



Robert Wood Johnson Foundation

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



2009 Call for Proposals—Round 2

Brief Proposal Deadline

June 3, 2009

Program Overview

(Please refer to specific sections for complete details.)

Purpose

Project HealthDesign: Rethinking the Power and Potential of Personal Health Records is a \$10-million national program funded through the Robert Wood Johnson Foundation's (RWJF) Pioneer Portfolio. In this second round of funding, Project HealthDesign will seek to test whether and how information about patterns of everyday living can be collected and interpreted such that patients can take action and clinicians can integrate new insights into clinical care processes.

Eligibility Criteria (page 11)

Applicants may be either public entities, nonprofit organizations that are tax-exempt under Section 501(c)(3) of the Internal Revenue Code and are not private foundations as defined under Section 509(a), or for-profit entities.

Selection Criteria (page 11)

- Potential health impact
- Vision
- Technical approach
- Qualifications of the team
- Feasibility and viability
- Patient and clinician engagement
- Evaluation design
- Partner commitment
- Commitment to the program

Total Awards

- A total of \$2.4 million is available. We anticipate grants of up to \$480,000 each will be awarded to five applicants for 24-month projects.

Key Dates and Deadlines

- **April 29 and May 7, 2009 (both at 2 p.m. ET)**—Optional Web conference calls for potential applicants.
- **June 3, 2009 (2 p.m. ET)**—Deadline for receipt of brief proposals.
- **July 20, 2009**—Select applicants notified if invited to submit full proposals.
- **September 1, 2009 (2 p.m. ET)**—Deadline for receipt of full proposals.
- **December 1, 2009**—Project start date.
- **December 16, 2009**—First design workshop.

How to Apply (page 16)

This program only accepts proposals submitted through the RWJF Grantmaking Online system.

Additional information may be obtained by contacting:

Gail Casper, R.N., Ph.D., *deputy director*

Project HealthDesign

Phone: (877) 674-3170

E-mail: info@projecthealthdesign.org

www.projecthealthdesign.org

Personal health records (PHRs) began as windows into the electronic medical record, provided by hospitals and clinics as a way to give patients a more complete understanding of their health care. Other PHRs developed as freestanding Web-based repositories of patient-entered information or as product offerings from pharmacies or health plans, providing users with a glimpse of the data collected about them. It's helpful to think about PHRs as a starting point, not the answer, to supporting individuals in their pursuit of healthy lives and healthy choices.

Contemporary PHRs are systems of interlocking components that capture, store and make accessible information relevant to an individual's health. PHRs can include information from a variety of sources, including a patient's clinical record and one's own observations about day-to-day experiences and feelings. PHRs are not just about capturing and storing data—increasingly PHRs also include specialized tools to help people visualize, interpret and manage this information. A new architecture, in which various PHR applications draw data from different sources for decision support or care coordination, is emerging. The idea of what constitutes the purpose and function of a PHR continues to evolve. Early ideas have given way to a vibrant marketplace of home care devices and Web portals that allow patients to view their clinical records and manage appointments. PHR platform services, such as Google Health, Microsoft HealthVault and Dossia, provide places to store health data independent of where or how they are collected. Home-based sensors or even smartphones provide on-the-spot monitors of important dimensions of health in everyday living. Additionally, social media tools such as blogs, online communities, Facebook and Twitter are redefining the boundaries of platform and functionality.

Project HealthDesign: Round One

In 2006, Project HealthDesign launched a national strategy to stimulate innovation in the development of personal health record systems by transforming the concept of PHRs as data collection tools to PHRs as a foundation for action. The program was grounded in three key ideas: 1) focus the design of PHRs on the personal health information challenges faced by people in their everyday lives; 2) employ a design approach that deliberately separated data from applications; and 3) pursue collaborative development of a common infrastructure and shared design approaches. Nine teams participated and created a broad range of tools that addressed specific but complex self-management tasks. For example, because people with chronic, non-cancer pain gain better control over their symptoms by understanding the interplay between activity, rest and pain medication, one group developed a personalized diary and checklist that was implemented on a small, hand-held device. Concerns over helping children manage medications while in school led another team to create a cell-phone enabled medication management system that not only alerted the youngster when medications were due, but also sent messages to parents if medications were missed. A third team employed natural language processing to create a computerized “conversational assistant” that helped people with heart failure recognize symptoms and create courses of action.

The nine Project HealthDesign grantee teams created innovative PHR applications to help people take healthy actions and worked together to derive requirements for a set of core components common to many applications. These core components were developed and tested in a Web-services implementation that served as a common platform for supporting multiple PHR applications. Thus, the initial Project HealthDesign efforts demonstrated how

user-centered design, a common technical platform and a variety of innovative tools could form the basis of an alternative vision for PHRs.

Observations in Daily Living

A key insight gleaned during the initial round of Project HealthDesign was the importance of the subtle but systematic cues that people attend to as they monitor their health progress. People often relied on information taken from observations in daily living (ODLs) to gauge how they were progressing, guide them in their choices of health actions and tell if the actions they have taken were producing the desired effect. Examples of ODLs ran the gamut from the moods teens experience in their day-to-day lives, to fluctuations in work- or home-related stress or to the exercise/eating patterns exhibited by a person with diabetes. These observations might also be useful to clinicians, for whom a richer picture of a patient's experience could yield insights that lead to new treatment regimens. Both patients and clinicians might benefit from systems that enable clinicians to keep in touch with their patients between office visits.

It's easy to think of ODLs, like pain levels and meal choices, as data that an individual deliberately records and might want to communicate to their clinicians. However, these observations are only the beginning of what might constitute important and meaningful information about a person's daily health experiences. Meaningful insights about activities affecting health may also come from a better understanding of data that are already passively captured about an individual, such as cell phone records or supermarket savings card histories. As technology becomes more pervasive in everyday living, one can imagine applying sensors, smartphones and embedded monitors to capture and generate a more complete understanding of how a person is doing.

Examples of the potential benefits of capturing and interpreting ODLs include:

- monitoring sleep-rest patterns and exploring the relationship to depression;
- noting how daily food choices contribute to fluctuations in blood pressure;
- examining the impact of family stress on eating patterns of persons with diabetes; and
- linking air travel with experiences of pain.

Challenges to Using Observations in Daily Living

Sensor technologies have the potential to collect enormous amounts of information episodically or over long periods of time, yet very little is known about how to interpret and glean health insights from information collected in the course of everyday living. Most importantly, strategies are needed to determine how to integrate ODLs with clinical observations, and how to detect when a pattern of ODL performance suggests a need to expand or constrict data collection. Large amounts of raw data are likely to overwhelm the individual and clinician alike, thus the challenge is to develop creative, effective ways to capture, store and glean meaning from ODLs.

There are additional challenges to using ODLs effectively. It is not clear which ODLs have the greatest potential for informing individuals and their care providers about how they are progressing towards health goals and whether or not disease management is really working. Other challenges include balancing the need to minimize the patient's burden for data collection with the need for sufficient and reliable data; determining how much data to collect, when to collect them, and how to do so in a way that balances individual privacy with comprehensive information-gathering and -sharing; how to integrate ODLs with clinical observations; and how to detect

when a pattern of ODL performance suggests a need to expand or constrict data collection. It is important to figure out how to gather and use ODLs under sub-optimal conditions, and in ways that do not compromise the interpretability of the data due to weak signals or missing observations.

The Program

Project HealthDesign: Rethinking the Power and Potential of Personal Health Records is a \$10-million national program funded through the Robert Wood Johnson Foundation's (RWJF) Pioneer Portfolio, which supports innovative ideas that can lead to significant breakthroughs in the future of health and health care. In this second round of funding, Project HealthDesign will seek to test whether and how information about patterns of everyday living can be collected and interpreted such that patients can take action and clinicians can integrate new insights into clinical care processes.

Specific objectives of the program include:

- broadening the understanding of health in everyday living by creating innovative, unobtrusive ways to capture a broad variety of ODLs and informative ways to interpret them;
- determining the value of making these observations available to clinical practitioners in ways that are meaningful but not burdensome;
- expanding regulatory and policy considerations to facilitate the sharing of and protection for personal health information generated outside of care settings and its integration into clinical practice; and
- stimulating industry investment in the technical infrastructure, products and services needed to manage personal health information.

Project HealthDesign will award up to five grantee teams up to \$480,000 each for 24-month grants.

Grantees will work with a target patient population to demonstrate the capture, storage and integration of ODLs into clinical care and self-management processes. Specifically, each grantee team will design, develop, implement and evaluate solutions that:

- capture and store several types of ODLs for their target population;
- analyze and interpret the data from these ODLs to extract clinically useful information;
- use this information to provide feedback to individuals so that they can take actions to manage their conditions and improve their health;
- enable individuals to share this information with their clinical care teams;
- present the information to clinicians and integrate it into clinical work flows; and
- identify and illuminate the policy and practice challenges associated with the overall approach.

Each project must:

- involve 30 to 50 individuals who suffer from two or more chronic conditions;
- include individuals with limited access to computers and with minimal computer experience;
- propose solutions that can tolerate conditions such as inconsistent user participation or interruptions in power or network access; and
- utilize a data storage and management platform that allows for:
 - the individual's control of the data (i.e., the patient decides which data to share with whom under what conditions);
 - data access by third-party applications;
 - analysis of data across multiple ODLs from multiple data sources; and
 - exporting of data for use by other information systems.

The program will be divided into three phases:

- *Refine/Design Phase:* Project teams meet early on to share proposals, determine common aspects, validate the balance of populations, ODLs and practice types, refine initial approaches, manage overlaps and gaps, establish and affirm program goals, and define the individual team's contribution to the program goal. This phase will culminate in the submission of a revised proposal to RWJF.
- *Implementation Phase:* Project teams work with their target population to validate ODLs and the strategy used to capture and interpret them, establish data sharing arrangements with clinical practice teams, and carry out work-practice refinements that support the integration of ODLs in to clinical practice.
- *Evaluation Phase:* Clinicians will care for 30–50 individuals who are actively monitoring ODLs over a six- to 12-month period and assess the marginal value of including the ODLs in the care process.

In addition, the program will provide technical core support and consultation on the legal and regulatory aspect of capturing ODLs and integrating them in to care processes. The program will provide common programming support and direction, as needed, to the grantee teams in: (1) interfacing with their technical partners, who may provide data capture devices, clinical repositories and clinical information systems; (2) working across grantee teams to identify common functions, create specifications for them and develop technical implementations; and (3) serving as a liaison for the project to data integrators and data repositories. The legal and regulatory consultant will advise individual grantee teams and the national program office (NPO) on certification requirements, applicable regulations and case law precedent that may alter the consequences of data-sharing between patients and clinicians.

Project HealthDesign is a highly collaborative program. Each grantee team is expected to work with the other teams to leverage and augment each other's work where appropriate and contribute to shared solutions. Applicants must budget for two to three participants to travel to attend six two-day workshops over the two-year grant period to support this collaboration.

To facilitate open exchange with the larger health care and health IT industries, we will encourage early and frequent communications between grantees and the public. Under the guidance of the NPO, all grantees will contribute to a range of communications outlets to include blogs, conference presentations, the media and professional journals. Grantee teams will be expected to contribute at least one post per month on the Project HealthDesign blog over the two-year grant period.

RWJF and Project HealthDesign will require grantees to put any intellectual property generated with the support of these grants in the public domain or to license it under open-source agreements.

RWJF reserves the right to use aggregated, de-identified data from submissions (including the removal of any proprietary information) or to grant third-party access to such data for research purposes. RWJF also reserves the right to share grant applications with other funders that might be interested in providing additional support to the program.

Grantees are expected to comply with RWJF evaluation and monitoring requirements as detailed below.

Eligibility Criteria

Applicants may be either public entities, nonprofit organizations that are tax-exempt under Section 501(c)(3) of the Internal Revenue Code and are not private foundations as defined under Section 509(a), or for-profit entities.

Each team must include a clinical practice partner. Clinical practices could include, but are not limited to, individual or group physician practices, nurse-managed clinics, federally qualified health centers, public health clinics, school-based clinics or hospital-based clinics. Grantee teams may also include informatics professionals, clinicians and experts in design, evaluation and behavioral science. Technical expertise may reside in the team or be acquired through subcontracting to commercial vendors, PHR platform service providers and clinical information technology departments.

Selection Criteria

Proposals will be selected for funding through a two-stage process. Applicants will initially submit brief proposals, which will be screened and rated by Project HealthDesign's NPO, RWJF staff and the program's national advisory committee (NAC) on each of the following selection criteria:

- *Potential health impact*
 - Does the proposed project address the needs of people trying to manage two or more chronic illnesses?
 - Does the proposed project identify a range of observations (e.g. behaviors, sensations, thoughts, activities) that may provide important and meaningful insights about health to individuals and to their professional care providers?
 - Will the project involve individuals who face challenges such as low income or education levels, limited access to computers or unstable housing situations?

■ *Vision*

- Is the vision about personal health information management sensitive to the illness concerns and living experience of persons with the identified conditions?
- Are the proposed ODLs novel and likely to lead to greater understanding of how the everyday experience of individuals contributes to and provides insight in to the health of individuals?
- Is there a compelling vision of how the use of ODLs could change clinical practice?

■ *Technical approach*

- Does the proposal incorporate user-centered design principles?
- Is the technical approach sufficiently innovative to yield new insights?
- Does the architecture include at least three components (data collection at the individual level, remote storage on a third-party platform, information presentation to patient and clinician)?
- Does the strategy make full use of existing devices, data integration platforms, available clinical records systems, data and communications standards, interpretive tools and decision logics?

■ *Qualifications of the team*

- Does the team possess the right mix of clinicians, behavioral scientists, design experts, information technology professionals and evaluation researchers necessary to accomplish the project goals?
- Does the proposal document the team members' experience in deployment and implementation of information systems innovations?
- Has the team had prior experience in collaborative projects?

After the brief proposals have been rated, RWJF will invite full proposals from approximately 15–25 applicants. The NAC will rate full proposals on both the above criteria and the following additional criteria:

■ *Feasibility and viability*

- Does the plan for data interpretation propose a credible strategy or make use of known guidelines and decision-support approaches?
- Are the technical challenges associated with capturing ODLs, storing them in a third-party platform, then interpreting them for clinician or individual use adequately identified and addressed?
- Is the plan for integrating ODLs into the clinical practice workflow feasible?
- Is there adequate consideration of and plans to mitigate the potential risks to successful implementation?
- Is the technical approach robust under sub-optimal conditions?
- Is the work likely to lead to commercialization or clinical practice change, or both?

■ *Patient and clinician engagement*

- Does the proposal provide a description of how the patient population will become engaged in defining key candidate observations, selecting ones to focus on, and collaboratively designing a strategy for collecting and interpreting those observations?
- Will patients be specifically incentivized to participate?
- Are there specific plans for engaging clinical practitioners throughout the entire process?
- Have the clinicians indicated an interest in, and willingness to use, information gleaned through the project?
- Does the clinical practice have access to the population of patients?
- Will clinicians have sufficient incentives, protection from liability and prominence in order to ensure their participation in both the design of the intervention and the conduct of the evaluation?

■ *Evaluation design*

- Does the proposed evaluation plan include a sufficient number of participants engaged over a sufficiently long period of time in a way that is likely to demonstrate the impact of capturing and sharing ODLs on the clinical care of the individual?
- Is the evaluation plan credible and capable of being operationalized?

■ *Partner commitment*

- Is there clear evidence of clinical and technical partners?
- Is there clear evidence, including letters of commitment, of strong support from the institution where the clinical partner resides? The institution's commitment should be indicated from both clinical and information management leadership.
- Is there a willingness to resolve technical challenges on the part of the team, the clinical partner and the technical partner?

■ *Commitment to the program*

- Does the proposal document an awareness of key themes important to the program, including separation of data from applications, user-centered design, integration of ODLs into clinical practice and effective use of existing technologies?
- Does the proposal reflect a commitment to work collaboratively with the other grantee teams?
- Does the team include time and resources to participate in all program-wide activities, including the collaboration workshops and communications and evaluation activities?

RWJF will make final award selections based on the overall merit of the proposals as judged by the above criteria and the degree to which the selected projects represent a diversity of populations and ODLs to be studied and contribute to the overall goals of the program.

Evaluation and Monitoring

As a condition of accepting RWJF funds, grantees will be required to participate in any evaluations of the program that RWJF commissions.

Grantees will be expected to meet RWJF requirements for the submission of narrative and financial reports, as well as periodic information needed for overall project performance monitoring and management. We may ask project directors to attend periodic meetings and give progress reports on their grants. At the close of each grant, the grantee is expected to provide a written report on the project and its findings that is suitable for wide dissemination.

Use of Grant Funds

Grant funds may be used for project staff salaries, consultant fees, meeting costs, project-related travel, supplies, computer software and other direct costs essential to the proposed project, including a limited amount of equipment.

In keeping with RWJF policy, grant funds may *not* be used to subsidize individuals for the costs of their health care, to support clinical trials of unapproved drugs or devices, to construct or renovate facilities, for lobbying, or as a substitute for funds currently being used to support similar activities.

How to Apply

All proposals must be submitted only through the RWJF Grantmaking Online system. To apply, use the Web link listed below. Guidelines and information, including a list of frequently asked questions, are available on the program's Web site at www.projecthealthdesign.org/faq. The program will host applicant Web conference calls (listed under Timetable) to answer questions about the program, as well as the proposal and selection processes. Participation in these calls is strongly encouraged but not required. For detailed formatting instructions, and to prepare and submit your proposal, please go to <http://grantmaking.rwjf.org/projecthealthdesign> prior to drafting your proposal.

Questions should be directed to
info@projecthealthdesign.org.

RWJF and the NPO do not provide individual critiques of submitted proposals.

Program Direction

Direction and technical assistance for Project HealthDesign are provided by the NPO, which is located at:

Project HealthDesign
University of Wisconsin-Madison School of Nursing
600 Highland Avenue, CSC H6/241
Madison, WI 53792
Phone: (877) 674-3170
Fax: (608) 263-5252
E-mail: info@projecthealthdesign.org
www.projecthealthdesign.org

Responsible staff members at the NPO are:

- Patricia Flatley Brennan, R.N., Ph.D., *national program director*
- Gail Casper, R.N., Ph.D., *deputy director*

Responsible staff members at the Robert Wood Johnson Foundation are:

- Stephen Downs, S.M., *assistant vice president, Health Group*
- Robert Hughes, Ph.D., *vice president and chief learning officer*
- Susan Promislo, M.A., *communications officer*
- Sofia Kounelias, *grants administrator*

Timetable

- **April 29 and May 7, 2009 (both at 2 p.m. ET)**
Optional Web conferences for potential applicants.

- **June 3, 2009 (2 p.m. ET)**
Deadline for receipt of brief proposals.

- **July 20, 2009**
Select applicants notified if invited to submit full proposals.

- **September 1, 2009 (2 p.m. ET)**
Deadline for receipt of full proposals.

- **December 1, 2009**
Project start date.

- **December 16, 2009**
First design workshop.

About the Robert Wood Johnson Foundation

The Robert Wood Johnson Foundation focuses on the pressing health and health care issues facing our country. As the nation's largest philanthropy devoted exclusively to improving the health and health care of all Americans, we work with a diverse group of organizations and individuals to identify solutions and achieve comprehensive, meaningful and timely change.

For more than 35 years we've brought experience, commitment and a rigorous, balanced approach to the problems that affect the health and health care of those we serve. When it comes to helping Americans lead healthier lives and get the care they need, we expect to make a difference in your lifetime.

For more information visit www.rwjf.org.

Sign up to receive e-mail alerts on upcoming calls for proposals at
www.rwjf.org/services.



Robert Wood Johnson
Foundation

Route 1 and College Road East
P.O. Box 2316
Princeton, NJ 08543-2316

April 2009