



Robert Wood Johnson Foundation

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TRACKING AND SHARING OBSERVATIONS FROM DAILY LIFE COULD TRANSFORM CHRONIC CARE MANAGEMENT

‘Project HealthDesign’ Selects Five Teams to Test Use of Personal Health Applications to Capture and Integrate Patient-Recorded Data into Clinical Care

Princeton, N.J. – The Robert Wood Johnson Foundation (RWJF) today named five teams selected for an innovative program to explore how patient-recorded observations of daily living (ODLs) can be captured and integrated into clinical care. New technologies, such as smartphones and sensors, make it possible to gather information – such as diet, exercise, sleep patterns, medication usage and pain – from the flow of people’s lives. RWJF, through its *Project HealthDesign: Rethinking the Power and Potential of Personal Health Records* national program, has awarded a total of more than \$2.4 million to five grantee teams to test whether and how information – such as the stress levels of caregivers of premature infants and medication-taking routines of seniors at risk of cognitive decline – can be collected, interpreted and acted upon by patients as well as clinicians in real-world clinical settings.

Each team will receive a two-year, \$480,000 grant. Since 2006, RWJF has committed a total of \$9.5 million in grant funds and technical assistance to *Project HealthDesign*, which is led by a team of experts working in health information technology and patient-centered care at the University of Wisconsin-Madison.

Earlier *Project HealthDesign* work revealed that the data needed to inform day-to-day health decisions came less often from the data contained in people’s official medical record and more from information gained by monitoring their health in everyday life. These data – on what they ate, how they slept, what their mood was, how their medications made them feel and other factors – appeared to be a valuable platform for software decision tools, or “apps,” that could help people record their data and make day-to-day decisions. Furthermore, sharing this information with their medical providers helped both parties determine how treatments were working and guide any needed adjustments.

“Data from ODLs can drive apps that help people eat better, manage their pain more effectively and understand how their behaviors, their treatments and their symptoms are related,” said Stephen Downs, S.M., assistant vice president for RWJF’s Health Group. “In addition, they can give clinicians a much richer understanding of what goes on with their patients in between office visits and then they can base their treatment recommendations on better, more comprehensive information.”

Grantee teams will work closely with patients with two or more chronic conditions to capture and store several types of ODLs and analyze and interpret the data with a goal of integrating the information into the clinical work flow. They will first participate in a refine/design phase to share ideas, establish goals and refine initial approaches. Project teams will then work with patients with complex chronic conditions to capture and interpret ODLs while establishing a relationship with a physician practice to share

information. Over the 12 months, clinicians will care for 30-50 patients who are actively monitoring ODLs and assess the value of including the ODLs in their real-world care processes.

In addition, the program provides legal and regulatory compliance support to grantees and contributes to the public discourse on the legal and regulatory aspects of capturing ODLs and integrating them into care processes. The program will develop resources around the cross-cutting issues regarding use and safe integrations of ODLs as well as specifically advise grantee teams on applicable law and regulations that may alter the consequences of data-sharing between patients and clinicians.

“Patients want better relationships with their providers and a different kind of engagement with the health care system,” said Patricia Flatley Brennan, R.N., Ph.D., *Project HealthDesign*’s national program director. “*Project HealthDesign* is focused on improving the health of patients by bringing their everyday experience into the clinical encounters with their doctors and health care providers. Being able to access and selectively share health information electronically – just as people do with their financial records and other data – empowers people to be more informed patients and better consumers of health care.”

Project HealthDesign is supported by RWJF’s Pioneer Portfolio, which funds innovative ideas and projects that may lead to significant breakthroughs in the future of health and health care. Launched in 2006, nine multi-disciplinary teams, supported through program’s first round of funding, engaged in a user-centered design process to create a broad range of innovative information technology (IT) tools that addressed specific but complex disease self-management tasks – from a cell phone-enabled medication management system that alerts children with cystic fibrosis when to take their medicines to a personal digital assistant that collects and supports self-reported pain and activity data and provides a fuller picture of patients’ everyday chronic pain experiences.

Throughout the course of the program, all grantee teams will provide frequent updates about their work through the *Project HealthDesign* blog and other interactive features at www.projecthealthdesign.org.

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About the Robert Wood Johnson Foundation and the Pioneer Portfolio

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. The Foundation's Pioneer Portfolio supports innovative ideas and projects that may lead to important breakthroughs in health and health care. Projects in the Pioneer Portfolio are future-oriented and look beyond conventional thinking to explore solutions at the cutting edge of health and health care. When it comes to helping Americans lead healthier lives and get the care they need, the Foundation expects to make a difference in your lifetime.

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 Grantee Teams

Carnegie Mellon University

Pittsburgh, Pennsylvania

It is often hard to detect subtle changes in everyday activities – such as the loss of the ability to make a sandwich, dial a phone, or take medications correctly – that could indicate the onset of dementia or physical decline in adults who live alone. *Carnegie Mellon University* will develop and evaluate new technology that will monitor the routine of older individuals who have arthritis and are at risk for cognitive decline, providing trustworthy data for long-term functional assessment and treatment. The technology will monitor routine tasks such as taking medication, movement around the home and cooking. It will then present the information to key stakeholders including participants, caregivers and clinicians, so that they can detect and better understand the individual's changing cognitive and physical abilities. By identifying decline at an early stage, caregivers will have a chance to halt or even reverse deterioration that might otherwise result in an unsafe living situation and ultimately require the person to be institutionalized.

RTI International and Virginia Commonwealth University

Richmond, Virginia

Asthma is a common, chronic illness, affecting over 23 million adults in this country. In addition to respiratory symptoms associated with the disease, individuals with asthma are also more likely to experience depression and anxiety. *RTI International* and *Virginia Commonwealth University* will design a personal health record application, *BreathEasy*, building on the latest clinical guidelines for treatment and self-monitoring for patients with asthma and depression. Patients will interact with the application through smartphone mobile devices and biomonitors to capture and report observations of daily living (ODLs) such as use of controller and rescue medications, symptom levels, quality of life and smoking. Clinicians will utilize a Web-based dashboard providing simple analysis and visualization tools that allow them to quickly view their patients' data, evaluate their health status and communicate any changes in treatment or monitoring. By providing a clearer picture of their health in everyday life, the ODLs will be used by both the patients and their clinicians to make lifestyle and treatment adjustments that will better manage their asthma and depression.

San Francisco State University

San Francisco, California

Youth from low-income backgrounds suffer disproportionately high rates of obesity. *San Francisco State University* will examine the potential of collecting observations of daily living (ODLs) via smartphones for low-income teens that are simultaneously managing obesity and depression. The project will utilize smartphone technology – wildly popular among young people – to make monitoring ODLs such as physical activity, food intake and mood easier and more convenient, thus making it more likely that they will enter the requested data at the appropriate times. In addition, the technology will allow the teens to easily share the data with their care team in order to help set health goals, track their progress and ultimately improve their physical and mental health.

University of California, Berkeley
Berkeley, California

There are 600,000 people in the United States who suffer from the digestive disorder Crohn's disease. The disease is most prevalent in young adults ages 18 to 35 and can not only be complicated and expensive to treat but also has significant social and emotional implications. The *University of California, Berkeley* in partnership with *The Healthy Communities Foundation* and the *University of California, San Francisco* will help young adults who suffer from the disease create visual narratives of their condition and treatment to provide concrete feedback to providers about how they feel from day to day. The project will include patients tracking observations of daily living (ODLs) such as physical symptoms like diarrhea, bleeding and profound weight loss, along with more complex social and emotional observations. The information will then be shared with the provider and discussed during their clinical appointments to help the patient and clinician get a more accurate picture of what's happening between appointments with the goal of being able to reduce exacerbation of symptoms and undesired consequences of treatment, ultimately increasing the quality of the patient's life and care.

University of California, Irvine and Charles Drew University
Irvine, California

Early-life health decisions for pre-term, low birth weight babies can make a big difference in how well they do down the road. The *University of California, Irvine* and *Charles Drew University* will create a mobile device for collecting information from pre-term low birth weight infants and their primary caregivers that will allow them to more easily interface with their health care providers to improve care and communication. Caregivers will use a specially designed mobile device, *FitBaby*, to record observations of daily living (ODLs) such as the baby's temperament, exercise, feeding and sleeping schedules, as well as the caregiver's stress level and attitude swings. Providing nearly real-time data to clinicians will help alert them to early signs of health problems, which is crucial in treating low birth weight infants. The project is unique both in its goals of incorporating patient-generated information into a clinical setting and also because it collects information about the primary patients and their caregivers.