

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

More than 50 million Americans suffer from chronic pain linked to common conditions such as spine disorders, osteoarthritis, neuropathy and headaches, adding up to an estimated cost of \$70 billion per year. Treatment may include several types of medication, physical therapy, massage and exercise, psychological counseling and relaxation, and spiritual practices like meditation and yoga. With all of these options, optimizing the treatment of chronic pain remains a significant challenge for both people living with pain and their primary care providers, who are responsible for most routine pain care.

A detailed, accurate history of a patient's pain experience (including what makes pain better or worse), physical functioning and response to therapies is essential for effectively managing pain, but there are many barriers to getting patients to communicate this history—and getting providers to hear and interpret it wisely. Patients in pain may have limited capacity for recall and/or lack communication skills to convey specific details regarding pain experiences. Clinic encounters are limited in time, and many providers have limited experience in pain management. Typical pain and function questionnaires, completed weekly, monthly or at the end of the day, cannot possibly capture all essential details of the pain experience as it unfolds and changes, sometimes by the minute, throughout the day and night.

The Solution: Where We Are Now

As part of *Project HealthDesign*, the team based at the University of Massachusetts Medical School has developed a handheld electronic pain and activity diary (EPAD) that will interact with an electronic personal health record (PHR). Built on a personal digital assistant platform and customized to users' typical experiences, the EPAD application allows people with pain to record structured information on their pain experience, treatment and physical activities every two hours throughout the day. The EPAD will allow people living with pain to generate rich and accurate information that can be used by their health care providers, as well as to help patients to learn about their own pain triggers, treatment effects and temporal pain patterns. The team is also working on developing software that will automate the analysis of information captured in the EPAD to offer patients and providers key insights about a patient's pain and treatments informed by best practices in pain management. In the next phase of this project, the team will field test the EPAD and analyze data about how well the device helps patients and their caregivers manage medications and control chronic pain.