Connecting Americans to Their Health Care: Empowered Consumers, Personal Health Records and Emerging Technologies: Lunch Keynote
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DAVID LANSKY, Ph.D.: Of course all morning we've heard about the potential and the reality of using information technology to help people play a more active role in their own care, help their families be more active in helping them get the possible care. Our luncheon speaker, Eric Dishman, comes to us from the Intel Corporation. At Intel in Eric's portfolio there he's charged with empowering patients and their families to better manage their health. Actually he's doing a great deal of work it's through here not only in our country but across the world. I first came to know Eric's work through Patty Brennan who is here somewhere and hearing about the work that Intel's been interested in in ethnography, anthropology, economics really trying to get their hands around how do all of us use health care. How do we manage our own health? How do we experience our daily lives? And then what are the opportunities we have with new technology to really make a difference in people's lives? I'm really thrilled to have the opportunity to present to you Eric Dishman from Intel.

ERIC DISHMAN: Well it's great to be here. Can you hear me? Is the microphone on? Can you hear me now? I think I have to pay fee if I actually say that out loud right since I come from Intel. Can you hear me now? Yes great okay. I'm in trouble because Patty Brennan sort of set expectations high so you need to lower your expectations. I'm competing with

calories and conversation which is never a fun thing to be in that position to do. I am going to speak to you today with a couple of hats on, my Intel hat of working in a worldwide research lab on health research and innovation and I also chair something called the Center for Aging Services Technologies which I'm going to talk in a little bit about but it's not official positions or titles that are probably the most defining moments for me that have standing here today. There are probably two in my life. One is being a CPA. By that I know nothing about accounting but I'm a care giver, a patient and an advocate. At the age of 16 I spent so much time care giving for care givers of my grandmother with Alzheimer's and helping to care for her with Alzheimer's that I didn't have time to get my drivers license. For a year and a half I did not have time to get my driver's license. Now think about a teenage boy who is delaying getting his driver's license because of the impact of that disease on your household. So care giving has been something important. Alzheimer's has been something important to me and I'm going to show you some research in a minute about work that we're doing around Alzheimer's not only to help the person dealing with the disease but the range of other people who are also struggling to help that person. I'm a patient. I was diagnosed when I was 20, I'm 37 now, with two very rare kidney conditions and I've been struggling with that for a good 17 years. I've been

using a personal health director for 17 years. For the first 10 years it was Microsoft Word and sort of following the various versions of Word as it moved through the pipeline. For a couple of years I built my own web tool with people I was working with and for the last couple of years have mostly been using Groove, the online community tool. I use that with all the patients that I do patient advocacy with and combination of a Google-like search engine on top of Groove. While it's painful to use because it's not really designed and customized for kind of a PHR experience, it has a lot of features that I don't see any of these other PHRs have that I think are going to be important capabilities as we move forward that need to get rolled into the PHR space.

I'm here to talk about the most important global human challenge and we all know what this is, the blinking VCR.

[Laughter]

You know you're out there. I work for Intel and just because I work for Intel doesn't mean that I know how to program my VCR any better than you do. The sad thing about this is you would think my industry and I've got a few Intel colleagues so I'm probably going to get punished when I get back to the office but you would think my industry think that this is the number one global human challenge and the consumer electronics industry as well. Because if you think about what's motivating technology adoption in the home and the

design of new technologies it's like we're going to develop a VCR that never blinks. The remote will automatically configure itself wirelessly. It's like, "WOO HOO."

[Laughter]

That's great that's what I want to leave my mark for. Maybe we ought to be thinking about whatever device mom is close to prompts her to take her nine medications safely with that same underlying infrastructure and technology. Or similarly I see my industry saying hey you can turn on the heater or air conditioner via any internet browser from anywhere in the world. Burning human problem there right, with that same technology maybe we can monitor mom or a frail father's safety and detect and even prevent falls before they happen. This one download any Hollywood movie, never a late fee, again these are nice conveniences. These are going to pave the way with infrastructure that we can then use personal health systems on top of so it's great that these things are getting into the marketplace but maybe we ought to be streaming a multi-media coach to help mom do her physical therapy correctly. So I don't really think that's the number one global human challenge. I think this one is. This is our planet at night stitched together from satellite photography showing the lights on. Unfortunately I think the lights are on but nobody's home because I think we're largely ignoring the real number one global human issue. You think about the

discussions from Speaker Gringrch today of avian flu and the possibility of that coming to impact us. Or you think about another tsunami or another earthquake or another hurricane. We have a schedule demographic tidal wave that's on the calendar that we know is coming that's going to have every big an impact as some of those events that surprise us. So we don't need to wait for that sort of 1% likelihood of some of these things happening. This one's here today. I'm not going to go through a lot on demographics. Most of you in this room know this but if you think about our planet today versus 2050 growing from six and a half billion people to nine billion people most of that is in the developing world. The developed world stays about the same. It's the 50 least developed countries that will double. So if we are going to pretty much stay the same in most of the developed world but as you look at global life expectancy and the changes of that going from 65 to 75. We're just having conditions and diseases and experiences as human beings that we didn't have before because we didn't live that long. That changes the needs about what we need to address from a health care standpoint. Probably the most impactful will be the shift, this tripling of the number of people over the age of 60 from 670 million people today to 1.9 billion people over the age of 60 worldwide. A lot of this is in quite some surprising places like India and China and many other parts of the world. I should point out that this has felt like

a very American-centric discussion today. I understand we're in DC and understand we're talking about American policy. I spend a lot of my time and my lab spends a lot of our time studying PHR users in other parts of the world and it's arguable we have much to learn from the government of Singapore who is trying to put a personal health record in place of every citizen. Or the government of South Korea who is putting broadband into every home as a core piece of infrastructure to deliver health and wellness services down the line. While they may not have the same policy landscape that we do and the same perverse incentives that we have in the United States that keep many of these from happening, we can learn from their pilot projects and learn from them and they ought to have a seat at this table as we move forward.

One of our big challenges is as you look at that demographic age wave mainframe health care cannot scale. What I mean by mainframe health care is the metaphor of the shift from mainframe computing to personal computing. Remember it was not that many decades ago when it was inconceivable to think that what used to take up a room this size for computing and we had to make a pilgrimage to go use a mainframe computer and to timeshare it now fits into a cell phone that goes into our pocket. That same shift needs to occur in health care. We've got to move from the mainframe mentality. This is the hospital that I go to quite frequently. This is OHSU Oregon

Health Science University. I spend more of my life here than I care not just as a researcher but also as a patient as one of those CPAs. There's nothing wrong OHSU. I'm not here to make fun of it but our model that says to get good quality of care we must make a pilgrimage to this large, expensive mainframe and timeshare it with others for that kind of 15 minutes of factory line frisking that you're going to get when you're there. [Laughter] There's something wrong with that model. That model we can't pay for today and we're not going to be able to pay for it as that demographic age wave moves through and triples the number of seniors who tend to be the most expensive coming through. Very much in the spirit of some of the things that Speaker Gringrch said today where he said you can't just digitize the paper away and the current paradigm of doing things and hope that we're all right. We've got to use personal health records and systems to change the game for how we do care. So if you think about the mainframe health care system today it's primarily crisis and reaction driven. It is these kinds of 15 minute exams if that. It's population based treatment which is a great thing but if somebody who was diagnosed with conditions that they told you will die within a year 17 years ago and you go look at the statistics and you see all those statistics are based on people who are in their 80s because that's the vast majority of people who get the condition I can tell you don't always believe what the

population-based studies tell you. You need to personalize that information to your contacts. We collect a lot of data primarily biological data in that environment and we send you home with pretty much today a brochure or maybe a website for information and hope. We wait until the next crisis sort of spins you back into the system and you're back at that pilgrimage to the mainframe again. There are exceptions to this. We all know there are exceptions to it. We all like to think that our institutions our own experiences are exceptions to it but by and large this is the prototype with which we work today. We've got to think about proactive care, prevention driven, 24x7 monitoring, personalized baselines, norms against these population studies and collecting not only biological data but behavioral data, psychological data, relational data, community data and collect these things in, on and around the body and go back with a compliance paradigm that says here's some customized care plans. Here are tools that optimized for you for your cell phone, for your Nintendo system, for your large entertainment system that you're buying at home. That's the platform for doing the future of compliance. If you think about it right now today, EHRs and PHRs are a great start. We're starting to see them come online but if we're really going to get significant health care savings then we're going to have to figure out early detection, prevention, compliance and care giving. If there are one in three adult Americans

today who are delivering care to some other family member and those numbers are expected to go to roughly two in three over the next three decades, it is that informal care network who is doing the lion's share of care giving today. If we continue to develop EHRs and PHRs that just optimize your mainframe experience yes we've got a little bit more efficiency when we're at the hospital. Yes I'm a doctor and nurse and myself are all on the same page. That's an important first step but if we get all and reap all the efficiencies out of that kind of systems we're not going to deal with the scaling problem of that aging demographic. If we could magically turn a switch today and said everybody's using the electronic health record and everybody magically knows how to use all the features of if you're still not going to get enough efficiencies out of that system to come in and fix the demographic age wave that we have that's going forward. We have to take prevention, detection, compliance and care giving more seriously.

I'm going to give you a quick example of this. This is not as corporate vision videos go it's not too bad. There's no Intel announcer going, "Brought to you the power of the Pentium 4 process," or anything like that.

[Laughter]

There is a reference to Vioxx in here. I haven't re-edited it to take the Vioxx reference out so we'll just sort of let it play for itself and give you some idea of what that

shift in mainframe to personal health may look like.

[VIDEO BEGINS]

[Music]

FEMALE SPEAKER 1: Since my father-in-law died my mother-in-law lives alone. She's not that far away, an hour depending on traffic.

[Speaking Indian]

FEMALE SPEAKER 1: We visit a lot but we can't be there all the time you know. We have to be here.

MALE SPEAKER 1: It's really difficult to run the store and at the same time take care of my mother.

MALE SPEAKER 2: It's very important to check up on grandma because she lives alone and even though she's very independent we still need to make sure she's taking her medications.

[Speaking Indian]

MALE SPEAKER 1: Some are different two times a day, some with food, some with water.

FEMALE SPEAKER 1: Beta blockers, Vioxx but others like comadine [misspelled?] she has to take them in the half hour window so it's hard to keep track for her and even for us to remember all that. She forgets to take her medicines. Sometimes she will take the medicine twice so I have to watch all that.

[Speaking Indian]

[Music]

FEMALE SPEAKER 1: Plus she has to remember all the normal things. If she's getting enough sleep, eating enough, we have to keep track of all those things.

MALE SPEAKER 2: I can see right away if everything's okay, if she's been taking her medicine, if she's getting the proper exercise, if she's fallen, does she need any help. We can get to her right away. She's got a bracelet which communicates with sensors in the house so we can tell if she's having a good day or if she needs some help.

FEMALE SPEAKER 1: My mother and Honsaven [misspelled?] have been friends for years. They like to go out for walks together but now with this technology my mother doesn't have to remember to call us.

MALE SPEAKER 2: When she reaches for her cane [Ringing] her friend gets a call. It's pretty cool. It works the other way too. She's got a lamp at her house that goes on when we reach home and it's comforting for her to know that we're home.

FEMALE SPEAKER 1: She likes to know what's going on. It helps her feel connected.

[Speaking Indian]

MALE SPEAKER 2: I love my grandma. She means the world to me and if she needs my help I can be there right away for her.

[Speaking Indian]

MALE SPEAKER 1: With this technology I know she is safe.

MALE SPEAKER 2: It's like being there even when we can't be.

FEMALE SPEAKER 1: For me family is everything.

[VIDEO ENDS]

ERIC DISHMAN: Now I don't want to pretend that technology is some panacea. There are a lot of problems in this video. Actually a couple of points about this video first of all this is not a technology vision video. Everything that's in there is real and it's stuff that we're testing with real people in some way shape or form now. This is not a technology problem. People have said that today. This is a political and sort of business value proposition vision video. It's not really about the technology. The technology is not the hard part here for the most part. There are some technical challenges to this but by and large that's not the hard part. People laugh at the moment about the cane. We actually did a quick study of a dozen seniors in an assisted living facility who either use a walker or a cane and put these little simple sensor network technologies on this. Granted it's going to be a long time. We are collecting this data to try to see if there are patterns in movement that suggest they're becoming more unstable on their feet so we could actually prevent falls

before they happen or see if they're becoming more unstable on their feet as a result of lack of sleep or medication. But I can tell you today just having the family know god mom hasn't picked up her cane today or her walker hasn't moved or better yet as the person with dementia is sort of getting out of their bed and forgetting that they have a hip problem and need to use a walker and we know the no where near to the bed, turning on the lights and say don't forget to use the walker. There are some simple interventions that we can start to do today that will deliver value on the way towards that longer term goal of saying let's eradicate the vast majority of falls using new technologies as protection out there.

Down from the clouds, two things that Intel is trying to do in this phase. My lab is trying to drive a lot around personal health R&D. We're called the Proactive Health Group really about how do we invent platforms that help people be more proactive about managing their own everyday health and wellness worldwide. So a lot of our research, I'm a social scientist by training, a lot of my lab are social scientists. We start by living with and observing and studying the needs of hundreds of households around the world before we actually ever go build the first thing. We focus a lot on early detection and prevention, care giver support and I mean informal care givers here, family and friend care givers. We do outcome study so it's not enough just to build a prototype and focus

group it. We actually embed these things in controlled studies to see if they deliver cost savings or early detection and that kind of thing and I'll show you examples of that. We collaborate with industries to try to accelerate the commercialization of these kinds of things. Intel's not a health care company. We're not going to be productizing these kinds of things but from our point of view there's more to technology innovation than solving the blinking VCR or some of the other problems that the industry is focusing on today. So we need to get out there and lead by doing.

The other hat that I'm wearing today and I want to make this clear. About three years ago when my little lab at that point was three people and we started to create some of the first Alzheimer's assistance prototypes. I'll show you in a minute. We got so much press attention but the depressing part of this was we got researchers from around the globe at big companies, small companies, universities writing to us saying how the heck did you get Intel to talk about aging in public. Or you know we've got some great technologies that could help with medication compliance but we're too afraid to even go do a small trial on it because of liability issues. And they would fill in the blank with why innovation was not happening in the space of home health care and specifically with regards to aging in place. So we formed the Center for Aging Service Technologies. It's a not for profit here in DC. It's housed

under the American Association of Homes and Services for the Aging. What better group to work with to invent the future of health care than the only part of the health care continuum long-term care that treats people holistically. They have to manage people's lives and take care of them for sometimes 30 or 40 years in the facility. They've got to take care of meals, transportation, activities of daily living and yes all of the kinds of medical events that go on in the acute care setting. So from our point of view if you want to invent an infrastructure, if you want to invent a national health information database we better design it with as much holism as possible and as many care paradigms as possible, long-term care is a great place to sort of situate that. We now have 300 tech companies and providers and universities who have come together around CAST to try to remove policy barriers and other kinds of issues preventing this kind of R&D. Our next big event and I hope many of you will be there, CAST is putting on a technology pavilion of many prototypes and cutting edge products to help with aging and independence as part of the White House Conference on Aging at the other Marriott, the Marriott at Workman Park December 11th through 14th as part of that event. Expect the President and cabinet members and others to be there as well. That's been part of our big challenge is to get people to have an imagination for where the puck is going. Don't skate to where the puck has been skate to where the puck

is going and try to figure out where these technologies are going and start doing outcome studies on them now while they're sort of not commonplace so that by the time they get wrapped around and into the culture we've already got outcomes data that shows the impact positively or negatively on health care for these things.

Let me show you a couple examples of this. Again this is a people driven, participatory perspective. Every fourth Friday of the month I have five Alzheimer's patients who are fairly severe who have to get in through Intel security in our lab in Oregon who are part of our design team. So I really appreciated seeing some patients on stage. We don't call them patients but people on stage who are part of that design team from the very beginning. We also have another participatory design group of home care nurses because if you want to design good home care technologies you better figure out what good humans do when they do home care first and hope that your technology can even remotely hold a candle to what those good humans are doing. We really try to track this from a social scientific perspective and I'm going to give you three examples of people that we've been studying. These are three examples of very commonplace experiences that we found in our research. The first is Phillip. That's not his real name. This is Phillip. He's aged 73. He struggles to take 11 medications at eight different times during the day. He has diabetes, heart

disease, a skin condition, asthma, and other problems that we were aware of that his physician wasn't aware of because we actually lived with him for a week. His wife recently passed away and as he says here, "Margaret was my timekeeper. She kept me on task with my meals and my pills for decades." He's dealing with the depression and the loss and this sort of structural loss in his life that kept him on track with all the various medications he had to take. He's been hospitalized twice over the past three years for medication side effects and interactions. His daughter, Mary, who lives far away, tries to help him with sticky notes. You'll see some of these here, sticky notes all over the boxes of medicine saying this is this one and this is how many and their own little coding system which I could barely parse. These kinds of notes, Dad call Mary if you have problems or bad dreams or diarrhea from your new medicine. Or these kinds of notes, Dad don't touch these pills, Mary Kate. [Laughter] This is what the most caring families do. I mean a lot of people don't actually help out but you try to sort of label the space with an infinite number of sticky notes to anticipate all the possibilities when you go. One of the things that we did we studied 100 households who are trying to deal with meds people like Phillip. It was clear that these existing medication caddies and these kinds of things just don't work by and large for these people. It breaks the mental model. People put their pills in places

where they anticipate they're going to be and people have very different customized approaches to how they remind and prompt themselves to take their meds. So this notion of throwing it all into a medication caddie that's going to beep, beep, beep until you come take it works for a small number of people but doesn't work for a whole lot more especially those who are active elders, active seniors wanting to live not around their little medication caddie, waiting for it to dispense Pez but waiting to get out into the world.

[Laughter]

So the question becomes can we use technologies to prompt Phillip at the right time at the right place on the right every day device that he's familiar with in the way with the interface simplified and optimized for him that he really prefers. This is a trial that we're just launching on a very small scale so we do have the wireless meds caddie because it does work for some people to put some of their meds in. We know whether they've opened the drawers to it. We can put little medication reminders right there on the device itself. We know actually whether somebody's come close to it or not or has gone near it during the course of the day but we also have sensors on pill bottles that they can place around their dashboard or in their kitchen or in other places as well. We don't know that that person took that pill but we do know that they came close to that pill bottle or interacted with that

pill bottle in some way shape or form. But the important part of this on the output side is the prompts; the reminding can come to them on whatever device they prefer. So we have a watch that can remind them and this is anywhere in the United States at this point, the television can prompt them, the phone can call them and prompt them. We've built this little audio prompter that they can put around because they don't want to wear anything so they put this little audio prompter in a lot of different rooms. They even have a voice badge that they can wear that can prompt them and that they can also say shut up and it doesn't keep bugging them anymore.

[Laughter]

The point is there are a variety of things here. Actually we have the ability to send it to the cell phone as well. We have different kinds of messages that we can send. Some people prefer the carrot approach; some people prefer the stick approach. Some of the people in our study very much liked the voice of their pharmacist being the person who is reminding them to take their meds. Others are far more compliant if it's Oprah telling them to take their meds.

[Laughter]

Some people like the beeping until it actually cajoles them into doing it. That's the point the behavior is highly personalized and the technology for the first time ever can personalize the experience of meds compliance. Now we don't

know yet we're just starting the trial of this to kick the tires on the technology and see if it works. If it does then we'll move it into a more controlled trial to see if compliance increases. I'm not ready to say that but I believe there's some hope here because if you go and actually study people taking their meds which is where we started with all of this you'll see that the current systems and the current technology systems don't meet the needs of real people.

Let me give you a second example. This is Carl. He's from our Parkinson's study. Again we spent a year or actually two years studying people with Parkinson's and other based dementias and Alzheimer's to really understand a range of neurological conditions. When we go out to study 100 homes people recruited with Parkinson's or Alzheimer's or [inaudible] impairment we end up studying several hundred others because we go study their care givers or their online jockey as somebody refers to them. We go study other people around the planet who help them do their care. Carl's case was very typical of a lot people that we saw with Parkinson's. He was diagnosed with Parkinson's after getting juggled from doctor to doctor for years trying to figure out what was wrong with him. His Parkinson's actually started out as shoulder pain and stiffness. This is him sitting in his shop. He's downstairs in a shop where he does a lot of woodworking and he thought it was just he had tweaked it wrong and that was actually what it

was. So for a long time they're sending him to physical therapists and other people thinking that it's actually a shoulder injury. They did all they could to stay off of L-dopa [misspelled?]. They got on the web, they knew what was coming if they went on it and the potential side effects of [inaudible] so his wife says, "You know we did all we could to keep him off the pills but he eventually had to take them and he's never been himself since." In fact what they describe in this house is kind of two periods of loss. One was when the tremors started and he actually couldn't use the big saws and nobody would fill his purpose jar with little pieces of paper about dad make me a cedar cabinet this large. He literally had a purpose jar and nobody would put it in there anymore because they were worried about him with tremor down there with the saws. He lost the rest of himself from the side effects when the L-dopa became so severe that he really couldn't even go outside anymore and get his walks and that kind of thing in. She sits on the other side of the door when he still insists on going down with the saw to go make some things. He'll occasionally do it and she'll literally be on the other side of the door just waiting for him to cut his arm off so she can call 911. This is the life that they go through. Now one of the big problems with Carl, we went with him to his physician encounters. We lived with him and monitored him at multiple times of the year. We went with him to his exams; his annual

exam, his annual neurological battery as well as we did 100 other patients. When they go and they're still driving and making that pilgrimage in many cases. They get there. They go do the various tests that they have to do in the clinical setting once a year. They do pretty well on those tests in that clinical setting but we know having lived with them and their spouses will tell you if you give them enough time that they're not doing nearly as well as they were able to rise to the occasion and do in the midst of that neurological exam. So this is a real challenge and this makes it very difficult to capture Parkinson's early. So we're going down two paths saying how can we capture it earlier and how can we someday titrate the drug so that Carl will take it based on how he's doing on a given day to day basis not just based on take three pills like everybody else is. The first section that we're looking at and we're just embedding this into a longitudinal study with funding from the NIA and Oregon Health and Science University is looking at keystroke intervals while Carl's using his computer, keystroke button pushes on the remote control of the TV and in a kind of novel game effect because Carl like many of the other people in our study were playing solitaire or freestyle on the computer and we're looking at movements and how quickly they're playing the game and how well they're doing over a period of time. How well is Carl doing? How long is it taking him to play the game or is he losing more games based on

his particular norm over a period of time? I'm not ready to say this is going to be best early detection of Parkinson's yet. I can tell you that it definitely correlates with other data that we get like reductions in activity around the house are occurring at the same time that he's starting to lose far more games over a given month than he would normally do. So it's enough to sort of alert that something's up, something's going on. At the same time I brought the device with me. I'm not going to show it all. We have some of the canonical tests that are done clinically and we're working with Christopher Goetz at the Rush Presbyterian in Chicago and several other university neurologists from around the country. Some of you may recognize the classic Purdue pegboard test given to Parkinson's patients where you move the pegs back and forth. Others of you may recognize finger tapping tests. There's a reaction time motion time test that says when it beeps you go back and forth a number of times to see how many times you can do it. Then we hook up a headset and they actually do two voice tests. They do one where they speak to photos that appear on the screen here and they're just trying to tell a story about the photo. We're measuring two things, the amount of energy in their voice and then what's called fundamental frequency variability. This is the amount of monotone in their voice. These are classically known and accepted as part of in many cases of the UPDRS, the Universal Parkinson's Disease

Riding Scale. So we're taking accepted clinical norms but now capturing this data daily if we needed to but at least weekly from their own home and developing a trend line based on their own personal trend. By the way we're capturing a lot more information here about the details of how much struggle they're having with the pegs than any of the instruments that exist today. This is about shifting left, shifting the diagnostic experience from the pilgrimage to the mainframe to the home and this is about personal baselines where you're going to yes want those large population studies to develop the UPDRS but then see how this person is doing based on that. Again not ready to come out and say we're going to adjust Carl's medication by how he's doing on any particular given day but this is a tool that you should be thinking about as these things. This is the guts of a laptop. As these things become open platforms that are secure, reliable, it's not running Intel, it's not running Windows, what that open platform could do for you. You're going to invent things just like somebody said earlier today with the Internet. You're going to invent things on that open, standardized home platform that we can't even begin to imagine and anticipate today. When we tested this in the first round with people with Parkinson's we don't allow them to see the day because it's kind of a cold trial. It's getting sent back to their neurologist at this point. I can tell you every one of these patients is like I want to see my data. I want to know

how I'm doing. I want a day or a weekly sort of measure to see and I'm going to practice really hard. I don't know if there's a therapeutic effect but their inclination and these are mostly 70 and 80 year olds is to get that data themselves and have access to it. These kinds of things are going to go into a personal health record as much as all the meds lists and things that we're talking about today.

Let me wind up with just a last example. I'm going to go through this one even faster than I just did. This is Barbara. She was age 59 just a couple of years ago, diagnosed with unspecified dementia in 1999 after years of weirdness. It's kind of interesting when my family talks about my own grandmother's Alzheimer's experience we all called it "oh she's having one of her spells again." No one called it Alzheimer's. This is when I was 16 so it was many years ago. We didn't even really have as much awareness of Alzheimer's in the popular culture as we do today. We all blamed it on her blood pressure medication. We'd be like, "oh we need to send her to Dr. Shook to get her blood pressure medication." A lot of these families describe the same kind of thing with Parkinson's and Alzheimer's where quite frankly if you go back and look they knew a decade before that came mind or they admitted it and sort of went in to sort of do something about it. Her husband, Jim, has retired early to help be a full time care giver for her. This was an upper middle class family. Both of them were

engineers at technology companies so have been pretty much forced to spend down frighteningly fast and are nearing the levels where they can get government assistance to kick in. Gone are the life savings. Gone are the stock options because of the expense that they have done and she's fairly young with the disease. Terrified to go outside now as she has her memory lose so she's not taking her walks as she says, "I'm withering away without my tree time, without my exercise anymore." I always wondered about this note on the door because she doesn't know the difference between a stranger some days and somebody else coming in. The other thing that we found with people with the early stages of cognitive decline and again this was a year and a half long in-depth study of living with these families. I lived with Barbara's family. Terrified of the phone. Now all the people who study the disease through a microscope told us oh it's because they can't understand how to interact with a phone anymore or they don't understand that the doorbell ringing means go answer the door. This was not true for the people with the early or moderate stages of the disease. We'd test whether they could use the phone or answer the door on multiple days of the week, different times of the year. They could do it just fine. Think about the structure of a phone call. The phone rings, you pick up the phone, you say hello and if the person knows you it's one of the ways that we show we're close to one another, you just start talking. You don't

even identify who you are. These people were going into self-imposed exile because of the fear of stigma of not knowing the difference between their spouse and the mailman at the front door or their daughter versus somebody calling to sell them something on the phone. That self-imposed oppression and isolation that results from any of them has got to be a problem clinically as you move forward. This is actually Barbara practicing the names and faces of some of her friends and children on the refrigerator. So it's not only that a personal health record is going to collect all this medical data. A personal health system needs to figure out how do you help somebody manage their day to day existence as struggling with something like that. So we're doing two things here. We have basically tried to say if could measure changes in social health in meaningful way in a medically meaningful way might someday changes in social health be the best indicator of the onset of certain kinds of dementia? Don't know. We have some hypothetical reasons to believe it but now we're going to go out and test this. This is a trial that we did with University of Nevada-Las Vegas, the Jewish Federation of Las Vegas and OHSU last year and we're going to do a new version of it. Where we collected a crude approximation of their social time by saying how much phone usage, how much cell phone usage, how many communication apps are they using on the PC if they used a PC like instant messaging and e-mail and how much time are they

spending with other people. We munged [misspelled?] that into this kind of social health index and collect data for many months to kind of “develop their norm” and then look for deviations in that. I don’t know whether that’s going to ever help with early detection or not but I can tell you at the same time the same data that we’re using and collecting longitudinally we’re now using to use with assistive technologies to help somebody like Barbara stay socially active. In this case she has a conversation journal where she types in a few notes and the people that she talks to on the phone, the chose people who she’s chosen to be in her care network and to see this data, type in a few notes so they can go back and look at it. There’s a caller ID on steroids little box. We put a little photo frame next to her landline phone and when a call comes in it shows the picture of the person who’s calling, what your relationship is with that person and based on the journal what you last talked about with them. I can tell you that this crude really crappy prototype that we’ve put in these people’s lives was game changing for them. They did not want to give it back they loved it. I’m not ready to say hey there’s a clinical outcome here yet but I’m ready to say these things made an impact on people’s lives.

I’ll show you one other example of what we did. So this is just an example of a little card that pops up of saying this is your friend Kevin calling. By the way all the Boomers

who have no memory problems whatsoever who are the family care givers wanted this as well. They're like where do I sign up.

[Laughter]

It just goes to show study the extremes and you'll design well for the rest of us, classic European argument of universal design. This was an interesting personal health visualization tool. This showed somebody like Barbara at the center of her social universe and these were people that she said are part of her care and communication network. What you're seeing in the trail there is some people moving closer to her based on what all the sensor data is collecting. Some people call this the inheritance detection system.

[Laughter]

Because the good children are in close and the bad children are way out on the edge and now you've got a computer data record to prove it.

[Laughter]

We laugh about that. It shows the ways in which these technologies will be used in unanticipated ways and real privacy issues based on the experiences people go through. But of the people who were in this study they liked this view as a therapeutic tool. They could look at their solar system and say oh my god Diane is way out there. She's one of my best friends from high school. I then put my little sticky notes and all the other things around me to make me say okay I'm

going to pull Diane in closer to my life. They start doing phone calls. They start going out for coffee and show slowly Diane starts to move in. They can see visually the progress that they're making. This is a personal health record. This is a personal health visualization tool. It's not what most of us are building but it's the kinds of killer apps if you will that are going to drive a lot of the people that we want to use these things to actually use them.

Let me close with just a couple of comments here. Most of the PHRs today are digital forms. I think there's an exception but this is actually just kind of a strict out version of the CCR. Most of them are kind of digital forms that do health care like we do today in the mainframe way. And we're really trying to optimize today the clinical encounter. It's not surprising. The clinical encounter is so data poverty such a poverty of data that we do need to improve that but I want to argue that we need to move much more to interactive kind of all device systems. What I mean by that is it is the cell phone, it is the television, it is the PC, it is the PDA, and it is whatever platform they have in their everyday life as the stuff you should be designing towards. It needs to look something more like this. This is just a prototype PHR that we've been playing around with with people. It shows my calendar, it can show a household view. It can go into different health spaces. It can pull in content from WebMD,

from Mayo, from Weight Watchers. Most of the people that we've studied especially outside of the United States want five to six content streams so they can compare them. They get a second opinion in the stream of data coming into them. What does WebMD say I should do? What does the Fruit Loop diet club say I should do about this disease? They need those points of view and to be able to dial between them in a fairly easy way. I was going to show you a demo of that. I'm going to skip over in the interest of time and just make a few final comments here.

If you think about personal health systems as opposed to records and in a record in itself kind of implies this kind of passive relationship to it even though it's dynamically updating. I like Speaker Gringrch's phrase of "personal health knowledge systems." It's a personal health community system, personal health activation systems. How do you activate people to do the right thing? I think we're kind of at this phase now of generation one or two where it's kind of a personal health record. We're going to get the meds in there. We're going to get the appointments in there. I just had a big medical interaction experience myself even though I've been using a PHR. The long and short of it is because of the medical interaction I had and the negative side effects of it I ended up missing a clinical trial that I was going to try to get on. That was the first time in 17 years of clinical trial focused

on my kidney disorder all because of a medical interaction error. I understand how important it is to start with that baseline. Then you see generation two where we're starting to add content and services to those that are somewhat interactive or somewhat personal. They tend to personal only if you've gone through the trouble of filling out the preference list which almost nobody ends up doing but they're getting there. We're starting to see doctor patient communication and disease management content come into those. If you think about the third generations where we're going to really add community, this is when I use Groove because it allows me to invite people in in a secure way and have presence like you do with instant messaging to say this patient that I'm advocating for is in the space right now. We can share a calendar with each other. We can share data that we just pulled into our records together. We can chat or we can not even say anything to each other but having that sense of community in there where you have a range of communication tools is a pretty powerful thing. The fourth generation is where you start to think about the diagnostics and the devices, these kinds of things just traditional home diagnostics that data populates it and starts to send the data back out to every day devices and to help you proactively do what you want to do. Think about that dashboard for the personal and family health system that starts to coordinate and makes sense of all that data. One of the studies that we're

funding is just how do people worldwide across cultures want and are able to visualize their own health information. That's a hard problem. People aren't good at charts and Excel sheets and things like that. What are the different trends and ways in which real people can visualize data in a meaningful way? Then kind of a fifth generation of personal health agents and assistants in some cases the best way to remind you to do something is like in the video call your daughter and she tells you to take your comadine. For other people an interactive agent or assistant is a perfectly fine way for them to remember to take this and maybe it is in the voice of Oprah or the voice of somebody that they care about in a highly personalized content and care plan with comparative search across. We've found this everywhere we've gone. People want comparative search. They want to be able to see this perspective, their physician's perspective read against the national perspective read against the Good Housekeeping Seal of Approval perspective and weight the consequences of those different points of view. As we think about moving towards personal health systems I think a couple big items. We've got to build a national infrastructure that supports this personal health paradigm. The worst thing we could do as a nation is build a national infrastructure for a 19th century model of care. I mean just digitizing all the stuff but doing it the old way is going to kill us literally and we can't scale to meet the demographics

of that. That's very frightening. It's one of the reasons CAST exists is to try to get the voice of long-term care at the table in the national standards debate about records because they have that much more holistic perspective of care than the acute care setting has that's driving most of that debate. We've got to accelerate a shift from these early static PHRs to advanced interactive personal health systems. These records need to be personal, private, portable – you heard about that today regardless of which health plan you're in – and I would argue proactive. If they don't make you proactive about changing behavior then we're not going to save a lot of money in the long run. There's going to be new data types that we're not even anticipating. These do your solitaire experience, how much social time that you have with other people. There are going to be increasingly connected and inter-operative health and wellness devices at home, personalized services for coaching and prompting and cajoling, and interactive content like I spoke about before. All of those pieces are existing. Some of you are vendors who are focusing on the little pieces of all of that but there's no integrated whole yet. None of us have tested the outcomes of a true personal health system I would argue at this point. We're testing outcomes in little bits and pieces and we may find because there's not much value in the bits and pieces but there's non-summative quality that if we tested the outcome of the whole working system it may be

exponentially better than the individual pieces as well. The last two we've got to catch up with Europe and Asia. I encourage you if you haven't gone to go spend time. I just got back from an EU meeting about personal health systems of the future. There's $12 billion in the seventh framework to fund health IT research but they're very open to funding home-oriented, consumer-oriented, personal-oriented research. The age wave is hitting European nations first. Because of CAST I can tell you with HP, GE and Honeywell and ADT and Philips and Medtronic and all the people who have come to CAST they're telling us liability fears are stifling innovation of doing this in the United States, the lack of cross-state licensure. At the EU meeting they were talking about how to do licensure for doctors and nurses across national borders and we can't fix it across North and South Carolina.

[Applause]

This is embarrassing. Broadband for every citizen is well behind in the United States than other nations whose governments have said this is a key future platform for delivering home care. Research funding I would argue here largely ignores personal and preventive health. We give lip service to it but we don't fund the kinds of systems research that really needs to take this seriously. Finally realize that this is not science fiction. This is starting to happen today. These technologies are not science fiction. I could have shown

some much more sort of new age science fiction technology than I did today. These are increasingly available and affordable. These will increasingly be adopted by the boomer population who are going to be the most proactive about their health and wellness than anybody. The vision is achievable if we can achieve that kind of go to the moon rallying cry to face this age wave head one. Back to that opening diagram I showed of the lights of all our nation but nobody's home. We're largely ignoring this issue and the fact that we only have an aging conference once every ten years I think should be indicative of that. Lastly the biggest barrier is imagination and perspective. We've got to re-imagine the health care mainframe. We've got re-imagine in my industry what the heck technologies are for. People don't need 400 cable TV channels. There are other things to spend their energy on. We've got to re-imagine who seniors and who users are. Our definition of elders and our stereotypes of elders based on our parents' situation is not going to necessarily apply towards this next boom that's coming through. I invite you to join us at the White House Conference on Aging. You can see these prototypes in action along with 30 other universities and research labs and early cutting edge products including some PHR vendors. I appreciate your time today. Thanks.

[Applause]

MALE SPEAKER 1: Thank you so much Eric. That was

remarkable, inspiring, and instructive, appreciate all that. We're now ready to break out to some smaller groups where we'll have a little more interaction and discussion. There are four locations and four topics. Each one lasts one hour. You have time for two of them. I know you indicated a preference. You're free to pick and choose right now where you want to go. Let me tell you what's coming up. One session will be in this room. I'm going to moderate in this room a policy discussion here. John Rother from AARP will kick it off with some perspective on behalf of consumer groups, how they view all this. Then we'll have four Congressional staffers and former Congressional staffers talk about what does this mean politically and in terms of policy making. Then we will have in the three rooms that are along that far wall outside in the foyer. I think the farthest one is Salon E if I have it right. My colleague Stuart Sheer from the Markle Foundation will moderate a discussion of the public opinion data you heard a little bit about earlier today in terms of public attitudes toward all that we've been talking about and the consumer principles that we mentioned earlier. Then Group Health of Puget Sound which has also been mentioned earlier which has both been supporting a personal health record for their members but also have done a lot of work in communicating to the community in the Seattle area about the benefits and the opportunity to use the technology. They will also be part of

that panel in Salon E that Stuart is managing. In Salon F Scott Young from the Agency on Health Care Research in Policy Quality will lead a discussion with two of the RHIO's the Massachusetts and North Carolina Regional Health Information Exchanges along with Alison Ryan from the National Consumer's League will talk about how do consumers how does the public get involved in these emerging regional health exchanges. That'll be I think in Salon F. And then in Salon G, this corner I believe, Esther Dyson probably our country's leading writer and analyst of the emerging information technology industry will moderate what I think you'll find a very edgy discussion that we're calling how do big changes happen and will be I think pursuant to Eric's comments talking all the way from Eastern Europe to cell phones. What are the ways that really transformative change happens in modern society? That'll be really a focus on the disruptive technologies that I think Eric has teed up for us. That's our plan. You have two opportunities to go to any of those four sessions. There'll be a break about 15 minutes at 2:30 I believe is the break and then we'll come back in here for the closing session at four o'clock try to make sense of the whole day. I'm sorry to tell you that unfortunately Congressman Kennedy who we had planned to have as our closing speaker just yesterday told us he has a personal matter and is unable to come this afternoon so we're going to have a closing round table discussion with some of our

experts and try to predict the future of this field in the next year or so. So with that I will send you off to these four sessions and hopefully see you back here at four o'clock. Thank you.

[END RECORDING]