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THE PALGRAVE HANDBOOK OF GLOBAL HEALTH DATA METHODS FOR POLICY AND PRACTICE

Edited by
Sarah B. Macfarlane and Carla AbouZahr

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Foreword

Investing in Global Health Information Systems: Learning from Nature

Countries and agencies have endorsed 17 Sustainable Development Goals and their associated 169 targets and 232 indicators. Now the global development community needs to invest—locally, nationally, and globally—to monitor and assess progress. When a potential pandemic, such as Ebola or Avian Influenza, strikes, questions are asked about the performance of public health surveillance and response systems and how much should be invested in them. It's time for us to *walk our talk*. It's time to invest adequately in our health information systems at all levels. Unless we do so, our global commitments will be just empty talk.

Those working in global public health and statistics have much to learn from nature.

The human body is one of nature's most complex systems with more than 20 organ systems and sub-systems working in a concerted manner effectively to maintain life. How can these diverse systems work together harmoniously? Only because nature invests continuously in information systems and feedback loops. Consider nature's investment in the nervous system which transmits data and information continually from conception to the last moments of life. While the human brain constitutes only 3 per cent of body weight, it consumes 25 per cent of the body's daily energy. Over 100 billion neurons connect through axons and dendrites to synapse with many other neurons, and every second the body transmits data by way of electrical signals that allow the nervous system to receive, analyse, and synthesize information, and

react accordingly. Other information systems, such as the immunological, biomedical, and hormonal systems, all contribute to maintain the functioning of the body. For example, when the immunological surveillance system senses alien pathogens, allergens, or cancerous cells, it triggers immunologic responses to remove them.

Are we ready to follow nature and direct 25 per cent of total health investments to health information systems? And if so, where should those investments be directed?

The two editors of this volume have between them decades of experience working with health information and statistics systems. Sarah Macfarlane led establishment of the Mekong Basin Disease Surveillance Network, which has built trust among disease surveillance and control experts of six Greater Mekong sub-region countries. Today these national experts share information about disease outbreaks with their peers in a prompt and timely manner, communicating information electronically and by phone and bringing together cross-border teams of experts to collect samples, identify possible contacts, and look for new cases. This immediate response is possible because of trust-based systems built through long-term collaboration that ensures reliability, credibility, and partnership based on *public-* not *self-*interests.

Carla AbouZahr, when she worked at the World Health Organization, led the start-up phase of the Health Metrics Network which, despite lasting for only eight years, has laid strong foundations for health information systems in many countries. The network created standards for national health information systems that set the foundation for ongoing efforts by multiple countries and development partners to improve health information, including the multi-partner Health Data Collaborative.

Together, the editors have mobilized the wisdom of more than 50 global experts to write and prepare the *Palgrave Handbook of Global Health Data Methods for Policy and Practice.* This handbook provides the best answer to the question about what and how to invest in generating data to inform health policy. The handbook serves three main purposes. It describes technical aspects of data sources and identifies capacity gaps for generating data. It highlights the importance of synthesizing and communicating evidence to policymakers and how to use evidence to influence policy. Finally, the handbook provides recommendations on how to improve the quality of data and information systems especially in low- and middle-income countries.

My recommendation for this book is based on my four views of global health. First, global health is the platform to make the world safer for all through global collaboration—this handbook underlines the necessity of creating country data architecture and platforms that link databases across the globe.

Second, global health enables countries and non-state actors to protect their national interests—the handbook describes methods for collecting and analysing data that will support member states when they propose resolutions on the global health stage. Third, global health enables countries to showcase their best practices—this handbook covers the disciplines that enable country health-related data to become global health data to be used to improve people's health. Finally, global health is the process of building long-term sustainable capacity—the handbook contributes to improving skills and capacities that will ensure a shared global voice in development and implementation of evidence-based health policies and practices.

This handbook not only guides the reader to develop a health information system but, more importantly, it provides advice and examples about how to ensure that the information generated is fed into decision-making and implementation to improve health.

This is a *must read* and *must use* handbook for health systems workers, researchers, managers, and decision-makers!!!

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Suwit Wibulpolprasert

Better Data for Better Health: An Ongoing Imperative

Data have driven advances in health since the early days of modern medicine. People live longer and healthier lives today because of pioneering work to collect and analyse data on the causes of disease and death and to generate evidence about interventions to prevent them. During the nineteenth century, Louis Pasteur and Robert Koch identified the pathogens involved in major infectious diseases such as anthrax, tuberculosis, and cholera. John Snow used mapping techniques to identify the sources of cholera in London. Florence Nightingale, renowned for her nursing skills, was a consummate statistician and developed innovative techniques for presenting data to elicit policy responses. Today, advances in statistical and epidemiological methods have vastly enhanced the availability and quality of health-related data. But these advances are not evenly spread. Many low- and middle-income countries have limited capacities to produce and use data to underpin decision-making.

The situation within countries is worse: the data needed to identify and target marginalized and hard-to-reach population groups are not widely available.

New challenging health conditions continue to emerge, both in relation to infectious diseases but also non-communicable diseases such as cancer, diabetes, and cardiovascular conditions. Addressing the environmental, social, and economic determinants of ill-health is central to continuing improvements in health status. These developments have profound implications for the data systems needed to identify and plan remedial action and to monitor progress and effectiveness. The continuous accumulation of data and statistics creates accountability by providing evidence of what works, what does not work and, more importantly why so.

The editors of this book have brought together a diverse group of authors whose rich perspectives on the generation and use of data across the health spectrum represent the most comprehensive description of health-related information systems yet available. The core theme that unites the chapters is that reliable data and statistics are public goods, essential for the maintenance and improvement of the health of the world's peoples. Good governance and sound administration depend on reliable information, a perception that led the post-apartheid government of South Africa to overhaul the existing health information and statistical systems.

Governments are primarily responsible for creating the conditions for accessible and responsive health systems and for ensuring that the basic sources and methods of statistics and epidemiology are in place. This handbook describes the essential building blocks of information covering tried-and-tested methods of data collection, such as the population census, as well as methodological innovations, such as spatio-temporal techniques and statistical modelling, and good practice such as publishing open data. It is a health imperative to adopt a systems approach to health and take full advantage of global good practices in health-related data and statistics.

The global health and statistical communities must provide countries with technical expertise and resources and support for capacity development at both individual and, critically, institutional levels. The generation and use of data for health policy—on inputs, processes, outcome, and impacts—is a human endeavour that must be collaborative, involving stakeholders across sectors locally as well as nationally and internationally. Data must be owned and used locally but also shared widely. As noted by the authors of these chapters, only through active citizenry will it be possible to improve health outcomes, health systems, health inputs, and ultimately achieve universal health care and equity. This book sets the roadmap for this glorious promise. It will be of interest to decision-makers and scholars of

public policy. It is a manifesto for health activism and a source of information and knowledge that all who wish to promote health will appreciate.

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Overcoming the Data Poverty Divide: Time for Structural Adjustment

The *Palgrave Handbook of Global Health Data Methods for Policy and Practice* is a very welcome and timely source of thinking and wisdom in this rapidly changing field. While *global health* might reasonably be taken to include the entire world, in reality major differences in the quality and quantity of health data continue to follow global economic divides. Thus historically *poor* countries in many cases continue in health data poverty—at the same time as facing some of the greatest global challenges in providing health services.

While the overall scope of the handbook is huge, and can by no means be summarized here, there are three structural issues in the field of global health data that seem particularly important:

- In today's world, the agenda against infectious diseases is progressing but is by no means concluded. Life expectancy is increasing, with the consequence that more people are living to ages where non-communicable disease risks increase, just as many population-based risks such as exposure to processed foods and sugary drinks are increasing. Hence global health parameters in particular settings can change rapidly, and if local population-based data are not available, such changes cannot readily be tracked. In particular, elaborate mathematically modelled estimates of global health data can often be insensitive to short-term local changes because of inherent inertia in the underlying models.
- The technical history of data is also relevant. Until the very end of the twentieth century, computing power for handling large databases was very limited compared with today's standards. At the same time, health data expertise was typically manifested among statisticians, demographers, and epidemiologists who had no formal training in informatics and computing but who comfortably handled datasets on a few hundreds or thousands of subjects. Now desktop computers can handle datasets with many millions of records in real-time. But human capacity development for handling the

so-called *big data* on global health sensibly and effectively lags far behind, especially in Africa.

- Access to health data as a global good is an increasingly important issue. Developments such as the International Network for the Demographic Evaluation of Populations and their Health (INDEPTH) Network's public data repository, supported by the Wellcome Trust, are key to achieving an open data environment that facilitates the effective use of data for policy purposes. At the same time, such initiatives need to be balanced by capacity building for analysis and interpretation in local academic and government institutions so that data can be made to *talk* in their own contexts. Reverting to historic norms of exporting data into better-resourced but far-away analytical environments is simply unacceptable.

There is now little more than a decade to run before the 2030 endpoints of the United Nations Sustainable Development Goals. Global understanding of the preceding Millennium Development Goals was compromised to some extent by a lack of appropriate local data and analytical capacity, and the world cannot afford to repeat the same mistake. This handbook is therefore an important milestone in the quest to move the field of global health data methods forward—but substantial further investment and progress is required.

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Preface

On September 25, 2015, 193 countries signed the 2030 Agenda for Sustainable Development agreeing a plan of action to 'transform our world', and pledging to 'leave no-one behind'. January 1, 2016 marked the transition from the 2000–15 Millennium Development Goals (MDGs) roadmap with 8 goals, 21 targets, and 60 indicators to the 2015–30 Sustainable Development Goals (SDGs) roadmap with 17 goals, 169 targets, and 232 indicators. The first (2016) SDG report concluded: 'The data requirements for the global indicators are almost as unprecedented as the SDGs themselves and constitute a tremendous challenge to all countries' [1]. The challenge is undoubtedly real for the health sector which has 1 goal, 13 targets, and over 50 health-related indicators.

The MDGs threw a harsh spotlight on poor statistical infrastructure in many countries. Because the United Nations (UN) developed MDG indicators after the MDG Declaration, there was little or no baseline information. Many national statistical systems were not ready to collect the data required to measure progress towards the goals. Countries reported indicators based on surveys and routinely collected data, but they were sparsely distributed over time and lacked comparability. To track progress globally, international agencies estimated indicators from these country reports.

In 2015, the UN called for a *data revolution for sustainable development* to build technical capacity to manage data. The UN's vision is that all countries and people benefit from expanding opportunities provided by data technology without which the 'gaps between developed and developing countries, between information-rich and information-poor people, and between the private and public sectors will widen, and risks of harm and abuses of human rights will grow' [2]. The *Palgrave Handbook of Global Health Data Methods*

for Policy and Practice is timely in addressing technical issues and capacity gaps in generating data for global health.

About This Handbook

Many people use many approaches to collect and manage data to improve health worldwide. Data managers and analysts generate statistics using methods drawn from epidemiology, demography, statistics, social sciences, economics, anthropology, and other disciplines. Researchers develop methods for modelling and predicting, for example, the burden of disease borne by people living in different parts of the world. While field manuals and discipline-specific textbooks describe some of these methodologies, this handbook presents for the first time a collection of approaches to gather and process data for global health. The reader—whether a student of global health or a producer or user of information, working nationally or internationally—will appreciate the descriptions of what it takes to set up systems for acquiring and sharing information to improve health globally.

We start by examining the data that national governments and their partners generate and use. Although governments are not solely responsible for setting the health agenda, they provide the context, including governance structures, within which a national or sub-national health system—public or private—operates. We argue for robust national information systems that inform and monitor local health programmes and thereby contribute to global health. Taking the country perspective, we examine how governments and many local and global partners supply data to develop and monitor their programmes. Governments share their data as indicators with the World Health Organization (WHO) and the UN system. Other institutions use the data to make global health estimates and cross-country comparisons. We also examine how academic institutions, non-governmental organizations, international agencies, and donors contribute to generating data and evidence for global health—in countries and across countries.

Emergence of Global Health and Global Health Data

Several authors in this handbook describe the historical development of the methods they introduce. We draw on their perspectives to explain the context for the current interest in and relevance of global health and global health data.

During the nineteenth and twentieth centuries, governments began to cooperate to prevent the spread of infectious diseases resulting from increased travel and trade. European governments convened the first International Sanitary Conference in 1851 and countries of the Americas established the Pan-American Sanitary Bureau in 1902. In 1946, 61 nations signed the constitution of the WHO signalling that they intended WHO to become a global organization. WHO member states agreed to share information about epidemics of infectious diseases like cholera and yellow fever and to control their spread across borders. In 1951, member states adopted the International Sanitary Regulations, later to be known as the International Health Regulations. These regulations still require WHO's, now 194, member states to share data about outbreaks of specific conditions and emergencies.

Sovereign states continued to develop global and regional intergovernmental mechanisms, focussing more widely on public health alongside disease outbreaks. As countries in sub-Saharan Africa and South and South East Asia gained independence from colonial rule, high-income countries (HICs) provided technical and financial assistance to build their health-care systems. WHO was the normative, standard-setting agency in health. Other agencies—notably the UN International Children's Fund (UNICEF) and the World Bank—with national governments, private donors and academic institutions supported these economically and demographically *developing* countries to combat disease and build health facilities. Academic institutions, mainly in colonizing or colonized countries, and one in the US, developed the field of *tropical medicine* to examine and assist in the control of diseases occurring in countries in the tropics. A wealthy shipowner founded the first school of tropical medicine in Liverpool in the UK in 1898. The Rockefeller Foundation in the US led international philanthropy in public health when it established an international health division in 1914.

During the 1960s and 1970s, international concern about population growth after the Second World War dominated health and population funding to developing countries. International agencies such as the UN Population Fund (UNFPA), bilateral donors, and private philanthropies supported data collection to inform family planning activities in these countries. Demographers collected data and developed techniques to measure fertility and mortality where census data were sparse. Agencies set up population surveillance sites in South Asia and sub-Saharan Africa to monitor demographic changes resulting from interventions to promote family planning. The global discussion was about the relative stages countries had reached in the demographic transition from higher to lower fertility and reduced child mortality rates.

In 1978, to address huge disparities in health status and access to health care between and within countries, 134 governments and representatives of 67 UN organizations, specialized agencies, and non-governmental organizations signed the Declaration of Alma Ata. With the vision of *Health for All,* the Declaration promoted primary health care as the vehicle 'for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world' [3]. The meeting recommended that each government monitor and evaluate its programmes to implement primary health care using the minimum of information 'with the help of a simple and relevant information system'.

The report of the Alma Ata meeting proposed starting by collecting qualitative rather than quantitative information since most systems were manual at that time. Nevertheless, Alma Ata marked the start of international target-setting with measureable indicators. At the time, censuses and surveys were the prevalent sources of data. The World Fertility Survey had supported countries to collect national survey data from the early 1970s and these became Demographic and Health Surveys in 1984. Backlash against this trend to quantify people's lives led international agencies to introduce participatory approaches to development such as *rural rapid appraisal* (RRA). RRA evolved into *participatory rural appraisal* (PRA) and the World Bank used similar methods to conduct *participatory poverty assessments* (PPA) leading to their publication of *Voices of the Poor* in 1999. Tension between the value of qualitative data and information provided by people versus quantitative data collected about them is live today.

Health progress stagnated in many countries following the economic crises of the 1970s and 1980s. Demographic statistics highlighted devastatingly high levels of child and maternal mortality in developing countries. Epidemiological data demonstrated high morbidity and mortality from *tropical* diseases such as malaria, schistosomiasis, onchocerciasis, and tuberculosis (TB). Global concern led to an era of *international health* characterized by assistance from developed to developing countries to build capacity to run health and information systems. When micro-computers became available, international support began to focus on health information systems. As governments decentralized administrative authority for health and other sectors to districts, managers developed district health management information systems.

The 1993 World Bank publication, *Investing in Health,* and the 1990 Global Burden of Disease (GBD) estimates on which it was based, was a landmark in development of global health data methods. Murray, Lopez, and Jamison introduced the disability-adjusted life years (DALYs) as a comprehensive indicator to measure burden of disease and injury. Using published and unpub-

lished data and informed expert opinion, they estimated DALYs for 100 causes by age, sex, and region of the world. They intended to: address inadequate mortality data especially for adults; measure disability which had hitherto only been considered a problem for HICs; and provide a 'framework for objectively identifying epidemiological priorities which together with information on the cost-effectiveness of interventions can help when decisions on the allocation of resources have to be made' [4]. *Investing in Health* did just that, proposing packages of public health and essential clinical care that could reduce the burden of disease in developing countries by 25 percent [5]. Since that time the World Bank, WHO, and researchers at the Institute of Health Metrics and Evaluation (IHME) have evolved techniques for estimating DALYs and the data on which they are based. The 2016 GBD study included 300 diseases and injuries for more than 195 countries.

The GBD study has helped to describe countries' transitions from infectious disease-driven mortality to chronic disease-driven morbidity and mortality. Data began to show that low- and middle-income countries (LMICs) were suffering a double burden of infectious and chronic diseases such as cancer, cardiovascular disease, and obesity. Additional threats such as HIV/AIDS, SARS, and Ebola emerged in the 1980s and 1990s and the international health community was manifestly unprepared. New global organizations with diverse partners evolved to address pressing health issues—including private and commercial enterprises, philanthropy, and academia—alongside the existing UN agencies and bilateral and multi-lateral governmental organizations. The President's Emergency Plan for AIDS Relief (PEPFAR), established in 2003, provides technical and financial support to 15 countries mainly in sub-Saharan Africa all with high HIV/AIDS prevalence rates. Entities, such as the Global Fund to fight AIDS, Tuberculosis and Malaria (2002) and Gavi the Vaccine Alliance (2010), have raised significant additional funding streams and distributed them to priority countries using a performance-based approach. Country accountability for large financial support required additional data collection and sometimes resulted in parallel disease-specific information systems.

By the turn of the twentieth century, the term global health had become ubiquitous. Global networks and entities have multiplied and academic institutions, particularly in HICs, now engage in *global health*. Although there are multiple definitions of global health, people use the term to describe activities aimed at improving people's health worldwide—acknowledging increasing complexity and diversity of health challenges that cross national boundaries, and that ill-health affects all peoples but especially the poorest and most vulnerable. While global health implies concerted action by multiple countries,

institutions, and sectors, it pivots on the work of institutions that plan services and deliver quality health care directly to populations.

Often unstated, but implicit, in most definitions of global health is a necessity that institutions create and share data within and across countries to develop and evaluate policies to improve health and enhance health equity for people wherever they live. Data for global health are now omnipresent, created by growing numbers of researchers and institutions, and morphing into the emerging field of *big data*. Technology is transforming the landscape for collecting, analysing, and disseminating large volumes of data. Data collection technologies, such as computer-assisted personal interviewing, digital mapping and global positioning systems are improving data collection and field operations. Enhanced computing capacity and software permit analysis of massive quantities of data. The Internet offers access to primary and secondary data and official and unofficial publications. The ready availability of data and information challenges users to understand their integrity and veracity.

Defining Global Health Data

Global health then is an umbrella term that encapsulates the contributions of all countries and multiple institutions to developing policies and implementing interventions to improve all people's health equitably worldwide. Interestingly, the term encompasses both activities and their goal, that is, people work *in* global health *to achieve* global health. In this handbook, we examine the data and methods policymakers and practitioners use to achieve global health.

But what are *global health data*? We haven't found a definition but, after speaking with colleagues and reading the literature, we realize that people use the term in different ways—just like its parent term, global health. The fundamental question is: when do health-related data become global health data?

We continued our discussion with colleagues and came up with the following argument and definition of global health data on which we base this handbook.

Health-related data may originate from any sector, and may be collected and analysed:

- *by* governmental and non-governmental organizations within health systems, public and private providers, researchers undertaking dedicated studies, or international agencies

- *to* manage health systems, evaluate interventions, manage preventive and clinical care, inform other sectors, develop global and local policy, or to advance research
- *as* primary data through formal and informal data collection systems or as independent research, using openly available secondary data, or by harvesting big data
- *through* observing, interviewing or examining populations using administrative systems or at the point of delivery
- *using the methods* of several disciplines including demography, statistics, epidemiology, social sciences, and economics
- *and managed* manually or by using information technology and specialized software
- *and disseminated* as management indicators, official national and international statistics, or in peer-reviewed journals

Health-related data are collected where people live, and should inform policy and practice to address local health challenges.

Health-related data become *global health data* when—aggregated, synthesized, and exchanged—they form the basis of estimates and evidence that drive international debate and collaborative efforts to improve health status and reduce disparities across populations, borders, and geographies. Numerous people and agencies create and use global health data, but national governments are obliged to maintain essential infrastructures to produce quality data to address their health priorities, and they share these data as indicators for international benchmarking against agreed targets.

Global health data must be trustworthy and represent populations fairly. Ideally, producers collect and manage these data consistently, economically, efficiently, ethically, and transparently, and disseminate them widely.

Global health data methods describe how governments and other agencies use traditional and new technologies to collect, clean, aggregate, synthesize, and disseminate health-related data; and transform them into indicators, estimates, and evidence that inform efforts to improve health status and reduce disparities across populations, borders, and geographies.

Organization and Contents of the Handbook

Such an ambitious definition of global health data made editing this handbook a daunting task. We decided to bring together the strands of global health data methods knowing that the result would be indicative rather than

comprehensive. We invited an exceptional group of colleagues—with a formidable range of experience in handling data in different contexts and countries—to provide the technical content of the handbook. We, as editors, have attempted to frame their contributions and to fill gaps in topics to include those we think necessary. We began by making a list of chapter topics but the list changed as some authors became too busy to write and others offered new and exciting suggestions. The combination of topics has matured over time and we are pleased with the end result. We also know there are other issues and perspectives we could have included. We hope that by bringing at least these themes together, we will stimulate others to continue to frame and enhance global health data and methods.

We made some hard decisions. First about data: we decided not to ask authors to provide data per se but only to illustrate the issues they introduce. Second about methods: we invited authors to give an overview—indicating where the reader might obtain additional resources—but not to delve deeply into any particular technique. Third about examples: we wanted to show how practitioners use the same methods in different contexts, so we asked authors to choose their examples from around the world. We have divided the contributions into five parts covering essential themes underpinning global health data and methods.

Part I: Lays the Foundations of Global Health Data for Policy and Practice With Tangcharoensathien (Chap. 1), we, as editors, examine the data sources that comprise a national health information system. We also trace the flow of locally generated data from communities and facilities as they translate into information through administrative levels to reach a central ministry of health—situated within a national statistical system—which then reports indicators internationally to WHO and other UN agencies. With Frank (Chap. 2), we explore the escalation in global demand for indicators and the tensions this creates for collecting enough relevant and reliable data. Brindis and Macfarlane (Chap. 3) examine the fragile interplay between data and policy and offer insights into how to maximize policymakers' use of data at any level from national to global. Macfarlane, Lecky, Adegoke, and Chuku (Chap. 4) follow the transformation of data into evidence of effective and efficacious interventions that contribute to health system performance. Finally, Karpati and Ellis (Chap. 5) lay out some principles for using quality data to inform government policy.

Part II: Presents the Major Sources of Global Health Data MacDonald (Chap. 6) introduces the census as the most long-standing source of population data which is as relevant to planning services today as it was for the ancient Greeks. AbouZahr, Mathenge, Brøndsted Sejersen, and Macfarlane (Chap. 7) explain the civil registration system that records vital events in people's lives from birth to death and how this process generates continuous population and health statistics. Macfarlane (Chap. 8) follows the evolution of national household surveys to provide a cross-sectional picture of a population's health and its access to and use of health services. Lippeveld, Azim, Boone, Dwivedi, Edwards, and AbouZahr (Chap. 9) examine the role of health management information systems in processing routine data from communities through district to national level. Finally, Ungchusak, Heymann, and Pollack (Chap. 10) demonstrate how surveillance systems collect data to monitor and protect people from disease and other unwanted public health events and conditions.

Part III: Provides Examples of Specialized Systems of Global Health Data Maina and Mwai (Chap. 11) introduce systems of National Health Accounts (NHA) which collect and analyse data on who pays and how much they pay for health services—providing a case study from Kenya. Siyam, Diallo, Lopes, and Campbell (Chap. 12) explain the importance of data to planning and organizing the health workforce. Silva and Mizoguchi (Chap. 13) examine challenges in obtaining mortality data in situations of armed conflict. Thomson, Lyon, and Ceccato (Chap. 14) explain the unique value of incorporating climate data in health information systems. Finally, Geraghty (Chap. 15) describes how geographic information systems guide resource allocation in health.

Part IV: Introduces Methods for Collecting and Analysing Global Health Data Singh, Krishan, and Telford (Chap. 16) show the value of qualitative data for gaining insights into health policy and practice particularly to target interventions towards vulnerable populations. Bawah and Binka (Chap. 17) provide the essentials of demography, the discipline that describes and predicts how population structures change over time, whether across the world or in a small geographic area. Lansang, Dennis, Volmink, and Macfarlane (Chap. 18) review epidemiological principles and methods, and offer some practical considerations in designing studies to inform policy and programme management. Kahn, Mwai, Kazi, and Marseille (Chap. 19) introduce methods of health economics as tools to assist policymakers choose intervention strategies that will maximize health gains with available resources. Diggle,

Giorgi, Chipeta, and Macfarlane (Chap. 20) explain spatial and spatio-temporal modelling to describe, predict, and map the distribution of health outcomes in space and over time to assist public health planners. Finally, Mathers, Hogan, and Stevens (Chap. 21) introduce statistical models that bring together sparse, diverse, and sometimes inaccurate country data to generate global health estimates of health indicators to facilitate cross-country comparisons over time.

Part V: Highlights Some Principles and Policies for Managing Global Health Data We, as editors (Chap. 22), provide some tools for data producers and users to address issues of data quality, integrity, and trust. Laessig, Jacob, and AbouZahr (Chap. 23) outline best practices for organizations to adopt to disseminate data openly for others to use. They demonstrate the significance of unlocking vast amounts of data generated from multiple sources. Thomas and McNabb (Chap. 24) explore ethical issues associated with collecting and using data for public health, emphasizing the importance of ensuring data confidentiality, establishing principles for sharing data, determining availability and ownership of data, maintaining transparency, and using routine data to monitor health equity. Finally, we as editors (Chap. 25) return to the theme of global health data and methods. We reflect on authors' contributions and endeavour to frame the many activities they have described and lay out how national and international stakeholders collaborate to strengthen the data environment. In looking to the future, we emphasize the need for strong governance and ethical frameworks, long-term investments in institutional capacity development, and much improved collaboration and cooperation across sectors, stakeholders, countries, and development agencies.

Levelling the Playing Field

Our short review of the history of global health and global health data shows that countries once referred to as developing, and now as LMICs, spent the last century catching up with the latest technical developments proposed by wealthy countries but without the human or financial resources to fully implement them. Big data provide the biggest opportunity and the biggest threat to the health information systems of LMICs. Unless the international community supports them to consolidate their information and surveillance systems, LMICs may learn their health data from others. Individuals or organizations

anywhere in the world can anticipate the next global epidemic by searching the Internet and they might even identify the village or household at its epicentre. Data scientists can extrapolate trends in people's opinions and choices about their health care; they can also estimate global health indicators by building large databases drawing on data from many sources. Independent researchers obtain funding to conduct dedicated surveys to describe the health conditions in a country or region of countries. We argue for strong global collaboration and investment to support LMICs maintain health information and surveillance systems to identify priorities and monitor interventions—especially at the granular level of districts and communities—while introducing appropriate technologies.

Authors of chapters in this handbook demonstrate remarkable advances in data methods and in harnessing these methods for global health. They also demonstrate immense disparities in technical and human resources to apply the methods to support local decision-making and to contribute global knowledge. We hope that, by describing traditional alongside innovative approaches, this handbook will inspire readers to share and build as well as to estimate and innovate.

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We thank all authors for their valuable contributions and for their patience in working with us to ensure that the chapters complement each other. As their short bios indicate, they represent a community of experts with years of experience working with global health data in many countries and global institutions. Several colleagues supported us through the journey of editing this book. We single out Wayne Enanoria, Hugo López-Gatell, Patrick Gerland, Robert Hiatt, Pavana Murthy, Janet Myers, Poonam Patel, Sara Seims, Vivek Singh, Stefaan Verhulst, and Andrew Young for their welcome advice and contributions. We thank Kerstin Svendsen for designing most of the figures and Geetha Raayanker for working on the references.

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Contents

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Part I

Global Health Data for Policy and Practice

Preface

Authors of these chapters examine the processes whereby data collected locally become useful information at different levels of the health system and eventually emerge as global health indicators. The chapters demonstrate tensions between collecting data to inform local policy and practice, and collecting data to report global health indicators. A recurring theme is the need to strengthen national and local information systems to ensure that they provide valid, reliable and useful indicators.

National health information systems coordinate data from many sources to produce information to meet users' needs at every level of a health system (Chap. 1). The health information system functions within the wider national statistical system led by a national statistical office, and eventually reports indicators internationally as official statistics, alongside those of other sectors. Governments use indicators to measure health sector performance against agreed targets and to compare health-care coverage and health outcomes across countries. However, as Chap. 2 describes, international agreements to attain development goals and targets have increased pressure on national governments to report escalating numbers of indicators. This pressure risks overburdening country health information and statistical systems and undermining the quality of data collected.

We argue that data are of little value unless decision-makers use them for policy and practice at any level of a health system. Chapter 3 examines the challenges of integrating data throughout policymaking, from problem recognition and agenda setting to formulation, adoption, implementation and

evaluation of policy. The authors highlight the importance of formulating good policy questions, maintaining responsive data systems and promoting effective communication between policymakers and data providers. Chapter 4 describes how researchers and international institutions gather evidence to identify and promote interventions to policymakers, and examines how programme managers monitor and evaluate health programmes. The authors describe a framework developed by international partners for governments to monitor overall health sector performance and progress towards the Sustainable Development Goals. Chapter 5 delineates key practices that create the conditions for a virtuous cycle of exemplary data use, in which government decision-makers leverage data for policymaking and planning, and, in turn, invest in data systems to improve the quality and availability of data.

1

National Systems for Generating and Managing Data for Health

Sarah B. Macfarlane, Carla AbouZahr, and Viroj Tangcharoensathien

1 Introduction

'What is measured matters so data matters' [1]. These are the words of Dr. Tedros Adhanom Ghebreyesus who, on July 1 2017, became the ninth Director-General of the World Health Organization (WHO). Dr. Tedros is steering WHO's contribution towards achieving the 17 Sustainable Development Goals (SDGs) and 169 targets of the 2030 Agenda for Sustainable Development, adopted by the United Nations (UN) General Assembly in September 2015. Ten days after his appointment, WHO published its estimate that the cost for 67 low- and middle-income countries (LMICs) to achieve the 13 SDG health targets could range between US $274 and US $371 billion per year in additional spending on health by 2030 [2].

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Dr. Tedros asked: 'Do we want our fellow citizens to die because they are poor?' vividly describing the human reality behind the statistics that 'at least 400 million people have no access to essential health services,' [3] and '40% of the world's population lack social protection' [4]. He committed that 'Based on evidence and data, WHO will track progress on how the world is meeting the health-related Sustainable Development Goal indicators.' [1].

The stakes then are high. But WHO alone cannot track progress towards meeting the SDGs. It is national governments that generate data and use statistics to underpin health policy and planning, and to manage their health systems. The SDG indicators are a subset of hundreds of indicators that governments use to measure progress and benchmark their health sector performance with peer countries, and to report on progress towards national and international goals.

Many LMICs, and some high-income countries (HICs), had difficulty reporting reliable indicators for the earlier Millennium Development Goals (MDGs). The data demands of the SDGs—including multiple targets related to attainment of universal health coverage (UHC)—are exponentially greater. The SDGs have more indicators than the MDGs and countries must disaggregate them to monitor the progress of vulnerable groups. Health data systems in many LMICs are already overloaded, face staff shortages and high turnover, and are chronically under-resourced. The WHO estimates that by 2030 the additional annual cost of strengthening health information systems (HISs) to meet the health SDG in the 67 LMICs will be between US $0.5 billion (progress scenario) and US $0.6 billion (ambitious scenario), less than 0.2 per cent of the total additional health spending needed [2]. If governments invest in human and digital resources to harness data to run their health systems, this money will be well spent.

We describe the evolution of the term HIS from the early 1970s, in parallel with development of computer systems and mobile technology. We explain how a national HIS functions as an integral component of the health system, and in the broader context of a country's national statistical system, and we describe the users of the data and information the HIS produces. We raise challenges facing national HISs and the need for coordination and good governance. We conclude by exploring the potential for future investments in HISs by examining one country's plans to revitalise its HIS.

2 Evolution of Health Information Systems

The term HIS first appeared in the literature in the early 1970s at a time when doctors and hospital managers began using mainframe computers to manage patient data. In 1973, Alderson defined a HIS to be 'a mechanism for the

collection, processing, analysis and dissemination of information required for the organisation and operation of health services, and also for research and training' [5]. In developing his vision of a HIS for the UK National Health Service (NHS), Alderson emphasised that hospital data would not suffice. He advocated for a range of information from a variety of sources 'to make valid comments on use of resources, costs, variation in medical practice within a given speciality, or the existing inequality of allocation of resources between different patient groups and different geographical areas' [6]. People have subsequently used the term HIS in different ways, some reflecting Alderson's comprehensive definition [7, 8] and some using HIS more narrowly to describe routine facility data systems, specific hospital systems or specialised clinical or management sub-systems [9]. In this handbook, we use HIS to describe the structures and processes that bring data together from diverse sources—within and beyond the health sector—to inform planning, monitoring and evaluation of health systems.

During the last decades of the twentieth century, enhanced computing capacity made it easier to manage, link and interrogate data. Health providers and planners in HICs developed information systems using ever-more sophisticated computer software and equipment. Even with limited resources, some LMICs developed or restructured their information systems and others strengthened sub-systems such as disease surveillance and routine facility data systems [7]. The 1978 Alma Ata *Declaration of Health for all* catalysed development of HISs to enable countries to measure indicators to monitor progress in delivering primary health care [10]. These efforts led to development of *health management information systems* (HMIS) (also called routine health information systems (RHIS)) to support districts manage their health services. Arrival of the microcomputer simultaneously transformed HIS development, making it easier for governments and projects to move from paper-based to electronic data systems.

Demand for health data has expanded along with expectations for rapid data management and transmission through the Internet. As external donors and development agencies have increased their financial contributions to health, they expect to monitor progress in the programmes they support. When routine data were insufficient or unreliable, agencies have funded programme-specific data collection. Initiatives such as the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM), the US President's Emergency Plan for AIDS Relief (PEPFAR) and Gavi the Vaccine Alliance have provided considerable resources to develop innovative measurement approaches and build country capacity for disease-specific data collection, management and analysis.

Partner investments have undoubtedly improved the timeliness and quality of data on critical aspects of health but they have also weakened national systems by collecting duplicative and inconsistent data (see Chap. 2). The growing use of performance-based funding by donor agencies has had mixed effects. For example, Gavi's provision of extra performance payments—US $20 for each additional immunised child beyond the baseline—coupled with regular *data quality audits* before performance grant disbursement, has resulted in more timely and better quality reporting. But extra payments for health workers responsible for data collection are not sustainable when donor funding ends.

Nonetheless, the international community has provided systemic support for information systems, especially in response to the evident need for improved and coordinated systems to enable countries to better report MDG indicators. In 2000, the World Bank and several bilateral donor agencies supported the Partnership in Statistics for Development in the 21st Century (PARIS21). PARIS21 supports development of national strategies for statistical development in countries with weak statistical capacity [11]. In 2001, with support from USAID, an international group set up the Routine Health Information Network (RHINO) [12] to strengthen facility-based routine information systems, or HMIS, particularly in LMICs [7].

Between 2005 and 2013, the Health Metrics Network (HMN), with funding from the Bill & Melinda Gates Foundation, supported countries to assess and develop plans to build strong, coordinated HISs [13, 14]. The HMN defined a national HIS to include coordination of all tools of data collection at any level in the health system that produce information for decision-making, whether or not the health sector manages the tool. The HMN approach to health information focused on the structures, processes and resources needed to build better overall data systems as opposed to data flows for specific diseases. Other development partners have taken a similarly broad systemic approach although they may define the boundaries of the HIS differently [9, 15].

In 2015, in preparation for the SDGs, leaders of global health agencies and participants in the Summit on Measurement and Accountability for Health issued a Call for Action. The call included a roadmap to implement priority actions and achieve critical targets to improve health measurement and accountability in LMICs [16]. In 2016, global and country partners set up the Health Data Collaborative to support countries 'to improve the availability, quality and use of data for local-decision-making and tracking progress towards the health-related Sustainable Development Goals (SDGs).' The

Collaborative encourages global health partners 'to align their financial and technical resources around a common agenda of measurement and accountability' [17].

3 Health Information and Health Systems

The purpose of a national HIS is to coordinate the collection, management, analysis and synthesis of data, and dissemination of timely, quality and relevant information to decision-makers within the health system and beyond, and to account to the general public and partner agencies. System managers and analysts deliberately generate and analyse data to provide indicators about the health status of populations and the functioning of the health system and provide evidence of determinants of health conditions and effective interventions. The HIS mirrors the objectives and organisational structure of the health system.

The levels at which the health system operates reflect the political and administrative structure, population size and geographic characteristics of the country. In Fig. 1.1, we simplify the hierarchy by identifying the national (or state) level, and one sub-national administrative level, which we call a district. Responsibility for delivery of health care may or may not be decentralised to the district. In practice, there can be many administrative levels, for example, county, sub-county, district and sub-district with different reporting structures.

The health system provides medical and preventive services, through public and private facilities, directly to people attending a facility and by reaching out to the community. Typical health facilities are community clinics, primary health-care centres, and secondary and tertiary hospitals. Health systems also run specific programmes focusing, for example on preventive care and health promotion, HIV/AIDS, malaria, tuberculosis, maternal and child health, or non-communicable diseases. Programmes may be managed at the national or state level, operated from the district level and function across facilities. Disease registries compile databases about people diagnosed with specific types of diseases, including cancers and birth defects, as well as recording coverage and survival outcomes of treatments, for example anti-retroviral therapy and renal replacement therapy. Health facilities may employ community health workers and other field staff to make home visits to the intended beneficiaries of health system activities, such as pregnant women, children, the elderly and persons with disability who cannot reach health facilities.

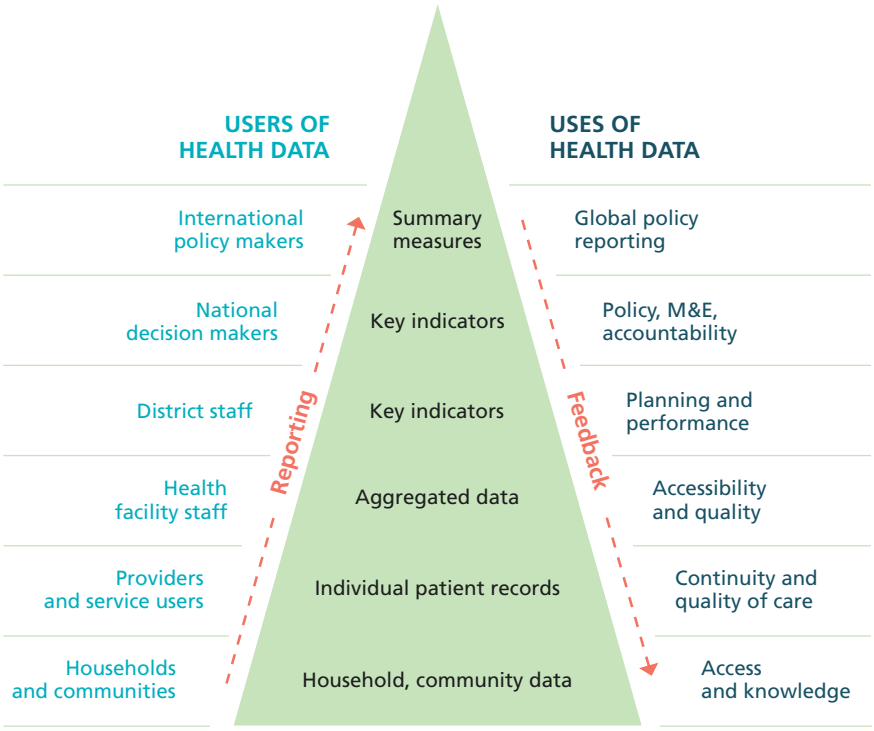

Fig. 1.1 Local health data to global health data: information reporting and feedback mechanisms. (Adapted from Health Metrics Network Framework and Standards for Country Health Information Systems [13])

Despite growing awareness of the need for health data, the 2000 WHO health systems performance framework made no specific mention of health information, subsuming the concept under *stewardship* [18]. Nearly a decade later, WHO included health information as one of six health-system *building blocks*, alongside service delivery, health workforce, access to essential medicines, financing and leadership/governance [19]. While this positioning gives information some visibility, it reinforces a narrow view of HISs, confining them to the health sector along with the other building blocks. Data and information about the determinants of health also lie beyond the health sector. These include, for example access to safe water and sanitation, nutrition, and avoidance of risky behaviours such as tobacco use, unhealthy diets and physical inactivity, all of which contribute to the onset of communicable and non-communicable diseases. The health system framework has yet to take into account the complex interactions and relationships between the different building blocks [20]. This is particularly important for the HIS which must generate information not only about each building block but also on how the

blocks interact to produce health systems goals and outcomes by way of the intermediary steps of improved access, coverage, quality and safety of care [21]. The Government of Ethiopia resolved this dilemma by identifying systematic information management as one of the four agendas of its 2015 Health Sector Transformation Plan [22].

4 Users and Uses of Health Information

A HIS coordinates data collection, reporting and feedback to meet users' needs at each level of the health system (Fig. 1.1):

To Understand Their Community's Health Issues and to Hold the Health System Accountable: individuals, communities, civil society groups, research organisations and the media require information about the socio-demographic structure of their neighbourhoods, and health status including birth and death rates, incidence of communicable and non-communicable diseases, and early warnings of disease outbreaks. The public and the media need health administrators to provide regular and transparent accounts of how the health system functions so that they can identify gaps and lobby for services. They need to understand disparities in access and health outcomes among population sub-groups and their neighbourhoods. Researchers contribute to this knowledge by analysing available open data.

To Ensure Continuity and Quality of Care: practitioners providing services and community outreach at health facilities require—and collect—data on individual clinical and diagnostic records to inform patient management, document clinical outcomes, and follow-up and refer patients. They also need information from surveys and censuses to understand the demographic and socio-economic structure, risk factors and health status of the population they serve, especially if they provide outreach services such as immunisation in schools and antenatal care in community clinics.

To Ensure Accessible and Quality Care: managers of health facilities generate information continuously through management record systems to guide procurement and staffing decisions, claim and allocate financial resources, and maintain facility infrastructure, equipment and supplies, including medicines and diagnostics. They too need demographic and socio-economic information about the facility's catchment area as well as information from service

records to target services, assess coverage and identify vulnerable groups not covered.

To Plan and Assess Performance: planners and managers at a sub-national (or district) level compile records on notifiable conditions seen at health facilities for surveillance and effective response and to track service coverage, coordinate service provision, allocate resources and implement, supervise and evaluate programmes across facilities and the population they serve. They need data on the distribution of health facilities, service utilisation, for example, outpatient visits or admissions, specific services offered, and the availability of equipment and supplies, the number of health workers and their skills and capacities, and gaps in the supply chain for essential medicines.

Programme managers at the district level also need data from other sectors. For example, they can use: data on food security from the agricultural sector to develop nutrition strategies; data on poverty from the national statistical office to target support for financial risk protection and to reduce inequalities; and data on temperature and rainfall from the climate sector to predict and prepare for epidemics.

To Set Policy, Monitor, Evaluate and Account for Health Sector Performance: policymakers and managers at the national level need information from all components of the health system to manage, monitor and review implementation of health sector plans across the country. They need to collect and report data to track results and develop information about critical aspects of programmes and their impact on population health. They need data not only for national averages but for sub-national administrative units, and that can be disaggregated to highlight the health challenges facing particular population groups. Such groups include the poorest households, and remote, marginalised and vulnerable populations such as the elderly, persons living with a disability and ethnic minorities.

While countries use data primarily for national and local decision-making, they also report indicators to WHO and other international and regional organisations so that these agencies can monitor global progress towards SDG targets and prepare global and regional policy and response (see Chap. 25).

5 Sources of Data

The HIS brings together data from multiple sources at all levels of the health system, and from outside the health sector. We provide an overview of the primary data sources but subsequent chapters in this handbook explain each source. Our description is consistent with the Measurement and Accountability for Health Roadmap [16].

Data Collected About Populations Through: (1) national and local household sample surveys (see Chap. 8). These describe, for example, health status, service coverage, health-related behaviours and risk factors, and out-of-pocket spending on health, including equity dimensions of health status and service coverage, and population knowledge such as use of antibiotics and awareness of antimicrobial resistance; (2) national decennial censuses that count the entire population and describe its demographic structure by geographic area and administrative level; (see Chap. 6); and (3) civil registration and vital statistics systems that continually record vital events such as births and deaths nationally and for local administrative areas (see Chap. 7).

Data Collected Through Facility and Community Records Including: (1) medical records about patients and families seen at the health facility or in the community including disease registers; (2) registers of services provided by health facilities and other programmes; (3) community-based systems such as community health worker registers; and (4) health facility assessments designed to track the availability and geographic distribution of public and private health facilities, the quality of infrastructure, availability of equipment and commodities, and readiness to offer specific services. Finally, public health surveillance systems operate locally and nationally, and draw on multiple sources of data to watch out for and respond to unwanted public health events that occur in the population (see Chap. 10).

Specialised Health Systems Data Including: (1) human resources for health information system (HRHIS) that enables countries to track, manage and plan the health workforce so that the required health workers are available in the right place at the right time and that they are properly trained, remunerated and supervised (see Chap. 12); (2) systems of National Health Accounts (NHA)

which describe health financing in a country to monitor the distribution of resources to reach health system goals (see Chap. 11); and (3) drug and medical supply systems to manage demand and supply, ensure drug safety and facilitate procurement [23].

Beyond the publically managed HIS, other bodies contribute data to inform the running of the health system and watch over the integrity of data and information available to policymakers. Private and non-governmental health organisations maintain information systems but are encouraged to link these with the public systems. Coverage of notifications of highly infectious and epidemic-prone diseases from private sector providers is critical for surveillance and effective response. Consumer watchdog groups collect data to assess the quality of and complaints about the health services available to them. Data analysts trawl the World Wide Web for health-related data to describe and predict trends in health status and health care. Academic and research institutions undertake assignments for governments and publish independent clinical and public health research supported by public and private funds.

6 Health Information Systems As Part of Multi-sectoral Statistical Systems

The health sector is both a consumer of and contributor to information about other social and economic sectors. A well-functioning HIS depends on activities undertaken not only within the health sector but in other sectors with responsibilities for statistical development. The HIS is part of a multi-sectoral national statistical system—defined as 'the combination of statistical organisations and units within a country that jointly collect, process and disseminate official statistics on behalf of a national government' [11]. Key contributors of health-related data include the national statistical office (NSO), census bureau, civil registration authority, and sectors generating, for example, data on environmental pollution, occupational and road safety, food safety, production and standards, poverty, income distributions and economic growth.

A national statistical system, led or coordinated by the NSO, provides an important coordinating mechanism for collecting and disseminating official statistics. Some systems, for example in Australia, Botswana, Finland and Pakistan operate centralised systems with the NSO publishing all official statistics itself. Other systems are wholly or partially decentralised, for example

in Malaysia, Mali, Thailand, the UK and the US, in which government agencies, such as the ministry of health, work with the NSO but publish their specialised statistics. A head of the Australian Statistical Service once described the tension between centralised and decentralised systems as 'policy relevance versus statistical integrity' [24]. A centralised office can coordinate and oversee the quality of statistics that agencies publish. In a decentralised system, sectoral agencies benefit from monitoring the policy-relevant statistics they publish but may lack the technical integrity provided by expertise at the NSO. Decentralised systems require effective multi-sectoral coordination.

Sectoral agencies may report different values for the same indicator. For example, the health sector reports on births and deaths occurring in health facilities will differ from those of the national civil registration system. If the NSO leads the national statistical system efficiently, agencies can minimise these problems by coordinating statistical activities, determining standards and sharing technical expertise across the system. The SDGs provide a significant stimulus for coordination as almost all sectoral agencies provide data to measure SDG indicators.

To perform their duties and produce credible statistics, agencies collecting data within the national statistical system must be independent, or 'distinct from those parts of the government that carry out enforcement and policy-making activities' [25] and free to decide the way they collect, analyse and disseminate data. A sectoral agency's impact assessment of its own policies and programmes can undermine the credibility of results because of its potential conflicts of interest. The UN Statistical Commission, representing chief statisticians from all member states, sets statistical standards such as the ten fundamental principles, which NSOs and other line ministries must follow in producing official statistics [26].

7 Challenges in Producing Data

The 2017 World Health Statistics report examined 42 SDG health-related indicators (counting UHC as one indicator) and judged CRVS to be the preferred (or equally preferred) source for 16 of them, population surveys for 22 and facility-based records for only six of the indicators. Many indicators also depend on population numbers enumerated by a decennial census. The report acknowledged that 'very few' of the 42 indicators 'are adequately measured in most countries' [27].

The problem lies less with the census as 91 per cent of countries participated in the 2010 round (see Chap. 6). In HICs, the main problem is that they do

not conduct national surveys with sufficient breadth to measure some of the required indicators. For example, for the MDGs, only 17 out of 57 countries classified as *developed* reported the percentage of people aged 15–49 years living with HIV, and only 10 reported percentage condom use at last high-risk sex among 15–24-year-old men. Data collection issues in LMICs have been well documented [7, 28] and we summarise them here:

Low Registration of Births and Deaths Through CRVSs In 2017, WHO reported that although nearly half of all deaths worldwide were registered in a national death registration system with some information on cause of death, countries only reported 23 per cent of deaths to WHO with 'precise and meaningful information' on their cause [27]. UNICEF estimates that around one in three infants do not have their births registered [29]. Strengthening such systems will take years of investment and capacity building, but there is an international movement to support vital registration and cause of death statistics [30]. Only 1 per cent of the population of Asia and Africa currently lives in countries which have complete death registration (see Chap. 7) [31].

Too Many Poorly Coordinated Surveys National household surveys served the MDGs well and promise to provide the primary data for the SDGs, especially for indicators of health service utilisation and for disaggregation by household wealth status. In LMICs, two surveys provide complementary and consistent information, namely the USAID supported Demographic and Health Survey (DHS) [32] and the UN Children's Fund's Multiple Indicator Cluster Survey (MICS) (see Chap. 8) [33]. But countries also undertake disease- and programme-specific national surveys to meet donor reporting requirements, thus adding to pressures on limited expertise and resources.

Inadequately-Resourced, Under-Performing Facility-Based Record Systems The major problems lie with facility reporting, management and surveillance systems. These systems are essential to monitor health system performance, but they are complicated and cumbersome to maintain. HMIS managers have problems maintaining data quality and completeness and timeliness of reporting, and in stimulating usage of the information they produce. Often the HMIS does not cover the private health sector despite its significant contribution to both service provision and surveillance of notifiable diseases prone to epidemics. Some countries have difficulty coordinating numerous separate disease data collection systems. Many pilot projects explore the potential of

e-health and mobile technology, but these are seldom well coordinated or integrated into a comprehensive and effective system. One promising development is the open source District Health Information Software (DHIS2) which, as of 2017, over 50 countries use on a national scale to manage their HMIS [34].

Inconsistencies Between Values of Indicators Managers of country HISs often have to explain indicator values that differ from one data source to another. For example, data on the percentage of under-1-year-old infants vaccinated against measles is likely to be different when the source is a survey compared with the routine HMIS. There are many reasons for this. Routine HMIS systems are beset by problems of bias and missing values (contributing to both the numerators and denominators of health indicators). Although household surveys should generate indicators of superior accuracy and reliability, much depends on the quality of the survey design, implementation and analysis.

To understand the reliability of country data, development partners and technical experts have created HIS assessment tools. Some, such as the HMN assessment tool, involve multiple stakeholders, and are too complex for monitoring purposes [35]. Other tools are simpler but are primarily applied by external parties, limiting country involvement and ownership. The available assessment tools [36] have not been formally compared and evaluated. The general consensus is that assessments with multi-sectoral stakeholder involvement are suited to developing a sound understanding of how the HIS works and fostering relationships across programmes and departments. Tools that combine stakeholder involvement with objectively verifiable performance indicators offer the best compromise between the ownership and independence of an assessment.

8 Governance and Coordination of Health Information Systems

The HMN framework emphasised the importance of good HIS governance but, after a series of LMIC self-assessments of their HISs, concluded in 2011 that 'The basic foundations of a good HIS, i.e. a policy and comprehensive plan, coordination mechanisms, sufficient investment, and a health information workforce, are inadequate in many low- and (lower) middle-

income countries' [37]. In 2015, WHO made similar recommendations on the importance of governance, emphasising four features: (1) legal, institutional and policy frameworks, including harmonisation and coordination among entities involved in health information; (2) data standards, comprising core indicators with associated metadata, and international classifications for categorising data into statistical categories, such as the International Classification of Diseases for mortality and morbidity data; (3) information system architecture, including semantic and technical or syntactic standards that enable different information sub-systems to work together in an interoperable way; and (4) human resources and capacities for data collection, supervision and quality assurance, data curation, analysis, interpretation and dissemination [38].

Whatever the form of institutional arrangements adopted, lessons from country experiences in HIS strengthening indicate that it is essential to bring together interdisciplinary teams to design and manage an information system; these include subject matter staff, methodologists, and operations and systems experts working closely with data users [39].

Not every country describes the sum of its information gathering as a HIS, but all countries collect and coordinate health-related data to develop and assess services and use some combination of the data sources we have described, for example:

In Botswana (as of 2015), the Department of Civil Registration in the Ministry of Labour and Home Affairs maintains birth and death registration – which began in 1966 [40]. The Health Statistics Unit, seconded from the Ministry of Finance and Development Planning to the Ministry of Health (MOH) collects data from health facilities to publish official statistics while the MOH Department of Public Health collects data from disease control programmes [41]. The Botswana Central Statistics Office undertakes an intercensal Demographic Survey and, with the MOH, regularly conducts a Family Health Survey among other national surveys. Given problems with the HMIS, Botswana generates most of the health indicators it reports to international partners through household surveys. Botswana's is a centralised statistical system in which the Health Statistics Unit, while hosted in the MOH, collects data and publishes statistics on behalf of the NSO.

In Thailand (as of 2017), multiple data platforms serve information needs for health policy and planning. Civil registration completeness is estimated at over 95 per cent as is population coverage by three insurance schemes. Routine health administrative data, such as national inpatient and outpatient datasets and discharge summaries, as well as diseases registries inform programme management. Data from health facilities are used to assess treatment outcomes and variations

across insurance schemes. The NSO has implemented Health and Welfare Surveys regularly since 1974 to produce data on health service utilization and financial risk protection. Thailand introduced National Health Examination Surveys in 1991 financed by domestic resources, and these have drawn attention to low effective coverage of key non-communicable disease interventions and prompted active screening and other management responses.

In the US, (as of 2017), the National Center for Health Statistics (NCHS) compiles data on births and deaths registered at the state and local levels through the National Vital Statistics System and collects data through national surveys, including the National Health and Nutrition Examination Survey (NHANES) which assesses the health and nutritional status of adults and children. The National Notifiable Diseases Surveillance System, based at the Centers for Disease Control and Prevention (CDC), coordinates all levels of public health—local, state, territorial, federal, and international—to collect, publish and share notifiable disease-related health information. At the state level, public health departments collect and use public health information from around the state, and hospitals. Insurance networks maintain their information systems mostly for clinical services. This is a decentralised statistical system in which the US Office of Management and Budget coordinates 13 independent major statistical agencies representing different sectors including the NCHS.

Ultimately, the range of data a HIS collects must be sufficient to inform users at any level. Preferably, the government makes the data available to the general public and researchers once it has ensured privacy and confidentiality of individual records (see Chap. 23). For example, the Finnish HIS aims to provide all users with free access to the data it collects. The system offers web-based portals with indicators and anonymised data for all three levels of its health system, which the government collects mainly through coordinated administrative registers and multiple surveys [42].

The analytical and statistical skills needed to tease out answers to policy questions from available data may be beyond the capacities of a ministry of health and is better found in academic and research institutions. Some countries outsource the task of making sense of the quantities of health data to external institutions. For example, the Thai International Health Policy Program is a semi-autonomous entity tasked with generating evidence and reliable information to inform national policymaking [43]. The Canadian Institute for Health Information (CIHI) plays a similar role (see Chap. 25) [44]. WHO suggests that countries work closely with national institutes of public health or similar bodies to analyse and interpret data in support of policymaking [2].

9 Conclusion

Information systems in HICs are well funded and built on long-standing cumulative investments in human capacity and information technology. Yet, even HICs are not ready to measure the SDGs. In March 2017, a UK House of Commons Environmental Audit Committee commented: 'While this Government is making big claims about what it can do to implement the Goals on the international stage our inquiry has revealed that it is doing very little at home, leaving a doughnut-shaped hole in place of efforts to implement the Goals in the UK.'—a position the committee emphasised must change by, for example in health, embedding the indicators into the mandate of the NHS [45]. Challenges reported to the committee included that only about 50 per cent of the SDG indicators had an existing equivalent national indicator. Finland, while committed to implementing the SDGs, found that it would still have to make special arrangements to collect data on about 30 per cent of the health indicators [46].

Finland and the UK are well-resourced countries with strong HIS capacities. Even though they may have built the necessary types of data sources over years, these governments dedicate resources to ensure the quality of the data they process. Their systems depend on reliable funding and a continuous and sufficient supply of professional expertise. Health professionals are trained to record data and expect to use data in their work. As new technology appears, system managers have funds to pilot and innovate.

We began this chapter by quoting the WHO estimates for the additional health spending needed between 2016 and 2030 to achieve the SDG health targets. Health information comprised a small proportion of the estimated total spending amounting to an average of between US $85 million (progress scenario) and US $106 million (ambitious scenario) for each of the 67 countries over 15 years [2]. WHO based its estimates on achieving the Measurement and Accountability for Health Roadmap [16], including strengthening facility information systems, financial information systems, human resources information systems, and survey programmes, and contributing to governance both at the NSO and in the ministry of health, with the establishment of a public health institute in each country. WHO included in these estimates budgets to develop and place specialised human resources at the district level and in the ministry of health and NSO. All these investments build long-term infrastructure for countries to monitor their overall health system performance [2].

Tanzania provides a remarkable example of how a country sets priorities for developing its HIS. In 2017, the government of Tanzania completed a six-year roadmap or *Journey to better data for better health* identifying 17 investment areas totalling US $74 million [47]. Tanzania formed a national Health Data Collaborative which brings together local and international partners from several sectors to implement the roadmap with a common monitoring and evaluation framework. The Collaborative's 2017 priorities were to: (1) address fragmentation of monitoring and evaluation and data systems; (2) align indicators and data collection processes; (3) align health facility assessments and surveys; (4) align joint investments in digital HISs; (5) strengthen capacity for analysis and use of data; and (6) enhance data dissemination and access [48]. Other countries in the vanguard of the Health Data Collaborative approach include Cameroon, Kenya, and Malawi.

Permanent Secretary Dr. Mpoki Ulisubisya of the Ministry of Health said at the launch of Tanzania's Health Data Collaborative: 'I want to believe that through our collaborative effort, we will have ONE platform that will allow us to collect all the information we need, be it information on what we do for HIV/AIDS interventions, for tuberculosis, for malaria, for reproductive and child health, for maternal health, you name it' [49]. The global vision must be that, through imaginative use of technology, increased technical capacity and appropriate investments, LMIC governments, like Tanzania, Cameroon, Kenya and Malawi, will leapfrog a long period of information system stagnation to harness the global data revolution equitably to benefit their people's health.

Key Messages

- Health policymakers, planners and managers require reliable data from inside and outside the health sector.
- National HISs coordinate information from many sources including surveys, censuses, civil registration, surveillance and management information systems.
- HISs in LMICs are overloaded and under-resourced, and fragmented by past donor focus on monitoring disease-specific initiatives.
- National and international stakeholders are aligning around common frameworks and standards for data collection, analysis and dissemination.

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2

Indicators for Monitoring Health Targets

Sarah B. Macfarlane, Carla AbouZahr, and John Frank

1 Introduction

In 2015, according to the World Bank, '2.4 billion people today lack any form of recognized identity (ID), including some 625 million children, aged 0–14 years, whose births have never been registered with a civil authority' [1]; according to the World Health Organization (WHO) in Nigeria, with an estimated 814 maternal deaths per 100,000 live births, 159 women died each day from pregnancy and childbirth-related causes [2]; and, according to the United States Centers for Disease Control and Prevention, 'drug overdoses accounted for 52,404 U.S. deaths, including 33,091 (63.1 per cent) that involved an opioid' [3].

These statements contain succinct summaries of, sometimes complex, data collection and analysis—expressed as indicators. Their simplicity is effective. Indicators can stimulate a member of the public to organise for change, a

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patient to insist on her rights, a researcher to initiate a study, a programme manager to review an intervention, a donor to prioritise differently, or a policymaker to re-allocate funds.

Policy advocates quote indicators to highlight dimensions of problems, identify vulnerable groups and point to need for intervention. For example, that almost 2.5 billion people lack birth records is an indicator around which governments, donors, scientists and civil society groups can coalesce to meet Sustainable Development Goal (SDG) 16 to 'provide legal identity to all, including birth registration, by 2030'. That maternal mortality in Nigeria is among the highest in the world highlights a crisis. With the slogan 'No Woman Should Die Giving Birth', the Nigerian government is addressing the problem in six states with the highest maternal mortality [4].

Indicator simplicity can also mislead. Indicators summarise observations made at some place and some time and always include some uncertainty or error, whether statistical or human. For example, the World Bank reworks its calculations of the number of people without any form of ID every year. By 2017, the number had fallen to 1.1 billion. Although still large, this figure was less than half the number provided in 2015. The difference partly reflected increased registration coverage in Bangladesh and India but also improved estimation methods and data sources [5].

By measuring one aspect of a problem, an indicator only represents one piece of reality. For example, rising death rates in the US from drug overdose flag an escalating emergency and point to geographic and demographic hotspots. But misdiagnosis of opioid deaths may underestimate the scale of the epidemic [6]. These rates, like Nigeria's maternal mortality ratios, certainly don't convey the suffering of families and communities. When combined, several indicators show a pattern in a jigsaw but cannot complete the picture; at best they provoke further investigation and action.

We describe the evolution of health indicators and their growing prominence in global health and development discourse. We examine types of indicators to assess health sector performance, monitor national and international targets and develop policy. We describe how international demand for indicators has grown and the burden this imposes on health information systems. We conclude by discussing measurement, presentation and interpretation of indicators.

2 Types of Indicators Used in the Health Sector

A single item of data comprises an *observation* (or *measurement*) made of a *characteristic* on an *observational unit*, for example, this birth was attended by a skilled birth attendant; this 3-year-old child weighs 12.1 kg; this man shows signs of

tuberculosis; three people live in this household. All data items have three attributes, that is: the unit of observation (birth, child, man, household); the characteristic observed or measured (type of birth attendance, weight, diagnosis of tuberculosis, number of people in a household); and the value of the observation (presence of a skilled attendant, 12.1 kg, signs of tuberculosis, three people).

When observers make multiple observations of the same kind on different units, they use indicators to summarise the dataset such as: 65 per cent of births were attended by a skilled birth attendant; the average weight of 3-year-old children was 12.4 kg; 12 per cent of the male population showed signs of tuberculosis; 94 out of 161 households had three or more people living in them. Hence, indicators summarise raw data and allow users to interpret them. They provide information that the raw data alone cannot. Indicators facilitate comparisons of data across population sub-groups, time and space.

Data for indicators derive from many sources, some reliable, others not. For health sector programming, the primary data sources are censuses, civil registration systems, surveys, health management information systems and surveillance systems. Quality of data varies across sources and circumstances and this affects the reliability of the resulting indicators. If the data originate from a sample, indicators estimate the *true* values in the target population sampled. The estimate requires a measure of uncertainty, usually expressed as a 95 per cent confidence interval (see Chap. 18). Table 2.1 summarises the basic types of indicators used for health sector planning (Chaps. 7, 17, and 18 explain demographic and epidemiological indicators). We describe some of these indicators in this section.

Epidemiologists classify people as having a condition, or not, during sample surveys. They count the proportion of people surveyed in a geographical area at a specified time who, for example, have high blood pressure or who test positive for a condition such as anaemia or malaria, or possess an attribute such as having access to safe drinking water. They report the proportion as an indicator of a condition's *prevalence* in the population which they designed the survey to represent. Epidemiologists also count numbers of new cases of a condition, for example, the number of new cases of a specific disease such as measles or breast cancer, which occur in a population during a time period. They divide this number by the average number of people who were at risk of the condition during the time period and report an incidence rate which indicates the frequency with which the condition occurs *de novo* in the population, in the time period. For example, the incidence rate of new cases of all types of cancers in Scotland in 2012, based on a high-quality cancer registry, was 436.8 per 100,000 persons in the total population [7]. Similarly, demographers express the numbers of births and deaths occurring in a population during a time period as rates (see Chap. 7).

Researchers classify study participants by potential socio-economic and demographic determinants of the condition, for example, using *categorical*

Table 2.1 Common types of indicators used in the health sector

Indicators are calculated from raw data observed on a sample from a target population, and sometimes from data for an entire population. Indicators based on samples estimate the true population value and have a margin of error, usually expressed as a 95 per cent confidence interval.

Proportion: *number of units that have an attribute at a specific point in time (or over a period of time) divided by the total number of units in the population at that time* (expressed as percentage, per 1,000 or, for rare attributes, per 10,000).

Disease/condition prevalence	Proportion of people having the disease/condition, for example, tuberculosis, anaemia, malaria parasite, HIV
Service coverage	Cumulative proportion of units in a population which are in receipt of service, for example, children immunised, pregnant women attending antenatal care
Other proportions	Proportion of a population with impoverishing health expenditure, living in rural areas, experiencing intimate partner violence, currently using tobacco

Rate: *number of new occurrences of an event in a time period divided by the average number (during the same time period) in the population in which the event could occur* (expressed as per 1,000 or, for rare events, per 10,000 or 100,000).

Disease/condition incidence rate	Incidence of new cases of a disease/condition in a population, for example, low birthweight, new cancers of a specific site/type, new cases of sexually transmitted infections
Case fatality rate	Cause-specific death rates per 100 cases or hospital admissions
Birth and death rates	Number of live births in a year divided by the total population
	Number of deaths in a year divided by the total population at risk, for example, neonatal, under five, between 15 and 60 years

Count: *number of cases, events, items in a time period and/or a geographic area*; for example, births in a year, health facilities in a district.

Ratio: *one count divided by the other*; for example, of males-to-females, of sentinel events reported to total adverse events reported.

Service density: *number of service units divided by the total population*; for example, hospital beds, health facilities, physicians per capita.

Presence/absence: for example of national health sector policy/strategy/plan, civil registration system.

Summary indicators of measurements with a distribution:
for example, age, blood pressure, weight-for-age, fasting plasma glucose, household size, patients per day.

Mean	*Sum of all the values divided by the number of values*
Median	*The value below which half the observations lie and above which half the observations lie*

Qualitative: *facts, assertion, opinions expressed as quotations or narratives*; for example, opinions about care provision; patients' understanding of their health.

data such as education, type of residence or gender, and report indicators as proportions of the sample falling into specific categories. In the Tanzanian Demographic and Health Survey of 2015–16, of the 13,266 women of childbearing age (15–49 years) surveyed, 52 per cent of those with virtually no education had begun childbearing by age 19 years, compared to 32 per cent with incomplete primary education, 34 per cent with complete primary education and 10 per cent of women with some secondary or higher education [8].

Researchers report *measurements* that have a population distribution, such as blood pressure or age, as a *mean* or *median* of a sample of person-specific measurements—with an indication of the range of variation across individuals. They can also report measurements as the proportion falling in a range of interest. For example, among 55,015 babies born alive in Scotland in 2012, 90.1 per cent were of normal birthweight (i.e. between the 5th and 95th percentiles of the birthweights of all babies of the same gestational age) [7].

Health managers calculate the mean of *counts* of the numbers of people attending outpatient clinics, or patients admitted to hospital or express the number of health facilities per population, that is as a *density*. They also count the number of complete immunisations delivered for a particular disease and express this as an indicator of immunisation *coverage*—the proportion immunised of the target population they intended to cover. Registrars may count the number of male and female births and express them as a ratio, that is the male-to-female ratio at birth. Other indicators useful to managers include the existence of a policy or practice, for example, or the *presence* of a record system (requiring precise definitions of the policy or record system).

Analysts draw on data from several sources to build models to estimate indicators and they study associations with factors that might influence the indicator, for example, to explain disparities in access to care by gender, household wealth or racial groups. They build global models to estimate national-level indicators when data are missing or unreliable, for example, to estimate maternal mortality, which many countries report unevenly (see Chap. 21).

Researchers also create composite indicators such as disability-adjusted life-years (DALYs) which estimate disease burden as the number of years lost by all persons in a specified population, over their lifetimes, due to ill-health, disability or early death (see Chap. 19). For example, a study of the burden of all diseases and injuries in the Coastal Regions of Tanzania found that the *years of life lost* (YLL)—without attempting to also include the number of years spent in illness or disability (i.e. DALYs)—for all local age-groups was greatest for malaria, accounting for no less than 38.5 per cent of all years of life lost [9].

Whereas the majority of indicators to track national and global health goals and targets are quantitative, understanding the explanatory factors behind the numbers often requires qualitative research and analysis. *Qualitative* researchers

undertake in-depth interviews or host focus group discussions with selected participants. They summarise their findings as people's judgements and perceptions about a topic such as their confidence in the quality of their health care. Qualitative data can summarise the range of opinions of participants in a focus group discussion about whether health workers respected their privacy, or their reasons for not attending antenatal care or using condoms during unsafe sex. These data can be expressed in words or as the number of persons reporting positive or negative feelings about an issue. Such information provides invaluable insights for community organisers or health planners to determine how to deliver or organise health education and care. Qualitative information can be very close to the *lived reality* of stakeholders while quantitative indicators aim to be objective, but are distanced. We refer mainly to quantitative indicators in this chapter (see Chap. 16 for a discussion of qualitative methods).

3 Proliferating Health Indicators

Practitioners have long used indicators to describe issues of public health concern and to assess progress in handling them. Etches et al. [10] trace development of population health indicators since the 1800s. Their paper summarises, across several historical periods, key indicators used for purposes ranging from reporting mortality through classifying and tracking disease, assessing health care, describing risk behaviours and health gaps, and exploring how multiple determinants interact. They describe parallel expansion and sophistication of data sources. Although some health systems operated computerised data systems from the 1950s, most health facilities collected data manually until the 1980s and 1990s—and many still do. The advent of the Internet and increasing computing capacity in the twenty-first century, coupled with expansion of health insurance schemes, has opened limitless opportunities and expectations for health systems to collect, analyse, report and link data.

We pick up the story in 1978 with the Declaration of Alma Ata which outlined a global strategy to attain Health For All, that is 'a level of health that permits all people to live a socially and economically productive life' [11]. To measure attainment of this goal, the WHO proposed 12 indicators for countries to report internationally and a choice of 19 plus indicators for national use, classified as health policy, social and economic, provision of health care and health status [12]. In 1985—when most health facilities only used manual, paper-based reporting systems—Hansluwka remarked on the emergence of an indicator movement, writing: 'It seems as if the international commu-

nity, including WHO, are bent on making up for the relative neglect of quantitative information in the past with an obvious risk of moving, at least temporarily, to the other extreme of quantophrenia.' [13]. The movement was not temporary and marked only a modest beginning of longer-term proliferation of indicators on the international scene.

In 1990, the World Summit for Children laid out 33 goals (some with multiple indicators) to achieve by the year 2000 [14]. During the 1990s, WHO identified 15 indicators to describe just reproductive health [15]. Other programmes developed lists of indicators, for example, in 1994, the HIV/AIDS programme began with 10 preventive indicators [16] and by 2014, WHO/UNICEF and UNAIDS were collecting 78 indicators reflecting preventive, promotive, curative and rehabilitative interventions [17]. In 2014, the Global Fund used 114 indicators to monitor just three diseases: AIDS, tuberculosis and malaria [17]. The Millennium Declaration laid out eight goals—of which four related directly to health—with 21 targets and 60 indicators [18]. The SDGs committed to achieving 17 goals, 169 targets and 232 indicators by 2030—with 13 targets and 26 indicators to achieve the health goal, including the target of Universal Health Coverage (UHC) [19].

In 2014, concerned about the burden on countries to report indicators, WHO and partners made a conservative estimate that some countries regularly reported as many as 600 indicators to donor partners and international disease programmes or to comply with international resolutions, often with different definitions and reporting frequencies. WHO estimated that these reporting requirements could increase by up to 50 per cent the number of indicators countries already used to monitor health system performance [17]. The greatest burden for excessive routine reporting falls to front-line health workers and can distract them from actually providing care.

In response, WHO led an inter-agency working group which created The Global Reference List of 100 Core Health Indicators to 'guide monitoring of health results nationally and globally; reduce excessive and duplicative reporting requirements; enhance efficiency of data collection investments in countries; enhance availability and quality of data on results; and improve transparency and accountability' [20]. They prioritised indicators if they were technically sound, had been used extensively and evaluated, were being used to monitor national plans and programmes, and at least met MDG, UHC and SDG reporting requirements. The Global Reference List describes the characteristics of each indicator—its *metadata*—including its definition, method of measurement and estimation, factors for disaggregation, reporting frequency, and appropriate data sources [21].

Monitoring progress in the health sector depends on improvements in other sectors. While health indicators constitute the primary targets for SDG 3, many SDG targets combine to meet several goals. For example, child nutrition (SDG 2), access to safe drinking water (SDG 6), clean household energy (SDG 7), and ambient air pollution (SDG 11) are closely related to risk factors or determinants of reproductive, maternal, newborn and child health, with social and economic goals related to poverty (SDG 1), education (SDG 4) and gender (SDG 5) [22]. The health sector collaborates with other sectors to set, measure and report all relevant indicators.

International agencies keep databases of the indicators which countries report; these are accessible online, mostly with interactive maps and other graphics. The WHO Global Health Observatory provides summaries of indicators and access to data on 30 health themes [23]. The United Nations Statistics Division maintains values of all the MDG and SDG indicators by country [24]. The Gapminder Foundation collates sustainable development indicators from several sectors and creatively displays them using animated bubble charts [25].

4 Indicators to Measure Universal Health Coverage

SDG target 3.8—to achieve UHC, including financial risk protection—is fundamental to meeting all health-related SDG targets and offers particular challenges in measuring indicators. Indicators of coverage and financial protection summarise complex sub-indicators which require data that are not readily available or of high quality in many countries [26]. The indicator 3.8.1, 'coverage of essential health services', comprises several proxy indicators that are not direct measures of health service coverage because most countries lack suitable data. Proxy indicators such as density of physicians and hospital beds and use of services offer imprecise impressions of service coverage and are difficult to interpret without knowledge of their optimal levels [27].

An indicator of *effective* service coverage is 'the proportion of people in need of services who receive services of sufficient quality to obtain potential health gains' whereas an indicator of service coverage is 'the proportion of people in need of a service that receive it, regardless of quality'[26]. For example, service coverage for malaria vector control with impregnated bed nets (ITNs) is measured by the proportion of people in need of ITNs who receive them, whereas effective service coverage would be measured by the proportion who receive

ITNs and whose blood smear tests were negative for malaria. Effective service coverage is much more difficult to measure than service coverage, but even service coverage is hard to measure. For some non-communicable conditions, proxy indicators that correlate with service coverage are easier to measure. For example, the 2017 UHC report uses mean fasting plasma glucose as a proxy for diabetes management. The 2017 UHC report identifies 16 tracer indicators and constructs a composite *UHC Coverage Index*, concluding that 'the UHC service coverage index has a value of 64 (out of 100) globally, with values ranging from 22 to 86 across countries in 2015'. Only 9 of the 16 indicators were available for at least 100 countries [26].

The SDG indicator for *financial risk protection* is 'the proportion of the population with large household expenditures on health as a share of total household expenditure or income' [26]. The indicator classifies *out-of-pocket* expenditures on health as *catastrophic* when they exceed a 10 per cent or a 25 per cent threshold of total household expenditure or income. Household expenditure surveys, for example, the World Bank's Living Standards Measurement Surveys, provide most of the data for this indicator. Despite many differences in definition and data availability, after cleaning, the 2017 UHC report was able to include data from 132 countries representing 93 per cent of the world's population in 2015. From these data, the report concluded that 'in 2010, 808 million people incurred out-of-pocket health payments exceeding 10 per cent of household total consumption or income, (some 11.7 per cent of the world's population)' [26].

5 Leaving No-One Behind: Disaggregating Indicators

In 2008, the WHO Commission on the Social Determinants of Health drew attention to widespread and persistent challenge of health inequalities—systematic differences in the health status of a jurisdiction's sub-population [28]. These become apparent when investigators disaggregate indicators by attributes such as socio-economic status (usually obtained from survey data on individual or household income, wealth, and/or education), racial or ethnic group (also typically from surveys or, in more resourced settings, census data) and geographic location (e.g. rural vs. small urban, vs. large urban).

The Commission on the Social Determinants of Health demonstrated that systematic differentials in health status occur in every society where they have been studied, with the vast majority of them showing better health among individuals and families at higher rungs of the social/economic ladder. These

social gradients in health are remarkably persistent, often through periods of historical change in the major causes of ill health. A minority of diseases show *reverse gradients* in disease occurrence or mortality—for example, higher rates of breast cancer among women with higher levels of education in some high-income countries [29]. The typical pattern is the opposite, with a remarkable range of medical conditions being associated with social and economic disadvantage [30].

The SDGs explicitly address equity in their vision of 'no-one left behind'. To measure progress towards this vision, analysts must disaggregate SDG indicators at least by residence, wealth, education, sex and age. WHO has produced guidelines for monitoring health inequalities, covering data collection, analysis and presentation [31].

Disaggregating indicators in this way places an even higher burden of data collection and analysis on country reporting systems. Marmot and Bell go further proposing that countries need to collect cross-sectoral information to tackle social, economic, environmental and political inequalities to improve overall population health and health equity. They suggest taking a life course approach 'including indicators related to outcomes and social determinants in early life (under 5 years of age), youth (15–24 years of age), adult life, and older ages, and adding measures of living standards that cut across the life course' [32].

6 Measuring and Using Indicators

6.1 Frameworks

Conceptual frameworks provide a logic to select and interpret indicators and explain more of reality. They can be, for example, mathematical models that explain associations between health outcomes and their determinants, logical frameworks to monitor health sector performance (see Chap. 4), or depictions of theories of change.

The Global Reference List uses two frameworks to classify its 100 indicators: first, the list classifies indicators by four health domains (with sub-domains), that is, health status (mortality by age and sex, mortality by cause, morbidity and fertility); risk factors (nutrition, infections, environmental risk factors, non-communicable disease risk factors and injuries); service coverage (reproductive, maternal, newborn, child and adolescent health, immunisation, HIV, HIV/TB, tuberculosis, malaria, neglected tropical diseases, screening and preventive care, and mental health); and health systems (quality and safety of care, access, health workforce, health information, health financing and health security). Secondly, the list classifies indicators as inputs, processes, outputs,

outcomes and impact, using the International Health Partnership (IHP+) Common Monitoring and Evaluation Framework (see Chap. 4) [33].

IHP+ developed this *results-chain* framework to assist countries to assess the performance of their national health strategies, and so it links national and global reporting systems. The IHP+ Framework also identifies the data sources countries can use to measure these core indicators. The framework facilitates temporal and cross-country comparisons. However, using the same set of indicators everywhere to track complex interventions risks losing sight of different patterns of causality of mortality and ill-health in different settings.

6.2 Selecting Indicators for Programme Management

While epidemiologists select indicators to meet their research questions, programme managers identify indicators to describe inputs, outputs, outcomes and impacts within their chosen framework (see Chap. 4). Technical considerations in selecting indicators include: clarity about the population and timescale to which indicators refer; reporting frequency; whether data sources are available and reliable; and whether it is possible to disaggregate indicators at multiple levels (national, state, local and community) and for selected populations.

Programme managers increasingly involve stakeholders in choosing indicators to meet public health objectives of the systems they set up, the programmes they evaluate or surveys they undertake. This enhances the relevance of the indicators and means that the general public, opinion leaders, and health and medical communities are more likely to understand the results. Indicators should reflect significant national health topics seen as having some social value, be underpinned by government health objectives, and address problems that public policy and operational initiatives could improve. Managers should choose and define indicators consistently across programmes, where possible selecting from the Global Reference List [21].

While technical soundness is essential, policy priorities also drive indicator selection. Many indicators, including some identified for global level SDG monitoring, are aspirational rather than operational because information systems cannot collect the data to construct them. At the end of 2017, the UN Inter-agency and Expert Group on SDG Indicators classified 93 of the 232 SDG indicators as 'conceptually clear, has an internationally established methodology and standards are available, and data are regularly produced by countries', 66 as 'conceptually clear, with an internationally

established methodology and standards are available, but data are not regularly produced by countries', and 68 as having 'no internationally established methodology or standards' (5 indicators had sub-components in multiple tiers). The latter category includes the UHC sub-indicator on the proportion of health facilities that have core essential medicines available on a sustainable and affordable basis [34].

Once an issue becomes a policy priority—often following emergence of a new disease or community-based advocacy campaigns—managers must develop methods to monitor implementation over time. For example, in the early years of the AIDS epidemic, clinicians based their case definitions on a series of physical signs and symptoms that could not be ascribed to causes other than HIV/AIDS. A decade later, when HIV antibody testing became available, measurement strategies became more certain and specific, enabling monitoring and evaluation of validated prevention and treatment methods. Especially during the initial phase of a disease-specific programme, indicators may well change over time, desirable indicators may not be immediately measureable, and what can be measured may not be the most relevant statistic for programme planning. Indicator selection should be sufficiently flexible to embrace new measurement methods and be part of regularly updated measurement strategies that generate valid, reliable, timely, and comparable measurements in the foreseeable future.

Indicators require target values together with baseline values against which their achievement can be measured or benchmarked. Where appropriate, these targets will be in line with those for the SDGs, for example, 'by 2030, end preventable deaths of newborns and children under five years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-five mortality to at least as low as 25 per 1,000 live births'. Absolute targets such as these make achievement harder for countries with baselines most distant from the target. Setting targets in relative terms—achievement of a defined percentage change compared with baseline—makes the global target easier to achieve for all countries but risks further exacerbating inequities between countries [35].

6.3 Measuring and Estimating Indicators

Calculating indicators can be straightforward but depends on the availability of suitable data. Prevalence rates of health conditions can be calculated directly from well-designed surveys and disaggregated by sub-population characteristics such as age, sex and socio-economic status, and by geographical region. Disease incidence rates can be calculated from data generated by high-quality surveillance systems that accurately record the number of new cases over time. Mortality rates can be calculated directly from civil

registers so long as death registration is complete. Because deaths are not registered in most low- and middle-income countries, demographers rely on household surveys—such as Demographic and Health Surveys—to estimate mortality, notably for children under five years (see Chap. 17). Coverage rates can be derived from facility records if the numerator (persons receiving a service) and denominator (local catchment population targeted for the service) are accurate. When facility records are unreliable, analysts derive coverage indicators from household surveys, relying on inhabitants' accurate recall of their receipt of a service—or, in some situations, corroboration from a hand-held immunisation record, or physical evidence of having received it—for example, the presence of a smallpox vaccination scar, during the period of smallpox eradication in the 1970s.

When analysts derive indicators from models, they take into account the values of other variables in the conceptual framework (see Chap. 21). WHO estimated Nigeria's maternal mortality ratio between 1985 and 2015 using data from two household surveys in 2008 and 2013 in a model that included gross domestic product, the general fertility rate and percentage of births attended by skilled health personnel as explanatory factors [2]. WHO concluded that the mortality ratio for 2015 was 814 maternal deaths per 100,000 live births with 95 per cent confidence intervals of 596–1,180. Confidence intervals such as these reflect uncertainty associated with the modelling approach and the input data, but often fail to take account of uncertainty around the independent variables used in the model (see Chap. 21).

Analysts also control indicator estimates for factors that might distribute differently among comparison groups, for example, they may adjust rates and ratios for age—in effect by assuming that age is represented equally in all comparison groups. Estimates of the same indicator for the same population can vary far beyond differences that can be explained by sampling error. Such differences usually result from inadequacies or basic differences in methods of data collection, non-response and poor recall, and provide good reason to use statistical estimation methods to harmonise results. But the value of estimates based on modelling can also vary enormously depending on the underlying databases, sources and statistical methods used by the institutions publishing them.

6.4 Presenting and Interpreting Indicators

Although a single value of an indicator for a given population at a given time can impact the way people think, it has more meaning when set in context. Understanding comes when analysts compare the indicator with values for earlier

time periods to show a trend, distribute its values across population categories to show differences or disparities or display its values on a map to demonstrate geographical patterns. (Figures in several chapters in this handbook illustrate trends over time as line graphs and by geographic area as maps.)

Returning to the examples in the opening paragraph of this chapter, Nigeria's estimated maternal mortality ratio is unacceptably high but has fallen to 814 from an estimated 1,350 maternal deaths per 100,000 live births (with 95 per cent confidence interval of 893–1,820) in 1990 [2]. Nigeria's challenge now is to reduce the ratio by 2030 to achieve the global SDG target of less than 70 deaths from pregnancy and childbirth-related causes per 100,000 live births. The 52,404 overdose deaths recorded by the US National Vital Statistics System in 2015 represented an age-adjusted death rate of 16.3 per 100,000 population and showed a two and a half-fold increase in the 1999 rate of 6.1, that is an average increase in death rate of 5.5 per cent per year. In 2015, the overdose death rate for males was 20.8 per 100,000 population, an increase of 5 per cent per year, compared to 11.8 per 100,000 for females, an increase of 6 per cent per year. Death rates varied by state from 6.9 per 100,000 to 41.5 per 100,000 [36]. The figures also showed that the pattern of drugs involved in overdose deaths has changed, for example, death rates involving natural/semisynthetic opioids, heroin and synthetic opioids other than methadone increased by 2.6 per cent, 20.6 per cent and 72.2 per cent, respectively between 2014 and 2015 [37]. These figures signalled opioid deaths as an increasing public health emergency in the US.

It is advisable to treat all indicators with caution. We offer some advice about interpreting published indicators in Box 2.1. Chapter 22 provides a comprehensive approach to ensuring and judging the quality of findings from different types of studies.

Box 2.1 Assessing and Interpreting Indicators

Quality: Is the indicator value credible? What is the quality of the data on which it is based? Was the indicator calculated using standard methods (e.g. WHO metadata)? What is the range of uncertainty?

Interpretation: How does the indicator value differ from earlier measurements for the same population? Does the indicator show a positive or negative change? Does it show a trend in a particular direction? How does the value differ between areas and sub-groups? How does the value compare with values reported by other countries?

Advice: Never generalise the indicator value beyond the time period and population group to which it refers. Check that the definition used for the indicator was the same as for any other values with which it is to be compared. Treat values based on small samples (typically rates based on numerators of less than ten cases, or denominators of less than 100 persons) with extreme caution.

7 Conclusion

Health indicators provide limited but often useful information about the state of a population's health and the functioning of its health system. Indicators cannot describe all aspects of health programmes, but they contribute to understanding by allowing comparisons over time, and within and between countries and populations.

Indicators are indirect statements or measures of something more complicated. Nonetheless, because they frequently measure progress towards targets, indicators tend to drive programmes and influence donor-funding decisions. By rewarding target attainment with additional funds, for example through performance-based funding mechanisms, the international development system exerts strong pressure to move indicators in the *right* direction. But as Saith remarked, 'Institutionalizing targets in bureaucracies and governmental regimes usually invites misuse and manipulation of statistics and the misrepresentation of outcomes' [38].

Once the management team has identified and adopted an indicator, programme interventions tend to focus on improving that indicator rather than on addressing the intended impact. For example, if managers use skilled attendance at delivery as a proxy for monitoring maternal mortality, they will try to ensure that all women deliver with a skilled attendant. But levels of maternal mortality may be high because of other factors, such as unsafe abortions or elevated levels of malaria. It is easier to guide programmes using readily quantifiable indicators such as numbers of vaccines distributed—a kind of *throughput* [39]—instead of exploring motivating factors that might contribute to successfully distributing the vaccines. Qualitative information, on the other hand, can explain the context in which the programme functions and how participants perceive its activities.

We have demonstrated that indicators tend to multiply over time—constant vigilance is needed to prevent this getting out of hand. But the reality is that given the many demands for monitoring and evaluation across multiple health programmes, the number of indicators is likely continue to grow. Fortunately, the MDGs and the SDGs have focussed international attention on the need for consistency and coherence between indicators. Ultimately, indicator reliability and validity depend on the quality of country information systems that provide data for their calculation; the quality of these systems is, in turn, threatened by the burden of indicators they measure.

Key Messages

- Indicators summarise sometimes complex, situations and inform policy, planning and collective action.
- Indicators represent part of reality and make the most sense within a conceptual framework.
- A good indicator is measurable, consistently defined and technically sound.
- The reliability and validity of indicators depends on robust information systems which can deteriorate under the burden of collecting too much data.
- Agencies must minimise the number of indicators they expect national programmes to report.

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3

Challenges in Shaping Policy with Data

Claire D. Brindis and Sarah B. Macfarlane

1 Introduction

'We have solid evidence that keeping intake of free sugars to less than 10% of total energy intake reduces the risk of overweight, obesity and tooth decay,' said the World Health Organization's (WHO) Director of Nutrition for Health and Development when issuing international sugars guidelines in March 2015. 'Making policy changes to support this will be key if countries are to live up to their commitments to reduce the burden of non-communicable diseases' [1].

Data can influence policy to improve people's health. To combat the rising epidemic of non-communicable diseases, WHO synthesized international

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evidence and proposed policies to reduce sugar consumption. Data specialists can advise national lawmakers about likely efficacy of these policies to control the sugar content of foods and beverages or to persuade people to consume less sugar. They can also assist programme managers evaluate policy interventions as the examples from France, Mexico, Norway and the US in Box 3.1 illustrate.

Box 3.1 The Value of Data in Developing Policies to Curb Global Sugar Consumption [2]

Global data show that: (1) the number of people overweight or obese has reached epidemic proportions—in 2013, about 37 per cent of men and 38 per cent of women worldwide were overweight or obese; (2) excess weight increases the risk of some non-communicable diseases; and (3) excessive sugar consumption is one factor promoting overweight and obesity, yet from 2000–01 to 2013–14 global sugar consumption grew from about 130 to 178m tonnes.

Data from some countries show the benefits of policies aimed at:

- *Reducing availability of sugar and sugary products:* France enforced a school vending machine ban in 2005 and observed a significant reduction in calories, fat, sodium and, especially, free sugar intakes in the morning nutrition break.
- *Decreasing affordability of sugar and sugary products:* Mexico introduced a sugary drinks tax in 2014. Early results showed about a 10 per cent decrease in sales.
- *Reducing acceptability of sugar and sugary products and increasing acceptability of alternatives:* Norway initiated a nationwide school fruit programme in 2007. Students increased fruit and vegetable intake and reduced their unhealthy snack consumption.
- *Increasing awareness of sugar in products:* Los Angeles County, in the US, ran a multimedia campaign, in 2011–12, which increased public knowledge and over 60 per cent of respondents reported they were likely to reduce their daily intake of sugary drinks.

While policymakers use data and evidence to make and evaluate their decisions, they also base their choices on philosophical, historical and societal values, on available resources and legal considerations, and on internal influences and political pressures. For example, despite clear evidence that sugar consumption adversely affects health and the existence of an inventory of evidence-based policy responses, lawmakers struggle with demands of the sugar industry, and political arguments that sugar taxes limit people's freedom to choose what they eat [3].

Data providers and users do not communicate well. Policymakers appear to ignore evidence when it is politically expedient or even use unsubstantiated

data instead. They respond to media reports of emerging issues and demand scientists provide data to confirm or negate rumours. Researchers aim to provide objective evidence but don't always convey their findings clearly and succinctly, or even ensure that their findings are relevant to current policymaking priorities.

Evidence has influenced policy shifts in global health, for example, introduction of voluntary male medical circumcision programmes that prevent HIV transmission, laws enforcing wearing automobile seatbelts and motor bicycle helmets that have reduced deaths and brain injuries from traffic accidents, and legislation to control tobacco use that has dramatically reduced lung cancer rates. In each case, scientists communicated their findings sufficiently clearly to eventually convince advocates and policymakers to champion and implement these laws; and scientists have demonstrated reductions in morbidity and mortality after the laws came into force.

We explore how data specialists and policymakers can collaborate to set and implement policy. In the next section, we highlight the importance of data and evidence to health policymaking and describe the origins of evidence-based policymaking. In Sect. 3, we describe how policy stakeholders and data specialists interact during stages of policymaking, and in Sect. 4, we explain policymakers' different needs for and use of data and evidence. In Sect. 5, we suggest how data specialists and policy stakeholders can increase demand for and use of data and evidence in policymaking. We use the term *data* to describe factual information and the term *evidence* to describe conclusions scientists have reached after synthesizing or analysing data to answer specific policy questions.

2 Building Data and Evidence into Policymaking

Democratic governments recognize that they need data to govern. They invest in statistical offices and information systems so they can target resources to meet documented priorities (see Chap. 1). Health policymakers respond to evidence of growing challenges, such as HIV/AIDS, opioid use and the Zika virus, while they maintain and monitor control of obesity and diabetes, cholera, malaria, and maternal and infant mortality. To highlight areas for policy focus, governments need up-to-date, reliable and relevant information about

morbidity and mortality trends, and differences in health outcomes between geographic regions, racial groups or gender. Comparative data from international databases, such as WHO maintains, anchor new policy directions.

In the 1990s, politicians and researchers began to use the term *evidence-based policy*. This was in contrast to *opinion-based policy* which relies 'heavily on either the selective use of evidence (e.g. on single studies irrespective of quality) or on the untested views of individuals or groups, often inspired by ideological standpoints, prejudices or speculative conjecture' [4]. The UK used the term evidence-based policymaking in its 1999 Modernising Government White Paper, explaining that 'policy decisions should be based on sound evidence. The raw ingredient of evidence is information. Good quality policymaking depends on high-quality information, derived from a variety of sources—expert knowledge; existing domestic and international research; existing statistics; stakeholder consultation; evaluation of previous policies' [5].

The expression evidence-based policy draws on experience of *evidence-based medicine* in which researchers evaluate treatments or interventions through randomized trials (see Chap. 18). Policymaking requires a broader range of methods, as the 1999 UK White Paper indicated [6]. Davies et al. defined evidence-based policymaking as an approach which 'helps people make well-informed decisions about policies, programmes, and projects by putting the best available evidence at the heart of policy development and implementation' [7]. More recently, the Australian Productivity Commission defined the approach as 'a process that transparently uses rigorous and tested evidence in the design, implementation, and refinement of policy to meet designated policy objectives' [8]. The evidence-based approach to policy is not as compact as its equivalent in medicine since it synthesizes findings of different types of data collection. The approach draws not only on the findings of dedicated epidemiological and social studies, targeted focus group discussions, clinical trials and intervention studies, cost benefit analyses, modelling, impact evaluation of interventions, and systematic reviews but also on routinely collected data from government statistical and information systems.

3 Participants in Policymaking

We differentiate between policy stakeholders as follows:

Policymakers or lawmakers conceive and develop policy agenda and argue for policy adoption. They are elected or nominated to prepare laws that protect the health of the people they represent.

Programme managers interpret policy directives, implement and evaluate policies and suggest refinements and expansion. They work for governmental, non-governmental or private agencies at the state, provincial or district level, or for international institutions.

Policy watchdogs are individuals and institutions who look for gaps in policy and policy implementation and lobby for policy change. They include advocacy and community groups, non-governmental organizations, media, individuals devoted to specific causes, and whistle-blowers.

Although their roles overlap, we differentiate between data specialists as follows:

Data generators are statisticians, information technology specialists or data managers who run health information systems and prepare regular performance reports. They maintain routine health facility records for governmental, non-governmental and private institutions, or run censuses, civil registration systems or disease surveillance systems, or regularly undertake large- and small-scale surveys. They work nationally or internationally.

Data analysts include statisticians, epidemiologists, sociologists or health economists who design qualitative and quantitative studies and analyse, model and present data to provide evidence for policy. They work in academic, governmental and other research institutions anywhere in the world.

Data brokers are policy analysts who are intermediaries between data generators and analysts and policymakers. They gather data and evidence to address policy issues, analyse secondary data and big data, conduct systematic reviews and prepare policy briefs. Brokers work for academic and governmental institutions or for independent policy units to advise local, national or international lawmakers.

Evaluators work with programme managers to evaluate policy implementation at any level nationally or internationally. They develop frameworks, select indicators, interpret data and provide quantitative and qualitative, contextualized data on why certain outcomes are achieved or not.

4 Data in Different Stages of Policymaking

Table 3.1 summarizes the stages through which policy develops [9–11]. We highlight questions policy stakeholders ask and suggest which data and sources data specialists use to answer these questions. Although we present the stages in sequence, they are seldom linear and do not necessarily result in policy preparation or adoption. Their order and timing depend on political will to pursue specific policy solutions, availability of appropriate and well-presented

Table 3.1 The role of data in different stages of policymaking

Stage	Questions	Relevance of data	Type of data gathering
1 Problem recognition: Policymaker becomes aware of an emerging issue. *2 Agenda setting:* Policymaker firmly adopts the issue and begins to seek viable policy solutions.	What is the scale of the issue? Who does the issue affect and how? When and how often does the issue occur? Where does the issue occur? How do people perceive the issue? Why should the issue be prioritized?	Proponents offer evidence about the importance of the issue (collected by data generators and analysts); Data brokers advise policymakers about the quality and validity of data.	Routine data collected through health information systems; Epidemiological and social surveys; Trend analyses; Focus group discussions.
3 Policy formulation: Policymaker formulates and proposes a bill comprising specific policy proposals.	What interventions have addressed the issue successfully elsewhere? Who will the proposed policy target? When will the policy be implemented? Where will the policy focus? How much and what type of resources will policy implementation require? Why will the chosen policy combination succeed?	Data brokers synthesize and present evidence for potential strategies to address the issue and advise on their cost and benefits.	Literature reviews; Synthesis of clinical trials or intervention studies; National and international consultations on experience with potential strategies; Cost benefit analyses.
4 Policy adoption: Through policy legitimization, the policymaker persuades other lawmakers to adopt the bill as law.		Data brokers prepare policymakers to answer questions from other lawmakers to assist them in their decision-making.	Policy briefs collating answers to potential questions from the data gathering described above; Assessment of resources to implement.
5 Policy implementation: Programme managers develop a blueprint for implementation that can be monitored to assess achievement of policy goals.	What monitoring and evaluation framework is most appropriate? Who will benefit and how? Where will the evaluation happen? When will the evaluation be undertaken and how frequently? How will the stakeholders know if the policy is successful? Why is the evaluation necessary?	Programme managers and data generators agree on reliable and relevant indicators to monitor policy implementation.	Specification of the logical framework and the indicators of input, output, outcomes and impact.
6 Policy evaluation: Programme managers continually assess the impacts, costs of implementation and if the policy achieved its intended goals.		Programme managers and programme evaluators measure the indicators and changes in impact over time.	Monitoring and evaluation of implementation using health information systems, dedicated systems, targeted surveys, trials and focus groups.

evidence, and competing priorities for resource allocation. Some policies fail early but are re-introduced years later when public opinion changes, for example, legislature for gay rights in the US. Other policies may start with one set of expectations and then be co-opted to address a different issue.

4.1 Problem Recognition and Policy Agenda Setting

Policymaking begins when a lawmaker recognizes an issue and considers developing or amending policy to address it (Stage 1). Issues usually correspond to political agendas but may arise organically through advocacy by policy watchdogs or reports from data brokers (see examples in Box 3.2).

Box 3.2 The Evidence Informed Policy Network (EVIPNet) [12]

In 2005, the World Health Organization established EVIPNet to promote systematic and transparent use of health research evidence in policymaking. By 2015, the network covered 36 low- and middle-income countries promoting partnerships between policymakers, civil society and researchers to support policy and its implementation, using the best research evidence available. Two examples illustrate how the network shared its evidence with policymakers:

In 2013, alcohol consumption accounted for around 10 per cent of all deaths in Moldova—double the global average. An EVIPNet group identified the ready availability and low cost of beer and home-made wine as a cause. The team developed an evidence brief outlining policy options and held a policy dialogue which led the government to amend its alcohol control legislation and improve the National Alcohol Control Programme.

In Lebanon, one in four adults suffers from a mental illness; yet they have limited access to suitable primary health care. In 2014, the EVIPNet-supported Knowledge to Practice Centre prepared evidence briefs and held policy dialogues. As a result, Lebanon set up a national health psychosocial support task force, started training primary health-care workers about mental illness, and added psychiatric medications to the national essential drug list.

Members of the public may observe unprecedented traffic accidents at a particular location and work with police to propose speed limit changes. Professional organizations or non-governmental organizations may identify inadequacies in human resources and campaign to train and employ suitable health workers. Academics may demonstrate inequalities in people's access to health care and press policymakers to address gaps in delivery. The media may spotlight health problems through investigative reporting and help mobilize communities to consider options to decrease adverse outcomes. International organizations, such as WHO, provide evidence from different countries to

highlight global issues, as in the obesity example in Sect. 1. The Institute of Health Metrics and Evaluation provides comparative information on disease burden for more than 195 countries [13].

Data generators and data brokers may analyse national data sets and flag emerging trends and areas requiring new investments, for example, pockets of HIV infection in populations previously untouched by the disease. Lawmakers can face challenging sentinel events. For example, evidence of increasing numbers of deaths and overdoses from opioid use, and media stories of families losing their loved ones to the epidemic challenge US lawmakers to act. They can make additional investments in drug treatment, particularly in hot-spots where the epidemic is most notable, as well as change in professionals' pain medication prescription practices which have contributed to the opioid crisis [14].

To understand why they should prioritize an issue, lawmakers need to know the size of the problem, where and when it occurs, the most vulnerable groups, and how people perceive the issue. Convinced of its importance, the champion lawmaker firmly adopts the issue, develops an agenda (Stage 2), and engages other policymakers, stakeholders and constituent groups. To make a firm commitment, lawmakers ascertain what hard evidence exists that makes agenda setting a high priority. Increasingly, international data sharing contributes to raising awareness about policy imperatives, as well as potential policy solutions.

4.2 Policy Formulation and Adoption

Having agreed an agenda, lawmakers propose and formulate policy options (Stage 3). They expect data brokers to review successes and failures of interventions implemented elsewhere and consider how interventions might work or be adapted to context. This includes systematic reviews and grading of evidence from journal articles [15] and grey literature and examination of experts' perspectives about best practices. The World Bank's Disease Control Priorities is a major source of information about effective interventions for conditions contributing to the global burden of disease including economic evaluations of policy choices, particularly for low- and middle-income countries [16].

Lawmakers may request that data analysts gather and analyse new data—either qualitative or quantitative—to test acceptability of policy options, for example, to undertake focus groups of likely programme recipients, or public opinion surveys to check the public's and business' perspectives on policy direction. Data brokers will analyse routine data or mine data sets that have

not been analysed for this purpose. They may consider social determinants that could underlie the problem, for example, unsafe communities that prevent families from playing outside, or lack of viable transportation that impacts access to grocery stores and physical activity.

Box 3.3 Challenges to Policy Formulation Even with Strong Advocacy

Extensive evidence shows oral contraceptives (OCs) are one of the safest and most effective forms of contraception and consumers accept OCs well [17]. Most women, particularly living in low- and middle-income countries, have legal or informal over-the-counter (OTC) access to OCs, but women in the US, Canada and most of Western Europe require prescriptions [18]. Women in the US want OTC access to OCs, but advocates must overcome the prescription barrier.

Since 2004, in the US, reproductive health, rights, and justice organizations, non-profit research and advocacy groups, university-based researchers, and prominent clinicians have convened as the OC OTC Working Group. The group has gathered evidence and advocated for access to safe, effective, acceptable and affordable contraceptives. Several states have introduced pharmacist prescription/provision of hormonal contraception to increase access. But a drug company must apply to the US Food and Drug Administration to make OCs available OTC, a process likely to take several years.

The champion policymaker then articulates the policy proposal, or bill, and attempts to persuade other lawmakers to adopt it as law (Stage 4). The champion builds support for the bill using bargaining, persuasion and compromise. Other lawmakers raise questions that require data brokers to collect and provide additional information. For example, scientists have had to produce significant data about safety of routine immunization against communicable diseases to convince policymakers to continue enforcement. In California, for example, mobilized constituent groups advocate allowing parents to opt out of vaccination requirements but, because of evidence of public health ramifications in a population without sufficient immunity, legislators passed a law that eliminates personal and religious exemptions for children [19].

4.3 Policy Implementation and Evaluation

Once a bill passes into law, bureaucracies translate the law into guidelines or rules and regulations (Stage 5). National, state or local governments implement new legislation, such as agency activities and public expenditures, through public programmes.

Evaluators support lawmakers and programme managers to conduct systematic evaluation of a policy—its actual impacts, costs and whether it achieved its intended results (Stage 6) (see Chap. 4). They inform policymakers of future policy options and suggest refinements they might consider (Box 3.4). When a policy does not achieve expected results, data generators and evaluators may provide nuanced data analyses to show what it has achieved, for example for population subgroups.

Box 3.4 Rigorous Evaluation Can Shape Policy: The Progressa/Opportunidades/Prospera Initiative [20]

In 1997, Mexico introduced the Education, Health, and Nutrition Program, PROGRESA, to break the intergenerational transmission of poverty. The International Food Policy Institute evaluated the programme by comparing eligible households receiving the intervention of cash benefits with control households in seven states. Several waves of survey data collection, before and following initiation of the cash-benefits in the treatment villages, and other evidence, concluded the programme impacted improvements in health status and utilization of health services, schooling, food consumption and employment outcomes.

Policymakers decided to continue the initiative, but also to strengthen its requirements. Cash payments for families became dependent upon family compliance with programme requirements, so children attend school and family members receive preventative health care. The mother became the rights holders and the government decreased overheads and the potential for corruption by making cash payments directly to the families. Families must participate in an evaluation to help ascertain target measures considered most likely to lift families out of poverty. Implementation of this programme and its evaluation led the Mexican Congress to mandate that monitoring and evaluation become integral to public policymaking [21].

In Box 3.5, we summarize the technical responsibilities of data specialists throughout policymaking.

Box 3.5 Responsibilities of Data Specialists in Answering the Policy Stakeholders' Questions

Data generators: Policy recognition and agenda setting

Maintain the health information system; undertake surveys to address specific issues; ascertain the public's opinions on government services; present and visualize data; and clarify data limitations.

Data analysts: Translating data into evidence at all stages of policy development

Provide advice on design of qualitative and quantitative studies; analyse data by paying attention to trends and inequalities; develop models to estimate and predict results of policy options; analyse big data available through social media; present and visualize data; provide and explain statistical inference; and describe data limitations.

Data brokers: Agenda setting, and policy formulation and adoption

Assess whether stakeholders' interpretations are valid; decide whether available data provide sufficient evidence; request additional data generation to justify policy options; conduct secondary data analysis, meta-analyses and systematic reviews; undertake interviews, focus group discussions and polls of public opinion; make inter-country comparisons; analyse big data available through social media; and prepare policy briefs, press releases and social media.

Evaluators: Policy implementation and evaluation

Provide advice on the monitoring and evaluation framework; select and justify the indicators to be used; provide advice on data collection and analysis; and prepare timely and comprehensive reports.

5 Strengthening Mechanisms for Harnessing Data and Evidence to Policy

We have described opportunities for data to influence policy. Yet, as AbouZahr points out, 'Even when the evidence for policy change is unequivocal, getting it implemented in practice can be a fraught process, with considerable risks of failure' [22]. For example, despite extensive evidence, policymakers may not act if options seem counter-intuitive or contradict what they perceive to be the moral standards of society (Box 3.6).

Box 3.6 Policymakers May Ignore Evidence That Seems Counter-Intuitive or Contradicts Their Interpretation of the Moral Standards of the Society

People who inject drugs often share drug paraphernalia or engage in high-risk sexual behaviour, putting them at risk of blood-borne infections, such as HIV. A syringe service programme (SSP), or needle-exchange, is a cost-effective strategy to prevent the spread of infection in US settings [23]. By 2014, there were needle exchange programmes in 197 US cities [24]. Concerned that funding SSPs would condone illegal behaviour, rather than prevent adverse health outcomes, the US federal government initially ignored this evidence by implementing a total ban on funding SSPs, and after lifting the ban in 2010, they provided only restricted support. By 2011, the government provided support for needle exchange, but legal barriers, insufficient resources to comply with funding processes, local politics and programme culture made it difficult for programmes to function [25]. The government reinstated the ban in 2012, but effectively lifted it again in 2015 by permitting federal support for operational costs, but not syringes; this was in response to concerns about HIV outbreaks in new geographic areas and populations [26].

There is growing disbelief, distrust and even disdain for data among politicians and the general public. It is easy to surf the web and find statistics that support any argument, or indeed to make up *alternative* facts [27]. No statistics represent the truth; they only quantify a perspective on what is known at a point in time, and findings change with new investigations. For example, in the 1990s epidemiologists and WHO affirmed that dietary fat caused obesity and rising rates of cardiovascular diseases, and they supported policy to encourage low-fat options. A few years later they affected a U-turn and announced that data showed full-fat to be a healthier option because use of low-fat products increase sugar consumption [28]. Not surprisingly, the scientific process of ongoing discovery often results in modifications and sometimes, dramatic changes in available evidence. Constancy in results may not be feasible over time, making it imperative that scientists package their findings in a manner that allows policymakers to make decisions with the data available. In turn, this process allows scientists to further test and learn how evidence is (or is not) used in the implementation of policy. Clearly, the availability of data and evidence alone will not result in significant behavioural changes. In the case of nutrition, people feel uncomfortable about changing policies or eating habits without clear explanation of why.

The Internet and social media have dramatically changed the availability of information and the debate about the authenticity of evidence. Consumers of published information, including policymakers, may not have the training or education to be able to sift through which sources are credible and which actually counter established scientific findings. This places a particular burden on data brokers and policymakers who may not be prepared to respond to the unwarranted beliefs they encounter as they attempt to make evidence-based decisions.

Recognizing the *knowledge-to-action* gap, Yamey et al. identify two approaches to knowledge transfer and exchange between researchers and policymakers [29]. One suggests 'there is a series of steps—a linear pathway—from generating research evidence to evidence-informed policymaking' similar to the stages we described in Sect. 4. For example, the data broker develops evidence briefs that summarize the results of a systematic review or a randomized controlled trial and discusses policy implications, tailored to the needs and interests of a policymaker. The alternative *political economy* approach suggests both the research process itself and the transfer of research evidence to policy are heavily influenced 'by competing economic interests, social values, and power dynamics' [30, 31]. These external elements determine the research questions that are prioritized, funded and studied, and if and how evidence from the research is used in decision-making. In practice, both approaches can

operate in parallel, but it is important for researchers and policymakers to acknowledge how their approach influences the knowledge they share.

After extensive literature review on factors affecting use of evidence in policy, Oliver et al. concluded that the primary barrier to policy uptake of research evidence is that policymakers don't have adequate access to timely, relevant and quality information. They suggest that better collaboration between researchers and policymakers, with improved relationships and skills, could facilitate use of evidence in policymaking [32]. We propose ways in which data specialists and policymakers can increase demand for and use of data and evidence in policymaking.

Communicate Data specialists and policymakers can network to share and appreciate each other's perspectives through discussion fora and staff exchanges between research institutions and government departments [33]. For example, the Evidence Informed Policy Network (EVIPNet) (Box 3.2) has changed how decisions are made in 36 countries by bringing all stakeholders together to influence policy [12].

Invest in Flexible Open Information Systems Many data that health information systems collect are not directly useful to decision-makers. Davies et al. suggest these systems need to be more flexible in the source, scale and timing of information and propose a framework to assist data specialists ascertain decision-makers' needs [34]. Data generators can build improvements into waves of data collection, while remaining consistent in how they measure indicators over time. Open sharing of public data supports the public and policy watchdogs to decide if policies meet their needs.

Formulate Policy Questions That Clarify Data Needs Sometimes, scientists do not answer the question that interests policymakers. If they establish better communication, data specialists and data users can collaborate to formulate policy relevant questions. This will help them ascertain fit between questions and data sources and also temper policymakers' expectations of the time it takes to collate data and to conduct thoughtful and balanced analyses. One way to ensure relevance is to align research strategies to government development plans [33].

Tailor Data Collection and Analysis to the Time Available Policymakers sometimes demand information from data specialists before the findings are ready. Instead of requesting a full-scale dedicated survey, the data broker can undertake secondary analyses and actively mine existing, and sometimes under-

used, data-sets. Focus groups and in-depth interviews provide snapshots of opinions and explain quantitative findings. Triangulating information from multiple sources can provide additional insights [11].

Explore and Discuss Data Limitations Scientists must provide a margin of error for their primary conclusions and clarify the time period and populations to which their findings apply. They should control data quality and assess findings for consistency over time and between sources. They may need to collect more data to explain unexpected results. Data specialists can advise lawmakers about how to recognize reliable evidence [33]. It is better to discuss any limitations of the findings than to leave the policymaker vulnerable to being accused of over- or under-stating their case. Researchers should declare personal bias and why they chose to study a topic and they should watch out for unconscious bias when they interpret their findings.

Present and Disseminate Findings Clearly Policymakers have limited time to review information provided to them. Unlike research papers, policy briefs are short and contain only information essential to make a clear argument. Infographics can summarize the same information on a single page or poster using a combination of text, diagrams, graphs and maps. Findings can be disseminated as infographics, posters, flyers, interactive internet features, videos or PowerPoint presentations [35].

Oliver et al. argue that 'rather than asking how research evidence can be made more influential, academics should aim to understand what influences and constitutes policy, and produce more critically and theoretically informed studies of decision-making' [32]. The data broker is in a unique position to assess why some evidence translates into policy and why some does not and to increase future usefulness of evidence to policy. We suggest the broker uses the above list as criteria to assess the success or failure of knowledge translation, that is, (1) effectiveness of communication, (2) responsiveness of data systems, (3) formulation of policy questions, (4) timeliness of data collection and analysis, (5) limitations of findings, and (6) presentation and dissemination of evidence.

6 Conclusion

The strength and quality of data to support policy decisions depend on investments countries make to ensure their information systems are robust. In 2015, the world community committed to the Sustainable Development

Goals for achievement by 2030 [36], and called for investments in data systems to measure progress with these policies and interventions [37]. Later chapters in this book explore ways to strengthen these systems. We emphasize that the systems only exist to support decision-making and so they must meet users' needs. Where the structures do exist, it does not always follow that the information is relevant and readily available to answer specific policy questions. Data may be fragmented between different data sources making it difficult to gather and triangulate them to support a policy under development. Scientific knowledge about the efficacy of an intervention may exist but researchers are not able to communicate their findings to policymakers. Alternatively, the policymaker may simply ignore or mis-interpret the evidence.

We highlight the significance of what we call a data broker, a role filled by an individual scientist or a group providing advice on data for policy analysis. Data brokers understand the full range of data and research evidence available and have skills to work with data generators and analyst researchers to triangulate information to answer specific policy questions. They may work in a government policy unit or an independent policy watchdog group. The Regional East African Community Health (REACH), for example, operates as a knowledge broker between policymakers, researchers from universities and civil society [12]. In the US, the Kaiser Family Foundation serves as a broker by synthesizing and publishing information on topical policy issues for policymakers, the media, the health policy community and the public [24].

Over-riding all else, data specialists need training to work with policy stakeholders—lawmakers, programme managers and policy watchdogs—to understand their needs and ensure that the data they collect and the research they undertake is relevant, timely and clearly presented. Their training should include direct experience of decision-making so that they are prepared to work effectively with policymakers in translating data and evidence into policy. We recommend that data specialists provide training tailored to the needs of data brokers. Policymakers also need to understand the strengths and limitations of data in answering complex policy questions, as well as the amount of time needed to generate the data required to ascertain whether sufficient progress is being made. We suggest creating a learning environment in which both policymakers and data professionals are willing to continue to improve and refine, as well as learn from their policy directives. Many factors can interfere with fulfilling the intent and implications of the evidence provided. Sustained relationships between policymakers and data specialists and follow-up are critical to the

success of the evidence-to-policy process. Ongoing relationships also engage both sets of actors in a dynamic process which is at the heart of evidence-driven policy.

Key Messages

- Accessible, relevant and timely data can enhance policymaking.
- Open, flexible information systems, supplemented by dedicated studies, can provide data to inform and monitor policy.
- If data specialists and policymakers communicate effectively, they are more likely to translate data into action.
- Data specialists can improve their contributions to policymaking by examining why some evidence translates into policy and some does not.

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4

Challenges in Shaping Health Programmes with Data

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1 Introduction

The argument for Universal Health Coverage (UHC) gained momentum when the United Nations adopted it as one of the health targets of the Sustainable Development Goals (SDGs): 'Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all' [1]. To realize this vision, national governments need to develop strategies, put in place policies and programmes, establish implementation frameworks and collect data to track progress. In 2014, Bangladesh assessed its capacity to monitor and evaluate UHC implementation and

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concluded that it needed to improve its routine health information system as the 'most crucial component of the successful monitoring and evaluation of both the health sector program and UHC' [2].

Because UHC is relevant to the entire health system, governments must integrate its evaluation within their assessments of health sector performance as a whole. By focusing on health service coverage and quality, UHC requires that programme managers collect data to track the coverage of effective preventive and treatment interventions. By focusing on equity and affordability, UHC requires that managers disaggregate data to compare intervention coverage and financial protection across population groups.

The SDGs set targets with indicators but they do not specify the policies and interventions to achieve them. In this chapter, we explore how organizations select and monitor interventions that could lead to improvements in coverage, mortality and morbidity. We follow the development and assessment of evidence-based interventions from research through to implementation against the backdrop of achieving the SDGs. We start by distinguishing between the types of evidence that policymakers need to select interventions. In Sects. 3 and 4, we review the methods researchers and international institutions use to gather evidence to develop, review and promote interventions for policymakers to adopt. In Sect. 5, we examine how programme managers monitor and evaluate implementation of the interventions they have adopted, and how they assess long-term impact of interventions taken to scale. We conclude the chapter by presenting an internationally agreed framework that governments can use to monitor overall health sector performance and progress towards the SDGs.

2 Data and Evidence to Assess Interventions

Policymakers require evidence of the likely effectiveness of the interventions they consider supporting. Once they have implemented an intervention as a programme, they need data to understand its coverage, effectiveness and impact, point to refinements and inform development of future policy (see Chap. 3). For example, after extensive review of the evidence, the United Kingdom Scientific Advisory Committee on Nutrition concluded that 'A reduction in the average salt intake of the population would proportionally lower population blood pressure levels and confer significant public health benefits by reducing the risk of cardiovascular disease.' [3]. The government implemented a national salt reduction programme in 2003–04 with an integral

monitoring and evaluation process. The programme showed reductions in salt content in many processed foods and a 15 per cent reduction in average 24-h urinary sodium over seven years. Lessons learned were valuable to the government not just in refining the policy itself but also in advising other countries considering adopting salt reduction policies [4]. Above all else, the government needed to account to itself and the public by demonstrating that the funds it spent on the programme, and the salt reduction strategies it promoted, reduced the population's salt intake.

Governments are accountable to themselves and the public for implementing policies, strategies and programmes to meet all health sector targets including the SDGs. A sound monitoring and evaluation strategy is key to accountability. Likewise, bilateral or multi-lateral donors hold recipients of their support accountable for the funds they receive. This accountability stretches from a non-profit organization running a small-scale community intervention, through a district implementing a disease-control programme to a national government running an entire health sector.

We distinguish between the evidence a government or organization needs to select an *efficacious* intervention and the data it needs to monitor and evaluate the intervention's effectiveness when implemented. We use Archie Cochrane's interpretation of *efficacy* to mean the extent to which an intervention does more good than harm under *the ideal circumstances* of a research environment, and *effectiveness* to mean the extent to which an intervention does more good than harm when provided under *usual circumstances* of health-care practice [5]. The UK government chose its salt interventions after assessing available evidence of efficacious and effective interventions, and then monitored and evaluated its chosen interventions to determine if they were effective. It is usually researchers who provide evidence of efficacy and effectiveness and programme managers, evaluators and/or researchers who monitor and evaluate programmes for their effectiveness once implemented.

The distribution and use of insecticide-treated bed nets (ITNs) exemplifies an efficacious and effective intervention of global significance. With an estimated 216 million malaria cases and 445,000 deaths in 2016 from malaria worldwide [6], the SDGs aim to reduce malaria incidence. Since there is strong evidence that people who sleep under ITNs are less likely to be bitten by mosquitoes, the UHC programme has selected the *per cent population at risk sleeping under ITNs* as one of 16 tracer indicators [1]. We illustrate the following sections with examples of how evaluators and researchers have evaluated the impact of malaria intervention programmes on coverage of ITNs and malaria incidence.

3 Intervention Research

We focus on interventions that researchers evaluate in the *field*, that is, in communities where people live—rather than in health facilities where most *clinical* trials take place. Researchers undertake field trials of interventions to assess their efficacy and likely impact should they be implemented in other locations and on a large scale. Interventions may be preventive such as introducing a nutrition education programme or curative such as delivering anti-retroviral treatment to HIV/AIDS patients in the community. Field trials can also assess health system interventions such as introducing a maternal and child health card for mothers to keep and present when they interact with a health worker. These interventions may begin life as experiments in laboratory or clinical settings. Researchers only evaluate interventions in field trials when their use in a community setting promises to improve the health of the targeted population. Use of ITNs is a preventive intervention which researchers have evaluated in many contexts from the 1980s—after extensive laboratory testing.

We summarize some features of field trials but refer readers to the open access resource *Field trials of health interventions: a toolbox* [7] for a comprehensive description of how to conduct a field trial.

3.1 Field Trials to Develop Evidence-Based Interventions

A useful way to summarize the key aspects of any intervention is to use the PICO technique. PICO defines a research question in terms of the *population* targeted (P), the *intervention* being considered (I), the *comparator* or alternative intervention/s (C), and the *outcome* of the intervention (O) [8]. For example, the original research question for a study to evaluate the efficacy of ITNs in reducing child mortality might have been: *Among children living in malarious areas (P), does sleeping under an ITN (I), compared to sleeping without an ITN (C), reduce their mortality rate (O)?* Now that researchers have demonstrated the effectiveness of ITNs, they ask questions about the additional effect of indoor residual spraying or about interventions to encourage people to sleep under nets.

Researchers design studies to obtain the highest quality evidence to answer their research questions. They want to be highly confident that their estimates of the effect of the intervention on the outcomes are correct [9, 10]. Researchers obtain the best evidence by conducting a randomized controlled trial (RCT) in which they randomly assign individuals, or clusters of individuals, in the target population to the intervention or to a control group, and compare the outcome in each group (see Chap. 18). In clinical settings, researchers randomly

allocate individual patients to a group receiving a new treatment or to a group receiving the current treatment or a placebo, and compare recovery rates between the two groups. In a field trial, researchers allocate individuals or clusters of individuals, perhaps villages, to an intervention or a control group. For example, in the original trials of ITNs, researchers would have compared mortality rates between a group of households to whom they had actively distributed ITNs and a group of households to whom they had not distributed ITN, with both groups being in receipt of any current government malaria protection activities.

If the researchers perform the randomization appropriately, they will eliminate selection bias. The comparison groups will be similar except for the treatments received. The researchers can objectively assess the effects of the treatment on the outcome and conclude whether or not the intervention had an effect on measured indicators, with a low level of statistical uncertainty. Because RCTs—known by epidemiologists as *experimental designs*—are difficult to manage in a field setting, researchers sometimes use *quasi-experimental* studies that provide poorer quality evidence (see Sect. 5). Investigators reduce the quality of their evidence if they introduce bias into the data they collect and analyse. We refer readers to Chaps. 18 and 22 of this handbook for discussion of ways to avoid and detect bias in the management of data.

3.2 Research to Evaluate the Implementation and Cost-Effectiveness of Evidence-Based Interventions

Having demonstrated efficacy through field trials, researchers and evaluators assist programme managers to assess their effectiveness in usual health-care settings (see Sect. 5). Some interventions are successful in highly-controlled environments but are not effective when organizations scale them up or implement them elsewhere. Another problem is when researchers are unable to convince practitioners to implement efficacious interventions beyond the research setting. For example, there are sufficient efficacious interventions for health workers to use to address mental health disorders in non-specialized health settings. Yet there is a large gap in the number of people who need and the number who receive treatment especially in low- and middle-income countries (LMICs) [11]. Shidaye suggests that *implementation science* can help to reduce the treatment gap by guiding implementers to 'understand the importance of contextual factors and the challenges posed by the attitudes of service providers while delivering mental health services' [11].

Implementation science is 'the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into

routine practice, and, hence, to improve the quality and effectiveness of health services' [12]. Researchers and programme managers use implementation science to understand if and how they can implement an intervention in a specific context. They consider factors that affect implementation such as the operational practicalities of distributing ITNs, the attitudes of mental health workers to their clients, and resource issues around setting up either intervention. The science is about generalizing and learning from specific situations to gain insights into how to implement innovations and evaluate that process by, for example, assessing typical barriers and developing solutions. The goal is 'determining the best way to introduce innovations into a health system, or to promote their large-scale use and sustainability' [13]. As de Savigny and Adams point out in their argument for *health systems thinking*, 'Every intervention, from the simplest to the most complex, has an effect on the overall system, and the overall system has an effect on every intervention' [14].

Once researchers have established the effectiveness of alternative interventions to address the same issue, they compare their relative *cost-effectiveness.* For example, Pulkki-Brännström et al. compared the cost-effectiveness of long-lasting ITNs that keep their protection for at least three years with conventional nets that need retreating every 6–12 months. Using a model that considered costs of purchase, delivery and replenishment in a large-scale programme with high coverage over a ten-year period, they concluded that long-lasting nets were more cost-effective so long as they were not priced at more than US $1.5 above the price of conventional nets [15]. We refer readers to Chap. 19 of this handbook for an explanation of cost effectiveness methods.

4 Synthesizing and Recommending Evidence-Based Interventions

The World Health Organization (WHO) issues global guidelines or recommendations 'that can impact upon health policies or clinical interventions' [16]. These cover, for example, clinical and public health interventions, health system strategies, use of diagnostic tests and disease surveillance. WHO's recommendations derive from a formal and lengthy process of consultation and literature review following the *WHO Handbook for guideline development* [17]. Central to any WHO-published guidelines is a rigorous and transparent assessment of available evidence on the topic of interest, known as a *systematic review* (see also Chap. 18).

Systematic reviews, such as the one in Box 4.1, systematically synthesize all known studies and draw conclusions about their combined evidence. They

provide higher level evidence even than an RCT. A review of several high-quality and efficacious trials may conclude that the intervention is effective, as Lengeler found for ITNs (Box 4.1). Systematic reviews underpin recommendations and guidelines for policies to deliver interventions. We describe the process briefly but provide readers with online resources for more detail.

Box 4.1 Systematic Review of Insecticide-Treated Bed Nets and Curtains for Preventing Malaria [18]

In 2009, Lengeler published a systematic review of trials to assess the impact of insecticide-treated bed nets or curtains on mortality, malarial illness, malaria parasitaemia, anaemia and spleen rates. He reviewed 22 trials, 13 in areas of stable endemicity and 9 in unstable areas, graded the risk of bias in the trials and then assessed the effect of their interventions. Overall, he found ITNs to be 'highly effective in reducing childhood mortality and morbidity from malaria.'

Lengeler identified five clustered RCTs that examined all-cause child mortality, all in areas of stable malaria in sub-Saharan Africa. He estimated from these studies that 5.5 lives (95% CI 3.39 to 7.67) could be saved each year for every 1,000 children protected by ITNs, and extrapolated that 370,000 deaths could be avoided if every child under five years in SSA were protected by an ITN. In 2016, 54 per cent of the at-risk population in sub-Saharan Africa slept under ITNs [6].

The systematic review team starts by formulating search question(s) using the PICO technique and then develops a strategy to search the available literature. The team identifies eligible papers, and extracts and records previously agreed data items from each paper, including details of the design, number of participants and findings about the effects of the intervention on outcomes. The team develops an evidence profile for each paper using internationally agreed standards or GRADE (Grading of Recommendations, Assessment, Development and Evaluation) [19]. The GRADE profile rates the quality of evidence provided by the paper on the basis of its design and any biases introduced during design or implementation. The team analyses data across multiple RCTs using *meta-analyses* in order to arrive at a single conclusion that provides higher quality evidence than a single study [20]. The team also provides a narrative summary of its findings.

The review team uses the GRADE system to weigh the quality of the evidence against their assessment of the benefits or harms of the intervention taking into account the beneficiaries' values and preferences, and the estimated costs of implementing the intervention. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement provides guidance for reporting systematic reviews [21]. The GRADE working group website provides details of its process with software and training modules [19].

The Cochrane initiative has spearheaded systematic reviews and maintains a comprehensive database of systematic reviews in health care together with resources to undertake a systematic review [22]. Other databases of systematic reviews in health include the Campbell collaboration [23] and PROSPERO, an international database of prospectively registered reviews in health and social care, welfare, public health, education, crime, justice and international development, where there is a health related outcome [24].

The Disease Control Priorities Network, managed by the University of Washington Department of Global Health and the Institute of Health Metrics and Evaluation, provides a comprehensive source of evidence-based public health interventions which network members have reviewed for their efficacy, effectiveness and cost-effectiveness. In Disease Control Priorities 3, network members provide 327 interventions, grouped by 21 packages, which they have assessed to: (1) provide good value for money in multiple settings; (2) address a significant disease burden; and (3) be feasible for implementation in LMICs. The authors grouped 218 of these interventions as an Essential UHC package, and 97 to form a Highest Priority Package for adoption in LMICs [25].

5 Monitoring and Evaluating an Intervention

Once an organization adopts an intervention or modifies an existing one, it needs a monitoring and evaluation plan to assess the effectiveness of the intervention in practice. The organization may be implementing an intervention locally or on a large scale such as rolling out a malaria control programme across a district or nationwide. The purpose of any intervention is to provide the best possible service to those who need it, and this should prescribe the design of the intervention and its monitoring and evaluation. Whatever the evaluation question, programme managers and evaluators need to collect and explore data that identify the people who most need the intervention. They will obtain valuable data from speaking to those people.

Programme managers routinely collect information to *monitor* an ongoing intervention so that they can track progress and perform oversight. They work with external evaluators to *evaluate* the intervention by systematically collecting information periodically before, during and after its implementation to better understand and assess the intervention. Monitoring is an immediate-term process that does not consider long-term impact on

intended beneficiaries. Evaluation primarily assesses effectiveness, relevance, impact and attainment of intended results, in an effort to improve future programmatic planning or services. Used together, *monitoring and evaluation* is a continuous process that assesses the progress of a project, underpins decisions throughout the project cycle and informs future project and policy formulation. In this section, we explore types of monitoring and evaluation frameworks and examine alternative types of evaluation.

5.1 Monitoring and Evaluation Frameworks

Managers create frameworks, or models, to describe how they intend to obtain the results they want to achieve, and to determine the information and data they need to collect to assess this strategy. They use different types of frameworks, for example the logic model (or theory of change) [26], logical framework (or logframe) [27] or results framework [28]. Frameworks show logically and diagrammatically how the intervention's resources and activities will achieve programme goals, and specify the indicators to measure these results. Frameworks differ in their organization and emphasis on objectives, inputs or results and the level of information they contain. The programme development team usually chooses the type of framework it wants to use but sometimes a donor prescribes its preferred framework.

Most frameworks describe the programme in terms of its *inputs, activities, outputs, outcomes* and *impact*. Table 4.1 shows a simple logic model (or *results chain*) format, with an example for a malaria vector control programme. *Input indicators* measure the availability of resources and can signal shortages of supplies, for example, available field workers or numbers of ITNs purchased. *Activity (or process) indicators* describe the services the programme provides and monitor progress, for example the number of training sessions given to field workers or workload across facilities. *Output indicators* describe the deliverables resulting from programme activities and monitor progress, for example the number of health education sessions provided or number of ITNs supplied to households. *Outcome indicators* measure the changes in behaviour resulting from the programme's activities, and monitor and evaluate achievements, for example the percentage of population using ITNs with knowledge of why ITNs protect them. *Impact indicators* measure the long-term changes in population health resulting from the programme, for example mortality rates or disease incidence.

Table 4.1 Logic model/results chain for programme monitoring and evaluation with a simplified example for a malaria vector control programme

Inputs	Activities	Outputs	Outcomes	Impact
Financial, human and material resources, logistics, transport	*Specific actions to complete the programme*	*Deliverables resulting from the activities*	*Changes in behaviour resulting from the activities*	*Measureable cumulative changes in health resulting from the outcomes*
Example programme to scale up malaria vector control				
Programme funding, supplies of ITNs and sprays, trained workers and so on	Distribution of ITNs to households	No. of ITNs distributed to households	Proportion of people sleeping under ITNs	No. of malaria cases and deaths; malaria parasite prevalence
	House spraying	No. of houses sprayed	Proportion of people sleeping in sprayed houses	

A framework template usually includes the objectives, theoretical assumptions and principles of the programme. Frameworks are not only useful for planning, implementation and evaluation but also for communication. Managers use the framework to clarify for others what works under what conditions. When they discuss the model with stakeholders, managers can build agreement over inputs, activities and outcomes and create ownership which also helps to sustain the programme.

5.2 Types of Monitoring and Evaluation

The evaluation approach depends on when the evaluation occurs in the timescale of the programme and the question/s the team asks of the evaluator/s. Table 4.2 summarizes some approaches to monitor and/or evaluate the development, process, outcomes and impact of a programme, and highlights major data sources for each. Programme staff commonly monitor the programme themselves although they may invite an external evaluator to contribute to its development (*formative* evaluation). They usually appoint independent evaluators to undertake outcome and impact evaluations. Depending on the stage at which they become involved, evaluators work with the programme team to establish the framework at the start of the programme, work with an established framework or retrospectively create a framework when none exists.

Table 4.2 Types of monitoring and/or evaluation and relevant data sources

Type of evaluation	When useful?	Why useful?	Data sources
Formative evaluation	Development of new program; modification of existing programme or adaptation to new setting	Is the programme necessary, feasible and acceptable? Should and how can it be implemented?	Review of literature and documents; analysis of administrative and secondary data; resource mapping; key informant interviews; focus group discussions; small surveys
Process evaluation and programme monitoring	When programme begins and during implementation	Is the programme implemented as designed and reaching target groups? Is it within budget? Does it need any modification?	Review of programme documents including framework; analysis of administrative records; special surveys, key informant interviews; focus groups; direct observation; rapid assessments, cost analysis
Outcome evaluation	At end of programme or implementation milestone	How is the programme impacting behaviour of targeted groups? Is it cost-effective?	RCTs, analysis of baseline and end-line surveys and any longitudinal panel data; key informant interviews; focus groups; analysis of contextual changes; cost analysis
Impact evaluation	Some time after the start of the program; at or even years after its completion	Has the programme achieved its ultimate goal of impacting the health status of the targeted groups? Informs policy and future programme development	RCTs, analysis of baseline and end-line surveys and any longitudinal panel data, and of trends in facility or CRVS data or in any parallel local surveys; key informant interviews; focus groups; analysis of contextual changes

Adapted from Centers for Disease Control and Prevention [29]

Design of the programme, and its framework and indicators, governs monitoring and evaluation activities. However, the programme team cannot anticipate all qualitative outcomes such as changes in behaviour, policies or practice arising from complex interventions. *Outcome harvesting* is an approach in which 'evaluators, grant makers, and/or programme managers and staff identify, formulate, verify, analyse and interpret 'outcomes' in programming contexts where relations of cause and effect are not fully understood.' The process

is well defined with engagement of stakeholders and feedback loops to ensure that the ultimate classification and list of outcomes are verifiable and useful to potential users [30, 31].

The fundamental issue for outcome and impact evaluation is whether evaluators can, or need to, attribute changes in coverage and behaviour (outcomes) or in health indicators (impact) to the programme. Habicht et al. classify assessments depending on the type of inference investigators intend to draw [32].

Adequacy Assessments investigate whether specific expected changes in indicators occurred. Evaluators use cross-sectional data and hold focus group discussions with stakeholders to examine whether the programme has achieved target values for selected indicators. They can further explore why the programme has or has not met certain targets. If evaluators repeat assessments over time, they can show trends towards long-term achievement of the targets. This is how governments monitor their efforts to reach the SDGs.

Probability Assessments investigate whether the programme had an effect on selected outcome or impact indicators. Using an RCT design, the programme team delivers the intervention in carefully controlled circumstances with dedicated data collection to measure outcome and impact indicators over time. Unlike research studies, it may not be feasible or ethical to randomize the population to control groups when implementing proven interventions on a large scale. One solution is to introduce the intervention using a *randomized stepped wedge* design in which the investigators maintain randomization while gradually exposing control groups to the intervention until the whole population is covered [33].

Plausibility Assessments investigate whether the programme appeared to have had an effect on the indicators above and beyond other external influences. The programme team chooses from a menu of *non-experimental* epidemiological methods. One approach is to identify a non-random control group and compare indicators between this group and the intervention group at the start, during and/or at the end of the programme. For example, instead of allocating villages at random to an intervention, the team might identify a conveniently located group of villages in which to deliver the intervention and demarcate a neighbouring group of villages to serve as the control group. An alternative would be to compare longitudinal changes in a population before and after the intervention without any control group. While these designs can introduce considerable bias, careful analysis of baseline, contextual, outcome and impact data within a logical or conceptual framework, can provide

evidence about the *plausibility* of an intervention effect. Plausibility designs require dedicated data collection and careful analysis. When the programme extends on a large scale and over many years, evaluators also use data from health facilities and concurrent local and national surveys. Qualitative methods for collecting information are vital to understand contextual factors around implementation.

The plausibility approach is essential when a ministry has implemented an intervention to scale nationwide and over a long period. Roll Back Malaria uses a plausibility framework to evaluate impact on morbidity and mortality of full-coverage malaria control in countries in sub-Saharan Africa. The framework analyses contextual data, for example, on the environment, health care, households and individuals to determine the plausibility that malaria control activities have had impact over and above these factors [34]. The Roll Back Malaria team used this approach in Rwanda to assess the impact of its intensified malaria control interventions—including indoor residual spraying, distribution of ITNs and improved case management—between 2000 and 2010. Eckert et al. concluded that the interventions contributed to an overall impressive decline in child mortality in the country, even as socio-economic and maternal and child health conditions improved alongside the intervention. For this evaluation, the researchers drew from data: on mortality, morbidity and contextual factors from four national Demographic and Health Surveys undertaken between 2000 and 2010; reports from the country's health management information, community information and disease surveillance systems; climate data from the national meteorological archive; and publications of locally relevant studies [35].

When it is difficult to obtain data for impact indicators, investigators can model them using other available data. The AIDS Spectrum modelling package assesses the impact of interventions to prevent mother-to-child transmission of HIV (PMTCT). Spectrum can predict the number of child HIV infections and the population-level MTCT rate using available HIV prevalence and anti-retroviral therapy (ART) coverage rates. This and other models, however, rely on routinely collected surveillance data. Since model predictions depend on the quality of those data, WHO advises that modellers triangulate them with empirical data [36]. Hill et al. used Spectrum to compare MTCT rates across 32 countries in sub-Saharan Africa with generalized HIV epidemics and found that 50 per cent of childhood infections in 2013 were in lower-prevalence countries and recommended targeting MTCT in these countries [37].

In conclusion, a monitoring and evaluation framework defines the indicators the programme will observe. If the programme stands alone, its managers will have to set up a dedicated data collection process but it is otherwise better to use and strengthen the existing health information system. Evaluators must be able to disaggregate data to assess whether the intervention reaches all who need it. This means, at the very least, disaggregation of the data by residence, socio-economic status, sex and age. If the intervention is nationwide, it will require sub-national evaluation.

It is easy to identify quantitative indicators that count events and to compare them during and at the end of the intervention. The ultimate success of the intervention, however, depends on understanding the public's or local community's views about how it might serve them better. We refer readers to Chap. 16 of this handbook for a discussion of approaches to obtain and synthesize qualitative data such as people's opinions and assertions. The programme team should seek the community's inputs at every stage of the evaluation especially to explain the quantitative indicators it measures.

6 Monitoring and Evaluating Health Sector Performance

In Sect. 5, we described an impact evaluation of Rwanda's national malaria control programme which demonstrated success in preventing malaria and reducing child mortality between 2000 and 2010. Through these achievements, the programme also contributed to reducing several performance indicators in Rwanda's Health Sector Strategic Plans (HSSPs) (2005/09 and 2009/12). Rwanda's HSSPs describe its strategies with targets for performance indicators across the entire health sector. A team of partners undertakes mid-term and end-term reviews which inform development of subsequent strategies. A mid-term review of Rwanda's HSSP 2012/18 noted, for example, that despite its malaria control programme preparing to enter a pre-elimination phase in 2018, malaria slide positivity had increased from 15 per cent in 2011 to 37 per cent in 2015 [38].

Like Rwanda, most countries develop strategies and conduct reviews of how their health sector performs. These reviews have come to be called joint annual health sector reviews (JARs) because they bring country and development partner stakeholders together to assess performance and agree an

improvement plan. A review of JARs in nine countries, published in 2013, found that they 'tend to strengthen policy dialogue, alignment, accountability, implementation of the sector plan and internal resource allocation' and 'have a potential to improve plans, mobilise additional resources and promote mutual accountability' [39].

Because of their breadth of scope, these reviews are complex and a major task for a country to take on [40]. JARs make heavy demands on data which health facility systems cannot satisfy alone and require countries to assemble and analyse data from additional sources across the health information system. A complication is that different donors require different accountability frameworks collecting different data in a single country. In 2008, the International Health Partnership (IHP+)—of donors, governmental representatives and other organizations—proposed 'a common framework for monitoring performance and evaluation of the scale-up for better health' to encourage coordination across partners and strengthen country health information systems to support evidenced-informed decision-making [41].

IHP+ identified a need to provide guidance to countries for what it calls *monitoring and evaluation and review* of national health plans and strategies [42]. In 2011, the partnership published guidelines which contain what is now known as the IHP+ Common Monitoring and Evaluation Framework (Fig. 4.1). The framework follows a results chain format classifying domains of indicators across health system inputs and processes, outputs, outcomes and impact. It aligns different data sources for these domains and indicates types of data analysis and synthesis necessary to assist national decision-makers assess levels and trends across multiple indicators. WHO subsequently developed a reference list of 100 core indicators which it classifies by the same domains (see Chap. 2). The purpose of this comprehensive monitoring and evaluation framework is to provide a common logic around which governments and partners can harmonize their data requirements and reporting. The IHP+ partnership has since become the UHC 2030 partnership which has adopted the framework for its activities to support health system strengthening [43]. The guidelines describe how to monitor, evaluate and review national health strategies [44]. The comprehensive approach is essential to monitor and evaluate a complex, multi-faceted set of interventions, such as UHC, that will evolve over time in response to demographic, epidemiological and technical changes [1].

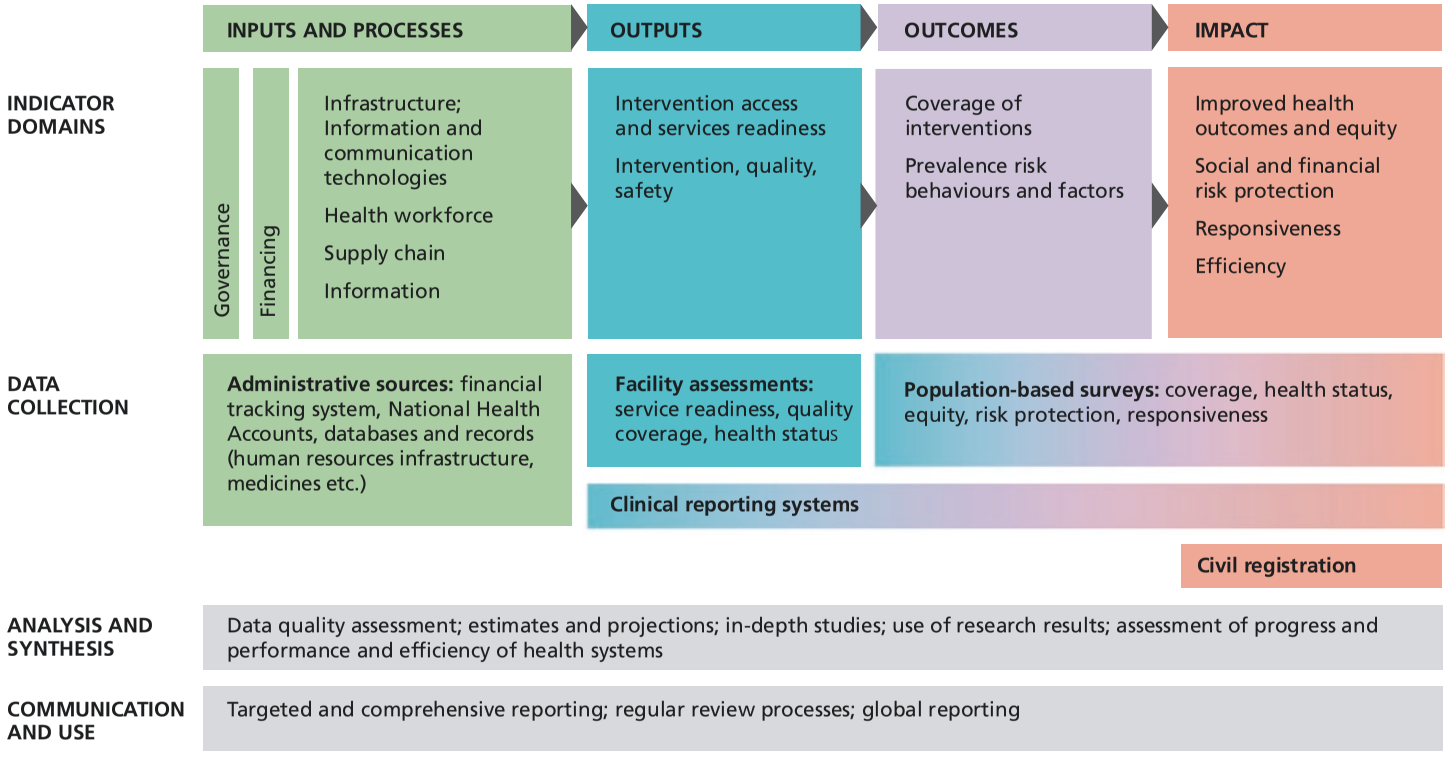

Fig. 4.1 IHP+ Common Monitoring and Evaluation Framework. (Source: World Health Organization [41])

7 Conclusion

The UHC 2017 Global Monitoring Report warns that 'unless health interventions are designed to promote equity, efforts to attain UHC may lead to improvements in the national average of service coverage while inequalities worsen at the same time' [1]. We have described how evidence-based interventions emerge through research and how monitoring and evaluation can improve their effective implementation. The evaluation process is cyclical with new interventions replacing old ones. Throughout this process, we need data that not only describe average success or failure but that also highlight the groups of people who benefit most and those who benefit least. What matters is that we know that the right person receives the right intervention at the right place and time.

Key Messages

- The SDGs require efficacious and effective interventions that information systems can monitor comprehensively across the health sector.
- Researchers evaluate the efficacy of potential interventions and use systematic reviews to synthesize findings across studies of the same intervention.
- Programme managers monitor inputs, processes, outputs and outcomes to develop and improve programmes.
- Evaluators assess programme effectiveness, that is, whether the programme achieves its desired outcomes and impact.

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5

Measure, Inform, Build: Enabling Data-Driven Government Policymaking

Adam Karpati and Jennifer Ellis

1 Introduction

In 2007, as part of New York City's first long-term plan for environmental sustainability, the Health Department established an air quality surveillance programme to inform the public and guide clean air policies. The programme estimated, for the first time, the number of deaths and hospital admissions attributable to air pollution overall, at neighbourhood scale and under different policy scenarios [1–5]. Specifically, epidemiologists attributed over 3,000 deaths a year in New York City to exposure to fine particulates, making it a leading cause of death. Analyses also revealed that combustion of high-sulphur heating oil in thousands of large buildings contributed significantly to poor air quality in the city. This finding catalysed new government regulations around heating oil, which phased out the most polluting formulations and led to sulphur dioxide levels falling by more than 65 per cent in five years. Other actions directly informed by the findings included regulations to control particle pollution from commercial cooking and a planning study of a low-emission zone for large diesel vehicles.

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This example illustrates how rigorous, quantitative assessments of factors impacting population health can influence policymaking not only in the health sector but across other sectors. It also demonstrates the value of building the capacity of health agencies to collect, analyse, interpret, and disseminate data in ways that can inform policy and action. By publishing its findings, the New York City Health Department educated and gained the support of the public for the needed policy changes.

Chapter 3 of this handbook describes the policy process and outlines ways in which policymakers and data analysts can interact to share data and information. We too consider data to be essential to policymaking and acknowledge that policymakers often give political and resource considerations greater priority. We suggest some practices that public health agencies can adopt to drive their policymaking processes. What we are calling the *data-to-policy* function focuses largely on local public health data sources and internal government analyses. We distinguish this *data-driven* approach from the related *evidence-to-policy* approach which primarily focuses on using research evidence from scientific literature to guide policy and inform practice (see Chaps. 3 and 4). We focus on governments—national, subnational, and local/urban public health agencies—given their responsibility for public health systems. But the principles and practices we offer are relevant to public health practitioners in other settings.

We direct our recommendations to two groups of government staff, mainly working in public health agencies: those who *produce* data, that is the staff and leadership of surveillance programmes, epidemiology units, monitoring and evaluation units, health information systems, and so on. They are the data collectors, compilers, analysts, and presenters of data. They are the authorities—with sophisticated understanding of data systems and analytic methods—who maintain the relevance and quality of data. The second group are those who *use* data, that is the executive leadership, policy and planning, communications, and finance staff whose role is to translate data they receive into action.

We start by describing the cycle of data production and use and a set of practices to optimize the way the cycle functions. We offer illustrations of such practices from the field of tobacco control and elsewhere, including from our experience working in the New York City Health Department and in global settings. Other chapters in this handbook develop some of the themes we introduce in more detail.

2 Framework for Data in Support of Public Health Functions

Data and statistics should drive planning and provision of all public health services, which are necessary to protect and promote the public's health and to prevent disease. These essential services are articulated by the World Health

Organization's European Office as including: monitoring of populations to identify health priorities, health hazards, and vulnerable groups; developing policies to promote health and prevent disease; and providing information and mobilizing society for health [6].

The data-driven approach involves leveraging government-generated data to produce insights, communicate information, and assess the health impact of policies and programmes. The approach generates information that describes the magnitude and extent of a health problem to inform potential strategies to address it, incorporates this information into communications to stakeholders and to the general public, and develops an evaluation plan to assess the implementation and actual impact of any policy interventions implemented.

Strong demand for data drives data collection and quality; in turn, data availability drives demand. Figure 5.1 depicts a cycle of data-driven policy and decision-making which begins and ends with a culture of demanding and using data. Similar frameworks also exist [7]. Leadership must ensure a strong data perspective in all aspects of how the organization functions; this includes how managers conduct meetings, review documents, prepare communications, and evaluate staff. The data-driven approach also requires leadership to invest in robust capacity and clear organizational structures to produce and use data. Externally, the press, legislators, funding agencies

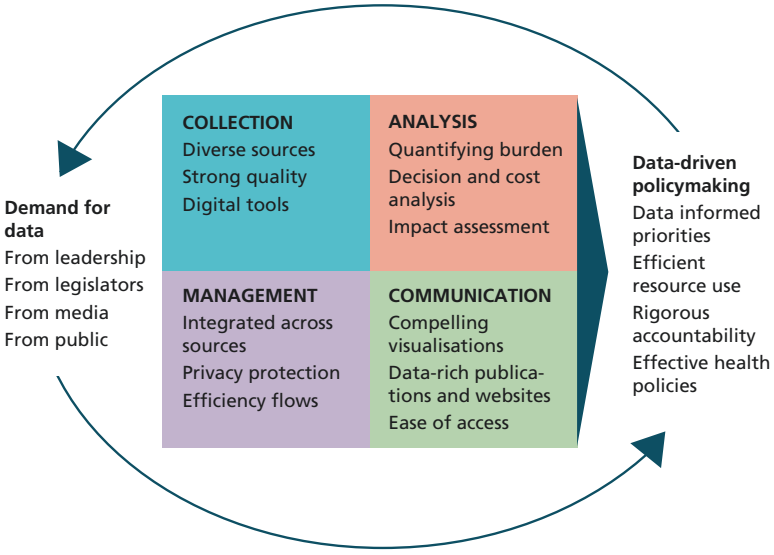

Fig. 5.1 Framework for data-driven policymaking

and international organizations should expect data in response to their questions about priorities, plans, and performance. This drives the data cycle, resulting in data-driven prioritization of health issues, development of legislative and regulatory proposals, programme planning, emergency response, budget allocation, and performance assessment.

Data Collection Refers to the operation, scale, quality, cost, completeness, and timeliness of the surveillance and survey systems that the health agency operates, including vital statistics, behavioural surveys, health services statistics, and disease surveillance. Agencies use multiple sources from inside and outside the health system, such as census, economic, and environmental data (see Chap. 1).

Data Management Refers to the system of databases and other information technology solutions necessary to house and integrate the extensive and complex data available to public health agencies. An example of a widely implemented data management system is the District Health Information System, DHIS2 [8]. Considerations for data management include linking and integrating data from diverse sources, transmitting data from point of collection to point of use, making data available within the government and to external users such as researchers and the general public, and maintaining confidentiality around personal identifiers (see Chap. 9).

Data Analysis Raw, unit record data must be cleaned, coded, and analysed to produce meaningful information. Analyses may be qualitative or quantitative and include statistical and economic modelling. Outputs of data analysis might include descriptions of health conditions or risk behaviours, health status of populations, health system functioning, or programme performance and impact. Decision analysis is a powerful tool to evaluate health impact with particular relevance for policymaking (Box 5.1).

Box 5.1 Decision Analysis to Assess Health and Economic Impact

Decision analysis is a method for modelling the health and economic impact of policy or programmatic actions. Key inputs into a decision analysis include the current magnitude and distribution of the health issue under consideration, the estimated health impact of different action options, the estimated costs of implementing the competing options, and the economic consequences of various outcomes. These parameters may be derived from the scientific literature or

from local data. Where local data are of inadequate quality, estimates can be obtained from WHO or other external sources. Decision analysis techniques can be complex and rigorous. However basic approaches are often sufficient to provide robust, actionable, quantitative guidance to decision-makers. Related approaches include economic evaluation, cost-effectiveness analysis, and comparative effectiveness analysis. An example of such an analysis was conducted in Bhutan to evaluate the cost-effectiveness of implementing screening in primary care settings to reduce non-communicable disease mortality, and to compare the predicted costs and outcomes of targeted versus universal screening [9]. Resources for these methodological approaches are available, for example from the US Centers for Disease Control and Prevention [10] (see also Chap. 19).

Data Communication Provides the interface between data producers and data users, including internal government decision-makers, legislators, the general public, press, advocates and civil society representatives, and researchers. Communicating data to stakeholders serves many purposes, including providing information, explaining priorities, defending resource allocation and policy choices, and establishing and conveying accountability to goals and benchmarks. Data should be disseminated in multiple forms such as discrete responses to specific queries, print or online reports on health issues or population health status, performance reviews and indicator tracking, policy briefs, part of press releases, speeches, and testimonies, and in budget and legislative proposals.

This data-use cycle is enabled by an institutional culture that encompasses internal and external operations, stakeholder expectations, and organizational values around using data. Often, data producers do not receive feedback around how data they provided have been used—who, how, and where the data were used, how they were received, and whether there were quality or other technical problems. Proper feedback increases incentives and motivation for data producers to improve data collection systems. Similarly, creative and accessible analytic outputs and data visualizations provide options for decision-makers to integrate data throughout their activities.

The language of epidemiology and data analysis is not compelling or even understandable to planners and policymakers. When analysts tailor their presentations to their audiences, they can generate more interest, and possibly gain attention for investments needed to maintain high-quality data collection and analysis. Data producers and users can share feedback during multidisciplinary committees, forums or meetings to present and discuss data and their implications for policymaking, performance review processes, or health sector reviews.

3 Practices to Improve Data Use

We describe a set of practices that government public health agencies can adopt to optimize the data-driven policymaking cycle. We have synthesized these practices from several sources and based them on our own professional experience. The practices are not exhaustive and are intentionally succinct. We have chosen those we think contribute most to identifying population health challenges, developing cost-effective interventions, and communicating these priorities to stakeholders.

We organize the practices into three broad categories: (1) MEASURE, that is high-quality, yet feasible monitoring of the magnitude and patterns of health risks and conditions; (2) INFORM, that is interpreting and communicating data and information internally and externally to inform and defend public health decision-making; and (3) BUILD, that is creating internal capacity and structures to sustain exemplary data practices and apply them across programme areas.

3.1 MEASURE

The need for sound measurement of the dimensions of a health challenge seems obvious. Yet experience shows that the absence of measurement strategies often thwarts effective public health action especially at local levels where health decisions are often made. Our opening example illustrates how a public health agency guided clean air policies in New York City by attributing mortality to pollution, and Box 5.2 offers an example of how improved measurement has been critical to developing and monitoring tobacco control policies globally.

Box 5.2 A Data-Driven Approach to Tobacco Control

Scientific knowledge about the harmful health effects of tobacco use has been available for many decades. Until recently, however, the only data available on tobacco use and on the existence of policies to reduce tobacco use was from high-income countries or estimates derived from statistical models. Many country policymakers did not know their own tobacco use prevalence or had limited data not representative of national populations. Fewer still conducted systematic tracking of risk factors such as exposure to tobacco smoke or tobacco advertising. Lack of data made it impossible to advocate for tobacco control strategies and to track declines in tobacco use and in related mortality and morbidity. This resulted in lack of attention to tobacco control, both globally and in low- and middle-income countries.

The 2003 Framework Convention on Tobacco Control (FCTC)—the world's first public health treaty—provides governments with guidance on priority measures to curb the tobacco epidemic [11]. In 2009, to accelerate implementation of the Convention, WHO introduced the MPOWER package of six proven policy interventions [12]. The first intervention—Monitor tobacco use and prevention policies—promotes the systematic use, analysis, and dissemination of data. The *WHO report on the global tobacco epidemic* regularly reports key indicators across the spectrum from tobacco exposure to the status of tobacco control policies [13]. These indicators provide information to governments about gaps in their tobacco control policies, to benchmark them against other countries, and to track progress and impact of their tobacco control policies. Data are also useful to advocates and other stakeholders, who use them to hold governments accountable for their commitments (or lack thereof). The 2017 report found that more countries have implemented tobacco control policies, ranging from graphic cigarette pack warnings and advertising bans to no smoking areas. About 4.7 billion people—63 per cent of the world's population—are now covered by at least one tobacco control measure, compared with 2007 when only 1 billion people and 15 per cent of the world's population were covered.

We suggest some key measurement strategies for public health agencies, and we illustrate them with examples of measuring the tobacco challenge:

Select and Monitor Core Indicators with Measureable Targets Public health agencies should specify indicators that describe the needs and priorities of populations, including their utilization of the health system, and that inform interventions and policies to address them. Indicators span metrics of health status (e.g. morbidity and mortality rates); health risk behaviours and exposures (e.g. drug and tobacco use, environmental pollution); and health service utilization (e.g. HIV testing rates). In the New York example we described at the beginning of this chapter, by monitoring both cause of death and pollution, the Health Department could flag potential associations between them. Indicators should aim for ambitious, achievable, and measurable targets that where possible conform to international standards, such as those in the WHO 100 Global Reference List of Core Health Indicators (see Chap. 2) [14].

For example, to monitor tobacco use and prevention policies, WHO recommends that agencies include, in regular national surveys, indicators such as respondents' exposure to second-hand smoke or exposure to tobacco and anti-tobacco advertising, the price paid for tobacco and place of purchase, their beliefs about the harmful effects of tobacco use, whether they received physician advice to quit, if they made any attempts to cease using tobacco,

and the proportion of users and former users of tobacco [15]. The SDG indicator of national implementation of the Framework Convention on Tobacco Control is the 'age-standardized prevalence of current tobacco use among persons aged 15 years and older'. Monitoring these and other indicators guides countries about the extent of tobacco use and informs prevention strategies.

In addition to epidemiologic indicators of behaviour and health status, standardized measures of policy adoption and implementation are critical components of robust monitoring systems. These measures help governments identify gaps and opportunities for action, and also serve an accountability function for internal and external stakeholders. For example, the *WHO report on the global tobacco epidemic* includes Likert-type indicators from countries that reflect whether a given country has passed legislation around the components of the MPOWER interventions, such as front-of-pack warnings, smoke-free public places, and taxation, and the degree to which legislation meets best-practice standards [13].

Translate Risk Factor Data into Attributable Mortality Health outcome data alone, such as cause-specific mortality or disease prevalence rates, provide only limited information to plan interventions. Especially as non-communicable diseases continue to increase, public health agencies need to measure the contributions that determinants and behaviours make to the health burden. Risk factors include, for example, tobacco and alcohol use, poor nutrition, and physical inactivity, as well as toxic exposures, such as poor air quality and social factors, such as poverty and discrimination. Quantifying these factors makes it possible to rank and estimate the cost-effectiveness of potential interventions.

Of particular interest from a policy perspective is what proportion of the disease burden in a population could be alleviated if the effects of certain causal or risk factors were reduced or eliminated. There are several epidemiological techniques for translating risk factor data into health outcomes, the most common of which is to calculate population attributable fractions (PAFs) [16]. The WHO estimates PAFs for various risk factors based on data reported by countries and these are the basis for statements such as that tobacco use kills more than seven million people per year [17], and that harmful alcohol consumption is responsible for over three million deaths per year [18, 19]. Because it is the prevalence of the risk factor that drives the PAFs, each country's burden and relative ranking of risk factors is unique. In order to inform prioritization, countries need to calculate their own PAFs using their own prevalence data. This can be done with varying levels of statistical sophistication, but all health agencies should have the capacity, or work with academic partners, to estimate PAFs.

Disaggregate Reported Data Public health agencies must stratify their data into relevant sub-groups. Restricting analysis to averages obscures differences across

sub-populations and can result in resource misallocation and persistent health inequalities. In New York City, neighbourhood-level associations between mortality and pollution were essential to the analysis, for example. Categories of stratification should be standardized and applied to all data sources systematically. Key stratifiers include age, sex, subnational (or sub-urban) geography, education, occupation and household wealth. The US Centers for Disease Control and Prevention (CDC), for example, surveyed 148,481 employed adults between 2014 and 2016 to ascertain smoking habits. They found that overall 22.1 per cent of the sample currently used tobacco and that there were discrepancies between sub-groups, for example, tobacco use was highest among men (27.4 per cent), those with high school education or less (30.1 per cent), those with no health insurance (33.9 per cent), and those living below the federal poverty level (28.5 per cent) [20]. The CDC can use this information to target intervention strategies.

Identify Vulnerable Populations with Poorest Health A fundamental mission of public health agencies is to identify and address differences in health between groups and identify and assist vulnerable populations. The first step is to describe health inequalities and relate them to the social and environmental factors that drive them. There are many ways to analyse and present data on health inequalities [21, 22]. At a minimum, it is useful to compare rates and rate ratios by sub-populations, as in the tobacco example above. Specific inequality metrics can quantify the differences in health burden, by comparing and visualizing excess mortality by sub-group or examining socio-economic inequalities in a health outcome, using, for example, the relative index of inequality, or a concentration index [23]. For example, India's 2009–2010 Global Adult Tobacco Survey examined tobacco consumption by wealth quintiles. Prevalence of current smokeless tobacco consumption varied from 30.3 per cent in the poorest quintile to 9.5 per cent in the richest. The authors also calculated odds ratios and concentration indices by state and concluded that tobacco control policies should differentially target the poor [24].

The WHO Health Equity Assessment Toolkit leverages data from Demographic and Health Surveys and assists in calculating, interpreting, and visualizing inequality measures for many countries worldwide [22].

3.2 INFORM

This group of practices focuses on how governments communicate their priorities to stakeholders to build support and hold themselves accountable. They also include practices around sharing of data.

Publish Data-Driven Reports and Communication Materials All public health agencies should publish up-to-date data reports to inform the public about

health issues and priorities, communicate progress on quantitative indicators as a means of demonstrating accountability, and build support for new policy and programmatic proposals. Reports can cover specific health issues (such as diabetes, tobacco use, or malaria), the health status of important subpopulations (such as the elderly, youth [25], children, poor, or living with disability), or of populations in specific neighbourhoods or districts. Communications departments should incorporate data routinely into press releases, testimonies, speeches, annual reports, and other public communication materials. Desirable characteristics of data reports for public health use include the following.

- Published as a series, with regular production; available in print and online;
- Each report should focus on a single key topic of public health priority;
- Short (fewer than 10 pages) with effective use of graphic design, and compelling data visualizations;
- Integrate multiple data sources (mortality, health services, surveillance, etc.);
- Incorporate explicit discussion about policy and programmatic implications and responses to the data; and
- Released with a well-considered communications/dissemination plan to the press and relevant stakeholders.

The New York City Health Department issues a range of data reports tailored for general audiences. These include: *Vital Signs*—a series of 4-page, topical reports on issues of public health significance that combine epidemiologic information with policy guidance; *Epi Data Briefs*—two-page summaries of key epidemiologic data on specific health issues, integrating surveillance, vital statistics, and health services sources; and *Community Health Profiles*—multi-dimensional profiles of demographic, socio-economic, and health status of the population of each city neighbourhood [26].

Several platforms are available for providing easy-to-navigate user interfaces that allow users to look up simple statistics from a variety of datasets. The New York City Health Department has two such web-based platforms: EpiQuery through which users select data sets, including of vital statistics and behavioural surveys and access simple analyses on a restricted set of variables [27]; and the Environmental Health Portal through which users identify particular health topics and obtain data summaries [28].

Share Data Sets with External Users Public health agencies should develop policies and procedures for releasing data to eligible stakeholders. It is critical

that this be done within supportive legal and administrative frameworks, in accordance with agreed standards for confidentiality and data security (see Chaps. 22 and 24). This can include sharing of individual record information as part of public health surveillance [29]. All individual identifiers should be removed from research data sets before sharing with external researchers. In particular, it is essential to guard against the risks of individual identification when providing detailed data for small geographic areas or population groups. Reporting small cell sizes in an epidemiologic report, even without identifiers, can provide sufficient information to match with another dataset that contains identifiers.

The government of South Africa, as part of its commitment to Open Government, has established an Open Data Portal with the aim of 'encouraging and fostering the development of Open Data/Information Platforms for social media-e-government and m-government to improve citizen access to information, data and services offered by government' [30]. The growing *open data* movement promotes a move away from *reactive* disclosure of data and information, driven by specific requests, to a *proactive approach* whereby public datasets are released in tandem with data collection so that government information is *open by default* (see Chap. 23). This implies that data release files are structured and non-proprietary so that potential users can extract maximum value from data [31].

Document Metadata and Data Cleaning Practices All empirical data sets are imperfect in some way and need to be adjusted, or cleaned, to maximize their utility. Necessary cleaning, coding, and grouping of data should be well documented in a detailed data dictionary and analytic notes/guidance (or metadata). This can include creating new variables (e.g. a *poverty* variable based on annual income); grouping variables (e.g. ages or dates); or assigning International Classification of Disease codes to diagnoses.

3.3 BUILD

We refer here to building institutional processes and structures that promote exemplary data use. This entails investment in human resources, workforce capacity-building, and potentially, organizational restructuring.

Make Data Available for Leadership Review Management requirements for information range from a minister or other leader needing readily available information on key initiatives and indicators, to an emergency manager

needing rapid updates on a public health crisis, to programme directors reviewing reports during a formal process of performance monitoring and programme review. Leadership should establish processes and use tools that leverage data to facilitate its use. Processes include routine compilation, analysis, and presentation of data to managers and leaders, for oversight and performance monitoring and for strategic review and planning. This should occur both in a high-frequency (daily, weekly, monthly) and in a distilled manner, as well as in more expansive and discursive forums requiring more preparation (e.g. quarterly or annual health sector reviews). Customized dashboards can be useful in conveying key indicators to managers and leaders–using simple visualizations. Data analysts should construct dashboards taking into account the needs of the intended users, availability and quality of data sources, and the overall management process into which the dashboard will fit.

Build a Specialized Data Unit Policymaking is a complex process that requires inputs from a variety of sources and perspectives. For example, the formulation of a plan to increase tobacco taxes has public health as well as economic implications and requires data from public health, finance, and law enforcement sources. This need to integrate wide-ranging information for the purposes of policy development should be supported with data management and analytic capacity. Moreover, assuring best data-use practices across a complex organization requires substantial *brokering* among various technical and nontechnical stakeholders to share data and agree upon interpretation and communication of findings. Public health agencies can establish central units to serve these cross-cutting needs.

Sometimes referred to as *public health observatories*, such units should have the following responsibilities:

- Compile and link agency datasets; identify and obtain access to external datasets;
- Perform advanced epidemiologic and economic analyses;
- Develop and disseminate reports and reviews;
- Establish policies and standards for management, sharing, analysis, and presentation of data across the agency; and develop, define, revise, and report core indicators;
- Respond to requests from leadership for policy analysis, economic analysis, and impact estimation;

- Provide guidance and training to technical staff across the organization and at other levels of government; and
- Liaise with external partners, such as universities and public health institutes.

An example is the London Health Observatory, which is embedded in the National Health Service system and provides a wide range of data services to government and non-government stakeholders. Its functions include conducting analyses on complex databases, creating easy-to-use data-use tools, disseminating public health information in various formats, and capacity-building for a wide range of data producers and users. Further information on the roles and functions of public health observatories is available [32–36]. To enhance some of these functions, ministries may seek to establish formal relationships with para-statal public health institutes or academic institutions that have technical resources beyond those of the government public health agency. The International Association of Public Health Institutes provides information and listings of public health institutes [37].

Build Capacity for Quality and Transparency Data quality limitations should rarely be an absolute impediment to data use. In most cases, with appropriate caveats and transparency about data limitations, even lower-quality data can provide actionable and valid insights. Data analysts and practitioners should apply some simple rules when deciding whether to use or to release data. Does examining this data set bring observers closer to the truth or further from the truth? Is this decision better-made or is the public better-informed if the data set is *not* used and *not* released? In the vast majority of cases, the answers will lead toward more use and more transparency.

Build Analytic Skills Across Departments and at Multiple Levels Though specialized units are essential, agencies should also build and maintain strong analytic capacity throughout programmatic departments. Agencies should strive to create a community of practice among data producers from across the organization in which they share information, agree on standard practices, access new skills and learn new methods, and so on. Such distributed capacity should also be fostered between the national and subnational level. Providing tools and training and promoting a culture of data use at the local level should be priorities for central agencies.

Extending a data component to all public health functions relies critically on the skills and capacities of health sector workers, who are often overloaded,

who necessarily prioritize care functions over data collection, and who may lack technical expertise, including in information technologies. On the other hand, such skills are often available in academic institutions and among health personnel involved in research studies. Leveraging capacities in academia can help develop the skills of government staff.

Building Alliances for Change New technologies in health data collection and management are generating vast quantities of information from multiple sources, including non-traditional sources such as social media and genomic analyses. There is potential for accidental or deliberate misuse of such data and risks of public hostility to sharing of data that could impede their use for improved public health. Open dialogue about the purposes and use of data collection—especially with regard to data derived from clinical and other individual records—should be part of a national data-use strategy. As emphasized by the American Health Information Management Association, discussions on ethics, informed consent, privacy, confidentiality, intellectual property, and commercial uses of data collected by public institutions should involve not only technical experts, researchers, public and private health institutions, and commercial entities, but also, critically, the public [38].

4 Conclusion

Challenges of translating data to action are common across government public health agencies, and ample research exists on the nature of such limitations [39–41]. They include deficits in technical and technological capacity and resources, as well as operational and cultural divides between data scientists and data users. Furthermore, ministers and other senior government public health officials often do not have technical backgrounds; may not be aware of or appreciate the potential value of data for decision-making, or may have biases against using data that derive from real or perceived flaws in data quality or reluctance to risk having data 'tell a bad story'.

Less evidence is available on successful strategies to address these challenges, including on how to sensitize and stimulate the embrace of data-driven leadership. For some leaders, data-driven decision-making is intuitive; for others, the practical value of such an approach is less obvious. Use of data for decision-making may provide a better defence of decisions to government and public stakeholders, more successful appeals for funding, stronger strategic relationships with global donors, and other political benefits. Similarly, external demand is a potentially powerful driver of institutional change. Press, academia, and civil society sectors that request data from government and frame

critiques and advocacy in a data-driven manner can influence governments toward improved use of data for decision-making. In some cases, for low- and middle-income governments, global donor expectations about data-driven attention to a particular issue also exert strong influence.

As technological tools become less expensive and widely available for data collection, through tablets and smartphones for example, and data presentation through free or inexpensive templates and programmes, it will be easier to create some of these exemplary data practices. But technology alone will not be sufficient to generate optimal conditions for data-driven policymaking; governments must also invest in staff technical capacity, in leadership approaches, and in management processes.

Governments at national and local levels should also promote the development of coordinated approaches to health data use and develop plans that address issues of data stewardship and curation. Examples are available of good practices and guidelines for data use that speak to the needs of both data producers and users [38]. These can contribute to broad-based discussions on how to balance the protection of individual privacy and the benefits of data sharing for improved health policy.

The MEASURE, INFORM, BUILD framework provides succinct guidance that public health agencies can adopt to rapidly create data-driven practices to inform decision-making. Some of these approaches can be implemented with relatively little investment, some using relatively small modifications to existing practices, and some require significant effort and investment—largely in human resources and capacity. Adopting the practices we describe creates within public health institutions the conditions to *act* on their data—creating laws and regulations, allocating financial and human resources, planning and implementing programmes, monitoring performance and impact, and influencing stakeholders.

Key Messages

- Data should drive all aspects of public health policymaking, including prioritization, resource allocation, legislative development, and programme planning, monitoring, and evaluation.
- Exemplary practices include monitoring key indicators, communicating with data, and applying analytics to policy development.
- Data sharing requires public trust, consensus, and balancing needs for open data with privacy and confidentiality.
- Health leaders should invest in skills development, institutional organization, policies, and technology to support data practices.

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Part II

Major Sources of Global Health Data

Preface

In these chapters, authors describe long-standing and well-tested instruments for collecting health-related data about populations around the world. With examples from many countries, the authors demonstrate the strengths of these instruments in producing valuable data and discuss the challenges countries face in maintaining them. The authors offer advice about ensuring the instruments function efficiently and that they provide quality data.

National governments undertake population censuses every ten years to obtain data about the number of people living in demarcated enumeration areas and to describe how they are distributed by age, sex and other socio-demographic characteristics (Chap. 6). Civil registration and vital statistics (CRVS) systems officially register, certify, aggregate and report key events in the lives of individuals—notably births, deaths, marriages, divorces and adoptions (Chap. 7), continually updating their population databases. Censuses and CRVSs, where they function, provide key national and sub-national demographic and health indicators such as fertility and mortality rates and rates of aging and population movements. When accumulated across countries, these data describe the changing dynamics of the world's population.

Regular national household health interview and examination surveys collect data to provide repeated cross-sectional descriptions of a population's health, health-related behaviour and access to health care (Chap. 8). For example, household surveys can estimate the prevalence of diseases, of over- or under-nutrition or tobacco use, and of service utilisation, such as antenatal care or immunisation. Well-designed surveys with standardised data collec-

tion instruments provide indicators that are comparable across populations and time. Survey data, combined with demographic data from censuses and CRVS systems, provide the basis for estimating most health-related sustainable development indicators.

A health management information system (HMIS) is a key source of administrative data for health policy and planning, drawing on patient records, health facility registers, health facility assessments and other administrative records (Chap. 9). Well-maintained and comprehensive HMISs, combined with up-to-date catchment population numbers from a census, provide estimates of health status and service coverage. Public health surveillance systems work in parallel with and complement HMISs to monitor the distribution of disease over space and time. Surveillance systems watch out for outbreaks, such as cholera or Ebola and other threats to population health to contain them in real-time (Chap. 10). National, regional and global surveillance systems, connected through international networks, describe the pattern of outbreaks around the world in order to predict, prepare and respond, for example, to eradicate polio from the planet.

6

The Population Census: Counting People Because They Count

Alphonse L. MacDonald

1 Introduction

> Census 96 and its army of one hundred thousand enumerators, marked a break with our divided past; by reaching every part of the country; by using the same methods for everyone; and by ensuring that as far possible everyone was asked for information in their own language [1].

With these words, in October 1998, President Nelson Mandela released the results of the first census for post-apartheid South Africa. Mandela's government had brought the census forward by five years because it wanted accurate information to plan the nation's future. President Mandela went on to say 'They [the findings] show a society which had enormous basic needs to be met, whether it is in terms of access to clean water, electricity, telephones or schooling. By measuring the extent of deprivation in October 1996, the results provide us with benchmarks against which our performance, as government and nation, should be measured year by year'. Statistics South Africa repeated the census five years later in 2001 and again in 2011, showing that its population had grown from 40.6 to 51.8 million in 15 years. The census continues to provide economic and social benchmarks that challenge government policy.

President Mandela's remarks are universally valid. To plan services and allocate resources, governments need to know the number of people they serve and where these people live. A population census provides this information by

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periodically counting each person in the country—or any defined geographic area—on a specific day, recording their personal characteristics and where they live. Ancient civilisations counted their populations and governments continue to do so today. In this chapter, I look back at how governments have made these head counts and how they have collaborated to standardise methods, and now support each other to document the world's population every ten years. I describe these census techniques and explore the value of census data to support policy and inform health decisions.

2 Uses of Census Data

As President Mandela recognised, census data support the democratic nature of society and promote equality; they provide rich cross-sectional material about changing demographics of society. Statistical offices make census data available on their websites as summary reports, anonymised raw data and cross-tabulations. Citizens, scientists, governmental agencies, non-governmental organisations and commercial and private sector entities can download and analyse the data for their own purposes.

Democratic governments use the data to determine electoral boundaries and representation. For example, the Constitution of the US mandates that the number of elected representatives for a state be determined by the number of residents in the state as established by a decennial enumeration [2]. Decentralised administrations use census data to transfer resources, for example, the Canadian government uses census population data to distribute funds proportionately to provincial and territorial governments [3]. If a census includes questions on foreign origin, it is possible to measure international migration flows.

Authorities and businesses use population data to plan and deliver health and social services, including, for example, to determine: where to build houses and set up shopping centres; how to arrange public transportation and provide refuse services; where to locate different levels of schools and how large they should be; and where to locate restaurants, places of entertainment and sports facilities. The health sector uses the data to position health centres and specialised referral services. Knowing the catchment size of the population, health authorities can plan services they expect to provide, for example, the number of children to immunise, number of pregnant mothers for antenatal care and the number of expected out- and in-patients. With this information, authorities can assess their coverage of risk groups, and provide population estimates of morbidity and mortality. In some countries, it is difficult to delineate health

facility catchment areas and to know their population sizes, in which case census figures provide a guide. If a census has used the International Standard Classification of Occupations (ISCO) [4], human resource planners can assess the geographic distribution of different levels of health personnel.

Population data from the world's 2000 and 2010 Census Programmes provided denominators for indicators to measure the Millennium Development Goals (MDGs). The 2020 and 2030 Census Programmes will be necessary instruments to measure many of the 232 indicators of the Sustainable Development Goals (SDGs) [5]. International comparisons by the World Health Organization, for example, of health indicators expressed as *per population* (usually by sex and age groups), are mostly based on population sizes estimated from decennial census figures.

3 History of the Population Census

3.1 Development of Census Methodology

Ancient civilisations, Babylon, Egypt and China, kept administrative records of population, agricultural plots, production and trade. Although they did not document their procedures thoroughly, they referred to censuses and registers. In medieval Europe, administrators of city-states, republics, duchies and kingdoms carried out headcounts and kept more or less systematic population records for taxation, defence or public works. Until the middle of the nineteenth century, these population enumerations generally used aggregate counts of families or households, not individuals. The earliest examples of true censuses are the 1666 census of Quebec (New France) and the 1703 census of Iceland then a dependency of Denmark. These population counts met the key requirements of a census—individual enumeration, complete coverage throughout a defined territory and undertaken at the same time. Other European countries claimed to have conducted censuses during the eighteenth century, Sweden in 1749 and France in 1770, but these were population registrations and not enumerations.

In the early nineteenth century, statistical societies established in the UK (1834) and the US (1839) began to standardise statistical methods. International Statistical Congresses in 1853 and 1872, led by the Belgian scholar Adolphe Quételet, made recommendations on the population census, its methodology and characteristics. These recommendations included the type of population to enumerate, frequency of census taking (once in ten years, preferably in years ending in zero), reference to the census date, use of the family or

household to identify individuals, and use of specially trained enumerators and a questionnaire. Variables proposed included name, sex, age, relation to the head of the family and household; civil state or conjugal condition; profession or occupation; religious affiliation; language(s) spoken; ability to read and write; origin; place of birth; nationality; usual residence; nature of the residence; where the census took place; and whether the individual was disabled, blind, deaf and *dumb*, being a *cretin*, an *idiot*, or of *unsound mind* [6, 7]. At the Jubilee session of the Royal Statistical Society in London in 1885, the International Statistical Institute (ISI) was established to continue international cooperation in standardizing methodologies and techniques, including the census.

After the Second World War, the United Nations (UN) Statistical Commission and the Population Commission promoted census methodology and organised technical and financial assistance to member states to execute decennial World Population and Housing Census Programmes. They issued a series of technical manuals on population and housing census methodology. In 1980, the UN published *Principles and Recommendations for Population and Housing Censuses* [8] which established the link between housing and population censuses, their linkage with other types of censuses, and promoted a regional approach. This manual, last updated in 2015, and additional technical handbooks and guidelines define the global standards for census methodology.

3.2 Worldwide Use of Censuses

In 1790, the US Federal Marshalls and their assistants enumerated the country's first decennial census, as mandated by the Constitution. In 1801, Great Britain started its decennial census programme, employing parish vicars and teachers to undertake the census. Until 1841 and 1850, respectively, enumerators in Great Britain and the US used the aggregate household approach, completing pre-formatted tables. Since then, both countries have conducted modern censuses characterised by using questionnaires and listing persons individually. France undertook its first modern census in 1851, followed by Sweden in 1860, Italy in 1861, the German Empire in 1871, and British India in 1872. In Latin America, Argentina and Mexico held censuses in 1895, but their regular census programmes only started in 1950. The Inter-American Statistical Institute (IASI), a regional branch of the ISI, was established in 1940. IASI organised the Census of the Americas (COTA) in which all independent countries of the continent carried out a census using a common questionnaire, but produced country-specific reports [9]. IASI also

promoted the COTA approach in the 1960, 1970 and 1980 census rounds. In Asia, modern censuses started in 1909 in Thailand, in 1920 in Japan, in 1953 in the People's Republic of China and in 1962 in Cambodia. Egypt carried out its first modern census in 1848. Some of the British African colonies held headcounts in the late 1800s and conducted censuses from 1948 onward. Independent countries of sub-Saharan Africa started regular census programmes from 1960. In 1970, the UN Economic Commission for Africa established the African Census Programme. The UN Population Fund (UNFPA) prioritised promotion of population statistics and, with support from major donors, organised a system of technical and financial assistance to countries to execute population and housing censuses. Increasing numbers of independent sub-Saharan African countries carried out censuses during the 1980 and 1990 World Population and Housing Census Programmes.

During the 2010 World Population and Housing Census programme, 214 countries or territories conducted a census covering 93 per cent of the estimated world population; 21 countries or areas did not participate [10].

4 The Census: Organisation, Phases and Outputs

4.1 Pre-Conditions to Undertake a Census

As an activity of national interest, a population and housing census must involve all segments of society. A census office is responsible for the technical and managerial aspects of the census. This office is usually part of a national statistical office and receives advice from a national census advisory commission representing all stakeholders. The success of a census depends on at least four conditions: (1) the country is at peace with political, social and environmental stability; (2) the government has enacted required legislative and administrative arrangements and identified sufficient and timely funding; (3) a critical mass of qualified professionals is available and able to plan and execute the census; and (4) the population is willing to provide the required information. In many countries, participation is obligatory, but it is crucial to convince society of the individual privacy and confidentiality of data and that the government will use data for statistical purposes only.

To ensure maximum support and to obtain a high response rate, society must know about and be involved in the census. The census office should

consult government agencies, the private sector, non-governmental organisations, professional, trade and religious organisations and the public on the potential content of the census questionnaire.

4.2 Objectives and Data

The census office needs to establish the objectives of the census early in the planning process as these will influence the content of the questionnaire. While the major objective is to describe the geographic and socio-demographic structure of the population at the time of the census, some censuses aim to describe additional features of the population, such as level of disability, birth rate and certain mortality rates. The census office restricts the range of objectives to keep the questionnaire short.

The topics included in recent censuses are similar to, or elaborations and extensions of, those recommended by the International Statistical Congresses in the mid-nineteenth century. *Core topics* are obligatory questions that should be included in the census and *non-core topics* can be included at the discretion of the census office and the government. For the 2010 World Census Programme, core topics were age, sex/gender, marital status, relationship to the household head, place of usual residence, educational status, occupation, number of live births, date of the last live birth, children still alive, deaths in the household in the last 12 months, and disability status. Typical non-core topics were age at first marriage, date of and duration of the first marriage, country of birth of father/mother, the age of mother at first birth, maternal or paternal orphanhood, time in current employment, and distance to place of work [11].

The International Statistical Congresses also recommended that governments create civil registration systems. As, even today, few countries have well-functioning civil registration systems (see Chap. 7), many turn to the census for information on fertility and mortality. During the 1970 and 1980 Census Programmes, African and Asian countries included questions on the number of births in the 12 months preceding the census date. The results provided critical inputs to develop UN population estimates and led directly to concerns about population growth which characterised development theories during that period. Similarly, countries collect deaths among household members in the year before the census date, from which they estimate infant and child mortality rates [12]. During the 2000 Census Programme, several African, Asian and Latin American countries asked whether recent deaths in women of reproductive age occurred during pregnancy or shortly after that in order to measure maternal mortality (see Chap. 17) [13].

4.3 Phases of a Census

The census process consists of four interlocking phases: preparatory; field operations; data preparation, evaluation and tabulation; and dissemination. The typical period from inception of the census to publication of the first report varies but with a minimum of three years.

During the preparatory phase, the census office prepares all administrative, technical and operational activities including training of field staff, setting up data management and comprehensive quality control systems, and developing a communication and publicity programme.

The census office should maintain continuous communication using all forms of media to inform the population of the objectives and purpose of the census (Box 6.1). In multi-cultural and multi-ethnic societies, messages should be presented in all major languages. The office should also establish a help-line, through which the population can obtain additional information and support. National statistical office websites can inform and engage the population. The forthcoming 2020 population census in the US entails a major modification in the census approach with the provision of digital response options and use of the Internet and the telephone. The US census communication strategy recognizes the importance of website-based interactions with the public [14].

Box 6.1 Everyone Counts: Estonia's Campaign Around Its 11th Census [15]

Estonia collected data for its 11th census from 31 December 2011 until 31 March 2012 with the slogan: 'Everyone counts'. It used mixed-mode data collection. Residents could complete the census questionnaire online and enumerators visited those who did not. Two publicity and media companies, who had won public procurement, designed and developed the publicity campaign using television, radio, print, outdoor and Internet advertising including mailing a detailed information leaflet in three languages to all known dwellings before the census started. The campaign had three stages. The first stage concentrated on ways people could participate in the census, the second on participating in the e-census, and the third focussed on enumerator visits.

The field operations phase includes preparatory activities for enumeration, the enumeration proper, and field verification processes. These activities include updating the census cartography, identifying dwellings, preparing dwelling and household lists, enumerating all households, verifying completeness and correctness of the enumeration and carrying out a post-enumeration survey to establish the level of census coverage [16].

Options to enumerate the population include: *face-to-face personal interviews* in which an interviewer visits each household and completes the questionnaire; *self-completion* using the mail-out-mail-in procedure in which the questionnaire is delivered to each household (address) and the occupants complete the questionnaire themselves; *telephone interviews* in which the household responds to the census questionnaire by telephone, either through its own initiative or after being contacted by the census office; or *Internet interviews* in which the occupants of the household complete an electronic version of the questionnaire. In the last two options, the responses to the questionnaire are verified during the interview and entered directly in the census data file. Sometimes countries combine these approaches, and it is then necessary to establish the validity and reliability of each method in terms of overall census coverage. Increasingly, enumerators utilise electronic handheld data collection devices. These devices use specially developed software applications, which the telephone and Internet approaches also use. Computer-assisted personal interviewing (CAPI) packages can verify the correctness of answers during interview instantly producing high-quality data, reducing or eliminating need for lengthy data management after field operations. These data are immediately available for analysis, reducing processing time and possibly the total census cost but there is no option to assess the quality of the original responses.

During the data preparation, evaluation and tabulation phase, specially trained staff manually process collected data and self-completed questionnaires at data centres; they transform the data into electronic formats, mostly using automated electronic scanning. Staff verify all data, whatever the collection format, for completeness, correctness and consistency, using data control techniques focussing particularly on age data [17].

The US Bureau of the Census offers software packages to evaluate and analyse data: PAS (Census Population Analysis System) [18]; and CSPro (Census and Survey Processing System) [19]. The Population Division of the Economic Commission for Latin America and the Caribbean of the United Nations (CELADE) have developed a system called REDATAM (REtrieval of DATa for small Areas by Microcomputer) that covers all phases of data entry, editing and tabulation including production of thematic maps and graphs [20]. The UN Population Division provides a set of tools in MORTPAK especially for mortality analyses for developing countries [21]. The International Union for the Scientific Study of Population (IUSSP) has published a set of techniques to assess data quality and analyse the results [22]. These software packages are available free of charge.

During the dissemination phase, the census office disseminates the results and output of the census to the government and society. The office may not make some census products publically available if there are confidentiality provisions or if the data have commercial value.

4.4 Census Output

The census report is the major output. It is usually published as a preliminary report, then as a final report and an administrative report. The preliminary report, issued soon after completion of fieldwork, tabulates population size by sex and age for the country and its main administrative subdivisions. The final report contains detailed tables on the population and its characteristics for administrative subdivisions. This report often describes the history of census taking in the country and chronological developments of the main population characteristics. Some countries issue thematic reports on topics linking census results to information from other sources. Some countries issue a series of reports dealing with particular aspects of the population. For a good example, see the list of reports and profiles issued by the Central Statistical Office of Ireland for its 2011 census [23]. The administrative report provides a full account of the census process, its challenges and solutions and includes copies of all relevant documents. This report is a key document with which to assess the quality of the census and its results. Other census outputs are as follows:

Census atlas presents results graphically especially as maps. With information from more than one census, atlases can show changes in population characteristics over time.

Updated census cartography serves as the national master sampling frame for surveys [24] and for other censuses such as agricultural or industrial censuses.

Updated inventories are lists of localities, inhabited or not, building types, dwellings and households with relevant geographical identification information. For an example, see the National Records of Scotland, Settlements and Localities [25].

Metadata are detailed and complete documentation of methods, techniques, procedures, variables, questions, response categories and coding instructions used in the census made available when the data become publically available.

Depersonalised anonymised data files of the population, or a sample, available for third-party research analyses. These data could be posted on the national statistical office's website, or shared with international data reposito-

ries, such as the IPUMS programmes of the Minnesota Population Center of the University of Minnesota, US [26].

*Historical completed questionnaires a*re publically available for genealogical and family research. In the UK and US completed questionnaires are available after 100 and 72 years respectively to safeguard privacy.

4.5 Presenting Census Data

Simple presentations of age, sex and location provide immediate insights into population structures. A population pyramid shows composition by sex and age and illustrates the effects of changes in fertility, mortality and migration over time. The pyramid for the 2011 Mauritius census with age in single years in Fig. 6.1 shows a narrow base indicating declining fertility, and the bulges at 31 and 18 years reflect higher births around 1981 and 1992. This pyramid also shows some preference for reporting ages ending in zero. Interesting patterns emerge when pyramids from several censuses are compared; particularly when the presentation

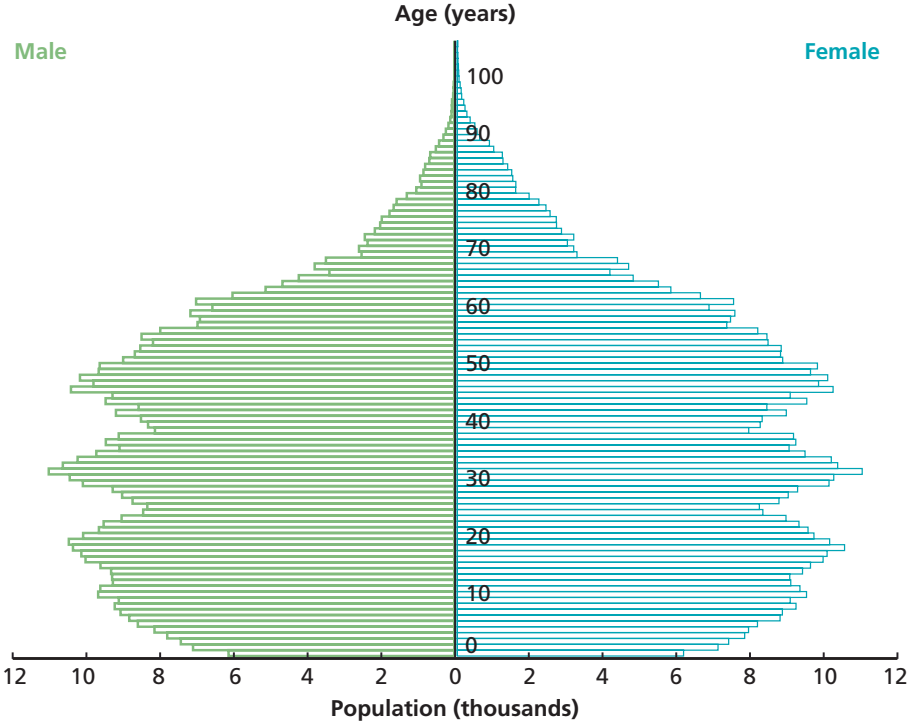

Fig. 6.1 Population pyramid by single year of age for the 2011 census, Republic of Mauritius. (Source: Statistics Mauritius [27])

is dynamic (see the World Life Expectancy website) [28]. Population pyramids also show changing male to female sex ratios by age. Although slightly more males are born (generally 1.05:1) than females, women tend to live longer; hence male to female sex ratios decline with age. The sex ratio can be distorted by selective under-reporting of specific categories, or by migration flows. In Fig. 6.2 the apparent increase in the male to female sex ratio in Mauritius, for example, in 1990 is due to the higher out-migration of females in the period before the 1990 census. Of special interest is the sex ratio at birth, for which the number of children aged zero years is a proxy. Excessive values (over 1.05) could indicate selective sex (female) abortion due to societal preference for males, although the exact causes of fluctuations of the sex ratio at birth have yet to be established. Maps vividly display any census findings by location; for example, Fig. 6.3 shows the changing distribution of overall sex ratio across Mauritius and between the 2000 and 2011 censuses.

4.6 Challenges in Undertaking a Census

The population and housing census should primarily serve the national interests and objectives. The main challenge facing low- and middle-income countries especially is lack of resources, mainly financial but also infra-structural and human resources. International donors have drastically reduced

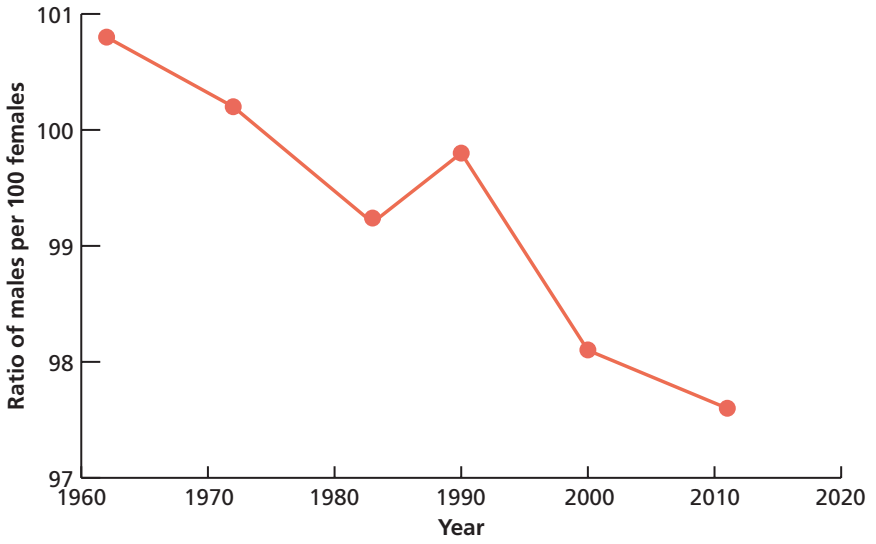

Fig. 6.2 Evolution of the population male to female sex ratio, 1962–2011 censuses, Republic of Mauritius. (Source: Statistics Mauritius [27])

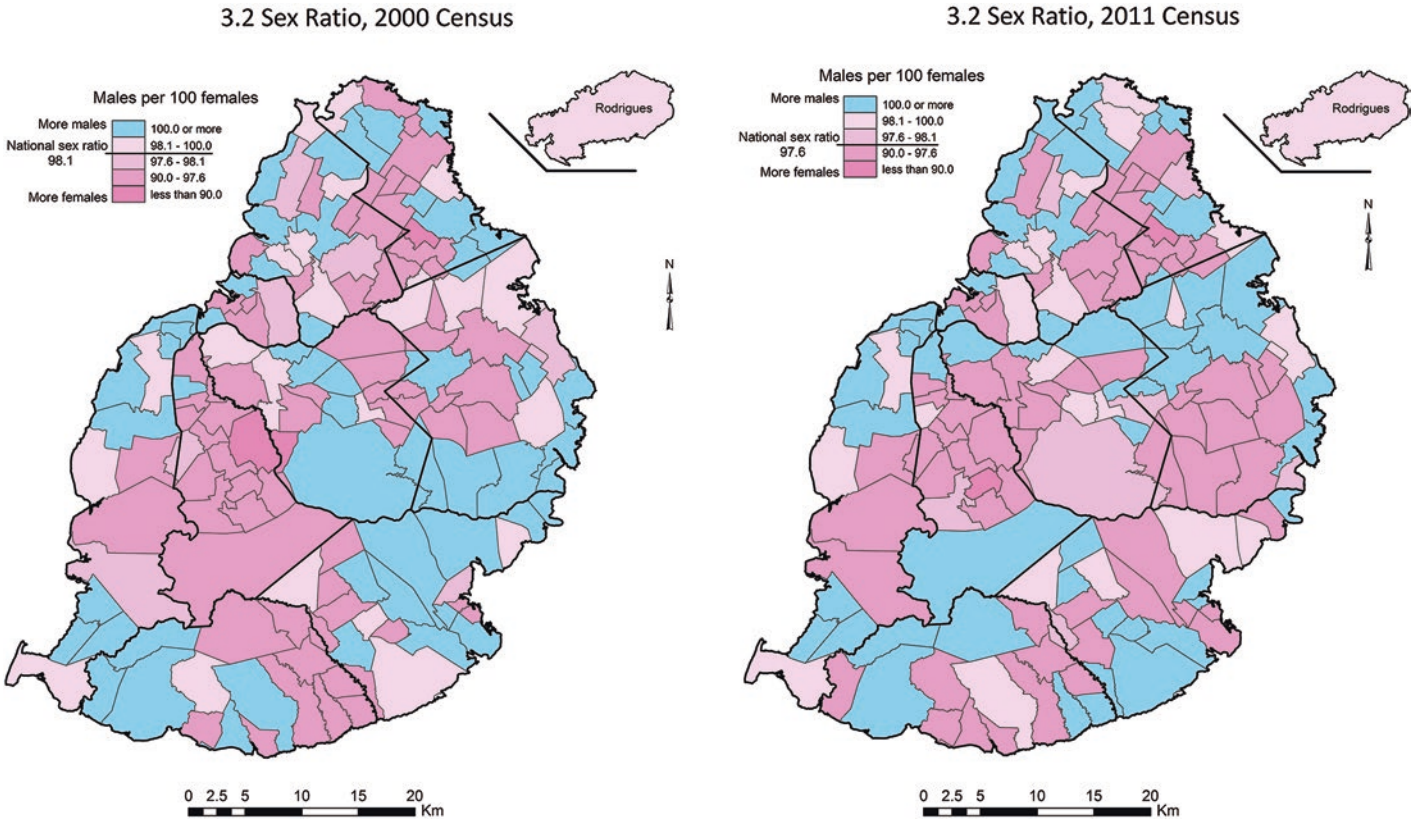

Fig. 6.3 Population male to female sex ratio by administrative unit, 2000 and 2011 censuses, Republic of Mauritius. (Source: Statistics Mauritius [29])

support for census operations, and some countries have been obliged to take concessional loans to carry out their censuses. Another concern is outside and national pressure to modify census procedures, either by changing the type of population to be enumerated, or to use sophisticated equipment without consideration of the necessary trained human resources and training opportunities, and what the equipment will be used for after the census. The census operations and quality may be compromised by having excessively lengthy questionnaires. Increasing the length of the questionnaire has serious resource consequences in that the average interview time will be longer and the period of fieldwork needs to be increased especially in countries with limited trained census workers. Given that most countries have an integrated statistical system with data derived from administrative sources, censuses and surveys, care should be exercised to use each of the sources appropriately. Finally, unanticipated security issues and environmental developments may affect the proper execution of the census activities.

5 Combining and Analysing Health and Health-Related Data

5.1 Analysing Health Data

Apart from questions about disability, censuses do not usually include direct questions about people's health. Although it is better to measure disabilities and mental health conditions through special surveys, censuses have included disability questions since the mid-nineteenth century; given national and international concerns about the quality of life. At present, countries require regular disability information to show compliance with the Convention on the Rights of Persons with Disabilities (CRPD). In 2001, the UK Census included specific health questions, namely self-reported general health, limiting long-term illness and voluntary provision of care [30]. In the regional recommendation for the 2010 Census Programme, the Economic Commission for Latin America and the Caribbean (ECLAC) included questions on fertility and mortality including maternal mortality, disability, sexual health (especially for adolescents), and access to and use of social security arrangements (Box 6.2). Including self-reported health information in a census requires close collaboration with the ministry of health and comes with additional cost in terms of time to complete the questionnaire. Otherwise, the health sector relies on surveys

Box 6.2 Measuring Inequality, Poverty and Exclusion in Latin America

Latin American countries have a tradition of using census data to study inequality, poverty and exclusion by analysing differentials in standard variables such as education, employment, urban-rural residency, demographic characteristics, including fertility (especially of teenagers), mortality and disabilities. By relating these questions to ethnicity and urban-rural residence, patterns of inequality, poverty and exclusion can be observed providing information for corrective developmental and political actions. Peru included questions on the possession of identity cards and access to social security services in its 2007 population and housing census.

and routine facility information systems to describe morbidity and other health conditions.

The census provides fundamentally important information for the health sector about the structures of populations and how they change over time—the realm of demography (see Chap. 17). Using current and historical census data, demographers estimate population growth, and provide estimates for the years between censuses, and use these to adjust any discrepancies in the actual census numbers. Demographers also create life tables from which they estimate life expectancies, fertility and adult mortality rates. Where countries have included questions about births and deaths in the household in the year preceding the census, demographers estimate infant and child mortality rates and maternal mortality ratios. These rates are useful in countries without proper civil registration systems and population registers.

5.2 Linking Census Data

Linking census data with previous censuses and data from other sources enriches the data. Combining geographical information about population distribution from the census cartography with the location of health facilities and linking this information with data from patient registers can inform planners in locating facilities and determining their coverage. Epidemiologists combine census data with survey results to map the prevalence of health conditions.

France has linked individuals in a series of censuses with information from the civil registration and health registration systems. The linked data files contain information of all sources used and allow the analysis of relationships between variables in the original databases. The INSEE Permanent Demographic Sample (EDP) [31] is based on the 1968 census, with linkages to subsequent censuses until 1999, and is supplemented by vital statistics. From 2004 onward,

the annual national surveys—part of France's Rolling Census—are linked to the EDP. Since 1974, a similar arrangement exists in England and Wales [32]—the longitudinal study based on the census of 1971 with links to subsequent censuses and vital statistics. More recently, Northern Ireland and Scotland developed similar designs linking civil registration data, hospital data and health registers. In 2005, Switzerland established a Swiss National Cohort study (SNC) which is a research platform that links census data with health information, including ongoing health-related cohort studies [33]. Linkage presents methodological and technical challenges which require good collaboration between national statistical offices and academic institutions. These arrangements are resource intensive and time-consuming and require specific legislation to safeguard confidentiality and privacy. Nevertheless, linkage of health questions with other information included in the census or with information from other sources provides new insights as exemplified by the 2011 censuses of England and Wales [34] and Scotland [35].

6 What Future the Census?

The methodology of the population census—a full enumeration of every individual in a specific geographical area, at the same time, with a specific periodicity—is well-tested and documented with established procedures to assess the quality and completeness of the information. It is said to be a costly operation, but this opinion is based on unscientific and unsystematic comparisons. The cost structure of the census is well established and covers a wide range of activities which produce intermediate and final results, with expenditures spread over several years. The census could actually save money. For example, absence of census-generated information could result in additional or unnecessary expenditures for national and local government and businesses due to inappropriate decision-making based on paucity of adequate information or absence of auxiliary statistical instruments such as sample frames for household surveys.

Two alternatives to the census are in use. The *rolling census*, only used by France, is a system of continuous sub-national rotating sample surveys. The rolling census cannot produce estimates for the whole country at a specific moment or a census reference date. The other alternative is a *register-based census* which is only possible when a country efficiently maintains and coordinates a system of registers linked to a national population register. During the 2010 World Census Programme, 15 countries used a register-based approach as their sole or main source of census data—2 in Asia, 12 in Europe and 1 in Northern America [36]. Countries follow different procedures, and there is

no standard methodology for a register-based census [37]. Proponents of the register-based approach present reduced costs, lessened respondent burden and more frequent, annual, availability of data as its main attractions. They have not yet developed methods to assess the completeness and quality of the estimates derived from the register-based approach. A UN Economic Commission for Europe (UNECE) Task Force on Register-Based and Combined Censuses is developing *guidelines on the use of registers and administrative data for population and housing censuses*.

As long as there is a need for verifiable and detailed information on the population and specific population groups, at different levels of a national territory, including small areas, and as long as the completeness of registers needs to be established or verified, countries will require a census. The scientific principles that the census adheres to are well established; it is flexible in incorporating new technologies and it is capable of enumerating rare populations or personal characteristics and measuring emerging phenomena. For example, the Office for National Statistics in the UK is planning to include questions on sexual and gender identity in future censuses [38]. Availability of enhanced electronic equipment and social media platforms will benefit the census and could lead to more cost-effective operations. Until there are alternative procedures to produce the same population information with identical quality and completeness, the census will remain the preferred way of obtaining periodic information on national and sub-national populations.

Key Messages

- The census is a well-tested instrument that generates essential population data including multiple demographic indicators.
- Health sector specialists can use census results to plan and monitor health interventions.
- Combining census with other sources of health data adds insights into local health conditions.
- The census provides the sampling frame for household surveys.

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7

Civil Registration and Vital Statistics: A Unique Source of Data for Policy

Carla AbouZahr, Gloria Mathenge, Tanja Brøndsted Sejersen, and Sarah B. Macfarlane

1 Introduction

In April 2016, the UK Office for National Statistics issued provisional death registration figures for England and Wales for 2015 [1]. The findings were troubling, showing the largest year-on-year percentage increase in deaths (6.3 per cent) for almost 40 years. Most of the increased deaths occurred in the first three months of 2015, with 24,065 more deaths registered in 2015 compared with the same period in 2014; 11,865 of the extra deaths were registered in

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January, when flu was at its highest levels [2]. Respiratory diseases were the underlying cause of over a third of the excess winter deaths in 2014–15. The report triggered a rapid response. The Chief Medical Officer for England made plans to alert people to the negative health effects of cold weather so that they could prepare and respond. The report also produced population-based data important for understanding the performance of flu vaccines.

This is a story about availability and use of statistics to underpin health and social policy decisions. It is also a story about the underlying system that generates statistics on a weekly basis, and analyses and disseminates annual figures for an entire country within four months of the year's end. The source for the mortality data was the national civil registration and vital statistics (CRVS) system which officially registers all deaths within days of occurrence, medically certifies each cause of death, and compiles and analyses the information to generate a continuous series of mortality statistics.

In this chapter, we introduce CRVS systems and demonstrate the policy uses of the statistics they generate. We describe the organization of CRVS and the key milestones that systems need to achieve to function efficiently. We summarize the status of CRVS systems around the world, and identify the interventions needed to ensure CRVS generates quality data to inform health policy and practice.

2 What Is CRVS?

According to the United Nations (UN), 'Civil registration is the continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events pertaining to the population, as provided through decree or regulation in accordance with the legal requirements in each country' [3]. Vital events are key events in the lives of individuals and include births, deaths, foetal deaths, marriages, registered partnerships, divorces, annulments, judicial separations, legal dissolution of registered partnerships, adoptions, legitimations and recognitions. We focus on births and deaths, the events most critical for public health policymaking.

Governments set up *civil registration* to provide a permanent record and official documentation of vital events occurring in their populations. Because, in principle, civil registration records cover the entire population and are available on a continuous basis, these records offer a complete and timely source of vital statistics. The *vital statistics system* is the process by which statistical offices develop official statistics using the registration records. Figure 7.1 provides an overview of a CRVS system and its contribution to administration and statistics across multiple sectors.

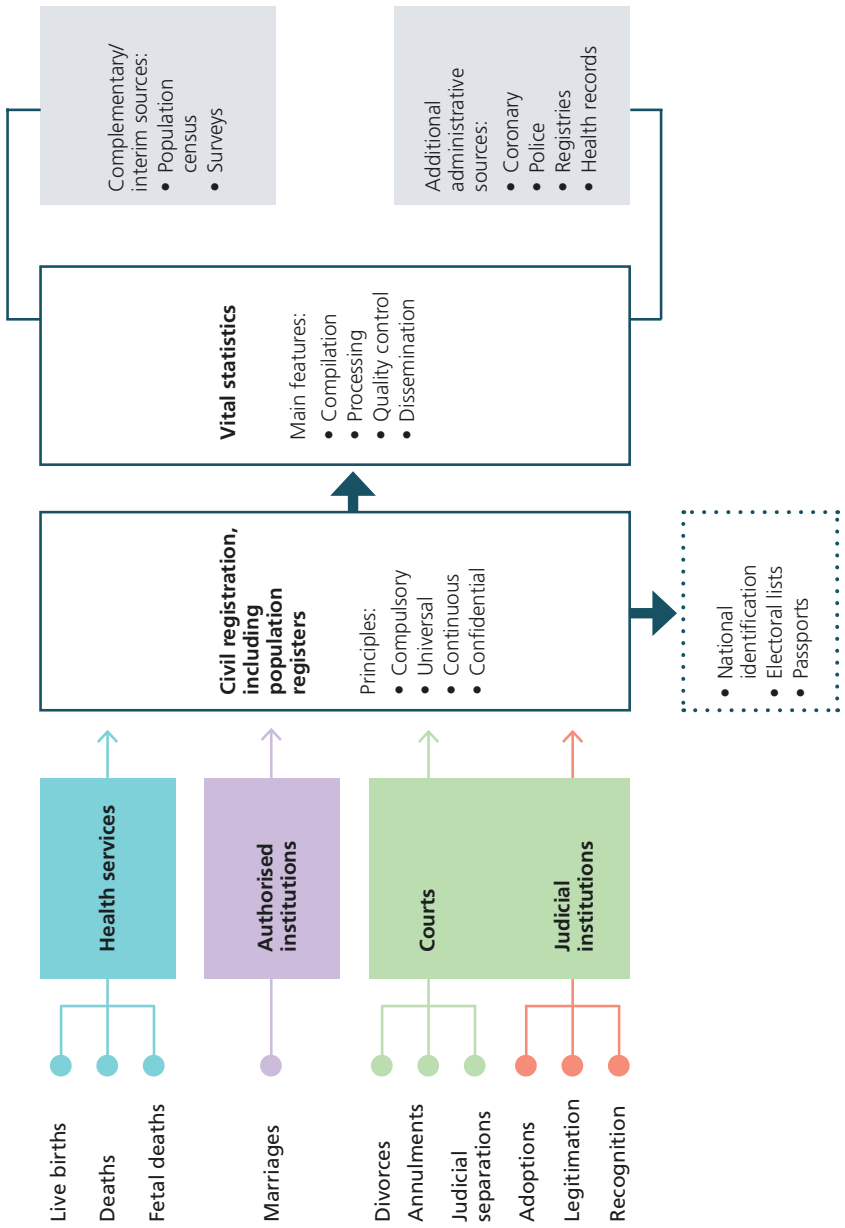

Fig. 7.1 Overview of a civil registration and vital statistics system. (Adapted from UN Principles and Recommendations for a Vital Statistics System, Revision 3, 2014 [3])

The core attributes of a CRVS system are continuity, permanence, universality and compulsoriness. *Continuity* and *permanence* refer to the capacity of the system to record vital events as they happen, thus generating a continuous flow of vital events, as compared to a cross-section of recent vital events over a specific period of time, such as is captured in a census or household survey. *Universality* means that the system records vital events occurring in the entire population and all areas within the boundaries of the country. To ensure continuity, permanence and universal coverage of vital events, national authorities make registration of vital events *compulsory* through a legal framework. A functioning CRVS system meeting the four attributes is the most reliable and comprehensive source of vital statistics in a country.

3 Benefits and Beneficiaries of CRVS

Uniquely among the common data sources available to health and development, the CRVS system benefits people first and foremost, with the statistical and administrative benefits accruing as valuable by-products.

3.1 Legal and Administrative Benefits for Individuals and Families

Civil registration benefits individuals and families in multiple ways. Registration of infants at birth records key elements of identity and family relationships, contributes to establishing entitlement to nationality under the law, and facilitates access to economic and social services, such as health care, child protection and benefits, schooling, academic and professional qualification, and employment [4]. Proof of identity enables people to claim citizenship, inheritance and insurance benefits, spousal pensions, and compensation following, for example, occupational accidents or military action [5, 6]. Persons who are registered and who hold civil registration documentation are less vulnerable to statelessness and associated protection risks. Registration records also provide evidence of family relationships which are critical for re-unification when families become separated during conflicts and disasters. Proof of age supports authorities to provide child protection and prosecute perpetrators of child trafficking, sexual offences, child marriage and child labour [7]. Legal proof of marriage and divorce is particularly important for female heads of households and the families they support in accessing services, such as education and health. Proof of marriage can also be instrumental in protecting women's rights of access to and guardianship of children and in helping them prove entitlement to inheritance, spousal benefits and

nationality under the law or at least legal residency in a country [8, 9]. Registration of deaths is essential for claims of inheritance, insurance, and survivor and spousal benefits. Civil registration helps protect refugees, displaced and migrant populations from discrimination and exploitation and provides documentary evidence of links with countries of origin. [10].

3.2 Statistical and Administrative Benefits for Policymakers

CRVS systems generate up-to-date demographic and health indicators such as fertility rates, population growth rates, life expectancy, death rates by age, sex, location and cause, and neonatal, infant and child mortality rates. Unlike other data collection systems, CRVS provides a continuous flow of vital statistics from the smallest administrative divisions to the national level. Timely knowledge of the size and characteristics of a population facilitates socio-economic planning. Decision-makers in any sector can use CRVS data to identify areas of population change and reallocate resources accordingly. A health ministry, for example, can use data on births to plan immunization programmes; determining the numbers of drugs to procure, identifying where to distribute them and estimating immunization coverage. Knowing the number of school-aged children disaggregated by areas, an education ministry, for example, can implement a universal education policy and compute enrolment and attendance rates by age and sex, at national and sub-national levels.

Continuous registration of deaths and their causes generates statistics that guide policies to reduce premature mortality. As our opening example demonstrates, functioning CRVS systems can monitor and detect abnormal increases in numbers of deaths and trigger measures to manage and curb the situation. Where systems are weak or non-existent, many deaths may occur before health authorities become aware of an epidemic. Real-time mortality statistics also permit public health surveillance of emerging trends such as a growing burden of mortality due to non-communicable diseases, violence and road traffic accidents.

4 Development of CRVS Systems

4.1 Early History

Routine death registration first occurred in mid-fifteenth-century Northern Italy, where city councillors established health boards to consider how best to deal with recurring epidemics that ravaged their populations. The boards required family members to report the name, age and sex of a deceased person with the cause

determined by a certified physician or surgeon before a burial certificate could be issued. The English began to collect data on death and their causes in 1532 after an outbreak of Bubonic plague. During the seventeenth century, a merchant, John Graunt, studied death records maintained by local parish churches since 1532.

Church-based registers of births and deaths existed also in France and Sweden in the fifteenth and sixteenth centuries and provided exemplars for subsequent government registration systems. In 1836, for example, the British government established the General Register Office for England and Wales, headed by a Registrar General appointed by the King [11]. The primary role was administrative, to record and document births, marriages and deaths. It was immediately apparent that this new office would also generate a continuous stream of official statistics on the population. In 1839, William Farr, a medically trained doctor with a keen interest in statistics, was appointed as the Registrar General's 'Compiler of Abstracts' (later changed to 'Superintendent of Statistics'). Farr developed innovative ways to use medical statistics for the prevention of diseases, and developed advanced forms of life tables and a framework and nomenclature for classifying diseases, which led directly to the International Classification of Diseases [12].

4.2 CRVS in the Modern Era

Despite clear benefits of functioning CRVS systems to national policymakers across multiple sectors, these systems are weak or dysfunctional in large parts of the world. Many millions of vital events are never officially registered or counted in national statistics. Some low- and middle-income countries have inherited civil registration systems that date back to colonial periods when colonizers intended the systems to cover and benefit themselves and not the general population. Legislation has not always kept up with changing needs and demands of the population for legal recognition, confidentiality and privacy. At the same time, governments require modern legal systems to deal with issues of individual identity and national security.

The UN Statistics Division estimates that, at the end of 2014, only 62 per cent of the world's countries, territories and areas registered at least 90 per cent of births, and only 57 per cent registered at least 90 per cent of deaths [13]. UNICEF estimates that, globally in 2017, nearly one third of children under five years old had never been registered; in the least developed countries, fully two thirds of children aged under five years had never been registered [14].

The registration of deaths is usually considerably lower than birth registration. The US-based Institute for Health Metrics and Evaluation estimated in 2013, the most recent year for which data were available, that global death registration

increased from 28 per cent in 1970 to 45 per cent in 2013, that is, by only 17 per cent in 43 years [15]. A report in 2017 noted that over the period 2005–15, only 49 of 194 countries in the world reported high-quality cause-of-death data to the World Health Organization (WHO) [16]. The majority of the world's people live in countries where cause of death data quality is inadequate to permit monitoring progress towards the Sustainable Development Goals (SDGs).

5 How Do CRVS Systems Work?

There is no standard template for a national CRVS system. Each country has its own way of structuring and managing its system, depending on its socio-economic and administrative history, cultural norms and practices, and specific policy, administrative and statistical needs. For CRVS to function effectively, governments must establish national systems within a legal framework, organized around essential functions, capable of producing vital statistics.

5.1 The Legal Framework

The UN recommends basic components for a civil registration law [17]. The law should nominate an agency in which to locate central or national authority for the system, for example the ministry of health, justice, local government or home affairs. The agency must protect confidentiality of personal data and ensure that data can be shared securely between approved departments for quality assurance and to produce vital statistics in compliance with the *Fundamental Principles of Official Statistics* [18]. In accordance with international standards, birth and death registration should be free of charge or incur a low fee for late registration.

Legislation needs to be up-to-date and relevant to respond to the accelerating reach of electronic systems for registration and data processing and analysis. The legislation should provide clear guidelines around how the civil registration system will work while allowing the system flexibility to respond to technological change and emerging requirements.

It is rare that a single law addresses all essential aspects of CRVS; specific laws may pertain to issues of registration, but also of identity, nationality, residence, data sharing, security, privacy, health, statistics, social protection and many more. In large federal or decentralized systems such as India, the Philippines or the US, legislation and CRVS practices may vary by state. In such circumstances, national-level authorities need to harmonize both the legal aspects of civil registration and the production of comprehensive vital statistics.

5.2 Organization of the CRVS System

Key agencies with responsibilities for aspects of the CRVS system include the office of the registrar general, the ministries or departments responsible for justice, the interior, national identification and health, and the national statistics office. The agency responsible for national identification systems is an essential partner, along with the agency overseeing information, communications and technology (ICT), given the growing role of ICT in facilitating all aspects of the CRVS system. Because a single agency or ministry cannot successfully handle all aspects of CRVS, the UN advises establishment of a national coordinating mechanism. The lead or anchor ministry or agency works with other ministries, agencies and development partners to oversee development and coordination of CRVS.

5.3 CRVS Processes and Milestones

The registration of vital events is a primary function of the government for its people and is a human right that the government should deliver to every member of the population.

Governments should ensure a well-functioning CRVS system, with registration points distributed across the country within reasonable distance for everyone in the population to reach, each point reporting to the national level. Availability of registration infrastructure is necessary but not sufficient to ensure that all vital events are registered. Many births and deaths are never registered because families do not attend the registration office, for reasons we describe in Sect. 6.3. Even when a vital event is registered, the information may not be included in the vital statistics system because of data transmission failures or incomplete registration records. As part of the Data for Health Initiative, researchers have described each of the steps that needs to happen to ensure that every birth or death is officially registered and included in the country vital statistics systems [19]. These steps are the ten milestones that a well-functioning CRVS system should aim to achieve, as shown in Table 7.1.

5.4 Production of Vital Statistics

The UN has defined a minimum set of legal and statistical variables that the CRVS system should collect for each event and from which vital statistics are derived. Table 7.2 provides the usual demographic rates and indicators that analysts calculate from the vital statistics data. Many of these rates require knowledge of the mid-year size of the population at risk, usually available from census projections. Examples of vital statistics reports with demographic indicators computed from civil registration data are available at these sites [20–23].

Table 7.1 Ten key milestones for civil registration and vital statistics systems

Civil registration →	Vital statistics
1. *Notification*: Informant shares the occurrence of a vital event with the civil registry	7. *Statistical compilation*: Statistician aggregates and tabulates the information
2. *Registration*: Registrar officially registers the vital event	8. *Quality control*: Statistician performs standard data quality checks
3. *Validation*: Registrar checks the documentation and validates the information	9. *Generation of vital statistics*: Office produces national and regional tabulations with key disaggregations
4. *Certification*: Registrar issues an official certificate	10. *Dissemination*: Office publishes and disseminates vital statistics reports to users, electronically and as hard copy
5. *Sharing*: Registry shares information about the vital event with other government departments	
6. *Archiving*: Registry stores and maintains the information to permit retrieval of vital event details as needed	

Adapted from Cobos et al. [19]

6 Challenges for CRVS Systems

6.1 Registration of Births

In principle, births should be registered as soon as possible, generally within around 30 days. The sooner a birth is registered, the more likely it is that the system will record all the associated information accurately, thus contributing to reliable statistics. Many countries introduce incentives to encourage timely registration, for example, by requiring evidence of registration before parents can access child benefits or the child can go to school. The birth certificate is the precursor to issuance of an individual identity card required for multiple legal and administrative purposes, such as attending higher education, participating in elections, running for political office, opening bank accounts and claiming nationality [24]. Because incentives, such as access to schooling or requiring a national identity card, arise sometime after birth, many births are registered several years late, as Fig. 7.2 shows [25]. Late and delayed registration leads to inaccurate information reporting, which adversely affects the quality of the vital statistics. Should the individual die prior to the registration of his or her birth, the death may not be reported either, resulting in underestimation of infant or child mortality.

6.2 Registration of Deaths

Although the registration system functions in the same way whether the vital event is a birth or a death, experience around the world shows that deaths are less likely to be registered than births. The major incentive for death registra-

Table 7.2 Core demographic rates and indicators that can be computed from civil registration data

Vital event	Rates and indicators	Numerator	Denominator
Live birth	Crude birth rate (births per 1,000 population)	No. of live births in the year	Mid-year population for that year[a]
	Sex ratio at birth (ratio of male to female births)	No. of male live births in the year	No. of female live births in that year
	General fertility rate (births per females aged 15–49 years)	No. of live births in the year	Mid-year female population (aged 15–49 years) for that year[a]
	Age specific fertility rate (number of births to women in a specified age group per 1,000 women in that age group)	No. of live births to women of a particular age group in the year	Mid-year female population of same age-group for that year[a]
Death	Crude death rate (deaths per 1,000 population)	No. of deaths in the year	Mid-year population for that year[a]
	Infant mortality rate (deaths of infants aged <1 year per 1,000 live births)	No. of deaths of infants (<1 year) in the year	No. of live births in that year
	Under five mortality rate (deaths of children below five years of age per 1,000 live births)	No. of deaths in children aged <5 years in the year	No. of live births in that year
	Neonatal mortality rate (neonatal deaths per 1,000 live births)	No. of neonatal deaths (deaths of live born infants occurring within the first 28 days of life) in the year	No. of live births in that year
	Post-neonatal mortality rate (post-neonatal deaths per 1,000 live births)	No. of post-neonatal deaths (deaths of live born infants aged between 28 and 365 days old) in the year	No. of live births in that year
	Maternal mortality ratio (maternal deaths per 100,000 live births)	No. of maternal deaths (deaths of women during pregnancy or within 42 days of delivery) in the year	No. of live births in that year
	Age-specific mortality rate (total deaths in a specified age group per 100,000 population in the same age group)	No. of deaths in a specified age group in the year	Mid-year population of same age-group for that year[a]
	Cause-specific mortality rate (deaths by cause per 100,000 population)	No. of deaths from a specific cause in the year	Mid-year population for that year[a]

(Adapted from UN Principles and Recommendations. Revision 3, 2014) [3]
[a]Requires data from other source in the absence of a population register

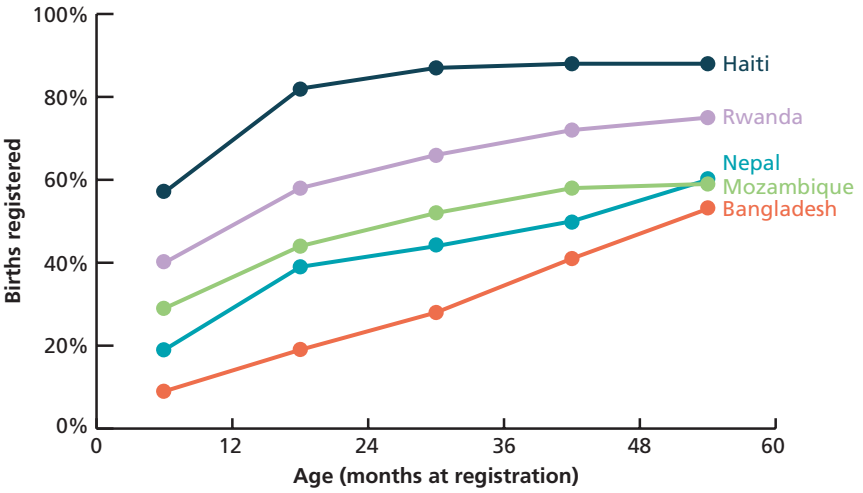

Fig. 7.2 Percentage of children under five years of age whose births are registered, by age at registration. (Source: UNICEF Birth Registration Database [14])

tion is when, for example, as in South Africa and the US, registration is a legal requirement for disposal of the body. Where religious rites require rapid burial and registration systems are slow and cumbersome, the burial permit may be issued by a local community authority or religious institution. Locally issued permits are generally non-standardized and informal so that they have little utility from a statistical perspective. It is not uncommon, particularly in remote and rural areas, for families to bury deceased relatives in their own burial plots, without any formal permission. This is less common in urban areas, where public health regulations requiring safe disposal of bodies are in place and enforced.

Apart from the burial permit, incentives to register deaths are limited, particularly for families with little in the way of inheritance or insurance benefits for survivors. There can be important legal benefits that accrue to surviving family members when deaths are officially registered, such as the right to remarry (in settings where monogamous marriage is the law) and claims to socio-economic benefits and/or nationality based on family relationships.

From the state's perspective, official registration of deaths is important for legal, administrative and statistical reasons. National social security and pension schemes need to purge recipients from the system in a timely way to avoid significant losses to the exchequer. To avoid fraud, national identification schemes must be able to remove deceased people from the active population list. Official registration of deaths also enables updating of electoral registers and avoids expensive and inefficient creation of new electoral rolls each time an election looms.

6.3 Barriers to Birth and Death Registration

Many births and deaths are not registered because CRVS systems are inherently passive, relying on families and individuals to come to the registration office. But families face multiple barriers; for example, they may be unaware of the legal requirement to register births and deaths and the benefits of doing so. They may face financial and opportunity costs and administrative hurdles such as the requirement to bring witnesses, or long queues and delays at registration offices. Marginalized or particular ethnic or religious groups may be inhibited from registering vital events because of perceived discrimination.

7 Ascertainment of Cause of Death

A major advantage of a functioning CRVS system compared to other sources of mortality data is that it generates up-to-date data essential for health policy on mortality and causes of death. For example, evidence from death registration systems in Australia, France, Japan, Sweden and the United States of America of rising lung cancer mortality since the 1960s [26] stimulated research on the causes of the increase and led to the introduction of tobacco control measures to cut smoking rates and subsequent declines in lung cancer mortality [27]. Similarly, evidence of the increasing death toll of road traffic accidents stimulated the introduction of measures to reduce drink-driving and excessive speed [28].

When it functions effectively, a CRVS system captures medically determined cause for each death. For this to happen, the national law must explicitly state that a physician or other person with the requisite medical training should certify the cause of death; all deaths must have a medical certificate of underlying cause of death (MCCD) [29]. The cause of death must be classified and statistically coded in line with the International Classification of Diseases (ICD) [30]. The underlying cause of death—the condition that initiated the sequence of events that ended in death—should be shared with the agency that compiles cause-of-death data, usually the national statistics agency or ministry of health. Meeting these conditions is feasible in situations where most deaths occur in a medical setting or, if at home, under the care of a medical attendant. In reality, this is the exception rather than the rule in most parts of the world.

Even where physicians certify cause of death, they may lack the knowledge and training to do so correctly. As a result, many deaths are attributed to so-called *garbage* unusable codes, such as symptoms, signs and ill-defined conditions; injuries undetermined whether intentional or unintentional; ill-defined cancers; and ill-defined cardiovascular diseases that are of little utility to guide public health decision-making [31].

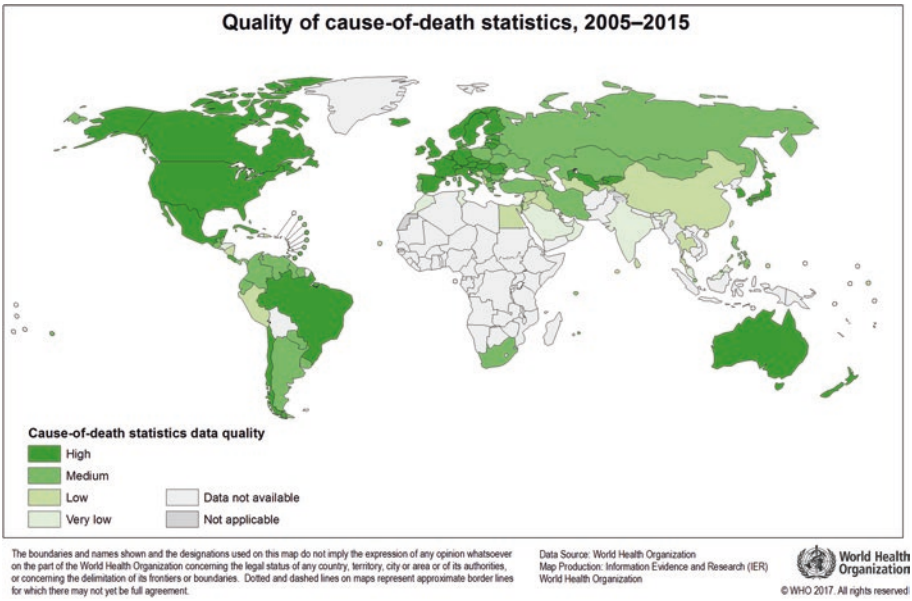

Fig. 7.3 Quality of cause-of-death statistics worldwide, 2005–15. (Source: Data extracted from World Health Organization (2017) World Health Statistics 2017, page 84 [16])

In 2017, WHO produced estimates of the quality of cause-of-death statistics (Fig. 7.3) [32] assessing a combination of registration completeness and quality of cause-of-death reporting. Forty-nine countries, representing 23 per cent of the world's population produced high-quality cause-of-death data, and most are in Europe and the Americas. Of the 47 countries in the WHO African region, only 4 (Cape Verde, Egypt, Mauritius and South Africa) provided acceptable quality cause-of-death data.

8 CRVS Performance Monitoring

The UN proposes that the quality of a CRVS system be assessed using: (1) level of completeness of registration; (2) correctness/accuracy of the information collected; (3) availability of the data collected for use; and (4) timeliness in registration of vital events. Most attempts to assess performance of CRVS systems have focused on registration completeness. Direct and indirect techniques are available to evaluate the completeness and accuracy of vital statistics data. In general, indirect methods indicate whether incompleteness or inaccuracies exist, while direct methods not only assess the coverage and accuracy of data but also point to likely sources of the problems [33, 34].

Tracking completeness of registration can help in timely identification of problems such as *leakage* of data that should be transferred between institu-

tions or levels of administration, performance of local registrars, or a drop off in reporting of events by the general public [35]. Knowledge of completeness of registration for different geographic areas covered by a CRVS system can provide evidence to target improvements. Ongoing monitoring can identify unusual seasonal patterns of mortality in specific age groups, for example, associated with climatic conditions [36, 37].

WHO publishes a summary quality indicator or *usability score* for mortality data calculated as completeness multiplied by the proportion of registered deaths that are assigned a meaningful cause of death [30].

Additional quality criteria, including accuracy, timeliness and dissemination, are also important. Researchers have developed a summary measure of CRVS performance, the *vital statistics performance index* (VSPI) [38]. The VSPI comprises six components: *completeness* of death reporting (estimated using a combination of indirect methods and statistical modelling); *quality* of cause-of-death reporting (assessed in terms of the proportion of all death ascribed to non-specific causes); *level of cause-specific* detail (number of separate categories of cause of death); internal *consistency* (biological plausibility of cause-of-death reports); *and quality* of age- and sex-reporting, and data *availability or timeliness*.

9 Strengthening CRVS Systems

Experiences around the world highlight common areas to address to improve weak and dysfunctional systems. The Regional Action Framework in Asia and the Pacific [39] and the Africa Programme for Accelerated Improvement in CRVS systems [40] offer similar recommendations on key actions needed, as summarized here.

Political commitment at the highest level is essential to bring together all stakeholders to improve CRVS and to ensure that CRVS systems are adequately resourced and are designed to be inclusive and responsive [41].

Public Engagement and Participation CRVS systems rely on the engagement of individuals, families, and communities who are called upon to play an important part in ensuring that reliable information on vital events is provided to the local civil registrar. People are more likely to do so when they have confidence in the integrity and security of the registration process and trust that the information will be used for the public good. CRVS systems need to work closely with health, education and other public services, as well as the media, social workers and civil society to facilitate registration and to demonstrate the value of CRVS for individuals and for society as a whole.

Coordination requires the full participation of the many entities involved in and benefiting from CRVS. A standing coordination committee can help ensure stakeholders understand their roles and responsibilities and work in harmonized and mutually supportive ways [41]. Coordination also assists in using the same definitions and terminologies, and in ensuring databases are interoperable.

The legal framework should be up-to-date, *fit-for-purpose* and in conformity with international best practice standards, as defined by the UN. A CRVS legal review toolkit offers a comprehensive evaluation of civil registration as it relates to vital statistics, focusing on registration of births, deaths and foetal deaths, as well as certifying causes of death. The review also evaluates foundational issues crucial to a functioning CRVS system, including laws related to the enabling environment, the structure of the registrar's office, technology and security issues, and production of vital statistics [42].

Infrastructure and resources should be sufficient, appropriately staffed and well distributed across the country, with registration points within a reasonable distance for each person in the population. Innovative approaches such as digital registration can facilitate civil registration in remote areas and hard-to-reach and marginalized populations.

Innovations in operational procedures and practices should be introduced to streamline essential CRVS functions. Digital data collection, maintenance and sharing of registration information greatly facilitate both registration processes for individuals and also the sharing of registration information across entitled agencies responsible for distribution of entitlements such as child benefits, pensions, social security, and electoral processes. At the same time, it is essential to ensure that registration archives are protected from damage due to natural disasters, civil strife or cyber attack. New technologies must be introduced within a sound legal and institutional framework, with appropriate operational procedures and practices consistently applied [42].

Production, sharing and dissemination of vital statistics are essential so that users have rapid access to essential data and key indicators. New data management technologies make it easier to overcome technical and logistical challenges in data compilation, quality assurance, analysis and dissemination. Visualization techniques are useful in generating summary reports on key issues and facilitate increased use of CRVS for policy and planning.

It is sometimes assumed that CRVS systems are relevant only in settings that are politically stable and where the population is largely based within the country. However, large populations live outside their countries or regions of origin, either due to voluntary migration or as a result of natural catastrophes, conflict or civil strife (see Chap. 13) [43]. The benefits of civil registration need to be available to everyone; both sending and receiving countries need to know the magnitude of issues to plan for when many of these displaced groups seek to return. In principle, refugees and displaced persons should be included in the

mainstream, foundational registration system in the country in which they are located. In addition, the UN High Commission on Refugees plays a key role in the *functional* registration of refugees and internally displaced persons and also in the registration of their life events, births, deaths and marriages.

10 Conclusion

The SDGs present new challenges for country data systems, in terms of scope and depth, with indicators of cause-specific mortality and key disaggregation to identify the most vulnerable populations. Within the SDGs, CRVS is both a target in its own right (Goal 16) and necessary to monitor key outcome indicators. CRVS is also a key strategy to effect progress in non-health related SDGs, such as social inclusion and access to education [44]. Out of the 17 SDGs, 12 require CRVS data to measure their indicators [45]. The SDGs and calls for a *data revolution* [46] have strengthened the case for civil registration systems as robust, sustainable and reliable sources of population data, and the means to establish fundamental human and civil rights. Major efforts and commitments are underway to strengthen CRVS systems particularly in Africa, Asia and the Pacific countries and regions [47–50]. At the same time, donors and development partners have intensified their support to countries and to the development of guidance and training materials on CRVS [51]. These initiatives could significantly enhance policymaking based on sound and comprehensive statistics of fertility and mortality.

Key Messages

- Health policymaking requires timely, continuous and disaggregated statistics on fertility and mortality.
- Well-functioning CRVS systems efficiently generate demographic and health indicators.
- A CRVS system provides documentary evidence of identity, civil status and family relationships.
- Many countries are improving their CRVS systems often as part of broader efforts to modernize administrative systems.

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8

National Household Surveys: Collecting Data Where People Live

Sarah B. Macfarlane

1 Introduction

'75th round of national sample survey kickstarts nationwide', read the Economic Times of India headline for July 3, 2017 [1]. The National Sample Survey (NSS) has measured social inequalities in India since, then Prime Minister, Pandit Jawaharlal Nehru called for its establishment in 1950, three years after India's Declaration of Independence. Professor P.C. Mahalanobis, a close advisor to Nehru, masterminded this ambitious project. At a time when many statisticians preferred to rely on censuses over sample surveys, Mahalanobis determined to implement a regular large-scale multi-topic household survey to measure and observe trends in social indicators for India's large and diverse population. He advanced statistical procedures that suited India's circumstances and, in so doing, Mahalanobis promoted the international development of sample surveys [2]. Believing that the aim of statistics is 'to improve the efficiency of action programmes for the welfare of humanity,' he campaigned for the creation, in 1947, of the United Nations Sub-commission on Statistical Sampling. In 1971, towards the end of his life, he observed: 'The use of sample surveys is spreading rapidly in underdeveloped countries,' and then he returned to his recurring concern, 'but the danger still remains of much waste of resources in work which is highly imitative of advanced countries.' [3].

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Mahalanobis highlighted a dilemma that remains valid to this day. On the one hand, large-scale surveys provide invaluable information for governments to plan and deliver services for their people but, on the other hand, surveys are costly and cumbersome to manage. Advances in the theory and practice of sampling address some of Mahalanobis's statistical concerns, but governments spend limited resources conducting multiple overlapping socio-demographic and health surveys. Innovations in electronic data management probably exceed what Mahalanobis could have imagined but they require continual investment in technical expertise and equipment.

In this chapter, I explore the evolution of household surveys in the early twentieth century to complement a longstanding tradition of enumerating populations through censuses. I differentiate between national health interview surveys which describe people's health based on their responses to questions, and national health examination surveys which also measure people's health using objective bio-clinical measures, and I trace the development of these surveys around the world. I describe the basic sampling principles that govern cross-sectional household surveys and how the organizers' choice of sampling method depends on practicalities and cost as well as the desired precision of population estimates. I refer readers to detailed guidance on undertaking a household survey and focus instead on challenges such as ethics, non-response, survey coordination, data linkage and dissemination. Although I focus on national health household surveys, most of the issues I cover are relevant to surveys conducted on any scale.

2 Sample Surveys: a Short History

The terms *sample* and *survey* are ubiquitous today. We sample in every aspect of our lives from tasting food and dipping into books to forming judgements about the goods and services we select to receive; that is, we examine a small part, or quantity, to gain knowledge about the larger whole. Almost everything we want to know about society, we glean from the findings of sample surveys—in any field. The results we can trust derive from surveys in which investigators follow strict sampling procedures. But it was not until the early twentieth century that statisticians began to accept that sample surveys could describe populations. Bethlehem provides a fascinating account of the struggle to introduce sample surveys in a statistical society that rated complete enumeration above all else. I draw on his account, among others [4, 5].

Chapters 6 and 7 of this handbook respectively trace census-taking and registration of births and deaths back to early civilization. Statisticians and demographers developed formal procedures for undertaking censuses around the middle of the nineteenth century. It became standard practice to describe populations and their demographic transitions by counting an entire population every decade, and to attempt to maintain ongoing registers of vital life events.

The early statistical pioneers also used sampling in their *political arithmetic*, that is, in their statistical and demographic *calculations* for national policy-making [6]. In 1662, John Graunt became the first person to use *partial information* when he published his estimates for the population of London using a sample of parishes which kept registers [7]. It was only in 1895 that Anders Kiaer, founding director of Statistics Norway, presented the *representative method* he had used for some years to conduct national sample surveys in Norway. He aimed to ensure that the proportionate distribution of units in the sample survey reflected the socio-demographic variation in the population as shown by the most recent census—otherwise known as *purposive sampling*. Kiaer's statistical peers were viciously critical. The Swiss statistician Milliet, for example, refused to recognize the representative method as being 'la statistique serieuse' [8]. The statistical community only accepted Kiaer's method 29 years later, five years after his death.

Kiaer's approach lacked a theory whereby he could estimate population characteristics from his sample observations, that is, a theory of *statistical inference*. In 1906, Bowley proposed using a simple random sample—for which each population unit has an equal chance of being selected—to find the average of the characteristic. He pointed out that since the theoretical distribution (*sampling distribution*) of such averages from multiple large random samples follows the predictable bell shape of a *Normal* distribution, its properties could be estimated [9]. In 1934, Neyman extended this theory definitively. He introduced estimation procedures based on what he called *confidence intervals*, and argued that *probability sampling*—using random selection of units—was preferable to any other form of sampling (which became known as *non-probability* sampling) [10]. He explained that, with probability sampling, we can calculate *confidence intervals* 'in which we may assume are contained the values of the estimated characters of the population' with a known probability of error. His notion was that by choosing the sampling method and using probability theory to describe the sampling distribution, investigators have complete control over the inferences they can draw. This approach didn't go unchallenged, for example, Bowley suggested that

confidence intervals were a 'confidence trick,' perhaps experiencing some of the difficulty that others still have in interpreting these intervals [5].

Neyman and others, including Mahalanobis, developed sampling theory to solve real-world problems of large-scale national surveys, in which it is not practical or even possible to enumerate every individual in a population to select a sample. They proposed the probability sampling methods that household surveys employ today, that is, *multi-stage*, *stratified* and *cluster* sampling—see Sect. 5.1. Their concerns, as Mahalanobis put it, were to 'evolve a sampling technique which will *give, for any given total expenditure,* the highest possible accuracy in the final estimate' [3].

3 Development of National Sample Surveys for Demography and Health

Surveys now rank 'among the most important innovations in social science research of the last century' [11]. In this section, I review the development of national household surveys to describe population demography and health. Researchers also made increasing use of large- and small-scale surveys to explore specific health topics and in other fields, particularly in economics and agriculture.

Early national surveys focused on socio-demographic data, aiming to complement census information and provide estimates of changing population demography. The US 1935/36 National Health Survey—using a sampling approach similar to Kiaer's representative method—was probably the world's first government-funded national morbidity survey, focussing on self-reported chronic disease and disability [12]. The NSS in India included morbidity in its seventh round in 1953–54, but only undertook a full-scale morbidity survey in its 28th round in 1973–74. The NSS subsequently included morbidity in its decennial surveys on social consumption, with a morbidity and healthcare survey in 2004 [13]. Modules cover morbidity, utilization of preventive and curative care, and household expenditures on health. India undertook its first dedicated National Family Health Survey from 1992 to 1993, focussing on maternal, child and reproductive health, which it repeats every six to seven years [14].

From the mid-1950s, governments have initiated two types of general national health household survey: (1) a national health interview survey (NHIS), during which trained interviewers ask individuals in sampled households a range of socio-demographic and health questions including perceived health, risk-taking behaviour and utilization of the health system; and (2) a

national health examination survey (NHES), during which interviewers also examine respondents (or a sample of them), for example, by taking measurements such as blood pressure and anthropometry, or blood specimens to measure blood glucose.

The following illustrates how these surveys have spread around the world, but is not definitive (discovered through a curious but non-rigorous search of the Internet in English. References are available on request). Some countries began with an NHIS which became an NHES, and others (like the US) operate both an NHIS and an NHES in parallel. Some surveys occur continuously (i.e. sampling rolls over month by month, year by year), others occur annually or every few years, and some were one-off or have discontinued. Many started out as nutrition surveys and others as modules of general household surveys.

The Japanese National Health and Nutrition Survey began in 1948 to monitor the impact of food shortages after the Second World War and is the oldest running annual NHES in the world. The UK ran a Survey of Sickness from 1943 to 1952 and included a health module in its General Household Survey from 1971. The US undertook an NHIS in 1957, which it has operated continuously since, and began an NHES in 1959, which became a National Health and Nutrition Examination Survey (NHANES) in 1971–1974. NHANES has run continuously since 1999 and has set a standard for other NHESs.

In Europe, West Germany introduced an NHIS in 1957, followed by France in 1960, Finland in 1964, the Netherlands in 1974, and Switzerland in 1980. In the rest of the world, Chile, Colombia, and Taiwan conducted national health surveys as health manpower surveys in the mid-1960s. Indonesia undertook an NHIS in 1972, Australia in 1977, Canada in 1978, Pakistan in 1982, China in 1989, Singapore, New Zealand, and Russia in 1992, Taiwan in 1993, and Brazil in 1998. Since the 1990s, most OECD and some other countries have organized NHISs.

Romania was the first European country to run an NHES in 1959 followed by Finland in 1965, Germany in 1984, the Netherlands and Slovakia in 1987, England and Latvia in 1991, Denmark and Norway in 1994, Scotland in 1995, and the Czech Republic and Ireland in 1998. Egypt ran an NHES in 1981, Iran and Thailand in 1991, and South Korea in 1998. Since 2000, over 20 countries have set up NHESs or similar surveys in most regions of the world. From 2002, well over 100 countries have conducted surveys using the WHO STEPwise approach to non-communicable disease surveillance (see Sect. 4).

Although researchers have undertaken numerous small-scale health surveys from the mid-1950s onwards, many governments in LMICs did not have the resources or capacity to organize regular national health surveys. From 1972 for about a decade, the International Statistical Institute—with financial support from UNFPA, the US and UK—ran the World Fertility Survey (WFS). The WFS provided funding and a protocol for 42 *developing* countries and 20 *developed* countries to run comparable nationally representative, mostly household, surveys focussed on fertility, child mortality and family planning. The programme also built some national capacity to undertake surveys [15, 16].

The Demographic and Health Surveys (DHS) Program, supported by the US Agency for International Development (USAID), took over from the WFS in 1984. DHS still has a focus on demography, and maternal, infant, child and reproductive health, but has gradually added optional modules, such as nutrition, HIV/AIDS prevalence, women's empowerment, domestic violence and tobacco use. While it began as an interview survey, DHS has added anthropometric measurements and some biomarker data such as testing for anaemia, HIV infection, malaria, blood glucose, blood pressure, lead exposure and immunity from vaccine-preventable diseases. DHS had by 2017 supported over 300 nationally representative and internationally comparable surveys in 44 countries in sub-Saharan Africa, 12 in North Africa, West Asia and Europe, 15 in South and Southeast Asia, 2 in Oceania and 15 in Latin America and the Caribbean [17, 18].

In 1995, the United Nations Children's Fund (UNICEF) established the Multiple Indicator Cluster Survey (MICS) to measure indicators to monitor the 1990 World Summit for Children. These surveys collect information related to women and children covering, for example, health, education, child protection and water and sanitation, and measure some of the indicators that DHS measures. Standard MICSs record anthropometric data but not biomarkers. By 2015, MICS had supported about 300 household surveys in 10 countries in East Asia and the Pacific, 41 in sub-Saharan Africa, 41 in Latin America, and 19 in Europe and Central Asia [19].

Since 1980, the World Bank has supported the Living Standards Measurement Study (LSMS). LSMS is a multi-purpose household survey which describes poverty and living standards with customized modules. Although it is not primarily a health survey, countries can choose to include a health module covering health-related behaviour and utilization of health services, health expenditures, insurance expenditures and access to health services [20]. By 2017, almost 40 countries had undertaken over 100 LMISs [21].

The above are national population health surveys but governments conduct other national and local health surveys focused on specific conditions, describing the prevalence, for example, of HIV/AIDs, tuberculosis, mental health, oral health, and dedicated nutrition surveys. WHO provides exhaustive guidance across all its offices and regions, coordinates multi-country household surveys such as the World Health Survey 2002–04 and conducts surveys of many specific conditions. WHO contributes to developing comparable indicators and survey instruments, and building capacity to organize national household surveys.

4 Why National Health Surveys?

Many high-income countries now run regular or continuous NHESs and well over 100 LMICs run a DHS, an MICS or both every four or five years. The European Union is establishing a common European NHES (EHES), with standardized protocols, and is building capacity for comparable NHES across European countries [22]. So why is the world running these costly and time-consuming surveys?

Surveys describe changing population health data which other sources cannot provide. Surveys can, for example, measure the extent of undiagnosed chronic diseases in a population, and their risk factors. This is especially important in situations where people do not or cannot access health facilities in which staff can diagnose chronic conditions such as diabetes, cancers and cardiovascular diseases.

One reason for moving towards NHESs is to expand the focus of household surveys to include adult health generally as well as maternal and child health. DHSs, for example, ask few questions of males, children aged 5–15 years, or of people over 49 years of age, nor ask for detailed information about chronic diseases [18]. The WHO established the STEPwise approach to surveillance (STEPS) in 2002 to support countries that do not already run NHESs to collect data about non-communicable diseases (NCDs) [23]. The steps cumulatively increase the content of household surveys from: (1) asking people to self-report behavioural risk factors; (2) taking physical measurements and blood pressure; and (3) taking specimens to measure fasting blood glucose, total cholesterol levels and urinary sodium. The programme emphasizes that these steps need not happen within the same survey but the protocols build capacity to include NCDs in household surveys, that is, to become full-scale NHESs and publish data for cross-country comparisons. Riley et. al. report that by 2016, 122 countries, in all regions of the world, had collected

data for STEPS or STEPS-aligned surveys, 112 of which had completed all three steps [23]. These surveys provide data to measure the 25 indicators of WHO's Global Monitoring Framework for non-communicable diseases (NCDs) [24]. The WHO records that, in 2017, 37 countries had a STEPS survey or a comprehensive health examination survey every five years [25].

Household surveys provided data for 21 of the Millennium Development Goal indicators and will provide data for most of the health-related Sustainable Development Goal (SDG) indicators, including Universal Health Coverage (UHC). Health facility data in many countries are inadequate to measure service coverage for all 16 UHC tracer indicators grouped as reproductive, maternal, neonatal and child health, infectious and non-communicable diseases. The Eastern Mediterranean Regional Office of WHO, for example, is supporting countries to undertake a new wave of NHESs to include measurement of UHC. Tunisia's 2016 NHES included service coverage and household spending on health [26]. EMRO sees this as an important way to strengthen national health information systems.

Household surveys do not stand alone; they complement data from other components of national health information systems. Censuses count entire populations (and ask some questions) every ten years. Civil registration systems document vital events continuously as they occur. Health management information systems record people's interactions with the health system. But interviewers conducting household surveys actually reach out and spend time with a sample of people. The catch is that the study organizers must use this precious time wisely, by asking the minimum of questions and conducting examinations whose aggregated findings will clearly inform efforts to improve people's health. For this, researchers must run the study efficiently and ethically.

5 Drawing Conclusions Efficiently and Ethically

The specific objectives of a cross-sectional national household survey are usually very simple. Primary objectives are to estimate multiple indicators either: as proportions, for example, the proportion of the sample who were ex-smokers, or who attended a health facility in the last month; or as averages, for example, of body mass index, haemoglobin or blood sugar. A secondary objective may be to disaggregate these indicators into pre-selected population sub-groups, for example, by province, sex or age group. Investigators carefully select the types of indicators to meet the overall aims of their surveys. They craft questions and measurements based on definitions and metadata from

previous surveys or comparable external surveys, adapting for culture. EHES, for example, is attempting to standardize survey tools across European countries.

Investigators present results in multiple cross-tabulations providing disaggregated estimates of the indicators with measures of variation, or confidence intervals. Although researchers may subsequently seek to demonstrate causality, this is not the primary goal of a national household survey. Because the sample size is usually very large and the survey carefully designed, researchers are free to undertake complex analyses of published survey data.

I do not describe the logistics of undertaking a household survey, but refer the reader to: Groves et al.'s *Survey Methodology* [27]; the United Nations *Guidelines for Undertaking Household Surveys in Developing and Transition Countries* [28]; manuals and guidelines on the DHS website [29]; EHES guidelines [22]; and the South Africa 2012 NHES (SANHANES I) manual and guidelines [30]. Instead, I focus on the principles of sampling to estimate indicators with confidence intervals.

5.1 Drawing Inferences from Sample to Population

The basic principles of probability sampling are: that investigators select units randomly from a defined population; that the probability of a unit being selected is known (not necessarily equal); and that investigators can, therefore, estimate population characteristics with a confidence interval. The width of the confidence interval, or the *precision* of the estimate, depends on the sample size.

Organizers of household surveys choose sample size by balancing precision against the cost of alternative sampling methods. They can specify precision for any population characteristic and then choose the sample size using a standard sample size calculator (which requires some basic preliminary knowledge of the characteristic, such as its expected value and likely variation). Since NHIS/NHESs include many indicators, investigators use an overall sample size that provides adequate precision for all indicators. The more subgroups by which investigators plan to disaggregate indicators, the larger the sample size they will require. A survey needs a larger sample size if it seeks to capture rare events such as maternal deaths. The sampling method affects both precision and cost, for example, for the same sample size, estimates based on random selection of clusters of households are less precise but cheaper than estimates based on random selection of individual households.

Most national household surveys use stratified multi-stage cluster sampling. Organizers select clusters of units at each of several stages, for example, by first selecting administrative units from a list, or sampling frame, of all such units and then selecting households from a list, or sampling frame, of all households in each selected administrative unit. Standard DHSs use two-stage cluster sampling with some stratification—adapted to country circumstances. Investigators start with a recent list of census enumeration areas (EAs) which they have grouped within *strata* such as urban/rural or province. During the first stage, they randomly select EAs within a stratum with their probability of being selected determined by their population size (imagine each EA takes a lottery ticket for each household, so larger EAs have higher chance of holding a winning ticket). Next, enumerators visit the selected EAs to prepare lists of households and map their locations. They then select a fixed number of households (usually 20–30) from each selected EA; these are clusters of secondary sampling units. When enumerators visit a household, they include in their sample all members who meet their selection criteria, for example, all women aged 15–49 years. Sometimes investigators deliberately over-represent certain population groups (e.g. minority ethnic groups) to ensure they are represented in sufficient numbers to make estimates about their characteristics.

Two preconditions for sampling are that the organizers can define what they mean by a household and that they have access to a comprehensive sampling frame from which to select them. For the first stage, the DHS recommends EAs but, if lists of EAs are not up-to-date or incomplete, DHS suggests using electoral zones, or lists of other administrative units such as villages and city zones. At the second stage, if there are no adequate lists, survey enumerators may demarcate and list households themselves but this increases the cost of the survey. Another possibility, for each stage, that DHS suggests is to use a gridded high-resolution satellite map with estimated numbers of structures for each grid [31]. Thomson et al. describe using GridSample, an algorithm in R, to replicate the 2010 Rwanda DHS two-stage stratified sampling using gridded population data as a sampling frame [32]. Household surveys may unintentionally exclude migrant, nomadic and undocumented populations, and usually intentionally omit people living in residential homes or prisons. South Africa's 2012 SANHANES defined a household as consisting of 'a person, or a group of persons, who occupied a common dwelling (or part of it) for at least four days a week and who provided for themselves jointly with food and other essentials for living.' They classified a household member as a person who slept in the household for at least four nights a week [30].

The sample size comprises the number of clusters (the number of EAs) and the number of households (and therefore individuals) in a cluster. Precision

varies according to the degree of similarity of households within a cluster (their *intra-cluster correlation*). If there were no intra-cluster correlation, estimates would be as precise as if the households were drawn at random from the population in one stage, that is, without clustering. The complexity of sampling logistics determines cost, for example, the more EAs (clusters) selected, the more fieldwork required. According to the DHS Program website, the number of households covered by a DHS ranges from 5,000 to 30,000 households. With an average cluster size of say 25, this means the number of clusters ranges from 200 to 1,200 clusters per country.

The sampling method affects population estimates in two ways. Firstly, if the sampling scheme has over-represented segments of the population, then the estimated values for those segments must be weighted. For example, in some situations, the sampled proportions of women aged 15–49 years in each province may not reflect the actual proportion of women across provinces. To make estimates about the characteristics of the total population, investigators must weight the observed numbers of women in each province by the actual number of women in each province. DHS provides and explains these weights in their reports. Secondly, the precision of the estimate is reflected by the *design effect*. The design effect is a ratio of the precision of the estimate for the design against the precision that an investigator would have obtained using simple random sampling. A design effect of 1 implies the sampling was as efficient as simple random sampling; the higher the design effect, the less efficient the design. Investigators guestimate a design effect in order to make the sample size calculation, that is, they increase the sample size to reach the same precision as for simple random sampling. Investigators can calculate the design effect for different population characteristics retrospectively from the data.

5.2 Total Survey Quality

As the early statistical thinkers emphasized, the ability of a survey to represent its population depends first and foremost on how investigators select the sample but after that, on how they implement the design and collect and analyse measurements. That is, the investigator needs to consider and control for errors arising through the entire survey process from design to dissemination. The concept of *total survey error* (TSE) includes errors arising from, for example, choice of sampling frames, interviewees' responses and interviewer's measurements, and data management (see Chap. 22) [33]. In principle, investigators need to balance survey costs not just against precision but also to minimize TSE.

Beimer sets TSE in the broader context of a *total survey quality framework* within which survey organizations usually include: (1) accuracy (TSE); (2) credibility (as judged by the survey community); (3) comparability (demographic and across geographies and time); (4) usability/interpretability (well documented with metadata); (5) relevance (data satisfy users' needs); (6) accessibility (ease of users' access to the data); (7) timeliness/punctuality (adheres to schedules); (8) completeness (data rich enough for analysis without too much burden on respondents); and (9) coherence (possible to combine estimates with different sources [33]. Some surveys produce quality reports or quality profiles covering these dimensions. At the very least, the total survey quality framework provides dimensions for investigators to consider when designing and budgeting a study, that is, to optimize survey quality (see Chap. 22).

5.3 Ethical Considerations

'It is really remarkable that you can go knock on a door and someone will actually allow you to "use" him for, say, half a day as a subject in a survey, be it a government survey or other research-based survey. That is a trust we must honor.' [34]. Wagener made this remark in 1995 when she presented a paper on the ethical issues associated with undertaking the examination component of NHANES. She examined the particular concerns around the taking of biomarkers but her remark holds true for all survey data collection. Surveys are intrusive and call for respect in every aspect of the undertaking (see Chap. 23 for a discussion of ethics in managing health information systems).

First and foremost, all survey organizers must obtain approval from the national institutional review board (IRB), and if, as in the case of DHS, a survey is also designed and carried out with an international partner, then the survey must comply with their IRB and governmental regulations. IRB approval requires informed consent and voluntary participation with assurance of total privacy and confidentiality. It is good practice for investigators to publish procedures for dealing with ethical issues; for example, the DHS describes on its webpage its procedures for maintaining confidentiality and how to handle biomarker referral treatment and counselling [35]. Specific to taking biomarkers are: the safety of the health workers handling the samples; decisions about when, how and who to inform about specimen results; banking and using tissue samples; and providing information about follow-up and possible retesting [34]. Pappas and Hyder explore ethical considerations for using biological and physiological markers in NHES in 'less developed coun-

tries' and conclude that 'while ethical principles may be global, implementation of those principles must be carefully considered within local contexts in which the health examination survey takes place.' [36].

6 Challenges and Opportunities

Although expensive, continuous or regular NHESs provide an important vehicle for harmonizing national health surveys. As the STEPS approach demonstrates, survey rounds can focus on different topics. The DHS has provided a coherent NHES-like service in many countries with standard and interim surveys, optional modules and dedicated indicator surveys—but without addressing non-communicable diseases. Some challenges and opportunities for conducting NHIS/NHESs include:

Coordination and Capacity Ministries of health run many surveys related to specific health conditions, but governments usually integrate NHIS/NHESs within a national programme of socio-economic household surveys, coordinated by a national statistical office (NSO). The NSO agrees and supervises a long-term plan for household surveys across sectors and attempts to harmonize their content, frequency and timing and therefore, the cost of surveys. Centralising survey operations also builds the specialized capacity to design and analyse surveys. Coordination ensures use of the same national sampling framework, shared technologies for data capture and management, and skilled use of sophisticated statistical software.

Data Quality Most NHIS/NHES are well designed and evaluated over years but controlling data quality remains priority after sample design. DHS, like other survey protocols, provide detailed procedures for interviewing, measuring and taking samples and for training enumerators [37]. An issue that overrides others is the increasing length of the questionnaire which can lead to respondent fatigue. For Ghana, Kenya, Uganda and Zimbabwe, Choi et al. found that the average length of the DHS interview had increased from the first to the sixth phase of the DHS (1988 to about 2011) corresponding to increasing questionnaire length. The researchers showed 'a clear positive association between interview length and a host of data inconsistencies' [38]. While there is scope for error in measurements, the questions most at risk to error—independent of interview length—are those that involve recall or relate to sensitive issues such as sexual practices. Researchers should continually validate answers to qualitative questions in household interviews.

Non-response Just as LMICs are expanding their use of household surveys, governments that have operated national surveys for decades are experiencing a *crisis* in participant response [39]. In the US, for example, there have been striking declines in response rates for national household surveys of all kinds, including NHIS and NHANES. From 1999–00 to 2012–14 rounds, the conditional response rate (the proportion of individuals who agree to participate from the participating households) to the NHANES interview fell from 81.9 to 71.0 per cent and to the examination from 76.3 to 68.5 per cent [39]. Meyer et al. point out that there is also a decline in the proportion of questions answered and in the accuracy of the answers [11]. Ironically, in 2013, Schoeni et al. observed that although response rates for cross-sectional surveys have fallen, response rates for national longitudinal surveys (general but including health)—in the US, Britain, Australia and Germany—representing 'the most widely used longitudinal surveys in the world' have remained constant [40]. In 1999, Hupkens et al. reviewed 43 NHISs conducted in 14 European countries since 1994, and found response rates varied from 95 to 52 per cent [41]. Response rates for DHS are 90 per cent or more [18]. For South Africa's SANHANES I: 77 per cent of sampled valid households participated, 93 per cent of individuals in these households answered the questionnaire, 44 per cent agreed to undergo the physical examination, and 29 per cent gave specimens [30].

Technology Advances in technology continue to revolutionize every stage of a household survey. Investigators take as given the availability of comprehensive software and computers with sufficient processing power to manage large quantities of data. Census sampling frames are usually available with geopositioning of households and, if not, investigators can use grid sampling as described in Sect. 5.1. Computer-assisted personal interviewing with tablets allows real-time data capture and validation. Investigators can produce survey results quickly and visualize them using data dashboards. Once they have tidied and described the data with metadata, investigators can publish them on the Internet for others to use. Assessment of data quality and choice of appropriate analyses, however, depend on technical human skills.

Data Linkage Sakshaug et al. point out that while declining response to household surveys, poor coverage and increasing costs threaten data quality, there is growing demand for data [42]. A solution to enhance the value of survey data, and to reduce survey content and cost, is to link an individual's survey records with their administrative records. Linkage depends on the existence of consistent administrative records of good quality, unique individual

identifiers, technical capacity to establish the linkages and sufficient procedures to protect personal data. The DAnish National COhort Study (DANCOS) combines individual data from the Danish NHIS with all Danish registers on health and welfare for the entire adult population [43]. Linking data is possible because Danish law allows record linkage and provides data protection. In most other countries, as Sakshaug et al. point out, obtaining consent to link data is challenging and consent rates vary considerably in different contexts [42]. Danish law also allows linkage of records for non-responders making it possible to research reasons for non-response [43].

Disaggregation and Sub-national Estimation The SDGs require countries to demonstrate that health services reach all segments of the population and improve their health status. Investigators must design surveys so that they can disaggregate indicators by population sub-groups and provide reports sub-nationally. As I pointed out in Sect. 5.1, this requires a larger sample size but not only that, two-stage cluster sampling does not permit estimation at the cluster level. The cluster design is intended to produce estimates by strata (e.g. province) but intra-cluster correlation can bias estimates for individual EAs. Researchers can obtain small area estimates by modelling information from censuses with relationships determined from survey data. Researchers have used this approach, for example, to develop small area maps of nutrition in Tanzania [44]. But a district, for example, cannot obtain reliable planning information from a national household survey. Langston et al. make the case for small population-based health surveys to inform district and sub-district management based on their experience in Rwanda [45].

Publishing and Using Data It is becoming standard practice for governments to make anonymised data available for others to use (see Chap. 23 on open access data). DANCOS, for example, makes NHIS data, along with registry data, available for researchers to explore, and the US National Center for Health Statistics publishes all the major national health surveys it undertakes [46]. With permission from countries, DHS publishes anonymised data from its surveys over time. The Institute of Health Metrics and Evaluation's Global Health Data Exchange provides links to datasets and tabulations from health surveys conducted worldwide [47]. But an ethical responsibility of the survey organizers is to analyse the data thoroughly and promptly and make indicators available to policymakers and other decision-makers. To make maximum use of the data, they may synthesize indicators from several sources and develop estimates for time periods not covered by the survey (see Chap. 21).

7 Conclusion

Mahalanobis would be interested to learn that in 2015, the United Nations Statistical Commission set up the Intersecretariat Working Group on Household Surveys, almost 70 years since the United Nations established its Sub-commission on Statistical Sampling. The Working Group's mandate is 'to foster improvement in the scope and quality of social statistics as delivered through national, regional and international household survey programmes' [48]. The Working Group will address major challenges arising from the escalating demand for survey data across sectors, that is, to harmonize surveys within countries and increase comparability of surveys undertaken in different countries to ensure their quality and cost-effectiveness.

The SDGs require longer, larger and more frequent surveys across sectors. It is important to ask whether laborious household surveys are still the right instrument to collect data - especially as response rates decrease. After all *big data* are out there. Future generations may look back and ask why we hung on to *making* survey data when there are plenty of big data to *find*—just as statisticians were reluctant to embrace surveys a hundred years ago. Japec et al. suggest that big data bring a 'paradigm shift for survey research' and, while remaining cautious, suggest development of a *big data total error framework* [49] (see Chap. 22). Household surveys are part of the backbone of a health information system as well as a national statistical system. Surveys cannot be discarded easily in favour of data from sources that are not readily validated. The future must lie in linking data intelligently from all sources, whether made or found, while enhancing data protection laws.

Key Messages

- Health interview surveys describe people's behaviours and opinions, health status and health service coverage.
- Health examination surveys provide additional information about undiagnosed chronic health conditions in a population.
- Sample design must balance precision of population estimates with the costs of obtaining them.
- Non-response is a growing problem. One solution is to link survey data with administrative records.
- To gain trust, investigators must use people's time ethically and wisely, and disseminate findings widely.

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9

Health Management Information Systems: Backbone of the Health System

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1 Introduction

In November 2017, the King's Fund, an independent charity working to improve health care in England, published its quarterly monitoring report that tracks, analyses and comments on how the country's health-care system

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is performing [1]. Surveying publicly available data on selected National Health Service (NHS) performance measures, the report found that in September 2017, 89.7 per cent of accident and emergency patients had been seen within four hours—missing the standard of 95 per cent—while there had been a 3.4 per cent increase in emergency admissions compared to the previous year. At the end of August 2017, 4.1 million patients were on the waiting list for elective treatment—the highest level in ten years; and in stark contrast, the NHS employed 1,300 fewer nurses and health visitors (full-term equivalents) than it had a year earlier. While not necessarily good news for the NHS, the figures demonstrate the power of collecting data routinely from health facilities and administrative services to monitor health system performance.

In this chapter, we describe the health management information system (HMIS) and how it manages routine data to inform a health service such as the NHS. We describe the users and uses of HMIS outputs and explain the limitations of HMIS data and how these can be addressed. Finally, we outline emerging possibilities to transform an HMIS, including new technologies that will strengthen its role in monitoring health system performance.

2 What Is an HMIS?

MEASURE Evaluation defines an HMIS as 'a data collection system designed to support planning, management and decision making in health facilities and organizations' [2]. The term eHMIS describes HMIS in settings with a high degree of automated data collection and analysis; in this chapter, we use HMIS to include eHMIS. An HMIS is separate from but complemented by other record systems such as a logistic management information system (LMIS) and a human resources for health information system (HRHIS) (see Chap. 12). An HMIS is a major component of the broader health information system (HIS) that brings together data from multiple sources—health and other sectors—such as household surveys, censuses, civil registration systems, disease and risk surveillance, administrative data sources, health facilities and community-based sources (see Chap. 1).

An HMIS derives much of its information from patient-provider interactions. Hospitals, health centres and community outreach services provide health care across preventive, promotive, medical and surgical, rehabilitation and palliative care interventions. These facilities collect data—which are integral to the services they provide—to ensure good management of patients.

When aggregated, these data provide information for epidemiological surveillance and for monitoring health services performance in terms of access, coverage, quality and equity at all levels of the health system. The data generated show the range and volume of services delivered to the population, including prevention, such as: immunization; antenatal, delivery and postnatal care; treatment of acute conditions such as malaria, diarrhoea and upper respiratory tract infections; chronic conditions such as HIV, tuberculosis, high blood pressure; and management of surgery and trauma. In addition to generating information on interventions—admissions, treatments administered and health outcomes—an HMIS also produces data on the availability of services, infrastructure, equipment and supplies needed to deliver such interventions.

The HMIS collects data from beyond government-run facilities including from non-profit, for-profit, faith-based facilities and from service delivery sites such as prisons, schools, workplaces and communities. While health managers first record HMIS data at a facility, they aggregate and report the data to higher administrative levels, for example, district, regional and national levels (see Chap. 1). Ultimately an HMIS collects, stores, analyses and evaluates health-related data from health facility to national levels, and provides analytical reports and visualizations that facilitate decision-making at all levels.

3 Main Sources of HMIS Data

HMISs are complex, reflecting the multi-faceted and heterogeneous nature of health-care provision and management. They draw on individual patient records, family record cards, admissions and discharge registers, ward registers and tally sheets, community-level records, infrastructure and resource records, records of health interventions delivered in communities, and periodic assessments of health facility infrastructure and resources. We classify these record systems as: (1) individual record systems including electronic medical records (EMRs); (2) facility-based registry systems; (3) community-based record systems; and (4) health facility assessments [3, 4].

Individual Patient Record Systems The majority of data that an HMIS collects at health facilities derives from individual records of patient-provider interactions that include, for example: patient identification; clinical diagnoses, results of laboratory and diagnostic tests; prescriptions; preventive, promo-

tive, curative and rehabilitative interventions delivered; and payments made. Only a subset of the data is reported to the next level of the health system and compiled to produce summary indicators. Most low-and middle-income countries (LMICs) continue to use paper-based systems for individual records, but hospitals increasingly use EMRs. EMR implementation requires advanced technology and networking skills, sophisticated management processes and maintenance that are often not available at remote facilities in low-resourced settings.

Facility-Based Registry Systems Facility-based registers include admission and discharge registers, ward registers and registers that list and follow particular individuals requiring ongoing management over a period for time, such as antenatal or immunization care registers, or registers of chronic diseases such as cancer. Each register maintains the minimum information necessary to follow up the patients. Regular review of registers enables the health team to identify patients who must be actively pursued to assure compliance with treatment interventions, such as completion of immunization, full treatment of tuberculosis, compliance with anti-retroviral regimens, or regular monitoring and control of blood pressure.

Patient registries are useful for monitoring the quality of health services and for capturing treatment interventions. In addition to data that identify individuals, these registries include diagnosis on admission and discharge, results of laboratory tests and treatments. If a patient died in hospital, the registry also provides cause of death assigned according to the standards of the International Classification of Diseases (ICD-10) (see Chap. 7).

Community-Level Record Systems HMISs integrate data from community-based workers who provide health promotion and disease prevention activities. These providers may formally work for the health system (such as the health extension workers in Ethiopia or community health workers in Kenya), or work informally as community-based providers (for instance volunteers serving people living with HIV) who may or may not be associated with the health system. The information these providers collect at the point of service is essential for community programme management and decision-making on budget, policies and human resources. Community health workers use data to follow up their clients and manage their care, especially for interventions that require longitudinal follow-up and community-facility linkages.

A review by WHO concluded that data collection at the community level can be complicated and demanding [4]. It is important to link these data to facility-based information systems in order to avoid double counting of health events and interventions. Data collection tools require literacy and numeracy skills. Community health workers should be supported and supervised by health facility staff in order to ensure properly delegated clinical services (e.g. community directly observed treatment of tuberculosis) and to help find clients or patients who are lost to follow-up.

Health Facility Assessments (HFAs) Alongside the routine collection of data as a by-product of patient management and facility administration, an HMIS also includes periodic collection of information from health facilities that is not included in routine reports. HFAs generate information on facility infrastructure, equipment and commodities, human resources, readiness to deliver specific interventions (such as tuberculosis management) and service utilization. HFAs provide an efficient way to collect information on facility availability and distribution and to identify where change is needed to strengthen the health system [5–7].

4 Users and Uses of HMIS Data

The main users of HMIS are managers and care providers at district level and below. Executive managers, public policymakers and researchers can also use HMIS data for governance and research. HMIS units at each level of the health system manage data to inform activities at that level and below, and to report a required subset of information to the next highest administrative level. For example, a hospital runs its own information system, which includes management of patients and of the commodities and supplies needed to run the hospital. Managers at higher administrative levels require health-care facilities, through the HMIS, to send regular reports, for example, numbers of notifiable conditions, vaccinations administered, antenatal care visits, facility deliveries and patients seen by diagnosis. The district level manages and coordinates reports from facilities as well as from different programmes. An HIV/AIDS programme, for example, will collate information from facilities on coverage of interventions for prevention of mother-to-child transmission of HIV (PMTCT) and uptake and continuity of anti-retroviral treatments. Thus, the HMIS contributes significantly to country-level monitoring and evaluation, research, policy and planning and generates indicators about inputs, outputs, outcomes and impact.

Routine facility data produce information on outcomes (such as intervention coverage) and impact (including health outcomes and equity). For indicators such as tuberculosis treatment outcomes, coverage of interventions for PMTCT, and uptake and continuity of antiretroviral treatments, facilities are the sole source of data [8]. The HMIS tracks delivery of clinical treatment for conditions, such as diabetes, hypertension, and cancers, that require long-term follow-up and monitoring of treatment compliance and health outcomes. This is important both from the individual patient perspective, but also for the management of services for these diseases and for programme planning and evaluation. For example, Afghanistan uses a Balanced Scorecard framework to measure the performance of reproductive maternal and child health programmes using HMIS data (the RMNCH Scorecard) (Box 9.1).

Box 9.1 Use of the Balanced Scorecard to Assess Health System Performance in Afghanistan [9]

In 2004, the Ministry of Public Health (MOPH), Afghanistan, adopted the Balanced Scorecard (BSC) as a measurement and management tool. The BSC provides a standardized framework for analysis of priority HMIS derived indicators with feedback. It promotes systematic usage of data on 29 core indicators and benchmarks representing six different domains of health services—patient and staff perspectives, capacity for service provision (structural inputs), service provision (technical quality), financial systems and overall vision for the health sector, with a focus on the continuum of care from pregnancy delivery, newborn, immunization, nutrition to child health. Using the BSC, data managers calculate scores at the district level, average them at provincial and national levels, and compare districts and provinces using moving benchmarks. The national average for the previous quarter provides a benchmark for the current quarter, permitting managers and health workers to track performance over time. The BSC is easy to read with a colour coding scheme that highlights technical and geographic areas by performance, identifying areas of weak performance. Since health workers report the basic data, the BSC builds ownership as they can see their own performance, identify gaps and compare with other districts. The scorecard is entirely based on routinely available data generated by the government health services through the HMIS.

While data managers organize collection and management of data, it is often the user who collects the data, for example, a physician or nurse who completes the patient records. So, managers and users must work closely together to obtain the information users require.

5 Limitations and Challenges

HMIS data in LMICs are beset by problems of quality so that end-users do not always trust or consider them *fit for purpose*. Data quality limitations include missing values, measurement errors and mistakes in data entry and computation. The perception that routine reports from health facilities and districts are often late, incomplete and inaccurate undermines credibility and hampers their use. Box 9.2 shows the findings of Ethiopia's 2006 assessment of its HMIS and the strategies it took to strengthen the contribution the HMIS could make to monitoring health sector performance [10].

Box 9.2 Health Management Information System Reform in Ethiopia [10]

In 2006, as part of its strategic health planning, the Ethiopian Federal Ministry of Health (FMOH) concluded that a robust HMIS was key to successful implementation of the Health Sector Development Program (HSDP). The FMOH conducted an in-depth assessment of the current HMIS and identified major areas of weaknesses including: unstandardized data collection; fragmented reporting and data transmission; weak information use (analysis, interpretation, and problem-solving capacity); and limited financial and human resources. Subsequently, the FMOH developed an HMIS strategic plan with a vision, mission, goals and guiding principles for national HMIS strengthening, and established a National Advisory Committee and a Core Technical Working Group to assist in the design and national roll-out of the plan. Guided by the principles of *standardization*, *integration* and *simplification*, the FMOH adopted these strategies to strengthen the HMIS: (1) revision of the National List of Essential Indicators; (2) standardization, integration, and simplification of data collection and reporting tools; (3) capacity building for staff; (4) action-oriented performance monitoring; and (5) use of appropriate technology to create an electronic HMIS data management application. As a result of these interventions, health centres and hospitals saw a reduction from 400 to 150 data items to report, significantly reducing the data burden of the health staff. Assessments undertaken in 2010 and 2014 showed remarkable improvement of HMIS performance.

Data from an HMIS are, by definition, limited to those who attend health facilities or use related community-based services. When hard-to-reach groups—such as undocumented migrants, ethnic minorities, or the very poor—have difficulty accessing health care, it is important to assess the extent of exclusion and how this will affect the completeness and reliability of HMIS data. In many LMICs, large proportions of the population have severely restricted access to health services because of geographic, economic and socio-cultural barriers. In such settings, facility-based data are not likely to represent the whole population in any given catchment area and the

resulting data and indicators will be incomplete and biased. For example, a 2010 quality assessment of facility data in 122 districts in Uganda found that completeness of district reporting was poor in 9 per cent of districts and completeness of health facility reporting was problematic for one-third of the districts. District population projections for the denominators were estimated to be off by more than one-third for 22 per cent of districts, rendering estimation of indicators of intervention coverage unreliable [11].

Where access to care is limited, countries estimate population denominators based on extrapolations from the most recent census, data that are generally provided by a national statistics agency. Inevitably, such estimates become less reliable over time and this is a particular problem at sub-national levels. It is not unusual to see coverage estimates for indicators such as immunization exceeding 120 per cent for some districts, while in others coverage is at unlikely low levels (below 80 per cent). While this may in part be due to inaccuracies in the numerators (numbers of immunized children), studies have found that it is more likely a problem of over-estimation or under-estimation of the target population.

WHO has worked with countries to develop methods to determine the adequacy of the population data used in evaluating the performance of health indicators, especially those referring to coverage [12]. These involve both assessment of the internal validity of the HMIS data, such as completeness of reporting from facilities and districts, as well as comparisons with external sources such as household surveys. For example, in Liberia a study compared intervention coverage rates obtained from HMIS data with those obtained through a health outcome survey, using lot quality assurance sampling (LQAS) (see Fig. 9.1). This study found good agreement between the data sources for some indicators but not for others, leading to investigation of the reasons for the discrepancies and actions to improve the quality of data collection.

HMIS managers need to undertake regular quality assessments of the relative strengths and weaknesses of the data sources. Adjustments of reported data to take into account incomplete reporting and missing values can help increase confidence in and utility of facility-based data but such adjustments must be based on scientific methods and made transparent to users. In 2017, several international agencies and donors collaborated to produce a data quality review (DQR) toolkit designed to 'contribute to the improvement of the quality of data used by countries for reviews of progress and performance—such as annual health sector reviews, programme planning, and monitoring and evaluation—to facilitate decision-making' [8]. The toolkit supports a comprehensive review of HMIS data quality, mainly from facili-

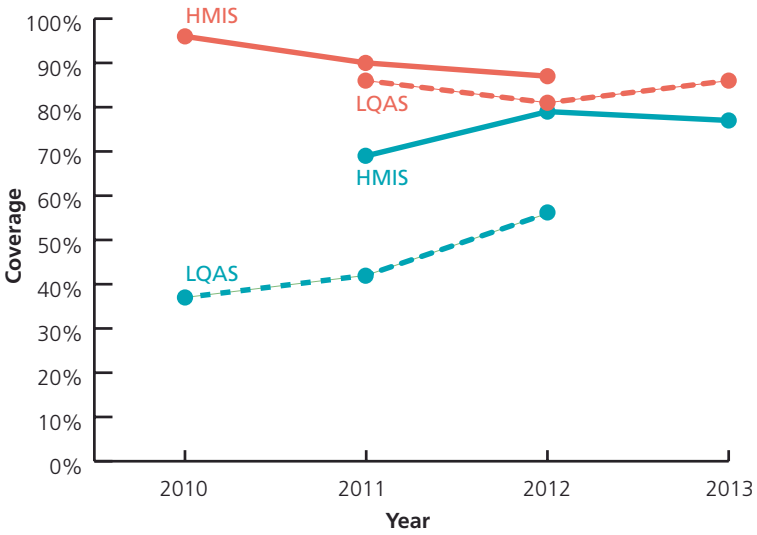

Fig. 9.1 Comparison of coverage rates using lot quality assurance sampling (LQAS) and health management information system (HMIS) data in Liberia. (Adapted from Watson et al. [13])
Blue lines: Children under one year who received DPT3/Pentavalent 3 vaccination
Red lines: Women of children aged less than 24 months whose deliveries were in a facility and were attended by a skilled birth attendant

ties, and consists of three components: (1) a guide for conducting monthly reviews of data quality with immediate checks and feedback so that errors can be identified and corrected as they occur; (2) an annual independent assessment of core indicators to identify gaps and errors in reporting and assess the plausibility of reported trend data; and (3) periodic in-depth programme-specific reviews timed to feed into programme planning. The reviews focus on a limited set of *tracer* indicators covering maternal health, immunization, HIV, tuberculosis and malaria but countries can include other tracer indicators if needed. Data quality metrics include completeness, timeliness, consistency and accuracy.

6 HMIS Innovations and Transformation

For years, health facilities and community health workers have collected data using paper forms or logbooks. This involves laborious and time-consuming data aggregation and compilation, transcription errors, inadequate analysis and visualization, difficulty in data sharing, and poor data storage and retrieval. To address such challenges, HMISs now use information and communication

technology (ICT) for data collection, aggregation, reporting, storage, analysis, visualization, and dissemination. While this revolution has yet to reach all countries and all levels of the health system, ICT can improve routine, facility-based and administrative data collection, management and use for policy and planning. Although ICT facilitates HMIS functionality, health managers need to select hardware and software appropriate to their country's infrastructure, capacity and resource availability.

6.1 Electronic HMIS and Decision Support Tools

Sophisticated and powerful data management applications are available for facilities to use to manage their data. For example, by 2018, 60 countries and 23 organizations around the world were using the District Health Information System 2 (DHIS2) developed by the University of Oslo. DHIS2 permits data capture on multiple fixed and mobile devices and, because the system allows users to enter data offline, it can be used in locations with poor connectivity. DHIS2 Academies facilitate sharing of experiences and strengthen national and regional capacities to successfully set up, design and maintain DHIS2 systems [14]. The iHRIS software is an application in support of human resources data management (see Chap. 12). The eLMIS supports logistics and commodities data management. In addition to data entry, data aggregation and storage functions, these applications mostly have a *decision support module* that can produce routine or ad hoc reports, as well as tailored data visualization products called *data dashboards*.

Electronic data management facilitates production of summary analyses and visualizations that are readily understandable by non-technical users (decision-support techniques). For example, *comparison* is a useful analytical method. Comparisons may be: spatial (by health facility; district or province); temporal (trends by week, month or year); indicator-specific (between inputs and outputs); or benchmarked (expected vs. achieved results) [15]. Comparisons can identify areas or groups that are disadvantaged or failing to achieve expected benchmarks and requiring remedial interventions.

Whereas cross-country comparisons of key indicators can be of interest, national decision-makers often prefer to limit external comparisons to countries at similar levels of development (e.g. at similar levels of gross domestic product per capita) or within regional groupings such as the Southern African Development Community (SADC), the Association of Southeast Asian Nations (ASEAN), or the Organization for Economic Co-operation and Development (OECD).

Analyses of relevance for policy include the four Ts: *Trends* (progress made), *Trajectories* (whether the direction of change is positive or negative), *Triggers* (minimum or maximum acceptable levels at which action needs to be taken) and *Targets* (indicator levels to be achieved). Data *dashboards* with summary tables, graphs and other visualizations can illustrate such analyses, showing progress towards goals and identify issues for health programmes to address. A geographic information system (GIS) is a powerful tool to analyse, organize and present spatial data in maps (see Chap. 15).

6.2 Data Architecture to Link Systems

To manage increasing amounts of electronic data that HMISs and other health and health-related information systems generate, health information scientists need to work within a national *eHealth architecture*. By eHealth architecture, we mean working with common principles and electronic communication standards (information exchange protocols—IEPs) across all systems to address data fragmentation and facilitate data exchange between electronic databases (known as interoperability). With coherent data architecture, analysts can, for example, link data from the census with data from the HMIS and calculate coverage rates using the most recent population estimates. Similarly by linking HMIS data to human resource information systems, analysts can calculate the workload of health-care providers. By linking HMIS data on services provided to logistic management information system data, analysts can forecast health commodity requirements.

The Open Health Information Exchange (OHIE) is an important resource that provides tools to support countries develop National eHealth architecture and increase interoperability [16]. Three key components of eHealth architecture are as follows:

A Master Health Facility List (MHFL) is an inventory of health facilities in a country (both public and private) comprising a set of administrative information, including geo-coordinates, that identify each facility (*signature domain*). The list also contains basic information on the service capacity of each facility (*service domain*) [17]. The MHFL is a prerequisite for national eHealth architecture as it provides unique facility identifiers to link data across facilities in the health system. The list is essential for analysing the geographic distribution of facilities, infrastructure, equipment and staff, the system's potential for delivery of interventions, and for estimating geographic accessibility of services.

A National Health Data Dictionary (NHDD) provides a common language for health policymakers, managers and care providers to communicate and exchange health information in a standard manner. The NHDD develops *metadata* to harmonize data definitions of commonly used data and indicators and facilitate mapping of definitions to international standards, such as the International Classification of Diseases (ICD-10) or the Systemized Nomenclature for Medicine (SNOMED-CT). SNOMED is a comprehensive, multi-lingual clinical health-care terminology that 'enables consistent, processable representation of clinical content in electronic health records' and is mapped to other international standards and used in more than 50 countries [18].

The NHDD requires a sound governance mechanism involving health, statistics and other relevant entities. For example, in Australia, the National Health Information Standards and Statistics Committee oversees development of health metadata standards. Through the Australian National Health Information Agreement 'all parties commit to ensuring that collection, compilation and interpretation of national information are all appropriate and carried out efficiently. This requires agreement on definitions, standards and rules for collecting information, and on guidelines for coordinating the access, interpretation and publication of national health information' [19]. The NHDD can be hosted on a software platform, ideally open software solutions such as the Open Concept Lab (OCL), known as a *terminology management service* [20].

A Data Warehouse is a centralized data storage system that facilitates integration of data into one, usually virtual, location, linking the data from all data sources via IEPs. This makes it possible to bring together data across health facilities at different levels, including from patient records and human resource management systems. Highly developed data warehouses incorporate data from sources other than the HMIS, such as household surveys or the census. If each individual has a unique identifier, then the system can link data on the same individual across different systems, such as health care, medical insurance and social security. Developing a data warehouse is a major technological and analytical undertaking, drawing upon multi-disciplinary skills including those of health analysts, statisticians, computer technicians, and data scientists. Once established, a warehouse can bring multiple benefits at different levels of the health system for patients, providers, health facilities and public health [21].

Notwithstanding the potential of these digital innovations, in many settings facility-based data collection and transfer are predominantly paper-based. WHO cautions that 'the architecture approach needs to be flexible and workable under many different configurations and assume that infrastructure, skills, and uptake will be uneven within and between countries' [8]. The architecture should be designed to evolve and be relevant across locations and levels of the health system, ready to become more granular and comprehensive with time.

7 Creating a Culture for Using HMIS Data

Many countries issue annual reports based on HMIS data but too often decision-makers do not use the information to improve health system performance. For example, India, Kenya, Nigeria, Tanzania and Uganda documented lack of use of data when they assessed their HMIS using the MEASURE Evaluation PRISM tools [22]. Poor use of information results not only from technical issues but also from organizational and behavioural barriers [23, 24]. Hierarchically organized health systems can leave managers at lower levels powerless to use the data. Health professionals, while generally well prepared for diagnosis and problem identification, are not trained for this type of problem solving. The question is how to build a culture of information use.

The private sector uses human-centred design (HCD) for product and technology development to better understand users' needs and involve them early in the design of solutions. HCD is a collaborative problem-solving approach that provides broadly applicable methods for developing in-depth understanding of human behaviour [25]. HCD could be applied to establish a culture of using health information, together with other interventions such as: role modelling by senior managers to promote use of data at the district level and below; incentive-based systems to promote use of information such as performance-based financing schemes; allocation of resources based on HMIS indicator results; and use of information as criteria for annual performance appraisals.

There is need for comprehensive capacity building interventions at the individual, organizational as well as system level. Critical focus areas in capacity building are data management and data quality assurance systems [26], as the Liberian experience demonstrates (Box 9.3). Technical partners are providing support for capacity development through an online curriculum for routine health information set up by MEASURE Evaluation in 2017 [27].

Box 9.3 Health Management Information System Capacity Building in Liberia [28]

The Liberian National Health and Social Welfare Plan, 2011–21, prioritized developing a decentralized HMIS as an integral part of the national health system. Starting in 2011, with support of the USAID-funded Rebuilding Basic Health Services (RBHS) project, the Liberian Ministry of Health and Social Welfare (MOHSW) initiated a massive capacity building effort to improve data quality and use for improved decision-making. Using the PRISM tools to assess HMIS performance, the MOHSW) showed that data accuracy in health facilities increased from 46 per cent in 2012 to 83 per cent in 2014; data completeness increased from 52 to 79 per cent; and use of information increased to 58 from 38 per cent. Data analysis and feedback to health facilities increased substantially. While these results were encouraging, the MOHSW recognized that more time and efforts were needed to further build HMIS capacity across all levels of the system.

8 Conclusion

An HMIS has different and sometimes conflicting functions: operational, informational and decision-making. The operational and decision-making functions are essential to ensure proper management of health services for patient/clients. The broader utility of the HMIS is to complement data from other HIS sources to build an evidence base for health sector performance assessment and strategic planning. We provide an example of this approach from the United Republic of Tanzania [29].

> In 2013, the Tanzanian Ministry of Health and Family Welfare brought together a team of experts from local research institutions and the WHO to undertake a mid-term review of its 2009–15 health sector strategic plan. The team used all available data from the HMIS, household surveys, and many other sources to describe progress on the Tanzania mainland towards performance targets. The report highlighted areas where significant progress had been achieved and areas where increased efforts were needed. A sub-national analysis identified populations or regions of the country needing an infusion of resources to achieve parity and raise the national average across several indicators. The report included a comparative analysis with neighbouring countries in the East and Southern Africa (ESA) region and the African continent as a whole.

The Tanzanian example demonstrates the value of harnessing the capacity of local research institutions—where the analytical skills are available—to make sense of multiple data points and convey meaning to users. Dissemination of quality information based on HMIS data engages policymakers and programme planners on the one side and district managers and service delivery managers on the other to work together to improve people's health.

Key Messages

- The HMIS provides data to hold all levels of the health system accountable.
- HMISs regularly produce data on resources, infrastructure, interventions, coverage, health status, equity, efficiency and patient satisfaction.
- Innovations can improve availability, quality, and use of HMIS data, enabling managers to make informed decisions.
- Governments have used HMIS data for policy and planning to improve quality of care and health systems performance.

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10

Public Health Surveillance: A Vital Alert and Response Function

Kumnuan Ungchusak, David Heymann, and Marjorie Pollack

1 Introduction

A three-month delay in identifying the outbreak of Ebola virus in rural Guinea in late 2013 resulted in its rapid spread to urban areas and to neighbouring Liberia and Sierra Leone [1]. Once local and international responders identified the virus, they took a year to interrupt its widespread transmission. By April 2016, Ebola had accounted for more than 28,000 cases and over 11,000 deaths. People around the world watched with increasing alarm, as this tragic course of events played out, and with concern that air travel could enable the virus to spread across continents. This epidemic highlighted not only the inadequacy of local health systems to recognise and respond but also that international organisations were not ready to provide timely expertise and resources to control the situation and ameliorate the virus's spread through the region. Had health officials identified Ebola in West Africa promptly, they

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could have minimised its impact on the lives and livelihoods of the populations of West Africa by implementing appropriate control procedures.

Public health officials coined the term *surveillance* to describe systems they set up to watch out for and control occurrence of health threats. Just as police, for example, set up closed-circuit television devices and community watch programmes to detect and prevent crime, public health surveillance systems engage all possible means to detect unwanted health events and prevent them from escalating and damaging population health. While public health surveillance originated to control spread of infectious diseases such as plague and cholera, it has evolved to include some non-communicable diseases, occupational health and injuries as well as surveillance of biological, behavioural and social determinants of these conditions.

We start by reviewing the public health need for surveillance and the development by the international community of regulations to control infectious diseases and other Public Health Emergencies of International Concern (PHEIC). We describe how epidemiologists use surveillance data to detect unusual events or outbreaks and to guide control programmes, and we provide guidance about maintaining data quality. We examine networks that contribute to global surveillance systems and highlight the role of social media and information technology in providing data to monitor new events of international importance. We consider challenges facing epidemiologists responsible for surveillance and describe efforts to address them.

2 Public Health Surveillance: The Policy Imperative

Public health surveillance is vital to the functioning of national and global health systems. Policymakers and health administrators need surveillance information to set priorities to address population health problems, allocate resources and monitor progress of prevention and control programmes; they need surveillance systems to alert them immediately of public health threats. Emerging infectious diseases, such as Avian influenza of different subtypes, Severe Acute Respiratory Syndrome (SARS) coronavirus, pandemic influenza H1N1 and the Zika virus (ZIKV) have the potential to spread rapidly causing severe loss of life and to impact socio-economic activity, especially trade and travel [2]. The outbreak of SARS in November 2002 highlighted the importance of every country having functioning and connected surveillance systems (see Box 10.1).

Box 10.1 The 2002–03 SARS Epidemic [3]

SARS originated in wildlife and spread silently among humans as atypical pneumonia in Guangdong province, China, two months before officials became aware of it. Authorities began surveillance to identify atypical pneumonia cases but this, and the containment response, were too late to stop SARS spreading. A Chinese urologist who was infected travelled to Hong Kong and spread SARS to another 16 persons. Within weeks, SARS spread to 25 countries with more than 8,000 reported cases (Fig. 10.1) [3]. By the end of the epidemic in July 2003, SARS had killed 774 people [4]. Although unable to contain the outbreak of SARS, the international community was able to bring the epidemic under control within six months—by collaborating across countries to identify and isolate all probable cases. Nevertheless, the Asian Development Bank estimated that the economic loss due to SARS in affected countries was up to US $28 billion with US$ 5.8 billion on Mainland China (approximately 1.2 per cent of its annual gross domestic product (GDP)) and US$ 6.6 billion in Hong Kong (approximately 4 per cent of its annual GDP) [5].

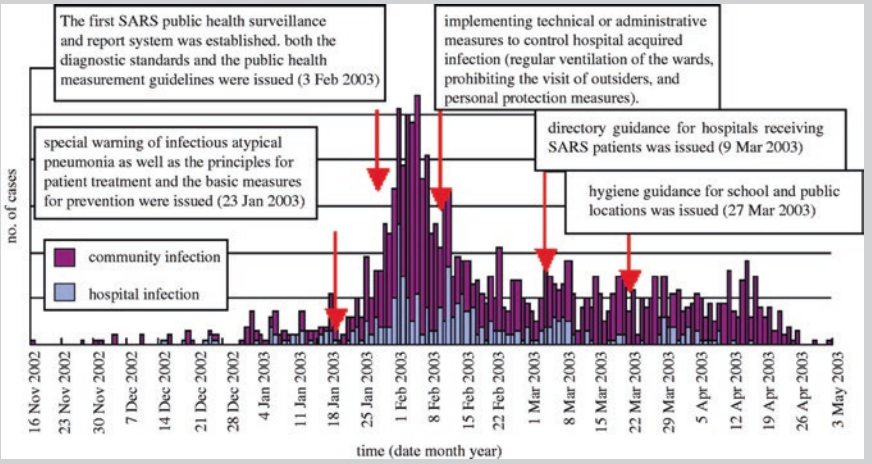

Fig. 10.1 Pattern of the 2002–03 SARS epidemic. (Source: Zhao [3])

Surveillance requires high-level government support, well-trained health workers, strong health information systems, well-functioning laboratories, effective communication systems and operational health facilities. To be effective, surveillance systems also require a strong legal framework to ensure that individual data can be shared while maintaining confidentiality as far as possible. Global cooperation between countries, with up-to-date international health agreements to build and maintain these capacities, is essential to decrease risk of international spread of infectious diseases and contain the risk of bio-terrorism.

3 Development of International Health Regulations: Rise of Global Surveillance

Plague ravaged Europe during the fourteenth century and although authorities had no cure, they realised it was important to swiftly identify and isolate cases to prevent and control this lethal condition. Authorities understood that international spread of such diseases followed cross-border trade, pilgrimage and war; and so prevention of disease was a national security issue. In the city-state of Venice, authorities instigated quarantine measures—keeping arriving ships in the harbour for 40 days before docking, and holding people in isolation for 40 days at land borders to prevent entry of plague [6].

In the mid-nineteenth century, recognising that quarantine measures were not enough, governments agreed international conventions aimed at stopping spread of plague and cholera—and two other infectious diseases, yellow fever and smallpox. The conventions required each country to report outbreaks of these diseases to all signatories of the convention, and permitted application of certain public health measures at international borders once a country reported of one of the diseases. In the early twentieth century, governments in the Americas and in Europe set up regional conventions called International Sanitary Bureaus.

In 1951, the newly formed World Health Organization (WHO) led establishment of the International Sanitary Regulations (ISR) to foster global cooperation in reporting and acting at international borders to guard against spread of cholera, plague, yellow fever and smallpox.

In 1969, the WHO replaced the ISR with the International Health Regulations (IHR) which required countries to report any cases of cholera, plague, yellow fever and smallpox to WHO [7]. If a country reported one of these diseases, other countries could apply pre-established control measures at international borders—such as a requirement of proof of vaccination against yellow fever of any passenger arriving from a country that reported yellow fever to WHO.

Some countries reported to WHO late, or not at all, because of lack of capacity for public health surveillance, or because of fear of stigmatisation and economic repercussions. After HIV spread across international borders before being identified in 1981, the international community realised that infectious diseases could not be stopped at borders. Diseases often cross borders while still being incubated in humans, or in non-human hosts—insects, animals, and food and agricultural goods. In 2005, after the 2003 SARS outbreak,

WHO updated and revised the IHR as a legal framework to include more diseases, and developed real-time evidence-based recommendations for prevention and control of outbreaks. WHO evaluates each newly identified outbreak for its potential to become a PHEIC by the country in which it is occurring.

The IHR 2005 mandate WHO member countries to report immediately the occurrence of a single case of four diseases (smallpox, poliomyelitis due to wild type poliovirus, human influenza caused by a new subtype, and SARS) [8]. Even though the world eradicated smallpox in 1980, the IHR still maintain it on the list to cover the risk of the virus escaping from a laboratory. Each country has an additional list of diseases that it requires its health workers to report by law. Diseases of greatest public health threat are *reportable*, meaning that health workers or laboratory technicians must report individual cases as they occur. Reportable diseases include those required by IHR and, for example, anthrax, cholera, Ebola, legionellosis, plague and the ZIKV. Other conditions are *notifiable*, meaning that health workers should report the number of cases that have occurred in a given time period. The number, frequency of reporting and breakdown of reportable and notifiable diseases varies by country. Diarrheal cases, influenza cases, tuberculosis, AIDS and other significant endemic diseases are usually required to be notified to local health authorities. In some countries the notifiable list can include non-infectious conditions such as maternal or infant deaths.

The IHR 2005 require countries to develop core capacities in public health, including surveillance systems and epidemiology services, that can analyse and act on surveillance information to detect and respond to diseases where and when they occur so that their potential to spread internationally is decreased.

4 National Public Health Surveillance in Practice

The purpose of surveillance activities is to: (1) detect at an early stage, acute public health threats from all hazards—biological, chemical, radiation, natural disaster and deliberate acts—which require rapid investigation and response; and (2) guide control programmes by measuring disease burden, monitoring trends, describing disease distribution and evaluating public health programme effectiveness (see Table 10.1).

The structure of government responsibilities for public health surveillance varies across countries. Most often, countries set up dedicated early warning

Table 10.1 Framework for public health surveillance

	For early detection and rapid response	To guide control programmes
Output (purpose)	Detection of outbreak, risk assessment and alert, initiate investigation, containment	Ascertain magnitude, pattern, distribution, forecast, monitor and evaluate
	⬆	⬆
Process		
Dissemination	Immediate, daily, weekly	Monthly, quarterly, annually
Interpretation	Abnormal, clustering, outbreak	Trends, progress, gaps
Analysis	Verification, frequency, distribution by time and place	
Data collection	Scanning, screening, event-based	Reporting, registration, surveys, indicator-based
	⬆	⬆
Inputs	High-level government support, well-trained health workers, strong health information systems, well-functioning laboratories, effective communication systems, operational health facilities, strong legal framework, financial resources, technologies, global cooperation	
	⬆	
	Reports of notifiable diseases, media, rumours	

and rapid response surveillance teams that work with or complement surveillance activities of vertical control programmes such as malaria, HIV/AIDS or tuberculosis. Surveillance and response teams detect early stage public health threats while control programmes gather disease (or condition) specific information to plan activities. Control programmes share information with surveillance teams as required. A national network of public health laboratories, often linked to international reference laboratories, confirms etiologic agents, genetic strains and antibiotic resistance patterns. Surveillance activities are said to be *active* when health workers pro-actively seek out cases and *passive* when the system relies on patients to report themselves to a clinic.

4.1 Surveillance Data to Detect Unusual Events or Outbreaks

Using standard case definitions, health workers report individual cases of reportable and notifiable diseases to the local or national surveillance centre

where staff aggregates reports, and clean and analyse the data. In cleaning the data, staff look for coding and classification errors, and for duplicate reports. Epidemiologists analyse the data to determine how many new cases have occurred during the past day or week and their distribution in time, place and by person to see whether the magnitude and pattern of the disease under surveillance is changing. They note any changes in frequency, clustering or distribution and flag them for verification and explanation. Box 10.2 illustrates how careful data analysis led to Malaysia identifying Nipah virus in 1999 [9].

Box 10.2 Analysing Epidemiological Data to Identify Nipah Virus in Malaysia in 1999

Japanese encephalitis commonly occurs in school-age children of both sexes. There is a seasonal pattern of disease related to the rainy season when transmission and therefore disease occurrence, increases; there is no difference in occurrence between ethnic or religious groups. From September 1998 to April 1999, surveillance teams sent reports of 229 cases of febrile encephalitis (48 per cent fatal) to the Malaysian Ministry of Health [9]. Initially, the ministry considered *Japanese encephalitis* virus to be the probable etiologic agent for this outbreak, and instituted conventional interventions of vaccination and insecticide to control mosquitoes. When they examined the surveillance data closely, the epidemiological pattern of encephalitis cases was different to what they expected—the disease occurred mostly among male adults of Chinese ethnic origin whose occupations related to pig farming. The ministry sought a different cause and found the etiologic agent to be a new paramyxovirus, later named *Nipah virus*.

Reporting of specific information about cases or patients or behaviour of populations under surveillance produces *indicator-based data*, that is individual or aggregated data derived from patients diagnosed—by syndrome description, clinical or laboratory confirmation—and identified through routine collection or active case search. The surveillance unit will also use *event-based data* about outbreaks, unusual events or changes in human exposure [10]. Rather than wait for official reports, the surveillance team gathers information and rumours through the media, Internet and unusual events reported by the community, and investigates these reports. The team captures abnormal health events in real-time and confirms potential outbreaks by triangulating these data with indicator-based data.

Epidemiologists responsible for surveillance use standard epidemiological methods to analyse trends, identify clusters and investigate suspected risk factors (see Chap. 18 for an overview of epidemiological methods). For example, high numbers of reported cases of Kaposi Sarcoma among young men in New York and California during the early 1980s led to an investigation which showed a

common risk factor of homosexual behaviour and its relationship with HIV/AIDS [11]. Using increasingly sophisticated technologies for data capture and analysis, surveillance teams can monitor real-time occurrence, in time and place, of unusual events such as cholera or legionella, or seasonal outbreaks such as malaria (see Chap. 20 for an introduction to spatial and spatio-temporal techniques and to Chap. 14 which discusses predicting climate-related health outcomes such as malaria).

Once epidemiologists have concluded their analyses (sometimes in real-time), they prepare reports which can trigger immediate action by a rapid response team to visit the site of the events, investigate the situation and contain the outbreak. The team also sends reports to clinicians in hospitals and to local and national programme managers. Many countries publish weekly disease surveillance reports that are also available to the general public: for example, the US Centers for Disease Control and Prevention (CDC) publish the Morbidity and Mortality Weekly Report (MMWR) [12], the European Centre for Disease Control (ECDC) publishes Eurosurveillance [13], and the WHO publishes the Weekly Epidemiological Record [14]. Box 10.3 shows how epidemiologists associated microcephaly with ZIKV which led WHO to declare ZIKV a PHEIC [15].

Box 10.3 Evidence to Identify the Zika Virus as a Public Health Event of International Concern [15]

In late 2015, ZIKV spread rapidly through Latin America especially in Brazil and El Salvador. Surveillance of birth defects in Brazil identified a major increase in microcephaly during the period when ZIKV transmission increased. This alerted policymakers and epidemiologists to study whether the increase in birth defects was associated with ZIKV infection during pregnancy. WHO declared the suspected increase in microcephaly in association with ZIKV infection of pregnant women a PHEIC and recommended pregnant women to protect themselves from mosquito bites and to avoid travel to areas with known ZIKV transmission. The observation that men who travelled to areas with known ZIKV transmission could sexually transmit ZIKV to their partners led WHO to recommend practising safer sex or abstinence for a period of six months for men and women returning from areas of active transmission.

4.2 Surveillance Data to Guide Control Programmes

Public health surveillance guides control programmes by undertaking the following functions:

Measuring the Occurrence and Burden of a Disease or Condition, and Describing Its Epidemiological Patterns Disease in humans results from interactions between the human host and causative agents or hazards of all types. The natural and socio-economic environment influences these interactions. Diseases usually occur in the same pattern when there is no change in the causative agent (such as mutation), in the human host (such as vaccination) or in the environment (such as climate change). A surveillance system can closely monitor any changes in these dynamic factors and their consequences, as illustrated by the case of Nipah virus in Malaysia (Box 10.1).

Monitoring and Forecasting Trends in Risk Behaviour Public health surveillance must also address risk. For example, surveillance of annual per capita cigarette consumption in the US showed an increased trend from 54 cigarettes in 1900 to 4,345 cigarettes in 1963. Researchers related this trend to advertising and an expansion in the number of cigarette companies. In 1998, after the first studies suggesting cigarette consumption was related to lung cancer, and the US Surgeon General issued a warning, the annual per capita consumption decreased to 2,261 [16]. With surveillance information, epidemiologists can forecast an increase in lung cancer without intervention thereby providing evidence for policy to implement effective interventions such as taxation to prevent smoking.

Evaluating Performance of Control Programmes After they have implemented interventions, health authorities use surveillance data to see if disease incidence declines. For example, when vaccine coverage increases, the number of cases of vaccine preventable diseases is expected to decrease. Increasing taxes on cigarettes is one way to reduce consumption. Surveillance data can document a correlation between increasing taxes and decreasing trends in cigarette consumption.

To achieve these functions, programme managers collect data through patient records, surveys, programme records or informal sources. Types of data include determinants of the condition, behaviours or risk factors associated with the condition, morbidity and mortality associated with the condition, programme responses, and abnormal or unusual events associated with the condition. Table 10.2 provides examples of these types of data for surveillance of an HIV/AIDS control programme.

Table 10.2 Major types of data needed for surveillance to guide control programmes: HIV/AIDS surveillance

	Determinants of the condition	Behaviour	Disease occurrence	Programme response	Abnormal events
Types of Data	Population, social, biological	Risk, protections	Infection, morbidity, mortality, complications	Policy, regulation, intervention, service coverage	Outbreak news, rumours
Example of indicators	Number of sex establishments and sex workers, Types of HIV virus circulating	Needle sharing among injecting drug users, Usage of condoms among clients of sex workers	HIV prevalence and incidence in at risk population, Number of HIV infected people, Number of AIDS cases and deaths	Percentage of AIDS cases on treatment, Coverage of test and treatment clinics	Clusters of HIV cases in a village

4.3 Maintaining Standards by Reviewing Surveillance Systems

To ensure surveillance programmes have adequate resources and produce useful information, public health authorities regularly review their surveillance activities. In 1988, the US CDC issued guidelines to evaluate surveillance systems which, with some updating, are still widely used [17]. These guidelines focus evaluation of public health surveillance on three areas: (1) the surveillance system itself, describing the system, its structure, diseases under surveillance, sources of data, and how data are processed, analysed and disseminated; (2) the resources used to operate the system, including funding sources, adequately trained staff and information technology; and (3) the usefulness and quality of surveillance information, using the following indicators:

Usefulness of Data Do the data and information disseminated to data providers and users contain comprehensible facts and findings and useful recommendations to improve control measures and guide programme management? Has the system detected outbreaks? How many of the detected outbreaks were investigated and controlled in a timely manner?

Timeliness of Data and Other Information Is data dissemination timely and regular? For example, epidemic prone diseases require weekly summary, while other diseases require only monthly or quarterly summaries. Are these requirements met?

Validity and Completeness of Data Much of the data come from clinical diagnoses that do not have laboratory confirmation. It is useful to conduct studies to determine the accuracy of diagnoses using standard laboratory confirmation testing. This helps in preparing estimates of the proportion of confirmed cases among all reported cases. When undertaking field investigations, investigators can compare the number of actual cases they find with the number of cases reported through the system. This provides an estimate of reporting completeness of the system.

5 Global Public Health Surveillance

Global public health surveillance is the collection, analysis and use of standardised information about health threats or their risk factors from more than one country, and usually worldwide. While surveillance mainly focuses on infectious diseases, global systems also seek to identify deliberate use of biological agents or toxins to cause harm.

WHO leads the global public health surveillance system, gathering information from formal and informal sources working through its country and regional offices. WHO extends its reach through the Global Outbreak and Response Network (GOARN) [18] which comprises over 120 national technical institutions that support WHO to detect public health threats and respond to outbreaks. WHO uses the information for risk assessment and analysis as part of its routine disease control and prevention programme activities. When requested by countries for support, WHO works with GOARN institutions to recruit suitable experts. GOARN includes regional networks of countries that cooperate independently to prevent and control infectious diseases occurring in their regions, for example, the East African Integrated Disease Surveillance Network (EAIDSNet), [19] and the Mekong Basin Disease Surveillance network (MBDS) [20].

WHO leads global networks that work to control specific diseases. These networks depend on cooperation of governments, public health workers and scientists to report cases, provide specimens and share information so that specific diseases can be controlled globally. These include:

Networks to Support Influenza Control Through Vaccine Development The Global Influenza Surveillance and Response System (GISRS) consists of national sentinel centres and national and regional laboratories which annually collect 200,000–250,000 nasal swabs from patients presenting with influenza-like illness. Their analyses provide information about the distribution of strains circulating each year and enable scientists to recommend the influenza vaccine composition for the following year based on predominant sequences. GISRS also uses FluNet, a public web-based data collection and reporting tool that tracks movement of influenza viruses globally and provides epidemiological data about influenza outbreaks [21].

Networks to Inform Polio Eradication The Global Polio Laboratory Network (GPLN) [22] underpins the Global Polio Eradication Initiative. Clinical health workers and epidemiologists report all cases of acute flaccid paralysis

(AFP) in children under 15 years of age from whom they have collected stool specimens for isolation and identification of the poliovirus. Through its network of national, regional and specialised laboratories, GPLN determines whether polio was the cause of the AFP, genetically sequences viruses and compares them to a global database to understand their geographic source. If a polio virus is found, GPLN informs the national authority and WHO regional office for appropriate action.

Networks to Support Control of Anti-Tuberculosis Drug Resistance The Global Project on Anti-Tuberculosis Drug Resistance Surveillance [23] is a common surveillance platform to which countries can provide data that are then used to monitor the evolution and spread of multi-drug resistant tuberculosis (MDR-TB) and extensively drug-resistant tuberculosis (XDR-TB). National laboratories provide susceptibility testing of tuberculosis organisms collected from patients, supported by a supranational tuberculosis reference laboratory network. The Global Project provides understanding of the prevalence and distribution of tuberculosis resistance worldwide.

Networks to Gain Information About the Spread of Anti-Microbial Resistance (AMR) WHO runs the Global Antimicrobial Resistance Surveillance System (GLASS) [24]. Its goal is to develop a standardised strategy to collect, analyse and share clinical, laboratory and epidemiological data globally, assess the burden and support local, national and global strategies to control AMR.

6 The Role of Information and Communication Technology in Surveillance

Until recently, surveillance systems depended on paper-based reporting, compilation and analysis of data. Computers and electronic reporting have made compilation and analysis of data much easier, and the World Wide Web (WWW) and the Internet improve the comprehensiveness of reporting. Digital and internet-based technology can retrieve information from medical records on a daily basis—but this must be done without infringing personal privacy. Hospitals, especially private ones, may refuse to provide patient information to the public health sector unless privacy issues are addressed.

Cell phone technology has extended the scope of informal and event-based surveillance while social media has transformed exploring rumours of new events. Some ground-breaking examples of the use of information and communication technology include:

Electronic Reporting of Events The Programme for Monitoring Emerging Diseases (ProMed-mail) is a fully moderated internet-based listserv, that receives and publishes reports of public health events in humans, animals, wildlife and plants from its subscribers and other traditional and non-traditional information sources [25]. ProMed-mail uses information available on the WWW and from voluntary listserv reporters who actively search for and report public health events in realtime from the media, Internet blogs and other sites. ProMed-mail editors and expert moderators review, analyse, evaluate and where possible validate reports, and then disseminate them to listserv members and post them on its website.

Using Big Data to Identify Events The subscription-based application *Global Public Health Intelligence Network* (GPHIN) continuously scans the WWW gathering information from multiple source news aggregators in real-time [26]. GPHIN searches in nine languages for key words that could indicate infectious disease outbreaks, or environmental, radioactive and natural disasters. Analysts identify new events and inform subscribers—who are governmental and non-governmental agencies with an established public health mandate. Every 24 hours, analysts communicate new information to WHO which validates reports through its network of regional and country offices. WHO discusses events that it validates in confidence with health departments in the countries involved.

Mapping Events in Real-Time HealthMap, a fully automated application, utilises online informal sources for disease outbreak monitoring and real-time surveillance of emerging public health threats [27]. HealthMap trawls WWW sources of information (in nine languages) including online eyewitness reports, expert-curated discussions such as ProMed-mail, validated official reports, for example from WHO, or the Food and Agriculture Organization of the United Nations, and news aggregation services such as Google News. Using open source software, HealthMap displays the events by time, geographic location and aetiology.

Participatory Flu Tracking Diseases and abnormal events happen all the time in the community. Only some patients, especially those presenting with severe disease manifestations, seek medical care. Flu Near You invites anyone living North America, over 12 years of age, to report if they have an influenza-like illness [28]. Once registered, participants are asked weekly by e-mail to complete a brief survey that seeks information on ten symptoms linked to influ-

enza, and other information such as whether or not the registered participant has had an influenza vaccination. Other countries, including the UK, have adopted similar participatory influenza surveillance systems, thereby adding a greater understanding of the epidemiology of influenza around the world.

Participatory Onehealth Disease Detection (PODD) Chang Mai University in Thailand, with support from the Skool Foundation, developed this mobile application which connects 296 volunteers in 71 local governments. When volunteers notice an abnormal event such as poultry dying off or sickness in animals or humans, they use PODD to notify local authorities who dispatch a surveillance and rapid response team to investigate and contain the event. After 16 months of implementation, PODD has enabled the detection of 1,029 abnormal events, including 26 chicken high-mortality outbreaks, four cattle disease outbreaks, three pig disease outbreaks and three fish disease outbreaks, all of which were detected and controlled [29].

7 Challenges and the Future

Since revision of the IHR in 2005, outbreaks due to infections, including the Middle East Respiratory Syndrome coronavirus and Ebola virus, have highlighted continued weaknesses in public health surveillance and response capacities in most countries, with international spread causing disruptions in trade and travel, and negatively impacting economies. We present some challenges and suggest some solutions.

7.1 Coordination of National Surveillance Activities

Most countries have established disease control programmes each with a surveillance component reporting from grassroots through provincial and national levels. National surveillance units may have sufficient staff for each disease control programme, but at lower levels of the health system, the same individuals often manage more than one programme and are heavily burdened by reporting requirements. There is also duplication of effort in reporting between programmes. WHO supports countries to coordinate surveillance activities across departments, programmes and administrative levels through Integrated Disease Surveillance and Response (IDSR) [30]. IDSR links surveillance with other health information activities and strengthens overall capacity of countries to maintain public health surveillance.

7.2 Building Capacity for a National Surveillance System

The IHR 2005 obligates countries to develop comprehensive disease surveillance, detection and response when and where infectious diseases and other acute public health threats occur. In reality, national surveillance capacity in many countries is still not at expected and necessary levels. This may be, as the Ebola epidemic demonstrated in West Africa, that health systems are weak and under-funded, or that the surveillance system itself does not function efficiently. Regular evaluation of the system, as we describe in Sect. 4.3, can identify which components need to be strengthened. An over-riding issue is for the system to deploy and maintain enough professionals throughout the system with the required skills—understanding the nature and limitations of the data they are working with and able to interpret and draw important findings from the analyses of the surveillance data. Since the US CDC initiated the Epidemic Intelligence Services (EIS) in 1951, other regions of the world have established similar training programmes and are graduating field-based epidemiologists with expertise in surveillance and response. Currently, there are 69 such programmes around the world forming the Training Programs in Epidemiology and Public Health Interventions Network (TEPHINET) [31].

7.3 Coordinating Surveillance Across Sectors

Approximately 75 per cent of newly identified human diseases are zoonotic in origin [32] and 70 per cent of these diseases have their origins in wildlife [33]. Since the 1997 outbreak of H5N1 Avian Influenza in Hong Kong, animal surveillance and human surveillance units have begun to share information and alert each other of unusual events. Environmental factors are also crucial to disease occurrence, for example, paralytic shellfish poisoning among people who consume shellfish affected by harmful algae growth in the sea [34]. The *One Health* approach involves sharing information between multiple health sectors and working together to identify and resolve outbreaks [35].

7.4 Sharing Information and Ensuring Equal Benefit

During the 2005 Avian Influenza outbreak, WHO requested all affected countries to share the virus isolated from humans for further study and vaccine development. Some governments expressed concern about potential negative economic consequences of sharing information and about

possible inequities in the benefits of sharing. This led to the 2007 Jakarta Declaration on responsible practices for sharing Avian Influenza viruses and resulting benefits [36]. This declaration underlined need for continued open, timely and equitable sharing of information, data and biological specimens related to influenza; it also emphasised need for more equitable sharing of benefits for example in the generation of diagnostics, drugs and vaccines. The Jakarta Declaration led to the Pandemic Influenza Preparedness Framework (PIP) under which manufacturers of influenza vaccines, diagnostics and pharmaceuticals that use GISRS information make annual financial contributions to WHO. WHO uses approximately 70 per cent of these contributions for pandemic preparedness activities and surveillance, and 30 per cent for pandemic response including purchase of vaccines and antivirals at the time of a pandemic for countries without access to these supplies.

In May 2017, the Chatham House Centre on Global Health Security, after a series of roundtable consultation with experts in public health surveillance, produced a guide on Strengthening Data Sharing for Public Health Surveillance. This guide facilitates both informal and formal data sharing. The guide proposes seven principles: building trust; articulating the value; planning; using quality data; understanding the legal context; coming to agreement; and evaluating. The guidelines help create the right environment for data sharing and to facilitate good practice in addressing technical, political, ethical, economic and legal concerns that may arise. The guidelines aim to ensure, to the greatest extent possible, that any benefits arising from use of the data are shared equitably [37].

7.5 Ethical Issues in Public Health Surveillance

Similar to clinical or public health practice, institutions or agencies responsible for public health surveillance need a set of ethical principles to guide their operations. The 2017 WHO guidelines on ethical issues in public health surveillance proposed 17 guidelines [38]. These guidelines fall into three major groups: first, the mandate and broad responsibility of the agency to undertake surveillance and subject it to ethical scrutiny; second, the obligation to ensure appropriate protection and rights of individuals under surveillance; and third, considerations in making decisions about how to communicate and share surveillance data to pursue common good and equity of population without harm to individual.

8 Conclusion

The West African Ebola outbreak provided a costly lesson that policymakers must commit to establishing, maintaining and advancing public health surveillance systems to protect and promote population health. To prepare for the next major outbreak, the world needs to invest in a strong warning and response system led by a global institution with sufficient authority and funding to react swiftly [39]. WHO serves this role but is chronically underfunded. Similar investment is needed in countries where a fully supported, well-functioning surveillance office or programme must coordinate different components of the surveillance system. Surveillance information should be disseminated widely to alert the public and health programmes of outbreaks so that they can contain the disease at source before it spreads internationally. Because the world urgently needs reliable and timely surveillance information, public health surveillance should continue to make innovative use of new technology to gather and share information strategically and fairly.

Key Messages

- The 2014 Ebola outbreak highlighted inadequacies of national and global surveillance systems to detect and respond to public health threats.
- Surveillance provides critical data and information to guide, improve and protect public health.
- More trained staff are needed for effective and efficient surveillance especially in low- and middle-income countries.
- Innovative use of information technology and social media can aid detection of public health threats.

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Part III

Specialised Systems for Global Health Data

Preface

In this section, authors provide important examples of how specialised systems provide data to inform global health—particularly to meet specific Sustainable Development Goals. Although the examples are quite different from each other, they highlight key data issues and demonstrate: (1) the need to interface and harmonise specialised data systems with the data sources authors describe in Part II; (2) that data are relevant to both local and global resource planning; and (3) that different systems must attain the best data quality standards even in very difficult situations.

National Health Accounts (NHA) collect and analyse financial data to track health spending, disaggregating expenditures by four dimensions: sources of financing, financing agents, types of health-care provider, and types of health-care functions (Chap. 11). NHA are vital to measuring progress towards Universal Health Coverage around the world, for example, they estimate out-of-pocket expenditures on health by households. Combined with demographic and epidemiological data collected through the instruments authors describe in Part II, NHA inform strategies to direct resources towards major health priorities, that is, they can measure whether expenditure for specific diseases are proportionate to their disease burden.

The extreme shortage of health workers worldwide emphasises the importance of data to plan and project workforce needs. Without having data on the ratio of physicians to population, for example, it is difficult to plan how many to educate. Chapter 12 introduces National Health Workforce Accounts as an internationally accepted system for standardising the architecture of

health workforce information and making it possible to share data with other information systems within a country and internationally. The authors describe challenges, progress, and future opportunities in strengthening and harmonising national information systems for human resources for health.

Many of the systems authors describe in Part II do not function in emergency situations, particularly in countries experiencing armed conflict; yet the world needs data to understand the health impact and to plan humanitarian assistance. Chapter 13 examines the advantages and limitations of traditional systems in collecting data during and after armed conflict, and offers alternative approaches for measuring mortality related directly or indirectly to conflict, such as asking informants about deaths occurring in the community. The authors provide examples and challenges for the global health community in producing high-quality, timely, and actionable mortality data in demanding circumstances.

The health sector depends on data from several non-health sectors and key among them is climate. While scientific evidence indicates that climate contributes significantly to certain health outcomes, climate data are not usually integrated into health data systems. Yet, knowledge of rainfall distribution, for example, can be vital in predicting malaria epidemics in small areas or across malaria endemic regions of the world. The authors of Chap. 14 describe types and sources of climate data, and how public health practitioners can incorporate them into health information and disease early warning systems.

Chapter 15 describes a system for data collection that can underpin all others, that is, a geographic information system (GIS). Organisations can lever a GIS to allocate resources, budget, support policies, improve equity, defend decisions, and improve operational efficiency. All the tools authors describe in Part II can be enhanced by using a GIS both as a means for collecting data and for analysing data across geographical areas. The chapter addresses three key *questions: What is where? Why is it there? and Why do I care?*

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Tracking Health Resources Using National Health Accounts

Thomas Maina and Daniel Mwai

1 Introduction

In the Republic of Serbia, in 2015, health-care expenditure per capita was 223 Euros, up from 195 Euros in 2010, according to estimates published by Gajić-Stevanović et al. [1]. Cardiovascular diseases accounted for 19.8 per cent of health-care expenditure, followed by diseases of the digestive system at 10.7 per cent and neoplasm at 10.6 per cent. The high relative medical expenditure burden of cardiovascular diseases was similar to that of other European countries. The authors of this study suggested that rising costs indicated 'insufficient investment in prevention, public health services, capital investment and other functions related to health care'.

During Serbia's health sector reform, beginning 2002, policymakers requested a tool to monitor health-care spending across the country. The government began setting up National Health Accounts (NHA) in 2004 and now publishes regular reports which the ministry of health uses to track health sector performance, develop national strategies and manage its resources. The

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accounts have offered new insights, for example, showing that households were responsible for 35 per cent of health spending, an observation that 'significantly differed from government officials' perceptions'. In 2014, the government included NHA in the Serbian Health Care Law [2].

NHA generate information on the state of health financing in a country including monitoring how resource distribution may affect the efficiency, equity and sustainability of health system activities. NHA measure total health spending in a country in a given period of time, providing answers to questions about how the health system mobilizes and manages its resources, who pays for health care and how much they pay, who uses which goods and services, how spending distributes across services, interventions and activities, and who benefits from the spending [3].

In this chapter, we describe the policy utility of NHA especially in the context of countries endeavouring to achieve Universal Health Coverage (UHC). We use data from several rounds of NHA undertaken in Kenya to show how the NHA framework can profile the health-financing situation of a country and inform policy development. We start by exploring the utility of tracking comprehensive health-financing data. We introduce different methods of tracking, including NHA, and discuss the relevance of such data for monitoring UHC. In Sect. 4, we examine the purpose of undertaking NHA and introduce the framework on which NHA are based. In Sect. 5, we describe use of the NHA method in producing health information. Finally, we demonstrate how NHA data can be used for international comparison and highlight challenges in collecting and using NHA data.

2 Utility and Collection of Comprehensive Health-Financing Data

Comprehensive and reliable health-financing data produced on a timely basis are critical to informing sound health policy development and planning. Such data are especially consequential for health policymaking and planning in countries where resources are scarce and their supply is unpredictable [4]. Without accurate data on the size and distribution of available health funds, policymakers cannot align allocation of scarce resources to a country's priority interventions. Lack of such data hinders efforts to improve the population's access to quality health-care services. To support achieving an efficient, equitable and effective health system, answers to questions like *how much do we spend on health?* and *on what type of goods and services?* and *to whom?* are of paramount importance.

Efforts to generate financial data to trace the flow of health resources within the health system—commonly referred to as *health resource tracking*—started in the 1950s mainly in high-income countries (HICs). In 1960, using national surveys, Abel-Smith produced comparative expenditure analyses for six countries including Chile and Sri Lanka (then Ceylon), marking the first efforts to track resources in low- and middle-income countries (LMICs) [4, 5]. He followed up with a comparative expenditure analysis for 29 countries, 14 of which he classified as *developing* countries [6]. Countries undertook further health expenditure analyses with support from the World Health Organization (WHO) and other institutions like the United States Agency for International Development (USAID), the World Bank (WB) and the Pan America Health Organization (PAHO). It was not until the 1970s that LMICs started to undertake health financing and expenditure surveys to produce health expenditure data—with production of manuals to guide the surveys also getting top priority [7]. Since that time, countries have begun to standardize their health resource tracking using NHA [4].

Although NHA now provide the most comprehensive and internationally accepted methodology for tracking the flow of health resources within the health system [3], other health resource tracking tools include: *National AIDS Spending Assessment (NASA)* that tracks the flow of resources spent responding to HIV/AIDS using methods similar to NHA [8]; *Public Expenditure Reviews (PER)* examine the composition and structure of public spending—they can be applied to specific sectors including health [9, 10]; *Public Expenditure Tracking Surveys (PETS)* track the flow of public resources and material resources from the level of the national government, through the administrative decision points, and ultimately to frontline service providers—with the aim of improving quality of services provided by the lower level structures [11]; *Health Budget Analysis (HBA)* examines trends and size of budget allocation to the health sector including splitting the budget by recurrent and development expenditure, by economic and functional classifications and by programmes to assess how governments allocate resources to the health sector and the areas these funds cover [12].

These tools, including NHA, collect financial and expenditure data from a combination of sources. Investigators usually extract government expenditure data from expenditure records that include appropriation records as well as budget documents. They use surveys, and in some cases censuses, to obtain expenditure data from other sources such as donors, insurance companies, private firms, parastatals and households. For instance, investigators administer a questionnaire to a sample of private firms to extract financial and health expenditure data from which they then extrapolate to generate an estimate that represents

health spending by all private firms in the country. To estimate how much households are spending on health at a particular point in time, investigators administer a household health expenditure and utilization survey to a representative sample of households. Examples of internationally conducted surveys that contain household expenditure for health are the World Health Survey [13], Living Standard Measurement Survey, Household Budget Survey and the Income and Expenditure Survey. The Demographic and Health Survey now has an optional household expenditure module [14].

3 Importance of NHA Resource Tracking for UHC

Achieving UHC dominates the policy discourse in many LMICs. UHC means that 'all people and communities can use health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the users to financial hardship' [15]. This definition of UHC embodies three related objectives: equity in access to health services—everyone who needs services should get them, not only those who can pay for them; the quality of health services—these services should improve the health of people receiving them; and financial protection—people using services should not be at risk of catastrophic expenditures. Tracking progress towards realizing these objectives is important in ensuring the movement towards UHC stays on track (see Chap. 4).

Tracking achievement of UHC as far as equity is concerned requires disaggregated data on utilization of health services by income group, as well as other socio-demographic characteristics. Disaggregation by income makes it possible to assess whether households in all income groups have an equal chance of accessing quality health-care services when they need them. Investigators usually collect these types of data using household health expenditure and utilization surveys. These surveys also provide information on spending on health-care services by households through out-of-pocket payments—which the NHA framework includes in its methodology.

Two indicators of *financial protection coverage* measure whether households have access to quality health services without facing financial hardship. *Catastrophic health spending* measures the proportion of households whose out-of-pocket expenditures on health exceed a threshold of their total income that could lead them into poverty (see Chap. 2). *Impoverishment* measures the

fraction of households that become impoverished because of having to pay for health care through out-of-pocket payments and are therefore pushed further into poverty. NHA can generate these financial protection coverage indicators.

4 NHA and Systems of Health Accounts

NHA provide health-financing data that inform health policy design and implementation as well as the dialogue around health-financing policy and strategies. NHA information is important to policymakers as it shows the sources financing health care and how much each source is contributing.

4.1 Development of NHA Based on SHA

NHA evolved from the Organization of Economic Cooperation and Development (OECD) System of Health Accounts (SHA) which requires member countries to report their domestic health expenditures annually using a standardized format [16]. The US refined the methodology, adopting the term NHA, and some LMICs, including India, the Philippines and Egypt, started using NHA in the 1990s further developing the methods for their use [17, 18].

In 2000, increased interest in using a standardized approach to collection and reporting comprehensive and detailed health expenditures data led OECD to develop the System of Health Accounts (SHA 1.0 framework. The USAID, WB and WHO supported the production of a *Guide to Producing NHA* that adapted the SHA version for use in LMICs [3]. The OECD updated the SHA framework in 2011 strengthening classifications to support production of detailed analyses and introducing new classifications that expand the scope of analysis and provide a more comprehensive look at the expenditure flows within a health system [19].

4.2 The SHA Framework for NHA

NHA/SHA answer four critical questions related to health financing: *where does the money come from?* (financing sources); *who manages and organizes the funds?* (financing agents); *where did the money go?* (health providers); and *what type of service was actually produced?* (health functions). The first

two questions are in line with the core functions of health-care financing which are revenue collection, fund pooling and purchasing of services as alluded to in Kutzin 2001 [20] and the World Health Report of 2010 [21]. SHA 2011 consist of three core dimensions that are mandatory for all OECD countries [19]:

> *Financing schemes*: The rules and regulations surrounding the financing arrangements that fund health-care or the main types of financing arrangements through which people receive health-care. Examples include national health insurance, private health insurance and government-funded programmes run through national ministries.
>
> *Health-care providers*: Actors that deliver health-care. Examples include clinics, hospitals, pharmacies and health centres.
>
> *Health-care functions:* Type of health services or goods that are consumed. Examples include prevention programmes, outpatient services, drugs consumed at home, and health systems governance and regulation.

The extended framework proposes four additional optional classifications: *revenues of health-financing schemes* which are types of revenue collected by financing schemes and include voluntary prepayment from employers for health insurance, internal transfers of tax revenue and mandatory prepayment from households; *financing agents* which manage health expenditures; *factors of provision* such as drugs, consumables, salaries and utilities; and *beneficiary characteristics* that describe the individuals that consume health care such as disease, gender, age and sub-national region.

4.3 Use of the NHA/SHA Framework

We draw on our experience in developing NHA in Kenya to illustrate the process. The Government of Kenya pioneered use of the NHA framework in the East and Southern Africa (ECSA) region, particularly by producing sub-account estimations. Kenya has undertaken six rounds of NHA between 1998 and 2016 with support from USAID and WHO (Box 11.1). Many international guidelines have incorporated Kenya's experience using NHA. Kenya is also beginning to serve as a centre for ECSA regional workshops on health accounts.

Box 11.1 Use of National Health Accounts (NHA) by the Government of Kenya

Kenya is a lower-middle income country with a per capita spending of about USD 1,417 and an economic growth rate of about 5.6 per cent in 2015 compared to 5.3 per cent in 2014 [22]. Kenya's population has doubled over the last 25 years to about 47 million people. The rapid population growth is the result of high fertility, currently estimated at 2.6 per cent, a reduction in mortality which has been attributed to improved access to quality health care as well as increase in life expectancy. The infant mortality rate (IMR) has fallen from 77 per 1,000 live births in 2003 to 39 in 2014 and the under-five mortality rate has also fallen from 115 per 1,000 live births in 2003 to 52 in 2014. Neonatal mortality has remained high contributing to about 35 per cent of the IMR. The maternal mortality ratio has remained high at 362 deaths per 100,000 live births against a global trend of declining ratios from 400 to 210 maternal deaths per 100,000 live births in 1990 and 2010 respectively [23].

Kenya's burden of disease has for some time been mostly related to communicable diseases such as HIV/AIDS, respiratory infections, malaria and tuberculosis [24]. However, evidence shows an emerging increase in the prevalence of non-communicable diseases such as cancers, heart diseases, diabetes and chronic respiratory diseases [25].

Kenya undertook its first round of NHA in 1998, using data for the financial year 1994/95. Publication of the first NHA findings produced some surprises. Stakeholders had generally assumed that the Kenyan Government was the main financier of the health sector. The report, however, showed that households contributed about 53 per cent of total health expenditure in Kenya compared to the government's contribution of only about 20 per cent.

The Ministry of Health commissioned the second round of NHA in 2003 using data for the financial year 2001/02 and included three disease sub-accounts, namely HIV/AIDS, tuberculosis and malaria. The third and fourth rounds covered the financial years 2005/06 and 2009/10. The first four rounds of NHA were based on SHA 1.0 with the fifth and sixth rounds, for the financial years 2012/13 and 2015/16, using the revised SHA 2011 framework. The 2015/16 NHA found that the government and households each contributed about 33 per cent of current health expenditure (CHE) [26].

5 The NHA Production Process

The NHA team usually consists of representatives from the national statistical office, ministries of health and finance and academic and research institutions. Figure 11.1 summarizes the NHA production process. The USAID-funded Health Systems 20/20 Project, with support from WHO and the WB, has developed the *NHA Production tool (NHAPT)* to streamline the process of data entry, analysis and results production. NHAPT reduces the need for technical assistance [27].

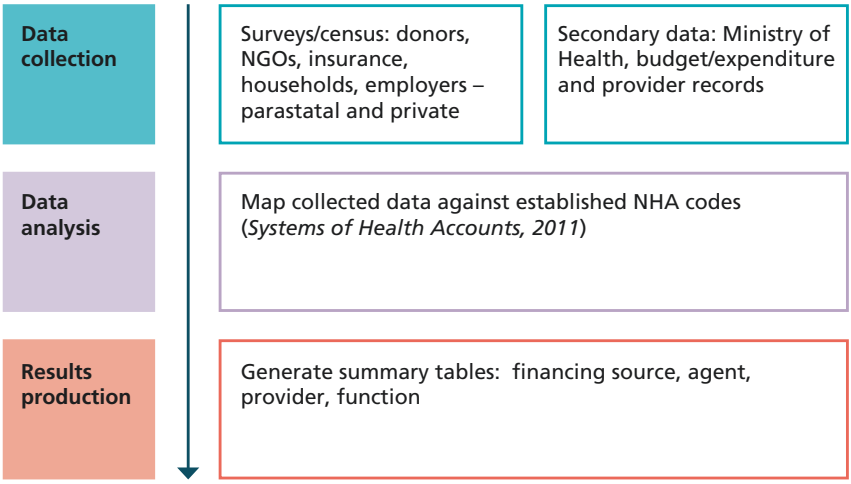

Fig. 11.1 The National Health Accounts (NHA) production process

5.1 Data Collection and Analysis

The NHA team collects data from primary and secondary sources. Primary sources include institutional surveys, key among them donors, private firms and insurance companies as well surveys of parastatals. The team uses the findings of available household health expenditure surveys to estimate total spending on health by households including out-of-pocket payments. Other secondary sources of NHA data include government executed budget and expenditure reports, Demographic and Health Surveys, service provision assessments, public expenditure reviews, and health information systems. For example, in Kenya:

> The 2015/16 Kenyan NHA team collected primary data by administering questionnaires to sampled employer firms (private and parastatals), insurance firms offering medical insurance cover, non-governmental organizations and development partners. The team interviewed 234 parastatals (88 per cent response), 295 private firms (80 per cent response), 218 non-governmental organizations (77 per cent response) and 29 insurance companies (97 per cent response). The team estimated household out-of-pocket spending on health from the 2013 Kenya Household Health Expenditure and Utilization Survey (KHHEUS) [28] which included questions about health-seeking behaviour of households, household out-of-pocket expenditure and health insurance coverage. The team adjusted the 2013 estimates for inflation and population change. It obtained county health expenditure data from county governments' estimates of recurrent and capital expenditures from appropriation accounts for the period 2015/16 (recurrent and capital). The team entered the data into NHAPT.

5.2 Results Production Summary Tables

Until the revised 2011 SHA framework, NHA primarily reported annual *total health expenditure* (THE) which is simply the sum of all public and private expenditures on health including capital health expenditures; expressed as per capita health expenditure or as a percentage of the gross domestic product. NHA now also report on both *current health expenditure* (CHE) and *capital spending* (HK). CHE refers to all health-care goods and services used or consumed during a year whereas capital spending or gross capital formation (HK) refers to purchases of new assets which are used repeatedly over several years. HK includes investments in buildings, machinery, technology and stocks of vaccines. The separation of current and capital expenditures improves comparability between individual countries and over time. The level of resources invested in infrastructure, equipment and information technology tends to fluctuate more than current spending on health services but improves the resilience of the health system [29]. See the SHA 2011 Framework for a detailed explanation for this change [19].

The NHA team usually produces four NHA tables by first disaggregating THE, and now CHE, by the revenue source *(where did the money come from?)*; and then disaggregates by the three core SHA dimensions: financing schemes *(who managed and organized the funds?)*; health providers *(where did the money go?)*; and health functions *(what type of service was actually produced?)* plus any of the extended classifications. For example, Fig. 11.2, based on one such table for Kenya, shows the breakdown of CHE by these four categories for the 2015/16 NHA in Kenya.

The 2015/16 Kenya NHA reported THE to be Kshs. 346 billion or (USD 3,476 million), an increase of about 30 per cent from what was reported in 2012/13, accounting for 5.2 per cent of GDP, with THE per capita of Kshs. 7,822 (or USD 78.6) up from Kshs. 6,602 (or USD 77.4) in 2012/13. CHE increased by 68 per cent from Kshs. 194 billion (or USD 2,557 million) in 2009/10 to Kshs. 326 billion (or USD 3,274 million) in 2015/16.

Where did the money come from? The three major sources of health revenues were government, households and donors (rest of the world). The proportion of CHE contributed by donors decreased from 32 per cent in 2009/10 to 22 per cent in 2015/16 while the proportion contributed by the government and households increased from 27 per cent and 30 per cent respectively to 33 per cent for each scheme.

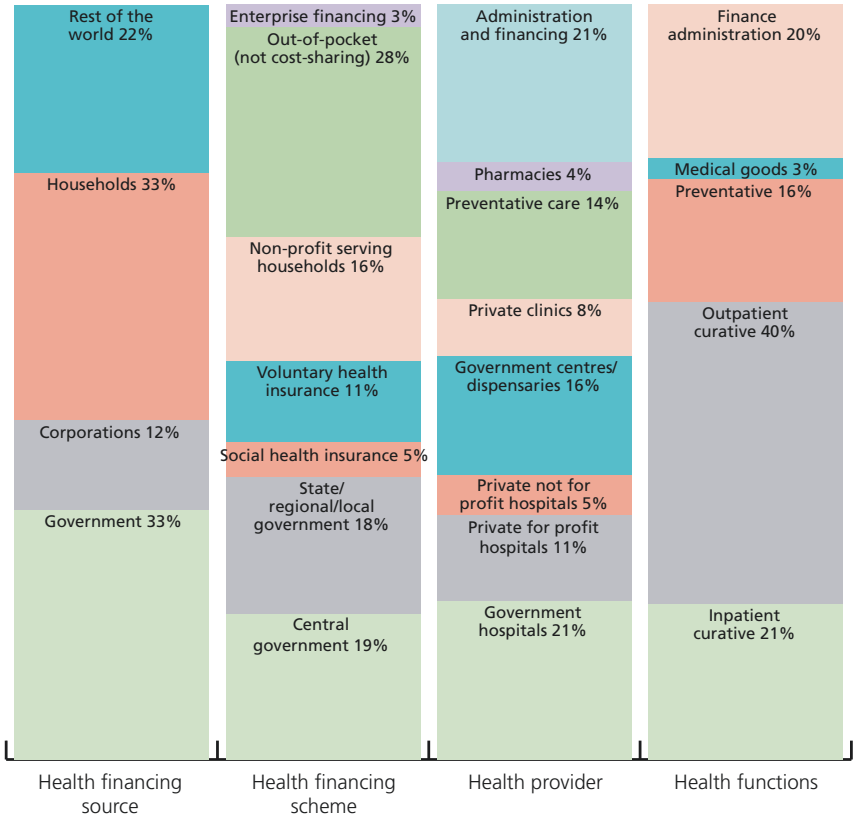

Fig. 11.2 Current health expenditure for the Kenya 2015/16 National Health Accounts by revenue source, financing schemes, health providers and health functions

Who managed and organized the funds? The majority of CHE in 2015/16 was mobilized through central government schemes and out-of-pocket expenses (excluding cost-sharing) at 37 per cent and 28 per cent respectively. Pre-paid schemes (voluntary and social health insurance schemes) accounted for 16 per cent of CHE 2015/16.

Where did the money go? Hospitals consumed the highest proportion of CHE at 37 per cent down from 48 per cent in 2009/10. The proportion of CHE consumed by primary health facilities was 24 per cent up from 14 per cent in 2009/10 while providers of preventive care accounted for about 14 per cent of CHE in all the three rounds of NHA. Providers of health system and financing administration accounted for 21 per cent of CHE in 2015/16 up from 8 per cent in 2009/10.

What type of service was actually produced? The highest proportion of CHE goes to finance facility based outpatient and inpatient curative care at 61 per cent in 2015/16, down from 63 per cent in 2009/10. The proportion of THE

> going to financed preventive health care has been low for the three rounds of NHA, dropping from 24 per cent in 2009/10 to 16 per cent in 2015/16 while the proportion of CHE spent on administration at 20 per cent more than doubled from 2009/10.

Because the NHA estimates are summarized in four dimensions, it is possible to cross-check entries that appear in at least two data sources [4]. For instance from a source point of view, a donor survey may show that donors channelled a certain sum of money to a certain financing agent, for example, the ministry of health. A review of health expenditure data from the ministry may show several sources of financing spending including from donors, and so the sources can be cross-checked. For example, the Kenyan 2015/16 NHA team collected data from development partners and reviewed *on-budget development support* through the national and county treasury to capture the total amount of development assistance for health. The team used these data to validate the data from non-governmental organizations (NGOs) which receive support through the partners.

Sub-accounts In addition to examining overall health-care expenditures, some NHA teams conduct sub-analyses for specific conditions or programmes. Information on expenditure by disease can assist in allocating resources to those programmes, answering questions such as: *what diseases/conditions are consuming health-care resources, and how much? which schemes pay for the services that address these diseases or conditions, and how much?* and *how is spending on certain diseases broken down according to types of care?* Switzerland disaggregated NHA data on health-care spending for 2011 by 21 major disease categories and found that non-communicable diseases accounted for 79.4 per cent of total health spending. Cardiovascular diseases stood out at 15.6 per cent of total spending [30]. This compares to 19.8 per cent in our opening example for Serbia in 2015 [1]. The authors of the Swiss study commented that the figures 'illustrate how health-care spending is influenced by the epidemiological transition and increasing life expectancy'. The Kenya NHA team develops sub-accounts for HIV/AIDS, tuberculosis, malaria, reproductive health and child health:

> Kenya bases its choice of diseases to include in the NHA on its top causes of death and disabilities as classified in the WHO International Classification of Diseases (ICD). They use both targeted expenditures that had already

been earmarked and untargeted expenditures that were apportioned between the diseases using distribution keys developed from the unit costs for treating a case and utilization data (case-loads). The unit costs data were sourced from costing information generated using the One-Health model [31] as well as the Dynamic Costing model [32]. Utilization data were sourced from the District Health Information System (DHIS2) [33] as well as the KHHEUS.

Figure 11.3 presents data on spending by disease (illness or condition) for 2015/16. The breakdown was very similar in 2012/13. HIV/AIDS took the largest share of resources mobilized for health at 20.1 per cent (Kshs. 69.4 billion or USD 698 million) followed by reproductive health at 12.1 per cent (Kshs. 34.5 billion or USD 405 million).

Donors accounted for the highest proportion of total of resources for HIV/AIDS in 2015/16 (62 per cent), followed by government at 22 per cent and households at 9 per cent. With respect to reproductive health, government accounted for the largest share of CHE in 2015/16 (32 per cent) with households accounting for 30 per cent. In terms of health-financing schemes, the Non-Profit Institutions serving Households (NPISH), or NGOs, pooled the largest proportion of CHE for HIV/AIDS at 62 per cent in 2015/16 down from 72 per cent in 2012/13 followed by central government schemes at 13 per cent. With respect to reproductive health, out-of-pocket financing schemes and government schemes pooled the largest share of CHE at 27 per cent and 33 per cent respectively.

Providers of preventive care for HIV/AIDS used the highest proportion of CHE for HIV/AIDS at 38 per cent in 2015/16, a drop from 42 per cent in 2012/13, while public facilities—hospitals, health centres and dispensaries consumed 22 per cent of CHE for HIV/AIDS in 2015/16, down from 27 per cent in 2012/13. In 2015/16, public facilities used 37 per cent of CHE for reproductive health, down from 42 per cent in 2012/13. Providers of preventive health care accounted for about 17 per cent of CHE for reproductive health which was increased from 7 per cent in 2012/13.

Outpatient curative care used the highest proportion of CHE for HIV/AIDS at 36 per cent and 39 per cent in 2012/13 and 2015/16 respectively, while preventive care consumed 42 per cent of CHE for HIV/AIDS, which was an increase from what was reported in 2012/13 (38 per cent). Curative care, which includes outpatient and inpatient care used the highest proportion of CHE for reproductive health at 68 per cent in 2015/16, which was an increased from what was reported in 2012/13—65 per cent. The proportion of CHE for reproductive health used by preventive care increased from 7 per cent in 2012/13 to 18 per cent in 2015/16.

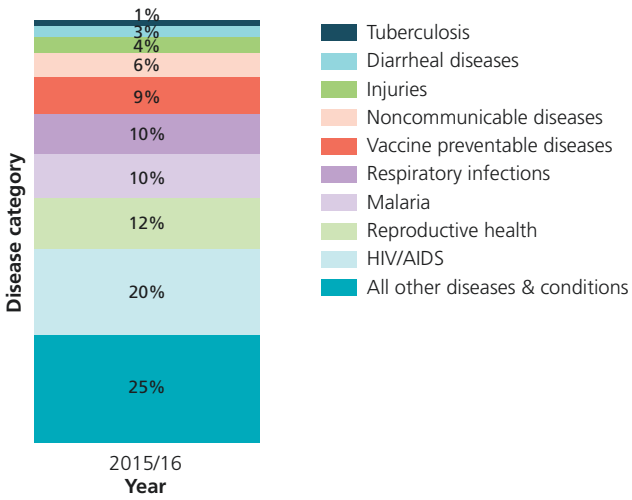

Fig. 11.3 Current health expenditure by disease (illness or condition), Kenya 2015/16 National Health Accounts

6 Policy Utility of NHA for Kenya

NHA provide a framework for measuring THE/CHE from public and private sources and from donors formatted in a standard set of simplified and user friendly tables and diagrams. They present health expenditure data in a simple format that policymakers can understand and interpret. The six rounds of NHA in Kenya have returned some interesting results with respect to the health-financing landscape in Kenya. The initial rounds showed a financing situation that was dominated by donors with the last two rounds showing a decreasing role of donors and increasing role of the Kenyan government with county governments also playing a critical role in financing health. Over time, households' contribution to health expenditure has increased.

On the basis of the evidence generated through the NHA, Kenya is reforming its health-financing system so that the system can generate adequate resources in a sustainable, efficient and effective manner and protect households from financial harm associated with having to make out-of-pocket payments for health care.

If implemented on a regular basis, NHA can track health expenditure trends to monitor and evaluate the impact of policy changes. We give a few examples of policy impact in Kenya. The Ministry of Health used the NHA of 2001/02 to mobilize more resources for health from the national government. Kenya's NHA of 2001/02 showed that households were financing 51 per cent of Kenya's total health spending with the government contributing 30 per cent of THE. The high household spending on health was significant given the high levels of poverty in the country. The then Minister

of Health used the NHA evidence to make a case for more funding and secured a 30 per cent budget increase in 2006 from the Ministry of Finance. This represented its biggest budget increase since 1963.

The NHA results of 2001/02 showed the extent of inequities in utilization and burden of financing on households. The Ministry of Health packaged the information and used it to inform debate and legislation on social health insurance (SHI). Legislation for SHI went to parliament in 2004 although a political decision was taken not to adopt this insurance model to finance health care in Kenya. SHI is however included as a major health policy in the country's long-term development blue print, the Vision 2030 [34]. The trends in health financing from the several rounds of NHA have informed development of the Kenya's draft health-financing strategy and to justify adoption of interventions that are meant to cushion the poor from catastrophic out-of-pocket expenses including the Free Maternity Health Policy Programme and the Free Health Services at Health Centres and Dispensaries.

7 Comparisons and Challenges

An important use of NHA is to make cross-country comparisons. The OECD maintains an interactive database of all NHA aggregates and indicators in each of the domains for each of its 35 member countries [35]. Comparisons of the indicators show patterns in health spending. For example, a 2015 report showed that in 2013 health spending across the then 34 countries grew by 1 per cent, in line with GDP growth, but a third of countries showed a real term cut in overall health spending; the average public share of health spending remained constant at about 73 per cent although there has been a shift towards private sources of health financing. The report also made comparisons with key emerging economies (China, Brazil, Indonesia and the Russian Federation) and showed increases in spending as they strive towards UHC [36].

WHO's Global Health Expenditure Database (GHED) provides harmonized health expenditure estimates and indicators for over 190 member countries now using SHA 2011 from the year 2000 onwards [37]. In 2017, using these data, WHO produced a report on global health spending to inform UHC, examining global expenditure on health, levels of public spending, the role of development assistance, out-of-pocket expenditures and the revenue sources for spending through social health insurance. The GHED also publishes dashboards showing regional distribution and structure of CHE.

Cross-country comparison was a strong motivation for OECD's development of the SHA methodology but the approach is difficult for some countries to implement. In a systematic review, Bui et al. found 872 NHA reports from

117 countries worldwide between 1996 and 2010 containing a total of 2,936 matrices or tables. Out of the 872 NHA reports that Bui et al. identified, only 252 presented data using all four NHA types of matrices for any country and year. Each OECD country produced all 15 annual reports for the period while non-OECD HICs produced none. The average number of reports over all the years from low-income countries and from middle-income countries were similar at 1.88 and 1.86 reports per country respectively. The average number of reports was lowest for countries in areas of the Eastern Mediterranean and North Africa, Latin America and the Caribbean, and sub-Saharan Africa [38].

A major challenge in generating NHA estimates is collection and triangulation of data from several sources. The process can be time-consuming and tedious and requires consistency. To maintain ownership, participation of all key stakeholders is important especially if the results are to inform the policy process. That is why it is recommended that trained members of the NHA team undertake the estimation process as opposed to employing external consultants to construct the NHA estimates. The purpose of undertaking the NHA estimation needs to be clear right from the beginning of the process as this will ensure all the required data are collected.

8 Conclusion

Comprehensive, reliable and timely health-financing data are critical in making sound health policy. Health-financing information allows policymakers, donors and other key stakeholders to make informed decisions about the financing of health care in a country. These data are critical at both the domestic and international level especially for comparison purposes. Policymakers require health-financing data to make informed decisions on how to allocate resources between competing priorities. NHA provide data that can be used to track the progress made by countries in their endeavour to achieve UHC.

Kenya demonstrates that NHA have been critical in ensuring comprehensive and reliable health-financing data are available to decision-makers faced with allocating scarce resources among competing needs.

Key Messages

- Comprehensive, reliable and timely health-financing data are critical in making sound health policy.
- NHA inform health-financing policy dialogues in LMICs.
- NHA methods are vital to inform progress towards achievement of UHC.
- In many countries, health-care financing is dominated by households mainly through out-of-pocket payments.

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12

Data to Monitor and Manage the Health Workforce

Amani Siyam, Khassoum Diallo, Sofia Lopes, and Jim Campbell

1 Introduction

In the US, the national demand for physician services is expected to exceed supply by 2025 [1]. Shortages are particularly severe in rural areas. The US Veterans Administration (VA), one of the largest US health-care systems, serves war veterans and their families and survivors through about 170 medical centres, 26 per cent of which are in rural areas. Given the national situation and growing demand for its services, the VA asked the Government Accountability Office to advise on whether the Veterans Health Administration (VHA) has enough physicians. The question seems simple enough, especially in a country with sophisticated human resource statistical systems. Yet the report found that the VHA was 'unable to accurately count the total number of physicians who provide care in its VA medical centers' and that it had 'not evaluated the

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effectiveness of its physician recruitment and retention strategies.' The report recommended that for effective workforce planning, the VHA develop a process to count all physicians, prepare guidance on productivity management and evaluate causes of recruitment and retention difficulties [1].

Human resources are the backbone of a functioning health system and central to achieving Universal Health Coverage (UHC). This example from a high-income country highlights the critical importance of accurate and detailed data on the health workforce for planning and accountability. Without such data, health agencies are unable to deliver on their mandates. Governments cannot achieve the vision of the Sustainable Development Goals (SDGs) [2], and in particular SDG3 on health and well-being [3], without adequate health workforces to deliver quality and equitable services.

There are serious shortages of health workers worldwide, particularly in low- and middle-income countries (LMICs). International organisations have issued resolutions and frameworks positioning human resources for health (HRH) at the centre of the global health agenda and calling for efforts to strengthen the health workforce. Few of these resolutions address the challenges of providing decision-makers with sufficient information and evidence to build a 'fit for purpose and a fit for practice health workforce,' [4] able to respond to the health needs of the people they serve.

In this chapter, we describe the historical trends in and progressive global commitment to strengthening HRH data and information, including production of harmonised metrics for understanding and planning the dynamics of the health and education labour markets. We then present an overview of HRH data sources, indicators, and analytical methods, and discuss, comparability and governance of HRH data. We introduce the National Health Workforce Accounts (NHWA) as a new evidenced-based inter-sectoral approach to improve HRH data availability, standardisation, comparability and interoperability.

2 The Health Workforce Crisis and International Agreements to Address It

The World Health Report 2006 unveiled the HRH crisis [5]. The report exposed the shortage and maldistribution of health workers, particularly in resource-poor countries and demonstrated that this impaired the delivery of health care and impacted health outcomes. Despite subsequent progress, international estimates show that globally the current stock of health workers cannot meet the health needs of the world's population, or achieve the SDGs and UHC. For example, in 2014, the International Labour Organization

(ILO) estimated a shortfall of 10.3 million health workers to achieve UHC [6]. In 2016, the World Health Organization (WHO) predicted a shortfall of 18 million health workers worldwide by 2030, using a minimum workforce density threshold of 4.45 physicians, nurses and midwives per 1,000 population needed to achieve the SDGs [4]. Fig. 12.1 shows that the largest projected needs-based shortages of health workers in 2030 will be in LMICs, especially in Africa at 6.1 million and South-East Asia at 4.7 million [4].

Since 2006, global and national leaders have agreed several resolutions to address the health workforce crisis [7]. In 2013, the Global Forum on Human Resources for Health [8] called for a change in the HRH paradigm suggesting a stronger focus on accessibility, acceptability, quality and productivity of the health workforce, rather than only on shortages. Among the SDGs, Goal 3c aims to 'substantially increase health financing and the recruitment, development, training and retention of the health workforce in developing countries, especially in least developed countries and Small Island developing States' [2].

In May 2016, the World Health Assembly adopted the Global Strategy on Human Resources for Health (GSHRH): Workforce 2030 [4]. This strategy—also endorsed by the United Nations General Assembly and subsequently supported by of the High Level Commission on Health Employment and Economic Growth [9]—framed HRH in terms of achieving the SDGs and

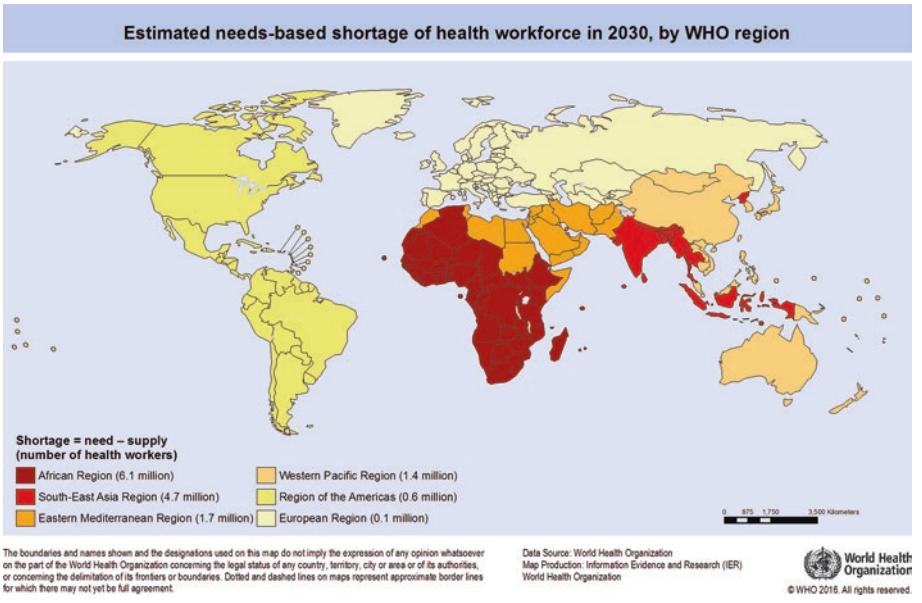

Fig. 12.1 Estimates of health worker needs-based shortages (in millions) below the SDG index threshold by WHO regions, 2030. Source: Table A1.3. Global Strategy for human resources for health: 2030 [4]

UHC, and prioritised strengthening HRH information systems (HRISs) to support health workforce policy development. The GSHRH 2030 proposed the development of NHWA to 'create a harmonized, integrated approach for annual and timely collection of health workforce information, improve the information architecture and interoperability, and define core indicators in support of strategic workforce planning and global monitoring' [4].

Despite progress since the World Health Report 2006, there are significant gaps in availability and quality of data describing the health workforce, and little consistency between countries in how they monitor and evaluate HRH strategies [10]. Few LMICs can provide regular accurate data on the size and distribution for the five main categories of health workforce, namely physicians, nurses, midwives, dentists and pharmacists. Increased mobility patterns and complex flows in and out of the health workforce need to be monitored and taken into account in planning the health workforce as well as in the development of new policies and strategies [4]. Reliable HRH data are essential to respond to these challenges. NHWA provide a novel approach to harmonise and strengthen health workforce information to respond to population needs and expectations at a time of changing demographic, economic and epidemiological profiles.

3 HRH Indicators and Their Data Sources

The World Health Report 2006 defined HRH 'as the stock of all individuals engaged in the promotion, protection or improvement of the health of the population' [5]. Strictly speaking, HRH include unpaid caregivers and volunteers who contribute to improvement of health but data are generally limited to people engaged in paid activities [5]. Operationally, there is no single measure of a health workforce but it is useful to categorise health workers by three elements: (1) their training (health and non-health); (2) their current occupation (tasks and duties performed in the job); and (3) the industry in which they work (activities of the establishment or enterprise) [11].

3.1 Indicators

National and global stakeholders use indicators originating from multiple sources to describe, manage and forecast the health workforce situation depending on the context. But even in national settings where the quantity and quality of HRH information are adequate, managers rarely establish

specific HRH targets and indicators let alone track them in national health systems policies, strategies and development frameworks. NHWA provide a framework to consolidate indicators to ensure their comparability and relevance for policy options to drive UHC. We describe some of the indicators that the international community has recommended for countries to use.

Two of WHO's Global Reference List of 100 Core Health Indicators (2015) [12] refer to the health workforce, in terms of supply (flows) and availability (stock):

The Production of Health Workers (Flows) The number of graduates from health workforce educational institutions (including schools of dentistry, medicine, midwifery, nursing, pharmacy) during the last academic year per 1,000 population which WHO recommends be obtained from training school databases.

The Availability and Distribution of Health Workers (Stock) Health worker density (by cadre) and distribution per 1,000 population which WHO recommends be based on data from national databases or health workforce registries. Health worker density and distribution is also the indicator for SDG target 3c.

NHWA build on this earlier work and include 78 indicators each falling into one of ten modules grouped into categories that correspond with the data required to develop policies to achieve 'UHC with safe, effective person-centred health services.' Figure 12.2 describes the Health Labour Market (HLM) framework developed for delivery of UHC [4] and shows the labour dynamics that require measurement in relation to four policies.

To measure and operationalise the HLM framework, the NHWA indicators are structured around ten modules, each of which addresses specific policy questions in the framework. These include indicators for developing and monitoring: (1) policies that aim to steer the production of health workers; (2) policies related to health labour market dynamics; (3) policies to address the maldistribution of health workers; and (4) policies related to the private sector, governance and regulation of HRH. Indicators for each of the ten modules can be found in the NHWA Handbook [13] which provides metadata for each indicator suggesting its ideal source and method of measurement [14].

The WHO and the Global Health Workforce Network [15] propose that measurement of a *fit-for-purpose* and a *fit-for-practice* health workforce (what the HLM framework (Fig. 12.2) calls a 'health workforce equipped to deliver

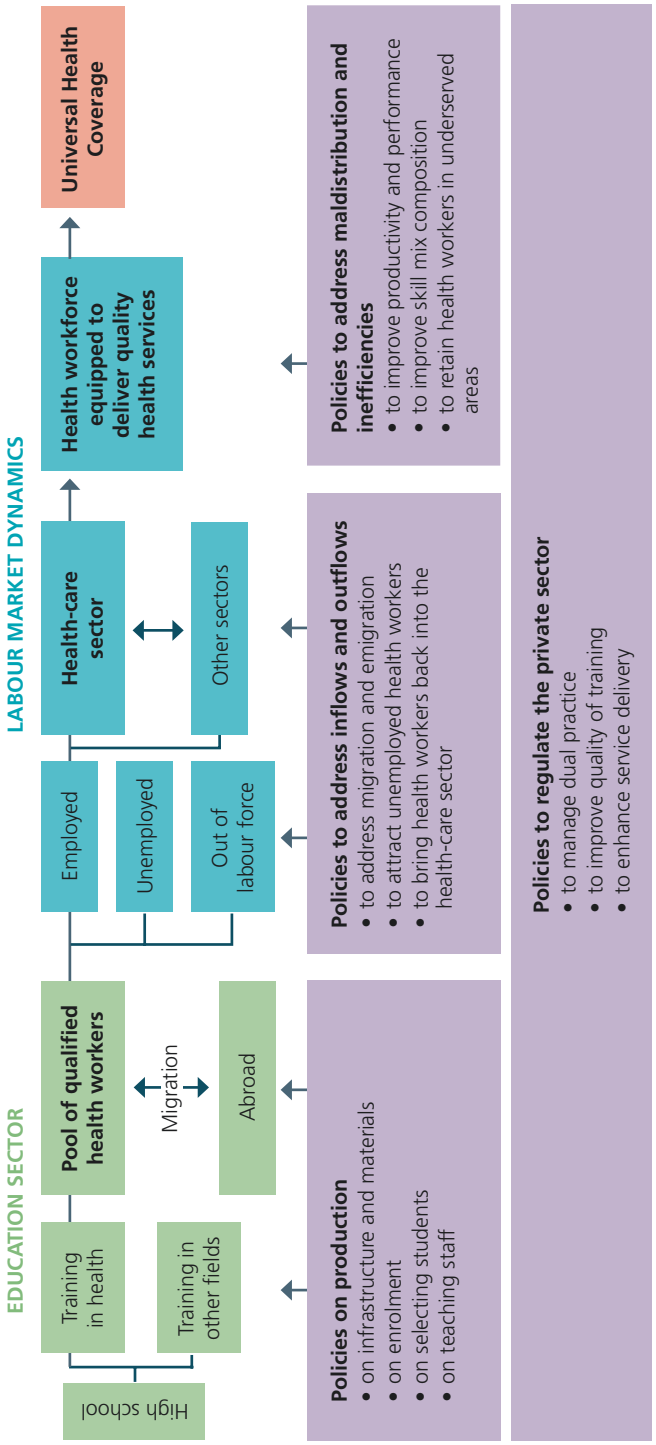

Fig. 12.2 Policy levers to shape health labour markets. Source: Global Strategy on Human resources for Health [4]

quality health service') involves four core dimensions, that is health workers are: (1) available; (2) physically and financially accessible; (3) culturally and socially acceptable to the population; and (4) enabled to provide high-quality care to all those in need [2]. NHWA contain indicators that measure all these dimensions but none that specifically address quality of care, nor do they include qualitative indicators of acceptability of the services to the population.

3.2 Data Sources

No single source or provider can supply the data for the range of NHWA indicators. The NHWA data source landscape requires a multi-stakeholder inter-sectoral approach, involving national statistical offices, ministries of health, finance, labour, education and immigration, and also professional associations or councils and communities. Health workforce data are produced by five major sources: national population censuses, labour force and employment surveys, health facility assessments, routine administrative information systems and health training institution or professional association's records or registries. We describe each source below and provide a comparison of their attributes in Table 12.1.

Population Censuses Most countries undertake a cross-sectional national census every five to ten years to enumerate and describe their total population at that time (see Chap. 6). If the census contains questions on occupation, planners can use the data to map the distribution of the health workforce by cadre, disaggregated by age and sex for census enumeration neighbourhoods. Censuses usually have high coverage and produce comprehensive data.

Labour Force Surveys These are regular cross-sectional national sample surveys of households designed to obtain employment data. These surveys enquire about occupation and delve into greater detail than censuses on, for example, place of work, industrial sector, remuneration, time worked and secondary employment [16]. Frequency varies by country from every month to every five years. The sampling process and sample size limitations can preclude detailed data disaggregation.

Health Facility Assessments There are many forms of health facility assessment but they usually involve a complete inventory of facility activities and resources. They may cover all facilities or a sample of facilities and occur at

Table 12.1 Analytical attributes of human resources for health data sources

	Population-based sources			Institution-based sources	
Attribute	**Census**	**Labour force surveys**	**Health facility surveys**	**Administrative sources (personnel record, payroll, registries)**	**Training institution databases**
Complete count of health workforce	***	***	**	**	**
Across sectors coverage (public, private)	***	***	*	**	**
Disaggregated data (age, sex, geography)	***	**	**	**	*
Capturing unemployment	*	***	–	*	–
Rigorous data collection / management	***	***	***	**	*
Periodicity	*	**	**	**	**
Occupational data coding	*	**	**	**	**
Sampling errors	***	**	*	**	**
Tracking of workforce entry to exit from labour market	*	**	–	**	–
Tracking of in-service training / productivity	–	–	***	*	–
Accessibility to micro-data	**	***	***	**	*
Relative cost	*	***	***	**	**

Key: *** Most favourable; ** Moderate; * Least favourable; – Not available

different time intervals. They only provide data for individuals working in the facility (including those with non-health field training) but they can be disaggregated by faculty type, geographical area and staff age and sex. They may collect data on salaries, in-service training, provider productivity, absenteeism, supervision and available skills for specific interventions [17, 18].

Administrative Sources These include records of public sector employees with details of professional training, registration and licensure. These data are maintained longitudinally for each employee and are usually accurate and up-

to-date. They can be disaggregated by staff demographics, job title, salary and place of work. These records do not include people working in the private sector and suffer from double counting and inclusion of ghost workers.

Training Institution and Professional Association Databases These include records and registries kept by school or university administrations on education and training, or by council boards on memberships. These databases provide a good basis for estimation of numbers and densities but in many countries they are not regularly updated; this challenges their quality and completeness especially when registration is not compulsory.

4 Human Resources Information Systems

Because HRH data derive from so many sources and reach across sectors, it is essential that human resource planners establish a centralised database, or at least a series of interoperable databases, so that they can analyse the national workforce situation, monitor trends and report indicators internationally. Health management information systems have not been successful in generating adequate HRH data and so human resource managers maintain information systems dedicated to human resources. An HRIS is a 'systematic procedure to acquire, store, manipulate, analyse, retrieve and distribute pertinent information regarding the health workforce' [19]. This specialised system is part of the broader complex of systems that make up a country's health information system (see Chap. 1).

HRISs provide a structure for collecting data, assessing their quality and analysing them to produce information on the size, distribution, composition, skill mix, productivity and performance of health workers. The systems are vital in supporting countries to develop, monitor and evaluate their health workforce. For example, a decade after Kenya established its HRIS—the Kenya Health Worker Information System (KHWIS)—in 2002, research demonstrated a range of improvements in health worker regulation, human resources management and workforce policy and planning at Kenya's ministry of health. 'This real time information helps decision making; we can query the existing numbers of nurses, their training and their current place of work,' senior officials said [20]. Although creating such information systems consumes resources, if well designed, managed and maintained, HRIS can be cost-effective and cost-efficient [21].

The main goal of an HRIS is to provide national and sub-national health decision-makers with useful and up-to-date information that can inform and support policymaking, and development, management, and planning of HRH. To do this, an HRIS draws on a complex system of inter-sectoral

sources of data including labour workforce statistics, education inputs, outputs and trajectories, supply and demand balances operating at national and/or at sub- national levels.

The HRIS should cover most of the 78 NHWA indicators, including workforce production, vacancy and recruitment, finance, registration, benefits, payroll, migration, performance management, training and retirement. A health workforce registry and HRH observatories are also central to the system [22]. The HRIS will evolve in response to the development of the NHWA and encourage a standardised approach to data management that supports comparability and interoperability.

A HRIS is typically a computerised structure—run at national and subnational levels—relying on sophisticated software for entering and updating data, databases for storage and tools for analysis and reporting. A digital and linked system improves the availability of real-time HRH data, enhances their accuracy, provides access to aggregated and disaggregated data, and regular analysis and reporting; and increases the system's ability to track people and their mobility.

Development of the HRIS is a lengthy stepwise process that engages the key people who supply and use HRH information [23]. Box 12.1 illustrates how Uganda set up its HRIS. The USAID-funded CapacityPlus project (previously the Capacity project) [23] and other USAID-funded projects have published guidelines and resources for building, maintaining, evaluating and improving the HRIS. CapacityPlus suggests the following five-step process to strengthen the HRIS:

1. *Build HRIS leadership*: a multi-sectoral multi-stakeholder's leadership group can initiate, lead and monitor all HRIS activities, and agree policy decisions the HRIS will inform.
2. *Assess and improve existing systems*: analyse existing HRIS capabilities and requirements of the ministries, councils and organisations that will use the new HRIS solution.
3. *Develop the system*: identify the functions the system will perform and develop a system that includes the functions that matter and are accessible and acceptable to users.
4. *Use the data to make decisions*: ensure the right leaders have easy and timely access to analyses and reports, and that they use this evidence to inform management and planning.
5. *Ensure sustainability*: develop monitoring and evaluation tools to assess the system's performance, with measurable indicators. Ensure the integration and interoperability of the HRIS with other information systems.

Box 12.1 Development of Human Resources Information System (HRIS) in Uganda [24]

In 2006, Uganda had several independent sources of HRH information but lacked a system to coordinate them to provide useful information to decision-makers. Management of HRH data was a weak link in the national health management information system. The Ministry of Health created a Human Resources Technical Working Group and set about developing an HRIS. Their approach was unique in that they integrated data from the government health information system with data from the four national health professional councils.

The ministry adopted the iHRIS software, developed by CapacityPlus, which offers modules in five aspects of HRH: management, qualification, training, planning and retention of health workers [23]. They implemented the HRIS in 81 districts, 14 regional referral hospitals and 2 national referral hospitals. The four professional councils (which previously used different software) used iHRIS to register and licence all health professionals. The end-result was an interoperable national HRIS. In their own words, the end users of the system 'perceived the system to have significantly improved day-to-day operations as well as longer term institutional mandates' [21].

5 Data Analysis, Presentation and Interpretation

The analysis of human resource data presents similar challenges to the analysis of other health data. Firstly, it is essential that data analysts assess the quality, completeness and consistency of available data. Quality HRH data should be reliable, efficient to collect, frequently updated, inclusive across cadres and settings, and supported by interoperable, open source information systems [25]. If the HRIS is computerised, key quality checks can be automated as can the calculation of the indicators, categorised by, for example, distribution or density of health workers by cadre, sex, age, administrative area, and over time; and migration rates by cadre, sex, age and receiving country over time. Visualization of the data using figures and maps help managers and policymakers see trends and inequities, for example, across urban and rural areas. Managers should be familiar with the details of the data system and use the regular reports produced by the system but also, where necessary, analysts should caution policymakers about the interpretation of the indicators they receive.

The analyses depend on the policy questions that need to be answered to inform decision-making, and on the methodology that is most appropriate to answer them. Some tailor-made tools, such as the Workload Indicators of Staffing Needs (WISN), have been designed to analyse HRH data for specific planning purposes [26].

Because the sources of data relevant to HRH are quite diverse [4], some countries use mathematical modelling of health workforce data to develop estimates and inform HRH plans [27]. Modelling may be needs-based (focussing on the need for health services), supply-based (focusing on the production and in-flows of health workers), demand-based (estimating future health service utilisation) or a combination of these approaches [28]. We provide an example of needs-based assessment for pharmacists in Jamaica in Box 12.2. In this example, the models are designed to enable policymakers to 'rehearse potential policies by altering the value of model parameters and examining the estimated effects of such changes on the supply' [29]. A recent literature review conducted to understand how, which and where different HRH metrics are available showed that it is high-income countries that most use the more sophisticated statistical analysis.

Box 12.2 A Planning Approach to Pharmacists in Jamaica [29]

A partnership in Jamaica developed a needs-based HRH simulation model to estimate the need for pharmacists. They wanted to better understand which and how factors affect the supply of and/or requirements for pharmacists, and to identify policy levers to address the needs identified. They integrated data into a simulation model with four modules:

Training: seats per year; programme attrition (per cent graduation); programme length; graduate out-migration.

Supply: in-migration; existing provider stock; exit rates (per cent per year).

Work and productivity: participation rate; activity rate (hours/week); productivity (e.g. number of items dispensed per pharmacist per year).

Need: population; need (incidence/prevalence of major health conditions); level of service (e.g. number of prescriptions per recipient per year).

Findings from the model led Jamaica's Ministry of Health to reconsider its approach to addressing the pharmacist shortage. Instead of increasing enrolment in training programmes, the ministry considered investing in strategies to improve retention by increasing the attractiveness of public sector positions, such as better salaries.

Planners and researchers have made limited use of qualitative methods to describe the HRH situation. Understanding motivations, for example around migration, requires a mix of quantitative and qualitative information. With the involvement of multiple stakeholders—including communities and patient groups–use of mobile technologies and analyses of social media, big data provide opportunities to improve both quantitative and qualitative evidence on HRH.

6 Measuring Health Workforce Migration and Mobility

Migration and mobility of health workers are key to labour market dynamics. They include international migration as well as movements out of and into the health sector or between urban and rural areas domestically. It is hard to obtain data to describe these movements and there are few tools to gather this information [30–33].

The international migration of health workers is accelerating. Over the last decade there has been a 60 per cent increase in the number of migrant doctors and nurses working in OECD countries, currently numbering almost two million [34]. Projections point to a continuing acceleration in the international migration of health workers, with an increasing mismatch between the supply of and economic demand for health workers [34].

Migratory patterns of health workers are also growing increasingly complex and are not limited to movement within and to OECD countries. WHO member states adopted the Global Code of Practice in the International Recruitment of Health Personnel in 2010 [35] which promotes ethical international recruitment of health personnel and encourages the exchange of information about migration, as well as, reporting every three years on measures taken to implement the Code under a National Reporting Instrument [35]. As of 2016, there have been some improvements in the efforts of countries to implement the Code, but the full potential of data on mobility of health workers has not yet been achieved [35]. Evidence to date [35, 36] points to substantial intra-regional, South-South and North-South movements and these need to be better quantified in order to complement the better understood movements from the Global South to the Global North. Temporary migration, including professional registration and employment in multiple jurisdictions, is also increasing in prominence. While emigration is difficult to measure given the complexity of health worker mobility patterns, better measurement of immigration across all countries and reporting through the third round of reporting of the WHO Global Code and implementation of NHWA will enable a fuller understanding of health worker migratory patterns. The linking of data held by professional councils and public employers, as evidenced in Ireland, also provides a more comprehensive picture of the health labour market and mobility [36].

7 From Data to Policy: The Role of HRH Observatories

Observatories are important in coordinating HRH data to inform policy. Since their inception in Brazil in 1999, national and regional HRH observatories have emerged in different parts of the world [37]. Observatories collect and analyse health workforce data and advocate for the use of the best evidence for the development and management of the workforce. In other words, observatories do not make or implement policies; their role is to contribute to building the evidence and capacity and strengthening partnership, at operational level between government and stakeholders to inform participatory decision-making [37].

The national health workforce observatory of Mozambique stands out as a prolific example in strengthening health workforce information generation, analysis and use. Created in 2011 by the ministry of health through a partnership with the National Institute of Health, National Institute for Statistics, other ministries, national university/school of medicine and cooperation partners, it is a national platform that uses HRIS information and produces semi-monthly HRH reports which are published on the ministry website. A recent review of Mozambique's coupling of the HRIS/HRH observatory experience shows strong evidence of strategic data use that is empowering the ministry of health to improve service delivery and resource allocation, and has informed development of the 2014–2019 Health Strategy [38].

At a global level, the WHO Global Health Workforce Statistics (GHWS), within the Global Health Observatory Data Repository, collects and compiles cross-national comparable data on the health workforce for all 194 Member states [39]. The GHO utilises publically available data from official publication and research papers based on the sources we described in Sect. 3.2. The counts and densities included in the GHO, can be considered the best available snapshot of global health workforce availability. WHO used thresholds (often referred to incorrectly as benchmarks) to permit cross-country comparisons. However, there is an ongoing debate as to whether these are planning targets that a country should or must achieve or soft measures for global monitoring.

8 Conclusion

Countries and the international community have made outstanding progress in strengthening HRH since the World Health Report 2006 drew attention to the health workforce crisis. HRH planners are producing more

information and are assisted by several international initiatives to collate and use data from multiple sources; the development of HRIS and the creation of HRH observatories are successful examples. However, lack of standardised approaches, specific data collection tools and data comparability limit or compromise the availability of HRH information. While data collection methods and systems have evolved significantly over the last decade, persistent gaps remain, making it difficult to prepare appropriate planning models and develop evidence-based policies and programmes.

The NHWA are an opportunity to scale-up standardised approaches to data collection. By using well-established processes and tools such as the International Standard Classification of Occupations (ISCO), NHWA improve comparability, and interoperability of multiple data systems. Well implemented, the NHWA, in particular their online platform, could be the best source of HRH information and facilitate inter-agency, inter-country and intra-country data exchange. Information could be linked to health outcomes to inform policies and decision-making with regard to the health workforce. Alongside tools and guidelines, implementation of the NHWA, requires a comprehensive approach to capacity building to support HRH planners in understanding, contextualising and implementing the NHWA and reporting up-to-date data to WHO.

The HLM framework and the mobility patterns of the health workforce set the basis for identification of priorities and definition of essential data and indicators. The NHWA, take this framework into account as well as aim for standardisation, comparison and interoperability of information. The NHWA are a remarkable step towards the improvement of essential data for planning and evidence-based decisions. NHWA implementation will enhance the understanding of health workforce dynamics between counts and competencies that emerge in response to rapid technological development [14, 40]. Sustained implementation of NHWA will depend on country ownership and particularly, the capacity of national stakeholders to collaborate and share information and knowledge emerging from existing fragmented HRH data systems.

Key Messages

- It is hard to harmonise health workforce information stemming from multiple data sources across sectors.
- National Health Workforce Accounts can support countries address data requirements, resolve quality issues and standardise data systems.

- The complexity of human resource information systems makes them difficult to sustain.
- Strengthening information systems will increase their value for national workforce planning and global comparability.

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13

Mortality Data in Service of Conflict-Affected Populations

Romesh Silva and Nobuko Mizoguchi

1 Introduction

As we write, in August 2017, Yemen faces the world's largest cholera crisis, on top of deadly conflict and air strikes by a Saudi-led coalition. The United Nations (UN) estimates that, as of July 2017, the conflict had killed more than 10,000 civilians, wounded approximately 40,000, and almost 70 per cent of the population of Yemen needs some form of humanitarian assistance. As early as 1997, Toole and Waldman noted that 'the crude mortality rate (CMR) most accurately represents (in a single measure) the health status of emergency-affected populations'. [1] This is in part due to the definitional, cultural and diagnostic unambiguity of death—as opposed to morbidity and injury—and the close relationship between mortality and population health. In Yemen, as in many conflict-affected countries, the health system, transportation system and communications systems have collapsed. The conflict itself has made even the recording of fatalities—resulting directly from violence

The views expressed in this chapter are those of the authors and do not necessarily reflect the views of the United Nations and the US Census Bureau.

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and indirectly from the collapse of public health and sanitation systems—a difficult undertaking. Lack of accurate and timely mortality statistics hampers the public health and humanitarian response; it is difficult to identify the immediate needs of the population and to coordinate a response.

Armed conflict results in substantial morbidity and injury, mortality, and displacement of individuals, households and entire communities. Conflict is also a serious public health problem [2] because it destabilises and damages the basic systems and infrastructure that underpin population health—food distribution, potable water delivery, public sanitation, transport, electricity, telecommunications and the health system. As armed conflict results in systems-level disruptions to population livelihoods, an effective public health response requires population-level data to guide effective and equitable allocation of resources. Humanitarian decision-making and response need to factor in the demographic effects of conflict—movements in and out of different areas, conflict-related deaths, and the fertility consequences of the conflict. These demographic effects involve changes in population size, distribution and composition—and thus influence the affected population and the population in need of assistance.

In 2016, armed conflict killed approximately 157,000 people around the world. The most lethal violence occurred in Syria, Mexico, Iraq, Afghanistan, Yemen and Somalia [3]. The eastern Mediterranean region has suffered disproportionately from the health consequences of conflict and instability. For example, since 2010, the difference in observed life expectancy and projected life expectancy (if conflict had not occurred) in Libya was nine years for males and six years for females [4]. In 2013, 38 per cent of years of life lost were attributable to conflict.

Despite the scale of mortality in conflicts, there are many data gaps and selection bias challenges, and estimates involve substantial uncertainty. It is difficult to ascertain the distribution of conflict mortality attributable to direct causes, for example, killings, versus indirect causes, for example, premature mortality resulting from a breakdown in the health, food or transportation systems. As mortality data in conflict are incomplete and it is rarely a physician who records a cause of death, the specificity and quality of the data make conclusions and generalisable inferences difficult.

The 2030 Agenda for Sustainable Development recognises international peace and security as a critical factor [5]. Goal 16 aims at 'significantly reducing all forms of violence and related death rates everywhere' with conflict-related deaths per 100,000 by sex, age and cause as an indicator. The inclusion of a conflict-related mortality indicator in the Sustainable Development Goals (SDGs) builds on the advocacy work of the Casualty Recorders Network and

more than 30 years of empirical research in advancing standards, methods and field practice for measuring civilian deaths in armed conflict situations [6]. Improving data and methods to measure conflict-related mortality is crucial to advance public health and protect human rights.

Because armed conflict destroys systems and infrastructure and displaces populations, it is difficult for health workers to provide and monitor population health. Routine data collection, using health information and civil registration systems, may not function, and conflict can hamper efforts to maintain surveillance and undertake surveys.

We review the changing nature of armed conflicts and the challenges they pose for measuring health and mortality of affected populations. While it is important to monitor and measure both mortality and morbidity, a substantial body of work exists on how best to track specific health outcomes [7]. We review recent work in measuring mortality, noting emerging practices, lessons learned and innovations. We describe how to collect and analyse mortality data in different conflict situations, and how health planners and practitioners can use these data to support affected populations. Given the nature of conflict situations, we discuss the considerable limitations of mortality data.

2 The Changing Nature of Conflict and Its Public Health Consequences

The nature of armed conflicts has changed substantially. Traditionally, regular armies fought wars to capture territory and advance geopolitical or ideological interests. Today state- and non-state actors fight over issues of identity, such as religion or ethnicity. While the number of conflicts and their direct casualties have decreased over time [8], conflicts last longer, especially in low-income and ethnically divided countries [9]. Conflicts often occur in densely populated urban areas in middle-income countries [10], displacing substantial numbers of people. At the end of 2015, over 21.3 million people were registered as refugees, 3.2 million as asylum seekers and 37.5 million as internally displaced persons worldwide [11]. Conflict-related displacement disturbs people's livelihoods, disrupts their access to basic health services and shelter, and increases uncertainty in their lives [12].

These changes in the nature of conflicts complicate health-sector responses to the needs of affected populations and the ability to collect and analyse relevant health and mortality data. Humanitarian response often focuses on the most pressing needs and on monitoring acute conditions arising from injuries and violence. As more middle-income countries experience conflict, and as conflicts last

longer, chronic conditions associated with non-communicable diseases are contributing a higher proportion of the disease burden among conflict-affected populations [10]. The war in Syria is a case in point. Syrian refugees needing ongoing medical care to manage their long-term non-communicable health conditions overwhelm the health systems of neighbouring Lebanon, Turkey and Jordan. At the end of 2016, Syrian refugees comprised approximately 18 per cent, 8 per cent and 3 per cent of the resident populations in Lebanon, Jordan and Turkey, respectively. In Lebanon and Jordan, Syrian refugees add to their long-standing Palestinian refugee populations. Public health systems in Lebanon, Turkey and Jordan have integrated Syrian refugees into their health systems to various levels, but significant barriers remain, such as the high cost of services, human resource shortages and insufficient medicines and equipment. Increasing numbers of refugees living in non-camp settings further challenge health service delivery.

The scale and nature of recent conflicts, particularly in the Middle East and North Africa, call for a coordinated regional response to address the health needs of affected populations. The Regional Refugee and Resilience Plan (3RP) to the Syrian Crisis includes direct interventions to meet short-term needs of Syrian refugees, through support of primary, secondary and tertiary health services in camps, rural and urban settings, as well as systematic investments that reinforce the capacity of national health systems [13].

The UN Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) has developed a coordinated health system to serve conflict-affected populations in Jordan, Lebanon, Syria, the Gaza Strip and the West Bank, including East Jerusalem. Given the protracted Palestinian refugee situation, the population is ageing with higher prevalence of non-communicable diseases. UNRWA adopted a model of primary health-care provision that serves family members throughout the life-course using multi-disciplinary teams [14]. Such efforts by the Office of the UN High Commissioner for Refugees (UNHCR), UNRWA and partner agencies substantially strengthen regional responses to support the health of refugees fleeing armed conflict situations.

Security threats faced by those providing humanitarian and health assistance to conflict-affected populations make it difficult to gain a complete, accurate and timely picture of mortality. Attacks on health workers and health facilities by armed actors pose a direct security challenge to the humanitarian health sector and undermine the viability of humanitarian health information systems. Attacks on medical facilities and personnel have been well documented in conflicts in Sri Lanka, Kosovo, Yemen, Nepal, the occupied Palestinian territories, Iraq, Syria and Colombia [15]. Such attacks weaken the health-care system and impair its ability to document health and mortality consequences of conflict. This, in turn, increases the proportion of undocumented injuries and deaths due to conflict.

3 Indicators of Mortality

Armed conflict causes civilian deaths both directly and indirectly. Direct conflict-related deaths occur when civilians die from events associated with combat, whether or not they were intended to harm civilians (such as bombings). Indirect conflict-related deaths—from, for example, malnutrition and preventable diseases—occur after the conflict has destroyed transportation networks, health facilities and critical components of the health system, or other infrastructure. Indirect conflict-related deaths usually outnumber direct conflict-related deaths [16].

It can be challenging to attribute ill health or premature mortality to conflict, especially when conditions do not improve immediately after a conflict. Conflict demographers and epidemiologists measure mortality using the crude mortality rate (CMR), infant mortality rate (IMR), under-five mortality rate (U5MR), adult mortality rate ($_{45}q_{15}$) and life expectancy at birth. There is much uncertainty associated with measurement of all-cause mortality during conflict. Measurement of cause-specific mortality during conflict is particularly challenging—often relying on coarse cause of death codes, given that a qualified medical practitioner seldom certifies deaths.

4 Collection of Mortality Data

Data on mortality have two primary uses in conflict situations: for programming, that is to inform programmatic decisions and plan relief operations; and for documentation and advocacy, that is to create a historical record, advocate on behalf of affected populations and create awareness about the impact of conflicts on mortality. Table 13.1 summarises the choice of methods to capture direct or indirect conflict-related mortality data in different settings and for different uses.

4.1 Prospective Mortality Surveillance

Prospective surveillance systems collect data continuously as soon as possible after deaths occur. Surveillance can be active or passive. Active surveillance is one in which a staff member visits households on a regular basis to gather information about deaths that occurred in the household. Passive surveillance is where the system relies on a household member or some other person to report the death. These include:

Table 13.1 Summary of mortality data collection methods in armed conflict settings

Data collection method	Best for direct or indirect conflict-related deaths	Mortality measures	Best setting and use
Prospective mortality surveillance			
Civil registration and vital statistics	Mostly indirect deaths. Can include direct deaths if registered	Number of deaths Child mortality Under-five mortality Adult mortality Life expectancy	National Documentation/ advocacy
Demographic surveillance systems	Mostly indirect deaths. Can include direct deaths if registered	Number of deaths Child mortality Under-five mortality Adult mortality Life expectancy	Rural or urban, camp or non-camp Documentation/ advocacy
Mortality surveillance system	Indirect deaths	Number of deaths Child mortality Under-five mortality Adult mortality Life expectancy	Camp Programming
Facility-based health information systems	Indirect deaths	Case-fatality ratios	Health facility Programming
Passive surveillance through media reports	Direct deaths	Number of deaths	Any defined geographic area or population Documentation/ advocacy
Retrospective surveys and censuses			
Retrospective surveys	Direct and indirect deaths	Number of deaths Child mortality Under-five mortality Adult mortality Life expectancy	Any defined geographic area or population Documentation/ programming
Population censuses	Direct and indirect deaths	Number of deaths Child mortality Under-five mortality Adult mortality Life expectancy	Any defined geographic area Documentation/ advocacy

Civil Registration and Vital Statistics (CRVS) systems provide the best source of mortality data when coverage is complete (see Chap. 7), but most low- and middle-income countries do not have complete CRVS even during peacetime [17], and these systems usually deteriorate or collapse during conflicts [18]. Exceptionally, the Federation of Bosnia and Herzegovina registered deaths throughout the Bosnian War of 1992–1995 [19].

Health and Demographic Surveillance Systems (HDSS) monitor ongoing demographic events occurring in a geographically defined population (see Chap. 17). So long as an HDSS operates during the conflict, it can provide mortality data for the small population it covers. The Bandim Health Project HDSS estimated mortality in Guinea-Bissau during the armed conflicts of 1998–1999 [20], and researchers estimated mortality for internally displaced persons at an HDSS in Western Kenya during the 2008 post-election violence [21].

Mortality Surveillance System When no CRVS or HDSS exists, an active surveillance system can be set up to monitor mortality and morbidity [22], as implemented in Chad [23]. Typically, a community health worker routinely visits households to ask about demographic events and updates the population figures; they may also monitor graveyards [18], although this method may under-report deaths and incur selection bias.

A Facility-based Health Information System records deaths and other health outcomes that occur in the health facility (see Chap. 9). The UNHCR has developed a standardised health information system for refugee settings [24] and a web application (Twine) that facilitates standardised data collection, analysis and sharing [25]. Because most conflict-related deaths occur outside health facilities [18], these sources can only provide data to calculate case-fatality ratios, not population-based mortality rates [26]. Box 13.1 describes an assessment of the UNHCR system as it is used in Yemen.

Box 13.1 Evaluation in Yemen of the UNHCR ProGres and Twine Data Systems [27]

Masquelier and Silva highlight challenges in estimating mortality in conflict-affected populations by evaluating data from UNHCR ProGres and Twine between 2008 and 2016 in three locations in Yemen. They found that: (1) completeness of birth and death reporting from Twine varied substantially between settlements and over time; (2) estimates of crude death rates from Twine showed significant under-reporting of deaths when compared with comparable estimates derived from the *World Population Prospects* and the CE-DAT complex emergencies database; and (3) cause-specific mortality fractions for the three locations showed notable variations for populations both under and over five-years of age when evaluated against model-based estimates from the Global Burden of Disease study.

Given the limitations of individual data systems that cover populations displaced by conflict, there is a need to systematically evaluate the strengths and limitations of routine data systems and triangulate these data with other data sources (such as surveys). However, lack of specificity in age reporting and coarseness of cause-specific mortality information in the Twine and ProGres data systems make such evaluations difficult. Despite these limitations and challenges in constructing mortality estimates, UNHCR's data systems constitute a foundational base for monitoring the population health and mortality outcomes of people displaced by conflict.

Media Reports provide a source of data that analysts can harvest for counts of deaths. The Iraq Body Count, for example, systematically records violent civilian deaths in Iraq since the US-led invasion of Iraq in 2003 based primarily on deaths documented by commercial news media [28]. These reports usually undercount deaths and are biased because news agencies tend to cover deaths that are newsworthy, for example, when large numbers of deaths occur at one time or when deaths occur in an unusual manner. Davenport and Ball explore the implications of using newspapers, human rights documents and interviews with eyewitnesses, between 1975 and 1999, as data sources to quantify the Guatemalan state terror [29].

4.2 Surveys and Censuses

When prospective surveillance data are not available, researchers can use retrospective surveys and censuses to collect data on mortality. Box 13.2 explains different ways in which an interviewer may ascertain whether a death has occurred in a household.

Box 13.2 Approaches to Collecting Mortality Data in Surveys and Censuses

Past household approach: the interviewer lists which household members were present at the beginning of the recall period and determines which of them are no longer present. For each member who is no longer present, the interviewer determines whether they have died or migrated [30].

Current household approach: the interviewer lists all members of the household on the day of the survey and then asks about any deaths that have occurred since the beginning of the recall period [30].

Standardised monitoring and assessment of relief and transitions (SMART) is similar to the current household census, but also asks about in- and out-migration [31].

Survival of children/birth histories and survival of parents, and sibling: the interviewer asks questions about children ever born and surviving birth histories, and survival of parents and siblings [32].

Retrospective Surveys ask about deaths and morbidity that occurred in a given time-period (see Chap. 8). Sampling is a major challenge in surveying conflict-affected populations. It is often impossible to prepare an accurate sampling frame from which to draw a simple random sample or to organise households in a clear pattern for systematic random sampling [33]. Researchers commonly use multi-stage cluster sampling instead. For example, in 2007, Coghlan et al. undertook a retrospective three-stage cluster survey to estimate

mortality rates in the Democratic Republic of Congo and compared the results across regions and to historical levels [34]. One drawback of this technique is that the true probability of a household being selected is unknown [33]. Since households selected within a cluster are not randomly distributed, they may be similar to each other, and there is excessive homogeneity within clusters [30, 33]. This clustering of risk of death may be more marked in conflict settings [33].

A Population Census is the complete enumeration of households and individuals in a country or a defined geographic area (see Chap. 6). Population data are not only necessary to provide denominators to calculate death rates, but also useful in estimating mortality. Since censuses cover the complete population, mortality rates can be calculated for small areas without sampling error. However, censuses occur infrequently, usually every ten years, making timely and up-to-date mortality estimation difficult. Armed conflicts often interrupt the decennial census schedule, making the duration between censuses even longer. Not all censuses include mortality questions (via inclusion of summary birth histories, sibling histories or accounts of household deaths). Migration during and after conflicts further complicates measurement of deaths using census data.

Mortality data from retrospective surveys and censuses are subject to non-sampling biases [30]. Recall bias occurs when respondents erroneously report or omit deaths. For example, respondents may over-report if the deaths were violent. They may under-report deaths to household members who were not related to the respondent or young children. Poor recall of date of death can also lead to over- or under-reporting of deaths within the recall period. Reporting bias may result from respondents intentionally under- or over-reporting deaths or the number of people living in the household. In conflict settings, there can be many reasons why respondents may want to under- or over-report deaths. Survival bias results from interviewing only households with at least one surviving member who can report the deaths.

Researchers are developing and testing methods that would improve traditional approaches to capture mortality. One trend is to rely on reporting by community informants. Based on *referrals from community informants*, Roberts et al. conducted exhaustive searches for deaths in Afghanistan, Thailand, Malawi and Tanzania and found this method moderately sensitive to capturing mortality (Box 13.3) [35]. In non-conflict settings, researchers have used community informants to report deaths in a demographic surveillance system [36]. Researchers have used the *neighbourhood method* in some countries to document incidences of violence against women, for example, during war and displacement in northern Uganda [37]. This method asks a sample of respon-

dents to identify four to six neighbours in adjacent households, and asks respondents about their neighbours', their sisters' and their own experiences with violence against women. Ethical issues around confidentiality are important when using this method [38]. Both referral-based sampling and neighbourhood methods reduce costs and staff time in data collection over full-scale surveys but both methods are subject to selection bias.

Box 13.3 The Informant-Based Method of Collecting Mortality Data [35]

This is an exhaustive search process to record all deaths occurring in a population within a recent time-period (usually 60 days). It begins with a focus group to identify key informants and locate other sources of death records. During key informant interviews, the informants independently list all deaths within the time-period. Interviewers visit all households which they identify as having had a death; and ask the next of kin, aged 18 years or older, for the date, cause, and place of death, and to list other deaths in the household or in the community in the time-period. Interviewers visit new households and repeat the process until they have visited all households so identified. To estimate mortality rates, the method requires knowledge of the population size (either from existing sources or through estimation).

Relative to retrospective surveys, the method is cheaper, requires less time for data collection, entry and analysis, and reduces respondent time. The method only measures mortality, whereas retrospective surveys can also measure other indicators.

5 Data Evaluation, Analysis and Data Repositories

Data should be checked for quality, consistency and assessed for bias (see Chap. 22), especially given the challenges of data collection in armed-conflict settings.

Estimation of Mortality Measures If numbers of deaths and population data have been collected, both direct and indirect conflict-related mortality measures can be calculated. If data include numbers of children ever born and those surviving, birth histories, and survival of parents and siblings, mortality rates may be estimated using indirect methods [32] (see Chap. 17). Mortality can also be estimated by applying demographic methods to the age and sex structure of a population before and after a conflict; for example, Heuveline analysed UN electoral lists to estimate excess mortality in Cambodia during the Khmer Rouge regime [39]. Indirect demographic methods only assess

overall mortality during the conflict period; they cannot differentiate between direct or indirect conflict-related deaths.

Comparison with Threshold Measures, or Other Estimates, and Excess Mortality Estimated CMR and U5MR can be compared against emergency thresholds to determine the level of response [22]. Thresholds, which vary by region based on baseline mortality, range from CMR of 0.3–0.8 deaths per 10,000 per day and U5MR of 0.1–2.1 deaths per 10,000 per day. Mortality measures from various data sources can also be compared to determine plausible levels. For example, the Iraq Family Health Survey (IFHS) found that the number of deaths from the IFHS [40], and the Iraq Body Count [28] were substantially lower than those found in a study by Burnham et al. [41] IFHS researchers concluded that the Burnham et al. study had over-estimated the number of violent deaths. Excess mortality is the amount that mortality exceeds the level expected if pre-conflict conditions had prevailed; for example, Silva and Ball used excess mortality to measure conflict-related mortality in Timor-Leste [42].

Multiple Systems Estimation (MSE) (or Capture-Recapture) MSE addresses the problem that some deaths are never recorded in armed conflict settings. This statistical approach uses multiple data sources and examines the overlaps among them to estimate the total number of deaths, including those missing from all data sources. Researchers have applied MSE in several countries to estimate the total number of deaths due to human rights violations and armed conflicts. For example, Silva and Ball describe how they used MSE, among other methods, to estimate killings in Timor-Leste between 1974 and 1999 [42]. These findings were included in a report to the Truth and Reconciliation Commissions in Timor-Leste [42]. Brunborg et al. used MSE among other methods to estimate the number killed after the fall of Srebrenica when they reported to the UN International Criminal Tribunal for the former Yugoslavia [43].

Two data repositories are available that contain mortality data from armed-conflict settings. Uppsala University and the Peace Research Institute, Oslo maintains a database (Uppsala/PRIO) containing passive reports of violent war-related deaths from 1900 onward [44]. The Complex Emergency Database (CE-DAT) is a repository of small-scale mortality and nutrition data from field surveys conducted by humanitarian agencies [45]. Since small-scale sample surveys involve large sampling errors, users should be cautious in interpreting their findings [46].

6 Emerging Opportunities

Opportunities have emerged to further advance the measurement of conflict-related mortality, for example, technologies in data capture and methods for data integration. Practitioners also need more guidance on how to interpret mortality statistics.

First, new technologies provide more ways to collect data on conflict deaths in challenging situations. For example, Elamein et al. used the popular messaging application, WhatsApp, to collect, coordinate and triangulate reported attacks on health workers and health facilities in Syria in real-time by members of the health cluster activated as part of the UN humanitarian response [47]. This mobile-based technology provided timely and reliable information and drew attention to violations of international humanitarian law.

Secondly, new approaches to data integration increase options for improved estimation and analysis. Data systems are under-utilised in humanitarian settings partly because there are few platforms to share and integrate data from multiple sources. Although MSE is not a new technique, this approach can provide accurate estimates or validate mortality data, as Roberts et al. have done to test the informant method [35]. The UNHCR used MSE to establish a minimum bound for conflict mortality in the early years of the Syria Crisis.

Health information systems, mortality data systems and displacement data systems are not linked in many humanitarian settings. Integrating multiple sources of mortality information can correct for under-enumeration in individual data systems. For example, by integrating data on internal displacement (such as from the International Organization for Migration's Internal Displacement Tracking Matrix) and international refugee stocks (such as from UNHCR's ProGres registration system), analysts can better estimate the population-at-risk and construct more accurate population mortality rates.

Combining geospatial data with demographic data, Pezzulo et al. have harnessed high-resolution satellite imagery to estimate child mortality at sub-national levels [48]. Use of satellite imagery (specifically satellite-based measures of night-time lights and satellite-based vegetation indices) along with socio-demographic covariates make it possible to estimate mortality at smaller geographic units. Although these are modelled estimates based on mortality at larger geographic levels rather than observed data, the integration of various available data is an innovative approach to estimating mortality in small areas. Such modelled estimates rely on assumptions about the homogeneity of mortality within geographic areas—an assumption that glosses over systems-level perturbations and forced migration effects in armed conflict

situations. Decisions about resource allocation and humanitarian response ultimately need to engage local contexts and factor in the variability in population processes and health outcomes that result from armed conflict. Satellite imagery can provide a sampling frame when undertaking retrospective mortality surveys. Galway et al. [49] used gridded population data and geographic information systems for first-stage sampling for a cluster mortality survey in Iraq. This meant they could draw a representative sample despite that the last census was outdated and security was tenuous in some parts of the country.

Thirdly, as new data sources become available and estimation methods more complex, end-users and practitioners require improved standards of reporting and technical guidance. It has been more than ten years since Checchi and Roberts developed their primer on interpreting and using mortality data in humanitarian emergencies [30]. Their primer provided an excellent overview of classical approaches to data collection, such as retrospective mortality surveys and prospective surveillance. It also presented fundamental concepts of interpretation of the data such as validity, reliability and bias. But the field has evolved substantially; new technologies have created new sources of data (such as satellite imagery and mobile-based data sources) and also facilitated more sophisticated modelling techniques such as MSE and spatio-temporal-regression models (see Chap. 20). These methods entail data quality issues and simplifying assumptions, which must be considered when interpreting or making decisions based on their findings. For example, MSE relies on strong assumptions of independence and error-free matching of data systems. Methods that use data from satellite imagery and geographic information systems, make strong assumptions about the relationship between geographic information and the demographic profile of small areas and their health and mortality outcomes [50]. Practitioners and decision-makers need practical guidance on how to responsibly use new types of mortality data and modelled mortality estimates.

7 Conclusion

Mortality is a key indicator of the public health consequences of armed conflict, but it is difficult to measure. Many of the challenges associated with mortality measurement also extend to measurement of health status and health effects of conflict. These include: conceptual issues of definition, such as distinguishing between direct and indirect deaths, delineating reference populations, time periods, and geographic areas; and technical problems of accessing and documenting the population when basic transport, health and

information systems are severely damaged and the security environment is unstable. The classic approach has mostly involved survey techniques, small observational (often facility-based) data systems, and sometimes census data. But the appropriateness and generalisability of these methods are highly context-specific. New technologies, including mobile hand-held devices and remote sensing techniques, now make it easier to collect data from multiple sources on mortality in unstable settings. More flexible data integration techniques make it easier to utilise available data comprehensively and describe the precision of bias of summary mortality measures. Such techniques provide a substantial advance from previous efforts that relied solely either on a survey estimate or on a passive surveillance data collection source.

Linking of peace and security to the 2030 Sustainable Development Agenda, and inclusion of conflict-related mortality as an SDG indicator, calls for stronger accountability for civilian casualties and deaths during armed conflict. Creating the SDG indicator also increases urgency for better integration of incomplete data systems, new approaches to data collection and more flexible estimation methods. Advancement of improved mortality measurement methods and increased global political and financial commitments are crucial to ensure that 'no one is left behind', especially civilian populations affected by protracted conflict and ongoing crises.

Key Messages

- Armed conflict is a serious public health problem; today its consequences disproportionately affect urban communities.
- Mortality rates measure population health in war-affected societies and guide public health interventions and humanitarian response.
- Measuring the mortality effects of conflict requires multiple data sources and complementary methods of estimation.
- Integrating multiple data sources can overcome biases inherent in individual data sources and methods.

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14

Climate Matters in Health Decision-Making

Madeleine Thomson, Bradfield Lyon, and Pietro Ceccato

1 Introduction

In October 1997, rain fell in north-eastern Kenya; more rain than anyone could remember. Observations from the region's meteorological stations and satellite measurements confirm the extreme nature of the rainfall. Flooding of this semi-arid region and the subsequent malaria epidemic resulted in catastrophic mortality among young children. Over 10,000 deaths, predominantly from malaria, occurred in one province alone [1]. Floods destroyed health facilities which—with an ongoing nurses' strike—worsened the impact of the rains. El Niño was the climate driver associated with this extreme weather, an event which affected most of Kenya during the 1997–98 short rains. Today many Kenyans associate the term El Niño with disaster.

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Climate, together with social, political, economic, environmental and technological influences, drives health outcomes from outside the health sector. Climate varies by location according to defined processes and has distinct cycles—diurnal, seasonal—as well as multi-year cycles such as those driven by El Niño [2]. What makes climate unique is that it is routinely measured—using land and sea observations, satellite-based remote sensing and global modelling outputs—modelled and predicted using standardised methods. This highly structured mass of data, in national and global repositories, provides hourly, daily, weekly or monthly information for most regions of the planet.

Climate information—based on analysis of historical data, monitoring of current conditions or predictions of future weather, climate events and trends—can inform public health policy and planning. When another El Niño associated climatic anomaly occurred in Kenya during the short rains of 2006–07, it did not have the dramatic health impact of its 1997–98 predecessor. This reduced impact was in part because local health services and international agencies, building on lessons learned from the earlier malaria epidemic, instigated a substantial vector-control response within three months of observing high rainfall, undoubtedly saving many lives [3].

Public health experts sometimes include climate as a predictor when developing early warning systems for infectious disease [4], but they could make more and better use of climate information. Health policy and practitioner communities need to understand climate data and methodologies, for example to quantify the impact of interventions to control malaria [5], improve timing and extent of insecticide residual spraying [6], or identify populations vulnerable to changing disease risks from warming temperature [7]. There is extensive literature on climate and malaria—a disease that is highly sensitive to climate—but we argue that prevention and control of other communicable and non-communicable diseases, including malnutrition, could also benefit from relevant and quality-assured climate data.

We lay out the value of climate data for health practitioners, and then describe different types of climate data and how to manage, analyse and present them. We offer a checklist for health planners considering incorporating climate data into information systems, suggest how they might be supported in doing this and provide links to relevant literature and resources.

2 Increasing Recognition of the Importance of Climate Data for Health

During the 1980s, scientists worked with health officials to use newly available data from earth observation satellites [8]. Geographical information system (GIS) tools and spatial statistics aided management, analysis and visualisation of vast amounts of environmental and health data [9]. Seasonal climate prediction became available to health decision-making [2]. Since these early days, public health specialists have used these new climate data sources and tools increasingly to support disease surveillance and control programmes.

In 2008, the World Health Assembly recognised climate change as a defining challenge of the twenty-first century, and the public health community began to prioritise protecting people's health from its impacts. Public health officials now recognise that climate data and information provide opportunities to improve current health programmes while preparing for future climate risks (Box 14.1) [10]. In 2014, the World Health Organization (WHO) and the World Meteorological Organization (WMO) opened a joint office to develop climate services for the health sector.

Box 14.1 Health Risks Sensitive to Changes in Weather and Climate

Adapted from Guillemot [10].

Direct human exposure to hazardous meteorological conditions can lead to morbidity and mortality, for instance, from heatwaves, cold waves, droughts, storms, floods, ultraviolet radiation, and cyclones.

Deteriorating environmental determinants of health, including availability and safety of fresh water and food, can result in under-nutrition, nutrient deficiencies and disease.

Changes in temperature and precipitation influence the environmental conditions that determine the geographic range and incidence of vector-, rodent-, water-, and food-borne diseases, and alterations in air pollution and aeroallergen related diseases.

Sea-level rises and increased sea-surface temperatures can reduce water quality and access to drinking water by salinisation of coastal aquifers, coastal erosion and land loss, and safety and availability of fish and marine food products.

Extreme weather events create social and economic losses that can significantly impact mental health and reduce access to health care or food. They can also disrupt or destroy critical health and water and sanitation infrastructure, with loss of health services.

3 Using Climate Information

3.1 Planning and Implementing Health Strategies

Health practitioners can use climate information to improve routine planning and surveillance, and preparedness activities to prevent and control specific diseases by:

Understanding How Climates Impact Health Outcomes For example, researchers found humidity wind and dustiness [11] in the Sahel to correlate with the development of bacterial meningitis epidemics and proposed that information on specific climate conditions could trigger an early response.

Identifying Populations at Risk of Climate-Sensitive Diseases Health practitioners improve prevention, control and elimination programmes by mapping the geographic range of vectors and pathogens using environmental and climate covariates [12].

Monitoring and Predicting Short-Term and Seasonal or Year-to-Year Variations in Incidence (Including Early Warning Systems for Epidemics) In France, the devastating heat wave of 2003 led to the development of heat early warning systems that alert health workers and the general public to dangerous weather conditions [13]. In Ethiopia, the National Meteorological Agency provides high-resolution rainfall and temperature data [14] along with information on El Niño to alert the National Malaria Control Programmes about potential malaria epidemics [15].

Monitoring and Predicting Longer Term Trends by Assessing Climate Change Impact and Vulnerability As climates warm, malaria and other climate-sensitive diseases may move to higher altitudes or more temperate regions [16]. Researchers have used national climate data to assess the impact of warming temperature trends on the numbers of individuals at risk of malaria in the Ethiopian highlands [7].

Assessing the Impact of Climate-Sensitive Interventions Control programmes for diseases that are sensitive to rainfall or temperature need to account for climate when assessing the impact of their interventions. For example, a decline in malaria in East Africa preceded large-scale implementation of anti-malaria interventions in some regions; major droughts (2000, 2003, 2005) may have caused this early decline [5].

3.2 Managing Health Outcomes

Three examples illustrate the significance of climate data in improving health outcomes:

Early Warning of Malaria Epidemics Studies demonstrate the feasibility of early warning systems for epidemics based on the lagged relationship of malaria to climate variables [17]. Localised epidemics may result from location-specific factors including unusual weather. Similar factors that act at scale may drive region-wide epidemics—for example, short-term climate events associated with changes in global climate drivers such as the El Niño Southern Oscillation (ENSO) [2]. WHO has prepared a framework for malaria early warning systems (MEWS) incorporating seasonal forecasts, rainfall and environmental monitoring and health facility surveillance which forms the basis for development of MEWS in different regions of the world [17]. Box 14.2 summarises the climate variables that can predict malaria outcomes weeks or months into the future. Thomson and colleagues provide a detailed description of available climate products for use in malaria control and elimination [5].

Box 14.2 Climate Variables That Can Predict Malaria Epidemics

Heavy rainfall creates puddles where malaria-transmitting mosquitoes lay eggs and increases humidity which promotes their survival [18]. Satellite estimates and local station data predict epidemics weeks to months ahead.

Rising temperature, especially in temperate or highland areas, hastens development of juvenile mosquitoes and reduces the time for parasites to develop in their female mosquito host, increasing the potential for epidemics.

High humidity reduces evaporation of breeding sites, so they stay productive for longer and increases the likelihood that adult mosquitoes will survive long enough to transmit disease. Meteorological stations provide the only quality near real-time humidity measurements for early warning. It is difficult to interpolate humidity accurately between weather stations.

Sea surface temperatures (SSTs) predict climate anomalies in certain regions and seasons where there are physical mechanisms that connect SSTs with local rainfall—for example, East African short rains. SSTs are available in near real-time and readily accessible as global products.

Zika Virus Prevention and Control Zika virus (ZIKV) epidemics emerged in Latin America and the Caribbean in 2015 during a period of severe drought and unusually high temperatures which, Muñoz et al. showed, resulted from a combination of natural climate variability and long-term changes [19]. High rainfall provides more outdoor breeding sites for ZIKV mosquito vectors (predominantly the container breeder *Aedes aegypti and Ae. albopictus*). However,

drought years may lead to greater water storage and many more domestic breeding sites. Warming temperatures increase development rates of both vector and virus. The study concluded that climate is a significant driver of seasonality, year-to-year variability and longer term trends in the geographic distribution of ZIKV and other arboviruses transmitted by *Aedes spp* mosquitoes. The authors recommended that public health officials work with climate experts to use climate information to improve the timing and targeting of ZIKV interventions.

Climate, Flooding and Malnutrition The 2015 Global Nutrition Report highlighted the risk of climate variability and changes in nutrition among vulnerable populations [20]. In Bangladesh, extreme flooding, driven in part by changes in global sea surface temperatures (SSTs) affects rice production, rice prices and child malnutrition. A preliminary study undertaken for the report indicated that seasonal rice production increases with the extent of the annual flood to a point after which flooding damages the crop. Monthly percentages of underweight children showed positive association with high prices and flood extent. These results are consistent with evidence that high rice prices following production shocks (including those associated with climate events) strongly associate with people's choices to spend less on non-rice foods (with higher densities of micronutrients) and increases in the number of underweight children [21].

4 Collection and Dissemination of Weather and Climate Data

National Meteorological and Hydrological Services (NMHSs) collect *ground-level measurements* of rainfall, temperature, humidity and other variables using meteorological stations. Other national and international agencies such the United States National Aeronautics and Space Agency (NASA) and the European Centre for Medium Range Weather (ECMWF) create *global climate monitoring products* that complement (and sometimes integrate) ground-based data. These global products comprise climate proxies (estimates) derived from satellite data, global or regional reanalysis products which combine climate models with station data, and climate indices that represent regional or large-scale atmospheric or oceanic phenomena.

4.1 Ground-Level Station Measurements

Ground-based observations are the gold standard for weather and climate data. In most countries, the NMHS makes these observations by strategically

placing weather stations; these can be simple rain gauges or highly sophisticated automatic weather and climate recording equipment. Snapshot hourly observations of weather—including wind direction, temperature, humidity, cloud cover—are known as *synoptic* observations. Daily summaries of weather—for example, minimum and maximum temperature—are known as *climate* observations (climate being the statistics of weather). Climate experts interpolate station data to produce gridded surfaces that provide information for areas where there are no stations.

Local station operators compile daily or monthly reports which they send to the NMHS head office electronically, by radio or on paper. The NMHS cleans, curates and archives the data in a central repository. The NMHS uses the data to develop and test climate products which it shares with partners or clients freely or for a fee.

The NMHS may automatically communicate some daily data to the WMO's Global Telecommunication System which provides the Global Weather Watch [22]. Researchers use these data because they are published as global databases and are freely available over the Internet. However, such data represents only a small proportion of data collected in a country and may not be entirely quality-controlled.

Other organisations and individuals, for example schools, agricultural research centres, and farmers, may collect weather and climate data. Some health facilities manage weather stations for their locality. Records from these volunteer stations vary in quality and consistency and may not be integrated into the NMHS historical archives.

4.2 Global Climate Products

Researchers can access climate and environmental information free of charge, from authoritative sources that collate and provide data from national providers, satellite data or model outputs.

Satellite Estimates for Rainfall and Temperature Satellite rainfall estimates derive mainly from measurements taken by sensors on-board geostationary and polar satellites and incorporate limited ground observations. While satellite data provide poor estimates of actual rainfall amount, they provide excellent estimates of the spatial distribution of rainfall. Satellite data can also provide estimates of land-surface temperature (LST). The relationship of LSTs to air temperature varies by location with LST acquired during the night providing a reasonable estimate of minimum air temperatures in some regions.

Reanalysis Estimates of Rainfall and Temperature Climate experts generate these products by systematically combining limited climate observations with model forecasts using data assimilation schemes and climate models [23]. The climate models used to generate reanalysis data are fixed over time. The ground observational data incorporated into reanalysis, however, vary over time due to changes in the meteorological station network, and this may introduce non-homogeneities in the time-series. While some consider reanalysis climate products poor sources of information for actual rainfall [24], experience indicates that they can capture changes in temperature reasonably well albeit at relatively large scales [25, 26].

Sea Surface Temperature (SST) Indices SST variations in the Atlantic [27], Indian [28] and Pacific [29] oceans influence climate on different time scales. ENSO is the prominent mode of climate variability worldwide that operates on season to yearly time scales (two to seven years) [2]. ENSO strongly influences climate variations in several regions of Africa where it provides much of the predictability in operational seasonal climate forecasts [2]. SSTs are monitored in specific regions of the world's oceans to indicate the current ENSO state (both El Niño and La Niña) [2].

5 Managing Climate and Health Data

Health planners may call on epidemiologists to study how climate helps to explain the occurrence and spread of a condition, such as malaria, and ask for information that helps plan and target prevention and control activities geographically and over time. To do this, epidemiologists collect and analyse historical and/or prospective data on climate variables and occurrences of the health outcome of interest together with other socio-demographic information, and present their findings. Alternatively, planners may already understand the climatic determinants of the condition and want to set up an early warning surveillance system to routinely predict when an outbreak might occur. Box 14.3 describes such a real-time system to predict dengue in Brazil.

Box 14.3 Real-Time Surveillance System to Predict Dengue in Brazil

When preparations for the 2014 World Cup in Brazil were underway, health officials put in place a prototype dengue early warning system, designed to predict changes in transmission risk three months before the June event [30]. They used seasonal climate forecasts for March–May 2014 along with February dengue cases to predict whether dengue cases in participating cities across Brazil

were likely to pass an epidemic threshold during the World Cup. The system correctly predicted the dengue risk level in June in 7 out of the 12 cities where the World Cup games took place, and two cities that were not forecasted to be at high-risk of experiencing epidemics. The success of the forecast system indicates the potential of the early warning tool to protect Brazilians and visitors during mass events and for routine use in annual dengue control.

Both the above scenarios entailed several large datasets with many variables, measured at specific locations and over a series of time points. Ideally, this requires the expertise of both climatologists and epidemiologists with strong statistical skills. As epidemiologists do not necessarily have access to climate experts, we present some basic principles for dealing with climate data.

5.1 Handling Climate Data

Researchers have to balance ease of access to climate data with data quality. The most accurate data come from local meteorological stations but, when they are not available, researchers resort to using global products (which may be calibrated using a subset of local observations). We describe some data errors for researchers to control for when analysing two key variables: rainfall and temperature.

Rainfall data from near-by meteorological rain-gauge stations are usually aggregated over time, for example, by week, month or season. Because rainfall is extremely variable in space and time—it can be raining heavily in one village while it is dry in a village 5 km away—measurement accuracy depends on density and distribution of observing stations. Aggregation of rainfall data in time (e.g. by month) means they are less variable geographically. Aggregated data, however, may contain errors that are invisible to the user, so it is essential to control for the quality of raw hourly or daily data; there are standard methods for doing this [16] and meteorological agencies should do this routinely. The user should ask: *how complete is the original dataset and how have missing daily observations and extreme values been handled?*

Temperature varies by elevation, geography, latitude, proximity to water bodies, type of land cover and so on. A common error in time-series of temperature data from weather stations is observable jumps in the records, frequently resulting from relocation of a station [16]. Spurious break points can influence analysis of temporal trends in temperature time-series and their removal requires adjustments to the original dataset. Ideally, the meteorological office would have recorded dates of any changes in station location and instrumentation to facilitate comparison with dates of any break points.

Different gridded satellite rainfall estimates exist and may give different results for the same area. Which dataset should be used? The best product will likely be the one that is calibrated using the most ground observations in the area of interest. Users can usually find this information in the documentation for the specific product.

5.2 Managing and Analysing Data

Data management and analysis tools range from simple Excel spreadsheets to sophisticated software requiring technical and statistical expertise. Increasingly health practitioners are using the District Health Information System 2 (DHIS2) to organise and visualise health data. Tanzania, for example, now integrates climate data into its DHIS2 for health planning. WHO and the United States Centers for Disease Control and Prevention have long promoted Epi Info™ as a simple, freely available tool for epidemiological analysis. Commercial packages such as SPSS and STATA provide a greater array of functionality but are often too expensive for routine use in lower income countries. R-software is a relatively new and freely available programing language and software environment for statistical computing and graphics which researchers use increasingly for epidemiological studies [31] including studies that integrate climate information into early warning systems [32]. The International Research Institute [15] at Columbia University in New York has a Data Library in which users can access, manage, analyse and visualise large climate and environmental datasets and build tools designed to inform health decision-making.

We summarise the approaches researchers use to model climate and infectious diseases in Box 14.4 and refer readers to technical resources for more detail. The choice of modelling method depends on the objectives of the study and the nature and quantity of the data. Researchers regularly use statistical models to reveal relationships between disease outcomes and potential risk factors. Notable among these are spatio-temporal models which predict the distribution of a condition's prevalence or incidence geographically and over time (see Chap. 20). Other approaches include mathematical models and machine learning [33]. The models underpin tools for climate informed decision-making—such as developing epidemic thresholds for vaccine delivery [11], maps for identification of populations at risk [12] and assessments of the cost-effectiveness of climate based interventions at different scales [34]. Researchers often establish and test these models against historical disease case data. They may use climate data for the same location and predict future cases based on climate data alone using the relationships identified.

Box 14.4 Some Methods of Analysis of Climate and Health Data

Empirical statistical models can analyse the spatial and temporal distribution of disease in relation to climatic and environmental drivers—including identifying outbreaks and epidemics. Relationships identified cannot be concluded causal unless a mechanism is identified. See Chaps. 20 and 21 of this handbook and Gelfand et al. for further information [35].

Mechanistic models, built on known or supposed relationship of external drivers to intrinsic processes in disease transmission, can explore the impact of the extrinsic climate drivers with other changes in the system. Here the causal relationship is assumed.

Some authors equate empirical to statistical and mechanistic to mathematical, but this is a false dichotomy (Diggle, *personal communication*). A more important distinction is between deterministic and stochastic models. Also, for any stochastic model principled statistical methods should, whenever possible, be used to estimate parameters and assess model fit. See Keeling and Rohani for further information [36].

Machine learning, for example, neural networks and other expert methods for forecasting the evolution of an ongoing epidemic. Here, the models are thoroughly empirical in the sense that no attempt is made either to understand the causal nature of the relationships observed or, typically to take explicit account of the scientific context. See Bishop for further information [37].

5.3 Presenting and Interpreting Information

Maps best visualise geographic distributions, seasonal patterns and year-to year-variations in risk over a region. Figure 14.1 is a map of the historical relationship between the October-to-December short rains and ENSO in Kenya, and Fig. 14.2 shows a time-series of ENSO events over the last three decades and rainfall for the same season in a district in north-eastern Kenya (Wajir). The rainfall was unusually heavy for both the 1997 and 2006 El Niño but the former was a more extreme event. Furthermore, 2011, a La Niña year, was also unusually wet. Thus, while ENSO may indicate a general tendency to be wetter or drier in a region, the impact of any event is somewhat uncertain, due in part to the influence of other climate drivers.

Attractive as they appear, maps simplify reality. It is important that researchers explain what the maps mean to health planners. Maps may describe the modelled relationship between climate predictors and health outcomes but often do not present the amount of uncertainty in the relationship. The model is unlikely to be predictive unless the relationship is plausibly causal, that is, there is a known physical mechanism by which the predictor may influence the health outcome. Choice of spatial and temporal scales influences interpretation. There are many ways to develop epidemic thresholds for epidemics which give very different results. Although there are usually optimal spatial or temporal resolutions that provide greatest specificity and sensitivity, researchers take into account data availability when choosing between models, and there may be political considerations.

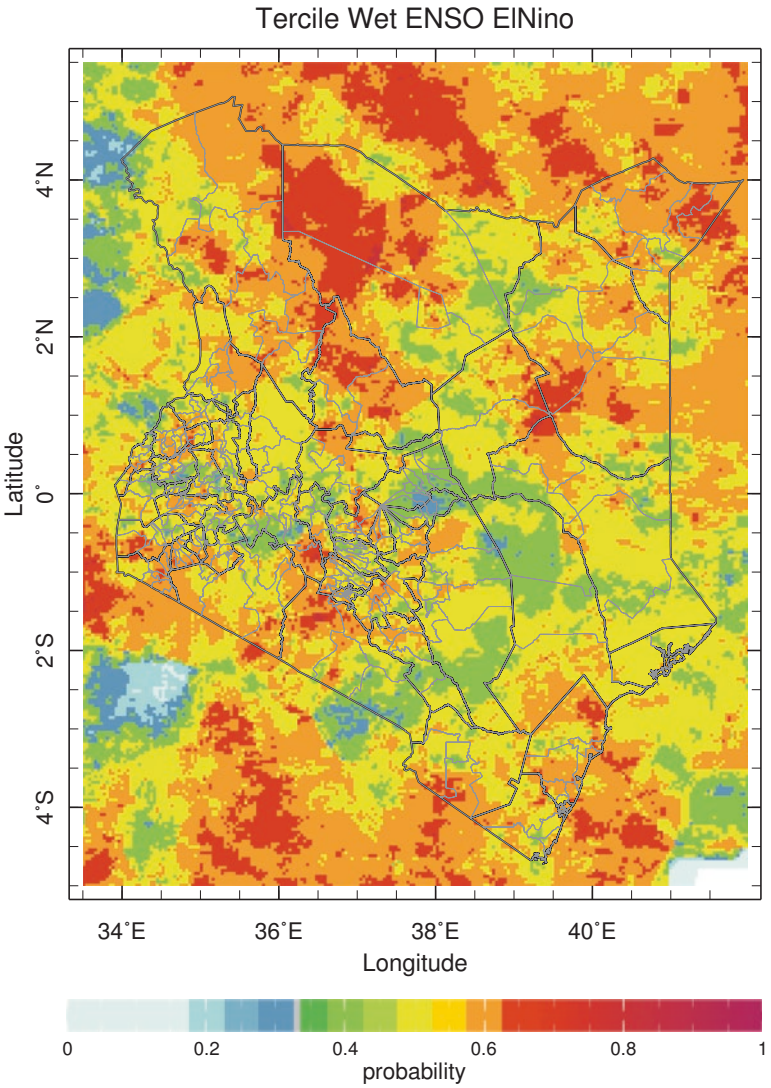

Fig. 14.1 Historical probability of seasonal monthly averages conditioned on El Niño in Kenya for seasonal average rainfall for the October to December season

5.4 A Checklist for Using Climate Information to Predict Health Outcomes

At the beginning of this section, we suggested two scenarios in which either the health planner seeks an epidemiological study to explain what is happening or the planner seeks assistance in setting up a surveillance system. Here we

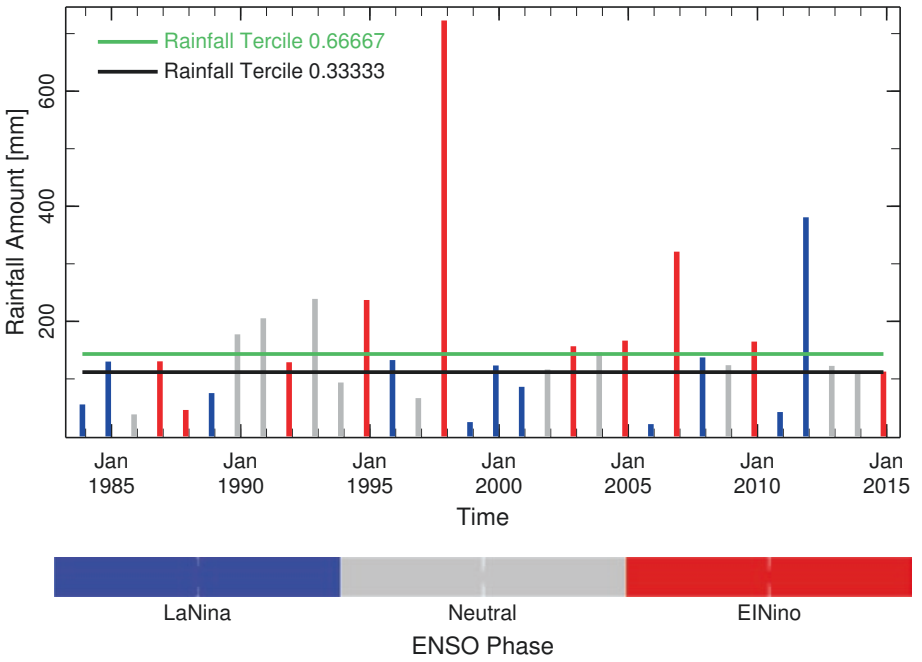

Fig. 14.2 Time-series of El Niño Southern Oscillation events and rainfall for the October to December season in Wajir district in north-eastern Kenya

consider a planner who wants to coordinate climate data systems with health information data on a routine basis. We offer a few questions the planner might answer.

Which Problem/s Do You Want to Address with Climate Data? Is it the identification of districts and villages that should be targeted for indoor residual spraying? Or is it to better to estimate the number of patients with specific needs (e.g. drugs, vaccines) that a district health facility might expect in the coming weeks?

Who Will Use the Data? Who are the stakeholders? Will you make your predictions publically available? How will you present the information to stakeholders? Developing the technical capacity for early warning must to go hand-in-hand with developing institutional capacity to use the information.

Where Do You Want to Collect and Use the Data? Do you want to set up systems in specific localities, a large region or the entire country? It is often useful to undertake a pilot in a small area but climate impacts may be easier to observe over a larger area with aggregate data.

What Climate Data Do You Need and Where Will You Find the Data? Will you access data from local meteorological stations or use global products? If the data are locally acquired, are they open access? Can you set up a data sharing policy? Is there a cost attached? Are suppliers of climate information able to provide data consistently and in a timely manner?

How Will You Manage the Climate Informed System? Consider approaches to integrating climate data with health data, for example, the types of software needed and their compatibility with systems in current use. Do you need to appoint experts or to train staff to understand and use the information operationally?

6 Challenges and Innovation

While many in the climate and health communities recognise the benefits of incorporating climate data and information into health decision-making, they face challenges in making this happen. The two communities have long-established methods for managing data within their sectors but have less experience in sharing data with each other. Much of the inter-sectoral collaboration to date has been led by researchers who want answers to specific research questions and who combine time-series of epidemiological data with historical global climate products. Some ministry of health epidemiologists work with research institutions to build models that predict epidemics, mainly of malaria and also of dengue, meningitis and cholera, for example. Ministries of health have only recently had the capacity to integrate climate data into their routine health information systems even at national level.

A significant challenge is lack of access to quality data from their meteorological agencies; as a consequence, local and international users turn to freely available global products despite their quality limitations. Global products contain a fraction of the detail of locally recorded NMHS observations, and users may not fully understand their relevance and quality. The Enhancing National Climate Services (ENACTS) attempts to address this problem [38]. ENACTS works directly with the NMHS to combine observations from the national observation network with global products—that is, satellite estimates for rainfall, and digital elevation models and reanalysis products for temperature. ENACTS also develops data and derived products and disseminates them via *maprooms* on the websites of the NMHSs (and via email on request). These quality assessed, spatially and temporally complete products (over 30 years of ten-day data at 4–5 km^2) make it possible to characterise

climate risks on a local scale. IRI initially developed ENACTS in response to requests for climate data by the Ethiopian Ministry of Health [39]. As of 2017, ten African countries and two regions (Western and Eastern Africa) have implemented ENACTS based products and services. Figures 14.1 and 14.2 demonstrate use of ENACTS data to investigate the impact of El Niño in Kenya.

A remaining challenge is the capacity to value, collect and analyse climate data in health. Ministries of health need to partner not only with climate experts but with academic epidemiologists with technical skills. Few health training initiatives whether in public health, medical or nursing schools include a practical understanding of climate in their curricula. New initiatives are emerging that bring awareness of climate change, and knowledge about climate data and information to the health sector. The Global Consortium on Climate and Health Education launched in February 2017, focusses on integrating climate into core curricula of today's health professionals [40]. To support this effort we have published *Climate Information for Public Health Action* [41] which provides a detailed introduction to the rationale and science underpinning climate-informed health decision-making. This book details the strengths and limitations of historical, monitoring and forecast climate products and provides examples of how they might be used in an operational context.

7 Conclusion

Since the 1980s, there has been an exponential increase in data, methods and tools for using climate information. These developments present exciting opportunities for health sector decision-making. Yet to-date, ministries of health seldom incorporate climate information into their routine planning processes or early warning systems. Technological, institutional and capacity issues remain significant obstacles to sharing quality climate data between NMHS and national partners. The Sustainable Development Goals, which have taken over from the health focused Millennium Development Goals, provide incentives for the health sector to collaborate with other sectors. It is the right time to for the global community and practitioners in the climate and health sectors to support and enhance the use of climate data to improve health outcomes.

Key Messages

- Many health outcomes are sensitive to climate.
- Climate information can improve health decision-making for climate-sensitive outcomes.
- Health planners need greater access to relevant and robust climate data.

- Collaboration between the health and climate sectors could overcome technical, institutional and capacity constraints to using climate data in health.
- The Sustainable Development Goals provide the environment for multisectoral collaboration to improve health outcomes.

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15

Advancing Health Policy Using a Geographic Approach

Estella Geraghty

1 Introduction

In 2017, San Diego County, California had the largest Hepatitis A outbreak in the US since the vaccine became available in 1996. Obtaining early measurements on the rapid spread of the disease prompted the county public health officer to declare a local public health emergency for Hepatitis A. This decision helped the county to shed light on an important problem and divert resources to address the concern promptly. Further analysis identified pockets of high-risk populations and prompted strategic interventions like sidewalk sanitation, mobile vaccination teams to reach highest risk people, and placement of handwashing stations in targeted areas of the county. Consideration of place was a key aspect of every decision.

Have you ever stopped to listen for references to place in everyday conversations? If so, you probably realize that words like *location*, *place*, and *where* come up frequently. In fact, the word *place* is the 107th most commonly used word in the English language and *where* is the 110th [1]. There is meaning in that—place matters. It's a part of everything we do and nearly every dataset that we collect and analyse. But despite the ubiquitous

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nature of location in our data and our lives, it is a variable that, in my view, we still under-utilize in health and health policy decisions.

One type of policy decision that is impossible to make without the benefit of location intelligence is the fair distribution of resources. Policymakers may unintentionally miss the critical distinction between fair versus equal distribution of health promoting assets in a community. Without understanding geographic differences in social determinants of health and population needs, leaders may choose to equally distribute diabetes education centres in a community that only has pockets of uncontrolled diabetes, or place senior day-care centres in a grid-like pattern despite certain areas having a predominantly younger demographic. It is far more useful and cost effective to place resources in the areas where people need them (equitable not equal). More importantly, fair and equitable distribution of resources is a key factor in mitigating health inequities and improving population health outcomes. Using geography to make these kinds of policy decisions is both ethical and economical.

How then, do we put geography to use in health policy decisions? Nowadays, technology provides the simplest answer—we use a geographic information system (GIS). A GIS lets us visualize, question, analyse, and interpret data to understand relationships, patterns, and trends [2]. It is a system like any other information system but with the addition of geographic references in the data. But that one simple addition packs a boat load of value.

So, what is the value proposition for GIS in real terms? A location perspective helps us to easily view and interpret vast amounts of data and forces us to think differently about what we're seeing. Those insights improve decision-making, ensuring that we allocate the right resources to the right people in the right places. Employing GIS to target and tailor action plans increases efficiency, accuracy, and productivity, reduces costs, and enhances communication, collaboration, and information access [3].

In the sections that follow, I will review the development of place-based decision-making in health. In *The evolution of geography in health*, I describe the spatial approach to important questions; in *What is where*? I articulate the kinds of questions that GIS can answer; in *Why is it there*? I focus on the decision support that results in *Why do I care*?. To put it all together, I'll step through an example of how we can apply GIS to all aspects of a major health challenge, homelessness. I'll conclude with some advice on how to make GIS happen in your organization so that you too can realize all of the benefits that geography has to offer.

2 The Evolution of Geography in Health

Historical evidence indicates an acknowledgement of the relationship between health and place going back to at least 400 BCE with the Father of Medicine himself, Hippocrates. In his writings, *On Airs, Waters, and Places* [4] Hippocrates begins the treatise with the following:

> *Whoever wishes to investigate medicine properly, should proceed thus: in the first place to consider the seasons of the year, and what effects each of them produces for they are not at all alike, but differ much from themselves in regard to their changes. Then the winds, the hot and the cold, especially such as are common to all countries, and then such as are peculiar to each locality. We must also consider the qualities of the waters, for as they differ from one another in taste and weight, so also do they differ much in their qualities. In the same manner, when one comes into a city to which he is a stranger, he ought to consider its situation, how it lies as to the winds and the rising of the sun; for its influence is not the same whether it lies to the north or the south, to the rising or the setting sun. These things one ought to consider most attentively.*

Later in his writings, Hippocrates described how specific environmental conditions influence health outcomes.

One very *early adopter* exploited the innate relationship between health and place to improve decision-making. The great Persian physician, Al Rhazes (AD 900), was ahead of his time in many ways, but particularly in his spatial thinking skills. It was said that Al Rhazes was asked to site a new hospital in Baghdad. To make a recommendation, he hung slabs of meat in various places around the city. With regular monitoring of putrefaction, he identified the slab of meat that spoiled at the slowest rate. That location, he hypothesized, must have the healthiest ambient environment and thus settled his recommendation [5].

Early contributions notwithstanding, it took nearly 800 years before place and health were sourced together in a map. That map was developed in 1694 and documented quarantine zones for plague in the Bari province of Italy [5, 6]. It seemed to be a real turning point in the history of visualization to improve communication. Over the next 225 years, public health officials used maps to understand and track infectious diseases like yellow fever, cholera, and the 1918 influenza pandemic [6, 7]. Unfortunately, in the early 1900s, such visualizations fell dormant in a period known as the Modern Dark Ages of Visualization [8].

By 1950, three major advances revitalized data visualization. John W. Tukey in the US developed the science of information visualization for statistics, Jacques Bertin in France provided a theoretical foundation for information visualization, drawing on his experience as a cartographer and geographer, and computers made large volume data processing and graphic form development possible [8]. These works underpinned the creation of computerized GIS in 1960 by Roger F. Tomlinson of Canada. The advent of computerized mapping opened a world of potential for decision support and public policy-making. Early applications of GIS in health made use of simple visual representations of disease and health information, like guinea-worm surveillance data in 1993 by the World Health Organization, to support eradication efforts [9].

Today, technological advances in GIS are changing the game. A GIS not only empowers organizations to visualize, analyse, and interpret data, it also handles mobile data collection, real-time analytics, and three-dimensional visualizations to name a few. These advances change the game because GIS moves from a helpful tool in the arsenal to a framework on which entire workflows can run. In other words, the breadth of a GIS platform is now catching up to the ubiquity of location in our lives.

3 What Is Where?

The first step in using geography to drive insight and policy decisions lies in answering the simple question *What is where*? In our daily lives, it's perfectly natural to query where things are located in the world. We tend to ask this question in two ways. The first kind of query is location focused and asks the question such as *What is at…*? Such questions are common to getting to know a place. For example, when we move to a new town, we may wish to know what kinds of local resources and community assets exist in the town. What does the built or natural environment look like in the new neighbourhood? Is the landscape mature? Are there pavements for pedestrians to keep safe from traffic? The second query type answers the conditional question, *Where is it…*? In this case, the question originates from a desire to locate a certain type of feature, like a school or a market. Placing things in geographic space brings them into immediate perspective.

In health geographics, we operationalize *What is where?* by developing and maintaining foundational data resources. These are data resources that become reference materials for analysis or information products. For example, health organizations may collect and update data on infrastructure assets such as

hospital facilities, programme locations, pharmacies, or substance use treatment centres. This is a valuable first step in geo-enabling a health information system. Having a clear picture (i.e. a map) about where key assets exist will not only help direct people to those facilities, but also helps a provider visually determine where potential gaps exist within their network. Consider a disaster situation, having foundational data available in advance makes it possible to quickly guide impacted populations to known shelter locations or to manage the surge on local health-care facilities.

In addition to capital assets, thematic data can also be foundational. That content will, of course, depend entirely upon the organizational mission. For example, a national government initiative on reducing the burden of diabetes may use diabetes prevalence data to map where diabetes exists across the country and visually compare the variation from one place to another, discerning broad patterns in the data (Fig. 15.1).

Comparative views, like those in Fig. 15.1, can highlight stark differences in health status, like the low prevalence of diabetes in Colorado against the very high prevalence in the south-eastern part of the US. We can glean different kinds of information when data contain a temporal component in addition to the spatial variation. In other words, we can answer the question

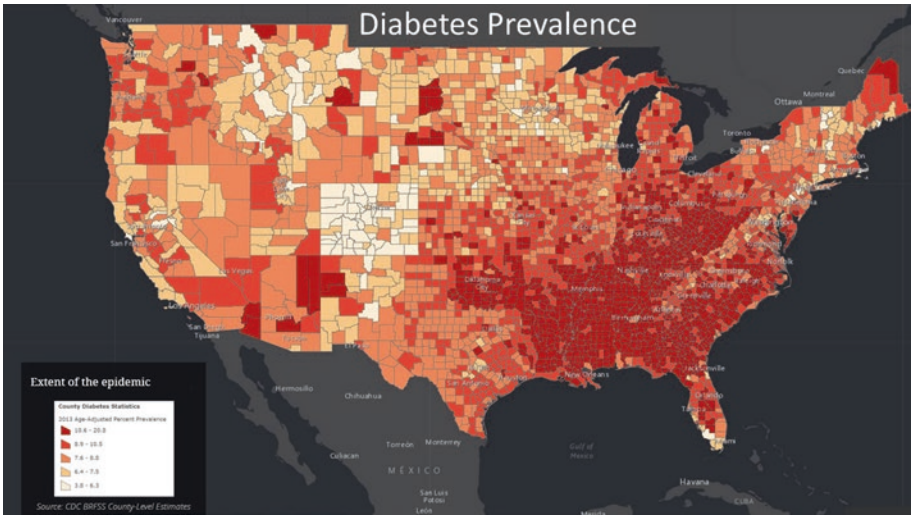

Fig. 15.1 Prevalence of diagnosed diabetes by county in the US, 2013. (Data were accessed from the Centers for Disease Control and Prevention's calculations of prevalence at the county level using both census information and survey responses from the Behavioural Risk Factor Surveillance Survey (BRFSS) [10])

Where are things changing? Understanding spatio-temporal patterns in data has significant policy implications (see Chap. 20). We can use such data in looking forward in time to see if certain patterns are predicting a future problem that may require a larger up-front resource allocation to avoid downstream consequences. On the other hand, examining the historical spatio-temporal variation in a dataset may tell a story about the success or failure of an intervention. I recall a powerful example of this during my tenure at the California Department of Public Health. A colleague created a set of comparative maps showing teen birth rates, by state, across the US in 2000 and in 2010. Calculating the difference between the two maps she produced a third map showing the rate of change for each state. Then governor, Arnold Schwarzenegger, was said to have been quite pleased to share the map highlighting California's significant decrease in the rate of teen births over the decade.

As in traditional statistics, there are some basic spatial statistics that help us to dig just a little deeper into the *What is where*? question. While we observe minima, maxima, means, and standard deviations in traditional datasets, we focus on measuring size, shapes, and spatial distributions and directions in a geographic dataset. For example, we might observe racial segregation/de-segregation over time, the increase in urban sprawl, the spread of infectious disease, or the path of a storm through populated areas. Understanding how things are moving through space and time helps policymakers to anticipate impacts and prepare response activities.

The most effective GIS systems begin with *What is where*? Foundational data needs have been carefully anticipated, collected, and kept updated so that they are ready when either a common or critical use arises. Foundational dataset examples for health include facilities and capital assets, partner locations, demographic data with population characteristics and potential vulnerabilities, and thematic information relevant to the organization's mission. The Ministry of Health and Sports in Myanmar shared its story about how geo-enabling foundational data in its health information system helped it to address Universal Health Coverage in obstetric care as well as respond to unexpected emergencies, like the Chauk earthquake of August 24, 2016 [11]. A GIS system, fuelled with relevant foundational datasets, moves an organization one step closer to creating well-designed information products that help people make better decisions.

4 Why Is It There?

Understanding *What is where*? grounds a decision-maker in the geographic distribution of a theme or concept of interest. That has great power since geographic visualization makes data more compelling, more readable, and engages the viewer at a deeper level. A natural consequence of that engagement is that viewers will begin to recognize patterns in their data and ask questions about them. Are they real? What's causing them? How do those causes or triggers vary over space and time? Ultimately, we need to employ analytics to address questions of why.

Geographic or spatial analysis is different from traditional analytic methods. The difference originates from a basic principle articulated by Waldo Tobler which states: 'Everything is related to everything else, but near things are more related than distant things' [12]. The weather offers a useful example of this idea. The temperature in adjacent towns is likely to be more similar than the weather in distant towns. This idea of relatedness, also known as spatial autocorrelation, is the first law of geography. It is exactly what makes geography worth studying. As a measure, spatial autocorrelation tells us the level of importance of geographic characteristics in affecting a given object, person, or population. Spatial autocorrelation helps us to understand pockets of disparity, varying access to care and clusters of cancer to name a few.

Given the value of spatial autocorrelation in health geographics, it is important to properly account for it in any geographic analysis. At the highest level, we must recognize the implications of relatedness in statistical procedures. A primary consideration is the impact of relatedness on the statistical power of a study. This is key since we require adequate statistical power to ensure that study data can support, with high probability, the appropriate rejection of the null hypothesis when a specific alternative hypothesis is true. In traditional statistics, ensuring power is usually straightforward. Studies are strategically designed so that observations are independent before undergoing testing. However, geographic observations, by their nature, and by Tobler's first law of geography, are related. This means that each observation is not independent and in fact, contributes to power less. More data are always needed to achieve adequate statistical power in a geographic study. This may be inconsequential when the study uses datasets with a plethora of observations, like hourly pollution monitoring from multiple sensors over an area. But the impact could be devastating when studying a rare health condition in a rural area. A second important component of spatial analysis that differs from traditional methods is the actual testing of the level of spatial autocorrelation. There are several

potential measures from Geary's C and Moran's I to the Mantel Test. No matter the test, the idea is to determine the intensity of spatial relatedness in a dataset. High levels of relatedness are called clustering, like when we find evidence of cancer cases proximate to a toxic waste site. Low levels of relatedness can be seen in completely uniform datasets, like arranging pharmacies at the Northeast corner of every block in an area. Accounting for statistical power and the intensity of spatial relatedness lays the groundwork for asking *Why is it there*?

Specific analytic methods for asking why can take many forms. I recommend that policymakers begin with the question needing resolution before deciding on a method of analysis. I know this sounds obvious, but too often, we see examples of data driving the analytic method or the analyst performing their work with the same set of tools with which they are most comfortable. This is so common that we might even call it human nature. However, to achieve the desired impact in making policy decisions, we must always begin with the question and let that drive data collection and analytic methods. In the paragraphs that follow, I will share examples that highlight how different geographic methods are applied to get at key answers.

Sometimes we want answers about how people and places are related. Diving into this analysis provides specifics about what may be nearby or coincident, what is closest, what is visible from a given location, what overlapping relationships exist in space and time, and how many of a thing exist within an area. Practical examples of this kind of analysis include correlations of increased lung or liver cancers in residents living near a sewage plant [13], gravity or choice models looking at the role of geography on patient access to treatment locations [14], and the number of disabled people living within a flood zone. Getting clear on the relationships between people and places provides needed insight for mitigation strategies when health concerns arise.

A second area for which decision-makers need answers is for finding the best location or the best way of getting somewhere. Finding a location or site selection is a common type of geographic analysis. Generally, a decision-maker has a set of criteria in mind befitting an ideal location. For example, a health system manager may decide to open a multi-specialty clinic and will look for a location that is currently under-served, well-populated, in need of specialty services, distant from major competitors, and low on neighbourhood crime. Each criterion in this example can be defined within a range and weighted in importance to determine a final list of compliant sites. The analysis of paths or calculating the best way to get somewhere can range from very simple to very complex. We should not underestimate the value of getting a person from point A to point B. Perhaps that value is easier to grasp when we

consider the consequence of not getting from point A to point B effectively. A 2005 study of 100 US hospitals found that operating room charges averaged $62/minute (range was $22 to $133/minute), so unused operating room time can add up quickly [15]. If simple outdoor and indoor navigation (finding places in hospitals is never easy) could get a patient to the surgery centre on time, then the hospital operating room ceases to lose money and can potentially function at capacity. This is good for both the hospital and the patients waiting to schedule a procedure. Path determination can become more complex as more factors come into play, such as routing to shelters during a hurricane. We must then account for real-time storm information, road closures, traffic patterns, and shelter types (regular vs. special needs). Stronger analytic methods in this instance will significantly improve decision support for the end-user.

Detecting and quantifying patterns comprises the most common of the spatial analytic methods. Techniques in this category include hot spot analysis, cluster and outlier analysis, time trends and feature grouping to name a few. It's critical for decision-making to know if a visualized pattern in the data is real. Analytically, we do this by testing for statistical significance, assessing the biologic plausibility, and observing the effect size. When we confirm significant clusters we can allocate resources to places with the highest need. Dr. Atul Gawande provided a great example in his 2011 article, *The Hot Spotters*, in which he related a story of hospital readmissions in Camden, New Jersey [16]. Hospital readmissions are an expensive problem that also reflects unfavourably on quality of care. Dr. Gawande highlighted how hot spot analysis, performed on a hospital's most expensive patients (those frequently readmitted to the hospital within 30 days of discharge), found that a large number of those patients lived in two of Camden's low-income housing complexes. Further analysis determined that the people in those buildings had difficulty accessing primary care services that would have helped them to manage their chronic diseases and avoid repeated hospitalizations. In the end, placing small primary care offices in the two buildings in question both improved the continuity and quality of care while also cutting hospital readmissions costs by nearly 50 per cent. Knowing the hot spots, determining the underlying causes, and smart resource allocation dramatically improved results.

The final analytic category helping us to understand *Why is it there*? is about making predictions. Many researchers are comfortable with observational studies that make use of historical information to bring new understanding to our collective intelligence. However, decision-makers frequently want to know what's coming next so they can prepare for it. The need for prediction spans all aspects of health. Health systems have a need to do capacity planning

which involves predicting population needs in the geographies they serve. Public health officials need to predict the spread of infectious diseases, whether locally contained, like a food-borne illness, or global like Zika virus, dengue fever, or malaria (Fig. 15.2). Social services departments can use their GIS to predict the areas at highest risk for homelessness (see Sect. 6—*Putting it all together: embedding GIS in a homelessness workflow*). Using geography to make predictions offers the potential to get ahead of health issues—a game changer for any decision-maker.

Although I focused in this section on spatial analysis and its inherent differences compared to traditional statistical analysis, it is important to note that some things remain the same. As we endeavour to understand why things happen, we must always exercise caution in how we present information. We've all heard that statistics can lie. Well, the same is true for maps. It is incumbent upon the GIS analyst to ensure that they use proper cartographic and visualization methods to show results that fairly and correctly answer the question. At the same time, map readers should also develop a fundamental understanding of geographic data presentation. When these things are

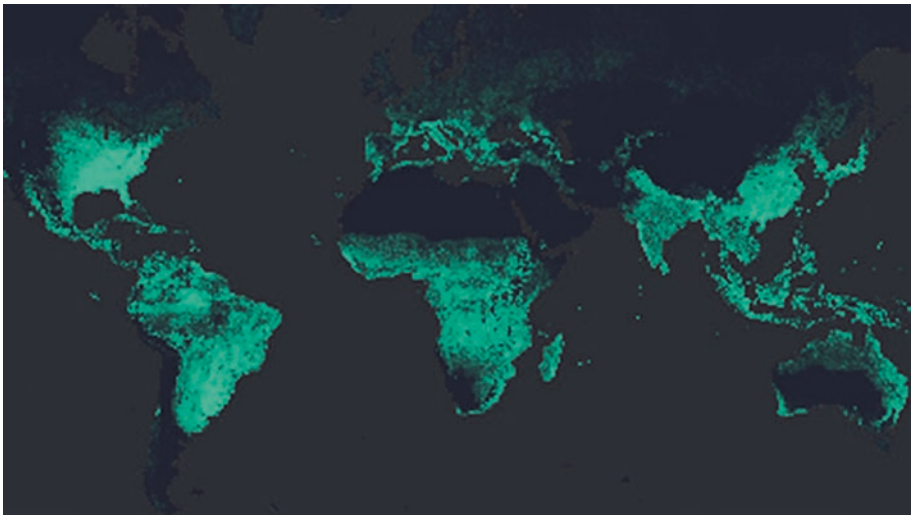

Fig. 15.2 Global map predicting possible locations for *Aedes albopictus* mosquitoes, one of the potential vectors for Zika virus, 2011. (Brighter green areas have the highest probability of being suitable habitats for these vectors based on modelling temperature, precipitation, elevation, and land cover. Data sources were publicly available from WorldClim 2009 (temperature, precipitation, elevation) and ESA 2010 and UCLouvain Team (land cover). The 2011 data on human population density from Oak Ridge National Laboratory's LandScan Database is available to researchers upon request. Additional details on the data sources can be found at [17])

properly achieved, answering *Why is it there*? provides the critical link between raw data and decision-making. For additional information about spatial analysis and specific tests and methods, I recommend the following journals: *Spatial Statistics*, *Spatial and Spatio-temporal Epidemiology* [18], *International Journal of Health Geographics* [19], and *Health and Place* [20] (see also Chap. 20). Readers may be interested in this website which provides several spatial statistics resources such as videos, slideshows, documentation, and hands-on tutorials [21].

5 Why Do I Care?

We might say that we answer the first two questions *What is where?* and *Why is it there?* to get to this last question *Why do I care?*. This is the part of the workflow where all the action takes place, where policy decisions are made, where resources are allocated, and where interventions are targeted and tailored for greatest impact.

We care because, as leaders, it is our responsibility to render the best possible decisions to improve health. Those decisions must be driven by timely and accurate data, sound analytic techniques, and the unique insight offered by geography to address some of the greatest health challenges of our day. The social determinants of health, the opioid crisis, tobacco use, and universal health coverage all serve as compelling use cases for a geographically based approach. And as such, GIS can have a profound effect on the way an organization functions and the confidence with which it makes decisions. Health decisions are often critical. For example, the World Health Organization's polio eradication programme used GIS tools to address the polio outbreak in Syria and Iraq in late 2013 and early 2014. Real-time data collection helped them to identify gaps of unvaccinated children and intervene to prevent the spread of this disabling and sometimes fatal disease [22].

Not only is a GIS an indispensable tool for evidence-based decisions, but it also promotes policy initiatives in transparency and engagement. The Northern Kentucky Health Department provides a great example. In an interactive story map, the department explains how it has educated the population about the severity of local opioid abuse usage and its sequelae, shared the resources available to the community, and showed how the department and other local organizations are responding to tackle the crisis. Over 15,000 people have engaged with the story map to date [23].

6 Putting It All Together: Embedding GIS in a Homelessness Workflow

To fully grasp the power of a geographic approach, it can be helpful to bring multiple GIS capabilities together to address an entire workflow. Homelessness is a health and social concern in many places around the world. In fact, in some cases, homelessness is syndemic with other health concerns which only increases the urgency for strategies to address it. For example, homelessness and opioid abuse may synergistically exacerbate one another in a community. A spatial perspective, using GIS, can shed new light on this issue and offer evidence-based approaches for interventions. In what follows, I describe how we can apply GIS to every step of the workflow aimed at mitigating homelessness.

We may want to start by identifying where people experiencing homelessness are located in our communities. In some places, this is a requirement—a regular count of sheltered or unsheltered homeless individuals. Mobile GIS tools can be deployed on tablets or smartphones to conduct surveys that gather important information on the homeless like location, basic demographic data, and duration of homelessness. Understanding where homeless people are supports targeted allocation of resources. Fortunately, given the state of the technology, some kinds of interventions and resource allocations can be initiated in real time. For example, a jurisdiction may set a goal to ensure that children under the age of 18 years do not spend another night on the street once they are known. A real-time GIS makes this possible. The moment a location-enabled homeless survey is submitted from the field with demographic information indicating a person under the age of 18 years, an alert could be triggered to immediately deploy resources to the child's location.

Analysis or asking why people in certain areas are experiencing homelessness is needed to identify risk factors. Taking an evidence-based approach, we may bring in data on unemployment rates, poverty rates, lack of health insurance, and lack of affordable housing. Other datasets may be relevant depending on the specific geography. Whatever our identified risk factors are, we can combine them through map overlay or by creating an index of risk that will not only explain why we are seeing homeless people (per our mobile GIS count) in certain areas, but will also help us to predict high-risk areas for prevention strategies.

The next steps in our workflow are about taking action. The first action is deceptively simple—connecting people with the health promoting resources they need. Most health organizations have endless lists of resources for the populations they serve, but it's a challenge to identify and select the right resource for a person given their location. That becomes especially difficult if

the population is transient. GIS can help by integrating all relevant programmes, community partners, and services in a location-aware app. Previous research indicates that, in the US, among homeless youth alone, more than 60 per cent own a cellular phone and many consider it as important to their survival as food [24]. Making resource information accessible through a mobile app, helping users find and navigate to the nearest resource given their current location empowers and connects people. And by the way, the policymaker can examine the same set of integrated and mapped resources to expose potential gaps in the network and take steps to fill them.

A second action that GIS supports in this homelessness workflow use case is in the long-term planning of affordable housing units for areas deemed to be high risk for homelessness. This represents a site selection scenario much like the multi-specialty clinic example discussed in the *Why is it there?* section. In this case, the difference is in the criteria needed to find the best places. It is likely that in addition to planning for affordable housing in areas proximate to high-risk areas, city planners would also want to consider areas near employment opportunities with access to public transportation, health care, and social services that can provide a safety net and prevent future families from the tragedy of homelessness.

Perhaps one of the most overlooked applications of GIS is operational efficiency. While there are multiple potential ways to streamline our work, one that relates to this scenario is the real-time monitoring of field workers. In the case of surveying homeless people, scads of volunteers are usually recruited. It can be a logistical nightmare to ensure everyone's safety, avoid duplicate coverage of areas, and coordinate activities. A modern GIS can assist by tracking devices, defining territories, communicating assignments, and observing activity levels to name a few. Keeping field workers safe and productive is a top priority in any organization.

Our workflow thus far has included gathering and analysing data, conducting interventions, and ensuring operational efficiency. The last two pieces of the homelessness workflow include stakeholder communication and evaluation of impact. It has already been suggested that maps are engaging. That trait is very useful in delivering public information, whether it's to simply share information about the extent of homelessness and the actions being taken or to proactively reach out and offer education to at risk communities. When it comes to assessing impact, spatial and temporal analytics can reveal before and after effects by place, compare results to goals or national averages, and provide evidence of future adjustments. A modern GIS is more than a map, it is a value-based approach to an entire workflow that offers a range of benefits and insights not available elsewhere.

7 Making It Happen

At this point, I hope that you share my conviction that GIS offers powerful value with a rich infrastructure and sophisticated analytic capabilities integrated in a platform that supports numerous tools and apps to get work done. The question remaining now is how to realize this value in your organization.

The first consideration for most organizations will be the price tag associated with purchasing software. There are many choices available to fit the needs of any health unit. The range of costs, however, is broad (from open source to vendor-based solutions), making choices more complicated. For that reason, multiple factors will enter in to a buying decision. What features and functions are essential to address the organizational need? How many people will use the system initially and what are their training needs? Will the system scale and expand as the business needs grow? Are developers required to write applications and ensure interoperability or is the system configurable and ready to go? Will this be a desktop solution or an enterprise solution? Does the organization want to manage the infrastructure (i.e. servers) or work in a cloud-based environment? Are prospective users of the system dealing with protected health information? How quickly can the system be implemented and used to create value? What kind of support needs are anticipated as the organization adjusts its workflows to leverage geography? Each of these questions will reframe the idea of *cost* in a way that helps you make the best choice for your unique situation. I'll explore these in more detail in the paragraphs that follow.

The fact of the matter is—it's not just about the software. Before the first tool is downloaded, I would suggest that the astute organization would begin with developing a location strategy. This means that people within the organization have taken the time to assess whether the geographic perspective will add value to their mission and they envision the specific value-based outcomes they plan to achieve. In fact, the expected value of the system should be greater than the cost of purchasing and implementing the system.

Once the location strategy has begun and initial outcomes are defined, then an organization should consider the other resources they'll need. The biggest investment in resources is generally in the human capital required to run the system, collect and organize data, run analytics, and evaluate progress. Investments should be made in proper training as well as change management to ensure that organization's success in implementing its new GIS programme. A 2011 study from IDC (International Data Corporation), a global advisory firm in information technology, found that a 6.25 per cent project budget dedicated to training led to an 80 per cent success rate for the project as com-

pared to a 4.75 per cent training investment resulting in only a 50 per cent chance of success [25]. It's also worth remembering that training is not always the same for every user. Depending on the role of the GIS user, they may need relatively simple skill development, like when using mobile survey tools, whereas the GIS analyst, performing statistical procedures on data, will need longer and deeper training.

Finally, you should determine the technology needs and deployment methods. Whatever GIS technology they use, purchasers should look for extensibility, scalability, and whichever features and functions are required for planned activities. Nowadays, interoperability is critical to technological efficiency, and should be a requirement imposed on any GIS software vendor before signing on the dotted line. Organizations should not have to write programmes to connect one technology to another.

There are several deployment options for a GIS platform system. A simple yet powerful approach is to use an online GIS, engaging in a software as a service (SaaS) model. In this model, the organization does not need to host the infrastructure to support an enterprise system, but can extract all of the value through the cloud. Some health-related organizations, however, may be unable to use or opposed to cloud-based models. One reason may be the need to pay for annual licencing of the services. This should be balanced against the costs of internal infrastructure over time. In most instances, however, the opposition to a cloud-based system is related to concerns about unintentional breaches of protected health information. Those organizations may prefer an enterprise deployment, on premises, and within firewalls. Between these two options is a hybrid approach that leverages the advantages of each method. An organization should consider which approach offers it the flexibility and security needed for its proposed usage.

Any organization that chooses to take advantage of the benefits of GIS for advancing its health agenda should also take the time to develop and systematize governance procedures. This effort will help to align staff on the policies surrounding the use of geographic data and keep the system humming.

8 Conclusion

Whether your goal is to improve access to your health services, stem the spread of infectious diseases, or systematically turn the tide on longstanding health problems, a GIS can positively change and improve how you do your work. Everything happens somewhere—don't let that ubiquitous data element go to waste!

Key Messages

- The importance of place and health has been recognized for more than 2,400 years.
- Understanding where things are in space offers insights for decision-making.
- Spatial analytics differ from traditional statistics in important ways.
- GIS for health policy promotes better decision-making, resource allocation, transparency, and constituent engagement.
- Deploying a GIS system is about much more than software.

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Part IV

Methods for Collecting and Analysing Global Health Data

Preface

This section brings together and introduces some of the major disciplinary approaches for collecting and analysing global health data.

The data collection instruments that authors describe in Part II and the other methodologies in this section are mainly quantitative. Chapter 16, however, explores the qualitative approach to gathering data for global health, and demonstrates that qualitative inquiry produces much richer information than the raw quantitative indicators. This chapter highlights the complementarity of both types of data collection, although the demand for global health indicators largely favours quantitative data.

Demography is arguably the oldest discipline contributing data to global health, describing and predicting how population structures change over time, whether across the world or in small geographic areas (Chap. 17). For example, demographic analyses alerted the public health community to the health implications of the population explosion after World War II, and are now warning of aging populations that will call upon new resources for health and social care. Demographic data—obtained and interpolated from censuses, civil registration systems, surveys and health and demographic surveillance sites—assist communities, governments, researchers and international agencies plan and distribute services not only in health but also for other sectors. These demographic data generate the denominator data needed to calculate almost all of the indicators used for national and global health-related reporting.

Chapter 18 introduces the basic methods and principles of epidemiology emphasising their importance to inform health policy and for programme planning. Epidemiology has served global health well and will undoubtedly maintain its centrality by describing and explaining health status and its determinants worldwide. Epidemiologists, for example, collected data on smallpox and polio to inform their eradication, alerted the world to the HIV/AIDS epidemic and are documenting the double burden of communicable and non-communicable diseases in many low- and middle-income countries.

Health economics contributes to global health by assisting policymakers choose intervention strategies that maximise health gains with available resources. Such analyses may inform recommendations to set global policy or provide a local decision-maker with information to choose between strategies, for example, whether or not offering male circumcision is a cost-effective strategy to prevent transmission of HIV/AIDS. Chapter 19 describes methods for calculating disability-adjusted life years (DALY) as a measure of disease burden and explains how cost-effectiveness analysis compares costs of health intervention with reductions in disease burden.

Increasing technical and computing capacity allow scientists to develop increasingly sophisticated statistical and mathematical models to analyse and predict health indicators. We have chosen to demonstrate the value of modelling in three situations: (1) for mapping health events/outcomes in space—using spatial modelling—typically by mapping the probability of the event/outcome occurring (Chap. 20); (2) for modelling events/outcomes in both space and time—using spatio-temporal modelling—typically showing predictive maps that vary over time, or for real-time surveillance of an infectious disease (Chap. 20); and (3) for modelling health indicators across countries, regions and time to publish global health indicators, for example, for the Sustainable Development Goals (Chap. 21). The authors of both Chaps. 20 and 21 caution about interpretation of the estimates that statistical models produce and emphasise the need to explain uncertainty to decision-makers.

Noticeable is the extent to which the methods/chapters complement each other. For example, demography describes the structure of the population while epidemiology seeks to identify and explain health events occurring within it. Epidemiologists provide evidence for an intervention and economists assess its cost-effectiveness. Epidemiologists contribute to the measurement of DALYs and economists use them to assess cost-effectiveness. Qualitative inquiry assists in explaining whether interventions will be acceptable to populations and why.

16

Seeking Insight: Using Qualitative Data for Policymaking

Suneeta Singh, Anjali Krishan, and Myriam Telford

1 Introduction

In Uganda, one in four teenage girls (aged 15–19 years) have already begun childbearing [1]. To inform policies to address this high rate of teenage pregnancy, Pulse Lab Kampala developed a pilot online dashboard to capture and track public Facebook posts for keywords associated with contraception and teenage pregnancy [2]. The dashboard obtained real-time information on perceptions about popular topics as they emerged. For example, Pulse observed that discussions about condoms frequently mentioned the words 'safe', 'free' and 'best' suggesting positive attitudes to condom use, and watched how the use of these terms changed over time. By capturing real-time qualitative data, such projects can supplement and explain information gathered through more formal, highly structured and intermittent quantitative data sources such as household surveys [2].

This study was part of the Global Pulse Project Series which uses social data to measure and achieve the Sustainable Development Goals (SDGs). Other Pulse projects have included the monitoring of tweets about vaccines and immunisation in Indonesia, and analysis of global conversations on social media to understand people's perceptions of sanitation [3]. Observations of

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this kind not only reflect the dynamics of online conversation but complement other sources of qualitative and quantitative data. While not part of this study, the Kampala researchers suggested that juxtaposition of the Pulse data with quantitative data, such as contraceptive sales figures, could yield indicators to fill the gap between perception and behaviour, customarily a difficult area to measure [2].

Innovative examples like these demonstrate that analysis of social data can assist health programme managers to understand why and how people make choices and the way they behave. Investigators describe methods for obtaining such information as qualitative because they rely on detecting patterns in opinion and on subjective explanations of human behaviour rather than on counts of their occurrence. Other methods of qualitative inquiry include observing and interviewing people, and holding discussions with them. The qualitative approach to obtaining information aims to 'emphasise the importance of understanding, from the viewpoint of the people involved, how individuals and groups interpret, experience, and make sense of social phenomena'. [4] The approach is vital to understand constraints under which policymakers operate and their motivations, and to develop solutions that are ground-up, community-based and context-specific. As our opening example illustrates, qualitative data, when triangulated with quantitative data, can provide innovative indicators to track the effect of a policy. But despite its potential, the health community has not wholeheartedly embraced the qualitative approach, neglecting to draw upon the subjective experiences of patients and front-line colleagues. There is a preference for hard evidence—read numbers [5].

In this chapter, we underscore the value of the qualitative approach for health policy and introduce some of its methods. We refer to people who collect and interpret qualitative data to advise policy as *researchers;* these include academics specialised in qualitative techniques, health and social science researchers applying qualitative or mixed methods, and investigators working for government, development or community agencies.

We start the chapter by describing the historical roots of qualitative inquiry and move on to provide practical advice about collecting and classifying data and judging their quality. We provide case studies to illustrate how the approach can add vital insights to health policymaking, and emphasise the growing popularity of mixed method approaches. We conclude by discussing some challenges to and opportunities for using qualitative data to inform health policy. Throughout, we refer readers to additional resources for in-depth explanations of the methods.

2 Evolution of Qualitative Inquiry

To claim that qualitative inquiry is 'as old as human civilisation itself' might seem exaggerated, but its methods have informed scientific progress across the centuries [6]. Early explorers used approaches akin to contemporary ethnographic studies to explore and understand foreign cultures.

The sixteenth-century British scientist and naturalist William Turner recognised that understanding people's stories is vital to appreciating how the world works when he said 'You have heard that the world is made up of atoms and molecules, but it's really made up of stories. When you sit with an individual that's been here, you can give quantitative data a qualitative overlay'.

In the early twentieth century, Franz Boas, 'the father of American Anthropology', pioneered the use of qualitative methods to study human societies more scientifically [7]. By abandoning former judgemental, and implicitly or explicitly racist, understandings of the evolution of cultures, he advocated cultural relativism—accepting that researchers need to weigh morals and behaviours relative to the culture within which they originate, rather than relative to the researcher's own culture. At the same time, anthropologists committed to empiricism, and grounded their understandings and conclusions firmly in observed evidence. Qualitative methodologies, explicitly championing ethnography, became more rigorous and systematic—moving away from journalistic accounts towards approaches in which researchers steeped themselves in their respondents' cultural context [8].

After World War II, quantitative methods based on experimental and biomedical traditions began to dominate public health. Seale argues this was in part because 'truly interpretive qualitative work had little to offer research funding bodies mesmerised by a narrow, numbers-based scientific vision' [9]. One review in the United Kingdom found no evidence of any qualitative research on health-related issues during the 1950s or 1960s [10]. The emergence of randomised control trials as a gold standard threatened what Gilson et al. called a 'disciplinary capture' with only one type of evidence having credence [11].

During the 1980s, the post-colonial and feminist movements revived qualitative inquiry [12]. The emphasis of these movements on the co-production of knowledge narrowed the gap between the expert and the layperson, and allowed the voices of marginalised groups to be heard; this promised a democratisation of knowledge. Influenced by these movements, policymakers and health professionals turned to qualitative methods to understand why health inequities persisted despite evidence of ambitious, well-funded remedial interventions

backed by randomised control trials [13]. Robert Chambers, for example, introduced a set of methods called *Rapid Rural Appraisal* to enable rural communities (mainly living in low- and middle-income countries) to work with development agencies to assess their own issues and propose solutions; this approach later became known as *Participatory Rural Appraisal* [14]. Researchers also began to use qualitative methods to examine critically both patients' health-seeking behaviour and the distribution of power within the medical sphere [15]. Use of such methods, particularly in conjunction with quantitative inquiries, shone light on how health practitioners could better reach the populations they serve.

While there is growing space for qualitative inquiry in health, quantitative methods still dominate the research arena. Yet qualitative methods have not been foreign to medical practitioners or policymakers—even if not explicitly labelled as such. Clinicians understand that they cannot apply norms blindly, but must temper them with clinical observation and professional judgement [16]. Public health practitioners recognise the need to study disease within its cultural and social setting and to understand patients as individual actors whose health decisions are subject to multiple constraints [17]. This bio-psycho-social model of disease raises new questions: for example, what factors influence a patient's delay in seeking medical intervention or whether a patient will follow the recommendations of a professional? Similarly, social factors such as training and motivation of staff influence the implementation of health policy. We cannot assume that an intervention that succeeds in one place will work the same way in another town, region or country [18]. Qualitative methods, in combination with other types of inquiries, can help explain these issues.

Policymakers are beginning to demand information that tells them not only what has worked but, crucially, why. Realising that people and communities best understand their own problems and can tailor solutions to their contexts, in 2013, the United Nations (UN) called for a global conversation bringing 'the voices of the people to the table' [19]. In response to the West Africa Ebola outbreak, the World Health Organization (WHO), observed that 'Communities have been, and will continue to be, the most critical part of an effective response' [20]. WHO partnered with anthropologists to understand and work with—rather than against—local cultures, beliefs and practices. For example, a year after the epidemic started, medical anthropologists found that technical safety guidelines for health workers, such as wearing gloves and masks, contradicted a cultural view of compassionate care, one in which professionals should prioritise the treatment of medical emergencies over all else [21]. Their findings revealed the need for new guidelines that respect a context in

which medical professionals routinely placed urgent patient care ahead of the recommended protocols for safeguarding their own health.

3 Functions of Qualitative Inquiry

Qualitative inquiry serves three distinct but overlapping functions: *exploration* to identify areas that need further investigation; *explanation* of social phenomena observed quantitatively or anecdotally; and *triangulation* to make sense of combinations of qualitative and, oftentimes, quantitative evidence [9, 17]. Further, qualitative inquiry is particularly suited to gathering evidence from marginalised and hard-to-reach groups [22].

Exploration This approach is inductive. Rather than looking for data to validate or disprove a given hypothesis, the researcher builds theories during data collection and analysis using an iterative approach which prioritises respondents' views. Findings can provide exploratory evidence about issues which others may not have considered. In time, exploratory findings may inform routine data collection; for example, it is now ubiquitous for researchers to ask about socio-economic status in health research. Box 16.1 describes how researchers in Mexico noticed a divergence between clinical and lay perceptions of pregnancy-related risks and identified limitations with both viewpoints. The researchers recommended that the medical establishment identify high-risk individuals by considering their social context—including their economic situation, marital status and social support—alongside medical factors.

Box 16.1 Exploring Lay Perceptions of Pregnancy Risk Among Marginalised Communities in Chiapas, Mexico [23]

In Chiapas, Mexico, civil society leaders wanted to know how pregnant women understood pregnancy-related risk and signals for seeking emergency care. Researchers conducted open-ended interviews with a convenience sample of women and their close relatives. They discovered that lay perceptions of risk and clinical criteria did not always overlap, and that both had limitations. Clinicians did not recognise how a woman's social context puts her pregnancy at risk. For example, while medical norms identified the woman's consumption of alcohol as a risk factor, community respondents were more concerned that a partner's excessive alcohol consumption increased domestic violence and physical harm for the woman and her baby. On the other hand, respondents believed that pregnancy involved pain and were unaware that pain was a risk factor.

Explanation Qualitative data can explain phenomena already identified through quantitative or anecdotal evidence. This deductive approach can help policymakers understand how policies and interventions work in everyday contexts by answering questions such as: What was it about this intervention that worked? What were the weaknesses of the intervention? Were any other factors responsible for its success or failure? The case study in Box 16.2 illustrates how researchers complemented the results of a randomised control trial by exploring the hows and whys of an intervention's lack of effectiveness.

Box 16.2 Explaining Why a Mobile Information Service Led to More, Not Less, Risky Sexual Behaviour in Uganda [24]

Researchers in central Uganda used a randomised control trial to evaluate a sexual health information intervention delivered via mobile phones. They demonstrated that risky sexual behaviour did not decrease among the intervention group compared to the non-intervention group, but that infidelity and promiscuity increased. Through qualitative interviews the researchers found that women who used the service demanded safer sexual practices, but several of their partners would not adopt safer behaviours and sought other women as their sexual partners. Factors such as the lack of access to resources and means to pay for recommended treatments, and gender inequities within romantic relationships, prevented women from following through with the advice they received through the service.

Triangulation Triangulation is a process of confirming results observed through one source by referring to results from another. While triangulation can add rigour to all investigations, the approach is particularly useful for mixed methods studies employing both qualitative and quantitative approaches. The case study in Box 16.3 illustrates how researchers used multiple research methods to verify survey results on young worker fatigue in Australia. They confirmed that the survey findings were valid and not an artefact of the way researchers had phrased or delivered the questionnaire, and shed light on the context in which workers manifested the fatigue. The researchers extended the sources of information by interviewing stakeholders such as teachers and supervisors. These interviews made the study more valuable for researchers and research users. Policymakers, in particular, need to know that the evidence-base behind their policies is appropriately diverse and based on multiple sources and methods.

Box 16.3 Triangulating Information on Fatigue Among Young Workers in Australia [25]

An Australian study investigated work, health and safety concerns of young workers about fatigue. Researchers took a mixed methods approach, combining a quantitative survey with group interviews and a workshop, with diverse stakeholders. The nationwide survey of young workers found that fatigue was the fourth highest selected work, health and safety issue, and most workers cited lack of confidence for not reporting it. Fatigue was a particular concern for those balancing study and work, and respondents noted that their precarious employment situation meant that they did not feel comfortable talking to employers about workload or fatigue. The study confirmed these findings through focus group discussions and qualitative data collection with other stakeholders such as teachers and work, health and safety professionals.

A key characteristic of the qualitative approach is that it aims to reduce the distance between the expert and respondent. This approach can be advantageous when trying to obtain information about marginalised and hard-to-reach groups who are distrustful of outsiders. In the case study in Box 16.4, sensitised researchers reached self-harm patients, historically difficult for service providers to contact. Initial recruitment of participants was difficult with a small number expressing interest in taking part in the study. It would have been impossible for researchers to use methodologies that required a larger sample size. They had to conduct the study in a considerate manner so that it would not trigger further hurt amongst respondents; the intimacy of the qualitative approach allowed researchers enough nuance and flexibility to cater to their respondents' needs.

Box 16.4 Designing Low-Intensity Follow-Up Interventions for Marginalised and Hard-to-Reach Groups in the United Kingdom [26]

In the United Kingdom, health authorities want to design interventions that reduce repeated self-harm. Service providers like to keep in contact with traditionally hard to reach vulnerable patients through phone calls, letters and crisis cards at relatively low cost. Researchers conducted in-depth interviews with self-harm patients and staff. The study suggested that interventions should provide information leaflets at discharge, followed by telephone calls and gradually, letters. Respondents indicated that they valued interventions that were genuine and took account of their situation, but that they were wary of interventions that threatened their privacy.

4 Gathering Data

A researcher's theoretical approach shapes their choice of methods. The choice of theory influences the topics that researchers investigate, the type of data they elicit, and how they approach data collection and analysis. Box 16.5 describes some theories that underlie qualitative data collection. Most of the research we describe falls under the heading of action research. For a detailed discussion of qualitative research methods, we refer the reader to some useful texts [27–29].

Box 16.5 Key Theories Underlying Qualitative Data Collection

- *Ethnography* is the systematic study of people within a particular cultural setting. It involves long-term observation and discussion with research subjects, to capture cultural meanings from their perspectives.
- *Phenomenology* is the study of the structures of consciousness and how meaning is constructed. It aims to capture how individuals experience and interpret social phenomena.
- *Grounded theory* is an inductive methodology for generating theory through a cycle of research, analysis and theory refinement. Through this, the researcher develops theories that directly explain the social phenomena being studied.
- *Action Research* is a form of applied research which aims to find effective solutions for practical issues through a spiral of planning, action and learning. It involves close collaboration with research participants, with the researcher participating in, or facilitating, the process of change.

The most common forms of data collection for qualitative inquiry include document reviews, focus group discussions, in-depth interviews and questionnaires:

For *document reviews*, the investigator systematically studies relevant texts. Documents may include peer-reviewed articles from published journals or grey literature that describe programmes, initiatives and small studies, or people's reactions to existing policies and programmes. Increasingly, analysts trawl news content and social media feeds to capture trends in dominant opinion.

For *focus group discussions,* a trained facilitator brings together a small group of respondents to discuss a topic of interest, and leads and documents the discussion. The facilitator chooses respondents purposively to embrace differing views so that the discussion captures the full range of experiences and explanations for the topic.

During *in-depth interviews*, the interviewer has a deep dive one-on-one conversation with a respondent. The interviewer selects respondents purposively to provide information on the subject of inquiry. Interviews may be

structured, semi-structured or unstructured; the choice depends on the need to put the respondent at ease and on the purpose of the inquiry.

To *quantify attitudes, values and opinions through questionnaires,* researchers may use Likert scales to find out how much respondents agree or disagree with a series of statements on a topic. The researcher assigns numeric values to respondents' opinions most commonly, using a scale of options of agreement, frequency, value, relevance, importance, quality or likelihood, and then analyses the values using statistical methods. As this method yields less in-depth information than other qualitative techniques, it can be used in conjunction with open-ended questions to allow respondents to explain their choices. Researchers may use other quantifiable techniques such as *ranking* or *ordering* opinions.

Qualitative researchers use other methods to collect information, Asking a person to narrate their *life history*, for example about their reproductive journey, can reveal unexpected events and information on types of contraception they have used at different points in their lives and the circumstances which triggered reproductive decisions. *Protocol analysis* asks respondents to share their decision-making process with the researcher—it can be used to see what factors patients consider when choosing a doctor, or deciding to seek help for a medical issue. Closely related to protocol analysis is the *méthode clinique* (also called *experimental phenomenology*) which documents through observation or questions how respondents handle a situation of interest. For instance, a researcher may sit with diabetic patients while they organise their weekly medicines to gain insight into how they approach illness and treatment. During *participant observation* the researcher completely immerses in a culture and sometimes spends several years in the field. Seminal medical anthropology studies such as these have yielded valuable insights for global health [30–32].

Participatory Rural Appraisal (PRA) captures information for public health with considerable accuracy. Researchers work with relevant community actors, for example, women, front-line workers and local self-government officials. They combine several techniques to construct a map of the community that portrays the factors in the environment that contribute to the health outcome. PRA techniques include Venn diagrams, transect walks, flow diagrams and daily routine charts; interviewing individuals and conducting focus group discussions; guiding preference ranking using matrix-ranking, proportion piling and wealth ranking; and mapping and modelling for social factors, resources and physical and hazard maps. PRA has been used as an alternative to large-scale surveys to identify persons with disabilities in a given geography.

In one study, while PRAs were less accurate than surveys in establishing the prevalence of impairment—as they relied on local definitions of disability—they were cheaper, faster and simpler to administer [33]. Maps developed in the course of a PRA exercise can provide insights about how respondents perceive and interact with medical problems and barriers that prevent their access.

Sampling and case selection work differently for the qualitative than for the quantitative approach. Researchers make great efforts to identify persons most relevant to the issue they are studying. For exploratory studies, the effort is to capture a wide but relevant range of views, so that a theory can be constructed. For explanatory studies, the purpose is to understand why people think a particular way, rather than to capture the most prevalent views. Hence qualitative researchers tend to use small samples of respondents selected through: *purposive sampling*, that is deliberately selecting respondents who have characteristics of interest to the survey; *convenience sampling*, that is choosing respondents who are easily accessible; or *snowball sampling*, that is by asking respondents to recommend other respondents. Researchers stop collecting data when they are no longer capturing new types of views, that is, when the data have reached *saturation*. It is seldom necessary to obtain a large sample.

5 Classifying and Analysing Qualitative Data

Qualitative data are rich, complex and challenging to interpret. In Fig. 16.1, we classify qualitative data as facts, assertions, opinions and narratives, and show how they work in tandem. Facts and opinions overlap to form assertions and these three classes inter-mingle to create narratives. In this section, we describe the classes and discuss how researchers can use them to understand qualitative data. We draw examples from a study we conducted in the state of Jharkhand, India, to explore the social determinants contributing to persistent poor child health in rural areas of the state. We undertook in-depth interviews and focus group discussions with children, parents, village leaders and front-line health workers in a rural district of Jharkhand that scored poorly on child health outcomes.

Facts are pieces of information that the researcher has verified to be objectively true, often through document review. In the Jharkhand study, our review revealed, for example, the fact that people living in a study village did not have a primary health-care centre. Researchers can obtain facts from people in authority or from multiple respondents who all report the same information,

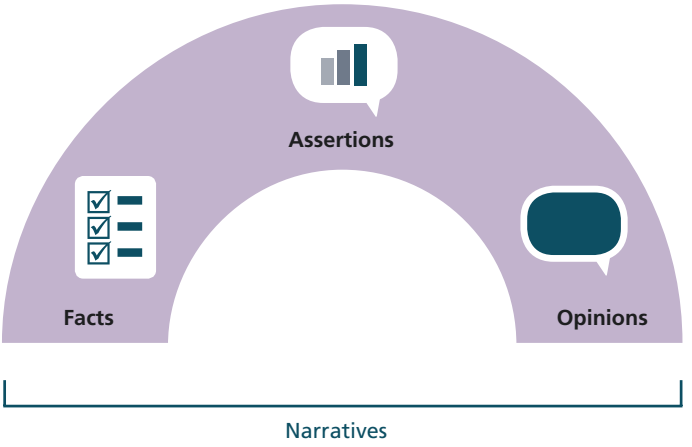

Fig. 16.1 The four classes of qualitative data

but they must independently verify the information. Facts provide structure to the situation being studied and are the unchanging constraints into which subjective data fit. The absence of a primary health-care centre in the village shaped the issues of health access and health-seeking behaviour that we studied.

Assertions are opinions that could be facts if verified. For instance, during a focus group discussion with mothers in the village in Jharkhand, respondents asserted that a local front-line worker, into whose jurisdiction the village fell, did not visit them. We later verified this assertion through an in-depth interview with the health worker herself who confirmed that she did not visit the village. It is important to understand that respondents treat assertions as fact, whether or not others can verify them. Assertions are the structural elements in their view of the situation and are unlikely to change. When it is not possible or worthwhile to verify an assertion, researchers should treat it as an opinion.

Opinions are the most common type of qualitative data. They are the perspectives, views and beliefs of the respondents, usually heralded by terms such as 'I think', 'I feel' or 'I believe'. Opinions are subjective and cannot be verified objectively. They are phenomenological insights into how respondents experience the situation. In the Jharkhand study, respondents voiced their belief that the health worker was lazy and that she looked down on them. The villagers' view was that the system didn't care if it didn't provide them with the services they needed. When analysing such data, it is important to see how opinions influence the behaviour of respondents and the meanings that they ascribe to situations and actions. In this case, respondents' views on the health worker's negligence led them to negative interpretations of her actions (she looks down on them) and of the system she represents (the state doesn't care about them),

and made villagers less likely to seek medical attention provided by the government. It is crucial to understand that opinions can change as people interact and react to their dynamic situations.

Narratives are a mix of opinions, facts and assertions. They are the stories that people tell when asked to explain a situation or an action. Narratives don't exist just at the individual level, but involve broader social narratives. Narratives are ethnographic; they go beyond the individual to embrace the culture which the respondent inhabits. In the village in Jharkhand, the health worker built a narrative around her opinion that village mothers were alcoholic and thus not worth visiting. In this case, the front-line worker tapped into broader social narratives about the immorality of people who drink alcohol, leading her to conclude that providing services to these people was a waste of effort. Although she did not explicitly refer to caste, her conversation borrowed from a broader discourse in which services could be withheld to tribal populations because her culture saw them as undeserving. Understanding how cultural narratives shape an individual's opinions and actions makes it possible to identify implicit deep-rooted social issues.

Qualitative researchers use several methods to analyse data, but most commonly they use *coding* to categorise, sort and organise their data. Researchers read the data, often in the form of transcripts and field notes, and assign *codes* to segments of text according to themes of interest. They iteratively refine the codes and explore how they relate and link to each other. Software such as ATLAS.ti [34] and NVivo [35] can streamline the coding process, allowing for the sorting of codes and quotes as well as the coding of data in audio and video formats.

Another method of analysis is *recursive abstraction* in which the researcher writes sequential summaries of the situation. In the Jharkhand case study, for example, we first wrote extensive hand-written notes in the field which we then summarised into typed notes. We made a third summary when we combined our notes. In a fourth summary, we categorised the themes identified in previous summaries. This analysis formed the basis for the final report. Recursive abstraction, while time-consuming, creates a brief and clear summary.

There are ways to analyse qualitative data, quantitatively. Likert scales, ranking and ordering yield numeric data that permit limited quantitative analysis. For large datasets, researchers rely on specialised computer software. For example, they use *content analysis* to sort through text, categorise themes and count the number of times keywords appear—in our opening example, Pulse Kampala counted the appearance of keywords about contraception and teenage pregnancy on Facebook [2, 36]. *Social network analysis* identifies and maps networks between social structures, for example providing visuals of social media groupings and connections

[37]. *Factor analysis* is useful to identify broad factors or components of interest and understand the frequency with which they occur [38].

6 How to Judge the Findings of Qualitative Research

While quantitative research has established methods to verify its findings, qualitative research has no standard quality measures. There are three camps: (1) those who think that quantitative measures for assessing rigour should apply to qualitative research; (2) those who think measures more suited to qualitative research are needed; and (3) those who think that any attempt to establish standardised quality measures for qualitative research will fail. The latter mostly argues that it is not possible to judge all qualitative research by one set of criteria because there is no unified qualitative research paradigm and its nature, methods and outputs are diverse. They conclude that the user should assess the credibility and usefulness of each study on its own merits.

We take a pragmatic approach and suggest that users ask the following questions about qualitative research findings:

- Who are the researchers, what are their interests in the study and how might these have influenced the results?
- Have the researchers provided reasonable justification for the sample they have selected?
- What were the data collection and analytical methods? Are these appropriate for the research questions and context?
- Is it possible to trace how the findings relate to the original data? Are there any cases that deviated from the others? If so, does this undermine the conclusions drawn from the data or is there a reasonable explanation for any outliers?
- Have the researchers double checked their analyses, and triangulated their findings; are the findings backed up by information from other sources and existing theories?

Users of qualitative research can make informed judgments about the credibility of the work and its relevance to their situations by carefully reading the qualitative text [16]. Rigorous qualitative researchers lay out their biases for the user's scrutiny—a process known as *reflexivity,* explaining how these biases may have influenced their interpretation [39]. Researchers document their respondents' views and highlight when their interpretations of the data go against a respondent's stated position, explaining why they do not

accept the respondent's statement at face value. When researchers share their findings with their respondents, it is important to find out if the respondents agree with the researcher's interpretations and if they think the findings give voice to their views. Sharing findings not only disseminates the research back to the community but also adds credibility and ethical value to the study.

7 Challenges and Opportunities

The qualitative approach operates in a different epistemological framework to that found in the *hard sciences*. The skills required to launch a qualitative inquiry are technical and take time and effort to learn—anthropologists, for instance, can spend a decade or more in post-graduate studies conducting ethnographies. Those trained in other knowledge systems may feel that the qualitative approach flouts their discipline's key assumptions about objectivity, methodology and validity, and may find the qualitative approach challenging. Because qualitative inquiry requires reflexivity, some health professionals deeply embedded in their field may find it difficult to engage with their own biases.

These challenges are not insurmountable; the divide between qualitative and quantitative methods is often artificial. Policymakers and medical professionals unwittingly deploy qualitative techniques all the time, such as when a policymaker has an unstructured discussion with potential beneficiaries of a public health scheme, a hospital administrator conducts rounds of patients' rooms or a doctor has an in-depth conversation with a patient's family. The challenge is to recognise that these interactions produce data which are as legitimate as hard numbers. Greater collaboration between qualitative and quantitative researchers can expand the range of methods used to answer policy questions. Such partnerships are crucial to promote better use of qualitative methods.

New technologies provide innovative ways to collect and synthesise qualitative data. *Open Space Technology workshops,* for example, allow any number of stakeholders to hold discussions on a topic [40]. Participants construct their own agenda by prioritising sub-topics of interest, and split organically into small groups to consider the issues. The format results in multi-level prioritising of sub-topics, issues within them, and the emergence of the most important findings. *Big data* provide more information than ever before and open possibilities to understand trends in individuals' health-seeking behaviour. They give much-needed context to variables, relationships and patterns [41, 42]. Big data offer new opportunities for qualitative research—traditionally rich in depth but, until recently, limited in breadth. The software for analysing vast data sources is becoming ever more refined.

8 Conclusion

Quantitative indicators alone cannot entirely describe the complex social factors that influence how policies are developed, implemented and accepted. Qualitative evidence is crucial to ensure that policy interventions work *in this place*, *in this time* and *with this group*.

Our case studies demonstrate that to provide effective health interventions, decision-makers need to understand the different cultural definitions, social narratives of inclusion and exclusion, personal situations and service characteristics. Health researchers increasingly recognise the importance of analysing and understanding people's opinions and social narratives—especially when experimental methods to demonstrate the effectiveness of an intervention in a specific situation cannot replicate the same success in other contexts [18]. Qualitative techniques can provide systematic and valid evidence to help those working in health policy to answer questions which are not amenable to quantification [16].

In their aim of 'Ensuring healthy lives and promoting well-being for all at all ages', the SDGs acknowledge that health is not just about the absence of disease, but also about the influence of wider social, economic and environmental determinants of health and well-being. The goals recognise the interconnectedness of health issues with questions of human settlements, environmental pollutants and economic growth, and the need for interventions that capture complex connections between determinants of health. The SDGs' promise 'to leave no one behind' mandates health practitioners, policymakers and the global community to seek out and work with marginalised populations to understand and address health inequities [43]. Qualitative inquiry is indispensable to achieving this vision.

Key Messages

- The qualitative approach provides insights into why and how people behave, and their opinions.
- Qualitative research is well suited to gathering data from marginalised and hard-to-reach groups.
- In contrast to the quantitative approach, researchers choose participants purposively; they seldom need large samples.
- Much qualitative data are textual; their analysis involves skilled coding and interpretation.
- Qualitative and quantitative methods provide complementary information for policymakers.

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17

Describing Dynamic Populations: Demographic Data Methods

Ayaga A. Bawah and Fred N. Binka

1 Introduction

Demographers at the United Nations (UN) estimate that the world's population reached 7.3 billion in July 2015 and project that it will reach 11.2 billion by the close of this century. The UN describes a world with declining fertility, decreasing under-five mortality, increasing life expectancy, and ageing populations. Between 2000 and 2015, an average of 4.1 million net migrants moved annually from low- and middle-income (LMICs) to high-income countries [1]. While populations in Europe are expected to decline, Africa is projected to account for more than half of global population growth between 2015 and the middle of this century.

Whether on a global scale or for a small geographic area, the demographer's task is to answer questions about the number of people in a population at a point in time, where they reside, how they distribute at least by age and sex, how these numbers have changed and how they will shift over years. Demographers estimate and explain these population dynamics for a given geographic area by describing changing patterns of fertility, mortality and migration. The equation below, which encapsulates the components of

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population change, is central to the demographer's quest to answer these questions.

> The change in population size in a geographic area over a time-period EQUALS the *natural increase* (number of births [*fertility*] minus number of deaths [*mortality*]) over the time-period PLUS *net migration* (number migrating minus number emigrating) over the same time-period.

Because demography deals with human populations, it also seeks to answer questions about the physical and social contexts in which people live. Thus, demography overlaps with other disciplines such as epidemiology, sociology, anthropology, geography, economics, biology, and public health. Demographic enquiry may focus narrowly on key demographic variables of fertility, mortality and migration, or broadly on relationships between demographic variables and social, economic and health phenomena [2, 3]. Demographers provide essential information to enable communities, governments, researchers and international agencies to plan the scale of population interventions.

We begin by introducing demography and its policy relevance, particularly for health. We describe some important demographic data sources, highlighting their advantages and disadvantages. We provide an overview of demographic methods of data analysis and identify institutions that collect, analyse and publish demographic data. Finally, we introduce challenges to the field of demography and identify promising innovations in data capture and analysis.

2 Policy Relevance of Demography As Population Science

Demography is both a social science and a policy science [4]. It is a policy science because demography provides policymakers and development planners with essential data across all sectors. In the United Kingdom, in the mid-seventeenth century, John Graunt provided King Charles II with estimates of the population of the City of London and helped to predict and explain bubonic plague by analysing causes of death. Graunt's *Natural and Political Observations Mentioned in a Following Index and Made Upon the Bills of Mortality*, published in 1662, is thought to be the first study in demography. More than a century later, in 1798, Thomas R. Malthus published *An Essay on The Principle of Population*, which changed the discourse about population growth when he observed that 'The power of population is indefinitely greater than the power in the earth to produce subsistence for man' [5]. This position became known as the Malthusian Trap and has influenced subsequent arguments about family planning and population control.

Post World War II, when the world's population began to surge in historical proportions, policymakers in the North (high-income countries) and the South (low-income countries) put population science high on their priority lists. During the second half of the 1960s, private foundations funded efforts to develop population science, supporting development of demography training and research institutions, particularly in LMICs where population growth was highest.

Population science was divided into two opposing camps. One camp, initially represented by the North, held that rates of population growth in the South were destabilising the world's population and that these rates should be reduced by encouraging uptake of contraception. The other side, largely represented by the South, held that rates of population growth could best be reduced through economic development. The rivalry between these positions reached a crescendo at the 1974 decennial UN Population Conference in Bucharest. It was at this conference that the non-aligned states coined the phrase 'development is the best contraceptive', while northern countries posited that providing access to contraception would be enough to reduce population growth. Ten years later at the UN Population Conference in Mexico City, the positions of the North and South had in some cases reversed. In the intervening years, many large developing countries such as China, India and Indonesia had established expansive national family planning programmes. In contrast, the US delegation argued that population growth was a *neutral factor* in development.

Nevertheless, donor funding for contraceptive services continued, including to establish the Matlab Demographic Surveillance Site as a population laboratory to evaluate family planning interventions in Bangladesh, and subsequently a site at Navrongo in Ghana [6]. Researchers set up these sites to assess whether improving the quality of voluntary family planning services within the context of health development would influence fertility behaviour irrespective of economic growth. Starting in the 1970s, donors also made massive investments to improve the timeliness of fertility relevant data. These data collection efforts began with the World Fertility Surveys and continue today with the Demographic and Health Surveys (DHS) (see Chap. 8). The US Agency for International Development is the largest bilateral donor by far for these data-related efforts.

The inextricable linkages between population science and public policy continue to this day. The last full UN International Conference on Population and Development took place in Cairo in 1994 from which emerged the Cairo Consensus. This consensus led more than 180 nations to endorse a programme of action that called for investments to provide high-quality family planning

and reproductive health as well as improvements in human capital primarily targeted at women and girls. The global community agreed that this approach was not only compatible with reducing rates of population growth but essential to achieving this goal. The family planning and reproductive health field has now aligned itself closely with a human rights approach.

Demographers have moved on too, concerning themselves less with controlling the total size of populations and more with population movements and composition. They predict the impact on population movements resulting from climate change, extreme refugee movements and changes in composition such as increased ageing. Analyses of population growth and structures, as well as the spatial distribution of populations, enables governments to plan transportation systems and locate facilities such as schools and hospitals. Estimations of mortality rates and how long people will be expected to live after attaining a certain age enable insurance industries to determine premiums for various categories of people.

Demography provides denominator data for most health indicators and necessary information to predict the scale of population needs for health planners to allocate resources. A practical demonstration of the policy relevance of demography is the projection of the impact of HIV/AIDS using Spectrum/Estimation Projection Package (EPP) [7]. This demographic estimation package models the consequences of current trends and future programme interventions on the HIV/AIDS epidemic in affected countries. EPP modules models: the future prevalence of the disease based on current data; resources governments will need to address the disease; the cost-effectiveness of prevention of mother to child transmission (PMTCT); and the impact of antiretroviral treatment on future development of the disease and on mortality. All these modules provide policy scenarios to allow governments to plan interventions to mitigate the impact of HIV/AIDS.

3 Obtaining Demographic Data

Demographers thus collect and analyse data to describe the size, structure, distribution and growth of populations. We review their primary data sources.

3.1 Traditional Sources of Demographic Data

Traditionally, demographers collect data using one or more of three complementary sources—population censuses, civil registration systems and household surveys (see Chaps. 6, 7, and 8 for more details). We summarise each approach and highlight its importance for demography.

Censuses

A population census is a periodic total count of all people living in a defined geographic area—a district or region, but usually covering an entire country—at a specific point in time (see Chap. 6). Census enumerators obtain answers to socio-economic questions which enable demographers to describe population structure, for example by geographic area, age and sex. Because census coverage is complete, demographers can analyse data for the smallest unit of census administration. Regular censuses provide data to estimate demographic indices and to build life tables (see Sect. 4.3) [8]. While national statistical authorities organise and conduct population and housing censuses—about every ten years—the UN Statistics Division issues standards and methods to assist them in planning and carrying them out [9].

Household Surveys

For surveys, households and individuals in households are randomly selected from a population for the interviewer to interview the household head or other members of the household, such as women within the reproductive ages. They obtain data about household characteristics, individual social and economic attributes, living arrangements within households, as well as any other specialised areas of interest, such as fertility and mortality, and contraception (see Chap. 8). The DHS, for example, has supported over 300 surveys in more than 90 LMICs to collect, analyse and disseminate similarly collected data on fertility, child mortality, family planning, maternal and child health, as well as disease-specific information such as malaria and HIV/AIDS [10]. Because surveys are based on samples rather than on entire populations, they are cheaper than censuses, and enumerators can collect more detailed information, but they are subject to measurement and sampling error. It is difficult to analyse data for small areas because data are few and not necessarily representative.

Civil Registration with Vital Statistics (CRVS)

Civil registration is the systematic recording of vital demographic events about populations as they occur (see Chap. 7). CRVS systems are supposed to be continuous and, if they function well, register all births and deaths, marriages and divorces, and migrations; and subsequently issue certificates for those events in a population. Based on this registration, authorities compile and disseminate vital statistics, including cause of death information [11].

While national statistical offices maintain CRVS for administrative purposes, these systems provide rich sources of demographic data. Except for countries in Western Europe and North America, completeness and coverage of civil registration range from what the UN refers to as 'low to reasonably fairly complete' [12]. Countries of sub-Saharan Africa and Asia have low coverage and cannot provide data to make reasonable and accurate demographic estimations.

3.2 Longitudinal Surveillance Systems

Longitudinal surveillance systems [13, 14] and their extensions, such as sample registration with verbal autopsy [14], add novel ways to collect demographic and health data—mainly cause of death information—in settings where vital registration systems are not functional.

Population Registers

Some high-income countries, such as Austria, Sweden, Denmark, Finland, Norway, The Netherlands, Japan, and Israel, maintain registers of their current living populations. These registers extend beyond individual registration of events through CRVS, to link records across events for an individual, including civil status, place of residence and migration events. For instance, when individuals die, the system records their deaths and removes them from the population currently alive. When individuals marry or divorce, or migrate in and out of the country, the system links these events to their records and updates the database using unique personal identifiers. A population register generates counts of events occurring in the population (the numerator) as well as the total population (the denominator) at a specific time. This means that demographers can compute rates without having to combine data from several sources. These registers require sophisticated data linkage software and depend on a functioning CRVS system.

Sample Registration Systems (SRS) and Verbal Autopsy

Some LMICs, where CRVS coverage is low, use sample registration to produce national demographic indicators. SRS is restricted to a nationally representative sample of small areas, such as villages or sections of urban areas [15]. Whereas the CRVS system is essentially passive, relying on families to notify births and

deaths to the registration authorities, SRS systems actively seek out vital events. However, this active case finding is for the purposes of enumeration and does not involve official registration of vital events by the local civil registrar. Resident enumerators in the sampled areas start by undertaking a baseline survey and then continuously record births and deaths in the population to generate annual fertility and mortality statistics. Regular retrospective surveys in the same vicinities as the SRS validate data and produce additional information.

SRS can use verbal autopsies to ascertain probable cause when deaths occur at home without medical certification using verbal autopsy (VA) techniques. Trained enumerators interview caregivers of relatives who have died, to ascertain the probable cause(s). They use a structured questionnaire that elicits information about the circumstances or events leading up to the death including illness history. To ensure reasonable certainty, a minimum of three physicians independently evaluates the VA interview to decide the probable cause of death. If there is agreement by at least two physicians, that cause is designated; if there is disagreement even after evaluation by other physicians, cause of death is declared indeterminate.

Researchers have used VA extensively for determining cause of death [16, 17]. This experience has led to cost- and time-effective improvements in VA questionnaire design, use of mobile devices, and use of computer algorithms for determining and coding the probable cause of death [18, 19]. These developments offer effective alternatives for physician certification of cause of deaths in situations where most deaths occur outside the hospital [20].

India initiated a pilot SRS in 1964–65, scaling it up to a full blown system in 1969–70, and has since continued to operate [21], generating fertility and mortality rates, as well as cause-specific mortality, on a regular basis. Similar systems operate in some provinces of China, and Tanzania is piloting a nationwide SRS with verbal autopsy.

Health and Demographic Surveillance Systems (HDSS)

In LMICs, the HDSS is a non-traditional source of population and health data that scientists use increasingly to obtain longitudinal data on small populations of individuals. These systems maintain a population register for all individuals living in a defined area by continually and actively observing all demographic dynamics, including births, deaths and migrations in and out of the area. We describe these sites in detail because they offer unique opportunities for simultaneous longitudinal demographic, health and social research.

The South African Ministry of Health set up the earliest of these longitudinal community-oriented programmes in rural Natal in 1940. Known as the Pholela Health Centre, the Centre studied prevalent diseases in a population of 10,000 people for about 15 years to formulate strategies to treat them [22]. The British Medical Research Council established the Keneba study in The Gambia in the 1950s, as an epidemiological study to investigate diseases in a tropical environment, and the French established a population observatory in Senegal to monitor vital events and disease episodes in a rural setting [22–24]. The International Centre for Diarrhoeal Disease Research in Bangladesh set up the Matlab demographic surveillance system in 1966 which has functioned continuously until today, now covering a population of about 223,000 people. Research groups have set up many more sites, some complementing routine information systems of ministries of health. Since 1998, the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) has coordinated HDSS sites providing a platform to share information, data, and standardised methods of analysis and disseminate findings [25]. As of 2017, INDEPTH coordinates research from more than 50 HDSS centres in about 20 countries in Africa, Asia and Oceania. Collectively, these centres follow more than four million population prospectively, collecting information on fertility, mortality and migrations, as well morbidity data on some health conditions.

A HDSS is a series of field operations that entail longitudinal follow up of well-defined entities—individuals, households, and residential units—and all related demographic and health outcomes within a well-defined geographic area [26]. A HDSS starts with enumerators undertaking a baseline census that allocates unique identifiers to households and individuals in the initial population. Enumerators visit each household at defined intervals to record changes that occur through births, deaths or in-and-out migrations, as depicted in Fig. 17.1. HDSSs may also include registration of marriages, divorces and changes in household status relationships.

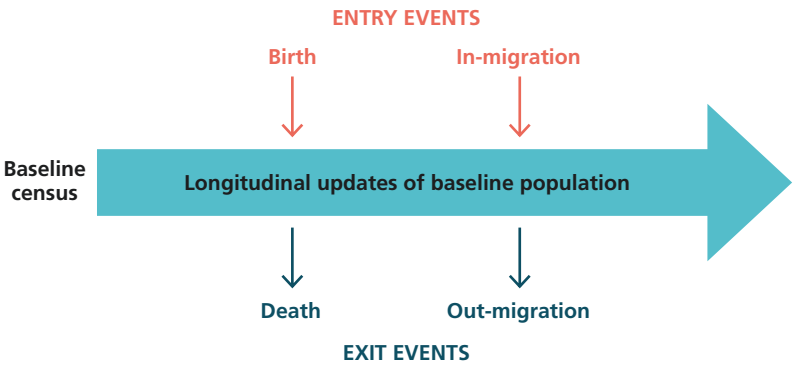

Fig. 17.1 How a health and demographic surveillance system (HDSS) site operates

Box 17.1 Use of health and demographic surveillance system (HDSS) Data to Demonstrate Impact [23]

HDSSs provide powerful data for monitoring health and population indices across LMICs, including the Millennium Development Goals and now the Sustainable Development Goals. In the early 1990s, the Navrongo Health Research Centre in northern Ghana implemented a series of malaria and reproductive health interventions and established a longitudinal demographic surveillance data system that collects information on births, deaths, migrations and other household community level attributes. In 2007, Binka, Bawah and Phillips conducted an evaluation analysis of the HDSS data to estimate the impact of the interventions. Figure 17.2 exemplifies the use of HDSS in monitoring progress of interventions.

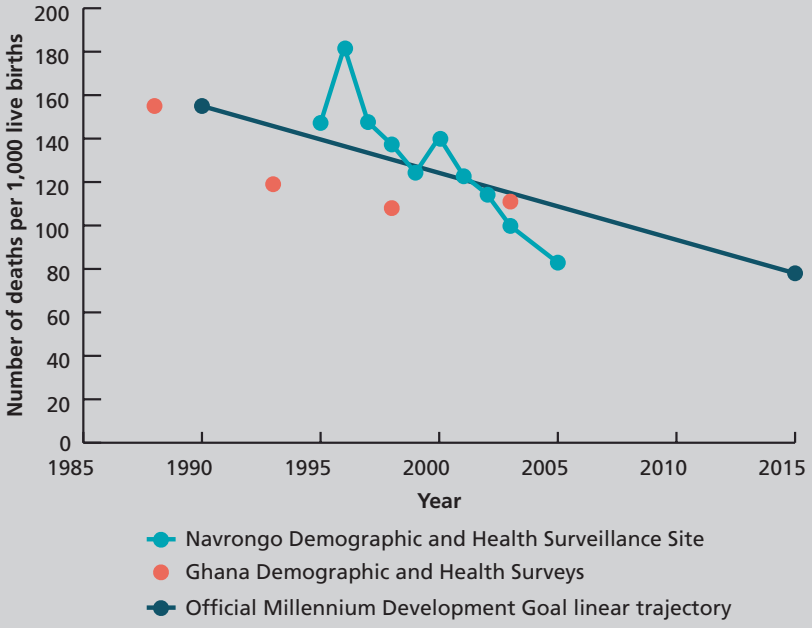

Fig. 17.2 Trends in under-five mortality in Ghana

Because everyone in the database has a unique identifier that links events to individuals within households, the HDSS centre can record all status changes occurring to all individuals within households. Using exact dates of birth, researchers link births to their mothers, so that women experiencing and not experiencing births are easily identified for analysis. Record linkages make it possible to examine risks attributable to changes in individual status, for example, death. Individuals surviving at a point in time are easily defined while registration of migrations in and out of the area permit precise individual level definition of censoring or loss to follow up. Using VAs, HDSSs can collect cause of death data at the population level where such data are rare.

HDSSs conduct a broad range of research. For example, many of the African sites conduct clinical and epidemiological studies on malaria, including safety, efficacy and effectiveness studies on antimalarials. Other African sites study HIV/AIDS including delivery and effectiveness of antiretrovirals on mortality, and reproductive health including maternal health and family. The Asian sites research ageing, environmental pollution, tuberculosis, and reproductive health and family planning. Other areas of focus include research on health insurance, migration, diarrhoeal diseases, equity and poverty. Box 17.1 demonstrates the impact of malaria and reproductive health interventions at a site in Ghana.

HDSSs provide invaluable information but have some limitations. One is that the study sites are their own population and not representative of a general population. Researchers choose sites because they want to study the demographic and epidemiological dynamics of a specific population or because they want a population laboratory to evaluate interventions and undertake a range of studies. Another limitation of the HDSS is the cost of maintaining consistent data collection over a sustained period. Fortunately, data management systems have become streamlined over the years, which takes some burden off enumerators. Finally, regularity of follow up can lead to respondent fatigue and raise ethical questions around respondents' choices about participating for the long-term.

4 Demographic Analysis

Demographers summarise data as indicators of: (1) fertility such as the crude birth rate, age-specific fertility rate, and total fertility rate; (2) mortality such as the neonatal, infant, childhood and under-five mortality rates, adult age-specific mortality rates, and the maternal mortality ratio; (3) migration, that is immigration and emigration rates; and (4) population change such as population growth and population density (see UNSTATS for definitions and country estimates [27].) Demographers provide population pyramids for age and sex categories, tables showing life expectancy by age and publish population projections. They apply statistical and mathematical methods to estimate these measures. We provide an overview of some of these methods.

4.1 Assessing Data Quality

A significant area of intellectual engagement for demographers is to develop methods for assessing and evaluating data quality and feasibility of findings. In addition to routine quality control on data collection and entry, they apply

internal and external consistency checks to ensure quality. Respondents who do not know their ages may guess or round their ages to multiples of five years, for example. Demographers check quality of age reporting by looking for specific digit preferences and by assessing the distribution of age and age-sex ratios using Whipple's and Myer's indices [28]. They also assess sex and age distributions by studying consistency between population pyramids obtained from different sources, for example between two censuses, and by comparing the distributions with external stable population models. Demographers triangulate their analyses using multiple methods and apply complex approaches to reanalyse data, for example using reverse survival methods to estimate fertility [29]. Some of these methods are described in detail in *Tools for Demographic Estimation* referenced above [28].

4.2 Estimating Demographic Indices Using Direct and Indirect Techniques

When CRVS systems are fully functional and complete, or when there are adequate survey or census data, demographers estimate most population indices *directly* from the data. For example, they calculate the infant mortality rate for a specific year by dividing the number of known infant deaths (from CRVS) by the number of infants in the population at the mid-point of the year (from the census).

Where CRVS data are lacking or incomplete, demographers use *indirect methods*, pioneered by Brass and Coale [30] to estimate rates from survey and census data. To estimate fertility and childhood mortality rates, for example, demographers ask women in surveys and censuses (between the ages of 15–49 years) about the number of children to whom they have ever given birth, how many of those children are still surviving, and how many are dead, separately for boys and girls. To ensure that they do not miss any children, they ask women whether the children are currently living with them or living elsewhere [28]. DHSs capture such data in the summary birth history section of the survey instrument labelled as reproductive history [10]. These data can then be tabulated as proportions alive or dead, and probabilities of dying calculated by age or duration of marriage.

Although indirect methods initially focused on child mortality and fertility, they were subsequently extended to estimate adult mortality, particularly maternal mortality using sibling or birth histories [31, 32]. Development of these methods allows for directly estimating maternal mortality [33]. The direct method asks respondents to provide more detailed information about

their sisters, numbers reaching adulthood, number who have died, their age at death, years in which the death occurred and years since the death. DHS now regularly collects this information to estimate maternal mortality directly.

Indirect methods are complex and have some limitations. First, most of these methods were based on assumptions that both fertility and mortality were high and unchanging. These assumptions are no longer valid because there have been dramatic declines in both fertility and mortality even in sub-Saharan Africa where fertility and mortality remained high for a long time. Many indirect methods also assume independence between the deaths of children and their parents, assumptions that are not true. These methods are also fraught with recall biases because respondents are asked to report events that occurred to themselves or their relatives many years ago; casting doubt on the completeness of data. The UN has compiled these methods in: *Manual X: Indirect Techniques for Demographic Estimation* [8].

The DHS programme has introduced refinements to the method by collecting data beyond the few Brass-type indirect questions to estimate fertility and mortality directly. In the DHS birth history module, the interviewer asks the woman to list each of her births; for every child to whom she gave birth, the interviewer asks about its sex, age, whether the child is still alive or dead, current age if alive, and if dead, how old it was at death. With this information for each child, demographers can estimate fertility and childhood mortality directly with very limited biases. The challenge of this module is that because the questions are only asked during sample surveys, the findings are subject to sampling errors.

4.3 Life Tables

A life table describes a cohort of individuals born to a specific population in a particular year going through life and diminished by death. The life table produces one of the most important summary measures of a population's health known as life expectancy, which shows the average expected duration of life in a population from a specific age. Its figures are based on mortality rates estimated for different age categories preferably using long-established CRVS data.

National statistical offices in countries with CRVS, such as in the United Kingdom, Australia, Canada, and the United States, regularly publish life tables even for sub-populations. The US Centers for Disease Control and the Social Security Administration, for example, produce annual life tables for all 50 States and the District of Columbia, for purposes of social security administration and to monitor progress in population health. Countries that do not have adequate CRVS data to produce their life tables, use model life tables published by the UN Population Division [34]. The World Health

Organization (WHO) also publishes life tables through its Global Health Observatory database, as does the Institute of Health Metrics and Evaluation (IHME) through its Global Burden of Diseases Study. In 2004, the INDEPTH Network published the first ever life table for sub-Saharan Africa based exclusively on empirical data from 18 demographic surveillance data in sub-Saharan Africa [35]. Before this publication, life tables for sub-Saharan Africa were largely based on limited mortality data from household surveys and censuses along with demographic modelling [36]. Although demographic surveillance sites are, by design, not nationally representative, they generate very detailed data over long periods of time. They thus contribute to a better understanding of the way that contextual factors may result in patterns of mortality in sub-Saharan Africa that differ from those generated through model life tables [37].

The life table is so versatile that its application goes well beyond mortality analysis. For instance, it can be used for nuptiality analyses such marriage transitions (marriage, divorce, remarriages), contraceptive use and discontinuation rates, and fertility analysis using parity progression analysis, among many others.

4.4 Population Projections

Population projections model size and composition of a population through time, such as world population growth with which we opened the chapter. The UN defines population projections as 'calculations which show future development of a population when certain assumptions are made about the future course of fertility, mortality, and migration. They are in general purely formal calculations, developing the implications of the assumptions that are made' [2]. Projections are predicated on the theory of population change expressed in the equation we introduced in Sect. 1; that change or growth is inevitable and depends primarily on fertility, mortality and migration.

Projection methodologies can be very simple, based on a few assumptions about the future, or extremely complex. Simple projections assume linear or exponential population growth. Component type projections, on the other hand, make detailed assumptions about fertility, mortality and migrations with anticipated trajectories of change within population subgroups, and have more complex data requirements and input parameters. The Spectrum/EPP we described in Sect. 2 is an example of complex modelling. Choice of projection method is a trade off between level of accuracy required, availability of data, and composition of the final product.

Several organisations regularly conduct projections, including the UN Population Division, the WHO, the International Institute for Applied Systems Analysis in Austria, the IHME, the Population Reference Bureau in

Washington DC, census organisations in countries and academic institutions such as universities. The UN Population Division regularly produces population projections for most regions and all countries of the world. They present the results of these projections in Excel files displaying key demographic indicators for different subgroups groups for major areas, region and countries, spanning the period 1950–2100 [38].

Population projections are used extensively for planning. At the micro level, government agencies use projections, for instance, to plan schools and educational needs of children. The health sector uses projections to determine future spread of diseases and how interventions will likely impact their distribution and growth. Actuarial scientists and financial institutions use projections to determine size of future pay out of social security, insurance, and so on. And, demographers use them to show likely trajectory of growth and distribution in population by age and the implications of these changes for future developments. For instance, the issue of demographic dividend has taken centre stage in the development discourse both at the international and national levels; that is the extent to which growing numbers of young people in the productive age groups could be harnessed for development. Discussions about the dividend are based on population projections. Unusually low levels of fertility and consistent improvements in survival to older ages all project a future in which many western European countries experience declining populations and increasing ageing. These predictions point to the need to plan and put in place necessary policy interventions to address these demographic changes.

5 Institutions That Collect, Analyse and Publish Demographic Data

National census organisations and statistical offices collect, collate and archive demographic data along with other statistical data. Internationally, the UN and its affiliate agencies such as the WHO and World Bank, support governments and other agencies to collect vital statistics, including demographic and health data. Within the UN, the Statistics Division is mainly responsible for collating and archiving demographic, social, economic, and health data. The UN Statistics Division publishes country data and indicates data it assesses to be incomplete or of doubtful quality. On the other hand, the UN Population Division uses country data to build statistical models to develop population predictions and estimates.

WHO also collates and reports on health statistics for all its 194 member countries. Other international institutions that support production and archiving of data include the African Development Bank, Asian Development Bank and the African Union through its data commission.

The IHME is another global research institution that produces demographic estimates, health statistics and impact evaluations [39]. The institute maintains a global health observatory where a large database provides innovative analytical tools to track trends in mortality, diseases, and risk factors. The Washington, DC, Population Reference Bureau publishes an annual *World Population Data Sheet*, with data from 200 countries and territories regarding important demographic and health issues, including population estimates, fertility rates, infant mortality rates, HIV/AIDS prevalence, and contraceptive use, among many others [40]. Other universities and institutes of higher learning and research constitute some of the big users of demographic data collected around the world. Many of these institutions archive these data primarily for analysis. Examples of data archives around the world by universities and research institutions include the University of Michigan *Inter-university Consortium for Political and Social Research (ICPSR)* in the United States [41]; Princeton University's Office of Population Research large data archive on legal migrants to the United States[42]; University of Minnesota Integrated Public Use Microdata on census data [43]; United Kingdom's University of Essex data archive [44]; and the Australian data archive at the Australian National University [45]. In Africa, examples of some of the data archives by universities and research institutions include: the South Africa Data Archive [46]; University of Cape Town's data archive in South Africa, *DataFirst* [47]; and, the University of Cape Coast data archive in Ghana [46]. These data span various disciplines, including demography and health, and have led to the training of population and health professionals across the world and produced some of the leading research publications in demography. The INDEPTH Network maintains a repository of longitudinal population and health data that its member institutions have collected in LMICs (see Chap. 23) [25].

6 Challenges and Innovation

A major challenge facing the field is dwindling funding to build demographic capacity. The Rockefeller Foundation and other donors who supported training and research opportunities in demography from the 1960s through to the 1990s have since cut back their support, leading to closures of many demographic training institutes in LMICs. Countries still need demographers to run censuses, develop CRVS, and make demographic estimations. Related to funding are dwindling numbers of technical demographers. The intellectual energy that was devoted to developing methods to estimate demographic phenomena in data deficient settings has diminished, mostly from lack of technical capacity.

In spite of advances in data collection, progress has been relatively slow regarding coverage especially for CRVS in LMICs. There have been tremendous improvements in survey and census data collection, but quality of data remains a problem in many parts of the world. The challenge also remains for countries to analyse and utilise their data properly for national development. Data warehousing and gatekeeping is another challenge; despite tremendous improvements in data collection, many countries impose such strict access rules on use of data that their full potential is not fully realised.

There have been some innovations. For instance, use of smartphones and other handheld devices, with Geographic Positioning Systems (GPS), have revolutionised data collection and improved accuracy, timeliness of data capture and processing, as well as the granularity of information captured. When households are geo-referenced, demographers use geographic information systems and statistical analyses to study the spatial distribution of demographic phenomena—a branch of demography now known as spatial demography (see Chaps. 15 and 20). As part of this, the WorldPop project provides high-resolution open data and maps on the distribution and composition of populations over time in LIMCs [48]. Biodemography has also emerged through collaborations between demographers, biologists and clinical researchers who collect a combination of demographic and biological data to understand human evolution, for example, the ageing process [49].

7 Conclusion

Measurement is more critical than ever before, because of international setting of measurable goals, such as the just-ended Millennium Development Goals and now the Sustainable Development Goals, which have agreed targets that require data to measure their endpoints. In this context, demography's role as a measurement science becomes imperative. Demography both as a social science and a policy science plays a critical role in all spheres of public life. In the area of health, demographic analyses allow planners to determine the number of hospitals and beds that are needed based on population size and structure, how many new doctors are required to maintain a constant stream of patients and so on. Demography also enables evaluation of public health interventions. For instance, if antiretroviral therapy is introduced in a HIV/AIDS population, estimation of trends in mortality and life expectancy over time will enable us to determine whether the intervention is making the needed impact or not.

Despite the value of demographic research, there are dwindling resources going into demographic training and research, creating a gap in the required

skill sets to perform technical demography. Also, the coverage and quality of demographic and health data collection remain low, particularly in LMICs. It is vital that global research and academic institutions that specialise in demography continue to improve methods and build capacity for high-quality data collection and analysis to improve much needed demographic estimates.

Key Messages

- Demography describes change in population structures resulting from the interplay between fertility, mortality and migration.
- Descriptions and projections of population change inform long-term planning and resource allocation.
- Sources of data include censuses, surveys, vital registration and longitudinal enumeration of populations.
- Reduced funding for demography threatens technical capacity in low- and middle-income countries.

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18

Epidemiology for Policy and Programme Management

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1 Introduction

In February 2016, the World Health Organization (WHO) declared an unusual clustering of congenital malformations and neurological disorders, among newborn infants in Brazil, to be a Public Health Emergency of International

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Concern [1]. Epidemiological studies on the occurrence and distribution of this so-called mystery disease suggested a strong association between the microcephaly cases and prenatal infection with the Zika virus (ZIKV). To support countries prevent infection, the WHO developed a Zika strategic response framework [2]. In another part of the globe, scientists released the first global mapping of resistance to the life-saving anti-malaria drug, artemisinin, and observed that, at that time, the dreaded K13 resistance gene was confined to Southeast Asia and had not yet spread to sub-Saharan Africa [3]. Mapping informs treatment guidelines to prevent further spread of resistance.

Epidemiologists describe the distribution of diseases and seek to understand their relationships with health-related states and events. They draw inferences on the causes and associations of health conditions and their determinants in order to intervene. An early and famous example of causal inference about disease was when John Snow in the nineteenth century described an association between contaminated sources of household water supply and increased incidence of cholera in districts of London [4]. Advances in epidemiological methods have accelerated discovery of causes and associations for old and new diseases. Modern epidemiology has been instrumental in controlling infectious diseases like cholera and smallpox, and in calling attention to the increasing burden of non-communicable diseases. By addressing social determinants of health, social epidemiology has contributed to developing interventions to address inequities in health and development [5]. Epigenetic epidemiology has revolutionized the study of complex and chronic diseases through analysis of inter-individual variations in how genes are regulated and expressed in their interactions with environmental triggers [6].

Despite tremendous advances in the discipline of epidemiology, evidence is unevenly produced across the world. Low- and middle-income countries (LMICs), with the greatest disease burden, have imprecise estimates of deaths and causes of illnesses. Implementation, evaluation, and scale-up of effective interventions remain a challenge in many of these countries. The Sustainable Development Goals (SDGs) offer benchmarks to assess progress. The principles of epidemiology provide a basis for developing interventions and for measuring achievement of many of the goals.

We illustrate how epidemiological methods can provide evidence for health-care policy and practice. For the researcher, we provide an introduction to epidemiological principles and methods, and practical considerations in designing major types of study. For the decision-maker, we provide guidance about the relevance of epidemiology to their work and about how to assess the appropriateness of evidence to improve policy formulation and implementation. We refer readers to comprehensive textbooks for detailed coverage of epidemiological design and analysis.

2 How Do Epidemiologists Contribute to Policy and Programming?

Epidemiology is the study of how often diseases and other health-related events or states occur in populations, why they occur, and which and how interventions can effectively address health problems [7, 8]. Epidemiologists observe health conditions among groups of individuals in populations at risk, offer estimates of the severity of the health condition in the population and identify factors and interventions that health programmes can target to prevent and control the condition. Epidemiologists work with others including, for example, statisticians, economists, social scientists, computer scientists, demographers and most health professionals, and they embrace approaches from several disciplines—but specific methods and principles govern how they operate. They tailor their approach to answer different types of questions and use the principles of statistics to attach measures of uncertainty to their findings. Epidemiologists design and use routine data systems such as those in Table 18.1 (and described elsewhere in this handbook) and they design epidemiological studies. They undertake these studies to answer questions about the spectrum of health conditions (cross-sectional surveys), their potential causes (case-control and cohort studies), or about the efficacy, effectiveness, efficiency and equity of proposed interventions (controlled trials). Epidemiologists select study designs to limit bias and the play of chance, and hence the likelihood of drawing incorrect conclusions. Figure 18.1 represents how these activities contribute to developing new health policy and programmes and improving existing ones [9].

An essential function of epidemiology which we do not cover in this chapter is public health surveillance. Public health field epidemiologists set-up and maintain early warning systems to actively monitor infectious diseases and other health threats so that they can prevent or respond to them in real-time. They estimate disease incidence rates by dividing the number of new cases they observe during a period of time by the average number of people in the population at risk during the same time period. Field epidemiologists also undertake surveys to better understand disease patterns and conduct rapid case-control studies to determine the cause of outbreaks, such as the emergence of ZIKV in Latin America in 2015-16 (see Chap. 10).

3 Epidemiological Studies and Principles

We summarize major study designs that epidemiologists have developed to describe the spectrum of health conditions, ascertain their determinants, and evaluate clinical and field interventions and programmes (Table 18.2). Box 18.1 provides a glossary of some of the epidemiological terms we use. For a more complete classification of study types, please see Rothman [10, 11].

Table 18.1 Sources of epidemiological data to inform health policy and manage programmes [11, 12]

Method	Definition	Use	Comments
Public health surveillance	Continual systematic monitoring of the occurrence of a disease/condition in a population using data from different sources	Provides managers with ongoing data about the occurrence and distribution of conditions; can provide real-time warning of when and where an outbreak will occur	Requires rapid and efficient long-term collaboration to collect and analyse data across health and other sectors
Disease registries	Legally mandated systematic registration, in a geographic area, of all individuals who contract a specific chronic disease, with longitudinal follow-up of all relevant events related to each individual	Offers detailed information on the incidence and duration, treatment and outcomes of a disease to advise prevention and control policies and programmes	Expensive and difficult to follow up cases especially in LMICs; requires efficient long-term collaboration across health facilities and multiple professionals to collect and analyse data
Health facility records of health events	Continuous systematic, reporting of the occurrences of health events and mandatory reporting of notifiable diseases	Assists public health departments to plan disease control and prevention policies and programmes; contributes to knowledge of global disease patterns	Requires efficient and rapid information systems; trade-off between number of diseases to notify and reporting workload
Civil registration and vital statistics	Mandatory continuous recording of all births and deaths (and cause) in a population	Supports planning by providing birth and death rates and causes of death	Not fully functional in many LMICs where causes of death are hard to ascertain

(*continued*)

Table 18.1 (continued)

Method	Definition	Use	Comments
Systematic review and meta-analysis	Systematic review of the literature that collects, appraises, and summarises multiple studies using objective, structured methods to answer specific questions	Provides highest level of evidence on overall efficacy or effectiveness of health-care interventions	Biased if data searches are not comprehensive, and if there is publication bias; requires judgment of study quality and of heterogeneous results between studies
Dedicated epidemiological studies	Cross-sectional surveys, case-control and cohort studies, interventions studies, and more	See Table 18.2	See Table 18.2

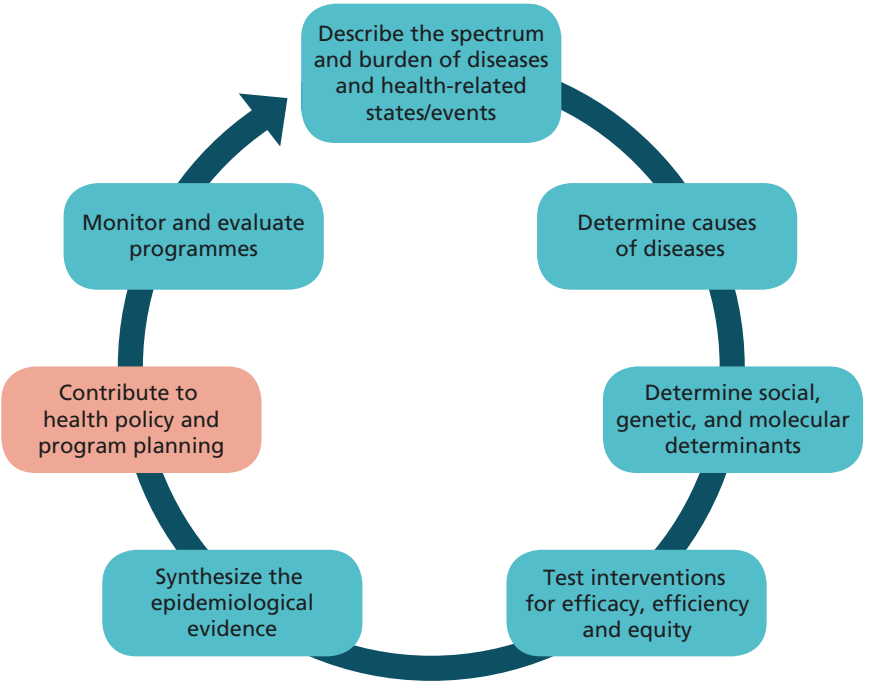

Fig. 18.1 Role of epidemiology in developing health policy and programmes. (Adapted from Tugwell et al. [9])

Table 18.2 Dedicated epidemiological studies that inform health policy and programme development [11, 12]

Method	Definition	Use	Comments
What is the prevalence of a disease/condition, where and among which groups is it prevalent?			
Cross-sectional study	Random samples of individuals in a population at a point in time; to describe the prevalence of the disease/condition by other characteristics of the population	Informs about the scale, and demographic and geographical distribution of condition/s; repeated surveys can establish trends; generates hypotheses	Not useful for rare conditions of very short duration; hard to control for confounding or to attribute causality
Which are the risk groups and factors associated with the disease/condition that an intervention could target?			
Cohort (longitudinal) study	Follows a well-defined population over time who are exposed to risk factors of interest; to compare incidence of a disease/ condition in those exposed and in those who are not (relative risk).	Describes incidence and the course of the condition (prognosis), and identifies risk factors to target for interventions	Takes time; not feasible for rare conditions or diseases with long latency; suitable cohorts can be difficult to identify and costly to follow; ethical considerations include confidentiality and privacy
Case-control (retrospective) study	Selects a group of cases with a disease/ condition and a group of controls without the condition (but otherwise similar) and records history of exposure to potential risk factors in both groups to examine odds ratio as a measure of association	Rapid way to establish (multiple) risk factors to target interventions, especially for diseases that are rare or have long latency	Information collected retrospectively; prone to confounding and measurement bias; difficult to establish a temporal relationship between risk and development of the condition; selection of a suitable control group can be difficult

(*continued*)

Table 18.2 (continued)

Method	Definition	Use	Comments
Which intervention to recommend?			
Randomized clinical trial (RCT)	Randomly assigns consenting participants, groups or communities to an experimental treatment, or to a standard treatment, no treatment, or a placebo; where possible assignment is masked and without the knowledge of treatment providers	Provides the best available evidence on the efficacy of treatments	Expensive and cumbersome; trade-off between internal and external validity due to selected samples; study of harm is not feasible for ethical reasons; for field interventions findings may not be generalizable beyond the study context
Quasi-experimental study designs	Utilises control groups which are selected or matched, or statistically simulated, to be as comparable as possible to the subjects exposed to the new intervention	Most useful when RCTs are not logistically feasible or ethically acceptable, for example, to evaluate the effects of legislation on entire populations	Each study design has its pros and cons (especially the risk of failure to control for potential confounders); considerable experience is required to judge the most appropriate design for a given situation

Box 18.1 Some Basic Epidemiological Terms

Indicators

Prevalence rate: proportion of people in a population who have a condition of interest at a point in time (or, for *period prevalence*, during a period of time).

Incidence rate: number of new occurrences of a condition in a time period divided by the average number of people in the population in which the condition could occur (during the same time period).

Relative risk: ratio of the incidence of the outcome of interest in a risk group to the incidence of the outcome in a comparison group.

Odds ratio: ratio of the odds that an outcome occurs in a risk group to the odds that the outcome occurs in a comparison group.

Interpretation

Bias: extent to which a study systematically underestimates or overestimates the indicator being described or an association reported between exposure and the outcome.

Confounding: an extraneous variable (not part of the purported chain of causality between exposure and outcome), often unobserved by the investigators, that distorts the relationship between the exposure and outcome of interest.

Conclusions (inference)
Confidence interval: a margin of error around the estimated indicator, calculated using statistical principles.
Significance: A finding is significant when the investigator rejects the hypothesis of no association between the risk factor and the outcome. There is some statistical evidence of an association between the risk factor and the outcome. A statistically significant association may not necessarily be biologically or clinically significant.

3.1 Ask the Right Question

A good question for an epidemiological investigation is focussed, relevant, important, and builds on what is previously known. To be certain that the question is pertinent, current, and not already answered, researchers review the literature to find systematic reviews that critically appraise the validity and applicability of existing evidence, or they undertake systematic reviews themselves (Box 18.2) (see Chap. 4).

Box 18.2 The Systematic Review [13–15]

The systematic review is an efficient scientific approach for summarizing the literature. Reviews use explicit and reproducible methods to identify relevant studies, assess risk of bias in studies, extract information and synthesize findings. The process begins with the preparation of a protocol that documents the objectives and proposed methods of the review. Publication of the review protocol in a publicly accessible register such as PROSPERO [16] and the Cochrane Database of Systematic Reviews [17] ensures transparency and avoids unnecessary duplication of effort. Guidelines for the reporting of systematic reviews are available in the form of the PRISMA Statement and its extensions (see also Chap. 4) [18].

Table 18.2 identifies three broad categories of questions relevant to policy and programme management that address: (1) the scale or prevalence of the problem; (2) association of the problem with exposure to risk factors; and, (3) choice of a treatment or intervention. We expand on these below.

3.2 What Is the Prevalence of the Health Condition?

Epidemiologists undertake cross-sectional surveys to answer questions about how many individuals suffer from a condition in a population, and who and where they are; and sometimes to answer additional questions about whether

there is an association between the health outcome and potential risk factors. They select a random sample from the defined population at a point in time and interview, and sometimes examine, sampled individuals to ascertain whether they have the condition or conditions, and record socio-demographic and other information. They estimate the proportion or prevalence of people having the condition in the population and provide a margin of error or confidence interval (Box 18.1).

If, for example, aid workers want to know how many young children are malnourished in a refugee population, they measure a random sample of the children and estimate, with a margin of error, the proportion of those who are malnourished at that time. To complement routine tuberculosis notification, countries conduct national prevalence surveys to determine the magnitude of the tuberculosis burden and which groups or regions are most affected. (See Chap. 8 for a description of household surveys).

3.3 Which Are the Risk Groups and Factors Associated with the Health Condition?

If programme managers know which factors are associated with a person having a condition, they can screen people for those factors, for example, aid workers might want to screen for children at risk of becoming malnourished. Investigators can test for associations within a cross-sectional survey if they have designed it to have enough participants in each outcome and risk factor category. Alternatively, they can undertake a prospective cohort study—which additionally describes the incidence of the condition in the population—or a retrospective case-control study to rapidly establish risk factors, especially for rare conditions. Investigators start with the hypothesis that there is no association between the risk factor and occurrence of the condition, for example between a child being orphaned and subsequently becoming malnourished. Based on their results and using statistical theory, they choose to reject the hypothesis, or not, and provide a significance level (Box 18.1) as a measure of the uncertainty in their decision.

For cohort studies, epidemiologists define and describe a population, and set up long-term mechanisms to observe if and when an individual contracts the condition, and describe their characteristics, including exposure to potential risk factors, geographic, socio-demographic and other determinants, as well as making clinical and laboratory observations. Researchers express association between exposure and disease outcome as a relative risk (RR) (Box 18.1). An RR of one indicates no association between the risk factor and the

outcome, a value greater than one indicates positive association, and a value less than one indicates negative association. For example, the RR for the association between smoking and lung cancer varies between less than 5 for light smokers to over 20 for heavy smokers [19]. Researchers may report average risk (also called cumulative incidence), which is the probability of developing the outcome over a specified period of time; or incidence density, where the numerator is the number of new cases with this outcome, and the denominator is the accrued person-time (person-years, person-months, or person-days) of observation of study participants after exposure to the risk factor. Investigators use average risk when participants have variable lengths of exposure to the risk factor.

For example, South African researchers wanted to know if presence of anaemia predicts tuberculosis in HIV-positive patients on antiretroviral therapy (ART). They recruited 1,659 HIV-positive, ART-naïve patients and updated their anaemia status and CD4 counts every four months. After a median follow-up of five years, they found that tuberculosis incidence rates were strongly associated with time-updated anaemia [20]. If the time element in this study had been backwards-looking, investigators would have reviewed records of the cohort of HIV-positive patients treated with ART in the past five years to determine whether anaemia preceded tuberculosis at some point during the follow-up. This example would be a retrospective cohort study in contrast to a conventional cohort study in which the investigator collects data prospectively.

Cohort studies come in many forms. Exposure need not be dichotomous (such as presence or absence of a risk factor) and investigators may follow a cohort for occurrence of more than one disease event or composites of related events. Researchers may set up two or more cohorts defined by whether participants have a risk factor or not. Some cohort studies follow participants prospectively for relatively short times, for example, women followed through their pregnancies. Other studies last beyond the lifetimes of their investigators, for example, the Framingham Heart Study in the US has recruited participants since 1948. In some LMICs, researchers maintain health and demographic surveillance systems (HDSS) (Chap. 17) that have surveyed generations of participants, for example, Matlab in Bangladesh has recruited everybody living within its catchment area since 1963—making it possible to follow cohorts prospectively and retrospectively. In countries with well-established population registries and linked health examination surveys (or suitable healthcare records) independent researchers can follow cohorts retrospectively and prospectively without setting up their own cohorts [21]. Retrospective cohorts avoid ethical issues associated with observing individuals longitudinally.

For case-control studies, epidemiologists identify a group of cases with the condition, and compare them with a group of controls without the condition but who are otherwise similar in most respects (e.g. for age group, sex, socio-economic status). They record past exposures to the hypothesized risk factor for cases and controls through interviews, history-taking, or measuring biochemical, serological, or molecular markers. They express association between exposure and health outcome as an odds ratio (OR) (Box 18.1). For uncommon outcomes, the OR approximates the RR for an association.

In March 2016, after increasing notifications of microcephaly in newborns, investigators in north-eastern Brazil retrospectively compared each of 64 babies born with probable congenital microcephaly between September 1, 2015 and January 5, 2016 with at least two newborns delivered in the same hospital without the condition; matching also on residence, week of delivery and gestational age at birth. Paediatricians interviewed by phone those mothers who agreed to participate to ascertain the signs and symptoms they experienced during pregnancy, and classified mothers as suspected of having ZIKV or not. Investigators concluded from this small study that 'Mothers who experienced symptoms associated with the Zika virus during pregnancy had 10 times higher odds of delivering newborns with congenital microcephaly when compared with mothers who did not exhibit Zika-like symptoms.' The investigators pointed out that 'This knowledge could have helped to limit some of the misguided speculation and could have expedited public health policies more effectively targeting the mosquito vector.' [22]

Investigators can nest case-control studies within a large cohort study (incidence case-control study) or within a cross-sectional survey (prevalence case-control study). They identify all, or a representative sample, of cases within the cohort study or cross-sectional survey and compare exposures to all or a sample of the non-cases (controls). For example, investigators in western Kenya conducted a survey of 151,408 individuals to assess prevalence of active convulsive epilepsy (ACE). To identify risk factors for ACE within the same survey, they age-matched 445 ACE cases with a control group that they drew at random from the survey. They asked participants (and guardians of children) in these groups about their history of potential risk factors. Through their analyses, investigators identified perinatal events, febrile illness, and head injury as risk factors that health workers could use to target persons at risk to prevent epilepsy [23].

A limitation of case-control studies is that investigators collect information retrospectively, leading to possible incorrect participant recall, for example mothers in the ZIKV study might not have remembered their symptoms accurately. Another limitation is a difficulty in selecting the controls to match the cases without bias.

3.4 Which Is the Best Treatment or Intervention?

A major use of epidemiological inference is for rigorous evaluation of interventions, for example, to assess a new treatment for a medical condition or a new health-care approach for delivering vaccines (see Chap. 4). Researchers no longer passively observe what happens but set up a controlled situation, or trial, in which they give one group of participants the new intervention and a control group an alternative [10]. They measure outcomes, for example, as the percentage in each group who survive, their time to recovery, weight gain, and so on. Investigators set out to test the hypothesis that there is no difference in outcome between the groups versus that there is a difference of an expected size.

The randomized controlled trial (RCT) is the most rigorous type of intervention study [24] producing the best evidence, that is, with least possibility of biased findings. Where feasible, authorities require an RCT before registering drugs and devices or adopting interventions. An essential design element in RCTs is the procedure of randomization in assigning eligible, consenting individuals either to the group offered the experimental treatment, or a control group offered a standard treatment, no treatment, or a placebo (an inactive treatment that appears similar to the experimental treatment). Randomization ensures that investigators do not use any biased assignment method (conscious or unconscious), which could, for example, result in placing participants with different levels of disease severity in the comparison group. Randomization is the only method that can ensure that comparison groups are similar apart from the treatment they receive. Investigators can randomize individuals (individually randomized trials) or groups, such as schools, medical practices or communities (cluster randomized trials).

Another characteristic of some RCTs is *blinding*, that is, when investigators ensure that the participant and/or the treatment provider do not know the group to which the participant belongs. Blinding is important when a trial's outcomes, and the way they are reported, could be influenced by the participants' or providers' knowledge of the treatment allocation [24]. Blinding is seldom feasible for trials of interventions that investigators cannot hide from the participants, such as health-care organizational changes or surgery. We refer readers interested in detailed procedures for RCTs to Pocock [25] and Altman and Bland [26].

During an RCT, researchers follow participants to assess how frequently the outcome occurs in two or more groups, and compare these rates. For

example, researchers wanted to know whether community mobilization improves the effectiveness of the government-run dengue control programmes in three communities in Nicaragua and one in Mexico. They randomized 75 census enumeration areas (clusters) to chemical-free prevention of mosquito control through community mobilization as well as the government dengue control programme, and 75 control clusters just to the government programme. Compared to baseline findings, the researchers found significant risk reductions in the intervention over the control group for dengue infection in children, reports of dengue illness, larvae or pupae in houses visited, containers with larvae or pupae among containers examined and among houses visited. The researchers concluded that 'Evidence based community mobilization can add effectiveness to dengue vector control.' But they cautioned that while this was a promising start, sustainability of the community participation might be difficult [27].

There are some situations where randomization of individuals or groups is not feasible or is ethically problematic. In such instances, investigators may use quasi-experimental designs to assess the effects—both positive and negative. There are many such study designs, the details of which are beyond the scope of this chapter; we refer the reader to Sanson-Fisher et al. [28] and Frank et al. [29] (See also Chap. 4).

3.5 Answer the Question

When epidemiologists present their results, they and their audiences must be satisfied that their findings answer the question they set out to address. They check for bias, and confounding, two well-used terms in epidemiology. They also explain random variation (the play of chance) in their findings and how this affects interpretation. There are many practical guides and tools to help researchers decide on the quality of evidence, for example Haynes [30] and Dans et al. [31]

Is There Any Bias?

Bias is the extent to which a study systematically underestimates or overestimates the indicator described or the association reported between exposure and the outcome [24]; most common are selection and measurement bias (Box 18.1).

Selection bias occurs in cross-sectional studies when sample members do not represent the population for which the investigator hopes to make inference, perhaps because they did not select the sample at random or because they did not select the sample from the entire population. Researchers may draw their sample from the wrong population, for example, if they want to estimate the prevalence of hypertension in the general population but draw their sample from patients attending an outpatient clinic or in an emergency room visit. For case-control or cohort studies, poor representativeness may not necessarily lead to bias, unless there is differential sample distortion with respect to exposure and outcome. In case-control studies, prevalent cases of long duration may have different risk-factor profiles than cases that have died early and are not represented in the selection process. In clinical trials, selection bias arises when there are systematic differences between treatment groups in factors that can influence the study outcomes being measured (confounding variables (Box 18.1)). Randomization stands alone in its ability to control for differences in both known and unknown factors that can influence treatment outcomes [32].

Measurement bias occurs through errors in recording observations, participant recall bias, instrument bias, and misclassification of exposure and disease status. In RCTs, knowledge of treatment assignment could lead to systematic differences in how health-care providers or researchers manage participants in comparison groups (performance bias) or in how investigators or patients themselves assess outcomes in these groups (detection bias), or both [32].

Is There Any Confounding?

A confounder is an extraneous variable, often unobserved by the investigators, that distorts the relationship between exposure and the outcome of interest (Box 18.1). Confounding happens when the third variable is associated with the exposure while also being a potential cause of the outcome. Figure 18.2 illustrates how previous history of cigarette smoking might confound an investigation into the association between periodontitis and development of cardiovascular disease. An observed association between periodontitis and cardiovascular disease could be entirely because long-term smokers have an elevated risk of both conditions. Researchers should consider all plausible potential confounders, design their studies to avoid confounding, and analyse data to account for the possibility of confounding (Fig. 18.2).

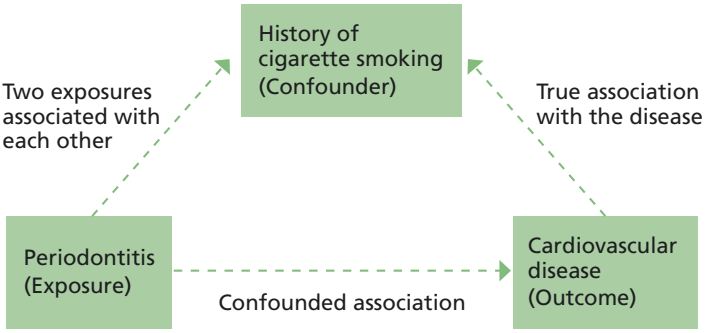

Fig. 18.2 Cigarette smoking as a confounder of the relationship between periodontitis and the development of cardiovascular disease. (Adapted from Bonita et al. [8])

Are the Results Due to Chance?

One of the main reasons for taking random samples is not only to avoid bias but also so that the investigator can interpret results against what might have happened by chance. Most studies report a 95 per cent confidence interval around their estimate of the indicator of interest. Assuming that investigators selected participants at random, statistical theory tells us that if the study were replicated many times, on 95 per cent of occasions the calculated interval would contain the true population value of the indicator. That is, there is a 95 per cent chance that the calculated confidence interval contains the true indicator, and a 5 per cent chance that the interval does not contain it at all. The smaller the sample size the wider and less informative the interval.

Similarly, when the investigator has set out to test a hypothesis, for example that there is no difference between two treatments versus there is a difference, the conclusion will either be to reject the hypothesis or not. When investigators report that a difference is significant at the 5 per cent level, they mean that, assuming they selected participants for treatment allocation at random and the hypothesis were true, there is less than a 5 per cent chance that the observed difference between the two treatments would occur by chance. That a difference is statistically significant does not mean that it is meaningful. Users must interpret the findings in the context of the study and with some understanding of the possible mechanisms leading to the difference. For example, a very large trial of a new anti-hypertension drug might find a difference of only 0.1 mm Hg, between patients' average blood pressures in the treatment and control arms, to be statistically significant (i.e. $p < 0.05$). However that difference is not biologically or clinically significant—largely because it is well within measurement error in standard clinical practice, where we can realistically only detect differences of at least a few mm Hg in blood pressure.

Does Evidence of an Association Mean There Is Evidence of Causality?

Having demonstrated an association, researchers may want to conclude that a risk factor or treatment causes the health outcome. In the ZIKV case-control study, researchers established a strong association between mothers who experienced symptoms of ZIKV during pregnancy and delivering babies with congenital microcephaly [22]. Could they also conclude that ZIKV caused the microcephaly? To establish causality after showing association, researchers need to: (1) satisfy themselves that potential biases have not importantly influenced their conclusions; (2) demonstrate that the risk factor occurred before the health outcome; (3) exclude spurious explanations for the association; and (4) describe a plausible chain of causality between the risk factor or treatment and the outcome. In the ZIKV study, researchers described credible attempts to avoid bias but listed as limitations: potential mothers' recall bias; and lack of and incomplete laboratory test results for other pathogens that could lead to microcephaly. They could establish that the signs and symptoms occurred before the women gave birth but not necessarily before conception; nor could they rule out other viruses (such as dengue or Chikungunya) as the cause of the mothers' symptoms. So the researchers concluded only that there was an association between ZIKV-like symptoms during pregnancy and giving birth to a newborn with congenital microcephaly. It is difficult to establish a temporal relationship between risk and development of the condition for case-control studies, whereas cohort studies make this possible. RCTs provide the best form of evidence of causality but—as we pointed out above—may not always be logistically or ethically feasible, as in this case.

4 Practical Considerations in Undertaking a Study

The EQUATOR Network provides online resources for writing protocols and reporting for most types of epidemiological studies [33]. Since serious ethical considerations cut through all aspects of design and implementation of studies of people, investigators must gain approval from nationally approved institutional review boards (see Chap. 24 for a discussion of ethics). For data management and analysis, we suggest the reader explore the open software Epi Info™ developed by the US Centers for Disease Control [34]. Epi Info™ provides customized tools for data entry and analysis, with excellent visualization including maps; it also supports development of small disease surveillance systems.

We highlight three critical aspects of study design:

Participant Selection Statistical inference usually assumes that the investigator chooses participants at random. Simple random sampling is not often feasible or appropriate, so epidemiologists use other methods, for which, as in random sampling, there is a known probability of the participant being selected. For cross-sectional studies, these methods include: stratified sampling in which the population is stratified by, for example sex or age, followed by random sampling within these strata; and cluster sampling in which investigators sample clusters from a population partitioned into homogeneous groups (or clusters), such as enumeration areas, villages or schools (see Chap. 8). For cohort and case-control studies and surveys, investigators may select participants systematically or use sequential sampling, that is they select elements from the source population based on a random starting point, and then use a fixed interval (usually based on sample size) to select all other elements. Explicit inclusion and exclusion criteria should define the target population and eligible participants. Specific working definitions for these criteria will minimize misclassification of participants, particularly in designs requiring comparison with a control group.

Measurement Accuracy Disease status can be ascertained by: examining participants for symptoms and signs consistent with the disease or event, using diagnostic laboratory tests; administering questionnaires or conducting interviews; or reviewing medical records, sometimes by linking subjects from different administrative or research databases. Accurate measurements are essential to assess exposure; for example, direct laboratory assays for exposure (such as hepatitis B surface antigenaemia among patients with hepatocellular carcinoma), careful interviews of cases, or surrogate information from several sources, and using standardized questionnaires to minimize recall bias. To ensure good data quality, investigators can conduct pilot studies, monitor and supervise procedures, employ laboratory quality assurance, and commission periodic audits of long-term studies.

Sample Size Epi Info™ provides a sample size calculator, which addresses the aim of the study, the type of study and the chosen sampling method [34]. If the aim is to estimate an indicator—a prevalence rate, for example—the investigator specifies a margin of error, or width of confidence interval they expect to obtain. The investigator also makes a guestimate of the value that the indicator is likely to take—by looking at values in the literature for similar populations or by doing a pilot study. The smaller the intended margin of error, the larger the required sample size. To test a hypothesis, the investigator needs to specify the

magnitude of a *minimum detectable* but clinically meaningful *difference* in the outcome they expect between the exposed and non-exposed groups. The investigator also specifies the probabilities of wrongly concluding there is a difference (a so-called Type I error—say 5 per cent), and of wrongly concluding there is no difference (a so-called Type II error—say 20 per cent). The smaller the difference the investigator is seeking to detect, or the lower the investigator sets either of the two error probabilities, the larger the sample size required.

5 Conclusion

Obtaining definitive answers to the kinds of questions policymakers ask is seldom straightforward. We have described an array of epidemiological methods to address specific questions but we have also shown that these methods are limited. Findings depend on the question, choice of design, and context of the study; and they are subject to the play of chance. For example, researchers have explored a possible association between periodontitis and cardiovascular disease (Sect. 3.5) for over 20 years using different study designs and with differing conclusions. A 2017 review undertaken on behalf of Public Health England concluded that there is high-quality evidence, independent of confounding factors, to support an association between cardiovascular disease and oral health, but it was unable to find conclusive evidence of a causal relationship [35].

Decision-makers become frustrated when different studies arrive at different conclusions. They want to know, once and for all, the causes of a disease or that a treatment or intervention will lead to good outcomes. The perfect study design is rarely possible. Scientists should critically appraise their choices and findings, and those of others. Users must understand that most individual studies are only indicative and must be complemented by a combination of different types of studies with synthesis over time to produce consensus.

Key Messages

- Epidemiology studies the spectrum of health conditions, their potential causes and the effectiveness of interventions.
- An investigation starts with a research question that is relevant, important, and builds on what is already known.
- Epidemiologists design studies to answer specific types of questions by using study designs that minimize bias and attach measures of uncertainty to their findings.
- The perfect study design is rarely possible. Scientists should critically appraise and share their findings with caution.

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Health Economics: Tools to Measure and Maximize Programme Impact

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1 Introduction

'Voluntary male circumcision can cut new HIV infections by half.' [1] This was the remarkable finding of a large clinical trial conducted in Orange Farm, South Africa, in 2005 [2]. Finally, a highly effective general population prevention strategy for HIV in Africa, with convincing biological outcome data! However, the health benefits of averted HIV disease are long-delayed while substantial costs are incurred now: voluntary medical male circumcision

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(VMMC) requires surgery, as well as risk reduction counselling and medical follow-up. Overall, is VMMC a good investment of limited public health funds? In 2006, we studied the cost of delivering VMMC, the gains in years of healthy life due to averted HIV infections, and the financial savings from unneeded lifetimes of HIV treatment. We found that VMMC costs much less than the averted health-care costs. Net savings; a very good investment indeed [3]. This information helped the World Health Organization (WHO) and other global agencies support widespread implementation of VMMC.

Global aspirations for health are ambitious, with the 2030 Sustainable Development Goals (SDGs) aiming to improve significantly on decades of progress in reducing disease burden [4]. Yet, after a period of rapid growth from 1997 to 2010, funding for global health is flattening largely due to a global economic slowdown. This divergence of mission and resources creates tensions for governments when choosing between evidence-based interventions to reach SDG targets. Economics can help resolve this contradiction. For example, SDG 3.4 states 'by 2030 reduce by one third premature mortality from non-communicable diseases through prevention and treatment'. Economics can inform an efficient combination of prevention (e.g. diet and exercise) and treatment (e.g. medications for hypertension and diabetes). Luckily, the tools of economics are increasingly sophisticated, and up to the task.

Economics uses and creates data that inform policy (Box 19.1). Economic analyses incorporate data from other public health disciplines, such as indices of disease prevalence and intervention efficacy. The analyses produce quantitative estimates of disease burden, costs, and cost-effectiveness which help policymakers prioritize diseases to target and choose between intervention strategies to maximize health gains with available resources.

Box 19.1 Policy-Relevant Questions That Economists Can Answer

- What does it cost to treat one person with a specified disease? Per cure? Per added year of life?
- What does it cost to deliver a prevention strategy? What is the estimated cost per case of disease averted?
- What is the most efficient balance of prevention and treatment strategies, for specific population groups and across the entire population?

We offer a broad review of health economics, focussing on methods to guide health-related resource allocation. We start with a brief discussion of economic systems, followed by a concise survey of major methods. We then explain two tools of economics most widely employed in global health: burden of disease metrics and cost-effectiveness analysis (CEA). We conclude

with a brief discussion of the ethical basis for use of efficiency, as captured by CEA, to make decisions about prioritization in health.

2 Health Economics

Although some of its methods have been available for centuries, academics first characterized the discipline of *health economics* in the 1960s [5]. Since then, health economists have made significant contributions to public health decision-making. Just as our analyses cited earlier informed South African policymakers about the cost-effectiveness of introducing VMMC, others have, for example, demonstrated the cost-effectiveness of smoking cessation efforts [6] and assisted in the evaluation of national vaccination programmes [7], long-lasting insecticide impregnated bednets and other strategies to prevent malaria [8].

Health economists view health systems as economic systems in which health-care and public health providers are the suppliers and individuals the consumers (and presumed beneficiaries), each making choices with limited resources and with goals of maximizing income or health status for themselves or for populations. Policymakers intervene in the system to achieve societal and political goals. Economists have the tools to assess these dynamics and measure the resulting effects on populations and individuals, for small and larger portions of the system. When decision-makers consider alternative public health policies, they are often interested in how the respective implementation costs of these policies compare with expected benefits to society. Whereas other researchers propose and demonstrate the health benefits of specific interventions, economists consider the costs of actually implementing these interventions and the expected benefits in real-world operation.

Health economists draw on the traditional arsenal of economic methods such as econometrics, micro-costing and cost-benefit analysis (CBA) and have developed approaches specific to the health sector. The range of methods which health economists combine or apply include:

Econometrics This statistical arm of economics aims to reveal and quantify causal relationships that drive economic systems, such as socio-demographic factors that determine utilization of medical services, lifestyles that influence longevity, or programme design features that determine intervention cost. Several econometric methods (e.g. instrumental variables and regression dis-

continuity design) are especially effective at confirming causality by ruling out self-selection and other reverse causality (known as endogeneity). An excellent example of econometrics is an analysis of the health effects of foreign assistance in health. Bendavid et al. applied econometric methods to cross-national panel data on health aid and health – as summarized by life expectancy at birth and under-5 mortality – in 140 LMICs. The study found that 'Foreign aid to the health sector is related to increasing life expectancy and declining under-5 mortality. The returns to aid appear to last for several years and have been greatest between 2000 and 2010, possibly because of improving health technologies or effective targeting of aid.' [9]

Cost-Benefit Analysis CBA, which derives from the academic field of social welfare, assesses if a particular economic activity is worth while in monetary terms. CBA can be used to demonstrate the economic returns of investment in an intervention, to compare the costs and benefits of alternative interventions, and to help policymakers allocate budgets. CBA compares the costs of production (e.g. of health services) with the monetary value that society places on the outcomes (e.g. the value of averted costs in health and other areas, or willingness to pay for improved health status). Keen et al., for example, compared the costs of family planning (FP) delivery in Sierra Leone with savings from five social services (primary education, child immunization, malaria prevention, maternal health services, and improved drinking water) [10]. They projected that, with high access to FP, the population would reach 8.3 million by 2035 versus 9.6 million with no FP expansion. They estimated a US$2.10 saving in social services for each dollar spent on FP, representing a 2:1 benefit-cost ratio. But Keen et al. also pointed out that there are other important health benefits associated with scaling up FP such as reduced maternal and child mortality that are not included in the benefit-cost calculation and that some benefits, such as improved women's rights and gender equity 'are more appropriately assessed qualitatively'.

Cost-Effectiveness Analysis CEA, used widely in health, assesses the cost of an intervention per unit of health gained. The *cost* component (the numerator) is the same as cost in CBA. However, the *effectiveness* component (the denominator) is expressed in health units: clinical events (e.g. deaths or illness episodes), other health outcomes (e.g. new infections), or, ultimately and preferred, a metric that quantitatively combines morbidity and mortality, such as Disability-Adjusted Life Years (DALYs). We explain DALYs in Sect. 3 and CEA in depth in Sect. 4.

Micro-costing Micro-costing quantifies resources and associated costs needed to deliver a set of services, such as a prevention or treatment intervention. Micro-costing is the standard of practice to characterize costs usually from the bottom up, and permits an excellent view into the production process. An important distinction: *price* is what buyers pay to sellers for a service or commodity, whereas *cost* represents the amount put into production. The difference is profit. An excellent example of micro-costing is from the ORPHEA study of HIV interventions in hundreds of facilities in multiple countries [11].

Behavioural Economics This discipline merges cognitive psychology and economics. It uses insights from the study of human motivation to design strategies to foster healthier behaviours or better clinical practices. Specific topics include the role of mental short cuts (our quick instinctive reactions to situations we encounter), framing (how a choice is posed), and incentives (e.g. monetary rewards or internal norms). A 2017 review of behavioural economics to encourage physical activity in patients found that tools such as precommitment contracts and framing are valuable in this setting [12]. A Kenyan field trial of bednets to prevent malaria examined if paying for (in behavioural economic terms, *investing in*) nets affects use [13]. It found that cost-sharing (as opposed to free nets) does not improve use but does reduce demand, suggesting the greater health impact of free distribution. A later Cochrane systematic review confirmed the consistency of these findings across studies [14].

Discrete Choice Experimentation DCE elicits preferences about potential actions (e.g. choice of a health clinic). Methods to explicitly ask individuals about their preferences may be inaccurate, distorted by social desirability (saying what is perceived as acceptable) and other cognitive biases. Instead, the discrete choice approach *observes* the choices, and then uses statistical techniques to infer what attributes (e.g. cleanliness, politeness, or drug stock) drive the choices. Thus discrete choice methods reveal actual rather than stated reasons for choices. Use of the approach in Ethiopia and Mozambique found that to retain women in lifelong HIV care, the important attributes were respectful provider attitudes and ability to obtain non-HIV health services during HIV-related visits. Facility type, that is hospital versus health centre, was less important [15].

Financing Financing addresses how funds are raised, for example, from taxes and insurance premiums, and how they are distributed to providers, for example, via fee-for-service or capitation. Thus, financing characterizes how money moves through, and lubricates, the economic system. Comprehensive

ongoing work led by Joseph Dieleman at the Institute of Health Metrics and Evaluation (IHME) documents domestic and international health financial flows by source and mechanism, country, and disease area [16].

Labour or Workforce Economics This area of inquiry describes the professionals, for example, doctors, clinical officers, and nurses, who perform the services required for the health system to function. This is the biggest (most costly) supply component of health systems. Projections of workforce need and training are critical to prepare for future health-care needs. An analysis of physician production and supply in Tanzania examined the potential impact of interventions to retain physicians in training and practice [17]. The World Health Organization (WHO) just launched a new initiative on health workforce development to pursue the Sustainable Development Goals (Chap. 12) [18].

Health economists use a combination of tools to apply economics to pressing challenges in global health. For example, an effort to define the optimal mix of interventions might rely on DALYs to quantify disease burden at baseline and after intervention, micro-costing to assess the resources required for alternative strategies, and CEA to assess health value for money. A study of a local market for primary medical care could use discrete choice experiments to understand patient preferences among providers with different traits, and econometrics to assess how those traits relate to actual utilization.

3 Measuring Burden of Disease

For economic analysis, a preferred measure of health benefits is one that can be compared across locations, over time, and by disease categories. Some studies use summary measures of health status such as life expectancy, infant and child mortality; others use disease-specific disease incidence or prevalence. Ideally what is needed is a single summary metric that comprises health gains encompassing both deaths averted and reductions in adverse non-fatal health states. Work in this area started during the 1970s with the QALY (Quality-Adjusted Life Year) and the DALY which was introduced in the 1990s. The DALY and the QALY are the converse of each other: DALYs measure burden of disease and QALYs measure health. The DALY is the metric used for the development of global and national/sub-national burden of disease estimates. IHME publishes the Global Burden of Disease (GBD) Study, and the WHO produces similar estimates [16, 19].

One DALY represents one year of *healthy* life lost and the measured disease burden represents the gap between a population's health status and that of a normative reference population [20]. The DALY for a specific condition is calculated as the sum of the *years of healthy life lost* from premature mortality due to the condition (the mortality component, YLL) and the *years of healthy life lost due to disability* due to that condition (the morbidity component, YLD). That is,

$$\text{DALYs} = \text{YLLs} + \text{YLDs}$$

YLL, the mortality component, is calculated as the number of deaths in the year due to the condition multiplied by the years lost from premature mortality from the condition, based on normative life tables that represent the potential maximum life span of an individual in good health, not exposed to avoidable health risks or severe injuries, and receiving appropriate health services [20]. Because of anticipated continuing increases in life expectancy, much burden of disease estimation will rely on frontier life expectancy projections, such as those for the year 2050 by the World Population Prospects 2012 [21]. Numbers of deaths by age and sex in a given country can be obtained from civil registration records, or estimated from the census, or household surveys. Information on deaths due to specific conditions may be available from vital registration or estimated from health facility data. Life expectancy data can be obtained from country- and age-specific life tables, and are used in many disease models for CEA. However, these do not provide a normative standard for global comparison.

YLD, the morbidity component, was originally calculated as the number of disability cases in the year (incidence) multiplied by their average duration and by a disability weight that reflects severity of the disease on a scale from 0 (perfect health) to 1 (dead). Since 2010, the GBD Study uses prevalence instead of incidence multiplied by duration. Thus, YLD can be calculated as the number of people living with the condition (prevalence) in a given year multiplied by the disability weight for the condition. Prevalence data can be obtained from household studies or facility records in the country, or modelled on data from countries in which the prevalence is thought to be similar. The IHME publishes disability weights, which it estimates by interviewing thousands of people (in-person and online), and asking them to rank the health status of two hypothetical individuals [22]. The underlying concept of disability thus is operationalized as respondent preferences for different health states.

Economists previously included age-weighting and time-discounting in the DALY calculation. After consulting philosophers, ethicists, and other economists on the value choices they should incorporate into the DALY calculation, since 2010, the GBD Study has chosen not to discount for time or use age weights [23, 24]. Most cost-effectiveness analysts still discount DALYs, but age-weighting is no longer used. WHO provides a detailed account of the methods and sources for calculating GBD 2000–15 [20]. In practice, because many countries lack detailed data on mortality and prevalence by age, sex and cause, estimation of DALYs generally involves complex data collection and analysis or modelling (see Chap. 21).

For an introduction to DALYs, watch a ten-minute video on YouTube entitled 'The DALY Show' [25].

4 Cost-Effectiveness Analysis

In this section, we delve into an important tool for optimizing decision-making, particularly for resource allocation: how funds are distributed towards a goal such as reducing DALYs. CEA is the most widely used tool of economics to inform decisions in health policy, thus warranting a major focus in this chapter.

4.1 Basic Principles

We all like being healthy; it makes us feel good. Health also leads to wealth. There is very good evidence that populations that are healthier develop more wealth [26]. This is a reinforcing cycle, since wealth also leads back to health. Thus effective health interventions increase happiness and wealth. It seems obvious from this hypothesis that we would like to implement every effective health intervention. The problem is, this is impossible. We do not have the time or money to provide every possible intervention. When we choose one intervention we lose the option to do other. This is called the *opportunity cost*: the resources we use for one activity result in giving up another activity with its benefits.

We all work with budgets – whether personal, household, or even national. Thus we know that resources are finite and must be allocated to a multitude of priorities. Hence situations where we cannot do *everything* are common. This implies the need to make informed decisions about how to spend the scarce resources that we have. In most situations, the guiding principle is that

we choose interventions that provide the most health benefits with available (or attainable) resources. In other words, we aim for efficient use of resources, measured in terms of *cost per health outcome (*e.g. *cost per year of healthy life added).* Understanding efficiency in this way is critical to making the right choices. Final investment decisions often also consider priorities – such as a desire to address inequities or to deliver on political commitments. However, the starting point for resource allocation – and often the primary driver – should be the optimization of resources to maximize health.

4.2 When to Use a CEA

Consider the example of a policymaker trying to optimize the cardiovascular health of her population. Should she invest in getting more patients with heart disease on low-cost, moderately effective cholesterol-lowering drugs called statins, or get the highest-risk patients on more advanced therapies that are highly effective but also very expensive? Note that the consideration here is not simply of the medication costs, but also costs associated with delivering the medication (e.g. provider time) and any side effects associated with the medication. A sound analysis should also consider the savings that accrue from averted heart attacks or strokes among persons receiving cholesterol-lowering therapies. How do we address these apparently competing priorities?

CEA is the primary tool for comparing the incremental cost of adopting a health intervention with the expected health gains. CEA examines competing action options in which both costs and health consequences are taken into account in a systematic way. For example, a CEA of lab monitoring of antiretroviral therapy for HIV compares the costs of the tests (e.g. CD4 and viral load counts) to the changes in observed mortality and associated DALYs averted. By quantifying trade-offs between resources consumed and health outcomes achieved with the use of specific interventions, CEA can help health planners, insurers, government agencies, and individuals to prioritize services and to allocate health-care resources in more optimal ways. For example, we analysed pricing of antiretroviral zidovudine used to prevent mother-to-child transmission of HIV mainly in sub-Saharan Africa. We showed that with an 80 per cent price reduction, this drug would provide health benefits at a cost per DALY averted comparable to other interventions. This analysis was used to guide successful price negotiations with the manufacturer [27].

Contemporary CEAs synthesize data from disparate sources: clinical trials, medical and death registries, government records such as vital statistics, as

well as, depending on the question being asked, local information about costs and health outcomes. To facilitate comparisons within and across health systems, a standardized set of analytic methods have been developed, ensuring that the method is valid, logically consistent, credible, and applied consistently. Several authors have described the general approach for performing a CEA [28–32]. We review the methodology, provide examples of CEAs in action, and discuss their limitations. We make the argument that a meticulous and transparent CEA can, despite limitations of the methodology, greatly enhance the returns on investment in health.

4.3 Undertaking a CEA

The first step is to identify the intervention to be assessed, as well as one or more comparison interventions. For instance, in examining community outreach for vaccination against Human Papillomavirus to reduce cervical cancer, we could compare the current *status quo* (no outreach for vaccination) or an alternative strategy that improves the quality of screening for early cervical cancer detection. For a CEA to be informative, the comparators must represent meaningful alternatives that is, the alternatives the decision-maker would consider feasible and promising.

Incremental Cost-Effectiveness Ratio (ICER)

Since the cost-effectiveness of an intervention is always defined relative to an alternative and depends on choice of comparator (or comparators), it is essential to include all meaningful alternatives in the analysis. CEA most commonly uses the ratio of incremental cost to incremental effectiveness, the *Incremental Cost-Effectiveness Ratio (ICER),* to compare one strategy (A) to an alternative (B).

$$\text{ICER} = \left[\text{Net Cost B} - \text{Net Cost A}\right] / \left[\text{DALYs A} - \text{DALYs B}\right] \text{or}$$

$$\text{ICER} = \left[\text{Net Cost B} - \text{Net Cost A}\right] / \left[\text{QALYs B} - \text{QALYs A}\right]$$

The numerator (incremental costs) typically includes all costs related to the intervention as well as any additional costs (e.g. side effects) or savings (e.g. from avoided hospitalizations downstream). The denominator (incremental

outcomes) typically includes some measure of survival and change in quality-of-life, but may also be simplified to the number of clinical events averted. The ICER is therefore an estimate of cost per unit health effect achieved by using a particular health intervention, compared with a specified alternative action. Note that the order of subtraction in the denominator depends on whether the study uses QALYs or DALYs; the goal of an intervention would be to gain QALYs or avert DALYs.

ICER Numerator Data on Costs for Each Strategy

To estimate net health-care costs, we must start by estimating the costs associated with the strategies under consideration. Typically, costs include 'all direct medical and health care costs (related to the condition under study) which includes costs of hospitalization, physician time, medications, laboratory services, counselling, and other ancillary services,' including costs 'associated with the adverse side effects of treatment,' and 'savings in health care, rehabilitation and custodial costs due to the prevention or alleviation of disease.' [29] Recently, the Second US Panel on Cost-Effectiveness in Health and Medicine proposed also including: a) costs associated with lost productivity related to the disease for the patient and caregivers; and b) background health-care costs related to any improved survival [30].

Costs may be estimated from a review of prior published research or prospective collection of cost data. Often key cost inputs, such as the lifetime cost of treating HIV or the cost of malaria treatment, are readily available in published academic literature and government policy documents. However, when two similar interventions are compared, for example, community versus health facility-based screening for cervical cancer, precise comparison requires prospective data collection. *Micro-costing* (Sect. 2) is the best way to characterize costs, revealing the production process. It should be noted that methods for health intervention costing are not well standardized, so cost definitions, data collection, analysis, and reporting can vary substantially across studies, leading to substantial challenges in interpreting and combining cost data. To foster better and more consistent cost data, the Global Health Cost Consortium (url: https://ghcosting.org/) developed a *reference case* with methods standards (involving several authors from this book).

ICER Denominator Data on Health Outcomes for Each Strategy

Data for health outcomes fall into three categories:

First, a CEA must incorporate reliable data on disease incidence and/or prevalence. These are usually derived from published studies and government health statistics. For example, for HIV available data typically include HIV prevalence surveys for low- and high-risk populations, and estimates of incidence from cohort studies and disease modelling.

Second, a CEA must include some measure of effectiveness for each of the interventions under consideration. This parameter may not be known precisely, particularly for new interventions or when one is trying to model effectiveness over the long-term. The main source for this information is systematic reviews and close scrutiny of important new studies. We have developed a *meta-synthesis* approach for all interventions for selected diseases in *What Works Reviews* [33]. Some CEAs are linked to specific clinical trials, which then provide the necessary effectiveness estimates.

The third category is estimating the quality-of-life or disability weight associated with each outcome. These parameters have been worked out better for some countries than others. The GBD Study has created a compendium of estimates to facilitate international comparisons [19]. Our preference is to rely on these numbers unless better estimates for a given country or condition are handily available. As described above, when the GBD estimates are poorly aligned with health states in the analysis, it is acceptable to rely on empirical measurements of health state utility or a functional status-based metric.

4.4 Time Frame in CEAs

An intervention can alter both costs and health effects long after it is administered. The standard recommendation is to calculate or estimate all future costs and health effects in a CEA. Traditionally, this has been limited to those costs and effects related to the disease under study, though the newest recommendation proposes a wider perspective [30]. Limited time frames can be misleading, though long time horizons may require uncertain extrapolation of costs and health effects. Examples include treatment of hepatitis C (a slowly progressing condition) [34], universal antiretroviral treatment for HIV [35], and elimination of tuberculosis in California [36]. The concept of discounting helps with long-term projections that take into account time preferences and alternative uses of money.

4.5 Sensitivity Analyses

Uncertainty in input parameters may alter the conclusion of the CEA. For instance, a higher drug price or lower efficacy will make the treatment ICER higher (less attractive). The effect of uncertainty is examined through sensitivity analyses. By varying one or more parameters across a range of plausible values, these analyses examine whether changing the value of the input parameter(s) alters the conclusion. One-way sensitivity analyses vary one input at a time, typically yielding a graph of the ICER on the vertical axis and the varied input parameter on the horizontal axis. Two-way sensitivity analyses vary two inputs, generating a set of roughly parallel lines. A large number of one-way sensitivity analyses can be summarized in tables or in a figure, such as a *spider chart,* that visually shows the outcome values as each input varies. The spider chart below (from Kahn et al. [3]) shows that for adult male circumcision to prevent HIV, the most important factors determining cost-effectiveness are the protective effect, the cost, and the HIV infection multiplier due to epidemic effects (Fig. 19.1). Finally, multi-way sensitivity analyses use Monte Carlo or similar methods to simultaneously and stochastically examine all inputs, yielding a distribution of results, typically following a normal distribution.

4.6 Choosing Between Strategies: Interpreting the ICER

The ICER can be used to select an intervention strategy. Most simply, we examine if the added cost per added health gain is acceptable. We first look at interventions one-by-one. If an intervention improves health at a cost of $50,000/DALY, should it be adopted? How about $5,000 per DALY? The current practice is to use a threshold – if the ICER is below the threshold, the strategy would be considered cost-effective. Such a threshold may vary by country and context. WHO suggests using annual GDP per capita to define a threshold. Consistent with this, in the US, strategies that come in with an ICER <50,000 per DALY averted are usually considered very cost-effective and strategies that exceed $150,000 per DALY are considered not cost-effective, though no formal examination of the threshold has occurred. Threshold values like this have downsides [37]. Most notably, this approach fails to consider all available intervention options, and also ignores the *revealed preferences* of current practices. Thus, a rote threshold may squander an opportunity to use the new information to improve current spending patterns.

An alternative approach relies on the creation of *league tables*, which rank strategies based on ICERs (the term is derived from football, where tables dis-

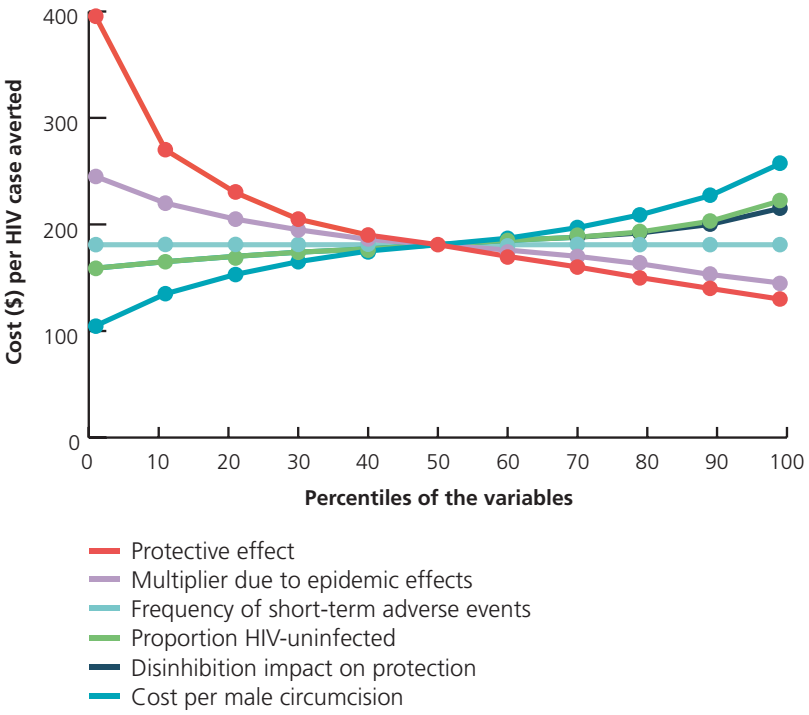

Fig. 19.1 One-way sensitivity analysis of the cost per HIV infection averted unadjusted for anticipated averted HIV treatment expenditures, South Africa 2006 [3]

The 50th percentile corresponds with the base case. Similarly, the first and 99th percentiles approximate the low and high end ranges. For example, the high-end cost per male circumcision corresponds to the 99th percentile, or $250 per HIV infection averted. The figure indicates that the unadjusted cost per HIV infection averted is most sensitive to uncertainty in the male circumcision protective effort, cost per male circumcision, and epidemic multiplier.

play team rankings). By compiling a league table of ICERs from the literature, one can examine how the ICER of the intervention under study compares with those of other interventions that society has already deemed worthy of investment. If the ICER is low, the intervention is termed a good value, while if the ICER is high, it is identified as a poor value relative to other accepted interventions. The league table approach also has limitations, as argued by Birch and Gafni [38]. For example, the studies summarized in the table may not use comparable data for costing or efficacy, and some of the CE ratios may not be properly incremental. Further, division of interventions into those with relatively good and relatively poor value depends highly on the specific alternatives displayed in each table. Authors of this chapter are working on potential refinements to methods to interpret and use ICERs to inform policy.

Table 19.1 Example of handling dominance in a cost-effectiveness analysis

Intervention	Cost	Added cost	DALYs	DALYs averted	ICER ($ per DALY averted)
No treatment	$100	n/a	3	n/a	n/a
Drug A	$150	$50	1	2	$25
Drug B	$160	$10	1.5	−0.5	Dominated
Drug C	$200	$50[a]	0.8	0.2[a]	$250

[a]Drug C is compared with Drug A because Drug B is dominated

We must add a few words on *dominance*. By going down the list and comparing each intervention with the prior one on the list, the analyst can determine if any intervention is *strictly dominated,* that is, less effective and more costly than the prior intervention. Such an intervention would not make a sound investment, since it is more expensive and less effective, and can be eliminated from further consideration. One can then calculate the ICERs between each adjacent pair of remaining interventions. Interventions that are less desirable by *extended dominance* can also be eliminated. Extended dominance occurs when the ICER falls as one moves down the results table. In the example in Table 19.1, going from intervention A to B adds cost but worsens outcome (more DALYs), hence B is dominated. Comparing C to A yields an ICER of $250 ($50 divided by 0.2). When this occurs, a linear combination of alternatives A and C will be cheaper and better than alternative B [39–41]. After relevant strategies are eliminated by extended and strict dominance, the ICER for each strategy is examined relative to the prior strategy. The ICERs can then be interpreted as above.

4.7 Limitations of CEA

The analyses are often limited in scope and do not evaluate all potential options, even within a given programme [42]. For example, a behavioural intervention aimed at STI-related risk reduction that is not cost-effective in women aged 18–40 years might be cost-effective to those aged 18–24 years. Most interventions (both behavioural and screening) fail to consider the complete set of alternative use of resources available to programmes because of data limitations, often limiting the focus to an intervention under study in relative isolation. Accurately determining intervention cost can be challenging for programmes which frequently lack line-item cost data for factors such as building space and other difficult to define costs (e.g. the amount of administrative staff effort to be apportioned to a given intervention). For some CEAs, factors such as patient transportation and lost productivity costs are especially important. For some it can be difficult to incorporate all outcomes associated with an intervention, whether they are beneficial or harmful [43].

4.8 Ethical Considerations in CEA

There are many issues to consider when balancing costs and fairness [44]. Some perceive that by representing human life in dollar terms and choosing among life-saving interventions based on return-on-investment metrics, CEA conflicts with ethical principles such as human rights, equity and the expression of empathy. We argue, to the contrary, that the utilitarian framework underlying CEA generally provides ethically trustworthy guidance. This is because, in the context of health-care delivery, efficiency is itself a laudable ethical value. That is, it is hard to justify not maximizing health with the resources available. In addition, non-utilitarian based principles are, in practice, often hard to interpret, contradictory, or likely to lead to outcomes that diverge dramatically from that of health maximization [45]. Human rights assertions, for example, can conflict with the Rule of Rescue (Jonsen's term for 'the imperative people feel to rescue identifiable individuals facing avoidable death' [46]) or other principled claims based on urgent need. We do not believe that utilitarianism is the only legitimate guide to resource allocation decisions. There may be instances, for example, when distributive goals should take precedence. However, efficiency should be the default. A decision to diverge from health maximization in pursuit of other ethical values needs to be acknowledged and justified. Where possible, we advocate for quantitative assessment of the trade-off between health benefit and other ethical principles. Specifically, what increase in disease burden results from favouring another ethics-based goal?

5 Conclusion

Health economics is a tool to efficiently improve health. Each of the methods we have discussed contributes to this purpose. DALYs quantify disease burden to properly quantify the outcome of improved health. CEA compares added spending to averted DALYs. Other economic methods inform the pursuit of efficiency, for example behavioural economics seeks simple *nudges* that result in important improvements in health behaviours and quality of care.

We encourage readers to consider these methods in their work. There is increasing support for doing so in LMICs, such as the International Decision Support Initiative (iDSI), the Global Health Cost Consortium (GHCC), and reference cases for cost-effectiveness and cost-benefit analysis. We welcome inquiries, and will guide individuals to appropriate technical resources and assistance.

Key Messages

- Health economics empowers decision-makers to efficiently improve the health of the population.
- Health economics examines how treatment and prevention are delivered, and their costs and health benefits.
- DALY is a metric for quantifying the burden of disease due to fatal and non-fatal conditions, and the benefits of intervening.
- CEA quantifies the cost per DALY averted for specific intervention strategies compared with each other.
- Other economics methods examine issues such as how individual resources, preferences, and cognitive biases affect choices about health behaviours and care.

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20

Tracking Health Outcomes in Space and Time: Spatial and Spatio-temporal Methods

Peter Diggle, Emanuele Giorgi, Michael Chipeta, and Sarah B. Macfarlane

1 Introduction

Maps and diagrams of raw data can be misleading. Figure 20.1 shows monthly numbers of inpatients at a large hospital in the north of England who experienced a MRSA (multi-resistant staphylococcus aureus) infection. For the month indicated by the question mark, the hospital's management asked the pathology laboratory to explain the peak in incidence. In fact, this peak is consistent with a steady decrease in incidence throughout the eight-year period covered by the data [1]. Scientists can avoid such misunderstandings by modelling the data and presenting the hospital management with a diagram that describes the modelled changes in numbers of infections over time. In this way, the model converts the raw data into evidence and the diagram illustrates the downward trend.

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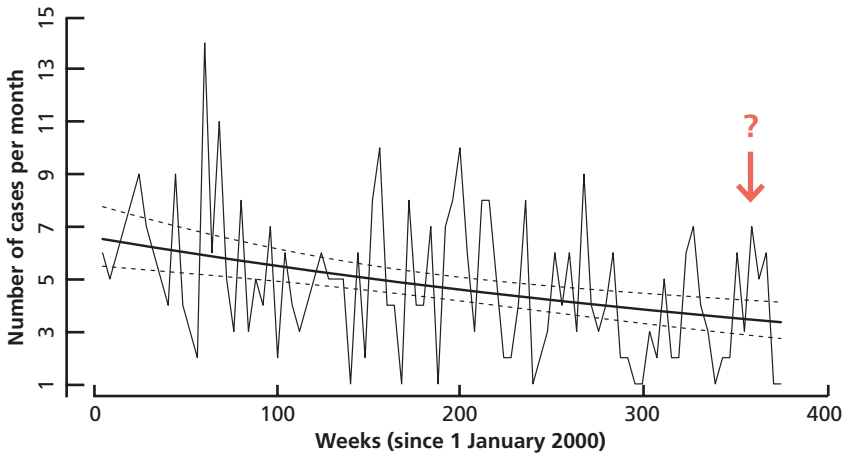

Fig. 20.1 Incidence of MRSA cases among inpatients at a large hospital in the north of England over a four-year period [1]. The hospital's management asked the pathology laboratory to explain the peak in incidence shown by the bold arrow. The solid and dashed curves show the estimates and 95 per cent confidence intervals for the underlying trend in incidence

People experience health outcomes, such as contracting a disease, at different points in time and in different geographic locations. Epidemiologists who want to describe, explain and predict disease occurrence use spatial models to account for location, and spatio-temporal models to account for location and time, along with any known or hypothesised determinants of the disease condition. They present their findings as a map or a sequence of maps predicting the prevalence or incidence of the condition.

Geographical information systems (GISs) have made it easy to visualise distributions of populations, diseases and resources across a map (see Chap. 15). In this chapter, we show how spatial and spatio-temporal statistical modelling can add value to a GIS for health outcome mapping and surveillance. Specifically, statistical modelling quantifies the uncertainty in a predictive map, and allows the user to judge the map's suitability to inform policy.

To map health outcomes, researchers analyse spatially referenced data either at a single point in time or aggregated over a time-period, often to inform long-term health policies. The World Health Organization (WHO), for example, maintains and updates world maps showing the geographic distribution of major and emerging infectious diseases, including malaria, HIV/AIDS, tuberculosis, meningitis, cholera, yellow fever and anti-infective drug resistance [2]. For health surveillance, researchers work with public health practitioners to perform real-time analysis of spatially and temporally

referenced outcome data to inform rapid response. To predict, and respond to the occurrence of malaria outbreaks, for example, a national surveillance team will continually monitor the time and location of malaria cases.

As these analyses require sophisticated statistical knowledge, public health officials usually invite statisticians to work with them to solve mapping and surveillance problems. Teamwork is essential because the statistical method is at its most effective when combined with local knowledge. We describe situations in which spatial and spatio-temporal models are applicable, drawing on our experience working with colleagues around the world. We describe some methods for collecting spatially and temporally referenced data and introduce a choice of spatial and spatio-temporal models. We refer readers to the statistical literature for a deeper understanding of the methods. We provide advice on choosing software and about presenting and interpreting findings, and conclude with a discussion of challenges to developing this type of research and to broadening its impact on policy.

2 What Is Spatio-temporal Analysis and How Can It Contribute to Policy?

As epidemiologists and statisticians, we use the term *spatial* to describe investigations in which we locate observations geographically at a specific time. Sometimes, we treat data as spatial, if we believe the period over which we collect them to be irrelevant, for example, when studying an endemic disease whose prevalence is stable over the duration of the investigation. We use the term *spatio-temporal* to describe studies in which we record and analyse both the locations and associated times of the observations.

Our goal in spatial analysis is to investigate geographic variation in the probability of occurrence of a health outcome. In spatio-temporal analysis, we explore variation in the average number of incident or prevalent cases in combinations of place and time units over the geographical region and time-period of interest—that is, the *spatio-temporal intensity* of incident or prevalent cases. Examples of health outcomes include incidence of traffic accidents, cases of Zika virus or pre-term births, or prevalence of tuberculosis, specific cancers or obesity. In addition to mapping distributions of these outcomes directly, we may compare their distributions with a random sample of disease-free members of the population at risk and examine risk factors, as in a *case-control* study. The key statistical question in all these studies is how to describe changes in the underlying pattern of the health outcome (signal) and differentiate

these from chance fluctuations (noise) in incidence or prevalence. We provide some examples here and later in the chapter to demonstrate the value that spatial and spatio-temporal analyses add to decision-making in the face of uncertainty.

Maps showing the current and historic distribution of a condition are useful to planners when making long-term decisions about where to allocate resources effectively so as to prevent and control disease among populations at risk. For example, the Environmental and Health Atlas of England and Wales provides interactive maps for 14 health conditions for neighbourhoods (census wards of about 6,000 people) in England and Wales [3]. These maps show risks for each census ward relative to the risk in England and Wales of contracting the condition. The risks are based on disease reporting and are age adjusted and averaged over a period of about 25 years. Health planners or members of the public can assess the relative risk, for example, of lung cancer, breast cancer, heart disease or still births for their neighbourhoods.

As a second example, snake bites are a serious public health problem in Sri Lanka. Ministry officials need to know where to locate treatment centres and distribute anti-venom. It is impossible to describe the incidence simply by analysing hospital records because not all case are reported at health facilities and those that are may well be a spatially biased sample, with cases more likely to be reported when they occur close to a health facility (Fig. 20.2) [4].

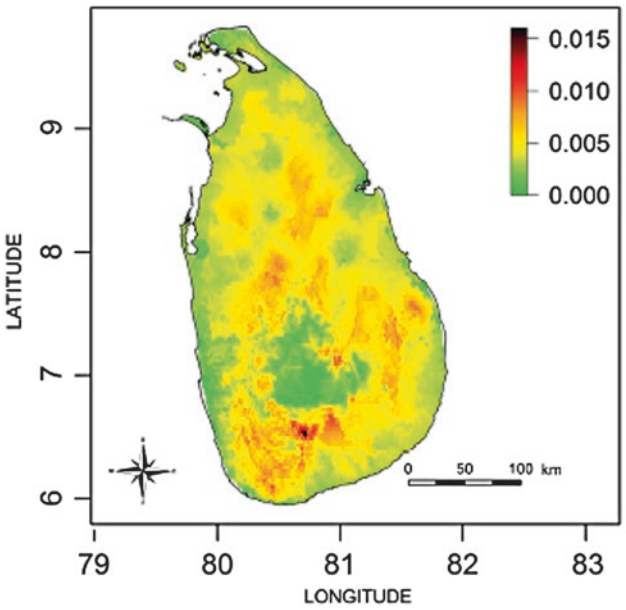

Fig. 20.2 Geographical variation in snake bite incidence per person per year in Sri Lanka, September 2011 to August 2012. (Source: Ediriweera et al. [4])

Real-time spatio-temporal surveillance, on the other hand, can inform a rapid response team about where and when to target prevention and control activities, as well as to make longer-term plans. For example, the New York City Department of Health developed a system that uses daily reports of the location and timing of 35 notifiable diseases to automatically detect epidemics. In 2015, the system identified a cluster of community-acquired legionellosis in a specific location three days before health professionals noticed an increase in cases; the cluster of observations expanded and became the largest outbreak in the United States [5].

At the global level, findings of spatio-temporal analyses informed a major public health milestone—withdrawal in April 2016 of serotype-2 oral poliovirus vaccine (OPV2) from the trivalent polio vaccine in use in 155 countries. On 20 September 2015, the Global Commission for Certification of Poliomyelitis Eradication (GCC) had announced worldwide eradication of wild poliovirus type 2 and plans to withdraw OPV2. To avoid outbreaks of serotype-2 vaccine-derived polioviruses after OPV2 withdrawal, the WHO needed to be sure that populations in high-risk countries had sufficient levels of serotype-2 immunity. A team of infectious disease researchers, working with representatives from WHO and the health ministries of Nigeria and Pakistan, used spatio-temporal methods to examine immunity levels by district over time in Nigeria and Pakistan. The researchers concluded there had been substantial improvements in serotype-2 population immunity over the five-year period prior to 2015, and projected improvements in April 2016 compared with the first half of 2015 [6]. This, with other evidence, cleared the way for withdrawal of OPV2 from the trivalent polio vaccine.

3 Design of Spatial and Spatio-temporal Studies

3.1 Types of Data

We can collect spatially referenced data in at least three different formats, depending on the study design. Consider, for example, a study of cholera in a geographical region. In a *spatial point pattern* dataset, our unit of observation is the individual case, geo-referenced to a single point in the region we are describing, for example all persons diagnosed with cholera in the region, each identified by their village address. In a *geostatistical* dataset, our unit of observation is

again a location in the region but we obtain data only from a sample of the susceptible population. Typically, each location identifies a village community but resource limitations dictate that we use only a sample of villages, rather than a complete census; we record the number of cholera cases in each sampled village. In a *small-area* dataset, we identify locations by partitioning the region into a set of sub-regions, and then counting all cases of cholera in each sub-region.

When our interest extends to the timing of the event, we can adapt any of these formats, for example, when we record both the location and time of occurrence of a cholera case during real-time surveillance, we obtain a spatio-temporal point pattern dataset of all cases. When we record cases longitudinally at sampled locations, we obtain a spatio-temporal geostatistical dataset, and similarly with small area datasets.

In practice, we most commonly use geostatistical data for disease mapping and surveillance in low-resource settings where collecting point pattern data is expensive and health registries may not exist to provide small area data.

3.2 Sampling

We provide an overview of sampling methods, first for spatial geostatistical studies and then for their extension to temporal studies. We refer the reader to Mateu and Müller for a fuller description of spatio-temporal design problems [7].

Without a properly designed sampling scheme, there is a risk that we will sample more accessible communities that do not represent the health experiences of the study-population, that is, the study will be biased. To obtain valid predictions, we require that the sample is unbiased spatially and temporally, otherwise we need to describe the biases. In practice, the latter is rarely possible, and the plausibility of the former requires qualitative judgement.

To collect geostatistical data, we avoid spatial bias either by selecting gridded locations from a gridded map of the geographic area of interest or by using a *probability sampling* scheme. Counter-intuitively, we do not recommend *simple random* sampling. The reason is that this leads to an irregular pattern of sampled locations. To construct an accurate map, it is preferable to choose sampling locations that are more evenly spaced throughout the region of interest. Chipeta et al. explain how this can be achieved without losing the guarantee of unbiasedness by choosing sampling locations at random subject to the constraint that no two sampled locations can be separated by less than a specified minimum distance [8].

Two other sampling designs that researchers commonly use are random sampling and multi-stage *cluster sampling*.

A *stratified random sample* consists of a set of simple random samples, one in each of a pre-defined set of sub-regions that form a partition of the region of interest. Accordingly, we again recommend using Chipeta et al.'s method to secure an even coverage of each sub-region without introducing bias. Stratification generally leads to gains in efficiency when contextual knowledge can be used to define the strata, so that between-strata variation in the outcome of interest dominates within-stratum variation.

Multi-stage cluster sampling, as used by the Demographic and Health Surveys [9], is when we divide the region of interest into administrative divisions and randomly select a number of clusters of households or villages in each division. Cluster sampling designs are typically less efficient statistically than simple or stratified designs with the same total sample size, but this is counterbalanced by their undoubted practical convenience, which may result in a larger sample size for fixed effort in the field—a delicate balance.

In practice, to reduce the length and cost of the study, researchers often use *opportunistic sampling*, in which they collect data from whatever locations data are available, for example, from presentations at health clinics. The limitations are obvious; the onus is on the investigators to convince themselves and their audience that such a design does not bias their results.

Giorgi et al. describe a spatial statistical model for jointly analysing malaria prevalence data collected from two sources: a randomised household survey; and presentations at health clinics [10]. They find clear evidence of sampling bias in the clinic data, which they account for by including a bias term in a joint analysis of the randomised survey data and the clinic presentation data. Ignoring this bias would have led to invalid prevalence mapping. In the Sri Lankan snake bite example we introduced earlier, the researchers avoided using hospital data and instead used two-stage cluster sampling to obtain representative estimates of snake bites across the country.

In the extension to the spatio-temporal setting, we draw on several design scenarios, depending on the objectives of the study and practical constraints. In a *longitudinal* design, we collect data repeatedly over time from the same set of sampled locations (selected using one of the sampling methods we described above). This is appropriate when temporal variation in the health outcome dominates spatial variation. A longitudinal design can be cost-effective when setting up a sampling location is expensive but subsequent data collection is cheap. Longitudinal designs can act as *sentinel* locations, when the locations may be chosen subjectively either to be representative of the population at large or, in the case of pollution monitoring for example, to capture extreme cases to monitor compliance with environmental legislation.

In a *repeated cross-sectional* design, we choose a different set of locations on each sampling occasion. This sacrifices direct information on changes in the underlying process over time in favour of more complete spatial coverage. For example, to predict stunting in children in Ghana, researchers drew data from four quinquennial national Demographic and Health Surveys, each of which used a similar two-stage cluster sampling strategy [9]. Repeated cross-sectional designs can also be *adaptive*, meaning that on any sampling occasion, the choice of sampling locations is informed by an analysis of the data collected on earlier occasions. Adaptive repeated cross-sectional designs are particularly suitable for applications in which temporal variation either is dominated by spatial variation or is strongly related to risk factors of interest [8].

4 Types of Spatial and Spatio-temporal Models

To analyse the data, we choose between two types of models depending on our purpose. We make a broad distinction between *empirical* and *mechanistic* models although the distinction is not always clear-cut. If we seek to describe and predict the phenomenon of interest, we can use an empirical model, that is, one whose suitability is determined by its fit to the data and its ability to make useful predictions. But if we also seek to explain why the phenomenon is as it is, we use a mechanistic model, that is, one that incorporates specific, subject-related knowledge. An example might help here. The data on MRSA infections shown in Fig. 20.1 can be well described by an exponential decay curve. However, we are aware of no bio-medically based theory that can justify this: the curve simply fits the data, and was used to reassure the hospital's manager that their MRSA incidence was continuing to decline, that is, it was an empirical model. In a different context, the physical laws governing nuclear fission imply that the same equation describes accurately how the radioactivity of a sample of fissile material decays over time: in this context, the model would be mechanistic.

Mechanistic models are conceptually more appealing than empirical models, but this appeal is not cost free. Adding complexity to a statistical model inevitably results in estimates of its parameters that are less precise, unless additional assumptions that are not easily validated from the available data can be justified by subject-matter knowledge [11]. For the rest of the chapter, we focus on disease mapping and surveillance methods based on regression

modelling of geostatistical data. We explain here three common applications of empirical models. For detailed descriptions of the underlying statistical methods, see Gelfand et al. [12]

4.1 Prevalence Mapping

In prevalence mapping, our goal is to predict the probability that a randomly sampled individual living at a specific location anywhere in the region of interest will be a case. We suppose the observed number of cases at any one location follows a specific distribution *(a binomial distribution)*. Also, we expect these observations to be spatially correlated, typically with the value of the correlation between any two observations depending on their spatial separation. We formulate a model *(a generalised linear mixed model)* to explain the observations in terms of measured explanatory variables and spatial variation, and estimate model parameters *(using likelihood-based methods)*. We then use the model and its parameters to predict the probability of a case occurring at observed and unobserved locations. Diggle and Giorgi further explain geostatistical modelling (and the terms italicised in brackets) for prevalence and incidence mapping [13].

Ediriweera et al. used the above model for the snake bite mapping we described earlier [4]. The researchers counted the number of snake bites reported by households at locations in each sampled district and observed socio-demographic data about the sampled community such as mean age, percentage males and mean income. They also classified each district environmentally, for example by its climatic zone, elevation and land cover. With these data, they built a model to explain the distribution of snake bites in terms of these variables, estimated its parameters, and then used the model to predict the probability of a snake bite occurring in all districts of Sri Lanka. To make predictions in districts that they had not sampled, they used published data on the explanatory variables for all districts, for example, from the census and from global environmental sources. They presented their findings as incidence of snake bites per person per year (Fig. 20.2) and as levels of snake bite probabilities as contours on a map of Sri Lanka.

Diggle et al. used the same modelling framework to map the geographical variation in *Loa loa* prevalence in rural communities throughout Cameroon [14]. Strictly, the true prevalence must vary over time, but because infection with *Loa loa* parasites is both endemic and long-lasting, in the absence of any intervention, a purely spatial map remains relevant for some time after it is produced. As well as mapping prevalence, the researchers mapped the proba-

bility that prevalence exceeded 20 per cent, for the following reason. The research was carried out under the auspices of the African programme for Onchocerciasis Control (APOC) [15]. As its name implies, APOC's focus was not on *Loa loa*, but on onchocerciasis, or river blindness. The programme's control strategy is mass prophylactic administration of a filaricide, ivermectin, in all onchocerciasis-endemic areas. APOC discovered, however, that communities in onchocerciasis-endemic areas, where there was also a high prevalence of *Loa loa,* were at risk of experiencing severe, occasionally fatal, reactions to ivermectin. They took a policy decision to declare areas with *Loa loa* prevalence greater than 20 per cent as high risk and to put in place precautionary measures before treating these high-risk areas. The policy-relevant question now becomes: where are the high-risk areas? The statistician's answer is to calculate *exceedance probabilities*, or the probability that an area is high risk—as the map in Fig. 20.3 shows. Dark red and pale cream areas in Fig. 20.3 are almost certainly high and low risk, respectively. The preponderance of pink areas in Fig. 20.3 is disappointing in the sense that these correspond to a 50–50 call, but an honestly imprecise answer is better than a dishonestly precise one.

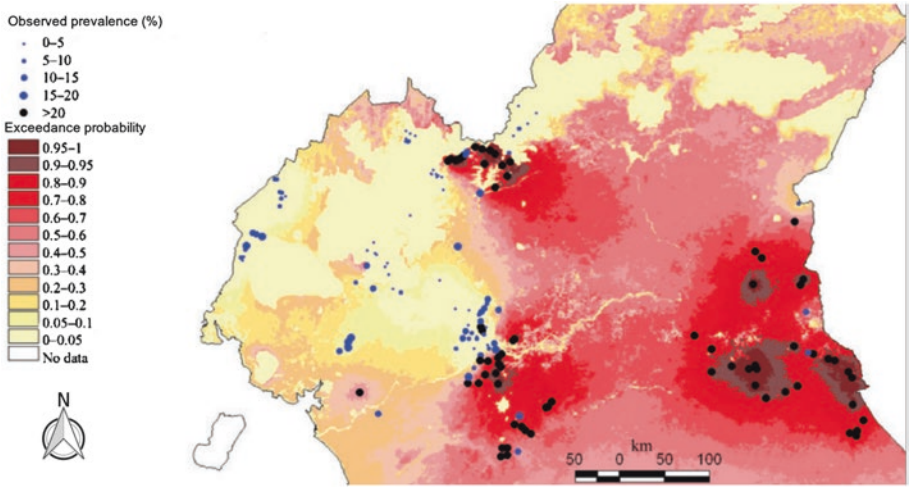

Fig. 20.3 Predictive probability that prevalence of *Loa loa* in rural communities in Cameroon exceeds 20 per cent. The map is derived by fitting a geostatistical model to prevalence survey data collected at each of the marked locations on the map, supplemented by digital image data on height above sea level and Normalised Digital Vegetation Index at a resolution of approximately 1 km. For details, see Diggle et al. [14]

The same type of model can also be used for case-control studies, where the response from each study participant is now one for a case and zero for a control. For example, to understand the spatial clustering of childhood cancers in Spain, Ramis et al. undertook a case-control study [16]. Cases were children aged 0–14 years diagnosed in five Spanish regions for the period 1996–2011, with three major childhood causes of cancer. For the control group, they sampled from the birth registry six controls for each case, matched by year of birth, autonomous region of residence and sex. They then geo-coded and validated the addresses of the cases and controls. By comparing the two point patterns, the authors drew conclusions about variation in risk within each autonomous region while controlling for age and sex effects. Note, however, that matching by autonomous region meant that they could not compare risks between different autonomous regions.

4.2 Spatio-temporal Mapping

When undertaking spatio-temporal analysis of geostatistical data, our goal is to predict the intensity, or the mean number, of cases per unit area per unit time at a specific location and a specific time over a geographical region of interest. We use the same approach we described in Sect. 4.1 but we associate time with the observations and the explanatory variables, and explain the remaining variation as correlations in both space and time. The problem with this type of analysis is that computations can become unwieldy so we make every effort to simplify the model. For example, in some applications annual variation in the outcome of interest might be explained by known seasonally varying risk factors, so that inclusion of appropriate seasonal explanatory variables may allow us to drop time from the unexplained variation. Models and inferential algorithms for spatio-temporal mapping are a continuing topic of statistical research; see, for example, Cressie and Wikle [17] or Shaddick and Zidek [18].

4.3 Real-Time Surveillance

A surveillance study sets out to understand the current status of a dynamically changing phenomenon. The data in this case are usually in the form of a spatio-temporal point pattern covering a defined geographic region. We use the same methods as we described in Sect. 4.2 but we use custom-made software to constantly update the model as we enter data in real time. A resource that explains spatio-temporal statistical methods for real-time surveillance is Diggle et al. [19]

Around the year 2000, some of the authors worked with the United Kingdom's Public Health Laboratory Service (now Public Health England) in the southern English county of Hampshire to identify anomalous incidence patterns of symptoms typically associated with foodborne disease. Their goal was to provide early warnings of possible outbreaks, using data from the then new NHS Direct, a 24-hour National Health Service (NHS) phone-in helpline [20]. They fed each day's NHS Direct data into a piece of bespoke software that ran a statistical analysis to compute, for each location, the probability that the underlying incidence at that place on that day exceeded expectation by a factor of two or more. The local Public Health Laboratory Service was then able to present the updated map of exceedance probabilities on a website by the start of the next working day. Figure 20.4 is a snapshot of the daily map; the team produced comparable maps in real time over a two-year period [21]. In Fig. 20.4, and in contrast to the *Loa loa* example we discussed earlier, the factor of two used to calculate the exceedance probabilities was purely illustrative. Note also from Fig. 20.4, which includes the residential locations from which individual calls were made over a five-day period, that the number of relevant calls made on any one day was rather small. An essential feature of the statistical model was its ability to integrate information over time, while progressively discounting past data.

In low-resource settings, reliable automated data feeds of the kind we described above are less likely to be available. In their absence, the same underlying principles nevertheless hold. The over-riding aim is to update results in response to new data in as timely a manner as possible. Furthermore, to make a virtue of necessity, if real-time data acquisition means collecting new data weekly or monthly, rather than daily, it may also be possible to build an adaptive design element onto a surveillance system to make the best use of the limited resources available for the next data collection, see Chipeta et al. [22]

Figure 20.5 shows three maps from a monthly sequence that researchers constructed to show the effects of control activities undertaken in the Chikwawa district of southern Malawi; the complete sequence, between May 2010 and June 2013, can be inspected at the site http://www.lancaster.ac.uk/staff/giorgi/malaria/. Chikwawa is a high-risk area for malaria, but prevalence varies substantially over just a few kilometres. The malaria control programme employs a rolling malaria indicator survey to monitor the month-to-month spatio-temporal variation in malaria in the district [23]. Enumerators visit a random sample of villages each month and test a random sample of individuals in each village for the presence of *falciparum* parasites. Although enumerators eventually revisit each village, the data are essentially repeated

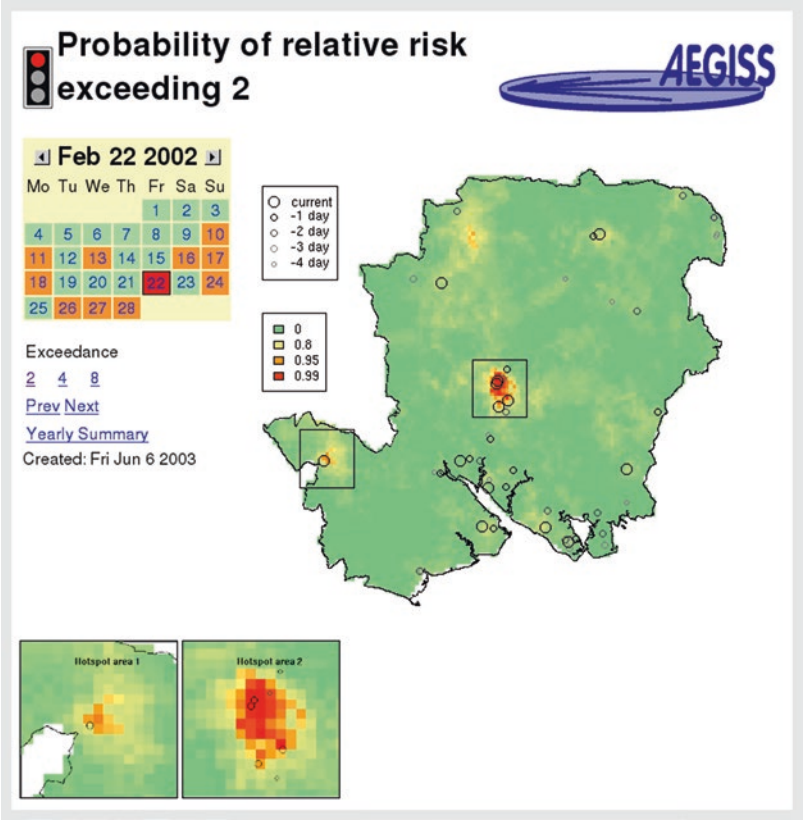

Fig. 20.4 Predictive probability, on 22 February 2002, that the daily rate of calls to the United Kingdom National Health Service Direct relating to vomiting and/or diarrhoea exceeded expectation by a factor of at least two. The open circles indicate the residential locations of all relevant calls over the five-day period ending on 22 February 2002. For details, see Diggle, Rowlingson and Su [21]

cross-sectional rather than longitudinal. However, since the underlying prevalence surface is likely to evolve smoothly over time, fitting a spatio-temporal geostatistical model rather than a series of separate spatial models leads to more precise estimates of prevalence at any one time. The resulting maps show the seasonal change between May and December 2010, and the substantial progress that has been made in reducing prevalence between 2010 and 2013. Maps like these can be an effective tool for communicating to health workers and the local population the value of community-engagement in locally based health research projects.

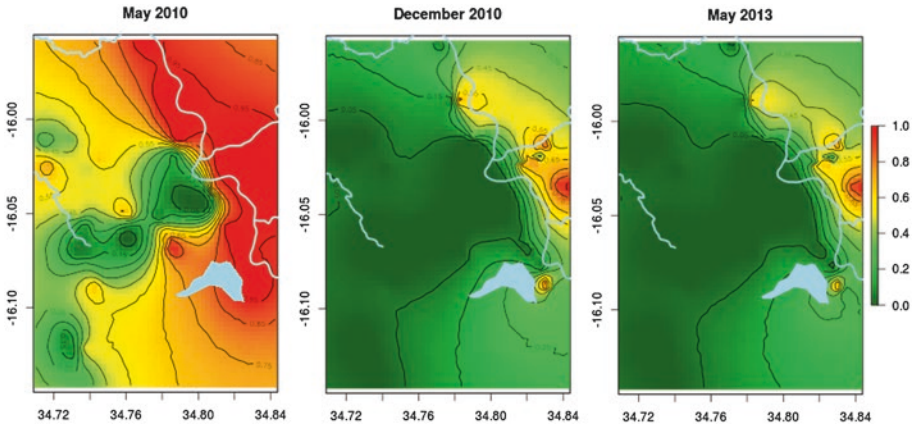

Fig. 20.5 Predictive probability that malaria prevalence exceeds 20 per cent in Chikwawa district, southern Malawi [23] (http://www.lancaster.ac.uk/staff/giorgi/malaria/ shows this as an interactive map from May 2010 to June 2013)

5 Computation, Presentation and Interpretation of the Findings

The computer revolution has altered statistical practice in many ways. Arguably, the ability to fit almost arbitrarily complex models to data using computationally intensive methods has been a mixed blessing. The benefits of not being confined to an artificially simple set of analytically tractable models are obvious. On the other hand, people can use the methods without understanding the underlying design issues. One unequivocal benefit has been the replacement of a plethora of seemingly unrelated, problem-specific statistical techniques by the following more principled, general approach: formulate a statistical model for the data; fit the model to the data using efficient (likelihood-based) methods of inference; and use the fitted model to answer the user's question.

The methods we have described are freely available via packages written for the R open-source statistical computing environment [24]. The R environment also offers packages that mimic many GIS features; alternatively, the users can conduct their statistical analysis in R and pass the output to their preferred GIS. GIS software can include implementations of some quite sophisticated spatial statistical methods, but we urge that these be used with caution unless the user is an experienced statistician; these implementations often make poor, sometimes automated, choices for the underlying model parameters and, more seriously, do not encourage the user to question the validity of the modelling assumptions made.

When it comes to visualising and interpreting *uncertainty in predictive maps,* we quote the distinguished statistician, Peter McCullagh, who once said something like: 'The answer to any prediction problem is a probability distribution.' The quote captures the essence of our preferred approach to conveying the uncertainty that is an inherent feature of any honest prediction.

A map showing a best guess for the true prevalence at any location has a superficial appeal but fails to distinguish a wild guess from a well-informed one. Our preference, which we have illustrated in Figs. 20.3, 20.4 and 20.5, is to map the predictive probability that prevalence exceeds a specified value, ideally one that relates to an operational, policy-based threshold. We call these *percentile maps*. An alternative would be to use a series of predictive *quantile maps* in which, rather than map the predictive probability at each location of exceeding a fixed threshold, we do the converse—map the value at each location that is exceeded with a fixed probability.

From the latter perspective, a pair of maps corresponding to, say, the 0.05 and 0.95 points in the predictive distribution at each location would represent pointwise 90 per cent credible intervals for the true prevalence. For a complete picture, this approach requires a series of maps to be produced at different percentile or quantile thresholds, ideally as a dynamic image with one or more sliders to control the display.

6 Conclusion

Spatial and spatio-temporal statistical methods have many areas of application, but our purpose has been to illustrate their potential to address public health issues. An early, and famous, example of a spatial point pattern map being used in a public health context is Dr John Snow's 1854 map of cholera in Soho, London [25], although interestingly a much less celebrated map of cholera in the northern England city of Leeds was produced by Dr Robert Baker 22 years earlier [26].

We have argued that the statistical methods described in this chapter are accessible to researchers working with public health planners. Nevertheless, real-world problems will continue to generate new research questions, some of which will motivate development of extensions to current methodology, which can then be implemented in software and used in other applications. Our example of real-time surveillance using NHS Direct data required us at the time (around the year 2000) to develop new statistical methodology and a bespoke software implementation [21, 27]. Some 15 years later, this methodology is freely available as an R package [28].

Not every health research or policy agency has an in-house team of professional statisticians. The shortage of statisticians in low- and middle-income countries can be alleviated by international collaboration but building in-country capacity in statistics should be the long-term strategy. Maintaining complex real-time surveillance systems can also be challenging. However, the deep penetration of mobile phone technology throughout the world makes it possible for field workers in remote locations to upload routine clinical data and transfer them to a central location for sophisticated, computationally intensive processing, and for results to be fed back to local users in real time.

The quality of data and databases is critical. No amount of sophisticated statistical modelling can produce reliable evidence from unreliable data. But statistical modelling can extract greater value from geographically sparse health outcome data by linking them with freely available geographically dense data on social and natural environmental factors. In low-income countries, for many health outcomes, hospital presentations are unlikely to be representative of the population as a whole, but if such data are combined with data from a small-scale, randomised study, the sources of bias in hospital presentations can be estimated and incidence/prevalence maps adjusted accordingly [9].

The reader may have noticed that not once have we mentioned statistical significance. In our opinion, significance tests are of very limited value in health outcome mapping and surveillance because they do not address the relevant question, which is: *What can we say about the risk of the health outcome of interest here, now and, perhaps, in the near future?* This is a prediction problem. That is, the quantity of interest—the risk of the health outcome at any relevant location and time—is a random variable that we cannot observe directly; we can only calculate its conditional probability distribution given the available data. This can be a difficult concept to convey to a lay audience, and we agree with Clements et al., writing about spatial analysis for malaria elimination, that 'research needs to be done to establish the needs and priorities of decision makers, and their capacity to understand abstract concepts such as prediction uncertainty.' [29]

Key Messages

- Health outcomes typically exhibit variation in space and time.
- Statistical models turn data into evidence by extracting signal from noise.
- Maps can show risk of prevalence or incidence of health outcomes by location and through time.
- An honest prediction is one that acknowledges, deals with and explains uncertainty.

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21

Global Health Estimates: Modelling and Predicting Health Outcomes

Colin Mathers, Dan Hogan, and Gretchen Stevens

1 Introduction

The World Health Organization (WHO) reported that, in 2016, 5.6 million children died before reaching their fifth birthday and almost half of them (46 per cent) died before reaching 27 days. Among the leading causes of their deaths were pneumonia (13 per cent), diarrhoea (8 per cent), congenital anomalies (8 per cent), injuries (6 per cent) and malaria (5 per cent) [1]. Yet about the same time, Countdown to 2030—an independent multi-institutional collaboration that gathers and analyses data on women's and children's health—reported a striking absence of data for causes of child mortality in its 81 high-priority countries. Only 5 of the countries had good quality data for cause of death, 34 had incomplete data and 47 countries had no data at all [2].

So how can WHO make such assertions if the data are so poor? The answer is that WHO uses all available country data on indicators such as these and then makes global and country estimates using statistical modelling. Countdown, on the other hand, 'makes only limited use of predictions and aims as much as possible, to allow country data to speak.' [2]

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We review the rationale for estimation in global health and then describe the situations in which models are useful, providing an overview of the major classes of models used. We also discuss issues in assessing the quality and plausibility of statistical estimates and describe recommended guidelines for reporting them. Finally, we examine the relevance of such estimates for countries. We provide references throughout the chapter, to which the reader can refer to learn more about these complex techniques.

2 Rationale and Emergence of Global Health Estimates

Global estimates of health indicators, which are comparable by country, are vital to track progress towards internationally agreed goals and for donors to prioritise their investments. However, the accuracy of these estimates depends on the methods used to create them, and more importantly, the amount and quality of data upon which they are based. Poor data quality or availability means alternative methods can lead to substantially different final estimates, which can cause considerable confusion among global agencies and donors.

A little less than half the deaths in the world are registered with their cause, and national death registration data are only available for four African countries [3]. Useful population level data on incidence or prevalence of disease and injury are even less available. Instead international agencies and academics use statistical models to prepare estimates of key health indicators that are comparable across countries and/or time. The agencies derive these *global health estimates* using reported or published data from multiple national sources, such as civil registration, health facilities and population surveys. Estimates are valuable in generating overviews of the global health situation and emerging trends, and for reporting on country and global progress towards the Millennium Development Goals (MDGs) and now the Sustainable Development Goals [4].

Starting from the 1950s, and with increasing scope and regularity since the 1990s, the United Nations (UN) and its specialised agencies, such as the WHO and the UN Children's Fund, have published annual global and country health estimates for major demographic and health indicators based on data reported by member states. Within the last decade, the Institute for Health Metrics and Evaluation (IHME), funded by the Bill & Melinda Gates Foundation, has also published annual updates of comprehensive global burden of disease (GBD) statistical time series based on available data for 195

countries and territories, with sub-national estimates for a growing number of countries [5].

The statistical models used by various groups vary widely and dramatic expansion of computing and storage capacity has facilitated increased technical complexity. For example, the WHO estimated that in 2010, there were 655,000 malaria deaths worldwide, with under 100,000 in those aged five years and over [6]. The IHME estimated equivalent figures of 1.24 million malaria deaths, with more than half a million occurring in those aged five years and older [7]. Differences in interpretation of data, inclusion criteria and methodologies have led to publication of very different values for the same indicator. This can have serious consequences for individual countries. Depending which estimate they think to be more reliable, global donors may assign funding and evaluate progress differently. This situation has heightened calls from international agencies, policymakers and researchers for more transparency and replicability of methods. Some national policymakers and data producers question the need for such techniques, preferring to use their national statistics, where they are available.

3 Why Model?

Raw health data derived from primary data collection are often reported as direct tabulations of counts or transformed into indicators, such as rates or ratios without any adjustments or corrections. These statistics may not be accurate, representative of the population of interest, or comparable. Drawing comparisons between populations can also be complicated by differences in data definitions and measurement methods. Some countries may have multiple sources of data for the same population-time period, but more often data are not available for every population and year. Box 21.1 describes some common sources of bias. To overcome these issues, statisticians use analytic methods, such as mathematical and statistical models, to produce unbiased estimates that are representative and comparable across populations and/or time.

The types of modelling used vary in sophistication, but share the goal of addressing some or all of these challenges. We describe below the key situations in which modelling is useful.

To Improve Accuracy and Comparability of Data. One major purpose of statistical modelling is to process raw data to improve its accuracy and comparability. The application of weighting factors to data collected in a cluster sample survey is a form of modelling to improve representativeness.

Box 21.1 Common Sources of Bias in Model Input Data. Adapted from the GATHER Statement [8]

Inconsistent case definitions or diagnostic criteria: Health data often identify persons who test positive for a particular case definition. Case definitions may vary by data source, limiting their comparability. Assessors' qualifications may vary, which can lead to differences in ascertained prevalence. In addition, laboratory protocols may change over time, reducing comparability even when case definitions have not changed. Changes in sensitivity or specificity of detection methods can have an important effect on case identification, as can decisions about whether to adjust for sensitivity or specificity.

Self-report biases: With some survey instruments, systematic biases can arise from difficulties in obtaining accurate responses from survey respondents. Examples of self-report biases include recall bias or social desirability bias. Self-reports of prior diagnosis often underestimate the true incidence or prevalence since some cases do not interact with the health system or are not diagnosed. These biases may vary systematically by populations and over time.

Incomplete population-based surveillance: Surveillance and registration systems designed to capture all events in a population are often incomplete. It may be difficult to quantify levels of completeness for events such as infectious disease incidence. For other types of events, demographic techniques or capture-recapture techniques may allow estimation of completeness.

Non-representative population bias: Some data types are collected for a subset of the general population by design, for example when data are collected from clinic attendees or samples of volunteers, or when data pertain to urban or rural groups only. Health status and health determinants may differ systematically between these selected populations and the general population.

Incompleteness of surveillance or registration data is an important source of bias that must be addressed, and poses a challenge because completeness cannot be assessed using primary data alone and data from other sources is also needed.

Analysts may address bias resulting from definitional and measurement issues a priori by adjusting the data before statistical modelling, drawing on external information. For example, it is possible to adjust the prevalence of hearing loss measured using different loudness decibel thresholds to a common threshold using a known or assumed relationship between threshold and cumulative prevalence. Alternately, adjustment of data using different measurement strategies may be carried out statistically in the model. This is known as *cross-walking* to a standard definition. For example, for multiple hearing loss surveys with different thresholds, analysts can use statistical models to estimate the relationships between thresholds and prevalence and produce estimates for a standard set of thresholds for all the populations.

A striking example of the challenge of comparability comes from Malawi. The 2001 National Micronutrient Survey found that 59 per cent of pre-school

age children had vitamin A deficiency, based on a measure of serum retinol [8]. Surveys in 2009 [9] and in 2015–2016 [10] found prevalence of 40.1 per cent and 3.6 per cent using a different measure—retinol binding protein. Development partners and funding agencies need to know whether the trend indicates programmatic success, or if it is simply due to the change in diagnostic methods, in order to decide how to allocate future funds. This example, and others, highlights the importance of understanding and communicating why and how global health estimates are produced, and their levels of uncertainty.

To Synthesise Data from Multiple and Overlapping Sources. Statistical modelling can also be used to generate comparable and consistent indicator values across populations and/or time—based on all the data which meet inclusion criteria. For example, some countries have multiple sources of data on under-five mortality, such as from the census and household surveys [11]. Synthesising data makes use of all existing information of sufficient quality, thereby avoiding the arbitrariness of an analyst picking the *best* single data source, which is challenging given the presence of measurement error. This approach is similar to estimating a treatment effect through a meta-analysis of several randomised trials as opposed to picking the treatment effect from only one of the trials.

To Fill Data Gaps in time series and project to a common target year or range of years. For most types of raw data, the date of most recently available data varies across populations. Because analysts usually want to estimate trends to a common recent year across all populations, they include a projection component in the model. These imputation methods often borrow information from neighbouring data, which could be, for example, from countries in the same region or other time points in a country's primary data series. Analysts may also seek to improve imputations and projections by including predictor variables in the model that correlate with the quantity of interest (these are known as *covariates*).

To Estimate Quantities that Cannot Be Directly Measured. When it is difficult or costly to measure a health outcome, it may be more feasible to measure intermediate outcomes, and then use a model to extrapolate to the outcome. Such models usually involve mathematical modelling of the causal chain. For example, WHO has based its estimates of measles mortality on estimates of measles cases multiplied by separately estimated case fatality rates [12].

To Evaluate Large-scale Public Health Interventions when a randomised controlled trial is not possible for ethical or practical reasons [13]. Investigators observe trends in the outcome of interest with the programme in place and

develop a counterfactual model to estimate the outcomes in the absence of the programme. This approach can also be used to assess the potential impact and cost-effectiveness of proposed interventions.

To Forecast Indicators for a standard time frame (base year to latest target year) using a forwards (and sometimes backwards) projection component. In some cases, the main aim of the modelling is longer range projection or forecasting. These types of models fall into two main classes: (1) deterministic covariate-driven projections that are usually *scenario-based* [14, 15]. These allow for modelling of alternate future policies or interventions through covariates or other modifiable parameter assumptions; and (2) statistical forecasts using time series projection techniques to extrapolate historical trends [16]. Hybrid models combine stochastic time series projections with covariate drivers and multi-level modelling [17].

We distinguish in the following sections between statistical models, which describe associations between variables, and mathematical models which postulate a causal pathway [16]. We describe statistical modelling in more detail as analysts use these most frequently to make global estimates.

4 Mathematical Modelling

Mathematical models set up a theoretical framework that represents and quantifies the causal pathways and mechanisms linking determinants and health outcomes. These types of models make predictions of health outcomes (which may be difficult to measure) based on parameter estimates derived from various data sources. An example of a simple mathematical model used in the first GBD study [18] was the DISMOD I model. This specified the basic relationships between incidence, prevalence, remission, case fatality and mortality in terms of a set of four interlinked differential equations (see Fig. 21.1).

Natural history models are commonly used to estimate mortality from various infectious diseases. Recent examples include the UNAIDS HIV Spectrum model [19], the WHO measles mortality model [12] and a rabies mortality model [20]. Garnett et al. [13] give a range of examples of more sophisticated mathematical models, which lend themselves to programme evaluation by modelling the consequences to the final outcome variables of variations in intermediate parameters such as intervention coverage or case fatality. The Comparative Risk Assessment methodology developed by WHO in the early 2000s [21] also uses a mathematical modelling framework. The model assesses the change in population mortality outcomes associated with counterfactual

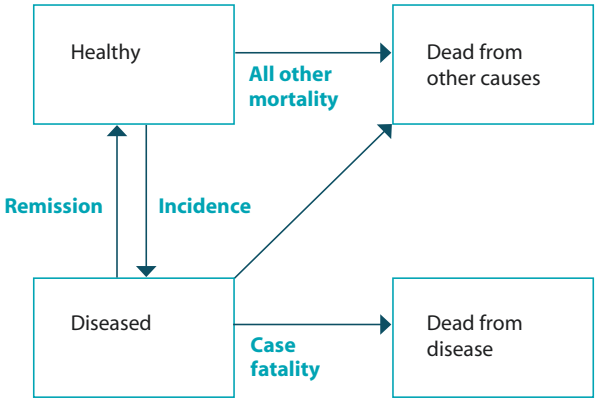

Fig. 21.1 The DISMOD 1 conceptual disease model [18]. The four boxes for prevalence and deaths are linked by four transmission hazards

exposure distributions for risk factors in order to assess the mortality attributable to current and past risk factor exposures.

5 Statistical Modelling

Statistical models estimate or predict outcome indicators using empirical data on the outcome as well as on correlated variables, or covariates. Statistical models commonly use regression techniques, identifying a functional form which fits the data, and which gives an adequate summary of the variation in the data [22]. Whereas explanatory modelling seeks to accurately characterise relationships between variables in the data, prediction modelling aims only to predict outcomes.

5.1 Methods of Estimation

Use of Covariates

Statistical models may estimate and use the correlation between data observations and covariates to improve predictive validity. This approach is frequently used to generate values for indicators in settings with no or very limited primary data on the outcome of interest, for example, levels and trends in maternal mortality [23] and other causes of death. Issues of causality are irrelevant for these types of models and users must be warned not to interpret the associations in causal terms. Analysts should not restrict the choice of covariates to those believed to be causal, as the aim is accurate prediction.

When using covariates, there is a danger that estimated trends reflect changes in covariates rather than changes in the estimated outcome indicator, particularly when there is little outcome data. For example, models to predict maternal mortality often include covariates such as gross domestic product (GDP) per capita which can vary depending on commodity prices. Rising GDP per se may have next to no impact on maternal health over short time periods but a model that includes GDP as a covariate will predict reductions in maternal mortality.

Inclusion of *data type* covariates in a regression is a common strategy when there are datasets or countries where data are available according to several definitions. It is possible to cross-walking to the preferred definition by including indicator variables for each alternate data type in a regression analysis and then setting data type to the preferred type for producing regression estimates. Alternately, it may be more convenient to do the cross-walking as a pre-processing step based on a separate regression analysis. An example is a recent study of diabetes mellitus prevalence which included some data sources that identify diabetes using HbA1c measurements and others that measure fasting plasma glucose [24].

An example of the use of covariates for both prediction of levels and trends and for cross-walking between two data types is the model used by WHO for estimating national homicide rates across countries [25]. After cross-validation, the final model included covariates for alcohol-drinking pattern, gender inequality index, per cent of the population living in urban areas, proportion of the population that are 15–30-year-old males, religious fractionalisation and infant mortality rate. An additional covariate for data type distinguished data from criminal justice and police systems from that derived from death registration, and adjusted for the differences between them.

Frequentist Versus Bayesian Estimation Methods

Frequentist statistical methods are based on interpretation of probabilities as objective summaries of repeated trials of the same process. *Frequentist* statistical modelling methods (such as ordinary least squares regression) rely on maximising a likelihood function which summarises the conditional probability of the actual observations as a function of the parameters to be estimated. In contrast, the Bayesian paradigm treats probabilities as subjective assessments based on prior knowledge (prior probability distributions) which are updated in the light of observed data [26].

Bayesian methods generally allow the fitting of more complex and flexible models, that seek to make many internal adjustments, enable more appropriate uncertainty characterisation and avoid the approximations required for many classical frequentist methods. These methods require greater computation than frequentist methods. With increasing computing power, Bayesian methods have become tractable for virtually all parametric methods and are being increasingly adopted for global health modelling, for example, UN agencies now use Bayesian methods to monitor child and maternal mortality [27, 28].

5.2 Types of Model

In Sect. 3, we identified a number of objectives for using statistical modelling; here we examine some of the main features and uses of the relevant modelling approaches.

Modelling to Produce Smooth Estimates Across Multiple Observations

Complex curve smoothing or time series projections allow flexibility in curve fitting using multiple and sometimes overlapping data inputs. For example, the UN Inter-agency Group on Mortality Estimation (UN-IGME) formerly used a *loess* regression method to estimate trends in child mortality for a country across a standard time period [28]. This method only used country-specific data to interpolate and extrapolate a smooth curve for a single population. UN-IGME now models time trends using Bayesian bias-adjusted B-splines which allow more objective curve fitting than loess regression [27]. We describe this example to illustrate the increasing sophistication of current statistical modelling.

Using the B-splines model, the UN-IGME estimates a best fit trend line for the under-five mortality rate (U5MR) based on multiple observations from multiple surveys at uneven intervals (see Fig. 21.2) [30]. The B-splines model includes a data model which simultaneously adjusts for statistically estimated biases for each type of measurement technique (such as indirect birth history vs. direct birth history). For example, if on average (across all country data) indirect birth history observations were 10 per cent lower than the final U5MR estimates based on all types of data, then the data model will apply an upward adjustment to the indirect birth history observations when estimating the final curve for U5MR. This means that the final

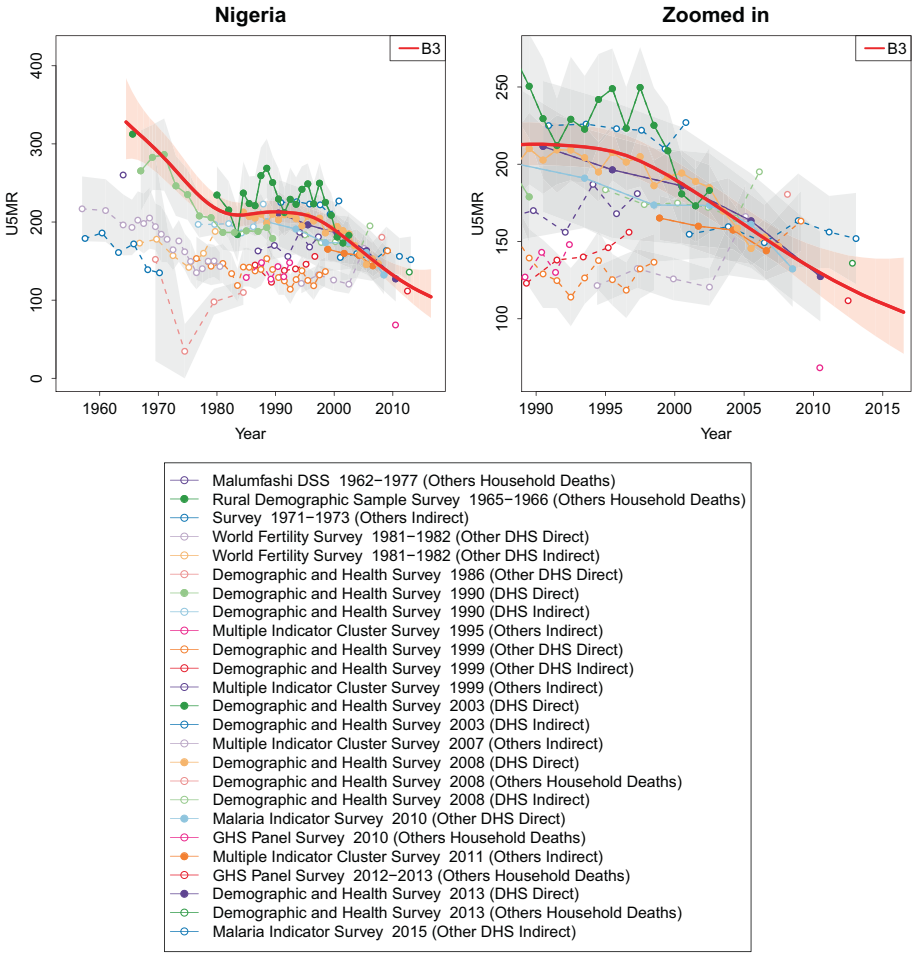

Fig. 21.2 Under-five mortality rates for Nigeria, 1955–2016. (Source: United Nations [30]). Empirical data from surveys and censuses included in the statistical analysis are shown as solid lines with symbols, data excluded on grounds of low quality shown as dashed lines, UN-IGME estimated time series shown as bold red line with 90 per cent uncertainty range

estimated U5MR curve for a country depends on the data for all countries, not just that specific to the country in question. It can also mean that if a country only has observations from biased data sources, the final estimates may lie entirely outside the original, raw data observation (often difficult to explain to users of the statistics).

Multi-level Modelling to Improve the Quality and Stability of Estimates Based on Relatively Sparse Data

Multi-level or hierarchical regression models allow for simultaneous modelling of parameters that vary at more than one level (e.g. country, region and world). Modelling parameters hierarchically allows data from other countries within a region, and in other regions, to inform estimation for countries with poor or missing data. In non-hierarchical regression models, a group *dummy variable* could be included to estimate the variation between groups as a *fixed effect*. Hierarchical models also permit the inclusion of random effects, which allow the model to share information from higher levels of the hierarchy to a greater extent when data from lower levels are poor [22]. We describe an application of hierarchical modelling to children's height and weight to illustrate how the method is typically used for global health estimates. Paciorek et al. used a Bayesian hierarchical model to estimate distributions of height-for-age and weight-for-age by place of residence (urban or rural) for 141 countries over a 35-year period [31]. The estimated values for each country-year were informed by data from the country-year itself, if available, and by data from other countries, especially those in the same region. The authors of the study explained that 'The hierarchical model shares information to a greater extent when data are non-existent or weakly informative (e.g., because they have a small sample size), and to a lesser extent in data-rich countries and regions.'

Complex Predictive Models to Interpolate and Extrapolate Outside the Available Data

Most statistical models use more than one of the techniques outlined above, including use of time-varying covariates, a multi-level structure and a temporal smoothing technique. For example, to estimate maternal mortality trends by country, the UN system uses a multi-level Bayesian regression model with time series modelling and covariates and random effects [28]. The Maternal Child Health Epidemiology Estimation collaboration with WHO uses a multi-nomial regression model, with covariates and fixed effects, that simultaneously models a complete set of cause-of-death fractions [32]. Other examples of complex statistical models include use by the IHME of Gaussian process regression to borrow strength and smooth across space and time [33]. Use of these statistical imputation and prediction methods along with predictive covariates now enables relatively sparse data to become *big estimates* with health indicators imputed to detailed spatial-temporal grids, for example, 5 km x 5 km grids for the world over 15 years [34].

5.3 Appropriateness of Model Frameworks and Validation Methods

Validation of predictive models differs from validation of explanatory models. Analysts validate explanatory models by examining whether their structure adequately represents the data and if the model fits the data. For example, validation of an explanatory model would examine whether addition of extra covariates to the model, transformations of covariates or additional nonlinear terms significantly increase its explanatory power. Model fit is assessed using goodness-of-fit tests and model diagnostics such as residual analysis [35].

In contrast, for predictive modelling where observations are missing for some populations or time periods, the focus of validation is on the ability of the model to predict missing data. This usually involves withholding some of the data from the model fitting and then testing the accuracy of the model predictions against the withheld data, known as *out-of-sample predictive validation* or *cross-validation* [36, 37]. Predictive validity depends on the question being asked and the nature of the data to which it is being applied, so there is no standard metric for evaluation of model performance. For example, a model focused on estimation of the outcome for all countries for a target year that falls outside the dataset will require the model to be particularly good at out-of-time predictions. If the focus is on prediction for countries with no primary data, this requires that the model predicts well out-of-sample across countries. For assessing the predictive validity of cause-of-death models used in the GBD 2010 study, the withheld data consisted of a mix of five types of missing data: countries with no data; countries with missing data years within the available data; countries with missing data years at earlier time periods; countries with missing data for later time periods; and countries with data missing for some age groups [38].

Advances in other disciplines [38, 39, 40] have found that an ensemble modelling approach may give better predictive validity than any single model. Recent modelling in the global health field has also made use of ensemble models that are the weighted combinations of different models [37–39]. Such ensemble modelling typically requires two sets of withheld data for validation. The first set is used to assess the predictive validity of the individual models, and the second set is used to assess and maximise the predictive validity of the ensemble average.

6 Understanding, Assessing and Using Statistical Estimates

Increasing complexity of models being used for health estimates and increasing concerns about the transparency and replicability of modelled results led WHO to assemble a working group in 2014 to define and promote best practice in reporting health estimates. This resulted in a consensus statement and reporting list known as Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER), published in 2016 simultaneously in the Lancet and PLoS Medicine [41, 42].

GATHER defines best reporting practices for global health estimates. GATHER comprises a checklist of 18 items that are essential for the best reporting practice. Key items in this checklist include information on all included data sources and their main characteristics, a detailed description of all steps of the analysis, types of uncertainty quantified and the methods used, how to obtain the analytic or statistical source code used, reasons for changes if updating an earlier set of estimates and a discussion of the modelling assumptions and data limitations that affect interpretation of the estimates. More details are available on the GATHER website [41].

GATHER provides an achievable standard for reporting health estimates, but there are many challenges in implementation. Full documentation of a study typically requires lengthy technical appendices, and ensuring open access to input data and computer code implies an additional reporting burden when publishing estimates. A clear description of the methods and fair discussion of limitations are important for understanding estimates, but are not easy to provide or verify.

6.1 Uncertainty Estimation

Quantifying uncertainty around modelled health estimates—typically by calculating and reporting uncertainty intervals—was considered by the GATHER working group to be a necessary component of reporting results, encouraged by GATHER [42]. Uncertainty ranges provide users with an understanding of the precision of the estimates, and are critical for making comparisons. However, the inclusion of the main sources of uncertainty usually requires substantial statistical expertise and computing power.

Potential sources of uncertainty include stochastic errors, sampling error, and non-sampling errors (resulting from measurement errors, missing data, errors in coverage and other systematic biases). They also include error in

model covariates, parameter uncertainty, model specification uncertainty, fundamental uncertainty and uncertainty arising from various data transformation steps and externally derived parameters [41]. In practice, most quantitative uncertainty estimates reflect only a subset of all possible sources of uncertainty in the estimates.

There is no established methodology for estimating some types of uncertainty. Analysts may use different methods, including developing new methods, or ignore the source of uncertainty and acknowledge this as a limitation of their analysis. In many cases, the data and information needed to quantify uncertainty do not exist (e.g. some sources of uncertainty may be unknown, or impossible to measure). This means that some modelling approaches have wider uncertainty than others, simply because the former may be capturing more sources of uncertainty. In general, accounting for multiple sources of uncertainty—and correctly reflecting these sources in resulting estimates—is more straightforward when Bayesian approaches are used. Uncertainty in values of covariates such as average income per capita or in denominator values such as population estimates is also typically not available and not included in quantitative uncertainty ranges for modelled health indicators.

6.2 Uncertainty Versus Sensitivity Analysis

All estimation processes involve assumptions, including about inclusion criteria for data and the functional form of a model. Some analysts may choose to use sensitivity analysis to assess the degree to which the final values of the estimates depend on these assumptions. If the sensitivity analysis suggests that various analytical approaches produce similar estimates, this lends credibility to the estimates and strengthens the results. If, on the other hand, the sensitivity analysis suggests that the estimates are highly dependent on the modelling approach or the data inclusion/exclusion criteria, this encourages readers to examine carefully the analytical assumptions, and may help to inform future research.

6.3 Transparency, Replicability and Complexity

Transparency is at the heart of controversies about global health estimates. The more diverse the available raw data, the modifications to the raw data and the statistical models, the more difficult it is for an external party to understand and replicate the findings. Also, analysts need to carefully consider the benefits of more model complexity. If their resulting estimates are

similar, a simpler model that others can more easily replicate and use is likely to be more effective than a more complicated model that can only be run and understood by a few individuals. Furthermore, while it is of value to offer greater technical documentation as per the GATHER guidelines, this alone may not be enough to inform users about appropriate interpretation. Many users may lack the technical understand the methods and their limitations. GATHER also requires a plain-language description of methods and a fair discussion of limitations, however, researchers and users may disagree about what constitutes plain language, and a frank discussion of limitations may be perceived as damaging the credibility of the estimates.

6.4 Communicating Estimates

In many cases, estimates that are largely imputed are not clearly flagged as such to users and full documentation of statistical methods is difficult to obtain or understand. Ideally, estimates are presented with uncertainty ranges or confidence intervals, but the utility of these uncertainties is often not clear to users and decision-makers. For its estimates of mortality by cause, WHO uses a four-colour coding system to indicate the strength of the underlying data and whether models and data have used mainly country-specific data or borrowed strength from other countries or covariates. More discussion is needed as to whether and how uncertainty ranges can contribute to better communication and use of estimates.

7 Divergent Health Statistics: Exposing the Limitations in Modelling and Data

For many health indicators multiple global health estimates are now available: one from the UN system and others from academic institutions. This can be of concern to international users such as donor agencies and to national governments [43, 44, 45].

Both WHO and IHME publish regular updates of estimated global deaths by cause [46, 47]. The WHO cause-of-death estimates draw on WHO and UN agency/inter-agency statistics and put them into a consistent comprehensive context for all causes. They also draw on death registration data and IHME GBD analyses for causes/countries without death registration data and where the UN system has not invested in detailed estimates. Over time, there has been some convergence between GBD and WHO estimates for some causes,

though major differences remain in some areas such as adult malaria mortality and tuberculosis cases [39].

The WHO estimates use the latest UN Population Division life tables for total deaths by age and sex, with some adjustments for high HIV countries and for countries with relatively complete death registration. The GBD model life tables differ significantly in some aspects. For example, the GBD 2015 estimated 8.0 million deaths for 2015 for the WHO African region compared with the UN providing an estimate of 9.1 million deaths. The most recent GBD update used IHME birth estimates substantially lower than the UN estimates, resulting in more than 10 per cent reduction in estimated child deaths compared with the latest UN inter-agency estimates [11]. Future revisions of the IHME GBD study will use IHME estimates of population numbers, likely resulting in additional divergences in numbers of deaths.

Like international rankings, dissonant health statistics can cut both ways. In some cases, they can be demoralising, undermining the ability or will to invest in programmes whose success is not yet reflected in global statistics. In other cases, they have led to national debate and greater national investment in data collection and analysis [48]. A critical lesson that has emerged from such debate is the need for much greater dialog between agencies carrying out global estimates and national authorities. They need to discuss the data limitations and biases being addressed through the global modelling process, and to develop a shared understanding of the strengths and limitations of both the input data and the estimates derived from global statistical models.

8 Are Modelled Estimates Helpful for Health Decision-Makers and Consumers?

Users of health statistics have different data needs. The perceived credibility and utility of different kinds of statistics vary significantly by user. National and sub-national data users often prefer empirically measured data that can inform decision-making at national and sub-national levels. Such users are less concerned about comparability with other national estimates or international standards. By contrast, global users, including international agencies, donors and development partners value estimates that are comparable across countries and over time. This translates into variations in the types of statistics that are considered most credible at different levels of governance. This, in turn, affects the likelihood that statistics will be used to inform policy.

Ways in which global estimates can be useful for countries include: comparative analyses of country values (benchmarking with peer countries); progress monitoring and reporting for global and regional goals and targets; reporting to donors and development partners, for example, for performance-based grants; and for estimating completeness and accuracy of empirical reported data.

One challenge for some users of global health estimates is that each revision typically involves a complete re-estimation of the whole time series rather than adding new values for recent years. In some cases, such as child mortality rates that incorporate survey responses with 15 or more years of historical recall, these changes to the time series are based on new empirical data and are explainable. However, in other cases, the data may remain the same, but changes to the estimation methods lead to substantial differences in the estimated series. This can cause confusion, for example, if baseline estimates change, with implications for the speed—and even the direction—of time trends and shifts away from or potentially even over final targets. While the differences usually fall within margins of uncertainty, it can be difficult to explain these changes to policymakers.

Another relevant factor is that health statistics are often used for political purposes. Globally produced statistics that differ substantially from country-reported data can be seized upon for political purposes. Governments may use favourable estimates to rally support for current policies. Conversely, unfavourable estimates bolster political opposition and civil society criticisms of the government. This makes it all the more important to ensure greater shared understanding of the reasons for global modelling adjustments to raw input data.

Global health estimates do not replace the need for countries to collect reliable, accurate and regular empirical data. However, using estimates to fill in missing data can mislead users into thinking the empirical data are available, and reduce pressure to improve information systems. Production of estimates remotely, using complex modelling techniques, may also undermine country understanding and ownership of their indicators. And in an era of global target setting, there is a danger that predicted statistics may be used for the evaluation of progress. The production of estimates should go hand-in-hand with development of tools and methods that build capacity in countries for data generation, analysis and interpretation.

9 Conclusion

In principle, it is possible to track events such as birth and death, cancer incidence and some types of injury by complete registration or surveillance systems. But most population health indicators will continue to be based on data from health information systems (which do not capture all events within populations), epidemiological studies and regular or irregular sample surveys that may rely on self-report by respondents. Synthesis of population indicators from such data will continue to require statistical modelling, though model complexity could diminish if countries adopt universal standards for regular representative sample surveys.

The increasing demand for health data for monitoring the Sustainable Development Goals [49], across a much broader range of health issues than the MDGs, may result in additional investment in good quality population health data, but this will take considerable time to achieve. The world will continue to rely on statistical modelling for almost all health indicators at global and regional levels for many years to come.

Key Messages

- Demand is high for global health statistics that are comparable across countries and time, to be used for priority setting and to monitor health systems performance.
- Reported statistics can be limited by non-standard data definitions, incompleteness and other sources of bias.
- International agencies and academic institutions use statistical and mathematical models to estimate comparable global health statistics.
- Model complexity is increasing as statistical methods advance and computing power increases.
- Good practice reporting principles are available to increase transparency and replicability of methods.

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Part V

Principles and Policies for Managing Global Health Data

Preface

In the preface to this handbook, we proposed that: 'Global health data must be trustworthy and represent populations fairly. Ideally, producers collect and manage these data consistently, economically, efficiently, ethically, and transparently, and disseminate them widely.' These are the issues that authors address in this section.

Chapter 22 examines how analysts plan data collection and assess data quality, and how users decide whether they understand and trust the findings. The authors provide tools for data producers and data users to assess data quality and information integrity. In principle, global health data should be widely available as primary and secondary data for others to use. Chapter 23 describes best practices for organisations to adopt to disseminate data for public use. The authors describe and share their Open Data Progression Model with its six stages for making data open: collecting data, documentating data, opening the data, engaging the community of users, making the data interoperable, and ultimately linking the data with other data sources.

Chapter 24 explores ethical issues associated with collecting and using data for public health, emphasising the importance of ensuring data confidentiality, establishing principles for sharing data, determining availability and ownership of data, maintaining transparency, and using routine data to monitor health equity. The authors warn that, while data facilitate health action, speed of technological advances and escalation of data availability threaten society's ability to maintain ethical principles, procedures, skills, and systems.

Finally, Chap. 25 draws the handbook to a conclusion by summarising authors' perspectives. The chapter examines the contributors to global health data and methods, their roles and how they influence global health priorities and country policymaking. The authors point to the dangers of a widening gap between information-rich and information-poor countries. They propose greater international collaboration and sharing, and long-term investments to build data infrastructures and capacities in low- and middle-income countries to redress the imbalance.

22

A Matter of Trust: Data Quality and Information Integrity

Sarah B. Macfarlane and Carla AbouZahr

1 Introduction

At the time of the 2016 Australian census, the Statistics Society of Australia criticized the Australian Bureau of Statistics for making changes to the census protocol. The Bureau had decided to maintain respondents' identifiers for four years (up from 18 months) so that they could link data with previous censuses and other data sources. The Bureau argued that the increased time period would allow them to build more comprehensive datasets and produce key indicators for government decision-making. The Statistics Society was concerned that the Bureau had not properly consulted the public about the change and warned that people might withhold their names and compromise subsequent data analyses. The president of the Statistics Society warned that the controversies 'may impact upon the quality of the data collected and may be raising unnecessary fears in the community' [1]. Following preliminary data analyses, an independent panel concluded that privacy concerns had impacted response with 1 per cent of respondents giving no name or a fake name and 3 per cent giving their age instead of their date of birth [2].

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Census data provide fundamental information about the demographic structure of society, but their integrity depends on the quality of the data their enumerators collect and process. Like other forms of data collection, censuses rely on the willingness of respondents to cooperate which, in turn, depends on their trust in the value of the data and how their data will be handled. Similarly, users of data, and information based on the data—whatever its source—need to distinguish data that are reliable and trustworthy from those that are inaccurate or misleading.

Epidemiologists describe comprehensive approaches for assessing survey quality by examining sampling and non-sampling error (see Chap. 8). The concept of *total survey error* provides a framework for describing errors that can occur during the design and conduct of a survey and how they can affect population estimates based on the data [3]. Holders of official data and statistics use similar approaches to assess data quality and information across several types of data source, including surveys, but they add dimensions that address their *fitness for use*. The Canadian Institute for Health Information (CIHI), for example, which hosts most Canadian public health data, developed a comprehensive *data quality framework* to guide data producers throughout data collection, management and documentation from a range of data sources [4]. In 2016, CIHI published a revised and renamed *information quality framework* which 'provides an overarching structure for all of CIHI's quality management practices related to capturing and processing data and transforming it into information products' [5].

We examine a common approach to assessing data and information quality across three critical data sources for health, that is, censuses, registries (with civil registration as our example) and population surveys, although the approach applies to most data sources. We provide guidance about preventing, detecting, addressing and documenting errors that can impact the quality of data and information, and we explore ways the products of data collection can be shared, combined, linked and triangulated to multiply information.

2 Producing and Assessing Quality Data and Information

The purpose of data collection—whether for a one-off survey or to maintain an ongoing register—is to describe *target* characteristics of a *target* population consisting of population units. A census aims to count an entire country's

population and describe its socio-demographic characteristics at a point in time. Civil registration intends to count all births and deaths in a defined geographic area as they occur and describe causes of death. A household survey might, for example, aim to describe the demographic structure and the prevalence of health conditions among adults in a country at a point in time.

Having established clear objectives, the programme team focusses on planning, collecting and processing data, and disseminating information based on the data. This process is never perfect. The team monitors and documents the process so that it can understand the extent to which the resulting observations actually represent the intended target characteristics of the intended target population.

The *dataset* is central to transforming data into information. During planning, the programme team aims to ensure that the dataset is adequate to provide the intended information. During data collection, the team aims to obtain data for the dataset as planned. During data management, the team aims to clean and organize the dataset so that it can be analysed. While analysing the dataset, the team aims to provide the required information. The team must defend the trustworthiness of the dataset when it disseminates information based on the data or when the team shares the dataset for secondary analysis or linkage with other datasets. Much hinges on the quality of the dataset.

In its simplest form, a dataset consists of a matrix of rows and columns. Each row (or record) represents an observed population unit, for example a newborn infant, a death or a household. Each column represents characteristic, for example birthweight, cause of death or type of dwelling. Each cell represents the value of an observed (or edited) characteristic for an observed unit (Table 22.1). Users of the dataset need to know: (1) whether the records in the rows represent the units in the target population, that is whether there are any missing, duplicated or redundant units that could bias the results; (2) whether the programme team has specified the measurements in each column correctly, that is, whether the team has used the correct instruments to measure or specify the characteristics it intends to describe; and (3) whether the cell values are correct, that is whether the enumerators have measured and edited them correctly and if there are any missing values that could bias results. Biemer developed the matrix like the one in Table 22.1 as a *total error framework* to summarize major errors that can occur for any data source, not just for surveys [6]. The extent of errors in the dataset depends on how well the programme team plans and implements data collection and processes the data, as we describe in Sects. 3 and 4.

Table 22.1 Representation of total error in a dataset

Records of units in the dataset	Measurements of characteristics Column errors: Have the measurements been specified correctly?					Rows: Do the units represent the target population?
	1	2	….			
1						Row errors: are there any missing, duplicated or redundant records?
2						
….						
Columns and cells: Do the observed values represent the target characteristics?	Cells errors: Are there any errors in cell values or any missing values?					Overall: How well does the dataset represent the target characteristics of the target population?

Adapted from Biemer [6]

3 Planning to Produce the Highest Quality Data and Information

Protocols or standard operating procedures (SOP) address why producers intend to collect data and the strategy they will employ to do so. They may describe, for example, how a civil registration and vital statistics (CRVS) system will record data on vital events or how a survey will meet its objectives. All protocols/SOP detail the context of the work, who needs the data/information and why, and how the data will be collected, managed and processed to achieve the project or programme objectives. Protocols/SOP also address ethical considerations and data security, include a budget and timeline, and describe roles and responsibilities, and how the programme team will manage and supervise data collection and processing. We focus on how the protocol/SOP attempts to ensure the quality of the dataset.

In Sect. 3.1, we examine the path by which data reach the rows of the dataset to understand the extent to which the records represent the target population. In Sect. 3.2, we examine the path by which the data reach the columns and cells of the dataset to understand the extent to which the observations represent the target characteristics. In Section 4, we examine how data processing can address some of these errors and can introduces cell and row errors. We follow Groves' survey lifecycle approach to quality [7] adapted by Zhang to include registries (Fig. 22.1) [8].

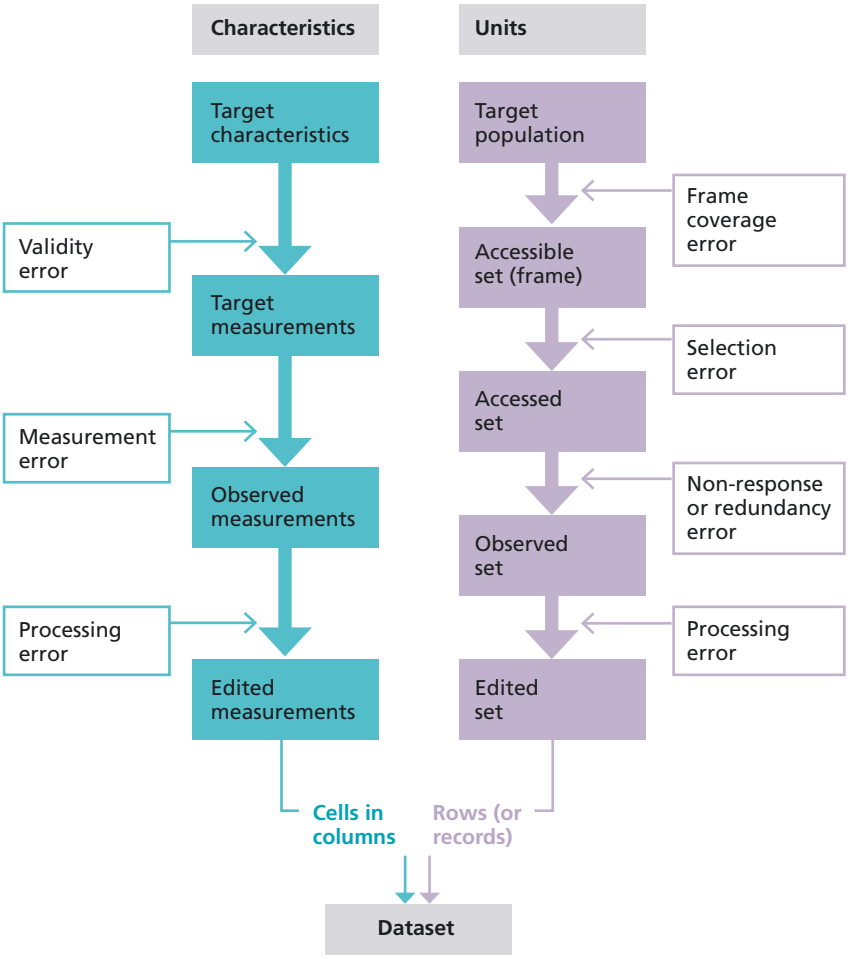

Fig. 22.1 Life cycle of data from planning to dataset from a quality perspective. Adapted from Groves [7] and Zhang [8]

3.1 Observing Units That Represent the Target Population

The protocol/SOP describes procedures either to recruit all units in the target population (for censuses and civil registration) or to recruit a sample of units that represents the target population (for surveys). There are three steps in this process. First the planning team attempts to establish a list or frame of all units in the target population, for example a list of households in a village, of census enumeration areas, or of hospitals reporting births and deaths to the

CRVS system. Secondly, the team accesses units from the frame, for example by selecting a sample for a survey, or using the complete list for censuses, or registering all births and deaths reported by the hospitals. Finally, enumerators attempt to observe the accessed units by interviewing and recording data about them. Errors occurring during each of these steps affect how completely the rows in the resulting dataset (observed units) represent the target population.

Establishing a Frame of Units in the Target Population: Preventing Coverage Error

Investigators attempt to draw up a list of all units in the target population or to describe a process to identify them. We use the term *frame* to describe this list or process. The frame is seldom complete. The frame may omit some units belonging to the target population (*under-coverage*) or contain redundant units that do not belong to the population or are duplicated (*over-coverage*). Thus the frame contains a list of accessible population units which are not necessarily the same as the units in the target population. The difference between the units in the list and the units in the target population results from coverage errors.

Under-coverage in a survey is when an investigator prepares a frame of villages in an area but omits some that have not yet been mapped, thus excluding those villages from being sampled. Over-coverage occurs when the list duplicates some villages giving them a higher chance of being selected. Under-coverage occurs in a census frame if organizers omit dwellings or enumeration areas from the frame. Under-coverage of births and deaths is a major problem for CRVS in low- and middle-income countries where registration systems are not available to the whole population, for example, ethnic minorities may be excluded from registration (see Chap. 7).

In developing the protocol/SOP, the planning team needs to assess the quality of alternative frames regarding the extent of coverage errors they might introduce and choose the frame that minimizes anticipated coverage error. Since the census frame, which attempts to locate all dwellings in a geographic area, also serves as a frame for CRVS and sample surveys, it is essential that the census team maintains it between censuses. Once the team has selected a frame, it should document the possibility of different types of coverage errors and assess the likely impact of these errors on the team's ability to describe the target population. If the team documents potential coverage errors, data analysts can take them into account during processing.

Accessing Units from the Frame: Preventing Selection Error

The programme team selects units from the frame for surveys and attempts to include all units for censuses and CRVS but either way this process introduces selection errors. For surveys that use random sampling, investigators select a sample from a *sampling* frame. This introduces *sampling error* which analysts use during data analysis to estimate indicators based on the data. To be able to describe the sampling error, the protocol must specify a procedure that ensures that every unit in the population has a known probability of being selected. Investigators' choice of sample size will affect the sampling error; the larger the sample size the smaller the sampling error. Chapter 8 describes the basics of sampling for surveys, or the reader can refer to an epidemiology textbook [7].

Selection errors can also occur when accessing units for censuses and registries. Since these errors are not usually planned as they are for random sampling, they can bias the dataset. In a census, for example, enumerators may exclude a street or village mistakenly or intentionally, although the SOP usually elaborate procedures to prevent this from happening. Alternatively, census forms may get lost in the mail and not reach the intended households. Similarly, in CRVS, certain hospitals may not systematically notify the civil registration system of the occurrence of a vital event. Such errors are difficult to take into account in the analysis since they are not random. This is also true for surveys that do not use random sampling, for example, when investigators select units *conveniently, consecutively or* interview *volunteers.* Investigators drawing up a protocol/SOP should seek to minimize unintended selection errors or, if intended, describe how they could impact their conclusions.

Observing Accessed Units: Preventing Non-response and Redundancy Error

Well-trained enumerators intend to observe all selected units but this is not always possible. *Unit non-response* occurs when selected units do not participate in the survey or census as planned, for example, survey enumerators are unable to interview heads of households, no one is present in the household, or the potential respondent declines to participate. Non-response is an increasing problem for household surveys (see Chap. 8). To reduce non-response, investigators should plan to visit households when participants are likely to be there and explain the purpose and benefits of the study very carefully.

Although in most settings householders are legally obliged to participate in censuses, they may omit people who should be included in the household on

that day. In countries where civil registration doesn't function well, many people do not present themselves at the civil registry office to register births and deaths even though the system exists, in which case registration is described as incomplete. Chapter 7 describes ways in which civil registration systems can enhance registration, for example, through legislation, improved service provision, and by promoting the value of birth and death registration. Over-response is also possible, but less common, for all these data sources. In a census, the same person may be listed in two dwellings, for example, a child whose parents live in different dwellings and both include the child on their respective forms. Births and deaths can be counted twice when hospitals and the relatives report the same birth/death. Relatives may report twice if they are unsure the event has been registered, forget they have already registered the event, or if they register at both place of occurrence and place of usual residence.

3.2 Collecting Valid, Accurate and Complete Measurements: Preventing Validity and Measurement Errors

The protocol/SOP describes the way in which an enumerator, registrar or respondent will make and record each observation or measurement aiming to ensure that all are valid, accurate and complete. The best way to avoid these errors is to adopt or modify standardized questionnaires and measurement tools that have been tried and tested. This will also help to ensure that measurements are comparable to those in other datasets collecting similar data.

The protocol/SOP itself controls the *validity* of each measurement, that is, the extent to which the technique the enumerator will use to measure a characteristic actually measures what it is intended to measure. For example, if the team wishes to measure height and weight but instructs enumerators to measure participants with their shoes on, they will not measure the actual height or weight of each individual. Similarly, if the programme team wants to measure age but does not specify that enumerators should collect information on exact date of birth, the resulting data will be a poor approximation for exact age.

Measurement errors occur when enumerators do not take measurements as instructed or a when a respondent does not answer questions correctly. This can result in incorrect or missing values (*item non-response*). Programmes can

reduce measurement errors by only observing characteristics that are essential to their objectives thus keeping the questionnaire/interview short. Protocols/SOP should detail thorough training and guidance for enumerators, and plan to pilot questionnaires and procedures to test instruments, and resolve ambiguities in questions and definitions. Enumerators can reduce missing values by carefully explaining the purpose of data collection to potential respondents.

If enumerators or registrars record information within a short period of the occurrence of an event or activity this reduces problems of data recall errors and can increase the accuracy of the data collected. Household surveys, for example, ask about recent health-related events or health-related behaviour. The time frame will depend on the nature of the event/behaviour but may extend from the previous month (tobacco use) to the previous three years (use of antenatal care). CRVS systems have a legal basis that makes registration compulsory for all people living in a defined area and aim to register births and deaths as they occur, usually within a maximum of 30 days, to maximize accuracy and minimize missing information items (see Chap. 7). If relatives report late, for example when a birth certificate is needed for entrance to secondary school, they may not give the correct date of occurrence.

Inaccuracies can also stem from failure to apply uniform standards when recording information. Even though, in principle, trained physicians attending hospital deaths determine cause of death using international standards, cause-of-death data are often problematic due to excessive use of so called *garbage codes,* that is, ill-defined or vague and unspecific causes of death (see Chap. 7). WHO estimates that the percentage of garbage codes is below 10 per cent where CRVS functions well and deaths are routinely medically certified by trained physicians, but over 30 per cent in settings where CRVS functions less well and physicians are not so well trained in how to complete the medical certificate of death, such as in Azerbaijan, Bahrain, Egypt, Georgia, Oman, Saudi Arabia, Sri Lanka and Thailand [9].

4 Checking, Cleaning and Processing the Dataset and Preventing Processing Errors

Whether data managers continually update data for civil registration or they collect data for a one-off study, they must check for deviations from the protocol/SOP and search for errors that occur during data collection. When

enumerators record data manually on questionnaires, their supervisors may check for specific types of error, and data managers look for further errors as and after they transcribe the data into a database. When enumerators collect data on electronic devices such as smartphones or tablets for direct transmission to the database, integrated software can recognize and query errors at the moment of data capture.

After data capture, data managers use standardized procedures to clean the dataset, that is, to detect and correct or remove incomplete or inaccurate records. They aim to ensure the dataset is consistent with other similar datasets and conforms with data quality standards. They screen the dataset looking for oddities such as data gaps or duplications, outliers, inconsistencies, and unexpected patterns and results. Data cleaning may be limited to removing typographical errors or involve harmonizing, standardizing or imputing values for erroneous observations. Most database and statistical software—for example, Epi Info™, SPSS and STATA—incorporate (sometimes dual) data capture and data cleaning tools. The data processing itself introduces errors which should be monitored and flagged when checking and cleaning the data.

4.1 Checking and Cleaning Data Records

The magnitude and distribution of response errors across population subgroups indicate the overall quality of the dataset. Examination of duplicated records against eligibility criteria will identify units that were wrongly included in the dataset. Missing records can be identified from the complete list of selected units that the team intended to observe. Redundant records (carefully checked) can be removed from the dataset, but missing records can introduce bias. In routine, ongoing data collection systems, duplicate records may occur due to the use of different spellings of names, unclear addresses, and absence of clear and unambiguous identifying characteristics. The use of a unique identification number in every registration record and associated certificate can help avoid this.

4.2 Checking and Cleaning Data Items

Ideally, the protocol/SOP, associated training and supervision of data enumerators, and automatic data capture procedures will keep data errors to a minimum. In practice, errors always occur and are often not apparent until the dataset is examined.

Typical measurement errors include: (1) values that are wrong, impossible, or missing, for example, incorrect dates or implausible coding; (2) values that fall outside the measurement range, for example, a haemoglobin count of 2 grams per decilitre or an adult height of 0.5 metres; (3) values that are inconsistent with other data items, for example, a child whose weight is impossibly low for its height, or a child of five years attending secondary school; and (4) measurements that are inconsistent between enumerators or coders over time, that is they consistently take the measurements or ask the questions differently from each other.

Age heaping commonly occurs in situations where respondents don't have birth certificates or when enumerators accept rounded ages instead of obtaining dates of birth. Heaping can occur for any measurement, for example, if weight recorded in kilograms to only one decimal point shows last digit preferences for zero and five, this would indicate that enumerators have measured weights poorly. Heaping is easily identified by looking at the distribution of the last digit (which should be evenly distributed). Heaping is best assessed during a pilot and rectified by giving enumerators further training or by using a different method of measurement. Demographers have developed indices for measuring age heaping and then accounting for them in their analyses (see Chap. 17).

Data managers must follow rules in dealing with missing values; and if they have corrected or imputed any values, they need to document what they have done. They have to decide what to do with problematic data. The options are to delete the data points, to correct them or to leave them unchanged. When a data point is biologically impossible—for example, a maternal death in a male—it should either be corrected or deleted. It is sometimes possible to recalculate data that have been poorly coded, for example, redistributing cause of death data that have been assigned to garbage codes [10]. Van den Broeck et al. provide advice about data cleaning, presenting it as a 'three-stage process, involving repeated cycles of screening, diagnosing, and editing of suspected data abnormalities' [11].

Box 22.1 illustrates how Demographic and Health Surveys (DHS) check for the quality of captured records and data items.

Box 22.1 Demographic and Health Surveys: Data Editing and Quality Assurance [12]

- Questionnaires are checked when they first arrive from the field, for the correct numbers of questionnaires and selection of eligible respondents. Responses that are open-ended (such as 'other' responses) or those that require coding (such as occupation) are also coded at this point.

- All questionnaires are checked after data entry to ensure that all that were expected were in fact entered. The numbers of questionnaires are also checked against the sample design.
- All questionnaires are entered twice and verified by comparing both data sets. All discrepancies are resolved.
- The entered data are checked for inconsistencies and where possible, they are resolved. Some missing data, such as dates of events, are imputed where possible.
- A set of quality control tables is generated on a regular basis. These tables indicate potential problems in the field. The tables include information on response rates, age displacement, and completeness of data. This information is then relayed to the field teams to help them improve the quality of data in the field.

4.3 Assessing the Overall Dataset and Making Adjustments During Analysis

Once the dataset has been cleaned, the data are available to produce basic tabulations and indicators. This is another opportunity to check information quality, for example, by checking the consistency of indicators with similar indicators based on datasets from previous years or based on other datasets. Analysis at this stage can also assess the possible impact on the findings of errors anticipated from the frame or discovered during data checking and to make adjustments to estimates, if that is possible. This is the time to return to the original question: how well does the dataset represent the target characteristics of the target population?

To check for bias caused by non-responders, analysts can compare any of their known characteristics with those of responders. This is difficult since non-responders by definition don't answer questions, but it may be possible to compare publically known demographic characteristics of the person, type of household or geographic area (obtained perhaps through the frame). The non-responder or a relative may have given a reason for their absence or refusal which can be helpful in understanding non-response. Documentation of the dataset must include a full description of response rates by important subgroups, such as those living in remote areas, persons without a fixed address, minorities, ethnic groups and so on. By definition, and by law, both the census and CRVS systems should cover all persons residing in the country or territory, irrespective of nationality. Special studies may be required to assess the extent to which such groups are excluded from the census or CRVS systems, whether for *de jure* or *de facto* reasons.

Item non-response can introduce bias for missing measurements. It is easier to assess the bias their absence might have introduced by comparing key information from their records with information from the records with a recorded value, for example, whether age was missing more often for units in rural than in urban areas.

When data collection includes all population units—as intended for censuses and CRVS systems—and depending on the assessed accuracy of the measurements, the indicators calculated from the data will be the *true* population values (as measured by the SOP) at that time or period. If there are gross measurement and coverage errors, the indicators could represent another population.

For sample surveys, the calculated indicators are estimates of the *true* population values. If the survey team has used probabilistic sampling, it can measure the uncertainty around the estimate usually expressed as a confidence interval. Again, gross measurement and coverage errors could affect the population that the survey describes. At this point, it is important to assess the uncertainty around the estimated indicators and assess if they are of an acceptable width to allow conclusions to be drawn. If investigators have over-sampled certain sub-groups, then they must weight estimates during processing to reflect the true proportions of each sub-group in the population.

Most census offices undertake a *post-enumeration survey* (PES) to assess the census population count. They conduct a sample census in a random sample of areas and observe the differences between this count and the census count. They then adjust the reported census count. For example, Statistics South Africa conducted a PES after its 2011 census. The uncorrected census population count was 42.51 million people, but the PES indicated that this figure omitted 6.29 million people, so the final count became 49.79 million people (indicating a net undercount of 14.6 per cent). They also used the PES findings to assess the content quality of key characteristics such as age and sex [13].

5 Additional Criteria for Assessing Data and Information Quality

All data quality frameworks focus on the extent to which the dataset reflects what it is intended to measure. These are issues that concern data producers, but users are also concerned about other quality dimensions of the dataset. The CIHI, for example, orients its information quality framework around *fitness for use*; seeking 'to ensure a level of quality relative to the intended use of the information.' CIHI considers data and information fit for use if they

satisfy the needs of users ranging from health system planners through healthcare providers and researchers. The CIHI information quality framework [5] assesses and rates the quality of information using dimensions (Box 22.2) based on the United Nations Statistical Commission's [14].

Box 22.2 Dimensions by Which the Canadian Institute for Health Information Assesses Information Quality [5]

Relevance:	Does the information meet users' current and potential needs?
Accuracy and reliability:	Does the information correctly and consistently describe what it was designed to measure?
Comparability and coherence:	Is the information consistent over time and across providers, and can it be easily combined with other sources?
Timeliness and punctuality:	Is the information current and released on schedule?
Accessibility and clarity:	Is the information and its supporting documentation easily accessed and clearly presented in a way that can be understood?

Mahapatra et al. provide an assessment framework for vital statistics from civil registration systems, demonstrating how the dimensions in Box 22.2 can be used to assess vital statistics and cause-of-death statistics [15]. Statistics South Africa illustrates their use in its report of 2015 death notifications [16].

An additional essential trust dimension is security, that is, protection of data or information from unauthorized access or editing. All institutions handling personal data must ensure that they protect and de-identify, where necessary, all personal data and that they publish and monitor their procedures for maintaining data confidentiality. The CIHI complements its information quality framework with a *Privacy and Security Risk Management Framework* to 'ensure CIHI protects the privacy of Canadians and maintains the confidentiality, security and integrity of their personal health information throughout the life cycle' [17].

Guidelines are available for maintaining key data sources and for assessing data quality and information integrity, including for census [18]; CRVS [19, 20]; household surveys [7]; routine health information systems [21–23]; surveillance of communicable [24, 25] and non-communicable diseases [26]; and for research studies [27, 28].

6 Documenting the Products of Data Collection

The major products of data collection are the dataset and any reports based on analysis of the data. Thorough documentation allows others to understand and assess quality and further analyse the data using more sophisticated techniques.

6.1 Documenting the Dataset

Whether the data are for the sole use of an investigating team or to be made publically available for others to analyse, datasets must be well-documented with data organized and stored in an accessible format—with clear description, or metadata (see Chap. 23). Standardized and consistent metadata standards are essential for data sharing. The Organization of Economic Co-operation and Development (OECD) Health Statistics publication, for example, links to a comprehensive metadata dictionary that covers data definitions, sources and methods for all the indicators [29]. The United Nations maintains a metadata dictionary for Sustainable Development Indicators [30].

The CIHI suggests that data managers document a metadata repository under the following headings: (1) description of the dataset with detailed background information about the context in which the data were collected; (2) criteria for selecting the units of observation; (3) methods of data collection and capture; (4) data processing procedures including description of data editing; (5) any data analysis and dissemination already undertaken; (6) details of data storage; and (7) all relevant documentation dealing with data quality [4].

Although post-collection data errors occur in all datasets, data managers rarely describe their data cleaning processes, especially for routine data collection activities [31]. To enhance the users' trust, data managers should specify how they have cleaned the data to address problems such as miscoding and follow rules in dealing with missing values; and if they have imputed any values, they need to document what they have done. This helps reassure data users of the integrity of the data and absence of manipulation.

Data producers may not publish data reports because they don't want to reveal poor data quality. We consider this to be a mistake. Data producers are more likely to gain the trust of data users if they are transparent about data limitations. And nothing is more conducive to improving data quality that making information available and throwing the light of day on the dark corners

of a dataset. For example, the 2015 Statistics South Africa report of mortality and causes of death is explicit about data quality limitations [16].

6.2 Documenting Information Based on the Dataset

Most reports based on these data sources present information quite simply as trends in indicators disaggregated by population sub-groups, time and space. Census reports publish the actual breakdown of the counted population by age, sex, enumeration area and provide further tables depending on the census questionnaire (see Chap. 6). Civil registration reports provide estimates of birth rates and death rates by age, sex, and cause, broken down by socio-demographic and geographic areas (see Chap. 7). National household surveys publish detailed cross-tabulations and estimates for specific population sub-groups. Reports should include tables showing non-response and missing values and summarize and assess the likely impact of any errors introduced during data collection and cleaning.

Tables provide the most detailed information, but diagrams can illustrate distributions of indicators between key groups, across time and by geographic area. Most people find simple visual presentations such as charts and maps easier to understand than large tables or long lists of numbers. Other chapters in this handbook illustrate line graphs (Chaps. 6, 7, 9,17), population pyramids (horizontal histograms) (Chap. 6), bar charts (Chap. 11), maps (Chaps. 12, 15, 20) and results of predictive modelling (Chaps. 19, 20, 21). However, there are many ways that visuals provide misleading information, whether deliberately or, as is more often the case, unintentionally [32].

The basic principles for interpreting both tables and diagrams are to ascertain: (1) the number of units on which the table/diagram is based; (2) whether there are any missing values and how they are distributed among sub-groups; (3) how percentages were calculated (using the total number of units, or numbers in sub-groups in their denominators); (4) the range or standard deviation of indicators expressed as averages (for example, average blood pressure); and (5) for diagrams, check the scales of each axis and whether there is any break in the axis that could misrepresent findings. Reference materials are available to guide the presentation of demographic and epidemiological information [33].

Sophisticated software makes it easy to produce charts, maps and innovative visualizations but a balance must be struck between design and function; complicated visualizations can fail to communicate [34]. Infographics are increasingly used to convey information that tells a story using easy to understand visuals and minimal text. Major challenges are how to present probabilities and uncertainty, particularly when users have different levels of statistical

literacy. Spiegelhalter et al. offer some sound advice on ways of visualizing uncertainty that are relevant to charts and figures in general [35]. Chapter 20 of this handbook shows how predictive maps incorporate uncertainty.

Uncertainty accompanies all data collection activities but cannot always be measured. However, sample surveys are designed to describe uncertainty. For example, the Nepal DHS 2016 estimated 95 per cent confidence intervals for neonatal mortality to be from 16.5 to 26.4 deaths per 1,000 live births in urban areas—that is, there is a high probability that this range contains the true neonatal mortality rate for the target population in urban areas. The study also estimated 95 per cent confidence intervals for rural areas to be from 26.0 to 39.7 deaths per 1,000 live births. There is very little overlap between the two ranges, suggesting that neonatal mortality is higher in rural areas [36].

All reports or papers should provide the context for the data collection. A conflict of interest statement can enhance users' trust in data, whether derived from routine data collection or from special studies and surveys. These statements can be particularly sensitive in areas where the interests of public health and of private sector businesses intersect. For example, in 2017, the World Health Assembly called for a consultation to bring together representatives from health, industry, NGOs, governments and civil society to examine ways of 'addressing and managing conflicts of interest in the planning and delivery of nutrition programmes at country level.' [37]

7 Sharing and Combining the Products of Data Collection

We have described processes for checking and documenting the quality of data products before their release. Not all users have the technical knowledge to critically review these products, but they can work with their technicians to satisfy their conclusions about the quality dimensions described in Box 22.2. Users can then combine and triangulate these data and information with those from other products, of which there are many!

Opening and Linking Datasets The Open Government movement encourages governments to make data publically available either as datasets or as indicators (see Chap. 23). Websites collate data from specific types of data across the world, for example, census data are available in one place [38] as they are for DHSs [39]. Researchers undertake more sophisticated analyses of individual or combinations of published datasets and so multiply available information. Fabic et al. reviewed 1,117 peer-reviewed papers based on DHSs published

between 1985 and 2010 and noted a progressive increase in the number published each year with a widening range of topics. They also noted an increase in publications that analysed multiple surveys either across time or across countries (representing 34 per cent of all the publications) [40].

Triangulating Data and Information Ministries need to compare indicators across different sources both to validate specific indicators but also to gain more insight into a specific issue. Rutherford et al. describe a triangulation approach which they have used to understand the dynamics of HIV transmission and to measure the impact of public health programmes. They define *public health triangulation* as 'the process of reviewing and interpreting existing data and trends in those data from multiple data sources that bear on different facets of a broad public health question in order to identify factors that underlie the observed data and to assist with public health decision-making and actions.' [41] Rutherford et al. describe steps from framing questions, through identifying, gathering, and reviewing data and interpreting and using the results to inform public health action. Qualitative and quantitative data include primary and secondary information from censuses, surveillance, public health programmes and results of local research studies. They emphasize the need to check for data quality in the way we have described, and they warn about the dangers of analysing trend data without an underlying model (*ecological fallacy*), dredging data without a hypothesis and ensuring the reproducibility of results.

Estimating SDG Indicators Since 1980, WHO and the United Nations Children's Fund have used triangulation to annually review data to estimate national immunization coverage. They do this by reviewing government reports and survey findings from published and unpublished literature, and in consultation with local experts and programme managers. They publish the estimates after feedback from national authorities [42]. In Chap. 21, Mathers et al. describe more complex statistical methods of bringing together disparate data to come up with indicator estimates, and in Fig. 21.1, they demonstrate the many sources used to estimate child mortality estimates in Nigeria from 1964 to 2017. Murray uses the term *systematic review* to describe the process of reviewing and using all available quantitative data and attempting to reconcile differences between data sources [43].

Combining Products with Big Data With burgeoning amounts of data now in the public domain, the discipline of data science has emerged. Data science is the process of finding, developing and communicating actionable information that stems from multiple sources, including from social media. For

instance, data science might bring together information from household surveys, routine health information systems, censuses and non-traditional sources like Facebook activity, Google searches, tweets and mobile phone data with the purpose of ascertaining people's health-seeking activities (see Chap. 16) modelling disease outbreaks (see Chap. 10) or predicting the effects of health interventions. Data scientists use *big data* which is defined by its *variety*, *velocity* and *volume*. Compared to the data we have described which are collected by *design*, big data are *found*, and so the same rules of analysis and interpretation don't necessarily apply [44].

We have suggested rigorous ways of checking designed data but what about the quality of found big data? Biemer [6] and subsequently Japec et al. [44] explore evolving Table 22.1 to become a Big Data Total Error Framework. Although big data do not arrive in matrix form, data scientists reduce them to such for analysis. To illustrate some data quality issues, we expand on one of Japec et al.'s examples. Suppose a data scientist decides to describe opinions of a population in a geographic area by harvesting Google searches made from *URLs* based in that location during the past week. Row errors would result from people being excluded because they didn't have Internet access (undercoverage), people conducting many searches (redundance) or searches being conducted by a robot not a person (ineligible). Column errors of misspecification could include inappropriate classification of phrases used in the Google search. Cell errors are similar to those in any other form of data collection, for example, misclassification or miscoding, and wrong content when people meant something different to what was recorded, and missing values such as people not including certain terms in their search.

8 Conclusion

We have described criteria for maintaining and assessing the quality of data and information but even adherence to the highest quality standards does not necessarily engender the user's trust.

The OECD has developed survey modules for countries to assess the public's trust in official statistics [45]. They suggest that trust in official statistics depends on trust in both the statistical products and the institution producing them. The OECD uses criteria similar to those in Box 22.2 to assess data products but they suggest that trust in the institution producing them depends on: the extent to which they are or are perceived to protect data confidentiality and operate impartially without political interference; produce statistics openly and trans-

parently; and maintain an honest relationship with the public and other key stakeholders. The latter includes the institution disseminating information about how and why it collects data, holding regular consultations, listening to criticism, correcting erroneous data and publically addressing misleading media reports.

External factors also influence the public's trust in data and these include the political environment. As we write, the United States is planning to introduce a question about citizenship into its 2020 census and to report these data by census block—which could be an apartment building. People are threatening to *#LeaveItBlank*. Despite all the checks we have described, and the privacy and security commitments that may be in place, the quality of data and information depend on the population's trust in the institution collecting the data, and in the government that finances and plans to use the results.

Key Messages

- All datasets are prone to errors that arise during data collection, design, implementation, compilation and analysis.
- Methods are available to prevent and manage errors so that users can be confident in the integrity of the information.
- Data producers should provide detailed metadata for each dataset and document the methods they used to maximize data quality.
- Data producers and analysts are responsible for building and maintaining trust in statistics as a global public good.

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Opening Data for Global Health

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1 Introduction

Dengue fever has been endemic in Paraguay since 2009. The Pan American Health Organization reported that there were over 173,000 probable cases in 2016, with 48 severe cases and 16 deaths from dengue. Recognizing the need for a robust system to warn the public of dengue-related dangers, the Direccion General de Vigilancia de la Salud (DGVS) made its dengue morbidity data openly available. Researchers at Facultad Politecnica-Universidad de Asunción worked with the data and provided DGVS with an early warning system that predicted dengue outbreaks a week ahead with an accuracy of 95 per cent [1]. This example demonstrates the catalytic value of making data open. By publishing its dataset, the DGVS potentially saved lives.

What are open data and why do they matter? The Open Knowledge Foundation [2] defines data as open 'if anyone is free to access, use, modify, and share it—subject, at most, to measures that preserve provenance and

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openness.' Open data share deep philosophical roots with other open movements, including the open source, open access, and open science movements. These movements believe that putting more resources and work in the public domain for others to use freely in a manner consistent with The Open Knowledge Foundation's definition will accelerate research and development on a global scale. Leveraging the work of others has led to historical breakthroughs; Newton said 'If I have seen further, it is by standing upon the shoulders of giants' [3].

Our purpose in writing this chapter is to assist health practitioners increase the quantity and quality of open data programmes to stimulate problem-solving on a global scale. We start with an overview of the development of the accelerating open data movement and emphasize its relevance and timeliness. We describe the role of open data in health and how such data have contributed to saving lives and improving public spending in health.

While much health data are open, there is little guidance about how to publish and promote new datasets. In Sect. 4, we provide a framework which we have developed—the *Open Data Progression Model*—to assist governments and organizations walk through the procedures and best practices of preparing and publishing open data. We discuss challenges facing the open data movement especially in health, but we emphasize that the value of making data publicly available is not theoretical; the movement has a proven track record of making an impact in material ways.

2 The Open Data Movement

The open data movement has roots in open access reforms spanning back to Ancient Greece, [4] and more recently in the open science movement which started in the 1950s, [5] but it only manifested in a modern technological sense in this millennium. The term *open data* first appeared in an American scientific agency document in 1995, [6] and the movement took a quantum leap forward in the early 2000s with the increased contribution of technology thought leaders to the open government movement [7].

Several recent developments have built momentum in the open data movement. In 2004, the Science Ministers of the Organisation for Economic Co-operation and Development (OECD) signed a declaration that data from all publicly funded efforts should be publicly available with consideration for 'the need for restriction of access in some instances to protect social, scientific and economic interests' [8]. In late 2007, 30 open government advocates with global interests met in the US, including technology and gov-

ernment policy notables Tim O'Reilly and Lawrence Lessig, to formulate the *8 principles of open government data* which provided a major catalyst and framework for the open data movement (Box 23.1) [9]. In 2009, on the first day of his first term, US President Barack Obama issued his *Memorandum on Transparency and Open Government* [10]. This marked his commitment to 'an unprecedented level of openness in Government' which would eventually include the launching of *data.gov* as a public repository for federal government data and the passing of the Data Act focussed on transparency in federal expenditure data. Within a similar timeframe, the UK launched *data.gov.uk*, providing another example of a progressive government setting a standard around data transparency and accessibility.

Box 23.1 Open Government Data Principles [9]

Government data shall be considered open if it is made public in a way that complies with the principles below:

1. Complete: All public data is made available. Public data is data that is not subject to valid privacy, security, or privilege limitations.
2. Primary: Data is as collected at the source, with the highest possible level of granularity, not in aggregate or modified forms.
3. Timely: Data is made available as quickly as necessary to preserve the value of the data.
4. Accessible: Data is available to the widest range of users for the widest range of purposes.
5. Machine processable: Data is reasonably structured to allow automated processing.
6. Non-discriminatory: Data is available to anyone, with no requirement of registration.
7. Non-proprietary: Data is available in a format over which no entity has exclusive control.
8. Licence free: Data is not subject to any copyright, patent, trademark, or trade secret regulation. Reasonable privacy, security, and privilege restrictions may be allowed.

Since 2007, thousands of national governments, non-governmental organizations, international governing bodies, research organizations, special interest groups, and local governments have embraced the open data movement. As of 2017, over 2,600 open data portals are available on the Internet [11] sharing millions of datasets. Resources like the Open Data Barometer actively track and score the progress and quality of over 100 open data programmes. Open data standards and collective commitments adopted internationally such as the G8 Open Data Charter [12] are proof that opening data is a shared prerogative worldwide.

So what is the value of all these open data? Advocates cite that in addition to improving government efficiency and transparency, they reduce corruption [13] and advance public policy analysis and formation by enabling the participation of citizenry. Furthermore, open data spur innovation and development of improved or new products and services in the private sector. A study by McKinsey & Company found that open data have the potential to generate more than $3 trillion a year in economic value across the education, healthcare and transportation sectors, among others [14]. Notwithstanding such assertions, not all datasets are equal when it comes to openness; in practice, some data are more open than others, and nowhere is this most apparent than in the health sector.

3 Open Data in the Health Sector

In the health sector, the open data movement has grown in parallel with the concept of *big data* [15, 16]. The latter refers to very large datasets, for example, those generated by linking data from electronic patient records, social media, and personal devices. Open data systems promise many opportunities ranging from generating early warning for outbreaks and pandemics, through offering personalized medicine to individuals, to supporting health system management. Box 23.2 illustrates Burundi's use of open data to introduce results-based financing (RBF) to improve the performance of its health system.

Box 23.2 Burundi's Open Results-Based Financing (RBF): Making Health Spending and Performance Transparent

Stefaan G. Verhulst and Andrew Young; Full case study is available at odimpact.org

Burundi was one of the first African countries to introduce RBF in the healthcare sector. RBF is an instrument that links development financing with predetermined results. Funders make payment only when providers have shown that they have achieved the agreed-upon results. Open RBF [17], a platform for opening data related to RBF initiatives, has been central to the Burundian Ministry of Health's efforts to strengthen accountability and quality in health care. Although the overall state of health care in Burundi remains poor, there are encouraging signs of improvement within RBF programmes, in particular that suggest the positive impact of Open RBF towards, for instance, reducing cases of severe malaria.

There are varying degrees of openness of health data, namely: open data files which anyone can freely download and analyse; restricted files which

people must request permission to download and use; and data that users can only interrogate using an analytic tool available on the website. The most restrictive categories apply to datasets that comprise individual health-related records of disease incidence/prevalence, treatment, compliance, and outcomes. Data providers remove individual identifiers before rendering the data available to external users. Health data may be: anonymized survey or research records of people, health events, specimens, households, facilities, resources and so on; linked anonymized patient records and specimens from health facilities and registries; aggregated data such as mortality rates or numbers of health workers per hospital, district, or country; or assorted information gathered and linked through social media or crowd-sourcing platforms. Health-related open data are abundantly available from their sectors, for example, census data, economic, employment and education survey data, and considerable climate data (see Chap.14). Files of open health data are available on data.gov websites, academic journal websites, institutional websites, United Nations agency websites, or general purpose websites. We provide just a few examples which demonstrate the value and potential for open data to make a difference in global health.

Monitoring and Surveillance of Infectious Diseases Our opening example demonstrates how researchers used anonymized data published by the Paraguayan government to predict dengue outbreaks. In the UK, Public Health England publishes weekly the number of methicillin resistant staphylococcus aureus infections in UK hospitals over a rolling 12-week period on data.gov.uk. Using these data hospitals can compare figures and share best practices. Box 23.3 demonstrates how a group of humanitarian agencies collaborated to share data to respond to the Ebola crisis in Sierra Leone.

Box 23.3 Battling Ebola in Sierra Leone: Data Sharing to Improve Crisis Response

Stefaan G. Verhulst and Andrew Young; Full case study is available at odimpact.org

In 2014, the largest Ebola outbreak in history occurred in West Africa. Efforts to combat the epidemic were hampered by limited information sharing between national governments, aid organizations and front-line actors like the rural health clinics that often bore the brunt of the crisis. Even the most basic information—for example, the number of cases or deaths—was hard to come by, making it difficult to assess the severity of the epidemic and target interventions.

Some (open) data-driven initiatives sought to increase and improve the quality of information available to those working to address the crisis.

Humanitarians on the ground noted that in some parts of Sierra Leone, traditional mapping tools like Google Maps were largely incomplete, and until the release of open geospatial data, the only way to find a certain village or the closest health treatment centre was to drive around asking for directions. Sierra Leone's National Ebola Response Centre (NERC), the United Nation's Humanitarian Data Exchange (HDX) and the Ebola GeoNode played important roles in making accessible and actionable important open government and crowd-sourced data to improve the response. Geospatial information—often collected through OpenStreetMap—supplemented and used by NERC, HDX and the GeoNode helped responders make difficult decisions on how to deploy scarce resources. Together, these efforts showed the potential of leveraging open data not just for Ebola response, but for addressing humanitarian crises more generally.

Linked Clinical Data The Danish National Patient Registry (DNPR) demonstrates the potential for linking patient data and making them available for research, under strict conditions of individual confidentiality. DNPR collects longitudinal administrative and clinical data for patients discharged from Danish Hospitals, including, for example, over eight million people between 1977 and 2012. According to Schmidt et al. 'The DNPR data are linkable at the patient level with data from other Danish administrative registries, clinical registries, randomized controlled trials, population surveys, and epidemiologic field studies—enabling researchers to reconstruct individual life and health trajectories for an entire population' [18].

Cross-sectional Government Health Surveys Countries that maintain data.gov websites usually publish national health survey data for researchers to analyse. For example, the US Behavioral Risk Factor Surveillance System undertakes telephone surveys of US residents about their risk behaviours, chronic health conditions, and use of preventive health-care services. The system completes more than 400,000 adult interviews annually, 'making it the largest continuously conducted health survey system in the world.' The data are openly available on data.gov for users anywhere in the world to access [19].

Cross-sectional and Longitudinal Survey Data from Multiple International Sites The USAID-funded Demographic and Health Surveys (DHS) Program has collaborated with over 90 countries to undertake more than 300 cross-sectional surveys over 30 years [20]. Every survey uses the same set of questionnaire modules, with common metadata and statistical analyses. This standardization has enabled the DHS programme to espouse the principle of open access to data from the start. Datasets are freely available on completion of a short registration form, and the DHS website provides a customized tool

to analyse aggregated indicators within or across surveys [21]. Box 23.4 describes the INDEPTH Network repository of longitudinal surveillance data collected by multiple independent research centres. Because each centre is independent, with its own priorities and data collection activities, combining the various datasets to permit comprehensive analysis across sites was challenging.

Box 23.4 Establishing the INDEPTH Data Repository

The International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) has created a data repository which contains 'the largest dataset on cause-specific mortality in LMICs ever published' [22, 23]. The repository contains harmonized longitudinal datasets of health and demographic events in geographically defined populations studied by the network's research centres in 20 countries across Africa, Asia, and the Pacific region.

INDEPTH documents every dataset in the repository using an internationally accepted metadata standard by the Data Documentation Initiative, and digital object identifiers are assigned to all the datasets to aid citation [24]. By 2015, the core micro datasets in the repository included data from 25 centres representing 2 million individuals and 24 million person years of observation.

The INDEPTH Data Access and Sharing Policy identifies several levels of access to the shared network data depending on its sensitivity, that is: open access (the user doesn't have to be logged in to analyse aggregated data); licenced access (the user must log in and register to download publically use data files); restricted licence access (the user must apply and receive permission to use licenced data files); and closed access (for highly sensitive or individually identifiable data) [25].

4 The Open Data Progression Model

Despite the potential of open data, a 2017 report by the World Wide Web Foundation found that only seven governments include a statement on open data by default in their policies, just one in four datasets has an open licence and half of all datasets are machine readable [26]. Significant barriers to adopting and implementing open data initiatives relate to intellectual property, technology, and data hygiene. Intellectual property restrictions increase alongside advances in data-sharing processes. Much of the approximately 10 per cent of data that meets the open data definition is of poor quality, making it difficult for potential data users to access, process, and work with them effectively[27]. *The New York Times,* for example, reported that data scientists handling big data spend 50–80 per cent of their time cleaning and preparing data for analysis [28]. In the health sector, the complexities of protected health information and sensitive personal data add a layer of difficulty that slows its adoption of open data principles.

The Open Data Progression Model provides a framework of stages for governments and organizations with open data initiatives to follow in making their data open. Each stage provides key programme aspects to include, questions to consider, and best practices to follow. Although there is consensus about best practices around an effective open data programme, there is less agreement about how to sequentially develop open data programmes. There are compelling arguments as to why one stage could precede another, and many of these stages overlap or cycle between each other, but in our experience the Open Data Progression Model minimizes repetition and maximizes utility of the data.

4.1 Stage 1: Collecting the Data

We could be accused of stating the obvious by highlighting that data collection is the foundation on which to build an open data programme. The success of any downstream use of the data depends on their quality and completeness. Other chapters in this handbook describe methods of collecting health data for specific purposes. We emphasize the additional information that investigators need to collect and provide to assist others to use their data, bearing in mind that they may not be subject specialists. For example, investigators must make sure that they capture data fields that potential users need to understand and validate the data (see Sect. 4.2), and use common data standards and schemas whenever possible (see Sect. 4.5).

Some significant open source solutions, like Open Data Kit [29] and KoBoToolbox [30], provide tools to make data collection and storage easier and more efficient. These resources use open source software which a community of developers, implementers, and users continually improve and develop. Tools include built-in collection forms and surveys combined with data storage and data collection on mobile devices which can synchronize and aggregate data to a central server. Two examples of open source tools to collect, manage, analyse and visualize data in global health are Epi Info™ [31] designed for researchers and public health practitioners, and DHIS2 [32] designed to assist governments and other organizations in their decision-making.

4.2 Stage 2: Documenting the Data

A common complaint of people who work with open data is that documentation does not provide sufficient description of context, making it difficult to

understand a dataset and to determine if it is useful. Providing metadata—or information about data—is critical to helping people understand and validate data, and to encourage usage. In our experience having interviewed hundreds of people who work with data, the following represent the most critical context issues to capture and share:

Provenance: What is the origin and source of the data? Who collected and aggregated them? Have the data been changed in any way since their original collection? By whom? When? How? What is the lineage of the data?
Licence: Who claims ownership of the dataset? What is the licence of the dataset? What are its terms of use? Publishing the licence clearly alongside the dataset is absolutely essential.
Collection Methodology: How were these data collected? Were they captured by an electronic system or manually? What was the population from which they collected the data? Over what time period?
Database schema: How are the data organized? If there are multiple files in the dataset, what is the relationship among the files?
Data Dictionary: What does each item of data mean? What do key abbreviations mean? Do identifier codes need to be translated?

4.3 Stage 3: Opening the Data

There are two dimensions to making the data open:

Publishing the Data The two primary criteria to use when choosing where to publish online are visibility and utility. Regarding visibility, it is best to consider using one of the many topical or geographical open data portals that have the infrastructure to release data rapidly and with high visibility. Many open data programmes also publish their data on general purpose open data portals such as data.world, Inc. which has a broad catalogue of open data on different topics and a large community of users (disclaimer:data.world, Inc. is the company of some of the authors of this chapter). Organizations such as CKAN, Socrata, or OpenDataSoft specialize in helping organizations custom build and manage their own open data portals. Concerning utility, functionality of the platform is key to assist consumers understand, access, and work with the data. Most open data portals offer nothing more than file storage without any capabilities for consumers to explore data quickly. Additionally, consider whether the platform offers Application Programming Interface (API) access which enables consumers to programmatically pull the data directly into software

tools that they use. APIs are increasingly the means to transfer data at scale among tools and systems, and are a big part of what makes the data genuinely *accessible* in a technical sense.

Selecting the Licence One of the most important aspects of an open data programme is having a clearly recognized licence that promotes a dataset's open and unrestricted usage and its ability to be combined with other datasets. Said another way, the absence of a licence or the selection of a restrictive or custom licence are some of the main reasons why open data programmes fail to reach their greatest potential impact. Often this barrier is unintentional—open data owners make the incorrect assumption that placing no licence on a dataset means they are not limiting its usage when in fact what they are doing is reserving all rights and prohibiting others from reusing the dataset in any form. To avoid this outcome, owners should either clearly relinquish all rights in their datasets and dedicate them to the public domain by noting *public domain* alongside the datasets or select an open recognized licence to apply to all their datasets. Licences developed by the Creative Commons are now the licences of choice among dataset owners given their breadth of adoption, their applicability to databases, and how they facilitate collaboration. On their informative website, Creative Commons includes a tool that helps to choose the appropriate licence depending on the purpose of the dataset [33].

A critical often overlooked dynamic of dataset licencing is that when analysts and researchers combine datasets from various sources, the most restrictive licence involved in that combination then becomes the licence for the enhanced dataset or derivative work. All derivative works that utilize the dataset, even if the dataset is a very small part of the derivative work, are now hampered in their usage by the constraints of that licence. Work that involves some datasets from multiple sources often faces a complex analysis concerning how different licences may conflict, restrict, or even prohibit certain types of work output.

4.4 Stage 4: Engaging the Community of Data Users

The Africa Data Consensus offers a useful definition of a data community: 'A data community refers to a group of people who share a social, economic or professional interest across the entire data value chain – spanning production, management, dissemination, archiving and use' [34]. A data community is likely composed of a broad range of people and entities with differing skill

sets. It will probably include large organizations, such as NGOs and government agencies as well as independent researchers, non-technical subject-matter experts, and citizen data scientists. A vibrant community is a force multiplier of an open data programme, creating value in three primary ways: (1) providing feedback on what data to release; (2) contributing to the quality of the data; and (3) collaborating with other members of the data community to accelerate work and solutions.

Feedback The community can provide feedback on what data they are interested in and details of the metadata and context that would be most useful for them. The community can indicate not only what data to invest in collecting but also how to collect and publish them.

Contribution Community members can help to clean, annotate, and enhance the data, whether this is improving the data dictionary or building schemas and ontologies that can help contextualize the data within a specific field or topic. A common lament whenever a data worker is facing data contextualization, cleaning, and preparation is that *surely* someone must have already performed these time-consuming tasks, and the world should be leveraging *their* work instead of replicating it unnecessarily.

Collaboration Good data work is inherently social, and the global effort for progress benefits not only from leveraging the work others have done cleaning and prepping the data, but also in the exploratory analysis, visualization, and derivative works others have created from those data. Seeing what others have done with the data will not only help avoid doing duplicative work, but may inspire new lines of analysis and direct collaboration.

A critically important aspect of facilitating the *feedback*, *contribution*, and *collaboration* dimensions of value that the community can offer is to create the mechanisms for them to work together efficiently. It is important to name an owner of a dataset who engages with the community to answer their questions, proactively seek their feedback and capture their user stories.

4.5 Stage 5: Ensuring Interoperability

Interoperability is the ability to exchange and use information between systems. Important issues to consider when optimizing interoperability are:

Prepare the data so that they are structured or machine readable as opposed to unstructured data meant to be read by people; think about the difference between a word processor document and a spreadsheet. Both might contain statistical data, but users need to read the document to pull data out, whereas they can query the data in a spreadsheet using software.

Use open formats and standards: It is best to publish structured data in *open formats and standards*, as opposed to proprietary, closed formats. Open formats and standards are supported by a growing number of open and commercial software programmes which allow consumers of the data to more easily interpret and convert the data within their existing tools. Proprietary formats, on the other hand, often rely on commercial software that consumers would need to purchase or open software based on unpublished specifications, and may have licencing or usage restrictions that make them unsuitable for many projects.

Use tidy data that provide a standard way to organize data connecting their meaning to their structure, such that a data consumer can easily discover what the columns, rows, and cell values represent: Consider a situation in which an enumerator interviews ten individuals and asked each of them their age, gender, and where they live. A tidy dataset will consist of ten rows (one for each individual) and three columns (one for each variable or type of observation); each cell will contain the value of the corresponding variable (column) for the corresponding individual (row).

Use standard vocabularies, codes, and taxonomies: Consider survey data collected from around the world—a variable in this dataset would represent the concept of *country,* and the values would indicate the country in which each observation was collected. It would be smart to restrict values of that variable to a controlled vocabulary—a fixed list of valid names for countries—ensuring that multiple observations from the same country use the same name for that country, supporting comparison and aggregation. Even better than using a controlled vocabulary is to use a standard code for values that have a commonly understood meaning. Where there are several common taxonomies for a concept, *cross-walk* data can map values from one taxonomy to another—allowing data using either one to be joined. Think of cross-walk data as being a translator between two distinct classification systems that address a common subject area. For example, to join data using the internationally recognized International Organization for Standardization (ISO) country codes with data using the World Health Organization (WHO) codes, a reusable dataset that mapped each ISO code to the corresponding WHO code could be used to handle the mapping, greatly increasing the universe of interoperable data to anyone using either of those taxonomies.

4.6 Stage 6: Linking Data

> *When you connect data, you get power in a way that doesn't happen just with the web, with documents. You get huge power out of it.*—Sir Tim Berners-Lee, the inventor of the World Wide Web, speaking at a Global TED event on *The Next Web*.

The possibilities of open health data become most fully realized at the final stage in the progression model when the data are *linked*. When data are converted into linked data, they become more interoperable, which in turn significantly improves discoverability and facilitates collaboration.

The health research community was one of the earliest adopters of linked data. The pharmaceutical industry has benefited from creating a body of knowledge around particular drug compounds. In DrugBank and RxNorm, for example, individual drugs are linked to clinical trials, drug-drug interaction data, and manufacturer information. This allows pharmaceutical researchers to see where a newly developed drug may be successfully applied or where dangerous side effects may arise if combined with other medications. A larger project, Linking Open Drug Data, has connected over eight million pharmaceutical data points from various drug databases and research repositories.

Tim Berners-Lee outlined four principles that would enable the potential of linked data and follow similar principles to the World Wide Web: (1) use Uniform Resource Identifiers (URIs) as names for things; (2) use HTTP URIs so that people can look up those names, when someone looks up a URI; (3) provide useful information about the data in standardized ways (Resource Description Framework and the query language SPARQL); and (4) include links to other URIs to discover more things. The four principles have a common purpose: to facilitate the organization of information and enable linkage to related concepts and to make it easier for both machines and humans to follow those linkages. One powerful way of leveraging these linked concepts, and the relationships between them, is to employ *ontologies.* Ontologies extend the idea of using standard identifiers and taxonomies for concepts by modelling the relationships themselves and the logical connections between them.

In a medical context, aligning research to existing ontologies can have far-reaching implications. In the study of rare diseases, a major impediment to research is the difficulty in obtaining a concentration of patients necessary for a controlled study. The team behind the Monarch Initiative, an effort funded by the US National Institutes of Health, aimed to semantically integrate genotype-phenotype data [35]. The team recognized that diseases in humans

may manifest themselves similarly in other species, but the vocabulary used to describe the anatomy and symptoms of different species varies by discipline. By using an ontology to link together comparable phenotypes, such as *phalange* in mice representing a similar appendage as *digit* in humans, the Monarch team unlocked a new area of research resulting in cures for several rare diseases as at the time of this writing. For additional information on the potential of linked data and tips for its practical adoption, please refer to the white paper *How linked data creates data-driven cultures* [36].

5 Challenges to Implementing Open Data in the Health Sector

While data sharing is widely regarded as best practice, there are many barriers and challenges, particularly to the sharing of health data at the individual level. International research collaborations accentuate the challenges. As Alter and Vardigan have pointed out there are 'ethical issues that arise when researchers conducting projects in low- and middle-income countries seek to share the data they produce.' Concerns relate to ethics of informed consent, data management, and intellectual property and ownership of personal data [37, 38]. Wyber and colleagues observe 'sheer size increases both the potential risks and potential benefits of [data sharing]. Although the approach may have most value in low-resource settings, it is also most vulnerable to fragmentation and misuse in such settings' [16].

Kostkova and colleagues acknowledge that whereas the potential of opening health-care data and sharing big datasets is enormous, the challenges and barriers to achieve this goal are similarly enormous, and are largely ethical, legal, and political in nature. A balance needs to be struck between the interests of government, businesses, health-care providers, and the public.

Interdisciplinary research will be needed if technological advances on data sharing and transparency are to be used effectively in research and implementation efforts. Kostkova et al. conclude that 'Ultimately, healthcare policymakers at international level need to develop a shared policy and regulatory framework supporting a balanced agenda that safeguards personal information, limits business exploitations, and gives out a clear message to the public while enabling the use of data for research and commercial use.' One such example is the International Code of Conduct for genomic and health-related data sharing [39]. The Code comprises six core elements, including: transparency; accountability; data security and quality; privacy, data protection, and

confidentiality; minimizing harm and maximizing benefits; recognition and attribution; and sustainability; and accessibility and dissemination.

6 Conclusion

> *If the universe of data were suddenly made available, it would unleash the creativity of problem-solvers to combine different data sets—public and private—to develop innovative solutions to innumerable challenges.*—Mikael Hagstrom, former Chair of the Global Agenda Council on Data-Driven Development at the World Economic Forum [40].

Readers may feel daunted by the task ahead after reading the stages and recommendations of our Open Data Progression Model, particularly the more technically complex final stages of *ensuring interoperability* and *linking data*. Mark Zuckerberg of Facebook famously advocates that 'done is better than perfect.' Incrementalism is not only acceptable but a perfectly appropriate approach to launching and progressing an open data programme. Far better to begin with a small catalogue of open data assets that follow best practices than delay launching a programme until a larger more comprehensive offering is ready. Beginning an open data programme will not only offer some immediate benefit to the global health ecosystem, it will facilitate invaluable feedback from that community on how to improve the programme to unlock the power of the data, contributing to and amplifying the collective work.

One of the greatest barriers to global progress is a lack of visibility into available data that could be relevant to the analysis at hand and the lack of connectedness among people and institutions seeking to solve similar problems. A sustained open data revolution that lowers this barrier by an order of magnitude would accelerate collaboration and problem-solving on a global scale, and would perhaps be the key to helping us solve some of the world's biggest challenges in global health.

Key Messages

- Open data herald an age of progress and creative problem-solving by allowing researchers to build upon each other's work.
- Governments and organizations have formalized their commitment to open data in a global movement.
- Quality data collection and documentation, and adoption of interoperability standards enhance open data effectiveness.

- Inherent challenges in health-care data around privacy and economic value impede adoption of open data practices.
- Despite these challenges and inconsistent adherence to best practices, the availability of open data has already contributed to improving lives.

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24

Principles and Ethics of Collecting and Managing Health Data

James Thomas and Sarah McNabb

1 Introduction

In December 1998, in light of Iceland's genomic innovations, its parliament passed the Health Sector Database Act that declared citizen health information to be a *national resource* controlled by the state. The Act authorised a private sector licensee to include national data in a genomic database to be used for profit while also protecting individual privacy. The licensee, for example, could not grant direct access to the database to third parties. The information had to be processed in ways that could not be linked to identifiable individuals, and penalties were envisaged for negligent disclosure of information or other violations of the Act. Civil society groups objected to the Act for its *presumed consent* and the Icelandic Medical Association opposed the Act for its ethical shortcomings, including 'the failure to protect the rights of research subjects to have informed consent, the lack of a mechanism for subjects to withdraw from the database once they were entered in, and the monopolistic aspects of the license' [1].

Although Iceland never built its national health database, the publicity around the Act generated widespread debate around the world on what norms

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and standards should apply to the management of population databases. The discussion it provoked is increasingly relevant in the modern era of health information. Ethical considerations apply not only to data generated in the context of health research, but also in relation to the terabytes of health data—including biometric and genetic information—generated in the course of routine health care [2].

Where there is power, there is ethics. Unethical practices often entail misuse of power. Misuses in health range from a physician not informing her patient about the risks of a procedure she will perform to the manager of a public health data system not protecting the confidentiality of patient records. Patients submit to physicians because they hope to benefit from their healing powers, but patients can suffer abuses of that power. Communities participate in government health surveillance because they expect the surveillance to benefit them by controlling disease, but they can suffer from data negligence, such as inadequate precautions to protect data confidentiality, or worse, intentional misuse of data.

While data are inherently powerful, they carry more power when managed by an electronic system. A well-functioning information system merges data from several sources to provide additional information with ease and speed. During surveillance, for example, of a deadly disease like Ebola, an information system might provide the ages, names, and addresses of family members and where an infected person worked. Public health workers could interview these contacts to place them in quarantine or monitor their health. Alternatively, health workers could spread or misuse the information to stigmatise contacts, affecting whether they could attend school, work, or visit the market.

In this chapter, we describe the emergence of public health ethics from medical research and through public health practice. By ethics, we mean generally accepted social norms of right and wrong in the interest of individuals and populations. We focus on ethical concerns arising from management and use of health information systems (HISs), raising issues that affect the ethical collection and use of health data. We consider issues around data confidentiality, establishing principles for sharing data, determining availability and ownership of data, maintaining transparency, and using routine data to achieve health equity. We conclude with a brief discussion of ethical challenges emerging from the rapidly evolving field of health informatics. The length of the chapter does not permit us to create an exhaustive list of ethical issues, or to explain each ethical concern in depth. Our purpose is to introduce readers to the landscape of ethics associated with HISs, and provide resources for further exploration.

2 Ethical Principles Emerging from Medical Research

Notions of what is ethical are not self-evident, they evolve. Western civilisations first accorded moral obligations to free men. Over time, civilisation's moral imagination, and thus moral obligations, extended (though not always equally) to women, slaves, and foreigners. More recently, societies have extended moral rights to animals and are increasingly concerned about societal obligations to protect nature and ecology.

The health profession became concerned about health ethics following reported physician abuse of people under their care. During World War II, Nazi doctors conducted medical experiments on prisoners of war. The power differential in this instance was not only between physician and patient but between an occupying power and a prisoner of war. Three years after the War ended, the United Nations published a Universal Declaration of Human Rights that 'no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment' [3].

Before the Universal Declaration of Human Rights, physicians in the US Public Health Service began a study of the natural history of syphilis among poor, uneducated, black men in rural Alabama. At the study's start in 1932 there was no effective treatment, but by 1947 it had become common practice to treat syphilis with penicillin. For another quarter of a century, the physicians withheld penicillin from study participants so that they could follow through on their initial question about the natural course of the infection. Withholding treatment was in itself unethical, but the racial and social disadvantages of the participants accentuated the power differential between them and the researchers. A whistle-blower brought the study to an abrupt end in 1972 [4].

Seven years later, the US National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research published the Belmont Report on research ethics, and its principles were encoded into US law (45 CFR 46) [5]. The Commission structured the report around three fundamental principles: (1) patient autonomy, or respect for persons (including protection of vulnerable persons); (2) beneficence (maximise the possible benefits and minimise the potential harms to study participants); and (3) justice (distribute the burdens and benefits of research equitably among all populations). Research ethics review boards, commonly referred to as institutional review boards (IRBs), have institutionalised these principles by requiring informed consent of research participants, data confidentiality, and protections for vulnerable populations, such as minors and prisoners.

The above examples underscore the tenuous relationship between ethics and law. Ideally, laws embody the ethics of a society, but this is not always the case. There were no laws against medical experimentation in Germany and the US in the 1940s; 45 CFR 46 was enacted after the fact. Further, the Universal Declaration of Human Rights is not a law. Countries sign the declaration to affirm the principles, but to enforce them they must incorporate the principles into law. Some people may regard certain laws as unethical—such as those that sanctioned eugenics in some US states in the early twenty-first century [6]; and others may regard practices that are against the law as ethical—such as needle exchanges for intravenous drug users. Standards for medical ethics evolve as the medical profession and the general public increase their understanding of a condition and their expectations of its prevention and treatment as Box 24.1 illustrates for HIV.

Box 24.1 Evolution of Ethical Standards in the Case of HIV [7]

In the US, in the early 1980s, when the cause of the HIV epidemic was unknown, physicians sero-tested patients, without personal identifiers, to monitor the incidence and spread of HIV. Unlinked anonymous testing became standard practice, justified as a means to improve the utility of HIV surveillance through decreased participation and selection bias. As procedures for caring for infected individuals developed—to include counselling about how to avoid further transmission and access social services, and later to include treatment with antiretroviral drugs—physicians and patients began to view sero-testing without follow-up as unethical. In 1995, the US Centers for Disease Control and Prevention halted the use of unlinked anonymous testing in antenatal clinic settings and developed new ethical standards for sero-surveillance including informed consent for testing, pre-test counselling, disclosure of test results to the patient, post-test counselling, and referral for HIV care and treatment for those with a positive test.

3 Ethics in Public Health Practice

The above examples entailed research on relatively few and selected participants. In contrast, public health surveillance systems, for example, routinely collect data on all occurrences of specific health outcomes in a population. The purpose of surveillance is quite different to that of research. One crucial difference is that practicing health workers collect data to inform actions to protect a specific population; they do not intend to generalise their observations beyond that population. For this reason, they are not required to obtain IRB approval for data collection. Researchers, on the other hand, signal their

intent to generalise—by publishing findings in the scientific literature—and thus they must apply for IRB approval.

Data from surveillance guide programmes that target disease prevention or treatment of a population. Faced with a rapidly emerging health threat, such as a highly infectious disease, a health department must act quickly and cannot necessarily follow the ethical practices that govern research. Public health systems must protect the confidentiality of sensitive information while ensuring the data can be used to provide health services equitably.

The principles of ethics coming from medicine, research, and human rights do not adequately address critical issues encountered by public health decision-makers. Individual autonomy is sometimes in tension with the good of the community. For example, to control an epidemic, health workers may have to quarantine an individual to prevent him from transmitting an infection to others in the community. In 2000, some public health practitioners in the US, with experience working in public health offices, agencies, and schools, came together to write a code of ethics with 12 principles that speak to the practice of public health [8]. The principles include: prevention by addressing fundamental causes of adverse health outcomes; working for the empowerment of disenfranchised community members; and acting promptly on the information in hand. The American Public Health Association (APHA) adopted the code in 2002. As of 2018, the APHA is reviewing the code to address newly emerging concerns.

4 Ethical Concerns Around Health Information Systems

A major development that the revised APHA code of ethics will need to address lies in the challenges facing public health practitioners when using electronic HISs, including mobile technologies such as cell-phones. Many countries are transitioning from manual to electronic district HISs, for example, using DHIS2 software. By adopting DHIS2, Sierra Leone, for example, has integrated data on key public health performance indicators from every district health facility in the country. The roll-out of this approach drew attention to disparate reporting structures and led to efforts to consolidate data and reduce redundancy across systems [9]. The speed of data collection, analysis, and use, made possible with an electronic system such as DHIS2, must be accompanied by practices that ensure high data quality. Quick availability of low-quality data can be a step backwards rather than a step forward. We identify some ethical challenges around using manual and electronic information systems.

4.1 Keeping Identities Confidential and Data Secure

The issue of confidentiality predates the digital revolution and applies as much to routine data collection as to research, for example, maintaining confidentiality when undertaking antenatal screening of pregnant women to determine their HIV/syphilis status. Data should be stored according to established policies for security and confidentiality of patient data. MEASURE Evaluation, for example, suggests standards for routine management of health information, including: (1) keeping data in a secure location; (2) providing permits to specific staff to access the data; (3) limiting movement of paper records; (4) ensuring password protection for electronic records and limited access; (5) transmitting only aggregated data; and (6) requiring staff to sign confidentiality agreements annually [10].

Digital data are powerful in part because they can be automatically linked between systems. To function together, or to be interoperable, two systems must intentionally select compatible conventions for data selection and definitions. Interoperability creates risks as well as opportunities for greater information, for example, consolidated databases are more attractive targets for cyber-attacks [11]. The medical/health-care industry in the US experienced the most identified breaches of any sector in 2012–14, representing 42.5 per cent of all identified breaches across the country in 2014 [12]. These breaches, by definition, violate the privacy and confidentiality of individuals in the database. The Canadian Institutes of Health Research developed best practices for protecting privacy in health research [13], and the US Centers for Disease Control and Prevention have developed a helpful set of answers to frequently asked questions on data security and confidentiality [14].

Increasing the amount of data associated with an individual creates additional opportunities to identify them—permitting *deductive identification*. Aggregating data provides some protection, for example, by reporting the number of women receiving antenatal care rather than maintaining a list of their names. But if the aggregated number is few or the community where the women live is small, readers of reports might be able to deduce their identities. In the era where analysts can create big data from electronic health records, electronic financial data, cell-phone use, social media, and geo-location devices, and triangulate data between sources, their ability to ensure anonymity is declining fast.

Incorporating geographically referenced data into a HIS can increase the risk of deductive identification, particularly in a small geographic area. Use of geo-coded data can lead to discrimination against people associated with a

particular geographic area. For example, data showing high rates of cholera infection could dampen tourism and associated income to the community or country. Tourism may have been a consideration in China's under- and late-reporting of cases in the epidemic of severe acute respiratory syndrome in 2002–03 [15].

4.2 Basing Action on Data and Evidence

Evidence-based decision-making has emerged in the last few decades as a primary strategy for improving public health outcomes (see Chap. 3). The WHO and the US Agency for International Development are strong proponents of evidence-based approaches, and the WHO advocates for HISs as a means to improve evidence-based decision-making at all levels of the health system. Several ethical implications must be considered when evaluating evidence and using data in decision-making. These include:

Data Quality Invalid data can lead to inappropriate analysis of health and service patterns and trends, and misappropriation of resources. For example, biases in data collection can systematically include or exclude a vulnerable segment of the population. If data are of such poor quality that they do not engender confidence, data usage will decline. Factors that improve data quality include training in data collection, designing forms that are clear and succinct, reducing the burden of data collection, and ensuring data ownership (see Chap. 22).

Conflicting Evidence Different HIS data sources may yield conflicting information, or there may be more than one interpretation of a single set of findings. In such cases, transparent decision-making can prevent one person or group from unilaterally imposing their view.

Under-Representation of Data on Complex Issues Health topics that require complex study designs or long time-frames are often more difficult and costly to study, for example, the evaluation of structural interventions. This can result in lack of evidence on particular topics, perpetuating their under-representation in policies and programmes [16]. If complex issues are not addressed, simpler, more direct efforts will be undermined or even counter-productive.

Lack of Data As an Excuse to Postpone Action Decision-makers seldom have all the evidence they need; they must make decisions with the information available. The dilemma for decision-makers can be: to act without sufficient evidence or to

postpone action until they have more complete information. Sometimes, decision-makers cast doubt on the validity of available data, even when it is plentiful. In an analysis of news coverage about Agent Orange, for example, Vietnamese media predominantly called for restitution, while stories in the American media noted calls for more research [17].

4.3 Making Public Health Data Open and Transparent

Transparency builds trust in a health system; promoting trust in data also promotes trust in analyses conducted with those data and decisions that utilise them. Public health managers can promote transparency by, for example, keeping individuals informed about how they use and share data collected about them. Governments and organisations can publish anonymised data openly to empower the public, encourage research and innovation, promote transparency, and inform decision-making. While open data can be beneficial, they can lead to unintended ethical issues (see Chap. 23). Amateur researchers may not understand or be able to account for data limitations such as quality, bias, and confounding (see Chap. 18). Some erroneous claims may be harmless, but others could have serious unintended consequences—such as propagating unfounded medical advice—or be used maliciously to promote an agenda to incite discrimination against a particular group [18].

4.4 Sharing Data

When stakeholders share data, each may have contributed to the collection of a single set of data, or may have contributed data to a merged set. In either case, the stakeholders agree to share access to the resulting dataset. Box 24.2 demonstrates challenges of sharing data between countries and how international agreements have mitigated conflicts and maximised use of shared data to control influenza globally (see Chap. 10).

Box 24.2 Global Initiative of Sharing All Influenza Data (GISAID) [19]

The Global Initiative of Sharing All Influenza Data (GISAID) database, established in 2008, promotes the sharing of influenza data and builds capacity to respond to global influenza outbreaks. GISAID maintains a policy of scientific etiquette, in which researchers must acknowledge the originating laboratory in publications and agree to collaborate with the data provider in further analysis and

research. In 2013, Chinese researchers uploaded genetic sequences from the first human cases of the new H7N9 avian flu virus to the GISAID database and began preparing a manuscript for publication. The Chinese researchers later became aware of other research teams planning to publish analyses based on the Chinese H7N9 genetic data, and worried that they would lose credit for their work in isolating and sequencing the virus. Working through GISAID, the Chinese researchers contacted the other research teams who agreed to hold their publications until the Chinese teams published their initial findings [20]. In this case, GISAID was able to mitigate a potential data sharing conflict, while providing rapid access to influenza data to support the global response to the virus.

HIS and research infrastructures in low- and middle-income countries (LMICs) may lack the data management and analysis capacities of their counterparts in high-income countries. Investigators in LMICs often share data with collaborators in high-income countries, who conduct the analyses and gain recognition from the work [21]. Some LMIC researchers feel they have been neglected and exploited in a process that also perpetuates unequal analytic capacities [22]. Researchers and HIS managers should support data sharing partnerships that give adequate recognition and benefit to all parties involved, and seek to build research capacity of LMICs. The Council on Health Research for Development has developed a Research Fairness Index which allows researchers to agree to the principles that make their partnerships fair [23]. Chatham House in the United Kingdom has developed guidelines for international data sharing for the benefit of public health surveillance [24]. For domestic US public health, the Centers for Disease Control and Prevention have developed standards for sharing surveillance data for public health action [25].

4.5 Avoiding Burdensome Data Collection

The desire for data can be insatiable. Every ministry or external donor has questions of interest to them, and their own set of indicators. At the point of data collection, be it in a health facility or at a home visit, each moment spent collecting data threatens to be a moment not caring for the patient or client. Taken to an absurd level, data collection could squeeze out service delivery altogether. To provide good care and good data, the HIS manager must keep data collection to a minimum, ensuring that each data item is essential and will be used frequently (see Chap. 2). Box 24.3 describes how India reduced the data items that health workers were expected to collect when it reformed the country's health management information system in 2005.

Box 24.3 Reform of India's Health Management Information System [26]

When India launched its National Rural Health Mission in 2005, it aimed to reform the health management information system. Its goals included streamlining data collection and analysis, automating data processes through a web-based system, implementing data validation mechanisms, and introducing analytic tools to improve monitoring and evaluation capacity. Lack of a standardised list of indicators across local, state, and national governments meant that health-care workers had to collect up to 3,000 data items. The reform process—which a director described as 'a difficult and often ruthless exercise, and often acrimonious'—reduced the list of critical indicators to approximately 200. This reform gave health workers considerably more time to spend with patients.

Data use is affected by data utility and vice versa. The more useful a set of information, the more it will be referenced; the more information is used, the more attention data managers will put into maintaining quality and presenting the data. This feedback loop can be broken when those collecting the data do not have access to them for local evaluation and decision-making. Rather, they pass data up the line to higher offices that do not share findings with the local data collectors or facilities. In such instances, data collection becomes a rote process lacking utility for the collectors.

Many LMICs rely on external funding to support large-scale data collection. Health indicators are frequently aligned with donor priorities or disease-specific initiatives rather than with overall health system goals. Uncoordinated initiatives can monopolise resources, duplicate efforts, and result in indicators that are not the most relevant to local populations [27]. The large quantities of data that result can lead to information overload and limited capacity to use data effectively. Siloed data sources also limit decision-makers' ability to consider the whole health system when allocating resources. To ensure data are parsimonious, a ministry of health needs to facilitate coordination between donors, other ministries, and offices within the ministries. They must also have and use the authority to decide which data are essential, and to curtail unnecessary data collection (see Chap. 1).

4.6 Enabling Those Who Collect Data to Own and Guide Data Use

When developing a HIS, efforts should be made to anticipate and address potential ownership issues before data collection. Issues around future data access and use should also be considered, to maximise opportunities to utilise the data and begin building the capacity to do so.

Data ownership encompasses maintaining and securing data, managing any changes made to the data collection processes and participating in the collection, analysis, and use of data. Patients, health-care providers, health insurance plans, registry developers, funding agencies, research institutions, and government agencies could all claim ownership to health information stored in a public health registry [28]. How far can ownership claims extend? If a patient consents to include her information in a health registry, does she maintain any right to refuse future, unforeseen uses of that information? Most countries do not have adequate policy and legal frameworks for data ownership, and in many cases, ownership claims to health information have not been legally tested, and public opinion about data ownership matters is uncertain, as our opening example from Iceland demonstrated [29]. Selling health information and de-identified patient data is a multi-billion-dollar industry, raising additional questions regarding data ownership [30]. Do patients need to give consent for their information to be sold? Is it unethical for one person to benefit from the sale of many people's data? The National Aboriginal and Torres Strait Islander Health Data Principles are one example of an attempt to address issues such as these [31].

More technical questions include who should be held accountable for data breaches or errors in data collection and to what extent are data managers accountable to individuals represented in the data, as well as other potential owners of the data? Mechanisms to define and transfer data ownership and accountability include licenses, data use agreements, and data sharing agreements. Additionally, system managers can use role-based access, login records, and audit trails to monitor and track user access and activities on a system.

4.7 Addressing Health Inequities

WHO defines health equity as 'the absence of systematic disparities in health between social groups who have different levels of underlying social advantage/disadvantage' [32]. Efforts to ameliorate health inequities are often impeded by lack of information and low health system capacity to address identified inequities. A HIS can address these needs by collecting actionable data on inequities and linking health data to social indicators to better address them.

The ability of a HIS to address health inequities is complicated. The areas of a city or country that have the fewest health services usually have the weakest HISs. Perhaps it goes without saying, that strengthening a HIS in a resource-poor area is more difficult than strengthening a HIS in situations where

resources—including trained personnel—are more abundant. Also, data on common sources of inequity, such as ethnicity and social position, are seldom collected. Managers must weigh the data collection burden of adding these variables to routine data collection. Box 24.4 illustrates how the Chilean Ministries of Planning and Health have integrated an Equity Gauge into their information systems by enhancing a national household survey to measure gaps in socio-economic status and relating them to differences in health status and access to care.

Box 24.4 Chilean Equity Gauge

The Global Equity Gauge seeks to improve the monitoring of health equity and to build capacity for research, advocacy, and community participation to improve health equity [33, 34]. In the early 2000s, the Gauge worked with the Chilean Ministries of Planning and Health to redesign the health module of the CASEN (Encuesta de Caracterización Socioeconómica Nacional), a nationwide household survey of living conditions [35]. The redesigned module sought to better identify and quantify socio-economic gaps and related differences in health status and access to care. The Gauge also developed Chile's National Equity Objectives, established a health equity forum, and designed a health equity training programme. Their work has led to improved monitoring and dissemination of data on health inequities, and the development of reforms favouring equity in health and social policies [24, 36, 37].

4.8 Emerging Challenges

Increased collaboration and connectivity across countries and proliferation of data through new technologies introduce ethical challenges for handling public health data.

What happens in one country often affects its neighbours. The Ebola epidemic of 2014–15, for example, occurred in three contiguous West African countries. Those addressing disease prevention or control in one country have an interest in the disease patterns of other countries. Countries may not, however, share their health data, or they may collect them in ways that are not useful to neighbouring states. When they share data, a highly infectious and pathogenic epidemic can challenge protections of patient privacy. There may be little time to identify ethical principles and practices; they must be put into policy, and even practised before they are needed.

The Internet and cell-phones have enabled the production and sharing of previously unimaginable amounts of data. Accumulated data include, for example, web search histories, online and social media profiles, and purchasing histories [38]. These new *big data* sources have many potential uses and

implications for public health, including enhanced disease detection and surveillance. Google famously claimed to anticipate the onset of the influenza season by analysing the use of search terms [39] but their analytic methods were faulty [40]. Attempts to improve methods continue [41]. In the meantime, ethical issues have emerged around transparency of methods of analysis, collaboration between private (for profit) and public (not for profit) institutions, data ownership and sharing, and individual privacy [42].

Societies, particularly in the West, often regard numbers as objective and value-free, and thus ethically and culturally neutral. Utilitarianism, the philosophy most closely aligned with the sciences of epidemiology and econometrics, aims for the greatest good for the greatest number. Decisions about what is good, such as disease cases prevented, or the most cost-beneficial approach, are typically based on numbers and data. But, as we have shown in this chapter, power differentials, including the power to collect and interpret data, raise ethical concerns. Groups with power or without power are often defined by cultural perspectives based on ethnicity, gender, income, or other social factors. These groups can hold different views on whether the data used are valid, how they are used, who has access to them, and so on. The interface of culture and HISs is relatively unexplored, and findings could have significant implications for the creation and use of the data systems [43].

5 Resources for Guiding the Ethical Collection and Use of Health Information Data

We suggest some resources to guide ethical approaches to collect and use data, in addition to those we have already referenced.

A set of datasets that comprises a HIS is often referred to as a data warehouse or data hub. These typically have an individual called a *data steward* responsible for their maintenance and use. Data stewards must consider the interests of the individuals whose data are stored in the system, as well as data use for the good of the community and stakeholders [44]. Thus, they can serve as a point of contact for issues of data security, data sharing agreements, and many other ethical concerns.

The Digital Development Principles Working Group, with representation from international development donors, non-governmental organisations, companies, and individuals working in international development, has produced nine principles for digital development. The principles which can be found online [45], include ‘design with the user’ and ‘address privacy and

security.' The working group also identified tools and resources for each principle.

HISs have many stakeholders and typically a governing group develops the policies that guide them. The group agrees on standards and rules, and allocates resources to create and maintain systems that embody them. The Electronic Data Methods Forum, established by the American Agency for Healthcare Research and Quality, has collected guidance and resources for these groups, and makes them available online [46].

The United Nations *Fundamental Principles of Official Statistics* includes professional ethics as one of its ten fundamental principles, and identifies a series of legal, administrative, and data-related principles that should be incorporated in the regulatory frameworks of a HIS to promote scientific standards and professional ethics [47].

As we mentioned at the beginning of this chapter, ethical perspectives and standards evolve as the fields they address evolve. Inevitably, some ethical decisions must be made before standards are developed. In these instances, we suggest the following as guidelines for making ethical decisions: (1) clarify the facts of the situation; (2) identify the ethical questions; (3) identify the stakeholders and what each stands to lose or gain; (4) describe what various schools of ethical thought highlight; (5) identify any relevant professional ethical principles, standards of practice, and laws; (6) identify possible alternative courses of action; (7) choose the alternative best supported by the preceding analysis; and (8) evaluate the actions taken and their eventual outcomes [48].

6 Conclusion

Recent advances in technology make possible near instantaneous collection and use of data in HISs. The data afford opportunities for public health action to allocate resources to improve public health. The power of this information also raises ethical concerns about potential misuses. In some cases, technologies are advancing faster than our identification of the ethical implications, and certainly faster than our ability to establish ethical principles, procedures, skills, and systems. The challenges are heightened in resource-poor settings as international donors press for creation of electronic HISs, even in the absence of resources to staff and maintain them. It is likely that the importance of known ethical issues and the will to address them will be realised only after the occurrence of harmful ethical lapses. The creation of policies and procedures to guard data ethics and the training of individuals to carry them out are in themselves urgent ethical imperatives.

Key Messages

- Digitised health data have the power to both help and harm individuals and groups.
- Advances in information technology are outpacing associated ethics awareness and policies.
- The lag between technological developments and associated ethical issues is especially significant in resource-poor countries.
- Data security is only one of the many ethical concerns for HISs.
- Other ethical considerations include data confidentiality, data sharing principles, data availability and ownership, and transparency.

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25

Global Health Data: An Unfinished Agenda

Carla AbouZahr and Sarah B. Macfarlane

1 Introduction

In the preface to this handbook, we proposed that health-related data 'become *global health data* when - aggregated, synthesised, and exchanged - they form the basis of estimates and evidence that drive international debate and collaborative efforts to improve health status and reduce disparities across populations, borders, and geographies.' Knowledge that more than 800 women die each day from preventable causes related to pregnancy and childbirth and that the majority of these deaths occur in rural areas of low- and middle-income countries (LMICs) drives international efforts to support these countries strengthen health systems to reach inaccessible populations and prevent maternal deaths. Knowledge that as many as 100 million people are forced into poverty each year because they have to pay for health services drives a global movement to achieve Universal Health Coverage (UHC) [1]. Knowledge of the cases of wild poliovirus spreading from the few infected countries continues to drive coordinated global efforts to interrupt its transmission.

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We also propose that global health data derive from health-related data collected where people live and that these data should inform policy and practice locally, in addition to being useful globally. This holds true for high-income countries with sophisticated health information systems which, for example, identify at-risk mothers and record and report cause on the rare occasions when mothers die. But for many LMICs, the situation is quite the opposite—while working to build adequate information infrastructure to manage their health programmes, they learn many of their health statistics from estimated indicators published by international institutions. Women in these countries not only die from preventable causes but most of their deaths and causes are unrecorded. Global statistics indicate that 36 million people die each year from preventable non-communicable diseases (NCDs)—again mainly in LMICs [2]—yet few of these deaths occur in a health facility where their cause is accurately diagnosed and recorded. Few LMICs conduct surveys to measure prevalence of NCDs or identify determinants of NCDs and disparities between socio-economic groups. With stronger information infrastructures, LMICs can collect health-related data that better inform local interventions while also contributing quality global health data.

In this final chapter, we examine the paradox that despite increasing availability of global health indicators, the capacity to produce and use health-related data is unevenly spread around the world. We review how organisations contribute to the development and availability of global health data and methods, and conclude with some thoughts about achieving an agenda in which all countries collect, analyse and use the quality data they need. We structure the chapter around five core activities that authors of this handbook have demonstrated to be essential in transforming health-related data into global health data, indicators and evidence (Box 25.1).

2 Contributors to Global Health Data and Methods

Contributors to global health data are similar to those who contribute to global health; while some work solely at the global level and some operate internationally, most contribute to health locally and globally from wherever they live. They collaborate in undertaking the activities we summarise in Box 25.1.

National governments maintain health information systems to provide data to inform and evaluate their health programmes. To do this, they work with

Box 25.1 Essential Core Activities in Transforming Country Health-Related Data into Global Health Data, Indicators and Evidence

- *Country production and use of health-related data, indicators and evidence,* using standard definitions, concepts and methodologies*;*
- *Global reporting of data by governments through the World Health Organization and other United Nations agencies*, that is: notifiable diseases and public health emergencies of international concern; deaths and cause of death; disease specific data; and Sustainable Development Goal indicators;
- *Cross-country creation and use of data by* generating data and evidence across countries and across programmes, and developing global health estimates;
- *Global sharing of data, estimates and evidence by* publishing databases, open data and evidence, and synthesising evidence for policy advocacy and action; and
- *Global support and guidance for maintaining information systems and data standards by* setting standards for systems and indicators, and providing financial and technical support to build systems.

the stakeholders that we describe below. Governments also share their official data through the World Health Organization (WHO) and other United Nations (UN) agencies. In principle, the ministry of health shares data with other sectors and works closely with the national statistical office (NSO).

Civil society organisations are active in health-care and social and economic aspects of development and often generate data as a product of these activities. They advocate for and evaluate health programmes, generally from the users' perspective. By networking, they contribute to global advocacy, for example, by demonstrating health inequalities and the need to address social determinants of health.

Non-governmental organisations (NGOs), including faith-based organisations**,** collect data as part of their health-related activities and contribute to strengthening local data systems. International NGOs also share data and evaluate their programmes across countries. Some NGOs provide support to strengthen statistical and health information systems.

Academic, research and training institutions undertake local and multi-country research, provide technical advice and training, analyse and disseminate health-related statistics and contribute to programme evaluation. They participate in international technical advisory groups such as those mandated to support agencies, develop global estimates and provide guidance on disease-specific monitoring and evaluation.

The private and business sectors, including information and communication technologies and medical insurance schemes, are present in countries and collect data on the health workforce, communities and environments in which they operate. Many companies integrate corporate responsibility into their business operations, and lever technological, business and scientific expertise to benefit health and data systems.

Public and philanthropic donors, including, for example, foundations and research councils, provide financial support for projects that involve research and health information system strengthening in their own countries and internationally, and support research, including multi-country studies.

Multi-lateral governmental development and financial agencies working at global, regional and country levels, such as WHO, UN Children's Fund (UNICEF), the UN Statistics Commission, the World Bank Group (WB), International Monetary Fund (IMF), regional development banks and the Organisation of Economic Co-operation and Development (OECD) provide grants and loans for development of health-related data and statistics. They also collect and disseminate data, and develop standards for information and statistical systems and data quality.

Donor governments, mostly belonging to the OECD, provide bilateral development assistance to LMICs and support for information system strengthening and data collection programmes and supervise evaluation of the health programmes they support.

Public-private partnership and funds, such as Gavi the Vaccine Alliance and the Global Fund to fight Aids Tuberculosis and Malaria, provide grants and technical support to countries to generate high-quality data in their focus areas as part of their ongoing monitoring and evaluation processes.

Global and regional networks and partnerships coordinate multiple stakeholders to promote integrated approaches to health challenges shared by several countries. Whereas most partnerships, such as Stop TB or Roll Bank Malaria, address particular health issues, some focus on data. Countdown to 2030 tracks coverage of health interventions proven to reduce maternal, newborn and child mortality. The Global Polio Eradication Initiative works through surveillance systems to identify children with symptoms of polio (paralysis)—thanks to better data available faster, every new outbreak can now be responded to within 72 hours.

The Health Data Collaborative promotes collaboration among donors and partners in support of country-led data governance, and development of national health sector and health information plans, unified digital health data architectures and common investment frameworks [3]. The Global Partnership for Sustainable Development Data focusses on the use of data to

improve policymaking and service delivery, increase accountability and promote entrepreneurship for better development [4].

In the statistics community, the Partnership in Statistics for Development in the 21st Century (PARIS21) brings together national statistics offices and multi-lateral, bilateral and financial agencies to support capacity development, advocate for the integration of reliable data in decision-making, and coordinate donor support to statistics [5]. It is striking, however, that coordination across the health and statistics sectors is weak, nationally and globally.

3 Country Production and Use of Health-Related Data, Indicators and Evidence

Chapter 1 describes the production and use of health-related data at country level and illustrates many international and inter-sectoral collaborations that contribute to these activities. It is unlikely that anyone collects any data or presents results anywhere without some international influence and interest. People and agencies share methodologies, collaborate and compare findings with colleagues and receive funding from sources in many countries. Chapters 14 and 20, for example, demonstrate the benefits of cross-sectoral and international academic and government partnerships in setting up climate-sensitive surveillance systems for malaria using spatial and spatio-temporal methods.

Governments maintain data infrastructures and collect and report data and official statistics as part of a broader national statistical system led by an NSO. While the ministry of health collects routine administrative data, the ministry usually works closely with the NSO to design and implement national health household surveys. The health ministry also contributes to the civil registration system by notifying births and deaths to the civil registry and providing information on causes of death. The NSO undertakes the census on which the health and other sectors depend for demographic data. The ministry of health and the NSO share data globally with their UN counterparts. All ministries work together to collect data and report indicators for the Sustainable Development Goals (SDGs). Chapter 11 demonstrates how ministries of health and finance collaborate to track resources spent on health through National Health Accounts—following a common international model developed by the OECD.

Academic institutions, civil society and NGOs operate independently to create data and evidence, promote accountability, and form local networks to advocate for and address key issues. Chapter 16 describes how qualitative

research involves working with communities and non-state agencies to complement the findings of quantitative investigations.

4 Global Reporting of Data by Governments Through WHO and Other UN Agencies

At its creation in 1948, WHO tasked Member States with 'communicating promptly to the Organization …. statistics pertaining to health which have been published in the State' [6]. Minimum official data reporting requirements by countries to WHO now include:

4.1 Reporting and Exchanging Data on Diseases and Public Health Emergencies of International Concern (PHEIC)

Chapter 10 describes the International Health Regulations (IHR) which seek 'to prevent, protect against, control and provide a public health response to the international spread of disease' while avoiding 'unnecessary interference with international traffic and trade' [7]. The IHR require WHO member countries and territories to report all cases of smallpox, poliomyelitis due to wild type poliovirus, human influenza caused by a new subtype, severe acute respiratory syndrome (SARS) and any event that constitutes a PHEIC, and to implement appropriate regulations when WHO declares a PHEIC [8]. All signatories must develop minimum core public health capacities 'to detect, assess, notify and report events' and 'respond promptly and effectively to public health risks and PHEICs' [7]. In 2015, WHO reported that 43 per cent of the 196 IHR States Parties had obtained extensions to be able to meet IHR core capacity requirements [9].

In 2014, the WHO Director General declared Ebola Viral Disease and Polio as PHEICs, both resulting from outbreaks in countries with inadequate core capacities. The Ebola outbreak demonstrated the centrality of data to maintaining national, regional and global health security, and the necessity that countries and the global community build local capacity to collect, spontaneously interpret and share data locally and internationally. In January 2016, the independent Commission on a Global Health Risk Framework for the Future proposed investments of $3.4 billion to upgrade national health systems to ensure they comply with IHR 2005 by 2020 [10].

4.2 Reporting Deaths and Cause of Death

Member States must report data annually to WHO on mortality by age, sex and cause of death. But, as Chap. 7 explains, many countries do not have functioning civil registration systems that record all deaths on an ongoing basis and their hospitals lack physicians trained to determine cause of death according to the standards described in the International Classification of Diseases [11]. Because of this, as Chap. 21 describes, WHO develops statistical estimates to fill data gaps, impute missing data values, and address bias and quality problems in reported data (see Sect. 5.3).

WHO and partners publish mortality and cause-of-death-related estimates for: life expectancy at birth; healthy life expectancy at birth; maternal mortality ratio; under-five mortality rate; neonatal mortality rate; probability of dying from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases between age 30 and 70 years; suicide, homicide and road traffic mortality rates; mortality rates attributed to household and ambient air pollution, attributed to unsafe water and sanitation services, and from unintentional poisoning; and death rates due to natural disasters and from major conflicts. Chapter 17 describes some of the demographic methods for measuring life expectancy and mortality. Chapter 13 focusses on the particular challenges of estimating mortality levels and trends in settings affected by conflict.

4.3 Reporting Disease-Specific Data

National disease-focussed programmes compile data from health facilities, surveillance systems, disease registries and share data and indicators with development partners at regional and global levels. For example, national malaria control programmes report data on malaria cases and deaths in health facilities, and from national malaria surveillance systems, as well as on the distribution of insecticide-treated bed nets, sales of rapid diagnostic tests, treatment courses distributed and findings from local household surveys. WHO compiles these data and disseminates the information in its annual World Malaria Report.

Annual updates on the HIV epidemic draw on multiple sources of data reported by national AIDS control programmes (NACPs). These data cover HIV testing during antenatal care, anonymised HIV testing in sentinel clinics, prevalence surveys in particular population such as sex workers and

men who have sex with men, and cases of HIV reported by medical doctors. The NACP collates the data with demographic data using the Spectrum software to build a comprehensive picture of the national HIV epidemic, including estimates of prevalence, incidence and mortality. The NACP shares the national estimates with UNAIDS and WHO and these provide the basis for regional and global estimates (see Chap. 21).

4.4 Reporting SDG Indicators

Most chapters (and Chap. 2 in particular) describe aspects of reporting SDG indicators. The Inter-agency and Expert Group on SDG Indicators [12]—composed of Member States and regional and international agencies as observers—has developed a global indicator framework [13] with recommended data sources for each of the 232 indicators. The UN Statistics Division (UNSD) coordinates global SDG reporting, in collaboration with multilateral agencies responsible for specific mandates. WHO, UNICEF and the UN Population Fund (UNFPA) share global reporting on the health-related SDGs. The annual SDG indicators report does not generally include data for individual countries, instead reporting regional and/or sub-regional aggregates calculated from national data by the relevant agencies [14]. Each country also develops an SDG report following UN guidelines that promote country-led, transparent and participatory processes.

5 Cross-country Creation and Use of Data

To fill information gaps and maximise consistency and comparability of data, international agencies and academic institutions support and undertake data collection across countries. These efforts not only enhance the availability and quality of data locally, but also accumulate global data. Thus, local data become global data when used in a different context.

5.1 Generating Data and Evidence Across Countries

Global and regional development agencies coordinate and support multi-country and regional studies and surveys, commission cross-cutting reports and conduct cross-country analyses. Academics, private and non-governmental organisations support these studies and network to conduct independent multi-country and regional studies and reports. Such collaborations have led

to major innovations. For example, development of rapid diagnostic tests have revolutionised the availability of data on the prevalence of HIV, malaria and tuberculosis, especially at the community level.

The US Agency for International Development supported Demographic and Health Survey (DHS) programme has established an HIV/AIDS Survey Indicators Database. This database facilitates graphing and mapping of HIV-related indicators and comparisons with other population and health indicators from DHS surveys [15]. Included are indicators to monitor the goals set at the UN General Assembly Special Session on HIV/AIDS, the Millennium Development Goals (MDGs), and strategic goals of the President's Emergency Plan for AIDS Relief. As of 2018, the database hosts 266 surveys—mainly from the DHS, Multiple Indicator Cluster Surveys, Reproductive Health Surveys, Sexual Behavior Surveys and Behavioral Surveillance Surveys.

Chapter 8 discusses the increasing importance of NCDs in overall mortality, and how this has driven efforts to improve data availability and quality, including both behavioural risk factors and also rapid diagnostics for conditions such as high glucose levels. The WHO STEPwise approach to Surveillance (STEPS) is a simple, standardised method for collecting, analysing and disseminating such data. The three step approach consists of: (1) behavioural questionnaire (diet, smoking, physical activity); (2) physical measurements (blood pressure, height, weight); and (3) biochemical measurement (blood glucose, cholesterol etc.).

5.2 Generating Data and Evidence Across Programmes

Chapter 4 describes methods for evaluating health programmes. International partners who support multi-country programmes monitor and evaluate their investments. Partners include WHO, other UN agencies, international partnerships, multi-lateral and bilateral donors, global funds, foundations, and international non-governmental organisations, and may involve academic institutions and independent consultants.

International agencies have developed reporting standards for indicators to expedite comparison across countries and time periods, and encourage countries to modify their health information systems to comply. Because development partners bring technical expertise and funding to the table, they influence which data countries collect and the methods they use to assess, compile and disseminate data. Countries have strong incentives to construct their health information systems around donor priorities (see Chaps. 1, 2 and 9).

5.3 Generating Global Health Estimates

Chapter 21 describes the benefits and limitations of global health estimation methods. WHO and the UN Population Division began making global estimates shortly after World War II, focussing largely on population size, fertility and mortality. Other agencies have taken on active roles in estimation, for example: UNICEF and WHO for infant and child mortality; UNFPA for fertility and contraception; UNAIDS and WHO for HIV/AIDS; WHO for tuberculosis; WHO, UNICEF, UNFPA and the WB for maternal mortality; and WHO and UNICEF for nutritional status. The process of estimation can add value to country-reported data by checking compliance with global statistical standards, verifying the use of international indicator definitions, harmonising data where necessary using standard conversions and peer-reviewed methodologies, and filling data gaps.

Academic institutions contribute significantly to developing estimation methods, generally by participating in independent advisory and technical reference groups set up in specific measurement areas, including HIV/AIDS, tuberculosis, malaria, maternal health and child health epidemiology [16]. These groups not only provide the UN system with valuable technical expertise but also with a degree of independence and objectivity, attributes that could be at risk when technical programmes responsible for advocacy are also in the forefront of developing estimates [17].

A striking development in health estimation has been the ongoing work to quantify for all countries and all diseases, the total burden of mortality and disability. This started in 1993 with the World Development Report *Investing in health* [18], and was followed by updates by WHO up to 2008 [19]. Since 2013, the Institute for Health Metrics and Evaluation (IHME) has regularly produced estimates of the global burden of disease (GBD) for global, national and, increasingly, sub-national levels [20, 21]. The GBD estimates are widely used by development agencies, funds, foundations, NGOs, researchers and health programmes and are hugely influential in determining global health policy.

6 Global Sharing of Data, Estimates and Evidence

When WHO undertook the mammoth task of estimating additional resources needed to attain the health SDGs in 67 LMICs [22], it argued that the results would serve these countries by providing 'evidence about the probable cost drivers within countries seeking to expand their health service coverage' and

that the findings could help 'guide national priority setting and resource allocation.' Global data analyses thus serve not only global agencies, donors and funds, but can also help country decision-makers to develop policy and planning responses to health challenges.

6.1 Publishing Databases, Open Data and Evidence

WHO publishes *World Health Statistics*, which summarises data available to the organisation on a range of topics, including the disease burden and trends in health-related SDGs. The annual update is part of the WHO Global Health Observatory which issues regular analytical reports on the current situation and trends for priority health issues and maintains a portal to track UHC [23]. The WHO and the IHME publish estimates of progress towards the SDGs [24]. Several WHO Regional Offices have also developed regional observatories.

The UN Statistical Division which collates social and economic statistics maintains operating procedures for major statistical activities and coordinates reporting of all SDG indicators publishing them on the UNData site [25]. The WB collates most sectoral and economic indicators on its open data website [26]. Development agencies' programmes report progress about target groups—such as infants, children and reproductive aged women—, or target health concerns—such as maternal mortality, HIV/AIDS, malaria, tuberculosis, nutrition, food insecurity, water and sanitation, neglected tropical diseases, NCDs and violence.

Countries use global data to benchmark their performance across priority indicators against those of other countries or global and regional averages. Such comparisons can be risky and counter-productive if based on inadequate data or analysis, even resulting in inappropriate policy responses—as WHO found when it ranked countries according to health system performance in the World Health Report 2000 [27].

6.2 Synthesising and Communicating Evidence for Policy Advocacy and Action

Availability of guidelines and tools can stimulate the production of sound data and evidence on health-related challenges. Chapters 4 and 18 illustrate how international collaborators have developed guidelines to assess the quality of the evidence that WHO and others use to recommend priority interventions.

Chapter 5 shows how strong structures, policies and procedures help institutionalise and sustain demand for data and statistics to underpin policy and practice. But, as Chaps. 3 and 5 point out, data alone are insufficient to change entrenched positions and the mind-set of decision-makers about the necessity and feasibility of policy action. Medical journals can be pivotal in changing attitudes because readers expect that they encapsulate the best available evidence and knowledge. However, their readership rarely includes policymakers.

For years, policymakers perceived health to be a cost to the economy. To turn this perception on its head and position health spending as an investment with high returns, WHO, the WB and health leaders around the world established the Global Commission on Macroeconomics and Health in 2001 [28]. The success of the Commission's format—as a forum for innovative thinking on specific health topics based on careful analysis of available data—was such that it has since been replicated multiple times. For example, the 2005–08 WHO Commission on the Social Determinants of Health was highly influential in drawing attention to the importance of including socio-economic determinants and inequities in all data analyses [29]. Commission reports are published in the medical journal, *The Lancet*, bringing together technical experts, data specialists, policy advocates to develop strategies to support evidence-based decision making.

Chapter 12 demonstrates how the World Health Report 2006 revealed the worldwide human resources for health crisis showing not only extreme shortages but also maldistributions of all cadres of health workers [30]. The data were sparse but sufficient to rally resources to invest in building human resources for health information systems.

7 Global Support and Guidance for Maintaining Information Systems and Data Standards

As Chap. 22 notes, standards for statistical and health information systems reassure users that data have been collected, analysed and presented in accordance with good statistical practice recommendations. Standards also help ensure that data are comparable over time and across geographies.

7.1 Setting Standards for Systems and Indicators

Responsibility for data integrity cuts across all WHO's core functions, that is: monitoring the health situation and assessing health trends; setting norms and standards and promoting and monitoring their implementation; provid-

ing technical support, catalysing change and building sustainable institutional capacity; shaping the research agenda and stimulating the generation, translation and dissemination of valuable knowledge; articulating ethical and evidence-based policy options; and providing leadership on matters critical to health and engaging in partnerships where joint action is needed [31].

The UN Statistical Commission, which brings together representatives of national statistical systems as well as international agencies, is the highest decision-making body for international statistical activities [32] and oversees the work of the UNSD. The UNSD compiles and distributes global statistical data and information, sets standards for and coordinates statistical activities and supports national efforts to strengthen statistical systems [33]. Just as ministries of health work within their national statistical systems, WHO works within this international statistical system along with other UN agencies that collect health-related data such as UNAIDS, UNICEF, UNFPA, the UN Development Programme and the WB. This international statistical system assists countries to harmonise concepts, definitions and classifications to monitor international commitments such as the SDGs.

UN Member States have, through their national statistics agencies, agreed to the *Fundamental Principles of Official Statistics* as universal standards by which producers of official government statistics should operate [34]. The principles build on the premise that trustworthy official statistics are indispensable to democracy. The ten principles state, inter alia, that statistical agencies should: be independent, impartial, follow scientific principles and ethics in data collection, analysis and interpretation; maintain data security and respect individual data confidentiality; and coordinate among country and international statistical agencies to ensure consistency and efficiency of statistical systems. The principles provide a framework to assess the performance of national statistics offices.

The UN Statistical Commission has also developed standards for the international statistical system. The *Principles Governing International Statistical Activities* [35] include, inter alia: ensuring free and open public access to key statistics; using strictly professional considerations for decisions on methodology, terminology, data dissemination and presentation; making a clear distinction, in statistical publications, between statistical and analytical comments and policy-prescriptive and advocacy comments; and publishing a policy to ensure that statistical functions are impartial, based on professional standards, and independent from political influence.

Several organisations offer frameworks for maintaining and assessing data quality (see Chap. 22). The OECD has developed statistical standards, guidelines and best practices specifically for development indicators [36].

These emphasise the importance of metadata—definitions, sources, data collection methods and so on—that should accompany all data reports, thus enabling users to evaluate data quality and fitness for use.

Some countries raise concern about the growing practice of international agencies estimating key indicators—in health and other sectors—and face loss of reputation when international estimates contradict the indicators they report [37, 38]. The UN recommends that when international entities see a need to adjust or estimate country-specific indicator values they should: fully document data sources and estimation methods 'in a manner that ensures the transparency of the methodology and the replicability of the estimates'; consult with countries 'with a view to validating and possibly improving the methodologies used to derive country-specific estimates'; and 'provide an opportunity for national statistical authorities to review country-specific estimates' [39].

7.2 Providing Financial and Technical Support to Build Systems

International agencies and donors provide financial and technical support for country data collection. Many prefer to support household surveys (see Chap. 8) and others support health management information systems (see Chap. 9), civil registration and vital statistics systems (see Chap. 7), and censuses (see Chap. 6). Agencies direct this support largely towards helping countries attain international standards for data collection and management.

The WB manages the Trust Fund for Statistical Capacity Building (TFSCB), a multi-donor trust fund that aims to improve the capacity of LMICs to produce and use statistics. The TFSCB works closely with PARIS21 to coordinate international efforts to improve statistics globally. Few countries have used the TFSCB for health statistics [40].

The work of development agencies and donors to define indicators, set standards, collect data and enhance data quality assurance would be of little value if not accompanied by strategies to build national capacities. Capacity building efforts mostly take the form of training workshops and technical support to national statistical agencies, ministries of health, public health institutes and academia. Some development partners support partnerships such as north-south collaboration and peer-to-peer learning. Statistics Norway, for example, has a long-running programme of cooperation with statistical agencies in LMICs.

UN agencies and development partners, especially at regional and country levels, organise inter-country training workshops on specific themes, such as improving mortality statistics, estimating HIV incidence and prevalence, implementing disease surveillance and response, and strengthening health management information systems. Regional development banks provide technical support and capacity development for statistics but generally focus on financial and economic data rather than on health.

8 Global Health Data Today

The situation we have described reflects a transformation in the landscape of health data over the last 50 years. Just a few UN partners participated during the 1970s, but today hundreds of governmental, non-governmental and commercial entities contribute to national and global health data. Whereas the 1970s saw the transition from manual to computer-based information systems, today's computing power and analytical capacity facilitate the handling of vast quantities of data for health management and research. Countries with sufficient resources and expertise manage complex information systems that link data across many sources to inform patient care and health system management, and publish data openly for others to analyse. Although significant data gaps remain, less well-resourced countries have also transformed aspects of their health information systems, by:

- counting populations through decennial national censuses. Ninety one per cent of all countries and areas took part in the 2010 census round covering 93 per cent of the estimated world's population (Chap. 6);
- modernising country CRVSs to deliver on both legal identity documentation and vital statistics—although progress has been slow. For example, globally between 2000 and 2015, birth registration of children aged under five years increased from 58 to 65 per cent. Death registration also increased albeit slowly, reaching 45 per cent in 2013, a growth rate of 1 per cent annually since 1970 (Chap. 7);
- undertaking more frequent and ambitious national household surveys to track health status, behaviours and use of health services. For example, DHS has supported over 300 surveys in 88 LMICs since 1984 (Chap. 8);
- introducing electronic record systems to transform health facility management. For example, between 2006 and 2018 almost 60 countries adopted the open source software DHIS2 to manage district health systems on a national scale (Chap. 9);

- building integrated disease surveillance and response systems in almost all countries of sub-Saharan Africa since 1998 (Chap. 10);
- tracking financial resources for health using a universal system of health accounts. For example, 72 LMICs have completed at least one set of National Health Accounts since 1997 (25 countries have undertaken three or more) (Chap. 11);
- developing information systems to manage human resources for health. For example, since the World Health Report 2006 highlighted the human resource crisis, most countries regularly assess their health worker densities and distributions by population (Chap. 12);
- using geocoded data to analyse and interpret large datasets and generate insights that improve decision-making. For example, household surveys today routinely collect geographic information in order to link survey data with routine health data and to study accessibility to health facilities. Such linking has been used to improve the delivery of health programmes such as malaria control and access to family planning and obstetric care (Chap. 15); and
- using data on costs in combination with estimates of disease burden to generate comparative data on cost-effectiveness to choose between intervention strategies. This is now routine in many settings as reflected by the number of published cost-effectiveness analyses on health-care interventions, which averaged 34 per year from 1990–99 and increased to over 500 per year in the 2000–2014 period. (Chap. 19) [41].

Only a limited set of global health indicators of mortality and morbidity were available before the publication of the first GBD estimates in 1990, but in 2015 GBD estimates were available for 300 diseases and injuries in 195 countries, and all regions of the world. In 1990, the UN also began publishing indicators to monitor nine health-related MDG targets and 23 indicators annually for all member states and, as of 2015, for 13 SDG health-related targets and over 50 health-related indicators. As we have described, the global community supports countries to collect the data to measure these and other indicators, and international institutions make estimates where the data are inadequate.

Data scientists are accumulating and analysing large datasets—or big data—across geographies and time. Chapter 15, for example, describes how a location perspective can help in the interpretation of large datasets and generate insights that improve decision-making. By analysing big data alongside geo-located data, it is possible to estimate inequities in mortality and health patterns at sub-national levels—an emerging new science of precision data in

public health [42]. However, the vast accumulation of detailed data—much of which relates to individuals—raises serious ethical and legal issues, especially concerning privacy, confidentiality and ownership, as described in Chap. 24.

New technologies, innovative analytical tools and expanding computing power offer new directions for global health data. The IHME, for example, has collated a vast database of health-related indicators and raw data covering countries and territories around the world dating from at least 1990. The IHME can analyse these data to study past and predict future health trends.

Technologies, however, are not evenly available around the world. Internet penetration rates (percentage of the total population of a region that uses the Internet) in mid-2018 were estimated at 95 per cent in North America, compared with 49 per cent in Asia and 36 per cent in Africa [43]. Additionally, international investments in the statistical activities of global entities such as the WHO, UNSD, WB, and IHME have not been matched by support to LMICs to strengthen their health data and statistical systems. There is a risk that the digital divide will also become a data divide—a world in which rich countries harvest data from poor countries and knowledge becomes a rich world monopoly.

9 Next Steps for an Ongoing Agenda

National health information systems are moving towards linking multiple government databases and openly publishing as much data as possible. Several well-resourced countries exemplify this model. For example, Finland links national administrative data registries, and Denmark links survey data with administrative data [44, 45]. The Canadian Institute of Health Information coordinates data and information across Canada's health system, ensuring their integrity and making them available for public use [46]. There are few examples of similar functional linkages between databases in LMICs, although some countries include data interoperability in their long-term vision.

Once countries link databases internally, the logical next step is to link databases across countries to form an internationally shared database for global health. This is easier said than done. The WHO, WB and IHME maintain publicly accessible global health databases but they are not semantically interoperable—based on a common information exchange reference model. Sharing data across countries is a complex undertaking with huge ethical, legal, political and operational implications. The statistics office of

the European Union spent four years developing systems to make official statistics interoperable within Europe, through what came to be called SDMX (Statistical Data and Metadata Exchange) [47].

Notwithstanding the challenges, the future must be one in which every country shares ownership of a common health database. For this to happen, all countries need to: (1) generate high-quality data—using standardised metadata—that are relevant to and underpin local decision-making; (2) build country data architecture and platforms that link databases across sources and sectors; (3) establish a legal framework that ensures ethical standards, individual privacy, confidentiality and data security; and (4) have the capacity to manipulate and analyse the data.

To achieve this vision, all countries should be able to harness local expertise to build processes for data collection and analysis according to international standards, and to create, curate and share data internally and externally with other countries and development partners. One scenario would be a cross-country collaboration of independent national multi-disciplinary institutions able to manage national health databases and provide objective assessments of data availability and quality.

In 2014, the UN Secretary-General called for a *data revolution for sustainable development* [48]. The UN report identified the multi-faceted nature of such a revolution. In part, it is about new technologies that harvest big data, facilitate data sharing and open data, and support powerful new tools, such as automated methods for data analysis. At the same time, the data revolution implies more effective responses to longstanding challenges, such as improving data producer and user interactions, measuring inequities, and productively linking traditional and modern data methods. These and other interventions have to be introduced in circumstances that foster transparency while maintaining ethical standards, confidentiality, privacy, data security, and local ownership.

Four years after the UN call for a data revolution, the volume of health-related data continues to expand and analytical techniques—including algorithms—have become more sophisticated. These developments do not necessarily make data easier for everyone to access or to understand and use. On the contrary, there is a risk that control and use of the data will concentrate in fewer hands. For the moment, the identity of the real beneficiaries of the data revolution remains an open question.

In this handbook, we have described activities to create and use global health data that occur at the national level or at the global level with reporting and feedback between the levels. In concluding, we suggest that the success of the data revolution depends on creating an equitable cross-country mechanism in which stakeholders in all countries develop, own, and access a shared health database. This new global health data architecture would place country

stakeholders at the centre as agents in data development and use, rather than being passive sources of global health data.

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