Dear Colleague:

More than seven years ago, Project HealthDesign began with the now-popular notion that sustained health care improvement requires people to be more engaged in their health, and the understanding that technology can foster that engagement. When the project began in 2006, the Robert Wood Johnson Foundation asked us to investigate the power and potential of personal technologies to enable people to be more involved in their own health care.

At the time, we thought personal health records (PHRs) held the most promise. We envisioned PHRs as evolving from more static repositories that house one’s health information to become dynamic, interactive tools that engage people in their own health care as they go about their daily lives. Along the way, through our first round of grantee teams, we discovered that the data people needed to fuel this engagement came less from their medical records and more from the patients themselves. People’s own observations about diet, activity, sleep, mood, pain, and medication use were often the information they found most meaningful, and what they wanted to track and share with their clinicians. The idea that collecting these ‘observations of daily living’—or ODLs—could improve the clinical experience intrigued us, and ushered Project HealthDesign into its second phase.

Along the way, we explored related ethical, legal, and social issues to help inform our projects. We worked with bioethics experts at the University of Miami to identify important questions surrounding issues like privacy, HIPAA, and decision support—which policy-makers and technology designers must increasingly address in the rapidly evolving personal health technology landscape. We also participated in numerous collaboration workshops at the Vanderbilt Center for Better Health, which brought all project teams together to discuss how they can leverage and augment each other’s work where appropriate and contribute to shared solutions.

A second set of grantee teams gleaned insights into the practical and technical aspects of collecting and sharing patient-generated data. Following a process of design-demonstrate-evaluate, and with input from Sujansky & Associates, technical partners to the project, and Manatt, Phelps & Phillips along with the Center for Democracy & Technology (CDT), our policy advisory group, our grantee teams piloted tools that enabled nearly 150 people to capture, display, and use their ODLs. They used the ODL information to examine potential changes to their health, and in consultation with their clinicians, they often modified behaviors as a result.

Ultimately Project HealthDesign grantees discovered that patient-generated data like ODLs matter to the individuals who capture them, and strengthen the patient-clinician partnership by allowing clinicians to see a more robust picture of a patient’s daily health experience—which leads to better clinical decision-making and saved lives. For example these data provided insight into missing medication doses, enabled better integration across care providers, alerted clinicians to health status changes between visits, etc. ODLs provide novel input to topics that are important but often not asked in clinical encounters, but which are often most meaningful to patients.

After two rounds of comprehensive learnings, we are proud of the program’s accomplishments and thank all who supported, informed, and shaped our work. The project’s findings can be found at www.projecthealthdesign.org where there are 10 short, informative videos showing how ODL capture enables and enhances engagement.

Sincerely,

Patricia Flatley Brennan, RN, PhD
National Program Director
Project HealthDesign
Project HealthDesign began with the goal of envisioning how personal health records (PHRs) could become valuable tools to foster better patient-clinician communications. By the close of Project HealthDesign’s first round of grantee projects, the grantee teams had created intriguing visions of how individual patients could use electronic devices to capture and share health information with their clinicians. These tools ranged from a mobile medication management system to alert children with cystic fibrosis to take various medicines, to a personal device that tracks patient-sourced pain and activity data, to a computerized “conversational assistant” providing patients with heart disease with a daily check-up.
As the first round’s nine grantee teams looked at what data could be valuable to patients and clinicians, they discovered that patient-generated data like observations of daily living (ODLs) matter because they allow clinicians to see a richer picture of the patient’s day-to-day health, which leads to better clinical decision-making.

ODLs are sensations, feelings, thoughts, attitudes, and behaviors that provide cues to a person about their health state. They provide “data” that patients define for themselves, generate, track, and often act on. This simple concept—that individuals can become active participants in managing their own health if they identify, collect, and pay attention to cues from their daily lives—was the focus of the second round of the project.
The second round’s five grantee teams worked with clinical partners and patients to:

- Identify, capture, and store several types of ODLs for a target patient population;
- Analyze and interpret ODL data to extract clinically useful information;
- Use this information to provide feedback to patients so they could better manage their conditions and improve their health;
- Enable patients to share this information with members of their clinical care team in ways that easily integrated into their clinical workflow;
- Identify and explain opportunities and challenges associated with this overall approach to policy-makers and clinical leaders.

**Grantee Focus Areas**

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<th>Project Overview</th>
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<td>Working with patients who have asthma to capture ODLs such as use of controller and rescue medications and symptom levels.</td>
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<tr>
<td>Chronology.MD</td>
<td>Tracking ODLs related to daily life with Crohn’s disease, including data about mood, weight loss and abdominal pain.</td>
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<td>dwellSense</td>
<td>Monitoring how elders complete routine tasks such as taking medication, talking on the phone and making coffee.</td>
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<td>Estrellita</td>
<td>Working with high-risk infants and their caregivers to collect ODLs related to both the infants’ and the caregivers’ day-to-day physical and emotional health.</td>
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<tr>
<td>iN Touch</td>
<td>Monitoring ODLs such as amount of exercise, mood, food intake and socializing for obese teenagers.</td>
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KEY LEARNING:

Observations of daily living are meaningful to improving health.

Crohn’s disease is a painful and often burdensome disease. The standard of treatment varies, depending on the severity and extent of the disease in the patient. For this reason, Crohn’s disease provides a good opportunity for patients and clinicians to explore the usefulness of observations of daily living in promoting increased collaboration and communication to understand and treat the disease.

During the course of the project, Chronology.MD engaged 30 patients with Crohn’s disease, their clinicians, and the project team to co-design an application to enable patients to input information about their ODLs into an iPad, iPhone or other device. The selected ODLs included information about health symptoms, medication adherence, activity, sleep, energy, laboratory data, and journaling related to their health and wellbeing. An electronic scale and an activity and sleep monitor allowed patients to upload that information automatically to their device. The project also developed a second application that provided a visual display of the data to help patients and clinicians understand ODL changes and interactions over time.

In the end, patients were highly enthusiastic about the project and reported many positive effects, including improved understanding and tracking of important symptoms, medication adherence, and health behaviors. One of the most important findings was that this system enabled patients to see important associations among health factors, and make changes accordingly. For example, patients reported that they noticed that when they got more sleep and exercise and took their medications, they felt better, could reduce pain medications, and manage their disease and life better. They concluded that people often require very personalized information to motivate them to make specific healthy changes.

Patients were very enthusiastic about the Chronology.MD applications and recorded more than 28,000 ODLs over an eight-month period. The percentage of patients who tracked their ODL-type symptoms and behaviors increased from 40 percent before using the system to 92 percent after eight months of using it. Overall, the ODLs that the patients felt were the most personally relevant to track and that the clinicians found most valuable were (in order of most frequently cited): abdominal pain, weight, energy, journal, stress, daily activity, medications, sleep, lab tests, and trigger foods.
KEY LEARNING:

Collecting ODL data engages patients and encourages conversation.

Patient engagement is an evolving term, but there is wide agreement that it involves patients working with clinicians to be more actively involved in their health care to achieve better outcomes at lower costs. Project HealthDesign worked to expand the definition of patient engagement to include a two-way conversation between patients and clinicians, with both parties held in equal status. The iN Touch team at San Francisco State University proved that technology is the vessel through which these partnerships can occur by creating a mobile application to help engage vulnerable youth struggling with obesity and depression.

Obesity management, like many other chronic diseases, depends upon the patient setting his or her own goals and following a particular plan of action. Through an iPod touch, participating youth were able to record their own ODLs, such as physical activity, food intake, weight, socialization and mood, and communicate with a health coach and clinical care team who encouraged them and answered questions throughout the study period. The ODLs served as indicators of how these action plans were going and helped to promote positive behavioral change. The application also allowed for the youth to work with their health teams to set health goals, track their progress, and ultimately improve their health.

The iN Touch team found that their project effectively used popular mobile technology to encourage youth to participate in and communicate about their health throughout the day and in any location. Mobile technology breaks down barriers to care that exist in purely clinic-based interventions. Instead of patients having to wait to have conversations about their health during an in-clinic visit, participants were able to communicate via text with their health coach to talk about the challenges they were having in real-time, and formulate a plan to overcome them. The coaches were able to provide support and reinforce the values of health and well-being when and where the patient needed it, another way of putting control in the patient’s hands.

Over the course of six months, the patients reduced their waist circumference by one and a half inches on average and reported higher levels of engagement and confidence in their ability to manage their own health.
KEY LEARNING:

Many types of technologies can bridge the gap between patients and clinicians.

Though some observations of daily living, like weight or amount of sleep, can be easily measured and quantified through mobile applications and tablet technology, things like cognitive decline in seniors (i.e., problems with memory, language, thinking, and judgment that are greater than normal age-related changes) can be more difficult to track. To be useful to seniors, technologies must be built mindful of their strengths and abilities. Specialized assessments, like trends in cognitive ability, take a long time to complete. In addition, it is important for older adults, their caregivers, and their clinicians to be aware of both how often and how well the person carries out routine and observable activities.

At the onset of the project, the dwellSense team formulated an approach to evaluate cognitive decline using sensor technology that automated the tracking process and was virtually invisible to the participating seniors. The team embedded sensors in pill boxes, phones, and coffee makers to generate data that recorded when tasks were performed, skipped, or performed improperly. Each of the sensors collected and stored the data for the patient and clinicians to view.

dwellSense found that the information collected helped clinicians know when to suggest changes in medication and therapies, and increased individuals’ self-awareness, so they knew when to expend more cognitive or physical effort to avoid mistakes. The most significant behavioral change the project saw was that with the help of a real-time feedback display (pictured) the seniors took their medicine more regularly, made fewer misdials when making phone calls, and were more attentive to the coffee-making task.

Overall, the technology enabled the seniors to feel more secure and achieve better health through increased awareness of changes in their functional abilities, and enabled clinicians to have more accurate information about the ability of the individuals to perform tasks. For cognitive decline, the lack of timely, frequent, and accurate patient information about the seniors’ lives outside the clinical visit hinders efforts to develop realistic action plans, or intervention at times when patients are most receptive. The ability of the sensors to capture data and the underlying algorithms to assess performance of routine activities on a continuous basis over a longer period of time was critical for achieving the best health outcomes.
KEY LEARNING:

Collecting ODL data enhances information-sharing with clinicians.

Approximately one in every eight babies born in the U.S. is born prematurely, and many of these infants will face long term-health problems. In addition, nearly 40 percent of mothers of premature babies suffer post-partum depression at some point during the first year after delivery. Early health decisions for high-risk babies, specifically babies born prematurely to low-income or otherwise vulnerable populations, can make a big difference in how well they mature and develop throughout life. Monitoring the parents’ emotional well-being can help parents understand their own health and identify the early signs of post-partum depression.

Many pre-term infants see three or four different physicians each week—they may see a cardiac specialist one day, and a lung specialist the next—and the constant shuffle from one office to another can make it very difficult for physicians to know what the other physicians are doing, and for the parents to manage all of the information. In an effort to support information transfer among the different clinicians and engage parents in the process, the Estrellita team developed and mobile application to allow the parents to more easily interface with clinicians and improve care and communication.

Through the Estrellita system, parents and family members recorded ODLs like the baby’s fussiness, diapering, weight, and their own stress levels and risk for post-partum depression. The application was designed to be an easy, portable, and convenient way for the caregiver to input ODLs in just minutes. The application also helped caregivers manage communication with clinicians by tracking clinical appointments and encouraging them to review the ODL data and ask questions during appointments. This is particularly important because access to baby and caregiver data can help clinicians make earlier diagnoses and treatment, which can improve the health outcomes of babies and caregivers.

The feedback the team received from the parents after the study was overwhelmingly positive. The parents did not consider the data entry to be burdensome, and reported that they found it useful to have the data so readily accessible. They reported feeling cared for and experiencing a sense of security that they had an easy way to communicate with a nurse case manager.

This work is particularly innovative in that we make it convenient for parents to record daily information about their babies. Pediatricians and other clinicians will have access to the information to make earlier diagnoses, which can improve the health outcomes of babies and caregivers.
KEY LEARNING:

- ODL data inform clinical decision-making.

More than 23 million adults in the U.S. are affected by asthma. In addition to the respiratory symptoms associated with the disease, individuals with asthma are more likely to experience depression and anxiety. Depression and anxiety can pose daunting challenges for individuals in managing their health on a daily basis, and the motivation to care for oneself and comply with recommendations made by clinicians can be even more challenging.

In an effort to motivate patients and bridge the gap between patient and clinician, the BreathEasy team developed a mobile application that incorporates the latest clinical guidelines for treatment and self-management for individuals with asthma and shares the data with participating clinicians. The ultimate goal was to help patients and clinicians better understand the factors affecting both asthma and depression or anxiety and integrate the findings into the clinical workflow to improve the patient's health and quality of life.

Through a smartphone application, patients participating in the study tracked and logged their ODLs. The clinicians, in turn, used a web-based dashboard to quickly view their patients' data, evaluate their health status, and communicate any changes in treatment or monitoring. The system prompted patients to monitor their symptoms, use medications as prescribed and record their use, and assess their overall health status. It also provided easy-to-use tools to enable users to review trends in medication use, and triggers that may exacerbate symptoms. Because the BreathEasy system allowed users to share information with their clinicians, it created a more informed partnership between patient and clinician.

The integration of the BreathEasy system into the clinical workflow proved to be instrumental to the success of the project. When the workflow was set up patients could send messages to nurses, and nurses would view the dashboard and take action. By providing a clearer picture of the patient’s health in everyday life, both patients and clinicians used the ODL data to make lifestyle and treatment adjustments and better manage asthma, anxiety, and depression symptoms.
Project HealthDesign Round 2 Grantee Teams

**BreathEasy**
RTI International and Virginia Commonwealth University

**Chronology.MD**
University of California at Berkeley, in partnership with Healthy Communities Foundation and University of California at San Francisco

**dwellSense**
Carnegie Mellon University

**Estrellita**
University of California at Irvine

**iN Touch**
San Francisco State University

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