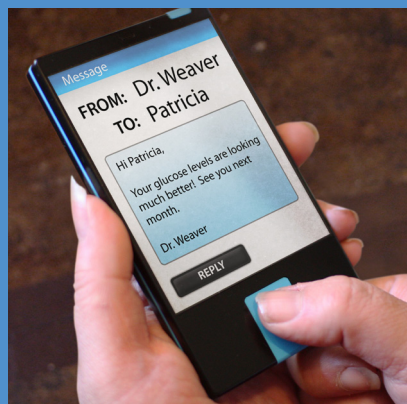
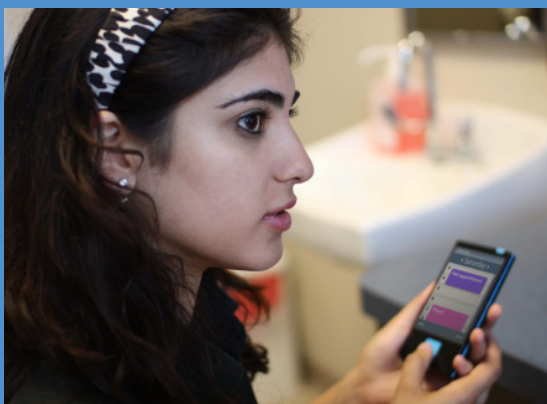




Robert Wood Johnson Foundation

Project HealthDesign:

Rethinking the Power and Potential of Personal Health Records



Round One Final Report

A Message from *Project HealthDesign*...

Just about two years ago, we asked you to join us in thinking through the vision for personal health records (PHRs) and how they should evolve. We believed currently available PHRs succeeded in providing people with access to some of their health care information, but they weren't sufficiently flexible or action-oriented to meet the practical needs of people as they went about trying to manage their health throughout their daily lives.

Project HealthDesign was created to explore the power and potential of next-generation PHRs—to demonstrate that their usefulness lay not so much in providing people with the ability to view information gathered from clinical episodes but in enabling a host of innovative PHR applications to be built that helped people make sense of their daily health and take informed actions. We pushed the potential to build and run such applications on a common platform and incorporate familiar technologies, like cell phones and PDAs. Through the work of our nine grantee teams, we quickly realized that if users were at the center of the design process, the notion of PHRs and related IT applications would look very different. Over 18 months, the teams created a range of robust, innovative prototypes that addressed specific self-management tasks to promote better health and wellness.

The project was speculative in nature, and was intended mostly to yield insights and directions for the field to pursue, but our grantees developed some great prototypes. Some of the prototypes provided technology developers with ideas. Others are being refined for potential commercialization. Soon, we will release open source codes for all nine prototypes for developers and others to use. We hope these codes spark more consumer-focused PHR systems that use a common platform approach.

We've prepared and attached a high-level summary that clearly explains what we did and what resulted. The audience for our work is very diverse and includes policymakers, the IT community, providers and individuals—and all have high variability in technological skills and knowledge. It's our hope that this project summary makes the initial work of *Project HealthDesign* accessible to the widest possible range of people. Please review it and share it with others to expand their knowledge and advance the vision.

So what happens next? A key insight gleaned during the first 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 of daily living (ODLs)—things like sleep, diet, exercise, mood or adherence to medication regimens—to gauge how they were progressing, guide them in the choices of health actions and tell if the actions they have taken were producing the desired effect. While you may be familiar with that term, we think our vision for how ODLs can sync with technology to help shape and strengthen the patient-provider relationship is fresh and worth exploring.

A new round of *Project HealthDesign* grants will test whether and how observations of activity patterns from daily life can be collected and acted upon by patients and clinicians. We know patients are experts at their personal experiences and clinicians are experts at clinical practice. To make health care more efficient and effective, we need to integrate their expertise so that providers can offer actionable advice when patients need it. The second round will select a new group of grantees in late 2009 who will explore how the identification, interpretation and integration of ODLs from individuals with multiple chronic conditions might integrate with passively captured data and clinical information, with the goal of improving outcomes through practice change. Teams will use PHR technologies to conduct small trials with patients and clinicians in real care settings.

Please follow and help contribute to our work by being part of the dialogue at www.projecthealthdesign.org. Your voice is needed.

Patricia Flatley Brennan, R.N., Ph.D.
National Program Director
Project HealthDesign

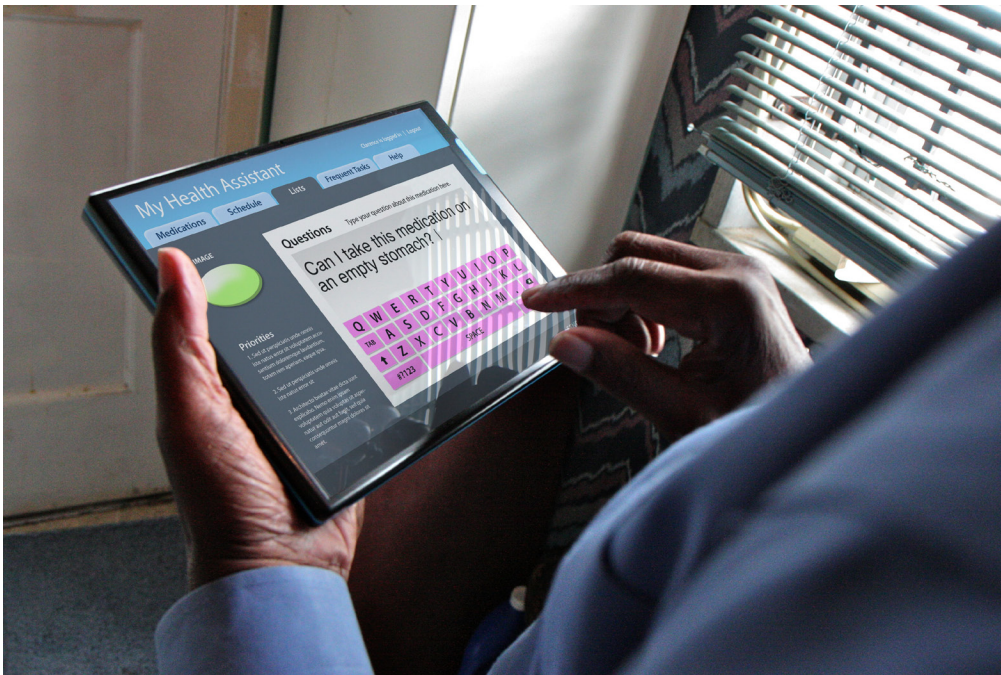
Stephen J. Downs, S.M.
Assistant Vice President, Health
Robert Wood Johnson Foundation

Project HealthDesign:

Rethinking the Power and Potential of Personal Health Records

Designing the ‘next-generation’ of personal health records (PHRs)

Moving perceptions of PHRs from static repositories of information to dynamic, interactive applications that are a seamless and integral part of daily life



The first health record, as originally conceived, was a paper file that was created, owned and maintained to document medical information in a clinical setting. As such, the record was designed to meet the needs of providers, consisting largely of notes inscribed by a doctor on what he or she thought was important. When health providers began to shift from paper-based to electronic health records (EHRs), EHRs became digitized versions of their paper predecessors—useful and instantly available but still based entirely on information that the provider, not the patient, deemed relevant.

“In the 21st century, people need—and want—to be actively involved in managing their health and health care. To take charge, they need access to a range of information and tools to help them understand and use it. By providing tools and systems that allow this information to be shared easily between patients and providers, we believe the users will experience a different level of engagement with their health and the health care system. The result might well be better patient-provider relationships and better clinical outcomes.”

*Patricia Flatley Brennan,
R.N., Ph.D.*

*Director, Project HealthDesign
National Program Office*



Progress in developing EHR systems, coupled with the growing patient demand to access their personal health information, has helped spur the development of personal health records—or PHRs. First-generation PHRs were provided to a limited number of people typically by their health care providers or insurers. While they went a long way toward moving patients from using baskets and binders to organizing their health information, the digital records still resided primarily within the clinical health care setting and provided only limited information to consumers. Choices about what information was included in the record were limited by the parameters set by the application chosen by the provider.

In 2006, *Project HealthDesign* offered a new vision of PHRs. The project believes that the development of PHR systems ought to be grounded in an understanding of the daily lives and health challenges of the individuals they are designed to support. Program organizers believe that PHRs must begin with an in-depth look at what patients need, and then find ways to collect, analyze and deliver tailored information that supports those objectives and fits easily into the user's daily life. The power of next-generation PHRs lies in their capacity to be coupled with alerts, reminders and other decision-support tools that help people take action to improve their health or manage their conditions. By doing this, PHR systems and applications will facilitate information to be shared easily between patients and providers and will become dynamic resources for action.

Supported 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 guided by extensive user-centered design, the program provided a variety of tools and services that draw on clinical records and relevant data from health observations generated in the course of people's daily lives.



Over 18 months, *Project HealthDesign* grantees and staff worked collaboratively to:

- design user-centered PHR applications
- operate on a common technology platform
- explore ethical, legal and social issues

KEY LEARNING:

■ Collecting ‘observations of daily living’ may be the most important feature of PHRs

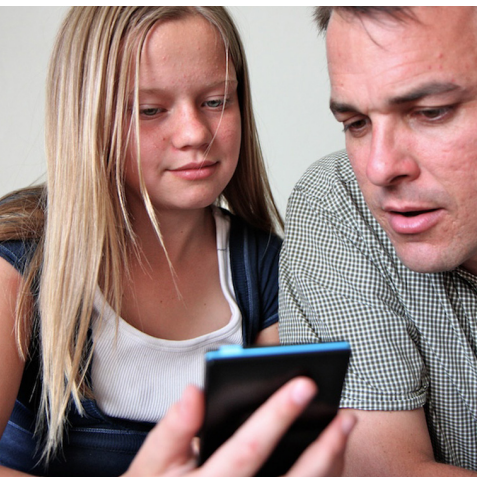
“One of the key outcomes of this project was an increasing focus on collecting data that are not typically part of one’s medical record but rather come from the flow of everyday life. In order to provide people with the actionable feedback they sought, PHR applications needed to collect these Observations of Daily Living.”

Stephen Downs, S.M.
Assistant Vice President,
Health, Robert Wood Johnson
Foundation

Observations of daily living (ODLs) are recordings that people make of selected activities and events that occur in the course of their day. Collecting and using ODL data—information on sleep, diet, exercise, mood, adherence to medication regimens—is an area of PHR development that is genuinely user-directed, both in the kind of information that is contained in the record and the health-related activities that stem from it.

Collecting ODL data through PHRs gives both clinicians and patients insights that are unattainable in records that capture information only from clinical encounters. They also allow different kinds of insights. *Project HealthDesign* researchers learned that patients would like to collect this type of information because it creates a fuller picture of their health—both individually, so patients can look at analyses of their own trend data, and in the aggregate, so patients can compare their symptoms with those that have similar diseases and conditions. Not only did patients want to collect ODLs but researchers learned that this information was required in order to give people the feedback they need to make everyday health decisions.

Patients testing PHR tools under *Project HealthDesign* grants gave researchers important feedback on what kind of ODLs they wish to provide and what information they prefer to keep to themselves (see, “ODL examples from the field”). The need to gather information that is important to individuals, but not necessarily collected in a clinical setting, may be the single most important defining feature of effective PHR applications.



Through the user-centered design phase, *Project HealthDesign* has learned that ODLs:

- create a more meaningful portrait of their health
- assist patients in understanding and shaping daily health decisions
- facilitate more productive conversations with clinicians

KEY LEARNING:**■ A common technology platform for PHR applications accelerates development, supports interoperability and improves security**

The project began with a vision where the PHR applications were separated from the data in the record and the record infrastructure (e.g, storage and security). The rationale behind this vision was that if the record could serve as a platform, and offer an application programming interface (API), then legions of third-party developers could design innovative applications that would run on the platform, creating a marketplace that would meet the diversity of people's needs. At the start of the program, such a platform with an API did not exist, so *Project HealthDesign* sought to learn what sort of functions it would need to provide. Since then, HealthVault, Google Health and Dossia have emerged as platforms.

To test this vision, working with the *Project HealthDesign* grantees, consultants from Sujansky & Associates identified and implemented technical requirements common to the *Project HealthDesign* projects, including medication list management, calendaring, collection of ODLs and identity management.

The resulting "common platform" is a set of software components that provides shared functions to a variety of personal health applications (PHAs). The goal of the common platform components was to reduce implementation time and enhance interoperability for PHAs.

Ultimately, the common platform helps applications understand how to interpret and dispense useful information. For example, for a patient, medication dispensing information such as "take one tablet three times a day" isn't relevant. But what becomes really relevant is, how much can the patient modify that dispensing? Does she have to be up every morning at 7:00 a.m. to take the first one? Or as long as she takes it three times a day, separated by at least six hours, she's all right? The common platform provides a way for bringing together the prescribing-dispensing information from a clinician and the consuming or dispensing information from the perspective of the patient.

The common platform allowed grantees to both experiment with and demonstrate that it is possible to separate data from applications. It enabled them to build applications while not really understanding exactly what the data structure is and essentially rely on the common platform to serve as a translator between the way the data looked originally and the way the application actually needed it to look. Not only did the project develop the common platform to provide its



"The nine grantee teams had some similar components in their PHR applications. Things like calendaring and managing medications were common to most of the designs, and allowed us to develop a common platform of resources that met their shared needs. These resources will be useful for the future development of products and services."

Walter Sujansky, M.D., Ph.D.
President, Sujansky & Associates

grantees with needed authentication, data storage and data-sharing services, but it also explored the optimal design and implementation of a common platform for PHRs. The learnings from this process can inform the development of PHR architectures, particularly those that distinguish between personal health applications and shared platform services.

Through the development of the common platform, *Project HealthDesign* learned two key lessons:

- 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

KEY LEARNING:

■ **Users’ ethical, legal and social concerns about sharing PHR information are real, but surmountable**

“New technologies also bring ethical challenges. It might be that using a particular device and sharing certain information is perfectly acceptable, or it might be inappropriate. In order for user-centered PHR applications to be used and expanded, we need to first identify the ethical, legal and social limits of the applications—and respect the wishes of the users.”

Kenneth W. Goodman, Ph.D.

Co-director of the University of Miami’s Ethics Programs and Founder and Director of the Bioethics Program and its Pan American Bioethics Initiative

Project HealthDesign engaged experts from the University of Miami Bioethics Program to help grantees identify and address the most pressing ethical, legal and social issues (ELSI) associated with their projects. The ELSI team addressed questions such as how individuals manage privacy and control access to their health information, as well as the implications of shifting personal health decisions previously shared with health professionals to consumers alone without the input of their provider. Through their work, the ELSI team identified important questions surrounding issues like privacy, HIPAA, HIPAA-2 and decision support, which policymakers, technology designers and consumers must increasingly address in this rapidly evolving personal health technology landscape.

One of the central issues for consideration with an expanded vision of PHRs is the extent to which consumers have the ability to control access to their information. From a design standpoint, the grantees found that, although the patients in the target populations they worked with care about privacy, they are more concerned about being able to access and use their health information in ways they choose. Similar to the shift in attitudes seen with online banking,

patients said that being able to access their health information easily—just as they do their financial records and other data—will empower them to be better consumers of health care and more informed patients. They also know that there are some privacy trade-offs to achieving this goal.

Through discussions with the grantee teams and the NPO on ethical issues, *Project HealthDesign* has validated that:

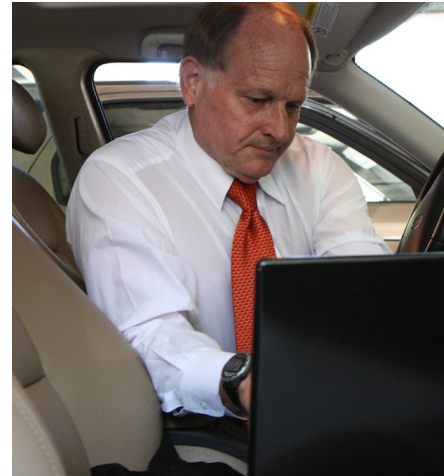
- Traditional concepts of privacy and confidentiality are in many respects inadequate to capture the way health information can be shared and distributed;
- Patients themselves have a large and unprecedented role in helping to safeguard their own health information;
- Society’s response to demands for privacy/confidentiality protection and best practices for information management must take into account the health aspirations and social and economic fears of patients.

Other overarching Issues identified by the ELSI team and the grantees were:

- Can clinicians who have been given explicit access to PHR data by their patients share those data with others?
If so, under what circumstances?
- Can some—but not all—of the information in a PHR be made available to a primary clinician or specialist?
- To what extent should family members or other members of one’s care team (e.g., home health workers, school nurses and teachers, neighbors, etc.) be granted access to information stored on a PHR?

Do special issues arise for dealing with these proxies?

- Who, if anyone, should have access to de-identified patient data for uses other than direct patient care (e.g., for biomedical research or public health)? Should patients be able to opt in or opt out of data use for broader public health purposes?
- Are existing data use notice and disclosure practices sufficient?
- What happens when sensitive health information is handled not just by those in the health care industry—hospitals, medical providers, employers or insurers—but also by non-traditional entrants in the PHR marketplace, such as Microsoft or Google?
- Should HIPAA regulators expand their definition of what constitutes a covered entity?



■ Effective PHRs are not about the record, they're about the actions they enable

The grantee teams focused on expanding the vision of PHRs from static repositories of information to dynamic, practical tools that help people manage their health. Working with patient focus groups, grantee teams looked to PHRs to move beyond warehousing data and more toward empowering patients to improve their quality of health.

“The ultimate test for a PHR is not the data it stores but the actions that result from its use. *Project HealthDesign* has designed PHRs that have the ability to empower patients to take a more active role in their health.”

David Ahern, Ph.D.

Assistant Professor of Psychology (Psychiatry), Harvard Medical School and National Program Director, Health eTechnologies Initiative

The PHR application prototypes designed by the following teams exemplify how PHRS are more about the actions that users can take:

Personal Health Application for Diabetes Self-Management

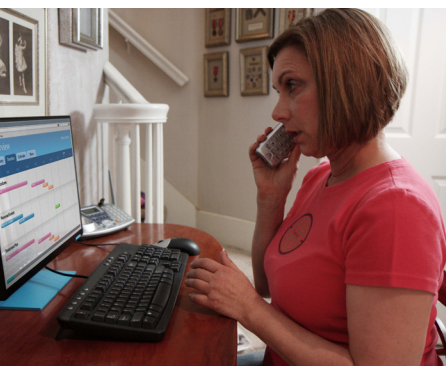
Responding to the needs of people with diabetes, **T.R.U.E. Research Foundation (TRUE)** and the **Diabetes Institute at Walter Reed Army Medical Center** designed a system to assist with the main components of diabetes self-management. The team learned that people with diabetes need on-the-spot advice about actions to be taken in the next few hours, such as what to eat to avert blood glucose dips or spikes. The system they designed captures information about daily living that is important for diabetes management, analyzes data directly from sensors and gives action-oriented advice for self-care via users' cell phones.

Assisting Older Adults with Transitions of Care

To improve the experience of transitional care for older adults from the hospital to home, the team at the **University of Colorado at Denver and Health Sciences Center** designed a portable touch-screen computer—the Colorado Care Tablet—that older patients or their caregivers could obtain from health care providers to better manage often complex medication regimens at home. The team sought to push the boundaries in ambient computing by older adults, using barcodes to generate medication lists and establish a semantic link between the medication list and an authoritative source of information, such as Medline Plus.

A Customized Care Plan for Breast Cancer Patients

To ease the stress and anxiety of managing breast cancer, the team at the **University of California, San Francisco** designed a calendar that integrates details of breast cancer patients' treatment schedules with their personal schedules to help them better understand and proactively coordinate their care. The application's components integrated a range of data—upcoming doctor's appointments, diagnostic tests, etc.—into patients' own electronic appointment calendars and provided a series of links and prompts with additional information. Using *Project HealthDesign*'s specifications, the team mapped data and treatment projections to the calendar, thus demonstrating the ability to get data, code them, represent them, and push them out to existing electronic calendars.



■ Dynamic PHRs operate well beyond the PC

Grantee prototypes demonstrated that applications can link PHRs with a range of technologies that people use every day—cell phones, digital assistants and others. They found that patients also are open to using new ways to interact with technologies—speech, gestures and even device-to-device connections.

The PHR application prototypes designed by the following teams exemplify how PHRs can break out beyond the PC:

Personal Health Management Assistant

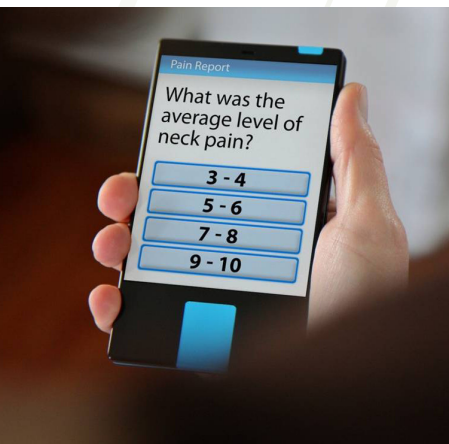
Looking at how technology can help people diagnosed with congestive heart failure manage their health from their homes as part of their daily lives, the **University of Rochester** team designed a computerized “conversational assistant” to provide patients with a “daily check-up.” Through a collaborative conversation using speech and/or text chat, the system is designed to help patients share information relevant to their conditions. The computer decodes the person’s own words and then interprets how they are doing each day. The person then receives personalized treatment recommendations based on established guidelines for heart failure patients, and the system collects longitudinal data to share with patients and their doctors.



“The average person is on the go, traveling from one place to another, which is why so many of the *Project HealthDesign* teams designed mobile, portable technologies—moving care outside of the traditional provider/office setting.”

**Michael Christopher Gibbons,
M.D., M.P.H.**

*Assistant Professor, Johns Hopkins
Bloomberg School of Public Health
and Associate Director, Johns
Hopkins Urban Health Institute*



Chronic Disease Medication Management Between Office Visits

To help patients better manage their chronic illnesses and to shift the organization of health care toward patients' needs, the team from the **University of Washington** designed a system that allows people with diabetes to record their blood glucose levels, blood pressure, food intake and exercise levels, and quickly upload these readings wirelessly over a mobile phone to their health care provider via the Internet. Ultimately, the PHR system not only encourages patients to improve their self-management skills; it also fosters an ongoing and collaborative dialogue between patients and physicians.

My-Medi-Health: A Vision for a Child-focused Personal Medication Management System

Looking at the challenges of teaching a child to take greater responsibility for his or her own health, the team at **Vanderbilt University** developed an application for children with cystic fibrosis and their caretakers to track medications, alert parents when doses have been taken, manage refills and more—both at home and in school and other settings. To help create a safer transition to self-care for children, the application uses a cell phone that can be embedded in age-appropriate skins, such as teddy bears or backpacks—a personal health device that is not stigmatizing. The device reminds children when to take medications at established intervals, and it also can notify parents, school personnel and others if there is no response to a reminder.

■ Recording observations from everyday life yields better health

The teams also focused on recording aspects of daily lives—how we feel, what we eat, what we do—and found that they can be the fuel for smart tools that help people feel better. The things that get recorded go far beyond what is usually considered health data to include exercise, conversations with friends and even the weather.

The PHR application prototypes designed by the following teams exemplify how ODLs can help create a fuller, richer picture of people's health, which can add meaningful information to the decisions they and their providers make about their care:

Living Profiles: Transmedia Personal Health Record Systems for Young Adults

Since teenagers see the world through a complex lens of dynamic friend and family relationships, high-tech gizmos, social interactions and media messages, **Stanford University** and the **Art Center College of Design** examined the possibility of developing a personal health application (PHA) that fits in with teenagers' everyday lives. To help adolescents with chronic illnesses transition from pediatric to the adult care system and assume greater responsibility for their personal health and health information, the team created "Living Profiles," a communication space where teens will aggregate multiple real-time data streams—mood, behaviors and visual representations such as photos or streaming video—visualized in the context of life goals. This system promotes teens' independence through them gaining a better understanding of their illness and its impact on their life, and through improved communication and more personalized treatment plans.

A PHR System for At-Risk Sedentary Adults

Working with The Cooper Institute, **RTI International** developed a tool to help sedentary adults become more physically active. Through a Web portal, individuals can input personalized information on their activity level and lifestyle and then receive a customized plan of activities designed to increase their activity level within the context of their daily routines. The portal also records important observations of daily living like mood and weight. The plan's emphasis is on personalized, small changes to people's daily lives that can realistically be achieved, augmented and sustained.



"People don't live from clinical episode to clinical episode; they manage their health every day. We have found some of the richest and most accurate data come from patients who manage their health in the context of their daily lives, not just intermittently with their providers. The challenge involves not only finding appropriate media and formats to share this information (via video, audio, etc.) but also perfecting the tone of communication. While some like to be praised for 'good' behavior, others prefer to be warned or admonished in connection with 'bad' behavior."

Alison Rein, M.S.

Senior Manager, AcademyHealth

Supporting Patient and Provider Management of Chronic Pain

Millions of Americans suffer from chronic pain linked to common conditions such as spine disorders, osteoarthritis, neuropathy and headaches. To help this population, the **University of Massachusetts Medical School** team designed an electronic diary that supports the collection of self-reported pain and activity data on a highly tailored handheld device like a personal digital assistant. This device will ultimately provide both patients and their health care providers with a menu of options for analyzing and displaying this data. The data and analysis will provide patients and providers insights into pain triggers and the efficacy of pharmacological and non-pharmacological approaches to relieve pain.

ODL examples from the field

A key insight gleaned during the first 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 of daily living (ODLs) to gauge how they were progressing, guide them in the choices of health actions and tell if the actions they have taken were producing the desired effect. Grantees used a variety of commonly available technology—computers, PDAs and cell phones—to capture and share this information with those who help patients manage their health.

Examples of ODLs collected by grantees ran the gamut from sleep patterns to fluctuations in work-or home-related stress, to the exercise/eating patterns exhibited by a person with diabetes. These observations differ from patient capture of clinical data, for example, in that they are personal expressions of what is important to the individual.

With an eye toward improving self-management of illnesses, Stanford University School of Medicine's Living Profiles project explored how chronically ill teens can capture moods

and events in their daily lives and share the information with friends, clinicians and family members in ways that help them manage their health. In another example, an electronic pain diary, created by the University of Massachusetts Medical School, enables individuals with chronic pain to record details about their pain experience—levels, duration, factors such as sleep quality, exercise and medication use—using their own words. This information helps patients to identify triggers and aggravators, complementing clinical information and helping the individuals manage their pain.

Although the first phase of the project has ended, *Project HealthDesign* will continue to explore ODLs through a second round of funding from the Robert Wood Johnson Foundation. The program will select a new group of grantees in late 2009 who will explore how the identification, interpretation and integration of ODLs from individuals with multiple chronic conditions might integrate with passively captured data and clinical data. What individuals pay attention to in their daily lives may well provide insights that, when added into the clinical workflow, can improve outcomes and even change clinical practice.

Project HealthDesign Grantee Teams

- RTI International, Atlanta, GA
- Stanford University School of Medicine, Stanford, CA
(initially awarded to the Art Center College of Design)
- T.R.U.E. Research Foundation, Washington, DC
(initially awarded to Joslin Diabetes Institute)
- University of California, San Francisco, Center of Excellence for Breast Cancer Care, San Francisco, CA
- University of Colorado at Denver and Health Sciences Center, Aurora, CO
- University of Massachusetts Medical School, Worcester, MA
- University of Rochester, Rochester, NY
- University of Washington, Seattle, WA
- Vanderbilt University Medical Center, Nashville, TN

Project HealthDesign National Program Office

The University of Wisconsin-Madison serves as the National Program Office and provides direction and technical assistance for *Project HealthDesign*.

For more information and to sign up for updates, visit www.projecthealthdesign.org.

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Project HealthDesign is a national program of the Robert Wood Johnson Foundation's Pioneer Portfolio, which supports innovative ideas that may lead to significant breakthroughs in the future of health and health care.



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