

Managing Personal Health Information: An Action Agenda

Prepared for:

Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
540 Gaither Road
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HEALTH IT

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Executive Summary

Background

This report presents key recommendations and an action agenda developed during a 2-day workshop convened by the Agency for Healthcare Research and Quality (AHRQ) on July 27-28, 2009, entitled “Building Bridges: Consumer Needs and the Design of Health Information Technology.” The purpose of this event was to develop a framework for characterizing personal health information management (PHIM) that would inform the design of effective consumer health information technology (health IT) systems. The workshop brought together leaders from multiple disciplines, including health sciences, health informatics, information science, consumer health IT, and human factors research, with specific expertise in the fields of PHIM and/or health IT. The workshop moderator was Patricia Flatley Brennan, who also served as an advisor on this report.

Through small-group discussions and presentations, the participants considered the diverse needs of different consumer groups with respect to managing their personal health information and how consumer health IT solutions can be designed to better meet those needs. Based on these discussions and presentations, the participants were asked to set an agenda for advancing the field of consumer health IT that would include specific recommendations for research, industry, and policy.

Key Workshop Themes

Effective management of personal health information empowers patients to actively partner with their health care providers in making important health care decisions, which can potentially lead to better health care and better health care outcomes. At the same time, PHIM involves a complex array of tasks that many consumers find challenging. These tasks may include tracking and integrating health-related information obtained from various sources; coordinating care across different health care providers; and making critical decisions about one’s health based on physician recommendations, test results, office visits, and other bits and pieces of personal medical information. The requisite tasks can be even more complicated for individuals with special needs, such as the elderly, whose health care needs often exceed those of the general population, and whose capacity to effectively manage those needs is typically compromised by poor health or other considerations.

In light of these considerations, workshop participants were asked to share their understanding of consumers’ current PHIM practices, and to identify what more needs to be known about those practices in order to design better consumer health IT solutions. Participants were also asked to consider the extent to which currently available tools meet consumer needs, and what changes or design innovations would be needed to produce more patient-centered health IT systems. The following points highlight the main themes that emerged from the workshop.

Defining PHIM

Health care consumers manage their personal health information in countless different ways, and many factors influence the methods they use to perform the tasks and activities that characterize PHIM, such as health status, age, and attitudes about health and medical care. Moreover, a consumer's health information management practices can change over time as his or her capacities, health status, family status, and needs change. PHIM can occur anywhere, anytime; in other words, it is not restricted to a single, isolated location or event like a doctor's office or a medical appointment. All of these considerations have important implications for the design of consumer health IT systems. For example, they point to the need for systems that are flexible and accessible to different types of users and across different settings.

Design Issues

Consumer health IT solutions can play an important role in enabling patient-centered care, which the Institute of Medicine (IOM) defines as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" (IOM, 2001). In order to truly benefit consumers in this way, however, consumer health IT solutions must, first and foremost, take into account the particular needs of the consumer, rather than the needs of the physician, the insurance company, or some other entity that has a stake in the patient's health care.

To ensure broad access to these solutions, developers will also need to consider the particular needs, goals, preferences, and capacities of subpopulations like the elderly, the chronically ill, the disabled, and the underserved, which typically face one or more barriers that interfere with their ability or willingness to use consumer health IT systems. Specific barriers may include access to, and comfort with, technology; cognitive and physical impairments; health literacy; and cost. Until the needs of these subpopulations, who likely pose the most challenging design considerations, are taken into account, the IT solutions that developers create will likely fall short of promoting patient-centered care.

Consistent with the principles of patient-centered care, these tools must also reflect respect for the patient. Specifically, these tools should, among other things, ensure that the patient decides who has access to his or her personal health information, and, for those tools that are interactive, they should communicate information to the patient in a way that the patient can easily understand.

In order to ensure that consumers will actually use consumer health IT solutions, it will also be important to design those solutions to fit seamlessly into the user's life.

Important Steps for the Advancement of Consumer Health IT

Workshop participants identified several steps that can be taken to promote innovation in consumer health IT. Key points included:

Build a knowledge base about consumers' PHIM needs and practices and related design principles.

Additional research is needed on consumers' PHIM practices and related design issues in order to develop consumer health interventions that can best support consumers in effectively managing their health and health-related information.

Support more interdisciplinary efforts to drive innovation.

Collaboration between academic institutions and the technology industry could lead to significant advances in consumer health IT, but too many factors prevent the two types of entities from working together. Within the technology industry, information sharing could potentially lead to better, more efficient designs, yet developers tend to avoid such alliances out of concern for the potential costs and risks of collaborative efforts. To facilitate more partnerships across and within academia and industry, mechanisms will need to be established that reward collaboration and protect the rights and investments of all stakeholders.

Build a more robust health IT infrastructure to ensure access to all health care consumers.

Innovations in consumer health IT will require the development of a robust infrastructure that can support the dissemination of new solutions across different platforms. This infrastructure will need to ensure that consumers have access to the technology regardless of their age, income, literacy level, or other potential barriers.

Recommendations

A. Research

1. User Needs and Context

Recommendation 1a: To inform the design of PHIM tools, technologies, and applications, research is needed to investigate:

- The needs and preferences of diverse user groups in different contexts.,
- User goals, activities, and PHIM practices.
- User capacities (e.g., cognitive, physical, health literacy).
- User motivation (including beliefs and preferences).

Recommendation 1b: To address current gaps in knowledge, researchers should develop a taxonomy of needs and users that can be mapped to design strategies.

Recommendation 1c: To inform the design of IT-based PHIM tools for the broader population, researchers should identify and study “expert” consumer groups (e.g., frequent health care consumers) as models.

2. Improving Design of Consumer Health IT

To improve consumer health IT design, researchers should:

Recommendation 2a: Investigate the application of design methodologies used in other industries to PHIM.

Recommendation 2b: Identify qualitative and quantitative metrics for evaluating good design.

Recommendation 2c: Test design feasibility before development.

Recommendation 2d: Identify and evaluate intervention strategies that encourage and facilitate adoption of consumer health IT among users.

3. Evaluation Research

Recommendation 3a: Rigorous research is needed to examine the impact of consumer health IT use on various outcomes (including behavioral, clinical, patient experience, provider experience, efficiency, and unanticipated outcomes), and the specific relationship of design to those outcomes.

Recommendation 3b: New research methods and approaches need to be developed to evaluate PHIM systems that are already in the field.

B. Industry and Policy

Recommendation 1: To advance the development of innovative consumer health IT solutions, new mechanisms need to be established that can facilitate collaboration between industry and academia.

Recommendation 2: To help support the development of consumer health IT solutions that meet the needs of all consumers, incentives should be established for industry to invest more resources in Research & Development of such solutions.

Recommendation 3: To build awareness about PHIM among young health care consumers, grade-appropriate PHIM education should be incorporated into school curricula.

Recommendation 4: Policymakers and industry stakeholders should agree upon and establish standard ethical guidelines for the use and reuse of personal health information.

Recommendation 5: To promote the development and adoption of consumer health IT, new and existing policy implications need to be evaluated.

Recommendation 6: To enable patient-centered care and ensure broad access to consumer health IT, policymakers and industry stakeholders need to identify ways to build a more robust health IT infrastructure.

Chapter I. Introduction

This report represents the culmination of work performed under the task order entitled “Personal Health Information Management and the Design of Consumer Health IT,” initiated by the Agency for Healthcare Research and Quality (AHRQ). The purpose of this task order was to propose an action agenda for the integration of patients’ PHIM practices into the design of consumer health IT. Toward this end, the following key tasks and deliverables were completed:

- A comprehensive background report that synthesizes existing research and evidence regarding patients’ PHIM practices and the linkages between those practices and the effective development and use of consumer health IT.
- A secondary Medical Expenditure Panel Survey-Household Component (MEPS-HC) analysis to identify variables that affect the techniques people use to recall information about past medical events.
- A multidisciplinary expert workshop to facilitate the design of health IT systems that are based on a solid understanding of individuals’ and families’ health information management practices.
- A final report including recommendations for ongoing research, industry, and policy work in this field.

This final report presents the recommendations and action agenda developed by experts who participated in the 2-day workshop, which was convened on July 27-28, 2009. The purpose of this workshop was to develop a framework for characterizing PHIM that would inform the design of effective consumer health IT systems. The recommendations, which reflect the perspectives of stakeholders from multiple disciplines and industries, are intended to advance the field of consumer health IT by identifying specific issues related to PHIM or health IT that merit further investment of intellectual, industrial, and fiscal resources. Related action items suggest specific mechanisms for implementing each recommendation.

The report is organized as follows. Chapter 2 provides (1) an overview of the workshop; (2) a brief summary of the background and MEPS-HC reports, which were distributed to the workshop’s participants; (3) the methods for recruiting the participants; and (4) a description of the workshop objectives. Chapter 3 discusses the importance of and challenges associated with PHIM, and the role of consumer health IT in supporting consumers’ PHIM practices. Chapter 4 reviews design considerations for consumer health IT solutions and the need for multi-disciplinary teams in the development of such solutions. Chapter 5 presents the recommendations and action items that emerged from the workshop with supporting rationale based on the workshop discussions and presentations.

The report also includes two Appendixes. Appendix A presents the workshop agenda. Appendix B lists the workshop’s participants.

Chapter II. Overview of the Building Bridges Workshop: Methods and Objectives

On July 27-28, 2009, AHRQ convened a group of multidisciplinary experts for a 2-day workshop entitled “Building Bridges: Consumer Needs and the Design of Health Information Technology.” Participants at this workshop were asked to develop a research, industry, and policy agenda with specific recommendations for improving understanding of PHIM and advancing the field of consumer health IT.

A. Background Materials

Two reports were developed to provide some context for the workshop and to facilitate discussion among the participants. The first report, entitled “Personal Health Information Management and the Design of Consumer Health Information Technology: Background Report,” synthesized existing literature and evidence relating to:

- Consumers' personal information management (PIM) and PHIM needs and goals.
- Practices used for PIM and PHIM.
- Tools and technologies available to date.
- Significant gaps in current understanding of PHIM.

The report indicated that researchers have yet to establish a comprehensive understanding of what individuals *do* when they manage their personal health information, and the inherent challenges associated with effectively performing that work (Agarwal & Khuntia, 2009). The report also identified areas where future research is needed to address incomplete knowledge about the different goals and motivations for consumers to engage in PHIM, incomplete knowledge of the health information management needs of subpopulations, and a lack of detailed descriptions of the functional requirements and design elements for consumer health IT tools.

The second report, entitled “Personal Health Information Management and the Design of Consumer Health Information Technology: Secondary Analysis of Data From the Medical Expenditure Panel Survey,” analyzed the most recent data from the Household Component of the “Medical Expenditure Panel Survey” (MEPS-HC) relevant to PHIM. Multivariate analysis was used to identify variables that affect the techniques people use to recall information about past medical events and any patterns among those variables. The results indicated that many factors seem to influence an individual’s choice of recall methods, including demographic and socioeconomic characteristics of the individual or family, the volume of health information managed, and the type of medical event (e.g., dental care, home health care). The results also showed that some groups are unlikely to keep documentation of their medical events. One implication of these results is that future consumer health IT applications may need to be designed to offer tailored support for these groups (Schneider, 2009).

B. Workshop Participants

Leading experts in the areas of PHIM and consumer health IT were asked to participate in the workshop. The 22 expert participants included leaders in health informatics, information science, consumer health IT, and human factors research. They represented a wide spectrum of industries, including academic institutions, technology, healthcare, and the Federal Government. A complete list of the participants is shown in Appendix A.

C. Workshop Objectives

The goal of the workshop was to promote the design of consumer health IT systems that are based on a solid understanding of consumers' PHIM practices. Workshop discussions addressed three objectives:

1. Characterization of the methods that individuals and families use to manage their personal health information.¹
2. Establishment of an action agenda (for research and design, industry, and policy) for supporting consumers' PHIM practices through health IT.
3. Development of recommendations for moving this agenda forward.

D. Workshop Overview

Over the course of the workshop, participants discussed consumers' PHIM practices and needs, and their discussions formed the basis of an action agenda for developing effective consumer health IT solutions. Day One opened with a welcome address by Carolyn Clancy, Director of AHRQ. After discussing AHRQ's investment in the use of health IT to improve safety and quality in health care, she introduced the workshop moderator, Patricia Flatley Brennan, who reviewed the workshop agenda and goals, and discussed key considerations for the design of effective consumer health IT solutions.

The keynote speaker was Eric Dishman, Fellow and Director of Health Innovation and Policy at Intel Corporation. Drawing upon his career researching and designing personal health information systems, he discussed some critical aspects of developing innovative, patient-centered technology solutions.

¹ For example, the level of health information management, the type of information managed, or the "types" of managers.

Following these presentations, the participants were assigned to one of three breakout groups, which were led by facilitators from Insight Policy Research. The morning breakout session focused generally on what is currently known about consumers' health information management practices. Participants were asked to brainstorm about consumer practices in three specific areas: observing and assessing their own health and the health of others for whom they are responsible; organizing and differentiating health-related information; and obtaining, retrieving, or tracking health-related information. These sessions laid the foundation for later discussions about effective design of consumer health IT applications. After the morning breakout session, the participants reconvened and a representative from each group delivered a brief presentation summarizing the group's discussion, followed by a question and answer period.

On the afternoon of Day One, participants were again divided into breakout groups. They were given the opportunity to self-select into one of three groups based on their area of interest. The afternoon session focused generally on design issues for consumer health information technology. One group was asked to consider some of the current strategies used in designing consumer health IT tools, a second group was asked to consider how future designs can fulfill consumers' unmet health information management needs, and a third group was asked to consider design strategies for specific subpopulations. Afterwards, one or more representatives from each group presented the main points of the session's discussion.

Day Two opened with a brief address by Jon White, Director of AHRQ's Health IT Portfolio. Next, Patricia Flatley Brennan reviewed some of the main take-away points from the previous day. Participants gathered into working groups once again. One group was tasked with developing recommendations and an action agenda for research, a second group focused on industry/implementation, and the third group focused on policy. In the morning, the participants reflected on the themes and issues discussed during Day One in order to begin developing their recommendations. They reconvened in the afternoon to refine those recommendations, and to develop supporting action items. The workshop concluded with each group presenting their recommendations for discussion.

Chapter III. Personal Health Information Management and the Role of Consumer Health IT

A. Personal Health Information Management: Understanding Its Importance and Associated Challenges

Personal health information management refers to the set of activities that support consumers' access, integration, organization, and use of their personal health information (Civan et al., 2006). Some types of personal health information that consumers need to remember, organize, and report include emergency medical information; biomedical, clinical, and genetic information; mental health or psychological information; and information dealing with insurance and financial matters relevant to health management (Agarwal & Khuntia, 2009). Consumers receive or obtain personal health information from many different sources, including health care providers, health care insurers, social networks, and the mass media, and from devices like pedometers, blood-glucose monitors, and thermometers. Ideally, PHIM involves successfully integrating these diverse types and sources of information so that the consumer can effectively participate in his or her own health care (Pratt et al., 2006).

Effective management of one's personal health information has become increasingly important in today's health care environment, where care is typically fragmented, physicians are spending less time with patients, and more services are being provided in outpatient settings (Pratt et al., 2006). Each of these factors places more responsibility on the patient. For example, today's health care consumers need to be able to coordinate care across providers, understand how to effectively communicate with those providers, know how to get their questions answered in the limited time allotted for an office visit, and learn how to effectively monitor and manage their health between visits. Consumers who can successfully perform these tasks are likely to become more active, empowered health care consumers, who typically enjoy better health care and better health outcomes (Brennan & Safran, 2005; Laine & Davidoff, 1996).

Managing one's personal health information is, however, complex, and presents consumers with numerous challenges. One of the challenges stems from the "anywhere, anytime" nature of PHIM activities. PHIM is not restricted to just the home or the doctor's office; its inherent tasks and activities occur across multiple settings and circumstances. The information generated from these activities is likely to be equally scattered across different places and devices, making it challenging for consumers to organize, access, and simply keep the information straight.

The volume and complexity of information that consumers need to keep, organize, interpret, and possibly report to their health care provider pose additional hurdles. As information accumulates, it becomes more difficult to manage on both a physical and a mental (cognitive and psychological) level, particularly when the information itself is not easy to understand, or is potentially upsetting (e.g., mounting health care bills or test results indicating a health problem). For individuals with chronic health conditions and other patients who are faced with making

difficult decisions about their treatment within a short timeframe, the need to consider and weigh information from different sources is critical, yet their ability to do so may be severely compromised by a feeling of information overload.

Another potentially challenging aspect of PHIM involves making decisions around information sharing. Consumers need to decide what personal health information they want to share with whom, and the best means for doing so. In light of the sensitive nature of many types of personal health information, concerns about privacy and security may also weigh upon consumers as they make decisions about what information to share with others.

Consumers may also struggle with questions about how to respond to physical symptoms or reactions they may experience. More specifically, they need to decide what information to attend to, record, and report to a physician. Participants noted that many consumers are unable to optimize the limited time that they have with their physicians simply because they feel unsure about what kinds of information they should be recording or reporting.

B. Understanding Consumers' PHIM Practices

To begin developing a framework for characterizing PHIM, the participants were asked to discuss who in the household typically performs the tasks associated with PHIM, what tools they may use to perform those tasks, when and where they perform them, and who or what they turn to for assistance. It was noted that the “personal health information manager” of a household can be one person, or it can be more than one person, depending on how tasks are delegated within the household. For example, in homes where more than one language is spoken, if a son or daughter has the best command of English, he or she may take on certain PHIM-related duties, such as scheduling appointments, whereas a parent may be responsible for others. Also, the person or people who fill the role may change over time. For example, parents will typically manage their child’s health information, but as that child moves into adulthood, he or she usually assumes responsibility for managing the information. Similarly, as an adult ages, or if the usual personal health information manager develops a serious illness, part or all of the PHIM responsibilities may be transferred to another family member or informal caregiver.

Whereas there is great variety in the methods and approaches that consumers use to manage their personal health information, participants noted that paper-based methods of PHIM storage and transfer are still most common. They also suggested that engagement in PHIM tends to wax and wane based on various factors, including the person’s health status, level of perceived need, and level of comfort in managing health information.

Informal social networks play a significant role in helping consumers manage their health and make decisions on care, as these networks are a trusted source of support as well as a source of information. Representatives from social networking Web sites for patients with medical conditions felt that the growing popularity of such sites indicates how much consumers value the ability to directly connect with and obtain information from others who are facing similar

conditions. Many consumers turn to these networks for support in making sense of symptoms, test results, and treatment recommendations.

Both the workshop discussions and the research literature on PHIM suggest that more work is needed in this field to develop a better understanding of the ways that consumers attempt to track, organize, interpret, and report the different types of personal health information they obtain through various sources. Multiple research methodologies are needed to gain a richer understanding of these practices. The secondary Medical Expenditure Panel Survey-Household Component (MEPS-HC) analysis conducted under this task order represents one method of developing a better understanding of consumers' PHIM practices. In his keynote address, Eric Dishman suggested several other methodological approaches that can be applied to the study of PHIM as well as to the design of PHIM tools. These methods include participatory observation, shadowing, and "informance design." This last method involves the use of improvisational actors role playing various scenarios using props in order to obtain candid feedback from onlookers about how well the actors modeled consumers' actual behaviors, or the extent to which the actors' use of the props reflects the way people typically perform a given task or activity.

In combination, application of these various methods should result in a more robust understanding of consumers' PHIM habits and practices, which in turn should lead to consumer health interventions that are best suited to support, extend, or optimize those practices. Some, but not all, of these consumer health interventions may be technology-based. Participants emphasized that many user groups face barriers that interfere with their ability or willingness to use a technology-based tool, including limited access to technology, cognitive impairments, cost, privacy and data security concerns, and anxiety about the use of computers or other IT-based tools. An important focus of future research into consumers' PHIM practices should be to identify the specific circumstances where technology solutions can provide the most benefit to consumers, for example by investigating the types of health information that can be most effectively managed through IT solutions, the types of consumers who would derive the greatest benefit, and the contexts in which those solutions might prove most effective, so that developers can invest resources accordingly.

C. Role of Consumer Health IT Applications

Consumer health IT is the collection of tools, technologies, and artifacts that consumers can use to support their PHIM tasks (Eysenbach, 2000). The potential benefits of consumer health IT applications can be realized in several ways. By helping consumers more easily record, access, and share information about their health, consumer health IT applications can facilitate more effective communication between consumers and their health care providers. More effective communication can, in turn, help consumers make more informed decisions about their health care. Well-designed consumer health IT applications also can ease the significant cognitive burdens associated with PHIM by providing tools that are expressly designed for information management. Interactive health IT tools that enable timely communication with clinicians have the potential to impact clinical outcomes by helping patients monitor and effectively manage

chronic conditions at home and between office visits. Although research on the impact of consumer health IT applications is still somewhat limited, evidence from a recent systematic review of the literature found that consumer health IT applications may positively impact certain health care processes, such as medication adherence among asthmatics, as well as some intermediate outcomes across a variety of clinical conditions and health behaviors, including cancer, diabetes mellitus, mental-health disorders, smoking, diet, and physical activity. Additionally, the evidence suggests consumer health IT applications have a positive impact on mental-health outcomes (Gibbons et al., 2009).

“One of the most underused resources in healthcare in America is the consumer.”

- Carolyn Clancy, Director, AHRQ

Finally, consumer health IT applications can empower consumers to assume greater control over their health care, which can positively impact consumers’ health outcomes and quality of life (Gustafson et al., 1999).

Chapter IV. Developing Consumer Health IT Applications

A. Design Considerations

The Institute of Medicine (IOM) defines patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” (IOM, 2001)

According to the IOM, patient-centered care is one of six dimensions of quality where improvements are needed in order to realize a better health care system. Consumer health IT applications can play an important role in enabling patient-centered care, but in order to do so, they need to be accessible, flexible, and tailored to the user’s capacities. In short, they need to reflect good user-centered design, defined as “a multidisciplinary design approach based on the active involvement of users to improve the understanding of user and task requirements, and the iteration of design and evaluation” (Ji-Ye Mao, et al, 2005).

“We want to have personal health information tools that live with people.”

- Patricia Flatley Brennan, Department Chair, School of Nursing and College of Engineering, University of Wisconsin-Madison

Consumer health IT solutions should also fit seamlessly into the user’s life. For example, they should not occupy too much of the patient’s time or physical space. Finally, respect for the patient should be a standard design principle for all consumer health IT solutions. For example, when designing interactive health interventions that transmit evidence-based guidelines or medical advice to a patient, developers need to ensure that the transmitted information is communicated in a way that the patient can understand. Also out of respect for patients, consumer health IT solutions should be designed to give the patient full control over who can access his or her health information.

Developing tools that meet these criteria requires a deep understanding of the interplay between user, tasks, tools, environment, and context. Each of these key design considerations is discussed below.

1. Users

According to the workshop participants, before developing a health IT product, designers should start with the question, *Who am I designing this tool for?* They noted that too often, in the interest of getting a product into the hands of consumers, developers devote inadequate attention to this question, and instead allow their untested assumptions to drive design, resulting in products that fail to meet the actual needs of consumers.

To design more fitting and innovative solutions, developers need to consider the full range of potential users who can benefit from consumer health IT, not just the technologically savvy.

Maximizing the impact of consumer health IT will require consideration of the particular needs, goals, preferences, and capacities of all consumers, including the elderly, the chronically ill, the disabled, and the underserved, who typically face one or more barriers that interfere with their ability or willingness to use consumer health IT systems. These barriers may include access to and comfort with technology, cognitive and physical impairments, health literacy, and cost/affordability. Until the needs of these groups, who likely pose the most challenging design considerations, are taken into account, the IT solutions that developers create will likely fall short of promoting patient-centered care.

As mentioned previously, the “user” of a consumer health IT application may be one person or several people. Accordingly, developers need to create tools that are flexible enough to accommodate one or more users, including the patient, a family member, or personal caregiver.

Additional research is needed to help define user needs in some areas, such as determining what level of granularity is most useful to consumers when it comes to information about their health or a health condition. Before developing a health IT tool, developers should know, for example, how much detail a diabetic patient might need to know about his or her blood sugar level in order to effectively manage it, or how much patients with heart disease need to know about their blood-cholesterol levels.

In the U.S. there are about 12.6 million households who are „netizens.’² We cannot use a „netizen-centric’ design philosophy for the design of personal health systems. We will not reach the vast majority of people who actually need them.”

-Eric Dishman, Intel Fellow

2. Tasks

The tasks that characterize PHIM are varied and complex. They may include record-keeping; scheduling appointments; communicating with and coordinating care across various health care providers; tracking symptoms, medications, and other health-related information; and making decisions about one’s health. In order to design tools that can facilitate performance of these tasks, developers need to understand consumers’ information-management strategies and workflow procedures (Agarwal & Khuntia, 2009). The research to date suggests that the approaches that consumers use to manage their health information are as diverse as the population itself. Some demographic characteristics—like race, ethnicity, and socioeconomic status—are associated with using different tools to recall information about past medical events (Schneider, 2009). Developers may need to examine the particular practices of their target audience, therefore, to ensure that the tools they develop are culturally competent. Additionally, developers need to gain a better understanding of which PHIM-related tasks may best be supported by consumer health IT applications, and how new applications can optimize or complement consumers’ current methods of performing those tasks.

² In this context, the word netizen refers to the population of people who are comfortable with technology, and have the resources to access it regularly.

3. Tools

Health IT designers need to consider several key attributes such as convenience, affordability, portability, interoperability, and cultural appropriateness when designing consumer health IT tools. A recent report by the Oregon Evidence-Based Practice Center confirmed that convenience is a key factor in consumer use of health IT (Jimison et al., 2008). This report, which reviewed the research literature on barriers and drivers to the use of interactive consumer health IT by the elderly, the chronically ill, and the underserved, found that consumers were more likely to use consumer health IT solutions that were convenient and could be accessed through devices that patients used routinely for other purposes. Conversely, patients were less likely to use systems that required access to equipment or technology that did not fit seamlessly into their daily routines. The report also found that, for these populations, cost and access to technology are likely barriers to the use of health IT.

The health information that consumers need to manage and integrate includes many different sources and formats, and may be located on many different devices. For this reason, consumer health IT solutions also need to be able to traverse various platforms and applications, so they can effectively support the patient in synthesizing all the bits and pieces of information that can guide them to make more informed health care decisions.

Consumer health IT applications also need to be flexible enough to accommodate changing patient needs, since PHIM tasks and managers can change markedly over time. For example, a patient who becomes increasingly ill has to manage a growing amount of information, and may ultimately need someone else to take over the task of managing his or her health information. In some cases, the patient will recover and resume management of the information. Consumer health IT applications that can adapt to these kinds of shifts are needed in order to continuously and seamlessly meet patient needs.

Finally, future health IT applications need to be designed with respect for the patient in mind. Participants noted that such respect includes not only moving away from a model where the physician's needs dominate, but also moving away from negative assumptions about patients' willingness or capacity to be actively involved in their own health care.

4. Environment and Context

Designing consumer health IT applications requires consideration of the environment within which the user lives and operates. Specifically, developers need to consider the living environment, the social environment, the psychological environment, the technological environment, and the health services environment of the user. All these factors influence the user's capacity to use and access IT-based tools.

B. The Need for an Interdisciplinary Approach to Design

Innovation in consumer health IT is hampered by several aspects of the current environment in which research and development occur. First and perhaps foremost, the incentive structures in academia and industry may not support collaboration or information sharing across different disciplines or industries, so the research and development work is conducted in silos, resulting in a lack of synergy among experts. Within the academic community, PHIM-related research is being carried out across many different disciplines, such as health sciences, health informatics, human factors, human-computer interaction, computer science, cognitive psychology, industrial engineering, and information systems. To date, there has been little effort to synthesize the knowledge and insights that each of these research communities have generated, resulting in a fragmented body of knowledge (Agarwal & Khuntia, 2009). In order to contribute to a broader, deeper, and more comprehensive understanding of PHIM, researchers need to start crossing these traditional boundaries to collaborate with each other. To actually facilitate such partnership, however, academic institutions will need to begin supporting such interdisciplinary efforts.

Within industry, competition and concerns about protecting intellectual property sometimes prevent developers from sharing information that would enable others to build on their work. Moreover, conflicting interests between academia and industry inhibit collaboration between the two parties, despite the ways that each could benefit from the other. For example, researchers have a wealth of knowledge that could inform the design of better products, as well as the expertise needed to analyze the large volume of usage data that developers accumulate, but product developers typically require researchers to sign nondisclosure agreements (NDAs), which many academic institutions do not allow. Even when an NDA is not required, other issues may prevent product developers from drawing upon the expertise of researchers. For example, in the interest of generating profits and ensuring sustainability, product developers often feel they do not have the time to invest in the kind of rigorous testing that is standard practice among researchers. Researchers in turn hesitate to partner with product developers because they need to appear independent and unbiased. The costs of these conflicting interests include untapped expertise and the production of ill-fitting consumer health IT applications.

In order to create the kind of climate where innovation can happen, several changes need to take place. Eric Dishman discussed some of these changes in his keynote address. First, he noted the importance of bringing together an interdisciplinary team of people from various domains—including social scientists, statisticians, engineers, health care professionals, and business and industry experts—who will work together over time to build the kind of deep knowledge that is needed to advance the PHIM industry. He further noted that it is important to consider the complete channel through which new PHIM technologies are conceived and sold to users. Ideally, this step involves representatives from the technology and business worlds as well as health-technology users, all who must traverse the boundaries within which they typically work, in order to collectively think about how the product is conceived, how users will first hear about it, how it will be marketed, and finally, when it will be launched. Innovation can happen at any point along the continuum, but all the players need to be engaged to ensure its success.

The participants noted that innovation will also require changes within academia and industry. Within academia, researchers are typically rewarded for accomplishments within their own discipline. So, for example, if a cognitive psychologist publishes a paper in a medical informatics journal, that work may not be recognized, or at least, it may not gain that researcher the same degree of recognition as a paper published in the journal “Cognitive Psychology.” Mechanisms are needed for rewarding interdisciplinary works in order to provide researchers with the incentives they need to collaborate with experts in other fields of study.

Within industry, workshop participants discussed the need for a common space or central repository where developers can share nonproprietary information and exchange ideas. To bridge the gap between industry and academia, the participants suggested that third-party managers be brought on to facilitate cooperation between researchers and developers. This third party could be responsible for developing guidelines for collaboration between research and industry, and for establishing ways of bringing experts from the two domains together. Additionally, funding for collaborative work needs to be available. Workshop participants suggested that grant solicitations specify the need for interdisciplinary research as a condition of the grant. They also stated that, in order to ensure that consumers will truly benefit from newly developed health IT systems, industry developers need to conduct more efficacy testing of those systems, and industry incentives may need to be enacted to promote more widespread testing.

Chapter V. Recommendations and Action Agenda

Participants were asked to develop recommendations and an action agenda for research, industry, and policy. The recommendations and associated action items are presented below, with background information and rationale to support each recommendation. Because the recommendations pertaining to both industry and policy are relevant to both parties, they are listed under one agenda.

A. Research: Recommendations and Action Agenda

The group of participants tasked with developing a research agenda proposed recommendations pertaining to three main areas: (1) understanding user needs and context, (2) improving design of consumer health IT tools, and (3) evaluation research. Each of these is described below.

1. Understanding User Needs and Context

A. Recommendations.

Recommendation #1a: To inform the design of PHIM tools, technologies and applications, research is needed to investigate:

- The needs and preferences of diverse user groups in different contexts,
- User goals, activities, and PHIM practices,
- User capacities (e.g., cognitive, physical, health literacy), and
- User motivation (including beliefs and preferences).

Recommendation #1b: To address current gaps in knowledge, researchers should develop a taxonomy of needs and users that can be mapped to design strategies.

Recommendation #1c: To inform the design of IT-based PHIM tools for the broader population, researchers should identify and study “expert” consumer groups (frequent health care consumers) as models.

B. Background and rationale.

The design of consumer health IT needs to be based on a deep understanding of its potential users and the context within which they live. The recommendations below are aimed at expanding current understanding of consumer needs and practices in order to develop more fitting health IT solutions.

Recommendation 1a.

Participants at this workshop noted that the field of health IT is so dominated by the provider side that the needs of the patient often get lost. Despite their intended focus on the consumer, existing consumer health IT applications seem to reflect this same bias. Some sources of bias may originate within industry, where untested assumptions about who the tools should be designed for, how they will be used, and what functions the tools should serve can sometimes drive design and development. Improvements in design require a more in-depth understanding of user needs and preferences in different contexts. Towards this end, the participants recommended four main avenues for future research, described below.

- *Needs and preferences of diverse user groups in different contexts.* In order to design well-fitting consumer health IT solutions, research is needed to answer the question, *Who and what are we designing these solutions for?* To address the “who” part of the question, it will be important to define the full range of potential user groups—taking into consideration factors like age, gender, socioeconomic status, race/ethnicity, cognitive and physical capacities, and health status—and to identify their needs, preferences, and the context within which they live and operate. Contextual factors that might affect use or adoption of a consumer health IT tool include the user’s living environment (*Does he or she have a home? Does he or she live in a private residence or facility?*), social environment (*Who is he or she connected to? Are those people involved in his or her health care decisions?*), psychological environment (*What are his or her fears or attitudes towards the medical field?*), technological environment (*Does he or she have Internet access?*) and the health care services environment in which he or she lives (*How close is the nearest medical facility? Can he or she get there easily?*) Another contextual factor that requires consideration is how many users will interact with a given PHIM tool. In some cases the user will be an individual health information manager, but in many cases there could be multiple users, including family members, formal or informal caregivers, physicians, and anyone else that the consumer designates as a shared user.
- *User goals and activities.* Health care consumers vary widely in their approach to managing personal health information, with disparate approaches typically reflecting very different goals and activities. One dimension in which users may vary is proactive versus passive. Proactive consumers may have clearly articulated goals and habits with respect to the way they organize and manage their health information, whereas passive consumers may not have any articulated goals, apart from wishing to avoid poor health. Regardless of the type of user, relatively little is known about the explicit or implicit health information management goals across various user groups. Research in this area could yield important findings for both tool design and consumer adoption. The observational research studies that have gathered information about the ways in which consumers keep, organize, and share their health information provide an important foundation for understanding consumers’ PHIM activities. Further research on the underlying reasons for the strategies that consumers choose has the potential to help to inform the design of tools that truly fit into consumers’ daily lives.

- *User capacities.* To ensure that consumer health IT tools are not designed expressly for the technologically savvy, research is needed to delineate the range of capacities of potential users, including cognitive capacity, physical capacity to operate a tool, and health literacy. Beyond these considerations, additional research should be conducted on human performance and cognition with respect to managing personal health information, given that this information has multiple sources, is typically complex, and can be extremely sensitive, which can impact the consumer's ability to process it. Gathering additional data about specific cognitive capacities in this context can help ensure that newly developed tools complement consumers' abilities and enhance their experience as opposed to imposing information overload upon them.
- *User motivation.* Whereas some research has examined the barriers and facilitators of consumer health IT use, more information is needed about the beliefs and concerns of various user groups with respect to using IT-based PHIM tools, and the incentives for adoption. This information can inform both the design and promotion of consumer health IT solutions among all types of users. Some specific avenues for research include differences among various user groups with respect to privacy and security concerns; beliefs about the patients' role versus the physicians' role in managing health information and making health care decisions; and physicians' beliefs about the potential impact of consumer health IT on his or her health care delivery practices (e.g., will it improve communication with the patient or will it impose additional burden on the physician?).

Recommendation 1b.

Although multiple disciplines with long research traditions have made important contributions to current understanding of PHIM, the field of PHIM itself is still in its nascence. As such, there are currently no existing systems, models, or taxonomies for defining different user types, needs, practices, and goals with respect to managing health and health-related information. A taxonomy would provide a common framework for stakeholders across multiple disciplines, and would provide a reference point for addressing the important question, *Who and what are we designing for?* Observational and other kinds of research are needed to match various user groups with appropriate design strategies.

Recommendation 1c.

Some populations, by virtue of their regular interactions with the health care system, have well-articulated needs and goals when it comes to PHIM. For example, parents of children with developmental disabilities often become veteran consumers and navigators of the health care system, given the number of health care providers and allied health professionals they interact with through the stages of assessment, diagnosis, and ongoing treatment therapies for their child. These and other frequent health care consumers can serve as a rich information source for researchers interested in investigating user needs in particular contexts. Identifying various "expert user groups" will allow researchers to assemble some foundational research for developing design solutions that may eventually be applied to the general population.

C. Action agenda.

To support the aforementioned research initiatives, research funders should develop targeted grant solicitations or funding opportunities and establish relevant grant-review criteria for future studies in these areas. This grant process should include interdisciplinary review panels for evaluation of the applications to promote collaboration among vested stakeholders across multiple domains.

2. Improving Design of Consumer Health IT Tools

A. Recommendations.

To improve consumer health IT design, researchers should:

Recommendation #2a: Investigate the application of design methodologies used in other industries to PHIM.

Recommendation #2b: Identify qualitative and quantitative metrics for evaluating good design.

Recommendation #2c: Test design feasibility before development.

Recommendation #2d: Identify and evaluate intervention strategies that encourage and facilitate adoption of consumer health IT among users.

B. Background and rationale.

Consumer health IT applications need to be designed around the way people actually live, as opposed to requiring consumers to think about and attend to their health in a “separate space.” In order to move closer to this ideal, some basic information gaps need to be filled with respect to what constitutes true user-centered design in this domain. Some recommended avenues for future research are noted below.

Recommendation 2a.

Too often, in the interest of getting a product into the hands of consumers, developers of consumer health IT solutions fail to devote adequate attention to user-centered design principles. In order to create PHIM tools and solutions that will benefit consumers in more direct and practical ways, developers would do well to consider design processes that have evolved over time in other industries. As an example, it was noted that other consumer IT products are typically subjected to extensive iterative testing, with ongoing user-feedback loops to ensure that the final result is a product that consumers want to use. If these same methodologies were applied to the design and development of consumer health IT solutions, they might result in better support for consumers through more user-centered products.

Recommendation 2b.

Currently, there are no established measures of good design for different segments of the patient population. Research is needed to answer some very basic usability questions; for instance, *How do we know if a consumer health IT solution “works”?* *How do we know when we have achieved good design for different population groups?* *How do we identify meaningful indicators?* Since these metrics involve directly measuring the effectiveness of a given solution in terms of how it meets the consumer’s needs, consumers will need to be at the center of this research.

Metrics need to be established to evaluate both proximal efficacy (e.g., *Do consumers enjoy using the product?*) and distal outcomes (*Does the product support the consumer in effectively managing a health condition?*) Researchers will also need to identify what features of a product are most important to evaluating its efficacy; for example, *Does it need to make the consumer feel more confident in his or her ability to manage a chronic health condition?* *Does it need to incorporate features that make consumers want to use it?* *Does it need to have audio features?* *Does it need to be portable?*

Establishing such metrics may require ongoing research on multiple fronts. For example, focus groups with consumers about their PHIM habits and needs, iterative testing of prototypes, and comprehensive reviews of patient populations and their particular challenges and health care needs could collectively address many questions about meaningful indicators of effectiveness.

Recommendation 2c.

Workshop participants stressed the need for adequate research and development before products are launched and disseminated. One research method that Eric Dishman described is “informance design,” which makes use of theatre to help potential users conceptualize a product before it is created. The idea behind informance design is that when developers build a realistic, late-stage prototype of a tool, they can spend considerable resources on that prototype without getting reliable feedback from consumer focus groups, because people hesitate to criticize a prototype in its penultimate state. Alternatively, with informance design, improvisational actors use cardboard boxes as props, and they interact with those boxes as they would with the imagined product. Because the “product” is a cardboard box, people are more inclined to tear it or otherwise alter it so it better reflects what they want it to be and do. The use of theatre helps people to visualize this future product that they otherwise cannot imagine, and provides a way of getting rich and reliable feedback.

Beyond this step, preliminary testing on actual prototypes is also important. The procedures used in Phase I and II clinical trials can serve as one model for testing a product prior to development. Although such clinical trials are typically designed to test the safety and efficacy of experimental drugs, product developers may find it useful to apply the basic methodology to the design of PHIM tools, technologies and applications. For example, during Phase I, they might select a very small group of consumers to assess the products’ basic efficacy, and any costs and benefits associated with its use. If the product is deemed worthy of further investigation, it might then be subject to more rigorous testing with a larger consumer group, as

in a Phase II clinical trial. These research and development procedures can help ensure that adequate data about a product's usability and effectiveness is obtained before the manufacturing process begins.

Recommendation 2d.

Participants noted that moving consumers towards adoption of consumer health IT applications is difficult, as many consumers do not recognize the potential benefits of using such tools, and they may actually perceive or experience several barriers to usage. The research literature identifies numerous barriers to adoption. For example, a review of evidence regarding health IT use among the elderly, chronically ill, and underserved identified a perceived lack of benefit as a frequent barrier to consumer use of interactive health IT (Jimison et al., 2008). Additional barriers include a perceived lack of convenience associated with using the application or system and difficulty integrating the IT intervention into the patient's everyday life. Lack of trust of the IT system is another potential deterrent. Some findings show that when the IT intervention provides the patient with unexpected advice that is not explained, the patient does not believe the information and therefore does not adhere to the recommendation. Difficulty adapting to the use of new technology represents an additional potential obstacle for consumers.

Participants discussed various ideas and incentives for encouraging more widespread adoption of PHIM tools and technologies, such as consumer health IT "starter kits" that are designed to familiarize users with some basic tools for managing health information; pairing IT-based PHIM tools with other widely used services like cable television, mobile phones, or personal digital assistants (PDAs); incorporating components that consumers are already drawn to, like social networking sites; and demonstrating some tangible benefits of use, such as saving time, money, or simplifying an otherwise dreaded task. Systematic research is needed to test the effectiveness of these and other strategies before pursuing any widespread efforts to promote consumer adoption of consumer health IT solutions.

C. Action agenda.

To support these research initiatives, research funding groups should provide the following:

- *Grant funding.* Funding groups can help researchers by developing grant solicitations and funding opportunities in support of such initiatives. These announcements should include review criteria focused on methods and metrics of user-centered design. For example, grant proposals should be required to have a detailed section defining the specific metrics and methods that will be used in the study. Additionally, to ensure that funded grants reach across different academic disciplines, requirements for interdisciplinary research should be established as part of the grant review process.
- *Resources to inform design.* To advance knowledge about effective design for consumer health IT, a library of recommended constructs, evidence-based design guidelines, and assessment methods should be established. Additionally, specific support for the development of evidence-based design guidelines is also needed.

- *Promote collaboration.* Funders should create mechanisms to foster ongoing collaboration between academia and industry.

3. Evaluation Research

A. Recommendations.

Recommendation #3a: Rigorous research is needed to examine the impact of consumer health IT use on various outcomes (including behavioral, clinical, patient experience, provider experience, efficiency, and unanticipated outcomes), and the specific relationship of design to those outcomes.

Recommendation #3b: New research methods and approaches need to be developed to evaluate new PHIM systems that are already in the field.

B. Background and rationale.

Participants suggested that effective PHIM should be considered a proximal goal in helping the consumer achieve good health, or at the very least, effective management of a health condition, by supporting more informed decisionmaking and active engagement with one's health care provider. At present, however, no research has examined the relationship between consumer health IT design features and patient outcomes. Research is also needed to assess the impact of consumer health IT on clinicians, caregivers, and health care usage. As more tools and technologies are developed to support consumers in managing their personal health information, it will become increasingly important to evaluate the extent to which these tools and technologies contribute to intended and unintended outcomes.

Recommendation 3a.

Some anticipated benefits of effective PHIM include patient empowerment, improved patient-clinician communication, and decisionmaking support. More research is needed, however, to investigate the impact of emerging PHIM tools, technologies, and applications on consumers' health knowledge and behaviors, their health care experiences, and their clinical outcomes. Researchers should also investigate the impact of consumer health IT on clinicians and caregivers (both formal and informal) in light of the important role they play in the consumers' health and health care experience. It will be important to identify outcome measures pertaining to all three stakeholder groups. Some measures might include patient quality of life, perceived quality of care, adherence to clinician recommendations, medical error rates, health care costs, efficiency gains for clinicians, and perceived caregiver stress.

Additional information is also needed on the unintended consequences of PHIM tools and technologies. For example, participants noted that some physicians worry that IT-based PHIM tools will leave their patients feeling overwhelmed as opposed to well informed. Given some patients' concerns over privacy and data security, it is also possible that certain IT solutions will elevate a patient's anxiety rather than help to alleviate it. Field studies are needed to examine how new tools are influencing patient satisfaction, health care outcomes, and health care interactions, among other things.

Finally, rigorous research is needed to examine the impact of specific design features on PHIM and health care outcomes and to effectively address research questions such as, *Are there particular user interfaces that encourage adoption of certain tools among specific population groups? If so, does adoption/use lead to positive behavior change? Are there measurable impacts on health? Are there measurable impacts on adherence to a doctor's regimen or treatment plan?* Answers to these questions have the potential to enhance the benefits of new tools and technologies by informing design innovations.

Recommendation 3b.

Alongside developing such metrics, researchers need sound methods for evaluating existing tools. Several methodologies for gaining deep cultural knowledge about the populations for whom tools are being designed might be applied to the evaluation of existing tools. For example, shadowing studies can enable researchers to witness how users interact with a tool, which can reveal what features satisfy users and what features frustrate them. Situational interviews enable researchers to gather information on why consumers make certain choices over others; for example, why they might record a piece of information on paper as opposed to recoding it electronically. Other methods may need to evolve as new tools with new capabilities are developed. Innovative designs will call for more innovative evaluation methods, because the old methods may no longer fit.

C. Action agenda.

Funding opportunities and grant solicitations should be developed to support the aforementioned research initiatives. Furthermore, the development of new research methods calls for input from multiple disciplines that can bring different knowledge and experiences to bear on the design and evaluation of new consumer health IT systems. To promote contributions from multiple disciplines, grant criteria should be established requiring (1) evidence of multidisciplinary teams and (2) detailed strategies for translating research into practice. Finally, interdisciplinary review panels should be established for evaluation of these applications.

B. Industry and Policy: Recommendations and Action Agenda

1. Promote Interdisciplinary Collaboration Between Academia and Industry

A. Recommendation.

Recommendation #1: To advance the development of innovative consumer health IT solutions, new mechanisms need to be established that can facilitate collaboration between industry and academia.

B. Background and rationale.

Innovations in consumer health IT are hindered by a lack of collaboration between the technology industry and academic researchers. Each party has something that can benefit the other, but those benefits cannot be realized unless the two work collaboratively. For example, industry can benefit from the research expertise of academics, and academia can benefit from the hands-on technological expertise of industry players. Furthermore, partnering with industry can provide academic researchers with an opportunity to see the practical application of their work, whereas partnering with academic researchers can provide industry with independent evaluations of product efficacy.

Despite these potential benefits, successful partnerships between academia and industry are not all that common, in part because it can be difficult for the two entities to resolve the complex set of technical, legal, and financial issues that can arise out of such partnerships. One example involves intellectual property. The current practice among most universities is to retain ownership of the intellectual property generated by their faculty. Whereas this practice protects the interests of the university, it does not meet the interests of industry very well, thereby hindering the establishment of effective working relationships between the two entities.

Partnerships between universities and small businesses could be an especially fruitful avenue for innovative developments in consumer health IT, but university policies governing such alliances sometimes prevent the realization of such partnerships. For example, some universities require that their business partners have large indemnity policies to protect both parties from any damages that could result from products developed through the partnership. This requirement effectively rules out the possibility of partnering with a small business, since such entities cannot typically meet the university's stringent financial requirements.

Other barriers to collaboration stem from the divergent priorities of industry and academic researchers. Whereas developers are concerned with timely and swift production and delivery of new products to the market in order to sustain business, researchers are focused on gathering empirical evidence through carefully designed studies, which are time-consuming to conduct.

Product developers may feel they cannot devote the amount of time required to conduct extensive usability testing, or to evaluate the end results of their products. On the other hand, researchers sometimes hesitate to collaborate with developers out of concern that their research will be considered biased in support of the developers' products.

An unfortunate result of this lack of collaboration is that information essential to innovation does not get shared. For example, academic researchers have gathered voluminous data about human performance capacity that could inform design, but many developers do not know where to look for such evidence. This tendency for work to be carried out in silos can also be found within industry, as competition and concerns about proprietary information keep developers from sharing information with each other.

C. Action agenda.

This recommendation calls for the establishment of formal mechanisms that can foster effective partnerships between academia and industry. Some of these mechanisms might take the form of new policies that protect the respective rights of industry, faculty, and universities when it comes to the ownership and use of intellectual property. The issues that interfere with the establishment of effective partnerships are complex and venture into some uncharted territory, but until these issues are addressed, it will be difficult to build the kind of collaborative climate that can drive innovation. Policymakers need to understand these issues to effectively lead a discussion among vested stakeholders and work towards policies that support fair and balanced agreements between industry and academia.

In addition to addressing some of the complex barriers to partnerships, mechanisms are also needed to provide universities and industry with incentives for collaboration. Foundations as well as industry leaders can play a key role in forging such alliances. The University-Industry Demonstration Partnership, funded by the Ewing Marion Kauffman Foundation and six other organizations (IBM, Hewlett-Packard, Wyeth Pharmaceuticals, Pfizer, University of Illinois at Urbana-Champaign, and University of North Carolina-Chapel Hill) represents one initiative that aims to connect universities and industry with the goal of bringing innovations to market. This particular initiative seeks primarily to foster dialog between the two parties on technology transfer, licensing, and other university-industry partnering issues; to identify and communicate best practices in university-industry partnering around the globe; and to achieve consensus on guiding principles for university-industry collaboration. Both industry and academic leaders can take responsibility for moving such initiatives forward, by seeking out and participating in such opportunities.

Foundations and Federal agencies can also create funding mechanisms that provide financial incentives for collaboration between academia and industry. Specific funding might be made available for translational research, whereby successful academic projects are developed into actual products for a wider audience. Expanding comparative effectiveness studies to include consumer health IT tools can also open the door between researchers who design and plan the studies and the industry developers that supply the products that are subject to evaluation.

Because many research grant funding channels flow primarily to academia, more efforts should be focused on engaging industry. The first step should be to explore ways of engaging large and small businesses dedicated to developing consumer health IT tools, for example, involving businesses in strategic discussions, Webinars, and events like the “Building Bridges” workshop.

2. Provide Incentives for Industry to Invest in the Development of Consumer Health IT Solutions

A. Recommendation.

Recommendation #2: To help support the development of consumer health IT solutions that meet the needs of all consumers, incentives should be established for industry to invest more resources in research and development of such solutions.

B. Background and rationale.

Considering the potential of benefits of consumer health IT solutions to patients and their health care providers, greater investments in research and development (R&D) of such solutions are warranted. To date, however, industry has devoted limited resources to R&D of these technologies, perhaps owing to the anticipated risks and barriers associated with such investments. To encourage businesses to devote more resources to consumer health IT development, incentives should be established to offset those anticipated risks, or to mitigate existing barriers.

Some anticipated risks may include the occurrence of a medical error that somehow gets attributed to a consumer health IT product, or the acquisition and use of personal health information by unauthorized parties. Other risks may be unanticipated and stem from the fact that, as developers create new systems for managing and transmitting personal health data, they are entering a relatively new frontier that may introduce a host of yet-to-be identified legal, ethical, and social concerns.

Open-source solutions represent one area where such concerns might become manifest. Proponents of an open-source design philosophy—where users share, enhance, amplify, and build upon information that is openly available and freely disseminated—suggest that the open-source model leads to higher quality, more reliable, more flexible, and more cost-effective solutions. Open-source solutions have also been said to result in efficiency gains. Despite their advantages and promise as an agent of innovation, open-source solutions are not widely embraced across industry, possibly due to concerns about accountability. For example, there may be concerns about an original developer being held accountable for any unintended effects of their work, or misuse of their developed products, whether those products be algorithms, source code, an interface, or some other application or solution that gets disseminated.

To address these concerns and to encourage more research and development of consumer health IT solutions, policymakers need to provide industry with incentives that mitigate the anticipated risks of investing in such development. Examples might include providing safety-net

services that afford businesses some financial protection against loss, or implementing hold-harmless provisions that establish an appropriate balance between accountability and protection from risk.

Another way to encourage greater industry investment in R&D of consumer health IT is to reduce the barriers to entry. Financial considerations represent one kind of barrier to entry (e.g., having the capital to meet opening costs), but there are other kinds of barriers that can prevent businesses from entering the market and taking a product from design to development. For example, new businesses may need support in gaining access to test beds,³ where they can quickly and affordably build prototypes, or they may need support in establishing partnerships or in expediting patents.

The Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) programs represent one existing mechanism to address financial barriers for smaller technology companies looking to enter the health IT market. These programs specifically offset start-up costs by awarding grants to small hi-tech businesses to stimulate technological innovation and to increase commercialization of such innovations. The grants target women-owned and socially and economically disadvantaged firms. Both the STTR and the SBIR programs are administered by the Small Business Administration's Office of Technology, but such initiatives need not be limited to the Federal Government. Private funders might develop comparable mechanisms that promote greater investments in R&D among industry leaders as well as small businesses. These mechanisms could specifically provide funding for (1) research to investigate the unique needs of particular user groups, who may present specific design challenges, and (2) the design and development of solutions that address those needs and challenges.

Incentives are also needed to encourage the development of consumer health IT solutions that meet the particular needs of underserved populations. Vulnerable groups like the elderly and the chronically ill typically require more health care services than other populations, and at the same time, they may face more barriers than their counterparts when it comes to health IT usage. For example, some may lack basic computer literacy or easy access to technology. In light of these considerations and the uncertain return on investment, industry developers may hesitate to dedicate adequate resources to research and development of consumer health IT solutions that meet the needs of these groups. This need could possibly be addressed through existing grant programs like the STTR and the SBIR by setting aside specific grant funds to support the development of products targeted to subpopulations with unique needs.

C. Action agenda.

New mechanisms are needed to stimulate the development of innovative solutions for this new market of personal health information technology. One step that policymakers can take is to provide support for the creation of information clearinghouses and communities that interact with each other to spark innovation through sharing of knowledge and common tools. Additionally, certain protections need to be extended to industry to encourage the development

³ An environment created for testing products (e.g., software, machinery, etc.) under simulated working conditions.

of new types of solutions that can support consumers in managing their health information. These protections might include Federal regulations that safeguard businesses from unanticipated liabilities. Finally, to promote greater investments in the development of consumer health IT, public and private funders need to invest more in small businesses—for example, by providing low-interest loans—so that those businesses have the resources they need to design and develop new products. Public and private funders should also establish specific mechanisms to support research and development of consumer health IT solutions targeted to specific subpopulation groups.

Finally, to encourage more R&D relating to consumer health IT, more programs like the Maryland Industrial Partnerships (MIPS) program should be established. Like the STTR and SBIR programs, the MIPS program provides competitive awards to companies to promote the development and commercialization of products and processes. MIPS also provides matching funds to help Maryland companies pay for university research. The industry/university partnerships established through the program helps participating companies meet their R&D goals in a cost-effective manner, while granting them access to state-of-the-art facilities and academic expertise.

3. Education

A. Recommendation.

Recommendation #3: To build awareness about PHIM among young health care consumers, grade-appropriate PHIM education should be incorporated into school curricula.

B. Background and rationale.

Currently, most adults do not have a clear mental model of PHIM. Unless faced with a severe or chronic health condition, they may not consider the need for or the benefits of monitoring, recording, and maintaining up-to-date information relating to their health. Changing the way the current adult population thinks, or fails to think, about PHIM may be a long and incremental process, but an opportunity exists to provide the next generation of adults with the skills and tools they need to start building lifelong habits for effective PHIM. Discussions about who in the home manages the household's health information revealed that children assume greater responsibility for their own health and health information as they move into adolescence and adulthood. Teaching young students about the importance of PHIM can better prepare them to step into this role when responsibilities begin to shift.

Schools could integrate PHIM education into the curriculum early on; one way could be to develop standardized, age-appropriate K-12 materials. A new PHIM curriculum could also be integrated into existing subjects, such as biology or health. Efforts to impart understanding of personal health information could also be tied to educating students more broadly about the impact of behavior, genetics, and the environment on health outcomes.

Students may also benefit from learning how to maintain an updated record of personal health information, technology-based or not. Schools might be an appropriate setting to teach students to maintain such records, thereby familiarizing them with the kinds of information they should be tracking throughout their life.

School-aged children also represent a population that might be more open to experimenting with new health IT applications that are accessible through technology they already use, like smart phones. Schools use students' interest in such applications as teaching opportunities. Innovative technologies that inform students about health matters or help them track personal health data can reinforce the message that students have the tools they need to take responsibility for their own health, while building PHIM-supporting habits for the future.

C. Action agenda.

Several actions were suggested to accomplish the recommended goal of early PHIM education. First, standardized, age-appropriate K-12 materials should be developed to start students down a path of taking personal responsibility for their health and health information. One step on this path might involve having students complete their own ICE (In Case of Emergency) health records. It would also be valuable to explore the viability of national standards for school-taught record components.

4. Establish Standard Ethical Guidelines for the Use and Reuse of Personal Health Information

A. Recommendation.

Recommendation #4: Policymakers and industry stakeholders should agree upon and establish standard ethical guidelines for the use and reuse of personal health information.

B. Background and rationale.

Widespread adoption of consumer health IT solutions among health care consumers is not likely until there is established trust among potential users that their personal health information is secure and will only be available to designated parties. One step that can be taken to build consumer trust is to establish ethical guidelines for the use of personal health data. For example, if consumer health IT vendors are going to be storing consumers' personal health information, they should explicitly agree to rules about guarding and sharing this information, to make certain that it is never used against the individual consumers. The guidelines could be akin to the Declaration of Helsinki,⁴ developed by the World Medical Association, and employed similarly. Users should be made aware of the guidelines and their personal rights.

⁴ The Declaration of Helsinki was adopted by the World Medical Association (WMA) as a set of ethical principles for medical research involving humans, including research on identifiable human material and data, and advocates patient protections including protection of the confidentiality and privacy of personal information. See <http://www.wma.net/en/30publications/10policies/b3/index.html>.

C. Action agenda.

Industry leaders can take initiative by identifying opportunities to explore issues regarding the use of consumers' personal health information, for example at international summits or industry conferences, and then developing policies that may later become the industry standard.

5. Evaluate Implications of New and Existing Health Policies

A. Recommendation.

Recommendation #5: To promote the development and adoption of consumer health IT, new and existing policy implications need to be evaluated.

B. Background and rationale.

In order to advance the field of consumer health IT, it will be necessary to (1) continuously evaluate the implications of new and existing health policies on consumers, developers, and other stakeholders and (2) identify policies that may hamper use of consumer health IT. For example, privacy and security policies vary by state, including what data can be shared among different users, and across state lines. One initiative that has started to address this issue is the Health Information Security and Privacy Collaboration (HISPC), funded through AHRQ and the Office of the National Coordinator for Health Information Technology (ONC). HISPC currently comprises 42 states and territories, and aims to address the privacy and security challenges presented by electronic health information exchange through multistate collaboration. Leveraging the work that has already been done by HISPC, and applying a similar process to the field of consumer health IT, is one step that can be taken to assess how current policies might support or hinder uptake of consumer health IT solutions, and what steps might be taken to reform policies that interfere with advances in the field.

C. Action agenda.

To be able to effectively evaluate new and existing policy barriers for promoting consumer health IT, policy makers need to first determine if consumer health IT systems are likely to be subject to regulation (and if so, by whom). Next, policy makers need to evaluate the implications of the upcoming and existing regulatory environments. Topics could include (1) the implications of different HIPAA regulations and American Recovery and Reinvestment Act of 2009 (ARRA) mandated expansions to HIPAA across health care settings, and (2) use of data entered into a consumer health IT application for other purposes, such as clinical research or public health.

6. Build a Health IT Infrastructure to Enable Patient-Centered Care

A. Recommendation.

Recommendation #6: To enable patient-centered care and ensure broad access to consumer health IT, policymakers and industry stakeholders need to identify ways to build a more robust health IT infrastructure.

B. Background and rationale.

Vast resources have been dedicated to health IT in recent years, but much of the work has focused primarily on health care providers. To meet the needs of health care consumers, greater attention needs to be dedicated to the development of a robust consumer health IT infrastructure that supports consumers in their daily health management activities and provides ready access to their health-related information. Investments in large-scale health information exchange networks and pathways are needed to complement consumer-based applications.

This infrastructure should aim to eliminate the digital divide by attending to the many barriers (e.g., economic, cognitive, and psychological) that currently prevent more widespread use of consumer health IT solutions. A starting point might involve greater investments in interoperable systems of care that are made available to consumers through the most commonly used technologies, like a cell phone. The infrastructure also should meet consumers' demand for better access to their health-related information and better means of communicating with their health care providers, so that they can more actively participate in their own health care. Towards creating this more integrated infrastructure, developing health IT applications that meet these demands is one important step; connecting these applications with broader systems that can match personal health information with the latest evidence and provide personalized decision support is another.

In addition to improving consumers' access to information, a consumer-centric health IT infrastructure should ensure that the information made available to consumers is understandable to those consumers; for example, when providing guidance based on "evidence-based research," the evidence should be presented in a way that has clear and practical implications for the consumer.

Building a more robust consumer health IT infrastructure can support the goal of patient-centered care in several ways. First, such an infrastructure would expand consumers' access to their personal health information, thereby empowering them to become more knowledgeable partners in their health care. Second, insofar as the infrastructure supports the use of tools that enable consumers to connect more regularly with their health care provider, it can facilitate better patient-provider communication. Finally, the infrastructure improvements would make consumer health IT tools and systems widely available to all consumers, not just those who can afford or easily obtain new technology, thereby ensuring that the health care needs of more patients are being met on some level.

C. Action agenda.

To build a more robust consumer health IT infrastructure and to ensure consumers' points of access to that infrastructure, policymakers should first identify current limitations with respect to access and the resources that are available to laypeople. Federal agencies should begin mapping where access is limited and where the "digital divide" is deepest in order to focus attention on areas of greatest need. A second priority should be to survey the landscape of resources that are available for development and dissemination of health IT systems that can connect patients with their personalized health information, their network of health care providers and other relevant sources of data.

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Appendix A: Workshop Agenda

BUILDING BRIDGES:

CONSUMER NEEDS AND THE DESIGN OF HEALTH INFORMATION TECHNOLOGY

July 27-28, 2009

AGENDA

DAY ONE: FROM PERSONAL HEALTH INFORMATION MANAGEMENT TO EFFECTIVE DESIGN

- 8:00 am** *Refreshments*
- 8:30 am** **Insight Policy Research, Inc. Welcome**
Anne Peterson, Principal
- 8:35 am** **Welcome and Comments by AHRQ**
Carolyn Clancy, Director
Teresa Zayas-Cabán, Senior Manager, Health IT
- 9:00 am** **Chair's Presentation**
Patricia Flatley Brennan, Lillian L. Moehlman Bascom Professor, School of Nursing and College of Engineering, University of Wisconsin-Madison, Madison, Wisconsin
- 9:30 am** **Keynote Presenter**
Eric Dishman, Intel Fellow, Digital Health Group, and Director, Health Innovation and Policy, Intel Corporation
- 9:50 am** **Plans for Day**
Patricia Flatley Brennan
- 10:00 am** *Break*
- 10:15 am** **Breakout Session: Setting the Stage: What do we know about how people manage personal health information and what else do we need to know?**
- Breakout Session A:** Observing, assessing, and surveying household members' health conditions
- Breakout Session B:** Organizing, separating, and differentiating information types according to perceived importance or relevance

Breakout Session C: Obtaining, retrieving, and keeping track of health information according to household needs

12:00 pm *Lunch*

1:00 pm **Presentations**

Each group has 15 minutes to present and receive questions.

2:00 pm **Breakout Session: A Closer Look at Design**

Breakout Session A: Key Strategies for Design

This group will discuss current strategies used in design and the link between personal health information management practices and design.

Breakout Session B: Unfilled Design Needs: Design that hasn't been designed yet

This group will focus on next steps in design, including what should exist and what needs to be invented. Discussion will focus on innovation and information required to transform ideas into reality.

Breakout Session C: Strategies of Design for Specific Sub-Populations

This group will talk about special design strategies/considerations that should be made for various sub-population groups, e.g. low-income, rural, disabled, vision impaired and low literacy.

3:45 pm *Break*

4:00 pm **Presentations**

Each group has 15 minutes to present and receive questions.

4:45 pm **Chair's Summary**

Patricia Flatley Brennan recaps day's discussion and announces agenda for Day Two of workshop

5:00 pm *Adjourn*

**BUILDING BRIDGES:
CONSUMER NEEDS AND THE DESIGN OF HEALTH INFORMATION TECHNOLOGY**

July 27-28, 2009

AGENDA

DAY TWO: FROM DISCUSSION TO ACTION: A PLAN FOR MOVING FORWARD

8:00 am *Refreshments*

8:30 am **Welcome and Comments by AHRQ**

Jon White, Director, Health IT

8:45 am **Plans for Day**

Patricia Flatley Brennan, Lillian L. Moehlman Bascom Professor, School of Nursing and College of Engineering, University of Wisconsin-Madison, Madison, Wisconsin

9:00 am **Breakout Session: Setting the Action Agenda**

Breakout Session A: Setting the Research Agenda

This group will develop a research agenda to advance current knowledge and understanding of PHIM practices and requirements for more effective implementation of information technology-based PHIM tools.

Breakout Session B: Setting the Technologies and Related Industries Agenda

This group will develop a technology agenda for advancing the design aspects of IT-based PHIM tools.

Breakout Session C: Setting the Policy Agenda

This group will develop a policy agenda that can facilitate better design of IT-based PHIM tools.

10:45 am *Break*

11:00 am **Presentations**

Each group has 15 minutes to present and receive questions.

12:00 pm *Lunch*

1:00 pm **Roundtable Discussion: Recommendations for Moving the Field Forward**

Led by Patricia Flatley Brennan

3:00 pm **Concluding Remarks**

3:30 pm *Adjourn*

Appendix B: Workshop Participants

Patricia Flatley Brennan (Chair)

Lillian L. Moehlman Bascom Professor
School of Nursing and College of Engineering
University of Wisconsin-Madison

Eric Dishman (Keynote Speaker)

Intel Fellow, Digital Health Group
Director, Health Innovation and Policy
Intel Corporation

Wendy Angst

General Manager
CapMed
Metavante Corporation

Deborah Boehm-Davis

University Professor and Chair
Department of Psychology
George Mason University

Elizabeth Chrischilles

Professor and Associate Head for Academic
Affairs
Marvin A. and Rose Lee Pomerantz Chair in
Public Health
College of Public Health, Department of
Epidemiology
University of Iowa

Sara Czaja

Professor, Departments of Psychiatry &
Behavioral Sciences and Engineering
Co-Director, Center on Aging
Director, Center for Research and Education on
Aging and Technology Enhancement (CREATE)
University of Miami

Jeana Frost

Research Scientist
PatientsLikeMe

Jennifer Griffith

Senior Strategist
Cerner Corporation

Linda Harris

Lead, Health Communication and eHealth Team
Office of Disease Prevention and Health
Promotion
U.S. Department of Health and Human Services

Holly Jimison

Associate Professor of Medical Informatics &
Clinical Epidemiology
Department of Medical Informatics & Clinical
Epidemiology
Oregon Health & Science University

William Johnson

Professor of Biomedical Informatics and Director
Center for Health Information & Research
(CHIR)
Arizona State University

Ben-Tzion Karsh

Associate Professor of Industrial and Systems
Engineering
University of Wisconsin-Madison

Kate Lapane

Professor and Chair
Epidemiology and Community Health
Virginia Commonwealth University

Pamela Larson

Director, Consumer Health, kp.org
Kaiser Permanente

Brian Loew

Founder and Chief Executive Officer
Inspire

Robert Logan

Senior Staff
U.S. National Library of Medicine

Julie Murchinson
Managing Director
Manatt Health Solutions
Executive Director
Health 2.0 Accelerator

Wanda Pratt
Associate Professor
Information School
Joint with Biomedical and Health Informatics
University of Washington

James Ralston
Associate Investigator
Center for Health Studies
Group Health Cooperative

Katie Siek
Assistant Professor, Department of Computer
Science
University of Colorado at Boulder

Ryan Tarzy
President
MediKeeper Inc.
Chief Executive Officer
Personal Health Labs

Gale Wilson-Steele
Founder and Chief Strategy Officer
MEDSEEK Inc.