

Facilitators and Barriers to Patients' Engagements with Personal Health Records: Systematic Review

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Abstract. The purpose of this paper is to identify the facilitators and barriers to patients' engagement with Personal Health Records (PHR). We performed systematic review searching Pub Med, IEEE, and Google Scholar for studies published between January, 2001 to September, 2012. Among the 508 articles identified, 14 articles included in the result. We extracted the key study characteristics and categorized facilitators and barriers using the Technology Acceptance Model (TAM). In total, there were 10 barriers, and 6 facilitators identified. The 6 facilitators were related to both perceived usefulness and ease of use, where the barriers were mostly related to ease of use. Recruited participants were mostly older patients with chronic diseases. The result of this review indicates that patients in general recognize the value of PHR but they appear to have technical difficulties.

Keywords: Systematic review, Personal Health Records PHR, Patients' engagement, Facilitators and Barriers, PHR Design.

1 Introduction

Personal Health Records (PHR) have the potential to contribute to solving many common problems in the American health care system such as cost, fragmentation, safety, medical errors, and inequality [2],[3]. The communication capabilities that PHR provide can keep both patients and providers on track with the recommended health plan. It was identified as "the missing link needed to bridge the patient-provider health information gap"[4].

With PHR, patients will have the tools to be involved in their healthcare and be more responsible and conscious about their health condition [1]. They will have the freedom to seek or choose between health providers. They will also be able to continually monitor their health condition more closely as well as understand their medical history, current situation, and progress. PHR can assist in creating a more complete and balanced view of patient's status by giving patients the opportunity to enter or edit information like demographic data, medical history and other health data.

1.1 Users Engagement

Patient engagement is more than simply using a system. It is a process of active participation where users invest time and attention. Successful engagement strategy

needs to consider people, process and technology [5]. Aligning technology and process with users' preference and need will increase the chance of users' engagement [5]. The National e-Health Collaborative created a framework for patients' engagement. The framework consists of five major stages that can be used as a roadmap to assist healthcare organizations in their patient engagement process [23].

The framework specified the technology and process needed to inform and engage patients. But it is the developers' job to translate the framework into design. The designer's understanding of users' psychology and the interpretation of this understanding into the system development will determine the acceptance of the system.

1.2 Users' Centered Design

Many PHR models have been released and tested, but very few achieved the desired outcome. In many cases the technology of these systems is advanced and the required functionalities are available. However, the adoption rate is still below the expectation. User centered design is frequently discussed in healthcare information systems but rarely applied when it comes to patients [6]. Many PHR studies evaluated the system by incorporating designers', physicians' and health professionals' feedback where in many cases patient perspectives were neglected or underestimated [6]. Understanding the end users is a critical part for a system's usability where every patient's need should be addressed.

Where many of the previous studies discussed the barriers to PHR adoption, very few studies have evaluated the situation by incorporating both positive and negative factors [7]. Investigating both positive and negative factors will help us generate a more holistic view and understanding of the underlying causes. In this paper we will conduct a systematic literature review to identify the factors associated with PHR adoption. We will focus on how PHR is perceived by patients, and we will summarize and draw an overall view of the facilitators and barriers to PHR adoption in the previous studies.

2 Method

The searched databases utilized in this study were IEEE, PubMed, and Google Scholar. The search was conducted using combinations of "PHR" and "Perception" synonyms (Table 1). The search was limited to English language articles published from January, 2001 to December, 2012. Initially, the number of articles generated was 150, 262, and 150 from Google Scholar, Pubmed, and IEEE respectively. The total number of results retrieved by our keyword combination from PubMed was included in our primary result. Both Google Scholar and IEEE started to show irrelevant results by the 90s and 80s, and we included the first 150 to increase the sensitivity of our result. Then all the results were imported into an Excel spreadsheet and filtered to remove duplicated articles.

Table 1. Search keywords

Personal health record PHR synonyms	Attitude synonyms
Patient health records PHR	Behavior
Electronic patient record EPR	Acceptance
Personal Health Information Management System	Perceptions
Web-based patient-centered personal health record	Satisfaction
Computer-based Patient Record	

Two reviewers reviewed the title and abstract of the remaining 508 articles independently. In this step the inclusion/exclusion criteria applied were as follows:

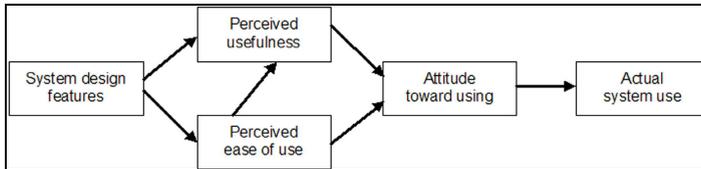
- The included article has to be an original study, not a review.
- The included study has to use PHR as defined by Healthcare Information and Management Systems Society (HIMSS). HIMSS defined PHR as “a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and ehealth tools. The ePHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations” [8].
- Studies have to discuss users’ attitudes, behaviors, acceptance or satisfaction. Studies that focus on PHR design, technology or functionalities were excluded.
- Users have to be patients. Studies that recruited physicians, designers, or medical students as primary sources of data were excluded. The recruited patients also have to be system users. Prospective users or readiness assessment studies were excluded.
- Studies have to include quantitative data.

After merging the results from each reviewer, 40 articles remained. The full texts of the remaining articles were reviewed comprehensively. During the review, 17 of the 40 articles were excluded due to one of the following reasons: full text was not in English, the study did not require participants to use the system, the study was system design focused, or the study focused on physicians and nurses.

For the remaining 23 articles, we applied 14 questions we developed for quality ranking. The list included questions about recruited participants, the system applied, and study design. The questions were yes or no questions where every question answered yes was weighted as one point. Then we set a cutoff point with 10 of 14 for quality ranking. Articles with 10 points or below were excluded from the study for not meeting the quality requirements. At this step, 9 articles were excluded and 14 articles remained.

The remaining 14 articles were summarized and key information extracted (Table 2). We also extracted the facilitators and barriers used in these studies and grouped them into similar categories (Table 3).

Facilitators and barriers were categorized using the Technology Acceptance Model (TAM). This model was used to analyze users' attitudes toward information systems for the purpose of predicting their use. In this model, the influencing factors are grouped into two main categories, "perceived ease of use" and "perceived usefulness"(Figure 1).



Source: Davis, et, al, (1989).

Fig. 1. Technology Acceptance Model (TAM)

3 Results and Discussion

The identified study characteristic of the 14 articles was participant related information (age, socioeconomic status, level of computer literacy, health condition), study related information (study design, system description, tethered capability), facilitators, barriers and outcome (Table 2).

One of the most relevant characteristics was the chronological condition of the diseases that participants had. Seven studies reported the condition as chronic, with two specified as diabetes and two cardiovascular diseases [9], [10], [15], [18]. Another frequent disease was HIV, with frequency of two [21], [22]. The majority of the recruited participants in most of the 14 studies included were elderly. As most participants were patients with chronic diseases, one explanation might be the association between chronic diseases and age. This could also be attributed to the clinical significance of PHR in managing chronic diseases that proportionally increase with age.

Other important characteristics were socioeconomic status and the level of computer literacy, which seem correlated. The level of computer literacy was reported in 9 of the 11 studies. The participants' socioeconomic status was reported in 10 of the 14 studies, 5 of which reported this level as low [9], [11], [12], [14], [22]. All 5 studies that reported low socioeconomic status also reported a low level of computer literacy [9], [11], [12], [14], [22]. Only 5 of the PHR systems used in the 14 studies were tethered [13], [15], [17], [20], [21]. In general, the systems supported most of the basic PHR functions such as entering, viewing, managing, and tracking health related information.

Table 2. Study Summary

Reference	Title	Participants age	Computer literacy	Socio-economic status
Kim 2010 [9]	Digital Divide: Use of Electronic Personal Health Record by Different Population Groups	site 1: mean of 66; site 2: mean of 47; site 3: mean of 25	low in old patients at site 1 and 2 and higher in site 3.	site 1) low-income, (site 2) no data, (site 3) college students
De Crenq 2006 [10]	A consumer health record for supporting the patient-centered management of chronic diseases.	N/A	daily PC users. More computer literate than average	N/A
Lieber 2006 [11]	Barriers to the use of a personal health record by an elderly population.	49 to 92; mean 69	low	low-income
Kim 2009 [12]	Challenges to using an electronic personal health record by a low-income elderly population.	mean 63	low	low-income
Nazi 2010 [13]	Veterans' voices: use of the American Customer Satisfaction Index (ACSI) Survey to identify My Health Ve personal health record users' characteristics, needs, and preferences	>51	medium to high	N/A
Kim 2005 [14]	Evaluation of Patient Centered Electronic Health Record to Overcome Digital Divide	mean 65	low	low-income
Hess 2007 [15]	Exploring Challenges and Potential of Personal Health Records in Diabetes Self-Management: Implementation and Initial Assessment	mean 55	N/A	majority have at least some college
Weitzman 2010 [16]	Sharing Medical Data for Health Research: The Early Personal Health Record Experience	groups mean 45 & 71.	N/A	high levels of education and moderately high levels of income
Yaman 2011 [17]	The Digital Divide in Adoption and Use of a Personal Health Record	>18	N/A	varied widely
Kearl 2011 [18]	Factors affecting home-care patients' acceptance of a web-based interactive self-management technology	mean 62	varied	varied widely
Duono 2001 [19]	Will Patients Use Electronic Personal Health Records? Responses from a Real Life Experience	35 to 85	N/A	N/A
Tom 2012 [20]	Integrated Personal Health Record Use: Association With Patient-Reported Care Experiences	mean 46	N/A	at least college degree
Hilton 2012 [21]	A Cross-Sectional Study of Barriers to Personal Health Record Use among Patients Attending a Safety-Net Clinic	mean 46	Medium 29%, high 51%	N/A
Truque 2012 [22]	Barriers to the Digital Divide in HIV Care: A Pilot Study of an IPed Personal Health Record	mean 48	low	mostly low educational level, and low income

Table 2. (continued)

Health condition/disease	Study Design	PHR description	Reduced	Barriers
Site 1 mostly chronic; Site 2 Cardiovascular; Site 3 mostly Diabetes	survey and usage activities survey and usage activities	collect and manage health information as well as enhancing communication web-based system to enter, view and edit the information.	No No	1- low computer literacy; 1- patients didn't fill some of the information where they didn't see the advantage of doing so.
Chronic diseases	patients observation and monitoring usage activities	organize self-reported patient histories and facilitate referral management.	No	1- Computer literacy; 2- computer anxiety; 3- cognitive barriers that limited their ability to use the computer; 4- difficulty in memorizing password; user name or the PHRS URL; 5-Health literacy (i.e. disease and diagnosis, medications, terminology); 6- Physical limitations of the upper extremities and 7- other conditions like: hearing and vision 1- digital divide includes a technical divide based on the availability of ICT infrastructure, hardware and software; 2- social divide resulting from the skills required to manipulate and utilize technical resources; 3- fear over computers and the Internet; 4- health information understanding related barriers; 4- limited physical/cognitive abilities.
Chronic diseases	survey and usage activities	enter and manage health information	No	1- One time in Person Authentication (IPV) at local VA facility required to access all features; 2- Many users not familiar with health information process; 3- not have internet access; Computer literacy a problem; 4- Not everyone who had internet access had the skills to use it; 5- Not everyone who had the time to complete the PH has access to everything; 6- Not everyone who used the system was invited to participate in feedback; 7- Navigation was difficult; 8- Medication information not available to users
N/A	survey	complete traditional services and improve managed care	Yes	1- Residents need access to internet to use Personal Health Information Management System (PHIMS)
N/A	survey and monitored activities	store and retrieve demographic and clinical data	No	
Diabetes	focus groups and monitoring communication activities	centralized information about diabetes management, report BS readings, appointment reminders	Yes	1- Last or unknown user names and passwords; 2- Patients unaware of the features of UPVC Health Track such as glucose tracking; 3- Conclusion noted that "simply placing resources within an environment is inadequate to stimulate patient use"
N/A	text surveys; structured protocol from PHR usability testers; focus groups	login view their information	No	1- only contains views of a regionally sampled, nonrepresentative set of subjects and a specific form of health record
Disease varies	monitored usage	access medications lists, lab results, appointment information and communicate with providers	Yes	1- Racial/ethnicity patients adopted a PHR less frequently than whites 2- "Fringing with chronic disease is associated with decreases in Internet access rate by 50%"; 3- Patients had to register for PHR on website and retrieve their account online
Cardiovascular disease	survey, phone interviews	N/A	No	N/A
Spine disorders	survey	N/A	No	N/A
Chronic diseases	survey	record viewing, secure messages, medication management, lab appointment management	yes	1- no time; 2- forgot login password; 3- access; 4- did not know about it; 5- did not have computer device; 6- difficult to use.
HIV	survey	populate selected data from EHR	yes	N/A
HIV	self-rated questionnaire	IPad device with PHR application allow store and retrieve medication and allow reminders for appointments and medication.	no	not specified

Table 2. (continued)

Facilitators	Outcome
<p>1- assistance were available</p> <p>1- system was updated with layout that could differentiate between fields or parts that required by patients or physicians (on users requested). 2- The screens were designed on the basis of existing forms that were regularly discussed with the patients.</p> <p>1- PowerPoint slides to explain the system. 2- Displaying posters and flyers to promote participation. 3- Assistance made available.</p>	<p>The study find that younger individuals used the PHR system without any difficulty compare to elderly participants.</p> <p>The development of such patient-centred health records is crucial for improving the patient's self-awareness regarding managing chronic diseases.</p> <p>Elderly and disabled residents of the EHA were able to create and maintain a PHR when assistance were available.</p>
<p>1- Informational sessions to explain what the PHIMS was and to demonstrate how to use it.</p> <p>1- The ability to delegate access to all or selected parts of the PHR. 2- New features are released often</p> <p>3- Secure messaging available for some users. 4- Site redesign was planned for 2009 to make navigation easier</p> <p>5- Program will continue to focus on meeting the needs of users by ensuring compatibility with dial-up access</p> <p>6- Ability to view and manage appointments was added. 7- Local education and training initiatives have been deployed at many VA facilities to address the need for computer literacy.</p> <p>1- Public computers. 2- Internet access. 3- Graduate Nursing students available to assist participant. 3- support printing and saving on CD, USB drive 4- system response timings were modified.</p> <p>1- Links to information about diabetes. 2- Communication with office practice.</p>	<p>The majority of the low-income elderly would not be in a position to benefit from PHR.</p> <p>Identified priority areas for improvement and provides important information about users' characteristics, preferences, and needs</p> <p>the system positively influenced their ability to manage health records and created more awareness about their health</p> <p>PHR has potential to improve chronic disease management and to link pt to physician office</p>
<p>1- health demonstration</p> <p>N/A</p> <p>1- free computers. 2- training from visiting nurses.</p> <p>1- Made free and available to all patients in practice.</p> <p>N/A</p>	<p>clear advantages to exploring use of PCHRs as a vehicle for collecting health information germane to public health research</p> <p>patients with chronic diseases were 25% more likely to adopt PHR than those without.</p> <p>Racial digital divide exists</p> <p>Perceived usefulness, perceived ease of use, subjective norms and healthcare knowledge predict most of the variance in patients' acceptance and use of the system</p> <p>30% of patients with spinal conditions will express interest in obtaining EPHRs</p> <p>Parents were willing to use PHR for their children.</p>
<p>1- training</p> <p>1- Participants provided with iPod devices. 2- two PHR apps were piloted to chose the easiest one. 3- one to one training sessions. 4- disease management classes.</p>	<p>Mental health condition and substance abuse were not barriers to patients use of PHR</p> <p>PHR was generally accepted by users.</p>

3.1 Facilitators and Barriers

The main purpose of this review is to better understand patients’ attitudes toward PHR as well as investigating the facilitators and barriers applied in previous studies. This review did not directly include PHR design studies, but it includes deeper understanding of user characteristics and preferences. Users’ understanding is the first step for designing a user centered system. Studies indicated that most of the available PHR did not incorporate users’ perspectives [6]. Vendors’, physicians’, and designers’ input is definitely important, but they have different levels of computer skills and health understanding than patients [6].

In this study, we identified the variables that may influence patients’ acceptance of PHR. The identified barriers and facilitators along with the frequency of each were presented in Table 3. The conceptual framework TAM was used to synthesize the facilitators’ and barriers’ findings. This model infers that user acceptance of technology can be predicted by the perceived usefulness and ease of use. In total there were 10 barriers and 6 facilitators identified. By categorizing the facilitators and barriers into perceived usefulness and ease of use, we found that 10 barriers and 4 facilitators were related to ease of use, and 1 barrier and 4 facilitators were related to the perceived usefulness (Table 3).

Table 3. Barriers and facilitators categories

Barriers	Frequency	Perceived usefulness	Perceived ease of use
Physical limitation (like upper extremities impairment)	2		x
Health Condition (vision, hearing,)	2		x
Not Knowing about the system or some of the system features	5	x	x
Access (username, password, URL, account registration, and activation)	5		x
Computer literacy	4		x
Social Divide	2		x
Digital divide	4		x
Computer anxiety	2		x
Cognitive barriers	1		x
Health literacy	2		x
Facilitators	Frequency	Perceived usefulness	Perceived ease of use
Promotional adds	2	x	
System modification to user preference	3	x	x
Training and education	6	x	x
Staff assistance	4		x
Communication features	2	x	
Providing free devices	1		x

The most frequent barriers were; not knowing about the system (5) and access related barriers (5). Not knowing about the system included issues such as participants’

unawareness of some of the available system functions or the inability to utilize them. Other frequent barriers were digital divide and computer literacy (4). Conversely, the most frequent facilitators were training sessions (6), staff assistance availability (4), and modifying system to user preference/need (3).

In our finding, only 4 of the 14 studies included system modification or selection to user preference. Three of them were modifying the system and adding features based on patient input, and one piloted two applications for patients to choose from. The first three studies were mainly concerned with providing patients with the features and functionalities they need whereas the last one was to find the easiest interface [10], [13], [14], [22].

As shown in Table 3, all barriers (except system feature awareness) were related to the perceived ease of use. Most of the barriers found were technical factors, such as difficulties in using the computer, certain applications, or Internet and unfamiliarity with computers or the technology in general. Generally, computer skill-related factors seem to be more common with elderly users. Younger or more educated groups tend to be more computer savvy than older or less educated users. Since the PHR use is mostly recommended for chronic disease management, those user groups are more likely to be older.

4 Conclusion

The purpose of this review was to better understand facilitators and barriers to PHR adoption. The result showed that patients in most studies are experiencing technical difficulties with PHR. However, no significant barriers were identified in their level of awareness of the system value and importance. They appear to be willing to accept and use PHR when they can.

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