

Evaluating the Usefulness and Usability of Collaborative Personal Health Record Systems

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ABSTRACT

Personal health record systems (PHR) have great potential to improve both health documentation and patient care. The introduction and adoption of these systems, however, have been relatively slow. In this work, through usability evaluations and clinician interviews, we evaluated the usability of, usefulness of, and the ability to communicate and share information through PHR. We describe the results of our evaluation, which demonstrate how a combination of usability, functionality, and socio-cultural influences are impeding PHR adoption and use.

Author Keywords

Personal health records, collaborative health technologies.

INTRODUCTION

Personal health records (PHR) are systems maintained by patients and their families to track health-related information. They offer one solution for ensuring accurate, updated, and comprehensive health records even in health care systems that lack a comprehensive interoperable standard for data storage and exchange. In many countries, it can be tedious for patients to obtain copies of their official health records from providers, making it extremely difficult for patients to seek second opinions, change providers, and so on. Furthermore, records that patients create themselves tend not to be included in the official patient record. Thus, a patient's view of his or her records—and potentially even health status—may be substantially different from that of the providers.

PHR can be desktop-based, Internet-based, or mobile (*e.g.*, phone-based or located entirely on portable storage). They can be linked to provider-owned Electronic Medical Record (EMR) systems or stand-alone. These records are created and monitored by the patients themselves, typically without the substantial restrictions and limitations of paper-based, centrally located medical records. If properly maintained, these systems can support patient-provider communication. In the United States, only 7 million adult patients make use of PHR [8]. The enormous potential of these electronic records systems when coupled with their limited adoption have left many pondering the disconnect [1].

Specifically, we set out to understand the particular challenges limiting the adoption and use of PHR through a systematic evaluation of three Internet-based PHR systems.

We conducted both in-lab usability evaluations and interviews with medical professionals and patients. This work begins to explain the limited adoption of these systems.

RELATED WORK

Past research on PHR has typically focused on the features and potential health outcomes of using such systems [10]. Krohn suggests that there are four different types of PHR models: stand-alone, health plan patient portals, EMR patient portals, and consumer-centric PHR [4], although most research in the area either describes PHR together as one general set of systems or focuses on the use of only one specific system. Some research projects have focused on PHR adoption and use, including one survey in which 50% of the people older than 65 reported that they would prefer a paper PHR over an online version, while only 20% of those under 65 said they would prefer a paper PHR [9]. Some studies have also proactively focused on the potential challenges and appropriate models for PHR [12, 4, 5]. To date, there have been limited evaluations conducted of specific applications of PHR technology [6, 2, 11].

Across this body of research, some indicators about the general challenges of PHR adoption emerge. Limitations of the technology itself may hinder both patients and clinicians from fully reaching the goals they set out for use of these systems. Limited standards exist, creating a systemic problem of interoperability. Finally, PHR add an additional challenge to those of records systems focused on use in clinics: they put patients and caregivers “in charge” of the creation and maintenance of electronic data that then may not be medically relevant nor acceptable to professionals. It is this collaborative engagement with health records that we specifically set out to explore in this work.

METHODS

To understand the challenges to adoption and use of PHR, we evaluated three PHR systems: Microsoft HealthVault¹, Google Health², and WorldMedCard, now known as WorldHealthRecord³. These were chosen from dozens based on the following criteria: available to the public (not

¹ <http://www.healthvault.com>

² <http://google.com/health>

³ <http://www.worldhealthrecord.com>

just patients of a particular healthcare system), Internet-based, and a mix of familiar and less known corporations.

We conducted a counter-balanced within subjects usability evaluation of the three PHR systems with 18 patients (18 to 55 years old) with a range of technical and medical experience and no previous PHR experience. Patient end-users were presented with specific tasks to be performed on each site using standardized reference patient data. These tasks were designed to mimic everyday activities in which end-users might engage. Following the tasks, we conducted a short interview asking the users about the challenges they found and their feelings about PHR. On average, it took approximately one hour for an end-user to complete the entire task list and the short interview.

We conducted semi-structured interviews with five clinicians about these three services and their views of PHR generally. Prior to interviews, clinicians were given access to the PHR services and a list of specific tasks patients did in our usability evaluation. The interviews lasted an average of thirty minutes and were audio-recorded and transcribed.

We documented and grouped issues from both evaluations using affinity analysis to uncover relevant themes.

RESULTS

Our results suggest that substantial usability challenges and the complexity of PHR systems can lead end users to believe they “*may not actually save time*” [EU14⁴] or that they would only be useful if a patient has a “*serious health condition*” [EU16]. Furthermore, both patients and clinicians describe apprehension about the potential for patient-created mistakes in the medical data resulting from the power and the complexity of these systems combined. This apprehension can lead some to support the idea of “*read-only*” PHR, which patients and their caregivers could use for “*double-checking*” of medical data [EU4] but not editing. Even physicians in favor of patient-managed data in our study were worried about the balance of burden and benefit. For example:

“...most of that information is really pretty easy to get on a first visit if they're...conscious. ...the only advantage would be if a patient kept it up to date... But [the PHR systems shown] almost seemed too simplistic...” [MP1]

A variety of challenges have hindered PHR adoption and acceptance. To realize the full potential of PHR systems, we must first understand and address these hurdles. In this section, we describe the themes that emerged in our evaluations that indicate challenges to PHR use.

Advanced Computational Functionality

Balancing an appropriate amount of functionality with simplicity of use can be a challenge for any interactive collaboration system but particularly arises in systems like

PHR that have highly varied users (*e.g.*, patients and clinicians). The three systems evaluated in this work all had similar core functionality of maintaining patient health data but each had a variety of features unique only to them: Microsoft HealthVault provided users with the ability to electronically “share,” which allowed them to give access to their PHR to certain people. Google Health also offered a function to search for a local physician within a specific medical field. WorldMedCard allowed users to input insurance information as part of their PHR.

Despite the large feature lists across all three systems, both clinicians and end-users often suggested additional features during interviews. For example, a primary care physician requested graphing and medical decision support:

“The [designers of PHR] that are creating these need to figure out...[how] to interpret the data electronically...say a potassium level... means the same thing to everybody, and so once you have all of this data, and you can actually graph it over time.” [MP1]

On the other hand, extensive functionality and information were also recognized as potential problems. For example, the potential for inclusion of billing or insurance information alongside patient-entered dietary and exercise information and the potential for physician-entered clinical data was confusing to many patients.

Collaboration, Communication, and Integration

A common basis for communication is important in any collaborative system. For PHR however, many end-users described specific information that could be confusing for users without medical training (*e.g.*, specific descriptions of diseases). End-users noted the advanced language and “*medical jargon*” [EU8]. These results are in keeping with other work that demonstrates the challenges that low health literacy can impart on patients [3]. Thus, our results suggest that specific medical jargon, particularly in applications like PHR that are geared toward the general population—who typically are not fluent in medical terminology—should be kept as basic as possible.

Keeping track of system status—including technological changes, records status, and messaging interfaces—can be a huge challenge in multi-user, data-intensive healthcare technologies. System status of some kind was present in all three PHR systems evaluated, but the particular implementations were not consistent across systems (*e.g.*, a primary status interface or individual status messages on each page). The minimal system status present failed to communicate when a change occurred. An added challenge to PHR systems over other web-based services involves tracking the status of records. The primary concern for both end-users and clinicians were the availability of lab results and tracking the status of various medical procedures.

All of the patient end-users in the usability evaluation welcomed the idea of sharing data with clinicians and many with other individuals as well. For example, one end-user emphasized how she liked the sharing function by saying,

⁴ EU denotes *end-users* (patients and their caregivers); MP denotes *medical personnel*.

“Sharing’s easy, plus you can specify how much they see or edit” [EU3]. Some patients wanted to share their data electronically and others by being able to print a comprehensive record to paper from the PHR system, but all wanted the ability to share. They were concerned, however, about the level of detail in the medical records. In part, these reactions may have originated with the limited model data we inputted for the scenarios used.

Aside from end-users, the idea of data transferring also appealed to many clinicians, where all of them mentioned that some type of information would be helpful to a point. Collaboration would also be a key component that many clinicians believed would be helpful in looking through patient records. For example, one clinician mentioned, *“to [be able to] glance by some ... visual coding where you can see exactly where the information comes from”* [MP1].

Consideration of communication and collaboration was not just limited to the idea of transferring data. Rather, the majority of clinicians—and many of the end users as well—requested that PHR records be integrated with official clinical records. Although one clinician described PHR as *“a virtual suitcase...of a patient’s own information that he or she [can] release or choose not to release”* [MP2] and therefore would not have a need to be integrated, most clinicians interviewed were more interested in discussing the concept of full integration of PHR with electronic medical records (EMR) than patient-originated sharing of data. With this model, medical records can:

“be written by the people who provided the care and who have the training and the knowledge of how to document medical problems. But then the patient [can point out errors]. So there’s accountability on both parts.” [MP4]

Privacy, Security, and Trust

Privacy and security in web-based collaborative applications are always concerns. These concerns can be more profound in the case of patient health information. Individual end-users incorporated feelings of trust and security from known corporations into their assessment of the trustworthiness of the PHR. Heavy users of other services by the same company tended to be concerned that the company *“already knows a lot about me, so putting my health information is somewhat of a concern”* [EU13]. Furthermore, security for the PHR integrated into other services (e.g., through Microsoft Passport) was not as trusted of a solution as more localized mechanisms. At the same time, users commented that unknown companies were not as trustworthy, *“I may have a bias against companies I don’t know—it is your health record”* [EU3].

None of the end-users noted the security indicators present in their web browsers, echoing former work focused on the use of these indicators for web sites generally [7]. They did note the security differences they perceived to be inherent to a web-based application as compared to a downloadable application that runs on a specific computer, typically indicating that the latter is more secure.

“If it was a downloadable program, I’d use it, because I don’t feel comfortable putting my information on a website” [EU4].

Finally, the cost of the service impacted the perceptions of security and privacy for many users, who often believed that a company not charging for a service (as none of these did) would be unlikely to secure the data properly. Generally, clinicians were less concerned than patients about the security of online health records. When they did describe concerns, they often equated them to those inherent to any medical record. For example, the director of an emergency department commented:

“There’s always a question about who’s going to be the custodian of the record, but really, if they had come from another hospital ... I would attach my hospital’s number to [the paper record] ...and actually submit this as part of our records, so, if it were ever an issue, you know, with a court or something, I acted on the best information I had at that time and here’s the information I have.” [MP2]

Accurate Data in Collaborative Health Systems

Clinicians consistently touted responsibility for the health of the patient as the most important factor in their feelings about PHR. Likewise, patients described their feelings about PHR as fundamentally linked to its ability to generate positive health outcomes. This shared purpose provided a basis for many participants to trust each party to act appropriately to keep accurate records. Thus, most clinicians generally reported not being concerned about patients deliberately altering their records, noting *“most patients just want to be cured”* [MP2]. The minority reported concern about the responsibility for the patient, commenting, *“If I take over, then that’s [for] the care of the patient...all of the responsibility of [their] well-being”* [MP5]. Some, in particular nurses and medical students as opposed to more senior physicians, described still wanting to question patients for greater depth and nuance because, *“We can look at their chart and...say, ‘So is this so?’ or you know, ‘Tell me about this.’”* [MP4]

PHR information provided to clinicians can be seen as a burden, in particular when patients deliver a large quantity of unprocessed data that must be analyzed and verified to ensure that its introduction does not increase the risk for medical errors. One family medicine clinician commented, *“20 pages... it takes a long time to go through it all and make sure that’s what they really mean.”* [MP1]

Along with the obligation to sort and understand this information, clinicians must determine which parts of the information a patient has given them is actually reliable. For example, a pediatrician noted that, *“...sometimes you give them a list of medications, even when I see them, they have no idea what medications they’re on.”* [MP3]

Both patients and clinicians described the accuracy of patient data in the PHR as fundamental to their ability to

adhere to recommendations (patients) and to prescribe those interventions in the first place (clinicians).

DESIGN RECOMMENDATIONS

The results of our evaluations uncovered a variety of usability hurdles and socio-technical challenges across all three PHR systems we evaluated. PHR developers should be mindful to provide customization, summarization, and analysis of the massive amounts of PHR data. Because there is just too much information in a health record for a clinician to glance over quickly, simple analysis and summarization would save clinicians an immense amount of time, making them more likely to use PHR generated data and communicate and collaborate more openly with their patients. PHR systems must appropriately secure records and provide appropriate access controls to ensure user privacy. Thus, both traditional security and privacy mechanisms must be used alongside new methods for tracking and displaying data provenance. Such an example would be allowing the user to choose if a password is needed to obtain access to certain information. PHR can also provide additional services over those of traditional paper records by utilizing advanced computational features, such as Google's conflicting medication checking.

An open challenge for PHR systems is designing them to suit the needs of a wide variety of potential users. Medical terminology may be difficult for patients to understand but significant and relevant to clinicians. PHR systems will need to provide educational or translational information for patients, caregivers, and clinicians to balance these concerns.

CONCLUSIONS AND FUTURE WORK

PHR have enormous potential for empowering patients, increasing patient-provider communication, and tracking and monitoring health and wellness over time. Furthermore, regular use of PHR can be beneficial in critical care situations, such as a trip to Emergency care, providing up-to-date information for a patient who may not normally be seen at the hospital. Like any CSCW system, before successful adoption can occur, however, the substantial challenges to usability and usefulness present in these systems must be addressed. Our results indicate that the lack of adoption by substantial numbers of patients and clinicians is in part due to these challenges in the usability of the systems but also in misunderstandings of the context of use by systems designers. Our results further reinforce the need for integrating traditional and more recently developed methods from the HCI literature into medical informatics, in particular in light of designing online systems for the general user population, such as PHR.

Our empirical evidence and subsequent analysis demonstrate how PHR systems are and are not being taken up by the general patient and clinician populations as well as the current challenges and potential opportunities for adoption and widespread use of these collaborative systems. There continues to be substantial need for addressing

patient-provider communication, collaboration, and information sharing to better patients' health.

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REFERENCES

1. Berner, E., Detmer D., Simborg D. Will the Wave Finally Break? A Brief View of the Adoption of Electronic Medical Records in the United States. *JAMIA*, 3-7. 2005.
2. Brennan, P., Downs, S., Casper, G., Kenron, D. Project HealthDesign: Stimulating the Next Generation of Personal Health Records. In *Proc. AMIA '07*, 70-74.
3. Jensen C., Potts C., Jensen C. Privacy Practices of Internet Users: Self-Reports Versus Observed Behavior. *International Journal of Human-Computer Studies*, 203-227. 2005.
4. Kim, E., Wang, M., Lau, C., Kim, Y. Application and Evaluation of Personal Health Information Management System. In *Proc. IEMBS'04*, 3159-3162.
5. Krohn R. The Consumer-Centric Personal Health Record – It's Time. *Journal of Healthcare Information Management*, 20-23. 2007.
6. Lee, M., Delaney, C., Moorhead, S. Building a Personal Health Record from a Nursing Perspective. *IJMI*, 308-316. 2007.
7. Morris, M., Intille, S., Beaudin, J. Embedded Assessment: Overcoming Barriers to Early Detection with Pervasive Computing. In *Proc. Pervasive '05*, 333-334.
8. Personal Health Records: Lots of Interest, but Few Users. http://www.readwriteweb.com/archives/personal_health_records_lots_of_interest_no_users.php.
9. Smolij, K., Dun, K. Patient Health Information Management: Searching for the Right Model. *Perspectives in Health Information Management*, 1-11. 2006.
10. Tang, P., Ash, J., Bates, D., Overhage, M., Sands, D. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. *JAMIA*, 121-126. 2005.
11. Williams, M., Parker, R., Baker, D., Parikh, N., Pitkin, K., Coates, W., Nurss, J. Inadequate Functional Health Literacy Among Patients at Two Public Hospitals. *JAMA*, 1677-1682. 1995.
12. Win, K., Susilo, W., Mu, Y. Personal Health Record Systems and Their Security Protection. *Journal of Medical Systems*, 309-315. 2006.