Personal Health Records for College Students: A Case Study

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Summary

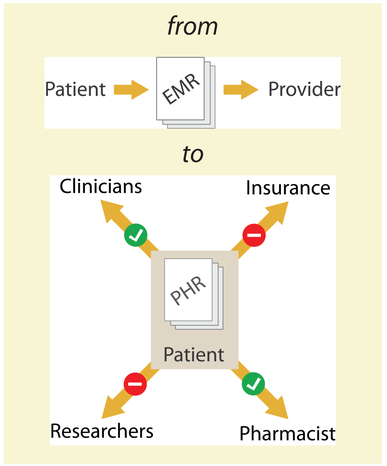
The health situation of American college students is deteriorating. Traditional problems such as binge drinking, poor diet, and intense academic stress are rapidly being compounded by an increasing prevalence of metabolic risk factors, obesity, and mental health disorders. Allowed to continue on the 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 enaged in a year long investigation of PHR use by college students at the Indiana University-Bloomington campus.

Background

Recent trends in patient-centered care are intended to give individuals a more prominent role in managing their health. To allow people 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. A solution is emerging in the form of Personal Health Records (PHRs), which help patients manage, maintain, and exchange their health information with support from medical practitioners becoming copilots of their own care.



This is a potentially positive development if we, indeed, turn PHRs into vehicles of personal engagement with health. PHRs are emerging technologies with a large degree of interpretative flexibility and uncertainty in terms of future development, diffusion, and use

Methodology

This project is part of an ongoing collaboration between The School of Library and Information Science and the IU Health Center at Indiana University. A mix of methods have been used to guide our initial exploratory investigation:

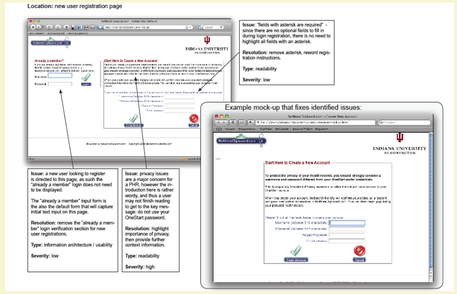
Heuristic evaluation: Usability analysis of existing electronic PHR at IU.

Survey: A 30 question survey with Likert responses, sent to 1,556 students.

Focus group: Follow up focus groups held with subset of survey respondents.

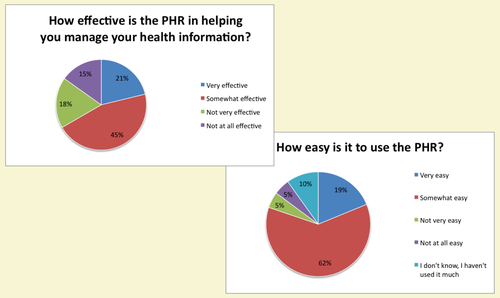
Prototype design: Master students were asked to take a user centered approach and redesign the PHR so that it met the needs of the IU Health Center and college-aged students.

Heuristic Evaluation



Our initial evaluation of the electronic PHR environment relied on the use of prescriptive heuristics to examine the system and make recommendations that would improve functionality, consistency, aesthetics, and efficiency.

Survey



In order to get an understanding of PHR use by students, we distributed a 30 question survey to 1,556 students. Analysis is ongoing, but initial results indicate that students have difficulty managing their health information and consider a PHR as being only somewhat effective towards meeting their health management needs.

Focus Group

"I'm not sure if America wants to better manage their own health"

"Only want it on there if it is true"

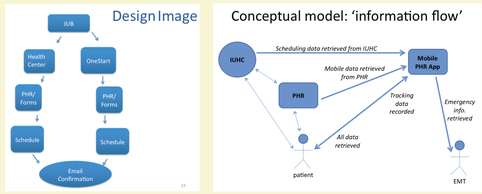
"I don't mind giving parents full access"

"I expect a doctor to tell me what is going on"

"Something that helps me make sense of the data I receive"

Focus group respondent were skeptical of the role that a PHR could play in their own lives. Initial perception often was one of "well I don't need it myself." However, once they better understood the various roles that a PHR could fulfill, they started to better understand the potential value of using such a system.

Prototype Development



Masters Students in an HCI class were tasked with taking a user centered approach (scenarios, interviews, conceptual models, questionnaires) to create a PHR mockup that met the needs of the student population. In addition, the IU Health Center had specific requests that the students had to address in the redesign.

For example: PHR support for mobile devices, a PHR that served students with autoimmune diseases, and a PHR with a social networking component.

Findings

We have identified several reucurring themes that seem to shape students perceptions towards PHR use and understanding:

Information Management

• Students are resistant towards the idea of self managing their information. Instead preferring that information automatically populate their record after or during the visit to a health care provider.

• There is a perception that information should only be placed into the PHR if it is created by a health care professional. This information is considered as being more valid for placement into a PHR.

• There is confusion in regards to what kind of information can go into a PHR. 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 a repository for the former.

Context

• Questions arose in regards to personal relevance of data in the PHR. Any educational or informative information that is provided by the PHR should take into account the individuals health data that resides in the system.

• For a student to find a PHR relevant, it should not just be a static container of digital information.

• After a visit to a healthcare professional, students want to be able review information that was collected or generated during a visit.

Integration

• Frustration was expressed when requests are made by the PHR for information that was not seen as being relevant.

• Data entry into a PHR was considered as being an extreme waste of time if the same information was requested again during a visit to a health care provider.

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

Conclusion

Students do not want their PHR to be a self-managed repository of health information. They prefer that the PHR be populated automatically by data generated during a visit to a health care professional, as well as for data to flow from the PHR to the EHR.

The PHR needs to also provide contextual information that is relevant to the individuals health record. There is an abundence of health information available online, however this availability of information leaves unanswered "is this relevant to my specific personal health needs?" A PHR could provide needed guidance in answering this question.

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