

Designing for Underserved Populations: Constraints and Requirements of Personal Health Record Systems

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

[Dr. Horan] Greetings, good afternoon. The front seats must be more expensive, I guess. And so, thanks for joining me, and thank you, Jason and Suzi, for inviting us to spend some time with you to discuss our research and activity in this area. It is on personal health records or, you know, slight semantic change here -- personal health information systems -- and underserved populations. I hear that there've been and will be several speakers in the personal health record space who have come here or will be coming here, which is just terrific. Some, who I know, like Patti Brennan, has recently completed a terrific project called Project Health Design, and I imagine she spoke about that.

In contrast to that, we're really beginning an exploration of personal health records in underserved populations. We have been doing some research over the last year, which I want to tell you about, and we have more that we'll be starting. The reason I mention this is, I really would like the spirit of this presentation and discussion to be interactive. And I'll try to set aside ample time so that we can have a discussion about this topic, which is really just emerging.

What I'd like to do is spend a few minutes introducing the Kay Center -- who are these masked people? And then talk about personal health records and underserved populations, and then speak to some case studies that we've done, and then move to some field testing that we will be doing on a particular aspect of bringing personal health records to underserved populations, and then close with a discussion about a framework, an evaluation framework, that could be undertaken.

And to start with the Kay Center, we're located in Southern California. We brought this warm weather to you -- part of the gift economy. And we did not bring the storms which I understand are coming. When we're not doing that, we run a research center, the mission of which is to advance scientific understanding and public policy improvements relative to electronic health systems, which deal with health, chronic, and disability needs so as to enable both industry efficiency and promote societal welfare. And I want to note that when we crafted this, we thought a lot of things about societal welfare, and I think the topic of today is a very current updating of that thinking. You know, we have, you know, a gang of gypsies doing the hard work -- Sue Feldman is with me here today. I want to point her out. Also from this list, I want to mention Nathan Botts, who has really been spearheading this effort and is getting his dissertation out of it... and might be listening just as we speak, so hi Nathan, if you're listening.

Now, moving to the activities that we've been doing. Are you hearing a? It's not the video, is it? It *is* the video. [Laughing] I thought I was hearing voices. And I was. At least I stopped one of the voices in my head. [Laughter] The -- We've been doing a number of research, educational, and outreach activities, and the first one is the one that I want to spend some time about -- personal health records' use in underserved populations. And another vector we've been looking at, innovative systems for disability determination and health management, and actually those cross over in some very interesting ways -- I think I'll want to make reference to that. In addition, we have a variety of education and training opportunities that are occurring. I taught a year ago a course in consumer health informatics, and we had several case studies that we featured, one of which I'll note today. And in collaboration

with Sue, teaching a course in public health informatics this semester at Claremont. And some of these -- some of this material has rendered itself as online cases that you can access.

In terms of outreach, we've done a number of national forums, some in Claremont, some in Washington, D.C. Most recently, we did a forum on cyber-infrastructure for public health and health services in combination with the HICCS Conference in Hawaii, and that's when I had the opportunity to meet Jason, and certainly one of the ideas that came out of that symposium, which was really, you know, kind of a star-studded panel, was, as cyber-infrastructure develops and investments are made, we need to think about how data can be used not just for the clinical improvement of -- clinical improvements, but how it can migrate up to give insight into population health and public health and how there can be very much of an iterative circle there. And I think it's in that spirit that we have gone on this activity.

And finally, by way of kind of overview, I've had the opportunity to be on the Consumer Empowerment Workgroup of AHIC One, I guess would be a way -- A1! [Laughing] Which -- and made a series of recommendations in that vein for personal health record use in both disability and underserved populations. So this is a bit of the bird's-eye view of what we've been doing, and I think it just paints an important context, as I start to move into the discussion.

To define some terms further, or at least why the motivation for the focus in talking about underserved populations, there are, you know, depending on which number you want to use, you know, approximately 47 million uninsured Americans, who don't have health insurance. Now, the lion's share, 80 percent, are U.S. residents, and have lost their job, work in a place that doesn't offer insurance, that kind of thing. And of course there's been recent growth in this regard, due to the downturn of the economy recently. In California, it's also an important issue. Less than 10 percent of adults who are uninsured in California have public health insurance, and the largest share are of Latino ethnicity. So it not only breaks down along income lines, but along ethnic lines, as well. And within this segment of the population, there is disproportionately low use of preventative measures, regular checkups, sporadic use of health services, and the like.

In the course that I'm teaching on public health informatics, we're reading George Halvorson's book, "Health Reform Now." He's the chairman of Kaiser. We were going to choose Daschle's book or Halvorson's book, and I don't know, I think we're a little easier off for having chosen the Halvorson book. And in that book, he talks about five chronic diseases accounting for 75 percent of U.S. health care dollars. And just as an "are you awake?" exercise out there, anybody want to take a shot -- I want to write these on my hands so I don't forget them -- anybody want to take a shot at the five? One? Guesses? Cardiovascular.

[Man] Arthritis?

[Dr. Horan] No.

[Woman] Diabetes?

[Dr. Horan] Diabetes. Obesity.

[Man] Hypertension.

[Dr. Horan] Yes. With... and then the fifth...

[Woman] Pulmonary?

[Dr. Horan] I'll give you a hint -- it's not physical. Depression. Depression. Now, actually, I have to do a quite -- you know, as I circle them through, it's not hypertension, it's asthma is one of the top five. So diabetes, cardiovascular, asthma, obesity, depression. And so that those five account for 75 percent of health care dollars and are disproportionately represented in uninsured, ethnic minority groups, and those living in poverty. And so we'll want to come back to that in some of what we're talking about.

Now, moving and transitioning to health IT, it's been our perception that health IT has focused on provider adoption, yet it's the active engagement of consumers that can be critical to positive health outcomes. And underserved communities are particularly important to achieving clinical and public health gains.

Now, turning to personal health records. As many of you know, personal health records have come into the marketplace, and while the statistics on uptake on the general population remain low, within the pockets that they're occurring, there is noteworthy traction -- certainly Google has made it more visible as un-tethered PHR, something not linked to a health plan, and increasingly has agreements, as does Microsoft HealthVault, to importing your records from Kaiser or Cleveland Health Clinic. Kaiser -- I'm a member of Kaiser -- has a very active -- I think two million users, I mean, just a large network base of health records, and the VA, also -- My HealtheVet has a very active program. So there's a lot of experience coming out of these, and findings, relative to the value of consumers.

Now, those cases and others have generally focused on use of relatively educated health care consumers -- that is, those who have health plans. Yet, keeping in mind what I just said, there's a need for health self-management resources in vulnerable populations, and really, the need for that cannot be understated, given the prevalence of a number of chronic and related conditions. So what to think about? One thing to think about is that the successful adoption of personal health records hinges on the ability to engage patients, to provide communication pathways, to allow for personalization, and create a transparent system, so that there's a notion of trust. And so this is a big challenge to need to get over. Another point to consider -- and this actually, you know, my thinking was affected by the Halvorson book -- is that there's really very little data on health system performance in, among the 47 [million] uninsured Americans, who don't have health insurance -- and that personal health records can play an important role in monitoring performance, as well as broader population and public health analyses, and that's really a key discussion point that I look forward to having with you this afternoon.

Now, what has been our research goals and objectives? The overarching goal of our research has been to identify how access to and use of personal health record systems can assist underserved and diverse populations in managing their health to achieve positive health outcomes. In terms of a specific research objective, it's been to create a conceptual and evaluative requirements framework that can be used for -- by health care providers for designing, implementing, and evaluating personal health and care management systems targeted for use in underserved populations. A third, unanticipated,

outcome, but a good one, has been the creation of a prototype of a personal health system for use in testing in underserved settings, and we'll want to show that to you as it goes on.

Here are some research questions that really drive what we've been looking at. First, beginning with the user -- How could PHR systems attend to specific needs and situations of underserved populations? Moving to the technology -- How well do PHR systems fit within the technology access and utilization patterns of underserved populations? And moving to the organizational issues -- How well does the PHR system integrate with organizational practices and resource constraints -- which are considerable in community clinics and the like -- serving underserved populations? And then, finally, last but not least -- How well does the PHR system attend to key policy interests and concerns regarding health care for underserved populations? And I think that is a particularly timely item.

In terms of our research design, we've done a number of things. This initial research, we were fortunate to receive funding from the Blue Shield Foundation to do this inquiry. And we looked at the users and the technologies and the organizations and the policies. For users, we conducted focus groups. For -- at the organization level, we conducted two case studies. And at the policy level, we did expert interviews. And for all, we looked at the relevant literature. In terms of the users, we were really interested in user needs and interests across different platforms. And organizations, we were particularly interested in finance and process issues and constraints to adoption in both emergency room and community clinic settings. And policies, we were interested in the policy needs and rationales for PHR systems, particularly as they relate to safety net usage and public health.

Now, I'm not going to read through all this, because it'll put you to sleep, but let me tell you, there is a nascent literature -- there's really hardly any literature on personal health records and the underserved. There's a variety of related literature that I think informs our thinking, and many of you know this literature, so I'll just tick through it.

First, there's the issue of access to health and access to e-health. And underserved populations have limited technological skills, due to limited access, as well as lower incomes, less education, misunderstanding of the value of such systems -- I don't know if -- a different understanding would probably be a better way to say that. There is a general lack of access to e-health services and resources, you know, which further increasing this digital divide. There's research to support that the adoption and implementation of personal health systems and access to information can support a positive impact on health -- particularly health activation, and that's the area that we've been looking at.

Moving to research related to design, there are the need to provide frameworks for designing systems that can meet the needs of most disadvantaged users, to ensure wider adoption. And the notion, the Ben Shneiderman notion of universal design, is that if you can design it well for the simple case, then, you know, everybody benefits, because it's just easier to use. Second, personal health record functionality findings have reported that representatives of underserved populations expressed concern of privacy, noted that they want to decide who will manage their health information, and would want the PHR to be portable in some manner -- due to a number of -- moving from one clinic or community to another rather often.

Moving up to more the organizational policy issues, there is fragmented health care in general, but it's more frequently encountered by communities with lower socioeconomic status, the majority of which are made up by racial and ethnic minorities, and consequently, this is associated with less use of preventive measures and regular checkups. There are significant organizational and financial constraints to implementing electronic medical records as a baseline, not to mention personal health records, within safety net providers. And then, as we move to the overall care and policy dimension, there -- it has been steadily identified that early intervention and access to quality outpatient care can assist in reducing morbidity and the suffering of patients when treating chronic diseases, such as many of the ones we just mentioned here. And this can result in significant reductions of health care costs.

And finally, there is considerable policy interest in how public programs, including CMS, SSA, and others, can become more effective in reducing acute-care costs, and this could be a dimension of health care reform. And I have to say, just moving forward, you know, I haven't seen to date a clear articulation of the value proposition of health IT within underserved populations. And I think that what we're talking about here is exactly that, that value proposition.

Moving to our case studies, our first case study was the Mi VIA program, which is in Northern California, and particularly within the field worker environment. And you won't be surprised, due to citizenship issues and uncertainty in this area and socioeconomic factors, migrants often have a very fragmented health care and health record history. The notion is that an un-tethered -- un-tethered means, you know, not connected to a health plan, just kind of stand-alone -- web-based personal health record targeted for use in this community and associated populations would be valuable.

It's been used -- this Mi VIA program, which we'll see a video on in a second -- has been used in collaboration with promotoras, with case workers and care managers, and has currently been implemented in Sonoma, Napa, and San Joaquin counties, with over 1,000 registered users. So this is an early experience which, I think, gives us some lessons moving forward about the use of personal health records. Now, I was given a...

[Music plays, video begins]

[Woman] Here we have this huge population that come from Mexico, move, migrate along this path. You know, our community comes together and provides medical care. We have this mobile van and have the clinic, and their information gets stuck behind.

[Speaking Spanish]

[Woman] What I do is, I bring a program called Mi VIA, which is an online medical record, and we have everything which your normal chart would have, like doctor visits, dental visits, medications that you're on, allergies, family history. I mean, we have it all in there.

[Woman] Field 14. Our population tends to, you know, to travel, and Mi VIA, if you have Internet access, you can access their chart.

[Alcantar] It's kind of nice to have information all together, so you're not going to different clinics and, you know, having double procedures on you, finding out that one medication doesn't work, when one clinic already found that out.

[Woman] So that if they were seen by a primary care clinic here and sent to a specialist, both sites would be able to have access and add to that information.

[Woman] And this is what the beauty of the Mi VIA program is, that, as a patient, you have a portable health record, you have access to it, your providers have access to it, and you always can have this information readily available.

[Woman] I feel the government's role is to, perhaps, focus on the privacy issue and protect the privacy of consumers using this technology. Seventy percent of people surveyed about personal health records did not want their employers to be the owner of their record, or give them the PHR. And the same thing with the insurance industry.

[Woman] And, unfortunately, the systems that hospitals are investing in, and doctors' offices, tend to be proprietary in nature.

[Woman] Can I get your name?

[Ficco] And not easy to automatically share or transfer that information. They're all trying to figure out how to inter-operate and to transfer information easily. And yet the Mi VIA is the perfect vehicle for doing that.

[Speaking Spanish]

[Stovall] Just by giving them this tool and teaching them their rights, as far as having access to their health information, it brings them into a loop that they didn't even know was there. With diabetes, by giving them the tool to keep track of their blood sugar, makes them pay more attention to their blood sugar, makes them pay more attention to their diet, which affects their blood sugar, and it brings them into the process, whereas before, a lot of times, it was just, show up at the doctor, "Tell me what I need to do, maybe I'll do it, maybe I won't. But if I have to become part, or if I am given a tool to become part of the process, I will engage more so."

The technology is way ahead of policy. Frankly, you know, we're afraid of our insurance companies. I don't want my insurance company knowing if my -- if I'm monitoring my high blood pressure. Our feeling is that there's a way to partner with these organizations, but still keep the control of the personal health record in the hands of the consumer.

[Video ends]

[Dr. Horan] Okay, so I hope that gives you a flavor of one of the case studies. A personal health record system in Northern California, used by migrant farm workers and vineyard workers, so that when they go into a clinic -- often a mobile clinic or varying clinics, and they're being treated, they know who the person is, what their condition is, that kind of thing, which was just not

available beforehand. And the hospital values it, as well, because it reduces unnecessary visits to the hospital and it's more informed when they come.

Now, part of our research was to go up and meet with users of the system, as well as with administrators, and get a sense of their system. This is just a visual that gives you a sense of what they want to have happen -- that there is, you know, a vision about using this technology, that they work with a provider base, including hospitals and enrollers, that -- I'm moving across the top there -- that they have outreach to sign people up to belong to the Mi VIA program; that they educate through farm worker education and empowerment about using personal health records in the community clinic system. And that this all leads to, stated as the goal, to provide and engage migrants to help improve health through access to personal health records, e-mail accounts, and identification cards. So this has been their system.

And when we talk to users of this system, these were some of the -- we did in-depth interviews when we were up there, and these were some of the things that they liked about it, which is access to community sites, access to clinics, they liked using it for themselves. We saw a little less use for their family. A couple of others that I want to point out here -- less direct view that it helped their health, but it helped them know more about their health. They weren't that concerned about using information online. They really like getting their first e-mail address. Many had not had an e-mail address. And they really liked the card. You know, they're given a card, and for many of the folks up there, they don't have another identification card. And so that card became a really valuable aspect.

In terms of some of the organizational issues or perspectives, the top one that was talked about was outreach -- how this was a positive way to connect with patients and have more self-management. They viewed this as more of a collaboration activity, which is the second to the bottom, which is important, and they viewed these cards as really an important aspect of identification in the process. I should note that there were some related issues -- and I'm not going to tick through all these -- about health access, privacy, those types of things, which were there, but still, the system was used.

Here's just a quote, I think, that summarizes it from a provider's perspective. You know, "Oh, my gosh, it makes all the difference in the world. When I talk to the physicians about this, they are excited because they don't have to start from ground zero or have inaccurate information. They can have an information resource they can trust. Often, people come in contact with the system, the clinic, and know that they have hypertension but don't know the meds, or have diabetes but don't know the medicines, or describe in a vague way, like a 'sugar problem.'" And so that's the level of very basic verbal communication that had been going on, that the system aims to improve.

Moving to the second case study, in Southern California, is the Camino de Salud network, and this is based out of the big hospital up there, which sees over 200,000 folks in their emergency room a year, and many wait 12 to 18 hours to be seen, as a county emergency room, and so the notion was to create a network to redirect those who are using the services to go to community clinics. And so, as it said here, the overall goal is the health and well-being of the patients and to maximize the availability of medical resources for the appropriate needs. Secondly, and this gets to a business model discussion, really, is to decrease the unnecessary and inappropriate utilization of high-cost and intensive, you know, emergency departments and inpatient services at the county hospital. And then third, to improve communication and coordination of services between the county hospital and the network of community clinics that surround them.

And so this program has been undertaken to work with folks who come in for a fifth time at the emergency room. They're flagged at that level, and then they're assigned a caregiver, and that caregiver works with them to identify their health conditions, their health plans, and to move them to a community clinic to receive more direct care.

So we did focus groups with caregivers in this area, and found a number of things. One, caregivers regularly communicate and develop care plans with patients, although this is typically done verbally. You know, "You need to take your medicine, you need to go to the doctor," that kind of stuff. Inconsistent follow-up on care plans is one of the major frustrations in achieving desired health outcomes. A person says, "Yeah, yeah, yeah, yeah," and then walks out of the clinic and, and there's no systematic way to understand what is happening. The concept of personal health records, though, is not readily understood, nor value readily appreciated. It just, it just isn't in the language, the vernacular of what's trying to be done. Though there's a need and an opportunity to facilitate care, care plan communication and adherence, but it needs to be executed through a very "lite" platform. The notion of the patients they treat in a community clinic going home and spending the evening and filling out their Google record is just not, is just not operative. And so something else really has to be devised to make it feasible and realistic.

Here are just some quotes from this case study. "They have like three appointment cards, and they get them mixed up -- their medications, their instructions, and their receipts. They bring some to the med center, some to the doctor, some to the clinic, and you have to sit down with the patient and spend some time in explaining what they've been asked to do." Second -- "So, one of the things is just printing out the calendar and all their appointments -- every time they miss one, just putting a red dot on it. It's just, visually, you see how many red dots you have, compared to this month." And we asked them to just open up -- not show us, but tell us the kinds of information they share in their folders, and they say they do that, they say, "Here's the calendar, here's all the appointments you missed." "You're not going to get better if you miss these appointments." And then third, "And something very -- you need something very simple, because most of our population is illiterate, or low literacy -- you know, very low levels of education and understanding." And so we left -- I have to tell you, we left these focus groups, perplexed about the concept of personal health records and how to connect it with this environment. And from that, we came up with some ideas, which I'll want to get to in a second.

Just, if I could, to kind of, at a midpoint here, reconnect these two case studies with those evaluation questions that I posed earlier, and start to give you a sense of where this was heading. And this kind of builds from the bottom up, if you will, so it's kind of like reading the Torah, I guess, we're going to go backwards. And so, beginning with the infrastructure, there's a lack of computers within the community in health care settings. There's issues about technical implementation and data processing and the ability to do it. In terms of the format, the technical format and what seems to really get traction, I mentioned the health card was one of the most valuable program components from the user point of view. Moving up, other kind of personal user issues -- there were numerous cultural issues. Although kind of not discussed explicitly, it was certainly an important context. There were notes of patient empowerment -- that, with cards and an ability to access mobile clinics, patients would take an assertive role. There were privacy concerns about inherent guarding of information, particularly as regards to citizenship. And that the access to computers was low, and actually, access to health care was pretty low, and these were challenges to overcome.

Moving up to the organizational level, there was a need to provide education on both the technical and health-related aspects of health IT. There was an interest in using the health IT and personal health records to bridge communication and finding ways to connect the caregivers to the patients in more direct ways. It was seen as a very positive outreach aspect, organizationally, and that the collaboration was viewed as both an issue, as well as a barrier in providing continuous care -- that is, across the different clinics.

And then at the policy level, you know, a key item is health care access, and that access to this health care was central, and as well, a political issue within the population. That is, you know, who's got the muscle to deliver the resources to allow for access? So, from this, we start to develop some ingredients of a multi-faceted set of metrics to judge the success of PHR systems in underserved communities. And I want to come back to this in a slightly broader way in a second.

But before I do, I want to get to the third research objective, which is really a spill-over of our research. We did the two case studies, and we wanted to develop this evaluation framework, but in the course of doing these case studies, particularly the focus groups that I mentioned to you, we came back and we said, you know, "We have to talk about this in a different way." This personal health record, electronic medical record really wasn't working. And so we scratched our heads and said, you know, "What's a way that really connects?" And, you know, ding, light bulb, I don't know how bright of a light bulb, but it definitely was a light bulb -- which was, we should talk about it like it's an ATM machine. I mean, everybody knows how to use an ATM machine. When -- you don't say to someone, "How would you like to use a worldwide financial network that's secure, that links up with your personal..." da da da, you know. No, I mean, just use the ATM machine. And so we thought about that some more, and part of what we liked is that it was, you know, simple and transaction-based, it facilitates health management communication, low organizational requirements -- that is, you know, you don't have to go through the whole EHR/EMR business. It's kind of, "Can we put a health ATM in your clinic?" And that it connects with policy needs, which is to deliver something of value, something tangible, as well as off-the-shelf platforms that it utilizes.

So we came up -- and this is a real prototype up there, that we have designed, of a HealthATM machine, which engages in some very basic health transactions. And it comes from the literature, which suggests personal health records, what's valued are some simple, demonstrable transactions -- scheduling appointments, ordering prescription drugs, contacting your caregiver, and such, and so we've delivered it, and you can see, kind of, sort of, down in the bottom corner, in a very, you know, touch-screen way, where it's "My health," and you click it, and it pulls up a care plan and shows what you need to do. You can also schedule an appointment, which is the next one -- it sends, you know, an e-mail to the caregiver to schedule an appointment. On the right is "Mobile health." There's a set of reminders that can be set up, that people can sign up for -- you know, if you want to, you know, be reminded to take your medication daily or weekly, do you want to monitor your weight, you know, daily or weekly? Do you want to be reminded, you know, et cetera. And then, once they sign up for those, they get a text message, because a lot of people have cell phones, about it, and they can click back, "Yes," or put in their weight, and it creates a bar chart of that, and it connects it into their health record. And there's education materials specifically related to their condition, such as diabetes --

[Dr. Horan] Yes, Jason?

[Man/Jason] I have a question, Tom.

[Dr. Horan] Yes.

[Jason] Just thought I'd go ahead and start making this interactive -- so, you know, Suzi had defined some sort of different PHRs in the beginning, and you had also talked about that, too. Is this -- this HealthATM example, which is a really interesting example, is it still, like, a form of a tethered PHR, in the sense that is it connected to the clinic in which it sits? And does it address the mobility issue?

[Dr. Horan]: Right, it has two ways to connect to it. It directly rides on top of the system within the clinic, the care management system. But it has an interface to Google Health and others, so that you can click through -- so it's kind of like the example is, you know, when you go to order something -- I'm trying to think -- like Orbitz, you know, they give the partner airlines first, and then the other ones later. Similarly, you know, whoever's sponsoring this, they're the direct connection within their item, but it has linkages to others, and we're working particularly on the Google Health one right now. So you can toggle it as tethered or un-tethered, I guess, to answer your question.

And our notion was, we just wanted to get something out there. There was nothing out there that had this kind of simple, transaction-based sensitivity. And so this shows how it would work. A patient is contacted after frequent ER visits and enrolled in the program, and then they get entered into NAVALINKS, which is the care manager system. And at that time, a patient -- a follow-up occurs with HealthATM application where their data is entered into the HealthATM, and so they have their own account, and they work with a care manager to establish how they will use the HealthATM, what transactions do they want, what reminders do they want? And then the patient can access this on their own to conduct their own health transactions, to review their progress, order prescriptions, appointments, that this is back-entered into their care management plan, and that in terms of continuity and sustainability, this is used as a continuing basis to monitor, you know, and to engage health activation. Yes?

[Woman] Are patients then to determine what information they want to share?

[Dr. Horan] Yes. You know, the way this is set up, it's really a patient opt-in, so they're, you know, choosing to use it, and so, in that sense -- also, we've been pretty light -- light meaning on the data requirements of what needs to be in it, because, for the most part, there are some pretty straightforward...conditions that are trying to be managed, and some pretty straightforward care plans that are being executed. And that's really the general focus. It can go deeper than that, but we're trying to start with something simple and transaction-based. And I'm getting a signal that you didn't ask that into the mic, and so, for the radio folks, the question was, can people choose what information to put into it?

So that was our notion, and we are delighted -- and I mentioned this at lunch -- that last week the California HealthCare Foundation notified us that they will be supporting our field testing of HealthATM in three community clinics, as well as in the emergency room over the next year. And, you know, we're just trying to get some experience out there and get some models out there. We'll be looking at assessment of care plan adherence, health activation, usability, value assessment, health utilization, and the like, really, in an iterative way. And so we're trying to move from, you know, from a conceptual model to a concept, to a prototype, to experience with the prototype, and learn from

there. As an interesting aside, we have another graduate school called Keck School of Life Sciences, and there's a team of graduate students that are analyzing and developing a sustainable business plan for this, you know, should there be traction, you know, what is -- what public-private partnership would be needed or could be possible, to roll this out in a scalable way? So, from an unanticipated idea, it has been quite exciting to just get something out there.

So that's very tangible, and we felt like we had to get -- you know, frameworks -- as academics, we love frameworks, but, you know, if you're going to do something, do it. And so we thought we'd try and get a model out there. At the other end of the spectrum, if you will, and certainly something, I think, I'd enjoy a conversation here about, is at the policy level. You know, this four-level framework that we have about users, technologies, organizations, and policy -- if there's a policy vacuum, then it's hard to have, you know, cascading positive impacts.

And so here are some items for discussion. One is the role of governmental services in facilitating PHR use in underserved communities. Whether or not that's, you know, CMS -- you know, there's a pilot going on with Medicare right now. What does it mean for Medicaid, if you can get your Medicaid information through such systems? I know there's been interesting discussions at CDC about public health information that could be customized and delivered and given back, and what might that be? We've done some related work at the Social Security Administration, where they're considering the use of personal health records for those who have a disability, and that actually, you know, kind of creates a whole user base of those who have a number of co-morbidities and managing their situation, and a life view of what happens, which is really important, I think, from a public health perspective, and an epidemiological perspective. Then there's the issue of the role of personal health records in underserved communities for promoting prevention and continuity of care, and how can you actually deliver that in a way that's perceived as valuable? A third is policy support for EHR/EMR -- thank you for doing the acronym definition at the beginning -- and for those who are expert in this area, you'll know that Word and PowerPoint constantly change EHR to "HER," so if you ever see HER, it's PowerPoint, EHR. Support for safety net providers -- right now, safety net providers -- I mentioned this before -- can adopt a fairly conservative view about this, which is, you know, "We've got our hands filled in trying to manage the patient load that we have, which has been growing. We have our hands filled with modest IT budgets. The notion of extending it to the patient is a great idea. Perhaps another day." And so I think there's a policy issue about how to bring consumer empowerment to all segments of society and have policy support, for that to be the case. And then finally -- and this is something I alluded to earlier and has kind of been on my mind of late -- which is the role of personal health records in creating performance metrics for health services within underserved communities. There is a notion out there that as part of health care reform, there needs to be metrics on performance, so that one can distinguish good performance from mediocre performance, and yet there's not a clear understanding of health care performance within the uninsured sphere, and that personal health records could start to create this viewpoint of services, continuity of services, use of best practices, and things like that, so that's a policy notion. Let me just do a time check here.

Returning, if I could, to the evaluation framework, because I want to cycle back to that. And this is a slightly more grown-up version of it. I showed you an interim one, based on the case studies. We're starting to flesh this out in some more detail as a generalizable framework that can create a set of metrics for evaluating a PHR strategy policy implementation for underserved populations. And again, in a kind of Torah fashion here, I'm going to work my way up from the person. And so, starting at the

personal level, there's the issue of health management and often not being able to maintain continuity of care required to assess and maintain health outcomes. And the notion here is to use personal health records to improve continuity of care to achieve positive health outcomes.

We know that there are a number of language and literacy issues that need to be addressed while delivering such a system, and different renditions that can do it. We know that there are privacy issues that need to be addressed. I think implicit in your opt-in question was the privacy issue. And so one item is the role of educating consumers so they have an understanding of the privacy mechanisms that can be used. Another is understanding patient motivation, how patient motivation may be inhibited to seek care as a consequence of documentation/legal status.

At the technical level, one needs to understand the user network and the kind of highly variable means of communicating with patients. You just can't expect everybody's on a PC. You have to think about new platforms and you can tell in our illustration, we're trying to think of new platforms that were not computer-centric. You need to also think about kind of standardization across community clinic settings and others, about, and how it can be achieved.

Moving up to the organizational level, as I said, you know, community safety-net providers have their hands filled and moving to an electronic backbone is an issue. The outreach, and issues in outreach, is a positive act -- contribution that PHRs can make. And then there's the issue of overall adoption and integration, and so that it's not just one clinic, but the network of clinics that use it.

And then, finally, at the top, policy level -- there's the need to identify how personal health records can be used within the context of health services, and to use agencies such as CMS, SSA, and others, to help deliver on that. So we're still noodling away at refining this, but I think this gives you a sense of the dimensions that we've been looking at.

In summary, the Mi VIA and Camino de Salud case studies demonstrate that personal health record systems can be devised to address unique requirements of both underserved populations and the organizations they serve. The HealthATM example I gave you provides an illustration of the need to continually innovate to create PHR systems that connect with the sensibilities of underserved populations. The Evaluation Framework that we're in the midst of refining provides a template for considering the multi-level considerations in designing and deploying PHR systems. And then finally, there are a range of policy and public health possibilities that could be considered within the context of health care reform.

And let me just make quick acknowledgements -- Kay Family Foundation, for some support, Blue Shield Foundation for our early work, and for the California HealthCare Foundation for their support for the field testing that we'll be undertaking. We're academics -- we want to publish, not perish, so we have a variety of articles on it.

And with that, why don't I open it up to questions and discussion? Thank you. [Applause]

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