Focus on People: Rethinking the Power and Potential of Personal Health Records – Q and A

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

[Host] So I'll ask a question. Thank you very much, Dr. Brennan, I appreciate your time here today and the presentation. So, I think you mentioned, obliquely, a little bit about sort of information sharing. You said, I think, some of the nine, with the adolescents, that there was sort of a notion of sharing the information, not a good sense of security or privacy, but people were more willing to share. I was wondering, as people sort of manage their information electronically in this way, does it change how they think about sharing that information with others, with -- obviously, with their clinicians, their physicians, with public health, with other kinds of entities? Since they have it, in some way, digitally, whereas they'd didn't really have it digitally before. So the question is, as patients have more and more digital information, does it change the way they think about information?

[Dr. Brennan] And -- ahem, excuse me -- our experience is that patients actually believe that a lot more is going on with their information already than truly is. They believe that more people know things about them than they, um -- than they're aware of, and they're not as bothered by it. They actually believe when you go into the emergency room that someone can find your medical record and can find your list of medications and can access it and review it pretty easily. The teens in the Arts Center project do not think of information as health information so they think nothing of disclosing in great detail, on Facebook, highly personal information that might deal with a diagnosis, might deal with socially complicated behaviors -- incest, self-mutilation. And their idea is: I know who I'm sharing this with. I'm saying only my friends can see this or only a subset of my friends; therefore, it's private. And their ability to understand the complexities of the environment, the context of digital information, is not at all developed. It's not at all developed in adults either, but for a very different reason -- adults view clinical information as being much less secure in electronic form than they do in a paper form. And in some ways, they are somewhat resigned to that, that they might get exposed, but they are -- they realize they have to share information so that their clinicians can take care of them.

Now, adults don't distinguish between a site like WebMD or, in the case of our RTI product, the health promoting site that's called Cooper's, from a clinical records system. They imbue in information tools that address health the same kind of protections and security that would be present in a clinical records system. So they really don't see the difference. They presume that, if they're using a MyChart product or a portal to their clinical record, that the institution has that as protected as a regular records system. And I think the challenge for us, in terms of serving as advocates for patient rights is going to be in finding efficient ways for people to learn to understand that information in a just-in-time fashion. I think giving a long explanation ahead of time or once a year is not the way to do this, I think we're going to have to have easy ways that can be returned to frequently to help people understand that. Yes.

[Woman] Hi. When you talked about using devices in the community or at home has there been much thought about the workplace environment and the fact that folks don't want you to be doing nonwork things? They block access to Internet or they have zones where you can't access outside of the system that's owned by the work environment. And those kind of things for an all-day, so you're only able to do things before 7:00 in the morning and after 6:00 at night kind of management which, if you have kids, that doesn't work so well. You're managing things at midnight or something.

[Dr. Brennan] So the question has to do with how do you use personal health tools, particularly Internet-based ones, in the workplace, especially when you're in an environment that either sanctions you or restricts you from using those during the day or, in some way, doesn't want you engaging in behavior that's not work behavior while you're being paid to work. As a faculty member, I will tell you I would be very happy to have some of those zones in my classroom so I could keep the students off the Internet while we're having class sessions. But I think we'll see a couple of things happening at work. First of all, there's been very little discussion of managing health problems at work. I mean, OSHA making sure there's a nurse somewhere in the building for some of our large plants and maybe having some discussion about whether your employer should have detailed access rights to your health records, but that's about it. So everything from lactation support for women with young children to a person who has to manage a colostomy appliance is almost not even discussed in the workplace.

And the idea of managing health information using a work-based computer -- the only discussions that I have ever seen about any of that -- some of you may have more ideas about that -- have been don't do it because your boss owns the computer and you just don't want to be exposed that way. Now, I think, with the recent attention to quality of work life and more attention to how to make workplaces family friendly, we're going to need to begin to take that issue head on. Probably, though, my guess is, first, it's going to come out of the workers who are taking care of dependents, whether they're dependent elders or dependent children, needing to access the web sites to be able to make appointments and receive health updates and health information. The questions, though, about privacy and whether or not an individual can be sure that information transmitted over a workplace work site might not in some way come back and harm them I don't think have even begun to be addressed yet. I think that's a really good point. Yes, sir.

[Man] Do you have any information on how the insurance companies are reacting to this kind of activity and what they might -- how they might respond to this?

[Dr. Brennan] Carmella Bocchino is Vice President for Strategy, I think, at the AHIP, America's Health Insurance Plans, and she's on our advisory board. And although she's been supportive, she says, but we already have this, the insurance companies are already making PHRs by making claims data available. Now, if you can buy the idea that a PHR is more than a data flow, then you get into the question of has it become a medical device, is this providing information, should this be FDA-certified? We're only at the very beginning of that. At this point in time, the applications that we've been dealing with are being treated much the same way as health-related web sites. That is, this information is advisory to you and you need to consult with your clinician before you use it. That's not going to last, it's not going to help us in the long run. Ahem, excuse me. Probably, the group that would know the most about that -- although I've not discussed this with them -- would be the University of Washington group, who are actually capturing information from the glucometer in the home or the workplace and transmitting it back into the clinical record. And I think they would be the ones to know best. So if a clinician employs this information to make a decision, where does this fit in the medical liability? Am I getting the question you're asking?

[Man] Well, I'm more thinking of insurance premiums. The cost of health care is a major issue, as you know, and I'm just wondering, you know, the fidelity of the information that might be self-reported by people who are not, you know, health care providers. How the accuracy of it and whether or not it could be manipulated one way or another such that somebody's insurance premiums would go through the roof erroneously.

[Dr. Brennan] Oh, wow, that's complicated. I certainly think that -- I'd like to hope there's an upper bound on accuracy of personally reported data that exceeds professionally gathered data. Because I think there's some difficulties in both of them. But if there's a possibility -- are you suggesting that, like, adverse impact because I've reported risky behaviors that I shouldn't have reported?

[Man] Well, yes, that, or insurance denied or -- you have to remember that 60% of all bankruptcies in the country occur because of health care issues. This could have a profound impact.

[Dr. Brennan] You know, these are really helpful questions, and I think that we actually have, because where Project HealthDesign has been working is in the innovation area, we haven't looked at the deployment quite in the same way. And I think that there will be -- there'll be a number of points for discussion. I mean, what you're bringing up are several things. Can I be inadvertently disclosing things that are going to put me at risk later? That isn't all that much different in a technologically mediated encounter as it is in a human-mediated encounter. Are there sanctions against adverse risk or retribution-type activities? I know some of the stuff that's coming out of the genomics literature is saying there shouldn't be, but there are no legal protections in place as of right now. Anybody have any more information about that? I actually don't know much more in that area. I'll take it to Carmella, though. That's a helpful thought.

[Man] One more thought, which, you may have seen this -- there's an ACLU video on this guy who calls up and wants to order two meat pizzas. Have you seen this interchange? That's the kind of thing, I think, you know, that -- it's humorous in a scary kind of way. But the fact that they want to jack his pizza up to $69.95 to put in the $20 health cost and the risk to the driver.

[Dr. Brennan] To cover the adverse risk that's going to come out of eating it. I think that there are -- the fundamental question has, in part, to do with understanding how health conclusions might be derived out of behavior data flows that are not governed by health care regulation. And a critical aspect that I think is important to consider when you look at using Google Health or Microsoft HealthVault as a platform for health information is both -- for personal health information storage. Both of those companies have explicitly identified their business plan, their financing plan is based on search and searching behaviors. While Google Health has said explicitly there will not be any ads on the health record pages that they display and Microsoft HealthVault is also talking about sequestering areas, there are a number of ways that behaviors while using search engine sites can be put together and analyzed in a way to predict future behaviors. And I think that's an area that most people are unaware of. And the question then becomes who's responsible to make sure they become aware of it and how do you become -- becoming a more informed health consumer requires more than just knowing about your health and your health problems, it requires knowing about health information management. Yes, in the back, last row.

[Man speaks indistinctly]

[Dr. Brennan] Oh, I'm sorry. Last guy.

[Man] We still have many, many people in our population who don't access health care for a variety of reasons. Is anything being done in areas of research to examine how PHRs can be utilized to encourage or facilitate access to health care among those populations who need it the most?

[Dr. Brennan] Well, although not created as a health care, as a PHR per se, a tool called MiVIA, M-I-V-I-A, was created to help migrant farmworkers. It was created to have a single repository of information that allowed an individual to use a web site to access from a variety of places. Which, recently, there's been a lot of interest in thinking about how to help federally qualified health care centers be able to use PHRs as a type of clinical record separate from creating their own information infrastructure because very few of them have much of an information infrastructure. One of the major questions that comes about is: What's the relationship between a PHR in fostering engagement in the health profession, in the health care services an individual gets? Some of the work that happened at Partners in Boston helped us to understand the idea of using a PHR as a way to help people prepare for care. It's really quite helpful in ensuring the people get more out of the encounter. In this case, their web site, which had a partial access to the clinical record and also a place where an individual could diary and report information, allowed individuals to receive probes, receive a certain series of questions a week before their clinical visit, respond to them, and then have the clinical visit occur in a smoother fashion.

One of the challenges that we have -- and I think we'll see it coming into sharper focus in the next year -- has to do with whether we think about the PHR as a single spot that is, for example, held by my health care provider or as a platform that integrates data from a number of sources. When we get into the idea of PHRs as data integrators, as a way to bring data from disparate sources, I think there is a greater chance that we would require more of the individual in understanding exactly how to use that to help them in either substituting for or gaining health services.

And finally, our group's experience, in the report we got from our grantee teams, that patients, by and large, think about PHRs as something related to their health care provider. So even though we say it's more than just a summary of information about your last health care encounter, they actually view it-- even if what they're doing is recording a lot of their personal observations throughout the day-- they view it as a tool they want their provider to be engaged with. So it appears to be supplementing health care that's already there, and what will happen in situations where there is no health care isn't completely clear. Some of the questions have to do with whether or not we should be building any more electronic-based tools before we ensure that there is adequate health care for all citizens.

Another question that is important to consider is that individuals with access to health care tend to be more trusting of the health care system than individuals without access, and so they may use a tool like this very differently. The person who, I think, writes the best about this and has been the most helpful to me is Chris Gibbons at Hopkins. G-I-B-B-O-N-S. And Chris directs an institute called the Institute for Urban Health and has a particular interest in health I.T.

[Host] So -- actually, before we take some more questions, why don't we see if there are any questions on the phone or online? All right, Envision has one. Okay, so, Les.

[Man] Hey, so, one of the questions -- I have a couple of questions. One is the model of Project HealthDesign was to try to get in front of the technologies that were available at the day. Were you able to do this? And then, how much in front did you get? And then, now that you're moving toward the end, where are you relative to actually what's going on in the market? I mean, you had some big things come in, like Google Health and HealthVault, so comment a little bit about that. And then can you tell us how you changed the project as you went along because of the changes in the technology?

[Dr. Brennan] Oh, my God. Sure, these are very good questions to be able to ask. So let me take the first one. Project HealthDesign was designed to get out in front of existing technologies, to try to envision what would health care technologies be five years from now that could be useful for solving some of the problems and how might we use them. And essentially, we weren't looking for any -- the motto we used to say to our applicants and to our grantees is "If you can do it now, you don't need us." How far out did we get? Not as far as I would have liked. And I can attribute that to three things. First of all, we had a very strong user-centered design. Each of our teams, first of all, had to propose a project that was done in collaboration, showing already good access to a user group. And secondly, to keep that user group engaged all the way through the design process. So as the teams got more and more intimately engaged with each other, the pressing demands of today -- how do I help this person now -- and the abject failure of most health I.T. to help patients became a driver.

And people started -- they'd say, yeah, I know -- the Massachusetts group that worked on the pain management really wanted to use voice interface, but the voice interface would have been much more complicated for them to develop on the type of platform they wanted to develop and, in fact, people really need help with pain management now, specifically with negotiating pain care when their primary clinician isn't ready. So they said, you know, we're just not going to invest that much more in the technology. The challenge of integrating clinical calendars, like from an IDX or from an operational firm and a patient-available calendar in a secure way is enormous, and that team chose to actually make it more feasible than actually full integration, so some of it requires double entry.

I think that, in another sense, though, by understanding the users better, we got out a lot further in knowing what technologies are likely to be useful. So some things, at the first pass, looked like they would be absolutely great. Taking pictures of wounds or images of meals, we thought this will be terrific. Patients aren't comfortable with it. Allowing elders to be able to have a conversational guide through a self-assessment and get some advice -- they don't want the voice, that bothers them too much. So the things that we thought would be compensatory for challenges or limitations that individuals had didn't always turn out to be that way. So in terms of understanding users, I think we did -- we went way beyond anything we could have imagined.

The field kept changing all the way along the course of the project. And yet some of our original designs presaged things like HealthVault and Google in the sense that we look to the idea of separating data from applications, we look to the idea of having APIs in common interfaces that would allow individuals to build on a data store without actually having to know all the specifics of that data store.

I think that, for the first year that Project HealthDesign was active, the whole idea of personal health records was still sort of under the radar screen. A couple of people were interested. Suddenly, about a year ago, lots and lots of people got interested in it, but they got interested in the data repository model. That is, let's collect more and more data. And there are serious challenges in that, and these challenges are not solved by Google or Microsoft right now.

One of the major challenges, as you can imagine, is the naming challenge. That Google and Microsoft both, and Dossia, for that matter, will accept data in any format you put it in. There's no validation checking. There's no attempt to map information so you could put in -- if you put your blood pressures in as two numbers or in two separate cells or one number -- rather, one cell -- with the numbers divided by a slash, the systems don't care, they don't recognize it. They're processing largely string variables. Microsoft, we were -- I'm getting ahead of myself a little bit, but we've been working pretty closely with both Microsoft and Google within our project. We're probably going to be -- well, that's not exactly true, actually. Our grantees have been meeting with and trying to attempt to build on both of the platforms. We're going to be working more closely with Microsoft in the next couple of months, but it's not -- it's because we're allowing our grantees direct access to them, not so much that -- it's not any kind of an endorsement.

The primary difference we see between Google and Microsoft is that Google is handling things as this document flow and that's really different than what we think of as Project HealthDesign's applications being really, um -- action-focused. And so in order to be able to extract information from Google Health right now, you have to open the whole document, search for the piece of information you want, and if it's not stored -- if it's not labeled according to some kind of standard terminology-- it's difficult to find. So, for example, looking at self-reported pain ratings or looking at diagnoses is a little bit more difficult. The challenge with HealthVault is that they've taken an approach to permissioning that requires you to give an all-or-nothing permission to the entire set of tools that are present. And we believe that, actually, effective health data management by individuals is going to need to have more flexibility.

So, in answer to your question, how have we modified things? One way, we've tried to keep in close touch with them. We've shared all of our documents with them as we've gone through the development phase. We've kept -- we've given our grantees time to work with them and in turn given them access to our grantees for some testing and conversation. The most important thing, frankly, is that we are here, two years later, with a pretty widespread acceptance of the idea that personal health records applications can run on top of multiple data sources. And that the challenge now is trying to find a way to help applications be useful. A lot of the old metrics that we used for evaluation, like how often was something used is going to get changed because you might use a personal application for a set period of time and then not use it again.

What was the last one? Where are we going to go next? I'm going to put myself out on a limb here and say I think the next directions for Project HealthDesign are going to be in three areas. First and foremost, I think we need to start thinking about a constrained set of resources, a constrained process that requires us to go beyond demonstrating to actually starting to solve a clinical care problem. And it might be more -- I mean, this time, we allowed lots of innovation across a very broad area. Next, I think we'll focus in and target a specific health information management challenge and look for resources that might advance solution around one problem. Second, I believe it's absolutely critical that we have a better link into the clinical practice, regardless of whether we have physicians reading PHRs I think is not the issue. But helping clinicians understand and helping our young clinicians know how -- ahem, excuse me -- helping our young clinicians know how to think about an activated patient who takes action on their own, as opposed to someone who's waiting for advice, I think, will be very critical. Um -- excuse me. Third, I think we absolutely have to continue to work in the policy arena. There's been some talk, in the last six months that we should begin to certify PHRs the same way we certify clinical information systems. And I, for one, am an advocate that we not push the certification too quickly because I'd like to see lots of kinds of personal health applications running on various data flows, and thinking about how one certifies those as complete products seems inconsistent. Yes.

[Man] One more question. What do you think the role is of purpose-built devices versus the sort of general computing? And do you feel that getting into the general computing paradigm that you were in most of the time, was it limiting or did, actually, people -- I didn't see too many, you know, I didn't see the plate, actually.

[Dr. Brennan] I didn't see the plate either. I think I would have liked it. I really, really wanted to see the plate. Um -- again, it was the tradeoff, I think, between feasibility and vision. And I think people saw things that were underutilized in the present feasible system, so they gravitated there first. I think there's an enormous role for devices. I think that the device -- we're working with -- I'm going to say it wrong. Cons-- The Consortium of Devices. Consortia? You know who I mean -- I'm sorry, I'll have to look it up. We're working with their group to try to make sure that what they're starting to propose about standard expression of information and standard functions can be at least shared between what we think of as the personal health record pattern – Continua-- that's the word I'm looking for -- the personal health record paradigm, and the device paradigm. The challenge there is that there's a lot of value in self-contained devices and there's not a lot of value from the device market right now in exporting information into a broader arena. Now, HealthVault's actually done some interesting things with it. They have maybe 25 partners, device partners, that are building a portal between the device and the HealthVault to allow for direct uploading of information. Once the information is uploaded, it's up to another application to then make some use of that. So if you have a pedometer from Polar, you can upload the health report. There's a couple of cardiac monitoring schemes also, I think, that are partners with them. But they're not working on the interpretation. Yes, sir.

[Man] We have a question online -- "Please comment on the consumer-centric health record bank model and information flow to and from personal health records, such as for medication lists, immunizations, advanced directives, et cetera."

[Dr. Brennan] What's the comment on the -- what's the first --

[Man] "Please comment on the consumer-centric health record bank model, information flow to and from personal health records."

[Dr. Brennan] That's helpful. So the consumer-centered health record bank is an idea that we would not only be able to access information from multiple places and integrate it into an application set of recommendations and then make the recommendations, but we might actually store the information. Dossia, HealthVault, and Google are all three types of approaches to health data banking in that the individual's information is stored external from the clinical care provider and external from their own home or their own computer in a publicly accessible place. "Publicly accessible" meaning that it's in a public area, not that it's got free market access. What do I think of health data banking, as opposed to other models? I think that, as we will see an increase in sensor technology in the next few years, I think we'll see an increase in people wanting to keep track of information about themselves, and I think it could become burgeoning and we could end up managing information without any really good purpose. So I believe that health data banking is not necessarily as valuable as it might appear because institutions will continue to keep records and individuals will continue to keep records. And combining those together and finding ways to map that data to each other may be more profitable than creating a data bank that is 100% redundant with every other record about a person. Yes, sir.

[Man] I come from the telecommunications industry, and we have evolved this problem called interoperability over the years.

[Dr. Brennan and Man] Bless you.

[Man] To what extent are you working toward standardizing the structure of the data to make them cross-platform portable? In other words, realities of commercial life are going to be that some will choose Google and some will go with Microsoft. And to what extent could a Microsoft-based institution gather data necessary for treating a patient who happens to have records stored in the Google platform, for example?

[Dr. Brennan] Well, there's already been some demonstrations of sending records back and forth between Google and Microsoft. Our role in this is to work at the level of specifying the requirements and creating the functional specifications not to, necessarily, specify terminology sets, for example. So we are providing more of a standard structured approach. Now, the idea of being able to use a common nomenclature for a particular kind of health problem -- some of that will be driven by the formal clinical records that individuals use which are slowly but purposely getting to more use of standardized nomenclatures. There will be circumstances where people will always call things differently, and I think that, to look at terminological standards on the level of consumers is not going to be a fruitful direction in the future. I think we'll see more -- maybe some promise from natural language processing -- not really even that.

I think there will be a limit to the full interoperability across all possible health information about me. So my sleep pattern, as it's recorded at home and as recorded at a sleep clinic might not be recorded in exactly the same way. Where there will be great benefit, I think, is in building small utilities that actually do that kind of mapping for special purposes. And then I think what we'll see is, again, more of a modular approach rather than a full, large data model. I don't know if I answered -- it's a complicated question, I think, because, in some ways, a lot of the information the consumers want to record about themselves, if it's not recorded in standard terminology, recorded in a more narrative form, should probably stay in that form because that's what's helpful to an individual -- journaling, for example, diarying about a health problem. And where information needs to be collected in a way that becomes integrated with data collected in the health care system, we may want to prespecify that a priori as opposed to hoping that whatever comes in can be eventually linked with all other possible data.

[Man] Thank you.

[Host] Okay. Thank you so much, Dr. Brennan. Oh, one more question. All right.

[Man speaks indistinctly]

[Dr. Brennan] Well, one of them, I think -- we're not talking about adopting one record, we're talking about adopting a framework of managing health information. And I think frameworks are hard to adopt. I think that there will be tools that will be more or less adopted by people. Right now, almost everyone who has diabetes has some type of a notebook that they write things down on. We're going to have to provide them with something that's really much more flexible and more powerful than that notebook before we get them to adopt that particular part of it. On the other hand, I think we actually will begin to see pretty quick acceptance of information about my medications and my key problems that could be accessed by any number of clinicians who have a right to treat me which is a type of personal health information. And so, I think we'll see that there'll be different -- there will be different kinds of applications and they will be adopted at different rates, but a monolithic personal health record that has every piece of information about me everywhere, I don't think we're going to see adopted too quickly. I think we'll see people will adopt applications faster.

[Host] Great. Thank you. Thank you very much, Dr. Brennan, appreciate it. Appreciate your interest.

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