

# Project HealthDesign

Rethinking the Power and Potential of Personal Health Records

[www.projecthealthdesign.org](http://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.

## National Program Contact

Patricia Flatley Brennan, R.N., Ph.D.  
National Program Director  
Project HealthDesign  
National Program Office  
University of Wisconsin—Madison  
School of Nursing  
600 Highland Avenue, CSC H6/297  
Madison, WI 53792

Linda Brei, Communications Liaison  
(608) 263-5250  
[lgbrei@wisc.edu](mailto:lgbrei@wisc.edu)

[www.projecthealthdesign.org](http://www.projecthealthdesign.org)

## Project Contact

Laura Esserman, M.D., M.B.A.  
Director, Translational Informatics  
University of California San Francisco  
Carol Franc Buck Breast Care Center  
1600 Divisadero Street  
San Francisco, CA 94115  
(415) 885-7691  
[laura.esserman@ucsfmedctr.org](mailto:laura.esserman@ucsfmedctr.org)

## The Challenge

When breast cancer is diagnosed, patients often find themselves overwhelmed and they need help with the challenge of balancing frequently complex treatment protocols with the demands of everyday life. Although there are many online tools to help patients choose among health care providers and lots of sites about breast cancer, few (if any) tools exist to assist patients in comparing and selecting treatment strategies, tracking their treatments across providers and institutions, and linking their treatment plan with the realities of their everyday lives.

To fill this void, a *Project HealthDesign* team led by the University of California, San Francisco (UCSF) is designing a personal health record (PHR) application to help breast cancer patients better understand and proactively coordinate their care. Using an open-source, free, Web-based PHR system, the team is developing a novel clinical information tool that is calendar-based, enabling patients to conveniently schedule and keep track of events important both to their lives and to the treatment of their illness. The tool will provide people who have breast cancer a voice and a window into the management of their own care.

## The Solution: Where We Are Now

Incorporating years of feedback and multiple patient and physician focus groups, the UCSF team has designed a prototype personal health record system for breast cancer patients and providers whose central feature enables the organization and display of information on a calendar to compare treatment options and show past and scheduled treatments. This application will collect critical data from patients and providers at the point of care. Using visualization tools, the PHR tool will facilitate the integration of treatment scheduling, care planning and reminders for visits, and make critical information such as prescriptions, next steps of care, and next visits easy to find. This tool supports collaborative decision making between the patient and provider and helps breast cancer patients gain better control over their treatment plan, giving them a clear sense of what has gone before and what is yet to come. Since fewer than 5 percent of all breast cancer patients receive the type of integrated care the plan could provide, this tool has the potential to revolutionize breast cancer care and the degree of control that patients have over their care. This tool is also designed to be a potential starting point for creating an anonymized patient-based registry open to patients, care providers and researchers. The UCSF team is planning a nationwide demonstration project to determine the viability of this patient-centered system as a transformative agent in breast cancer care.