E-Primer 1

Project HealthDesign:
Rethinking the Power and Potential of Personal Health Records

A New Vision for Personal Health Records

Health care institutions and software developers currently offer an array of personal health record (PHR) products that give patients access to institutional health care records or help them compile freestanding collections of personal health observations. While this move toward paperless systems is a significant step in the right direction, most PHRs derived from institutional records generally become inaccessible to patients when they change providers, while those that are freestanding rarely integrate well with institutional records. And, because many current PHR products are proprietary in nature, most consumers cannot build on or customize existing PHRs to fit their widely varied health needs.

Leaders of Project HealthDesign aim to move the field toward a broader vision of how PHRs might help consumers lead healthier lives. The program, a national initiative funded by the Pioneer Portfolio of the Robert Wood Johnson Foundation (RWJF) and the California HealthCare Foundation, supports the development of PHR systems designed to help patients not simply access their own medical records, but use personal health information in real-time to manage and improve their own care.

Project HealthDesign starts from the perspective that PHRs ought to reflect and respond to what is going on in our individual lives.

"The focus of PHR development so far has been on what is contained in the medical system: claims, lab results, clinical data, diagnosis," says Patricia Flatley Brennan, RN, PhD, professor of Nursing and Industrial Engineering at the University of Wisconsin-Madison and director of Project HealthDesign's National Program Office. "That's a good start, but we believe that information about how you live and how you feel on a day-to-day basis is important, and can be incorporated into PHRs to empower patients to make better health care decisions on a daily basis."

"Project HealthDesign hopes to usher in widespread development of next-generation PHR systems that integrate personal medical information with an array of smart, practical tools that overlay the core record to help patients actively manage chronic conditions and offer suggestions to improve their health," says Brennan. It is critical to simultaneously stimulate the marketplace to enhance innovation in

personal health applications. Project HealthDesign believes that public-private-patient partnerships hold great promise in creating bold visions of novel, useful personal health applications that enable patients to play an active role in their health and health care. To accomplish this vision, it is necessary to engage both the health care community and the business sector in collaborative efforts that meld emerging directions in technology development with clearly articulated goals and benefits, which include improved health and increased involvement of individuals and families.

"The current understanding of a PHR is of an online repository of all of the information in your medical record—and that's way too limiting," says Stephen Downs, SM, senior program officer and deputy director of RWJF's Health Group. "We want to stretch the vision so that technology designers and policy-makers see PHRs as resources that don't just allow patients to review their medical information, but instead enable them to make more informed decisions because of it. Project

Using PHRs to Fight Diabetes Day by Day

Managing diabetes is a complex task that requires, among other things, precise use of medications and careful monitoring of blood glucose levels, blood pressure, diet and physical activity. Monitoring and lowering levels of stress can also have a significant impact.

"All of these factors are interrelated, and the patient has to understand how they work together," says **Stephanie Fonda, PhD**, who heads a Project HealthDesign team at the **Joslin Diabetes Center, Inc.** in Boston. "We're developing a PHR application that takes into account personal data a person needs to manage diabetes."

The Joslin team began with focus groups, in which they asked patients who are currently trying to control their diabetes what resources and tools would improve the process. The team then came up with scenarios of how patients might use PHRs to more effectively collect and use real-time data to better manage their diabetes.

The team is looking at how data might someday be added to a PHR and how that data might be used. For example, cell phone cameras might relay patients' food consumption information to dietitians; scales might wirelessly transmit weight readings into the system; and glucose monitors might wirelessly capture data and provide real-time trend analyses.

"Our major focus is developing the intelligence in the system, so as the data come in, this application will do the interpretation, analysis, synthesis and feedback," Fonda says. "We'll be able to provide PHR tools that tell patients with diabetes how they're doing, how they got there and what they can do."

HealthDesign is supporting design teams that are working with people to understand the actions they need to take to manage their health on a day-to-day basis, and then exploring how PHRs can provide them with relevant information about these actions at the point in time that makes the most sense."

Since its launch in December 2006, Project HealthDesign has awarded grants to nine multi-disciplinary teams of medical, design and informatics experts. The teams are now beginning to design next-generation prototype PHR applications specially developed to meet specific patient needs.

PHRs Helping Kids Manage Meds

At **Vanderbilt University Medical Center**, a Project HealthDesign team is building a three-part PHR system to help children take a stronger role in managing medications for cystic fibrosis.

"We've spent the past five months collecting data from parents, children and schools," says team leader **Kevin Johnson, MD**, vice chair of Vanderbilt's department of Biomedical Informatics. "How do we make sure kids get their medications on time in all of the settings where they need to get those medications? How can we help caregivers and schools support these kids? How do we make sure side effects get reported and addressed? These are questions we've grappled with."

Johnson says the team is learning that an effective PHR application should link electronically with databases detailing medication dosages, scheduling and treatment protocols, and disease processes and stages. The PHR should also incorporate patient-specific data, medication history and information about the child's school environment.

The emerging system, called 'My-Medi-Health,' features a medication management assistant for younger kids, text messages to older children, and reminder mechanisms for schools and communications tools that send just-in-time messages to caregivers.

"This system should have an enormous impact on outcomes," Johnson says. "We will radically decrease instances of kids getting the wrong dosage and have much better data to understand when and why a child is experiencing side effects. We will have a very significant impact on adherence, making sure children take medication on time and appropriately."

Johnson says that the PHR will improve communication with physicians, which should help improve teacher and patient education about medication management. "This sharing of information should strengthen the intimacy between patient and doctor," he says.

PHRs Provide a 'Virtual Coach' for Healthier Living

A Project HealthDesign team at **RTI International** in Atlanta is working to develop a web-based PHR application that will help adults increase physical activity.

"Most Americans are sedentary, and even if they don't have a problem with weight, they could still have other risk factors for chronic disease related to their inactivity," says team leader **Barbara Massoudi, MPH, PhD**, RTI senior research health scientist.

The team is building a system that collects information about frequency, duration and intensity of a person's physical activity; takes into account personal health status and goals; and offers a plan for activity that the individual has a better likelihood of following. The RTI team is analyzing techniques that personal coaches use to effectively increase physical activity and building these into the system as a virtual coach.

"The system will help you set reasonable goals and provide feedback with supportive messages. It can link you with others facing similar problems and help you reward yourself when you succeed," Massoudi says.

It will also help with problem-solving by teaching users to think differently about situations. Are you putting off exercise because of a stressful schedule? The system can help you think of exercise as a way to get some relief from stress, instead of one more thing you have to do.

"Patients are hungry for help with their health care," says Project HealthDesign's Brennan. "Building PHR systems that serve as virtual assistants or companions for better health will help address a great unmet need."

"The value of having your medical record in a PHR lies in how that information can help you manage and improve your health—such as taking your medications on time, controlling your blood sugar and weight, avoiding allergic reactions or having richer, more constructive communications with physicians," Downs said. "That's the direction that personal health records need to move toward to be most useful. We also need to expand our understanding of the health information that's relevant. Beyond thinking about diagnoses, lab results and current prescriptions—what you'd typically find in a medical record—we need to look at pain symptoms, sleep, diet, exercise and actual medication intake. Understanding that information can go a long way toward helping someone manage a chronic disease."

Ultimately, Project HealthDesign is bringing together designers and policy-makers to look at the big-picture of emerging technologies like PHRs and rethinking how they can be designed and produced in ways that help consumers manage their health care choices and achieve better health outcomes.

As I See It…

PERSONAL HEALTH RECORDS MUST FIRST BE PERSONAL

By Mark E. Frisse, MD, MBA, MSc

Remember seeing photos of what the first cars looked like? They looked just like carriages, but without the horses. It took years to evolve away from the concept of simply putting an engine on a carriage.

For advocates of health information technology, Project HealthDesign is trying to help us leap over all of the years of building bigger, horseless buggies and think instead about how to build an effective transportation system. Project HealthDesign is rethinking current concepts of what personal health records can and should be before ideas become firmly entrenched—and policies to govern the limited visions are established. Rather than just view PHRs as inactive repositories of information, Project HealthDesign challenges all of us to create PHRs that are highly tailored to help consumers meet their specific health care needs and provide a record of information that's important to patients and their doctors.

That's exciting. And for the health care profession, it's also revolutionary—because institutions and clinicians mainly think about what general information they have available to give patients, not what specific information patients might want and need to know to improve their daily lives and manage their own health.

I think it's clear to many of us that the PHRs being developed today are not as useful as they need to be if each of us is going to use them to take charge of our own health and health care. That's because currently available PHRs are not very personal—and they cannot be customized very well. Many people think PHRs offer us a valuable service if they let us log on to see all of our own clinical data in one spot—and that's true. But what can we do with this information? How can we use it to help us improve our own health? That's the challenge Project HealthDesign aims to solve.

Take obesity, for example. It is one of the greatest problems of American society today, but no PHR as currently envisioned will be ideal for helping patients lose weight. PHRs of the future, the kind that Project HealthDesign hopes to spark, could daily prompt a person to get involved in his or her own health care—creating a meal and exercise plan that is right for his or her particular needs, tracking progress over time and sharing information with his or her doctor in a timely fashion.

Technology designers and policy-makers need to look at emerging technologies like cell phones and social networks on the Web and reconsider how they can be used to manage our health as part of a broader PHR framework. When Project HealthDesign concludes, we will have a handful of solid, working prototypes that demonstrate innovative approaches for how PHRs can help us drive our own health care decisions. We should also have more people creating PHRs that are much more useful than what many of us have currently envisioned. That kind of big-picture thinking is sorely needed.

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