



Summary Report of Consumer eHealth Unintended Consequences Work Group Activities

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Building Better Consumer eHealth

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Abstract

As part of a contract from the Office of the National Coordinator for Health Information Technology to Westat, Inc., the authors constituted a Work Group on Consumer eHealth, charged to describe anticipated and actual benefits of consumer eHealth, to predict the adverse, unintended consequences, and to identify strategies that will maximize benefits and minimize adverse effects. Relying on the literature and their own expertise, the authors identified a number of benefits, unintended consequences, strategies for success, and questions for research. They organized these using a sociotechnical model to focus on the consumer's interactions with other people (clinicians, lay caregivers, and peers), with the hardware and software of eHealth tools, with care processes, with healthcare organizations, and with the external environment, including the culture of health and healthcare, the information available to consumers, and the privacy and security of information generated by consumers. The report concludes with lists of strategies for achieving the benefits and preventing or mitigating adverse events.

1.0 Context

In 2010, the Office of the National Coordinator for Health Information Technology (ONC) of the U.S. Department of Health and Human Services awarded a contract to Westat, Inc. to predict the adverse, unintended consequences that might arise from several of ONC's initiatives and to propose strategies to prevent or mitigate the negative events. A Technical Expert Panel chaired by Judy Ozbolt was appointed to oversee the efforts. Three Work Groups focused on specific aspects of the adoption and use of health information technologies. The Electronic Health Records (EHR) Work Group, chaired by Justin Starren, identified potential unintended consequences and prioritized those with particular impact on patient safety. Following that effort, teams led by Joan Ash, Dean Sittig, and Hardeep Singh are working on a subcontract from Westat to develop and test safety checklists for users of EHRs, from solo practices to complex healthcare systems. The Health Information Exchange Work Group, co-chaired by Gilad Kuperman and Julie McGowan, addressed unintended consequences related to exchanging health

information, with input from a range of stakeholder groups. The Consumer eHealth Work Group, co-chaired by Judy Ozbolt and Daniel Sands, considered unintended consequences that might arise when individuals and families are expected to take on more responsibility for managing their own health with the aid of electronic resources. At the request of the Project Officer, the Health Information Exchange Work Group and the Consumer eHealth Work Group expanded their scope to describe benefits of health information exchange and of consumer eHealth as substantiated by the peer-reviewed literature. This paper reports the work and the findings of the Consumer eHealth Work Group.

2.0 eHealth: Engaging Individuals and Families to Improve Health and Healthcare

Patient and consumer eHealth initiatives include such actions as introducing secure portals for patient access to information in the electronic health record (EHR) and for non-urgent communications with clinicians, maintaining personal health records and journals of health behaviors and parameters, using monitoring devices to manage personal health, complementing in-person, telephone, or written communications with electronic communications, and using Internet-based resources for health education, information, advice, and peer support. Numerous studies have shown that these innovations can have many benefits.

With mounting evidence of the benefits of eHealth, the Federal Government and many healthcare providers are promoting the use of eHealth resources, with the goal of increasing the engagement of individuals and families in collaborating with their healthcare providers to improve their health and the healthcare system. If patient and consumer eHealth initiatives are to help consumers, patients, and their lay caregivers to become more active in managing their health, substantial changes in public perceptions and in the roles of patients and the other members of their care teams will be required. Expected benefits of this enhanced collaboration include better shared decision making, greater patient knowledge of their conditions and treatments, better communication, more effective self-care, reduced healthcare costs, and better health outcomes.

3.0 Methods and Limitations

The Consumer eHealth Work Group was formed in fall 2011 with an initial focus on identifying unintended consequences of eHealth and mitigating strategies. Members suggested articles to be considered, and an initial review of the literature was distributed in January 2012. Members suggested additional articles to expand and enhance the review and the list of unintended consequences derived from the review. In spring 2012, the group reviewed the unintended consequences, mitigating strategies, and questions for research. In a meeting on May 9, 2012, the group proposed analyzing the unintended consequences and mitigating strategies according to a sociotechnical model of healthcare used by the Institute of Medicine in its 2012 report, *Health IT and Patient Safety: Building Safer Systems for Better Care*. As this work was nearing

completion, the ONC project officer requested that the benefits of eHealth, which had been cited but not emphasized in the report, be explicitly incorporated into an analysis that gave more balanced consideration to demonstrated benefits, potential unintended consequences, and strategies for success. Drafts of the resulting paper were reviewed and revised until consensus was reached.

Although foundational clinical and scientific explorations of consumer engagement in therapeutic partnerships began to appear in the professional literature as early as the 1970's, the authors focused their review primarily on peer-reviewed publications since 2009. A few seminal articles from earlier years were included because of their pertinence to this work. The focus on recent peer-reviewed literature enabled an assessment of the current state of the science, and consequently provided a scientific basis for identifying benefits that had been demonstrated in well designed investigations, discovering or inferring potential unintended consequences, and proposing strategies for success. The omission from the review of blogs and other forms of social media dealing with issues and experiences in eHealth means that valuable insights from personal experiences may be missed. It may be useful in the future to review such anecdotal experiences for additional perspectives on strategies for moving forward.

The benefits described in this report are based on empirical evidence. Few of the studies reviewed here, however, were explicitly designed to discover unintended consequences of consumer eHealth. Thus, the potential unintended consequences identified represent the Work Group's interpretations of reported findings unless the unintended consequences are explicitly attributed to the investigators. Strategies for success were either reported in the literature and referenced accordingly or proposed on the basis of the expertise and experience of the Work Group. Others may not agree that the potential unintended consequences identified are logically derived from the content of the articles, and they may derive different or additional unintended consequences. Similarly, others may have additional knowledge and experience to add to the understanding of effective strategies for success. This report is intended to be the start of a discussion, not the conclusion.

4.0 Consumer and Clinician Perspectives on eHealth

Using electronic resources to promote the engagement of individuals and families in managing their health changes the roles, responsibilities, and relationships of clinicians, patients, and lay caregivers. All may encounter unexpected and unwelcome consequences. Equally, all have the potential to discover ways to maximize benefits and to minimize adverse experiences.

To investigate consumer and clinician perspectives on eHealth, between November 2006 and January 2007, Walker, Ahern, Le, and Delbanco (2009) conducted 6 focus groups with consumers and 2 focus groups with healthcare professionals, with group sizes ranging from 9 to 12 persons. Focus groups were convened in geographically diverse parts of the United States (Boston, MA, Portland, ME, Tampa, FL, and Denver, CO) to tap into rural, suburban, and urban populations and a variety of regional settings. Participants were diverse in age, occupation,

education, health and illness status, and gender. The investigators recorded and transcribed the focus group interactions and used qualitative methods to extract themes. They itemized the following findings:

- “Patients want full access to their provider-based records” (p. 729). Except for the college-age group, most kept some kind of records of their own health, but thought it would be better to have full access to the provider’s records—including the ability to find and correct errors in the records.
- “Patients may value privacy far more when well than when sick” (p. 729). Health professionals expressed more concern about privacy than did consumers, and the healthy consumers expressed more concern than the chronically ill. All valued the availability of online records in emergency situations.
- “Patients expect computers to foster far more self-care in the future” (p. 730). Many consumers believed that the power of the doctor-patient relationship would be needed primarily for those with chronic illness. Commonly occurring minor ailments, they believed, should be amenable to computer-aided diagnosis and treatment in the home. Enabling self-care in such situations would reduce treatment delays, save money, and preserve clinician time for complex cases. One physician noted “that society would have to ‘allow people to make bad decisions’” (p. 730).
- “Patients expect new technologies will watch over them” (p. 730). Consumers envisioned a variety of implanted or external devices such as smart phones or smart homes that would monitor physiological parameters, behaviors, or incidents such as falls and alert them and/or a provider if values were beyond a desired threshold—or just keep continuous records of values so that they could track their health. Patients expressed little concern about the privacy of this information, but did think they should be able to control who had access to it.
- “Patients envision a truly personal computer” (p. 730). Consumers wanted their computers to “understand” enough about them, their literacy, and their health needs to filter information available on the Internet for relevance, appropriateness, and trustworthiness. They expressed frustration with their current difficulties in evaluating the flood of health information on the Internet and deciding what was trustworthy and what applied to them. Consumers also wanted their computers to have enough knowledge specific to the consumer’s personal and family health risks and history, as well as enough general health knowledge, to serve as sophisticated health coaches for lifestyle choices, health maintenance and improvement, and preventive actions.

Walker et al. (2009) observed that the attitudes and beliefs of healthcare professionals were generally similar to those of consumers, except where otherwise noted. The authors added further that, “Consumers . . . were keenly interested in finding ways to optimize clinicians’ services. Many described strategies for improving the efficiency of communications with providers. They would like to prepare for appointments by forwarding their past medical history and current health questions to the clinician before the visit. They expect to research the Internet

ahead of time, to batch questions, and to correct misinformation in their records. Consumers see PHRs as the prime mechanism for such communication, viewing them as overlapping with EMRs” (p. 731).

Walker and colleagues (2009) speculated about a patient-centered world in which EMRs and PHRs would be shared documents among patients and multiple providers, patients would be much more pro-active about managing their health, and clinicians would spend more time monitoring fragile patients in their homes in near-real time via electronic communications. Such a world might fundamentally change the provider-patient relationship, whether for better or for worse from the clinician’s perspective remaining an open question.

Walker et al. (2009) concluded with three hypotheses:

First, particularly in the world of primary care, patients may be willing to do without a doctor, or to substitute a virtual encounter for a face-to-face visit, even when they could travel to the provider’s office. Second, as the population ages and faces more illness, privacy of health information may be far less important than it is today. Finally, patients may demand full access to everything in their records, and many will carefully read and perhaps add to clinicians’ notes (p. 731).

Following the focus groups, Walker and colleagues (2011) conducted a survey of patients and primary care providers to determine their expectations and attitudes toward permitting patients access to providers’ clinical notes following outpatient visits. The surveys were administered online prior to initiating patient access to provider notes at three sites: Beth Israel Deaconess Medical Center in Boston, Geisinger Health System in largely rural northeastern and north central Pennsylvania, and Harborview Medical Center in Seattle, a county hospital serving mostly indigent patients. Patients at Beth Israel Deaconess and Geisinger were already accustomed to using a patient portal for access to information and communications. A patient portal at Harborview was opened after the survey, simultaneously with offering access to clinical notes. The investigators found, in brief, that patients were enthusiastic, anticipating many benefits from viewing providers’ clinical notes; providers who planned to participate in the upcoming OpenNotes project were generally positive, with some misgivings; and providers who declined to participate were decidedly negative. “Overall, PCPs who declined to participate predicted that open visit notes would lead to negative consequences for the way they practiced and would have little positive effect on their patients” (p. 816). Among the concerns of providers were fears of lengthier visits, more demands on their time between visits, possibly frightening or confusing patients, and negative consequences for writing candidly about such matters as cancer, substance abuse, obesity, and mental illness. In addition, Delbanco, Walker, et al. (2010), reviewing the same data, noted that providers worried about increased time that might be required to correct notes and about looking unprofessional because of typographical errors and poor phrasing. Patients worried about getting information they would rather not have and about misunderstanding medical terminology. Both providers and patients saw potential advantages in more accurate notes and greater patient participation in care.

The OpenNotes project is ongoing, using observational methods to study the effects of letting patients use a secure portal to read their clinical notes (Delbanco, Walker, Darer, Elmore, Feldman, et al., 2010). More than 100 primary care providers and more than 25,000 patients have agreed to participate in permitting patients to review their providers' signed notes following an ambulatory visit and prior to the next visit. The investigators foretold a time when notes would be drafted collaboratively by clinicians and patients and become a contract for care.

Commenting on the OpenNotes work, Feely and Shine (2011) observed that allowing patients and referring providers unrestricted access to patients' electronic health records at the M. D. Anderson Cancer Center had resulted in no adverse consequences and many benefits, including better informed patients who asked better questions and improved communications with referring physicians. "Although physicians occasionally complain about the time it takes to explain something they wrote, feedback from patients and physicians has generally been positive" (p. 853).

Although patients in the OpenNotes studies expressed few concerns about the privacy and security of their personal health information, respondents to a 2009 survey in Buffalo, NY, indicated that although they would like to share their information across providers, they would not want it disclosed to employers or health insurers (Patel, Abramson, Edwards, Cheung, Dhopeswarkar, & Kaushal, 2011).

The positive expectations of the OpenNotes participants and the positive experiences of the M. D. Anderson participants are consonant with an observational study in Australia involving 20 primary care physicians and 141 of their adult patients (Pearce, Arnold, Phillips, Trumble, & Dwan, 2011). The investigators found that the inclusion of the computer in the clinical consultation helped patients shift the balance of power and authority toward shared decision-making and patient-centered care. About one-third of the patients in this study actively included the computer as a party to the consultation, drawing the physician's attention to it as a source of information or authority. They concluded:

In the future, computers will have greater agency, not less, and patients will involve themselves in the three-way consultation in more creative ways—for example, through online communication, or through the plugging into computers of their own electronic records, creating a situation where they co-own the information in the computer. . . By democratizing and commoditizing information flows and authority in the consultation, we may in fact create truly patient-centered medicine, with the patient directing the action (p. 142).

Caligtan, Carroll, Hurley, Gersh-Zaremski, and Dykes (2012) investigated the perspectives of nurses and hospitalized patients about information that should be available to hospitalized patients and their lay caregivers at the bedside. Patients wanted information about the healthcare professionals on their care team, including photographs and names continually updated at shift changes, as well as information about their schedule of care and medications. Nurses gave higher

priority to posting safety-related information at the bedside, such as restrictions on activities and oral intake or needs for assistance with transitions and mobility. Nurses expressed concerns about inducing cognitive overload in patients and lay caregivers if too much information was provided and about causing distress and disruption in the clinical workflow if medications and other care activities did not occur according to a schedule available at the bedside. Caligtan et al. noted that redesigning care for greater openness and patient-centeredness would require resolving the tension between patients and healthcare professionals about the amount and types of information that should be made available at the bedside.

When psychiatric nurses in Finland were asked about the possibility of incorporating Internet contact with adolescents as an adjunct to face-to-face outpatient treatment, they saw some potential benefits, but they also identified a number of concerns. In an Internet contact, nurses would not have access to potentially important non-verbal cues to such conditions as worsening depression. Likewise, in an Internet exchange, patients might find it easier to avoid expressing distressing facts such as suicidal ideation. The nurses also expressed concerns about time requirements and changes to roles and workflow (Kurki, Koivunen, Anttila, Hätönen, & Välimäki, 2011).

Haase and Loiselle (2011) studied the perceptions of patients and other members of the care team of an Internet-based resource designed to help cancer patients and their lay caregivers to learn about their illness, treatment options, and local healthcare facilities and community services and to provide psychosocial support. Patients found many benefits from using the resource independently of their healthcare providers. Healthcare professionals and volunteers also acknowledged the potential benefits of incorporating the resource into oncology services but expressed concerns about the time requirements for introducing patients to the resource and answering their questions. Some also expressed concerns about computer and Internet access for patients and lay caregivers.

5.0 Demonstrated Benefits of Consumer eHealth

5.1 Better Communication and Collaboration within the Healthcare Team

When consumers and their lay caregivers enter into a therapeutic collaboration with their healthcare providers, all become part of a healthcare team. Consumers who use eHealth resources feel better prepared for clinical encounters and ask more personally relevant questions (Pew Internet and American Life Project, 2012). This may be because of access to knowledge and information relevant to their condition. Users of the Veterans Health Administration MyHealthVet personal health record expressed great satisfaction with the functions of secure messaging, refilling prescriptions, and viewing test results (Nazi, 2009). Older veterans with diabetes who were not yet using MyHealthVet expressed interest in using it to manage their condition (Cho, Arar, Edelman, Hartwell, Oddone, and Yancy, 2010). At Kaiser Permanente in Portland, Oregon, members who used secure messaging were matched to others who did not on

all measures of the Healthcare Effectiveness Data and Information Set (HEDIS). At follow-up, those who used messaging had improved on all measures an average of 2.4% to 6.5% more than those who did not use messaging. All differences were significant. These improvements resulted in better control of blood pressure, diabetes mellitus, and congestive heart failure (Zhou, Kanter, Wang, & Garrido, 2010).

5.2 Better Quality of Care at Lower Cost

Many investigations have shown that complementing face-to-face or telephone communications with electronic communications between clinicians and patients can improve health outcomes with greater efficiency and lower costs.

In the Hawaii region of Kaiser Permanente, the introduction of an EHR with a personal health record component and secure messaging resulted in an eight-fold increase in scheduled telephone contacts and a one-quarter decrease in office visits, while maintaining measures of quality and satisfaction (Chen, Garrido, Chock, Okawa, & Liang, 2009). Contacts between patients and providers changed from 99.6 % office visits in 1999 to 66% office visits in 2007, with 30% of contacts being by scheduled telephone visits and 4% by secure messaging. Patients preferred options to manage their care that did not require office visits. In addition, nephrologists used the EHR and secure messaging to advise primary care providers about the care of patients with chronic renal failure, decreasing the number of specialty visits.

To give patients in rural areas better access to medical specialists in academic health centers, telemedicine is a possible strategy. A small study in California found no difference in parental satisfaction when children received a telemedicine consultation about obesity versus a face-to-face consultation. However, parents in the telemedicine condition were less likely to agree that the doctor had given explanations in terms they could readily understand (Mulgrew, Shaikh, & Nettiksimmons, 2011).

At the University of Washington, McCarrier et al. (2009) conducted a 12-month randomized controlled trial of a Web-based intervention for patients aged 21-49 with Type I diabetes mellitus and A1C values equal to or greater than 7. The intervention offered five functions: 1) unrestricted access to the patient's electronic health record as maintained by the provider; 2) ability of patients to upload glucose readings to a health record viewable by both the patient and the case manager; 3) ability of patients to enter into an online daily diary and for patients and the case manager to view data about nutrition, exercise, and medications and display trends of these data along with A1C values; 4) ability to collaborate with the case manager to generate self-care action plans; 5) access to educational materials and links sanctioned by the medical director of the clinic. The case manager had 25 years' experience as a diabetes educator and 10 years' experience as an advanced registered nurse practitioner specializing in diabetes. The case manager assisted patients to use all functions of the Web-based intervention during the recruitment visit, viewed uploaded information weekly, and contacted patients by email weekly for the first month and at least monthly thereafter, depending on their personal health goals. Although 61% of patients in the intervention arm used at least one component of the intervention

on more than one occasion, only a quarter used it consistently. The sample size (41 patients completing the intervention arm; 36 completing the control arm) was too small to test for effects of differential “dosage” of the intervention. Although mean A1C values increased slightly for the control group and decreased modestly for the intervention group, the difference did not achieve statistical significance in this small sample. The investigators noted that such a between-group difference (-0.48) would be clinically significant if replicated in a more powerful study. Patients in the intervention group did achieve statistically significant gains in self-efficacy, as measured by the short form Diabetes Empowerment Scale, while patients in the control group experienced a modest decrease in the mean score.

Similarly good results have occurred in psychiatric care. A study of 208 patients starting treatment for depression in nine primary care clinics of an integrated health system in Washington state found that those who were offered an online intervention (three online care management contacts with a psychiatric nurse) were more likely to adhere to their medication regime 5 months later (81% versus 61%), to have lower Symptom Checklist depression scores (0.95 vs. 1.17), and to be more satisfied with their treatment (53% “very satisfied” vs. 33%) (Simon, Ralston, Salvarino, Pabiniak, Wentzel, & Operskalski, 2011). Similarly, Knaevelsrud and Maercker (2010) found that cognitive behavioral therapy offered to persons suffering from post-traumatic stress disorder via Internet contact between patients and therapists was effective in reducing symptoms, and the improvements were sustained 18 months after the end of treatment.

Investigators at the University of Pittsburg also found good results when they used a randomized controlled trial to test a Web site specifically designed for persons with schizophrenia and their lay caregivers (Rotondi, Anderson, Haas, Eack, Spring, Ganguli, Newhill, & Rosenstock, 2010). This feasibility trial included 31 persons with schizophrenia and 24 support persons, with about half of each group randomly assigned to the teleHealth arm and half to the usual treatment arm. The Web site was designed to be easy to navigate, understandable by persons with cognitive impairments, and low on distracting or stimulating features such as images that might evoke an increase in symptoms in a schizophrenic population. It included three therapy forums led and moderated by a therapist, one for persons with schizophrenia, one for support persons, and one for both groups. Therapy sessions emphasized solving problems, reducing stress, and interacting with peers. The site also included a mode of asking questions of an expert and receiving an answer within 24 – 48 hours and a library of previously asked and answered questions. In addition, there were a collection of reading materials and a roster of community resources. In the teleHealth group, all persons with schizophrenia and all but one of the support persons showed full engagement with the Web site, as measured by automatically logged records of the frequency and duration of their visits to the site and the kinds of resources used. Persons who initially had a higher level of symptoms showed the greatest engagement. After twelve months, persons with schizophrenia in the teleHealth arm had achieved a large and significant reduction in symptoms, while those in usual treatment had only a modest reduction. Persons in the teleHealth arm also had a large and significant gain in their knowledge of schizophrenia, while

the usual treatment group had no change in knowledge. Support persons in the teleHealth arm experienced a large and significant gain in their knowledge of the prognosis. The investigators concluded that teleHealth interventions designed for this population offered an effective and economical way to bring education and therapy to persons who might not have local access to therapeutic services and to those who might prefer a teleHealth intervention because of its lower stimulation, availability at all hours, and lower social stress compared to face-to-face interventions.

5.3 Better Personal Health Management through the Use of eHealth Resources

Frequent electronic contact between clinicians and patients can support better self-care actions. Park and Kim (2012) studied the effects of a combined mobile phone and computer intervention in reducing waist circumference, blood pressure, and lipids in obese, post-menopausal Korean women. Over a 12-week period, women in the intervention group received three messages a week from the investigators. The Monday and Wednesday messages contained general information about diet or exercise and were sent to the mobile phone only. The Friday message contained specific feedback about information the woman had posted via phone or computer about her diet, exercise, and waist circumference with a suggestion for action. The Friday message was sent both to the woman's computer and to her mobile phone. All messages were very brief. In addition, women saw an obesity expert, a family physician, a nurse, and a nutritionist at a healthcare facility at the beginning and the end of the study and once or twice during the 12 weeks. Women in the control group received the same professional healthcare and in-person counseling as those in the intervention group. Healthcare professionals were blinded to the women's study status. At the end of 12 weeks, those in the intervention group were found to have significant reductions in waist circumference, blood pressure, and LDL cholesterol, while those in the control group experienced increases in these measures.

Patients with cancer and their lay caregivers were offered the opportunity to use an online resource designed to teach them about their illness, treatment options, and available community resources, as well as to provide emotional support (Hasse & Loiselle, 2011). Patients using the resource gained knowledge of cancer and a greater sense of competence in managing decisions and self-care. In addition, they liked the accessibility of the information and the opportunity to pace their exposure to it. They experienced less anxiety and knew more about available community services.

Many consumers find that online peer support groups help them to cope with health challenges. Content analysis of 1313 postings to a Huntington Disease peer support site showed that 56.2% offered advice, referral to expert sources, factual or technical information, or situation appraisals that might help an individual to see a positive aspect of a difficult disease (Coulson, Buchanan, & Aubeeluck, 2007). Almost as many, 51%, offered emotional support in the form of empathy, validation, support for expressed emotions, and expressions of caring or affection. A much smaller number (21.7%) offered esteem support in the form of compliments or a sense of membership in the peer community. Tangible assistance was offered least frequently (9.8%).

A content analysis of “wall posts” and “discussion threads” in the 15 largest sites on Facebook devoted to diabetes also showed that persons apparently found value from using the sites for information, emotional support, building a sense of community, and sharing personal experiences (Greene, Choudry, Kilabuk, and Shrank, 2010). Nearly two-thirds of items shared personal experiences with diabetes, many offering advice. More than a quarter of the posts (28.8%) offered emotional support.

6.0 Potential Unintended Consequences of Consumer eHealth

As with any healthcare intervention, benefits of consumer eHealth may be accompanied by unintended, adverse consequences. When planning to introduce eHealth strategies, clinicians and healthcare organizations should be aware that they are not just automating existing work processes but significantly changing the roles and responsibilities of clinicians, patients, and lay caregivers. In a classic paper on difficulties arising from the introduction of a medical information system (MIS) into an academic medical center, Massaro (1993) provided a caution that might also be applied when introducing patient and consumer eHealth strategies:

It is prudent to consider ‘What if . . .?’ to analyze the potential difficulties, to consider all possible options, and to understand the implications of each decision that may be required. This anticipatory anxiety is both appropriate and perhaps prophylactic in dealing with many of the significant organizational conflicts that are certain to accompany an undertaking as complicated and as invasive as the introduction of an MIS into the patient care environment of an academic medical center. (p. 30)

In the most general terms, unintended consequences are events or reactions arising from the introduction of an innovation that are not part of the intended purpose or goal of the innovation. Unintended consequences may be either anticipated or unanticipated, and within those categories they may be further classified as desirable (serendipity) or undesirable (adverse effects) (Ash, Sittig, Poon, Guappone, Campbell, & Dykstra, 2007). Serendipitous effects of consumer eHealth might enhance health and healthcare processes in unexpected ways. Adverse effects, however, have the potential to disrupt the care process and to degrade health outcomes. It is therefore important to predict and to counteract potential adverse effects, preferably before they occur. As members of the Consumer eHealth Work Group, the authors were charged to anticipate potential adverse unintended consequences of patient and consumer eHealth initiatives and to identify strategies to maximize benefits and minimize harm.

6.1 Potential Unintended Consequences of Using eHealth Resources to Increase Communication and Collaboration

Consumers and providers in the OpenNotes studies (Walker et al., 2009; DelBanco et al., 2010; Walker et al., 2011) envisioned a time when consumers would take much more responsibility for managing their own health and rely much more on information technologies for guidance in doing so. However, the AHRQ report, “Guide to Patient and Family Engagement” (2012) noted that while most patients and family members wish to receive information from their clinicians,

they differ in the degree to which they want to be involved in shared decision-making; younger, female, more highly educated patients are more likely to seek involvement, and those who communicate through an interpreter are the least likely. Similarly, physicians supported shared decision-making in general, but were concerned that patient characteristics, clinical exigencies, or time requirements might preclude involving patients and family members in clinical decisions.

Thus, consumers who prefer to “follow doctor’s orders” and be more passive with regard to their health might resist the transformation to greater personal responsibility and technology-based guidance. If providers expect full engagement from all patients in using eHealth tools for engagement in care, some patients and lay caregivers may find themselves without adequate support to manage their health. Providers who prefer an authoritative role might resist the shift of power and knowledge toward patients and find themselves ill prepared for a therapeutic alliance.

Some of these misgivings are affirmed by a set of surveys and interviews commissioned by PricewaterhouseCoopers, LLC (PwC) and carried out by The Economist Intelligence Unit (EIU) (PwC, 2012). The study investigated attitudes and expectations of physicians, consumers, and payers regarding mHealth, defined as the use of mobile devices (smart phones, tablets, and monitoring devices) to engage individuals in seeking health information, communicating with providers, and managing their own health. To compare and contrast responses between developed nations and emerging economies, the investigation spanned 10 countries: Brazil, China, Denmark, Germany, India, South Africa, Spain, Turkey, the UK, and the US. In the emerging economies, where healthcare infrastructure is lacking and cell phones are becoming ubiquitous, expectations and attitudes of all parties were significantly more favorable than in the developed nations. Around the world, physicians held the most negative attitudes. A full 42% anticipated that mHealth would make their patients “too independent.” “Only 27% encourage patients to use mHealth applications in order to become more active in managing their health; 13% actively discourage this” (PwC, p. 14). Among younger physicians (those with less than 5 years experience), the attitudes are even more negative. Over half of the younger physicians worry that mHealth will make patients too independent, and a quarter actively discourage patients from using mHealth applications to manage their health. Payers, by contrast, are generally willing to support provider time and effort expended on supporting patients’ use of mHealth because they anticipate that engagement in personal health management will lead to better health outcomes and lower costs. Patients are most interested in gaining greater access to their providers, reducing their personal healthcare costs, taking greater control of their health, getting health information, and obtaining better healthcare. These surveys show that while many patients and payers are ready to embrace eHealth (and mHealth) as a means to personal health management, better care, and better outcomes, many physicians can be expected to resist the loss of power and authority.

In other studies, nurses, too, expressed concerns about increasing patient engagement. If hospitalized patients had access to information about their schedule of care, nurses worried that

the patients might disrupt the nurses' workflow with inflexible demands (Caligtan et al., 2012). Similarly, psychiatric nurses in Finland expressed concerns about changes to roles and workflow if they were to use Internet contacts with adolescent patients instead of some face-to-face visits. They were also concerned about the loss of valuable non-verbal information if Internet contacts were substituted.

Healthcare professionals and volunteers in a cancer center were concerned about increased work and tighter time constraints for themselves if they were to introduce patients and lay caregivers to an Internet-based resource for learning about and managing cancer. They also worried about whether patients and family members would have Internet access (Haase & Loiselle, 2011).

When patients use electronic communications with providers, clinicians have special responsibilities to assure safe, ethical, patient-centered care. Mittal et al. (2010) measured 18 indicators of response quality to a fictional patient email as part of a clinical simulation examination. The respondents were 50 first- or second-year rheumatology residents from six different fellowship programs over a period of four years (2005-2008). Responses tended to be concise (74%) and courteous (68%). However, the residents did less well on two other dimensions: understanding the role of email as a complement to a visit and not for urgent matters, and understanding the administrative and legal aspects of email, such as the need for proper documentation and encryption. Thus, even though 92% of the residents acknowledged that the patient's condition (as described in the fictional email) required immediate medical attention, few (30%) took steps to contact the patient other than by email response. None of the residents encrypted their messages. The investigators acknowledged that the residents might have responded differently to an email from a real patient but concluded that there is a need for more formal training in the proper use of email in the provider-patient relationship. Another unintended consequence inferred by the Consumer eHealth Work Group is that when providers respond to an urgent email via email rather than by telephone, they may contribute to dangerous delays in care.

Secure messaging may be one function of a personal health record linked to a provider organization. Many other functions are possible. Krist and Woolf (2011) described five levels of functionality for personal health records:

- Level 1: An electronic substitute for the home medical file
- Level 2: A link to information in the electronic medical record or claims data
- Level 3: An explanation of technical information in language patients easily understand
- Level 4: A source of clinical advice, such as reminders that screenings are due
- Level 5: Assistance in taking action in the interests of one's health

The highest level includes vetted information tailored to the patient's specific health needs, such as smoking cessation programs or nutritional advice. Personal health records can offer a platform for decision aids and, if coordinated with the electronic health record, can extend clinical encounters beyond the office visit. Patients prefer PHRs with greater functionality, tailored to

their particular health profile. The authors concluded, “The personal health record is a legacy term—the modern patient has more to do than keep records. Information technology holds great promise in empowering patients to manage their health, but the patient must become the focus of the design if the technology is to be used or fulfill its potential” (p. 301). The authors noted that PHRs that lack sophistication and complexity may fail at each level, capturing and transferring erroneous information, confusing patients with jargon, and providing outdated, misguided, or otherwise inappropriate advice.

Personal health records (PHRs) may be designed to give patients a secure portal into the electronic medical record (EMR) and may offer secure messaging between patients and clinicians. At the end of 2007, Reti, Feldman, Ross, and Safran (2010) assessed the patient-centeredness of personal health records (PHRs) in seven large organizations that were early adopters of PHRs. They used evidence of respect for patient preferences as the criterion of patient-centeredness. Although all organizations provided some patient-centered features, their policies and procedures varied. None permitted patients access to clinical notes in the electronic record, and most delayed patients’ access to normal laboratory results. The investigators proposed a “best practice” policy model that would, among other provisions, give patients complete access to information in the electronic medical record and control over others’ access to information in the PHR (with “break the glass” access by identifiable medical personnel in emergencies). The patient-centered policy model also called for clinicians to respond to patient emails within 24 hours, a shorter time than any of the organizations provided.

Thus, potential unintended consequences of personal health records that lack desired functionality or patient-centeredness include the following:

- 1) If PHRs with secure portals to the provider deny patients timely access to information or to responses from clinicians, patients may become frustrated and disengaged from their providers.
- 2) Some clinicians are uncomfortable with the idea of patient access to information, particularly in clinical notes; these clinicians may find increased questions from and interactions with patients burdensome.
- 3) To meet the recommended guideline of response to all patient-generated messages within 24 hours, practices may have to reassign existing personnel or acquire additional personnel to monitor patient communications and triage them for immediate response by an advice nurse, immediate response by a physician, nurse practitioner, or physician’s assistant, or delayed response (within 24 hours) by a physician, nurse practitioner, or physician’s assistant. This would require a change in personnel roles and workflows and possibly additional expense to the practice.

The principles described by Krist & Woolf (2011) and by Reti et al. (2010) are reflected in the experiences of the Military Health System (MHS). Charged with providing patients with access to their health information through an interoperable system, MHS initiated a pilot project in 2008 to allow patients a choice of platforms, Google Health (now-defunct) or Microsoft HealthVault, as the repository for their health data. (Do, Barnhill, Heermann-Do, Salzman, & Gimbel, 2011). A patient portal called MiCare was created as the gateway to the repository of choice and to

other PHR functionalities. MiCare also provided the platform for transferring data, at the patient's request, from various Department of Defense sources to the PHR repository of choice. Users were generally satisfied with MiCare as a portal to their information, but they wanted more functions, such as secure messaging and appointment scheduling. The investigators cited four important lessons learned. First, although most patients requested automatic transfer of all their data to the repository, this slowed response time to an unacceptable level. The designers then changed the model to transfer data only upon specific patient request. Second, although the patient representatives to the project requested instant access to all their data, providers insisted on a seven-day publication delay for routine information, to give them time to contact the patient and explain the results. For sensitive information such as pregnancy, positive cancer findings, and sexually transmitted diseases, the providers required direct contact with the patient, with publication happening only with patient request and provider concurrence. Third, providers found that accessing the PHR impeded their workflow and that lack of complete information from the MHS might pose a danger of ill-informed clinical decisions. A dashboard that integrated patient requests with full MHS data on the patient might have helped. Fourth, giving patients the power to determine what medical information to share with the provider could similarly lead to clinical decisions made in the absence of vital information, with resulting harm to patients.

The investigators concluded that while there is broad agreement on desired functions for PHRs, challenging tensions remain between patients' desire for access to and control of health information and providers' needs for full information about the patient and for appropriate opportunities for ethical disclosure of information to patients. The Consumer eHealth Work Group infers three corollary unintended consequences. First, to the degree that patients limit providers' access to information in health records, patients may inadvertently withhold information germane to their care, resulting in suboptimal decisions by providers. Second, when patients have the ability to introduce imprecisely sourced or uncurated data into the EMR, providers may rely on incorrect information and consequently reach poor clinical decisions. Third, although physicians may prefer to delay release of results to patients until the providers can review the findings and determine appropriate ways to communicate them to patients, such delays, especially if prolonged, can disadvantage patients when findings require prompt action.

The personal health record in use at the Veterans Health Administration, MyHealthVet, provides some of the functions that users of MiCare desired. MyHealthVet allows Veterans to self-register at the Web site and to enter data about their health and medications (Zulman, Nazi, Turvey, Wagner, Woods, & An, 2011). Registered users who receive healthcare from the VA can request medication refills from the site. Those who have undergone in-person authentication at a VA facility can view additional information about their medications and appointments, receive wellness reminders, and view and download certain (but not all) information from their electronic health records. Approximately 4% of users of the site are randomly invited to participate in a customer satisfaction survey via a pop-up window. For a three-month period in 2010, the investigators added custom questions to the survey to ascertain whether MyHealthVet

users would like to share information from their PHR with friend or family caregivers or with healthcare providers outside the VA system, and what information they would like to share. About 40% of those invited to participate in the survey completed the survey, yielding more than 18,000 completed surveys. Most respondents (79%) were interested in designating someone outside the VA health system to have access to parts of their PHR. The spouse or partner was most often the person designated (62%), but other family and non-related caregivers were also indicated. About a quarter of respondents wanted to share information with healthcare providers outside the VA system. Respondents were more interested in sharing medication lists, appointment scheduling, and laboratory test results with their designee than self-entered health information or communications with VA providers. Likewise, they were more interested in delegating appointment scheduling and prescription refill requests to a family or friend caregiver than delegating communications with a VA healthcare provider. The investigators noted that sharing information in the PHR currently requires users to download and print the information they wish to share. Permitting electronic access to selected information by designated caregivers and healthcare providers would enhance the ease of use and value of the PHR to users. It would also facilitate communications among caregivers and providers. Allowing designated caregivers to enter information into the PHR would potentially increase the accuracy and completeness of information in the record. The investigators noted the challenges entailed in balancing ease of information exchange with patients' privacy rights and concerns.

The potential unintended consequences of MyHealthVet are similar to those of MiCare. Sharing incomplete health information with providers carries the risk of suboptimal decisions made in the absence of needed information. Allowing designated caregivers to enter information into the PHR, while potentially enhancing the completeness and accuracy of information, involves risks of uncurated and improperly sourced information similar to those of patient-entered information. In addition, caregivers entering information into the PHR on behalf of the patient may not consult the patient before doing so, leading to filtered, imprecise, or erroneous information. Finally, patients sharing the record with outside physicians may alienate their in-system physicians.

At Columbia-Presbyterian Hospital in 2011, a pilot study with 5 hospitalized patients tested the feasibility of using a tablet computer to give patients access to information about their hospital medication history, links via MedlinePlus/Connect to information specific to their medications, and photos of their providers identifying the role of each in the patient's care (Vawdrey, Wilcox, Collins, Bakken, Feiner, Boyer, & Restaino, 2011). None of the patients had used a tablet computer before. All the patients believed that use of the tablet computer would increase their ability to participate in their care and their resulting satisfaction. One remarked on the usefulness of having information available when he had the energy to review and understand it. Patients found the medication history useful in a variety of ways. It reduced the burden of remembering all the medications and changes, it enabled them to verify that medication orders and administration were consistent, and it provided assurance that their requests regarding medications had been acted upon. Links to MedlinePlus/Connect did not always work well

because of technical limitations in the hospital's EHR, resulting in frustration to patients. Photos of the care team were especially well received, helping patients to feel more connected and better able to interact when they saw the clinicians. Enhancements the patients proposed included the ability to communicate directly with clinicians through the tablet, increased information about the credentials of the clinicians, and ability to compare home medications with hospital medications. This small pilot study showed that hospitalized patients have many unmet information needs and that an application such as the prototype tested here can help to meet those needs. However, the authors identified the following potential unintended consequences: 1) providing information to patients may result in more questions to their providers; 2) providers may feel uncomfortable when patients have greater ability to scrutinize their work; 3) information may confuse or worry patients and complicate, rather than facilitate, communications.

The importance of patient-centeredness in the design and use of consumer eHealth resources is clear when patient-centeredness is lacking. In 2006-2007, Wald et al. (2009) conducted a randomized controlled trial of the use of an electronic journal to prepare for scheduled ambulatory visits. The intervention group consisted of 126 patients with Type II diabetes mellitus. The journal was a component of a personal health record linked to an electronic medical record. To minimize physicians' burden of reading the journals, patients were allowed to enter only structured information and only information related to diabetes care. During the study period, patients submitted 140 journals (some for more than one visit), and physicians opened 114 of the journals. Of the 126 patients in the intervention group, 55 were offered a survey to express their experiences, and 37 responded. Although most respondents felt that the journals helped them to prepare for the visit and to provide information for the doctor to use during the visit, many were frustrated by the inability to enter free-text data about other concerns that they wished to discuss with the doctor. They also disliked the journal's requesting the same information for future visits when the information had not changed. Another frustration was the doctor's not opening the journal or using the information during visits. Most patients did not believe that the use of the journal enhanced the quality of care, communication with the doctor, or satisfaction with the visit. However, patients who used the journals were more likely to have their medications adjusted during their visit. The investigators concluded:

With advanced journal capabilities come a number of challenges, including complexity of design, iterative user testing, content tailoring, and the need to engage both patients and physicians in workflow changes.

Research to identify and overcome barriers to adoption should focus on engaging patients and physicians in use of an electronic journal; tailoring content to provide more value; improving usability; fitting the electronic journal more seamlessly into a collaborative care workflow; and supporting patient-provider dialogue beyond the boundaries of a visit. (p. 682)

In addition to the patient frustrations noted above, the Consumer eHealth Work Group observes that to use journals effectively as a recording and communicating tool, providers have to change

their workflow to review journal information during a visit; however, time allotted to visits may not allow for journal review. Furthermore, providers may be stretched to accommodate the increased time and effort necessary for visits if patients are given the means and opportunity to bring up concerns beyond those that providers anticipated during the visit.

6.2 Potential Unintended Consequences of Integrating eHealth Strategies into Care Delivery

A number of studies show that even when healthcare organizations provide excellent eHealth resources for communication and collaboration, patients and lay caregivers vary in their preferences and abilities to use the resources.

From October 2005 to November 2007, Roblin, Houston, Allison, Joski, and Becker (2009) surveyed members of Kaiser Permanente Georgia to determine factors associated with differences in enrollment in <http://kp.org>, a personal health record and patient portal that offers secure communications, information from one's health record, and patient-specific educational resources. They found that differences in income, education, and Internet access affected enrollment in kp.org, but these factors did not account for disparities between whites and African Americans, the latter being less likely to enroll (41.7% of whites versus 30.1% of African Americans enrolled). Similarly, a study of Kaiser Permanente members in northern California found that although education affected the likelihood of logging on to kp.org, African Americans and Latinos, regardless of education, were less likely than non-Hispanic Caucasians to ever log on (Sarkar, Karter, Liu, Adler, Nguyen, López, & Schillinger, 2011). The Consumer eHealth Work Group has concerns that increasing reliance on PHRs and secure portals to communicate with patients and their lay caregivers could contribute to wider disparities in healthcare across races and ethnicities.

Nielsen, Halamka, and Kinkel (2012) found similar results when they examined the use of a secure patient portal by multiple sclerosis patients seen in an academic medical center clinic in 2008 and 2009. Compared to non-users, portal users were likely to be younger Caucasians, less disabled, employed, and privately insured. They noted that incorporation into the portal of functions such as responsiveness to voice commands might have increased use by more disabled patients. According to the investigators, healthcare professionals in the clinic emphasized to patients that the portal was the preferred means of communication between visits. For the Consumer eHealth Work Group, this emphasis raises the concern that patients who are older, more disabled, less affluent, and of non-Caucasian race or ethnicity, or for other reasons disinclined to use the portal, may receive less support from clinicians than do portal users.

Demographic differences in use of online records and communications have also been found in other large healthcare providers. Group Health Cooperative provides care and health insurance to about 500,000 residents of the northwestern United States. Weppner et al. (2010) conducted a retrospective analysis of patient use of shared medical records (including communications, requests for scheduling appointments and refilling prescriptions, and review of one's own health information) involving more than 6000 patients with diabetes who were age 65 or older at the

start of the review period, August 2003 – December 2007. Overall, about 1/3 of the subjects used the shared medical record during the study period. Analyses showed that younger age, male gender, residence in a higher socioeconomic status neighborhood, and the primary care provider's use of secure messaging were associated with greater likelihood of use. Within a month of changing to a provider who offered a higher level of secure messaging use, patients were three times as likely to sign up for and use the shared record. Similarly, patients were 60% more likely to initiate use within three months of an increase in morbidity. The most frequent types of uses, in order, were to review test results, to request prescription refills, and to send and receive secure messages. The investigators concluded that many older patients find it useful to use shared records to manage their care, especially if encouraged by their providers. However, the authors described the following unintended consequences:

Provider engagement may be difficult because of concerns of increased workload, responsibilities, and reimbursement issues. . . . Systems seeking to implement such changes need to acknowledge additional pressures on workflow, identify reimbursement and productivity measures, and collaborate with providers to address these constraints (p. 2318).

These findings show that although Internet-based collaboration between patients and providers has the potential to increase patient involvement, patients are likely to self-select their level of usage. Further, requiring extra effort on the part of patients (e.g., manual entry of glucometer data into the online diary) may mean that less motivated or less technologically comfortable patients may be deprived of the benefits of online tracking of health parameters and behaviors. Consequently, providers may face the expense and burden of offering diverse types of interventions to accord with patients' abilities and preferences.

6.3 Potential Unintended Consequences of Using eHealth Resources for Personal Health Management

Increasingly, consumers are using a variety of eHealth resources to learn about health conditions, to monitor and record health behaviors and parameters, and to receive guidance on personal health management. Such usage can produce many benefits, but it also carries risks of unintended, adverse consequences.

Ossebaard, Seydel, and van Gemert-Pijnen (2012) studied the usability by persons with asthma, arthritis, or diabetes of the Dutch national portal designed to provide access to information about health conditions, healthcare providers, health insurance options, healthy living, and self-management. Patients and lay caregivers performed information-searching tasks specific to the patient's disease while the investigators observed. Interviews and focus groups were used to follow up on observed experiences. Consumers wanted the site to be easier to read (larger font) and easier to navigate. They wanted more specific information than was available on the site. Only 40% said they would rely on online sources for help with making decisions about their health. Based on the usability study, a number of changes were made to the portal. The Consumer eHealth Work Group infers from these findings that even when a site contains valid

and relevant information, consumers may not return to it or see it as trustworthy if usability is not high.

In another study of the general population of the Netherlands, van Deursen (2011) found that older age and lower levels of education were associated with lower operational skills such as saving files, bookmarking Web sites, and using search engines. Older subjects, however, were better able to judge the relevance and appropriateness of the information they found. To the Consumer eHealth Work Group, this study suggests that older persons may need help learning operational skills before they can use eHealth tools effectively. Conversely, younger persons may possess operational skills but need help learning how to judge the validity and relevance of information.

To provide patients with high quality information resources, many healthcare organizations are offering their own Web sites and portals. Atkinson et al. (2011) demonstrated the importance of involving users in evaluating the design of such resources, including giving them more than one version to evaluate and varying the order of presentation. Notably, the investigators found that users liked the opportunity to explore the site and assess its credibility and authoritativeness before registering and entering personal information. A survey of individuals using health-related social networking sites provided by three major medical centers found that the most important factor determining the degree of empathy that people perceived they received from the site was the effectiveness of seeking information, as compared with social support or personal similarity of participants (Nambisan, 2011). The investigator recommended that healthcare organizations providing such sites take pains to make it easy for participants to find the information they need. The Consumer eHealth Work Group observes that healthcare organizations that offer Web-based information and peer support for patients and other consumers may cause users to disengage if their sites fail to follow principles of patient-centered design and usability.

Increasingly, patients and family members engaged in promoting their own health turn to social networking sites on the Internet. Greene et al. (2010) found that users of diabetes sites on Facebook apparently found value in reporting and reading personal experiences and advice and building a sense of community. Disturbingly, however, more than a quarter of the posts promoted non-FDA-approved “natural” remedies as “cures” for diabetes. Moreover, these advertisements were couched as personal testimonials, and there was no way to verify the identity of the poster—a real patient, or a manufacturer or marketer of the product promoted. Many of the posts showed a preference for information obtained on the social networking site as more credible than information provided by healthcare professionals.

Another examination of 10 Internet sites focused on diabetes mellitus also found significant gaps in quality and safety (Weitzman, Cole, Kaci, & Mandl, 2011). On only half the sites was content aligned with current medical science. Of nine sites that carried advertising, only four made a clear distinction between advertising and editorial content; two sites contained advertisements about a “cure” for diabetes. Six sites, including four moderated sites, contained member-posted misinformation about a “cure” for diabetes. Privacy practices were generally poor. Weitzman et

al. offered straightforward, readily implementable recommendations for improving the quality and safety of health-related social networking sites, but they noted that there is no authority or agency empowered to enforce them. A systematic review and evaluation of Web resources for diabetes found few that met criteria for effectiveness, usefulness, sustainability, and usability (Yu, Bahniwal, Laupacis, Leung, Orr, & Straus, 2012). These investigators also urged more reporting of Web site quality measures. For the Consumer eHealth Work Group, findings such as these raise concerns that consumers seeking online information and support from peer groups may not differentiate between accurate, up-to-date information and spurious information, nor know which sources to trust. Consequently, while becoming more engaged in managing their health, they may be misled into actions contrary to their own well-being.

Fortunately, resources are available to clinicians and consumers to help in evaluating the quality of Web sites that provide health information. Although it has no enforcement powers, the Health on the Net Foundation offers a set of criteria for evaluating health information offered to consumers on the Internet. Sites that meet its criteria may apply for HONcode certification to be displayed on the site. In brief, the criteria (quoted from <http://www.hon.ch>) are as follows:

1. Authoritative: Indicate the qualifications of the authors
2. Complementarity: Information should support, not replace, the doctor-patient relationship
3. Privacy: Respect the privacy and confidentiality of personal data submitted to the site by the visitor
4. Attribution: Cite the source(s) of published information, date medical and health pages
5. Justifiability: Site must back up claims relating to benefits and performance
6. Transparency: Accessible presentation, accurate email contact
7. Financial disclosure: Identify funding sources
8. Advertising policy: Clearly distinguish advertising from editorial content

The Health on the Net criteria may be most useful for clinicians considering whether to refer patients to a given site. For consumers' own use, the Medical Library Association offers a suite of resources to guide consumers through the maze of good and not-so-good health information to be found on the Internet, available at http://mlanet.org/resources/consumr_index.html. These include a guide to finding and evaluating health information, examples of excellent sites, and aids to deciphering medical terminology. Resources are available in English and Spanish.

In addition to the potential harm that consumers may incur by relying on poor sources of information, they may suffer adverse effects related to the frequency of using the Internet for health information. Bessière, Pressman, Kiesler, and Kraut (2010) analyzed longitudinal data from a US national panel survey conducted from 2000 to 2002. The 740 respondents reported in three successive surveys how frequently they used the Internet for various purposes and whether they had or were caring for anyone who had any of 13 serious illnesses. In addition, they responded to a 12-item version of the Center for Epidemiologic Studies Depression Scale (CES-D). In the first and third surveys, they were also asked to rank their general health from 1 (poor) to 5 (excellent). Irrespective of caregiver status and the level of personal health, and with no

reported change in general health, those who increased the frequency of their Internet use for seeking health information from 3-5 days per week to daily experienced a slight but statistically significant increase in depressive symptoms. Those who increased their frequency of Internet use for communicating with friends and family experienced a slight decrease in depressive symptoms. Other types of Internet usage (shopping, seeking entertainment and escape, retrieving and using non-health information, and communicating in online groups and to meet new people) were not associated with any change in depressive symptoms. Bessièrè et al. suggested that the increase in using the Internet for health information might have been associated with more rumination about health issues, or with receiving poor health information or advice, thus giving rise to an increase in depressive symptoms. From these findings, the Consumer eHealth Work Group infers that consumers who frequently use the Internet for health information outside the context of a therapeutic alliance with healthcare professionals may risk an increase in depressive symptoms.

Chan, Ghose, and Ansari (2012) examined self-disclosure of mentally ill patients using a large, health-related social networking site. They found that persons were more likely to disclose health information when others disclosed more information, and when they themselves had been using the site for a longer period of time. They also found that disclosing personal health information more frequently was associated with a fall in self-reported physiological health scores. These findings suggest the possibility that consumers who frequently use online health-related social networking sites outside the context of a therapeutic alliance with healthcare professionals may risk an increase in physiologic symptoms.

A final concern about the use of Internet sites for recording and disclosing personal health information is the risk to the privacy and security of the information, including the risk of medical identity theft. Although consumers in the focus groups cited in the OpenNotes work expressed little concern about the privacy implications of ubiquitous devices to track their health parameters and behaviors, such devices are likely to record and store information that could be used against the consumers' best interests. Furthermore, it has recently been shown that insulin pumps are vulnerable to hacking (Associated Press, August 4, 2011). Other personal health monitoring and regulating devices might also cause harm if malefactors intrude electronically and change values.

7.0 Sociotechnical Strategies for Better Consumer eHealth

In its 2012 Report, *Health IT and Patient Safety: Building Safer Systems for Better Care* (p. 62), the Institute of Medicine used the following figure to illustrate the sociotechnical system of health IT-assisted care:

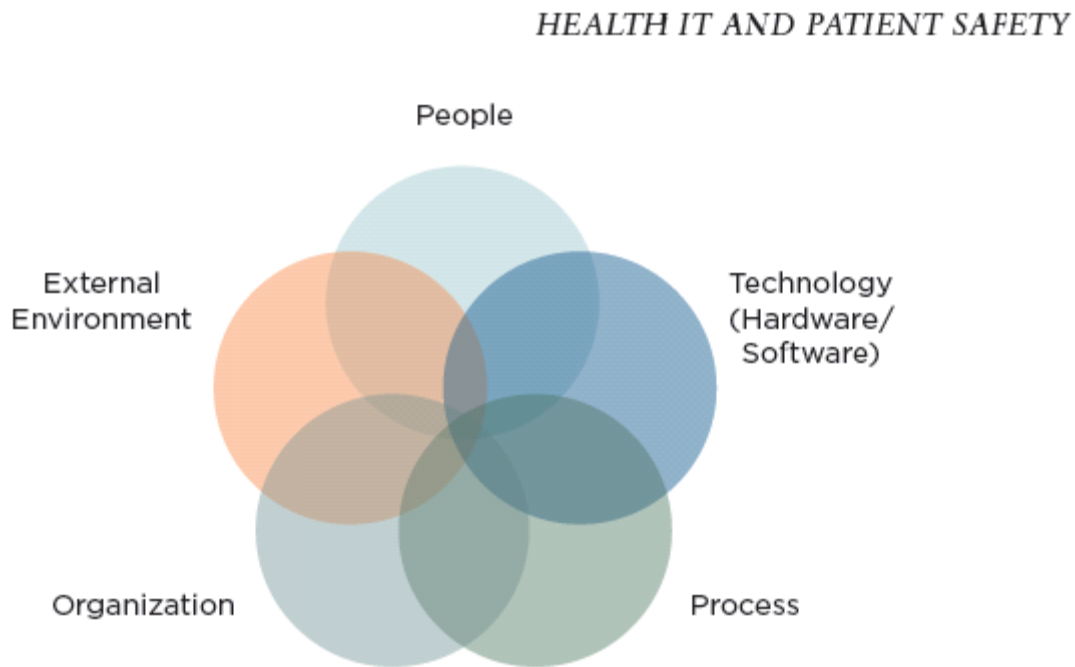


FIGURE 3-1
Sociotechnical system underlying health IT-related adverse events.

SOURCE: Adapted from Harrington et al. (2010), Sittig and Singh (2010), and Walker et al. (2008).

Reprinted with permission from “Health IT and Patient Safety: Building Safer Systems for Better Care” (2012) by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, D.C.

The IOM report described the five components from the perspective of a healthcare organization using information technologies to deliver services. The components can also be described from a consumer eHealth perspective.

“Consumer” as used here may apply to persons acting independently of healthcare professionals or to patients and their lay caregivers—often, but not necessarily, family members. Principles of patient-centered care would place the consumer at the very center of the figure, where all the components overlap.

Consumers in the sociotechnical eHealth system interact with other *people*: with clinicians, with lay caregivers, and with peer support groups. These interactions are intended to enhance the

consumers' engagement in shared decision-making and personal actions to improve their health and healthcare. Under certain circumstances, however, some interactions may frustrate and disengage the consumer or lead to misguided actions.

Consumers also interact with *the hardware and software* of health information technologies. Well designed, user-friendly systems that take into account factors such as age, illness, and disability can and do support consumers in taking appropriate health actions. Systems that are not based on user-centered design principles can make it harder for consumers to act in the interests of their health.

Consumers use *processes* to perform healthcare actions. Well designed electronic resources can make it easier for individuals and their lay caregivers to monitor and track health behaviors, health parameters such as weight and blood pressure, and progress toward their health goals. Tools that entail difficult procedures or require extra work, such as re-entering data previously provided, can discourage and disengage consumers. Clinicians also use processes to care for patients. The clinical workflow of ambulatory visits has not typically allowed for reviewing and discussing records kept by patients or their lay caregivers. Redesigned processes may be needed to capitalize on patient engagement.

Consumers obtain healthcare through *organizations* that vary in their support for engaging patients through eHealth strategies. Organizations put into place the policies, procedures, and technologies whereby clinicians respond to patient-generated information, questions, and concerns. Organizational roles and procedures are required to assure that communications from patients are triaged to the appropriate person and receive a prompt response. Organizational values and resources may support to varying degrees the work of reviewing records generated by patients and their lay caregivers and providing health coaching.

Consumers interact with an *external environment* that influences their interactions with all the other components of the system. One dimension of the external environment is the *culture of health and healthcare*. The healthcare culture of the 20th century was predominantly one in which doctors issued “orders” and patients were expected to “comply.” Many forces in the 21st century are combining to reshape the culture into a more collaborative model, where well informed, engaged patients confer with their clinicians to reach mutual decisions about health actions. Both clinicians and consumers vary in their preferences for patient participation in healthcare and health decisions; mismatched preferences and expectations can disrupt care relationships and processes. Another critical dimension of the external environment in this context is *the nature and quality of health information and advice available* through the Internet and other eHealth resources. Consumers may find evidence-based information tailored to their needs, baseless claims motivated by the search for profits, and almost anything else. Internet-based peer groups may provide excellent advice and support or the contrary. Clinicians may direct patients and their lay caregivers toward valid and reliable resources, but they cannot control what consumers may find in the environment. A third dimension of the external environment concerns the *privacy and security of the information consumers generate* about

their health. Once the information exists in electronic form, it is susceptible to disclosure to the external environment. Strong policy and technological protections can shield the information, but individuals may increase vulnerabilities without fully grasping the consequences.

For building better eHealth strategies, it is useful to consider the potential unintended, adverse consequences that may arise as consumers interact with each component of the sociotechnical system and actions that can be taken to prevent or mitigate the adverse events.

7.1 Consumer eHealth and Interactions between Consumers and Clinicians

As consumers interact with healthcare professionals and lay caregivers in the context of a changing culture of care, a number of unintended consequences may arise. Some of these are described below, along with mitigating strategies and questions for research.

7.1.1 Dissonance between the expectations of providers, employers, and payers that patients will use eHealth resources to engage in health decisions and actions and the willingness or ability of patients and lay caregivers to do so. Some patients may not be ready, willing, or able to take an active role in making decisions and changing health behaviors to improve their health or healthcare (Park & Kim, 2012). This lack of engagement may stem from health challenges and disabilities or from locus of control and self-efficacy states that do not support self-care actions and the use of electronic resources (Bandura, 1977; Strecher et al., 1986; Coughlin et al., 2000; Neil & Paul, 2001). The AHRQ “Guide to Patient and Family Engagement” (2012) reported that patients with higher self-efficacy were twice as likely to engage with providers in promoting safety.

Strategies for Success:

- Healthcare professionals should tailor communications and expectations to the patients’ preferences and abilities.
- Screening tools for locus and control of self-efficacy might help healthcare professionals to understand and respond appropriately to patients who do not move toward greater engagement when given the opportunity to participate more actively in their own care. Tools with demonstrated validity in an elderly, low-income population (Chu, Huber, Mastel-Smith, & Cesario, 2009) include the Computer Anxiety Subscale and The Computer Confidence Subscale of the Computer Attitudes Scale (Gressard & Lloyd, 1986) and the Computer Self-Efficacy Measure (Campbell, 2004).

Questions for Research:

- How do locus of control and self-efficacy affect adoption of self-care practices and use of electronic health information resources?
- Do interventions designed to enhance internal locus of control and to increase self-efficacy affect adoption of self-care practices and/or use of electronic health information resources?

7.1.2 Increased patient anxiety or confusion arising from the discovery of inaccurate, misleading, ambiguous, poorly contextualized, or unwelcome information in the electronic health record (EHR). When patients and their lay caregivers are given access to information in the EHR, they may have difficulty interpreting what they read there, or they may discover negative, sensitive, or frightening information (Delbanco et al., 2010; Caligtan et al., 2012; Pew Internet & American Life Project, 2012). As a result, their relationship with other members of the care team may be disrupted (Delbanco, Walker, et al., 2010; Kurki et al., 2011; Walker, Leveille, et al., 2011; Vawdrey et al., 2011; Beard et al., 2012; Chan et al., 2012).

Strategies for Success:

- Clinicians who give patients and lay caregivers access to information from the EHR should implement processes whereby the patients and lay caregivers can comfortably communicate their questions and concerns and receive timely and respectful responses.
- Consumers would benefit from a guide to understanding and interpreting information from the EHR.
- Clinicians would benefit from a guide to best practices in communicating with patients regarding information in the EHR.

Questions for Research:

- How does access to the EHR affect the relationship between the patient and the other members of the healthcare team?
- What processes are most beneficial in helping patients and lay caregivers to understand the information in the EHR and use it to improve their health and healthcare?

7.1.3 Disruption of the relationship between patients and lay caregivers and other members of the care team arising from the provider's delay or denial of access to information in the EHR or the provider's inattention to patient-generated health records and concerns.

When patients and lay caregivers engage in using the EHR to monitor health information, they become frustrated if the provider delays or denies access to information that they want (Reti et al., 2010; Krist & Woolf, 2011; Zulman et al., 2011; Beard et al., 2012). Similarly, if patients and lay caregivers have carefully kept journals or other records of their health parameters and behaviors, they expect that the healthcare professionals on their team will review and comment on the records. When this does not happen, patients and lay caregivers lose confidence in the clinicians and become less engaged in their own care (Wald et al., 2009; Bear et al., 2012).

Strategies for Success:

- Clinicians should read and use the guide to patient-centeredness of electronic communications between healthcare professionals and patients and lay caregivers provided by Reti et al. (2012).

- The AHRQ “Guide to Patient and Family Engagement” (2012) cites interventions leading to more effective, patient-centered communication by physicians.

Questions for Research:

- How can providers effectively manage the expectations of patients and lay caregivers with regard to electronic communications so that all are satisfied?
- What designs for journals and other health records best facilitate entry of information by patients and lay caregivers and review by healthcare professionals?

7.1.4 Dissonance between expectations of patients and lay caregivers based on schedule information in the EHR and actual delivery of medications and care activities.

When patients and lay caregivers have access to information in the EHR about the schedule of medications, treatments, and other services, they expect the performance of their care team to match the schedule, unaware of the many events and uncertainties that may cause variation in the plan (Caligtan et al., 2012). When activities do not occur according to the schedule, patients and lay caregivers may experience distress and may even disrupt the clinical workflow by demanding care activities according to the schedule.

Strategies for Success:

- Designers of applications that will give patients and lay caregivers access to scheduling information should allow options for displaying ranges of time for scheduled events to promote realistic expectations.

Questions for Research:

- What events cause disruptions in the schedule of care activities?
- At what point, and for which care activities, does variation from the scheduled time begin to risk harm to the patient?

7.1.5 Healthcare professionals’ discomfort with patient and lay caregiver scrutiny of records, notes, and actions.

When patients and lay caregivers discover unwelcome information in the EHR or criticize healthcare professionals because their actions do not meet expectations, the professionals suffer discomfort. In addition, clinicians are sometimes concerned that the reaction of patients and lay caregivers to sensitive information may lead to harm. These concerns continue to motivate healthcare professionals to shield some if not all information in the EHR from perusal by patients and lay caregivers (Delbanco et al., 2010, Walker et al., 2011; Vawdrey et al., 2011, Beard et al., 2012).

Strategies for Success:

- Strategies for helping clinicians and patients to interact appropriately over information in the EHR can be found at “Increase Patient Participation with Health IT,” <http://www.healthit.gov/providers-professionals/patient-participation>.

Questions for Research:

- How does access to information in the EHR affect the roles and relationships of clinicians, patients, and lay caregivers?
- How do patients and lay caregivers vary in their desire for information from the EHR, and what factors affect this variation? How do they use the information they glean from the EHR?

7.1.6 Unwelcome loss of clinician power and authority as patients take more responsibility for health decisions and actions. Just as some patients may not be ready for full engagement in their health, some clinicians may find it difficult to give up their traditional power and authority (Walker et al., 2009; Kurki et al., 2011). Clinicians may be genuinely concerned that patients and lay caregivers will make suboptimal decisions.

Strategies for Success:

- Clinicians should negotiate health decisions with patients and lay caregivers with recognition for their autonomy and with consideration for the levels and types of engagement that meet their needs, abilities, and preferences.

Questions for Research:

- How do strategies that increase patient engagement affect the job satisfaction of clinicians?
- How does the integration of consumer eHealth strategies into a clinical practice affect the way clinicians define their roles?

7.2 Hardware and Software Issues in Consumer eHealth

Consumer eHealth strategies depend for their effectiveness on the quality of the hardware and software that support them. Unintended consequences arise when the hardware and software are not tailored to the user's needs and abilities or are not accessible. Some of these unintended consequences, with mitigating strategies and research questions, are described below.

7.2.1 Redistribution of health information management tasks to patients and their lay caregivers without tailoring to their needs, abilities, and preferences. If clinicians expect that all patients and lay caregivers will use eHealth tools (even those who may not have the time, energy, or ability), eHealth strategies will fail. The ability of people to benefit from eHealth resources may be limited by their health literacy, decreased vision, limited education, poverty, chronic illness or disability, or lack of access or skills (Caligtan et al., 2012; Pew Internet & American Life Project, 2012; van Deursen, 2012). Determining which tools will be useful for particular individuals requires careful assessment (Dedding et al., 2011).

Strategies for Success:

- Clinicians would benefit from guidelines for distributing roles and responsibilities among members of the care team, including the patient and any lay caregivers, with consideration for patient and caregiver needs, abilities, and preferences.

- A list of validated assessment tools can be found in the W. K. Kellogg Report, “Patient-Centered Care for Underserved Populations: Definition and Best Practices.” See <http://hsc.unm.edu/community/toolkit/docs8/Overview.pdf>.
- Persons who cannot use computers may benefit from telemedicine (Kaufman et al., 2003) or cell phones, especially smart phones, for promoting engagement in their health (Chan & Kaufman, 2009; PwC, 2012).

Questions for Research:

- What factors influence the ability of people to use eHealth tools?
- What design considerations are important when creating consumer eHealth tools for targeted populations where particular chronic illnesses are present?
- How can education and communication tools be designed to serve the full range of individual preferences and abilities?

7.2.2 Decreased participation in self-care because of problems with access, usability, or comfort with using eHealth tools. Patients and lay caregivers who are unable to use eHealth tools may disengage from self-care unless they are offered other means of engagement (McCarrier et al., 2009; Nielsen et al., 2012).

Strategies for Success:

- For those who would like to use eHealth tools but lack skills, AHIMA’s “My PHR” site offers education designed for consumers. See <http://www.myphr.com/Default.aspx>.
- For those whose preferences, abilities, or access preclude using electronic resources, clinicians should provide non-electronic options for education and communications to support self-care. Examples might include print materials, group classes, and telephone counseling.
- Clinicians should also be aware of the educational materials designed for consumers and available to print through MedlinePlus and other reliable sources.

Questions for Research:

- What clinical processes are effective in promoting self-care?
- What are effective user-centered design principles for eHealth applications?

7.2.3 Increase in physiological or depressive symptoms brought on by too frequent use of the Internet for health information and peer support. Increasing frequency of Internet use for health information has been associated with an increase in depressive symptoms (Bessière et al., 2010), and increasing frequency of disclosing personal health information in peer support sites has been associated with an increase in physiological symptoms (Chan, Ghose, and Ansari, 2012).

Strategies for Success:

- Clinicians should ask patients and lay caregivers about their use of the Internet for health information and peer support and should monitor for adverse effects.

Questions for Research:

- What population characteristics are associated with benefits or adverse effects from using the Internet for health information and peer support?

- What types of Internet use are associated with benefits or adverse effects?

7.2.4 Cognitive overload, confusion, or anxiety brought on by usability problems or excessive information. When patients are given access to information in the EHR without consideration for their state of health or technological skills, they may be overwhelmed (Caligton et al., 2012; Pew Internet and American Life Project, 2012).

Strategies for Success:

- Clinicians should assess the preferences and abilities of patients and lay caregivers with regard to recording and receiving health data, managing information, and communicating. They can find validated assessment tools in the W. K. Kellogg Report, “Patient-Centered Care for Underserved Populations,” available at <http://hsc.unm.edu/community/toolkit/docs8/Overview.pdf>.
- Clinicians should select applications to give patients and lay caregivers access to the EHR that are designed according to user-centered principles and that provide resources (Infobuttons being one example) to “layer” the information for contextually appropriate retrieval as needed.

Questions for Research:

- How much information, and what types of information, are different populations of patients able to process (e.g., hospitalized, chronically ill, elderly)?
- What types of information do specific populations want, and when do they want it? What types of information do they prefer to avoid?
- How can tools be designed for selective disclosure of information to reduce overload?

7.2.5 Suboptimal clinical decisions based on information provided by patients and lay caregivers. Whether or not eHealth resources are used, there is a risk that patients and lay caregivers may deliberately or inadvertently provide clinicians with incomplete or inaccurate information, resulting in suboptimal clinical decisions. When patients and lay caregivers use electronic journals or monitoring devices to track and report their health behaviors and parameters, the problem may be compounded by excessive or disorganized information (Do et al., 2010).

Strategies for Success:

- Principles of user-centered design are especially important when creating or selecting applications that enable lay people to monitor and track their health behaviors and parameters. Ease of use is important both for the entry of information (to assure completeness, accuracy, and consistency) and for the retrieval and review by clinicians. Critical values and trends should be discernible at a glance.

Questions for Research:

- How can tools be designed to encourage consistent, accurate monitoring and recording of health behaviors and parameters?

- What visual presentations of information are most readily comprehended by clinicians?

7.2.6 Increased healthcare disparities across races and ethnicities. The goal of consumer eHealth initiatives is to improve the health and healthcare of all people by engaging them in their care. Such initiatives can be effective, however, only if people can and do use the technologies. A number of studies have shown lower use of Internet-based health resources by African-Americans and Hispanics, irrespective of education and income (Roblin et al., 2009; Sarker et al., 2011; Alemagno & Kenne, 2012; Beard et al., 2012; Haase & Loiselle, 2012; Pew Internet and American Life Project, 2012). If clinicians rely excessively on eHealth tools for patient education and engagement in better health practices, they risk adding to racial and ethnic disparities in health and healthcare.

Strategies for Success:

- Clinicians must continue to provide options other than computer usage for education and communications to support self-care. Examples include print materials, group classes, telephone counseling, text messaging to phones, and use of smart phone applications.
- All interventions, whether computer-based or otherwise, should be tailored to the language, culture, and literacy of the patient and any lay caregivers. Two resources for clinicians are “National Standards on Culturally and Linguistically Appropriate Services (CLAS)” available at <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15> and the W. K. Kellogg report, “Patient-Centered Care for Underserved Populations: Definition and Best Practices,” available at <http://hsc.unm.edu/community/toolkit/docs8/Overview.pdf>.

Questions for Research:

- How can mobile phones (a technology widely adopted by racial and ethnic minorities) be used to foster effective self-care?
- Which strategies are most effective for promoting effective self-care in particular ethnic or racial populations?

7.3 Consumer eHealth and Clinical and Self-Care Processes

The introduction of consumer eHealth strategies alters both clinical and self-care processes, ideally in ways that improve healthcare and promote the engagement of patients and lay caregivers in managing their health. An overreliance on eHealth tools without full understanding, however, can produce negative unintended consequences. Four of these are described below, along with mitigating strategies and related questions for research.

7.3.1 Insufficient attention by clinicians to the needs and preferences of patients and lay caregivers for health education and guidance. If providers assume that patients and their lay caregivers will find all the information and guidance they need from eHealth

resources, educational needs may go unmet (Simon et al., 2011; Kurki et al., 2011). Like any other educational medium, eHealth resources vary in quality, usability, and use by patients (Yu et al., 2012).

Strategies for Success:

- When clinicians decide to use eHealth resources to promote the engagement of patients and lay caregivers, they need to put in place assessment tools and processes to determine preferences and abilities. The tools in the Kellogg Report have already been referenced several times:
<http://hsc.unm.edu/community/toolkit/docs8/Overview.pdf>.
- Clinicians should be aware of reliable sources of health information tailored to lay people, such as MedlinePlus and the sites of respected healthcare organizations, and they should provide the education in the modality that best suits the learner—electronic, print, or face-to-face, for example.
- For patients and lay caregivers who wish to seek health information on the Internet, clinicians should make available the Medical Library Association’s “Consumer Guidance for Evaluating Health Information,” available at
http://mlanet.org/resources/consumr_index.html.

Questions for Research:

- What clinical processes are most effective for assessing and meeting the educational needs of patients and lay caregivers?
- What educational practices are effective for enabling patients and lay caregivers to become adept at finding and evaluating pertinent health information on the Internet?

7.3.2 Delayed, missed, or misunderstood communications. Secure messaging provides a means whereby patients and their lay caregivers can manage appointments, request prescription refills, provide information, or ask questions. This modality, however, also carries the risks that a message may be missed, that a response may be delayed, or that either party misunderstands what the other was attempting to communicate.

Strategies for Success:

- Healthcare organizations that are new to eHealth strategies should consult with more experienced colleagues and review the literature to discover lessons learned and best practices (Silvestre, Sue, & Allen, 2009).
- When clinicians introduce secure messaging, they should put in place processes for monitoring incoming messages, triaging them to the appropriate member of the staff, and assuring timely responses. Often this function is assumed by the staff member who has had the role of telephone advice nurse.
- Clinicians should educate patients and lay caregivers on the proper use of secure messaging, emphasizing that it is not for urgent communications (Mittal et al., 2010).

Questions for Research:

- How do patients and lay caregivers use the secure messaging function?
- What is the impact of secure messaging on the satisfaction of patients and lay caregivers?
- How does the introduction of secure messaging affect the roles, responsibilities, workloads and job satisfaction of each staff member in an ambulatory care practice?

7.3.3 Neglect of error-prevention tasks because of misplaced confidence in EHRs and other eHealth tools. Clinicians often have only a superficial understanding of how electronic health records and other eHealth tools function. Consequently, they may misinterpret what they see on a screen (for example, thinking that pharmacy inventories are dosing recommendations) or assume that they have received a complete report because they are mistakenly relying on a level of interoperability that does not exist (Siek et al., 2011).

Strategies for Success:

- Clinicians and healthcare organizations should adopt and use the SAFER checklists currently under development by Ash, Singh, and Sittig.

Questions for Research:

- What is the effect of implementing the SAFER checklists on clinicians' perceptions of the safety of eHealth resources?
- To what degree will policies and procedures be modified based on the SAFER checklists?
- To what degree will clinical errors be reduced following implementation of the SAFER checklists?

7.4 Consumer eHealth and Healthcare Organizations

The integration of consumer eHealth strategies into clinical processes is intended to support patient-centered care. Patient-centeredness is a long-held value in healthcare, and its importance has been increasingly recognized since its description in the Institute of Medicine's 2001 report, *Crossing the Quality Chasm*. For many healthcare organizations, therefore, patient-centeredness is at the core of clinical and business processes. For others, however, adopting patient-centered care processes adds to the complexity of introducing consumer eHealth strategies. Some of the potential unintended consequences, along with associated mitigating strategies and research questions, are described below.

7.4.1 Loss of revenue to providers with a fee-for-service payment model. Organizations (from small practices to complex health systems) that are limited to a fee-for-service model will be disadvantaged as they employ eHealth and other patient-centered strategies that result in fewer office visits and less hospital care (Chen et al., 2009; Weppner et al., 2010). Furthermore, time spent responding to patient messages, reviewing patient journals, and providing health coaching may not be reimbursable under fee-for-service

rules, and may limit the time available for reimbursable services (Wald et al., 2009; Walker, Leveille, et al., 2011; Haase & Loiselle, 2012). Indeed, standard codes do not exist for recording many wellness and health management services, especially those provided in home and community settings (Hägglund et al., 2011).

Strategies for Success:

- Although fee-for-service business models have been predominant in the United States, many forces are combining in a cultural change to encourage providers to shift to other service delivery and payment models, such as accountable care organizations and pay for performance, that reward healthcare organizations for strategies that promote better outcomes.
- For documenting services that promote engagement of patients and lay caregivers, clinicians and healthcare organizations should employ data and terminology standards when available. For example, HIT SP 03, “Consumer Empowerment: The Consumer Empowerment and Access to Clinical Information via Networks Interoperability Specification” defines specific standards needed to assist patients in making decisions regarding care and healthy lifestyles. See http://www.hitsp.org/interoperabilitySet_Details.aspx?MasterIS=true&InteroperabilityID=50&PrefixAlpha=1&APrefix=IS&PrefixNumeric=03.

Questions for Research:

- What is the impact of consumer eHealth and other patient-centered strategies on costs and revenues in healthcare organizations?
- What data and terminology standards are needed to record health, illness, and care phenomena in the home and community, including self-care and dependent care?

7.4.2 Change in roles, responsibilities, and clinical workflow and increased time requirements to monitor and respond to patient messages and to review and discuss patient-generated information. Introducing new modes of communication between patients and clinicians requires new roles and responsibilities to assure that messages are monitored, triaged to the appropriate staff member, and responded to promptly (Reti et al., 2010; Beard et al., 2012). In addition, the clinical encounter must be redesigned to incorporate review and discussion of patient-generated records of health behaviors and parameters, with consideration for whether such review and discussion is best managed face-to-face or by secure messaging (Wald et al., 2009; Walker, Leveille, et al., 2011; Haase & Loiselle, 2012).

Strategies for Success:

- Healthcare organizations that are new to eHealth strategies should consult with more experienced colleagues and review the literature to discover lessons learned and best practices (Silvestre, Sue, & Allen, 2009).

- Healthcare organizations from small practices to complex systems should implement a process to monitor and triage patient messages and assure a timely response. This may be managed by nurses or physician assistants, who can respond within their scope of practice, much as telephone advice nurses have done.
- Nurses and physician assistants may also have appropriate skills to manage much of the review and response to patient-generated information, and to bring important deviations or successes to the attention of the physician.

Questions for Research:

- What are the most efficacious and cost-effective models for monitoring, triaging, and responding to patient messages?
- What are the most efficacious and cost-effective ways to review information generated by patients and lay caregivers, to assess their self-management needs and concerns, and to provide health coaching? What types of healthcare professionals can best provide these services?

7.4.3 Increased time and expense to healthcare organizations to identify and provide appropriate educational resources to promote engagement in personal health management by patients and lay care-givers, including both eHealth resources and other modes of education. Consumers and patients differ in their use of eHealth resources based on race, ethnicity, access, ability, and personal preferences (McCarrier et al., 2009; Weppner et al., 2010; Sarkar et al., 2011; Simon et al., 2011; van Deursen, 2012). Consequently, the burden is on healthcare organizations to provide actionable, personally engaging education about personal health management for diverse populations, using modalities that suit individual preferences and abilities.

Strategies for Success:

- The National Library of Medicine offers the option to generate patient educational materials directly from codes in the EHR through MedlinePlus/Connect. Materials are available in English and in Spanish, and they may be perused on screen or printed.
- Clinicians should write educational “prescriptions” to MedlinePlus and other reliable sources such as trusted healthcare organizations for patients and lay caregivers who can and do use computer-based resources. Resources such as these provide content targeted to the lay public that clinicians can use in individual or group teaching.

Questions for Research:

- What are the relative benefits and costs of various educational strategies with different patient populations?
- How can these strategies inform the design of high quality, high efficiency care processes?

- How effective are specific mobile apps in helping individuals and lay caregivers to manage common chronic illnesses?
- What are the most efficacious and cost-effective models (e.g., device/hardware, software, decision support/content) for delivering tailored patient educational materials to support self-care and health management?

7.4.4 Waste of time and resources on poorly designed eHealth resources that have little impact on patient decisions and self-management. The marketplace and the Internet contain many poorly designed tools for health education and personal health management (Ossebaard et al., 2012). Healthcare organizations can ill afford to waste resources on ineffective strategies.

Strategies for Success:

- The Agency for Healthcare Research and Quality (AHRQ) offers a guide to sources of reliable, well designed, and validated educational resources and self management tools. See http://healthit.ahrq.gov/portal/server.pt/community/health_it_tools_and_resources/919/usability.

Questions for Research:

- What attributes of eHealth resources are associated with improved patient engagement, decision making, and self management behaviors?
- Which strategies are most effective for particular populations?

7.5 Consumer eHealth and the External Environment

This report has already described how changes in an important component of the external environment, the culture of health and healthcare, are affecting the interactions of consumers/patients and lay caregivers with clinicians, with eHealth tools, with clinical and self-care processes, and with healthcare organizations. Other components of the external environment, the nature and quality of health information available to consumers and lay caregivers and the privacy and security of information generated by consumers and lay caregivers, can also have unintended consequences. Some of those consequences and related mitigating strategies and research questions are described below.

7.5.1 Frustration, disengagement, or counterproductive self-care actions based on poor sources of information and advice found on the Internet. Health information and self-management tools available on the Internet vary widely in quality and usability (Krist & Woolf, 2011; Nielsen et al., 2012; Ossebaard et al., 2012; Yu et al., 2012), and consumers may have limited ability to distinguish the excellent from the specious, or to adapt even excellent information to their unique and dynamic needs (Weitzman et al., 2011; Beard et al., 2012; van Deursen, 2012).

Strategies for Success:

- Federal and state agencies, healthcare organizations, and others concerned with promoting consumer eHealth should point consumers toward the

excellent consumer guidance for evaluating health information available from the Medical Library Association. See

http://mlanet.org/resources/consumr_index.html.

- Clinicians should ask patients and lay caregivers what sources of health information they are using to guide self-care and what actions they are taking, and discuss the wisdom or otherwise of the information and actions.

Questions for Research:

- What approaches are effective for teaching patients of diverse health and demographic status to evaluate information in the context of their own needs?
- Can tools be developed to tailor information automatically to individual consumers'/patients'/ situations?
- Can tools help consumers, patients, and lay caregivers to assess the quality and relevance of the information they find?

7.5.2 Risk of privacy breaches to health information recorded by consumers, patients, and lay caregivers, resulting in unauthorized or inappropriate disclosure of information or medical identity theft.

Although regulations under HIPAA provide significant protections to the privacy and security of health information, gaps remain, particularly with regard to information individuals record outside the context of a healthcare organization. Recent reports indicate that medical devices themselves can be hacked. In addition, consumers, patients, and lay caregivers may lack awareness of risks and of appropriate actions to improve security (Walker et al., 2009; Beard et al., 2012; Caligtan et al., 2012). Mashima & Ahamad (2012) proposed integrating into the architecture of EHRs, PHRs, and other eHealth tools a monitoring agent that will log every access to a patient's information and that can be queried at will by the patient or a trusted delegate, such as the physician.

Strategies for Success:

- As consumer eHealth expands, the sources and modes of transmission of personally identifiable health information proliferate. Federal agencies should consider strategies for gaps in privacy and security protections, such as encouraging transparency regarding data practices. The PHR Model Privacy Notice (<http://www.healthit.gov/policy-researchers-implementers/personal-health-record-phr-model-privacy-notice>) is a tool for this, and more widespread use of it should be encouraged.
- Clinicians and healthcare organizations would benefit from a directory of validated educational resources about privacy and security designed for different audiences.
- Federal and state agencies, healthcare organizations, clinicians, and others concerned with the privacy and security of health information should point patients and consumers to the HHS Health Information Privacy Website for Consumers/ Patients at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html>.
- For concerns about medical identity theft, the same entities should direct patients and consumers to the Federal Trade Commission Consumer

Protection Fact Sheet: Medical Identity Theft available at <http://www.ftc.gov/bcp/edu/pubs/consumer/idtheft/idt10.shtm>.

- The forthcoming SAFER checklists being developed by Ash, Singh, and Sittig will guide healthcare organizations with regard to security of information.

Questions for Research:

- What are best practices for informing patients and lay caregivers about security risks and protections related to their health information?
- How can explanations be adapted effectively to the patient’s and lay caregiver’s literacy, culture, and other relevant variables?
- What behaviors of consumers, patients, and lay caregivers are associated with medical identity theft? What behaviors of consumers, patients, and lay caregivers are protective against medical identity theft?

8.0 Summary of Strategies for Better Consumer eHealth

8.1 Achieving Better Communication and Collaboration

Strategies for Better Communication and Collaboration	Unintended Consequences Prevented or Mitigated
<p>7.1.1 Clinicians should use screening tools for locus of control and self-efficacy to assess the readiness of patients and lay caregivers to engage in health management and use of eHealth resources. The Computer Anxiety Subscale and the Computer Confidence Subscale of the Computer Attitudes Scale (Gressard & Lloyd, 1986) and the Computer Self-Efficacy Measure (Campbell, 2004) have been used successfully in an elderly, low-income population (Chu et al., 2009).</p>	<p>7.1.1 Dissonance between expectations that patients and lay caregivers will use eHealth resources and their willingness or ability to do so</p>
<p>7.2.1 and 7.3.1 Clinicians should use validated tools for assessing the needs, abilities, and preferences of patients and lay caregivers for participation in healthcare and use of eHealth resources. Such tools are available from the W. K. Kellogg report, “Patient-Centered Care for Underserved Populations: Definition and Best Practices” at http://hsc.unm.edu/community/toolkit/docs8/Overview.pdf.</p>	<p>7.1.1 Dissonance between expectations that patients and lay caregivers will use eHealth resources and their willingness or ability to do so</p> <p>7.2.1 Redistribution of health information management tasks to patients and their lay caregivers without tailoring to their needs, abilities, and preferences</p> <p>7.3.1 Insufficient attention by clinicians to the needs and preferences of patients and lay caregivers for health education and guidance</p>

Strategies for Better Communication and Collaboration	Unintended Consequences Prevented or Mitigated
<p>7.2.6 For guidance on tailoring interventions to the language, culture, and literacy of the patient and lay caregivers, clinicians should consult “National Standards on Culturally and Linguistically Appropriate Services (CLAS) at http://minorityhealth.hhs.gov/templates/browse.aspx?lvl-2&lolID=15.</p>	<p>7.1.1 Dissonance between expectations that patients and lay caregivers will use eHealth resources and their willingness or ability to do so</p> <p>7.2.1 Redistribution of health information management tasks to patients and their lay caregivers without tailoring to their needs, abilities, and preferences</p> <p>7.3.1 Insufficient attention by clinicians to the needs and preferences of patients and lay caregivers for health education and guidance</p> <p>7.2.4 Cognitive overload, confusion, or anxiety for patients and lay caregivers, brought on by usability problems or excessive information</p> <p>7.2.6 Increased healthcare disparities across races and ethnicities</p>
<p>7.2.4 and 7.2.5 Clinicians and consumers should select eHealth tools for use by patients and lay caregivers that apply principles of user-centered design to assure ease of use in both data entry and data retrieval and review.</p>	<p>7.2.4 Cognitive overload, confusion, or anxiety for patients and lay caregivers, brought on by usability problems or excessive information</p> <p>7.2.2 Decreased participation in self-care because of problems with access, usability, or comfort with using eHealth tools</p> <p>7.2.4 Suboptimal clinical decisions based on information provided by patients and lay caregivers, including excessive or disorganized information</p>
<p>7.2.1 and 7.2.2 Clinicians should obtain valid health education materials available from MedlinePlus and other trusted sources (some available in Spanish or English) and present the education in a mode adapted to the learner’s needs, abilities, and preferences (for example, print, oral discussion, group classes, demonstrations, etc.).</p> <p>7.4.3 Clinicians and healthcare organizations should make use of MedlinePlus/Connect, available from the National Library of Medicine, to generate patient-specific information from codes in the EHR, saving time and resources for the provider or healthcare organization.</p> <p>7.1.1 Clinicians should consider the use of telemedicine (Kaufman et al., 2003) or mobile devices (Chan & Kaufman, 2009) to assist persons who cannot use computers.</p>	<p>7.1.1 Dissonance between expectations that patients and lay caregivers will use eHealth resources and their willingness or ability to do so</p> <p>7.2.1 Redistribution of health information management tasks to patients and their lay caregivers without tailoring to their needs, abilities, and preferences</p> <p>7.3.1 Insufficient attention by clinicians to the needs and preferences of patients and lay caregivers for health education and guidance</p> <p>7.2.4 Cognitive overload, confusion, or anxiety for patients and lay caregivers, brought on by usability problems or excessive information</p> <p>7.2.2 Decreased participation in self-care because of problems with access, usability, or comfort with using eHealth tools</p> <p>7.2.6 Increased healthcare disparities across races and ethnicities</p>

Strategies for Better Communication and Collaboration	Unintended Consequences Prevented or Mitigated
<p>7.1.3 For guidance on increasing the patient-centeredness of electronic communications, clinicians should read Reti et al., 2012.</p> <p>7.1.3. Clinicians and healthcare organizations should use educational interventions for clinicians that lead to more effective, patient-centered communications, as cited in the AHRQ “Guide to Patient and Family Engagement” (2012).</p>	<p>7.2.2 Decreased participation in self-care because of problems with access, usability, or comfort with using eHealth tools</p> <p>7.3.1 Insufficient attention by clinicians to the needs and preferences of patients and lay caregivers for health education and guidance</p> <p>7.2.6 Increased healthcare disparities across races and ethnicities</p> <p>7.4.3 Increased time and expense to healthcare organizations to identify and provide appropriate educational resources to promote engagement in personal health management by patients and lay caregivers, including both eHealth resources and other modes of education</p>
<p>7.3.2 Clinicians should educate patients and lay caregivers on the appropriate use of secure messaging, including that it is not for urgent matters.</p>	<p>7.3.2 Delayed, missed, or misunderstood communications</p>
<p>7.1.4 For guidance on assisting patients and lay caregivers to understand and interpret information in the EHR, clinicians should consult “Increase Patient Participation with Health IT” at http://www.healthit.gov/providers-professionals/patient-participation</p> <p>7.1.2 Clinicians should initiate processes for patients and lay caregivers to raise questions about EHRs, PHRs, and other eHealth resources and to receive timely responses.</p> <p>7.1.2 Clinicians should direct patients and lay caregivers to a consumer guide to understanding and interpreting information from the EHR: see “Health IT.gov—Patients and Families” at http://www.healthit.gov/patients-families</p> <p>7.2.1 Clinicians should direct patients and lay caregivers to a consumer guide to use of a personal health record. The American Health Information Management Association (AHIMA) offers “My PHR” at http://www.myphr.com/Default.aspx.</p>	<p>7.1.4 Dissonance between expectations of patients and lay caregivers based on schedule information in the EHR and actual delivery of medications and care activities</p> <p>7.1.5 Healthcare professionals’ discomfort with patient and lay caregiver scrutiny of records, notes, and actions</p> <p>7.2.1 Redistribution of health information management tasks to patients and their lay caregivers without tailoring to their needs, abilities, and preferences</p> <p>7.2.4 Cognitive overload, confusion, or anxiety for patients and lay caregivers, brought on by usability problems or excessive information</p>
<p>7.1.6 Clinicians should negotiate health decisions with patients and lay caregivers, recognizing the autonomy of patients and lay caregivers and considering levels and types of engagement that individuals desire.</p>	<p>7.1.6 Unwelcome loss of clinician power and authority as patients and lay caregivers take more responsibility for health decisions and actions</p>

8.2 Achieving Higher Quality of Care at Lower Cost

Strategies for Higher Quality of Care at Lower Cost	Unintended Consequences Prevented or Mitigated
<p>7.3.2. and 7.4.2 Healthcare organizations that are new to eHealth strategies should consult with more experienced colleagues and review the literature for lessons learned and best practices.</p> <p>7.3.2 and 7.4.2 Healthcare organizations, from small practices to complex systems, should implement a process for monitoring incoming messages, triaging them to the appropriate member of the staff, and assuring timely responses (often assigned to the person who has served as telephone advice nurse).</p> <p>7.3.2 Clinicians should educate patients and lay caregivers on the appropriate use of secure messaging, including that it is not for urgent matters.</p> <p>7.4.2 Healthcare organizations, from small practices to complex systems, should implement a process for reviewing and discussing records generated by patients and lay caregivers. This may be managed by nurses or physician assistants within their scope of practice. The AHRQ “Guide to Patient and Family Engagement” (2012) cites coaching or structured interviews immediately before the patient sees the physician as helping patients to formulate clear questions and increasing patient satisfaction. The same report cites shared care plans linked to the EHR as effective in helping all members of the care team (including patients and lay caregivers) communicate about health management, including management of chronic conditions.</p>	<p>7.3.2 Delayed, missed, or misunderstood communications</p> <p>7.4.2 Change in roles, responsibilities, and clinical workflow and increased time requirements to monitor and respond to messages and to review and discuss information generated by patients and lay caregivers</p> <p>7.3.1 Insufficient attention by clinicians to the needs and preferences of patients and lay caregivers for health education and guidance</p> <p>7.1.3 Disruption of the relationship between patients and lay caregivers and other members of the care team arising from the provider’s delay or denial of access to information in the EHR or the provider’s inattention to patient-generated health records and concerns</p>
<p>7.3.3 and 7.5.2 Clinicians and healthcare organizations should use the SAFER checklists currently under development by Ash, Singh, and Sittig to assure safe and secure use of EHRs, PHRs, and other eHealth resources.</p>	<p>7.2.4 Cognitive overload, confusion, or anxiety for patients and lay caregivers, brought on by usability problems or excessive information</p> <p>7.2.4 Suboptimal clinical decisions based on information provided by patients and lay caregivers, including excessive or disorganized information</p> <p>7.3.3 Neglect of error-prevention tasks because of misplaced confidence in EHRs and other eHealth tools</p> <p>7.5.2 Risk of privacy breaches to health information recorded by consumers, patients, and lay caregivers, resulting in unauthorized or inappropriate disclosure of information or medical identity theft</p>

Strategies for Higher Quality of Care at Lower Cost	Unintended Consequences Prevented or Mitigated
<p>7.4.1 Healthcare organizations should make the transition from fee-for-service payment models to models rewarding strategies that promote better outcomes.</p> <p>7.4.1. When available, clinicians should use data and terminology standards for documenting services that promote engagement of patients and lay caregivers; see, for example, HIT SP 03, “Consumer Empowerment: The Consumer Empowerment and Access to Clinical Information via Networks Interoperability Specification” at http://www.hitsp.org/interoperabilitySet_Details.aspx?MasterIS=true&InteroperabilityID=50&PrefixAlpha=1&APrefix=IS&PrefixNumeric=03.</p>	<p>7.4.1 Loss of revenue to fee-for-service providers after implementing strategies that promote patient engagement and require clinician time spent on health coaching</p>

8.3 Achieving Better Personal Health Management with eHealth Resources

Strategies for Better Personal Health Management	Unintended Consequences Prevented or Mitigated
<p>7.3.1 Clinicians, consumers, patients, and lay caregivers should consult the Medical Library Association’s “Consumer Guidance for Evaluating Health Information” available at http://mlanet.org/resources/consumr_index.html.</p> <p>7.4.4 Clinicians, consumers, patients, and lay caregivers should consult the guide to sources of reliable, well designed, and validated educational resources and self-management tools provided by the Agency for Healthcare Research and Quality (AHRQ): see http://healthit.ahrq.gov/portal/server.pt/community/health_it_to_ols_and_resources/919/usability.</p> <p>7.4.3 Clinicians should provide “prescriptions” for educational material to be obtained by the patient or lay caregiver from MedlinePlus or other trusted sources.</p> <p>7.5.1 Clinicians should initiate discussions with patients and lay caregivers about the sources of health information they are using to guide self-care actions and the actions taken.</p> <p>7.2.3 Clinicians should implement processes for monitoring and evaluating the effects of using eHealth resources.</p>	<p>7.3.1 Insufficient attention by clinicians to the needs and preferences of patients and lay caregivers for health education and guidance</p> <p>7.4.4 Waste of time and resources on poorly designed eHealth resources that have little impact on patient decisions and self-management</p> <p>7.5.1 Frustration, disengagement, counterproductive self-care actions based on poor sources of information and advice found on the Internet</p> <p>7.2.3 Increase in physiological or depressive symptoms brought on by excessive use of Internet resources in the absence of a therapeutic alliance</p> <p>7.2.4 Cognitive overload, confusion, or anxiety for patients and lay caregivers, brought on by usability problems or excessive information</p>
<p>7.5.2 As consumer eHealth expands and sources of personally identifiable health information proliferate, Federal agencies consider strategies for gaps in privacy and security protections, such as encouraging transparency regarding data practices. The PHR Model Privacy Notice (http://www.healthit.gov/policy-researchers-implementers/personal-health-record-phr-model-privacy-notice) is a tool for this, and more widespread use of it should be encouraged.</p> <p>7.5.2 Federal agencies should develop a readily accessible directory of validated educational resources about the privacy and security of health information designed for audiences of consumers and clinicians.</p> <p>7.5.2 Federal and state agencies, healthcare organizations, clinicians, and others concerned with the privacy and security of health information should direct patients and consumers to the HHS Health Information Privacy website for Consumers/ Patients at http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html.</p> <p>7.5.2 For concerns about medical identity theft, Federal and state agencies, healthcare organizations, and others should direct consumers and patients to the Federal Trade Commission Consumer Protection Fact Sheet: Medical Identity Theft available at http://www.ftc.gov/bcp/edu/pubs/consumer/idtheft/idt10.shtm.</p>	<p>7.5.2 Risk of privacy breaches to health information recorded by consumers, patients, and lay caregivers, resulting in unauthorized or inappropriate disclosure of information or medical identity theft</p>

9.0 Conclusions

Consumer eHealth innovations hold great promise for increasing the engagement of consumers, patients, and lay caregivers in acting to improve their health and the healthcare system. Benefits can be categorized as providing better communication and collaboration among clinicians, patients, lay caregivers, and consumers; higher quality healthcare and better outcomes at lower cost; and better personal health management. Along with the benefits, eHealth innovations also carry risks of adverse, unintended consequences to consumers, patients, lay caregivers, clinicians, and healthcare organizations. Anticipating the potential unintended consequences and taking action to promote success create the opportunity to maximize the benefits and minimize the adverse effects.

A number of resources exist to assist clinicians, healthcare organizations, and consumers to select and use eHealth resources that are valid, effective, and adapted to the consumers' needs and preferences. Some of these resources are available through Federal agencies such as the National Library of Medicine and the Agency for Healthcare Research and Quality. Others are available through private sources such as foundations and academic health centers. The Office of the National Coordinator could provide a valuable service by creating an easy-to-use online directory of available resources for clinicians and consumers.

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