Focus on People: Rethinking the Power and Potential of Personal Health Records - Part 2

[Announcer] This podcast is presented by the Centers for Disease Control and Prevention. CDC – safer, healthier people.

[Dr. Brennan] Finally, from the beginning, the Foundation invested in an ethics, legal, and social issues consultancy. Personal health records, especially innovative uses of personal health records, have the potential to actually change the ethical challenges, and we found three of being particular interest.

First of all, privacy: Defining what does privacy mean when you are in an individual's home, using devices that might have multiple purposes. Secondly, identity management: How do we make sure an individual is who they say they are and they're reporting about something accurately when they're using a personal health records tool? It's been our experience, very often, that, even if you design for an individual person, the family caregiver, the mother, the sister who manages health in the family is the one who actually interacts with the tool. That changes our whole idea of identity and identity management. And finally, intellectual property. I'm going to talk to you about this, about two dimensions of it.

First and foremost, when we try to look at creating a process of design where applications are separated from the data itself and we look for shareable tools, we're actually shifting the idea of intellectual property from something that an individual or designer owns and develops with a goal of making money in the future or having a significant financial reward to one that becomes part of a shared service system. That changes both the possibility of financial remuneration and also some of the challenges-- some of our presumptions about who is accountable for decisions made using that; what is the liability of this information?

The second intellectual property challenge we've run into is trying to understand just how valuable is knowing a lot of information about an individual person. If we were able to capture and characterize individuals' behavior through the day, they're developing stories about themselves which could, in fact, become quite useful for others to use. For example, in understanding phenotypic expression of certain gene-environmental interactions or perhaps for providing prototype for design of other products. Can an individual use a personal health record for personal financial gain? It's a question that becomes increasingly important as we think about putting genetic information into the personal health record where an individual could actually sell a unique gene structure. We didn't resolve that one, by the way.

Okay, so Project HealthDesign grantee teams. We had nine teams that worked both independently and together over the period of about twenty months to create innovation in personal health records, to create ideas, to demonstrate ideas that were responsive to users' needs, made effective use of technology, provided a focus on an application without worrying about data flows and then began to help us to better understand what the core components were, the common functions that we find across all personal health records.

So, first, I'm going to talk with you about two teams that focused on transitioning to health. These two teams -- the RTI, Research Triangle International; and the Art Center College of Design, now Stanford University -- tried to use personal health records tools not to help people cope with health problems but to help them achieve higher levels of well being. So our graphic on the left depicts the goal of the PHR system from RTI, which is to move couch potatoes into active French fries, to help sedentary adults get up and move around more. Now, interestingly enough, they were the only team that brought forward a well-thought, well-validated behavioral change model to bring into an environment where remote sensors, web sites, and cell phone interaction would be used to help an individual stay connected and coached through this process of change. We talked at lunch briefly about the challenge of moving interventions that appeared to be successful in an interpersonal environment into an electronic environment and the team is starting to help us better understand. What they found is, when an individual has the freedom to let the electronic environment mimic the personal environment that they choose -- that is, the level of activity they want, the number of reminders they want -- they have much better engagement. The collage at the lower right-hand side depicts the Art Center College of Design's attempt to understand health among teens. They were addressing a really challenging problem and that is the transition from parent-directed health care to self-directed health care that occurs between the ages of, say, 16 and 20. They were specifically looking at a group of healthy teens and a group of teens who were managing a chronic, complex illness, and they began with first trying to understand what did health mean to the teens. So by using a series of probes and innovations such as simulated cell phone picture-taking, requests about music, graphic drawings, the Art Center College of Design product brought us to the realization that health, for teens, is focused on their friends and on images and music and not at all on words or numbers or blood glucoses or achievement as we calibrated from the health care delivery system. That suggested that, if we're going to create personal health records for teens, we need to have a lot more in it than graphs of their weight as it's changing over time. It also suggested that we needed to rethink the whole privacy issue because, if teens are sharing health across their friends and each other, then they need to have an attempt to both understand the risks inherent in data sharing as well as have the capacity to very easily share health information.

Two of our teams tried to focus on management of diabetes. In the upper left-hand corner, you see the Personal Health Application for Diabetes Self-Management that came from, originally, Joslin Clinic in Boston, now through Research Center in Washington, D.C. They are building decision engines to help an individual make an in-the-point choice about actions and behavior, specifically related to managing diabetes, specifically related to short windows, 8 to 12 hours of time. Most recommendations for people with diabetes have nutrition and dosing of their insulin either at very, very small points -- your blood sugar is too high, you need to take this much insulin right now; or very large points -- you need to balance your caloric intake, 1,800 calories a day. What they've learned from talking to their patients is that there are several trigger times during the day -- 10:30 in the morning, 3:00 in the afternoon -- where choices have to be made -- I haven't eaten enough yet today, I have to eat more calories; I haven't exercised yet, should I reduce my insulin -- that are very unique to that very local situation. So they're building decision rules based on these very, what we call, decisions in the small.

The University of Washington in Seattle, their group is working with people who have chronic metabolic syndrome -- mostly, again, people with diabetes. And they're trying to address the problem of how do you help a patient manage in between visits and how do you make sure that whatever happens in that management gets communicated back into the clinical record? So this is the linking of the home and the clinical care. They developed a phone-based intervention that both captures information from a glucometer, uploads the information to the patient's clinical record, and so the process of technically coordinating all those steps has been somewhat resolved and appears to have worked fairly well. And also, to give on-the-spot nutritional counseling, where the individuals would use cell phones to take photographs of foods they're eating and get advice immediately, instantaneously, not through artificial intelligence, but through consultation with a nutritionist. In addition, they found out that this could provide a food diary over several weeks in time to be able to be reviewed with the patient.

A group at University of California-San Francisco is trying to help schedule disease treatment into everyday living. This team found that, for women with breast cancer, one of the biggest challenges that they faced was integrating the treatment into their lives, that simply having breast cancer didn't stop your experience of living. So they worked with the team to be able to bring the clinical counter -- excuse me -- the clinical calendar, the patient's calendar, together into a single view and also to use the calendar not only to identify events, but to identify decision points. After the diagnosis of breast cancer, there are certain critical points where decisions must be made, and they become calendar events to better help the individual know when they might need extra time or extra resources to help them think through challenges.

Two of our teams are trying to help people better take medications. The left-hand side shows a barcode scanner scanning a medication bottle and then providing a display of that information on a tablet-based PC. This is the University of Colorado's project attempting to provide elders at the point of transition from institutional care to home care with the advice that they need. They would find: the elders would come home, they'd have a brown bag of pills, and they'd get home and they wouldn't know exactly what to do with it. And dumping it out on the table didn't really give them very much to do. Having a printed piece of paper also didn't help them because the paper and the pills weren't connected. But when they were able to use a barcode scanner -- that looks about the size of a small microphone, actually -- to get information from the exact pill bottle and see it displayed immediately, they began to get a better understanding of how to control their medication.

Vanderbilt University thought they could use something called a Medi-Teddy -- a Teddy bear. Embedded in the Teddy bear, a timer and a pill-dispensing device so that they could help kids better take their medication. They wanted to understand how to mostly help the kid in school who skips medication because she doesn't want to go down and stand in front of the nurse's office to get the medication. So they were looking for a secure way to give the medication in school. Well, they found many, many things, and I'll tell you a few of them in a minute, but the biggest one they found is that no kid in school will carry a Teddy bear anywhere, period, end of story. If you're over four years old, Teddy bears don't work. But what they did find is, cool skins around iPhones work very well. So you can engage kids in self-management. They also found that self-management of medications in the school is much more of a school district issue than it is a health policy issue. So that they needed to bring in different teams in the conversation.

The last two that I want to talk to you about are the two teams that are trying to understand the everyday experience. And the left-hand side depicts a PDA with a picture of a body. This is the University of Massachusetts's attempt to better understand pain management for people with complex, chronic, but noncancerous pain. They used a bar slider and a pointer to identify where is the pain occurring, how serious is the pain. And the row of icons across the bottom give the person a chance to input more information -- what's the temperature, what activity have I been doing. What they found in this group so far is that patients are actually very willing to describe in depth, either prompted -- that is, every certain number of hours in a day -- or ad hoc, descriptions of what kind of pain they're having and how severe it is and what else is going on. What they don't like is that slider, trying to give input of intensity by simply sliding along a barcode -- I mean -- I'm sorry -- a bar, doesn't work for the patients. Not clear if it's because it's too imprecise or because it wasn't perceived to be gathering information as relevant as the person wanted. But the bar slider is gone and there's now radio buttons to help individuals work better with their pain assessment.

In the lower right-hand corner, we see the University of Rochester's attempt to use conversational interfaces to help a patient understand what they're feeling and what to do about it on a given day. They were originally envisioning this as a spoken interface. The patient would wake up in the morning, they'd be asked how are you feeling and a series of tailored probes based on their previous responses. What they found, first off, is that older people do not like disembodied voices talking to them first thing in the morning. Didn't work. But, in fact, they were very willing to go and sit down at a computer screen and type responses. And especially when small amounts of natural language processing could be done to actually decode and feed back to the person part of what they were experiencing. So that's coming along in a very exciting way.

The common themes we found -- that health occurs in everyday living and the health tools need to fit into the everyday lives of a person, but they can't be too small. The UMASS project with the pain assessment has had to go to a device that's slightly larger than any cell phone you can imagine because the screen real estate was too small to have all the information on it that patients wanted, even with the use of icons. Patients didn't like flipping screens too much -- they forgot where they were. Conversely, the first barcoder that the University of Colorado group brought in for the elders was the size of the one at Wal-Mart, it's a great big barcoder. The elders didn't like that, it was too big. It was too embarrassing to have it on the counter -- somebody would ask you what it was for. So, now, they have this small device that, actually, looks like a small flashlight. So it fits into their lives and they can manipulate it.

Secondly, we've learned, over and over again, that patients want to know what their clinicians recommend to them. So, for the group of patients that we work with, they see personal health records as a way of staying connected to their clinicians. And they also want their clinicians to know about their everyday lives. Now, when I say that sentence to a bunch of practicing clinicians, they all go -- [Yelp] I can't do that. Too much, I can't take any more information. So one of the things that teams like ours have to be thinking about as we drive to a future where personal health records help ensure that the everyday experience of a patient is brought into their clinical practice, we have to find efficient ways to get it in there. We can't expect a clinician to sit and page through page after page of information with an individual. That problem remains to be signed -- solved later.

Let me talk to you about a few of our early lessons, and then we'll finish up with some broad-based themes and directions.

First early lesson: Laypeople already have very robust health information management strategies. And so, whatever we bring to them in personal health records is building on a skill set they already have, it's not giving them a brand-new skill set. Now, that should be reassuring to those of you who are in design because we need to remember people already know a little bit about monitoring their health and well-being. What you see here are different ways and places people store things, including file drawers, on top of counters in the kitchen, maybe in a specialized file for life or emergency care. But this is not a de novo skill, this is not something people have never done before, it's something we have to capitalize on their strength as we build new tools for them.

Second, dosing strategies often change. One of the most important things we learned about medication management in the two or three projects -- four projects, I guess, that are working with medication -- is that people want assistance with how to make choices about how to modify and adjust their dosing strategies and medication. So they need to know less about you're on Lasix, you're taking 75 milligrams, it should be taken once a day, and more to say if you overslept and it's 10:00 instead of 7:30, how much of the Lasix should you still take? They want tailored dispensing information, dosing strategies.

Third -- and the Colorado group is really good about this one -- "medication reconciliation" means something very different to patients than to clinicians. You know, and this is the key to health and safety in the future, is medication reconciliation. At every point in the care process, we're going to reconcile medications. Well, if you envision medication reconciliation, meaning that the two lists of medication and the general dispensing instructions are the same, then you get the gist of what we're trying to accomplish here. But what patients believe and what patients want to work with is that they want to attend to what their clinicians want them to do and they do want to have tools that help them to know how to carry it out. So instead of giving formalized prescribing lists, like we tend to give at our point of discharge, patients prefer handwritten materials. They prefer more casually presented materials. Their idea of reconciliation is knowing that I'm doing what I'm supposed to be doing. And although the reconciliation activities that we have going on thinks of there being an exchange of content, basically, what patients are interested in is getting the information presented to them in ways that are understandable and can easily be used.

Reconciling calendars is important and this is really a very challenging process, both from the side of the clinicians and the patients. One of the leads on the UCSF project for women with breast cancer told a story of having gone through a great deal of effort to try to get a woman seen very quickly by a specialist who was well known for treating the particular kind of breast cancer this woman had, only to be told that that woman's daughter was getting married that day and the woman wasn't going to be in town, can't be there for the special assessment. So the calendaring challenge is not just can the patients know what the clinicians want us to show up to do, but also, can the clinicians know what's important to the patients so that efforts about care are done in a meaningful and positive way.

The Washington group learned that people do not want to take pictures of food. And they don't want to take pictures of food for one reason that might not be too surprising so this is another audience participation moment for a minute. Why might people not want to take pictures of food? They don't want somebody to know what they're eating? That would be my reason. That's actually not it. They don't want to disrupt the flow of conversation at dinner. Oh, excuse me, I got to take a picture. They found it embarrassing. And so if we're going to ask people to take pictures of food, we need that camera-in-the-tie thing like "Get Smart" has so they can do it surreptitiously. They just found the action of it embarrassing. Interesting piece of insight.

And finally, to kids, health involves friends, music, and photos and nothing that looks at all like a clinical record. So if we're going to build really good PHRs for kids, we got to be thinking more along the Facebook, MySpace kind of lines and less along the MyChart and Epic.

Okay, let's take a look at the architecture that supports data integration, protects patient privacy, insures rights, and promotes innovation. This is a challenge. We've got so many architectures already building in personal health, in the health I.T. environment in general. Why do we need another one for personal health records? Well, we need another one for four -- I'm sorry -- for three key reasons.

First of all, the current HIT approach -- and I say HIT deliberately, and not informatics -- optimizes information flows within an organization, but people need information that flows across organizations. So we need architectures that actually promote exchange rather than protect information resources.

Secondly, health I.T. emphasizes coordination within a system already committed to a common goal. There's a strategy in place. But actually, people need to support multiple goals. They may both, at one and the same time, want to have less pain as well as be clear in their ability to interact with their family members. So the clinical pain management regime cannot rely on opioids that constantly keep the person feeling confused. Information tools that bring only one set of information to the patient's hands are not going to be useful. They need to be able to help with tradeoffs, with multiple goals.

Finally, HITs are really designed to capture business processes and, as we said earlier, there aren't business processes in the home. People need personal health practices and they need information tools that help them with that.

So we, in Project HealthDesign, tried to make a stab at what this architecture might look like by developing something that we call the common platform. The common platform is both a set of data definitions as well as a set of technical functions that were driven, first and foremost, by our gleaning information from our nine projects. We learned, across the nine projects, that almost all of them required some information about medication coordination, strategies to manage identity, assistance for calendaring, and ways to capture observations in daily living. Not just capture what my clinician wants me to see in daily living, but observations and such.

So, through the last fall and winter, we spent time describing the core functional requirements and then had a technical team build the functional specifications that those requirements were needed and, finally, we created a testbed for actually testing this. Now, you can see this information described in much greater detail on our project web site, which I'll give you at the end. But essentially, what we were trying to do here is to see if the idea of separating applications from data and allowing design teams to focus only on the innovation and the application and provide, in essence, a shared library of resources might advance innovations in the personal health records space. And we're very happy to see that there's been very good uptake among our grantees with this approach and we have, now -- excuse me -- the beginnings of a chance to share information across various applications.

So, since all the applications are describing and defining observations in daily living using a common structure, even though they're looking at different kinds of observations, we're better able to integrate. So that now, the group from RTI that focuses on sedentary behavior management and the group at Massachusetts that is focusing on the -- excuse me -- focusing on pain management is coming together on a project to increase activity among people with arthritis who have chronic pain so that the products can grow on each other. Excuse me.

I did promise you that we looked at some ELSI considerations and four things have come to the forefront. Again, these are discussed in some depth in some position papers and tools that are available on our web site. First and foremost, we've learned "privacy" means something very different in the home than in the hospital. "Privacy" means my discretionary right to share with the people that I want to share for the period of time that I want to share them. People have a very dynamic view of privacy. They want to be able to withdraw access rights on their own at a moment's notice, they don't want to have to sign a legal form to be able to do that. Secondly, identity management tools need to support the way people actually live, like giving a care partner access to information. Third, human subjects issues are very complex in testing in this area, and it's absolutely ridiculous to have every team start their own human subjects protocol. So we've learned to build model human subjects protocol and agreements and materials which are available on the web site because we are talking about testing, we are talking about innovation that requires protecting the rights of patients as they're involved in this design activity. But trying to communicate this to human subjects committees who largely think in terms of clinical trials was a major challenge across all of our teams. And so we've tried to provide some resources there.

And finally, the question keeps reappearing -- should HIPAA cover PHRs? Does it make sense to have HIPAA worry about what's on the dinner plate or should we have HIPAA protection over that vest that will alert you when you need your inhaler? Our group, right now, is working to better understand how to make sure data protection and data security strategies are made without medicalizing the data. That is, HIPAA is a set of tools that's necessary for institutions to protect the data they're entrusted with. Personal health records are really far outside of that realm. Although every time we post a message, we post papers or blog about this particular topic, we get a lot of responses, a lot of concern on both sides, and I think the issue's not resolved.

Let me close by taking a look at the larger context. We've been involved in the Project HealthDesign activity for two years. We thought we were so far ahead of the pack, and we find, after two years, that we're just about running, keeping up with them, because so much is changing so quickly in health I.T. and in information technology in general.

In the last six months, we've seen two major integrators and one firm that is proposing an integration come on to the scene. So we have Microsoft's HealthVault, Google Health, and Dossia (Indivo). These are three different approaches to creating PHR platforms. And we're really excited to see this level of activity. There's different approaches taken in each one of them. Microsoft HealthVault uses a rather reductionistic strategy with lots of small data elements; Google Health takes a document approach strategy, linking all information about a particular event in a single document, and allows -- ahem, excuse me -- for much easier transfer, much less manipulation. The Dossia (Indivo) strategy is implementing the Indivo product, which has a large amount of patient control, patient access controls in it. It's probably the most sophisticated in terms of patient access and patient information control. Ahem, excuse me.

I'll be happy to, when we go into the conversation, to talk a little bit more about these. We are working with our grantees to see where their products could actually also work on some of these platforms--linking social networks and personal observations. In the last year, the number of social network operations that have appeared is phenomenal. My students, now, make YouTube videos to give their class presentations and my son, who's 14, has 500 friends on Facebook.

There are beginnings of applications of uses of these environments for health purposes. For example, the Red Cross now has, in some communities, a widget in Facebook that allows you to put your blood type in so that when there's a need for blood of a certain type, they have a quick access to a group of people who have that blood. So there's lots of innovation coming in this area. Del.icio.us is a social bookmarking site that allows people to rapidly put together a number of pointers to different web sites and share them among their friends and have theirs added to. These tools are presented here, now, not because they're personal health record tools but because they're platforms that might help us in creating the information that people need to accomplish what they have to do in managing their own care. I'd like to point to one site that's blending the two ideas, social networking and clinical information, together. And that's a site called PatientsLikeMe. You may have encountered this before. This is a site created by a layperson to allow people who share common illness and diagnoses to self-report their experiences, thus providing a large body of experience and expertise that allows patients to interact with each other as well as to determine how normal is their experience of this disease or not.

There's all sorts of new tools coming out, all sorts of new tools that are going to be available. I present to you today, I hope, an idea that we need to rethink the concept of personal health records from an information flow to a foundation for action and that we need to consider how tools like Web 2.0 and new, emerging tools, will allow us to capitalize on these resources.

In the next -- I think we have about 30 minutes for comments and discussion, so I'd like -- my starting point would be to think about how do we capitalize on consumer awareness, Web 2.0 tools, and the health system's readiness to move towards the idea of personal health records, from a self-contained data dump to plug-and-play applications that promote the health of individuals.

While you're beginning to think about that, I'd like to introduce you to my team in Wisconsin and show you our web site. If you want more information about Project HealthDesign, please check there. And that concludes my formal remarks -- thank you. Yes.

[Woman speaks indistinctly]

[Dr. Brennan] Sure, there's a couple of things with identity management. The question was, with respect to the core functions, can we discuss identity management? We're -- ahem, excuse me -- interested in basically having two things occur properly -- knowing who you are and knowing who owns the information you're putting in. So, first, authentication is a function that the system requires to know that this is, in fact, a blood glucose being uploaded by Mary. Secondly, once that blood glucose is up, it has to be linked with the rest of Mary's records. We saw this as a challenge that occurs in every personal health record application, although it's not often addressed, and I'll come back to that in just a moment. And so rather than expecting every team to solve it their own way, we created, basically, a set of functions that the teams could import into their application, not having to create it on their own. Why do people not address this? I mean, nobody addresses this, not just our teams. And one of our groups had enough insight to at least remind us we had to do this.

Most of the time, when people think about PHRs, they presume that the person touching the device is the patient and they presume that the data is staying inside the device. And so there's no moving around of the data and we don't think about sharing glucometers across two people or having more than one person using the same web site interface. We think that authentication happens elsewhere. So what we needed to do was to actually build a robust enough authentication and authorization scheme and data tagging scheme that would not overburden the user. And one of our teams is looking at biometrics. Most of them are looking at a much less robust, more password-identification type of a process. Once you have authenticated information into a personal application, it then can be transported along the line into, for example, back into a clinical record. And in order to be able to export information from a PHR into a clinical record, which is happening at the Washington group, the Diabetes Management Group, the receiving system has to trust you well enough. And so, although our designers are saying, ah, don't bother with identity, it's really not that important right now. If you really want to pass information on beyond the device, the receiving systems demand a high level of identity and strong authentication.

[Announcer] For the most accurate health information, visit www.cdc.gov or call 1-800-CDC-INFO, 24/7.