Executive Summary

Project HealthDesign: Rethinking the Power and Potential of Personal Health Records

Project HealthDesign: Rethinking the Power and Potential of Personal Health Records, a Robert Wood Johnson Foundation (RWJF) national program, sought to expand the vision of personal health records beyond being essentially electronic copies of patient medical records that patients can view online, and to encourage the market to develop a variety of products that will meet the diverse needs of patients—by finding ways to use electronic technologies to put a wide range of useful, actionable information into their hands. Project HealthDesign’s leaders hoped not only to support the development of devices that would show the true potential of personal health records, but, more fundamentally, to demonstrate a novel, patient-centered approach to health information technologies.

In two rounds of funding, Project HealthDesign awarded grants to 14 interdisciplinary teams that completed a series of projects designed to stimulate innovation in personal health information technology. Project HealthDesign ran from February 2006 through June 2014. Over its eight-year duration RWJF funding totaled $9,447,565.

Read the full report. Learn more about the program here.

CONTEXT

Experts believed that improvements in health information technology, especially personal health records, could improve communication between physicians and patients, provide physicians with more complete medical records, and promote better coordination of patient care across providers—leading to improved patient health.
Yet, despite the dramatic evolution in the availability and capacities of personal health care technologies, and in the willingness and ability of patients to observe, monitor, and record health information, many limitations persisted in the types of data collected and the ability to share information electronically between patients and providers. The personal health record marketplace remained fragmented, with little ability for the individual consumer, whether patient or physician, to combine sources of health data in a multidimensional, easily comprehensible format.

**THE PROGRAM**

*Project HealthDesign* awarded 14 grants in two rounds of funding.

The nine teams receiving grants in Round 1\(^1\) (running from December 2006 through February 2009) focused on developing personal health record applications that would enhance the range of services and data available to patients. These applications were designed to:

- Help sedentary adults become more physically active—Research Triangle Institute (Research Triangle Park, N.C.)
- Help adolescents manage chronic disease—Stanford University School of Medicine (Stanford, Calif.) and Art Center College of Design (Pasadena, Calif.)
- Help breast cancer patients understand and coordinate their care—University of California, San Francisco
- Help older adults manage medication regimens—University of Colorado Denver Fitzsimons Early Learning Center (Aurora)
- Help patients manage chronic pain—University of Massachusetts Medical School (Worcester)
- Help cardiac patients monitor their condition—University of Rochester (Rochester, N.Y.)
- Help diabetes patients monitor their condition via cell phone—University of Washington (Seattle)
- Help children manage cystic fibrosis—Vanderbilt University Medical Center and Vanderbilt University School of Medicine (Nashville, Tenn.)
- Help adults self-manage diabetes—Walter Reed National Military Medical Center (Bethesda, Md.)

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\(^1\) Funding for Round 1 was about $350,000 per project.
Project leaders encouraged the five research teams funded in Round 2 (from December 2009 to April, May, or June 2012) to build on the key lessons learned in Round 1. Chief among these was the understanding that the personal health information individuals find most valuable derives less from their medical records than from their own observations regarding their day-to-day activities and behaviors. These applications were designed to:

- Help older individuals watch for signs of cognitive decline—Carnegie Mellon University School of Computer Science, Human-Computer Interaction Institute (Pittsburgh)
- Help asthma patients monitor and control symptoms—Research Triangle Institute (Research Triangle Park, N.C.)
- Help low-income teenagers and young adults manage obesity—San Francisco State University, Health Equity Institute for Research, Practice, and Policy
- Help young adults manage Crohn’s disease—University of California, Berkeley
- Help protect the health of preterm, low-birthweight infants—University of California, Irvine

**Help for the Grantees**

Program leaders and staff from the national program office at the University of Wisconsin-Madison School of Nursing supported the funded projects through:

- Direct-to-grantee support, such as conference calls and site visits
- Funding of experts in focus group research; technology; regulatory, legal, and ethical issues; communications; and future scenario planning

A team of researchers at the Oregon Health & Science University in Portland, Ore., conducted an evaluation of the five projects in Round 2.

**KEY FINDINGS**

**Round 1**

Leaders of *Project HealthDesign* cited one especially significant finding that emerged from the projects in Round 1:

- **Observations of daily living**—the experiences of their day-to-day lives—turn out to be most meaningful to patients, more so than clinical data.

Other important findings from Round 1 cited by program leaders included the following:

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2 Funding for Round 2 was about $500,000 per project.
• Participants seemed willing to use a wide variety of technologies to record, enter, and receive data in their personal health records, from a smartphone to a Fitbit body monitor.

• Having access to their personal health information and control over it seemed to be even more important to patients than privacy.

Round 2

Program leaders cited the most significant finding of Round 2:

• **Observations of daily living can improve clinical decisions.** The Round 2 projects demonstrated that combining observations of daily living with traditional clinical data gives physicians and other providers a more robust picture of a patient’s health, leading to improved clinical decision-making and saved lives.

Other important findings from Round 2 cited by program leaders included the following:

• **Observations of daily living are most often incorporated into the clinical workflow not by physicians but by nurses, health coaches, and other providers.**

• **Available technologies make it possible to track a patient’s progress with far more specificity than can be done through weekly or monthly visits to a doctor’s office.**

Findings From Consultants

In order to provide advice to the program overall and support to grantees in key areas, leaders of Project HealthDesign funded experts in a range of fields.

Focus group researchers reported the following key findings:

• **Consumers want full access to the health records kept by their providers.**

• **Consumer participants focused far more on the benefits of electronically available records than on concerns regarding privacy.**

Technical consultants reported the following important lessons related to the development of a common software platform for personal health record applications:

• **A common technical platform can support a variety of personal health application tools.**

• **Centralizing common functions reduces implementation time and increases interoperability among personal health applications.**

Regulatory, legal, and ethical consultants reported key concerns:
With regard to privacy and security:

— In the new world of health technologies, patients themselves play an unprecedented role in safeguarding their health information.

— Patients may not feel comfortable sharing all of the data in their personal health records with all of their health care providers.

With regard to mobile security:

— The responsibility of health care providers for implementing security measures increases when the provider is supplying patients with mobile devices and encouraging them to share health information on them.

— Patients can be easily overburdened by security measures, both because they do not want to be inconvenienced and because their technical skills may be limited.

Questions about clinician liability:

— When do physicians become liable for failing to respond to information submitted by patients through a personal health application?

— How do clinicians know that patient-generated data are accurate, or that some relevant data have not been lost or compromised in transmission?

EVALUATION RESULTS

A team of researchers headed by Deborah J. Cohen, PhD, MA, of the Oregon Health & Science University in Portland, Ore., conducted an evaluation of the five projects in Round 2 of Project HealthDesign.

The evaluation team developed a model with six factors that explain patient motivation to collect observations of daily living: usability, information technology infrastructure, perceived relevance of the data, burden involved in collecting data, emotional activation, and variations in health or illness state.

MAJOR CHALLENGES

Program leaders cited several significant challenges that surfaced during the program. While Project HealthDesign has ended, these challenges persist and must be considered as the personal health technology world continues to develop and expand.

Keeping up with technology—the remarkable speed with which health technologies evolved over the program’s life span, and keep on evolving

Accommodating technology—the numerous barriers standing in the way of integrating observations of daily living into clinical practice

Technical compatibility—among health information applications and systems
• Questions regarding patient privacy—and the need for protocols addressing the sharing of information

AFTERWARD

As of late 2014, many of Project HealthDesign’s grantees are continuing their project work in various ways, though not with RWJF funding. Two other RWJF-funded projects with relevance to Project HealthDesign are:

• Health Data Exploration Project, which aims to find ways to use unprecedented quantities of personal health data being collected by individuals for research

• Real World/Real Time Data Opportunity Space initiative, in which nine projects are demonstrating the value and usefulness of data generated in real time and in the real world to patients, providers, public health officials, and researchers.

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