Making the Connection: Helping Health Care Providers Collaborate Via Health Information Networks
May 9, 2005

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ED HOWARD: My name is Ed Howard with the Alliance for Health Reform on behalf of our Chairman, J. Rockefeller, our Vice Chairman, Bill Frist, I want to welcome you to this briefing that is designed to look at one of the very few issues in this town that triggers genuine bipartisan interest, that is how we can use information technology to both improve quality in health care and constrained health costs increases. Our partner in today's program is Robert Wood Johnson Foundation, the nation's largest philanthropy dealing exclusively with health in health care. I want to thank their President, Risa Lavizzo-Mourey, John Lumpkin, David Morris, and their colleagues for their interest in this important subject, and we were supposed to have Steve Downs, the Foundation's IT guru with us today, but he's developed stomach flu over the weekend, and so if you'll bear with me I'm going to channel Steve Downs by reading to you his prepared remarks. They are very brief but right to the point.

"The truth is that the Robert Wood Johnson Foundation hasn't focused specifically on health information technology in the past, but we have always cared passionately about improving the quality of health care. Likewise, we care passionately about reducing disparities in treatment, and we care passionately about making sure that people and their caregivers have the information they need to manage their

health care, choose their providers, and make wise health decisions. We see health information technology as holding the promise for vital improvements in all of these areas. Merging that highly personal realm of peoples' health with the complex, often impersonal world of information technology raises many tough controversial questions. As you will see from today's session, it's not simply an issue of accelerating the adoption of health information technology and building a network faster, it's essential to carefully consider how such a network is designed and governed. The principles and values that underlie a national network are critical, and we need to get them right. Decisions we make today will shape the network and shape the future of health care. That's why we felt it was important for us to join forces with the Markle Foundation on connecting for health. Zoë Baird and Carol Diamond, and the team at Markle have been pioneers at raising the visibility of this issue and bringing the stakeholders together to role up their sleeves and tackle the touch questions. We are proud to be partners with them in this effort, we're committed to generating momentum, and as today's forum is so aptly named, 'To Making the Connections' that will spark sound innovative solutions. We are confident that it will yield significant advances toward improving the health and health care of all Americans."

And, as Steve said in his remarks, one of the smart

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things that Robert Wood Johnson has done IT is to support the work of the Markle Foundation, which is the organizer of connecting for health, about which you are going to hear more, and we are very pleased to have with us today the President of Markle, Zoë Baird. Zoe?

ZOE BAIRD: Thank you very much. It is a pleasure for us to collaborate with the Alliance for Health Reform, and Robert Wood Johnson Foundation [inaudible]. We have been focused for the last several years on the potential that information technology has to address previously intractable social problems. We have heard a lot, and certainly in the 90's we heard a lot about the potential to transform business processes and to transform the consumer experience through the growth of information technology, but at that same time we set out to collaborate with the people in information technology and those working on major social problems to try to figure out how the growth of IT could most effectively address critical issues that we have been unable to resolve earlier. Over the last three years we've focused principally on the potential of information technology to improve our nation's health care and to improve national security. In both cases importantly, while preserving traditional civil liberties and privacy protections, we have found that in both these areas there is a tremendous hunger for information and tremendous potential for information if shared and residing

in the proper places to address the public interest, but that that can't happen in a sustainable way unless it also attends to the consumer and citizen interest in their privacy and in their civil liberties. Congress has increasingly recognized the power of IT, and it is increasingly searching for its role in accelerating the power of IT to address social problems. In the 90's during the internet bubble, Congress, I think, was skeptical that – most people in Congress were skeptical that they should play any role because they were concerned that they would stand in the way of innovation. But, I think at this point in time, and reflected by the fact that so many of you are sitting here, I think there is a recognition that there is a role for government somehow to accelerate the use of IT to address these problems, and recently in the last Congress, there was enacted as a major part of the intelligence reform legislation coming out of the 911 Commission, an information sharing approach that was directly the product of the Markle National Security Task Force work, and that is now being implemented by the administration, and is an approach which allows – is very analogous to what you will see in the Connecting for Health Approach, which allows information to be used by people, as we call it, at the edge of the network, the users who are local that are needing to address the services and identify what is happening in a local community, but to do that in a

way which protects the security and privacy of the information as well. And so it is both a policy and a technology approach to using information and IT for national security that Congress has now embraced on a bipartisan basis with very broad support, and similarly I would encourage you to look at the Connecting for Health Road Map. Both of these products, The Approach to National Security and the Approach To Use of Information in Health Care, have been developed by experts in the field, not only experts in the substance but experts in civil liberties and experts in consumers' expectations, so that what you will find in The Connecting for Health Road Map is an approach to the acceleration of the use of IT to improve health care that has the potential for being sustainable and avoiding back lash that might come from the kinds of problems and the misuse of information that you've seen with the choice point example or the loss of data that has taken place by Time Warner and some others. So, the two areas I would encourage you to focus on as you're hearing these various presentations, and you're thinking about what's different – we've talked about health care reform in Congress for 30 years – what's different now, the difference now is that there is a set of new tools, so what can we do with them, and I would encourage you to be thinking – to be observing these presentations with the frame of mind, "How do my constituents think about this, the consumer, the patient?" It is going to be

the critical element in causing the change, and secondly, “What are the innovations that exist that can create a new environment for health care?” – the Googles, the E-bays, the new kinds of technologies that have been brought on board by companies like Intel – “What is it out there that I want to encourage and inspire in order to change the health care experience and the outcome in health care for my own constituents?” So, I thank you very much for being here, and we look forward to your engagement. Thank you.

ED HOWARD: Thank you very much Zoë. Let me just do a couple of logistical tasks. Most of you know this drill well. In your packets of information that you got when you came in, you’re going to find a lot of background information including extensive biographical information on our speakers, more than I’m going to have time to give them in introductions. There will also be copies of the slides if we got them in time to include them. By the end of today, you will be able to view a web cast of this briefing on kaisernetwork.org, and within a couple of days both on that website and on allhealth.org, ours, you can find a transcript for today’s briefing, along with most of the materials that you have found in your packets as well. And, you’ll also find in those packets green cards you can write questions on at the appropriate time. There are microphones both at the back of the room and at the front of the room for you to ask those questions from. We have

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structured today's briefing somewhat differently from our usual format to take advantage of an unusually distinguished panel of speakers. We are first going to hear from Speaker Gingrich, and then take time for a few questions that you may have for him before he has to escape for another engagement, and then we will hear from our other presenters in a format that I will describe as we get into it. As I said, I can't do justice to anybody's biographical background, but especially our leadoff speaker, Newt Gingrich. We are going to have an overview from the former Speaker of the House. There is no need for an elaborate introduction. Let me just say a couple of quick things, one, he is the founder of the Center for Health Transformation; second, he is author of a book called "Saving Lives and Saving Money" that is directly relevant to our topic today; and third, as a personification of the bipartisan nature of this issue in an increasingly partisan atmosphere in this town, he is the co-author of an off head [misspelled] and some other things on this topic with Senator Hillary Clinton. So, we are very pleased to have you with us Mr. Speaker, and we look forward to your remarks.

NEWT GINGRICH: Thank you very much, and I appreciate the chance to be here and to share with you what we are trying to do at the Center for Health Transformation and at the American Enterprise Institute. Let me start by saying it's particularly appropriate to be using this room because I

mention this room in almost every speech I give, and I do so because I try to get people to understand that when you talk about information technology and health care, we are actually talking about visiting the past, not getting into the future, because if your take – how many of you have a cell phone with a camera? Raise your hand. Look around the room. Nobody has yet figured out that with a slight improvement in the camera, that the cell phone is an automatic health instrument that can be carried by every nursing home aide all night long connected back to a doctor in real time and it changes, but nobody has thought that through because there is no consultant who makes money out of selling the cell phone. So, it's cheap, it's available, it ubiquitous, and therefore it's unused, the same thing by those trooper home health aides who all become a virtual public health service if we rethought their role and if they had a device like that. But the reason I site this room is I walk people through automatic teller machines. How many of you get cash out of automatic teller machines? Just raise your hand. This is part of my answer to the security concerns of people who worry about electronic records. I then go on to say in my standard speech, "How many of you have not written a check for cash in at least six months?" I then site an incident that happened in this room. I was talking to 700 college interns, and I asked that question, and a third of them did not raise their hand, and I turned to a student and I said,

"I cannot believe that many college students still write checks for cash?" And she said, "Oh no, they didn't understand the term, write a check for cash." So, I just want to start with that because when we talk about IT in health, we talk about it as though it's this great new world, and it's like getting together at the Stage Coach Association and saying, "Gee, have you heard about airplanes?" "Well, I don't know about airplanes, you know, they've only been running for a hundred years; who knows, there's not enough statistical data", and that's where we are with health [inaudible]. So, here are a couple of examples. The Financial Times reported two weeks ago on a Price Waterhouse Cooper's Analysis of the Indiana Heart Hospital, which is paperless and has had an 87 percent reduction in medication error, an 80 percent reduction in the cost of patient paperwork, and 30 percent reduction in the amount of time doctors spend coding records, and a 35 percent reduction in length of stay in the hospital. Now you would think that in a time when we can't afford Medicaid – we're about to not afford Medicare, we're worried about the tri-care of the Defense Department, etc., you'd think somebody would read that and say, "Gee, I'll bet this could be a replicable experience." Not in health. OMV won't score it, CBO – oh, and by the way any of you who have friends on the budget committees, they're highest value is to find a way to OMV and CBO to score investment rather than cost, because you can't

make any changes in health today because they're all costs. That's a direct quote from Fred Smith at FedEx. He said, "The biggest problem with government in the modern world is it can never distinguish cost from investment, so you could never bill UPS or FedEx, because all their investments would come of as a cost so you couldn't afford it, so you'd always cut them out every year, and you'd always wonder why nothing ever improved." And that's a core problem for the largest single investor in health, which is the Federal Government. I was on a Peace Health recently in Oregon, and they have a 1,400,000 electronic records. They also sent me a note the other day on how much it has worked with their Medicaid patients. Kaiser Permanente has 51 million years of records in Northern California, 17 years times 3 million people, 51 million years of electronic records. NIH has still not figured out that we actually have existing databases you could mine as opposed to going out and creating brand new studies, because it doesn't fit their model. The Veterans Administration, of course, has had electronic records for about a decade. Wednesday this week, Tim Murphy of Pennsylvania and Patrick Kennedy of Rhode Island will be introducing a bill in the House. Senator Clinton and I will be there to support them. One of the things the bill does is it waives Stark and Anti-Kickback to allow hospitals to provide IT to hospitals. If the administration won't pay for it, and the budget committees won't pay for, then we have got to find a way

to get the capital out there, and we got to do it in a way that is sustainable, and that may be the way that is most effective way to get it done rapidly. I know that Senator Frist and Senator Clinton are also working on a bill on the Senate side that moves in that general direction. The 33 largest vendors in the sale of health information technology has a committee who believe they are very close to being able to announce standards for interoperability on a universal basis, and I think that will be a very major break that could happen some time this month.

At the Center for Health Transformation we start out with a very simple premise, and you can see all this if you go to healthtransformation.net. Our premise is very simple, that you cannot reform the parent system. The core model for this system doesn't work. First of all third party payment models don't work in general economically because they maximize confusion and efficiency and theft. Second, paper doesn't work. I have a standard rule, "Paper Kills". It's not complicated. You want to tell me how long you want prescriptions? Just tell me how many people need to die. I used to be on the Aviation Subcommittee. We would never tolerate in aviation for one day what we tolerate everyday in health care. We kill, according to the Institute of Medicine, between 44,000 and 98,000 people a year in hospitals from medical errors, specific term – medical error. In three years of repeating that study, I've only had

one person walk up to me and complain about it. It was a medical doctor. He walked up after my speech. He said, “The number is way too high, it can’t be more than 25,000 a year.” I stared at him, and after 30 seconds he said, “Yea, you’re right” and walked off. Just think about that,8000 to 9000 dead a year from medication error because “paper kills”. At least 8,000 a year dead from hospital infections, which can be avoided if you use expert systems to identify the source of infection and track it down. I’m just walking you through these models because if you would simply apply the urgency and intensity that we apply to a civilian airliner crash to getting rid of death in the health system, you’d save over a hundred thousand Americans a year. That’s a fact, and yet nobody can quite get excited about it. Let me go a step further. The current system doesn’t work because it is professionally centered rather than individually centered. I did not say patient centered. I used to say patient-centered until I went to Nestle, which is the largest food company in the world, which runs 18 laboratories in nutrition and has a bigger research budget than the Jet Propulsion Laboratory at Cal-Tech, and their nutrition doctors convinced me that if you affect attitude, activity, and nutrition then you allow individuals to avoid patient status for years, maybe for decades. So, for example – and some of this is cultural, some of it is societal, some of it is personal. For example, I favor adamantly every

state requiring physical education for K-12, five days a week. You look at the statistical incidence of diabetes among children, you should be terrified about the health bills you're going to pay the rest of your live. Type II diabetes used to occur at 40, 50, or 60 years of age. It is now occurring at 12 to 14. Those people are going to go blind, they're going to have their feet amputated, they're going to end up in kidney dialysis, and they're going to have heart disease. All of it unnecessary because in most cases it's an avoidable disease, not Type I diabetes, which is inherited, but Type II. So, you've got to look at the whole gamete of how you shift to the individual from the professional. How do you shift to wellness, early detection, and prevention. Andy von Eschenbach, the head of the National Cancer Institute, has posted on his website at the National Cancer Institute – you can go look at it yourself – we could eliminate cancer as a cause of death by 2015, and he means it. He may be optimistic, maybe it's 2017 or 2020. But he means literally you could detect so early and you could either eliminate surgically, or deal with in some other manner having cancer so it either ceases to exist in your body or becomes a chronic disease that we manage the way we do arthritis. Now that's extraordinary if you think about people who have cancer, and yet we cannot get up the energy to focus on it to make it real because we're caught in this, what I think of, as this overwhelming focus on a treadmill, so we

spend $30 billion in NIH, but we can't think about how we spent it because we're just too busy. We know that we need to have real time 24-7 continuing medical education, but the AMA may not be totally happy. We know that every hospital should have an electronic intensive care unit, but then our hospital representatives may not be happy. So, you've got to decide whether you're for real change or whether you're just for making speeches and not having things changed. Real change is possible. One of the levers of real change is health IT, partially because health IT surfaces and makes obvious problems that are otherwise hidden. At the Center for Health Transformation we describe what we are trying to create as a 21st century intelligent health system. I recommend that to you as a phrase because it works pretty well, and your opponent is going to have a fairly hard time being against it. I mean, it's 21st century, because you can say to the finest system in America "great 20th century system, now tell me what you're going to do in the 21st century". And 21st century means cell phones with cameras in them, it means ATM's, it means Travelocity, it means e-ticketing, it means all the things you're familiar with in every commercial part of your life, and can't find at all in education and health care.

I have six principles: (1) Paper kills. Just apply that everyday. Ninety percent of the country favors mandatory electronic prescribing because the country gets it. The country

knows it much better than the politicians. Seventy-eight percent of the country strongly favors it, 80 percent of doctors favor it. Just go out and say, “Would you have to electronic prescribing so we can check to make sure you’re getting the right medicine?” Ninety percent normally is a pretty good number. Most politicians could run for re-election and probably win with 90 percent issues. Most are just stunningly tactically stupid.

Second, information technology will save money. There is no industry in America that doesn’t think information technology has led to massive productivity improvements, and the fact that CBO and OMV won’t score it should be a scandal of the first order, because it is a reactionary model which is keeping us from making rational investments. And by example, which I lost totally last year, I fought all year to try to get the administration to insist the Welcome to Medicare physicals were going to be electronic. I mean, it is stunningly stupid to say to a 65-year-old who is going to live 30 more years, travel every year, go visit their grandchildren in another state, and say to them, “We’re going to give you a physical but it’s going to be in paper.” And we just couldn’t move the beauracracy. It was just one of the most mindless efforts I have made since I stepped down as Speaker.

Third, national security requires us to go to a real time information technology virtual public health system, now.

We get hit with an engineered biological, we could lose 20 or 30 million people. The flu epidemic of 1918 killed more people than the first World War killed in four years. Ideally, the administration should propose the equivalent of Eisenhower's 1955 National Defense Highway Act. Ideally, we would connect every doctor, every nurse, every veterinarian, every pharmacy, every nursing home, every hospital, and every lab, including retirees, because if you get hit with a pandemic, you're going to have to mobilize every retired nurse, doctor, and pharmacist in the country, and nobody is – all this talk about Homeland Security, nobody is taking this seriously, and then we will have a new 911 Commission who will say, "Gee, why did 20 million people die?" Well, it isn't a mystery, and we ought to be doing it right now.

Fourth, you have to have real time continuing medical education if doctors are going to be competent in the 21st century. The number of new discoveries is going to be so breathtaking, the amount of new information is so powerful, that you want to be able to, you want to make sure that when you walk in to see your doctor that they can pull up, and this is a pull-forward system, and the doctor can go in just like Google and say, "My patient has asked what's the latest about that topic" because it's going to change that rapidly. Today – I mentioned to you about Andy von Eschenbach's vision of ending cancer in 2015 – today the Eye Institute of Medicine estimates

it takes up to 17 years for a doctor to learn a new best practice, so if we finish curing cancer in 2015, and you go to an average doctor, they'll learn about it in 2032. Now, you decide how many people are going to die unnecessarily because we don't have a standard that says "minimum best practices". In aviation, two things to remember, in aviation best practice is minimum practice. The best way to land it national is the minimum way to land it national, and in aviation everybody has the same safety standards. You don't get on an airplane and say, "It must have been a tough year and we did the best we could with maintenance, but after all budgets have been tight, so we do have an oxygen mask for every seat in first class, and those of you who are back there in coach, well we got one in the center seat for each aisle, and we hope you'll share some." You'd close the airline. You've got to have a standard that says, "I want to know that the doctor I go to and the hospital I go to know what best standard is, know what this morning's science is, and know how to reach me if something changes." That's going to be my fifth point.

All this has to be recentered on the individual. We should have 300 million individual health records in this country, and it occurs in two layers. You should have a personal health record, which is the record you use for yourself to go in and you and the doctor may well have email conversations, etc., but you know that sitting there. I would

actually describe it, not as a record, because record is a passive word. I would describe it as a personal health knowledge system. I'm on the Board of Regents of the National Library of Medicine, and we are doing a project looking at the 2015. It's very clear that we could keep your data suspended in such a way that we could both mine it, in a depersonalized manner so you create a Framingham Study of 300 million people in real time, and we would then know that if Vioxx needed to be recalled you'd get the email at 10:00 that morning. You would change the whole pulsing of the system. If you'd go out to FDA they'd function in a totally different manner, because you'd now have real time capacity for contacting people if anything goes wrong, and you'd have real time monitoring so you'd know if something was going wrong. There is no accident that Kaiser produces some of the earliest studies because they've got electronic data, and they're seeing things go wrong long before they show up in other kinds of studies. So, it has to be individually based. Every American has to have it. That may mean in some cases we may have to do something. In 1995, as Speaker I testified at Ways and Means that every second grader should be given a laptop, so I'm here to say to you, "Okay, if that means we have to figure out a way to mass produce inexpensive laptops so every senior gets a laptop, or we have to figure out how to have a cell phone or a blackberry that functions like a laptop, get over it." We can find a way to do

this. It is to our advantage as a country to have every American wired, both in education and in health. It is to our advantage as a country to have every American with individual health record, and if you're going to have people live the longest possible life and have active healthy aging and avoid being in a long term care facility, then you want to have a system where they're getting personal feedback about that everyday.

Last point, if you move to a 21st century intelligent house system and you wire everybody and you're able to monitor the outcome data, I think you can practically eliminate non-culture bound disparities, and I want to draw distinguish here. If you come out of a culture where you are determined to do things that destructive to your body, there is a limit to what good health systems can do for you, and that's an argument we have to have among ourselves. So, people who are determined to be overweight and not exercise and drink two gallons of gin a day are going to have a real problem, and there ain't much you can do about it. We have to have an honest conversation about that. It's fascinating to me that the Pima Indians in Arizona are 50 percent diabetic, and the Pima Indians in Northern Mexico have almost no diabetes, same genetics though. It's a culture difference, and so I don't want us to be able to identify these problems are, move in and have honest dialogues. I think that intelligent health systems would dramatically

lower the number of disparities in our health outcomes and would enable us to focus on what is causing the ones that are left.

So, that is a sweeping overview, and I appreciate to share it with you.

ED HOWARD: Thanks very much, Mr. Gingrich. We have time for a few quick questions if folks want to prepare to the microphones here or in the back, identify yourself, keep your question as short as you possibly can. I also invite our panelists to offer an observation.

Let me just pick up on something you said while we're doing this, Mr. Speaker. You said that there is no doubt in your mind that health care IT would save money, and I've heard some commentators speculate that what that money would then be devoted to would be more and more sophisticated health care that wouldn't really either hold down expenditures or improve the health of the American public much. Do you have a response to that?

NEWT GINGRICH: Sure, I think first of all – well, L.E. Hesterhoony [misspelled] looked at the model we're describing of focusing on individuals, focusing on wellness early prevention, trying to keep people from patient status for as long as possible by keeping them healthy. His estimate was we could take 40 percent out of the system. That's 6 percent of the gross domestic product. There aren't enough expensive

health problems to eat up 6 percent, unless you decide you have a seller's market, and you allow people to go wild. Second, I actually favor spending a fair amount of the savings at 100 percent insurance coverage. I would voucherize Medicaid, I would have a tax credit for the working poor, I'd have a mandate for people above $50,000 to require them to have insurance, but I think we ought to have as a goal in this country that everybody is inside the system in some form, because I think it is both very bad health policy to have people outside it, and it is economically and utterly irrational you have the kind of cost shifting that makes no sense at all. So, that's how I'd use the savings.

ED HOWARD: Yes, identify yourself.

PETER McVENAMIN [misspelled?]: I'm Peter McVenamin [misspelled?], a Health Economist from Silver Spring, Maryland. Mr. Speaker, are we going to need a system of national personal health identifiers to make the system work, and if so, why aren't we there now?

NEWT GINGRICH: I would curious of somebody's reaction if there is somebody in here who thinks of themselves as a really hard-line privacy person. The two groups of privacy people, the group on the left who worry about the state, and the group on the right who worry about black helicopters, which is their version of the statement, but you have a legitimate concern. I testified a couple of years ago coming off the Hart-

Rudman Commission about identifiers at the airport, and I want to apply the same thing to health. We get into these abstract fights over the last one half of one percent. I think we have established a voluntary national identifier. Everybody who wants to have their data known, who wants to be told if you're using the wrong drug, who wants to have an intervention if something will save your life, give them the identifier. Most of you will do it almost immediately. You'll talk to each other fairly rapidly and within a very short time 95 or 98 percent of the country will do that. We had this discussion on airport security, and I said, "Don't get into a fight that says you have to have something to get through airport security. Set up two lines. If you're a frequent flyer and you want to give us a biological indicator, probably an iris scan, fine you go through the short line, you're through in four minutes. If you don't want to do that because you're big on privacy, terrific, it will take an hour and a half. Within about six weeks 98 percent of the country will be going through the short line and a longer line will be shorter because nobody will be in it." But, it won't be done by cooers ion, so I would say make it available as a safety device and say to people, "If in terms of your own safety, or in my case my two grandchildren's safety, you would like them to have something which allows us to track accurately who they are no matter where they are in the country, so if they go in —." A good example that happened, and

I think I can talk about it. We just put it in our CHT newsletter, didn't we Dave, on Sally Canfield's mother? This is Speaker Haster's health aide. Sally Canfield's mother has been very aggressive about taking care of her father's health. Her father went in to get an MRI. Her mother filled out five times in paper. He has a pacemaker. Finally, her mother, who is really very vigilant, walked into the room where they were getting him ready for the MRI and said, "You do know he has a pacemaker?" They stopped instantly. They said, "He can't have an MRI, it will kill him." Now, she had circled it five times. So, I started the idea, "If you know you have an electronic record, and you know that we can accurately identify you in Florida over the weekend when you're in a car wreck and in a coma, and you know that that's going to tell us you have a pacemaker before we do something to kill you, you ought to voluntarily do it." Within a couple of years people will do it almost everywhere. I'll give you just one number. In 1999, 14 percent of the country went on line to check the price of a car before they bought the car. On average they saved 2 percent. In 2003, 64 percent of the country went on line to check the price of a car before they bought a car. Now, no federal mandate, no training program, people just talked to each other. If we say, "Here is your national safety number for health purposes, and you don't need to use it if you don't want to, but by the way you will be a lot less safe, you will see the country migrate

to it within six months or a year."

CAROL DIAMOND: I just wanted to offer another response to that question. We spent about a year at looking at this issue of the identifier because as you point out a lot of people have raised the need potentially to have it in order to establish this level of connectivity. The upside of our work is I would say threefold. One is that there isn't one immediately on the horizon that we are going to be able to use, yet with the urgency that Mr. Gingrich laid out, we need to get to that endpoint, to the connectivity that we are all after. The second is that if you look entities that are managing lots and lots of individual information, what they will tell you is that we are in a state now where no single identifier is going to be able to be used on its own. There are enough complexities in our population and in the use of identifiers that we'll need a system that allows us to match people based on multiple identifiers, that no single one will suffice. And the third point I would make is that to the point of having increased risk of having a single key to all of your health information, there are alternatives, and there are ways to address this problem, which we are in the throws of experimenting with a community in Massachusetts to try to advance the ball today rather than wait for potentially an issue that has been talked about for a long time but is nowhere near on the horizon.

NEWT GINGRICH: It is conceivable, not in the next five

years but ultimately, your iris will be the identifier because it is the most sophisticated hardest to forge identifier that we have, much more than a thumb print, and it is conceivable we will just use your iris, with your permission, we will know exactly who you are, and you will be the same iris all over the planet.

ED HOWARD: Speaker has graciously accepted the challenge of going through to the three-questions to be offered by the questioners now standing at the microphones.

BARBARA KRIMGOLD: Thank you, Barbara Krimgold, the Defender for the Advancement of Health. Speaker Gingrich, you have a very activist approach obviously to health care IT and reform of the system and physical exercise for children. Like you I am extremely concerned by the high rates of obesity, especially among very young children, and I wondered to what extent you have an active approach with respect to the food and beverage industry and fast food industry because it seems the parallels with smoking where smoking was marketed to young children who developed that habit and then go on to have all the tobacco related diseases is paralleled by early childhood habits of sugar drinks and poor choices in food, and that our schools and our systems could do something about that. So, I'm curious what your activist approach would be in that area.

NEWT GINGRICH: I should say by the way that I was born in Harrisburg, Pennsylvania, and my relatives were Republicans

in the Theodore Roosevelt-Gifford Pinchot tradition, so there is, in fact, a pattern of Republican activism. Roosevelt supposedly read Upton Sinclair's "The Jungle" which has a scene where a man falls into a vat and becomes sausage in Chicago, shortly after having had breakfast, and then sent up the Food and Drug Act. I've always said, "I'm willing to be interventionist enough to make sure that the water is drinkable and that the hamburger is actually beef." I don't find many audiences that jump up and say, "Oh no, your descendents can always sue after you die." It's a hard core libertarian view, which I don't actually agree with. I tell audiences that schools should not have anything in them which is clearly and obviously unhealthy. I've told the soft drink companies for five years that if they don't find ways to produce products that are desirable and healthy, they shouldn't expect them to be available on any public property for kids. So, I would start with there. I'm happy to go beyond that, but I don't believe in a nanny state, but I also don't believe in a suicidal society. I think that obesity and diabetes are to our generation what tuberculosis was to the urban slums of the 19th century. It is a cultural disease of the information age, and it comes from too little activity, too much intake, and the fact that biologically we are actually designed to hunter-gatherers who walk all day everyday and who have a relatively low fat, low sugar diet, and we now live in a world where we don't walk at

all and we have a high fat, high sugar diet. I don't think it's a society that we should be actively engaged in killing ourselves. I think it's a very serious cultural crisis.

DIANE DUSTIN: I am Dianne Dustin with Prudential Equity Group. I was wondering, Speaker Gingrich, what reaction the doctors have to all of this. It would seem to me that the whole culture of the medical profession could be moving this a lot faster unless there is active resistance there, and what are you finding about that?

NEWT GINGRICH: I find that if your with doctors in favor of litigation reform, which is their biggest active threat, and if you're with doctors in favor of having less red tape and more opportunity to focus on their profession, and then if you solve the capital problem, which is why I am for modifying Stark and Anti-Kickback to allow hospitals to provide the IT, as long as there is no contract requiring the doctor to send patients to the hospital to provide the IT. We've talked, for example, with Sutter and Kaiser in Northern California, and they think it is very likely that between those two systems and Catholic West you might well cover every doctor in Northern California voluntarily. My sense is that doctors will migrate fairly rapidly within that framework. The people at Peace Health who now are rolling out a pretty powerful system at the doctor's office level think that you are going to see very rapid uptake. Rapid means two or three years. I had a

pediatrician in Alpharetta came to see us at our office in Atlanta, and he uses a small firm called JMJ, which is a pediatrician developed work flow, an electronic health record. He has increased the number of children in his practice from 10,000 to 15,000 with no additional clerical staff, and he has done it with Expert Systems, which have, for example, fewer than dozen of the two-year-olds lack immunization because the Expert System automatically puts it in the front page as soon as Mom or Dad calls. And so you just automatically remind them. He loves the system. He will talk to any pediatrician in the country about why this is the baseline of the future. It has increased his income, decreased the paperwork, increased the accuracy of what he is doing, given him a better legal defense on any kind of malpractice suit, and improved the outcome for his patients. Now, that's the future, and I think if it takes a little while for people to understand it, but I think if we would find a way to eliminate the capital investment and maintenance problem – and again, any of you who have maintained IT on your own, it's very practical why a small doctor's office is very leery of getting into this. That's why I think you need to have either a public utility approach or a hospital approach, but some system big enough to do the maintenance. It has to be the provider because it's actually much more complicated than just giving people a laptop.

JIM CANTWELL: I'm Jim Cantwell with the House Budget

Committee. Speaker Gingrich, I would like to thank you for coming here today and for your work and passion in this area. I would like to ask you a question about the President's budget. There is a handout in our packet, and it has an overview of the President's budget. It suggests that the President proposed $75 million for the National Coordinator for Health Information Technology and $50 million for AHRQ. My question is are these amounts appropriate, and are the assignments to the various components in HHS appropriate in your view?

NEWT GINGRICH: You're the right person for me to direct my CBLOMB comments to, because you can actually help us solve this. I believe if this administration could have won the argument internally with its own beauracrats, they'd be investing $3 to $5 billion this year in IT. I think if you would have asked them on a non-budget basis how big a deal is this — I know the Vice President personally is very worried about biological warfare and understands how devastating it would be. I know that Mark McClelland and Secretary Leavitt, and before him Secretary Thompson and David Brailer all know that we ought to be in the several billion dollar a year investment range. The budget is clearly inadequate, but the budget is written within a fairly nonsensical model. I say this having authored four consecutive balanced budgets and help pay off $405 billion of federal debt, so this is not a trivial comment. The way we score is irrational. Just think about it.

I will give you a very specific example, which you could go back and try to get scored. Bridges to Excellence in Cincinnati and Louisville believes that they are now saving a net of $250 per doctor on diabetes and obesity. They pay $100 to the doctor to take better care of the patients in an organized, systematic manner, and they then save $350 gross, net $250. All Scripts believes in Eastman Chemical in Tennessee that they have a co-morbidity management project with a large doctor group, and they are saving $1100 per patient by managing multiple co-morbidities in a very effective, very sophisticated way. Now, if you could get any of that scored, if you could get the Indiana Heart Hospital scored, you could then walk back in and say to Josh Bolton and to other people in the White House, "Gee, how would you like to make an investment that over the last three years of the President's term will in fact save him 17 times what he is investing." You've got about six bureaucrats at CBO and six bureaucrats at OMB. They are stuck in a stagecoach era model where it takes 27 stops between New York and Los Angeles, and therefore you have to score staying at a hotel 27 times, and you walk in and say, "What about a Boeing 747?" and they go, "It's not proven yet." And so you say, "Okay, I got on a plane today and I flew all the way." They say, "Yea, but we're going to score it as 27 stops." And that's literally what you are faced with. If you'll unlock how they score, I think the administration will probably invest $3

to $5 billion overnight.

JIM CANTWELL: Thank you very much.

NEWT GINGRICH: Let me just say in closing, I really appreciate both Robert Woods Johnson and The Markle Foundation hosting this and we are thrilled at the center to work with you. I also want to say that we're going to have Megan Meehan who is going to be here. Stand up and let them all see you. She is from the Center, and she will be here after I leave. All the really hard questions that you wanted to ask and didn't get to her, just go to her. She will take care of all of them. Thank you.

ED HOWARD: All the questions that Speaker Gingrich had broad fresh answers for we now attack with some particularity. What we are going to try to do – we've got some wonderful speakers with us now, we're going to hear briefly from each of our three speakers about health IT and their involvement in it, and then we will present some specific issues that have, many of them already raised, but we will focus on them and give everybody a chance to respond to those questions, and you a chance to question the answers if you will. Pay close attention. We need to stay on topic, and that's going to include staying on topic in the questions that you ask in that particular part of the discussion.

I'm going to start with Carol Diamond. She is the Managing Directing of the Markle Foundation's Health Program,

she is a physician, she holds a Public Health Degree as well. She came to Markle from the Performance Measurement Affiliate of Aetna US Healthcare. She has done work as a consultant for among others the Robert Wood Johnson Foundation, and Carol is going to give us a broad look at some of the work of Connecting for Health about which Zoë has already told you a little bit that has been organized by Markle to deal with these specific questions.

CAROL DIAMOND: Thank you, Ed. Thank you all for being here today. I'm going to run through some high level issues, and then hopefully you will hear this theme run throughout the panel. I would say that in order to make all of the things that Speaker Gingrich talked about today possible, in order to overt a bio-terror attack, in order for that e-prescribing system to know what medications you are on so that it can in fact prevent an error from happening, in order for you as a consumer to aggregate your information, all of that depends on connectivity, which is really the topic that we are here to talk about today. It's the title of this session. All of these statistics that I have up here, which I know you're all familiar with, and Speaker Gingrich highlighted many of these, all of these problems can be, in part, addressed using information technology, but only to the extent that we understand that that information technology needs to be about sharing information across the health care delivery system. As

we all know form our own experiences, we are in a very fragmented health care system. We know that we see one doctor or specialist or pharmacy or laboratory and all pieces of the health care system have a hard time sharing information about us when we are there. All the things that we want to make possible, which is not to get the wrong medication, depends on everyone knowing what medications you are on when you show up, and making that possible is entirely dependent upon us building information systems that talk to each other. We use this term interoperability to be the phrase that means information systems that can share information, and we know that many of the benefits of IT, quality, safety, efficiency, cannot be realized without it. If all we do is automate the silo of an office, a doctor's office, and we turn those mountains of paper into electronic information that's better than nothing, but it doesn't get us all the way to addressing these problems unless those information systems can really do what they do best, which is to take complicated information and provide it in a way that allows somebody to make the right decision from multiple sources. So, that's really our focus.

We then focus on this issue, as you heard, through an initiative called Connecting for Health. We are fortunate to have the Robert Wood Johnson Foundation, as you heard, collaborate with us. This is an initiative that includes major stakeholders from both the public and the private sector, and

it includes all the stakeholders in healthcare, so we've been working with doctors and hospitals and consumer groups and accrediting bodies and so on and so forth to try to bring everybody together around how you make this connectivity happen. All the things that the Speaker talked about are not possible without it, and yet all the stakeholders have to agree on a path forward, and that's been the focus of our work for the last couple of years. Our premise is clearly that we want authorized users of the system to be able to access the information that they need when they need it, and that is, in fact, the future that we are after.

About six months ago, or actually more, almost a year ago now, in July we released this road map which was a call to action really from our own readers in connecting for health. And as I said, they represent all the stakeholders for what can we do in the near term to advance this agenda. Lucky for you I'm not going to through all the areas of the road map today, but I am going to focus on a handful of these issues. I do think it is important to understand that all of these issues come up in some way when you talk about information technology, and we're going to try to narrow down on this issue of connectivity and standards. We came up with some design principles for the path forward, and these design principles again came together through having people with a variety of views on how to make progress happen sit together in a room and

figure out what could be done.

The first was that we have to build on what we have already done, and you heard the Speaker talk about Kaiser and the VA and other examples of infrastructure and networks and electronic health records that are out there. We can't start from scratch. We have to build from where we are, and that was a key premise in designing this solution. We also think you have to design to safeguard privacy, not worry about it later as a sort of add-on feature to the system, but design for it at the front end, and that really was a driver in the way we envisioned the network happening. Third is that all this connectivity that we talked about, all this ability to detect a bio-terrorist attack or to have any prescribing system give the doctor the right information when they are prescribing that medication, all of that depends on what we call interoperability, which is allowing systems to talk to each other based on standards, standard ways of sharing information. And then finally, there is a role for local and community based activity in establishing this connectivity, and we are very fortunate to have Micky here today to talk about what they are doing in Massachusetts, and there is also a role for some overarching policies and principles that need to get put in place to allow this all to happen. So, we have several action items in the road map, and I am only going to focus on the first two highlighted in blue here. But, I do want to mention

them as parts of a whole. The first is that this needs to be based on a common framework, a common framework for how we share information, and I'll talk more about that. The second is that we need to have an entity that for the nation defines the standards and policies for information sharing, that without that we are going to continue to struggle with people always saying, "the beautiful thing about standards is that there are so many to chose from". Third, is that we very much in our model don't advocate for trying to create a system where you push all the information into one place. It is completely unrealistic, but we need to have a way to leave information where it is locally, yet move it when it needs to move, and that really is the premise of the approach. You heard a little bit about incentives, both financial and non-financial incentives from the Speaker, and I'm not going to go into that today, but they are clearly a piece of this picture. And finally, we have to have the public trust as we move forward on this, and this includes giving them control and access to their information. If this agenda cannot lead the very profound change that will come when we as consumers, patients, individuals, whatever you're terminology is going to be, have access to our health information, and the role that we can play in improving safety and improving health care in this country as individuals.

So, the two points we are going to focus on, the first

is the common framework, and this merely is a common tool kit of both standards for exchanging clinical information, as well as explicit policies on how information is handled, and we couple these together, we don't separate them. In many ways we have to think about these two attendant issues as one.

Very often we develop technologies and then we realize that the policies get defined through those technologies, and it is important to think about these things as a unified approach. To make that point, we mention Choice Point. This is the Choice Point website privacy policy, and it's a really well-written, well-done privacy policy, and yet we know that recently there has been a lot in the newspapers about the spill of data that occurred when essentially Choice Point, which is a company that aggregates data, inadvertently released that data to a ring of identity thieves, and it was a significant number of people, and that story first broke in California, but it clearly affected people all across the country. This is an example of having a policy like authentication, which is "I need to know who I'm giving information to and I give it to them" yet having that policy be somewhat weak, so that someone could walk into a Kinko's, open an account as a fake financial institution, and get half a million records of people's personal financial information. These are the kinds of policies that I think we need to think through as we get to this completely networked information sharing world in health care.

In order to achieve all the benefits with the urgency that the Speaker laid out, you need to do it in a way that we're thoughtful about the protections that need to be in place.

Second, as I mentioned this issue of standards, there really does need to be – and there is missing, I think most people will agree in health care – there is this missing function of an entity, a body that identifies and promulgates the standards and policies for information sharing. Right now we have a very fragmented approach for the development of those standards, and it is going to be very hard to move this agenda without having that appropriately defined. Again, back to the list of key action items, just as a take away I would say that one thing we should not forget in our approach to information technology is the profound change that can come about by using interoperability and the sharing of information to give us as individuals and consumers the access to our health information.

This is the close of an article that appeared in "The Economist" just last week actually, and I'll read it to you. It says, "This goes to the very heart of the matter, for even though it is fine to start hoping for the day when interoperable health records create vast pools of medical information that can be used to find new cures and battle epidemics in real time, their ultimate purpose is to make one simple and shockingly overdue change to enable individuals at last have access to and possession of information about their

own health." Thank you.

ED HOWARD: Thanks very much Carol. Now, we are going to hear from our other presenters. Colin Evans and then Micky Tripathi. Let me just introduce them now so I won't disrupt the flow.

Colin Evans is Director of Policy and Standards for the Digital Health Group, a newly formed unit of Intel. He's been with Intel for longer than I knew Intel had been in existence, 24 years or so. Obviously one of the main sources of information technology in health care sectors is a company like Intel, so Colin Evans' ideas of how to make health IT work are very much appreciated.

Then, we will hear from Micky Tripathi who is the CEO of Massachusetts eHealth Collaborative, a non-profit grouping of 34 major organizations, including many potential users of and beneficiaries from use of IT in health care. So, gentlemen, sketch out some of the reactions of the people who are actively involved in this issue.

COLIN EVANS: Thank you very much. My brief introduction about Intel is Intel is not a name you would naturally associate with health care, but I think based on the discussion today, given that information technology is going to play a very large role in fixing some of these problems including our name becomes a little bit more important. So, I will briefly talk about what we are up to. This is, by way of

introduction, a picture of what most people think the health care system looks like. This is Oregon Health Science University in my town. I live just over that hill. It's a very large daunting complex inefficient, unshakeable, highly expensive undertaking, as we heard today, needs a lot of work to help it keep working with the number of people that get older and want to use it in the near future.

ED HOWARD: Sorry, Steve Gates' presentation in Las Vegas didn't work either.

COLIN EVANS: Okay, well what the page before that said was that the hospital system is complex and difficult to deal with. It's sort of a coral reef of complexity. It is also much more likely than if you replaced it with what is complimented with health care that's delivered in other settings, in the home for instance, and one of Intel's particular interests here is that health care rebalances itself between essentially large institutional once-a-year visit, or emergency visit, to a hospital to a more 24x7 constantly monitored kind of environment then a lot of the reasons that that is going to happen enabling technology are really ones we are concerned about. So, broadband communication, wide scale use of wireless, as well as new diagnostic techniques will in fact create an environment in which health care takes place as Speaker Gingrich said, effectively 24 x 7 in the home and carried about as not just in the hospital environment. Things that we are

doing as a company to organize around that – we have a, as I said, we just reorganized to sort of focus around a digital health group. We have a group focused around a digital hospital. We've got a group beginning to think more about individual consumer based technologies that are required to enable families to look after themselves and doctors to empower telemedicine, but also increasing use of biomedical diagnostic technology to the convergence of biotech and nanotechnology is the other sort of leg of the stool here. The overall challenges that we see moving forward – complexity, enormous fragmentation and econo models. We can talk about what– we can spend a day talking about each one of these. Our particular role is not just as a technology provider, but also as a health care provider. We employ 50,000 people in the U.S. By definition that makes us one of the major health care providers in this country, and our role is to sort of leverage both aspects of the company, so activity is going forward. That's a brief introduction of Intel.

MICKY TRIPATHI: Thanks for the opportunity. I'll give a brief description of what we are going up in Massachusetts. It really is a way of introducing the idea of regional health collaboratives. Many of you may know that these things are kind of springing up all around the country in various forms in no small part due to the efforts of the Markle Foundation, Connecting for Health, Robert Wood Johnson, as well as the

Health Initiative. They all have sort of their own slightly different flavors, depending on what the facts are on the ground, what institutions are involved, but I think there is sort of a common thread across all of them. Let me just describe to you what we are doing in Massachusetts, the way of giving you one instance that I think might give you a concrete sense of what they look like.

So the Massachusetts eHealth Collaborative has roots really in a movement to use IT to improve quality, safety, and efficiency of care, and there are three threads. I'll just describe two of them just to give you a flavor of how we started. The first is that we're really a physician lead organization started about a year and a half ago. The Massachusetts Chapter of the American College of Physicians had a series of seminars to discuss things like tort reform, other kinds of issues on the physician agenda, and they themselves turned that conversation into one about "were physicians themselves doing everything they could to improve quality and safety of patient care" and they decided the answer was no, that until they advocated for universal adoption of electronic health records, that they didn't think that they themselves were sort of in good conscience saying that they were doing everything that they could to improve the quality and safety of patient care. And, so they put forward as their top priority a program for universal adoption in all ambulatory settings in

Massachusetts of electronic health records systems. That, at the same time, Massachusetts Blue Cross/Blue Shield had identified $50 million that they wanted to invest in some type of electronic health infrastructure across the state, and were approaching the governor's office, Governor Romney's office, to try to figure out ways to do that. So, in effect you kind of had the ACP with a program looking for funding matched up with the Blue Cross/Blue Shield's investment that was looking for a program, but sort of funding without a specific program. That marriage kind of brought together the eHealth Collaborative, which was launched in September 2004, represents 34 organizations in the State of Massachusetts. One thing that I would point out that I think is kind of a common theme across the regional health collaboratives, or at least the ones that are going to be successful over time, I think is getting representation across every significant aspect of the health care delivery chain, and within each piece of the health care delivery chain. So, what you see in those 34 organizations is representation from institutional providers like Partners and CareGroup in Massachusetts, health care professionals. We have the Massachusetts Nursing Association, The American College of Physicians, The Massachusetts Medical Society, all represented on the Board. Insurers, all five of the big insurers in Massachusetts, are on the Board, Blue Cross obviously is, as well as the other four, all of whom have a single vote, and

other ancillary type organizations as well, all represented on the Board. So, the idea was that every segment ought to be represented, and then with any segment no significant player could be left out, because health care is so complicated that if any one of them ended up getting left out, we wouldn't accomplish what we wanted to accomplish, which is systems change in health care delivery.

The vision for the Collaborative is kind of three-part really. One is about providing tools for better, more accessible health care, and as I said coming from the ACP that really has amounted to universal adoption of electronic health records in all clinical settings. And, it's really about the more, higher quality stay for care that I would like to stress there. The idea is that we want to get the right tools to improve care, which is getting tools that are high value, as well as tools that are convenient to use and that physicians will actually use. We could make each office sort of bristling with technology, but we could waste a whole lot of effort in doing that as well, so the idea is to really identify what tools are really going to focus on better quality and more cost effective care. The second part, which is related to that, which is about incorporating into clinical practice, so overcoming some of the adoption barriers that we know exist, such as the financing barriers, both with respect to up front capital, as well as a sustaining model going forward, and we

can talk about that a little bit later. But, the idea is that the economic incentives don't exist right now for this to happen in the marketplace by itself, as well as immature technology standards, which I think we have talked about with interoperability for example. That's a part of it and a significant part, but there is also just the lack of any clear sense of what a quality system is out there. So, if you're a physician in a relatively small practice it's a pretty risky thing to do right now to invest $25,000 to $30,000 it might take for a well-functioning system with embedded physician support when you really don't know if it really is the high quality system you were hoping to get.

So, let me just jump to sort of a picture of what the different pieces look like in Massachusetts. I think, again, this could be one model for the way that other states, as well as the nation, kind of roles up into this network of networks idea. What I've scattered there on the map of Massachusetts is 35 communities that have applied to be pilot projects in this $50 million project we have, so Blue Cross gave financial support for $50 million. We decided to embark on pilot projects that would completely wire three communities in Massachusetts for health care, and one of the things we did is we had the communities define themselves, so we had a request for applications, communities define themselves as self-contained referral markets, and they applied to be pilot projects, and we

got 35 applications. That's the scattering that you see. There are two activities that really sort of fall quite in line with this network of networks idea that you see in the Connecting for Health blueprint, and is kind of the foundation of the national model. One is kind of the idea of the grid, which is what I call it, which is an organization called MA-SHARE, which is a partner, not for profit, community collaboration as well in Massachusetts, and they are really focused on intercommunity connectivity, and really using as a basis some of the prototype work that the Markle Foundation has funded to create an implementation guide for workable standard for dealing with some of these architecture questions for exchanging clinical information. They are really focused on that intercommunity exchange, which would be, for example, for the first [inaudible] that travels from Brockton to Boston, what is sort of the information highway to get that information passed. What we are focused on at the Health Collaborative is kind of the last mile, to continue with the tortured analogy, and that's really within each of those dots. How do you, first off, get every node on the network, as it were, every physician office electronic? And then the second piece is how do you connect them in a way that makes sense in their community? If you think that, for instance, Brockton, which is one of our pilot communities, 70 to 75 percent of medical encounters for that underlying population happen within Brockton, and so the need

for exchange is really most pronounced within Brockton, a need for sort of high density, high quality, rich type of exchange is most pronounced there, and much less pronounced at the state level. So the idea is to really focus on that community vision for what exchange could be and what the value would be, and then at a minimum require that it be interoperable with that grid. That's really the real constraint that we are putting on them, is that we will develop a community vision that could be repository, it could be the single database type of model if that's what the community vision is, or it could be a very decentralized Napster for doctors type of system as well. It really depends on the type of trust that exists in the community and what the vision is from the community perspective. But, at a minimum, as I said, we will just require that it interoperate with that statewide grid so that we have this network of networks idea, so that information does role up in a way that allows the transmission of clinically relevant data across larger geographies and across communities when necessary. So, let me just conclude my remarks here and I'm happy to take questions.

ED HOWARD: Thanks very much Micky. Now, let's circle back and go at a couple of these specific questions, ones that have been raised in some instances, first by the speaker and also elaborated on by Carol, and maybe the first one I will direct our panelists to talk about has to do with the

respective roles of the private sector and government, and I guess state government versus the federal government as well. Mike Leavitt said a couple of days ago that this was going to be a forced march to get to the right standards, and that the federal government was going to be, I guess, the drill sergeant. What is the proper role and are there differing views about that? How do we sort it out?

MICKY TRIPATHI: It seems to me that there is a very strong and important role that the government can play in terms of setting up the guardrails really, and I use that analogy quite deliberately. The idea is that you want to allow a lot of variation within the guardrails but make sure that no one deviates too far from the general direction and certainly doesn't turn around and go in another direction or that direction is perpendicular to where we want to go. I think it raises an interesting issue for some of the exchanges that are out there implementing things right now in Massachusetts, as well as Indiana and some other places in the country, because we are a little bit out ahead of the federal government right now in implementing these things. Thanks to efforts like coming back to Connecting for Health, but thanks to efforts such as that, eHealth Initiative, other types of efforts, we are allowed – we do have the ability to say, "Well here are some guardrails that we can work with and align ourselves with that I think will head us all in the same direction, whatever comes

from the national perspective.” I would also add to that the initiatives that CMS has ongoing with the docket program, which is a demonstration project, as well as paper performance, and what we are trying to do at least in Massachusetts is make sure that everything that we do and every investment that we make is aligned with the significant ongoing federal, as well as national, initiatives that are going on so that we are supporting those and moving in the same direction while the standards get developed. In the end, I think at for those two activities, we’ll see the federal standards are probably going to have to follow the contours of the significant efforts that are already out there whatever those are because we certainly wouldn’t want any type of rip and replace on a geographic level just like we don’t want it on an institutional level.

COLIN EVANS: Yea, from an industry perspective, we most certainly – our experience is being the very fine job of creating technology standards, and if you look at the explosion of e-commerce in other sectors, that’s proven to be the case, there has been an explosion of the use of the internet based on one or two very small mature standards that allow the web to become the sort of bizarre that it’s become. That innovation has been built on a layer of pretty straightforward technical standards. Going back to a point that Zoë made earlier on, I think from a government perspective it would be a little unfortunate to want to legislate some of those existing

incentives in health care today just because there is a real risk that it will stifle innovation. There is a lot to learn here. There is a lot of new technology being developed. We heard about the opportunities for home care, mobile care, the comment that Speaker Gingrich made about cell phones and cameras and so forth, there is a awful lot of creativity to come out of this system, so being too restrictive today on standards would be certainly be a bad thing. There are also a number of initiatives already going on where the industry is beginning, both the technology industry and the health industry, are beginning to close in on some standards. The Continuous Care Record Center has been mentioned. I think it's a good one. The Integrated Healthcare Enterprise is another initiative that's trying to sort of figure out to make some of these systems connect within a hospital institution, and both the Markle Foundation and the Intra Ability Consortium that Intel is a member of are proposed ways of creating a National Health Infrastructure. Ultimately, though, government is going to have to play a role, I believe, in sponsoring pilots because someone's got to first, and there is a real first-mover disadvantage to many people in adopting standards to adapt and have to be overcome with a little bit of nudging, and ultimately I think, as Micky said, to create some guardrails for bounding the cooperation.

ED HOWARD: You should feel free to offer questions on

this topic of standards. I think it might be very useful. Let me just, if I can, pursue the implications of what you gentlemen were saying and Carol was saying earlier, which is that standards are very popular. We have dozens of them. Does government choose from among those? Do they convene other people to choose? Do they provide the money to set up the decision-making organizations? Can you spell out the ideal government rule with anymore particularity?

COLIN EVANS: I think in the case of the national health infrastructure that Dr. Brailer has [inaudible] a very large number of groups got together to respond to provide ideas, and I think already there is a combined intelligence of the country laying on David Brailer's desk right now, and I think first of all to sort of try and distill that down to show some signals as to the encouraged directive will be a good step in the direction. I think there's a lot to be drawn from that experience already. I think you can certainly put money behind encouraging the right kind of pilots, the right kind of experimentation to steer us towards some closure on some of these issues.

MICKY TRIPATHI: I would agree. I think that a lot of these issues aren't necessarily about the technology, so it's really about getting the significant people whose lives are going to be affected directly, namely the health care professionals involved in this early as well, and I think that

is part of the collaborative response you see on Dr. Brailer's desk to develop a set of standards that set up the guardrails but don't try to articulate too much from the center, and I think in that way what we are doing in Massachusetts is a microcosm of the national experiment as well. There are a lot of things in each of the pilot communities for example that we can't dictate even from Waltham where our offices are, and we need to allow the community conversation to happen to figure out all of those little things that are going to be decisions on the ground that the health care professionals themselves will be engaged in and will decide. So, the question is how does that role up into something that is sensible and interoperable?

ZOE BAIRD: Let me try to put this in a bit of a context for people who are not experts at technical standards. There are a whole set of attributes that you should want to see any health care IT investment achieve, so whether you sit on an appropriations committee and you're looking at the IT spending by government, which touches an estimated range of 40 to 60 percent of all health care spending, or government does, federal and state, or whether you are thinking about what kind of health reform in a substantive committee is most important, I think it is something that you can expect of those who are working on standards that they can achieve the attributes that you'd like to see the system have. So, let me give you a couple

of examples, and this is a place Congress was very comfortable going in the Intelligence Reform legislation. They couldn't mandate what the standards looked like for information sharing in national security, but they could say that "We don't want the originator to control the information; we want the information available to the analysts or the other agencies or the state and local players who need to be able to see what might inform them about a problem they're working on." Similarly here you can say that an attribute of any IT spending or standards that are developed is one which allows the kinds of community decisions that Micky has referenced when he said local communities should decide whether they want centralized databases or whether they want information to reside with the doctors, just to pick up something that has been said. So, I would encourage you to think as you engage in this debate, what are the attributes you want to see achieved, and then when Carol talked about the standards and policy entity that needs to exist, we're all grappling with the question of who should be developing the standards and who should be determining those policy attributes that the standards have to achieve. I'll give you another example just to take you way back to the beginning of the use of the internet by consumers. When the worldwide consortium developed the standards for cookies, there wasn't any engagement by Congress or people with a policy point of view debating the question of whether consumers should decide

who gets their information, whether the architecture should allow someone's computer number to be transmitted so that spam could wind up in their computer. So these were just not thought of because it was a bunch of technical folks sitting around thinking around how an we enable the internet to grow and flourish from a technical point of view, as opposed to what were the public policy attributes that we want to see baked into any standards that are developed. So, I would encourage you to think about that question, "What are those public policy attributes?" and then one of them that is critical, and I've said this often, including regularly publicly to David Brailer, a very important role for government is to insure that innovation can flourish, to try to eliminate barriers to entry, and I think this is what Colin was saying as well.

ED HOWARD: We have two people back there and one up here. If you will identify yourself please.

BOB GUIDOS: My name is Bob Guidos. I'm with the Infectious Disease Society of America. We represent about 8000 infectious disease doctors. We recently set up a list for practice managers across the country, and last week we had about — someone sent out an email about setting up an electronic medical records within their office. That was followed by about 40 emails by other practice managers saying, "We want to know about that too." Some people have set it up and some people haven't, so we decided to set up a

teleconference for them this week. Are there online resources that I can refer these people to, because I'm not an expert in this area, that I can refer them to, and also how do I assure them after they make this significant investment that whatever they do or implement is not going to be superceded or become obsolete as the standards go into place?

ED HOWARD: Anybody here want to pay to VCR? [misspelled?]

MICKY TRIPATHI: Let me deal with the last question first. There is no guarantee right now that what they buy won't be superceded, and that is the significant risk. I think that we are really at the brink of solving, but it's still not solved yet, and so in terms of the former question you had, and there are a number of resources out there, The American Academy of Family Physicians, the Massachusetts Medical Society has a website. There are a number of sources out there that have CLASS, as well as another one, TEPER [misspelled?], and there are a number of organizations that have ratings of electronic medical records along a variety of dimensions.

COLIN EVANS: I'll add one to that, the Health Information Management System Society, HIMS, initiated an effort call the Certification Commission for Health Information Technology that Mike Leavitt is chairing, not Mike Leavitt, a different Leavitt. I would encourage you to go to their website. They are very specifically focused on trying to

understand how to create the very criteria you're talking about. What are the basics that a criteria to which EMR vendors could comply that would enable – particularly the smaller practice – that they have an idea that what they're buying is not going to be obsolete overnight either because of technology or data standards. That doesn't guarantee that it won't be but at least they are focused on trying to establish some framework for making this do, so I would encourage you to go there as well – CCHIT.org.

ED HOWARD: Okay. I think probably we ought to take these two questions and then maybe move on to the next issue if we could. Yes ma'am.

ALLISON REINER: My name is Allison Reiner. I'm with the National [inaudible] League. I think it's laudable to have a discussion about data and technology standards and how that integrates into the development of technology to support this, but as a consumer advocate, I'm always a little challenged by the notion of how consumers have been to some extent less out of the process at determining what the process standards are for their interaction with the system, because obviously we need advocates for patient safety, but I'm wondering if you could talk a little bit about the foundation, the government, and also the industry role in educating consumers about their needs for this, because I would wager that most consumers don't realize how fragmented the system is and the lack of continuity

that does exist and access it for their records.

CAROL DIAMOND: Allison, thank you for your question, and as you know we've been trying to get after these principles for a while now in our work about what the system does need to look like. I will whole heartedly agree with your statement that the average consumer doesn't really understand the problem that we're talking about today, and in fact, our research bares that out. They grossly overestimate the extent to which electronic records are being used by several orders of magnitude. They think their information does tend to move when it needs to move. The only place we see a flexion point in that data is with the chronically ill who very much want the benefits of all the things we've been talking about today. I do think, and this has been a part of the way we have done the work at the foundation, but those views and those viewpoints need to be part and parcel of the way the system evolves, and that those principles need to be incorporated into any solution going forward. Finally, I would just say that to your point about educating consumers or getting the message out, we recently convened 17 organizations who have an interest in doing just that, each from their own vantage point, and not so much to try to have one approach to it, but to rather collaborate on testing some messages that we know are going to work for people to help them understand this issue. You may know or have seen in our road map we actually tested some of

those messages and those statements in the form of advertisements, literally, that we did a random telephone survey around, and the one that was most compelling to people, or at least made them understand this issue in a way that made them want to do something differently was this picture of someone falling off the ladder and the caption read, “You have three seconds to remember every doctor you’ve seen, every medication you’re taking, every procedure you’ve undergone.” It was a very compelling message that people really got, because everybody at some point has been faced with the clipboard or the emergency room where you have to remember all these things, and understanding the potential of information technology to help solve some of those things. So, thank you for your points and they are right on and well taken.

COLIN EVANS: It’s interesting that Speaker Gingrich left us to go to an announcement of such a system to empower those health records. I think there are a lot of interesting ideas out there as to how to empower consumers with personal health systems rather than being treated more as consumers than as patients. I think the consumer power here is an enormous thing if you look at the changes that were wrought in systems because of consumer advocacy in e-commerce. If you look at the reactions that banks had, for instance, to downloading data. They originally didn’t want any part of downloading to people’s Quicken systems or whatever, but when their most informed best

customers demanded it, then guess way, they made the investment to make it happen. I think a very similar thing could happen in health care where patients take charge or patients and their families take charge of their need for information. It could have a really racing effect. I would encourage the consumer groups to get more vocal on this stuff.

ED HOWARD: Yes, let's get one last question on the standards.

SHARON CANNER: Sharon Canner with e-Health Initiatives. I wanted to get back to something that Mr. Gingrich mentioned, which was the scoring issue, and given that Medicare and Medicaid are such huge payers, that if we could get the CBO to score the savings for IT that would to a lot in terms of leadership, and I wonder if there are any suggestions or recommendations of what kinds of information, what kinds of research we need to convince those at CBO what is needed.

ED HOWARD: Wasn't Jim Cantwell convinced? I thought he was going to go right back and make a change in policy?

ZOE BAIRD: We've been trying.

MICKY TRIPATHI: I would just add that the reason that we are doing pilot projects in Massachusetts rather than just spending the $50 million on specific projects that would really just fund implementation is that it's our sense that we move from an understanding based on efficacy to something more like effectiveness, so that there is lots of evidence now about how

the benefits play out and where the benefits are with careful study of individual practices and even groups of practices, but implementation on the community wide basis in the messy real world is really what we want to measure now. So, hopefully as part of these pilot projects we will be able to at least inform some of that conversation about how to score based on information.

ED HOWARD: As we move to a second topic that Carol highlighted, let me just ask you to remember that as we finish up this discussion we would love for you to fill out those blue evaluation forms on paper. We haven't figured out a way to get you do it online within the room, anyway, so that we can make these sessions even more valuable for you. I should say that we have been talking with some of the folks involved in this briefing about doing a follow-up session specifically on the privacy issues that get raised in this context because they are so important, not only to the consumer groups, but to the willingness of ordinary folks to be part of it, and therefore its efficacy in the end. Carol mentioned the question of how you structure these networks, or a network. Is it some sort of national system? Is it a series of regional or community wide networks that somehow tap in at the margin for the providers and individuals to get the information they need when they needed as they are falling off the ladder? How do you decide? What are the pros and cons of structuring it in the way that

we've heard described as a network of networks, or as a single standard that might be simpler to envision and maybe to advocate? Anybody?

COLIN EVANS: Obviously, this is a complex topic, and because you're trying to span connectivity from the two-doctor office up to the multi-hundred bed hospital, and therefore one technical solution is unlikely to fit all those different areas. I think there is some strong argument, I believe, for saying that some of the connection for the health position has been a large sort of a basically – I don't want to say peer to peer is probably putting to subtlety, but data stays where it is, people can find it when they need it, and the model works if you can guarantee the data is there, and you can go back to some hospital data center that is up 24 x 7. If the data resides in a small doctor's office that by definition is not an IT support professional, that model might not necessarily work if that guy turns the computer off at night. So, I think there actually has to be a room for a certain amount of aggregation of information along the way, either to bring people together in some kind of constant of information or to provide them with services to do this. The technical model of leaving data largely where it is sort of works generally, but there has to be a lot of aggregation in some place to make this work. The other thing I think we should do in the U.S. is look very carefully at what's happened in many other countries that

frankly are a good deal ahead of the U.S. in solving this problem, and people tend to think that the U.S. is ahead in all things. Sadly, in this case, not so if you took today, for example, in Europe the U.K. is busily investing in a very significant health care rejig of its IT systems around, sort of a semi-aggregated model. Other countries like Norway and so forth are probably almost 100 percent electronic, and they have models of doing this, but are not completely peer to peer. So, there are experiences we can use in other countries to sort of steal with pride as they say to make these models work.

MICKY TRIPATHI: As I described earlier, in the collaborative we are allowing a tremendous amount of variation at the community level. The idea being that it really is focused on what they want, what the whole community, consumers as well as health care professionals and the institutions, want to do and what they want to get out of it. I think there is clear tradeoff in terms of how much structure data you get. I think that the repository versus non-repository question is really about how much do you want to impose a structure so that everyone's data looks the same and is something that you can aggregate, and the easiest way to do that is if you store it centrally. But, it's really a question of how much you're going to structure that data. So, what do I mean by this ambiguous kind of thing? If you can take that information from a variety of sources and put it all together into a database, that allows

you to do a whole bunch of decision support and get things like community guidelines. It also allows you to do population level research in a way that you couldn't do if you had just put that data together, but it wasn't the sort of the same format so that you could essentially put it all into one database. So, those are the kinds of tradeoffs that I think you end up having at a community level. In effect, it will taking Napster, which is very decentralized, and many of you are probably familiar with Napster, that identifies where the songs are and stops there essentially, and lets you put them together, go and get them, but it doesn't let you say, for example, "Give me every song that has the term 'you broke my heart' it in" or "Give me every song that has three band members, two guitarists and a drummer" or something like that. Then you are imposing a much higher standard in terms of the type of information and being able to look within each of those files as it were to consolidate them. But, as I said, those are real tradeoffs on what you want to do and how much you're willing to give up to do it.

ZOE BAIRD: If I could just comment on that before Carol makes a broader comment, there actually are tools that will allow you to search across just aggregated databases that achieve exactly the same thing, even on an anonymized basis, so you could even search, you could anonymized everybody's data and still search across anonymized data, so I think that the

technology has facilitated our having a choice between centralized databases and just aggregated systems, and will increasingly facilitate that although there are some limitations.

CAROL DIAMOND: The only thing that I would add to just sort of lay out the way we have been thinking about things, is that if centralization is a requirement it will fail, because we know that you can't just keep growing a database bigger and bigger and bigger that's going to have every possible piece of information you're ever going to want for research or public health or clinical care or what have you, and it's going to sit in the basement of some building in Washington. We know we can't get to that, so any level of local decisions about when to aggregate and how to aggregate need to be balanced with the fact that we still need a way for either aggregates or completely decentralized data to move when it needs to move. We can't get to one big pot that has everything. I will say that as Micky pointed out most communities that are working on this are trying to do this with some eye toward efficiency. There are many who are, to Colin's point about having data available, hosting in one place where there is a first among equals institution that is hosting information for everybody else, but the data isn't necessarily commingled. And, there is also the issue that has forced people to do that which is very often the participants in themselves don't want their data commingled,

either because they have different levels of privacy they want imposed on certain data, or because for competitive reasons or sensitivity about the data, they don't want it all commingled, but they will support a system where that data that is authorized to move when it needs to move and can be aggregated somewhere else can happen, and that that can be facilitated. Those are the tensions, I think, we need to balance in trying to figure out the path forward, but the path forward, at its most basic level, means that we are never going to get to this giant database in the sky that's got everything that we need, and we are going to need to find a way to make an already decentralized system. We have a decentralized system work, and that's really been the premise of our approach.

ED HOWARD: Well, speaking of decentralized systems, the way we've set this up is that we are now out of time. We've been very patient with some very difficult concepts, and I want to thank you for hanging in there. We haven't talked at all about timing of these things. We haven't talked about what Mr. Gingrich raised in terms of aggregate costs and who ought to bear them. There's a lot yet to be discussed about this including, as I mentioned, the privacy issues so I know that we're not done with this topic. There are a lot of people who are interested in it. I do want to thank our friends at the Markle Foundation and at the Robert Wood Foundation for their interest in these issues early on and their support for those

issues, and for this forum. And, before I thank the speakers I want to just congratulate Markle on one of the smart things that it has done, and that is to hire Stuart Schear who has been a Senior Communications Officer at the Robert Wood Johnson Foundation for the last seven years. Stuart has been the driving force behind Cover the Uninsured Week, which ended yesterday, which allowed him to come to the briefing today. Otherwise, we would have had to salute him in absentia. So, we thank you for making that resource available to this range of issues, and I look forward to good things coming, not only continuing to come from the Markle Foundation, but for even more people to know about them because of their Communications Director.

ZOE BAIRD: We are grateful to R.W. Chafin [misspelled?] for his investment in Markle as well as [inaudible].

ED HOWARD: I ask you to help me thank our speakers for a very interesting and compelling discussion.

[END RECORDING]