Project HealthDesign:
Rethinking the Power and Potential of Personal Health Records

Health in Everyday Living

Through applications that gather health information from everyday life, next- generation personal health records provide individuals with new tools to help them engage in and manage their health.

What kind of information should exist in a health record? And, who determines what should be done with that information? These are essential questions that underlie the development of personal health records (PHRs) and differentiate them from clinical or other kinds of health records.

The first "health record," as originally conceived, was a paper-based file that was designed, owned and maintained to record medical information in a clinical setting. As such, the record was provider-centric, consisting largely of notes inscribed by a doctor of what he or she thought was important. Its primary purpose was to assist the provider in the care process.

When health providers began to shift from paper-based to electronic health records (EHRs), the EHRs became digitized versions of their paper predecessors, useful and instantly available, but still based on information that the provider, not the patient, deemed necessary.

In recent years, another "health record" was introduced and was touted as a personal health record.

It made use of the new electronic record technology to provide patients with Web access to some information about their own health. These records offered a variety of services, from access to test results to the ability to chat with a provider online. However, they were owned by a health care institution – clinic, hospital, physician or health care provider—and what sort of information the user had access to was also determined by the institution and its needs.

Next-generation PHRs change all that. Because PHRs are designed for individual users to help them engage in their own health management, the information they contain can be radically different from EHRs or first-generation PHRs, and can be used for entirely different purposes. While there are areas of clear overlap—both an EHR and a PHR should contain accurate data on current lab values and medications, for example—they are aimed at different users and designed for different purposes.

Nowhere is this truer than with the recording of information related to observations of daily living (ODL).

Collection and use of ODL information – which includes information on such activities and experiences as sleep, diet, exercise, mood and adherence to medication regimens – is one area 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.

This is one of the key lessons being discovered by *Project HealthDesign*, a national program of the Robert Wood Johnson Foundation (RWJF) that is designing next-generation PHR systems. Patients testing PHR tools under *Project HealthDesign* grants are giving researchers important feedback on what kind of ODLs they wish to provide and what information they prefer to keep to themselves. The difference in its conception – gathering information that is important to individuals, but not necessarily collected in a clinical setting – may be the single most important defining feature of next-generation PHRs.

According to Patricia Flatley Brennan, R.N., Ph.D., professor of Nursing and Industrial Engineering at the University of Wisconsin-Madison and director of *Project HealthDesign*, patients can gather and analyze their own ODL data via PHRs to determine ways to live healthier, rather than simply to manage their illnesses.

Consider the distinction this way: the traditional health record and the EHR revolve around data collected at (and important to) the clinical episode. But people don't live from clinical episode to clinical episode – and health-related information, such as whether one's stress is elevated due to family or work pressures or whether one's chronic pain spikes with a sudden change in temperature (which would never make it into a traditional health record), are just as important to many people as standard clinical data are to providers.

The kind of experience-based information the patient can add to a PHR creates a much richer portrait. "A person benefits in two key ways: by getting data that can serve as useful feedback that he or she can use to shape daily decisions, and by the gathering of data that allow that person to have a more productive conversation with the clinician," says Stephen Downs, S.M., senior program officer and deputy director of the Health Group at RWJF, which supports *Project HealthDesign* along with the California HealthCare Foundation.

ODL data can take many forms – from quantitative measures of sleep (e.g., sensors indicating how long the patient slept and how much the patient moved during the night) to qualitative self-reports (e.g., the patient reporting his or her own mood). Some PHRs are experimenting with ways to convert typically qualitative metrics into numeric, quantitative ones.

Collection of ODL data through PHRs gives both clinicians and patients insights that are unattainable if records contain only data captured in clinical settings. They also allow different kinds of insights; *Project HealthDesign* researchers are learning that patients would like to record or know information that is not generally collected during clinical encounters. These patient-originated, patient-defined data present the opportunity to create a fuller picture of health – both individually, so patients can look at analyses of their own trend information, and in the aggregate, so patients can compare their symptoms with those of other patients with similar disease and condition profiles, or so disease outbreaks can be detected faster at a population level.

"Indeed, patients are a largely untapped resource of medical data," says Farzad Mostashari, M.D., M.S.P.H., assistant commissioner, Epidemiology Services with the New York City Department of

Health and Mental Hygiene. Mostashari, who is an advisor to *Project HealthDesign*, envisions a system in which "tethered" PHRs, linked to a system-based EHR, could collect information from vast numbers of people quickly – for instance, if a large number of residents of one neighborhood reported gastric distress or flu-like symptoms at once. "It would be nice to put these tools to use for public health surveillance," he says.

Similarly, individual patients could learn from their peers, says James Heywood, co-founder of PatientsLikeMe, a treatment-and outcome-sharing Web site for people with life-changing diseases. "People with diseases have an incredible amount of information to share, and other people with similar diseases can benefit enormously from that information," Heywood says. "The challenge is to take all the information that patients can offer and compress it into a usable format so others can use it."

This prospect, while interesting and potentially clinically valuable, presents ethical, legal and social issues that demand attention. Patient-originated data are not considered as confidential, legally speaking, as are data in a traditional health record. They do not fall under the protection of the Health Insurance Portability and Accountability Act. When ODL data are entered into a PHR by whatever means (either actively or passively), people will need to understand that traditional definitions of medical privacy may no longer be at work, and PHR developers will need to offer individuals a means to protect portions of their information if they feel they need it.

PHRs and ODLs: LESSONS FROM THE FIELD

Recording observations of daily living (ODL) in a health record is not a new concept. The traditional health record contained information that was not always quantitative; it could and often did capture qualitative information obtained at the clinical encounter.

But personal health records (PHRs) are demonstrating new ways of collecting, organizing, displaying and using that information. The ultimate goal: to use data to understand the experience of an individual as he or she goes about daily living, and how personal choices affect one's health. As PHR developers work to integrate ODL data into their records, *Project HealthDesign* grantees are learning important lessons about how people want to interact with their records, and how they do not.

Two grantees – T.R.U.E. Research Foundation and the University of Washington – have projects that focus specifically on people with diabetes, with an eye toward assisting self-management of the disease. They collect information on daily behaviors (such as diet and exercise) and then provide patients with individualized feedback and recommendations based on that information. Collection of ODL data has been critical, researchers have learned, because these are the kinds of data that can add up to real information about how a patient should change his or her behavior.

It turns out that patients are highly receptive to learning lessons based on their own data. "Stress has a profound impact on the body – it can increase blood sugar levels, and it's hard to bring those levels back down," says Stephanie Fonda, Ph.D., senior research scientist at T.R.U.E. Research Foundation. "If we can show patients that with facts from their own lives that we collect through the PHR, that can be very powerful."

T.R.U.E. is designing a personal health application to analyze, summarize, display and make recommendations on many daily activities. Its PHR will also enable consumers to conduct "what if" analyses, which will predict the results of choices they might be considering (such as the metabolic effects of particular meals).

But the means of data collection can make or break a project. Because diet is so important to diabetic patients, University of Washington researchers wanted to record what patients ate, when they ate it. One method they tried was to have patients take photos of their food as they were sitting down to eat, using a cell phone camera, and then e-mailing those photos to their providers. The hope was that patients would embrace this new technology as a means of dialogue with their providers.

"People just wouldn't do it," says principal investigator James Ralston, M.D., Ph.D. "They felt it was invasive, or else that it stigmatized them. When people sat down to eat their dinner, they didn't want to take pictures of their food, they wanted to eat." Instead, Ralston's team found other ways of collecting information that was important to diabetic patients – such as uploading blood-sugar levels over a cell phone via a Bluetooth device – were more popular among the study group.

At the University of Rochester, a grantee team led by computer scientist George Ferguson, Ph.D., and researcher Cecilia Horwitz, M.B.A., are working with the university's Center for Future Health to design a computerized "conversational assistant" to provide heart disease patients with a daily checkup via a series of voice-activated questions and responses. The result: personalized, guideline-based treatment recommendations.

The voice activation, using natural language, shows promise because patients are immediately comfortable with it, Ferguson says. "Some of the key data points you need for heart failure – like tracking weight, or sodium intake – are not really rocket science, but people don't do it," he says. "If you make it easy to interact with a system, people are more likely to use it."

Ease of use is also important to the personal health application being used at the University of Massachusetts Medical Center, where Roger Luckman, M.D., M.P.H., is leading a team of researchers who are using a personal health application to construct a "pain diary" to help patients document their pain to better manage their health. After trying multiple devices, researchers settled on a small device that prompts users to input their pain information using a simple interface – but in a sophisticated manner – every two hours. "It's important that the device be flexible. Patients will like that," Luckman says.

Outlook for PHRs

While there are distinct public health and clinical research opportunities for PHRs, they remain first and foremost a tool to engage individuals in their own health management. Thus, as *Project HealthDesign* creates a vision for next-generation PHRs, it is the individual use, not the collective one, that is currently being emphasized.

Because ODL data are often subjective, the broader uses are difficult to achieve. But subjective data can be of great utility to individuals – as long as those data are measured and reported consistently. For instance, if one is self-reporting pain on a zero-to-10 scale, it doesn't matter if one individual's threshold for pain is higher than another's; what matters is how each person rates pain on his or her own personal scale compared with a previous period of time. A sophisticated PHR could pick up this information and make sense of it – and also integrate data from multiple observations to create a meaningful narrative for the individual.

It's a big challenge, however, because too many data that are not properly integrated can come across to patients and providers as noise, not useful information. Smart, interpretive tools that turn data into usable information can help to find real indicators amidst the noise. Brennan draws a distinction between data that need to be stored in order to analyze trends and data that are immediately usable and then can be discarded. "This could revolutionize the way people relate to their health," she says. "Say a person with asthma walks into a meadow that has a high pollen count. A sensor can read the pollen count, and send an alert to the user to tell him to take his inhaler, and then delete the information; we don't need to remember what the pollen count was, only that an event triggered a response."

Project HealthDesign's grantees are showing the exciting potential of how capturing ODLs can help people to better manage their health. But, this work is still in an early stage. Many interesting challenges lie ahead. As PHRs evolve to capture more ODL data, additional research will be needed to develop methods for finding meaningful indicators amidst the noise. Clinicians will need to figure out how to glean real information from the data to gain fuller pictures of their patients' health, and people will wrestle with decisions about how much information about themselves they want to be collected, stored and shared.

PERSPECTIVES:

Health Information Should Be Collected in the Home, Not in My Office

By Jay H. Sanders, M.D.

Clinical providers spend too much time treating "white coat hypertension."

White coat hypertension is that phenomenon in which a patient's blood pressure spikes just because he or she sees me. I don't take it personally. It's not me that my patients are reacting to, it's my white physician's coat, the sterile examination room, the cold instruments, and all the other trappings of a clinical encounter that almost seem designed to put the patient ill at ease.

Continued from page 5

For many patients, blood pressure will rise by a measurable amount merely because they're nervous – hence, "white coat hypertension" – and we end up treating the patient for a condition that doesn't really exist outside of the health care setting.

This is not to diminish the importance of treating hypertension, which is a serious and, if not treated, deadly disease, but rather to point out the weakness of traditional methods of data collection. Personal health records, with their ability to collect data in more natural settings, offer an exciting opportunity to improve the gathering of information, which will improve health care.

We should start by acknowledging that a PHR is not a static component of data that just sits there. When used properly, it's a dynamic, real-time, living record. And let us underline the word "personal" in PHR; this record gets built with certain normative values in it for each individual patient.

Consider the blood pressure example. The American Heart Association defines "normal" blood pressure as lower than 120/80 – based on millions of patients, regardless of age, gender or other factors that are bound to influence one's blood pressure. We are all blanketed by normative values based on millions of people who have no relevance to us individually.

But consider a woman whose normal blood pressure is 90/60. If her BP rises to 100/70 at her next checkup, and six months later it's 110/75, for her, that's hypertension – and it would never get picked up in the course of a normal clinical encounter, because we're usually looking for deviations from a norm that has nothing to do with her.

In the way medicine is traditionally practiced, blood pressure is taken on an apparently healthy person once every year or so, when she visits the doctor. It's a snapshot in time. What we need instead is not a single measurement at a point in time, but several measurements over time to really assess what her blood pressure ought to be.

And we need those measurements taken in the right place. A blood pressure reading taken in the doctor's office is rather ridiculous, because patients don't live in the doctor's office. For most conditions, hypertension certainly being one of them, examining the patient in his or her environment, not in our environment, is better medical care.

This is where a PHR can be of extraordinary value, as a dynamic, living database that is in effect constantly physiologically evaluating us. That is the greatest advantage of the PHR. It is also its biggest potential weakness.

While there is exciting technology being tested with respect to PHRs, the value is not in the technology, but rather in how it is used. Put another way, the PHR is only as good as the information that's in it.

Let's revisit that potentially hypertensive patient once more. So far, we don't know anything about her family history – whether she comes from a family in which her parents had hypertension. We don't know her weight or her diet or even her age. A PHR without these critical pieces of information would be of little

utility, wouldn't it? But a PHR with that kind of information, and then supplemented with all those rich daily readings, could be a gold mine of information.

We live in an age in which patients – or, in common parlance today, "consumers" – are being given unprecedented responsibility for managing many aspects of their own care, including financial and medical aspects. PHRs can enable the latter. If they are designed smartly so that their use is intuitive, PHRs will help patients become their own primary care providers; the result should be a higher state of health.

Jay H. Sanders, M.D., F.A.C.P., is president and chief executive officer of the Global Telemedicine Group consultancy. Dr. Sanders has spent the majority of his professional career involved in teaching and health care research, and has spent more than 30 years in the development and implementation of telecommunications and information technologies to address problems relating to quality, cost and access to care.

For More Information

Project HealthDesign is funded by the Robert Wood Johnson Foundation and the California HealthCare Foundation. The University of Wisconsin-Madison serves as the National Program Office (NPO) and provides direction and technical assistance for the initiative. For more information and to sign up for program updates, please visit www.projecthealthdesign.org.

Project HealthDesign

Patricia Flatley Brennan, RN, PhD
National Program Director
University of Wisconsin-Madison School of Nursing
600 Highland Avenue, CSC H6/297
Madison, WI 53792
info@projecthealthdesign.org
www.projecthealthdesign.org