

Checklists, checklists, every where, but not a list to easily check: An exploratory study of personal health information management practices

Full Paper

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Abstract

Preventive healthcare services require consumers to coordinate and manage several healthcare activities with multiple service providers. In this paper we set out to understand what challenges people face in managing personal healthcare requirements. We conducted a qualitative study of consumers who participate in a preventive care program called the Health Enhancement Program in the State of Connecticut. Data from the interviews of 15 participants of this program highlighted several challenges faced by participants in scheduling and managing their healthcare requirements. While some of the challenges were due to lack of communication between several stakeholders of the process, others provide implications for design of technology that can support management of personal healthcare requirements.

Introduction

With increasing emphasis being placed on preventive health services, as reflected in the recently passed Affordable Care Act (Levey, 2010), consumers are having to bear the responsibility of managing personal healthcare activities such as medical exams/screenings, immunizations, medical visits and the related health records. The importance of personal health information management has long been recognized by researchers in academia as well as industry (AHRQ National Resource Center for Health IT; Civan et al., 2006). In spite of this awareness, the tools developed to provide support for personal health information management have either failed or are inadequate as there is a disconnect between what support people want/need to what the healthcare service providers think people want/need (Kohr, 2011; Bechtel & Ness, 2010; Civan et al., 2006). In this paper we specifically focus on a state government implemented program in the USA that aims to encourage preventive healthcare among its employees called Health Enhancement Program (HEP) - to encourage participation in preventive healthcare the State of Connecticut implemented a Value-Based Insurance design program (Office of the State Comptroller, 2013). This program offers incentives to participants in the form of lower monthly premiums for partaking in age-appropriate wellness exams/screenings/immunizations and cash rewards for regular follow up on chronic conditions such as Asthma. While compliance with the HEP program is incentivized, defaulting on the program requirements results in higher insurance premiums and consequently puts the responsibility of coordinating and scheduling appropriate healthcare activities on the consumer. This provides a unique challenge to consumers unlike other day-to-day scheduling activities such as paying bills or attending parent-teacher meetings because 1) it involves a set of non-routine scheduling and planning tasks with no specific pre-determined dates except that personal healthcare milestones be met any time within a period of one year 2) it requires effective communication, coordination and scheduling based on

clinician/technician availability while keeping in mind one's own personal and professional constraints and 3) it may require keeping track of not only one's own personal healthcare milestones but also those of other participating family members whose requirements will vary and change with age, gender and time. Such complexities and information overload often result in people deferring tasks; engaging in last minute scheduling that may or may not work; or even complete oversight. This research proposes to understand what the current challenges are for consumers in managing their personal healthcare requirements, and how we can design technology to help them effectively manage.

Background

This paper draws from Civan et al.'s (2006) definition of personal health information management described as the set of activities that support health consumers' access, integration, organization, and use of their personal health information. Health consumers are faced with the need to organize their health information in order to effectively access and use them when the need arises. Examples of personal health information to manage include number of hospital visits and corresponding reasons for each visit, genealogical health patterns in the family, and insurance information. These pieces of information are typically obtained from a myriad of sources, including health care providers (Pratt et al., 2006), health care insurers (Civan et al., 2006), social networks (Osatuyi, 2013), the mass media (Wade and Schramm, 1969), and from devices such as pedometers, blood-glucose monitors, and thermometers (Alwan et al., 2006; Wang, Lau, Matsen III and Kim, 2004).

Although there is a variety of methods and approaches that health consumers use to manage their personal health information, studies show that paper-based methods of PHIM storage and transfer are still the most common (Eysenbach, 2000). Engagement in PHIM has been shown to be challenged by various factors, including the person's health status, level of perceived need, and level of comfort in managing health information (Civan et al., 2006). Extant literature on PHIM suggests that more work is needed in this field to develop a better understanding of the ways health consumers attempt to track, organize, interpret, and report the different types of personal health information they obtain through various sources (Bandyopadhyay, Ozdemir and Barron, 2012; Pratt et al., 2006).

Patients have long been considered incompetent to participate in their health care due to their perceived inability to scientifically process their health information and make rational and reliable decisions (Auerbach, 2000). However, personal health care management also includes scheduling and coordination activities revolving around health care. Furthermore reports indicate that physician decision-making is often influenced by non-scientific factors such as attributing illness to prevailing weather conditions (Forrow, Taylor and Arnold, 1992; McNeil, Pauker, Sox Jr and Tversky, 1982). More importantly, a major challenge with PHIM is that it is a situated activity that is fundamentally personal in nature. Hence, it is expected that PHIM activities will vary from person to person to the extent that the health consumer is capable of locating, managing and utilizing their health information when in need of care.

Health consumers are burdened to remember and manage every piece of health information they encounter amidst their daily endeavors, resulting in information overload (Schnipper et al., 2012). Today's health care consumers need to be able to coordinate care across providers, understand how to effectively communicate with those providers, know how to get their questions answered in the limited time allotted for an office visit, and learn how to effectively monitor and manage their health between visits. Consumers who can successfully perform these tasks are likely to become more active, empowered health care consumers; who typically enjoy better health care and better health outcomes (Brennan and Safran, 2005).

Research Questions

In order to design effective consumer healthcare tools it is important to understand people's current personal health information practices. Specifically we address the following broad research questions in the context of Health Enhancement Program (HEP) in the state of Connecticut.

RQ1: How do people currently manage their personal healthcare requirements and those of their family members?

RQ2: How do people use various tools (paper-based and digital) to support and plan their personal health care requirements and those of their family members?

Method

Study Procedure

To address the above research questions we conducted an interview study at a state university where participating in the HEP was mandatory for the employees. Participants were recruited through word of mouth and emails. Following the principles of user-centered design of technology that stress the importance of understanding user context, our interviews aimed at obtaining rich contextual understanding of people's current information management practices in general as well as in the context of HEP. The semi-structured interview questions focused on the various social and technical challenges they face in planning and scheduling HEP requirements.

Participants

Interview data was collected from a total of 15 employees (10 males and 5 females). Respondents were between the age range of 20 and 70 years of age, 7 of who were married and 8 were single. Eight of the respondents have dependent children and 2 were dependents of state employees. Job description included 5 professors, 3 associate professors, 1 social worker, 1 library technician, 1 liaison to social media, 1 assistant to director of housing, 1 construction worker, 1 sports statistician and 1 secretary for academic services.

Findings

We recorded 281 minutes of semi-structured interviews and transcribed all interviews. Using interpretive principles outlined in (Klein and Myers, 1999; Pratt, 2008), we analyzed the transcriptions that resulted in several themes within the broad research questions of the study. We present these themes below along with representative quotes to illustrate them with names changed to preserve participants' anonymity.

Uncertainty over HEP program

While people were aware that under the HEP, certain preventive healthcare requirements were mandatory, finer details such as the exact requirements, compliance deadlines, and non-compliance penalties, were not clear to them. Comments such as these from Jake, a library technician in his 20s and Hannah secretary in her 50s were very typical:

Jake: *"I learned about the requirements but I am not aware that it affects my insurance"*.

Hannah: *"No. I don't know a lot about it, other than they send me a lot of things in the mail to remind us that we're supposed to be scheduled for certain types of appointments, doctors' appointments, like yearly physical exams, gynecological exams, eye doctor and that kind of thing."*

This lack of knowledge was either because they didn't actively keep track of it since they thought there was a clearly defined one-stop place they could go to if needed or because another family member took responsibility for it. When asked where they would go to get more information and detail, they often referred to the family member managing it or hoped that the HEP website or a human resource (HR) representative would provide that information. Beth, a professor in her 60s, explained how she did not know what the compliance dates/deadlines were: *"No. I'd ask my husband. He knows."*, while Jake explained how his mother delegates and manages the requirements for him, *"My mother delegates all of our HEP related tasks."*

Charles, an assistant to housing director, in his 20s, explained how he believed his HR representative can answer his questions *"I know some of my requirements. I'm pretty sure I could probably contact my HR people about that to see where to go for that but other than that I don't know where I would specifically find that information"*; while Sam, a professor in his 60s thinks all information is on the website to access when needed *"I do know but I haven't memorized them. If they are online then I don't need to memorize them."*

While websites, HR, and managing family members were considered to be good sources of information, respondents expressed frustrations over tracking/managing other family members' compliance status. Sam explained how even though he helps his family manage the requirements he has no way to confirm that they have been met: *"I'm not quite sure. I tell everybody [family] that they have to have certain things done, the HEP requirements met and usually the appointments are then made and everything is taken care of...I don't know - She's a fellow state employee and she has her own HEP account"*. Beth expressed concerns over enforcing the requirements with children: *"Sometimes the children aren't up-to-date...Call doctors, call providers... make appointment...put on family calendar, large, very large family calendar and tell children who record appointments electronically on their phones. ... The easy part is actually making the appointment. The difficult part is making sure the kids get there, because they don't listen or there is a soccer game."*

Multiple user needs resulting in multiple tool use

People used a varied number of digital as well as non-digital methods for scheduling and managing appointments. Often more than one tool is used to ensure that they have access to information in multiple places, provide access to multiple people and be able to set up multiple reminders and back ups.

Some use explicit calendaring tools such as cellphone calendars, wall based calendars, while others use other tools such as sticky notes, appointment cards in wallets, little personal planners and text messages. Hannah, secretary in her 50s talked about using non-digital tools: *"Just the agenda book. I have a calendar at home in the kitchen. I use appointment cards to fill in dates on both agenda and home calendar."* On the other hand, Jason, academic associate in his 50s, explained how he uses a combination of digital and non-digital tools: *"Either scribble a date on a piece of paper. Try to keep them all in 1 place near the phone. Informal calendar at home. If it is something that I am going to have to do right after work or something like that I do put it in my Outlook calendar at work."*

A combination of paper-based and digital technology was also used in order to have access to information in multiple places as well as allow access to multiple people. John, a head sports statistician in his 20s, explained how he used multiple tools as a backup *"I write it down, put it in my phone, make note of it in my room... sticky notes and all that - keeping information in front of you is key to remembering...I always like to use both because if one doesn't work out I have (other) ones to fall back on"*. Derek, a construction worker in his 20s, expressed a similar sentiment, with a different combination of tools *"if it's really important I'll put it in my phone... Uh, maybe use a calendar - mark some stuff down on it - on the calendar too to remind myself."* Sam, on the other hand used multiple tools to include other members of the family regarding the HEP requirements: *"I set up appointments by telephoning the doctor and I keep track of them by entering the dates and times on the calendars - the cell phone calendar and the big wall calendar so that everybody knows."*

People also used different tools to differentiate between work and personal appointments. Beth spoke of her choices: *"Day planner. A paper day planner and the home calendar. ...I use an electronic calendar, a computerized electronic calendar for work."* Charles, said *"Outlook calendar mainly. I put my work related deadlines in there. When it comes to personal and educational appointments they do go in the calendar, but the majority of those are just written on a pen and paper list/calendar."* Jake explained how he separates them based on perceived security of the tool *"I keep track of things [social events] like this, just by holding all my text messages with plans I have with others"*. However when it comes to work related coordination and scheduling appointments he says *"certainly by email. I wouldn't text any work information. Email is much more secure"*.

Delayed Reporting and incorrect compliance updates

While respondents met the requirements, it was not often reflected on the HEP website or the paper reminders/notifications they received. Adam, a professor in his 30s described how the lack of communication between the service providers and insurance companies was contributing to this problem: *"Yes... they [requirements] have been fulfilled, but they do not know that. They have not been very good at coordinating with insurance along with coordinating with the provider."* This puts the responsibility on the consumers to follow through often requiring switching to offline methods such as bringing the necessary paper work to the doctor. Sometimes this process was relatively straightforward as explained by

Hannah: *"My doctor's office always reports my statistics to the insurance company already, and I don't know if they were aware of the HEP, but when I have the paperwork with me I show them everything that I have with me, so it is easy to verify and they know. They are pretty much in sync with it now because they told me what and where I had to fill out and that kind of thing. I get it done when it is humanly possible, if it is not humanly possible then it's just not going to happen."* Lily, an associate professor in her 30s, on the other hand expressed frustration over the lack of communication when she updates on her son's requirements met were not reflected on the website *"Through the HEP they have their own nurses that is associated with that website, where you can consult with a nurse. ... Calling them that time to...like... figure out what was going on - I sent several notes where I explained the situation and I heard nothing back. it was like hell for me, and so having an online system in theory is really good thing, it just wasn't working."*

Lack of push confirmation

Once all requirements were met respondents noted lack of confirmation sent to them. The only methods to confirm were to go to the website or call the HEP office thus putting the burden on the consumer. Chris, a professor in his 50s, said the following on lack of confirmation about having met requirements: *"I don't think they give me anything, but I had to make sure they had the information so I remember I had to call them in December to verify that they had everything."*

On visiting the website respondents mentioned several usability issues concerning signing in and finding information. Adam expressed frustration over accessibility, *"You can log onto their website, it's all on line to find the information... Unfortunately I can't remember the username and password. It's like a thousand different ways you can get to it. ...But by the time you have to visit again, you probably lose your user name and password, so then you have to go through that extra step... I just wish it were more streamlined."* Jason, talked about how he had difficulty in finding an online survey as one of the HEP requirement for a chronic condition he had, *"... but I couldn't find the online survey anywhere, there was no link anywhere. I looked around on their website and I couldn't find it...If they are going to put the option on the website, you would think they would make the option available."*

While some took the trouble of confirming, others remained in dark and hoped they would be able to confirm if needed. Derek: *"Uh, yeah I'm sure we all made, met the requirements. I have no way to confirm that but I'm sure I can find out on HEP website."* A similar sentiment was expressed by Jake: *"Honestly, I have no idea if I met them or not. I have to ask my insurance provider or get the information on the health care enhancement program website. Which I haven't visited in the past."* Others expressed frustration over not knowing how to even get to the website even if they were aware of its availability. Charles: *"I don't even know how to access the website honestly. I wouldn't even know what to be looking for at this point."* Adam: *"For a while you couldn't find it, I would go on to the CT government website, and I couldn't find it, then the office of the Comptroller, it wasn't very easy to find."*

Reactive vs. proactive scheduling

Meeting the HEP requirements meant scheduling appointments with healthcare providers and keeping the appointments. Many relied on the paper-based reminders HEP sent by snail mail. Many appreciated the utility of it as expressed by Chris: *"Around the beginning of September by letter, and I got a card that was sent some time in June. Oh yes, definitely [they are useful]."* Hannah explained how she used these notifications as a reminder to set up appointments: *"Whenever I have a letter and it says that I have to act on it, or whatever, I put it in my purse, I contact my doctor and then I set up an appointment and go from there.... I do it as soon as humanly possible."* Jason on the other hand appreciated it as reminder of things he already knew he had to take care of: *"So far at the end of the year they will send me something telling me what I haven't met and I usually know already that I haven't met it - but it's nice to get the reminder. Then I will make sure I will have it scheduled."*

Some respondents expressed frustrations over the nature and timing of reminders. Charles talked about how the reminders often arrived at times that made last minute scheduling a problem: *"I would get something saying 'Hey you're not in compliance with A, B, & C. You have to meet these requirements by December 31st or whatever it is or whatever the date was. So I would be scrambling to that...you're telling me in December that I have a month to get 3 requirements done when I am just finding out and"*

it's gonna cost me a few hundred dollars to take care of some stuff that may need to be taken care of. I may not have that money right then to be able to do what I need to do or have the time to go and do that." Others felt overwhelmed by them as expressed by Hannah: *They send stuff for whatever, but I don't always have time to open it up to read everything on it. I haven't seen any of those letter things"*

Some felt the reminders were superfluous as Adam described: *"Yeah thanks for the reminder, but we did it 2 months ago...I appreciate the reminders in the email, but I am already on top of it."* This is because many respondents did not depend on the HEP official reminders and proactively scheduled their appointments. Respondents used different strategies to schedule appointments. Some plan elaborately with the entire family involved as Raul, a social media activities liaison in his 20s explained: *"Every year we kind of sit down and we just go over what we need to do, what we need to get done. Health insurance as you can imagine is really important to me and my family, so we always make sure we are on top of the ball, when it comes to things like that"* Others schedule appointments around breaks and birthdates as Adam described: *"...it mainly functions around the same time of the year. January 1st which is still the break around here. So I have the thought, let's get my dental cleaning. It is by semester, my life has been by semesters my whole life. I have had a summer break and a winter break my whole life. It has less to do with the calendar that they tell you and more about the actual time of the year that I remind myself. And my wife's birthday is during the holidays so it is easy to track it by that".* Jason and Beth on the other hand scheduled the next appointment at the end of the current one. Jason: *"Most of them the same time I saw them before, 6 months to a year before that. Made appointments upon leaving every appointment."* Beth: *"At my annual checkup, I make an appointment for my next annual checkup. They are always a year apart."*

Challenges in scheduling appointments

Respondents often mentioned the difficulty in scheduling appointments meaningfully due to, multiple service providers for various family members, long waits at the service providers, family availability and uncertainty about work/future.

Beth and Hannah mentioned the importance for ensuring availability of family members. Beth: *"We have to make sure, when we make appointments that the people are available, the family members are available."* Hannah: *"My doctors are right over here on C... street. So it is very, very close. I just go to my appointment and come right back to work. He [my husband] has to take off time, not me, because he works in Hartford...It's [appointment] based on availability, of course, also too when you can actually get an appointment because doctor hours are always going to be different."*

Beth and Chris's accounts described the complexity of an entire family's scheduling with multiple service providers. Beth: *"Oh God, I have to work this out. I've got 4. Molly has 2. Uli has 3 physicians, eyes, and dentist, so that is 5. Sally has 2 physician and dentist. Jonny has 3. 16. The overlap would be Jonny & Sally go to the same dentist. Uli, Molly & I go to the same dentist. Uli & I go to the same eye doctor. Actually since it is the same practice, Uli & I have the same medical physician and Jonny & Sally have the same physician. So there is a lot of overlap."* Chris: *"Last year around 4, for each of us. We have both the same primary care physician, we have the same dentist, but the rest are different."*

Other mentioned difficulties in scheduling appointments due to long waits with service providers. Charles: *"Some of the difficulties is making appointments in advance because of the time tables that are provided per the physician I am seeing or the person I am seeing in the office. It may be a month or 2 before they can get me in there, so I don't know my schedule necessarily a couple of months in advance, so it is definitely difficult to... sometimes I am not able to make those appointments and I have to wait again."* John explained his challenges given his school schedule: *"As far as getting people on the phone and getting someone to talk to its very easy, but as far as the difficulty I see I would say is scheduling appointments. They are very backed up and as a student you don't have much time to miss classes and go down to appointments so you have to find the perfect slot with their little availabilities. I think that would be the only difficulty"*.

Discussion and Implications for Design

The findings from the semi-structured interviews provided insights on peoples' current practices in managing HEP requirements. Every participant of the HEP program needed to meet a checklist of requirements but they faced challenges in smoothly checking off this requirements list. These challenges were illustrated by how participants 1) experienced uncertainty about HEP requirements 2) felt confusion over delayed reporting or incorrect compliance updates 3) juggled multiple tools both digital and non-digital 4) lacked automatic confirmation updates from HEP 5) coordinated, scheduled, and kept track of appointments of family members and service providers. Together they highlighted how people faced a lack of information availability, a lack of easy and timely information access, and a lack of easy information sharing. Frustration from lack of information and confusion over delayed or incorrect compliance updates can be brought down to a large extent with improved and streamlined communication between relevant stakeholders such as service providers, HEP program staff and insurance, while, challenges of information accessibility and sharing can be addressed through appropriate design of support tools. People do not want to carry the cognitive burden of remembering HEP related information be it requirements, or scheduling them or knowing the compliance status. Below we discuss how the findings of this study provide several implications for design of technology that can help people manage HEP requirements effectively.

1. Users need to know where to go if they need to find relevant HEP information. People having trouble recalling website address or password log in suggests that they not only require a clearly defined one-stop place to access information but it has to be ubiquitous, easily accessible from anywhere at any time and support recognition vs. recall. This can be achieved by using push technology to deliver HEP information regularly or at least send messages to enable easy seamless transfer to the website through links in the message.
2. When customers want to learn the requirements they used the website or the paper-based lists. They then had to switch to voice calls to schedule appointments with doctors. Such media switching can be minimized by designing a complete electronic process (this being the vision for our healthcare system) that provides links to doctors' offices and their calendar indicating physician availability and schedules to make the process of scheduling seamless. Alternatively consumer apps can allow for doctor's information as well as HEP requirements to be co-located for seamless scheduling.
3. People use tools that are most convenient or intuitive to them to set reminders and notifications. As a result some used paper-based calendars and books, while others used electronic devices. This suggests that reminders and notifications should cater to people's preferences. Designing a mobile or web app to these preferences is crucial in order to minimize frustration over undesirable notification methods as well as notification overload.
4. People's scheduling habits are either proactive or reactive to the HEP requirements. For those who are proactive, flexibility to set reminders on devices and the web app from HEP based on their own preferred dates such as birthdays or work breaks is important. For those who are reactive, it is important to enable a progressive reminder service that begins early in the year with multiple reminders indicating physician availability and schedules.
5. Often requirements have to be met for several members in a family and one family member manages and coordinates this process. It is thus important to provide a single interface on the phone or a web app to 1) enable access to relevant physicians of each family member, 2) show updates on family members appointments and compliance status, 3) provide the ability to send personalized reminders for the family member in charge (such as from the parent to the child or one spouse to the other).

The above design implications also provide new directions for further research that can examine the effectiveness of various designs in personal health care management. For instance, different interventions may be designed to investigate users' adoption intentions across various types of push technology to deliver HEP information. The moderating influence of demographic variables such as age, gender and employment status on users' adoption could also be examined to gain additional insights into how different user constituencies can take an active role in managing their health information.

Conclusion

In this paper we set out to understand what challenges people face in personal healthcare information management. With particular focus on a preventive care program in the State of Connecticut, our qualitative interview study highlighted several challenges faced by participants of the program in scheduling and managing their healthcare requirements. While we learned that some of the challenges were due to lack of communication between several stakeholders of the process, we were able to provide implications for the design of technology to make information access easy and timely as well as support easy coordination and scheduling of preventive care.

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