Project **HealthDesign**

Rethinking the Power and Potential of Personal Health Records

Robert Wood Johnson Foundation

Project HealthDesign is helping to create the next generation of personal health records (PHRs)—smart, consumer-friendly PHR systems that are tailored to help patients manage their health and health care more effectively. The program will design and test interoperable PHR applications that address specific health challenges. The goal is to help individuals and families manage complex health data, improve their health and get the care they need.

Launched in December 2006, **Project HealthDesign** is funded primarily by the Pioneer Portfolio of the Robert Wood Johnson Foundation (RWJF), with additional support from the California HealthCare Foundation. The program supports nine multi-disciplinary teams to design a suite of PHR applications that provides patients with clear, actionable information to help them manage their health and achieve their health goals. These tools will be built upon a common technological platform to promote interoperability among diverse applications. Beyond just giving patients access to their health information, smart PHR systems will help them manage and apply that data to improve their health, care and quality of life.

A New Vision for PHRs

Until now, PHR design has focused mainly on giving patients access to institutional health care records or to freestanding collections of personal health observations. Those that are derived from institutional records generally become inaccessible to patients when they change providers, and those that are freestanding rarely integrate well with institutional records. Because many current PHR products are proprietary in nature, few opportunities exist to build on or customize them to meet the diverse health needs of different users.

Project HealthDesign starts from a different perspective: that the development of PHR systems ought to be grounded in an understanding of the daily lives and health challenges of the individuals they are designed to support. Creating the next generation of PHRs must begin with an in-depth look at what patients need, and then find ways to collect, analyze and deliver tailored information that supports their health objectives and fits easily into their daily lives.

The goal in designing and building PHRs should be to:

- Help patients make decisions about improving their health or managing their conditions.
- Monitor real-time vital signs or disease-specific data that are fed into the PHR by sensors and other biomonitors.
- Provide tailored information that integrates patient lifestyle preferences with clinical records from multiple sources, including doctors' offices, hospitals and labs.

What might this look like, and how might patients benefit in the future? Next-generation PHR systems should link personal information with alerts, reminders and other tools that help patients exercise greater control over their health. The vision is that a woman managing asthma and diabetes, for example, uses a PHR system outfitted with tailored tools that remind her to take medications, monitor glucose levels and even incorporate air quality updates into daily decisions. Other patients may soon use PHR-enabled smart phones to monitor glucose levels, weight, blood pressure and biological factors that influence heart disease, hypertension, diabetes and other chronic conditions—and seamlessly transmit data to and from their health care providers.

Project Goals

Project HealthDesign enlists the expertise and vision of patients, health professionals, design experts and informatics leaders in an effort to design and test PHRs that meet patients' needs and improve the ability of health care providers to provide optimal care. Other key goals include:

- Generating insight into the challenges associated with serving diverse populations;
- Ensuring the privacy of patient information and building knowledge of the ethical, legal and social issues associated with next-generation PHR systems;
- Developing an initial set of requirements for data access, storage and transfer that can support a wide range of applications while ensuring patient privacy; and
- Stimulating the health information technology industry to develop consumer-focused personal health records system products and services.

Support for Health Info-Tech Pioneers

In the program's initial six months, teams are designing user-centered personal health applications to help patients living with specific medical conditions. In the subsequent 12 months, they will build application prototypes and test them with their target patient populations. Ultimately, **Project HealthDesign** plans to make promising applications available for further commercial development and dissemination.

Grantee teams around the country are currently working on:

- **Customized Care Plan for Breast Cancer Patients.** A team led by the University of California, San Francisco (Center of Excellence for Breast Cancer Care) is designing an application that helps to build a customized care plan that keeps patients informed about disease and treatment specifics, course of treatment and how to work it into the course of their daily lives.
- **Personal Health Management Assistant.** A team led by the University of Rochester, NY (Department of Computer Science) is designing an application that interprets what patients with heart disease are doing, meaningfully links it to their health care goals and practices and assists them in solving problems to help them manage their conditions at home.
- **Personal Health Application for Diabetes Self-Management.** A team led by the Joslin Diabetes Center, Inc. in Boston is designing an application for patients with diabetes that integrates and analyzes data including nutrition intake, physical activity, medications and biometric information. The tool will provide users with information on: their disease management, how their behaviors influence their progress and recommendations for improved health.
- **Chronic Disease Medication Management Between Office Visits.** A team led by the University of Washington, Seattle is designing three interrelated PHR applications for overweight patients with symptoms of metabolic syndrome. These applications will enable patients to monitor blood glucose, blood pressure and exercise data, and also use cell phones to capture nutritional intake and upload data to their providers' electronic records. This two-way feedback will enable patients to safely adjust medication regimens between office visits.
- **ActivHealth: A PHR System for At-Risk Sedentary Adults.** A team led by the Research Triangle Institute, Atlanta is designing innovative personal health record tools that use biomonitors and other devices to help sedentary adults at risk for, or suffering from, chronic diseases to become more physically active.
- **Supporting Patient and Provider Management of Chronic Pain with Personal Digital Assistant (PDA) Applications Linked to Personal Health Records.** A team led by the University of Massachusetts Medical School (Department of Family Medicine) is designing an application for handheld PDAs that helps patients with chronic pain manage complex medication regimens, adhere to physical therapy protocols, track appointments, maintain pain diaries and practice stress reduction techniques.
- **My-Medi-Health: A Child-Focused Personal Medication Management System.** A team led by Vanderbilt University Medical Center, Nashville (Department of Biomedical Informatics) is designing an application for medication management that recognizes the role that children living with chronic diseases may play in their own care process. The PHR application features a medication management assistant to help children with cystic fibrosis manage medications with their caregivers at home, in school and in other settings. It also facilitates real-time communication about their condition with parents, caregivers and school personnel.
- **Living Profiles: Transmedia Personal Health Record Systems for Young Adults.** A team led by the Art Center College of Design, Pasadena, CA is designing a system that helps teens create and use PHRs on different media as they transition from pediatric to adult care. The applications will help both healthy adolescents and those managing chronic conditions to contextualize personal health events, evaluate potential health risks and establish unique health histories.
- **Assisting Older Adults with Transitions of Care.** A team led by the University of Colorado at Denver (Health Sciences Center, Aurora) is designing a PHR that addresses information management challenges faced by older patients and their caregivers. The team's focus is on improving the quality of transitional care, particularly as it relates to medication management among patients dealing with multiple chronic conditions.

For More Information

Project HealthDesign is a national program of the Robert Wood Johnson Foundation based at the University of Wisconsin-Madison. Patricia Flatley Brennan, RN, PhD, professor of Nursing and Industrial Engineering, is the national program director. For more information and to sign up for program updates, please visit www.projecthealthdesign.org

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