Transcript of Audio File:

A National Web Conference on Evaluation of Personal Health Record (PHR) Systems and their Impact on Chronic Disease

BEGIN TRANSCRIPT

Operator: Welcome. Please note that as an attendee, you are a part of a larger audience. We will be holding a question-and-answer session at the conclusion of today's presentation. You may ask an online question at any time throughout the presentation by typing your questions in the Q and A panel. Type your questions in the text field and hit send. With that, we invite you to sit back, relax, and enjoy today's presentation. I would like to introduce Angela Lavanderos from The Agency for Healthcare Research and Quality. Angela, you now have the floor.

ANGELA LAVANDEROS: Hello, everyone. This is entitled *A National Web Conference on Evaluation of Personal Health Record Systems and Their Impact on Chronic Disease*. Due to unexpected circumstances, there has been a change in moderator for today's session, so some of the promotional materials may have been incorrect. I am required to let you know that neither myself as the moderator nor any of our presenters have any personal conflicts of interest to disclose at this time. The overview for today's presentation will be that we have three presenters who will present for 20 minutes and have a 30-minute Q and A session at the end. With that, I would like to introduce our first speaker for today. Our first speaker is Dr. Peggy Wagner. This is a collaborative research effort between the University of South Carolina and the Greenville Academic Health System. Dr. Wagner is helping to develop a new medical school in Greenville that will open in August 2012. She joined the University of South Carolina after 20-plus years at Georgia Health Sciences University, where she conducted research in patient-centered care, delivery, and education. The work she is discussing today results from an AHRQ grant that examined personal health record implementation in ambulatory patients with hypertension.

PEGGY WAGNER: Thank you. Good morning everybody, or afternoon. I am pleased to be able to present the findings of our study on using a personal health record in patients with hypertension. I want to talk about some of the barriers that happened when we first rolled out this study. Second, I will summarize our results very briefly. Third, I will describe provider and patient perceptions of the personal health record after everybody had used it for approximately a year. Finally, I am going to make some suggestions about strategies to overcome barriers and enable more effective use of a personal health record.

Our study design was a cluster randomized trial. We randomized 24 physicians to either the personal health record condition or a control no personal health record condition. Within each physician then, all of his or her patients were assigned to either the personal health record or not, depending on how the physician had been randomized. We had to approach 1,646 patients in order to get 443 to consent to this study. Right off the top, you can see that it was a bit of a challenge to get patients willing to study the impact of a personal health record. When all was

said and done, we had 443 patients, 250 of whom received a personal health record and 193 who did not. Notice that 207, or 83 percent, remained at visit four, which was 9 to 12 months from study enrollment. In the control group, that was significantly lower at about 62 percent. So if nothing else, at least the personal health record was kind of a sticky product in getting them to finish the study.

Our primary outcome measure was blood pressure. We had a number of secondary outcome measures for patient health belief, we used the patient activation measure that Judy Hibbard developed; we had them evaluate the care that they received using the group CAHPs survey. Also, the patient assessment of chronic illness care, which I will probably call the PACIC as we talk through this. We also examined medical utilization based on self report of patients at the study end, as well as medical record retrieval of that information. Although I am not going to talk about it today, we did look at adherence to treatment guidelines. Finally at the end of this study, we examined patient provider attitudes towards the PHR after they had used it for a year rather than just being naive users.

When we went to start this study, before we even rolled it out, we got some reactions. Even though we had a lot of institutional support, it was an interesting process to go through for the first 6 months or so. Our providers, our physicians, thought it was going to take too much time, they worried about security. Several of them complained that patients did not need the information that is contained in a personal health record and worried about legal issues. Patients also had issues. They felt they would not know what anything meant. They worried they were not savvy enough with the technology, and they had this perception that with a personal health record their doctor was going to check on them through the personal health record, which is not the way it works, as we know. We got comments from the IT staff. The way we set up our study was that we had two rounds of input from patients and from a national panel of patients, as well as local patients where they used the PHR for about 2 weeks and then gave us input and sat with us while we worked with IT staff in trying to implement patient-centered recommendations.

The IT staff was worried about a lot of work and not enough time to change the technology we were using. We were using a product from off the shelf that interfaced with our EMR. We were able to probably incorporate about 50 percent of the patient suggestions before we started the trial. We also had concerns from the administrative leadership. The first thing they said is we need to form committees, which we did. We had lots of committees. They also had legal concerns and cost concerns if one continued provision of a portal that was a purchased product through after the study. As I said, we modified the personal health record based on patient suggestions. At the time of the trial, our PHR included messaging, scheduling, and the ability for patients to check blood pressure and a couple of other variables if they so choose. It was tethered to the EMR in that laboratory, and medications that rolled over to the personal health record were not stored in the personal health record, but they appeared when the patient opened it. It was considered secure. The patient controlled access to the record, and it linked to lots of different kinds of educational material.

The next three slides give you a snapshot of what it looks like. On the left of this slide, you can see that patients could look at allergies, as I mentioned, laboratories, and medications rolled over. We did not, based on physician decision, incorporate chart notes or other kinds of information to the PHR during the trial.

The next slide shows the hypertension center that we worked with Cerner to set up. It suggests and shows you that there is some diary functionality to the personal record, and you could track medication schedules that way.

This slide shows how we could track goals and enter things. You can see that it is relatively minimal in terms of what they are able to track. We were interested in blood pressure, so that one is there. That is kind of what it looks like. We brought patients in and trained them on the personal health record. We met with them four times, and they could get additional training at that point if they requested it. We hired a nurse who worked as sort of our personal health record triage nurse and handled the messaging and notes and communications with the physicians.

In terms of analysis, we did a hierarchical cluster modeling approach. We examined patients who were nested within physicians who were nested within one of the two clinics that we were doing the study in. We used mix models, comparing improvement from Time One to Time Four, using Visit One data as the covariate data to control for time differences at time of entry. We modeled all the independent variables independently controlling for condition of the study, clinic, age, race, gender, and education as covariates.

We did a couple of secondary analyses because we found that the use of the PHR was actually less than we had anticipated. We then went on and classified within the PHR group only. We classified patients as either users or non users and performed logistic regression. We also further did covariance models comparing Visit One to Visit Four changes just within the PHR intervention group based on frequency of use of the PHR.

Disappointingly, in the main intention to treat analysis, we found no clinically significant differences between the patients who had the PHR and those who did not in terms of our main outcome measure, blood pressure, and also in terms of the other measures that we were examining.

This table gives you some example of the main differences between the two groups. Although we found some statistical differences, I would not consider them clinically meaningful. If you look at the doctor rating score, it is only a difference of four hundredths. That was disappointing.

Because we had a lower uptake of the PHR than we had anticipated, we looked at frequency of use. You can see in this figure that approximately a third of our intervention group never used the PHR after the initial training. Similarly, about a third, a little bit less, 26 percent, we

classified as frequent user and those patients who used the PHR at least two times or more per month during the course of the study.

What changes did we observe then in the frequent users? This gives us a little bit of optimism. We did see a reduction in both systolic and diastolic blood pressure between four and five points there among the frequent user groups. Contrastingly, we saw a decrease in their rating of their physician and the physician communication score. We were able to use some of the CAHPS health technology items that were being tested at that point at the time of our study. We found that their perception of the usefulness of health technology decreased slightly, which was not in the expected direction.

We went on to ask what predicts frequent use then, with the assumption that if we could encourage folks in the right direction, we might be able to scale the effect of the personal health record in patients with hypertension. We found that younger age was associated with more frequent use. Self-rated technology skills were associated also, as well as access to technology. I should mention that we did not exclude patients who did not have access at home. We provided kiosk access around the hospital campus and also provided patients maps of local places that they could access the PHR if they so chose. It did have an impact. We also believe that the salience of the clinical need impacted the use. We found that those patients who had the highest initial blood pressures were more likely to use the portal, and patients with the initial higher patient activation scores were also more likely to use the PHR. Similarly, the more positive they scored their patient provider relationship, the more likely they were to use the PHR. We also found significant clinic effect, with the patients from the family medicine clinic being the most likely to use. I think that was for two reasons: they were pretty familiar with technology at that point, they had had an EMR in place since 1996, and they also stressed continuity of relationship between provider and patient.

Shifting now, I am going to talk about some of the end-of-the study perceptions of the patient and providers. We did this in two ways. We administered an instrument called the Patient Empowerment Scale, which is not actually personal health record specific, but it looks at what do you think are the effects on patients of providers sharing information from the ambulatory medical record. We also did interviews and focus groups and developed our questions based on the Technology Acceptance Model. In terms of the Patient Empowerment Scale, there are two versions of this scale, one you administer to patients and one you administer to providers.

When we looked at the results of the perceptions of the benefits of the PHR, you see very few differences between the patients and the providers, except in the area of the percentages of patients and providers that think that the access to their personal health information improves the understanding of their medical condition. In that case, patients are much more likely to think that that will happen.

When you look at the risks that folks perceive in terms of personal access to personal health information, there is tremendous difference between patient and provider perceptions. Providers think patients will have more questions between visits and that they will be confused by test results and by their provider notes. More physicians think that patients will worry more because they have access and they might be offended by some things in their records. We cannot say that patients and providers are interrupting those questions exactly the same. The differences are quite large and quite significant.

The interviews and focus groups were conducted with 122 patients who came to visit in the intervention group and 29 providers. The patients tended to be from the family medicine clinic, 74 percent female, 55 percent white, and 40 percent black. Eighty percent had some college. We were able to interview 13 physicians and 16 nursing staff at the end of the study.

I just have here a few quotes from patients and providers to give you a sense of the kinds of things, and we have massive amounts of quotes we can share. Here are some examples. Patients felt that the ability to send messages was important. They liked the idea they could go back and review information that their providers might have told them in case there were discrepancies. Obviously, they liked the tracking the best. Our tracking was not as sophisticated as I would have liked it to have been.

Providers thought it gave patients the opportunity to review information. They thought that maybe some medication errors would be identified by patients themselves. As this last provider suggested, knowledge is power. They thought that it empowered the patient to take more control of their health and would increase compliance levels.

Providers mentioned two things patients did not. One is a concern about the wording of things in the personal health record, suggesting that they even wanted a translator so things, before they went across, could be placed into layman's language. The other issue is time. It is a big one. The physicians felt that if they were expected to educate patients on information that was coming to them through the personal health record, then it was going to take a lot of extra time and they did not know who would ever do that.

Patients felt that it would keep the doctor more informed. Many patients had the perception that the personal health record is viewed, and some even thought it would be viewed daily by someone checking on them if they entered data into it. There was a belief that patients have the right to know this and have the right to access all their personal health information.

Providers agreed that it would be help to patient rapport. They worried about medical legal ramifications. Several of them noticed a justice aspect to this. They felt that differences in access to technology and skill to technology would increase disparities. There was some concern with that.

Again, providers mentioned time. In this particular quote, this "time" refers to the time, although minimal, that it might take to pull up a personal health record in the office setting and if that even adding 2 minutes onto a visit, they saw could be quite burdensome. Providers requested guidelines on best practices of care.

In summary, things that might encourage PHR use among patients is continuing to work on this philosophical shift in attitude that cares partnering versus one giving and one receiving and an emphasis on the continuity relationship between patients and providers. I believe that thinking about personal health records in terms of how tailored they could be to the particular individual or patient using them, and in fact, making them more patient-centered that would increase utilization. Better PHR design and usability. Ours again was a standard product we modified and did not develop directly ourselves. We should not disappoint patients' expectations about what health technology can do and how it will work for them. Given that our most frequent users reflected some derogation of perception of how useful health technology can be by of the end of the study is of concern. Again, increase access to all consumers with technology.

In contrast, to encourage PHR use in providers, the continued dialogue about who owns personal health information needs to happen. We had difficulty, even though our EMR could feed additional information into the PHR, physicians were not comfortable with that; therefore, we chose not to use all the potential interoperability between those systems. Time will help as our providers and patients become more sophisticated. Just a note, several of our providers at this study end wanted guidelines about how to use and incorporate PHRs into the clinical care that they provide. I think that is an area where we could do lots of research about how the best way to do that will be. Work load continues to be a major issue. Thank you for listening. That is my contact.

ANGELA LAVANDEROS: We are going to move onto our second presentation. Our next presenter is Dr. Carl Stepnowsky. Dr. Stepnowsky is an assistant adjunct professor in the Department of Medicine at the University of California at San Diego and a research health scientist at the VA San Diego health care system. Trained as a clinical psychologist with an emphasis in behavioral medicine, Dr. Stepnowksy's current research efforts are focused on merging behavioral sleep medicine and health information technology. His program of research focuses on how to best organize and deliver patient-centered collaborative care to those diagnosed with chronic illness and sleep apnea in particular.

CARL STEPNOWSKY: Great. Thank you for the introduction Angela. Today, I am going to talk about the effect of an Internet intervention on CPAP adherence. The way we had started this off is not necessarily designing it as a PHR, but rather designing the tools and testing an intervention that could ultimately find its way into this project 4 or 5 years ago.

What I would like to do first is give some background to those of you who may not be as familiar with sleep apnea and its treatment. I have a few slides on the background. Sleep apnea is a

chronic disorder. It is characterized by repetitive cessations of breath during sleep. Apnea is referred to or defined as literally no breath while sleeping for 10 seconds or longer. Hypopneas are defined as 50 percent reduction in breaths, so there is still some airflow. Both lead to arousals from sleep and/or oxygen desaturations. The main measure of disease severity is called the apnea hypopnea index, so we do a count of the total numbers of apneas plus hypopneas and we divide it by the hours of sleep so we can get a measure of disease severity. I point this out because we use this both diagnostically and later on to track treatment progress. Sleep apnea, the cardinal symptom is daytime sleepiness as a result of the fragmented sleep at night. It is also associated with serious cardiovascular consequences, increased risk of stroke, increased risk of hypertension, et cetera. There is also a two to three times risk of shortened survival. Sleep apnea is the most common sleep disorder represented by 80 percent of all diagnosis in sleep clinics. It is prevalent in 2 to 4 percent of middle aged working adults and has a higher prevalence in older adults.

CPAP is the main treatment, and the gold treatment, for sleep apnea. It stands for continuous positive airway pressure therapy. It is comprised of a flow generator and a hose that is connected to a mask. The mask is put over the face and held in place by the gear. It keeps the airway open so someone can continuously breathe throughout the night. It is not easy to wear. You can tell there might be some issues with adherence. Its prescribed use is whenever asleep, even in naps.

Historically, sleep apnea has been under diagnosed. There are a lot of unidentified cases in the United States and elsewhere. Historically, there has been a large emphasis on making the diagnosis, case identification, and there is only been an evolving emphasis on how do we treat them and do good chronic illness care and do the appropriate follow ups. Most recently, Medicare has implemented a 90-day rule where compliance has to be shown for reimbursement. That brought the spotlight to how do we best increase adherence for patients who are prescribed CPAP.

Rates have not been very good. If we look at it the following way, about 75 or 80 percent of patients who are asked to use CPAP, 20 percent will not even give it a try. Of those that use it, only half continue to use it at the end of 1 year. They are only using it for about half the night. This is in light of the prescription to use it all night every night and including naps. They are only using this device about half the night in general, which is considered a partial-use pattern.

There have been a number of CPAP interventional studies that be done to date. I just provided a brief classification of how we can group those interventional studies. Interventions that are focused just on providing extra education, interventions that are specific to providing clinical support, providing therapeutic changes, or advice. Those kinds of studies tend to have taken the form of if we do more will it have a larger effect. There has been mixed findings there. There have been some studies that look at behavioral change, increasing motivation, cognitive behavior therapy, or self-management therapy. Since the one we are going to be talking about is really

kind of using health information and technology tool, we are going to focus in on a couple of the health technology ones that have been done to date.

One is a health device called the Health Buddy. It was a simple device. Questions pop up on the screen, and the buttons can provide the answers. It has extensive branching logic behind it. In a trial of Health Buddy versus usual care, there was no difference in adherence.

Another study looked at video teleconferences. This was different because it looked at nonadherent patients. They found that the video teleconferencing had an effect on increasing the percentage of those who were adherent. We do not know how many hours per night they wore it, but it was over 4 hours on greater than 9 out of 14 nights.

Another one was on interactive voice response. So it was similar to the Health Buddy, but this time it was via a telephone. It could automatically generate phone calls. Again, branching logic to assess symptoms, health behaviors, et cetera. It could provide troubleshooting. If need be, could connect with the provider. Phone calls were weekly over the first month and monthly thereafter. It was a 1-year study, with an assessment at 6 months. Overall adherence was 2.4 hours per night in the active intervention group and 1.5 hours in the usual care group. Of concern is we really are hoping people can use this for at least half the night, so approximately 4 hours.

What we did initially was to look at the effect of CPAP telemonitoring. When a wireless device first came out that we could attach to the back of the CPAP machine, we set up a study to take advantage of using that data. We could have daily access to that CPAP adherence and efficacy data and act proactively. I will have some slides to show you what was done. There was no intervention on the patient's side. This was just getting the data to the provider and allowing the provider to view the data and act proactively. We had 25 participates in the active intervention group and 20 in the usual care group. The usual care group was characterized by a Week 1 phone call and a Month 1 data download. We found that for the folks who were telemonitored, we had 4.1 hours per night verses 2.8 hours per night. So an effective 1.3 hours of an increase in CPAP adherence.

That lays the background for the current study objective, which was to develop and evaluate the Internet intervention using CPAP adherence as the primary outcome. On the providers side, we wanted to take the telemonitoring data and feed it back to the provider. We realized we needed to engage the patient. Some previous work of ours was based on a group of self-management program where we had folks come in to our clinic. We asked groups, “Are you interested in looking at your data?” They were all interested in looking at their data, sharing their data, and talking about progress. We designed this study with that in mind. We also wanted to create an online resource for participants.

We had an RTC looking at the usual care group versus what we termed patient-centered collaborative care, the PC3 group. One hundred and twenty patients per group, recruited from

one sleep clinic supplemented by word of mouth referrals from the community, and we included moderate to severe folks with sleep apnea.

I wanted to show this slide because we also like to think about what the clinical care process is and how are interventions and protocols able to be incorporated in the current clinical care process. Here, what we did was we controlled what happened at CPAP set up. Oftentimes, there is lack of standardization in terms of what gets done. That is where we start, providing standardized instructions on CPAP set up. For the usual care folks, there is a Week 1 phone call and Month 1 clinic visit and a Month 2 clinic visit. Access to the data for both patient and provider, you can see the gray box; it starts at the month 1 download. For the patients in the collaborative care group, the access is nearly identical, except the access starts early. One of the challenges in doing this kind of research is that what we are doing is not comparing something to nothing. We are comparing more of something to a little less of something. The effects we find are inherently going to be small to moderate effects.

We do this on purpose because we really want to see whether simple interventions have an effect. The PC3 group was based largely on The Chronic Care Model. I have always been attracted to this model because of the bottom portion, which is, "How do we best support those productive interactions between an informed patient and a prepared proactive practice team?" With health IT, a lot of times, those data do get to the practice team, but not necessarily to the patient. That is one of the things that we really tried to focus on with this internet intervention: "How do we provide that extra education, that extra tracking, to the patient so they can kind of walk the walk and talk the language the providers are using too?"

Here are some details on the telemonitoring system we used. There is a picture of the AutoSet Spirit, which was an auto adjusting flow generator. We attached the wireless module to the back. It is not a real-time data transfer, but rather, store and forward. So if someone wears the machine last night starting at 12:00 or 1:00 today, the wireless device would get pinged and the data transferred.

On the providers side, we used what is called the ResTraxx Data Center; this is a manufacturer website, and we just used this website because it was good enough for our purposes at the time. We only used de-identified data on this to keep things compliant. There were four different screens; there was a demographics tab, where we would put in our identifying information and it would link the study ID number with that serial number on the machine and we would be able to identify the person on our side. We can set thresholds for this adherence and efficacy data, and we can monitor the progress for the patient.

The color-coding screen, this is an example of what the provider might see for any one patient. Before they got to this screen, we would use the exception reporting screen so providers could see the last 7 days for all the people who might be enrolled in the study at one time. Then they could dive into the people who maybe were having trouble. Green is good, yellow or red is not

so good. We used thresholds to set cutoffs so the upper left was adherence so we set a 4-hour threshold, green if it was above 4 hours, red if it was below 4 hours. On the lower right side was efficacy, so there are two key pieces of data that we tracked to see how well someone is doing on CPAP. One is mask leak to the extent that if mask leak is high, they are probably going to take it off. Number two is residual AHIs. This is where the AHIs come back in. The CPAP machine can get a proxy measure of the apnea hypopnea index. We set a threshold of 10, so if someone was above 10 it would be color-coded as problematic. If it was below 10, then that would meet our goals.

We set up a very specific algorithm for the providers on what to do and when. We called it the green/green pathway. If all was going well, we just would monitor and wait to see how things were going. We would also, if things were going well, would still have phone calls and say great job and provide some positive reinforcement.

There was a red/yellow pathway to identify what the problem was. Then we had a clinician management chart to structure what kinds of interventions could be done.

On the patients' side, what our thought was that there is a lot of information that needs to be communicated to someone who has sleep apnea. This is a disorder that happens at night while someone is asleep. There is no pain. They usually adjust to all the consequences of sleep deprivation over time so they are unaware of how sleepy they are and the chronic problems that are resulting. Education and information about the disease is important. What we find is that is one of the weak links in the current clinical care process who has the time to provide that adequately. The Learning Center was developed with that in mind, where we came up with a Flash-based tutorial to provide information on sleep apnea and CPAP. We also came up with a reference manual to give information about the machine and how to use the machine. Something else to note here is that when someone has sleep apnea, one of the cardinal symptoms is sleepiness. If any of your have had a few bad nights or all nighters, you know the fog that can happen. We have people sometimes during CPAP set ups falling asleep. The information they are able to receive during that time, there is a lot of information and they are only retaining a portion of it. We really wanted to have this online resource that they can go back to over time. We also added interactive components, the MyCharts, and this was taking that data, the CPAP adherence and efficacy data, and feeding it back to the patient so they could track it over time. We also had a troubleshooting

I will show you some screenshots of these to give a sense of what we did. There was a unique user name and password so patients could access their own information.

There is a dashboard so they can see what they can do at any time. We also conducted research assessments through the website. If there was time to conduct the research assessment, they could fill it out here. The other thing I did not mention that we did was allowed for patient symptom tracking. One of the sleep apnea quality-of-life indices allows for the patients to rank

their most important symptoms or the symptoms that cause them the most problems. This way, we can tailor what they are tracking to allow them to potentially see progress.

The Learning Center had seven lessons on sleep apnea and five on CPAP. The patient could just click on one, and then it would be a tutorial; we tried to make it a multimedia, interesting enough to keep their attention, all made by us as part of the project. It incorporated kind of diagrams, charts, a narrator who would read, and then some keywords. So, this way, as it was hitting them they could watch visually, could listen and read.

The tracking was for the adherence and efficacy data so they could track their own data.

We had it so they could see a week at a time. They could see one day or see monthly trends. We tried to have a green dotted line to show the thresholds we were trying to get them below.

Here is the Apnea Hypopnea Index, and the average week so they can see their progress at a glance.

We also did troubleshooting and a manual. On the troubleshooting side, or the left side, we wanted to offload some things they could do on their own before contacting a provider. The goal was to ask three questions and get to a list of solutions. So for example, “Are you having trouble with your body or machine? If it is the machine, is it the mask or the flow generator?” If it is the mask, we can have a list of solutions they could potentially try. We really wanted this to be interactive so the next time they went on the dashboard they could say, “You tried the X solution, how did it work for you?” We did not quite get to that point. On the machine side, these are new devices for folks. There are quite a few buttons on the top, there is lots of cleaning that might be necessary. There is a humidifier. Oftentimes, they go home, look at this device and say, “How do I use this?” We also created Flash-based tutorials on how to do certain tasks on their machine. We only used one type of machine and about 10 different masks, so our development with limited here.

At baseline, we had folks that were an average age of 50, BMI or about 32. In the severe range, above 30 events per hour is considered severe. On average, they were in the severe rage. On average, they were sleeping anything above 9 or 10 on the sleepiness scales. There is no difference in that baseline between the groups.

In terms of adherence at 2 months, I should mention there is a methodological advantage to studying CPAP adherence, and that is we get an objective measure of the amount of time that someone uses the machine at their prescribed pressure. So it is a really nice measure of adherence. The usual care group used it about 3.1 or 3.2 hours. The PC 3 group used it 4.1 hours, so there was a difference of about 0.8 or 0.9 hours a night.

At 4 months, the difference held.

I also wanted to show a slide on the 90 days of use. You can see that there is a difference. Usual care is the bottom line, the PC3 group is the top line. One of the things that struck us is the difference holds across the duration, but the difference within that first week or 10 days where it seemed like there was a difference, the usual care group drops off, the active care is able to maintain above 4 hours per night. There might have been something with that early intervention that helped to carry the effect.

Unfortunately, we did not see differences on some important symptoms and outcomes. We did not see a difference in sleepiness, quality of life, sleep apnea-specific level of depressive symptoms, or even patient satisfaction. This probably has to do with the fact that an hour difference in CPAP maybe we would not see differences on these. The no difference held at 4 months as well.

The CP3 intervention has the potential to help improve adherence in clinical settings. Whether or not it has an effect on outcomes remains to be seen.

CPAP interventions, based on health information technologies, have the potential to be cost effective relative to more labor-intensive interventions. I did not mention, but one intensive clinical support protocol resulted in about 40 hours of patient contact. The active intervention CPAP adherence was not any higher than what we had found, for example. Maybe offloading some of the education and clinical support could be part of a stepped care plan. We found that the engagement with the website was variable. We did stop short. We were designing this during a time where things were kind of clamped down at our local institution in terms of what we could do on this. So, for example, we did not include e-mail messaging, online forums, peer support. I think there were some other things we could have done to make it more attractive and more rewarding to go to the site and use the site. Future sites would do well to take a look at some of those sorts of things.

What I would also like to say is I think this does represent the minimum of what could be done with this sort of thing, and future studies could examine other methods as well. We are starting to look at having this data accessible, for example, on the smart phone and connecting with providers on a more frequent basis. We are looking at doing video teleconferencing for example and access to this data at the patient's convenience. I would like to acknowledge all the project team members and my colleagues, the sleep clinic staff, and AHRQ for their funding. Thank you.

ANGELA LAVANDEROS: Thank you Dr. Stepnowsky. So now we are going to move onto our last presenter of the day. Our last presenter is Ms. Lygeia Ricciardi. Ms. Ricciardi recently joined The Office of the National Coordinator for Health IT, better known as ONC, as a senior policy advisor. She is responsible for developing and managing ONC's national consumer e- health program, which launched last fall. Before joining ONC, Ms. Ricciardi ran her own consulting business focused on consumer e-health, served as a director in the health program at the Markel

Foundation, and served as a policy analyst at the Federal Communications Commission, as a content producer at a dot com, and as a case study writer for Harvard Business School.

LYGEIA RICCIARDI: Thanks Angela. Thanks to AHRQ generally for including me this webinar today. I am trying to move to the next slide. There we go. Okay, as Angela said, I am in The Office for the National Coordinator for Health IT. For those who are not familiar with it, it is within the Secretary's office at HHS. It is primary charged with encouraging providers to adopt electronic health records and use them to enhance quality of care. It works to link or network EHRs together so they can share information in an interoperable way. Much of what it is concerned with currently is using approximately $60 billion that were allocated for this task via the recovery act. The other part of ONC's job is acting, based on its title, as a coordinator of some activities that go on with health IT in other parts of the government.

Consumer e-health and consumer engagement in health is a new part of its emphasis or focus. We have this consumer e-health program that launched last September, last fall. Its mission is to empower individuals to partner in their health through information technology. Probably most of you on the phone would agree that that is generally a worthwhile aim. There have been numerous studies that show that greater patient and family engagement in care can lead to better health outcomes. Notably, there was a report in 2001 by the IOM that reached that conclusion, as well as a number of studies in the 80s and since then as well. We believe that there is an incredible potential for the role of technology to add to consumer engagement.

The program officially launched last September. We had an event at HHS headquarters where we had a lot of people participating, both in person and online, about 1,400. We had the Surgeon General there, as well as the Secretary of Health. As importantly, we had a lot of participation of folks from the private sector, as well as other government agencies who were pledging support to help consumer to engage in their health via IT. I will talk to you a little more about that pledging opportunity in a moment. Additionally, we released some proposed regulations, which would give consumers direct access to their lab data. For the first time, the federal government issued a lot of information really geared specifically towards consumers explaining what health information technology is and how they can use it, what the benefits are for them, and really sharing some individual personal stories about that. The last piece up here on this slide, the other we did on that day was to release a PHR model notice through which PHR companies can explain to consumers what their privacy policies are in a way that can be easily compared across products. So it was modeled on the FDA food label, where you can check to see which soup has a greater amount of fat or sodium or sugar or whatever else you are interested in. This is for personal health records. It talks about different ways in which your information is sold. We have some of the industry leaders, such as Microsoft and Dosia, who signed onto use it, again, with the hope that consumers would be able to make more informed choices with respect to PHR use, particularly in the privacy context.

Moving on from the launch event, I wanted to talk little bit about some of the underlying assumptions and reasons why we launched this program. I think it is important to note that ONC released a strategic plan also in September, but it had been in the works for quite a while before that, that laid out several goals, not only for ONC's work, but for health IT work that spans the federal government. Of the five primary goals, the fourth one was about engaging consumers, individuals and their families in care in order to improve both health and health care. That is something that I think ONC has been contemplating for a while. Getting to these particular assumptions that we are working with, the first is that consumer engagement in health is a fairly broad category. The Center for Advanced Health, which this first bullet point is derived from, has done some good work in defining 10 different elements of engagement and health care. Some of them are finding good care resources, making good treatment decisions, participating in care, communicating with providers, and promoting good health and other behaviors. The point being that engagement in care spans a pretty broad spectrum of activities. The next assumption we work on, and this is where information technology comes in, is having the right information technology at the right place at the right time, or the right information rather contributes to people's ability to engage effectively in their care. Again, technology can greatly enable that, particularly through mobile devices, but certainly other devices as well. What can people do with all this information once they have it? Well, we think that it can contribute to positive outcomes in the following areas. One is to increase people's ability to coordinate care among multiple providers. As you all know from probably personal experience, that is a huge need. At the same time that the broader health care system is coming online and connecting between providers and networks, it is not as if the problem of care coordination has been fully addressed or solved. In many cases we need individuals to help be the locus of information in a PHR or another device so that they can be the one, the conduit of information, between multiple providers. The average cancer patient sees 32 different providers. You can imagine most of the time they are not all working from the same information. Often, the burden falls on the individual or their caregivers to help connect those dots. This second point is that stronger partnerships with providers in patient center care can also be a result of the use of actionable information. Being able to e-mail or text or otherwise communicate with your provider or just read the information that will he or she has put into your record, maybe share some back, can strengthen communications and make you part of a more cohesive team. The third point has to do with self management, which may or may not be connected to direct work that as an individual patient you may be doing with your provider. This could be about managing your diet or training for an exercise; challenging yourself to do a running event, for example, or just managing your chronic condition. In any case, that may or may not be within the context of communicating about it regularly with your provider.

A couple of other assumptions, we talk about consumer engagement. We do not necessarily want more engagement, we want effective engagement. More engagement would be great too, but we do realize that there is a spectrum of patient activation across the population, and as much as we love to move everybody into the more engagement categories, we also do not want people

necessarily to spend time any more time that they already do worrying about their care, particularly those who are quite engaged. We want to make it easier and more effective for them to do so. A couple other points are that there is not just a matter of figuring out how to use technology and share information, but there also has to be a shift in attitudes about patient roles and providers roles moving us towards getting partnership. The last point is as we think through this, there are certainly a lot of issues we need to address in terms of making new tools and services available to a wide range of populations that include a diverse range of literacy levels and other kinds of needs.

This next page is not so much about the health care and health-related assumptions and the role of the consumer, but more about the role of technology. I will not read through every point on here. The main point really is that technology, information technology, has been revolutionizing most other parts of our society and it continues to do so. It is getting faster, cheaper, and more ubiquitous. That will begin to impact health care even more than it already has. The market for fitness apps on smart phones was $120 million in 2010, and it is estimated to grow to $400 million by 2016. There has been a 400 percent increase within the last 2 years in the number of hospitals who are participating in social media networks. It is not only patients, but also health care institutions and providers who are beginning to jump onto this and embrace the trend of greater use of technology for engagement. That is buffeted, I think, by some of the changes going on with health reform in which patients will take on increasingly greater responsibility for their own care. Lastly, I think it is important in this context to recognize that, at least from our perspective, the federal government's role is to catalyze these changes. They are coming from these outside trends and efforts of other stake holders like industry and consumers themselves.

Against this context, our strategic approach for our consumer e-health program has three prongs. First is to give consumers access to information. So secure timely electronic access to their personal health information. That has to be the starting point from which the other two prongs flow. The second is about action and supporting the ability of people to take action with their information. So we want to support the development of tools and services that help people make sense of the information they get and use it in worthwhile ways. The third piece has to do with attitudes and the need for a shift in attitudes. I think Dr. Wagner put it nicely by saying that a philosophical shift in needed that increases partnership in care delivery. That is what I was talking about with the, you know, with this shift in attitude. I think in general where AHRQ fits into this whole big picture, I think the research that both the presenters today presented, but also that the agency does in general supports all three prongs of this strategy, but particularly the action piece. You are helping us understand how PHRs and other tools can fit in and be used. I highlighted not only consumers but also providers. I think you are helping us understand how with integrate health information technology into this nexus of care that links patients and their providers to the clinical care that they are receiving in traditional settings, as well as the care they are providing for themselves and the decisions they are making that impact that care about diet, exercise, and everything else that they make every day.

I wanted to give you a few examples of things we are doing in each of these three strategic areas here at ONC and tell you about what we are thinking about for the future. To begin, in terms of increasing access to information, as I said, when we launched our program in September, we had, we also kicked off a pledge program through which we had 30 major organizations coming together and saying that they would sign on to sort of be the engine to power some of this change we are talking about. We had data holder organizations, which are those that hold patient information, so hospitals, providers, payers. We had non data holders, which are other kinds of organizations like consumer organizations like AARP or Consumer's Union, employers and developers of tools who pledged primarily to get the word out about the importance of health information technology and consumer engagement through it. The data holders pledged to specifically use particular types of ways to get information out quickly, such as the blue button or the direct protocols, which are different ways of making sure that information is sent to consumers essentially in a form or format they can use and the non data holders agreed to really share with their participants, with their members some understanding of why it is valuable to engage in your health. The data holders agreed to do that to so in other words, they agreed that they would not only for instance, make a patient portal available through their hospital, but their doctors and nurses would talk to patients and make sure that people understood its value.

When we started the program back in September, we had about 30 organizations sign on. We now have more than 250, which is exciting because on the data holder side of things, they can reach about a third of the country. So if they all follow through on their pledges and they make information easily accessible in an electronic format to the people they serve, we should have approximately a third of the country in a relatively short period of time that has access to their information.

Why are they joining? I think part of it is they get public recognition of their efforts. We try to highlight some of the good work that is already going on and are continuing to do that on an ongoing basis. They are finding opportunities to network and partner with one another. They have a chance to really a forum to elevate issues that are important to them and bring to our attention some of the challenges and also some of the good things, best practices, and so on that they have found that they can share with others. We also have opportunities to work with them to develop new materials to help spread the word about health information technology. I think it was Dr. Wagner who was describing the need for more materials to help providers understand how to talk to patients and engage them through health information technology. That is one of the things we are working on, and we would love to have input from AHRQ and their research on how to do that better. We are working also with the national e-health collaborative, which is a nonprofit public private partnership, which is pulling together many of the participants in the pledge program and others to help us shape and refine tools of these sorts. We also have webinars, as well as in person events, which different members can learn from one another and exchange best practices. Those are the things that folks are finding appealing. We are hoping to

really encourage them to keep working with one another and meet the goals they have set for themselves.

A second initiative of something that we are doing at ONC supports our action prong of our strategy. In this area, we have released a number of challenges, mostly to the technology developer community, to develop new apps and tools. We jointly have a challenge going with the Surgeon General's office in which we are having app developers submit apps that they have developed that provide user-tailored health information in several different categories. That challenge has actually closed, and the apps are being reviewed and winners will be announced toward the end of February in several different categories, fitness and exercise, nutrition, and integrated health.

The other, the third prong of or strategy about shifting attitudes, we have a couple of things going on in that area. We launched a website that has some basic information for patients and families. This is a shot of that site, as well as for providers and professionals about what health IT is. It includes not only the basis of what it is and the benefits, but some personal stories that let people understand it.

In this area too, we are using challenges. This time we have challenges that are geared towards the members of the public. We released a Health New Year video challenge in which people can submit brief videos they can make them on something simple like a smart phone that talk about how they are using technology to reach a health or health care goal in the New Year. This is the first of several different challenges we will be releasing throughout the year. Prizes are relatively significant: there are $5,000 in prizes for each contest and the first prize gets $2,000. We are also doing an animation to help people understand in real kind of simple layman's terms what the value of health IT is and the changes our country is undergoing.

Those are the things we already have going. We are also working on preparing for the future by exploring a variety of what we call frontier issues. This is an area in which, again, I think we can partner with AHRQ. Some of the issues that we are already working on, but want to do more work in, include the integration of patient generated data back into the EHR or clinical care. Some of the monitoring devices for example that Dr. Stepnowsky was talking about and other kinds of devices that may monitor weight or, you know, fitness levels and so on. We want to figure out how to feed those back into the EHR so the doctor can see them and understand them and not be overwhelmed and have their work flow totally jeopardized. We want to understand better the use of social media for health. We want to enable more easily proxy access on the part of a parent, spouse, or child to personal data, online or by others. Maybe it is an outside company you hired to act on your behalf. We would love to see greater integration of information about the costs and quality of care with clinical data so you are not just getting your personal health record, tests results, but you can see with that a sense of what your different treatment options might cost or did cost and have that all integrated in one place. I think we also need a lot of greater information on how we can use information technology to better support behavior

change. So those are some of the areas that are top of our list for things to think about in 2012 and beyond. We look forward to partnering with AHRQ and others in helping to understand this better. Thank you.

ANGELA LAVANDEROS: Thank you. So now we are going to move into our Q and A session of the web event. As you have seen, each of the presenters has provided you with some contact information in case you would like to follow up with them separately. I am going to begin with the questions. I just wanted to address one thing before I started in with all the great questions that we have gotten from the audience that is regarding the slides. Just so the audience knows, the slide presentations and transcript and the recording of the event will be available very soon after we finish up today at our website, which is http://www.healthit.ahrq.gov, and it will be under our events tab. So, there were quite a few questions that came in while Dr. Wagner was speaking. I would like to start there. Some starters questions, Dr. Wagner. The first question that came in, is this study published, is there a reference for your study?

PEGGY WAGNER: Two articles so far have been published. The one about the main trial came out in the *Journal of the American Medical Informatics Association*. It is available online now. I do not know if it is in print yet. It is called "Personal Health Records and Hypertension Control." Some of the initial qualitative data was published, and I cannot remember the citation, but if people would contact me, I would be glad to send it to it to them and then we have a couple of things out under review.

ANGELA LAVANDEROS: Thank you. Another question for you, Dr. Wagner. How and why was blood pressure selected as the chronic problem, and so hypertension, which was the focus of your study? Was diabetes considered?

PEGGY WAGNER: Diabetes was considered. Hypertension, both of these issues are major concerns in the South, where we did the study. It was done in Georgia. We are sort of in a stroke belt, and so hypertension was an issue for us when I was at The Medical College of Georgia. Certainly, many of our patients had both conditions. I have not done sub-analyses of the combination effect.

ANGELA LAVANDEROS: Okay. Another question, did you give them cell phone access or BP data entry or just PHR access?

PEGGY WAGNER: Just PHR access.

ANGELA LAVANDEROS: In the slide presentation, on one of the slides you say younger age, 4.7 years. Can you clarify what that means?

PEGGY WAGNER: Yeah. The main difference in age between the users and the nonusers was 4.7 years within the intervention group. In the sub-analysis, that we did just within the intervention subjects.

ANGELA LAVANDEROS: Okay. Another question for you Dr. Wagner before we move onto some others. Do you think the side for frequent users was large enough to indicate that the results for this group are meaningful? If so, why do you think so?

PEGGY WAGNER: I think it is suggestive. Whoever asked that question is absolutely correct, that by the time you look at just the intervention group and then those who were just frequent users, I think it is suggestive that if we can get folks to utilize a PHR, a PHR really is not a PHR until there is some level of use by the patient. It is the interaction with the data and the information that makes it active I think. I think it is suggestive, I do not think it is conclusive.

ANGELA LAVANDEROS: Okay. I think the next question is directed towards Dr. Stepnowsky. This question refers to a Blue Button. Does the Blue Button give patients access to their clinical data or only a very limited view of some data for example the self entered PHR information?

CARL STEPNOWSKY: We did not have a Blue Button in ours so I do not know if someone, Dr. Wagner, did you have that in your presentation?

PEGGY WAGNER: No, I think Lygeia talked about it.

LYGEIA RICCIARDI: The thing about the Blue Button is it is currently a somewhat limited view of the data, it is not, let me clarify. It is not a view of the data. It sends basic information, a subset of the information, in the full record to the patient directly in an e-mail that is in human readable form. So it is not a comprehensive record, but it is a pretty good, you know, sort of hits the most important high points. The Blue Button is a program that has been pioneered by the VA, as well as the DOD and CMS, and I know a couple of private sectors entities are working with it as well, including Aetna. I have heard about some amazing circumstances in which patients have been able to use Blue Button data not only for their own knowledge enhancement, but downloading a copy of their record and carrying it in to an ER and showing it on an iPad in the case of someone that was not able to speak. Yeah, it is a really, I think, useful, although basic set of information. I think the plan is to evolve the Blue Button over time so it becomes more sophisticated and includes a greater richness of data.

ANGELA LAVANDEROS: I think this next question may be for you as well. What are you doing to address the challenges for consumers using PHRs with challenges, such as access, social expectation, and educational gaps?

LYGEIA RICCIARDI: That is a really good question. It is a challenging one certainly. I think we need to think about access issues on a couple of levels. One is simple technology access and access to the Internet, such as broad band, for example. I know that the Federal Communications Commission is doing a great deal of work in that area in terms of providing incentives to extend broad band access to people with lower incomes through its Universal Service Fund. There is also access to other types of tools. Increasingly, people are accessing their PHRs via mobile phones and other devices. The growth of those devices is intense. The vast majority does not

have smart phones. One thing that we are doing is using basic text services, which are available via any kind of cell phone. For example, there is a program called *Text for Baby*, which sends reminders to pregnant women about checking in and doing various health tests and so on throughout their pregnancy. There is another one for smoking cessation. They were used specifically in text form to reach a variety of people. It is important to think about the technology access, but the accessibility of the content of the information. Through that, we need to think carefully about making things available in different languages, as well as at lower literacy levels that are broadly accessible to a wide majority of the population. I think there is a lot of work that remains to be done in both areas. We are no means done with either. I think the way ONC looks at it is we are working in partnership with a number of other organizations that can help us do local outreach. It is the community organizations, not even necessarily health organizations, but a church who can help to mobilize people and reach out particularly to those who are disadvantaged and may not be looking on the Internet for new opportunities or that kind of thing. Partnering with organizations that can help get the word out and can help provide some hand holding and coaching at the local level too.

ANGELA LAVANDEROS: Great. Thank you. The next question that came in is for both of the studies. Were any of the patients involved in the studies on Medicaid or were they primarily Medicare recipients?

CARL STEPNOWSKY: I would have to go back and take a look. I think we had a small percentage of Medicaid participants in our study.

PEGGY WAGNER: I do not know the answer to that for the hypertension study off the top of my head, but generally speaking, about 25 percent of our patients in these clinics were Medicaid. I am assuming our enrollment was similar, but I can check on that if someone wants to follow up with me.

ANGELA LAVANDEROS: I am going to go over, I think I am going to try to get the contact information and folks have asked for that one more time. A few more questions about your study, Dr. Wagner. Can you touch on any of the effects of the PHR intervention on treatment adherence?

PEGGY WAGNER: In terms of looking at the guidelines in the medical record is what I am assuming is being asked. It appears as if it did not make much of a difference in terms of adherence to guidelines at this point. We did only the intention to treat analysis at this point. I have not done a similar thing that I did in this presentation looking at the patients who were the most frequent users. That is what we need to go back and look at now.

ANGELA LAVANDEROS: Also for Dr. Wagner, how did your objectives address the objections raised by doctors?

PEGGY WAGNER: I have to admit I was stunned. I was very surprised. We just sort of went on and recognized that the physicians were also consented to participate in the study, so not all physicians participated. What you are seeing in the 24 physicians who did participate are those that probably had lower levels of objections. I will say that by the end of the trial many of the objections had dissipated. The physicians were not barraged with phone calls, not overwhelmed; they had not been sued thank goodness. What we observed then was greater acceptance of the potential of the PHR at the end of the study than at the beginning.

LYGEIA RICCIARDI: Is it okay if I jump in for a second? I think some of what we are seeing in terms of provider resistance to PHRs follows a pattern that we have seen with the adoption of other technologies, like even with the telephone in which case I understand in early days, you know, doctors were really concerned that their patients we were going to call them all the time, not only overwhelm hem with inquiries or input, but not understand when to use different technologies as opposed to others, like I have heard a lot of concerns about, oh patient, my patients are going to e-mail me that they think they are having a heart attack and they are not going to take action. But in fact, that is generally not borne out by use. You know, for the institutions that have pushed forward and implemented these technologies, like e-mail exchanges with patients and PHRs, that is not what they are finding at all. In fact, people are pretty smart about when to use which technologies. If you put together a series of sort of guidelines on how to use the technologies an when it is appropriate, people will follow those. It is common sense.

PEGGY WAGNER: I think the other point I would make is that acceptance of the PHR by providers will be greater once they are reimbursed for communicating and transmitting information to patients that way reviewing information that way.

CARL STEPNOWSKY: Along those lines, California just passed a telehealth act so some of those communications may be reimbursable. I do not know all the details, but I know that law went into effect on January 1st. Reimbursement, you are right, is a huge issue.

PEGGY WAGNER: Right.

ANGELA LAVANDEROS: So this one is for Lygeia. Any discussions or goals from the ONC to actually measure provider progress on engaging patients in their care through health IT tools?

LYGEIA RICCIARDI: Yes. For one thing, for those of you familiar with ONC and what it is doing, through the incentive program that I mentioned, this comes from the stimulus package. We are providing incentives to providers and hospitals to adopt EHRs. In order to do that, they have to attest that they are following numerous specific guidelines that together are called meaningful use, that they are meaningfully using these EHRs. One whole category of meaningful use requirements is related to patient and family engagement. The way our program is structured, only a few core items were required in the initial phase of this. Over progressive years, the patient and family engagement requirements are going to get greater. They include things like giving patients a printed or other form of summary of their health information when they leave

after a visit to a hospital or clinic or outpatient office. Also giving patients electronic access to their information, secure messaging with patients. We are really looking into expanding these requirements, again, in ways that really encourage providers to partner more strongly with patients over time. So by virtue of our incentive program that we jointly administer with CMS, we are doing some basic measurement in that area. Additionally, we are doing some work in terms of building questions into some existing national surveys about the general access by the population to online health information and what they are doing with it. We are measuring not only through participation in our own programs, but through the surveys of others that are done by, for example, by NCI and other organizations.

PEGGY WAGNER: One of my concerns about meaningful use is in our study where we observed that when given information, personal health record access, only 26 percent of the patients used it. Somehow, we have to up that number and think about what meaningful use means to patients because giving information is not sufficient for changing behavior and improving health outcomes. Somehow, the next step in that road of meaningful use will have to go that direction I think.

LYGEIA RICCIARDI: I think that is right. That is part of what we are trying to get at through our pledge program. We know that most patients really trust their provider above all others in terms of health information and when their provider takes an active role in encouraging them to use the information and apply it, they are much more likely to do so. We are trying to build that in through our pledge program as well. The other thing we are trying to do is really encourage the development of tools people find useful. I think we have a ways to go in understanding what really is going to be useful for people. I think increasingly, make it very, very easy and painless to use. I believe mobile technologies are going to play a big role. I think we have learned that there—obviously, there had not been a huge uptake in the traditional PHR. It is funny to call it traditional since it is a relative new technology. People have voted with their feet or not voted in showing there has not been an overriding desire for the file cabinet version of a PHR that just stores your information. I think we need to figure out how to make it more interactive, more engaging, and more compelling for people.

PEGGY WAGNER: I agree.

CARL STEPNOWSKY: Yeah.

ANGELA LAVANDEROS: One clarification question is what is the difference between partial portals and PHR? Some of the audience members did not see a difference in the way we were using those terms.

PEGGY WAGNER: Yes. I know that I slipped at one point and said patient portal. I do not know the official definitions, but my sense of what a portal is is just a doorway into information. A personal health record is more interactive and more of an ownership model. I do not know if

there is any tie in, I do not know if the other presenters can clarify in terms of the tethering to the medical electronic record versus a standalone option.

LYGEIA RICCIARDI: I think that is a good basic, you know definition of the two. Essentially, a PHR does imply greater portability, possibility it may not be at all linked to a particular provider or payer organization where as a portal always is. It is kind a window into a record held about you by someone else, your payer, or your provider. It is not only an ownership issue, but a portability issue. If I switch providers or insurance can I take my information with me? You could have a portal through which you can download your information. It could be movable as well, but the idea is the PHR is something that is particularly offered independently. You could just continue you know, you hold that regardless of who you work for or who you receive care from.

ANGELA LAVANDEROS: Okay. So we are coming up on 2:30. I will end with one last question that is sort of open ended. Of course there are a lot of great questions. You can contact the presenters. It is open ended for all of the presenters here. Who are the experts emerging in this field at the intersection of clinical decision support for the patient/family and clinical providers? That is just sort of the question we will end on.

CARL STEPNOWSKY: I can take a stab at that. We are doing some work here, to kind of follow up on the PHR question, when we review the EMR that it is provider facing the PHR tends to be patient facing. The future generation might be called EHR electronic health record so there is a tethering or connection between the two. I can give you a list of the people on our team that we are trying to put together to work on that combined EHR. We have informatics people, software developers, human computer folks, kind of like human factors folks, domain experts, MDs, nurses, psychologists, et cetera, regulatory compliance and administrative people. That is an example of one team we have put together.

PEGGY WAGNER: And patients.

CARL STEPNOWSKY: And patients, absolutely. You are right. We actually have them too. It is all designed for them, right?

PEGGY WAGNER: Right.

CARL STEPNOWSKY: In fact, one of the key phrases we are using is user-driven. All of this has been driven with the end user in mind. When you think of some of the great corporate models, the reason why a lot of people use Amazon and it continues to get bigger is because the barriers to using it is fairly low. It is easy to hop on and do it. I think that is important as we move forward.

LYGEIA RICCIARDI: In term of expertise in this area, I would throw in I think there are a number of organizations who are doing interesting research beyond what AHRQ is doing. Project Health Design is a $10 million project of the Robert E. Johnson Foundation, which is run out of the University of Wisconsin. They have been looking into PHRs and their implications and design attributes for a number of years. Again, wanted to underscore the input from the patient voice and one organization that pulls together patients around a lot of these issues of social security is The Society for Participatory Medicine. There is always the Consumer Partnership for E- health, which is a more policy oriented group for consumer organizations that is really focused on health information technology and that is run by the National Partnership for Women and Families. Another group that is really interested in these issues in and trying to shape this field is the National E- health Collaborative Consumers Consortium. There are definitely a lot of folks who are interested in these issues and coming at them from a variety of approaches.

ANGELA LAVANDEROS: Dr. Wagner, did you have anything to add?

PEGGY WAGNER: I do not think I have anything to add. Thank you.

ANGELA LAVANDEROS: Okay. Great. So with that I would like to officially end the webinar today. I would like to thank all the presenters for presenting for AHRQ today and also the audience for attending and asking some great questions. Thank you very much.

END TRANSCRIPT