Consumer Health Informatics and Personal Health Records

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After reading this chapter, you should know the answers to these questions:

- What is the central tenet of consumer health informatics?
- What are the issues that biomedical informatics research can address relating to consumer communication, decision-making, and information access needs?
- Although technology is a major focus of the discussion around consumer health informatics, we realize that any technology of interest today will be obsolete in the next 10 years. However, the issues this technology is trying to address will continue to be prevalent. With that in mind, what are the larger biomedical informatics topics this technology is being used to address?
- Define patient portals, personal health records, patient-controlled health records, and personal health applications.

17.1 Introduction

Complexity and collaboration characterize health care in the early twenty-first century. Complexity arises from a deeper or more sophisticated understanding of health and diseases, wherein etiological models must take into account both molecular processes and physical environments. Collaboration reflects not only inter-professional collaboration, but also a realization that successful attainment of optimal well being and effective management of disease processes necessitate active engagement of clinicians, lay persons, concerned family members, and society as a whole. This chapter introduces technologies forming the foundation of **consumer health informatics**, including **personal health records** (PHR), **patient portals**, **personal health applications**, and **social networking**. We will illustrate how each of these tools embraces the complexity of health care and makes possible the collaborations necessary to engage consumers in health promotion, disease management, and preventive

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care. In the first part of this chapter, we introduce four common health care challenges that consumer health informatics addresses: consumer engagement, information sharing, communication and decision facilitation. We then describe the history of consumer health informatics and the tools commonly available to address the above challenges. We conclude the chapter by describing many of the emerging trends in the discipline and some of the continuing opportunities.

17.1.1 The Challenge of Improving Consumer Engagement

Contemporary consumers are under greater pressure to participate in their own care than have patients at any time since the emergence of modern health care. Patient participation takes many forms, including shared decision-making, self-care, and collaborative practices (Mead and Bower 2000). The role of the consumer as a full partner in health promotion and disease management has never been more necessary than now. In the distributed managed-care models of health care, consumers serve as their own case managers, brokering care from generalists, specialists, and ancillary groups. Rarely do consumers receive all of their clinical services from a single provider. Although health information technology, such as the electronic health record, provides an integrated data repository and communication service, the view of the patient from a single electronic health record often will not include a record of services provided through the continuum of care. Moreover, for some patients, the inability to access this record may represent a barrier to optimal care delivery (Detmer 2003). Consumer health informatics as a subdiscipline is founded on this need for access. A central tenet of consumer health informatics is that although not all patients will participate, patients participating in their health care leads to higher quality care than that which is achievable without patient participation.

Patient engagement is not purely driven by the patient. Seminal work by sociologists such as Goffman (1959) and psychologists such as Skinner (1938) and Deci and Ryan (1985) observed that consumers may become engaged because of an innate desire to be rewarded by participation or through external rewards. These observers of human behavior have reinforced the notion that in many individuals, innate desire motivates engagement without the apparent presence of an extrinsic reward or punishment as a consequence of engaging in the activity. These observers also note, importantly, that not every person will have an innate desire to engage, or may lack the desire as the perception of the cost of engaging increases. For these individuals, extrinsic motivators (money, material goods, and praise) may catalyze behavior change. It is also the case for many of these individuals that peers, family members, and even others in their social network may provide a surrogate for the patient's lack of engagement by actively participating in information gathering and health care decision making. All of these observations may be addressed by consumer health informatics researchers.

17.1.2 The Challenge of Improving the Information Available to Consumers

It has long been recognized that information sharing can lead to improved decision making and health care system vigilance. Pamplets, newpaper articles, and phone communication about disease outbreaks were once the only methods to accomplish information dissemination. These methods were suboptimal in their ability to address challenges with health literacy, numeracy, widespread access, appropriately timed access, or proper formatting/tailoring (for example, so that they could benefit adolescents as well as adults, or men as well as women.) The advent of the Internet, **interactive television** and a host of widely available home technologies provide a rich source of tools to address this challenge.

17.1.3 The Challenge of Improving the Communication Among Consumers and Providers

Consumer health informatics also strives to improve consumer-provider interactions by both helping to prepare patients for meaningful discussions with their clinicians and by facilitating shared decision making. A full discussion of the efforts in this area may be found in the chapter on Telemedicine (Chap. 18).

Consumer-to-consumer communication has been an important source of relevant information for patients with diseases of all sorts. Before the Internet became available, this type of communication was difficult, though many health care institutes, churches, and communities developed support groups for common diseases or interests (Lieberman 1988).

17.1.4 The Challenge of Improving Consumer Decision-Making

One of the most important aspects of consumer health informatics has to do with moving beyond providing background health information toward helping consumers make quality health decisions and appropriate actions. Before the increased availability of home computing and the Internet, patients facing difficult decisions used information available in public libraries or sent to them (via stamped, self-addressed envelopes!) They relied on conversations and advice from family, close friends, church members, other patients, or doctors. Importantly, they made decisions often with no attention given to the evidence supporting each treatment alternative, without an objective assessment of risks and benefits, and without recognizing their own personal characteristics that might impact the outcome of the chosen approach.

Each of these challenges to consumer engagement has rationalized work in the field of consumer health informatics since its inception. We will now briefly review the history of this sub discipline.

17.2 Historical Perspective of Consumer Health Informatics

17.2.1 The Rise of Consumer-Oriented Health Communications

In essence, what we think of as consumer engagement reflects a shift from the patient as the silent recipient of ministrations from a wise, beneficent clinician to an active collaborator whose values, preferences, and lifestyle not only alter predisposition to certain illnesses but also shape the characteristics of desirable treatments.

Patients, family members and the general public have long-played an active role in health care and have actively sought information from health professionals and government agencies. During the early twentieth century, the US Federal Children's Bureau served as a major source of health information for the public. Mothers could write to this federal agency, asking questions about normal child development, nutrition, and disease management. Written materials, such as letters and pamphlets served as the primary mechanism for delivering information that supported lay people in their handling of health challenges. Patient education companies such as Krames[1] would partner with organizations like the American Heart Association to provide general printed material on heart disease or with the American Cancer Society to provide information on cancer. As television became commonplace, broadcast and reproduction media including television, videotapes and audiotapes, were quickly harnessed by health professionals as a means for presenting complex information and health care instructions to people in their homes. Consumer health broadcasts, and eventually dedicated channels covering topics such as nutrition, fitness, and women's health issues, became common and were broadcast on local daytime television and radio networks. This mechanism continues today, and often uses consumer panels, live phoned in

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[1] www.krames.com (accessed 4/23/13).

Fig. 17.1 Early use of computing in consumer health informatics, here taking a medical history directly from a patient (Slack, WV, et al. (1966). *NEJM* with permission)

questions, expert guests, audience participation, and other ways to provide general advice for consumers.

Computers and telecommunications have been used since the early 1940's for patient assessment, patient education, and clinical information sharing. In the 1950's Collen and colleagues at Kaiser Permanente created a health appraisal system that prompted for patient data and returned a systematic risk appraisal (Collen et al. 1964). Then in the 1960's Warner Slack and colleagues at the University of Wisconsin used a mainframe computer system as a health assessment tool. Patients sat at a cathode ray tube (CRT) terminal and responded to text questions, receiving a printed summary of their health appraisal at the end of the session (Slack et al. 1967). Figure 17.1 shows an early example of the mainframe-based tool developed by Slack. At Massachusetts General Hospital in the late 1950's, computer-driven telephone systems were used to conduct home-based follow-up with post-surgery cardiac patients, calling them daily to obtain pulse readings. From the very beginning, these advocates for integrating technology into the examination room were intrigued by the aspect of computer use both by patients for their needs, as well as by patients to assist with health care professional needs.

17.2.2 Early Advances in Consumer Information Sharing and Decision Making

The legacy of the self-help movement of the 1970s and the consumerism of the 1980s was growth in the importance of the patient as a full participant in health care. At the time, the failure of bioscience research to produce definitive evidence-based guidelines for most common diseases required that medical science be combined with patient preferences (e.g., between surgical and radiation therapies). Patients participated by self-monitoring, by evaluating and choosing therapeutic strategies from a set of acceptable alternatives, by implementing the therapies, and by evaluating their effects. In addition, social and clinical changes in the manner in which care was provided shifted activities that were once the purview of licensed professionals to patients and their family caregivers. Furthermore, there was growing belief that behavioral interventions and alternative therapies held great promise as adjuncts, or even replacements, for traditional medical therapies.

In the 1980s clinicians and health educators capitalized on the increasingly common personal computers as vehicles for health education. Initially, computers were used primarily for computer-assisted learning programs, providing general coaching regarding topics such as nutrition and home care of the elderly. As shown in Fig. 17.2, The Body Awareness Resource Network (BARN), developed in the 1980s by Gustafson and colleagues at the University of Wisconsin, engaged adolescents in game-like interactions to help them learn about growth and development, develop healthy attitudes towards avoidance of risky behaviors, and rehearse strategies for negotiating the complex interpersonal world of adolescence (Bosworth et al. 1983). Later developments in the 1980s and 1990s moved beyond computer

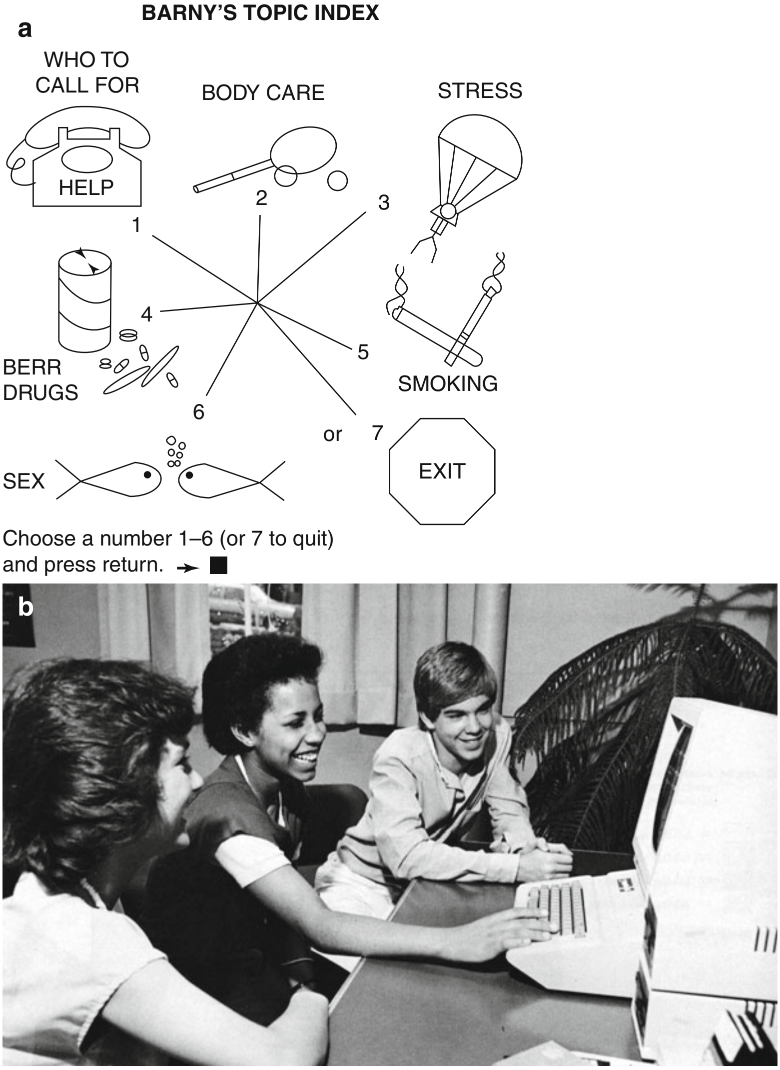

Fig. 17.2 BARN topic index and use by teens. Bosworth (1983). This picture shows teens interacting with a game on the an early graphical computer. The figure on the left is the topic index as displayed on the screen (With permission from Gustafson, D, personal communication)

aided learning to values clarification and risk appraisal exercises, thus capitalizing on the computational power as well as the visual display capabilities of the computer. As the Internet became more available in homes, Internet support groups gathered momentum. One such example, Hopkins Teen Central developed by Ravert and colleagues (2001), allowed otherwise isolated children with cystic fibrosis to meet virtually and to discuss health and developmental issues that impacted healthy decision making. This additional computational power eventually found its way into computer games (Kato and Beale 2006). Although these games were both time-consuming and expensive to build, they were relatively easy to disseminate, and were associated with measurable changes in knowledge (Lieberman 2001) and, in some cases, symptom management—such as with nausea in pediatric cancer (Redd et al. 1987) and anxiety management (Patel et al. 2006).

17.2.3 Early Advances in Consumer-Consumer Communication

Early electronic newsgroups, bulletin boards, and a precursor to the World Wide Web known as Gopher connected patients to information about various rare and chronic diseases (Grunfeld and Ho 1997; Grunfeld et al. 1996; National Research Council (U.S.). Committee on Enhancing the Internet for Health and Biomedical Applications: Technical Requirements and Implementation Strategies. 2000) One of the earliest such examples was patient handouts made available through the National Heart, Lung, and Blood Institute (Grunfeld and Ho 1997). This medium of distribution was attractive to many health care institutions because of the nature of the Internet, which allowed patients to retrieve information that was of interest without requiring the author to actively disseminate this information to a previously-identified group of people. Ferguson was heavily influential in the 1980's and 90's in creating and analyzing online social support groups for patients (Ferguson 1996). Later, Gustafson and colleagues in Wisconsin demonstrated that online social support could reduce anxiety and hopelessness, with suggestive evidence for improving coping skills and life expectancy (Ferguson 1997). Soon, the idea of the Internet support group became an active area of development, continuing through today (Eysenbach et al. 2004).

At the same time, this increasing use of the Internet raised concerns about the quality of the material available to consumers (Kershaw 2003). This concern, in turn, fueled an industry of groups consisting of content editors, clinicians, and technologists charged with creating legible and responsive consumer information that could be subscribed to on the Web, as well as others focused on rating the quality of this information. One notable group that promotes the deployment of useful online health information is the **Health on the Net Foundation** (HON),[2] pioneered by an international panel of experts and supported by the numerous European groups. Although many of these pioneering companies have long since vanished, the access to consumer health information has remained a core function of the Internet—with 56 % of American adults seeking information about a personal health concern annually (Tu and Cohen 2008).

17.2.4 Early Advances in Consumer Decision-Facilitation

Given that most health care activities actually take place in the home, away from clinics and hospitals (Ferguson 1996), it has always been important that individuals be active and informed participants in their own care. A variety of approaches have been used to provide "just-in-time" information and decision assistance to consumers. As noted above, pamphlets and videos were created to explain treatment options and medical procedures to patients, as background for decision-making. This was followed by an era of interactive video systems to help patients understand the risks and benefits associated with treatment options, but also to help define their values for possible future health outcomes. The prime examples of this type of system originated with the Foundation for Informed Medical Decision Making.[3] As early as 1973, Wennberg and others discovered that the rates of many expensive surgeries and other treatments would vary from location to location throughout the U.S. (Wennberg and Gittelsohn 1973). This variation seemed to occur for medical conditions where there were multiple viable treatment options and choices depended more on physician and resource availability than need or patient characteristics. Wennberg and Mulley focused on developing interactive video consumer decision aids that focused on these conditions (e.g., prostate cancer, breast cancer, back pain, etc.), discovering that patient preferences and priorities for possible health outcomes could vary dramatically from person to person, and could be critical to defining an optimal decision.

17.3 Current Trends

17.3.1 Consumer-Facing Software

There is an enormous amount of momentum in consumer activation. In part, this momentum is fueled by lessons discovered by pioneers in the

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[2] www.hon.ch (accessed 4/23/13).

[3] www.informedmedicaldecisions.org (accessed 4/23/13).

Table 17.1 Various modes of consumer engagement with health care technology

Mode of engagement	Definition	Examples
Communication	Support for patient-to-patient, computer-to-patient and patient-to-provider knowledge or information dissemination	Patient portals Patient-physician secure email Online support groups Social networking sites
Data storage	A patient-centered and managed repository for patient-entered data or "liquid" health-related information	Personal health records Data portals for devices, health systems and, pharmaceutical companies
Behavior management	Tools to support personal health goals, often by combining data storage, care protocols, information dissemination, and communication	Weight management tools Physical activity tools Medication reminder systems
Decision aids	Prepare people to participate in 'close call' decisions that involve weighing benefits, harms, and scientific uncertainty	Interactive tools for Breast Ca, Prostate Ca, Back Pain, End of Life, Heart Disease

field. In addition, this momentum is the consequence of a contemporary health care environment that is more diffuse and involves more people than ever before. The home and the community are fast becoming the most common sites where health care is provided. Information technologies necessary to support patients and their family caregivers must not only migrate from the inpatient institution to the community but also be populated with information resources that help to guide patients in complex health care decision-making, to communicate with health professionals and to access the clinical records and health science knowledge necessary to help them comprehend their health states and participate in appropriate treatments.

With the ready availability of home computers and cellular phone platforms that support Web browsing and extensible software via "apps," there is a wealth of what is called "consumer-facing" software now available to consumers. Although the types of consumer-facing health technology will come and go over the years, these technologies can be categorized into four modes in which consumers engage with health care through the use of technology. Table 17.1 summarizes these modes. Each mode of engagement will be discussed below, along with some examples illustrating the potential for this mode of engagement.

17.3.2 Communication

17.3.2.1 Patient-Centered Communication

For decades, as the health care system has had to wrestle with chronic illness and as an increasing knowledge base required practicing technically sophisticated and high quality care, the process of disease management has become more and more specialized. It is not uncommon for a patient to see up to seven different providers to manage the average chronic illness. Patients frequently express frustration about the inability for electronic health records to support record-sharing. This frustration has led to recommendations by the **Institute of Medicine** (IOM) that recognize the central role of patients as a repository of their own medical information in their "To Err is Human" book series (Aspden and Institute of Medicine (U.S.). Committee on Data Standards for Patient Safety. 2004; Institute of Medicine Committee on Improving the Patient Record (2001); Kohn et al. 2000), culminating the explicit notion that quality health care should be "patient-centered" among other attributes, and noting that six out of ten rules to improve health care quality depend on patient involvement in their care (Institute of Medicine (U.S.). Committee on Quality of Health Care in America. 2001). The role of patients in communicating also was a central component of early visions for the **National Health Information**

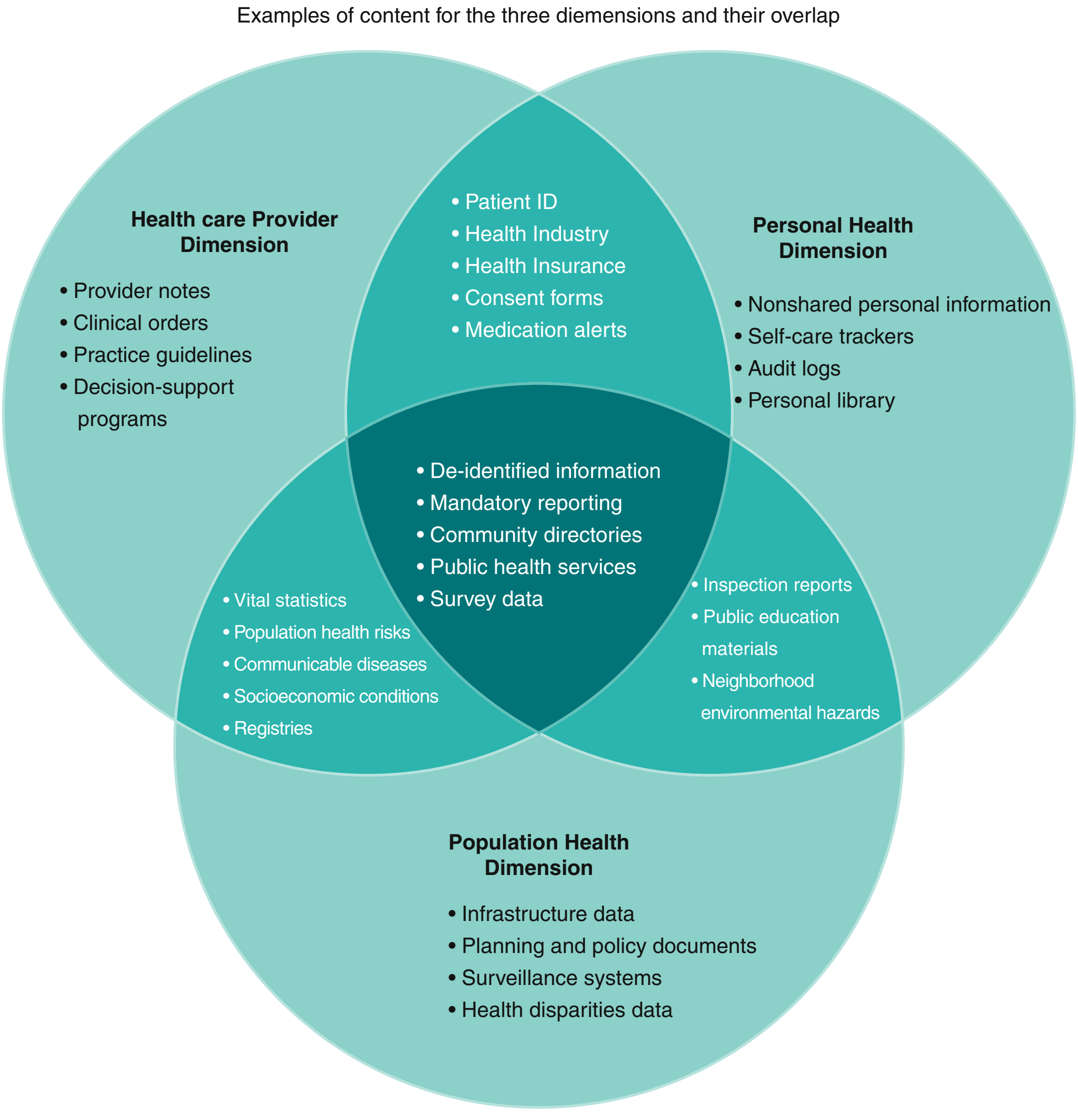


Fig. 17.3 Information dimensions. *Information for health: a strategy for building the National Health Information Infrastructure* (2001) (Source: http://aspe.hhs.gov/sp/nhii/documents/NHIIReport2001/default.htm)

Infrastructure. Figure 17.3 depicts the information dimensions outlined in this work, which included a personal health dimension that emphasized data required for patients to communicate among or on behalf of their providers.

In addition to this lack of what has been termed "data liquidity" (Courtney 2011) – representing the ideal state of fast, free-flowing, and interoperable data - there are data important to health that may not be in the typical electronic health record. For example, patient over-the-counter medications, home therapy for allergies or trauma, many health screening forms, and data derived in physiologic monitoring in the home may provide valuable information to caregivers.

Part of the STEEEP ("Safe, Timely, Effective, Efficient, Equitable, Patient-Centered") care framework by the IOM (Institute of Medicine (U.S.). Committee on Quality of Health Care in America. 2001), patient-centeredness implies that liquidity is facilitated by patients being able to access and direct other's access to their information according to clearer laws and protocols that provide consistency and transparency. This ensures that clinicians will have the right information to make informed decisions at the point of care.

17.3.2.2 Electronic Support Groups

As mentioned above, concomitant with the era of home computers and later, the Internet, there was an immediate recognition that technology had removed geographic and physiologic obstacles to communication. Patients who had rare diseases, or people in need of support to help make tough decisions or to face lifestyle altering conditions suddenly had a way to communicate with one another. One of the earliest electronic support groups was developed by Johnson and Ravert, who recognized the ease with which adolescents adopted technology. Hopkins Teen Central was an internet support group developed initially using a device known as WebTV™, which provided Internet access via phone lines and household televisions (Johnson et al. 2001). This project proved extremely successful. It demonstrated, for example, the power of patient-to-patient email, as well as the role of moderated health discussions in answering questions common to patients with a shared medical need.

Electronic support groups, also known as **Internet Support Groups** (ISGs), have since become an almost ubiquitous way for patients comfortable with the Internet to communicate with each other. One study has suggested that over 28 % of Internet users have visited at least one ISG (Horrigan et al. 2001). ISGs use four modes of communication alone or in combination: e-mail lists, instant messaging, bulletin boards, and chat rooms. While the sustained availability of these sites suggests their value to patients, a recent meta-analysis of ISGs for depression noted the poor quality of the evidence. Chat room use appeared to be associated with lower levels of depression. Patients with breast cancer appeared to get the most value from ISGs, although the results all came from one site. These equivocal results will benefit from more sophisticated multicenter trials; however, the lack of negative findings, coupled with the widespread acceptance of ISGs among consumer organizations suggests that this mode of communication should be considered as a part of armamentarium for biomedical informatics research and health information technology tools. Further research in this area includes the use of group videoconferencing and socialization interventions to more closely simulate the face-to-face support groups that have been shown to be effective.

17.3.2.3 Social Networks

The phenomenon of **social networking** has grown rapidly and is a new form of patient-patient communication. Such sites, epitomized by Facebook (www.facebook.com), are online virtual communities where participants describe themselves with member-entered attributes, establish or break connections to other members, communicate, and share information. This simple strategy results in an exponential number of community members sharing one or more attributes, allowing users to connect with people with similar conditions. The for-profit online health-related social networking community Patients Like Me has demonstrated that individuals with a severe chronic disease—amyotrophic lateral sclerosis—are highly willing, even without compensation, to contribute data and observations to a patient community (Frost and Massagli 2008) to accelerate learning about their disease. The site has no ties to the conventional health care system and short-circuits the traditional research enterprise, rewarding participants, not just researchers, with knowledge. The patient outcomes of diverse therapies are collected using crowd sourcing, where patients contribute their information to a common database that can be queried to obtain summaries of an aggregated experience of their peers.

Social networking Web sites share most or all of the features of electronic support groups, and even some data commonly provided through a portal (through creating an affiliation with a group who externalizes public or private information). Social networking platforms combined with personal health records provide a means for social network members to share and aggregate data obtained from the traditional health system,

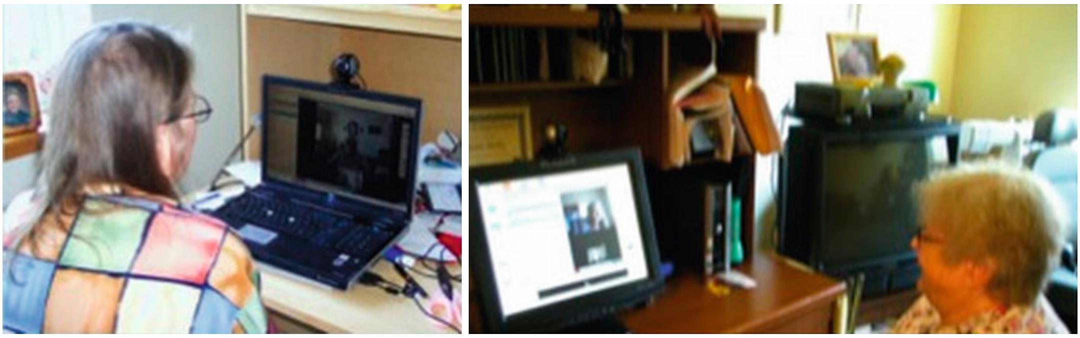


Fig. 17.4 These computer users are part of a cognitive health coaching study where they use their home computers to communicate with their coach, receive feedback from home monitoring data on cognitive exercise, sleep, physical exercise, and socialization. These photos show two study participants communicating with each other from their homes using Skype as part of the socialization protocol (Jimison et al. (2007) with permission)

and to do so in a private manner (Eysenbach 2008; Weitzman et al. 2011a).

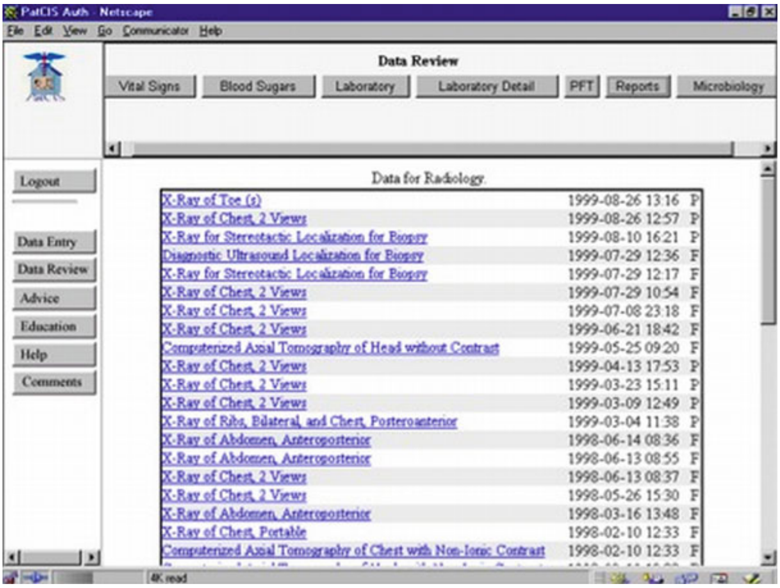
One of the features of health-related online social networks is the rapid dissemination of information across a network; however, there is great variability in the quality of discourse on health-related social networking sites. As shown in Fig. 17.4, conversations may be moderated (in this case by a health coach). Conversations also may be unmoderated and commercial influences may enter the discourse without transparency. There are also concerns around privacy. Compared with the restrictive institutional consents and compacts with patients that limit use of data and specimens under federal regulations applicable to much federally sponsored research, online social networks are generally governed by no more than a terms of use statement, often subject to change without notice in 30 days. These privacy policies may be difficult to find and not written in language accessible by a population with a broad range of health literacy (Weitzman et al. 2011b). Industry standards governing safety and privacy of online health-related social networking are yet to emerge.

17.3.3 Patient Access to Health Information

Szolovits' **Guardian Angel Proposal** represents one of the first, if not the first, example of recognizing the role of the patient as a curator of his or her lifetime of health data (Riva et al. 2001). The Guardian Angel "Manifesto" was posted when the Web was only 2 years old at the then readily available 2-letter domain name www.ga.org. The Manifesto presented a comprehensive vision of a Web-based process that would be spawned at a person's birth and care for them through management of health records, decision support, insurance benefits, education and communication. Over the past two decades, this vision has been realized through advances in personal health records.

17.3.3.1 Portals

As the electronic health record gains acceptance, its relevance to individual patients also grows. Many hospitals and clinics have begun providing direct patient access to the clinical record. These **portals** are defined as consumer-facing systems tethered to electronic health records, allowing patient views of clinical or claims data in a single institutional electronic health record system or payer system (Conn and Lubell 2006). Portals provide motivated individuals with a way to electronically access sections of their records to recall salient instructions or obtain results of tests (Markle Foundation 2004). Some of the first such personal health records (PHRs) were Columbia's PatCIS system (Cimino et al. 1998) and Beth Israel Deaconess's PatientSite, developed in 1999 (Weingart et al. 2006). Some of the most widely deployed are Epic's MyChart (which is used



Data for Radiology.

X-Ray of Toe (s)	1999-08-26 13:16	P
X-Ray of Chest, 2 Views	1999-08-26 12:57	P
X-Ray for Stereotactic Localization for Biopsy	1999-08-10 16:21	P
Diagnostic Ultrasound Localization for Biopsy	1999-07-29 12:36	F
X-Ray for Stereotactic Localization for Biopsy	1999-07-29 12:17	F
X-Ray of Chest, 2 Views	1999-07-29 10:54	F
X-Ray of Chest, 2 Views	1999-07-08 23:18	F
X-Ray of Chest, 2 Views	1999-06-21 18:42	F
Computerized Axial Tomography of Head without Contrast	1999-05-25 09:20	F
X-Ray of Chest, 2 Views	1999-04-13 17:53	P
X-Ray of Chest, 2 Views	1999-03-23 15:11	P
X-Ray of Chest, 2 Views	1999-03-09 12:49	P
X-Ray of Ribs, Bilateral, and Chest, Posteroanterior	1999-03-04 11:38	P
X-Ray of Abdomen, Anteroposterior	1998-06-14 08:36	F
X-Ray of Abdomen, Anteroposterior	1998-06-13 08:55	F
X-Ray of Chest, 2 Views	1998-06-13 08:37	F
X-Ray of Chest, 2 Views	1998-05-26 15:30	F
X-Ray of Abdomen, Anteroposterior	1998-03-16 13:48	F
X-Ray of Chest, Portable	1998-02-10 12:33	F
Computerized Axial Tomography of Chest with Non-Ionic Contrast	1998-02-10 12:33	F

Fig. 17.5 Example screen snapshot from PatCIS, a portal developed at Columbia University. Cimino (1998) (Source: Cimino, J, personal communication, 2011)

across large HMO's with Epic electronic health record deployments, including Kaiser and Group Health Cooperative) and My HealtheVet (used by over half a million US Veterans (Nazi et al. 2008)). Many of these portals also include functions besides viewing EHR information, such as secure physician-patient messaging, appointment scheduling, and viewing and managing medical bills. Users of the Group Health Cooperative patient portal most frequently viewed test results, requested medication refills, participated in secure messaging with their provider(s), and viewed after-visit summaries (Ralston et al. 2007). The range of functions available in patient portal systems varies widely.

Figure 17.5 shows the PatCIS system developed at Columbia University (Cimino et al. 2002) Critical aspects of security, privacy and accurate identification of patients must be addressed, as well as compliance with government regulations (see Chap. 5). Additionally, designers must take special care to insure that the language used in presenting personal health data enhances the patient's understanding of his or her health concerns. Many of these portals also provide secure messaging systems, allowing patients to communicate concerns about their clinical record to their health care providers. One article comparing four patient portals (Halamka et al. 2008) demonstrated the challenges and opportunities associated with deploying this technology, noting important issues such as authentication, policies around minors desiring patient portal access to a PHR, decisions about how much of the EHR should be available, and a host of other issues. This article, as well as two by Osborn et al. (2010, 2011) articulates the pervasive way that even simple shifts from a provider-centric to patient-centric view precipitate ripples in the processes and culture of health care.

17.3.3.2 Personal Health Records

The PHR has become the foundation for developing tools to store data and to facilitate its reuse in ways patients find engaging. According to the Markle Foundation, a PHR is "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment"(Markle Foundation 2004).

The idea of a personal repository for medical information is far from new. Families with infants have used an immunization record book for decades. The immunization blue book is a quintessential, efficient system with portable information that supports entry by multiple providers and storage by the patient. Clayton Christensen, who invented the concept of "disruptive innovation," summarizes the widely held promise of this technology in his book, the *Innovator's Prescription: A Disruptive Solution for Health Care* (Christensen et al. 2009). "We cannot overstate how important PHRs are to the efficient functioning of a low-cost, high quality health care system…. We think that the Indivo system [described below], or something like it is a good place to start." PHRs are an inversion of the current approach to medical records in that they are created by, and reside with patients who grant permissions to institutions, clinicians, researchers, public health agencies, and other users of medical information. By contrast, electronic health records store data in thousands of individual silos which later need to be united through some form of health information exchange. PHRs are designed to enable users to acquire copies of their data from every site of care, a capability that will become commonly leveraged under the HHS's **Meaningful Use** certification requiring EHRs to provide an export to patients. In some ways, this model advances information flow far more than models requiring inter-institutional data sharing agreements. Hence, data from two competing health care networks may reside in the same PHR without cumbersome agreements between those two networks. The patient asserts her claim to the data for each network independently. This consumer-driven model of data aggregation may promote data liquidity far more than competing approaches, such as health information exchanges (Adler-Milstein et al. 2008), which require centralized management of data sharing agreements between networks and institutions.

17.3.3.3 Personally-Controlled Health Records

Closely replicating the patient-centered functionality and convenience of the immunization blue book is the **personally controlled health record** (PCHR), a special instance of personal health records (Halamka, et al. 2008; Pagliari et al. 2007). The first instance, called the **Personal Internetworked Notary and Guardian** or PING (Riva, et al. 2001) and was developed in 1998, with funding from the National Library of Medicine (National Institutes of Health) under the **Next Generation Internet Initiative** (National Library of Medicine) and the Advanced Networks programs (National Library of Medicine). PING was later renamed to Indivo (Mandl et al. 2007) in 2006. Figure 17.6 provides an overview of a PCHR architecture.

After diffusion of the PCHR model at two Harvard Medical School invitational conferences,[4] Indivo became the reference model for subsequent PCHRs, including Microsoft's HealthVault, which used Indivo software code, GoogleHealth (now defunct), which implemented the model on its own servers with its own code, and the Dossia consortium of large employers, which contracted with the Indivo creators to create a version for deployment to populations of employees of the consortium founders, including Wal-Mart, AT&T and Intel.

Despite the initial enthusiasm for the PCHR model, uptake of this technology has been gradual, primarily because PCHRs work best when they can readily obtain a copy of data from the EHR. Although many EHRs and other sources of patient data are willing to provide this access to patients, there are numerous barriers to the vision of the PCHR that have, to date, negated this willingness to share data. First and foremost, EHR vendors have been slow to allow data liquidity. Important data may reside in unstructured clinical notes, text blobs, or even scanned images—all formats that compromise liquidity. Data may be structured but may not be sufficiently demarcated to separate the entry into usable pieces. The evolution from a less to more structure prescribing standard in recent years is a good example of this barrier. Data within an EHR may not conform to published standards for interoperability. For example, although the system may share laboratory data, it may not code the data in a standard such as **LOINC**. Therefore, a receiving system may not be able to merge these data with other laboratory data. Finally, data may conform to a content standard, but may use a proprietary form of a messaging standard, making transit difficult.

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[4] www.pchri2006.org and www.pchri2007.org (accessed 4/23/13).

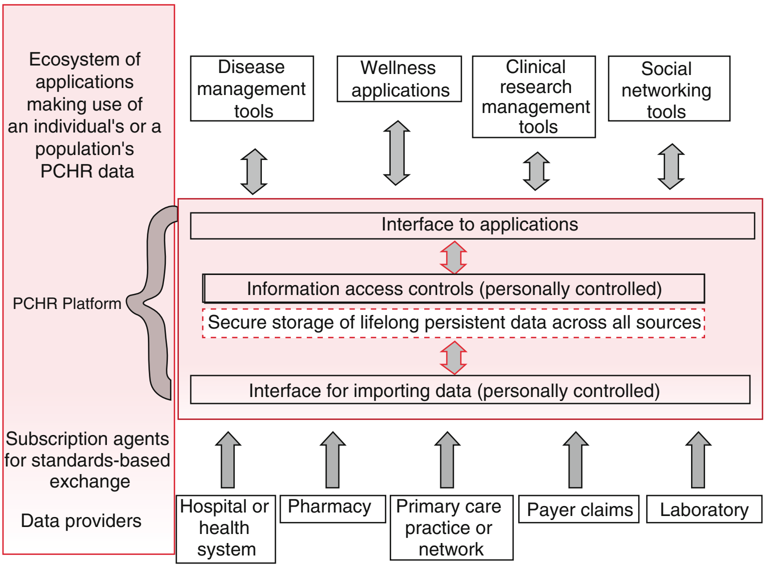

Fig. 17.6 An architecture for a personally controlled health record system. The personally controlled health record (PCHR) has a secure repository of data with subsequent accesses controlled by the patient or her proxy. PCHRs facilitate consumer-driven data aggregation in a manner analogous to a health care version of the financial Quicken product, thus advancing information flow far more than models requiring inter-institutional data-sharing agreements. PCHR users acquire copies of their data across sites of care. Importantly, patients can not only share data with family members and physicisins, but also with ecosystem of apps – modular, self-contained, software applications – that can interact with users and contribute to, analyze, and monitor their personal health data stores

The belief in the importance of an interoperable platform promoting data liquidity has been validated through Project HealthDesign (www.projecthealthdesign.org). The PCHR, similar to how Quicken and MINT.com function for financial data, is a tool enabling a patient to collect copies of her data across sites of care and over time. This functionality is similar to that provided by PHRs. Where PCHRs diverge is the notion of "control" of the data. First, PCHR data can be given attributes based on the semantics of the information content or based on the patient preferences. The patient may, for example, hide specific encounter data, or may allow only a subset of authorized users to see all data in the PCHR. For example, the PCHR model enables the patient to authorize access to individuals including clinical providers, family members, health care proxies, and researchers information (views or even copies of the record) or to intelligent software agents ("apps"). Thus, beyond its properties as a "data sponge", the PCHR is envisioned as a consumer gateway to a rich ecosystem built around data stored in individual health records. Analogous to the iPhone™ and Android™ platforms, PCHRs expose those data, under patient control, to third party apps across an open application programming interface (Mandl and Kohane 2008, 2009). Hence, PCHRs are designed to spawn apps that provide additional functionality without stifling innovation. A platform promoting market competition among apps is intended to address shortcomings of current HIT in terms of user interface and utility (Kim and Johnson 2004). The major PCHR platform providers offer a programming interface that third parties can use to provide "value-added" software-based applications and services such as interpretation of laboratory tests, referrals, and customized medical advice. Employers, governmental and nongovernmental organizations and health centers can create substitutable applications that connect to PCHRs, upon patient approval, through the interface. Healthvault lists scores of such Web apps on its site. The SMART (Substitutable Medical Applications, Reusable

Technologies) Platforms project (www.smartplatforms.org), a part of the Strategic Health IT Advanced Research Projects (SHARP) Program, extends the Indivo PCHR model and seeks to develop a common application programming interface across EHRs and PCHRS that supports the ready creation and use of substitutable applications across the health care system.

17.3.4 Behavior Management

Tools to assist in the achievement of personal health goals have had a long history of development in the consumer sector. Many patients have believed in the concept of health prevention through wellness activities (active lifestyle development, stress reduction, weight control) long before health care professionals endorsed this mode of self-care. However, with the advent of preventive medicine and data supporting the role that wellness activities can play in maintaining health, many of these tenets have become a part of the armamentarium for disease management and are an area of discovery supported by the Agency for Health care Research and Quality (AHRQ) and other Federal institutes.

A complete discussion of foundational models of behavior change is beyond the scope of this chapter, but key works are listed in Table 17.2. Researchers and educators capitalize on these theories in helping to reduce risky behaviors (e.g., cigarette smoking, unprotected sexual intercourse, and unhealthy eating) and to promote desirable health behaviors (i.e., referred to as behavior change.)

Many of the early games targeted at behavior change (described above) attempted to remove the stigma (attitude) associated with engaging in healthy behaviors (such as taking medications to combat a chronic illness.)

Beginning in 2007, the Robert Wood Johnson Foundation, in the Project HealthDesign Initiative (Brennan et al. 2007) catalyzed the development of personal health applications, with the belief that a properly developed common platform would be essential to the spread of intelligent, interoperable and theoretically-based behavior change tools. This initiative demonstrated many tools that could help consumers with behavior change, as will be discussed later. These demonstrations leveraged the widespread adoption of "smart" phone technology across geographic and socio-economic divides. This widespread adoption, coupled with easy to use software development environments, enables the development of personal health applications that operate as stand-alone or integrated tools available to most consumers.

Table 17.2 Models of health behavior change

Name and source	Summary
Self-efficacy (Bandura 1977)	An individual's impression of one's own knowledge and skill to perform any task, based on prior success, physical ability, and outside sources of persuasion. Predicts the amount of effort a person will expend to change behavior. It is a key component of other theories, such as the Theory of Planned Behavior.
Social cognitive theory (Bandura 1989)	Behavior change is determined by personal, environmental and behavioral elements, which are interdependent.
Theory of planned behavior (Ajzen 1985)	A link between attitudes and behavior. It asserts that behaviors viewed positively and supported by others (subjective norm) are more likely to have higher levels of motivation and more likely to be performed.
Transtheoretical/ stages of change model (Prochaska 2005)	This model asserts that behavioral change is a 5-step process, between which a person may oscillate before achieving complete change.

17.3.5 Consumer Decision-Making

Social trends, coupled with the introduction of managed care and the rapid growth of computer tools, networks, and multimedia, led to both an explosion of need for health care information by the lay public and a dramatic rise in the use of information technology to meet that need. Lay persons need information about health promotion, illness prevention, and disease management. At present, special computer programs, health-focused CD-ROMs, and health-related Internet-based Web sites all provide information likely to be useful to the lay public in participating in health care management and treatment decisions. These applications of medical informatics technologies focus on the patient as the primary user.

We have seen decision tools develop for helping parents know when to take their child to the doctor or start treatment at home, decision tools for helping someone decide to have a screening test, and tools for deciding between surgery or drug therapy. Simpler decision aids are offered in paper form. These consumer health decision aids sometimes take the form of decision trees, where answers to questions lead patients to a recommendation. Many of the newer tools provide dynamic assistance for health behavior change interventions through mobile devices. Other systems, typically offered on the Web, are based on complex decision models that support tailored risk information and utility assessment tools aimed at measuring individual patient preferences for multiple possible health outcomes. O'Connor and colleagues reviewed a variety of patient decision aids (O'Connor et al. 2009), defining these as tools that "prepare people to participate in 'close call' decisions that involve weighing benefits, harms, and scientific uncertainty." In their review of the literature they found that consumer decision aids improve knowledge, reduce decisional conflict (both in relation to feeling uninformed and in regard to personal values), reduce passivity, and reduce indecision. Tools such as Weight Watchers Online[5] represent more reference-based decision aids, while numerous tools, such as Vandemheen's decision aid to help patients with cystic fibrosis consider lung transplantation as an option, use more sophisticated approaches (Vandemheen et al. 2010).

These researchers noted that while the physicians and evidence from the literature provide expertise about the diagnosis and prognosis for a patient with a given condition and with treatment alternatives, it is the patient who must provide values and preferences associated with these possible outcomes. These interactive decision aids provide descriptions and testimonials about future outcomes from the patient perspective (usually video or quotes of patients describing their experiences). Evidence from the literature has shown that these types of decision aids increase consumers' knowledge (O'Connor et al. 2009) and satisfaction with their treatment decision (Whelan et al. 2004); in addition, when patients and physicians use these types of decision tools, the patients are more likely to choose the less invasive treatment.

Currently, consumer health decision aids are offered for the full spectrum from assistance for routine health decisions in the home to intricate sophisticated systems for serious conditions with complex treatment options. Many new health decision aids are still provided in paper-based form, but most are interactive and easily delivered in a Web format. Challenges still remain in integrating these systems into clinical work flow, easily explaining and assessing patient preferences, and in tailoring the risk and probability information and recommended protocols to individual patients.

17.3.6 Consumer Information Access

Patients need quick, private access to accurate information that can calm fears and ensure direct access to currently accepted treatment for their illness. Unfortunately, most existing health care delivery systems are not designed to satisfy these "just-in-time" information requests. Instead of providing this information just in time, it is provided "just in case", typically by a busy clinician as a part of a standardized monolog that covers frequently asked questions. Computer technology can supplement clinicians' teaching with more detailed information that can be referenced repeatedly by a patient in the privacy of his home, and at the time it is most relevant.

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[5] www.weightwatchers.com (accessed 4/23/13).

17.3.6.1 Passive Information Access

Consumer health informatics resources provide substantive and procedural knowledge about health problems and promising interventions. These information resources may be derived from carefully conducted, theoretically grounded, resource-intensive processes, or they may be extracted from information published for other purposes to save time or money. For this reason, information resources vary in content and sophistication. Some of these resources are little more than digitized brochures, presenting in an electronic form exactly what can be found in available printed materials. Others include interactive or multimedia presentations of information about specific conditions and appropriate actions to prevent, cure, or ameliorate the problem. Multimedia presentations capitalize on the features of computer systems to enrich the presentation of health-related materials with pictures, short movies, and drawings.

Consumer health informatics resources provide patients with condition-specific and disease-specific information about the problems they face. Some resources explain the etiology and natural history of disease in terms comprehensible to lay people. Other resources provide procedural information, explain diagnostic procedures or services, detail expected treatment activities, and provide any relevant warnings and precautions. The presentation of CHI is heavily influenced by the perspective of the system developer. Medically oriented clinical resources demonstrate an emphasis on locally accepted medical practice. Community health-oriented resources are more likely to include information relevant to living in the community with a specific disease or condition.

Consumer health informatics resources originate from two major perspectives: professional and self-help. Professional-developed consumer resources are those developed by health care clinicians and their organizations. Health care organizations—such as HMOs, managed-care companies, and group practices—develop information resources as a service to the patient populations that they treat. These resources tend to complement and extend the clinical services offered by the professional group and may be based on a desire to ensure adherence with accepted therapies or to triage and manage access to care for common health problems. Examples include Kaiser Permanente Health Facts, a program designed to help Kaiser members answer questions about common health problems, and the Mayo Health Advisor, a commercially available CDROM that any interested person can purchase and use to help manage his health at home. Examples of other commercially available programs that have a professional orientation include Health Wise and Health Desk. Figure 17.7 shows an example of professional-developed CHI resources accessible via the Internet.

Consumer health informatics resources developed from a self-help perspective complement and augment those provided by the formal health care delivery system. A self-help perspective is generally more inclusive than a professional perspective. The information may address daily living concerns and lifestyle issues along with, or in place of, content deemed credible by established medical authorities.

Many CHI resources represent a combination of professional and self-help perspectives. Web-based resources, such as those provided by the Fred Hutchinson Cancer Research Center, provide pointers to other Web sites that represent professional or self-help perspectives. Commercial vendors, such as HealthGate Data Corporation, provide access via a Web site to professional-developed and self-help–oriented CHI resources for a subscription or transaction-based fee.

17.3.6.2 Active Information Access

In addition to the passive models that require patients to search for information, there is an increasing number of personal health applications that actively provide information based on specific patient needs. The Project HealthDesign teams developed many demonstrations of active

YOUR LIFE

Whether you are new to diabetes or have been dealing with it for a long time, there is something here for you.

If You're New to Diabetes

Even though it brings so many changes into your life, diabetes is not your whole life. It is only a part of it! It is important to remember that you are still you, and that there is much more to you than this disease. Here's help with the new things that you will have to do or think about.

If You're an "Old Pro"

As a busy kid, you are probably meeting new people and facing new situations all the time—and taking more responsibility for your diabetes care as you go along. Check out the topics on the left for advice and ideas from kids and diabetes experts.

Fig. 17.7 Professionally developed consumer health information. Note the informal language style and easy navigation (*Photo provided courtesy of JDRF* (http://kids.jdrf.org/index.cfm))

access (Brennan, et al. 2007). For example, a team at the University of Rochester developed a "conversational assistant" to provide patients with a daily checkup and information to mitigate exacerbations of their heart disease (Ferguson et al. 2010). Another project, developed by Siek and Ross at the University of Colorado, allowed older adults to manage complex medication regimens at home, using active information access to denote possible side effects, duplicate therapies and special instructions related to dosing (Siek et al. 2011). Jimison and researchers at the Oregon Center for Aging & Technology additionally use monitoring data from sensors in the home to produce automated feedback and intelligent alerts for coaching interventions in the areas of cognitive exercise, physical exercise, sleep management, socialization, and intelligent medication reminding. Figure 17.8 depicts the variety of sensors available for home care (Pavel et al. 2010; Jimison et al. 2007). With tailored interfaces to a common database, these new approaches enable coaches and informal caregivers to help manage large panels of patients remotely and enable patients and family members to participate as active and informed members of the care team.

Researchers also have begun leveraging text messaging as a medium to provide information actively to patients. For example, in the project MyMediHealth, Johnson and colleagues provide medication reminders to patients in real time using text messaging to their phones. When a dose is missed, MyMediHealth is able to escalate its medication reminder to a parent or other adult

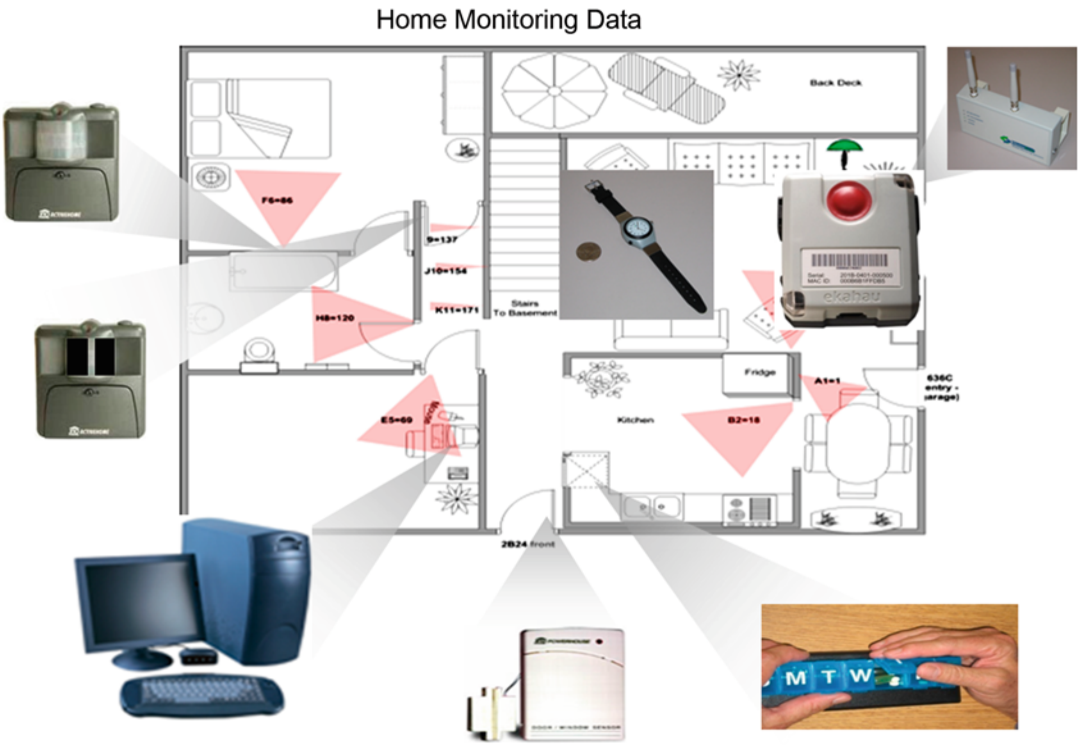

Fig. 17.8 A variety of sensors in the home can provide feedback for health behavior change coaching systems (motion sensors, pressure mats, contact switches, wireless medication dispensers, etc.). This figure shows a sample apartment layout with sensors for monitoring older adults in the home (Jimison et al. (2007) with permission)

(Slagle et al. 2010). Studies also have demonstrated the utility of appointment or preventive care reminders in reducing clinic no-show rates (Brannan et al. 2011; Leong et al. 2006)

17.4 Opportunities and Challenges

17.4.1 Health Information Technology for Economic and Clinical Health Act of 2009

The **Health Information Technology for Economic and Clinical Health Act of 2009** (HITECH) ("Health Information Technology for Economic and Clinical Health (HITECH) Act, Title XIII of Division A and Title IV of Division B of the American Recovery and Reinvestment Act of 2009 (ARRA).", 2009) may help increase the momentum behind this model. The HITECH Act provides that, for covered entities using or maintaining an EHR, "the individual shall have a right to obtain from such covered entity a copy of such information in an electronic format." By 2013, this feature of EHRs will be required under the final rule for meaningful use of certified electronic health record technology. In preparation for this, early stage efforts have arisen to promote data liquidity through the very well-marketed **Blue Button** initiative from the Department Veterans Affairs (Chopra et al. 2010), and the Direct Project, a federally initiated, health specific implementation of the **SMTP protocol** to enable point-to-point communication of health information in a secure, standards-based (www.directproject.org). Unfortunately these approaches to data liquidity came too late for the Google Health project, which was closed down after not gaining a foothold in the health space. While patients and institutions may have had issues viewing Google as a trusted intermediary to store and manage health data, an at least equally major issue for the service was that even the early adopters, the technophiles who wanted to make this work, experienced challenges populating their PHRs with data.

Hence we can expect that even before 2013 a "tectonic shift in the health information economy" (Mandl and Kohane 2008) will begin, mediated by a change in the locus of control of health information from institutions to individuals. While this shift will be largely driven by a need to improve clinical care processes, it will also have a deep impact on population health research. The ability to reach out to populations directly, thereby disintermediating traditional institutions, will produce very large cohorts of individuals who can share EHR data and provide detailed self-reported information about their care and health states. And patients are willing to share data for aggregate knowledge, research, and public health (Weitzman et al. 2010). A major area of focus for research and policy needs to be development of a properly aligned compact with patients to share data for research and public health by engaging them on their own terms; the PCHR is a technology designed to do just that.

As CHI and telehealth evolve from being research novelties, to being the way health care is delivered, many challenges must be overcome. Some of these challenges arise because the one patient, one doctor model no longer applies. Basic questions of identity and trust become paramount. At the same time, the shifting focus from treating illness to managing health and wellness requires that clinicians know not only the history of the individuals they treat but also information about the social and environmental context within which those individuals reside.

17.4.2 Information Credentialing

The amount of information available to consumers is growing rapidly. This volume of information can be overwhelming. Therefore, consumers may need help in sifting through the mass of available resources. Furthermore, the quality of such information varies widely not only in terms of the extent to which it is accepted by the formal medical community but also in its basic clinical or scientific accuracy. Therefore, a key issue in CHI lies in determining the quality and relevance of health information found on Web sites. Credentialing or certification by recognized bodies, such as respected health care providers or clinical professional associations, represents one approach to ensuring the quality of health information available to consumers. This approach differs from the HON approach (see Sect. 17.2.3) in that it bases its quality ratings on reviews and evaluations conducted by established knowledgeable sources. It has the advantage of delivering an imprimatur to a Web site, which informs the user that the information presented meets a standard of quality. Credentialing is most useful when the credential itself is accompanied by a statement indicating the perspectives and biases of those granting it. Information presented by alternative therapies and other non-clinical groups is no less susceptible to bias than is information presented by professional sources.

Inherent in the credentialing approach are three disadvantages. First, the challenge to ensure that every information element—every link in a decision program or pathway in a Web site—is tested exceeds the resources available to do so. In many cases, the credentialing approach rests on certification of the group or individuals providing the information rather than approval of the content itself. Second, the credentialing approach leaves control of the authority for health care information in the hands of traditional care providers, reflecting both the expertise and the biases of established medical sources. Third, credentialing alone is inherently contradictory to healthcare consumerism, which empowers the consumer to make choices consistent with her own worldview. A source's credential is just an additional piece of information that may be considered in making personal health decisions.

An approach to evaluating the quality and relevance of CHI resources that is consistent with a philosophy of patient participation is based on teaching patients and lay people how to evaluate CHI resources. Consumers with sufficient literacy and evaluation skills can locate CHI resources and determine these resources' relevance to their individual health concerns.

17.4.3 Privacy and Security

Because of the public, shared nature of the Internet, its resources are widely accessible by citizens and health care organizations. This public nature also presents challenges to the security of data transmitted along the Internet. The openness of the Internet leaves the transmitted data vulnerable to interception and inappropriate access. In spite of significant improvements in the security of Web browsing several areas, including protection against viruses, authentication of individuals and the security of email, remain problematic.

One of the most important challenges and responsibilities associated with the new developments in interactive health systems for patients is ensuring the privacy and security of health information in a way that protects the security of the data and truly incorporates patient preferences for data sharing. Consumer health Web sites often offer users the capability of entering personal data in order to obtain tailored feedback. This ranges from calculators of body mass index to ongoing weight management or smoking cessation programs. These Web sites typically display their privacy practices. Consumers also can look for certificates of accreditation from organizations such as URAC,[6] TRUSTe[7] and HON.[8] These accreditation groups each have a set of policies to protect consumers' privacy and certify that processes that encourage high quality accurate information is presented. Given that the privacy policies for consumer health Web sites are often quite long and complicated; this approach allows consumers to feel confident that the site follows best practices. Privacy policies are also posted for search engines – the most common tool that consumers use for finding health information. Companies associated with the search engines have the capability to infer a good deal about the health status of the user or the user's family from the search terms used and from the sites visited. However, users very rarely investigate the privacy policies and also rarely understand the implications of how data about them might be used.

More complicated privacy situations arise with the new technologies for home monitoring. Data is collected in the home and then typically encrypted and transferred to a secure server in another location. A wide variety of data may be collected (blood pressures, blood glucose, activity, location, sleep quality, etc.) and then potentially shared with a variety of care team members (care manager, clinical, specialist, family caregiver, etc.). Not all care team members should necessarily have the same access to data. Role-based access representations are beginning to be used to make it easier and more meaningful for patients to indicate their preferences on who (if anyone) should see what data about them.

There has recently been a dramatic upsurge in the use of mobile applications for consumer health monitoring and data sharing. However, the privacy and security techniques for this area are still lagging behind the development and use of the systems. In 2010 there was a 250 % jump in mobile phone viruses and spyware, and 61 % of the reported smartphone infections were spyware that could monitor communication from the device (Bela and Hamel 2010). Health care systems are working rapidly to address the privacy and security issues as technology and consumers' way of using it change.

17.4.4 Technology Digital Divide

Ensuring every citizen access to the Internet represents a second important challenge to the ability to use it for public health and consumer health purposes. Access to the Internet presently requires computer equipment that may be out of reach for persons with marginal income levels.

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[6] www.urac.org (accessed 4/23/13).

[7] www.truste.com (accessed 4/23/13).

[8] www.hon.ch (accessed 4/23/13).

The digital divide with respect to access to computer-based health care information occurs for many reasons, including economic disparity, unequal broadband access in various geographical locations, and cultural issues. Majority-language literacy and the physical capability to type and read present additional requirements for effective use of the Internet. Preventing unequal access to health care resources delivered via the Internet will require that health care agencies work with other social service and educational groups to make available the technology necessary to capitalize on this electronic environment for health care.

17.4.5 Workflow Integration

Systems that are designed to facilitate shared decision making with a physician are difficult to integrate into routine clinical workflow. This integration requires overcoming two main challenges. First, many care providers are reluctant to review patient-generated information until it is a reimbursable activity. Therefore, the preferred workflow is to have these data brought in by the patient for review at the time of a patient encounter. This approach may be helpful for many medical conditions, but is potentially less efficient for the patient who may be able to improve health outcomes sooner by more timely professional review of data.

The second challenge relates to the health information technology used by clinicians. Ideally, data that are created by patients should be easily imported into the physician's repository and provided as a view alongside clinician-generated data. However this model has yet to be standardized. This model would be a requirement to achieve clinician buy-in with timely data review, and is very important even for the visit-based data review if decisions are made based on these data.

Additionally, it has been difficult to reliably and meaningfully explain outcomes and probabilities to patients in a way that helps them weigh risks and benefits of complex scenarios. Finally, much more work needs to be done to improve the process of assessing patient preferences (utilities on outcomes) and communicating this to the clinician. These issues are all critical for improving health care decision-making.

17.5 Future Directions

The advances in consumer health informatics over the past 20 years have been made under assumptions about the availability of home computing power, the general willingness of patients to communicate, and the ways in which data informs knowledge. The future of the field is most likely to be shaped by disruptions in each of these assumptions.

17.5.1 Home Computing Power

In 1988, inspired by discussions with social scientists, philosophers, anthropologists, and computer scientists, Mark Weiser, then at Xerox PARC asserted that a "third wave" of computing would transform society. The first wave, mainframe computers, allowed many people to access one computer. This wave was complemented by the personal computer wave that supported one person on one computer. The third wave, "ubiquitous computing" further complemented the first and second waves by allowing one person to have many computers. This era will usher in "calm technology," where technology becomes embedded into all aspects of our life and allows us to focus on the task, not the tool. Examples of this technology have been incorporated into the plots of science fiction movies for years.

The average person now uses dozens of computer-enabled devices, ranging from smartphones and cars to coffee-makers, digital thermometers, HDTVs, and thermostats. The availability of computers, coupled with the power of the technology, will be leveraged by consumer health informatics researchers. Already, programs such as Robert Wood Johnson's Project HealthDesign[9] have demonstrated how home

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[9] www.projecthealthdesign.org (accessed 4/23/13).

biosensors, mobile computing platforms, and other innovations can transform personal health applications.

As computer power increases and the integration of computer technology into everyday life becomes more commonplace, we anticipate that health information will follow suit. Why doesn't a pill container send data directly to a personal health record when opened? Why doesn't that pill container use wifi, speech recognition, and publically available and appropriately tagged data to answer consumer questions about side effects or special instructions? Why can't a need to refill that medication be transmitted to a schedule automatically, or included as a reminder when a car starts? It is likely that Federal groups such as the US Army's Telemedicine and Advanced Technology Resource Center (TATRC) or the National Science Foundation will lead the way toward this level of interoperability and seamless information dissemination to consumers. As data liquidity is increased, influential consumer health technologies will flourish. In the mean time, efforts such as Google Health™ stumble waiting for data from the health system to enter the hands of consumers. In fact, it is clear that Google Health and personal data repositories may follow the path of other notable technologies, such as personal digital assistants or the Apple Newton MessagePad™, which emerged before supporting technologies or market awareness was there to sustain them. In the case of personal health data repositories, the key driver may be these personal health applications integrated into daily life.

17.5.2 Patient Communication

It is estimated that 83 % of U.S. adults have a cell phone of some kind, and that 42 % of them own a smartphone (Smith 2011). In addition to cellular technology, social networking adoption has exploded in the past decade. The widespread use of these technologies affirms the belief that patients are more willing than ever to communicate about their health issues. In study after study about the tradeoff between communication and privacy, it has become clear that we value communication and hope that there is privacy through anonymity.

One example of patient willingness to communicate about health is the success of tools like researchmatch.org[10] developed by Harris and colleagues. This tool allows patients to voluntarily create a profile that is then used to alert them to studies in which they might be able to participate. Patients using this system trust that the security in place is sufficient and that any risk of a security breach is offset by the potential personal or societal gains associated with patient research.

We can expect various tools to leverage patient's willingness to communicate. For example, social networks might be used to connect a person with a home health need to a person who is willing to help. Online forums or classified advertisements that already connect patients to patients for physician referrals or durable equipment sales could do more to help patients find information or other commodities.

17.5.3 Data Informing Knowledge

One of the most exciting, though potentially alarming consequences of our extensive use of the Web for shopping, communicating, and learning is that each of us leaves behind a profile of who we are, what we like or dislike, what we know or don't know, and what we want or already have. When combined with data mining and natural language processing techniques, it is possible to create highly targeted and predictive personal knowledge. It is this ability that search engines exploit to create a profile of each searcher and to improve the relevance of retrieved results. This technology also is likely to improve the ways in which consumers and consumer-facing technologies operate. We can expect the use of these massive data sets (also called "big data") to impact how medical care is personalized. Data created by consumers, coupled with ubiquitous computing, might provide just–in-time nutritional consults, over the counter medication

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[10] www.researchmatch.org (accessed 4/23/13).

advice, or advice that might prevent illnesses, such as convenient locations to receive a flu vaccine or when to begin medications for seasonal allergies.

While the direction that consumer health informatics will take in the future is at best, educated speculation, it is clear that as long as patient-provider partnerships are endorsed, technology will be a third partner in ensuring that activated consumers manage their health and disease effectively.

Suggested Readings

The 1994 Guardian Angel Manifesto. www.ga.org. This site describes a collaborative project begun in 1994 to "put power and responsibility for health care more into the hands of patients." It also provides a comprehensive set of references to many other personal health record projects.

Susanna Fox's blogs and reports. http://www.pewinternet.org/Experts/Susannah-Fox.aspx. This site provides a collection of presentations from form Pew Internet and American Life Project, which studies the technology-related cultural shifts in health care.

Mandl, K. D., & Kohane, I. S. (2008). The architecture of Personally Controlled Health Records. Tectonic shifts in the health information economy. *New England Journal of Medicine, 358*(16), 1732–1737. This is a recent review of the transformation taking place in health care as a result of widespread introduction of personally controlled health records.

Questions for Discussion

1. What is the role of the health system in monitoring the quality of discourse on online social networks?
2. What is the optimal model for personal health records? Should personal health records display advertisements?
3. Which populations of consumers would be most likely to use personal health records?
4. Which consumer technologies do you think will be most influential in consumer-focused health informatics?
5. What is the right balance between privacy of personal health information and ready access to it? For example for an unconscious patient in the emergency department?