



Project HealthDesign: Rethinking the power and potential of personal health records

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ABSTRACT

Project HealthDesign, a multi-year, multi-site project sponsored by the Robert Wood Johnson Foundation with additional support from the California HealthCare Foundation, is designed to stimulate innovation in personal health records (PHRs). Project HealthDesign teams employed user-centered design processes to create designs and prototypes of computer-based applications to support and enhance human health for a wide range of patients, from children with chronic health conditions to elders transitioning from hospital to home. A program design philosophy encouraged designers to envision PHRs as a suite of personal health information management tools, or applications, separate from, but drawing upon, personal health data from a variety of sources. In addition to information contained in one's medical record, these personal health data included patient-supplied clinical parameters such as blood glucose and daily weights; as well as patient-generated observations of daily living (ODLs) – the unique, idiosyncratic cues, such as sleep adequacy or confidence in self care, that inform patients about their abilities to manage health challenges and take healthy action. A common technical platform provided infrastructure services such as data standards and identity-management protocols, and helped to demonstrate a scalable, efficient approach to user-centered design of personal health information management systems. The program's ethical, legal and social issues consultancy identified challenges to acceleration of action-focused PHRs: personal control of privacy choices, management of privacy in home conditions, and rebalancing power structures in shared decision making.

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1. Introduction

Personal health records (PHRs) represent an important and increasingly accepted health information technology innovation necessary to support patient-centered care, self-management, and effective use of health care delivery systems resources. Yet, at the time of the inception of Project HealthDesign, the emphasis in the design and deployment of PHRs had largely focused on their ability to serve as views into electronic health records [1,2]. PHRs could serve as external storage space for parts of the clinical record, such as the problem list or prescriptions [2], or, if implemented in a web environment, serve as a window into selected segments of the electronic health record. Today, most PHRs on the market bundle a person's data (their "record") with any additional features, such as displaying trend information, providing health risk appraisals or supplying links to educational materials, to form an overall PHR product.

Lay people need more from PHRs than simple access to medical records. Indeed, patients who do want to review part of the clinical

record do so by seeking very specific information (e.g., laboratory results) in a rather episodic fashion [3]. Yet patients have actually developed very sophisticated and complex ways to observe, monitor and record health information they perceive as valuable [4] and seem to be ready to use PHRs to accomplish the challenges of personal health information management. To address the gap between what people do with health information and how PHRs were emerging, Project HealthDesign was developed to stimulate innovation in personal health information technology.

2. Project HealthDesign general approach

Project HealthDesign began with a vision: PHRs should stimulate health action. Real innovation in this space required a novel approach to design, one that focuses on the patient as the key user of health information technology. Nine teams were selected to receive grants from the over 150 applicants who responded in a national competition to the Robert Wood Johnson Foundation's (RWJF) challenge to envision personal health records not as a repository of data but as a platform for action in support of personal health. Teams were challenged to design and build prototypes of personal health applications that could draw upon data

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contained in a personal health record. They were, in effect, freed of the responsibility to develop a data platform and told instead to focus only on the applications. Each team proposed a user-centered design approach to identify and create innovative technical responses to the health information management needs of a defined population (e.g., school-age children with cystic fibrosis; elders with multiple chronic conditions being discharged from the hospital; adults with chronic, non-cancerous pain). Design consultants facilitated a structured, collaborative design process in which all grantee teams participated in semi-annual workshops established to identify common points of engagement across the teams. Identification and potential resolution of ethical legal and social issues (ELSI) germane to the PHR design process were handled by an ELSI consultation team. To accelerate rapid cycle innovation, we created a technical consultation resource that guided teams in a requirements determination process, which in turn led to generating core functional specifications necessary for PHRs and a web-implementation of a common platform encompassing selected key functions. Thus, the grantee teams were free to focus their innovation resources on user-centered design activities towards a prototype solution to their defined population's needs, and the 'back end' data management support for the projects was provided by a common platform [5].

In addition to engaging grantees in an innovative design exercise, Project HealthDesign attempted to stimulate innovation in the broader health information technology vendor community. Two facets of the project were directed towards these goals: using an open source model of distribution and capitalizing on public policy communication channels. All software products developed with project funds were distributed under the Lesser General Public License (LGPL) open source agreement through the project website [6]. We used multiple pathways for communicating project lessons throughout the course of the program, including regular updates on the project website, written primers summarizing key findings of the grantee teams, policy briefings, and regular posts on project-related blog sites.

3. Project accomplishments

Nine grantee teams completed a 30 month design-and-prototype building process. Table 1 summarizes the teams, their target audiences and a high-level summary of their solutions. Details,

including reports, interview guides, source code, and project images are available at the project website. A key technical accomplishment is the release of a publically-accessible web-deployment of the Project HealthDesign common platform, open source distribution of the source code from the common platform and complete requirements definition and functional specifications. The papers in this supplement complement materials on the Project HealthDesign web site and serve as an archival record of the work produced in this initiative.

4. Lessons learned

Through Project HealthDesign over 200 lay people with a variety of health concerns participated in one of the most extensive user-centered design exercises documented to date in the evolution of personal health records. Engagement of this broad range of individuals revealed much about health practices and the features that make technological solutions to personal health-management viable. Perhaps the most important lesson that emerged was that user demand for personal health applications revealed a greater need for day-to-day data (observations of daily living, ODLs) than for the relatively static clinical record data. Through design and prototyping activities, grantees demonstrated the feasibility of collecting and storing ODLs in a PHR, thus providing individuals with opportunities for better informed and higher quality health care.

Discussions with and observations of participants across the nine teams uncovered a range of rich, sophisticated personal health-management strategies. Lay people engage in health practices and health behaviors everyday, not just during visits to clinicians. They revealed that they attend not only to signs and symptoms of illness as directed by clinicians, but also to the idiosyncratic, highly personal thoughts, behaviors, attitudes, sensations, and environmental conditions that inform them about their health state and alert them to take action related to health. These observations of daily living (ODLs) complement traditional signs and symptoms of disease (e.g., blood pressure, shortness of breath) and highlight the personal experience of health and disease. ODLs include attending to cues such as the quantity and quality of sleep, the confidence one feels in self-management, the tenor of family dinner conversations, the cadence of speech, or the ease of doing daily tasks like opening a jar. We believe that further investigation of ODLs is essential, because they form the first signals that draw a person's attention to

Table 1
Summary of the grantees from Project HealthDesign.

Project title	Project team	Population	Solution	Observations
My Medi-Health	Vanderbilt University	Children with complex disease	Smartphone with "skins" for medication storage	Self-management of medications
A personal health-management assistant	University of Rochester	Elders with congestive heart failure	Spoken natural language query-and-response system for self-assessment	Elder's concerns and self-assessment of pain, rest, joint and limb swelling and mood
Living profiles	Art Center College of Design/Stanford University	Teens with special health needs	Quality of life timeline integrates moodmeter, activity, and decisions	Mood, activity, engagement with friends, medications
HealthReachMobile	University of Washington	Adults with diabetes	Glucometer-cell phone-coaching and feedback system	Meals, medication dosing, trends relating meals and insulin doses
My diabetes data manager	Joslin/TRUE Research Center	Adults with diabetes	iGoogle gadgets for diabetes management	Meals, activity, mood, care choices forecasts
Colorado care tablet	University of Colorado Denver	Elders on discharge from acute care	Tablet PC with blue-tooth hand scanner	Photos of medications, prompts for key issues
EPTAD: electronic pain/treatment/activity diary	University of Massachusetts	Adults with non-cancerous pain	HP iPAq with touch interface; seven recording modules	Meds, acute and chronic symptoms of pain, activity, treatments
ActivHealth	RTI, International	Adults with sedentary lifestyles	Implement behavior change plan on the web	Activity, motivation, goals, progress towards goals
Customized care plan	UCSF	Women with Breast Cancer	Single point of access for calendar, treatment schedule, images	Important events in personal life, pain, goals

health concerns, and may co-vary in important and meaningful ways with traditional indicators of health.

Many of the technological solutions developed by grantees employed existing general purpose solutions (e.g., smartphones, web portals). Project HealthDesign stimulated much learning about the acceptability of such solutions to lay people. We learned the importance of making data capture easy if individuals need to do it often. In some cases, emerging technologies like blue-tooth enabled pedometers were rejected in favor of simpler approaches such as typing in numbers. Capturing images of food failed as an input strategy; users preferred menu-driven food choice approaches. Visualization through charts and tables, particularly of health experiences across time, proved particularly valuable to individuals. On the other hand, some teams found that text messages, even from trusted clinicians, were annoying and off-putting.

The activities of Project HealthDesign occurred during a period of great innovation in health information technology. Technology firms, such as Google and Microsoft, released consumer health information products that represented a next generation of PHRs that paralleled the Project HealthDesign model of separating the data from the applications through a common platform. Social media, including such applications as Facebook, gained acceptance by the general public, affording support for personal health information management using information technologies. Within the health policy arena, the Office of the National Coordinator of Health Information Technology stimulated the creation of standards and use cases. Against this backdrop of increasing public awareness, industry investment, and policy sophistication, the general concept of technology-based personal health information management flourished.

5. Conclusion

Project HealthDesign demonstrated a vision of health information technology wherein PHRs serve as platforms for action, using technology to bring together health monitoring data, observations of daily living, and clinical guidance. Separating data from the applications that used the data enhanced the innovation in the tools available for lay people engaged in self-management, and portends increased innovation and flexibility in design and application. Significant, non-trivial technical and policy problems remain, including efficient ways to permit users to manage privacy and access rights, to insure integration of data from disparate sources – including the patient – and to generate trusted data ex-

change agreements between formal health care organizations and third party data integrators like Microsoft HealthVault.

6. Overview implications

The real value of PHRs lies not in their role as effective records, but in the action they enable. Separating the data from the applications enables greater innovation in the applications which can facilitate that action. Expanding the concept of the PHR to include observations of daily living further enhances the provision of actionable health information. By incorporating a focus on observations of daily living PHRs can help realize the potential to bring everyday life experiences into the health care encounter and health care into the everyday life experience.

7. Role of the funding agencies

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8. Disclosure statement

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