

Project Title:	Personal Health Information Management and Design of Consumer Health Information Technology
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Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

Business Goal: Synthesis and Dissemination

Target Population: General

Summary: The purpose of this contract was to establish a foundation and propose an action agenda for the integration of patients’ personal health information management into the design of consumer health information technology (IT). These aims were achieved through a 2-day workshop convened by the Agency for Healthcare Research and Quality on July 27 and 28, 2009, titled “Building Bridges: Consumer Needs and the Design of Health Information Technology,” and subsequent final report, titled “Managing Personal Health Information: An Action Agenda.” The report presents key recommendations and an action agenda developed during the workshop.

The goal of the workshop was to assist in the framework development for characterizing personal health information management (PHIM) that would inform the design of effective consumer 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. 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. 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) characterize the methods that individuals and families use to manage their personal health information, 2) establish an action agenda (for research and design, industry, and policy) for supporting consumers’ PHIM practices through health IT, and 3) develop recommendations for moving this agenda forward.

Specific Aims

- Assess and synthesize existing research and evidence regarding patients’ PHIM practices and their linkages to effective development and use of consumer health IT. **(Achieved)**
- Conduct secondary analysis of the Medical Expenditure Panel Survey (MEPS) data regarding what records respondents use to retrieve information about a medical service to understand the degree to which the household received various medical services in the past year are associated with the manner in which the household kept records of those medical services. **(Achieved)**
- Identify and convene a multi-disciplinary expert workshop to establish a research agenda around PHIM and health IT. **(Achieved)**

- Synthesize the information gained into a final report to include a preliminary framework for studying this topic and recommendations for ongoing research, implementation, and policy work in this field. **(Achieved)**

2009 Activities: 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 MEPS-Household Component 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.

The data analysis included utilizing both SAS and SUDAAN statistical software and the findings were presented in one of the following two reports that were developed to provide some context for the workshop and to facilitate discussion among the participants. The first report synthesized existing literature and evidence relating to PHIM needs, goals, tools, and significant gaps in current understanding of PHIM. The second report analyzed the most recent data from the Household Component of the MEPS 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 workshop took place on July 27 and 28, 2009, with 22 expert participants, including leaders in health informatics, information science, consumer health IT, and human factors research. They represented a wide spectrum of perspectives, including academic institutions, technology, health care, and the Federal Government. Presentations and discussions were transcribed following the meeting, and the break-out group sessions were summarized by their facilitators. The final report incorporated the “action items” into a narrative that would support each explicit recommendation, somewhat similar to the position paper published in the *Journal of the American Medical Informatics Association*, titled “A Consensus Action Agenda for Achieving the National Health Information Infrastructure.”

Impact and Findings: The background report synthesized existing literature and evidence relating to PHIM needs, goals, tools, and 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. 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 data analysis from the MEPS 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).

Workshop participants were asked to share their understanding of consumers' current PHIM practices and to identify what else 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 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 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.” 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 various factors can often prevent the two types of entities from working together. 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 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.

In addition, the workshop participants developed a research agenda proposing recommendations pertaining to three main areas: 1) understanding user needs and context, 2) improving design of consumer health IT tools, and 3) evaluation research. The detail behind these recommendations can be found in the final report.

Selected Outputs

Peterson A. Managing Personal Health Information: An Action Agenda (Prepared by Insight Policy Research, under Contract No. HHS290200710072T). Rockville (MD): Agency for Healthcare Research and Quality; March 2010. AHRQ Publication No. 10-0048-EF.

Schneider SJ. Personal Health Information and the Design of Consumer Health Information Technology: Secondary Analysis of Data from the Medical Expenditure Panel Survey. (Prepared by Insight Policy Research, under Contract No. HHS290200710072T). Rockville (MD): Agency for Healthcare Research and Quality; July 2009. AHRQ Publication No. 09-0090-EF.

Agarwal R, Khuntia J. Personal Health Information and the Design of Consumer Health Information Technology: Background Report. (Prepared by Insight Policy Research under Contract No. HHS290200710072T). Rockville (MD): Agency for Healthcare Research and Quality; June 2009. AHRQ Publication No. 09-0075-EF.