

**Connecting Americans to Their Health Care: Empowered Consumers, Personal Health Records and Emerging Technologies:
Users Panel: Moderated Discussion
October 11, 2005**

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[START RECORDING]

MALE SPEAKER: We've had a very provocative start to the day. We are going to now turn and listen to two panels, the first of which I will moderate. We have seen a number of the approaches to putting your health information online, getting access to it, and talked about some of the issues entailed there. What we would like to do now is hear from some of the people who have been using these products themselves, and have them talk about their experiences, what is working, what is not working, and how it has affected what they do, both from a provider, sponsor, and a patient point of view. I'd like to just introduce each of the people you see up on the stage, and then we will allow several of them to make some brief introductions of how they are using these tools, and then we will just have a conversation in front of you.

Starting immediately here on my right, your left, Mark Pierson is a physician in Washington State who has been a key developer and a user of the shared care plan, which is an approach for doctors, patients, and other caregivers to work together to better manage chronic illness. Bonny Parton, who is sitting right next to Mark, again, using the shared care plan to care for her father in the same health care system in Bellingham, Washington. Mike Stocker next to Bonny is the chief executive officer of Empire Blue Cross of New York. It

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is of course one of the country's largest health insurance plans, and I think its testimony to the importance of what we are all doing here today that Mike was able and committed to joining us and talking himself personally about the importance of using the personal health record to the strategy of his health plan. Next to Mike is Cynthia Solomon. Next to Cynthia is her son, Alex. They have together been instrumental in developing a personal health record product called "Follow Me" which helps families who are facing serious and chronic high risk health problems manage complex and life critical information that they really need to have in their hands every day. Cynthia may also talk with us a bit about another system she has worked on which helps migrant farm workers keep track of their health information. We are going to have each of the three approaches I just described make a very brief presentation about how they are using the tools, and then we will have a roundtable discussion. I think we will start with Mark.

MARC PIERSON: Good morning. It is a privilege to be here representing my community and my organization, which is definitely a part of our community. A little bit of background, in the last five years we have had some support. Prior to that, we did everything with our own money, but Robert Wood Johnson Foundation pursued and perfection grant really

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informed the production of the development of this particular form of personal health record and the goal was to find a dramatically different way to provide perfect chronic care for patients at the community level. Then we subsequently got an HRQ safety implementation grant to create the single accurate medication list. We learned an awful lot about the only way you could possibly do that, clearly the patient is the only one who could have an accurate medication list. Then, Markle Foundation and the connecting for health folks gave us a small grant for e-prescribing across the whole community, and that is going very well and connected to the personal health record. A couple of words about Whatcom County, because you may ask yourselves at the end of this why we have been able to do this or how you might do it, we have essentially a regional or community health information infrastructure. We have since the mid 90's and Peace Health put a lot of effort and money into that as did the payers and the doctors, and now we are engaging the patients. So we have had every patient, every physician, the hospital, a single hospital which definitely makes it easier, connected together since 1996 with all lab values, all imaging results online. Then, I think the seminal thing that happened to this country, at least in my mind, we awakened with the IOM report crossing the quality chasm, and that report stimulated the Robert Wood Johnson Foundation to create

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pursuing perfection grants and what they asked us to do was to have emerge a new way of providing chronic care. Well, the director who lobbied hard to be the director of that program, I am the executive, suggested at the planning grant stage that well, we will just invite patients on to the team, so all the design teams because one of the six aims, right, the first one is patient centered. It sounded logical. We haven't met anyone else except, well there are a couple of other organizations, certainly Cincinnati Children's, but it's an unusual event, and I said sure, it makes sense to me, so everything that has happened since then in our community around personal health records and chronic care has been designed by the patients with the providers, and I think that gives it a completely different flavor, a significantly different flavor. Thirty patients used that extremely expensive, complicated development platform called Microsoft Word to develop the personal health record iteratively. These folks had congestive heart failure or diabetes or both. When they got what they wanted, then we went out and put it on the web for them. They had two major innovations, one of which I won't talk about here but Bonny may, and that is a new role in health care, a care coach. They call this role the clinical care specialist, which was a name I didn't particularly like, but they always win in the votes. This is essentially a lifeguard navigator coach

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translator, and this role is really valued by the patients, their families, and the providers, but they also innovated a technology. We thought they wanted to see into our business medical records, we actually took our vendor with us to Boston to these meetings, and they said as they have said many times thank you for thinking of us. That actually won't help, but if you will do this it will make our lives better, and the "this" was creating a personal health record that they control, much as Newt was saying, they control, they had access to see who has looked at it. They can invite whoever they want.

The other thing I want to say, and this is not to go against what Mr. Gingrich was saying, but patient paper actually is important. You have to print out the electronic record for it to be real useful, because remember in chronic conditions what we are trying to do is change behaviors, and behaviors only change in conversations, and conversations that occur around a cultural artifact, a document, that has on it what the patient wants and their diagnoses, that is the key stimulus around which new conversations occur, the missing conversations a day, whether it is with your doctor or with your care giver or your family. So, whatever you do with personal health records, make sure that the printed copy is as useable as the electronic one. Doctors love it, only 30-percent of the docs in our community have business medical

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records, so the paper is critical for them as well because they are not going to use two different systems in their work flow until we make this stuff integrated, so when patients show up with paper the docs love it, families love it, and we haven't met a doc yet who isn't excited to see an accurate medication list instead of, if they are lucky, a brown bag of your medications from home. So, that is pretty much what I have to say, but when you realize families love it, families are voters. There are a lot more families than there are doctors and hospital administrators, so when you do this right, you will get a lot of people on your side. [Applause]

MALE SPEAKER: Next we will hear from Mike Stocker. Mike, you want to come up here?

MIKE STOCKER: [Inaudible] In June of this year, we have five million members. We put up a populated personal health record populated from our claims database, our pharmacy, and or lab databases. We particularly didn't want it to be a pilot, and we had already had a self-population record. The response from our members was huge. We have 3.6 million members that can call up their records. Within the first two months, we had 30,000 people. We almost had 1,000 percent increase on the website that could call up their own records. You all know a lot of about this; I just want to lay to rest one thing. The fact is, for good or bad, this is all

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information that payers have had for a long time. The lab, the pharmacy, and the claims data, it's been available for a long time and honestly isn't all that hard to put it together into a relatively dense personal health record. The reason I put this up on the screen is to show you the level of detail for really what is just an average prototype of a patient. I can also be self-populated, so the members can put information in that they wish to have on the record. There is a lot of information here. The lab data shows you the actual lab tests, explains if they are normal or abnormal, what it means. If you click on the drugs that you take, it tells you what the side effects are, what other drugs interact with them, the reasons you might be taking the drug, and so on. It's a huge amount of information when you get it done and honestly, it's not a huge technology leap to get it available to individual members.

So, why did we do this? Actually the best reason we never planned was we have about 20,000 members in the path of Hurricane Katrina in our national accounts, the Blue Cross/Blue Shield National Account System. Not a huge number, but about 20 of them were able to access and we had only been up for a couple of months then, were able to access their records. If you think of the numbers of people that were displaced by the hurricane and the difficulty of getting their records, they were either destroyed or they were unavailable and getting

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health care someplace else and people who lost their I.D. cards or their medications, it was a huge asset and it has been a real boon to the companies that we provide services for. So, the last feature, we just actually started this last Friday, we can now download this information. A member can download this information at will, so they can talk online to their doctor. We use relay health as the vendor for that. They can be referred to a specialist. They can download all their information to a doctor or specialist at will. It means if you are going to the emergency room you can, before you get there, download the information to the emergency room anyplace that has access to the internet, and the information would be available when you get to the emergency room. So, why did we do this? I mean, I have to say it's a reasonable investment in terms of resources and time, and what I'd really like to talk about a little bit is because we are a business is what we think, I can't show you an ROI on this, what we think is the business case for this kind of activity, and we specifically wanted to make it available to our accounts because we believe it will give us advantage in the market place. We also think it's a service to our members. If you think of the core competencies of payers, the assessment of risk, and making sure you have enough money to pay for the risk of medical costs, the management of networks, claims payment, a lot of those things

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are becoming more and more generic as time goes on, and with the continual consolidation of the industry. There is a saying, there's not a lot of small neighborhood health insurers, they tend to get bigger and bigger, and in fact we are all becoming a little bit like each other and so the ability to have a strategic advantage in the market place, at least for a period of time, is a strong desire of all plans like ours. Our experience with our members, and we have done a lot of polling with our members on this, this is not something they expect insurers to do. It's just not the first thing that comes to mind, and so if you don't explain what it is you are doing, they kind of register a neutral in terms of desire or ability, but for our members who are online, and in our case that's about 50-percent of our members who are actively online, the ability to have their own medical information and to transmit it to doctors is the most highly desired benefit of anything that they could get online, and the acceptance of it, once it's explained, is huge. I can't give you a mathematical ROI in terms of will this help us, in terms of getting more members in the future and competing better in a very competitive market place but I can tell you the initial response in the market place, especially among national accounts which drive most of the innovation in our business, is extremely positive and we believe that it will be a strategic

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advantage for a period of time. Compatibility raises an issue and that is, we are not the only people doing this. Several of our large competitors are doing something similar. United has talked about that, and so has Aetna. At some point, we are going to have to face the reality that these records need to be compatible at the national level, so it's just not going to work for us to have a unique proprietary medical record and somebody comes to us from United. They have another medical record that is not compatible with ours. We just don't think that is going to be a possibility. One of the companies that we have worked with extensively in partnership here, and would work with us on that venture, is Web MD. Phil Marshall, I don't know where you are in the audience, but if you want to raise your hand, we have really developed a very good partnership with them and it has been extremely effective for us. They've been a good partner in kind of a difficult area in terms of putting this together. The personal health record raises a whole bunch of issues about confidentiality and security, personal health information and so on like that. Suffice it to say that our approach has been to just put the member in charge, so it's not the electronic medical record that you hear about in the newspapers, it's not complete. Doctors have more complete information. We don't capture all the lab work. We particularly don't capture lab work that is

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in hospitals, it's all reference lab works. So, it's not complete. The member can change it at will. They can delete information they don't like. They can self populate with the information they want to have on the record. We have all kinds of warnings about the information. It raises a lot of issues in that regard, but we think it is worth it because it is information that often the physician doesn't otherwise have, and as a physician I can tell you I was always paranoid about what other doctors were doing and what kind of medications the member was on. Having this information is universally treated by physicians as something with great pleasure. They love the ability to have information they didn't have before. The reference to the brown bag with the medications in it, they have an accurate list of lab tests over time and medications is a huge asset for a physician. A number of things have really been helpful here in terms of promulgating the record. First is, we have a very activist administration in this area, so thank you for that if anybody here is in the audience. The second is, the technology is just better in terms of [inaudible] incompatible databases, it's just a lot better than it was five or six years ago. The emphasis on patient safety and computerized physician order entry and so on has been a huge asset. I mean, everybody kind of accepts the fact that this is something that ought to be part of medical practice and

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so this is a way to begin. In fact if we do this right, this could be a skeletal that the doctors could gradually populate their own medical records onto and we will move to that wonderful event that is unfortunately far into the future when we will have a real electronic medical record for everybody but we believe this is a very strong start and we believe it's a good business case for it. We want you to get into it a year and a half or two years after we do so we can speed the market advantage, but we welcome everybody into this business because we think it's a good thing and frankly, it's very good if you are in the business of health insurance, it's very good for the industry to have a core confidence, they don't come a long very often, that the industry didn't have before. So with that, thank you. [Applause]

MALE SPEAKER: Thank you, Mike, and our third model, Cynthia Solomon, will address.

CYNTHIA SOLOMON: Good morning. Rather than talk about business models and return on investment, I would like to talk about my role as a mother and why I am in the PHR business. Some 20 years ago, a little more than that, my life changed very drastically as did that of my family. My son Alex was diagnosed with a brain lesion and resulting hydrocephalus, and as a result of that, over the next 15 years, suffered more than 18 neurosurgical procedures, more than 25 hospitalizations, and

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a nightmare of a life trying to coordinate his care with five doctors, with CAT scans, and then MRI scans, medical appointments, and Alex's records were literally kept in my car in a box along with his scans so that if he had a shunt malfunction, we could get to the nearest medical center, at that time UCSF, to get his care taken care of and get a revision done. For those of you who are familiar with hydrocephalus and shunts, if your shunt fails, then you can go into a coma and you can die in a relatively short period of time. So at a mother, as a terrified mother, I knew that I had to keep Alex safe, and the only way that I could keep him safe was to keep his information with me and to know where he was at all times. Things got pretty complicated, and then as he got older life calmed down and I was feeling pretty safe and our life was moving on, and in 1999 Alex was out of state and suffered a head injury and showed up at a small rural hospital. They had no knowledge of his medical condition, no knowledge of his allergies to certain medications, no knowledge of the types of shunts that he had or how he should be treated, and there began a four hour period of again, terror. How was I going to keep Alex safe? It took several hours. We did reach the neurosurgeon. I had to fax back and forth some signed forms just to get information from the emergency room because Alex was an adult by then, but we managed to get that under way. A

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few weeks later, really thinking about it, Alex is shunted. He will always be shunted. I will always be here to manage his care, so there began the idea of what if we could take Alex's information and store it on the web and make it accessible to any emergency room, to any neurosurgeon, to any physician that needed that information? So, I took a second mortgage on my home, hired some really talented programmers, and we developed "Follow Me". I think we released it in 2000, and "Follow Me" today is a subscriber based product that helps individuals store their medical information about their conditions, their history, and their hospitalizations. It is actually HIPAA compliant, it is password protected, and it comes with encrypted e-mail. What happens is our subscribers can give their physicians their log in password and their other care providers can actually look at the information or enter the information through a clinician portal as well. Since that time, we have gone on to develop other services that we feel are relevant to consumers and protecting consumers and also looking at this technology as a way, as a tool, to engage consumers as true partners. So, in 2002, we actually worked with Denver Children's Hospital in the neurosurgery department to develop my HIN, which a hydrocephalus specific PHR, and then in 2003 working with several non-profits in the California endowment. We launched MEVA [ph], which an online medical

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record for migrant and seasonal workers. Let me back up a little bit, I live in Sonoma, California, the heart of the wine country, and it's a pleasure and a joy to live there. We have many migrant workers who come through our county and our community every year, and many of these people have chronic medical conditions such as diabetes, hypertension, asthma, pesticide exposure, and when they access care at local clinics or mobile medical units, they get that care and then they move on to the next community, but that information doesn't follow them. Even if they show up at a hospital that has an electronic health record and they are treated, that information doesn't follow them. Usually there is a language issue, so in addition to giving the correct history on a patient or a migrant farm worker, so in 2003 when we launched MEVA, we started with 50 migrant workers in Sonoma Valley, and within six weeks we were up to 250. What it did, it did several things, one is it provided an emergency medical card with their photo I.D. so then it became a way for patients or consumers or workers to identify themselves even when they didn't speak English and also when they showed up at the emergency room, the hospital or the doctor at the clinic would see their name as they understand how their name is written. It also identifies certain serious conditions and allergies and emergency contact information, and something that contact information is in other

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states and sometimes it is in Mexico. It also provided them with an e-mail account, and let me tell you these guys love their e-mail. They are on it all the time, they enjoy it, they count on it, and for many of them it is their only permanent address in the United States. We also feel that MEVA, now that we have, just back up a little bit, today we have nearly 2,000 workers enrolled and we are expanding to an additional 2,000 in three other counties over the next six months, so we feel that not only has MEVA provided an opportunity, here you are with a special population for the most part, an uneducated population, but they care enough about their health care and their information that they are willing to at least have their information entered and carry it with them, so we feel that the MEVA project, which is very dear to my heart, really does narrow the digital divide. Think about it. You've got migrant seasonal workers who rarely have access to a computer but in our community we have resource centers, they go to libraries, they go to schools, they are accessing the internet and they are learning about their health. Each PHR is tied to chronic conditions, so they are about to learn about their conditions in their language. We link it to Medline Plus so they have the accurate information for outreach workers to help them, and frankly it's the most exciting thing that I have ever been involved with is to watch these workers, and if you have

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migrant and seasonal workers wanting and using a PHR. Most of them, not all of them do, but I'd say 60 to 70-percent of the ones that have it offered to them do, and their children, then think about what that means to the rest of us in our populations. Here you have a very vulnerable, fragile population willing and wanting to have better health care and access and more control of that care and they have been able to do that. So with that, it's just so exciting to be here. It's been a long haul. I am very grateful to the Markle Foundation for finding us and for really promoting the mission and vision of consumer owned personal health record where you own it. You, the consumer, own it and control it, and I think that we have many challenges and also many responsibilities ahead as we face the policy issues. Thank you so much! [Applause]

MALE SPEAKER: I'd like to ask our patients, Bonny and Alex, to talk a little bit about their experiences. Bonny, if I can start with you. Can you talk, I know you helped provide some care for your father using the shared care plan, and I understand you have also been using it with other members of your family. Can you talk a little bit about how using the approach that Mark's sketch has altered the way you and your family have received care?

BONNY PARTEN: My father was diagnosed with multiple

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illnesses. He had congestive heart failure, he had acute diabetes. Does that mean they can't hear me?

MALE SPEAKER: That's good.

BONNY PARTEN: Oh sorry. I don't do this a lot.

[Laughter] This is different than talking to a group of patients in our meetings [inaudible] meet with bi-monthly, and sharing our concerns than talking to a large group of people, so I thank you for your patience and I will tell you some things that it's done for our family.

I am the oldest of five children, and our extended family runs to about 25 people. When my father was first diagnosed with his illnesses, it was something that wasn't discussed in families years ago, or even in our family anyhow, because the father just took care of everything and protected his family and he didn't want to be a burden or bother any of us, let alone with anything that might be health related, so he wanted to make sure that we knew he was okay, when deep down we knew that he did have some illnesses going on but we didn't know anything about them because there was no way that we could find out unless he told us. So, he became part of a project about five years ago in which he was given a clinical care specialist [inaudible] Nancy Stoddard who is an R.N. who worked with him through a project, and in this project he was given the opportunity to share his illness with her, and it was

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documented at that time in Word, I think it was, you just wrote down what your blood sugar levels were, what your weight was, and things of that sort. After about a few months, it was discovered that this probably wasn't working and so they devised a plan called the "Shared Care Plan", which was on the computer and since my father was not computer literate, then Nancy would put in information, like if he would go to the doctor she would put down what his medicines were and that type of thing. Well, she had 35 other people that she was doing this for, so as a family, my concern was what if something happens to Nancy Stoddard? Because dad had been admitted to the emergency room on one occasion to where he was prescribed a medication, but the night before he had talked to his doctor and the doctor had said well no, just cut it in half and then don't take all of your Lasix today and things of this sort. Well, when he went into the hospital none of this information was available and so he almost died three times due to different medical facilities not having the current medications. Well, as a family member when you are brought to the emergency room the first thing is they are asking you what medications you are on, [inaudible] and you don't even really care at that point, you just want them to save your family member. Well, with the "Shared Care Plan" that we now were putting information into, it became like a security blanket for

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my family. If I was on a trip, I knew that dad had a shared care plan on his refrigerator that was current at all times because if his clinical care specialist hadn't been able to put in the information, I have four other brothers and sisters who could go on the web, who have internet access, who could update it at any given time and then print out a new one for my father. My mother then all of a sudden felt much more at ease. They could take trips and go back to Minnesota now because they had all their medical information with them on a card, especially the medications and the history of the things and his doctors and how they could get hold of me. It opened up a whole new avenue for our family to discuss diseases. I learned all about hypertension, so when I was diagnosed with hypertension, I knew when they gave me my numbers exactly what it meant because I had been following dad's. It gave us an opportunity in our family to have a common ground to discuss things about, to discuss hereditary, to discuss concerns, to discuss end of life issues, and when I was in Germany, I was at a USO worried about dad, I could go onto the internet and look and see exactly what his blood sugars were and I knew that there were some problems, but it wasn't a surprise because I knew and understood, and all of us did because my sister now was upkeeping it, so it made a huge difference in our lives and a huge educational experience for us and right now there are 17

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of us in our family with shared care plans.

MALE SPEAKER: Thank you. That's wonderful, thanks.

[Applause] Alex, can I ask you to talk a little bit about how having the "Follow Me" tools have affected the way you take care of your health or how you feel about your health?

ALEX SOLOMON: How is everybody doing? My name is Alex Solomon. I am actually representing "Access Strategies", my mom's company. I come from Sonoma, California. I just wanted to let you know I am not drinking wine tonight. This is actually apple juice. [Laughter] Everybody had commented that earlier. It's just basically "Follow Me" is a secure tool for me to travel, whether I want to go to Mogadishu, Africa, or go snow boarding in the Swiss Alps, my mom mentioned earlier that I do have a tendency to hit my head quite a bit. This year, I am actually buying a helmet for my snowboard! [Laughter] So if I am rendered unconscious and getting in a situation like I did last season, I can go to the hospital and be safe to know that with my medical card, with the "Follow Me" card on me at all times, paramedics, EMT's which look back behind your driver's license and that is where I keep my card that has access to all my allergies. It has all my journals of symptoms, my recent scans from the MRI's. It's easy to log. It's user friendly. Also, I don't want to carry around all my hard copies, although my current neurosurgeon right now wants to see my updated hard

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copies, but if I do see someone overseas I can just have them upload that so basically it has my picture I.D. on it, it's got all my conditions on there, and that's about it.

MALE SPEAKER: So if you're in a situation where you think some doctor needs to see some of your scans, is there a way they can go to the web, or do you have a memory stick, or how does it work for you?

ALEX SOLOMON: Well the card itself has my picture on it. It has my password on it. Like she said, it's also got my e-mail address. It goes straight to a home page and just downloads with my password. It has all my information and it has it all journaled out, all my medications, allergies, immunizations, current surgeries.

MALE SPEAKER: Thank you. [Applause] Let me ask a few more questions of our panel. Let me start off with you, Mark. We have heard just from this panel alone and earlier today about a number of different products and approaches that are out there, and each of the people here are using one of them in various ways. As you look at it, if there is a proliferation of very well intentioned products that are all offering a personal health record for different groups, different circumstances, whether it's from their health plan or physician association, how do these all come together at some point? Are we all going to have six different personal health records?

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MARK PIERSON, M.D.: Well first, I think our model, as I was listening to the first panel for the enumerated first, second, and third model, I think our model is the fourth model, which is a community model. I think it kind of coincides with the concept around RIO's, but I become quite anxious sometimes, not in this setting but fairly vocal when I hear folks wanting to differentiate themselves by putting personal health records forward. I can assure you our patients aren't particularly excited about your differentiating yourselves. The way they would like to see you differentiate yourselves is by cooperating. I think that when payers and providers and hospitals start using the same personal health record or one that is truly interoperable, your patients actually will respect and like you a lot more, and much more importantly, their health will improve and your costs will go down. The average time, at least in our neck of the woods, that a person is with a health plan is four years, though if you switch after four years and you have lost that data or the other health plan doesn't want it, that's not such a cool thing. When your health plan changes, your doctors often change, and you actually have the option in some communities to change doctors, even when your health plan doesn't change, though what patients with chronic conditions need, and that is where I'm focusing, that is where our community is focusing, they typically see,

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even in group health, they often see physicians who are outside the HMO, so you need a new personal health record that works wherever you go across all sites and I would encourage you not to wait for the end game, which is where we have national standards for interoperability. I think you can do it today. We have done it today. I actually am quite radical in my thinking. I think when you give patients this kind of tool, it will actually inform the whole what I call business medical record industry, and the tail is wagging the dog at the moment. I think we really want personal health records to be at least on par with business medical records and they are much easier to implement.

MALE SPEAKER: Thanks. [Applause] Mike, you might want to comment on Mark's comments about the role of the portability across the platforms. I want you to talk, if you could, about the connectivity to the electronic health record or other systems and to follow-up on this question: How do all these things start to knit together?

MIKE STOCKER: I'm sympathetic with what you said. The question you have to ask yourself, it's so obvious that this is something that has great utility and there are no real technology barriers. Why don't we have it? That is the thing that makes the discussion all so poignant. This is clearly something we have and it's clearly within our ability to do it.

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Part of this just related to the fact that in our very complicated medical system, nobody is really in charge. There are various people and they all have their interests and they pursue them and it's hard to get people in a large scale to work together, and so one of the reasons I emphasize the business aspects of this, this has always been something that our organizations wanted to do for a whole bunch of reasons, but one of the reasons I emphasize the business aspects of this is that in fact, at some point in time, large, millions and millions of people are going to have to get their databases enrolled in this, and it's not an easy thing to get done and if you can make a business case it's more likely that this will happen. Having said that, there is simply no utility in making these things incompatible, and it would be a huge shame if that happened. I don't think it will. I can only describe it as activism in the current administration if a peer, or a consortium of peers tried to do that would not allow that, I think in this area a remarkably active administration and they are very big on the interoperability which is the right place to do. So, it is not technically difficult to make these things interoperable. It can be done. It's not necessarily easy, but it can be done, and it probably needs to be done by some third party, you know, rather than the individual people who have proprietary interests and that is a trick that is

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important to get done, but it is absolutely critical that this be something that hopefully in the future is universally acceptable and available to everybody in a common format. Thank you.

MALE SPEAKER: Cynthia, let me follow-up on a question with you, almost the flip side of this. You have been very effective and it's been very moving to see the approaches you have taken have served populations that have very special needs. [Inaudible] not to the hydrocephalus population and the migrant worker population, they tend to be not very large in number and they are very scattered typically, geographically, so I think the question, what is the business model, if you will? How do we have an environment which would stimulate the ability of people like yourself to develop solutions that really fit the target for people with special needs in a way that might be different, maybe not, but then what Dr. Stocker's talked about, serving a very large population in a health plan environment, what would it take in the environment to make your approach really more visible?

CYNTHIA SOLOMON: I think that is an excellent question, but I just want to mention in California alone we have 1.6 million migrant seasonal workers, just to give you an example, but I think the business model really, in terms of this type of technology for special populations and vulnerable

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populations is cost savings. When you look at, let's take the migrant worker who goes to a hospital because they have been diagnosed or they are symptomatic with diabetes and gets a test, or has a head injury and gets a test, gets a CAT scan, and then moves onto the next system of care, maybe 100 miles away, maybe 500 miles away, present with the same symptoms at another institution and those tests start all over, so those tests cost usually the taxpayer, frankly, or the hospital, so you are looking at, in terms of cost savings. In terms of Alex's CAT scan, let's say that he was in New York and he has an injury and rather than having them do a baseline and then waiting six hours, they can go online, look at his baseline, and that saves the whole cost of one CAT scan, so I think when you are talking about products and return investment, that is great and I think it is important when you are running a business, but I think it's also important as a community, as tax payers, as policy makers, that we look at saving dollars in the system, and so I look at the PHR as a way of not only empowering consumers to manage and control their own health care, but also of cost savings for them and for the payers.

MALE SPEAKER: Thank you. Let me come back to Bonny if I could. You have now had quite a bit of experience with the shared care plan and have heard about all these approaches, what do you think for your own experience could be done

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differently or better? Is there anything missing, a function or a feature, a dimension that you would like to see this process evolve at its next steps?

BONNY PARTEN: I think the number one thing on my wish list would be that doctors looked at it. [Laughter - Applause]

MALE SPEAKER: Do you have any ideas about how that might be [interposing - inaudible]?

BONNY PARTEN: And how that is changing just in the care that I am being given now and that my father was being given and other family members is when we go into the clinic, it's pretty much here they come, they have a shared care plan, so they printed it out and a lot of times they will attach it to our appointment and that is really important for us, or when you first go in to a new doctor, we will give them the shared care plan and now we don't have to fill out all that paperwork, and just those two time saving things have been important to us, and we have a different relationship with our physicians now when they know that we are empowered and that we do understand what is going on.

MALE SPEAKER: Alex, let me ask you the same question. Have you had this experience with the follow me approach, is there anything you wish it did that it doesn't yet, or you would like to see it be improved in some way?

ALEX SOLOMON: Basically I just wish that the health

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care providers would help me collaborate all that information and translate all that medical terminology into one clean file so I can get it all condensed because I have stacks and stacks of hard copies at my disposal, which I don't have time to put together. That's basically it.

MALE SPEAKER: Great, thank you. Well thank you all. [Applause] I think that will wrap up this panel and I want to just again thank, especially our patients, for traveling so far. Alex and Bonny came so far to join us today and share their stories. I just think that what all the people on this panel are doing is really heroic and providing a service to everyone in the country to see what is possible if we work together in the ways they have described, so thank them again. [Applause]

We're going to go to our last panel of the morning before lunch. As they take the stage, let me introduce them. So, this morning we have seen some of the products and we have talked to some of the users, and we have had a policy perspective from Speaker Gingrich. We want to now shift gears as the day unfolds toward some of the policy challenges of implementing this in a way that addresses the needs of the society as a whole. When the Markle Foundation began its connecting for health collaborative now about three plus years ago, what the goal really at the time of focusing on how do we

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create an interoperable, national health information environment? And at the time, I think a lot of us were talking about electronic medical records and then electronic health records, and an interoperability, and we were thinking about connecting the professional silos of health care to each other, but our moderator for this next panel in convening that group I think had an insight that all the rest of us here are gradually now understanding that the best ultimate purpose of this national connected health network will be its ability to also connect to patients and families and consumers. Dr. Carol Diamond has really been a remarkable national leader in designing these networks using today's technologies and at the same time designing them to protect privacy and assure that the public interest is met. I am very proud to present to you the managing director of the health program at the Markle Foundation and the director of the "Connecting for Health" collaborative, Carol Diamond. [Applause]

CARL DIAMOND, M.D., M.P.H.: Thank you. It's a pleasure to be here. Thank you for that warm welcome. I think five years ago when I joined Markle, had somebody said to me so you're going to have this conference just about patients getting access to their medical records and hundreds of people are going to come, I would have said no way. So, it's remarkable to see what is really transformed in this industry,

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both in the way of thinking and in the way of expectations of information technology, and health care. I will tell you when we started "Connecting for Health" and several of my steering group members are in the room and I know you will remember this, it wasn't taken for granted that patient access to their own health information was a part of this whole dialogue about information technology and standards, and today's conversation is evidence that we have really come a long way. I'm going to introduce the panel. They will each come up and make some opening remarks and then we will run it similar to the format of the last panel. I will tee up some questions, and if we have time, we will take some from the audience. So, let me introduce them in the order that they are sitting closest to me first. Paul Shields is the president and CEO of the Aetna Health Information Solutions company, which is a new data and information unit of Aetna, Inc. Paul and I share some pedigree in that respect, and he is clearly a seasoned health care and publishing executive. Next to him is a good friend and colleague and wonderful partner for this conference, Helen Burstyn, who is the director of the Center for Primary Care Prevention and Clinical Partnerships at the Agency for Health Care Research and Quality, a position she has held since 2000. Finally, it's my pleasure to introduce Dr. Marie Savard, who is a nationally known internist, columnist, and women's health

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expert. She has written books and columns and is widely known for her views about an empowered consumer and the importance of them having their own medical information. Before I turn it over the panel, each to make some opening remarks, I'll just make a few myself very briefly and say that I think we have heard so many times already this morning that the technology is there. Zoey [ph], Mike Stocker, the speaker, everybody has made the point that the technology is already there and I think the speaker used the term as a question of adapting to the present, which I really like. I hope the last panel also makes it clear, and it should be to everyone who is here, there is no doubt about the value to patients and their families in navigating this "complex health care system", I say in quotes, that we have. I think there is also no question about the urgency. A couple of people have mentioned Katrina and how Katrina has really highlighted the importance of having access to your health information, and I had the privilege of participating in some work after the hurricane in an attempt to get people access to their prescription drug history. How many people know of Katrina Health.org in the room? Could you raise your hands? Wow! Great! Okay, terrific. So you all know that with the enormous cooperation and willingness of SureScripts and RX Hub, and a company called Gold Standard and the American Medical Association. In a matter of days, not

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months, time measured in days and health IT is almost unheard of, but we were able to amass the capability to access prescription drug history for I would say the majority of the evacuees from Hurricane Katrina and this included Medicaid patients, Medicare, even the Veteran's Administration collaborated in this as well as the private chain pharmacies and the PDM's through RX Hub, and we worked through the office of the national coordinator. I don't know if Gloria Evans is in the room, but she was also an enormous part of making this possible, and it truly was in the spirit of what wonderful public private collaboration can do. We tackled some big issues and I know, I saw Kevin Hutchinson and I saw Shelly [Inaudible] earlier today. I know they would agree with me when I say that the things that kept us up those nights, those early nights that we were trying to solve had nothing to do with technology. Nothing. They were all about the business processes, the legal issues, the policies associated with information sharing, and for me anyway, it was a changing experience. Even though I had been working in "Connecting for Health" for the last couple of years and we have been very focused on policy issues, it was an acute reminder of how important it is to tackle these issues in a thoughtful way. So with that, where is it? Hopefully that's what we will talk about today, the policy issues that I know loom large over this

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agenda and that we need to solve to make good use of the technology that is already there. So, I'll just ask each of you to come up in the order you are sitting is fine and make some opening remarks.

PAUL SHEILS: Thank you, Carol. My name is Paul Shields. I thought I would expand upon the important discussion in the previous panel just for a second to give you an insight into what is going on in the health plan analysis of this PHR initiative, and Mike Stocker I think made some excellent points about the fact that there is not a clear ROI for a health plan yet to adopt PHR, and yet I think it's fair to say that once Mike Stocker's PHR gets into the market place as it is, there will be a significant amount of traction behind other health plans adopting similar technology. In fact, I think I should mention that there is an industry group, the America's Health Insurance Plans, already working at a very high level in terms of encouraging every health plan in America and AHIP covers 200 million Americans. I think there is 1200 plans associated with AHIP to adopt a personal health record, and it's going to be very similar to the one Mike showed you, it's going to be based on a very substantial amount of data that all health plans currently collect about their patients from medical claims, lab values, and prescription data all currently available in the plans, so not a huge technical leap

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to make that available to the members of the plans for purposes of a personal health record. So I think that over the next couple of months, actually, you will see a significant number of health plans promulgating personal health records to 200 million Americans. They will become a commodity in the health plans phase, and to an earlier conversation, I think the differentiating factor among health plans will be not so much the raw record, but the decision support tools on top of that record that individual plans can then use to deliver personalized content, to deliver care considerations, care anomalies to the members based upon an analysis of the data that they have. I'll mention two other things, one of which is that the same industry group pushing the promulgation of PHR's to all health plans are also working on two very critical components of interoperability. It is clear that the PHR, a plan based PHR, has to be interoperable with the EHR for it to make any sense. It's got to get to the provider. All of the plans can certainly put up a website like Mike showed you that gives access immediately to the member, but we've got to get the data down to the provider community through interoperability. That is actually the harder thing to do, not just to put up a plan based website for Aetna members to come to so that their providers can come to the Aetna website. That's not going to happen. We've got to get these

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interoperability standards to get the data from the plans into the EHR work flow at the provider level. So that is one level of interoperability that is being worked on. The second is, believe it or not, interoperability plan to plan, so that in order to address the issue of longitudinality of the record, these interoperability standards have to be that God forbid somebody moves from Aetna to Cigna, that the plan moves from Aetna to Cigna, so that will happen the interoperability standards will actually suggest that the Aetna has to move that record to the subsequent plan, so lots going on in the industry based surrounding PRH's that I think is very critical for the pushing of the momentum of PHR's, plans have a significant amount of data, they are going to be pushing it out. I think PHR's will be a commodity. The battle will be in terms of the plans based upon the value add on top of that in terms of decision support and after the chat about questions later.

HELEN BURSTIN, M.D., M.P.H.: It's really a pleasure to be here as well. Paul and I both put our blackberries on the table and I warned him he probably didn't want mine if he walked out of here and asked some clinical questions. Really thrilling to be here. I was really particularly struck by the last panel and how much more powerful all of this is when it comes from the voice of the patient, and I really found myself reflecting on how in some ways what we are really trying to do

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today is actually put the patient and the consumer into the heart of health IT, but really hasn't been as reflecting personally for to have not spent very much time as a patient but when I had my last baby, I remember talking to the nurse at the OB's office and I said so how will I get the results of this triple screen, which they do to check for birth defects. She said oh, don't worry honey, if we don't call you, it's all fine. I remember having the sense of how could that possibly be in this day and age that we just assume no news is good news, when most of us know certainly about the number of medical errors and things that is just not the case, so we are very delighted to be here, and I'm really delighted as well that some of our other federal partners since I get to give the federal [inaudible] today just a small task in three minutes including NCI, CMS, and HERSA, and many others here at the meeting are all part of this effort and really I think to move this forward will take lots of effort and lots of time across the department. We have been really lucky to have Secretary Levitt's leadership. I think we have seen dramatic changes and there is something about PHR's that I think has finally caught on in a way that I think just a couple of years ago even people just didn't really quite get. We have all mentioned Katrina and it's hard not to, but in some ways, it really did put so much of this in perspective because it really taught us how

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important it is to have information in your hands in bad times, but also in good times, and I think another lesson of Katrina also is the remarkable work of the Markle Foundation and this extraordinary public private partnership that really seemed to move heaven and earth in just a matter of days and weeks was just extraordinary and really, my compliments to all, but it also reminds us in some ways at times the most vulnerable patients are the ones left out, so I think we need to be intentional as we think about particularly PHR's and opening access across the board here that we intentionally think about patients who are probably the ones most likely to be left out. Across the board, CMS, our colleagues [inaudible] the Centers for Medicare and Medicaid studies have been doing a lot of work thinking about PHR's, how to move that forward, have a request for information that they have just completed, getting information about how to best bring this power of PHR's to consumers within Medicare and I think we will hear lots more in the future. I was just talking with Monel [ph] Donaldson for example from NCI. They are beginning to look at some symptoms databases that patients can enter who have cancer. Herse has been working very closely with our community health centers to bring IT to some of our most vulnerable patients and the providers who care for them. And probably most excitingly, from a federal perspective, just this past Friday at the first

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meeting of the American Health Information Community, the AHIC, PHR's really had a very prominent place as part of the discussion, and there is very much a sense as they thought about some of the potential breakthroughs that would really come in the next few years that PHR's were really a part of it. And, there was very much a sense that PHR's range from the most simplest tool of just being able to have the elimination of those clipboards and having that registration information all the way through medications to being able to locate your records anywhere electronically and then ultimately, really getting to a fully integrated PHR that is interoperable. The bottom line was there is extraordinary enthusiasm and not only that, there was actually a commitment to a workgroup specifically on consumer empowerment and how IT can be brought to bear. So, I think that is really remarkable and very exciting.

From our end, we have certainly worked hard over the last couple of years and we have been blessed to have a significant amount of money in IT to push out as far as we could on health IT into more than 100 communities across the nation in 40 states. I think we are just beginning to understand the impact of what this can really mean, and we initially weren't sure how much of our work actually concentrated on PHR's until we looked at the agenda today and

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realized how many of the folks were speaking, in fact, have received our funding over the last few years. I think some of these projects are going to ask for some really important questions for us. First of all, what are the unique benefits that a PHR brings to the table that really an EHR that is separate from the patient can't, and certainly Martin Harris, I told you a little bit about their product, but in some ways we are actually going to have a clinical trial that does a head to head comparison. If you have an EHR or if you have a PHR, probably really the "holy grail", if you actually have both, how does it really impact on diabetic outcomes? This is the important information we need is really to push PHR's out there. We have to show the value of them, and this is the kind of work that I think will help.

How can we make sure these patient center systems really get to the patients who are most vulnerable and most in need? People like we heard, an elderly patient with CHF who some of our projects are looking at, or among children. We've got a project, for example, in Boston that is combining parent derived data with some evidence based information to improve emergency department care for children.

I think one of the issues that has come up a lot is we've heard about RIO'S over the last year in regional health information exchange. Is it so common that patients are just

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not part anywhere of those discussions, and I think we increasingly need to make sure that all of these regional information efforts always have a patient at the table or a consumer at the table to make sure that their interests are represented as all these data are being exchanged to make sure that the patient actually benefits from that exchange. Finally, I think we really need to ensure that there is privacy and security. I really liked what the speaker had to say about certainly people will vote with their feet if it seems like it is important for their own safety, but I do think there is a real role for us, particularly thinking about the federal government and trying to make sense of some of the privacy and security, and we've got a recent contract that was just let to begin looking at some of those state privacy practices and business to business practices to really begin to give us more information. Outside of HSS, I think our federal partners in fact have really been leading by example. The VA has been mentioned, certainly Dept. of Defense as well, have really demonstrated already that by putting evidence based information into the hands of providers through decision support and computerized order entry, we have really made improvements in quality and safety, and now I think by having these systems in place, hopefully they will begin to demonstrate the power of putting that information into patients hands as well.

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Just wrapping up, I think as we look towards an exciting future, we really don't have a clear roadmap, and I think if we just had a couple of parting thoughts about things to make sure, first of all I think we've got to prove that evidence base. Just as a point of information, the bills that are currently in congress that are all about health IT don't mention PHR's. I don't think most lawmakers know what a PHR is, and I hope one thing that will come out of this meeting today is to be getting a little more clarity that we can begin to describe to policymakers what this means and why it is so important as we develop the evidence base of showing what it can do. As we work to develop a new program on effective health care for Medicare, where we can begin to get customized information for consumers about medications and treatments, there needs to be a place and a PHR can in fact be a wonderful vehicle to begin getting that trail of information out. Lastly, as somebody who practices here in D.C. at a free Latino clinic, I have been really pleased to hear how often that people have mentioned the people who often get left out of this debate, but it's really hard to imagine moving forward without really thinking about the issues of the digital divide. We need to make sure that these technologies are available to all. Also, though, on the flip side, we shouldn't make superficial assumptions about people's inability to use it either. I think

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at times we do people as much of a disservice, we assume they probably couldn't use it or wouldn't want to use it as we do when we make the technology too complicated. Before I came to the agency, I was in Boston at the Brigham. Even though we didn't have a PHR, the power of being able to turn the computer screen and showing an HIV patient their trend of viral loads is very powerful, so let's not make assumptions about people and really give them the chance to take the full advantage. With that, I think the power within this realm of the public and private partnerships and the federal government as a [inaudible] and a partner I think can really help move this forward. Thank you. [Applause]

MARIE SAVARD, M.D.: Last January, actually my secretary was diagnosed with cervical cancer. I said how could that be, Louise? You get a Pap test every year. She said to me, this is what happened. She went to her gynecologist, the gynecologist gets the chart from the door because of course it was hidden on the door, name to the wall. She brings it in the room, thumbing through the chart and suddenly finds a sheet of paper, looks up and says, Louise you had an abnormal Pap test last year. Didn't you get our letter? Well, it could have been didn't you get our e-mail? How often have you heard that? The truth was she had an abnormal pap smear. Not only that, the lab came back with the positive HPV test. Her doctor's

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practice was doing evidence based medicine but that information didn't get relayed to her. The bottom line is with Louise, as Helen just pointed out, we have been trained to believe, as patients, that no news is just that: Good news, right? Yes! And she believed it. So, the largest barrier, and I have been working in this space of getting consumers to get their health records for along time. It's almost ten years now, and what I've seen, the biggest challenge over and over and it continues today is that patients have no idea that they need to even ask for this information. We are told there are over one hundred and some medical schools that teach doctors how to be doctors. There is no school that teaches a patient how to be a patient, and so we've got to remember that. Number one, it's so critical. A quick story some of you have heard before about my dad. As I said, for a long time I developed a paper based system, God forbid paper, and for ten years I have had people, doctors raising their hands in the audience when I would speak, and they would say but what about the smart card? What about this that is coming down the line? I kept hearing that and I started saying I've got something better, I've got a smarter card, and that means information right now that works. Ten years ago the information "right now that worked" was actually a loose leaf binder and a fold-out, and I have seen some other health plans now have this little guy. But the reality is it's

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what works today. We can't wait for tomorrow. I was overwhelmed by Speaker Gingrich, if he's still here, his talk. He painted a picture of what we could do today. Well guess what? As a practitioner, there is one thing I want. We have heard this from Katrina over and over. When I was interviewed with the Dallas News around the medical records, this health reporter said to me, he was speaking to countless physicians. Every physician that went in there said the one thing that they needed and didn't have was the list of medications. Okay, are you bored of hearing that now? Well, guess what? We can't say it enough. That is the one critical piece of information. Ask a practicing physician, if you had one piece of information you could give that practicing physician when they see that patient with the chronic illness, which 80-percent of health care is all about, meaning many, many chronic illnesses on at least seven to twelve drugs, what is the one piece of information that would help you if you could only, you were on an island, could have one bit of it? What would it be? It would be the list of medications, doses and directions. So, if you do nothing else today but solve that problem, you have done a tremendous service to patients. I can tell you as an example, so when my dad had a heart attack and was post-bypass surgery, now it's five years ago, actually over five years ago, I had already had this nice little binder system. He was getting his

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medical records and I was involved and I thought I was really smart in my practice, but he rushes to the emergency room. I tell me mom, brown bag, we think that's cool. Put all the drugs in the brown bag, get him to the hospital. She does it. Now, I knew that I had to get there, you know, two hours away. I get there and see that he has a serious arrhythmia. I thought he was digitoxic. The doctor said no, can't be. It wasn't in the brown bag. In her haste, she didn't throw the digibottle [ph] in the brown bag. So, actually a brown bag isn't good enough. That is when I developed this simple little thing. Now, this is so obvious. I'm sure many of you ever have it, but guess what I don't think you have and I don't think any of us have, and that is a campaign around "just show it, just know it". When that patient, excuse me I forget her name, she was so powerful, was asked what is her biggest challenge? She said it's getting my doctors to look at it. That's exactly what it is about. We, as physicians, are the biggest barrier in the adoption of personal health records. Patients get it if they are told. This isn't baseball, you know if you build it they will come. Patients need to understand what it is all about. But I've found that the language of this card every senior gets, everybody with a chronic illness gets, and if it's first the card and then it's the chip and then it's on the computer and it's on the health

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plan, and then it forces them to go and it excites them and it's [inaudible], that's great however, it happens, but people do get the idea of medications, but you know what speaks every louder? They get the idea of their physician, every physician saying to them I can't prescribe a drug until you show me your list, because I need to know what you are taking over the counter, your vitamins, and your herbs. Respect the patient's information. The pharmacist, I can't really fill this prescription until you show me your current list of medications. If they are asked at every opportunity, it makes all the difference in the world.

A final really quick story, I am very involved in [inaudible] and for years I've been talking to some of the professors around doing this kind of thing. So, this one woman in the second year, the second kind of go round, she raised her hand in the audience and she said I did your system! I got the binder! I got all my records, and here I was, I was diagnosed with aplastic anemia and she got all her records from different specialists. She went for a second opinion. That consult, [inaudible] consult thing and when she got in there with the hematologist had her binder there with her. It could have been a disc, but that would have been worse because they didn't have a place to stick it in, because they didn't have a computer I'm sure. The hematologist said to her, do you have nothing better

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to do than collect your medical records? This just happened!
So, these are the challenges that we face. I think we need CME
for patients, CPE, I think Mr. Gingrich is right on about that.
It's the very same information; the patient cares more than
their doc about their one condition. We need to start simple
with medications. If nothing else, if we don't make it easy
for doctors, they are not going to do it either. So, what is
going to save them time and make them money indirectly through
saving time? Giving a list of medicines. That is the biggest
challenge when a new patient comes in to the office. That is
what we've got to accomplish and if we can have a win with
something as simple as that, something that patients understand
and everybody gets, and we have the opportunity of Katrina to
really sort of do the messaging around, we can really then
build this phenomenal personal health record that ultimately I
think at the end of the day does have the ability to sort of
transform health care, because really it's the patient that is
the final safety net.

I would like to close with the words of Ursula Le Guin,
the science fiction writer. When I'm challenged about patients
and can they go forward with this, I think of her words. She
said, and I will paraphrase: As a patient's power grows, and
her knowledge widens, ever the way that she follows grows
narrower until at last she chooses nothing, but does only and

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holy that which she is meant to do." Personal health records has the ability to give patients the power and the knowledge to choose personally what they need to do. Thank you. [Applause]

FEMALE SPEAKER: All right, we're going to try to take a few [inaudible], is that better? All right. So, we will try to take a few questions now from the panel. I guess I am going to pick up, Marie, where you left off and also your comment about there is no school for patients. In other words, there is nowhere that people learn the importance of this information. Clearly, for the personal health record and this whole agenda, the demand for personal health records from consumers is low. Everyone we have talked to offers a personal health record whether it's a health plan or an integrated delivery system or what have you, will say that a small proportion of people who could have access actually make use of the system. I wonder, from each of your perspectives, what you think is the single most important thing we can do to begin to turn that tide? Because clearly without that demand, we will see these low use rates.

MARIE SAVARD, M.D.: I would answer by saying first we need to find the [inaudible]. We have heard of that repeatedly, and disease management. I am working with American Health Rates, for example. They have the extraordinary infrastructure already in place, and they have patients that

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are already signed up who are already kind of informed engaged consumers. I think disease management is a place to really pilot it, to test it, to have it work, and then physicians see how well it goes. Disease management organizations already have this nursing base. The nurses can be the coaches. They already have the data that they get, both the health plan data which is extraordinary and you've heard that, but they also have a very patient specific data. What are the opportunities, barriers, challenges, the OTC drugs, etc? They are all in one system right now. If they transferred that to that very engaged patient already, I think that model could continue to repeat itself. So, I think start with the population, such as the patients in a disease management program that already have had issues. It's the patients that have had issues that are really going to make the difference. Yes, of course we want to look at it as something proactive. Let's don't wait until you have the problem, but start with those who have the unfortunate experience. I will tell you, Louise and my dad will never ever not have their own medical records again, or information available to them.

HELEN BURSTIN, M.D., M.P.H.: A few points. I think first of all, we really don't know the answer to that question and I think, I guess perhaps because I work for research agency, I think some of these questions are [inaudible] and I

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think we need to ask patients. I was really struck by Bonny's point about what they sat around talking about, these focus groups of patients coming up with what they want and need. I think that is part of it. I think secondly you might think, for example, that patients who have the most chronic illnesses and the providers who care for them, are probably the most frustrated, and I think probably going to them and finding out what they want and need. Also, I was really struck recently. We were at a meeting that the DOD and VA had actually pulled together on PHR's, and Andrew McAffey [ph] was there from Harvard Business School and he said well, what is the care app here? And I think we need to figure out what the care app is and actually in some ways, for the Dept. Of Defense they said it was the fact that patients could go on and do same day appointment scheduling themselves. We need to think about what it is that will really drive patients, because it's really what they want to do and they will see some real value added there.

PAUL SHEILS: I think that's right. I think there are several things going on, one of which most focus groups will indicate that there is not a lot of interest among patients for PHR's because they don't understand them. They don't know what they are. They confuse them with the HR's and PHR's, so there is an enormous amount of education that has to go on in the country regarding the relevance of a personal health record to

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an individual's health maintenance. That is first. I think the health plans are going to be involved in that in a big way obviously. But I also think that unforeseen events will have a huge impact on personal health records. Katrina, everybody knows a lot about the fact that those folks now, look at all the people in the room who raised their hands, can have access to their list of medications through Katrina health.org. Five years ago, two years ago, or even ten months ago, that would have been unheard of, so there is a national debate occurring that is elevating the awareness of PHR's in the country to a point where certainly soon, I wouldn't say most but a significant amount of Americans will know what they are and will demand one.

CARL DIAMOND, M.D., M.P.H.: Okay, I guess now I'd just like to take the flip side of that question, which is the research that exists about patient behavior change and even in the area of preventive health, shows that the physician is a very important part of the equation for the patient, and even if you have a patient that is motivated to collect their records, it doesn't help to have the physician say to a patient don't you have anything else to do with your time? That is clearly a demotivating factor even for a highly motivated patient who may have a chronic illness and is motivated to collect their information. What, in your minds, is the most

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important thing that we can do to improve both the acceptance and the use of personal health records. I was totally struck by the earlier panel and the comment that the single greatest challenge is really getting the physician to cooperate, either to get my information or to look at what's in my PHR.

MARIE SAVARD, M.D.: I think it's interesting as we are moving more towards this paper performance model. We will see where that goes, but if you think about it, and as I say to physicians and I speak to physicians all the time, if that really takes off, the more engaged you get that patient, a PHR is really going to be the opportunity for you to do less work and get paid more, I mean to be perfectly blunt. I think that has to be the message to physicians, how a PHR is going to save time for them. They are going to have better outcomes. They are going to make more money. That is the language that matters, and they are going to have time.

CARL DIAMOND, M.D., M.P.H.: I will add that I think inherently physicians and other providers, this really isn't just doctorcentric either, a lot of us are cared for by nurse practitioners and PA's and others, really want to do the right thing, and I think in some ways having the ability to do the right thing in concert with a patient is really very important and very powerful. I have got to tell you the amount of time I spend in clinic flipping through pages and pages to find that

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one pap smear result frustrates me and ruins my day, and if I could actually share this personal health record with a patient and I guess my bias is as much as possible getting to the model where in fact the PHR and the EHR are part of the same thing because I think they are such quality improvement to be gained on the provider's side by having that information and the reduced duplication, but I think being able to show the provider that not only is care better, but actually taking care of patients is actually more enjoyable. I was really struck by a piece [Inaudible] and David Laskey had actually written in the special health affairs which all of you got, because there are stacks of them out there, really talking about how transformational having a PHR is. I think it actually can make practice more enjoyable. It takes you back to doing what most of us went to med school or nursing school in the first place to do, which is to actually be an active partner with our patients to make their care better.

PAUL SHEILS: I think that the provider adoption of EHR's or PHR's is the biggest single challenge that we face. I don't think it's going to be as big a patient adoption or member adoption of PHR's is not going to be as difficult as provider adoption. However, I think they are going to be related. I think that the more patients have access to PHR's, that will propel the provider community to have better access

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to EHR's or PHR's. I think there is also a technical problem. Katrina health.org, by the way, you have to go on to a separate site to get access to that data. I think that the provider community really wants or needs access to the PHR or EHR in the current work flow in their office, not going to a separate site, so the real debate now is how to have that happen. How do you get either plan based PHR data or PBM based data into the work flow at the provider office in a way that will facilitate their use of it as opposed to changing their behavior to go to a site for a specific purpose. Once we get that solved, then I think you are going to see a dramatic increase in provider use of EHR's and PHR's, but it's going to be a tough fight.

FEMALE SPEAKER: All right, if I could just ask you now to sort of levitate up to the national policy agenda, and think of this in the context where in Washington there is a lot of activity within the federal government, the hill, what have you, to try to get this health IT agenda moving. If you could waive your magic wand and solve one key issue on the national policy agenda, no matter what you think the most important issue is, and you could shape that policy agenda for the coming year, what is the issue you think would most accelerate the ability for patients to get their information and to use it, as Helen was saying, to use it in the context of their day to day

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care with their physician, which is ultimately what we are all after. It's not really about an application being made available to them. It is its use in the day to day setting. What is the most important policy issue you think that needs to be addressed?

MARIE SAVARD, M.D.: I don't know that I can really answer that question. That is a big one. But what comes to my mind, what I've seen as the biggest challenge in going out and speaking to this is the confusion around HIPAA. All the barriers and things, I think HIPAA, I thought it was going to be a great service to mankind and instead in the interpretation of it and the translation of it down to the level of the doctor's office and to that family member and a caregiver, it has been a big barrier so somehow clean that up, whatever that looks like, in a way that there are no barriers to people having unfettered access to their personal information and to their loved ones having equally, given that they sign off on it, obviously, that information. That I think is a huge issue.

FEMALE SPEAKER: I think certainly the privacy and security issues are important, but I think part of what we really need to do in terms of a policy level is just to begin to find what we are talking about. I think of all this we're in fact talking with one voice about what it is we are really trying to achieve, I think we could make huge efforts here and

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I know that has been a lot of the work of what the Personal Health Technology Council, for example, they are trying to think about what these principles are. How do we move forward with one voice as to what is most important and try to get us there I think would be really important. I think as much as possible, to bring people out, like Bonny and Alex, who told their story today, and have people at the national level and policymakers hear these stories of how having this information at your fingertips changes care, it changes outcomes, and I think that is the powerful [inaudible].

PAUL SHEILS: Other than HIPAA, which is obviously huge, I'd argue that the state privacy laws are also going to be a challenge. You guys probably saw the article, whatever it is, three weeks ago in the journal about different state privacy laws prohibiting certain plans or PHR vendors from delivering information about adolescence, because in California you can have access to it, in Texas you can't, so harmonizing those state laws around the display or distribution of PHR data, so that it's consistent across the country is a big deal I think.

FEMALE SPEAKER: Okay. One last question, picking up on the HIPAA issue, aside from the operational challenges of HIPAA, which I think is what you are expressing, what it translates into when the patient is sitting in front of the

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physician and what their interpretation of HIPAA is and what it means for how they care for that patient and how they share information, aside from the operational issues, you heard the speaker today use the term "non participation", and you suggested that in order to avoid non-participation, we need to deal with things like discrimination, audit, and other things, and we also have the principles of the personal health technology council, which raise some of the issues that are important to consumers and may be important policy objectives. In your views, how do you think the role of addressing these issues and building these principles into this agenda going forward, how important do you think that is? How much do you think that will shape the coming years in PHR implementation and use? In other words, in your ranking, everybody I think immediately refers to the operational challenges of HIPAA, but the reality of trying to do this in a way that does offer people a safe way to have access to their medical information and to share it looms large in everybody's mind and our poll that we released today also demonstrates that, so what is your view on the importance of really addressing these challenges?

MARIE SAVARD, M.D.: I think health information is without question the most private information. People say that they don't want their financial records shared, but ultimately I think health, there isn't anything more private, and I think

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that is a challenge. I could not [inaudible] when Speaker Gingrich was talking about the, I was thinking of easy pass when he was saying I'm going through easy pass really fast and there are the guys on the line that don't want their credit cards on easy pass, so God forbid they wait hours. I get it. One line on the turnpike and you get it, but I think that is fun. That is my credit card information, but your health information, and your track record, and to know. I have seen in many years of practice, patients would often say to me don't write that down, I tell you, don't write that down. My smoking history, whatever it is. I even understand that for myself, having a bone density, well I won't even admit my bone, too many health people here, but the truth is, I think that is a challenge and that is where the personal control of the patient having it and totally understanding it in a way that maybe only the pieces, the health at a glance, the summary gets let out or the lab tests. I do think building in a sense of maintaining exclusivity somehow. I just miss the reality of the health information that we are dealing with, and I don't want my internists to know that I'm on the anti-depressant that the psychiatrist knows or something, that might be something that is not going to ever change. You're always going to want to maintain firewalls of sorts.

CARL DIAMOND, M.D., M.P.H.: I think I would actually

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draw the parallel to what is going to happen on the provider side, and I think in some ways, the way I think providers will begin to adopt IT is by incrementally showing them, this is really good stuff, and I think we are beginning to see that as providers use e-mail, as providers begin to use e-prescribing, you sort of think, or even the uptake of palm pilots and using accessible information, providers begin to think I can do this. This makes sense! And it doesn't seem as scary, and I think in some ways we need to start small and think about what on the PHR side we could try to make available to as many people as possible while those privacy and security safeguards are certainly in place, and I think patients need to have some of that control over who sees it. But at the same time, as a general internist, I would be terrified to think that I wouldn't see the medications my patients take that are given to them by a psychiatrist because I need to know that. So I think incrementally, making some small steps and accomplishments that people can begin to see how well this can really impact on their own health care I think is really important, while maintaining some of those safeguards.

PAUL SHEILS: I think one of the challenges of this whole initiative is the number of different standards that we have to come up with. You have IT standards, you have business rule standards, you have clinical standards, and I would argue

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this whole patient privacy, patient control as a whole subset of standards we need to come up with. What I would like to focus on just for a second that I think often gets lost in the shuffle are the clinical standards. For example, when a PHR has the ability to display a lab value in real time, there is an enormous issue with respect to the provider or physician not wanting the member or the patient to have access to that first, or before the provider has the time to actually interpret that. That is just one example of all the clinical rules that have to get generated around the correct and appropriate display of the information, that technology enables you to make available to the patient in real time but the provider may have a real interest in saying I don't want to see that if in fact it's alarming that I need to get involved in that. So, of the four sets of standards, the practical ones are the easiest, I think. The more difficult ones are the clinical rules and the privacy rules and the control rules.

FEMALE SPEAKER: I would like to add one thing brought up by Paul's comment, recently we had this discussion with some of the folks at the VA and they have the same issue and yet they have set a clinical rule, for example, that says within seven days the results get released and so in some ways it is not only really important for the patients to know that they can get their results, but it sets a quality standard for the

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providers to make sure they have in fact looked at all these results and done something with them within seven days. So, I guess the point I would make is that others are in fact experiencing these same issues and I would hope that part of what the collective wisdom of this group could actually do, is begin to collect those best practices and share them, because others are beginning to cross these same bridges and need that same collective wisdom.

FEMALE SPEAKER: Great. Paul, I wonder if I would just pick up on this last issue a little bit since we heard that Aetna is now trying to compile a personal health record for their members and we heard from Mike Stocker earlier, and we also know obviously from the research we have done on consumers that some of the people they most worry about in terms of getting access to information are their health plans or their employers. That is a very scary thing to them. What steps are you taking, or do you think health plans need to take, in order to have their members make the maximum use of this opportunity?

PAUL SHEILS: It's THE question, and that is how can a health plan transform itself from a denier of claims into a trusted [laughter] partner in health and medicine? [Laughter continues - Applause] I think Mike actually pointed to it, health plans have to transform. There business is becoming a commodity. It's not that difficult to manage this process to a

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point where you are not differentiated in the market place so you will see health plans do whatever they can to become more of a management partner with both providers and members. Obviously there is an enormous challenge to overcome the distrust that current and most certain members have against the plans for many years. So one of the things obviously is, like everybody else is saying, demonstrate the value. You have the data. In fact, most members I would argue don't know you have the data. They don't know that for decades, plans have been analyzing this data to determine trend analysis, to determine all kinds of things that many people on the panel have been doing for years. The data has always been there, so it's a matter of transforming the data into a personal health record that demonstrates real value to the member in terms of being able to use it to better manage the care. I keep going back to this. The fact that the data is available is going to become fairly well known pretty soon. Every plan in America is going to have at least the rawest form of PHR fairly soon. In terms of making it attractive to a member, the plans have the ability to apply analytic skills to that data to deliver personalized content, to deliver personalized aid, therapeutic alternatives, personalized health content based upon not just that you are diabetic, but that you have these particular characteristics of diabetes and we can deliver this kind of content to you. It's

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the power of the ability to deliver personalized care considerations to patients that should, I'm not saying it might I'm saying it will, overcome the notion that there is true value here, and why not take advantage of it, whether it comes from the plan or whomever, you're going to have a lot of people saying this is fabulous information, I should be taking advantage of it.

FEMALE SPEAKER: Okay, with that we will wrap up our panel. We want to thank everybody for a stimulating conversation. Thank you. [Applause]

MALE SPEAKER: Thanks you, Carol and the whole panel. We have filled our brains with a lot of ideas, challenges, and opportunities. We are going to take a break for a little break for lunch. Let me mention a couple of housekeeping things, first of all if when you came in you did not check in at the registration desk on the right hand side back there, we would appreciate it if you would do so and get your name badge. As far as lunch goes, there are boxed lunches which are labeled in the back. There is vegetarian, chicken, and fish I believe, and they are marked so you should certainly come and take one. We will take about 15 minutes to go and walk around a little bit, capture your lunch, bring it back in here and eat it. In about 15 minutes, we will start a very stimulating multimedia international discussion about breakthrough technologies.

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