

**Connecting Americans to Their Health Care:
Empowered Consumers, Personal Health Records
and Emerging Technologies:
Welcoming Remarks and First Session; Opening Keynote;
Interactive Demonstrations: Moderated Discussion
October 11, 2005**

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**Connecting Americans to Their Health Care: Empowered Consumers,
Personal Health Records and Emerging Technologies:
Welcoming Remarks and First Session; Opening Keynote; Interactive
Demonstrations: Moderated Discussion**
10/11/05

2

[START RECORDING]

DAVID LANSKY, Ph.D.: Once again, thank you all for coming. I think we'll get started now. I hope you all have a cup of coffee and are ready for a very full day of activity. My name is David Lansky. I am the Senior Director of the Health Program at the Markle Foundation. We are very proud to be one of the three co-sponsors of today's event. Our colleagues, as you've seen from the materials and the slides are the Robert Wood Johnson Foundation and the Agency for Healthcare Research and Quality. We'll have the opportunity in the next couple of minutes to hear from each of the sponsoring organizations about what they are hoping for from today and from this field as a whole. I really want to express my special thanks to them for helping us put this event together. It's, I think, a remarkable opportunity to talk about the issues facing consumers and patients as the health information technology revolution begins to spread. This is the first conference I know of where we've devoted a whole day just to the question of how can consumers and patients take advantage of the new technologies to improve their health and to be more effective in getting the best possible health care in this country. You all are a key part of our discussion today. This is a wonderful cross section of all of America's health care,

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Connecting Americans to Their Health Care: Empowered Consumers, Personal Health Records and Emerging Technologies: Welcoming Remarks and First Session; Opening Keynote; Interactive Demonstrations: Moderated Discussion 3
10/11/05

America's technology sector, patient and consumer advocates, government representatives, industry people, technology people, all coming together to think about ways to allow every American to take advantage of the new technologies that are there. We had a surprisingly wonderful turn out. We didn't really expect to have this much interest in this field at this stage of development as it is. In fact, we were joking this morning that at this point the personal health record is probably a Rorschach Test for each of us. We all read into it a little bit of what we imagine the need to be and how we can best fill it. Hopefully in the course of the day we will come to understanding of what the potential is for personal health records is to help us all.

Let me tell you just a bit about the structure of the day you have in mind. You have your packets I hope. I hope everyone has got a blue binder. It has inside of it an agenda for the day, the registration list and some other materials. In addition for some of the breakout sessions there's additional material for each session in the rooms as you travel around this afternoon. Our basic approach for today is to begin with a series of presentations here as a plenary group which will include some demonstrations of how personal health records are being designed and deployed today, some discussions with users of these technologies and some thinking about the

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**Connecting Americans to Their Health Care: Empowered Consumers,
Personal Health Records and Emerging Technologies:
Welcoming Remarks and First Session; Opening Keynote; Interactive
Demonstrations: Moderated Discussion
10/11/05**

4

policy implications of the proliferations of these technologies. We'll then have a luncheon gathering again in this room to hear about some future developments, expected developments, in personal health technology. Then in the afternoon we will spread out to participate in four different tracks dealing with four different sub-topics within this larger arena and then at the end of the day we'll come back here together.

To kick the day off, I am very pleased that we will have an opportunity to hear from our sponsors who are all leaders in this field. I'm especially pleased, frankly, to introduce to you our first speaker of the day, who is Zoe Baird the President of the Markle Foundation. Zoe is a remarkable leader, I can attest to that from my personal experience. She has for many years been very active in the National Security field and the defense field and has also been working with us in the health care arena to help us really think through all the implications of a networked society in the way we think about the construction of public policy and protection of civil liberties and the deployment of technology for the best interest of the public as a whole. As you see from the bios which are also in your books, she has a very distinguished history in both the business sector and in government and has really become a leader in helping all of us think about the

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

ways information technology can produce great benefit for our society and also the issues that information technology raises as we go forward. So with great pleasure I'll introduce to you Zoe Baird.

ZOE BAIRD: Thank you David for the very generous introduction which I encourage you all to discount substantially since we work together. But David and Carol Diamond [misspelled?] as so many of you know have been tremendous leaders in the health care field and have done so much to focus the health care community on the needs of consumers and patients that we all ought to thank them but this conference is certainly a testament to their efforts. This conference, Connecting Americans to Their Health Care, marks the first time as David said, connecting Americans to their health care is the first time that we've had a conference of this size that has brought together so many people to focus on the consumer and the patient at the center of health care IT. It would seem obvious since health care is all about improving consumer and patient's quality of care and quality of life that we would think of them at the center of any healthcare conversation but in fact much of the health care IT conversation has been about systems and the players in the health care system and about technology and about standards, but has not been singularly focused on what is the role of the

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**Connecting Americans to Their Health Care: Empowered Consumers,
Personal Health Records and Emerging Technologies:
Welcoming Remarks and First Session; Opening Keynote; Interactive
Demonstrations: Moderated Discussion
10/11/05**

6

consumer and the patient and how can all of this; so the rest of our investment, the rest of our design of information architectures and policies, truly improve the quality of the care that individuals receive and their ability to improve their own health and health care. Today, we're going to change that, we're going to join with you and so many of you think about the consumer all the time and IT a lot less, we're going to join with all of you to try to build a health care system that draws on the power of information technology to meet the needs of consumers and patients. We're here to challenge the status quo that allows health care to remain remarkably behind every other sector of the economy whether it be finance, you know we can go online and print a boarding pass to get on an airplane but we can't go online and find out the basic information about our own health or health care or compare the quality of health care while we can compare the price of airline tickets and books and find things related to our interests in so many other things. Health care has to catch up with the emerging networked world or we're vastly under-serving consumers. I know that many of you are very familiar with the continuing challenges for our health care system in general; the costs of health care continue to grow exponentially and so many Americans are uninsured because they can't afford health care, even though we're paying more for our health care we're

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

not necessarily getting better care. An estimated 100,000 people a year die from medical errors and hospitals alone, many of which could be avoided with the proper information being available. Best practice care is delivered only about half the time. The pace of medical research is slower than it should be because important information is difficult to collect and analyze and correlate, and research breakthroughs can take years to reach patients because there's no structured way to insure that even their doctors have that information right away at the point of care, let alone the consumers. Even in the information age it's been estimated that it takes an average of 17 years for new knowledge generated in randomized clinical trials to get into every day medical practice. And even then the application remains highly uneven. One big reason for this delay in deploying the new data is because we haven't figured out to make this new information manageable and useful for practitioners and so some of what we're talking about today in terms of the consumer and patient role in health care we have to keep in mind is critically important when the patient is interacting with the provider of care, the physicians and other health care providers and focus our efforts on making those important moments work better and the providers themselves able to use information more rapidly as well.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Sometimes our health care system seems too big and overwhelming and as some of us were talking about in the hallway before we came in, no system at all. How could we possibly think that we could come together like this and impact that, change that? I just would encourage of you to think of so many other sectors which seemed large and intransigent, again whether it be airlines or the way books are sold, the debates people were having before Amazon were the independents going to be put out of business by the Barnes and Nobles and the chains that were going to dominate book selling. You can take almost any sector and the view of it has been transformed by what has occurred using information technology. All of us need to be thinking today and hopefully beyond this that we can improve the quality and cost effectiveness of health care if we think about how to create simpler, more accessible tools for consumers and patients and their providers than the information technology that's available today in health care.

We are able through our discussions today to talk about the many ways that personal health records can be developed and the ways that other technologies can help us change the way people interact with the health care system and you'll see today many examples from individual personal health records to broader more systemic efforts. All these technologies, whether they be devices, wireless devices, home computers, can support

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

better partnerships between patients and their doctors and that can support better communication across the whole health care system. It is critically important, of course, as so many of you are aware that we do this in a manner which protects individual's privacy and their ability to manage how their information is shared and with whom it's shared. You will also have the opportunity today to talk about some of those issues and think about them. If you just have an image in your mind as you go into these discussions about how far we have to go and how you know we can go far quickly, I would give you one image. When you walk into to a doctor's office today what are you handed? You are handed a clip board and a pen. Now what other sector where the information you write down on a piece of paper is as important as health care hands you a clip board and a pen? Today I can't think of any sector that uses clip boards anymore other than health care. So keep that image in your mind and realize, man there's so much we know how to do today in every other sector that we can apply to health care and move away from that clip board and pen. I would just encourage you to realize we are not talking about new and complicated technologies. It's great if you're designing something that's you know the moon shot for health care and we'll be ready for you in five years when you've got it ready. But today there is so much we can do to move away from that clip board and pen and

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

I would encourage you to keep that in mind and in all these discussions realize that each one of you have ideas of what could be done tomorrow, what could be done next week, what could be done six months from now, that in the hands of the consumer and the provider that's serving them could transform how they're getting health care.

If you've got a serious illness, we all have talked about the stories of what that image is. If you have any kind of chronic or serious illness you are walking around from doctor to doctor with a manilla file full of your copies of your records, your images, your test results, and how long does a doctor have to sit and look through that before they serve you and answer your current questions or recommend a treatment. Even if they had the current treatment information that we know takes on average 17 years to get into clinical practice. They are going to be very ill-equipped and continue to be very ill-equipped because we're not using the technology that we can use in so many other areas to quickly correlate data. Where's the Google search technology that goes through your medical record if you're cancer patient and says how many times you've had an infection in the last two years. You're sitting there with a two inch thick file. Where's the technology that immediately pulls up for you that there are 12 instances of something the doctor ought to know about, if he saw them all together would

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

have some meaning. Where's the information that says what medications you're allergic to? I remember I'm allergic to erythromycin but do I know what erythromycin is? Do I remember the word? Do I, as a patient, know to tell the doctor, well I'm a cancer patient and two years ago this is what was tried and this is the way it was adjusted and this is what led to my remission? These are questions of things that in other sector would be considered low hanging fruit but in health care we really haven't figured out, across the board obviously there are wonderful, wonderful, pockets of things being done in a given hospital system or a given community, but we haven't figured out how to make the benefits of information technology to substantial percentages of Americans let alone most Americans.

It's therefore incumbent on us to imagine what a new vibrant health care system would be like and to begin today to build it together. I like to think about a story John Halumka [misspelled?] who is the CIO of Care Group and may be in this room actually has pointed out in an op ed where John says imagine a patient with an allergy to aspirin who has a heart attack while driving on vacation in California, loses consciousness and crashes into a telephone pole. In the emergency department the first medication likely to be given to him is therapy for the heart attack, aspirin. I see a lot

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

probably docs shaking their heads. Adding the allergic reaction to the existing heart attack and trauma results in shock and the patient dies. That is such a simple, avoidable medical error. How many times has this patient had a reaction to aspirin? How aware are they? Are they wearing medic alert bracelet? Obviously you hope so. But there are so many examples of ways that lives can be saved or care improved if we simply have basic information. We don't need to imagine this any longer. We know it can be done today. We know that that's why we're all joining together today. We're making it clear that consumers need health IT tools that are going to make the difference between illness and health, even life and death. They need tools that will allow them to get their information into the right hands at the right time. They need tools that will allow them to get information from and share information with those who can help them achieve their own personal health goals and we know that the challenges of making this a reality are not solely dependent on technology. Most of the information technologies as I've said are available but we need to change the way we work in health care and we need to address the policy challenges through a collaborative dialogue with all interested parties and create an environment that protects the privacy of our most personal information in a networked health care system.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

That's why the Markle Foundation under David's leadership created a personal health technology council that's comprised of many of you, leaders from across health care, technology, and the consumer sectors. The council's begun to discuss the policy questions that are raised by a new networked health information environment and has developed an initial set of core principals which if I hadn't disabled the technology we would put on the board for you right now but you can find in your packets there's a set of core principles that can bring patient and consumer concerns into the design of the health technology environment. And I'll give you a quick overview of those principles and later on you can look in your blue packet and you'll see them there. But more than 40 consumer and patient groups, business leaders, and others developed these principles. Let me just run through them quickly for you.

The council's principles say that people should be able to; one, access their own health information. Two, decide when their health information is shared and with whom. Three, designate someone else to manage their health information if they're unable to do it themselves. Four, understand how their health information may be used. Five, see which entities had access to their health information. Six, know that health data exchanges protect the integrity and privacy of their health information. And seven, hold accountable and be represented on

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

independent oversight bodies for health information exchanges. These principles are written out in some more detail in your materials as I say and are also on the conference Web site. We hope that everyone from the smallest IT vendor to the members of the American Health Information Community set up Secretary Leavitt will use and discuss these principles and work with the personal health technology council to enrich and refine them.

To further your thinking about the issues at today's conference we also commissioned a public opinion poll by Bill MacInterf [misspelled?] of Public Opinion Strategies. Bill, are you here? I don't know if he's here yet but Bill and his team will discuss the research in detail in one of the breakout sessions this afternoon. And I think you'll find it very instructive to see where the public is on many of these key issues, including the principles that we just reviewed which we tested with the public. Bill's research shows that American's see the benefit from using IT and health care and as won't surprise you they're much more likely to support using the internet to transmit health care information if they're assured that privacy and security is protected. We should all keep this in mind obviously as we work on today's agenda.

We look forward to working with you as we all seek to realize the full potential of information technology for consumers and patients. Today I hope we can look back on as

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

the day that marked the end of the status quo that allows health care to lag so far behind all other sectors. I hope that when we meet together in future years that we no longer need to imagine what a networked health care system might be like for someone with a heart attack who lands in a distant ER or for a diabetic woman who's trying to manage her health care at home. We should have thousands of people from those environments and thousands of others come to teach us about the technology they are using to change their lives and tell us how the things that you have developed or you have enabled are improving their lives and what the next generation of changes are that they need. So please join me today in thinking hard and thinking about what your role is and committing to energetically and immediately pursuing that role and to committing to this new future that we all together can make possible. Thank you.

DAVID LANSKY, Ph.D.: Thanks so much Zoe. Sorry for our technology adjustments here, give us a second while we get set up here let me introduce our next speaker. This conference as you know is also supported very generously by the Robert Wood Johnson Foundation, our partner. And I'm very pleased today that Steve Downs the Senior Program Officer there is joining us. Steve leads the foundation's really remarkable new Pioneer's Portfolio which is an opportunity for them to look at

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

a variety of breakthrough and innovative ideas that may be outside of some of the traditional channels. I think in doing that work Steve has really helped me and all of us think about innovative ways to address the challenges facing health care. Steve has also played a leadership role there in looking at all their e-health initiatives across their whole portfolio. I'm very pleased now to ask Steve Downs to come up and join us.

STEPHEN DOWNS: Thank you very much David. Today's conference is just another project where we've had an opportunity to collaborate and it's always such a pleasure to work with you and your colleagues at Markle and support the ground breaking work that you're all doing. I'm also really pleased that we're joined by Carolyn Clancy and AHRQ today, who've also contributed such terrific and important leadership on this issue. The Robert Wood Johnson Foundation is delighted to be a co-sponsor of this conference, not only because we believe that health IT speaking broadly is a vital ingredient to improved healthcare in public health but because today's conference focuses on the personal dimension of health IT. The conference is not about using health IT to treat patients, it's about how people can use health IT to take care of themselves; to manage their conditions, to communicate with their providers, and to seek valuable information, to seek the right medical care. The more that we at the foundation have looked

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

at the health challenges facing our country the more we have come to realize that the key to this issue is to have health care consumers who are motivated, engaged, and informed. To the extent that people and those who care for them can use health IT to help them monitor their health, communicate with their providers, and find valuable information then we care a lot about health IT. For the past several years we've been investing in it in a number of fronts; we created the Healthy Technologies Program which has supported rigorous research studies around behavior change and disease management programs that use health IT. I know that you'll hear from at least of our grantees today. We've actually got several studies in the field right now that are looking at the use of personal health records in disease management programs. We of course have joined forces with the Markle Foundation on Connecting For Health because it's so important that underlying network infrastructure enable the kinds of personal health record applications that we're going to discuss today. I expect that there'll be more investments to come.

The personal dimension of health IT is a really exciting place to be right now. It's a time of experimentation, a time of emergence. As you'll see from the panels and talks today there are many different flavors of personal health records being developed and offered right now.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

There are advances in the underlying infrastructure that open up new possibilities and I think you'll also see there's a whole world out there of sensors and smart band aids and other bio-monitoring technologies that open up a whole new, that form another key piece of the puzzle. The visions are here and the potential is great but there are many unknowns. We don't know how all of this is going to shake out. We don't know which technologies are going to dominate, which business models have legs. Most importantly we don't know how people are going to embrace and transform these services. What features are they going to adopt? What are going to be the show stoppers? What applications perhaps that we haven't even thought of yet will they demand? It's useful to step back and remind ourselves that at the time of the Internet's emergence we didn't really expect that people were going to use it to sell the junk in their attic to people halfway across the country, or to store and share their family photo albums, or to download all their music or even to live blog conferences like this. So in the personal dimension of health IT it's still so very early.

That's why it's important for you to get involved now. We can't foresee how the realm of personal health technologies is going to take shape over the next five, ten, or twenty years. But what we can predict that the form it will take will depend largely on who's involved. And it matters. It matters

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

whether systems are open or closed because that affects the pace of innovation. It matters whether all the pieces of the puzzle can come together and work together so you can manage your health as a whole well person and not as somebody who's compartmentalized into five different disease conditions or five separate treatments. It matters whether you as an individual have some control over how your health information is used. It matters if technology simply reinforces the current way of providing health care that we do now or whether it creates new opportunities to make health care better and safer and more patient centered. I want to thank you all for coming I hope that you'll find today's program really engaging and that you'll stay engaged after we leave. Thanks very much.

DAVID LANSKY, Ph.D.: Thank you so much Steve. We will soon have technology at a technology conference. Our third sponsor is the Agency for Health Care Research and Quality within the Department of Health and Human Services in the United States government. I will tell you my personal belief that our country and all of us interested in better health care and in having consumers more engaged in their health care are very fortunate that our next speaker, Dr. Carolyn Clancy has been at the helm of the agency for these last several years. Carolyn is a distinguished clinician, an influential researcher, and I think a very capable leader of a federal

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

agency. Carolyn, I really appreciate your support for all the work in the health IT arena and we welcome your sponsorship at this event today, thank you.

CAROLYN CLANCY, M.D.: Good morning and thank you for a lovely introduction. We're really delighted to be joining the Markle Foundation and the Robert Wood Johnson Foundation in sponsoring this conference. Under Zoe Baird and Carol Diamond's leadership and then recently joined to make a real dream team by David Lansky the Markle Foundation has consistently been ahead of the curve in just about all aspects of health information technology and their partnering with RWJ, with AHRQ, CMS, and all parts of HHS, I think is a lovely model of what a future connected health care information community can and should look like? I think we all appreciate that this conference is taking people what might be called a rare teachable moment. The hurricanes in the Gulf have had a profound impact on each of us and I think all of us feel a need to draw out some positive lessons for the future from the recent tragedies.

One of the lessons of course is that there's no substitute for a health record that's available for the patient wherever the patient has to be. The very disturbing image for me was people holding up baggies with their pills that had melted together because of the heat and the water and so forth.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

That was really the only information that they had available with them. The lesson of the importance of health information was made pretty stark by the hurricanes. Thousands of people with urgent medical needs were shut off from their sources of medical care and basic medical information. That story is a pretty unforgettable one when you hear about it unfolding. As Carol Diamond's recent testimony emphasized the situation could be just as urgent for any one of us if we found ourselves needing in treatment in an emergency room say here in Washington D.C. where our medical records were unavailable. And indeed every day in thousands of encounters across the country physicians and nurses are missing the information they need to deliver the care that patients deserve and need and interestingly patients are aware of that. 32% of patients in survey we sponsored last year report that they've had to come back for another encounter, another visit, because information was missing at the first visit they went in for. And here I thought we were so skillful at downplaying the fact that paper was missing. When I was training I thought that being medical detective would require searching out rare diagnoses, maybe even making new discoveries and when I got into practice I learned that being medical detective meant finding all those pieces of paper that had been connected to clipboards. The

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

time is more than here to bring the power of information technology to the health care sector.

From the day that President Bush announced his health IT initiative, Americans quickly saw the importance of electronic health records in emergencies but health IT has so much more to offer including decision support, that is to say evidence based information at the point of care or when decisions are made, coordination of care, especially for chronic illnesses and quality measurement and improvement. The survey that's being released today that Zoe described briefly indicates that Americans are getting it and that is great news. They understand that health IT is first and foremost about improving quality and safety in care. And as Gail McGrath [misspelled?] who's here and others who are able to listen to the discussions of Secretary Leavitt and the American Health Information community last Friday can report the American Health Information Community also gets the power of personal health records. A lot of excitement in the room, people weren't quite levitating out of chairs but very, very close.

So the survey suggests more strongly than ever that Americans are ready for electronic health records and health information exchange, if. If privacy and security are insured, if patients have access to their own records, and if patients have control and a voice in how that health information is

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

shared. This isn't surprise. Trust is at the heart of medical care and that's one thing they can't change. But more than that these concerns are part of a broader picture and a longer term promise, the promise of a new kind of engagement by the patient with his or her own health care. At it's best, health IT can offer new tools and a new vocabulary for providers and patients, it can literally help transform that relationship, for the pioneers in health IT this has always been the ultimate goal. Any of you who've had the opportunity to see Paul Tang's [misspelled?] video of how this works in their system will know that it's not unusual to see others in the audience with tears in their eyes because it's so different from how they usually receive health care. And that's really why since the very beginning the idea of the personal health record, putting the record in the hands of the patient has been a key part of the discussion. A key part, but perhaps not the clearest part of the discussion.

And in truth as the previous speakers have noted personal health records mean many things to many people. For some they're simply an electronic collection of basic personal health information maintained by the consumer with no connection to an electronic health records. For others, they're more complex tools that can share information from the medical record and conduct secure transactions. Neither

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

version is right or wrong and there's many variations on those themes. Today the patient maintained personal health record is feasible for most of us and consumers can indeed create their own basic personal record aimed at emergency medical situation. In the Gulf Coast even rudimentary records would have made a night and day difference for many, many individuals. Instead, working with pharmacy benefit managers which did have the information stored electronically in retail pharmacies, Markle working with HHS and a whole array of other public and private sector partners was able to launch a secure Web site where that information about patient's prescriptions could be obtained.

But as new capabilities become available the power of the personal health record will offer so much more. It can be integrated with systems of health information exchanges those systems are built. And indeed the distinctions between personal health records and physician based or plan based records seem sure to be narrow. What we have today then are important questions. What kind of involvement will consumers really want and what kind of personal health record can best enhance and transform the physician patient relationship and for whom? Under what circumstances? What kind of record works best for those with chronic conditions who were served by several or multiple or different providers and how should we provide access to family or friends who can speak for us if the

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

need arises? The critical question is as we build interoperable systems and put the infrastructure in place, how can we guarantee a consumer's seat at the table? And not least of all how can we build momentum right now for personal health records.

Like everything else in health IT we're learning as we go, in my agency we're committed to building and protecting a new role for the health care consumer. Our health IT initiative is aimed at finding what works best in real clinical settings. It can help establish, and identify, and examine the role of the consumers and physicians alike find most useful. Just last week we announced that this initiative is expanding with 16 grantees receiving more than 22 million dollars to implement community health IT systems over the next several years. And I'm really excited that you're going to be hearing from four of our grantees today, Martin Harris [misspelled?] who's down front here, Cynthia Solomon [misspelled?], Mark Pearson [misspelled?], and Matthew Hadley [misspelled?]. Our work with the office of the national coordinator on privacy and security will help build the technical and legal foundations that need to underlie all of health IT. Our national health IT resource center is helping to accelerate implementation and through the center we'll share our findings broadly and as rapidly as possible.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

And finally our broad scale work to improve quality through evidence based medicine will be a growing resource for patients and providers alike. Our new effective health care program is aimed especially at helping consumers find clear, understandable advice about drugs and treatments that work best so that they can identify what works best for their individual needs. It will be an important new resource for all facets of health IT as they come online and I'm very much looking forward to our being able to deliver customized information to individual patients so that they can make decisions in an informed way. This conference comes not just at teachable moment for America, but at a moment when all of us need to learn from each other and take stock of next steps. The timing is particularly good because health plans in many health care organizations are starting to get the power of personal health records as well so it's critically important that we make sure that the consumer's voice remains clear and focused throughout. However we ultimately define and use personal health records, the truth is that patient access, patient control, and patient responsibility are critical for improving our health care system. Personal health records are an important vehicle for achieving those goals. The conference will help sort out the questions and put some light on the road ahead. I can't even tell you how excited we've been at AHRQ about the conference

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

for the past few months and I particularly wanted to salute the efforts of Helen Burston [misspelled?] who served on the planning committee. I always knew what day she was having these discussions because her normally enthusiastic self reached a new level of excitement. Again, thank you for being here and thanks for your leadership on behalf of health care consumers.

DAVID LANSKY, Ph.D.: Thank you so much Carol. I also want to acknowledge we had wonderful participation and support of planning this conference from both the National Cancer Institute and the Centers for Medicare and Medicaid Services. Please join me in thanking all of our sponsors in putting this together. [Applause.] Unfortunately our key note speaker for the morning has been delayed in some bad traffic out here today. So we're going to make an ad hoc adjustment in our schedule with your forbearance and we're going to begin with the first panel which is immediately after the keynote in your agenda. I'm going to ask Steve Downs to come up and set us up for this discussion as the panel takes their seats. We're going to be getting an overview of personal health records and then we'll come back to the key note address when our speaker's able to join us. Steve?

STEPHEN DOWNS: Okay so I mentioned earlier that there are many different flavors of personal health records on the

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

market today and in this session we want to give you all a sense of what the applications actually look like in a sense of what you can do with them. Our panelists are going to show us three different models, three different types of personal health record services and then I'm actually going to wrap up with a quick overview of some of the other types that are out there. First up is Wendy Angst, Wendy is the General Manager of CapMed, a division of Bio-Imaging Technologies, and she's going to show us their products.

WENDY ANGST: Okay. Hi. My name is Wendy Angst with CapMed and I had that moment of panic when they said I couldn't use my laptop and now I can so I'm calming down. I'm so excited to be here today this is so exciting to have a whole room of people dedicated towards personal health records and I'm going to take you through just an overview about who CapMed is and then really quickly take you through our product.

CapMed really focuses on providing interactive solutions for patients and we do that in a couple of different ways. One is B to B, where we customize our products for our partners which could be an employer, a hospital, a pharmaceutical company, and we also provide them direct to consumers. Consumers can log onto to our Web site and buy the products directly to manage their own health. We primarily provide the products in two tangible formats. One is a CD-ROM

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

and the other is USB technology that we call the Personal Health Key. We have about a half a million personal health records on the market today. We got started in the early nineties, so we're one of the groups that's been out there and really got knocked around quite a bit as this industry's been growing. And we're a division of Bio-Imaging Technologies which is really great but as we're a growing company we're owned by a publicly traded company which has been wonderful.

So as an overview of our solutions the best analogy that we have for our product is like Quicken, when people started using Quicken, there wasn't a lot of sources of electronic financial data so people really used it as a checkbook. And today that's the reality with personal health records, there is not a lot of electronic information available to populate health records for consumers today but that is changing. We've developed our product that consumers can update the record as well as any electronic sources of data that's available that meet the standards. We'll be launching a project later this year, we'll be populating the health record with claims data. We have been involved interoperability showcases to date, one in which the patient was a chauffeur of their own information. They traveled from EMR participant to EMR participant and aggregated their own records and communicated that to their next provider. And one

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

where we exchanged that data on line through [inaudible]
showcase at Hims [misspelled?].

We've also been working on interfaces with home monitoring devices to enable consumers to upload those results into their health record and again self entered data through wizards and pick lists and all of this data then triggers automatic reminders for consumers. So the capabilities of our health record are for consumers to really track all levels of information, health and wellness information and even track medical images. Information can be communicated online, through printed reports, through USB transfer of the Personal Health Key. The way that the health key is designed is that everything is self contained, that a patient would need to manage their record right on their device so wherever they go additional hardware or software would be needed. Also the fourth bullet there, we have a partner Medic Alert [misspelled?] that's here today as well. And consumers who are using the Medic Alert Personal Health Key or E-Health Key can upload their results which also enables a call center back up. And interaction, direct links to custom content, reminders, interaction checkers and personalized alerts tied to the values in PHR.

So just as a screen shot and I'll take you through the product in just a moment, I'm highlighting the drug tamoxifen

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

citrate in the patient's health record which then lets you see that that medication is tied to the condition breast cancer. Furthermore that there's an image available that the patient has stored in their personal health record relative to their breast cancer condition and a link out to their pharmacy to refill their medication, and a link to any relevant content. So all of this happens in an electronic form simultaneously if the consumer is self-entering the information than any information they enter links them to the appropriate content and then reminders can be triggered from that as well.

So in summary places that you'll see the personal health record rolled out later this year, are again, we have a pharmaceutical pilot we're launching, a managed care pilot, hospital pilots, we're really trying out a lot of different industries because there's a lot that can be learned as far as how you engage consumers with using health records. Again, the Medic Alert group, David Harrington [misspelled?] is here right in the front row. They have a great product, the E-Health Key that they have 4,000,000 currently that use their Medic Alert services, which most people refer to them as the bracelet company but they're moving away from that to be more electronic. But again information can be seamlessly backed up online so it's really a great system with a great brand so that's been taking off quite nicely so far.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

What I just did was plugged in a personal health key that is branded to Christiana Care [misspelled?]. So we recently launched a project with the Helen Graham [misspelled?] Cancer Center in Wilmington, Delaware and they've provided the health key patients and have built in the registration forms as Zoe Baird was talking about the clipboard and how frustrating that can be, especially who are managing a chronic condition. So with the Helen Graham Cancer Center we have built in their registration form so we've simplified that process for the patients. What you're looking at is the dashboard of the Christiana Care Personal Health Key. We have direct links out to their helpful resources for patients out here in the left, their medical history questionnaire built in right here, and it's designed again so anything they put into their questionnaire they can print it out or they can actually transfer this directly at the point of care when they're at the Helen Graham Cancer Center. They can track multiple family members within the one health record and a lot of wizards and tutorials built in to simplify them entering information. Looking at the personal health record itself, going over the medical history, here's a summary of all the information the patient can have stored into their health record. Again, we looked at this a little bit, but images can be tied directly and all this running from the portable health key device so the

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

patient will have everything they need with them at the point of care. And as the maneuver through the Christiana system all that's needed is a USB port with the physician has an EMR are or not the patient has everything they need to communicate and update their health care record.

That's the quick overview. We do have some handouts in the back and I'm available here all day if anyone has any questions. But the big take away that we have is there's a lot of different solutions and models for personal health records and it's really about giving consumers choices in finding the ones that help work today as the environment continues to evolve and hopefully becomes seamless in electronic practical solutions today can help consumers just simplify their care and be better partners in their care. Thank you. [Applause.]

STEPHEN DOWNS: Thanks very much Wendy. We're going to take just a second to flip through, we don't want to preview all of Mr. Gingrich's slides. Okay. Thank you. Next up we have Gloria Austin, Gloria is the CEO of Brown and Toland Medical Group which is a multi-specialty comprehensive physician organization that serves over 200,000 people in the San Francisco and the Bay area. Brown and Toland is an early adopted of Medem's [misspelled?] I-Health record product and Gloria's going to demonstrate how they're using that in their practice.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

GLORIA AUSTIN: Good morning. I know I have a lot of slides so I'm going to try to distill the information in a quick fashion. Just by way of introduction, Brown and Toland is a large community physician practice organization and we've taken an aggressive approach to pushing technology out to our physicians in a very unique way. We've adopted technology that includes both an electronic medical record as well as the I-Health record. So today I'll focus a little bit on both but for the most part we'll talk about how we use the personal health record. Again, we have 200,000 patients and we also have over 1,500 physicians. We use the I-Health record in conjunction with Medem, Dr. Ed Foch [misspelled?] is here and he is the CEO of Medem and they've been our partner in this endeavor. It's always great to be at a technology conference and have to work with it. At any rate, we really believe that what we're doing in San Francisco is differentiating us in a big way because we're doing it. A lot of people are talking. We're actually doing it and we've been the leader in the Bay area and actually nationwide we are an organization that is again connecting individual physicians and so this is in an entrepreneurial private practice model which is I think the first in the nation that's moving in this direction. We launched our electronic medical record in 2004 and then we launched actually Medem who introduced the I-Health record for

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

all Americans shortly thereafter. The reason we did that is because it will integrate with Touchworks [misspelled?] our product so that the consumer doesn't have to constantly update their own information which is the case with PHRs.

The strategic imperative, all I want to point out and this I think is probably very apparent to those of you who know the value chain, we've invested more than 10 million in fact probably closer to 20 million in our technology efforts and the reason why we do this is obviously we understand that over the long run consumer driven health care will require more transparency and will require products that demonstrate outcomes. Fortunately our physician leadership gets this because there are not a lot of physician organizations that want to invest this kind of capital.

Why I-Health and why now? I don't need to go over this most people are already talking about it. Obviously physicians and patients are online, it improves quality and actually the health care information that they receive medication adherence on and on. Also there's a communication linkage here between the physician and the consumer and one that with our system will be again integrated with a product called Touchworks in the electronic health work. All of the personal health information will be available to any physician for any one of their patients throughout the entire community network.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Again, why do patients want I-Health? These reasons have been touched upon. When women are caring for families and children they want to make sure that all of the physicians have access to their family's health records. When they're in the ER they want to make sure that someone can pull up the information quickly and on and on so I won't go through that?

Our I-Health records provides a standard space personal health record. It's available via the internet and the patient's ability to grant viewing privileges is their own. There is an automated patient education system built in and integration again and pre-population of our Touchworks product. It's custom built web sites, by the way, for Brown and Toland physicians.

I'm going to give you just a brief demonstration of how this works through Medem. It actually comes on to our Web site so patients can build it by going to the four members area, there's a direct icon that has the I-Health record on our web page, so there's multiple places to reach it. There's find a physician which links patients to an actual physician within our network and then that particular physician has the opportunity to build their own Web site and from that Web site patients may log in and establish their own I-Health record. They have a secure password and ID and they can establish the record or they can and view their record. They also input

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

basic information, it's a very easy system to use, I've developed my own. There's screens for every medical condition and then once you hit a particular condition you can drop down and populate that and actually update that with additional information. There are secure E-mails to patients for messages and medications and they can be our programs, Brown and Toland specific. Also the clinician can update programs and build their own information.

All of this information is again easily handled by both the clinician and by the patient. Patients get a wallet sized I-Health record card for emergencies, so once they if they do find themselves in the emergency room they have access and the clinician can have access to their information by looking at a wallet card. Patients can grant access to other physicians and then they're able to audit their own screen and see who's had access. The one exciting part is that we've already pushed this to the community of San Francisco and so we've publicized it widely and I'm excited about this because we've targeted female audiences who typically are the ones who want to develop this information, produce it for their families. In our physician offices we have and are developing I-Health record kiosks in order to quickly and effectively enter the information. We're positioning our company as being an e-technology leader and letting the consumers know that.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

This is just a copy of an ad that has been presented on outdoor billboards and others, it demonstrates that the I-Health record goes everywhere you go. This is a vacation setting but obviously through out the country we know that, again, in Katrina and other events this would have been a really helpful thing for people. We also pushed it out in terms of letting people, letting consumers know that our doctors are wired, meaning that we have the technology now for consumers not to have to repeat their laboratory tests and not to have to go through a lot of things. We're still in the process of pushing the technology out so we're not fully there yet but for the most part our physicians do now have access to all laboratory online. We do, again, more advertising.

And we pushed this out in a radio setting: "My husband just collapsed." "No one plans an emergency but you can be prepared." "I've got a 45 year old male complaining of chest pains." "10-4" "What if your medical health records traveled everywhere you did? A digital health record could save the life of someone you love. Starting today you may choose to create one for you and your family just by visiting BrownandToland.com. That's BrownandToland.com." That was actually a radio spot that we played often in San Francisco and it was very successful. We actually saw immediately after playing that particular spot our Web site activity went up 36%.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

This is actually a smaller number, there are 1,300 users who've developed an I-Health record but that is actually increasing dramatically. We have just in terms of press, a number of press inquiries as well as separate mentions of what we're doing. So one thing I want to mention though is this isn't just for Brown and Toland members. Any one can go on to our Web site and create an I-Health record, it's free, it's offered through Medem as well so San Fransiscans now have this opportunity within their control. We, obviously, are in synch with the rest of the nation, we feel like we're actually on the leading edge and are proud to say that. Our path forward, we want to expand the use again, the most important thing that I think here is that this I-Health record integrates with an electronic health record so the information will be populated as results are in so the member doesn't have to go and update their own information. I think that's critical. That should happen within the next few months. We already have robust disease management programs but this gives us the opportunity to interact with consumers online. Obviously the increased use of I-Health by physicians so physicians are adopting it both by us pushing it and some of them are pulling so that's a nice kind of phenomenon to see. Also it enables us to have a great collaboration with potential RIOs [misspelled?] and we have a robust RIO that is developing California and other data sharing

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

initiatives. So that's our path forward and again thank you for letting me demonstrate what we're doing in San Francisco. [Applause].

STEPHEN DOWNS: Thanks very much Gloria. So the third type of personal health record we're showing is one that's tightly integrated with the provider's electronic medical record. Martin Harris is the Chief Information Officer and Chairman of the Information Technology Division of the Cleveland Clinic Foundation. He's also one of our grantees, he's a principle investigator on a research study that we're funding through the healthy technologies program. He's going to show us the My Chart [misspelled?].

MARTIN HARRIS, M.D., M.B.A.: Good morning and as Steve said we really represent a third model which is a model that's tightly integrated between the patient and the physician using a shared tool in what we like to think of as the shared practice of medicine. I want to walk through just an example of how we use this tool today.

The first thing is this tool has really allowed us to eliminate barriers. I practice at the Cleveland Clinic, it's an 1,800 physician group practice. We have facilities that really span most of northeastern Ohio, it crosses all the way to the Pennsylvania border as far as west as Toledo and then down into southern Ohio. There is only one way that we can

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

practice in an integrated way and that is through the effective use of information technology. About four years ago we made a decision to convert our practice to an online model of care that will be shared with our patients. Our challenge was really to meet our patient's expectations which were well ahead of our ability to deliver care in the year 2000 and our goal was to create an environment that no matter where the patient went across our health system they would be known and they could tell by the way the medical practitioners interacted with them that they in fact had the information they needed to make the best decisions with them about their care no matter where they were. The way we decided to do that was by connecting all of our clinicians and nurses and administrators through a single tool and then making sure that that tool was absolutely shared with our patients at making their information available to them as well.

So the first step in that model really was creating the electronic medical record. This is the conversion that I talked about. So today at the Cleveland Clinic, last year we saw just under 3,000,000 patients visits in our ambulatory practice, every visit was done online. There's a computer in every exam room. The visits are documented as part of the care process and the notes are signed as the patients leave the room. You can see here we have 1,600 physicians that use the

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

system every day. About 10:30 every morning you have about 5,000 concurrent users on the system and we have three and half million patients in the database, last year we wrote about 3,000,000 electronic prescriptions on the system. When you think about it from a functionality point of view, this is what the practitioner is looking at when you're in the office. It is a work flow tool so we manage everything here. Last year in the month of September before we completed the roll out of the system we delivered about 100,000 medical records to appointments in the month of September. This year the delivery rate was negligible. We really have moved to an online model, this is how we care for our patients.

Up in that right hand corner is where a practitioner looks to see if there's additional work to be done; if there's a prescription, a note that needs to be signed, there's a little blue light that comes on up there. Then you can see it is a computerized physician order entry system so we bring the patient's safety factors to the point of care. We use it for messaging internally as well messaging out to our patients and then we manage all of the other practice activities through this tool. This is the base, all the practitioners are using it and then we decided that it was now time to make this exact same tool the same database available to our patients and we do that through an outreach technology that we call My Chart.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

My Chart is an online portal back to the same database that the physician is using. Our patients do not populate the core information. They don't have to type in their name. They don't have to type in their medical record number. They don't have to type in their medication list, it's all automatically available as the result of practicing medicine and sharing that practice with our patients. When you look at it from a functionality point of view, from a patient's perspective they can view their medical information, they see an automated health reminders list which is based on the fact that the system knows about them; so we know their age, we know their gender, we know their medications that they're on. Their health reminders list is a function of who they are. They can manage their schedule. They can review that schedule. They can make an appointment request and now working with Shore Scrips [misspelled?] in our community they can make a prescription renewal and that will pass all the way through to the retail pharmacy as well. The patient can watch that happen on line.

I'm just going to take you through in closing, just a few functions from the patient's perspective then. They're at home, they've logged on here to their portal, it's personalized for them. If there's something new that happens they get a message that would run across the top of this but I just wanted

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

to pick out a couple of things and walk through them. Here's a patient who wants to look at some health information and they've logged in to what's called their health summary and it's a list of their - we call them health issues instead of medical problems - they can see their medications, they can see those health reminders that I talked about. If they wanted some additional information they could click on that hypertension list that you just saw and it would take them directly too information about hypertension. Again we have tailored this to the patient, so if this was a severe hypertensive patient they might be looking at different document than someone with mild hypertension. If you compare that to Googling this if you will you would be looking at about 14,000,000 articles through which you would have to search in order to find the information that would be most suitable to you. We've been able to provide a real consumer service here in a way that saves patients time and also improves the relationship between the provider and the patient as they begin to discuss these issues.

The second one is really medication management and I just wanted to walk through that one really quickly. Here's a patient that needs to make a prescription renewal request. That now has become an online mechanism, clearly 30% of the telephone calls into our family health centers which is where

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

most of our primary care happens relate to two things; prescription renewals and what's my next appointment or can I cancel it and change it? We've now converted that to an online model, don't use the telephone go online and make that function happen. Here a patient simply goes on, they don't have to retype anything, their medications are right in front of them if this is the med they want to renew they simply click on it and then it gets submitted back to their physician.

I think the last one that I have in here is I just simply wanted to walk through a test result that would also happen with the patient. Again, physicians are in, they're seeing their patients results come back and again online we can then release those results out to the patient so they simply click and now from the patient's point of view what happened was I was in the office seeing patients, this result came back. I no longer batch my work. When I see that result if it's clear cut I don't need to do a lot else with it I can release that result immediately to the patient. They receive an E-mail wherever they'd like at work, at home, whatever account they use and all the E-mail says is that they need to go to this secure Web site and there's something new on it. When they click on that new Web site from that link they'll log into the system and across the top it will tell them that this result is available to them, they can log into it. Again, it's all

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

tailored for their personal information so that if they don't know what triglycerides are they can simply click right there and they will see the additional customer friendly information about that.

As Steve mentioned and as Carolyn mentioned earlier this morning we are recipients of grants from both AHRQ and Robert Wood Johnson and we've been focused over the last year on doing a structured clinical trial around the utility of this technology both from a medical quality point of view, can we truly make a difference in the quality and outcomes of care delivered to patients and second can we alter the service paradigm in order to make that happen. It's really been exciting to do that work. We're about a year into and I think we're about to break the code on the data so we can make a decision about how to move forward here. Over the last year we really began the roll out to our patients. So up until June this year we really had a structured process that allowed us to conduct the research that I was talking about but since June we've really opened it up to the public. We've been using as was mentioned earlier, newspaper, print ads, radio, and television to drive the program. What you see here is really the effects so through June of this year we really had about 5 or 6,000 patients on the system as we were loading the study. We've now opened it up and we've been running at several

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

thousands per month at this point in time. It has made a dramatic difference in the way we practice medicine from a provider's perspective but I also think a tremendous difference in the way patients think about how they will receive their care. I just wanted to end on that point. I think what's really clear about this tool is that it absolutely empowers the patient to be an active participant in their care. They see information in near real time. They know what their providers are looking at because they are looking at exactly the same thing. Then finally, it does raise expectations and we get some of our absolute best ideas about where to go next from our patients who are thinking about services in a whole new way. Thank you. [Applause].

STEPHEN DOWNS: Thank you very much Martin. You've just seen three different models of personal health records but as they say, that's not all. The Markle Foundation has actually found that there are about 160 various types of personal health record products out there on the market today and I'm just going to take a couple of minutes to give you quick sketch of that variety.

As you've seen already in the demonstrations there's a broad range of technology models; they can be stored on the Web, your data can be stored on your home computer, or on a memory stick and there's even work going on in terms of storing

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

that on little chips that can be planted under your skin, optional of course. It's also important to remember that some people prefer to having computers and we can't discount the value of hard copy. There are a whole wide range of suppliers of personal health record products and I think one of the things you notice here is that different types of suppliers have different assets they bring to the product, some of them have particular data about you that they can leverage and package for you. Like your physician group may have a very good relationship with a patient so that forms the basis of that. Data can come from a number of sources, obviously you've seen examples of patients entering their own data, there are data based on the EMR as in the case of the Cleveland Clinic, and of course monitoring device data. When I think about that, you think about let's say a home glucometer where you can upload the data from that into a personal health record or of course coming soon the wi-fi enabled bathroom scale.

Wendy mentioned Medic Alert and here's an example of a personal health record that is designed to provide key information when you find yourself in the emergency room, so your meds list, your allergies and I'm sure other information is available. This is a retail pharmacy that again has your prescription information and allows you to enter some notes about yourself as well. This is an example of a product that's

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

targeting a specific disease condition, so in this case type 1 diabetes. It allows you to check that in great detail, do some charting and trending of your values there. There are others that provide medical images so for example here's a product that all women to store their mammogram images and be able to look at the changes over time. And last not by least even the food guide pyramid has its own personal health record attached, so anyone in the world and every day you can enter your nutrition intake and you can see how you're doing against the food guide. These folks aren't doing so well. Thank you and I want to quick check with David, do we have time for a couple of questions? One or two questions and I see the first hand up over there. Can you stand up? I don't think there's a mic, so —

FEMALE SPEAKER: [Inaudible] at all to help design the solution that you came up with and if so what were you looking for from that private company.

MARTIN HARRIS, M.D., M.B.A.: We decided that the technology side of it really wasn't our core business so we used the mixed strategy. For the basic EMR we used a commercial company to do that. The My Chart product that you saw here, you should really think of that as simply one phase of our outreach programs and we used a commercial product for that. We do, as Steve mentioned, My Monitoring which allows

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

people with implanted medical devices to actually connect and send that information back to the electronic medical record. We have something that's called My Consult which is really a function of a second opinion. Sort of once in a lifetime that's for anyone in the world and again we developed that for ourselves but it all connects to that electronic medical record. That strategy is a little too much for us so we used the commercial approach for that.

STEPHEN DOWNS: Right there and the mic is coming so just hold on a second?

MALE SPEAKER: I'm just curious in terms of the Medicaid population how many of your organizations or practices serve Medicaid patients.

STEPHEN DOWNS: I guess I would ask each of you and I don't know Wendy if you have any comment.

MARTIN HARRIS, M.D., M.B.A.: We serve all patient populations and we have Medicaid, Medicare, commercial clients. The neat thing about this technology though is that there's no charge for the My Chart service. The real challenge is really bridging the divide in terms of gaining that access on the home side. There are really two challenges there one is getting the technology in the home I think into the right price structure. I'm counting on television to really do that. I'm not sure that you need a computer to be able to do this at all. Any web

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

enable device should allow you to do this. In fact, I'll just tell you a really quick story, I did see one patient. We both went to the airport together. I went to San Diego and that person went to Germany I think. It turns out they had an abnormal result, it wasn't an emergency but I wanted to make sure they got it back. I didn't have a computer with me and through that internet interface that you see in most hotels today I was able to log into the electronic medical record, sent that person a note which they saw on their television in Germany. My hope is over time that we will get the basic access to the Internet on to some consumer appliance in the home which will then really help bridge that gap in that divide in terms of access.

GLORIA AUSTIN: My answer is very similar. We also in addition our physicians do see Medicaid patients and so all of the technology is available for all of their patient populations regardless of whether it's a managed care patient or a fee for service patient. But we also take care of thousands of Medicare recipients and so that's a population that's also very important to us in terms of getting to their disease states and managing their care across the continuum. We use this technology for all products if you will.

DAVID LANSKY, Ph.D.: Martin mentioned the notion of using the television as an access point and I was just going to

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

mention that one of the grants that we supported through our Pioneer Portfolio at the University of Washington who is actually with Nintendo on Game Cube is their platform so a game console based browser access to your medical records as well.

I'm afraid we're going to have to stop now and get to our keynote speaker. But I want to make sure that we give the panel a hand. [Applause]. Thank you Steve and the whole entire panel, a very helpful overview and now we're going to skip back a step and go back onto our earlier schedule. I am very pleased to tell you that our keynote speaker has successfully navigated the traffic and the weather. When we began to plan this conference we were very excited that our initial outreach to Secretary Mike Leavitt from Health and Human Services, you discovered he was enthusiastic about personal health records as a part of overall national strategy. You may have seen that he signed on to be our keynote speaker. If you've been watching the news this last week, you've also seen that he's in Asia so he was ultimately unable to join us because of his important in dealing with the Avian Flu challenge that we're facing now. When Secretary Leavitt unfortunately was unable to join us today, we were very fortunate on short notice to be able to adjust our schedule and that our next speaker was also able to adjust his to accommodate us today.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

As you know the keynote speaker this morning is probably the most dynamic and passionate leader in the political space in this field today. Since he left the congress Speaker Gingrich has created one of the most thoughtful think tanks really trying to move forward the idea of electronic health information and consumer involvement in their care at the Center for Health Transformation. I think Speaker Gingrich in helping us all realize the opportunity we have to bring consumers and patients into the heart of our health care system and becoming part of the process of improving it. No one really articulates the opportunity to improve our health care system through greater patient and consumer involvement than Speaker Newt Gingrich.

NEWT GINGRICH: Thank you very much David and thank you all for being flexible and allowing me to join you a little bit late. I really appreciate the chance to talk with you because I think what you're doing today is very, very important and I hope that part of what will come out of today's proceedings will be an effort to develop a model federal bill that will help explain the citizen's rights as we move into an age of electronic connectivity. I want to come back to that but I want to put my personal marker, the reason that I was delighted to have a chance to come here and chat with you is that I really think we need the kind of principled thinking that

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

starts with the individual citizen and says, "If this is the world of the future then what it is we should expect and how do we legally construct that system to insure individuals rights in context that is going to be very dynamic?" I also think this is very, very important because I think we're at a historic turning point and the only real question is how long the political system will be too dumb to get there. Because most of what the problems we're faced with are essentially political.

Let me explain part of my background. When I stepped down as speaker I decided I would spend about 40% of my time on national security and about 40% of my time on health. It turns out, and this was a surprise to me frankly as I worked on these issues, it turns out that health is about thirty times more complicated than national security. I go to the Pentagon, the intelligence community, the State Department, the National Security Council, take all of their problems Iran, Iraq et cetera and drop them into a box, the health box is thirty times bigger, 3,000%. That's part of why it's been so difficult to get large scale change because health is this extraordinary almost ecosystem of highly decentralized power centers each of which sub-optimizes it's interest. And each of which has hired seven lobbyists, the first two who didn't very much, the three who promised they would do more, and the two that they got

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

recently in despair at the first five, all of them now walking around Capitol Hill basically saying, "No." Every group that currently exists in health understands that your interests already exist and it wonders why you are doing this weird thing.

Now I gave you that as background on the one front. This is also dominated if might by an enormous in intellectually and that is the end of the 1880-1935 model of government. I'm going to be very clear about this because I think its part of what you have to be thinking about. The great lesson of Katrina is that for six straight days government failed. The city of New Orleans government failed, the state of Louisiana government failed, the government of the United States failed. As a result you saw on television things happen to American that are utterly unacceptable to America. 34 senior citizens drowned in isolation having been abandoned, a man's body laying in the street being covered by television for three days because there was no organized mechanism for picking up dead people, 22,000 people trapped in the Superdome without water while private corporations had trucks full of water going past the front of the Superdome and the government couldn't figure out how to get the trucks to stop. This is literally true. The reason I cite that is I think we are potentially depending on the courage of people like you. We

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

are potentially at as big a turning point as we reached with the Galveston hurricane of 1900. In 1900 a hurricane flattened the city of Galveston, it was a five foot surge of water over the city. The city government couldn't respond. In response to that failure they invented the commission city manager system of government which swept the country. It became one of the opening rounds of the progressive movement. From 1901 to 1915 under Theodore Roosevelt and Woodrow Wilson you have a bipartisan surge of reform. I just want to suggest to you that what you're trying to work around today is an 1880 civil service system created when mail clerks sat high stools using quill pens dipped into open ink wells modernized by a 1935 bureaucracy when manual typewriters worked on carbon paper. And it doesn't work. Now I didn't get to this because of Katrina I got to this because I spent, starting in December, I spent long sections of time involved with Iraq and with the global world on terror and you could just see the system collapsing. You could see it couldn't function. I have designed a model which you can get if you go to healthtransformation.net you'll see a paper we did on the lessons of Katrina. The model is basically simple it says here is a box. The box is the 1880-1935 totally obsolete, utterly impossible model. Over here is a circle and the circle is pretty straightforward and this is one of my core messages to

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

all of you. This is not about the future. This is about adopting the present. UPS, I want to go through a series of these if I get to one you don't know raise your hand. UPS, FedEx, EBay, Google, Amazon, cell phones with cameras, automatic teller machines, Travelocity and Expedia allowing you to control, think what you control, you control the time, the airplane, the seat, the price, the airline 24 hours a day, seven days a week. Because of that level of information going into an open market that access of new inference the price per passenger mile has dropped from 23 cents a passenger mile in 1978 to 12 cents a passenger mile two years ago in constant dollars. It's been enormously painful for the producers. If the airlines could have stopped it they would have. The result is today is Southwest is the largest domestic carrier in the United States and makes money at 12 cents a mile. I'm giving this as background because as you think through where we're going the electronic health record which I would actually re-describe as a personal health knowledge system and I'll tell you in a minute, but the personal health knowledge system is actually a part of the circle. Paper records are inherently a part of the box. I just want to start with that. I have very simple model, I'll be glad for you all to challenge later one which is paper kills. So when you talk about how long we're going to stay with paper records I just need to know how many

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

people you want to kill. We know that paper prescriptions kill people with medication errors. We know that paper records kill people because you end up in strange town on a visit, have a heart attack, go unconsciousness and they can't find your cardiologist. This is literally a case we had of somebody visiting us whose father had that happen on a Saturday and his cardiologist was in very small town in rural Louisiana and Johns Hopkins couldn't find him for 72 hours. So Hopkins is very cautious about what to do in that setting.

I just start with the idea that paper is inherently a part of the failed world of the recent past and that electronics is part of the future. Now it has to be a personal health knowledge system because electronic health records sound like we're simply going to digitize paper. That's not what's going to happen. You will be personally involved in a secure way in a nationwide Framingham project that will be a real time 24-7 longitudinal study of health outcomes that will have somewhere between 250 and 300,000,000 involved in it all of them voluntarily. And this is one of the points I want to make to you all of you, you don't have to mandate things. We've got to get the government out of this notion, we have to invent the perfect system so we can coerce you into it. Just adopt things are better and allow people to voluntarily adopt them. I testified three years ago in front of a house subcommittee that

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

if you really want to speed up getting through the airports, design a system that using an iris scan and a thumbprint, make it available to anybody who voluntarily wants to offer up their iris scan and their thumbprint. Make that system work in less than two minutes, and then have a line that takes an hour and a half for people who are really deeply into personal privacy [laughter]. What will happen is 97% of the country will voluntarily decide after about two trips to the airport they want to be part of the fast system. Everybody on the left who is in ACLU privacy person will not say, "Not me." And everybody who on the right who believes in black helicopters will say, "Not me." And that 3% will be happily queued up. We've got to get to a point where people are allowed to have choices again instead of assuming that some know it all government can magically create the optimum circumstance which leads to a fight so devastating you can't get the legislation through. You've got to think about an electronic personal health system, or a personal health knowledge system, as first of all being voluntary. And then having informed consent. If you prefer to die, that's your prerogative but by the way the likelihood of your dying goes up the following amount if you insist on paper records and that's quantifiable.

Second when you're in a personal health knowledge system we will not only have vastly greater information flow

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

because we will begin to be able to talk about quality because we'll understand, for example, what are the outcomes of women under various circumstances when they have breast cancer. We'll start getting quantitative data on that scale. The people who have done the best job of this are actually the Veterans Administration and Kaiser Permanente they have big databases. They scan the databases. They know a fair amount about relatively small populations. If you're talking between the two of them about 26,000,0000 people. Something like I think more than 10% of the country has an electronic health record. It's just we don't count any of those when we talk about the notion of having electronic health records but increasingly you're seeing institutions adopt health records. Some of them have actually been clever about getting around all the federal health so that Peace Health [misspelled?] in Oregon for example allows doctors to buy into the electronic health record system that Peace Health has, 1,400,000 records by charging \$10.00 a month more than the cost so they're technically not giving it away. So they're not in violation of Stark [misspelled?] and anti-kickback. I just met with a Florida, Ft. Lauderdale hospital that is the loaning the doctors laptop but it's under a deal where if the doctor loses it they've got to pay for it so they're technically not giving them anything of value. It tells you how stupid the government

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

is right now that we are finding clever, creative people working their way around obsolete federal laws.

What we need to do in the short run is modify Stark and anti-kickback legislation so that hospitals could provide interoperable health records for doctors in a format in which they are not allowed to create any monopoly relationship. I think as you long as you cover those two grounds. It cannot involve the doctor having to send patients that hospital and the record has to be interoperable you'll frankly get more than 80% of the doctors online very rapidly. Here's why we have to do something like this. First of all, the sheer drive of modern knowledge. One of the things I stipulate is that there will be four times as much scientific knowledge in the generated in the next quarter century as in the last quarter century. That's probably an understatement but it's a useful working tool. That is you should assume that we will learn enough between now and 2030 that it equal 1905 to 2005. That means in terms of your life if you end up with a particular disease we may literally be discovering the cure that morning. But currently as you know the Institute of Medicine estimates it takes 17 years for doctors to learn a new best practice. So you could be one of the causalities during the delay between learning and doing. You need personal health knowledge system because one we want to integrate you into the exploding world

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

of knowledge. We want to integrate your doctor into a real time 24-7 demand pool continuing medical education. We want you to be able to have access to the same continuing medical education because we absolutely know if you have something which really threatens your life your willingness to study it is greater than your doctor's and you and your family will in fact learn an amazing amount about taking care yourself if it's made available and a form you can understand.

Now in that system we're also going to want to know your DNA. I just had, we had a session on Capitol Hill last week about genetic privacy act and a genetic anti-discrimination act and the reason we want to know your DNA is very basic. If you are a small number of people your DNA indicates that you should not eat high fiber food because it will trigger colon cancer. If you're everybody else you should eat high fiber food because it inhibits colon cancer. I find myself in the position of suggesting to you that before you buy your breakfast cereal you find out what your DNA is. That sounds crazy except it's truer and it's going to be truer as we learn more and more. That can only be handled by expert systems mediating personal information in a stunningly accurate way in real time. I have no doubt that within five or eight years you'll literally go to your Blackberry and you will order up your grocery list for the week and it will be mediated in

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

part by an expert systems that says, "Since you're diabetic and last week you were pretty bad and this is what's happened to your blood sugar and you're still 4 pounds overweight you should order this." I'll go a step further and say I suspect we will modify food stamps to optimize and incentivize [misspelled?] people to be able to buy the food they need because we're faced with an explosion of diabetes and obesity. All this requires personal knowledge.

To carry it a step a further there's a Korean company that now produces a diabetes cell phone, where you can literally prick your blood, put it in the phone, the phone does all the analysis and sends the data to your doctor and sends the data to your own personal health record and the phone can be programmed to call you to remind you to do it. If you haven't sent your blood sugar in within a certain a number of hours you get a phone call that says, "You need to check your blood sugar." This is a real a phone this is not the future.

In that context what you're working on today is really important because I believe we have a national security interest in moving to an electronic health record now. Let me say this as clearly as I can and all you who are in the administration can go back and report this and all of you who are in Capitol Hill can back and report this. We are crazy as a country if we don't set as a national goal every American

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

having an electronic health record by December of next year. We're just utterly insane. There are two classic reasons, Katrina and Avian Flu. In Katrina the 50,000 veterans who had electronic health records in New Orleans did not lose any information because all the information was sent out of the city electronically the day before the hurricane. There's an oncology center in New Orleans which had electronic data and didn't lose a piece of data. But imagine you're halfway through chemotherapy and you were one of the million people whose paper records were destroyed. And you're oncologist is not sure which patient you were. Which is exactly the case, go ask any oncologist to sit down right now off the top of their head and recapture as of this morning where their patients are in chemotherapy. It's impossible, too much data flow, you can't handle it as a person. One, the record of Katrina should be more than enough to convince this administration they will pay so much more in Medicare to reconstruct the paper records. Figure out how many doctor visits, how many lab tests, how many MRIs is it going to take to rebuild the Medicare patient record for the people who were displaced by Katrina. But it's more dangerous, I don't care how often Leavitt goes to Asia, if we don't have serious change we are not going to be ready if Avian Flu crosses over. I think it's relatively unlikely that Avian Flu will cross over, I actually think it's somewhere in the 1-

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

3% range. But I think for planning purposes it out to be considered a one to three possibility because if it does cross over the downside costs are so horrendous they will make Katrina and 9/11 disappear.

Again you have all these arguments, the flu still mutating which is what flues do. You can tell me about whatever your vaccine was yesterday I hope it's close to the vaccine you need in a year, it may not be. The number one characteristic is to know instantaneously when it enters the population. You can't do that off paper records. You can do it if you combine electronic prescribing with electronic health records. I would argue that there's a national, just as Eisenhower built the interstate highways, which you saw used Houston as it turned out the worked exactly as Eisenhower envisioned it. Remember it was originally in 1955 the National Defense Interstate Highway Act and the goal was to evacuate the cities before a nuclear attack. Well it turns out it works reasonably well for hurricanes. But they were dual use systems. He didn't say, "Let's build National Security Highways and we'll let them sit pristine while you drive around on two lane roads." We ought to be approaching electronic health records or personal health knowledge systems as a dual use national security, homeland security issue. We should match that up with a virtual public health system which links

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

together electronically all the different assets we're going to need in case of a real crisis. I cannot say this too strongly, homeland security failed in New Orleans. I have zero reason to believe it will do better with Avian Flu because we're not seeing the scale of change you needed. We're seeing nice meetings with nice public relations with nice expressions of concern. That isn't what you need. And I say this having helped author the homeland security concept and the Hart Rudman Commission which President Clinton actually I created, which I served on when I stepped down. I would urge you as your thinking about this, assume that what you're going to discuss today has a sense of urgency driven by the objective need that the longer we stay with paper the more people we're going to kill, the longer we stay with paper the more money we're going to waste, and the longer we stay with paper the more vulnerable we are either to a major event like a nuclear attack, or a Katrina, or a California earthquake and the more vulnerable to Avian Flu crossing over or some other pandemic including a biological attack. For all of those reasons I think the pressure should be dramatic to get to an electronic health record or a personal health knowledge system.

Having said that, what you're doing then becomes really important because we need to set up now the rules of the game. I'm very clear about this in my own mind. The base record

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

actually belongs to the individual. The hospital can have a copy, the doctor can have a copy, but this is about your personal health and you should personally own it. Second, anybody who enters it should leave a record. You should always know who's had access and that means in a medical emergency the emergency room doc can enter it. It means in a pandemic the nurse can enter it. But they ought to leave a thumbprint or they ought to leave some clear indicator that your record has been entered. Third, I would make it illegal for the insurance company or your employer to use the record without your permission and fourth I personally would make it slander for anyone who is not a public figure to have their record made public. That is if a newspaper printed it, if a blog site put it up, if it showed up on television I would make it an act of slander. I would argue that if you're a public figure, in my case or people who are voluntarily public figures that's a different game. You're at risk because you volunteered but nobody else should be at risk. If we don't set a standard that high you're going to have a significant non-participation rate and a significant participation rate increases the risk to all of us. So I hope that today you'll do the following; 1) figure out how you can communicate the urgency of getting to these kind of systems as rapidly as possible in an interoperable way. 2) Begin to lay out the base of a model bill that could be

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

proposed in the congress this fall that would clearly be the citizens rights in the electronic health record world because we need to have that debate. We need to lay that out and I think it's a very important component. 3) Help think through how we create a permissive instead of a coercive system. We want to incent people and to migrate to the best possible electronic system. We don't want to coerce the unwilling into having to participate a system that they fear and that they deeply don't want to be part of. I think that actually lowers the hurdle to getting this stuff set up and done in the right way. At the Center for Health Transformation we are working to build a 21st century intelligent health system. We think it is a huge change from the system we've inherited in the past. We think it's a system which focuses on the individual, focuses on prevention, wellness, and early detection and focuses on electronic capability replacing and wireless capability replacing paper. We believe it is possible to create a 21st century intelligent health system. We think in the process you'll both save a lot of lives and save a lot of money but we also believe you'll give the country a capability of withstanding a biological event which is we think very, very important in terms of the next 20 or 25 years. I'm delighted to be here. I think that what you're doing today is very, very important, I think it's terrific that the Markle Foundation and

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Roberts Wood Johnson and the Agency for Health Research and Quality have all agree to do this. It's been one of the great pleasures of my career to be able to work with Carolyn Clancy and the folks at AHRQ who I think are doing a tremendous job on very limited resources of trying to leverage the federal behemoth into acting as though it is in the 21st century and I'm actually an optimist. I think we'll get there and if we're lucky we'll get there before we get hit by something really bad. I look forward to seeing your report. I look forward to seeing what the principles would be like. And I'll do all I can both on the hill and in the executive branch to try to convince them that they should really take seriously your deliberations today and that they should try to pass that kind of legislation. Thank you all very, very much. [Applause].

DAVID LANSKY, Ph.D.: Thank you Mr. Speaker. You've been very accommodating to adjust your schedule this morning. We have a couple minutes for questions and the speaker's agreed to a couple so if there are any questions I know there are microphones in the back. Let's just see if we can squeeze in a couple. There's one up front here Patrick.

FEMALE SPEAKER: Thank you very much. Mr. Speaker do we need genetic non-discrimination piece of legislation?

NEWT GINGRICH: Yes, I met last week at a public meeting on Capitol Hill talking about precisely that. The

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Senate's passed a bill twice now by I think virtually unanimous 98 to zero or something and we're trying to get the bill passed in the House and I've pledged to do all I can to convince the business community that they in fact it's in their interest to have that kind of bill passed so hopefully we'll get that done.

FEMALE SPEAKER: Thank you.

FEMALE SPEAKER: Thank you for your speech I came away a lot of questions. But one I have is that given the fact that the government as you said has made such a mess of Katrina and every thing else that you're not proposing a solution for a model bill. Can we trust congress to produce a model bill given that the fact that the privacy bill really has not worked for patients? I guess I'm concerned about that.

NEWT GINGRICH: I never asked anybody to trust Congress [laughter]. I don't think you ever trust people to whom loan power. I think Regan's sense of trust it verifies probably as close as I've ever gotten. But I'm not a Libertarian in the sense that I'm a Federalist and the Federalists actually believed in the Constitution and they believed in a fairly strong, lean, non-bureaucratic but strong government. When you're dealing with large complex systems I don't know any other way to do it except to have baselines that are low. Again I'm not in favor of bureaucracies implementing most of this but I do think setting the standards and setting the

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

patterns does become inevitable an act of law. I would favor working the congress, educating the Congress; I think if you look over time as a country we've been relatively successful. You'd have been very frustrated between about 1880 and 1901 as the industrial world outstripped government but you've been pretty excited between 1901 and 1915 as the government caught up at a fairly rapid pace and actually created the institutions that we think of as the modern government which are almost all a product of that period then expanded upon later one. I would say the same thing here. I think we're entering a new world. It's a new world that you see faster in business and in the private sector than you see in government. Government will have to catch up and your work talking to a congressman saying this works, this doesn't is important. Think of the congressional in a way as a cybernetic system, it is in fact over time a learning institution. One of the ways that they learn frankly is elections and raising noise and people visiting them and not being able to avoid your questions at town hall meetings. All of those different things actually work over time. It's just very frustrating on any given day but it's actually been a more self modernizing system than any other one I know of on the planet right now.

MALE SPEAKER: A tool which would tremendously leverage our ability to have an interoperable national medical record on

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

a short term basis would be the use of personal identifier based on the Social Security number. Do you think that the congress and the public would be accepting of this?

NEWT GINGRICH: I think if you make the personal identifier optional and not mandatory it gets radically easier to happen. I think personally, again I'm not an expert on this stuff, but my sense is intuitively as a historian you're going to end up with an identifier if the system is going to work. Now those of you who are absolutely committed and some of you if you want you can write me, I'm Newt@newt.org if you strongly disagree with this, those of you who are totally committed to having a system with no identifier are going to try to be a set of rubrics which are an identifier but that's what they are. If you say, "The way we're going to do this is you'll never have a number but by the way there'll be 73 things that will magically appear in cyber space and they will collectively be you." That's an identifier. We're back to the same problem. My attitude is, this is why I said make it permissive not coercive. If you said tomorrow morning, "You can have an identifier it can be your Social Security number." I think you would ultimately have an iris scan and a thumbprint because you want to find some mechanism that's fairly tough to counterfeit my guess that 80% of the country would get to it in a year, 95% would get to it in five years and if you had a pandemic you'd

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

have virtually a 100% of the country getting to it, because they decide, okay having an identity number is less dangerous than getting killed. It's that straightforward. Anyway what you're doing is very important. This is precisely how this country talks to itself. What you will come out of here with will in fact matter and I think you are focused on some key questions that are central to how we as a free society modernize while protecting liberty and I think it's very, very, important and I'm delighted that these three institutions have come together to host this kind of event. Thank you again.

[Applause]

DAVID LANSKY, Ph.D.: Thank you Mr. Speaker that was wonderful. Hopefully we're all charged up now for a break. You have a chance to take about 15 minutes in the hall there should be some refreshments out there and we'll re-gather in here in 15. Thank you.

[END RECORDING]

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.