Consumer Use of Computerized Applications

to Address Health and Health Care Needs

Contract No. HHSP233200800001T

Prepared for:
U.S. Department of Health and Human Services
Office of the Secretary
Assistant Secretary for Planning and Evaluation

NORC
at the UNIVERSITY OF CHICAGO

Prepared by:
Jessica Kronstadt
Adil Moiduddin
Will Sellheim

NORC at the University of Chicago
4350 East West Highway, Suite 800
Bethesda, MD 20814

March 2009

Table of Contents

Executive Summary

As a growing number of health applications are available online, it is important to understand how and to what extent individuals are taking advantage of these applications. Given the existence of disparities in health status among individuals of different ethnic, racial, and socioeconomic backgrounds, it is useful to examine whether use of health-related information technology (IT) also varies by these dimensions. Finally, to the extent that such applications have been demonstrated to have a positive impact on patients' behaviors and health, it is worthwhile to understand barriers to wider use and potential opportunities to address them. Informed by an extensive literature review and a series of discussions with thought leaders in the consumer health IT field, this paper focuses on those issues.

What consumer health needs can be addressed using health IT?

Individuals can use IT to address a number of health needs and can access health applications through several pathways. Many resources, particularly information sites, are available online for anyone who is interested in them. Other individuals come in contact with these web tools through their relationships with their medical providers. A final entrance point is through entities that pay for health care—insurers and employers.   Consumers use health IT to:

Seek health information: A variety of commercial, nonprofit, and government sites provide articles, tips, and other information about disease and wellness topics.

Take action to monitor and improve health: Computerized applications can help consumers make decisions, monitor their chronic conditions, or receive assistance in engaging in healthier behaviors. Common topics for computerized tools are nutrition, weight management, tobacco cessation, and cancer and diabetes prevention and management.[1] A variety of products are available, including decision aids, games to promote healthy behaviors, and health monitoring systems.

Communicate with relatives, friends, and other patients: Individuals use email to exchange information about their health conditions with friends and relatives—for example, adult children can keep an eye on their infirm parents from afar. Individuals can also participate in online communities where they can learn about the symptoms and treatment of individuals with similar conditions.

Interact with the health care system: Individuals can go online to select an insurance plan, to learn about the benefits covered by that plan, and to find medical providers. To help them make health care decisions, consumers can gain information about the quality of health care providers and insurance plans. Some patients can also use the websites of their providers to schedule appointments, re-fill prescriptions, or otherwise communicate with physicians and office staff.

Use a personal health record or multi-function portal: Some individuals see physicians who provide access to patient portals which, in addition to allowing for the functions described above, can be associated with an electronic health record (EHR), allowing patients to view part or all of their medical charts. A popular component of many of these portals is that the ability to view the results of lab and other diagnostic tests and view lists of their medications, immunizations, and allergies.[2] Another approach to monitoring one's health data is the personal health record (PHR), through which individuals have control over their own health data and can integrate information from a variety of providers and other sources.

Emerging trends in consumer health IT: Several of the experts consulted as part of this project highlighted social networking—including blogging—as an increasingly important trend. One expert talked about a growing interest in wellness and speculated that as consumers are paying a larger share of their health care costs they may express a greater interest in maintaining their good health. This may lead

to further development of consumer driven products that are accessible through PDAs and cell phones. Products that can remotely track health and health care costs are also just emerging.

How are consumers currently using these resources?

It is difficult to ascertain the proportion of Americans who have used health-related IT, but it is clear that many millions of individuals have gone online to use at least one of these health applications. In order to understand the scope of potential online health IT engagement it is important to note that about three out of every four Americans use the internet.[3] Access to high-speed internet connections may also determine consumer health IT use.

Seek health information: Estimates for the proportion of American adults that have used the internet to look for information about health range from approximately 40% to around 60%.[4] Some evidence suggests that this use has grown over time. In understanding the reach of online health information seeking, it is important to consider the fact that many of the individuals who are looking online for health information are doing so on behalf of someone else. A 2005 survey found that the percentage of respondents looking for health information for themselves was equal to the percent looking for others—59.5% and 58.4%, respectively.[5]

Research and purchase prescription drugs: In a 2004 study, 21% of adults said they had looked online for information on prescription drugs, while another 5% said someone else had conducted such a search on their behalf.[6] Yet only 4% or 5% of Americans say they have purchased prescription drugs online.[7]

Take action to monitor and improve health: It is difficult to discern how many individuals use applications to take action on their health, but studies suggest modest use of IT applications like remote disease monitoring and decision support tools.

Communicate with relatives, friends, and other patients: Online support groups appear to only attract a very small number of individuals.[8] Although support groups are not widely used, 11% of adults use online communications to interact with people with similar health issues and almost one-quarter use the internet or email to communicate with relatives or friends about health or health care.[9]

Interact with the health care system: Although many individuals express interest in electronically contacting their providers, using email or secure messaging to communicate with providers is not a common practice. One survey found that over 80% of adults said they would favor or strongly favor being able to email their physicians; yet the same survey found that only 8% currently do so.[10]

Use a personal health record or multi-function portal: There are few good estimates of the number of individuals who manage their health data through a PHR or use a provider-sponsored web portal. Even among patients who see providers with portals, the extent to which individuals decide to take advantage of them varies widely from approximately 10% to 50%. This disparity may reflect the degree to which a practitioners advocates use of online resources. It has been estimated that between 15-20% of patients who have the option to access a PHR through their health plan will decide to sign up.[11]

Evidence on effectiveness: The majority of evaluations on the quality of online health information identify problems with accuracy and completeness; yet due to a lack of consensus on evaluation criteria and other methodological concerns it is difficult to draw concrete conclusions from this research. While many users report satisfaction with electronic health tools, in most studies only a minority of respondents say that those tools have changed their behavior. More rigorous studies that involve randomized control trials have linked applications to positive results; however such evaluations have not been conducted on many of the health tools that are most commonly used.

Differences in use by demographic group

Few data are available comparing the use of different health IT applications across subpopulations. The information that is available primarily focuses on information seeking. Evidence suggests that individuals who have lower educational attainment, are male, lack health problems, and are either young (and healthy) or older (and less comfortable with computers) are less likely to go online looking for information about health.

Socioeconomic status: Efficacy in using online health tools may have more to do with likelihood of seeking health information online than does economic status.

Race and ethnicity: One study found that 59.5% of nonHispanic white respondents had looked for medical information for themselves, while around 53-54% of Hispanic and nonHispanic black respondents had.[12]

Gender: Women are more likely to engage in consumer health IT activities than are men.[13] One expert attributed this to the fact that women often become large consumers of health information when they are pregnant or as they help care for family members.

Health: Health status repeatedly is an important factor in consumer health IT use. When individuals are facing a health problem, an estimated 46% turn to the internet.[14]

Age: The relationship between age and health IT use is not linear. Individuals in the middle years (their 30s to early 60s) are more likely to go online than are their younger and healthier or their older and less computer-savvy counterparts.

Computer and internet use: The likelihood of looking for health information online also varies by individual's online access and experience. A study shows that 86% of internet users who had been online for at least six years have looked for health information online, compared to just 62% of those who had two or three years of experience online.[15]

Other e-health activities: A 2006 report remarked on the lack of data about how use of many consumer health tools varies by subpopulation[16]—a finding that one of the experts confirmed still rings true today. Also, due to the low overall levels of use of some of these resources—like online support services—it is hard to identify distinctive patterns by demographic group.[17] For some of these activities, the patterns above still hold true. However, in other cases there are fewer subpopulation gaps. For example, in 2005, educational attainment no longer was associated with communicating online with providers.

What is necessary to expand health IT use?

There is interest from the federal government and individual consumers to increase the prevalence of consumer health IT use. Yet, several challenges must be addressed to bolster overall use and fill gaps among demographic groups:

- Consumers need the resources to access computerized applications, including the relevant technology and the skills to use it.
- Consumers need to be aware of the applications.
- Economic and technical problems must be addressed to encourage the use of these applications.
- Applications must guarantee privacy and be of high quality so they will be appealing to consumers and health care providers.

These items are, of course, related. Consumer demand might drive the creation of more high-quality e-health tools. At the same time, the presence of more high-caliber resources might increase the likelihood that physicians promote their use and make consumers more aware of them.

Access to technology and skills: "Health policy makers should follow developments in telecommunications carefully," remarked one researcher interviewed as part of this project. As so many health applications require the internet—and most perform better with high-speed access—the importance of ensuring access to such technology cannot be understated. Although gaps in internet and computer access have been closing in recent years, they still remain.

In addition to ensuring access to technology, several steps could increase ability to use it. First, more appropriate tools could be designed to take into account the reading level of users and to be more relevant and culturally competent for diverse populations.[18] Second, individuals could be better prepared to use applications, for example, through health education, possibly at hospitals, in order to help them use online resources upon discharge. Third, there could be a larger role for friends, family members, and community health providers to use online applications on behalf of others who are less able to do so.

Lack of awareness: Many e-health resources are new and evidence suggests there is limited awareness of applications like remote disease monitoring and PHRs. Word of mouth may be one of the most powerful tools propelling individuals to health web sites, and providers may be one of the most important means to convey these messages. Representatives from three provider groups all emphasized the critical role of physicians in encouraging patients to use their online resources. As one noted, "most of what draws people to the portal is what happens in the exam room."

Financial and technical barriers: Because of the perceived benefits of messaging, PHRs, and the ability to exchange health data, large integrated health care delivery systems may be willing to absorb the costs involved in building these applications and compensating providers for the time spent using them. Practitioners who are not in a closed system may struggle more with low or nonexistent reimbursement for responding to patients' messages. One survey of physicians noted that 80% claimed they would be willing to exchange secure messages with patients if they received payment for that service.[19] Identifying a party willing to pay for consumer health IT is a critical issue, as patients are unlikely to be willing to pay for it.[20]

There are technical obstacles as well. The ability to exchange lab results and other information to make PHRs most useful and appealing to consumers may depend on the development and implementation of standards for data security, permissions for sharing information, and interoperability.[21] Addressing these challenges is a central component of the work of the Office of the National Coordinator for Health Information Technology in DHHS.

Privacy and quality: Assuring the privacy of personal health information is a key component of developing the demand for online resources among consumers. More than half of respondents to one survey said they were very concerned about their information falling into the hands of employers or health insurers.[22] Privacy concerns and related legal issues may also limit the take-up of some applications among providers.[23] It is unclear the extent to which privacy concerns will continue to be a barrier for consumers. As one interviewee pointed out, many individuals have overcome their concerns about the privacy of their financial information and engage in online banking.

Providers may also resist recommending online tools if they are uncertain of the quality of the information available online. Indeed one researcher suggested that the quality barrier may be more of an issue for health professionals than it is for consumers.

Conclusions and policy areas requiring actions

Consumer health IT has the potential to allow users to be more informed about their health and take a more active role in monitoring chronic conditions and tracking wellness behaviors. To address the above challenges, the engagement of many stakeholders may be required.[24]

- Providers play a key role in granting access to portals and encouraging the use of an array of e-health tools.
- Payers may drive provider behavior by shifting reimbursement policy.
- The vendors and developers of health IT products could also affect uptake by focusing on tools' design and fit with consumers.
- The federal government could continue to help to establish standards to promote interoperability and safeguards to ensure privacy. The government could also support or promote research on who is using e-tools and what characteristics make them most accessible and appropriate to users across subpopulations.

As new technologies emerge to give individuals greater ability to manipulate their health data and to interact and learn from other online patients, it is important to understand who is already part of that trend, which groups are being left behind, what the obstacles appear to be for greater uptake, and what policies can help overcome those barriers.

I. Introduction

NORC is pleased to present this white paper entitled "Consumer Use of Computerized Applications to Address Health and Health Care Needs," commissioned by the Office of the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services (DHHS). The paper seeks to create a better understanding of the ways in which individuals use information technology (IT) to improve their health and manage health care tasks.

As a growing number of health applications are available online, it is important to understand how and to what extent individuals are taking advantage of these applications. Given the existence of disparities in health status among individuals of different ethnic, racial, and socioeconomic backgrounds, it is useful to examine whether use of health-related IT also varies by these dimensions. Finally, to the extent that such applications have been demonstrated to have a positive impact on patients' behaviors and health, it is worthwhile to understand barriers to wider use and potential opportunities to address them.

Computerized applications allow individuals to engage in a range of activities. This paper will highlight some of those tasks:
- *Seek health information* – Consumers can use search engines to find, or be directed by their physicians to visit, websites on a range of health and medical topics.
- *Take action to monitor and improve health* – Individuals can receive assistance in decision making and tracking their chronic conditions or wellness behaviors.
- *Communicate with relatives, friends, and other patients* – Interactive technologies allow individuals to stay up-to-date on the conditions of friends and loved ones from afar, and foster new avenues of communication among patients with similar diagnoses.
- *Interact with the health care system* – From locating providers and learning about their performance, to scheduling appointments and refilling prescriptions, to communicating with providers, the internet can allow for a range of transactions between patients and providers.
- *Use a personal health record (PHR) or multi-function portal* – PHRs allow individuals to organize and selectively share data about their health. If integrated with a provider portal, these resources can also grant patients access to their lab results and online communication tools.

There are several pathways through which individuals can access these applications. A number of resources are sponsored by government, nonprofit, commercial, and academic entities and are publicly available online for all interested consumers. Other individuals receive these services through an insurer, a health care provider, or employer.

The extent to which individuals use these resources varies greatly by application. While the majority of internet users have viewed medical or health information online, by some estimates fewer than 4% of Americans use an electronic PHR.[25] Although the data are limited on how use of these services ranges across population groups, some trends emerge. Individuals with more education and those who are neither very young nor very old are the most frequent users of health IT.

In order to address these inequities and to expand use of consumer health IT, certain conditions will likely need to be met:

- Consumers need the resources to access computerized applications, including technology and the skills to use it.
- Consumers need to be aware of the applications.
- Economic and technical problems must be addressed to encourage the use of these applications.

- Applications must guarantee privacy and be of high quality so they will be appealing to consumers and health care providers.

The federal government as a stakeholder has a role in helping to accomplish these goals. It can help coordinate standards to improve privacy and overcome some of the technical problems that may prevent these tools from being as attractive as possible to consumers. Reimbursing providers may encourage their use of health IT and increase their likelihood of endorsing these tools to their patients, thus indirectly spurring on consumer use. Additionally, the federal government could help steer the research agenda to foster an understanding of the current use of these resources across subpopulations and the components of effective consumer-centered technology.

Methodology. This paper was informed by an extensive literature review and a series of discussions with thought leaders in the field. More than 60 documents were reviewed in the process of drafting this report (see bibliography). In order to gain a broad understanding of the current state of knowledge about consumer use of health IT, the authors conducted searches of the published literature using Medline and other bibliographic databases. In addition, reports from government agencies—including the 2006 report *Expanding the Reach and Impact of Consumer e-Health Tools* from the Office of Disease Prevention and Promotion in DHHS—and other research organizations were consulted. To get a more complete picture of the types of survey questions that have been asked about the prevalence of consumer use of IT for health reasons, the authors also searched the Polling the Nation database.

Although there are a number of articles and reports on the topic, most of the rigorous, national data on prevalence rates of health IT use comes from two sources—a biennial survey conducted by the National Cancer Institute and research from the Pew Internet & American Life Project. Additional articles that describe health IT use typically focus on smaller, convenience samples. To supplement these written sources, the authors of this white paper consulted with representatives from federal agencies, research organizations, commercial web-resource providers, and health provider organizations. Throughout the report, we will often refer to the comments and perspectives of these experts.

Organizations Represented in Discussions with Key Informants	
Government and research	Centers for Disease Control and Prevention
	National Cancer Institute
	Pew Internet & American Life Project
Health provider	Group Health Puget Sound
	Kaiser Permanente
	Palo Alto Medical Foundation
	Partners HealthCare
Web resource	Google Health
	Microsoft Health Vault
	WebMD

This paper begins by describing the needs that individuals can address by using their computers or going online and discusses some of the ways in which consumers can access applications to meet those needs. The next section summarizes the data on how many people are using these applications. It also includes a brief summary on the existing evidence about the effectiveness of these health tools. The fourth section discusses how use of health IT varies among different subpopulations of consumers. Next, the paper discusses some of the obstacles for greater uptake of consumer use of health IT. This paper concludes by identifying policy approaches and stakeholders to foster increasing use of these applications.

II. What consumer health needs can be addressed using health IT?

As highlighted above, there are a number of health needs that IT can help individuals address. There are also several pathways individuals can follow to access health applications. First, a number of resources, particularly information sites, are available online for anyone who is interested in them. Other individuals come in contact with these web tools through their relationship with their medical providers. A final entrance point is through entities that pay for health care—insurers and employers. This section runs through tasks that health IT can facilitate and discusses which pathways users can follow to address those needs.

Seek health information

The web is a source of information about a wide array of topics and a growing number of Americans are turning to the internet to find answers to health questions. A variety of commercial, nonprofit, and government sites provide articles, tips, and other information about disease and wellness topics.

The commercial site WebMD is a particularly popular source of free health information. In the third quarter of 2008, approximately 50 million unique monthly users visited the WebMD Health Network. Over the course of a year, it is estimated that WebMD content is accessed by 95% of U.S. adults who view health information online.[26] Studies from several years ago confirm the popularity of WebMD. One online survey that asked individuals to name up to three websites for health information, found that more than half selected WebMD, with 25% each choosing MSN Health or Yahoo! Health.[27]

A study of internet usage data from September 2004 noted many visits to sites sponsored by the federal government, including the National Institutes of Health (NIH) website (2.4 million visitors), the CDC site (740,000 visitors), and the main site of DHHS (384,000).[28] The NIH domain includes the National Library of Medicine's MedlinePlus site, which contains information on 750 health topics, as well as news reports, tutorials, and information on prescription and over-the-counter drugs.[29]

Another set of players in the online information world includes companies that produce health products. For example, Knoll, a company that produces a thyroid treatment, sponsored the Gland Central site. In exchange for having access to that site, users were required to provide information about themselves and their medications, which provided the company with potentially valuable information for targeted marketing efforts.[30] (At the time of this report, the site was no longer operational.) Companies that sell diet products are also popular among internet health searchers, with 5% of searchers reporting visiting Weight Watchers and an equal percentage visiting eDiets.com.[31] In another health promotion realm, one study found that two of the three websites most commonly mentioned as sources of assistance for smoking cessation were sponsored by tobacco companies.[32]

Nonprofit organizations, health providers, universities, and medical associations also sponsor websites with information on a range of health topics.[33] One study found that websites sponsored by online services were the most popular type of site, with about twice as many viewers than the next most popular options—sites sponsored by pharmaceutical companies, academic or research institutions, and medical journals.[34]

One study explored the ways that health seekers begin their online quest for health information. About two-thirds of the respondents said that they had used a general search engine (for example, Google or Yahoo) at the start of their most recent online health session, while the remaining one-third went directly to a specific website.[35] That study did not examine the use of health-specific search engines, although the

author noted the growing popularity of such search engines as Healthline.com, Healia.com, Kosmix.com, Mammahealth.com, and Medstory.com.

In addition to individuals seeking health information on their own initiative, providers can play a role in directing patients to information. First introduced in 1992, "information therapy" involves helping consumers gain knowledge to improve their own health and well-being.[36] This practice has gained increasing prominence. Following a pilot project in 2002-2003, the American College of Physicians Foundation and the National Library of Medicine launched nationwide their Information Rx Program in 2006.[37] Through this effort, physicians can use a special prescription pad to inform patients how to access information from MedlinePlus to better understand their conditions. Kaiser Permanente and other health care organizations have also adopted an information therapy approach.[38]

Once individuals land on a health-related website, they might be directed to information that is applicable to them. For example, in 2008 WebMD introduced a series of slideshows on their website to allow people to view pictures of such items as rashes, tick bites, and bed bugs. Visitors who recognize their own bites or rashes can then access related text. Similarly, the "symptom checker" function helps individuals to determine whether they are showing signs that might be consistent with a particular ailment. Another feature to help viewers access relevant information is the pill identifier, which was designed to assist consumers who have removed medications from their original pillboxes. The website www.howsyourhealth.org is another example of how information can be tailored to users. After individuals complete a questionnaire of more than 100 items, the website generates a page of information with links to modules on health topics the survey identified as potential areas of concern.[39]

Take action to monitor and improve health

Complementing the articles and other information available online, computerized applications can also help consumers make decisions, monitor their chronic conditions, or receive assistance in engaging in healthier behaviors. According to one recent literature review, the most common topics for computerized tools are nutrition, weight management, tobacco cessation, and cancer and diabetes prevention and management.[40]

Decision aids are designed to provide an individual with information about the condition and the probable outcomes of different treatment courses, to help her determine which outcomes are of the greatest importance, and then to facilitate a decision process that matches her preferences with the treatment options. [41] As decision aids are emerging in growing numbers, several organizations, including the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI), have established lists to catalogue available tools.

Games can help bring to life the importance of engaging in healthy behaviors and managing diseases. As a sign of the increased interest in this more dynamic approach to health promotion, in May 2008 the Robert Wood Johnson Foundation awarded $2-million in grants as the first round of its Health Games Research project.[42] The programs being evaluated in this initial round of the grant program include a mobile-phone based game to encourage adolescents to eat nutritiously; several "exergames" that involve engaging participants in physical activity; and a video game that gathers breath biofeedback from cystic fibrosis patients and helps them monitor their condition.

Some applications help users monitor symptoms. Patient diaries allow individuals with chronic conditions to record their symptoms systematically. These applications may also allow for interaction between individuals and their providers. In one pilot project at a Veterans Affairs hospital, patients could take note of their experiences with intermittent chronic pain in a patient diary.[43] This information was relayed to a

pain management specialist for periodic review. Such a system could be designed to include automatic alerts that would notify a physician if symptoms surpassed a predetermined threshold. Rather than manually entering symptoms in the online tool, various health monitoring devices (including scales, blood glucose monitors, and blood pressure monitors) can be plugged directly into a computer. Some web portals allow users to download information directly from these monitoring devices, integrate it into an existing health profile, and potentially make this output accessible to providers.

Of course, just as 71% of internet-using adults have purchased something online,[44] the web could be a marketplace for health-related products. Not only can consumers buy these health monitors, but they can also find diet and wellness products, medications, and other items.

Communicate with relatives, friends, and other patients

In addition to allowing medical providers to view symptom monitoring information, individuals can decide to share it with friends and relatives. This allows individuals to stay abreast of new health-related developments their loved ones experience—for example, it could allow adult children to keep an eye on their infirm parents from afar.

PatientsLikeMe offers a series of online "communities" organized around different conditions, including amyotrophic lateral sclerosis (also known as ALS or Lou Gehrig's disease), depression, and HIV/AIDS. In the ALS community, patients provide information about their health history and current health status.[45] The website generates a series of charts that represent progression of symptoms, changes in functional impairment, and treatments over time. Not only can patients review graphics mapping their own condition compared to a benchmark of other patients, but they can view the profiles of other members of the online community as well. A participant in the community can search for others who have similar symptoms or are undergoing similar treatment and leave a comment on those individuals' profiles. The comments can ask specific questions about the other patient's experiences, offer advice or recommendations, or seek to develop a relationship based on common ground between the two patients. The website includes an online forum where patients can discuss topics of interest. The system also generates treatment reports that contain aggregate information about the dosage of a particular medication and the reasons why community members started and stopped taking the treatment. These reports are hyperlinked to related information in the forum and to profiles of individuals who are using that particular treatment.

One expert described this interest in seeing which treatment options are most commonly used by others as part of an "iTunes mentality," drawing an analogy to the graphic in the music-download store that allows users to view which songs are most popular. There is an apparent desire among patients to use how others are managing their health as an input in their own health decisions. Another expert noted that there are communities developing online around common experiences like taking antidepressants or experiencing infertility. As she explained, individuals are "hungry for personal testimonies;" they want to learn from others with firsthand experience what side effects to expect from treatments or how to use drugs off-label. WebMD has also introduced a similar function; to complement the monographs about pharmaceuticals, individuals can view one of the 47,000 reviews covering 3,000 medications that have been posted by other consumers.

This type of function is part of a broader phenomenon of social media, through which individuals contribute to the content on the internet. One expert described the emergence of blogs, wikis, and other related technologies as giving individuals access to "industrial strength" data rather than "commercial strength data," by which she meant that consumers can read raw data—i.e., the actual experiences of patients, the full version of a report—rather than the versions of those data that are relayed by the news media. Blogs and social networking websites can also foster collaborative advocacy efforts around health policy issues.

Interact with the health care system

In addition to helping individuals address their health needs, computerized applications can assist in navigating and interacting with the health care world. Individuals can go online to select an insurance plan, to learn about the benefits covered by that plan, and to find medical providers. Some providers also allow their patients to engage in a range of activities related to their medical needs through their web portals, including communicating with providers and ordering prescription drugs.

The majority of Americans receive their health insurance through employers. Firms are often active in providing their employees with information about the cost and quality of the health plans they can chose among.[46] In an effort to boost productivity and reduce absenteeism, employers may also use their websites to promote wellness.

Online resources can facilitate the selection of health care providers and plans. An estimated 17% of individuals with private health insurance plans switch coverage annually and 11% of the population changes their doctor.[47] Individuals can access directories of physicians from a range of national websites, including WebMD, appointmentnet.com, and the American Medical Association's DoctorFinder. Health insurance websites often allow individuals to search the list of providers who accept that coverage. Individuals may also be able to find doctors and receive recommendations from other locals through websites and listservs that are established to share information about a particular community.

As individuals make these decisions, they can consult websites, like Medicare.gov, to gain information about the quality of new doctors or health plan options. In 2006 President Bush signed an executive order mandating that providers who see Medicare beneficiaries or otherwise have transactions with the federal government make cost and quality data available to the public by the beginning of 2007.[48] Through the Medicare website, individuals can find hospitals and nursing homes and compare them based on some of these quality data. Beneficiaries can also compare Part D prescription drug plans, look up drugs in their formularies, and enroll in plans. Unfortunately, a survey conducted in 2005 found that only 2% of respondents ages 65 and older had visited the site—a slightly smaller percentage than individuals in that age group who had visited the commercial WebMD.[49]

In addition to Medicare.gov and its related Hospital Compare site, information about the quality of providers is available through sites sponsored by a variety of types of organizations, including:[50]
- Government agencies and nonprofit organizations that post data on clinical performance measures (ex. sites sponsored by state governments or hospital associations in at least 16 states)
- Media outlets (ex. the annual "America's Best Hospitals" issue of *U.S. News and World Report,* other local and national magazines)
- Commercial websites that allow users to rate the quality of their providers (ex.RateMDs.com, Suggestadoctor.com, RevolutionHealth.com)
- Sites that have integrated comparative data on mortality rates, complication rates, and lengths of stay for selected procedures within search functions to find providers (ex. WebMD)[51]
- Subscription or fee-based databases that are typically purchased by health insurance sponsors, groups of employers, and health care providers rather than individual consumers[52]

After selecting an insurer, some individuals can visit the website of their insurance company to manage their health care needs. The Anthem Blue Cross and Blue Shield plan offered through the Federal Employee Health Benefits program illustrates some of the services that can be available online. The site lets enrollees see information about their membership; search for, select, or change providers; view information on health and wellness topics; and purchase discounted health-related products and services.[53]

Other popular features of insurer sites include allowing individuals to view their lab results, find medications on the formulary, and renew prescriptions.[54]

Similarly, once enrolled with a provider, patients might gain access to assorted health applications if their providers have a web portal. Academic medical centers and integrated delivery systems are often more able to leverage sufficient resources to offer portals to their patients.[55] In addition to private practices initiating these portals, government entities have gotten involved. For example, there are between 5 to 7 million veterans enrolled in the My Health*e*Vet program of the Department of Veteran Affairs (VA). [56] Community-based organizations can help fill these needs as well. Several such organizations in Sonoma Valley, California, collaborated to launch MiVIA in 2003 to help migrant and seasonal workers track their health care.

These portals can allow individuals to use a number of functions, which may include scheduling appointments, re-filling prescriptions, or otherwise communicating with physicians and office staff. Practices can establish automated systems to allow patients to directly schedule appointments, or they can accept appointment requests via email or other messaging systems. Patients are communicating online with their providers both about these logistical concerns and about their health needs. One study found that the most common type of message (comprising about two-fifths of the communications) was an information update sent from a patient to a physician.[57] About one-quarter of the messages were requests for prescription renewals. Messages about test results and referrals each accounted for roughly 10% of the messages. According to one practitioner, some of these communications take the place of office visits.

Although practices can opt to use online interfaces, such as MyDocOnline or RelayHealth, to send and receive secure messages with their patients, one study found that the vast majority of doctors who communicate online with their patients simply use e-mail.[58] Yet using a messaging platform may provide advantages, particularly if it is includes encryption for greater privacy protection, as well as other features like templates to help users craft more structured messages and systems to route messages to the appropriate staff members.[59]

Use a personal health record or multi-function portal

In addition to facilitating electronic communication between patients and their physicians and office staff, provider portals can be associated with an electronic health record (EHR), allowing patients to view part or all of their medical charts. A particularly popular component of many of these portals is that they often allow individuals to see the results of lab and other diagnostic tests and view lists of their medications, immunizations, and allergies.[60]

These portals may also be a source of health information for patients, as some providers purchase subscriptions to health information databases and allow their patients to search for information in those databases. This health information can be integrated into other portions of the portal. In a pilot test conducted at one provider organization, one-half of individuals followed hyperlinks from the lab results page to the information section. Some portals include decision aids to assist patients in selecting appropriate treatment options, and the ability to deliver reminders about screenings and check-ups.[61]

Another approach to monitoring one's health data is the personal health record (PHR). Currently, despite growing interest in the concept, there is no consensus definition of a PHR.[62] One working group described the ideal PHR as "an internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it."[63] PHRs are often distinguished from EHRs by the fact that patients control the information in a PHR. Rather than solely containing information entered by providers, PHRs often allow patients to add information about such

topics as symptoms, over-the-counter medication, and diet or exercise regimens, as well as information produced from personal monitoring devices.[64]

Comprehensive PHRs could offer a variety of benefits to patients.[65] Web-based PHRs are portable, allowing patients to take their health histories with them on vacation or through an interstate move. They also can help ensure more accurate and complete records are kept, which in turn could improve the quality of care if it gives providers more information in making diagnoses and helps them avoid potential adverse drug interactions. (One publicly available PHR—Google Health—includes a feature that checks for potential interactions between the medications, allergies, and conditions that an individual has entered into his health profile.) PHRs, if shared with providers, have been touted as a means of making care more efficient for both doctors and patients (and potentially lowering costs) by reducing the likelihood of repeated recording of medical histories and duplicative tests or diagnostic procedures. In light of these potential benefits, the Bush administration and the Institute of Medicine advocate a comprehensive PHR for the majority of Americans that would allow them to gather data from all of their providers and to input additional personal information.

PHRs can be constructed in several ways: they can be built around a patient's EHR from a particular provider; they can be formed by the patient independent of a provider using an online or other type of software application; or they can be coordinated by insurers and populated with insurance claims.[66] According to several experts, PHRs may be more attractive to consumers if there is a mechanism to allow individuals to avoid entering in their medical data themselves because that task is accomplished by another entity—a provider, insurer, or a web-services provider that acts as an "infomediary" and collects data from other sources.

For patients looking to establish a PHR on their own, a variety of websites are available. Although there was a series of unsuccessful attempts by commercial vendors to establish PHRs in the early years of the decade,[67] in more recent years they have become more prevalent.[68] The American Health Information Management Association provides links to about 90 PHR applications on its website.[69] The recent launches of PHR-related sites from Google and Microsoft may have a large impact on PHR use in this country, but it is too early to appreciate how they will change the landscape.

Microsoft HealthVault, which began in September of 2007, is not itself a PHR, but a platform through which individuals can access PHRs and other applications from a wide number of partner organizations. Microsoft helps coordinate these different services. For example, users can plug glucometers and other monitoring devices into their computers, download the results, and integrate them with the rest of their health data.

Launched in May 2008, Google Health is a PHR that also serves to aggregate data from multiple sources. The company has partnered with hospitals, labs, and pharmacies so that individuals who receive care from those partners can grant permission for their data to be exported and incorporated into their Google Health profile. Google Health account members can also grant permission to other third-party partners to offer tailored services for a fee, such as sending a member research related to the conditions in her profile.

WebMD also offers a PHR. As one company representative remarked, many people are aware of the WebMD brand and will therefore visit the site when seeking health information. Once they arrive, they are exposed to the PHR, provider search, and other functions.

In addition to these PHRs that are initiated by individuals using public websites, several large private employers have sought to allow their employees to view their health records. One large initiative is Dossia—created by Wal-Mart, Intel, Pitney-Bowes, Applied Materials, and BP America—which provides patients access to their electronic medical records.[70] Although Dossia is a patient data system rather than a

PHR, other employers, like Dell, provide PHRs for their employees. Employer-sponsored access to PHRs is not yet universal among big firms, but Helen Darling, president of the National Business Group on Health, predicts it will be: "It is very safe to say that every large employer in the United States will either enable through a health plan or portal or help make available through some vendor personal health records and benefits."[71]

By one estimate, 70 million individuals can access a PHR through their health plan.[72] The Centers for Medicare and Medicaid Services (CMS) are also exploring the role of PHRs for Medicare beneficiaries in Medicare Advantage plans, and among a small subset of fee-for-service beneficiaries.

Emerging Trends in Consumer Health IT

Several of the experts consulted as part of this project highlighted social networking as an increasingly important trend. Blogging has emerged as a major force in the last several years. In May 2008, 33% of internet users said they had read someone's blog and 12% have worked on their own blog or online journal.[73] Some experts suggest that these statistics fail to fully capture the impact of blogs because of their multiplicative effect. Even if relatively few people report regularly reading blogs, information from blogs often finds its way into more mainstream media.

One expert talked about an increasing interest in wellness and speculated that as consumers are paying a larger share of their health care costs they may express a greater interest in maintaining their good health. Another expert spoke about the "chronically well"—individuals who are very interested in engaging in healthful behaviors who might want to be able to quickly track their diets or exercise regimens with a few taps on their PDA. Along a similar vein, many of the applications discussed above that are now focused primarily on helping patients with chronic conditions may be useful for consumers without such conditions. One expert predicted that pedometers would be an increasingly popular device whose readings could be integrated with a PHR. Also, consumers could receive reminders about flu shots and women could receive reminders at appropriate times throughout their pregnancy to alert them to when they should start or stop eating certain foods, at what stages they need tests, and which physiological changes should be expected at what time so women can consult their doctors about deviations.[74] Alerts could come from more unusual sources. For example, sensors on pillboxes could generate automatic reminders to take medications that are routed to cell phones.[75]

Future generations of disease monitoring devices could give children of ill parents visual representations of what is happening at a remote location. For example, one potential innovation is having a lamp in the child's home that would change colors depending on a parent's activity in his home—for example, the lamp could be responsive to data relayed from bed sensors to alert the child about when a parent gets out of bed.[76]

Emerging applications might focus on practical aspects of health care. Health IT could help patients with chronic diseases better manage their time—including incorporating doctor's appointments into consumers' workflows. Another area under exploration is helping people manage their health expenses. Around 8 out of 10 respondents of one survey expressed an interest in tracking insurance payments, out-of-pocket expenses, and other health-related financial costs.[77] This year (2008), Intuit, the maker of Turbo Tax and Quicken, launched Quicken Health. Individuals enrolled in several health plans can sign up to have their claims and benefit information transmitted to this online application.[78] The program then translates the information into language that is designed to be more clear for consumers. For example, it explains why a claim was denied and advises the consumer on steps to take to address the problem. Although not currently integrated with Turbo Tax, the application provides users with the total eligible expenses that could be used to complete the appropriate form for a medical expense tax deduction.[79]

III. How are consumers currently using these resources?

Given the breadth of activities that health IT allows consumers to engage in, how many users are actually turning on their computers to take advantage of these resources? In addition to considering prevalence rates of the various types of applications, this section provides an overview of the ways these applications have been evaluated.

Extent of use of health IT applications

It is difficult to ascertain the proportion of Americans who have used computerized applications related to health. But it is clear that there are many millions of individuals who have gone online for at least one of these health applications. Several indications suggest that the number of consumers engaging in e-health has been increasing.[80]

Before describing the frequency with which consumers go online for health reasons, it is useful to put this in the context of the potential universe of health IT users. Some individuals may lack health literacy skills or access to the computer or internet to take advantage of these applications. Differences by population group in health literacy and computer/internet access may also help to explain variation in consumer use of computer applications for health. (See "Health IT Prerequisites: General Trends in Health Literacy and Internet Access.")

Another useful baseline comparison is other types of consumer use of IT. The most frequent online activities among respondents who had gone online the day before include using search engines (49%), viewing news media (39%), and looking up the weather (30%).[81]

Many of the experts we consulted drew an analogy between health IT and online banking, in part because the two fields face similar challenges related to privacy and data security. Despite past resistance, a substantial population conducts its banking online. In 2007, the Pew Internet & American Life Project reported that 53% of internet users had at some point banked online, and that 21% said they had done so the day before.[82]

A final point to consider before delving into the prevalence of consumer use of health IT is the nature of the data available to investigate this question. Although several studies address who goes online looking for health information, there are fewer available data on other health applications. In 2006, one report decried that with the exception of studies on penetration rates within large, closed health care systems, "little is known about the actual uptake and use of e-health tools."[83]

There are two primary sources of rigorous data on the topic:
- Health Information National Trends Survey (HINTS) – Biannual survey conducted by the National Cancer Institute, first administered in 2003.
- Pew Internet & American Life Project – Surveys on health topics have been administered on a two-year cycle starting in 2000. The Project tracks other online behavior more frequently.

(A sample of the questions that are asked in these and a handful of other surveys is available in the appendix.) In addition to these surveys, there are a number of private companies that follow trends in internet use—particularly related to transactions like purchasing drugs—but a subscription or payment is often required to access the findings.

The findings across different surveys are not always consistent. This may reflect the rigor of the sampling process. (For example, some studies conduct all of their recruitment online, thus excluding people who do not use the internet.) Also, questions that are asked in slightly different ways may yield different results.

Health IT Prerequisites: General Trends in Health Literacy and Internet Access
To understand the universe of who might be in a position to take advantage of consumer health IT, it is helpful to understand some potential barriers to online health activities. In this section, we focus on two factors that could slow the uptake of consumer health IT—health literacy and access to computers and the internet—and how these barriers differ by subpopulation.

Health literacy
Health literacy is defined as the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[84]

In the general population, many experience limited health literacy levels. One study places 53% of the population at an intermediate level of health literacy, 22% basic, and 14% below basic, leaving only 12% of adults with a proficient level of health literacy.[85] A large majority of health information materials are written at a 10th grade reading level or higher, well out of the range for a large portion of Americans.[86] Low levels of health literacy are associated with being less likely to have undergone preventative measures such as screening and higher rates of illness and mortality.[87]

Health literacy is lower in most racial groups other than white and Asian/Pacific Islander.[88] Hispanic and African American adults are far more likely to have the lowest health literacy levels and this is particularly the case among those Spanish speakers who spoke only Spanish before starting school. Studies also consistently show that younger age groups and individuals who have achieved higher degrees of educational attainment have stronger health literacy skills.[89]

Internet use
According to a Pew Internet & American Life Project poll conducted in 2008, 75% of Americans use the internet.[90] These finding are consistent with a total of eight previous surveys that Pew conducted; since 2005, the percentage of overall usage has not dropped below 69%.

Internet and computer use varies by population.
- *Age* - Surveys consistently show that younger Americans are more likely to use the internet. For example, the most recent Pew study found that 91% of individuals ages 18-29 use the internet, as do 86% of 30-49-year-olds, and 74% of people ages 50-64.[91] A dramatic decline in internet use occurs among individuals over the age of 70; while 53% Americans ages 60 to 69 use the internet, only 22% of individuals who are 70 and above do.[92] Similarly, only 28% of respondents 65 and older said they use a computer.[93]
- *Socioeconomic status* - Internet users are more likely to have higher incomes and be more educated than their offline counterparts. Americans with household incomes less than $30-thousand annually are the least likely to use the Internet (56%).[94] Conversely, higher earners, who make $75-thousand or more, are the most likely to use the internet (95%). Less than half of those who have not completed high school use the internet (38%), while the majority of high school graduates are internet users (66%). Over 95% of individuals who have at least one degree are internet users.
- *Race* - Whites and Hispanics are the most likely to use the internet. In the most recent Pew survey 75% of white, nonHispanics, 80% of English-speaking Hispanics, and 70% of nonHispanic African Americans use the internet.[95] Not only do Hispanics lead in internet use, they are also one

of the most rapidly growing internet demographics.[96]

- *Health* **-** Research shows that Americans without internet access are more likely to suffer from chronic health conditions.[97]
- *Gender* - In the August 2008 Pew survey, slightly more men and women use the internet.[98]
- *Geography* - Rates of urban and rural internet use vary by 11 percentage points. Even though they lag behind their urban counterparts, the majority of people from rural areas (64%) do use the internet.[99]

High-speed internet access

Not only does whether one goes online or not play a role in this discussion, but the type of the connection may also be crucial. Researchers have identified a "broadband effect" by which individuals who have access to a broadband connection, even accounting for other demographic characteristics, are more effective at using the internet to address problems.[100] According to Pew, broadband access at home has become increasingly widespread. Currently 55% of Americans have broadband access to the internet.[101] This represents a 17% increase from 2007 to 2008.

Some demographic groups once thought to be slow to adopt broadband are showing significant rates of growth between 2007 and 2008. Currently 50% of older Americans ages 50 and above have home broadband, as do 45% of people with annual incomes between $20-thousand to $40-thousand, and 38% of individuals living in rural areas. Other groups, in contrast, did not experience significant growth since 2007. Only 25% of Americans making less than $20-thousand a year said they had broadband and 40% of African Americans said the same.

The 2008 Pew survey also seeks to learn why respondents do not have broadband. Among those who report that they still do not have high-speed access, 62% say they are interested in adopting broadband. The most prevalent reason for not adopting was the price of broadband (35%). Another 19% said they simply don't want broadband. Twenty-four percent of rural dial-up users said that broadband was not offered where they lived.

Other prerequisites

In addition to the above prerequisites, the ability for individuals to gain something meaningful from e-health resources may also be tied to these five factors proposed by the Institute of Medicine (IOM): Access, Availability, Appropriateness, Acceptability, and Applicability of content. [102]

Seek health information

Estimates for the proportion of American adults that have used the internet to look for information about health range from approximately 40% to around 60%.[103] Some evidence suggests that this use has grown over time. For example, in the 2003 HINTS survey only 50.7% of respondents said they had looked for health or medical information online about themselves, while two years later that number had increased by 7.7 percentage points.[104] Among internet-using adults, one survey found that about 80% have looked for information about at least one major health topic online, a statistic that has remained relatively consistent since 2002.[105*] Extrapolating out, this implies that approximately 113 million American adults

---

[*] The different prevalence rates in these two studies stems in part from the different ways in which they ask the question. HINTS contains two separate variables: "use the internet to look for medical information for self" and "use the internet to look for medical information for other;" while the Pew studies ask if you have ever looked online for a wide range of topics—including information about medical, health care, and wellness topics. The broader

visit websites for health information. Among internet-using adults, an estimated 7% report looking for health information online on a typical day, comparable to the percentage who use the internet to pay bills or look up a phone number or address on a given day.

Different studies paint different pictures of the internet's role as a source of information relative to other sources. One study found that among those looking for information about health, 69% mentioned the internet as a source, compared to 59% who mentioned their own physicians, and 39% who cited other health care professionals.[106] However, only a small number of individuals mention the internet as the *main* source of their health information.[107]

In understanding the reach of online health information seeking, it is important to consider the fact that many of the individuals who are looking online for health information are doing so on behalf of someone else. For example, the HINTS survey found that in 2005 nearly the same percentage of respondents were looking for medical information for others as were looking for that type of information for themselves—59.5% and 58.4%, respectively.[108] Another study found that about one-third of caregivers have sought information online.[109]

Individuals are interested in a range of health topics. About 64% of all internet users said they were looking for information on a specific disease or medical problem.[110] Wellness topics appear to be quite compelling, with about half of internet users reporting looking online for information about diet, nutrition, and vitamins; and a similar share seeking information on exercise or fitness. About a fifth (22% of internet users) go online to learn about mental health issues, with smaller percentages looking for information on dental health (15%), sexual health (11%), quitting smoking (8%), or problems with drugs or alcohol (8%). In addition to learning about specific medical issues, many go online to find out about health care topics, with 28% interested in health insurance and 13% seeking information on Medicare or Medicaid. In another survey, finding out information about treatments was a goal of 72% of people who went online seeking health related information, only a slightly smaller share than the 84% who were looking for general information on a condition.[111]

Research and purchase prescription drugs

One aspect of treatment that sparks some interest among online searchers is prescription drugs. In a 2004 study, 21% of adults said they had looked online for that type of information, while another 5% said someone else had conducted such a search on their behalf.[112] Yet only 4% or 5% of Americans say they have purchased prescription drugs online.[113] Part of the reason for these relatively low numbers may be that only 5% of those surveyed who were insured reported that they were required to use mail-in or online systems to order certain prescription drugs.[114] A small number of individuals reported using the internet for other drug-related purposes. Only 2% of individuals in a 2003 survey who had taken at least one prescription drug in the past year said they had contacted their physician over email or secure message to ask for a prescription.[115] (However, conversations with representatives from provider groups that offer the ability to request prescription refills online state that it is a popular feature.)

Take action to monitor and improve health

It is difficult to discern how many individuals are using applications that allow them to take action on their health. For example, a 2002 study found that about 7% of doctors who reported going online said they engaged in remote disease monitoring,[116] but it is possible that a larger proportion of individuals

---

definition of health information used in the Pew studies may, at least partially, account for the fact that Pew's estimates are consistently higher than those from the HINTS data set.

were monitoring their own symptoms without interacting online with their providers. It is also difficult to ascertain how many individuals are using decision aids; several producers of these products estimated that they were used approximately nine million times in 2006, primarily through the internet.[117]

Communicate with relatives, friends, and other patients

Online support groups appear to only attract a very small number of individuals. In the 2003 and 2005 HINTS surveys, 3.9% of respondents reported participating in online support groups.[118] Research on PatientsLikeMe yields similar results; a year and a half after its community for individuals with ALS was launched, about 4% (1,140 individuals) of the estimated U.S. population of individuals with the condition, had enrolled.[119] However, even if not formally participating in a support group, the web allows individuals to connect with others around health issues. Almost one-quarter of adults use the internet or email as a means of communicating with relatives or friends about health or health care and 11% had used online communications to interact with people with similar health issues.[120]

Interact with the health care system

Using email or secure messaging to communicate with providers is a less common practice than communicating with friends and peers, although many individuals express interest in electronically contacting their providers. One survey found that over 80% of adults said they would favor or strongly favor being able to email their physicians; yet the same survey found that only 8% currently do so.[121] Other studies have developed a range of estimates of the proportion of patients who are emailing their health care providers from 6% to 37%.[122][†] The percentage of people communicating with providers online has experienced a slow, but statistically significant increase over time.[123]

One of the key factors behind the disparity between the number of patients who would like to email their providers and the number who actually do so is whether individuals are seeing providers who offer this service. Although one study found that roughly one-quarter of doctors are communicating with patients online,[124] other estimates are lower. The number of consumers who said they had access to online communications with their physicians increased from 12 million in 2004 to 15 million in 2005, but these numbers still account for a small share of the 100 million US patients who would like to communicate electronically with their providers.[125] Despite the fact that online communications between physicians and providers is apparently growing at a slower rate than other forms of online use, many doctors predict that it will become increasingly common in coming years, particularly because of the large demand from patients.[126]

Visiting insurer websites is also growing in popularity. By one estimate, 26 million individuals visited the website of their health plan in 2005—a dramatic increase from the estimated 4 million who did so in 2001.[127] Yet using the web to learn more about providers is still not a widely embraced practice. In one study, 18% of people who seek health information were in search of information on physicians who specialize in treatments and 13% sought to learn about hospitals.[128]

It is not clear how many consumers consult online provider quality data. Two surveys found that twice as many individuals report being likely to gather information about the quality of providers from friends, relatives, and other health care providers, compared to individuals who would look to publicly available sources, including the internet.[129] These studies found that 19%-36% of respondents say they would likely use the internet as a source of quality information.

[†] The different populations examined in the surveys may account for a portion of this range. For example, some studies only ask this question of email users.

Use a personal health record or multi-function portal

There are few good estimates of the number of individuals who manage their health data through a PHR or use a provider-sponsored web portal. It is difficult to determine the number of patients who see providers that offer patient portals; although one article pointed out that the potential reach is not insubstantial because some of the early adapters of patient portals—like the VA and Kaiser Permanente—have large patient rolls.[130]

Even among patients who see providers with portals, the extent to which individuals decide to take advantage of them and log on to the system varies widely. Two provider organizations boasted enrollment or login rates of around 50% of their total patient population. However, results from two other providers had penetration rates hovering around 10%.[131] This type of disparity may reflect, in part, the fact that some practitioners advocate use of the web resources more than others do. It has been estimated that between 15-20% of patients who have the option to access a PHR through their health plan will decide to sign up.[132]

It is important to note that merely signing up for a portal does not necessarily translate into using it. One provider estimated that nearly one-third (31%) of individuals who sign up for an account on its portal actually activate the account. Among those who do login, another one-half do not make a request or otherwise communicate with providers. A study of one portal provides insight on which aspects of the site are most popular. The most common use is reviewing medical test results (54 out of every 1,000 patients enrolled in the site), followed by medication refills (44 of 1,000), summaries of office visits (32 of 1,000), and clinical messaging with providers (31 of 1,000).[133] These numbers may appear low, but some patients may not have had a need to use those resources in the period studied. For example, looking only at individuals who actually had taken a lab test and are enrolled in the portal, one expert estimated that more than 90% of individuals reviewed the test result.

It is more difficult to find data on PHR use in the population as a whole, yet most studies suggest that it is very limited.[134] An online survey conducted in 2003 found that only 1.5% of respondents said they use a computer to manage their health records, with an additional 0.5% saying they go online to do so.[135] (The same survey found that almost three-quarters of respondents would be interested in using a least one of the features of PHRs.) In 2005, two experts in the field estimated that fewer than 1% of Americans are using fully functional PHRs.[136] A 2007 survey estimated that 4% of the population uses a PHR in some form.[137]

Evidence on effectiveness

There are several approaches for evaluating consumer health tools. The first tactic is to conduct an evaluation of their quality relative to pre-established criteria, such as accuracy of information or ease of use. A second method is to gauge user satisfaction. Building on consumer satisfaction surveys are surveys that ask individuals whether they changed their behavior because of exposure to the tool. The final and most compelling—although also the most difficult to come by—type of evaluation involves randomized control trials and evidence of improved health outcomes or reduced costs or avoidable medical use. This section will discuss each of these approaches in turn.

Quality - There are several different dimensions of health-website quality that are discussed in the literature:[138]
- Accuracy (evidence-based, up-to-date, peer-reviewed)
- Credibility and transparency of source (including listing conflicts of interest)

- Ease of use (reading level appropriate for audience, readable format, easy navigation)
- Completeness
- Consumer-centeredness
- Privacy and security of personal data

As is the case with research on prevalence rates, the most data on the quality of web tools are available related to websites that provide health information. About 70% of studies included in one meta-analysis identified problems with quality of information on the internet, with only 9% coming to a positive conclusion and the rest staying neutral.[139] Problems with accuracy and lack of completeness were often cited by the authors of the studies in that analysis. The authors point out that there is also a good deal of inaccurate or misleading information about health presented in other media, like television, and that internet sites on other topics also often have quality problems.

One potential indicator of quality is whether a site explains where its information is coming from. A very small portion of websites that discuss health topics include the source and date of that information,[140] and only about one-fifth to one-quarter of people who look for health information online report that they look for the source at least most of the time.[141] However, some research suggests that there is no correlation between having the source and date on a page and the quality of the information contained on it.[142] Another discouraging finding comes from a study of websites devoted to smoking cessation, which found that the three sites that were deemed of highest quality were viewed by only 7% of individuals who visited websites on those topics.[143] Health web sites can seek accreditation by the nonprofit organization URAC to certify that the content meets certain standards, but it is not a universal practice.[144]

Although a substantial number of quantitative studies have sought to evaluate the quality of health-related information online, there is little consensus about the criteria that should be used to define a high-quality site. Because of this, as well as the lack of rigor of some studies and the fact that different studies focus on information about different health topics, it is difficult to draw concrete conclusions about the overall quality of health information online.[145]

Satisfaction - Several studies have revealed high levels of satisfaction about the information found online. For example, one survey found that 55% of people who sought information online to help them make treatment decisions were very satisfied with the information they found and another 38% were somewhat satisfied.[146] In another study looking broadly at searches about health topics, 70% said they felt satisfied with the information their search revealed, with an equal share saying that after they went online they were more comfortable with the information that a health provider had given them.[147] Yet, some individuals report negative experiences, with one-quarter reporting feeling overwhelmed by the quantity of online health information and slightly smaller shares expressing frustration (22%) and confusion (18%).[148] Some evidence suggests that individuals' experience with online health information gets worse with age.[149]

Moving beyond looking for health information, most studies suggest that people generally report high levels of satisfaction for a range of e-health tools.[150] For example, in several studies the percentage of people reporting they were satisfied with tools that are meant to encourage healthy behaviors, such as smoking cessation or nutrition sites, was in the 90s.

Surveys of users of provider portals also reveal a good amount of satisfaction. Several portals report that more than 90% of surveyed users are satisfied with the sites.[151] Particularly high percentages of users said they were *very* satisfied with ability to refill medications (81%), engage in secure messaging with providers (65%), and view test results (55%).[152] It is important to note that most of these analyses are only

looking at people who decide to enroll in the patient portals, which may introduce self-selection bias and inflate satisfaction ratings.

Self-reported impact on consumers **-** In one study, 42% of respondents said that the information they found online in their most recent search had no impact on the health care they received or that they helped others with; only 11% reported that it had a major impact.[153] (The percentage of searchers who experienced a major impact is slightly higher among those who reported a serious diagnosis or health crisis than among those who did not.) Roughly 20% of respondents to a survey about one provider portal said they had changed their behavior because of the suite of tools offered through their provider.[154] One online study found that approximately 65% of respondents reported being more compliant with the treatments prescribed by their doctors because of their online health activities.[155]

Health IT can affect health treatment by altering the communication between patients and health care providers. Depending on the survey, between one-third and a little over one-half of people who look for information online say that they discuss that information with their health care providers.[156] However, another study found that fewer than 10% said that using the internet or email affected the number of doctor visits or phone calls in the previous year.[157]

There is little evidence suggesting that access to publicly reported quality information on providers succeeds in steering patients to providers of a higher caliber.[158] (Some studies suggest such reporting does improve the quality of care at hospitals that had been under-performing.) One study looked more broadly at self-reported behavior upon learning about providers and treatments (not necessarily quality data). Roughly one-third of people who found information about available treatments or their costs said that information affected the treatment they received.[159]

All of these findings should be viewed cautiously as they represent perceived changes among individuals who participate in a survey.

Randomized trials and outcomes **-** In contrast to the efforts described above, some research has more rigorously examined clinical or other outcomes of specific computer-based applications. A 2006 overview of research in this area reached several broad conclusions:[160]
- There are a variety of tools related to a range of health topics that have been linked with positive outcomes in randomized control studies, but the evidence on improved health outcomes is not as consistent as research on self-reported increases in understanding about conditions or improved attitudes and intentions to change behavior.
- The tools that tend to be used the most frequently are not often the ones that have undergone rigorous evaluation by third parties; the latter are typically developed as part of research projects and not widely available to the public. In particular, although there are many commercial weight loss sites available online, there are limited data on their effectiveness.[161]
- Tools to encourage behavior change that are tailored to match how ready individuals are to change or the user's initial behavior and knowledge, have had positive results.
- With some exceptions, many studies rely on convenience samples and include a disproportionately high number of white women with higher education. Several studies have found that individuals with less education or minorities might benefit more than those with more education.

A meta-analysis of studies regarding computer-based applications that include both health information and either social support, decision support, or behavior-change support, found evidence of positive improvements on knowledge, social support, and clinical outcomes, and mixed results on behavior change outcomes.[162] A summary of research comparing the ability of web-based interventions to affect behavior

change relative to the ability of non-web-based interventions, found that 16 of the 17 studies reviewed were in favor of web-based approaches.[163] (However, the effect was only significant in six studies.)

In addition to looking at clinical outcomes, some studies have focused on financial implications.[164] For example, one randomized clinical study found that a small sample of children and adolescents reduced their emergency and urgent visits after playing a video game that included education about diabetes management.[165] Another study noted that a managed care organization discovered that hospitals' use of remote disease monitoring devices allowed patients with chronic heart failure to return home sooner and reduced the number of cardiac events, ultimately yielding a nearly 175% return on investment.[166] Remote monitoring might also save costs if it allows patients to assume control over tasks that would otherwise need to be performed by health care providers.[167] Additionally, there is a small amount of evidence suggesting that decision aids may reduce the likelihood of invasive procedures, while at the same time improving consumer knowledge and expectations of harms and benefits, and decreasing their internal conflict about the decision.[168]

Because of the novelty of PHRs, there is little empirical evidence about their financial benefits or the extent to which they improve the quality of care.[169]

IV. Differences in use by demographic group

Disparities exist across racial, ethnic, and socioeconomic status lines with regard to health status, insurance rates, access to health care services, and quality of care.[170] If patterns of consumer use of health information technology follow similar patterns, it could serve to exacerbate these health disparities. This section reviews the evidence on how individuals with different characteristics use computerized applications for health.

Few data are available comparing the use of different health IT applications across subpopulations. The information that is available primarily focuses on information seeking. In this arena, there is some evidence suggesting that individuals who have lower educational attainment and are either young (and healthy) or older (and less comfortable with computers) are less likely to go online looking for information about health.

In reviewing the evidence on how use of health IT varies by demographic group, it is helpful to reflect on the differences in use of the internet (see "Health IT Prerequisites: General Trends in Health Literacy and Internet Access"). For example, just as more highly educated individuals are substantially more likely to use the internet, higher education is also associated with greater use of health IT tools.

Information seeking

One researcher noted that looking for health information is universally popular; however some differences appear across demographic groups.

Socioeconomic status

Individuals with college degrees are disproportionately represented among internet health information seekers.[171] One study found that individuals with less than a high school education made up only 5% of all online health information seekers, although they comprise 12% of the U.S. population.[172] (However, even though individuals with less than a high school education may be less likely than their more highly educated peers to go online for health information, the same survey found that a sizable majority (71%) of

internet users in this group have gone online looking for information about health.) A smaller percentage (20%) of adults who have below basic health literacy receive information about health topics online than those who had basic (42%), intermediate (67%), or proficient (85%) health literacy.[173] On some sites, the skew towards a more highly educated audience may be even more pronounced. For example, according to a 2005 study of visitors to the National Library of Medicine's Medline Plus webpage, approximately 40% of respondents reported having at least some graduate-level education.[174]

Although there is credible evidence about the education-health IT link, there is less compelling proof about the relationship between household income and going online looking for health information, among internet users. For example, in the 2005 HINTS survey, internet users with household incomes below $25,000 were almost as likely to look for medical information about themselves, and were *more* likely to do so than individuals with household incomes that fell between $25,000 and $75,000.[175] Another study that used multivariate regression to control for other characteristics found little evidence of differences in health-related internet use by income.[176]

One expert we consulted suggested that the main construct for understanding who uses the internet for health and who does not centers on who is skilled at finding information. He suggested that "the new digital divide is not a purely economic one, but it relates to whether individuals possess the necessary skills in today's information economy, which have to do with finding information, finding the right information, making sense of that information and then using it." Our expert reported that this skill set is linked to education, but does not appear to correlate with race or ethnicity.

Race and ethnicity

There is little evidence that among internet users, the percentage who look for health information varies widely along racial and ethnic lines. One study found that 59.5% of nonHispanic white respondents had looked for medical information for themselves, while around 53-54% of Hispanic and nonHispanic black respondents had.[177] The results from the MedlinePlus user study are more striking with 77% of the users identifying their race as white and only 5% calling themselves black or African American.[178] In that study the vast majority—93%—described their ethnicity as nonHispanic.[‡] However, one expert pointed out that among Hispanics there appears to be a difference based on language skills. Perhaps because there is a limited number of online health resources in Spanish, those who speak Spanish as their main language lag behind others. However, bilingual Hispanics have information-seeking rates that more closely match individuals in other ethnic groups.

Gender

A common finding is that women are more likely to engage in consumer health IT activities than are men. One survey found that 82% of female internet users looked for information about a health topic, while only 77% of males had.[179] HINTS data also suggest that a larger share of woman internet users (65.5%) than men (50.8%) look online for medical information about themselves.[180]

A representative of a commercial health website said she believed that women are an appealing target audience for their services for two reasons. First, when women are pregnant they may be particularly interested in accessing health information and resources. Second, women often find themselves in the role of "family manager" looking after the health of their children.

[‡] It should be noted that 95% of the respondents who used the Spanish-language version of the page are Hispanic. However, the majority of those individuals were not using the website from within the United States and did not currently reside in the country.

Health

Health status repeatedly is demonstrated to be a factor in consumer health IT use. One of our informants observed, "Diagnosis changes people and probably changes them as internet users." A representative from a commercial health website observed that people tend to visit their webpages when "something new in their health life" occurs, whether that event is pregnancy, the appearance of a rash, a recommendation from a doctor to lose weight, or a family member's diagnosis. When individuals are facing a health problem, an estimated 46% turn to the internet.[181]

The fact that use would differ by health need is not surprising, yet the relationship between health and going online for related information is complicated by the fact that the odds of being an internet user are nearly twice as high for people in excellent or good health compared to those who are in fair or poor health.[182] Yet, even though poor health may prevent some individuals from going online, within the community of people who access the internet, those very conditions may prompt more health-seeking behavior. One study found that although internet use tends to be lower for those who have disabilities or chronic illnesses, among internet users, about 86% of individuals with medical conditions or chronic diseases look online for information about various health topics, compared to 79% of internet users without those conditions.[183] Similarly, while about 89% of individuals who had 10 or more doctor visits in the past year searched for health information, only 37% of those who had not seen a physician in the previous year were searchers. [184]

Age

The relationship between health IT use and age is not linear. On one end of the spectrum, younger individuals are more likely to use the computer and the internet. On the other end of the spectrum, older people may have greater health needs—a key factor in predicting health IT use. As a result, individuals in the middle years (their 30s to early 60s) are more likely to go online than are their younger and healthier or their older and less computer-savvy counterparts.

Empirically, one survey found that 95% of adolescents ages 12-19 were internet users, but only about one-quarter of those internet users looked for health information online.[185] In every other age group, the proportion of internet users who had looked for health information online exceeded the percentage of internet users who had NOT looked up health information online. There are, however, some topics that are more popular among younger internet users (ages 18-29) than those ages 30-49, including information on exercise or fitness, sexual health, and smoking, alcohol and drugs.[186]

Other studies have found that health information seeking remains relatively high among internet users ages 19-64 (between 78%-84% in one survey), and begins to drop off among internet users above the age of 65 (68%).[187] Older individuals are more likely to say that most of their health information comes from doctors or other health professionals than younger adults. Similarly, they are less likely to cite the internet as that main source of health information.[188] Lower income seniors are particularly unlikely to use the internet for health information; one study found that 8% of individuals ages 65 or over who have incomes under $20,000 had gone online for health information, compared to 43% of individuals in that age group with incomes greater than $50,000.

Older adults who do go online for health information may have different experiences. About 20% of older adults reported that searching online for health information required a lot of effort, while none of the adolescents surveyed said the same.[189] A larger share of adults ages 65 and older also say that they don't trust the internet "at all" as a source of accurate information related to important health topics, than do adults ages 50-64.[190]

Computer and internet use

Likelihood of looking for health information online also varies by individual's online access and experience. For example, one survey found that 86% of internet users who had been online for at least six years have looked for health information online, compared to just 62% of those who had two or three years of experience online.[191] Additionally, internet users who have high-speed connections at home are more likely to have sought out health information over the internet than those using dial up.[192] It should be noted that some evidence suggests that even after you take into account differences in internet use, some of the differences in looking online for health information still persist along gender and age categories.[193]

Other e-health activities

A 2006 report remarked on the lack of data about how use of many consumer health tools varies by subpopulation[194]—a finding that one of the experts confirmed still rings true today. Also, due to the low overall levels of use of some of these resources it is hard to identify distinctive patterns by demographic group.[195] As one expert explained, for many of these applications, the existing nationally representative data sets are often not sensitive enough to identify distinctions by demographic group and developing a sample large enough to do so would be cost prohibitive. Some of the data that do exist mirror the findings above about seeking health information.

Research and purchase prescription drugs
Several groups of individuals have been identified as having a higher propensity for looking online for information about prescription medications, including those with high-speed internet connections, who have been online for six or more years, who have a college degree, and who are part of the Baby Boom generation.[196] Additionally, internet users who have either chronic conditions or disabilities are much more likely to seek drug information online (51%) than those without (35%).[197]

Prevalence rates for purchasing medicines or vitamins online are low for all groups of internet users (around 13%), but patterns seem generally consistent with other types of online health use, with internet users who are female, between the ages 50-64, nonHispanic whites, and college graduates having slightly higher rates of buying medicines or drugs online than internet users in other demographic groups.[198]

Communicate with relatives, friends, and other patients
Little research is available about how online communication with nonmedical professionals varies by demographic group. The HINTS project does report on variations of use of online support services, however, although some patterns are revealed—more females, 35-39-year-olds, and college graduates have used these services—the overall rate of use (3.9%) is so low, it may not be appropriate to place too much weight in these variations by subpopulation.[199] The impact of these resources may vary by subpopulation. For example, one study on a website that provides social support services as well as information for women with breast cancer, suggests that it may be particularly effective for lower income or uninsured women.[200]

Interact with the health care system
Communicating with a doctor or doctor's office—another activity that is relatively rare among internet users—follows subpopulation patterns similar to searching online for health information.[201] However, in a regression analysis that took into account a range of demographic factors, many of those relationships, including those for socioeconomic status and race, are not significant.[202] One study that looked at data from both 2003 and 2005 noted that some of the factors that had in the earlier round predicted greater likelihood of online communications—such as higher education level and living in a metropolitan area— did not appear as significant factors in the later round.[203] Consistent with the evidence on information

seeking, having a health condition,[204] being a cancer survivor[205] and being female are significantly associated with communicating online with providers. The evidence on age is not consistent across studies.

As for learning about the health care system, one study notes that the tendency to go online for information about providers also follows the same bell-shaped pattern for age that peeks when individuals are between age 30 and 64.[206]

Use a personal health record or multi-function portal
Much of the data about which subpopulations are using PHR-type applications come from provider groups. Several studies found that patients with commercial insurance were more likely to enroll in provider portals than those who were on Medicare or Medicaid.[207] Some evidence suggests that white patients are more likely to enroll than other patients.[208] The evidence on the relationship between health need and portal use is mixed. One multivariate regression analysis concluded that individuals who did not enroll in a patient portal were more likely to be on more prescription medications and have more medical conditions.[209] On the other hand, analysis of a different patient portal found that individuals who were expected to have greater clinical need were more likely to sign on to the patient portal.[210] A survey assessing interest (rather than use) of PHRs found that those with chronic conditions or their caretakers found the prospect of a PHR most compelling.[211] One expert described the appeal that a PHR might offer an individual with a complex chronic condition like lupus who might be able to exchange her binder full of medical notes and records for one coherent, organized online record.

Studies also present conflicting findings about whether older or younger adults are more likely to enroll in patient portals.[212] What is clear is that individuals across the age spectrum have signed up for patient portals. In one provider group, one-third of patients in their sixties and one-quarter of those patients in their seventies had enrolled in the PHR.[213] In another portal, even though the median age at enrollment was 45, about 580 patients had signed up when they were in their 80s.

V. What is necessary to expand health IT use?

To fill in gaps in health IT use across populations and to increase the overall prevalence of use, several challenges must be addressed. These include making sure consumers have access to computers and ability to use them, increasing awareness about health IT, reducing financial and technical barriers, and ensuring privacy and quality of applications to make them more appealing to consumers and providers.

Interest in addressing challenges

Before delving into those challenges and some of the approaches to addressing them, it is encouraging to note that both the federal government and consumers exhibit interest in increasing prevalence of consumer health IT.

The Bush Administration has advocated for the expansion of health IT, as reflected in the President's 2004 declaration that the majority of Americans should have interoperable electronic health records by 2014. A "framework for strategic action" also emerged from this policy platform.[214] Encouraging "consumer-centric" care (including promoting the use of PHRs) is an important component of this framework.

The push for consumer use of these technologies coincides with a larger trend towards consumer-directed health care, which also includes high-deductible insurance plans and other means of reinforcing personal responsibility for health.[215] One expert speculated that as individuals are assuming more of the

costs of their care through larger deductibles and higher copayments, their demand for computerized wellness products might grow.

There are indications that consumers would be interested in engaging more with electronic tools. For example, although the actual level of PHR use is low, a majority of Americans agree that they would like to be able to use some of the functions associated with them. For example, one survey found that 90% of respondents believe that monitoring their symptoms via a secure online network would be very important.[216] Individuals with health concerns and those who perform other online activities are particularly likely to state their interest in the benefits PHRs could deliver.[217] Online communications with providers is another area where interest levels appear higher than current use levels. The majority of survey respondents said they would be interested in electronic communications with providers in order to: ask questions when a visit is not necessary (80%); set appointments (69%); receive test results (69%); and receive prescriptions (67%).[218]

Challenges that must be met

There are several prerequisites for consumer use of health information technology.
- Consumers need the resources to access computerized applications, including the relevant technology and the skills to use it.
- Consumers need to be aware of the applications.
- Economic and technical problems must be addressed to encourage the use of these applications.
- Applications must guarantee privacy and be of high quality so they will be appealing to consumers and health care providers.

These items are, of course, related. Consumer demand might drive the creation of more high-quality e-health tools. At the same time, the presence of more high-caliber resources might increase the likelihood that physicians promote their use and make consumers more aware of them.

Also, it is important to keep in mind that one of the main reasons people say they do not use consumer health resources is that they are not experiencing health problems and do not perceive a need.[219] In these instances, low take-up may not necessarily indicate a problem. (On the other hand, some experts point out that growing interest for wellness products may make health IT resonate even among those in good health.)

Access to technology and skills

"Health policy makers should follow developments in telecommunications carefully," remarked one researcher we interviewed. As so many health applications require the internet—and most perform better with broadband access—the importance of ensuring access to such technology cannot be understated. This appreciation of the importance of online connectivity is reflected in the *Healthy People 2010* objective calling for increased internet access in the home.[220] Although gaps in internet and computer access have been closing in recent years, they still remain.

One strategy to address these needs is the promotion of publically available computers. Indeed public libraries do serve as an important venue from which low-income and African American children access the web.[221] Another alternative is placing health kiosks—computer stations with software to help individuals address their health and health insurance needs—in health centers or other locations that provide health and social services.[222] However, for privacy reasons, public computers may not be ideal for health-related purposes. Given the fact that mobile phone use is growing rapidly and is particularly popular among Hispanics, some of the experts with whom we spoke suggested that applications for

mobile phones may become increasingly popular in coming years as advances are made to make such applications more feasible.

Gaining access to hardware, software, and the internet is not sufficient to assure "meaningful access" to health IT, as individuals will also need the skills to use them.[223] Some of these necessary skills may be physical ones; one analysis of e-health tools pointed out that physical manipulation of a mouse may be challenging for some people and many sites are not accessible for individuals with visual impairments.[224] As discussed above, cognitive skills are essential for successfully identifying usable health information.

There are three different approaches for addressing these cognitive capacity issues. First, more appropriate tools could be designed to take into account the needs of users with regard to reading level and navigation and to pay particular attention to making materials relevant and culturally competent for diverse populations.[225] Part of the process of making materials more appropriate for users involves conducting content analysis with an eye to information quality and readability and engaging consumers to understand their perceptions of the material.

A second policy approach involves preparing individuals to be able to use applications. One interviewee discussed the potential role of health education, possibly at hospitals, in order to help consumers use online resources upon discharge.

Third, there could be a larger role for individuals using online applications on behalf of others who are less able to do so. The role could be filled by friends and family or by promotoras or other community health providers. Several caveats attach to this approach. As one of the experts pointed out, it is not clear that the family member, caregiver, or promotora is himself capable of using the online tools. Another consideration involves privacy, as captured by one anecdote relayed to us by one of our experts: an older woman relied on her grandson to look up information for her about a leg injury; however, when she needed to learn more about a "female problem" she no longer felt comfortable requesting his assistance.

Lack of awareness

In order for people to use a resource they must be aware of its existence. Yet many resources are new and evidence suggests that awareness of applications like remote disease monitoring may be limited even among providers.[226] At least a partial explanation of the low rates of use of PHRs may lie in the finding of a 2007 survey that almost two-thirds of respondents were not familiar with the term "personal health record."[227] One hopeful prospect for increasing use is the observation that even if the majority of consumers have not previously considered the benefits of PHRs, many people say they would find value in PHRs once they learn about them.[228]

Public campaigns about the benefits of PHRs represent one approach to overcoming the awareness barrier. Connecting for Health has tested various messages to determine which ones might be most successful in promoting the use of PHRs.[229] Word of mouth may be one of the most powerful tools propelling individuals to health web sites,[230] and providers may be one of the most important mouthpieces to convey these messages. Representatives from three provider groups all emphasized the critical role of physicians in encouraging patients to use their online resources. As one noted, "most of what draws people to the portal is what happens in the exam room." He explained that it is useful for providers to explain while making a prescription that the portal can be used to request refills or to tell a patient as she is getting a lab test that the results will be available online.

Given that physician encouragement might play a critical role in fostering consumer use of health IT, it is important to explore why physicians may not be doing as much as possible to promote it. One obstacle

preventing some providers from engaging in information prescription is underestimating the ability of patients to access websites or understand the health information they read.[231] One 2005 survey found that only 9% of individuals ages 50-64 and 5% of those 65 and older reported having been asked by their doctor if they used the internet—smaller percentages (3% and 1%, respectively) said that they had received a recommendation to visit a specific website.[232]

The wealth of information available online may also alter the doctor-patient relationship. In fact, a 2001 American Medical Association press release encouraged Americans to adopt a New Year's resolution to "trust your physician, not a chat room."[233] One expert speculated that doctors may feel threatened if patients can bring their own information to visits. However, he proposed that doctors envision their role as shifting; rather than serving as the sole source of health information, they may serve in a more advisory capacity to help patients understand and respond to the information they obtain. He likened this new role to that of a financial advisor. Providers may also be concerned about the ways that messaging, particularly if there are perceived or actual breaches in confidentiality, might weaken their relationship with patients.[234] Physicians may be reluctant to begin messaging with patients because of concern about adding another responsibility to their workload.[235] However, some of this concern about the time burden of messaging may be overstated. One practice noticed that the introduction of secure messaging actually decreased the total message volume because allowing for asynchronous communication via the internet was more efficient than relying on phone calls and having to play phone tag.[236] Physicians also express concerns about potential liability if they do not react promptly to all the information exchanged electronically from their patients or if that information proves to be inaccurate.

Although there may be fear from physicians about using new health IT applications, one of our experts assured us that it could be overcome with strong leadership. Some provider organizations embrace these new consumer health IT opportunities. One provider mentioned that he saw "the great value of consumer health information technology as lying within the patient-provider relationship." He believed that greater ability to exchange information with patients would be valued by providers because it helps them to fulfill their ultimate goal—to improve the care of their patients.

Financial and technical barriers

It is important to note that the above sentiment came from a provider in a staff-model HMO. Because of the perceived benefits of messaging, PHRs, and the ability to exchange health data, large providers may be willing to absorb the costs involved in building these systems and compensating providers for the time spent using them. Practitioners who are not in a closed system may struggle more with low or nonexistent reimbursement for responding to patients' messages. For example, one survey of physicians noted that 80% claimed they would be willing to exchange secure messages with patients if they received payment for that service.[237] A slowly growing number of insurers are paying for messages and online consultations.[238] However, in those cases, the payments tend to be low in comparison to office visits.[239]

Identifying a party willing to pay for consumer health IT is a critical issue. There is little reason to be optimistic that individual patients will be willing to pay for it.[240] As an example, Qutinet originally pursued a model through which individuals would pay to access smoking-cessation services. With little demand, the company re-thought its approach and is now selling group subscriptions to health plans, employers, and state health departments.[241] From a policy perspective, rigorous research on the health impacts of consumer health IT may be necessary to motivate insurers and employers to shoulder its costs. As Ted Dacko, president and CEO of HealthMedia, explains "There is only one thing that matters in health care: outcomes."[242] It is also worth pointing out that if, as is asserted by many e-health experts, health plans and providers will play such a central role in promoting greater use of these technologies, individuals who lack insurance may be at a disadvantage.[243]

In addition to the challenges in building the economic case for providers to engage in health information technology and thus promote its use among patients, there are technical obstacles as well. The ability to exchange lab results and other information to make PHRs most useful and appealing to consumers may depend on the development and implementation of standards for data security, permissions for sharing information, and interoperability.[244] Addressing these challenges is a central component of the work of the Office of the National Coordinator for Health Information Technology in DHHS.

Privacy and quality

Assuring the privacy of personal health information is a key component of developing the demand for online resources among consumers. More than half of respondents to one survey said they were very concerned about their information falling into the hands of employers or health insurers.[245] One expert explained that even though surveys have found concern about privacy among users, individuals may underestimate the risks that could be involved, particularly, in his perspective, from PHR sites maintained by private companies rather than by providers. Concerns about having health information stored online may be even higher among underserved minority populations. One focus group study found that such individuals might prefer to carry a "smart card" with health data rather than entering it online.[246]

Privacy concerns and related legal issues may also limit the take-up of some applications among providers[247]—for example, it may make them reluctant or unwilling to release test results or may stop them from communicating with patients via email if a secure messaging system is unavailable.

It is unclear the extent to which privacy concerns will continue to be a barrier for consumers. As one interviewee pointed out, two items that individuals like to keep private are health and finances. Many have overcome their concerns about finances and engage in online banking; could storing health information online similarly become less threatening over time? Research suggests that a smaller percentage of individuals (39%) who have a long history of going online experience high levels of concern about making online purchases, compared to new users (55%).[248]

A thorough discussion of the policy options for addressing these privacy concerns is beyond the scope of this paper. One interviewee summarized two policy approaches—legislation mandating vendors' responsibilities in following provisions like those in the Health Insurance Portability and Accountability Act; or a self-regulatory system with voluntary certification of privacy policies.

For consumers to use health tools they must be confident not only that their privacy will be maintained, but also that they will be using tools that are accurate and safe. Purchasing drugs online, for example, may take some time to gain traction because a 2004 survey found that only one in five Americans think such purchases are equally safe as in-person ones.[249] Another study found a similar share (19%) of respondents said they trust health information a lot.[250] This trust of online information varies by demographic characteristics; people with more education and higher incomes are more likely to trust it and individuals age 80 or older are particularly unlikely to express that type of confidence. (For context, a survey about general internet use found that 55% of internet users believe that most or all of the information on the internet is reliable and accurate, while less than 40% of non-users feel that way.[251])

Providers may also resist recommending online tools if they are uncertain of the quality of the information available online. Indeed one researcher suggested that the quality barrier may be more of an issue for health professionals than it is for consumers. It may be particularly difficult for providers to verify the accuracy of information in more complex tools. For example, because the underlying logic in decision support aids may not be transparent, it might not be possible for a doctor to determine if the site

will provide the user with appropriate guidance. Also, one provider mentioned that concern over false information has thus far prevented his organization from including a non-moderated chat or discussion group feature that would connect patients to each other. He explained that information on a provider portal would be held to a higher threshold of accuracy than chat groups that operate on commercial sites, because consumers might have higher expectations about materials they access through their providers.

Additionally, individuals must find using health IT to be compelling. Our experts described some characteristics of consumer health IT that could increase its value in the eyes of users. Convenience and ease of use are key. This could involve reducing the amount of information a user must enter into a PHR, or enabling people to use mobile phones and PDAs. Also, several experts expressed that applications need to be consumer-centered and provide information or services tailored to individuals. Helping individuals access the information and tools that are most appropriate for them individually may prevent the confusion that can come from exposure to an "information glut."[252]

VI. Conclusions and policy areas requiring actions

As discussed throughout this paper, consumer health IT has the potential to allow users to be more informed about their health and take a more active role in monitoring chronic conditions and tracking wellness behaviors. Emerging applications that create social networks among patients may also empower consumers. If more widely adapted, PHRs could help ensure that providers and patients have convenient access to more complete medical records.

Meeting these goals will require the engagement of many stakeholders.[253] As discussed above, patients' interest in consumer health IT may be motivated by a desire to improve their health and to make their medical experiences more convenient and potentially less costly. Advocacy and disease organizations may also have a role in highlighting the needs of the consumer and encouraging patient-centered health IT. Providers play a key role in granting access to portals and encouraging the use of an array of e-health tools. They may be motivated by desire to improve their patients' care and possibly by efficiency gains. Payers also seek to make consumers (or employees) healthier and to make care more cost effective. Given the importance of reimbursement, payer policy may drive provider behavior. The vendors and developers of health IT products are, naturally, an important part of the picture as tools' design and fit with consumers could affect uptake.

The federal government has several roles in expanding consumer use of health IT. Several experts also spoke of a continuing role of the government in helping to establish standards to promote interoperability and safeguards to ensure privacy. The need for better research, and the potential role of the government in helping to support or promote this research, was a theme echoed by several experts. A better understanding of who is using e-tools and what characteristics make them most accessible and appropriate to users may help elevate health IT use across subpopulations. As discussed above, there are relatively few nationally representative rigorous studies that address consumer use of health IT. This has left gaps particularly in detecting differences in prevalence rates by subpopulation of emerging technologies. Longitudinal studies that follow individuals before, during, and after a health event could also be valuable. Another facet of research that may be important is evidence to demonstrate the impact of consumer health IT. If it can be established that greater use of e-health tools will improve health and cut costs, one expert argued, then not only may individuals be more interested in trying them, but support from providers and payers may be more forthcoming.

Studying the use of health IT is a moving target. A report from 2004 quoted a consumer, who said: "I guess I've gotten to the point where I expect to be able to do these transactions electronically. I just expect to do business this way with the organizations that I deal with…Expectations change. In 2004 you

expect to be able to do everything online. That's different from 2002."[254] Imagine how many other individuals have developed similar expectations in 2008 and how many more will do so in the coming years. As one of the experts we consulted put it, "We're on the brink of something big." As new technologies emerge to give individuals greater ability to manipulate their health data and to interact and learn from other online patients, it is important to understand who is already part of that trend, which groups are being left behind, what the obstacles appear to be for greater uptake, and what policies can help overcome those barriers.

Appendix: Sample of questions and topics covered by national surveys

Questions/Topics Covered	Year(s) Asked
The Center for the Digital Future, University of Southern California Annenberg School	
Do you use the Internet as a source of health or medical information?	2004
Reasons for seeking health or medical information on the Internet	2004
How do you find online information?	2004
Are you confident in your ability to find health information online?	2004
Views about Internet searches for health or medical information	2004
What Internet users do with the health information they find	2004
Email communication with heath care professionals?	2002, 2003, 2006
Pew Internet & American Life Project	
Ever looked online for information about…? [range of health and health care topics]	2006
Online information affected a decision about how to treat an illness or condition?	2006
Led you to ask a doctor new questions or to get a second opinion from another doctor?	2006
Changed the way you cope with a chronic condition or manage pain?	2006
Changed the way you think about diet, exercise, or stress management?	2006
Changed overall approach to maintaining their health or the health of someone they help take care of?	2006
Affected a decision about whether to see a doctor?	2006
Chronic condition (online information)?	2006
Positive experience (online health)	2006
Check date of online source?	2006
Serious diagnosis and impact (online health information)?	2006
Recently challenged or diagnosed e-patients?	2006
Which internet health resources?	2003
Prescription drugs online?	2004
Look for health/medical info (daily and overall)?	2000-2008
Participate in an online discussion, a list serve, or other online group forum that helps people with personal issues or health problems (daily and overall)?	2006
Ever look for information about a mental health issue like depression or anxiety (daily and overall)?	2002
National Cancer Institute, *Health Information National Trends Survey*	
On a typical weekday, about how many hours do you use the Internet for personal reasons?	2005
Have you ever visited an Internet web site to learn specifically about cancer?	2003, 2005
How useful was the cancer-related information you got from the Internet?	2003, 2005
Past 12 months only, how much have you heard about nutrition and cancer on the Internet?	2005
Go on-line to use the Internet or World Wide Web, or to send and receive e-mail?	2003, 2005
Where do you use the Internet from most often?	2005
Where do you go on-line from to use the Internet?	2005
At home access through telephone modem, a cable or satellite modem, a DSL modem, a wireless device such as a PDA, or some other way?	2003, 2005
Trust information about health or medical topics on the Internet?	2003, 2005

National Cancer Institute, *Health Information National Trends Survey* (continued)	
During a typical weekend, about how many hours do you use the Internet for personal reasons?	2005
In the past 12 months looked for health or medical information for yourself?	2003, 2005
Used e-mail or the Internet to communicate with a doctor or a doctor's office?	2003, 2005
Done anything else health-related on the Internet?	2003
Have you done the following things while using the Internet? Bought medicine or vitamins on-line?	2003
Did you use the Internet, whether from home or somewhere else to look for health or medical information for someone else?	2003
By using an interactive computer CD-ROM that lets you select information you want?	2003
Is there an internet site you especially like? [As a source of information about cancer]	2003
People get information about cancer, including how to prevent it and find it early, from many sources... How about by email or the internet?	2003
When you talked with a health care provider, how interested were they in hearing about the information you found on-line?	2005
Have you ever talked to a doctor, nurse, or other health care provider about any kind of health information you have gotten from the Internet?	2005
NORC, *General Social Survey*	
In the past 30 days, how often have you visited a website for health and fitness?	2000, 2002, 2004
Do you look for online information about a health concern or medical problem?	2000
Agency for Healthcare Research and Quality and the Henry J Kaiser Family Foundation	
Go online to an Internet web site that posts quality information about quality do doctors, hospitals and health plans?	1996, 2000, 2004
Do you trust each of the following sources to provide accurate information about…prescription drugs? Health websites on the Internet?	2000
National Center for Health Statistics, *National Ambulatory Medical Care Survey*	
Physician and patient encounters online during last week of practice	2003-2004, 2005-2006

Bibliography

Adler, Kenneth G., Web Portals in Primary Care: An Evaluation of Patient Readiness and Willingness to Pay for Online Services. *Journal of Medical Internet Research*, 2006. 8(4): p. e26.

As Enrollment Begins, New Survey Underscores Challenges If Seniors Are To Take Advantage of Medicare Drug Benefit. Menlo Park, CA: Henry J. Kaiser Family Foundation, Press release November 10, 2005. Available at: http://www.kff.org/kaiserpolls/med111005nr.cfm.

Baker, L. et al., Use of the Internet and E-mail for Health Care Information: Results from a National Survey. *Journal of the American Medial Association*, 2003. 289(18): p. 2400-2406.

Beauchamp, N. and T.R. Eng, eHealth: The Momentum Is Building. Seattle, WA: eHealth Institute, 2006. Available at: http://www.ehealthinstitute.org/Summit/Agenda.aspx.

Beckjord, E.B. et al., Use of the Internet to Communicate with Health Care Providers in the United States: Estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). *Journal of Medical Internet Research*, 2007. 9(3): p. e20.

Blumenthal, D. and J.P. Glaser, Information Technology Comes to Medicine. *New England Journal of Medicine*, 2007. 356(24): p. 2527-2534.

Connecting Americans to Their Healthcare: A Common Framework for Networked Personal Health Information. New York, NY: Connecting for Health, 2006. Available at: http://www.connectingforhealth.org/commonframework/docs/P9_NetworkedPHRs.pdf.

Connecting Americans to Their Healthcare: Final Report. New York, NY: Connecting for Health, 2004. Available at: http://www.connectingforhealth.org/resources/wg_eis_final_report_0704.pdf.

Crutzen, Rik et al., Internet-delivered Interventions Aimed at Adolescents: A Delphi Study on Dissemination and Exposure. *Health Education Research*, 2008. 23(3): p. 427-439.

D'Alessandro, Donna M. et al., A Randomized Controlled Trial of an Information Prescription for Pediatric Patient Education on the Internet. *Archives of Pediatrics & Adolescent Medicine*, 2004. 158(9): p. 857-862.

Day, Jennifer Cheeseman, Alex Janus, and Jessica Davis, Computer and Internet Use in the United States: 2003. Washington, DC: U.S. Census Bureau, 2005. Current Population Reports P23-208. Available at: http://www.census.gov/prod/2005pubs/p23-208.pdf

Demographics of Internet Users. Washington, DC: Pew Internet & American Life Project, survey conducted April-May 2008. Available at: http://www.pewinternet.org/trends.asp.

Discovering How Video Games Can Motivate Healthy Behaviors: More than $2 Million Awarded to 12 Research Teams. Princeton, NJ: Robert Wood Johnson Foundation, Press Release from May 29, 2008. Available at: http://www.rwjf.org/pr/product.jsp?id=30932.

E-Health and the Elderly: How Seniors Use the Internet for Health Information. Menlo Park, CA: Henry J. Kaiser Family Foundation, 2005. Available at: http://www.kff.org/entmedia/7223.cfm.

Eichner J. and P. Dullabh, Accessible Health Information Technology (Health IT) for Populations With Limited Literacy: A Guide for Developers and Purchasers of Health IT. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, October 2007. AHRQ Pub. No. 08-0010-EF.

Etter, Jean-Francois, A List of the Most Popular Smoking Cessation Web Sites and a Comparison of Their Quality. *Nicotine & Tobacco Research*, 2006. 8(Suppl 1): p. S27-34.

Expanding the Reach and Impact of Consumer e-Health Tools. Rockville, MD: U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2006. Available at: http://www.health.gov/communication/ehealth/ehealthtools/default.htm.

Eysenbach G. et al., Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web. *Journal of the American Medical Association*, 2002. 287(20): p. 2691-2700.

Fox, Susannah, Digital Divisions. Washington, DC: Pew Internet & American Life Project, 2005. Available at: www.pewinternet.org/PPF/r/165/report_display.asp.

Fox, Susannah, E-Patients with a Disability or Chronic Disease. Washington, DC: Pew Internet & American Life Project, 2007.

Fox, Susannah, Online Health Search 2006. Washington, DC: Pew Internet & American Life Project, 2006. Available at: http://www.pewinternet.org/PPF/r/190/report_display.asp.

Fox, Susannah, Prescription Drugs Online. Washington, DC: Pew Internet & American Life Project, 2004.

Fox, Susannah, Recruit Doctors. Let e-Patients Lead. Go Mobile. Posted on e-patients.net on March 6, 2008. Available at: http://www.e-patients.net/archives/2008/03/recruit_doctors.html.

Frost, J.H. and M.P. Massagli, Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. *Journal of Medical Internet Research*, 2008. 10(3): p. e15.

Goldner, Melinda. Using the Internet and Email for Health Purposes: The Impact of Health Status. *Social Science Quarterly*, 2006. 87(3): p. 690-710.

Harris, K.M. and Buntin M. Beeuwkes, Choosing a Health Care Provider: The Role of Quality Information. Princeton, NJ: The Robert Wood Johnson Foundation, 2008. Research Synthesis Report no. 14. Available at: http://www.rwjf.org/pr/product.jsp?id=29683.

Health Poll Report Survey. Menlo Park, CA: Henry J. Kaiser Family Foundation, conducted June 2-5, 2005. Available at: http://www.kff.org/kaiserpolls/pomr071805oth.cfm.

Hesse, Bradford W., Enhancing Consumer Involvement in Health Care, in *Health Care Communication in the New Media Landscape*, eds. Jerry C. Parker and Esther Thorson. New York, NY: Springer Publishing Company, 2008.

Hoover, J. Nicholas, Coalition Including Intel and Wal-Mart Plan Electronic Medical Records for Employees. *Information Week*, December 4, 2006.

Horrigan, John B. and Katherine Murray, Rural Broadband Internet Use. Washington, DC: Pew Internet & American Life Project, 2006. Available at: http://www.pewinternet.org/pdfs/PIP_Rural_Broadband.pdf.

Horrigan, John B., A Typology of Information and Communication Technology Users. Washington, DC: Pew Internet & American Life Project, 2007.

Horrigan, John B., Home Broadband 2008. Washington, DC: Pew Internet & American Life Project, 2008. Available at: http://www.pewinternet.org/PPF/r/257/report_display.asp.

Internet Activities. Washington, DC: Pew Internet & American Life Project, surveys conducted March 2000-December 2007. Available at: http://www.pewinternet.org/trends.asp.

Kutner, M. et al., Health Literacy of America's Adults: Results from the 2003 National Assessment of Health Literacy. Washington, DC: U.S. Department of Education, National Center for Health Education Statistics, 2006. NCES Pub. No. 2006-483. Available at: http://nces.ed.gov/pubs2006/2006483.pdf.

Lebo, Harlan, *The 2007 Digital Future Report: Surveying the Digital Future, Year Six*. Los Angeles, CA: USC Annenberg School, Center for the Digital Future, 2007.

Liederman, E.M. et al., Web Messaging: The Impact on Message Volume and Satisfaction. *Journal of General Internal Medicine,* 2005. 20(1): p. 52-57.

Madden, Mary, Internet Penetration and Impact. Washington, DC: Pew Internet & American Life Project, 2006. Available at: http://www.pewinternet.org/pdfs/PIP_Internet_Impact.pdf.

Many Nationwide Believe in the Potential Benefits of Electronic Medical Records and are Interested in Online Communications with Physicians. Harris Interactive, survey conducted 2005. Available at: http://www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=895.

Murray, E. et al., Interactive Health Communication Applications for People with Chronic Disease, *Cochrane Database of Systematic Reviews,* 2005.

NORC, Literature Review and Environmental Scan: Evaluation of Personal Health Records Pilots for Fee-for-Service Medicare Enrollees. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2008 (not yet released).

O'Connor, Annette M. et al., Toward the 'Tipping Point': Decision Aids and Informed Patient Choice. *Health Affairs*, 2007. 26(3): p. 716-725.

Online Behavior Change and Disease Management: A Research Dialogue. Washington, DC: National Cancer Institute and The Robert Wood Johnson Foundation, 2001. Available at: www.hetinitiative.org/content/Behav_Chng_and_Disease_Mgt.pdf.

Paasche-Orlow, M.K. et al., The Prevalence of Limited Health Literacy. *Journal of General Internal Medicine,* 2005. 20(2): p. 175-184.

Pagliari, C. et al., What is eHealth: A Scoping Exercise to Map the Field. *Journal of Medical Internet Research,* 2005. 7(1): p. e9.

Ralston, James D., Patient Web Services Integrated with a Shared Medical Record: Patient Use and Satisfaction. *Journal of the American Medical Information Association*, 2007. 14: p. 798-806.

RAND Corporation, Consumer Use of Information When Making Treatment Decisions. Chicago, IL: BlueCross BlueShield Association, 2005. Available at: http://www.bcbs.com/blueresources/cost/consumer-use-of-information.html.

Rutten, L.F., et al., Cancer Communication: Health Information National Trends Survey 2003 and 2005. Washington, DC: National Institutes of Health, National Cancer Institute, 2007. NIH Pub. No. 07-6214. Available at: http://hints.cancer.gov/hints/docs/hints_report.pdf.

Schiavo, Renata, The Rise of e-Health: Current Trends and Topics on Online Health Communications. *Journal of Medical Marketing*, 2008. 8(1): p. 9-18.

Sciamanna, Christopher N. et al., Patient Access to U.S. Physicians Who Conduct Internet or E-mail Consults. *Journal of General Internal Medicine,* 2007. 22(3): p. 378-381.

Seniors' Early Experiences with the Medicare Prescription Drug Benefit. Menlo Park, CA: Henry J. Kaiser Family Foundation, Poll conducted April 2006. Available at: http://www.kff.org/kaiserpolls/pomr042506pkg.cfm.

Siegel, E.R. et al., Information Rx: Evaluation of a New Informatics Tool for Physicians, Patients, and Libraries. *Information Services and Use,* 2006. 26(1): p. 1-10.

Silow-Carroll, Sharon and Lisa Duchon, E-health Options for Business: Evaluating the Choices. New York, NY: The Commonwealth Fund, 2002.

Stone, J.H., Communication between Physicians and Patients in the Era of E-Medicine. *New England Journal of Medicine, 2007.* 356(24): p. 2451-2455.

Survey Finds Americans Want Electronic Personal Health Information to Improve Own Health Care. New York, NY: Connecting for Health, 2006.

Swartz, S., T. Cowan, and I. Batista, Using Claims Data to Examine Patients Using Practice-based Internet Communication: Is There a Clinical Digital Divide? *Journal of Medical Internet Research*, 2004. 6(1): p. e1.

Tang, P.C. and D. Lansky, The Missing Link: Bridging the Patient-provider Health Information Gap. *Health Affairs*, 2005. 24(5): p. 1290-1295.

Thompson T.G. and D.J. Brailer, The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care. Washington, DC: U.S. Department of Health and Human Services, 2004.

von Knoop, Carina et al., Vital Signs: E-Health in the United States. Boston, MA: Boston Consulting Group, 2003. Available at: http://www.bcg.com/impact_expertise/publications/files/Vital_Signs_E_Health_United_States_Jan2003.pdf.

Wantland, D.J. et al., The Effectiveness of Web-based vs. Non-Web-based Interventions: A Meta-analysis of Behavioral Change Outcomes. *Journal of Medical Internet Research*, 2004. 6(4): p. e40.

Wasson, John H., Todd A. MacKenzie, and Michael Hall, Patients Use an Internet Technology to Report When Things Go Wrong. *Quality & Safety in Health Care*, 2007. 16(3): p. 213-215.

Weingart, S.N. et al., Who Uses the Patient Internet Portal? The PatientSite Experience. *Journal of the American Medical Informatics Association,* 2006. 13(1): p. 91-95.

White, Casey B. et al., A Content Analysis of E-mail Communication Between Patients and Providers: Patients Get the Message. *Journal of the American Medical Informatics Association*, 2004. 11(4): p. 260-267.

Wood, Fred B. et al., Use of Internet Audience Measurement Data to Gauge Market Share for Online Health Information Services. *Journal of Medical Internet Research*, 2005. 7(3): p. e31.

Ybarra, M. and M. Suman, Reasons, Assessments and Actions Taken: Sex and Age Differences in Uses of Internet Health Information. *Health Education Research*, 2008. 23(3): p. 512-521.

[1] Expanding the Reach and Impact of Consumer e-Health Tools. Rockville, MD: U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2006, p. 59. Available at: http://www.health.gov/communication/ehealth/ehealthtools/default.htm.

[2] Connecting Americans to Their Healthcare: Final Report. New York, NY: Connecting for Health, 2004, p. 6. Available at: http://www.connectingforhealth.org/resources/wg_eis_final_report_0704.pdf.

[3] Demographics of Internet Users. Washington, DC: Pew Internet & American Life Project, survey conducted August 2008. Available at: http://www.pewinternet.org/trends.asp.

[4] Estimates from: Baker, L. et al., Use of the Internet and E-mail for Health Care Information: Results from a National Survey. *Journal of the American Medial Association*, 2003. 289(18): p. 2400-2406; Pew Internet & American Life Project, Internet Activities; RAND Corporation, Consumer Use of Information When Making Treatment Decisions. Chicago, IL: BlueCross BlueShield Association, 2005. Available at: http://www.bcbs.com/blueresources/cost/consumer-use-of-information.html; Rutten L.F., et al., Cancer Communication: Health Information National Trends Survey 2003 and 2005. Washington, DC: National Institutes of Health, National Cancer Institute, 2007. NIH Pub. No. 07-6214. Available at: http://hints.cancer.gov/hints/docs/hints_report.pdf; and Ybarra, M. and M. Suman, Reasons, Assessments and Actions Taken: Sex and Age Differences in Uses of Internet Health Information. *Health Education Research*, 2008. 23(3): p. 512-521.

[5] Rutten et al. 2007, p. 13.

[6] Fox, Susannah, Prescription Drugs Online. Washington, DC: Pew Internet & American Life Project, 2004, p. 2.

[7] Fox 2004, p. 6; and Baker et al. 2003.

[8] Rutten et al. 2007, p. 13.

[9] Baker et al. 2003.

[10] Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing Poll Indicates Strong Support for New Medical Technologies. *The Wall Street Journal Online,* October 7, 2005.

[11] NORC, Literature Review and Environmental Scan: Evaluation of Personal Health Records Pilots for Fee-for-Service Medicare Enrollees. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2008 (not yet released), citing D. Lansky, A National Agenda for Personal Health Records? How Will We Really Empower Consumers in the Next Decade? presentation for Connecting for Health, 2006.

[12] Rutten et al. 2007.

[13] Fox, Susannah, Online Health Search 2006. Washington, DC: Pew Internet & American Life Project, 2006, p. 2. Available at: http://www.pewinternet.org/PPF/r/190/report_display.asp.

[14] Estabrook, Leigh, Evans Witt, and Lee Rainie, Information Searches that Solve Problems. Washington, DC: Pew Internet & American Life Project, 2007. Available at: http://www.pewinternet.org/pdfs/Pew_UI_LibrariesReport.pdf.

[15] Fox 2006.

[16] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[17] Rutten et al. 2007.

[18] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[19] Adler, Kenneth G., Web Portals in Primary Care: An Evaluation of Patient Readiness and Willingness to Pay for Online Services. *Journal of Medical Internet Research*, 2006. 8(4): p. e26; citing Anne Kittler et al., Primary Care Physician Attitudes towards Using a Secure Web-based Portal Designed to Facilitate Electronic Communication with Patients. *Informatics in Primary Care,* 2004. 12(3): p. 129-138.

[20] Beauchamp, N. and T.R. Eng, eHealth: The Momentum Is Building. Seattle, WA: eHealth Institute, 2006, p. 7. Available at: http://www.ehealthinstitute.org/Summit/Agenda.aspx; Many Nationwide Believe in the Potential Benefits of Electronic Medical Records and are Interested in Online Communications with Physicians. Harris Interactive, survey conducted 2005. Available at: http://www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=895.

[21] Beckjord, E.B. et al., Use of the Internet to Communicate with Health Care Providers in the United States: Estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). *Journal of Medical Internet Research*, 2007. 9(3).

[22] Survey Finds Americans Want Electronic Personal Health Information to Improve Own Health Care. New York, NY: Connecting for Health, 2006, p. 3.

[23] Tang, P.C. and D. Lansky, The Missing Link: Bridging the Patient-provider Health Information Gap. *Health Affairs*, 2005. 24(5): p. 1294.

[24] Hesse, Bradford W., Enhancing Consumer Involvement in Health Care, in *Health Care Communication in the New Media Landscape*, eds. Jerry C. Parker and Esther Thorson. New York, NY: Springer Publishing Company, 2008; Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[25] NORC 2008, citing Aetna: Nearly Two-Thirds of Americans Are Not Familiar with Personal Health Records, a Resource Available to Millions of Consumers, *Biotech Week*, August 1 2007.

[26] Manhattan Research, CyberCitizen Health Study 2007, and internal WebMD numbers.

[27] von Knoop, Carina et al., Vital Signs: E-Health in the United States. Boston, MA: Boston Consulting Group, 2003. Available at:
http://www.bcg.com/impact_expertise/publications/files/Vital_Signs_E_Health_United_States_Jan2003.pdf.

[28] Wood, Fred B. et al., Use of Internet Audience Measurement Data to Gauge Market Share for Online Health Information Services. *Journal of Medical Internet Research*, 2005. 7(3): p. e31.

[29] Siegel, E.R. et al., Information Rx: Evaluation of a New Informatics Tool for Physicians, Patients, and Libraries. *Information Services and Use,* 2006. 26(1): p. 2-3.

[30] von Knoop et al. 2003, p. 31

[31] von Knoop et al. 2003.

[32] Etter, Jean-Francois, A List of the Most Popular Smoking Cessation Web Sites and a Comparison of Their Quality. *Nicotine & Tobacco Research*, 2006. 8(Suppl 1): p. s29.

[33] Wood et al. 2005.

[34] von Knoop et al. 2003.

[35] Fox 2006.

[36] D'Alessandro, Donna M. et al., A Randomized Controlled Trial of an Information Prescription for Pediatric Patient Education on the Internet. *Archives of Pediatrics & Adolescent Medicine*, 2004. 158(9): p. 857-862; citing Lindner, K., A Piece of My Mind: Encourage Information Therapy [comment]. *Journal of the American Medical Association,* 1992. 267: p. 2592.

[37] Siegel et al. 2006.

[38] Expanding the Reach and Impact of Consumer e-Health Tools, 2006, p. 83.

[39] Wasson, John H., Todd A. MacKenzie, and Michael Hall, Patients Use an Internet Technology to Report When Things Go Wrong. *Quality & Safety in Health Care*, 2007. 16(3): p. 213-215.

[40] Expanding the Reach and Impact of Consumer e-Health Tools, 2006, p. 59.

[41] O'Connor, Annette M. et al., Toward the 'Tipping Point': Decision Aids and Informed Patient Choice. *Health Affairs*, 2007. 26(3): p. 716-725.

[42] Discovering How Video Games Can Motivate Healthy Behaviors: More than $2 Million Awarded to 12 Research Teams. Princeton, NJ: Robert Wood Johnson Foundation, Press Release from May 29, 2008. Available at:
http://www.rwjf.org/pr/product.jsp?id=30932.

[43] Connecting Americans to Their Healthcare: Final Report, 2004, p. 97.

[44] Internet Activities. Washington, DC: Pew Internet & American Life Project, survey conducted March 2000-December 2007. Available at: http://www.pewinternet.org/trends.asp.

[45] Frost, J.H. and M.P. Massagli, Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. *Journal of Medical Internet Research*, 2008. 10(3): p. e15.

[46] Harris, K.M. and Buntin M. Beeuwkes, Choosing a Health Care Provider: The Role of Quality Information. Princeton, NJ: The Robert Wood Johnson Foundation, 2008, p. 4. Research Synthesis Report no. 14. Available at: http://www.rwjf.org/pr/product.jsp?id=29683.

[47] Connecting Americans to Their Healthcare: Final Report, 2004; citing P.J. Cunningham and L. Kohn, Health Plan Switching: Choice or Circumstance? *Health Affairs*, 2000. 19: p. 158-164; and M.C. Reed and S. Trude, Tracking Report: Results from the Community Tracking Study. Washington, DC: Center for Studying Health System Change, 2002.

[48] Blumenthal, D. and J.P. Glaser, Information Technology Comes to Medicine. *New England Journal of Medicine*, 2007. 356(24): p. 2527-2534.

[49] E-Health and the Elderly: How Seniors Use the Internet for Health Information. Menlo Park, CA: Henry J. Kaiser Family Foundation, 2005, p. 52. Available at: http://www.kff.org/entmedia/7223.cfm.

[50] Harris and Beeuwkes 2008.

[51] Hoover, J. Nicholas, Coalition Including Intel and Wal-Mart Plan Electronic Medical Records for Employees. *Information Week*, December 4, 2006.

[52] Harris and Beeuwkes 2008, p. 4.

[53] Thompson T.G. and D.J. Brailer, The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care. Washington, DC: U.S. Department of Health and Human Services, 2004.

[54] Beauchamp and Eng, p. 10.

[55] von Knoop et al. 2003, p. 35.

[56] Expanding the Reach and Impact of Consumer e-Health Tools 2006, p. 82.

[57] White, Casey B. et al., A Content Analysis of E-mail Communication Between Patients and Providers: Patients Get the Message. *Journal of the American Medical Informatics Association*, 2004. 11(4): p. 260-267.

[58] von Knoop et al. 2003.

[59] E. M. Liederman et al., Patient-Physician Web Messaging, *Journal of General Internal Medicine,* 2005. 20(1).

[60] Connecting Americans to Their Healthcare: Final Report, 2004, p. 6.

[61] Hesse 2008; and O'Connor et al. 2007, p. 719-720.

[62] NORC 2008, citing Personal Health Records and Personal Health Record Systems. Washington, DC: U.S. Department of Health and Human Services, 2006.

[63] Connecting Americans to Their Healthcare: Final Report 2004.

[64] Tang and Lansky 2005, p. 1291.

[65] Connecting Americans to Their Healthcare: Final Report 2004.

[66] Tang and Lansky 2006, p. 1292; and Blumenthal and Glasser 2007.

[67] Connecting Americans to Their Healthcare: Final Report 2004, p. 55.

[68] Connecting Americans to Their Healthcare: A Common Framework for Networked Personal Health Information. New York, NY: Connecting for Health, 2006. Available at: http://www.connectingforhealth.org/commonframework/docs/P9_NetworkedPHRs.pdf.

[69] NORC 2008.

[70] NORC 2008.

[71] Hoover 2006.

[72] NORC 2008, citing C. Bocchino, "AHIC Testimony," American Health Information Community, Consumer Empowerment Subgroup, 2006.

[73] Pew Internet & American Life Project, Internet Activities.

[74] Bosworth, Adam, Presentation as part of The Future: Consumer Health Information Technologies webcast for the National Institutes of Health, December 10, 2007.

[75] Shen, Bern, Presentation as part of The Future: Consumer Health Information Technologies webcast for the National Institutes of Health, December 10, 2007.

[76] Bosworth 2007.

[77] Survey Finds Americans Want Electronic Personal Health Information to Improve Own Health Care 2006, p. 3.

[78] NORC 2008.

[79] Intuit, Frequently Asked Questions about Quicken Health. Available at: http://quickenhealth.intuit.com/faqs_integration.jsp. Accessed 16 August 2008.

[80] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[81] Horrigan, John B., Home Broadband 2008. Washington, DC: Pew Internet & American Life Project, 2008. Available at: http://www.pewinternet.org/PPF/r/257/report_display.asp.

[82] Pew Internet & American Life Project, Internet Activities.

[83] Expanding the Reach and Impact of Consumer e-Health Tools 2006, p. 59.

[84] Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing Institute of Medicine, *Health Literacy: a Prescription to End Confusion.* Washington, DC: National Academies Press, 2004; and U.S. Department of Health and Human Services, *Healthy People 2010*. 2nd ed. Washington, DC: U.S. Government Printing Office, November 2000.

[85] Kutner, M. et al., Health Literacy of America's Adults: Results from the 2003 National Assessment of Health Literacy. Washington, DC: U.S. Department of Education, National Center for Health Education Statistics, 2006. NCES Pub. No. 2006-483. Available at: http://nces.ed.gov/pubs2006/2006483.pdf.

[86] Eichner J. and P. Dullabh, Accessible Health Information Technology (Health IT) for Populations With Limited Literacy: A Guide for Developers and Purchasers of Health IT. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, October 2007. AHRQ Pub. No. 08-0010-EF.

[87] Kutner et al. 2006, p. 1; Paasche-Orlow, M.K. et al., The Prevalence of Limited Health Literacy. *Journal of General Internal Medicine,* 2005. 20(2): p. 175.

[88] Kutner et al. 2006, p. 11.

[89] Paasche-Orlow 2005, p. 179.

[90] Demographics of Internet Users. Washington, DC: Pew Internet & American Life Project, survey conducted August 2008. Available at: http://www.pewinternet.org/trends.asp.

[91] Pew Internet & American Life Project, Demographics of Internet Users.

[92] Fox 2005, p. 2.

[93] Pew Internet & American Life Project, Demographics of Internet Users.

[94] Pew Internet & American Life Project, Demographics of Internet Users.

[95] Pew Internet & American Life Project, Demographics of Internet Users.

[96] Expanding the Reach and Impact of Consumer e-Health Tools 2006, p. 44.

[97] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[98] Pew Internet & American Life Project, Demographics of Internet Users.

[99] Pew Internet & American Life Project, Demographics of Internet Users.

[100] Horrigan, John B., Home Broadband 2008. Washington, DC: Pew Internet & American Life Project, 2008. Available at: http://www.pewinternet.org/PPF/r/257/report_display.asp.

[101] Horrigan 2008.

[102] Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing Institute of Medicine, *Speaking of Health: Assessing Health Communication Strategies for Diverse Populations.* Washington, DC: National Academies Press, 2002.

[103] Estimates from: Baker, L. et al., Use of the Internet and E-mail for Health Care Information: Results from a National Survey. *Journal of the American Medial Association*, 2003. 289(18): p. 2400-2406; Pew Internet & American Life Project, Internet Activities; RAND Corporation, Consumer Use of Information When Making Treatment Decisions. Chicago, IL: BlueCross BlueShield Association, 2005. Available at: http://www.bcbs.com/blueresources/cost/consumer-use-of-information.html; Rutten L.F., et al., Cancer Communication: Health Information National Trends Survey 2003 and 2005. Washington, DC: National Institutes of Health, National Cancer Institute, 2007. NIH Pub. No. 07-6214. Available at: http://hints.cancer.gov/hints/docs/hints_report.pdf; and Ybarra, M. and M. Suman, Reasons, Assessments and Actions Taken: Sex and Age Differences in Uses of Internet Health Information. *Health Education Research*, 2008. 23(3): p. 512-521.

[104] Rutten et al. 2007.

[105] Fox 2006.

[106] RAND Corporation 2005.

[107] Health Poll Report Survey. Menlo Park, CA: Henry J. Kaiser Family Foundation, conducted June 2-5, 2005. Available at: http://www.kff.org/kaiserpolls/pomr071805oth.cfm.

[108] Rutten et al. 2007, p. 13.

[109] Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing Caregiving in the U.S. National Alliance for Caregiving and AARP, 2004.

[110] Fox 2006, p. 4.

[111] RAND Corporation 2005.

[112] Fox, Susannah, Prescription Drugs Online. Washington, DC: Pew Internet & American Life Project, 2004, p. 2.

[113] Fox 2004, p. 6; and Baker et al. 2003.

[114] Fox 2004, p. 5.

[115] Baker et al. 2003.

[116] von Knoop et al. 2003, p. 16.

[117] O'Connor et al. 2007, p. 718-719.

[118] Rutten et al. 2007, p. 13.

[119] Frost and Massagli 2008.

[120] Baker et al. 2003.

[121] Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing Poll Indicates Strong Support for New Medical Technologies. *The Wall Street Journal Online,* October 7, 2005.

[122] Goldner, Melinda. Using the Internet and Email for Health Purposes: The Impact of Health Status. *Social Science Quarterly*, 2006. 87(3): p. 690-710.

[123] Beckjord et al. 2007. p. e20.

[124] von Knoop et al. 2003, p. 18.

[125] Beauchamp and Eng 2006, p. 10.

[126] Connecting Americans to Their Healthcare: Final Report 2004, p. 66.

[127] Beauchamp and Eng 2006, p. 10.

[128] RAND Corporation 2005.

[129] Harris and Beeuwkes 2008.

[130] Weingart, S.N. et al., Who Uses the Patient Internet Portal? The PatientSite Experience. *Journal of the American Medical Informatics Association,* 2006. 13(1): p. 91.

[131] Weingart et al. 2006; and Swartz, S., T. Cowan, and I. Batista, Using Claims Data to Examine Patients Using Practice-based Internet Communication: Is There a Clinical Digital Divide? *Journal of Medical Internet Research*, 2004. 6(1): p. e1.

[132] NORC 2008, citing D. Lansky, A National Agenda for Personal Health Records? How Will We Really Empower Consumers in the Next Decade? presentation for Connecting for Health, 2006.

[133] Ralston, James D., Patient Web Services Integrated with a Shared Medical Record: Patient Use and Satisfaction. *Journal of the American Medical Information Association*, 2007. 14: p. 798-806.

[134] Connecting Americans to Their Healthcare: A Common Framework for Networked Personal Health Information 2006, p. 2.

[135] Connecting Americans to Their Healthcare: Final Report 2004, p. 48.

[136] Tang and Lansky 2005, p. 1293.

[137] NORC 2008, citing Aetna: Nearly Two-Thirds of Americans Are Not Familiar with Personal Health Records, a Resource Available to Millions of Consumers.

[138] Schiavo, Renata, The Rise of e-Health: Current Trends and Topics on Online Health Communications. *Journal of Medical Marketing*, 2008. 8(1): p. 9-18; Eysenbach G. et al., Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web. *Journal of the American Medical Association*, 2002. 287(20): 2691-2700.

[139] Eysenbach 2002.

[140] Fox 2006, citing CDC Wonder Data 2010. Healthy People 2010 Health Communication Focus Area 11, Objective 11-4.

[141] E-Health and the Elderly: How Seniors Use the Internet for Health Information 2005; Fox 2006, p. 11.

[142] Fox, Susannah, Recruit Doctors. Let e-Patients Lead. Go Mobile. Posted on e-patients.net on March 6, 2008. Available at: http://www.e-patients.net/archives/2008/03/recruit_doctors.html.

[143] Etter 2006, p.s33.

[144] Expanding the Reach and Impact of Consumer e-Health Tools 2006, p. 94.

[145] Eysenbach 2002.

[146] RAND Corporation 2005.

[147] Ybarra and Suman 2008.

[148] Fox 2006, p. 9.

[149] Ybarra and Suman 2008.

[150] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[151] Ralston 2007, p. 803; Tang and Lansky 2005, p. 1293.

[152] Ralston 2007, p. 803.

[153] Fox 2006, p. 7.

[154] Tang and Lansky 2005, p. 1294.

[155] von Knoop et al. 2003, p. 25.

[156] Fox 2006, p. 10; E-Health and the Elderly: How Seniors Use the Internet for Health Information 2005, p. 10; Ybarra and Suman 2008; Siegel et al. 2006, p. 6.

[157] Baker et al. 2003.

[158] Harris and Beeuwkes 2008.

[159] RAND Corporation 2005.

[160] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[161] Beauchamp and Eng 2006.

[162] Murray, E. et al., Interactive Health Communication Applications for People with Chronic Disease, *Cochrane Database of Systematic Reviews,* 2005.

[163] Wantland, D.J. et al., The Effectiveness of Web-based vs. Non-Web-based Interventions: A Meta-analysis of Behavioral Change Outcomes. *Journal of Medical Internet Research*, 2004. 6(4): p. e40.

[164] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[165] Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing Lieberman, D., Management of Chronic Pediatric Diseases with Interactive Health Games: Theory and Research Findings. *Journal of Ambulatory Care Management,* 2001. 24: p. 26-38.

[166] von Knoop et al. 2003, p. 16.

[167] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[168] Murray et al 2005, p. 18; Rand Corporation 2005.

[169] NORC 2008, p. 3; Blumenthal and Glaser 2007.

[170] 2007 National Healthcare Disparities Report. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality; February 2008. AHRQ Pub. No. 08-0041; and Mead, Holly et al., "Racial and Ethnic Disparities in U.S. Health Care: A Chartbook." New York, NY: The Commonwealth Fund, 2008.

[171] Rutten et al. 2007; Fox 2006.

[172] Fox 2006.

[173] Kutner et al. 2006, p. 18.

[174] U.S. National Library of Medicine, "MedlinePlus Survey Results: 2005" webpage. http://www.nlm.nih.gov/medlineplus/survey2005/index.html.

[175] Rutten et al. 2007.

[176] Baker et al. 2003.

[177] Rutten et al. 2007.

[178] U.S. National Library of Medicine, "MedlinePlus Survey Results 2005" webpage.

[179] Fox 2006, p. 2.

[180] Rutten et al. 2007.

[181] Estabrook, Leigh, Evans Witt, and Lee Rainie, Information Searches that Solve Problems. Washington, DC: Pew Internet & American Life Project, 2007. Available at: http://www.pewinternet.org/pdfs/Pew_UI_LibrariesReport.pdf.

[182] Goldner 2006, p. 698.

[183] Fox, Susannah, E-Patients with a Disability or Chronic Disease. Washington, DC: Pew Internet & American Life Project, 2007.

[184] Rand Corporation 2005.

[185] Ybarra and Suman 2008.

[186] Fox 2006, p. 4.

[187] Fox 2006; Rutten et al. 2007.

[188] Kaiser Family Foundation. 2005. Health Poll Report Survey (Conducted June 2-5, 2005) http://www.kff.org/kaiserpolls/pomr071805oth.cfm

[189] Ybarra and Suman 2008.

[190] E-Health and the Elderly: How Seniors Use the Internet for Health Information 2005, p. 6.

[191] Fox 2006.

[192] Fox 2006, p. 3

[193] Ybarra and Suman 2008.

[194] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[195] Rutten et al. 2007.

[196] Fox 2004.

[197] Fox 2007.

[198] Rutten et al. 2007.

[199] Rutten et al. 2007.

[200] Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing DH Gustafson et al., Effect of Computer Support on Younger Women with Breast Cancer. *Journal of General Internal Medicine,* 2001.16: p. 435-445.

[201] Rutten et al. 2007.

[202] Baker et al. 2003; Beckjord et al. 2007.

[203] Beckjord et al. 2007.

[204] Goldner 2006, p. 702.

[205] Beckjord et al. 2007.

[206] E-Health and the Elderly: How Seniors Use the Internet for Health Information 2005; Fox 2006, p. 4.

[207] Ralston 2007, p. 802; Weingart et al. 2006, p. 94.

[208] Weingart et al. 2006.

[209] Weingart et al. 2006, p. 94.

[210] Ralston 2007, p. 802.

[211] NORC 2008, citing a survey conducted by the Foundation for Accountability (FACCT) as part of the Markle Foundation's Connecting for Health Collaborative.

[212] Weingart et al. 2006, p, 94; Tang and Lansky 2005.

[213] Tang and Lansky 2005, p. 1293.

[214] Thompson and Brailer 2004.

[215] Hoover 2006.

[216] Survey Finds Americans Want Electronic Personal Health Information to Improve Own Health Care 2006, p. 3.

[217] Connecting Americans to Their Healthcare: Final Report 2004, p. 54.

[218] Many Nationwide Believe in the Potential Benefits of Electronic Medical Records and are Interested in Online Communications with Physicians, 2005.

[219] Harris and Beeuwkes 2008, p. 10.

[220] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[221] Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing Children, the Digital Divide, and Federal Policy. Menlo Park, CA: Henry J. Kaiser Foundation, 2004.

[222] NORC, The Underserved and Health Information Technology—Issues and Opportunities. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2008 (not yet released).

[223] "Meaningful access" may also entail items like the availability of technical support and sites with appropriate content. Expanding the Reach and Impact of Consumer e-Health Tools 2006, citing Communicating Health: Priorities and Strategies for Progress. Washington, DC: U.S. Department of Health and Human Services, 2003.

[224] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[225] Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[226] von Knoop et al. 2003.

[227] NORC 2008 citing Aetna: Nearly Two-Thirds of Americans Are Not Familiar with Personal Health Records, a Resource Available to Millions of Consumers.

[228] Connecting Americans to Their Healthcare: Final Report 2004.

[229] Connecting Americans to Their Healthcare: Final Report 2004.

[230] Crutzen, Rik et al., Internet-delivered Interventions Aimed at Adolescents: A Delphi Study on Dissemination and Exposure. *Health Education Research*, 2008. 23(3): p. 427-439.

[231] Siegel et al. 2006, p. 6.

[232] E-Health and the Elderly: How Seniors Use the Internet for Health Information 2005, p. 7.

[233] Fox 2008.

[234] Goldner 2006, p. 705; von Knoop et al. 2003, p 203.

[235] Stone, J.H., Communication between Physicians and Patients in the Era of E-Medicine. *New England Journal of Medicine, 2007.* 356(24): p. 2451-2455.

[236] Liederman, E.M. et al., Web Messaging: The Impact on Message Volume and Satisfaction. *Journal of General Internal Medicine,* 2005. 20(1): p. 52-57.

[237] Adler, Kenneth G., Web Portals in Primary Care: An Evaluation of Patient Readiness and Willingness to Pay for Online Services. *Journal of Medical Internet Research*, 2006. 8(4): p. e26; citing Anne Kittler et al., Primary Care Physician Attitudes towards Using a Secure Web-based Portal Designed to Facilitate Electronic Communication with Patients. *Informatics in Primary Care,* 2004. 12(3): p. 129-138.

[238] Sciamanna, Christopher N. et al., Patient Access to U.S. Physicians Who Conduct Internet or E-mail Consults. *Journal of General Internal Medicine,* 2007. 22(3): p. 378-381; Stone 2007.

[239] Beauchamp and Eng 2006, p. 10.

[240] Beauchamp and Eng 2006, p. 7; Many Nationwide Believe in the Potential Benefits of Electronic Medical Records and are Interested in Online Communications with Physicians 2005.

[241] Beauchamp and Eng 2006, p. 23.

[242] Beauchamp and Eng 2006, p. 26.

[243] Expanding the Reach and Impact of Consumer e-Health Tools 2006, p. 88.

[244] Beckjord et al. 2007.

[245] Survey Finds Americans Want Electronic Personal Health Information to Improve Own Health Care 2006, p.3.

[246] NORC 2008, citing L. Moreno, et al., Personal Health Records: What Do Underserved Consumers Want. Washington, DC: Mathematica Policy Research, 2007. Issue Brief no. 4.

[247] Tang and Lansky 2005, p. 1294.

[248] Lebo, Harlan, *The 2007 Digital Future Report: Surveying the Digital Future, Year Six*. Los Angeles, CA: USC Annenberg School, Center for the Digital Future, 2007, p. 79.

[249] Fox 2004, p. 5.

[250] Rutten et al. 2007.

[251] Lebo 2007, p. 52.

[252] Hesse 2008, p. 4.

[253] Hesse 2008; Expanding the Reach and Impact of Consumer e-Health Tools 2006.

[254] Connecting Americans to Their Healthcare: Final Report 2004, p. 17.