



Robert Wood Johnson Foundation

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EXPERT TEAMS TO DESIGN NEW SOLUTIONS FOR PERSONAL HEALTH RECORDS TO HELP CONSUMERS MANAGE THEIR HEALTH

'Project HealthDesign' Selects Eight Teams to Design and Test Innovative, Consumer-Centered PHR Applications

Princeton, N.J. – The Robert Wood Johnson Foundation (RWJF) today kicked off a landmark program to design and test bold ideas for how consumers can use information technology to better manage their health and navigate the health care system.

Project HealthDesign: Rethinking the Power and Potential of Personal Health Records, a \$4.1 million initiative, has selected eight multidisciplinary teams that will build new tools that advance the field of personal health record (PHR) systems. Grant teams will work collaboratively to design and test a suite of PHR applications that can be built upon a common platform to help people better meet their health care needs in an integrated fashion. Such PHR tools may remind a patient to take medications, provide tailored decision prompts to help people adhere to treatment regimens for diabetes or pain therapy, or transmit data to providers – such as blood pressure readings or exercise levels – that are collected from patient self-testing and biomonitoring devices in the home.

“It’s not just the wider use of personal health records or online access to the data they store that is so revolutionary,” said Stephen Downs, S.M., RWJF senior program officer and deputy director of the Health Group. “*Project HealthDesign* is challenging the PHR field to focus on the potential for patients, providers and caregivers to use this information to improve their health. The design of the systems over which this information flows is critical, and that is why we’re excited to support the efforts of these technology pioneers to develop the next generation of PHR systems.”

In this two-phased initiative, design teams will first participate in a six-month structured process to design user-centered personal health applications that address specific health challenges faced by individuals and caregivers. In the subsequent 12-month phase, prototypes of these personal health tools will be tested with target populations.

At every step, teams will work closely with a specialist in the ethical, legal and social implications (ELSI) of health information technology and personal data sharing. Ensuring the privacy of patient information and gaining an early understanding of the ELSI issues associated with the next generation of PHR systems are key objectives guiding the efforts of *Project HealthDesign* grantees. RWJF is supporting the ELSI consultation through a separate \$149,000 grant to Kenneth W. Goodman, Ph.D., founder and

director of the University of Miami's Bioethics Program and associate professor in its School of Medicine.

The eight grantee teams were chosen from a pool of more than 165 applicants and each has been selected to receive an 18-month, \$300,000 grant. Primary funding for *Project HealthDesign* is provided by RWJF's Pioneer Portfolio, which supports innovative projects that may lead to breakthrough improvements in health and health care. RWJF is pleased to collaborate with The California HealthCare Foundation, which contributed an additional \$600,000 to the initiative. The program is directed by Patricia Flatley Brennan, R.N., Ph.D., professor of Nursing and Industrial Engineering at the University of Wisconsin-Madison.

“By designing a variety of applications that can operate seamlessly within a broader PHR system, we can provide practical, consumer-oriented tools that fit the needs, preferences and lifestyles of individuals,” said Dr. Brennan. “Our vision is that the bold design efforts led by *Project HealthDesign* grantees will help empower patients to use PHR tools to manage health information, communicate with their providers and caregivers, and make sound decisions that can improve their health and health care.”

Program activities will launch immediately with an initial design workshop involving all grantees, where they will further define the needs and preferences of the intended users of the PHR applications. More information about the project is available at www.projecthealthdesign.org.

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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, the Foundation works with a diverse group of organizations and individuals to identify solutions and achieve comprehensive, meaningful and timely change. For more than 30 years, the Foundation has brought experience, commitment, and a rigorous, balanced approach to the problems that affect the health and health care of those it serves. By helping Americans lead healthier lives and get the care they need, the Foundation expects to make a difference in your lifetime.

About the California HealthCare Foundation

The California HealthCare Foundation, based in Oakland, is an independent philanthropy committed to improving the delivery and financing of health care in California.

About the University of Wisconsin

Founded in 1848, the University of Wisconsin-Madison is one of the nation's oldest and most comprehensive public research universities, with more than 41,000 enrolled students participating in 136 undergraduate degrees, 155 master's programs and 110 doctoral programs, and a research enterprise that generates more than \$700 million in annual extramural support.

Project HealthDesign List of Teams

Principal Investigator:

George Ferguson, Ph.D.
Research Scientist
Department of Computer Science
University of Rochester
Rochester, NY

Project Title and Description — *Personal Health Management Assistant*

The grant team will design a Personal Health Management Assistant tool intended to assist patients diagnosed with heart failure and heart disease (HF/HD) in self-managing their condition at home. They envision a software system that interacts naturally with HF/HD patients to help them collect, manage and use their personal health information. Drawing on a dozen years of experience researching and developing knowledge-based, spoken-language systems, they will design an application that interprets what patients are doing, meaningfully links it to their health care goals and practices, and assists them in solving problems and answering questions.

Principal Investigator:

Stephanie Fonda, Ph.D.
Assistant Research Investigator
Joslin Diabetes Center, Inc.
Boston, MA

Project Title and Description — *Personal Health Application for Diabetes Self-Management*

This team will design a personal health application for patients with diabetes that integrates and analyzes data including nutrition intake, physical activity levels, medications and biometric information collected through personal monitoring, such as blood glucose levels and weight. By addressing the complex relationships between patient lifestyle/behavior and diabetes outcomes, the tool will provide users with information on a) their progress in managing their disease, b) how their behaviors affect their condition, and c) changes they may consider to improve their care and their health. The information will be portable and available at the individual's point of need – at home or school, on the job or in transit.

Principal Investigator:

Harold Goldberg, M.D.
Professor of Medicine
University of Washington
Seattle, WA

Project Title and Description — *Chronic Disease Medication Management Between Office Visits*

University of Washington researchers aim to design three interrelated personal health applications for overweight patients that exhibit one or more conditions that make up the metabolic syndrome. In order to facilitate effective, safe at-home changes in drug therapy in between office visits, these applications should help patients and caregivers to: monitor blood glucose, blood pressure and exercise data and upload it wirelessly to their provider's electronic medical records; use cell phones to pictorially capture nutritional intake data and share it with providers in real-time; and check the safety of medication changes

against a drug interaction and electronic medical record database. This project will advance their vision of shifting the locus of chronic disease care from the medical institutional environment to the home, work or other environments where patients make most of their daily lifestyle and health decisions.

Principal Investigator:

Kevin Johnson, M.D., M.S.
Associate Professor
Department of Biomedical Informatics
Vanderbilt University Medical Center
Nashville, TN

Project Title and Description — *My-Medi-Health: A Vision for a Child-focused Personal Medication Management System*

The grant team will design a bold personal health record system for medication management that recognizes the role that children living with chronic diseases may play in their own care process. Called “My-Medi-Health,” this three-part system features 1) a medication management assistant for children, 2) a reminder system for schools and other identified organizations, and 3) a communications toolset that sends just-in-time messages to caregivers or, in the case of adolescents, their text messaging appliance. The applications will be tailored to address the needs of kids and caregiving teams that are managing cystic fibrosis.

Principal Investigator:

Roger Luckmann, M.D., M.P.H.
Associate Professor
Department of Family Medicine and Community Health
University of Massachusetts Medical School
Worcester, MA

Project Title and Description — *Supporting Patient and Provider Management of Chronic Pain with PDA Applications Linked to Personal Health Records*

Patients suffering from non-cancer chronic pain often must manage complex medication regimens, adhere to challenging physical therapy protocols, keep track of multiple appointments with providers, maintain pain diaries and practice stress reduction techniques. This project team will design an application to run on a handheld personal digital assistant, which will interface with an individual’s personal health record, to better meet the treatment and information needs of patients following common pain therapy plans.

Principal Investigator:

Barbara Leah Massoudi, Ph.D., M.P.H.
Senior Research Health Scientist
Research Triangle Institute
Atlanta, GA

Project Title and Description — *ActivHealth: A PHR System for At-Risk Sedentary Adults*

The Research Triangle Institute team will design innovative personal health record tools that assist sedentary adults that are at risk for or suffering from chronic diseases in becoming more physically active.

The project will look to integrate user input from various devices, data streaming from biomonitors, and information from data systems maintained by the user's health care providers.

Principal Investigator:

Lisa Nugent, M.F.A.
Core Faculty
Graduate Media Design Program
Art Center College of Design
Pasadena, CA

Project Title and Description — *Living Profiles: Transmedia Personal Health Record Systems for Young Adults*

This effort aims to help adolescent youth play a more active role in their health and health care at a pivotal moment – as they transition from pediatric to adult care systems. The team will design a transmedia system (i.e., one that works with different media types to fulfill a strategic goal) that encourages both healthy teens and those with health conditions to create and maintain personal health records. Recognizing that they are targeting a technology savvy, DIY population, the team will test mobile devices and Internet applications with teen users to design those tools that are most effective and best-received by end users. The applications are intended to help adolescents and young adults contextualize personal health events, evaluate potential health risks, and establish unique health histories.

Principal Investigator:

Stephen Eisenhard Ross, M.D.
Associate Professor
Division of General Internal Medicine
University of Colorado at Denver and Health Sciences Center
Aurora, CO

Project Title and Description — *Assisting Older Adults with Transitions of Care*

Older adults with multiple chronic conditions (MCCs) often undergo care transitions, such as seeing a new doctor or being discharged after a prolonged hospital stay. The University of Colorado at Denver's *Care Transitions Intervention* has improved the quality and safety of transitional care by using a paper personal health record (PHR) to inform and empower patients and caregivers. Building on this effort, this team will design a tailored, interoperable PHR prototype that further addresses the information management challenges faced by older patients and their caregivers as they grapple with multiple chronic diseases.