Designing for the Invincible: Health Engagement and Information Management

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Abstract

Personal Health Records (PHRs) are often promoted as tools for self-management of health. However, current adoption rates of PHRs at the national level suggest serious barriers that need to be overcome before they turn into ubiquitous technologies. In this paper, we report on a case study of PHR introduction and adoption on a large university campus. The aim of the study is to engage students in their health through a user-centered (re)design of a PHR. To this end, we have engaged in a multi-method study, including a survey, focus groups, and web metric data. The findings from the study have led to useful themes and design ideas, which we discuss here, presenting preliminary design recommendations.

1. Introduction

To allow people to manage their health, we must provide them with tools and technologies that enable and encourage informed decision making to maintain their wellbeing. One proposed solution towards active health management comes in the form of Personal Health Records (PHRs), which help patients manage, maintain, and exchange their health information with medical providers, pharmacies, family members, and other relevant parties. The belief is that by having a patient become an active participant in their health management, in coordination with their medical providers, a healthier lifestyle can be maintained [19, 32].

Many researchers and practitioners see the computerization of personal health records as the next step in improving patient healthcare. Electronic PHRs are being promoted as a solution that will improve patient healthcare, reduce costs for care providers (and patients), reduce medical errors, and ease the process of record keeping [19, 25, 28, 32]. However, much of the research that expounds on the benefits of PHRs and what they are capable of comes from health practitioners or technology vendors. As shown by Forsythe [15:101-105], such a practitioner-oriented approach can overshadow the needs of other stakeholders such as patients. Furthermore, PHRs are often designed as generic technologies that can be equally used by all segments of the population. Lastly, most of current research on self-management of health targets populations with manifest health problems, not those like college students with apparently healthy but imperceptibly high health risks. Taking these limitations into account, we will discuss in this paper a user-centered approach towards understanding the needs of individuals with no clear health issues and no prior experience of health management — namely, college students, particularly freshmen. Furthermore, we do not focus on a hypothetical user but instead target a specific population of patients using a PHR, with particular dispositions toward technology.

Our work looks to expand on existing research that takes a user-centered approach [8, 16, 22, 24]. However, we target college-aged students, as they have not received much scholarly attention in regards to health management and electronic PHR use and who in their own mind feel as if they have no need for such a service. This perception may in part be due to feelings of youthful invincibility and also due to PHRs not providing the features that this population expects. We will discuss the limitations of PHRs to this population and recommend improvements in this paper.

2. Background

The health situation of American college students is deteriorating. Traditional problems such as binge drinking, poor diet, and intense academic stress are rapidly being compounded by an increasing prevalence of metabolic risk factors, obesity, and mental health disorders [5, 23]. The growing trend is alarming. For instance, findings from a recent large-scale longitudinal study reveals a growing trend in
heavy episodic drinking [9]. The number of alcohol-related unintentional injury deaths in 2005 among college students ages 18 to 24 is estimated at 1,825, showing a significant increase in recent years. From 1999 to 2005, the proportions of college students ages 18-24 who reported consuming five or more drinks on at least one occasion in the past month increased from 41.7% to 44.7%, and the proportions who drove under the influence of alcohol in the past year increased from 26.5% to 28.9%—7% and 9% proportional increases, respectively. “Heavy drinking also places college students at high risk for immediate and long-term health consequences, including alcohol-use disorders, driving under the influence, physical/sexual assault, property damage, risky sexual behavior, and academic problems [1].” Allowed to continue on the current trajectory, college students will become a greater health burden by the age of 50 than their parents.

With a young population ill-prepared to deal with these issues, while experiencing its first true taste of independence, we have set out to understand if the use of personal health records (PHRs) can help stop or slow down, early on, this trajectory of potential health decline? To help answer this, we engaged in a yearlong investigation of PHR use by college students at the Indiana University-Bloomington campus.

We chose this population as we saw an opportunity to study college-aged adoption of PHR use by a new cohort of students. During the summer of 2009 the university health center sent out an information packet informing incoming freshman students of the availability of a free to use online (web-based) electronic PHR. The intended benefit to students of using such a system is that it allows for the collection of health-related information (e.g., vaccination history, allergies, family history) with the assistance of their parents at home. Parents typically manage most of these issues when the individual lives with the family. The second benefit advertised to students was that by filling out a PHR ahead of time, they would not have to submit any redundant paperwork when they decided to use the health center services on campus.

This generation of college aged students is also unique when it comes towards their relationship with information technology. Having grown up around it, the expectation is that they will be on the forefront of using existing and emerging forms of information technology [21, 26]. At the same time, scholars question if they truly are able to critically understand and work with the wealth of information and technology that they now have access to [3, 27].

Lastly, by targeting this incoming cohort of students who previously have not been exposed to an electronic PHR, we are given the opportunity to not only examine adoption and use over a four-year period, but also obtain a longitudinal understanding of change in perception towards personal health management and PHR use.

To allow students to manage their health, we must provide them with tools and technologies that enable and encourage informed decisions concerning their short- and long-term health. Self-management support (SMS) is defined by the Institute for Healthcare Improvement as the care and encouragement provided to people to help them understand their central role in managing their health, make informed decisions about care, and engage in healthy behaviors [19]. Currently, there is a wealth of health-related resources available online through services such as WebMD or MayoClinic. While the quality of information provided by these resources is typically high, they are not as effective as self-management alternatives that focus on active participation of individuals rather than just the transfer of information. Information transfer, by itself, has been found insufficient in impacting outcomes, as greater patient knowledge does not amount to greater patient engagement [4]. Furthermore, these resources are limited in that they cannot be personalized to an individual’s specific health conditions and health risks.

Institutions of higher education are ripe settings for reaching young people as they are just beginning to manage their lives and their health. Upon entering college, students often gain their first taste of true independence. However, they do not have much experience in managing their health. One part of the solution is emerging in the form of PHRs which help patients manage, maintain, and exchange their health information with support from medical practitioners [25, 28, 31]; becoming co-pilots of their own care [31]. PHRs are more than just a repository. They can "include tools to help individuals take a more active role in their own health,... [and they] can also include decision-support capabilities that can assist patients in managing chronic conditions” [32]. Unfortunately, there are currently several overarching challenges with the wide scale use of PHRs, as current national adoption rates are estimated at below 5% [7]. There are multiple technical, structural, privacy, and motivational barriers that contribute to this. In the long run, our study specifically aims to address motivation to use PHRs. If people do not know about PHRs and how they are relevant in their lives, or they do not understand their capabilities, potentials, and limitations, they will not be motivated...
to use them. The recent introduction of PHRs on the campus of Indiana University (IU) creates an opportunity for this kind of study [20].

3. Literature Review

Looking at the literature to identify work that takes a user centered approach towards the design and improvement of PHRs turns up only a small number of examples. Kim and Johnson [22] look at how different forms of data entry influence the accuracy of patient entered data into a PHR. Their experimental study shows that the type of input that works best depends on the content and form of the data that needs to be entered. Hasssol et. al. [16] examine how patients can communicate with their provider via a web portal provided by an EHR. Their findings show that preferred mediums of communication varies, with patients preferring email and medical providers direct contact or the telephone. Lafky and Horan [24] use a survey and interviews to get an understanding of what patients’ perceptions are towards PHRs. They find that electronic personal health records play an important role in emergencies for individuals with disabilities. The researchers also find different attitudes towards the format that a PHR should take, with disabled individuals having a preference for using smart cards as opposed to an online PHR. Dawson, Schooley and Tulu [8] examine what the concerns are of employees towards PHR use. Via a survey the researchers identify that only a small percentage of employees are using a PHR. The authors argue that lack of use is due to employees not trusting who has access to their health data (such as their employer).

4. Research Question

This paper reports on findings from an ongoing long-term study. In this paper we set out to answer three questions: how do college age students go about using an online PHR? What are students’ perceptions towards electronic personal health records? And lastly, what are their perceptions towards health information in general?

5. Methodology

During this year-long study, we have used several methodological approaches in an attempt to get a better understanding of how the PHR system is being used by college students. This includes (i) a heuristic evaluation [29] that identified basic usability issues in the PHR resulting in prescriptive recommendations that would improve functionality, consistency, aesthetics, and efficiency [13, 14]; (ii) a 30 question exploratory survey with Likert and multiple choice responses that was sent to 1,556 students [11]; (iii) focus groups with 6 individuals; and (iv) the analysis of demographic data and web metrics provided by our PHR vendor that allow us to examine activity patterns of students as they use a PHR in addition to other demographic and health markers such as age, conditions, and medications taken.

In this paper we discuss results from our web metric, demographic, and health data obtained from our PHR vendor; the survey we sent to students, and qualitative data obtained from our focus groups. The metrics give us an understanding of who the users are and how they use a PHR. The focus group on the other hand gives us insight into users perceptions and feedback in regards to the experiences they had while using the PHR. We leave out the heuristic evaluation in this paper as these were done during the start of our study and primarily served as tools for the researchers to help get an initial understanding of the usability and use issues of the PHR implementation.

6. Use Results

6.1. Demographic data

We obtained demographic data by our PHR provider that gives us insight about the age range of students using the PHR, and other markers such as health conditions and medication taken. As of May 2010 we have 5325 students using an electronic based personal health record at Indiana University. The total student enrollment for Fall of 09 was 42,347 students, of which 23,975 were first year undergraduates [18]. That means that 22% of the incoming freshman signed up for an electronic personal health record. Table 1 below shows PHR use based on year of study.

<table>
<thead>
<tr>
<th>Year of Study</th>
<th>#</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freshman</td>
<td>2,306</td>
</tr>
<tr>
<td>Sophomore</td>
<td>386</td>
</tr>
<tr>
<td>Junior</td>
<td>225</td>
</tr>
<tr>
<td>Senior</td>
<td>177</td>
</tr>
<tr>
<td>Post Grad</td>
<td>386</td>
</tr>
</tbody>
</table>

Freshman account for the highest number of users \((n=2306)\), and exceed the total number of users for the remaining grades \((n=1174)\). Freshman use of a
PHR is higher by a factor of 10 compared to the remaining grades largely due to the fact that informational packets were sent out specifically to this incoming class during the summer of 2009. These packets informed them in regards to the availability of an electronic PHR and encouraged them to fill out their own personal health profile.

The fact that a large number of freshman are using the PHR is also reflected in the age distribution (Table 2).

### Table 2. Age distribution

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number of students</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 17</td>
<td>125</td>
</tr>
<tr>
<td>18 to 21</td>
<td>3,656</td>
</tr>
<tr>
<td>22 to 25</td>
<td>616</td>
</tr>
<tr>
<td>26 to 29</td>
<td>294</td>
</tr>
<tr>
<td>30 to 33</td>
<td>123</td>
</tr>
<tr>
<td>34+</td>
<td>326</td>
</tr>
</tbody>
</table>

The majority of users using the PHR are within the 18 to 21 age group. Within this group, 19 year olds are the most predominant age group using the PHR, consisting of 2187 individuals. 18, 20 and 21 year olds make up respectively 548, 575, and 346 of the remaining individuals using the PHR.

There is also a noticeable gender difference between women using a PHR as opposed to men (Table 3). Women make up 59% of the individuals using a PHR. This indicates a gender disparity when compared to the larger student population, which has close to equal representation of both genders (50.48% of students at the university are women [18]).

### Table 3. Gender breakdown

<table>
<thead>
<tr>
<th>Sex</th>
<th>Students</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>3,097</td>
</tr>
<tr>
<td>Male</td>
<td>2,138</td>
</tr>
<tr>
<td>Not entered</td>
<td>90</td>
</tr>
</tbody>
</table>

#### 6.2. Health profile

Our PHR vendor was able to give us access to anonymized health information of the students using the PHR. This allows us to put together a health profile of the students using the system. For example, students were asked to report any conditions that run in the family. Table 4 below shows the top 10 reported conditions.

### Table 4. Family conditions report

<table>
<thead>
<tr>
<th>Condition</th>
<th>#</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure</td>
<td>290</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>169</td>
</tr>
<tr>
<td>Heart attack</td>
<td>134</td>
</tr>
<tr>
<td>Heart disease</td>
<td>121</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>112</td>
</tr>
<tr>
<td>Diabetes</td>
<td>93</td>
</tr>
<tr>
<td>Hypertension</td>
<td>80</td>
</tr>
<tr>
<td>Depression</td>
<td>69</td>
</tr>
<tr>
<td>Skin cancer</td>
<td>63</td>
</tr>
<tr>
<td>Cancer</td>
<td>62</td>
</tr>
</tbody>
</table>

Though we are only showing the top ten conditions, students reported a total of 3452 family-related health conditions. This indicates that students are aware of health threats that run in the family, or they were informed about these conditions by their parents when they initially filled out their profiles. It might also represent a hidden pattern of use in favor of students with high-risk health histories in the family.

#### 6.3. Web metrics

By examining web metrics for the electronic PHR we are able to get an understanding of how users are interacting with the system and what features they are engaging with. The PHR vendor provided us with Google analytics information that allows us to get an overview of user activity.

Over a one-month period (June to May, 2010) there were 549 visits to the IU Health PHR. On average for each visit 29 pages were viewed and on average the visitor spent 23 minutes on the website. 82% of these visits ($n=452$) were first time visitors.

This web metric data indicates that the majority of visitors are filling out a profile for the first time based on the average number of pages visited ($n=29$). The initial interview that a patient fills out in the PHR consists of around 35 pages, more or less depending on gender and health conditions selected. Since the large cohort of freshman filled out their PHR during the summer of 2009 before the start of the school year, what we are seeing are individuals from the larger IU community filling out a PHR before going to the health center. Students that make an appointment with the health center are encouraged to fill out an electronic personal health record before coming in for their appointment.

When looking at the technical profile, a bit more than half of the users were connecting via cable
broadband (Table 6). This indicates that most of the users connecting to the PHR during the month of June are connecting from off campus (via a local cable or DSL broadband provider).

Table 6. Connection speed

<table>
<thead>
<tr>
<th>Connection</th>
<th>#</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cable</td>
<td>295</td>
<td>53.73%</td>
</tr>
<tr>
<td>DSL</td>
<td>134</td>
<td>24.41%</td>
</tr>
<tr>
<td>T1</td>
<td>70</td>
<td>12.75%</td>
</tr>
<tr>
<td>Unknown</td>
<td>45</td>
<td>8.20%</td>
</tr>
<tr>
<td>Dialup</td>
<td>5</td>
<td>0.91%</td>
</tr>
</tbody>
</table>

T1 users consist of those that are using the on-campus network. There were also cases of 5 individuals using dialup to connect the PHR, which again highlights the need to make sure that these systems are accessible to individuals who do not have the latest computer hardware and or a broadband Internet connection.

When using the PHR at IU students have the ability to submit forms directly to the health center. These forms are digitized versions of paper-based forms that get used within the clinic. A student, when requesting an appointment, will be asked to fill out various forms based on what they are coming in for. Table 7 below lists the most popular forms that are sent to the health center via the PHR.

Table 7. Documents sent

<table>
<thead>
<tr>
<th>Form</th>
<th>#</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Student Registration Form</td>
<td>2,076</td>
</tr>
<tr>
<td>Women's Health History</td>
<td>241</td>
</tr>
<tr>
<td>OBGYN Questionnaire</td>
<td>141</td>
</tr>
<tr>
<td>Mens Health Questionnaire</td>
<td>51</td>
</tr>
<tr>
<td>Contraceptive Form</td>
<td>25</td>
</tr>
<tr>
<td>HIV Consent</td>
<td>16</td>
</tr>
<tr>
<td>IUD Questionnaire</td>
<td>11</td>
</tr>
<tr>
<td>International Travel</td>
<td>4</td>
</tr>
<tr>
<td>IUHC – Health History</td>
<td>1</td>
</tr>
</tbody>
</table>

The majority of documents submitted are student registration forms. These are documents that are filled out by first-time visitors coming to the health center.

A total of 2566 documents were sent to the Health Center. Another 1144 documents were created but not submitted. This means that 50% of the users do not finish documents that get started. However, the majority of visits ($n$=5944) do not result in the creation of any additional documents to be submitted to the health center. This would indicate that users are either browsing or updating their personal health record but refraining from submitting any requested data to the health center.

6.4. Survey

The survey served as the initial exploratory device to help us get an understanding of how students engage with the school’s PHR. The survey contains 30 questions in the form of a Likert scale and multiple-choice questions. We also added two open-ended response questions that asked the students what they thought were the most positive and negative aspects of the system. We sent out our survey to 1,556 students and received responses from 37, a lower response than expected [11]. Out of the total respondents around half indicated that they have not used the PHR much for the various features that we questioned them about. Since we sent the survey to individuals who had signed up for a PHR, this may indicate that they have signed up for an account but do not actively use it. Response in regards to usability was mixed. Out of the individuals that used the PHR, 58% of respondents ($n$=11) indicated that the PHR was only somewhat effective in helping them manage their health information. However when asked if the use of this system helped them save time when sharing information with their provider they indicated that helped them save time “some times” (37%, $n$=7) or “a lot of times” (32%, $n$=6). Furthermore, the majority of respondents who used the PHR (71%, $n$=12) felt that the PHR helped them meet their needs in managing their health information.

Though we received a limited number of responses, the results indicate to us that the students did see value in using a PHR, but that the there were usability problems in the system that limited its use. This was evident in the open response section of the survey. When asked what the most positive aspects of the PHR were, students responded with comments that were related to the ease of having information in one area: “data contained in one place,” “central location, easy access,” “easy access to health records later on” and a “one-stop shop for medical information.” However, when asked about the negative aspects, the comments focused on the usability of the system and data entry concerns:

“Not easy to input initial background info if not previously known”, “it’s kind of confusing, and I’ve had to enter the same info twice for two different depts.”
and,

"Interface could use some polish. At times, it seems as if there is way too much information displayed all at once and it feels kind of cluttered."

7. Focus group results

To explain part of the findings from the web metrics and survey, we now turn to some of the qualitative information obtained through two focus groups in which we invited existing users of the system to come in and discuss their experiences. A total of 6 individuals were interviewed (3 graduate students and 3 undergraduates). The focus group was exploratory in nature, attempting to identify what students’ perceptions were towards PHR use and health information in general. From these focus groups several themes emerged, which we will discuss in detail below.

7.1. Health information management

A key theme that emerged out of the interviews is that students were not interested in manually managing their health information in a PHR. An initial step towards setting up a PHR consists of the initial interview, which requires the entry of a large set of health-related information. However, most students did not seem to be interested in doing this. They did not see the purpose or benefit of this. Resistance was also especially prominent when it came towards updating records after a visit to a healthcare provider. The PHR gives students the ability to manually migrate data over from the health center’s EMR. However, students in the focus group were expressing stronger interest in having the PHR automatically be populated with data after the visit and not being forced to manually update.

Another theme that came up in regards to information management is that students perceived a personal health record as only containing information that is quantitatively “true”. Students seem to perceive a health record as being similar to a school record, an immutable object containing a permanent record of one’s health. This sentiment was frequently encountered when we questioned the participants in regards to if they would consider using a PHR to self-track personal health information such as the state of one’s personal well being, amount and types of food consumed, or time spent exercising. These options were put forward when during the proceedings of our focus group we noticed that the students in their cohort did not feel the need to track disease-based information in a PHR. The students believed that their age does not make them susceptible to chronic or temporary illnesses. However, respondents were even more resistant to the idea of using a PHR to self-track personal health information. Some respondents even expressed doubt as to whether such information should be placed into a PHR. One of the respondents was accommodating to the idea of self-tracking personal health metrics, which they referred to as “holistic information,” but still wanted it to be separate from official health-related information:

“I would still like to keep the holistic separate from the personal health info.”

What can be concluded from these responses is that respondents are unsure of what should go into a PHR besides official “true” health related information as provided by a medical provider. Anything else that is entered into a PHR by the respondents themselves is seen as information that might dilute the record with potentially subjective or wrongful information.

7.2. Context

Another major theme that emerged from the focus group has to do with context. Respondents felt that PHR use was outside of their context of use. This points towards perceptions and self-expressions of invulnerability and perceived healthiness by this population. Especially to some of the younger participants, the use of a PHR did not make sense. However, some of the older respondents did understand the purpose and role of a PHR, but disagreed with the existing model of it being a repository of personal health information. Respondents were interested in contextual information. As one participant put it: “explain what those numbers mean.” In other words, their expectation of a PHR was more akin to an analytic tool rather than a repository.

This type of commentary by the respondents points to an interesting phenomenon — namely, that there is a wealth of health-related information available on the web nowadays that can be quickly accessed. However, one can never be sure if the information is relevant to one’s own personal health needs. Responses from the focus group point towards the need to provide contextual information and links. In this fashion, a patient can be provided with a distilled subset of health-related information which is relevant to them individually.
Responses bring to mind the educational pamphlets that a health provider gives to the patient during a visit. The information that is provided by the health provider is contextually related to the patient’s condition. As such, they take it home and reference it in order to get a better understanding of their disease and what needs to be done to minimize symptoms or overcome the condition.

7.3. Integration

The last theme that was identified in the focus groups was the need for integration. The identified issues here are more specific to how the PHR is implemented at IU, but is still worth exploring.

Specifically, the students had concerns that the data that they entered into the PHR was superfluous, since when it came time to see a health care practitioner, they frequently had to fill out the same paper-based forms that were previously answered online in digital form. In other cases, the respondents had to verbally provide answers to the same questions to the doctor, nurse, or physician’s assistant, even though (from the patient’s perspective) they have answered these questions previously via the PHR.

Though not an HCI issue (in the traditional sense), this observation does point to a larger organizational-integration problem. Namely, it is the perception of the patient that the information they provide in a PHR gets automatically distributed to the right individuals at the health center. However if in reality the health center is still integrating the PHR to their EHR, then there may be some redundancy during the data collection process. If there is excessive redundancy in the questions asked in the PHR and during the health visit, then the patient will lose interest in entering data in the PHR. Or as one respondent put it:

“I was disappointed, I had filled out the info, and they had me enter it again on the clipboard, and I wasn’t even sure what the answers were, even though I had them all online.”

This sense of disappointment also points back to the previously identified theme of information management. Students are not interested in spending a time filling out or maintaining a PHR. As such if they perceive any redundancy in the collection process, they will skip the voluntary process (creating a PHR) in favor of the required process (filling out forms on a clipboard in the waiting room).

8. Conclusion

In our study, we set out to establish what the needs and perceptions of undergraduate students were towards health management and online personal health records. We wanted to identify a cohort of students who would be using an online personal health record for the first time to see how they adjust to these systems. The ultimate goal of the study is to engage students in their personal health, and the assumption is that PHRs can contribute to this if they become available to a technically savvy population such as college students. Furthermore, we assume that a user-centric approach to the design of PHRs, which would involve them in the process of design and the choice of functionalities, would increase the likelihood of not only adoption but sustained use of this technology.

By looking at how these groups are using a PHR through a survey, web metrics, and talking to students to get a qualitative understanding of health perceptions we are in a better position now to design a PHR to meet their needs. Our focus groups identified several themes and ideas towards PHRs and health management summarized below.

8.1. Information management

Students are resistant towards the idea of self-managing their health information, instead preferring for information to automatically populate their record after or during their visit to a health care provider.

According to students, information should only be placed into the PHR if it is generated by a health care professional. There is a perception that only “valid” information should be placed into the record. Students separate medical information generated by a health care provider from self-generated health information (e.g., dietary habits) and assume that a PHR is primarily or only a repository for the former. This indicates a narrow understanding of health information and its components on the part of students. An educational approach that challenges this perception would be useful in promoting self-management.

On a more practical note, data entry seems to constitute a major barrier in PHR use. The idea of entering data about dietary intake, exercise, and other health-related behaviors takes time away from other activities, and is therefore not appealing to students. The development of sensory technologies (e.g., pedometers, calorimeters, etc.) that would facilitate and automate this process would diminish the perceived magnitude of this barrier.
8.2. Context

For a student to find a PHR relevant, it should not just be a static container of digital information. Instead, after a visit to a health care professional, students want to be able review information that was collected or generated during a visit. Any educational or information that is provided by the PHR should take into account the individual’s health data that resides in the system. The current federal initiative to promote EMR adoption health providers creates a promising context for the integration of PHRs and EMRs as components of an integrated healthcare system.

8.3. Integration

Another aspect of an integrated system is the adoption of a collaborative model of health that seeks to “promote effective self-management of health habits that keep people healthy through their lifespan” [2]. To maintain healthy lives, minimize risks, and effectively achieve optimal health outcomes, individuals need to understand risks and to make significant changes in lifestyle, such as increasing exercise, dietary modifications, weight loss, and cessation of unhealthy habits. These activities require both patient-provider collaboration and the education of self-management [4]. To accomplish these, a shift of perspective is needed from a "transactional" to an "interactional" view of health care. This requires ongoing exchange of information between PHRs and EMRs, but also active participation and adoption by both patients and providers.

The electronic PHR at IU ties into an existing student academic and course management system. This led to some confusion by students, as they do not consider health information as being contained within or being part of a larger online academic management system.

On the basis of the above observations, our design team has recommended the integration of the PHR with the EMR currently used at the Health Center.

8.4. Design implications

The purpose of working on getting an in-depth understanding of the health information needs of this specific population is that a PHR cannot be a single solution for all “users.” The PHR needs of adult employees [8] might vary from the disabled [24], which may in turn differ from college-aged students. Based on our observation of use and themes identified during the focus group, we have established a set of design recommendations that, we argue, need to be present in order for PHRs to be successfully embraced by this population:

1. More than just a vault: the ability of being able to store one’s health information in a central repository that is easily accessible by the patient (and medical providers) is not enough for college age students. Context matters. Students are interested in understanding what the data actually means that sits in their PHR. They are aware that doctor visits are quick and thus they need to do their own research on their own time. A PHR needs to be designed so that it can provide a venue for engaging in this process of sense making.

This recommendation originates from the feedback received from our focus group in which students expressed that they desire health information that is contextually relevant to their needs. The initial survey did not directly indicate this need, in part because, it did not ask any questions in regards to contextual health information. Free form responses in the survey only indicated that the students liked having a central location where their health information is stored and did not express any concern that this information lacks contextual relevance. In the focus group, however, we were able to tease out that students desired for this information to support their health-related sense-making process.

These findings seem to support existing research that argues that even though the Millennial or Net-generation has access to an unprecedented amount of information, they still lack the tools to critically understand and process it [27]. This behavior may be present in our examination of PHR use. The students when confronted with personal health related information in addition to links to generic health related resources have problems in processing what is relevant to their specific health needs.

2. Leave the management to professionals: Medical practitioners and researchers may want to empower patients so that they can manage their own health, deciding on what information to put into a PHR and what to share with a health practitioners and from this lead a more healthy lifestyle. However, college age students do not seem to share this sentiment. Their interest seems to be focused on minimizing the amount of time spent managing a PHR. This, in part, may be due to youthful naïveté that defers to medical authority in the belief that they are the experts. Or it may be due the feeling of invincibility among youth.

Given this sentiment, a PHR that targets this population should allow students to mange their
health profile without a great deal (or, ideally, any sort) of data entry activity. Potentially in a way so that they do not have to engage in any data entry.

This design recommendation is based on the web metrics we collected, feedback from the focus groups, and survey results. Web metric data shows limited engagement with the PHR, which would be indicative of students not actively engaging with the PHR. This could be either due to them not seeing the value of using such a system, or this being a usability problem and students having difficulty engaging with the technology. Our survey helps clarify this ambiguity as responses indicate that yes there were some usability issues in regards to data entry and management. However, even with these issues, according to the survey, students did believe that the use of the system was of value to them as it helped them save time when it came to sharing their health related information with the health care professional. Follow-up questioning during the focus further uncovered that the students were looking to minimize their interaction time with a PHR and that, to a certain extent, they only wanted valid information from a health professional stored in the system.

Our findings are supported by existing research, which argues that the Net-generation takes the existence of information technology for granted and considers it ordinary [17, 30]. As such, a web-based PHR may not be met with active engagement and interest. Instead there is an expectation that it should automatically work and provide what is needed. By way of a rough analogy, someone who has grown up with electricity in the home expects it to work automatically and without any intervention.

There is a strong caveat that goes along with this design recommendation. We only talked to students who seemed healthy and did not self-report any major illness and conditions. Students who do have disabilities or chronic conditions may have a different perception towards how a PHR should be managed.

8.5. Limitations and future research

There are several limitations in our study. Our focus groups are fairly small made up of 6 individuals. As such, the themes we identified may not be representative of a larger student body. Another limitation is that we critique existing work on PHRs by arguing that they need to take a user-centered approach and focus on specific subpopulations and not generalize to just “users.” However, we also engage in generalization in that we lump college age students together as one group. In reality, college age students are diverse, made up of non-traditional students, international students, first generation students, students with disabilities, students with chronic illnesses and more. Due to the makeup of participants that volunteered in the focus group, our design recommendations target the traditional student (without any major chronic conditions) and thus our results may not be fully generalizable to other populations.

In future, we plan to take our findings and apply them towards a redesign of the existing PHR implementation. Currently, we are having Masters students who are taking a HCI class at IU take a user centered approach (scenarios, interviews, conceptual models, questionnaires) and create PHR mock-ups that meet the needs of the student population [10, 12]. The findings of these student groups are part of the preliminary steps for the redesign of the current PHR.

9. References


