Abstract

Project HealthDesign is a national program designed to rethink the power and potential of personal health records. It intends to stimulate development of new personal health management tools by harnessing the content of the personal health record and making advice, recommendations, and data-tracking tools available to lay people. The program goals include creating a set of prototype personal health records applications, deriving the core functions needed to support interoperable ‘plug-and-play’ resources for managing health challenges, and addressing the ethical, legal, and social issues that confront the development of computer tools to promote health actions. Response to the call for proposals was tremendous; from the over 160 groups who submitted proposals, 9 teams were selected to design and create prototypes of innovative personal health management tools. This paper summarizes the full set of proposals, their populations of interest, and the technical challenges that await full implementation of the PHR-based applications designed to promote health.

Introduction

The concept of personal health records (PHRs) enjoys wide acceptance by the medical informatics research community, health care providers and payers, and the lay public. Generally PHRs are thought of as collections of information from clinical encounters or self-collected observations of clinical parameters. Project HealthDesign seeks to expand the idea of PHRs from data collection and storage tools to vibrant, powerful tools that assist lay persons to take action that promotes accomplishment of health goals and management of complex health problems.

In June, 2006, the Robert Wood Johnson Foundation (RWJF) released a call for proposals, inviting design teams to propose innovative, expansive applications of personal health records that could engage lay people in the promotion of health and the accomplishment of health goals. Over 160 teams from around the United States responded to the call; from these exciting proposals 9 were selected to transform their ideas into working prototypes. Grantee teams participate in a 6-month intensive design experience, set up to insure that their design strategies engage and respond to the needs of their self-identified populations of interest. We anticipate that all nine design teams will create working prototypes of their personal health applications.

Creating a new vision of PHRs, one that encompassed the idea that PHRs should guide action for health, required exciting the medical informatics community, health information technology (HIT) vendors, behavioral health specialists, and clinicians engaged in the use of HIT to improve health. Exploration of the full set of responses to the call for proposals provides a rich and instructive insight into the personal health records environment.

Background

The personal health record, currently envisioned as...

...an electronic application through which individuals can access, manage, and share their information, and that of others for whom they are authorized, in a private, secure, and confidential environment, complements and extends information gathered at the point of care by providing a focal point of integration around the patient, not the clinical care provider or institution. Such records are envisioned to include both clinically-generated as well as patient-contributed information; however, the perceived primary value, and consequently the informatics development efforts, favor institution-generated data and needs over those which may best serve the patient.

Current approaches to patient-contributed health records are found among pediatric care settings and in behavioral health interventions. The wide-spread adoption of WWW tools contributed to the development of web-based access to clinical information systems (e.g. PatCIS, PatientSite). Health information technology vendors are rapidly developing patient access tools among their suite of electronic medical records (e.g. Epic MyChart, www.epicsystems.com) However, most of these approaches are “tethered” to a given institution or care situation, and largely focus on insuring patient access to data collected in the course of clinical care. “Untethered” personal health records are free-standing repositories into which an individual can record various observations, such as dietary plans or exercise monitoring information. An example of an unethered PHR is that provide by include WebMD (www.webmd.com). The grantees of Project HealthDesign are charged with leveraging the positive...
aspects of the current personal health record as well as those of emerging and future technologies to provide a PHR that not only captures health data, but also integrates and transforms it into actionable information for improving health.

Tang and colleagues provided a state-of-knowledge assessment of personal health records, with an emphasis on computer-based implementations. Personal health records serve as repositories of clinical and self-monitoring information, and hold greatest value when the personal health record is closely integrated with the records created in the course of clinical care. Tang and colleagues acknowledge the need for augmenting access to clinically-generated data with the ability to record personal observations and gain access to helpful resources such as decision support and care management guidelines.

The very idea of using clinical records to engage lay people in personal health information management is not new. Indeed, in 1975, Ruth Lubic, a nurse midwife, created a then-revolutionary clinical information management system at the Maternity Center in New York. In the Maternity Center, patient charts were kept in front of, not behind, a reception station, and on arrival, the patient recorded observations such as weight, urine protein, etc. Lubic’s records presaged a fundamental concept found in today’s personal health records agenda: patients and clinicians serve as co-authors of the clinical record, and the record itself as an information link between the clinician and the patient. However, Lubic’s records remained stored off-site at the clinic, and did not offer any support for health information management in the home.

Lay people develop robust, rich strategies for managing health information in the home. Work by Brennan and colleagues explored the personal health information management challenges faced by 49 community-dwelling adults. They documented that most households handle 8-10 different types of health information, including treatment advice and instructions, insurance claim forms, appointments and clinical contact data, and general health resources and health promotion information. Although physicians and clinics were the most common sources of information, lay people also valued health information they received from family and friends, local news reports, and the public library. The family calendar served as a common health information management tool, as did binders, file drawers, and, occasionally, computerized files. Importantly, in more than two-thirds of the households, a single member, usually a woman, served as the primary health information manager.

**Stimulating Innovation in PHRs**

Currently the personal health records development can be characterized as fragmented and non-scalable. The absence of data standards, shared terminologies, and common architectures plague the personal health records as much as their absence continues to challenge the development of electronic health records. The most serious limitation to the current approach to personal health records arises from the separation between an institution-centric record and the health information management challenges faced by individuals. Personal health records cannot substitute for creating interoperability and robust information exchange across institutional information systems, and it is not clear that simply providing portals to view clinical information systems or free-standing collections of personal observations will ever fully achieve the support needed by patients as they face an ever-increasing role in health information management.

Current conceptualizations of the personal health record carry an implicit expectation that a person (clinician, patient, parent) must literally read, then process the specified content of the record. Indeed many discussions of personal health records emphasize screen design, layout, and the availability of on-screen navigation and interpretation assistance as critical success factors. However, the benefits of PHRs could be greater if the PHRs supported dynamic capture of data gleaned in day-to-day living situations; integrated those observations with advice, recommendations or engaging displays; and guided action, not simply data collection. For example, a camera-equipped cell phone could be used to capture a picture of a meal, send the image through an analysis program, query a nutritional database, and make a recommendation about modifications or warnings for food allergies. Sophisticated processes, such as medication reconciliation now recommended for every clinical encounter could be accomplished by automatic, agent-directed review of electronic documents, rather than having the nurse and patient together review a screen-summary or a printout of recent prescriptions. Additionally, configuring patient preferences for care activities (e.g. life support, advanced directives) as a type of guideline implementation and inserting that guideline into an electronic record system could form the foundation of rules to govern subsequent care decisions.
One way to stimulate innovation in personal health records is to encourage designers to think about separating the unique aspects of an application from the infrastructure needed to support the application. Unique aspects of an application include the specific components, such as blood glucose level capture and presentation or nutritional advice based on food preferences. The infrastructure dimension includes general health information and technical functions that undergird the application. These might include core data elements, such as medications, laboratory results, allergies, diagnoses and family history, and technical services, such as message handling and access controls that can be shared by multiple applications. For example, two personal health applications could include a medication management tool that would alert someone when it was time to take one of his or her medications and a tool that could help someone minimize medication expenses by searching the Internet to offer generic substitutions or discover the lowest available prices. Both of these applications would rely on access to an accurate, up-to-date medication list, which could be provided as part of a common platform. Having a standards-based common platform with open application programming interfaces (APIs) and a highly flexible architecture could stimulate greater competition and innovation in the development and marketing of PHR applications, which could lead to a greater diversity of products and services.

Encouraging designers to develop PHR applications that can easily enter the public domain represents a second approach to stimulating innovation. The contemporary proprietary approach to software development contributes to a legacy of non-interoperable applications. Lay people face many health problems concurrently, and a proprietary approach to PHR development necessitates that the individual cope with multiple stand-alone, potentially incompatible tools to manage their health information and health practices.

Methods and Approach

Stimulating Innovation: The Call for Proposals

A call for proposals was released nationally via the RWJF website, through electronic mail, and via regular U.S. mail. A 75 day proposal preparation period followed, during which two web-delivered informational seminars were held to advise potential grantees about the scope and vision of the next generation of PHRs. Individual consultations were available from the National Program Office (NPO) of Project HealthDesign, hosted at the University of Wisconsin-Madison. Potential grantees were asked to address five criteria:

1. Vision and significance of the PHR application
2. Effective strategies to engage a target population in requirements determination and prototype development
3. Contribution to the overall effort, including the use of standards-based approaches and a willingness to collaborate in the specification of the core functions expected of a common infrastructure.
4. Technical merit of the approach, including anticipating future technologies
5. A robust, interdisciplinary design team

Potential grantees were given the dual challenge of engaging a specific, target population in defining the requirements needed for personal health management and creating a bold vision of technology support for to meet those requirements. Potential grantees were encouraged to focus attention on creative PHR applications that expanded the current scope of PHRs far beyond the information integration tools presently available, rather than restricting their visions to what is currently available or feasible.

Selecting the Most Promising Innovations

All proposals received by the deadline (September 19, 2006) were vetted by the RWJF staff and the NPO. Proposals were then reviewed by the National Advisory Committee (see www.projecthealthdesign.org for the full list); finally nine proposals were selected for an 18 month award to engage in an intensive design process and prototype development activity.

Characterizing Innovations: Summarizing the Proposals

While the nine grantee teams are proceeding with their design work, an analysis of the full set of proposals reveals the vision and intensity of PHR initiatives designed to promote health present in our contemporary environment. Using simple counts and content analysis, we provide a summary of the full set of proposals to the Project HealthDesign initiative.

Results

One hundred sixty-seven proposals were received from a wide range of universities, health care and health information management providing organizations (See Figure 1).
From among these, the nine grantee teams were selected. The proposers came largely from educational, clinical and other not-for-profit institutions.

The teams addressed the health problems of many groups, including those shown in Table 1:

<table>
<thead>
<tr>
<th>Target Population</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>General population</td>
<td>52</td>
</tr>
<tr>
<td>Diabetes</td>
<td>25</td>
</tr>
<tr>
<td>Preventative care</td>
<td>10</td>
</tr>
<tr>
<td>Obesity</td>
<td>8</td>
</tr>
<tr>
<td>Mental health</td>
<td>5</td>
</tr>
<tr>
<td>Cancer in remission</td>
<td>4</td>
</tr>
<tr>
<td>Chronic Care and pain mgmt</td>
<td>6</td>
</tr>
<tr>
<td>Cancer</td>
<td>4</td>
</tr>
<tr>
<td>Asthma</td>
<td>3</td>
</tr>
<tr>
<td>Heart failure</td>
<td>4</td>
</tr>
</tbody>
</table>

Note: Some proposals did not identify a target population

Two major classes of technical challenges must be addressed to make the applications envisioned in these projects fully functional. The first set includes a range of tools needed to capture and display data in real time. For example, some of the proposed PHR applications required a way to capture and record the food consumed or the activities undertaken in the course of day to day activity. Applicants envisioned using videophones, diaries contained on personal digital assistants or web sites, and audio recordings to capture these data. The second technical challenge focused on the need to extract data from electronic clinical records or personal health records. Many challenges exist in this area: identity, authorization and authentication management, efficient tools for locating and extracting information from clinical records, language and message standardization to ensure that information drawn from disparate sources can be integrated into a single view.

Discussion

The vision and enthusiasm of responders to the RWJF Project HealthDesign call for proposals portends a bright future for extending personal health records from passive information archives to tools for active engagement in healthy behaviors. Applicants focused on creating tools for use in the day-to-day lives, and for creating better linkages between the personal day-to-day lives of people and the experience in the clinical care encounter.
The potential grantees to the Project HealthDesign program described applications that embrace innovations in the use of commercial electronics to deliver health innovations. Most applications rest on a robust personal health record on which to base innovation designed to drive personalized health behaviors actions. Potential grantees envisioned ways to use portable devices (cell phones, palm-based devices), reflecting the recognition that health occurs in the day-to-day behaviors of lay people.

The proposals described PHR applications that largely relied on applying existing proven technologies to the challenges of health information management. Sensor technologies, including wireless monitors and motion sensors were envisioned by fewer than 20% of the proposals.

The potential of creating useful personal health applications can be stymied by the technical challenges that underlie effective electronic information capture, transfer, and integration. These challenges are not unique to the personal health records arena; indeed, devising effective strategies to integrate data from different electronic health records would benefit the entire health IT industry and health care as a whole. Nonetheless, it is through envisioning the potential of personal health records that it will be possible to enumerate the challenges common across various applications and begin to set priorities for solving them.

By envisioning the technical challenges that are common across multiple personal health applications we hope to stimulate development in this area. Rather than having each PHR and personal health application solve the same technical challenge repeatedly and potentially in a suboptimal manner, identifying the common shared challenges will allow creating common, shared solutions.

**Conclusion**

The future for personal health records that can support health promotion actions is bright and vibrant! Over 160 visions of personal health records envision a wide range of health promoting applications. While many of the technical challenges are daunting, focusing attention on the design of applications will reveal a core set of functions that can promote interoperable personal health applications likely to engage laypeople in health promoting behaviors and full realization of the benefits of contemporary health care.

**References**