

**Connecting Americans to Their Health Care:
Empowered Consumers, Personal Health Records, and
Emerging Technologies:
Breakout Session - Think Nationally: Consumer Principles and
Policy Implications
October 11, 2005**

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[START RECORDING]

DAVID LANSKY, Ph.D.: I think that a lot of you were comfortable wherever you happened to be earlier but now that we are a smaller group if you want to move up toward the front and have the chance of a little bit more dialogue, please do. On the screens, we will have one or two slides so if you want to be in just the right vector where you can see the screen, that is not a bad idea too. Feel free to reposition yourselves for closer access in this big room. I would assume you all are happy where you are. Speaker encouraged us to advise patient choice but you have that choice.

This panel we are going to talk about those principles that were raised this morning. Really, this is a starting point as a framework for discussion. What I want to do is first just remind you what some of those principles, where they came from, just very briefly. Then John Rother from AARP will talk a bit about why organizations like his have taken an interest in this field and what they are seeing. Then we will ask a number of questions for open discussion for our panel. So, let me walk through these principles and introduce everybody you have here.

The slide now shows, and you have this in your folder from this morning on a one-pager. We actually wrote a prologue to these principles after we realized that there were some contextual things and not everyone understood commonly and we

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should even a partial of the principles later so having new information to people in timely ways is just critical. The benefits are of course reducing errors and improving the quality of care but these networks are available today, they are emerging today. I think what the consumer groups who crafted these principles felt was it was very important to state today what are the guidelines within which all of these developments should be happening. To our best ability, sitting here today, can we say that there are some principles that all the developments, even the ones that are most ambitious that Eric talked about over lunch, one of the cornerstone principles of American culture and values that need to be articulated, that any developer or implementator whether it is Cleveland Clinic or InTel or the VA, anybody working in this space is alerted and sensitive to some principles.

Now articulating those principles as these groups have done is one thing. Then we have the silhouette question. How do those principles become incorporated in technology and policy and law and practice and behavior and attitudes between people? That is what we want to try to grapple with today.

The seven principles that the groups have identified as Zoie [misspelled?] mentioned earlier this morning, people, you and I should be able to access our health and medical data conveniently and affordably. People should be able to decide

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who can see their information and when it is shared. They should be able to refuse to have their information shared if they so choose. We heard that in the last panel, Marie talked about that some. People should be able to designate someone else, such as a loved one to have access to and exercise control over the information. People should understand what is happening with your own information, how it is being used. Individuals should be able to review who has had access to their personal health data. We call this the audit concept. The sixth one, all of these exchanges that are being built and designed now should protect the integrity of the information, the security of it, the private treatment of it and the confidentiality of it. And the last point is around oversight, that the oversight of all of these structures should be transparent, independent, accountable to the public and the consumers and their representatives should themselves be involved in the oversight process of these new networks.

Those are the seven principles we have articulated. Our panel this afternoon starting closest to me is John Rother who is legislative and policy director of the AARP. John was a consultant staffer a couple years ago for Jacob Jabets, if I remember right, and Senator Hines as well. So, he is joined now by four of his colleagues in that role.

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Closest to John is Kathleen Weldon, who works with the House Ways and Means Committee. Next to her is Andrea Palm, who works for Senator Hilary Clinton. Next to her is Jane Loewenson, who until the end of last year, the beginning of this year, worked for Senator Tom DASHAL and next to Jane is Dean Rosen, who until a couple months ago worked for Senator Frist.

We have an extremely experienced and distinguished group of people who hopefully will probe the inner policy making machine. John we start with you if you would like to say a little bit about where your group is at. I should just by the way; this is a set of organizations that apart from the personal health technology counsel, which you have in your packet, these individual organizations have also endorsed those principles.

JOHN ROTHER: Thank you, David. And David omitted one of my credentials which was I was a founding board member of the Foundation for Accountability that David headed up and really kind of paved the way for much of the movement for accountability and use of information as a way of improving health care quality.

So today, it is kind of a time to talk about motherhood and apple pie. I mean these are seven principles were overwhelmingly endorsed by the American public, you could

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wonder what could be controversial that individuals should be able to access their health and medical data conveniently and affordably. Or that they should be able to decide and authorize when data should be shared and with whom. Or they should be able to designate someone else when they are incapacitated, they should know when somebody else is having access to their data. They should be able to review, which entities have looked at their data, that their privacy and confidentiality should be protected by formal protections for electronic data exchanges. And those independent bodies accountable to the public should oversee the system.

Who here would disagree with any of those? I think that the fact that they are there is very helpful. I suspect that what we are going to be talking about today is not so much whether these are the right or appropriate principles but rather how should they be implemented. I think that is an important discussion to have.

AARP is very interested in these for several fairly obvious reasons. One, as this entire conference has demonstrated health information can and does improve the quality of health decision making, not only by the physician but also by the patient. Designing personal health records so that they support appropriate decisions is the key to achieving that goal. We also know that they can reduce costs. But I think

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what really attracts patients is the idea of control and being more of a partner in their own health care. Certainly our leadership those people are on board, who are volunteer leaders who are very highly motivated in this whole health care reform arena really believe strongly that patients should be partners in decision-making about their care and that their own decisions have an impact on that care. It is not just about the providers. But lacking appropriate information, lacking access to their own information is hard to operationalize that.

So I think our interest in this issue is pretty straightforward. I think that what a kind of interesting question is if these are obvious and consensus standards then why aren't we there. What is blocking us from implementing these standards? And there I think that is probably going to be the focus of the discussion today. Who is responsible for making this happen? This is something that should happen as a matter of Congressional legislation. This is something that should happen in terms of plans taking the initiative. This is something that should happen as some kind of a collaborative in the private sector, assuming you can overcome the various anti-trust kinds of concerns. Or is this something that will inevitably emerge as other standards emerge when somebody invents the color apt to that destroys the competition and there you are left with one approach that will be dominant in

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the marketplace. How long will that take and how expensive will it be?

So I think there is plenty to talk about. And maybe even some controversy in terms of how we get implementation of these seven principles. Let me just say even though the document itself says it, these are not just window dressing. These are not just nice. These are necessary. If we are going to have a personal health record or a health IT infrastructure that is worthy of the confidence and participation of patients and consumers then trust is the key word that must be there. And trust around health information is got to be earned. It is not assumed so trust is what flows out of adherence and systems that implement these seven principles. So, I think that from our point of view creating a national health information infrastructure with secure accounts, patient permission, and patient control. Proxy access, this is all critical. And it is founded on what the speaker said earlier today. This information legally belongs to the patient. This information is so personal to the patient that it has to be clarified as belonging to them and there has to be consequences for violations of that philosophy. So, that clearly is going to take legislation. Some kind of bill of rights or some kind of legal protection for such sensitive information. But I think beyond that, it is kind of an open question. Should Congress

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try to implement this directly or should we let a thousand flowers bloom and see what emerges out of the marketplace. I look forward to some of the comments of my fellow panelists on that issue. Thank you.

DAVID LANSKY, Ph.D.: Dean Rosen, I will start with you. Eric's slide and over the lunch hour, he pointed out that the first layer of all of this is having some kind of a national electronic health information infrastructure where the data sits in laboratories and pharmacies and providers offices is available first electronically and then it can be feed back into the patient controlled tools. We did the survey that was on in our packets today and 72-percent of people in the public said they would like to see a national health information network come into place that provides for them to control their information. And based on a set of principles the kind that John just summarized, given such a high percentage of American public wanting to see that come into being, what is the barrier, why isn't it happening. We have been sitting through the legislative process now for a long time, what can or should Congress do to accelerate that layer of infrastructure being created?

DEAN ROSEN: I think one, you know, every thing in Congress just takes a while. That is way things generally work even good ideas. I think that I am kind of interested in the

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prospective of my colleagues here but I think that really until the last several months, it wasn't clear to I think the policy makers at least at the national level what the right set of steps were that could be taken to try to facilitate the development of this kind of infrastructure with appropriate security protections and privacy protections and access and other things. I think what is surprising to me actually looking at a whole range of other health care issues where things tend to be in my experience even more controversial than almost any other issue that Congress has before it be it energy policy, or transportation or anything else, is once I think those key barriers to adoption became clear, what is surprising to me actually, is the amount of consensus across the politicians spectrum on what those steps are. So you see partisan bills emerging in the house and the Senate with names like you know Frist and Clinton on them and names Stab Allen, Snow on them. You see bills in the house as well and I as sure Kathleen will talk about it that have principles that are very, very similar and I think you know now that there is an emerging consensus about those steps of how to set standard reduce barriers to adoption. I think the differences have to do more with the matter of degree around how you do that and maybe in particular how you fund things. But there is wide consensus that Congress has and event this administration has taken steps, has a

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standard setting role to play here with appropriate private sector involvement to allow the facilitation that there is a role in terms of some funding and encouragement in people to use these standards in an integrated way that they are a number of these steps that you see sort of weaving through. So I think at this point it is just a matter of you know can you get things sort of the through the legislative process but I think up until now there really wasn't that degree of unanimity. It is less kind of left right clash Republicans democratic clash or a sort of philosophical clash, I think now it is just, at least from my opinion trying move through the legislative process and finally I would say you know also have an administration that has been relatively aggressive in using the tools at their disposal and the current law in trying to push things forward so they set up this health information collaborative to try to develop standard and they have done some things. So Congress is sort of feeling its way along too I think in trying to figure out well how much can the administration do, how much can we do. Finally because I always been sort of a private sector guy too and we are really not like England in my opinion in the sense that our country is much larger, more pluralistic, we have got many, many more pairs involved for better or for worse. But the fact is that it is harder to do this in one fatal swop and just do it by feel.

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You have got to do it in a way that builds on what works and brings people together. So I think it is just a matter of time and it is important that you know this organization and others continue to articulate it. But that is my sense. I would be interested in what other folks.

DAVID LANSKY, Ph.D.: Would you say that democratic leadership sees it the same way as deemed as protective?

JANE LOEWENSON: I am not speaking from the democratic leadership anymore. I am actually now at the National Partnership for Women and Families, which has endorsed these principles. But I think it is an interesting issue having worked in the democratic leadership for a number of years and worked on a number of polarizing issues. It really is remarkable how much partisanship there is on this issue.

There are very parallel things going on with the administration and the development of standards and a move towards an inoperable system. What I think will have to come along is the confidence by consumers that their health information will be safe and that they see quite clearly what the benefits of these kind of technologies are. There have been great examples here today but the survey data that I seen and that is probably many of you have seen show that almost half of the public worries significantly about the privacy of their information and that number also think that the potential risks

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outweigh the benefits of the technology. So in all of these efforts and a lot is less in both the legislation and in the efforts of the administration is undertaking is left to this public private partnership to develop standards and in that context it is going to be very important that these issues of privacy, the issues of consumer engagement are addressed right at the very front of this effort because ultimately if you want to see the wide spread adoption which hasn't happened the public generally has to have confidence in the system.

DAVID LANSKY, Ph.D.: A comment as well and how you see things [inaudible]

KATHLEEN WELDON: I guess I would have to generally agree with Dean. I don't see it as a matter of if but when and I think we continue to make progress. I think some of it is that while parts of the private sector are ready to go and raring to go we continue to sort of bring other partners in this adventure up to speed and including consumer groups and others who really have an important voice and important seat at the table but it is sort of been an educational effort. You know there are number of leaders in Congress but you know it took a while to get it to the point where we got an unanimous vote out of the health committee. You know it is continuing to build that momentum, continuing to have all the voices that we need at the table to craft a piece of legislation that

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continues to have the unanimity and the partisan support that we currently have but really to me, it's not an if it is a when. I think the when is sooner rather than later. We keep our fingers crossed so I mean I think that we just continue to make good progress and we continue to have organizations like this and the consumer groups continue to bring their members up to speed, to figure out what their stake in the game is, what is really important from that prospective and to continue to feed that to those of us who are struggling with some issues just like you are today.

ANDREA PALM: It doesn't seem the way it is developing that you have asked what sort of needs to happen or should Congress do something. I think in this whole area we are struggling and that we are trying to move on three separate fronts all at once. We are trying to develop more sophisticated health IT systems. This is an early generation now that can be used for decision support and used to build personal health records and used for a whole range of things. And those are being developed but they still need to be refined. We are trying to encourage adoption by providers of those same systems. And I don't think we can underestimate the impact that that has that requires a lot of changes in terms of the way providers have operated in the past, the way that physicians have operated in the past. I am sure over the last several

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years those of you who have gone to your doctor and suddenly your doctor has a computer in the examining room and that is new and it changes the way that their work flows. Those changes are important. Then once we have those things in place, we also are working on conductivity to make sure that as we are building these systems and getting providers to adopt them, we are ensuring that they can talk to each other because those are the real benefits of an electronic health care system. It is not simply digitizing a paper world but a allowing information to be communicated between providers. So I think the complexity of this issue is that we are trying to do those three things simultaneously and we need to move along on all three of them at same time. The role of Congress I think who had been struggling to figure out what the role is because the private sector is moving in some regard because the administration is able to do things that administratively like they did last week issuing the proposed regulations on some STARK exceptions. So, we are trying to figure out at least from the prospective of Ms. Johnson who has been developing a bill, where can Congress act or where does Congress need to get regulation or barriers to adoption out of the way and how can we intervene selectively so that we are creating an environment in which all of these things can happen. I think in all this there is a huge role for the consumer, I think but the consumer needs to be involved in

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encouraging their providers to adopt this technology. I think in many cases consumers don't even know what to expect from a health care experience that has got technology, to go to a doctors office and not have to repeat your medical history for the tenth year in a row, to not to have them make a photocopy of your health insurance card for the tenth time. I just looked at my recently digitized scanned health record at my physician's office and in the file they have got PDS of ten different copies of my insurance card so I don't know how valuable that is. So the consumer I think certainly do worry about confidentiality of information but the consumer, I also think has a role to play in pulling this through the system and in asking their providers to sort of move into the next phase and move out of the world of paper records.

DAVID LANSKY, Ph.D.: Let me ask you a question though. Eric in his last slides again, showed us the international comparison that globally we are behind on a number of dimensions he thinks is important. Is Congress doing enough in the proposals that we just heard summarized briefly that address to some degree that pay for performance [inaudible] to some degree of the STARK situation and to some degree the IT loans and grants and so on and standard development. Is that the right level of activity you think Congress should be operating at for the next couple of years.

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JOHN ROTHER: No, I think it is maybe my job to be a devil's advocate here but I don't think it is that hard. I think that talking to my doctor he participates with the IT with Atnea, the Sigma and with the Blues. They each have separate systems. How is he suppose to invest in this. Then I ask him well what protections do I have as an individual. They are not clarified. It seems to me that there is some pretty serious barriers here to moving forward in the real world that aren't going to be that easy to resolve unless Congress takes some action or unless industry voluntarily comes together with consumers and with physicians and others to reach some protocols, some agreements on this. But I just don't see it inevitably happening because when I talk to my physician, he kind of throws up his hands and says, you know this is going to cost a lot of money and what system should I go with. He is not getting a clear signal and I as a patient am not getting a clear reassurance either that whatever information is there that can be shared that I want to be shared would be protected. So I do think there is more to be done, I think the health IT bill now in front of the Congress is certainly an important first step but it is by no means sufficient in my mind.

DAVID LANSKY, Ph.D.: Let's move to the personal health care record the piece of legislation that we have had today and how that builds upon this last discussion. There has been a

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belief I guess that we had to go through some steps. We had to get some standards and then get the doctors and hospitals to adopt IT and then have interoperability among all those partners and then the patient can get access to that information. That seems like that might be a slow road. It is a long time coming and there is not a lot of money as John just suggested to help the doctor acquire the technology. Is there a separate road or a parallel road by which Congress in particular could accelerate personal health records as a strategy without necessarily waiting for each of those building blocks to be in place? Does Congress have any role on the PHR side of this? We will start at end if anyone wants to comment.

Again, I mentioned in our survey that we released phrases of sixty nine percent of the public thought they should be having access to their personal health care record today.

DEAN ROSEN: I mean personally and I didn't see all of Eric's presentation but I think personally you know my sense is that it is not going to happen by sort of legislative fiat in as an organized way. It almost never does. One of the interesting discussions that I listened to was as part of Medicare bill that passed in 2003, Congress set up this commission on interoperability and one of the participants in that was from a phone company, a cell phone company and I thought the early discussions was sort of interesting in that

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it really took that person who is sort of outside of the Washington health policy, you know sort of intelligence here what you normally think about as people who pay attention to how we legislate or regulate on these issues. He said you know when we try to establish cell phone conductivity it wasn't like the government said let's put up these towers and let's invest in this and let's place them here. What we did was we basically gave consumers access to phones. And it was the consumers because of the convenience of being able to be at the grocery store and pick up the phone and call home or walk you home at night or being able to connect from anywhere and sort of share an experience that drove the tremendous expansion. It was those consumers wanting to talk to their families or other consumers that in fact decided where those things were placed. So the point is I don't think - I believe that Congress does have a role because just as John said the physicians are in a difficult place. Not only do they have health plans to choose from but a lot of the systems now are based in hospitals so you might have a physician practice where the physicians are practicing at two or three different hospitals and all them have proprietary records and they don't have any way to compare their patients that they are treating across those different hospitals and they are not going to invest in systems. Its like you know the old beta discussions, unless they know that this

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is going – so I think the Congress and the government do have a role in standard setting and in some other areas but I think that the interesting thing, back to this discussion that I took from it, is that I think consumers have a role to that we don't exactly know where they are going to drive it but if they are given the tools and if they see some of the benefits, they clearly see some of the barriers in terms of privacy and those are things that have to be dealt with. But I think there are tremendous benefits that they see too that Kathleen alluded to as well which is you don't have to fill out the forms for the fifteenth or second time. You don't have to remember when you are in a state of trauma or when you are with a family member what the medications are so you can spin back, the physician has those at his fingertips. I think once consumers start to see the advantage of that, I think that will help drive it too. So, I see these things the long way saying sort of happening a little bit stimulationsly that if you can take it – Washington has a role, business has a role and consumers have a role. It is not sort of an either or.

JANE LOEWENSON: I want to echo what Dean said that there are a number of things that we have to move on. There are number of people who are playing a role. And one prospective I think we can look at this. We worry – you know consumers are obviously concerned about the confidentiality of their

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information but that always has to be weighted with the potential benefits. And I think that is what consumers need to understand and if you look - an example of this is all the evacuees from hurricane Katrina. And in fact that all of these people were very suddenly dislocated, sent across state lines, medical records were lost. Paper records were lost, I think. I think a number of companies engaged to get prescription information together for those individuals and get that up online. But I think a lot of people who were being triaged out of New Orleans and sent to Texas and being treated by physicians at that point might have made their choices a little bit differently in terms of I would like the physician who is treating you right now to know what medications I am on and what my medical history is. That is a clear sign of the benefit of having a interoperable electronic health care system that needs to be considered when we are talking about privacy, when we are talking about confidentiality. I think what Dean said is really important. That the consumer needs to see the benefit of this. A lot of us will tolerate far less technology in a physician office visit than we tolerate in walking into a bookstore. And that we need to get consumers involved in understanding that there are easier ways to communicate with your physician than making five phone calls. Or an easier way to get referral than having someone fax a prescription back and

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forth and that I think is where the consumer can really be involved in transforming how we think about how we interact with the medical.

ANDREA PALM: I agree with that completely and I think that the benefits do have to be discuss and emphasized and there needs to be public education. Speaker Gringrich was talking this morning, not only about Katrina, but also about the potential for Anidean flu and the importance of a system of electronic records for that. I say though there are other risks that need to be addressed and I am not saying that we shouldn't go forward with this because I think the benefits are so significant but if someone's information, if their personal health information is breached there is the potential for discrimination on health insurance. There is potential that they are discriminated against in their access to credit. They can experience identity theft. And there has been so much in the news over the past year regarding breaches of information that if you want to get to a wide spread adoption of health records, a lot of these issues needs to be addressed. And it needs to be done simultaneously. And I don't think that how daunting that sounds should stop anyone from, you know from moving forward on this front. But I don't think those issues can be ignored if this personal health records are going to be

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used broadly not just by those who really see that immediate benefits of it.

JOHN ROTHER: I just wanted to say something about consumer education. I think that consumers certainly have a role to play and an important one at the collective level as well as at the personal level. But I also think that it is awkward to try to educate people about something that they don't have access to today. Usually when people hear about something and they want to know what they can do about it right away. And if a personal health record is not available then as a Medicare patient, then what is it that we want them to do and what is the message then as an educator in public that asks your member of Congress to vote for something or is it to push your plan to propagate or to go to your doctor and urge him to make the investment. What is it that we want consumers to do if there is not something for them to participate in right away? So, I think that is a real challenge and the speaker this morning gives the image why it was great image of the easy pass tolling where you see all those people zipping by you while you are line and then you get it. And I think that is kind of what we need here. We need the word of mouth from trusted people, family, neighbors, people in your community. I got this great thing that allows me to make appointments online, to refill my prescriptions online to tell me when it is I need to see a

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doctor. That is really going to be what is effective in terms of getting consumers to get aboard. So, it is trick in an egg kind of problem. You have to have the system in place for some to really build that stronger sense of support. Medicare I think is the name of the game. I think that it is great that we have the VA. It is out there; it shows that it can be done. But it is a closed system. Kaiser Permanente is a closed system. Gyseringter [misspelled?] is a closed system. It is great that we have got these examples but until we get Medicare into the game, doctors aren't going to know what system they should use and most of the patients who could really benefit from this aren't going to have access to it a personal health record system.

JANE LOEWENSON: Just one piggyback and then I think that the other thing that we know is that the benefits of health IT while they exist through a personal health record and there will be consumers who help drive this and shape this. That piece is important but the largest benefit, the greatest percentage of the benefit is out of an inoperatable health IT infrastructure were there is an exchange of data, where it is integrated, where all your pieces are talking to each other and say well like I don't want to down play the role of the consumer and their ability to help drive this, I think that we should be clear that the savings and the efficiency and the

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improvements in quality are much more realized in an arena where you have the standard setting processes where you have the fully integrated framework and where you have married and integrated quality measures and those kind of performance indicators. So I just sort of want to emphasize that the infrastructure piece we start talking about should we propagate a bunch of personal health care records or does Congress have a role to play in that. I think that we certainly do but I think that the most important thing that we can do is to build a framework, as I said an infrastructure that helps the market, helps John, the doctors he is talking about who participated in a bunch of plans know that when they purchase something it has got that standard seal of approval and certification so that they can live in a world where they can fully realize the whole benefit of it and in turn will help IT infrastructure.

KATHLEEN WELDON: I think what is important or not is we are back to the issue of increasing adoption on providers. Because I think right now there are tools available online where you can put up your health information or immunizations and allergies and some basic information up on an Internet based system. But that is not as helpful if when you go to the doctor some of that information isn't automatically populated with what the doctors. So we have to increase adoption among consumers getting comfortable with the tools that are available

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to them to be able to better manage their own health care and interact with their doctors but also we have to increase adoption among providers to keep that record constantly updated. So there had got to be that connection. And I agree with Dean that people want to make sure that their information is safe and secure and we need to make sure that they are appropriate sanctions for violations. I think one thing right now that is maybe under estimated is people may have a false sense of security about how safe their information is with paper records. Right now, we have no idea who is looking at your paper records. And it a digital age while it is on paper, it can be fairly easily be scanned and disseminated just as readily as an electronic records. So, we need to look at sanctions for those types of violations. I think right now the lack of security of paper records and the fact that you have no idea who has looked at them whereas at least in the electronic world if there is a breach, you can track down who was involved in that which is a huge step forward, I think in the confidentiality of information. So I think it is in educating folks we need to understand that the current system we are under isn't as secure as people might like to think it is. All of us probably want -

DAVID LANSKY, Ph.D.: Let me answer your question I guess on the PHR front. Can you imagine any role for Congress

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in sensitizing consumer adoption of personal health records so there is more of the consumer pull, tax credit, an incentive to physicians as part of CMS pay for performance that if your doctor offers you an access to the EMR, the doctor gets an additional incentive or any other ways around - we are fairly free in talking about incentivizing doctors to adopt IT. We haven't really talked about incentivizing consumers and patients to adopt IT. Could Congress play that role or should it?

JOHN ROTHER: I am not sure I see the need of - because I think the benefits will be self evident to patients once they hear about it. And once they have the opportunity to try it. I don't really see a need for a financial incentive. On the other hand, for physicians, you know for many years we have rewarded physicians of Medicare who submit their claims electronically. That was a worthwhile incentive and it served the system well. And it sped up payment to the physician so they got something out of it. I don't see why we couldn't adopt a similar rationale here if we are convinced that being part of a health IT performance measuring system is good for Medicare, good for the quality of care, good for patients, why we couldn't have incentives there to differentiate payment based on who participates in that.

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DAVID LANSKY, Ph.D.: Anybody else wants to talk about that.

JANE LOEWENSON: I agree with John. I don't know that there is in terms of incentatizing consumers, I think that will come as you increase adoption and people realize that it is much easier to communicate with your doctor and get your key care information in one place as opposed to running around looking for the last record of immunizations or what I hear from my friends who are moms all the time, every time your kid wants to go to camp you have to track down what immunizations are. So I think there are enough incentiatives out there. The tools are there. In terms of incentiatives for physicians I think one of the things Ms. Johnson is focused is looking at some structural barriers that exists. And everyone talks about the fact the adopting health IT by physicians isn't simply a financial issue. It's a workflow issue. It's a patterns of practice issue. So in taking a look at some of the structural barriers that may exist and some of the issues in terms of simplifying the technology that exists out there and making it more palatable to physicians. I think it is important to look at getting some of those out of the way with the changes to start because the administration has done to free up some private sources of funding, getting the standard systems put in place that you have got a public private partnership for

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standards and certification so that if people invest in systems they know that they do certain things and are going to be interoperable to the extent that those standard have been developed. That we make some of those structural changes before we start putting funding out there to see if some of the private sectors versus the funds will be ready to invest. I think that is an important distinction.

DAVID LANSKY, Ph.D.: Anyone else want to speak to that?

KATHLEEN WELDON: It is hard to picture exactly what financial incentiatives - I mean I guess it could be pay for performance but I think the bill is under consideration in the Senate right now starts to take steps toward looking at how an individual can access their record and requiring the AHIC to look at the manner in which individuals can access their own information. Now I suppose that could be something that would be integrated into the standards then ultimately the federal government has to comply with but in terms of the direct incentiative to individuals - it is hard to imagine that happening.

DEAN ROSEN: I was just going to say, just to add one thing that one of the things that I worked on before I left the Hill was maybe about a year ago Senator Frist wrote this article in the New England Journal of Medicine and what we did

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in and it was hard to sort of imagine what would the health care system might look like ten years from now if we took a number of policy steps including, you know, incentatizing the adoption of health records. And it just occurred to me while I don't think you know any of the legislative efforts now are looking at and kind of direct incentiatives to individuals or bribes to individuals to participate in this system. You know one of the things that article sort of positive was you know you might get to place where at the endpoint where there is a direct financial benefit for the consumer to participate that in the case of this patient that we fictionalized you know he was much better able to manage in this case his own hypertension over time and other chronic illnesses to the extent that when he eventually had to go use the hospital because he had sort of stuck to this performance plan in a sense that he worked on with his own physician and again this is all hypothetical but he paid a lower hospital deductible or something like that. I could see those kinds of financial incentiatives being built in by the private participants but I think you need of the have a system where you set up this basic platform. And I - the only other thing I want to underscore is I think we have these pockets of information now where as John has described these closed systems are using it but consumers broadly just kind of before we leave the consumers, she don't

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really understand – most consumers don't really understand because they haven't in this other world. I had the experience a couple of months ago of taking my grandmother to the emergency room and she had just been in the same hospital a month before that and she had to sit there having gone through this sort of going through with the intake nurse. You think boy, there is really very little issue of security here. It is the same facility and then literally a couple of months after that I took my dog to the veterinarian and I don't know what it is, maybe if you know government or health plans or something get out of the way things are better. But I took – my dog's picture was scanned, all of her records, she had to go to the emergency room and within like five minutes they had e-mailed my dog's records to this emergency room. They knew exactly the date was that she went in and what medications. I said, you know, geez I wish would have had my grandmother with me at the vet visit and maybe she should have seen the advantage of not having to kind of repeat in the emergency room the medications she was on, when the last time she visited. I think the more these systems get used by physicians and it is happening a lot in medical schools, the more that patients see even in these closed systems some of the benefits, I think and we can help a platform or the policy makers can help build platform. The more consumers are going to be an active participant in demanding

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not only that level of facilitation of sharing of information but also I think that demanding, not only through the legislative process but also through the marketplace so degree of security and privacy.

DAVID LANSKY, Ph.D.: Let me ask you a question. The HIPPA question. And several of the principles that was up here. Raise issues about privacy and control and HIPPA was obviously originally conceived and drafted in error before we were talking much electronic networks and digital data and interoperateably and personal health records. I think lots of types you have both because of political reasons but as you all have had to look closely at and live through it what is the appropriate role for any national legislation to extend, modify, in parallel address the emerging environment, network information environment that we address the public's desire to have access to the records, audit their records, audit other people's access to their records, exercise control over who sees what in this electronic environment. What do you think should be done next if anything legislatively?

JANE LOEWENSON: I think you make an excellent point that HIPPA was propropogated before we were talking electronic records and before you could e-mail records from California to Connecticut in an instant. I think HIPPA initially propropogated as a floor and we have had a whole patchwork of state laws

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built on top of that floor and the way the regulations have been interpreted right now providers have to – as long as it is not impossible to comply with both state and federal law, they got to comply with all state and federal laws that are involved in there that they run across in terms of transmitting information. In some cases, those state laws are more stringent. In some cases, they are not necessarily more stringent, they are simply different. I think having a patchwork of all these various laws in an era in which we want to try to build information systems and transmit information securely, possibly across state lines, [inaudible] the adopted state of Tennessee I think borders eight other states. We have got huge cross-bordered patterns of care in which people in certain cities may cross borders to get care. That we need to start thinking about having some uniform standards so that it is easier for us to know what the privacy and confidentiality scheme is and in order to build systems in which information can be more readily shared. So I think an important thing that we are discussing is how do we get to a uniform system so that people know the terms in which and the areas in which they are dealing?

The other thing I just want to make a quick distinction between is the notion of privacy of information meaning this is my information and no one can see it versus maintaining the

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confidentiality of patient information within this sphere of individuals who need to have access to it, in order to get that individual the care that they need. Privacy to me speaks of I control this and no one sees it. If we keep the information confidential with the appropriate sanctions for breach of that confidentiality. We need to still ensure that the people who are trying to treat a patient have the information they need to so appropriately. So I think in the HIPPA realm those two notions of uniformity of laws nationwide so that we can transmit information more effectively and thinking about confidentiality are important as we start to look at this.

KATHLEEN WELDON: There is a contract that was just awarded last week to look at the variability in state laws and different business practices. And to identify where those might impede an interoperateable health system. While that maybe one part of advancing, you know, advancing the ultimate outcome of national electronic health network, there is also the piece that is what does HIPPA not cover. I think there needs to be a comparable to that contract, a comparable effort to look at where they are holding HIPPA and how HIPPA in this electronic environment may be different. I am not an expert in HIPPA but as I have been told there are entities that will participate in a national health information network that are not covered entities under HIPPA, for example, companies that develop

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personal health records. So I think there has to be, you know side by side an effort to look at what is the variation. A very careful discussion about whether or not those variations really do provide impediments and what are the trade offs if you either take away some protections that people already have or you create a more protective environment for everyone. There has to be a very open discussion about all the risks and benefits involved.

DEAN ROSEN: [inaudible] related to HIPPA, one is whether the standards that were developed in 1999 or 2000 or whatever it was, are applicable five or six years later. In fact, there regulations that there started to be develop in '97 or '98. Whether almost a decade later they are still applicable in this increasingly, you know, digitized information age where state borders and national borders in Anidean flu and other examples, you know matter less and less. The other issue, the second part of it is the one that Kathleen raised which is you know what role to various state privacy protections relative to electronic transmission have as we are trying to build this as well. Are they - do those knock down barriers because they give patients greater comfort, that you know heck if I am in California I am more secure or they do in fact raise barriers because it is impossible to comply with the fifty state system. I think both of those are valid questions. In all the

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legislation, where I should say all most of the legislation that is out there, in fact the secretary in a regulatory means in sort of starting to address this issue I think. You know Andrea and I were working on the Frist and Clinton Bill, it took one approach which was we said here is some money for the states to try to find ways to collaborate and here is some money to study what the impact would be essentially the kind of contract that Jane talked about. But I think they are valid arguments. The one thing I want to remind people of in terms of HIPPA trivia and unfortunately I have worked on that legislation as well back in '96 when I was with Senator Castlebamb [misspelled?] was that the reason - there is no HIPPA privacy law. It is all done by regulation. The privacy rules under federal rule and HIPPA is one line basically and it says that if Congress cant come up with legislation after a couple of years the secretary basically gets to do whatever he or she wants to do. And in fact it was one of the last regulations that the Clinton administration propagated because guess what, three years later Congress couldn't figure what to do. So my only point is I think if we wait around for Congress to sort of solve this and figure out exactly the issue to be covered in what form, we are going to delay even more the implementation so we have to look at these things simultaneously and that is why I actually think that the

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approach that the Frist and Clinton Bill and some of these other things adopt is a good thing, which is look we recognize it is a problem but we need to simultaneously be building the system as well as looking at the applicability of appropriate privacy protections or else you are never ever going to get there.

DAVID LANSKY, Ph.D.: If there are some questions? Any questions in the room that we can answer [inaudible]

FEMALE SPEAKER: It seems to me if you ask people consumers what they would like to see in a patient or in a consumer bill of rights where their financial information, it would look very much like that. And we all know that we don't live in that environment. I think that not only are people concerned as consumers about the immediate horizon with respect to privacy and confidentiality and that sort of thing but much more so what happens when you have a data base full of information about people and business interests or whoever is interest in clarifying that information so that you end up with the health care equivalent of a credit score, access once a year if you pay twenty five dollars to your - for your record. Lots of things like that that could be used to segment people for profit interest and that sort of thing. and are any of you thinking about you know because I think all of us see how beneficial the financial platform is as well. We can access

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money from all over the world. You know it is - you can walk in to a creditor and get an answer in minutes. So there is great benefit that we see and certainly in the health care industry even much more so. But there are these other things where people - you know smokers already paying more, when our overweight people going to pay more, and that sort of thing that I think are concerns for consumers about this information would get used, would get segmented and that sort of thing.

DEAN ROSEN: I guess the one thing I would say, I think it is a key point, is that I think in some ways from a legislative or regulatory stand point, one of the things I think that now Kathleen and Andrea need to be cautious about is trying to accomplish too much through you know this legislation that would enable electronic information. For example, I think a lot of those issues dealing with let's say insurance discrimination or credit discrimination or other things are real life issues and Congress has spoken those and the states have spoken those. I mean HIPPA is a good example where you got some protections. They may not be sufficient for some folks, but you got some protections and look you just cant be dropped from a health plan. You got some level of portability. You got guaranteed assets under certain circumstances and guaranteed renewal and those issues to me are sort of less about who can use information or when and forcing a lid on it as making sure

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that because we know that no system no matter it designed or how well intended it is fail safe, that you have got some of those other protections that are reasonable in place as well and I think a lot of those are already in existence so I think that my only comment would be you just have to be careful about trying to do too much through this law recognizing that there are some other things that need to be out there. Again to give consumers the confidence to buy in to this system.

JANE LOEWENSON: I would just echo what Dean said. One of the interesting things about health information technology is because the health industry is lagging behind so many others in terms of implementation of technology there is a I think a drive to try solve every problem before it happens here in ways that we could have learned as we went in other industries. I certainly think that we need to build all of this in as we trying to build this infrastructure but we are certainly have to keep coming back and addressing this as we increase adoption, as the tools become more sophisticated, as we get interoperable infrastructure but we are not even there yet. Adoption is a less than twenty percent per physicians I think. We don't have interoperated ability yet. We don't have standards yet so I think we are going to have to keep returning to these issues and it is important to have dialogue like this to make sure we are considering all of them but I think what we

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have tried to do, Ms. Johnson in thinking about putting her bill together has tried to figure out what are the keys things that we can do right now to move this to the next step forward. Then when we get to the next step forward, we are going to have to think about the keepings to keep moving but it is tricky now because we have experience in so many other areas.

JOHN ROTHER: One place where we can learn is from the international experience. In Great Britain for example, it is developing personal health records. And what they have as I understand it is a secure box with a tighter set of keys that you can put certain information in. So many people for example, might not want mental health information or substance abuse or sexually transmitted diseases to be as accessible as other parts of their health record so there is an especially tight control on certain parts of your personal health record. But other parts, you know the kind of medications you are taking or information relevant to say emergency room treatment, you might not want to be so tightly held so I think we can start to kind of differentiate a little bit and learn from how other countries are doing this in a way that might make people more comfortable and more confident in overall security.

DEAN ROSEN: I just had one thing, John. I just, I think you know I am obviously sort of a glass half full person but I think actually the good news is that you already at the federal

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level do have HIPPA in place. So even though it was done by regulation a lot of these issues were contemplated that wasn't contemplated in the total current environment and it probably does need to be looked at Jane suggested to make sure that you know you have got all the people covered that you want to be covered appropriately and it probably does needs to be looked as Kathleen suggested to make sure that you are impeding progress by allowing you know various state laws that may provide little additional protection but significant barriers but the fact is that you have got something in place so that you can move forward and I think it's more of an issue of you know of tweaking than it is building some thing from scratch to allow this move forward.

JANE LOEWENSON: I think part of the role of Congress potentially is the oversight of the standards development though and that these things need to be built in. who has access and how much information and can you limit the types of information that are available to different people. I heard the speakers Speaker Gringrich say this morning that the individuals should have the right to decided whether or not their employer or their insurance company has access to that information. I think that makes sense.

ANDREA PALM: I think that is actually one of the important pieces of the legislation that is currently being

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considered is the transparency and the stake holder participation that is conceived in this AHIC classes that it is really going to be the policy setting role and who is at that table and who get to weigh in that is going to be really important as some of these decisions that you are not going to legislate but that are going to need to be made, get made and have that happen.

KATHLEEN WELDON: I think what is important about the AHIC process is it's inherently more flexible than a legislative process. There is consumer representation in there and it is a public private process that will be open to public input so I think that will be important as we go forward and again addressing these issues that may take longer to go through the legislative process but we have as Dean said some of the elements in place. I think that that collaboration and the consumer input that - public input that will be involved there is going to be critically important.

DAVID LANSKY, Ph.D.: We have come to our two thirty - two thirty five now - stopping point. So, we will have to break here and you will have a chance to go to the other sessions in the other rooms. Or feel free to stay with us and we will continue on in the next hour after a little break. Well thank our panel for their conversation just now. Thank you.

[Applause]

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