Project **HealthDesign**

Rethinking the Power and Potential of Personal Health Records

Designing PHRs for Living:

Project Challenges Experts to Create Personal Health Record Technologies that People Want *and* Need in their Daily Lives

From the White House and Capitol Hill, to insurance companies and some of the nation's largest employers, hopes are pinned on the power of information technologies like personal health records (PHRs) to transform America's health care landscape. There seems to be universal agreement that if care is to be more effective and of higher quality, doctors need to store patient records electronically and patients need to use the information to better manage their health. PHRs are a bridge between provider's records and the records kept by patients.

But how will PHRs help people live healthier lives as they go about their daily routines? How will PHRs shift from being online repositories of medical records to smart, consumer-friendly tools that consumers will find valuable?

Robert Wood Johnson Foundation

Project HealthDesign's Bold Experiment

Project HealthDesign is helping to create the next generation of PHRs and PHR systems. The program, a national initiative funded by the Robert Wood Johnson Foundation (RWJF) and the California HealthCare Foundation, supports nine cross-cutting teams in developing new approaches to PHRs that will help patients take charge of their health and better manage their care.

PHRs have emerged largely as an extension of traditional, institutionally maintained medical records. In their current format, they seem to be designed to benefit doctors and other health care providers – allowing them to access a patient's medical history where the patient has gathered, entered and reviewed all of their own health data. That's a heavy burden to place on consumers – and doesn't yield a personal health record that helps people improve their own health. Project Health Design hopes to change all that.

The program is directed by Patricia Flatley Brennan, R.N., Ph.D., professor of Nursing and Industrial and Systems Engineering at the University of Wisconsin-Madison. In developing the project, she and others

Early Findings from *Project HealthDesign:*

1. **Using PHRs for medical record keeping is only the tip of the iceberg.**
   As the *Project HealthDesign* teams design and test their prototypes, they are learning that using PHRs to record observations of daily living – such as sleep, diet, mood, medications taken, etc. — may provide helpful clues to patients and doctors about how to better manage their care.

2. **The need to make day-to-day observations about mood, pain, etc. is consistent across all patient groups and lends itself to common approaches to record, store and analyze this data**
   As PHRs are further developed, technology designers could create personal health applications that respond to trends in daily information to empower patients to make minor lifestyle and health adjustments, thereby improving how they feel.

3. **Successful PHRs and their applications need to mesh with the tools that consumers rely on in their everyday routines.**
   For example, patients aren't likely to use a separate calendar that highlights timing for breast cancer treatments; they want information about their breast cancer treatments to sync with the electronic calendar they already use to organize the rest of their lives.

wanted the design of PHR technologies to be an outgrowth of specific patient needs and preferences. This helps ensure that the products will ultimately be wanted and used by consumers.

"Whatever the product, good design requires an equally good understanding of how the users live their lives," Brennan said. "It's not enough to create a personal health record and then ask patients if they like it. You have to know if they will live with it, if it fits into their routines and enhances their lives. PHR applications that do that are the types of bold experiments we're encouraging."

From a Basket by the Fridge to Personalized Electronic Tools

Part of Brennan's motivation for *Project HealthDesign* is rooted in a basket that sits next to the refrigerator in her Madison kitchen. Stuffed with papers, prescriptions, phone numbers and a calendar, it serves as command central for managing the health of Brennan and her family.

"That basket is my own little health care repository and it's a pretty good one," Brennan said. "It's easy to access and contains everything in one place. It's inexpensive, easy to use and located in a spot I pass every day. Millions of moms use something similar. How do we improve on that?"

By all accounts, Brennan has been relentless in challenging the nine *Project HealthDesign* teams to think about what information specific patients need in their daily lives, but don't always have. She thinks gathering this information is essential for designing PHR applications that will be used.

"Patients don't think in terms of their diagnosis – whether it's diabetes or congestive heart failure or asthma," she said. "They think about how they got tired today, or how they need to watch their diet or what the air is like outside. People will use tools that help them manage their real lives."

Collaborating to Design for the Future

The *Project HealthDesign* grantee teams are engaged in an 18-month, highly collaborative process to design and test prototype PHR applications that are informed by end-user input and fulfill the needs of specific patient groups. Teams must involve experts from a range of disciplines in the design process and test their product ideas with patient populations, a panel of outside advisors and each other.

"We told people that most importantly they needed to be open to their concepts changing in the first six months," said Stephen Downs, S.M., senior program officer and deputy director of RWJF's Health Group. "We wanted them to listen to end-users and each other, learn from different perspectives and design products that were based on that interaction."

Now about halfway into the project, most teams have completed extensive interviews with patients to determine a potential prototype. For one group, this has involved breast cancer patients. For another, they have spoken with teens dealing with lupus and other chronic diseases. Others heard from people with diabetes about tools that may help them manage their condition as they go about their daily routines.

"Each of these teams is trying to create something that fills a need, that works exceedingly well for consumers and that ultimately has viability in the marketplace. It's a tall order," Downs said.

Design theorists have shown that innovation is most successful when the design process is social and supportive, which appealed to Brennan when considering how best to channel the talents of these teams to design cutting-edge, patient-centered PHR applications.

"I think it's important to work together to question assumptions and long-held beliefs and provide honest feedback from a range of perspectives, all of which help innovation," Brennan said. "All of the teams working on this project bring unique perspectives and we have brought in a number of

Approaching PHR Design with an Artist's Eye

The Art Center College of Design in Pasadena is not a typical grantee for *Project HealthDesign* — other teams tended to be more firmly rooted in health and health care sectors. Project leaders, though, think the team's unique ways of looking at identity, culture and science make it well-suited to design health care interventions that respond to consumer needs.

"Media designers have a lot to offer to the health community and visa versa — we continually help each other understand ways in which to navigate and respond to information," said Lisa Nugent, leader of the Art Center team, which is working with the Children's Hospital of Orange County, Stanford University School of Medicine and MOTO Development Group on the *Project HealthDesign* effort.

The team is developing a PHR application to help adolescents with chronic illnesses transition from pediatric into adult care settings and assume a larger role in managing their health. It will help these young patients make health decisions and maintain their personal health information — tasks their parents heretofore managed.

The project team is currently in the pre-design phase, conducting in-home visits to assure that their concepts are rooted in the actual experiences of teens and young adults. Extensive interviews are being held, analyzed and interpreted to shape potential interventions.

Based on user-research completed to date, the project team is considering an aggregate set of tools for inclusion in its PHR prototype, including a mood meter to track and show how patients feel each day; a reminder device that serves as a gentle prompt towards wellness behaviors through evocative means; utilizing mobile video tools to record and share health information with caregivers; all living in an interactive center that collects various personal health information.

"The workshops forced us to define our project when we thought it was too early to define, and then redefine it as we received more insight," said Nugent. "They also allowed our team to talk, debate, argue and share ideas among ourselves. It has been a good process."

professionals and lay people to contribute their own ideas. It makes for an exciting collaboration."

Workshops to Facilitate Better Design

Working with the Vanderbilt Center for Better Health, project leaders planned a series of workshops designed to help the teams develop PHR applications that hold promise. The Center features a highly flexible meeting space that promotes a wide variety of collaborative work, forcing participants to break out of comfort zones and think in new ways.

"The Vanderbilt workshops are like 'kindergarten for adults.' There is no way to blend into the background and not participate, and it forces creative thinking," Brennan said.

Groups made up of clinicians, academics, sociologists, technology designers and others share their PHR ideas and get feedback from all participants. At a recent workshop, small groups were charged with determining the best way to test a given product for usability — whether through focus groups, diaries, videotaping patients using the products, etc. Another session involved looking at one team's potential product and thinking about how it could be combined with another. Ensuring that multiple PHR applications can work with each other in an interoperable fashion is an important goal of the project.

Joslin Thrives Using Collaboration and Interactive Design

A team based at Joslin Diabetes Center and involving representatives from diverse health care settings has thrived in part because of *Project HealthDesign*'s highly interactive process.

Joslin team members combined their own knowledge — namely that most diabetes care is self-administered and takes place outside of the clinic — with feedback from other *Project HealthDesign* teams to determine the focus of their project and shape their approach.

The Joslin team, composed of a psychologist, people with diabetes, a nutritionist who is also a certified diabetes educator, a sociologist, a biophysicist and a technologist, is designing a personal health application (PHA) to help people with diabetes understand and track aspects of their daily self-care.

To ensure that their product is patient-centered, the team began its work by conducting extensive focus groups, asking people with diabetes what they needed.

"This was the largest response to a call for study participants that I have experienced in my career," said Stephanie Fonda, Ph.D., principal investigator. "Unlike most focus groups, we were not asking patients to react to something. Instead, we were asking them what they want and need, and that really resonated with them. Even after we completed the focus groups, we continued to get calls from people who wanted to tell us their stories."

Based on the focus groups, the team initially developed an ambitious plan to incorporate every aspect of a patient's life into their PHA. Team members said this process was further enhanced by the design workshops and interaction with the other grantees. After listening to feedback and presentations at the second design workshop, the Joslin team decided to focus on six major domains of diabetes self-management: a) nutrition/diet; b) physical activity; c) blood glucose levels; d) medications; e) emotional state; and f) how these things interrelate.

Their PHA will show people with diabetes how their behaviors influence their progress and how they feel, while providing specific recommendations for improving their daily routine. The team is now incorporating feedback from colleagues on how to best test the PHA with users.

"Working with our fellow grantees helped us develop a much more targeted product, one that we think has in-depth functionality and intelligence behind it," said Fonda.

Preparing Prototypes to Stimulate Market Change

During the second half of the project, teams must refine their PHR prototypes and test how they might work in real-world settings. The goal is not necessarily to create market-ready products, but instead to design prototypes that are both bold enough and sufficiently tested to attract the attention of the PHR industry and encourage technology designers to think beyond current notions of PHRs' purpose, design and utility.

Downs said the Foundation wants to show technology innovators both what is possible and what is desired by end-users, by emphasizing that all of the prototypes will be tested with patient groups. In certain cases, simulated products will be tested because the technology is not yet developed for the specific innovation to work precisely as envisioned.

"We told the teams that they could assume that the basic PHR capability for their project already exists, and they should build applications on top of it — even though in reality some of these capabilities do not exist," Downs said. "If someone thinks that is a 'pie in the sky' philosophy, that's criticism I am happy to accept. We are trying to both drive new visions of what is possible, and also look at how the designs we are creating can be implemented, to some degree, based on what is already available. We think it's the right mix."

Several teams are now starting to test actual prototypes and evaluate their effectiveness, which Downs and Brennan speculate will lead to more revision and refinement. They say one of the most important findings from across all of the design teams is that closely observing the "actual experience of daily living" reveals a lot about how consumers respond to their health.

"The more we focus on consumer-focused design and really question how these products fit into daily life, the more we learn about how people manage their health," Brennan said. "I think of this process of PHR innovation as being on a pilgrimage. You don't know where you're going at first, but if you proceed with purpose, you will ultimately overcome the challenge of getting there. In this case, our journey is proving to be a very interesting and very necessary trip."

Thinking (Way) Outside of the Box at Vanderbilt

PHR tools aren't often thought of as cute and fuzzy, but that's the first design feature that comes to mind for members of Vanderbilt University's *Project HealthDesign* team. Thanks to some very creative thinking, they see teddy bears as vehicles that can distribute medicines to kids.

The team is developing a PHR application for caretakers of children with cystic fibrosis — both at home and in schools — to track medications, alert parents when doses have been taken, manage refills, and more. Team members developed a medication distribution device disguised as a teddy bear to work with the PHR. The device dispenses medications to kids at established intervals and can notify parents and others when the drugs are — or are not — taken.

The product is the offshoot of interviews with patients, as well as consultations with parents, doctors, school nurses and teachers.

"It has been fascinating to watch how all of the *Project HeathDesign* teams have formed an idea, and then reshaped it based on input from different communities," said Kevin Johnson, M.D., M.S, who directs the Vanderbilt team's efforts. "For instance, a school nurse will learn about our device, react as a school-based health provider and quickly come up with suggestions for how it can be improved. Everyone adds a unique perspective and improves the concept."

The Vanderbilt team also appreciated advice from other teams. Their initial design called for inputting information through typing, but several *Project HealthDesign* grantees warned that children will not consistently read and type into a device and recommended speech activation instead. It also became apparent from others' feedback that the product did not need to be a bear, but could come in various "skins" that were appropriate to the age and interests of the user.

"This has been the most fun project I have worked on in 20 years, and we have learned so much from our fellow grantees," Johnson said. "We build their experience and knowledge into how we view the capabilities of our own projects."

Updates from the Field

ATLANTA, GA

Personalized Tools to Keep You Moving

Range of Opinions Shape Applications to Reduce Sedentary Lifestyles

The collaborative philosophy of *Project HealthDesign* is helping a team at the Research Triangle Institute include many perspectives in designing PHR applications.

"Usually organizations are driven to think from a similar perspective, but this project has everyone bringing different perspectives to shape a vision of a consumer-driven PHR," said team member Barbara Massoudi, M.P.H, Ph.D. "The team-oriented framework is refreshing and very helpful."

RTI International is working with the Cooper Institute to develop a PHR tool focused on helping sedentary adults with or without chronic disease to become more physically active. Through a Web portal, patients can input personalized information on their activity level and lifestyle in order to receive a customized plan of activities that both increases their activity level and fits into their daily routine, such as taking the stairs rather than the elevator, parking a bit further from the office, etc. The emphasis is on small changes to people's daily lives that can realistically be achieved and sustained.

"All of our team members have very different lifestyles and bring different ideas to the table," Massoudi said. "It is helping us create something that will be unique and helpful to a wide range of patients."

SAN FRANCISCO, CA

Putting the Patient at the Center

Enabling Patients with Breast Cancer to Manage Their Treatment Plan

When breast cancer is diagnosed, patients often find themselves overwhelmed by the details of the illness without understanding information being presented to them, when decisions need to be made or what the ramifications are. The result is that physicians tend to manage everything in a directive process, and patients can feel lost in the process.

A *Project HealthDesign* team led by the University of California, San Francisco (UCSF) is designing a PHR application to help breast cancer patients better understand and proactively coordinate their care.

"The loss of control is one of the most disheartening things for patients when faced with a diagnosis of cancer," said team member Laura Esserman, M.D. "A web-based PHR application can improve the patient experience by letting them know what to expect and when to expect it, and by giving them the information they need when they want it, where they want it and how they want it."

Incorporating years of feedback and several patient and physician focus groups, the UCSF team is designing PHR components that integrate a range of data – upcoming doctor's appointments, prescriptions, questions to ask, etc. — into patients' own electronic appointment calendars, and provide a series of links and prompts with additional information. For example, depending on what will happen at her appointment, the PHR system can help a breast cancer patient understand what her energy level is likely to be after the appointment and what the next step in the care process will be.

DENVER, CO

Reducing Confusion and Risk in Managing Medications

Helping Older Patients Improve Transitional Care

As hospitalized older patients prepare for discharge, they often receive a flurry of instructions. Once home, many patients struggle with following and understanding these instructions — especially as they relate to medications. That's why a *Project HealthDesign* team led by the University of Colorado at Denver and Health Sciences Center is trying to improve transitional care for older adults.

"This is a vulnerable patient population — many of whom are managing many prescriptions for various conditions — and they are trying to navigate a complicated medical experience," said team member Stephen Ross, M.D. "For many older patients, medication errors during transition result in re-hospitalization. We want to prevent that."

Through interviews, patients told the project team that they need help tracking and taking medications. They were most concerned about knowing when to take medicines and what to do if a dose was missed. Patients also felt that they did not have enough information about complications and side effects.

The team is developing a portable touch-screen computer device that patients or their caregivers could receive upon hospital discharge. The tablet-sized PC will help patients feel more confident about taking their medications safely and effectively. Because it includes a scanner for the bar codes on medicine bottles, the device can provide patients with clear, authoritative information about the uses and side effects of medications without requiring them to type information. It will also help patients track and organize medications, allowing them to coordinate their medication lists with their doctors. Additional applications will assist in scheduling prescriptions, ordering refills, preparing for visits and more.

WORCESTER, MA

Better Management of Chronic Pain

PDA Helps Both Patients and Providers Chart Course for Care

Millions of adults suffer with chronic pain on a daily basis. A *Project HealthDesign* team at the University of Massachusetts Medical School is designing a personal digital assistant (PDA) to help patients more tightly manage their medications, so that they can feel better more of the time.

"Patients with chronic pain have the responsibility of managing medication regimes that can be very complex, confusing and dangerous given the strong dosages of pain medications they may be on," says team member Roger Luckmann, M.D. "At the same time, it's hard to understand exactly what effect the medicine is having over the long haul. When a patient comes in once a month or less, it's difficult to get an accurate read on his or her level of pain. They tend to tell me how they feel that day, rather than gauging their pain levels over time."

The team's PDA prototype takes the complicated medication regimes prescribed by doctors and translates it into easy, understandable prompts, alerting patients when they should or should not take their medications, and at what amounts. The device also allows patients to record their pain levels on a day-to-day basis. The patient can then print a monthly graph of their pain levels to share with their provider.

Updates from the Field

ROCHESTER, NY

Tracking Everyday Patterns for a Fuller Health Picture

Monitoring Heart Disease at Home with Conversational PHR Device

A *Project HealthDesign* team at the University of Rochester is building on a decade of research on how people interact with technology to solve problems and improve their health.

"There is a lot of health care technology available today, but most of it is focused on helping physicians or hospitals," said team member George Ferguson, Ph.D. "We want to help people better manage their health from their own home as part of their daily life."

Focusing on heart failure patients, the team conducted focus groups, interviews and surveys to shape designs for a relevant PHR application. They found that the most common questions these patients have include "How am I doing today?" and "What can I do to help myself?" They also found that patients were willing to check in with a computerized device, but wanted to spend as little time as possible using it, perhaps as few as five minutes per day.

Because the team's previous experience demonstrated the inherent power of the spoken word in capturing information, the team designed a computerized "conversational assistant" to provide a "daily check-up." Through a series of voice-activated questions and responses, patients share information relevant to their condition. The computer will then interpret how they are doing each day, personalize treatment recommendations based on established guidelines for heart failure patients, and collect longitudinal data to share with patients and their doctors.

SEATTLE, WA

Using Cell Phones to Manage Chronic Illness

Consistent Patient-Provider Communications Increases Quality of Care

A *Project HealthDesign* team at the University of Washington is designing PHRs to help people better manage chronic illness by communicating with providers using cell phones and the Internet.

"Right now, our health care system is focused on acute, episodic care – rather than managing health over the long-term," said team member James Ralston, M.D., M.P.H. "Our goal is to increase communication between patients with chronic illness and their team of health care providers so patients can feel better on a daily basis, rather than waiting to get really ill and then seeing the doctor."

The team conducted in-depth interviews with people who live with diabetes, examining how they manage their health. Now they are developing a device that allows patients to record their blood glucose levels, blood pressure, food intake and exercise levels, and quickly upload these readings wirelessly over a cell phone to their provider. Providers review the information and sync it with the patient's medical record, providing feedback and counsel as needed.

The result is that patients can easily share information with their provider, using the cell phone and the PC as the mediums over which they communicate. In most cases, these technologies are already part of the fabric of users' everyday lives. The system not only encourages patients to improve their self-management skills, but it also fosters an ongoing and collaborative patient-doctor dialogue.

For More Information

Project HealthDesign is a national program of the Robert Wood Johnson Foundation with additional funding from the California Healthcare Foundation. The project is based at the University of Wisconsin-Madison with Patricia Flatley Brennan, RN, PhD, professor of Nursing and Industrial and Systems Engineering, acting as the national program director. For more information and to sign up for program updates, please visit www.projecthealthdesign.org.