

**Connecting Americans to Their Health Care:
Empowered Consumers, Personal Health Records, and
Emerging Technologies:
Closing Remarks
October 11, 2005**

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DAVID LANSKY, Ph.D.: I am speaking for myself, we have had an enormous amount of information and a thousand interesting ideas to challenge us and moving forward. What we thought we would do in this last session - as you know, Congressman Kennedy was not able to join us, but we are fortunate indeed to have a remarkable group of people in this room, including my colleagues here on the panel.

What we thought we would do - a lot of today, the way we planned it, was we knew we had a lot to do to get people with a common understanding of personal health records and the issues that surround them and the opportunities going forward. We had a lot of material to share. We did not have as much time as we would like to have to really hear back from you about where we go from here and what the needs are.

What we would like to do is to begin by asking you some questions and then by having a dialogue here with our panel for a few minutes. You can hopefully tell us where you think this field needs to go and what you personally are prepared to do, coming out of today, to move it forward and what we should be doing to move it forward.

Let me ask you a couple specific questions. First, did anything happen for you today coming to this meeting that changed your basic picture of how health information will be

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generated and shared and made available and help people manage their health? Is there something, a transformational experience for you today that you could help us understand what is new and compelling in this arena? Esther? Or a little insight. You do not have to be transformed. You can be the same person with a little insight. Anybody? Yes, ma'am.

FEMALE SPEAKER: [Inaudible] spoke at lunch. It was just mind-boggling to me all of the research and development that Intel, I believe it was, is doing. It was fabulous. I am a nurse by background and to think what can be done for these folks, these Alzheimer's patients and what not, it is wonderful. It is just wonderful. So that was just one little piece of what I am going home with today.

DAVID LANSKY, Ph.D.: Thank you. Anyone else have a new understanding today? Yes, Ma'am?

FEMALE SPEAKER: One of the things that I [inaudible] do what is available today [inaudible] presentation [inaudible] many aspects of how we have to change the whole way we address medical education, nursing education and the whole concept of seeing what is the roadmap that needs to be put in place to train our young people, as well as those in continuing education to be able to feel at home, to realize that this is the health care of the 21st century and I think maybe if anything, that emphasis was not made and I would like to just

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put a plug in for that. Many of us who are in academia and who are very interested in seeing how to move that forward are in the process of seeing what can we do to transform not only the undergraduate education, but we could also think about what we do in the school systems, what we do to change and transform how we all think about health care for the 21st century. But all in all, the Johnson Foundation, Markle Foundation and some of the wonderful presentations, hats off to all. Thank you very much.

DAVID LANSKY, Ph.D.: Anyone else have a new insight from today? Over here, right here.

MALE SPEAKER: I am from the University of North Carolina. Again, I would also like to say this has been a most interesting day. But I would also like to build on what my colleague from Johns Hopkins has said in terms of one of the issues that we are looking into is personal health records and their usability for the patient, the consumer. And that was one of the missing elements in an otherwise superb day.

And that, in terms of being able to help patients understand complex medical issues and be able to represent data and information in a way that is accessible to them and helps empower them to make their decisions. Because this is the other side of the decision-making process, and that is it is not just providers, the patients have decisions to make as

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well. And in order to help them be informed, personal health records are a tremendous way to do that, but if we do not engineer in a sensitive way the needs and address their needs, then no matter what tremendous resources we have under the covers, we may not be able to be successful because they will try in and say, "It doesn't work for me." Thank you.

DAVID LANSKY, Ph.D.: Another comment I think over here.

MALE SPEAKER: To build on the previous comments, one thing which I think we are very well aware of - certainly physicians are well aware of - is the problem with health literacy and it is quite clear that as individuals get older, their level of health literacy declines and it is probably because they are not taking continuing medical education programs after 65 or 70.

You come from, as it was mentioned earlier, is linking the information that is in that health record to [inaudible] individual as to what their disease is and how to deal with it because it is about the only way you are ever going to be able to accomplish that. A physician in the office is not going to be able to do it on an individual patient one-on-one because it would take too much time and you cannot expect people who are 10, 20, 30 years out of their educational system to go back and relearn anything.

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So I think one of the major components that one would see out of the benefit of an individual having a health record, is that you link to the ability to educate the individual about their particular disease and how to manage it, and how to use ancillary services, which was pointed out in terms of a link to the health record.

DAVID LANSKY, Ph.D.: Thank you. Anyone else have a comment of something that happened for them today that we should understand. Phil?

PHIL: It really all depends on how you hold this. One of the things that I thought was interesting was a comment that Paul Sheils made earlier today. And that was that for him, the PHR really was not what it was all about - that the PHR itself, at least the data would be a commodity in the health plan industry. He instead thought... [Laughter] He instead focused on the value added decision support applications that they wrap around the PHR in order to distinguish themselves and provide value directly to the consumer.

I was a little bit taken aback by the amount of focus elsewhere in today's discussions around the value of the PHR really only being in the context encounter. [Inaudible] and if there is an opportunity maybe to expand the horizons and the thoughts around the PHR and the kind of ongoing longitudinal day-to-day, week-to-week value, whether it be decision support,

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patient education or otherwise, that it provides directly to the consumer, not just within the clinical encounter setting, that would be helpful.

DAVID LANSKY, Ph.D.: Good. Someone in the back here has a question, comment? Maybe we could swap mic's, Mike. Sorry, we will get a mic over there in a second.

FEMALE SPEAKER: I guess I had a similar observation about the personal health record, that the context was within the old-style model of the physician-patient interaction. There was not anything about patient-to-patient interaction, there was not anything about patient-to-physician education, although the point was made that the patient is likely to learn more about their issue than the physician was. And just next year, I hope you have got that vision.

DAVID LANSKY, Ph.D.: [Inaudible]

FEMALE SPEAKER: I was just amazed by the amount of - there was not any patients here. And the amount of people that have come up to me and thanked me for coming. And I just hope if there is another one, there are many more of us who can tell our stories about how it really has been a patient-to-patient interaction and patient-to-physicians. So thank you for letting me come and I hope to see you again. [Applause]

DAVID LANSKY, Ph.D.: Anyone else with a comment about their experience today? Oh yes, please. Then I would like to

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ask the panel.

FEMALE SPEAKER: I feel the need to just talk about the population that I serve, which are uninsured women, the generally people who do not have health insurance. And this discussion really did center around people who had health insurance it seemed. And the people without health insurance are the ones who really need this system the most because they are bopping from one emergency room to another or getting health care here and there. Though, as you move forward in this process, I would like you to remember that there is 45 million or so people who do not have access to that.

DAVID LANSKY, Ph.D.: Thank you very much. A theme has come up several times today and I think one of the things that this discussion we have had today does is it touches the surface of so many components in the American society, economy and policy. And we keep always finding, as we tackle health care issues that the tentacles interweave so often and make the issue so hard to untangle. But this one is one that is very important for us all to keep attending to.

Let me ask the panel members to reflect on the day as they have experienced it. Those of you who would like to be reminded who we have here - Helen Burstin is with the Agency for Health Care Policy and Research, one of our sponsors. Esther Dyson is a private sector visitor on the panel today.

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Steve Downs with the Robert Wood Johnson Foundation and Zoe Baird with the Markle Foundation.

So you all represent different components of the health care enterprise as it goes forward. Having heard what you heard today, what do you think are the critical actions to take where we are today and move it forward so that more people have more access to their own information and more ability to influence their care?

HELEN BURSTIN, M.D., M.P.H.: Is this working? Good it is. I won't have to stand on my head and twist my head backwards to talk. I actually just want to also reflect on the question that you asked the audience earlier because I think two observations as well, is I think that although we keep talking about a PHR, I still think it is a bit of a Rushak [misspelled?] test and I have been really struck by the comments - towards the end of the day we were hearing more about sort of the patient side of PHRs and I think we have had a lot of concentration on it.

Maybe because I am a clinician, I guess I still think about it in a clinical context. So I think it is really helpful to kind of break out of that box. I still do not think, for me at least, in terms of next steps. I am still not sure I know right now or that we know right now what are the things consumers really want in a record like this. Is it even

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a record or is it sort of the - I am not sure knowledge system is the right term either. Not every consumer is the same and I am not sure we know from most consumers what are the key applications and the key pieces of it that would make us kind of push towards doing it at a broad level.

ESTHER DYSON: I have a couple of things to say. The first is thanks Markle, Robert Wood Johnson, HRQ for a really wonderful day. And let me incorporate everything that happened by reference. There is no point in repeating all the good things that happened, so I want to start with the critical constructive what else I think needs to be discussed and so forth.

I come from the private sector. I spend a lot of time with venture capitalists who are always funding the best new thing. A lot of what they fund is useless, like Pets.com. But some of what they fund is really, really good. Let me be crass and vulgar and commercial - if we were sitting around here trying to figure out how to get the population of the United States to use deodorant, we would not be talking about government legislation or we might, but most of us would laugh those guys out of the room. And we would be saying, "Well what is it that drives people to want to use deodorant?"

We might go out and do some focus groups. We might think we already know and we would go out and we would market.

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We would market it like crazy. We would market deodorant to active, healthy males who want to look like football stars. We would market it to sexy 20-year old women who want to be attractive. We would find different market segments. We would try out different marketing message. We believe these guys are empowered because they've got money. We do not talk about empowered deodorant consumers, we assume it. We want their money. We figure out what messages will attract them and then we use the messages that work. The consumers for their part, they know they are being manipulated, but they listen to the messages, they look at the other people around them, watch what other people are doing. We are two kind of wholly and we consider ourselves too sacrosanct to go out and be crassly commercial.

But health care is not just doctors competing with doctors and possibly with alternative medicine. Health care is also competing with - if I feel really rotten, I can go see a shrink, I can take a pill, or I can buy a new pink sweater. [Laughter] Maybe I can take a drink or I can go to Alcoholics Anonymous so that I do not drink. But the people we are dealing with, they have real lives. Their lives do not revolve around health care, even though their wellness affects the rest of their lives.

We need to talk to them where they are in their real

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lives, which include pink sweaters and children and alternative ways to spend their money. They do not really have a health care budget as much as they have a budget in total. They have a way to make themselves feel better. They have long-term and short motivations. We need to figure out how do we motivate them long-term to do the right thing for their health in the short-term. How do we attract their interest, make them want to talk about health care with other people?

And then yes, the one thing I heard today that was so heartrending was the woman in my second session who said her aunt goes to the doctor and she does not want to ask the doctor for a list of her medications because she is afraid of making her doctor angry. We need to tell people that is okay.

STEPHEN DOWNS: I mentioned earlier and David mentioned earlier that at the Robert Wood Johnson Foundation, I work in something called our Pioneer Portfolio. I think about this not in terms of how we can bring about substantial improvement in health and health care, but I think about it from the perspective of the US spends twice as much per capita on health care as any nation in the world. And by WH rankings, our health outcomes are somewhere between I think it is 35 and 40. I think about that as not, "Let's get it 20 percent better," I think about it as, "How do we radically change it?"

And so when I think about all these technologies, I

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worry about us focusing on how do we graph them onto an existing health care system that is fundamentally not doing the job? And so what I like to imagine, as we all think about this is how do you use technologies to bring about very different ways of managing your health, or interacting with a system of putting pressure on the system and demanding more from it?

I guess that is what I would encourage is all of you to sort of go beyond the notion of, "How is this going to incorporate or accommodate the way we currently practice health care?" but think about, again, the boomers and Eric talked about it - this is the generation that has always wanted to change the world and frequently has. So I think we can take this on. That is my perspective.

DAVID LANSKY, Ph.D.: Thank you.

ZOE BAIRD: At risk of ending the day with a lot of people jumping me, I am going to make just one comment that I did not hear as much as I expected to today. And that is that both doctors and patients are dissatisfied with today's health care system, that both doctors and patients are dissatisfied with the quality of care, with the lack of the kinds of services or opportunities or options, non-profit or for-profit, that we find in other aspects of our life, are dissatisfied with the cost, the increasing burden of costs on patients and co-pays and deductibles and premiums and every other variant of

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a way of getting costs without any increase in the quality or control or access to care.

And when you have a health care environment, which works for institutions and not for the key people in the environment, the patients or the doctors, you have a crisis. It seems to me that what we are talking about today is that these information technology tools that we use in every other part of our lives and that is because that can become competitive whether it is non-profit medical alert, medical record or a for-profit context, service, whatever, there is really a prescription for change that exists in the fact that the people in health care, both the doctors and the patients [inaudible] service is about, are dissatisfied and that the tools that have transformed so many other sectors exist out there.

So if I were an institution, I would be saying, "This is going to happen to me, so what am I going to do to compete and make those patients and doctors happier with the tools?" And if I am an individual or if I am a non-profit, or if I am a doc, I am going to be saying, "What can I do to force this competition?" And I think we will be sitting here a year from now pointing to many examples of patients and doctors and others who are facilitating this change and I bet we will be sitting here three and four years from now saying, "It just

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happened. It slipped right through and did each one of us make it move in the direction that we want to see it move in?" Because I believe the change is going to happen and I think the competitive environment Esther is looking for is going to be there and I think that we are going to find that this conference and conferences like this and activities that you are engaged in, in your own daily lives, are going to take a momentum that is going to be very exciting and very thrilling and you are going to be happy that you were a major part of it. So thank you for letting us be part of it. [Applause]

ESTHER DYSON: I just want to add one short thought about change - change is really difficult. It is not just that it is hard work, but in some sense, change is a rejection of the past that says, "I was wrong. Now I am going to be right." It is hard. It is hard if you are in a big institution not just to change yourself, but to change everybody around you. It is a lot easier to change is small startups, but then you need to lead and have the courage to go to a small startup. What gives people courage? Courage is not being afraid. Courage is being afraid and doing the right thing anyway because we really believe in it.

One thing that gives people courage is seeing other people around them with courage. And that is why I think meetings like this are incredibly important because I hope all

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of you met a few people who, when you feel your courage lagging, you can call them up or you can e-mail them or you can write to David or Steve or Zoe or somebody and get that courage reignited so that you can indeed go out of here and do the kinds of things that you were required to do by what you heard here today.

DAVID LANSKY, Ph.D.: Thank you Esther. Thank you all. Thank you all for being with us today. I think as Zoe and Esther just said, you are the engines of moving this change forward. We have just begun a conversation about these issues. We don't even have our terminology fully set here in this new arena, but I think working together, talking with each other, we will begin to craft a set of services and products and policies which can really give people a lot more ability to shape their own health care and we really appreciate the dialogue with you. Please do not hesitate to e-mail me. Stay in touch with us and we will look forward to working with you all in the future. Thank you all. [Applause]

[END RECORDING]