Usage Patterns of a Personal Health Record by Elderly and Disabled Users

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Abstract

Personal Health Records (PHRs) are increasingly recognized as a strategy to improve patient-provider communication, availability of health information, and quality of care, by making the delivery of care more patient-centered. However, not much is known about the effects of self-managing personal health information (PeHI), patients’ perception of PeHI and patient workflow around PeHI management. We studied PHR use in a low-income, elderly and/or disabled population for 18 months, and describe how the PHR was used through an analysis of database access server log data. Some patients may not keep their PHR up-to-date because they don’t value, can’t access, or don’t understand certain categories of their health information. Understanding of usage patterns can guide the development and maintenance of more usable and pragmatic PHR systems.

Introduction

Lack of access to personal health information (PeHI) has highlighted a need to consolidate patient information in one place so that it can be more easily available to both the patient and their providers. Personal Health Records (PHR) are a promising tool aimed at helping individuals collect, manage and use their PeHI to improve their health and the quality of care they receive. The Markle Foundation defines a PHR, as “an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it”. Not much is known about utilization of PHRs, barriers to their use, user satisfaction, or perception of health information.

Personal Health Information Management System (PHIMS) is a PHR that was developed, implemented and deployed at a federally-funded housing authority near Seattle, WA. The system is used by low-income, elderly and disabled residents. We have studied the utility of PHIMS, user satisfaction associated with it, and barriers to its use. These were the first steps toward improving the PHR and its adoption. However, it is also important to characterize, in detail, the patterns of use. These data may reflect the importance to users of specific categories of PeHI, sequences with which information is accessed, specific features of the system that are (or are not) used, and may highlight difficulties that users may experience while managing personal health data. PHIMS usage data presented here represents the use patterns we observed in the first 18 months of a patient-centered personal health information system implementation.

Methods

PHIMS is a web-based repository of patient health information. The system architecture is described in detail elsewhere. It is a patient-centered application that provides an interface for storing and retrieving structured and categorized personal health information. Each category of information contains additional elements as described below (Figure 1).

- **General information (demographics):** name, address, gender, phone #s (home, work and cell), background information*.
- **Contacts:** name, phone #, relationship*.
- **Insurance:** type, name, subscriber id #, subscriber name, group #, address, phone #, fax #, additional information*.
- **Health care providers:** name, address, specialty, reason for seeing a provider*.
- **Family health survey:** checkbox list of most common conditions.
- **Health problems:** problem name, diagnosis date, treatments received, questions ask to provider*.
- **Lab tests:** name, date, place, result*.
- **Immunizations:** dropdown list of immunization options.
- **Medications:** name, dosage, date started, date stopped, prescribing doctor, reason for taking*, effectiveness*, reason for stopping medication*.
- **Surgeries:** name, date, additional information*.

Figure 1. PeHI categories and their elements (elements with * denotes free-text fields).

Study Setting and Participant Recruitment

The PHIMS study is approved by the University of Washington Institutional Review Board (IRB) under the application no. 04-2634-C01.

Virtually all of the 170 residents at the study site where PHIMS has been deployed are elderly or
disabled, and receive medical care from a variety of physicians and specialists. Their health information is scattered across different providers and clinics. This vulnerable population has fixed or limited incomes, high incidence of multiple chronic illnesses, and may be socially isolated\(^5\). A centralized personal health information management system could help improve the care process for these individuals.

Study enrollment has been open to all adult residents since December 2004. Access to the Internet is required to use PHIMS. At the start of the study, approximately 80% of residents did not have a computer or Internet access in their apartment. Consequently, a computer room equipped with 6 PCs with broadband Internet connections and a printer was set up at the apartment complex for PHIMS use. Since January 2005, graduate nursing students have been available for three hours on most Thursdays to provide help and support for residents using PHIMS. They help residents use the PHIMS application to enter and manage personal health information.

Before and after deployment, the investigators held informational meetings, demonstrations and Q&A sessions to teach residents about PHIMS. Sessions included instructions on how residents could use PHIMS to effectively utilize their time during interactions with healthcare providers, thereby improving the quality of healthcare they receive.

All PHIMS users accepted the terms of the online consent form that clearly stated the purpose and benefits of the study, procedures, risks and other information. Members of the project staff signed confidentiality agreements.

**Data Collection**

This paper reports on PHIMS database access and usage log data, collected from December 2004 through May 2006. These usage data span the time from initial deployment until new system features were introduced in May 2006. Database access and system log data events were triggered by client requests and include log-in and log-out events, health information update events, and preference update events (e.g., password changes).

**Results and Analysis**

**Registration, Responses and Demographics**

Most PHIMS users were over 40 years of age, and more than half were over 60 years of age. The average age was 66.2±14.2 years, which is not significantly different (unpaired two-tailed t-test; \(p=0.63\)) from the overall resident population (67.5±16.3 years).

User registrations spanned the length of the study period. In December 2004, the first month of deployment, five residents started to use the PHIMS system. By April 2005, with assistance and support from the student nurses, participation increased to 28. By May 2006, the number of users had increased gradually to 46. Of these, 23 used the system on at least one other day after initially entering data.

<table>
<thead>
<tr>
<th># Days Used</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users</td>
<td>23</td>
<td>11</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 1. Number of users compared to the number of discrete days they used the system. ("6+ users" were observed with 8, 12, 16, and 19 days of use.)

On average, users updated their record on 3 different days during the 18-month study period. Individuals who accessed their record at least twice did so at an intervals ranging between 1 and 97 days, with an average of 35.4 days.

**Information Categories Usage**

Over a course of eighteen and half months, 46 users recorded 870 events. Among them, 247 were log-in and log-out events, 592 were information updates, and the remaining 4 events were personal preference updates, including password changes. On average, each user entered at least one health information unit (HIU) in 9.37 of the 11 information categories (Figure 2).

**Figure 2.** Distribution of the number of users by the number of categories that have at least one HIU.

The number of users who updated a specific health category at least once during the study period and the number and percentage of update events in each specific information category are listed below in Table 2.

<table>
<thead>
<tr>
<th>Health Information Category</th>
<th>Users (N=46)</th>
<th>Update Events (total: 592)</th>
</tr>
</thead>
</table>

Each study participant has recorded at least one health problem, and “Health Problems” information update events (IUEs) account for 70 (11.8%) health update events. Of the 46 participating residents, 44 populated their medication information in the PHIMS system and corresponding IUEs account for 81 (13.7%) of the 592 total IUEs, making “Medications” the most actively used information category. Only 18 residents (39.1%) populated “Immunizations (Vaccination)” information, the least frequently used category. “Lab Tests” and “Allergies” were second and third least updated information categories.

Individual Elements Usage

Most PHIMS pages allow users to add multiple observations, such as any number of individual medications, problems, surgeries, or medications, in a category. We refer to each individual observation as a health information unit (HIU). When adding an HIU only the name is a required field, and usually at least one field does not dictate exactly the type of information that can be entered. Below, we review by category the field users chose to populate. We report only on longitudinal health information categories. Missing fields can indicate that users did not understand what information was being asked for in those fields, did not have information available to them or felt it was not important enough to enter.

Medications (Table 3)

Forty-four users entered at least one medication. Twenty nine users (63%) recorded 5 or more current medications. The large number of medications entered suggests patients had ready access to the detailed information about their prescriptions.

<table>
<thead>
<tr>
<th>Field Name</th>
<th>Number of Entries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>343 (100.0%)</td>
</tr>
</tbody>
</table>

Dosage | 331 (96.5%)  
Date Started | 306 (89.2%)  
Date Stopped | 24 (7.0%)  
Prescribing Dr.'s Name | 306 (89.2%)  
Reason for taking | 320 (93.3%)  
How effective was it? | 276 (80.5%)  
If stopped, why? | 32 (9.3%)  

Table 3. “Medications” category field entries.

Health Problems (Table 4)

Thirty two users (70%) listed four or more health problems with an average of 7.8 problems per user. 93 (37%) of the 251 health problem HIUs had additional information. Some HIUs may include resolved and not clinically significant problems. In the “Additional Information” text box, users were encouraged by a prompt to enter questions they wanted to ask their physicians about their conditions.

<table>
<thead>
<tr>
<th>Name of Field</th>
<th>Number of Entries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (Type of problem)</td>
<td>251 (100.0%)</td>
</tr>
<tr>
<td>First Diagnosed</td>
<td>227 (90.4%)</td>
</tr>
<tr>
<td>How Managed</td>
<td>237 (94.4%)</td>
</tr>
<tr>
<td>Additional Information (Questions for provider)</td>
<td>93 (37.1%)</td>
</tr>
</tbody>
</table>

Table 4. “Health Problems” category field entries.

Surgeries (Table 5)

Forty-one users listed at least one surgery, with an average of 4.2 surgeries per user. For additional surgery information, users entered the surgery date more often than other additional information.

<table>
<thead>
<tr>
<th>Name of Field</th>
<th>Number of Entries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (Type of Surgery)</td>
<td>173 (100.0%)</td>
</tr>
<tr>
<td>Date of Surgery</td>
<td>171 (98.8%)</td>
</tr>
<tr>
<td>Additional Information</td>
<td>88 (50.9%)</td>
</tr>
</tbody>
</table>

Table 5. “Surgeries” category field entries.

Lab Tests (Table 6)

Twenty-five users chose to enter at least one lab HIU. On average, each user had 3.5 lab test entries. Only 87% of lab test HIUs had test results recorded. The “Result” field was free text, so users could have entered “normal” or “abnormal” or a lab test value.

<table>
<thead>
<tr>
<th>Name of Field</th>
<th>Number of Entries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (Type of lab test)</td>
<td>83 (100.0%)</td>
</tr>
</tbody>
</table>
Date of Test  81 (97.6%)
Institution (Place)  75 (90.4%)
Result  72 (86.7%)

Table 6. “Lab Tests” category field entries.

Allergies (Table 7)

Thirty-five individuals entered at least one allergy HIU. Only, 95% of allergy HIUs listed the allergic reaction. On average, users listed 2.3 allergies.

<table>
<thead>
<tr>
<th>Name of Field</th>
<th>Number of Entries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (Type of reaction)</td>
<td>79 (100.0%)</td>
</tr>
<tr>
<td>Reaction</td>
<td>75 (94.9%)</td>
</tr>
<tr>
<td>When Happened</td>
<td>71 (89.9%)</td>
</tr>
<tr>
<td>Specific Treatment</td>
<td>48 (60.8%)</td>
</tr>
</tbody>
</table>

Table 7. “Allergies” category field entries.

Immunizations (Table 8)

Eighteen users entered at least one immunization. On average, 2.1 immunizations per user were entered. If the user did not find the immunization they wanted to enter in the drop down list, they could enter it manually into the “Other Immunization” box. 74% of users chose to enter the vaccination type manually.

<table>
<thead>
<tr>
<th>Name of Field</th>
<th>Number of Entries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (Type of immun.)</td>
<td>38 (100.0%)</td>
</tr>
<tr>
<td>Other Immunization</td>
<td>28 (73.7%)</td>
</tr>
</tbody>
</table>

Table 8. “Immunizations” category field entries.

Discussion

Half of the 46 users accessed the system only on a single day, but all entered information in at least seven of the 11 categories. This amount of activity suggests that the users found value in even a single PHIMS session, and were not simply entering a few fields and then deciding to abandon the system. All users received a print-out summary of the health information they entered, which may have provided sufficient value to them.

Many users treat updating PHIMS as an important task and come to update visits ready with information such as new prescription bottles, written changes in treatments from their physician, and so on. We intend to explore in future research individual variation in use, and better characterize the value of PHIMS to users.

Categories of Usage

“Medications” were updated by most users (96%) and more frequently than other categories of health information in PHIMS. Of the total 343 medication health information units (HIUs), 33 had the field “Date Stopped” and/or “If stopped, why?” filled in, suggesting that users recognized the value of recording their medications history and adverse effects as well as current medications. 29 users (63%) reported being on 5 or more medications, which is higher than the recently reported rate of 41% in a similar population\(^6\). PHIMS records may include non-prescription information, which may account for this difference.

The active use of the Medications category suggests that users know their medication information reasonably well. Medication information may be more available to users because drug, dose, and date are present on medication bottles.

“Health Problems” was the second most frequently updated information category. All users entered at least one HIU in PHIMS. The relatively high number of HIUs (average 7.8 problems per user) compared to other categories suggests users may be well aware of their current and/or past problems and interested in filling in this information.

The “Lab Tests” category was the second least frequently used, only 63% of users populated this category. This may be because patients do not always obtain copies of the lab test results, and often commit results to memory, making it difficult to reliably enter data. It is also possible that some users simply did not have any recent lab tests, but given both the age and frequency of chronic illness in this population, this seems unlikely. It is also possible, that patients do not
understand laboratory tests well and rely on physicians for both interpretation and record keeping. “Immunizations” was the least frequently updated information category. In addition, among 38 immunization HIUs, 28 immunization units utilized the “Other Immunization” field. This unusual result, suggested a problem with the user interface. The immunization options were not well tailored for the immunizations of the older user population. The immunization page was significantly updated to focus on adult immunizations and a new page design was deployed in October 2006.

Use of Reminder Fields

We believe that free-text fields are an important and useful feature for PHIMS users. While updating their records, users frequently think of questions they forgot to ask during their provider visits. They have used the free-text fields in PHIMS to record these questions and other notes and reminders to themselves to trigger their memory during their next visit. However, we need to be careful while incorporating free-text fields, since it is more error prone (e.g., typo) and difficult to reconcile with other health information systems.

Limitations

In this study, we looked at usage from the system perspective, not at individual patterns or variations of use. Some participants who enrolled in the study at a later period may not have had the opportunity to update their record as frequently as the longer term users. With the benefit of additional data collected since this initial study period, we are now able to analyze comparative usage patterns, controlling for exposure to the system, and will report on those patterns in the future.

Conclusions

System usage logs have brought our attention to areas of PHIMS experiencing or causing problems, guided improvements to the usability and utility of PHIMS, and helped us tailor the application to meet the needs of our users. Analysis of database access and system log data has been able to show us areas of a PHR that are more heavily used and some which are less used. We have also observed that patients choose to not fill out all fields under certain health information categories. There are many possible reasons why patients may not be entering all of their health information into their PHIMS record. Further studies with PHR users are needed to discover these reasons.

We plan to conduct future studies to further explore this setting where a personal health record has been made available to an underserved population. We intend to study the information behavior of both PHIMS users and non-users, as well as how PHIMS records are used during provider visits. We also intend to explore health care provider views of PHIMS. Finally, we hope to conduct further studies of system usage data and individual variations in use patterns, including: the association between frequency and the type of information used, and individual health status and characteristics. Our goal is to develop a deeper understanding of system usage patterns, value of PHIMS to patients and providers, and potential impacts of personal health record systems like the University of Washington, Personal Health Information Management System (PHIMS).

Acknowledgements/Further information

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