# Personal Health Information Management and the Design of Consumer Health Information Technology

## Background Report

**Prepared for:**

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U.S. Department of Health and Human Services
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# Executive Summary

## Objectives of the Report

Health information technology (health IT) has been identified as a crucial component of addressing persistent deficiencies in the United States health care system, including patient safety, quality of care, and high costs. A series of influential reports published by the Institute of Medicine including *Crossing the Quality Chasm* (2001), *Exploring Innovation and Quality and Improvement* (2001), and *To Err is Human: Building a Safer Health System* (2000) have underscored the importance of delivering patient-centered care and using health IT in care delivery, accelerating advances in consumer health IT and provided the impetus for a nationwide focus on patient empowerment through consumer health IT.

Consumer health IT is the collection of tools, technologies, and artifacts that consumers can use to support their health care management tasks. "Patient empowerment" where the individual health care consumer is conceptualized as a focal player in the flow of health information, and where information technology is viewed as a key enabler of this empowerment is an important and recurrent theme in the national discourse on health. Such empowerment in health care is critically dependent on consumers' ability to capture, store, and manage their "*personal health information"* (PHI). PHI includes a wide range of information relevant to the individual's health, such as body-mass data, health status, existing ailments, symptoms, disease specific vital information, physiological details, medication lists and schedules for taking medication. Personal health information management (PHIM) has been defined as the activity involving the integration of personal, professional, and health-related information, which helps people manage their lives and actively participate in their own health care.

Evidence suggests that the value potential of consumer health IT and PHIM is compelling: the management of information related to health has been shown to have a direct bearing on the health and welfare of individuals. In order to design appropriate consumer health IT applications that will enable patients to manage their own health and health care, it is imperative to understand what consumer needs and practices are with respect to PHI and PHIM, so that

solutions that are best suited to support, extend or optimize those management practices can be developed. To this end, in July 2008, the Agency for Healthcare Research and Quality (AHRQ) awarded Insight Policy Research of Arlington, Virginia a contract titled "Personal Health Information Management and the Design of Consumer Health Information Technology (IT)." One of the tasks in that contract is to develop a background report based on an extensive literature review and synthesis of existing research on PHIM and consumer health IT. The report is motivated by a growing emphasis on a consumer-centric health care system and the desire to enable consumers to become more empowered in the management of their health. The goals of the report are to: (1) define the domain of personal health information management, (2) summarize extant research on this topic, and (3) offer recommendations that can enable better design of PHIM tools that create value for users.

Research relevant to PHIM and the design of consumer health IT can be found in multiple disciplines including health informatics, human factors, human-computer interaction, information sciences, and information systems. As such, literature from each of these disciplines was reviewed for this report. Articles were initially screened for relevance to the goals of the report. Those selected for further review were examined in detail and classified into topic areas based on their content and the specific aspect of PHIM practices and tools they addressed. The report synthesizes and summarizes the existing literature across the following topic areas:

- Existing evidence on consumers' personal information management (PIM) and personal health information management needs and goals.
- Practices used for PHIM and PIM.
- Tools and technologies available to date, either commercially or in prototype form.
- Gaps in the literature regarding the understanding of PHIM.

Additionally, the report identifies areas in which future research is necessary in order to drive the design of effective consumer health IT.

# Key Themes in the Literature

Below are some of the key themes identified from the literature review across all disciplines.

***PHIM as a special case of the activity of personal information management (PIM).*** PIM refers to the collection of tasks that people perform in order to acquire, organize, maintain, retrieve and use *information items* such as forms and documents (that may exist in paper-based or digital) format), web pages, and email messages *to complete tasks* (professional or personal) and *fulfill their various roles* (as parent, employee, friend, or member of a community). Core tasks of PIM include the search, retrieval, and refinding of previously encountered information from both personal and shared space. Personal information management occurs in a complex milieu or "system" that includes the interactions between characteristics of users, information, and needs. PHIM can therefore be considered a special case of personal information management because PIM and PHIM overlap in their overarching goals, except that the latter relates specifically to the management of health information. Thus, the individual's PIM practices and the tools that used to support the PIM activities will doubtless influence PHIM practices.

***There are a variety of different types of information that constitute the set of personal health information*** that a consumer may need to collect, organize, store, and retrieve while engaging in PHIM activities. ***This information comes from a multiplicity of information sources*** with which the individual interacts with varying frequency and intensity. Based on the literature review, two classification schemes were developed: one for types of personal health information (with seven categories), and another for sources of personal health information (with five categories). PHI can be classified into seven categories based on the value derived from the content of the information beyond its specific purpose or *primary* value; and for purposes other than what it was originally created for (i.e., *informational* value): (1) personal identifiers, (2) personal demographics, (3) emergency medical and critical information, (4) biomedical, clinical and genetic personal health information, (5) mental or psychological personal health information, (6) physical activity, body-mass information, exercise regime, nutrition and energy levels, and (7) information dealing with insurance or financial matters relevant to health management. The

sources of PHI fall into five categories: (1) health care provider (2) health care insurer, (3) individuals' social network, (4) mass media and public institutions, and (5) others.

***Users of PHIM vary*** along the dimensions of the nature and scope of information use, its intended purpose and the boundary of use. While the individual is often the collator and owner of the personal health information that is needed for future needs that he/she might foresee, actual use might extend from him/her to others such as family members, relatives, acquaintances, doctors, clinicians, health providers and payors. Attributes of the user such as demographic characteristics and health status affect the nature and scope of PHIM activities and have implications for the design of tools and artifacts that support these activities. Users follow ***different strategies for managing and organizing their personal health information***. The strategies deployed can be influenced by many factors including the characteristics of the medium (i.e., paper-based versus digital) and user characteristics. The literature identifies several strategies for organizing and retrieving information stored in paper and digital form, such as the personal project planner, human digital memory, folders, projects, task management, personal archives, and collections. Each strategy adopts a particular conceptual approach for representing the discrete collections of information that constitute the stock of personal information items that the user seeks to manage and organize for subsequent access and retrieval.

The complex process underlying the ***management of personal health information can be supported in various ways with tools, devices, and artifacts***. Although paper-based solutions are still widely prevalent and work efficiently in many contexts, they are nonetheless limited in important functionality such as easy retrieval of stored information, and the capability of efficiently managing large volumes of data. A review of artifacts described in the literature suggests a four category classification based on their functionalities and application orientation. The categories of existing tools include the following: (1) tools that support health information storage, archival, and retrieval, (2) tools that support health monitoring, (3) tools that support health information seeking and searching, and (4) infrastructural tools and artifacts for PHIM. Many of these artifacts are still in a prototype stage and are not available as commercial tools. Further, field testing and evaluation of many of the tools is still at a very early stage.

Existing knowledge related to ***design principles and considerations for the design of consumer health IT tools*** for personal information management is limited. The concept and principles of "user-centered" design are highly relevant to consumer health IT and to identifying user requirements. General design considerations for PHIM and PIM tools include support for a range of use, support for variety in location and distribution, support for multiple media, support for context, and an incorporation of PIM activity level considerations. The literature also contains some normative prescriptions for the design of specific PIM and PHIM tools such as PHRs, task list managers, and mobile artifacts. An overarching design consideration that emerges from prior work is that the design of consumer health IT must take into account the context, tasks, goals, and characteristics of the user.

A user attempting to manage his/her personal health information ***faces many barriers and must overcome multiple challenges in order to execute the PHIM activities successfully***. General barriers related to the management of PHIM arise from the user's cognitive and behavioral limitations in understanding, structuring, and organizing the potentially extensive volume of health related personal information that must be managed, and from the diversity of forms in which personal health information exists. Privacy issues also constrain the user's motivation to structure and organize PHIM. In the case of tools and technologies that are deployed to support PHIM, the research literature suggests that the design principles guiding the design of extant tools are not anchored in a deep understanding of the user's tasks, context, goals, and preferences. As with the PHIM activity, the use of tools to support PHIM faces a significant barrier in the form of privacy concerns.

***Current methodological approaches to the study of PIM and PHIM practices and tools fall into the two broad categories of naturalistic and laboratory-based inquiries***. Each of these approaches has unique strengths and weaknesses and neither can be used to the exclusion of the other. Understanding and knowledge development in this domain must necessarily follow an iterative cycle of using the field to gain initial insights into practices, incorporating this understanding into tools, learning about the efficacy of these tools in laboratory and field settings, and successively refining the tools based on users' experiences and responses. Given the relatively recent nascence of research on PHIM, it is not surprising that large scale

experimental or field studies have yet to be conducted. Further, to the degree that PHIM is a somewhat idiosyncratic activity for users depending on their specific goals, the context, and their characteristics, situated inquiry is necessary to deeply understand personal health information management practices.

## Gaps in the Literature

The review of existing literature on PIM and PHIM practices and tools shows that although there is a fairly extensive and growing body of research in this domain, some critical gaps remain. The study of PHIM is complicated by many factors. One core challenge is the inherently multi-disciplinary nature of the domain that demands a synthesis of insights from work that originates in different research communities including health informatics, information retrieval and search, human factors, human-computer interaction, computer science, cognitive psychology, industrial engineering, and information systems in order to advance understanding. This implies that the traditional disciplinary boundaries need to be crossed in the study of PHIM to overcome the fragmentation that exists in the body of knowledge. A second core challenge emerges from the inherent nature of PHIM and the fact that it is an idiosyncratic, situated activity that is fundamentally personal in nature. The individual is constrained by limited cognitive capacity to remember and manage each and every piece of information that is relevant to her/him and encountered in daily life. There is a mismatch between the complexity of individuals' lives and their cognitive capacity, resulting in information overload, and the need to learn and remember increasingly more information. Thus, developing generalizable theories about PHIM practices or even obtaining a detailed understanding of how individuals with diverse backgrounds, characteristics, and goals manage their personal health information is a daunting task.

There are **six critical areas that demand continued research attention** in order to advance the goal of consumer empowerment with respect to the management of personal health information.

- Taxonomies and classifications of users, use activities, and use contexts.
- PHIM practices of subpopulations that have not been studied to date.
- Comparative effectiveness of PHIM practices.

- Articulation of functional requirements of tools and design philosophies.
- Details of design elements.
- Rigorous evaluation of tools and technologies.

# Conclusion

PHIM is a relatively new and emerging area of research that is highly consequential for achieving the goal of a consumer-centric health care system. Although evidence related to PHIM practices and design considerations for tools is slowly accumulating, much work remains to be done. Gaps in current understanding range from incomplete knowledge about the different goals and motivations for consumers to engage in PHIM, to the health information management needs of subpopulations, to detailed descriptions of the functional requirements and design elements for consumer health IT tools. The key gap that needs to be addressed is ***comprehensive and situated understandings of what individuals actually do when they manage their personal health information, and what challenges they face in doing so effectively***. Filling this knowledge gap is a crucial precondition to determining what is needed from PHIM tools. However, in much the same way as discretionary software applications have changed individual behaviors with respect to managing personal, financial information, tools and technologies that can help individuals become more effective, efficient, and empowered users of their personal health information have the potential to more fully address key needs in health care management.

# Chapter 1: The Domain of Personal Health Information and Consumer Health Information Technology

## 1.1 Background and Introduction

The delivery of health care is, at its very core, an information-based science (Hersh, 2002). It is not surprising, therefore, that health IT has been identified as a crucial component of addressing persistent deficiencies in the health care system, including patient safety, quality of care, medical errors, and high costs (Institute of Medicine, 2001). "Patient empowerment" where the individual health care consumer is conceptualized as a focal player in the flow of health information (Masys et al., 2002), and where information technology is viewed as a key enabler of this empowerment is an important and recurrent theme in the national discourse on health. As Eysenbach (2000) notes, "information technology and consumerism are synergistic forces that promote an 'information age health-care system' in which consumers can, ideally, use information technology to gain access to information and control their own health care, thereby utilizing health care resources more efficiently." The consensus on achieving the vision of the National Health Information Network (NHIN) further reinforces the pivotal role of individuals in "controlling and managing their own health information" (Yasnoff et al., 2004). In addition to more effective utilization of health care resources, greater engagement by patients with their own health care should have a positive effect on health outcomes and lead to quality of life improvements and a reduction in the time spent in ambulatory care visits (Gustafson et al., 1999).

Consumer empowerment in health care is critically dependent on consumers' ability to capture, store, and manage their "*personal health information*" (PHI) in order to assume greater control over their own health and health care. PHI includes a wide range of information relevant to the individual's health, such as body-mass data, health status, existing ailments, symptoms, disease specific vital information, physiological details, medication lists and schedules for taking medication. PHI encompasses any information that is necessary for the individual to maintain good health. This includes (1) information needed to aid him or her in obtaining care for illness and disease; (2) information that is relevant to provide a support system for his or her health care

such as whom to contact in case of an emergency; (3) information related to facilitating access to health care such as, contact information of doctors, insurers, payors, referred hospitals; and (4) health-related financial information. The criterion of *"what is relevant to the individual's health"* is the primary touchstone for what should be included in the category of PHI. However, the *"individual self"* may not be the only one to decide which information might be considered as his or her PHI. At times care providers or other key stakeholders may extend the scope of what is contained in the individual's PHI in the process of dealing with the individual's health. For example, a doctor may need a person's genetic information to test for the presence of certain markers. In this instance, the doctor determines that *"genetic information"* should be added to the collection of PHI, for the specific purpose of treatment. Thus, the collection of information that constitutes an individual's PHI is constructed over time, through the multiple health-related episodes the individual experiences in his/her life.

Widespread agreement on the need for consumer empowerment has led to a growing interest in developing tools and technologies that can enable and support consumers in gaining greater control over their health. Consumer health IT is the collection of tools, technologies, and artifacts that consumers can use to support their *personal health information management* tasks (Eysenbach, 2000). Civan et al. (2006) define personal health information management (PHIM) as the set of activities that support consumers' access, integration, organization, and use of their personal health information. Similarly, Pratt et al. (2006) define PHIM as the activity involving the integration of personal, professional, and health-related information, which helps people manage their lives and actively participate in their own health care. Hence, as an inclusive definition, consumer personal health information management is the process and strategies adopted by people to find, keep, organize, and share a broad range of personal and health information in order to manage a variety of health-related tasks including scheduling, planning, coordination, decision making, tracking, and communicating with others (Moen & Brennan, 2005; Pratt et al., 2006).

The value potential of consumer health IT and PHIM is clear. The management of information related to health has a direct bearing on the health and welfare of individuals. Access to and control of information that is relevant for health information management is a critical component

of enabling better health care, and is a first step towards consumer empowerment in health management activities (Brennan & Safran, 2005). Researchers have suggested that electronic health information use by patients should yield many positive outcomes, including providing better comparison with existing data from earlier examinations, reducing the number of ineffective treatments, increasing patient's ability to follow treatment plans and recommendations, reducing length of stay in hospitals, and providing a lifelong health record across institutional boundaries (Ueckert et al., 2003).

The variety of consumer health IT applications is growing every day, as are the sources from which consumers[1] receive health information. Artifacts encompass a wide range of functionality, to include technologies such as personal health records (PHRs)[2] that receive, provide and store health information (Agarwal & Angst, 2006; Tang et al., 2006); medical devices and monitoring systems for general health parameters such as heart rate, breathing rate, and activities of daily living (Alwan et al., 2006); and systems that automatically capture and transmit relevant health data for various disease specific conditions (Casper & Kenron, 2005). Although many of these devices, applications and systems are tools targeted at providers, care managers, or nurses to provide health care to consumers, they frequently generate information that is used by the individual, and further, provide feedback information to the individual on his/her current state of health. With regard to sources of health information, in addition to the traditional sources such as health care providers, the increased availability of information on the Internet has fundamentally changed the health information search, acquisition, and use behaviors of the United States population in unprecedented ways (Risk & Dzenowagis, 2001). Although estimates vary, researchers agree that there are more than 100,000 health-focused websites on the Internet and close to 100 million individuals in the U.S. engage in e-health activities online (including accessing information and participating in health-related, online communities). Increasingly, the information obtained is driving the behaviors of consumers and influencing the

[1] The labels are used "consumer", "user", and "patient" interchangeably in this report.

[2] The National Alliance for Health Information Technology in their Report to the Office of the National Coordinator for Health Information Technology defines a PHR as: "an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual." (The National Alliance for Health Information Technology Report to the Office of the National Coordinator for Health Information Technology On Defining Key Health Information Technology Terms, April 28, 2008, available at : http://www.dhhs.gov/healthit/documents/m20080603/10_2_hit_terms.pdf)

health management decisions they make. In fact, a recent study based on data collected by the Pew Internet and American Life Project reported that information obtained online is more likely to affect the treatment decisions, interactions with doctors, ability to cope with the medical condition, and diet and fitness regimen of individuals suffering from a disability or chronic condition compared to other users of online health information (Fox, 2007). Together, these findings suggest that consumers are assuming greater control over their health management activities, and that access to information is a critical component of this role.

Prior research on the PHIM practices and behaviors of individuals reveals many dimensions of complexity in this activity. For example, relevant health information tends to be fragmented; it is scattered in multiple repositories and in multiple media using a variety of tools and artifacts that range from paper-based storage to electronic databases; it is often not structured and organized for easy access and retrieval; the sheer volume and complexity of the information places considerable cognitive burden on individuals to understand and use it; and health information management activities are conducted in diverse settings including the home, while consumers are traveling, and when consumers interact with care providers (Pratt et al., 2006, Moen & Brennan, 2005). There is also significant variety and diversity in the users of personal health information and their specific goals with respect to the PHIM activity. Individuals develop behaviors, routines, and strategies to manage their PHIM activities, and obtain or create information management tools to assist in these tasks. To the degree that effective PHIM is a critical prerequisite for patient empowerment and participation in their own health care, an understanding of the efficacy of different PHIM practices is important to educate consumers about how to more effectively manage their PHI. Further, given the complexity in PHIM activities, a better understanding of PHIM is essential for the design of technologies, incentives, and processes that can help realize the anticipated value from consumer health IT applications. Researchers generally agree that a number of demographic, behavioral, and situational contingencies affect both individual perceptions of various PHIM technologies and the manner in which PHIM activities are executed. Thus, the design of consumer health IT must take into account the patient's environment, support system (family, neighbors, providers, etc), and information management goals and tasks.

## 1.2 Goal of the Report

The Agency for Healthcare Research and Quality (AHRQ) commissioned this report as a key deliverable for the task order entitled "Personal Health Information Management and Design of Consumer Health IT." The work reported is motivated by the growing emphasis on a consumer-centric health care system and the desire to enable consumers to become more empowered in the management of their health. The broad goals of the report are to: (1) define the domain of personal health information management, (2) summarize extant research on this topic, and (3) offer recommendations that can enable better design of PHIM tools that create value for users. Research relevant to PHIM and the design of consumer health IT can be found in multiple disciplines including health informatics, human-computer interaction, information sciences, and information systems. Bodies of literature from each of these disciplines were examined in preparing this report. The report summarizes the foundation of existing evidence on consumers' PHIM needs and goals, the practices used for PHIM, the tools and technologies currently in use, and various gaps in understanding. It identifies areas in which future research is necessary in order to drive the design and deployment of consumer health IT.

## 1.3 Personal Health Information Management as a Special Case of Personal Information Management

It is important to note that PHIM is a special case of the activity of personal information management (PIM). PIM refers to the collection of tasks that people perform in order to acquire, organize, maintain, retrieve and use *information items* such as documents (that may exist in paper-based or digital format), web pages, and email messages *to complete tasks* (professional or personal) and *fulfill their various roles* (as parent, employee, friend, or member of a community). Core tasks of PIM include the search, retrieval, and refinding of previously encountered information from both personal and shared space (Barreau et al., 2008; Jones 2007). This report includes a robust and growing literature in PIM because fundamentally, PIM and PHIM overlap in their overarching goals, except that the latter relates specifically to the management of health information. Thus, the individual's PIM practices and the tools used to support them will doubtlessly influence PHIM practices. However, it is also important to recognize that the

management of health information is potentially more consequential for an individual than the management of other types of personal information. An implication of this difference is that individuals may have varied levels of sensitivity with regard to the privacy and security of different types of information (Anderson & Agarwal, 2008). Therefore, while research on PIM is clearly useful to help frame and understand PHIM, the subtle distinction between the domains of information must be kept in mind when identifying requirements and design considerations for consumer health IT.

## 1.4 Organization of the Report

The report is organized into 11 chapters, including this introductory chapter. Chapter 2 provides a conceptual map for framing the research literature on PIM and PHIM and its enablement through technologies. It provides definitions of key concepts in the domains of PIM and PHIM, and highlights the situated and sociotechnical nature of PHIM activities.

Chapter 3 summarizes evidence related to sources and types of personal health information. Types of personal health information may include clinical data (medical visits, prescription information, test results), financial data (insurance, payments), and other types of information relevant to the management of personal health such as basic demographics. Sources of personal health information are diverse and include information accessed from the Internet and other sources, data from home monitoring devices, and information provided by an individual's social network. A classification scheme for types of personal health information, and another for sources of personal information is presented.

Chapter 4 provides a discussion of the users of personal health information, noting that the "user" in PHIM is not necessarily only the individual who is managing his/her personal health information. Often individuals have responsibility for managing the health information for the entire family. Further, the information may be shared with other "users," including families, caregivers, friends, and neighbors. This chapter highlights the different goals and needs of users with respect to PHIM, and diversity among users in regard to their personal characteristics. It discusses the tensions created by such user diversity and its implications for PHIM.

Chapter 5 includes a summary of existing evidence on the strategies followed by users for managing and organizing personal health and other personal information. Strategies may involve the use of paper-based or electronic storage media. A variety of strategies is reviewed, including those used in the home setting. In the literature, strategies and tools are often intertwined as the design of tools explicitly or implicitly embed a model of information storage and retrieval.

Chapter 6 discusses the tools and artifacts that support and enable PIM and PHIM. These artifacts may exist in paper or digital form. A classification scheme for categorizing the wide range of artifacts described in prior research that includes the categories of: (1) tools and artifacts that support health information storage, archival and retrieval, (2) tools and artifacts that support health monitoring, (3) tools and artifacts that support health information seeking and searching, and (4) infrastructural tools and artifacts for personal health information management.

Chapter 7 presents design considerations and principles for the design of consumer health IT. It describes considerations related to the design process, namely, the notion of user-centered design. This chapter includes a categorization of general design considerations that have been discussed in the literature. It also includes specific design guidelines that have been proposed in the context of particular classes of consumer health IT tools such as personal health records and websites that provide health information and/or support online health communities.

In Chapter 8 two categories of barriers to effective personal health information management that have been discussed in the research literature are identified. The barriers that focus on the management of personal information in general and the types of challenges users encounter in executing PIM activities fall into one category, and those that highlight specific challenges in using IT solutions for personal health information management comprise the other.

Chapter 9 summarizes research approaches used to study the phenomenon of PHIM and tools that may be used to support the activity. The methodological approaches to the study of PIM in extant literature can be classified into two major categories: naturalistic approaches, that seek to

study PIM practices and the use of tools *in situ*, and laboratory approaches that investigate PIM practices and tools in controlled environments.

Chapter 10 provides a critical assessment of gaps in knowledge and understanding related to the personal health information management practices of consumers and how those consumers may be more effectively supported and enabled through tools and technologies. A key gap that needs to be addressed is the comprehensive and situated understandings of what individuals actually do when they manage their personal health information, and the challenges they face in doing so effectively. Five specific opportunities for future work are identified. Chapter 11 concludes this report.

# Chapter 2: A Conceptual Map of the Literature

In the past two decades a rich literature has emerged that directly or indirectly addresses issues in the PHIM domain. Researchers working in this area are affiliated with a wide variety of reference disciplines and address a broad range of research questions. The disciplines include

- Health IT and health informatics, where questions related to specific health information management issues and the use of tools are addressed (e.g., Moen & Brennan, 2005);
- The information and design science community, that focuses on understanding personal information management practices, optimal design strategies for consumer tools, and human factors issues (e.g., Jones, 2007); and
- Information systems, where the emphasis is on understanding the barriers and facilitators of consumer use of health IT (e.g., Angst & Agarwal, 2009).

Figure 1 provides a conceptual model for framing the research literature. Its structure is derived from a synthesis of prior work by Smith and Carayon-Sainfort (1989), Zayas-Caban (2005), Moen and Brennan (2005), and Jones (2007). This model is used to provide an overview of the key concepts in this domain.

## 2.1 The "Informational" Foundation of Personal Information Management and Personal Health Information Management

As depicted in the model, shown in Figure 1, an individual can be characterized as operating in a "personal space of information (PSI)" and managing multiple "personal information collections (PICs.)" The PSI and PIC constitute the informational foundation of PIM and PHIM. The PSI is the set of information items that are under the control of the individual, although this control may be shared by others such as a family member (Jones, 2007). The PSI is conceptualized broadly, so it may include not only tangible items such as notebooks or files, but also electronic documents or references to web pages. Located within this PSI are multiple PICs, or a "personally managed subset of a PSI" (Jones, 2007). The key notion behind a PIC is that it represents an individual's attempts at organizing related information so that other PIM activities are facilitated.

The level of sophistication in the organizing approach varies widely across individuals and PICs, and can range from a pile of papers simply lying together to connote relatedness, or an indexed and filed collection of tax papers stored in a three-ring binder (see Chapter 5). One important feature of a PIC is that the information it contains is generally of the same form, e.g., an electronic folder of received email messages that pertain to the same subject or come from the same sender. However, as noted by Jones (2007), the property that all items in a PIC are of the same form may not always be observed in reality. For instance, a PIC may be organized such that it consists of items that satisfy the information needs of the individual in a particular domain such as managing finances. In such instances, the PIC will likely contain information in diverse forms including paper credit card statement, electronic account information, or data in a spreadsheet or a software package. The PSI together with the PICs constitutes the foundation for the individual's PIM activities.

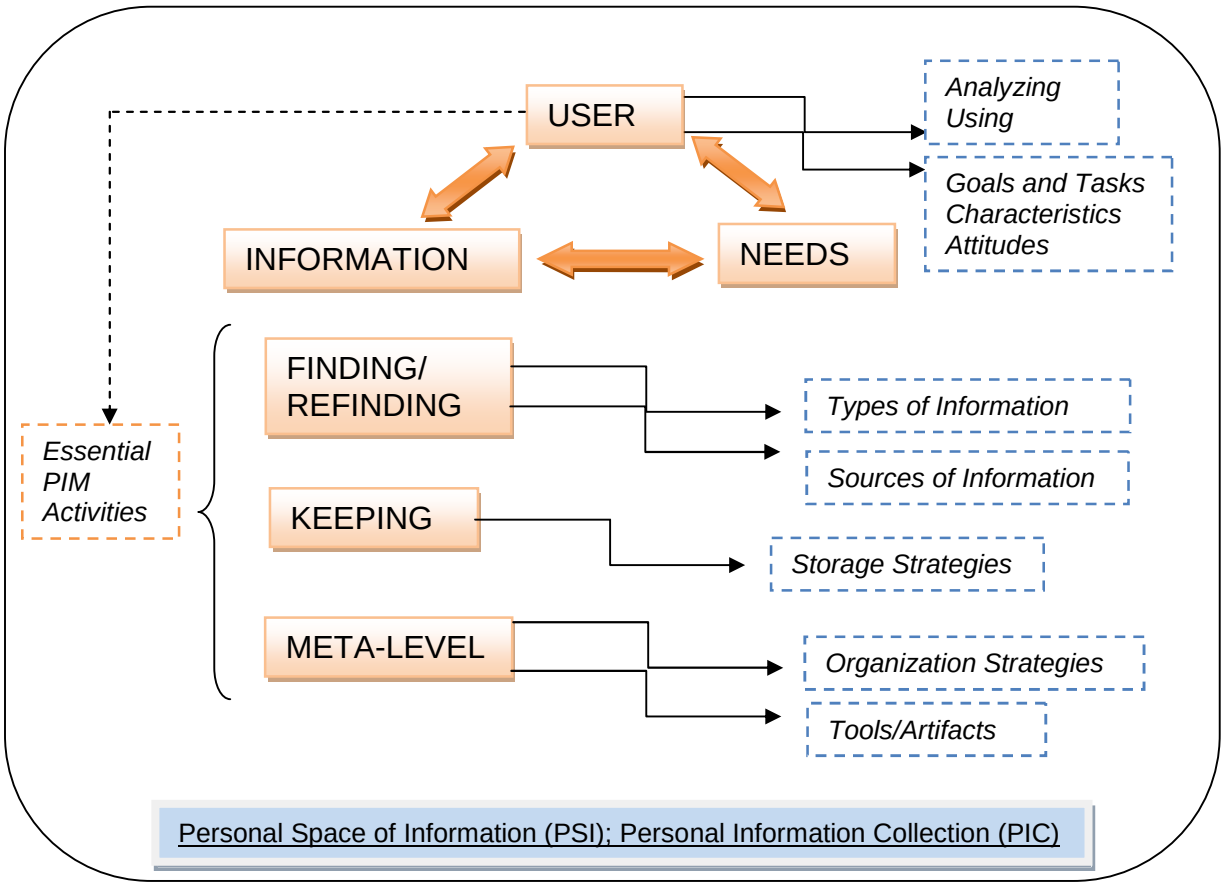


**Figure 1. The Domain of Personal Information Management**

## 2.2 Essential Personal Information Management Activities

The overarching objective of PIM is to establish a mapping between a user's need for information and the information itself. This mapping is achieved through a core set of three activities, finding/refinding, keeping, and meta-level actions (Jones, 2007). The mapping may be an observable physical manifestation, such as indexed folder that specifies the location of information items, or it may exist in the individual's head, such as a telephone number that is stored in memory and retrieved by the need to initiate a telephone call. PIM activities can then be viewed as implicit or explicit attempts to facilitate the mapping process.

An *information need* typically serves as the trigger for finding and refinding activities. These activities involve actions that seek old (i.e., information already available in the PSI which may or may not be organized into a PIC), and/or attempt to locate new information. The information sought can be both personal as well as public. As Jones (2007) notes, there are many variations of finding activities, including finding and refinding public information, discovery in the case of personal information (i.e., the user may not even realize that he/she possesses the information), and refinding personal information that is in the PSI. This latter type of finding activity is generally considered to be the core task of PIM, and involves four steps: (1) remembering to look (generally instigated by an information need), (2) remembering meta-information to narrow the subsequent scan, (3) recognizing the information item when it is encountered, and (4) repeating the activity until the information need is satisfied. Thus, "finding" can be conceptually treated as an activity that involves interplay between memory, recall, and recognition. As depicted in Figure 1, finding actions are dependent on the type of information as well as the sources or repositories where this information is stored. These information sources and types in the specific instance of personal health information are discussed in Chapter 3.

A second key PIM activity is that of "keeping," where individuals make decisions about retaining information that may be purposively or accidentally encountered. For example, a user could be browsing a web page and may decide that the information contained there would be relevant to satisfy some future information need and decides to "save" it. Keeping actions can

also be initiated when the user's task is interrupted and there is a need to save the current state so that the work may be resumed at a later point in time. In summarizing the research on keeping, Jones (2007) makes the following observations: (1) keeping is fraught with errors and is a complex task; (2) with the increase in the quantity and diversity of information types and associated tools, making the correct decisions about what to keep it and how to keep it is becoming progressively more difficult; and (4) although the costs of incorrect keeping are declining (because storage is less expensive, and/or because items not kept can more easily be searched and found later), they are not nonexistent. The two major decisions related to keeping are (1) what to keep and (2) what storage or keeping strategy to deploy.

The third and final core activity of PIM is meta-level action, where a user proactively attempts to establish the mapping between information needs and information items such that future search and retrieval is facilitated. Here the user decides upon an appropriate organizational strategy for the information, such as folder hierarchies, piles, or indexes (Jones, 2007). He/She also determines whether electronic or non-electronic tools should be used to support the organizing of information. Strategies for organizing information and the utilization of tools and artifacts are summarized in Chapters 5 and 6, respectively. This is an activity that users frequently tend to pay less attention to but is arguably, the most significant for effective information "finding."

## 2.3 The Personal Information Management "System"

Figure 1 captures one recurrent and important theme in the research literature: that personal information management occurs in a complex milieu or "system" that includes the interactions between characteristics of users, information, and needs. Indeed, as noted above, PIM activities are initiated to establish a mapping between a need for information and the information itself. Having established this mapping, the user engages in analyzing and using the information. Broadly speaking, PIM can be viewed as a type of work that occurs within a sociotechnical or work system (Smith & Carayon-Sainfort, 1989; Trist, 1981) to understand interactions between the different elements that are present when an individual is trying to accomplish a specific task (Zayas-Caban, 2005.)

Smith and Carayon-Sainfort (1989) describe the "balance model" for understanding any work system that situates the individual at the center of the work system, and includes the environment, tasks, organizational factors, and tools and technologies (Figure 2). The individual's characteristics, personality, perceptions, and other attributes affect the manner in which the individual interacts with and performs within the work system. Chapter 4 summarizes research related to the user in personal health information management contexts and identifies specific characteristics of the user that may be relevant to understanding and explaining variation in PHIM approaches. The physical environment simultaneously facilitates and constrains the accomplishment of work. For example, in the context of PIM specifically, allocated space in the user's environment that is solely devoted to the storage of information such as a filing cabinet located in a home office can simplify the task of finding, keeping, and organizing information. Zayas-Caban (2005) describes the environment component of the balance model as the physical three-dimensional space where all information is located. She extends the notion of environment to also include the social context within which the user will complete his/her tasks.

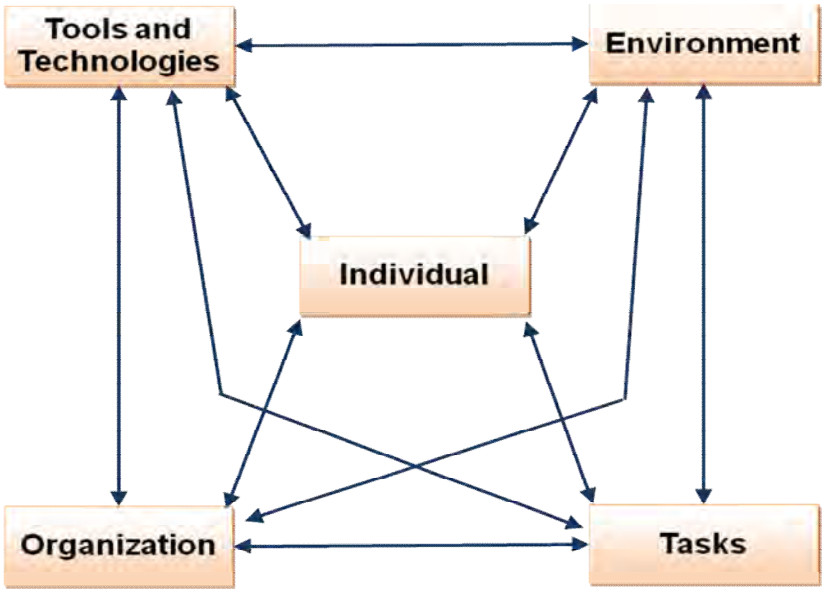


**Figure 2. The Balance Model of a Work System**
**(Adapted from Smith and Carayon-Sainfort (1989))**

Organizational factors relevant to the effective accomplishment of tasks include training, skills, and available support (Smith & Carayon-Sainfort, 1989). Zayas-Caban (2005) includes in the

balance model family policies such as the ownership of information and the consequent decision about where to store that information. Tasks are specific actions that a user needs to undertake to accomplish particular goals. For example, in the context of health information, a goal could be to "schedule a doctor's appointment for myself." Specific tasks needed to accomplish this goal involve multiple actions such as locating the physician's telephone number, identifying availability on one's personal schedule, initiating the telephone call to the doctor's office, agreeing upon an appointment time, and recording the appointment. Goals can be articulated at multiple levels of granularity; for instance, a goal may be expressed at a higher level of abstraction, such as the need to "get healthier." Such a goal would then trigger multiple tasks such as scheduling a doctor's appointment or commencing an exercise regimen. Tasks can be described along multiple dimensions, including repetitiveness (e.g., record weight weekly), meaningfulness, and novelty (Smith and Carayon-Sainfort, 1989).

The final component of the balance model is the tools and artifacts that are used for the accomplishment of tasks. To illustrate, relevant tools for the accomplishment of the "schedule a doctor's appointment for myself" task could include a telephone book (physical or electronic), a personal calendar, and a device such as a phone to initiate the call. A number of tools have been described in the literature, including the personal health record (Tang et al., 2006), and devices that monitor and store relevant personal medical data such as heart rate (Casper & Kenron, 2005). These are summarized in Chapter 6.

## 2.4 Summary

The existing discourse on PIM and PHIM acknowledges that these activities are embedded within a complex "system" that contains multiple interacting components. While the balance model draws attention to the elements of a work system initially described in the context of a workplace (Smith & Carayon-Sainfort, 1989) and subsequently extended to work-at-home (Zayas-Caban, 2005; Moen & Brennan, 2005), research on PIM identifies the specific activities that comprise personal information management. Extant knowledge and literature related to the balance model as well as PIM research are relevant to mapping the domain of personal health information management, and are summarized in the remainder of this report.

# Chapter 3: Sources and Types of Personal Health Information

The collection of health information that is under the control of a consumer has increased sharply. This information originates from a variety of sources and assumes many different forms. The volume of information, the variety in its functional form, and the diversity of its sources create significant complexity for the individual consumer. For example, today's consumer needs to manage multiple types of information such as lab results, vital signs, provider information, and medication lists to name a few (Agarwal & Angst, 2006; Brennan & Kwiatkowski, 2003; Civan et al., 2006). This information may come from doctor's visits, health magazines, the Internet, or a device that automatically records vital signs (Brennan & Kwiatkowski, 2003; Fox, 2007; Moen & Brennan, 2005). The literature identifies several types of information that an individual may have to collect and manage for effective PHIM, as well as multiple sources of this information (Figure 3).

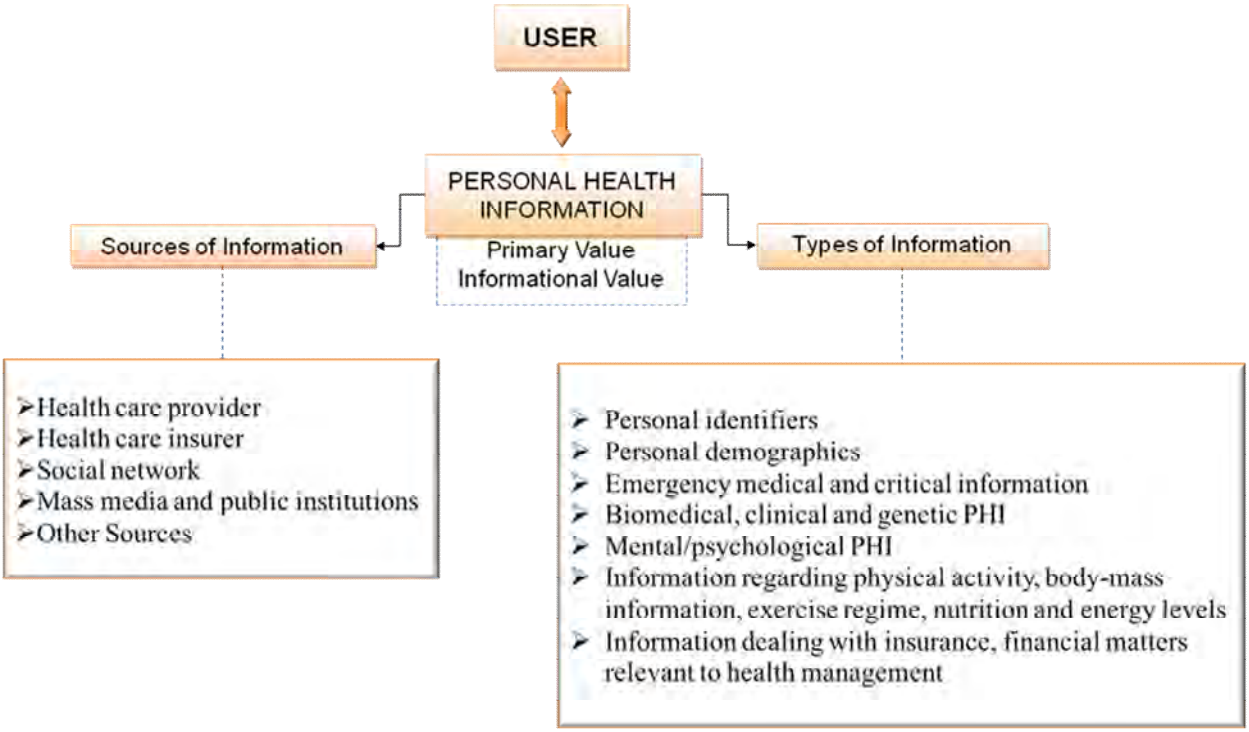


**Figure 3. Classification Schema of Information for Personal Health Information Management**

Chapter 1 noted that PHI can potentially consist of a wide variety of information, and can vary across individuals and contexts. The literature today does not provide a precise boundary of what is within the scope of PHI and what is not. Across all studies in this domain, the general point of consensus that emerges is that for the purposes of PHIM, PHI is any and all information that might be relevant for the individual in managing his or her health either today or in the future.

## 3.1 Types of Personal Health Information

A variety of different "information scraps" or discrete collections of information constitute the stock of health information that the user seeks to manage (Agarwal & Angst, 2006; Brennan & Kwiatkowski, 2003; Civan et al., 2006). For example, any document containing PHI constitutes an information scrap, and such scraps typically originate from a source for a certain primary purpose. In other words, as a byproduct of the activities of the source, information scraps are created to achieve some purpose and, for some period of time, have value for that specific purpose. This is the "primary value" of the information scrap, and can generally be related to the administrative, operational, and transactional requirements associated with the source-individual interaction. The primary value diminishes with time as these "transactions" are completed, or the transaction effects come to an end. For instance, a prescription provided by a doctor has a primary value as that of a medication list for the individual as part of a treatment regimen, and is an outcome of the doctor-individual interaction process. If the individual gets cured or feels better without the medication, he may not even use the prescription for its primary value, after the interaction with the source is over.

The "informational value" of the information scrap relates to the value derived from the content beyond its specific purpose or primary value; and for purposes other than what it was originally created for. In the case of the prescription, an example of the informational value is any inference that could be drawn from the contents of the prescription. The specific content delivering informational value then might consist of disease information, specific name and dosage of the medication, noted possible side effects, or the total number of refills of the drugs, age and other information about the individual, and specific clinical information. This

information has more enduring value than the primary value: it can be used in the present as well as in future, for different inferences related to the individual, for study or research purposes, or even for administrative and decision-making processes in different contexts. Hence, unlike primary value, the informational value does not necessarily diminish with time. Further, the informational value from the content might be extracted by the individual himself or someone else, depending on the context and situation. The primary value and informational value might be complementary.

In the existing literature of PIM and PHIM, researchers allude to different informational value for different levels and types of personal health information. Although health information scraps can be categorized in various ways, there is no particular comprehensive classification scheme that is widely accepted in the literature. Using the information scrap and informational value metaphors, the individual's total personal health information has been grouped into seven categories. While discussing the informational value of personal health information, researchers generally have associated it with contextual inquiry for sources which deal with such personal health information. In Table 3.1, these sources are matched to the informational value categories and provide references for research in these areas. It is important to note that all of these information types need not necessarily be under the direct control of the individual user today, or may not be within the scope of existing PHIM practices. However, a common, shared characteristic of all these pieces of information is that they are "personal" in that they refer to a specific, individual consumer, albeit with potential value beyond the context of that individual's unique PHIM goals and activities. Thus, as the scope and sophistication of PHIM expands, it is feasible that in the future, each one of these information types will be part of the individual's personal space of information.

### 3.1.1 Personal identifiers

Personal identifiers include a person's name, address, ID numbers, insurance information and other information that can be used to identify the individual to whom the personal health information refers.

### 3.1.2 Personal Demographics

A person's demographics consist of information that places the individual in a specific group based on such data as: age, gender, race, religion, family size, level of education, occupation or profession, income, and address. Demographic data also may be certain characteristic features of the locality or community that the individual is engaged within day-to-day life. Some of these data including one's age, gender, and possibly race may be useful in making medical treatment decisions, or even making inferences about life style patterns of the individual. Further, some of this information may provide useful insight into the genetic or mental health related characteristics of the individual. Demographic data are essential for most clinical research and provide value for other population-level conclusions.

### 3.1.3 Emergency Medical and Critical Information

Information such as blood type, allergies, vital past and current medical conditions, medications and dosages form the category of critical information. This type of information is needed in case of emergency medical situations when it would be difficult to collect it at the time of need. To help avoid adverse consequences during emergency medical treatment the availability of critical personal health information is important. Emergency contact information (family, primary care and other physicians) and advanced directives (living wills, powers of attorney) are also part of this category.

### 3.1.4 Biomedical, Clinical and Genetic Personal Health Information

Biomedical, clinical and genetic personal health information broadly refers to health history, current health status, disease specific information, health risk information, as well as genetic information. Included in this category are biomedical and clinical data about a person's existing symptoms, current and past health conditions or problems, current and past medications, current and past exams and interventions or treatments, risks posing a threat to one's future health status, biometrics (e.g., weight, blood pressure, cholesterol levels, and vital signs), imaging studies (e.g., x-rays, CT scans, MRIs, and ultrasounds), genetic makeup, dental signatures, and DNA reports. Much of this information would be useful for physicians treating a patient, as well as for the person’s other health advisors such as counselors or fitness instructors who are helping the individual manage his or her physical wellbeing. The information structure and content for this

category is detailed and complex; and the literature suggest that this category is less likely to form part of the individual's collection and archive of personal information. Parts of this information such as CT scan reports, MRIs, or dental signatures may have to be collected from the respective person or agency dealing with such information for the individual.

### 3.1.5 Mental or Psychological Personal Health Information

This category of health information includes the individual's psychological, psychiatric, and psychosocial information. In general, such information is not collected by or available with the individual, unless there is a clinical diagnosis or identification of a disorder related to a mental or psychological state. Mental or psychological personal health information would also consist of information such as eating problems, poor appetite, excessive dieting or fasting, vomiting or use of laxatives, binging and purging, or psycho-physiological information such as loss of body weight due to stress, sleep problems, and psychological sexual disorders.

### 3.1.6 Personal Health Information Regarding Physical Activity, Body-Mass Information, Exercise Regime, Nutrition and Energy Levels

This information category exists at a second or lower level of granularity than the previous categories. Personal health information regarding one's level of physical activity, degree of exercise, nutrition, and energy drains and boosters can be useful to the individual as well as to health care providers. Further, this can serve as key input for counselors and instructors assisting with the individual's health regime, and is frequently captured in association with corporate wellness programs.

### 3.1.7 Information Dealing With Insurance, Financial Matters Relevant to Health Management

This category of information includes the individual's health insurance, financial matters related to health care, administrative procedures, identification and access numbers for the insurance providers, the payer-provider information and the primary and specialist providers that the individual has chosen for his treatment and care. Although this information category may not always directly deal with or reveal specific health information of the individual, it is nonetheless one of the vital components of the total set of health related information that individuals manage.

## 3.2 An Alternate Classification Based on Chronology

In addition to this classification scheme that was constructed from the literature review, a different perspective on types of personal health information is discussed by Gwizdka (2000). His conceptual classification of information distinguishes among information based on its value from a temporal perspective and includes four information types: (1) prospective (future), (2) ephemeral (current, short-lived), (3) working (current, medium-span), and (4) retrospective (past). For example, prospective information is characterized by its reference to a specific time in the future, such as a future meeting; whereas ephemeral information is that generated at the current instant. An important distinction between prospective and ephemeral information is that the former retains value as time passes as information about past events (i.e., it is transformed into retrospective information), while the latter does not. Gwizdka (2000) finds that different tools are being used for managing these types of information, such as loose notes for ephemeral, date book for prospective, and address book for retrospective information.

**Table 3.1: Classification of Personal Health Information (PHI) and Related Sources – Illustrations from Literature***

| **Sources of PHI** | **Personal identifiers** | **Personal demographics** | **Emergency medical and critical information** | **Biomedical, clinical and genetic personal health information** | **Mental or psychological personal health information** | **Regarding physical activity, body-mass information, exercise regime, nutrition and energy levels** | **Information dealing with insurance, financial matters relevant to health management** |
|---|---|---|---|---|---|---|---|
| Alternate medical sources | Brennan & Kwiatkowski, 2003<br><br>Moen & Brennan, 2005 | | Moen & Brennan, 2005 | | | | |
| Clinics or hospitals: copies of medical records, doctor's visits. | Brennan & Kwiatkowski, 2003<br><br>Moen & Brennan, 2005 | Maisie et al., 2004 | Tang et al., 2006 | Brennan & Hsieh, 2004<br><br>Leonard, 2004<br><br>Tang et al., 2006<br><br>Maisie et al., 2004 | | Tang et al., 2006 | |
| Commercial laboratories | | | Tang et al., 2006 | Tang et al., 2006 | | Tang et al., 2006 | |
| Electronic health records | | | Tang et al., 2006 | Tang et al., 2006 | | Tang et al., 2006 | |
| Health care providers, such as doctors, generalist and specialist, clinicians, nurse, pharmacists, physicians, alternative health care practitioners, therapists. | | | Tang et al., 2006<br><br>Bath, 2008 | Brennan & Hsieh, 2004<br><br>Zayas-Caban et al., 2004<br><br>Leonard, 2004<br><br>Tang et al., 2006<br><br>Bath 2008 | Bath, 2008 | Tang et al., 2006 | Maisie et al., 2004<br><br>Terry, 2008 |
| Insurers, claims databases and claims history | | | Tang et al., 2006 | Tang et al., 2006<br><br>Maisie et al., 2004 | | | Maisie et al., 2004 |
| National health advice and announcements | | | | Kivits, 2004 | | | |

***The categorization is based on the informational value of PHI, and examples for sources of PHI for the categories of PHI from literature.

**Table 3.1: Classification of Personal Health Information (PHI) and Related Sources – Illustrations from Literature (continued)**

| Sources of PHI | Personal Identifiers | Personal Demographics | Emergency medical and critical information | Biomedical, clinical and genetic personal health information | Mental/psychological personal health information | Physical activity, body-mass information, exercise regime, nutrition and energy levels | Information dealing with insurance, financial matters relevant to health management |
|---|---|---|---|---|---|---|---|
| Professionally-sourced data: any clinical (e.g., provider, laboratory) or financial (e.g. payer, pharmacy) with entities responsible for the delivery and administration of health care. | | | | Civan et al., 2006 | | | |
| "Local experts" - individuals who have tangible experience in the health care profession or patients who themselves once experienced the medical condition | | Lober et al., 2006 | | Kivits, 2004 | | | |
| Family, relatives, friends, informal networks (doctors and health professionals —who are friends, or acquaintances) | Brennan & Kwiatkowski, 2003<br><br>Moen & Brennan, 2005 | Lober et al., 2006 | Moen & Brennan, 2005<br><br>Bath, 2008 | Brennan & Hsieh, 2004<br><br>Zayas-Caban et al., 2004<br><br>Kivits, 2004<br><br>Bath, 2008 | Bath, 2008 | Kivits, 2004 | |
| Online support communities with similar diseases | Brennan & Kwiatkowski 2003<br><br>Moen & Brennan 2005 | Lober et al., 2006 | | Kivits, 2004<br><br>Lasker, 2005 | | Lasker, 2005 | |
| Broadcast programs, radio talk shows, television news programs | Brennan & Kwiatkowski, 2003<br><br>Moen & Brennan, 2005 | | | | | | |
| Computer-based resources, information CDs, web | | | | Zayas-Caban, 2002 | | | |

**Table 3.1: Classification of Personal Health Information (PHI) and Related Sources – Illustrations from Literature (continued)**

| Sources of PHI | Personal identifiers | Personal demographics | Emergency medical and critical information | Biomedical, clinical and genetic personal health information | Mental/psychological personal health information | Physical activity, body-mass information, exercise regime, nutrition and energy levels | Information dealing with insurance, financial matters relevant to health management |
|---|---|---|---|---|---|---|---|
| Printed health publications, brochures, health magazines, printed news media, newspapers, news magazines, newsletters, reference books | Brennan & Kwiatkowski, 2003<br><br>Moen & Brennan, 2005 | | | Brennan & Hsieh, 2004<br><br>Moen & Brennan, 2005 | | | |
| Home instrumentation - automated interface with equipment | | | Tang et al., 2006 | Tang et al., 2006 | | | |
| Hotlines, Internet, websites , email | Brennan & Kwiatkowski, 2003<br><br>Moen & Brennan, 2005 | Moen & Brennan, 2005 | Zayas-Caban, 2002 | Civan et al., 2006<br><br>Vincent et al., 2008 | | Kivits, 2004 | |
| Public library, schools, classes | Brennan & Kwiatkowski, 2003<br><br>Moen & Brennan, 2005 | | | | | | |
| Public health organizations such as, local, State, national health groups, national public policy groups | Brennan & Kwiatkowski, 2003<br><br>Moen & Brennan, 2005 | | | | | | |
| Patient-keyed data: any data that is provided to the patient by a professional source that is then typed into the PHR by the patient manually rather than uploaded electronically | | | | Vincent et al., 2008 | | Vincent et al., 2008 | |

**Table 3.1: Classification of Personal Health Information (PHI) and Related Sources – Illustrations from Literature (continued)**

| Sources of PHI | Personal identifiers | Personal demographics | Emergency medical and critical information | Biomedical, clinical and genetic personal health information | Mental/psychological personal health information | Physical activity, body-mass information, exercise regime, nutrition and energy levels | Information dealing with insurance, financial matters relevant to health management |
|---|---|---|---|---|---|---|---|
| Patient-sourced data: any data entered by the patient that is not provided by a professional organization, such as a patient diary, over-the-counter medication lists, or medical device data | | | | Civan et al., 2006 | | Vincent et al., 2008 | Vincent et al., 2008 |

## 3.3 Sources of Personal Health Information

The sources of personal health information that the individual interacts with in the process of collection, management, and retrieval of personal health information vary widely. There is no comprehensive classification scheme available. Rather, individual studies related to some specific and situated aspect of personal health information management discuss one or more information sources.

Table 3.2 presents a classification scheme for sources or originators of personal health information synthesized and constructed from the literature. Looking across all relevant work in this domain five "meta-level" categories have been identified: (1) health care provider, (2) health care insurer, (3) the individual's social network, (4) mass media and other public sources, and (5) other sources. Within each meta-level category several subsources are listed, and the types of personal information that the subsources can provide. Finally, the published work that has discussed these subsources is identified. However, there is some degree of overlap between the categories. For example, an online support community that the individual merely visits to collect information about a disease but does not actively participate in could arguably be classified as mass media as opposed to the social network. Further, the classification of a particular subsource within a meta-category can be context dependent. To illustrate, an individual may have a close personal relationship with their pharmacist and acquire health related information such as the best foods for lowering cholesterol from them during the course of an informal conversation. In this instance, the pharmacy belongs to two meta-categories of the health care provider, and the social network. Given the limited research that exists related to sources of personal health information, such nuanced differences among sources cannot be effectively resolved at this point in time.

### 3.3.1 Health Care Provider as the Relevant Source

This category represents entities, which are broadly responsible for the delivery and administration of health care, including providers, laboratories, and pharmacies. The subsources in this category discussed in existing research include alternative medical sources, clinics or hospitals (copies of medical records, doctor's visits); commercial laboratories; EHRs; health care

providers (doctors, generalists and specialists, clinicians, nurses, pharmacists, physicians, alternative health care practitioners, therapists); and other professional sources. As illustrated in Table 3.2, the information provided by these sources can be of multiple types, ranging from clinical data to useful financial data.

### 3.3.2 Health Care Insurer as the Relevant Source

This category represents the health insurance payor organization as a source for personal health information for the individual. The insurance provider organizations include any program that helps pay for medical expenses; whether through privately purchased insurance, social insurance or a social welfare program funded by the government. In addition to medical expense insurance, insurers also provide coverage for disability or long-term nursing or custodial care needs. The payor collects and stores the information about the individual, his family, profession, eligibility and other relevant information such as the individual's past and present health care service information. Health care service information includes the information about what health care services the individual has received, the related costs, what is or was covered, and what the individual has already paid and currently owes for this service. Insurance agencies store all this information in the form of the individual's history and claims database; and refer to it at the times of inquiry or need.

### 3.3.3 Individual's Social Network as the Relevant Source

The individual's social network consists of friends, family, and other entities that constitute the social space within which the individual functions on a daily basis. Subsources within the social network are "local experts" whom the individual may interact with on a casual basis (in contrast to other providers with whom the individual has a formal relationship): family, friends, informal networks, and online support communities. The individual's family, relatives, friends, informal networks (acquaintances, doctors) may both provide as well as need certain information about the individual such as emergency contact information, blood groups, and previous medications. The individual also collects information relevant to his/her current health condition to assess, make decisions, diagnose, or treat his/her health. Such information may be sought from local experts, i.e., individuals who have tangible experience in the health care profession or patients who themselves once experienced the medical condition. In recent times, online support

communities consisting of people with similar diseases also constitute an important subsource in the social network category.

### 3.3.4 Mass Media and Public Institutions as the Relevant Source

A third information source for the individual's health information is the media and other public institutions. There are numerous subsources in this category, including health websites, printed health publications, the public library classes that the individual may be enrolled in, and public health organizations. Researchers have observed that these sources typically provide information related to prevalent diseases and their precautions, treatments, nutrition and diet, and instructions on self-care.

### 3.3.5 Other Sources

The final meta-category contains those sources of personal health information that do not readily belong to any of the other three meta-categories but nonetheless act as plausible information sources for the individual's personal health information seeking and collection process. For example, a patient may use a pedometer to track how much they walk every day, or use a blood pressure monitor on occasion at home. Other devices which belong to this category of sources are, for example, pacemakers, fetal monitors, blood glucose monitors, electronic thermometers, and treadmills recording pulse rates. Each of these devices generates data that can inform either the user or any other entity that wishes to draw inferences from the data. The data may be intentionally keyed by the patient (such as a pedometer reading) or it may be captured in a system such as the blood glucose monitor readings from a device, recorded several times throughout the day.

**Table 3.2: Categorization of the sources of personal health information and related types – illustrations from literature**

| Category | Sources of Personal Information | Types of Personal Information | Citations |
|---|---|---|---|
| Health care provider | ➢ Alternative medical sources<br>➢ Clinics or hospitals, copies of medical records, doctor's visits<br>➢ Commercial laboratories<br>➢ Electronic Health Record (EHR)<br>➢ Health care providers(doctors, generalists and specialists, clinicians, nurses, pharmacists, physicians, alternative health care practitioners, therapists)<br>➢ Professionally sourced data: any clinical (e.g., provider, laboratory) or financial (e.g. payer, pharmacy) data provided by entities responsible for the delivery and administration of health care; usually entered into PHRs automatically via data exchange between different types of health care information systems or interfaces between different applications.<br>➢ NHS direct and 'other' such as leaflets from pharmacists or those that come with drugs<br>➢ Pharmacies | ➢ Clinical encounters<br>➢ Medical records and information; such as: x-rays, lab results, ECG, discharge summary, medical checkup information, operative notes, treatment regimes, procedure information, surgeries, treatments, doctor's appointment schedule<br>➢ Medical bills and receipts, medication and prescription information<br>➢ Allergy data, blood type, details of major illness (e.g., HIV status), medical condition, birth/death certificates, date of birth, address, emergency contact<br>➢ Contact information, immunization records | Brennan & Kwiatkowski, 2003<br>Brennan & Hsieh, 2004<br>Detlefsen, 2004<br>Zayas-Caban et al., 2004<br>Kivits, 2004<br>Leonard, 2004<br>Moen & Brennan, 2005<br>Zayas-Caban, 2005<br>Lasker, 2005<br>Tang et al., 2006<br>Lober et al., 2006<br>Bath, 2008 |

**Table 3.2: Categorization of the sources of personal health information and related types – illustrations from literature (continued)**

| Category | Sources of Personal Information | Types of Personal Information | Citations |
|---|---|---|---|
| Health care insurer | Insurers (claims databases - claims history) | ➢ Insurance, administrative data and claims data<br>➢ Financial information related to insurance and claims<br>➢ Health care providers and contact information, doctor or primary care physician's contact information, hospital or clinic information | Brennan & Kwiatkowski, 2003<br>Zayas-Caban et al., 2004<br>Brennan & Hsieh, 2004<br>Moen & Brennan, 2005 |
| Mass media and public institutions | ➢ Broadcast (radio talk shows, television news programs)<br>➢ Computer-based resources, informational CDs, web<br>➢ Printed health publications, brochures, health magazines, printed news media, newspapers, news magazines, newsletters, reference books<br>➢ Hotlines<br>➢ Intentional sources or sources which give out particular health related information, campaigns, street signs or billboards<br>➢ Internet, websites, email<br>➢<br>➢ Public library, schools, classes<br>➢ Public Health Organizations, health groups operating at local, State or national level, national public policy groups<br>➢ Organized health events, women's health fairs, support groups, resource centers | ➢ Instructions on self-care<br>➢ First aid information, explanation of benefit<br>➢ Nutrition and diet<br>➢ Literature, health-related articles and web pages, patient leaflet, pamphlets, books, newsletters<br>➢ Medical information portals and websites for information collection<br>➢ Online support groups, communities, online chat logs for support and health information collection | Moen & Brennan, 2005<br>Morey, 2007<br>Zayas-Caban, 2002<br>Kivits, 2004<br>Lasker, 2005<br>Cotten & Gupta, 2004<br>Henwood et al., 2003<br>Nicholson et al., 2005<br>Wilson, 1997<br>Detlefsen, 2004<br>Nicholson et al., 2005 |

**Table 3.2: Categorization of the sources of personal health information and related types – illustrations from literature (continued)**

| Category | Sources of Personal Information | Types of Personal Information | Citations |
|---|---|---|---|
| Others | ➢ Patient-keyed data: any data that is provided to the patient by a professional source<br><br>➢ Patient-sourced data: any data entered by the patient that is not provided by a professional organization, such as a patient diary, over-the-counter medication lists, or medical device data. | ➢ Calendar entries, diary entries, daily planners, medications and tools, reference material, referrals<br><br>➢ Entries and postings on refrigerator door, kitchen cabinets, notes next to telephone<br><br>➢ Poison control, cancer surveys, observations, instructions, over-the-counter medications, exercise and diet, self-care logs<br><br>➢ Home-monitored data (e.g., BP, glucose, peak flow), logs of symptoms, pedometer data | Civan et al., 2006<br><br>Moen, 2004<br><br>Zayas-Caban, 2005 |

## 3.4 Summary

There is a variety of different types of information that constitute the set of personal health information that a consumer need to collect, organize, store, and retrieve during his/her PHIM activities. This information comes from a multiplicity of information sources with which the individual interacts with varying frequency and intensity. At present there are no dominant or comprehensive classification schemes for sources and types of personal health information. Classifications are important abstraction tools for the study of any complex domain. Thus, a comprehensive classification scheme is necessary to help clarify the approach that is needed for effective and efficient PHIM activities, and guide the design of tools that enable these activities. Based on the literature review, two classification schemes were developed: one for personal health information types that contains seven categories, and another for sources of personal health information with four meta-categories. The relevance and value of any particular type of PHI as well as its information source are highly context-dependent and can be different for different consumers depending on their goals and characteristics. Future research is needed to develop a detailed classification that maps information types at different levels of granularity to information sources. Such work would help identify overlaps between sources for different types of information, and shed light on the potential for data inconsistencies and redundancies. Finally, while the literature appears to use a fairly broad and inclusive definition of what information can be treated as PHI, exclusion criteria have yet to be defined. Hence, there are two questions that remain to be addressed: (1) Where should the boundary of PHI be drawn and what should be or should not be considered as PHI for the purposes of PHIM?[3] (2) What criteria should be used to determine whether something should constitute PHI and fall within the realm of PHIM activities?

[3] The label PHI is also used by HIPAA to denote "protected" health information. According to the HIPAA guidelines (http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html), protected health information includes (1) information doctors, nurses, and other health care providers put in an individual's medical record, (2) conversations a doctor has about an individual's care or treatment with nurses and others, (3) information about an individual in their health insurer's computer system, (4) billing information about individuals at the clinics they visit, and (5) most other health information about individuals collected by those who must follow the HIPAA law. The definition of PHI used in this report is broader and includes personal health information that may not be protected under HIPAA.

# Chapter 4: Users of Personal Health Information

In order to understand the concept of a user in PHIM, it is first necessary to articulate what triggers the activities of PHIM. As noted in Chapter 2, PHIM is activated by a need. In particular, a user's need for personal information management arises from the gap or discontinuity that exists between the user's activities at different times and in different spaces. Spurgin (2006) argues that the basic concept of PIM emerges from the existence of this discontinuity or gap, and the gap defines who the user is. Any individual can be viewed as an entity moving through time and space, interacting with other entities, which may include other people, artifacts, systems, or institutions. The individual grapples with interpreting and "making sense" of the empirical reality he or she observes. During the sense making process he/she encounters gaps in understanding, and seeks information to address these gaps, i.e., the individual engages in PIM. Thus, PHIM, a specific instance of PIM in the context of health, may be conceptually viewed as the strategy to bridge this gap and facilitate understanding. The gaps that arise are manifold, and are affected by the self's situated needs and understanding, at different points in space and time, for different purposes and goals. The activities of locating, keeping, and managing information allow the present-self to provide for communication with the future-self at different points in time for processing and/or using. For example, re-finding information in a personal information space is an instance of the present self in dialog with past self (Spurgin, 2006).

## 4.1 Who is the User in Personal Health Information Management? Extending the Concept of User

One perspective for defining a user in PHIM is based on the target of PHIM activities, i.e., *whose* information is being managed. While conventional wisdom suggests that the "user" in personal information management is typically the individual managing his/her own personal information, in the context of health information, studies note that individuals are often responsible for managing the health information of a family (Moen & Brennan, 2005). Health information managers in the home structure, organize, store, and retrieve health information for the entire

family. In their role as the family's personal health information manager, they participate in a variety of informal (comprising of friends, acquaintances) and formal networks (including physicians and other stakeholders) with whom information needs to be exchanged (Moen & Brennan, 2005).

The literature suggests that that the sphere of PHIM activities must be expanded beyond the home. It also observes that the concept of a "user" in PHIM needs to be expanded to other entities who have a need to access the information, or who may be the source of such information. In other words, an individual user or a family health information manager is not the only one who will be "using" the personal health information collection. Indeed, a singular focus on information management in the home may overlook the fact that individuals need to manage health information beyond the home. As shown in Figure 4, the notion of "user" extends beyond the self, the family and the home; and includes the community, and formal and informal networks. The formal network includes clinicians and other providers who may need to access personal health information for the delivery of care. It also encompasses stakeholders such as public health officials and researchers who may need to use PHI for purposes such as disease surveillance and bio-medical research. Finally, to the extent that individuals increasingly "share" their personal health information with virtual strangers in online communities (Frost & Massagli, 2008), users may also include the larger community within which the focal user is embedded. It is evident, therefore, that the users of PHIM operate in two spheres: a private domain, and a public domain. In the private sphere, PHIM simply supports one's personal tasks and the information is purely for use by its owner. In the public sphere, PHIM is often executed with some degree of sharing in mind, and this has implications for the types of tools and artifacts that are used to support PHIM.

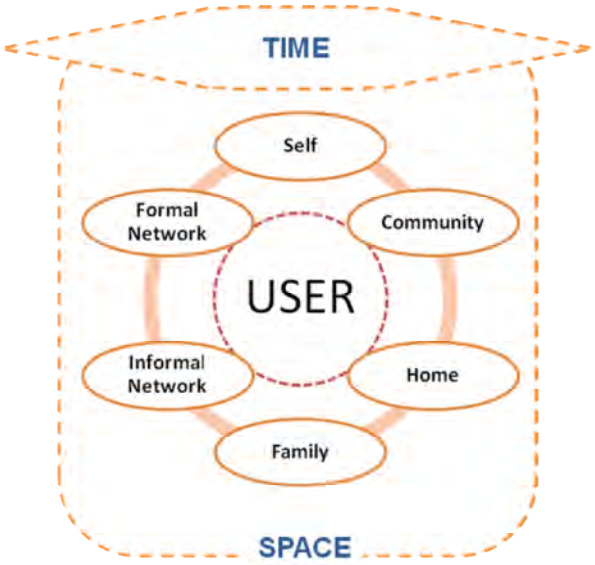


**Figure 4. Extending the Concept of User**

PIM involving the community or the public sphere rather than the 'private self' is conceptualized as 'group information management' in the literature (Erickson, 2006; Lutters et al., 2007). This literature notes that although people acquire, organize, maintain, retrieve and subsequently, use information items to support individual needs most of the time, the context of these activities may involve groups or organizations. Therefore, users in PHIM may have varied degrees of sharing in mind when they create and manage personal information (Erickson, 2006). The extended set of users of PHIM in the group or public sphere would be involved in the exchange of or interaction with the individual's personal health information at their time of need. For example, a physician may need to know what prescriptions medications the individual is currently taking, or a family member may need to schedule a joint appointment with a health care provider. Information sharing may be done through multiple means, e.g., through a common calendar at home, a folder shared amongst all home members, paper-based document management systems, electronically designed systems such as PHRs or through more recent collaborative systems or software such as shared web spaces, online communities, and WIKIs.

## 4.2 Diversity in User Goals and Attributes

In order to fully understand the PHIM user, it is important to isolate what specific user characteristics are likely to be relevant in the context of PHIM. As shown in Figure 5, researchers have identified two such sets of characteristics: user goals and user attributes.

Goals represent the overarching objective of engaging in PHIM. The existing literature does not provide a comprehensive classification of user goals with respect to PHIM, but does offer some insight into what these goals might be. For example, research suggests that whether within the private-self or public sphere, users' goals for PHIM may include monitoring and assessing health, making health-related decisions, planning preventive or treatment actions, and performing these actions. These goals form the foundation for tasks such as creating a history, making lists, integrating information, and establishing reminders (Civan et al., 2006). The PIM literature also describes different motives for archiving personal information including building a legacy, sharing resources, fear of loss, and identity construction (Kaye et al., 2006). The tasks or goals of users play a crucial role in the way the information is collected, integrated, organized or presented. For example, to the degree that personal health information needs to be shared with another, a person's whose handwriting in everyday writing may be sloppy or hasty, while presenting to another may write a bit more carefully than usual. Similarly, a person who is maintaining a doctor's visit calendar for the family at home may develop a practice of sharing their calendar with others to facilitate scheduling.

Beyond the intended uses of personal health information and the specific health management goals of users, the attributes of users also define the scope and nature of PHIM activities. Users of PHIM come from a range of socioeconomic and demographic backgrounds. The information needs of users as well as the concerns they have with respect to privacy and security in the context of health information have been found to vary by several demographic characteristics, including age, gender, education, income (Agarwal & Angst, 2006; Angst et al., 2008), and race and ethnicity (Zayas-Caban et al., 2004). Lafky and Horan (2008) provide evidence that user preferences for different types of PHR delivery (i.e., the technology), as well as their preferences related to privacy, security, interoperability, and portability vary as a function of health status

(well, unwell, and disabled). Fox (2007) found that although adults living with a disability or chronic disease are less likely than others to go online, once they are online, they are avid consumers of health information. Underscoring the importance of health status, Fox's findings suggest the health-related behaviors and attitudes of the chronically ill or disabled are more significantly influenced by health information found online than those online users who do not have any chronic conditions.

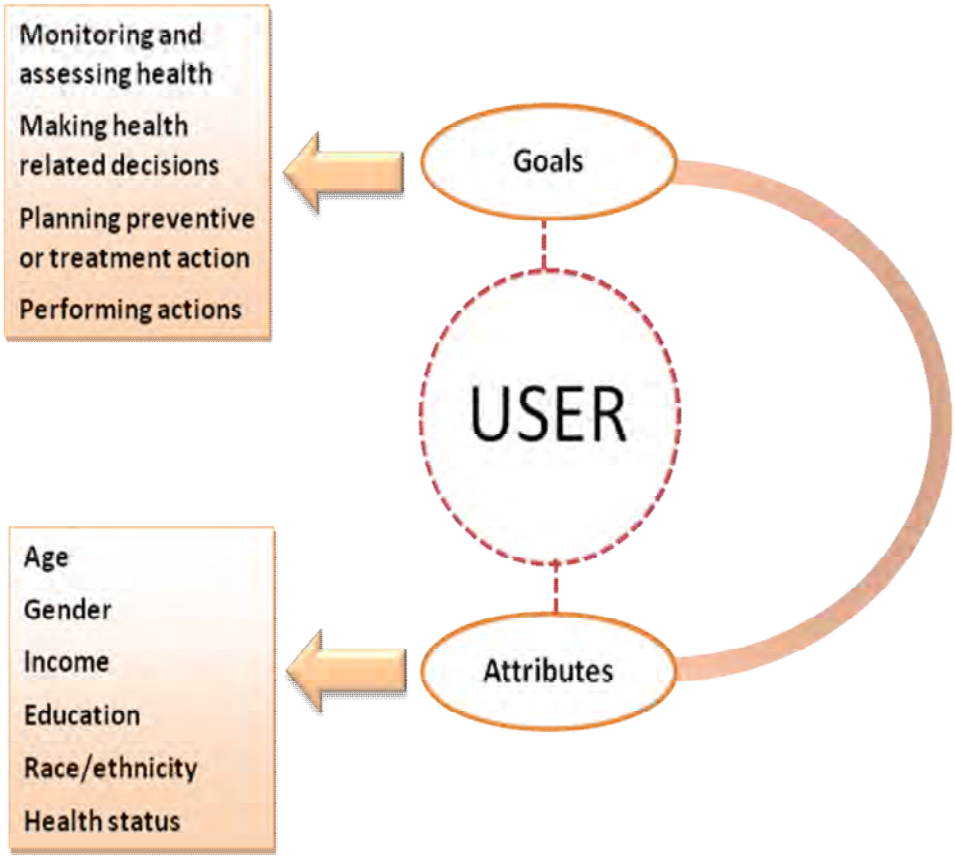


**Figure 5. User Goals and Attributes Relevant for Personal Health Information Management**

## 4.3 Tensions Caused by User Diversity

The inherent diversity in user goals and user attributes often results in a series of tensions that are complex and intertwined. One set of tensions relates to user control, privacy, trust, ownership, and access. As PHIM extends beyond the individual user to include instances when the information of multiple individuals is being managed by a single person, or when PHIM is being done for the purposes of sharing, the boundary of what is "personal" becomes blurred. For instance, as noted, when users engage in PHIM for the public sphere, they may "share" personal schedule information through a calendar. While this sharing serves the specified goal of visiting the doctor, it may also inadvertently reveal details about the user that he/she would not explicitly want to share, such as doctor appointments, medical procedures, or free time. A person reviewing the calendar might then draw inferences such as this person is a 'regularly sick person', or he/she has a lot of free time. Thus, unless managed appropriately, users' goals with respect to sharing may lead to unintended consequences. Prior studies in the context of consumer information reveal that individuals are generally unwilling to allow the secondary use of information that they provide for a specific purpose (Culnan, 1993). The use of personal health information for non-specified uses or unintended uses is clearly an undesirable outcome for the user. To avoid such outcomes, it is necessary to address questions such as what should the individual user choose to reveal or conceal? How the disclosure of personal information is related to the end result that the user seeks to achieve? And, what are the ethical issues underlying such sharing and disclosure?

A second set of tensions in PHIM, also an outcome of the facts that the "user" is not necessarily the single individual and that "use" involves other entities, relates to standards and interoperability. Shared public spaces demand following a standard that is used by all in the group, and users have to rely on these standards. This naturally constrains some of the open-ended activities for the individual user related to PHIM. For example, a user may be constrained in the specific software that he/she may use for storing health information if that software is not a widely available and used tool within the larger group where the information needs to be shared.

## 4.4 Summary

Users of PHIM vary along the dimensions of the nature and scope of information use, its intended purpose and the boundary of use. While the individual is often the collator and owner of the personal health information that is needed for future needs that he/she might foresee, actual use might extend from him/her to others such as doctors, clinicians, health providers and payors, that exist beyond the 'boundary of the private space' of the individual. Indeed, the PIM literature emphasizes the importance of delineating the distinction between finding and refinding in personal space as opposed to shared space, and the distinction between information that is personally owned or accessed for personal reasons and information that is about other people (e.g., medical records) (Barreau et al., 2008; Jones, 2007). Attributes of the user such as demographic characteristics and health status also affect the nature and scope of PHIM activities and have implications for the design of tools and artifacts that support these activities. The extension of personal health information 'users' from the 'self' to 'others' can give rise to several tensions, such as privacy and control issues.

# Chapter 5: Strategies for Managing and Organizing Personal Health and Other Personal Information

The strategy for managing and organizing information reflects the user's intentional actions to structure his/her personal information collections such that future access and retrieval for decision making is facilitated. Indeed, as noted in Chapter 2, the essential functions of PIM are the storage, organization, and retrieval of information (Bergman et al., 2004). As shown in Figure 6 below, strategies for managing and organizing information exhibit significant diversity in the approach followed for organization. These strategies are influenced by the characteristics of the medium, the characteristics of the individual, and the individual's values with respect to archiving information. The approaches to organization, as well as the influencing factors collectively provide important inputs for the artifact design and development process.

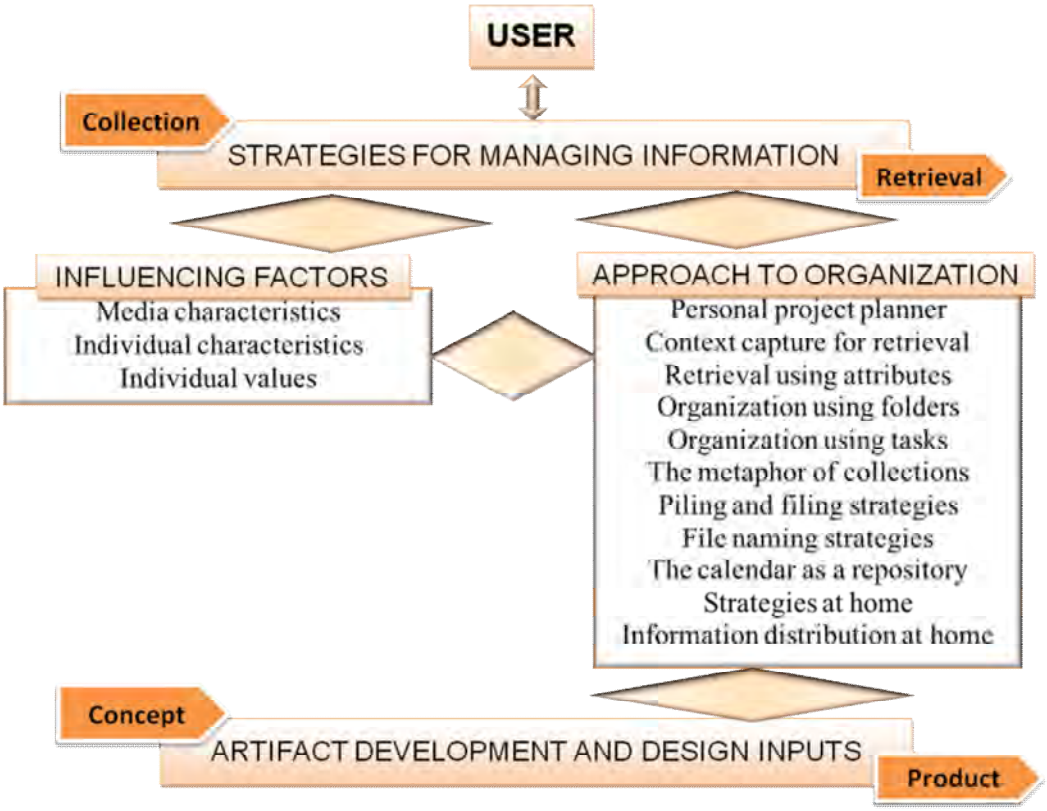


**Figure 6. Personal Information Management Strategies**

The importance of strategy in the management and organization of information cannot be overemphasized: it is clear that strategy is a crucial determinant of the efficacy with which each of the PIM functions can be executed. Today, many instances of PIM are visible in the computer-based activities of individuals when they organize digital files, emails, contacts, reminders, and other information both at the work at home. However, as discussed extensively in the literature, the dominance of paper for information collection and storage persists in society. Paper media continues to constitute a major repository for personal information, and hence a significant proportion of PIM activities occur in the world of paper. In the context of personal health information management, paper based forms, reports, prescriptions, diagnoses, and results are still ubiquitous in daily life. Thus, discussions of PIM or PHIM strategy cover both paper and digital media, and how individuals strategize their activities of management and organization of information in these different media settings.

## 5.1 Overview of Managing and Organizing Personal Information

Existing research does not always provide a sharp distinction between a conceptual strategy for managing and organizing personal information and a specific tool that supports the strategy. In other words, many prototype PIM systems described in the literature (summarized later in this chapter) **implicitly embed an organization and management strategy in the design concept of the system**. In general, paper based strategies become quickly cumbersome as the volume of information to be managed grows, leading to increased difficulty in information retrieval at a later stage, especially if the items are poorly organized. Technological advances have led to the increasing use of digital artifacts and software and information technology systems specifically developed to efficiently execute storage and structuring activities and to ease the retrieval process. The common goal for such systems is typically to provide the end user with a user-friendly interactive interface and a system of management strategies through which PIM tasks can be executed. Several such strategies are followed by different systems, tools and artifacts that have been developed recently, and are summarized in Section 5.2.

The literature also notes that along with media characteristics (i.e., paper-based versus digital), an individual's characteristics play a vital role in the strategies used for managing and organizing personal health or other personal information. Differences among individuals have been implicated as the cause for observed information organization strategies such as the "piling" and "filing" metaphors discussed later. For example, individuals who are by nature disciplined, ordered, and tidy, prefer to structure objects in a more organized manner. In contrast, others may be chaotic or disorganized in managing their things, and hence would be chaotic or disorganized in managing their personal information. Researchers have observed that the individual characteristic of being orderly has a positive bearing at a later point in time when the individual needs to find this information, and hence is very important in the process of personal information management (Malone, 1983; Mander et al., 1992; Whittaker & Hirschberg, 2001).

To further emphasize the importance of strategy, researchers note that the successful retrieval of personal information depends on prior processes used to organize relevant information and the extent to which those processes were appropriately planned. Information that is not organized through a planned process has a higher likelihood of getting lost. Therefore, differences in the organizing strategy can affect how successful the retrieval of lost items is, usually to the benefit of the "tidy" user. However, there are other aspects of finding items that suggest that more "chaos" in organizing is not necessarily dysfunctional. Regardless of the level of organization or chaos in the information organization strategy, an advantage that the individual who stored the information originally has when searching for the same information at a later stage is that some part of the information is already known to him/her. Based on this understanding, his/her search for information that is needed will be more effective than someone else's. Therefore, a distinct property of personal information retrieval compared to other information retrieval processes is that the piece of information sought for is already known to the user. The temporal gap between initially managing and storing the item and subsequently retrieving it may range from a few minutes to several years, further highlighting the importance of an overarching strategy in organizing the information.

## 5.2 Strategies for Managing and Organizing Personal Information

To deal with the increasing volume and types of user items, a wide range of personal information retrieval systems have been developed. All the digital tools incorporate some aspect of the strategies needed for the organization and retrieval of information. Distinctions among the strategies/tools exist along many dimensions including their core design approach, i.e., the type of conceptualization they use for "chunking" personal information objects and organizing personal information collections, the manner in which they facilitate retrieval (i.e., "tagging" items), and whether they are computer-based or operate purely on paper-based information.

### 5.2.1 Personal Project Planner and Project Contexts for Situating Personal Information

The personal project planner is a strategy that works through a project planner tool as an extension to the file manager in the digital environment (Jones et al., 2006; Jones et al., 2008). In the personal project planner tool, the basis for an association of information is the project and the planning involved in its completion. Each activity in daily life can be in a project mode for which individuals store, organize and manage information. Each project involves planning and this can be done through the personal project planner, along with the storage of task-relevant information through its interface. The planner supports the creation of rich-text overlays to the information (i.e., folders, files, email, web pages, or notes) through software based interconnects and hyperlinks. It has several features to help in the organization, search and retrieval process. For example, document-like project plans provide a context in which to create or reference documents, email messages, or web pages that are needed to complete the plan. The user can later locate an information item such as an email message with reference to the plan (e.g., as an alternative to searching through the inbox or sent mail).

### 5.2.2 Retrieval from Human Digital Memory

Kelly et al. (2008) describe the challenge of information retrieval from personal archives that are stored in digital formats, also known as human digital memories (HDMs). Individuals increasingly develop such archives that contain their personal life experiences including items read, information items created, videos, music, and photographs. HDMs are unique personal archives, and are fundamentally "personal" in that the individual will have personal memories about all items in the HDM related to such things as time and place of item creation and subsequent access. Thus, the individual's memories associated with the HDM items play an important role in the information storage and retrieval process from HDM archives, and these memories can be used as the context data (such as user location at the time of item access) to aid the retrieval process. HDMs pose many challenges for PIM: there is the potential for a large percentage of noisy data in these archives and many items in the archive may be very similar, repeatedly covering the same topic. Individuals may recall different types of context data for different item types, and the depth of their recollection may be dependent on the type of item being retrieved. Different context may be important for different data types, and different context may be recalled in different situations. The relationship between recalled context and the usefulness of specific context features for retrieval can be used to design and develop retrieval systems. The study by Kelly et al. (2008) to test and validate this concept with one person's HDM reveals that although the narrative or textual content failed to be recalled, context information (such as the location which is closely related to personal experiences at the time of encoding) and file types (which easily tend to be triggered by the queries or targets themselves) were well remembered over a specific time period. Thus, this 'longer term' remembered context data can be used to improve retrieval performance for content in HDM tools.

### 5.2.3 Attributes as a Strategy for Storage and Retrieval

The literature suggests that the attributes of documents such as size, title, or color can play a vital role in the PIM organization and retrieval strategy. Indeed, individuals have different levels of skill at recalling the attributes of stored information and use different strategies for retrieval (e.g., recall-directed search followed by recognition-based scanning) (Blanc-Brude & Scapin, 2007). In a study by Blanc-Brude & Scapin (2007), individuals were asked to first recall features about one (or several) of their own work documents and second, to retrieve these documents. The

results of the recall task indicates that attributes such as keywords and type, are better candidates for facilitating file retrieval. The authors note that search tools should use these attributes for successful retrieval mechanisms. Further, their results also demonstrate the fact that the recall of certain attributes can depend, on the one hand, on the type of user and, on the other hand, on the frequency of use of the documents, and the contextual relationship between the documents.

### 5.2.4 Folder Structures – Divide and Conquer

The folder structure is a popular structure for organizing information in paper or digital media. An empirical study of folder structures to organize project information, especially electronic documents and other files, suggested the existence of a "divide and conquer" strategy in which problems are decomposed into subfolders corresponding to major components (subprojects) of the project (Jones et al., 2005). Generalizing this concept, a strategy to divide and conquer by subdividing and categorizing the entire collection of information into folders or subgroups is a useful way of successfully managing individual's personal information. In a study exploring the way people organize information in support of projects ("teach a course" or "plan a wedding"), Jones et al. (2005) explain that individuals organize information in folders mainly to facilitate retrieval (of files and other information items). Further, they also found that:

1. File folder hierarchies are more than a means to an end—the re-access of information items. Folder hierarchies are information in their own right. Folders, if only crudely, summarize as well as organize—they represent an emerging understanding of the associated information items and their various relationships to one another.
2. The folders associated with a project frequently reflect basic problem decomposition or, alternatively, a plan for project completion.
3. Additional information is often "squeezed" into folder hierarchies—information that is not well-represented in a single hierarchy or is best represented through properties that cross folder boundaries."

They also note that one limitation of this approach is that folders frequently can get unstructured over time as they become overloaded with information content or the ordering pattern does not reflect reality as closely as it originally did. Thus, there is an inherent tension in organizing information in folder hierarchies for current use versus repeated re-use (Jones et al., 2005).

### 5.2.5 Task Management Strategies, in Support of a Task List Manager

One of the strategies to manage personal information is to organize and categorize information by specific tasks and by any follow up that may be needed for task execution. Bellotti et al., (2004) explore this strategy, along with the possibility of embodying such a task management strategy in a digital task list manager system that could help users manage and execute their to-dos. They studied the different task management strategies that individuals use such as task vistas, informal priority lists, state tracking resources, and time management. They report the results of their study of media used to record and organize to-dos and how tasks are completed over time. Their results show that such a strategy and system would help to (1) capture the person's daily tasks; (2) plan and execute simple actions; prioritize, manage, and reason about tasks; (3) learn to improve by being told, observing the user, asking questions, and reflection; (4) record notes, action items and ideas; and (5) answer questions and offer advice and assist in planning and problem solving. Further, their work shows that, contrary to popular wisdom, people are not poor at prioritizing and have the capability to execute skilled strategies for tackling particular task management challenges. Hence, following a task management strategy for the design of personal information management organization and retrieval systems would be efficient and effective. In the context of health behavior, a task management strategy might reflect how an individual approaches the management of a particular chronic condition such as diabetes that might include a series of tasks such as monitoring blood glucose levels, regularly scheduled laboratory testing, and a specific exercise regimen.

### 5.2.6 Structures for Personal Archiving, Use of Physical Space, Use of Digital Space

A key activity in PIM is the development of personal archives with the strategies underlying their construction. Kaye et al. (2006) propose that the personal archiving activity goes beyond simply efficient storage and retrieval of information and suggest that it is an activity that occurs across media, locations, careers, and time. Personal archiving is an ongoing practice of selection, organization, collation, display, storage, retrieval, and disposal. Individuals use both physical and digital space for information archiving, and any design of comprehensive archiving tools or artifacts should adopt a holistic perspective on the archive, rather than focus on one medium, such as the email folder or filing cabinet, or a single set of needs, such as sharing

papers with a group. Kaye et al. (2006) studied the personal archiving system of forty-eight academics and the techniques and tools they use to manage their digital and physical archiving of papers, emails, documents, internet bookmarks, correspondence, and other artifacts. Their study shows that personal archiving satisfies diverse objectives or values beyond information retrieval to include creating a legacy, sharing resources, confronting fears and anxieties, and identity construction. Mapping these functions to the individual's physical, social and electronic spaces, they find that information archiving is quintessentially a personal system. A user's values related to legacy, sharing, anxiety, and identity construction drive not only the underlying function and structure of the personal archive; they also define the criteria for judging its success (Kaye et al., 2006). Thus, as a design guideline, they recommend that personal archiving tools should focus more on supporting the user's values rather than on the capabilities or limitations of a single medium.

### 5.2.7 The Metaphor of "Collections"

The storage, archival and organization of personal information relies on the principle and concept of "collection" to a great extent. In general, the term collection refers to the process of seeking, locating, acquiring, organizing, cataloging, displaying, storing, and maintaining whatever items are of interest to the individual collector. Indeed, Karger and Quan (2004) view "collections", whether they take the form of file system directories or piles of paperwork, as important tools for helping people get their work done. In particular, two aspects of collection management are highlighted by Karger and Quan (2004). First, all forms of collections help people navigate and retrieve information; and second, some collections also play an important role in structuring and organizing knowledge. In other words, individuals' collections, organized using aggregation mechanisms such as folders, buddy lists, or photo albums, play a central role in information management. They note that current approaches to collection management create difficulties for users because different applications such as media players and email clients impose their own unique restrictions for creating collections. Their conceptual solution to this information management problem is an abstraction approach that uses a single unified concept of collection that enables data from different applications to be integrated together. Using the prototype of the Haystack system; an information management platform being developed at the MIT Computer Science and Artificial Intelligence Laboratory; Karger and Quan provide

evidence and several examples showing that use of the abstraction of collections would help in everyday information management. For example, Haystack allows users to select information items from multiple repositories such as an email system and a to-do list to create one unified collection of the items, and users find the flexibility of being able to place items of different types into one collection useful,

### 5.2.8 Creating "Piles"

A specific strategy for organizing and storing personal information management is to create "piles," i.e., to stack information together in a heap or group. Malone (1983) identified two basic strategies for handling paper: *filing* and *piling*. The difference between *filers* and *pilers* is that *filers* maintain ordered information categorization and organization strategies (desktops), and do not allow papers to simply pile up. They systematize their archives (using alphabetical, conceptual, or temporal methods) to support straightforward access to stored data. In contrast, *pilers* follow disorganized strategies, have messy desktops cluttered with paper piles, and make few attempts to organize stored information. Malone (1983) speculated that paper-handling strategies are a response to job requirements. Predictable work encourages the use of structured filing systems, whereas less procedural work elicits piling strategies. A commonly held intuition is that *filing* is a superior approach to paper processing, leading to smaller, better organized, and hence more accessible archives.

Subsequently, the concept of "piles" was used in a study investigating how individuals deal with the flow of information in their workspaces (Mander et al., 1992). This study explored the behavioral characteristics of users who like to group items spatially and often prefer to deal with information by creating physical piles of paper, rather than immediately categorizing it into specific folders. This strategy of organizing information can be used in digital environment as well, by using 'piles' within a graphical user interface. This would help in handling the large amount of information that is typically processed using computers and address the limitations of the hierarchical filing system that is available now. The study conducted by Mander et al. (1992) examined two different models for pile construction captured in the interface of a computer system: a "pile-centered" approach and a "document-centered" approach. They found that

although users tended to have a clear preference for one pile construction model over another, neither approach was judged to be unequivocally superior.

In another study related to the concept of "piling and filing," Whittaker and Hirschberg (2001) explored general issues concerning personal information management by investigating the characteristics of office workers' paper-based information in an industrial research environment. They noted that individuals use a variety of paper processing strategies for organizing information archives (filing and piling). In a comparison between the two strategies, their findings were that filers amassed more information, and accessed it less frequently than pilers. While filing had the benefits of applying a formal structure to paper data, filers also incurred costs. Further, filers end up with greater amounts of information than pilers, largely due to premature filing. By contrast, pilers benefited from the greater availability of recent information, and experienced less overhead in managing their data, and found it easy to clean their archives. However, pilers experienced difficulty in accessing information once piles had begun to multiply, in comparison to filers.

Building on Malone's conceptualization of filers, several researchers have categorized filers into different groups, such as frequent filers, spring cleaner, and no-filers, categorized by Whittaker & Sidner (1996); or no-filers, creation-time filers, end-of-session filers, and sporadic filers, categorized by Abrams et. al (1998). In a longitudinal study, Boardman and Sasse (2004) profiled user practices across file management (total filers, extensive filers, and occasional filers), email management, and bookmark management strategies used in PIM. Their findings were that individuals employ multiple PIM strategies within specific collections and they may not fall into the simple categorization based on 'extreme' behaviors of being tidy or messy, filers or no-filers. Rather they found people use multiple strategies and vary in the management and organization strategy of personal information depending on the nature of the information, tools they use, likelihood or style of retrieval, acquisition of the information and personality factors. Boardman and Sasse (2004) emphasize that a consideration of these factors in the design aspects of personal management tools would (1) provide synergies between tools that can be exploited to improve integration, and (2) remove the differences between tool usage that may indicate barriers to integration.

### 5.2.9 Other Strategies for Electronic File Management

Hicks et al. (2008) conducted a qualitative and quantitative examination of the electronic file management strategies used by mechanical engineers and analyzed the organization of these files across their personal computers. They describe these strategies in detail, and conclude with recommendations for improving access and management of electronic files. Their study enumerates the functional scheme of file naming, the sharing and exchange of files, and the personal strategies developed by the engineers to manage their file systems. They highlight the importance of a shared scheme for organizing personal directories and naming files in this specific context of engineers' information management in an organization.

In a study of knowledge workers, Henderson (2005) found that folder names for electronic documents are based on genre, task, topic, and time. This research provides a starting point for understanding how individuals structure and manage their electronic documents. These studies were conducted in the professional environment of the participants, and an implicit assumption in them is that people use similar strategies for personal and professional file organization. In other words, file organization strategies are more dependent on the personal behavior of the individual than the specific context in which they are being executed. However, this may not be the case at all times, and individuals might follow different strategies for managing and organizing files in their personal and professional environments.

### 5.2.10 The Calendar or Diary as a Focal Repository of Personal Information

Calendars serve many purposes, including temporal maps, emotional awareness artifacts, PIM tools, hand-held tools, and diaries (Tomitsch et al., 2006). The calendar is used as a personal information management strategy for the individual and sometimes as a shared space for the family for personal and family information organization and sharing. Similar to calendars, diaries are tools for time allocation and organizing personal priorities (such as work, leisure, and family time). They are used for short and long term planning of future commitments, such as appointments and meetings in all areas of life. Hence, the *diary* can serve as an individual's personal information management tool; or as a family communication tool in the context of PIM (Fleuriot et al., 1998). Depending on the person's integration or separation between home and

work, and depending on the time and work association, he might be using a diary or calendar, or both, or more than one of the forms of each. The basic unit of decomposition of information in the case of both the diary and the calendar is, typically, time, i.e., these artifacts reflect an information management strategy that is temporal in nature.

### 5.2.11 Information Management Strategies for Health Information Management in the Household

The recent focus on consumer health care has placed greater burden and responsibility for health information management on the consumer. In general, health information management at home (HIMH) by individuals can be described by the strategies they develop and deploy, constrained by their insights, skills and tools in hand. Moen and Brennan (2005) conceptualized that the work of HIMH is largely the responsibility of a single individual, primarily engaged in the tasks of acquiring, managing, and organizing a diverse set of health information. They analyzed the HIMH process and found that growing amounts of health information are brought into the household and retained, under assumptions of future needs. They categorized the storage strategies followed by individuals along a structural dimension and differentiated them as follows (Moen & Brennan, 2005):

1. Just-in-time. Information and/or artifacts are with a household member at most times.
2. Just-at-hand. Information and/or artifacts are visible or stored in readily accessible, highly familiar locations in the household.
3. Just-in-case. Information and/or artifacts, either personal health files or general health information resources, are kept away but accessible within reasonable time for any future situation.
4. Just-because. Information and/or artifacts about a health concern are brought into and kept in the household but, because of temporal relevance, no other storage strategy is assigned.

Their descriptive study and the characterization of these four strategies provide useful insights for the functionality and design of personal health information management tools and systems.

### 5.2.12 The Distribution Strategy for Personal Health Information Management at Home

Where and how information is stored in the home, and how it is distributed, is an important strategic dimension of PHIM for an individual or family. In a study of households, Zayas-Caban (2005) sought to understand health information management at home, and examined household layouts, photographs and health information storage behaviors. She found that health information is scattered in "spaces" throughout the home, distributed across the space and physical location in the household. The storage patterns of such information can be associated with where or when the information is used, frequency and urgency of use, and ownership. Households with multiple artifacts and locations may have multiple users and varying frequency of use for different kinds of health information, which determines the way health information is distributed across the space. An important implication of these findings is that the presumed one-household-one-individual health information management scheme may not hold true in reality and must therefore be addressed in the design of health informatics solutions for helping families manage their health information needs.

## 5.3 The Interplay between Personal Information Management Strategy and the Design of Tools

An understanding of the strategies that individuals use for managing and organizing personal health information is vital for the design and development of tools, technologies and applications for PHIM. Several tools are being developed that incorporate these strategies and studies with prototypes and are providing new insights for research and development. For example, RecipeSheet is a tool that supports the extraction of information from diverse sources, editing and processing of the information, and explorations of changes in end results because of the processing (Lunzer & Hornbæk, 2006). RecipeSheet allows users to create information processors, called recipes, which may take input in a variety of forms such as text, web pages, or XML, and produce results in a similar variety of forms. This general purpose tool supports manual intervention and control by users as to which information flows through the dependency connections, and simplifies the management of tasks through improved processing. As its developers point out, the construction of the tool has benefited significantly from an

understanding of PIM task management strategies and user experience studies (Lunzer & Hornbæk, 2006).

Similarly, with an understanding of the complexity of personal data management, researchers have begun to develop personal data management systems to manage personal data more efficiently and effectively. For instance, Li and Meng (2008) developed and analyzed a conceptual model of personal data space management that supports data integration, data organization, and data operations such as query, update, and backup. They implemented their conceptualization and the design guidelines that emerge from it in a prototype called OrientSpace. This system supports two functions: data integration and data query processing, in personal data integration and management. Each of the systems described above illustrates how field-based insights and/or assumptions about PIM practices made by researchers are informing the design of tools.

## 5.4 Summary

Users follow different strategies for managing and organizing their personal health information. The strategies deployed can be influenced by many factors including the characteristics of the medium (i.e., paper-based versus digital), and user characteristics. The PIM and PHIM literature identifies several strategies for organizing and retrieving information stored in paper and digital form, such as the personal project planner, human digital memory, folders, projects, task management, personal archives, and collections. Each strategy adopts a particular conceptual approach for decomposing and tagging information objects, and for organizing subsequent access and retrieval. Tools that incorporate an explicit information management strategy in their design approach are beginning to emerge in prototype implementations. A detailed, granular understanding of the range of strategies and normative insight into which strategies are more effective in different contexts with different types of users is not currently available in the research literature.

# Chapter 6: Tools and Artifacts for Personal Information Management

As with any other complex activity that involves storage, processing, and retrieval of information, PIM and PHIM are ideal candidates for the application of digital technologies. Chapter 3 outlined the wide ranging scope of health related information that users seek to manage, and Chapter 5 described the strategies that individuals use for organizing and managing their personal information, noting considerable variety in the strategies followed. As highlighted in earlier chapters, the management and use of large volumes of information places significant cognitive burden on users that can be alleviated through appropriate tools that support the execution of PHIM activities. Further, some routine aspects of the cognitive processes can be automated using technology. Thus, a "cognitively overloaded process," can be transformed into a fully or semi-automated process, rendering the overall PIM activity more effective and efficient (e.g., Pratt et al., 2006; Moen & Brennan, 2005; Jones, 2007). The literature describes a series of tools that have been developed and/or are in use to support PIM and PHIM activities; these tools are categorized and summarized in this chapter (see Figure 7.)

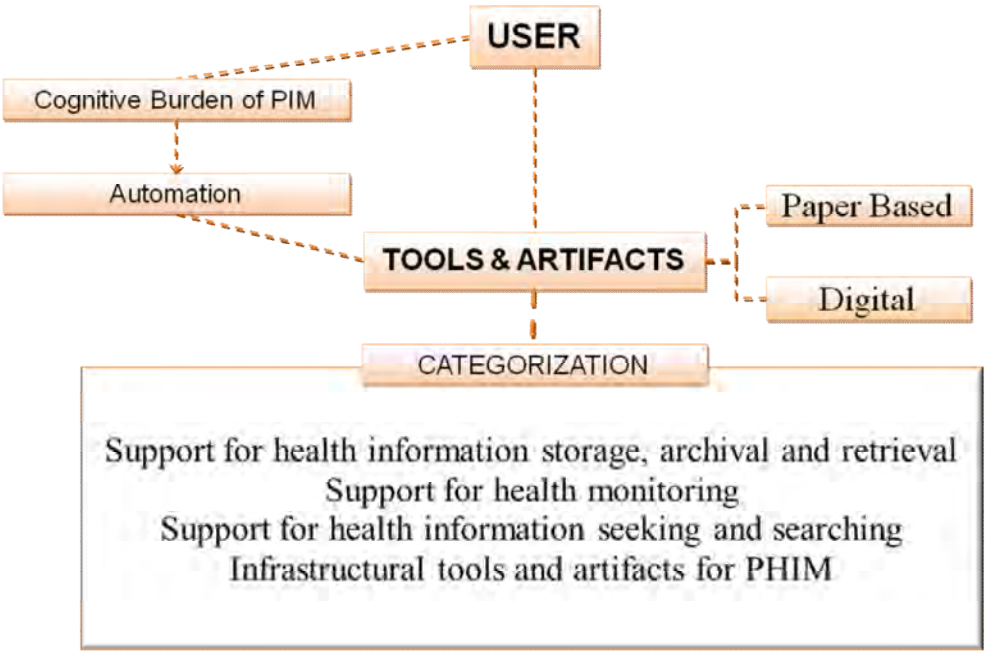


**Figure 7. Tools and Artifacts for Supporting Personal Health Information Management**

Descriptions of tools are scattered throughout the literature and there is no comprehensive classification for situating different artifacts. Further, tools typically address one or more of the core PIM activities of finding/refinding, keeping, and meta-level actions, but very few artifacts provide support for the entire gamut of PIM activities. For example, in the report *Connecting Americans to Their Healthcare*, the Markle Foundation defines a personal health record as "an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment" (Markle Foundation, 2004). Most PHRs have an information structure and organizational logic already built in; thus, the degree of flexibility that the user has in performing meta-level actions of deciding how to structure the information is limited. The characteristics of a predefined information structure and organizational logic apply to most PIM and PHIM tools, as each embeds a specific model of and assumptions about how individuals structure and organize information. Likewise, although paper-based folders provide significant flexibility in the structuring of information, they are less effective in facilitating refinding because of the absence of automated search and retrieval processes.

## 6.1 Paper and Digital Forms of Artifacts for Personal Information Management and Personal Health Information Management

Chapter 5 discussed how strategies for managing and organizing information address both paper-based and digital media. In a similar fashion, the tools and artifacts used for PIM and PHIM range from simple paper-based storage forms such as paper-calendars and diaries or sophisticated technological devices such as personal health records and disease management applications. In many empirical studies of PHIM practices, paper-based storage of information has been identified as a dominant strategy for personal health information (Moen & Brennan, 2005) and still constitutes the core foundation for the organization of personal information collections; even after the introduction of several IT based tools and devices. Indeed, PIM researchers highlight the prevalent use of paper as a medium for information storage, identifying three important distinguishing characteristics of information management through paper archives: (1) paper archives follow the course of *"obsolescence"* by increasingly becoming irrelevant, because of general changes in the nature of information processing and the conversion

of paper data to digital form; (2) paper as a storage medium follows the *"uniqueness"* attribute, indicating that people are rational about retaining and storage of information, and tend to retain only unique data in paper forms due to the inefficiency of paper forms to store duplicates of data available elsewhere; and (3) as a strategy for handling paper data archival, paper forms follow either a *"filing"* or *"piling"* approach (Whittaker & Hirschberg, 2001).

The limitations of paper forms to provide easy duplication and replication of archives, and the increasing adoption of digital forms for information processing has opened new opportunities for managing personal health information. In some instances, paper forms are being supplemented with electronic devices such as personal digital assistants or general-purpose computers. Emerging tools and devices such as personal health records (PHR) or home health monitoring devices offer individuals access to some elements of their personal health management, such as diagnostic results, doctor's visit summaries or test results from laboratories. Further, these tools provide support to manage logistical issues involved with the health care management, such as secure messaging and appointment scheduling. However, whether these tools and devices are effective for personal health information management remains to be established. Nonetheless, such tools are increasingly becoming integrated into the fabric of daily existence for consumers, and will become even more ubiquitous as technological advances result in the development of more user-friendly systems.

## 6.2 Categorization of Tools and Artifacts for Personal Information Management and Personal Health Information Management

Studies in the literature typically discuss one or a small number of PHIM tools and do not focus on classifying them. As shown in Figure 7, the literature was synthesized in relation to specific tools and artifacts to construct a classification scheme containing four categories of devices: (1) tools and artifacts that support health information storage, archival and retrieval, (2) tools and artifacts that support health monitoring, (3) tools and artifacts that support health information seeking and searching, and (4) infrastructural tools and artifacts for PHIM. This categorization of artifacts presented is based on the functions of PHIM that each tool supports and enables.

Amongst the categories, the first category of tools and artifacts is more central to PHIM activities and functions than the latter three categories, which could be peripheral for PHIM activities depending on the context or situation. For example, a web-based tool that supports information seeking may be useful to gather information relevant to an individual's current disease. The information that is searched and collected may be stored by the user and utilized at a later point in time as personal health information, or it may simply serve to increase the knowledge of the individual about the disease. As noted in Chapter 1 of this report, Pratt et al. (2006) define PHIM as activities that involve the integration of personal, professional, and health-related information, which helps people manage their lives and actively participate in their own health care. Hence, any tool or artifact that helps the individuals to not only execute the core PHIM activities of finding, keeping, and refinding, but also promotes enhanced understanding of one's health condition and personal health management is, arguably, a PHIM tool.

There is a potential overlap between the four categories described below as an artifact in one category could plausibly be placed in another depending on how it is used. In some ways this is not surprising because fundamentally each tool is attempting to address one of more aspects of the core PHIM activities. Nevertheless, the categorization is a useful starting point for understanding the range of tools available to consumers today. Specific citations and examples of the tools and artifacts in these categories are illustrated in Table 6.1.

### 6.2.1 Tools and Artifacts That Support Health Information Storage, Archival and Retrieval

This category includes tools that directly help in the function of storage, archival and retrieval of personal health information. At their core, each one of these artifacts serve as a information storage or repository of personal health information; which then can be retrieved at a later point of time or at the time of need. These tools provide functionalities such that either the individual or other users can access and use health information for different purposes, such as diagnosis, intervention, and treatment.

One class of tools that provide the health information storage and archival functions are different types of health records. Health records can be either paper- based or electronic systems for the

storage and retrieval of health information. They may be created by the individual through his or her personal endeavors or created by others for the individual (Häyrinen et al., 2008) and can contain a wide range of medical information such as personal information, health conditions, medical history and medication refill information. Health records are slowly transitioning from paper to digital form. Based on their architectural components and intended use, the commonly followed terminology for these kinds of artifacts includes personal health record (PHR) and personally controlled health record (PCHR).

Among the electronic forms of health records, the one closest to the consumer is the PHR. The PHR has been defined and studied in a variety of ways (Mandl et al., 2007; Tang et al., 2006), and in various form factors such as an un-tethered stand-alone PHR or a tethered, web-based PHR (Angst et al., 2008). Mandl et al. (2007) described an open source, open standards personally controlled health record (PCHR) with an open application program interface. Some definitions of a PHR view it simply as a data storage or repository tool, while other research envisions it as a functional tool for personal health information management (Tang et al., 2006). Vincent et al. (2008) developed taxonomy for PHR architectures, further highlighting the fact that varied conceptualizations of a PHR exist in the literature.

Although field data about the modalities of PHR use for health information storage and management and the effects of such use is limited, Angst and Agarwal (2006) document various types of health information management value that individuals perceive as being provided by the PHR, including structure, organization, and compliance with medication and treatment regimens; relationship and connectedness with the care providers; and convenience and empowerment regarding easy access to and availability of personal health information at all times. A recent study by Nazi and Woods (2008), in the context of the My Health**e**Vet® PHR, demonstrates that the medication refill function and various health information functions provide significant value for users. This provides evidence that PHRs could be useful to consumers, through their impact on medication management for diseases, supporting the PHIM goal of personal health management.

The current issue with the digitally developed and integrated health record systems is that most of them are proprietary and hence, the spread and reach of these systems to the consumers is still

very low. However, although the penetration of personal health records is still fairly low, the adoption of these systems may increase, subject to the assumption that the embedded functionalities have value to the consumers for their personal health information management.

Along with health records, the category of tools and artifacts that support information storage, archival and retrieval includes several other types of information systems applications. These applications consist of patient self-management systems, applications for information storage and retrieval, and artifacts and devices dealing with specific user-oriented functions associated with storage, archival or retrieval. Whereas the discussion of user-oriented artifacts in the health informatics literature is a relatively recent phenomenon, electronic artifacts for PIM started appearing in the literature as early as 1990 in the form of an "item/category" database called "Agenda" (Kaplan et al., 1990). Since that time, the information science and computer science communities have developed a range of prototype systems based on the strategies discussed in Chapter 4 of this report. Examples of systems include SeeTrieve (Gyllstrom & Soules, 2008), MyMedicationList (Zeng et al., 2008), RecipeSheet (Lunzer & Hornbæk, 2006), OrientSpace (Li & Meng, 2008), Personal Equilibrium Tool (PET) (Fleuriot et al., 1998), CEO (cue-event-object) model for information storage and retrieval (Huggett, 2007), Haystack, a system for managing information collections (Karger & Quan, 2004), PROTEUS, a personal electronic notebook (Erickson, 1996), and Lifestreams, a storage model for personal data (Freeman & Gelernter, 1996). These tools and artifacts provide various types of functionality that can be useful for analyzing trends by collecting information across different individuals, for managing information collections, for storage, integration and management of personal data, for helping users manage their medication lists and making information records readily available. Further, some artifacts in this category also serve the purpose of helping users balance work and family schedules, such as a personal document retrieval and classification system, or help in other functions, such as a system that facilitates information re-use.

### 6.2.2 Tools and Artifacts That Support Health Monitoring

This category of artifacts includes systems and tools for assessing and monitoring the users' health status and/or monitoring specific health conditions. Monitoring through these devices may be done in the home directly, passively or through remote surveillance. Personal observations that can be monitored through these devices may include heart rate, breathing rate, activities of daily living, physical activity and lifestyle, or specific observations related to a particular chronic condition or illness, such as a blood sugar reading for diabetic patients. Although these tools are primarily data generating devices, or are used for the monitoring of specific conditions; to the degree that the information obtained from these devices is potentially relevant for personal health management, they constitute PHIM tools. For example, weight readings measured by a weighing scale can be used to find the body-mass index for an individual to determine his or her current health condition. Similarly, the readings obtained from a blood pressure measurement device can be used to monitor daily variation in the blood pressure levels of an individual, thereby showing the effect of exercise on his/her health. Further, these devices can be combined with different information systems applications, to provide a tool or device that can measure, monitor, alert or provide feedback as a personal health management tool. In the study conducted by Alwan et al. (2006), monitoring systems were installed in assisted living units to track the activities of daily living of residents. Coupled with information system devices these systems were able to produce activity reports and alert notifications; that were then used to provide care to residents participating in the study. The pre- and post-installation satisfaction survey results suggest that monitoring technologies could provide care coordination tools that are accepted by residents and may have a positive impact on their quality of life.

Studies related to health monitoring devices include: the study of health monitoring systems for general health parameters such as heart rate, breathing rate, and activities of daily living (Alwan et al., 2006), and the study of systems that automatically capture and transmit relevant health data for various disease specific conditions (Casper & Kenron, 2005; Chappell & Vanden Plas, 2008). In this context, one emerging area of development is 'home and remote health monitoring', which refers to monitoring the health of patients at their homes or, more generally, at any location away from a health care facility. It involves the use of technologically advanced devices that are designed to monitor the daily health conditions of patients, to send regular

readings about the patients' conditions to their doctors' systems, and to send alerts to doctors about any abnormalities in the patient's conditions (Kunze et al., 2001; Alwan et al., 2006). Home monitoring systems and medical devices save patients the trouble of going to the doctor for regular check-ups, which is especially helpful in the case of those patients for whom mobility is difficult. The use of communication tools, internet platforms, and information technologies for health monitoring has provided capabilities in the consumer health IT domain, in the form of *telemedicine* (Koch, 2006), *telehealth* (Hensel et al., 2006) and *eHealth* (Eysenbach, 2000a) systems. When applied to a patient's home environment, telemedicine and/ or telehealth are usually termed as *tele-homecare* or, more recently, *home telehealth* or *home based eHealth* (Hensel et al., 2006).

These technologies are largely geared toward allowing the provider to access relevant information about the patient. However, the information captured by these systems may be provided to the individual for his/her reference or archival; which could serve as a future reference for personal health information. Moreover, at the time of need, the data available in these devices can allow the user to establish the mapping between an information need and the information itself. Therefore, although these emerging technologies may not be of direct relevance to PHIM activities today, the concept of monitoring provides a feedback and control mechanism for the activities involved with personal health information management. Further, in addition to their role in health maintenance, from the perspective of PHIM, home monitoring devices capture important personal health data that the individual may want to retain as part of a personal health archive. Finally, with the deployment and use of such monitoring systems, individuals become aware of their role in managing their personal health; and develop more affinity, and become more actively engaged with their personal health information management activities (Balas & Iakovidis, 1999; Koch, 2006).

### 6.2.3 Tools and Artifacts That Support Health Information Seeking and Searching

With the increasing reach and penetration of the Internet, a variety of tools and applications, websites, and health information portals have emerged as artifacts for PHIM. The growth of health-related content on the Internet has been striking, and the range of capabilities for

supporting PHIM activities is expanding every day. The artifacts in this category make use of the Internet as the platform and backbone and include health focused websites such as WebMD, online communities that address specific disease conditions (e.g., Inspire.com; PatientsLikeMe.com), collaboration tools such as "exercise buddies," online tools (e.g., for computing body-mass index and calorie consumption), and online data repositories for seeking specific information related to any disease condition. This category of artifacts also includes data repositories of the scientific literature (e.g., MedlinePlus® and HealthFinder.Gov) which provide a major source to validate information and discover new clinical findings on the efficacy of treatment alternatives or risk behaviors associated with specific health conditions. From the perspective of PHIM, these artifacts have the potential to support the entire set of PHIM activities related to health information seeking, searching, and collecting; and to some extent support the functions of managing and retrieving the relevant information for use. Research studies examining a wide range of issues with Internet enabled health information management are beginning to emerge in the literature. In addition to focusing on the usefulness and value of this category of tools, researchers have also discussed issues pertaining to quality, credibility, completeness, usability, safety, ethics, user's loyalty, and consumer attitude towards such artifacts (Dutta-Bergman, 2004; Berland et al., 2001; Cline & Haynes, 2001; Murray et al., 2003; Eysenbach et al., 1998)

### 6.2.4 Infrastructural Tools and Artifacts for Personal Health Information Management

This category of tools and artifacts consists of emerging devices, applications and design concepts that constitute the foundations for specific consumer health IT applications. Many of these tools or artifacts are in the conceptualization or prototype stage and are being developed and tested in academic research settings. For instance, because locating information is a core PIM activity, researchers have developed tools and algorithms for facilitating information search and retrieval processes in electronic repositories which have been implemented in many of the artifacts described here. An examples of such system is the SIS (Stuff I've Seen) (Cutrell et al., 2006; Dumais et al., 2003), that facilitates information re-use through two ways: by providing a unified index of information that a person has seen, and second, by providing rich contextual cues for the search interface. Similarly, the SEMEX (Semantic Explorer) system offers users a

flexible platform for personal information management, through organizing information in a semantically meaningful way, and then leveraging the personal information management environment to support on-the-fly integration of personal and public data (Cai et al., 2005).

## 6.3 Summary

The complex process underlying the management of personal health information can be supported in various ways with tools, devices and artifacts. Although paper-based solutions are still widely prevalent and work efficiently in many contexts, they are nonetheless limited in important functionality such as easy retrieval of stored information, and the capability of efficiently managing large volumes of data. A review of artifacts described in the literature suggests a four category classification based on their functionalities and application orientation. Many of these artifacts are still in a prototype stage and are not available as commercial tools. Further, field testing and evaluation of many of the tools is still at a very early stage, suggesting the need for continued research and development.

**Table 6.1: Tools and artifacts for personal health information: categorization and examples**

| Category | Description or context of tool or artifact discussed in the paper | Citation(s) |
|---|---|---|
| Tools and artifacts that support health information storage, archival and retrieval | Proteus, a personal electronic notebook to help in personal information management | Erickson, 1996 |
| | How patients living with chronic inflammatory bowel disease value internet-based patient access to electronic patient records. | Winkelman et al., 2005 |
| | My Health**e**Vet Personal Health Record, the medication refill function and various health information functions provide significant value for users | Nazi & Woods, 2008 |
| | "Agenda" and "item/category" database for personal information management | Kaplan et al., 1990 |
| | Automated home based patient management system | Farzanfar et al., 2004 |
| | CEO (cue-event-object) model for information storage and retrieval | Huggett, 2007 |
| | Haystack, a system for managing information collections | Karger & Quan, 2004 |
| | PROTEUS, a personal electronic notebook and customizable system for PIM | Erickson, 1996 |
| | RecipeSheet, a general-purpose tool for assisting users in PIM tasks | Lunzer & Hornbæk, 2006 |
| | Lifestreams, storage model for personal data | Freeman & Gelernter, 1996 |
| | MyMedicationList, a prototype application developed at the National Library of Medicine that helps users manage their medication lists and make the records readily available when needed | Zeng et al., 2008 |
| | OrientSpace, a prototype system developed for personal data integration and management | Li & Meng, 2008 |
| | Personal Equilibrium Tool (PET) a tool to help coordinate activity and balance work and family schedules, that would be especially useful for dual-career families | Fleuriot et al., 1998 |

**Table 6.1: Tools and artifacts for personal health information: categorization and examples (continued)**

| | | |
|---|---|---|
| | SeeTrieve, a personal document retrieval and classification system | Gyllstrom & Soules, 2008 |
| | Personal health record (PHR), personally controlled health record (PCHR), barriers towards PHR study, design and challenges, consumer perceptions towards PHR and applications of PHR | Maisie et al., 2004<br>Kim et al., 2005<br>Tang & Lansky, 2005<br>Agarwal & Angst, 2006<br>Lober et al., 2006<br>Tang, et al., 2006<br>Ball et al., 2007<br>Mandl et al., 2007<br>Marchionini et al., 2007<br>Grant et al., 2008<br>Mandl & Kohane, 2008<br>Mitchell, 2008<br>Kidd, 2008<br>Steinbrook, 2008<br>Terry, 2008 |
| Tools and artifacts that support health monitoring | Home or remote health monitoring technologies | Balas & Iakovidis, 1999<br>Chappell & Vanden Plas, 2008 |
| | Monitoring systems for general health parameters such as heart rate, breathing rate, and activities of daily living | Alwan et al., 2006 |
| | Application of ubiquitous computing for personal health monitoring | Kunze et al., 2001 |
| | Sensewear armband, an assessment device to assess physical activity and lifestyle | Andre et al., 2006 |
| | Current and future trends on home telehealth, telemedicine solutions and personal health monitoring and diagnosis services | Koch; 2006<br>Schwaibold et al., 2002 |
| | *eHealth* for health care practice which is supported by electronic processes and communication | Eysenbach, 2000a |
| | Study of a patient's home environment for the obtrusiveness towards home telehealth technologies | Hensel et al., 2006 |

**Table 6.1: Tools and artifacts for personal health information: categorization and examples (continued)**

| | | |
|---|---|---|
| Tools and artifacts that support health information seeking and searching | Health websites helping in health information search and use | Hong, 2006 |
| | Smartsource – online service that helps patients link records and research | Freudenheim, 2008 |
| | Use of online health websites | Woolf et al., 2006 |
| | Health information seeking system design | Kinzie et al., 2002 |
| | Personalized health information, online health usage review and outlook | Sillence et al., 2006 |
| | Health information search, credibility and completeness | Dutta-Bergman, 2004 |
| | Consumer health websites for the purpose of seeking health information | Keselman et al., 2008 |
| | Credibility of health websites for information search and accuracy | Kunst et al., 2002 |
| | Health information on internet, search, use, information seeking behavior | Berland et al., 2001<br>Cline & Haynes, 2001<br>Cotten & Gupta, 2004<br>Rice, 2006<br>Hesse et al., 2005<br>Murray et al., 2003<br>Hansen et al., 2003<br>Eysenbach & Kohler, 2002<br>Eysenbach et al., 1998<br>Eysenbach et al., 2002<br>Detlefsen, 2004<br>Lorence & Greenberg, 2006 |
| | Cancer patients' online health search attitudes and internet as a source of information for cancer patients | LaCoursiere et al., 2005 |
| | MyGroupHealth – patient website providing a shared medical record between patients and health professionals | Ralston et al., 2007 |
| | Online health community and online health information usability | Maloney-Krichmar & Preece, 2005<br>Lasker, 2005 |
| Infrastructural tools and artifacts for PHIM | SEMEX (Semantic Explorer) | Cai et al., 2005 |
| | SIS (Stuff I've Seen), system that facilitates information re-use | Cutrell et al., 2003 |

# Chapter 7: Design Considerations and Principles for Consumer Health IT

Design considerations and principles for consumer health IT reflect the requirements that must be satisfied by technologies in order to support consumers as they engage in their personal health information management endeavors. An overarching design consideration and principle is that of "usability." Usability has been defined as an *attribute* of a product, i.e., "The extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use (ISO 9241-11, 1998)." Usability design or usability engineering includes the methods and approaches for improving ease of use during the design process (Nielsen, 1993). Usability is important for all consumer products but arguably particularly vital in the design of consumer health IT solutions since many users have limiting conditions that constrain effective use. For instance, artifacts must be designed to accommodate the special needs of individuals with disabilities such as impaired hearing or vision in order to be effective (Brown & Robinson, 2006).

As discussed in Chapter 1, the increasing emphasis on consumer-directed health care and associated consumer empowerment has fueled the interest of researchers and industry players, who have begun to develop prototypes or to offer new tools and artifacts in the marketplace. Despite the availability of tools, to date, as described in earlier chapters of this report, there is limited detailed knowledge and understanding of how individuals manage their personal health information and what their preferences are with respect to tools that support PHIM. Further, many of the tools that are commercially available today have yet to demonstrate their efficacy across a wide range of user populations and contexts (Jimison et al., 2008). In other words, the *usefulness* of these tools has not been established.

A basic design approach that is deployed to ensure that the products of the design process are useful is "user-centered design," which is described below. Further, the existing literature focused on PIM and PHIM practices provides some insights into general design considerations and principles that should guide the design of tools. However, the research literature on specific principles for the design of consumer health IT is modest. This is an outcome of two gaps in the

literature: (1) there are too few studies exploring the personal health information practices of users to be able to construct specific usability prescriptions; (2) many of the tools developed for PHIM and PIM have not been extensively tested in usability and use studies and therefore, there is limited knowledge of what design principles are effective. As shown in Figure 8, two broad categories of prescriptions may be found in the existing literature. One category relates to general principles for the design of consumer health IT, while the second focuses more on usability design guidelines for specific classes and types of tools. A synthesis of this research and the normative principles that emerge from it are summarized here.

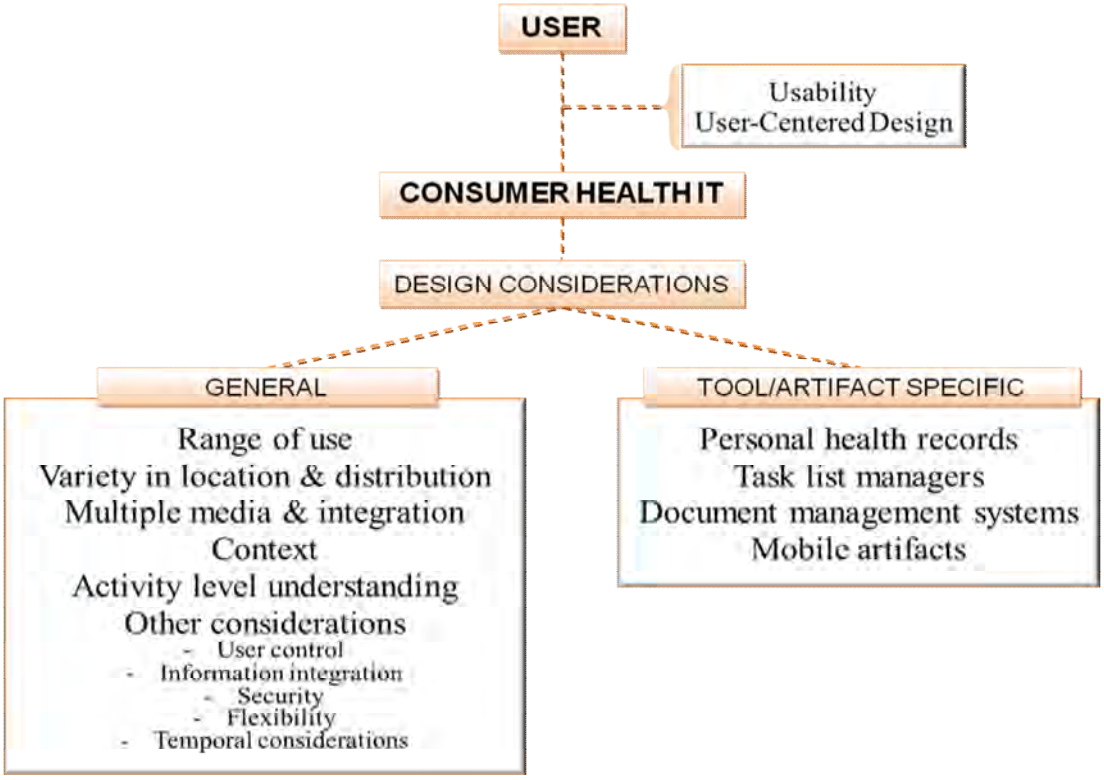


**Figure 8. Design Considerations for Consumer Health IT**

# 7.1 The Design Process

To the degree that the overarching objective of consumer health IT is to support and enable the individual user in the management of his/her health information, the concept and principles of "user-centered" design (ISO 13407, 1999; Ji-Ye Mao et al., 2005; Spinuzzi, 2005) are particularly appropriate for identifying the requirements that must be satisfied by consumer health IT. The essence of user-centered design (UCD) is to place the user center-stage during the artifact design process and to construct the solution so that it takes into account the needs, values, goals and limitations of the user. UCD is predicated on a process of iterative design and refinement so that the product that emerges at the end of the design process matches the users' requirements effectively. UCD seeks to answer the following types of questions (Katz-Haas, 1998):

- Who are the users of this 'thing'?
- What are the users' tasks and goals?
- What are the users' experience levels with this thing, and things like it?
- What functions do the users need from this thing?
- What information might the users need, and in what form do they need it?
- How do users think this 'thing' should work?
- How can the design of this 'thing' facilitate users' cognitive processes?

In the context of consumer health IT, researchers have noted that UCD may be a particularly valuable design approach for tools such as PHRs as well as for other consumer health IT applications (Rodriguez et al., 2007). Since 2006 the Robert Wood Johnson Foundation has been funding a project for deploying UCD design concepts in PHRs so that they can be seamlessly integrated into the daily life of individuals (http://www.projecthealthdesign.org/).

## 7.2 General Design Considerations and Principles for Personal Information Management and Personal Health Information Management Tools

Prescriptions for the design of PIM and PHIM tools are scattered through the literature. As described below, in most instances the specific guidelines that are proposed are an outcome of the characteristics and context of the research study (e.g., a study on PHIM done in a home setting or a study of PIM in an office environment.) However, to the degree that individuals engage in PHIM activities in multiple settings, the recommendations emerging from these studies are likely to be relevant.

One overarching meta-level design principle that is implicitly or explicitly echoed in the existing research literature is the importance of context, task, and user in designing PHIM tools. This meta-design principle is reflected in the work of Bergman et al. (2003) that describes the concept of a user-subjective approach to PIM design (http://www.user-subjective.com). The core idea behind this approach is the requirement for PIM systems to accommodate the "*subjective value-added attributes*" that users give to the information in order to facilitate the user-system interaction. These *subjective value-added attributes* should help the user find the information item again, recall it when needed, and use it effectively in the next interaction with the item. Based on this user-subjective approach, Bergman et al. suggest three generic principles that should be taken into account while designing PIM artifacts: (a) the *subjective classification* principle stating that all information items related to the same subjective topic should be classified together, regardless of their technological format, (b) The *subjective importance* principle proposing that the subjective importance of information should determine its degree of visual salience and accessibility, and (c) The *subjective context* principle suggesting that information should be retrieved and viewed by the user in the same context in which it was previously used. Their work again highlights the principle that PIM and PHIM tools must be able to support activities in diverse settings for different types of users, their context and interactions; while being able to perform a variety of information management tasks.

### 7.2.1 Tools Should Support a Range of Use

Brennan and Kwiatkowski (2003) explored home health information management by studying the physical, social, and technological environments of the family home. They found that most households manage ten different types of health information, such as disease information, medication schedule, insurance information, medical history, laboratory results, and self-monitoring results. Further, the households use various technologies at home, either for information management or other purposes. The households' PHIM activities span disease-specific and general health care tasks, concerns, and information. Among their sample of 49 families, 50 percent of the households had Internet access from home and 80 percent had Cable TV access. They note that it is imperative that these existing technologies and traditions of health management at home be integrated with newer designs or health information management innovations. Their observations further support the notion that health information management must span a range of disease-specific to general health content, and from individual-health problems to population-health problems. Hence, range of use plays a vital role in the design consideration of devices, which should take into account all the applications and characteristics of health information management in households. Along with the range of use, other design characteristics that are important for the design of such devices include factors such as portability, ease of updating and viewing, and capacity to manage diverse types of information artifacts (Brennan & Kwiatkowski, 2003).

### 7.2.2 Tools Should Incorporate Variety in Location and Distribution

The diverse range and types of health information that households store is distributed across locations for use and access. The examination of household layouts and the health information storage behaviors of families by Zayas-Caban (2005) showed that health information is distributed across the household, with the location of different artifacts varying depending upon the user's needs in terms of accessibility and frequency of use. For instance, contact information for the doctor, prescription information or medications, and immunization records may be stored in the kitchen, due to the need for immediate or frequent access, whereas literature on health information may be stored in the bedroom or office, because it is likely to be accessed less frequently. This suggests that future devices may need to be deployed throughout the household,

with different levels of access to information for different family members, and must provide varying levels of customizability at the "point" and "location" of use (Zayas-Caban, 2005).

### 7.2.3 Tools Should Support Multiple Media and Integration with Other Artifacts

As discussed in Chapter 6 of this report, PIM involves the use of multiple media. Despite the pervasiveness of computers and other electronic tools in the individual's personal information management sphere of activities, paper-based artifacts such as pads, diaries, calendars, notepads, and folders continue to be widely used. Researchers have noted that digital tools still do not support the management of documents and personal information completely, and there is a lack of support towards this integration (Malone, 1983). In the context of personal health information management by households, field studies have found that most of the tools and technologies used are paper-based (Moen & Brennan, 2005). An emerging consensus is that to support personal health information management by individuals and households, tools and technologies should provide support for and integrate traditional PIM artifacts such as calendars, phonebook, medical history, separate sheets of paper containing health information such as medication side effects, and, the less commonly used personal digital assistants or personal computers. Further, such tools and technologies should also support needs specific to health condition management in a household: e.g., special cards holding vital information such as medication, blood type, medication information; folders and notebooks with personal health information or insurance information; medical record information; and general information such as from books, from internet searches, and from mass media (most commonly, television and radio). In other words, health information management artifacts must include mechanisms for combining and integrating electronic and paper based information (Moen & Brennan, 2005).

An important question that arises is whether the design of a PIM technology should take into consideration the advantages of paper as an established medium for many people, and the extent to which paper-based media should be integrated with newer technology. While the answer seems to be to use paper-digital integration, there are inherent user and technology complexities associated with such integration. In a study with the use of a "pilot paper-PDA technology," where the PDA was used to scan and store the paper based information integrated with the digital

media, Bellotti and Smith (2000) found that the paper-PDA idea is not a viable option for its end users. Rather, such a system resulted in greater complexity and would impose additional cognitive burden for users. The findings of their study further indicate that general design principles for PIM artifacts include embedding PIM in an application that supports ongoing work, and that is flexible, lightweight, and simple to use (Bellotti & Smith, 2000).

### 7.2.4 Tools Should Support Context

An important design consideration for PHIM or consumer health IT systems is an understanding of the users' perspective and the interaction of the tool with the user's context, location, and routines. Several studies provide evidence for the importance of context. For example, Bonarenko and Jansen's (2005) study of the personal document management practices of 28 information workers revealed that document management is strongly related to task management, and hence the context of the activity in which they are involved. In comparing digital and paper tools used by these workers they find that digital tools do not support the embedding of contextual information (task-related) effectively while paper tools are able to do so.

A user's context can also be defined in terms of location and temporality. Church and Smyth (2008) conducted a diary study of mobile information needs with the objective of understanding users' goals with regard to their mobile information needs and how information needs change based on context. Their 4-week diary study of 20 participants resulted in the identification of three key goals among diary entries: informational, geographical, and PIM related. Informational needs are focused on the goal of obtaining information about a topic, geographical needs are focused on the goal of finding an answer to a question, and PIM needs are focused on the goal of finding out something private related to the individual. They also found that many of these entries have high temporal and location dependencies, such as the location and time associated with the information (Church & Smyth, 2008), further supporting the notion that context is crucial for personal information management activities.

Other studies that emphasize the importance of contextual factors as a design consideration include Cai et al. (2005) who present their experiences with the building and testing of a

prototype tool called Semex. This tool provides access to data stored in multiple applications and sources, such as emails and address book contacts, pages in the user's web cache, files in the user's personal or shared directory, and data in more structured sources (e.g., spreadsheets and databases). Semex creates the data repository of objects and associations using a collection of object-and-association extraction algorithms. Cai et al. note that many of the challenges associated with PIM arise because PIM manages long-lived and evolving data; and most databases are not expressly designed to handle this type of data. Cai et al. (2005) found that factors that need to be considered in designing a system like Semex include database schemas (structured and unstructured), user's knowledge and skills, and the perspectives of users. They conclude that rather than trying to fit users' activities into traditional data management systems, it would be more effective to build systems to support users in their own habitat.

### 7.2.5 Tools Should Incorporate Personal Information Management Activity Level Understanding

People collect information as a natural consequence of completing tasks and generate information that is unique to them according to their own personal experiences. Thus, one of the major difficulties in designing PIM or PHIM artifacts is embedding the design within a personalized context, and accounting for the nature of activities related to the information collection process. An understanding of the tasks that individuals engage in will provide insight into the nature of information they collect. A significant body of research emphasizes the fact that task type, complexity, and the activities involved in completing the task affect the information seeking and retrieval behavior of individuals (Byström & Järvelin, 1995; Vakkari, 1999). For example, Elsweiler and Ruthven (2007) explored the kinds of tasks that cause people to search their personal stores or refind information that they have seen or come across previously. In a study with 36 participants, they tried to understand PIM behavior at the task level by evaluating the distribution of tasks and identifying the kinds of refinding tasks that were perceived as difficult. They found that people perform three main types of refinding tasks: tasks that require specific information from within a single resource; tasks that require a single complete resource; and, tasks that require information to be recovered from multiple resources. This implies that even though finding, keeping, and refinding are related tasks for PIM, *refinding* is characterized by complex factors related to memory and to the initially encountered and

current contexts; and hence quite different from the *finding* and *keeping* tasks (Barreau et al., 2008; Elsweiler & Ruthven, 2007). By contrast, *finding is* driven by immediate goals and *keeping* is driven in part by anticipated use and value, but based on current situations. Hence, finding and keeping do not carry any memory or contextual relationship to the memory. Given these differences across the core PIM activities, the design of PHIM tools must incorporate an understanding of activities and reflect this understanding in the type of support they provide.

### 7.2.6 Other Considerations for the Design of Personal Health Information Management Tools

To address the question of what types of technology and design consumers suggest for supporting PHIM activities, Civan et al. (2006) involved health consumers in the design task and decision-making process in a collaborative environment with researchers. The participants talked through prominent PHIM activities, created a paper mock-up, initial designs and shared their ideas with the group. The major findings from this participatory design process were that when managing their personal health information, individuals face challenges in managing fragmented information and are heavily reliant on human memory. Several PHIM artifact design principles evolved from this participatory design session and process (Civan et al., 2006):

- Users want control over their information.
- Scattered information should be integrated.
- Personal health information must be secure.
- PHIM tools need flexibility.

In a study of the information recording, organizing, and access behaviors of users in everyday life, Hayes et al. (2003) collected data from 22 participants using questionnaires and interviews. Reiterating the importance of integrating paper and digital tools, they conclude that a next generation PIM tool or system should provide pen-and-paper input, flexibility, multimodality, and ubiquity. Hayes et al. (2003) also observe that a PIM tool should support a mixed initiative, where in some instances the user takes control in terms of guiding system actions; and in others the system initiates and controls activities. In an earlier field study undertaken to examine the relationship between tools and the information life-cycle, Gwizdka (2000) identified four types of information: prospective, ephemeral, working and retrospective. He found that different PIM

tools such as email, datebooks, loose notes, or file folders are used for different information types. The design principle that emerges from his findings is the following: PIM tools must be designed to incorporate an understanding of the different types of information in regard to their temporal attributes.

## 7.3 Design Considerations and Principles for Specific Personal Information Management and Personal Health Information Management Tools

In recent work Jimison et al. (2008) reviewed 54 studies that addressed usefulness and usability issues of interactive consumer health IT solutions. Most of the studies reviewed by them address usefulness and usability as a secondary component of the study, rather than as a core objective of the study. In their sample of studies, most researchers measured usefulness as part of their usability assessment and not as a separate area of outcome assessment. They found that the users' perceived usefulness was generally rated high, especially for self-management systems.

> "…with regard to the ease-of-use of systems, it is important to note that usability in these studies was always evaluated for a single type of system with a particular implementation, making it difficult to make general claims about usability findings. For each type of interactive consumer health information system there were examples of some that the users felt were easy to use and others with usability issues. There were a small number of studies that focused on usability testing early on in system design. In these cases, the goal was to discover and fix usability issues early on in the process. Most issues had to do with clarity and simplicity of graphics for older or impaired users." - Jimison et al. (2008)

In the consumer health informatics and PIM literatures a handful of specific design principles have been identified for specific classes of tools. These are summarized below.

### 7.3.1 Personal Health Records

Personal health records have recently emerged as a tool for providing users with access to their health information and a potential artifact for personal health information management. A number of usability studies have been conducted in the context of PHRs (Kim et al., 2005; Maisie et al., 2004; Marchionini et al., 2007; Terry, 2008). Echoing prior work on usability, this research suggests some general principles for the design of usable PHRs, such as the need to display health information in chart as opposed to table format to allow for more effective cognitive processing. Further, this stream of research also emphasizes the importance of usability factors such as complexity, interaction and control, accessibility, compatibility and flexibility in the design of the artifacts for the design of PHRs.

In one of the most detailed studies of usability in the context of PHRs, Marchionini et al. (2007) provide a comprehensive review of the literature on PHR usability. One broad conclusion they draw from prior work is the importance of user interface, the design of which has crucial implications for the PHR's ease of use. For example, they note that because the users of PHRs could likely be older adults, their unfamiliarity with navigation conventions such as scrolling and clicking, motor-related challenges in using a mouse, and a lack of understanding of technical jargon could also negatively compromise system usability. The design principle that emerges from this review is the need to construct interfaces that are tailored to the specific skills of the individual; or alternatively the need to develop interfaces that can be used by a broad range of users with varying physical and cognitive capabilities.

Based on their review of extant literature and their own primary research with PHR usage, Marchionini et al. (2007) present a "Usability Guidelines Framework" that can be used as the basis for developing usability guidelines. The framework uses three characteristics of PHRs to organize the guidelines:

1. PHRs are inherently complex in terms of actors involved, the types of information they contain, and the sensitivity of the information. Therefore, a "divide-and-conquer" layered strategy for usability is appropriate.

2. Personal health information is relevant for all people, regardless of their level of technology sophistication, socioeconomic status, or health condition. This suggests the need for customization in PHR designs.
3. Personal health information spans the entire life-span of an individual. The requirement for data persistence over time suggests that usefulness and usability issues must address the preservation and maintenance of digital archives.

Building on these characteristics of a PHR, the framework developed by Marchionini et al. proposes that guidelines for PHRs be developed along three dimensions or facets: (1) PHR Function Classes, that include actions such as find data, enter data, view data, analyze and make sense of data, (2) PHR Data Dimension, that includes various data types such as complaints, clinical encounters, allergies, medications, and financial data, and (3) PHR Usability Issues, covering issues related to complexity, interaction and control, and user characteristics. The extent to which these guidelines apply to the design of other consumer health IT tools such as health risk assessments, decision-support systems, or disease management applications is not immediately obvious and requires further research. Furthermore, PHRs are now increasingly being developed on web-based platforms (e.g., Microsoft® HealthVault (http://www.healthvault.com/) and Google's online PHR (http://www.google.com/health) and therefore, the usability considerations described in Section 7.3.4 are relevant for these tools.

### 7.3.2 Task List Manager

In their study of a task-list management system, Belloti et al. (2004) emphasize the importance of minimizing complexity in the design of artifacts and making them more interactive, thereby increasing ease of use. They recommend that the design of a task-list manager should incorporate features such as: (1) diverse ways to view and manipulate to-dos, (2) the "in-the-way" property, whereby the task list manager becomes the habitual place where users expect to encounter reminders, (3) an instant on feature, to support quick and easy input and clear visualization, and to avoid the slow, laborious input and attenuated output challenges, (4) not require a formal task description, categorization or decomposition from users, and support any level of abstraction for atomic task entries, and (5) a mechanism for handling stale to-dos of low

importance that are diminishingly likely to ever get done but have not been explicitly deleted (Bellotti et al., 2004).

### 7.3.3 Document Management Systems

Because of the need to manage "documents" of various types, automated personal health information management systems are likely to incorporate an underlying document management system. Hence, the design considerations for digital document management systems (DMS) are relevant for the design of consumer health IT. Building upon the notion that context is important, Bondarenko and Jansen (2005) recommend the following for designing a document management system: (1) place documents into their task-related context, (2) support combining documents from various sources, (3) provide an easy way of (re)grouping documents, (4) allow flexible ad-hoc restructuring within a group of documents, (5) base the tool on a system that is already in use, and (6) design the tool so that it requires as little cognitive effort as possible.

### 7.3.4 Internet-based Applications

Another emerging class of tools and artifacts used for personal information management are websites, which may be used for sourcing, managing, and retrieving health information. Clearly the usability of these systems is important in the context of the personal health information activities of individuals. While there are numerous studies focused on the usability factors associated with the internet or websites , few researchers have specifically evoked discussions around health information management using the internet or websites . In the handful of existing studies, specific design criteria for websites that provide health related information (Dutta-Bergman, 2004; Gummerus et al., 2004; Hong, 2006; Kinzie et al., 2002) include completeness of information, credibility of information, and the ability to visualize information. Outside of the health information domain, studies that have examined specific usability guidelines for web-based applications include the influential work of Nielsen (1993), and field work by Agarwal and Venkatesh (2002). Additionally, Venkatesh and Agarwal (2006) have developed a tool that measures website usability using Microsoft Usability Guidelines and, in the context of online purchasing by users, examines the effects of usability on purchase outcomes. The latter two studies found that usability assessments of different websites were strongly influenced by the nature of the product and the specific task that the user is engaged in. These studies also suggest

that different aspects of usability such as content and ease of use vary in importance for users based on the individual characteristics of gender, age, and income.

### 7.3.5 Mobile Artifacts

With their increasing adoption, handheld and mobile technologies are emerging as important personal health information management artifacts. Ham et al. (2006) describe several usability axioms in the context of mobile phones, and develop a hierarchical model of usability impact factors. They suggest that mobile device applications must satisfy the following objectives: an integrated interface that allows all pertinent items, regardless of type, to be viewed; creation of logical connections between related items; and, allowing users to clearly visualize these connections.

## 7.4 Discussion

Apart from the studies based on a specific artifact or specific health information management need, there is a lack of general usability and usefulness studies relevant to the personal health information management domain. As Jimison et al. (2008) point out, no study directly compares differences in usefulness or usability issues for general populations versus populations of interest (elderly, chronically ill, and underserved). This implies that the representative user studies should observe and characterize what the users do, where they succeed, where they have difficulties with the user interface, and what they find useful. These factors with respect to the representative users', their specific environment, characteristic and operational issues would provide the necessary inputs for the design process. At the same time, a comparison of the issues or design challenges of the representative specific users with that of general users would provide the inferences that need to be drawn to enable generic tools or artifacts.

Another emphasis evident in the literature is that of iterative input and feedback for artifact design, with user interaction and evaluation incorporated into the early stages of the design process (Bellotti & Smith, 2000; Kelley, 1984). This helps in progressively refining the design rather than refining it at the end of the design process. Indeed, many of the initial adoption issues related to personal health information tools and artifacts are likely to be structural, and

fixing them would require major architectural adjustments (Kelley, 1984). The only way to ensure a high-quality user experience is to start user testing early in the design process and to keep testing every step of the way.

## 7.5 Summary

Existing knowledge related to design principles and considerations for the design of consumer health IT tools for personal information management is limited. The concept and principles of "user-centered" design are highly relevant to consumer health IT and to identifying user requirements. General design considerations for PHIM and PIM tools include support for a range of use, support for variety in location and distribution, support for multiple media, support for context, and an incorporation of PIM activity level considerations. The literature also contains some normative prescriptions for the design of specific PIM and PHIM tools such as PHRs, task list managers, and mobile artifacts. Consistent with the concept of the "PIM system" described in Chapter 2, an overarching design consideration that emerges from prior work is that the design of consumer health IT must take into account the context, task, goals, and characteristics of the user.

# Chapter 8: Barriers to Effective Personal Health Information Management

As has been extensively discussed in the research summarized in earlier chapters of this report, PIM and PHIM are highly complex activities that pose considerable cognitive burden on users and therefore, understanding the barriers to effective PHIM is important. As shown in Figure 9, the literature identifies two major categories of barriers to effective PHIM. One category focuses on the management of personal information in general, and the types of challenges users encounter in executing PIM activities. The second category highlights specific challenges in using IT solutions for personal health information management. The latter category of barriers is largely attributable to the fact that the design of extant tools has not followed the prescriptions of sociotechnical systems design or macroergonomics (Hendrick & Kleiner, 2002), and accounted for the variety of individual, environmental, organization, and task-related considerations that affect individuals' information management activities.

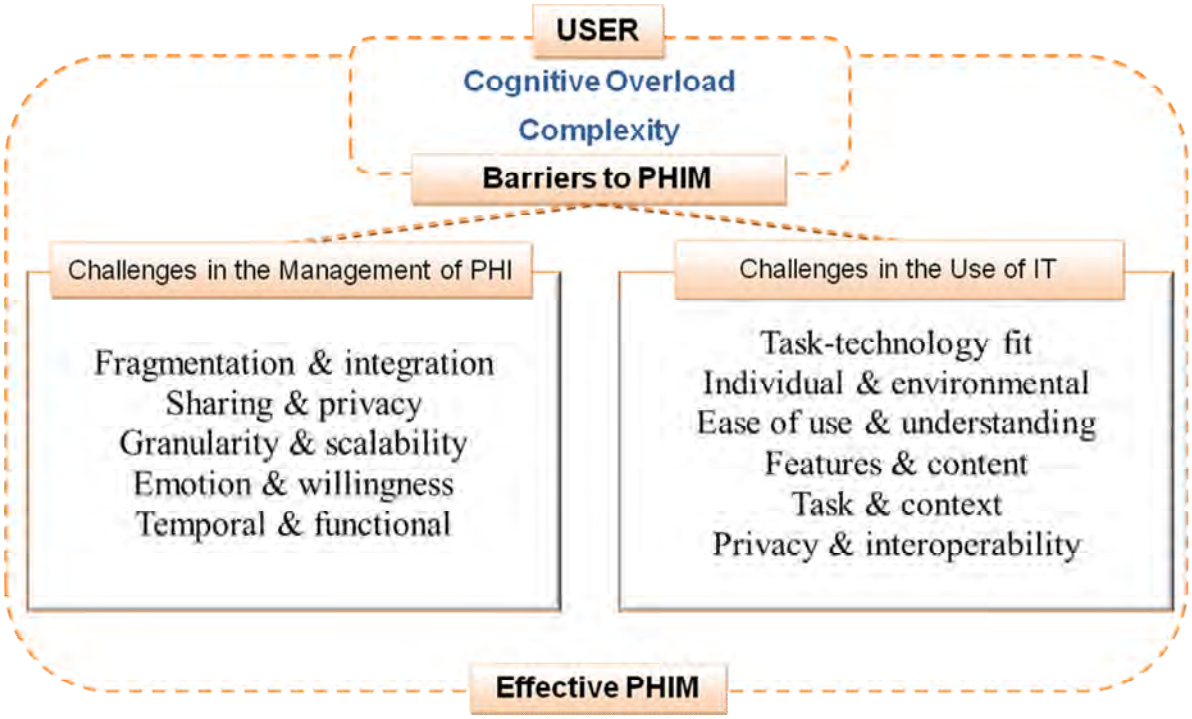


**Figure 9. Barriers to Effective Personal Health Information Management**

## 8.1 Barriers to Effective Personal Information Management and Personal Health Information Management

With respect to PIM and the more specialized case of personal health information management, a variety of barriers related to integration and fragmentation of information have been identified, including information sharing and privacy protection. Pratt et al., (2006) isolate three challenges inherent in PHIM. First, users need to integrate multiple types of information that may be located on multiple devices and exist in different formats. Synthesizing this information is critical in order for the user to obtain a holistic perspective on the information to satisfy the need at hand. Second, there is a problem of information overload and comprehension that poses a challenge to effective decision making. Often, the sheer volume of information and a lack of detailed knowledge about how to interpret it inhibit the user from utilizing the available information in the most effective manner possible. Third, information sharing poses a burden. The user must make decisions on how to share the information and with whom to share it, and simultaneously ensure that the desired level of privacy is maintained.

In addition to the aforementioned integration problem, Bergman et al. (2006) describe the project fragmentation problem in PIM, whereby an individual working on a single project is required to store and retrieve information items from multiple locations that may not be connected in any structural way. Although Bergman et al. address the problem in the context of information storage on personal computers, such fragmentation can also occur in non-electronic based settings such as when the needed information items are recorded on a notepad, filed in a paper folder, and maintained in a diary. Fragmentation is problematic for two related reasons; one, it makes finding the correct information items difficult, and two, it poses additional cognitive burden on the user who may forget where the information is stored. Jones (2007) observes that the PIM activity of “keeping” is significantly more difficult if the information is fragmented. Research on health information management at home by Moen and Brennan (2005) and Zayas-Caban (2005) reinforces the existence of the fragmentation problem in PHIM; both studies found strong evidence of health information being scattered across the home in multiple locations and captured in different artifacts. Finally, Teevan and Jones (2008) identified two additional barriers to PIM that are related to the integration problem described in Pratt et al. (2006). First,

they note that PIM cannot succeed if a person is considered in isolation from other individuals and groups he/she interacts with. Second, they allude to the importance of finding specific PIM approaches that are tailored to the domain of the information being managed, such as financial or health data.

At its core, personal information management involves the storage, organization, retrieval, and use of personal data for decision making. Because of its personal nature, frequently this information is sensitive. Therefore, it is not surprising that the privacy barrier to personal health information management recurs in discussions of challenges to PHIM and has recently been elevated to a matter of considerable national importance (Glaser et al., 2008). The fundamental concern here is that individuals desire to protect the privacy of their personal health information and therefore, privacy concerns circumscribe their information storage, retrieval, and sharing activities. Privacy concerns may inhibit users from maintaining structured repositories of health data because of fears that such organized collections are more easily compromised than information that is scattered all over. In a nationwide survey Agarwal and Anderson (2008) found that individuals' willingness to share identified health information was sharply distinct across different types of health information such as general health condition, mental health information, and genetic information, and also across different stakeholders such as the government, pharmaceutical companies, and physicians. Recent work by Marquard and Brennan (2009) challenged conventional wisdom about consumers' willingness to share medication information with doctors. They found that in anticipation of clinical benefits, consumers were willing to reveal medication information; however, they were unaware of the consequences of their disclosure, suggesting that consumer awareness of privacy implications may be limited.

In recent work, Unruh and Pratt (2008) conducted an extensive qualitative, longitudinal field study of cancer patients to understand the challenges they faced in organizing health information. They found four major classes of barriers: **emotional**, **scalable**, **temporal**, and **functional**. The **emotional** barrier exists because a user's emotional response to the information influences the degree to which they can interact with the information meaningfully. Emotional reactions of two types can occur: an emotional reaction to information that is increasingly accumulating and becoming even more overwhelming to organize, and an emotional response to the organizing

task, where a user may simply not wish to "deal with it" because the content of the information is disturbing for the user. For example, emotional responses to the organizing task can be triggered when bills for health care are mounting, or when diagnoses contain information that signals a worsening health status.

A second challenge is labeled as **scalable** barriers. When the volume of information is small, users find it relatively simple to store and organize it. As the volume begins to scale up, perhaps because the patient gets sicker and needs more interactions with care providers, the task of organizing the information becomes correspondingly more arduous. Yet, effective organization and storage is even more critical at such times in order to be able to find needed information. Unruh and Pratt observed that their respondents frequently allowed information to accumulate until such time when they experienced difficulty accessing and using it. The challenge for the patients was that the information was being generated and needed to be organized for effective access at the same time when the patient had to focus on clinical activities such as getting treated.

**Temporal** barriers were identified as the third category of PHIM challenges. To the degree that organizing information takes time away from other activities, temporal barriers are bound to exist. Unruh and Pratt (2008) found two types of temporal barriers: time compression, when patients do not have the time to effectively understand large quantities of information being generated, such as what may occur during the early stages of cancer treatment. Time compression limits the user's ability to engage with the information to understand its meaning and significance, and therefore, he/she is unable to develop a mental model for how it should be organized. A second temporal barrier is the fragmentation of tasks over time. Here although the user may have an effective organizing strategy at the beginning, over time the information organization starts to break down as he/she lacks time to keep the organization updated with new information that may be generated at a rapid pace.

A fourth and final class of barriers are **functional** barriers that arise simply because users lack an understanding of how to use the information they have collected in the future. In other words, users find it difficult to construct an organizing scheme for the information because dimensions

along which information may be related are not immediately evident. A patient's story narrated by Unruh and Pratt vividly illustrates this functional barrier. The patient indicated that she stored all her cancer-related paperwork in one folder because she did not fully understand the ramifications of insurance. Despite familiarity with the documents, the patient lacked the context to make sense of them and to anticipate how she might use them in the future. She was also unaware of the division of information management tasks between her and the insurance company.

## 8.2 Barriers to the Use of Electronic Tools for Personal Health Information Management

Perhaps the most significant barrier to the effective use of electronic tools for PHIM is that the design of these artifacts is not based on a robust and grounded understanding of users' information management strategies and workflows (Lober et al., 2006; Tang et al., 2006). As illustrated in earlier chapters of this report, there are only a handful of studies that provide a nuanced understanding of how users manage their personal health information (e.g., Pratt et al., 2006; Moen & Brennan, 2005, Zayas-Caban, 2005). Therefore, the functionality and design elements of existing PIM and PHIM tools may not "fit" with the way users actually accomplish their PIM tasks.

Several studies reinforce this lack of task-technology fit in the context of different types of tools. Lober et al. (2006) noted that very little work has been done on studying the usability of PHRs in regard to patient preferences for entering, maintaining, and disclosing portions of their record, and what assistance special populations such as the elderly, the disabled, and immigrants need in order to use PHRs effectively. They identified barriers related to access, i.e., the users were unable to obtain access to the PHR either because they did not own a computer or for other reasons such as the computer room being open only at limited times. They further identified a variety of barriers they labeled "patient-centered" barriers. These included computer literacy, computer anxiety, cognitive impairment, health literacy and physical impairment.

Tang et al. (2006) identified multiple barriers to PHR adoption. They classified these into two categories: environmental barriers, and individual barriers. Environmental barriers included the fact that PHRs must interface with data from EHRs in order to include a comprehensive set of an individual's health records but currently EHR use is not ubiquitous and, as a result, patient data is either scattered across multiple repositories or in some instances not digitized at all. As Tang et al. suggest, digital health information is a prerequisite for making the information available to the patient in electronic form. Other environmental barriers identified were economic and market forces where the financial viability of many EHR and PHR vendors was at risk, legal concerns on the part of providers, and patient privacy concerns. Echoing the barriers identified by Lober et al. (2006), individual-level barriers included a lack of task-technology fit because of poor understanding of the workflow and mental models of clinicians and patients in regard to how they manage and use health information. Additional barriers identified by Tang et al. (2006) include a perceived threat to the autonomy and control of clinicians, and change management issues spanning a range of stakeholders including providers, patients, and regulators.

In a study of two automated home-based patient management systems Farfanzar et al. (2004) reached similar conclusions that the adoption, uptake, and use of such systems must take into account how the systems fit into the everyday life of users and the extent to which they corresponded to users' personal preferences. They categorized the issues or barriers into two classes: medium specific issues that arose as a result of users' reactions to the tool interface including ease of use and ease of understanding, and content-specific issues, related to users' reactions to the messages delivered by the system. Medium-specific issues were an outcome of both the design of the system and of the user's cognitive capabilities. With respect to content, identified issues included inappropriate advice provided by the system (i.e., not tailored to the specific individual), and the presentation of information in non-lay terms that made it difficult to comprehend.

As discussed, several studies have underscored the barrier of privacy concerns in the context of tools for managing personal health information. The key issue here is that electronic capture of personal health information raises the specter of a potential compromise of individual privacy.

Angst and Agarwal (2009) found that individuals' willingness to opt-in to the use of personal health records was strongly and negatively influenced by their concerns for information privacy. Their findings suggest that users may experience such concerns even when they have control over the artifact in which the data are being captured, as is the case of PHIM tools. Agarwal and Anderson's (2008) study showed that the concept of health information privacy concerns is highly complex and varies with the context in which information is being captured. They also found that individuals' emotional state associated with their health status (e.g., sad, anxious) was a significant influence in the extent to which they were willing to allow their personal health information to be digitized. Citing data from a Markle Foundation study, Terry (2008) reported that the top reason for individuals not being interested in using a PHR was privacy. Tracy et al. (2004) explored the practical, legal, and ethical issues in personal health information exchange and found that privacy concerns varied across different stakeholders in the context of health information related to dementia. While professionals supported disclosure to colleagues and family caregivers, patients were more likely to resist information sharing with family members. In contrast, family caregivers valued having access to information about the patient's condition, even if the patient did not consent to providing such access.

Echoing the concern that current PIM tools are not designed on the basis of an adequate understanding of the user's task and context, research by Jones and Thomas (1999) emphasizes the importance of nationality, geography, and cultural background for the methods and tools by which individuals create, store, and utilize information. In a study of two diverse populations in the United Kingdom and the Czech Republic they found that although there was no significant difference in the usage of electronic items by the two groups of subjects, a "nationality" effect, reflecting cultural differences was present in the use of traditional, paper-based artifacts. Their study provides initial evidence of cultural differences in information management practices that, unless explicitly addressed in the design of tools for PIM, may pose a barrier to the use of these tools.

Finally, in a systematic review of the literature on interactive consumer health IT use by the elderly, chronically ill, and underserved populations, Jimison et al. (2008) identified 53 different studies that addressed the barriers. A lack of perceived benefit was the most frequently used

barrier suggesting again that the interactive health IT tools had not been designed with the user's needs in mind. Other barriers included a lack of convenience, where access to equipment and/or technology inhibited use, or the user was disinclined to use the system because it did not fit a routine or use was limited because of the difficulty of data entry. Their review of the literature also identified other barriers such as costs, access to technology, the fact that limited clinician involvement has a negative effect on system use, and technical issues with systems that tend to be found predominantly at a prototype stage.

## 8.3 Summary

A user attempting to manage his/her personal health information faces many barriers and must overcome multiple challenges in order to execute the PHIM activities successfully. General barriers related to the management of PHIM arise from the user's cognitive and behavioral limitations in understanding, structuring, and organizing the potentially extensive volume of health related personal information that must be managed, and from the diversity of forms in which it exists. Privacy issues also constrain the user's motivation to structure and organize PHIM. In the case of tools and technologies that are deployed to support PHIM, the research literature suggests that the design principles guiding the design of extant tools are not anchored in a deep understanding of the user's tasks, context, goals, and preferences. In other words, the tools do not fit into the "balance" model described in Chapter 2, nor do they satisfy the principles of sociotechnical systems design (Clegg, 2000) or macroergonomics (Hendrick & Kleiner, 2002). As with the PHIM activity, the use of tools to support PHIM faces a significant barrier in the form of privacy concerns.

# Chapter 9: Research Methods Used to Study Personal Information Management and Personal Health Information Management

The research summarized in this report employs a variety of research methods in its execution. Scholars have noted that the study of PIM and PHIM is complicated by numerous factors, including the uniqueness of each individual's PIM practices, the fact that PIM activities are distributed across multiple tools, applications, and exist in a variety of information collections, and the fundamentally temporal nature of PIM activities (Jones, 2007; Kelly, 2006). These characteristics suggest that no single methodological approach is likely to be sufficient to obtain a complete understanding of PHIM practices across multiple types of users operating in different contexts, and with different information needs. Broadly speaking, methodological approaches to the study of PIM in extant literature can be classified into two major categories: naturalistic approaches, that seek to study PIM practices and the use of tools *in situ*, and laboratory approaches that investigate PIM practices and tools in controlled environments (Figure 10).

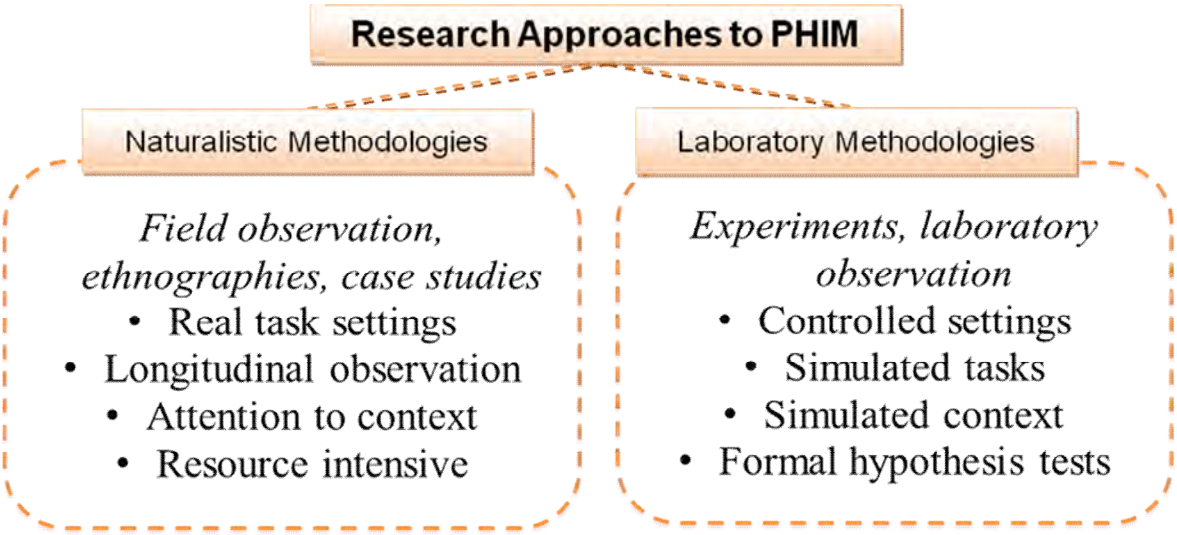


**Figure 10. Research Approaches Used in Personal Information Management and Personal Health Information Management Studies**

Each approach has its own strengths and weaknesses and researchers conclude that the study of PIM needs to utilize both in a complementary fashion (Jones, 2007). The advantages of naturalistic approaches include the use of "real" tasks in settings that are not simulated, and an ability to perform observations over extended periods of time (Elsweiler and Ruthven, 2007). Naturalistic approaches typically focus the researcher's attention to *context*, as exemplified in the research methodologies of situated activity (Suchman, 1983), contextual inquiry (Beyer & Holtzblatt, 1998), and situated design (Greenbaum & Kyng, 1991). However, they suffer from the disadvantages of resource intensiveness in terms of requiring large investments of researcher time that typically limit sample sizes and generalizability, the inability to perform formal hypothesis tests, and potential biases that may introduced based on the researcher's choice of when to conduct data collection.

Laboratory studies permit the design of controlled settings where extraneous sources of variance can be limited if not completely eliminated, and they are more likely than naturalistic settings to generate data that are amenable to hypothesis testing. On the other hand, by their very nature such methods are artificially constructed and may not provide deep insight into actual PIM behavior that would occur in the real world. Further, laboratory studies are more challenging to design as they require the careful construction of the experimental task (Elsweiler & Ruthven 2007; Jones, 2007).

It is important to note that the two categories described above are broad-based classifications and the methodological approaches to PIM can be characterized along other dimensions as well, such as a simple distinction between surveys and experiments. Further, naturalistic approaches do not always generate qualitative data and laboratory approaches do not necessarily yield quantitative data. For example, a study of PIM could entail a natural experiment conducted in a field setting, while a laboratory study of PIM might involve video-taping information finding behavior and performing a qualitative analysis of the data captured.

## 9.1 Naturalistic Approaches

Naturalistic approaches are predicated on the assumption that the study of PIM is most appropriately executed in the "natural" and familiar environment of the user where behavior with known tools and information items can be observed. They are often characterized as "descriptive" methods since their primary objective is to document the information management practices of users in a rich and grounded manner. They may be designed and executed in many different ways and can use different approaches for data collection, including (1) interviews, (2) the recording of diaries as information needs are identified and finding activities initiated, i.e., the mapping between information and need is established, (3) focus groups that bring together multiple users in a structured setting for discussions of PIM, and (4) observation, where the researcher "watches" the user in their natural environment, as PIM tasks are completed. In addition to the qualitative data that is generated by these methods, researchers may also deploy data collection methods in naturalistic studies that generate more quantitative data, such as surveys.

Further, naturalistic approaches can be designed to be cross-sectional, where the researcher studies a subject pool at a single point in time, or longitudinal, where data are collected temporally. The latter type of the study provides the researcher the ability to progressively and iteratively modify the data collection protocol as needed based on earlier findings, such as refining the questions being asked of respondents, including additional questions and observations about behaviors observed in an earlier phase. Naturalistic approaches also include ethnographic observation, where the researcher immerses him/herself in the user's context, and critical incident reviews, that are similar to a diary except that the researcher probes the user to elicit behaviors and attitudes following the critical incident. They can have distinct units of analysis; such as the individual information manager, or the household or family. Finally, researchers can understand and document personal information practices more vividly by supplementing traditional data gathering techniques with photographs illustrating physical locations of information or tools used for PIM.

Examples of studies using naturalistic approaches in the domain of PHIM include Moen and Brennan (2005), Zayas-Caban (2005), Lober et al. (2006), Farzanfar et al. (2004), Tracy et al. (2004), Civan et al. (2006), and Unruh and Pratt (2008). PIM researchers using naturalistic approaches include Jones et al. (2005), Elsweiler and Ruthven (2007), Bondraneko and Janssen (2005), Bellotti and Smith (2000), Jones (2008), Whittaker and Hirschberg (2001), and Church and Smyth (2008). Finally, Blanc-Brude and Scapin (2007) describe a study that uses experimental procedures in a naturalistic setting.

In their cross-sectional study of health information management practices in the home, Moen and Brennan (2005) collected data using semi-structured interviews with self-identified health information managers. They complemented these interviews with photographs of information management artifacts. Zayas-Caban (2005) used a multistage case study approach in her naturalistic study of the health information management practices of four families. The three stages were a structured interview with the primary health manager of the family, semi-structured family interviews, and direct observation of a subset of information management tasks identified in earlier stages. The multistage approach supported the iterative refinement of the data collection protocol.

Lober et al.'s (2006) descriptive study of the usability of a personal health information system by a low-income and elderly population involved providing the subjects with the tool, training them on its use, assisting with usage during the time period of the study, and collecting data on usability via observations and through electronic logs. This was followed by a survey of all subjects. In their usability study of two automated home-based patient management system, Farfanzar et al. (2004) used a similar cycle of system demonstration, followed by training, and finally interviews to elicit users' reactions to the systems. In their study of information exchange and sharing practices in community-based care around dementia, Tracy et al. (2004) conducted six focus groups of multiple professional stakeholders in care delivery such as community nurses, social workers, occupational therapists, and family physicians.

Civan et al. (2006) used group methodologies to study consumer perspectives on their health information needs and the design of technology that could be utilized to support these needs.

The techniques used by them included a nominal group technique to identify the major PHIM activities, and a participatory design session to engage consumers with researchers in the artifact design process. Other recent studies of PHIM using naturalistic approaches include that of Unruh and Pratt (2008). To investigate barriers to organizing information faced by cancer patients, they conducted a three stage field study with multiple data collection methods. These were in-depth interviews, surveys for demographic information, critical incident reviews, personal health information collection reviews, and a review of photographs from patient's diaries.

In the PIM research community, Church and Smyth (2008) report the use the "diary" technique for identifying mobile information needs. Arguing that information needs differ when individuals are "mobile", i.e., away from their familiar contexts, their information needs are likely to be different. In their study participants were asked to maintain a diary where they logged the date and time, their current location, and their information need. This technique is also used Elsweiler and Rutheven (2007) for a study of information refinding tasks related to the web and email. They collected data by asking 36 participants to digitally record all details of their information finding activities over a 3-week period.

Bondarenko and Janssen (2005) describe a 2-year ethnographic study of the personal document management practices of 28 information workers using a contextual inquiry method. Their data collection methods included interviews, artifact walkthroughs, and critical incident reviews. Data analysis was performed using the qualitative method of affinity diagrams. In their study of how individuals organize information in support of a specific project such as "teach a course" or "plan a wedding" Jones et al. (2005) used interviews of 14 participants complemented by photographs of various information collections that were used to support the project. Whittaker and Hirschberg (2001) report the use of multiple data collection methods in their investigation of office workers' paper-based information. The methods included an online survey, and semi-structured interviews with a subset of respondents.

Bellotti and Smith (2000) describe a design process for a PIM system that involved multiple interactions between fieldwork and design thinking. They interwove system conceptualization

and design with interviews that included four pilot in-house interviews where interviewees and interviewers demonstrated ideas and explanations with photographs and video to gain initial feedback on design ideas; 8 in-depth two-way show and tell interviews to obtain feedback on a subsequent version of the system, and 24 "in-breadth" interviews to verify specific observations. The multistage strategy enabled them to develop and refine a comprehensive set of questions and to develop hypotheses during the study that could be qualitatively verified in a subsequent phase of data collection.

Blanc-Brude and Scapin (2007) describe a field experiment conducted in the natural setting of the workplace of participants to determine which attributes individuals recall about their documents and what the characteristics of their recall are. Their research protocol included semi-structured interviews followed by an experiment. The goal of the interview was to identify documents that would be salient to the user. The experiment focused on one to three documents and was conducted in two phases: a "recall" phase followed by a retrieval phase. Data analysis included both qualitative and quantitative analyses of answers to the recall phase and the behaviors exhibited by participants during the retrieval phase.

As evident in the studies described above, naturalistic approaches provide rich, situated insights into individuals' personal information management practices and behaviors. They are generally resource intensive in terms of researcher time, and are potentially subject to observer bias.

## 9.2 Laboratory Approaches

In comparison to naturalistic approaches, the research literature contains relatively fewer studies that have examined PIM or PHIM practices and tools in laboratory settings. Elsweiler and Ruthven (2007) and Kelly (2006) note that laboratory-based studies require a rich set of reference tasks and an agreed upon task classification in order for researchers to build a cumulative body of knowledge. However, there is no widely accepted set of dimensions along which to characterize a set of information management tasks, and the fundamentally "personal" nature of PIM makes the construction of information collections for laboratory studies difficult. Using generic tasks and information collections renders the findings from the laboratory study

less useful. In addition to observing PIM behaviors, laboratory based research approaches described in existing literature on PIM typically address the evaluation of prototype systems developed for specific PIM activities.

Jones et al. (2008) developed a prototype PIM labeled the Personal Project Planner that provides individuals with rich-text overlays to their information. They report findings from an interim evaluation of this tool conducted in a quasi-field setting where participants were first asked to watch a brief video that described the tool. The tool was then installed on the participant's computer, and a 40-minute evaluation performed. The evaluation entailed the selection of a project, the creation of a rough outline of the project and a trial of the features of the tool, and a rating of each feature on its frequency of use and usefulness.

Karger and Quan (2004) performed user studies to investigate user preferences and performance with a PIM system based on two organizational schemes: multiple categorizations and a traditional hierarchical folder approach. In the first session of the study users were asked to organize a collection of articles in two phases, with each phase requiring them to use a different organizational scheme. In the second session of the study that was conducted a week after the first, users were asked to navigate the two collections and answer questions related to the information contained in them. The second session also involved two phases, one for each of the two organizational schemes.

As part a series of related studies conducted for the National Cancer Institute to evaluate a personal health record, Marchionini et al. (2007) describe three distinct studies conducted in a laboratory setting. In Study 1, the goal was to identify optimal ways to present medical test information to patients electronically. The researchers conducted two experiments using presentation format (bar charts versus tables) using a within subjects and a between subjects design. The objective of Study 2 was to understand how adults aged 55 and over managed information about their medications, who they shared this information with, what information was shared, and what display formats they preferred. After some initial data gathering related to current methods for managing medications, participants were asked to complete a series of tests to see how well they could recall their current or recent medication history. In a second session

participants viewed three different computer-based visualization tools for displaying medication history, received training on one tool and were asked to interact with it, and then they completed the same set of tests as in the first session. The third study used a 3x2 between subjects' factorial experimental design to investigate the interaction between interactivity and information complexity on outcomes such as task efficiency, effectiveness, and satisfaction. The tool examined in this experiment was a mock PHR interface. This is one of the few studies in the domain of consumer health IT that has performed a rigorous, experimental evaluation of the usability of a tool. However, it is important to note that the study did not explicitly examine PHIM activities and the extent to which the tool supported or optimized them in some way.

The studies reviewed above illustrate how laboratory approaches can be used to perform more formal and rigorous tests of the usability of different types of PIM and PHIM tool design elements. They also show the value of using the laboratory as a setting for exploring information management behaviors in simulated tasks. However, as noted earlier, laboratory approaches offer limited insight into understanding the core activities of PHIM.

## 9.3 Summary

Current methodological approaches to the study of PIM and PHIM practices and tools fall into the two broad categories of naturalistic and laboratory based inquiries. Each of these approaches has unique strengths and weaknesses and neither can be used to the exclusion of the other. Researchers have noted that understanding and knowledge development in this domain must necessarily follow an iterative cycle of using the field to gain initial insights into practices, incorporating this understanding into tools, learning about the efficacy of these tools in laboratory and field settings, and successively refining the tools based on users' experiences and responses. Given the relatively recent nascence of research on PHIM, it is not surprising that large scale experimental or field studies have yet to be conducted. Further, to the degree that PHIM is a somewhat idiosyncratic activity for users depending on their specific goals, the context, and their characteristics, situated inquiry is necessary to deeply understand PIM practices. Researchers have observed that the effectiveness of PIM research can be improved by

the development of reference tasks (Whittaker et al., 2000) and by isolating units of analysis at an appropriate level of granularity (e.g., a personal project (Jones et al., 2005)).

# Chapter 10: Critical Assessment of Gaps in Knowledge and Understanding

A few broad themes are evident in what is known today about PHIM. The existing body of research on PHIM suggests that this activity is one part of a complex sociotechnical system (Karsh & Holden, 2006; Mumford, 2000) that encompasses people, processes and workflow, technological artifacts, and the environment, including the home context and the larger community within which the individual is embedded. Individual PHIM behaviors exhibit heterogeneity with respect to the type of information being managed, as well as the specific use context of that information. The adoption of PHIM practices and technologies faces many obstacles, including concerns about data security and privacy (Angst & Agarwal, 2009), data quality and accuracy, ease of use and interface considerations, and individual self-efficacy with respect to technologies and information (Agarwal & Angst, 2006; Angst, Agarwal, & Downing, 2007).

## 10.1 Gaps in Knowledge and Understanding

The review of existing literature on PIM and PHIM practices and tools shows that although there is a fairly extensive and growing body of research in this domain, some critical gaps remain. The study of PHIM is complicated by many factors. One core challenge is the inherently multi-disciplinary nature of the domain that demands a synthesis of insights from work that originates in different research communities including health informatics, information retrieval and search, human factors, human-computer interaction, computer science, cognitive psychology, industrial engineering, and information systems in order to advance understanding. This implies that the traditional disciplinary boundaries need to be crossed in the study of PHIM to overcome the fragmentation that exists in the body of knowledge. At the current time, incentives in most academic disciplines do not necessarily align well with these types of research efforts. As a result, there is limited knowledge transfer across researchers working in the different disciplines.

A second core challenge emerges from the inherent nature of PHIM and the fact that it is an idiosyncratic, situated activity that is fundamentally “personal in nature.” The individual is

constrained by limited cognitive capacity to remember and manage each and every piece of information that is relevant and encountered in daily life. There is doubtless a mismatch between the complexity of individuals' lives and their cognitive abilities, resulting in information overload, and the need to learn and remember increasingly more information. In this regard, three major challenges emerge from the literature: (1) it is difficult to remember information (what is known), (2) it is difficult to find existing information (what is needed) and, (3) it is time consuming to manage every piece on information on the *personal self*, for the personal self, at the level of personal self, and by the personal self. Thus, developing generalizable theories about PHIM practices or even obtaining a detailed understanding of how individuals with diverse backgrounds, characteristics, and goals manage their personal health information is a daunting task.

A consequence of this challenge is that there is a dearth of studies that explore PHIM practices in different types of "use" contexts and, therefore, limited knowledge about how tasks and activities related to personal health information management are actually executed. As a corollary of limited understanding about users, the design of extant consumer facing technology for PHIM does not incorporate a sophisticated and comprehensive perspective on how consumers prefer to manage their personal health information, and the ways in which technology can be used to facilitate and support their preferences.

## 10.2 Recommendations for Future Work

There are six critical areas that demand continued research attention in order to advance the goal of consumer empowerment with respect to the management of personal health information.

### 10.2.1 Taxonomies and Classifications of Users, Use Activities, and Use Contexts

As noted, while acknowledging that PHIM is fundamentally personal, to advance knowledge it is important to evolve towards classification schemes that help manage the complexity associated with user goals, PHIM practices, and contexts. Such schemes would then reveal the common patterns and strategies across different types of contextual situations and inform the development

of tools and technologies. An example of a taxonomy of practices used to manage health information is available in Moen and Brennan (2005), but this is one of the few studies to formally classify how PHIM activities actually occur. At the present time there is no overarching classification of users in PHIM or of PHIM activities.

Additional work is needed in the following areas: (1) classifications of user goals with respect to PHIM, (2) classifications of user types in PHIM based on the urgency of the need for PHIM (e.g., the healthy individual, one with a chronic condition, or family health manager), (3) classifications of user efficacy with respect to the use of the tools (e.g., dimensions of technology competence that are relevant in how effectively users and able to leverage tools and technologies), (4) PHIM use contexts (e.g., at home, while interacting with a care provider or while traveling), and (5) PHIM practices in these use contexts.

### 10.2.2 PHIM Practices of Subpopulations

The paucity of studies of PHIM practices are particularly striking with respect to subpopulations such as, minorities, low income groups, and rural populations. The information sciences research community has explored PIM practices but the targets of study tend to be largely the subpopulations in urban areas, or in medium- to high-income groups than in low-income groups. To the extent that underserved populations may present some unique needs, future work in PHIM and the design of artifacts is needed to obtain a granular understanding of their needs, behaviors, and constraints.

### 10.2.3 Comparative Effectiveness of PHIM Practices

A promising area for future work is comparative assessments of different PHIM practices and their effects on health outcomes. Although the literature shows that PHIM practices and user and context sensitive, it is feasible that there is a set of “best practices” related to PHIM that have a demonstrable effect on improving health outcomes. Users incur “costs” in executing PHIM activities (including, but not limited to time spent, cognitive burden, and technology acquisition costs) that must be traded-off with the benefits accruing from the activities. Longitudinal studies of different sets of PHIM practices (e.g., supported solely by paper and supported by technology)

with populations that suffer from chronic conditions such as diabetes or hypertension can shed important light on the relationship between PHIM practice and health maintenance.

### 10.2.4 Articulation of Functional Requirements of Tools and Design Philosophies

The principles of user-centered design imply that design functionality for tools must be based on a deep and thorough understanding of the needs, goals, and values of the user. Addressing the first two gaps would help isolate some functional requirements for tools that support PHIM, i.e., "what the tool must do." The outcome from such an effort would be a comprehensive contingency mapping that relates users, contexts, PHIM activities, and functional requirements. This mapping can then be used to drive the detailed design elements

Research and discourse is also necessary to answer some important questions related to the overarching design philosophies that should be followed for PHIM tools. One unanswered question about design philosophy is the level of customization and flexibility that a PHIM tool must support. Although flexibility and the ability to personalize the tool to individual preferences is a desirable goal, it comes at a cost. The costs of customization are not simply the cognitive burden placed on the user because he/she has to tailor the system to specific preferences, but also the costs of integration, from a systemic level. For example, looking ten years into the future one plausible scenario is the need to link individuals' PHIM devices to repositories maintained by providers, researchers, health information exchanges, and the myriad other stakeholders in the health care value chain. Early consideration of possible interoperability needs would help alleviate future challenges of integration.

A second important question for the design community is to address the inherent tension between single versus multiple artifacts. As the need for functionality increases and the complexity and range of tasks involved in PHIM grows, one potential pitfall is the proliferation of devices that can result in the same type of fragmentation that challenge the practice of personal health information management today.

### 10.2.5 Details of Design Elements

It is not surprising that given the limited knowledge about PHIM practices, to date, the design elements for tools have not been adequately described. For example, it has been shown that presenting partial context information about an event helps people remember more about it, i.e., the reconstruction of context improves efficiency in recalling details. It is also possible to match the current context of users with predefined information, and automatically suggest relevant information without the user having to explicitly ask for it and remember details – an emerging approach in digital environments such as pointers to products depending on search or automatic address search based on the calendar entries for activities. The related literature points to the importance of "cues" in aiding human memory with recall and recognition. But what are the best cues? What is the way to integrate them? For instance, some of these might be the physical location of an event, who was there, what was happening at the same time and what happened immediately before and after. Such event-based or other type of classifications of context is missing.

A second example of limited understanding of design elements is the extent to which PHIM devices need to be imbued with "intelligence." Should PHIM tools be unobtrusive or actively intervene and guide the user through HIM management tasks? What user representations should be incorporated? How much judgment should be relegated to the tool versus the user?

A final illustration of what is not known about design elements relates to the temporal nature of PHIM. At the present time most existing tools do not have explicit incorporation of "time" in their design aspects. However, PHIM is an activity that spans the entire life of individuals, and the storage and management of data must explicitly model temporality in relationships. Gaps remain in regard to the most effective form of such modeling and need to be addressed in future research.

### 10.2.6 Rigorous Evaluation of Tools and Technologies

A final and significant area for future research is studies that perform rigorous evaluations of PHIM tools and technologies in field and laboratory settings. An idealized design process is iterative, where rich field observation precedes prototyping, and prototypes are progressively

refined through cycles of testing and feedback. When the prototype has demonstrated adequate and acceptable performance, rigorous tests of its efficacy are necessary to provide evidence that it addresses the high-level goal of enabling consumers to have greater control over their health information and to be supported in their PHIM activities.

Although the gold standard for evaluation processes, randomized, double-blind controlled trials are probably infeasible and cost-prohibitive in the context of PHIM, it is possible to design quasi experiments and other innovative research approaches to evaluate PHIM tools. A variety of outcomes need to be considered in such studies, including actual behavior (levels of use, types of use), perceptions (usefulness, ease of use, compatibility, etc), attitudes towards the tool, and effects on efficiency and performance.

## 10.3 Summary

PHIM is a relatively new and emerging area of research. Although progress has been made, significant gaps exist in current knowledge and understanding about PHIM practices and the design requirements of tools that support PHIM. The key gap that needs to be addressed is comprehensive and situated understandings of what individuals actually do when they manage their personal health information, and what challenges they face in doing so effectively. Filling this knowledge gap is a crucial precondition to determining what is needed from PHIM tools. Finally, competing tools need to be subject to rigorous evaluations to determine the extent to which they are able to fulfill the desired requirements.

# Chapter 11: Conclusion

This report was motivated by the fact that a consumer-centric health care system can potentially address many limitations evident in current health care delivery and practice related to quality and cost outcomes. A consumer-centric health care system is one where consumers are empowered to take control of their own health and well being, and is fundamentally predicated on the capture, access, and management of large volumes of personal health information. Consumer health IT has the potential to play a crucial role in creating empowered consumers. However, despite the increasing importance of the consumer in the health care value chain, little is known about the processes and tasks underlying consumers' personal health information management activities. A detailed understanding of PHIM practices and use contexts is a critical precondition for the design of consumer health IT tools that can support and enable PHIM.

The extensive review and synthesis of the literature conducted for this report reveals that PHIM is a highly complex activity that unfolds in diverse social and technical contexts. Users accumulate, store, and retrieve many types of health information that arise from different sources and exist in varied formats. Effectively structuring and organizing this information so as to facilitate retrieval is challenging. The development of useful tools and technologies for PHIM, and further, the willingness of the consumers to use such tools and technologies faces many obstacles. These obstacles include concerns about data security and privacy, data quality and accuracy, ease of use and interface considerations, and individual self-efficacy with respect to technologies and information. Although paper continues to dominate as the preferred medium for PHIM activities, a range of electronic artifacts are being developed. Much of the existing literature has focused on the management of personal information in general, and not specifically health related information. The few studies that focused specifically on the management of health information consistently find that PHIM is a highly situated, personal endeavor and is deeply influenced by the context in which it occurs, the type of user that is engaging in PHIM, and the specific constraints that the user faces. Studies of PHIM have used a variety of methodological approaches ranging from naturalistic research to laboratory studies.

Although evidence related to PHIM practices and design considerations for tools is slowly accumulating, much work remains to be done. Gaps in current understanding range from incomplete knowledge about the different goals and motivations for consumers to engage in PHIM, to the health information management needs of special populations, to detailed descriptions of the functional requirements and design elements for consumer health IT tools. However, in much the same way as discretionary software applications have changed individual behaviors with respect to managing personal, financial information, tools and technologies that can help individuals become more effective, efficient, and empowered users of their personal health information have the potential to more fully address key needs in health care management.

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# Appendix: Literature Review Methodology

The purpose of this report was to: (i) summarize and critically appraise studies in the personal information management and personal health information management domain of research, and (ii) identify gaps in the literature to guide the next generation design process of PIM and PHIM artifacts and devices. This appendix details the search methodology undertaken to identify relevant literature and the methodology used to review the literature collected.

## Search and Review Process

### Initial Conceptualization and Consultation with Experts

The initial part of the search strategy involved consulting several key people. Initial inputs were taken from a multistakeholder faculty and expert group convened by CHIDS in June 2008 at the University of Maryland for a workshop "Health Information Management: The Next Wave." The discussions of the expert group, initial input from AHRQ, and preliminary ideas from the project team provided guidance towards the domains of research related to PIM and PHIM. The search process began in August 2008 and continued until January 2009 in the following phases.

### Phase-I: Initial Key Word Collection and Preliminary Search

Based on the input received from experts and other sources, a review of literature search terms was compiled (Table 1) by the researchers. Several key words were used for a preliminary search in order to identify the major databases and areas of search. In the first step of the literature search strategy, approximately 400-500 references from different databases were identified as potentially relevant. The University of Maryland Library was utilized to gain access to all necessary databases. Upon completion of this step, several major topic areas and publications were identified for collection to guide the outline of the initial background report.

**Table 1: Search themes, key words, phrases, and concepts**

| | |
|---|---|
| 1. | Personalized health information systems/management/technology |
| 2. | Health information search, acquisition, and use behaviors |
| 3. | Store and receive health information |
| 4. | Monitoring systems for general health parameters such as heart rate, breathing rate, and activities for daily living |
| 5. | Health IT systems that automatically capture and transmit relevant health data for various disease specific conditions |
| 6. | E-health activities, online health access activities |
| 7. | Accessing information, participating in health-related online communities |
| 8. | Online health information for individuals suffering from a disability or chronic condition |
| 9. | Capture, access, and management of large volumes of health-related data |
| 10. | Importance of the consumer in the health care value chain |
| 11. | Process and activities underlying individuals' personal health information management activities |
| 12. | How patients manage their health information |
| 13. | Patient's environment, support system for information management goals and tasks |
| 14. | Goals and motivations for engaging in health information management |
| 15. | Strategies currently in use to store, manage, and access health information |
| 16. | Integrating personal, professional, and health-related information |
| 17. | Using integrated information to make health-related decisions |
| 18. | Sharing information with individuals from social, professional, and health-care networks |
| 19. | Usability of health IT |
| 20. | Human computer interaction in health IT |
| 21. | Personal information management |

## Phase-II: Detailed Search and Review

The search matrix of key words was applied to different databases for an initial search to retrieve abstracts and papers. The relevant abstracts were reviewed and coded for priority retrieval. Several major electronic bibliographic databases were used in the search process, which are listed in Table 2. At this stage, some of the initial keywords needed modification, and more keywords were added to identify additional papers. Further, the search yielded limited numbers of published papers in the PHIM area, and so more emphasis was given to the relevant PIM literature. A focused research revealed that several *ACM Special Interest Group* conference

proceedings had a number of articles relevant to PIM; subsequently, the search strategy concentrated more on these proceedings. Simultaneously, the background report outline was prepared from the literature collected to-date, and feedback solicited from AHRQ and the research team to refine and focus the search and review process.

**Table 2: Databases used for search process**

| |
|---|
| ➢ ABI/Inform |
| ➢ Academic Search Premier |
| ➢ ACM Digital Library |
| ➢ Business Source Complete (EBSCO) |
| ➢ Computers and Applied Sciences Complete (EBSCO) |
| ➢ Education Research Complete (EBSCO) |
| ➢ IEEE Xplore |
| ➢ Ingenta Connect Complete |
| ➢ JSTOR |
| ➢ LexisNexis Academic |
| ➢ Medline |
| ➢ PsycInfo |
| ➢ PubMed |
| ➢ ScienceDirect |
| ➢ Social Sciences Citation Index |
| ➢ Web of Science |
| ➢ WorldCat |

The full paper retrieval, review, and data compilation phases continued along with the review of the background report outline. Simultaneously, evaluation criteria were developed to guide the selection of studies for detailed review. In the subsequent steps, literature which did not meet the inclusion criteria as given in Table 3 was excluded. The major inclusion criterion was that the article should be relevant to one of the topic areas described in report outline. Further, the article had to address one of the variables relevant to PIM or PHIM and its level of analysis should be that of the individual. The focus of the review was on articles that provided definitive primary data from empirical studies, but also included systematic reviews of all other collected literature to determine whether these contained any additional information not covered by the studies dealing with primary data.

At least two researchers reviewed each article according to the inclusion and exclusion criteria to ensure consistent application of the criteria. Discrepancies in inclusion were resolved by discussion and a re-review process.

**Table 3: Inclusion and exclusion criteria during the review process**

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| ➢ Relevance to the conceptual map of PIM and PHIM studies<br>➢ Systematic reviews<br>➢ Meta-analyses<br>➢ Prospective/retrospective observational studies<br>➢ Practice guidelines<br>➢ Narrative (non-systematic) reviews<br>➢ Grey literature, recent news reports<br>➢ Evidence studies<br>➢ Empirical studies | ➢ Related to topic but does not meet inclusion criteria, unspecified<br>➢ Wrong level, not “individual’ level of analysis<br>➢ Wrong technology or artifact<br>➢ Lack of supportive data<br>➢ No relevance to background report goals |

## Phase-III: Specific Search and Secondary Literature Search

The third phase focused more on specific areas of the PIM literature such as finding, or specific artifacts and processes. As report writing commenced and proceeded, additional articles were located for inclusion based on citations in previously reviewed articles. Further, during the writing and summarization process, conceptual classifications for several components of the domain of PHIM to provide readers with a broader synthesis were developed. These included classification of the literature by source and type of personal health information, and by artifacts used for PHIM and PIM activities.