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SCOTT YOUNG, M.D.: My name is Scott Young, not Carolyn Clancy, as you might notice from appearances. You may or may not notice. I direct the health IT portfolio at the Agency for Healthcare Research and Quality. And it's my pleasure to moderate this panel on Lessons from the Field.

I've got to tell you, just by way of introduction, I am a family practice doctor, and still look at that as the one thing I know how to do and know how to do really well. And I'm a family practice doctor who has tried to take—and I think with some success—has taken health IT systems and integrated it into a practice setting in the state of Utah. That was difficult. It was an uphill battle. We did not have the kinds of tools and experiences that we needed at that time to get the job done. But that's really where the rubber meets the road.

This morning we're going to hear from three individuals, three different perspectives about what it looks like. And this really culminates on the messages we've heard this morning. We've gotten a national perspective. We've heard Mark McClennan, Dave Brailer, Newt Gingrich. We've heard from purchasers, and we've heard from those who are paying for health care services what's important to them: improving quality, safety, efficiency and effectiveness of care. Now we're going to hear how do you take all those needs, wants, desires, all of the pressures that go all the way from how do we capitalize these purchases to how we integrate the systems, how we really turn all this capacity, all this promise, into real products and services to improve the lives and the health of our fellow Americans.

I'm going to introduce our speakers in order of appearance. And they're going to give us a ten-minute overview of their perspectives, and then we'll have time to have a dialogue and to hear from you.

Leisa Jenkins is the executive director of CareSpark, an RHIO in the Appalachian area of Tennessee and Virginia. She is well known throughout her region for her skills as a facilitator, resource developer and project manager. Leisa has served on the board of directors of numerous non-profit organizations, and has been honored with several recognitions, including the 2005 Health Care Hero.

Providing the physician perspective, we have Dr. James Morrow, the vice president and chief information officer of North Fulton Family Medicine in Cumming, Georgia. Dr. Morrow is a board certified family practitioner and practices full time in family medicine. He is a 2004 winner of the HIMSS Primary Care Davies Award for excellence in the implementation of electronic medical records and is president and founder of

Health Care Quality Technology and Research, a health care information and technology consulting firm.

Rounding out our panel is Dr. Glenn Steele, who's the president and chief executive officer of the Geisinger Health System in Danville, Pennsylvania. Dr. Steele is a past chairman of the American Board of Surgery and serves on the editorial boards of numerous prominent medical journals. He is a prolific writer and has authored or co-authored more than 450 scientific and professional articles. I am impressed by that number. Dr. Steele was most recently honored last night at the CEO IT Achievement Award for his leadership and commitment to using information technology to advance strategic goals.

We appreciate each of you participating today. And Leisa, we're going to turn the floor over to you.

LEISA JENKINS: Thank you, Scott. It always makes me a little bit nervous to be on a panel of experts, because my background does not include health or IT. I am one of those folks that Newt Gingrich this morning asked each of us to be: an empowered citizen, someone who knows how important this is for my community, for our country, and therefore have been nagging and pushing and kicking with all of our leaders in our community to get their act together and do what needs to be done. So every RHIO needs a pushy one. As a guarantee of success, I would tell you that's one critical thing.

The region that I live in is the Appalachian region that crosses over literally five state boundaries. We happen to be in the place where there is no one dominant, or very few large, employers. Our payer mix is very fragmented, and we have a lot of rural, small family practice or solo practice docs. And we do have an employer that's been very key to us. Eastman Chemical Company is one of those involved in leapfrogs and others, and we're proud to say that they have really helped us throughout the way.

But as you look at our region, you can see that we have lots and lots of challenges to overcome. We recognized very early that we can't look to government, particularly state government, because we have multi-state government, to provide the answer to us. So our community accepted the challenge and the responsibility of stepping up to the plate and figuring out how to make it work across all of those boundaries and barriers. We have some of the highest health care costs in the country, with some of the worst outcomes. This area of central Appalachia has significant disparities in health, and so we have to find a way to do that.

I'm going to skip ahead to a page for a minute, because I want to call attention to the fact of all of the entities that have collaborated with us in getting us to the point where we are now. And we continue to pick those up. What you see there are employers, health plans, hospitals, physician groups, graduate medical education, public health departments, community organizations, patient advocacy groups and local IT firms, all of whom have been a part of our effort to date.

But what I also want to let you know is that when we started down this path three, four years ago, there were several other names on that list, that first bullet there of employers, that are not there anymore. We specifically had three companies, all of whom were involved in lean management and quality management, et cetera, all of whom had been involved in our coalition for over ten years, and were long standing, good corporate citizens trying to do the best for their employees. They have gone out of business since 2002. One was a textile company. One was a foundry. And one was an auto parts manufacturer. So it is very much in the forefront of our mind and our community why it is critical for all of us to help resolve the problems that we have to do for the good of our economy in our region.

Now, going back to this point, what we recognized very early from listening to our providers, those family practice physicians and others who see patients, who tell us what they need is information at their hand that enables them support their abilities to take care of patients. We obviously can do things more cost effectively. We know that better than most.

And we need to be focused on the outcome, not just the process, pieces of it. In a region that has very poor public health, that's a high priority for us. And all of those are stakeholders for us. One piece that needs to be on here, that we have not put on there yet, are the technology partners that we can all work with, and have worked with very successfully.

So, by looking at what those components of a regional system, a regional network, need to be, we have gone through literally a two year planning process to figure out how to put all of these elements together to deliver what needs to be done for folks. We did a very comprehensive business feasibility study. What we learned is, if we can get over the capital expense in year one, that by year two we can be a break even and by year three we should be able to show a three to one return on investment collectively for the community.

So, we have to work on three tracks at once. Individual organizations, be they providers, hospitals, whatever, have to get to the point where they are able to exchange information electronically and participate in the system. We can provide that connectivity at a regional level, but it must be aligned with what's going on at the national and the state levels as well. And if we can do that, with the goal in mind of improving individual patient outcomes, then we will get to the point where we can also improve population health outcome. That is going to require, and I'm proud to say that we have, involvement from our employers and our payers to help figure out how to get beyond the barriers financially.

So we have set up CareSpark as an independent non-profit. One of the things I would say that is going on and has been a challenge for us is that our application for 501c3 determination is languishing away in the IRS office, where it has been for close to a year. But we hope that very soon there will be some policy decisions on the part of the IRS about exactly what does constitute a RHIO; how can we provide safe harbor that allows everybody to participate in a way that puts no one in legal liability unduly. And we're working very hard to secure the dollars and the technology that we need to put this system in place.

So what I want to close by saying is that we have decided in our community to do rather than be done to. And we believe in the concept of regional networks. We want to be a RHIO who does it right. And we are working very hard on that. I hope that each one of you, wherever you be, in your community will either lead the way or participate in the work that has to be done, because we all must succeed. And we're there to help and work with you. Thank you. [Applause]

JIM MORROW, M.D.: I appreciate being here today. I am Jim Morrow. I'm a family doctor, and been practicing since

1985. And I have been practicing very differently since 1998. I don't have a bank of slides. I didn't know what I was going to say until I got here, and listening this morning and deciding what I wanted to tell you, because I could talk the rest of the day and you'd get sick of me.

I wanted to say a couple of things. First is, I want to invite Leisa to move to Georgia. If you would, that would be just the best thing that's happened in a long time. We need that kind of thing. We're working on that, but you are so far ahead of what we're doing, it's remarkable.

I want to talk, too, about the effect that the EMR has had on my life and on my practice and on my patients' lives, because it's something that for a lot of people is a little bit difficult to get their hands around. We started out in 1998, not knowing that we had no business as a four doctor practice; not knowing that we really couldn't afford it; not knowing that we couldn't do it; not knowing all the things that you hear about everywhere you go now about how difficult this is. And we did it because we needed to survive. Financially, we were struggling with decreased reimbursements and increased costs, and spending $110,000 a year on transcription. And we wanted to find a way, and had to find a way, that we could decrease those costs so that we could continue to do what we wanted to do, and to grow. And in the area where we are, just north of

Atlanta, the growth was ridiculous. And we knew there was no way we could continue to spend that much more money on transcription and survive.

So we looked and looked and finally went through the whole process of how to find and EMR and implement it. And as soon as we did, we moved the transcription costs, on December 17th, 1998 being $110,000 a year, to being zero a year on December 18th, 1998. We were able to take that money and put it directly into the cost of the system. A lot of family practices—and if you are a practicing physician out here, you're sitting here probably thinking, well, I don't dictate my notes. I can't save that chunk of money right off the bat. And that's very true for a lot of people. There's no question. I've done notes every way you can do them, and some ways are cheap and you can't read them, and some ways are expensive, and you don't say everything you need to say because of the costs. So there are problems with all of them.

But if you're not doing transcription, then you get the benefit of the money saved with FTE decrease. We went from 4.2 to 2.8 FTEs per provider. We were able to decrease costs associated with hunting charts. And if any of you have ever worked in a doctor's office or been a patient in a doctor's office, you know what it must be like when you've got to find the chart for the visit.

And the cost of telephones two years ago: we implemented a web portal that allows patients to see their lab results online and to communicate with us. They can initiate communication with us through a secure email system. And we have decreased dramatically the costs associated with taking care of patients that way, and increased the quality, because everybody can have access to their labs. And no, 100-percent of my patients don't get on the Internet, but 80 plus-percent do, and it makes it a lot easier for the nurses to contact those that don't when there's only 20-percent of them left. The telephone thing has been huge. After HIPAA, we realized that it was taking us about 4.2 phone calls to tell a patient, "Your cholesterol is normal." And that's ridiculous, with phone tag and not wanting to leave it on the voicemail and that kind of thing.

So this has really changed dramatically all of those different aspects. In the first year, we saved $253,000. And even if you eliminate $110,000 as transcription, that's $140,000 a year for four doctors seeing 100 people a day. And now we're ten doctors seeing 400 people a day. We have ten PAs also; we've got an extra office. We've been able to do some of the things we wanted to do all because of that cost savings.

But the big savings has been in the area of quality, because we've been able to watch our A1C levels come down.

We've been able to watch the quality of care go up, which is our opinion, and fortunately, recently, the opinion of the health care insurers in our area, telling us that we're doing a better job. When Vioxx was recalled, we ran a little search on the system and found out we had 389 people that needed to be notified that Vioxx had been pulled. And they probably heard it before we did, to tell you the truth, because they weren't in the exam room. But we were able to call them and say, "Make an appointment; let's get you in here and change your medication, check you out," and so forth and so on. And there's no way in the word to do that in the paper world. So quality is definitely increased there.

Another thing that I hear a lot is that a lot of doctors will say, "I immunize 100-percent of my patients with Pneumovax, against the pneumococcal bacteria." And what they do—and it's admirable—but what they do is they immunize 100-percent of the patients that present at the office. And there are a lot of patients that are our patients, a lot of people who are our patients, and they consider me their physician, and I won't see them. They just don't get sick. They don't come in. With a system like this, you can look for these people in the system. You can send them notes and say, "Hey, there's this great vaccine out there that could protect you. You should come and get this." And the same thing's obviously true with colonoscopies, mammograms, pap smears and everything else there is; whatever you might be looking at.

But the difference is that you can look at your entire patient population, not just the sick population that actually comes to the office, and they're already sick anyway. In order for the system to pay for itself, you've got to be able to demonstrate this quality. And like I mentioned earlier, we've been able to do that, and the health care plans have recognized that. And I don't mean to stand here and say that we're getting rich, or we're making tremendously more money, but we're not getting the decreases in pay that some people see. and we have had a bump from the major insurers because of our increase in quality.

Now, how are you going to pay for it? That's tough. And although you might see that in the first year you can save money, the out-of-pocket expense is very, very real, and it's a real concern for the majority of practices, as it should be. But my analogy to that is that when the time came to start billing electronically for services, and people had to go from a pegboard system to an electronic billing system, they didn't go into that, as doctors and businessmen, they didn't go into that thinking, now, how much money am I going to make off of this system? This was a cost of doing business.

And it's my opinion that electronic medical records are a cost of doing business today. If we're going to continue to take care of people like we need to, and increase the quality of care, which absolutely needs to be increased, and stop the medical errors that absolutely need to be stopped, this is a cost of doing business. And I believe that the sooner that the practitioners in this country decide that this is just the way it's going to be, then I believe we will make great strides in doing what everybody in this room is trying to push forward, which is obviously implementation of health IT. But we've got to past the idea that an EMR has to make you money. That's the doctor's job. That's his job to make his office more efficient, which this will do. It's his job to practice better medicine, which this helps you do. And by doing that, all these things will come together. But the decision to implement health care IT has got to be made as a business decision that is the right thing to do, and it's a necessity to do it.

In the future, I look greatly forward to being able to incorporate the other data in our community. We don't have a RHIO in Georgia like they have in Tennessee, but if a patient could go to the ER on Saturday night or Sunday night and present to my office for follow-up on Monday morning, and I did not have to repeat the CBC to see what's going on, or to see what it might have been doing over the weekend, that's money that I can save every single day.

And it's so very simple to get that. I'm working with a company now and hope to, in the not terribly distant future, be able to implement a system that will allow a software agent that works a lot like that one they mentioned this morning that rhymes with frugal, that would search for records all over the area. And when someone comes in and registers in my office or already is registered, then when you bring that chart up, it would say to me, "They have data in the system. Do you want to look at it?" And if the patient's given permission for me to look at it, then I can. And when we bring the rest of the information in the neighborhood back into the doctor's office, where it's really used day after day, this is going to be as big a change certainly as there was since the EMR, and if not since the telephone, because this is really going to revolutionize our ability to take better care of patients faster and in a much more efficient way.

That's really all I have. I look forward to your questions. Thank you for having me here. [Applause]

GLENN STEELE, M.D., Ph.D.: I have this fear of getting the CEO IT award last night and not being able to get my PowerPoints up there. [Laughter] We could actually have both Leisa and Jim come to our area, and then you probably wouldn't need Geisinger. I'd like to go over a bit of what we've done, give you some data, and then give you some caveats about whether it's scalable, whether it's generalizable to non-integrated health system practices.

We're in the T in Pennsylvania. We cover about 2.5 million patients or potential patients. We're in 40 rural counties. We have a doctor group of 650 employee docs. They're incented, but they're employed. We have 41 community practice sites, now about 230 primary care physicians that are then hooked to four hub tertiary and quadinary hospitals. And then we also have a health plan, one of the larger rural HMOs and managed care plans in the country. And we deal with a lot of non-Geisinger physicians through our insurance company. We also, as I'm going to show you in a minute, deal with a lot of non-Geisinger physicians and non-Geisinger hospitals in how we reach out with our IT, which was a strategic decision made a number of years ago. This is where we are. These are the three market areas, with the hubs being the hospitals. And then there are 15 non-Geisinger hospitals, where we also give care close to where patients live in their communities if they don't need to have specialized or sub-specialized care.

We have, as I said, 41 community practice sites that vary in size from practices of two docs and a PA all the way up to 40 docs. And some of these sites are really pretty rural.

They're all linked, as of 1995, electronically. We started with Epic Systems, built from the outside in, as opposed to most hospital based systems, which is kind of interesting. We might get into that in discussion. And we're very proud of the fact that we're now relating to almost, I think well over 500, maybe 600 non-Geisinger docs, where we have essentially provided web-based portals for information transfer when we're caring for patients in partnership. We're also part of an ARC-sponsored RHIO in this area, since our fantasy in this area of extraordinarily stable patients is actually a lifetime electronic health record, and the ability to transmit that information throughout any provider or any platform, whether it's Geisinger or non-Geisinger in this part of rural Pennsylvania.

This was the rationale. You can read the slide. I'll just mention that if we didn't have the electronic connectivity between our clinicians, and between our clinicians and our patients, we really wouldn't be a system, since this is so physically disparate and covers so many different rural areas. So it was a wise decision, but it was really the only decision.

Now, as far as return on investment is concerned, this company is blessed with a great balance sheet. It went through a dysfunctional merger and de-merger, but it remained very healthy in terms of its balance sheet, which really allowed it to spend 70 million bucks as a down stroke on this EHR; $70 million. And we're now looking at 4.2-percent of our annual $1.7-, $1.8 billion revenue on IT costs. So it is not cheap. We've tried to estimate with our CIO and or medical information officers how long it took to get return on investment; real return on investment, calculated real numbers. And it was probably somewhere around five years; short end, maybe seven years. Now, we're getting a real kick in. I'll end by just summarizing what the kick in is in terms of return, particularly in quality and value. We have a goal this year of getting up to 100,000 patients that connect to us and use us, exclusively or predominantly, in communication through electronic. We're up to about 60,000 patients, and the rest of that's obvious.

We've really got two ways of looking at return on investment. One is obviously easy to calculate. The other is harder to calculate, and basically, almost on an annual basis, we try to analyze what the more easy to quantitate benefits are. And similar to what Jim said, but obviously on a grander scale in terms of our size, we're really starting to show significant return on investment. What wasn't mentioned, which we can I think have pretty good numbers on, is the amount of inefficiencies and the length of time of the inefficiencies when we first started to transect these electronic health record changes and the cultural changes and the systems practice changes in our community practice sites. And it was a significant decrease in the ability to actually work the product for a period of time. Now, obviously, as we've transacted upgrades in our system, that transaction has become much more efficient. The down time is much less. But there's probably anywhere from a 5- to 10-percent decrease in productivity, at least early on in our experience in community practice when EHR was implemented; probably about six to eight months' worth before there was recovery, and then there was in increase in productivity. Appointments, telephone encounters, orders, immunizations—these are all easy to quantitate; tremendous increase in efficiency and cost savings, but probably with a significant down stroke and a significant lag in this setting.

I want to end by saying that our next five years' strategic goals are summarized here. And the top goal is to get as perfect as we can, as close to perfection as we can, in a number of our chronic disease management programs. And again, similar to Dr. Morrow, the diabetic patient—our average patient has five chronic diseases. And so how do you optimize the 33 by consensus things that need to be done perfectly in diabetes and take care of the hypertension, which is on board, the coronary disease which is usually there, and probably one or two other additional chronic diseases, without having your physician, who's well meaning, hard working, set up to look at things that should be done that aren't done, even though he or she thinks they're done. We think that that's impossible without actually having the electronic enabler.

We have a series of tools that are trying to help us progress to this near perfect, or as close to perfect care as we can get: pay for performance models; patient engagement in care, a tremendous way of redesigning care with patients activated through this My Geisinger, which is their own direct connection to our physicians, whether they're primary care physicians or specialists.

And then, two things that we can do, which are very, very important as an integrated health system: we can actually report to our board on a quarterly basis dashboards that we think are inpatient and outpatient quality dashboards. And an example, obviously, would be the time to third available appointment. We can hold ourselves accountable to that. And we do that on a quarterly basis, with about 14 dashboards as inpatient, and somewhere around 14 to 15 dashboards as outpatients. As an outpatient, what we're striving for in our community practice and with our specialist—because it's the continuum of care that's important—is to get as close to all the important parameters for optimizing a Type II diabetic care, get as close to that as we possibly can. Now, you're not going to believe this, but if you ask any of your doctors, "How close to perfection are you in your diabetic care?" they'll say, "Pretty close." But if you actually quantitate it, and look at the nine categories and 33 by consensus markers—and we've done the study—you will be astounded at how infrequently care is given optimally.

And we think we can kind of get that up, but it's very complex. This is an example of the information that's provided to our physicians. It's a population medicine based approach, where markers come up if things are out of whack, the only way that we think this can be done. Docs, no matter how well meaning they are, no matter how bright, no matter how hard working, are not going to be able to give optimal care to the average patient with a multiplicity of chronic diseases without having this enabler.

And these are the things that we've learned as we've gone through this process. I mentioned a number of them. And the caveats really are: is this scalable to non-Geisinger, smaller practices? It is generalizable to areas where you're actually incented in terms of your reimbursement based on getting more specialty work done when the care isn't perfect, preventing the need for the specialist? Is it applicable to fee for service, or are we actually going to have to change our reimbursement system? And then, our demographics are very unusual, with this very stable population. People come to us, and have come to us for 20, 25 years. Our insurance company basically insures them for 20, 25 years, so we do the right thing. We actually not only help patients, but we get a better return. It's kind of unusual. It's not applicable in most parts of the country.

So, I look forward to your questions. Thank you very much. [Applause]

SCOTT YOUNG, M.D.: All right. Now it's your turn. If you have questions for the panel, please queue up the microphones in the audience. And I'll tell you, while we're waiting on those, I'm going to take the moderator's prerogative and ask a question.

So, Dr. Morrow—I'm going to pick on the family doctor, too, being one, so I'm going to go right to it. Dr. Morrow, we really hear about the power of health IT in systems of care, and really how we can maximize to that 1-percent of patients who are 25-percent of the total cost, or 30-percent, depending on which numbers you look at. So the independent practitioner, the four, five, six, eight FTE practices, how does health IT—what's needed to really bring them into those kinds of systems? And how can health IT and others in this audience help out with that?

JIM MORROW, M.D.: Well, as far as bringing them into the system, one of the number one things is to increase their awareness of the system. It's amazing to me how many people even today are pretty much still ignorant of the existence of systems like this. And then, once they are aware of that, a big problem is that they hear the horror stories before they hear the successes. And so they need to be educated like they do about a lot of things, like all docs to. We need to be educating these people about what is available and how it can be done.

And one thing I think hospitals can do, if we can manage to change the Stark law enough, if the hospitals are able to provide some assistance, if the payers are able to provide some assistance—because there's no doubt in my mind that one of the biggest places that savings will occur is at the payer level—if we can get that kind of thing to happen, then we can get these people on board. They are generally very eager about providing better quality. And as businessmen, they're all pretty eager about saving money and doing a better return on investment. And if we can do that, then I think we will be able drag them into this whole field.

SCOTT YOUNG, M.D.: We're going to go back and forth here. If you would give us your name and your question, and please, if you want to direct it to somebody.

NANCY STETSON, R.N.: I'm Nancy Stetson. I work for MedPlus, Incorporated. And I just want to tell Leisa, I think that pushy women rock. [Laughter] But I do have a question in regards to: in the 90s, there was the CHIN Initiative, and some of the barriers to that were best practices and licensure, particularly across state boundaries. And I just wanted to know if you see that as still kind of an issue, or have we progressed a little bit about that?

LEISA JENKINS: That has been something we've been very concerned about all along, whether they be data standards or reporting requirements or HIPAA compliance regulations and all those kinds of thing. How do those vary from state to state, because our region has multiple states that we have to comply with? What we have tried to do, number one, is be an advocate for the states to communicate with each other and to participate in the national dialogue that's going on. Secondly, we speak up.

And really, if you keep the patient in the forefront, all of this is about how we can deliver the best care to the patient. How do we get the best outcomes for the patient? So that's kind of the mom and apple pie, and everybody can agree, yes. We just need to get beyond the barriers there and figure out how to do that.

NANCY STETSON, R.N.: Thank you.

K.C. FOON: Hi, I'm K.C. Foon [misspelled?] from 3M Health Information Systems. Leisa, I was wondering if you'd give us some more details about that CareSpark business model, because you were saying that in year two you had positive cash flow, but what are your sources of revenue? Are you charging providers, insurers, hospitals? And if not, do you plan on doing that in the future?

LEISA JENKINS: We have all of the above. We leave no stone unturned when it comes to funding. So our start up capital has been basically with grants and contributions. We have not had major, large grants. We're envious of those communities who have that capability, but we've had to cobble together small donations and contributions.

However, our employers are beginning to step up to the plate. Our purchasers, our health plans have been involved all along. And they really are building, restructuring their fee schedules to provide not only the reimbursement to the providers that will help them with the acquisition and ongoing operations for IT, but also for some additional costs to cover the expenses of the RHIO infrastructure. And then we do have some involvement from the state with start up money. Neither state has decided yet exactly how they're going to handle their payments, through Medicaid or through the state employees.

But the way we have approached this is by trying as best we can to estimate what the cost is, what's the fair share, based on the anticipated return, and then a real principle of accountability and transparency about the savings that are going to be realized, so that all stakeholders can kind of see what savings are coming back out of that, and that there's a proportionate share of the return coming back, proportionate to the amount that they invested.

TIP GHOSH: Tip Ghosh from UNLV. This is a question for Dr. Morrow. You mentioned that electronic medical records are sort of the cost of doing business and the reduction in transcription costs that you had. Can you sort of address the change in mindset, because it is a change in mindset, especially among practices that are smaller, in rural areas, to say that this is sort of the new way of doing things, and we need to sort of get there.

JIM MORROW, M.D.: Well, there's no question that it's a change in mindset. That's absolutely true, and it's true whether it's a large practice or small. It's just more difficult for the small one to get there.

I think, again, it comes down to educating the physician and letting them understand that they can do this. They need to hopefully go to the AAFP to the annual conference and see where people have done it. And I think the more they become aware of that, they will see that not only is this something that will benefit them financially but from a quality standpoint.

Now, that still doesn't make it cheap, and it still doesn't make it easy. It's still $25,000 or so per doctor to do this. And that's the tough part. That's the thing where they're already working on very thin margins. And I do realize that.

What it comes down to, though, it that they are going to have to realize that this is going to happen in the long run. I've told everybody that will listen that I'm a big believer that in the single digit number of years in the future, this is going to be mandated if we've not already pulled it off, much like having to do an electronic billing system pretty much was. I don't think this will be any different. If you're going to participate in this, that or the other plan, you're going to be electronic. And I think that they need to understand that, too. And doing it on their timetable will certainly be easier.

I think also there's a place for bringing communities together to do this kind of thing. Even though you might be a community of a half dozen small practices, that doesn't mean you have to go into this thing as six individuals. And if you go into this thing as six in a group, you're going to be able to do better in that regard. If you're in an area that does have a large employer, talk to them about bringing that in. Get some help from them.

There are a lot of things that can be done. You don't have to just go to the bank and say, "I need a quarter of a million dollars." That's not necessarily the way it has to be done. But it does begin with educating them about what's out there and what all the different options are for doing it.

FRED EVERLINE: Thank you. My name is Fred Everline. I'm the founder and CEO of ReliefInite.com. It's a web based, electronic pain diary service which was just launched last month. And I'm a huge believer in IT; it's been my life. We've been working on this project for six years. But we assume that clarity is a good thing. And I think one of the threats that we face is that some people see it as a threat, right? I heard an anecdote Dr. Steele touched on. And I've come across this anecdotally as a business person, when sometimes people say, "Hmm. That's all great," and then they kind of roll their eyes and say, "Well, then they'll know," as though the truth is an impedance. And, "I don't want, as a physician, to be measured by somebody out there who might get it wrong." Because it's an evolution, isn't it? Collecting, analyzing, re-checking, discussing, debating. It's not a panacea.

So my question is: what do you do to overcome that perceived threat?

SCOTT YOUNG, M.D.: We have Leisa, then Glenn.

LEISA JENKINS: From our standpoint, we try to approach it very non-threatening, and so we use words like, "We support the provider to make the best decision possible. We support the decision that needs to be made between the physician and the patient." And that really is what our intent is.

But I'm also not afraid to challenge any organization or any individual who is involved in health care. People don't go into health care because they want to do bad for patients. They're very humanitarian folks, or they wouldn't have gone into that profession in the first place. And I think you have to appeal to that, and ask them, "What do you need to do our job better? And how can we help you do that?" And if you frame it in that way and do that in a way that we all are working towards the common goal, you have a role and I have a role, so let's figure out what those roles are.

SCOTT YOUNG, M.D.: Glenn?

FRED EVERLINE: At what point does it become a mandate?

LEISA JENKINS: Ours is purely voluntary participation by patients and providers at this point. And we are not advocating for anything that is mandatory for either of those.

GLENN STEELE, M.D., Ph.D.: Yeah. Ours is certainly not a mandate at all. We have the additional issue, as I'm sure all of you are aware, of being huge and then dealing with small practices that are intrinsically fearful of us. And then, for a period of time, there was a strategy essentially to wipe those practices out. This was a number of years ago. So we have that to overcome.

So it's really been a matter of developing an open relationship—I mean, it sounds maudlin, but a lot of trust; basically creating a system—and this is an interesting philosophical deal—creating a system to link out to the non-Geisinger physicians that's probably inadequate to start with, but overly simple. And it gets people kind of connected. And then they start demanding the next evolution of complexity. It's really kind of an interesting approach. So the web based portal is really based on that. And then it's a demand from the outside in, which is very, very different.

And then the other thing is—and I agree completely with Leisa—you know, docs are really trying to do the right thing. I was a doc before I went to the dark side. [Laughter] And if you really approach them with what is going to help them take care of their patients better and not put them out of business, after a while, you get one, you get two practices, you get ten practices. And then of course the market comes in as well.

People are eventually going to say, "Maybe I need to do this or I'm just not going to be competitive."

One additional thing is the demography. As the medical school demography changes, and we get more women coming out—we get 50-percent going in, 50-percent coming out now, even in the specialties—first of all, there's much more facility in general, whether it's men or women, with electronic enablers. But secondly, the women want to practice differently, we found in our rural area, than certainly my colleagues and my peers wanted to practice, because they actually want to have a life as well as a good profession. And so their view of infrastructure and connections and partnerships and what have you may be a little bit different. So I just wanted to throw that out as well, and give us an advantage.

SCOTT YOUNG, M.D.: We have time for one very, very quick last question, so quickly to the point.

MARTY STEIN, M.D.: Okay. Marty Stein, a physician. I started with EMR back in the mid 80s, I guess, with a DOS based program running on D-Base. I could play it like a piano, it was so easy. It was Mark Leavitt's program. And then later, these things started getting more sophisticated. And I'm a geek. I like this stuff. My program is still too hard for me. I still don't understand all the bells and whistles. And if I can't figure it out, I can't imagine how so many of these doctors can take on these programs and be able to manage them. And then you go to the exhibits, and there are some where you have to check everything with a click on it. It's structured entries; sometimes it's not structured. How do you get these doctors to learn? Or do you have an idiot system? Or we need a special toggle on all the fancy systems that goes to idiot mode [laughter], so everybody can use it. And also, when the staff, like the nurses, transcript to another hospital, they could click it on and use the same kind of program. The idiot mode: that should be universal. But I don't know how you get the doctors to do it.

SCOTT YOUNG, M.D.: How do you get people like me, who couldn't save their life, to do this?

JIM MORROW, M.D.: Well, first of all, unlike these people, with us it's mandatory. [Laughter] [Applause] We learned early on, the first six weeks, that there was no way to do this if you didn't just say, "Okay, this is how we're going to do it now." And when we started, I tell the story about us starting, and it's four docs. But truth be told, we were five doctors, and about six weeks into it, the youngest guy in the group said, "I didn't go to medical school to ride a keyboard. I'm going to go back to transcribing and dictating and transcribing." We said, "Well, there's a module for that. You can do that. That's fine. But we're not going to pay for it.

You're going to have to pay for it yourself." And he said, "Well, I'm not going to pay for it. The practice should pay for it."

"Well, no."

"Yes."

"No." And so he left on good terms and went down the street to join another group. Six months later, they put in EMR. [Laughter] And he's still there.

But it's a very good question about how to learn the complex programs. And really, it's much like Microsoft Windows or Microsoft Word or Excel. You can go in and create a document very easily in Microsoft Word. But you can also go in there and you can use mail merge and databases and graphs and charts and send things electronically and do all kinds of stuff that I don't know anything about. But you don't have to do that to use it.

So what it comes down to for us is making sure that people understand the basics, and that any and all questions they have get answered, and that they are exposed, at least, to some of the finer points that the program will do. I'm like you, sir. I'm a geek also. And I enjoy doing the charts for the patients and seeing what their sugar's done over the years. Or I like being able to print out a prospectus, basically, of what would happen if they did this, that and the other. But so many of the people who use the system use it to create a very good note and keep track of their problems and their medications and look to see when their last colonoscopy was and that kind of thing. And they don't get into some of the more intricate things that those who want to can.

And it all boils down to training. And if you ask any of the HIMSS people, they will tell you that I've become a lightening rod for training. And very briefly I'll tell you, because last year, this time of year, we put in a beta version of our AMR, and it had a couple of things that were pretty different. And I thought, oh, we're experts at this. This won't be any problem. And they installed it. I was in Phoenix doing a talk for HIMSS and it went miserably. And we had to call training sessions all of a sudden to get everybody to learn what we'd been doing for eight years. And the reason is that I don't care how good you are at this, there's always something you can learn. And the only way to do it is training, training, training.

SCOTT YOUNG, M.D.: Glenn, you have the last word on this.

GLENN STEELE, M.D., Ph.D.: Yeah. First of all, Jim, for our 650 Geisinger docs, it was mandatory. [Laughter] Secondly, I just want to emphasize the fact that there's not this point in time epiphany that occurs. It really is an evolving process. And you've got to have the docs—real docs; real docs, not people like me—real docs down there who are advocates for this in each of the different units, divisions, departments, what have you. And they've got to be involved, in our case, with our vendor in an ongoing relationship to continue to improve. Without that, you're dead.

SCOTT YOUNG, M.D.: All right. If you will join me in thanking each of our panelists. [Applause]

Our final speaker today—we're going to go right into our next speaker—our final speak today is somebody who's important to me personally and to this town, and a real thought leader in health policy and the future of health care. Myrl Weinberg is the president of the National Health Council, which is an umbrella organization that has served as the place where the health community meets for 83 years. The Council's 110 members are national health related organizations, and its goals are to promote quality health care for all people, promote the importance of medical research, and to promote the role of voluntary health agencies for patient based groups.

Ms. Weinberg's career has focused on health, medical research, long term care, Social Security and related issues that affect persons with chronic disease and/or disabilities. She has a long history of broad community and committee service, including services with the Institute of Medicine

Health Sciences Policy Board. She was honored to be selected to serve on the congressionally mandated IOM Committee, created to assess how research priorities are established at the National Institutes of Heath. Most recently, she served on the National Research Council IOM Committee on their organizational structure for the NIH.

I'll tell you, when I came here to Washington, DC as a Robert Wood Johnson Health Policy fellow, Myrl was one of the folks that we were taken around to and introduced to. And it because very apparent to me that this was an important person who knew how we got things done, who knew the future, had a clear vision for that future. We welcome you and welcome your comments today. [Applause]

MRYL WEINBERG: Boy, thank you so much for a lovely introduction.

I want you all to know that I, like you, realize it's kind of cool in this room, and we're probably all hungry. So I will try to stay on track here.

I think that most of us, by this time of the morning, and because we're here, we're all in agreement that health IT in general, and electronic personal health records in particular, can make and are making in some placed a tremendous contribution to helping patients, providers, payers, policy makers, all of us achieve our different goals for better health care and better health in this country. At the National Health Council, we have a stated goal at this point to normalize the practice of electronic personal health records as a new standard of care. Today I’m going to tell you a little bit about our work toward that goal, why we’re approaching it the way we are, and share some of the recent consumer/patient research that we have conducted.

First, let me tell you just a couple of things about the council; just a couple of things more than what you already know, so you’ll understand our perspective. You heard that we are an umbrella non-profit, and we are unique in the world in that we have, as our members, the patient groups, about 50—so it’s American Cancer Society, diabetes, Lupus Foundation—but we also have those other categories. We have professional societies, like the American Academy of Family Physicians, and we have business in industry, which includes pharmaceutical and biotech companies as well as their umbrella trade associations, and the organizations that have an interest in health, which include Hospice & Palliative Care, Family Caregiving, AARP. And so you see that we have, really, all of the stakeholders, just about, in our membership, and we try to work on areas of mutual concern.

We do try to support increase in medical research, the need for fundamental reform to the health care delivery system, especially with regard to making it much more patient focused than it is today, and the need, always, to engage patients and their families to be more active participants in their health and in the health care practice and system. I think it was mentioned, but collectively our patient groups represent approximately 100 million people with chronic disease or disability in this country. And in addition to that, of course, we have all of the family caregivers associated with those persons.

So, as part of our Putting Patients First initiative, which is a major program of the Council that we established more than a decade ago, we have the goal of empowering people to play and active role, as I said, in promoting their own health in preventing disease and managing their own health care decisions. And we believe that giving patients access to their own health information is the logical starting point. Electronic personal health records—and I say personal health records to continue to distinguish it from the electronic medical record, which is focused more on the needs of the providers—electronic personal health records will provide an electronic source, as we've heard, for patients to access, manage and share their health information among their providers in a secure and confidential manner.

These kinds of records will allow patients to input important indicators, such as blood pressure and blood sugar levels, levels of pain between doctor's visits. But in addition, patients can enter personal preferences that are relevant to their care and that should be relevant to their providers. So these would include things like the complimentary and alternative medicines and therapies that many of us make use of, homeopathic remedies, spiritual needs, medical directives and caregiving authority. Patients will also see the information that comes from the providers, such as the diagnosis, the treatment, the lab results, and their entire medical history.

Electronic personal health records we believe will lay the foundation for many of the other health system changes that we know will benefit patients. EPHRs will not only improve patient care and medical outcomes, but we think will catalyze many other needed changes in the health care system. They will cause the real integration of care across time, as we talked about this morning, across settings, across providers, and the integration of those other types of information like alternative and complementary therapies. They're going to focus, we believe, on managing the patient. Electronic personal health records are the key to helping us think about this in a way where we're managing the patient, not the disease or the disability. It allows us to provide a more holistic view of the person. And we know that evidence has shown this creates better health outcomes.

The patient centered and health IT may seem like a nuance to many or simply an add-on to the architecture of a system well under way. But we believe that integrating patient focus now is central to the success of health IT in the future. We and our members know from extensive consumer research that people are often confused and frustrated by a system the do not understand, while decision that affect their health care are made every day without their direct involvement. And a person that I greatly admire that's here today reminded me that we often say, "Nothing about me without me."

As a result, if people don't have the information, they do not comply with medication regimens, they don't schedule necessary follow-up visits. Information about previous tests and treatments is lost. Terminally ill patients are often denied appropriate end of life care. Emergency room doctors are forced to make life altering decisions without access to complete information. And a host of many other problems can occur.

As we've heard—and I'll just really quickly summarize some of the main benefits of electronic personal health records—they are:

- We can reduce staff and patient time completing repetitive paper forms, producing greater efficiency.
- Reducing human errors caused by completing forms or transferring data from one form to another.
- Reducing medication errors and other treatment errors, and in turn reducing liability.
- Providing instant access to entire medical histories, with computer programs red flagging potential complications.
- Insuring the sharing of information across settings, fostering greater integration of care.
- Enhancing patient satisfaction by having patients more involved and active in their own care.
- Creating a much strong patient/provider relationship by breaking down a lot of the information and communication barriers.

So I want to just give you one example of the importance of electronic personal health records. It comes from one of our member organizations, the Alpha-1 Foundation. Alpha-1 antitrypsin deficiency is a genetic disorder that can result in liver and lung disease. So people with Alpha-1 can have episodes of severe breathing problems or liver failure. In the ER, they are often unable to communicate their diagnosis because of the severity of their symptoms and condition, and they are often misdiagnosed as having acute asthma, smoking related lung disease or alcohol related liver disease. These mistakes can prove fatal to a patient with Alpha-1, because the treatment of asthma or alcohol related liver disease may be of no benefit or even harmful. And Alpha-1 patient presumed to have asthma may be intubated, placed on high pressure mechanical ventilation and wind up blowing out one or both of their lungs. And a member of my board from that organization has two friends who just recently had this situation occur.

I'm going to skip ahead over a note about a very specific example from an emergency situation which went back to Hurricane Katrina, but we've heard about that this morning, so I'm just going to move on.

I think we probably all have examples from our personal lives about how electronic personal health records could have helped us in certain situations. But what we've done at the Council is we've actually commissioned extensive research among patients, especially those who are our members with chronic disease or disabilities, about electronic personal health records. So I want to just share a little bit of what we've learned.

First, how we did the research: we conducted the research in several phases, beginning with a literature review, an environmental scan, to identify various efforts and programs aimed at promoting electronic personal health records, or electronic medical records. We looked at how they were being promoted, and how consumers were or were not engaged. The second phase of the research involved exploratory nationwide telephone focus groups. These were with patients who have chronic conditions. And we wanted to identify what issues regarding health care delivery and information interest and concern them, and to guide the development of messages that will engage them on their own terms I their own language.

From these groups, we developed message concepts, and then detailed messages. And we examined those in one on one individual interviews with people from a variety of backgrounds. Dr. Brailer mentioned this morning there are pockets, and that’s what our research shows. We have about four different groups of persons who are probably on the curve of ready to act. They’re way up there. So our research participants were a mix of various chronic conditions, education levels, ages—you all know this—races, ethnicities, locations, family caregivers of children with a chronic condition. And we also did very specific detail message testing with those who believe they already have a fairly well functioning electronic personal health record and those who have not, and have not really heard of them.

So overall, our research shows that while patients are eager to have better access to their own records, to have their providers more aware of their health data, and to see systems streamlined, coordinated and integrated, they do have serious concerns about privacy, security, accuracy and the user friendliness—which we just heard is a concern for doctors and everyone else—of the systems themselves. By early in the research, we learned that brief sound bite explanations will not engage people. Research participants immediately perceived that the devil is in the details, and wanted thorough explanations about access, security and privacy.

We learned that people have a natural curiosity about how EPHRs would work. They did not get impatient when we provided more detailed information. And we realized—and even for us it was a little surprising—that this runs contrary to our society's seeming assumption that everything must be simplified to appeal to supposedly ever shrinking attention spans. But when you think about it, we know that people are willing to spend lots of time online and elsewhere researching health information, and learning about EPHRs is no exception. We then adapted the description of EPHRs in later stages of the testing to provide this kind of thorough information and detail, and it was very well received.

We also learned emphatically that patients' security and privacy worried can't be skimmed over. They must be answered. And so we found it was better to raise them right at the beginning and to begin to address them at the get go. Many were skeptical that any system could be truly secure, and they pointed to widely publicized large security breaches of supposedly secure credit card information. But other people found it fairly easy to sort of overcome their concerns about privacy and security. Our research also revealed the need to clearly list the benefits to the patient. We found that the more we explained the benefits to patients, and what would directly benefit them from having an electronic personal health record—and you've heard them all: increasing safety, helping alert providers to important information, et cetera—the more they liked what they heard and the less they were concerned about the privacy and security.

Not surprisingly, we found that real life examples help convey the importance of the issue. And we created a message concept that referenced weather, fire, burst pipes, Hurricane Katrina, and it strongly resonated with everyone. We also learned, and again were a little bit surprised, that people disliked anything that sounded like a slogan or sounded too promotional. So, for example, our disaster message ended with the phrase, "Because when a natural disaster or other emergency strikes, you have enough to worry about." Many people singled out this phrase as sounding like advertising hype and thought it would make people think that someone was trying to sell them something. Several people decided that EPHRs were being promoted by the computer industry for profit.

Another important finding for us was the complexity of the task. We were not surprised about this. It will be a challenge to get patients to actively engage in this topic because it seems technical to some people and they are skeptical that it can make a difference. And they are skeptical that their voices will actually be respected and heard. But, as usual, we also found that a few activists can stir up others. We just heard a panel of activists. And that phenomenon played out in our research groups and in our focus groups. Motivating patients to get involved will be a challenge, but we believe it is a challenge that we can overcome.

Consumers emphatically did not like one message that we tested, based on an analogy to the banking industry, in which we likened electronic personal health records to the convenience of electronic banking and ATMs. They thought the comparison was irrelevant and it made them think that EPHRs were an effort to reduce human contact with providers.

As in almost every research project we've conducted, patients perceived the voluntary health agencies, the patient based groups, like our 50 members, that these organizations are the most credible and caring source of messages, and they found them again to be that kind of source on this topic. We find that people trust their personal doctor and these organizations more than any other sources of information.

The research revealed many other aspects of patient attitudes that we'll use as we go forward in our program, Putting Patients First, and we'll be conducting more research as we go along. From what we heard, we're convinced that we can strike a balance between offering patients the many benefits of electronic personal health records and allaying their concerns about the security and privacy of the information. We know that people are dying every day from lack of critical information and other inefficiencies in our health care system, and we think that we cannot wait any longer for that perfect, fine-tuned product.

We're encouraged and excited that many in the health care industry, and all of you today, are involved and working toward electronic medical records and other health technology solutions that will provide far more cost effective and better quality treatment. But, as is often the case, many of these efforts have not focused on the needs of the patient, or even the simple concept that making information available to the patient can directly improve care. In addition, these efforts have not focused on how to engage patients in developing, and consequently embracing, the new technology.

And I want to just stop and stress that point one more time. Too often, the patients are the last to be involved; they're the last stakeholder. And everyone feels that it's too complicated, or we need to get it all ready to go and then we'll go ask the patients and get them involved. And I continually remind people that we are they. We're going to face these things, and we need to involve patients from the beginning, get their input, what their needs are, what is useful to them, and make sure that at the end of the day they welcome the technology, they're enthusiastic to use it, and they're not resisting it because they weren't involved and it doesn't meet their needs. I can promise you that without patient engagement and demand, it is unlikely EPHRs will be adopted smoothly or even succeed. A movement, as I said, that is perceived to come from the system will face much greater challenges than one that is perceived as coming from patients' desire for better care.

The National Health Council wants to see us all work together to address the needs of providers, the industry, and patients and their families alike. We acknowledge that much more comprehensive reform of the system is needed, but widespread use of electronic personal health records is the first essential step that can catalyze other system changes while also improving care immediately.

Through our voluntary help agency members, the Council has access to an active network of grassroots activists, people who have one or more chronic diseases or disabilities in their families, and therefore have regular interaction with the health care system, and who are eager for a role to help make fundamental improvements in health care in America. A massive army of motivated patients and their families can drive demand for EPHRs that will speed their use and acceptance. And in fact, a future study that I was privileged to be at the conference when the results were announced by the Robert Wood Johnson Foundation actually indicated that the only way that we can have a national movement is to have patients and families get involved. And their involvement will significantly influence the speed and quality of improvements to the nation's health care system.

To accomplish our goals for patient focused electronic personal health records, we have three objectives, and I'll just highlight those really quickly.

- We want to create awareness among people with chronic diseases and/or disabilities and their families of the advantages of electronic personal health records and the inherent disadvantages of current paper based systems and the substandard care and medical errors that they can cause.

- We want to decrease concerns and allay fears that exist among patients about the privacy, security, ease of use and accuracy of electronic personal health records.
- The last was to motivate patients to take actions to really create the demand. Some of those actions include asking their current providers and provider systems or networks to use electronic or offer electronic personal health records, to select new providers based on whether they actually have electronic personal health records, to advocate support of EPHR systems, including writing letters to policymakers and newspaper editors, and making use of EPHR systems as they become available, to be more actively involved in their own health care and in the health care in their community.

We're currently planning stages of a pilot program, and so we will first start in one to three states. Right now we're considering Massachusetts—I almost said Michigan after hearing about Michigan so much—Massachusetts, Florida and California, so that we're going to actually go into states with all of the stakeholders who are all in our membership, as well as anyone else who's interested, and get involved in advocating for electronic personal health records. Based on our experience with similar programs, we have very high hopes for great success.

And in closing, to borrow an idea from astronaut Neil Armstrong, while electronic personal health records may seem like a small step to some in the health care industry, they can be the next giant leap forward for patient care. But for the patient, there are certain risks and challenges, as I said, associated with health IT in general, and specifically electronic personal health records. So, even though we all know that electronic personal health records can ultimately improve the quality of health care, reduce health care costs and improve overall health outcomes, it is critical that we work together to insure that patient perspectives are addressed. And we must address patient concerns now and throughout the evolution of all health IT, not as an afterthought, because it's easier to prevent a problem than to fix it. If we ignore patient concerns, we will create unnecessary problems and face resistance.

We also believe that while issues of privacy and system security may not yet be resolved to perfection, we should move forward immediately to put EPHRs into practice. We can solve the security issues while the new technology is saving lives. This is the classic situation of the saying, “The perfect is the worst enemy of the good.” We have the technology now. We’ve heard about it this morning. Let’s use it and get on with the business of saving lives, and perfect the technology as we go along. If we embrace and respect patient issues as part of the process from the beginning, we will speed the process of the giant leap forward.

Thank you very much. [Applause]

SCOTT YOUNG, M.D.: So, any question for Myrl? We have one over on the—

MALE SPEAKER: If, when a patient when in to see a doctor, the doctor gave their patient informed consent, such as, “Before you tell me anything, I want you to know that this will be used by many people against you. It will try to be used as a pre-existing condition to deny you health insurance, et cetera, et cetera, et cetera. It may be used by the CIA to check you out, if you’re okay for a job,” nobody would open their mouths, basically. And so it’s really a kind of—it’s unfortunate, but the kinds of questions we want to get from patients, particularly medication histories and so forth, often, in my experience, have been used to deny them benefits.

And I think that somehow we're not all in it together. There are a bunch of people out there who hire staff to make sure they don't give people benefits, and try to find some reason. "Oh, you took Prozac about ten years ago. That's a pre-existing condition of a depression. You can't be treated for that."

So, I don't agree with you that you go ahead, forget about the security, forget about the consequences, go ahead and start this right away. There are going to be some people who are going to get snagged in the process. And we need to find some way to really protect this data, to say, "It can't be used by insurance companies; it can't be used to find any reason to deny you care."

MRYL WEINBERG: Right. First of all, let me correct. I certainly didn't mean to say or imply that we should go ahead without concern about privacy and security. I hope I made it more clear than it seems I did that we are very concerned about privacy and security of the information. What I think I was saying is that we don't have to have everything in the whole electronic personal health record perfect.

Now, let me just say, I agree with you. My background originally, for many years, was in the disability field. But certainly people with chronic diseases have the same concerns, and those are: how can this information be used to deny me insurance or to affect my employment status? Thos are top issues for us and for all of our members. And so, we do feel we must address those. We must have the information protected in a way that cannot happen. We look at legal ways to do that, laws, regulations and others.

So, I just thank you for the question, because it allows me to clarify. That was not what I intended to communicate.

Mike, hi.

MIKE: Myrl, thank you for a stimulating presentation. It's good to have a national representative of the consumer point of view.

I can go online and I can find out how my mutual funds are doing, Vanguard, T. Rowe Price and others. I can go to something like E*Trade and find out how individual stocks are doing. And I can lump them all together in the *Washington Post* and add them up, and it will tell me every day how my portfolio is changing. It doesn't come close to the gross domestic product, but it's my domestic product.

When I go online to find out something about my personal health, I can't find it. I would love to know what happened in a hospitalization, or when I saw my doctor. I'd like to have the stuff online. Yes, I want to protect it like you want to protect it, but I want access to that information.

The best I can do is go to each doctor, each provider's office and say, "HIPAA lets you give me the information. I would like it. And, in fact, HIPAA requires that you give me the information. You can charge me for it, if you'd like," and stack up a bunch of papers. But it's in no kind of regular order.

Well, imagine to my amazement that last week I saw a blurb, and then went to the HITSP meeting, Healthcare Information Technology Standards Panel meeting, where Blue Cross association and America's Health Insurance Plans said, "We're going to take our administrative data and put it out to our customers, our beneficiaries and let them see their personal health record based upon the data we have in our files." Well, it's not clinical data, but yet it's something. It's diagnosis, it's procedures, and I hope it would be in layman's terms. This is just the start of it.

But I represent the side that wants to see more of this information available to me. But I also go along with Myrl that I want it to be protected. So, give me some passwords. Give me some way to do it.

The question is: have you taken a look at this effort to make available administrative data to individual patients? I did get from them that they would have to get individual authorizations in order to release that information to the patient. Is this something too new to form a position on, or are you aware of it and are thinking about it?

MRYL WEINBERG: We are very aware of it. We actually have a national advisory commission on electronic personal health records. So we've been talking about how you populate them at the very beginning. We are in the process, and having discussions with Karen Ignagni, who is the president and CEO of America's Health Insurance Plans. We are very supportive of and very aware of their efforts to look at some common ways that they can have all of the health plans in their membership agree to use their data, as you said, the claims data, to populate originally the personal health records for people and give individuals access to that in a protected manner. We're actually hoping to work very closely with them on this.

And what we also have learned is that people don't want to get all of the paper, that you can't necessarily translate, and try to input it into the record themselves. The reaction seems to be, if you can populate my health record with the claims data as a starting point, as Mike said, that is great. I can then start to interpret; I can add on to it. And what my understanding is that with AHIP, the health insurance plans, once they did that, then they would be looking at, and are looking at, standardized ways to interpret it or to make it potentially more user friendly to add information around it.

And the clearly the plans would compete, once you get beyond that core information, the plans would be competing for plan members by all of the disease management, educational and other information they offer.

So we are aware of it. We are very supportive of it. That’s a quick, good way to get started and get these things up and running and then have them accessible, we believe, in a secure way to all of us at home.

SCOTT YOUNG, M.D.: We are a little pressed for time, so last two questions, right to the point.

MALE SPEAKER: Thanks so much for a wonderful presentation emphasizing the critical need for consumer participation in this. I’m wondering if, in your research, you dealt at all with the issue of consumer willingness to pay anything for this, even a small amount.

MRYL WEINBERG: We did not, at least not to date. And I can’t really answer that. The one thing that I found interesting prior to this research was research that others conducted about the value of being able to email doctors back and forth. And if I’m remembering correctly, that was so valuable, both to the doctors, once they understood that I could actually save a lot of time, and certainly to employers, because the patients could just have a quick email exchange with a doctor rather than going to the office and waiting and losing half a day of work, that that was very valued. And the employers were the first to say they would pay additional at one point to make sure that those email exchanges were paid for, for the providers. But that's the only financial information about it I have at this moment.

Yes, sir.

MALE SPEAKER: Thank you for bringing in the patient perspective. There was a lot of emphasis placed on standardization this morning, earlier. And now you spoke about the challenge of educating the general population. Now, I wonder if we shouldn't start thinking about delivering a unified message, which starts very simply by just the terminology. We now heard EHR, EMR, and EPHR, and if they are interchangeable, perhaps we should coordinate so we don't confuse the patient population with different terminology, which may indicate to them different items.

MRYL WEINBERG: You know, that's a very good point. And I could be that at the very beginning of the day, someone should have provided those definitions. I know David Lansky's here from the Markle Foundation. There are others in the room. I know AHIP also has a definition. There are some very clear definitions of what an electronic personal health record is and what it isn't, and what an electronic medical record is. They're not interchangeable. They're not the same thing.

However, the electronic medical record is a core component of the electronic personal health record, around which you can build this other information that I talked about. We can’t do it now, and there’s not one perfect definition, but there are some excellent, clear, I think, definitions that do distinguish between those three different records or health technology in general. And I would just say to the conference organizers, and if I’m back, we should make sure we do that up front.

Thank you very much. Have a good lunch. [Applause]

SCOTT YOUNG, M.D.: So, I have just three last items for you, and then we’re going to get you out of here. One is brief conclusion remarks; the second is good news, and then just some notes on a transition.

So, concluding remarks: I’ll tell you, if you’ll just join me one last time in a round of applause for all of our panelists today. It was just a wonderful day. Thank you.

[Applause]

I’ll tell you, what I’ve heard all through the morning, from government leaders, our academic leaders, those of you from the private sector, our thought leaders, is that this is all about energy and momentum. We started out behind in health IT integration in this country. We started out not having the kind of penetration and integration that we needed. But we’re catching up rapidly with our partners from around the globe, and it really is about momentum. It's not an "if" but a "when." And even the "when" is getting sooner and sooner and sooner and closer to tomorrow, is what I'm hearing over and over and over again today. And that's what this day, this summit is all about, to really energize us and inform us about that future, that future that is just around the corner. And I want to thank each and every one of you for that. So, concluding remarks.

Now, the good news: I want to remind everybody—and this is all about food, which is always good news to me—I want to remind everybody that the HIMSS Summit, the 2006 Summit, begins immediately. I think 2:30 is the opening session. And I'm looking for somebody to nod if I'm correct on that. Yes. For those attending, lunch will be set up in the Exhibit Hall now. If you've not registered, please check with the registration desk to do so.

And now, for the last point, the point about transition: Earlier this week my boss, Carolyn Clancy announced my transition at the end of this month. I am taking over the reins from Paul Wallace at Kaiser Permanente's Care Management Institute. And I'll be leaving you and kind of going out and being on the front lines beginning at that time. I want to tell you just how important these last few years have been to me personally, professionally, in being with you arm in arm and making this a reality. At ARC, we have 122 programs in 41 states. We affect 40 million Americans, and each and every one of you have been part of that dream. We've been there, when we brought up the office of the national coordinator, we heard visionaries such as Myrl talk about how this works into the work that she's been doing on for years and years. And I want to thank each and every one of you for quite a ride as we're going on.

So, at that, we are concluded. And thank you.

[Applause]

[END RECORDING]