

Project HealthDesign

Rethinking the Power and Potential of Personal Health Records

www.projecthealthdesign.org



Robert Wood Johnson Foundation

Who We Are

Project HealthDesign is a \$5 million national program designed to support health and information technology pioneers in creating a new generation of personal health record (PHR) systems that can share common technical functions. The project is funded by the Robert Wood Johnson Foundation's Pioneer Portfolio, which funds innovative ideas that may lead to future breakthroughs in health and health care, with additional support from the California HealthCare Foundation.

Project HealthDesign funded nine multidisciplinary teams to develop PHR applications that extend and enhance the range of services offered by existing PHRs. Through creative use of information technology that is guided by extensive user-centered design activities, this bold new program provides a variety of tools and services that draw on clinical records and relevant information from people's daily lives. The *Project HealthDesign* teams' PHR applications go beyond providing access to health information to interpret consumers' health data and provide customized, easy-to-use feedback that can guide daily health decisions and empower consumers to manage their health more effectively. The grantees' prototypes are now being tested by patients and families to help them manage complex health data, improve their health and get the care they need. Complementing the individual work of each team, technical specialists created a common platform of computer resources that will make it easier and more efficient in the future to build highly tailored PHR tools.

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The Challenge

As every parent knows, teenagers see the world through a complex lens of dynamic friend and family relationships, high tech gizmos, social interactions and media messages. They don't think like adults—and this is particularly true when it comes to their health. So, how **do** you get a teen living with a chronic illness to take responsibility for the unglamorous, sometimes annoying details of her health? Members of *Project HealthDesign's* Living Profiles team, including experts from the Art Center College of Design in Pasadena, Stanford University Medical School and the Children's Hospital of Orange County have come up with an answer: Give them something that mirrors their own tech-savvy, mobile, pop culture-driven lives. The Living Profiles team's goal is to create a personal health record (PHR) application for chronically ill teens that will help adolescents ages 14–18 assume the skills and responsibility needed to transition from pediatric into adult care settings, make health decisions and maintain their personal health information—tasks their parents used to manage for them.

The Solution: Where We Are Now

The Living Profiles team researched teens' culture and experiences to determine how best to design tools—gadgets and Web spaces/places—to help them become aware of activities and events in their lives that impact their health and then assume responsibility for managing those factors. The teens were clear that if a PHR application is to be meaningful (and used), it must exist within their world and help to improve their quality of life as *defined by them*. In addition, the research showed that, while teens are keenly interested in and curious about their health, they may lack the communication skills that would allow them to talk effectively about their health and how they're doing with adults in a clinical setting.

The team developed Living Profiles, a prototype that serves both as an information source for chronically ill teens about their conditions—in this case, juvenile arthritis, systemic lupus and hemophilia—as well as a new communication space. Functioning somewhat like a health-focused MySpace, the Living Profiles PHR application will help teens share and negotiate their health care status and needs with their providers. Teens will aggregate multiple real-time data streams—mood, behaviors and visual representations such as photos or streaming video—visualized in the context of life goals. The intent of Living Profiles is to encourage teens to share this information with their medical and family care-giving team so that they are better informed about a teen's short- or long-term goals. Adjustments to their treatment will be negotiated to fit the teen's needs. For example, one teen is excited about her upcoming prom. Living Profiles will allow her to share this goal with her caregivers. Her family and medical team can use the information to relay concerns each has about the event and negotiate an acceptable management plan to ultimately attend Prom.

This PHR system promotes a teen's independence through them gaining a better understanding of their illness and its impact on their life and through improved communication and more personalized treatment plans. Ultimately, this improves the health outcomes of teens with chronic illnesses and supports their transition to self-management.