

**A National Web Conference on Personal Health Records: Practical Solutions for Engaging Consumers in the Design and Use of PHRs Beyond User Centered Design**

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**Patricia Flatley Brennan  
Kathy Hajopoulos**

Good afternoon, everyone. I am Brian Dixon. I am with the AHRQ National Resource Center for Health Information Technology and I'd like to welcome you all to this afternoon's session, entitled "Practical Solutions for Engaging Consumers in the Design and Use of PHRs Beyond User Centered Design." In a moment, I will turn things over to our moderator, who will introduce our panel and get us started. But first, I wanted to remind everyone who is logged onto the call of a couple of things. First, there is a quick poll that I will begin shortly that asks questions about your user experience today and logging in and getting connected to the session. It also allows you to suggest future topics. AHRQ and the NRC are both keenly interested in this information and really do use it for planning future events. So please fill that out. There will be a similar poll at the end that will ask you to provide feedback on today's session and I ask that you also fill that out before you log out. Second, I will say that we are in the final throes of getting the slides ready for posting on the web site. They will be available after today's session. Teresa will make a small announcement about that at the end, too, for those who join us later. But I did want to point that out right away. At this time, I would like to turn things over to Teresa Zayas-Caban from the Agency for Healthcare Research and Quality, who will be moderating today's session and also introducing the rest of our panel to you.

Thanks, Brian. Thank you all for coming today. We are very excited. This is a third in a series of teleconferences on PHRs. We have a great panel for you and a great set of presentations. Our first speaker, who will also wrap things up today is Patricia Flatley Brennan, a great mentor and friend. She is a professor at the School of Nursing and at the College of Engineering at the University of Wisconsin, Madison. She is currently the Chair of the Department of Industrial and Systems Engineering in the College of Engineering and received a master's of science and nursing from the University of Pennsylvania and a Ph.D. in industrial engineering from the University of Wisconsin, Madison. Following seven years of clinical practice and critical care nursing and psychiatric nursing, Dr. Brennan held several academic positions. She developed the ComputerLink, an electronic network designed to reduce isolation and improve self care among home care patients. Dr. Brennan currently directs Heart Care, a web-based tailored information and communication service that helps home-dwelling cardiac patients recover faster and with fewer symptoms. Dr. Brennan is the National Program Director of Project HealthDesign, a Robert Wood Johnson funded initiative designed to stimulate the next generation of personal health records. Additionally, she leads the Wisconsin Technology Enhanced Collaborative Nursing Education Project, a state-wide nursing-faculty development effort supported by HRSA that will improve the integration of informatics and telehealth into nursing curricula. A fellow of both the Academy of Nursing and the American College of Medical Informatics, Dr. Brennan was elected to

the Institute of Medicine in 2002. Today, she will be presenting on a PHR user design translating observations into design requirements. Our second speaker for today is Kathy Hajopoulos, who holds over 18 years of health care policy, strategy and management experience and is currently the Director of Business Development and Operations at the University of California, San Francisco Breast Care Center of Excellence. She was previously the Vice President of Affordability Consulting at United Health Group, where she worked with large employers to develop clinical and financial strategies related to their employee health and benefit plans. Before joining United, Kathy served as a senior program officer for the California HealthCare Foundation, where she focused on strategic initiatives related to healthcare quality and service delivery. Kathy has also held senior leadership roles within network development and contract administration for PacifiCare of California. She received her Master's of Public Health degree from San Diego State University and her Bachelor of Science degree in kinesiology from California Polytechnic University. She will be presenting on communication and care plan for breast cancer treatment, creating a tool for patient-centered care. Patty—you can go ahead and take it away.

Thank you, very much. Thank you for the time and opportunity to explore what I think is a really critical step in improving the availability of personal health records tools for lay people and their usefulness and relevance in everyday life. I would like to begin just by going over some basic terms. I suspect most of you are aware of what these terms mean but, frankly, they take on such subtle differences that I think it is useful to lay out a few ground rules. Personal health records—what are they? In my view, as Director of the National Program on Project Health Design, personal health records are a suite of applications that run on top of a number of different data stores. There are applications being designed to help people live in a manner that is more aligned with their health goals. However, in common parlance, personal health records tend to refer to data stores that are organized and held by the individual, usually electronic, may or may not be physically held by the individual (they might exist on a portal, such as MyChart or PatientSite, or they might exist in the patient's system at home.) One of the goals of the Project Health Design, and you will hear this peppered throughout my remarks today, is to make sure that we move personal health records away from the record part and closer to the personal part, trying to achieve a sense of information for action, helping individuals devise tools. But the basic concept of personal health records is that it is an information resource for use by an individual person. Largely that means reading use, meaning I get to look on a computer screen or telephone screen and see information about me, information about my health, my health state and some actions I should take. Increasingly though, I envision personal health records as also having a non-readable part, that is that the record exists may be to serve as an agent that carries my preferences and values forward into my clinical record when I get hospitalized—or where the record exists as an agent operating on the Internet that looks for the least expensive source of medications that I may need. So I'd like to think of personal health records as broadly information for action, either information that I read or information that contributes to further action for me.

Now, user centered design—it's worth it to take a few minutes to talk about that also. User centered design actually exists as an ISO standard and a specified process. Essentially, user centered design is the application of systematic approaches to understanding the person who is the intended user of a device or product throughout the entire process. We will talk about both personal health records and user-centered design today, but the long-term goal is to go beyond the PHR and user-centered design concepts into some practical strategies. How do you actually do it? How do you bring these tools into usefulness in an environment where we have a moving target of the object we are designing for, the personal health records, and we have a challenge for individuals as they are developing these tools. We have moved now to the first slide where we are discussing some of the current landscape for personal health records. We assert that personal health records have emerged as tools for individuals but the personal health management tasks occur in the specific context or environment of an individual and their individual needs. Because personal health records are used by people at home and in offices where they live every day, it is critical to better understand that context. We will return to that in just a few minutes. Systematic studies are needed to gather the elements of users, the information tasks and the context. Largely now we see an emphasis on the content that individuals need. We want to expand beyond that and go into the context. These models then that we are proposing today will help translate what we understand about patients into design requirements that may be making it possible for individuals to better understand their health. I apologize for the background noise. I hope this is clearer. Let me know if this is better. Okay.

Let's look at PHRs and context. Who are the intended users of personal health records? The intended user of a personal health record is generally first an individual, a person, but that person be supported in their care by what Mark Pearson calls the personal care team. That personal care team might be a spouse, a neighbor, but might also be a health professional. So there are primary and secondary users of personal health records. Second, it's useful to ask what the user will do with the personal health record. Sometimes, they will enter information into it or sometimes, they'll retrieve information from it. Sometimes, the individual will use the personal health records for only certain periods of time, for example during a health crisis or after the birth of a new child. Other times, the personal health record becomes somewhat of a silent companion through life, providing a place to store information about health and also to produce reminders for actions and for individuals to grow better in understanding how to better handle their health. Now, where are individuals handling their health? By and large, we think of personal health records as something that individuals use when they are at home. That is not unlikely. But we have also found through our work that individuals with personal health challenges actually experience them all day long. They experience them at work, while they are traveling and while they are socializing. Personal health records may be accessed and may be used from a variety of places. What is critical here, and this is where the user centered design can influence new records in a new way, is to envision as richly as possible the variety of contexts. Do we envision an individual sitting quietly at a computer screen typing and reading? Frankly, if you look at most personal health records, that is exactly what most people envision. But more and more, we need to think about teenagers on the go, looking at their cell phone display screens, or individual that

are at work who are receiving an e-mail message in the middle of a workday and needing to understand, how does the context shape what we expect an individual to be able to do with the personal health record? One thing that helps us to do that envisioning is user-centered design. We think of the user-centered design as a philosophy of engagement of the intended user or a representative of that user in the design life cycle. Largely, this will be the identified person, this primary user of the personal health records. But it is important to note throughout the user-centered design process that we might engage others in the individual's care team to use the PHR. The user-centered design is a systematic design and evaluation method that ensures, first and foremost, user involvement in all stages of development from requirements gathering to early prototyping to the final evaluation. Secondly, the user input is actually incorporated into the design. That is sometimes challenging to figure out exactly how we go from the user's response or reaction to a design principal. More about that one later. Finally, while user-centered design initially came out of the Human Computer Interface area of study, user-centered design is more than just creating interfaces that are pleasing to users. User-centered design should result in complete products that end-users are more likely to accept. That might mean that there is content available displayed in a certain way at a certain period of time with the assistance of as much technology as is needed to help the user understand and grasp it and figure out how to use it.

Now, user-centered design strategies are systematic and these strategies are purposely chosen to enhance the naturalistic engagement. That is, although much user-centered design can occur in a laboratory, it is critical to have the experience of the person likely to be the ultimate consumer of the product in the context where they likely are. We start off now with our three strategies we will be talking about today. First, the users can be engaged as members of the design team. This works well when the design process is going to happen over a series of months. The user becomes a part of, learns the conversation and the culture of, how a design team behaves. More importantly, the design team learns to incorporate into their interaction and into their daily engagement a person who might have a different set of skills than they do but maybe has a more intimate knowledge of the process and the problem that is trying to be addressed. Secondly, focus groups and target audiences give us an opportunity to have single shot, one time access to sets of users. The value here is that users can help each other, stimulating ideas, thinking through different approaches and building on the stories of others to create a richer perspective of what a user needs to do and where they need to do it. Finally, we have strategies like ethnography and participant-observation that actually involve entering into the user's environment, maybe their home or workplace, and using systematic approaches in order to try to glean some understanding of what is occurring with the individual at that point in time.

Now, nowhere in the healthcare IT environment is user-centered design more critical than in personal health records. We believe that because the person's health is such an idiosyncratic and highly emotional experience, user-centered design strategies are necessary to be sure we capture that. Now, user-centered design, of course, is used in other aspects of health IT but it specifically is needed for the development of personal health records and personal health applications development because of challenges of

developing in this area. As I said earlier, we are trying to move the whole ecosystem away from health records as an extension of the healthcare delivery system and more toward what an individual needs for themselves. We believe that the ultimate usefulness of PHRs to consumers, not necessarily to the care delivery system, but to consumers will depend on the quality of information provided, the relevance and value of that information and its functionality to the person to address, 'can this be used in his/her life', and also the feasibility of integrating PHR-based information into daily life. It is not useful to give patients a series of blood results if there is not also interpreting information that helps them to integrate that into their lives. This might sound ambitious and you might be wondering if it can be done. To date, in the PHR space, it is not done very much. Sometimes, user satisfaction surveys are employed and conducted after the system is developed to see if the user likes the system. Part of the reason that the users are not engaged early, frankly, is that PHRs are used in such idiosyncratic ways, that users use and manage health information in rather idiosyncratic ways. But we need to try to address greater engagement of individuals across the span where PHRs are likely to be useful.

The emphasis in user-centered design brings us into understanding the patients' needs and values as a basis for customizations. Because of the emphasis on PHRs as supporting an individual's approach to healthcare, there is a natural fit to bringing user-centered design strategies into the PHR process. It is useful to consider what we are trying to get from the primary users. We are focusing on the primary users and understanding their skills, needs, preferences and their limitations. Importantly, we also need to understand the context where they are likely to be using personal health records. By doing this, we'll gain insight and guidance for: content selection, the data about the individuals as well as publicly available data, such as evidence-based recommendations; functionality, how does the system have to work, what kind of data should it capture, what kind of information and presentation is more useful to this person (i.e. charts as opposed to graphs); and then utilities. Utilities are those aspects of information that are common across lots of IT products, such as identification, authorization, storage capacities, etc. The user-centered design process, by focusing on the primary users, provides insight into these areas. The user-centered design process is a series of techniques that should be employed to the entire design process. If we think of the design process beginning with requirements gathering (what does a person need), early prototyping and then finally evaluation, then there are a series of techniques that can be used at different points in time. The techniques are employed across time with an intention to give progressive refinement towards the final product. In addition, the techniques are used after market for surveillance and determining whether or not a product actually was employed. Now, some examples of the techniques that are used in the user-centered design process include the use of mockups and prototypes, interactive tools that demonstrate what is being developed and solicit feedback from the intended user. The example we have here, allowing a diabetic person to use a prototype of a food calculator to determine meal choices, allows us to ensure that feedback is based on real experience. Mock ups and prototypes have a range of fidelities, from very low fidelity cardboard or paper and pencil drawings, to very high fidelity, mock ups of computers or computer screens, or in one of our cases in our project, cellphone data capturing system. One of the aspects about the

user-centered design that is most efficient, and makes most efficient use of the design process, is that we make designs that are driven by the user's experience and from them, build in the remaining functionalities and utilities of the system. User-centered design has been applied in a lot of other areas already with a great deal of success. These are products and processes that tend to have a broader base of user involvement, including the use of mobile phones where the nub that is placed on the number five in the center of the phone helps individuals to orient the process of creating a phone number. In aviation, the user-centered design has improved navigation displays so that there is tractable evidence that more effective displays lead to decreased errors and better pilot control in times of challenge. In healthcare, we found that user-centered design, a process of leaving the last 10% of the design of an education program up to the individual user, comes up with a very targeted training program that helps, for example, in smoking cessation programs.

Well I said earlier that user-centered design is intended to inform the entire personal health record process. There are certainly aspects of the interface that are also captured in the user-centered design process. Part of the benefits that we expect, the benefits and the outcome of spending this much time on user-centered design, is ensuring, first of all, that the effort of the design process is invested in the elements that are likely to lead to the highest level of success, that products are kept flexible enough to build in what a user needs and leave out what is not needed by the user, even though that might be perceived as useful by others, and to use an iterative process to ensure that users remain engaged throughout the full product development. This helps to help manage the user's expectation. What are you likely to have acquired from the system? What benefits are you likely to get?

Let's talk for just a few minutes about the challenges of user-centered design in the PHR environment. User-centered design can sometimes be burdensome. I have talked a lot about individual engagement and you might have been counting the clock hours in your mind about how long this could possibly take. The users may be engaged in a way that makes efficient use of their time. But still, it does require attention and time spent with the user to keep them informed and help them understand enough about the product to be able to react to it. User-centered design is expensive. It costs money. We need to think about compensating our participants and helping them to help us better understand their process. In addition, there have been other techniques that have been employed in personal health records that appear to have given fairly similar results but, in fact, lack the ability to really understand user's experience. That is expert review. I can give you a good example of that from Project HealthDesign. One of our teams is working with patients with diabetes. They thought that providing them with tools to take photographs of food would allow them to get better nutritional consultations. The experts thought this would be great; we could give on-the-spot nutritional consultations. The patients told us forget it. We don't want to take pictures of dinner. That is too embarrassing. Understanding from the users what they will and will not do is particularly important. We have a diverse user base in health care and it's difficult to enact strategies to come up with meaningful feedback from all potential users. That will be the topic I return to at the end of this discussion. I want you to remember now as we are leaving this part, and

moving on to the specific examples from Kathy's work, that the challenge in user centered design for us to think about is identifying who really is the user. What do we understand about that user? All people with cancer are not alike. All adolescents trying to learn how to manage their diabetes are not alike. Designers need assistance with understanding how much they need to know about one set of users to begin to make sure that their designs are built in accord with the needs of those users. As people are scarce resources and users are scarce, we need to consider, carefully, in the funding of the design process, how much time and effort should be put towards creating a good user base for design. Having laid out these principles of user-centered design and the idea of using multiple activities, I am now going to turn this conference over to Kathy, where she will be discussing work that they are doing at the University of California, San Francisco.

Thank you. Good afternoon everybody. I apologize for my hoarse voice, but hopefully, you can hear me okay. As Patty mentioned, we at the University of California at San Francisco are part of the Project HealthDesign Initiative. We are developing and testing models for breast cancer patients. Just to set the context a little bit, we provide a wide range of services for breast cancer patients. We have a multidisciplinary group of physicians and providers. We have support services, genetic counseling, mental health services, nutritionists and such. The goal is to develop a patient-centered model of care. We also have a very strong and active group of advocates at UCSF, which will be important as I lay out the process that we've gone through. And as I mentioned, we are one of the grantees of the Project HealthDesign, funded through the Robert Wood Johnson Foundation and the California HealthCare Foundation. Essentially, the current paradigm as we saw it was that the systems of care are currently structured around providers, hospitals, reimbursement strategies, etc., and that a lot of the data collected, historically, has been about claims payment or encounter data. Providers, basically, diagnose a problem and develop a treatment plan. Patients consume the care and accept the treatment offered to them but really are not key players in the treatment planning process. Our tool, which we call the Communication and Care Planning Tool, is a personal health record that assists in the care planning process at the front end to make sure that we incorporate patients' values and their goals in the treatment planning process and ensure that communication is maximized between the patient and provider. By doing that, we are looking to create a new patient-centered paradigm where providers have access to synthesized information so they are able to share, whether it is a treatment planning protocol, or some synthesized data that is available, with patients. They get to own their data and drive how they would like data or information to be shared with them, and most importantly, design a system of care that addresses the patients' needs and values, more than anything else.

So, this is a very busy slide and really I just put it out there as an example for those of you that are not aware of what the breast cancer treatment process entails. It really is as confusing and overwhelming for patients. We put that out there as an example of the type of information that comes at patients at diagnosis and the types of decisions they need to make and the type of information they need to collect to be able to manage their treatment and their healthcare.

So, where did we start? What have we learned so far? This Communication and Care Planning Tool or CCPT, as you'll hear throughout this presentation, is being developed to enter data, organize the information that's there and to integrate the information about care and the various services that entail a breast cancer treatment process. We currently have a lot of decision support tools at UCSF for patients that are in paper format. It was trying to solicit feedback from patients on how they would like any of this information automated. We collected a lot of information on this topic by holding a series of focus groups, which I will go into in a little more detail in just a minute. We are in the process of developing a prototype model that reflects the feedback we received. We are starting with the calendar and timeline functionality because that is what we heard, surprisingly for us actually, was the most important component for patients. They needed a tool to not only contain all their healthcare data in one place for them but to help them organize and see where they were in their treatment process. So, the process we went through to pull together these focus groups—we maybe went down a unique route in that we used listservs. There are some support groups. There is a young survivor group here in San Francisco so we used that listserv to solicit patients for a patient focus group. We used Craig's List, which is very popular in the San Francisco Bay Area. I think it is gaining popularity across the country. We also have a very engaged group of advocates. Now, we only used breast cancer survivors who had actually completed their care. We felt that the information was too sensitive to have women engaged in their treatment plan currently to be part of a focus group. We have had a series of three different focus groups and once we have this final prototype developed, we will reconvene the groups to review what we have developed. So, in total, we had 20 breast cancer survivors who had completed treatment. We have three different focus groups. Interestingly enough, the first focus group, because we did use the young survivor listserv, was really comprised of women under the age of 45 who tended to be much more internet-savvy and almost all were college educated. They use the internet to get health information, manage their non-health-related calendars, etc. So it was a very different group of women in that first group. The second group was comprised of a much more diverse group of women, both in the age of the participants, in the ethnic diversity and most importantly, in the women's current use of the internet or on-line tools to manage their health or any other parts of their lives. We did put out surveys at the end of these focus groups and we did receive feedback from 90% of the participants, which we were quite excited about. One of the key findings was that most of the women did use the internet or e-mail. Only 20% used a PDA to manage their calendars, which we were surprised by because one of our goals, initially, was to link the treatment calendar with the PDA. We still think that is a viable goal but did not appear as important to the women that we had talked to initially. Although most of the women wanted a web-based care plan that they can share with family and friends and other providers, most also wanted a printed copy of that treatment care plan.

Some of the other important criteria: we heard from patients, of course, that security and confidentiality were big issues for them. Who else would access this information? The inclusion of pathology and MRI images was very important both for patients and providers, because this would allow a second opinion to be rendered much more easily than the current process where women are running around from the pathology lab to the

MRI lab to get their images, to hand deliver them to their second opinion provider. That is a very important piece that we would like to build into our tool going forward. Again, the different mediums that they would look to us to provide, such as a CD or DVD of the visit information, are not technically related to the personal health record, but can be a core part of that, demonstrating how to collect the information in a different format. Interestingly enough, we had some of the initial prototypes that we shared—we started with a white board and moved things around to a power point presentation to a flash demo that had a lot of information as far as probabilities of reoccurrence, mortality rates, morbidity rates and overwhelmingly, the women said that this is too much information. At the initial diagnosis, they said they would prefer that the information is slowly provided as opposed to in-your-face, here is what the data shows. That was very interesting learning for us, as well.

Also, as far as different users, we had a participant that represented a large Latina population. Although ninety-nine percent of her patients are Spanish-speaking only, she thought this tool would be very helpful. We were looking at, possibly, providing a format of the tool that would have a coach associated with it to do the translation and walk the women through the system. Those are some of the interesting findings that we learned. As far as some of the requested functionality, we heard back from the patients that having the information in one place was important. Most said that they created giant binders as they were going through their breast cancer treatment. Things that may seem basic to most of us, such as our original diagnosis, any second opinions, post-treatment care, etc., those things are not so easy to put your hands on. Sometimes, the diagnosis might change once the typology comes in. They wanted one place that this information would be easily accessible for them to refer back to as needed and one place for all of their tests and treatment plans around chemotherapy, radiation, and any types of medications they are taking would be contained in one place for them. This would help them be able to understand where they are in the treatment process and what is the continuum of care. Also, they wanted to know the side effects to be able to manage their overall treatment process, and then, related to that, because there is so much information involved in breast cancer treatment, a summary page of the key information that would be easily accessible was also something they would find very useful.

The other thing that came up, given that there is so much information currently out on the internet and there are so many clinical trial matching sites and so many different resources, is to point them to credible websites that can provide information that can be useful for them. Finally, they wanted a reminder system, part of the calendar function to remind them when appointments were due or needed to be scheduled or when medications needed to be taken.

We held two focus groups with providers. These providers were UCSF surgeons, medical oncologists and nurse practitioners. We wanted to understand from them what they would look for in a personal health record and a treatment and care planning tool for their patients. Although all providers said they would prefer something electronic, they very clearly said they would be unwilling to use yet one more tool if it was not connected to the tools, EMRs and systems that they already use. They also indicated that a hard copy

version of whatever the treatment planning process was that they had completed with the patient online also be included because paper charts are important, even though a lot of facilities have EMRs and although personal health records are becoming more common. The paper charts still prevail in the hospital system. As I mentioned, for the physicians, it was a <inaudible> for them to have to enter information in another place. We needed to find a way to collect structured data to re-use it in multiple different applications as opposed to collecting the information over and over again. Some of the current frustrations that physicians have with the current system include not having organized, clear information readily available. They also felt that collecting the patient history demographics initially can be very time-consuming. There is definitely an easier way to do that. We need to understand what the critical data is that is necessary to be able to help these patients come up with a treatment plan and having the data accessible in one place and then coordinating services between providers. Breast cancer care is very much a coordinated process between surgeons, oncologists, radiation therapists, etc. Believe it or not, that currently still happens in a paper format. Monday morning meetings at UCSF, the key providers get in a meeting and review who is doing what to whom and they shuffle through binders of paper. They really want some kind of automated way to track the critical information and make sure it is available to all providers who it impacts. That was the provider feedback. Some of the functionality they were looking for includes collecting some of the pathology information, tumor size and receptors status. This is something that is not usually collected in the administrative data, as you probably know. The information collected is usually for claims data. This information is not usually collected, yet very critical in managing the breast cancer patient's care. Providers also want a clear timeline of the different treatment plans and to be able to collect data from other provider settings. Patients do not always go to one institution for all of their care. Another desired functionality is being able to collect the relevant information to understand what the patient has had in the past and what is the next step here. Also, they want a tool to be able to help them manage the order of treatment, help them link all of that to a time line, and have a flow sheet with labs connecting to the system so that all of the information is in one place. They also would like a tool to point the patients to credible and relevant educational material related to their specific diagnosis. Again, a lot of this functionality they requested is not traditionally all part of a personal health record, but things identified as being critical in having the Communication and Care Planning Tool.

What I will go into now are just some sample screen shots of the prototype we are developing, and again, trying to come up with what are some of the things that patients and providers wanted to see. What is their chemotherapy regimen? What to do in radiation? What are their lab values? This was critical: although this looks like a calendar, this is intended to be more of a swim lane of the different treatment options on a timeline so that the patient and provider can make decisions on whether you do chemo first or surgery first, depending on different life events that you have going on. Believe it or not, that is critical for some patients. For example, if a patient's daughter is getting married and she wants to have hair for the wedding, she might choose to have surgery first and chemo later or vice versa. This was very, very important. As you are looking at it in the swim lane, you can click on a specific one and it will tell you the start and end

dates, the frequency of care, the recovery period, which is also very important, and the treatment plan, again, the order of therapy. That was very much requested by both patients and providers. Then, the goal, ultimately, is to link their treatment planning calendar with their personal calendar so that they have one place where they can look at everything.

Given all of this, where do we go from here? We are planning to have our prototype completed by June. We will share it with patients and providers and clinic staff, who we also shared it with but I neglected to mention this earlier. In the fall of this year, we are planning to link it into a national clinical trial matching site in phase two of this product. We are working on a different project here at UCSF, in which we are developing an application to collect common data elements around pathology data. It will be critical to have that data available for this Communication and Care Planning Tool. We also have patient-intake surveys that we've launched here at UCSF where we are able to collect basic family history and demographic information and we will use that structured data to populate the Communication and Care Planning Tool in phase two. Also our plan is to migrate some of our decision tools that are currently in the video format or in a book to some of our online decision aids. So, that is it for me. I will pass it back to Patty.

Thanks very much. I appreciate that and it is always exciting to go through the tour. Now comes the part where we are going to give you some practical strategies to take away from this. To implement user-centered design in a PHR environment requires more than just talking to a handful of users. It is important to know: where are the users? How do you get a hold of them? How do you engage them? What techniques do you want to engage them in? And what is the proper strategy? Primary versus secondary users? One set of users all the way through the design? An evaluation process or different teams of users at different points? In order to help think this through, we use a number of different important considerations about the users. As I mentioned earlier, persons who are ill are considered a scarce resource. That does not mean that you should not ever approach a person who is ill. However, as Kathy illustrated, approaching survivors of an illness provides certain kinds of insights. It is, however, also useful to engage people at the point at which an illness is unfolding with them. Finding strategies to do so many times requires partnering with the secondary users. Now, sometimes users who participate in the user-centered design are motivated by the ability to give to others, the ability to find meaning in illness. I encourage you to work closely with clinical partners, to work closely with intended users; you may be able to find effective ways to bring users at various points of the illness process. As Kathy illustrated very nicely, secondary users as well as clinicians and family members, also provide important sources of insight. Our process is designed to provide tools that are not only useful for what people want and need but congruent with their lives. Engaging people at the point where they live with the illness as opposed to just the points where they are treated for the illness is a challenging and important aspect of user-centered design. The benefits are most likely to occur when user input is brought in fully throughout the design and evaluation process. It might be brought in in different ways at different points in time. There is a great deal of flexibility in the sets of tools and the sets of strategies that are used to bring users into the process. The goal is to keep technology flexible enough and to assist designers in making sure that

the tools focus on the function and the functionality needed by the users, the focus on what they need to perform and what would be a proper level of automation.

To manage all of these strategies, to take all of these recommendations, we are going to provide you with a framework that we use here at Wisconsin called the SEIPS framework, the Systems Engineering Initiative for Patient Safety--the URL is on the screen right now. The framework organizes a number of aspects of the healthcare delivery system and helps us understand work in healthcare and also the contribution of various components of work into outcomes. The screen you see displayed in front of you shows the model itself. On the left-hand box, you see the work system. It has five components: a person who has to accomplish certain tasks, in the lower left-hand corner, using certain titles and technologies within a particular organizational structure, in our case, families and healthcare delivery systems, who is working and living in a certain environment. This work system applies as much for health care providers in the workplace as it does for patients and families living at home trying to accomplish the work of being healthy. The work system contributes to processes of care, which ultimately contribute to outcomes of care, which have both patient-level outcomes and system-level outcomes. But I'd like you to focus your attention to the left-hand side of this slide for just a few minutes and I will walk through critical questions for each of these elements.

As one begins the user-centered design process, appropriately, you begin in the center of this model, that is with the person. You want to think carefully through four particular questions. First of all, do I need primary or secondary users? Or both? Secondly, do I want to engage one person or many people in the process of the user-centered design activity? Third, do I want to have a singular engagement or multiple engagements? One user engaged once or over many periods of time or multiple users engaged over many periods of time or once? These are all acceptable strategies. Finally, is it critical to engage people who are currently in the illness process and are currently in the care-challenge process, whether it is managing a new cancer diagnosis or taking on a new exercise regime? Or is it acceptable and will I learn as much from engaging those individuals who are recovered? Answering these four questions begins your user-centered design process. Then, I ask you to try to think about the tasks that the user has to <inaudible>. In general, we began by a scan, having defined our users, of the many tasks they might be engaged with to whittle down, or focus on, a select few. Sometimes, it is important to acknowledge to your users that you recognize the myriad of tasks that they have to take on but emphasizing the one or two or three that you hope the personal health record applications will support and give the most efficient start in the user-centered design process. The third step is to examine some of the organizational characteristics. Now, organizational characteristics might sound a little odd when talking about patients and families but there are three aspects that are quite important for user-centered design. First and foremost is the current, intimate family or neighborhood structure of the individual. Who do they live with? Who is important in their life? Who makes decisions with them? Who do they have to communicate with? The intimate family organization is where we find strengths as well as needs for compensation from personal health records. Second, we look at the organizations that the individual engages in for care. Do they go

to a high level integrated delivery system or are they visiting a rural hospital? Do they see many providers or few? Kathy identified a really good example wherein a complex care system, there might be many, many, many providers involved. Being aware of the demands of the multiple provider system can make an individual challenge in managing health information is really a critical process. The third organizational component that is important to consider, frankly in this day and age in the U.S., is payors and insurers. To what extent does the individual have access to important information, like claims data, or restrictions on accessibility of information, as in certain insurance systems, and how does that play out in the design of the personal health record system. Following the examination of the person facing certain tasks in a given organization, we look to the environment. Where are they actually going to be? Location. Location. Location is critically important here. Understanding the range of places where people need to engage and interact with information in their personal health record will give some insights into the portability, the flexibility and the features that have to be present. And finally, up in the upper left-hand corner, we will look at the tools and technology.

Here, I want you to focus your attention on three key questions. First of all, what do the users currently use? This will give you a sense of their inclination towards or their avoidance of technologies and may provide some assistance in determining the extent to which a PHR has to be flexible over multiple platforms, including paper as well as electronic. Secondly, what do they anticipate that they will continue to use as they face this health challenge or as they face their future time in life? Do they expect to continue to have a land line telephone? Will cell phones become a part of their lives? Can they envision themselves using an electronic diary or being willing to go to a computer screen to type in information? Finally, this is where speculation begins to come into play, what can be made, re-purposed or bought in the present environment that might be of use to the individual? Paper diaries or PDAs are tools that exist for other purposes that might be brought in to supply the technologies that are needed to help a person accomplish their health goals. So, the SEIPS model helps us organize the launch of the user-centered design, giving us attention of areas to focus on. Now, let's turn how we might use this for evaluation.

When we were trying to use the SEIPS model to help us translate user needs into requirements, we take this framework and we look at the design requirements that will merge in four areas: the technical requirements, the content requirements, the functional requirements and the contextual requirements. Let's look at them in a little more depth.

The SEIPS model helps direct the transformation of needs organized into these areas into the selected design requirements. One would look for the technical requirements in the answers to the tools and technology question. One would look for the answers to the content, which is what content should be included in a personal health record, at the responses provided to the tasks and the people who do those tasks. Guidance for the functional requirements necessary for a PHR might come from the examination of the responses to the tasks as well as to the organization and the environment, giving some idea of what kind of information flows might be accessible to a person and what kind of care providers and others might be involved in accomplishing tasks. Finally, examining

the context where individuals are going to be managing their healthcare—guidance from that comes from looking at the answers to the organization and to the environment. As we are looking at the SEIPS model, what we find is a way of organizing both how to begin to target user-centered design activities as well as how to organize the information.

I am going to take you back for a few minutes to emphasize one last point about the user-centered design model. If you'll look carefully at our work systems model on the left side of this page, you will see that within the box with the five elements of the work system that I am suggesting provide an anchor for user-centered design, there is a large number of arrows that pass back and forth. These arrows are meant to indicate that changes in one aspect of the system have the ability to affect change in another aspect of the system. What the arrows also do is to tell us that we are able to gain or glean additional information and additional understanding of challenges. For example, the individual trying to manage their diabetes testing in their workplace, we combine an understanding of the task and environment where it occurs to get better insights into what kind of portability would be needed to capture the results of the glucose monitoring testing. In addition, looking at the person in the context of a long and extended family organization who is trying to manage the task of managing post-diagnosis for cardiac disease may have a large number of individuals in their families that they want to keep informed of their health process. One of the tasks, in addition to adopt new ways of eating and living, is communicating with other family members. By looking at the union of information about the tasks, the organization and person, we are refining and becoming more explicit with our person of the kind of tools that they need in the personal health record system. Ultimately, the personal health record system will be advantaged by building on a user-centered design model. User-centered design is the application of systematic approaches to understanding their user in context attempting to do certain tasks. We provide here an example of one socio-technical systems model, known as the Work Systems Model, as a way of beginning to initiate the user-centered design process and organizing the information that comes out of it. I want to thank you all for your time and for listening to our exploration of user-centered design and to Kathy's example. Now, I think we will turn it over to Q&A and comments from the audience. Teresa, I think it is back to you now.

Thank you Kathy and Patty for a great presentation. We will now open it up for Q&A. Feel free to use the chat and send the questions to all panelists and I will help moderate some of the questions.

Ok, we have some questions coming in. This person is asking if you have any words of advice of someone trying to introduce UCD into a health care organization.

Kathy, do you want to take that first?

Sure. The one thing that I would recommend that came up loud and clear for us, and I mentioned it earlier, is that you absolutely must integrate and find ways to share data with existing systems. If you create yet another new system that is not linked or reuses data

already collected, it does not fit from a work flow perspective. That would be my advice, from our experience.

I would add from our experience here that actually gaining buy-in into the concept of user-centered design is critical before you introduce it. You need to know if user-centered design is something your organization is already ready for or if it represents a departure from the way you usually do business. This is really critical, not only with your designer group, but also with your clinical practice and your organizational management group. The user-centered design puts the user in the center and position of power of choice in healthcare IT design. This is a different model than we frequently see happening when we build electronic medical record systems, for example. I would encourage you to do an environmental scan to see to what extent you are bringing a disruptive way of thinking into the workplace before you bring it in. Second, I think it is useful to have small but focused educational programs on user-centered design, whether it be a handout, an email or 15 minutes at the beginning of a conference, to explain what you are going about doing and how you are doing it. As Kathy mentioned, the idea of understanding the consequences to workflow and the consequences to individual practice is important. Data sets are huge. Those cannot always be anticipated ahead of time. By the very nature of introducing in a non-directive way some information about user-centered design as a prelude to actually implementing it, you can field the questions and get better understanding. Finally, user-centered design is expensive and it is worth forecasting the cost of gathering the information as well as interpreting and using it and placing the real cost of doing business, at least your best guess, early on will save a lot of difficulties later on when, suddenly, either the patients had been engaged for a long time and their input was never used because there was no way to use it, or people are disgruntled because they thought there was going to be greater participation in the process than there actually was.

Thank you both. A related question: one of the attendees says that they are having a hard time finding UCD practitioners. Where would you recommend that they find professionals?

This is Patty. Actually, individuals skilled in user-centered design come from a variety of different areas. You see them in industrial engineering and in psychology. Sometimes they come together with a set of skills, from say anthropology. The point that I would go for in building UCD resources is to look at a multidisciplinary team approach as opposed to finding all the skills in an individual person. It might mean retraining some of your current design team and bringing in expertise. User-centered design tends to be a process that occurs across time. However, it does not necessarily mean an unending process of design. Design deadlines can be made still having a sufficient user-centered design focus. I would not abandon current design approaches as much as I would augment current design strategies with the right set of teams, whether they be people who understand how to elicit and interpret user needs or people who understand how to translate those into requirements on your current design team.

Thanks, Patty. There is a person asking about accessibility with PHRs for persons with disabilities. This person is wondering if there are persons with disabilities using a cross disability model that are being included in your work and what are your reflections on accessibility in the industry realizing that lack of accessibility falls under the U.S. Civil Rights laws exposing developers to litigation.

This is Patty. I think this is an appropriate and timely question in terms of both the expectation that any resource that becomes integrated into the clinical care delivery system has got to be accessible to every person in the care delivery system. Secondly, the proper way to engage people with different levels of ability in design around tools for promoting health. I do not have a lot of answers for this one. I do know that there are issues related to accessibility that address technical platforms broader than PHR, for example cell phone accessibility or computer browser accessibility. I can speak for Project HealthDesign that our designers were encouraged to maintain themselves in accord with the basic design and accessibility principals of the technologies that they were using. Now, beyond that, for example, things like having spoken words, interpretations of images, such as x-ray images, I believe that that still has not become standard in PHR. Although the statement suggests that under civil rights laws, this exposes the PHR developers to litigation, I have to say that you might want to reframe that and find ways to get to accessibility criteria into PHR certification strategies. I believe that PHRs are too early to be considered an industry standard for use in tools although I think we are moving in that direction.

Thanks Patty. Kathy, this question is primarily for you, but Patty, you might want to speak to your experience across other projects. Did you have patients that identified family members or surrogates that they would want to give access to the PHR?

Yes. That was a big part of our discussion and data gathering. Having access control to allow family members or significant others to have access to their PHR, but also just as important, to be able to discontinue that access after a certain amount of time. That absolutely came up as something that would be important to patients as they go forward in this process.

This is Patty. Kathy refers to something that we consider in Project HealthDesign as rights management. Who has the right to enter, look at your system or at parts of your data? And when should you restrict that? All rights management is a challenge and also a task that is common to a lot of PHR applications. We identified strategies for rights management in what we call our common platform, which is the suite of tools that might need to be used by all users or all developers of a personal health record system. We have found, as Kathy just mentioned, that among our individuals engaged in the prototype testing and in our projects that there are both people that want to provide lots of access, maybe not necessarily to family members but to a friend that is supporting them with care, and also those who want to restrict access and having the ability to have fairly easy interfaces for rights management is very important. I will say that this is, actually, a really new area for people to think about. Although patients have gotten used to thinking about HIPAA and HIPAA privacy, they have yet to develop a lot of experience in deciding

whether or not they want their brother to be able to see all of their health data or not. Some of the work we are finding here in our team in Madison is suggesting that this is a separate skill, much like understanding your insurance claims. We need to help people to think about it as this skill that they use across a lot of health data questions, not just a PHR.

Thank you both. One of the attendees is asking what is the optimal time to complete the design of a PHR. Maybe you can speak to the timeline for your project, Kathy, and Patty, you can talk about the process and how long it is taking for the other projects as well.

I am not sure that I understand—the timeline for the project?

Yeah, the question is about the optimal time to design the PHR. I do not know if there is an optimal time for design. Maybe you can speak to the timeline for your project in terms of design.

We have been working on it for over a year now. It is definitely a longer process than I think some of us had envisioned. It is soliciting input, developing a mock-up, in whatever format that is, sharing that again, getting more feedback to get to the point where you are comfortable that the requirements you have put together are solid and reflect what you heard. For us, so far, it has been about a year. It will probably be about another three or four months until we get the prototype of just one component of the tool that we eventually want to build.

Can I comment on that?

Yes.

If I am reading the question right, I think the participant might want to know how fast can we get it done as opposed to what time in the person's lifespan but I am going to try to address both of those, if I can. When a design team makes a commitment to building tools for patients to use for self management, they are making a long-term commitment and will be most efficient if the idea of having a way to consistently engage patients and make sure that patients and lay people are available to cooperate with the team over long periods of time might actually be quite useful. For example, developing a registry of patients who are willing to participate in design activities. There are some fast-track design activities that have built applications in under 6 to 8 weeks, still engaging individuals and gaining input from them. But remember, in a user-centered design process, you can engage the intended user in a lot of different ways. It can be through previously recorded stories about how people operate in this environment or what kinds of challenges they face as well as newly collected data for a specific project. Remember that user-centered design does not mean that you follow through the same set of steps in every single product that you design, but rather that you have ways to make sure that the individual's perspectives, needs, values, etc., are incorporated and their feedback and experiences informs the design process. If I can speak for just a minute about what is the optimal time to design a PHR, we need to think about PHRs as having multiple

instantiations. There will be all kinds of different personal health management tools. The idea of creating data resources that might be drawn from by PHRs is a concurrent process. Think about, for example, the kind of PHR tool that might be needed for a person who is going through a phase of trying to become pregnant or trying to lose weight. It will be very different from something an individual will want to maintain their year to year history on the annual physical exams and exercise tolerance and things that are important. What is critical to think about here is the idea of multiple applications running on top of multiple streams of data to help people better manage their health.

Thanks Patty. We have another great question, which is something that is faced probably not only by you but some of the AHRQ grantees developing consumer health informatics applications. In personal health record development and use, how would you balance the patient's wants and needs with the clinician's wants and needs? Kathy, maybe you can speak to how you would address some of that, balancing the functionality requested by providers as opposed to the patients.

I am not sure that we have actually solved that had yet. I know in our discussions, we are envisioning, perhaps, a different view of similar data. Our tool is intended to actually be a collaborative process that the patient and provider will walk through together. The providers will have access to some of the more data driven pieces of it that the patients won't. We have not solved that yet other than knowing that that is something that needs to occur. Whether it is just a different view of similar data or more technical versus more layperson, we have not solved that yet.

Thank you. Another question that was raised was how standard health information exchange can be ensured in a highly tailored patient centered record system.

I can take that on for a try. If I am looking at the question correctly, the participant also asked about CCR, the continuity of care record. I would like you to think of PHRs as having lots of different purposes and one of them being sharing information between patients and providers. That might not be the only one or most important one. Certainly, there are particular observations that a clinician wants a patient to make over a period of time. During the course of the pain management therapy, how do we help a patient to keep track of the sensation of pain and the experience of it and report that back to providers in systematic ways? There will be certain clinically important parameters that need to be observed and making sure that those are captured in a way that can be mapped to standard terminologies is essential and important. Other kinds of uses of PHRs, for example, helping me gain insight into the different times of the day that I experience anxiety, I might never have the full dialogue, the full recordings that I make about my emotions at any given point in time conveyed to a healthcare provider and it might be unnecessary to map that part of my PHR to a standard language and standard terminology. Does the continuity of care record provide the right basis for PHRs? I certainly think the continuity of care record provides a structure that allows us to share certain kinds of information between patients and providers that might be relevant to a personal health record. In and of itself, though, I do not think that CCR would be a fully functional personal health record. Largely, the elements in the continuity of care record

are elements defined by and deployed as a healthcare professional believes them best. Patients may describe their symptoms or experiences in very different terms than the clinician may. On occasion, for example, in pain monitoring, looking at responses to certain medications, you may want to have a patient use a fixed or forced set of terms to describe what they are experiencing. In other cases, that might not be necessary. A full personal health record may be part union of what's an electronic health record, what I keep myself as my own diary and maybe information about the community in which I am living, such as the pollen or water quality. We think of a personal health record as a suite of tools that are robust and flexible drawing from multiple data sources rather than one large bucket of certain kinds of data.

Thanks, Patty. This is an interesting question and I know it will be hard to answer. One of the participants is asking how many users you need to examine their needs in the interview or in other processes.

This is Patty. I hate to keep saying that it depends, but it really depends. Think back to the Work System Model, the SEIPS model, and think about what is it that you need to understand about the individual. Some of that you might be able to draw from national statistics. What is the typical onset of prostate disease? How common are the symptoms following chemotherapy? This information may be obtainable through existing data sources. When you have to engage individuals in the design process, you generally are less well guided by statistical significance and more guided by concepts from interpretive research, such as saturation or maturation of the concept. We frequently deal with this when we try to make an application to our human subjects committee. We do expect that all UCD processes that go in our research environment are reviewed by our human subjects committee. They are almost always defined as exempt because they are design projects, not statistical or research projects. They frequently ask us how we know that we have enough people to make it worth engaging anyone in the process. In that case, we try to identify 3 to 5 key characteristics that we are looking to better understand and then determine whether we are trying to understand them in as much depth as possible or with as much breadth as possible. More subjects are needed to understand the breadth of experience, say of back pain in middle age women, than the depth of experience, such as whether the pain occurs more often in the morning or in the evening. There are some guides for engaging users who are unfamiliar with the previous part of the project, that is, if you need to know whether you have created a product that is understandable to a novice, you cannot engage the person that was involved in the design of that project. You need to engage a person that is unfamiliar with the product. Your choice of how many to involve really depends on at what point in the process are you involving them, do you need to understand the depth or the breadth, how much of your information requires you to have new users and what is your ultimate goal at this point at this part of the design.

Thanks, Patty. This question is for you, Kathy. Patty, I think you can contribute as well. One of the attendees asked if there are any plans for moving these products beyond the university or research settings and integrating into commercial products. Maybe you can speak to further dissemination plans, whether they be during the course of the Project HealthDesign or after that.

Our plans are to disseminate this to a broader audience. We are building everything on open source technology. We are not planning to "commercialize" the product and sell it but to make it available to any folks who want to use it. There are several other providers in the San Francisco Bay area that we partner with on other projects that we will begin engaging once we have a more viable prototype to share and are able to put it up in their locations as well. That is our plan.

This is Patty. Let me try to answer that on a couple levels. Project HealthDesign was conceived as a way to stimulate innovation. Not every one of the projects that people are involved with, not every one of the prototypes, is ever going to go to commercialization. We certainly believe the learnings from them will take us a long way. Having said that, all of our grantees are expected to put into the public domain as many of the elements of their prototypes as possible. This might include source code, documentation of experience records with the prototype or artifacts. Some of our teams are developing APIs that allow the data captured in their system to be transferred to another storage system. There might be a handful of our products that become commercially viable and actually get brought all the way through the market process. More importantly will be the repository of the artifacts from the different nine teams that will be accessible, as I said, through a public domain web repository.

That is great. Thank you, Patty and Kathy. One of the comments is that it seems that UCD easily applies to many e-health products. Have you applied it to other e-health product designs? Can you think of other health IT products that have used the UCD techniques.

This is Patty. By and large, there are two phases of health IT design. There is the industrial development phase and then there is the deployment phase. UCD plays a role in both phases. More often than not, companies and institutions that build electronic health tools, whether they be web-based interfaces for patient access, like the MyChart product, or intellectual resources like MedlinePlus, have a series of users who provide assistance on the design, accessibility, interactivity, searching strategies, etc., of these different tools. Very often, though, there has been a commitment made a priori to the content that will be provided and sometimes to the platform it will be provided on so that the user's input is more around what do you think of what we have built, rather than what is it that you would like us to build for you. I think that is true also, frankly, in a lot of health IT environments. Clinicians, for instance, are presented with a CPOE system and they were not asked what they need to help make orders, although certainly, there is a lot of exploration on different kinds of neat structures. We are also seeing a real interest in something that Kathy mentioned earlier that is actually bigger than user-centered design. That is understanding where information technology fits into workflow. It might be anywhere from how an electronic registration system fits into a clinic's operations to whether or not a regional health exchange ensures that patients that are living in rural areas get access to timely treatment for cancer. This modeling of workflow actually draws from socio-technical systems principles and proposes a little bit beyond what we currently describe in user-centered design because it more formally considers the

different number of people that might be engaged. For instance, you might have multiple users come together in a work force model. The way our team thinks about this distinction here is that in user-centered design, the focus is on a key actor, that is the person and the people that support that person. Our workflow models, on the other hand, that look at the acceptability of an IT solution to a particular care delivery systems or care process, have multiple users engaged, maybe not even in exactly the same activities. The interface will be different by user but the overall product has to support the workflow.

Thanks, Patty. Kathy, you spoke to this a little bit when you talk about care giver or surrogate access to information in personal health record. Another question that came in is if you have any experience incorporating patient privacy preferences on personal health records when sharing information with providers. Do you have any comments on this issue?

Great question. The way we have gotten involved around that is with the second opinions. What we have heard, clearly, from patients is that they would love to be able to use this tool to easily share test results and previous treatments with a second opinion provider. We have not dealt in a lot of detail as far as access controls and what, exactly, does that mean (i.e., in the limited amount of time since you have had your appointment). We have not gone down that road yet.

Okay. Thank you. Another question relates to the dialogue around PHR's focus on the transition to a patient-controlled record paradigm. Has this come up as part of the feedback from any of the patients involved with your work, Kathy, specifically, and Patty, across the other projects? Also, how might this impact the typical UCD process that you have the deployed for your current work?

Kathy: the patient-controlled aspect of it?

Yes.

Our premise is that the patient will absolutely control who has access to their record, what it is used for, how it is integrated with other PHR information, etc. The health plans now are the place where most patients now are experiencing PHR activity. It is the patient driving that process from our perspective. We are just in the prototype development phase, so we've not actually implemented this yet, but that is our premise going forward.

This is Patty. I would like to comment on this a little bit also because it is a theme that comes up in a number of discussions. As I understand the patient-controlled health record paradigm, this is a model that has been initiated and advocated by Ken Mandel and a group in Boston. Their belief is that it is critical to have records that patients control both the access to and use of. This is viewed as a step in creating synthesized or complete medical records as well as personal records for an individual, the key there being that the patient controls who sees and who does not see the information. We identify and understand that there are multiple kinds of records in the healthcare process. Records that

are created in the course of providing care at a given institution are the purview and property of that institution. The content of the record, of course, is specific to the patient. Institutions need to have records and be held accountable for managing and handling those records. When we think about patient-controlled health records, we are talking about records that are external to the institution that are managed in a way in which individuals have a choice over who sees them and who does not see them, as well as what goes in them and how and where they are maintained. Now, the question asked if we have any feedback from patients about this. We have lots of different kinds of feedback. Most of our research that we've been doing here about people's willingness to share data in PHRs tells us that patients are so hungry for good care that they are willing to share almost anything with any healthcare provider that they think will help them. They are more concerned about promoting access to their data than restricting access. At the same time, there are patients who have been disadvantaged by exposure of their health data, for example, who may have been labeled in the pejorative way as drug seeking, or patients that believe there is a risk for disclosure (i.e., letting my obstetrician know my psychiatric history). These patients tend to feel vulnerable about that level of exposure. They would, therefore, prefer to be able to restrict access rights. The personally controlled health record is external to institutions. You can control access to that. Other institution-based record becomes difficult to determine how people would exercise individual rights of control. I see this as a fertile area for the next few years. We recognize that institutions have responsibilities in managing records in accord with patient preferences. They also have accountability for ensuring that clinicians have access to information as they need to for providing care. I think this will continue for quite some time. How does this impact the typical UCD processes? If you look back at the SEIPS model, we presume about organizations that we will continue to have organizational records held separate from personal health records. In that process of designing PHRs, we are trying to help patients understand the difference between a copy of your record as opposed to the only copy of your record represents an important challenge. Thank you.

Thank you, Patty. I would like to thank both our speakers for a great panel and great question and answer session. I'd like to turn it over to Brian Dixon for some housekeeping items.

Thank you, Teresa and thank you also to the panel for an excellent presentation and a great Q&A session. Thank you to Teresa for moderating that. I want to remind folks before they hang up today that our next event is a week from today. It will be on the formative evaluation health IT. We have folks that will explain what formative evaluation is and why it is important to health IT projects and we will hear from an AHRQ grantee that has used a publicly available toolkit to help them put together cost effective evaluation plans for implementation. Details of that are available at the AHRQ web site and the URL is available at the bottom of the slide. Also, we do not have dates and times specifically yet but in June, we will be doing a webinar on bar-coded medication administration, and in July, we will have one on the new critical decision support contracts that AHRQ awarded earlier this year. Stay tuned for that information and we hope to see you back online then. Finally, thank you all for attending today's session. A recording of this web conference has been made available. As soon as we are able to get a

transcript of that up online with the recording, we will make it available. In addition, later today, we will have the slides up as well as their HTML equivalent. Please look for an e-mail letting you know when those things have come online. It will be done in the near future. Again, thank you, for your time and participation today. We look forward to seeing you back at another event in the future. Take care.

Thank you, very much.

[Relay event has concluded ].