

# Chapter 19

## Consumer Health Informatics: Engaging and Empowering Patients and Families

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### Learning Objectives

- Define the field of Consumer Health Informatics as a critical domain of biomedical informatics and describe the elements that comprise a sociotechnical perspective
- Identify major drivers that are changing the role of the patient in contemporary health care
- Explain key Consumer Health Informatics functions and describe representative technologies; differentiate between different types of personal health records

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- Describe the factors that influence the adoption and use of Consumer Health Informatics tools, and describe strategies for assessing impact
- Identify significant emerging trends in the field of Consumer Health Informatics

## Core Content

- Personal health
- The flow of data, information, and knowledge within the health system
- Policy & regulatory framework
- Forces shaping health care delivery
- Fundamental knowledge in the effective use of biomedical data, information, and knowledge in the field of personal health: patient, consumer, provider, families, health promotion, personal health records
- Procedural knowledge and skills: apply, analyze, evaluate and create systems approaches to the solution of substantive problems in biomedical informatics in terms of people, organizations, and socio-technical systems
- Awareness of forces shaping health care delivery

## Key Terms

**Blue Button®** The Blue Button represents a national movement that enables consumers to have easy access to their own health information in a format that they can use. The Blue Button logo signifies that consumers can download a single electronic file that contains their available health data.

**Computer Literacy** the range of skills and level of familiarity and comfort that a person has with using computers and computer applications.

**Consumer Engagement** motivating and activating consumers to increase their knowledge, skills and confidence to manage their health and health care.

**Consumer Empowerment** empowering consumers to manage their health care and advocate for themselves as they use healthcare services.

**eHealth** a field of research and practice focused on the use of information and communication technologies to improve health care.

**Health Information Technology (HIT)** the area of Information Technology involving the design development, creation, use and maintenance of information systems for the healthcare industry.

**Health Literacy** the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness.

**Information and Communication Technologies** an overarching term used to refer to technology that supports communication and/or the gathering, sharing, and use of information.

**OpenNotes** a national initiative in the United States to give patients easier access to the clinical notes written by their healthcare providers and other healthcare professionals.

**Patient-Centered Care** an approach to healthcare in which the locus of control and decision-making is centered upon the patient and aligned with the patient's individual needs and preferences.

**Patient-Generated Data** health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern, including health history, treatment history, biometric data, symptoms, lifestyle choices, etc.

**Patient Portal** a secure online website that gives patients convenient 24-hour access to personal health information from anywhere with an Internet connection in order to enable them to interact with their medical information via the Internet.

**Personal Health Information Management** the activities that support individuals' access, organization, and use of information pertaining to their own health.

**Personal Health Record** a private, secure application through which an individual may access, manage, and share his or her health information, including information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and healthcare providers.

**Secure Electronic Messaging** the ability for patients to send and receive asynchronous, secure electronic messages with their healthcare providers (i.e., secure email, secure messaging).

**Sociotechnical Perspective** the idea that to fully understand information and communication technologies, it is necessary to examine the interrelation between the technology and its social environment.

## Case Vignette

Mary Smith is a 72-year-old widow who lives independently with help from her daughter who lives nearby, and her son who resides far away. She typically sees her primary care doctor about three times per year to monitor her high blood pressure, osteoarthritis and history of skin cancer. She has a basic cell phone and uses her laptop to email and see photos from her family. Her son helps to manage her care as a delegate user of her clinic's patient portal, and can view information from her medical record including visit notes, test results and medications.

After Mary confided to her son about having several weeks of fatigue, he logged into the portal to view available appointments. Unable to see her usual doctor for 2 weeks, he scheduled an appointment for her to see another doctor in the clinic the next day. Still concerned, that night he logged into the portal and read over the visit notes and test results for the past few years. Upon noticing an abnormal hemoglobin result from 1 year ago, he searched the portal's education library to learn more about low hemoglobin and fatigue. He sent a secure electronic message to his mother's healthcare team through the portal, asking about the low hemoglobin test results and

possible causes of her low iron. Could this be causing her fatigue? He then called his sister, who was planning to drive their mom to the clinic for her appointment, letting her know about the information. The following morning, the triage nurse at the clinic read the secure message from Mrs. Smith's son, who also mentioned that she had an appointment but would not be seeing her usual doctor. The nurse confirmed the prior test result and alerted the healthcare team that Mary was scheduled to see, along with her usual primary care doctor. At the visit, the doctor seeing Mary already knew about her issues and her son's concerns. Additional history, exam and testing that day revealed iron deficiency in the context of a change in bowel habits. Mary was referred to a specialist and scheduled for a colonoscopy the following week.

## Introduction

Several powerful forces are transforming the role of the contemporary healthcare consumer and creating new opportunities to improve patient care. Technological advances, coupled with a shift toward patient-centered care and unprecedented consumer access to information, have created a new era of consumer engagement, empowerment, and activation. This transformation has striking implications and opportunities for all the major stakeholders groups engaged in the delivery and receipt of health care – patients, providers, purchasers, payors, and public health institutions. It is also directly shaping the work of clinical informaticians, including the emergence and evolution of the interdisciplinary field of Consumer Health Informatics.

Consumer Health Informatics is a critical domain of biomedical informatics, focusing on informatics from consumer or patient perspectives [1]. Drawing on multiple disciplines, Consumer Health Informatics emphasizes information structures and processes that augment the capacity of consumers to manage their health, and enable them to collaborate with healthcare professionals for their care, in accordance with their needs and preferences. Clinical informaticians must apply knowledge in the field of personal health as well as procedural knowledge and skills in order to effectively design, develop, and evaluate systems approaches to improve consumer health and management of their conditions [2, 3]. Recognizing that patients are consumers of healthcare services, and that consumers will inevitably assume the role of “patient” in some form and degree across the course of their lives, we use the terms “consumer” and “patient” interchangeably. We also emphasize that family members and informal caregivers are crucial resources for patients, and are often integrally involved in their support and care.

Historically, the social context of medicine was characterized by professional dominance and authority [4]. By the 1970s, the economic and moral problems of American healthcare were drawing public attention, including increased focus on the imbalance of power in the structuring of medicine, the dynamics of the physician-patient relationship, and patient rights [5]. With the emergence of managed care in the 1980s, the notion of patients as “consumers” of healthcare services

emphasized the importance of patients engaging in shared decision-making [6]. The paradigmatic shift towards more “patient-centered” care [7, 8] also set the stage for the emergence of a new era of consumer empowerment [9, 10].

As these developments in health care continued to unfold, the evolution of the Internet and other advances in information technology in the late 1990s enabled unprecedented consumer access to information and new forms of communication. Information technology was seen to play a central role in improving healthcare delivery, and clinicians and scholars began to refer to a new field of “eHealth” which was focused on the use of information and communication technologies (ICTs) to improve health care [11–13]. Eysenbach defined the emerging field of health care informatics as “the branch of medical informatics that analyses consumers’ needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers’ preferences into medical information systems” ([14], p. 1713). Noting the shifting focus of traditional medical informatics, consumer informatics “stands at the crossroads of other disciplines, such as nursing informatics, public health, health promotion, health education, library science, and communication science” ([14], p. 1715), paving the way for ‘health care in the information age.’

In its landmark report *Crossing the Quality Chasm*, the Institute of Medicine proposed six guiding aims to redesign health care for the twenty-first century: providing safe, effective, patient-centered, timely, efficient, and equitable health care [15]. Inherent in these aims was a new approach to health care design, including the fostering of continuous healing relationships between patients and providers, and the provision of tools to help patients become more active participants in their care. More than a decade later, significant progress has been made, yet there is still much to be accomplished. ICTs have an instrumental role to play in advancing this transformation. The use of web-enabled electronic health information systems such as Personal Health Records (PHRs), patient portals, and other technology-supported tools offers promising potential; yet realizing anticipated benefits will require strong collaboration between the science of informatics and the art of medicine.

In this chapter we examine the fundamentals of Consumer Health Informatics from a sociotechnical perspective, emphasizing that the field pivots on the information structures and communication pathways that arise from the interactions between people, processes, and technology. Next, we describe the major drivers of Consumer Health Informatics, along with factors which influence consumer adoption and use of ICTs, and key elements and strategies associated with implementation. Finally, we provide an overview of evidence in the literature and methods for assessing impact, concluding with a brief discussion of emerging trends.

## Fundamentals

Similar to the broader field of clinical informatics, Consumer Health Informatics has come to embrace the notion that a wide range of factors at different ecological levels (e.g., the individual, interpersonal, organizational, and community) can influence the

**Table 19.1** Sociotechnical dimensions for understanding ICTs in healthcare settings [17]

Dimension	Description
Hardware and software computing infrastructure	Technical dimension composed of physical devices and software
Clinical content	All data, information, and knowledge stored in a system
Human computer interface	Aspects of a system that support interaction
People	Those individuals involved in the design, development, implementation, and use of the technology
Workflow and communication	Tasks necessary to ensure that patients receive the appropriate care and services
Internal organizational policies, procedures, and culture	Structures, policies, and procedures of an organization that influence all other dimensions
External rules, regulations, and pressures	Forces outside an organization that facilitate or impede efforts to design, implement, use, and evaluate technology
System measurement and monitoring	Includes system availability, its use by stakeholders, its effectiveness, and associated unintended consequences

adoption and use of ICTs. Perspectives that once focused narrowly on technology alone have given way to more encompassing approaches aimed at understanding how consumers and technology interact, and the kinds of impacts that they can have on one another. The term “sociotechnical” is commonly used to express the idea that to fully understand ICTs, it is necessary to examine the interrelation between the technology and the social environment [16]. Applied to Consumer Health Informatics, a sociotechnical perspective emphasizes that consumers, as well as ICTs designed for use by consumers, are products of the social, organizational, and cultural contexts in which they are situated; and that efforts to study the relationships between consumers and ICTs must foreground these contextual forces.

Proponents of the sociotechnical perspective have argued that healthcare delivery settings are high-pressure, fast-paced, distributed, and uncertain; and as such, are best characterized as complex, adaptive systems [17]. Table 19.1 presents a series of eight dimensions that proponents argue are critical to understanding the design, implementation, and evaluation of ICTs in health care [17]. As suggested by Table 19.1, in such complex contexts, interactions among people, processes, and technologies combine to create powerful forces that have implications for consumer adoption and use of ICTs. In this section, we examine the people, processes, and technologies that are the focus of much of the contemporary work in Consumer Health Informatics.

### ***People: The Experiences of Patients and Informal Caregivers***

The onset of any health condition introduces challenges. In most cases, these challenges are not strictly limited to management of the condition, but extend outward, impacting many aspects of an individual’s life. The need to respond to the

progression of a condition, manage symptoms and treatments, cope with changes in family dynamics, and coordinate resources are critical activities, the responsibility for which falls not only to the patient, but also to their family members and other informal caregivers. The majority of these activities are performed outside of health-care facilities – in homes, workplaces, and other everyday life settings. Researchers have used the concept of a “trajectory” to describe both the physiological unfolding of a health condition and the activities performed by patients and their informal caregivers to manage it [18, 19].

The trajectory concept is important to Consumer Health Informatics for three reasons. First, it highlights the importance of collaboration between patients and informal caregivers; second, it recognizes that many health conditions are managed mostly outside of formal healthcare settings; and third, it emphasizes that as circumstances change, so too do the activities and resources associated with managing one’s health. These three points have direct implications for how ICTs are designed, the functionalities and content that they provide, and the ways in which they are used by consumers. Finally, in its careful accounting of the perspectives of patients and informal caregivers, the trajectory concept also offers a foundation for the emerging paradigm of patient-centered care; the goal of which is to optimize health by shifting away from traditional, paternalistic, provider-driven, disease-focused approaches towards healthcare systems that ensure the patient—including his or her unique circumstances, attitudes, perceptions, needs and experiences—is fully integrated into every phase of medical consultation, treatment and follow-up [7, 20].

### ***Processes: The Work of Managing Health***

Information has long been understood as an important resource for individuals who are confronted with a health condition. Social scientists have argued that information can lessen a person’s fears and misunderstandings, help individuals develop practical coping strategies, and effectively manage treatments [21]. Just as important as recognizing information as a resource, however, is appreciating that the many health-related processes in which consumers engage involve interaction with and use or exchange of information. We briefly describe the most salient of these processes below.

#### **Seeking and Managing Personal Health Information**

There is a substantial literature spanning psychology, sociology, and the information and communication sciences regarding consumer health information-seeking behavior. Much of this research follows from the premise that when confronted with information needs pertaining to their health, individuals respond by gathering and using information. In the process, they may consult preferred information sources, avoid unwanted information, and negotiate various factors that can facilitate or

impede their efforts. While a certain amount of consumer health information seeking is accurately characterized in this manner, some scholars have commented on the limitations that accompany such an individualistic view [22]. Overlooked is the considerable evidence that health information seeking is also often collaborative, and that in many cases, individuals seek health information not only for themselves but on behalf of others – an activity sometimes referred to as surrogate seeking [23]. Balancing both an individualistic and more socially-oriented view of health information seeking is important as the field of Consumer Health Informatics advances. Similarly, personal health information management refers to the activities that support individuals' access, organization, and use of information pertaining to their own health [24, 25]. Sharing or “exchanging” information to support health-related tasks is an important aspect of personal health information management that commonly involves individuals' informal caregivers as well as their healthcare providers. Research has shown that health information is often gathered and organized with sharing in mind, and that information sharing is performed through various means, including both paper-based and electronic systems [26]. As indicated elsewhere in this section, the seeking and sharing of health information is also important to consumer education initiatives and the realization of shared-decision making in practice.

## **Self-Management**

As chronic conditions have become more prevalent in the population, there has been increasing recognition of the shortcomings associated with models of care in which healthcare providers take responsibility for treatment decisions on the basis of their clinical expertise, and patients are expected to adhere to designated management plans [27, 28]. While perhaps fitting for acute conditions where treatment is mostly confined to medical settings, such models do not accurately represent the experiences of consumers faced with conditions where the majority of management happens in the course of daily life. As expressed in the trajectory concept, the onset of chronic health conditions can introduce complex treatment plans, emotional turmoil, and social repercussions for patients and their informal caregivers.

In the most fundamental sense, self-management refers to a patient's participation in the management of his or her own health and has been framed as an alternative to more established, provider-driven models of care [28, 29]. It foregrounds a patient's expertise, circumstances, and responsibility. The concept of self-management also accounts for the point that to effectively manage their health, patients require a repertoire of skills and accompanying resources, including problem-solving, decision-making, help-seeking, action-taking, and establishing supportive relationships with healthcare providers and other stakeholders [30]. Consumer Health Informatics applications can facilitate consumer education regarding self-management skills and resources, and enable effective communication between patients and providers. As part of a personal health maintenance model, ICTs can also augment the ability of patients to perform common self-management tasks by enabling



access to high quality information, providing decision support tools, offering accessible and convenient options for interactions with the healthcare system, and creating a comprehensive longitudinal Electronic Health Record (EHR) that also includes patient-supplied information.

### **Changing Health Behavior**

The everyday behaviors in which consumers engage have direct implications for their health. Regardless of whether they are healthy or living with a health condition, it is often possible for consumers to improve their well-being through health promotion behaviors or more effective condition management activities. Health behavior change refers to the processes and intervening factors involved in reducing or eliminating unhealthy behaviors and adopting and maintaining healthy ones. The importance of health behavior change as a field has grown in conjunction with alternative models of care, including self-management and patient-centered care. Changing any behavior can be challenging, and there are a variety of behavior change principles and theories available to inform the design, implementation, and evaluation of behavior change interventions [31]. As we describe further below, ICTs including personal health records, secure electronic messaging systems, and other networked tools can be used as platforms on which to deliver behavior change interventions to consumers and to help them integrate changes into their daily lives.

### **Communicating with Others**

Communication processes have been called “a link between personal, social, cultural, and institutional factors and various facets of health and illness” [32]. Health communication refers to the study and use of communication strategies to inform and influence individual and community decisions that enhance health [33, 34]. As described in the landmark *Healthy People 2010* report [35], effective communication is critical across healthcare contexts and can support all aspects of disease prevention and health promotion.

Clinical informaticians must appreciate that consumers are members of communities and social networks comprised of family members, friends, peers, and others. These are the settings in which beliefs about health are shared and information is exchanged. Communication about health also transpires through many channels, and regardless of the channel, ICTs are changing the consumer’s experience of that communication. More so than ever before, consumers have access to information from sources representing different perspectives and content that reflects individual situations and preferences. The emerging patient-centered care paradigm has also focused attention on patient-centered communication. Patient-centered communication is a crucial component of the delivery of patient-centered care and aims to strengthen patient-provider partnerships through a focus on patients’ perspectives, needs, and values, providing patients with the information needed to participate in

care to the extent that they desire, and building a shared understandings of health conditions and treatments [36, 37]. Patient-centered communication is continually influenced by overlapping factors pertaining to the patient, the health system, relationships among stakeholders, and the availability of resources – including ICTs – to support its realization in practice.

### **Coordinating Care**

The Institute of Medicine (IOM) [15] described coordination across patient conditions, services, and settings as one of the most formidable challenges facing our nation's healthcare system, and included care coordination as one of 20 national priorities to improve healthcare quality [38]. The growing prevalence of multi-morbid, chronic conditions among consumers, coupled with increasing clinical specialization and fragmentation of services across settings and time, has only exacerbated this issue in recent years. Care coordination has been defined as the deliberate organization of patient care activities among stakeholders in an effort to facilitate the appropriate delivery and receipt of healthcare services [39]. Integral to this organization of activities is effective sharing of health information across settings (e.g., clinic to clinic; home to clinic) and stakeholders (e.g., patients, informal caregivers, primary care providers, subspecialist providers, etc.).

Patients and their informal caregivers have long had a recognized role to play in the process of coordinating care, for example, updating a primary care provider on events that have transpired since a previous visit or delivering test results to a specialist consultation. Still, effective sharing of information among patients, informal caregivers, and their various healthcare providers is often limited at best, increasing the potential for adverse outcomes and increased costs [40, 41]. What has changed in recent years is the range of ICTs and other tools available to support patients and informal caregivers in their efforts to access information about their care, capture that information in formats that are readily usable (and reusable), and share it in a convenient way with others. As we describe further in the Emerging Trends section of this chapter, some of the most influential developments in consumer-mediated information exchange include tools like Blue Button® and the OpenNotes movement [42]. As argued by the IOM [15], when thoughtfully and effectively implemented, such tools can reduce the need to develop laborious, case-by-case strategies for coordinating patient care.

### ***Technologies: A Rapidly Changing Landscape***

The design, implementation, and use of ICTs to improve consumer health and to support the kinds of health-related processes just described is a defining feature of Consumer Health Informatics, the eHealth movement, and related efforts to engage patients and informal caregivers in their own care. Functional groupings of

consumer ICTs intended to conceptualize the kinds of services that will become increasingly available to patients in the future have been articulated in the literature, and emphasize the ability to conduct healthcare system transactions, access expert care, and support self-care and community [43]. In this section, we briefly describe some of the major representative technologies at the core of such functional groupings, with the caveat that the technologies themselves continue to rapidly evolve.

### **Personal Health Records (PHRs)**

The concept of a PHR is not new; patients and their informal caregivers have always used paper-based systems – lists, diaries, calendars, and other jottings – to track symptoms, medical history, medications, appointments, and other noteworthy health events. Although functions and features vary across systems, most PHRs share a fundamental goal – “to give patients better access to their own healthcare data and enable them to be stewards of their own information” [44]. Many early electronic PHRs were stand-alone tools untied from specific healthcare systems and into which consumers could self-enter their personal health information. These “static-repositories” [45] have since given way to web-based PHRs and mobile applications that are linked or tethered to specific healthcare systems (e.g., an electronic health record), and offer a range of associated functionality [46]. The joint PHR Task Force of the Medical Library Association and the National Library of Medicine [47] offered a thorough definition of the electronic PHR, stating that it is:

“A private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR. PHR sponsors include vendors who may or may not charge a fee, health care organizations such as hospitals, health insurance companies, or employers.”

Examples of PHR features supporting various health-related tasks and activities are shown in Table 19.2.

### **Patient Portals and Shared Access to Electronic Health Records**

The tethered PHR model requires that consumers have a secure, Internet or web-based location where they can access the personal health information available to them from the supporting healthcare system, and also access other functions. This is commonly referred to as a “patient portal.” In recent years, many patient portals have advanced; from offering consumers a means to view select portions of the EHR, to providing collections of tools that support transactions, information tracking, and communication with clinical team members [48]. Some portals may also have a means by which consumers can identify a proxy or set of proxy users and delegate access to their

**Table 19.2** Health-related tasks and supporting PHR features

Health-related tasks	Examples of supporting PHR features
Accessing and sharing personal health information	Blue Button®, OpenNotes, consumer mediated health information exchange
Educating oneself about his or her health and making informed decisions	Consumer-oriented online health education libraries, personalized education, decision support tools
Tracking personal health information	Journals, logs, diaries, etc.
Managing medications	Online prescription refills, medication lists, medication reconciliation tools
Managing appointments	Appointment views, appointment reminders, appointment scheduling capabilities
Communicating with stakeholders	Secure messaging
Changing health-related behaviors	Reminder tools, health assessments, motivational tools, web-based interventions
Coordinating care across providers and systems	Consumer mediated health information exchange

personal health information and use of portal features on their behalf. Supporting delegation and proxy use embraces the collaborative nature of consumer health information seeking and personal health information management and also aligns with the tenants of alternative care models described earlier, including self-management and patient-centered care. It is important to note that many patient portals are tethered to one healthcare system, which often limits the ability for consumers to connect, share, and exchange data with other healthcare systems. Moving forward, the next generation of PHRs and patient portals will likely support consumer access to personal health information that is dispersed across multiple healthcare systems and aggregate that information to create a more comprehensive record of their health [48]. Networked PHRs of this kind inherently require interoperability across systems and have profound implications for consumer efforts to coordinate the care that they receive in different settings, along with the associated transactions.

### **Secure Electronic Communication Between Patients and Healthcare Providers**

One common function supported by many tethered PHRs is the ability for patients to send and receive asynchronous, secure electronic messages with their healthcare providers. In many cases, the messages that patients and healthcare providers exchange automatically become part of the healthcare system's EHR. In addition to serving as a convenient, protected channel for non-urgent communication [49–51], secure electronic messaging also has the potential to strengthen patient/provider relationships [50, 52, 53]. The sense of “digital anonymity” that accompanies the exchange of electronic messages can empower patients to broach topics that they might not feel comfortable discussing in the course of a face-to-face clinical visit.

In addition, whereas patient recall of verbal communications tends to deteriorate over time, patients can access and review secure messages from their healthcare providers at any time. Having such information “at the ready” can facilitate the comprehension and recall of care plans, medication instructions, and other complex information. If used effectively, secure messaging also has the potential to realize the principles of patient-centered care by fostering a focus on the patient-as-person, and promoting shared power through improved access to information and communication, shared-decision-making, and ongoing support.

### **Sharing and Integration of Patient-Generated Data**

As noted above, many PHRs provide patients with the ability to self-enter various kinds of information about their health; for example, personal and family medical history, use of alternative treatments, and details about dietary habits, exercise routines, and measurements like weight and blood pressure. This patient-generated data can be a valuable complement to information included in a healthcare system’s EHR – potentially clarifying, expanding upon, or filling in gaps in the medical record. However, as patient-generated data continues to accumulate, there are important questions about how best to use it in the course of clinical practice, and how best to store and integrate it with information from other sources, principally, the EHR [54]. These are questions that the field of Consumer Health Informatics will have to address moving forward, and clinical informaticians will play a key role in collaborating with clinical experts and patients to define optimal solutions.

### **Internet or Web-Based Interventions**

With the increasing availability of Internet access and its capacity to deliver content and functions in engaging and understandable ways, many clinicians and scientists have turned to Internet or web-based interventions to promote health and support the management of health conditions. These have been described as self-guided interventions executed through prescriptive online programs comprised of quality health materials and interactive components and used by consumers who are seeking health-related assistance [55]. Regardless of whether they were developed specifically for a web environment or based on previous interventions originally offered through a different channel (e.g., in-person), web-based interventions are intended to promote awareness and understanding of one’s health and support desirable health behaviors. They have been implemented in a variety of contexts, including chronic disease self-management, mental health, and substance use. Three broad types of web-based interventions have been described in the literature: (1) web-based education interventions designed to support consumer access to information about a specific aspect of health (e.g., an online self-management tutorial for those recently diagnosed with a chronic disease); (2) self-guided web-based therapeutic interventions designed to create desirable change in consumer thoughts, behaviors,

or emotions (e.g., an online self-management skills building program comprised of educational information, interactive skills-building activities, and automated feedback); and (3) human-supported web-based therapeutic interventions designed to create desirable change in consumers and involving a person to offer support, guidance, or feedback (e.g. the aforementioned online self-management skills building program augmented with feedback from a peer or professional) [55]. Although adherence to their content can be challenging [56], previous analyses have revealed improved outcomes for individuals using web-based interventions to achieve desired knowledge or health behaviors, as compared to non-web-based interventions [57]. More so than interventions delivered through other channels, web-based interventions have tremendous potential to reach large numbers of consumers, and can be used at the time, place, and pace most suitable for the individual.

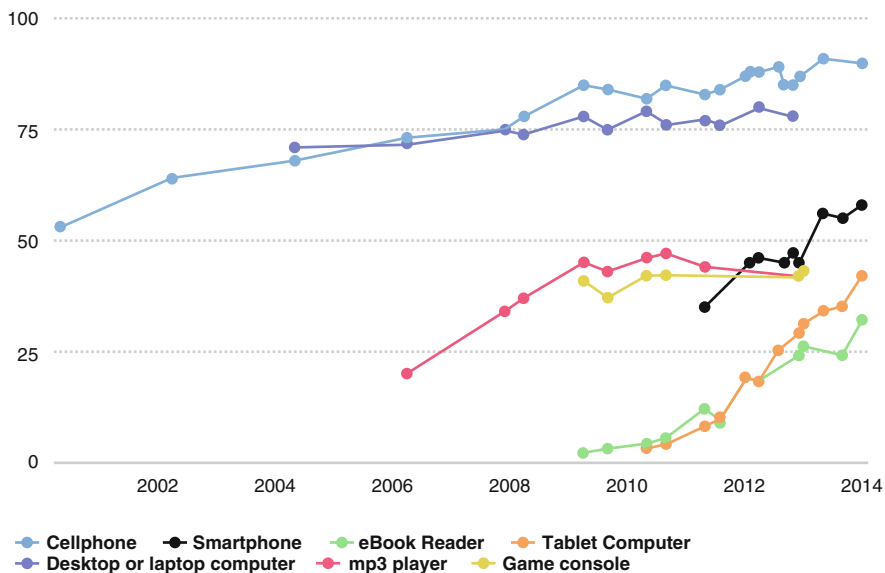
The experiences of consumers, the healthcare processes in which they engage, and the technologies that they use to support those processes will continue to evolve with changes in healthcare and advances in technology. As we emphasize in this fundamentals section, clinical informaticists have an important responsibility to foreground the interactions among these elements and to understand the kinds of forces that influence those interactions. These drivers are the subject of the next section.

## **Major Drivers**

As described at the outset of this chapter, there has been a fundamental sea change in how consumers use technology. Along with dramatic increases in access to and overall use of the Internet and digital technologies, is a societal consumer expectation that online services will be commonplace – at work, at home and throughout their daily lives. Such anticipation exists for health care as well. While healthcare systems have invested substantially in computerized systems and other technologies for healthcare professionals, they have continued to lag behind other businesses like banks, airlines, and retail companies to fully leverage the power of computers and networks for consumers to connect remotely and interact seamlessly. Still, remarkable strides have been made to provide patients and caregivers with electronic information and services. This section will explore current drivers of Consumer Health Informatics, including current trends in technology availability and use; increased focus on consumer information needs, consumer desire for engagement, and meaningful use of health information technology (HIT); and continued pressure to control mounting health care costs.

### ***Increased Availability and Use of Technology***

A major stimulus for consumer adoption and use of technology-enabled tools and services (ICTs) has been growing public engagement with technology. Pew Research Center's Internet & American Life Project continues to serve as a rich source of data



**Fig. 19.1** Device Ownership Over Time (Reproduced from Ref. [58] with permission from Pew Research Center)

on consumer perspectives and behavior [58]. Nationally, 87 % of American adults now use the Internet, reflecting a rapid rise over the past decade [59]. While Internet use remains generally lower among individuals age 65 and older or with a lower level of education, rates of use continue to rise within these subgroups as well. As younger cohorts get older, the “digital divide” is expected to narrow substantially. More than nine out of ten teenagers use the Internet regularly, including those who reside in households with lower incomes. Factors playing a role in increased Internet adoption include the geographic expansion of broadband and changes in mobile device availability and usage. Desktop and laptop computers are giving way to greater use of mobile devices. Presently, 91 % of adults own cell phones, and more than half of these are smart phones (see Fig. 19.1). As people transition from accessing the Internet intermittently to carrying a personal “always on” portable device, online activity continues to soar.

### *Consumer Information Needs and Desire for Engagement*

Consumer need for health information and a growing desire to engage in shared decision-making have also helped to drive the evolution of consumer ICTs. Patients and families have always sought answers to their health issues. The exponential growth of readily available information, previously inaccessible before the Internet, offers consumers the promise of greater control of their health, and greater

participation in healthcare decisions. Fully 60 % of adults report searching online for health information on a range of health topics, and 35 % attempt to diagnose a problem they experience, or to search on behalf of someone else [60]. Today, many consumers are active in gathering and sharing health-related information, both online and offline, so that they can be informed and participate more fully in decisions about their care. Caregivers, in particular, take part in a wide range of online health-related activities.

Patients and caregivers are also highly interested in using a wide variety of tools to participate in their health and their health care, such as virtual visits, home health monitoring, and online communication with providers and patient communities [61]. Health care has been slow to fully embrace such technologies, but this is changing. Pioneers, such as Dr. Tom Ferguson, characterized traditional care as “industrial age” medicine that did not assist patients with self-management [62]. Believing such care to be expensive and inefficient, he advocated for health care to empower consumers, including the development of computer systems specifically designed for their use. He and his contemporaries coined the term “e-patients” to describe individuals who are equipped, enabled, empowered and engaged in their health and care decisions [63]. Interestingly, e-patients report two effects of their online health research—“better health information and services, and different (but not always better) relationships with their doctors” [64]. These activated patients can improve their self-rated health status, cope better with fatigue and other generic features of chronic disease such as role limitation, and reduce disability and their dependence on hospital care [65].

### ***Financial Incentives and Meaningful Use of Health IT***

An equally important factor currently driving Consumer Health Informatics is the transformation happening inside the medical community. As noted in Chap. 3, the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 accelerated the investment in and use of EHRs as a way of improving care and enhancing patient outcomes [66]. The \$30 billion program, regulated by the National Coordinator for Health Information Technology and administered by the Centers for Medicare & Medicaid Services, authorizes financial incentive payments and penalties based on compliance with criteria for Meaningful Use [67]. Practices and providers across the nation are incentivized to deliver functions which demonstrate the meaningful use of HIT, with the aim of improving the quality of care while reducing costs. While many of these measures focus on how electronic records are to be used within health systems, several call for HIT functions which impact patients directly. Meaningful Use Stage 2 criteria include providing patients with (1) the ability to view online, download, and transmit their personal health information; (2) timely access to clinical summaries for each visit; (3) secure electronic messaging to communicate with clinicians for health issues;



and (4) patient-specific educational resources. To receive incentive payments and avoid penalties, eligible professionals and systems must follow a specific set of criteria for each measure.

### ***Impact of Major Drivers***

Taken together, EHRs with integrated patient online services are foundational tools that can help meet the needs of consumers to access and aggregate their own health information, and to access their healthcare providers remotely [43]. While shared health data and secure electronic messaging can enhance patient experience and health outcomes [52, 68], these tools also have significant ramifications for healthcare teams. Providers express concerns about patients finding poor quality information on the Internet, risks arising from patients reading clinical notes and test results without accompanying interpretation, and workflow challenges with secure electronic messaging. Yet national surveys demonstrate that consumers still perceive health professionals as the most trusted source of health information [69]. Further, providers who encourage patient self-management and shared decision-making report having more engaged patients and improved patient-provider relationships [70].

Finally, consumer-facing ICTs are increasingly seen as mechanisms to deliver new models of care and to achieve greater efficiency and reduce healthcare costs. As a result, many industry vendors are advancing consumer health technology development. Health systems, insurers and payers increasingly cite remote encounters and patient self-monitoring as important strategic ventures with the potential for both clinical and financial benefits. However, consistent, high quality data reporting evidence of such tools to achieve desired outcomes is still needed [71]. As these drivers continue to foster and shape changes in health care, clinical informaticists will play a critical role in addressing both opportunities and related challenges.

### **Major Factors Influencing Adoption and Use**

Despite the influence of major drivers and the increasing availability of a variety of consumer ICTs, most of these technologies have not yet been fully integrated into usual care across large populations. Moreover, while consumers continue to express high interest in eHealth tools and services, with some notable exceptions, adoption on average remains relatively low [53, 72, 73]. In this section we discuss some of the major factors which influence the adoption and use of consumer ICTs. In keeping with our emphasis on the sociotechnical perspective, we include both social and technology-related factors. Our understanding of patient adoption and use of consumer ICTs comes largely from roughly a decade of experience with the use of

web-based patient portals in large integrated delivery systems and academic medical centers. Using patient portals as a representative technology, we draw upon this experience and the related literature to discuss these factors in this context, keeping in mind that they have broader applicability across the field of Consumer Health Informatics.

### *Access and Usability*

Evidence accrued to date highlights the importance of ensuring equitable and open access to all points of care when implementing consumer ICTs; whether online, in-person, or over the telephone. Fundamental barriers to use of consumer ICTs can include lack of computer and/or Internet access; although as previously noted, these trends have been changing as access to broadband networks increase and consumers adopt portable Internet-enabled devices. However, a more nuanced understanding of access also includes the concepts of computer and health literacy [74] to ensure that users have the ability and necessary functional and cognitive skills to enable effective use [75]. As ICTs are increasingly provided to enable consumer access to healthcare resources and services, care must be taken to ensure that they do not inadvertently create or exacerbate disparities, especially among vulnerable segments of the population [76].

Patterns of adoption in large delivery systems suggest that patient portals have the potential to exacerbate existing disparities among patients related to race, age, literacy, socioeconomic status (SES), and other characteristics. Online use of portal services is less likely among older patients [77, 78], racial and ethnic minorities [49, 79–83], non-English speaking patients, the uninsured [84], and patients without broadband Internet access or with lower income [83], computer abilities [84], health literacy [85], and education [81, 83]. However, if carefully designed and implemented based on user needs, abilities, and preferences; consumer ICTs may also have the potential to eliminate disparities [86]. Unfortunately, however, many existing patient portals are limited in their usability [87–89], particularly for vulnerable populations [90, 91]. In addition to addressing general usability principles related to user interfaces and navigation, patient portals and PHRs present additional challenges related to the complexity of health information, the lack of a universal user population, and the longitudinal scale of the information contained [92]. Usability improvements that are needed include the ability to easily import, export, and trend information [93]. Importantly, mobile health approaches, such as text messaging outreach that requires only a basic-feature phone, are showing particular promise in some of these populations [94]. As portal features are further tailored and consumer access to mobile devices and the Internet continues to increase, use of portal services may also grow in vulnerable populations. Clinical informaticists must remember, however, that some patients will continue to be less capable or less interested in using them.

## *Awareness, Motivation, and Usefulness*

Despite efforts to promote the availability and potential benefits of using patient portal systems and other consumer ICTs, lack of awareness among consumers continues to be a significant factor inhibiting use [79, 95, 96]. An assessment in 2011 revealed that more than half of consumers were still not familiar with the concept of a PHR [97]. More recent data demonstrate that lack of awareness of portals and their features continues to be a major factor in inhibiting use [90, 98, 99]. As emphasized by prominent implementation theorists, having adequate knowledge of a technology and its features is a prerequisite for adoption and assimilation [100]. Research continues to emphasize that consumers must be educated and encouraged to adopt and use portal services. Notably, in integrated delivery systems and academic centers where patients are being actively made aware of the availability of a patient portal, patient use has continued to grow over the past decade with as many as 70 % of enrolled populations signed up for the technology [101].

Like other technologies, motivation to utilize consumer ICTs is also dependent upon perceived relevance and value [100], including the relative advantages of use among available alternatives. To facilitate ongoing use, portals need to be seen as reliable tools that are characterized by quality interactions. Among the different services available through patient portals, patients most commonly use and report highest satisfaction with exchanging secure electronic messages with providers, ordering medication refills and viewing the results of medical tests [102–105]. However, adoption of patient portals also appears to depend on providing a constellation of convenient and functional services rather than selected functionality [102]. In healthcare systems which engage with patients online, secure messaging encounters can become an important component of patient-provider communication. Two large healthcare systems recently reported that one third of all primary care contacts with patients were conducted through secure messaging [102, 106]. Offering portal services also appears to be important to retention of patients by providers and health plans [107, 108]. While the evidence about use of patient portals by specific patient populations remains mixed [109], some studies show that patients with chronic health conditions and new healthcare needs are more likely to use them, including those with diabetes, depression, and HIV [77, 103, 110].

## *Clinician Endorsement*

Healthcare professionals are key determinants of whether patients use the technologies available to them, including patient portals. Although portals and PHRs have historically been cast as tools for patients, provider endorsement is an important factor in a patient's choice to adopt such tools [53, 111]. Additionally, clinician engagement with portals and PHRs may be required to achieve and sustain anticipated positive outcomes [97, 112]. Although there has been a prominent focus on portals

and PHRs as tools to support consumers, much of the value that consumers derive from the use of these ICTs will be directly affected by the attitudes and actions of healthcare providers within clinical settings. Providers can increase patient portal use by encouraging patients to enroll and use them [53, 83] or, alternatively, further impede use by actively discouraging or passively failing to address patient assumptions about provider engagement, interruptions or reimbursement [113]. As patients continue to see healthcare providers as a source of expert information, encouraging and also demonstrating use of consumer ICTs will be crucial [48].

Research also reveals that patients are more likely to use portals if they had a primary care provider, or switched to one, who more regularly used secure messaging to communicate with patients [77, 78]. Patients have also been more likely to use a portal when they trust their primary care provider, and report better communication with their provider [114], and when a provider is female and younger [83, 109]. The role that providers play in influencing patient adoption and use of portals highlights the importance of the portal as an environment for ongoing collaboration in the processes of care [115].

Despite the evidence and the opportunity for building enhanced partnerships with patients, some providers remain reluctant to communicate through the secure messaging features of patient portals, citing several barriers. Chief among them is lack of reimbursement [116]. Electronic communications with patients are not regularly reimbursed in the fee-for-service environment. This barrier has been partly addressed recently by financial incentives through meaningful use attestation and in the patient-centered medical home by coupling secure messaging with care coordination [117]. The second most commonly cited barrier for providers is added workload. Even for salaried providers, adding electronic communication to a busy schedule of in-person visits can be a resource strain [118, 119]. Finally, many providers cite concerns about data security and privacy and medical liability issues as barriers. However, secure messaging systems and patient and family online access to visit summaries is now required of all certified EHRs which, in part, will help to address these barriers. Provider reimbursement and sufficient time remain significant barriers to further engaging patients and families through the secure electronic messaging features of patient portals. In the next section we describe implementation strategies that can be developed and deployed to encourage the adoption and effective use of consumer ICTs.

## **Implementation of Consumer Health Informatics**

Addressing the factors described above to realize the IOM vision for delivering safe and sustainable health care in an era of greater consumer access and empowerment will require effectively leveraging technology. Clinical informaticists play a key role in the design of health informatics technology for consumers, and equally important, in promoting effective implementation within healthcare settings as complex adaptive systems. Like any innovation, the implementation of consumer

ICTs often precipitates change for stakeholders; particularly in their existing patterns of activity, practice, and behavior. Drawing upon implementation science, specific strategies can be employed to thoughtfully plan and execute programs of implementation for consumer ICTs that are tailored to specific settings and contexts. In their systemic review, Powell and colleagues define these implementation strategies as “a systematic intervention process to adopt and integrate evidence-based interventions into usual care” [120]. In this section, we describe four general strategies that can enhance the implementation of consumer ICTs. They include (1) following the principles of user-centered design; (2) integrating ICTs with existing activities, practices, and workflow; (3) engaging stakeholders, leadership, and clinical champions; and (4) providing education and incentives.

### ***User-Centered Design***

To be useful, eHealth applications and tools must be designed to be easy to adopt and use [121], and to meet patient’s actual needs and capabilities [122]. User-centered design (UCD) is a design philosophy which focuses on the end user’s needs, preferences, and limitations at all stages within the design process and development lifecycle [123]. The emphasis is on understanding the end user’s tasks and goals, and optimizing the product for the user to fulfill these, rather than having to adapt to the designer’s preferences [124]. User-centered design of eHealth applications and tools necessitates understanding and incorporating relevant consumer perspectives. If it also connects to clinical functions and workflow (e.g., secure electronic communication), then it must also be informed by the perspectives of healthcare professionals.

### ***Integration with Existing Activities, Practices, and Workflow***

Consumer Health Informatics entails not only providing patients with useful and usable tools that empower them to be active participants in their health care, but also creating an environment that supports use of the tools within the organizational context of healthcare delivery; from patient/physician interactions (e.g., secure electronic communication) to the representation of information within the clinical information system (e.g., patient generated data). Understanding how patient use of ICTs integrates within the context of the healthcare interaction, and impacts the provision of services by healthcare professionals in organizational settings is critical to achieve broadly anticipated benefits [53]. All types of work involve some creation, capture, application, or exchange of information. In health care, activities often pivot around such information use [125–127]. Implementing technology in healthcare settings must take into account the collaborative nature of healthcare work, the primacy of information in this work, and the importance of the flow of information

between participants as key elements of this collaboration [128]. In some cases, implementation of ICTs may even require a fundamental redesign of healthcare processes to focus on a patient-centric model with careful attention to ethical and policy considerations to avoid unintended consequences [129].

Changes in the type or flow of information may have profound implications for the activities and work practices that are part of the delivery of healthcare services [130]. Workflow represents a commonly understood set of procedures for and sequence of work tasks, along with the assignment of specific roles for individuals to accomplish these tasks. Taken together, these comprise processes that organizations manage to accomplish work. In healthcare settings, if a technology is to be implemented successfully, alignment with the larger clinical workflow is needed in order for its use to be effective and efficient for the healthcare team. In addition, integration with existing organizational systems and business practices is crucial or the consumer-oriented technology will be disconnected, resulting in minimal benefit. As an example, implementing a triage team model for secure electronic messaging allows many incoming messages to be handled appropriately and efficiently by members of the broader healthcare team (e.g., physician assistant, pharmacist), reserving the more complex clinical issues for review and response by a physician. This approach can alleviate some of the potential workload strain described earlier, while aligning new technology with existing processes.

### ***Engaging Stakeholders, Leadership, and Clinical Champions***

Although traditional implementation efforts often focused on the technical aspects of information technology, a significant body of literature emphasizes the importance of social and organizational factors which influence the implementation and use of the technology [131–133]. An ecological perspective that emphasizes the interactions between people, processes, and technology [134] highlights the need for all stakeholders to be involved in the decision-making process, for example, ensuring that healthcare professionals are engaged in planning efforts related to consumer-oriented tools and services. Since implementation may involve a new or modified practice for healthcare professionals, it is crucial to also consider their perspectives, professional values, and local practice patterns. Ensuring visible leadership support and engaging clinical champions is an important strategy for effective implementation [135, 136].

Drawing upon diffusion of innovation theory [100], implementation efforts require effective communication processes in which relative advantages are highlighted, while ensuring compatibility with existing norms, values, and beliefs. In addition, the technology and the impact of its use by consumers must be perceived by individuals as relevant to their work, and as having greater value than the available alternatives for accomplishing specific work tasks (e.g., using secure electronic messaging as an efficient alternative to telephone communication).

## ***Providing Education and Incentives***

Implementation science recognizes the importance of education and training to ensure that intended users have the knowledge and skills to make effective use of the technology [137]. In the past, Consumer Health Informatics initiatives have often focused on the provision of education and training for consumers, while neglecting similar needs for healthcare professionals. Yet the single most effective strategy for promoting patient adoption and use of PHRs is the encouragement of a trusted health professional and concordant support from administrative and clinical staff [138]. Providing staff with opportunities for training that fit with their needs is a key implementation strategy to ensure a cohesive approach to patient endorsement, encouragement and support [53].

If the implementation of a new technology is accompanied by incentives that affect intended users, the adoption and use of the technology can also be facilitated. Incentives can drive the prioritization of staff activities, the allocation of resources to meet established goals and targets, and the continuous measurement and monitoring of progress. Incentives can operate at the organizational level or at the individual and/or team level. Organizational incentives for performance can be financial (e.g., performance pay) or non-financial (e.g., transparency of performance indicators both internally and externally). At the individual level, incentives can include remuneration for work efforts that can be either financial (e.g., reimbursement for specific activity) or non-financial (e.g., workload credit for activity). Whereas fee-for-service models incentivize quantity of workload, pay-for-performance models incentivize accomplishment of organizationally defined performance measures. Although performance measures have previously been focused mostly on clinical quality measures, the addition of measures related to technology use exemplifies the application of incentives at the organizational level to facilitate the role of healthcare professionals in patient adoption and use of consumer ICTs.

Although the aforementioned strategies can be effective at furthering implementation of consumer ICTs, it is also important to recognize that a variety of factors can also influence the degree to which consumer health informatics implementation efforts will be successful. We provide an overview of such factors in the next section.

## **Assessing the Impact of Consumer Health Informatics**

As the field of Consumer Health Informatics continues to evolve, measuring the impact of consumer ICTs on healthcare stakeholders and the delivery and receipt of healthcare services is similarly beginning to take shape. Emblematic of a developing field, however, studies to date have primarily focused on descriptions of consumer health informatics tools and their features, characterizations of users, and the need for additional research to generate scientific evidence of impact [109, 139, 140]. In this section, we begin with overarching recommendations for future research directions of special importance to clinical informaticists. We then describe

the current state of published evidence regarding the effectiveness of two classes of consumer ICTs – patient portals and mobile health technology – to exemplify the state of the science, followed by a discussion of actual and potential unintended consequences of consumer ICT interventions. We conclude with areas that warrant further research.

### ***Methodological Approaches to Consumer Health Informatics Research***

Analysis of the evidence available to date points to three needed directions for research in Consumer Health Informatics, each of which has important implications for clinical informaticists. First, as evidenced throughout this chapter, the range of consumer ICTs now available or in development is vast and quickly evolving, and represents diverse technical systems. Assessments of impact should be stratified to examine the effects of distinct functions, and the mechanisms by which these capabilities influence explicit outcomes; recognizing that the heterogeneity of platforms, populations, and other contextual variables will still have considerable influence on the relevance of findings to other settings.

Secondly, there is a need for greater methodological pluralism, including use of both qualitative and quantitative approaches. Studies that focus either on the technical aspects or anticipated outcomes may fail to take into account social, organizational, professional, and other contextual considerations [141]. Ethnographic approaches to studying consumer ICTs as they are actually used in healthcare settings is crucial [142], avoiding a limited focus on pre-determined outcome measures, and further enabling the identification of unanticipated consequences or “emergent effects that may be enduring” ([141], p 41). Indeed, we advocate for examining Consumer Health Informatics as a component of healthcare work, influenced by and influencing organizational actors and their work within the healthcare ecosystem [53]. As such, research and evaluation must inherently include an examination of processes of care and associated health behaviors [42], employing participatory research approaches to engage both consumers and health care professionals [143]. Informaticists will play an important role in constructing a bridge between the technology and its use, ensuring that the analysis and mapping of processes engages all of the participants involved in the nexus of patient care, with careful attention to the flow of information.

The third needed direction for research in Consumer Health Informatics is the advancement of patient centered outcomes research (PCOR) [144]. PCOR extends the concept of patient-centered care discussed earlier to health care research by “helping people and their caregivers communicate and make informed healthcare decisions and allowing their voices to be heard in assessing the value of healthcare options” [145]. This research, in turn, informs patient health care decisions by providing patients and their caregivers with evidence on the effectiveness, benefits, and potential harms of different treatment options for different patients. Including the



perspective of end users has the potential to inform the research and also enhance the relevance of research findings, while also improving the likelihood that patients will achieve the health outcomes they desire.

## *Patient Portals*

Characterizing the impact of patient portals on outcomes must consider the various ways in which a patient portal could affect patient health and behavior, including use of specific features. However, simply enrolling (or being enrolled) in a patient portal may itself have positive outcomes, on the basis of patients having improved ability to view (and sometimes modify) elements of their own medical record, review laboratory test results, and communicate securely with their healthcare providers via electronic communication. Additionally, a patient portal creates the opportunity for the healthcare system to reach out proactively to enrolled patients, with targeted and perhaps even tailored interventions that can further engage patients and potentially change behavior. Research studies will need to disentangle the nuanced effects of patient enrollment from targeted outreach efforts.

Evidence remains limited on the impact of patient portals and other consumer health technologies on healthcare quality and utilization. Studies from early adopting healthcare providers and integrated delivery systems have found that portals which offer secure electronic messaging can improve access to care [146], patient satisfaction [102, 103] and chronic care outcomes [103] for many patients. Patient portals may be particularly valuable when combined with new models of primary care, such as the patient-centered medical home (PCMH) [147, 148]. Patients using portals which provide access to electronic health records report better understanding of health conditions and the plan of care [99]. Better patient adherence has also been reported among those using a portal-based medication refill function [149] and accessing their provider's clinical notes [99, 107].

To date, evidence remains mixed on the impact of patient portals on traditional forms of healthcare utilization. Some studies suggest that use of a patient portal increases utilization of in-person outpatient visits, emergency room visits and hospitalizations; while other studies suggest it leads to less outpatient and urgent care utilization [103, 150]. Most studies of utilization have thus far been observational and challenged by the difficulties of being able to compare healthcare use among those who sign up and use portals with those who do not.

In terms of effects of patient portal enrollment, a 2011 systematic review [151] identified four controlled studies published between 1990 and 2011 reporting the effects of electronic patient portals on patient care; three randomized controlled trials (RCTs) and one retrospective cohort study. In the two RCTs that examined the effects of patient portals on health outcomes, such as mortality or hospitalization, there was no statistically significant difference between the intervention and control groups [152, 153]. In the third RCT, use of the patient portal had no effect on indicators of patient engagement [154]. More recently, four additional RCTs published in

2012–2013 further evaluated the effects of patient portals on health outcomes [155–158]. These studies also showed heterogeneity in their results; while one study showed convincing increases in rates of herpes zoster vaccination among patients randomly identified to receive an outreach message delivered electronically via a patient portal [155], another study showed no effect of a patient portal on rates of adverse drug events [159]. Randomized trials engaging patients through outreach over portals with secure messaging have shown improvements in glycemic control in type 2 diabetes patients, blood pressure control in hypertensive patients, easing of depression in patients recently starting antidepressants, and improved receipt of preventive care services [109]. As more interventions that utilize patient portals and other consumer health technologies are developed and adopted over the next 5–10 years, the evidence base assessing impact on health outcomes will continue to grow for increasingly sophisticated and diverse interventions.

### ***Mobile Health (mHealth) Technology***

Owing to the exponential growth in the number of patients who have mobile phones, increasingly health systems and researchers have attempted to use this medium to change patient behavior and, ultimately, improve health outcomes. Although smartphone applications (apps) hold immense promise for patient engagement and health behavior change, most studies to date have capitalized on the more widely accessible Short Message Service (SMS), or text messaging. A 2014 systematic review identified 20 comparative studies, including 13 RCTs, that used SMS to improve adherence to medications, with interventions targeting patients with human immunodeficiency virus (HIV) infection or other chronic conditions (e.g., hypertension or diabetes mellitus) [160]. The review indicated that adherence to medications improved in the SMS-intervention group in a majority of studies. Similarly, another systematic review assembled 59 trials investigating the use of mobile technologies to improve disease management and 26 trials evaluating their use to change health behaviors [161]. The authors found strong evidence that SMS-based interventions improve adherence to medication treatment for patients with HIV and also found that texting interventions improved smoking cessation. Finally, mobile health interventions using text messaging are showing promise including improvements in sustaining weight loss [162], improving immunization rates [163], and improving medication adherence [164].

While considerable evidence thus suggests that SMS-based interventions – a relatively primitive technological approach – can improve certain health measures, there is much more uncertainty about the potential for more technologically advanced mHealth strategies to improve health outcomes. Despite their widespread appearance and increasing use among patients and healthcare providers, mHealth interventions relying on smartphone applications have generally not yet been tested in rigorous RCTs.

## *Unintended Consequences*

Moving forward, scientific evidence demonstrating the impact of consumer ICT use will be critical, including understanding the potential for unintended consequences [42]. These consequences could be desirable, enhancing health processes or outcomes, or undesirable adverse effects which could disrupt the care process or degrade outcomes. Various harms could be associated with consumer ICTs, including the risk of data breach and inadvertent disclosure of personal health information. With the US Department of Health and Human Services' documentation of more than 1600 data breaches involving 500 or more individual patients' health records since 2009 [165], consumer ICTs must inherently incorporate safeguards to protect patient privacy and ensure information security. Ozbolt and colleagues have assembled a comprehensive list of potential unintended consequences related to consumer ICTs along with strategies for mitigation [166]. Primarily these entail effectively striking the balance between enabling ease of information exchange and protecting patients' privacy rights, concerns, and preferences. Unintended consequences that can result from the tension between patient desire for access to and control of health information and providers' needs for full information about the patient include patients inadvertently or purposefully restricting access to information that may be needed by healthcare providers for clinical decision-making, and the introduction of uncurated and potentially imprecise data into the EHR with at least the potential for negative impact on clinical decisions. While researchers and policy makers need to be attuned to the emergence of unexpected behaviors or outcomes associated with use of consumer ICTs, clinical informaticists are well-positioned to identify and proactively mitigate potential undesirable consequences.

## *Future Research*

Over the next several years, the expansion of Meaningful Use is expected to increase adoption of patient portal services including secure electronic messaging and direct patient access to electronic health records. At the same time, a broad variety of new consumer health technologies will be developed, tested, and deployed. These changes in policy and technologies may extend the reach of consumer health technologies into populations that have not yet been able or interested in using the functions of traditional patient portals. These shifts may also provide new opportunities to improve the quality and cost of care. As the examples of patient portals and mHealth illustrate, relatively few RCTs of consumer ICTs have been conducted, and even among these studies, many suffer from methodological limitations such as small sample sizes, inability to conceal allocation of the intervention and limited generalizability. As previously noted, other methods will also be crucial to develop a robust evidence base around the impact of consumer ICTs. With their knowledge and skills, clinical informaticists represent key resources to support the collaborative design, implementation, and evaluation of these tools.

**Fig. 19.2** Blue Button® logo (*Blue Button*, the slogan, ‘*Download My Data*,’ the *Blue Button* Logo, and the *Blue Button* Combined Logo are registered service marks owned by the U.S. Department of Health and Human Services)



## Emerging Trends

The domain of Consumer Health Informatics is rapidly evolving both in terms of the paradigm shifts discussed earlier, and in the explosion of available web-based services, mobile health applications, and other technology-enabled tools. In this section we describe several important trends that are emerging in this field. We focus on tools and services that are becoming accessible to consumers, although not yet uniformly available to all, nor broadly adopted or institutionalized.

### *Blue Button*®

The Blue Button® concept emerged in 2010, aimed at enabling more direct consumer access to personal health information by adding a “Download My Data” button to patient portal systems [167]. Within the next 6 months, the US Department of Veterans Affairs (VA) added the Blue Button® symbol (see Fig. 19.2) to the VA patient portal, My HealtheVet, enabling Veterans to securely download their own health record electronically. Since then, the Blue Button® has spread beyond VA to other government agencies and the private sector. Over time, technology developers have demonstrated innovative ways to enhance visual representation of Blue Button® data, and novel applications emerged to enable consumers to import and aggregate their Blue Button® data from various sources [168, 169]. Responsibility for encouraging broader use of Blue Button® and enhancing its technical standards was transferred to the Office of the National Coordinator for Health Information Technology (ONC), a division of the US Department of Health and Human Services,

in 2012. In 2014, ONC also launched a Blue Button® Connector website [170] to help consumers locate and access their personal health information sources.

As discussed in the Major Drivers section, to promote broader availability, Stage 2 of Meaningful Use incentivizes healthcare organizations and professionals to provide patients with the ability to view, download, and transmit their personal health information. While many consumers are beginning to use Blue Button® features, additional work is needed to enhance consumer awareness and provide education and training for effective use [90], and to evaluate the impact of enhanced consumer access to electronic data on both processes of care and outcomes [42]. Blue Button® represents a fundamental shift in health care, promoting unprecedented consumer access to and ability to use personal health data.

### *OpenNotes*

OpenNotes is a national initiative in the United States to give patients easier access to the clinical notes written by their healthcare providers. The OpenNotes movement began with an innovative 12 month study at three diverse medical institutions to explore how sharing clinical notes with patients may affect their health care [171]. Early evidence demonstrated positive effects with minimal impact on provider's workflow. Patients with access to their doctors' notes felt in more control of their care, and reported better understanding of their health and conditions, improved recall of their care plan, and being more likely to take their medications as prescribed [107]. These findings were replicated on a nation-wide scale when the VA enabled online patient access to all clinical notes in January 2013. The experiences of early adopters demonstrated that patients both value and benefit from online access to their clinical notes [99]. Additional outreach and education is needed to inform and educate patients about their ability to access clinical notes, and the potential role that this information can play in their care. While additional research is needed, advocates argue that transparency and access to notes for even sensitive topics like mental health issues may have additional therapeutic benefit [172]. The VA study concluded that healthcare professionals who are authoring clinical notes should keep in mind the opportunity that patient note access presents for supplemental communication, for example reinforcing the treatment plan and medication instructions. Future research should examine the kinds of support that healthcare professionals need to effectively capitalize on patient access to notes.

### *Consumer Mediated Exchange and Health Record Banks*

Health information exchange (HIE) is defined as the electronic movement of health-related information among organizations according to nationally recognized standards [173]. As described in Chap. 11, the goal of health information exchange is to facilitate

access to and retrieval of clinical data to provide safer, timelier, efficient, effective, equitable, patient-centered care across care settings. Organizational health information exchange (HIE) models including query-based exchange (the ability for providers to find and/or request information on a patient from other providers, often used for unplanned care) and directed exchange (the ability to send and receive secure information electronically between care providers to support coordinated care). Despite anticipated benefits, some challenges remain including workflow issues, privacy and security concerns, and the lack of a compelling business case for system sustainability [174]. Recognizing that consumers can play an important role in ensuring timely access to information across care settings, Meaningful Use is also driving a new complementary model of HIE: consumer-mediated exchange. In this form of HIE, patients are provided with the ability to aggregate and control the use of their health information among providers through patient portals and systems that enable them to view, download, and securely transmit their personal health information [175]. While significant progress has been made, issues with interoperability and technical maturity will need to progress in order to accomplish the goal of enabling consumers to securely transmit their personal health information across systems and settings. Moving forward, understanding how organizational health information exchange and consumer-mediated exchange models can meaningfully coexist and complement one another will be an important question for the field of Consumer Health Informatics.

An alternative model to an institution-centric health information infrastructure is a patient-centric model that can enable a more comprehensive and longitudinal patient health record: health record banking [131, 176]. A health record bank is an independent organization that provides a secure electronic repository for storing and maintaining an individual's lifetime health and medical records from multiple sources, while assuring that the individual always has control over who accesses those records [177]. A health record bank model may offer distinct advantages including more comprehensive information for clinical decision-making, simplified patient access to aggregated data from multiple care settings, centralized management of patient permissions, more effective record deposits and retrievals, and more sustainable economies of scale [178].

### ***Mobile Health: Devices, Monitors, and Sensors***

We include mobile health or “mHealth” as an emerging trend in this chapter mainly because of the rapidity with which the area is evolving and expanding, and its considerable implications for health care practice, research, and public health. As noted by Susannah Fox, “in 10 years we have seen the Internet go from a slow, stationary, information vending machine to a fast, mobile, communications appliance that fits in your pocket. Information has become portable, personalized, and participatory” [179]. The term “mHealth” was coined by Robert Istepanian in 2005

to describe the emerging use of mobile communications and network technologies for healthcare [180]. More recently, mHealth has been described simply as “the delivery of healthcare services via mobile communication devices” [181]. These devices include a growing array of mobile phones (including smart phones), tablet computers, personal data assistants (PDAs), and patient monitoring systems and sensors that enable consumers to access and share information, track data, communicate, exchange information, and/or accomplish other health-related tasks. Increasingly, the consumer marketplace also includes wearable technologies and remote sensors which enable consumers to measure and monitor various types of data: from fitness activity to sleep patterns and other types of measurements.

The convergence of portable computing power and increases in broadband and wireless Internet access have resulted in new opportunities which are shifting consumer access to eHealth tools with some potential to reduce the digital divide [182]. Advocates of mobile health technologies point to many advantages including: anytime/anywhere access, the convenience of portability, cost effectiveness, and increased rates of consumer adoption. Analysts predict that the market for mobile is poised for growth [183]. Advances in technology, however, are outpacing the science of mHealth and more research is needed to understand evolving trends in consumer behavior, and to also assess the impact of mHealth tools with scientific rigor [184]. Clinical informaticists will play a crucial role in the evolution of mHealth, as early pilots move towards fuller implementation.

### ***Complementary Models of In-Person and Virtual Care***

Consumer Health Informatics tools and services have also laid the foundation for complementing traditional in-person care with virtual care. With the growing recognition that some types of patient-physician encounters can be appropriately completed without requiring face to face contact, use of alternative methods such as online assessment forms and/or secure email messaging offer the advantages of convenience, efficiency, and cost effectiveness [185]. One method of incorporating these technologies into clinical practice settings is providing patients with the option of online electronic office visits or “eVisits.” Increasing numbers of healthcare systems are now beginning to offer eVisits to their patients for certain types of health care needs; allowing physicians to provide a patient consultation online. Enabling this functionality more broadly will require addressing several challenges, including establishing effective reimbursement structures, ensuring patient health and computer literacy, and developing models that allow for integration with existing clinical workflow, organizational structures, and business and clinical processes [186]. Early assessments reveal that these forms of virtual care may also attract a younger patient population who place high value in convenience [187].

## Summary

As the nascent field of Consumer Health Informatics evolves, driven by unprecedented technological advances and the rise of a new consumer e-patient, the stakes are high. As Dr. William Frist cautions, “America’s health care delivery sector stands at a tipping point—a convergence of a growing, graying, and highly consumptive population with increasingly limited financial and human capital resources” [188]. He also notes, however, that the combination of newly empowered consumers armed with actionable information plus significant advances in information technology have the potential to “radically transform and improve health care delivery.” Clinical informaticists will be essential in realizing that potential.

Equipped with fundamental knowledge and diverse skill sets, clinical informaticists will create strong foundations to support the effective, design, implementation, and evaluation of technology-enabled systems. They will serve as expert consultants, innovators, and problem solvers. They will create collaborative approaches that leverage the interactions between people, organizations, and socio-technical systems, and help us to apply consumer ICTs in ways that complement and enhance traditional methods of health care delivery. Clinical informaticists will build the bridges connecting the science of technology and the art of medicine. As such, they play a key role in transforming health care.

## Questions for Discussion

1. Although the hospital network has provided a patient portal for the last 7 years, only 5 % of enrolled patients have signed up to use the portal service. What strategies should the clinical informaticist recommend in order to improve adoption and use?
2. The new strategic plan for a mid-sized integrated healthcare system calls for the purchase and installation of a new patient portal within the next 6 months in order to meet Meaningful Use Stage 2 guidelines. What implementation strategies should be used to develop an effective approach?
3. The Chief of Staff has requested a presentation by the clinical informaticist that includes recommendations on whether to join the OpenNotes movement and enable patient access to clinical notes. What recommendations should the presentation include?
4. The hospital technology department recently launched a new mobile application that allows patients to securely communicate with their healthcare provider; however clinicians were not made aware or provided with education or training in advance of the launch of the new feature. Patient complaints have been coming in to the hospital director’s office that messages are not being responded to. What went wrong and what can the clinical informaticist do now to develop an action plan to begin to solve the problem?



5. The clinical informaticist has been asked to consult with the research team to develop an evaluation plan for the healthcare system's patient portal. What methods should be included in order to effectively evaluate the patient portal-?

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