for Binary Large Object. The BLOB data type allows other digital files, such as medical images, spreadsheets, and word processing documents to be stored in a database. If you download a file from a website, that file may have been stored in a database as a Binary Large Object.

Table 20.1 is not an exhaustive list. However, when combining data from multiple sources, informaticists must understand the data types with which they are working. If the data, particularly numeric data, is obtained from different Database Management Systems (DBMS) then each system may have used a unique or somewhat proprietary data type; the informaticist will likely have to *transform* or convert the data into a common data type. It is important for public health managers to understand that there are different data types associated with different DBMS platforms, and that careful management of data types within an organization's information systems portfolio can promote consistency and comparability of data across systems. Management of the numeric data sub-types is generally the most interesting, or problematic, depending on your perspective. One of the keys to understanding the numeric data types and sub-types is to understand the type of mathematical operations (addition, subtraction, calculation of a mean, etc.) the system will need to support in relation to a particular numeric data field. If no mathematical operations are to be performed on that data, such as a phone number, then it does not need to be defined as a numeric field.

The examples provided demonstrate that public health data elements are quite varied. They may relate to demographics, diagnoses, medical procedures performed, or episodes of care, and may also include environmental and community-level data. This means that the public health informaticist must understand and select data sources carefully when approaching the study of a public health issue, and also consider the technical data types with which they will be working. Keppel and Friedman have described a three-step process involving (1) monitoring for health status and risk factors, (2) identifying and evaluating the data resources available, and (3) informing and advising managers, policy makers, and the public of the findings [16].

## Data Collection in Public Health

Collecting data in public health has typically been an arduous process. Until recently, public health professionals working in association with primary care generally gained access to relevant patient information by abstracting paper charts. Practices varied from one medical facility to another and from one public health department to another. Data collected on paper was often not collected using standard definitions for the condition(s) of interest, and different formats and layouts were often used by different healthcare organizations in their charting process. The advent of telecommunications began to change the way public health data were collected and reported.

Currently, we might classify methods of transferring data and reporting to public health as either (1) adaptations of traditional paper-based reporting, or (2) electronic information exchange. While substantial strides have been made in recent years, the near-universal adoption of EHR technology has yet to occur [17, 18]. As a result we

have many traditional means of collecting data operating within public health agencies, which continue to exist side-by-side with more automated emerging methods of data collection.

### ***Paper-Based Reporting***

Paper represents the oldest method of reporting to public health. Because of its labor intensive nature and the frequent requirement to manually copy patient data from a paper chart to a paper form, it is generally used by healthcare providers only to make the minimum legally-required reports to public health agencies. A paper report, if it must be sent through the mail, lacks timeliness. Additionally, there is no realistic way to check the accuracy of the data written on a paper form. Dates or codes may be entered incorrectly. Data collection and reporting through the use of the telephone usually may be considered an extension of paper-based data collection. Reporting by phone has the advantage of immediacy. However, one of the major disadvantages to the public health organization is that someone with suitable expertise must be available to take the report. This individual often ends up filling out the agency's paper form by hand for the condition of interest. Telephone-based surveys are often similarly labor intensive for the public health agency.

### ***Adaptations of Traditional Reporting: Fax Technology***

Fax technology may actually be thought of as a minor adaptation of paper reporting methods. When using fax technology to share data, such as transmitting a disease report to public health, the submitting organization often has to manually fill out a form, print, and fax it. However, more automated faxing technology is available to some public health and healthcare organizations. In these cases, a form may not need to be printed or filled out by hand; it can be generated electronically and sent through the fax system to another fax machine or fax server. If received by a fax machine, the form will be printed out, but if received by a fax server, the receiving public health organization may simply be able to store an electronic image of the document without printing it. However, data entered into a form, even if the form is sent electronically by fax from one site to another, still generally fails to consist of structured or "fielded" data, so missing data and data entry errors are quite likely. Additionally, receipt of a faxed report generally means that a person on the receiving end of the connection must enter the form's data manually into the public health agency's electronic systems. This certainly transmits the information in a more timely fashion than the mail, but health department staff must still enter the case information by hand.

### ***Adaptations of Traditional Reporting: OCR***

Optical Character Recognition (OCR) is sometimes used by public health organizations that need to manage a large volume of submissions by paper. Under these systems, the individuals submitting data usually fill out highly-structured paper forms, which are then mailed to the public health agency. After the forms arrive at the public health agency, they are scanned. Speciality software recognizes the characters on the form, automatically converting the written characters on the paper form into electronic text. The specialty software is frequently configured to load data directly into an electronic data store. However, the weakness of this type of system is timeliness, as forms must often be mailed. Also, it is relatively labor intensive, as staff must scan the forms and, not infrequently, manually review those forms where the characters that could not be fully or correctly interpreted by the OCR software. An additional weakness of these systems is that they tend to be somewhat costly and relatively challenging to set up and maintain, especially if the system must have a high-volume capacity. Moreover, there are no data quality checks when a user fills out a scannable form, so it is possible that users will fail to enter all required information or could possibly enter incorrect data. Both fax and OCR technology may be thought of as transitional technologies on the way to truly electronic reporting.

### ***Electronic Information Exchange: “Fill-able” Electronic Forms***

Various technologies have been developed to create fillable electronic forms in an attempt to combine the conceptual simplicity of filling out a paper form with the efficiency of submitting an electronic document. These forms are typically downloaded from a public health agency’s website and filled out electronically by the user. After attaching the completed form to an e-mail message, the user sends it back to a specified e-mail account at the relevant agency. Fillable forms may also be designed to allow built-in data checks, to ensure that data is entered completely and correctly, and the system may be configured to automatically update a database. However, users of fillable forms must generally use a PC and have access to the Internet and e-mail. They must also possess adequate file management skills in order to administer their own submissions. Additionally, for any data sent via e-mail, security is a very important consideration.

This section has reviewed the limited advantages and the very substantial disadvantages of some of the more traditional methods of collecting data in public. The following section begins the introduction of new means of data collection and reporting. The four new means of data collection that will be discussed include (1) messaging between systems as a vehicle for data sharing, with HL7<sup>®</sup> messaging briefly introduced as an example; (2) the use of web-based interfaces to provide more direct and efficient access to a public health agency’s systems, and (3) mobile

health (mHealth) as an end-user technology that may permit more efficient data collection while promoting access to public health information, if coupled with the right infrastructure. (4) The EHR and Health Information Exchange (HIE) will also be introduced as potential sources of data for the public health enterprise.

## **New Means of Data Collection and Reporting: HL7<sup>®</sup> Messages**

Messaging standards such as Electronic Data Interchange (EDI) are used extensively to support business transactions by establishing how data is moved between systems [19]. The Health Level 7 (HL7<sup>®</sup>) set of messaging standards is the most widely adopted in healthcare. At its most basic, HL7<sup>®</sup> is a set of specifications. The most important, and extensively used, of these specifications is a messaging standard that enables healthcare information systems to exchange defined sets of both administrative and clinical data. Administrative data tends to be more universally supported across the HL7<sup>®</sup> standard and is more uniform in the way in which its segments are defined. Clinical data tends to require separate efforts to more specifically define the types of messages required, through use of a standard data vocabulary (i.e., “values”) and code sets for those domains of clinical practice. This has often involved incorporating already extant code sets into the HL7<sup>®</sup> standard, so as not to duplicate work or breed confusion. For example, the Codes for Vaccines Administered (CVX) code set, which is maintained by the CDC’s National Center for Immunization and Respiratory Diseases, was defined to promote uniformity for the values stored in immunization registries and is continually expanded as new vaccines are recommended for use. The adoption of CVX as an HL7<sup>®</sup> code set for use across all health IT helps to promote conformance to vocabulary standards [20, 21].

### ***Structure of an HL7<sup>®</sup> Message***

An HL7<sup>®</sup> version 2.x message is made up by a sequence of segments, with each segment located on its own line in the message. The specific content of each segment is denoted by the tags leading that particular segment. In this way, HL7<sup>®</sup> is based on the general concept of mark-up languages, such as hyper-text markup language (HTML) or extensible markup language (XML), which are used to separate format from content. Just as an HTML or XML tag defines the format of a web document, the tags leading an HL7<sup>®</sup> segment define the content of the field. This is in contrast to more traditional methods of data transmission, such as fixed-width or comma separated value formats, where the position of the data itself provides the structure that is used to identify the data for import into the target system. HL7<sup>®</sup> messages can be very extensive, encompassing a large amount of detailed data.

## ***Electronic Data Collection and Reporting: Web-Based Interfaces***

Web-based interfaces have changed the face of electronic data collection and reporting. A health department can develop a web interface that would provide direct access to some of its core systems, such as a state-level immunization registry, and end-users can update the database directly through the web interface. In other words, web-based interfaces permit public health agencies to open up their systems to direct data entry and direct data access by their trusted information trading partners, instead of having to create complex and costly EDI-based messaging between systems [7]. The advantages of web-based interfaces include the abilities to add substantial capacity to check and verify data quality at the point of data entry along with minimal investments in infrastructure and technology; the end-user generally only requires an Internet connection and web browser.

## ***New Means of Data Collection: Mobile Health (mHealth)***

The advantage of mobile devices, such as ultra-light laptops, smartphones, or tablets, is ready access to data for public health professionals and clients. When a public health professional utilizes a tablet on a public health home visit, the professional may improve documentation and data collection by being able to complete the client encounter record during the interview, or in a few spare moments following the examination. Clients may benefit from the use of mobile, wireless devices as a support for more continuous and routine monitoring, for example, by transferring data from their home-based self-monitoring devices directly into the provider's EHR [22]. The convenience of direct data transfer increases the likelihood of patient compliance with their monitoring regime and improves the availability of data to the health professional. Adoption of mobile health (mHealth) tools has increased along with improvements in their form-factor (hardware size, configuration, etc.); these tools have been transformed into small, highly portable, lightweight devices, with expanded wireless network coverage.

Mobile and wireless computing *reduces the cost of technology infrastructure*, as a single device may be assigned to a public health professional who will carry the device with them, instead of needing to install a workstation at every possible location where the individual would access electronic data. The costs of cabling a wired network are also reduced or eliminated, as mobile devices are generally wireless. Mobile technology also enables *more efficient work processes*. Providers may now have access to virtually complete electronic client information at the point-of-care, and need not spend time waiting for information to be manually retrieved or hand-delivered in order to make decisions. mHealth also supports *reductions in errors*. Errors may originate from a variety of sources, including inaccurate transcription or data entry, as well as the lack of ready availability of a decision support tool or



reference materials. Wireless technology and mobile devices may help to eliminate these sources of error by supporting structured documentation and ensuring that every public health provider and professional has access to decision support systems and electronic references at all times.

Several of the most important emerging uses of mobile devices for clinicians and public health professionals may be occurring in the area of global health. Healthcare in developing nations may be substantially enhanced by mobile and wireless devices. It seems increasingly likely that much of the developing world may “leap-frog” the need to develop a fully-wired infrastructure and proceed directly to high-speed wireless infrastructures. Additionally the capacities of relatively affordable devices, such as smartphones and tablets, now exceed the processing power of many older desktop computers. For example, inexpensive attachments are available that can turn a smartphone camera into a “microscope” that may aid in the diagnosis of skin diseases or even infections such as malaria. Even with current capabilities, mobile phone cameras may be used for tele-dermatology and remote consultations from the field using streaming or recorded video [23].

### ***Future Trends: EHRs and HIEs as Data Sources***

The Health Information Technology for Economic and Clinical Health Act (HITECH) established an incentive program reimbursing eligible providers for the “meaningful use” of certified EHR technology [24]. Stage 1 of this program allows providers the option of submitting electronic data to a state’s immunization registry and/or exercising a second option to submit syndromic surveillance data to a public health agency [25–27]. Stage 2 of the meaningful use objectives encourages the electronic submission of data to a state cancer registry and also allows the option of submitting data to an unstipulated “specialized registry” [28]. Developing the capacity to submit to registries in stages 1 and 2, particularly an unnamed specialized registry, will require the cooperation of providers interested in submitting electronic data to a registry as well as a commitment of resources from invested federal, state and local public health agencies.

The options for submission to public health registries under the current meaningful use program are focused on a limited number of public health systems. A 2012 Institute of Medicine report titled “Primary Care and Public Health: Exploring Integration to Improve Population Health” highlights the need to integrate and align healthcare delivery more broadly [29]. One of the challenges to obtaining the data needed to support public health surveillance activities is that it comes from independent sources outside the traditional public health system where population health and data quality have not, traditionally, been a major concern [30]. The IOM report recommends linking “...staff, funds, and data at the regional, state, and local levels” and offers several concrete steps for leveraging existing programs to achieve this alignment [29].

Building on the IOM's recommendations for better integration under existing programs, there are additional opportunities for the alignment of primary care with public health through another of HITECH's existing programs, the Regional Extension Centers (REC). Each state is served by a designated REC and is charged with assisting hospitals and clinicians in their efforts to implement the EHR and achieve meaningful use [31]. However, in many states, public health agencies likely will be required to take the initiative in establishing partnerships across the health delivery system by working through the federally-funded RECs as points of contact.

Additionally, the Affordable Care Act (ACA) of 2010 established incentives to create Accountable Care Organizations (ACOs) [32]. The ACO model aims to incentivize the provision of highly coordinated care for patients as well as improving health outcomes for populations; aligning the goals of public health with those of primary care [32]. ACO's will rely heavily on technology to create integrated networks for the coordination of care across independent healthcare organizations. ACOs offer an opportunity to break out of the traditional silos that constrain public health and the healthcare delivery systems, by creating structures better integrated by the application of Health Information Exchange (HIE) technologies. Coordination between public health agencies, RECs, and ACOs may offer a tangible proving ground to demonstrate the feasibility of achieving the IOM's recommendations for greater integration and improvements in data collection and accessibility between the public health and primary care systems.

In summary, EHRs have significant potential as data sources and their applicability to public health efforts, include the potential to populate immunization registries, syndromic surveillance systems, cancer/tumor registries and other systems. Health Information Exchanges (HIEs) also represent a potential source of data for public health agencies if HIEs are implemented with the needs of public health as one of their principle considerations.

### *Challenges to the New Ways of Data Collection*

We currently have a relatively chaotic hodge-podge of methods to collect data in public health. Some providers and public health agencies on the "have-not" side of the digital divide are still collecting data on paper or making reports by phone. State and local health jurisdictions, concerned over the loss of reports of conditions of interest, may be reluctant to mandate, either in statute or rule, that healthcare professionals may submit data only in certain electronic formats. Other public health agencies have opened up key systems to trusted external users by deploying web interfaces, such as a state health agency giving trained staff at a local health department the rights to access and directly enter data into a state immunization registry.

In contrast, some public health agencies have worked extensively to develop EDI-based data collection with key trading partners. The capacity to successfully

implement EDI is predicated on both trading partners having sufficiently compatible electronic systems. It also requires sufficient resources to work with all the relevant trading partners toward the exchange of select health information. In general, state health agencies are limited in their available resources. When implementing an EDI program, agencies will focus on the largest information trading partners where they will obtain the greatest benefit for their effort and expense (in terms of the amount of data collected). Small trading partners, such as physician offices, often do not have the resources to automate the transfer of data to a state or local health agency and therefore cannot participate in the EDI.

### **Public Health Resources and Readiness**

While the new technologies have distinct advantages, the simplicity for the end-user generally translates into greater complexity and expense for the public health agency that is hosting the web application or building out a messaging infrastructure. Developing and maintaining a web application is generally more complex and costly than developing a traditional client/server application. Additionally, the readiness of the public health enterprise to engage with the primary care sector, even as the primary care engages in significant new HIT initiatives, is somewhat open to question. The shortage of formally-trained informaticists, coupled with resource limitations, tend to constrain public health's capacity to engage with the rest of the healthcare delivery system in the technological arena.

### **Challenges Associated with Messaging and Data Standards**

Issues around inter-system messaging and data standards may serve to illustrate some of the constraints placed on the public health technology enterprise. Standards in messaging and data (i.e., "content" standards) are not static in healthcare or public health. For example, when utilizing HL7<sup>®</sup> messaging for immunization data reporting, new vaccines continue to be added to the immunization schedule. This is a simple example of the ongoing additions to data standards in public health and healthcare. Messaging standards also continue to change and evolve. Health departments that had invested substantially in early EDI must likely now move to HL7<sup>®</sup> as their information trading partners change and upgrade their technologies. In brief, data and messaging standards must not only be initially developed and adopted, they must also be maintained and upgraded. Technology is not static and, even as primary care systems moves forward in the use of Health IT, public health must prepare to keep pace with and also benefit from the widespread adoption and use of EHR and other technologies. The section that follows will discuss the advanced infrastructures capable of supporting both data collection and vastly improved *data accessibility* for public health's partners, using Cloud-based technologies and a Service Oriented Architecture (SOA).

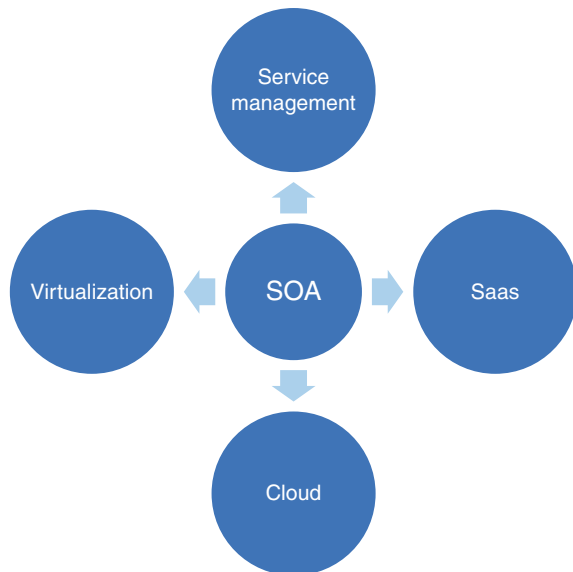
## New Means of Data Accessibility

Population health-related data is being generated electronically across the United States and the world. The customers for this data include: public health managers and policy-makers, epidemiologists, researchers, educators, clinical organizations, providers, and the public. How can this data be gathered, stored, and made available for public health and other stakeholders? The IOM recommends an inventory of existing databases and technology, and the creation of new shared platforms between public health and primary care [29]. The diagram in Fig. 20.1 illustrates the enabling technologies that can make data accessibility a reality. The section will describe new means of data accessibility, followed by the practical use of enabling technologies to support the accessibility of public health data.

### *Data Accessibility and Cloud Computing*

Cloud computing is a model for enabling convenient, on-demand network access to a shared pool of configurable computing resources (e.g., networks, servers, storage, applications, and services) that can be rapidly provisioned and released with minimal management effort or service provider interaction. The cloud model is composed of [33]:

- Five essential characteristics
  - On-demand self-service
  - Broad network access



**Fig. 20.1** Technologies for data accessibility

- Resource pooling
- Rapid elasticity
- Measured Service
- Three service models
  - Cloud Software as a Service (SaaS)
  - Cloud Platform as a Service (PaaS)
  - Cloud Infrastructure as a Service (IaaS)
- Four deployment models
  - Private cloud
  - Community cloud
  - Public cloud
  - Hybrid cloud
- Key enabling technologies
  - Fast wide-area networks
  - Powerful, inexpensive server computers
  - High-performance virtualization for commodity hardware

### ***The Cloud Service Models***

Cloud Software as a Service (SaaS) allows the user to access the application with a web browser or application programming interface (API). The user does not control the application, the servers, the operating system (OS), data backup, or the network resources. Cloud Platform as a Service (PaaS) enables the end-user to deploy their applications on hardware that is owned and maintained by another company, using the tools provided by the cloud vendor. Cloud Infrastructure as a Service (IaaS) enables the end-user to deploy applications with greater control of the servers, including installation of the OS, while not controlling the underlying cloud infrastructure [33] (Table 20.2).

### ***Software as a Service (SaaS)***

SaaS is the easiest and least expensive of the three service models for users/consumers to utilize. The vendor supplies the hardware, software including the OS, and the application. From the user's perspective, capital costs are eliminated and the application is available from anywhere. With a SaaS, a public health department does not have to maintain a server, perform upgrades, or perform data backups. For example, many providers have elected to implement electronic health records using a SaaS model. This allows the providers to focus on their core functions rather than hire or

**Table 20.2** Cloud deployment models

Deployment model	Description of model
Private cloud	The cloud infrastructure is provisioned for exclusive use by a single organization comprising multiple consumers (e.g., business units). It may be owned, managed, and operated by the organization, a third party, or some combination of them, and it may exist on or off premises.
Community cloud	The cloud infrastructure is provisioned for exclusive use by a specific community of consumers from organizations that have shared concerns (e.g., mission, security requirements, policy, and compliance considerations). It may be owned, managed, and operated by one or more of the organizations in the community, a third party, or some combination of them, and it may exist on or off premises.
Public cloud	The cloud infrastructure is provisioned for open use by the general public. It may be owned, managed, and operated by a business, academic, or government organization, or some combination of them. It exists on the premises of the cloud provider.
Hybrid cloud	The cloud infrastructure is a composition of two or more distinct cloud infrastructures (private, community, or public) that remain unique entities, but are bound together by standardized or proprietary technology that enables data and application portability (e.g., cloud bursting for load balancing between clouds).

Source: Mell and Grance [33]

worry about information technology infrastructure and hiring needs. The SaaS model also eliminates silos, makes data easier to access, and can be scaled to fit the organization. For example, a 400-bed Level 1 trauma center hospital will have a larger formulary (and therefore larger data accessibility needs) than would a critical access hospital in a rural community.

### ***Practical Use of Enabling Technologies for Public Health Data Accessibility***

Which model will be the most effective for public health data accessibility depends on the kind of data, the potential stakeholders, and the reporting requirements. The different deployment models lend themselves to the different types of data availability and stakeholders that interact with public health, such as providers, researchers, educators, and the public. The public model may be beneficial for analytics and business intelligence, such as healthcare and public health strategic planning. The public model uses de-identified data and encompasses SaaS. The private model, which has heightened security protocols, can use identified information, which would be useful when making communicable disease reports.

A hybrid model may be modified based upon stakeholder needs. For instance, a community cloud may include healthcare delivery organizations, which regularly collect data. If both public health and the local hospital had access, then duplication

of systems would not occur. Shared governance with the same security standards would also apply to the community model. Further, SaaS can be used to consolidate public health reporting and data aggregation. From another perspective, the infrastructure required would be minimal and an effective use of resources. In other words, state and local public health departments can pool their resources together rather than purchase stand-alone systems. If a public health department has not upgraded to electronic systems, then the new enabling technologies may be a practical solution.

## Summary and Conclusions

This chapter has discussed the closely-related issues of data collection and data accessibility in public health. Public health's need for data is grounded in the Ten Essential Services [5]. The discussion of the many different data elements required by the public health enterprise, as well as the data collection and information systems that have been or are being used to collect that data, illustrates the challenges faced by the practicing public health informaticist. The broad list of topics covered by this chapter, ranging from national programs of Health IT implementation to cloud-based infrastructure, suggests the complexity of the processes by which data is both collected and accessed. The breadth of public health practice requires equally ambitious systems of data collection. Data collection and data access systems must be part of a robust, and more ideally, unified health information systems infrastructure.

While new technologies for data collection and access exist, public health continues to lag in its investment in new infrastructure. Public health agencies need not transition to or use all the technologies described in the chapter. However, when the opportunities arise, public health organizations would be advised to opt for investment in the newer, more accessible technologies. Further, the benefits of newer technologies include the ability to efficiently utilize scarce resources, including personnel, while at the same time becoming more aligned with key stakeholders in the healthcare delivery system. The IOM has suggested the use of existing programs and infrastructure to better align the interests of population health and primary care [29]. Rather than being intimidated by the challenges posed by the rapid expansion of the use of the Health IT, the authors suggest that existing programs, in the form of RECs and ACOs, represent significant prospects that may offer concrete opportunities for partnership if approached by public health agencies.

### Review Questions

1. Select one of the traditional data collection and reporting systems described in the chapter and one of the “new means” of data collection also described. Compare and contrast these methods of data collection; listing and describing the advantages and disadvantages of each means of data collection.

2. Review the federal programs (ACOs and RECs) that the authors suggest may provide opportunities for public health. Select the program that you think would offer the greatest opportunities for a successful partnership with public health from the perspective of data collection and accessibility. Why did you select that program over the other program? Justify your answer.
3. If healthcare quality and preventive services were a major emphasis of the meaningful use program, and the adoption of Health IT is intended to support preventive and population health, why did public health receive so little formal funding through the HITECH Act?
4. What are some of the barriers to having the electronic health record provide data in support of public health data collection and reporting?
5. What recommendations would you make to assure that the electronic health record could successfully provide data capable of meeting public health's requirements and needs?
6. If you were creating a database and wanted to add a field to capture phone numbers, what data type would you assign to that field? Why?
7. Develop your own definition of the term *public health data*. Do you tend to favor a broad definition of public health data or a narrow definition? Research additional sources for other definitions of the term *public health data*. Do you agree or disagree with these authorities? Why?
8. Research the REC or an ACO in your home state and describe this organization. Questions you may want to address are: What is this organization's stage of development (i.e., planning, piloting, operational, etc.)? What is this organization's governance structure? What systems does it support? How many partners/clients does it currently have? And, most importantly, what is this organization's relationship to and level of support for population health?

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# Chapter 21

## Geographic Information Systems

Carol L. Hanchette

**Abstract** Geographic information systems provide powerful tools that can enable public health practitioners to analyze and visualize data and to make informed decisions in a timely and relevant manner. Since the publication of the first edition of *Public Health Informatics and Information Systems*, GIS has become increasingly more accessible and widely used. It has also become more powerful as new applications are developed and more spatial statistics are incorporated into GIS software programs. Many public health professionals—in epidemiology and disease surveillance, environmental health, and community assessment—are using GIS as a tool for analysis and decision-making. While the educational background of such professionals often does not include GIS, it is important for these GIS users to understand basic geographic and GIS concepts and to be able to interpret and critically analyze GIS maps created by others. Eventually, as such part-time GIS users become more familiar with the technology and its wide range of applications, they will go beyond mapping and begin to use GIS for more sophisticated forms of spatial analysis. However, GIS users must recognize that GIS is not a panacea; they must be aware of its limitations. Some of these limitations are tied to issues of map scale and the accuracy and completeness of available data; others concern the proper use of visualization and spatial analysis tools.

**Keywords** Geographic information systems • Topologically Integrated Geographic Encoding and Referencing • GIScience • Spatial data • Topology • Attribute data • Geocode • Geocoding • X-coordinate • Y-coordinate • Geographic coordinate system • Map projection • Scale • Vector • Raster • Point • Line • Polygon • Choropleth mapping • Address matching • Distance • Spatial query • Buffer functions • Overlay

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analysis • Point-in-polygon overlay • Polygon overlay • Spatial join • Areal interpolation • Spatial statistics • Color ramps • Desktop GIS • Shapefile • Metadata • Equal interval • Quantile • Natural breaks • Mean • Standard deviation

### Learning Objectives

1. Describe how geographic information systems (GIS) can be used to analyze public health information.
2. Identify specific GIS functions that can be applied to health data analysis.
3. Explain the limitations of GIS software and spatial data.
4. Discuss the emerging technologies that have implications for GIS use in public health.

## Overview

Geographic information systems provide powerful tools that can enable public health practitioners to analyze and visualize data and to make informed decisions in a timely and relevant manner. Since the publication of the first edition of *Public Health Informatics and Information Systems*, GIS has become increasingly more accessible and widely used. It has also become more powerful as new applications are developed and more spatial statistics are incorporated into GIS software programs. Many public health professionals—in epidemiology and disease surveillance, environmental health, and community assessment—are using GIS as a tool for analysis and decision-making. While the educational background of such professionals often does not include GIS, it is important for these GIS users to understand basic geographic and GIS concepts and to be able to interpret and critically analyze GIS maps created by others. Eventually, as such part-time GIS users become more familiar with the technology and its wide range of applications, they will go beyond mapping and begin to use GIS for more sophisticated forms of spatial analysis. However, GIS users must recognize that GIS is not a panacea; they must be aware of its limitations. Some of these limitations are tied to issues of map scale and the accuracy and completeness of available data; others concern the proper use of visualization and spatial analysis tools.

This chapter describes what a geographic information system (GIS) is, how it works, and the contributions it can make to analysis and decision making in public health. Commonly-used functions and limitations are also discussed.

## Introduction

During the past few years, the contribution of information technology to the practice of public health has become increasingly apparent and has led to the emergence of the discipline of *public health informatics*, defined as “...the systematic application

of information and computer science and technology to public health practice, research and learning [1]”. Savel and Foldy [2] highlighted three functions of public health informatics: (1) the study and description of complex systems, such as disease transmission models; (2) innovative use of data collection and information to improve the efficiency and efficacy of public health systems; and (3) the implementation and maintenance of systems that achieve the first two functions. Geographic information systems hold the potential to make significant contributions to all three.

A *geographic information system* (GIS) is a computer mapping and analysis technology, consisting of hardware, software, and data, all of which allow large quantities of information to be viewed and analyzed in a geographic context. It has nearly all of the features of a database management system, with a major enhancement: Every item of information in a GIS is tied to a geographic location. Lasker et al. [3] identified three basic types of information needs essential to public health services: (1) data collection and analysis, (2) communication, and (3) support in decision-making. Geographic information systems have enormous potential to contribute to the analysis of population-based public health with their ability to support all three types of information needs. With geographic information systems, public health professionals can manage large quantities of information; map and model the distribution of diseases and health care resources; analyze the relationships among environmental factors, socioeconomic environments, and disease outcomes; determine where to locate a new hospital or clinic; and even make decisions about the development or implementation of health policy.

## The Importance of GIS and Its Contribution to Public Health

Many introductory texts on medical geography and epidemiology begin with a reference to John Snow, the London physician who mapped cholera cases in the Soho District of London during the cholera epidemic of 1854 [4]. Snow was able to show that these cases clustered around the Broad Street pump. The closure of the pump, through the removal of the pump handle, and subsequent reduction in cases supported Snow’s contention that cholera was a water-borne disease.

Perhaps more interesting than Snow’s map, however, was his “medical detective” work preceding the 1854 epidemic and following the epidemic of 1849, which helped him to recognize the association between contaminated water and cholera. The cholera epidemic of 1849 killed over 52,000 people in Great Britain and over 13,000 in London alone [5]. While Snow published a brief account of this epidemic in 1849, he continued to carry out research over the next few years, leading to an 1854 edition of *On the Mode of Communication of Cholera* that was a more substantial work [6].

In that later account, Snow noted the association between cholera, poverty, elevation, and the water supply of the various London districts. A fascinating reconstruction, mapping, and geographic analysis of these associations was provided by Cliff and Haggett [5]. As the authors noted, “these associations result in some striking geographical distributions...” such as the higher mortality rates in areas adjacent to the River Thames and the relationship between cholera and water supplies of London Districts [5]. At that time, a number of metropolitan water companies

were supplying water to the city from a myriad of sources—some directly from the Thames, others from reservoirs. Cholera mortality was linked to contaminated water supplies provided by companies drawing their water directly from the Thames.

Today's technology makes it possible to carry out an analysis such as Snow's in a very small amount of time, at the desktop. Imagine Dr. John Snow at his desk with a powerful computer mapping and information system. On his computer screen, he has maps of London districts, their water supplies, and the locations of cholera cases. In addition, his water supply map database contains information about characteristics of the water, such as pH factor and water source. He also has a map of soils, with information about their characteristics, and a digital elevation model. With the tools available in a geographic information system, Dr. Snow could do point mapping of cholera cases, calculate distances to water sources, and examine the relationship of cholera incidence to water source, water type, soils, and elevation.

Snow's work provides an indication of how a GIS can benefit public health practice. Medical geographers, epidemiologists, statisticians and health practitioners have been carrying out mapping and spatial analysis for centuries, but have been doing it "longhand," so to speak. Some of the classic geographic research on probability mapping [7], disease diffusion and modeling [8], the spatial organization of cancer mortality [9], cardiovascular disease [10], and the allocation of health services [11] would have benefited from the use of GIS, or, more specifically, from the combination of GIS and statistical analysis software—all used some combination of mapping, spatial analysis, and statistical analysis.

Obviously, GIS is needed for more efficient processing and analysis of geographic data. It is also needed to integrate public health data from a wide range of sources, to perform population-based public health analyses, and to provide sound information on which to base decisions. Geography is a great integrator: Nearly every entity of public health information is located somewhere in space, whether it be a county, a ZIP code, a dot on a map, a hospital room, or even a point within the human body. GIS provides a means of integrating all this information through a spatial referencing system.

GIS technology, then, has much to offer public health practitioners. Perhaps most importantly, the analysis and display of geographic data is an efficient and effective means of providing data for decision-making; for example, how to implement lead screening guidelines [12]. GIS also permits the development of new types of data, the establishment of data partnerships and data sharing, and the development of new methods and tools for use by public health professionals [13, 14]. An additional benefit of GIS is that it can be used for quality control of health datasets. Geographically-based logical consistency checks can be carried out to verify the accuracy of geographic identifiers in health datasets.

The use of GIS among public health professionals has been on the increase, but it is still not a mainstream activity. In 1999, two editions of the *Journal for Public Health Management and Practice* were devoted entirely to GIS applications [15, 16]. In 2002, the first volume of *International Journal of Health Geographics* was published. Cromley and McLafferty have now published two editions of their *GIS and Public Health* textbook [17, 18]. For nearly a decade, Environmental Systems Research Institute (ESRI), the developer of ArcGIS software, has sponsored

a “Health GIS” conference; in 2013, the Urban and Regional Information Systems Association (URISA) will host its fourth “GIS and Public Health” conference.

The activities outlined above illustrate both the current importance of GIS and its potential to contribute to the ongoing assessment of health status in a community within the context of the second essential service of public health, namely the capacity to detect, “...diagnose and investigate health problems and health hazards in the community” [19]. It is therefore essential that public health managers and front-line practitioners develop a deeper understanding of GIS. This includes an understanding of some of the limitations of GIS, as well as an appreciation for the tool’s extraordinary capacity to support both the analysis of data and the presentation of that data in a way that is often more intuitively comprehensible to policy-makers, practitioners and community groups than the presentation of bare statistics and facts.

## What Is GIS?

What is a geographic information system? Many definitions exist. Essentially, it is a system of computer hardware and software that allows users to input, analyze, and display geographic data. Clarke refers to GIS as (1) a toolbox, (2) an information system, and (3) an approach to science [20]. As a toolbox, GIS is a software package that contains a variety of tools for processing, analyzing, and visualizing spatial data. Public health professionals might use these tools to map infant mortality rates across a state, identify areas with underserved populations, maintain an infectious disease surveillance system, or model environmental exposures to toxic substances.

As an information system, a GIS consists of a series of databases that contain observations about features or events that can be located in space and, hence, mapped and analyzed. This component of GIS includes a focus on data structures. GIS also functions as a means of spatial data storage [21]. Information that previously was on physical maps now can be stored in digital format in a GIS.

In some circles, the meaning of GIS has shifted from “geographic information system” to “geographic information science,” sometimes referred to as *GIScience* [22]. *GIScience* refers to the science behind the technology – the disciplines and technologies that have contributed to the development of today’s GIS software. These disciplines include geography, cartography, geodesy, photogrammetry, computer science, spatial statistics, and a wide range of physical and social sciences.

## Theoretical Foundations and the Development of GIS

As a science, the theoretical roots of GIS lie in geography, cartography, and spatial analysis. Certain paradigms in the discipline of geography have had a strong impact on the development of GIS technology. In the mid-1950s, geography experienced a shift from integrated, regional science approaches to a paradigm that embraced logical positivism and the quantitative revolution. Logical positivism incorporated a

theory of knowledge that was based on empiricism (sensory experience) and required deductive instead of inductive reasoning and laws of probability. In geography, this involved a heavy use of mathematics and statistics. Emerging computer technology contributed to this shift by providing faster computations and a means of storing and retrieving vast quantities of information [23]. During this time, methods of spatial analysis that had been developed earlier in the century were automated, and many new spatial/statistical methods were developed. For example, Glick used the concept of spatial autocorrelation to examine cancer mortality in Pennsylvania [24]. Other schools of thought in geography, such as the landscape and human ecology schools, which focused on the relationships between humans and their environment, had an impact on the development of automated mapping techniques to store and map environmental information.

Many US federal government agencies were important to the evolution of GIS technology and the development of digital cartographic data, perhaps most notably the US Bureau of the Census. In 1967, the agency piloted the use of digital geographic files (streets and census blocks) for a pilot project in New Haven, Connecticut. These files, the Geographic Base File Dual Independent Map Encoding files (otherwise known as GBF/DIME files), were used in urban areas for the 1970 and 1980 censuses. Today, the most commonly used spatial data in the country are probably the US Bureau of the Census TIGER/Line files, usually referred to as simply TIGER (Topologically Integrated Geographic Encoding and Referencing system) files. These were first used in 1990.

In the late 1980s, the move away from mainframe computers toward workstation and PC technologies resulted in dramatic changes to GIS software and functionality. Most notably, software became increasingly easy to use with the development of graphical user interfaces and menu-driven systems, and large collections of digital datasets were developed for use with the software. Today, computer users with a day's training or less can easily begin using GIS. This facility of use has obvious advantages, but there are drawbacks as well. After all, geographic data are complex. Without a sound knowledge of basic geographic principles, data issues, and map design, it is easy for an uninformed user to make errors, to mislead, and to be misled.

## How Do Geographic Information Systems Work?

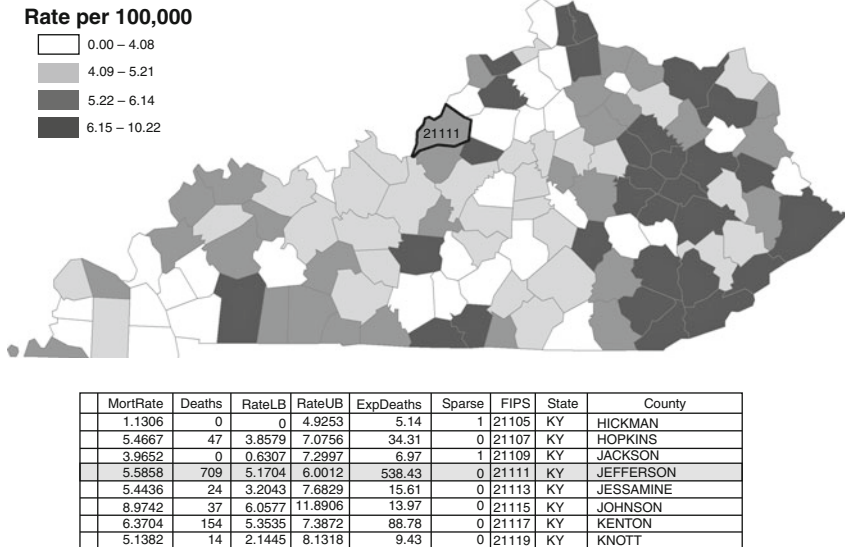
Geographic Information Systems have several important concepts in common: the relationship between spatial and attribute data, map projections and spatial referencing systems, map scale, and spatial data representation.

### *Spatial and Attribute Data*

Although recent developments in hardware and database management software have led to the development of many new data structures, we can think of GIS data as having two components. The first is *spatial data*, consisting of geographic



**Cervical Cancer Mortality Rates for Kentucky Counties  
All Women, 1970–2004**



**Fig. 21.1** Spatial and attribute data for Kentucky counties. The record for Jefferson County is highlighted in the table, along with its corresponding map location. The FIPS code for Kentucky is 21, and the FIPS code for Jefferson County is 111, providing a combined FIPS code and unique identifier of 21111. This value is contained in the table’s FIPS field. The Kentucky county boundary file has a FIPS code associated with each county, and the attribute data are linked to the appropriate boundary through this geocode (Data Source: National Cancer Institute)

coordinates that provide information about the location and dimensions of features on earth and the relationships among these features. These spatial data are stored in a *topologic* data structure—a data structure that maintains information about the spatial relationships among features, such as adjacency, connectivity, and containment.

The second component is *attribute data*. Most people who use standard spreadsheet or database software think of these data as ‘columns’ or ‘fields.’ In other words, these are variables that describe the non-spatial aspects of the database, such as the total population of a given county, or its lung cancer mortality rate. Attribute and geographic data are linked through a *geocode*, a geographic identifier that is contained in both data components. This geocode can be a county name or a state name, a ZIP code, a street address, or some other numeric code. Standard numeric codes or geocodes for states and counties were developed by the National Institute of Standards and Technology (NIST) as part of the Federal Information Processing Standard (FIPS). Figure 21.1 displays a map of Kentucky showing cervical cancer mortality rates. The spatial data on the map are the Kentucky county boundaries. Attribute data are contained in the table below the map and are represented on the map by a series of shading patterns. Each record contains information for a single county; in this case, the information includes a county name, its FIPS code, and the cervical cancer mortality rate.

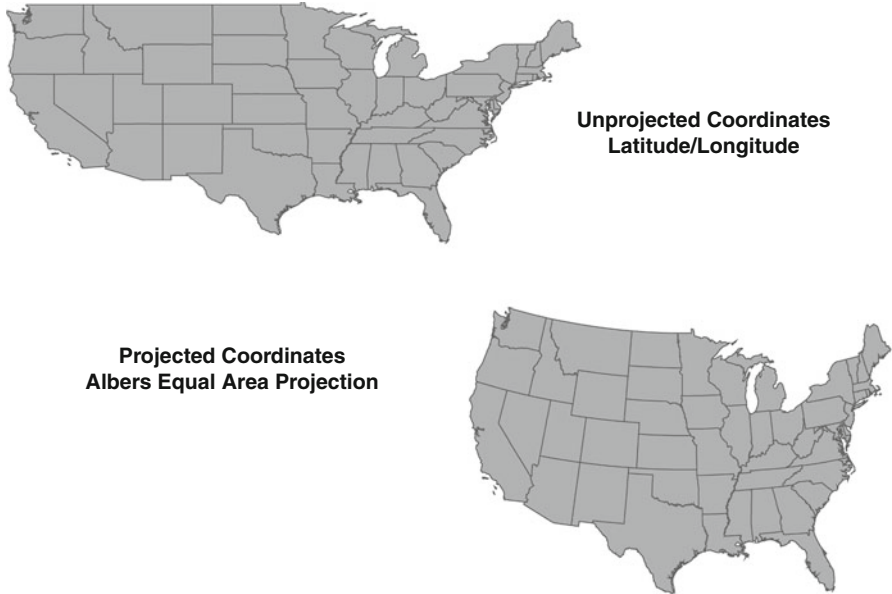
Most federal geographic data, such as census data, use a set of FIPS codes. However, the federal codes are not always used by state agencies or other organizations. Geographic files, such as the county boundary file in Fig. 21.1, often contain more than one set of geocodes. If health agencies in the state of Kentucky coded health data by county name, for example, these data could be mapped using county name as a geocode, so long as that information was also contained in a field in the spatial database and no county names were misspelled.

Attribute data come in a wide range of formats from a variety of sources. One of the challenges of using health and demographic data in a GIS is working with different data formats and structures. Attribute data are typically stored in tables, where columns represent fields or variables and rows represent cases or observations. These tables or files are often stored in a database. The original data may be stored in proprietary software such as Oracle (Redwood City, CA), SAS (Cary, NC), IBM SPSS (Armonk, NY), Microsoft (Redmond, WA) Access databases or Excel spreadsheets, or other formats such as delimited text files. Linking these data to spatial data usually requires importing them into the GIS software, so users must be knowledgeable about the native format of the GIS software they're using and which database formats can be imported. Spreadsheets and databases are not the same, and importing spreadsheets into GIS software can be problematic. For instance, spreadsheets can contain random text cells or column names that don't conform to database standards. Many GIS users view dBase (.dbf) as a preferred file transfer format because it is readable by many GIS software applications and requires little or no formatting. Recent developments in both GIS and database management software allow direct linkage between some GIS applications and database management systems.

For years, the main database management system utilized by GIS applications has been the relational model, where two or more tables can be linked easily via a common identifier, or key. This is the method by which attribute data are linked to spatial data using a common geocode. Recent trends in the larger GIS software applications are toward the use of object-oriented databases, which are capable of modeling complex spatial objects. These spatial objects contain not only attributes, but also the methods and procedures that operate on them.

## ***Map Projections and Coordinate Systems***

In a GIS, all geographic features, such as hospital location, county boundaries, and street networks, must be defined in terms of a common frame of reference, or coordinate system. Coordinates are defined by their distance from a fixed set of axes. In general, an *x-coordinate* refers to an east/west location; a *y-coordinate* defines a north/south location. Features on the earth can be located with the *geographic coordinate system*, which uses latitude for a north/south position and longitude for an east/west position. However, this system pinpoints location on a spherical earth. Maps and computer monitors, on the other hand, are flat. Therefore, the transformation of features from a three-dimensional sphere to a two-dimensional surface,



**Fig. 21.2** Unprojected and projected coordinates (Map Source: ESRI, Redlands, CA)

known as a *map projection*, must take place in order for the system to produce accurate mapping and analysis. Because degrees of longitude vary in actual distance across the globe (i.e., they converge at the poles), projections are used to establish a grid system with uniform units of measurement and to reduce the distortion in unprojected map coordinates.

Map projection is a science in and of itself. Projections are mathematical transformations of endless variety and, while they reduce the distortion inherent in geographic coordinates, they all involve some sort of distortion of shape, area, direction, or distance. Imagine drawing a map on the entire outside of an orange, then trying to remove and flatten the peel while maintaining the integrity of the map features. While it takes time and experience to learn which projections are best suited for a particular application, it is important for the new GIS user to understand that all map layers used in an application must use the same projection and coordinate system. Indeed, this is one of the strengths of GIS: Multiple map layers can be overlaid and relationships among them can be analyzed and displayed when they are tied to a common coordinate system.

Many geographic databases are stored as unprojected data—i.e., as latitude/longitude coordinates. These coordinates are a sort of *lingua franca*, a standard data exchange format, and must be projected using GIS software for more accurate analysis and visualization. Projections and/or coordinate systems commonly used in the US include (1) state plane coordinate systems, (2) Albers Equal Area projection, (3) Lambert Conformal Conic projection, and (4) Universal Transverse Mercator (UTM) projection. Figure 21.2 displays a map of the continental United

States in latitude/longitude coordinates (unprojected) and in Albers Equal Area coordinates (projected). More information about map projections can be found in Harvey [25].

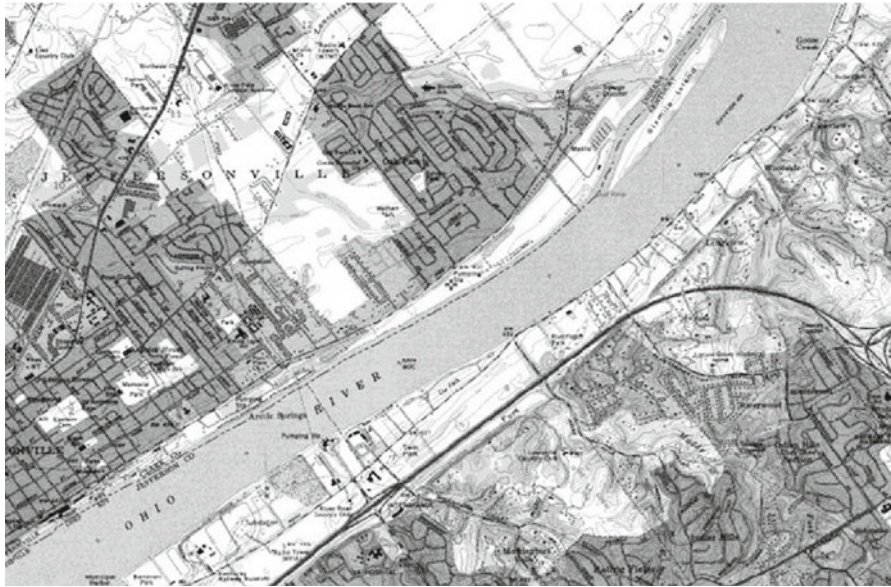
## ***Scale***

Scale refers to the ratio of a distance on a map to the corresponding distance on the ground. A scale of 1/100,000 (usually represented as 1:100,000) means that 1 inch on the map is equal to 100,000 inch on the real earth. The ratio is true for any unit of measurement (1 cm on the map is equal to 100,000 cm on the ground). Large-scale maps show more detail than small-scale maps. The concept of scale can be confusing because the larger the denominator in the fraction is, the smaller the scale is. In other words, a map at a scale of 1:12,000 is a larger-scale map than one at 1:2,000,000. Smaller-scale maps are generally used to show a larger area (such as the world or the US), whereas larger-scale maps can be used to “zoom in” to a smaller area (such as a city or a neighborhood). Because many map details are lost in smaller-scale maps, scale has an important effect on the precision of location. Figure 21.3 shows an area of Louisville, Kentucky, represented at two different scales. It is important to remember that although GIS software allows users to zoom in and out to different scales, the amount of detail in a map depends entirely on the scale of the source map!

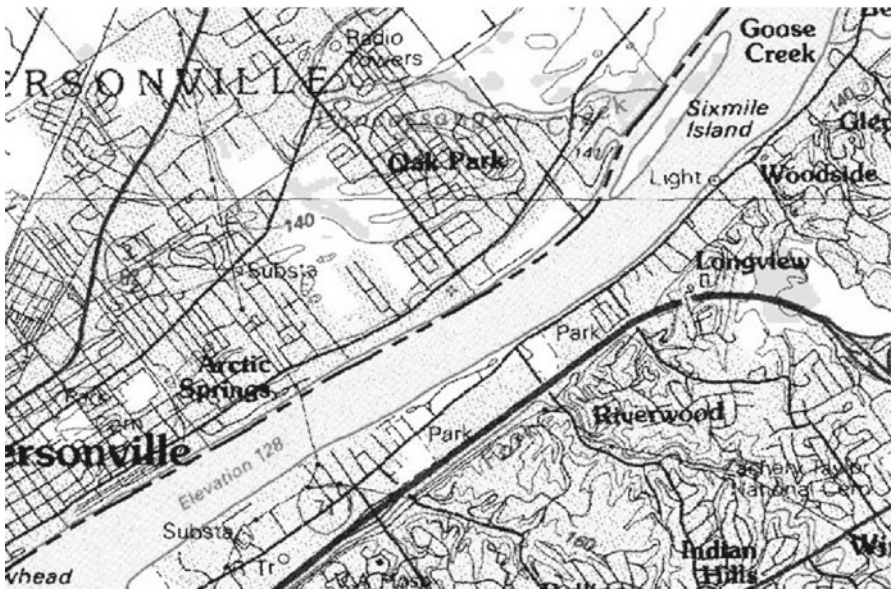
## ***Representations of Spatial Data***

Most spatial data in a GIS are either feature-based or image-based, often referred to as *vector* or *raster*, respectively. Vector data are represented by feature types that resemble the way we visualize and draw maps by hand—by use of (1) *point*, a single  $x, y$  location (example: a residence); (2) *line*, a string of coordinates (example: a road); and (3) *polygon*, a chain of coordinates that define an area (example: a county boundary).

Satellite images, digital aerial photography, and other forms of remotely-sensed data are the most commonly used raster data. These data are stored, not as features, but as a series of pixels or grid cells. Both types of data can (and should) be registered to a real-world coordinate system for display and analysis. Figure 21.4 displays examples of feature (vector) and image (raster) data and the ability of the GIS software to overlay these by use of a common coordinate system. Most computer and smart phone users are now familiar with the satellite imagery used in mapping applications such as Google Maps (Mountain View, CA). Satellite images and other remote sensing data have become increasingly important for monitoring and modeling human health [26].

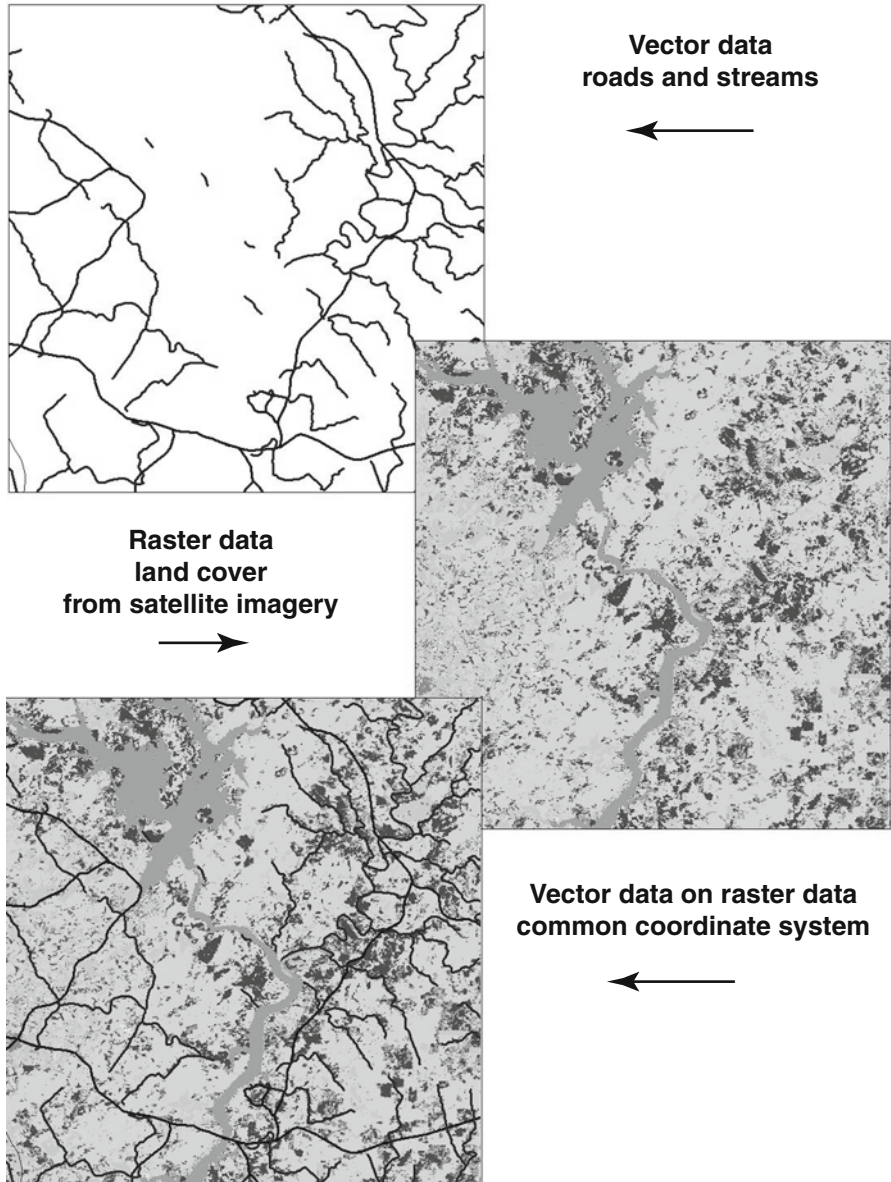


1:24,000



1:100,000

Fig. 21.3 A portion of Louisville, Kentucky, shown at two map scales (Source: US Geological Survey)



**Fig. 21.4** Vector and raster data (Map Source: ESRI, Redlands, CA; USGS National Land Cover Data)

***Functionality: Mapping and Spatial Analysis  
for Health Applications***

A discussion of GIS functions used for public health applications can be found in Vine et al. [27] and Cromley and McLafferty [18]. Some of the more generic functions are described in the next few paragraphs. For the beginning GIS user, the most

heavily utilized application of GIS probably will be the display of map layers and the production of thematic maps, most likely shaded (choropleth) maps. Thematic maps show the distribution of a variable, or theme, such as disease mortality, across space and are very important for understanding patterns of health outcomes.

*Choropleth mapping* assigns different shades or colors to geographic areas, according to their values; it was the technique used to produce the map in Fig. 21.1. In health applications, it may be used with counties, ZIP codes, health service areas, census tracts, or other geographic units to show the distribution of health outcomes, socio-demographic characteristics, health services, or other relevant variables. Because correct interpretation of the message or pattern displayed on a choropleth map is so critical to analysis and decision-making, a more detailed discussion of choropleth map production is provided in a later section in this chapter concerning visual display of spatial data.

*Automated address matching* can be used to map clinics, patient residences, and other locations that contain street addresses. *Address matching* is a term often used synonymously with *geocoding*, but it is actually only one of many methods of geocoding. Essentially, an address, such as 525 Fuller Street, is a geocode—it refers to a specific location along Fuller Street. Address matching works by comparing a specific street address in a database to a map layer of streets. If the map layer contains relevant information about the street name and the range of addresses along that street, the software can interpolate the location of the address and place it along the street. Most computer and smart phone users are familiar with address-matching functions: they use software such as Google Maps (Mountain View, CA), Yahoo! Maps (Sunnyvale, CA), MapQuest (Denver, CO), or other global positioning system (GPS) software to provide travel directions. Most GIS software allows the user either to enter addresses interactively (one at a time), or to process an entire database of addresses in batch mode.

*Distances* among geographic features can be determined with nearly all GIS or mapping software. In health applications, distances often are needed to analyze access to health care or to model exposure to an environmental contaminant, among other things. Most GIS software allows users to determine distances either interactively or in batch mode through the use of a distance function. In the case of batch mode determination, the distance calculation is stored in a variable that may be used for later analysis, such as regression or some sort of exposure modeling [28].

*Spatial query* allows a GIS user to query the attribute database and display the results geographically. For instance, a user could make a query to display the location of all rabies cases that have occurred in a county during the past year, or to show all census tracts in which more than 50 % of households have a household income below the poverty rate. Queries also can be based on distance: A GIS can be used to display all ZIP codes within a 25-mile radius of a particular health clinic or to show all patients within 15 miles of a field phlebotomist.

*Buffer functions* can define and display a region or “ring” of specified radius around a point, a line, or an area. GIS software allows the user to define the width of the buffer—i.e., the distance of the outside edge of the buffer from the feature boundary. A 150-m buffer might be created to determine the number of residences close to a toxic release event. A 25-m buffer zone around major roads could identify

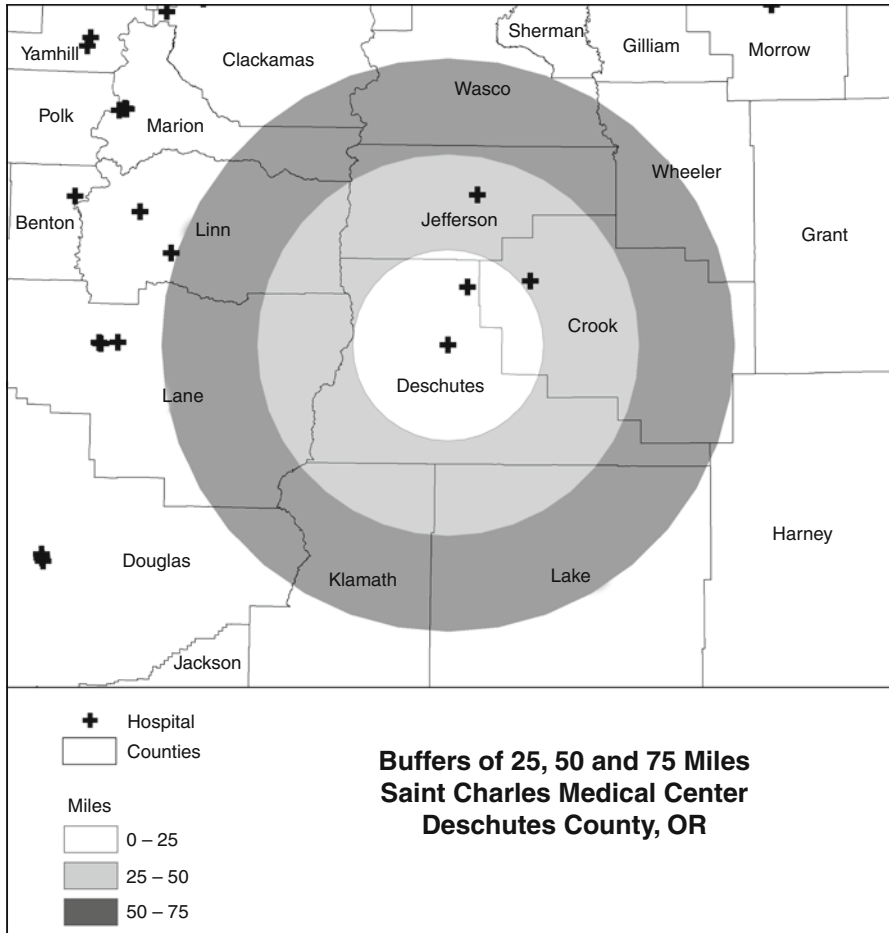


Fig. 21.5 Buffer function (Map Source: ESRI, Redlands, CA)

areas with potential lead hazards in soil from past use of leaded gasoline. Figure 21.5 shows buffers of 25, 50, and 75 miles from Saint Charles Medical Center in Bend, Oregon. Another hospital is located within 25 miles of Saint Charles Medical Center and there are three hospitals within 50 miles of the center.

*Overlay analysis* allows GIS users to integrate feature types and data from different sources. It is not to be confused with visual overlay, which occurs when several map layers are registered to a common coordinate system and displayed together, as in Fig. 21.4. Overlay analysis involves some spatial data processing and results in the creation of new data or modification of existing data. Two commonly used types of overlay analysis are *point-in-polygon overlay* and *polygon overlay*.

*Point-in-polygon* overlay is used to determine which area, or polygon, a point or set of points lies in, or whether a point lies inside or outside a particular geographic



area. For example, a point map of patient residences might be overlaid on a map layer of census tracts to determine which census tract each patient resides in. This application is important when a user is examining the association of census variables, particularly socioeconomic ones, with health outcomes. Some GIS software refers to this process as a *spatial join*.

*Polygon overlay* can be used to create a new map layer from two existing polygon map layers, when their boundaries are not coincident. For example, a ZIP code map layer can be overlaid on a layer of primary sampling units to obtain a map layer showing all complete and partial ZIP codes within a sampling area. Polygon overlay is sometimes used to estimate populations within a geographic area where boundaries differ from census boundaries, using an *areal interpolation* method. This method operates in a “cookie cutter” fashion to create new polygons; population is then prorated by comparison of the area of the new polygon to that of the original. An example of *areal interpolation* is shown in Fig. 21.6.

While these are only a few examples of GIS functions, they are all commonly used in health applications and are easy to learn. Many other functions exist, ranging from relatively simple techniques to complex methods of spatial modeling. Lai et al. [29] have written an excellent text on spatial approaches to disease analysis which discusses more advanced methods.

## Spatial Statistics

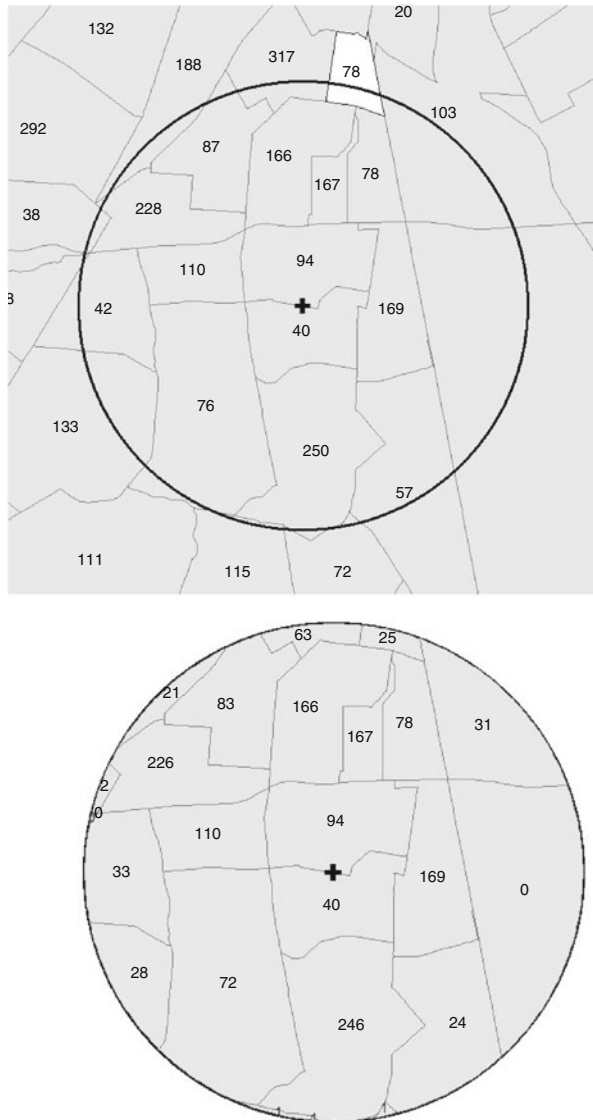
There are many time-honored spatial analysis techniques that recently have been incorporated into some of the more widely used GIS software products. Still, using statistical or more advanced spatial analysis techniques often requires additional programming, or reformatting GIS data for use with statistical software such as SAS or SPSS. Currently, two free software programs are extremely useful for the geostatistical analysis of health data: (1) SaTScan, developed for the analysis of disease clusters [30] and (2) GeoDa, which performs spatial data analysis, visualization, spatial autocorrelation and modeling procedures [31]. Figure 21.7 shows how GeoDa’s Local Index of Spatial Autocorrelation (LISA) method can be used to identify regions with statistically high cervical cancer mortality rates.

## Visual Display of Spatial Data

The proper display of spatial data requires an understanding of cartographic design, levels of measurement, and the wide range of symbols and color schemes that can be used to represent feature and image data. A thorough treatment of this subject is beyond the scope of this chapter, but it can be found in any number of cartography references and primers [32–36]. Unfortunately, the proliferation of GIS and the development of user-friendly interfaces to GIS software has made it easy for the

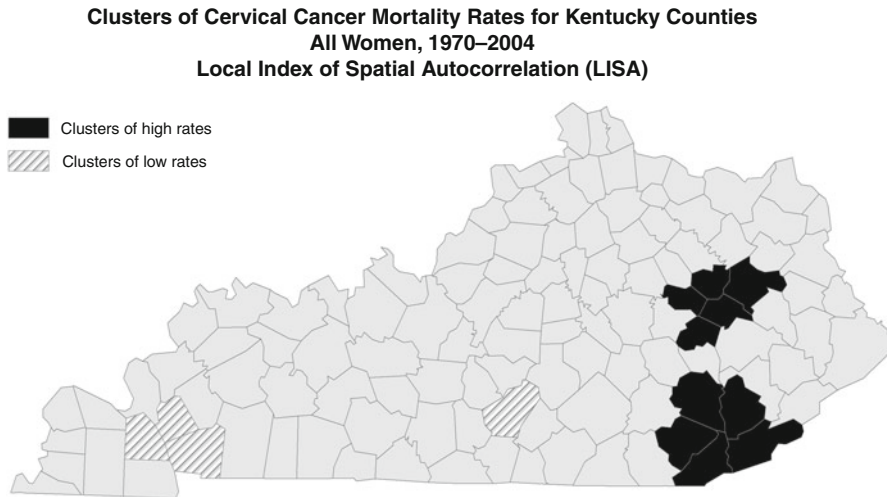
**Fig. 21.6** Areal interpolation. The top diagram shows a hospital in the center, with a three-mile buffer, overlaid on census tracts. Each tract is labeled by the number of women 45 years or older in poverty. The areal interpolation method estimates counts by determining the percentage of area inside the buffer and applying it to the count. The number of women in the tract just north of the hospital is 94. Since this tract is entirely contained in the buffer, all will be counted. The number of women in the highlighted tract on the buffer's northern perimeters is 78. However, only 32 % of this tract is inside the buffer, so only 25 women will be counted ( $78 \times 32\% = 25$ ). This process is accomplished by clipping the census tract map with the buffer in a cookie-cutter fashion, then comparing the tract area with the old area. Each tract in the bottom diagram is labeled by the number obtained from areal interpolation. The total population of women within the 3-mile buffer is 1680

**Mammography Screening for Women in Poverty  
3-Mile Radius of Hospital**



“cartographically illiterate” to produce bad maps. Bad maps can result from the improper use of map projections, unfamiliarity with basic principles of map design, lack of understanding of data type and distribution, and poor symbol choice.

Because choropleth maps are so frequently produced and because they convey such a powerful image of the distribution and quantity of phenomena, two critical



**Fig. 21.7** LISA cervical cancer (Data Source: National Cancer Institute)

aspects of their production are discussed briefly in this chapter: (1) grouping data into classes for mapping and (2) appropriate use of symbols for choropleth mapping.

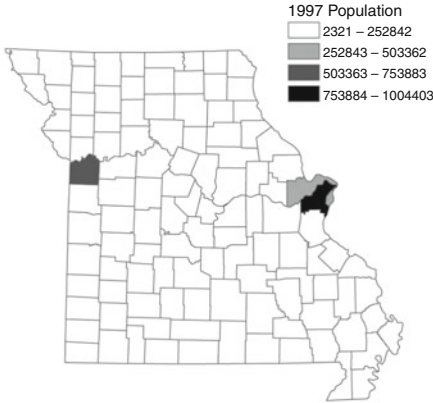
## Grouping Data into Classes for Mapping

The way in which data are grouped or classified has a strong effect on the appearance of the map and can result in maps that look very dissimilar but use the same set of data. The mapmaker must determine how many categories or classes to use and the intervals, or cut-off points, for each class. Most shaded maps use from three to six classes, which are represented in the legend. Most GIS or mapping software provides users with a number of options for classifying numeric data. Four commonly used methods are (1) equal interval, (2) quantile, (3) natural breaks, and (4) mean and standard deviation. Figure 21.8 provides examples of these methods. The viewer can discern immediately how different each of these maps looks, but they all use the exact same data!

Generally, there is no consistent “right” or “wrong” classification method to use for classifying data, but some methods are more appropriate for certain data distributions. The mean and standard deviation method is probably used least, because the general public may not understand the concept of standard deviation. A disadvantage of using the equal interval method is that, because classes are determined by dividing the range of data, and not by data distribution, it is possible to have data classes with no observations. In this case, a class (and associated shade) would be represented in the legend, but not on the map. Probably the best rule of thumb for those who are uncertain is to use either the natural breaks or the quantile method. In fact, the quantile method has been supported for epidemiological rate mapping [37].

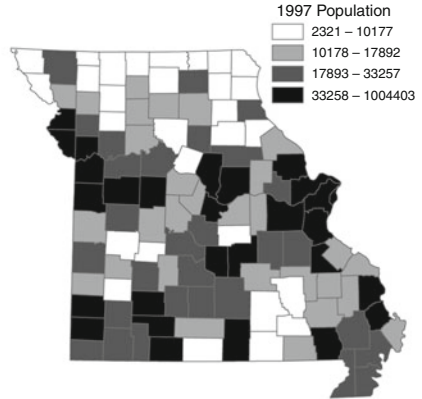
### Equal interval

The range of the data is determined by subtracting the lowest value from the highest value. The range is then divided by the desired number of classes, usually four or five, to determine the beginning and end values for each class.



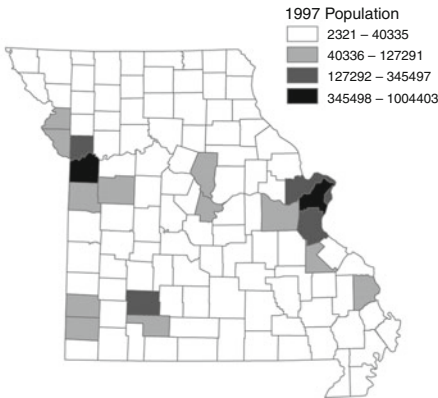
### Quantiles

The data are arranged in sequence from low to high values. The observations are then separated into the desired number of classes so that each class contains the same number of observations, or geographic units.



### Natural breaks

Natural breaks are points where there are gaps in the distribution of the data, i.e. fewer or no observations. These break points are often used as dividing points for the classes.



### Mean and standard deviation

The mean is computed and established as the center of the data distribution. Class intervals are determined by the standard deviation, a measure that determines the spread of the data around the mean.

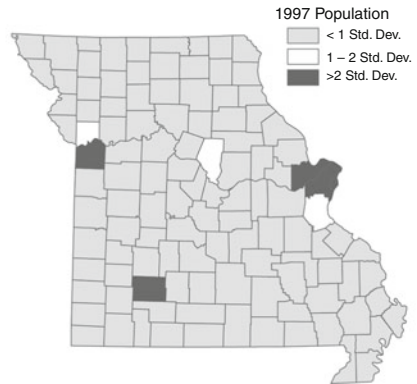


Fig. 21.8 Data grouping methods for choropleth mapping (Map Source: ESRI, Redlands, CA)

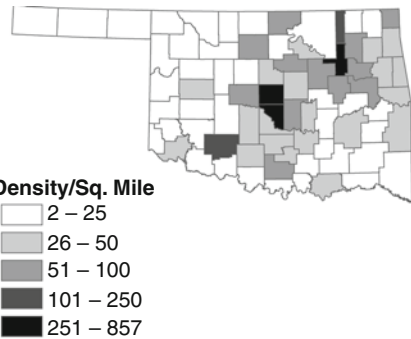
## Appropriate Use of Symbols for Choropleth Mapping

With the availability of color in computer hardware and software, it is tempting to use a wide range of colors in map production. However, a user working with numeric data should choose colors and shading patterns that communicate the map's

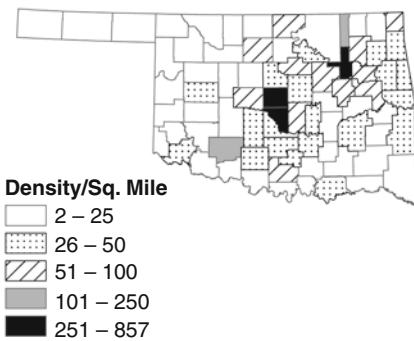
### Use of Map Symbols for Choropleth Mapping of Numeric Data

Different values of the same hue, a progression of hues, or black and white shading can be used to show patterns that are intuitive to the viewer. Dot and hatch patterns also can be used effectively. The map in the lower right corner shows a pattern resulting from a poor choice of shades.

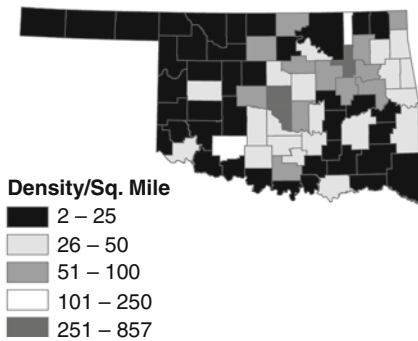
#### Black, white and grey shading



#### Dot and hatch patterns



#### Inappropriate use of symbols



**Fig. 21.9** Use of map symbols for choropleth mapping of numeric data (Map Source: ESRI, Redlands, CA)

message as clearly as possible and reflect the value of the data so that the patterns on the map are intuitive to the viewer.

In color terminology, *hue* refers to the name of the color (e.g., red, blue, green) and *value* is the lightness or darkness of a hue [38]. In general, it is best to use light colors for low data values and intense or dark colors for high data values. A gradation of values for one hue works well with numeric data, as does a range of hues from light to dark. These configurations of colors are often available in GIS or mapping software as *color ramps*, a range of hues or colors set up in the software that the user can quickly apply to numeric data. When producing a map series, color and shading patterns should be standardized for consistent interpretation across the series, such as the patterns used in the *Atlas of Cancer Mortality in the United States, 1950–94* [39]. Figure 21.9 provides examples of both appropriate and inappropriate use of symbols.

Maps are often produced for publications or reports. When color maps are too expensive to produce, the map’s message can be conveyed effectively in black and white. Gray shades can be used in place of a range of colors. However, gray shades

do not always print or copy well, and solid black can obscure boundaries, text, and other features. Dot and hatch patterns can be a more effective way to present the information.

### ***GIS Implementation: Software and Hardware***

In previous decades, GIS implementation strategies have focused on the acquisition of hardware and software, the collection of data, and aspects of managing the system, including organization and staffing. While all of the considerations addressed by these formal implementation strategies remain important today, the rapid evolution of computing technologies and increasing availability of geospatial data have resulted in a wide range of products and ‘apps’ that offer varying levels of GIS functionality. This flexibility provides the technological basis for a continuum of organizational models and implementation strategies. At one end of the continuum, an individual uses GIS on a computer, tablet, or smart phone; at the other extreme is enterprise GIS, where an entire organization uses GIS.

Much of the GIS software today falls under the general category of *desktop GIS*, which runs on a personal computer instead of being executed from a more powerful server. The GIS software and data reside on the personal computer. Over the past two decades, GIS software has become increasingly user-friendly with easy-to-use graphical user interfaces consisting of menus and tool bars. Many inexpensive, user-friendly GIS or mapping software products are now available. *Desktop GIS* does not include the broad category of web-based GIS, a technology that provides access to mapping capabilities through the use of a Web browser such as Internet Explorer, Firefox, or Safari.

GIS software falls into two primary categories: commercial (proprietary) and open source. The former costs money; the latter refers to free software whose source code can be modified by various programming languages. Some open source software is referred to as FOSS (free and open-source software). Up-to-date information about GIS platforms and their functionality can be found in Dempsey [40] and Steiniger and Hunter [41]. The suite of GIS software products developed by ESRI (Redlands, CA), such as ArcGIS, currently has the highest market share of the proprietary GIS software products. Estimates of ESRI market share range from 70 % [40] to 30 or 40 % [42]. Other products with high market share include Pitney Bowes MapInfo (Troy, NY) and GE Smallworld (Atlanta, GA). One of the better-known open source products is GRASS (Geographic Resources Analysis Support System) initially developed in 1982 by the US Army Corps of Engineers [43].

In order to evaluate hardware and software needs, GIS users in public health must determine which GIS organizational model meets their needs, the availability and format of digital geographic data, and how their GIS activities will be integrated with other research or operational units. In many cases, a powerful PC with desktop software will be sufficient. With more sophisticated systems, such as those used in

a departmental or an enterprise GIS, larger investments in data servers and software will be necessary. Potential GIS users should check with other units in their organization to determine whether any existing GIS software license agreements are in place. For example, some states have a statewide agreement that allows employees of government agencies or universities to access the licensed software. No matter which GIS system is utilized, spatial data are always disk-space-intensive. Geographic data files are large; a user should have plenty of hard drive space available.

### ***Spatial Data Access and Development***

In the 1980s and early 1990s, the primary bottleneck in GIS implementation was the need to develop and/or acquire high quality geographic data, a factor that was (and still is) often underestimated. Fortunately, during the past several years, there has been a proliferation of digital spatial data as a result of improvements in technology, the ever-increasing use of GIS, and coordination efforts by federal, state, and local government agencies, such as the Federal Geographic Data Committee (FGDC). Many of these spatial data layers are part of the FGDC's National Spatial Data Infrastructure (NSDI). They are free or can be purchased at a minimal cost from federal or state agencies. Others are sold by private vendors who have either created spatial data themselves or else added value to spatial data obtained from government and other sources.

Probably the most commonly-used spatial data in the country are the US Bureau of the Census TIGER/Line files. These files, usually referred to as simply TIGER files, were first produced for the 1990 census and contain map layers for census geography, physical landmarks, rivers and streams, transportation networks, and other features. These spatial data files can be linked with the census attribute data files for mapping and analysis of census socio-demographic variables. The street network data can be used for address matching. TIGER files can be obtained at no cost from the US Census Bureau web site [44]. Commonly-used census units are blocks, block groups and tracts. A relatively new statistical unit, the ZIP Code Tabulation Area (ZCTA), consists of an aggregation of census blocks that closely approximates a post office ZIP code area. ZCTA is beneficial for many health professionals because it allows them to link the ZIP code information in many health datasets with census socio-demographic data with greater accuracy than has been possible in the past. Of course, ZIP codes are relatively small geographic units, so users need to be cautious about HIPAA regulations and statistical small numbers issues.

As a result of the FGDC's work on the National Spatial Data Infrastructure, many states now have spatial data clearinghouses, which are often web-based 'go to' locations for free and trusted geospatial data downloads. Many of the available vector databases are in *shapefile* format, a vector spatial data format developed by ESRI, but recognized by a number of other GIS software products.

A web search on ‘GIS data’ yields many pages of results, but the links may not lead users to trusted data sources; therefore, information about the creation and lineage of spatial data is critical. The FGDC spent several years developing a standard for *metadata* that describes the content and quality of a spatial database, or, in FGDC’s words, “data about data.” Metadata provides important information about who developed the database, the scale of the original data, the time period of the content, and attribute and positional accuracy. While metadata does not guarantee the quality of the data, it does provide important information with which a user can determine appropriateness of the data’s use. Metadata is usually in XML format. Developing metadata is time consuming; therefore it might not accompany all spatial data. The metadata standard has been adopted by federal agencies as well as many state and local agencies.

GIS data for public health applications are often created by linking health attribute data from state and local government agencies to geographic boundary files by geocode. For instance, county-level mortality data can be linked to a state’s county boundary file by county code. Health datasets that contain ZIP code fields can be linked to a ZIP code boundary file. Many public health datasets are created through the address matching process, described previously.

### ***Web-Based GIS***

Internet map server technology allows nearly anyone with access to a web browser to produce maps and perform rudimentary spatial analysis. Most people are probably familiar with Google Maps or Bing Bing (Microsoft, Redmond, WA), and the ability to view map data and aerial imagery, turn layers on and off, and obtain driving directions. Google Earth, a free software download, provides more layers and functions. The FGDC manages the Geospatial Platform [45], a portfolio of geospatial data from trusted sources that includes a mapping application. The United States Geological Survey (USGS) has developed The National Map Viewer with a wide variety of map layers available for viewing and download [46]. With web-based GIS, geographic information is provided via a client–server model where an application server accesses data from a data server or data warehouse and provides the data to a client using a map server application.

In the past few years, the number of health-related map servers has proliferated. A few examples include the National Cancer Institute’s *Cancer Mortality Maps*, where the user can define anatomical site, time period, spatial unit, number of class intervals, and color scheme [47]. The Centers for Disease Control and Prevention (CDC) hosts a number of interactive atlases, such as the one for heart disease and stroke, which provides county-level mapping [48]. Not all map servers work well with all browsers. One of the emerging technologies in GIS is cloud computing, where powerful servers store data and provide applications over the internet. In this environment, spatial data, GIS software, and applications are part of the cloud infrastructure and accessible via a number of hardware options, including mobile devices.



## ***GIS Training***

All organizational models of GIS require personnel with high levels of technical competence to develop the databases and applications that provide effective, high quality analysis and results for decision support. Somers [49] made a distinction between (1) full-time GIS users, (2) part-time GIS users, and (3) support staff. Full-time GIS users are often technicians, analysts, or managers, who have educational backgrounds in geography or GIS; part-time users might have backgrounds in a field of expertise, such as environmental health, with training in the use of GIS.

For the most part, learning how to use GIS or desktop mapping software is not difficult or time-consuming, a fact that can be deceptive because it obscures the complexity of GIS. GIS software vendors often offer their own training courses and many universities now offer online postbaccalaureate certificates in GIS, such as the one offered through Pennsylvania State University's World Campus [50].

GIS users in the public health fields have additional concepts that they must master, many of which can be gleaned from a course in epidemiology or biostatistics. These concepts include the use of rates, statistical variation involving the use of small numbers in either the numerator or denominator, the concept of rate adjustment, and the impact of different standard populations on rates. In addition, state and local public health GIS users need to have a sound understanding of the ecological fallacy in the analysis of cause-and-effect relationships, i.e. that one cannot make assumptions about individuals based on group-level data, and of issues involved in modeling exposure to environmental factors.

## ***Social and Institutional Issues***

Individual and organizational users of GIS typically need to address a number of social and institutional issues. These issues include confidentiality, security and data access, coordination with other agencies, and organizational politics.

## ***Protected Health Information and HIPAA***

Many health datasets contain sensitive information. Patient addresses and other geocodes can serve as individual identifiers. Consequently, public law mandates that agencies and researchers maintain the confidentiality of patient records and health statistics. The Health Insurance Portability and Accountability Act (HIPAA) sets out detailed regulations on the dissemination of personal health information (PHI), including geography [51]. HIPAA regulations mandate that all geographic subdivisions smaller than a state must be removed before the data is considered de-identified enough for publication. The exception to this is the 3-digit ZIP code, an area generic enough to protect privacy and produce meaningless results. GIS

users must be very cautious about which maps are produced for internal use vs. those that are distributed to the public or shown in presentations. Some researchers have suggested that HIPAA restrictions have had a negative impact on public health research in a GIS context [52]. One of the best approaches is to discuss the project with an Institutional Review Board (IRB) member; it may be possible to obtain a HIPAA waiver.

### ***Security and Data Access***

Many of the security and data access concerns are closely related to data privacy and confidentiality issues discussed earlier in Chap. 9. All of the major computer operating systems have security features that can restrict access to files and data through the use of logins, passwords, and encryption software. In addition, firewalls are often set up to limit access from outside an organization. It is critical to have competent system administration and information technology staff to handle data security issues. GIS users need to think carefully about the data on their personal computers and USB devices to prevent security breaches.

### ***Coordination with Other Agencies***

In addition to federal coordination agencies, such as the FGDC, many states and regions are involved in data sharing and coordination activities. For instance, the Louisville Metro (KY) health department has access to a wealth of spatial data developed by the Louisville/Jefferson County Information Consortium (LOJIC) [53]. Coordination activities provide GIS users with opportunities for: sharing data and applications; keeping abreast of developments in the technology; training; and access to important information for decision-making, such as software purchases.

### ***Organizational Politics***

The impact of organizational politics on GIS operations should not be overlooked. For example, upper level managers might veto GIS applications that address politically sensitive or controversial issues. In addition, reorganization in government agencies, common and usually political, can have either positive or adverse impacts on GIS operations. Moreover, GIS is a technology that nearly everyone wants. Consequently, the location of a GIS unit in the organizational structure in an agency can affect which projects receive priority and/or funding.

## **GIS Limitations**

While GIS is a powerful tool that is increasingly easy to use, GIS users must recognize the limitations of the software and the spatial data and make attempts to work around those limitations. Some common limitations are discussed below.

### ***Accuracy and Completeness of Spatial Data***

Mapping and spatial analysis can be severely impacted by the quality of the geographic data. In addition, errors can be propagated during data processing or modeling activities. Coordinate precision, i.e., the number of significant digits that are stored for each coordinate, plays a role in some of these errors, as does the use of different map projections. Three good rules to follow are to (1) never assume that a geographic database is free of error, (2) acquire the metadata and read it to obtain information about the creation of the data, and (3) whenever possible, develop methods of assessing data quality.

### ***Accuracy and Completeness of Attribute Data***

Inaccuracies also exist in non-spatial databases. Character fields may have misspellings, and numeric fields may have data entry errors. As with spatial databases, quality control procedures should be developed to the extent possible, as illustrated by the following example. In 1998, the author conducted extensive mapping and geographic analysis using one of the public health screening databases maintained by the State of North Carolina [54]. During this study, it became apparent that many of the county geocodes in the database were incorrect. The author compared data from 1994–96, consisting of 265,492 records, to a master lookup table containing City, County and ZIP Code fields to check for correspondence in the screening database, and discovered that only 158,552 records (59.72 %) contained accurate and/or complete information. Some incorrect geocodes resulted from laboratory manual data entry errors (i.e., typos, which are easy to make since most geocodes are numeric), while others resulted from confusion over city and county names: many North Carolina towns and counties have the same names but very different locations. These types of errors are common, and in this case went unnoticed until these data were used in a GIS.

### ***Currency and Time Period of Data Content***

One data characteristic that is often neglected is that of time. When were the data collected? When were they last updated? It is easier to obtain funds to create GIS databases than to maintain and update them. Currency has been a serious issue

with census data, which are commonly used in health analyses. Prior to the implementation of the American Community Survey, census data were only collected every 10 years. Thus, a study of 1998 mortality had to utilize 1990 census data, or intercensal estimates. Now, census data are collected continually via the American Community Survey, but such timely data are not always available for smaller geographic areas such as block groups.

### ***Address Matching Issues***

Address matching is commonly used with health datasets to create a map layer of points showing facility locations or patient residences. The proliferation of street network data by private companies over the past few years has resulted in much greater accuracy in both urban and rural areas. However, not all addresses will match a street database – for example, there may be typographic errors, or multiple units in a large apartment complex– and the user will need to make decisions about how to process the ‘rejects.’ Many health surveys obtain information about mailing address, which sometimes differs from address of residence. For epidemiologic studies, it is important to remember that address of residence does not always infer location of exposure. Also, an address provides no indication of residential mobility: information about previous addresses or length of residence at current address is rarely contained in health datasets.

### ***Use of ZIP Codes***

Many health datasets do not contain an address field, and attempts to conduct sub-county analyses may therefore be limited to the use of ZIP codes. However, ZIP codes were developed by the US Postal Service for the delivery of mail, not for geographic analysis and mapping. Unlike census units (e.g., tracts, block groups) ZIP codes were not intended to be homogeneous with respect to socio-demographic variables. Although census data are now tabulated by ZCTA, the heterogeneity of populations within a specific ZCTA can still lead to averaging of values. ZIP codes can also cross county lines. One additional problem with ZIP code boundaries is that they change over time. Therefore, health data from 2006, for example, should not be mapped using a 2010 ZIP code file. Sometimes there is no choice but to use available data. In such a case, a user should always document the source of the data and its time period.

### ***Scale and Precision of Location***

Metadata should include information about the processes used to create the database. For example, the scale of the source map has a great impact on the

coordinate precision of a feature's location. The location of features digitized from a large-scale map will be more precise than those obtained from a small-scale map. The precision of point data is dependent on the method used to locate the points. Points that have been address-matched to a street network will generally be more precise than points matched to a ZIP code centroid, but less precise than those matched to the centroid of a tax parcel (i.e., property).

### ***Proximity vs. Exposure***

In epidemiologic studies, it is important to remember that proximity to a feature, such as a hazardous waste site, does not always imply exposure. Beware of associations gleaned from map overlay or geographic analysis. GIS is a wonderful tool for understanding relationships among features and for generating hypotheses about etiology, but GIS must be supplemented with standard epidemiological methods when analyzing spatial correlates of health outcomes.

### **Summary**

In summary, GIS is an information system, an approach to science, and a powerful set of analysis and visualization tools that can be used by public health professionals to enhance their analysis and understanding of public health issues and to provide a basis for sound decision-making. GIS is deceptively easy to use; however, geographic data, spatial or epidemiologic analysis, and GIS information systems are more complex than they appear to the casual user. The effective use of GIS requires a combination of good training and experience. In the years ahead, that training and experience will grow in importance as GIS becomes an increasingly powerful and common tool in the practice of public health.

#### **Review Questions**

1. Explain three ways in which GIS can be useful to public health practitioners.
2. Describe the difference between *spatial* and *attribute* data in a GIS.
3. Define *raster* and *vector* data.
4. Why is it important to understand cartographic principles such as map projections and data classification?
5. What steps must be taken to protect sensitive information in health datasets?
6. GIS is a powerful tool, but what are some of its limitations?
7. What is *metadata* and why is it important?
8. Explain the principles underlying (1) the use of colors in maps that display data and (2) the principles for appropriate use of black and white.

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## Chapter 22

# Public Health Informatics and Health Information Exchange

J.A. Magnuson and Paul C. Fu, Jr.

**Abstract** *Health information exchange (HIE)* describes both (1) the act of sharing of clinical and administrative health care data between interested stakeholders and (2) the actual health information technologies and systems that facilitate this sharing. There have been multiple iterations of this concept over the past three decades, starting with the Community Health Information Networks of the 1980s, the Regional Health Information Organizations of the late 1990s - early 2000s, and now the health information exchanges that exist in various forms and offer services ranging from basic connectivity to more advanced functions such as master patient indexes, provider directories, trust services, e-prescribing, and public health reporting. The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 has helped to promote HIE by including HIE reporting as a Meaningful Use Stage 2 measure and funding the State HIE Cooperative Agreement Program which provides funding for a state designated entity (SDE) to plan and build HIE capacity. There are many challenges to address. Data and messaging standards are required for semantic interoperability. The complexity of information privacy and security policies and regulations increases proportionately with the number of HIE participants. Governance and sustainability are also major challenges that must be met. The future of HIE is promising. The increasing adoption of EHR

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systems creates a pool of electronic health data that can support public health needs, such as automated reporting for communicable diseases, predictive analysis for syndromic surveillance, and population health reporting.

**Keywords** Synchronous • Asynchronous • Vertical • Horizontal • Diagonal • Health information exchange • Community health information network • Regional health information organization • Nationwide Health Information Network • Interoperability • Governance • Privacy • Security • Meaningful use • Information models

### Learning Objectives

1. Analyze the history of health information exchange (HIE) and give examples of lessons learned that affect electronic health record (EHR) interoperability initiatives.
2. List and define the types and architectures of different HIE models and the services provided.
3. Describe the value of HIEs to public health.
4. Summarize the barriers to HIE implementation and describe how these barriers affect the development of a Nationwide Health Information Network (NwHIN).
5. Explain how HIEs can maintain the privacy and security of personal health information.

## Introduction to Health Information Exchange in the Context of Public Health

### *History of Health Information Exchange (HIE)*

#### **Background to Public Health Information Exchange**

Originally, the term *health information exchange (HIE)* referred to early regional efforts to provide data exchange and other services to stakeholders across the health and public health spectrum. It has evolved since then to also describe the sharing of clinical and healthcare administrative data among health care practitioners and across practice settings who are not part of the same organization [1].

The concept of exchanging data between health information systems is not new; conceptually it existed before the advent of computerized systems, when paper forms were copied, traded, and reordered within and between record-keeping, billing, and insurance departments and partners. With the arrival of electronic data storage came new modes of *asynchronous* (one direction at a time) data exchange, such as punch cards, tape reels, floppy disks, hard drives, and flash RAM. Earlier

telecommunications tools, like analog telephone lines or ISDN connections, allowed for slow (by today's standards) but *synchronous* (simultaneous) exchange. Faster connections, such as leased frame relay or ATM connections, allowed for faster data speeds, but were very costly and were geographically bounded, making them the province of corporations, governments, and large educational institutions. What has changed significantly over the past three decades is the technical capability to exchange vast quantities of data in real-time, using relatively inexpensive telecommunications networks and international messaging standards.

The early condition of public health HIE reflected that of general healthcare information exchange. In 1988, a landmark report "The Future of Public Health" was published by the Institute of Medicine [2]. This report characterized the public health infrastructure as being in "disarray," and described the State of the Infrastructure as: "outdated and vulnerable technologies; a public health workforce lacking training and reinforcements; antiquated laboratory capacity; lack of real-time surveillance and epidemiological systems; ineffective and fragmented communications networks; incomplete domestic preparedness and emergency-response capabilities; and communities without access to essential public health services."

One of the primary factors leading to the IOM report's characterization of public health infrastructure was the historic basis of public health system architecture and funding. Public health programs and funding can be characterized as following three main directions: *vertical* (focusing on a single condition or initiative, such as tuberculosis); *horizontal* (focusing on building an infrastructure first); or *diagonal* (using focused priorities to improve the general infrastructure) [3]. While vertical funding has the advantage of providing specific focus, it can lead to fragmented, non-interoperable systems. And while the horizontal approach provides the advantage of improving the general public health system environment, it is possible that some diseases or initiatives would not receive the attention or support that they need. The diagonal category has been framed more recently, and may offer significant benefits to public health.

### **Early HIEs, CHINs, RHIOs**

The earliest examples of health data exchange between unaffiliated groups were the Community Health Information Networks (CHIN) that were established in the 1980s but began being replaced by RHIOs during the 1990s. A CHIN was broadly defined as an information technology-based network that supported information sharing between community stakeholders [4]. The main challenge encountered by CHINs was that the CHIN concept required clinical data to be electronically available as well as administrative data but, at that time, very few providers had Computer-based Patient Record systems (CPR), an earlier term for the Electronic Health Record systems (EHR) of today, and there was very limited data networking. The value was apparent to all, but the overall health care system needed further advancement in order to attain the benefits [5].

A Regional Health Information Organization (RHIO) was a subsequent form of health information exchange, and focused upon the sharing of clinical and administrative data within a regional collaboration of healthcare entities, typically

broader in scope than the CHINs, which were often local community focused. The RHIO model emphasized flexibility, allowing customization of governance, technology, and policy depending on regional needs [6]. RHIOs have been shown to have potentially large economic value on a population or regional basis [7]. They have also been shown to have perceived clinical benefit to emergency clinicians and yield theoretical financial savings when used to assist in outpatient care of chronic diseases [8, 9].

As with all data and information sharing projects, RHIOs include several inherent challenges [10]. *Successful interoperability* in healthcare is completely dependent upon the presence and use of widely adopted data and messaging standards in order to achieve a network effect. *Network effect* describes the phenomenon where a service becomes increasingly useful as more people have or use the service, like electronic mail. Organizationally, a major challenge is having the requisite *governance and leadership* in order to first, bring all stakeholders together to organize the service, and second, to ensure that there is sufficient inter-organizational support and commitment towards operationalizing the exchange. Bridging the technical and organizational domains is the challenge of ensuring that there are appropriate safeguards to *maintain the privacy and security* of protected information and of building sufficient consensus from all stakeholders that such safeguards are practical and effective. Clear metrics showing a *return-on-investment*, including accounting for competitive tensions between erstwhile data sharing partners, will improve the case for sustained operations.

### **Nationwide Health Information Network (NwHIN)**

The concept of a nationwide network that supports the healthcare system has evolved substantially over the past decade. The concept of a National Health Information Infrastructure (NHII) was first articulated by the National Committee on Vital and Health Statistics in 2001 [11]. The NHII was conceptual, and focused on the framework of principles, standards, procedures, and policies, not on a specific technology or system [12]. The landmark Institute of Medicine “Crossing the Quality Chasm” report moved a step further and defined a need for a National Health Information Network (NHIN) [13]. Subsequent ONC and federal initiatives, such as the NHIN prototype and demonstration projects, used NHIN to refer to a physical network of interoperable health IT systems (such as EHRs) and regional HIE networks that, when aggregated, spanned the nation. Econometric evaluations suggested that although the start-up costs and operational costs were high, as much as US\$156 billion in one study [14], downstream efficiencies and cost-avoidance could yield similarly large savings [15]. These analyses helped to build the initial case for HITECH funding.

The regional HIEs, formerly RHIOs, were considered essential to the development of the NHIN, although some concerns about sustainability were voiced [16–18]. Over time, many of the same challenges faced by RHIOs were also faced by the largely federally-funded NHIN HIEs, leading to further advancements. The physical network of NHIN thus evolved into the Nationwide Health Information Network

(NwHIN), defined by ONC as “the standards, services, and policies that enable the secure exchange of health information over the Internet” [19]. It can be considered that it is the actual exchange of data that represents the value, rather than the physical network that facilitates the exchange. Using the terminology standards necessary for interoperability, such as ICD-9/10 and Systematized Nomenclature of Medicine (SNOMED®) coding for medical diagnoses, Common Procedural Terminology (CPT) codes for procedures, RxNORM codes for medications, and messaging standards, such as Health Level 7 (HL7®), clinical or administrative data can be exchanged between existing health information exchange models and enabled for exchange with models that are still emerging.

### **Health Information Exchanges (HIEs)**

Health Information Exchanges (HIEs) provide for the mobilization of healthcare information electronically across organizations within a region, community, or hospital system. HIEs can provide critical improvements to exchange of healthcare information. For example, when patients are moving between healthcare settings, Emergency Department (ED) providers often have access to incomplete data since a patient may have received previous care from multiple providers. As of February 2012, there were 255 HIE initiatives at state, regional, and local levels within the US. As HIEs continue to evolve, their future is linked to the Meaningful Use initiative and will need to be closely aligned with both healthcare and public health outcomes in order to succeed [20].

## **Public Health and Health Information Exchanges**

### ***ARRA and HITECH Provide HIE Resources***

On February 17th, 2009, as part of the American Recovery and Reinvestment Act (ARRA), the Health Information Technology for Economic and Clinical Health (HITECH) Act implemented a series of incentives, grants, and programs to increase the use of health information technology to improve clinical care, reduce healthcare costs, and support population and public health.

The HITECH Act has provided an exciting and unique opportunity for public health to build strong partnerships in order to impact public health outcomes through greater interoperability and data sharing. In order to prepare, the public health community is assessing the capability of systems to report and receive data from professionals and hospitals for public health objectives.

The HITECH Act appropriated funding for the Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Medicare and Medicaid Services to implement a number of programs. ONC implemented Health Information exchange funding programs for a State Designated Entity (SDE) in

**Table 22.1** The intent of HITECH, based on “Launching HITECH,” 2010 [21].*Ultimate goals of HITECH:*

1. Improved individual and population health outcomes
2. Increased transparency and efficiency
3. Improved ability to study and improve care delivery

*HITECH actions encompass:*

1. Adoption of Electronic Health Records (EHRs), fostered by  
Regional Extension Centers  
Workforce Training
2. Meaningful use of EHRs, enabled by  
Medicare and Medicaid incentives and penalties
3. Exchange of health information, fostered by  
State grants for Health Information Exchange (HIE)  
Framework for standards and certification  
Framework for privacy and security

every state and territory to plan and build a health information exchange. Each SDE uses this funding to support an existing HIE, groups of HIEs or Regional Health Information Organizations, or to build an HIE. The general outline of HITECH is illustrated in Table 22.1.

### **The Patient Protection and Affordable Care Act (PPACA)**

The Patient Protection and Affordable Care Act (PPACA), most commonly known as the Affordable Care Act (ACA), was signed into law on March 30, 2010. Estimates by the Congressional Budget Office (CBO) put the net reduction of the national deficit from healthcare provisions to be US\$124 billion [22]. There are specific provisions in the PPACA for health IT and specifically health information exchange. PPACA more fully integrates the aims of HITECH by highlighting new care delivery and reimbursement models which require a high level of care coordination. PPACA encourages care delivery models to leverage HIE functionalities in order to meet quality standards such as care coordination, patient safety, and preventative services.

There are three main provisions in the PPACA for health IT. These provisions are intended both to address the challenges in electronic health information exchange and to encourage innovative reimbursement models for high-quality care. Specifically, provisions were created for activities that:

1. Improve the quality of healthcare by increasing the quality of data collected, creating new programs that involve health IT, and providing payment to existing entities for the use and improvement of health IT.
2. Set new operating rules and standards that either directly or indirectly control the use and innovation of health IT.
3. Increase the size of the health IT workforce across sectors.

## Accountable Care Organizations (ACOs)

Due to the ACA, new care delivery and reimbursement models were developed. These models require a high level of coordination, availability of appropriate technological solutions, and access to patient records. One such emerging model is the Accountable Care Organization. Accountable Care Organizations (ACOs) are intended to create incentives for doctors, hospitals, and other health care providers to coordinate patient care more effectively across care facilities. Through focus on patient care coordination and linking payment rewards to health outcomes as part of the PPACA, Medicare will potentially save US\$960 million over a 3-year period. In order to receive these rewards from the Medicare Shared Savings Program, ACOs will need to meet quality standards in five key areas:

1. Patient and caregiver experiences of care
2. Care coordination
3. Patient safety
4. Preventative health
5. At-risk population and elderly health

In order to meet these quality standards, some ACOs are working closely with HIEs to leverage advanced HIE functions which are key to coordinating patient care, quality improvement, and organizational efficiency and effectiveness.

HIEs tie PPACA efforts back to the HITECH act and meeting the Meaningful Use requirements for incentive payments. HIEs enable patient data to be readily available in usable form and some advanced HIE functionalities, such as bidirectional exchange, can be leveraged effectively to help ACOs meet quality standards in order to qualify for reward payments.

## Meaningful Use Incentive Program

Under the HITECH Meaningful Use Incentive program, eligible professionals and hospitals may receive incentives for purchasing and using Certified Electronic Health Record Technology (CEHRT). Each Medicare *meaningful user* will receive up to US\$44,000 for purchasing and using CEHRT during calendar years 2011–2015, while Medicaid providers could receive up to US\$63,750 per year over 6 years for using CEHRT between 2011 and 2021. For Medicare incentive payments, hospitals that purchase and use CEHRT receive a base of US\$2 million, plus further funding based on a number of factors including total discharges, total gross revenue, total charity cases, Medicare inpatient days, and total inpatient days.

Many hospitals are also dual eligible and can receive additional Medicaid incentive payments. Medicare providers and hospitals that do not use certified CEHRT will be penalized; their payments will be adjusted downward over time, to a maximum of a 5 % penalty per year [23].

The amounts of these incentive payments are large. Through February 2013, US\$12.6 billion in Medicare and Medicaid EHR incentive payments have been made, including US\$4.31 billion to 264,292 eligible professionals (EPs) and US\$8.16 billion to 4,299 eligible hospitals (EHs) [24].

The Meaningful Use (MU) incentive program was carefully defined by the Department of Health and Human Services to assure that it would advance health. The concept of Meaningful Use was built using the “five pillars” of health outcome policy priorities:

- improve the quality, safety, and efficiency of care, and reduce disparities in healthcare
- engage patients and families in their care
- improve care coordination between providers and facilities
- promote the privacy and security of health information (especially as contained in EHRs)
- promote public and population health

The achievement of Meaningful Use was intended to be a phased implementation. A three-stage plan was created to enable eligible providers and hospitals to adopt certified EHR technology and use that technology to achieve specific objectives and measures.

Stage 1 (2011–2012) is focused on data capture and sharing. This stage concentrates on capturing data electronically and in standardized format, and reporting clinical quality measures (such as blood pressure measurement, smoking status assessment, etc.) and public health information. Stage 2 (planned for 2014) emphasizes increased health information exchange (HIE) and e-prescribing, and incorporation of laboratory results. Finally, Stage 3 (planned for 2016) is planned to lead to better outcomes through elevated quality, safety, and efficiency, and to improved population health. Table 22.2 provides a more detailed overview of the three stages.

For Stage 1, EPs must complete [26]:

- 15 core objectives
- Five out of ten from menu set objectives (including one public health objective)
- Six total clinical quality measures
  - Three core or alternate core
  - Three out of 38 from additional set

Stage 1 EHs must complete:

- 14 core objectives
- Five out of ten from menu set objectives (including one public health objective)
- 15 clinical quality measures

Core objectives include items such as record demographics and maintain an active medication list. The Menu Set objectives include three that are specific to public health. Of these three, EPs and EHs may choose to (a) submit electronic data to immunization registries or (b) provide electronic syndromic surveillance data to

**Table 22.2** Stages of meaningful use, from HealthIT.gov [25]

Stage 1: meaningful use criteria focus on:	Stage 2: meaningful use criteria focus on:	Stage 3: meaningful use criteria focus on:
Electronically capturing health information in a standardized format	More rigorous health information exchange (HIE)	Improving quality, safety, and efficiency, leading to improved health outcomes
Using that information to track key clinical conditions	Increased requirements for e-prescribing and incorporating lab results	Decision support for national high-priority conditions
Communicating that information for care coordination processes	Electronic transmission of patient care summaries across multiple settings	Patient access to self-management tools
Initiating the reporting of clinical quality measures and public health information	More patient-controlled data	Access to comprehensive patient data through patient-centered HIE
Using information to engage patients and their families in their care		Improving population health

public health agencies. Only EHs may select the third public health menu objective, which is (c) provide electronic submission of reportable laboratory results to public health agencies.

***Public Health Meaningful Use Objectives***

Under the Meaningful Use Incentive Program, EPs and EHs in Stage 1 would select at least one public health option from the menu objectives. In response to the MU objectives, public health jurisdictions worked to support the three menu set objectives, create supporting documentation or instruction available to participants, and establish a methodology to provide verification of successful test submission to the participants.

**Immunization Information Systems (IIS)**

For Stage 1 MU, EPs and EHs need to meet one of three of public health measures by sending a test message, and if successful, to establish a connection from their CEHRT to the state immunization information system (IIS). For Stage 2, EPs and EHs are required to submit, on an ongoing basis, immunization results to their jurisdiction’s IIS. Several states are leveraging their existing IIS as a clear value-added proposition for collaboration with HIEs. Providers can submit immunization data to the HIE and have that sent to the jurisdiction’s public health IIS, thus meeting their MU requirements.



### **Electronic Laboratory Reporting (ELR)**

Electronic Laboratory Reporting (ELR) is the secure electronic transmission of reportable condition standards-based laboratory reports from laboratories to public health. For Stage 1 in MU, a test of an EHR's capacity to send electronic reports to public health agencies is required; in Stage 2, this is upgraded to ongoing submission of results.

### **Syndromic Surveillance (SS)**

Public health syndromic surveillance is the routine submission of inpatient and ambulatory clinical care EHR data to public health. For Stage 1 MU, a test of an EHR's capacity to send ELRs to public health agencies is required; in Stage 2, this is upgraded to ongoing submission of results.

### **Reporting to a Cancer Registry**

A new public health objective for Stage 2 MU is cancer reporting from ambulatory providers to state cancer registries. This objective is intended to address the current underreporting of cancer information. Due to changing medical practices, an increasing number of cancer cases are not seen in a hospital setting; therefore, past practices of collecting cancer cases based on diagnosis or treatment in a hospital setting are no longer considered sufficient. This measure only applies to eligible professionals and requires ongoing submission of data to meet the requirement.

### **Standards for Reporting to Public Health**

For each of these measures, both Stage 1 and Stage 2 defined specific standards and implementation guides that must be used in order for providers to meet the requirements of Meaningful Use (Table 22.3.).

For Stage 1, as noted in the table, multiple formats were allowed for Immunization and syndromic reporting while ELR required a specific HL7<sup>®</sup> 2.5.1 format. The requirement of an HL7<sup>®</sup> 2.5.1 message created some challenges for public health agencies, as many of them had been accepting HL7<sup>®</sup> 2.3.1 messages prior to the requirements of Meaningful Use. The standards for Stage 2 reduced the variability of the messages allowed to meet the measures; all of the previous measures moved to an HL7<sup>®</sup> 2.5.1 standard while the new cancer requirement chose the single standard of CDA. To improve nationwide interoperability, the implementation guides for Stage 2 also reduced much of the regional variation previously allowed in Stage 1.

**Table 22.3** Standards for reporting to public health

Public health measure	Stage 1 standard	Stage 2 standard	Vocabulary standard
Immunization registry reporting	Standard – HL7 <sup>®</sup> 2.3.1 Implementation guide for immunization data transactions using version 2.3.1 of the Health Level Seven (HL7 <sup>®</sup> ) standard protocol implementation guide version 2.2	Standard – HL7 <sup>®</sup> 2.5.1	HL7 <sup>®</sup> standard code set CVX – vaccines administered
	Standard – HL7 <sup>®</sup> 2.5.1 HL7 <sup>®</sup> 2.5.1 implementation guide for immunization messaging release 1.0	HL7 <sup>®</sup> 2.5.1 implementation guide for immunization messaging release 1.4	
Reportable lab results	Standard – HL7 <sup>®</sup> 2.5.1 HL7 <sup>®</sup> version 2.5.1 implementation guide: electronic laboratory reporting to public health, release 1	Standard – HL7 <sup>®</sup> 2.5.1 HL7 <sup>®</sup> version 2.5.1 implementation guide: electronic laboratory reporting to public health, release 1 with errata and clarifications	SNOMED-CT <sup>®</sup> and logical observation identifiers names and codes (LOINC <sup>®</sup> ) database version 2.40
Syndromic surveillance	Standard – HL7 <sup>®</sup> 2.3.1	Standard – HL7 <sup>®</sup> 2.5.1 PHIN messaging guide for syndromic surveillance: emergency department and urgent care release 1.1 August 2012 (required for inpatient and optional for ambulatory)	
	Standard – HL7 <sup>®</sup> 2.5.1		
Cancer registries		CDA	IHTSTO
		Implementation guide for ambulatory healthcare provider reporting to central cancer registries, August 2012	SNOMED-CT <sup>®</sup> international release July 2012 and US extension to SNOMED-CT <sup>®</sup> March 2012 and LOINC <sup>®</sup>

**State HIE Cooperative Agreement Program**

The Office of the National Coordinator for Health Information Technology (ONC) implemented Health Information Exchange funding programs for a state designated entity (SDE) in every state and selected territories, to be used to plan and build

Health Information Exchange (HIE) capacity. A system developed to support this capacity can also be referred to as an HIE. Each SDE could use this funding to support an existing HIE system or groups of systems, or build a new HIE [27].

HIEs can offer a variety of services ranging from basic connectivity functions to more advanced functions like master patient indexes. The availability of such services allows HIEs to add value. For example, an HIE may connect providers to services such as e-prescribing (electronically sending a prescription to a pharmacy), exchange of clinical care summaries, or provider alerting services (for example, alerting a primary care physician when a patient visits an ED).

Provider directories are another function of HIEs and contain basic information on HIE participants, including entity-level as well as individual-level provider information. Without this service, not only would each individual EHR system have to maintain this information, but exchange partners would have to update their information in multiple locations [28].

Trust Services are another type of HIE service, and encompass digital certificate services that allow authentication as well as encryption, signing, and validation of information requests and messages [29]. Other services include those enabling HIEs to provide secure transport of health information (such as Health Information Service Provider (HISP) services), and adapters that can help transform messages from one standard to another without decryption of the message.

On a more advanced level, HIEs offer services such as a Master Patient Index (MPI). MPIs enable searches and de-duplication within an HIE by reconciling patient identities across care setting; basic demographic information can be stored, as well as identifiers (IDs) that are utilized by different providers. HIEs may offer consent databases that allow patients to have more granular control over the data shared with different types of providers. More advanced HIEs may even support a query-based exchange, where a provider's EHR system can send a query message and receive a response from the HIE. For example, a provider could send a request for a patient's medical history and receive the information directly from the HIE system [30].

### ***Models for Building State HIE Infrastructure***

State governments or their SDEs are critical in ensuring HIE success which would naturally accelerate Meaningful Use, improve care outcomes, and increase efficiency of care delivery. State leaders and ONC, as partners in the State HIE Cooperative Agreement Program which takes place over the course of four years, have been working closely together to create strategic and operational plans. These plans reveal varied approaches to meet program goals. These models are tailored to current capacity and exchange workflows within the state. Through review and close partnerships, ONC identified predominant models which are described in this chapter: the elevator model, the capacity building model, the orchestrator model, and the public utility model.

The elevator model utilizes an initial outburst of intense, focused effort which enables a rapid progress to simple interoperability through directed exchange.

This ensures that providers have an option to meet the Meaningful Use requirements. A vital aspect of this model is the development of Health Information Service Providers (HISPs) which are used to facilitate directed exchange services across the state and directory services in order to support care summary exchange across providers. Leveraging private entities such as vendors or sub-state nodes for their directed exchange capabilities is an important aspect to this approach.

A key component of this strategy is to build capacity through a focused effort to assist providers and other data exchange partners who may have limited information exchange capabilities to participate in the HIE, through technical assistance and outreach work to small or rural pharmacies and labs. Even though the initial phase relies on basic interoperability, this model has the potential to evolve into offering significant services in order to meet requirements of later stages of the Meaningful Use program.

The capacity builder model focuses initially on increasing current exchange capability and capacity through incentives aimed at financial or technical support. The main difference between orchestrator and the capacity-builder model is the capacity-builder's *early focus* on building upon existing or developing exchanges to increase the support to their local regions or communities as opposed to connecting them at the state-level. Similar existing preconditions or environmental factors create the foundation for the capacity-builder to potentially evolve into an orchestrator model in situations where sufficient market demand and buy-in exist.

The orchestrator model can be defined as a thin-layer state-level network which forms a network-of-networks through modulating HIE transactions across existing sub-state exchanges. It can be differentiated from other models in its focus on creating a statewide network instead of increasing the capacity of sub-state nodes. The orchestrator model's primary focus is to connect existing nodes instead of working to provide services directly to providers.

The public utility model can be characterized as having the most centralized approach and policies of the models described in this chapter. The success of this model is founded in a highly proactive approach taken by states which results in an SDE which has buy-in and participation across a broad range of stakeholders. This ensures that it has a highly trained staff and management team who work in varied areas of policy, project management, implementation of new technology, and business analysis. This model provides retail services directly to providers. This model is different from the orchestrator model because it places primary focus on the SDE as the main node of state-wide HIE activities as opposed to coordinating a network-of-networks. Expanding state-level infrastructure is the main area of resource allocation as the SDE is the main node that handles messages and provides shared services directly to providers [31].

## ***HIE Information Models***

There are a myriad of approaches that have been taken in delivering shared services to end users of HIEs. Whether it is leveraging existing HIE infrastructure or

starting from the ground up, an understanding of state viewpoints and potential challenges is a vital component in determining the information model and approach taken.

This section showcases the three most popular approaches that have been taken. These are not tailored specifically to an individual state, and as such, variation should be expected in actual state implementation approaches. The spectrum of models highlighted ranges from the centralized model, which can be characterized by its robust infrastructure, to the decentralized model, which lies on the other side of the spectrum and focuses on creating bridges between existing HIEs.

The centralized state information model, as mentioned above, designates one entity as the state-wide health information organization. This creates one portal through which providers and organizations, such as Medicaid and RHIOs, can interface with the HIE. The SDE can offer a core set of exchange services by being the hub of all stakeholder interaction. A variety of implementations have been seen, which include examples where the state-wide HIE is a state-run entity. As the hub, the SDE will manage, match, and execute the exchange of all health information among stakeholders, which requires that a master patient index (MPI) and record locator service are located within the HIE. As examples of services provided, lab ordering and result delivery can be enabled as well as e-prescribing.

On the other end of the spectrum, a decentralized state information model focuses primarily on coordination and collaboration functions between stakeholders. This may mean that the state has to develop policies or procedures in order to facilitate access to patient data, verification of provider identities, and to exchange information between the health organizations. The emphasis in this model is on facilitation, as no actual exchange of data takes place through a central state-wide HIE. While no exchange happens through a single state hub, the state may still support a gateway for health information exchange between stakeholders through different mechanisms such as NwHIN standards. Several key functions for a decentralized state HIE ensure accuracy, secure data transfer, standardization, and validation of messages sent and received. Through these functions, the state HIE builds trust among the organizations sharing data.

Most state HIEs incorporate elements of both the centralized and decentralized models. These are referred to as hybrid state information models and provide a spectrum of services. While they may not be true centralized models, with exchange managed only at the state level, services such as consent management, creation and maintenance of a master patient index, and record locator service are common. These models tend to require that the HIE implement policies regarding data exchange and offer varying levels of shared services. As data sharing between various organizations continues to increase and build momentum, states utilizing a hybrid information model are investing in technology infrastructure to support exchange with a variety of HIOs, such as enterprise HIEs and regional HIEs, and other providers. Through these state information models, shared services are provided through which accurate and efficient health information exchange can take place [32].

## Public Health Benefits

As public health sought to build the infrastructure to accept meaningful use transactions, partnerships with HIEs proved beneficial. The basic infrastructure supplied by an HIE greatly reduces the implementation costs for public health reporting streams such as syndromic surveillance. Without an HIE in place, public health would need to support a point-to-point infrastructure with every provider within their jurisdiction. Additionally, public health would need to replicate many of the services already provided by an HIE, such as certificate management, provider directories, and HISP services. By utilizing HIE transport mechanisms, public health will reduce their infrastructure needs to potentially one interface with the HIE, which would already have existing connections to the community providers. This could provide significant resource savings for both public health and providers.

HIEs also help both providers and public health agencies accept data that meets the requirements of Meaningful Use. The final rules for both Stage 1 and Stage 2 state that the message sent to public health must come from certified technology [33]. In the first model, certified EHR systems could send data directly to a public health agency or through an HIE service and meet the requirements of meaningful use. In the second model, some providers utilized systems separate from their main EHR product. For example, a Laboratory Information Management System or a separate Emergency Department registration system could have modular certification for ELR or Syndromic Surveillance reporting. These separate systems, since they have modular certification for the appropriate meaningful use measure, could send data directly to public health or through HIE aggregation services to meet the meaningful use requirement. In the third model, HIEs can provide value-added services to both the provider and public health. In this model, the provider does not have to send data in the required meaningful use format or from a certified system: the HIE can take transactions that do not meet the standards for meaningful use and transform them into standard messages that do meet the requirements of meaningful use. For example, an HIE could accept an HL7<sup>®</sup> 2.3.1 message from a LIMS and transform it into an HL7<sup>®</sup> 2.5.1 message that meets the requirements of meaningful use before passing it on to public health. Another example could be an HIE accepting Syndromic Surveillance data in a simple text message from an ED registration system and then transforming that into the appropriate HL7<sup>®</sup> version before passing the message on to public health. If an HIE does provide these types of services, it must possess modular certification for the appropriate measure in order for the transaction to meet the requirements of meaningful use [34]. For ELR, some HIEs also offer vocabulary translation services where they may take local codes for a laboratory test name and translate that code into the appropriate LOINC<sup>®</sup> code before passing the message on to public health. If HIEs are only translating local codes to standard code sets and the hospital system has the appropriate certification, then the HIE does not have to have modular certification.

## ***Challenges***

There is a wide array of privacy and security laws around health information at both the federal and state level in the US. Each state has internal laws and interpretations which in turn influence the approach to enabling health information exchange. Work has been done to identify challenges and solutions. In 2005, ONC and the Agency for Healthcare Research and Quality (AHRQ) collaborated to assess and identify best practices and policies around interoperable health information exchange. It is commonly referred to as the Health Information Security and Privacy Collaboration (HISPC), and engaged 42 states and territories. Often, privacy and security laws were created for paper-based systems and directly conflict with electronic exchange.

A common issue is a misunderstanding of whether and when the Health Insurance Portability and Accountability Act (HIPAA) privacy rule applies to health information exchange. There is also variance in state laws on the use and definition of terms such as consent, authorization, and release, in regards to privacy and security policies. In fact, many states have adopted stricter privacy policies than required by HIPAA. Moving state or regional health information exchanges to interstate requires an advance understanding of both inter- and intra-state privacy and security policies and options.

Meaningful Use requires eligible providers and hospitals to submit information “except where prohibited by law,” in order to align with the variance in policies in states. A future challenge will be the creation of a framework of common privacy and security policies which allow for state to state variance while still ensuring nationwide information exchange networks [35].

## **Sustainability**

Sustainability models for HIEs are an important consideration, and one which is still under development. A key aspect in long term success of an HIE is proving the value and return on investment to stakeholders. One component in showing long-term stability is reaching a critical mass of both data and users. In order to reach that critical mass of participants and data, participation by state, local, and federal government agencies, including public health, will be key [36]. Public Health can also play a key role in sustainability by helping HIEs provide value-added services to their providers.

## ***Future Collaborations between HIEs and Public Health***

Although the current partnerships between public health and HIEs remain limited, there are potential collaborations which could provide value-added services to public health. Similarly to what has happened with ELR, *automated case reporting* from an EHR to public health could make disease reporting more timely and

complete. Some pilot initiatives have shown the potential benefit of this type of case reporting. The Public Health Data Standards Consortium demonstrated that EHRs could be successfully configured to send a CDA standard to public health for pertussis and tuberculosis; the information went beyond the basic laboratory information included in ELR to include key variables required for case reporting, such as symptom onset date and risk factors [37]. Kentucky also demonstrated that cancer case reports in Clinical Document Architecture (CDA) standard format, required for Stage 2 MU, could flow through the HIE to public health [38]. During the fungal meningitis outbreak of 2012, public health officials were granted access to EHR systems from key providers; this access allowed them to have near real-time access to patient data as the outbreak investigation continued [39], which played a key role in allowing public health to contain the outbreak. If HIEs had been in place, information from multiple providers could have been accessed directly through the HIE, greatly simplifying the process for public health.

In western New York, public health has actually developed relationships with the HIE that allows them access to the HIE for case investigations. Local public health agencies have found this extremely useful for investigation of cases such as sexually-transmitted diseases (STDs) and perinatal hepatitis B. In most public health jurisdictions, the volume of STD reporting overwhelms public health investigative resources. However, access to the HIE allows public health to look up key additional information, such as pregnancy status and treatment information, allowing prioritization of cases for follow-up. For perinatal hepatitis B cases, access to the HIE allows public health to locate laboratory and immunization information for both the mother and the child, streamlining the entire case management process. In future, these manual lookups could be replaced by automated case reporting from the HIE, making the process even more efficient.

Potentially, HIEs could assist public health's goal of monitoring population health measures. Most of the current models of collaboration involve helping public health obtain individual case data, but population health measures, especially around chronic conditions, are also important to public health. A pilot project in Massachusetts, based on Query Health MDPHnet [40], enables public health to query a broad range of private providers and community health centers. The system allows public health to identify chronic conditions in specific patient populations, and helps define interventions aimed at these problems. Initially, the pilot involved risk factors associated with gestational diabetes; future efforts are planned to include conditions such as hypertension to help identify targeted intervention strategies for at-risk communities.

Consumer engagement is another area of potential collaboration. Many HIEs plan on building infrastructure to enable consumers to have access to their own data, either through portals built by the HIEs or through interfaces with products such as Microsoft's HealthVault [41]. Public health could similarly enable consumers to have direct access to IIS records. In most jurisdictions, the IIS has the most complete immunization history on their pediatric populations. Since children often receive their immunizations from a variety of providers, access to the complete record is critical for both the provider and parent. HIEs, already building interfaces



to immunization registries for providers, could include products to enable parents and consumers to access their own data. Since the HIEs will already manage issues like authentication and security, public health agencies would be able to provide consumer engagement with minimal infrastructure costs.

## Conclusion

Although HIEs were originally a mandated proposition targeted to the general field of healthcare, the current and potential benefits are gathering increasing public health interest. Potential benefits to public health include faster delivery of higher-quality, standards-based data from an increased number of partners. The opportunity to collaborate and benefit with HIE partners is a compelling one.

### Review Questions

1. Describe the Stage 1 and Stage 2 public health meaningful use measures.
2. What are the challenges for Public Health associated with the different data models for Health Information Exchanges?
3. How can HIEs assist Public Health to receive meaningful use transactions?
4. Describe the different structures that HIEs use to build infrastructure with their region.
5. What are some population health questions that a Query Health model could answer for Public Health?
6. What are some of the interoperability challenges for public health and how can HIEs help address this problem?
7. How can HIEs and public health further partner to form a mutually beneficial relationship, and what are the challenges?

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## Chapter 23

# Decision Support and Expert Systems in Public Health

William A. Yasnoff and Perry L. Miller

**Abstract** The expanding quantity of health data and the complexity of its applications are pointing to the need for greater application of computer resources to provide support for decision-making in public health and clinical practice. Decision support and expert systems, as illustrated by the immunization-forecasting program IMM/Serve, offer such support, both now and in the future. Would-be developers of such systems, however, must recognize that the systems are both inherently complex and work-intensive in development. Successful decision support and expert systems require incorporation of comprehensive knowledge and sound logic, extensive testing by use of a variety of methods, and consideration of the nature of the decision-making to be supported and the appropriateness of the environment in which such systems will be placed, including the willingness of users to participate in the development process. Clearly, decision support systems can be appropriate for a number of potential applications in public health practice, including analysis of surveillance data, resource management, and the dissemination of practice guidelines.

**Keywords** Electronic medical records • Immunization forecasting • If-then rules • Decision support • Knowledge representation • Expert system • Semantic network • Flowchart • Model-based knowledge • Procedural knowledge • Tabular knowledge • Knowledge testing • Knowledge maintenance • Test cases • Decision characteristics • User environment

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### Learning Objectives

1. Define and describe the purpose of decision support and expert systems.
2. List and explain the three reasons that decision support and expert systems are needed in public health.
3. Differentiate among (1) tabular knowledge, (2) rule-based knowledge, and (3) procedural knowledge in decision support and expert systems, as illustrated by the IMM/Serve system.
4. Describe decision support and expert system testing through (1) automated tools for knowledge testing, (2) testing with hand-crafted sets of test cases, and (3) testing with pilot use, as illustrated by the IMM/Serve system.
5. Describe the goals for choosing knowledge representation in encoding health knowledge in a computer to be used for decision support, and indicate the uses and limitations, if any, of (1) tables, (2) rules, (3) flowcharts, (4) semantic networks, (5) model-based knowledge, and (6) procedural knowledge.
6. Describe the characteristics of an environment in which development and implementation of a decision support or an expert system is likely to be successful, and list the steps that a development team must take in building such a system.

## Overview

The expanding quantity of health data and the complexity of its applications are pointing to the need for greater application of computer resources to provide support for decision-making in public health and clinical practice. Decision support and expert systems, as illustrated by the immunization-forecasting program IMM/Serve, offer such support, both now and in the future. Would-be developers of such systems, however, must recognize that the systems are both inherently complex and work-intensive in development. Successful decision support and expert systems require incorporation of comprehensive knowledge and sound logic, extensive testing by use of a variety of methods, and consideration of the nature of the decision-making to be supported and the appropriateness of the environment in which such systems will be placed, including the willingness of users to participate in the development process. Clearly, decision support systems can be appropriate for a number of potential applications in public health practice, including analysis of surveillance data, resource management, and the dissemination of practice guidelines.

## Introduction

Information systems that assist in the analysis of data to assist decision-making are known as *decision support* and *expert systems*. While it may be difficult to distinguish clearly between these two types of systems, decision support systems

generally incorporate simpler and more straightforward knowledge. Expert systems, on the other hand, usually include substantial and complex representations of policies, rules, and facts that are important in evaluating alternative courses of action or recommendations. In any case, the goal of such systems is to bring external knowledge to the process of data analysis in an effort to improve the speed, accuracy, and consistency of human decision-making.

Why are decision support and expert systems needed in public health? There are three basic reasons:

- Increasing quantities of data
- The need for more rapid decision making
- The need for better dissemination of best practices

As we move through the twenty-first century, the sheer quantity of public health data is expanding rapidly. We are working on improving our surveillance systems so that a larger proportion of reportable diseases are actually reported. In addition, the development and dissemination of electronic laboratory reporting systems and electronic medical record systems will greatly increase the volume of case reports to the public health system. Increasingly, state and local governments are collecting and disseminating community health status information at greater and greater levels of detail. In addition, performance data about the health system and from health plans is becoming more abundant. There is certainly no shortage of data, although accurate, complete, and timely data are still difficult to obtain. It can be argued that the application of computer-based information systems to public health is, to some extent, responsible for this explosion of data. Nevertheless, we must increase our capacity to handle such data and analyze and act on them. Existing methods, mostly manual, are not sufficient to permit the public health system to cope. Decision support systems can provide preliminary analysis that allows scarce human resources to focus on the key problems while ignoring a vast sea of irrelevancy.

Public health is also facing major new challenges that require more rapid decision-making. Foremost among these challenges is the threat of bioterrorism. It is clear that the earlier a bioterrorism event is detected, the more effective the response can be in limiting both the associated morbidity and mortality. Another key threat involves emerging infections. Tracking these new and sometimes confusing diseases requires very quick responses. We are also facing increasing demands from policy makers for information and for justifications for both existing and proposed public health initiatives.

Public health also is challenged to be more effective in dissemination of best practices. Such a challenge requires public health to possess the ability to both discover and disseminate successful programs and interventions. By sharing knowledge and experience effectively, we can avoid the unnecessary rediscovery of successful practice strategies and help insure more uniform performance of the public health system.

We also need to improve compliance with preventive medicine guidelines. Although most physicians are very supportive of preventive measures for their patients, it is not a primary focus of their practice. The increasing use of *electronic medical record (EMR)* systems provides an opportunity to deliver reminders at the

point of care in order to improve compliance [1]. In addition, guidelines that require specific patient data can obtain this input directly from EMR systems, thereby relieving providers of an administrative obstacle to their use.

In addition to the clear need for decision support and expert systems in public health, we are fortunate that the delivery mechanisms for these systems are improving rapidly. The increasing use of EMR systems has already been mentioned with respect to dissemination of clinical preventive guidelines.

Finally, the Internet provides a common network and user interface for public health information systems of all types. Decision support and expert systems can both access data and deliver recommendations by use of the Internet. Furthermore, the availability of this common network can both reduce the cost of system development and ease widespread deployment. In such an environment, the cost of an expensive system may be more easily justified through its nationwide dissemination and use. Finally, the continuing improvement of the price-performance characteristics of computer systems allows the cost-effective use of extremely sophisticated and complex algorithms. Although the application of certain expert systems has in the past been limited by the speed and cost of computation, such limitations are increasingly disappearing.

## **An Example of the Use of Decision Support Systems: Childhood Immunization Forecasting**

There is a wide range of potential applications for computer-based decision support within public health. The IMM/Serve *immunization forecasting* program [2] illustrates many of the issues involved. IMM/Serve is a computer program built to provide patient-specific recommendations for childhood immunization, based primarily on the guidelines of the CDC's Advisory Committee on Immunization Practices (ACIP). IMM/Serve started with six vaccine series and eventually expanded to cover twelve, including, for example: diphtheria tetanus pertussis (DTP), hepatitis A (HepA), hepatitis B (HepB), *Haemophilus influenzae* Type b (Hib), measles mumps rubella (MMR), polio, and varicella (Var).

Childhood immunization is a particularly good domain in which to implement decision support because (1) many different organizations nationwide have built immunization registries [3], (2) national panels maintain detailed guidelines that are quite complex, and (3) many clinicians will benefit if these recommendations can be produced automatically based on data contained in a registry database. IMM/Serve has been used for many years in several State and Federal settings. For example, the US Indian Health Service (IHS) has used IMM/Serve in several hundred clinics nationwide.

IMM/Serve takes as its input a child's vaccination history, together with a small amount of additional information. Table 23.1 shows a case that might have been submitted to IMM/Serve. This input specifies the vaccine doses the child has received as well as the date of each vaccination. For the Hib series, the vaccine brand is also specified (PRP-OMP). The input also specifies the child's date of birth,

**Table 23.1** An example case to be analyzed by IMM/Serve

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Date of birth:	7/10/1999
Date used for forecast:	10/1/2000
Contraindicated vaccines:	none
Other facts:	none
HepB:	7/10/1999, 9/12/1999, 1/20/2000
DTaP:	9/12/1999, 11/15/1999, 1/20/2000
Hib:	PRP-OMP 9/12/1999, PRP-OMP 11/15/1999
IPV:	9/12/1999, 11/15/1999
MMR:	7/14/2000

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**Table 23.2** The output produced by IMM/serve for the case shown in Table 23.1

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The following immunization(s) are due on 10/1/2000:

DTaP 4  
 Hib 3 (PRP-OMP)  
 IPV 3  
 MMR 2 or Me 2  
 Var 1

The following immunization(s) will be due:

D/T series dose 5, on or after 7/10/2003 but before 7/10/2004 (if DTaP 4 is given on 10/1/2000)  
 IPV 4, on or after 7/10/2003 but before 7/10/2004 (if IPV 3 is given on 10/1/2000)  
 HepA 1, on or after 7/10/2001 but before 1/10/2002

The following vaccine series are either complete or no longer relevant for this case: HepB

Note: For the doses due today, the Vaccine for Children (VFC) Program will pay for the following doses:

DTaP  
 Hib  
 IPV MMR Var

---

the “forecast” date for which recommendations are desired, any vaccines that are contraindicated, and other facts, such as whether the child’s mother is “HBsAg positive,” that could affect the schedule for Hepatitis B vaccination. IMM/Serve processes this input and produces the output seen in Table 23.2.

IMM/Serve’s output indicates (1) which vaccinations are due “now” (i.e., as of the requested forecast date), (2) when the next dose for each vaccine series will be due, and (3) which series are complete. It also indicates which doses are covered by the national Vaccine for Children (VFC) Program for economically eligible children.

### *Sources of Complexity in the Immunization Domain*

IMM/Serve’s goal is to take the recommendations produced by the ACIP expert panel and encode those recommendations into computer-based form so that they can be automatically delivered to a clinician in the context of a patient’s care. There are a number of sources of complexity that make this process much more complicated than it might first appear.



A major source of complexity is the guideline logic itself. When the guideline logic is published in paper form, there is typically a time chart for each vaccine series indicating when each vaccination should be given, augmented by a detailed set of footnotes dealing with various special circumstances in which this basic logic must be modified. When a child is brought to the clinic on a regular basis and when no special circumstances apply, the relevant logic is quite straightforward. However, when the child has been receiving irregular care, the relevant logic can be quite complex. Examples of complexity in the guideline logic include the following:

1. Minimum ages and wait-intervals for immunization forecasting. For each dose in each vaccine series, there is a set of associated ages and wait-intervals to be used for forecasting that dose. For example, there are minimum ages at which the dose can be given. The minimum recommended age is the age at which the child should be scheduled for the dose. The minimum acceptable age is usually a younger age: If the child is already at the clinic, the dose may be given as of that age. There is also an age at which the dose becomes "past due." In addition, for most doses there are minimum "wait-intervals." One type of wait-interval indicates how long one should wait from the previous dose in that series. Even if the child is over the minimum age for a dose, the dose should not be given until this wait-interval is past. For live vaccine doses, there may also be wait-intervals from previous live vaccine doses in other series. Other wait-intervals can also be used, including a minimum wait-interval between dose 1 and dose 3 for Hepatitis B, and wait-intervals before a dose becomes past due.
2. Logic variation for different clinical conditions. For most vaccine series, the logic of the recommendations varies in different clinical conditions. For example, if the child's mother is HBsAg positive, there may be an accelerated HepB vaccination schedule. In other series, there is special logic for "late starts." For example, in the Hib vaccine series, there is different logic for later doses if the age at dose 1 is under 7 months, or if it occurs at 7–11, 12–14, or 15 months or more. In each of these four circumstances, there may be different minimum ages and wait-intervals for subsequent doses and/or a different number of doses needed to complete the series. In addition, in the Hib vaccine series, the schedule and number of doses required varies with the brand of vaccine used. These are just a few examples of the many different variations in the guideline logic. As a result of these variations, each dose of a vaccine series may have several distinct sets of minimum ages and wait-intervals. The clinical logic determines which set of parameters applies to a particular child at a particular time.
3. Invalid doses based on immunization screening. In addition to the forecasting parameters described above, there is a similar set of screening parameters (minimum ages and wait-intervals) for each vaccine dose. Any dose that is given too early based on these screening parameters is not counted as part of the series for purposes of forecasting. If an invalid dose involves a live vaccine, however, it may still impose a wait-interval for other live vaccine doses.
4. What is a month? Another interesting complexity concerns the definition of a month. Sometimes it makes most sense to consider a month to be a calendar

month, but at other times it makes more sense to consider a month to have a fixed length, such as 28 days.

These are just a few examples of the complexity inherent in the immunization guidelines logic. A further source of complexity arises because the recommendations produced by the panel of clinical experts typically contain “logical gaps.” Clinical experts are accustomed to treating patients one at a time, but they are usually not adept at specifying logic that responds appropriately to all possible combinations of conditions that could conceivably arise. Examples of such gaps include the following.

- Originally, the ACIP guidelines did not make a distinction between minimum ages and wait-intervals to be used for screening vs. forecasting, even though it is clear that these frequently are not the same.
- At one point, the ACIP guidelines recommended a “sequential” approach to giving polio vaccine, an approach that involved giving two doses of inactivated polio vaccine (IPV) followed by two doses of oral polio vaccine (OPV). The guideline did not specify, however, whether IPV or OPV should be used for dose 2 with a child who had already received OPV as dose 1.

Frequently, these logical gaps become apparent only in the process of converting the logic into computer-based form, a process that forces a comprehensive analysis of all the implications in a systematic fashion. Some gaps become evident only when one is running the program with real patient data.

The only way to fill in these gaps in the logic is to work with clinician users (e.g., a group of immunization registry staff) to discuss all such gaps and decide how the guideline should deal with each. This work involves a great deal of iterative discussion and is very time-consuming.

Another source of complexity arises because of the need for local customization. Different users of the system may want their own customized versions of the recommendations. This problem is discussed in more detail later.

These complexities are further compounded by the fact that the national panel produces a new version of its recommendations roughly once a year. The new version typically contains important revisions or additions. As a result, approximately once a year, a significant portion of the logic must be changed, new gaps may need to be resolved, and any local customization may need to be adapted. Then, the entire program must be thoroughly re-tested. If this process is not performed in a rapid, timely fashion, the program will never be up to date.

### ***Encoding IMM/Serve’s Immunization Knowledge***

IMM/Serve uses three different approaches to represent its immunization domain knowledge: (1) *tabular knowledge* (tables), (2) rule-based knowledge (“if-then” rules), and (3) *procedural knowledge* (conventional computer programming).

**Table 23.3** A simplified table of immunization forecasting parameters

Immunization	Acceptable age	Recommended age	Past-due age	Wait-interval
Hib1	6 weeks	2 months	3 months	—
Hib2	10 weeks	4 months	5 months	Hib1 1 month
Hib2_final	12 months	15 months	16 months	Hib1 2 months
Hib3	18 weeks	6 months	7 months	Hib2 1 month
Hib3_final	12 months	15 months	16 months	Hib2 2 months
Hib4	12 months	15 months	16 months	Hib3 2 months

### Tabular Knowledge

IMM/Serve uses tables to represent all of the forecasting parameters for each dose—for example, the minimum acceptable age, the minimum recommended age, and the minimum wait-intervals from previous doses, etc. For each dose of each vaccine series, IMM/Serve may store several sets of such parameters, corresponding to the different clinical conditions in which different sets of parameters apply to that dose. Table 23.3 illustrates how this tabular forecasting knowledge is stored. For purposes of this illustration, the information seen in Table 23.3 has been somewhat simplified. In fact, even more parameters are stored for each dose. Each line of this table contains one set of related parameters. Each line shows three minimum ages (acceptable, recommended, and past-due), and also the minimum wait-interval for each dose after the previous dose. Two doses (Hib 1 and Hib 4) have only a single parameter set. Doses Hib 2 and Hib3, however, each have two different parameter sets. The child’s age at Hib dose 1 and the Hib brand received determine which of these parameter sets will apply.

IMM/Serve also uses tables (a) to store the screening parameters that allow it to recognize when a dose has been given too early and should be considered invalid, and (b) to define which live-vaccine interactions should be enforced and what wait-intervals to use for each.

### Rule-Based Knowledge

IMM/Serve uses if–then rules to store the clinical logic that determines when a dose should be given and which set of tabular parameters applies to a particular child at a particular time. The rules also determine other factors, such as which vaccine brand or preparation should be recommended, if alternatives exist (for example, there are five different vaccine preparations in the DTP vaccine series: DT, DTP, DTaP, Tdap, and Td).

Table 23.4 shows example rules that partially specify the clinical logic for Hib dose 2. The first rule says “if there has been one previous Hib dose (Hib\_prior=1) and the Hib series is active and the Hib dose 1 was given at or over 12 months of age and the Hib2\_final parameter set is met (e.g., the minimum ages and wait-interval criteria are satisfied), then dose Hib 2 is due, and the parameters in the Hib2\_final

**Table 23.4** Example of if-then rules used by IMM/Serve to represent the clinical logic that determines which set of tabular parameters applies to a particular case

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if: Hib.prior= 1 and not Hib_inactive and Hib1_age_in_months ≥ 12
    and Hib2_final_parameters_met
then: due.Hib2_final
if: Hib.prior= 1 and not Hib_inactive and Hib1_age_in_months < 12
    and Hib2_parameters_met
then: due.Hib2
if: Hib.prior= 1 and not Hib_inactive and Hib1_age_in_months ≥ 12
    and not Hib2_final_parameters_met
then: next.Hib2_final
if: Hib.prior= 1 and not Hib_inactive and Hib1_age_in_months < 12
    and not Hib2_parameters_met
then: next.Hib2

```

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parameter set apply.” The other three rules test different combinations of (1) whether the child is over 12 months of age, and (2) whether the Hib2 or Hib2\_final parameter sets are met. IMM/Serve’s knowledge base contains roughly 300 rules.

### Procedural Knowledge

Procedural logic (conventional computer programs) is used to represent aspects of the immunization knowledge that is complex but not expected to change very much over time. For example, the temporal logic that combines dates, minimum ages, and several wait-intervals (which may be expressed in a combination of days, weeks, months, and years) to determine when a dose is due (accommodating the different lengths of different months, including the effect of leap years) is written procedurally. As long as we continue to use our current calendar, this logic is not likely to require major change.

The goal in combining these different forms of *knowledge representation* is to make it easy to modify and test the knowledge as that knowledge evolves over time. The biggest advantage of IMM/Serve’s tabular knowledge is that it is very easy to modify parameter tables. Similarly, the complex clinical logic is written by use of if-then rules to better separate it from the rest of the IMM/Serve program (which consists of several hundred pages of C programs), so that the rule-based logic can be more easily inspected, tested, modified, and refined.

### *The Development Process*

IMM/Serve was developed by a collaborative interdisciplinary team. This team included (1) a computer programmer who implemented the major programming components of IMM/Serve, (2) a “knowledge engineer” who had experience building a wide range of different clinical consultation programs, (3) several clinical domain experts who had extensive clinical experience with childhood immunization

and immunization registries, and (4) a project manager responsible for coordinating the project as a whole. The project manager worked closely with the clinical domain experts to discuss the various issues (e.g., how the guidelines should be interpreted, how any gaps in the guidelines should be resolved), to translate the results of these discussions into table entries and rules, to explain any nuances to the knowledge engineer and programmer, and to conduct iterative testing of the knowledge. This process of development, refinement, testing, and maintenance has extended over a period of years, involving many extensive conference phone calls, electronic mail exchanges, and testing of IMM/Serve at different sites.

## ***Testing***

IMM/Serve has been tested in several ways. A high-priority goal was to develop a set of computer-based tools to assist in this *knowledge testing* process.

### **Automated Tools for Knowledge Testing**

Two automated tools that were quite extensively used for knowledge testing are IMM/Def and IMM/Test [4, 5]. IMM/Def is designed to help the knowledge engineers double-check IMM/Serve's rule "kernel," the most complex part of the knowledge in which the logic must react appropriately to a range of different combinations of conditions. IMM/Test is designed to generate automatically a set of *test cases* that are intended to exercise all meaningful combinations of clinical conditions contained within the rule kernel.

### **Testing with Hand-Crafted Sets of Test Cases**

Although IMM/Def and IMM/Test are designed to help test the most complex portion of IMM/Serve's logic, there are many other parts of the logic that these tools do not handle. To help test these portions of the logic, sets of test cases have been constructed by hand.

### **Testing with Pilot Use**

Once a new version of IMM/Serve has been thoroughly tested as described above, the next step is further testing in the context of pilot use. Here, IMM/Serve is linked to a real immunization database and run on real patient records, either in test mode or in monitored operational use by a member of the development team. Real patient data may well expose additional unanticipated issues and problems.

## ***Implementation***

When IMM/Serve is run operationally, it currently runs on the local computer of an immunization registry as a callable module. The patient data are extracted from the registry database and passed to IMM/Serve for its analysis. The actual input to and output from IMM/Serve are coded forms of the information shown in Tables 23.1 and 23.2. The coded output produced by IMM/Serve can be used in different ways. To generate recommendations for a single case, the output is passed to a report generator. Table 23.2 shows the output produced by one such report generator. Specific users may wish to use a different report generator that presents this information in different ways. Alternatively, if IMM/Serve is being used to generate a list of patients for a forthcoming clinic, IMM/Serve might be run on a set of patients and its output used to construct a list showing patients who will have vaccinations due, which vaccinations will be due for those patients, and which vaccinations will become due in the near future. Staff can then use this list to determine which patients should be called in for that clinic and which might best be delayed to allow more vaccinations to be given at one time.

Another potentially valuable strategy for using IMM/Serve operationally is to run it on a powerful central server on the Internet and to allow many registry computers to link to that single version of IMM/Serve remotely. The advantage of this approach is that as IMM/Serve needs to be modified, the modification need only be performed on a single machine.

## ***Local Customization***

Clinics that use IMM/Serve have frequently wanted to use customized versions of the logic [6]. The US Indian Health Service (IHS) provides an interesting case study of this phenomenon. Eleven versions of IMM/Serve's tabular knowledge were defined for use by different IHS clinics. (A single version of IMM/Serve may contain several different versions of each table, as well as several variations of the rules. When IMM/Serve is run, a version name is passed in on a case-by-case basis, indicating which version of the knowledge should be used.) These eleven versions of the tables define alternative sets of forecasting parameters for 12 vaccine series. At one point, for example, the number of such sets of tabular knowledge for each series included the following: DTP (2), HepA (1), HepB (2), Hib (4), MMR (2), Polio (3), and Var (2).

At one point, the IHS also requested a specific variant of the Hib rule-based knowledge for use at two clinics and two changes in the DTP rule-based logic that differed from the national ACIP guidelines for use at all IHS clinics. Another capability that the IHS requested was the ability to accommodate incomplete vaccination histories. The IHS registries stored a dose number with each vaccine dose (many other registries do not store dose numbers). The registries frequently show

missing doses—for example, because a child has moved from one location to another. As a result, IMM/Serve's underlying engine was modified to allow the system to operate in the presence of certain types of incomplete IHS vaccination histories [7].

## ***Maintenance***

It was an exciting challenge to build IMM/Serve and to refine it as an operational tool. It has been at least an equal challenge to maintain IMM/Serve's knowledge as the field evolves over time and as increasing numbers of users request local customizations. As described previously, the national ACIP panel typically makes major changes in its recommendations every year. These changes have needed to be rapidly incorporated into IMM/Serve and thoroughly tested. As a result, maintaining the knowledge requires a continuing collaboration between IMM/Serve's developers and its domain experts. Computer-based tools have been particularly useful in assisting with this knowledge maintenance process.

## **Design Considerations**

Designing a decision support system requires consideration of how knowledge is to be represented and of how the system will interface with data sources.

## ***Knowledge Representation***

Once one has decided to encode health knowledge in the computer to be used for decision support, a major decision concerns what form of knowledge representation to use. The desirable goals in choosing a knowledge representation are:

1. To make it easy for computer-unsophisticated health experts to understand the encoded knowledge;
2. To make the knowledge easy to modify as the health domain evolves;
3. To facilitate building computer-based tools to help test and validate the knowledge; and
4. To separate as cleanly as possible the complex health-related logic from the rest of the computer program required for implementation of the application as a whole.

The choice of the best knowledge representation to use will vary with the nature of the domain. In general, one would like to use a technique that is as simple as possible, yet powerful enough to solve the problem. For example, tables, which are

very simple and easy to modify, can be a very straightforward approach. On the other hand, it may become clear that different parts of the problem will most naturally fit different knowledge representation approaches. If so, as was the case with IMM/Serve, one may choose to combine several approaches. We will discuss examples of different knowledge representations.

### ***Tables***

As we have indicated, tables are probably the simplest form for knowledge representation. Tabular knowledge can be used in many ways. In IMM/Serve, tables are used to store parameter values. Tables can also include decision logic as well. These are called decision tables. A decision table might contain a set of rows, each containing a condition and a set of actions. For a given case, each row whose condition is satisfied by the input describing the case specifies a set of actions that should be performed.

### ***Rules***

*If-then* rules have been widely used in health-related decision support programs. Rules provide a simple way to encode small atomistic “chunks” of logic. A potential advantage is that the action of each rule can be readily understood and modified. New rules can easily be added. A potential drawback in a large, complex, interrelated domain is that it can be difficult to anticipate the interactions of a large number of rules operating together.

### ***Flowcharts***

*Flowcharts*, graphical representations of the steps and decisions comprising a process or algorithm, have been extensively used to represent computer logic, and they may provide a convenient way to structure certain domains to help make the logic easy to understand and visualize.

### ***Semantic Networks***

A *semantic network* is a graphical representation of concepts that shows their relationships. When complex interrelated knowledge needs to be stored in the computer, semantic networks can be used to explicitly represent the various relationships between data items in a flexible fashion.



### ***Model-Based Knowledge***

Certain decision support systems contain within them one or more models that operate on the data. These might be statistical models, simulation models, or models of scientific processes. When one or more models of this type can be combined with other knowledge representations, the result is a potentially powerful system.

### ***Procedural Knowledge***

Conventional computer programming is widely used to build many computing applications. Certain decision support systems may be most easily built by use of a conventional programming language. In systems such as IMM/Serve, a part of the domain knowledge may most easily be built by use of conventional programming.

### ***Interface with Data Sources***

As increasing amounts of health data are placed into computer-based form and as increasing numbers of software tools are developed for analyzing those data in different ways, it will be essential to develop standards for describing that data. Without standards, data will not readily be passed from one health database to another and to the growing set of software tools. There are a variety of levels at which health data standards are being developed.

## **System Development Strategies**

Development of decision support and expert systems requires some special considerations in addition to the usual issues related to creating any information system. First and perhaps most important of these is consideration of the sources of knowledge to be incorporated in the system. Ideally, existing written guidelines are already in place, along with a system to revise and maintain them. This was the case, for example, with the childhood immunization forecasting expert system just described. Unfortunately, however, the existence of such written guidelines is the exception, rather than the rule.

More commonly, there are no written guidelines to explicitly guide decision-making. In such cases, extensive efforts will be required to capture the relevant knowledge prior to system development. If the guidelines exist but are not written, it may be possible to convene and work with a group of experts to formally express consensus rules and procedures. Such work itself can be a long and tedious process.

If decision rules do not really exist, development of a decision support system is probably premature. A useful alternative is to develop mechanisms for integrating and presenting information to decision makers in an improved fashion – either faster or more easily interpretable, or some combination. Once such information is available, it may lead to the development of informal decision rules that can later be incorporated in a more advanced system.

The development of a decision support or an expert system is most likely to succeed in an environment where written guidelines are already in place. On the other hand, if the knowledge is well-known but not codified, development efforts can be successful but are much more difficult. However, in cases in which decision rules are largely unknown or there is substantial controversy regarding the best approach, attempts to develop decision support systems should be avoided, as they are likely to be futile.

As with all public health information systems, the development of decision support and expert systems should be led by an interdisciplinary team. This team should include experts in public health practice, in the subject matter of the system, and in knowledge engineering, the subspecialty of computer science that deals with the formal encoding of knowledge. Naturally, there should be a steering committee composed primarily of users to guide the development process.

The first step in the development process is to define the overall architecture of the system, requiring primarily making a determination of how the knowledge will be delivered. The key consideration in this first step is the limitations in the user environment. Developers must address issues including time, space, needed level of detail, and requirements for explanations and references. Of course, the infrastructure to deliver the recommendations, such as computer systems connected to a network, must be in place. Furthermore, the user must have access to the relevant systems at the time and in the place where decisions are made. Another key architectural consideration that should be addressed from the outset is maintenance. Knowledge is not static over time. Without a mechanism in place for maintaining and updating the knowledge, development of a system is merely an academic exercise.

During system development itself, the use of existing tools will greatly increase productivity. There are many tools available for encoding and processing knowledge. We have already described several examples of such tools in the discussion of childhood immunization forecasting. Sometimes, it is necessary to create new tools where none are available. In the childhood immunization forecasting system, for example, new tools were necessary—such as the tool for automatic generation of test cases to revalidate the system when changes are made.

As with other information systems, dividing the problem domain into segments and then implementing and testing those segments independently is one of the best approaches to development. For each segment, an iterative approach involving the creation of multiple rapid prototypes is typically very effective. When the various independent segments of the system are combined, interactions between them can be identified and addressed appropriately.

It is also important to anticipate specific problems that are likely to occur in the process of creating a decision support or an expert system. The first of these problems relates to the significant demands on the time of the subject matter experts. For example, even when written guidelines are already in place, development of an expert system is likely to reveal many gaps in the knowledge base that have not been previously considered. These gaps can occur, for instance, because of unanticipated or unusual combinations of inputs. These gaps—and other ambiguous situations—require subject matter experts to make many decisions about the desired system output.

In addition, it is extremely important for system developers to conduct rigorous testing. One reason is that it is easy for developers to become overly confident in the initial output of a decision support or an expert system. The output tends to have the aura of accuracy and authority because it is formatted nicely and produced quickly. However, more detailed testing involving the creation of test cases that exercise every portion of the system's knowledge base may reveal flaws in the output. For this reason, developers should undertake both manual and automatic testing at every stage in the development process. The creation and verification of an extensive library of test cases for such testing is itself a substantial effort. Nevertheless, it is highly inadvisable to shortchange or circumvent this aspect of system development work.

As always, user feedback throughout the system development process is crucial to success. After all, the goal is not to produce the "perfect" system. Rather, the goal is to provide meaningful assistance in decision making for the users. Therefore, the users must be involved in the creation and refinement of the system at every stage. In particular, they must be comfortable with the mechanism and with the formatting for delivery of both the information and the recommendations derived from that information. Typically, users must have the ability to override the system when other factors supervene. In addition, adequate explanations of the recommendations must usually be accessible to reassure the users and provide justification for the output of the system.

### ***Criteria for Determining the Desirability of Decision Support and Expert Systems***

In light of these considerations, it is possible to suggest criteria that may be used to determine whether a decision support or an expert system would be desirable in a given environment. There are two major factors in making such a determination: the *decision characteristics* and the nature of the *user environment*.

With regard to the decision characteristics, the decisions to be made should be complex, or at least not trivial, in order for a decision support system to be useful. In the decision-making, there should be well-defined rules or algorithms that are subject to relatively rapid and continuous change. Naturally, the existence of a high

degree of consensus with respect to the appropriate criteria for decision-making will greatly ease the system development process.

The second of the criteria requires that the user environment include a convenient delivery mechanism for recommendations generated by a decision support or an expert system. Ideally, this delivery mechanism should (1) already be in place and (2) provide easy and inexpensive access for users. In addition, the environment should include multiple application sites for the system, allowing the costs, which can be substantial, to be widely distributed. However, even when multiple application sites exist, system developers need to keep in mind that while customization of decision support and expert systems for specific sites is certainly possible, it adds to the cost of the system, both initially and in the maintenance phase. In addition, it is very positive for the user community to recognize that the decisions to be supported by a proposed system could be improved through the use of technology. After all, it is much easier to enlist the cooperation of users in the development of a decision support or an expert system when they are the ones demanding the help that such a system can provide.

### *Illustration of the Criteria*

To illustrate these criteria, here are some examples of potential applications of decision support in public health practice.

The analysis of surveillance data to detect aberrations that may represent outbreaks is an obvious application of decision support. Here, the justification is the expected increase in surveillance data received by public health without a concomitant increase in personnel available for its analysis. Another area related to outbreaks that might benefit from decision support is the preparation of outbreak-specific surveys that can be used in interviews that accompany disease investigations.

Resource management is another area in which decision support might be helpful. System estimation of cost/benefit ratios for specific public health programmatic interventions could be used to generate recommended priorities for expenditures. Of course, using such a system would require much better baseline information about both the expenditures and the results of various public health programs.

Finally, decision support is clearly applicable to the dissemination of practice guidelines, as described in the example of childhood immunization forecasting. By encoding such guidelines in computable form and delivering them to public health clinics and other relevant healthcare settings, we should be able to increase greatly the delivery of effective preventive services [8]. While development of decision support and expert systems based on clinical prevention guidelines is clearly a substantial undertaking, the results of many previous studies indicating the benefits of clinician reminders in improving compliance provide a substantial body of evidence for the expectation that the benefits of this work would be well worth the effort [9–11].

### Review Questions

Questions 1–11 are based on the following short case.

The head of a state public health department wants to build a decision support system for use by public environmental specialists who are responsible for monitoring contaminants in well water, streams, and lakes in the state. The decision support system would provide the environmental specialists with access via laptop computers to toxicological profiles of the Agency for Toxic Substances and Disease Registry (ATSDR) and to the Environmental Protection Agency's Reference Dose Media Evaluation Guide (RMEG) comparison values. It would provide recommended action levels through incorporation of the EPA's Maximum Contaminant Levels (MCLs). As conceived by the head of the department, the system would permit public environmental specialists to enter data related to contaminant measurements, then send that data via remote hookup to the state's contaminant databases. This data would be site-specific. The system would then compare this data to the RMEG comparison values and to the MCLs and generate an action to be taken by an environmental specialist at the site. These specialists have used laptop computers in their work for many years, and they have complained frequently about the slowness of the current assessment processes, which require manual collection of data and then a considerable wait before agency officials analyze the data and provide recommended courses of action. However, many of the specialists are not schooled in the use of databases. In addition, some have expressed concerns that the proposed decision support system might not meet all their needs or else would bypass their judgment. Finally, the guidelines to be incorporated in the system change over time.

1. What data in the proposed decision support system would lend themselves to being represented by tables?
2. What knowledge would best be represented by if-then rules?
3. In what ways might the guideline logic of this system, as conceived by the department head, fail to recognize all the applicable conditions to be encountered by an environmental specialist in addressing contaminant levels found in water?
4. How would testing via automated tools, hand-crafted sets of test cases, and pilot use help to address any gaps in the guideline logic?
5. Suppose the environmental specialists charged with measuring contaminant levels in community wells want a customized version of the proposed system. What challenges would such customization present?
6. What difficulties are likely to be inherent in maintaining the decision support system, assuming it is developed?
7. What knowledge representation goals should a development team establish in building the proposed decision support system?

8. What criteria should already be in place within the department's functions in order to maximize the likelihood that the decision support system will be successful if it is built?
9. What is the first step in the development process for the decision support system?
10. What should be the composition of the system development team? Explain why the team should have this composition.
11. To what extent has the department met the criteria for determining the desirability of the decision support system?

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## Chapter 24

# Delivery of Preventive Medicine in Primary Care

Paul C. Fu, Jr., Alan Tomines, and Larry L. Dickey

**Abstract** Historically, medical services have been weighted heavily towards diagnostic and curative functions rather than preventive functions. This imbalance has proven to be unsustainable for many reasons, most notably the continuing rise in healthcare costs. The health care system has embraced the delivery of preventive care services in order to reduce disease and the economic burden of disease. In the last decade, the successful use of health information technologies at the primary, secondary, and tertiary preventive care levels has demonstrated the ability for public health informatics tools to improve the timeliness and quality of preventive care in a cost-effective manner. Electronic health record systems coupled with decision support tools provide a means of integrating preventive care recommendations into the clinician workflow. Disease registries aggregate cohorts of similar patients, such as by gender (e.g., women) or chronic disease (e.g., diabetes) and allow for the application of evidence-based preventive interventions to high-risk groups. Successful preventive care relies upon consumer understanding of the rationale behind specific preventive care recommendations and consumer engagement to

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embrace those recommendations. Similarly, the Internet and the rise of social media, Health 2.0, and mobile health (mHealth) tools hold great promise for a fuller clinician-consumer partnership to emerge. Although the application of technology to preventive medicine faces many challenges and barriers, there seems to be little question that, with creativity and care, clinicians and patients can learn to use health information technology tools to promote health and prevent disease much more effectively and efficiently than ever before.

**Keywords** Preventive health • Clinical preventive services • Health risk assessment • Electronic health records • Reminder systems • Interactive voice recording systems • mHealth • Primary prevention services • Secondary prevention services • Tertiary prevention services

### **Learning Objectives**

1. Describe clinical preventive services and the process behind development of evidence-based recommendations for preventive care.
2. Explain the potential of health information technology to improve preventive care.
3. Discuss specific health information technology tools that support preventive care delivery.
4. Discuss the future challenges for increasing the use of health information technology in the practice of preventive care.

## **Overview**

Historically, medical services have been weighted heavily towards diagnostic and curative functions rather than preventive functions. This imbalance has proven to be unsustainable for many reasons, most notably the continuing rise in healthcare costs. The health care system has embraced the delivery of preventive care services in order to reduce disease and the economic burden of disease. In the last decade, the successful use of health information technologies at the primary, secondary, and tertiary preventive care levels has demonstrated the ability for public health informatics tools to improve the timeliness and quality of preventive care in a cost-effective manner. Electronic health record systems coupled with decision support tools provide a means of integrating preventive care recommendations into the clinician workflow. Disease registries aggregate cohorts of similar patients, such as by gender (e.g., women) or chronic disease (e.g., diabetes) and allow for the application of evidence-based preventive interventions to high-risk groups. Successful preventive care relies upon consumer understanding of the rationale behind specific preventive care recommendations and consumer engagement to embrace those recommendations. Similarly, the Internet and the rise of social media, Health 2.0, and



mobile health (mHealth) tools hold great promise for a fuller clinician-consumer partnership to emerge. Although the application of technology to preventive medicine faces many challenges and barriers, there seems to be little question that, with creativity and care, clinicians and patients can learn to use health information technology tools to promote health and prevent disease much more effectively and efficiently than ever before.

## Introduction

The Oxford English Dictionary (OED) defines medicine first as “a substance or preparation used in the treatment of illness; a drug; *esp.* one taken by mouth” [1]. This is the lay perception of medicine – something tangible, such as new drugs that make treating diseases more precise and more effective or new medical technologies that make diagnosis easier, faster, and more accurate. So for many people, *preventive medicine* may appear to be an oxymoron. After all, medicine is used primarily to treat illness, not to prevent it. If people are healthy, then what medicine is required? Our understanding of health and health behaviors also has evolved over time, in step with advances in pharmaceuticals and medical technologies. We better understand that there are multiple determinants that affect an individual’s health, from genetic, biologic, and psychological endowments, to environmental and social factors. Preventive care services are most likely to be effective when they address the complexity of multiple determinants. So it is under the less common framework of medicine as “the science or practice of the diagnosis, treatment, and prevention of disease” where the integration of informatics tools into the entire breadth of diagnosis, treatment, and prevention of disease will help to achieve the goal of healthy populations [1].

Historically, health care systems have focused upon the response to acute problems rather than prevention. However, for the past 30 years, the top three leading causes of death – heart disease, cancer, and stroke – are chronic conditions that can be influenced by preventive health directed at the individual patient and to populations [2]. Preventive services are recognized to have the potential to be effective in improving health and some services have been found to be cost-effective as well [3, 4]. A review of United States mortality data showed that about half of all deaths in 2000 could be attributed to largely preventable behaviors and exposures [5]. A 2010 analysis showed that increasing the use of 20 specific clinical preventive services, each with good evidence of effectiveness, could result in saving more than 2.3 million life-years annually in the US [3]. However, funding for preventive services continues to lag. Total US medical spending has increased almost 10 % annually for the past five decades, largely driven by technological advances, although there has been a significant deceleration during the past decade due to macroeconomic factors and efforts to reform the health care system [6–8]. Although determining US spending on primary and secondary prevention services is an imprecise exercise, a 2004 analysis estimated that barely more than 8 % of total

health expenditures went towards preventive services, and a separate review of historical trends revealed that there was actually a net decrease in the share of federal funding for preventive services over the past decade [9, 10]. Why is there such a gap between knowledge and practice and how can health information technologies bridge that gap?

## Preventive Health Services

Preventive health services include medications, procedures, devices, tests, education, and counseling. Either individually or in conjunction with other services, the goal is to improve the health or well-being of an individual and reduce risk or delay onset of a chronic disease or condition. Our approach towards clinical preventive services has also become more nuanced. Understanding the importance of multiple health determinants, we recognize that different population groups, such as minorities or the homeless, have different health needs and benefit from different preventive services. Benefits include modification of risk factors that prevent disease, early identification of disease leading to earlier intervention, and improved health outcomes. Possible risks from preventive health services include adverse effects from tests or interventions that comprise the preventive health service or inaccurate results that lead to unnecessary follow-up evaluation and treatments.

*Primary prevention services*, such as immunizations and disease management counseling, intercede even before precursor signs of disease are detectable. *Secondary prevention services*, such as screening tests or clinical examinations, detect disease before symptoms develop, thus enabling interventions for early management and treatment. *Tertiary prevention services* involve treatment and counseling for symptomatic diseases, such as diabetes or hypertension, to prevent progression and the development of complications.

Full implementation of clinical preventive services has proven to be an elusive goal for the US healthcare system. A review of 1997–2004 data from the Behavioral Risk Factor Surveillance System showed that less than half of older adults are up-to-date on a core set of clinical preventive services [11]. A review of adult periodic health examinations in southeast Michigan, from 2007 to 2009, found that almost as many preventive health services went undelivered as delivered [12]. The reason for this underperformance is complex. Delivery of preventive health services is dependent upon the interaction between provider and patient and the environment in which the encounter occurs.

While seemingly a pre-requisite, physician inclination actually does not guarantee that patients in primary care practices will receive recommended preventive care [13]. The clinician's values, experience, and perceived effectiveness of the preventive care tool impact whether the service will be introduced into the encounter at all [14]. A lack of clinician self-efficacy and knowledge, limited encounter time, and poor reimbursement for preventive services are also factors that impact low rates of preventive service delivery [14–16].

The work of the US Preventive Services Task Force (USPTF) is central to the preventive benefits covered under the Patient Protection and Affordable Care Act of 2010. Under the new law, preventive services with an evidence grade of A or B will be covered with no cost-sharing requirements [17]. However, the sheer volume of preventive services recommended by USPTF for the average patient panel has been estimated at taking more than seven hours each day (see Table 24.1) [15].

Reviews of nationally representative data on adult women, from the Medical Expenditure Panel Survey and the Behavioral Risk Factor Surveillance System, reveal that low socioeconomic status and lack of a usual source of care represent significant barriers to the receipt of appropriate preventive care [19, 20]. Lack of medical insurance and subsequent high copayment costs are also major factors for non-receipt of and non-compliance with preventive services by many patients [19, 21, 22]. A Commonwealth Fund report from 2009 indicated that U.S. adults were less likely than adults in ten other developed countries to have confidence in their ability to afford appropriate and necessary health care [23]. Finally, patients receiving health care at university-based clinics, community health clinics, and larger group practices tend to receive more recommended preventive services than from providers located in smaller practices [24–26]. Other environmental factors include the presence of a clinician-champion in practices with higher rates of clinical preventive service delivery [27].

Health information technology can help address the problem by efficiently integrating preventive care tools for (1) measurement and reporting of preventive care delivery for patients or populations, (2) supporting clinical provider workflow, and (3) supporting the empowerment of patients and families.

## Using Information Technology for Preventive Service Delivery

### *The Electronic Health Record (EHR)*

At its core, the EHR captures and tracks the clinical data necessary for patient care over time. However, functionality varies by EHR product. Some functionality, such as electronic prescribing and viewing of laboratory data, is considered *basic EHR* and is common across the majority of vendor offerings. Others, such as computerized provider order entry and clinical decision support are only available in more *comprehensive EHR* solutions [28].

Many comprehensive EHRs have the ability to generate clinician preventive care alerts and there are certain preventive health quality measures in which performance has been shown to improve following EHR implementation: breast cancer screening, diabetic retinopathy screening, chlamydia screening in women, and colorectal screening [29]. The key to this improvement is in the provision of *clinical decision support* (CDS). CDS uses logic rules to provide context-specific data and knowledge to the user at the right time to be actionable. For example, a CDS could display

**Table 24.1** US Preventive Services Task Force A and B recommendations [18]

Topic	Eligibility
Abdominal aortic aneurysm screening	Men, ages 65–75, history of smoking
Alcohol misuse counseling	Adults
Anemia screening	Pregnant women
Aspirin to prevent cardiovascular disease	Men, ages 45–79 Women, ages 55–79
Bacteriuria screening	Pregnant women
Blood pressure screening	Adults
BRCA screening	Women at risk for mutations in BRCA1 or BRCA2
Breast cancer preventive medication	Women at high risk for breast cancer
Breast cancer screening	Women, ages 40+
Breastfeeding counseling	Pregnant women
Cervical cancer screening	Women, ages 21–65
Chlamydial infection screening	Women, sexually active, non-pregnant Pregnant women
Cholesterol abnormalities screening	Men, ages 20–35 at increased risk Men, ages 35+ Women, ages 20–45 at increased risk Women, ages 45+
Colorectal cancer screening	Adults, ages 50–75
Dental caries prevention	Preschool children
Depression screening	Adolescents Adults
Diabetes screening	Adults
Falls prevention in older adults	Adults, ages 65+ who are at increased risk
Folic acid supplementation	Women planning or capable of pregnancy
Gonorrhea prophylactic medication	Newborns
Gonorrhea screening	Women, sexually active
Healthy diet counseling	Adults at increased risk
Hearing loss screening	Newborns
Hemoglobinopathies screening	Newborns
Hepatitis B screening	Pregnant women
HIV screening	Adolescents Adults
Hypothyroidism screening	Newborns
Intimate partner violence screening	Women of childbearing age
Iron supplementation	Children, 6–12 months at increased risk
Obesity screening and counseling: adults	Adults Children, ages 6+ Women, ages 65+ Women with increased risk
Osteoporosis screening	Women, ages 65+ Women with increased risk
Phenylketonuria screening	Newborns
Rh incompatibility screening	Pregnant women
Sexually transmitted infections counseling	Adolescents, sexually active Adults, sexually active

a recommendation and one-click order entry for breast mammography screening at the point-of-care for a newly 40-year-old woman. A review of CDS systems showed that the presence of actionable information made improvements in clinical practice more likely [30].

## *Reminder Systems*

Because of the complexity of preventive service guidelines and the unavoidable distractions of busy professional and personal lives, providers and patients frequently need to receive reminders about preventive care. The goal of a reminder system is the “five rights” – the right information in the right format to the right person at the right place and right time.

Paper-based, manually-updated reminder tools are difficult to maintain and generally result in only modest improvements in preventive care delivery rates [31]. Numerous studies have demonstrated the utility and effectiveness of electronic reminding and prompting systems for preventive care. Computerized systems such as patient registries and the EHR greatly facilitate reminder processes [31–34]. These reminders may be provided through computer-generated printed reminders or computerized alerts. Provider reminders in the form of paper printouts or EHR alerts cue the busy clinician about preventive care that is not up-to-date for patients. These cues are most useful when issued at the time of patient visits, when the needed tests, immunizations, and counseling can be provided immediately.

A 2012 Cochrane review of the literature reported that computer-generated printed reminders, such as from a patient registry, for health care professionals resulted in a moderate improvement in the processes of care but no improvement in outcomes of care [35]. Reminders about immunizations, cardiac care, and smoking cessation have been noted to be the most effective [35, 36]. Even with an EHR, a paper-based solution may be easier to use given clinician workflow in certain circumstances, such as if the number of preventive health recommendations is few [36]. However, in a large study of primary care practices in New York, more than half of the practices that began using EHR-based, point-of-care clinical preventive services reminders showed an increase of greater than 5 % in delivery rates [37].

Unfortunately, even when using electronic tools, providers may have trouble finding the time for preventive care. Some studies have found that providers may ignore the preventive care tracking functions of electronic medical records [38, 39]. This tendency has prompted some electronic medical record designers to require users to actively dismiss or respond to alerts. Also, there is evidence that the effectiveness of reminders decreases with time—perhaps because clinicians learn to filter them [40]. In fact, the concern of alert fatigue is increasingly of concern. Comprehensive EHRs have the ability to generate so many alerts

about abnormal results that providers are vulnerable to information overload; one study revealed that primary care providers received a mean of 56.4 alerts per day [41, 42].

## Using Information Technology for Preventive Care Measurement and Reporting

The first challenge clinicians face is simply determining what preventive care a patient has already received and what they additionally need. Patients' needs vary according to age, gender, and risk factors (such as family history). Most practices determine their own workflow and protocols for preventive service delivery. Paper-based protocols are often misplaced and not consistently utilized in a busy practice settings [43].

### Health Risk Assessment

A concept is proposed for the use of health-hazard appraisal as a method of outlining a preventive medicine program in comprehensive health care by the physician. The principle is based upon the fact that every individual is faced with certain quantifiable health hazards as a member of a sex-age-race constituted group; and further, that these average risks may be adjusted to the individual if the clinician knows the patient's prognostic characteristics and the mortality experience of cohorts with similar prognostic characteristics.

– Joseph F. Sadusk, MD and Lewis C. Robbins, MD [44]

Assessment of risk factors is a complex task that involves gathering information from patients regarding a wide variety of specific and often personally sensitive behaviors. Health risk assessment (or appraisal) (HRA) collects and analyzes health-related data and then uses statistical methods to compare this data to epidemiological and actuarial tables. HRA results in an assessment of current health status, the identification of risk factors for injury or illness, and the provision of evidence-based feedback and education to participants to modify behavior that will reduce the risk of injury and disease [45].

The concept of HRA originated with Dr. Lewis Robbins, whose work on cervical cancer and heart disease prevention in the 1940s eventually led to the publication of "How to Practice Prospective Medicine," which included a complete HRA example package [46]. It was largely ignored by the medical profession, but was picked up by employers, community-based health promotion programs, and government agencies to characterize the general health status of workers and inform workplace policies and employee benefit plans [46, 47]. In 1977, the US Centers for Disease Control and Prevention acquired the Canadian HRA computer program from Health and Welfare Canada and released a modified 31-item, self-administered questionnaire to compute health adult risk in 1980 [48]. This release raised the profile of HRA. CDC subsequently collaborated with the Carter Center of Emory University to update the risk tables and release an updated 45-item questionnaire as Healthier People in 1988 [49].

Typically, an HRA collects data on demographics, lifestyle (e.g., exercise, smoking, drug and alcohol use), physiologic data (e.g., weight, height, blood pressure, cholesterol, glucose), and personal and family medical history. As a note, the collection of family medical history is prohibited if the data is used in the process of insurance enrollment or underwriting by the Genetic Information Non-Discrimination Act (GINA) of 2008 [50]. HRAs then use data from actuarial tables and epidemiologic studies to estimate the risks of adverse events (e.g., reductions in life expectancy, the probability of heart disease) based on the collected patient-level data [51]. Then, education and interventional services are offered that target the mitigation of the identified risk factors in the hope that feedback will convey the importance of behavioral change.

A 2003 review by RAND reported that HRA programs have demonstrated beneficial effects on behavior (especially exercise), blood pressure, weight, and general health status [52]. A separate study noted that smoking, dietary fat consumption, seatbelt non-use, high risk drinking, and serum cholesterol levels could also be positively affected by HRA use [53].

There are some limitations with HRA data. In 1987, Smith et al. [47] examined the validity of over 40 HRA instruments in order to assess the accuracy of risk estimates. He noted that a correlation with criterion-based models (e.g., the Framingham heart study) was associated with how risk was defined and what risk was under-study. For example, HRAs that focused on calculating risk for morbidity and mortality correlated better with reported cohort data from epidemiological studies than did studies that focused on assessing general health status. Many instruments that had low correlations generated general health scores or identified non-evidence-based risk factors – a cautionary tale for mHealth and Health 2.0 applications. Data quality was another observed limitation. Recall bias, reticence about reporting socially unacceptable behaviors, misunderstanding HRA questions, health literacy status, age, and cultural context were all sources of inaccurate data [54]. Data collection bias was also noted as HRA was often conducted outside standard clinical workflow through employer-based programs. HRA cost-effectiveness has not been well-studied [52].

Investigators have examined the impact of HRAs on physicians' preventive service delivery, as well as on patients' health behaviors and health status. A study conducted by Geiger and colleagues [55] showed individuals receiving the HRA were more likely to be counseled about risks (e.g., those related to diet, exercise, substance abuse, and injury prevention) than patients in a comparison sample. However, improvements in these areas were difficult to attribute exclusively to the HRAs, because the HRAs were administered in conjunction with other important services, such as outpatient visits specifically focusing on health promotion. Early studies on the role of information technology and HRA showed that HRAs that provided computer-generated, personalized feedback were more likely to change risk behaviors than patients who received generic feedback or no feedback at all [56]. Glasgow and colleagues studied the effects of a brief HRA on diet, barriers to behavior changes, and attainment of goals for incremental dietary improvements

administered via a touch-screen computer located in physicians' waiting rooms [57, 58]. The HRA then generated reports summarizing the session for both the patient and the provider that were used to structure dietary counseling sessions and promote behavioral adherence between office visits. Those receiving the HRA-guided intervention had lower cholesterol levels and consumed a lower proportion of fat calories than controls at three months and at one year. More recent studies on the use of web-based HRA show similar results and, because they are web-based, can be done in a private setting [59, 60]. The use of the Internet also allows for more individually-tailored interventions [61].

A recent review shows that HRA with feedback as a gateway to more intensive and prolonged health promotion and risk reduction interventions (*HRA Plus*) leads to better outcomes than HRA with feedback alone [62]. Examples of interventions include workplace policies to improve health, such as smoking restrictions, as well as extended employee benefits such as access to fitness programs and health education classes [52, 53].

The Patient Protection and Affordable Care Act of 2010 (PPACA) includes provisions to support greater use of HRA by covering the cost of HRA with the development of a customized prevention plan when done at a Medicare Annual Wellness Visit [63]. PPACA also establishes standards for interactive telephonic or web-based programs for HRAs. In order to provide evidence-based guidance for implementation of new programs, or evolve existing programs to support the expansion of HRA by providers, CDC developed a framework for HRA Plus – or “the implementation of patient-centered HRAs, follow-up activities and monitoring of progress towards achieving health improvement goals” [62]. At a high-level, the HRA Plus framework aims to provide guidance to providers on ways to use HRAs with evidence-based health improvement programs; reduce health disparities through HRA and follow-up interventions that are linguistically and culturally aware; and improve health outcomes by identifying modifiable health risks and providing behavior change interventions [62] (Table 24.2).

Over the last 40 years, much work has been devoted to developing and testing new tools for health risk assessment. HRAs are accepted tools to identify high-risk

**Table 24.2** Framework for Patient-Centered Health Risk Assessments [62]

1	Balance comprehensiveness of assessment with provider and patient burden
2	Build upon high priority questions
3	Use person-centered and culturally appropriate processes
4	Comply with all federal laws and regulations regarding access for persons with disabilities
5	Use a shared decision-making process
6	Offer training to health providers
7	Offer action-oriented information
8	Use principles of quality improvement
9	Incorporate information into secure electronic health records
10	Conduct research to quantify long term outcomes

Accessed at: <http://www.cdc.gov/policy/opt/hra/FrameworkForHRA.pdf>



health behavior factors for acute or chronic disease conditions. In combination with evidence-based counseling and persistent health education intervention programs, HRAs can improve short-term health outcomes. Another informatics tool to support the data aggregation and decision support necessary for effective electronic preventive service delivery is the patient registry.

### ***Patient Registries***

Underuse of health information technology (HIT) has been acknowledged to be a barrier in improving preventive care quality [64]. A registry “uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition or exposure, and that services one or more predetermined scientific, clinical or policy purposes” [65]. At Denver Health, use of registries in community health center network, over three years, increased colorectal cancer screening rates by 100 %, breast cancer by 20 %, and improved hypertension control from 60 to 72 % [66]. International experiences with registries also have shown an improvement in health outcomes, decreases in health care costs, and increases in the value of certain health care services [67]. They are tools for change that facilitate improved processes.

Data collated within a registry is either primary data, which is collected for the registry and recorded directly in the registry, or secondary data, which is collected by another source, such as an EHR, administrative health data, vital records, or census databases, and secondarily entered or messaged into the registry. Although many registries are purpose-built for a specific function, a registry is more defined by the capability to generate a list of individuals based upon defined characteristics, rather than by a specific HIT system (Table 24.3).

It is because of these capabilities that registries have been recognized as tools in two models of care, the Chronic Care Model and the Patient-Centered Medical

**Table 24.3** Core registry capabilities

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Key registry capabilities

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1. Generate lists of patients using search criteria (e.g., presence of diagnosis, procedure, medication, or lab result) or calculated criteria (e.g., hemoglobin A1c <7.0) or a combination
  2. Present a unified view of disparate information types (e.g., demographics, diagnoses, procedures, laboratory data, quality measures, recommended care) for single patients
  3. Generate reports showing performance against evidence-based measures
  4. Use of evidence-based guidelines to provide decision support to users
  5. Provide feedback to clinicians for individual patients and cohorts
  6. Alert clinicians with reminders for screening, recommended treatment
  7. Create standard patient communication materials
- 

After Gabbay et al. [68]

Home, as being integral to the delivery of high quality healthcare [69, 70]. Registries also vary in scope and complexity. At a high-level, registries can:

1. describe the natural history of disease (characteristics, management, and outcomes) to produce a real-world picture of a population,
2. determine cost and clinical effectiveness, e.g., translating research discoveries into practice,
3. monitor safety and harm, e.g., post-marketing surveillance,
4. measure quality of health care e.g., comparison to evidence-based screening recommendations.

For preventive health, the registries of greatest interest are those that focus on patients or diseases and help to address the gap between the care that is delivered and what is recommended, such as evidence-based guidelines or comparative benchmarks from the US Preventive Services Task Force [17]. There is a natural secondary function in support of research. A 2009 report by the Federal Coordinating Council for Comparative Effectiveness Research noted that registries are an essential component of the comparative effectiveness research infrastructure [71].

As with any HIT, there are many challenges that show that simply adopting a technology solution does not by itself improve care [72]. Inputting data into the stand-alone registry is perhaps the most daunting problem. If registry data is electronically populated, then care must be taken to ensure that data is appropriately mapped and validated from source to destination, or in other words, to ensure that an apple in the source system is an apple in the registry. If data is manually entered, then it must be periodically validated for accuracy. The other major challenge for the stand-alone registry is the lack of integration into the clinical workflow and the subsequent need to design care processes around the technology solution.

Practices with EHRs are more likely to use registry capability than practices with paper records and stand-alone registry systems [73]. While this approach has the benefit of being integrated into the clinician workflow and eliminating manual data entry for most information, it is limited by EHR data constraints where there may not be a place to collect and enter non-clinical data, and the data that is entered may not be easily searched. The increase in EHR adoption due to the CMS EHR incentive programs is likely to lead to increased use of registry capability within EHRs [74].

## **Using Information Technology for Preventive Care Consumer Engagement**

The health care system of the next decade is based upon the premise that consumers will become active participants in their own care, and that when provided with the right information, they will be able to push their providers into providing high-quality care and to assist in maintaining their health and self-managing chronic

diseases. The rate change of new medical knowledge is increasing so rapidly that even providers are challenged to assimilate new knowledge. How can we expect a consumer, regardless of how informed or engaged, to keep pace?

Just as providers need alerts and reminders, so does the engaged consumer in order to know what preventive health services are due [75]. The USPTF has recommended the use of the 5A's framework (assess, advise, agree, assist, arrange follow-up) to engage consumers in collaborating in preventive health care [76]. Health IT in the form of HRA, reminders, and decision support, has been shown to enhance the success of interventions [77]. Computer-based patient education also has been successful in primary care.

### *Interactive Voice Response Systems*

The prevention of chronic disease progression (tertiary prevention) requires the timely reporting and assessment of patient signs, symptoms, and tests. This can be difficult in a health care delivery system that heretofore has only focused on data capture during clinician-patient encounters. The health of an individual is not episodic, however. Technology provides the opportunity to bridge the data gaps between visits.

Interactive voice response (IVR) systems use phone reminders, automated human recordings, and scripted dialogues to engage the patient who has difficulty coming to clinic visits in person, who lacks the ability to access or utilize computers, or is simply between health care visits. Patients use wired or mobile telephones to interact with an IVR system using keypad tones or through speech recognition technology. As just 2.0 % of US households do not have telephone access, IVR has the potential to be very effective, especially with underserved or difficult to reach consumers [78]. In general, patients provide clinically useful information during IVR health assessments. Not only is IVR reporting comparable to "live" telephone interviews [79, 80], but more health problems are identified as patients report less embarrassment when reporting sensitive information, such as depression or alcohol abuse, to a computer than to a clinician [81, 82].

The large number of preventive health recommendations means that it is unlikely that every recommended screening can be performed at a single patient visit. IVR can help to remind consumers both of the importance of preventive health and of the appointment date. One study showed that IVR reminders increased utilization of mammograms, Pap smears, and immunizations [83]. A recent meta-analysis of IVR clinical trials showed that IVRS-based interventions were associated with a 7.9 % improvement in adherence to recommended treatment and tests [84]. IVR assessments can also help to identify important differences in understanding health status between patients and their clinicians. Using branching logic in the development of IVR scripts also facilitates the provision of personalized medical interventions and feedback [80].

## *mHealth*

By some accounts, in 2017 there will be more mobile devices than people [85]. Health text messaging, smartphone apps, remote monitoring, and portable sensors will accelerate the closing of data gaps between health care visits and help transition us from episodic health data collection to a continuous health data feed.

Text messaging is a basic function for many wireless plans and has been shown to have potential as a tool to effect behavior change [86]. There have been several health-focused text messaging campaigns, such as text4baby (promoting maternal and infant health), the National Cancer Institute's SmokeFreeTXT (smoking cessation service), and HRSA's TXT4Tots (provides evidence-based information on nutrition and physical activity for caregivers of children ages 1–5 years) [87–89]. However, there is very limited evidence that text messaging interventions can support preventive health care [90].

Similarly, while there has been a rapid proliferation of healthcare smartphone applications, there is very little evidence on their impact upon outcomes. Further research will be necessary to evaluate the efficacy of this approach. For now, the proliferation of application “standards” that are not aligned to existing health care standards such as HL7® and SNOMED-CT®, the inability to synchronize data with EHR and registry systems, and the lack of evidence-generating research to support promulgation will continue to limit adoption [91].

## **Challenges**

Semantic interoperability represents the most significant technical challenge to the improvement of preventive health delivery. There is increasing evidence that health risk assessments do support preventive health by collecting socio-behavioral data for use in predictive modeling. Ideally, HRA would be integrated into a patient portal supported by an EHR. However, many EHRs and patient registries do not have structured documentation for non-clinical data and this represents a significant barrier for search and summary reporting [37]. Providers will need to be trained to document appropriately, and even if trained, the completeness of EHR data for any individual patient will be clinician dependent [92]. While decision support has been shown to improve accuracy of documentation, natural language processing may hold key to better reporting [93]. Better tools for interacting with the provider at the point-of-care are needed.

Evidence informs the development of appropriate preventive health recommendations. These recommendations then form the basis for the development of quality measures that are used in clinical decision support. Quality measures are logic statements that are used to compare measured actual care against a standard of care that is usually evidence-based. CDSS rules are executed and presented through

reminders and alerts. However, many existing quality measures were written with manual chart review in mind, and may not be suitable for use with EHRs in an automated reporting fashion without rewriting the measure logic. The National Quality Forum is currently working with measure developers to develop the new reporting and measure logic formats necessary to create eMeasures [94]. Other measures are reliant upon administrative claims data as proxies for delivered, but unmeasurable care, and must be completely revised to account for real-time performance data available in the EHR or patient registry. Administrative claims data is also known to be incomplete [95]. Combining EHR data with administrative claims data may provide a more complete picture of services received [96]. But the real solution is to build an EHR that comprehensively collects data that is searchable for all the quality data elements that are necessary to assess performance and delivery of care.

## The Future

It is difficult to fully envision how clinical preventive care will change in the next century, because there are so many opportunities. One thing seems certain, however: it will become much more complex and targeted. Using genetic analysis, we may be able to determine precisely which patients need which types of screening, immunization, prophylactic use of medications, or even counseling. The age- and gender-based protocols now used to target these services may appear quite crude in retrospect. As a consequence, clinicians' need for assistance in assessing, reminding, delivering, and auditing preventive care activities will become even more acute. Health information technologies will continue to evolve to meet these changes.

Stand-alone registries, reminder systems, and mHealth applications will eventually fade away as the need for semantic interoperability, or the ability to exchange data with unambiguous meaning, grows. The technical challenges behind the change from episodic health data collection to a continuous health data feed will lead EHR systems to change as well, with better user interfaces and decision support tools becoming essential for the management of vast quantities of data. As the Meaningful Use EHR incentive programs continue to accelerate adoption, the focus will change from process changes to health outcomes. Health promotion and education sites are widespread across the Internet, as are many online communities of patients, but the evidence base for these so-called Health 2.0 sites that combine social media, search, and network effect theory is limited.

Existing HIT systems are not optimized to serve both providers and patients, and a new paradigm will be necessary. Still, it is doubtful that computers or information technology will ever replace the health-promoting relationships of primary care clinicians with their patients. However, with creativity and care, the tools will be developed that will empower clinicians and patients to promote health and prevent disease much more effectively and efficiently than ever before.

### Review Questions

*Questions 1–6 are based on the following short case:*

The Valley Medical Clinic provides both preventive health and direct health care services to patients who live within an 80-mile distance in the surrounding exurban/rural areas, although it has placed more emphasis on curative rather than preventive services. Recently, the management of the clinic has decided to increase emphasis on the delivery of preventive services to patients, offering a dedicated wellness clinic. The current clinic uses a basic EHR, it does not use technology for preventive care assessment, delivery of preventive services, preventive care reminders, or preventive care auditing. Management has decided to invest several million dollars in acquiring new health information technology in order to improve preventive care services.

1. List some of the factors that may have led the Valley Medical Clinic to concentrate on the delivery of curative services, rather than preventive services, to patients in the past.
2. What kind of health information technology can help the clinic to deliver preventive health services more efficiently during a 15-minute clinical visit by a patient?
3. Explain how the use of the following computerized applications could help the clinic to lower the costs of preventive care assessment while improving its efficiency and effectiveness:
  - (a) Comprehensive EHR
  - (b) Computerized health risk assessments
  - (c) Interactive voice response systems
  - (d) Patient registry
4. How might a reminder system, either stand-alone or integrated into the EHR, be used to improve their preventive care quality measures?
5. Explain the benefits and limitations that the clinic might face in using mHealth tools to facilitate preventive health services.
6. How should preventive health services be structured and planned, given the available technologies?

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# Chapter 25

## Case-Based Learning in Public Health Informatics

**Herman Tolentino, Sridhar R. Papagari Sangareddy, Catherine Pepper, and J.A. Magnuson**

**Abstract** The public health landscape is undergoing profound changes, including rapid advances in technology, increasing use of electronic health records, and health reform. Improving population health requires knowledge and skills in managing and working within the adaptive complexity of underlying societal structures and functions. These advances in technology, and profound changes within these structures and functions, introduce enormous opportunities for creating efficiencies and economies of scale, not simply for improving public health practice, but for learning as well. Finding informatics solutions to cross-cutting information needs, while solving complex health problems, requires cross-disciplinary education, research, and practice.

Approaches to overcoming these challenges should address the complexity of problems within both the work and learning environments. These problem-based

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approaches build skills in collaborative problem solving, critical thinking, systems thinking and lifelong learning. This chapter discusses case-based learning (CBL) as one of the methods for problem-based learning (PBL) and is aimed at the student of public health informatics (PHI) exploring this topic for the first time. The chapter concludes with a student exercise developed for fellows in the CDC Public Health Informatics Fellowship Program.

**Keywords** Problem-based learning • Case-based learning • Information Value Cycle • Case study • Complex adaptive systems • Electronic laboratory reporting • Clinical laboratory information systems

### Learning Objectives

1. Briefly describe the public health context for case-based learning.
2. Explain why case-based learning is an important aspect of applied PHI training.
3. Describe important concepts involved in case-based learning.
4. Describe benefits of case-based learning.
5. Illustrate understand a PHI case study through an example provided at the end of the chapter.

## Overview

The public health landscape is undergoing profound changes, including rapid advances in technology, increasing use of electronic health records, and health reform. Improving population health requires knowledge and skills in managing and working within the adaptive complexity of underlying societal structures and functions. These advances in technology, and profound changes within these structures and functions, introduce enormous opportunities for creating efficiencies and economies of scale not just for improving public health practice but for learning as well. Finding informatics solutions to cross-cutting information needs while solving complex health problems requires cross-disciplinary education, research, and practice.

Approaches to overcome this challenge must address the complexity of problems within both the work and learning environments. These problem-based approaches build skills in collaborative problem solving, critical thinking, systems thinking, and lifelong learning. This chapter discusses case-based learning (CBL) as one of the methods for problem-based learning (PBL) and is aimed at the student of public health informatics (PHI) exploring this topic for the first time. The chapter concludes with a student exercise developed for fellows in the CDC Public Health Informatics Fellowship Program.

## Background

The public health (PH) landscape is undergoing profound changes including rapid advances in information and communications technology, increasing use of electronic health records (EHRs), the integration of health care, and PH systems and health reform. PH agencies face additional challenges with these changes (e.g., shrinking financial and manpower resources) for the foreseeable future. These changes represent the increasing systems complexity of problems faced by PH workers, including PH informaticians. They also highlight the need for a PH workforce with the capability to address complex problem-solving situations systematically. To meet these challenges, the PH workforce must be able to integrate knowledge from multiple disciplines and create cross-cutting solutions through collective action and reflection, individually, as teams, or groups, or as a learning community of practice. Training programs have been developed to help guide PH practitioners in developing and improving information systems for improved knowledge integration.

Public health informatics (PHI) is defined as “the systematic application of knowledge about systems that capture, manage, analyze and use information to improve population health” [1]. From a systems perspective [2], the PHI practitioner needs to develop knowledge and skills to be able to examine and work within three kinds of systems, as follows: first, a population health causal web, i.e., a system of interacting factors and determinants that yields health outcomes (3); second, the set of PH information systems that captures the information dimensions of the causal web; and third, the overall health system that encompasses the first and second systems and consequently affects health outcomes through programs, policies, and interventions (see Table 25.1). Public health and health care systems are part of the overall health system, together with other societal systems that impact health outcomes (e.g., law enforcement, education,

**Table 25.1** Three systems critical to the practice of public health informatics

System	Description
Population health causal web	The level and distribution of health outcomes within a population are a result of interactions within a causal web of individual, group, societal, and environmental factors [4]. Population health is defined as the health outcomes of a group of individuals and the distribution of these outcomes within the group [5].
Health and health-related information systems	Information systems are made up of people, process, and technology, including the underlying management of these components [6]. Information systems used in public health and health care enable the capture, management, analysis, and meaningful use of information to improve population health through programs, policies, and interventions within the health system.
Health system (includes public health and health care)	The health system is made up of organizations, people, and actions whose primary intent is to promote, restore, or maintain health. Its goals are to improve health and health equity in ways that are responsive, financially fair, and make the best, or most efficient, use of available resources [7].

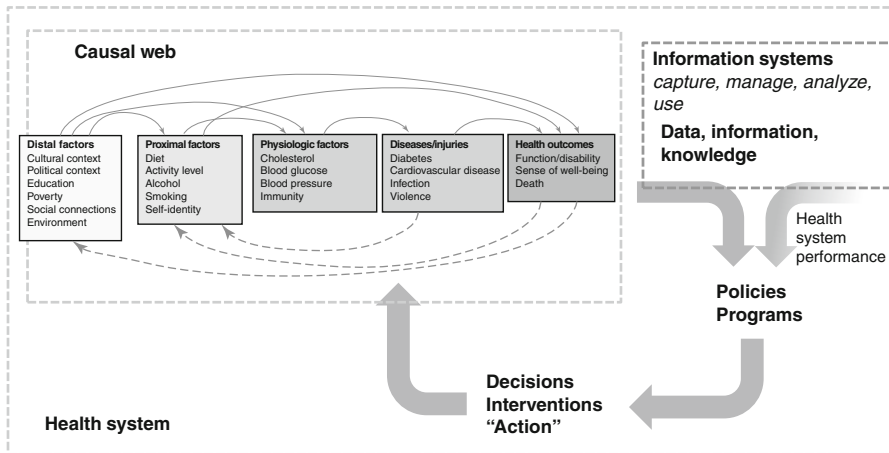


Fig. 25.1 Relationships between the three systems critical to public health informatics

business sector) [3]. From this perspective, information systems are an important component to complete the feedback loop between the causal web and its information dimension, and health system actions and interventions. If an information system malfunctions or becomes “sick,” this feedback loop becomes ineffective or inefficient. The information system will partially or completely fail to create value out of data that it captures about the causal web and its various components.

These three systems are interrelated in PHI practice. In the web of potential causal relationships among factors, diseases or injuries, and health outcomes [4], the measurable components and their relationships can be represented as data captured using information systems. PH informaticians design, develop and implement the information systems that help capture this information dimension. The knowledge generated from captured information helps define PH policies and programs that subsequently drive interventions to effect changes in the interactions between determinants and health outcomes.

The value to be created from processes within an information system [8] can be visualized by looking at the functional steps in the *Information Value Cycle (IVC)* for information systems (Fig. 25.1). PH informaticians need to be able to “diagnose” and “treat” various “malfunctions” within information systems. These malfunctions or “information pathologies” are avoidable failures of information processing within the IVC. During information system design and development, informatician can prevent information pathologies in the IVC steps by planning, designing, and developing information systems that maximize the creation of value in each IVC step. This type of investigative work and problem solving can be transformed into absorbing and engaging narratives, or cases, that depict real life PHI problems and the complexity surrounding them. Such cases can help students learn, and prepare to practice problem solving in PHI.

## The Case for Case-based Learning (CBL) in PHI

The challenge of finding informatics solutions for complex health system problems for the benefit of the public's health requires cross-disciplinary education, research, practice, and collaboration. The three systems described in Table 25.1 and Fig. 25.1 are *complex adaptive systems*, which are defined as collections of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent's actions changes the context for other agents. Within complex adaptive systems, agents whose context has changed adapt to the new environment and inevitably also change this very same context [9]. Training PH Informatician to transform the complex landscape of these three systems through informatics interventions requires specific skills, including:

1. imparting systems-based knowledge and skills to the diverse, multidisciplinary PHI workforce so they can design, develop, and implement solutions that lead to system change; and,
2. providing applied training for PH informaticians in solving real-world, complex problems.

Approaches to learning in this context must (a) address the complexity of both work and learning environments; (b) build collaborative problem solving, critical thinking, and systems thinking skills; and, (c) promote lifelong learning. The use of cases or problem-solving scenarios for teaching PHI (the CBL approach), combined with traditional classroom training, provides a well-rounded approach to leverage diversity of learner backgrounds and experiences in PHI training programs. As with the anonymous saying, "Give someone a fish and they live for day, teach them to fish and they live for a lifetime," using cases teaches learners "how to fish," no matter what their future environments or goals.

## Key Concepts in Case-Based Learning (CBL)

CBL is among approaches to problem-based learning (PBL) [10, 11]. Based on Barrows' work in PBL for medical education [12], CBL can address at least four important educational objectives in PHI training:

1. *Structuring of knowledge for use in practice contexts.* To facilitate recall of PHI knowledge, learning should occur in the context of real-world PHI work. While participating in a CBL activity, students integrate learning into the reasoning process for solving informatics problems. This promotes organization of knowledge that supports practice.
2. *Development of an effective problem-solving reasoning process.* The skills developed in PHI problem solving are honed and refined through deliberate practice [13]. These problem-solving skills include problem formulation, communicating problems to peers, solution design, solution implementation, outcome tracking,

and reflective practice [14]. CBL develops these skills while integrating basic PHI concepts and problem-solving information within a PHI case. This ensures that problem solving and use of relevant knowledge work together.

3. *Development of effective self-directed learning skills.* In PHI, the problems to be solved are dynamic and constantly changing, resulting in problem-solving situations that may not be quite similar to previous problems. Self-directed learning is an essential skill that ensures learning of new concepts and skills, whose application in problem solving happens in both familiar and unfamiliar settings. It is a key learning capability to acquire because knowledge for solving PHI problems needs to be retrieved across various reference disciplines (e.g., public health sciences, computer science, information science, social sciences, engineering).
4. *Increased motivation for learning.* The challenge of solving problems provides substantial motivation for learning. Motivation provides the drive to persevere through difficult problem-solving situations, and to extract and understand information from diverse learning resources.

Cases used for instruction in PHI can be examined using the following variables adapted from Barrows [12]:

1. *Completeness of case data provided to students.* The data about the case can be provided either before or after a lecture. The case can be complete, with all the details and resources incorporated as a package; a short summary, to be used for emphasizing specific concepts during a lecture; or incomplete, where the students have to discover information through open inquiry.
2. *Source of direction.* Teachers usually determine the amount and sequence of information provided to students in the course (teacher-directed) and in certain methods, students can be given this responsibility under the guidance and facilitation of teachers (student-directed).

On the basis of the objectives and variables by Barrows, a taxonomy of CBL comprising three methods can be developed (Table 25.2) for PHI. Learning objectives for each of the three methods can be mapped to the six cognitive levels of Bloom's Taxonomy [15] as revised by Anderson et al. [16]. From lowest to highest, the revised Blooms' Taxonomy levels are: (1) remembering, (2) understanding, (3) applying, (4) analyzing, (5) evaluating, and (6) creating. Each of these categories subsumes a group of verbs used for developing learning objectives for instructional design.

*Method 1 – Cases within lecture.* The teacher presents information to students through lecture and provides a case or two (usually short vignettes). Students are expected to understand cases in the context of information presented in the lecture and use that information with prior knowledge to understand and discuss the case. An alternative approach is for the teacher to provide students a case or two followed by presentation of information. In this approach, students have to analyze the case with their prior knowledge. This allows structuring of information from the lecture according to concepts presented in the case.



**Table 25.2** Taxonomy of problem-based learning (PBL) for public health informatics (PHI)

PBL method	Source of direction	Problem content	Educational objectives	
			Bloom’s Taxonomy level	Barrow’s objectives
(1) Cases within lecture	Teacher	Complete case or short case	1, 2	1, 2, 4
(2) Case-based	Mixed	Complete case	1–3	1–4
(3) Problem-based	Student (teacher-guided exploration)	Full problem simulation and field exercise	1–6	1–4

- Bloom’s taxonomy for cognitive levels of learning: 1, remembering; 2, understanding; 3, applying; 4, analyzing; 5, evaluating; and 6, creating. Adapted from: Taxonomy of educational objectives: Handbook I: Cognitive domain. New York: Longman, 1956
- Barrow’s problem-based learning objectives: 1, structuring of knowledge for use in practice contexts; 2, development of an effective problem-solving reasoning process; 3, development of effective self-directed learning skills; and 4, increased motivation for learning. Adapted from: A taxonomy of problem-based learning methods. Med Educ 1986;20(6):481–486

*Method 2 – Case-based method.* Students are given a complete case for study and research with subsequent class discussion. The interactive class discussion is facilitated by the teacher and students can direct discussion to points of inquiry that spark their interest. This method motivates students more but provides reduced opportunities for reasoning because of structured case presentation. (See the ELR case study near the end of the chapter.)

*Method 3 – Problem-based method.* Students are presented with initial information in simulated or actual formats to allow open inquiry. Students form their hypothesis and proceed to apply a problem-solving framework. In this scenario, teachers use facilitation to guide student exploration of the problem and activate prior knowledge. The activation also becomes diagnostic of the completeness and correctness of knowledge that is retained by students. The iterative nature of problem solving in this highly motivating method also provides opportunities for increasing knowledge and honing communication and stakeholder engagement skills. (Further discussion of this method is beyond the scope of this chapter.)

Methods 1 and 2 in Table 25.2 use written case narratives. Method 3 involves the use of simulated or live cases.

## CBL in an Applied PHI Training Program

The Public Health Informatics Fellowship Program (PHIFP) [17] at the Centers for Disease Control and Prevention (CDC) is a two-year, applied training program for professionals with backgrounds in PH or related disciplines and information and computer science or related disciplines. PHI fellows typically come from diverse

**Table 25.3** Example of an Info-Aid: World Trade Organization Meeting Seattle Info-Aid.

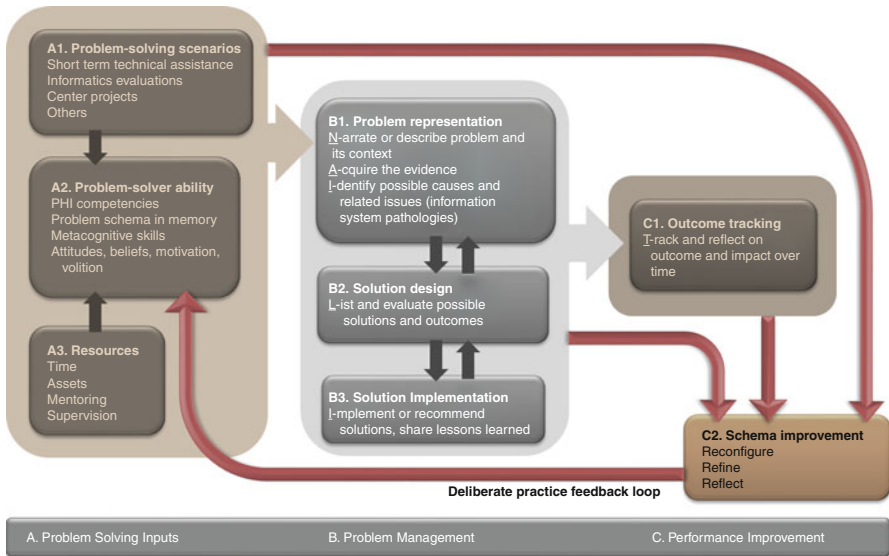
Requesting agency	Seattle King County Health Department in collaboration with Defense Advanced Research Projects Agency (DARPA)
Context	The World Trade Organization (WTO) Ministerial Meeting was held in Seattle, Washington on November 30, 1999 to begin global trade negotiations. The summit was marred with violent street protests, riots, and encounters between protesters and law enforcement. The health department required assistance in detecting potential bioterrorist threats during the WTO Meeting.
Informatics problem	Establish an electronic drop-in (temporary) surveillance system for syndromic surveillance to monitor potential bioterrorism events during the WTO meeting in Seattle and to test the use of this surveillance system during such an event.
Learning activity	A team of four people from CDC was dispatched to Seattle to implement a based structured query language (SQL) drop-in surveillance system for emergency departments. The PHIFP fellow provided informatics support to the team.

backgrounds (public health, medicine, nursing, veterinary medicine, engineering, library science, epidemiology, statistics, and information and computer science and technology), countries, and cultures. These diverse backgrounds present unique opportunities for fellows to learn to leverage multicultural and multidisciplinary perspectives during collaborative problem-solving activities. For example, fellows from other countries bring their unique cultural perspectives to discussions about information systems implemented in the local context. When fellows provide their unique disciplinary insights into informatics problem solving, the activity results in richer discussions and innovative solutions.

As participants in an applied science fellowship, PHI fellows are assigned to CDC centers, institutes, or offices (CIOs) and work on projects related to design, development, use, maintenance, and evaluation of PH information systems and related artifacts (e.g., data and information exchange standards, information architecture, information security policies). Outside their CIOs, fellows work on short-term projects arising from requests for technical assistance (Info-Aids) from state and local health departments, CDC programs in and outside Atlanta, GA, and international agencies. Between 1996 and 2012, PHIFP conducted a total of 62 Info-Aids (52 US-based and 10 international). Table 25.3 describes an example of an Info-Aid project (the first Info-Aid in PHIFP historical records). CBL can help fellows situate themselves and collaboratively provide informatics expertise within teams engaged in intense problem-solving situations, as in this example.

The development and use of cases in PHIFP offers multiple potential benefits, as follows:

- provide opportunities for fellows to apply knowledge gained from didactic training;



**Fig. 25.2** A problem-solving framework for public health informatics

- provide fellows with an interactive environment for collaborative learning and problem-solving, which are critical skills needed for working with complex projects in PH;
- allow the codification of knowledge and lessons learned from solving complex problems in PHI projects, specifically past Info-Aids; and
- provide opportunities for PHIFP to develop novel problem-solving approaches to technical assistance projects;

PHIFP teaches fellows the use of a problem-solving framework [14] during orientation training, before they participate in other training modules and case studies (Fig. 25.2). Within this framework, the key steps in informatics problem solving are represented in the acronym “NAIL-IT”. The PHI problem-solving framework was developed by the PHIFP to support the learning and problem-solving activities of the fellows in the program. The framework was developed by incorporating lessons learned from practice and applied training in PHI, and supports various PHIFP applied learning activities (e.g., Info-Aids, informatics evaluation projects, other informatics projects). The core components of the framework, with examples taken from Table 25.3, are as follows:

- *Problem-solving inputs*: elements necessary for initiating a problem-solving activity. Problem solving inputs from Table 25.3 include the Info-Aid request from Seattle and King County, with a CDC team dispatched to Seattle and the collective technical skills of team members, available resources in the health department (i.e., database servers, to support work of CDC team).

- *Problem management*: elements of problem solving that support identification and formulation of a problem as well as design and implementation of a solution to the formulated problem. Potential terrorism activity within the background of violent World Trade Organization street protests provide a complex public health setting for collecting data about public health threats, which enabled the capture of data about potential public health threats from multiple electronic and nonelectronic data sources. Limited technological options available at that time provided a challenging situation for designing technical solutions.
- *Performance improvement*: elements of problem solving that focus on tracking the outcomes (usually up to a year) of the implemented solutions and incorporate learning through deliberative and reflective practice.

The Seattle experience heralded further evolution of syndromic surveillance systems. These systems helped conceptualize new methods for capturing, analyzing, and visualizing data from disparate electronic sources at different time points of a health event and defining novel uses of syndrome data from electronic health records.

PHIFP case studies fit within this larger picture of using problem solving for training. Additionally, PHIFP case studies provide an early opportunity for fellows to begin building the collaborative problem-solving and critical-thinking skills that the fellowship program seeks to instill among its graduates. After participating in multiple case study sessions, the fellows subsequently participate in a field team exercise in a closely supervised Info-Aid. This step prepares new fellows for the next level of learning in solving problems, which is leading their own Info-Aids. The field exercise and Info-Aid would fall under PBL Method 3 in Table 25.2.

PHIFP has modeled its case studies after those of the CDC's Epidemic Intelligence Service (EIS) Fellowship [18], using previously conducted Info-Aids as a major source of content. EIS has been using case studies for decades and has engaged its alumni in developing and delivering case study sessions during the EIS Summer Course for new EIS Officers.

### **PHI Case Study Example: Challenges in Implementing Electronic Lab Reporting in State Oz**

This anonymized case, set during the early 2000s, was developed and written by three former PHIFP fellows for use during summer orientation for new PHIFP fellows [19]. On the basis of one of the author's experience setting up a state electronic laboratory reporting (ELR) system, the case study was originally written in 2009, and subsequently updated in 2011 to include information related to Meaningful Use of electronic health records in PH [20] and rewritten

using the textbook on case writing by Naumes and Naumes [21] as a guide. The case study begins with an introduction to a mythical (but typical) state environment in Oz and its need for ELR. The state was dealing with typical local government challenges (e.g., budget reductions) that not only restricted options for purchasing equipment and hiring additional personnel, but also imposed mandatory unpaid furlough days upon existing employees as a cost-cutting measure. Although electronic transmission of laboratory results to PH was easily justified by the increased speed and accuracy of data, faster integration of data with state information systems, and reduced costly manual entry of data, the actual setup of an ELR system was a novel, difficult, and complex venture.

The State of Oz encountered typical challenges in setting up an ELR system.

- *Data standards.* The state wanted to receive ELR data in standardized format (HL7<sup>®</sup>) and content (laboratory test-LOINC [22] and result coding-SNOMED [23])
- *Laboratory participation.* Not all laboratories had resources (e.g., personnel and monetary), available to collect, format, and transmit their data to ELR specifications
- *Local health department.* The state's multiple local health departments were the first responders for disease investigation and response, and had to be included as ELR partners, increasing the number of stakeholders and requirements to be accommodated.
- *State standalone systems.* Multiple siloed state systems were in use, and needed to receive ELR data. The initial state program areas targeted for participation in ELR were blood lead levels, Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome (HIV/AIDS), enteric diseases, zoonotic and parasitic diseases, hepatitis C, tuberculosis, and bioterrorism

The use of this case entailed group review and discussion of the case study materials. Students then worked collaboratively to develop solutions to questions such as:

- How does one develop an initial assessment of the informatics problem in the PH context?
- Are standards the only way to solve information exchange in ELR?
- What kind of innovations will be needed to accommodate conflicting requirements asked of or imposed on labs by their outside partners?

The following ELR case study has been very useful in introducing new fellows to the real-life challenges in PH informatics at a state level. It has been used for 5 years during PHIFP summer orientation for new fellows.

### **Case Study Exercise – Challenges in Implementing Electronic Lab Reporting in State Oz**

*Student Guide: Challenges in Implementing Electronic Lab Reporting in State Oz*

Note: This anonymized case was developed and written by Herman Tolentino, JA Magnuson, and Arunkumar Srinivasan from January–July 2009 for the CDC Public Health Informatics Fellowship Program (PHIFP). The authors are all former PHIFP fellows. The content of this case study was synthesized from experience related to implementation of electronic laboratory reporting (ELR) at the state level by one of the co-authors of this book chapter. During June 2011, the case study was revised to provide the Meaningful Use context for ELR adoption.

The mention of brand names of commercial/intellectual property products in this document does not constitute an endorsement and is merely coincidental. The entities alluded to in this document have been altered to protect the identities of individuals and organizations involved.

#### *Learning Objectives*

By the end of this session, the participant should be able to achieve proficiency at certain skills.

1. Describe what ELR is – and what it is not
2. Given a public health (PH) scenario, describe the scope of ELR solutions
3. Discuss challenges potentially encountered in implementing ELRs
4. Identify sustainability challenges for a specific ELR project

#### *Footnote – Julia Martinez’s Biosketch*

Julia Martinez is a microbiologist with 5 years of experience working in a private laboratory before she obtained her Master in Public Health degree at the University of North Carolina and her PhD in Informatics from the Swiss Institute of Technology in Zurich. While in the second year of the PHIFP, she was assigned to the National Center for Hepatitis, HIV/AIDS, Sexually Transmitted Diseases, Tuberculosis Prevention (NCHHSTP) at CDC. After graduating from the program, she was accepted into the third-year PHIFP field practicum and was assigned to the State of Oz.

#### *Introduction*

Julia watches the golden West Coast sun as it fades away from her office window, taking time to reflect on the long days she has spent writing up an implementation plan for electronic lab reporting for the State of Oz. Tomorrow is one of the mandatory unpaid furlough days the state has adopted in response to its budget crisis, but much work remains to be done. The plan still needs some additional improvements as she tries to address the complexity of implementing ELR at the state level.

Julia told herself, “Surely, I still have a lot to learn about electronic lab reporting. It is not as straightforward as I originally thought.”

Julia began to reflect on events that transpired within the last several weeks.

**Table 25.4** Use of public health surveillance data

Public health uses of surveillance data	Public health system components and emphases (+++=greatest emphasis)		
	Local	State	Federal
Identification of cases for investigation and follow-up	+++	+++	+
Estimate the magnitude of a health problem; follow trends in incidence and distribution	+	+++	+++
Detect outbreaks or epidemics to trigger interventions	+++	+++	+
Evaluate control and prevention measures	+	+++	+++
Monitor changes in infectious agents (e.g., antibiotic resistance, clinical spectrum)		++	+++
Facilitate epidemiologic and laboratory research; formulate prevention strategies; formulate hypotheses	+	++	+++
Detect changes in health practice (e.g., impact of use of new diagnostic methods on case counts)	+	+	++
Facilitate planning (e.g., allocation of program resources, policy development)	+	+++	+++

Source: Adapted from CDC 1997 [21]

### *Background*

During March 1997, a meeting of experts sponsored by CDC, the Council of State and Territorial Epidemiologists (CSTE), and the Association of State and Territorial Public Health Laboratory Directors (ASTPHLD) was held to provide a discussion forum for barriers to creative and practical implementation of effective laboratory reporting standards. The report summarized recommendations in three main areas [24]:

1. Flow – where, when, and how data should move to and from users.
2. Format – the mechanics of data transfer, including use of Health Level 7 (HL7<sup>®</sup>) messages and/or other reporting formats and ways to ensure security
3. Content – the determination of which data elements should be included in an electronic system for clinical laboratories

Table 25.4 outlines uses of PH surveillance data (specifically laboratory data). Laboratory reports are important to PH surveillance when they indicate possible occurrence of reportable or infectious disease outbreaks. The traditional system of laboratory reporting, however, was slow and incomplete as it often relied on paper reports delivered by mail [25]. In 2008, an evaluation that compared the completeness and timeliness of automated, standards-based

electronic laboratory reports and spontaneous, paper-based reporting for a broad spectrum of notifiable diseases in Indiana indicated that automated ELR improves the completeness and timeliness of disease surveillance, which will enhance PH awareness and reporting efficiency [26].

In the United States, adoption of ELR has increased steadily. During 2000–2010, the number of jurisdictions self-identifying as “not involved in ELR” dropped from 69.6 to 0 % [27]. The American Recovery and Reinvestment Act (ARRA) and Health Information Technology for Economic and Clinical Health (HITECH) Act Meaningful Use requirements [28] offered financial incentives to eligible providers and hospitals to adopt Electronic Health Records (EHR). One of the PH options available to hospitals is ELR: this incentive is further advancing the adoption of ELR in PH.

### *Research Experiment*

In March 2011, state of Oz received \$300,000 grant funding from the federal government to establish ELR. As the new CDC PHI Fellow assigned to this state, Julia Martinez was specifically assigned to help develop an implementation plan for ELR at the state level and to develop translations, identify, test, and evaluate secure transmission methods, collaborate with local health laboratories, engage local health departments, and involve state program areas to participate in ELR.

### *The Systems*

Julia found out that the state operated the following systems that could potentially benefit from ELR:

1. HIV/AIDS monitoring – Enhanced HIV/AIDS Reporting System (eHARS) is a browser-based application that collects, stores, and retrieves data through a secure data network, that CDC has identified as necessary for monitoring the HIV/AIDS epidemic, identifying current trends in the epidemic, and evaluate HIV prevention, care, and treatment planning
2. Environment monitoring (heavy metal poisoning, air quality, water quality) – An example is blood lead monitoring which usually comprises a huge volume of ELR data flowing to PH. The Systematic Tracking of Elevated Lead Levels and Remediation (STELLAR) is a software application provided free of charge by the Centers of Disease Control (CDC) to State and local Childhood Lead Poisoning Prevention Programs (CLPPPs) as a practical means of tracking medical and environmental activities in lead poisoning cases. The intent of this application is to provide an electronic means of storing childhood lead exposures, medical, and laboratory data that the state program receives from labs, providers, clinics, parents, and local health departments.
3. Other notifiable conditions – The National Electronic Disease Surveillance System (NEDSS) [29] is an initiative that promotes the use of using data and information system standards to advance the development of efficient,



integrated, and interoperable surveillance systems at federal, state, and local levels. A primary goal of NEDSS is the ongoing, automatic capture and analysis of data that are already available electronically. NEDSS system architecture is designed to integrate and replace multiple CDC surveillance systems, including the National Electronic Telecommunications System for Surveillance (NETSS, see below), the HIV/AIDS reporting system, the vaccine preventable diseases system, and systems for tuberculosis (TB) and infectious diseases [30].

4. Pathology reporting (cancer) – Cancer Registries are information systems that collect data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment. In each registry, medical facilities (including hospitals, physicians’ offices, therapeutic radiation facilities, freestanding surgical centers, and anatomic pathology laboratories) report these data to the State central cancer registry. The cancer information gathered is critical for a Health Department to have the ability to report cancer statistics. Cancer registry data is used to provide information on cancer trends, survival, treatment standards, and access to healthcare and serves as a resource for research.
5. Federal reporting – State Oz currently uses several digitally encrypted, interconnected information exchange frameworks (including the old NETSS, which is being replaced), for reporting notifiable diseases to CDC.

Although she had encountered some of the systems mentioned above while at CDC, Julia wanted to review examples of data standards used in PH and laboratory reporting. She went to her supervisor, Debra Moore, to find out more information about this. Following are excerpts from their conversation:

Julia      “I am just now getting to appreciate the state perspective. Can you please enlighten me on use of standards in lab reporting?”

Debra      “That’s an interesting question. Well, we promote the use of standards but public health departments are just as guilty as anyone else of creating their own local data standards. Since most legacy PH systems have grown organically – often created by local, state, or federal epidemiologists with no database or data standards background, on an as-needed and as-funded basis – they may have little to no standardization, normalization, etc. So PH data “standards” (Debra gestures quotes) include a number of local code systems. Some systems are more formal than others – for example, systems with payer-functions are more likely to include standard codes, such as CPT (current procedural terminology – a billing code system) or hospital-related diagnostic codes (ICD-International Classification of Disease), etc.”

Julia:      “That’s very enlightening!”

Debra:      “Oh, it gets better!”

Julia: “Tell me!”

Debra: “Laboratories have their own coding systems, that allow them to track and bill laboratory work. The coding system in use can be vendor-supplied (built into the Laboratory Information System (LIS)) or can be managed in-house. In any case, the use of data standards for PH reporting is not the primary concern of laboratories – these have only become important to public health with the relatively recent advance of electronic data systems. PH is attempting to get labs to use LOINC® (*Regenstrief Institute, Incorporated, Indianapolis, Indiana*) and SNOMED® (*International Health Terminology Standards Development Organization, Copenhagen, Denmark*) coding for their PH reporting, but these are still not in use by many laboratories. Remember that it is difficult, time-consuming, and expensive for laboratories to incorporate a new coding system into their existing system.”

### *The Issues*

After several weeks in Oz, the local laboratory environment was beginning to make sense to Julia. She enumerated the data partners in Table 25.5 and filled in the cells with information from the interviews she conducted with these partners.

Julia showed the table to her supervisor.

Debra: “Julia, this is excellent work!”

Julia: “Thanks, just wanted you to see this.”

Debra: “So what do you think is our problem?”

After further analysis of information she obtained from her interviews, casual conversations in the hallway, and site visits, Julia was able to summarize the challenges by the type of laboratory being considered for ELR implementation (Table 25.6).

Additional information Julia found out included recipients of laboratory data from state of Oz as outlined:

#### 1. State Program Areas:

- (a) blood lead levels
- (b) HIV/AIDS
- (c) enteric diseases
- (d) zoonotic diseases
- (e) hepatitis C
- (f) tuberculosis
- (g) parasitology
- (h) bioterrorism

#### 2. Local health departments

- (a) have identical programs as the state health department, and
- (b) certain metro areas have their own ELR systems.

**Table 25.5** Laboratory data partners of Oz State health department

Laboratory	Type	Population coverage	Cost estimate for implementing lab reporting standards	Level of use of ELR-specific standard test and result codes	Incentive to use standards	Potential Return on Investment (ROI) for ELR
National Reference Lab (Hydra Diagnostics)	Commercial	Nationwide	Low	High	PH request	High
Midwest Regional Lab (commercial)	Commercial	Regional (3 states)	Medium	Low	PH request	High
State Hospital Lab (Kingston Memorial Hospital)	State hospital lab	State	High	Low	PH request	High
Vanguard Lab Systems	commercial	Local	High	Low	PH request	High
Beaumont Integrated Labs	Commercial	Local	High	Low	PH request	High
State Oz public health lab	Local public health lab	State	Medium	Low	PH need	High
Atlantic City public health lab	Local public health lab	City	Low	Low	PH need	High

**Table 25.6** Challenges in implementing ELR for different kinds of laboratories.

Type	Challenges/limitations
National Reference Laboratory	The national lab has limitations separating results from notes in their lab reporting data. They also have reservations about adopting state-recommended transmission methods and are not willing to spend their money to retrofit their Lab Information System (LIS) to include standards for public health reporting. And like all reference labs, they frequently have very little of the patient demographic data so important to public health (like address, phone number).
Regional Laboratory	The regional lab also has the same limitations above. In addition, as far as their lab information systems are concerned, they are unable to generate or extract batch report files. They are unfamiliar with HL7® formatting largely due to lack of capacity to implement it and would need very convincing reasons to adopt ELR.
Public Health Laboratory (PHL)	The PHL is working to replace its current LIS but hasn't decided on a final solution (challenges in evaluating options), so lab is reluctant to put effort into adopting ELR. The lab is looking for an ideal LIS, which is probably not practical. In addition, they have a lack of sufficient technical knowledge or expertise to make these choices, and will be relying on state public health to assist with the ELR implementation.
Commercial Laboratories	The local laboratories will experience savings in labor once a paperless reporting system is established, although they find no direct financial benefit from use of standards. They argue that converting systems to use standards will be a drain on their resources. These for-profit labs insist that they will need more resources available to change their systems to accommodate all of the requirements for ELR.

She also learned that state of Oz receives records of residents from neighboring states. For example, if a resident of State Looking-Glass travels to state of Oz to see a doctor, the lab report might be routed to Oz health department in error. These out-of-state reports are manually routed back to their respective health departments in error.

The federal funding that state of Oz is receiving comes attached with the certain conditions:

1. ELR systems adhere to national standards – the funding stipulates use of LOINC® and SNOMED® data standards, and HL7® formatting standards.
2. That the ELR systems be Public Health Information Network (PHIN) compliant and compatible, which affects certain facets, including transmission security, data storage conditions, and other criteria.

Debra also informed Julia of recent developments that might impact the development of systems and lab reporting in state of Oz:

1. Any system to be developed has to be compliant with current security protocols of the state.
2. Regarding local legislation, a bill in the state of Oz Senate to mandate ELR had been initiated. Debra showed Julia last week's copy of the *Oz Express*, including a short article about PH initiatives in the Oz legislature, "Representative Rankle Cares for the Public's Health."

### **Questions for Students:**

Question 1: Given this background information, please help Julia systematically develop an initial assessment of the informatics problem in the PH context. You can use the following to group statements in your description: PH context, informatics problem, main challenges, and possible approaches to meet these challenges.

Question 2: Are standards the only way to solve information exchange in ELR? Why or why not? If you are pushing for the use of standards, what criteria would you use to determine what the best standards would be?

Question 3: What kind of innovations do you think will be needed to accommodate conflicting requirements asked of or imposed on laboratories by their outside partners?

### **Possible Approaches**

After weeks of studying the background of laboratory reporting in State Oz, Julia decided to sit down and write up an initial draft of her project proposal to implement ELR. It seems that there are many potential approaches to implement ELR in State Oz, as she has begun to outline in Table 25.7.

### **Question for Students:**

Question 4: If you were Julia, what do you think would be pros/cons to each approach (Table 25.7) in developing ELR for the state? What kind of innovations do you think will be needed to accommodate conflicting requirements? (Fill in the advantages and disadvantages column of the table that follows.)

### **Question for Students:**

Question 5: In developing a checklist for implementing this ELR project, how should Julia put the key items in Column A, Table 25.8 in order? Use Column B to arrange in sequence the items from Column A. Be prepared to justify the sequencing of items in Column B.

### **Conclusion**

After reflecting on the events from the past weeks, Julia proceeded to finish up her plan for approaching ELR implementation in state of Oz. Tomorrow is one of the mandatory unpaid furlough days the state has adopted in response to its budget crisis, but much work to be done.

**Table 25.7** Possible approaches for implementing ELR in State Oz

Possible solutions	Brief description	Pros/Cons
CDC-provided solutions or government off-the-shelf (GOTS <sup>a</sup> )	<i>NEDSS Base System (NBS)</i>	
Commercial Off-the-Shelf (COTS <sup>b</sup> )	<i>Many possible vendors.</i>	
Solution developed in-house	<i>(Think of your own example if you know one.)</i>	
Combinations of above	<i>(Think of your own example if you know one.)</i>	

<sup>a</sup>**Government off-the-shelf (GOTS)** is a term for software and hardware products that are typically developed by the technical staff of the government agency for which it is created. It is sometimes developed by an external entity, but with funding and specification from the agency. Because agencies can directly control all aspects of GOTS products, these are generally preferred for government purposes. GOTS software solutions can normally be shared among Federal agencies without additional cost

<sup>b</sup>**Commercial, off-the-shelf (COTS)** is a term for software or hardware, generally technology or computer products, that are ready-made and available for sale, lease, or license to the general public. The use of COTS is being mandated across many government and business programs, as they may offer significant savings in procurement and maintenance. However, since COTS software specifications are written by external sources, government agencies are sometimes wary of these products because they fear that future changes to the product will not be under their control

**Table 25.8** Checklist for implementing ELR project

Column A	Column B
A. Inventory of information standards and technologies used by partners	
B. Identify need for electronic information exchange – willingness to send data	
C. Ensure buy-in	
D. Identify resources (technical, human, financial) for implementing the project	
E. Develop infrastructure for exchange of electronic messages	
F. Identify stakeholders	
G. Develop a new messaging guide for lab reporting in the state	

**Question for Students:**

Question 6: If you were Julia, how would you present a planned approach to the State?

**Summary**

In this chapter, we describe why CBL is an important activity in applied PH training. As the PH landscape undergoes profound changes, building capacity to solve problems in this environment requires cross-disciplinary education, research, and

practice. Specifically, the workforce needs to develop skills in collaborative problem solving, critical thinking, systems thinking, and lifelong learning. We briefly discuss this landscape in terms of three systems critical to PHI practice, highlighting the role of information systems as a feedback loop to support interventions that improve population health. Transforming this landscape requires systems-based knowledge and the ability to solve complex problems within the three systems. We also provide a taxonomy of CBL to help the reader classify use of cases on the basis of desired cognitive levels of learning and capacity for problem solving, and we use examples from an applied training in PHI at CDC. We end the chapter with an example case on the challenges of implementing ELR in a hypothetical state from the perspective of an informatics fellow working at the state health department.

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**Part V**  
**Case Studies: Information Systems**  
**and the Strata of Public Health**

# Chapter 26

## Local and Regional Public Health Informatics

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**Abstract** Local public health has a high degree of interaction with the public it serves, and is driven by local needs, budgetary constraints, limited capacity, and external influences. Public health at the local level is an information-rich yet resource-poor environment, generally lacking the informatics capacity found at state and federal levels. While the local environment is defined by the differences found between jurisdictions, there are many operational similarities that can be leveraged to advance informatics activities within and across jurisdictions. Advances in technology have provided local public health informaticians with opportunities that were previously only available to large states and the federal government. Through proper vision, planning, and implementation, local public health can position itself in a way that provides a sustainable, comprehensive solution to informatics needs.

**Keywords** Local Health Department • Public Health Informatics • Disease surveillance • Electronic messaging • Open Source • Work flow • Process improvement

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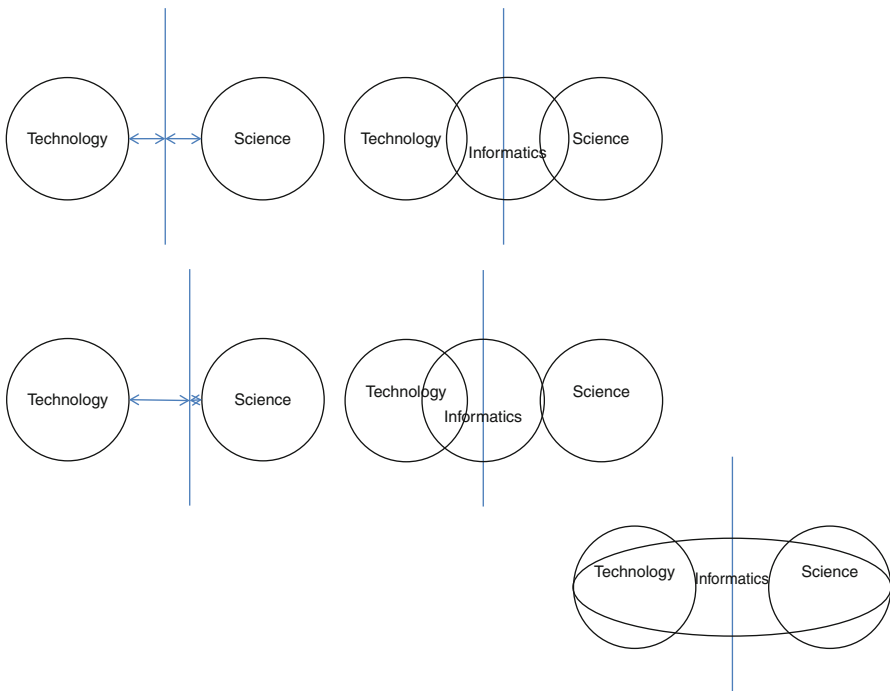
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**Learning Objectives**

- 1. Describe local public health informatics environments.
- 2. Discuss the informatics challenges faced by public health at the local level.
- 3. Explain the benefits of the informatics approach taken in the Case Study.

**Preface: The Local Public Health Informatician**

A key element of success in any organization is the ability to recruit and retain personnel with appropriate skill sets for the tasks and challenges faced by such organization. As illustrated in Fig. 26.1, there is a natural divide between the disciplines that now commonly support the operations of the Local Health Department (LHD): the scientific disciplines of epidemiology, clinical services, and environmental health, and the technical discipline of information technology (IT). As experienced by those engaged in local practice, the scientific practitioners and IT specialists are required to work together, albeit they “speak different languages.” Each group has well-defined technical languages necessary to properly express their work tasks. However, this specialization comes at the cost of reducing their ability to communicate “requirements” to other groups. It is the public health



**Fig. 26.1** The natural divide between science and technology. The domains of IT and EPI

informatician's task to overcome this "Tower of Babel" problem. The informatician needs to be knowledgeable of not only the respective technical jargons, but also cultures and overall programmatic initiatives. A public health informatician, in turn, needs to possess the necessary skill set to be a good translator and also lead strategic change. As shown in Fig. 26.1, the roles in which the informatician is likely to participate promote reciprocal interdependence and intensive technology [1], where the activities from one discipline to the next are seamlessly integrated. In some instances, they will play more of a technological role whilst in others they will play more of a scientific role, this is dependent upon the particular needs of the LHD at different times.

Due to the lack of informaticians operating at the local level, it is likely that LHDs will have to resort to retraining or enhancing the knowledge of personnel currently fulfilling different roles. In this instance, it is up to the LHD to identify individuals who are closer to the "other side" of the divide and provide proper training. Recently there has been an emergence of informatics training programs, many directed towards working professionals, which can support such instruction.

As demonstrated by Fig. 26.1, the disciplines of science and technology do not encroach upon one another; while some scientists may have some technology skills, the reverse is not usually true. Typically, an informatician has a large degree of informatics methods and background, and in-depth knowledge of the domains in which they practice. Ideally, the informatician possesses a diverse skill set and has significant exposure across the domains under their direction, allowing them to realize the interconnectedness of the domains. The diagrams only represent two of a host of domains, as further specialization may be required given the duties of the informatician, for example, workflow development, process improvement, project management, etc.

## Overview

Local public health departments support fundamental activities critical to the communities in which they serve, borne by the science of public health, and resulting in data and information which is propagated and leveraged throughout the public health continuum. This chapter focuses on the LHD activities, which should be understood in the broader context of the continuum as defined by state and national public health initiatives. It is the alignment of these initiatives to LHD core activities, processes, and practices that is fundamental to the continuity of information flow throughout the domain, and to the development of a comprehensive health informatics infrastructure. This chapter further defines the intersection of public health domains, authorities, community partners, and their respective initiatives. Finally, it offers suggestions toward a unified approach that will likely improve operations, reduce costs, increase access to information, and facilitate decision making to enhance the overall well-being of the community.

## **Introduction: The Local Health Department**

An old joke in public health is that “if you’ve seen one health department, you’ve seen... one health department.” While each local health department is unique, they all share the common fundamental purpose of being the agency directly responsible for the health of a population. At its heart, all public health activities, from childhood immunization to injury prevention to ensuring the safety of the food supply, are local activities. These local activities occur within a state or territory at the city or county level, and may include multi-county, regional agencies. The 2,794 local health departments in the United States each face unique challenges, but at the core, the basic operational activities of public health are the same throughout the country.

### *Informatics Needs*

The LHD is an information-rich environment, where data management and use is one of the primary functions of the organization. This creates a diverse set of informatics needs stemming from the multidisciplinary nature of the data being handled. The LHD acts as subscriber, receiver, consumer, and integrator of data from hospitals, laboratories, registries, fire, police, emergency medical services, regulatory bodies, weather services, and more. Each data source has intrinsic demands not only of interpretation, but of transport, storage, management, standardization, quality assurance, and integration. In response to the requirements imposed, LHDs must implement the appropriate mechanisms to facilitate the programmatic use of these data, including analysis and dissemination. Many of the activities supporting public health practice are commonly found across jurisdictions. In consequence, the business processes that operationalize these needs are similar in nature; examples include disease surveillance, maintenance of immunization registries, conduction of smoking cessation campaigns, promotion of healthy hygiene, etc. These activities have inherent challenges that are also common to all local health departments.

In the case of disease surveillance, LHDs need to manage information captured by laboratories, clinical partners, and patients alike. These records usually range from the sparse to the comprehensive, and may be borne from different information collection methods and systems, each with a mixture of standards. Once the data from these systems are collected, they need to be converted into a format that can be used internally, and paired up with other datasets relevant to the disease-specific epidemiological, environmental, and clinical public health questions. Once all data sets are converted, integrated, and made available, the epidemiological search for answers can begin. This scenario tends to be an oversimplified version of what really happens. In many instances, the data are only partially collected since, for instance, additional information is not required in a clinical record – thus, answering a question such as “Did the patient swim in a pool?” or “Did the patient eat raw

oysters?” may not have been asked for clinical purposes. These risk factor data, however, remain equally as important as the clinical data in a medical record. When conducting an investigation, it is critical to determine the source of exposure and whether members of the local community may have frequented the same pool, eaten at the same establishment, etc. It is these disease-specific risk factor data that are the underpinnings for epidemiological questioning, and that only personnel with significant epidemiological expertise are prepared to interpret. However, understanding how the data are collected, in which format, how discrepancies are handled, when supplemental data is used to provide context, and how to apply filters to remove extraneous information in order to construct a final dataset (that could actually answer the question originally posed) is a multidisciplinary activity, one best suited for qualified public health informaticians.

In the previous example, data had to be collected and disseminated to LHDs from various partner agencies. Another example of what is common practice, utilized across jurisdictions, is the targeting for immunization outreach campaigns. Back-to-school immunization clinics are established and services delivered in response to community need; children that are not immunized through the aforementioned intervention rely upon alternative outreach. Public health professionals must formulate these alternatives based upon community knowledge. However this information may not be readily available, and it is the intersection of epidemiology and the application of informatics that may provide insights to enhance the effectiveness of these activities. By combining disparate information from multidisciplinary sources, including information from Vaccine For Children (VFC) [2] providers, bus routes, and population demographics such as socioeconomic status (SES), the LHD may target specific locations such as shopping plazas or religious facilities, which can serve as alternative locations to extend immunization coverage.

These demonstrations of an ever-increasing focus on evidence-based public health practice at the LHD illustrate the need for similar informatics efforts across the continuum. Unfortunately, many of these common approaches are driven by the reality that restricted technical capacity, knowledge, and funding, and competing priorities at the local level, limit the LHD’s ability to realize the full potential of informatics across the organization.

### ***Technological Capacity***

The technical capacity of LHDs tends to vary in relation to their size and budget. It is common for LHDs in metropolitan areas to have large IT infrastructures, including IT and informatics specialists, whereas more rural LHDs may have less advanced infrastructure. As such, local public health departments frequently possess limited ability to deal with the technical and socio-technical challenges imposed by the intrinsic nature of public health. As stated earlier, personnel with proper understanding of the problems faced by the organization are scarce due to (1) the relatively recent evolution of public health informatics as a field; (2) a lack

of training programs that put emphasis in public health informatics; and (3) the mischaracterization of the magnitude of the challenges at hand by the public health discipline.

The lack of awareness of public health informatics as a field in expanding informatics capacity at the LHD often leads to the hiring of personnel with only IT expertise, which can solve organizational problems only up to a certain point. These problems, then, either linger or are even exacerbated by using an “IT-only” approach. It is reasonable that after a particular failure, public health organizations may be motivated to take a different approach and include people with actual public health informatics expertise.

However, once an organization hires personnel with expertise in public health informatics, they often are seen as IT experts by program staff, which limits their ability to truly solve problems within the organization. In this regard, many challenges go unsolved if the problems are not necessarily IT-centric but more socio-technical. These include problems with workflows, misalignment of initiatives and technologies, and constraints imposed by misguided budgetary decisions and/or the selection of technology choices that are not appropriate, yet are mandated programmatically.

Another challenge is that government organizations are naturally resistant to change. Such resistance can be either beneficial or detrimental, depending on the situation, which can lead to limited capacity to make changes. Resistance may be beneficial if the suggested change is not optimal or is even harmful, yet it can prove discouraging if the change is good but will take long time to take effect. In the latter situation, personnel with public health informatics expertise, who have managed to exert enough influence within the organization to actually enact change, may not stay long enough to see those changes take place. It is important to note that such personnel are in great demand and are likely to have defined a career path in which the participation in a local public health department assignment is probably of a temporary nature. Thus, in the end, organizations need to plan for having backup plans, in terms of existing personnel or personnel in the training pipeline, as more seasoned informaticians transition to senior roles.

### ***Knowledge, Vision, and Priorities***

As public health informatics makes inroads into mainstream public health and epidemiology, more and more directors of LHDs are embracing the incorporation of informatics principles and practice into their decision-making. Executive leadership, the group responsible for setting the agency vision, typically has too limited an understanding of the field to set priorities at the enterprise level. Contributing to this lack of an enterprise vision is the silo-ed nature of public health, with information systems that have evolved independently of each other with no concern for the development of common, reusable subsystems. Additionally, it is very challenging for most LHDs to cope with the demands of their day-to-day operations while maintaining focus on

the future. In this regard, the vision is limited to an IT-centric approach in which, hopefully, technologies will naturally lend themselves to solve the problems appropriately. Undertaking informatics projects without adequate expertise introduces risk, and on many occasions the LHDs end up paying the consequences, either through failed projects or costly revamping of legacy or even newly-developed systems.

In order to define need, the organization must understand how informatics principles can be applied to improve the LHD, its strategic vision, and future plans. As we will describe later, there are specific steps that can ameliorate these challenges, but it is important that, as a first step, organizations develop a better understanding of their limitations and upcoming hurdles. This understanding can help them steer the organization in a direction that will allow them to overcome these limitations.

It is also important to highlight that many health departments do not have informatics activities, only more “IT-centric” activities. It can be difficult for organizations to distinguish the difference, and it is likely that prioritization is given to what is known or is influenced by external factors, such as the information provided by particular vendors or what is learned at professional meetings. Again, it is more likely that progressive LHDs have identified informatics as one of their key priorities.

In an ideal world, LHD activities are prioritized by the needs of the community and the agency’s mission. In reality, these priorities are driven by a combination of community needs, state regulations, external initiatives, and public and private funding. Similarly, informatics activities are driven by more than just the operational needs of the health department; they must take into account resource limitations (both funding and staffing) and external constraints (such as grant requirements). This inherent tension between community needs, resource limitations, and external constraints places unnecessary burdens on the system, resulting in LHD operations that are not driven by the agency vision.

## ***Funding***

Historically, public health has been funded at a level that, while taking care of the basic needs of the population, does not allow for long-term planning and preparation, often resulting in reactionary activities and the need to support isolated systems living on in perpetuity (out of necessity). The task of convincing policymakers to fund a public health informatics program in order to ensure the sustainability of *other* funded activities is daunting, especially considering that the benefits of most preventative public health programs are not apparent for decades. Due to the difficulty of directly funding informatics professionals through public means, they remain scarce, as they must rely on alternate sources of funding.

Public health departments are typically funded by a mix of tax-based funds, fees for service, and grants. This diversity provides greater stability for public health departments in dealing with changing funding priorities than if they were dependent on a single funding source, however, it introduces a number of limitations in the way that the funding can be utilized for informatics activities.



Tax-based funding typically has the fewest restrictions, although the political nature of the appropriation process may introduce limitations as to how it is spent. The same limitations may be placed on the agency by an outside political entity, through the process of developing and approving a budget. Service fees are based on the cost of the administration of a program, which may include an informatics component, but this typically accounts for ongoing expenses and not future informatics planning. While some grant opportunities for enterprise informatics planning and development are available, these funds are typically limited, highly competitive, and often restricted to state health departments and several very large metropolitan areas.

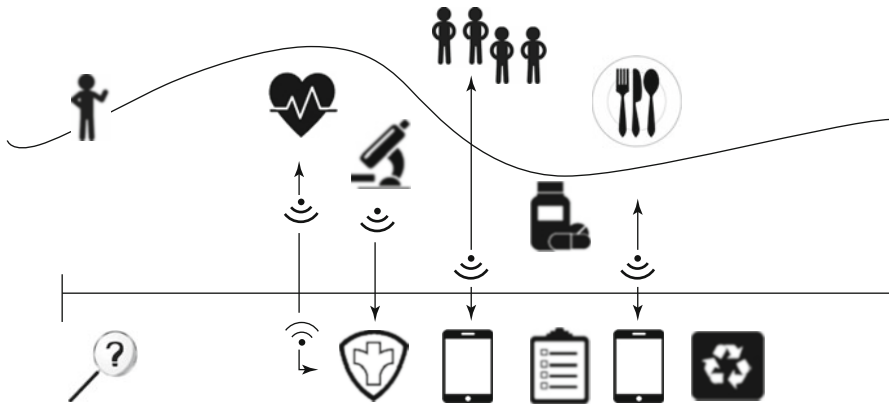
The result of these funding challenges is that agency priorities are often shifted to what can be funded, rather than to the actual needs of the population. As an example, the funding of biosurveillance initiatives at the local level has been questioned, and part of the debate includes both the direct and indirect effects of such initiatives. On one hand, there are clear benefits, such as the introduction of new and innovative ways to conduct public health surveillance. Indirectly, such initiatives provide opportunities to modernize the equipment of the organizations, as well as create jobs which can provide overall support for the local health department. On the other hand, local public health departments can have more pressingly urgent needs, such as connecting established information systems, removing legacy software, or re-architecting their overall operations.

## **Alignment of Informatics to Programmatic Activities**

Local public health departments are made up of a diverse set of disciplines, including clinical practice, epidemiology, environmental health, and administration, each needing informatics support. Demands on well-trained professionals are ever increasing, due to the rising number of initiatives focused on compliance with standards, processes, and policy defined by local, state, and national authorities. The alignment of informatics to programmatic activities has never been more critical to capitalize on these opportunities for change. However, given the constraints outlined above, it is often not immediately achieved. This section assesses the necessary components to ensure the proper and timely alignment of informatics to programmatic activities.

### ***Architecture***

Establishing architectures that are driven by informatics principles does not simply create value for a project or program, but facilitates the realization of both global and strategic visions. Using such principles results in an architectural blueprint, which tends to be organic and evolutionary, merging best practices developed throughout encounters across interdisciplinary sciences. For example, our ideal informatician is immersed into a public health surveillance scenario as illustrated in



**Fig. 26.2** A public health surveillance scenario - opportunities for informatics

the following figure, in which they must determine the necessary processes and mechanisms to carry out communication, intervention, and dissemination of information amongst public health partners.

In the public health surveillance scenario illustrated in Fig. 26.2, the sequence of events is as follows, from left to right:

- the patient enters feeling ill and seeks out medical attention;
- the health care professional orders laboratory tests, which are evaluated and communicated to the local public health agency through electronic means;
- local public health begins an investigation and determines a linkage through condition-specific risk factors of several cases, and confirms this through assessment and conversion to morbidity during field investigations;
- the disease surveillance record is updated real-time to reflect the findings, which are based upon electronic knowledge;
- the local public health department's environment health unit is alerted and conducts an investigation of a dining establishment, communicating back to the surveillance staff through an integrated system with detailed information about the potential causative agent;
- environmental health in turn remediates the issue, and the disease investigator completes and closes out the investigation.

With certain approaches (principles), the informatician expects that the most important key to success is to secure understanding and approval from the different stakeholders. In the scenario above, it is essential that the informatician collaborate closely with clinical infection preventionists, disease investigation staff, and epidemiologists to understand the workflow processes and information touch points. This is the human component necessary in defining the problem space. For this task, it is up to the organization to secure early buy-in from key stakeholders. Subsequently, this needs to be tied in to appropriate policy agreements that will replicate the trust partnerships. Finally, and as a last step, the appropriate technology will be chosen

and implemented to reflect what is suggested by the agreements and findings. As challenges arise throughout this process, it is less costly to navigate changes and make corrections since (a) agreements have been predefined and common end goals have been pre-established, and more importantly, (b) there is trust between the partners, which makes the discussion of differences amicable and less confrontational, leading to an expeditious resolution.

### ***Information Technology and Informatics***

It is the responsibility of an informatician to be well-versed in the different technologies necessary to support all the operations of the organization. This in itself is a challenge, given the variety of aspects that have to be handled. A more or less comprehensive list of relevant technologies would include programming languages, databases, GIS, networking, Big Data, mobile platforms, and in the case of public health-specific technologies, these also would include surveillance systems, electronic health records, health information exchanges, data exchange standards and vocabulary services, knowledge management, security services, statistical data management, and visualization and reporting applications. Data generated, manipulated, and stored using all these systems needs to be normalized, standardized and integrated, allowing its use for public health purposes. However, these challenges are no different than are found at every other level of public health or throughout industry. Recent developments in remotely-hosted hardware and software (e.g., cloud-based computing, and software as a service) have made it easier for local health departments to gain access to technology that was previously only affordable for much larger organizations, and allow for the offloading of many day-to-day operational and management challenges to outside entities in a cost-effective manner.

### **Leveraging the Community**

While public health informatics is a fledgling community, there is an increasing amount of interest in various informatics topics within the field. A number of national organizations have developed informatics working groups for their areas of particular interest. For example, the Council of State and Territorial Epidemiologists [3] and the National Association of City and County Health Officials [4] both have active informatics working groups in their organizational area of epidemiology, and hold dedicated informatics sessions at their national conferences. The Association of Public Health Laboratories [5] has working groups focusing on laboratory messaging and laboratory information management systems. These groups function not just as a way to share information and lessons learned, but as a means to participate in driving national public health informatics policy. The groups actively encourage participation from professionals at all levels of public health, and allow local professionals to participate on equal footing with health departments of all sizes and types.

Informatics working groups are not often found at the state or local level, but existing national or statewide workgroups often cover these activities. For example, a statewide environmental health group, while not focused on informatics, will often cover domain-specific informatics activities as part of the larger goals of the group. Another avenue for discussion of informatics issues is through user groups created around a particular software system, such as a group of users of a state's vital records system or immunization registry. These groups may include the decision makers related to technology throughout the state, and provide an avenue to affect state and local policies. And of course, if these groups do not exist, it is always possible to create them.

### **Case Study: Southern Nevada Health District (SNHD)**

This section focuses on the planning and execution of works conducted from 2009 to 2012 at the Southern Nevada Health District (SNHD), a county health department located in Las Vegas, Nevada. Two of the initiatives described align common informatics needs and solutions across regional boundaries through the implementation of an Open Source framework for disease surveillance and electronic messaging. Both were done in collaboration with the Utah Department of Health (UDOH) and the Kansas Department of Health and the Environment (KDHE).

#### ***Executive Planning***

In late 2009, the Southern Nevada Health District successfully recruited an informatics scientist to guide the health department in the creation of an enterprise informatics vision. This recruitment was in response to a rising concern that the outdated processes and legacy supporting systems were no longer meeting the programmatic needs and were unable to fulfill the enterprise mission, and that the resultant inefficiencies were affecting community-focused programs.

Subsequently, executive leadership chartered the formation of an integrated informatics team, led by the public health informatics scientist and a senior epidemiologist, and including two disease investigators, an IT architect, network architect, and a database administrator. The team was given direct authority to do what was needed, and to leverage resources from around the agency in obtaining its objective: develop a state of the art, sustainable public health infrastructure.

#### ***Identifying the Business Need***

The complexities introduced by the *ad hoc* nature in which many public health agencies have evolved resulted in a fractionated environment in southern Nevada,

which included silo-ed programs, processes, systems, and supporting infrastructure cobbled together out of need, and often not evolving along with practice and the surrounding environment. In assessing SNHDs needs within this complex and evolutionary space, a System of Systems Engineering (SoSE) approach (an evaluation of multiple, complex systems, coexisting within the enterprise) was utilized in order to better understand the Health District holistically, as an ecosystem instead of as individual programs existing in isolation. The informatics team applied a modified SoSE method in order to (a) understand the problem, (b) design the assessment, (c) perform an analysis, and (d) operationalize the findings.

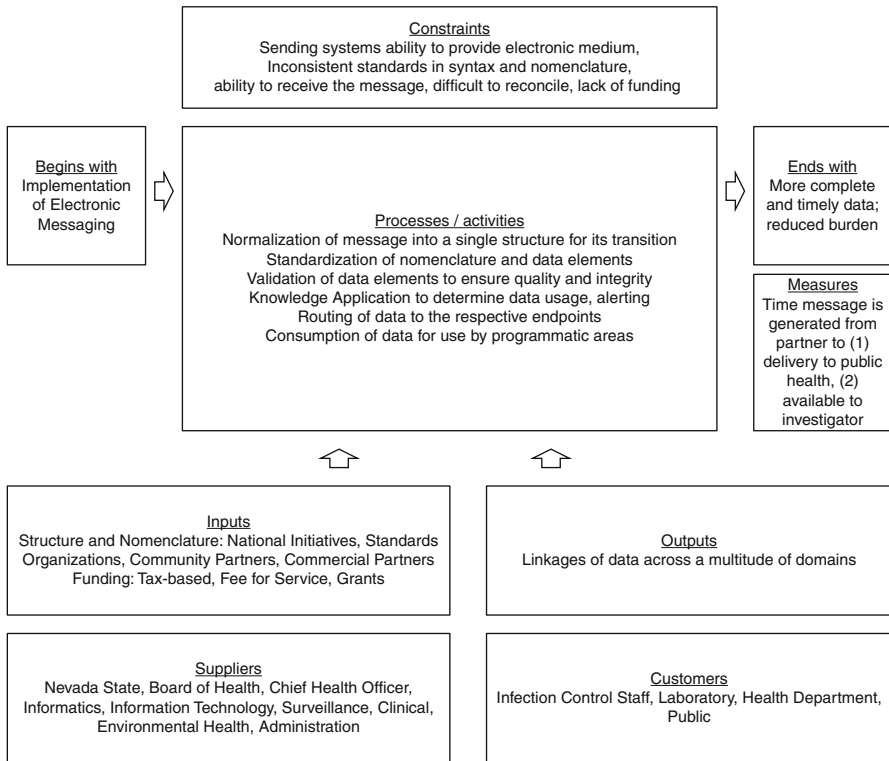
Initially, the team focused on understanding the problem space within SNHD, and reached out to the program areas for help in understanding the basic premises of programmatic processes, the interrelatedness of the programs and their respective partners, and the impact on the community. The information was compiled utilizing a SIPOC (Supplier, Input, Process, Output, Customer) diagram in order to communicate the information gathered to a varying audience in a clear and concise manner. One example of the usage of this method was in defining the problem space for electronic messaging between partner agencies and program areas within SNHD, as illustrated in Fig. 26.3.

The SIPOC diagrams [6] provided SNHD with a basic overview of need from which to begin formulating plans, setting priorities, and defining scope through a high-level functional description. This was accomplished through the alignment of technical requirements and the definition of the underlying process and data flows, which mapped the core business activities and movement of data based upon the current state (as-is). Also included was the future state (to-be) and respective high level use-cases to better understand characteristics of operational need, how they fit into the overall operational environment, and whether or not the needs were in scope and in fact feasible or subject to external constraints. The resulting planning document ensured that the objective (perspective), position, capabilities, benefits, and feasibility were communicated in a standardized format, and in a common language.

### ***Gathering Requirements***

Through 2007–2008, epidemiologists in Nevada collaborated to define the attributes of an ideal disease surveillance and investigation system. This document was used as the basis for a matrix to evaluate the functional attributes of each system facet, and was expanded to include electronic messaging and program areas and cost considerations not previously included. This requirements-gathering process took place over several months, and included input from system users and the informatics team.

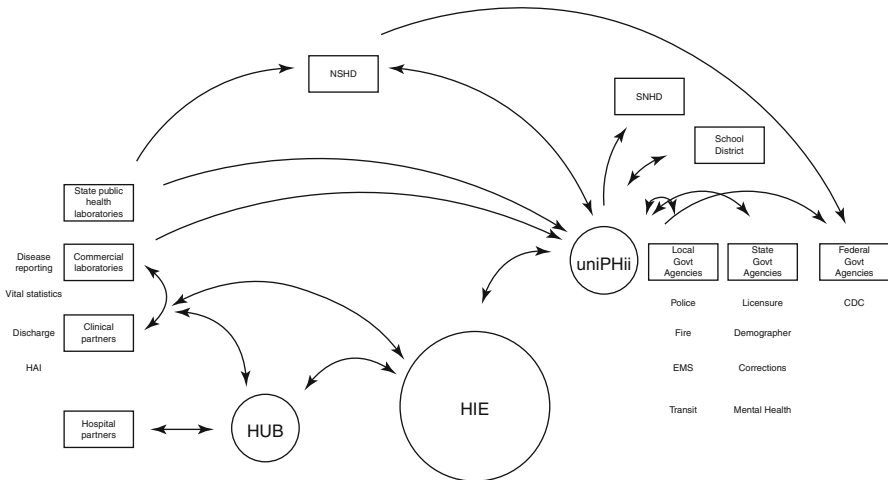
From this process, a major gap was identified in the area of electronic message processing. While available systems were able to receive and import electronic laboratory results, no existing systems were able to normalize, standardize, validate, apply knowledge to, and route electronic messages. Electronic messaging (EM) is



**Fig. 26.3** Supplier, input, process, output, customer (SIPOC) diagram used to convey the basic processes necessary for electronic messaging from external partners to SNHD and program areas

the generalized term for the electronic exchange of data. The limited use case defined by SNHD was uni-directional and used a highly constrained message for exchange of laboratory information. EM became the basis on which requirements gathering was performed, as it considers the broader scope of information flow, directionality, constraints, and inherently incorporates mechanisms to handle a variety of syntax, nomenclature, and knowledge. This resulted in a framework to enhance the overall communication of information between providers and public health; leveraging a bi-directional construct to facilitate the request for supplemental data from the originating provider, and implementation of a public health case report in hopes of receiving critical contextual data along with the limited laboratory message(illustrated by the EM data flow in Figs. 26.4 and 26.5).The objective was to reduce the overall burden in communication wait states between public health and clinical partners.

Figure 26.4 illustrates an expanded Electronic Messaging (EM) data flow between local public health partners, as defined within the 2009 evaluation. This data flow diagram (DFD) represents the proposed SNHD solution, as an information hub serving a larger need of the community, interfacing across agencies and disciplines to paint a more accurate picture of the community status. The process



**Fig. 26.4** Expanded electronic messaging (EM) data flow

flow diagram (PFD) in Fig. 26.5 is demonstrative of both the necessary manual mechanisms for reporting and the needs for an integrated electronic system supporting several partner agencies.

### *Defining the System*

Defining the architecture of the different technical solutions was not only guided by the requirements-gathering process, but also by external factors such as budgetary constraints, organizational policies, and short- and long-term personnel capacity. The architecture also reflected part of the organizational culture, with the goal of leveraging the implementation of the system for one program to multiple surveillance activities, and eventually to the enterprise level.

Ultimately, the movement towards an Open Source framework to support EM and disease surveillance activities was selected, as it best met the requirements set forth by users and the informatics team. This framework provided flexibility for future development and enhancement, matched well with the existing technology capacity, and provided a long-term sustainable solution given budgetary constraints. As a result, (a) a modular universal messaging bus (uniPHii) was developed internally, integrating Open Source components to support the step-wise message life-cycle (an example of which can be seen in Fig. 26.6), and (b) an existing Open Source disease surveillance system was chosen over alternative solutions.

The iterative development of the cloud-based Platform as a Service (PaaS) messaging architecture will provide the ability for a data partner(s), either internal or external to SNHD, to subscribe to the service and act as a provider and/or consumer with the public health authority. As a subscriber, the partner has the ability to see the

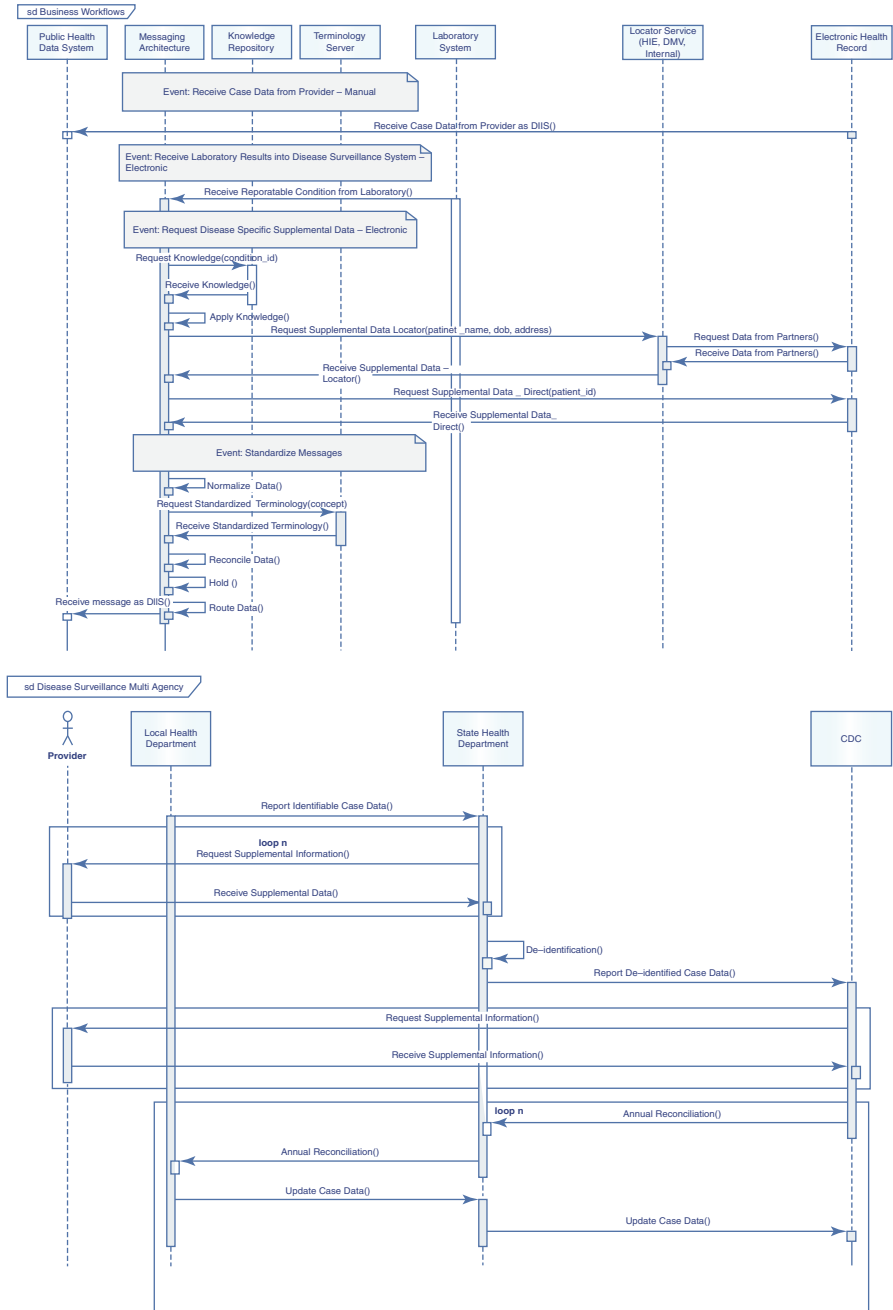


Fig. 26.5 Expanded electronic messaging (EM) laboratory reporting process flow as defined in the 2009 evaluation



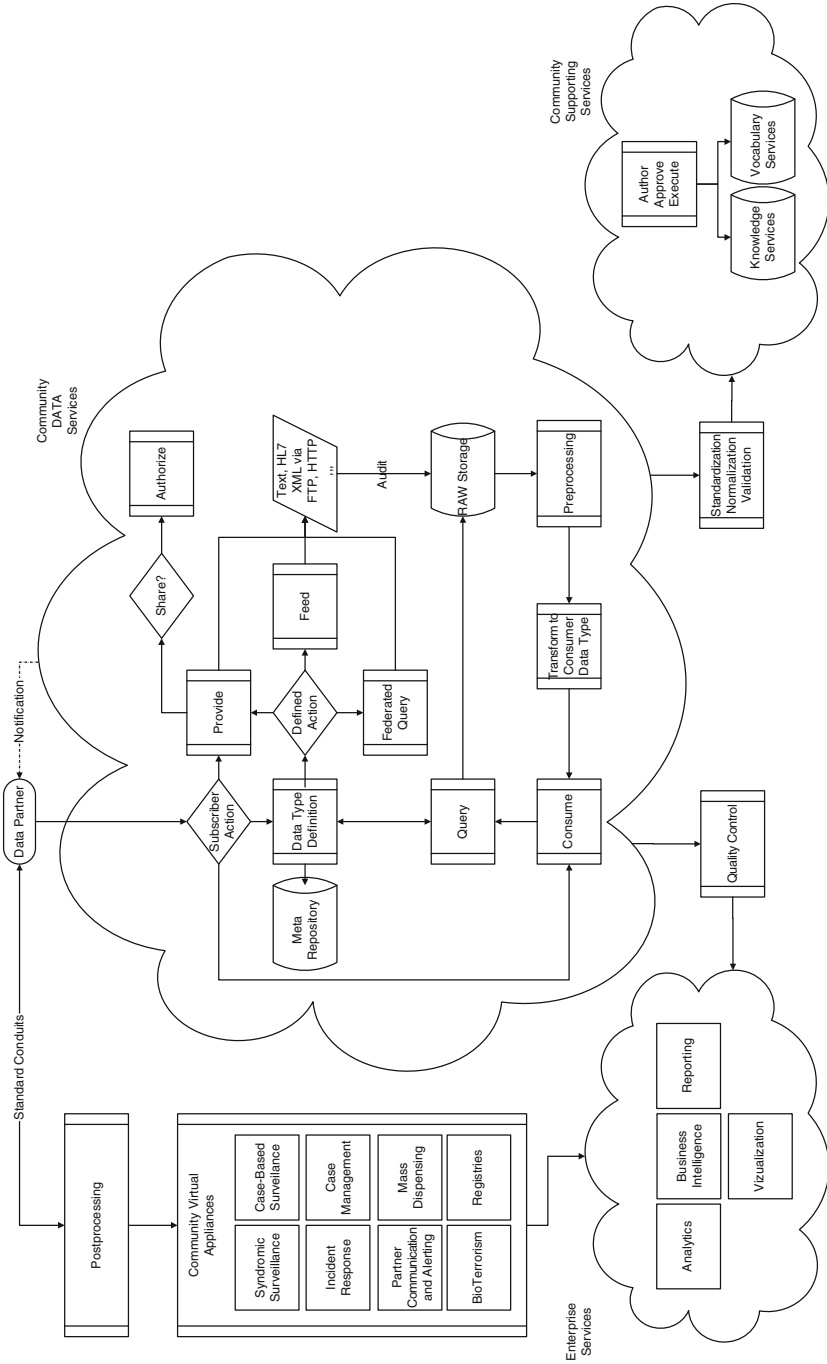


Fig. 26.6 Community centric electronic messaging (EM) process flow (message agnostic)

information catalog, assess their need, and establish a dialogue in which to do business by accepting the terms and conditions of the subscription. As a provider, the partner may configure a data source(s) meta information, which defines the data source characteristics, including the data exchange type which may be represented as a one-time upload, an ongoing data feed (push), or query (pull), and the data dictionary and transmission template which defines how to operationalize the interaction (transport protocol, structure, data lifecycle, etc.). As a consumer, the partner may select a data source(s), send a request for access, and once approved, setup their environment to receive the data based upon the providers meta information, including the data dictionary and transmission template.

### ***Implementation***

The development and implementation of these integrated systems were conducted over a 6-month period and resulted in a significant shift in burden from time intensive management processes to a seamless, secure, simultaneous flow of data through multiple systems in real-time, between and throughout SNHD's public health partners. The enhanced data these systems provided allowed programs to direct efforts towards populations with the greatest needs and problems. Working within the integrated system enforced the standardized collection of data and documentation of public health activities, which in turn facilitated cross-program interoperability, but the success of this implementation did not come without its challenges.

The greatest challenges in implementing this inclusive architecture were not technical, but were user-based, which was expected and typical. The implementation was used as an opportunity to improve existing processes. This caused a cultural rift, as it introduced a change in the way end users conducted their long established activities. In addition, not all user requirements could be met, disappointing some users who had seen their involvement in the requirements gathering process as an opportunity to design their ideal system. Finally, program administrators unfamiliar with the development process put strong external pressure on the informatics team to implement the system within a compressed timeframe, setting unrealistic expectations throughout the organization. Challenges such as these lead to stronger emphasis on the management of user expectations, communications, and an embedded evaluation process, to ensure needs were being met and users were included throughout the informatics project lifecycles.

### **Conclusion**

Local health departments are data-rich environments, often lacking the vision, funding, and expertise needed to handle such data. As a result, informatics at the local level often encounters a number of isolated systems built with no thought to the

overarching enterprise. While the specific challenges facing each local health department are unique, common informatics approaches can help LHDs meet these challenges. Local health departments need to incorporate informatics personnel in key positions, understand internal workflows, and empower decision makers to restructure the way things operate. These changes need to be paired up with equivalent changes in technology that reflect the new direction towards an organizational vision.

It is up to local public health departments to identify the ways in which such change will be driven. Ideally, change will be informed not only by specific budgets or political decisions but by good informatics principles and practices. As it has been the experience demonstrated herein, this path is not only feasible but much more effective and efficient.

### Review Questions

1. What set of skills is needed for an informatician to be successful at the local level of public health?
2. What are the main challenges facing local public health informatics specialists?
3. How are local health departments funded, and what limitations does this place on informatics?
4. How can local public health informaticians become a part of the larger public health discussion?
5. Discuss two of the best practices that were applied at the Southern Nevada Health District to overcome the informatics challenges it faced.

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# Chapter 27

## Public Health Informatics in High Population States: New York and Ohio

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**Abstract** Public health agencies and practitioners are transforming from a “shoe leather” to an “informatics-savvy” based practice of public health where, increasingly, data and technology are used to answer the key questions necessary to improve the health of the population. Recent advances in healthcare information technology (IT), health data standards, electronic health records (EHRs) and

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health information exchange (HIE) implementations are accelerating the growth and future potential of public health informatics. It is critical for public health officials, programs, their longstanding partners, and new public-private partnerships to drive cross-programmatic data and system coordination, integration, and new development efforts; only with this leadership and collaboration will they be able to realize improvements in surveillance, prevention, response, and control activities and in the overall health and safety of the population and communities. It is also critical for public health informaticians to understand public health problems, as well as analytical solutions and the infrastructure necessary to support them.

There have been significant accomplishments within many state public health departments, such as the establishment of public-private partnerships and governance. However, many challenges remain, including managing and integrating large amounts of legacy public health and newly available electronic health data, meeting HIT interoperability standards, learning and adopting industry IT standards, and working with limited financial and staff resources. To address these challenges and achieve the goals of PHI, public health needs to develop an informatics competency and create an achievable roadmap, supported by performance measures.

**Keywords** Health information technology • Health information exchange • Electronic health record • Regional Extension Center • Electronic laboratory reporting • Health Level Seven • Strategic planning • Data integration • Governance • Program requirements • Project management • Informatics inventory

### **Learning Objectives**

1. Understand the importance and priorities of state-level public health informatics.
2. Appreciate the critical interactions between medical and public health informatics.
3. Compare and contrast the public health informatics perspectives of two large state health departments.
4. Describe a public health informatics challenge that a high population state would encounter, and discuss some possible strategies to address it.
5. Compare and contrast two large state health department real life solutions to a common public health informatics challenge.

## **Overview**

Public health agencies and practitioners are transforming from a “shoe leather” to an “informatics-savvy” based practice of public health where, increasingly, data and technology are used to answer the key questions necessary to improve

the health of the population. Recent advances in healthcare information technology (IT), health data standards, electronic health records (EHRs) and health information exchange (HIE) implementations are accelerating the growth and future potential of public health informatics. It is critical for public health officials, programs, their longstanding partners, and new public-private partnerships to drive cross-programmatic data and system coordination, integration, and new development efforts; only with this leadership and collaboration will they be able to realize improvements in surveillance, prevention, response, and control activities and in the overall health and safety of the population and communities. It is also critical for public health informaticians to understand public health problems, as well as analytical solutions and the infrastructure necessary to support them.

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## **New York State Public Health Informatics**

New York State (NYS) is home to more than 19.4 million people, 8.2 million of whom live in New York City (NYC). While urban areas may be both ethnically and economically diverse, residents of other areas of NYS are predominantly white, rural, and low to middle income [1]. The population is served by 57 local health departments (LHDs) and the New York City Department of Health and Mental Hygiene (NYCDOHMH). Outside of NYC, the number of persons residing within each public health agency's jurisdiction varies widely, ranging from approximately 5,000–1.5 million [1].

The mission of New York State Department of Health (NYSDOH) is to protect, improve, and promote the health, productivity, and well-being of all New Yorkers. The vision is that New Yorkers will be the healthiest people in the world - living in communities that promote health, are protected from health threats, and having access to quality, evidence-based, cost-effective health services. NYSDOH values are dedication to the public good, innovation, excellence, integrity, teamwork, and efficiency. Guided by NYSDOH's mission, vision, and values, the Office of Public Health (OPH) and the Office of Health Information Technology Transformation (OHITT) are leading public health informatics activities.

OPH strengthens coordination among the Department's public health programs and ensures public health input into all the Department's programs. Key objectives include:

- Keeping New York active as an innovator in the emerging areas on the cutting edge of public health practice including genomics and informatics;
- Coordinating public health activities with the Centers for Disease Control and Prevention, other federal agencies, other state health departments, and LHDs in New York;
- Convening partners in the community, academia and the health care system to further public health goals; and
- Rebuilding and strengthening the state and local public health infrastructure.

The OPH Public Health Informatics and Project Management Office (PHIPMO) oversees multi-disciplinary informatics activities that require public health practice, data management/analysis, and technology expertise. Grounded in public health practice, project management, and business analysis experience and knowledge, PHIPMO works to ensure appropriate program engagement; ensure that data collection, management, integration, and use needs are met; and that the necessary underlying technology support is available to achieve public health strategic goals and objectives.

OHITT is charged with coordinating health IT programs and policies across the public and private health-care sectors. These programs and policies will establish an interoperable HIT infrastructure and capacity so that health information can be exchanged and used by practitioners', institutions' and government agencies' various information technology systems. This will assure that health information is electronically available at the time and place of care and that information is accessible to and can be used across health care settings to:

- Provide accurate information for medical decisions and advance the delivery of appropriate evidence based medical care;
- Improve health care quality, reduce medical errors, and rein in health care costs;
- Improve care coordination among physician offices and other ambulatory care providers, laboratories, pharmacies, hospitals, community health centers and long term care and home health facilities;
- Support new quality based health care reimbursement models for Medicaid and commercial insurers;
- Support new disease management capabilities;
- Enable sharing of public health surveillance and reporting information between public health agencies, providers and health care institutions;
- Support health IT needs of long term care, home care, and behavioral health as part of the care continuum; and
- Support emergency preparedness and response and other health improvement initiatives.

### ***State Perspective on Public Health Informatics***

Public Health Informatics (PHI) in NYS is considered a component of public health science and practice. The main goal is to improve the health of the

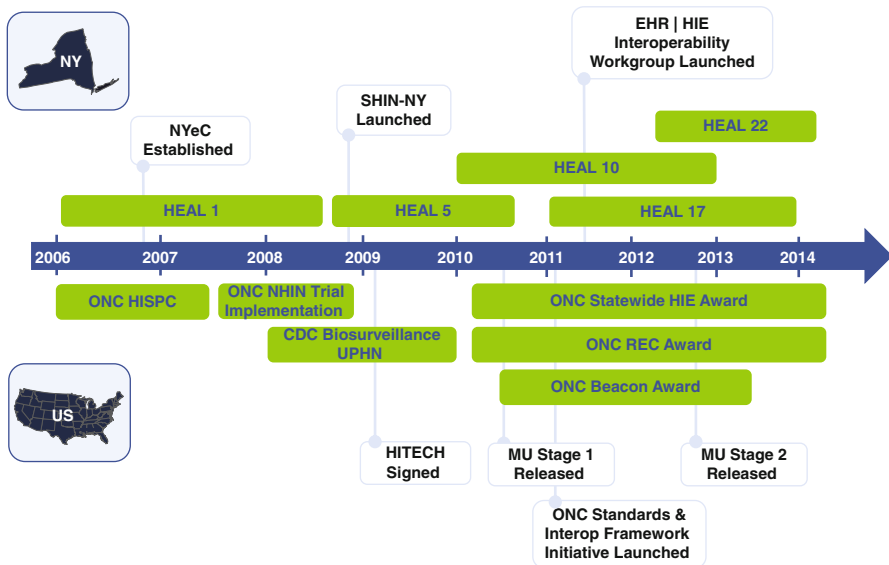
population by using data and technology to answer key questions. It is critical that public health informaticians understand public health problems, as well as analytical solutions and the infrastructure necessary to support them. PHI methods need to encompass complex public health assumptions that can complicate programming and data modeling or place limitations on conclusions that can be made, such as estimating community prevalence or incidence of disease using a convenience data sample made available through provider participation in an EHR incentive program. Through its longstanding promotion of public health informatics as a discipline and development of general workforce capabilities, NYSDOH continues the transformation from a “shoe leather” to an “informatics-savvy” based practice of public health.

At the core of NYSDOH PHI are two key objectives. The first is to promote data and information sharing by identifying opportunities and addressing barriers across the spectrum of national, state, and local public health, healthcare, and other partners. The second objective is to create a technical and data management infrastructure to accelerate achievement of public health goals. Health-driven data and interoperable technology standards are critical to these efforts. For more than a decade, NYSDOH has been actively developing and implementing standards-based electronic data exchange for more effective and efficient data collection, analysis, interpretation, and use in state, local, and New York City public health programs.

NYSDOH maintains numerous information systems that provide baselines to monitor timely, accurate information about the health of the population, including outbreak identification and emergency response at the state, regional and local levels. These public health systems are tightly integrated within the NYS Health Commerce System, which is a statewide, web-based infrastructure that provides services and support for 24×7, reliable and secure data reporting and communication, and is utilized by public health partners, LHDs, NYCDOHMH, hospitals, nursing homes, clinical and environmental labs, pharmacies, and providers.

This section will provide examples of the development of several important public health data systems at the NYSDOH and the informatics lessons learned in the process. The emphasis has been, and continues to be, on the transformation of the healthcare continuum, including the individual patient, healthcare delivery system, and public health, made possible by advances in informatics. Critical systems and a key initiative in this transformation include the Statewide Health Information Network for New York (SHIN-NY), the Electronic Clinical Laboratory Reporting System (ECLRS) [2], and the child health data integration (CHI<sup>2</sup>) project. SHIN-NY is the ‘pipeline’ for clinical and public health data exchange and ECLRS [3] is a mission-critical system that reports laboratory results indicative of legally-mandated reportable diseases to the health department. CHI<sup>2</sup> seeks to link all child health data across program-specific silos and make it available to providers and to public health programs to improve outcomes for individual children, as well as to inform population-based public health programs. Together, they and other core public health systems provide a uniform means of communicating health-related information by standard protocols, and of carrying out public health surveillance and





**Fig. 27.1** New York Investments in Health Information Technology

sharing public health data. They will also provide decision support to internal and external public health officials and practitioners, healthcare facilities, individual healthcare providers, clinical laboratories, and other public health partners. These initiatives are described below in greater detail.

### Statewide Health Information Network of New York (SHIN-NY)

Since 2006, NYS has made significant investments in technology, operational capacity, and collaborative governance structures and processes, establishing a Statewide Health Information Network for New York (SHIN-NY) [4] to improve the quality, safety, efficiency, and affordability of health care and public health services (Fig. 27.1). NYS investments include the Healthcare Efficiency and Affordability Law for New Yorkers Capital Grant Program in 2004, often referred to as HEAL health information technology (HIT) projects, and the public-private partnership with the New York eHealth Collaborative (NYeC), a non-profit organization working to improve healthcare for all New Yorkers through HIT. Federal investments include security and privacy, the Nationwide Health Information Network, statewide HIE, Universal Public Health Node (UPHN), and EHR adoption (Meaningful Use) initiatives. In addition to ensuring that the right information is available to the right person at the right time in the clinical setting, interoperable HIT services and common HIE policies create standardized health information that can be aggregated, linked, and analyzed to enhance public health surveillance and dramatically accelerate population health improvement.

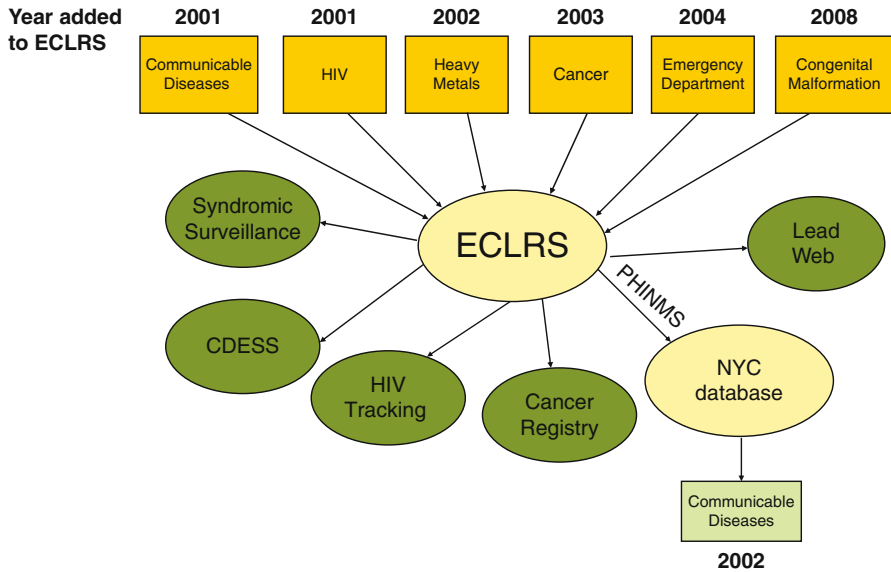
Improved electronic health data, together with communication with providers' EHRs through the statewide health information network, will greatly increase the capacity of state, regional, and LHDs to improve the health of their communities, while taking advantage of and adding value to the infrastructure investment already made. Data on health care utilization patterns can better inform health systems planning and also provide the ability to conduct data-driven program and policy evaluations. Access to clinical data also will enhance the effectiveness and efficiency of public health surveillance and case investigation capabilities. This data can augment community health assessments, allowing for more effectively targeted quality improvement interventions.

Integrated into the SHIN-NY is the UPHN. Developed with CDC funding, UPHN is a NYSDOH strategic initiative to streamline the way providers interact with multiple public health information systems, decrease reporting burdens, promote bidirectional information exchange, and advance public health priorities. This combination of HIT and public health informatics, including data standards, an interoperable infrastructure, analytic tools, and decision support, is critical to the enterprise and is being driven by a unique public-private partnership, which is also establishing necessary policy for the state's health departments and health care providers.

### **Electronic Clinical Laboratory Reporting System (ECLRS)**

Clinical laboratory test results indicative of diseases of public health interest are critically important to public health surveillance and response. In 2001, ECLRS was launched statewide. It provides a single, secure point for all clinical laboratories to meet public health reporting requirements. As of 2008, laboratories are legally required to report evidence of a reportable disease or health condition electronically to NYSDOH through ECLRS [3]. This system provides rapid transmission of laboratory test results for reportable conditions, including general communicable, vaccine preventable, and sexually-transmitted diseases, and tuberculosis, HIV, cancer, lead, and congenital malformations to NYSDOH and local and city health departments. To date, over 70 million records for 140 diseases have been captured. As of 2012, 549 laboratories were certified to report test results via ECLRS. Laboratories are able to report to ECLRS through electronic file transfer (HL7<sup>®</sup>HL7<sup>®</sup> or ASCII formats) or web data entry. With continued expansion of electronic laboratory reporting, a growing number of laboratory test results are being received for patients who reside outside of NYS. NYSDOH has successfully partnered with New Jersey, Ohio, and Florida to electronically disseminate these results from one electronic laboratory reporting system to another using HL7<sup>®</sup>.

ECLRS is also an enterprise-wide information system that transforms incoming data by parsing it from electronic files, grouping laboratory results by disease, and running automated data extracts that are then made available to multiple public health programs. Additionally, ECLRS is integrated with the statewide Communicable Disease Electronic Surveillance System (CDESS) and other surveillance systems (Fig. 27.2), enabling the initiation of case reports directly from communicable disease laboratory reports and triggering public health case investigations conducted



**Fig. 27.2** ECLRS Integration with Public Health Surveillance Systems

by LHDs for the identification, treatment, and prevention of disease. ECLRS data is made available to CDESS through an interface where users can automatically populate case reports with laboratory data. Pre-populated follow-up “Dear Doctor” letters can be generated through either ECLRS or CDESS.

The informatics principles of establishing and utilizing data standards are critical to successful data system development. Since ECLRS is able to receive and use standardized LOINC<sup>®</sup> and SNOMED<sup>®</sup> vocabulary and HL7<sup>®</sup> messaging, both version 2.3 and 2.5.1, NYSDOH is able to participate in the Centers for Medicare and Medicaid Services (CMS) electronic health record (EHR) incentive, and help to advance the use of EHRs for public health purposes. A total of 239 labs report to ECLRS using HL7<sup>®</sup> message format and 113 labs use the LOINC<sup>®</sup> or SNOMED<sup>®</sup> coding schemes. The UPHN is replacing the longstanding Centers for Disease Control and Prevention (CDC) Public Health Information Network (PHIN) messaging standard (PHIN-MS) [5] in NYS; it is now the transport mechanism used by ECLRS and other public health systems. Unlike PHIN-MS messaging protocol, the UPHN is based on national healthcare information technology standards and is scalable to support the broader needs of public health and their health data contributors (including providers, laboratories, hospitals, pharmacies, etc.).

**Child Health Information Integration (CHI<sup>2</sup>)**

Health departments like the NYSDOH are repositories of a large amount of data on their state residents. In particular, a large amount of data is collected on children, in a variety of data systems; this data would be useful to providers, parents, and public



Fig. 27.3 Child Health Information Integration Portal (CHI<sup>2</sup>)

health programs if it could be aggregated and made readily available for legally authorized uses. The CHI<sup>2</sup> project is building a seamlessly integrated and aggregate, context-relevant view of the health information of New York’s children, to be available to clinicians, other external partners, and public health practitioners. The ability to link child health information across multiple data sources will improve healthcare delivery and outcomes of children in NYS, by enabling the identification and monitoring of different child health-related populations; identification and follow-up of individual children with specific health needs; and identification and assessment of child-related public health needs and issues. To date, child information is linked among immunization, lead, and newborn hearing registries, and a single entry point is provided for users (Fig. 27.3). This also eliminates both redundant reporting for providers and storage of child information by NYSDOH.

**Public Health Informatics Challenges, Strategies, Solutions**

Now more than ever, public health agencies are faced with significant PHI opportunities and challenges. There are incentives for hospitals and individual providers to adopt EHRs, which include new functionality to meet key public health objectives including laboratory result reporting, syndromic surveillance, and reporting to public health registries (immunization and cancer). Historically by necessity, public health architectures were developed independently, often without the capacity to communicate with other public health systems even when capable of communicating with our external partner systems. The resulting siloed data has not been able to be utilized to its fullest potential by either the public health or healthcare

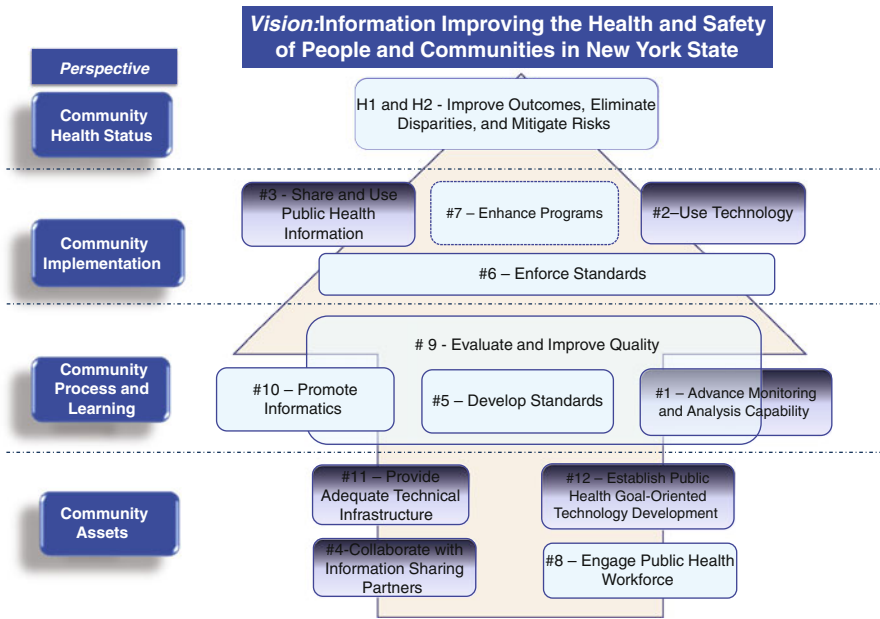
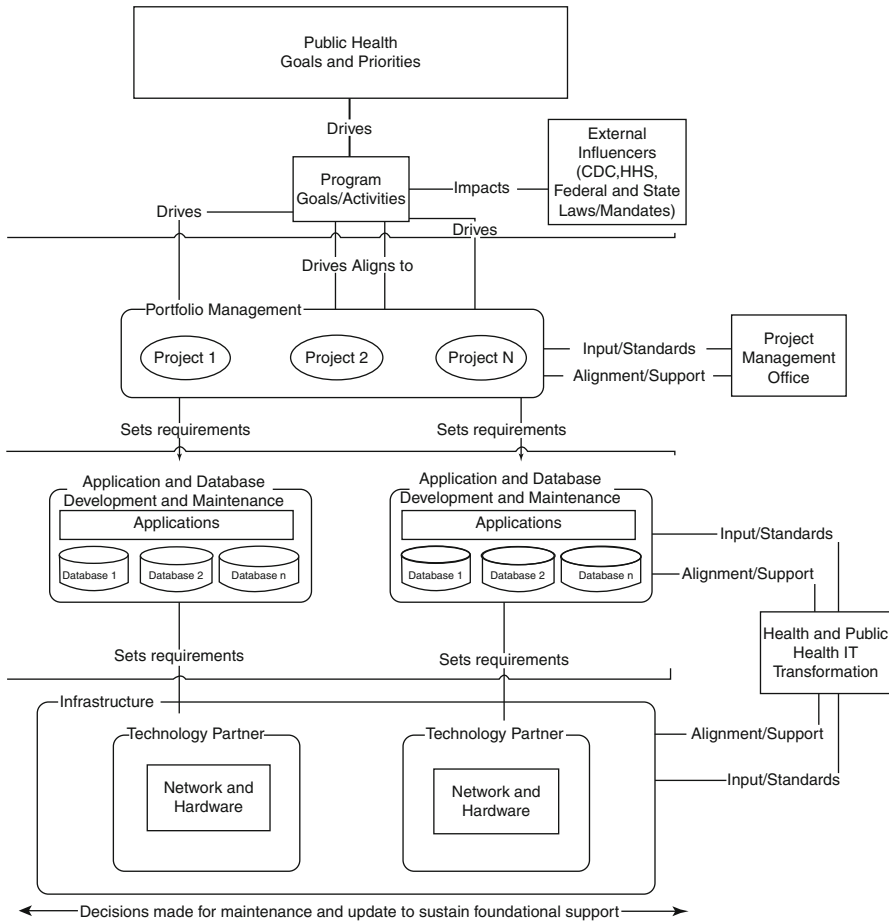


Fig. 27.4 Office of Public Health Information Management Strategy Map

community. With the window of opportunity offered by HIT advancements and the current public health infrastructure and data challenges, it is critical for public health to develop both long-term strategies and immediate solutions in order to continue electronic data exchange with current partners and to expand to new partners.

**Going from As-Is to Desired State**

There is national recognition of the need for cross-programmatic data and system coordination and integration. To accomplish this, public health must develop informatics competency and create an achievable roadmap for the future, supported by performance measures. Within NYSDOH OPH, a cross-organizational and cross-functional workgroup was formed to align public health information and technology goals, objectives, strategies, and resources across the spectrum of public health practice, research, and service delivery. Representatives included Communicable and Chronic Disease, Family Health, HIV/AIDS, Environmental Health, and the Public Health Laboratory. Public health roles included physicians, epidemiologists, program management, policy and planning, IT, and project managers. A community balanced scorecard (CBCS) [6] approach, grounded in the Public Health Accreditation Board (PHAB) standards that address the array of public health functions set forth in the ten Essential Public Health Services and Core Functions [7], was used to guide the development of an information management strategic plan that was aligned with the overall NYSDOH strategic plan (Fig. 27.4).

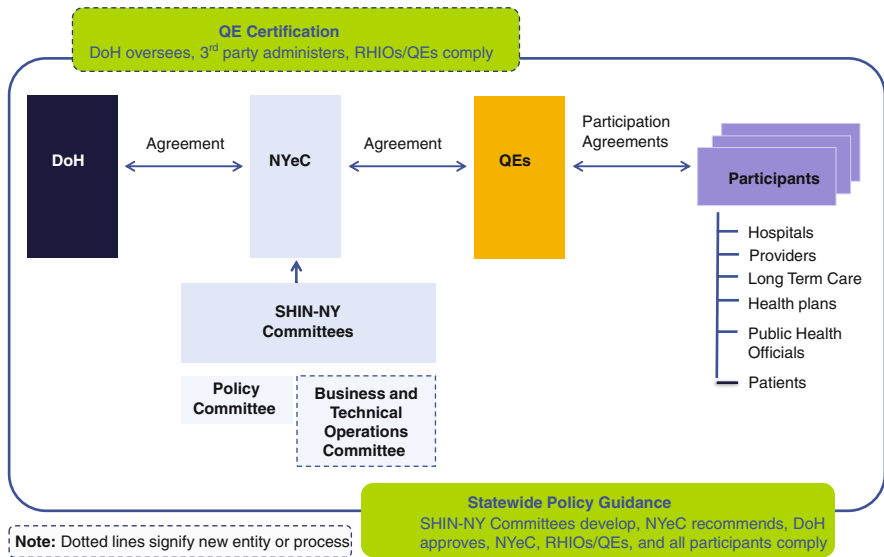


**Fig. 27.5** Office of Public Health Application and Project Drivers and Inventory Components

Conducting and maintaining an informatics inventory is also critical for PHI, management, and executive staff to monitor progress on active projects/applications, guide immediate decision-making and strategic planning, and ensure use of established methodologies and standards for system development. Key application and project inventory components (Fig. 27.5) captured by NYSDOH include public health goals, priorities, and activities supported, as well as ownership, usage, data collection, hardware, software, communication interfaces, continuity needs, disaster recovery plan, and expenditures.

**Establish Effective Governance**

The importance of executive leadership and multi-stakeholder collaboration are critical to ensuring that investments in HIT and PHI translate to a public good that



**Fig. 27.6** Statewide Health Information Network of New York Framework

benefits all healthcare stakeholders – patients, providers, health plans, and public health programs alike. Active engagement of these diverse constituents ensures that policies, technical services, operational capabilities, and system usability drive value and deliver on the promise of improved health outcomes and system performance, and ultimately, better health.

NYSDOH has a strategic public-private partnership with NYeC to drive the development of Statewide Policy Guidance for HIE utilizing an open and transparent process that involves key stakeholders across the state (Fig. 27.6). Guidance includes policies related to privacy and security, technical approaches, and standards. With NYSDOH Executive Leadership, a Public Health Leadership Team with representatives from state, local, and city health departments was established and included in the Statewide Collaborative Process. Key activities include: outlining and prioritizing public health opportunities; setting feasible and sustainable strategic technology priorities in support of program requirements, including leveraging HIT investments; developing a roadmap for public HIT/HIE to be implemented by participating qualified entities including Regional Health Information Organizations, using the statewide health information network and public health infrastructure; and ensuring that public health business requirements inform the development of the technical solutions.

### Technology and Data Barriers to Data Integration and Information Sharing

Establishing an infrastructure, to enable data integration and information sharing to achieve public health strategic goals and objectives, requires a multi-disciplinary approach that includes public health practice, legal, data management/analysis, and

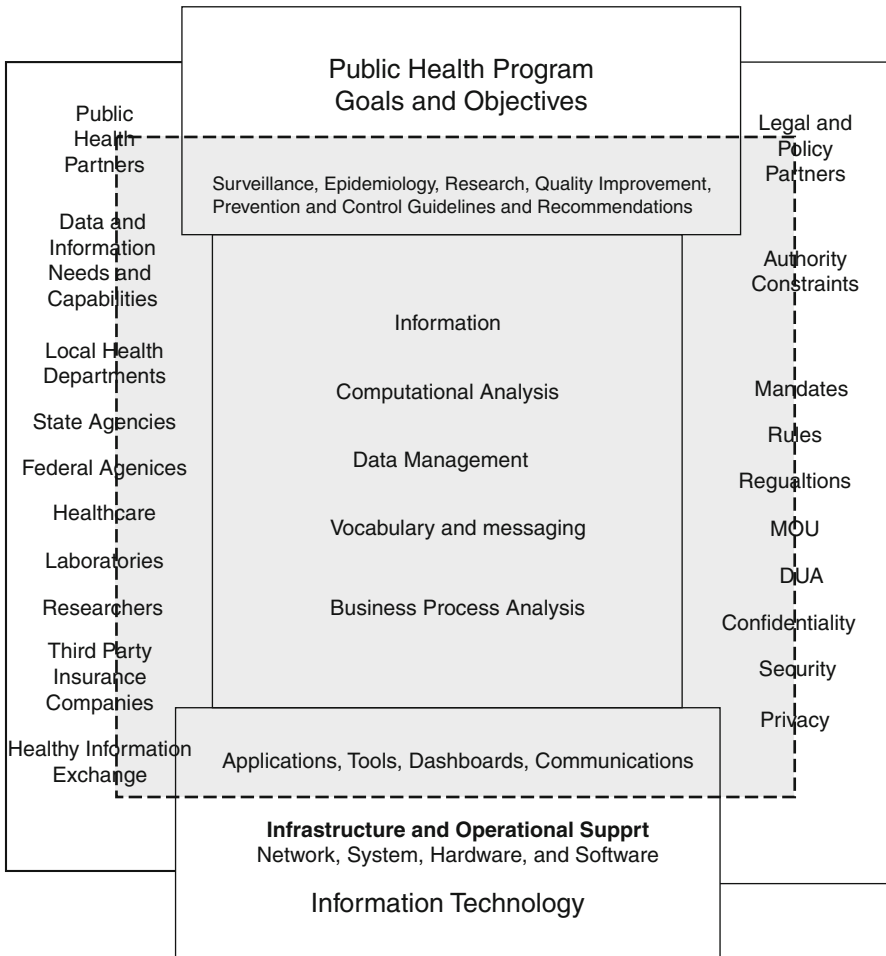


Fig. 27.7 Public Health Informatics: a Multidisciplinary Framework

technology expertise (Fig. 27.7). Public health programs need to work with information technology, data analysts, and other key partners to meet immediate needs and conduct long term strategic planning. This includes updating existing program applications, infrastructure, and data requirements, and/or establishing a new infrastructure able to support statewide surveillance, case management, and service delivery-related data collection, analysis, and exchange; high-throughput scientific computational and statistical data analysis; and response to unpredictable health and safety emergencies and threats.

Through public health data integration (such as the CHI<sup>2</sup> project), NYSDOH is identifying and tackling technical, data, and legal barriers to linking data and information sharing with internal and external partners. Since both HIT infrastructure, such as the SHIN-NY, UPHN, and to-be-integrated data systems, are individually going through technology changes and modifications, executive leadership is



necessary for strategic decision making and risk management. Data analyses, integration algorithms, and their validation are needed and underway to ensure delivery of correct data, in the correct context, across NYSDOH data systems. To overcome legal barriers, a memorandum of understanding (MOU) with internal and external public health partners has been established, while legal and regulatory efforts are being pursued as a longer-term solution.

### **Financial Barriers**

Public health funding is often programmatically driven, with limited and/or categorical funding for PHI related activities. External funding opportunities, such as competitive grants, will typically provide funds for novel research and development of informatics solutions, or for start-up costs for mission critical systems. Agencies may then be faced with limited internal resources or mechanisms for future expansion or ongoing maintenance and support over the life of the system. Since health-care has always been, and will continue to be, a key partner, public health should leverage HIT investments to modernize public health infrastructure and integrate with other health-related infrastructures.

National funding for PHI is beginning to be less categorical in scope, offering an opportunity to establish a more global and sustainable infrastructure. In addition to aggressively pursuing these public health specific funds, NYSDOH Executive Leadership is leveraging funding and infrastructure development of the SHIN-NY and other healthcare reform incentives. Additionally, a NYS Health Care Innovation Plan, of which public health promotion is an integral part, is establishing a comprehensive strategic framework across all domains of health and health care to address the most important health and health care concerns. This Healthcare Innovation plan is built on the foundation of the State's already significant investments in health care transformation, including development of a robust health information infrastructure and supports the State Health Improvement Plan (SHIP) [8], which comprises the state's Prevention Agenda [9]. The SHIP provides a common framework of public health priorities to drive state- and community-level improvement activities.

### **Informatics Capacity Building**

The field of informatics in general, and PHI in particular, is an emerging discipline and tends to be poorly understood outside the practice. By its multidisciplinary nature, PHI requires competencies in public health practice or research, data management, mathematics or computer science, and information technology. Given this, along with rapidly changing technologies and growing project management and business analysis fields, public health agencies may lack informatics expertise or knowledge among public health staff engaged in informatics-related activities. It is essential that public health subject matter experts be actively engaged in

The screenshot shows the website for the Governor's Office of Employee Relations (GOER) in New York State. The header includes the state logo and navigation links. The main content area features a search bar and a list of training topics: CSEA, PEF, SSU, UUP, M/C, SLMS, Statewide Learning and Development, and Resources. The selected course is 'Fundamentals of Project Management', which is 'Classroom Only'. The audience includes project managers, team members, and employees. The description states the course is for developing project management knowledge and skills. Topics listed include differentiating processes and projects, understanding project management terminology, applying the five phases of the project management lifecycle, and distinguishing key roles and responsibilities. The course length is 2 days.

Fig. 27.8 NYS Informatics-Related Training and Tools

informatics-related activities, have training opportunities available, and participate in trainings specific to PHI and those focusing on new technologies, industry standards in information technology development, system development lifecycle, project management, and business process analysis.

In addition to participating in externally-available training, the knowledge gained and training materials obtained are informally shared among staff and formally incorporated into NYSDOH training and operational procedures. Informatics staff have delivered informatics training to staff, participated actively in the NYSDOH Project Management Office Advisory Group, led the development of an agency-wide Requirements Management Process and Toolkit, and assisted with the development of a statewide project management training class available to all state employees (Fig. 27.8).

### *State Experience: Biggest Triumphs and Ongoing Challenges*

NYSDOH has long recognized the importance and ongoing potential of PHI, including a robust technological infrastructure, quality data, and data analysis and interpretation for the purpose of protecting and improving the health safety of NYS residents and their communities. PHI staff are encouraged to be forward-looking, continually seeking to advance the discipline, improve its methods, and ultimately serve public health through the support of activities performed by public health officials, program staff, and their partners.

In addition to the electronic footprint in healthcare data exchange created over the past decade, there have been multiple recent PHI triumphs. Public Health Accreditation Board [7] domains and key PHI objectives were linked to form an information management strategic plan within the health department. This will assist with continuing to keep public health goals and objectives as the primary driver for PHI initiatives. A CHI<sup>2</sup> portal was deployed for healthcare providers and public health practitioners, and includes an integrated platform for multiple child health data systems. Additionally, through NYSDOH Executive Leadership, public health is able to participate in public-private partnerships and leverage funding, infrastructure, activities, and outcomes of healthcare reform, including statewide HIE development and Medicaid redesign.

As PHI goals and objectives expand, the complexity of staff skills, time, and resources necessary to meet those goals and objectives also increases. Although there is significant investment in HIT, there are limited funds directly available to public health. Without active engagement or strategic planning by public health practitioners, PHI efforts and outcomes may not adequately meet the immediate or future needs. With rapid technology development and expanded electronic healthcare data soon to be available, it is necessary to continually prioritize efforts and set realistic goals, timelines, and expectations.

## **Ohio Public Health Informatics**

### ***Introduction to the Ohio Department of Health***

The Ohio Department of Health (ODH) is Ohio's lead public health agency covering an urban, suburban and rural population of 11.5 million people. As the nation's seventh largest state, Ohio is located on the eastern edge of the Midwest and is considered part of the Great Lakes Region. Fifty-one percent of Ohio's population is female. Six percent of Ohio's population is under 6 years of age and almost 20 % are 60 years of age or greater. Nearly 20 % of Ohio's population is comprised of minorities (non-White, non-Hispanic). Ohio's major cities include Columbus, Cleveland, Cincinnati, Toledo, Akron, and Dayton.

The mission of the Ohio Department of Health (ODH) is to "Protect and Improve the Health of All Ohioans by Preventing Disease, Promoting Good Health and Assuring Access to Quality Care." The ODH public health vision is "Optimal Health for All Ohioans." ODH is a separate, cabinet-level agency with over 1,000 staff focusing exclusively on public health. The director reports to the governor and serves as a member of the Executive Branch of Ohio's state government. Public health informatics activities are housed in several ODH program areas within the Division of Prevention and Health Promotion (DPHP) and the Office of Management Information Systems (OMIS). This illustrates the recognition that informatics can provide benefits to improve the health outcomes of Ohio residents.

Local public health in Ohio is comprised of 125 city or county health departments that are independent entities (i.e., not part of state government). The vast majority of direct public health services are performed by these local departments. ODH provides federal and state funds for many of these services, along with programmatic oversight, but most local agencies obtain additional funds from local levies, foundations, businesses, and other sources.

### ***State Perspective on Public Health Informatics***

The ODH places emphasis on informatics by incorporating many informatics concepts into statewide initiatives. ODH has a *Health Information Technology (HIT)* Coordinator who directs and coordinates statewide HIT projects related to public health. In addition, at least five full-time employees spend at least 50 % of their time on informatics-related projects. The ODH HIT Coordinator has been closely involved in the planning and development of HIT activities in Ohio, promoting public health involvement in all aspects of *health information exchange (HIE)*, confidentiality and security, health information analyses, and *electronic health record (EHR)* adoption by state agencies and local health departments (LHDs). ODH is sufficiently large to have dedicated informatics staff. Furthermore, ODH has a dedicated information technology (IT) staff of network, systems, and programming staff within OMIS, unlike many other states where IT staff are centralized at the state government level, often not located in the same building and therefore less available to address state health department IT needs.

The State Health Improvement Plan includes a priority specifically for data exchanges, including those with EHR and HIE systems [10]. This priority is listed as an operational component and covers topics including assessment, workforce development, and adoption or implementation of EHRs and HIEs. The assessment strategy is targeted towards identifying the status of EHR and HIE data exchanges, informing legislators and providers, and assessing public health data needs. Assessing and enhancing current training opportunities, as well as encouraging conference attendance at public health and informatics conferences, are covered in the workforce development strategy to provide additional opportunities for education. Finally, the implementation of EHRs among health care providers, and subsequent linkage to HIEs outlined in the State Health Improvement Plan includes assessment of the state's capability to provide two-way exchange of electronic health data. This strategy will also ensure that the state public health system data needs are addressed through systematic assessments of both state and local system customers and stakeholders. Furthermore, public health-HIE interfaces will provide the foundation for interoperability with other state agencies' health information systems, to provide seamless sharing of health information among Ohio's other governmental and private health care providers. The State Health Improvement Plan will provide guidance to improve health by providing more complete, timely, and higher quality health information. In addition, the state goal is mature HIEs that should reduce

costs and improve the timeliness of health information for both public health and other health care providers, through system automation, standardization, and shared systems and interfaces.

Ohio has committed to public health informatics by extensive collaboration and dedication to interoperability by the HIT Coordinator. State and local public health organizations have partnered to support the adoption of EHR systems, HIE, and the creation and integration of HIT systems.

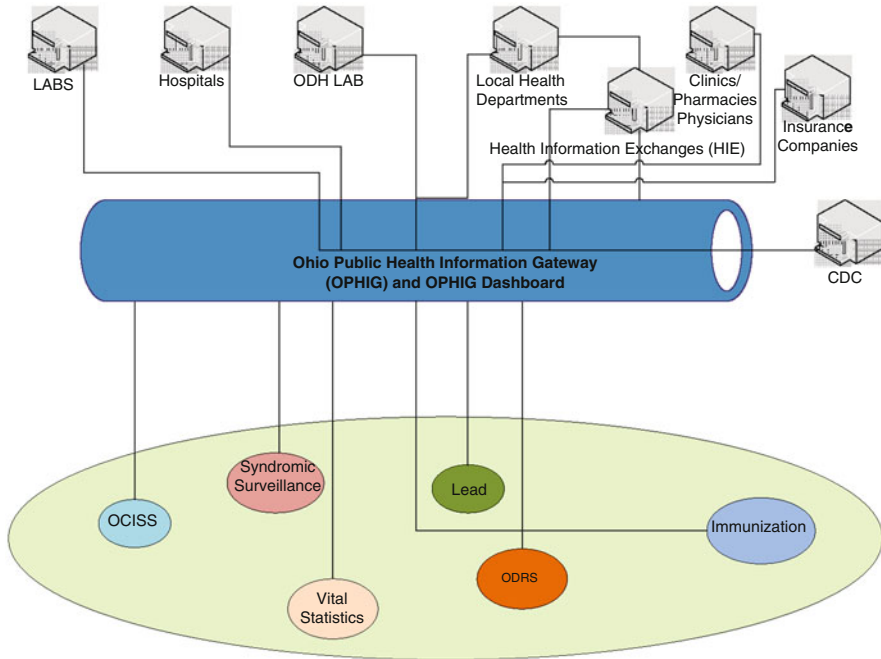
### ***The Ohio Public Health Informatics Committee (TOPHIC)***

One example of this partnership between state and local public health is The Ohio Public Health Informatics Committee (TOPHIC) [11]. TOPHIC consists of ODH as well as LHD employees, along with representatives from academia and key health agencies (e.g., the Ohio Hospital Association). There are two co-chairs of the committee; one from ODH and one from an LHD. The committee is charged with assessing progress towards the EHR, HIE, and data-sharing objectives in the State Health Improvement Plan. Committee co-chairs meet with their respective leadership quarterly, and ODH staff use the committee to discuss new ideas and get feedback from stakeholders on projects currently in development. Regular meetings are held once a month, at an offsite location that provides everyone with a neutral ground. The meeting agenda also includes regular updates of ongoing projects, subcommittee updates, and presentations and discussions of timely topics.

One of TOPHIC's subcommittees is the HIT subcommittee, which holds a monthly conference call and includes members from state and local public health agencies. The HIT subcommittee agenda items usually revolve around EHR activities for LHDs. Those LHDs that are in the process of or have implemented an EHR system provide updates on challenges and on implementation and maintenance successes. Currently about 20 LHDs have signed up with the *Regional Extension Center (REC)*, the federally-funded agency that provides technical assistance both in EHR selection and implementation and in meeting "Meaningful Use." Representatives from these LHDs provide updates for the REC process and guidance. Historically, guests from HIEs, the ONC community college consortium training program, and vendors of EHRs have been invited to the call. TOPHIC also supports a forum called the Ohio Health Data Symposium. This is a new effort with the first meeting convened in 2012; the 2013 topic is Bridging Health Information Exchanges and Public Health.

### ***Ohio Public Health Information Gateway (OPHIG)***

The ODH has made a commitment that all new systems and major system upgrades will utilize shared national and state data and IT standards in order to achieve



**Fig. 27.9** Ohio Public Health Information Gateway (OPHIG)

systems integration. The first step in this direction was implementation of an IT project governance process, to ensure integration and adoption of standards for all new projects (including upgrades). One of the first projects approved was Ohio's link to the HIEs using the shared Ohio Public Health Information Gateway (OPHIG), which allows bi-directional flow of health data. Eventually, this gateway will be the foundation for a single portal system for all health data to flow among private and government health information systems in Ohio.

OPHIG was designed (utilizing a variety of Microsoft technologies, including .NET, SQL Server, and BizTalk) as a multi-tier solution comprised of a web front-end (dashboard), middle-tier processing (message parsing & mapping, business rules engine and message delivery) and a backend database. As the demand for processing public health data continues to grow the system can scale as needed to meet the demand. Currently, the gateway receives *electronic laboratory reporting (ELR)* of reportable infectious diseases and immunization data. Additionally, OPHIG is undergoing development and enhancements to the user dashboard, to address needs such as file- and message-level tracking, fail-point monitoring, and reporting. The OPHIG application was architected to standardize health message processing. Each message is tracked from its point of entry, processed into a standard format, and then delivered to each requesting program in the required format (Fig. 27.9).

ODH is committed to partnering with the two major HIEs in Ohio (HealthBridge and CliniSync) to create ongoing *Health Level Seven (HL7®)*-formatted data

exchange with ODH programs. The partnership will enhance online new-provider enrollment for electronic reporting and provide HL7<sup>®</sup> validation for new health care providers interested in submitting immunization and ELR for infectious diseases to include additional ODH programs. Provider communications for enrollment and file evaluation utilizes a contact management system which logs and tracks correspondence between providers and ODH. Utilizing a single shared system helps reduce redundancy in providing the same information for multiple programs, and reduces the development costs of duplicative communication systems across ODH programs. The development team for this system is working with a number of the other larger ODH programs to facilitate inclusion in the ODH contact management system.

Ohio has been aggressive in application of health informatics to assist partners in achieving the national priority of “Meaningful Use” (MU) [12] of electronic health information. Providers achieving MU furthers public health through accelerated adoption of EHRs and linkage to HIEs in general, as well as providers achieving the specific MU objectives for public health–ELR, immunization and syndromic surveillance reporting.

Ohio’s designated REC, the Ohio Health Information Partnership (OHIP), successfully completed a federal grant in January 2012 to recruit 6,000 primary care providers to adopt and begin implementing EHRs, the highest among RECs in the nation. These providers receive consultation services to adopt EHRs and reach all MU required measures, not just the public health measures. While 512 additional physicians signed up, they are not eligible for grant assistance because they are in larger practices (more than 10 physicians).

Ohio is among the leaders in federal reimbursement by the Centers for Medicare and Medicaid Services (CMS). By the end of October 2012, Ohio had over 8,200 providers in the process of implementing EHRs and who had received enhanced federal reimbursement for MU. Ohio providers have received US\$368,756,196 in payments: 4,721 eligible professionals and hospitals have received US\$209,538,932 in Medicare EHR Incentives for MU Stage 1 attestation [13], and 3,481 eligible professionals and hospitals have received US\$159,217,264 in Medicaid EHR incentive money for adopting, implementing or upgrading their EHR systems [14].

In Ohio, MU is promoting broad improvements in health systems. Examples of health transformation include modernization of the state’s Medicaid program, which is reducing the number of different eligibility standards across state programs from over 100 to under 10. In addition, the Medicaid payment system is being upgraded, with plans to integrate claims processing through the state HIEs.

## ***Public Health Informatics Challenges, Strategies, Solutions***

### **Financial Barriers**

As is the case in many areas of public health, one of the largest challenges to informatics development is lack of resources. Currently there are few funding sources

specifically targeted for cross-cutting public health informatics measures; most funding is limited to a specific task or program without regard for broader implementation or integration with other information systems. This explains why current public health infrastructure is comprised of historic siloed systems, presenting a major challenge to public health informatics. Many of these systems use and rely on different data standards and terminology. Program managers generally are not supportive of system integration, since the required compromises are often a step back for them; their existing systems are generally adequate for their specific program, but hinder enterprise interoperability. Becoming (and staying) involved in national organizations can help overcome these barriers to system integration, and foster opportunities to partner on grant proposals.

### **Establish Effective Governance**

Leadership of the state of Ohio, ODH, and local public health agencies are barraged with competing priorities, which hinders cross-program information system planning and integration. Therefore, recognition from agency management teams on the importance of integrating siloed systems is critical. Informatics staff need to find opportunities to demonstrate to management the importance and benefits of integrated systems. Such demonstrations might include a request to produce cannot be done in the timely and precise manner needed with existing, or an illustration of the efficiencies to be gained from system integration, such as developing a shared HL7® messaging interface to be used for both immunization and infectious disease lab reporting. Additionally, when leadership changes, momentum can slow while new personnel are educated on the value of these enterprise information system projects; informatics concepts are not simple to explain. Therefore, it would be ideal to have an informatician as a part of the agency senior management team.

There are many other challenges related to connecting internal systems with external providers. In Ohio, the large number of hospitals and LHDs complicate coordination and system integration. Another challenge involves the lack of common standards and terminologies used among ODH and LHDs; one potential solution would be to have centralized system development. Working through such issues can be challenging, and the size of the state can play a role in this.

### **Informatics Capacity Building**

Workforce development has been a challenge in public health informatics. Ohio currently does not have a formal public health informatician job classification in the state personnel system. Staff who do informatics work are using such classifications as epidemiologist, data administration manager, health planner administrator, or deputy director. In many cases, formally-trained public health informaticians are not qualified to be hired in these job classifications. The process for creating new job classifications can be complicated, and requires negotiation with union leadership



and state management. This lack of informatician job classifications also complicates the addition of informatics duties to other types of position descriptions.

At the federal level, the Department of Labor recently recognized the CDC's Public Health Informatics Fellowship Program as a Registered Apprenticeship program [15], adding credibility to the job classification. Currently, formal informatics skills are often non-existent, or vary widely, at the LHD level. This poses challenges in addressing the integration of systems across the state. Therefore, state and local staff need to seek out workforce development opportunities.

### **State Experience: Biggest Triumphs and Ongoing Challenges**

During the past few years, the most pressing public health informatics challenge in Ohio has been engaging both state and local public health as key players in the incentive programs for EHR and HIE implementation. The initial development of the HITECH Act did not emphasize enough an important part of the healthcare system - public health. Thus, public health has been aggressively working for inclusion in these discussions and planning. From Ohio's state perspective, a significant triumph was the initial inclusion of an ODH representative as a member of the state designated HIT agency for ONC funds in 2010. However, in 2012 the state began certifying HIEs, so Board membership was deemed a conflict of interest.

Another important accomplishment for public health informatics in Ohio was the successful receipt of immunization reports directly from a health care provider's EHR through an HIE to the ODH single portal and into the immunization registry, with no manual intervention. The linking of the state disease reporting system and a data analysis and alerting application was another triumph for both state and local public health. The ODH has also developed and implemented the Ohio Public Health Information Warehouse, a web-based system providing both secure and public access to health information. This fully-automated system provides real-time, individual-level information to authorized public health personnel and researchers, and in the future, aggregated information for the public. The warehouse also includes analytic graphing and mapping tools that can be shared and utilized by public health, other external partners, and the public. A success specific to LHDs was the ability to sign up with regional extension centers for the MU reimbursement. Over a dozen departments have now received significant federal reimbursement to offset their costs of EHRs.

An ongoing challenge for the state of Ohio has been demonstrating what public health can do for health information exchanges and providers, such as reducing costs and receiving higher quality population-based information. Public health can assist with activities such as population-based data analysis and population health management. However, public health is challenged by low visibility, and needs to be strategic when speaking of the activities and services that can be contributed. Often public health at national, state, and local levels is so varied and complex, it does not convey an organized and cohesive message for others in the health care community or the general public; public health needs to more clearly convey its needs as well as its assets.

### Review Questions

1. Why is public health informatics considered to be a multi-disciplinary field?
2. What are the benefits and challenges associated with data integration? What are some potential solutions to overcoming these barriers?
3. Who should be actively engaged in public health informatics governance? Describe the role for each.
4. Why must public health work closely with the medical provider community in developing public health information systems?
5. What are some of the challenges in adopting national standards for public health systems?
6. Discuss some of the various focus areas for public health informatics workforce training and what types of specialties, backgrounds and personal skills and experience might be best suited for these areas.

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# Chapter 28

## State Public Health Informatics: Perspective from a Low Population State

James Aspevig

**Abstract** This chapter provides an overview of issues affecting the practice of public health informatics and the support of public health information systems (IS) in the rural environment. Issues important to public health IS management are presented in the context of the “five-component framework of information systems.” The five-component framework is a widely-used model designed to aid in the identification and understanding of issues that might affect an IS. Issues that complicate the management of public health IS projects at the state and local levels in a rural environment are also discussed, and opportunities for success through collaboration are described. Solutions to challenges that may be implementable by local public health officials are introduced. Other solutions to more systemic challenges are also examined, but these would require federal leadership and concerted action at virtually all levels of the public health system; federal, state, and local. The process being used to manage and promote the meaningful use of Health IT at the federal level is discussed as a model for public health IS planning.

**Keywords** Rural health • Rurality • RUCA • Public health informatics • Information systems • Data silo • Immunization registry • Meaningful Use • Silo system • Categorical funding • Health Information Exchange • Population-based funding

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### Learning Objectives

1. Compare and contrast at least two definitions of *rural*.
2. Describe challenges to the practice of public health information systems management in the rural environment.
3. Identify and describe the five components of an information system.
4. Apply the five-component IS framework as a tool to understand the challenges associated with the practice of informatics in the rural public health environment.

## Overview

The public health manager charged with implementing an IS, who also works in the rural setting, faces a significant number of unique challenges. These include (1) resource limitations related to low population densities and population-based funding; (2) a general shortage of public health staff and a particular shortage of trained public health informatics, and information systems professionals familiar with public health; and (3) a complex and relatively inefficient technology environment created by the need to implement and support numerous silo systems. The chapter presents the “*Five Component Framework*” which provides a model used by many Management Information System (MIS) professionals that may also be useful to non-technical public health managers. The framework helps a manager conceptualize all of the elements needed for the successful implementation of an IS. Under the *Five Component Framework*, IS are not just systems based on technology, but actually consist of the five elements of (1) hardware; (2) software; (3) data; (4) procedures; and (5) people. Public health staff working in rural communities must frequently master many aspects of public health program management that are often handled by specialists in more populous communities. The effective use of MIS in support of public and population health is no exception. As the reliance on IS in health care and public health increases, additional staff training and education will be necessary to assist rural public health workers as they make the transition from end-users of systems to population health analysts capable of maximizing the value of the public health data they collect in support of both public health program, and population health assessment.

## Introduction

When we begin to list the challenges associated with the practice of public health informatics in the rural setting, it is easy for practitioners in low population public health jurisdictions to become overwhelmed. However, in this chapter we will not only attempt to enumerate the challenges, we will also attempt to place these

challenges in their broader contexts; demonstrating that they are linked to the changes sweeping through health care delivery system and that they are also very closely related to the challenges faced by the entire rural health care delivery system.

In general, many of these challenges are common issues associated with the practice of informatics and the effective use of information systems that are faced by many organizations in public health. Because rural public health agencies are not alone in facing these challenges, placing these issues in their broader contexts may also suggest some solutions that small public health agencies might use to improve their situation. Understanding the context will also highlight the need for more comprehensive, system-wide, action in other areas, particularly the state and federal levels. This chapter will consist of three main sections. The first will define the rural health context, as rural areas comprise most of the low population public health jurisdictions in the US. This section will broadly define terms and describe the environment of practice for public health informatics in a low population jurisdiction. The chapter's second section presents a conceptual model called the "Five Component Framework" which is a tool for understanding information systems that managers may use to ensure that they are addressing all of the aspects of the management of an Information System (IS). The third section discusses the interaction of the Rural Health Context and Public Health Informatics/IS using the Five Component Framework to describe and explore issues associated with rural public health IS.

## **The Low Population Public Health Context: What is "Rural"?**

In the minds of many health professionals, the concept of a low population public health jurisdiction is generally synonymous with a rural public health jurisdiction with a low population density. Policy-makers, when considering rural issues, also often seem to envision agricultural communities surrounded by farms and ranches, and a vast landscape dotted with villages and small towns. However, when public health professionals and demographers consider the definition of "rural" and "low population," several important issues emerge. Although the US population has migrated increasingly to more urban areas over the last 100 years, there also has been an out-migration from urban areas into the suburbs, and from the suburbs farther out into the countryside somewhat more distant from the urban cores. Those who have migrated out into the suburbs and beyond, generally do not work in and are not dependent upon agricultural production to earn their incomes. These individuals often commute back toward the urban/suburban centers on an almost daily basis for employment, dependent on these more population-dense centers for the bulk of their economic activity. Demographers and public health professionals must wrestle with these concepts, because the percent of the US population considered to be rural can range from 17 to 49 %, depending upon definition used [6].

## *Definitions of the Term “Rural”*

The US Census Bureau still tends to use a definition of *rural* that is heavily dependent on absolute population within a jurisdiction. It defines *Urbanized Areas* (UAs) as consisting of 50,000 or more people; *Urban Clusters* (UCs) as consisting of a minimum of 2,500 and less than 50,000 people and *Rural Areas* (RAs) as consisting of all other areas [21]. Metrics based on the population and population-density (i.e., people per square mile) of a given jurisdiction or geographic area, may be the simplest and the most straight-forward metrics available, but they may fail to capture significant features of the issues associated with a high level of “rurality,” such as (1) isolation; (2) dependence on a local agricultural economy, which may also be associated with reduced income levels and earning potential; (3) lack of ready access to services based in the local community, such as health care and higher education; or (4) limitations on the quality and extent of those services, even when available at a basic level in the community [8]. This complexity is why simplistic, density-based definitions of “rural” have progressively fallen out of favor. Public health researchers, informaticists, and rural policy-makers are seeking to develop and use more sophisticated tools and constructs to better classify and understand the influence of “rurality” on health, health care and public health [23].

## *Comparing Urban and Rural Capacity*

When most policy-makers and public health planners discuss “low population,” which is an element of the title of this chapter, they are referring to low absolute numbers of people living in a given public health jurisdiction, which largely corresponds to a low population density. However, the issues facing the rural public health practitioner are *not* purely related to low population density. A complex range of factors, including social and cultural influences, appear to be affecting rural health care and public health [8].

For example, consider an outbreak of pertussis (whooping cough) in a small rural community. The entire staff of the local public health department may consist of a half-time public health nurse and a three-quarter time administrative assistant. To supplement her income the public health nurse also works half-time in the local primary care clinic. The pertussis outbreak is rapidly spreading through the community, initially affecting primarily adults who had not received their combined Tdap (Tetanus, Diphtheria and Pertussis) vaccination as a routine preventive measure [4]. The outbreak then spreads through the population of under-immunized school-age and pre-school children. Will this very small health department have sufficient resources, both in terms of time and expertise in communicable disease outbreak investigation, to contain this outbreak before it begins to spread to neighboring, more populous, communities?

In contrast, a large public health department in an urban center may employ a number of staff having more substantial experience in outbreak investigations. This

health department may even have a nurse who specializes in the investigation of outbreaks of communicable diseases and STIs (Sexually Transmitted Infections). Very interested in epidemiology, this public health nurse stays “in practice” by routinely following up on small clusters of Chlamydia reports at the two colleges located in the city and by taking epidemiology and statistics courses from the local university. This public health nurse also routinely assists in the investigation of outbreaks of foodborne illness in coordination with the city’s environmental health agency, and wants to start reviewing data received from the electronic health record (EHR) systems of the city’s major clinics to begin to automate their public health agency’s disease surveillance processes.

The two health departments in our scenario obviously have very different capacities. They may even have very different goals and missions as defined by their state and local policy makers. Issues such as the degree of specialization, experience, and expertise may be more directly related to the size of a public health agency. And the size of the public health agency is usually very highly correlated to the size of the community that the public health agency serves. However, as suburbanites and others continue an emigration from population centers and the urban cores of larger communities, public health planners increasingly face a situation where individuals may reside in the rural landscape but may more routinely seek public health and other services from nearby urban centers. This may begin to produce a disconnect between funding sources for public services, such as education and health, and the capacity of the local public health jurisdiction to deliver those services to an expanding population that does not fully identify with the jurisdiction where they reside. In the next section, we will explore an alternative taxonomy that may help public health planners, informaticists, and policy-makers more accurately assess the public health needs, and therefore the required IS needs, of rural public health jurisdictions.

### ***Rural-Urban Commuting Area (RUCA): An Alternative Taxonomy***

If our definition of *rural* is not to be based purely on population density; then what other factors must be considered? One alternative that has matured and is becoming more widely used is the RUCA or *Rural-Urban Commuting Area*. RUCA differs from traditional classification methods in that it attempts to measure the “functional population” of an area by taking into account the commuting flows of its residents [22]. The RUCA score is calculated at the level of the census tract, which generally gives a finer granularity when compared to a larger geographic unit, such as a county. The census tract’s score of “rurality” is also related to the commuting flow of its residents to their nearest population center [24]. For example, a relatively small number of individuals in a newly created housing development located well away from the suburbs surrounding a highly populous metropolitan area might think of themselves as being rural. Locally, this area might even be considered “remote” and therefore very rural. However, if the majority of the individuals residing in this area frequently commute to the large urban center for work, school,



shopping, and many other activities, then this area would receive a more “urban” RUCA classification because the people who live there are, by both effect and action, much more functionally related to the populous metropolitan area. Similarly, people living within the boundaries of a smaller population center, such as small town, might then receive a more “rural” classification if they routinely remain in the small town for their activities and do not generally commute to a larger population center. Even though the residents of this small town may not think of themselves as “remote,” in practical terms they are functionally linked to a much smaller population center. The classification of jurisdictions produced by this method is not simply either rural or urban. The RUCA formula can be used to classify jurisdictions on a continuum and these codes can be aggregated in different ways for a variety of health assessment purposes [24].

### ***Rural Versus Low Population***

In summarizing the first section of this chapter, it is clear that “rurality” is not simply a function of numbers of people and the population density of a given local public health jurisdiction. It is important to think of the issues associated with the practice of public health informatics in rural communities as consisting of more than simply installing information technology in places where people aren’t. A more nuanced understanding of the issues is required. Although the definition of *rural* will continue to evolve, we will use the term “rural” in preference to the term “low population” to more precisely describe the issues faced by public health professionals who serve these communities and practice public health informatics in these settings in the remainder of this chapter.

## **The Information Systems Context for Rural Public Health Informatics**

Having explored some of the so-called “low population” issues associated with public health in the rural context, we can now specifically examine the information systems context as it relates to public health practice in rural settings. When most people, including public health managers, hear the phrase “information system” they tend to focus exclusively on the technological components of the system. However, information systems (IS) actually have components that go beyond the technological aspects of the system. The current view of an information system is that a truly functional information system is comprised of five different components [10]. The first two components, which many people commonly identify as describing the entirety of an information system, are (1) hardware and (2) software. However, fully operational IS actually have three additional components that

include (3) data, (4) procedures, and (5) people. A brief description of each of the components of an information system is given below.

1. *Hardware*: The physical components of the IS. This includes workstations and servers, as well as telecommunications and networking equipment and services, such as an Internet connection.
2. *Software*: The component of the IS that interfaces with the hardware and, most importantly, is used to carry out the instructions of the system's users, such as saving the record of a public health client in a database, or creating a report based on epidemiologic data.
3. *Data*: The facts and information collected by the organization to support its operations and functions. In local city and/or county health departments that deliver clinical services, this includes information on individual clients served by the local health department. At the state and federal levels, public health agencies generally have no little or no need to track the identity of individuals. States, and particularly federal agencies, often do not even receive individually identifiable data, and are generally more invested in processing any data they receive on individuals into information to better describe the population as a whole; this helps to eliminate the possibility of re-identification that may be associated with any release of population-based information.
4. *Procedures*: The policies and processes that govern the operation of the information system. These are rules developed by the organization that include, for example, policies on data collection, such as naming the data elements that must be collected on every client of the local health department, or data retention and management of portable devices.
5. *People*: The individuals who use and maintain a public health organization's IS. All organizations are becoming increasingly reliant on IS and public health organizations are no exception. The use of technology and IS to support communications, the delivery of preventive health services, environmental health operations, and data reporting and analysis, assures that virtually all workers in a public health organization have a strong stake in managing, implementing, using, or otherwise participating in the organization's use of IS. This includes public health managers, who, even though they may not be actively entering data into their agency's IS, are retrieving and being presented with data queried from those systems and, in all probability, are using that information to make decisions regarding the future of their agency and its programs.

An understanding of the *five-component framework* for information systems is useful to the public health informaticist, providing a basis for public health managers and policy-makers to arrive at more informed decisions about the resources a public health agency needs to successfully use the IS it deploys. A very elaborate application (hardware and software components) requires adequately trained users (people component) in order that data entered is complete (data and procedures components) and the ultimate results are satisfactory. Addressing each of the five components of an information system (IS) provides a sound basis for planning and also gives us a framework to address several issues which represent particular

challenges to the practice of public health informatics and support for public health IS in the rural setting.

### ***Rural Public Health and the Hardware Component***

Some of the principal challenges to implementing and maintaining IS in the rural environment are issues associated with the base costs of hardware and telecommunications. For our purposes, the *base cost* of the hardware component may be thought of as the minimum acceptable hardware configuration or telecommunications services necessary for the system to function at a satisfactory level. For example, a slow network or internet connection may lead to unsatisfactory system performance. Unfortunately, rural telecommunications costs are often inversely proportional to population. This leaves more remote areas, with the lowest populations, with the highest costs for connectivity and also the fewest partners available through the government or healthcare sectors to share those costs [9].

The impact of rurality on a public health agency is amplified by population-based funding. When support for public health programs is provided using population-based funding models based on the number of people in a jurisdiction and not on the actual cost of system infrastructure, then the challenges created by this funding model are amplified in terms of the rural public health agencies' capacity to implement and support systems. Population-based funding models mean that, although the hardware and telecommunications costs may be the same or greater, rural public health organizations are awarded proportionately fewer resources than urban health agencies to pay for them. In addition, rural health agencies are generally more challenged to achieve the economies of scale needed to justify or recoup their investment in an IS. New technologies such as cloud computing and virtualization may offer options to help rural public health agencies, allowing them to aggregate their demand for services, reduce support costs, improve their access to systems and data, and achieve some economies of scale. However, even though these newer technologies may result in improved service and cost-savings over time, they still require a substantial initial investment in technology, and rural policy-makers may be reluctant to make that investment without substantial organizational and technical support.

### ***Rural Public Health and the Software Component***

A local rural public health agency in a sparsely populated county may employ only a very limited number of staff who will take on many different roles, ranging from environmental health to public health nursing, epidemiology, and leadership in policy-setting at the local and state levels. Each of these roles generally demands a high level of professional education well as experience, and increasingly is also

accompanied by the requirement to use a certain software application or set of applications to either aid in public health client management, support operations, or meet reporting requirements. On the surface, it seems reasonable to assume that a system which meets the functional requirements of the larger agency will surely be adequate to meet the more modest requirements of the smaller local public health agency. However, as functional requirements expand, system complexity also generally increases. This brings out two issues, (1) application usability and (2) the availability of technical support, that serve to establish the need for different types of IS for small, rural public health agencies.

### **Challenges Associated with Application Complexity and Usability**

A comprehensive client service application capable of serving the needs of different public health programs and clients is likely to consist of a set of modules. These would include a core module that maintains general demographic information, such as date of birth and insurance information, on all clients of the agency and more specialized modules designed to address the service delivery and information collection needs of specific public health programs. An example of this type of module would be an immunization module that maintains a client's vaccination history in a way that is accessible to all public health programs that require access to this data. This may include the local Vaccines For Children (VFC) program, and also other programs, such as the supplemental nutrition program or the communicable disease program, as a client's vaccination history can provide very useful information when assessing risk during the investigation of an outbreak of a vaccine preventable disease. These program-specific modules typically require relatively frequent updates in response to changes in federal and state agencies' policies and regulations.

Application complexity will, therefore, pose a unique challenge for the staff of a small local public health agency, in terms of becoming proficient in the use of a software application with many specialized modules. Within larger public health agencies, staff may be allowed to specialize and support a limited number of public health programs. For example, a public health nurse who works in a large health local health department and who specializes in the vaccination program will become very adept at navigating the immunization module of a public health software application. However, an additional knowledge and training burden is placed on many rural public health agencies as there are fewer individuals to master all the modules of a relatively complex application, making their routine use of IS more challenging.

### **Requirement to Master Multiple Applications**

The support and training challenge may be even more substantial for local public health agencies where different software applications are used to support different public health programs, such as a specialized immunization information system

which supports the vaccination program and a separate software application supporting the supplemental nutrition program. In a small public health agency, staff may cover multiple public health programs and must learn and use a relatively large number of highly varied software applications in order to support their work. Deploying either a large, comprehensive, multi-program client services application or numerous small, often inconsistently designed, program-focused, silo applications yields a complex training and technology support environment that frequently exceeds the capacity of rural public health staff to readily master these application(s). It also tends to exceed the capacity of the limited number of technology support professionals serving rural public health agencies to provide services cost-effectively. A reliance on silo applications to support specific public health programs complicates rural technical support challenges, as these applications often depend on different technology platforms (e.g., different databases or operating systems) and the need to implement and support multiple applications with multiple architectures inevitably leads to a very chaotic technical support environment.

### ***Rural Public Health and the Data Component***

Public health agencies generally act at the community level through the implementation of organized programs designed to address specific health issues and these actions usually emphasize improving the health status of populations. In some rural jurisdictions, local public health agencies deliver very few preventive health services directly to individuals. However, other rural health agencies deliver an extensive menu of preventive health services directly to individual clients. As a result, these agencies require data that supports the delivery of preventive services to individuals and also data that assists in making an accurate assessment of the overall health of a population in relation to a given health issue. Examples of the types of data elements that need to be captured include tracking the number of doses in a series of vaccinations a child needs to receive and reporting on the proportion of the people in the community who are appropriately immunized (vaccination programs) and surveying the population to determine the proportion who identify themselves as users of tobacco products (tobacco use cessation programs) [15, 16]. The data management needs of a local public health agency may consist, therefore, of identifiable, patient-oriented data needed to manage the care of the individual client, as well as aggregate, de-identified information that must be submitted for the purposes of reporting the process, performance, and outcome measures important to the overall assessment of various public health programs.

The structure of the governmental component of the public health system is traditionally split along federal, state and local jurisdictional lines. Data important to a given public health program is generally collected at the local level and is then sent “up-the-chain” to the lead public health agency at the state level for review. The data is then subjected to additional processing, and, if necessary, de-identified, aggregated, and forwarded to the federal level where it is further aggregated and most commonly used to assess: (1) the health of the overall target population; and (2) the

impact and effectiveness of a given public health program. For example, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) aggregated local data and found differences in cervical screening and biopsy results by race/ethnicity among groups of women. This analysis helped to focus attention on addressing a potential health disparity particularly affecting African-American women [1]. Researchers have also used NBCCEDP data to assess the timeliness of mammography rescreening and evaluate the program's performance in this area [2].

Local Public Health Agencies (LPHAs) generally operate as part of a decentralized governmental structure, under the jurisdiction of units of local government that includes counties, cities, towns and special districts, and are the basic source of much of this data. However, in many cases, LPHAs are also charged with the local delivery of preventive health services to individual clients; these data needs are distinct from those at the federal and state levels [20]. In other words, LPHAs that deliver services to individuals must also have systems capable of scheduling client appointments, processing insurance billing claims where applicable, and adequately documenting the particular preventive care service provided, such as the administration of a dose of vaccine in a manner compliant with state and federal regulations pertaining to the documentation of clinical services. LPHAs also face the additional responsibility of collecting sufficient data to meet the reporting requirements of various state and federal program sponsors. While the need to collect data to support both the assessment of population health and the delivery of preventive services to individual clients is common to both rural and urban public health agencies, rural public health agencies face a particular burden in this regard as they often lack the support infrastructure to master and maintain a large number of individual data collection systems, as well as the additional burden of a reduced analytical capacity and the expertise to abstract summary data from the transaction processing systems supporting the delivery of preventive services. As a result, rural public agencies may be at a substantial disadvantage in terms of their capacity to maximize the value that may be derived from the secondary use of the client service data they collect.

### ***Rural Public Health and the Procedures Component***

Initiatives from the private and governmental sectors are currently pressing primary care providers to adopt a population health approach in their use of IS [17]. The federally-initiated Electronic Health Record (EHR) software certification process provides an example of a process that may offer a model that the public health community should consider emulating. The certification procedure is, among other functional standards, intended to ensure that population health functions are being "built-in" to the EHR software applications. This approach has not been historically taken with public health IS products. In the case of the *Meaningful Use* program, if a clinician acquires a certified EHR product, then that product will have been reviewed and certified so as to assure that the EHR will be capable of performing the basic population health functions needed to meet the requirements of the

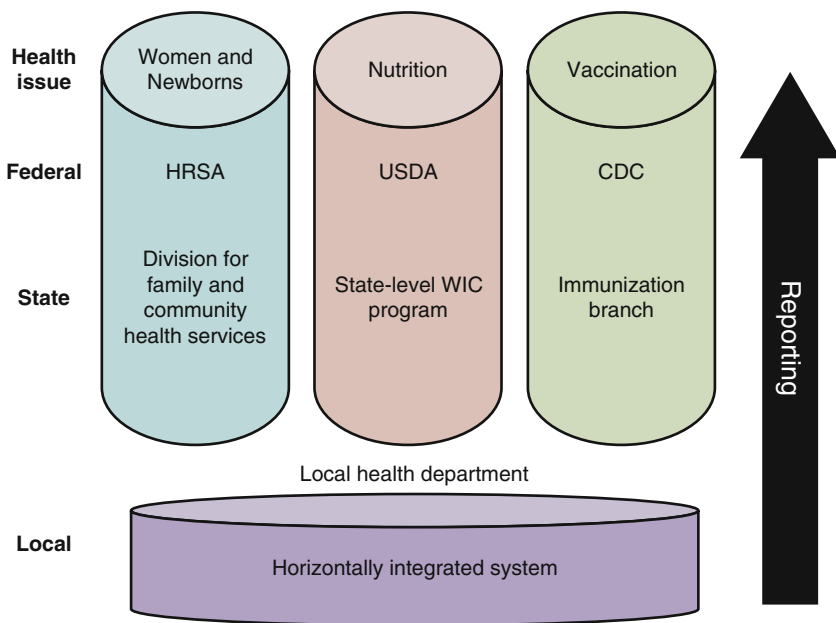


Fig. 28.1 Data silos in public health

program [5, 14, 17–19]. Setting the standards for the EHR’s population health functions has been a massive undertaking at the federal level involving significant public/private partnership [3, 11].

In contrast to the *Meaningful Use* program, no similar comprehensive effort has occurred at the federal level, in terms of certifying software deployed to state and local public health agencies, and extensive cooperation between federal programs to jointly sponsor or create standards-based software designed to serve multiple agencies and programs has generally not been consistently pursued for any extended period of time. Rather, the norm has been the creation, and re-creation, of data silos. Figure 28.1 illustrates the concept of separate systems, each related to a different health issue or public health constituency and represented by a different federal agency. These systems extend from the federal level through to the state and local levels. However, many local health departments see clients who are accessing multiple public health programs and their information must be recreated and maintained in each “silo system.” Not only is this something of a disservice to the client, it also makes it relatively difficult to assess the coordination and comprehensiveness of the local public health agency’s preventive services.

A system-wide focus on the elimination of data silos would not only benefit rural public health practitioners, but would also likely benefit their more urban counterparts. Activities in the federal Meaningful Use program demonstrate that sustained commitment to partnerships promoting standardization, data exchange, and interoperability may be possible. It is possible that the processes and procedures developed for the certification of EHR applications may have some applicability as a template for public health IS development.

## ***Technical Support and Informatics: The People Component***

A rural LPHA typically does not have an in-house public health IT support staff available to install, maintain, and troubleshoot application and network issues, and is fortunate if such services are provided through the city and/or county government. Even then, the small LPHA must often compete for these IT support staff resources with other local government departments; a competition that may be exacerbated if a commercial vendor is contracted for these services and there is a monetary cap placed on the amount of support to a local government as a whole. As a result, rural LPHAs often have a very limited capacity to provide the technical support needed to maintain and operate an installed base of public health IS. Fortunately, there may be solutions to this problem. Rural health departments may be able to use an Application Service Provider (ASP) model to access applications hosted by a third party with more robust technical capabilities. For example, a rural LPHA may access a virtualized application or desktop hosted by the state health department. While the ASP model may offer advantages to both small and large LPHAs, it will be particularly advantageous to rural LPHAs who are more likely to suffer from a limited capacity to support an independent IS infrastructure.

### **The People Component and Support for Analytics**

All LPHAs are required to monitor the health of their communities, and rural public health workers must develop expertise in the way they obtain data to perform community health monitoring and conduct surveillance of population health, such as abstracting data from different systems. Because of the small size of rural LPHAs, they must often act as data analysts as well, and have the ability to use multiple analytical tools to evaluate the collected data. This suggests that the historically self-reliant rural public health worker may be moving from a situation where they are largely end-users of software applications and into a position where they must serve as their community's data analyst; leading to the conclusion that the knowledge requirements and skills that rural public health professionals must possess in the area of informatics need to be expanded. Public health agencies, both urban and rural, need to explore partnerships for the training of public health professionals in the discipline of informatics. This training need not be degree-oriented in a formal academic model, but should begin to address the reality that the need for the public health professional to have a much more sophisticated understanding of data and analytics is only increasing [7]. Rural public health policy makers are capable of recognizing these shifts and can elect to build partnerships with public health and health informatics programs housed in rural institutions of higher education. Partnerships between public health agencies and rural institutions of higher education may permit rural health agencies to maximize the value of the public health information in the agency's possession and achieve a greater return on their investment in IS; particularly in support of efforts to conduct community health assessments.



## Summary and Recommendations

The practice of public health informatics in the rural setting is particularly challenging. Resources are extremely limited and otherwise strained due to (1) population-based funding, (2) the shortage of both trained public health staff and experienced public health informaticists, and (3) the complexity and inefficiency created by the need to support multiple, silo systems. State and local public health agencies are increasingly working to implement integrated public health IS to comprehensively serve the operational and patient management needs of public health agencies at the local level, while also adapting enterprise systems to meet state and federal requirements for data collection and reporting [12].

The Five Component Framework provides a model that may help non-technical public health managers to better conceptualize all of the elements needed for a successful IS. The framework allows for a better understanding of all the costs associated with the components of an IS, particularly the people component, which consists of the informaticists needed to effectively collect and analyze data, as well as technical staff to maintain systems and front-line staff adequately trained to use the IS effectively. In applying the model it becomes evident that the people component of an IS, most particularly, does not cost out in a manner purely proportional to the population served. It is a simple reality that low population public health jurisdictions may never enjoy the economies of scale available to larger population centers. As a result, it is important for managers and policy-makers to understand that funding programs based purely on the proportion of the population served (i.e., population-based funding) will almost inevitably lead to a decline in the capacity of rural jurisdictions to support the effective use of technology in the day-to-day practice of public health. It may be necessary for higher level policy-makers to recognize that some constant, base level of funding is necessary to support an IS, regardless of the size of the population served.

Program managers and public health professionals, particularly at the federal level, also need to become more familiar with the discipline of change management as a competency important to the practice of public health informatics [13]. Much of change management involves walking a fine line between extremes. For the public health community, the extreme of little or no guidance in support of the implementation of information systems is almost as dysfunctional as an excessively prescriptive federal approach to state and local IS projects. The federal *Meaningful Use* program is attempting to take a middle course between extremes. Non-interoperable systems have been identified as a major barrier to the delivery of high quality health care and preventive services, and the *Meaningful Use* program is demonstrating that it is possible to undertake large-scale projects that certify technology, promote data exchange and collaboration, and make more effective use of information systems and emerging technologies in the service of population health. Public health policy-makers at the federal level are urged to consider permanently moving away from a silo systems approach, in those agencies where it may still exist, to a more flexible approach where a variety of applications and platforms might be evaluated for their capacity to support rural public health agencies. A view

of public health information systems as more than just hardware and software, but as comprehensive systems which also include data, procedures, and, most critically, *people* is central to this process. It is also through this understanding of the five-component framework, that state and local public health program managers may begin to develop a sense of the importance of the informaticist to the successful use of an IS in any setting.

In sum, the major issues and corresponding solutions discussed in this chapter may, therefore, be framed as follows:

*Challenge A:* Rural public health agencies often need to collect and manage client-specific data to support the delivery of patient-care services while also producing aggregate data and information to support the effective management of public health programs.

*Solution A:* Information Systems must be designed and implemented with an understanding of both the client-specific data required and the reports that will need to be generated from that data. Additionally, IS must be understood as consisting of hardware/software/data/procedures and *people*. The people who will use the IS must receive adequate training and education in order to maximize the value of the IS to the public health organization. This includes education in the area of data analysis.

*Challenge B:* The basic costs for IS implementation in the rural environment may be higher than corresponding systems implementation costs in more urban environments. This challenge is exacerbated by (1) population-based funding formulas; (2) higher technology infrastructure costs in the rural environment; and (3) the relative absence of economies of scale.

*Solution B:* Rural public health agencies may benefit from simpler, consistently designed, and easier to maintain applications and infrastructures, such as those types of features provided by web apps and through application virtualization and application service providers. Opportunities for funding and enhanced systems of support, allowing rural states to experiment with these approaches, should be made available.

*Challenge C:* Rural public health agencies may find it difficult to use and support enterprise-level, multi-program client management systems as well as multiple, program-specific silo systems.

*Solution C:* Public health staff who work within rural agencies “wear many hats” and will be increasingly expected to serve as data analysts within their communities as our reliance on IS in health care grows. Additional staff training and education will help rural public health workers make the transition from end-users of systems to data analysts capable of maximizing the value of the information collected. The capacity to assist in both obtaining and analyzing health data has the potential to make public health professionals, and the agencies they represent, invaluable partners in the Community Health Needs Assessment (CHNA) process. Moreover, a move from a silo-systems approach at the federal level to a model of public health IS implementation similar to the *meaningful use* program currently being carried out at the federal level may bring many benefits to the public health agencies involved.

### Review Questions

1. What criteria would use to define “rurality” or classify a public jurisdiction as *rural*? You are not limited to the options presented in the text. You may research additional taxonomies. How would you apply the definition you choose to your hometown? What would be the resulting classification? Are there greater advantages to a simple measure or to a more complex measure? Justify your answer.
2. Review the situations of the two public health departments (rural and urban) described in the pertussis outbreak scenario in the “Comparing Urban and Rural Capacity” subsection of “[The Low Population Public Health Context: What is “Rural”?](#)” in this chapter. The rural public health department is working in a significantly smaller community and will, even if everyone in town becomes ill, likely have fewer cases to track and follow-up and a much smaller population to vaccinate. Given that information, which public health department do you believe will contain an outbreak more effectively? Are there other assets the rural public health practitioner may have at their disposal? Consider these aspects of the situation as you develop your response.
3. Which of the five components of an information system do you think is most important to support in the practice of public health informatics? Why? Are there differences between the component(s) you would judge to be the most important in a rural setting as opposed to an urban setting? Justify your answer.
4. A rural state public health department has experienced several failed IS projects. Officials from the state’s local public health agencies have been highly critical of the state’s failed efforts. As a result, the senior management of the state public health department has become very reluctant to undertake any new information systems initiatives or to exercise leadership in the area of IS standards or the implementation of new information systems. What effects do you believe this might have on the public health IS and technology infrastructure at both the state and local levels over the long-term?
5. Find the RUCA codes for your community at the WWAMI Rural Health Research Center web site. Data files can be downloaded by state from the following link: <http://depts.washington.edu/uwruca/ruca-data.php>

The data can also be reviewed for a variety of purposes. For example, ZIP Codes have been mapped to RUCA scores. Review these uses at the following link:

<http://depts.washington.edu/uwruca/ruca-uses.php>

Answer the following questions:

How does your jurisdiction compare to other jurisdictions in your state?  
Are you surprised by the results?

If your instructor supports these efforts, work to group and perhaps even graph the data in a tool like a spreadsheet.

Note: The URLs provided to help you conduct the exercise were accurate at the time of the publication of the text. However, they are subject to change. As a student of informatics, you should be able to perform a simple web-search and find the WWAMI Rural Health Research Center and the associated data files if the links have changed. Similar data on the rural classification of jurisdictions can also be found at the USDA (see link <http://www.ers.usda.gov/topics/rural-economy-population/rural-classifications.aspx>)

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# Chapter 29

## National Public Health Informatics, United States

Seth Foldy

**Abstract** Informaticians looking at national public health information management in the US may ask, “Who designed it this way?” Most systems are not straightforward or easy to understand, in part due to their historical evolution in a decentralized federal structure that located most public health authority at the state level. Thus, many national systems have been built from the bottom-up in a heterogeneous fashion based on voluntary cooperation, sometimes induced through federal funding. In other cases, federal powers related to interstate commerce or national defense gave rise to centralized systems. More recently, federal agencies have played an important role in convening stakeholders, coordinating practice and information standards, and using funding to support implementation and induce conformance to standards. This chapter describes local, state and federal public health roles in the United States, points to collaborative products defining information requirements for various public health activities, outlines the evolution toward national information exchange standards, and describes health informatics roles (highlighting several important regulations) played by several federal and national agencies.

**Keywords** Federal government • Local health department • State health department • Police power • Interstate commerce • Taxing and spending authority • National vital statistics • Nationally notifiable conditions • Department of Health and Human Services • Public Health Service • Centers for Disease Control and Prevention • Food and Drug Administration • World Health Organization • International Health Regulations • Health Insurance Portability and Accountability Act • Centers for Medicare and Medicaid Services • Core functions of public health • Public health essential services • Public Health Accreditation Board • Business

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process • Public health emergency preparedness • Information supply chain • Situational awareness • Passive surveillance • Electronic health record systems • Clinical Laboratory Improvement Act • Health Information Technology for Economic and Clinical Health (HITECH) Act • Patient Protection and Affordable Care Act (PPACA, ACA) • Electronic laboratory reporting • Immunization information system • National Electronic Disease Surveillance System • Office of the National Coordinator for Health Information Technology (ONC) • National Healthcare Safety Network • BioSense • Mini-Sentinel • Cancer registry • Environmental Health Tracking Network • Standards and Interoperability Framework • Health Information Technology Policy Committee (HITPC) and Standards Committee (HITSC) • National Committee on Vital and Health Statistics • National Center for Health Statistics • Office of Surveillance, Epidemiology and Laboratory Services • Public Health Information Network (PHIN) • Nationwide Health Information Network • National Academies • Institute of Medicine • Health Resources and Services Administration • Agency for Healthcare Research and Quality • National Institutes of Health • National Library of Medicine • Value Set Authority Center • Veterans Administration • Approved Testing and Certification Body • Federal Health Architecture • CONNECT • Substance Abuse and Mental Health Services Administration • Office of Civil Rights • Office of Management and Budget • Paperwork Reduction Act • All payer claims database

### **Learning Objectives**

1. Describe the historic framework of state, local, and federal public health and its influence on the public health information supply chain.
2. Identify key public health informatics roles and regulations of different federal health and information agencies.
3. Become familiar with several key national health information collection systems.

## **Overview**

Informaticians looking at national public health information management in the US may ask, “Who designed it this way?” Most systems are not straightforward or easy to understand, in part due to their historical evolution in a decentralized federal structure that located most public health authority at the state level. Thus, many national systems have been built from the bottom-up in a heterogeneous fashion based on voluntary cooperation, sometimes induced through federal funding. In other cases, federal powers related to interstate commerce or national defense gave rise to centralized systems. More recently, federal agencies have played an important

role in convening stakeholders, coordinating practice and information standards, and using funding to support implementation and induce conformance to standards. This chapter describes local, state and federal public health roles in the United States, points to collaborative products defining information requirements for various public health activities, outlines the evolution toward national information exchange standards, and describes health informatics roles (highlighting several important regulations) played by several federal and national agencies.

## Historical Framework

The United States of America was born as a confederation of independent states; its Constitution reflects this by limiting the powers of the national or “federal” government. Police power, including the establishment and enforcement of public health laws, was reserved to states. Federal responsibilities included national defense, the regulation of international and interstate commerce, and taxing and spending power.

As a result, there historically has been a fairly high level of variation between states in the management of public health (and of public health information). From an information perspective, state governments, and sometimes local governments (depending on state constitutions), have been the major regulators of what information is reportable by law, how it is reported, and how it is used and re-used. In recent decades, variability in such information management has been reduced in two ways: interstate agreement, and expanding federal influence using national constitutional powers.

Examples of interstate agreements include standardized state and territorial birth and death registration and reporting to create national vital statistics [1] and the selection, specification, and notification of Nationally Notifiable Conditions (e.g., cases of communicable diseases) [2, 3]. For those impatient with the pace of developing nationwide informatics standards for public health reporting, it is instructive that it took decades just to achieve comprehensive national reporting of vital and communicable disease statistics. Federal agencies played important coordinating and enabling roles for both of these national systems.

Federal authority for national defense and international trade gave rise to the predecessors of the Public Health Service (PHS) that performed port quarantine and other duties, and its modern progeny including the Centers for Disease Control and Prevention (CDC). The regulation of interstate commerce evolved to include oversight of food, drug, and environmental safety through the Food and Drug Administration, the Department of Agriculture, the Environmental Protection Agency, and other agencies. The taxing and spending authority has been used to support research, to induce adoption and standardization of public health practices through federal grants, and to influence health care delivery through reimbursement systems like Medicare (for elders and disabled) and Medicaid (for low-income individuals). Federal funds (excluding Medicare and Medicaid) now account for 45 %



of state and 20 % of local health department budgets [4, 5]. This illustrates that while states retain authority, the power of the purse gives federal public health agencies real influence if grant and contract requirements are focused and coordinated.

Laws and regulations related to information privacy and, to a lesser extent, telecommunication, have also been subject to this mix of state and national authority. For example, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 [6, 7] created national minimum regulations for privacy and security of electronic health information, but states may have stricter controls, which vary from state to state.

A casual observer may decide there is no such thing as a “national system” in the United States, but in fact, there has been a gradual evolution of a national framework, built partly by consensus from below, and partly by coordination and funding from above. There has been no central authority to design the best information systems from scratch to meet the nation’s public health needs; what exists today is the result of many actors struggling toward similar goals over time. It is important for public health informaticians to recognize this state of affairs, to consider local, state, *and* national laws and requirements, and to encourage further harmonization whenever possible. The pace of change toward national standards is quickening, pushed by legislation and regulations described below.

International influence on domestic public health information management expanded after the 2002–2003 Severe Acute Respiratory Syndrome (SARS) outbreak and the ensuing revision of World Health Organization International Health Regulations (IHR) effective in 2007 [8, 9]. The IHR, by treaty, established expectations regarding prompt detection, investigation, and international reporting of Public Health Emergencies of International Concern. US systems of local, state, and federal surveillance and communication address IHR requirements [10].

## **Variability of Health Departments and Public Health Work**

Few US states enjoyed statewide systems to protect public health in the eighteenth and most of the nineteenth centuries. City health departments developed rapidly during the rapid urbanization and associated epidemics in the early twentieth century, and their practices were adopted unevenly across local and state governments. Even today, there is wide variation in services offered. Widely offered programs include communicable disease control, environmental health, nutrition, registration of vital events (births, deaths, marriages, and divorces), maternal and child health programs, and chronic disease prevention and management programs [11, 12]. However, there is great interstate variability in laws authorizing and regulating public health functions. These functions are performed by the state health department in some states and the local level in others. They may be performed by different departments (for example, environmental health programs may be managed by environmental protection departments instead of public health) or by private organizations under contract or government charter. Some activities rely almost entirely

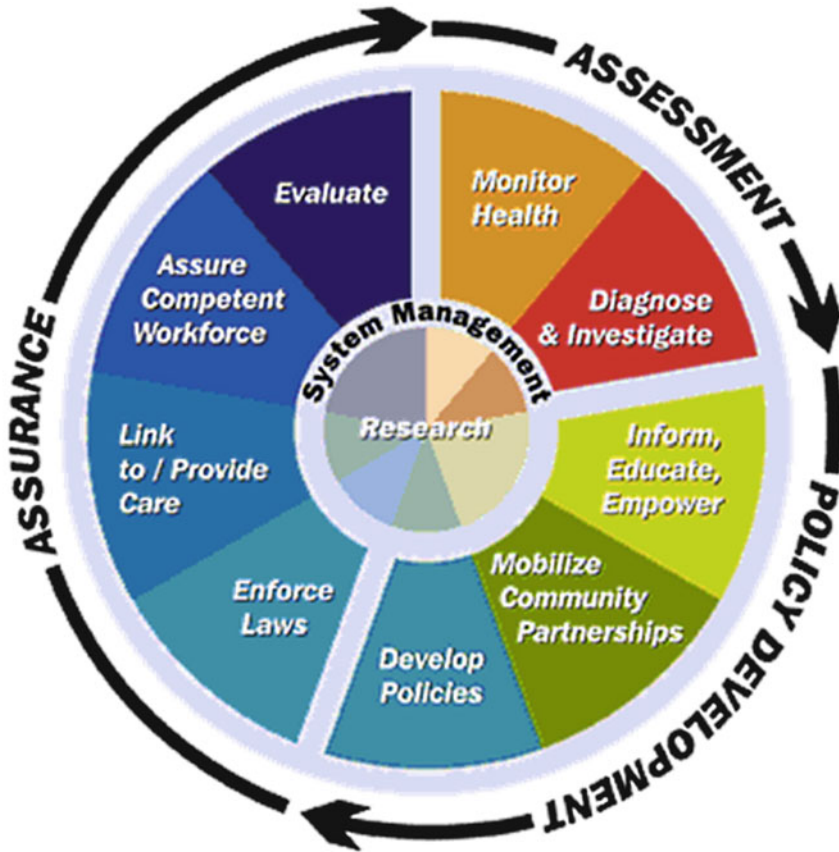


Fig. 29.1 The ten essential services and their relationship to three core functions [13]

on federal grants and contracts, which may not be available or awarded to all jurisdictions.

Public health laboratories are another critical part of the public health system. Virtually every state and territory has a designated state public health laboratory, but its location and governance (whether inside or outside the state health department) vary from one jurisdiction to the next.

All of these factors have led to a common complaint: “If you’ve seen one health department, you’ve seen one health department.” Consequently, it is difficult to generalize with assurance about the work and the informatics requirements of ‘health departments.’

A catalytic 1988 report by the Institute of Medicine [13] helped establish a national vision of a public health system with three core functions of assessment, policy development, and assurance, which were further elaborated into ten essential services [14] (Fig. 29.1), and more recently into an operational definition of local health departments [15] and voluntary Public Health Accreditation Board (PHAB)

standards for local and state health departments [16, 17]. These are critical documents to understand the context of public health information management, but remain too abstract to guide most application and system development.

Recently several collaborations have sought to categorize and describe with greater richness and precision the business processes associated with domains of public health work across many different health departments, and their associated information system requirements (Table 29.1). For example, the Common Ground collaboration on public health emergency preparedness identified similar business processes and information needs that affect most health departments and their information management systems [18].

## The Information Supply Chain

As a result of this historical evolution, state or local health departments, rather than national systems, are typically the first recipients and users of public health information for their jurisdictions. This information is derived from four major sources:

1. Clinicians, hospitals, and laboratories sending mandated or voluntary reports including case reports and/or laboratory results about reportable conditions, birth and death certification, newborn screening results, immunization events, cancer and other disease registry reports, etc. Many health departments also collect and analyze administrative healthcare records, such as in an all-payer claims database or hospital discharge database.
2. Information received from members of the public responding to surveys, reporting complaints, or using health department services
3. Environmental information from licensing and inspection, monitoring systems, etc.
4. Information associated with the logistics of public health laboratory test management and medical countermeasures for natural and terrorist threats.

This information is used at the local or state level for activities like case management, outbreak detection and management, program planning and evaluation, and enforcement of sanitary regulations. Information is also sent up to the national level, typically without identifiers, for national-level surveillance, situational awareness (tracking multiple aspects of fast-moving outbreaks or emergencies), grant and contract management, supply chain management, and evaluation and research.

In addition to information used for surveillance purposes, clinical laboratory specimens and their associated information are sent to and from reference laboratories at health departments, CDC, and other federal agencies for specialized public health laboratory tests. Environmental laboratory specimens (for example, well water, food, or air samples) are also analyzed in public health laboratories. Laboratory information management must ensure the right tests are performed, the source, type and circumstances of the specimen are identified, that chain of custody is documented for tests with legal significance, and that meaningful, accurate

**Table 29.1** Examples of collaborative public health business analyses and related specifications

Topic	Title	Organization	Website
Chronic disease management	Common Ground: Chronic Disease Management Toolkit: Tools and Methodology for Business Process Analysis and Redesign, 2011	Public Health Informatics Institute	<a href="http://phii.org/sites/default/files/resource/pdfs/ChronicToolKit_website.pdf">http://phii.org/sites/default/files/resource/pdfs/ChronicToolKit_website.pdf</a>
Diabetes management and surveillance	Standards for Public Health Data Exchange: Functional Requirements Standard for Diabetes Care Management and Surveillance, 2008.	Public Health Data Standards Consortium	<a href="http://phdsc.org/health_info/pdfs/Standards-for-Public-Health-PHDSC-FINAL-Report.pdf">http://phdsc.org/health_info/pdfs/Standards-for-Public-Health-PHDSC-FINAL-Report.pdf</a>
Emergency preparedness	Common Ground: Public Health Preparedness Toolkit: Tools and Methodology for Business Process Analysis and Redesign, 2011.	Public Health Informatics Institute	<a href="http://phii.org/sites/default/files/resource/pdfs/PrepToolKit_forwebsite.pdf">http://phii.org/sites/default/files/resource/pdfs/PrepToolKit_forwebsite.pdf</a>
Newborn screening	Newborn Dried Bloodspot Screening Business Process Analysis Report of the NDBS Workgroup: Screening through transition to Long-term Follow-up, 2008.	Public Health Informatics Institute	<a href="http://phii.org/sites/default/files/resource/pdfs/NDBSReportFinal.pdf">http://phii.org/sites/default/files/resource/pdfs/NDBSReportFinal.pdf</a>
Syndromic Surveillance	Electronic Syndromic Surveillance Using Hospital Inpatient and Ambulatory Clinical Care Electronic Health Record Data: Recommendations from the ISDS Meaningful Use Workgroup, 2012.	International Society for Disease Surveillance	<a href="https://s3.amazonaws.com/ISDS/Meaningful+Use/ISDS_2012-MUSe-Recommendations.pdf">https://s3.amazonaws.com/ISDS/Meaningful+Use/ISDS_2012-MUSe-Recommendations.pdf</a>
Immunization registries	Defining Functional Requirements for Immunization Information Systems, 2012.	Public Health Informatics Institute	<a href="http://www.phii.org/sites/default/files/resource/pdfs/IIS%20FINAL%2010302012.pdf">http://www.phii.org/sites/default/files/resource/pdfs/IIS%20FINAL%2010302012.pdf</a>
Clinical Care and Case Management	Public Health EHR Requirements, 2012.	Public Health Informatics Institute	<a href="http://www.phii.org/sites/default/files/resource/pdfs/EHR_Requirements.pdf">http://www.phii.org/sites/default/files/resource/pdfs/EHR_Requirements.pdf</a>

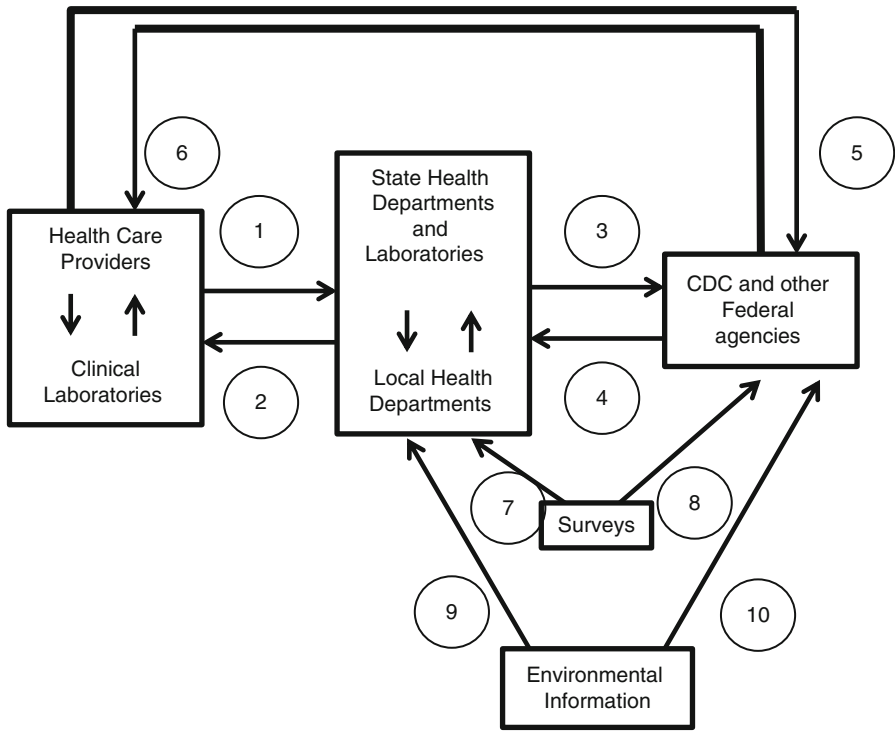
(continued)

**Table 29.1** (continued)

Topic	Title	Organization	Website
Surveillance	Redesigning Public Health Surveillance in an eHealth World, 2012.	Public Health Informatics Institute	<a href="http://www.phii.org/sites/default/files/resource/pdfs/Requirements%20Lab_Final%20Deliverables_RWJ%20Sureveillance.pdf">http://www.phii.org/sites/default/files/resource/pdfs/Requirements%20Lab_Final%20Deliverables_RWJ%20Sureveillance.pdf</a>
Case Reporting	Public Health Reporting Initiative Lead Team. Public Health Reporting Initiative Functional Requirements Description, 2012.	Public Health Reporting Initiative, Standards and Interoperability Framework	<a href="http://wiki.siframework.org/file/view/PHRI%20Functional%20Requirements%2009252012%20Consensus%20Approved.pdf/367698936/PHRI%20Functional%20Requirements%2009252012%20Consensus%20Approved.pdf">http://wiki.siframework.org/file/view/PHRI%20Functional%20Requirements%2009252012%20Consensus%20Approved.pdf/367698936/PHRI%20Functional%20Requirements%2009252012%20Consensus%20Approved.pdf</a>

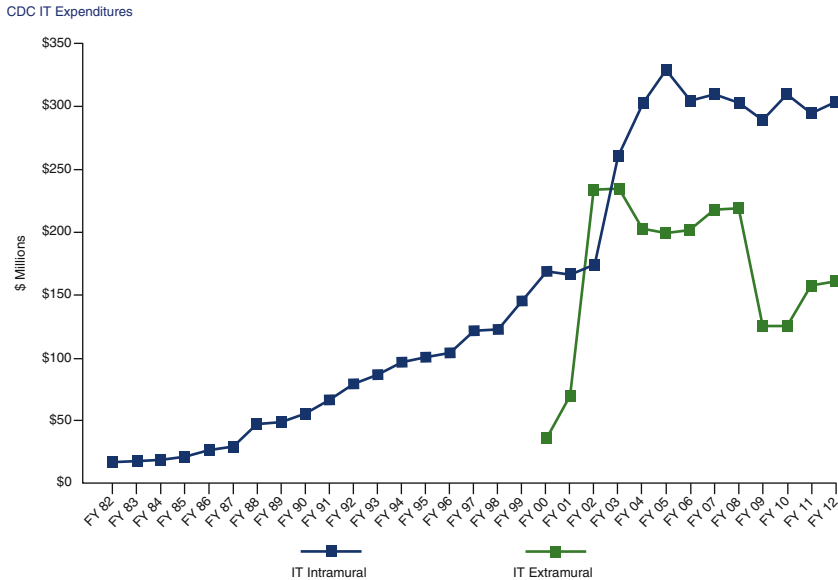
information about the results ultimately reach the professional that ordered them. (For clinical laboratory tests, these are regulated in part by the Clinical Laboratory Improvement Act [CLIA] [19]). Systems to manage supply chains of federal assets, like the Vaccine Tracking System (VTrckS) and Countermeasure Tracking System (CTS) are also becoming a more prominent part of the information system landscape of health departments [20, 21].

A simplified schema of information exchange is presented in Fig. 29.2 with examples. What is clear from the diagram is that (1) state and local health departments are a critical part of a national information supply chain, receiving and transmitting large numbers of different types of transactions, and as a result, (2) they would benefit greatly from interoperable information systems that could receive, reuse, and send information with minimal human labor. The numbers of exchanges between clinical care providers and state or local health departments are particularly numerous and complex. For example, each year over 6.5 million vital records are processed, 1.5 million nationally notifiable conditions are reported, and two million infants screened [22]. These transactions may trigger multiple local actions, of which reporting to the federal level is but one. Despite these needs at the health department level, CDC funding for information technology distributed to other entities such as health departments (extramural funding) has been almost halved since 2004, after a surge of funding following the major 2001 terror attacks (Fig. 29.3) [23]. Not surprisingly, much federal investment has focused on the transfer of information to national levels, rather than day-to-day information management at local and state levels. Concerns have been raised about whether funding is sufficient and focused enough to assure a beginning-to-end supply chain for biosurveillance and other information needs [24–26].



**Fig. 29.2** A schematic of U.S. public health information flow. Examples (keyed to circles) include: 1. disease case reports (lab results and/or clinical information), birth and death reports; newborn screening results, jurisdictional syndromic surveillance systems; 2. jurisdictional disease and outbreak statistics, alerts and guidance, reference lab results; 3. National Notifiable Disease Surveillance reports, vital statistics summaries, Public Health Laboratory Interoperability Project (PHLIP) reports; 4. National statistics and guidance; reference lab results, National Healthcare Safety Network (NHSN) jurisdiction level reports; 5. NHSN reports, FDA MedWatch adverse event reports, 6. Health Alert Network alerts and guidance, national statistics, institution-level information from NHSN; 7. Behavioral Risk Factor Survey, local surveys; 8. National Health and Nutrition Examination Survey; 9. license inspections, lead poisoning hazard assessments, BioWatch bioterrorism assays; 10. BioWatch event notifications, FDA inspections, US Department of Agriculture inspections. NOT REPRESENTED: Information exchange with members of the public (e.g., websites, publications, press releases); international notifications of Public Health Emergencies of International Concern

Apart from surveillance systems based on reports (sometimes described as *passive surveillance*, with public health relying on another actor to initiate a report), there has been an explosion of health data availability through digitalized electronic health record (EHR) systems, billing, quality measurement, and other systems. The Food and Drug Administration has developed Mini-Sentinel, a system of distributed queries to EHR and other electronic data systems of large healthcare providers and payers to investigate the safety of regulated healthcare products [27]. Data accessible to query include administrative and claims data from 2000 to 2011 for over 300 million person-years, 2.4 billion encounters, 38 million inpatient hospitalizations,



**Fig. 29.3** Trends in CDC spending on intramural and extramural information technology [24]

and 2.9 billion dispensings of medication. For example, FDA's Center for Biologics Evaluation and Safety is using Mini-Sentinel to assess the incidence of rare adverse events for vaccines after they have entered general use [28]. Mini-Sentinel is one initiative in a larger FDA program to leverage newly available electronic health information [29].

Many states have established voluntary or mandated all-payer hospital discharge and claims data systems that have been used to track the impact of policy changes, to characterize care-seeking patterns, and to assess variations in medical costs among many other uses. An important evolving feature of such databases is the capability to track the care of individuals across multiple providers and payers over time, for example, to aggregate and compare the services and costs of a longitudinal episode of care, like pregnancy and childbirth, or acute myocardial infarction [30]. A similar national-level database is being developed to support comparative effectiveness research (see below) [31]. Medicare claims data is frequently used in research on utilization, outcomes, and disparities (such as the incidence of clinical preventive services, or the association of products or services with health outcomes). Further information on access to Centers for Medicare and Medicaid Services (CMS) data can be found at the Research Data Assistance Center [32]. Quality measures submitted by health care providers to the federally funded Medicare and Medicaid programs are another emerging source of public health information. These include measures of the prevalence of preventive screenings and vaccination [33]. Federal authority to use healthcare reimbursement to incentivize changes in information collection, reporting, and analysis has accelerated with the Health Information Technology for Economic and Clinical Health Act (HITECH 2009)

[34] and the Patient Protection and Affordable Care Act (2010) [35], and promises to make larger amounts of more standardized information available over time (described below).

## **Federal Role in Information Management and Standardization**

Local variation in public health practices is less an issue when the Federal Government has the predominant authority for a program, as in the case of drug and medical device safety. In that case, the Food and Drug Administration has been able to establish centralized and nationally funded information systems like MedWatch for adverse event reporting [36]. In other domains where state authority reigns, federal programs have worked with health departments and other partners to develop more standardized processes and information systems. In some of these cases (particularly for newer programs with less legacy of state-level systems), a single predominant and nationally-funded system has been created: for example, the National Healthcare Safety Network (NHSN), a national platform used by healthcare providers and health departments to track and improve healthcare-associated infections [37]. More often, federal agencies support evolutionary efforts to define program requirements, standards, and implementation tools for state and local levels, as for example, the National Electronic Disease Surveillance System (NEDSS) [38], electronic laboratory reporting (ELR) of results for reportable condition [39], immunization information systems [40], cancer registries [41], vital statistics [42], syndromic surveillance [44] and environmental health metrics (Environmental Health Tracking Network) [44]. In some cases a federal application or information system is offered, but not required (for example, the NEDSS Base System and the BioSense syndromic surveillance system) [45]. In most cases funding is made available to help some, if not all, health departments adopt national standards of practice and information management. Unfortunately, local difficulty migrating from legacy approaches often causes new processes, standards, and tools to be adopted unevenly, sometimes accreting atop old ones, resulting in increased complexity and cost rather than the efficiency of an industry-wide approach [46]. Examples of several national public health information systems are listed in Table 29.2.

Several initiatives, particularly at CDC, have sought to increase public health migration to electronic information management and more system interoperability [47, 48]. The concept for a National Health Information Infrastructure (NHII) to support health information transactions emerged from the National Committee on Vital and Health Statistics, affiliated with the CDC National Center for Health Statistics [49]. Efforts accelerated after the 2001 September 11 terror attacks. In 2004, the Public Health Information Network (PHIN) initiative at CDC sought to implement greater interoperability in six domains related to public health emergency preparedness: early event detection; outbreak management; connecting laboratory systems; countermeasure and response administration; partner communications and alerting;



**Table 29.2** Examples of major US public health information programs in 2013

Function	Name	Primary information source	Primary authority/mandate for data collection	Enablers of national collection	Federal approaches to state standardization	Current Federal agency and website	Major Partners
Vital Statistics (births, deaths)	Vital Statistics System	Certified reports of births and deaths from licensed health professionals	State/territorial <sup>a</sup>	By agreement, funding requirement	Model state legislation and certificate templates, stakeholder conferences, electronic reporting guides	CDC <sup>b</sup> National Center for Health Statistics (NCHS) <a href="http://www.cdc.gov/nchs/nvss.htm">www.cdc.gov/nchs/nvss.htm</a>	National Association for Public Health Statistics and Information Systems
Communicable disease surveillance	National Notifiable Disease Surveillance System (NNDSS)/ National Electronic Disease Surveillance System (NEDSS)	Reports from health care professionals and laboratories	State/territorial <sup>a</sup> (CMS/ONC established incentives and associated standards for electronic laboratory reporting in 2010)	By agreement, funding requirement	Electronic reporting guides and standards, stakeholder conferences, provision of software product.	CDC Office of Surveillance, Epidemiology and Laboratory Services <sup>d</sup> (OSEL) and CMS/ONC	Council of State and Territorial Epidemiologists

Risk Factor Surveillance	Behavioral Risk Factor Surveillance System (BRFSS)	State-based random telephone survey of public	State/territorial	By agreement, funding requirement	Questionnaire and sampling design, stakeholder conferences	CDC Office of Surveillance, Epidemiology and Laboratory Services <sup>d</sup> ( <a href="http://OSEL.S">www.cdc.gov/brfss/</a> )	International Society for Disease Surveillance; Council of State and Territorial Health Officials; Association of State and Territorial Health Officials
Syndromic surveillance	BioSense Program (national tool); Public Health Emergency Preparedness cooperative agreement	Electronic surveillance of healthcare utilization data (most often admission/discharge/transfer system data)	State/territorial <sup>a</sup> (CMS/ONC <sup>c</sup> established incentives and associated standards for syndromic surveillance reporting in 2010)	Voluntary adoption of BioSense system, or data sharing agreement, funding requirement	Provision of BioSense platform, electronic reporting guides and standards, stakeholder conferences	CDC Office of Surveillance, Epidemiology and Laboratory Services <sup>d</sup> (OSEL.S) and Office of Public Health Preparedness and Response (OPHPR) <a href="http://www.cdc.gov/biosense/">www.cdc.gov/biosense/</a>	International Society for Disease Surveillance; Council of State and Territorial Health Officials; Association of State and Territorial Health Officials
Health status measurement	National Health and Nutrition Examination Survey (NHANES)	National-level random survey with physical/laboratory examination	Federal	NA	NA	CDC National Center for Health Statistics <a href="http://www.cdc.gov/nchs/nhanes.htm">www.cdc.gov/nchs/nhanes.htm</a>	National Institutes of Health, Food and Drug Administration, Department of Agriculture, Environmental Protection Agency

(continued)

Table 29.2 (continued)

Function	Name	Primary information source	Primary authority/mandate for data collection	Enablers of national collection	Federal approaches to state standardization	Current Federal agency and website	Major Partners
Immunization registration	Immunization Information Systems (at state or local level, often called Immunization Registries)	Healthcare provider reports of immunization events	State/territorial <sup>a</sup> (CMS/ONC <sup>c</sup> ) established incentives and associated standards for reporting to immunization information systems in 2010)	Funding requirement to report system characteristics (not immunization prevalence)	Electronic reporting guides and standards, funding requirements, stakeholder conferences	CDC National Center for Immunization and Respiratory Diseases (NCIRD) Immunization Information Services Support Branch and CMS/ONC <a href="http://www.cdc.gov/vaccines/programs/iis/index.html">www.cdc.gov/vaccines/programs/iis/index.html</a>	American Immunization Registry Association
Immunization prevalence	National Immunization Survey	Random telephone and follow-up mail survey of immunization prevalence	Federal	NA	NA	CDC NCIRD and NCHS <a href="http://www.cdc.gov/nchs/nis.htm">www.cdc.gov/nchs/nis.htm</a>	
Vaccine supply chain	Vaccine Tracking System (VTrackS)	Systems to manage ordering, use and inventory of publicly-funded vaccines	Federal	NA	Software applications, funding requirement, stakeholder conferences	CDC NCIRD <a href="http://www.cdc.gov/vaccines/programs/vtrcks/">www.cdc.gov/vaccines/programs/vtrcks/</a>	Association of Immunization Managers and other associations

Emergency medical countermeasure supply chain	Countermeasure Tracking System (CTS)	Systems for inventory awareness, management and administration of medical countermeasures	State/territorial	By agreement, funding requirement	Software applications, funding requirement, stakeholder conferences	CDC OSELS and OPHPR <a href="http://www.cdc.gov/phinf/tools/cts/">www.cdc.gov/phinf/tools/cts/</a>
Post-marketing product adverse event surveillance	MedWatch	Voluntary reporting of adverse events from FDA regulated drugs, devices, biologics and supplements	Federal (voluntary reporting)	NA	NA	Food and Drug Administration <a href="http://www.fda.gov/Safety/MedWatch/default.htm">www.fda.gov/Safety/MedWatch/default.htm</a>
Post-marketing product adverse event surveillance	Mini-Sentinel Pilot program	Distributed queries of electronic health records	Federal (voluntary reporting)	NA	NA	Food and Drug Administration <a href="http://www.fda.gov/safety/FDAsSentinelInitiative/ucm2007250.htm">www.fda.gov/safety/FDAsSentinelInitiative/ucm2007250.htm</a> HMO Research Network and other collaborating institutions

(continued)

Table 29.2 (continued)

Function	Name	Primary information source	Primary authority/mandate for data collection	Enablers of national collection	Federal approaches to state standardization	Current Federal agency and website	Major Partners
Healthcare associated infection reporting	National Healthcare Safety Network	Reporting of data on infections associated with healthcare	State/territorial or voluntary	By agreement (at state or health-care provider level); funding requirement	Provision of NHSN platform, funding requirements, electronic reporting guides and standards, stakeholder conferences	CDC National Center for Emerging and Zoonotic Infectious Diseases <a href="http://www.cdc.gov/nhsn/">www.cdc.gov/nhsn/</a>	Council of State and Territorial Epidemiologists
Cancer registration	National Program of Cancer Registries	Provider and laboratory reports of cancer diagnoses and associated care	State/territorial (CMS/ONC <sup>c</sup> established incentives and associated standards for reporting to cancer registries in 2012)	By agreement, funding requirement	Funding requirement, electronic reporting guides and standards, stakeholder conferences	CDC National Center for Chronic Disease Prevention and Health Promotion <a href="http://www.cdc.gov/cancer/npcr/">www.cdc.gov/cancer/npcr/</a>	North American Association of Central Cancer Registries, National Cancer Institute SEER program

Environment health tracking	National Environmental Health Tracking Network	Data on environmental exposures and effects	State/territorial	By agreement, funding requirement	Funding requirement, indicator and metadata standards, stakeholder conferences	CDC National Center for Environmental Health <a href="http://ephtracking.cdc.gov/showHome.action">http://ephtracking.cdc.gov/showHome.action</a>	Environmental Protection Agency, National Environmental Health Association and other associations
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<sup>a</sup>In some (“home rule”) states, this authority may devolve to the local jurisdiction

<sup>b</sup>Centers for Disease Control and Prevention, US Department of Health and Human Services

<sup>c</sup>Centers for Medicare and Medicaid Services/Office of the National Coordinator for Health Information Technology, both parts of the US Department of Health and Human Services with shared responsibility for the Electronic Health Record Incentive (“Meaningful Use”) Program

<sup>d</sup>As of September, 2013 OSELS is proposed to be reorganized as the Office of Public Health Scientific Standards. However OSELS websites still function

and cross-functional capabilities and components [50]. Some standardization was achieved, but support for these initiatives at CDC and in health departments waxed and waned, and was affected by frequent reorganizations and leadership changes.

Also in 2004, US President George W. Bush directed federal agencies to increase the adoption of electronic health records and electronic health information exchange, and established the Office of the National Coordinator for Health Information Technology (ONC) [51]. ONC organized a public-private American Health Information Council (AHIC) which selected and defined high priority use cases (including public health reporting); interoperability specifications were developed by a Health Information Technology Standards Panel (HITSP), and software was certified for interoperability by a Certification Commission for HIT [52]. Simultaneous with these efforts were modest public and private initiatives to create Regional Health Information Organizations (RHIOs, now often called Health Information Exchange Organizations) to facilitate health information exchange [53]. Lack of Congressional authorization and funding, and mal-aligned incentives for the private sector limited progress until the 2009 passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act [54, 55]. HITECH required the Secretary of the Department of Health and Human Services (HHS) to establish standards and rules for HIT interoperability and information exchange, privacy and security, and increased funding of ONC toward these ends. More importantly, it created a multi-billion dollar Medicare and Medicaid Electronic Health Record Incentive Program (better known as “Meaningful Use”) to encourage health care providers to adopt and use nationally certified EHR systems for data capture, care improvement, and information exchange [56]. The high stakes engendered by this program is driving the US toward national adoption of syntactic, semantic and transport standards for health information faster than previous efforts. Healthcare providers must perform certain types of standardized public health reporting to receive incentives, thus the program is both creating *de facto* national standards for reporting and radically increasing the numbers of providers wishing to implement exchange with health departments. As of 2013, Meaningful Use rules affect electronic laboratory reporting (ELR) of results for reportable conditions, and reporting to immunization information systems (sometimes called immunization registries), syndromic surveillance systems, and cancer registries. The regulations also address other matters of public health interest, such as mandating EHR recording of race and ethnicity and smoking status, quality measurement reporting regarding the use of preventive clinical services, and affecting how public health laboratory results may be received and displayed in electronic health records. More requirements will be issued in additional stages of regulation over time [57–60].

Public health and clinical stakeholders are also using the Standards and Interoperability Framework, facilitated by the Office of the National Coordinator (ONC), to harmonize standards and to establish and pilot reference implementations for public health use cases [61, 62]. Unfortunately, the HITECH Act offered little funding for health departments. Since the peak in funding to health departments for technology preceded the new HITECH standards by several years, there has been a mismatch between the standards deployed in health departments and

those cited in Meaningful Use regulations. Health departments have had to migrate to the new standards and digital reporting relationships with limited federal support. However, the emergence of more universal national standards and their incentivized adoption in EHR systems appears to have created momentum for increasing interoperability in the public health information supply chain. In 2010, the CDC Public Health Information Network (PHIN) program was re-oriented to focus on accelerated harmonization and implementation in concert with Meaningful Use standards with renewed input from health departments and other stakeholders [63].

## **Federal Agencies with Important Informatics Roles**

### ***Cross-Agency Coordination***

Because federal roles in health care, information and telecommunication policy, science, and national security (including preparedness for public health emergencies) necessarily span multiple cabinet departments, the Executive Office of the President has become involved in activities affecting public health informatics. The Office of Management and Budget (OMB) includes the Office of Electronic Government headed by the nation's Chief Information Officer (CIO) [64]. Armed with OMB's powers over budget and procurement policies, the office seeks to improve federal efficiency and effectiveness including: adoption of cloud services; data center consolidation; encouragement of shared services across agencies and programs; enhanced cyber security; improved federal enterprise architecture; and improved public access to digital information from government. These policies are developed and executed in conjunction with a council of CIOs across the various federal agencies. Notably, the CIO Council helped develop Data.gov, a data transparency initiative that makes government data sets and application programming interfaces (APIs) available to the public and developers over the Internet. As of early 2013, over 387 health datasets were available at the site, including demographic, survey, reportable condition, and healthcare utilization and cost data [65]. The Office of Management and Budget is also responsible for administering the Paperwork Reduction Act of 1995 (PRA) which establishes important limits on and requires prior review of most federal data collection efforts [66, 67].

The White House Office of Science and Technology Policy (OSTP) supports the President's Council of Advisors on Science and Technology (PCAST), which sought to enlarge the vision for HIT in a 2010 report advocating health record systems standards that enable standardized query for public health and other purposes while preserving record privacy and security [68]. OSTP is also the home of the US Chief Technology Officer, an office created in 2009 and which in 2012 was focused on improving access and use of health data [69]. OSTP also sponsors the Health Information Technology Research and Development Senior Steering Group to coordinate multi-departmental efforts related to big data analytics and health systems interoperability [70].



Biosurveillance is a complex activity involving multiple agencies. Biosurveillance is described as “the process of active data-gathering with appropriate analysis and interpretation of biosphere data that might relate to disease activity and threats to human or animal health – whether infectious, toxic, metabolic, or otherwise, and regardless of intentional or natural origin – in order to achieve early warning of health threats, early detection of health events, and overall situational awareness of disease activity” and is part of an overarching strategy for countering biological threats [71]. The National Security Council, in collaboration with OSTP, has created a high-level biosurveillance strategy and inter-agency team to support implementation [72]. The Department of Homeland Security is responsible for biosurveillance integration across domains like geopolitical intelligence, agriculture, and human health. The Department of Health and Human Services is primarily accountable for human health biosurveillance [73]. Thus public health national notifiable and syndromic disease surveillance systems are envisioned as part of a multi-source information stream directed to federal emergency decision-makers.

The Federal Health Architecture (FHA) initiative, supported by ONC and co-led by the Veterans Administration (VA) and the Department of Defense (DoD), seeks to help 33 federal agencies leverage digital health interoperability and information sharing [74]. Among other initiatives, FHA oversees CONNECT, an open-source solution to support health information exchange.

The Section 508 amendment to the Rehabilitation Act of 1973 requires that Federal information offered electronically must be accessible for those with disabilities. This creates accessibility expectations for websites and other information systems created by (or funded by) federal agencies. The US General Services Administration (GSA) serves as the government-wide resource for 508-compliant services and infrastructure, and these requirements are typically incorporated into agency system lifecycle management and funding requirements for federally supported systems.

### ***The Department of Health and Human Services***

HHS includes several agencies now under the umbrella of the Public Health Service, including CDC and FDA, as well as the National Institutes of Health (NIH), the Agency for Toxic Substances and Disease Registry (ATSDR, administered by CDC), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Indian Health Service (IHS) and the Health Services and Resources Administration (HRSA) [75]. The Public Health Service also includes the Surgeon General and a uniformed corps of health professionals (the PHS Commissioned Corps) assigned to these agencies and other health functions. HHS also includes the previously mentioned ONC, CMS, the Office of the Assistant Secretary for Prevention and Response (ASPR), and the Office of Civil Rights, in addition to agencies focused on the welfare of children and families, elders, and the disabled.

The ONC in the Office of the Secretary of HHS provides leadership, program resources, and services needed to guide nationwide implementation and meaningful use of HIT. This work includes: strategic planning [76]; helping the Secretary select information standards for department rules including Meaningful Use; standards harmonization and implementation for health use cases; research on major informatics problems like usability, data mining, and privacy and security; support for state level health information exchange (and the framework for national exchange through a Nationwide Health Information Network, NwHIN); and community-level demonstration projects. The ONC is a relatively new office, with funding that rose from about \$60 million US in 2008 to over \$2 billion US during the economic stimulus of 2009–2010, and back to about \$60 million US in each of 2011 and 2012 [77, 78]. Thus, the long-term portfolio of this office is still being defined. The ONC supports two Federal Advisory Committees (HIT Policy and HIT Standards), which are major forums for discussing and proposing regulation. The HHS Office of Civil Rights is responsible for writing and enforcing information privacy and security rules associated with the Health Insurance Portability and Accountability Act (HIPAA).

CDC supports many public health programs at national, state, and local levels, with major emphasis on surveillance of disease, injury and environmental hazards, prevention services, emergency public health response, and public health laboratory services. CDC is structured as a group of National Centers, with cross-cutting functions performed by Offices [79]. It is the major federal supporter of public health programs at the state and local level. Each National Center and some Offices operate many systems for national collection or management of public health information (see Table 29.2 for examples). As previously described, the agency has worked to support interoperability between local, state, and federal public health information systems, and increasingly to ensure that the implementation of information exchange between health care providers and public health agencies is harmonized, effective, and efficient for both. The key locus of interoperability work has been renamed and reorganized several times, and in 2013 resides at the CDC Office of Surveillance, Epidemiology and Laboratory Services (OSELs) [80]. As of September, 2013 CDC has proposed to reorganize OSELs as the Office of Public Health Scientific Standards, the latest of multiple reorganizations and leadership changes. This Office includes: the PHIN program and associated interoperability efforts (like the PHIN Vocabulary Access and Distribution System and development of public health report implementation specifications); support for public health in the Meaningful Use incentive program; the Public Health Informatics Research Laboratory for research and prototyping [81]; support for notifiable disease and syndromic surveillance (including the BioSense system); the Public Health Informatics Fellowship; the EpiInfo epidemiology software application; the Behavioral Risk Factor Survey; a program for public health clinical decision support; and programs supporting laboratory systems interoperability. Another cross-cutting program, governed elsewhere at CDC, addresses the need to sequence and share information on CDC's large microbial collection [82].

CDC's National Center for Health Statistics (NCHS) performs other major surveys, supports the Vital Records System, and is responsible for adapting the use of the International Statistical Classification of Diseases and Related Health Problems

for recording morbidity in the United States (the latest version is ICD-10-CM) [83, 84]. It also serves as the home for the National Committee on Vital and Health Statistics, which advises the HHS Secretary on health data, statistics, and national health information policy.

The Centers for Medicare and Medicaid Services (CMS) is the largest payer for US personal health care services and thus has considerable influence and access to information. It writes and administers the EHR Incentive Program Meaningful Use regulations (employing information standards endorsed by the ONC), and its claims, quality reporting, and other data are frequently used for public health research. As the driver of new models of healthcare purchasing and delivery, authorized by the 2010 Patient Protection and Affordable Care Act (PPACA) national health care finance reform, CMS will have considerable leverage over the future direction of health information management. CMS and CDC collaborate on enforcement and training associated with the previously discussed Clinical Laboratory Improvement Act (CLIA).

The National Library of Medicine (NLM) at NIH has a long history of developing wide-ranging health-related databases, and developing and/or distributing necessary metadata and semantic standards; examples include the Unified Medical Language System (UMLS), which integrates and distributes key terminology, classification and coding standards, and associated resources [85] and RxNorm, a normalized naming system for generic and branded drugs [86]. In 2013, it was named as the Value Set Authority Center to distribute official value sets for 2014 Meaningful Use quality measures [87]. NLM also supports biomedical informatics training programs at many universities, and access to library resources through the multi-agency Partners in Information Access for the Public Health Workforce [88]. Other NIH Institutes fund internal and extramural research in bioinformatics, diagnostics, and therapeutics.

The CDC, FDA, CMS, AHRQ, NIH, and HRSA each sponsor initiatives to measure and improve various aspects of health care quality and safety, some of which are listed in Table 29.2. An important function of AHRQ is to assess and address gaps in knowledge about the effectiveness of health care. The PPACA also established the Patient-Centered Outcomes Research Institute (PCORI), a non-profit, tax-exempt corporation (with NIH and AHRQ Directors serving as board members) to support and disseminate research that compares effectiveness between two or more medical treatments or services in a way that helps patients, clinicians, purchasers, and policy makers make informed health decisions [89]. The FDA regulates and performs post-marketing surveillance of the safety of drugs, devices, biologics, and some nutritional supplements, and in the case of vaccines, collaborates with CDC on the Vaccine Adverse Events Reporting system (VAERS).

HRSA, IHS and SAMHSA (along with the Veterans Administration and Department of Defense outside HHS), each have programs to support and improve digital information collection and management by the healthcare providers they fund or employ. For example they support electronic health record implementation by their various programs, grantees, and contractors. HRSA is also a federal leader in supporting: rural telehealth programs (electronically-assisted healthcare delivery

at a distance); resources for data sharing and quality measurement by community health centers; and informatics workforce development.

### ***Other Organizations of Note***

The National Institute for Standards and Technology (NIST) is a non-regulatory federal agency within the US Department of Commerce that is focused on measurement, including conformance with technical standards. It develops conformance-testing procedures for the Meaningful Use certification of EHRs by private ONC-authorized Testing and Certification Bodies (ATCBs) [90].

The National Academies (National Academy of Science, National Academy of Engineering, Institute of Medicine (IOM) and National Research Council) are private, non-profit but congressionally chartered organizations that serve as independent advisers on scientific matters. They convene expert panels to address specific requests, and the Institute of Medicine has recently issued multiple reports related to public health surveillance, health care information management, and the requirements for developing a “learning health system” based on improved information management practices.

The National Science Foundation is a major funder of research into “big data” (massive scale and high speed) computing and information management. As of this writing, it supports grants addressing scientific, governance, and policy issues addressing large-scale analysis and sharing of biomedical data. National Laboratories (such as Sandia, Los Alamos, and Argonne National Laboratories) supported by the Department of Energy are sources for super-computing systems and expertise for such functions.

## **Conclusion**

The onset of global trade at jet speeds and the potential for rapid spread of emerging and terrorist disease threats has created demand for national systems of surveillance and response unanticipated by federal constitution-writers at the end of the eighteenth century. National information systems are emerging through a combination of consensus building and federal funding and incentives. Today this is further accelerated by initiatives seeking national information standards across health care, the major source of information used by public health agencies. Because most public health practice is performed at the local or state level, systems of information collection and exchange must serve both local business processes and national information needs. US public health informaticians must navigate the intersecting influence of both local *and* federal requirements, and work collaboratively to ensure critical information needs are met at all levels: local, state and federal. They should also seek to identify and leverage relevant national interoperability initiatives, and

prepare to migrate public health information systems to emerging national standards in an orderly way.

### Review Questions

1. How did the US Constitution influence the evolution of government public health structures and information systems?
2. Where do local and state health departments fit into the US public health information supply chain? What does this imply regarding their informatics capacity requirements?
3. What levers can federal agencies use to encourage and support standardized public health practice and information systems, even if they do not hold the direct authority for a particular public health activity?
4. Identify the following: (a) the office that advises the Secretary of Health and Human Services on interoperability standards for health information technology; (b) the agency that provides the greatest direct federal support to state health departments; (c) the agency creating a Value Set Authority Center related to Meaningful Use objectives; (d) the home of a federal public health informatics research and prototyping laboratory.
5. Identify at least three Acts that established regulations on whether and how electronic information is gathered or used by federal agencies.

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# Chapter 30

## Public Health Informatics in Canada

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**Abstract** Canadian healthcare and public health services are provided to all citizens and to most non-citizen residents of a country with an increasingly multicultural and multi-linguistic population experiencing significant social, economic, and population health disparities. Early successes in Canadian public health informatics included the Global Public Health Intelligence Network (GPHIN), a surveillance system employing automated analysis of international news sources to achieve early identification of public health threats. Two important organizations, “the Canadian Institute for Health Information” Institute and Canada Health Infoway have respectively contributed to national capabilities for data analysis and informatics. The

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nation's public health infrastructure was greatly strengthened following the 2003 severe acute respiratory syndrome (SARS) outbreak, during which a variety of surveillance, communication, and management challenges complicated effective public health response. Many of these challenges called for solutions based on informatics concepts and tools.

Three programs, telehealth/telemedicine, the Ontario Community Health Survey, and British Columbia's "HealthLink BC" exemplify Canadian public health informatics. Telehealth provides consultation and health information to rural residents; the Ontario Health Survey is an internet-based population cohort to facilitate epidemiology studies of cancer and other non-communicable disorders, and HealthLink BC uses a variety of tools to provide preventive and self-care information to patients in the province of British Columbia.

**Keywords** Canada Health Infoway • Canadian Institute for Health Information • Climate change • Geography • Global Public Health Intelligence Network • Métis • Natural language processing ontology • Panorama • Telehealth • Telemedicine

### Learning Objectives

1. Compare the Canadian model for distributing healthcare financing responsibilities between federal and provincial governments to that which exists in the US between federal and state governments.
2. Indicate how reports criticizing the Canadian response to Severe Acute Respiratory Syndrome (SARS) led to informatics enhancements in public health services.
3. Explain how modern public health informatics tools will change outbreak management of SARS or a similar dangerous and highly contagious pathogen compared to the 2003 Canadian experience.
4. Analyze how the GPHIN program combines complex informatics tools with human expert knowledge to assess national news coverage for clues to the possible occurrence of disease outbreaks.
5. List three recently developed informatics systems which have been developed in Canada to meet public health needs.

## Introduction: What Makes Canada Unique

In comparison to the United States, Canadians are more supportive of a strong government role in health and somewhat less willing to accept social inequity. Some Canadians, especially those influenced by an increasingly conservative economic climate in the US and Europe, have expressed concern that many aspects of the health care system, including the very small role for a private sector in healthcare delivery, have adversely affected both the quality of health care and health care

innovation [1]. Nonetheless, despite a variety of economic, access, and quality challenges the majority of Canadians likely favor at most limited change in the structure and financing of healthcare [2]. And given the predominance of public care, many of the health and public health informatics projects emerging across Canada do involve the private sector.

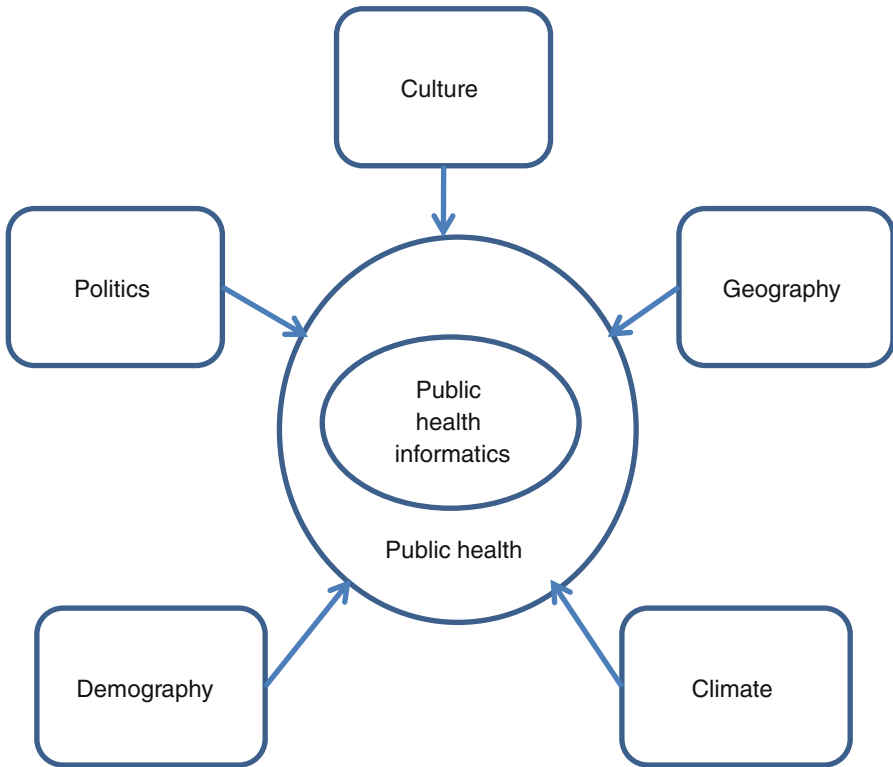
In Canada, health information systems often are procured or purchased from private sector corporations by physicians, federal, provincial, and territorial governments as well as regional health authorities. For example, there are many differing types of electronic medical record systems being used by physicians across the country. These systems are sold by private companies that compete for physician customers. Larger scale procurements and purchases have also been made by federal, provincial, and territorial governments as well as by regional health authorities.

There are arguably fewer differences between Canada and the US in public health and public health informatics, though in policy and focus Canada has tended to occupy a middle ground between Europe and the US. The Canadian “public intellectual” and novelist John Ralston Saul has advanced the thesis that, in contrast to the US and Europe, Canada’s traditional culture and social contract has been formed out of its heritage as a “Métis” nation [3]. Métis are a major Canadian ethnic group who trace their origins to marriages between Europeans and First Nations or Aboriginals. Saul contends that the Métis heritage has bequeathed to Canadians a sense of fairness and a penchant for negotiation, as an alternative to violence, in this way distinguishing them from their southern neighbor, whose historical relationship with her Native American co-continental inhabitants might most generously be described as a form of ethnic cleansing.

It is within this cultural context (i.e., Canada’s fairness and penchant for negotiation) that we consider the factors that have influenced and continue to influence public health and public health informatics in Canada. These factors include geography, climate change, demography, and politics. When considered together they have had a significant impact on Canada’s public health system and the subsequent evolution of public health informatics in Canada (Fig. 30.1).

## **Factors Affecting Public Health and Public Health Informatics in Canada**

*Geography* exerts a major influence on health and healthcare in Canada. Canada is a very large landmass, as a country it is exceeded in size only by Russia. Of the ten largest countries in the world, only Australia has a (slightly) lower population density. Most of Canada’s large population centers are close to its southern border with the US, and the northern regions of the country are for the most part sparsely settled. While much of the Canadian north lies below the Arctic Circle, winters are harsh and Northern soil is often inhospitable to agriculture. Transportation infrastructure is limited in the north, though winter ice roads facilitate travel and movement of commercial products between more southern centers and some communities north



**Fig. 30.1** Factors that have influenced the Public Health System and Public Health Informatics in Canada

of Yellowknife in the Northwest Territories. While manufacturing is well-developed, especially in eastern areas bordering the US, much of the rest of the economy relies on resource extraction. Resource extraction industries such as forestry, mining, and fishing have important public health challenges because of high injury rates and the distance of worksites from major healthcare facilities. Providing healthcare and public health services to dispersed populations living in remote areas remains a challenge that has been partly met by the widespread development of telehealth services [4]. While clinical care for rural populations remains the major telehealth focus, this technology has significant potential to address a variety of public health and public policy issues affecting rural and remote communities [5–7]. We will discuss Canadian telehealth applications in more detail later in this chapter.

*Climate change*, already clearly evident in the north of Canada, will bring major changes to the country; some of these changes will affect public health. As one of the world's largest contributors to atmospheric CO<sub>2</sub>, Canada is exerting an effect on global climate far out of proportion to its population. Much of this effect is due to recent Canadian exploitation of very large deposits of oil-yielding sands in northern Alberta. Removing petroleum from these formations requires large amounts of

energy and water and has resulted in the clear-cutting of very large tracts of land. While potential reserves of oil in Alberta's northern oil sands are estimated to be the second largest in the world, exceeded only by those in Saudi Arabia, extracting this resource comes at a huge environmental cost that has important public health (and informatics) implications [8–10].

*Demography* also has important implications for public health and public health informatics in Canada. Canada is currently one of the world's most multi-cultural societies. Over much of the past several decades Canada has had a policy of relatively open immigration that has brought in very large numbers of new residents and citizens primarily to urban areas. At present nearly a fifth of Canadian residents were born outside of Canada, and nearly a quarter speak a language other than English or French (the two official Canadian languages). With a low birthrate, "traditional" Canadians are aging and not increasing in numbers – a pattern familiar in contemporary Europe, Japan, and China. Nearly all of Canada's recent population growth is attributable to immigration. Providing appropriate prevention and other public health services have led to innovative informatics strategies, especially for refugee immigrants [11].

While this pattern of large-scale immigration has significant implications for both public health and for public health informatics, many feel that Canada's major public health challenge is achieving health equity for its First Nations and Aboriginal populations. Throughout the nineteenth and especially the twentieth century, Canada and its provinces engaged in active, often brutal, suppression of traditional cultural values and indigenous languages. The most egregious of these assaults on First Nation traditions was the forcing of children into often-violent and tuberculosis-ridden boarding schools far from their families and homes [12–14]. Many of these children suffered physical and sexual abuse that has social and psychological consequences well into adulthood [13]. Canadian public health authorities contributed further to serious cultural damage by enforcing tuberculosis hospitalization of First Nations and Aboriginal persons during the early to mid-twentieth century. Tuberculosis facilities were usually far from patients' homes; those who recovered from tuberculosis – like boarding school survivors – carried lasting social and psychological scars from their experiences [15, 16].

If Canada's public health history – and the subsequent health and social disparities experienced by First Nations and Aboriginal citizens – was initially formed by boarding school and tuberculosis policies, Canada's most recent formative public health experience was the sudden emergence of Severe Acute Respiratory Syndrome (SARS) in 2003 [17]. Although detected in a timely fashion by the Canadian Global Public Health Intelligence Network (GPHIN) surveillance system, which will be discussed in more detail later in this chapter, awareness of the rapid emergence of SARS was hampered by incomplete development of public health informatics structures in Canada. A report published by Health Canada, the federal department responsible for national oversight of Canadian health, was highly critical of the Canadian response to the SARS outbreak. Health Canada's assessment identified multiple system failures, including the lack of infrastructure to effectively warn doctors and hospitals about the likelihood of impending SARS cases, appropriate

surveillance requirements, and protective measures required for staff and patients in response to a previously unknown contagious pathogen [17].

SARS severely taxed the healthcare delivery system in Toronto, where the majority of cases occurred. Canada's outbreak was the largest outside of China, and had the highest recorded national case-fatality rate: 44 deaths among 251 cases. Reflection by Canadian experts following the SARS outbreak led to the realization that only public health systems could respond effectively to a health emergency such as SARS. Following SARS, Canada saw enhanced investment in public health infrastructure and a national recognition that providing hospital care alone would not meet all of the country's health requirements.

Long before SARS, evidence of actual and potential harm to the health of Canadians from weaknesses in public health infrastructure had been mounting but had not catalyzed a comprehensive and multi-level governmental response. The National Advisory Committee on SARS and Public Health has found that there was much to learn from the outbreak of SARS in Canada – in large part because too many earlier lessons were ignored [17].

*Politics* greatly influences the organization of public health information systems in Canada because the Canada Health Act gives government a major role in the provision of healthcare [18]. Canada is divided into ten provinces and three territories, and each province and territory has responsibility for providing healthcare and public health services to its inhabitants. The federal government has a very limited role in healthcare, but does have responsibilities to prevent chronic disease and injury as well as to respond to public health emergencies and communicable disease outbreaks [19].

## **The Canadian Institute for Health Information**

In 1994 the Federal government created the Canadian Institute for Health Information (CIHI) as an independent not-for-profit corporation whose role is “to serve as the national mechanism to coordinate the development and maintenance of a comprehensive and integrated health information system for Canada” [20]. While much of CIHI's work involves health services data compiled from the healthcare delivery system, with only limited relevance to public health informatics, in 1999 Health Canada gave CIHI responsibility for the Canadian Population Health Initiative (CPHI) [21].

As the Public Health arm of CIHI, CPHI has two main goals:

- to foster a better understanding of factors that affect the health of individuals and communities
- to contribute to the development of policies that reduce inequities and improve the health and well-being of Canadians

CPHI analyzes existing evidence and policy, commissions new research where needed, and seeks to inform Canadians about the determinants of individual and community health [21]. Publicly available results of CPHI analysis are almost



exclusively in the form of reports intended for the public and for policy makers. Much health services data is accessible through CIHI's "Quick Stats" interactive data pages [22]. Most health authorities purchase portal access, and provincial/territorial governments have ready access to CIHI data. CIHI's mandate as a public corporation requires that it recover its costs for services provided, potentially creating data access barriers for researchers, or for others who are not registered users of CIHI's data "portal" [23]. While the responsibility for collecting national public health data is shared among CIHI, Statistics Canada, the Public Health Agency of Canada, and Health Canada, for public health informaticians CPHI remains the best source of Canadian public health data aggregated at the national level.

In 2001, the federal government created a second independent not-for-profit corporation called Canada Health Infoway Inc. [24, 25]. Infoway's purpose is to channel federal funding into a variety of health-related informatics activities, including public health surveillance. One of Infoway's major accomplishments is *Panorama*, an information system being constructed for provincial and territorial Public Health. Other health informatics system solutions have been developed or extended in innovative ways to address the public health issues that arise from the unique factors influencing the health of Canada's population (i.e., culture, geography, politics, demography, and climate), one of which (GPHIN) will be discussed in more detail.

## The Global Public Health Intelligence Network (GPHIN)

In September 1994, Canadian television showed people fleeing the city of Surat, India due to an outbreak of possible pneumonic plague. While at the time there might have seemed to be minimal significance or threat to Canadians from a public health tragedy halfway around the world, circumstances proved otherwise. Several hours after the airing of news reports, workers at Canada's largest airport threatened a complete work stoppage in response to the arrival of an Air India flight. It became clear to public health officials that distance was no longer a protection, and that with modern transportation a communicable disease in a distant place could impact Canada within hours or days. Surat's plague was a wake-up call: there was a need for early warning of possible threats to the Canadian public generated by movement of potentially-diseased or contaminated people, animals, animal products, and processed foods around the world.

By the early 1990s, the Canadian government was determined to utilize innovative communications and information technologies for health information systems [26]. A set of pilot projects to demonstrate the use of the Internet for accessing and exchanging health surveillance information was undertaken, and included the development of the GPHIN prototype system in 1998. GPHIN was designed to continuously monitor global news media on the Internet and gather current information about possible disease outbreaks worldwide. Because news media may be imprecise and subject to reporters' biases, GPHIN entered into an agreement with

the World Health Organization (WHO) to establish a process to verify disease outbreaks of potential international public health concern [27]. WHO's role was to request verification by Member States to corroborate information originating from unofficial sources on the Internet.

## ***GPHIN Architecture***

Once verification was assured, GPHIN proceeded to build an infrastructure, processes, and components for a robust early-warning system, using reports from news media sources around the world. Rather than scanning individual web sites, GPHIN chose to use news aggregators as the primary information source. News aggregators are websites or other electronic data sources that use automated systems to scan and collate news reports from a variety of sources [28]. As the prototype GPHIN system evolved, news media sources and languages were expanded to include Arabic, Chinese (simplified and traditional), Farsi, Portuguese, Russian, and Spanish media sources. New public health issues such as infectious diseases in animals and food, radiation events, product safety concerns, and natural disasters were added. The automated Internet-based monitoring component operates 24/7, gathering, filtering, and categorizing relevant news reports. The reports are presented in chronological order for human analysis by a multilingual, multidisciplinary team of analysts, who ensure public health relevance and identify conditions notifiable under the revised International Health Regulations [29]. During public health emergencies such as SARS, GPHIN analysts work around the clock to provide users with regularly updated status reports on the emerging situation.

## ***GPHIN: Management of Information***

GPHIN has added advanced informatics technologies to accommodate an expanding volume of news reports and the continuing addition of new languages. These technologies include a machine translation engine combined with data filtering and manipulation tools to identify duplicate or irrelevant reports [30]:

- **Rating Algorithm:** Reports are rated for quality and relevancy according to an algorithm developed for use by human raters.
- **Categorization:** GPHIN uses a filtering structure to categorize reports into a variety of categories, examples of which include human diseases, animal diseases, plant diseases, natural disasters, and chemical or radiological exposure incidents. This process utilizes a *natural language processing ontology* system that classifies reports by automated content analysis.
- **Relevancy Scoring:** A computerized algorithm uses a combination of subject categories and keywords identified in the articles to produce a numerical score for each article. Those with low automatically-assigned relevancy are not posted

but receive expert human analysis. Those with moderately high scores are also sent to analysts for review, but are simultaneously posted on the GPHIN site accompanied by a statement that human review is pending. Articles with very high scores are posted immediately.

Currently, over 20,000 news media sources are monitored in nine languages. Search syntaxes are used to identify and gather relevant news reports that are then forwarded to the multilingual platform. News reports are further filtered and categorized according to the GPHIN system taxonomy as described above. Occasionally, news reports not captured by the automated process are manually entered into the GPHIN system. Each news report is assigned a relevancy score based on keywords, automated news report analyses, and the GPHIN system taxonomy. Analysts systematically review reports given low relevancy scores to ensure the accuracy of data mining algorithms. Analysts may use query functions applied to an archive of prior reports to confirm the relevance of the filtered news reports and to identify trends or possible relationships between apparently disparate events. These tools greatly facilitate the work of human analysts.

To be effective, the GPHIN system must identify relevant information and separate it from “noise”, such as irrelevant and duplicate media reports. As is often the case in public health informatics, establishing criteria to monitor and retrieve relevant news reports involves a delicate balance between being too specific and being too general. While duplicate reports are filtered automatically, other criteria are adjusted regularly to ensure comprehensive capture of relevant public health issues. Because of its informatics complexity, GPHIN requires multidisciplinary human analytic and interpretive skills of a high order. Analysts play a crucial role in identifying situations that may have serious public health consequences and flagging them as alerts. In addition to linguistic skills, GPHIN analysts require broad knowledge in public health, journalism, medicine, biology, chemistry, environmental science, economics, and surveillance technologies.

Users of the GPHIN system are able, without cost, to access the multilingual system from anywhere there is Internet service using a password-protected interface. Users have ready access to GPHIN analysts so they can request assistance regarding specific queries, ask for clarification on translated news reports, or provide feedback on any of the features and functions of the GPHIN system.

### ***GPHIN Value***

Based on several studies, GPHIN’s system has proven to be valuable both during and in the absence of a public health emergency. GPHIN has been a primary source of event-based information utilized by WHO and the International Health Regulations [30–32]. The proportion of verified events for which news media were the initial reporting source has varied from year to year, but GPHIN remains an important early warning and situational awareness tool.

Some of GPHIN's more important contributions came during the SARS epidemic, the appearance of avian influenza (H5N1), and the H1N1 influenza pandemic. During all the recent major global outbreaks, GPHIN reported not only on the magnitude of the outbreak, but also on related issues such as the type of control and prevention measures being considered and implemented by countries worldwide.

### ***GPHIN Challenges***

While the information from news media is useful, there are ongoing challenges to ensure that the information is reliable and accurate. It is often difficult for GPHIN analysts to ascertain which news reports provide the most accurate information. While analysts favor news reports in which the source for the information is an official representing a governmental healthcare organization or an international body, over the years analysts have become aware of news sources that may have political motivations to potentially distort factual material. GPHIN has also noted that social media such as Twitter and Facebook have emerged as potentially important sources that can indicate that an event of significance is beginning.

False positives occur occasionally, especially when information has been incorrectly translated from one language to another. For example, in Arabic the word for chicken pox is very similar to the word for smallpox and thus can easily be misinterpreted. Subsequent news reports in Chinese and French clarified that a reported outbreak of chicken pox in Yemen had been incorrectly translated from Arabic to English as smallpox [33]. To ensure accuracy of the system, GPHIN analysts must understand the style of writing and the use of language in different regions of the world.

Timeliness is important. While delays may occur before a GPHIN analyst can issue an alert published in a distant time zone, GPHIN has exploited advances in technology to shorten the time between the publication and retrieval of news reports. The GPHIN system gathers news reports every 15 min, and automated processing makes these reports available for initial viewing in less than a minute. New technologies are enabling ever-faster dissemination of both news and alert reporting. Speech-to-text and text-to-speech technologies allow a statement made by an official during a press conference to be automatically transformed into text and quickly disseminated worldwide, while alerts generated by the GPHIN system can be sent equally rapidly to users via email, which can be rapidly accessed by the user directly or through smart-phones and other digital devices.

### ***GPHIN Summary***

The GPHIN system has been stable and robust for nearly two decades. The team of IT specialists who support the GPHIN system has been instrumental in managing

technical difficulties that have arisen. The team continuously assesses the functionality of the GPHIN system to see where improvements can be made to benefit users and analysts. The continuing trend of globalization and increased human mobility means that global public health security is increasingly under threat [34]. Large scale migration and human incursion into areas shared with wildlife increase the risk of infectious disease transmission. War and other conflict often destroys surveillance and communication pathways that make large-scale emergence of these diseases more probable. With the 2005 revision of the International Health Regulations, all nations have an increased need for rapid information to comply with reporting regulations [29]. As an event-based surveillance system, GPHIN has demonstrated its capability to enrich traditional surveillance and support early-warning functions by monitoring the occurrence and evolution of disease outbreaks and other events of public health importance.

## **Leveraging Electronic Health Records for Public Health**

Public health surveillance tools are an essential component of Canada's health information infrastructure, but many other components also have important public health applications. For example, data extracted from provincial information systems has been used for occupational disease and injury surveillance; to study the risk of falls; to evaluate whether methadone, in conjunction with other harm reduction initiatives, can reduce transmission of Hepatitis C among individuals who inject opiates; and for many other topics. Likewise, electronic medical records have also been used to assist with public health interventions. For instance, a large group practice in Sault Ste. Marie, Ontario, used its electronic records to identify and schedule vaccinations for patients who might most benefit from H1N1 vaccination [35]. Many other similar applications are possible. Public health units in Vancouver have managed to link a legacy public health electronic record system to Panorama so that some vaccination-related information can be shared between the two systems, reducing the need for duplicate data entry [35].

## **HealthLink BC**

### ***Telehealth for Public Health Surveillance and Response***

There has been a substantive growth in *telehealth* services and usage across Canada over the past decade. Telehealth services use computer and video technology to allow patient-clinician interaction from a distance. Not only does this technology allow specialist services for clients who live far from major medical centers, but it can serve to provide information, advice, and clinical consultation for those seeking

assistance with health issues. Telehealth practitioners, policy makers, and researchers have also observed that telehealth can be a source of public health information and surveillance intervention as it helps citizens to address their health needs, while at the same time supporting population health. For example, HLBC played a key role in the Provincial H1N1 outbreak management response, including notification, trending, and responses such as immunization.

HealthLink BC (HLBC) is a non-emergency health information service that provides BC and Yukon residents with 24-h access to medically-approved information and advice from anywhere in the province [39]. HLBC was launched in 2008 and operates as a branch within the Health Sector Information Management/Information Technology Division (HSIMIT) of the B.C. Provincial Ministry of Health. HLBC operates, maintains and enhances a 24/7/365 contact center and web-based platform that provides the general public, within British Columbia and the Yukon, with access to health related information and advice, health navigation services, and timely disposition and/or resolution of health related problems. HLBC provides access to an organized system of real-time health advice, information, and navigation that supports and educates the public and health care providers around both episodic and chronic care through multiple delivery channels, including telephone services (8-1-1 and 10 digit dialing) for delivery of HLBC nursing, dietitian, pharmacy, navigation, and print and web services. Because of partnerships with the British Columbia Centre for Disease Control (BCCDC) and the Ministry of Health (MOH), HLBC is able to access and publish real-time information and advice researched and developed by these key governmental agencies [36].

The HLBC contact centre is staffed by registered nurses, dietitians, and pharmacists, and services include:

- *Health information* – provision of credible, reliable information on a wide variety of health topics.
- *Health advice* – the application of clinical skills and knowledge to triage, advise, and assist an individual (or their care giver) with self-care or management, or a colleague with enhanced practice and/or service provision.
- *Clinical consultation* – the provision of specialized clinical advice to health professionals to assist in the management of an individual in their care.
- *Professional engagement* – engagement with relevant professional communities and supporting governance bodies on matters related to the best provision of service. This may include working with the public sector, private sector, research bodies, academic institutions, and professional licensing organizations.
- *Encounter information* – pertinent information about the person(s) in receipt of service and their interaction with HLBC.

HLBC maintains key records and analytics related to its services, appropriately capturing data from both phone- and web-based interactions. This data includes the geographic location of the client and the topic or area of concern. HLBC routinely

processes this data for significance, correlation, and clustering, and has utilized this data to predict and respond to various public health-based occurrences.

Using H1N1 as a case study, HLBC was able to identify its capacity as an organization to assist in public health surveillance. Through routine analysis of data captured in its decision support and integrated client record system, HLBC identified an increased incidence of respiratory and gastrointestinal-based symptoms, and was further able to associate this variation to both geographical area and demographical age and gender information. Upon recognition of this emerging issue, data was circulated to other public health agencies such as the BCCDC and the Ministry of Health (MOH.) This analysis assisted with response readiness, targeting of responses, and timely dissemination of key information to the general public, serving to enhance the content and timeliness of BC's response to this public health concern.

HLBC is working the the MOH to analyze HLBC telephone call classifications and volumes and web data (searches, views and Google trends) to support the identification of emerging public health issues. HLBC continues to enhance its role as a key sentinel public health surveillance program.

Health information and advice can be provided using Internet and telephone services. Telehealth organizations like HealthLink BC are partnering with public health organizations (e.g., BCCDC) as well as ministries of health to share and access information about disease outbreaks. Such work is essential not only in recognizing a disease outbreak when it is occurring, but in developing a response that will help the public during such events.

## Summary

Canada has a rich cultural and political history that has been greatly influenced by its complex relationship with Aboriginal peoples and by successive waves of immigration to a large country rich in natural resources. The Canadian healthcare system provides near-universal access to all residents through a public "single payer" structure, which stands in sharp contrast to the more privately focused system in the US. While Canada's public health infrastructure is much smaller than that in its more populous southern neighbor, Canada has made a number of unique contributions to public health informatics; among these are the GPHIN surveillance system, Panorama, HealthLink BC, and the Internet-based Ontario Health Study [37]. GPHIN was arguably the first automated surveillance tool for international public health event surveillance and served as the model for a variety of similar and complementary surveillance systems. While perhaps of less international importance, Panorama, HLBC, and other telehealth programs provide national and regional informatics solutions to the provision of public health to Canada's unique demographic mixture of dense urban populations and highly dispersed rural and remote settings.

### Review Questions

1. Compare the role of the Canadian Federal government in health and public health care to that in the US.
2. How did Canada's 2003 experience with SARS lead to changes for the Canadian Public Health system?
3. How was GPHIN able to identify the SARS outbreak in China well before it was reported in the professional media or on "standard" communicable disease surveillance sites?
4. What is the role of the Canadian Institute for Health Information (CIHI)? What unit within CIHI is responsible for the collection and analysis of public health data?
5. What contributions does telehealth make to the improvement of public health in sparsely populated rural and remote areas of Canada?

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# Chapter 31

## Perspectives on Global Public Health Informatics

Janise Richards, Gerry Douglas, and Hamish S.F. Fraser

**Abstract** Public health professionals' functions are rapidly expanding beyond their countries' borders. Many academic centers are recognizing the importance of global health and are creating programs to train students to meet this growing demand. Global health centers and institutes also are being created to focus on the research and programmatic efforts needed to understand the burden of disease worldwide, as well as the financial, political, medical, policy, workforce, and infrastructure issues surrounding any solutions. Due to this emerging interest by the public health community, we need to understand where the intersection between global health and informatics occurs. For many years, the promise of what technology can do to alleviate suffering and support disease surveillance and other public health activities took precedence over understanding the environment in which the technology has to function. People and their participation in the implementation of the technological solution are critical for success. In resource-poor environments, the deployment of technological solutions faces other challenges for success. Lack of stable electrical power, availability of Internet connections, and a workforce that can support the information technology remain barriers to successful implementation. Yet, through experiences in the implementation of information technology as supported by

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international donors and the US President's Emergency Plan for AIDS Relief, lessons are being learned to move forward towards the benefits that global health informatics can bring.

**Keywords** Global health • Global health informatics • OpenMRS • PEPFAR • HIV/AIDS • Malawi • Rwanda • EHR • Low income • Resource-constrained

### **Learning Objectives**

1. Define global health informatics.
2. List and describe some global policies that support public health in low-income, resource-constrained countries.
3. Describe public health informatics interventions that have been successfully developed and deployed in low-income, resource-constrained countries.
4. Cite examples of public health informatics interventions that have been developed and deployed in a low-income, resource-constrained country, add value, and have been sustained.
5. Articulate challenges surrounding the use of information technology in healthcare in a low-income, resource-constrained country.
6. Describe solutions to common problems confronted in the deployment of systems in low-income, resource-constrained countries.

## **Overview**

Public health professionals' functions are rapidly expanding beyond their countries' borders. Many academic centers are recognizing the importance of global health and are creating programs to train students to meet this growing demand. Global health centers and institutes also are being created to focus on the research and programmatic efforts needed to understand the burden of disease worldwide, as well as the financial, political, medical, policy, workforce, and infrastructure issues surrounding any solutions. Due to this emerging interest by the public health community, we need to understand where the intersection between global health and informatics occurs. For many years, the promise of what technology can do to alleviate suffering and support disease surveillance and other public health activities took precedence over understanding the environment in which the technology has to function. People and their participation in the implementation of the technological solution are critical for success. In resource-poor environments, the deployment of technological solutions faces other challenges for success. Lack of stable electrical power, availability of Internet connections, and a workforce that can support the information technology remain barriers to successful implementation. Yet, through experiences in the

implementation of information technology as supported by international donors and the US President's Emergency Plan for AIDS Relief, lessons are being learned to move forward towards the benefits that global health informatics can bring.

## **Introduction**

As the world becomes more interconnected through travel, migration, and economic forces, many health issues are being increasingly recognized as a concern not for only one country, but for all nations. Infectious diseases such as lung infections, tuberculosis, and human immunodeficiency virus (HIV), and chronic diseases such as diabetes, cancer, and ischemic heart disease, are leading factors of death worldwide [1]. Sudden outbreaks, such as severe acute respiratory syndrome (SARS), H5N1 influenza, and novel Ebola virus have captured the world's attention [2]. The neglected tropical diseases, so named for lack of adequate response, also are gaining attention and, in some cases, severity [3, 4]. For example, global incidence of severe dengue, a mosquito-borne viral infection with no specific treatment, has grown rapidly in the past four decades, from only nine countries before 1970 to more than 100 countries in 2010 [1]. None of these health issues are limited to particular continents or countries, socio-economic class, race, or gender. They are health issues that are important to all people.

Informatics has been involved in infectious disease [5], chronic disease [6], and neglected tropical diseases [7, 8]. Surveillance systems, laboratory information systems (LIS), data warehouses, electronic health records (EHR), and other electronic health information systems (HIS) are used by public health professionals in detecting and responding to infectious disease outbreaks and supporting the continuity of care for chronic disease. Since global action is necessary to effectively reach the highest attainable standard of health and well-being for the world's people, global health informatics is necessary to tackle these worldwide health issues.

## ***Global Health***

Global health is a term that has gained widespread use. For many years, international health was a fixture in the public health vocabulary to describe public health activities outside of one's country or between countries. As times and situations in the world have evolved, the terms to reflect these global changes have become more refined. However, to date, no single definition of global health has been widely adopted. As often occurs in a relatively new field, there appears to be ambiguity and elusiveness about what the field is. Most of the literature about global health suggests that global health includes health-related issues that cross national boundaries, are common to all people, and for which solutions can be translated to many different communities.

A good place to start in looking at the field is to examine its genesis. Often, the terms international health and global health have been considered to be synonyms,

**Table 31.1** Comparison of global, international and public health

	Global health	International health	Public health
Geographical reach	Focuses on issues that directly or indirectly affect health but that can transcend national boundaries	Focuses on health issues of countries other than one's own, especially those of low-income and middle-income	Focuses on issues that affect the health of the population of a particular community or country
Level of cooperation	Development and implementation of solutions often requires global cooperation	Development and implementation of solutions usually requires bi-national cooperation	Development and implementation of solutions does not usually require global cooperation
Individual or populations	Embraces both prevention in populations and clinical care of individuals	Embraces both prevention in populations and clinical care of individuals	Embraces both prevention in populations and clinical care of individuals
Access to health	Health equity among nations and for all people is a major objective	Seeks to help people of other nations	Health equity within a nation or community is a major objective
Range of disciplines	Highly interdisciplinary and multidisciplinary within and beyond health sciences	Embraces a few disciplines but has not emphasized multi-disciplinarity	Encourages multidisciplinary approaches, particularly within health sciences and with social sciences

Source: Koplan et al. [11]

and many considered it unnecessary to differentiate between them [9]. Conversely, others believe that differentiating the two terms helps global health practitioners develop clearer policy and direction. Brown et al.'s view is that the term international was meaningful in the late nineteenth and early twentieth century when the focus was "control of epidemics across boundaries between nations," and the relationships regarding policies and practices of public health between the sovereign nations were central to solving health problems [10]. As the focus developed into a consideration of health needs of people worldwide "above that of particular nations", with increasing involvement of non-governmental organizations (NGOs), the term global health better described the worldview. As part of an initiative from the Consortium of Universities for Global Health (CUGH) Executive Board, an examination was made to highlight the fundamental similarities and differences between global, international, and public health [11]. They determined that attributes of geography, cooperation, populations, access, and disciplines offer the best insights. In global health, the health issues transcend national boundaries, solutions require worldwide cooperation and involve both prevention and clinical care, health equity is a necessary pursuit among all nations, and collaborations are developed within and among multiple disciplines (Table 31.1).

The Koplan et al.'s [11] definition is frequently cited and has been adopted by the 2011 Expert Panel on Canada's Strategic Role in Global Health [12]:

Global health is an area for study, research, and practice that places a priority on improving health and achieving equity in health for all people worldwide. Global health emphasizes transnational health issues, determinants, and solutions; involves many disciplines within and beyond the health sciences and promotes interdisciplinary collaboration; and is a synthesis of population-based prevention with individual-level clinical care.

### ***Global Health Informatics***

Global health informatics uses many different terms, concepts, and technologies. A thorough scan of the multiple scientific and grey literature databases and multiple Internet search engines indicate that there are few instances that use the full term – global health informatics. This begs the question: what is global health informatics? We propose that global health informatics is the informatics discipline focused on empowering people to use appropriate technology to provide information-based solutions with a global perspective that support health care for all. The mission of global health informatics is to share informatics knowledge, skills, and research, and foster local innovations to promote highest standards of health for all with an emphasis on low income, low resource countries and the medically underserved.

### ***The Influence of Global Health Policy***

Over the past 30 years the state of the world's health has improved significantly. Life expectancy rates have increased and quality of life has improved in almost all countries. Public health measures, new medical technologies that have been readily adopted, and improved health literacy have all played a role in this increase. Collective global health actions also have been central to increasing the standard of health for all people. The foundation for these changes can be traced back to two critical policy statements: the 1978 WHO Declaration of Alma-Ata, which called for urgent action by governments and the world community to promote health of all the people of the world, and the 2000 United Nations (UN) Millennium Declaration, which built upon the ideas of the Alma-Ata Declaration more specifically by outlining eight goals, each with measureable objectives to be achieved by 2015 [13]. Of these eight goals, now known as the Millennium Development Goals (MDGs), three are directly related to health – Goal 4: Reduce child mortality rate; Goal 5: Improve maternal health; and Goal 6: Combat HIV/AIDS, malaria, and other diseases.

The establishment of these concrete goals provided the catalyst and focus for many other UN agencies and related programs. Countries also have used the framework of the MDGs to target their developmental aid funds, such as Sweden (SIDA),

Norway (Norad), Germany (GIZ), United Kingdom (DIFD), Canada (CIDA/IDRC), Australia (AusAID), and the United States (USAID/HHS-CDC). International organizations, such as the World Bank, Global Fund, and Asia Development Bank, have used the MDGs as a focus for funding in-country projects. During the last decade, many US-based NGOs began to play a major role in supporting initiatives to reach the MDG health-related goals, including the Bill and Melinda Gates Foundation, Rockefeller Foundation, Ford Foundation, and the William J. Clinton Foundation [14].

For many decades, the United States (US) has been actively involved in working with other nations to improve global health. In 2003, President George W. Bush called for the creation of the President's Emergency Plan for AIDS Relief (PEPFAR), formally authorized by US Public Law 108–25, United States Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act of 2003 [15]. The authorization was for 5 years and up to US\$15 billion for HIV care, treatment, and prevention, and included support for capacity building and strategic information (i.e., surveillance, monitoring, and evaluation) in 15 focus countries, and for initiatives by the Global Fund to Fight AIDS and UNAIDS. This initiative is considered to be the largest commitment by any nation to combat a single disease in history [16]. The 15 focus countries were among the countries hardest hit by HIV disease: Botswana, Cote d'Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Viet Nam, and Zambia. In 2008, US Public Law 110–293, Tom Lantos and Henry J. Hyde United States Global Leadership Against HIV/AIDS, Tuberculosis, and Malaria Reauthorization Act of 2008, re-authorized PEPFAR for an additional 5 years and up to US\$48 billion to expand to 49 countries and regional programs. Building on the established prevention, care and treatment, capacity building, and strategic information programs, PEPFAR II emphasizes country partnership and ownership, and strengthening of health systems. PEPFAR remains the largest funder of global health initiatives and has many successes in reducing the burden of HIV/AIDS in the focus countries. In fiscal year 2011, PEPFAR directly supported HIV testing and counseling for more than 9.8 million pregnant women, and care and treatment for nearly 13 million people including more than 4.1 million orphans and vulnerable children [17].

## **Health Information Systems in PEPFAR**

From the beginning, the use of electronic health information systems was a critical component of the PEPFAR implementation. High-quality data are essential to HIV prevention, care and treatment, policy development, resource planning, and accountability. Understanding the burden of disease requires functioning surveillance and aggregate indicator monitoring systems. Providing effective patient treatment requires consistent and available patient, laboratory and pharmacy data. All of the PEPFAR focus countries had major deficiencies in their national health information systems. During the first years of PEPFAR, the aim was to assist countries in



developing health information system infrastructure that would support the national and PEPFAR HIV/AIDS programs. Health management information systems (HMIS) were developed to help report the 41 core indicators that were required as a condition of funding. These indicators and other nationally-oriented indicators were also used for policy development, program planning, implementation, and identification of best practices. These systems frequently were paper-based at the facility and district-levels of a country, and then captured into an electronic system at or before arriving at the Ministry of Health. In the countries with electronic data systems in facilities or districts, the effort was placed on harmonizing data elements and core data sets. As health information infrastructure matured in countries, patient-level data collection systems were implemented to be used for both patient care and for routine health information for surveillance, monitoring and evaluation, and resource planning.

Over the past 8 years, counseling and testing have identified millions of people with HIV/AIDS and anti-retroviral treatment has extended the life span of people living with HIV. Due to this impact, electronic systems have become more necessary to manage the volume of patient data created by longitudinal health records. Electronic medical records (EMR), laboratory information systems (LIS), and other patient-level systems are being implemented.

This growth in patient-level systems has created a greater need to standardize functional and technical requirements for health information systems, design systems that facilitate and enable interoperability between different systems (e.g., EMRs, LIS, pharmacy, and others), facilitate linkage and de-duplication of records, and strengthen data security, privacy, and confidentiality measures. This work will be done partly through innovative technical solutions. Most of the work will be accomplished through strengthening strategic planning and governance, developing in-country human capacity, and on-going evaluation of health information system implementations to identify effective informatics practices, efficiencies gained, and health impacts.

Building partnerships with countries to create sustainable health information systems is a foundational goal of PEPFAR II. Working with Ministries of Health to build infrastructure and human capacity, PEPFAR has encouraged countries to assume more leadership responsibility. The focus has shifted from health information systems developed and supported by PEPFAR to a situation where Ministries of Health recognize the necessity of leveraging and coordinating the investments in health information infrastructure and systems among donors and develop country-level strategic health information system plans with measureable goals and objectives. Across Africa, Asia, and Latin America, huge advances have occurred in information and communication technologies, and Ministries of Health are seeking to take fuller advantage of these tools to improve service delivery.

How these policies have played out in countries has depended on many factors. Some countries have a more stable governmental infrastructure and are able to establish long-standing health information system policies; others have a more fluid governmental situation where leadership changes frequently and health information system policies may be retracted or radically changed. Environmental factors

including lack of navigable roads, potable water, sanitary conditions, electrical power, and sheer distance between communities can impact countries' motivation and ability to prioritize or implement an electronic health information system. The small gains in developing and retaining informatics skills and knowledge in-country may not be enough to sustain the systems. Sustainable and country-owned health information systems are the goal; the global informatics community is the supporting actor.

Below are two case studies that describe the evolution of health information systems to support care and treatment of people with HIV/AIDS in two low-income, resource-constrained countries. These cases provide insights into lessons learned, technologies used, and policies needed. They are illustrative of many health information system implementation endeavors within low-income, resource-constrained, and HIV/AIDS-burdened countries.

## **Case Studies of Health Information System Implementation**

### *A Decade of Public Health Informatics in Malawi*

#### **Background**

Malawi is a landlocked country in sub-Saharan Africa with a population of approximately 15 million people. The Malawi Ministry of Health provides healthcare at no cost through a network of government health facilities comprising roughly 400 health centers, supported by 24 district hospitals and 4 central referral hospitals. In 2007, health adjusted life expectancy at birth was 44 years. The World Health Organization (WHO) ranks Malawi 185 out of 191 in overall health system performance [18]. Roughly one in 17 children die before reaching 12 months of age and one in 11 die before reaching 5 years of age (2010). Roughly 11 % of the age 15–49 population is HIV positive (2009). Malawi, like many low- and middle-income countries, is hampered in its ability to provide healthcare by a severe shortage of medical staff, medications, and diagnostic resources. Malawi has the lowest ratio of doctors per capita of any country (~1 physician per 50,000 capita in 2012). In 2012, spending on healthcare was US\$65 per capita [19].

The Central Monitoring and Evaluation Division (CMED) housed within the Ministry of Health is responsible for the collection, analysis, and reporting of key health indicators from all health facilities in Malawi. Prior to 2000, the collection of morbidity and mortality data relied on the completion of pre-printed forms by clinicians, nurses, and clerks. Outpatient diagnoses were recorded on a monthly tally sheet, and inpatient data was abstracted from a three-part discharge form. A team of data entry clerks entered data from the paper forms into computers using custom-developed data entry software written in dBase IV. Following a national review in 2001, a series of paper-registers were introduced, replacing tally sheets and discharge forms as the primary form of data collection. This shift to using registers for

data collection required that health facilities manually aggregate their own data before reporting it. Particularly at district and central hospitals, the registers were increasingly being completed by lay clerks with little or no training in health or medical terminology, rather than by clinicians and nurses. To produce district-level and national-level reports from the manually-aggregated totals derived from paper registers, the District Health Information System (DHIS) software was adopted [20].

## Issues and Solutions

Our initial work piloting informatics solutions with the Malawi Ministry of Health started in 2001. We started our investigations at Kamuzu Central Hospital (KCH), a 700+ bed referral hospital located in Malawi's capital city of Lilongwe. We observed that ward clerks had no training in medical terminology, but were required to both transcribe medical data as well as map diagnoses into indicators (e.g., Diabetes was mapped into an indicator called Other Non-communicable Diseases of Public Health Importance), raising questions about the completeness and accuracy of the reported data. Clinicians were over-burdened with patient care, and perceived documentation for "statistical" purposes as outside the scope of clinical work and therefore not part of their responsibilities. We hypothesized that an electronic information system designed to support the delivery of healthcare in a resource-poor setting may provide clinicians and nurses with tools that would augment their ability to efficiently and effectively deliver healthcare, while collecting data as a transparent byproduct of system use. We proposed the idea of a rudimentary electronic medical record (EMR) that would be used by clinicians in real-time at the point-of-care, and moved ahead with the development of a system to be piloted in the pediatric department at KCH.

As we developed hardware and software solutions for our pilot work, we identified several potential and two critical barriers. First, health workers had little or no training in using computers. We believed that this could be mitigated by emphasizing simplicity and usability as part of the system design [21, 22]. Recognizing that to develop computer literacy among the users would take time, we opted for an entirely touchscreen-driven user interface. Secondly, power outages at the hospital were frequent, and would be a significant threat to building a reliable system. To address this, we developed a power back-up solution around locally-available deep-cycle batteries used for solar power installations. However, rather than charging them from solar panels, we simply connected them to a charger powered by the national grid. This solution, combined with the efficient low-power touchscreen computers, allowed the system to run for 36–48 hrs. in the absence of power from the grid [23].

## System Description

Our pilot system was aimed at supporting the care of children attending the outpatient clinic as well as those admitted on the wards at KCH (216 beds). At that time, no records were kept for patients seen in the outpatient setting. Paper charts were

created for patients admitted to the ward, and for the most part could be retrieved during the normal workday on subsequent admission, provided the patient's name and date of last admission were known. For our pilot, we aimed to create a permanent electronic record of outpatient visits, capturing a limited set of diagnostically-relevant signs and symptoms and a diagnosis. For inpatients, we chose only to capture the date of admission, discharge diagnosis, and the date of discharge, from which length of stay could be derived. While this seems trivial in the context of a western incarnation of an EMR, it allowed us to do a basic proof of concept. Furthermore, it represented an improvement over the current paper system, allowing clinicians in both the outpatient clinic as well as on the wards to see a patient's past medical history, albeit limited.

The greatest impediment to creating this time-series of patient visits was re-identifying the patient on subsequent visits to the hospital. Malawi has no form of national registration system, eliminating a national ID number as a possible unique patient identifier. Many patients were illiterate, making it impossible for them to verify the spelling of their name. Many older patients knew their year of birth, but not the month and day. We chose to implement a simple patient registration system that allowed a clerk to capture a limited set of demographic information from a patient and generate a unique patient identifier. This information was stored in an electronic Master Patient Index as well as printed on an inexpensive adhesive label to be affixed to a patient's health passport, a small patient-kept booklet issued to patients by the Ministry of Health. To facilitate ease-of-use and reduce the chance of transcription or data-entry error, the patient's unique identifier was represented in barcode form as well as in human-readable text on the label. The inpatient module primarily tracked admissions and discharges and was operated by clerks. The outpatient module was developed with the intention of clinicians' use, but was not well-adopted and subsequently discontinued as the system was both too onerous and not sufficiently detailed [24].

Following discussions with pediatricians at KCH as well as the College of Medicine in Blantyre, we decided to focus on strengthening the admission process. We created an admission module modeled off a paper-based admission guideline developed at the College of Medicine [25]. The module systematically stepped the clinician through the assessment of the patient and creation of a treatment plan, including medications to be prescribed and diagnostic tests to be ordered. Time-saving features of the module included automatic medication dosage calculation based on the child's weight and age, and generation of specimen labels for all samples to be drawn for laboratory testing. On completion of the process, the system printed an admission note, a pre-populated medication administration record, and a nursing plan template. We felt that this was the first example of a true point-of-care application working in a low-resource setting, and concluded that there was sufficient evidence that this approach could be extended to other clinical domains.

In 2003 and 2004, we undertook two small demonstration projects to determine the potential use of information systems for supporting ancillary services in the hospital. Working with pharmacy technicians in the KCH pharmacy dispensary, we developed a simple medication dispensation tracking system. At that time, tracking

of medication usage was done at the level of bulk containers. For example, the pharmacy would document that the dispensary had received 5,000 tabs of Ibuprofen, but not how many or to whom those tabs had been dispensed. While only a small portion of the medications had barcodes printed on the packaging, we were able to create a simple barcoding system by labeling the shelf on which the medications were stored at the dispensation window. We arbitrarily assigned medication ID numbers to all drugs in the pharmacy and printed barcoded labels for each section of the shelf. Using these barcodes to identify medications being dispensed, and patient identifiers in barcode form on the patients' health passports, pharmacy technicians were able to record patient-level dispensation of medication in real-time using a touchscreen computer located at each of the four dispensation windows in the pharmacy.

Working with the radiology department at KCH and with the assistance of a consultant radiologist, we developed and deployed a simple touchscreen-based system to improve the labeling of radiology films. Prior to this intervention, x-ray films were labeled in the top left-hand corner by transferring the patient's name from a hand-written note onto the x-ray film using a photo-imprinting process at the time of developing the film. Legibility of the label was poor, making it hard to identify to which patient the film belonged, and making filing of films almost impossible. Our solution used a touchscreen computer, barcode scanner, and thermal label printer located in the radiology department to retrieve the patient's demographic record from the master patient index, select the type of study ordered and referring department using on-screen prompts, and print a legible adhesive label to first be used for photo-imprinting onto the film, and then be affixed to the film envelope for clear identification.

In 2005, with support from the United States Agency for International Development (USAID), we developed and piloted a touchscreen-based electronic pharmacy inventory control system (ePICS) to manage medication inventory at the stockroom level. The system combined features found in advanced inventory management software, with the high usability offered by the touchscreen user interface.

### Supporting HIV Care and Treatment

In 2003, working with a Malawian NGO providing voluntary counseling and testing (VCT) services, and with support from the US Centers for Disease Control and Prevention (CDC), we developed a touchscreen system designed to guide counselors through the counseling process, while collecting data to be used for monitoring and evaluation (M&E) [26]. This system was deployed at three VCT sites in Malawi, where it was used by dozens of counselors with no prior computer training. This apparent success increased our confidence that electronic systems, if appropriately designed, could be used in real-time in low-resource settings. In 2004, working with the Lighthouse Clinic, an HIV Center of Excellence in Malawi, our focus on HIV moved into the development of a prototype EMR for managing patients receiving

antiretroviral therapy (ART). This was our first encounter with designing a system to accommodate multiple points of care (patient check-in, vital signs station, nurses exam room, clinicians exam room, and pharmacy), and multiple workflows. This was a large undertaking, and pushed the limits of both our capacity and our capabilities. While still under development there were many revisions to the system specification, partially due to changes in treatment regimens and guidelines, and progress was painfully slow.

In mid-2005, we made the decision to change our development platform to take advantage of free and open source software as much as possible. This was motivated by the vision that these systems, if successful, would be adopted by the Malawi Ministry of Health, and the cost of scaling-up could be reduced if license costs for operating system and database management systems could be eliminated. An additional appeal of open source was the emphasis on community-based support rather than vendor-based support, which we perceived to be a better model for supporting systems in low-resource settings.

By 2006, Malawi's national response to providing antiretroviral therapy was in full swing, with some of the more well-established clinics managing several thousand patients. Overwhelmed with the challenges of generating quarterly and cumulative cohort reports for programmatic M&E, the Department of HIV and AIDS within the Ministry of Health issued a request for proposals for the development of an electronic system to automate the generation of reports at high-burden sites. Working in collaboration with the Ministry of Health and through a cooperative agreement with the CDC, we created a prototype point-of-care EMR system informed by our previous experiences to manage patients receiving ART that was developed around newly-introduced clinical practice guidelines, and the newly introduced cohort reporting M&E framework, and using the Ruby on Rails open-source software stack with parts of the OpenMRS system, particularly the data model [27, 28]. The EMR was piloted at two district hospitals in 2007. Refining the system, and particularly creation of the detailed cohort reports, took much longer than anticipated and was complicated by changes in national guidelines and the introduction of new drug regimens. However, following a lengthy pilot period, the system was adopted by the Ministry of Health in 2010 for national scale-up to high burden sites pending the availability of funds. By the end of 2012, the national ART EMR was deployed at 21 high-burden ART clinics (including the Lighthouse Clinic) collectively managing care and treatment for roughly 98,000 patients [23].

## Beyond HIV

Having established a model to support HIV care and treatment in low-resource settings using an EMR, we explored the feasibility of supporting the management of chronic non-communicable disease in the same way. In 2009, in collaboration with the International Union Against Tuberculosis and Lung Disease and the Malawi College of Medicine, we developed and piloted an EMR to support care and treatment for patients with diabetes mellitus. The system was piloted at Queen Elizabeth

Central Hospital in Blantyre, and later expanded to the remaining three central hospitals in Malawi [29]. In 2011, clinical modules were expanded to support antenatal care, maternity, and under-5 services. As of 2013, work is in progress to address a broader package of non-communicable diseases.

### **A Model for Sustainability**

These efforts had prioritized clinical benefit and enhanced monitoring and evaluation over cost. In 2010, we modeled the potential return on investment that might result from deploying these systems. Focusing on the specifics of KCH, we projected potential annual savings in three distinct areas that could be generated by the use of EMR modules. Using estimated costs for installing and maintaining a hospital-wide EMR system at KCH, and projected savings over a 5-year period, we constructed a financial model to determine the potential return on investment. Based on this model, we were able to demonstrate a complete recapture of the initial investment costs of a hospital-wide system in less than 3 years [30]. This finding generated some optimism that the use of information technology in low-resource settings might actually be a cost-saving intervention, and we believe that this important finding may be the basis for the long-term sustainability of these systems.

### **Lessons Learned**

Findings were mixed. While many of the systems we developed and piloted could not be sustained, others have been integrated into the clinic workflow.

#### **False Starts and Experience Gained**

The outpatient module developed in 2001 was so constrained in its functionality that it resembled an electronic register more than an electronic medical record system. Once we recognized the poor fit, we discontinued the use of this module. The pediatric admission module was significantly more successful, running for more than 18 months before being discontinued. Despite the apparent goodness of fit, and the positive feedback from users, it was difficult to keep the system running. Unlike other systems we had developed, the pediatric admission module relied on the use of laser printers. At the time we had no technical solution to powering laser printers from a backup source of power (now solved). Consequently, during periods of power failure clinicians would have to complete the admission note by hand. Other problems arose when printers ran out of paper, and there was no paper available to refill the tray. These problems frustrated clinicians. The system was finally discontinued when both laser printers were damaged by a power surge and there was no funding to replace them. KCH pharmacy staff reported the ePICS system deployed in 2005 was greatly beneficial to the smooth running of the pharmacy. However, without a directive from

hospital management, the pharmacy staff was unable to discontinue using the paper-based stock system, and doing both was far too time-consuming. Struggling with the burden of maintaining parallel systems in the absence of a strong champion, staff use of ePICS became inconsistent several months after the ePICS system went live. This resulted in inaccurate stock levels in the system, and a general agreement to terminate the pilot. Both the pediatric admission module and the ePICS module were essentially demonstration projects that had no clear strategy to sustain them.

### Exemplars for Sustainability

Despite these challenges, several systems have been sustained. The patient registration system is now in its 12th year of use, having issued more than 1.6 million unique IDs to patients. The specimen-labeling component of the pediatric admission module was implemented as a stand-alone module and deployed at the Lighthouse Clinic in 2003, where it continues to generate labels for CD4, full blood count, and TB sputum testing at both the main site as well as its sister clinic, the Martin Preuss Center. The radiology module has been in continuous use at KCH since 2005. Both systems are stand-alone, simple in their functionality, and have a strong value proposition for the user. Yet despite their simplicity, these systems generate a large volume of data that can be reported in multiple ways. Not unlike the discontinued systems described above, both the radiology system and specimen labeling system were demonstration projects with no clear model for sustainability. We believe that the continued use of these systems is a result of the low overhead required for maintenance and support, combined with the strong value proposition for the user.

### Keys to Success

Establishing a patient identifier scheme and master patient index at the beginning simplified the development of other modules, as it provided a level of interoperability through which different modules could share patient information. Designing systems for simplicity and usability was a core design principle and appears to have been a prudent decision. Health workers with little or no previous exposure to training in the use of computers quickly became proficient in the use of the touchscreen systems. To increase the sustainability of the systems being built, a strategic decision was made early on to develop a local team to build the systems, rather than rely on international contractors and consultants. The availability of experienced local software developers was limited, requiring that many of the developers be trained on-the-job. This slowed down productivity, often resulting in milestones being missed. Emphasis on adapting hardware to work with a centralized 48 Volts Direct Current (DC) power backup system required extra work, but ultimately paid off in increased system up-time in the presence of grid power failures. Despite these challenges, we believe this 10+ year legacy of systems in Malawi validates our vision for local development and ownership.



## The Past is Prologue

Looking back over a decade of work in Malawi, had we expanded our demonstration projects beyond medications and laboratory testing, we may have had a broader impact on health systems strengthening and healthcare delivery, rather than the somewhat narrower scope of managing HIV and non-communicable diseases that has been achieved to date. Our experience reinforced the importance of addressing the needs of the system users as the highest priority. In low-resource settings, where supervision is minimal or nonexistent, the mandated use of systems does not work and shifts the strategy for sustained system use to having a strong value proposition for system users.

We started this work in Malawi with the hypothesis that small, highly-usable systems designed to address challenges in process or work-flow identified by health workers can add value, fully recognizing that the use of these systems would create large amounts of valuable data, but setting the primary purpose as process improvement. From time to time, we deviated from this strategy, creating large monolithic solutions, often seduced by the appeal of collecting data for later benefits rather than addressing a more immediate problem, and without a clear understanding of the mechanisms (such as decision support) that these systems were trying to leverage at the point-of-care. As we move ahead, we must go back to basics, leveraging the lessons we have learned and refocusing on the mechanisms through which EMR use at the point-of-care can both improve patient outcomes and reduce healthcare delivery costs. This will require a strategic approach at the country level, with involvement and cooperation of the Ministry of Health, technical partners, and funding agencies. The development of a strategic plan for the evolution of eHealth solutions in Malawi will serve both as a road-map for the future and a model through which we can share ideas, facilitate discussions, and validate design decisions and priorities.

## ***Public Health Informatics in Rwanda: The OpenMRS EMR Project***

### **Background**

Rwanda is a small, landlocked country in central Africa with 11 million people. In 2005 Rwanda had a gross domestic product (GPD) per person of less than US\$230 per year, one of the lowest in the world. Infectious diseases remain among the largest health challenges, along with maternal and child health, trauma, and mental health. Non-communicable diseases, including oncology and heart disease, are of increasing importance. HIV prevalence was 3.3 % in 2005, causing a major burden of disease. Substantial progress has been made by Rwanda over the last 7 years with GDP per person rising to US\$582 in 2011, and while HIV prevalence remains about 3 %, 108,113 HIV patients were receiving ARV treatment in June 2012, the second highest rate in Africa [31]. Challenges for the Rwandan health system were very similar to those in Malawi, including lack of roads and communications to remote clinics, a

severe shortage of trained healthcare workers, and limited investment in clinic infrastructure. There was limited knowledge of the disease burden in communities, including prevalence of HIV, and a need to track lifelong care for those patients. The existing processes for managing clinical data were also similar to Malawi, with a focus on multiple paper registers and paper charts that were often difficult to locate.

### History of Partners in Health Informatics Projects in Rwanda, 2005 Onward

Partners In Health (PIH) was first invited to work in Rwanda by the Ministry of Health (MOH) in 2004, to help develop a strategy to support the expansion of HIV care to remote rural areas. The MOH were aware of PIH's successful provision of HIV care in the remote and extremely impoverished Central Plateau area of Haiti and they wanted to achieve the same success in the large, underserved rural areas of Rwanda [32]. In 2005, the first PIH supported Rwandan clinic was established in Rwinkwavu hospital in the east of the country – an area with exceptionally poor infrastructure. In Haiti, 2 years previously, PIH had developed and deployed a web-based electronic medical record (EMR) system to support HIV care [34]. This EMR was adapted to the needs of the Rwandan health system. We found however that the level of customization was extensive and time-consuming; changes included the language, demographic data and address structure, form and report design, and workflow, and further extensive modification would be required to support other disease types. At this time the PIH informatics team had started to collaborate with the Regenstrief Institute in Indiana and their AMPATH project in Kenya, as well as the South African Medical Research Council (MRC), to develop a new, flexible, open source EMR platform – OpenMRS. This offered a more sustainable way of building EMR systems in resource poor environments. The decision was made to pioneer the system in Rwanda and Kenya. The first version of OpenMRS went live in Eldoret, Kenya in February 2006, followed by Rwinkwavu hospital in August that year, and shortly after, in Richmond hospital in KwaZulu, South Africa.

### Technical, Organizational and Functional Description of the OpenMRS

OpenMRS is an open source software project written in Java. It uses the MySQL database, and can run on Linux or Windows [27]. It is designed around a “concept dictionary” of structured data items that defines virtually all the data that can be stored in OpenMRS (other than patient demographics). An unlimited number of concepts can be added to the system without modifying the underlying software, and concept dictionaries can be standardized or shared. Unusual for an EMR system, it has a modular architecture that allows new functionality to be programmed without modifying the core system. More than 130 modules are available in the OpenMRS module repository, ranging from core functions such as form creation and reporting tools, to more customized code for specific implementations. However, it is not necessary to write new modules to implement the system. Core groups of paid programmers have

supported OpenMRS from the beginning, with Rwanda playing an important role in the development of the core code as well as customization and field testing [33]. The international OpenMRS community is playing an increasing role in development, testing, and support [28]. Until recently, with the exception of AMPATH, most implementations of OpenMRS have been small, usually one or more clinics running the system on a single desktop PC. Sites with good Internet access can use an offsite web server, simplifying support of individual clinics and sharing of data, such as laboratory results and patient transfers. Most sites in low-income countries require a local copy of OpenMRS to provide “good enough” performance, which implies stable power, information technology (IT) support, and a strategy for offsite data backup.

Current Status and Uses of OpenMRS at IMB

As of March 2013, OpenMRS was used in more than 30 MOH clinics supported by Inshuti Mu Buzima (IMB, meaning Partners In Health in the Rwandan national language) in Eastern and Northern districts of Rwanda, covering a population of almost one million people. All sites collect HIV patient data for clinical use, analysis, and reporting. This includes capturing data on intake and follow-up forms and clinical flowsheets, with the help of data entry staff. Over the last 2 years, this has been extended to cover voluntary counseling and testing (VCT) and prevention of mother-to-child transmission (PMTCT) programs and pediatric HIV care. Data are used for a range of purposes including:

- Supporting clinical care through printed patient consult sheets (Fig. 31.1) and direct lookup of patient records by clinicians
- Creating reports to the MOH and funders

Health Center:		HIV-Adult Consultation Sheet										
Group:												
Date Generated: 01 Apr 2013												
IMB ID	Name	Age	Weight	BMI	CD4	Decline	Viral Load	Last TB result	TB (current regimen and start date)	ARV (current regimen and start date)	accompagenatuer	Alerts
1000	AAAA	37	63.0 @04Mar13	27.3	796 @12Nov12		41 @06Jul11	NEGATIVE		Triomune-30 @12Apr08	HHHH	CD4 decline(80).
1001	BBBB	36	59.0 @04Mar13	25.9	1243 @04Mar13		39 @06Jul11	NEGATIVE		Triomune-30 @15Jun06	JJJJ	
1002	CCCC	36	45.0 @17Jan13	16.3	492 @22Nov12		19 @25Oct12	NEGATIVE		Triomune-30 @21Aug06	LLLL	CD4 decline(117). WTdecline (8%, 4Kg) Low BMI (16.3).
1003	DDDD	38	32.0 @04Mar13	13.9	463 @10Dec12		39 @06Jul11	NEGATIVE		AZT+3TC + NVP @30Oct07	MMMM	Very low BMI (13.9).
1004	EEEE	33	54.0 @04Mar13	24.3	864 @10Dec12		19 @06Jul11	NEGATIVE		TDF 300 + 3TC + NVP @17Mar11	NNNN	
1005	FFFF	49	53.0 @04Mar13	17.9	393 @10Dec12			NEGATIVE		AZT+3TC + EFV @06May08	PPPP	CD4 decline (51). Low BMI (17.9).
1006	GGGG	40	62.0 @04Feb13	23.6	854 @24Sep12			NEGATIVE		Triomune-30 @12Apr08	RRRR	CD4 decline (328). Late CD4 (7 months ago).

Fig. 31.1 An HIV consult sheet from Rwinkwavu hospital

- Clinical research on HIV care
- Assistance with forecasting medication requirements

A patient registration module is used in Rwinkwavu for all primary care patients presenting to the health center. This module is based on the designs and experience of the project in Malawi and includes the ability to print a barcoded ID card for each patient. In addition to HIV care, OpenMRS is used to support the care of heart failure and diabetes patients in some sites.

### Current Status and Uses of the System at MOH

After observing the OpenMRS implementation in IMB sites, in 2009 the MOH decided to initiate a rollout of the system to several hundred clinics in mostly rural areas of the country. With support from the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM) and the International Development Research Centre of Canada (IDRC), the MOH hired seven Rwandan programmers who had graduated from a PIH/IMB run training program. The initial clinical focus was for HIV and primary care. Then they started to customize the systems to support new functions for pharmacy and supply chain management, laboratory data management, billing, and reporting. OpenMRS was set up in four initial sites in 2010 and then the rollout was scaled up in 2011. As of March 2013, more than 200 clinics have the system installed and training of staff is ongoing.

### **Informatics-Related Issues Faced and Challenges Overcome During the Implementation**

OpenMRS hardware requirements are simple; the basic version can be downloaded from the OpenMRS web site and run on a basic PC. There are several key challenges in getting the system running smoothly, which are very similar to those described for Malawi. Unstable power can be very disruptive, especially if clinicians rely on the system during clinics. Recently, smaller clinics in Rwanda have started to use laptop computers as servers, providing several hours of running time and ensuring that the system shuts down safely. Lack of Internet connectivity makes supporting OpenMRS more difficult and prevents use of one central server to share data. Initially, IMB provided satellite Internet access to clinics and hospitals, greatly simplifying the rollout and support of information systems, but this connection was expensive and variable in quality. More recently, the cellular phone GPRS network has been used to link clinics to a central server in Rwinkwavu hospital over a virtual private network. However, this connection is still too slow to allow direct web-based access to the OpenMRS server so a module was created that allows data to be synchronized between instances of OpenMRS and a central server over an intermittent connection. This has greatly improved the performance of OpenMRS in remote clinics, as it now allows clinical reporting across all sites in a district, facilitates pushing laboratory results out to clinics, allows lookup of records for patients transferring between clinics in the district, and provides an automatic offsite data backup.

The main disadvantage is that synchronization requires more technical support than a standard installation, an issue we are still working to improve. As OpenMRS is rolled out to additional sites, it will be particularly important to track system performance, including down time, data entry and completeness, and daily use, and to evaluate the cost of system implementation and support. Tools are being developed to track these parameters and transmit data to a central site for monitoring.

### Improving Reporting Tools

Reporting and data use is a core function of OpenMRS, whether for clinical care, program management, or research. The flexibility and power of the OpenMRS concept dictionary comes at the price of making certain types of data export and analysis more difficult than simple database designs. A number of different reporting tools have been developed over the past 5 years to address these challenges. The OpenMRS reporting framework is the most flexible example, and was partly developed in Rwanda with support from the Rockefeller Foundation. It is used extensively at IMB and increasingly at the MOH. The challenge now is to improve the flexibility of this framework and to simplify its use by non-programmers. OpenMRS data is increasingly used for research studies such as a recent analysis of HIV care outcomes at IMB [34] and a large clinical epidemiology study in Peru [35].

### Clinical Evaluation

As the use of OpenMRS has grown in Rwanda, there has been increasing interest in evaluating the system and assessing what benefits this investment has brought to the health system. A key requirement in the management of HIV is access to CD4 counts that indicate the status of the patient's immune system. At IMB, it was found that many CD4 counts in patients' charts were out of date. Amoroso and colleagues studied the impact of adding a module to OpenMRS to allow direct entry of CD4 counts in the laboratory [36]. The findings showed that the number of CD4 counts that were out of date fell from 25.7 to 16.7 % ( $p < 0.002$ ). Were et al. [37] in Kenya studied the impact of giving clinicians access to printed clinical summaries from OpenMRS that contained warnings of low CD4 counts. Their results showed that ordering of repeat CD4 counts increased from 38 to 63 % ( $p < 0.0001$ ). More extensive evaluation is planned of the clinical impact of the system.

### Capacity Building and the EHSDI Training Program

Finding Rwandan programmers with good Java programming skills proved to be very difficult. In 2008, with support from the IDRC, PIH set up a training program for programmers to obtain hands-on skills in enterprise Java programming and OpenMRS development [38]. A total of 34 programmers graduated over the 3 years to 2011. Many graduates are now working with the MOH, IMB, and other organizations, developing and implementing OpenMRS.

## Vocabulary Management

Over the last 2 years, a standard OpenMRS concept dictionary has been created by a team at Columbia University combining the concepts from several projects including IMB, the MOH, AMPATH, and the Millennium Villages project. The Rwanda Health Enterprise Architecture (RHEA) project is using that dictionary and a set of custom vocabulary management tools to create a core data set for maternal health projects using OpenMRS and other systems, including RapidSMS.

## The Future for the System

The initial use of OpenMRS in resource-poor environments nearly always involved clinicians collecting data on paper forms that were later transcribed by data entry staff. Outputs were usually in the form of printed patient summaries, consultation sheets, and reports. As in Malawi, clinicians at IMB-supported sites were keen to access clinical data directly to ensure that they had the most up-to-date clinical findings, laboratory results, and drug regimens. This required the addition of a clinical summary for HIV care, and training for the clinicians on searching for patient records. It also required upgrading the infrastructure and IT hardware to ensure that systems were available consistently on clinic days. These improvements were made possible by a grant from the US Centers for Disease Control and Prevention (CDC).

## Supporting a Broader Range of Diseases

Most of the initial implementations of OpenMRS were designed to support HIV care, with many also covering TB co-infection. Adding the capability to manage new clinical areas can be as simple as adding one or more forms and reports and a patient summary. However, more extensive customization and programming may be required for more complex care processes, particularly if healthcare staff use the system directly. The first example of this was OpenMRS-TB, designed to support the care of Multi-Drug Resistant TB (MDR-TB). It includes custom tools for managing and viewing laboratory and medication data, a variety of WHO specified reports, and a custom timeline for visualizing the whole treatment process (Fig. 31.2) [39].

Similar customization was carried out by IMB in 2012 to support the care of oncology patients in Rwanda. Programming was also required to support patient registration and management of barcoded ID cards, as well as capturing clinical diagnoses and problems. An additional challenge is to program these clinical components as generalizable modules that can be reused worldwide, which requires substantially more investment in design, programming, and testing than simply customizing the system for one site.

Overview | [Chart](#) | [Visits](#) | [Treatment](#) | [Lab Results](#) | [Patient Details](#)

Month	Date Collected	Bacteriologies			DSTs																						
		Smears	Cultures	Bacteria	INH	R	E	Z	S	CM	KM	AMK	CPX	OFX	LFX	Moxi	Ethio	CS	PAS	Prothio	THA	AMX/CLV	CLR	RFB	CFZ	TRD	
Prior	28/Jun/0010	Change	-																								
	29/Jun/0010	Change	-																								
	12/Feb/0010	MSLI	POS	POS	M. TUBERCULOSIS COMPLEX	R	R	R	S	S	S	S	S				S										
	24/Feb/0010	Change	-																								
Baseline	25/Feb/0010	Change	POS/POS																								
	01/Mar/0010	Change	POS																								
	03/Mar/0010	Change	POS/POS																								
0	25/Mar/0010	Change	Treatment Start Date																								
	24/Apr/0010	Change	-																								
1	27/Apr/0010	Change	-																								
	28/Apr/0010	Change	-/-/-																								
	19/May/0010	Change	-																								
	20/May/0010	Change	-/-																								
2	27/May/0010	MSLI	POS	POS	M. TUBERCULOSIS COMPLEX	R	R	R	S	S	S	S	S				S										
3	29/Jun/0010	Change	-																								
4	24/Aug/0010	Change	-																								
5	25/Aug/0010	Change	-/-																								
6																											
7	11/Nov/0010	Change	-																								
	12/Nov/0010	Change	-/-																								

Fig. 31.2 Timeline for the MDR-TB management including laboratory data and drug regimens

## Rwanda eHealth Enterprise Architecture

In 2010, the Rwanda eHealth Enterprise Architecture Project was started as a collaboration between the MOH, Jembi Health Systems in South Africa, the Regenstrief Institute in Indiana, IDRC, the Rockefeller Foundation, and the PEPFAR program. The goals of this project are to create an overarching plan for all eHealth systems in the country, with clear specifications of their functions, and using medical data standards and tools to ensure interoperability. The first stage of implementation of this project is underway in the Rwamagana district in the south east of the country, to support maternal health care. Data are being collected by clinic and hospital-based staff using OpenMRS, as well as community healthcare workers using mobile phones and text messaging with RapidSMS software. An instance of OpenMRS is installed on a server in the national data center and functions as a shared health record, combining data from local OpenMRS installations as well as from RapidSMS. Three national registries provide shared resources for patients, providers, and facilities, and there is a terminology server. The goal is to roll this system out nationally and extend it to cover other disease areas including HIV, TB, and primary care. OpenMRS installations managed by MOH and IMB will be included over time. An additional project is using a data standard called SDMX-HD to send reports from OpenMRS to a web-based national reporting system called TRACnet.

## Hospital Information Systems Based on OpenMRS

In addition to supporting clinics with OpenMRS the MOH is starting to focus on the needs of district hospitals. Starting with a government-run hospital in Kigali, they have implemented tools for management of patients in a range of clinical services. These include modules for:

- patient registration system (described above)
- medication prescribing, dispensing, and inventory
- laboratory orders and results
- capturing diagnoses and problem lists
- forms for a range of clinical services

The OpenMRS community is also starting to focus on direct use of the system by clinical staff in hospitals, with a particular focus on a new teaching hospital built by PIH at Mirebalais in Haiti. This should provide additional tools for the pioneering projects in Rwanda.

## Broader International Rollouts Based on Rwanda Experience

Rwanda and Kenya have been the main sites for much of the early development and implementation of OpenMRS. Rwanda's contributions include the first use of OpenMRS on Linux, and the first deployments of many core modules including



HTML form entry, the reporting framework, and data synchronization. Other key initiatives have been direct clinician viewing of patient summaries and implementation of patient registration with barcoded IDs (building on the experience from Malawi). The MOH team has pioneered work on a broader national rollout of OpenMRS and initial use in hospitals. There is now a large and growing international community developing and implementing OpenMRS. More than 50 developing countries are currently using OpenMRS clinically; many are carrying out development of new modules or contributing to improving the core system. Key initiatives include the development of standard concept dictionaries shared between implementations and countries, and tools to standardize core dictionaries for maternal health care. Many projects are linking OpenMRS to a range of mobile phone-based software tools including ODK, CommCare, Sana, and OpenXdata. The Kenyan MOH is currently rolling out OpenMRS to 300 rural clinics, building on the experience in Rwanda with help from programmers at PIH. Going forward, top priorities for the OpenMRS project are to simplify the setup of OpenMRS in new projects and provide reusable tools for managing diseases like HIV, primary care, and maternal health, as has been done for MDR-TB. The core goal will continue to be the use of data from OpenMRS for clinical care, program management, forecasting of supplies, and clinical research.

Rwanda has played a critical role in the development and evaluation of OpenMRS. The software developed for the projects here and the lessons learned are helping many projects around the world decide whether or not to use the OpenMRS software. With the current work on rolling out OpenMRS nationwide, the direct use of OpenMRS by clinicians, the development of tools for oncology, and the RHEA project, this pioneering role is likely to continue.

## **The Way Forward**

The growth of global health informatics is continuing. Policies and funding are shaping the course of global health informatics as the field seeks to better understand the impact that solutions have on health outcomes of the medically underserved. We promote an approach that is both top-down and bottom-up. Working in global health informatics requires an implicit recognition that the differences in countries' characteristics, health challenges, and priorities have a direct bearing on how information systems should be developed and used. When developing health information systems in low-income, resource-restrained environments, simple, focused solutions can work well in specific sites but are usually of limited general value. More comprehensive and adaptable informatics solutions are necessary to scale to multiples sites, multiple diseases, and large numbers of patients. Keeping a focus on the clinical and programmatic needs, not the technology, is essential to achieve better acceptance, adoption, and sustainability. Remembering that the little things do count, such as stable power, printer repair, and even paper, leads to success when a system is deployed in the field. Building local expertise in system development and maintenance is necessary for on-going success and system sustainability.

Determining the value add that the users will gain from the system and then creating a system that provides the added value is critical. Interoperability between systems is necessary to be able to provide comprehensive patient care and conduct accurate disease surveillance. Monitoring and evaluation of the performance, cost and impact of systems is essential to allow resource and policy decisions based on data. The world of health, information, and technology is a rapidly changing place. Exciting opportunities exist in keeping pace with that change and discovering new informatics solutions to provide health for all.

### Review Questions

1. There are many different ways to view the discipline of global health informatics. What are some of the defining attributes that set it apart from other informatics disciplines?
2. Policy is foundational to global health informatics. Why is policy so important?
3. When might eHealth and mHealth tools be appropriate to apply?
4. The Malawi case describes how clerks are used to capture admission and discharge information at Kamuzu Central Hospital. What factors may compromise both the completeness as well as the accuracy of this data?
5. Describe three challenges to operationalizing electronic information systems designed to support patient care in low-resource settings.
6. The Malawi case study describes a system developed to create computer-generated order labels to attach to test-tubes being sent to the laboratory for testing. Describe the mechanisms through which this might reduce the length of stay for a patient admitted to the hospital.
7. The pediatric admission module described in the Malawi case incorporated automatic medication dosage calculation based on the child's weight and age. Speculate how this system may benefit (a) the clinician, (b) the patient, and (c) the hospital administration.
8. In developing the electronic medical record system to support HIV care and treatment, a point-of-care solution was selected over a paper-based data collection system with retrospective data entry. What was the rationale for this decision?
9. How can the benefits of creating a common database of patients be achieved when clinic sites have unreliable network connections?

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**Part VI**  
**Epilogue**

# Chapter 32

## Public Health Informatics: The Path Forward

J.A. Magnuson

**Abstract** As the health information technology (HIT) environment is being shaped by the converging catalysts of technological improvements and large-scale financial investments in healthcare and technology, global efforts to implement and integrate ever-better health information systems and communications should lead to a more optimal public health infrastructure. Not only is there a clear need for public health informaticists, there is a corresponding need for continued refinement and agreement upon what constitutes effective training in public health informatics. Knowledge domains and competencies for public health informatics have evolved over the past decade; 13 core competency areas are discussed. Education and training opportunities for informatics continue to grow, and encompass avenues including universities, certificate courses and other continuing education, community college offerings, fellowship programs, in-service courses, and internships.

**Keywords** Knowledge domain • Core competency • Public health informatics • Skills • Training • Education • Registered apprenticeship

### Learning Objectives

1. Explain the importance of agreement upon knowledge domains and competencies in public health informatics.
2. Understand the similarities and differences between knowledge domains and competencies for public health professionals, medical professionals, and public health informaticists.

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3. Describe the core competency areas for public health informatics.
4. Illustrate the different avenues for training and education in public health informatics.

## Overview

As the health information technology (HIT) environment is being shaped by the converging catalysts of technological improvements and large-scale financial investments in healthcare and technology, global efforts to implement and integrate ever-better health information systems and communications should lead to a more optimal public health infrastructure. Not only is there a clear need for public health informaticists, there is a corresponding need for continued refinement and agreement upon what constitutes effective training in public health informatics. Knowledge domains and competencies for public health informatics have evolved over the past decade; thirteen core competency areas are discussed. Education and training opportunities for informatics continue to grow, and encompass avenues including universities, certificate courses and other continuing education, community college offerings, fellowship programs, in-service courses, and internships

## Perspectives

The health information technology (HIT) environment in the US is being shaped by the converging catalysts of technological improvements and large-scale financial investments in healthcare and technology. Much as optimal decision-making can be fostered by the collective efforts of masses of neurons (as in primate brains) or individuals (as in honeybee swarms) [1], mass global efforts to implement and integrate ever-better health information systems and communications should lead – eventually – to a more optimal public health infrastructure.

In this book, we have explored standards, architecture, infrastructure, security, and many other important informatics topics: we covered the context and background of Public Health Informatics, the science of informatics, key information systems, new challenges and emerging solutions, and more. In the final section of this book we discussed examples of informatics in action, in the form of case studies from different public health strata in the US and other countries.

The justification for Public Health Informatics has been demonstrated amply in this textbook, and even more importantly, in the real-world arena of HIT. The need for skilled informaticists is evident: both public and private healthcare endeavor to cope with the proliferation of silo-ed systems, accommodate the need to incorporate standards, and comply with the increased pressure to communicate data to varied

partners and to integrate systems. In addition to the need for informaticists and their work, there is a corresponding need for continued refinement and agreement upon what constitutes effective training for public health informaticists. As with any field of study, there must be agreement upon and standardization of skill sets, competencies, and knowledge domains.

## Domains and Competencies

In the first chapter of this book, we re-iterated the definition of informatics that was put forth in the first edition: the “systematic application of information and computer science and technology to public health practice, research, and learning” [2]. Putting this definition into practice requires further specification of both the knowledge domains and the core competencies of public health informatics. Additionally, these informatics areas must be established both for public health practitioners and for public health informaticists. Fortunately, these topics have been well explored in the past decade, and will be briefly reviewed here.

A concise review of the knowledge domains of related fields is useful to create context. A European study by Czabanowska et al. [3] developed a Quality Improvement Competencies Framework for *general practice or family medicine physicians*. The framework organized 35 competencies into six domains: Patient Care and Safety; Effectiveness and Efficiency; Equity and Ethical Practice; Methods and Tools; Leadership and Management; and Continuing Professional Education.

In 2010, the Council on Linkages between Academia and Public Health Practice published a revision to the core competencies for *public health professionals*. Eight core public health knowledge domains were specified: Analytic/Assessment Skills; Policy Development/Program Planning Skills; Communication Skills; Cultural Competency Skills; Community Dimensions of Practice Skills; Public Health Sciences Skills; Financial Planning and Management Skills; and Leadership and Systems Thinking Skills [4].

## Core Competencies

Richards [5] defined a *core competency* as the “fundamental knowledge, ability, or skill for the specific subject of public health informatics.” In 2009, a set of competencies for *public health informatics professionals* was developed collaboratively by the Centers for Disease Control and Prevention, the Association of Schools of Public Health, and the University of Washington Center for Public Health Informatics [6]. The list of competencies created through this collaboration was intended to help provide a framework for training and career development in public health informatics.



**Table 32.1** Thirteen areas of competency for public health informatics, condensed from the 2009 core competencies for public health informaticians

Areas of competency for public health informatics
Strategic direction for public health informatics
Knowledge management and tools
Informatics standards
Knowledge, information, and data needs of project or people
Public health information system development, procurement, and implementation
IT operations, both internal and external
Communication
Evaluation of information systems and applications
Public health informatics research
Interoperability of public health information systems
Integration of clinical health, environmental risk, and population health
Confidentiality, security, and integrity of solutions
Education and training in public health informatics

Source: Centers for Disease Control and Prevention Office of Workforce and Career Development and University of Washington School of Public Health and Community Medicine's Center for Public Health Informatics. Competencies for Public Health Informaticians [6]

The core competencies identified in the 2009 list addressed 13 subject areas, which are condensed and summarized here in Table 32.1. The core competencies developed were divided into two categories, the *public health informaticist* and the *senior public health informaticist*. These categories differed by degree of complexity and responsibility. For example, the tenth competency addressed system interoperability: for the category of *public health informaticist*, the competency specified “contributes to development of” interoperable public health information systems, while the *senior public health informaticist* was specified to “ensure” system interoperability. Similarly, for the competency regarding confidentiality, security, and integrity, the public health informaticist “implements solutions that ensure confidentiality, security, and integrity while maximizing availability of information for public health,” while the senior informaticist competency substitutes the word “develops” for “implements.”

This cumulative work on informatics competencies has added tremendous value to the field. The current work will continue to grow as in all fields, not just informatics, competencies continue to be investigated, discussed, argued, and sometimes, changed.

## Education and Training

The importance of effective education to successful implementation of skills is evident, but the path of that education is variable. While universities offer unparalleled opportunities for academic learning, other equally valid paths for informatics education could include certificate courses and other continuing education, community college offerings, fellowship programs, in-service courses, and internships.

In early 2013, the National Center for Education Statistics [7] recognized 45 universities offering Bachelor of Science degrees in informatics, bioinformatics, or medical informatics, and 77 offering advanced degrees in those subjects. Public Health Informatics was not available as a specific search criteria at that time.

An item indicating the growth of the field of Public Health Informatics is the recent recognition of the CDC Public Health Informatics Fellowship Program (PHIFP) as the first public health informatics fellowship program to be designated as a Department of Labor (DOL) Registered Apprenticeship [8]. That announcement discusses potential outcomes of the new designation, including its beneficial effect upon career development and promotion, tracing and documenting training investments, and development of job descriptions.

## Conclusion

The brief review of knowledge domains and core competencies in this chapter adds a final note to our coverage of the field of public health informatics. In this book we have discussed the past, present, and future of public health informatics. This field continues to increase in importance, both to public health professionals, who have a growing need for familiarity with the principles and practice of informatics, and to public health informaticists, who are increasingly being recognized for the enormous value they can bring to the public health arena.

### Review Questions

1. Why is it important to establish competencies for Public Health Informatics?
2. Discuss two important differences between the knowledge domains for public health professionals and public health informaticists, and elaborate on why they are different.
3. What are some ways by which a professional could receive education in informatics?
4. What is one reason that the recognition of the CDC PHIFP as a DOL Registered Apprenticeship is important to public health? Explain your reasoning.

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