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LONG PAPER

Older adults' perceptions of usefulness of personal health records

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Abstract Electronic personal health records (PHRs) have the potential to both make health information more accessible to patients and function as a decision-support system for patients managing chronic conditions. Age-related changes in cognition may make traditional strategies of integrating and understanding existing (i.e., paper-based) health information more difficult for older adults. The centralized and integrated nature of health information, as well as the long-term tracking capabilities present in many PHRs, may be especially beneficial for older patients' management of health. However, older adults tend to be late adopters of technology and may be hesitant to adopt a PHR if the benefits are not made clear (perceived usefulness). Toward the design of a useful PHR, a needs analysis was conducted to determine how people currently manage their health information, what they perceive as useful, and to identify any unmet needs. This paper describes two qualitative studies examining the health information needs of both younger and older adults. The first study used a 2-week diary methodology to examine everyday health questions or concerns, while the second study examined maintenance of health information and perceptions of PHRs through the use of a three-part interview. User's perceptions of the usefulness of PHRs are provided as recommendations for the design of e-health technology, especially those targeted for older adult healthcare consumers. The results suggest that both older and younger adults would deem a PHR useful if it provides memory support in the form of reminders, provides tools to aid in comprehension of one's health concerns, is interactive and provides automatic functions, and is highly accessible to authorized users, yet one's information is kept secure and private.

Keywords Personal health records · Aging · Technology adoption model · Psychology · Perceived usefulness

1 Introduction

Keeping track of one's own health information may have a positive impact on health management, especially for those with chronic illnesses [1]. For example, diabetes patients would be in a better position to understand the relationship among food intake, medication, and exercise on their health by managing their condition on a daily basis. Personal health records (PHRs) are Internet-based tools that facilitate the management of health information by enabling patients to store, manage, and share their health information [2]. Although there is still debate over the definition of a PHR and the International Organization for Standardization (ISO) has not yet released a standard definition (ISO/DTR 14292) [3], the American health information management association (AHIMA) defines a PHR as "an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the

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individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider" [4]. PHRs can vary by both the format type (paper, electronic, desktop application, or an Internet-based service) and the provider type (employee, insurance, or healthcare provider sponsored) [4]; however, electronic and Internet-based PHRs are the focus of the current research. Despite the variations, potential benefits of PHRs include:

- Convenience of keeping personal health information in a single, accessible location, which may encourage active participation in one's daily health management [5].
- Improved doctor–patient communication because patients have access to information to prepare questions for an appointment [1].
- Prevention of duplicate tests or procedures [1].
- Ability for patients to verify and correct information (e.g., allergies, medications) that may otherwise lead to a serious medical outcome (e.g., negative drug interaction).
- The electronic and consumer-centric nature of PHRs offers consumers the unique ability to easily share their information with whomever they choose, such as a spouse, doctor, or a health-related social network (e.g., http://PatientsLikeMe.com) in contrast to EHRs or paper records.
- Collection of historical health data can provide some level of information visualization, which may help users detect trends and assist in managing chronic disease.

However, only 7% of patients in the United States currently maintain an online PHR [3], despite the finding that 55% of consumers report being interested in e-health tools that would help them manage and assess their health information [6]. This discrepancy shows that despite the widespread availability of e-health tools, users (who ostensibly would like to use and benefit from them) are not adopting them.

Older adults (65 years or older), in particular, would be a user group who would benefit from the use of PHRs, as they more likely need to manage chronic conditions [7]. According to the Centers for Disease Control and Prevention Web site [8], chronic diseases such as diabetes, heart disease, stroke, cancer, and arthritis are some of the most common and costly of all, and older adults are at an increased risk [8]. For example, 50% of all older adults aged 65 or older have been diagnosed with diabetes or prediabetes in 2010 [8]. Diabetes is also the major cause of heart disease and stroke, and thus, older adults are also at an increased risk for these chronic illnesses as well.

1.1 The older health consumer

Healthcare consumers with chronic illnesses seek medical care more frequently and have more emergency medical needs [7], which can lead to what is essentially an information management problem. For example, after just a few visits, the patient may need to keep track of: changes in their drug regimen, specific test results (e.g., cholesterol, blood glucose, liver enzymes), appointments that require a new test beforehand, or doctor-recommended changes in diet and exercise.

Age-related changes in cognition may make integrating health information and making health-related decisions more difficult [9, 10]. For example, older adults may have greater difficulty remembering to incorporate a new medication into their daily regimen [11], or remembering to make an appointment after getting a specific test (a prospective memory task [10]). The difficulty for older adults may be attributed to a reduced working memory capacity (the amount of information one can simultaneously store and manipulate at any given time). Working memory capacity is required to integrate information, to retrieve information from long-term memory, and for encoding new information to memory.

PHRs may make health information tasks more manageable by providing a central place for all integrated information and tools that can help older adults make well-informed health decisions. Internet use may be one barrier to Web-based electronic PHR adoption, as only about half of adults with chronic illnesses use the Internet [7].

1.2 Determinants of adoption

The technology acceptance model (TAM) posits that eventual adoption of technology is determined by two constructs: the user's perceptions of the usability of the system (ease of use) and the perceived usefulness of the system [12]. Ease of use refers to the usability or "degree to which the prospective user expects the target system to be free of effort" [12, p. 4] and "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) [13, p. 1]. Technology usability includes how efficient the user is able to find what they are looking for, recover from errors, quality of feedback, and user's subjective ratings of frustration. Ease of task or goal completion is important, because it can directly influence the adoption (and continued use) of a system.

There is a wealth of literature that has examined the role of usability of PHRs [14–17]. TAM predicts that better usability will result in higher adoption rates, which is consistent with the literature on PHR usability. Preference for one PHR over another was tied to the site's ease of

access, clear navigation, search usability, and feedback [18].

While usability is important, none of these studies examined the role of perceived usefulness as a determinant of PHR adoption. Perceived usefulness is defined as "the prospective user's subjective probability that using a specific application system will increase his or her (job) performance (within an organizational context)" [12, p. 4]. This original definition has been expanded beyond the job and organizational context [19] and can be applied to any consumer task or system.

Across many studies, perceived usefulness or benefit has a greater influence on technology adoption than the perceived cost (e.g., effort or usability [19]). That is, if the user perceives the technology as beneficial, then they are willing to expend more effort to learn how to use the system or overlook frustration due to bad usability. A noteworthy example of this balance made between costs and benefits was found in a study examining communication technology adoption by older adults. In focus group sessions, Melenhorst et al. [20] found that for older adults, the *absence of benefit* was more influential to the adoption of email and cell phones compared to the perceived cost (e.g., availability, accessibility, need to learn a new skill [21]). Similarly, in a recent survey, older adults were more likely to choose a more complex, technologically innovative PHR, over a simple, less complex and thus more usable form [22].

Clearly defining the benefits of a PHR may be the most important factor influencing its adoption by older health consumers. However, according to TAM, the new system (PHRs) not only needs to be better, but also has to offer higher perceived utility (i.e., more benefits) than the current strategy. Therefore, the benefits need to be framed in terms of how users currently manage their health information. Despite a plethora of research on the usability of PHRs, there exists a dearth of information with regards to how PHRs compare to the current strategies people use to keep track of health information.

1.3 Overview of the studies

The goal of the two studies presented in this paper was to explore perceptions of usefulness of an electronic personal health record by younger and older users. Younger adults were included in the analyses so that the needs unique to older adults could be identified and considered in PHR design. The concept of the perceived usefulness of personal e-health records was examined using two study methods. First, an event-based diary methodology was used to inventory the nature of personal health information problems people encounter in situ. The purpose of this study was to gather information about the specific nature of health information issues and typical ways in which they are resolved. Next, an interview was conducted to examine how people currently manage their personal health information. The interview combined aspects of ethnography to understand issues people have in managing their health, how they resolve those issues, and how the process could be improved. To summarize, the two studies sought to answer three research questions: (1) What are the everyday health information needs of younger and older healthcare consumers? (2) What strategies do healthcare consumers use to keep track of health information? and (3) What needs are not being met by their current strategies that could potentially be addressed by a PHR?

2 Study #1: event-based diary

The first study was designed to help answer question (1): What are the everyday health information needs of younger and older healthcare consumers? One challenge in examining health information management is the personal and private nature of health information. Each person's health information is unique and thus makes studying strategies for health information in the laboratory difficult. Exploring health-seeking behaviors by giving participants fictitious, non-personal examples of scenarios may not lead to an accurate representation of the needs or the strategies actually used, because they may be unable to relate to the event in the scenario. Second, participants may not be willing to share such personal information with experimenters or with other participants (i.e., in the context of focus groups; [23]). Third, retrospective recall of recent or past health scenarios is subject to error because participants may forget or misremember past events. Fourth, although direct observation is one method of getting around the recall issue, it is impractical in this context. The need for health information can arise at any time, and the personal nature of the events is not amenable for direct observation.

A diary methodology was most suitable for examining health information needs and the strategies people use to answer their questions. A diary study employs the use of a structured, event-based diary in which participants recorded health needs and questions as they occurred [24]. This method helps minimize the forgetting of events and details, because participants record the information as it occurs.

2.1 Methods

2.1.1 Participants

Twenty-four older adults (11 female) and seventeen younger adults (13 female) participated in the study. Older adults ranged in age from 61 to 83 (M = 72, SD = 5.6)

Table 1 Participant demographics

Demographic information	Age group	
	Younger adults ($N = 17$) (%)	Older adults ($N = 24$) (%)
Subjective health rating		
Poor	0	0
Fair	0	8.3
Good	17.6	45.8
Very good	64.7	41.7
Excellent	17.6	4.2
Computers use		
<6 months	0	8.4
6 months but <1 year	0	0
1 year but <3 years	0	8.3
3 years but <5 years	5.4	12.5
At least 5 years	94.1	62.5

and were recruited from the local Clemson community. Younger adults ranged in age from 18 to 20 (M = 19, SD = 0.66) and were introductory college students. Table 1 provides participant's subjective rating (poor being the lowest, excellent being the highest) of their overall health status and the length of computer use. Older adults were compensated $25.00, and younger adults chose to either receive course credit or $25.00 for participating.

2.2 Materials

2.2.1 Diary

A spiral-bound booklet (5.5″ × 8.5″) with fifty preprinted pages was provided to participants (Fig. 1). Instructions were printed on the first two pages of the booklet, and two sample entries were provided. Each page contained questions for a single health event (i.e., anytime participants had a question or concern about their health). The booklet was mailed to participants along with instructions for use.

2.3 Procedure

Participants were briefed over the phone as to the purpose of the experiment. A health event was defined as anytime the participant had a question or concern about their health (or someone else's). Participants were instructed to describe the event in as much or as little detail as they felt comfortable providing. Instead of writing down a specific illness or outcome, they were able to record the event more generally without leaving out information that is pertinent to the study. For example, instead of logging that they had a question about side effects of a particular medication they

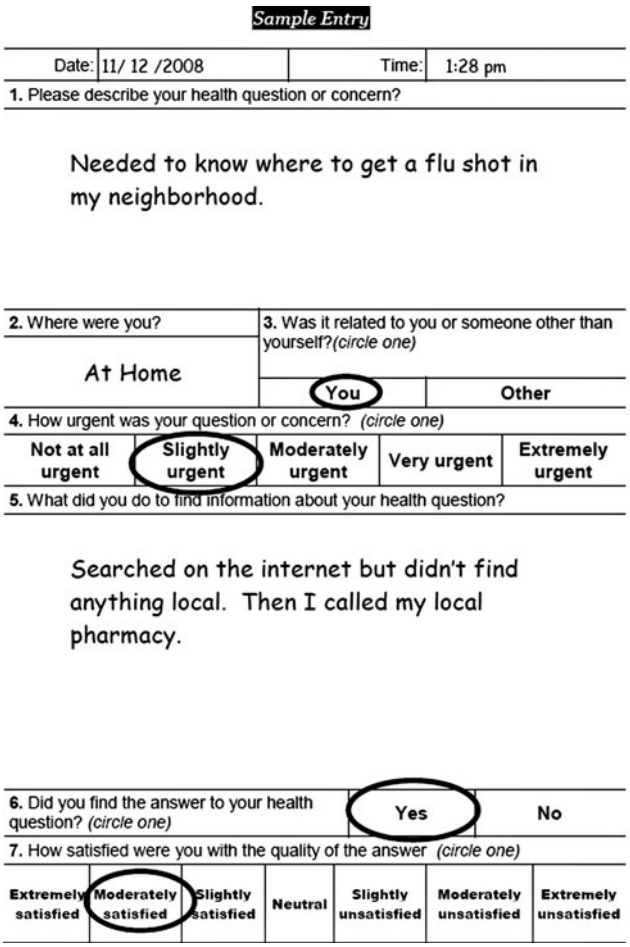

Fig. 1 A sample page containing one of the example diary entries provided

are on for a specific illness, the participant simply wrote down that they had a medication question and the strategy used to answer the question. In addition to the health event, participants recorded whether the event was about them or someone else, and urgency of the event (along a five-point scale). Next, participants described the strategy used, indicated whether they were successful in alleviating the concern, and described how satisfied they were with the information found (along a seven-point scale). Experimenters contacted participants by phone several times throughout the 2-week period to answer questions and encourage participation. At the end of the 2-week period, participants mailed the diary back to the experimenter.

2.4 Results and discussion

The qualitative data were analyzed using methods similar to a grounded theory approach augmented with top–down enforcement of categories. A primary coding scheme was developed beforehand, but the subcategories of the coding scheme were informed by responses. The main categories

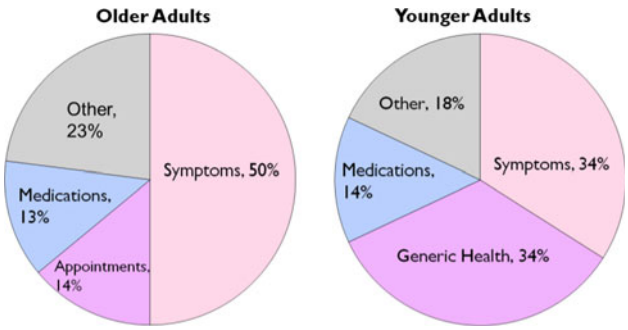

Fig. 2 Summary of health concerns by age group

of the coding scheme were organized around the main questions in the diary: (a) the kind of health question or concern, (b) the location where the problem occurred, (c) who the problem was related to, (d) the urgency of the problem, (e) the strategy used to satisfy the information need, (f) the success of the strategy used, and (g) satisfaction with the information found. Within each of these primary categories, mutually exclusive subcategories were created from a portion of the data. Once the coding scheme was finalized, three independent coders reached an inter-rater reliability of >90% and coded the complete data set.

The results are organized by the structured questions from the diary. Frequency data were used to interpret the trends in the data. The following analyses are based on the total number of segments (comments) made, rather than the number of participants, because participants often contributed more than one health information need or strategy that was in the same category. Percentages for older adults are based on a total of 143 codable entries, and younger adult percentages are based on a total of 137 codable entries. Older adults averaged 5.3 entries per person (SD = 4.5), and younger adults averaged 8.1 (5.6); however, this difference was not significant.

2.4.1 *What kinds of health information needs do people have?*

Older adults and younger adults both had questions or concerns about symptoms (50, 34%, respectively; see Fig. 2 and Table 2). A symptom-related question or concern was defined as a statement about a symptom but not about a treatment or medication. An example of a symptom-related question from an older adult was "(I am) concerned about my blood pressure which seems to be higher than it has been." A younger adult symptom-related question was, "why do I have a rash near my belly button that hurts and itches." Consistent with the literature, older adults had more chronic health issues than younger adults and thus may have had more questions about symptoms [5, 22].

Younger adults also had just as many symptom-related questions as they did general health concerns (34%).

Table 2 Health information needs by age group

Concern category	Age group	
	Younger adults (%)	Older adults (%)
Appointment related	2	14
Generic health	34	1
Medication related	14	13
Nutrition related	8	4
Symptom related	34	50
Treatment question	4	8
Other	5	11
Not mentioned	0	1
Total	100	100

Participants generated a total of 280 codable entries (older adults $N = 143$, younger adults $N = 137$)

General health concerns were defined as health questions less specific than nutrition and not related to a symptom or treatment. An example was, "What is a healthy weight for someone my age?" Older adults did not have any questions related to general health. This may be because they have more experiential health knowledge acquired throughout their life and therefore less questions about their general health, unlike the younger adults in this study who perhaps are just learning to manage their health on their own.

Older adults also had appointment-related questions (14%), which younger adults did not. Appointment-related concerns included needing to make a new appointment, remembering to make a follow-up appointment, or remembering to ask a doctor about a problem at an appointment. This finding also reflects a unique need that older adults have—managing appointments for chronic issues and information regarding those appointments, in addition to regularly scheduled annual appointments.

Both older and younger adults had questions or concerns about medications (13%, 14%). Demographic data show a significant difference in the number of medications older adults take (M = 5.37, SD = 3.17) compared to younger adults (M = 1.06, SD = 1.48), $F\ (1,\ 38) = 25.64$, $p < 0.01$, $\eta_p^2 = 0.48$. Older adults had more concerns about refilling medications (72%), while younger adults had questions about what medications to take (42%) and side effects (26%). Although participants were not asked to specify the types of medication they had questions about, the need to refill medications indicates that older adults had questions and concerns about prescription medications. Younger adults, on the other hand, had questions about what to take, a decision one would have to make if purchasing over the counter medications but not if a doctor prescribed them. This may be an important distinction for health information technology that targets both age groups.

Most health events occurred in the home (older adults = 77%, younger adults = 64%) and were rated not at all urgent to moderately urgent (older adults = 84%, younger adults = 82%). The fact that health needs happen at home and are not urgent is interesting from a health information technology point of view. At home, people have access to many potential sources of information (e.g., a computer, family, television, or their paper health records) and non-urgent concerns may be answered by less costly strategies like e-health tools, instead of making an appointment with a healthcare provider.

2.4.2 *What strategies do people use to find health information?*

Older adults were more likely to call a healthcare provider (50%) than any other strategy (Table 3). Younger adults are more likely to take advantage of online health tools (44%) and only consulted a healthcare provider 21% of the time. Older adults' alternative strategies were to read some form of paper health literature, instructions, book, or label (11%), or self-medicate to take care of the issue (13%). Younger adults also contacted a family member 13% of the time. The type of question or concern also influenced the strategies that older and younger adults used. Younger adults were likely to use the Internet when they had a generic health question (63%). Older adults turned to a healthcare provider 70% of the time to answer a symptom or appointment-related question.

In general, younger adults were significantly more successful (83%) than older adults (71%), χ^2 (2, $N = 280$) = 8.306, $p < 0.05$ at finding answers to their questions. When both groups chose a more traditional strategy (e.g., consulting a healthcare provider, consulting a family member, reading literature or a label), they were successful over 80% of the time. However, older adults were only successful 40% of the time when they chose to use an online search engine, compared to younger adults' 90% success rate. Older adults were as successful (100%) as younger adults (80%) when using health-related Web sites such as WebMD. Providing a health-specific site where older adults can both store, manage, and search for information may help them find the answers they need instead of using more costly strategies (e.g., consulting a healthcare provider). Additionally, both older and younger adults may be able to better prepare questions and get more information from their healthcare provider, which may reduce the number of subsequent appointments or phone calls.

There was no significant difference between satisfaction ratings of younger (M = 2.35, SD = 1.25) and older adults (M = 2.49, SD = 1.56); however, the strategies differed between age groups. Younger adults were able to get answers using less costly strategies without losing their satisfaction with the information they find. If the success rate with online search or health information technology can be improved for older adults, they may be able to use less costly strategies than consulting a healthcare provider and get answers more quickly without reducing the subjective quality of the information. Older adults might benefit from having one central place to start a search that is health related and comprehensive.

Table 3 Strategy categories by age group

Strategy category	Age group	
	Younger adults (%)	Older adults (%)
Consulted a doctor/nurse/other medical professional	21	50
Consulted a friend/family member/other	13	7
Read label/instructions/book/flyer/literature	6	11
Self-medicated	4	13
Used an online health site	4	1
Used an Internet search engine	44	4
Did nothing	4	2
Other	4	12
Total	100	100

Participants generated a total of 280 codable entries (older adults $N = 143$, younger adults $N = 137$)

The purpose of this study was to inventory the health information needs of people in their daily lives. The results can be interpreted as a needs assessment of any potential e-health solution. For any e-health solution to be perceived as useful, it must satisfy these basic information needs and must also be compatible or complementary with the ways in which users chose to solve their problems. Overall, study 1 was successful in identifying key types of non-urgent health concerns and questions that arise in the home for both older and younger adults. Additionally, this study determined the types of strategies people use to find answers to non-urgent health concerns. However, seeking answers to everyday health questions and concerns may not be the only health information task that people perform. Maintaining health information may be another aspect to health information management. What and how people manage their health information over time is another aspect of health information management that still needs to be addressed.

3 Study #2: interview

While study 1 answered questions about what kinds of questions people have about their health and how they find

answers, it did not address the maintenance of health information. The second study was designed to answer the questions: (1) What strategies do healthcare consumers currently use to manage existing information? and (2) What needs are not being met? A semi-structured interview was conducted and consisted of three main parts: (1) general health information needs and strategies, (2) strategies in context, and (3) user needs for a health information tool.

3.1 Interview parts 1 and 2 methods: general health information, strategies, and needs

3.1.1 Participants

Twelve older adults (8 female) and nineteen younger adults (12 female) participated in the study. Older adults ranged in age from 65 to 84 (M = 74, SD = 6.07) and were recruited from the surrounding community. Younger adults ranged in age from 19 to 25 (M = 20, SD = 1.52) and were introductory college students. Participants from study 1 were given the opportunity to participate in study 2. Nine older adults who participated in the diary study agreed to participate in the interview study; however, none of the younger adults agreed to continue on with the interview. The additional participants were recruited from an existing database, and other than age restrictions (over 65 for the older adult group; 18–25 for the younger adult group), there were no other inclusion criteria. Older adults were compensated $25.00, and younger adults chose to either receive course credit or $25.00 for participating.

Participants were asked to rate their overall health status on a 5-point scale, ranging from 1 being poor health to 5 being excellent health. In addition, participants were asked how often they use a computer. These results are summarized in Table 4.

Table 4 Demographics by age group

Demographic information	Age group	
	Younger adults ($N = 19$) (%)	Older adults ($N = 12$) (%)
Subjective health rating		
Poor	0	0
Fair	10.5	16.7
Good	5.3	16.7
Very good	52.6	33.3
Excellent	31.6	33.3
Length of time used computers		
1 year but <3 years	5.3	8.3
3 years but <5 years	5.3	8.3
At least 5 years	89.5	75

3.1.2 Procedure

At-home interviews were conducted with older adults, which allowed observation of current strategies as they are applied, and allowed the participant to both explain and show the processes they use to manage health information. Younger adults were interviewed on campus. The interview questions were structured, but open-ended. All responses were audio-recorded. The interviews were transcribed verbatim, and two experimenters coded each section separately once reliability above 90% was reached. The results and related discussion are presented and organized around the three different portions of the interview.

In part 1 of the interview, participants were asked generally about the kinds of health information they currently track, store, and manage. The purpose was to get participants thinking and talking about their needs. A card was provided with examples of different health information (e.g., medical history, immunizations); however, participants were encouraged to elaborate beyond what was listed on the card. An example questions was, "can you tell me how you keep track of your health information?" For part 1, the same categories of needs and strategies were used as in the diary study. For the general needs, responses were also coded for the source of information (where the information came from), the information owner (who's information it was), and urgency. The following analyses are based on the total number of segments (comments) made, rather than the number of participants, because participants often contributed more than one health information need or strategy that was in the same category.

3.2 Results for interview parts 1 and 2

3.2.1 Health information needs

The type of health information kept was similar for both age groups (Table 5). Younger adults' biggest category was "other," which included statements about non-health-related comments. Older adults' and younger adults' both generally keep more information related to procedures, test results, and immunizations. Similar to the results from study 1, older adults also keep track of more appointment-related information and medication information. Younger adults were more likely to keep track of symptoms and other acute illnesses. Older adults' needs were also unique in that they also keep track of bills and statements more than younger adults. Younger adults in this study were college students, and thus, a majority of their health-related costs are covered under a student plan or under their parents' health policies. Interestingly, 10% of the information older adults keep track of is related to preventative care. Although in study 1 older adults did not have concerns or

Table 5 Health information categories by age group

Health information category	Age group	
	Younger adults (%)	Older adults (%)
Appointments	27	17.9
Bills/statements	2.7	12.8
Medications	5.4	15.4
Preventative care	–	10.3
Procedures/tests/immunizations	21.6	28.2
Symptoms or conditions	13.5	7.7
Other	29.7	7.7

Percentages based on number of segments. Younger adults $N = 37$, older adults $N = 39$

questions related to preventative care, they are still likely to keep and store information related to preventative measures.

3.2.2 *General information keeping strategies*

The general strategies were coded for complexity (low, medium, and high). Other category codes were as follows: the format of information or strategy (non-electronic, electronic, or in person), limitation category (perceptual, physical, memory, or comprehension/understanding), and memory-support category (retrospective or prospective).

The most frequently used strategies for keeping track of health information for both age groups was keeping a paper file (34% for younger adults, 30% for older adults) and making or placing reminders (30 and 23%, Table 6). Younger and older adults kept calendars and planners (21 and 10%). Unlike younger adults, older adults were likely to read some form of written information on a medication label or within a book (10%). Most strategies for younger adults were used to keep information about themselves (97%), while older adults were likely to keep information about themselves (59%) and for someone else (e.g., spouse) (41%).

Strategy complexity was also examined. Ten younger adult participants who did not participate in any other portion of the study were asked to rank order a complete list of the strategies mentioned in the interview. The strategies were then split into 3 categories based on the average rank: low, medium, or high complexity.

Older adults are most likely to use low-complexity strategies (37.5%—making/placing reminders) to medium-complexity (47.5%—keeping a paper file, using the computer to look up information) strategies. Younger adults were most likely to use a medium-complexity strategy (73.9%). High-complexity strategies include talking to a doctor or relying on printed materials (in a magazine or newspaper). Currently used strategies indicate that there is motivation to keep track of health information—and that people are willing to use a low-to-medium complex strategy to keep up with their health information.

One possible motivation for using more complex strategies may be reflected in the type of support these strategies are used for. Ninety-one percent of younger adults' strategies and 72% of older adults' strategies were used to support memory limitations. Of these memory-supporting strategies, most reflect the need for retrospective memory support (56% of younger adults, 52% of older adults), which refers to remembering past events or experiences [25]. In addition, strategies that support prospective memory (the ability to remember to do something in the future) were also used by both younger (39%) and older (25%) adults.

Older adults differed from younger adults in that 27% of their strategies were used to better understand or comprehend health information. It may be that older adults have more chronic health concerns and have a need for understanding the underlying causes, or how a medication might affect that concern. Health information technology should help older adults both keep track of general information and have support for these comprehension needs

Both age groups mostly rely on non-electronic strategies (e.g., do not use a computer or phone calendar) (72% for older adults, 91% for younger adults). Contrary to the literature regarding the digital divide between younger and older adults as a significant barrier to the adoption of e-health tools [26], older adults in this study were more likely to adopt some form of technology than younger adults (e.g., create a medication list within a word document). Older adults' willingness to adopt some form of

Table 6 General strategies by age group

Strategy	Age group	
	Younger adults (%)	Older adults (%)
Consulted a healthcare professional	–	2.6
Consulted friend/family member/other	8.7	7.7
Kept a calendar or planner	21.7	10.3
Kept a file	34.8	30.8
Kept an electronic file	–	5.1
Made or placed reminders	30.4	23.1
Read label/instructions/book/flyer/literature	–	10.3
Used the Internet	–	7.7
Other	4.3	2.6

Percentages based on number of segments. Younger adults $N = 23$, older adults $N = 40$

technology may reflect the perceived usefulness and importance of the task of remembering medications, as well as the usefulness of being able to easily edit and print the same information to a multitude of healthcare providers. This finding suggests that if PHRs provide similar benefits, older adults are likely to adopt and maintain an electronic or online PHR technology.

3.2.3 *In-context strategies*

Participants were given scenarios from the top categories of study 1 to examine how they would answer a question or address a concern (i.e., "can you tell me what you would do if you had a question about a medication?"). During this portion of the interview, participants were asked to walk the interviewer through the steps they would take and show the interviewer what they would use and how they would use it. Participants' responses were coded using a similar coding scheme as the first part of the interview, but information owner was not coded, because all questions were directed toward the participants' health information.

When faced with a current question or concern, both age groups chose similar strategies (Table 7). Consulting a healthcare provider was older adults' top strategy (24%) and younger adults' second most frequently used strategy (20%). Older adults were as likely to make or place reminders (e.g., write on a white board, make a note, or set medication next to the coffee pot to remind them to take it) (20%) as were younger adults (25%). Keeping a calendar or planner was a frequent strategy of older adults (18%), but not for younger adults (11%), which may be related to the number of appointments that older adults have in relation to younger adults. The additional appointment needs may be related to older adults' greater likelihood to have a chronic illness, but may be similar for those of other age groups that suffer from chronic illnesses. Both age groups report an increase in likelihood to use a strategy that does depend on technology (4–22% for younger adults, 17–26% for older adults) when the concern is immediate, rather than a passive information management task (general strategy). However, a majority of needs for both age groups was solved using a non-electronic strategy (55% for younger adults, 62% for older adults).

Only 13% of younger adults' concerns were searched for on the Internet, the same percentage of concerns that were answered by contacting a family member or friend (13%). The use of the Internet when facing a new or immediate issue (e.g., a new symptom or question about a medication) is low for both age groups (2% for older adults). These types of strategies were more likely used to better understand or comprehend a health concern (38% for younger adults, 33% of older adults) than general strategies. However, a large percentage of these in-context strategies are used for supporting memory limitations (54% for younger adults, 64% for older adults). Most strategies used to support memory limitations were used to support prospective memory tasks (42% for both age groups).

Table 7 In-context strategies by age group

Strategy	Age group	
	Younger adults (%)	Older adults (%)
Consulted a healthcare professional	20.6	24.2
Consulted friend/family member/other	13.2	7.1
Kept a calendar or planner	11.0	18.2
Kept a file	4.4	11.1
Made or placed reminders	25.0	20.2
Read label/instructions/book/flyer/literature	4.4	7.1
Used the Internet	13.2	2.0
Other	8.1	10.1

Percentages based on number of segments. Younger adults $N = 136$, older adults $N = 99$

In sum, there appears to be two types of health information management tasks. The first is general information keeping, where a doctor might give the patient a copy of test results and the patient files it away at home in a paper-based record. The second is what happens when the patient experiences a new problem, such as a new symptom or a new medication that one has to remember to take because it is not part of their usual routine. A health information management tool or PHR should support both of these types of tasks.

3.3 Interview part 3: what do people want?

In part 3 of the interview, participants were asked to imagine they had a "magic box" tool that would help them manage their health information. Research exploring interactive technology has illustrated that using a "magic box" without technological limitations helps participants provide richer and more creative responses [27, 28]. The purpose of using the "magic box" methodology was to get participants to focus on their needs and wants outside the boundaries of current technology capability. Participants were told that the "magic box" had no limitations and thus anything participants wanted it to do was possible. The results are grouped by the questions asked of participants in relation to the "magic box" and can be found in Table 8. All participants' comments were coded separately for each question. The percentages presented are based on the total number of codable segments uttered by participants in response to each individual question. The number of codable segments for each question is listed at the bottom of Table 8. The results of this portion are interpreted as

benefits that both age groups would need to perceive in order to adopt e-health technology.

Both age groups expressed a need for a tool that will store all their health information in one place and allow them to share this information with healthcare providers and family members. A common trend in the statements made about the e-health tool is that it would need to be interactive. Participants want a tool that will help them manage appointments, medications, bills, and statements. An e-health tool would also be perceived as useful if it could provide reminders for various health tasks (e.g., take medications) and provide a diagnosis or answer questions about a concern based on the personal health information stored within the tool. Older adults want a tool that would track their health status over time (e.g., blood pressure in the form of a chart). Both age groups were also interested in having a tool that would give general health advice (e.g., diet, nutrition, exercise) based on their personal health information.

Older adults indicated that they would prefer to have the responsibility of entering information into the "magic box," while younger adults felt that their doctor was equally responsible for maintaining their health information, when the method of entry was not considered. Although the ease of use of getting information into a "magic box" would likely influence adoption, the purpose of the question was to gauge people's perception of responsibility of their own health information. Older adults are also more willing to share their health information with their spouse or other family members than younger adults, but both expressed a need to provide easy accessibility to their records for healthcare providers. Although the ability to share information with others is perceived as an important benefit to using an e-health tool, privacy is also the biggest concern. Privacy was the bigger barrier to adoption, more so than usability. To overcome this barrier, both age groups would need assurance that their information is both secure and backed up (Table 8).

4 General discussion

These two studies examined the health information needs, current strategies, and the unmet needs of both younger and older healthcare consumers in an effort to understand why so few health consumers have adopted PHRs. Two unique methods were utilized to better understand younger and older consumer's health information needs and strategies. The first study utilized an event-based diary methodology to examine consumer's daily health information needs and the strategies they used to meet those needs. In study two, at-home interviews allowed us to get an in-context look at the strategies people use in their homes to manage their health information. The benefit of using these two methods was that it allowed participants to talk about their own unique health information needs, rather than fictitious health information that participants may not relate to well. In addition, omitting information due to forgetting was minimized by using a diary in the home, and having the interview in the context of the home.

Using the TAM framework, the focus was on examining the factors that would most likely predict adoption of PHRs: perceived ease of use and perceived usefulness. In previous studies examining other technologies such as email [20], online shopping [29], and business applications [12, 19], these two factors were most likely to impact consumer's adoption of that technology. Furthermore, for older adults, the absence of benefit or lack of perceived usefulness has been shown to be more influential than the perceived cost, which includes usability and the effort to learn a new skill. Given that older adults are much slower than younger cohorts to adopt new technology in general, understanding and conveying the usefulness of new technology is crucial for widespread adoption. An analysis of the usefulness of a new technology, in this case PHRs, requires an understanding of the needs consumers currently have, how they successfully address those needs, and the needs that are currently not met. It is not enough to provide a technology that has the same benefits as current strategies, because the additional perceived benefit will not outweigh the cost of acquiring new skills needed to use new technology. In other words, the system has to not only meet the same needs as current strategies, but also provide additional benefits. PHRs have the potential to make complicated health information more available and interpretable for the health consumer. However, what the consumer values as useful may not be the same as what the designers have in mind. This may help explain why so few Americans utilize PHRs, given their free availability to anyone on the Internet.

The findings from this study provide evidence for why PHRs are not being widely used and what consumer's ultimately need PHRs to provide in order to motivate adoption. Currently, older and younger adults are likely to keep a paper file folder with all of their health information in it, make or place reminders around the home, and keep a calendar of appointments. These are all simple, paper-based strategies that do not take a lot effort on the part of the healthcare consumer. This is important because it reflects the perceived ease of use of the system. A PHR that does the same tasks as their current strategies, but instead requires a computer, Internet access, and a new set of skills may detour healthcare consumers, especially older consumers, from adoption. The fact that older consumers in this study felt that it was their responsibility to keep track of their health information shows that they are motivated

Table 8 User needs for a health information management tool by age group

"Magic box" results by question	Age group	
	Younger adults (%)	Older adults (%)
What should it do?[a]		
Data access		
Provide access to doctor's records	2	1
Direct access to the doctor	2	1
Easily accessible by both doctor and patient	4	12
Provide access for caretakers later in life	–	4
Store information		
Keep all records in one place	36	24
Manage appointments	7	9
Manage statements and bills	4	7
Manage medication information	14	13
Store test results	–	
Decision support		
Personally diagnose or answer questions	7	7
Remind me or keep track of daily tasks	16	4
Other	7	–
How should it get into the magic box?[b]		
Input by me	33	67
Input by doctor	33	–
Other	33	–
Who should have access?[c]		
Family	19	29
Healthcare provider	42	39
Spouse	–	32
Other	24	–
How could it improve your health?[d]		
General health advice (e.g., diet, nutrition, exercise)	50	62
Help with scheduling appointments	–	8
Track health over time	–	50
Other	50	15
Concerns about using the magic box?[e]		
No backup of health information	13	7
Having the ability to use it	–	14
Privacy	63	79
Other	25	–
What could alleviate your concerns?[f]		
Assurance in the security of the system	50	60
Backup of information	20	10
Guarantee help if identity theft occurs	30	20
Other	25	–

[a] Younger adults $N = 56$, older adults $N = 67$

[b] Younger adults $N = 21$, older adults $N = 18$

[c] Younger adults $N = 28$, older adults $N = 18$

[d] Younger adults $N = 16$, older adults $N = 13$

[e] Younger adults $N = 16$, older adults $N = 14$

[f] Younger adults $N = 10$, older adults $N = 10$

enough to use some strategy, most likely the one that is perceived as easier to use if there are no additional benefits.

When older consumers have questions or concerns about their health, they choose the costly strategy of contacting a healthcare provider, unlike younger adults who are likely to turn to the Internet. However, the few older adults in this study who did turn to the Internet were successful once they reached a health-specific site. Although PHRs may require computer and Internet knowledge, the monetary cost of contacting a doctor for every question may help motivate adoption. The benefit of saving money from doctor visits may be a motivating factor toward adoption. A PHR is a health-related site, so older consumers may be successful finding answers to their concerns if the PHR

provides access to more information. For example, older consumers expressed an interest in having a system that provided diagnosis information based on their own unique health record, a system that would help them answer their questions, help in diagnosing or identifying a health risk before it becomes a problem, and preventative health information tailored to their health status and lifestyle. Essentially, they want a system that does not just store their information, but instead makes information more interpretable and usable and provides advice that they would normally need a doctor or nurse to provide.

Having this information may also help healthcare consumers play a more central role in their health. Gaining knowledge and understanding about health issues prior to a doctor's visit may help consumers prepare questions and concerns ahead of time, so that they can get the most out of their limited time with a healthcare provider. Sharing their record with their provider is something that both older and younger consumers were interested in; however, the issue of how they would share this information with healthcare providers was not examined in the study. If a PHR could help a health consumer better understand their complex health issues, treatments, and effects, it perhaps would empower the consumer to share this information with their healthcare provider through better-informed questions.

Both older and younger adults had concerns about privacy, backup of information, and identity theft. Although these are very important issues, if assurance is given to the consumer that their information is protected and backed up, that may be enough to thwart the concern. When technologies such as online banking, shopping, or email were first introduced, consumers faced the same concerns about privacy. These technologies are now widely used by consumers of all ages, which indicates that although there was a potentially high risk involved, the perceived benefit combined with assurance in the system was enough to get passed these barriers. PHR providers should look to these previous technologies as examples of what measures can be taken to provide assurance to users.

Although recommendations are provided in the next section, it is important to consider the limitations of both the diary study and the interview study. The young participants involved in this study were from a pool of undergraduate students at Clemson University and thus may not be fully representative of the general population. Socioeconomic data were not collected for participants and neither was Internet usage, both of which may influence adoption of PHRs. Computer experience and subjective health rating was collected however, and thus, for the population who are fairly regular computer users and in relatively good health, these results may be generalizable. Another limitation was that chronic illnesses were not inventoried for each participant, which should be examined in future studies.

Several methodological limitations were also present in these two studies. The diary study was only conducted for a period of 2 weeks, which may not be enough time to capture the needs of those people who are in relatively good health, who have fewer appointments, and fewer health concerns. Strategy complexity was determined by having younger adults rank order the strategies. It may be worthwhile in future research to look further into the concept of complexity and cost; time, money, and difficulty may contribute to the perception of cost, and it may be beneficial to rate the strategies using this type of taxonomy. Finally, the current study focused only on the initial adoption of PHRs; however, the obtained results suggest that compliance would improve if the PHR offered decision support, not just information management. Future research should examine how perceived usefulness and usability influence the continued use of or compliance with PHRs over time.

5 Recommendations for e-health technology

Focusing on the benefits using a PHR versus current strategies helped identify four major areas that an online PHR would need to address in order to motivate new users, both young and old, to switch from their current strategy to a PHR.

1. *Memory support* An e-health tool would benefit both older adults and younger adults if it could help support retrospective and prospective memory tasks. It should provide a history of procedures, test results, or immunizations, and other health events in a way that limits the amount of information an user must remember in order to find this information. In addition, the system should help the user remember to do health tasks, such as adding a new medication into their daily regimen so that the user does not forget.
2. *Comprehension* Both age groups are more likely to use technology if they are trying to better comprehend or understand a health concern. Study 1 indicated that older adults might be most successful when using a health site, rather than given the option to search the entire Web. An e-health tool would be advantageous for older adults if it could enable them to navigate from their record to health information without leaving the site.
3. *Interactive and automatic* An e-health tool should not just be a static repository of health information, but provide interactive and automatic information processing. The system should remind users of upcoming

appointments, when medication needs to be refilled, and when to take medications. It should process one's health information, monitor changes, provide suggestions that would improve one's health, and act as a decision aid by providing the user with a comprehensive view of their health status.

4. *Accessibility and privacy* Users should be able to easily share information with whomever they choose, while also maintaining privacy. Future work should focus on the aspects of health information that older adults are most concerned about and the factors that contribute to maintaining a feeling of assurance in the security of the system.

Tang and Lansky [30] provided a list of five optimal characteristics of a PHR: (1) lifelong and comprehensive, (2) available from any place at any time, (3) provides tools to help people understand the information contained in the record, along with recommendations for improving health, (4) private and secure, and (5) users should control access to the record. While this study provides similar recommendations, it also addressed the specific needs of older adults and identified key benefits that may help improve older healthcare consumers' adoption rates.

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