

Focus on People: Rethinking the Power and Potential of Personal Health Records – Part 1

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

[Host] And our guest today is Dr. Patricia Flatley Brennan. She is currently the Lillian L. Moehlman-Bascom Professor, School of Nursing and College of Engineering, the University of Wisconsin at Madison. Currently, she's the Chair of the Department of Industrial and Systems Engineering in the College of Engineering. She received a Masters of Science in Nursing from the University of Pennsylvania and a Ph.D. in Industrial Engineering from the University of Wisconsin at Madison. Following seven years of clinical practice in critical care nursing and psychiatric nursing, Dr. Brennan held several academic positions. She developed the Computer Link, an electronic network designed to reduce isolation and improve self-care among home care patients. She currently directs HeartCare, a World Wide Web based tailored information and communication service that helps home-dwelling cardiac patients recover faster and with fewer symptoms. Additionally, she's also the National Program Director for Project HealthDesign, a Robert Wood Johnson funded initiative designed to stimulate the next generation of personal health records, largely the basis of the conversation today, and a Fellow of both the American Academy of Nursing and the American College of Medical Informatics. Dr. Brennan was elected to the Institute of Medicine in 2002. So today, she'll be talking about "Focus on the People: Rethinking the Power and Potential of Personal Health Records." Welcome, Dr. Brennan.

[Dr. Brennan] Thanks, Jason. Good afternoon, people here in the room and those connecting by technology. I am very grateful to have this opportunity to talk about a passionate part of my life, that is, creating the tools that people need to have to be able to better manage their own health and health care. Now, I have to give you two warnings as I start this talk. The first is that this is an audience participation talk. There are several points along the way that I'll be asking you to either vocalize aloud or to say to each other - some answers to some questions. The second warning I have to give you is that I'm from West Philadelphia, and although I've been out of West Philadelphia for 28 years, I still talk very fast and I have a Philadelphia slur. So if you run into difficulties hearing me, please let someone know and I'll try -- and let them let me know -- so I can try and slow down.

[Man speaks indistinctly]

[Dr. Brennan] I'm to be silent now? [Laughter]

Man, I knew you guys were powerful, but that's pretty good. [Laughter]

Personal health records, we talk about as if this is some sort of a new idea, a new topic, didn't have this before. But, in fact, as long as fifty years ago, MGH was calling people at home and asking them to input information, actually, through an automatic calling line. Input information about what the process of recovery from cardiac surgery was. So the idea of capturing information for clinical purposes live from a patient's home is not all that brand-new.

The idea of organizing it in purposeful ways is also not all that brand-new. In the sixties, Warner Slack was trying to help people figure out what kinds of -- how to prepare for a clinical

encounter, particularly related to their experiences with allergies, and he was using an old CRT tube to pose questions, but then creating a nice paper-written form that allowed the patient, in his or her own words, to express what was going on.

Into the seventies and eighties, there were many different opportunities for clinical records, but I want to point out two of them to you that were not computerized, but were still focused on personal health. The first was Ruth Lubbeck's work in the Maternity Center in New York. In Ruth Lubbeck's work, she was caring for women in an out-of-hospital maternity center -- that is, a birthing center -- and innovatively, she moved the clinical records from behind the desk to the front of the desk so that, as a woman came in for a weekly or a monthly visit, she would pick up her own record, do her own measurement of weight, of protein in her urine, write the report down, write down how her week has been, and provide that to the clinician, engaging patients actively in the use of their own information for health purposes. Excuse me.

In the eighties, the British were studying how to better help patients with schizophrenia participate in their clinical treatment regimes. And what they found is, if they gave them a little booklet that described what the treatment regime was and also some of the things that they might experience during the process of recovery or management of their illness, that the person was more likely to, first of all, become a more accurate historian, secondly, stay engaged in treatment, and third, bring some insight that the clinicians hadn't heard before.

So patients have actively been involved in managing their own information for years. Now, starting in the mid-nineties, we saw an interest in consumer health informatics and the idea of using information technology tools, not just for the purposes of taking care of -- sorry -- managing the clinical enterprise, but also to help people take better care of themselves.

Now, personal health records grew out of a belief that consumers had a right to information technology tools. But they also grew out of a longstanding tradition that the medical record is the golden shield, the de facto standard of valuable health information. And today, we're going to be rethinking both of those premises.

First, that patients have a right to information tools, but it might not necessarily be just computer tools. It might be a full range of information tools -- cell phones and innovative devices. And secondly, there may be more to health data than the medical record. So creating a personal health record as a subset of a medical record may be a necessary, but not sufficient, process.

I'm going to talk with you today about some of the basics, as I see personal health records, and the strategies necessary to focus on people. Then I'm going to talk with you for a while about Project HealthDesign, which is now in its twentieth month. Our project will be completed in about six more months. A strategy to develop innovation in personal health records and personal health tools for individuals. I'm going to share with you some of the very hot-off-the-press insights that our teams are generating and I'm going to finish by pointing out some of the co-occurring events, both in the health IT world, as well as in the information technology world, that might shape the future of personal health records. Then there'll be time for discussion, and that's where a big audience participation part is coming into play.

I'm going to be asking you a couple of things. You might want to jot these questions down so when we get to the end, we can talk about them together. The first question I'm going to ask you is: What should happen next? So you'll learn, as I go through the data today, that people are actually very interested in getting information tools that will help them, because they desperately need help. But we have a challenge in getting innovative tools. So what kind of innovation might best be fostered in the realm of personal health records? Secondly, I'm going to ask you to think about what are the ethical, legal, and social issues that we've missed in Project Health Design? Because one of the very key aspects of creating an information flow into the homes and bedrooms of people is that we change the landscape where ethical and legal issues occur. We change the social structure, we change power relationships, we change self-advocacy relationships. So we'll spend some time talking about that.

Okay, now we're up to the first audience participation moment. If you're going to rethink the power and potential of something, you have to be able to imagine. So I want you to get comfortable with me and I want you to imagine a personal health information tool that might be quite helpful. I want you to imagine the dinner plate that knows what's on it. Sounds a little bit like what we talked about at lunch. Imagine a dinner plate that knows what's on it that can actually, first of all, weigh the food, using those little dispersion and MEMS sensors; secondly, do a chemical analysis of the content that's present there, and then use an embedded chip to obtain nutritional information from a USDA database and query your own health record, your goals, and your recent intake, and finally, flash green if it's okay or red if you have to skip dessert.

Now, would this be helpful? We're bringing together personal health information at a point of action that requires and supports the ability of an individual to take better care of themselves. Anybody want the plate? Oh, one person does. Two people do. All right. Usually, I get nobody wanting the plate. I've actually talked to some of our engineering guys at home. Right now, this would be about \$1,800 a plate, a little expensive, but -- in the prototype phase -- it actually could get into mass production. I don't know if I'd ever want anybody to know I ate that kind of a chicken-fried steak up there.

So let's take another imagination exercise, since you did so well with the first one. Imagine... a vest that stores your cell phone -- up in the left-hand side -- that can tell where you are, evaluate the quality of ambient air around you, and stores coaching tools, medication, and water, and has a sensor that vibrates in anticipation of your need for a rescue inhaler. Imagine that it knows, before you do, that that rescue inhaler might be needed. Again, we have information, integrated at the point of action, where an individual's health state can be positively affected by the ability to synthesize and integrate content from the environment, content from their health history, and activities that they perform.

What if there was an information pathway from a point of care to anywhere? What if all hospitals had such a plate, as we described in the beginning, so that they could accurately evaluate nutritional status? Now, maybe that would be useful, maybe not. But a typical hospital spends four and a half FTEs a day monitoring nutritional status of patients. So imagine if we had a technological support so that some of the effort currently devoted to simply counting and

adding could be redirected, could be redeployed to something that helped coaching people or training people to take better care of themselves.

What if a kid with a peanut allergy had a lunchbox with a sensor that would alert her every time a peanut-containing substance was entered? This way, materials, products that children have for lunch, barcoded or coded properly with the nutritional substance, could be avoided and therefore preventing an allergic reaction among a child? What if a Band-Aid could call your cell phone to tell you if an infection was starting?

These examples that I've given you this afternoon are the starting point of rethinking personal health records, of rethinking the power and potential of information in the hands of patients to take good action for health. Mostly, you should be sensing, seeing, that in these innovations, there would be an ability to draw from information stores, whether it be a clinical record or a person's health diary. There would be sets of decision logics, properly validated and properly vetted, made available to the individual. There would be awareness tools, understanding the context where a person was and the ability to take action in that context. Imagine if all of this was present. We would be able to have the kind of health and health care system that the Institute of Medicine tells us is necessary for our citizens. We would be able to have a health care system that is efficient, effective, and accessible, safe and affordable and ubiquitous.

We have the potential to use information technology to deliver health care where people live their everyday lives. And as I go through the talk today, I want you to keep reflecting on that phrase, "everyday lives." because it is very much in the everyday living of individuals that they both become the healthy people they're able to become, as well as require the assistance that health professionals might give them.

Now, health information systems show some promise in doing this in a clinical setting. And the promise is slowly being realized in most places. But frankly, institutionally-based, business-process health IT is not going to create the personal health information management tools that laypeople need to be able to take care of themselves. We need to move beyond the institution. Thinking that not -- although health care, to the health professional, occurs in an institution, to many of you, as public health professionals, already know this is insufficient, already know that much of health and health care happens in the community.

Now, let's take a minute and talk about what are the facets of the community that might make it challenging to build effective IT for that? Well, certainly, we have the technological infrastructure that is in place or lacking. And yet, increasingly, the technological infrastructure is in place to allow us to build the health information tools that we need to have. Second, we have voluntary users. Nobody gets paid for being healthy in this country. Although, I guess I understand now, there is a demonstration, maybe in Boston, that is awarding people who take their tuberculosis medications with cell phone minutes. So I guess there is some bartering going on about being healthy. But for the most part, nobody gets paid to use IT, so we have an ever-increasing demand. If we're going to provide information tools for patients, we have an ever-increasing demand to make them interesting, useful, able to fit into a person's everyday life.

When we move from an institution to a community, most business practice rules fall apart and social values and social structures become the dominant mode of engagement. So aspects like privacy, what constitutes authority, who is allowed to review a record, suddenly become family discussions and not workplace policies. When we move into the community with device-based interventions, we expose the health status of an individual. So being mindful that going to a web site that looks at sexually transmitted disease identifies that a person has an interest in that area, or having a device that allows you to take your blood glucose and load it through your cell phone, put it into your clinical record, still announces that that person is in our illness category in this country, changes the environment. Most people in the institutions expect to see people who are patients, and build an entire frame of understanding that person as dependent, in need of services, perhaps grateful. In the community, most people look to others and expect they look just like themselves -- healthy, robust, young, and thin. If we want to create a health intervention in the community that somehow sets people off from others, we have to make sure there's a strong enough value in it. And, importantly, we do have to make connections between the institutions and the home. For I'm not, in any way, suggesting that personal health records should be tossed at individuals and let them be to their own devices with them. I'm not, in any way, suggesting that it's possible or feasible to manage your own health without professional intervention. Yet, I'm also suggesting that it's impossible to accomplish health goals in this day and age without active engagement of the patient and sufficient tools for them to remain engaged.

So this personal health record that we're talking about has been labeled and defined in lots of different ways, but I present to you here a definition that's provided by the Markle Foundation's Personal Health Record Group. This, although dated now - five years old, provides the broadest definition of what a personal health record might be. A personal health record is maybe electronic, maybe not -- let's assume for now, Internet-based for the ubiquity -- is a set of tools, not just data, but a set of tools -- that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.

I want to call your attention to a couple components of this definition. First of all, "Internet-based." Does the personal health record need to be Internet-based? Well, if we think of the Internet as providing the broad-base communication tool that allows us to access everything from everywhere, then, yes, some kind of communication pathway is essential. Will it be the Internet in five years? I don't know. I don't think the Internet's going away, frankly, but I think there might be different kinds of communication channels we might be using. Second, "set of tools." What kind of tools are needed to manage personal health information? Sometimes those tools are fairly simple access control—"Can I look at this?" "Who's allowed to look at this?" Sometimes, they're much more complex -- decision logics, creating of the ability to locate information related to me and pull it together into a single place, identifying information and advising tools that are relevant to my health problem. Finally, the last two lines -- "access and coordinate health information and make appropriate parts of it available to those who need it." Fundamental to the personal health records concept is the idea that an individual retains control over this.

Now, I'm very happy to report to you that the debates that were occurring five years ago that suggested whether or not patients could hide part of their record from clinicians or would they be

allowed to erase part or overwrite parts have largely fallen away. Because there's been a growing recognition that personal health records are a component of the health IT system, that electronic health records created in an institution will remain a part of that. But let's take a slightly deeper look at personal health records for just a minute.

First and foremost, you do find personal health records being found useful as extracts of clinical record systems. I'm able to look up my laboratory tests, I'm able to keep track of the history of treatments that I've had for my back injury, what have you. Personal health records, as a subset, as a small repository of things that have happened to me in the professional environment, is likely to stay a useful opportunity for individuals.

Second, personal health records are records of personal observations. How do I experience my everyday living? And that's where I think we've made some great advances in Project HealthDesign. But don't, please, confuse personal observations with patient-contributed observations. So personal observations might be me taking my blood pressure at home every day or me reporting to my clinician what my blood sugars are. That's information and observations defined by another that an individual must participate in, must contribute in. But there might also be things that are important for the individual to contribute. How was I feeling when I took that blood pressure? How much had I been worried about my diabetes the days that I was looking at those blood sugars? So, patient-contributed, as well as clinically-generated information, may still both arise in the home of an individual. "Patient-controlled," meaning the patient has the right to both control, who receives as well as who deposits information, ubiquitous and, finally, action-focused. For, if we begin to think about personal health records as simply another bucket to dump data in, we will be wasting the power and potential of personal health records.

This diagram is helpful to me when I think about the landscape of health IT. The broad pink circle identifies all aspects of health information technologies, including monitoring systems, public health information networks, clinical -- ahem, excuse me -- clinical image devices and imaging system. In the center happens to be, because my focus does come out of a care delivery system, we see the unifying of electronic health record, electronic patient record, and a personal health record. Note that they overlap, but not completely, because there are things in a clinical record that will always need to be in a clinical record that will largely be of no interest to the patient. At the same time, the personal health record will include many things that might be of enormous interest to the patient, but not necessarily be of critical value to their clinician. Monitoring an exercise routine, for example, or looking at my strength and development when I'm doing a weight training program.

Now, I want you to look at this diagram for one more minute because I'm going to make you change it in a second because I think it's actually, although it's useful, it's the wrong orientation. It puts the information, it puts the record, it puts the repository, front and center. This will not help create information for action. Let's just flip it down on its side and think of the information systems that exist, including the electronic patient record and the personal health record, as a foundation, as a platform, as a resource for action, as opposed to a product in themselves.

Shifting the focus of personal health records from the front and center, we're going to focus on the data, we're going to have it organized, we're going to have it standardized, we're going to

have it freely flowing to the foundation, we're going to be able to take action based on what we know about this individual -- reframes the entire discussion of what a personal health record is for and what applications are that may ride above this. It also, fortunately, removes the debate of which is the more important record, the EPR or the PHR. Which one, who should control it? It allows for thinking about various flows of data, various flows of information, into the patient's life. Also allows for supporting action. Think about applications, whether they be the plate that knows what's on it or a web site or a health buddy -- that you see in the upper left-hand corner -- as tools supported by the data flows.

Now, how do we move from data to health? How do we take PHRs to move from the idea of a repository collection of information to action for health? Well, I submit that requires three things. First and foremost, a vision of information for action. What information is needed to help people take action? Secondly, fun, functional, and easy-to-use devices. No one has had to tell a kid how to use a Gameboy or an iPod. They know intuitively how to use that. You watch an adult fumble with an iPod, trying to figure out how to make the music play, and you'll know immediately that device is not fun for the adult, but it is fun for the kid. We need to think about devices that are fun, functional, and easy-to-use across the lifespan. Second -- sorry -- third, we need to think about architectures that support data integration, protect patient privacy, ensure rights, and promote innovation. We need to move from a monolithic, institution, vendor-driven approach to creating health IT products, to creating health IT modules, plug-and-play that fit together, that work together in the symphony of support that patients need to be able to take care of themselves.

Let me take a few minutes to talk through these. First of all, a vision for action. Think, for a moment, what do people need to be able to do to be healthy? Now, maybe you immediately went to a long list of things -- that they have to eat properly and they have to walk properly, they have to take a nap, they have to sleep, or maybe they have to take medications. We think about the action that people have in various ways, but largely because we're health professionals, we think about it from a formalized perspective. I want you to, instead, think about what your mother needs to do to be healthy. Or what your kid needs to do to be healthy. And I want you to think about five M's.

First of all, they need to be motivated to engage in health. Healthy behavior is not an instinctive pattern of most adults. And, frankly, children are a little bit better at this than we are. Adults need cognitive engagement, need a reason to participate. Maybe it comes from a powerful other, maybe it comes from a physician guiding their care, maybe it comes from their own sense of a future orientation. Motivation is essential. They need tools to help monitor their progress towards health or monitor deviations from health, if that's what they're dealing with at the time.

People need mentoring in order to be healthy. They need to learn new ways for health behaviors to take a hold. They need to learn new ways to modify their own lives if they're conducting some kind of a behavior that is, in some way, inappropriate or interfering with their health.

Sometimes people need to mend, they need to heal, they need to get better. Understanding what it takes to do that, both in terms of the information needed, as well as the action needed gives you a basis for beginning to design personal health records with an action focus.

And finally, in this day and age in the U.S. -- and hopefully for not much longer, but my fear is, at least for my lifetime -- people need to manage the health care system as much as be managed by it. People need to remember their claims, they need to know when to show up and when not to show up, they need to know when to call, they need to remember the difference of calling the customer service agent from the insurance company versus the customer service agent from the clinician. People have an enormous amount of logistical management -- recalling what was said in clinical encounters to knowing how to be sure they're paid for. These five M's give you an idea of what people need to do to be healthy, regardless of if we're talking about accomplishing future or achievement health goals or recovery goals.

The fun, functional, and easy-to-use devices has been the thrust of Project HealthDesign. Project HealthDesign is an initiative that's sponsored by the Robert Wood Johnson Foundation with additional support from California Healthcare Foundation. We're about two years old now, as an activity. And we were specifically seeking disruption--disruptive interventions, a chance to change the way we thought about personal health records. Initially, personal health records, although they were very new, got very quick uptake as being good ways to store data from a clinical encounter. We need, and we believed, and we have strived to create fun and functional devices to achieve some of the power that we see in personal health records and make sure their potential is realized. The power being ensuring an individual of having personally controlled ubiquitous access to health data and ensuring their potential, focusing on the ability to create not just access to information, but ways to fold that information into action.

So, Project HealthDesign followed a process over the last few years that I'd like to go over with and in a little depth first and then tell you about the products that resulted from it. We had a four-component process in Project HealthDesign. First, "User-Centered Design" to develop an understanding of the needs and challenges as experienced by the individual. Second, a belief that it was essential to focus on the application, not the data. This led our design teams -- gave our design teams -- the freedom to build simply the front end of an application, to make a credible enough prototype to convey the experience. We saw this as a major departure from traditional health IT design approaches, in part because the work that's been done to date has had to create, top to bottom, a fully self-contained system. And we said to the grantees in this project, let's just see what we could do if we built the front ends that look like what people needed them to look like. How do we develop, how can we think about new uses of personal health records? Third, we created a common platform. So as not to leave individuals off without any data source, we used the development of applications to drive the uncovering of what are the core functions that must be present in any personal health record systems and can we implement those core functions in a test bed? Or, as we've recently tried to do, can we use emerging platforms, like Microsoft's HealthVault or Google Health to provide a platform that allows us to run applications on top, separating the applications from the data, using creative talents to develop good and interesting applications that fit the needs of users.

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