

Personal Health Information Management: Consumers' Perspectives

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Abstract

Personal health information management (PHIM) refers to activities that support consumers' access, integration, organization, and use of their personal health information. We investigated PHIM in the health consumer population using a focus group and participatory design. In collaboration with health consumers, we identified PHIM activities and explored the design of new supportive technology. Our findings describe prominent PHIM activities such as monitoring and assessing health, as well as health-related decision making, planning, and action. We describe design principles our participants used during the participatory design of a PHIM tool. These include individual control, sharing, integration, security and flexibility. These findings provide new insights into emerging ideas in consumer health informatics research and technology design. Understanding health consumers' PHIM needs is an important step in creating technology to support these needs.

Keywords: Consumer health informatics, personal health information management, participatory design, focus groups

Information Management Problem

Emerging findings demonstrate that PHIM is an important issue in consumer health informatics. Personal Health Information Management (PHIM) involves integrating and managing personal and health information to stay healthy and combat illness.¹ We are just beginning to build a foundation of knowledge about consumers' PHIM needs, and few existing technological solutions support this activity well. PHIM research is in its infancy. Lack of a strong body of research and an accepted model of PHIM provide little guidance for tool design. Some existing technologies could support aspects of PHIM, particularly for specific populations of consumers, but we do not fully understand what PHIM support people need, regardless of their health status.

People find, keep, organize, and share a broad range of personal and health information to manage a variety of tasks (e.g., scheduling, planning, coordination, decision making, tracking, and communicating with others).^{1,2} They show wide variation in the strategies they use to store personal health information in their homes² and have specific needs for managing the communication of their personal health information with others in their social and clinical networks.³ Fur-

thermore, good management of one's own personal health information can directly influence the quality of one's own care.⁴

Several existing patient tools, such as personal health records (PHR) and condition-specific health management systems, could support aspects of PHIM. Although these tools have improved patient and provider communication, as well as patient adherence, satisfaction, and empowerment,^{5,6} our study indicates that these isolated systems could be useful, yet insufficient. Development of new supportive tools needs to evolve from additional exploratory research that complements and expands emerging findings in PHIM. In our research, we chose group methodologies⁷ to explore PHIM needs and preferences for technological support from consumers' perspectives.

Methods

We used two variations of group methodologies to explore consumers' perspectives about their PHIM needs and their design ideas for supporting these needs. We used these variations to answer our main research questions:

1. What are prominent PHIM activities?
2. What types of technology and design do consumers suggest to support these PHIM activities?

We recruited adult, health consumers from the University of Washington campus to take part in one of two 90-minute group sessions. We recruited people with an interest in PHIM using flyers. For each group, we selected a group methodology to answer one research question. During the sessions, one member of the research team moderated the discussion while two other members took notes. We analyzed notes and artifacts gathered from both groups using affinity diagramming⁸ to identify emergent themes.

Group 1: Nominal Group Technique

The Nominal group technique⁹ is a structured discussion for collaborative decision making that fosters a balance of participation among group members. We used this technique to identify prominent PHIM activities (research question 1). First, the moderator led a discussion to explore types and forms of personal health information with the group. Next, each participant independently wrote down examples of PHIM activities (i.e. the kinds of things managing your per-

sonal health information allows you to do). Afterwards, participants shared their examples with the group and discussed the details to clarify and contrast them. Through discussion, participants identified a list of prominent PHIM activities and prioritized them according to their preferences for support.

Group 2: Participatory Design

Participatory design¹⁰ is a methodology that makes participants active members of the design process. Participants do design tasks and discuss design decisions in a collaborative atmosphere with researchers. The moderator poses questions during the design process to identify tradeoffs and the rationale behind the group’s design decisions. We used participatory design¹⁰ to explore PHIM tool design (research question 2). The group discussed and expanded upon the list of the types and forms of personal health information. Next, the group talked through a prominent PHIM activity posed by the moderator and generated examples both of this activity and of the difficulties they experience trying to accomplish this activity. Next, participants each created a paper mock-up or list of initial design ideas for a technology to help people with this activity.¹¹ Participants shared their ideas with the group and talked through their solutions. The group then transitioned to design one system by bringing their ideas together through discussion and negotiation. The moderator used a whiteboard to record the group’s ideas.

Results

Seven health consumers participated in these group sessions, three in the first group and four in the second group. Three of the participants were men and four were women. All participants were students at the University of Washington and ranged in age from 18 to 50. The median age range was 25-30 years. Participants described their level of computer experience as average (2 participants), above average (1 participant), and expert (4 participants).

Between groups, participants discussed a wide range of types and forms of personal health information (see Table 1). Of particular importance was participants’ heavy reliance on memory and sensory-observation (i.e. attention). One participant describes sensory-observation this way: *“getting on the scale in the morning –that’s information up here [points to head], there’s some information that is personal health information, but it’s in the moment, not written down...it’s more of an awareness type thing...it’s real time instantaneous feedback... it’s sensory or observational.”* Although used frequently, participants referred negatively to memory as a form of personal health information. One participant remarked: *“there are things that are just in memory,*

Types	
Contacts	Medical bills & receipts
Calendar	Explanation of benefits
Online chat logs	Medication & self care logs
First aid	Health-related articles & web pages
Immunizations	Medication & appointment schedules
Diaries	Medical records (x-rays, labs, etc)
Referrals	Educational materials
Prescriptions	Family history & genealogy
Cancer surveys	Insurance cards
Forms	
Electronic (spreadsheets, lists, contacts, email, calendar)	
Paper (business cards, to do lists, printouts, file folders)	
Images (paper and electronic)	
Devices (computer, cell phone, PDA, glucose monitor, pill box)	
Memory (remembering when you had your last physical)	
Sensory-observation (attention to weight scale readings)	

Table 1. Types and forms of personal health information *kind of a faulty form.”*

Participants in both groups also shared conceptualizations about PHIM. They made two important differentiations surrounding their PHIM activity. First, they differentiated between PHIM activities that support their own needs and those activities that support the needs of others, such as their doctor. They also differentiated between routine PHIM, which several described as preventive in focus, and PHIM in response to emergent health events.

Group 1: Prominent PHIM Activities

Participants identified major PHIM activities that underlie three important goals: monitoring and assessing health, making health-related decisions and planning preventive or treatment actions, and performing these health-related actions. These goals give rise to prominent, yet highly interrelated, PHIM activities that rely on the same core types of personal health information. These activities included such things as creating history, making lists, bundling together related information, and setting reminders.

Monitoring and Assessing Health

Participants characterized the creation of personal health history as a PHIM activity that helps them to monitor and assess their health. They place value in their personal health history as an information resource and differentiated between two strategies for creating this history.

The first strategy involves constructing health history prospectively. Participants described actively and routinely logging or tracking health-related symptoms, events, and behaviors as they occur. Participants record history in memory (e.g., *“logging in your head”*), on paper, or in electronic logs and calendars (e.g., *“I’m at an extreme, I write everything down –I write it on a calendar or I make a spread-*

sheet or a chart”). Participants described accessing this history later for health-related decision making and planning. For example, one participant described the process this way: “*tracking a condition, like a side-ache, remembering how long you’ve had it and deciding if it’s ok or if you need to go to a doctor.*”

The second strategy involves retrospective reconstruction of personal health history. Participants described their need to reconstruct their health history following emergent health events. They reconstruct health history by recalling health symptoms, events, or behaviors from memory or from artifacts (e.g., prescription dates on medication bottles, events they recorded on calendars) well after these events have occurred. One participant describes the retrospective strategy this way: “*If I have a problem and am trying to explain it to the doctor or nurse, I need to remember what happened, when, and for how long.*”

The prospective strategy for creating personal health history involves recording personal health information as events occur, whereas the retrospective strategy involves going back through recorded information to reconstruct these events. Two of the three participants stated they use the prospective strategy for some aspects of their health-related monitoring and assessment, while the third wished they did. Although the prospective strategy requires a great deal of up front and routine effort, participants described it as less error prone than the retrospective strategy. One possible explanation is the memory dependency participants associated with the retrospective strategy. Thus, participants agreed on the benefit of using paper and electronic forms over memory for history creation. One participant stated: “*You would put it on a calendar so that you don’t have to recall it [later], calendaring is so much more accurate*”. Another stated, “*Calendaring is so much more accurate, it’s different than recall...memory is faulty.*”

Independent of the strategy taken, participants’ descriptions indicate they differentiate between creating history to support their own needs and the needs of others, such as their health-care provider: “*There is a difference between keeping a calendar for yourself and recalling history for others.*”

Health-related Decision Making and Planning

Participants indicated that keeping personal health history was a vital precursor for subsequent PHIM activities that support their health-related decisions and planning. Participants described PHIM activities such as making lists and bundling together related information to support these goals. Personal health history provided a valuable information source for these information management activities: “*If you get a gash in the leg, you want to look at health informa-*

tion like tetanus shots, these [pre-existing health care events] influence your plan.” Participants described information management activities that support both routine and emergent decision-making and planning: “*[PHIM] involves decisions. I use it [personal health information] to create an action plan for treatment.*” Another participant added “*not necessarily treatment though, also preventative and what [my clinician and I] should track.*” Another participant described their planning activity related to health care visits: “*I make a plan of what to talk to the doctor about, my last labs, notes from other specialists.*”

Performing Health-related Actions

Although participants stated that performing prevention- or treatment-related action was an important goal of their PHIM activity, they described far fewer of these PHIM activities than those that support health-related monitoring, assessment, decision making, or planning. Creating reminders is one PHIM activity that emerged. For example, one participant described several preventive actions: “*[PHIM involves] things that happen on a routine basis like breast exam, vitamins, another thing was what happens on a daily basis: sometimes nothing, taking birth control pills.*” This participant goes on to describe a treatment action: “*treating a condition, remembering if I’m on antibiotics [and] to take it twice a day.*”

Group 2: Participatory Design Ideas

The participatory design group yielded multiple types of results. The group provided additional insight into PHIM activities through their discussion of the problem introduced by the moderator and design of a PHIM tool. The group offered insight into the underlying assumptions, explicit trade-offs, and values they considered during the design of the tool.

The participatory design group focused on designing a system to support reconstructing a history, an activity prioritized highly for needing support by the focus group. During the initial discussion about this activity, participants provided additional examples of reconstructing a history, and it became evident that they identified with this activity. One participant explained that the purpose of reconstructing history is “*to get a comprehensive perspective of the situation.*” They also affirmed that this could be difficult because it often relies on memory, which they recognized to be problematic. The group explained that health information exists before you are sick, but that when you are sick is when you need it. Participants thought that if there was a way to track “*current status*”, it could be used to look back on later to reconstruct a history surrounding some health event. They discussed needing to reconstruct a history for

themselves to determine if an anomaly had occurred that required some kind of action well before they would need to convey this history to someone else, such as a doctor.

The tool participants designed was a centralized collection of a wide variety of types of personal health information, ranging from diary entries to logs of symptoms to pedometer data. They described a multitude of ways to enter health information and envisioned allowing select individuals to view parts of their personal health information collection. As the design progressed, it became clear that participants viewed themselves as the main users of the PHIM tool they were creating.

Extracted Principles

The assumptions, trade-offs, and values that emerged from the participatory design session are of particular interest because they can be used to identify the underlying design principles, described in this section, that guided the participants' design process.

Individuals Want Control over their Information

One principle that permeated the participatory design group was individual control over personal health information. Participants designed their system so the individual has full control over what information is in the collection and who can access that information. They envisioned a way for other people, particularly clinicians, to enter information, but that when a submission occurs they want to be notified. They envisioned being able to append notes to the submission and then integrate it into their collection. The principle of individual control is visible in the ways participants set up inputting information, sharing information, and managing the collection. Participants situated the motivation for the PHIM tool squarely on activities performed by the individual. Although it facilitates conveying information to other people, participants envisioned the PHIM tool as encompassing information that is always under the control of the individual.

Sharing Information Is Useful

Although participants envisioned full individual control over the personal health information collection, they also wanted to share their information. They wanted their clinicians to have all the information necessary for quality care, but at the same time they said things like, "*You have some information that the doctor doesn't need to see*" and "*Just because you're my doctor doesn't mean you can look at everything.*" Participants wanted to be able to share their information with select people, and they designed ways to give people access to subsets of their collection. One participant said she would use tailored permissions to give her doctor access to part of her collection. How-

ever, she said she would be willing to give her doctor access to more information if he asked for it.

Scattered Information Should be Integrated

Participants thought that there was health information interspersed in many aspects of their lives. One participant explained that "*Life is full of drops of information*" and another described how she considered the "*squishy*" information that she keeps in her diary a source of health information. Another participant mentioned that her calendar has appointments on it that she has used to determine when health-related events took place in the past. The PHIM tool would need to be able to integrate these diverse types of information. Another source of health information identified by participants was copies of their medical records kept by their clinicians. More than one participant voiced frustration at the difficulty they face obtaining copies of their records. They thought that this record could be important because it includes information that would be useful for both them and for their clinicians to see in the future.

Personal Health Information Must Be Secure

Participants identified a trade-off between security and ease of access. Participants wanted to be able to access and add to their personal health information collections easily, and they wanted to be able to give access to other people. At the same time, they were concerned about the ability to secure such a system. They discussed how a trusted third party could house the tool they designed so that the information would be secure. Besides protecting information from other people, participants also discussed the need for backups to ensure that they would not lose this valuable information.

PHIM Tools Need Flexibility

Flexibility arose in several contexts. Participants recognized that individuals would be motivated to use the PHIM tool for diverse reasons. Healthy people who are not actively managing health information might frequently be inclined to "*do the bare minimum,*" while people with health concerns might be more active in logging and tracking health information. Participants wanted the PHIM tool to support both approaches and decided flexibility in the types of information entered, the input method, and the available system functions would be important. For input methods, they suggested open standards to allow individuals to choose how their information is collected and entered into the system. They envisioned entering information via a PDA, cell phone, voice prompts over the phone, from email, through a journal or diary, from a calendar, or through some method of ambient capture (e.g., sensors) or text-mining. Participants wanted to capture health infor-

mation that reflects their “*current status*”, and discussed using ambient capture or other quick and convenient input methods. Participants also envisioned that clinicians could provide tailored guides for the PHIM tool based on age and condition. These would suggest the kinds of things that would be most relevant to track. Participants also felt there would be additional information they would want to track, but that the clinician might not identify in a guide. They wanted to be able to make their own guides to help them remember to record health information that they themselves identify as important, too.

Discussion

Our findings indicate that PHIM is a rich area that is ripe for further research. When managing their personal health information, our participants identified clear challenges they face, such as fragmentation of personal health information and reliance on human memory, as they engage in PHIM activities. These challenges confirm findings in previous PHIM research² and indicate the promising potential for new PHIM tools.

Our participants identified a breadth of personal health information they manage and use. Our focus on PHIM activities allowed us to both support and extend existing research. This focus brings new insights and clarity to the informatics needs of health consumers, such as the need to support prospective strategies for creating health history. We identified several principles that participants used while designing a new PHIM tool. These principles arose through participants’ discussion and debate about how to create technology to support PHIM activities. These principles provide insight into the necessary attributes of a PHIM tool that meets consumers’ needs in ways they find useful.

The diversity of personal health information that participants considered relevant to PHIM has direct implications for the design of new PHIM tools. The scope of this information extends far beyond the content common to many existing patient tools, such as condition-specific health management systems. High-level recommendations for consumer tools, such as PHRs, propose functionality consistent with our findings. However, those high-level recommendations lack the specifics about consumers’ PHIM activities, needs, and values necessary for implementation. Although many existing tools could facilitate health benefits to health consumers and support aspects of PHIM, they do not provide sufficient breadth of information or functionality to support PHIM in the ways our findings suggest is essential.

Studying the activities through which consumers manage personal health information and their per-

spective about these activities and their technological support provides unique insight into the kinds of content and functionality new tools could incorporate to support the needs of health consumers. Findings from this study provide valuable empirical insights into the design of these new tools. In future work, we plan to explore consumers’ perspectives on PHIM with a more diverse range of people, over a larger number of group iterations, and through observation of actual PHIM work consumers currently do.

Conclusion

Our investigation of PHIM from the perspectives of consumers reveals a promising area for future study. We identified prominent PHIM activities and principles for the design of new tools to support needs surrounding these activities. Our findings support and extend an emerging foundation of PHIM research and provide empirically based insights that can facilitate development of new tools to support consumers’ PHIM activities.

Acknowledgement

This work was supported by the National Library of Medicine Training Grant #LM007442.

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