

# 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.

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## The Challenge

Teaching a child to take responsibility for his or her own health is challenging for any parent, but when the child is living with a chronic disease, the task can be both frightening and overwhelming. Researchers at Vanderbilt University Medical School saw *Project HealthDesign* as the perfect opportunity to help ease their young patients into taking charge of their health using a personal health record (PHR) application. The Vanderbilt team asked young patients and their families what they needed most to facilitate a smooth transition to self-care. They found that children were anxious to accept responsibility even when they were given the opportunity and had appropriate tools to support their efforts. The team then suggested a PHR application for 5- to 9-year-old children with cystic fibrosis and their caretakers to use—both at home and in daily activities at school and other settings—to track medications, alert parents when doses have been taken (or not taken), and manage prescription refills. With the help of such a tool, medication management does not have to take place in isolation from other activities of a child's and family's daily living.

## The Solution: Where We Are Now

To help create a safer transition to self-care for children, Vanderbilt team members are developing a medication management device that can be placed in a variety of age-appropriate packaging to work with the application. Children can allow or disallow alerts based on their needs and the application can be tightly tailored to meet the family's needs. The device reminds kids to take medications at established intervals and can notify parents, school personnel and others if there is no response to a reminder. Currently, the team is interactively developing and evaluating a functional prototype using pagers and cell phones linked to a PHR designed to support the ability to: create a medication schedule; review that schedule and specific medication information on the phone; and audit activities that are performed on the device.

The child will have access to a device that is not stigmatizing, and that is able to provide a visual or auditory prompt to self-administer a specific medication at a pre-set time (or after a specific event). The system logs any mistakes the child may make in taking his or her medication and passes that information on to caregivers. It also provides opportunities for the child or others to log details if a side effect occurs. This device integrates with a PHR that is used to set up a dosing schedule, download medication-specific data (such as the picture and name of the medication to administer), and identify the side effects to look for in age-appropriate language. The phone will communicate between the patient and other caregivers using a common messaging standard.