

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH  
INFORMATION TECHNOLOGY

ROUNDTABLE: PERSONAL HEALTH RECORDS  
UNDERSTANDING THE EVOLVING LANDSCAPE

Federal Trade Commission Conference Center

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## 23 Panel 4:

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1 P R O C E E D I N G S

2 (8:30 a.m.)

3 MS. PRITTS: Can I get everybody to take  
4 their seats, please?

5 Welcome. It's good to see everybody  
6 here this morning. I am glad that we had such a  
7 good attendance for this event. We're very  
8 excited about our program for today. We have --  
9 are we on the webcasting at this moment?

10 I'd also like to extend a welcome to  
11 everybody who is listening over the Internet. It  
12 greatly expands our audience, and we want to make  
13 sure that we include you in all of our discussion  
14 today.

15 We're here today to talk about personal  
16 health records, understanding the evolving  
17 landscape. Before we get started, I'm going to go  
18 over the necessary housekeeping details here to  
19 make sure everybody knows everything about what we  
20 need to do in case of emergencies, personal or  
21 otherwise.

22 So anyone who goes outside the building

1 without an FTC badge will be required to show your  
2 ID again as well as go through all the security  
3 again when you come back in. So if you leave,  
4 you've got to go through the whole same process  
5 when you come back in.

6 In the event of fire or evacuation --  
7 pay attention here -- of the building, leave the  
8 building in an orderly fashion. Now, this looks  
9 like a good group. I think you can follow  
10 directions, so I'm pretty confident that we can do  
11 this.

12 Once outside the building you need to  
13 orient yourself to New Jersey Avenue. Across from  
14 the FTC is Georgetown Law Center. Look to the  
15 right front sidewalk, that's our rallying point.  
16 Everyone will rally by floors. We'll all just  
17 rally together, okay? And then we'll just make  
18 sure that -- we'll try to make sure that everybody  
19 is out.

20 In the event it's safer to remain  
21 inside, you will be told where to go inside the  
22 building -- that's a loaded question.

1           Okay, if you spot suspicious activity,  
2           please alert security -- that's very suspicious  
3           activity, not somebody who's swiping your pen,  
4           okay?

5           The restrooms are located on this floor.  
6           You go out these doors here. You go out the main  
7           door that you walked in when you signed in and you  
8           will see where the guards are. You just job a  
9           little bit to the left and go down that hall and  
10          you're down there.

11          We have breakfast items that are still  
12          available until 9:00 a.m. Lunch items will be  
13          available for purchase in the hallway from 11:45  
14          to 1:45, and we are very grateful for the vendor  
15          who came in to offer these items to us because it  
16          was not an easy process, and so we are very  
17          thankful for them who were willing to come in for  
18          a relatively small crowd and provide this service  
19          to us.

20          Importantly now, pretend like you're at  
21          the movie theater and please turn off your cell  
22          phone. Put it on vibrate or turn it off, and if

1       you need to use your phone, please go out in the  
2       hall to do so and stand away from the door so that  
3       it doesn't interrupt the proceedings. These  
4       proceedings are being videotaped so not only will  
5       you interrupt us now, you will interrupt us  
6       forever on the website. And if I know your name,  
7       I will say it.

8                 WiFi is available in this conference  
9       room, and you can see the registration for further  
10      information.

11                Is there any other housekeeping detail  
12      that anybody feels a pressing need to know right  
13      now?

14                SPEAKER: Hash tag? Is there a Twitter  
15      hash tag for the Roundtable?

16                MS. PRITTS: I'm sorry?

17                SPEAKER: Is there a Twitter hash tag  
18      with the (inaudible)?

19                MS. PRITTS: Is there a Twitter? I  
20      don't know the answer to that?

21                SPEAKER: PHRR.

22                MS. PRITTS: PHRR?



1                   SPEAKER: Yes.

2                   MS. PRITTS: There you go. Somebody in  
3 the audience knew the answer. Good. I'm glad.  
4 I'll get you for that, Steve, okay.

5                   All right. So now we're ready to get  
6 the show on the road, and it's going to be a  
7 fascinating day talking about personal health  
8 records. Here to welcome you this morning we are  
9 very fortunate to have -- we're very fortunate to  
10 have David Blumenthal, who has been leading the  
11 Office of the National Coordinator for Health  
12 Information Technology.

13                   I've been at ONC now for since February,  
14 and I will tell you that ONC is not an easy  
15 organization to lead. It is like an Internet  
16 startup company, but in addition to having all  
17 those techie type of people, we have a whole  
18 concentration of doctors and lawyers, and, you  
19 know, I can't think of a more interesting mix to  
20 have in one organization, all of whom are sure  
21 they have the right solutions for the right  
22 problems and they're all different. So it's a

1 very good, exciting challenge. And David has his  
2 hands full on an hourly basis, and we're very  
3 fortunate to have him lead us from being a very  
4 small office to a much, much larger office in  
5 these really exciting times.

6 So I'm going to turn it over to David to  
7 make a few welcoming remarks. (Applause)

8 DR. BLUMENTHAL: Thank you, Joy. Thanks  
9 to you and to all the ONC staff and colleagues  
10 that have been organizing this activity today.  
11 Thanks to all of you who have come. Joy is a  
12 terrific asset for the ONC in terms of the privacy  
13 and security, and other issues we have to deal  
14 with. Her post, as many of you may know, was  
15 created under the HITECH Act, the first time that  
16 the Department of Health and Human Services has  
17 had a chief privacy officer, and it's added  
18 enormously to our ability to focus on these  
19 terribly important issues and incorporate them  
20 into our planning the way they should be.

21 This program is part of a  
22 congressionally mandated activity for the Office

1 of the National Coordinator that we examine the  
2 privacy and security concerns surrounding  
3 non-HIPAA-covered entities.

4 You're having trouble hearing me?

5 SPEAKER: They just turned on the AC  
6 (inaudible).

7 DR. BLUMENTHAL: Is this better? This  
8 would definitely be better. So I'm height  
9 handicapped, and often the AV stuff just doesn't  
10 work for me, so I will talk, I will bring the  
11 microphone to me rather than move to the  
12 microphone.

13 As I was saying, this activity today is  
14 part of a HIPAA -- I'm sorry, a HITECH-required  
15 study of the implications of the need for privacy  
16 and security activities related to  
17 non-HIPAA-covered entities and not -- and their  
18 business associates. We're doing this in  
19 collaboration with the Federal Trade Commission,  
20 who -- which has very generously have given us  
21 access to this facility for the day, and we will  
22 be working with them over time.

1           As many of you know, they've also been  
2 active in the general area of privacy and security  
3 for commercial activities beyond the HIPAA rules  
4 and have published a report on that just this  
5 week.

6           The question of personal health records  
7 and other novel devices and mechanisms for moving  
8 patient and consumer health information around the  
9 health care system is a critical part of the  
10 larger challenge that we at the Office of the  
11 National Coordinator have to take on. And I want  
12 to just put it briefly in that larger context for  
13 you. The Office of the National Coordinator is  
14 charged under the HITECH Act with creating a  
15 nationwide, interoperable, private and secure  
16 electronic health information system. That's a  
17 lot of words. It's also a lot of work and a big  
18 challenge.

19           I try to remind my staff, when things  
20 look almost insuperable, that this is something  
21 that has never been done before. It's the  
22 equivalent of a Mars shot. So there are a few

1 countries the size of modest-sized states in the  
2 United States that have made significant progress  
3 along this route, and we are very happy to see  
4 that progress, and it provides a great example of  
5 potential routes to success.

6 But the idea of taking a country and a  
7 health care system that extends from the Bering  
8 Straits to Key West, and also out to Hawaii, and  
9 making an information system that is  
10 interoperable, private and secure, usable,  
11 user-friendly, doing that in the modern world with  
12 all the political and organizational and economic  
13 challenges that our country faces, as well as the  
14 appropriate and necessary demands for consumer  
15 access and consumer protection and privacy and  
16 security, that is truly a novel, unprecedented  
17 effort at social change, the improvement of  
18 society broadly. Our success will depend on at  
19 least two things: First of all our ability to  
20 relate, but then also our ability to stay constant  
21 to certain important principles.

22 The innovation will include the

1 innovation and technology. The technologies that  
2 we are here to talk about: the personal health  
3 records, multiple devices, all the other things  
4 that seem to spring up, suddenly becoming apparent  
5 on the front pages of the paper and the tech  
6 sections of the paper or in the technical  
7 journals. Those are part of the key to our  
8 success, and we want very much to not only be  
9 receptive to that innovation but to encourage it.

10 Most of you, I hope, are familiar with  
11 the meaningful use framework, that part of the  
12 HITECH law that provides incentives for providers  
13 of care to adopt certified electronic health  
14 records and use them in a way that promotes  
15 patient health and health system improvement.  
16 That meaningful use framework has done already one  
17 very, very important thing, and something that our  
18 office can claim very little responsibility for,  
19 and that is to set off an explosion of innovation  
20 and the recruiting to the health sector of IT  
21 talent that before had largely focused on other  
22 areas of the economy.

1           So it's hard to see a day go by without  
2           hearing about some large IT company that is now  
3           making a commitment to the health space when  
4           before it was focused on completely different  
5           areas. It could be Intel, it could be Verizon, or  
6           it could be IBM, it could be Hewlett-Packard, it  
7           could be Google, or it could be Microsoft, but all  
8           these companies are flocking in, and even more  
9           interesting, there are just tons of new companies  
10          that didn't exist a couple of years ago that are  
11          bringing novel products to the market. And we  
12          cannot be successful unless that process of  
13          innovation continues. And where it will take us  
14          nobody can predict, but we will not be successful  
15          without it.

16                 At the same time, while we allow and  
17          encourage that innovation, we have to be  
18          consistently constant in our commitment to certain  
19          basic principles. One principle is that the  
20          patient and the consumer come first; that  
21          everything we do is guided by its potential  
22          benefits and takes into account its potential

1 impact on the average individual, the patient who  
2 every day contacts his or her provider of care,  
3 whether it's in a nurse's office or a physician's  
4 office, or a large hospital or critical access  
5 facility, whether it's online getting health care  
6 advice or shopping for -- online for a piece of  
7 durable medical equipment, whatever it is. The  
8 patient's interest, the consumer's interest has to  
9 be a guiding light for us, and as part of that,  
10 their faith in the privacy and security of what  
11 they're doing, of their personal health  
12 information also has to be a guiding principle in  
13 our work to assure that that their faith maintains  
14 strong and is justly placed.

15 Innovation will be one of the assets to  
16 assuring that and containing that principle  
17 because as technology improves, our ability, I  
18 hope, both to advance the patient's interest in  
19 information-sharing and the patient's interest in  
20 privacy and security, our ability to advance both  
21 those simultaneously we hope will improve.

22 Part of that, maintaining that



1 principle, is meetings like this one where these  
2 issues are discussed in an open and transparent  
3 way. We heard a lot about security in Joy's  
4 introduction, but we are distinctly not making  
5 this a private event. We want it to be open. We  
6 want people to have access to this discussion, and  
7 in the workings of the Office of the National  
8 Coordinator over the last 18 months, we have had  
9 well over 200 public meetings of our federal  
10 advisory committees in which all the issues that  
11 are before us have been discussed in the open, so  
12 that anyone who's interested can tune in.

13 We hope this study will continue along  
14 those veins and in an open and transparent way  
15 continue the process of dealing with the most  
16 critical, or one of the most critical issues that  
17 we face, and that is to maintain trust in our  
18 health information systems.

19 We have a terrific group of scholars,  
20 experts, policymakers, and others here today to  
21 help us with that work. We have consistently  
22 benefited from the expertise of people in the

1 various fields in which we work. We could never  
2 have done what we have accomplished without them,  
3 so we thank you. We thank you for being here, we  
4 thank you for your continued commitment to the  
5 work we're doing, and we look forward to  
6 benefiting from your expertise.

7 Thanks again to Joy for organizing this,  
8 and I look forward to listening in as the  
9 discussion proceeds.

10 (Applause)

11 MS. PRITTS: Thank you, David. I'm  
12 going to do just a little bit of setting the stage  
13 here before we move into a main part of our  
14 program, and before I get that, I would like to  
15 point out -- Kathryn, could you raise your hand,  
16 please? As Kathryn Marchesini, if you have some  
17 issues today -- Jennifer, are you in the room,  
18 too? Lazenby?

19 Well, if you -- there she is -- there is  
20 Kathryn and Marchesini, and Jennifer Lazenby, and  
21 if you have questions or issues that you need help  
22 resolving today, they're here to help assist us.

1 They have been both very instrumental in putting  
2 this panel together and, among their other duties,  
3 they're just here to make sure that things run  
4 smoothly. So thank you very much.

5 So let's set the stage a little bit  
6 about PHRs and how health care and health  
7 information is evolving even as we stand here  
8 today. We're entering a period of which is almost  
9 like the perfect storm for the development of  
10 health information technology around consumers.  
11 We have all these general efforts going on for the  
12 adoption of health information technology and  
13 health information exchange trying to get  
14 providers to actually get the information into  
15 electronic form so that it can be easily shared  
16 with each other.

17 We also have health care reform and  
18 along with a lot of the efforts of health care  
19 reform that are centered on making sure that  
20 people have more access to care, that their care  
21 is better coordinated, that the patient is really  
22 the central focus of health care is the idea that

1       it is, and that the patient is at the core of that  
2       health care and has some responsibility for  
3       ensuring that health care and taking care of their  
4       own health in helping to ensure that their health  
5       care is coordinated, making sure that they are a  
6       part of the process here. It's not -- health care  
7       is not something that is being done to an  
8       individual; they are a partner in that, and that  
9       surely is part of health care reform.

10                In both of these efforts, the individual  
11       becomes key. It is not about - it is  
12       patient-centered care is what we're really aiming  
13       for. We need both the technology and the other  
14       incentives in order to make that happen.

15                We have a lot of efforts going on to  
16       make sure that the providers are brought into the  
17       system, so in our office in particular we have  
18       regional extension centers to help bring the  
19       health care providers along so that they can  
20       qualify for meaningful use payments, and really  
21       get them up to speed on electronic health records  
22       and adopting this new technology. They are also

1 working with some of the critical care hospitals.

2 We also have efforts at the state level  
3 to help bring, make this a coordinated effort on a  
4 more regional basis so that the information can  
5 actually be shared regionally at the state level.  
6 So we have at that level, level of the providers  
7 and at the levels of the administrators, and we're  
8 making a lot of efforts in those areas.

9 So what are we doing to help the  
10 individual because right now the way most  
11 individuals take care of their health information,  
12 if they do it all, is with a paper file, or boxes,  
13 or a bag full of prescription medications that  
14 they take in to the doctor and say, "This is what  
15 I am on." And I think we've all concluded that  
16 that just is not acceptable anymore. That is so  
17 19th century and here we are in the 21st century,  
18 and we really have to make a little progress in  
19 this area.

20 So some of the ways that we are going to  
21 -- that we're making efforts to help the patient  
22 in this whole effort are set out in meaningful

1 use. For those of you who are -- I can't believe  
2 anybody in this crowd would not be familiar with  
3 the meaningful use terminology, but meaningful use  
4 relates to the fact that if a health care provider  
5 meaningfully uses an electronic health record,  
6 they will receive incentive payments? And as part  
7 of that effort, they are going to be expected to  
8 give patients access to their own health records.

9           HITECH also focused on patients in  
10 particular, and there are provisions in HITECH  
11 that provide for the electronic access of  
12 information upon a patient's request. There are  
13 also portions of HITECH that address PHRs and  
14 similar technology, in specific. Congress  
15 recognized that there is a burgeoning effort in  
16 this area and wanted to ensure that at least that  
17 the information -- at the very least -- that if  
18 the information was breached, if there is a  
19 security breach or it was obtained  
20 inappropriately, that the individual would be made  
21 aware of it.

22           But Congress was also concerned about

1       whether there are other, potentially other  
2       requirements that might be necessary in order to  
3       continue to protect this information as we move  
4       forward, and as part of that they required that  
5       this study be done to inform them of what should,  
6       if anything, should be done with respect to  
7       protecting the privacy and security and the  
8       safeguarding of health information as it moves  
9       beyond medical records into these other forms of  
10      transferring and using health information.

11                 We have in the United States a very  
12      sector-driven approach to regulating health care,  
13      and what that means is that our laws are written  
14      so that they apply to doctors, to hospitals.  
15      HIPAA itself is somewhat sector-driven and applies  
16      to health care providers and health plans and  
17      health care clearing houses, and now with the  
18      amendments at HITECH also to business associates.  
19      But we all recognize that that still leaves some  
20      gaps in protecting of the health information.

21                 So we have a lot of information, we are  
22      encouraging it to be shared, and there are a lot

1 of things going on here, as you will soon learn  
2 from the panels coming up, but a lot of it raises  
3 what -- a new but also what I would call an  
4 age-old question -- which was posed by Thomas  
5 Jefferson, who had said that our laws and  
6 institutions must keep pace with the progress of a  
7 human mind. Well that is quite a challenge today  
8 when we look at the differences in even what a  
9 computer -- a flash drive.

10           When I started using a computer, I'm  
11 ashamed to admit almost that we used punch cards,  
12 and in my lifetime we've gone from the computer  
13 capability of something that's in a room can now  
14 be held on a flash drive that's this big. And  
15 with that kind of change, it's very difficult for  
16 the policy to stay up with the technology, but  
17 that's exactly the challenge that we face today.  
18 That's exactly the issue that we're looking at  
19 today is how are we going to be able to strike  
20 that right balance between maintaining the  
21 innovation but making sure that the information is  
22 being used for the purpose that the individual



1 believes that it's being used for and has agreed  
2 that it should be used for.

3 In order to do that, we have four panels  
4 with us today. We have some amazing talent in  
5 this room, and we are very grateful that everybody  
6 was able to join us.

7 Our first panel is -- we will introduce  
8 all of the individuals speakers by the panel -- so  
9 that you will have a better understanding of how  
10 they fit into the scheme of things. In our first  
11 panel, we'll discuss PHR origins, developments,  
12 privacy and security practice. They will be  
13 followed by a panel that addresses the new forms,  
14 the new audiences, and the new challenges of PHRs.

15 After our little lunch break, we'll have  
16 privacy and security of identifiable health  
17 information in PHRs and related technology, the  
18 expectations and concerns, and then our last panel  
19 will address the perspectives on privacy and  
20 security requirements for these PHRs and related  
21 technologies, and they'll explore a little bit  
22 about what the current state of regulation is and

1       whether any additional, any additional means of  
2       protecting the information, whether it be  
3       self-regulation, industry standards, legal  
4       regulation, those types of things are required and  
5       necessary, or may they actually impede  
6       development?

7                       We'll then have a brief period for  
8       public comments.

9                       So I'm glad to have you all here. I  
10       think it's going to be a long and very interesting  
11       day today, and we're going to start with our first  
12       panel, if they can come up to the stage, please.

13                      Our first panel today addresses the  
14       origins, developments and privacy and security  
15       practices in PHRs. We are sorry to say that Jodi  
16       Daniel, who was originally scheduled to present on  
17       this, to moderate this panel, is not able to be  
18       with us today. She has been ill week. In her  
19       stead we have Kathy Kenyon, who is very familiar  
20       with this area. She's been working very hard with  
21       us over the summer in putting this panel and some  
22       of the other panels together.

1                   Kathy is a senior policy analyst at  
2                   ONC's Office of Policy and Planning. She works  
3                   with Jodi in that role. She's been here with us  
4                   for about 15 months now. She's an old hander by  
5                   ONC standards. She comes with 23 years of  
6                   experience as a health lawyer working mainly with  
7                   large provider organizations that have been early  
8                   adopters of health information technology. And at  
9                   ONC she works on consumer engagement and patient  
10                  safety issues among other things, and we are very  
11                  grateful for her for being here today and stepping  
12                  in when she was needed and for helping us just in  
13                  general. And she will moderate this session and  
14                  introduce her panelists.

15                  Thank you, Kathy. (Applause)

16                  MS. KENYON: Thank you very much. First  
17                  I want to extend Jodi's regrets. I heard from her  
18                  by e-mail this morning, and she has no voice, but  
19                  she would have loved to have been here.

20                  The panelists we have here today will  
21                  help us understand the origins and business models  
22                  of different approaches to personal health records

1 with special attention to the privacy and security  
2 practices. Each panelist represents a distinctive  
3 chapter in what is really a very brief story of  
4 PHRs. Kaiser Permanente, represented by Tim  
5 McKay, who's Director of Digital Identity  
6 Services, Kaiser, of course, has been a leader  
7 among large integrated health systems in use of  
8 electronic health records and in development of  
9 ways to get information to patients, including  
10 through personal health records.

11 Tim has been a part of Kaiser  
12 Permanente's Internet Services Group since 2000.  
13 He began his career as a pediatric clinical  
14 psychologist and applied researcher in population  
15 health management. Today he's responsible for  
16 Kaiser's flagship website, which is KP.org. That  
17 website hosts more than 3.2 million active  
18 personal health record accounts for Kaiser  
19 Permanente's 8.6 million members.

20 The next is Shared Care Plan,  
21 represented by Lori Nichols. She's Director of  
22 Whatcom Health Information Network and represents

1 a community-based approach to PHRs driven both by  
2 providers in the community and consumers. Whatcom  
3 County in Washington is north of Seattle and south  
4 of the border with Canada, as I understand it.

5 MS. NICHOLS: Just barely.

6 MS. KENYON: I understand, okay. Ms.  
7 Nichols has served as program director on six  
8 different major grants to build an E-health  
9 infrastructure in Whatcom County in areas such as  
10 health information exchange, E-prescribing and a  
11 person health record bank pilot.

12 Then we have Active Management PHR.  
13 It's represented by its President and CEO, Dr.  
14 George Steinberg.

15 DR. STEINBERG: Greg. Gregory  
16 Steinberg.

17 MS. KENYON: Greg. No, it's not, not  
18 George, Gregory.

19 DR. STEINBERG: It's all right.

20 MS. KENYON: And ActiveHealth Management  
21 has its roots in Aetna Healthcare, but it's moved  
22 front and beyond that, and we'll hear more about

1       that later. But its roots in Aetna means it's  
2       based in a covered entity. Obviously, health  
3       plans have been major drivers of PHR development,  
4       so he represents that perspective.

5                 Dr. Steinberg is a cardiologist who is  
6       also an associate clinical professor of medicine  
7       of Columbia University and a senior attending  
8       emeritus physician at St. Luke's Roosevelt  
9       Hospital in New York City.

10                The next panelist is Dossia represented  
11       by its CEO, Colin Evans. It's a PHR company that  
12       was established by large employers as they try to  
13       address the health care needs of their employees.  
14       Colin Evans comes to us initially from the United  
15       Kingdom. He became Dossia's CEO in 2009 after 29  
16       years with Intel where, among other things, he  
17       served as the Director of Digital Health Policy  
18       and Standards. He's been deeply involved in  
19       industry standards initiatives and has led  
20       research on virtualization, trust and content  
21       protection technologies, and on the development of  
22       platforms for home health monitoring.

1                   And finally, we have Microsoft  
2 HealthVault represented by George Scriban, who's a  
3 senior program manager. Of course, Microsoft  
4 HealthVault is one of the best known vault model  
5 PHRs by a major technology company. Mr. Scriban  
6 has been involved in the business side of  
7 technology for 15 years and is responsible for  
8 product strategy, marketing, and planning for the  
9 core Microsoft HealthVault platform with regard to  
10 privacy, security, and compatibility with industry  
11 standards. This is a relatively new and dynamic  
12 industry, and the panelists today will help us see  
13 it from their perspective.

14                   And with that I think we're going to  
15 move right into some of the questions.

16                   Now, the format for this in each of the  
17 panels is going to be kind of I'm going to ask  
18 questions, but these won't be new to the  
19 panelists. The panelists know what the questions  
20 are, and so they've kind of planned their answers.  
21 I'm hoping that we get some interaction because,  
22 as it turns out, they know a whole lot more about

1 PHRs than I do. And so, you know, it's okay for,  
2 once I have a question, if you think that you need  
3 to make a point about how you're different or like  
4 the other people who are here, please feel free.

5 So I'd like to start by asking each of  
6 the panelists to describe basically their story.  
7 Now, of course, we've given them two minutes to do  
8 this, so, you know, they may have some difficulty  
9 in that time frame. But basically, you know, what  
10 are the origins of your PHR basic functionality?  
11 How and why do individuals use it? How is it  
12 similar to or different from other personal health  
13 records?

14 So I think what I'd like to do is start  
15 with Tim, with Kaiser.

16 DR. MCKAY: So most of you know that  
17 Kaiser Permanente is a nonprofit organization and  
18 that we serve eight distinct regional areas. And  
19 a lot of our history of the PHR is based on our  
20 organization, so if we look at the origins in the  
21 beginnings, it really started in the mid-1990s  
22 when we had the emergence of the beginnings of



1       electronic medical records systems, stubs in a  
2       number of our different regions. Of course, we  
3       weren't on the same system in any of the regions.  
4       We had the emergence of public websites so that  
5       they were mostly informational directory services,  
6       some health information, but again they were  
7       regionally based.

8                 And then we had a national initiative  
9       that was looking at what kinds of secure services  
10       could we offer to our members, and those services  
11       began, launched in the mid-to-late '90s.

12                By 2002, though, as a company we made a  
13       decision to standardize on one medical record -  
14       electronic medical records system -- and that was  
15       an amazing decision, and we are just now at the  
16       point where we've realized the fruits of that  
17       decision where we have electronic medical records  
18       rolled out to all of our service areas, and it's  
19       completely integrated into our medical offices and  
20       operations.

21                So along with that, we had convergence  
22       in our public websites from one, from a

1 regionally-based system to a national system, and  
2 we integrated our secure services with our public  
3 services so that if you go to KP.org now, you can  
4 cruise, use many of the services until you get to  
5 something that's secured, then you're challenged.  
6 And we decided to try to make it as naturalistic  
7 for our members as possible so that they would  
8 access the services that we need -- we would  
9 authenticate identity as we needed to.

10 I would say at this point we're at the  
11 beginning of a phase of maturity, so our services  
12 that we offer on the site are around health  
13 improvement and health information, like many  
14 providers and PHRs will have health and drug  
15 encyclopedias, total health assessment that will  
16 then integrate back into the electronic record  
17 that can be viewable by our providers; condition  
18 management programs, the use of health alerts for  
19 preventive services, directory services, claims  
20 and plan management services.

21 But then we get into the really  
22 interesting stuff to be able to view parts of your

1       medical record for seeing your allergies list,  
2       your medications list, your problem list,  
3       immunizations, lab test results all of which when  
4       you see information, we hyperlink into information  
5       that's in our health and drug encyclopedias to  
6       give further explanation of tests and procedures.

7                We also have the ability to make proxy  
8       assignments so that if you, as an account holder,  
9       want someone else to be able to view your record,  
10      you have the ability to do that.  There's also,  
11      then, a suite of transactional services, of arts  
12      refill which integrates into a robotics  
13      fulfillment system, a real-time appointing so you  
14      schedule the appointment that you're actually  
15      going to see your primary care provider for, and  
16      secure messaging services where our patients have  
17      the ability to message physicians, nurses,  
18      pharmacists, psychologists, and other care  
19      providers.

20               We're often asked, now, do you have a  
21      personal health record, or is this a patient  
22      portal?  Our best answer to that is yes because we

1 truly have a shared, integrated record so that the  
2 information that our patient sees is the  
3 information that our doctors and providers see and  
4 use. We are seeing our systems as continuing to  
5 evolve, and our emphasis has been on operability  
6 before interoperability, and we'll be able to talk  
7 about some of the interoperability and patient  
8 controls, I think, later on in the discussion.

9 But I think at this point that's -- my  
10 two minutes are up.

11 MS. KENYON: Thank you very much. Lori,  
12 let's talk about Shared Care Plan.

13 MS. NICHOLS: Okay, sure. So we're not  
14 quite as -- well, we've had an EMR in our  
15 community for since 1996, but we're not a single  
16 organization, we're a community of various  
17 independent practices. We do have a single  
18 hospital, so we actually have 80 percent adoption  
19 of EMRs in our community, but that's silos, that  
20 doesn't give tools to patients. So in about 2001,  
21 we were participants in a Robert Wood Johnson  
22 Foundation-funded grant, Pursuing Perfection

1 grant, and in the interest of being patient-  
2 centered, one of the six aims of the Chasm Report,  
3 we had patients at the table, and we asked them  
4 what we wanted. And we were ready to expose the  
5 hospital's record to them, and they said thank you  
6 very much, we want our own.

7           And so we started out in 2002 building  
8 -- you know, starting with a word document, what  
9 do you want to track? And migrated through an  
10 HTML version, and now we have a very robust  
11 application that can accommodate web services  
12 interactions that's connected to HealthVault.  
13 We're about to roll out SmartPhone versions so  
14 patients can track, and they can see information  
15 from within the hospital system. We're working to  
16 integrate some additional EMR data feeds. And  
17 with the connection to HealthVault, any system  
18 that connects to HealthVault then can have that  
19 information show up in the Shared Care Plan.

20           Patients have a very granular level of  
21 control over who has access to what in their plan,  
22 so they could grant a general level of access to a

1 family member. That's the reason it's called  
2 "shared" is that patients really did want to share  
3 it with their small social network that helps them  
4 manage their care when they are not in the  
5 practice, when they're not in the hospital because  
6 really, we expect patients to manage their health  
7 on their own, and they have very few tools. It's  
8 so exciting to see this room and participate in  
9 this event. We're focusing on making tools  
10 available to individuals and their families and  
11 those they care for.

12           So we do have integration to our state  
13 immunization registry. People can print out the  
14 certificate of immunization form for schools,  
15 integration to HealthVault. as I mentioned,  
16 integration of lab results into the record, and  
17 patients can, with all of the talk about  
18 technology, I really want to emphasize we can't  
19 get rid of the value or dismiss the value of  
20 paper. People can print out a paper summary that  
21 folds up to a credit card size piece of paper, and  
22 if you're down on the street and you look through

1 your pocket, a flash drive's not going to do you a  
2 lot of good, but if they have something that they  
3 can read, that would indicate who they should  
4 call, what meds is this person on, and what  
5 diagnoses.

6           People have that ability to control  
7 their information at a granular level, they can  
8 say you have general level of access but you can't  
9 see a particular medication. What else? We're  
10 also building the technology to support workflow  
11 transitions because people don't exist. Kaiser  
12 has kind of a golden world where everybody -- all  
13 the care really does happen kind of within one  
14 organization.

15           In our community, even our large  
16 northwest HMO is pretty much like any other payer,  
17 and access to those kinds of systems doesn't  
18 exist. So we're creating tools for patients to  
19 help them bridge the gaps between practices with  
20 calendared reminders and rules-based alerts, you  
21 know, enter your blood pressure, what if it's  
22 missed? What if it's out of range? Who do we

1       notify and how, so we can support SMS messaging or  
2       messaging to e-mail or ring a phone.

3               MS. KENYON:  Lori, what kind of adoption  
4       do you have?  I mean with all of this wonderful  
5       functionality, are people using it in --

6               MS. NICHOLS:  People are using it.  Our  
7       community is just under 200,000.  It gets bigger  
8       every time I say it, and we have about 2,200,  
9       2,300 active Shared Care Plans.

10              There's a reason for that.  We have not  
11       intentionally really tried to push it because we  
12       knew it wasn't ready.  We started out when we  
13       built the initial version.  It was built as simply  
14       as a chronic care tool for people to track their  
15       chronic conditions, and we're building more and  
16       more functionality to support robust active  
17       healthy people to help them stay that way.  And so  
18       with the connection to HealthVault, that really  
19       helps where people can download their exercise  
20       watches and to help support care in the home --  
21       glucometers, blood pressure cuffs, that sort of  
22       thing.  Downloading data from those is really



1       where we're going to really start to feel the  
2       benefit of having technology for patients that  
3       interacts.  It's not about providers having EMRs  
4       and patients having PHRs; it's how they interact  
5       with one another and how the data flows, and try  
6       to get some efficiencies through collecting  
7       information once and using it over and over.

8                   MS. KENYON:  Okay.  Thank you so much.  
9       Next we're going to go to Greg, and there is logic  
10      here because for those of you who know HIPAA,  
11      Kaiser Permanente is a covered entity and so my --  
12      you're covered by HIPAA.

13                   DR. MCKAY:  Yes.

14                   MS. KENYON:  Right.  We go to Lori, who  
15      starts with a provider based in the community, so  
16      also a covered entity, but there is some  
17      straddling between HIPAA and non-HIPAA as I  
18      understand it, and we'll talk about that more.

19                   Next we're going to go to a health  
20      plan-based PHR model, and that, of course, is also  
21      a covered entity, but we're going to see how it  
22      moves into the non-covered entity world as well,

1 so, with that, Frank.

2 DR. STEINBERG: Okay, thank you.

3 Probably worth going through a very big history of  
4 ActiveHealth Management and trying to make the  
5 distinction between that and Aetna, so  
6 ActiveHealth Management was formally incorporated  
7 in 1998 with private venture capital funding.

8 We are in the business of providing  
9 clinical decision support services to various  
10 groups. We initially started as providing those  
11 services only to physicians. We had a number of  
12 health plan clients and large employer clients.  
13 One of those health plans was Aetna. They started  
14 in about 2002.

15 In 2005, they did the Remington Razor  
16 thing where they liked it and bought the company,  
17 and we -- but we function as an independent  
18 stand-alone business, so we provide our services  
19 to Aetna and Aetna members, including but not  
20 limited to the PHR. But we also provide those  
21 same services to a whole host of non-Aetna health  
22 plans and other -- and large employers.

1           The PHR was really born for us in about  
2 2007. It came out of an articulated need by our  
3 various customers that we needed to have a  
4 consumer-facing, user-friendly and intelligent  
5 tool that would help patients, individuals make  
6 better health care decisions. We believed that --  
7 the way we look at it is that the PHR is part of  
8 an integrated suite of decision-support enabled  
9 products that are designed to improve the overall  
10 quality of care by helping doctors and patients  
11 make better and more informed decisions about  
12 their care. We view it as a really a  
13 member-engagement platform that promotes health  
14 accountability.

15           In the PHR, one of the main features is  
16 that it provides patients with an intelligent,  
17 prioritized, and crisp sort of to-do list that's  
18 based on an intelligent analysis of all the data  
19 that we have on them, which includes data that we  
20 get from the health plans, data that we get from  
21 the PBMs, data that we get from labs, and  
22 obviously the data that individuals enter

1 themselves.

2           There is pretty robust clinical  
3 decisions support that is truly in real time, so  
4 what that means is that when you're in the tool  
5 and you complete our health risk assessment, and  
6 you press Submit, all of that information that  
7 you've just entered goes back into our systems, is  
8 appended to the data that we already have on you  
9 from the various sources that I mentioned, it runs  
10 up against our sophisticated clinical rules  
11 engine, and to the extent that a clinical alert  
12 needs to be generated, it goes back into your PHR.  
13 Everything that I just said happens within one  
14 second.

15           MS. KENYON: And the clinical decision  
16 support you're talking about is to the individual.

17           DR. STEINBERG: To the individual.

18           MS. KENYON: The individual, we usually  
19 think about CDS in terms of supporting physicians.

20           DR. STEINBERG: It is both. So the  
21 individual gets the message back electronically  
22 within one second; the physicians get their

1 messages through a variety of means, electronic  
2 and sort of more standard, more standard ways.

3           The PHR and the content is fully  
4 integrated with our other so-called care  
5 management products, so our decision, our disease  
6 management product, our health and wellness  
7 coaching, all of that, and those systems talk to  
8 each other so that data entered in one system is  
9 automatically populated into the other system.  
10 And then the last thing that I'll say is as we are  
11 entering the new era of health information  
12 exchange, we are entering into arrangements with  
13 groups where, in addition to those other kinds of  
14 data, we are receiving data directly through those  
15 health information exchanges into our systems and  
16 providing information back out through the health  
17 information exchanges to the appropriate folks.

18           I'll stop there.

19           MS. KENYON: Thank you very much. I  
20 think Dossia, Colin?

21           MR. EVANS: Sure. Okay, good morning.  
22 Thank you. Thanks for inviting us to 201st

1 meeting of the various people discussing national  
2 health infrastructure.

3           And so Dossia was founded by a number of  
4 large employers that are concerned by, you know, a  
5 health care system that has costs spiraling out of  
6 control and a quality that's indifferent and no  
7 hope of changing. So I think the way Dossia got  
8 started was these employers wanting to found a  
9 system that would help try and reverse that trend  
10 a little bit. I mean, the health care  
11 inefficiency is sort of a tax on every business  
12 and every employee in America, and we want to try  
13 and change some of that.

14           The system was founded on really two key  
15 principles which I think we're going to hear  
16 discussed a lot today. One is that an individual  
17 that's empowered and informed and engaged in their  
18 health is likely to make smarter health care  
19 decisions and likely to be a more demanding  
20 consumer of health care, and consumers have  
21 changed every other industry in terms of  
22 efficiency and cost, and we hope we will do some

1 of the same things in health care.

2           The second key principle that we're  
3 founded on is that employers, as payers of health  
4 care, have got some influence in making sure that  
5 the data can be made available to employees  
6 because, you know, employees pay the bills and  
7 they should have some influence on the people in  
8 the system. HIPAA and ARRA, as has been pointed  
9 out, give everybody a right to a copy of their  
10 information. We're just acting as a repository  
11 for that information in a secure and private way,  
12 and we're acting as an agent on behalf of  
13 individuals helping them collect their information  
14 from the different sources whether it be  
15 institutional data or biometrics, or devices, or  
16 self- entered information.

17           We aggregate information from different  
18 data sources, and we serve as a platform to  
19 launch, theoretically, an infinite number of  
20 different applications and services that can sit  
21 on top of that platform. And why would somebody  
22 use that? I think you have heard some of those

1 examples from the panelists already. I think  
2 generally, you know, safety care coordination,  
3 convenience, the ability to care for others are  
4 all some of the key drivers that we hear from  
5 people in wanting to get access to their  
6 information.

7 MS. KENYON: How many people use  
8 Dossia's PHR?

9 MR. EVANS: That number's all over the  
10 place. We've got in some companies that have  
11 rolled Dossia out to their employees, they have  
12 done so without incentives or without any  
13 particular drive. And they've got, you know, 10,  
14 15 percent of their employees signing up. And in  
15 other cases there are companies that have got --  
16 rolled out a Dossia link to their other incentives  
17 that are tied to other reduced health care costs  
18 or the benefits they get, and the adoption rates  
19 have been much, much higher from those companies.

20 So it ranges everything from 10 percent  
21 to 80 percent, depending on whether incentive's  
22 involved, and it's, you know, it's a big circuit



1 and we can get into that later, maybe.

2           So it's currently offered to employees  
3 of our founders, of our customers. You can't go  
4 to a website and sign up for a Dossia account.  
5 One of the benefits of doing that is that we've  
6 got very high capability to authenticate people as  
7 part of a health plan where you can't put Barack  
8 Obama or Donald Duck into our system and set up a  
9 health record. You have to be who you say you  
10 are.

11           It also allows us to maintain a very  
12 close control over family recognition so that  
13 someone that is covered by a health plan can also  
14 identify their, you know, other dependents,  
15 spouse, their kids, and so forth. In fact, in our  
16 last open enrollment at one of our customers, we  
17 had more kids enrolled than adults because people  
18 were adding their children.

19           I think somebody pointed out to me once  
20 that most people's family priorities are the kids,  
21 the wife, the dog, me, you know, is usually what  
22 people's priorities are. So the gathering family

1 information is pretty important to people.

2 I thought it was interesting that -- and  
3 I'm sure we'll talk about this more later -- that  
4 the FTC issued a report this week on consumer  
5 privacy. I thought that was highly appropriate to  
6 today's dialogue, and, you know, I'd  
7 wholeheartedly support all the recommendations in  
8 it. And it's easy for me to say because we built  
9 out system basically based on those  
10 recommendations. So, you know, I'm pretty pleased  
11 that they finally got written down. I think, you  
12 know, the kind of patient ownership of data,  
13 transparency, and all those kind of things that  
14 are built into those rules are, you know, clear up  
15 front. Conspicuous rules are pretty key to us.

16 And I think, you know, just in closing,  
17 I'd say I hope my -- my hope for the day is that,  
18 you know, I think HHS and FTC in pulling this  
19 together is a pretty interesting combination of  
20 groups, and there's two responsibilities that I'd  
21 like to hear discussed today: One is clearly we  
22 need to set standards and rules for the

1       expectations of people managing their own data in  
2       a real private way; but I also think that, you  
3       know, FTC particularly has a responsibility to  
4       make sure that privacy is not weighed spuriously  
5       by many plays in health care as a barrier to  
6       getting people their own information, or as a way  
7       to stifle competition.

8                   I think, you know, data should be,  
9       should belong to the individual. The law's pretty  
10      clear on that. You know, we implement a system  
11      and make that happen, and I hope we can, you know,  
12      move strongly in that direction through the  
13      scrutiny of today.

14                   MS. KENYON: Thank you very much. One  
15      of the things that the last reflection there I  
16      think demonstrates is that we clearly moved from,  
17      you know, three organizations that probably, you  
18      know, may look a lot to the OCR, to the Office of  
19      Civil Rights, and HIPAA regulation -- except, of  
20      course, Greg is probably in both camps more -- to  
21      Dossia, which is not based in covered entities.

22                   MR. EVANS: Well, but I think that's

1 kind of a myth. I think, you know, we've -- we're  
2 receiving data from them. And employers,  
3 self-insured employers' plans are covered  
4 entities.

5 MS. KENYON: Oh, okay. good point.

6 MR. EVANS: So if we're working on their  
7 behalf for the most part, we're a business  
8 associate, or if, whether we have an agreement or  
9 not, the law seems pretty clear that we're going  
10 to be treated like a business associate. So, you  
11 know, HHS and the FTC is an interesting sort of,  
12 you know, dual-headed monster here because, you  
13 know, Dossia could have a business associate  
14 agreement written with every doctor in America,  
15 and the FTC could still throw me in jail, all  
16 right, because I'm making promises --

17 MS. KENYON: Do you have criminal  
18 authority? Do we have --

19 MR. EVANS: I believe so.

20 MS. KENYON: Yes, we do.

21 MR. EVANS: I mean I'm making -- you  
22 know, my system's making promises to consumers

1       that we'll preserve and protect and maintain their  
2       information whether, regardless of what HIPAA  
3       says.

4                   MS. KENYON:  Oh, okay.

5                   MR. EVANS:  So I think, you know, we're  
6       covered by both.

7                   MS. KENYON:  We're laying the foundation  
8       for Panel 4 here, so -- okay, and then finally I'd  
9       like to turn to George Scriban from Microsoft  
10      HealthVault.

11                  MR. SCRIBAN:  Right.  So Microsoft's  
12      interest in the personal -- in the health care  
13      space has been driven primarily by the, I guess,  
14      the principle that pivoting the health care system  
15      and pivoting care around the patient requires some  
16      - a different set of tools than ones physicians  
17      and providers have been equipped with to date.  
18      And that's part of what my group at Microsoft, the  
19      Health Solutions Group does.  It's solutions to  
20      help transition, you know, providers to  
21      patient-centric care.

22                  On the patient side, that's where

1 something like HealthVault comes in. What we also  
2 realized is that, you know, individual patients  
3 ourselves, you know, individual consumers, we're  
4 not really enabled to manage the fragmentation and  
5 the diversity, and the sort of the sheer volume of  
6 information about us that is produced by our  
7 encounters with the health care system, much less  
8 the stuff that we generate ourselves, because  
9 health care happens 365 days a year. It just so  
10 happens that 300-some, plus some- odd days, it  
11 happens without doctors and nurses present with  
12 you; it happens with your family. And it happens  
13 about, you know, with your family and caregivers  
14 in the community, and, you know, and it's -- and  
15 it happens kind of among your family as well.

16 So there's this need to not only  
17 coordinate and aggregate all of the information  
18 about yourself as an individual patient but to do  
19 so for your entire family, because, generally  
20 speaking, there's one or two people within every  
21 family that manages health care decisions and the  
22 health care processes for every family.

1                   So this is -- that was the genesis of  
2 HealthVault. We spend time with consumers. We  
3 spend time with the family health manager,  
4 generally speaking, you know, moms in families,  
5 and looked at the way they managed health  
6 information. And, as everybody knows, it's in  
7 boxes. To the extent that they can collect the  
8 stuff, it's on paper in boxes spread throughout  
9 the house; it's never where they need it to be,  
10 it's never in the format they need it to be in.  
11 And it doesn't really help them even if they  
12 aggregate it. It doesn't really help them manage  
13 in the day to day.

14                   What we created with HealthVault was a  
15 completely consumer-controlled, cloud-based  
16 service that allows consumers to collect and store  
17 their health information. And we created  
18 interfaces that allow entities within the health  
19 care world -- providers, plans, PBMs, labs, device  
20 manufacturers-- all these different players that  
21 have information about you, all these fragments of  
22 information about you to contribute data under

1 your control and at your request to your  
2 HealthVault record.

3           These interfaces also enable third-party  
4 services to help you day to day. So third parties  
5 ranging from the American Heart Association to the  
6 American Cancer Society, to the Mayo Clinic, the  
7 Planned Parenthood, have all developed to little  
8 start-ups, have all developed applications that  
9 help people with HealthVault records manage their  
10 health care.

11           So the AHA, for example, developed an  
12 application called Heart 360. It's a pretty  
13 interesting, reasonably straightforward way of  
14 managing your cardiovascular health using the data  
15 that's in your HealthVault record. And that data  
16 can come from any place, right. It's all  
17 aggregated into this single platform. It can come  
18 from your providers, it could come from your blood  
19 pressure cuff device that's HealthVault compatible  
20 that you could buy it at a drugstore. And in so  
21 doing, what we have done is we've taken the burden  
22 of collecting and controlling this information,



1 protecting it, ensuring that consumer wishes with  
2 regards to privacy and security are respected, and  
3 we have taken that burden upon the platform, onto  
4 HealthVault and freed up the third parties like  
5 the American Heart Association to worry about  
6 delivering the smart stuff, right?

7           So we never -- we -- so, interestingly  
8 enough, I'm sitting here on a panel discussing  
9 personal health records. We don't really consider  
10 ourselves a personal health record. It may be a  
11 fine distinction, but what we consider ourselves,  
12 consider ourselves to be a personal health  
13 information platform where the brands and the  
14 services that individuals trust to deliver health  
15 information and health advice will come from other  
16 sources. Basically, this is just my fancy way of  
17 saying I don't think anybody ever - at Microsoft  
18 ever predicted or expected people to think that  
19 Microsoft's going to help you manage your  
20 diabetes, probably because we would give it a  
21 terrible name like Microsoft blood sugar, you  
22 know, 2010 released to consumer edition.

1                   I kid. I kid because I love my  
2                   marketing department. But because people trust  
3                   other entities, whether it's their personal  
4                   physician, their community hospital, or Mayo  
5                   Clinic, or Johns Hopkins or whomever, implicitly  
6                   more directly, and we didn't want to get in the  
7                   way of that relationship. What we did want to do,  
8                   though, was make sure that there was a place where  
9                   we could exercise as consumers, exercise our right  
10                  to our -- to obtain our health information and  
11                  make it useful in some way.

12                 MS. KENYON: You know, my next question  
13                 as I've, you know, have gone, as we've heard this,  
14                 is profoundly naive because it was about how we've  
15                 moved away from the original vault style model of  
16                 a PHR into, you know, something that has a lot  
17                 more functionality for patients. And I think that  
18                 what we've just had described by George is that  
19                 movement. You are not just a platform for -- a  
20                 repository for information anymore.

21                 Now, my sense -- let me ask the others  
22                 to tell me the extent to which that, what George

1 just described with HealthVault in terms of the  
2 connections to an AHA-developed application, is  
3 happening. My sense is that other people are  
4 bringing in the apps in the same way. Am I  
5 correct?

6 MR. EVANS: Yeah. I mean --

7 MS. KENYON: (inaudible) Dossia?

8 MR. EVANS: -- I think we're probably  
9 closest to HealthVault architecturally. I think  
10 absolutely we're doing that. We're -- it's an  
11 open-ended system that's intended deliberately, as  
12 George said, to provide the data that someone's  
13 got in a way that they can control who sees it,  
14 where it goes to, who they're accessing and then  
15 enable that to be used by any number of people to  
16 make sense out of it.

17 MS. KENYON: And, Greg, is that pretty  
18 much how you're --

19 DR. STEINBERG: Yeah. We actually have  
20 the capability-- we have embedded the capability  
21 in our PHR for members at their discretion to  
22 actually upload their data directly into

1 HealthVault.

2           Interestingly, you know, we have between  
3 the 8 million members that are Aetna and the 2  
4 million or so members that are not Aetna on our  
5 system, I don't have the exact numbers, but it's  
6 not a lot of those members that have, for whatever  
7 reason, elected to do that.

8           MS. KENYON: Okay. Tim, for Kaiser,  
9 because you're more of a control system --

10          DR. MCKAY: Sure.

11          MS. KENYON: How did -- do people have  
12 the ability, if they leave Kaiser, to take a PHR  
13 with them? How do you transition that?

14          DR. MCKAY: So there are a couple of  
15 things. So folks right now have the ability to  
16 download their information into a summary that can  
17 be then printed off, saved as a PDF or put on a  
18 USB memory stick. In fact, many of our medical  
19 offices provide those password-protected sticks  
20 for people to carry and put on their key chains.

21                 What we're starting, a large initiative,  
22 and most likely we're going to start it at the end

1 of next year, we're expanding our whole identity  
2 structure so that it's going to be inclusive of  
3 not only our members but nonmembers as well. And  
4 we're looking at identity more as a lifecycle --  
5 that people will come in and out of membership,  
6 have needs at different times, and we want them to  
7 be able to get access to their historic  
8 information even when they've left our plan.

9 As we get more mature in  
10 interoperability, we expect that it will just be  
11 common course for people to download their  
12 information to some trusted source under the  
13 consumer's control and to be able to take that  
14 information with them and then reapply it to a new  
15 health plan.

16 MS. KENYON: Mm-hmm. Are you building  
17 access to apps from outside --

18 DR. MCKAY: Yeah.

19 MS. KENYON: -- companies into Kaiser?

20 DR. MCKAY: In fact we already have. We  
21 do contract with a few different companies that  
22 are our business associates that provide certain

1 services that provide certain services. And the  
2 -- in fact, right now we're completing about a  
3 three-year redesign of our website to make it more  
4 service-compatible so that it's easier to plug in  
5 applications from other providers to do  
6 distributed developments. And we, because as  
7 Internet Services Group, we -- our mission has  
8 been to provide a core suite of services and  
9 realized that as new needs come up and they emerge  
10 in new technologies and new services, we want to  
11 be able to adapt those into our site as quickly as  
12 possible.

13 MS. KENYON: Okay. I'm going to move  
14 now to asking a little bit about the business  
15 model. Let me get one thing clear to begin with:  
16 Do patients, do individuals who have a PHR ever  
17 pay for that? Is the payment for it ever coming  
18 out of an individual's pocket? No? Okay. That  
19 -- that I've -- so clearly when we move into  
20 talking about a business model, we're not talking  
21 about a business model that the individual owner  
22 of the PHR is paying for. That means that you're

1 getting your resources from someplace else.

2 So I'm going to ask you to talk about  
3 what is the source of revenue to sustain your PHR.  
4 Have you been growing? Has the growth met your  
5 expectations? You know, what is the business  
6 model that might sustain your PHR?

7 And I think that I'll just start at this  
8 end this time with you, Colin.

9 MR. EVANS: Okay. All right, keep us on  
10 our toes.

11 MS. KENYON: Mm-hmm, yes.

12 MR. EVANS: Well, Dossia is, you know,  
13 was founded by employers, so we get paid by those  
14 employers to provide a benefit to their employees  
15 so that we get paid subscriptions on their behalf  
16 and to -- so the employee themselves sees the  
17 solution at no cost to them, as provided by their  
18 employer. And we are also in conversations with  
19 other potential users of the platform providers  
20 and plans also that would have a similar model or  
21 similar rationale for providing that kind of  
22 untethered system.

1                   Our business model is based on the  
2                   system being untethered from other parts of the  
3                   health care system. We're an independent  
4                   repository of information. Ultimately, we're  
5                   under a not-for-profit umbrella, and the Dossia  
6                   Consortium is an organization that's, when we set  
7                   it up, it was very important for us to make sure  
8                   that employees would realize that the system would  
9                   not have its motives compromised by, you know,  
10                  inappropriate business goals. You know, trust in  
11                  the system isn't just a question, you know, of  
12                  privacy and security technology; it's do you  
13                  understand what someone's doing with this  
14                  information and why they're doing it?

15                  So we're founded as an, you know,  
16                  independent organization from the employers  
17                  particularly.

18                  In terms of growth, yes, we're rolling  
19                  out to more and more employers. We just rolled at  
20                  AT&T and BP and we've got, you know, most of our  
21                  founders are rolling the system out. The level of  
22                  adoption is -- varies depending on the particular



1 program that an employer is using. Some are  
2 interested in getting a lot of people to do a  
3 little bit on the system; other employers focus  
4 more the particular employees that are sort of  
5 frequent flyers in the health care system because  
6 that's where the money is, and that's where the  
7 benefit could be. If you actually help somebody  
8 manage their care, you make someone's life a lot  
9 better, and you actually save a lot more money for  
10 them and for the company.

11 So different companies have got their  
12 roll-out models. It's really not easy to talk  
13 about a percentage of adoption because they have  
14 different business goals.

15 MS. KENYON: And so Dossia is one tool  
16 that employers might use to help their employees  
17 control their --

18 MR. EVANS: Typically, we're kind of a  
19 launch platform for wellness programs for  
20 employers. They've got -- they certainly would  
21 have just general, you know, health risk  
22 assessment employee engagement, but they also

1 might use it as a launch vehicle for particularly,  
2 you know, a diabetic program for disease  
3 management or smoking cessation.

4 MS. KENYON: So you're --

5 MR. EVANS: Or some companies link it to  
6 their on-site clinics; some companies link it to  
7 their on-site fitness centers. We've got feeds in  
8 from exercise bikes, all right, in on-site  
9 exercise facilities.

10 MS. KENYON: To a very different  
11 business model. Tim, explain.

12 DR. MCKAY: Sure. Our model, we get our  
13 funding from our member dues. And, honestly, we  
14 approached the whole PHR space in the evolution of  
15 our Web portal as more of a social mission,  
16 frankly; that we were focused on meeting the  
17 health and improving the health of our members in  
18 our community, and that this is one step in being  
19 able to do that.

20 What we do find is that there is offset  
21 to some degree for the services that we provide.  
22 So if you think that when a person gets a lab test

1 result, and the process of getting that result  
2 written down, put in an envelope and mailed, it's  
3 easily, when you look at the work flow cost, it's  
4 a buck, a buck a pop when they go out. And if you  
5 look at 25 million lab tests, the results being  
6 resulted online last year, that's substantial  
7 savings.

8 Now, the caution is that the more  
9 distributed your program is, the more distributed  
10 those savings are going to be. So, honestly, you  
11 see more savings in terms of work flow  
12 productivity than you can attribute to any  
13 particular cost center. So we see those in  
14 pharmacy refill, in direct booking as well.

15 Our growth has been surprising to us,  
16 honestly. We know that these services were good,  
17 that we had really put a lot of time and  
18 investment in them, but we have grown, for  
19 example, from 2006 with 20 percent of our eligible  
20 members having a current account, to this year  
21 having close to 60 percent of our eligible  
22 members.

1           But registration and account growth is  
2 really only one metric, so if we look at our  
3 account growth from last year to this year, about  
4 a 20 percent increase. But we've seen a 40  
5 percent increase in actual use. So the more that  
6 people have exposure to the tools, the more that  
7 they're promoted within the doctor's office, and  
8 it's very much a part of the natural work flow.

9           So you go into the doctor's office, the  
10 physician has their terminal that they are writing  
11 their progress note, they're looking up  
12 information, they're maybe sharing information  
13 with you on the screen, and at the end say, you  
14 know, I really want to hear about how this is  
15 going for you. Can you send me an e-mail in a  
16 couple of days? And there's kind of an  
17 expectation that our members have these tools at  
18 their disposal and that the system as a whole  
19 promotes its use in a very naturalistic  
20 non-coercive way.

21           MS. KENYON: And so you've directly  
22 reduced some of the cost of doing business.

1 DR. MCKAY: Yes.

2 MS. KENYON: And you've also, you know,  
3 promoted better quality care which can reduce cost  
4 in a Kaiser model.

5 DR. MCKAY: I think one of the  
6 interesting things about a shared record when you  
7 know what you're seeing that the provider is also  
8 seeing, that if you're seeing something as a  
9 patient that isn't correct, you have the ability  
10 to facilitate getting that corrected quickly. And  
11 we find that the patient's safety alone of  
12 exposing that information is well worth the cost  
13 of the system.

14 MS. KENYON: Okay. Fabulous. Lori?

15 MS. NICHOLS: The development so far has  
16 been largely grant-funded. We've reached the  
17 point now where we're going to roll the cost of  
18 our ongoing support into our regular access fees  
19 for our intranet. And I kind of nodded in a  
20 delayed fashion to the no-cost-to-consumers  
21 because it is free to consumers and our Web  
22 version will be. But as we roll out the

1 SmartPhone versions, there would be a small charge  
2 for that. And we're also looking.

3 MS. KENYON: - Now the small charge  
4 would be paid by...

5 MS. NICHOLS: By the consumer to  
6 download the app.

7 MS. KENYON: Okay.

8 MS. NICHOLS: Because they do it all the  
9 time.

10 MS. KENYON: Yeah.

11 MS. NICHOLS: There goes another 99  
12 cents. So, and then we're also looking, as we  
13 build out our work flow functionality, especially  
14 supporting transitions from acute care settings to  
15 out, that hospitals will be interested in  
16 purchasing that functionality to achieve the kind  
17 of costs savings that was just described by Tim.

18 And then we're also working with  
19 Microsoft implementing HealthVault community  
20 connect on the front end of the process to support  
21 people being able to fill out their registration  
22 forms and to track that process of, you know,

1 we're working with the joint center. And they  
2 looked at the number of times that people filled  
3 out the same form as part of this one process.  
4 So, you know, sleep studies and those sorts of,  
5 you know, do we need a sleep apnea study, those  
6 sorts of things.

7           So we're trying to bridge the gaps  
8 between, you know, the clinical systems, the home  
9 system, and the processes and support those  
10 processes. And those would be billed services.

11           MS. KENYON: So you've moved from  
12 grant-funding and you're looking at a sustainable  
13 model, and right now you're looking at mainly  
14 providers.

15           MS. NICHOLS: We'd love to continue to  
16 receive grants.

17           MS. KENYON: Okay.

18           MS. NICHOLS: But we were actually going  
19 to be -- we just got word that we did get another  
20 small grant that's going to facilitate working  
21 with our local area Agency on Aging to have them  
22 become people who can register, go out and

1 register their clients in the home so that there  
2 is some more ability for them to track and  
3 coordinate care.

4 MS. KENYON: Out of curiosity, have  
5 either employers or health plans supported you at  
6 all because of the savings they may have?

7 MS. NICHOLS: Those are both kind of  
8 notably absent in part because patients have said  
9 they really don't want those entities to have  
10 access to their health information. It's been one  
11 concern that we have heard. That said, we are  
12 looking at large, self-insured employers as people  
13 who actually understand what the cost is and what  
14 the cost savings could be by being more efficient  
15 in providing better care.

16 MS. KENYON: How do you get consumer --  
17 consumers telling you that? Do you have them on  
18 your board or --

19 MS. NICHOLS: We have a Consumer  
20 Advisory Group. We do presentations. We, you  
21 know, we talk to people.

22 MS. KENYON: Okay.



1           MR. SCRIBAN: All you really have to do  
2 is show up at one of these things. You will hear  
3 that patients are most concerned when they talk  
4 about putting -- when individuals talk about  
5 putting their health information online. Their  
6 number one concern is, will this, you know, allow  
7 a plan to deny me coverage, or when I, you know,  
8 search for life insurance, when I try to get life  
9 insurance, will this become a problem? And will  
10 employers be able to deny me employment as a  
11 consequence of my health information being online.

12           MS. KENYON: I'm looking forward to the  
13 privacy questions that I've got coming up here.  
14 We're getting into them already.

15           Yeah, so tell us your -- you mean you  
16 give away your --

17           MR. SCRIBAN: So, we're just good guys.

18           MS. KENYON: -- your PHR.

19           MR. SCRIBAN: We're known for our  
20 generosity, I find. No, one of the reasons I  
21 mention the broader group that I work for,  
22 Microsoft Health Solutions, is that we don't view

1 HealthVault in isolation from the other products  
2 and the other solutions in our portfolio. We know  
3 that there are entities out there, health care  
4 providers in particular, who are very interested  
5 in actually being able to systemically improve the  
6 care that they deliver, and they're interested in  
7 a vehicle to get that, to extend the systemic  
8 improvements to the patient, literally, a vehicle  
9 that allows them to reach out to the patient and  
10 engage them in health care.

11 On the flipside, they also understand,  
12 like we do, that patient trust is paramount. No  
13 one's going to participate and engage in this  
14 process unless they feel that the data that  
15 they're contributing and the place where they're  
16 storing their information is trustworthy. So we  
17 had to be very, very clear that the last-mile  
18 piece of what we were doing, distinct from the  
19 enterprise solutions for which we charge, you  
20 know, directly to providers to roll out and  
21 implement, distinct from that there is this last-  
22 mile bit of infrastructure that we call

1 HealthVault is under the control of the patient,  
2 and we had to drop the barrier and be very clear  
3 about who our customer was, that it is a free  
4 platform that we offer to consumers in the United  
5 States that they control.

6 Mind you, the United States -- and I  
7 will, you know, in the interest of full disclosure  
8 -- say that I'm actually a permanent resident  
9 here. I'm a Canadian citizen, so I've seen other  
10 health care systems at work, and I also happen to  
11 have my information fragmented across borders now.  
12 But I've seen other health care systems at work,  
13 and where there are more concentrated bearers of  
14 risk in health care, it becomes a little bit  
15 easier to think about HealthVault in a, you know,  
16 from a -- or something like HealthVault as a  
17 commercial enterprise. So in countries like  
18 Canada or in Germany, HealthVault is actually  
19 licensed to a partner in Canada to talk about --  
20 in a big health information company called Telus,  
21 to Siemens in Germany, and in countries like the  
22 U.K. Where we've launched, there are commercial

1 models behind it because there are very large  
2 bearers of risk and more centralized, you know,  
3 ways in which health care is not only delivered  
4 but also paid for.

5           That doesn't exist in the United States,  
6 so the United States is a bit of a -- you know,  
7 our chief technology officer at Health Solutions  
8 Group likes to call the U.S. our HealthVault Test  
9 Kitchen. So that's the model for HealthVault,  
10 but, really, it's driven largely by the  
11 recognition on the part of everybody that we serve  
12 at the Health Solutions Group that it's such a  
13 critical thing to get the patient and the consumer  
14 involved and engaged and using this, that you  
15 cannot muddy the waters too much and appear to be,  
16 you know, really have -- your customers are really  
17 over here in the provider plan/government employer  
18 space, but, you know, trust us. It's safe to put  
19 your information here.

20           MS. KENYON: Your business model, then,  
21 really requires that you're part of a -- of an  
22 income, of a revenue source that's bigger than --

1 because you're pulling, you're basically  
2 supporting your PHR --

3 MR. SCRIBAN: That's true.

4 MS. KENYON: -- out of other business  
5 lines. Okay, Greg.

6 DR. STEINBERG: Right. So, as I said  
7 before, our customers are health plans and large  
8 employers, and they buy a set of services from us  
9 that are designed to improve quality and lower  
10 costs. The PHR is one of those services. It is  
11 never purchased alone. We are typically paid on a  
12 per-member-per-month basis for those services,  
13 and, as I said, the PHR is never purchased on its  
14 own. It is always purchased with some combination  
15 of decision support and usually disease management  
16 or a lifestyle management.

17 As we move into this world of health  
18 information exchange and health information  
19 technology where our customer base are now  
20 increasingly large integrated delivery systems,  
21 there the payers are these provider groups, the  
22 physician, large physician groups. And the PHR is

1 a -- is also considered part of the suite of  
2 services that we provide to these guys in order  
3 for them to communicate bilaterally with their  
4 patients over the health information exchange. In  
5 that situation, the revenue model is a  
6 per-provider-per-month basis.

7 In terms of growth, we're definitely  
8 growing. We're exiting 2010 excluding, as I said,  
9 the 8 million Aetna members with about 1.9 million  
10 members on the non- Aetna PHR, and in January, in  
11 a couple of days we'll probably be up to about 2.7  
12 million.

13 Just to echo what was said in terms of  
14 the use, it is our experience as well that  
15 incentives play an acute role in dictating the  
16 actual usage as well as how well or badly the  
17 tools are promoted.

18 Incentives are an interesting thing.  
19 Just to give you a little anecdote here, one of  
20 our large customers, it was a commercial bank, had  
21 an incentive for their employees to fill out their  
22 health risk assessment in the PHR, which was a

1 sort of credit card thing for about \$75, and we  
2 had a tremendous rate of adoption that was good,  
3 about 75 percent. But being that it's a bank and  
4 it's a credit card, they could track where the  
5 money was spent, and the largest amount that was  
6 spent on Kentucky Fried Chicken.

7 MS. KENYON: Not -- not right. Yes,  
8 okay. Uh, you know, I'm going to warn a couple  
9 people in the room that I'm going give you an  
10 opportunity to ask questions as we move into the  
11 privacy section.

12 Dr. Blumenthal, if you have any  
13 questions that you'd like to ask, be thinking  
14 about it because I'm going -- since you've stayed,  
15 you're going to get the opportunity to ask them.

16 And, also, Joy, are you here? Where's  
17 Joy? Okay, I'm going to also give you that  
18 opportunity as we move into the privacy questions.

19 We've really laid the foundation now and  
20 actually started talking about privacy somewhat.  
21 My first question on my planned list is, how do  
22 you inform individuals about how you use and

1 disclose health information in the PHR? I think  
2 I'm going to ask each of you to answer that  
3 question as we go into -- I'm going to ask you a  
4 specific question about your particular  
5 organization, and again I'm going to start with  
6 you, Colin, at Dossia, because we heard Lori say  
7 that consumers are sometimes concerned about  
8 employers, and we do hear that.

9           And so one of the things I'd like to  
10 know is, you know, how do you inform your  
11 individuals about how their information is going  
12 to be used and disclosed? What, if any,  
13 information do you give to an employer sponsors?  
14 And how do you reassure people that their  
15 information is private?

16           MR. EVANS: Well, it's, you know, I  
17 often hear this sort of, you know, oh, my  
18 goodness, a system provided by employers, so they  
19 must see my data. Well, you know, we go to a lot  
20 of trouble both in terms of our overall privacy  
21 statement of policy, and the mechanics of people  
22 signing up with the system make it clear this is



1 an independent system that is keeping your  
2 information, you know, your supervisors from  
3 reading this database as you put in information.

4 We do that through the mechanics of  
5 people signing up. We do it through our project  
6 statement, we do it through the way most employers  
7 promote the system inside their companies, and in  
8 kind of legal words -- "clear and conspicuous" I  
9 think are the words in the law -- you know, there  
10 are clear and conspicuous choices that people make  
11 as they go through a role in deciding which data  
12 sources they want to subscribe to authorizing  
13 which applications they want to use, at a very  
14 granular level deciding which information they  
15 would like to share, which information they'd like  
16 to protect or annotate. And there are a lot of  
17 tool sites.

18 There's no doubt to anybody as they're  
19 using the system this information is for them and,  
20 you know, this is not shared information unless  
21 they want to share it to anybody. We don't share  
22 any information with employers other than kind of,

1       you know, this is how many people have signed up.  
2       That's about it. And we make it clear we don't  
3       mine the information, we don't sell it. So I  
4       think we're as clear as we can be to everybody.

5                   MS. KENYON: Okay.

6                   MR. EVANS: And then to some extent I  
7       think people are concerned about their employer,  
8       but, you know, for people, you know, employees of  
9       large companies, I think they understand that  
10      there's a bargain here in terms of the way they  
11      get health insurance from their employer.

12                  MS. KENYON: Mm-hmm.

13                  MR. EVANS: The information at Dossia is  
14      completely private, and they know that.

15                  MS. KENYON: And you answered a question  
16      that I was going to ask later, and that has to do  
17      with, do you, as part of your business model and  
18      part of your privacy practice-- I mean, how do you  
19      handle the potential to de-identify or aggregate  
20      data and share it. And, as I understand it --

21                  MR. EVANS: Just say no.

22                  MS. KENYON: Okay. Greg, you kind of

1 had the same problem, I think, that people don't  
2 necessarily trust their health plans, they're  
3 worried about their health plan -- I shouldn't put  
4 it that way. They trust their health plans. They  
5 worry about their health plans having access to  
6 information on them.

7 DR. STEINBERG: Yeah. I think,  
8 actually, in our experience there is some concern  
9 about the health plan, but I think there's a sort  
10 of understanding on some level which is true that  
11 the health plan already has a lot of this data  
12 anyway--

13 MS. KENYON: Yeah.

14 DR. STEINBERG: -- so, you know, okay.  
15 I think there's more concern relative to their  
16 employers.

17 MS. KENYON: Okay.

18 DR. STEINBERG: There's more concern  
19 there, and so, you know, we go through a lot of  
20 the same hoops that I think that were pretty  
21 clearly articulated just now. We do tell them the  
22 type of data that we have access to and that we

1 get data from the health plans, from the PBMs,  
2 from the lab systems. Also, obviously the data  
3 that they enter, explain to them how this data  
4 might be used in terms of providing them and their  
5 physicians with the clinical decision support that  
6 will hopefully improve their health; that it is  
7 going to be shared within the other applications  
8 in our system to the extent that that's necessary  
9 like lifestyle coaching and disease management;  
10 and that it will not be shared at all with their  
11 employer other than to the limited extent that  
12 would need to happen, say, with respect to  
13 incentive management.

14 MS. KENYON: Okay. Lori from Shared  
15 Care Plan, do individuals who use your services,  
16 do they -- you clearly have a connection with  
17 Microsoft HealthVault.

18 MS. NICHOLS: Mm-hmm.

19 MS. KENYON: And so is there -- do you  
20 go from an entity that is, you know, sharing  
21 that's within a covered entity under HIPAA and  
22 then over to Microsoft HealthVault? Do people

1 understand that transition and how are the privacy  
2 practices different?

3 MS. NICHOLS: They are presented with  
4 both privacy policies. As part of signing up,  
5 they sign up for a Shared Care Plan account, and  
6 that also then has them create a HealthVault  
7 account. They're presented with and have to, you  
8 know, acknowledge both privacy policies.

9 We have an online tutorial, online  
10 description that talks about that, the brochure.  
11 We have live people who answer the phone, but I  
12 think the key thing is one thing I think we do  
13 that's a little bit different than other folks is  
14 that we show the audit trail to the consumer, so  
15 as to see --

16 MS. KENYON: Explain that one.

17 MS. NICHOLS: You can see who has access  
18 to your plan. You know, obviously we don't have  
19 the same concerns, you know, live concerns about  
20 addressing access by insurance companies. The  
21 question comes up and we address it. But people  
22 can see who has accessed their plan, and more

1 often than not they see who hasn't accessed their  
2 plan because usually they're the only ones that  
3 are accessing it. And they can also see for any  
4 item that gets changed in their Shared Care Plan.  
5 If they've granted someone else access to it, they  
6 can see if that item is flagged as having been  
7 changed since the last time they logged on.

8 And that's true for both the individual  
9 -- that's true for anyone who logs into anyone's  
10 Shared Care Plan, if they have the authority to do  
11 so.

12 MS. KENYON: I'm going to give George an  
13 opportunity to speak to this, but are you pretty  
14 much in the same boat with Dossia and Greg with  
15 Aetna, ActiveHealth?

16 MR. SCRIBAN: You know, to an extent.  
17 It's a little clearer for us simply because we,  
18 you know, we are quite -- we are one of those, the  
19 services where a consumer can just dial up,  
20 [www.HealthVault.com](http://www.HealthVault.com), and sign up for an account.  
21 So, you know, if that's the way that they initiate  
22 their relationship, there is sort of an

1 expectation set up that, you know, that this is a  
2 service that is a contract between them and  
3 Microsoft to collect, store, and share their  
4 personal health information. So they, you know,  
5 the expectation is set up slightly differently.

6           The defining, you know, kind of the core  
7 principles upon which -- we boil down our privacy  
8 practices to four central principles, and then  
9 articulated them thus: The record that you create  
10 in HealthVault is yours, you control it. You own  
11 it. Nothing goes into that record without your  
12 explicit consent and action, nothing leaves that  
13 record or is used by anybody in that record  
14 without your explicit action and consent.

15           And the fourth one is that Microsoft  
16 won't make use of any of that information, not to  
17 target advertising, not to customize your  
18 experience, not to market to you unless we  
19 explicitly ask and you explicitly give us  
20 permission.

21           The whole point is to engender trust,  
22 and trust is really rooted from the consumer

1       standpoint in control, in transparency, and in  
2       security. So the, you know, some of the stuff,  
3       some of the things that we do in terms of giving  
4       consumers control of their health information  
5       include allowing them to choose what credential  
6       they're going to use to secure their HealthVault  
7       information. They have the option of Windows Live  
8       Art using the Windows Live ID, for example, or  
9       using an open ID with a, you know, with a second  
10      factor.

11                 They get to control, of course, what  
12      sources of data they connect to, and, obviously,  
13      they can, when they connect to a source of data or  
14      when they connect to a third-party service --  
15      let's take the American Heart Association again --  
16      each one of those services has to be very explicit  
17      about exactly which types of information they're  
18      going to have access to in a HealthVault record,  
19      and what they're going to do with that  
20      information.

21                 MS. KENYON: I am concerned about those  
22      transitions between your set of privacy



1 principles, and I'm interested in this for others  
2 as well, and when you're basically linking to a  
3 different entity, how is it that individuals would  
4 know they're moving between privacy practices?  
5 And do they really understand it?

6 MR. SCRIBAN: It's an interesting  
7 question, and there is a whole body of scholarship  
8 around choice, notice, consent, do people read  
9 privacy policies, do they understand what they are  
10 seeing. I think to a large degree, I think what,  
11 you know, anecdotally what a lot of researchers  
12 showed is that the existence of that little  
13 privacy link at the foot of the web page for most  
14 people means that their privacy is protected. Is  
15 that sufficient?

16 We try to make the decision an informed  
17 one. We control that experience. We're not an  
18 open platform. It's not Facebook. It's not like  
19 any third party can deliver a HealthVault  
20 application and, you know, we don't know about it.  
21 So we do try to constrain the degrees of freedom  
22 our third parties have.

1           So when, for example, I, say I would  
2     like to use Heart 360, when I go through the  
3     process, say I'm on the American Heart Association  
4     site and I think this is a very interesting  
5     looking application, and, you know, I would like  
6     to use this. And I -- so, you know, I just happen  
7     to have a HealthVault account where I have data.  
8     So I realize, you know, this is a  
9     HealthVault-compatible application. The  
10    experience of authorizing that application, to  
11    have access to my HealthVault record is controlled  
12    by HealthVault. I go literally from Heart360.org  
13    to HealthVault.com to sign into my account to  
14    where the platform steps the user through the  
15    processing: This application wants access to one  
16    of the records in your HealthVault account. Which  
17    one of them do you want granted access to?

18           Because, say, for example, I would have  
19    -- I could have my record, and, you know, those  
20    are my children and that of my spouse in my  
21    account. Then the next step is: This application  
22    wants to have access to your blood pressure

1 measurements, your medication list, your condition  
2 list, your allergies, maybe a few other data  
3 types. Out of the 80-some data types that we  
4 store, we require our third parties to be explicit  
5 about which subset they're going to have access to  
6 and what they're going to do with it. They're  
7 just going to read it? They're going to be able  
8 to augment that data, append data to it? That  
9 kind of thing.

10           They also have to present their privacy  
11 policy for that particular application, including  
12 what they're going to do with that data, if they  
13 have read-access, for example, to that  
14 information, and their terms of service. And I  
15 get to see all of this in an explanation, data  
16 type by data type, as to why before I click --  
17 before I give them my consent, before I say: I  
18 authorize this application. We handle all of  
19 that, and that's one of the technical measures of  
20 control that we put in the hands of users. And  
21 then we back that up by embedding within  
22 HealthVault itself a granular -- and by "granular"

1 I mean right down to the individual data element  
2 -- so to every, like, right down to an individual  
3 blood pressure measurement and audit trail that is  
4 immutable.

5 So you can tell what applications have  
6 access or what other people have access to a data  
7 type, and then you can watch the history of the  
8 specific piece of data: This blood pressure  
9 measurement was written by this application at  
10 this time; it was modified by this application,  
11 and so on and so forth.

12 MS. KENYON: Okay. Colin, you wanted to  
13 say something about Dossia.

14 MR. EVANS: No, I just wanted from an  
15 architectural perspective, I think we're, you  
16 know, similar in the same boat that the  
17 HealthVault is in terms of the way we look at  
18 things.

19 MS. KENYON: Yeah.

20 MR. EVANS: But when I listen to this  
21 discussion, it feels like we're looking through  
22 the looking glass the wrong way. I mean, people's

1 information for the most part, I think for most of  
2 the panelists, you'll see here goes from a world  
3 that is totally incomprehensible to most consumers  
4 about where the -- and totally invisible and  
5 opaque -- where is my data? Who is using it?  
6 What are they using it for? You have no idea.  
7 Your data then goes to a place where you have very  
8 explicit, very clear, very granular control. You  
9 know exactly what's going on.

10 I think, you know, when we look at this  
11 whole privacy debate, we're looking at the  
12 telescope the wrong way. I mean we're sort of  
13 looking at these systems, in some sense, as being  
14 very over-engineered for the level of control  
15 that's needed legally, in order to establish the  
16 kind of credibility and trust that George is  
17 talking about, from a system where you have no  
18 idea what's happening to your data. I think we're  
19 sort of looking at the world a little bit the  
20 wrong way.

21 MS. KENYON: You know, it's interesting  
22 because, you know, I come at this as a lawyer, and

1 one of the --

2 MR. EVANS: Don't we all?

3 MS. KENYON: -- and so, Tim, you know,  
4 we know that Tim is, his PHR is under HIPAA.

5 MR. EVANS: Yes.

6 MS. KENYON: We know the privacy  
7 protections there. What I'm hearing from both  
8 Colin at Dossia and, you know, George at Microsoft  
9 HealthVault, and I assume Greg, is that even for  
10 your PHRs that are not subject to HIPAA  
11 protections, that you have -- you're quite  
12 convinced that it actually gives individuals more  
13 control. Am I hearing that with their privacy?

14 MR. SCRIBAN: Well, I mean --

15 MS. KENYON: Though you don't have, as I  
16 understand it, you don't have explicit legal -- I  
17 mean your controls are contractual, am I correct,  
18 on privacy?

19 MR. SCRIBAN: Our controls are  
20 contractual. Our controls are governed under, you  
21 know, you know, unfair and deceptive trade  
22 practices under the FTC. I mean we have that,

1       that kind of implicit contract with the end user  
2       as well.

3                You know, I get questions from  
4       individual users. I tend to respond to them.  
5       They get forwarded to me, and quite a few of them  
6       come to me asking, is this service covered under  
7       HIPAA? Is HealthVault a HIPAA-covered service?  
8       And I -- sometimes I feel like responding by  
9       saying, you realize the P in HIPAA doesn't stand  
10      for privacy, right?

11              The -- and there's -- although it might  
12      not be -- we have a saying at Microsoft, we use a  
13      phrase called "the rathole." We might not want to  
14      go down the rathole as to what privacy protections  
15      are and aren't covered under HIPAA, and whether  
16      HIPAA is sufficient as a consumer privacy  
17      protection law, which I think a lot of patients  
18      believe it is, but we don't have -- we don't -- we  
19      explicitly close off loopholes, Dossia and  
20      ourselves, at this table. We don't permit  
21      secondary use of information or onward transfer.  
22      There is no payment, treatment, or operations

1 mechanism for us to do something else with your  
2 information that you don't explicitly consent to.  
3 We have to earn the trust of our users and keep it  
4 by being very clear about what's going on.

5 It's not the same as E-prescribing, and  
6 all of the different players in the information  
7 supply chain who probably do legitimately require  
8 access to this information in order to make a  
9 simple prescription written on a pad over here  
10 wind up in a bottle of pills in my hands over  
11 there.

12 MS. KENYON: Okay. You know, because we  
13 end it, I want to make certain that if, Dr.  
14 Blumenthal, do you have a question you'd like to  
15 ask, and if you do you're going to have to come up  
16 and use the speaker, I'm afraid.

17 DR. BLUMENTHAL: I'm sorry, I'll pass.

18 MS. KENYON: You're -- okay, Dr.  
19 Blumenthal's going to pass.

20 Joy, I'm going to let you ask some  
21 questions here.

22 MS. PRITTS: I can never -- I'm sorry,



1 but I used to be a trial attorney, so I can never  
2 pass up the opportunity.

3 MR. EVANS: I put it to you --

4 MS. PRITTS: Is it true, as we start,  
5 yeah I won't do that...

6 MR. SCRIBAN: Yes or no, Mr. Evans? Yes  
7 or no?

8 MS. PRITTS: When did you stop beating  
9 your wife? Okay, my first question is kind of  
10 along the lines of the one that Kathy was just  
11 asking, and this is for Colin. I believe that you  
12 said that you believed that a lot of your  
13 programs, because of the way you interact with the  
14 employers is usually through the employers' health  
15 plan, that you are HIPAA-covered or a business  
16 associate, but in actuality what I believe you  
17 said was, that you go beyond what is required by  
18 the Privacy Rule and in your assurances that you  
19 make to individuals about how their information is  
20 handled. Is that accurate?

21 MR. EVANS: Yeah, I think so. And I'd  
22 kind of go along with the stuff that George is

1 saying, in terms of the level of control and  
2 clarity that we provide to individuals when about  
3 the way they manage information, yeah.

4 But I also think, it's not -- there's no  
5 such thing as a sort of certifiable system under  
6 HIPAA. I mean there's the CCHIT for certifying  
7 EMRs, but there's no sort of official stamp of  
8 approval that says you've got HIPAA certification.  
9 I mean, we subject ourselves to audit that way.  
10 Our (inaudible) audit and our financial auditors,  
11 inspect us from a HIPAA perspective, but there's  
12 no sort of clear, you know, label that says where  
13 you are and are not relative to HIPAA.

14 MS. PRITTS: Okay. Since I have you on  
15 the stand, is Dossia interoperable with other,  
16 like, HealthVault or Google, or any of the other  
17 --

18 MR. EVANS: Individuals can offload  
19 their information not just in a PDF but in a  
20 computable form to transfer somewhere else if they  
21 want to. But, you know, we haven't had many  
22 people want to do that yet.

1           MS. PRITTS: Okay. My next question is  
2 a more general question. In my limited  
3 understanding of the huge Health Care Reform Bill,  
4 I understand that employee assistance programs are  
5 going to be playing a more central role and that  
6 there are more incentives for individuals to meet  
7 certain health goals and more penalties if they  
8 don't in the way that the insurance is evolving;  
9 that employers will be able to charge them higher  
10 premiums if they don't meet certain goals. And  
11 it's increased quite a bit from what it used to be  
12 prior to Health Care Reform.

13           Do you see these PHRs and technology  
14 being used to implement that part of Health Care  
15 Reform? And I'll toss that to anybody at the  
16 table.

17           DR. STEINBERG: Yeah. I mean, the short  
18 answer is I think it probably will. I think,  
19 clearly, it's going to be problematic to figure  
20 out exactly what kind of information could and  
21 should be shared in order to effectuate that. But  
22 in terms of having the underlying tools and

1 capabilities to monitor that, that's fundamentally  
2 exactly what, at least at our end, what we have.

3 And when we - as I mentioned we have  
4 these very clearly-defined, prioritized,  
5 clinically-intelligent health actions, if you  
6 will, that are dynamically adjusted as an  
7 individual goes through and sort of checks off  
8 that they have done or have not done whatever it  
9 is that's being suggested and provides them with a  
10 score and an output on that, and to the extent  
11 that those may be tied to various kinds of  
12 negative and/or positive incentives, you know,  
13 it's the carrot, the stick, and then the frozen  
14 carrot. You know, there's clearly the mechanism  
15 to tie those two together.

16 MS. PRITTS: Do you see this as  
17 potential incentive, or, you know, like a real  
18 incentive for people moving more towards this kind  
19 of technology? Do you think this is going to be  
20 one of the big factors going forward?

21 DR. STEINBERG: Uh, it already kind of  
22 is. So, as I mentioned, you know, the positive

1 incentives have clearly -- and I think this has  
2 been echoed, I mean to the extent that you provide  
3 incentives for people to use these tools -- they  
4 do. And it's actually sort of interesting how  
5 relatively meager it is these incentives have to  
6 be in order to significantly move the dial in  
7 terms of usage.

8 MR. SCRIBAN: Although while I agree, I  
9 think that's sort of just one component of it.  
10 Our experience kind of -- our experience indicates  
11 that the number one factor, not necessarily an  
12 uptake -- and I believe incentives can really help  
13 drive initial adoption -- but ongoing engagement  
14 and use, ultimately that utility really only is  
15 maximized when more of your primary care tier is  
16 digital. And right now that's kind of the big  
17 gap, right. If all of our care was delivered, you  
18 know, through integrated delivery networks or  
19 through at the acute care level, it would be easy  
20 to get your digital records.

21 But for most people the part where it  
22 drops off in terms of utility is not having your

1       pediatrician, your gynecologist, your family  
2       doctor, you know, using an electronic medical  
3       record so that you can't actually meaningfully  
4       come to them except with stuff on paper out of  
5       your HealthVault record, out of your Google Health  
6       record, out of Dossia record, or, you know, with  
7       information from your other providers and present  
8       sort of like a coordinated, you know, family  
9       health or personal health history in front of your  
10      physicians.

11                 DR. STEINBERG:  And I would completely  
12      agree with that, but I would add even one further  
13      layer, which is moving information around the  
14      health care system is tremendous.  Providing  
15      individuals with actionable information is better.

16                 MR. SCRIBAN:  Yep.

17                 MS. NICHOLS:  Yes.

18                 MR. EVANS:  Agreed.

19                 MS. PRITTS:  I think we're unanimous on  
20      that point, aren't we?

21                 MS. NICHOLS:  Yeah.  The only other  
22      thing I think I would add is that it has to be

1 easy and -- I'll say it, sexy. I mean it's got to  
2 be --

3 MS. PRITTS: Fun.

4 MS. NICHOLS: -- people have -- yeah,  
5 it's got to be fun, people have to want to use it,  
6 it has to be convenient. So I think, you know, as  
7 we move, you know, more to the SmartPhone  
8 accessible applications, we're going to be  
9 reaching the audience that we have a chance to  
10 keep healthier, because some of the people who  
11 need PHRs the most right now and who actually get  
12 it are not the highest users of technology. But  
13 they can be supported, and that's, you know, we're  
14 going to be doing a project with our area Agency  
15 on Aging to help support people who need help with  
16 the computer part of it.

17 But it's, you know, it's a continuum.

18 MS. PRITTS: Okay. I'd like to go back.  
19 I had another question here about - Oh, did you  
20 want to go?

21 MS. KENYON: I just have a couple more  
22 questions, not yet.

1           MS. PRITTS: Oh, I'm sorry. I'm just  
2 hogging the mic here. Look, you know, the  
3 incentives to sign up for PHRs -- I found your  
4 story entertaining, but also I was sitting here  
5 thinking about it. So we're going to have more  
6 incentives to sign up for a PHR or to record your  
7 health information in order to tie that to your  
8 premiums and then the employer health care  
9 setting.

10           So is there any incentive for anybody to  
11 actually verify that the information that the  
12 patient has entered into their system is accurate?

13           DR. STEINBERG: Hmm. Not yet that I'm  
14 aware of anyways. We also have, you know,  
15 increasingly -- we haven't really had a lot of  
16 experience in dealing with it for real, but,  
17 hypothetically, clearly, there's, you know, we're  
18 getting, for example, medication information. So  
19 we get it from the PBMs, we get it from the  
20 patient which one's the right one. Is it both?

21           Right, so these are the -- particularly,  
22 and it's particularly important for us, because we



1 use that information not just in a passive way to  
2 sort of put it somewhere for somebody, for an  
3 individual to see it, but we are using that  
4 information to run up against decision support  
5 roles, that then spits out information that goes  
6 back to the physician and the patient saying, you  
7 know, based on the information we've been given,  
8 you should do X, Y, and Z, or should at least  
9 consider it. So it becomes a potential conflict.

10 Now, so far we've not experienced that  
11 conflict in reality yet that I'm aware of, but I  
12 suspect it's coming.

13 MS. PRITTS: Lori?

14 MS. NICHOLS: We have, and I think  
15 there's a fallacy that somewhere in existence  
16 there's a single accurate medication list.

17 DR. STEINBERG: Mm-hmm.

18 MS. NICHOLS: It's a series of  
19 conversations. Just because something's been  
20 prescribed doesn't mean it's been filled, doesn't  
21 mean it's being taken the way it was prescribed.

22 DR. STEINBERG: Right.

1 MS. PRITTS: Doesn't mean they didn't  
2 get their friend's meds.

3 DR. STEINBERG: Right.

4 MS. NICHOLS: And people share. We  
5 actually did have some experience and did study as  
6 part of an AHRQ grant where we built our  
7 medication reconciliation function in the Shared  
8 Care Plan that they were using an electronic  
9 medical record. They had the meds. The patient's  
10 list was more accurate, and this was stated by a  
11 pharmacist that -- because the patients know what  
12 they're taking.

13 MS. KENYON: Joy, are you --

14 MS. PRITTS: Okay, I had a few more --  
15 I'm going to change, shift the topic because I  
16 have a whole list of questions here now -- to I  
17 wanted to ask a little bit more about the notices  
18 that people were explaining. Do you -- does  
19 anybody, when you're posting your privacy notices  
20 or you're trying to explain to individuals how  
21 their information is to be shared, can you explain  
22 to me your process for developing those? Do you

1 have literacy specialists involved? Do you  
2 consult with consumers? How does that process  
3 take place? And again I will throw it out on the  
4 table for anybody to answer.

5 DR. MCKAY: It's really layered, so our  
6 privacy has been noted already. We're really  
7 under our notice of privacy practices. As a  
8 company, though, we have eight different notices  
9 of privacy practices which are largely the same,  
10 have some state variation in them that we have to  
11 account for.

12 We have another layer under that with  
13 our web privacy practices which is, it's compliant  
14 with the notice but goes into specific practices  
15 like the use of web beacons, the use of cookies,  
16 et cetera.

17 And then we have a third layer which is  
18 terms of service. So in the particular services  
19 we offer, then how is that information  
20 specifically used and disclosed?

21 One thing that we -- and also it's been  
22 noted -- is very, very few people read those

1 statements. When we look at counts of the numbers  
2 of people who actually go to the privacy notices,  
3 it's minuscule.

4 So we made a decision in --

5 MS. PRITTS: Can I interrupt you? You  
6 have those counts? Can I get those from you --  
7 not right now, but --

8 DR. MCKAY: Possibly, yeah. Let's talk.

9 MS. PRITTS: Yes, let's talk because  
10 that's very interesting information for us to  
11 know.

12 DR. MCKAY: Oh, but one thing that we  
13 decided to do with our site redesign was to look  
14 at when we present our terms of service, could we  
15 take out and bullet out the concerns that people  
16 mostly have so, especially with third-party  
17 sharing of information we just don't do it, but to  
18 state that up front to give what the salient  
19 points are, and then give people the opportunity  
20 to read the full notice we found it actually  
21 improved people's understanding of what our  
22 privacy practices were.

1                   We have a general principle with  
2           everything we do on the site is we usability test,  
3           and test and test and test until things are  
4           understood and usable by our population. In  
5           particular, our average intake is about --

6                   MS. PRITTS: Can I, can I --

7                   DR. MCKAY: Sure.

8                   MS. PRITTS: -- when you say you  
9           usability test, do you do that with your actual  
10          members?

11                  DR. MCKAY: We do it with members and  
12          nonmembers.

13                  MS. PRITTS: Okay.

14                  DR. MCKAY: So it's a pretty  
15          well-designed process. It follows a lot of normal  
16          industry standards. But we do usability testing  
17          in conjunction with rapid prototyping, so we bring  
18          in actual prototypes of the services that we  
19          expect to use, do rounds of testing. We'll go  
20          back and make prototype changes, do additional  
21          rounds of testing until we get a usability score  
22          for our population that is high enough for us to

1 launch the service.

2 MS. PRITTS: Anybody else want to -- do  
3 you do any testing:

4 MR. EVANS: We've done quite a lot of  
5 work to try and distill a privacy policy and  
6 practice to -- as simple a policy it can possibly  
7 be. We send out eight different ways of doing it,  
8 but I have had some quarters when I've spent more  
9 money on lawyers than developers, and some of them  
10 in this room -- lawyers, that is.

11 But, you know, I think this discussion  
12 just sort of reinforces to me the kind of thing  
13 that keeps coming back to me which is that, you  
14 know, individuals understand medicine; they just  
15 don't understand health care, right? And all of  
16 this kind of stuff is just getting in the way of  
17 people actually connecting to their doctor and  
18 their data. And I think a lot of these layers and  
19 layers and layers of stuff, unless we figure out  
20 to simplify it, will prevent people from feeling  
21 like any enthusiasm for getting involved in their  
22 own health because this is just too confusing for

1 people, really.

2 MS. PRITTS: Mm-hmm.

3 MR. EVANS: We've got to keep it simple.

4 DR. MCKAY: There was a small study that  
5 we did last year that looked at the idea of how  
6 does trust in brand trust move over into  
7 perceptions of privacy and security. And what we  
8 found, at least for our population, is that  
9 they're very highly correlated so that if you have  
10 trust in the organization, and our members have  
11 had trust over the years, with how we deal with  
12 health information, that that trust is also  
13 translated over to the web.

14 MS. PRITTS: Can I ask if any of you  
15 provide your privacy notices or other materials  
16 like that in languages other than English?

17 DR. STEINBERG: Spanish.

18 DR. MCKAY: Spanish. And Chinese, I  
19 believe. Mandarin and -- it's escaping me, yes.

20 MS. PRITTS: Kathy, I'm going to turn it  
21 back over to you. Thank you very much.

22 MR. EVANS: A pleasure. A pleasure, Your

1 Honor.

2 (Laughter)

3 MS. KENYON: Well, my questions are not  
4 as much fun. I should give -- we have until  
5 10:40. I have one question that I'm going to ask  
6 which I hope will be quick, and then if there are  
7 questions that panelists have of each other, I'm  
8 going to give you a couple seconds at the very end  
9 to ask that.

10 I'm just going to skip the questions on  
11 security, we're going to run out of time for that.  
12 My question has to do with the National Committee  
13 on Vital Health Statistics, has recently urged the  
14 development of the capacity to allow more data  
15 segmentation, meaning the ability to allow  
16 individuals to mask information that's more  
17 sensitive. I think we've heard from Microsoft  
18 HealthVault that you do that, but I'd like to hear  
19 from some of the others about whether this is an  
20 issue that you hear from people that they want  
21 that ability, and are you providing it?

22 Why don't we -- well, let's start with



1 Kaiser.

2 DR. MCKAY: In a shared record, masking  
3 is basically impossible so that, because we're  
4 drawing off the same data sources. What we do,  
5 though, in terms of internal controls are using  
6 role-based access to the records so that people  
7 should only have access to the information that  
8 they need to do their job. And so we rely on that  
9 mechanism, we rely on audit to make sure that the  
10 controls are in place.

11 Now, the question is when you send  
12 something out, then as an organization like Kaiser  
13 Permanente what do we do with vetting? So if it's  
14 to, say the information is from our source, at  
15 what point when a person starts to redacting the  
16 record do we withdraw that vetting and say it's  
17 unacceptable? You can't rely on us as the  
18 authoritative source.

19 Or what we've heard in working with  
20 standards groups is that the tension is with  
21 physician adoption and redaction. In practice,  
22 people redact all the time. They just do it

1 orally. But when something is on paper, it gives  
2 the appearance of being more authoritative than a  
3 verbal source. And I think we're going to have to  
4 find that balance as an industry of the point of  
5 comfort with where providers are willing to accept  
6 the information and to use it, and to realize it's  
7 just a different form of the game that's been  
8 played for years and years and years.

9 MS. KENYON: Okay. Anybody else on data  
10 segmentation?

11 MS. NICHOLS: We allow, you know, a very  
12 granular level of, you know, item-level detail. I  
13 can block one med from one member of my care team.

14 MS. KENYON: Wow.

15 MS. NICHOLS: But I think what I was  
16 hearing you describe was something more in terms  
17 of having standards or creating standards to  
18 generalize "I want my mental health issues  
19 private," and you could have some sort of a break-  
20 the-glass access to it.

21 We also use role-based access as we  
22 grant Shared Care Plan within the application.

1 But I think it would be useful to have those kinds  
2 of categories and linking because I think one of  
3 the dangers, if people are marking information as  
4 private, they may not go all the way through to  
5 link the medication to the lab test to the  
6 diagnosis. And if people truly want to be able to  
7 mark something as private, it would be wonderful  
8 to have some mechanism or standards that would do  
9 that and be able to be applied.

10 DR. MCKAY: I've got to say that that  
11 would be wonderful of -- we run into this problem  
12 with parent access to teen records. And we're  
13 given -- given that every single state has  
14 different rules of what kids can consent to, what  
15 they can't, the age that parents have full control  
16 of the record to when they don't -- to case law  
17 that says the older that the child gets the more  
18 they should be able to consent for their own care,  
19 and that that happens as a conversation, between  
20 the provider and the patient, how in the world do  
21 you operationalize that electronically.

22 And it makes it very difficult to tell a

1 parent, "because we can't automate this, we can't  
2 provide it to you through this channel." You can  
3 get the information by asking for a copy of the  
4 record. But it is very problematic.

5 DR. STEINBERG: So we -- our customers  
6 actually have asked us pretty uniformly until now  
7 with one exception I'll get to in a minute to  
8 actually filter out certain types of conditions,  
9 particularly HIV, mental health, substance abuse,  
10 from the records that are viewable by the members.

11 MS. KENYON: So it's not in your PHR at  
12 all?

13 DR. STEINBERG: It's not in the PHR.  
14 Now, that said, that has changed, and we have the  
15 ability to do that in yes or no on a  
16 customer-specific basis. Increasingly, we  
17 recently have this situation with one of our new  
18 health information exchange partners in Brooklyn  
19 where what we're doing with them is specifically  
20 revolving around HIV and mental health. So, by  
21 definition, we are having to include those  
22 diagnoses in the personal health record. So that

1       seems to be an evolving thing.

2                   And the other thing I would say, though,  
3       you know, sort of the flipside of this, and, you  
4       know, about what data is viewable, you have to be  
5       a little sometimes careful. One is the thing is  
6       to provide the information, at least on a  
7       diagnostic side, in consumer-friendly terms. I  
8       mean a lot of the ICD-9 diagnostic terminology,  
9       unless you're a physician or, you know, a health  
10      care provider, is completely incoherent and  
11      difficult to understand if not outright  
12      terrifying. So you've had all sorts of anecdotal  
13      issues where people have said I didn't know I had  
14      a brain tumor, right. So you need to be careful  
15      of that.

16                   And one of the ways, for example, we get  
17      around that is we provide the granular detail  
18      that's there in patient-friendly terms, but, in  
19      addition, we have a section where we present  
20      individuals with their diagnosed conditions, their  
21      actual conditions that have undergone some level  
22      of clinically intelligent analysis and say, well,

1       you may have all these ICD-9 codes over here, but  
2       here is a subset of validated conditions that you  
3       actually have.

4               DR. MCKAY:  At Kaiser Permanente we took  
5       actually the opposite approach, and it was again  
6       based on feedback that we got from our members,  
7       which was that they wanted to see the terms that  
8       their doctors were seeing and for two reasons:  
9       One is that they didn't want to be talked down to;  
10      and they also wanted the ability to take those  
11      terms to be able to search more broadly on the  
12      Internet for health information.

13              So what we do instead is we present the  
14      terms.  There are some things: like, that, with,  
15      et cetera, et cetera, et cetera, that get dropped  
16      -- but then we link that information to our health  
17      and drug encyclopedia so that people can read  
18      about the conditions themselves.

19              MS. NICHOLS:  Yeah, we do something  
20      similar.  We have a link to a health-fit knowledge  
21      database, but I can't agree more that patients are  
22      surprisingly competent, and they don't need to be

1 shielded from actual information.

2 DR. STEINBERG: Yeah. And again, I  
3 think, you know, all the data is there. It's just  
4 if you've read what it looks like in, you know,  
5 these long diagnostic categories, as you said you  
6 even, you know, chopping it up already. So it's a  
7 matter of just putting them into something that is  
8 understandable, and all those links are there as  
9 well.

10 So I think we're actually agreeing,  
11 vehemently, rather than disagreeing.

12 MS. KENYON: Okay. Do you have -- do  
13 any of you have a question that you'd like to  
14 answer or that you'd like to ask to somebody else?

15 MR. EVANS: I can answer.

16 MS. KENYON: Okay, let's start with  
17 Lori. No, that's not --

18 MS. NICHOLS: Don't start with me.

19 MS. KENYON: Don't start with you, okay.  
20 Tim?

21 DR. MCKAY: With one of the questions  
22 that we were presented with, I thought, was,

1 really interesting, with where do we see the  
2 security and privacy challenges that are on the  
3 horizon?

4 MS. KENYON: Okay. Let me ask you that  
5 one: Where do you see? (Laughter)

6 DR. MCKAY: In places that are maybe a  
7 little different than you would think, we  
8 perpetually have to enforce secure coding  
9 practices, that there are certain things that you  
10 just should not do when you're coding an Internet  
11 application that you need to train your developers  
12 in well. Otherwise you start opening security  
13 holes.

14 Another would be the need to do greater  
15 and greater in-depth testing, especially due to  
16 browser proliferation, so all browsers do not  
17 behave the same, and we need to test against  
18 multiple versions of Internet Explorer, Firefox,  
19 Chrome, and Safari as a matter of course.

20 The more complex that the systems get,  
21 the more time, relative time that needs to be  
22 spent and money needs to be given to testing in



1 relation to the amount of development that you're  
2 doing. And being able to maintain innovation  
3 while increasing complexity, I think is one of  
4 those challenges that we're going to have to find  
5 a happy medium.

6 MS. KENYON: Okay. Let me ask a  
7 security challenges from Colin Evans, Dossia,  
8 because I know that's in your background.

9 MR. EVANS: You know, we don't -- I  
10 mean, technologically, I don't think we've come  
11 across anything that's particularly difficult.  
12 Frankly, when I was looking at that question, the  
13 one area that came, that struck me most when I was  
14 sort of thinking about it, was the apparent  
15 difficulty most of the rest of the industry has in  
16 passing secure data.

17 We had one large health plan that will  
18 remain nameless, you know, wanted to send us data  
19 on a CD, or their IT people didn't want to send  
20 secure FTP. I mean, there were a lot of issues  
21 where we were trying to get basic things in place  
22 that I thought were pretty routine industry

1 standard, normal ways of transmitting data. And  
2 we've -- now that may just be because they were  
3 throwing logs on the railroad because they didn't  
4 want to send the data. But, you know, some of the  
5 difficulty we had is actually in some of those  
6 external connections. We think there are pretty  
7 well-formed industry-recognized practices for  
8 secure data transfer that many people don't seem  
9 to know how to use.

10 MS. KENYON: That's interesting. So  
11 it's the human factor.

12 MR. EVANS: I could never figure out  
13 whether it was really they did have incompetent  
14 security people or they just didn't want to send  
15 us the data. And right now, you know, the jury's  
16 still out.

17 MS. KENYON: So it the major security  
18 issue is incompetent security people, so -- Greg?  
19 On security challenges.

20 DR. STEINBERG: Yeah. I mean I think  
21 that from our perspective what's been sort of  
22 interesting, we have -- like I'm sure everyone

1 else here, I mean, we have from an architectural  
2 perspective, I think, you know, we have security  
3 around our presentation layer, our application  
4 layer, our basic database layer. And we have all  
5 sorts of internal and external audits that are  
6 performed, ethical hacks -- which is a sort of  
7 interestingly oxymoronic term -- that occur. So,  
8 you know, and to my knowledge these have always  
9 been fine.

10 MS. KENYON: Have you had security  
11 breaches?

12 DR. STEINBERG: No. No.

13 MS. KENYON: Okay. And George:

14 MR. SCRIBAN: Are you asking me if we've  
15 had security breaches?

16 MS. KENYON: Well, you know, I -- you  
17 will be free to answer that question, but I'm  
18 asking you for security challenges.

19 MR. SCRIBAN: Security, well, I think  
20 you're going to get a very different answer from  
21 the technology-centric companies here than the  
22 health care-oriented entities. You know, we have

1 a reasonably long tradition and, in fact, have  
2 kind of established that the industry standard  
3 around secure development practices with the  
4 security development lifecycle at Microsoft, which  
5 is not proprietary to us but something that we  
6 share with the rest of the industry.

7           So, you know, it's ingrained to us to  
8 bake security into the development lifecycle, to  
9 bake privacy concerns into the development  
10 lifecycle of all the products that we release. So  
11 as to, you know, specific security concerns around  
12 data interchange, I think, you know, my experience  
13 is a lot like, like Dossia's and Colin's to the  
14 extent that, you know, not us; some of our  
15 partners may have an interesting -- it's  
16 interesting doing engagements with partners.

17           And I think there's the other thing that  
18 I find myself constantly coming up against is when  
19 we deal with third parties' data sources,  
20 community hospitals, or health care providers, or  
21 payers or PBMs who want to deal with, who want to  
22 enable their patients or members to pull a copy of

1 the record into HealthVault, the information-risk  
2 people on the traditional health care entity side  
3 looking at us and trying to figure out, okay, so  
4 how do you guys fit into HIPAA? I want to know,  
5 do you comply with HIPAA? So we're constantly  
6 being asked questions in terms of information,  
7 governance risk, security questions, always  
8 through the lens of the HIPAA Security Rule and  
9 the HIPAA Privacy Rule.

10 I'm not saying it doesn't apply. And,  
11 in fact, we've gone out and we've been accredited  
12 as a HIPAA Security-covered entity by URAC just to  
13 show, you know, our good faith in our practices  
14 and to try and make it translatable and relatable.  
15 But we've got this -- it's almost like an  
16 impedance mismatch. I've got a situation where  
17 the rest of the health care ecosystem speaks,  
18 thinks, lives, breathes HIPAA, and it's various  
19 strengthenings and modifications, and we're  
20 outside of that realm. We talk possibly, you  
21 know, in terms of different information security  
22 and privacy frameworks, and the twain are having a

1 hard time meeting. They meet in me.

2 MS. KENYON: Well, you know, I think --

3 MR. SCRIBAN: And we are filling out  
4 forms --

5 MS. KENYON: -- we're going to get to  
6 pick this one up, especially in Panel 4.

7 Thank you very much. This has been a  
8 fascinating --

9 MS. NICHOLS: (inaudible)

10 MS. KENYON: I'm over. I'm into the  
11 next panel, I am sorry, Lori.

12 Okay, thank you very much.

13 MS. NICHOLS: These are experienced  
14 challenges.

15 (Applause)

16 MS. KENYON: Yeah.

17 MS. PRITTS: We're going to take a quick  
18 five-minute break while we set up for the next  
19 panel.

20 (Recess)

21 MS. PRITTS: If we could please get  
22 people to take their seats, we can start with the

1 next panel. For people who do not take their  
2 seats, I'm going to start singing and you will all  
3 regret it. We have bouncers. See, that got  
4 everybody's attention. Okay, please take your  
5 seats so we can start with our next panel.

6 For our next panel, we will be  
7 discussing new forms, new audiences and new  
8 challenges. And we heard a little bit of new  
9 challenges in our last panel, but this is just  
10 going to expand our horizons even more. It's  
11 going to be a very interesting panel, just like  
12 our first one, and I'm really psyched about  
13 hearing what is going to be said on this one,  
14 because I know some of the things that are in this  
15 panel, and it's some really cool stuff.

16 So to moderate this panel, we have a  
17 really cool person from ONC, Wil Yu, who is a  
18 Special Assistant of Innovation and Research for  
19 us. He leads innovation efforts of ONC, he's a  
20 Senior Project Officer for the Strategic Health IT  
21 Advanced Research Projects, many of you have heard  
22 this referred to as SHARP. And this project funds

1 research on achieving breakthrough advances to  
2 address some of the barriers that have impeded the  
3 adoption of health IT, including some in security,  
4 patient-centered cognitive support, secondary use,  
5 and applications and architecture. So I will turn  
6 these proceedings over into the capable hands of  
7 Wil Yu. Thank you.

8 MR. YU: Thank you, Joy, a lovely  
9 introduction. Thank you all for joining me today.  
10 It's very exciting to be here, and it's wonderful  
11 to see so many eager and enthusiastic faces in the  
12 audience.

13 We have a very distinguished group of  
14 individuals today to speak a little bit about the  
15 evolution of PHRs and related technologies. We  
16 hope to cover a diverse set of issues regarding I  
17 guess different communication channels, different  
18 organizational and business models, as well as the  
19 various types of audiences that are being  
20 connected to digital health and their own consumer  
21 health data.

22 So let me first start off with a brief



1 introduction of the panelists. Immediately to my  
2 left I have Steve Downs. Steve Downs is Assistant  
3 Vice President of the Health Group of the Robert  
4 Wood Johnson Foundation. His responsibilities  
5 include serving as a member of the RWJF Pioneer  
6 Portfolio Team, which seeks innovative projects  
7 that catalyze fundamental breakthroughs in health  
8 and health care. He works with program staff to  
9 achieve the Foundation's goals in reversing the  
10 epidemic of childhood obesity, driving fundamental  
11 improvements in the nation's public health system,  
12 and addressing the needs of vulnerable  
13 populations.

14 Mr. Downs and Foundation staff are  
15 developing programs to expand health information  
16 technologies that can dramatically improve the  
17 quality of American health care. So welcome,  
18 Steve.

19 MR. DOWNS: Thank you.

20 MR. YU: I'd like to introduce Darcy  
21 Gruttadaro. Darcy is the Director of the National  
22 Alliance on Mental Illness and Child and

1 Adolescent Action Center. She recently played an  
2 instrumental role in developing StrengthofUs.org,  
3 which she'll be describing in a little bit, NAMI's  
4 online resource center and social networking  
5 website for young adults living with mental health  
6 conditions.

7 Before joining NAMI, Ms. Gruttadaro  
8 worked as an independent legal adviser and policy  
9 analyst for the American Managed Behavioral  
10 Healthcare Association and other health care and  
11 advocacy organizations. So welcome, Darcy.

12 MS. GRUTTADARO: Thank you.

13 MR. YU: To Darcy's left we have John  
14 Moore of Chilmark Research. John has been an IT  
15 industry analyst for more than 15 years,  
16 predominantly in the manufacturing sector. But in  
17 2007, founded an analyst firm, Chilmark Research,  
18 to apply his research expertise and knowledge in  
19 the health IT market sector.

20 A core focus for Chilmark is adoption  
21 trends and use of consumer focused health IT  
22 solutions including PHRs. And he puts out a

1 regular blog on the space and industry which I  
2 encourage you all to visit to continue to read his  
3 thoughts on the space. So welcome, John.

4 MR. MOORE: Thank you, Wil.

5 MR. YU: To his left, Gail Nunlee-Bland,  
6 Director of the Diabetes Treatment Center at  
7 Howard University, Interim Chief of Endocrinology,  
8 and Director of the Center at Howard. She is an  
9 associate professor of pediatrics and medicine and  
10 is a graduate of Howard University for the class  
11 of 1980.

12 Dr. Nunlee-Bland is focused on improving  
13 access to quality diabetes care, and this passion  
14 has been born out through the Diabetes Treatment  
15 Center, which is a resource for patients and  
16 practitioners to have access to the expertise of  
17 nutritionists, diabetes educators, podiatrists and  
18 diabetes specialists. So welcome, Gail.

19 DR. NUNLEE-BLAND: Thank you.

20 MR. YU: And finally, but not least, we  
21 have Doug Trauner. Doug is the founder of Health  
22 Analytic Services, Inc., and in 2007, launched

1 TheCarrot.com, in 2008, to provide consumers with  
2 mobile and online health programs that allow them  
3 to better engage with and manage their health and  
4 wellness.

5 Previously he co-founded PM Squared,  
6 Inc., a health information company that was  
7 acquired by United Health Care. TheCarrot.com,  
8 however, offers health programs for individuals,  
9 employers and health plans, and its unique  
10 approach allows users to monitor more than 15  
11 different health activities and conditions such as  
12 nutrition, exercise, medications, moods, symptoms,  
13 et cetera. So welcome, Doug. We look forward to  
14 your perspective courtesy of TheCarrot.com.

15 MR. TRAUNER: Thank you.

16 MR. YU: As you can see, we have I guess  
17 a diverse set of backgrounds joining us today,  
18 some from a 30,000 macro perspective on the  
19 consumer health data space and some that are  
20 actively part of organizations that are in the  
21 trenches trying to better understand and develop a  
22 sustainable model for success. And it's my hope

1       that we can learn from both those perspectives as  
2       people begin to discuss what the future of the  
3       space looks like.

4               So the first open ended question that  
5       I'd like to throw out to the group is, please,  
6       each of you begin to talk a little bit about your  
7       organization, I guess how you play within the  
8       ecosystem, and really a kind of macro-level  
9       perspective on what the next three- to five-year  
10      holds. We'll begin to drill down and try to have  
11      a lively, interactive discussion following this  
12      set of answers. So, Steve, why don't I throw it  
13      out to you first.

14              MR. DOWNS: Sure, thank you, Wil. So  
15      I'm thinking back to how I got started in working  
16      around I guess what I would call consumer health  
17      IT for the Robert Wood Johnson Foundation, and it  
18      goes back to when I first started, and I had a  
19      conversation with our CEO, Risa Lavizzo-Mourey,  
20      and she said one of the trends that was starting  
21      to give her some discomfort was that we were going  
22      to increasingly place a burden on consumers and

1 patients to manage their finances, to manage their  
2 care, to be able to sort of, you know, if you  
3 thought about consumer-to-find health care, they  
4 were starting to put more financial risk  
5 associated with their health care, and she said  
6 I'm not sure they're going to have the tools to do  
7 that, and so it's something that we have to really  
8 think about, is how might they be better equipped  
9 to handle that responsibility that is increasing.

10           And so that started a number of ventures  
11 for us, but I think most of my remarks and  
12 discussion today is going to come from the  
13 perspective of a few projects that I'm currently  
14 involved with.

15           The first is a program called Project  
16 HealthDesign, and this is a program we launched,  
17 it's now four-and-a-half years ago, and we  
18 launched it with the purpose of how do you -- how  
19 can we re-envision personal health records and  
20 take them more from the type of PHR that was being  
21 discussed and operated a lot at the time, which  
22 was really focused on the idea of enabling

1 patients to view their medical data, to go online  
2 and see their record, see their lab results, and  
3 really push it much more to what do you do with  
4 that data, and make it much more actionable as was  
5 discussed in the last panel, and really focus on  
6 the apps. So that's a program that we created  
7 four-and-a-half years ago. And I should also give  
8 a nod to Doug, who is actually partnered with one  
9 of our current grantees on that.

10           The second program is one -- it's a  
11 large study we're doing right now, sponsoring  
12 right now called Open Notes, and this is a program  
13 that tests what happens if physician notes are  
14 made available to their patients in a quick, easy,  
15 electronic way.

16           So you all technically have the right to  
17 go and ask your physician for your full medical  
18 record, and we all know how easy that is to do and  
19 how smoothly that usually goes. But in this  
20 study, what's going to happen is, you go to see  
21 your doctor, and at the end of, you know, maybe  
22 end of the day, early the next day when they

1 finish signing their note about you, you get a  
2 security e-mail that says your physician's note is  
3 ready for your review, click here to see it, and  
4 if you have any questions, click there to email  
5 your physician.

6           Some physicians think this will end  
7 medicine as we know it, and some say, well, you  
8 know, this is kind of the way the world is  
9 starting to work, we might as well get used to it.  
10 But this is something we're going to study. We've  
11 got 100 doctors, probably about 25,000 patients  
12 who are going to be going through this, and I  
13 think we're going to learn a lot from it.

14           The third sort of project initiative  
15 activity I'm going to talk about is the Blue  
16 Button Initiative. And I cannot claim a whole lot  
17 of involvement in this other than we co-sponsored  
18 a Health 2.0 developer challenger of the Markle  
19 Foundation, and in general, I'm trying to play a  
20 cheerleader role, and I'm doing that because I  
21 think it is actually critically important to  
22 innovation, and I think it's actually



1       fundamentally important to the discussion we're  
2       having today about privacy.

3               But I want to tee up sort of three  
4       themes that I hope we can discuss in some depth  
5       that come from those projects, and I think these  
6       have been alluded to in the first panel, but I  
7       want to sort of lay them out sharply. One has to  
8       do with separating the apps from the data.

9               And again, typically we think of PHRs as  
10      having your medical record and then a number of  
11      features that help with display, interpretations  
12      and transactions wrapped around them. But more  
13      and more we're starting to see with services like  
14      HealthVault that the data live over here, and then  
15      there are lots of apps in other places that draw  
16      on those data. And there's some interesting  
17      discussions about that, whether it's important to  
18      have platforms like HealthVault. Matthew Holt  
19      likes to talk about, you know, there are no  
20      platforms, there's only data and apps. But, you  
21      know, I think it's an important trend for how we  
22      think about privacy and how we think about the PHR

1 industry.

2           The second is expanding the definition  
3 of health information. And I think the point was  
4 made earlier that health is not what happens when  
5 you go to visit your doctor, health happens 24  
6 hours a day, 365 days a year, it is based on the  
7 behavioral decisions you make every day, and it's  
8 based on the circumstances in which you live, and  
9 it's based on whether you have access to fresh  
10 foods, it's based on whether you can walk to a  
11 playground, there's all sorts of things like that.

12           And if you think about health data,  
13 health data are things like how well did you sleep  
14 last night, what did you eat yesterday, did you  
15 get to go for a walk, and again, it's also about  
16 your circumstances, whether it's environmental  
17 exposures, where you go all day, and what is  
18 located near where you go all day.

19           And this is a major focus right now of  
20 Project HealthDesign, is that we're focusing on  
21 what we call observations of daily living or ODLs,  
22 meaning it's data about your diet, your exercise,

1 your pain, the mood, the meds you actually took as  
2 opposed to the meds that have been prescribed to  
3 you.

4 So now the third thing is sharing, and I  
5 think it is so important that whenever we have a  
6 discussion about privacy, we think about the  
7 importance of sharing, because as important as it  
8 is for people to be able to keep some of their  
9 data about their health and many other things in  
10 their life private, there is a fundamental desire  
11 and need to share that information with some  
12 people, and we see people doing this all the time.

13 And so I hope as we talk about privacy  
14 today, we think about how do you design systems  
15 and design policies that don't optimize first for  
16 privacy and then think about how do we share data  
17 or how do we let people share data, but really  
18 think about those in conjunction. And I'll stop  
19 there and hope we come back to some of these.

20 MR. YU: Thank you, Steve. Darcy, I'd  
21 like to turn it to you.

22 MS. GRUTTADARO: Thank you, and thank

1     you for inviting me to participate. So we are  
2     sort of in the related technologies area, we're  
3     not really working in personal health records,  
4     although it depends on how we ultimately define  
5     them at some point in time. NAMI is a very large  
6     family and consumer advocacy organization. We  
7     have 1,100 state and affiliate chapters across the  
8     country. And we came to develop StrengthOfUs.org  
9     out of sort of necessity in recognizing that  
10    people in this transition age group of 18 to 25  
11    were not able to connect very well particularly  
12    when they had a mental illness and substance use  
13    disorder, so -- and that we knew they were using  
14    technology to gather information, to connect with  
15    each other, and we wanted to create something that  
16    would be uniquely theirs.

17                 So we developed this online social  
18    networking website. We didn't have privacy and  
19    security in mind at all, that was not part of our  
20    goal. I'm sure all the lawyers in the room are  
21    horrified to know that, but that was not our  
22    primary focus.

1           And we, in fact, weren't thinking about  
2 things like personal health records and sharing of  
3 that kind of information, we were more really  
4 focused on combating social isolation. What we  
5 found, though, is that people, in fact, share a  
6 huge -- first of all, the site has been an  
7 overwhelming success. We launched it in March, we  
8 pilot-tested it for a month, we have 1,300 active  
9 users now, which, given that we really went live  
10 in late April, we think is pretty impressive.  
11 This is a fairly -- it's a sliver of the  
12 population, obviously, in this age group.

13           But what we have found is that people  
14 are, in fact, connecting online, they're sharing a  
15 lot of information about their health, they share  
16 the medications they're on, they share the  
17 treatment they're in, they share information about  
18 how to address lifestyle issues that significantly  
19 impact their health, they provide mutual support  
20 about treatment adherence. There's a lot of  
21 really good information, support and sharing that  
22 is going on on the site.

1           So I would say that this kind of a  
2           social networking approach, and I think it was  
3           alluded to earlier on the panel, that we can  
4           really incentivize and motivate people,  
5           particularly through peer support, when they have  
6           similar health conditions, by creating social  
7           networking opportunities.

8           We actually modeled our site after  
9           Facebook. We have blogging, we have something  
10          that's equivalent to Twitter, it's called The  
11          Wire, where you can put in little clips about  
12          what's happening that day in your life. We have  
13          guest bloggers and experts coming on talking about  
14          how to manage schizophrenia, how to manage bipolar  
15          disorder, so we're pushing out information because  
16          we want to be seen as a reliable source of  
17          information around difficult-to-treat conditions.

18          And the value in this really is that we  
19          can get people very engaged and involved and get  
20          peer perspectives on what really works and how to  
21          live a fairly stable life even with these serious  
22          conditions.

1           So I guess I would say we were a bit  
2 naïve on the privacy and security side, and, in  
3 fact, we think our data is pretty secure. But I'm  
4 probably very naïve, I'm not an IT expert, and  
5 people probably could fairly easily hack in or  
6 register and come online and begin to use the  
7 information that we are collecting.

8           So there are a lot of -- and  
9 particularly with mental health, this was alluded  
10 to earlier. Unfortunately there remains a lot of  
11 stigma, a lot of myths, and a lot of  
12 misunderstandings around having a diagnosis and  
13 what that means in the way that you live your life  
14 and in your capability and in your employability  
15 and in a number of other factors. So I guess I  
16 would say I look forward to having a conversation  
17 around the value of social networking. As we all  
18 know, Facebook is absolutely just enormous and  
19 very powerful and important to a lot of people's  
20 lives for connection, but also how we can manage  
21 the sort of creating innovative approaches like we  
22 think we've done while still protecting people's

1 privacy and keeping data and information secure.  
2 So I look forward to having that conversation and  
3 I'm happy to be part of this discussion.

4 MR. YU: Thank you, Darcy. Moving on to  
5 John. John, as the only member of the panel who  
6 is not directly tied to a I guess consumer health  
7 data organization or a PHR, please let us know  
8 what your thoughts are.

9 MR. MOORE: Okay. Yeah, I was an  
10 industry analyst in the manufacturing sector for a  
11 number of years, and frankly, it got boring, so I  
12 was looking for a new adventure and started  
13 looking at different verticals and stumbled into  
14 health care and started peeling the onion and  
15 went, oh my God, what a mess, this is perfect for  
16 an analyst.

17 And then when I started looking deeper  
18 and looking at the macro trends in the market,  
19 realizing that, you know, increasingly there's  
20 going to be a lot more consumer involvement.  
21 They're not going to be able to sit back and let  
22 their employer just take care of things for them,



1 that they are going to, you know, as we see more  
2 and more consumer directed health plans with  
3 higher deductibles, what have you, a consumer's  
4 role in managing their health is going to  
5 increase, so that's clear.

6           So that led to our first study where we  
7 looked at the PHR market and published a report on  
8 that market back in May of 2008. Since that time,  
9 as I looked at this market and looked at how it's  
10 developed and tracked some of the successes, as  
11 well as some of the failures in the market, a  
12 couple of things have become quite clear to me in  
13 the research that I've done.

14           The first thing is that, you know, I  
15 believe language is a very important thing. And I  
16 think that in having the terms EHR and PHR, we  
17 are, indeed, creating artificial barriers, and  
18 that there is actually only one record, and I  
19 don't know if we call it a unified health record  
20 or a collaborative health record, but there really  
21 should be only one record that is used by the  
22 whole care team and all stakeholders therein.

1           And I think until we get to that point,  
2 we're still going to struggle with these  
3 definitions, with these privacy issues, these  
4 policy questions. So I think that's one of the  
5 things that I see right now. Secondly, as I  
6 think, you know, both Dossia and HealthVault  
7 talked about a little bit, it's not some, you  
8 know, people aren't really interested in a PHR as  
9 what has been commonly defined, which is basically  
10 a digital file cabinet for their records. People  
11 could care less about that, that's why we have not  
12 seen very high adoption.

13           But if you look at where we have seen  
14 high adoption rates, there's a couple of things  
15 that occur, either the patient/consumer can do  
16 something with the data, you know, it's actually  
17 actionable, that they can actually make sort of  
18 decision based on the information in that record  
19 and that that decision perpetuates into some  
20 action by another individual, i.e., their doctor,  
21 a nurse, what have you, but that's what's  
22 important, you know, is it actionable within the

1 context, and that's why I'd like to just kind of  
2 get rid of the PHR term all together, you can call  
3 them platforms, I don't care, the unified health  
4 record, collaborative health record.

5 One of the things before coming to this,  
6 I actually looked at the table of contents in all  
7 the PHR vendors that I profiled in that report  
8 back in 2008, and just one after another we click,  
9 yeah, they're no longer in the market, no, they're  
10 no longer in, they're out, they're out, they're  
11 out, you know, and we interviewed, you know, we  
12 profiled some 20 vendors, and most of them are  
13 gone. It's just -- it's a very, very hard market  
14 to actually make work and make money at.

15 But another thing I've seen is also  
16 recently I had the pleasure of sitting down with  
17 Gail, who worked with a PHR company. A couple  
18 years ago they brought in this PHR to look at how  
19 could this be used in the context of delivering  
20 better care for diabetes patients and helping  
21 diabetes patients take on more ownership to manage  
22 their diabetes.

1           And I'm not going to steal her thunder,  
2 I'll let her talk about it, but an incredibly  
3 intriguing story, and as I wrote on a quick tweet  
4 when I posted this piece that I wrote on it,  
5 basically this analyst got schooled, and it  
6 really, you know, broke down a lot of assumptions  
7 that I had and myths that I had created in my own  
8 mind as to how people may use these things.

9           And I think that's why we really have to  
10 keep a very open mind as to, you know, as we  
11 proceed forward, you know, certainly privacy and  
12 security are important, but I think it's also  
13 very, very dangerous if we look at this that's  
14 going to be in the consumer's hands and treat it  
15 the same way we treat a physician with HIPAA  
16 inside the context of a health care organization  
17 or institution and how they manage the data. And  
18 I think we can really make it too onerous for  
19 patients and consumers if we're not careful.

20           MR. YU: Thank you, John. Quite an  
21 introduction for Gail.

22           DR. NUNLEE-BLAND: Thank you.

1 MR. MOORE: Well deserved.

2 DR. NUNLEE-BLAND: I became involved in  
3 the PHR about two and a half years ago. I had  
4 received a grant from the District of Columbia,  
5 Washington, D.C., to explore novel technologies to  
6 improve outcomes of diabetes care, particularly in  
7 minority communities.

8 Just to give you a little background,  
9 Washington, D.C. has some of the highest rates of  
10 diabetes, and the morbidity and mortality in some  
11 communities where there's a large percentage of  
12 African Americans, their rates are pretty high and  
13 the mortality and morbidity is pretty high.

14 So I explored the personal health record  
15 because the care is somewhat fragmented. They  
16 move from plan to plan, and particularly with  
17 Medicaid population, doctor to doctor, and they  
18 never really seem to have a health care with them.  
19 And the doctor's office, it's very difficult for  
20 them to get their records and so forth. So  
21 NoMoreClipboards, I worked with them to integrate  
22 -- we were already using electronic medical

1 record, CliniPro, which is a disease management  
2 software geared for diabetes, and we integrated it  
3 with NoMoreClipboards. And actually the data that  
4 flows over from our EHR to the personal health  
5 record is basic demographics, basic insurance  
6 information, the patient's problem list, their  
7 medications, their allergies, and also labs that  
8 we deemed important in terms of their diabetes  
9 management, they can actually import their labs.

10 Also, patients have the ability to track  
11 their blood glucoses, they can enter their blood  
12 glucoses, they can enter their blood pressure, and  
13 so they could really be involved with their care.

14 Before I even started with this, the  
15 question was asked, well, you know, our  
16 population, 90 percent of our patients that we see  
17 are African Americans, and the majority of them  
18 are on a Medicaid medical assistance plan. Do  
19 your patients have computers, how are they going  
20 to use this, and this is a web-based platform.

21 So I surveyed and I found out that 70  
22 percent of our patients actually have computers

1 and actually have access to the web, so this was  
2 not a barrier for them. And just recently I  
3 looked at our data, and now that's up to 85  
4 percent, so more and more are using computers and  
5 the web.

6           So we've been doing this now for two and  
7 a half years, and we've been monitoring them, and  
8 actually we've seen improvement in outcomes, and  
9 we actually compared it to a group that did not  
10 sign up for the personal health record and to  
11 those that have used the personal health record,  
12 and we saw actually a 0.9 decrease on the  
13 hemoglobin A1C.

14           Now, that is a blood test that we use to  
15 assess how well someone is doing in terms of their  
16 disease management for their diabetes. And  
17 actually that probably rivals many of the  
18 medications that patients use to manage their  
19 diabetes, and this is just with a personal health  
20 record.

21           I was really pleased with a lot of the  
22 patients. They would come in and they would ask

1 me, well, did you see, I entered my data into my  
2 personal health record, I got my numbers in there,  
3 or I forgot my meter, but it's in my personal  
4 health record. And also, they told me that when  
5 they travel, if they've gone to other places, if  
6 they've gone to an emergency room, they were able  
7 to pull up their health record to share with the  
8 emergency room physician, so they've really  
9 adopted to this particular technology. We also  
10 surveyed them because security was a concern, you  
11 know, are you concerned about whether your data  
12 would be accessed by others, and really only 13  
13 percent had any concerns about security, and even  
14 those who did have concerns about security, many  
15 of them went on to sign up anyway.

16 So really only 5 percent of the patients  
17 that we surveyed refused to sign up because they  
18 were concerned about security, so that was not a  
19 major concern to them. They were more concerned  
20 about sharing data, having access to their data,  
21 and using it in a meaningful way.

22 MR. YU: Thank you, Gail. And Doug.





1       okay, how do you bring together a whole health  
2       approach. We see an individual in health like  
3       we're talking on this panel, and it's not just if  
4       you're dealing with hypertension, yeah, blood  
5       pressure and cholesterol levels are one part of  
6       it, but also exercise and nutrition, stress  
7       management, work time management, it starts to,  
8       you know, move very quickly into just lifestyle.

9               And if you think about so much of the  
10       medical costs in this country being around  
11       lifestyle related questions, then how are you  
12       going to bring together the lifestyle choices that  
13       people are faced with making every day, as people  
14       are already talking about here on this panel, and  
15       bring it together to work in a clinical setting  
16       and work in a support setting. There are people  
17       interested in helping you achieve your health  
18       objectives, as well as on a social level. People  
19       are interested in demographics, where it varies by  
20       age, but increasingly, there's a lot of people  
21       that are interested in participating and sharing  
22       that information with other people on a broader

1 level.

2           So you see some of that dialogue taking  
3 place on very insecure, open places today, but  
4 giving people the choice of being able to manage  
5 that, bring all that together, again, in a secure  
6 manner if you want, but at the same time, the  
7 ability to share it within your health care, so  
8 being able to address the needs of health care,  
9 being able to address social networks, and being  
10 able to address your support network for your  
11 health care coverage.

12           So we started TheCarrot about three  
13 years ago now. We've gotten some great feedback.  
14 We've got a strong user base today, about 50,000  
15 users using TheCarrot. We have a number of about  
16 15 different -- 35 different trackers today of  
17 what people can do. It's online, TheCarrot is a  
18 relatively consumer-friendly brand. We have an  
19 online experience, as well as a mobile experience,  
20 what we're bringing live now -- so if you've gone  
21 to TheCarrot today, you would see it's a private  
22 place. What you do there is for you. You can

1 record anything you want about yourself,  
2 understand and figure out and learn about  
3 different conditions, different objectives. What  
4 we're bringing now is the ability for people to  
5 start to really share that with these different  
6 groups that we're talking about both in public and  
7 private and addressing the challenges of, okay, if  
8 you're working with -- and the real questions  
9 we're faced with are, if I'm working on clinical  
10 level with my physician and sharing some of that  
11 information with them, and I'm also participating  
12 in a fully open challenge around any of my  
13 measures, let's just say my physical activity,  
14 what exercise am I doing, and I'm sharing that  
15 with maybe even the whole world through that, what  
16 challenges or what are the requirements that we  
17 need to be addressing to meet those requirements?

18 We've been a locked down, private,  
19 secure place where people can interact with that,  
20 I'm really interested in that dialogue today,  
21 around what do we need to do to make that work.  
22 It's not clear.

1           Our lawyers, if you ask them to review  
2     it, the answer is universally, well, you know, I  
3     can't figure this out very clearly, so no, but I  
4     don't think that's the right answer. I think when  
5     you're looking at addressing health care, and the  
6     value of these three areas: clinical, social, and  
7     then your health support network, whether it be a  
8     nutritionist, physical therapist, people outside  
9     of the pure clinical setting, bringing those three  
10    pieces together we see as fundamental and I am  
11    very excited about participating on this panel.

12           MR. YU: Very good, Doug, and I hope to  
13    address some of those topics during this session.  
14    It's a very exciting time for innovators in the  
15    space, especially with a great deal of volatility.  
16    Demographic trends are changing, and technology  
17    development continues at a rate that's unabated.

18           Let me throw out a question first to the  
19    folks who are championing organizations directly  
20    working with consumers and patients. What are the  
21    evolving trends that you see in terms of consumer  
22    or user demand?

1           Darcy, you mentioned social media; Gail,  
2           you mentioned that the technology literacy of your  
3           population is ever increasing. With respect to  
4           health data, with respect to PHRs, are there any  
5           trends or issues that you see? Darcy, let me  
6           throw it out to you. And hopefully both Steve and  
7           John can comment on how the innovators are  
8           responding from a commercial organizational  
9           perspective.

10           MS. GRUTTADARO: Yeah, I mean, I would  
11           say I think there's a real interest in managing  
12           health conditions, and I think that presents a  
13           tremendous opportunity.

14           MR. YU: And this is at an increasing  
15           rate or --

16           MS. GRUTTADARO: At an increasing rate.  
17           I think people are recognizing there's a lot that  
18           we're hearing about in just the sort of mainstream  
19           media about managing your health condition. And I  
20           think also there's, in the mental health world,  
21           which is the world I operate in, there's a lot  
22           more recognition that people can do more, so

1       there's sort of incentives to manage your  
2       condition better.

3                 And I think there's also a real interest  
4       in connecting with others who have the same lived  
5       experience, because I think there's sort of a --  
6       there's a kindred spirit aspect to this, like  
7       you're in the same boat I am, you understand my  
8       health condition as well as I do, so that  
9       connection among people with the same condition I  
10      think is very important, because there's sort of  
11      this perception that people understand better when  
12      they're in the same boat as others.

13                So I think -- and the other thing is, I  
14      think just reaching out for support when people  
15      are at different stages of resiliency raising and  
16      recovery, so recognizing that other people that  
17      may have a health condition may be farther down  
18      the road than you are and may have a lot to share  
19      in how they got to a point of being deeper in  
20      their recovery phase.

21                So I think all of this lends itself to  
22      creating connections. And I like the way actually

1 Doug presented this in sort of a three part way.  
2 You know, there's the clinical, there's -- I don't  
3 know if I'm saying this right, but the lifestyle  
4 and the social, the sort of -- you have to -- if  
5 we're going to really do well in the health care  
6 world in this country and control costs, I mean we  
7 have to really be thinking about how do we  
8 incentivize people in all of those areas, and  
9 social networking is one way to do that, and I  
10 think we're seeing that more and more, and we're  
11 seeing that in the work that we're doing.

12 MR. YU: Very good. Gail, would you  
13 like to respond to some of that social aspect?

14 DR. NUNLEE-BLAND: Okay. Well, you  
15 know, one of the things that we implemented just  
16 recently, over the last six months, has actually  
17 been cell phones, we've been using the cell phone  
18 technology, and we actually are finding that  
19 patients are really -- they really like that  
20 because they always have their cell phone with  
21 them. And so now they're entering their blood  
22 glucose and the cell phones integrate with our



1 personal health record and it is uploaded so that  
2 they don't have to enter dually, and the patient  
3 says I always have my cell phone and I prefer this  
4 as a way of communicating with my doctor.

5           The other aspect of it, which I think  
6 has been very helpful is that with the cell phone  
7 technology that we've integrated, it gives them  
8 alerts and reminders, have you had your eyes  
9 examined, is it time for the podiatry visit, have  
10 you had your flu shot. And so, again, because the  
11 cell phone is with them at all times, it gives  
12 that that reminder, as well as your appointment  
13 time. And then there's questionnaires that we  
14 sometimes ask them to keep them in tune with their  
15 health.

16           So using these multiple medias really I  
17 think engages people. And I'm sure the social  
18 media, we haven't quite got into the blogs and the  
19 Facebooks yet, but I think it really does help in  
20 terms of management, that the patient is the one  
21 that is involved with their care, and that they  
22 should be in control of what they're doing, and

1 the more they can interact with their health care  
2 providers and other people around in their social  
3 network really is of benefit. Another aspect,  
4 too, is they can add other members or other  
5 families or other support to their network so that  
6 if they need an alert or reminder sent to a family  
7 member or a friend, they can elect to do that, as  
8 well, and that has been very helpful.

9 MS. GRUTTADARO: I just want to say one  
10 other thing, too, about the sensitivity of  
11 information, because when it comes to mental  
12 health, and I'm sure this is true for other health  
13 conditions, people -- it's not a topic or a  
14 subject that people feel necessarily comfortable  
15 always approaching a medical professional about,  
16 so they're seeking information online, and they  
17 can really -- the more we can provide information  
18 on sensitive topics that's reliable, whether it's  
19 through social networking or -- I think it's --  
20 people increasingly have turned to online  
21 resources for sensitive information and for  
22 conversing on sensitive topics, and this is

1 particularly true in mental health and substance  
2 use.

3 MR. YU: Right; Doug, do you see any  
4 special populations with emerging needs, or I  
5 guess --

6 MR. TRAUNER: I mean there are the  
7 standard breakdowns of disease management and sort  
8 of health improvement that we -- when we look at  
9 what people have been doing on TheCarrot -- it  
10 sort of tends to follow, you know, weight,  
11 exercise, nutrition, and then chronic conditions,  
12 diabetes, asthma, hypertension tend to be some of  
13 the activities that people are trying to  
14 participate in, we've definitely seen an uptick in  
15 the number of people have been using the service,  
16 that are getting engaged and participating in  
17 that.

18 To be fair, our social aspect is what's  
19 coming on now, the social's been mostly around  
20 what people want to see from the site. It's been  
21 very consumer-driven by what kinds of things  
22 people want to be able to track, how they want to

1 be doing that better and we've been responding to  
2 that.

3 But what we're bringing now is the  
4 ability to share all that information and  
5 addressing that. So we're definitely seeing an up  
6 tick in terms of how people are interested in  
7 participating in what we're doing, as well as  
8 also, we're getting a lot of companies that are  
9 saying we'd like to be able to bring this quickly  
10 to other wellness companies that are saying we'd  
11 like to use what you're doing, but we have some  
12 ideas of how we want to package it up, and we're  
13 working with them, as well.

14 So I think there's a lot of interest in  
15 companies saying look I don't want to be building  
16 the technology around this, what we want to be  
17 doing is taking and putting programs in place that  
18 can make a difference and helping them to achieve  
19 that, as well.

20 MR. YU: John, if you could comment.  
21 Are these trends that you're seeing in the wider  
22 spectrum with regards to emerging needs and

1 innovators that fill them?

2 MR. MOORE: Well, I think right now what  
3 I'm seeing is, in the market, is a couple of  
4 things. First off, and I was talking actually to  
5 one of the innovators out there in the market this  
6 week, and I asked him what is he seeing in the  
7 market, and he says, you know, on the provider  
8 side they're seeing nothing, the providers are --  
9 and even amongst providers, that even will talk to  
10 them, it's still about marketing and consumer  
11 retention.

12 Basically, you know, they put up the PHR  
13 or the patient portal, but it's all about  
14 retention of the patients so they'll keep coming  
15 back to that particular institution for their  
16 care, so it's a marketing play.

17 Where they're seeing some traction is,  
18 of all places, in the HIE space. As regional --  
19 in particular, regional exchanges are looking at  
20 how do we become sustainable over time, and  
21 they're looking at, okay, is there a way that we  
22 can start providing, particularly around what this

1 particular firm calls care units, but looking at  
2 specific chronic diseases and creating within the  
3 context of a RHIO or an HIE, care plans around  
4 that to help people in that community share  
5 information amongst each other, as well as promote  
6 the care around say diabetes, or maybe in mental  
7 health.

8           You know, right now they're really  
9 looking at the typical chronic diseases of  
10 diabetes, you know, COPD, things like that, not  
11 necessarily mental health, but I think what we're  
12 seeing in the market in general as a trend is -- I  
13 hate to call it disease management because disease  
14 management right now has a bad name out there in  
15 the market, so I really don't like going down that  
16 path, but it's more personalizing the platform  
17 around specific areas of -- to help people  
18 actually manage their disease, their care,  
19 personally, on a personal level.

20           And getting to Gail's point, yeah, you  
21 asked I think in your previous question what do we  
22 see three to five years out, and for me, all I see

1 is mobile, mobile, mobile, mobile. It's with you  
2 wherever you are, and, as I like to say, health is  
3 mobile, it does not happen in front of your desk  
4 top, it happens wherever you happen to be, and the  
5 only thing that can really provide that capability  
6 is a SmartPhone or even a feature phone with  
7 texting features.

8 MR. YU: Very good; and Steve.

9 MR. DOWNS: Yeah, this is an interesting  
10 question. I agree with a lot of the same trends.  
11 I think one of the most important things to hear  
12 is, this is a time of rapid experimentation, and  
13 things are evolving, they're not figured out, the  
14 industry hasn't sort of jelled, and in some ways I  
15 defy you to think about what a personal health  
16 record is, and, you know, and really then try to  
17 regulate it, you know, and good luck.

18 And so I think the -- and then just a  
19 way to express that, if you think about some  
20 elements of personal health data and how you use  
21 them, there are input devices or input  
22 opportunities, there are storage and maintenance,

1 and then there's also sort of the display and  
2 action triggers kind of thing, and you think about  
3 diversity of inputs.

4           You can gather health data from sensors,  
5 you can gather health data from SmartPhones, you  
6 can gather health data from somebody sitting down  
7 and typing something in, you can gather health  
8 data from an office visit. If you think about  
9 storage, you've got places like TheCarrot. Think  
10 about Nike Plus, Nike Plus has an unbelievable  
11 number of users entering data about their exercise  
12 every day. Every app on the iPhone store is  
13 tracking somehow-- all 6000 health apps, you know,  
14 they're tracking data about you. HealthVault,  
15 Google Health, and then, of course, you know, the  
16 Kaiser model, as well, has a lot of your health  
17 data.

18           And actually Twitter, you know, I mean I  
19 remember following somebody who was tweeting his  
20 weight every day for a while, he stopped after a  
21 while, but --

22           MR. MOORE: Was that a good thing?



1 MR. DOWNS: That he stopped?

2 MR. MOORE: Yeah.

3 MR. DOWNS: No, but -- and, you know,  
4 there are actually people that are working on sort  
5 of secure ways to use Twitter as a platform for  
6 storing your data, and I can talk more about that.

7 But then also again, think about how you  
8 access these data and use them. You know, again,  
9 you can log on from a PC or you can be hit by  
10 something on your SmartPhone. So again, thinking  
11 about the concept of a record, when information is  
12 this distributed and takes so many different forms  
13 and it is changing every single day I think is a  
14 real challenge.

15 The other thing I wanted to speak to in  
16 terms of the trend, you know, and I mentioned this  
17 observations of daily living idea earlier, you  
18 know, so there's a group that started out in the  
19 Bay area called the Quantified Self, and there's a  
20 great article in the New York Times magazine from  
21 about six months ago by Gary Wolf, who's actually  
22 very involved with the movement. And so

1 Quantified Self is people -- and these are -- it  
2 started out very much kind of sort of the Bay area  
3 geeks, and I say that in the nicest possible way,  
4 because I love them, and these are folks who  
5 professionally have learned the value of tracking  
6 data and using feedback to make systems better.

7           And so they say why not apply this to my  
8 life, you know, so these are people who track  
9 exactly how long it takes to drive to work every  
10 day based on the day of the week and the time they  
11 leave the house, and then they say, well, what if  
12 I left five minutes earlier, and then they say,  
13 you know what, I actually got there ten minutes  
14 sooner, you know, and so they do this constantly  
15 in their life and they're starting to apply it to  
16 their health.

17           And it was great when Gary's article  
18 came out because, you know, there are all these  
19 things on the Times website, and people are saying  
20 these folks are crazy, they're really weird, you  
21 know. But what's actually happening is, it's  
22 starting to go mainstream. So Quantified Self now

1 has chapters in 12 cities. And Susannah Fox from  
2 the Pew Internet and American Life Project is  
3 working on a report, it's not published yet, but  
4 she has actually released these data points which  
5 say that 15 percent of Internet users are tracking  
6 diet, weight, exercise online, so they're putting  
7 their own data online, 15 percent of Internet  
8 users, and then 17 percent are actually tracking  
9 symptoms besides diet, weight and exercise.

10 So, you know, we have really moved from  
11 the alpha geeks to a much sort of an early adopter  
12 part of the curve. So I think this is a trend  
13 that is -- that we need to be paying attention to.

14 MR. YU: Thank you, Steve. Steve,  
15 originally you brought up a point about the  
16 separation of the apps from the data, and we've  
17 heard a discussion around new collection  
18 modalities for what seems to be an ocean of data  
19 that's emerging. I'd like to throw out to the  
20 panel, what are the new types of analysis and new  
21 applications that are taking place as a result of  
22 this data? You know, as the data becomes stored,

1 especially in an identifiable form, what do we see  
2 as future iterations of analysis, applications  
3 specifically designed for the end user either in a  
4 social sense or in an individual sense? I'm going  
5 to throw this out to Doug first since your  
6 organization seems to be very nimble in terms of  
7 collecting data. Can you speak a little bit to  
8 this point?

9 MR. TRAUNER: Sure. I think there are a  
10 couple different ways to look at the analysis,  
11 part one, just the ability to look at all the data  
12 in a meaningful way, in a simple way, in a  
13 non-aggregated way, so just showing a week of your  
14 information at various times, how people look at  
15 nutrition and what they're doing.

16 You can even do it with pictures, for  
17 example, being about to just see that information.  
18 So there's just the immediate -- there's a  
19 feedback story and people can respond to that.

20 MR. YU: Longitudinal, right?

21 MR. TRAUNER: There's a longitude,  
22 exactly. And then being able to compare that with

1 other different measures that you're looking at.  
2 So it could be your mood or your symptoms and are  
3 there relationships between those, and that starts  
4 to get another type of, well, what is going on  
5 with my blood pressure when I'm getting exercise  
6 or not getting exercise, those kinds of questions  
7 that, on an ad hoc basis, people like to look at.

8           You then start to have another set of  
9 questions that come up, especially when you start  
10 to tie into clinical, they don't want that  
11 information necessarily. Providing, you know,  
12 there are great stories of people using The Daily  
13 Plate, and they show up with the report, which is  
14 15 pages of everything they ate, and they're  
15 sitting down for a 15-minute visit, and it doesn't  
16 facilitate the conversation, it's more, well,  
17 that's interesting, now tell me what's going on.

18           So the ability to then structure very  
19 consolidated, very meaningful reports that a  
20 physician in a clinical setting would be relevant  
21 in a succinct way, as well as not, quite frankly,  
22 introducing a new type of legal liability.

1           If you give them all of the information  
2           and they then are responsible for going through  
3           and figuring out, is there a problem that I need  
4           to respond to, and they're not getting paid for  
5           that, so addressing that question in a succinct  
6           way that makes sense for them, this is their  
7           report in a succinct way for diabetes, it doesn't  
8           have extraneous information that they didn't want  
9           to see, those are kind of three areas that we're  
10          addressing right now. Does that kind of --

11           MR. YU: Yes. Gail, would you just like  
12          to speak a little bit about the diabetes related  
13          data that I guess you're collecting and the  
14          applications that might be generated as a result?

15           DR. NUNLEE-BLAND: Well, you know, we  
16          always like to look at glucose trends, so that  
17          when we can see that and see patterns in terms of  
18          where their blood sugars are going, we can make  
19          adjustments in terms of their medications, so that  
20          is very helpful to us, also the trends in terms of  
21          some of the other labs that we look at in terms of  
22          how well the patient is being managed in a useful

1 way.

2                   And I agree with you, we really don't  
3 want stacks of papers, but we want something that  
4 is sort of consolidated because we really don't  
5 have a lot of time. And so when we can get data  
6 that is consolidated or at least graphically  
7 displayed to us or averaged out, that is very  
8 helpful to us in a clinical setting.

9                   MR. YU: And is this something that the  
10 users are requesting, as well, or are responding  
11 to?

12                   DR. NUNLEE-BLAND: The users, really all  
13 they -- if they enter their blood sugar, they're  
14 just entering their blood sugar. But I want an  
15 application that would average it out to me, let  
16 me see the trends. They're not concerned about,  
17 you know, whether it was an average or whether --  
18 all they want to do is put their data in and  
19 hopefully something goes in a black box and it  
20 does the work for them. So users pretty much want  
21 things simple, and that's what I found in terms of  
22 our set-up, that really users don't have to put a

1 lot of data in, because there's a lot of  
2 transferred data back and forth between our  
3 systems, so they like that part of it, and then it  
4 will graph it out for us and we can begin to look  
5 at averages and so forth.

6 MR. YU: I see, so from a clinician  
7 perspective, okay, very good. So, Darcy, would  
8 you like to respond from a --

9 MS. GRUTTADARO: Yeah, you know, it's  
10 funny, when you first asked the question, I was  
11 going to say, well, we don't really -- we're not  
12 really looking at the data in that way because  
13 we're really a social networking site, but then I  
14 remembered that, yes, we are actually looking at  
15 what people are blogging about and tweeting about,  
16 and we're looking at what their questions are, and  
17 we're sort of looking at it in an unscientific way  
18 to say what are people saying about their treating  
19 providers, what can we communicate back through  
20 our advocacy work and our policy work to provider  
21 organizations that can have an influence on how  
22 services are delivered. We're thinking about what



1 kinds of information are people seeking that may  
2 not be available in their communities and from  
3 their practitioners, and how can we supplement  
4 what they have so that they can better understand  
5 what the research is showing, because,  
6 unfortunately, mental health, a lot of what's  
7 delivered is not evidence-based and is not leading  
8 to positive outcomes and we have a long way to go,  
9 so we are educating consumers about what kinds of  
10 services they should be getting.

11           If you want major depression, are you  
12 getting cognitive behavioral therapy? If you're  
13 not because there's not a provider in your  
14 community that's been trained in that, we have  
15 work to do to advocate, to ensure that providers  
16 are trained in the most effective intervention.

17           So, in a sense, you know, my initial gut  
18 reaction was, we're not really looking at the  
19 data, but we are, and we're using it to say there  
20 are some overriding policy issues here and how we  
21 can better address the needs of this demographic  
22 so that we can produce better outcomes.

1           We can bring down our overall health  
2     care costs, we can keep people working, we can  
3     keep them living in the community, we can do  
4     things that will make communities healthier and  
5     will lead to lowering an overall health costs. So  
6     we are looking at the data, and I think it's --  
7     there are a lot of important social change that  
8     can happen from learning about what's going on in  
9     these social networking sites.

10           MR. YU: Steve, any implications in  
11     terms of application development?

12           MR. DOWNS: Well, I mean so one of the  
13     things that we are focusing in on Project  
14     HealthDesign is, how do you tie back to the  
15     clinical care team, and I think a lot of what's  
16     been said, whether it's by Gail or Doug, you know,  
17     that you have to figure out how do you fit both  
18     into the time that a clinician has and also their  
19     work flow.

20           And so each of the teams that we're  
21     supporting are looking at what kind of data are we  
22     gathering in terms of people's day-to-day lives

1 and then how do you both analyze it for sort of  
2 clinical signals, I guess I would say, separating  
3 the signal from the noise, and then how do you  
4 display it in a way that's useful, and then again,  
5 how do you fit it into the work flow. And I won't  
6 say that we have answers yet on those, they're  
7 sort of -- the projects are kind of in flight.

8 But I also want to bring back an  
9 analogy, and I owe this, again, to Susannah Fox,  
10 which was, she pointed out that about 15 -- 16  
11 years ago now, people started walking into their  
12 doctor's offices with reams of paper from Internet  
13 searches they had done about their conditions, and  
14 some of the doctors sort of said, you know, get  
15 away, you know, this is not the proper role of a  
16 patient and all that stuff on the Internet is  
17 wrong anyway, and some said, this is really neat  
18 that you've actually taken this time to do that,  
19 and, you know, it's probably not the best thing  
20 just to bring me a stack of 30 pages of this, but  
21 let's start to have a conversation about how we  
22 can have a dialogue that's informed by your

1 research.

2           And she was saying we were going to  
3 start -- we are starting to see and we're going to  
4 start to see more of the patient who brings in,  
5 you know, the 30 pages of sleep and exercise data.  
6 And again, some docs will say don't you ever do  
7 that again, and others will say, okay, that's not  
8 a helpful format, but the idea is right. And I  
9 think it's interesting to think that this may  
10 actually be a legitimate analogy. I mean, I think  
11 that it's an open question.

12           MR. YU: Very good. And, John, do you  
13 want to talk a little bit about the long tale of  
14 applications?

15           MR. MOORE: Well, yeah, I think one  
16 thing that has not been touched upon, because at  
17 least based on what I've heard so far has been  
18 patient-clinician, clinician-patient interchange.  
19 We haven't talked about patient-to-patient  
20 interchange.

21           And what they're doing in terms of  
22 sharing information, you know, we mentioned --

1 Darcy mentioned something about social networking,  
2 and, you know, they have a blog and some tweet  
3 type capabilities within their site that they  
4 developed, and there's a fairly well known site  
5 that we talked about quite a bit, PatientsLikeMe,  
6 which has become somewhat of a legend in the sense  
7 that people share incredible amounts of  
8 information, knowing that that information will  
9 be, you know, what pays the bills is the  
10 pharmaceutical companies, but people are still  
11 willing to share information on this because it  
12 helps them help each other, and they have just  
13 intermediated the clinician from the equation.

14           And there's a number of different  
15 stories that, you know, both Jamie and Ben that  
16 started this site can tell you, but just a quick  
17 one, for example, was, there was a clinical trial  
18 in Italy saying that lithium helped mitigate ALS,  
19 and addressed some of the symptoms of ALS, which  
20 is basically a death sentence. So a bunch of, you  
21 know, PatientsLikeMe started around ALS because  
22 their brother died of ALS. Anyway, 300 people

1 started taking lithium. They found out very  
2 quickly that it did not work. How long would it  
3 have taken us here in the United States to set up  
4 a clinical trial with the IRB in a clinical  
5 institution to actually get to that result? It  
6 would have been years, they found out in six  
7 months.

8           So I think we really have to start  
9 thinking a little bit more broadly instead of just  
10 physician-patient, patient-physician, we really  
11 need to start thinking of health care, how do we  
12 as a community address health care and help each  
13 other.

14           MR. YU: This level of intermediation,  
15 do you think it's an isolated case or do you think  
16 --

17           MR. MOORE: Absolutely not, absolutely  
18 not. If you -- and I'm talking about  
19 PatientsLikeMe, but you can go to Navigating  
20 Cancer, which has all sorts of forums on various  
21 cancers that people go there and share their  
22 experiences, share, you know, what kind of

1 medications they're on, what kind of side effects  
2 they're experiencing, how to address those side  
3 effects, there's no physicians there. These are  
4 patients helping patients.

5 MS. GRUTTADARO: Yeah, that's all  
6 StrengthOfUs.org is about, that we are totally a  
7 peer-to-peer, it's all people living with, so  
8 that's what they are. We don't interject, it's  
9 their community, they're talking to each other,  
10 that's all what we're about, so I just wanted to  
11 clarify that, yeah.

12 MR. MOORE: Okay.

13 MS. GRUTTADARO: And it works. I mean  
14 people are really -- people really share a lot of  
15 information around treatment medication, treatment  
16 approaches, and how to stay healthy and all of  
17 that, so I just wanted to clarify that because I  
18 might not have explained that.

19 MR. MOORE: Yeah, and I think from a  
20 policy point of view, when you start thinking  
21 about privacy and security, you really have to be  
22 very, very careful, because people do want to

1 share information to help each other.

2 MR. DOWNS: And I think that part of  
3 what they get out of the sharing is, they get  
4 personal value, as well. So it's not just sort of  
5 communitarian and altruistic, you know, I want to  
6 give my data to the greater good. Paul Wicks is  
7 the Research Director at PatientsLikeMe, he gave a  
8 talk recently in which he said in effect, and I'm  
9 paraphrasing, we are religious about providing  
10 feedback to every piece of data that someone  
11 submits. So even if we do a questionnaire that  
12 says do you like the new design of these pages,  
13 and you say yes, they immediately give you  
14 something back that says, well, you're part of the  
15 29 percent that likes it, because 71 percent  
16 don't.

17 So everything you do, where you say this  
18 is -- I am now taking 100 milligrams of this  
19 thing, they will say, that's funny because 75  
20 percent of people are taking 200 milligrams and  
21 you're taking 100. And he's saying you're  
22 immediately giving value, you're essentially, you



1 know, again, this is not his word, but you're  
2 essentially training users that when they do  
3 something by sharing information, they're going to  
4 get something back that really helps them.

5 MR. YU: Very good. I want to touch on  
6 the security and privacy aspects of the discussion  
7 so far, but before I do so, Gail, you know, would  
8 you like to share some thoughts as a clinician,  
9 how do you respond to, you know, the patients I  
10 guess acting at this level with response -- with  
11 regards to their own data?

12 DR. NUNLEE-BLAND: You know, it's just  
13 interesting, and I guess, you know, I'm surprised  
14 that there's a lot of concern about the security,  
15 because, you know, when we surveyed our patients,  
16 they were not that concerned about security, so  
17 from a patient's perspective, they didn't see --  
18 they saw it as a benefit that I have my  
19 information, I have my problem list, I have my  
20 medication list, I have labs, you know, because  
21 patients call, it's very difficult sometimes for  
22 them to get their results, and so that wasn't a

1 major concern to them.

2 Now, I guess who will eventually get the  
3 data maybe that is, and I think concerns about  
4 whether my insurance company will get it and do  
5 something with it or my employer, I think that may  
6 be where the concerns are.

7 But I think the way we have it set up  
8 where it is just between the provider and the  
9 patient, and the patient has that data and takes  
10 it to another provider, they feel as though they  
11 have more ownership rather than a covered entity  
12 providing it or an employer providing it and what  
13 are they going to do with it. So I just found  
14 that less than five percent really just refused to  
15 sign up for it because they were concerned about  
16 security.

17 And from a clinician's point of view, if  
18 I can have accurate data from a patient that I  
19 know that is provided by a provider, that I know  
20 that the medication list is correct, the problem  
21 list is correct, the labs have been imported, you  
22 know, correctly, that facilitates my care. If

1       they happen to be seen at another facility, they  
2       come to my facility, I can look at that and feel  
3       fairly confident that I will treat this patient  
4       appropriately versus not having any information at  
5       all.

6                   MR. YU:  Very good.  Darcy, are the  
7       views with regards to security and privacy shared  
8       by your user, your audiences?

9                   MS. GRUTTADARO:  Yeah, well, I did read  
10       a little bit of the FTC report, which was 122  
11       pages, so I didn't read the whole thing, but --  
12       and I was very impressed with the discussion  
13       around the fact that I think a lot of consumers  
14       really don't appreciate when they share data and  
15       information, what that really means.

16                   So I think in terms of a regulatory role  
17       when it comes to privacy and security.  And I  
18       think the report really alluded to this very  
19       nicely, we need to really make sure that people  
20       understand what the implications are when they  
21       share data, and we need to do that in an easy to  
22       understand manner.  And it's funny, this week I

1 did a webinar on mental health screening, and as  
2 soon as I disconnected from the webinar, I got an  
3 email in my email box from a vendor that was  
4 selling mental health screening tools, and I just  
5 thought, oh my gosh, this is wild. I mean it just  
6 occurred to me that I am so naïve in my  
7 professional role even of, you know, how  
8 information is being used in an aggressive way.

9           So I think one of the areas, and  
10 particularly with mental health, although I hope  
11 we can some day normalize mental health as any  
12 other health condition, we're not there yet, but I  
13 hope we can, and so it does get included on EMRs,  
14 and people aren't afraid to have it on their  
15 personal health records, but we are definitely not  
16 there yet.

17           So I think one of the things in general  
18 is making sure that people understand how their  
19 information can be used and the vulnerabilities.  
20 And I think we could go a long way if we did that,  
21 even the developers. And we have to make it easy,  
22 and we have to make it easy for the people that

1 are developing these innovative approaches to  
2 connecting people like we are.

3 We create a peer-to-peer site, we don't  
4 fully appreciate, and we have lawyers that look at  
5 it in the end, but I don't think that the typical  
6 person who's using these products and developing  
7 them has a real grasp. And I just think we've way  
8 over complicated the whole data and privacy world,  
9 so I think we have to figure out a way to simplify  
10 it more so there's an appreciation.

11 MR. YU: There's an appreciation, but  
12 there's room for education.

13 MR. GRUTTADARO: But there's room for  
14 innovation. And I realize that's a -- there's a  
15 real tension there, because I think rapid  
16 innovation, as Steve was alluding to the fact that  
17 this is, you know, an exciting time, can lend  
18 itself to exploitation.

19 MR. YU: Doug, would you care to chime  
20 in on this?

21 MR. TRAUNER: So I mean there's clear  
22 disclosure of information. I think the Microsoft

1 discussion, the previous panel had very clear and  
2 obviously were addressing them in a very similar  
3 way. As people are sharing information, there's  
4 transparency. But I think the discussion here is,  
5 are people understanding it? Is it easy to use?  
6 Is it clear? If information is being sent  
7 somewhere when you enter it, is it listed in one  
8 simple place that you can easily access it or do  
9 you have to navigate through four or five  
10 different places to actually understand that? And  
11 I think, you know, the discussion here is about  
12 privacy, but it keeps coming back to what was on  
13 the previous panel on trust. And I think also the  
14 point of if you ask people how big of an issue  
15 privacy is, you'll get sort of two ends of the  
16 spectrum: One, it's incredibly important to me,  
17 or it's not important but it becomes important to  
18 those people when they realize something, like you  
19 were telling the story of now you're going on the  
20 web and you're seeing the ads run, you kind of  
21 wonder how did they figure that out.

22 I mean, everywhere I go on the web, I

1 see a PracticeFusion ad, I don't know how they  
2 know that I would be even remotely interested.  
3 But it's the same question of, as people are using  
4 these services, the ads are remarkably  
5 coincidental, then there's concern, well, how did  
6 they know that, and if they're seeing that when  
7 they're now on other websites, I think that's  
8 where people are starting -- I think the FTC is  
9 now actually addressing that discussion, and I  
10 think that's incredibly important, and it sort of  
11 says if I'm using this site, how is it being used  
12 as I'm no longer on that site.

13 And, you know, there are people --  
14 there's a lot of -- I think the other part of the  
15 question is the monetization of these kinds of  
16 services. The reason the ads are being sold, the  
17 reason that people are selling this data is, there  
18 really isn't a monetary -- there are real  
19 questions about how to monetize these kinds of  
20 services. Physicians are not reimbursed, a large  
21 percentage of them, based on certain, you know,  
22 doing electronic visits, so I think there's a

1 reimbursement set of questions.

2           So if you look at the success of the  
3 vendors in this space, a lot of it does come out  
4 to some of the reimbursement models for electronic  
5 activities, and that those they are not in place.  
6 So I think there is a series of broader questions,  
7 as well. But certainly the privacy, obviously  
8 we're addressing it in a technical way, and, you  
9 know, I have a personal letter up there about how  
10 -- what does it mean in a summary way about look  
11 we're not sharing it, we don't sell it, we're not  
12 -- this is about you and your privacy.

13           So trust, but I think there's a broader  
14 set of questions about how to facilitate these  
15 interactions which could significantly reduce  
16 total health care costs, but there needs to be  
17 some means of a financial model to make it work,  
18 and today that is not really in place.

19           MR. YU: Do you agree with Darcy's point  
20 that users may not be fully cognizant of the  
21 implications of the --

22           MR. TRAUNER: I think most people when



1       they accept applications and then look at the  
2       terms of use and then start scrolling through it,  
3       no. I mean, there are -- I mean, a lawyer  
4       reviewing it, it's still going to come back with  
5       ambiguity. I think they tend to be very long and  
6       confusing, they have to be because they're legal  
7       documents. But how to summarize it, even getting  
8       a sign-off on a summary statement of what that is,  
9       that can be difficult.

10                So, no, I don't think it's -- I don't  
11       think there's a simple way to be addressing the  
12       legal requirements and to make it intuitive. You  
13       have to do it, you disclose it, you report it,  
14       and, you know, the fine print allows a lot of  
15       latitude, and I think it comes down to the trust  
16       of the organization that you're working with to  
17       know are they actually in alignment with what I  
18       want to achieve.

19                MR. YU: Very good. Steve.

20                MR. DOWNS: Yeah, I'm certainly not the  
21       first person who said that, but I think a lot of  
22       the times it simply boils down to control, to be

1       able to control who sees your data and who  
2       doesn't. And just two quick anecdotes on this;  
3       one is, we had a grant in Project HealthDesign to  
4       the -- it started with the Art Center College of  
5       Design, and they were working with teen  
6       population, and everybody said, oh, it's those  
7       crazy teenagers, they just put everything up  
8       publicly, they don't care at all about this, and  
9       really what they got from their research was, no,  
10      that's not at all true. I may share my behavior,  
11      my mood, my health conditions with the 80 people  
12      that I choose to share them with, but you better  
13      not let my mom see any of this, you know. So it  
14      is actually a very fine-tuned control, it's just  
15      their parameters may be a little different than  
16      some of ours.

17                 The second anecdote is, I was actually  
18      on my way to a conference on health information  
19      privacy a couple of years ago, and I was talking  
20      with the cab driver, he was asking me where I was  
21      headed, and he said, oh, wow, health information  
22      privacy, that's a big deal, that's really serious,

1     you know, I mean, like, god, you know, I wouldn't  
2     want anybody to know that I'm on, and then  
3     proceeded to list three medications that he was  
4     taking.

5             And to be fair, this was not my first  
6     cab ride with him, we had had a couple of  
7     conversations before, but again, the point is, he  
8     chose to share it with me, and he was very worried  
9     about other people having that.

10            And then last thing I would say, also  
11     speaking with control, is, I'm very interested in  
12     the notion that people should be able to sell  
13     their health data. If you think about it, we sell  
14     our personal information all the time. Any of us  
15     that has those supermarket cards that give us  
16     discounts, tell them everything that we buy, you  
17     know, we're making a deal, whether we know it or  
18     not, we're saying, you know, this is worth a  
19     certain amount.

20            I'm quite happy to sell my privacy about  
21     what I buy as long as I get, you know, \$7 off  
22     every time they go shopping in your supermarket.

1       So, you know, people's health data have value,  
2       clearly, and I think people should be able to  
3       think about and have platforms where they can  
4       negotiate the sale.

5                       MR. YU:  Steve, as a funder of  
6       innovators and future development, could you speak  
7       a little bit about, I guess, what are the concerns  
8       from the development community with regards to  
9       security and privacy and how they're, I guess,  
10      trying to operate an environment, develop new  
11      operational models without a great deal of clarity  
12      or assuredness of what will ultimately be born  
13      out?

14                      MR. DOWNS:  Yeah, you know, I'm not sure  
15      how well I can speak to that, except -- as I think  
16      you almost put the answer in the question, and we  
17      heard about it a little bit this morning, and we  
18      certainly heard it from Doug, and I think he's a  
19      really good person to talk about it, which is,  
20      it's about the clarity, you know, it's about not  
21      quite understanding the environment, the legal  
22      environment, about what you're developing to.  You

1 know, I mean, one of the great things about  
2 developers is that they need very clear  
3 requirements and then they force you to know what  
4 you want so that they can build it to that  
5 specification, and when things are unclear, it can  
6 be frustrating. And, Doug, I don't know if you  
7 want to jump in on this.

8 MR. TRAUNER: On the clarity of  
9 development or --

10 MR. DOWNS: The clarity of rules around  
11 privacy and security in terms of being able to  
12 offer a service and knowing what's okay.

13 MR. TRAUNER: Sure. Well we address it  
14 from the standpoint of the ability to create  
15 relationships, would it make a very clear what a  
16 relationship is and what information will be  
17 shared in that relationship and the other part is  
18 that both parties are accepting the terms of that  
19 relationship and either party can terminate it. I  
20 think that's standard technical requirements for  
21 doing that, but I think your point is on a broader  
22 one of how to make that intuitive and obvious to a

1 user when they're going to decide and to make that  
2 experience actually make sense. I don't think  
3 most people are used to signing up for services  
4 and accepting terms of use on a broad level, but  
5 you seem like you have another question.

6 MR. DOWNS: Yeah, I was thinking more in  
7 terms of the experience, when you seek the  
8 lawyer's review of what you're trying to do and  
9 they say --

10 MR. TRAUNER: Oh, there's --

11 MR. DOWNS: You know -- we're not really  
12 sure, so why don't you --

13 MR. TRAUNER: Yeah, I mean today with  
14 most of the discussions, and we want to be doing,  
15 you know, X-service, I can pretty much guarantee  
16 the review that we got, after a very expensive  
17 review, is, we don't quite understand it, the laws  
18 are ambiguous, and we think you can do it, but  
19 actually it's not an explicit, yes, you can do it.

20 And so I mean it's traditionally couched  
21 from a -- so I think getting points of  
22 clarification about what it means to be

1 communicating with -- when you're receiving  
2 physician-messaging over a system, what does that  
3 require.

4 So now you have, you know, a partner  
5 agreement with, on a clinical side, and you have  
6 to have terms that support that, and at the same  
7 time supporting other types of communication that  
8 may not be meeting those requirements, it becomes  
9 -- it's not entirely obvious how to do it, and  
10 those are the questions that, you know, we're  
11 really trying to figure out right now. If anyone  
12 wants to give us clear guidance on it, we'd love  
13 to have it.

14 MR. YU: John, you wanted to chime in on  
15 this, on the innovation development?

16 MR. MOORE: Yeah, it's been mentioned  
17 many, many times already, so I'll just restate it.  
18 It's really with regards to trust, trust, trust,  
19 trust. I'm a Mac fan. I get my little software  
20 updates automatically. I go to -- say yes, I want  
21 to update, and then it has some privacy, you know,  
22 some sort of agreement, do you agree to this user

1 agreement, and I look at it, and it says it's 56  
2 pages long, I agree, okay, done.

3 I trust Apple to do the right thing and  
4 install the Apple fix, I don't worry about that.  
5 Sure, I've got 56 pages of text I could go review,  
6 do you think anyone is reviewing that, anyone?  
7 No, it's done by lawyers for lawyers, and I don't  
8 even think lawyers who are using Macs read it.

9 So that being said, I think we really  
10 have to put it in context of people trusting who  
11 they're working with and who is holding that data.  
12 My hat's off really to I think Microsoft, for  
13 example, has done a very good job in creating a  
14 privacy agreement that is very simple and straight  
15 forward to read, and when they launched -- shortly  
16 after launching HealthVault, I tried it, and I  
17 said, well, what about all your third party, you  
18 know, vendors on the ecosystem, what about them,  
19 and they actually said, yeah, good point, so they  
20 got all their third party vendors to sign that  
21 same agreement, that when they come onto the  
22 ecosystem of HealthVault, they agree to the same



1 terms and conditions that HealthVault already  
2 agrees to with the person that's using that site,  
3 and it's very simple language.

4 Of course, they've got more language you  
5 can read if you wish, but the basics are right  
6 there, we will not use your data for anything, we  
7 will not sell your data, it's very simple and  
8 straight forward, and I think that gets to -- and  
9 then that gets to the whole issue of trust, and  
10 whether or not people trust Microsoft is a whole  
11 another ball of wax, but personally, myself, I  
12 trust Microsoft with my health data more than I  
13 trust my hospital, simply because they have a  
14 very, very big vested interest in securing that  
15 data, because if anything happened and they had a  
16 breach, can you imagine the PR nightmare Microsoft  
17 would have on its hands? It would basically just  
18 blow up in their face. My hospital, if they had a  
19 breach, gee, well, sorry, guy, we'll try not to  
20 make that happen again, but, yeah, your records  
21 got breached, your social security number is out  
22 there somewhere, who knows where, as long as, you

1 know, you're a Blue Cross/Blue Shield member and  
2 everything else, and we'll try to make sure no one  
3 hacks you, that's it.

4 So I think it really does come down to  
5 educating the public as to what are the  
6 vulnerabilities, and then letting them make the  
7 decision as to who they trust.

8 MR. YU: Very good. Well, we're about  
9 to reach the end of our time. What I'd like to do  
10 is I guess let each of the panelists respond in a,  
11 you know, two minute response of any closing  
12 thoughts that they have as a result of the very  
13 fruitful discussion that we've had today, you  
14 know, reflecting on the pace of development, the  
15 pace of consumer demand, but also the  
16 privacy/security concerns, liability concerns, and  
17 I guess I'll throw it out. Does anyone want to  
18 start off with that? Otherwise, I'm calling  
19 someone.

20 MS. GRUTTADARO: I'm happy to start. I  
21 just want to -- I've learned a lot from the  
22 StrengthofUs.org project we've done, and I think

1 social -- I'm a big fan -- I'm not on Facebook,  
2 and I don't want to be on Facebook, so all those  
3 people who are chasing me out there who keep  
4 saying you've got friends, I'm not responding.  
5 But I do want to say that I am now a big fan, and  
6 I think for people with chronic health conditions  
7 who want to connect with others who have similar  
8 experiences and challenges in life, it is going to  
9 be very explosive.

10           And we're just one little piece, but  
11 this is I think something that we are going to see  
12 really explode as people are looking to connect  
13 with others with similar experiences.

14           So I just -- I quickly made a note of  
15 some of the value and benefits of social  
16 networking to people with chronic health  
17 conditions. There's mutual support, there's  
18 access to reliable information resources, there's  
19 connections with peers, there's idea sharing on  
20 medication, treatment, therapy, and there's  
21 increased resiliency and opportunity for recovery,  
22 and there's combating social isolation that often

1 comes with chronic health conditions, which I put  
2 last, but was really the reason we developed the  
3 site, because we've seen all of those other things  
4 really evolving.

5 So I guess I would say to ONC and the  
6 FTC, you have a job in front of you, because on  
7 the one hand, I think it's important to encourage  
8 the sharing of information and innovative  
9 technologies that can really connect people with  
10 chronic health conditions in these important ways,  
11 and help to lower our health care costs, and help  
12 to result in improved outcomes for people with  
13 chronic health conditions, but we really have to  
14 be careful about the inherent risks of data  
15 information sharing that can come with people that  
16 have chronic health conditions.

17 MR. YU: Very good. Anyone else?

18 MR. DOWNS: Sure, I can jump in. Just a  
19 couple of things that perhaps we haven't touched  
20 on as much that I thought it would be useful to  
21 get out there. One is just really to talk about  
22 sensors and just how that's emerging and the kind

1 of data that you can get off of it.

2           So I think in the marketplace they're  
3 starting to do things like Fitbit and Zeo that can  
4 track, you know, Zeo tracking your sleep patterns  
5 and Fitbit activity and other things like that. A  
6 couple of Project HealthDesign projects, Carnegie  
7 Mellon University is tracking sort of literally  
8 the activities of older people as they go about  
9 their lives within their apartments. And so, you  
10 know, looking for things like cognitive decline,  
11 are they getting confused when they're making  
12 their morning coffee, are they spending the whole  
13 day in bed, you know, so stuff that they can do  
14 completely passively without anybody noticing,  
15 including, you know, are you taking your meds.

16           We actually, believe it or not, and I'm  
17 not making this up, one of our grantees is working  
18 with premature infants who return home from the  
19 hospital, and you really do have to monitor quite  
20 a bit. They've actually figured out how to sensor  
21 baby poop and look for, you know, nutritional  
22 content on it, you've got to love it.

1           But -- so my point is just that this is  
2 really starting to happen in ways. And in a lot  
3 of cases it's one layer of the sensing and then a  
4 whole sort of analysis layer, which is actually  
5 converting that basic raw data into interesting  
6 and useful health information.

7           And that bridges to another point, which  
8 is that what is health information is very hard to  
9 define right now. So Sandy Pentland at the MIT  
10 Media Lab has done a study of -- he looked at  
11 German geolocation data from cell phones and was  
12 actually able to predict diabetes in something  
13 like 50 percent of users based on their  
14 geolocation data. So where they're going all day  
15 is actually a predictor. But if you think about  
16 it, I mean, you know, just a really simple  
17 example, you go to, you know, you go back and  
18 forth to an HIV clinic, and that's on your cell  
19 phone, you know, so that's, in effect, disclosing  
20 your status there. So I think anything is  
21 potentially health information, which I think  
22 makes -- you have to think about, you know, if

1       you're trying to create policy around health  
2       information, it's really about information more  
3       generally.

4               MR. YU: Very good. Gail, a brief  
5       response?

6               DR. NUNLEE-BLAND: I just wanted to, as  
7       we're developing these medias, if we can identify  
8       what is patient-entered versus health care  
9       provider-entered so that we know where the data  
10      came from, I think that would be very helpful.

11              MR. TRAUNER: Following up on Steve's  
12      comment, I think there's one part of the  
13      conversation that's -- maybe it's out of scope  
14      right now, but if your sensor information were to  
15      flow to a physician, there's another regulatory  
16      agency, the FDA, who's also stepping into that  
17      process and requiring FDA approvals if it's going  
18      to a mobile phone. So I think there's another  
19      level to if we're trying to facilitate this kind  
20      of communication and we see value in it, it starts  
21      to become another layer of regulatory questions,  
22      or are there ways to have things expedited or

1 reviewed, what are some ways to make that work  
2 easily? I think there's some incredible  
3 opportunities. I think there's some incredible  
4 innovation going on. And what people are bringing  
5 from a clinical perspective or a research  
6 perspective and bringing that to market quickly,  
7 there's some really interesting ideas. So helping  
8 to facilitate that, it would be great.

9 MR. YU: Thank you, Doug. In closing,  
10 John?

11 MR. MOORE: In closing, okay, thanks,  
12 Wil. Well, I guess in closing, I think what I see  
13 as most important is that we really have to  
14 continue to educate the public about the use of  
15 the -- the appropriate use and the safe use of  
16 this information and the sharing of that  
17 information.

18 And when I say the public, I'm not  
19 meaning just the patient consumer, I'm also saying  
20 the physician, because I still think we have a  
21 really big issue with physicians willing to use  
22 and trust this information when someone shows up



1 at an appointment.

2 And to Gail's point, I think it's very  
3 important if, you know, talking policy, that, you  
4 know, we need to create these systems if we're  
5 going to be sharing them with physicians that have  
6 some way of preserving the true medical document,  
7 that if a patient wants to annotate that, then  
8 that's fine, but they can't change the core data  
9 elements within that medical piece of information,  
10 like a lab result. And I don't think we have very  
11 clear policy and rules around that, and I think  
12 that's something that does need to be addressed.

13 MR. YU: Very good; well, I'd like to  
14 thank each of the panelists at this time, and a  
15 round of applause for our guests. [Applause].

16 MS. PRITTS: We now have a one hour  
17 break for lunch, so please be back here around  
18 1:15, thank you.

19 (Recess)

20 MS. PRITTS: Okay, good afternoon. I'd  
21 like to welcome everybody back from lunch. We're  
22 getting ready to start our afternoon session, so

1 please take your seats. Oh, thank you. That's my  
2 technology expert. I have to have her with me  
3 wherever I go. So our first panel this afternoon  
4 is going to talk about -- specifically focus on  
5 privacy and security issues. You've heard that  
6 conversation sprinkled throughout the panels this  
7 morning. I'm very glad that a number of the  
8 people who are up here were able to be here this  
9 morning and hear some of the things that are going  
10 on that are very innovative in the field and kind  
11 of change the landscape of what we've  
12 traditionally thought of as medical information  
13 and where it's held and how it's used.

14 So this panel is going to focus on, as I  
15 said, privacy and security of identifiable health  
16 information in PHRs and related technologies and  
17 focus on consumer expectations and concerns, as  
18 well of those of the attitudes of health care  
19 providers and the industry groups to these same  
20 issues, so we should have a broad range of  
21 perspectives here.

22 I'm going to introduce the panel and

1       then we're going to have a little, you know, one  
2       or two minutes of opportunity for the panel to  
3       give a little background on themselves that I  
4       haven't covered or their perspectives on things  
5       and then we're going to go into our discussion,  
6       which I think will be very interesting.

7                        So first on my left here is Bob Gellman,  
8       who I have known for very many years and who has  
9       been in this area as long as anybody I know. He's  
10      a privacy and information policy consultant in  
11      Washington, D.C. He advises large and small  
12      companies, for-profit and nonprofit organizations,  
13      trade associations, government agencies, foreign  
14      governments. Have you reported that, Bob?

15                      MR. GELLMAN: I absolutely have.

16                      MS. PRITTS: Okay, just checking. And  
17      advocacy organizations how to develop, analyze,  
18      implement and maintain policies for personal,  
19      privacy and fair information practices. His  
20      specialty areas include privacy policy for health,  
21      including HIPAA, the Internet, the homeless,  
22      freedom of information, and other information

1 policy areas.

2 As I was saying, everybody who works in  
3 this area in D.C. certainly knows Bob. He's the  
4 author of numerous columns, conference papers,  
5 congressional reports and scholarly articles on  
6 privacy and other information policy issues. And  
7 he, of course, has his own website which you --  
8 will find on the handout here.

9 Next to Bob is Josh Lemieux, and I've  
10 had the pleasure of working with Josh over the  
11 years. I was a member, full disclosure, I was a  
12 member of the Markle Group that worked --  
13 Connecting for Health Group that worked on PHRs a  
14 number of years ago now, and Josh was also on that  
15 panel. And what did we work on before that? I  
16 don't even remember. But I've known him for a  
17 number of years. And he is an expert on policy  
18 and technology for emerging personal health  
19 information tools and services. I will also say  
20 that Josh is one of the best writers I have ever  
21 met in my life, that's true.

22 MR. LEMIEUX: Just can't speak.

1           MS. PRITTS: Since 2004, he's managed  
2 Markle's research and policy development for  
3 electronic personal health records and  
4 collaborative efforts on patient engagement as a  
5 means to transform health care.

6           He's the lead writer and editor of the  
7 Markle Connecting for Health Common Framework for  
8 Networked Personal Health Information. In  
9 previous positions, he directed the launch of  
10 health benefit decision support tools at WebMD and  
11 led project teams creating interactive  
12 applications at WellMed, Discovery Channel, and  
13 Mayo Clinic.

14           Josh began his career writing for, and  
15 this is why he's such a good writer, he began his  
16 career of writing with UPI in Brazil and worked  
17 seven years as a correspondent for the AP,  
18 assigned at the Mexican border. So you and Bob  
19 probably have some international connections, is  
20 that right?

21           MR. LEMIEUX: I doubt it.

22           MR. PRITTS: You doubt it, okay. Next

1 to him is Lee Tien, he's a staff attorney for  
2 Electronic Frontier Foundation. And I've only  
3 made acquaintance with him, although I have read  
4 some of his work in the past. He's very well  
5 known, particularly in California, where he does  
6 most of his work.

7 He's a senior staff attorney with  
8 Electronic Frontier Foundation, specializing in  
9 free speech law and privacy law. As part of his  
10 policy work in electronic health records, he  
11 advises the California Health and Human Services  
12 Agency and its Office of Health Information  
13 Integrity, as a member of the California Privacy  
14 and Security Advisory Board Privacy Steering Team.

15 California is a state that we all look  
16 to for its innovations and how it approaches  
17 privacy, and some look to it with admiration and  
18 some look to the state with fear and trepidation.

19 Mr. Tien has published articles on  
20 children's sexuality and information technology,  
21 anonymity, surveillance, and First Amendment  
22 status of publishing computer software, and the

1 state secrets privilege. He received his  
2 undergraduate degree in psychology from Stanford  
3 University and his law degree from UC-Berkeley,  
4 where he also did graduate work in Program in  
5 Jurisprudence and Social Policy.

6 Our sole female member of the panel over  
7 there is Tresa Udem, who's the Vice President of  
8 Lake Research Partners. Tresa Udem has been with  
9 Lake Research since 2004, where she works with  
10 foundations, nonprofit organizations, and issue  
11 organizations on health and health care. She  
12 leads public opinion research on a variety of  
13 policy issues, including health IT and the use of  
14 PHRs, chronic illness, health care access and  
15 quality, and reform.

16 Ms. Udem specializes in conducting  
17 multivariate statistical analysis so the rest of  
18 us don't have to, to examine how messages and  
19 arguments predict attitude and behavior. Ms.  
20 Udem is the author of the California Health Care  
21 Foundation's Consumers and Health Information  
22 Technology: A National Survey, which was released

1       this April, and we are going to use her study as  
2       part of the framework for the discussion today,  
3       because it has a lot of very recent pertinent data  
4       for the discussion that we have on the table, and  
5       it's just an excellent study.

6                   And last, but certainly not least at  
7       all, is -- can I call you Matt since we all do?  
8       Okay. Matt Wynia, who's the director of the  
9       Institute for Ethics at the American Medical  
10      Association. And he was named director of this  
11      Institute in May, 2000, so he's been there a  
12      while. And the mission of this Institute is to  
13      foster the health care of patients and the public  
14      by promoting the integrated place of ethics in  
15      medicine through research and educational  
16      outreach.

17                   As director of the Institute, Dr. Wynia  
18      oversees the Institute's Fellowship and Visiting  
19      Scholars Program and a wide range of research  
20      projects on topics including physician's responses  
21      to utilization review and market pressures in  
22      medicine comparing the codes of ethics of medical



1 professional associations and the ethics-related  
2 policies of health care organizations, exploring  
3 physician professionalism and the role of  
4 professionals in society and creating performance  
5 measures for health care ethics, very interesting  
6 cross-cutting issues there.

7           As the director of the Institute, Doctor  
8 Wynia conducted the AMA study of the attitudes of  
9 physicians to PHRs, another one of the studies  
10 that we will be exploring a little bit in-depth  
11 today. He also practices, in his spare time,  
12 internal medicine and infectious diseases at the  
13 University of Chicago Hospitals, where he's Chief  
14 Clinical Assistant Professor of Medicine. So we  
15 have a wonderful panel here this afternoon, and I  
16 am honored to be able to moderate this panel. The  
17 first thing we're going to do is, we're going to  
18 let everybody have a few moments to give their  
19 perspective on the issue and then we'll launch  
20 into some more question and answer type  
21 discussion.

22           So since we started here with Bob, I'm

1 going to start at the other end with Matt. And if  
2 you want to take a couple minutes and tell us  
3 where you're coming from, it will be really great.

4 DR. WYNIA: Sure, thank you. It's a  
5 real pleasure to be here today. I'm honored to be  
6 in this company. It was mentioned that I do a  
7 little work at the University of Chicago in  
8 clinical medicine there and infectious diseases.  
9 And my primary patient panel is comprised of  
10 patients with HIV infection.

11 So there are a number of reasons why the  
12 topics today are of particular personal and  
13 professional interest to me, as well as being of  
14 interest sort of on an academic and, if you will,  
15 policy basis, and this will show up in some of the  
16 comments around the survey results that we found.

17 I guess by way of introductory comments,  
18 I would say that, by and large, physicians, you  
19 know, not 100 percent obviously, but many  
20 physicians are really excited about the  
21 opportunities that health information technologies  
22 hold for improving communications with patients

1 and for improving delivery of important  
2 information, you know, from place to place within  
3 the health care system and between patients and  
4 doctors.

5           With regard to privacy, obviously the  
6 confidentiality of patient information is a core  
7 ethical promise of doctors to their patients and  
8 of other health professionals to patients. And,  
9 in fact, I guess the thing I would emphasize is  
10 that given the nature of the health care system  
11 today, it's not a promise that any of us can keep  
12 without the help of everyone else on the health  
13 care team, including those who don't know about  
14 the ways in which information ends up in their  
15 laps, frankly.

16           The reality is, in my view at least, if  
17 you have personal health information in your  
18 possession, the reason you have it from someone  
19 else is because they trusted someone with that  
20 information, and that chain of trust ends up with  
21 you in possession of their information. And you  
22 may not feel like you've ever taken a Hippocratic

1 Oath, but you have, because you're holding  
2 someone's personal health information. So I'm  
3 very interested in ensuring that that chain of  
4 trust retains its strength and allows us to  
5 maintain that promise of confidentiality.

6           The other thing by way of background  
7 I'll say is, because this came up in the earlier  
8 discussion, and I don't think we're going to get a  
9 chance to talk about it a lot this afternoon,  
10 there are even with good privacy and  
11 confidentiality protection, still risks to some of  
12 the HIT tools that we're talking about, one of  
13 which -- some of the issues around the Blue Button  
14 download, for example.

15           We talked earlier about, one of the  
16 earlier panels, about the new security risks, and  
17 I would say one of the new security risks is  
18 patients inadvertently disclosing their  
19 information, downloading and leaving it on the  
20 library computer without recognizing that that is  
21 happening. So I hope either on this panel or the  
22 subsequent one, maybe we'll get a chance to talk

1 about that as a risk.

2           And then the other risk that we may not  
3 get a chance to talk about through the rest of the  
4 panel, so I'll bring it up now, is, any time you  
5 intervene in a care process or create a tool which  
6 intends to change the way care is delivered, there  
7 is a possibility that it will backfire and care  
8 will be harmed and patients will be hurt. And you  
9 don't have to be in clinical medicine for very  
10 long to come across a number of examples of things  
11 where we, in our hubris, thought it made perfect  
12 sense to put every post-menopausal woman on  
13 estrogen, or everyone with, you know, osteoporotic  
14 fracture on fluoride treatment.

15           You know, you can name dozens and dozens  
16 of things that made so much sense that we didn't  
17 even think they needed to be studied, they should  
18 just be implemented and done, and we ended up  
19 hurting people as a result. And I think there is  
20 the possibility that that kind of outcome could  
21 occur with some HIT interventions. So the ways in  
22 which we track the clinical implementation of HIT

1 interventions is of great interest to me and I  
2 think to many doctors.

3 MS. PRITTS: Thank you, Matt. Tresa.

4 MS. UNDEM: Yes, so again, I'm Tresa. I  
5 guess what I'll be drawing from mostly is our  
6 study, as Joy mentioned, from the California  
7 HealthCare Foundation, which was really an  
8 exciting study. It was the first one that had a  
9 nationally representative sample of PHR users, so  
10 that was really sort of the most exciting part of  
11 the study. And we got to ask a bunch of questions  
12 about users and non-users, as well, so I'm going  
13 to be drawing on that. I have worked with Josh in  
14 the past and the Markle Foundation on surveys, and  
15 Josh also has a really good grasp on public  
16 opinion on this issue.

17 I think I just -- a few things that  
18 really stand out to me, just from the perspective  
19 of a pollster -- well, first of all let me say, I  
20 don't know Bob, so that's how much I know about  
21 this topic. I'm much more like the public than  
22 the people in this room. I don't know half of the

1       acronyms.

2                   And one thing I'll say is, the public,  
3       number one, is clueless about PHRs. The majority  
4       have no idea that they exist, know nothing about  
5       them, so I think that's one thing we need to  
6       always keep in mind.

7                   Number two thing that really stood out I  
8       think from our study, and I think we'll get into  
9       this, but privacy is an issue, but when we really  
10      dug deep, and I did some statistical analysis, it  
11      wasn't the number one barrier, it really didn't do  
12      a lot in predicting people saying, no, I'm not  
13      going to sign up. What did predict, what was, by  
14      far, three times more powerful as a barrier to  
15      signing up for a PHR was not thinking that --  
16      thinking that I don't need this for my health  
17      needs, that was far more important than privacy.  
18      And it's not to say privacy isn't important, we'll  
19      get into that, but that, you know, I reran those  
20      regressions like four different times, I had a  
21      colleague do it, I was really surprised, but then  
22      there's other data, too, in the study and from

1 other studies that help tell that story, but that  
2 was a really interesting finding.

3 And I think -- and part of that relates  
4 to, you know, this lack of awareness of PHRs and  
5 all the concerns and privacy implications.

6 I think the other thing from the study  
7 that was really fascinating was the outcomes of  
8 using a PHR. We asked a bunch of questions about,  
9 has having your information online made you more  
10 knowledgeable about your health, I think fifty-six  
11 percent said yes.

12 Fifty-two percent were more  
13 knowledgeable about their health care that they  
14 got. Forty percent asked their doctor a question  
15 they wouldn't have otherwise asked just because  
16 they have a PHR. Thirty-eight percent felt more  
17 connected to their doctor. Thirty-two percent  
18 said they'd taken a step to improve their health  
19 as a result of having a PHR. So that was now --  
20 that's self-reported, so those are probably  
21 inflated a little bit, but still really stunning.  
22 And we found that PHR users actually who are more



1 vulnerable, typically vulnerable populations,  
2 lower income, more educated, more chronic  
3 diseases, they were much more likely to benefit  
4 from -- have these outcomes than other people. So  
5 I would say those are sort of the three things  
6 that really, you know, from my view as a non-  
7 expert pollster, that was really sort of exciting  
8 for us.

9 MS. PRITTS: Before we go on, I'm going  
10 to take my executive privilege here and ask you a  
11 question, which is, how hard was it for you to  
12 find enough PHR users to actually field a national  
13 poll on this?

14 MS. UNDEM: Yeah, I mean it's hard.  
15 This was fielded last December and January, so  
16 almost a year ago, and seven percent of the  
17 population at that time reported having used a  
18 PHR, and so we had to oversample, and so, yeah,  
19 it's kind of a needle in a haystack right now.

20 MS. PRITTS: Thank you, Tresa. Lee.

21 MR. TIEN: Hi, so I'm Lee, and I was  
22 going to say that I probably know less about

1 health privacy law than anyone else on the panel,  
2 but maybe, maybe not, but probably pretty close.  
3 What I do know a fair amount about, though, is  
4 privacy and privacy law in general, and that's  
5 where I'm coming from. What we know, our  
6 experience with privacy and privacy law online in  
7 particular in this country, but also offline, is,  
8 you know, people don't understand it, people don't  
9 know very much about it, people don't know what  
10 they are worried about, but what they actually  
11 should be worried about often has nothing to do  
12 with what they actually are worried about, because  
13 they don't know what the reality of actual  
14 information practices in the world are, and they  
15 have a misguided view of what companies or what  
16 the government can or can't do.

17           And so because they're secure often in  
18 believing that those risks don't exist, they're,  
19 therefore, unconcerned about their privacy, or  
20 they think they're making this very calculated  
21 choice about their benefits and their risks when,  
22 in fact, they're completely under, you know,

1       estimating the risks and the costs.

2                   And so I guess the single -- the main  
3       point I want to make in my little intro is just  
4       that I don't think we do ourselves a whole lot of  
5       good looking at or paying attention to what  
6       patients say their concerns are anymore than I  
7       would say really judge my 14-year-old daughter's  
8       use of Facebook based on what her expressed  
9       concerns are, because the fact is, I know she has  
10      no idea what she should be concerned about, and I  
11      think, in general, we have no idea, or the  
12      American consumer has no idea about what they  
13      should be concerned about online. And I think  
14      that, you know, this week we saw the FTC's staff  
15      report on online privacy, and many -- some of the  
16      studies that we'll be talking about, talk very  
17      much about how poorly informed, you know, the  
18      public is about these things.

19                   None of that is to say that PHRs and  
20      electronic health records in general aren't going  
21      to be good things and aren't things that we should  
22      have, but simply that we have to be -- really be

1       careful when we are designing these systems and  
2       thinking about what should or shouldn't be the  
3       case, not to let the consumer's perceptions be the  
4       touch tool, we actually have to be in touch with  
5       the real risk so that we, as folks inside the  
6       system, know and protect against those and not  
7       just against what the public believes.

8               MS. PRITTS: Thank you, Lee. Josh.

9               MR. LEMIEUX: It's really good on each  
10       of your parts there, and it's going to be an  
11       interesting discussion, because I definitely agree  
12       that anytime somebody opens up a personal health  
13       record or creates a new data flow, even if it's a  
14       data flow to yourself by downloading information  
15       from a patient portal or a health insurer site,  
16       there's going to be, of course, new risk. It's  
17       also a risk not to have your information. So if  
18       you're going from care provider to care provider  
19       and you don't have your information, that can also  
20       be a significant risk to your health. And so  
21       these things are complex and very interesting.

22               So in 2003, Markle started to study this

1 area fairly carefully, and we did it with the help  
2 of a great many people that are pioneers in  
3 privacy and Internet services, providers,  
4 insurers, lots of people who are eyeing this  
5 nascent concept of what is a personal health  
6 record.

7           And our approach has been to try to get  
8 those people together to agree on what the right  
9 practices should be in this space, and it's always  
10 going to be an evolving area and a moving target.

11           But we think that there is some  
12 foundational work done with the help of a lot of  
13 people here, Matt and Joy not in any way the  
14 least, to describe what the practices should be,  
15 whether a service is covered by HIPAA or not. In  
16 other words, whether you're covered by HIPAA or  
17 not, if you have a personal health record, it  
18 should have an audit trail, log, transactions of  
19 data transfers and things like that, that's just a  
20 good practice, and so we've tried to describe some  
21 of those things. And parallel to that effort of  
22 getting lots of different interests together in a

1 room to hammer out those types of practices, we've  
2 also surveyed the American public, and we've done  
3 it in a -- fielded six surveys since 2003, and the  
4 overall learning, if I were to put it in a couple  
5 sentences, is that, I agree, people do not think  
6 about these things, these are not top of mind  
7 issues, you have to present the idea to them in a  
8 survey, so we're measuring sort of anticipation or  
9 response, it's not experience.

10 But they like the idea. They do think  
11 that -- very strong majorities of the American  
12 public consistently have said that if they had  
13 their information electronically, they could do a  
14 lot of things to improve their health and health  
15 care.

16 And I think the California HealthCare  
17 Foundation Study this year also showed that, and  
18 they took the effort to actually look at personal  
19 health record users, and some of that concept,  
20 that idea that this would be helpful was borne out  
21 in that data.

22 The other thing is, they want privacy

1 protection, specific practices, and I'm sure we'll  
2 get into that in this discussion. We do have some  
3 new data coming out in the next couple weeks in a  
4 survey, and this time, after some experimentation  
5 with Matt on polling both doctors and patients, we  
6 are coming out with a survey that asks patients  
7 and providers the same questions about health IT,  
8 about meaningful use of health IT, about privacy,  
9 about information-sharing behaviors and  
10 expectations and aspirations, even about payment  
11 reform and some social networking, and so we do  
12 have some results that we can talk about during  
13 this panel.

14 There is in your handout, and for those  
15 of you online, it's the -- there's a document  
16 that's the feature document on the Markle.org  
17 website, M-A-R-K-L-E.org. So I look forward to  
18 this discussion.

19 MS. PRITTS: Thank you, Josh. Bob.

20 MR. GELLMAN: I've been in health  
21 privacy for more than 30 years. A good part of  
22 that period, I was on Capital Hill, and that's

1 more in the dim, dark, distant past. If anyone is  
2 interested in the history of failed attempts to  
3 pass federal health privacy legislation, I know it  
4 all.

5 More recently I did a report on PHRs and  
6 privacy for the World Privacy Forum, it's  
7 available at the World Privacy Forum website or  
8 through my website, and while I think the report  
9 is still very relevant, the issues are still the  
10 same, I think it probably covers what you might  
11 call the classical period of PHRs, with the model  
12 of PHRs as sort of the Microsoft model, of you  
13 know, you get a copy of your record and have  
14 somebody maintain it and it's clear that the world  
15 has evolved in a lot of ways.

16 My particular -- my number one hobby  
17 horse here, but by no means my only one, is  
18 commercial advertising-supported PHRs, which I  
19 think are essentially devices to transfer health  
20 records to marketers in a way that will raise  
21 health care costs.

22 There are many other models of PHRs,



1 clearly, and they don't necessarily all have the  
2 same problem, but the issue of data leakage out of  
3 all of these activities is still important.

4 I think generally the problems that we  
5 face here are a lot of ways the same ones that we  
6 face in a lot of other privacy areas, and the  
7 theme here is borders. How do we find the  
8 borders? What is health information, what is  
9 sensitive health information? What is a PHR?  
10 It's much less clear than it ever was. And how do  
11 we make all of these distinctions in order to  
12 establish rules? Whichever way you're going to  
13 have rules, whether they're regulations or laws or  
14 something else, you've got to be able to define  
15 what it is you're doing, and it all seems to be  
16 extremely messy and getting messier, and it's all  
17 against the background of Internet activities  
18 where essentially we have virtually everybody's  
19 Internet activity is being tracked by numerous  
20 different organizations that you've never heard  
21 of, and you don't know that they are following  
22 you, you don't know what information they have

1 about you, and all the health information is just  
2 leaking all over the place into this, and we don't  
3 know how to solve that problem, and we don't know  
4 how to solve this problem, but we've got to try.

5 MS. PRITTS: Thank you. All right. So  
6 with that as background, we're going to start a  
7 discussion with a little context setting. Just  
8 for those who are following us on a web cast,  
9 these are some of the data sources of the surveys  
10 that we're going to be speaking about today. And  
11 for those of you who are here in person, this is  
12 where you can go back and read the full stories.  
13 We're going to start with Tresa. In your survey,  
14 you asked a question about what's useful, what  
15 people find useful in a PHR, so can you talk to us  
16 a little bit about that?

17 MS. UNDEM: Yes, and I'm going to share  
18 your thing. But, yeah, the most useful thing  
19 among PHR users in a list of things we asked about  
20 was making sure the information, their information  
21 in the PHR was correct. And this is -- I do a lot  
22 of -- probably 90 percent of my polling, research,

1 focus groups, surveys is on health care issues  
2 among patients and consumers.

3           And we, you know, most people think  
4 their quality of health care is good when you say,  
5 you know, when you poll in the survey, but the  
6 growing sort of concern among patients is that  
7 doctors aren't talking to each other, that there's  
8 drug interactions, because one doctor prescribes  
9 it, and you know, another one isn't aware of it.

10           So this wasn't really too surprising  
11 that this was the top thing, you know, just  
12 wanting to make sure everything is there,  
13 everything is correct. And that's also the number  
14 one thing that non-users would be interested in.  
15 And it's also just sort of a baseline, doesn't  
16 take a lot of work, it's sort of a baseline, you  
17 know, this is what I'd use it for.

18           Also it's checking lab tests and test  
19 results and things is another high one that's both  
20 for the PHR users was most useful, and for  
21 non-users, most interested in. And we've seen  
22 that for a number of years, that lab tests is one

1 of the highest ones.

2 MS. PRITTS: Is that what you found over  
3 time, Josh? Have you looked at that issue?

4 MR. LEMIEUX: Well, we ask about what do  
5 you think this would do to help you, not did this  
6 help you, so that's a very critical distinction.  
7 But when we ask, for example, what would be the --  
8 how would PHRs improve your ability, we found that  
9 87 percent -- this is in the survey in 2008, 87  
10 percent said, and the highest, was checking for  
11 mistakes or errors or tracking their health  
12 related expenses, and then 86 percent said, for  
13 each of these things, avoiding duplicate tests,  
14 procedures, keeping doctors informed of your  
15 health status, moving more easily from doctors.

16 And then in the 88 percent category,  
17 also, managing family member's health, getting  
18 treatments tailored to your health status. And so  
19 labs did come up, but we didn't ask about that  
20 recently. I'd say Tresa's data is a lot more  
21 relevant at this point.

22 MS. PRITTS: But what it sounds like is

1       that you did a survey of what people expected  
2       would be helpful, and Tresa's survey said that  
3       after people had started using PHRs, they actually  
4       did find those same things to be useful. So  
5       that's kind of a good check, to say that people --  
6       the expectations in this area are probably, at  
7       least at this point, being met in the benefit  
8       side. So, Matt, turning to you, how do providers  
9       view this, do they think that this is going to be  
10      a useful thing, or we heard earlier that there  
11      were some people, some docs, when approached with  
12      a PHR, basically put garlic around their neck and  
13      put a stake in their heart.

14                 DR. WYNIA: So I mean as a baseline, a  
15      couple things should be recognized. One is,  
16      there's about 20 percent of doctors who say I will  
17      never do anything electronic in my practice  
18      lifetime.

19                 MS. PRITTS: Okay. And how old are  
20      they?

21                 DR. WYNIA: Well, they're older.

22                 MS. PRITTS: Okay.

1 DR. WYNIA: And it may well be that  
2 these are, you know, nearing retirement, and  
3 they're thinking, you know, it's just -- there are  
4 too many barriers to converting my practice, I  
5 don't intend to start emailing my patients now,  
6 I've never done it before, I'm never going to, I'm  
7 not even emailing my daughter, why would I email  
8 my, you know, so there's a group of people --

9 MS. PRITTS: Twenty percent is not  
10 insignificant.

11 DR. WYNIA: It's not insignificant, but  
12 there is a group -- so you've got to sort of set  
13 that group in your mind, not necessarily aside,  
14 but there is a cohort like that.

15 MS. PRITTS: Okay.

16 DR. WYNIA: The other thing as a  
17 baseline to understand is, doctors, like the  
18 general population, don't know a lot about this.  
19 Only around 10 or 15 percent of doctors have any  
20 meaningful experience with a PHR, ever.

21 MS. PRITTS: Really?

22 DR. WYNIA: So about 25 -- 30 percent

1 say they have ever seen a PHR, but it's in the 10,  
2 15 percent range who have actually interacted with  
3 a patients' PHR in some way or another. So we're  
4 looking also at a --

5 MS. PRITTS: I'm compulsive about asking  
6 questions. So when you're looking at those  
7 doctors who -- were you just looking at the group  
8 who had an EHR or all doctors?

9 DR. WYNIA: All doctors; and when you  
10 start asking about having EHR, you then get into  
11 defining what you mean by an EHR.

12 MS. PRITTS: Okay.

13 DR. WYNIA: Many physicians believe they  
14 have an electronic record system of some sort.  
15 Whether that would qualify as, you know, the New  
16 England Journal article definition of an EHR, many  
17 of them probably don't.

18 MS. PRITTS: Okay.

19 DR. WYNIA: And so --

20 MS. PRITTS: Against that background --

21 DR. WYNIA: Against that background,  
22 right, not a lot of expertise, but there are, you

1 know, some of the same potential benefits are  
2 there. More, I think, doctors are interested in  
3 the ways in which PHRs might engage patients in  
4 their care and improve communication between  
5 patients and their caregiver team.

6           They're less convinced on a number of  
7 other markers, but I think it's more, you know, I  
8 assume everyone can see the slide, it's more that  
9 people just don't know. You can see the plurality  
10 of doctors in almost every instance except for the  
11 PHRs empower patients to participate more in their  
12 own care. The plurality usually says, I don't  
13 know. So physicians are at least willing to  
14 acknowledge that they don't have experience with  
15 these yet and they're not sure, so that's where  
16 we're at.

17           MS. PRITTS: Out of curiosity, did you  
18 -- they asked about the -- one of the things that  
19 the patients are really interested in is the  
20 ability to collect their information or check to  
21 see if it's correct.

22           DR. WYNIA: Did Josh put you up to this



1 question?

2 MS. PRITTS: Well, actually he did.

3 DR. WYNIA: So it's a very interesting  
4 finding. It's a rare doctor, it turns out, who  
5 thinks that patients provide a meaningful check on  
6 the accuracy of the medical record. Most  
7 physicians -- and, by the way, we looked very  
8 carefully at this because it was a somewhat  
9 unexpected finding, given how common it is that  
10 patients say this is one of the expected benefits.

11 So we looked, for example, at that ten  
12 or 15 percent of doctors who have regular  
13 experience using a PHR, so these are presumably  
14 doctors in systems where all their patients have  
15 PHRs, for example, they were equally, or just  
16 about equally uncertain or they didn't believe  
17 that patients were going to be going through the  
18 records, finding inaccurate lab test results. So  
19 in this instance, and I don't know, you know, why  
20 that is, it could be that those physicians with  
21 experience using PHRs have had patients come in  
22 with things that they thought were inaccurate,

1 that were not, in fact, inaccurate, and it ended  
2 up being a hassle for the doctor, and so when we  
3 asked them that question, not only did they say  
4 no, it doesn't work that way, they say it works  
5 the opposite way. I could envision that. It  
6 wouldn't take a lot of these doctors to have had  
7 one or two experiences like that.

8 MS. PRITTS: I think it'll be very  
9 interesting as we go forward for there to be some  
10 sort of objective measurement of whether it  
11 actually -- whether patients actually are finding  
12 discrepancies in the record or not.

13 MR. TIEN: Joy, could we ask Tresa if  
14 she has any sense from her survey why patients  
15 said that that ability to amend or correct was so  
16 important to them?

17 MS. UNDEM: We actually didn't ask that  
18 in the survey, the ability to. Josh, you've  
19 probably asked it.

20 MR. LEMIEUX: When we first started  
21 asking this question in 2004, we were surprised  
22 that the, I'd like to check my record just in case

1 message, was registered really quite high. When  
2 we were asking people sort of like, okay, which of  
3 these messages about a PHR is most persuasive to  
4 you, the sort of -- you got injured and you've got  
5 to go to the hospital and you need your records  
6 fast, that was the biggest reason. But checking  
7 for mistakes was very, very high. And then  
8 consistently over the years as we've asked it,  
9 there's just this perception that that would be a  
10 benefit on the part of consumers.

11 We didn't really focus group it to a  
12 level to see why do people feel that way. I  
13 guess, you know, there's the Seinfeld episode  
14 where Elaine is like what did you write in my  
15 record?

16 MS. PRITTS: For those of you who  
17 haven't seen that, you should really see it, it's  
18 very funny.

19 MR. LEMIEUX: So maybe it's just a, you  
20 know, and we haven't measured it across other  
21 sectors. Do you think that you could check the  
22 record in your, you know, mistakes in your

1 Department of Motor Vehicle record, you know, we  
2 have --

3 MR. TIEN: In other privacy areas, I  
4 mean certainly like with credit reports and stuff  
5 like that, it's very well documented they're full  
6 of errors, and so I mean it may just be picking up  
7 that people expect their official dossiers of all  
8 sorts to have errors in them and they want the  
9 ability to correct, and I was curious.

10 MS. UNDEM: And I don't think it's  
11 errors in lab test results or things like that, I  
12 think it's, you know, I think we all kind of  
13 wonder, for those of us who have doctors who are  
14 still writing down by hand, what the hell are you  
15 putting in my chart, you know, and do you have all  
16 the information, and all the right information,  
17 and are you hearing what I'm saying, and are you  
18 interpreting me correctly, I think it's probably  
19 more along those lines.

20 MR. GELLMAN: Another factor may be the  
21 rise in medical identity theft, which is a real  
22 problem.

1           MS. PRITTS: Okay. Well, those are all  
2 very interesting points, too. I don't think you  
3 were here earlier, Tresa, when Steve Downs was  
4 talking about that they're doing a -- RWJ is doing  
5 a study where they're actually having the  
6 providers furnish the patients with a copy of  
7 their notes at the end of the visit, to see how  
8 that goes on both sides, so that should be a very  
9 interesting outcome on that.

10           So we have both providers and patients  
11 thinking at some extent that these PHRs and this  
12 type of thing may be a good idea, but from what  
13 both of you said, not that many people are using  
14 them. And, Tresa, I think that you have some data  
15 here on the non-user's preferences towards the PHR  
16 source. So one of the things that I think is  
17 important in here is, what is it that they're  
18 looking for, who do they trust to give the  
19 information and that sort of thing, so can you  
20 tell us a little bit about what you found there?

21           MS. UNDEM: Yeah, and we found this over  
22 time, too, in other studies, and it's not

1 surprising, doctors, medical practices that you  
2 use, hospitals you use, that would be -- that's  
3 the number one preference. We've also found in  
4 this study, and I think it's the slide up there,  
5 the next is your health insurance plan, and some  
6 people might be surprised by this.

7 I think if we were to ask something like  
8 do you trust doctors with, you know, as a source  
9 for the PHR, do you trust health insurance  
10 companies, we would get a very different answer.

11 But often when -- and we see this is  
12 other issues, that people tend to rate their own  
13 health plan, you know, more highly and trust them  
14 more than insurance companies in general, just  
15 like I hate Congress, but I like my member of  
16 Congress type of thing.

17 And then after that, it's government  
18 agencies and non-profits and employers, and then  
19 sort of at the bottom is the private technology  
20 companies, and I think, Josh, that's pretty  
21 consistent.

22 MR. LEMIEUX: Yeah, we ask in these

1 questions and found the doctors at the top and  
2 then actually insurers second. But the way that  
3 we asked the question was, if this were offered,  
4 if this type of service were offered by this type  
5 of entity, would you be more likely to use it or  
6 less, or the same, you know, is it neutral, and  
7 the bulk of people, more than 50 percent said  
8 neutral.

9           So it's too big -- it's not right to  
10 generalize that only the doctor supply PHRs are  
11 trusted and the others are not. I think people --  
12 this is an experimental new model, and there isn't  
13 a lot of experience, and a lot of people are  
14 reserving judgment on it.

15           MS. PRITTS: So, Matt, what do -- in  
16 your survey, you did kind of a flip of that,  
17 looked at the flipside of that as to what the  
18 provider -- what source of information the  
19 providers would trust the most, right?

20           DR. WYNIA: Yeah, and I think, again, by  
21 way of background knowledge for this question,  
22 this question came towards the end of a survey, it

1 was about a four-page survey, and so you can kind  
2 of think of surveys sometimes as educational in  
3 nature, and so by this time we had asked a number  
4 of questions about the accuracy of the information  
5 that might be in a PHR, so now we get to the  
6 question of, if a PHR were offered by the  
7 following, would you trust it.

8 MS. PRITTS: Right.

9 DR. WYNIA: And I guess, incidentally,  
10 Bob, we did ask in a separate question, not on  
11 this chart, whether you would be willing to use a  
12 PHR that contained advertising, and only 8 percent  
13 of doctors said they would be willing to use a PHR  
14 that contained advertising. Now, whether that is  
15 reflective of what might happen in real time, we  
16 don't know, but that's what people said.

17 Otherwise, I feel like our results are  
18 somewhat similar to what we've heard so far from  
19 the consumer community, which is to say  
20 physicians, too, are more likely to be trusting of  
21 a PHR that's run by their own group or the  
22 hospital within which they practice.



1           Next would be a specialty society or  
2           some other professional association, the AMA State  
3           Medical Society, something like that. Third would  
4           be a government agency, Medicare or Medicaid, and  
5           that's how we said it was a government agency such  
6           as Medicare or Medicaid. We then said a health  
7           plan such as Kaiser or Aetna, so those were the  
8           example categories, and then Google or Microsoft.

9           MS. PRITTS: In fact, what we heard from  
10          our earlier panels is that Google -- well, I don't  
11          know about Google because they weren't here, but  
12          Microsoft actually works very much hand-in-hand  
13          with some of these other organizations, so it's  
14          really hard to make that distinction at this  
15          point, isn't it?

16          DR. WYNIA: Yes, and what we said is a  
17          commercial entity such as Google or Microsoft, you  
18          know --

19          MS. PRITTS: Right.

20          DR. WYNIA: -- for what it's worth,  
21          that's how the question was framed.

22          MS. PRITTS: Okay. We also -- so that's

1 a theme that came up a couple times today, or  
2 repeatedly today I would say, is the trust of, you  
3 know, trusting the source, trusting that the  
4 information would be accurate. Tresa, in your  
5 survey, there are also some other -- you asked  
6 about other potential barriers to using a PHR, and  
7 would you talk to that a little bit for us?

8 MS. UNDEM: Sure. Well, first of all, I  
9 think the number one barrier is not knowing it  
10 exists. So --

11 MS. PRITTS: That's a significant  
12 barrier.

13 MS. UNDEM: Yes, that's a very  
14 significant barrier. So we asked in our survey a  
15 number of questions, worry about the privacy of my  
16 information, 75 percent agree. The strongly agree  
17 is less, I think it's about 35 percent. We asked  
18 about whether they think they need it to handle  
19 their health needs, it might cost too much, I  
20 don't like computers, it might take too much time,  
21 these were the main barriers we asked about.

22 And then, again, what I did was, I ran

1 regressions on a post measure that asked how  
2 interested are you in signing up for a PHR. And  
3 regressions basically look at the -- is it really  
4 statistically correlated with wanting to sign up.

5           So people who say, yes, I'm worried  
6 about privacy, but that has nothing to do with  
7 whether they're going to sign up or not. So  
8 regression helps tease that out, and that's where  
9 we found that really the number one thing is  
10 feeling that I don't need this, and that's the 61  
11 percent. So that was -- in fact, all of these  
12 barriers were more significant than -- had a more  
13 significant relationship with not wanting to sign  
14 up than privacy.

15           MS. PRITTS: So let me ask you this, and  
16 I'm going to throw this out to the table in  
17 general, what it sounds like is that there are a  
18 lot of people who don't find the PHR concept to be  
19 very useful in the way they're looking at health  
20 care, and if you added on top of that some  
21 concerns about privacy, as to whether that  
22 information they would put up there, what kind of

1 effect do you think that would have, Bob?

2 MR. GELLMAN: Well, I don't know, you're  
3 sort of adding ignorance to ignorance. I mean  
4 people don't really understand what the privacy  
5 rules are, and people may not -- I don't think --  
6 I'm not sure I understand what a PHR is anymore.  
7 There are just so many different flavors of  
8 things, so I don't know how you put that together  
9 and draw any kind of, you know, in another way,  
10 it's like you talk to -- the panel earlier talked  
11 about trust and do people have trust, well, trust  
12 is very nice, but that has nothing to do with  
13 knowledge, you know.

14 I've seen surveys of government  
15 agencies, do you trust government agencies to  
16 handle your records, and I've been doing  
17 government privacy for a long time, I have no way  
18 of assessing whether they're doing a good job.  
19 When we ask people in the public, who presumably  
20 make perhaps occasional exceptions know less than  
21 I do, what are you learning here? What does it  
22 mean? I don't know.

1 MS. PRITTS: Josh.

2 MR. LEMIEUX: I kind of disagree with  
3 the first part of the question. We're living in  
4 an information age where people see the ability to  
5 connect to information, connect to services, log  
6 on to get things, make transactions. You know, I  
7 challenge anybody to just ask a stranger about,  
8 you know, hey, if you had your records online, do  
9 you think that would be helpful.

10 I think people understand that the  
11 possibility would be helpful. Now, converting  
12 that to action has certainly been a lot slower  
13 than many proponents would like, but the  
14 fundamental concept is not a difficult thing for  
15 people to understand, I think it's more sort of  
16 opportunity.

17 Now, when it gets to privacy, rather  
18 than asking whether people are concerned about it,  
19 we've kind of taken the approach of, well, which  
20 of these types of protections do you think are  
21 most important.

22 MS. PRITTS: And what do they say?

1                   MR. LEMIEUX: Well, when we ask things  
2 like should you be able to review who has had  
3 access to your record, audit trail, should you be  
4 able to -- should you be notified if there's a  
5 breach of your information, should there be a  
6 mechanism to request a correction of information,  
7 should there be an ability to exercise choices  
8 over how your information is used. Eighty percent  
9 to 70 percent range people say, yes, that's  
10 important. What's interesting also is, 80 percent  
11 to 70 percent range of doctors also say those  
12 things should be important for people, and we ask  
13 it specifically in the context of meaningful use.

14                   DR. WYNIA: Further proof that doctors  
15 are people.

16                   MR. LEMIEUX: Very good, yes, we  
17 confirmed that, we confirmed the hypothesis. So  
18 very large -- and if you look at the disagreement  
19 column, and these are in this handout here, very  
20 few people disagree that those four policies,  
21 those practices are unimportant. Let me say that  
22 again. Almost nobody says that they're

1 unimportant, a vast majority say that they're  
2 important in both groups.

3 MR. TIEN: If I could throw something in  
4 here, what we, again, this picks up something that  
5 may end up not being very important or its impact  
6 is ambiguous, because on the one hand, people tend  
7 to believe that those kinds of protections  
8 actually already exist. The studies we've shown  
9 of things as mundane as, you know, pizza delivery  
10 or charitable donations and product warranties.  
11 People believe falsely that they have all these  
12 kinds of rights, and basically, you know, they  
13 don't. And not only do they believe that they  
14 have these rights under law, they apparently  
15 believe that these companies aren't doing any of  
16 the things that they shouldn't be doing, even  
17 though the law says they can.

18 And so there's a whole sort of happy  
19 ignorance about what's going on in the background  
20 of the data world, which I think makes it really  
21 hard to sort of figure out what these things, you  
22 know, what they really mean for.

1                   So the other half of it is, if we're  
2 talking in surveys about privacy as a very general  
3 sort of concept or trust or even, you know, health  
4 information, you know, we already talked today  
5 about sensitive health information, and, you know,  
6 if we don't know when people are talking about  
7 what's important to them, whether or not they're  
8 thinking about, I'll use the example of my tennis  
9 elbow, on the one hand, or whether they're  
10 thinking about, you know, their daughter's, you  
11 know, anorexia, or some kind of a mental illness,  
12 or HIV status or whatever, you know, their  
13 perception of what the risk of some kind of  
14 sharing or some kind of electronic environment may  
15 be, you know, very, very different, which is one  
16 of the reasons why this morning, from the earlier  
17 panels, we were talking about this going social  
18 and this whole sort of sharing community thing,  
19 and I'm going, oh, I was, you know, I learned  
20 something, I wasn't aware of this -- what people  
21 were doing in this era with PHRs, and that struck  
22 me as being a very powerless sort of thing to be



1       doing given how little we know -- any of those  
2       patients know about how information is going to be  
3       accessible.

4               So, you know, and there are legal -- the  
5       last -- because the law itself is so unclear, you  
6       know, even leaving HIPAA aside, which no one  
7       really knows about, I mean I think a lot of people  
8       do believe and know about things like the  
9       doctor-patient privilege; whether they realize  
10      that the moment they hand information to someone  
11      who's not a doctor, that they waived that  
12      privilege, and it just doesn't exist anymore, and  
13      if the belief and the privilege is part of what  
14      makes them believe that the law protects them, and  
15      they don't realize when they waive it and how,  
16      even if it's coming in from a doctor into their  
17      personal health record, but because the personal  
18      health record is held by a non-provider,  
19      therefore, the privilege is gone. I mean I'm just  
20      not sure how anyone has any, you know, comfort in  
21      what people think about this.

22               MS. PRITTS: Okay. So you raised a new

1 point. Tresa, did you want to say something?

2 MS. UNDEM: I just wanted to say that,  
3 you know, when we did this analysis, just to  
4 repeat what Lee has been saying, and Bob, too, the  
5 public doesn't know anything really about privacy  
6 and what's going on and what -- how their  
7 information is shared, they don't know anything.

8 So at this base level of no knowledge,  
9 they're not concerned about privacy, okay, so  
10 that's what I was making the point, with no  
11 knowledge, they're not concerned about privacy.  
12 What's really going to make them be interested is  
13 whether they need this, whether it's useful.

14 So when you bring in -- first of all, we  
15 can't expect the public to know about this really,  
16 and they're not going to learn about this. I  
17 mean, they just -- we don't have time to learn  
18 about every single issue on the planet. So we  
19 have, you know, family anyway. So in surveys when  
20 we do say, you know, we even asked in our survey,  
21 so would it be okay to share your information if  
22 your name is not attached, your address, your date

1 of birth, social security, you know, whatever, is  
2 that okay to share your information, are you  
3 comfortable with that, only 31 percent say yes.  
4 So --

5 MS. PRITTS: If -- I wouldn't call it  
6 de-identified, but when the information has been  
7 what I would call anonymized, people still were  
8 not comfortable with it?

9 MS. UNDEM: Right, right; and also, I'd  
10 just add from, again, from polling, when the  
11 public lacks -- it just lacks information, the  
12 question wording really matters. So I know a  
13 recent poll asked something like, do you think  
14 doctors and health systems should be allowed to  
15 share or sell your sensitive information without  
16 your consent, and 97 percent said no, not a really  
17 great polling question, by the way, when you get  
18 97 percent saying no, and who are those other 3  
19 percent?

20 MS. PRITTS: Yeah.

21 MS. UNDEM: I don't think they read the  
22 question right or something.

1                   SPEAKER: They said if I got a cut,  
2 right? No.

3                   MS. UNDEM: Right. So there's, you  
4 know, and it's just complicated. It's when you  
5 ask them, okay, but here's what you get, in  
6 exchange: We get better quality care, we get, you  
7 know, we learn about the best treatments, and  
8 they're more willing I think. And I think in  
9 terms of trust, when you don't have knowledge,  
10 that the trust is the proxy. They're not going to  
11 get the knowledge we want them to have, that Lee  
12 has, that the experts have, so trust is a proxy,  
13 and for PHR users, that was one of the things that  
14 reassured them, was sort of the trust in their  
15 doctor or the trust in their health plan, the  
16 reputation of their health plan.

17                   MS. PRITTS: Josh, you had a point?

18                   MR. LEMIEUX: Well, just on this very  
19 issue of personal data and supposedly, you know,  
20 de-identified data. We asked, in the context of  
21 the Federal Stimulus Program, which policies  
22 people -- doctors and patients -- think should be

1 important requirements in order for that money to  
2 be well spent, and one of the policies we asked  
3 about was that the government could not collect  
4 health information as personally identifiable for  
5 health information technology or health care  
6 quality improvement programs.

7           Sixty-five percent of the public and 75  
8 percent of the doctors said that that's important,  
9 that the government not be able to collect  
10 personally identifiable information. But when we  
11 said, if there are safeguards to protect identity,  
12 77 percent of the public is either somewhat or  
13 very willing to allow their composite information  
14 to be used. So, again, people don't know all the  
15 ins and outs of stripping identity from  
16 information, which is actually a very, very  
17 complex area. But at the conceptual level, they  
18 want to be able to help, they see that there's  
19 public interest uses that are good, and as long as  
20 they feel protected, they have consistently over a  
21 couple surveys shown to be willing to -- that  
22 their information be used as long as it's

1 de-identified for many public interest uses,  
2 including quality improvement.

3 MR. TIEN: If I could throw in one more  
4 point, which is actually Bob's point which he  
5 mentioned to me at lunch, about the fact that it's  
6 not just about you, right. Bob, do you want to go  
7 ahead and make the point?

8 MR. GELLMAN: Go ahead.

9 MR. TIEN: Well, I mean, I started with  
10 the idea, coming from a state where there are a  
11 lot of direct-to-consumer genetic testing  
12 companies. And so one of the things, interesting  
13 things about genetic data, of course, is that it's  
14 not just about you, it's about your entire family  
15 and everyone you're related to.

16 But once you start looking at how much  
17 we know about ancestry and what not, then we  
18 really almost -- many of your health conditions  
19 end up being things that are going to, you know,  
20 if they know that I have, you know, high blood  
21 pressure and it has a genetic component, then  
22 people that I'm related to may be at higher risk

1 of this or that. And so in really, in many, many  
2 cases, even though we're thinking about an  
3 individual making a choice about whether or not to  
4 disclose or share, they are really making choices  
5 that effect, you know, everyone they're related  
6 to, and we don't have really a -- we certainly  
7 don't have a legal framework for dealing with that  
8 kind of problem.

9 MR. GELLMAN: Can I add a word on that,  
10 and just the obvious point that once your medical  
11 information is out somewhere in the marketing  
12 world, it's out there forever, and it won't -- I  
13 don't think -- if it's not going on today, it will  
14 be tomorrow, that marketing companies will have  
15 medical family pedigrees with all of the  
16 information that they can scarf up from all of  
17 these various sources about everybody and they're  
18 going to use it for marketing, and you will get  
19 messages that say your family is at 20 percent  
20 greater risk for, fill in the blank, than anybody  
21 else, buy our product, it's guaranteed to come.

22 MS. PRITTS: Matt.

1 DR. WYNIA: I want to go back and  
2 reinforce a point that Lee made just a minute ago,  
3 which is the legal frameworks around privacy may  
4 or may not be clear to most people, I suspect are  
5 not, but the ethical framework is perceived to be  
6 very clear. And it gets back to where I started  
7 the afternoon, around -- to my mind, because of  
8 that, we're not really that interested in the  
9 matter of trust, per se, we should be interested  
10 in the matter of trust worthiness.

11 We know we have trust, doctors, the  
12 health care system, by and large, we know we are  
13 trusted, and we're trusted to do things which we  
14 may or may not be doing effectively, in part  
15 because of the partnerships that we're forming in  
16 order to try and do our work more effectively and  
17 so on, but we have this trust, we have to do  
18 everything possible to merit that trust.

19 And whether, you know, that may or may  
20 not be reflected in public opinion polling, but  
21 it's still our job, that's the policy challenge.

22 MS. PRITTS: Right.



1 DR. WYNIA: It's not to say, oh, we've  
2 got the trust already, let's go ahead and take  
3 advantage of it, it's we have trust now, what can  
4 we do to make sure we warrant that trust.

5 MS. PRITTS: So you're making -- I hear  
6 very clearly the distinction you're making is that  
7 we hear the - we've heard this theme of trust, we  
8 see that, from some of the surveys, that people,  
9 when they kind of trust the institutions, they  
10 think that this is a more reputable resource for  
11 the information, and someone -- they're more  
12 willing to have hold their information, and your  
13 point is, maybe not, that we can't just rely on  
14 that individual to have that trust, you have to  
15 have the person who's having the information  
16 behave in such a way that they actually -- that  
17 trust is actually well placed?

18 DR. WYNIA: Yes, right.

19 MS. PRITTS: Okay. So I would like to  
20 turn a little bit to some of the particular issues  
21 that we talked about a little bit, we touched on a  
22 little bit earlier. I think I'm going in the

1 wrong way. Here we go, there's the trusted  
2 organization there. I'm just going to flip here  
3 to where -- okay.

4           So these were -- Tresa, when you did  
5 your survey, I think this shows one of the things  
6 that we were talking about here earlier, which is,  
7 that it was the trusted websites that people who  
8 actually were using PHRs, that made them feel  
9 comfortable. And what Matt is saying, maybe  
10 you're feeling more comfortable than you should be  
11 feeling. But some of the things, and password  
12 protection, that made people feel a little bit  
13 more comfortable. The secure website made people  
14 feel comfortable. And can you explain a little  
15 bit about what --

16           MS. UNDEM: Yeah, the HTTPS or the lock  
17 symbol.

18           MS. PRITTS: So people are familiar with  
19 those and they have an idea what they mean?

20           MS. UNDEM: This was an open ended  
21 question, so we said what made you feel that your  
22 information was safe and private, what reassured

1       you, and so those were the secure ones, that's  
2       where people said, because I saw the lock symbol  
3       or the HTTPS.

4               MS. PRITTS: And I was surprised when I  
5       saw this, because the site's privacy policy and  
6       HIPAA did not rank very high at all.

7               MS. UNDEM: Yeah.

8               MS. PRITTS: And nobody else is  
9       surprised by that, okay.

10              MS. UNDEM: I mean it's alarming really.  
11       I'm scared now that I'm learning more from these  
12       people. I mean one in five weren't worried at  
13       all. And then to just say, you know, 15 percent  
14       said, oh, because I had a password and user name,  
15       and then 15 percent say, or 16, whatever it was,  
16       that it was a secure website. I mean there's --  
17       and yes, I think Bob and others have data about  
18       whether people read the privacy policy and whether  
19       it matters at all.

20              MS. PRITTS: I think so. I think, Lee  
21       or Bob, have you looked at the, I think it was the  
22       Hoofnagle study at all?

1                   MR. GELLMAN: Chris Hoofnagle at  
2 Berkeley did a study, and basically what they  
3 found was, people think that if a website has a  
4 privacy policy, that that means they can't  
5 disclose their information to somebody else, just  
6 because they have a policy, not the content of the  
7 policy. So there's tremendous fundamental  
8 misunderstanding on the part of the public.

9                   MR. TIEN: Which I think is also shown  
10 by the answer about HTTPS and the locks, because  
11 what it tells you is that the threat -- to the  
12 extent they know what those things mean, they're  
13 only looking at a very limited threat model,  
14 right. If they know what SSL is, they're saying,  
15 oh, someone's not snooping on my transaction, or,  
16 you know, there's a lock, oh, it's secure against  
17 the unauthorized, you know, outsider. But  
18 obviously, the biggest hole in all of this is,  
19 well, when the person you're handing your data to  
20 decides to share it with someone else, and, of  
21 course, there's no piece of technology other than  
22 encrypting the whole record in such a way that the

1 holder can't actually get to it that's going to  
2 prevent that, and so it just tells us that they  
3 don't know what to be worried about.

4 MS. PRITTS: I think it was from the  
5 Hoofnagle study that said that people don't even  
6 read the privacy policies. Is that right?

7 MR. TIEN: Well, that one is in a lot of  
8 studies.

9 MS. PRITTS: When they say they don't  
10 read them, do you have a rough percentage of how  
11 many people have actually read them?

12 MR. GELLMAN: Whatever it is, it's a  
13 really small number.

14 MR. LEMIEUX: And it's important not to  
15 conclude from that that those policy statements  
16 aren't unimportant or that the plain language  
17 summary that was talked about in the previous  
18 panel are unimportant. In fact, the extremely  
19 important thing to do, for an organization to  
20 think about what they're committing to, and those  
21 commitments are enforceable by the FTC if somebody  
22 violates them and it gets to that level. And so

1 state attorneys general --

2 MS. PRITTS: But don't you think people  
3 need to know -- people need to read them first?  
4 So it seems to me that you have a disconnect. If  
5 you have something called a privacy policy and  
6 nobody is reading it, there must be something  
7 there that -- some action needs to be taken so  
8 that people would maybe read it.

9 MR. TIEN: Well, I think they're picking  
10 up two different things. They're picking up one,  
11 which is what we talked about before, the default,  
12 the idea that they already believe that, absent  
13 anything else, the law protects them in a lot of  
14 ways, and that's one of the Hoofnagle study that,  
15 like I said, with the pizza delivery, et cetera,  
16 et cetera, they just don't think that companies  
17 can share because that's what the law says, A, and  
18 --

19 MS. PRITTS: A lot of us don't know what  
20 the pizza delivery thing is, so can you explain it  
21 a little bit?

22 MR. TIEN: Oh, it's like, you know, you

1 call Domino's up, right, and you give them your  
2 credit card and whatever information, they just  
3 assume that the law prohibits Domino's from doing  
4 anything with that data other than to deliver your  
5 pizza, which is completely not the case. But --  
6 and so my point is the default level of protection  
7 that the law sort of lays -- puts down for  
8 everyone, the consumer gets wrong. And then  
9 second, they think that the fact that a company  
10 has a privacy policy means that they've also  
11 undertaken some additional privacy protections,  
12 and so the -- I mean, Hoofnagle's conclusion in  
13 that paper is that the very use of the phrase  
14 "privacy policy" is essentially -- ought to be  
15 prohibited or treated by the FTC as an unfair,  
16 deceptive and misleading trade practice, because  
17 it is known empirically that people actually think  
18 they're protected, no matter what the privacy  
19 policy says.

20           So, you know, Josh is absolutely right,  
21 I mean it is important what they say, and we do  
22 want them to know, and it does provide --

1                   MS. PRITTS: But there's an important  
2 step before you get there, which is somehow  
3 signaling to people that this is not what you  
4 think it is.

5                   MR. LEMIEUX: And it's why in the Common  
6 Framework we focus so much on the concept of  
7 independent consent, that there's an umbrella  
8 terms and conditions you sign on when you sign  
9 onto a service, blah, blah, blah, yeah, I'm not  
10 going to read that, click, and I'm in. But when  
11 the action that is being asked is to actually move  
12 my information to, you know, disclose it to a  
13 third party, or some type of activity that is  
14 unexpected by, you know, a normal person or a  
15 reasonable person, then the choice mechanism  
16 should be discreet and specific and should make  
17 clear what is happening in a concise way right at  
18 the decision-making moment, and so that's another  
19 practice, you know, best practice protection that  
20 helps, because we can't rely on the umbrella  
21 statement.

22                   MR. GELLMAN: People will -- I don't



1 think there's any reason to expect people to read  
2 most privacy notices. If you just think about the  
3 HIPAA notice, it's all there, people will read it  
4 when it makes a difference to them, which is less  
5 than 100 percent of the time, most of the time it  
6 doesn't matter to you.

7           When you run into an issue, when you  
8 have a dispute, when you have a problem with  
9 payment of a bill or whatever, then you're going  
10 to look to see what your rights are, and then  
11 you'll read the notice, and that's perfectly all  
12 right.

13           MR. LEMIEUX: And public opinion, just  
14 on this question, we asked very clearly, do you  
15 agree or disagree with the following statement, no  
16 matter what I signed -- what I agreed to when I  
17 signed on, do I want to be asked specifically  
18 whether my information is going to a third party  
19 or being sold, and 84 percent of the public -  
20 maybe 85 percent of the public said yes.

21           MR. TIEN: And the FTC staff report that  
22 came out this week on online privacy, one of the

1 points that they made was that they are -- they  
2 want to push harder for what they call just in  
3 time, you know, sort of notice, because, again,  
4 they also see as a general matter that the blanket  
5 general in-advance consent that sort of gives away  
6 all your rights just isn't enough to protect  
7 anyone.

8 DR. WYNIA: And the other thing that  
9 makes this all kind of moot is, if you're given  
10 notice, but you actually have no choice, right, if  
11 it's the pizza shop, I can choose to go to another  
12 pizza shop. I can stop using Domino's  
13 conceivably, right. I could, although the new  
14 crust is good.

15 But I'm already seeing my doctor, my  
16 family is already seeing my doctor, I've got  
17 relationships with the clinic staff, you know, and  
18 now they've got a new PHR that they're rolling  
19 out, and I'm going to click, and it really doesn't  
20 matter whether I read it or not because I have to  
21 trust them, you know, otherwise it's going to  
22 affect the quality of care that I'm receiving.

1           So, I mean, there are places in medicine  
2       where consumerism works and there are places in  
3       medicine where the whole consumer model, where  
4       they pretend that we have, you know, wide open  
5       choices, and there's easy entry and exit into the  
6       market, and free, you know, access to switch  
7       providers just doesn't work.

8           MS. PRITTS: So how do you think --  
9       there was a little bit of talk about accountable  
10      care organizations at some point this morning I  
11      think. Maybe that was just in my world, but --

12           DR. WYNIA: You were thinking about  
13      ACOs.

14           MS. PRITTS: Yeah, I think I was. How  
15      do you think that's going to play into this?

16           DR. WYNIA: Well, I mean it's a great  
17      question, of course, because the regs are being  
18      written right now. But I hope that, in the end,  
19      we see accountable care organizations that further  
20      this notion that everyone in contact with the  
21      patient's personal health information understands  
22      their ethical, if not their legal obligation, to

1       treat that information as though it were entrusted  
2       to them just as it was entrusted to the doctor in  
3       a closed exam room, where that patient assumes  
4       that the doctor is not going to, you know, turn  
5       around and sell the information to someone.

6                 They, you know, when you go to see a  
7       doctor, you have to make that assumption or you  
8       can't have an effective patient-doctor  
9       interaction. And if some additional member of the  
10      health care team now gets access to that  
11      information, they got it because the patient  
12      trusted the system, the doctor and the system, and  
13      we've got to be worthy of that trust.

14                MS. PRITTS: Okay. There are two other  
15      points that I want to make sure that we get to in  
16      our last few minutes here; well, actually there's  
17      three. So the way you were describing this, that  
18      was within the context of a patient- and a  
19      provider- oriented PHR. It is a little bit  
20      different, though, when the PHR is what I would  
21      call disassociated from a health care practice, or  
22      I guess even a health plan, and in those cases,

1 people actually do probably have a choice as to  
2 what they want or what service they could use a  
3 little bit more.

4 MR. LEMIEUX: This may be where the Blue  
5 Button issue comes in, as well.

6 MS. PRITTS: Yeah.

7 MR. LEMIEUX: The notion of downloading  
8 your information to a separate site, which could  
9 then be manipulated in a variety of different  
10 ways.

11 MS. PRITTS: And is it in that context  
12 where it's even more important that the  
13 information as to who it can be shared with and --  
14 is that even more important there or is that not  
15 -- do you see that not being the case?

16 MR. LEMIEUX: Well, you know, we always  
17 approach privacy as not only protecting the  
18 information, but also giving people access to it.  
19 Getting access to your information is a component  
20 of privacy along with transparency and choice  
21 mechanisms and a lot of the other -- and  
22 enforcement and redress and error correction and a

1 lot of these other things, that's why privacy is  
2 so difficult to define, no one activity protects  
3 it, no one definition defines it, it's  
4 multifaceted.

5 But in terms of the Blue Button, you  
6 know, we -- the idea that you can download your  
7 information just for your own possession is a  
8 fairly powerful idea. Seventy percent of the  
9 people in our new survey, the public said that  
10 they thought that patients ought to be able to do  
11 that, and sixty-five percent of doctors said that  
12 they thought that patients ought to be able to  
13 download their information.

14 And we've seen, you know, with the  
15 proliferation of things, like iPhone apps, iPad  
16 apps, you know, just the power of innovation when  
17 there's lots of people that can create value added  
18 services on top of the data, we don't want to shut  
19 that off.

20 MS. PRITTS: Can I ask you a question?  
21 So when you do the download, is it a secure  
22 connection, is it encrypted?

1           MR. LEMIEUX: Yes, in order to get the  
2 download, according to, you know, the practices  
3 that I think organizations that have implemented  
4 it, including the VA and CMS, is, you get it, you  
5 log in, so you're entered into a secure  
6 environment.

7           MS. PRITTS: Okay.

8           MR. LEMIEUX: And then you download it  
9 under SSL and things like that, and there are even  
10 other mechanisms to protect it further, including  
11 things like those annoying captchas, those are the  
12 little squiggly lines that can help determine  
13 whether or not the download is being requested by  
14 an actual human or some type of automated process  
15 and things like that.

16           And so we have a paper on this that is  
17 just sort of trying to plow some of this ground,  
18 and a lot of people, you know, 50 different  
19 organizations, you know, signed onto it, so we  
20 think it's a good potential for innovation, not  
21 without risks, but certainly, as I said at the  
22 very beginning, not having your information is

1 also a risk.

2 MS. PRITTS: But it sounds like the  
3 encryption at least avoids some of the problems  
4 that we've been reading about lately in the Wall  
5 Street Journal, with the data being essentially  
6 scraped as it goes through the Internet by data  
7 aggregators, and if you didn't have that kind of a  
8 connection, it could readily happen, where people  
9 could be -- organizations could be scraping your  
10 information and adding that to their data profile  
11 of people.

12 MR. LEMIEUX: Yeah, PHRs have to be  
13 behind a secure socket layer if they're using, you  
14 know, real medical data, but we also can't  
15 preclude models like PatientsLikeMe, which are  
16 entirely different models.

17 MR. GELLMAN: But it's worse than that.  
18 I mean if you get your medical record and you sit  
19 on your PC and you go through all the pieces of  
20 your record and you put it all into a search  
21 engine, the search engine has all of your  
22 requests, and they know your entire medical



1 history now, and it's good, bad, or otherwise, but  
2 that's what happens.

3 MS. PRITTS: Okay.

4 DR. WYNIA: It may come to you securely,  
5 but once you have control of it, with control  
6 comes responsibility, and it may or may not be the  
7 patient sitting in the library having downloaded,  
8 you know, their entire medical record onto the  
9 library computer, or you know, on the subway  
10 downloading it onto their SmartPhone, understands  
11 what happens when that now gets imported into an  
12 app.

13 MR. TIEN: Well, we know they don't  
14 understand, I mean --

15 MS. PRITTS: Yeah, that's right. I  
16 don't know about you, but I don't know that I want  
17 to know. Before -- we only have a few minutes  
18 left here, and one of the issues that I wanted to  
19 conclude with was that, well, I go to a lot of  
20 conferences, and I am always, always told, well,  
21 don't worry about it because this younger  
22 generation, they don't care.

1                   Privacy concerns are waning, you know,  
2           in another ten years this is not going to be an  
3           issue. So I'd like to toss that on that table and  
4           then stand back and get some reaction to that and  
5           see what you think about that issue.

6                   MR. GELLMAN: There are studies that  
7           seem to undercut that, one done by Chris Hoofnagle  
8           out at Berkeley, that basically found, A, that  
9           kids know less about privacy than adults, B, that  
10          kids actually make greater use of some of the  
11          privacy controls than adults do, partly because  
12          perhaps they understand better than adults do, but  
13          I don't think the attitudes of kids are  
14          particularly interesting. Kids go out and get  
15          rip-roaring drunk all the time, they text while  
16          they drive. I don't know that we need to change  
17          our habits or our laws to suit what kids are doing  
18          today. Kids don't always know what's in their  
19          best interest.

20                   MR. TIEN: Or maybe to put it more  
21          bluntly, when I was a kid --

22                   DR. WYNIA: More bluntly?

1                   MR. TIEN: True, you know, it's -- and  
2 then, you know, you grow up. So I mean, I think  
3 that there is -- I think there is a real -- I  
4 think the idea that we see a generational  
5 difference is because every generation sees a  
6 generational difference.

7                   And, you know, there's a great social  
8 psychologist, danah boyd, at Microsoft Research,  
9 who does an enormous amount of study of social  
10 media and how youth operate. And, you know, she  
11 starts out from the point that you have to  
12 remember that kids, certainly the teenagers, are  
13 -- live in -- they exist in the most highly  
14 surveilled sort of situation of any kind of person  
15 in say, at least in, American society. They're  
16 constantly being watched by their parents, by  
17 their siblings, by their teachers, et cetera.  
18 They have as little privacy as anyone except for  
19 maybe someone in a prison or something. And so we  
20 shouldn't --

21                   MS. PRITTS: She's been talking to my  
22 daughter, hasn't she?

1           MR. TIEN: Maybe; and we shouldn't be  
2 surprised by the fact that 14, 15, 16 year olds  
3 have sort of funny attitudes about privacy  
4 compared to folks who are able to actually live on  
5 their own. And at the same time, danah's research  
6 shows that they cope and they use all sorts of  
7 tools in order to try to protect privacy, to  
8 communicate in certain ways using the tools that  
9 are available to them in social media.

10           I mean it's a different issue as to  
11 whether or not they're effective, given that even  
12 experts that I know on Facebook privacy settings  
13 constantly find that they just shared information  
14 they didn't intend to. And I mean that's people  
15 who have, you know, who know it well enough to do  
16 videos explaining how to change, you know,  
17 personalization, and they still screw up.

18           So for teens to fail shouldn't be a  
19 surprise. But the point is that they still care.  
20 And, you know, danah's big overall point is that  
21 what we are seeing in the social media world, and  
22 a lot of the online world, is a big shift in

1 privacy, right. In the old days, we were private  
2 by default, public by effort, and so you had to  
3 work to actually get something out, and if you  
4 didn't do anything, you know, it stayed in one  
5 place. Today's world, especially in the social  
6 media world, it's public by default and private by  
7 effort.

8           So whatever effort is required for  
9 something, there's going to be less of it, and  
10 that's sort of the environmental condition for all  
11 of this, and I think that's as true, you know, in  
12 the, unfortunately, in the electronic world for  
13 health records as it is in the rest of the  
14 Internet, and that's why, you know, I sound like  
15 sort of a grumpy person about these privacy issues  
16 on these things.

17           MS. UNDEM: Not as bad as Bob.

18           MR. TIEN: Only almost?

19           MS. PRITTS: Okay, I think we're at the  
20 end of our session. I want to thank you all, this  
21 has been very interesting and enlightening. So we  
22 will now move on to - if we can thank this panel,

1 we'll now move on to our last one of the day.

2 I am sorry, we're taking a five- minute  
3 break and then we'll be back for the last panel.

4 (Recess)

5 MS. PRITTS: Can we please sit down so  
6 we can get ready for our final panel for the day.  
7 Thank you. We are getting ready now for our final  
8 panel of the day. Our final panel is actually two  
9 subpanels, which I will let Leslie explain a  
10 little bit. How is that, Leslie? Is that fine?  
11 The two panels will be moderated by Leslie Francis  
12 who is sitting here in the middle because she's  
13 much more comfortable there than she is over here  
14 at the podium with her back to half of the  
15 audience, so she is more considerate than the rest  
16 of us, too. This last panel is going to speak on  
17 the perspectives of privacy and security  
18 requirements for PHRs and related technologies.  
19 And at one point we had called these regulations,  
20 but we concluded that that was probably too narrow  
21 for focus and we used the term requirements very  
22 intentionally here. This panel is divided into

1 two and it's going to address the need for privacy  
2 and security requirements for PHRs and related  
3 noncovered entities. The second part will provide  
4 a forum for different views on the appropriate  
5 regulation, if any, or other requirements that  
6 should be applicable to non-covered PHRs and  
7 related service providers and technologies.

8 But the first subpanel we are very  
9 fortunate to have with us, representatives from  
10 some of the major, the committee, and the major  
11 agencies that actually do regulate in this area  
12 who are going to give us a little bit of  
13 background. We're also fortunate to have with us  
14 Leslie Francis who has been with us all day as the  
15 moderator of this panel. Leslie is a  
16 Distinguished Professor of Law and Philosophy and  
17 the Alfred C. Emery Professor of Law at the  
18 University of Utah. I know Leslie from the  
19 National Committee of Vital and Health Statistics,  
20 where she is the Co-Chair of the Privacy and  
21 Security Subcommittee on that panel, where she has  
22 given a lot of thought and consideration of these

1 issues. Leslie holds an adjunct appointment in  
2 Family and Preventive Medicine in the Division of  
3 Public Health, Internal Medicine and Political  
4 Science also at the University of Utah. She  
5 received her B.A. From Wellesley and she  
6 graduated with high honors in philosophy, so she's  
7 not just a lawyer, she's a philosopher, which is a  
8 very nice combination. She received her Ph.D. in  
9 philosophy from the University of Michigan and she  
10 served as a law clerk to Judge Abner Mikva of the  
11 United States Court of Appeals for the District of  
12 Columbia Court. A lot of us in the District  
13 remember Judge Mikva very, very well so that must  
14 have been quite the experience. She was appointed  
15 to the law faculty in '82 and she teaches and  
16 writes extensively in the areas of health law,  
17 bioethics and disability and we are fortunate  
18 enough to have Leslie working with us under  
19 subcontract with MAXIMUS on collecting some  
20 information and doing a study on PHRs and  
21 noncovered entities over the summer, which we are  
22 still in the process of -- and the study is still



1 ongoing and this information that we have gathered  
2 today will become part of that. Leslie, I will  
3 now turn it over to you. Thank you.

4 DR. FRANCIS: Thank you very much. I  
5 want to thank all of you for staying with this for  
6 what I hope will be as rich a panel as all the  
7 others have been so far today. So for the first  
8 part of this last session, our goal is to  
9 understand from these panelists what the current,  
10 and I'll call it regulatory for this part of it  
11 because what the current structure is of the  
12 requirements that apply to personal health records  
13 and related entities. I have with me three  
14 panelists. The first is Adam Greene who is the  
15 Senior Health Information Technology and Privacy  
16 Specialist at the Department of Health and Human  
17 Services in the Office for Civil Rights. Adam  
18 advises OCR on the application of the HIPAA  
19 Privacy Rule in the area of health IT, including  
20 electronic health records, personal health records  
21 and health information exchanges. Additionally,  
22 Mr. Greene represents OCR in Department matters

1 related to health IT, such as by acting as a HIPAA  
2 Privacy and Security Rule subject matter expert to  
3 the HIT Policy and Standards Committees. So that  
4 is Adam, here.

5 On my right is Loretta Garrison, who is  
6 Senior Attorney in the Division of Privacy and  
7 Identity Protection at the Federal Trade  
8 Commission. Loretta is here.

9 And on my far left is Joanne McNabb who  
10 is Chief of California's Office of Privacy  
11 Protection. You may have heard already today that  
12 California, among the states, is a leader in  
13 health privacy law and is the state that has, in  
14 state laws, specifically addressed personal health  
15 records and we'll be hearing about that from  
16 Joanne as we proceed.

17 So what I want to do with the panelists  
18 in the beginning is start out by setting the  
19 stage. I'm going to ask Adam to discuss what the  
20 Office for Civil Rights does, its scope of  
21 authority, the approach it takes to PHRs and the  
22 approach it takes, more generally, to the

1 regulation of health information. Then we're  
2 going to ask Loretta to answer the same question  
3 about the Federal Trade Commission. And then  
4 we'll turn to Joanne to give us an overview of  
5 what California is doing with respect to the  
6 regulation of PHR providers.

7 This is somewhat technical material and  
8 I think each of the panelists is going to take a  
9 little more than the 2 minutes that the sets of  
10 panelists did with the primary questions in the  
11 other panels. So without more ado, Adam?

12 MR. GREENE: Thank you, Leslie. So, the  
13 Office for Civil Rights, amongst its other duties,  
14 administers the HIPAA Privacy, Security and the  
15 HIPAA breach notification rules. Now as has been  
16 alluded to earlier today, HIPAA jurisdiction does  
17 not follow the data like some other laws do.  
18 Rather, HIPAA jurisdiction, our Office's  
19 jurisdiction, is tied to the type of provider, or  
20 other type of entity. Specifically, under the  
21 original HIPAA statute, we have jurisdiction over  
22 covered entities; three types of covered entities:

1 health care providers although not all health care  
2 providers, rather, only those that do electronic  
3 transactions such as electronic billing; health  
4 plans generally; and also health care  
5 clearinghouses, which I'll just say does not  
6 really relate to this discussion so I won't go  
7 into that in any great detail.

8           So, we also though under the HITECH Act  
9 now have direct liability, direct jurisdiction,  
10 over business associates which you can almost  
11 think of as an extension of covered entities in  
12 the sense that there cannot be a business  
13 associate without there being some covered entity  
14 that the business associate is acting on behalf  
15 of. I don't mean to suggest that it's always more  
16 of a master-servant relationship. I mean, often  
17 times there might be only one health information  
18 exchange for example and they may be a business  
19 associate even though they have all the cards so  
20 to speak, but the treatment is still that they are  
21 acting on behalf of covered entities in this  
22 context.

1                   So the reason we're here today is to  
2 talk about PHRs. So are PHRs covered by HIPAA?  
3 The answer is sometimes, which I know that  
4 provides a clear, concise answer to everyone. So  
5 PHRs are covered by HIPAA when they're furnished  
6 directly by a covered entity and we saw an example  
7 of that with Kaiser, and also when they are  
8 provided on behalf of a covered entity by a third  
9 party. So that's really what you're looking at is  
10 the PHR provided on behalf of the covered entity  
11 which can be a very fact-specific test. It's not  
12 always easy to determine that. Interoperability  
13 for example, the fact that the provider systems  
14 may be connected to and able to exchange data with  
15 a PHR, that does not necessarily mean that the PHR  
16 vendor is acting on behalf of the covered entity  
17 even if they market it as such, even if there's an  
18 exclusive relationship, that does not necessarily  
19 mean that the PHR vendor is acting on behalf of  
20 the covered entity. Rather, we really look  
21 towards whether the PHR vendor is specifically  
22 providing a service to the covered entity for its

1 population. Often times this would take the form  
2 of some sort of an agreement, it doesn't have to  
3 be in writing, but a good factor to look at is if  
4 a PHR vendor refused to provide, for example, a  
5 PHR to one of the covered entities' patients or  
6 enrollees, are they in violation of some sort of  
7 agreement? Is there some sort reason that they  
8 can't chose not to? That's one helpful test.  
9 Certainly if money is changing hands, that can  
10 also be an important factor for looking at things.

11 PHR vendors can be business associates  
12 in some lines of business and not others so you  
13 could have a company that has a direct-to-consumer  
14 PHR model, but also has contracted with a number  
15 of covered entities to specifically provide PHRs  
16 to their population. In that case they may be  
17 covered by HIPAA with respect to the  
18 covered-entity population, but not covered by  
19 HIPAA for their direct-to-consumer population. So  
20 it's not as simple as saying whether a PHR vendor  
21 is necessarily covered by HIPAA.

22 Under HIPAA our rules include the

1 Privacy, the Security and breach notification  
2 rules. I'll save those details for a little bit  
3 later in the discussion. Our enforcement  
4 mechanism is that we do have civil monetary  
5 penalties that can be imposed for violations that  
6 used to be limited strictly to the covered  
7 entities themselves and used to be capped at \$100  
8 per violation, which may sound small but  
9 continuing violations could be up to \$25,000 per  
10 calendar year and often times if you violate one  
11 provision it's often times likely that you're  
12 violating a number of provision so that that could  
13 add up under the old system, but post-HITECH the  
14 penalties have gone up significantly to a minimum  
15 rather than maximum of \$100 and often times  
16 \$50,000 or more per violation and then up to \$1.5  
17 million per continuing violation per a particular  
18 provision. So once again if you are violating 10  
19 different HIPAA provisions, that could be more  
20 like \$15 million per year liability so that the  
21 stakes have gone up pretty significantly here.  
22 With that I'll turn it back to Leslie.

1 DR. FRANCIS: Loretta, please tell us  
2 about the Federal Trade Commission.

3 MS. GARRISON: Thank you very much,  
4 Leslie, and thank you to OCR and ONC for hosting  
5 this important event today. First I have to give  
6 the obligatory disclaimer. I'm here speaking only  
7 on behalf of myself and not officially for the  
8 Commission or any individual Commissioner.

9 As Leslie said, I'm with the Division of  
10 Privacy and Identity Protection at the Federal  
11 Trade Commission. We are part of the Bureau of  
12 Consumer Protection so that as an independent  
13 agency roughly half of our mission is consumer  
14 protection and the other half very roughly shares  
15 antitrust review jurisdiction with the Department  
16 of Justice.

17 In our division, we enforce a number of  
18 laws relating to privacy and security such as the  
19 Fair Credit Reporting Act and the  
20 Gramm-Leach-Bliley Act, and for those of you who  
21 receive your financial privacy notices from your  
22 banks, our securities firms and so forth, these



1 are notices that are mandated under the  
2 Gramm-Leach-Bliley Act. We also enforce Section 5  
3 of the Federal Trade Commission Act and this is  
4 very broadly for the agency, it applies to unfair  
5 or deceptive acts or practices in or affecting  
6 commerce. So, in our area we use both of those  
7 prongs, the unfairness prong and the deceptive  
8 acts or misrepresentations prong in both of our  
9 privacy and data security cases. In the deceptive  
10 prong it means misrepresentations for consumers  
11 that are material so if you have a statement in  
12 your privacy policy or anywhere else that you make  
13 to consumers, that is a promise and it's material  
14 to the consumers in terms of the way they would  
15 make a decision, and that is wrong, it is  
16 incorrect in the sense of the way your practices  
17 are carried out, that is deceptive and it is a  
18 violation of the FTC Act. On the unfairness, if  
19 your act causes or is likely to cause substantial  
20 consumer injury which is not reasonably avoidable  
21 by consumers themselves and which is not  
22 outweighed by countervailing benefits to consumers

1 or to competition.

2 Now we also have in companion with our  
3 FTC Act, Section 5 authority on the data-security  
4 side, the Gramm-Leach-Bliley Safeguards Rule.  
5 This rule has the standard that is reasonable and  
6 appropriate safeguards to protect sensitive  
7 information. It is a scalable and flexible  
8 standard, and our Section 5 cases and our  
9 Safeguard cases, we generally track along the same  
10 lines so that our standard in security is  
11 reasonable and appropriate for the circumstances  
12 and that will depend on the size of the entity and  
13 the sensitivity of the information.

14 In our data security cases, our approach  
15 is that we are not complaint driven. We  
16 investigate when we learn about privacy or  
17 security issues, and I have to thank Joanne  
18 because when California announced its or  
19 implemented its Data Breach Notification Law, we  
20 had been looking before that for potential  
21 problems, but once the Data Breach Notification  
22 Law came out which clearly made public what had

1       likely been occurring before and unknown to the  
2       public, then our caseload or potential caseload  
3       jumped exponentially. Our cases typically involve  
4       companies that fail in very fundamental ways.  
5       They have either no or scant policies and  
6       procedures. There is no training. There is  
7       failure to address multiple attack vectors. And  
8       there are missed opportunities to prevent, detect  
9       or respond to intrusions. So we have now about 30  
10       cases that we have brought to date, data security  
11       cases. They are all available on our website.  
12       Our respondents are varied. We've brought actions  
13       or have settled and brought under order a credit  
14       card processor, a security software vendor,  
15       mortgage brokers and lenders, data brokers such as  
16       Choice Point and Lexis/Nexis, a drug manufacturer,  
17       and a pharmacy chain and PBM, CVS Caremark, as  
18       well as most recently Rite-Aid Pharmacy and a  
19       number of retail merchants such as BJ's Wholesale  
20       Club and TJX and others. The types of sensitive  
21       information that we found about consumers and  
22       employees are financial information, such as

1 credit card and bank account information,  
2 employment information and records, health  
3 information including prescription information,  
4 Social Security numbers, driver's license numbers,  
5 and date of birth. The concern here is that this  
6 information is very rich information for identity  
7 theft, and so that if you have very sensitive  
8 information of this type, you need to take steps  
9 to secure the information. But the types of  
10 security problems that we've seen run from  
11 improper disposal of paper documents to electronic  
12 security failures, such as poor wireless security.

13           Generally our cases stem from several  
14 general principles. If you make a claim about  
15 data security, be sure it's accurate. You should  
16 protect against common technology threats. You  
17 need to know with whom you're sharing sensitive  
18 personal information. You shouldn't retain  
19 sensitive information any longer than you have a  
20 business need for it. And you should dispose of  
21 sensitive information carefully. I just want to  
22 highlight a couple of emerging issues which are

1 important and play a role in the health area. Peer  
2 to peer: we announced early this year an  
3 investigation where we had sent letters to about  
4 100 companies that ranged from very small to major  
5 corporations that involved loss of or leakage of  
6 very sensitive information, including medical  
7 information on peer-to-peer networks because  
8 companies had allowed, or in some way peer-to-peer  
9 software applications were found on computers at  
10 the work place, and so information was leaked to  
11 these networks. When they are leaked in that  
12 manner then they're accessible to anybody who is  
13 on the network and it's very difficult if not  
14 impossible to retrieve it and to get rid of it.

15 Photocopiers are another issue. People  
16 don't realize that now when you do Xeroxing, those  
17 photocopiers have hard drives in them and they  
18 save and store all of that sensitive information  
19 including just plain recipes or travel information  
20 that you may be copying so that you need to take  
21 steps to make sure that you either override those  
22 hard drives or contractually retain them and

1       destroy them.

2                   I wanted to thank Colin for mentioning  
3       our FTC report that just came out. I have a copy  
4       here. It is available online. But some of the  
5       issues that we discuss in this report are very  
6       pertinent to the discussions we've had here. For  
7       example, online tracking or online behavioral  
8       advertising. Among our discussions in this report  
9       we've talked about a potential of a do-not-track  
10      proposal, in other words, to give some consumers  
11      not only awareness but control over what may be  
12      happening to their information. In addition, our  
13      view on sensitive information is that this  
14      includes information about children, financial and  
15      medical information and geolocation data, all very  
16      critical pieces of information that are at play in  
17      the PHRs and involve often medical data.

18                   Health websites. We've seen that there  
19      is a proliferation of these kinds of websites,  
20      which also include social networking websites --  
21      we've heard about some of this today. All of this  
22      as we discussed earlier, falls completely outside

1 of HIPAA. It means that are no baseline ground  
2 rules in terms of how this information is managed,  
3 collected, shared or disposed of and the only  
4 thing behind it is our Section 5 authority when we  
5 find unfair or deceptive acts or practices and we  
6 can bring an action against a company. We've seen  
7 as there are many different models for these kinds  
8 of PHRs and these other emerging health websites  
9 or social networking sites, there are as many  
10 different models as there are people in this room  
11 and they all have very different practices. And  
12 so one of the things that we've tried to lay out  
13 in our report is that we need to have some  
14 baseline standards of behavior by companies. We  
15 heard today from Colin and also from Microsoft  
16 about the fact that they appreciated the standards  
17 or principles that we laid out here and that they  
18 already follow them and that's wonderful. But  
19 many companies are under the radar. They are  
20 collecting this information and in fact they are  
21 not following standards that are the same as we've  
22 heard this morning. So with that I'll close.

1 DR. FRANCIS: California has a history  
2 of going further and perhaps covering some of the  
3 companies that are under or over the radar so I'm  
4 going to ask Joanne to talk about what California  
5 is doing.

6 MS. MCNABB: Thank you, Leslie. Thank  
7 you for inviting me here, whoever invited me here.  
8 It's been a very informative day so far. Just  
9 briefly for those of you who are not aware of the  
10 California Office of Privacy Protection, we are  
11 not a regulatory body. I would say I'm not a  
12 regulator, I'm a cajoler. We have a consumer  
13 privacy advocacy and education mission. In  
14 addition to educating and assisting consumers or  
15 individuals in exercising or asserting privacy  
16 rights, we also by statute make best practice  
17 recommendations to organizations. I was really  
18 struck by some things that Matt said about the  
19 focus in organizations needing to be on -- being  
20 trustworthy and talking about the ethical thing to  
21 do. That's sort of the approach that we take when  
22 we are being asked for advice from businesses and



1 organizations, talking about what is the privacy  
2 protective ethical thing to do in that situation  
3 which certainly would not be against the law.

4 I want to tell you a little bit the law  
5 that Leslie alluded to but only a little bit  
6 because I think we're going to get into it in more  
7 detail later, as well as a couple of other  
8 California laws that apply to PHRs. We have a  
9 pre-HIPAA version of medical privacy law, the  
10 Confidentiality of Medical Information Act, that  
11 was amended in 2008 with the intention of bringing  
12 in personal health records. It brings them in to  
13 its scope by asserting that they are deemed to be  
14 providers for the purposes of the Confidentiality  
15 of Medical Information Act. The definition of  
16 what I would call a PHR operator is a business  
17 organized for the purpose of maintaining medical  
18 information in order to make it available to an  
19 individual or to a provider of health care at the  
20 request of the individual or a provider for  
21 purposes of allowing the individual to manage his  
22 or her information or for diagnosis and treatment

1 of the individual. Got that? So it would seem to  
2 encompass a fairly broad spectrum of the types of  
3 PHRs, it would seem.

4 So by deeming such a business to be a  
5 provider for the purposes of the CMIA, that means  
6 that those businesses are then subject to the  
7 limits on use and disclosure of patient  
8 information that are in the Act. Those limits are  
9 very similar to HIPAA's in most regards, generally  
10 okay for TPO, otherwise it takes consent with the  
11 logical exceptions, public health, et cetera. And  
12 requires -- it also applies to contractors, so it  
13 also applies to in many cases what would be called  
14 business associates.

15 There are a couple of other privacy  
16 statutes in California that would also apply to  
17 personal health record businesses. One is our  
18 General Breach Notice Law which I did not pass I  
19 will say. I was there but I don't make those  
20 laws. It's a very interesting law and I know that  
21 many, many people feel that started a trend that  
22 has gotten things very complicated, but I think

1       it's one of the more effective privacy laws on the  
2       books in that it deals with the consequences of  
3       bad practices rather than specifying practices.  
4       Originally when that law took effect in 2003, it  
5       was focused on identity theft and focused on  
6       financial information: Social Security numbers as  
7       a factor in financial information and others.  
8       Effective in 2008, it was amended in recognition  
9       of the growth of or growing awareness of medical  
10      identity theft, it was amended to bring in medical  
11      information and health insurance information very  
12      broadly defined, but the medical information term  
13      that would certainly bring in any information that  
14      would be on a personal health record.

15                One other statute -- there are more that  
16      apply to businesses in California -- but another  
17      one that I think is particularly relevant that  
18      would apply to a PHR business that is subject to  
19      California law is the Online Privacy Protection  
20      Act, the California, our COPPA, which applies to  
21      operators of commercial websites and requires them  
22      to post a privacy policy and then to abide by it.

1 It doesn't have many specific requirements about  
2 what must be in that policy, but one of the  
3 requirements that I think that's particularly  
4 interesting and relevant and potentially useful in  
5 the area of online personal health records is the  
6 requirement that the privacy policy disclose the  
7 categories of third parties with whom information  
8 collected from site visitors might be shared so  
9 that's not just users, but visitors. So as we go  
10 on to talk a little more about some of the issues  
11 that are hard to address such as behavioral  
12 tracking, I think this law might be germane.

13 DR. FRANCIS: Thank you. What I want to  
14 do quickly now is look at, we've heard a little  
15 bit about how security is protected under HIPAA  
16 and by the Federal Trade Commission and we just  
17 heard California on breach notification. Both OCR  
18 and the Federal Trade Commission have a role at  
19 the federal level with respect to breach  
20 notification. I'd like Adam to add anything he'd  
21 like to add about the HIPAA Security Rule and then  
22 comment briefly on how breach notification works

1 with respect to OCR, what it covers and quickly  
2 how it works, and then I'll ask Loretta to do the  
3 same thing.

4 MR. GREENE: Certainly. So the HIPAA  
5 Security Rule consists of over 50 standards and  
6 implementation specifications which may seem  
7 daunting, but in fact almost all of these I would  
8 expect are standards or implementation  
9 specifications that one would expect in any  
10 reasonable security program. And one thing that  
11 some covered entities may misguidedly do is look  
12 at these implementation specs distinctly and try  
13 to take more of a checklist approach of OK have I  
14 done this one, have I done that one. And the  
15 Security Rule while it does include these more  
16 detailed requirements, the most important aspect  
17 of it is that you should have a cohesive,  
18 comprehensive security program in place. So that  
19 starts with a risk-analysis under the Security  
20 Rule looking at what electronic protected health  
21 information you have, where you have it, the  
22 criticality of the different pieces of PHI and

1       then recognizing the reasonably foreseeable  
2       threats and vulnerabilities to that information.  
3       Then once you've done a thorough risk-analysis you  
4       then have to create your own risk-management  
5       strategy, which -- what people's favorite part and  
6       what people's least favorite part of the Security  
7       Rule probably is -- is the flexible approach. We  
8       often times have people going thank you for  
9       appreciating that not all covered entities are  
10      equal, that the appropriate security program for  
11      your large integrated delivery system is not  
12      necessarily the same for your single practitioner.  
13      Just as often, if not more so, we have people  
14      coming to us saying, OK I've read your regulation,  
15      could you just tell me what I need to do? The  
16      answer is you need to do what's reasonable and  
17      appropriate for your practice, which is going to  
18      differ based on factors such as the size,  
19      resources and threats to your practice. So that's  
20      the approach that the Security Rule takes.

21                   Then most recently under the HITECH Act  
22      we've added the HIPAA Breach Notification Rule,

1       which is very similar to the FTC's Breach  
2       Notification Rule that Loretta will address and  
3       involves notification to the individual when  
4       there's a breach, it involves notification to the  
5       Secretary of HHS, which may differ in that if it's  
6       a small breach of under 500 people involved that  
7       can be an annual notification, whereas if it's a  
8       large breach of over 500 people then you have to  
9       do it without unreasonable delay -- no later than  
10      60 days. As I think everyone in this room knows,  
11      those large breaches get posted, amongst other  
12      things, on the HHS website in what is I know  
13      lovingly called the Wall of Shame on our website.  
14      And also in certain cases where there are 500 or  
15      more people in a particular state or jurisdiction  
16      there is also a notification requirement for local  
17      media so that individuals may learn that way.

18                 The timeframe for breach notification is  
19      also something that is frequently misunderstood.  
20      You'll often times hear people saying under HIPAA  
21      you've got 60 days and that's not accurate. Your  
22      requirement is to notify the individual, and if

1       it's a large breach the Secretary, without  
2       unreasonable delay and that may not be longer than  
3       60 days. Without unreasonable delay means for  
4       example, the information is pretty  
5       straightforward, doesn't require a long  
6       investigation, you've set a fax to the wrong  
7       number for example, you know all the facts, then  
8       notification may be the next day or even sooner,  
9       it's that you can't sit on it for 60 days and  
10      that's something that's been a frequent  
11      misconception.

12                 With respect to business associates,  
13      there is a breach notification requirement on  
14      business associates but it's for them to notify  
15      the covered entity and that's also without  
16      unreasonable delay and in the worst case no  
17      greater than 60 days, so that the responsibility  
18      generally falls to the covered entity to notify  
19      the individuals and that's based on the assumption  
20      that the covered entity is probably the one that  
21      has the relationship with the individuals,  
22      although we recognize that in certain



1       circumstances it may actually be the business  
2       associate that has the relationship, where for  
3       some other reason it may be appropriate to  
4       delegate that responsibility to the business  
5       associate although the liability still falls to  
6       the covered entity in that case.

7                 DR. FRANCIS: Loretta, do you want to  
8       comment, and I know we have to move quickly, on  
9       breach notification at the FTC?

10                MS. GARRISON: Sure, just very briefly  
11       on the security standards that I had set out  
12       before, unlike HIPAA, we do not have detailed  
13       specifications, we don't endorse particular  
14       technologies because we do not want a checklist  
15       approach, and in fact sometimes the technology may  
16       work and other times it may not, but certainly  
17       technologies will change over time. Encryption is  
18       certainly one. We've had companies that say they  
19       encrypted but they used poor encryption or they  
20       provided the key to decrypt which means of course  
21       the information was accessible. So again the  
22       standard is reasonable and appropriate under the

1 circumstances.

2           Very briefly on the PHR breach  
3 notification, that was a specific authority that  
4 was given to the FTC in the HITECH Act. It's only  
5 for PHRs, it's only data breach notification and  
6 it's very similar in terms of the reporting  
7 requirements to the HHS standard. The trigger for  
8 reporting is the acquisition of information  
9 without the authorization of the individual, and  
10 we have included in our rule a rebuttable  
11 presumption that unauthorized acquisition will  
12 presume to include the unauthorized access to  
13 unsecured personal health record identifiable  
14 health information unless the vendor of the  
15 personal health records, the PHR-related entity or  
16 third-party service provider that experienced the  
17 breach has reliable evidence showing that there  
18 has not been or could not reasonably have been  
19 unauthorized acquisition of such information. So  
20 we want to make sure that if somebody gets into a  
21 database and in fact they move around it and they  
22 see the data and then they leave, that in fact

1       that is a breach notification or it meets the  
2       breach notification requirement under our rule.

3               DR. FRANCIS: Thank you. We only have 5  
4       minutes left for this very rich part of the panel,  
5       or maybe seven or something like that. I want to  
6       ask Joanne to comment on what you see as the  
7       ongoing role of the states in privacy protection.  
8       Will that work as a question?

9               MS. MCNABB: Sure. I know that Lee  
10       mentioned earlier an advisory body at the state  
11       level that's been making policy recommendations to  
12       our state Health and Human Services Secretary  
13       regarding privacy and security in HIE, so that's  
14       sort of an example. And really the challenge on  
15       that board I think exemplifies the challenge of  
16       the states versus the federal government. The  
17       challenge on that board is to find a way to  
18       preserve or enable the greater protections of  
19       consumer privacy that exist in certain parts of  
20       the California state law while facilitating some  
21       of the desirable results of information sharing  
22       across state lines and it is not an easy thing to

1 do. It's the old laboratories of democracy point  
2 -- the states have been the leaders of the federal  
3 government in establishing privacy protections in  
4 statute in the past 10 years or so and there is  
5 certainly, in my opinion, a benefit to allowing  
6 them to continue to do so. The role of a federal  
7 law in consumer protection as establishing a floor  
8 is a good one and allowing the states to be more  
9 protective, to offer more protections, seems to be  
10 a good idea, that the federal government can learn  
11 from that. I notice that these new federal breach  
12 requirements are built on the state laws and tweak  
13 it a little, for example making it a little less  
14 intense than the California law which provides  
15 greater protection and requires more rapid notice  
16 of individuals. Is this going to be the last  
17 thing I get to say?

18 DR. FRANCIS: No, not necessarily.

19 MS. MCNABB: If you're not going to get  
20 to the other questions, let me quickly answer the  
21 other two questions. I want to give an example of  
22 one of the greater protections offered in our

1 Confidentiality of Medical Information law and  
2 that is the definition of marketing that is  
3 prohibited without consent. It is a tighter  
4 definition than under HIPAA and applies to a  
5 greater body of marketing communications that are  
6 made for remuneration and that could be construed  
7 to cover, I assert, online behavioral advertising  
8 and marketing in many of its configurations on  
9 personal health records. And are you going to ask  
10 about mobile?

11 DR. FRANCIS: Go for mobile.

12 MS. MCNABB: Be careful. My Office did  
13 a consumer guide a year ago on personal health  
14 records which is available on our website at  
15 [privacy.ca.gov](http://privacy.ca.gov) and the staff person whose  
16 assignment it was to do the research for that came  
17 back after 3 weeks and said my advice is don't do  
18 it, don't do it. I said OK, now let's stop and  
19 think. There are some cases where this makes  
20 sense and it's out there, so let's give people  
21 some advice. So I'm kind of in the same place  
22 about using mobile devices to move your health

1 information around. I want to say don't do it,  
2 don't do it. So what we would say at this point  
3 is we aren't giving any advice on this yet, just  
4 be careful, go slow, convenience may not be the  
5 most important value in this arena.

6 DR. FRANCIS: Thank you. I want to ask  
7 Adam and Loretta to comment on one example where  
8 they have partnered with respect to privacy  
9 protection. Then if each of them has something  
10 that they want to be sure that we didn't get to  
11 ask that's on the table, I think I have enough  
12 time.

13 MS. GARRISON: Certainly. The FTC and  
14 OCR did two joint investigations on CVS Caremark  
15 and Rite-Aid Corporation, which was most recently  
16 announced. In both of those cases the facts grew  
17 out of an investigative reporter working in  
18 Indianapolis who discovered that when he went to  
19 the dumpsters behind a number of pharmacies in the  
20 Indianapolis area, he found bags full of intact  
21 non-electronic, that is, pill bottles or other  
22 paper, with personal health information in it that

1 was simply available, publicly accessible, from  
2 these dumpsters. He collected these bags and he  
3 did a report on it. He then went to 10 cities  
4 around the country and found similar problems so  
5 that this is clearly widespread. We worked  
6 together, we thought that the synergies between  
7 our two agencies in terms of our authorities and  
8 our approaches would be beneficial to bringing the  
9 two companies in question under consent orders.  
10 Now our orders are different but they're  
11 complementary. The HHS order, as Adam said OCR  
12 has civil penalty authority and so that they were  
13 able to use that authority in both cases and get  
14 monetary funds.

15           Their order covers the disposal of PHI  
16 by the pharmacy for a period of -- it will be  
17 monitored for three years. They have to do  
18 independent outside audits of their practices on  
19 disposal of the paper in the pharmacy. Our order  
20 is much broader. We do what's called fencing-in  
21 relief so that we cover all information whether  
22 it's in paper form or electronic in our orders.

1 In this case we also covered not only the patients  
2 in the pharmacy but customers at the front of the  
3 store who went there to get prescriptions as well  
4 as employees and we said all of their information  
5 needed to have the same protections.

6 The order also covered not just the  
7 pharmacy but the PBM so that's why we brought  
8 Caremark into our order. Our orders are for 20  
9 years. We require among other things an  
10 independent third-party assessment of the entire  
11 security practices of the company for every other  
12 year for the 20-year period. Are we going to have  
13 extra time here?

14 DR. FRANCIS: The three clocks on the  
15 wall are different. Adam, I'm going to ask you to  
16 comment briefly on examples, and that clock is the  
17 best one. So I'm going to ask you to comment  
18 briefly on the examples and then I'll ask each one  
19 of you for a parting shot. How's that?

20 MR. GREENE: Certainly. Well I'll just  
21 say that the experience - I actually before coming  
22 to OCR was over at the Office of General Counsel



1 and I was able to work with Loretta on these  
2 cases, and it just goes to show sometimes people  
3 are asking the wrong question when they say which  
4 agency should have authority over PHRs? It  
5 doesn't necessarily have to be one. Agencies can  
6 work together and sometimes we had a very  
7 complementary approach with respect to our  
8 different enforcement mechanisms so it was very  
9 helpful there and I think we're going to see this  
10 more also in the federal and state areas with the  
11 state attorneys general having authority under  
12 HIPAA, there's going to be more joint actions we  
13 would expect in that front. And so certainly  
14 agencies can work together and the results can be  
15 quite harmonious.

16 DR. FRANCIS: Thank you - last two  
17 sentences from each of you.

18 MS. GARRISON: Only two?

19 DR. FRANCIS: Or three.

20 MS. GARRISON: We heard a lot about  
21 trust today and about trustworthiness. Of course  
22 that is really dependent not on just an assumption

1       that you'll have trust, but it's on the way in  
2       which you behave. There is a recent Ponemon study  
3       that looks at -- it did interviews of hospital  
4       senior managers and talked about their security in  
5       their settings which were a number of hospitals,  
6       but other kinds of medical facilities. Basically,  
7       the report was pretty alarming because the overall  
8       consensus was that security was not ranked very  
9       highly, that in fact they've had a number of data  
10      breaches, and in fact Ponemon was able to  
11      extrapolate that the cost of these breaches not  
12      just in terms of trust through what's called  
13      churning -- that means in the retail sense that  
14      you're losing people -- but also in terms of  
15      dollars was running into the billions of dollars.  
16      Here we're talking about PHRs saving money, but if  
17      you're really going to save money you need to  
18      build in at the very beginning your privacy and  
19      your security because that is part of what makes  
20      you have a trustworthy product.

21                   Now a couple of things. What John Moore  
22      said which was a little alarming was of the 20

1 PHRs he said that he had surveyed only 2 years  
2 ago, that most of them have disappeared. The  
3 question is what has happened to the data that  
4 they had? We had a case recently where we heard  
5 about a bankruptcy setting where there was a  
6 customer list of a magazine of young male  
7 homosexuals and that customer list was viewed as  
8 an asset, which the court was going to sell. Our  
9 Bureau Director David Vladeck sent a letter to the  
10 judge asking that it not be sold saying that it  
11 was contrary to the promises made by the company  
12 in its privacy policy, that the disclosure of that  
13 information to this other group would be very  
14 damaging to these people, and to the judge's  
15 credit he in fact ordered that this be destroyed.  
16 I agree with Joanne also that the move to mobile  
17 is one that you need to be very careful of. We've  
18 had a lot of problems with wireless technology  
19 which of course is being used increasingly in  
20 hospitals where that's been a very vulnerable  
21 point in terms of entry into a system and to get  
22 access to information. So you need to have

1       caution. Security by the way is not a checklist.  
2       It's an ongoing defense in-depth. You need to  
3       build redundant systems. You need to do risk  
4       assessments as an ongoing process to make sure  
5       that in fact you're meeting current  
6       vulnerabilities and threats.

7                     DR. FRANCIS: Thank you. Adam?

8                     MR. GREENE: I think one of the biggest  
9       challenges in this space with PHRs especially  
10      since they are by definition really the closest  
11      link to the consumer is protecting individual's  
12      privacy without necessarily making their privacy  
13      decisions for them. We have an evolving  
14      marketplace here and the potential to unfairly  
15      stifle innovations based on assumptions that may  
16      be false about what values people have with  
17      respect to privacy is a very tough area, so that's  
18      one, I think, of the biggest challenges that we  
19      have moving forward in regulating this area.

20                    DR. FRANCIS: Joanne?

21                    MS. MCNABB: I kind of blurted out my  
22      closing lines earlier. One last closing thing. I

1 think you heard a lot about the ignorance -- lack  
2 of information -- ignorance, that individuals,  
3 that we all have as individuals, about how our  
4 information flows and particularly in a medical  
5 context. I don't think that the takeaway for  
6 people in the business side of the medical  
7 industrial complex should be we have to do more  
8 patient education first, that in fact it's the  
9 trustworthy practices and secure systems that need  
10 to come first, that the burden can't all be  
11 shifted to the consumers.

12 DR. FRANCIS: Thank you all very much  
13 and let's have a round of applause for these  
14 folks. [Applause].

15 We're going to move to - well, we've  
16 already been partly on the question of what should  
17 be happening with respect to considering rules,  
18 standards and the like and we're going to move  
19 more directly to what should be. I'm going to ask  
20 these panelists to shift and we'll have a change  
21 in guard.

22 My last three panelists are, on my

1 right, Robert Hudock, who is Counsel at  
2 EpsteinBeckerGreen. On my immediate left is Frank  
3 Pasquale who is the Schering-Plough Professor in  
4 Health Care Regulation and Enforcement at Seton  
5 Hall Law School and a Visiting Fellow at Princeton  
6 University's Center for Information Technology  
7 Policy. And on my very far left is Nick Terry who  
8 is the Chester A. Myers Professor of Law at St.  
9 Louis School of University School of law. Both  
10 Frank and Nick are prolific writers in the area of  
11 health policy and health information technology  
12 and more specifically on personal health records.

13 I'm going to start this panel off by  
14 asking -- going this way -- alphabetically for  
15 each of the panelists in a couple of sentences,  
16 maybe a paragraph but no more, to give us an  
17 overview of what each sees as the core regulatory  
18 choices to address when we think about PHRs that  
19 are not covered by HIPAA.

20 MR. HUDOCK: Thank you. We have a range  
21 of options available to us as we see the HIPAA  
22 Security Rules and regulations in the Ponemon

1 study that was spoken of by the colleague from the  
2 FTC where we're looking at a billion-or-so  
3 breaches. One of the most useful forms of  
4 documentation and support to people in the private  
5 industry with respect to HIPAA privacy and  
6 security was the NIST 800-66 publication. I see  
7 something similar to that being very useful for  
8 the public health record situation where an  
9 educated body can provide meaningful guidance  
10 about what a PHR is and what sort of security  
11 controls are appropriate.

12 DR. FRANCIS: Thank you. Frank?

13 MR. PASQUALE: Thank you. I think just  
14 to run through some of the core issues that I  
15 think are both going on right now and emerging, I  
16 think one clear one that we will get into later on  
17 the panel is what levels of security are necessary  
18 for these types of entities, especially the FTC  
19 regulated entities. The second is the nature of  
20 consent, whether it's general and how far general  
21 consent can go and where specific consent needs to  
22 be used. A third is about data integrity and

1       disputes over that. The Boston Globe had a very  
2       interesting article recently about a dispute by  
3       someone who found that lots of records loaded into  
4       his personal health record he felt were inaccurate  
5       but that he felt that he couldn't actually get at  
6       them and try to change them. There might be best  
7       practices from the Fair Credit Reporting Act in  
8       terms of how to access and ensure that sort of  
9       integrity. A fourth issue is banned uses. Are  
10      there any sort of uses or compelled disclosures  
11      that we need to ban or just stop at the outset in  
12      order to encourage people to really want to become  
13      part of personal health record systems? My final  
14      point I guess would just be that what are consumer  
15      expectations and how should those play into that?  
16      I think that's been a big divide today between  
17      those who really emphasize consumer expectations  
18      and others who stated that given how fast the  
19      technology is moving maybe we should try to get  
20      the regulation ahead of expectations as opposed to  
21      sort of letting it continue to erode them.

22                   DR. FRANCIS: Thank you. Nick?



1           MR. TERRY: Thank you, and thanks for  
2 the invite and to you guys for hanging around and  
3 the three people who are on the web thing who  
4 logged in thinking it was World of Warcraft,  
5 welcome.

6           So first, terminology. Security  
7 regulates unconsented-to access to data whether  
8 outside hackers or insiders without authorization.  
9 That has to be distinguished from privacy  
10 regulation, which regulates data collection, its  
11 acquisition and in some countries with better  
12 privacy protection its processing. Third,  
13 confidentiality, which is all that HIPAA does,  
14 which is to regulate the disclosure or  
15 dissemination of data. That's my first problem,  
16 making sure we have the terminology right.

17           The second concern I have is  
18 definitional. What is a PHR? Specifically, are  
19 PHR privacy, security, confidentiality issues  
20 truly distinct on one hand from the  
21 HIPAA-regulated EHR and on the other hand do they  
22 pose any different problems from the average

1 website that allows medical data to be scraped off  
2 it, so I have a real problem with sort of trying  
3 to come to terms with the word PHR. Then the  
4 third major area that interests me when we look at  
5 the regulatory models; firstly, the problem of the  
6 regulatory indeterminacy as medical data gets  
7 pulled and pushed out of EHRs, back into PHRs, and  
8 then back again as to which particular regulatory  
9 regime applies at any one point and sometimes more  
10 than one will apply. Then finally, before Leslie  
11 has a stroke, I'd like to get back to some basic  
12 discussion of some basic privacy protective  
13 principles. I'd like to talk about  
14 proportionality later today and move away from  
15 what I think are defective models that we put in  
16 instead of true privacy, things like consent  
17 privacy policies. I have a long list.

18 DR. FRANCIS: Thank you, and I hope we  
19 get to at least some of that list. For starters,  
20 I'd like each of you to think about security with  
21 us for a minute and pick one security issue that  
22 you think ought to be on the table, thought about

1 as ongoing choices get made and I'll continue to  
2 go right to left.

3 MR. HUDOCK: Security in the traditional  
4 sense means confidentiality, integrity and  
5 availability, and I believe integrity is the  
6 biggest problem and that we really haven't been  
7 focusing on the implications of incorrect data,  
8 data quality. It's not only having the patient  
9 have the right to correct the information, it's  
10 about having maybe a PHR where the patient can  
11 manipulate the data. Then we also see where  
12 depending on the source of the PHR, the physician  
13 doubts it more or less, really that's all about  
14 integrity of the PHR. Can I trust that other  
15 physician who's across the country on the data  
16 that they inputted? We haven't seen much guidance  
17 on how to know whether that medical record or that  
18 PHR is something that I can rely on.

19 DR. FRANCIS: Thank you. We've talked  
20 about data integrity. The next security issue?

21 MR. PASQUALE: I wanted to pick up on a  
22 contribution that I think both the Markle

1 Foundation and the Center for Democracy and  
2 Technology have made in this debate and other  
3 debates which is on Immutable Data Trails and  
4 we've heard a little bit about that earlier this  
5 afternoon, but I think that one key to ensuring  
6 data integrity is being aware of the versioning of  
7 the record of what got input where, when, at what  
8 point, watermarking interventions or any other  
9 efforts. I think that type of technology, sort of  
10 write once, read many type of drives; things used  
11 even by Wikipedia in order to keep versions of  
12 things correct. There are lots of very  
13 interesting technology out there and I think that  
14 trying to integrate those types of immutable audit  
15 trails, that should be a baseline minimum  
16 standard. The other ideas that I think are out  
17 there that we can get into more detail later on  
18 are learning from the use of research data. There  
19 are lots of debates in pharmacogenomics regulation  
20 going on right now about the ongoing convergence  
21 of people's data, people being seen as patients  
22 who are to be treated and then as research

1 subjects. I think as we see this sort of  
2 proliferation of uses for the data, that's going  
3 to be very important to all of these security  
4 issues, I mean there is lots of stuff out there in  
5 the Common Rule and other sort of areas impinging  
6 on research that talk about delinking,  
7 de-identifying, particularly identifying,  
8 reidentifying of data, and I think learning from  
9 those areas would be very key here.

10 DR. FRANCIS: Thank you. Nick?

11 MR. TERRY: Again securing what?  
12 Securing a website that people are posting on? Do  
13 we mean securing the LBS, location-based services,  
14 of people's mobile devices? Or the one I'm going  
15 to pick on which is securing the data stream, the  
16 coffee shop problem, the WiFi problem. I think it  
17 is unconscionable that any website whether it's a  
18 PHR site or not that takes, that requires  
19 individual identifiers to logon such as a user  
20 name or password does not use a secure layer and  
21 the FTC should whack them for it.

22 DR. FRANCIS: Let me ask just a little

1 follow-up on SmartPhones and I'll tuck that in  
2 here about security issues. Are there separate  
3 security issues with SmartPhones that you think,  
4 Robert, we should be reminded of here?

5 MR. HUDOCK: Well, I see SmartPhones as  
6 being more secure than your typical computer for a  
7 couple of different reasons. For example, most of  
8 you may or may not realize that SSL is really  
9 broken and that's the encryption protocol that we  
10 use for communicating sensitive information over  
11 the Internet. Now, cell phone communications  
12 follow an entirely different communications  
13 protocol so when I'm sending something over the  
14 cell phone network itself, I'm a little bit more  
15 comfortable than I am when I'm sending it over an  
16 Internet browser.

17 Now with that distinction I'll go on to  
18 say that I think that the right strategy right now  
19 for mobile telephones and iPads and things like  
20 that is to let industry evolve because I think  
21 that what we're going to see are consumers going  
22 to become interested in PHRs because of their

1 mobile device. But we can't really perceive  
2 exactly how that mobile device will be used right  
3 now. But a couple of positive things are  
4 happening. For example, Apple released a version  
5 of the new IOS for the iPad that has a FIPS-140-2  
6 encryption built into it. That's a good thing.  
7 It's nice to see that the technology vendors are  
8 moving in that way. So I'm hesitant to put  
9 restrictions on a technology where we don't  
10 exactly understand how it's going to be used and I  
11 think that moreover it's going to hurt adoption of  
12 PHRs which in the end I think are going to be what  
13 our EHRs will be because this PHR/EHR thing is so  
14 nebulous that who knows what's what. I think  
15 we'll end up with something like a PHR that will  
16 be driven by consumer demand and it will come from  
17 the mobile telephone industry and SmartPhones.

18 DR. FRANCIS: This sounds rather  
19 different from taking HIPAA and expanding it out.  
20 One of the questions on the table is whether a  
21 possible strategy here would be to take the HIPAA  
22 Security Rule, after all people are accustomed to

1 HIPAA in the health care setting and some of this  
2 data come out of the health care setting. So I'd  
3 like to ask any of the rest of you or Robert to  
4 comment on, the first question I'm going to  
5 follow-up on here is, whether it makes sense at  
6 all or any comments people have on expanding the  
7 HIPAA Security Rule to other PHRs that are  
8 currently not covered entities? The other  
9 question we're going to look at is whether the  
10 Federal Trade Commission, what authority people  
11 think that -- or would it take statutory change to  
12 think that certain kinds of security practices or  
13 poor security practices are unfair trade  
14 practices. First let me go to HIPAA and any  
15 comments on the pros and cons further on expanding  
16 the HIPAA Security Rule.

17 MR. TERRY: I think HIPAA -- unless you  
18 tear it up and start again and do something more  
19 like the California model which impresses me -- I  
20 think HIPAA has probably been extended through  
21 HITECH to the BAs as far as we probably are going  
22 to be able to do it. There is also a sense I



1 think that one has that privacy, confidentiality,  
2 security at least traditionally, historically,  
3 have been addressed contextually. We look at  
4 these vertical segments or domains or subdomains  
5 and we come up with privacy, confidentiality,  
6 security models that we think are best attuned to  
7 those. A good example of that is, and I think I  
8 ripped this off from Helen Nissenbaum's book  
9 "Privacy in Context," imagine if every single move  
10 you made was being written down or even filmed,  
11 that everything you said or did was being  
12 documented, that every mood swing, every piece of  
13 information over 24 hours was being documented.  
14 You'd go - oh that is just Orwellian. In a  
15 hospital that's what we could call good care, so  
16 that I think context is really important.

17           The other thing is that legal norms by  
18 themselves don't always win, and so it's important  
19 to tune your legal norms to existing social or  
20 ethical or professional norms. The  
21 hospital/physician environment has those set up so  
22 that one of the challenges for the regulator is to

1 find legal rules that map to those and there is  
2 mutual reinforcement. I don't really see any of  
3 those existing rules operating for the untethered  
4 as I call it, the pure PHR, and therefore I'm not  
5 sure there's much point in trying to - in wasting  
6 energy in trying to extend HIPAA to those types of  
7 PHRs.

8 DR. FRANCIS: So that would start us  
9 with the Federal Trade Commission. The question  
10 was, and I'll ask Frank to address this, whether  
11 we need more than the current unfair or deceptive  
12 Section 5 authority to address security if it were  
13 to happen through the FTC rather than through  
14 HIPAA.

15 MR. PASQUALE: Thanks. I think that  
16 we've seen some really impressive initiatives out  
17 of both ONC and FTC and the FTC does have a lot of  
18 powers and it's a broad statute, the Section 5 of  
19 the FTC Act, so you've got a lot of adjudicative  
20 powers there and a lot of, I think, room for say  
21 even rulemaking to really delineate what best  
22 practices would be and what these entities ought

1 to be doing. I think the problem comes with what  
2 happens when you start seeing sites pop up, and I  
3 think this was mentioned briefly by Loretta  
4 Garrison, that may say we offer no guarantees,  
5 what if you get sites that just say listen, you  
6 put your stuff up here, we really don't promise  
7 anything. I think that is a possibility and even  
8 when you talk about changes of attitudes toward  
9 privacy, you have to start worrying about that,  
10 and you have that description on The Wall Street  
11 Journal's "What They Know" series, an incredible  
12 series at [wsj.com/wtk](http://wsj.com/wtk), "What They Know." They've  
13 done a great job of showing how data can sort of  
14 be unleashed.

15           And I just want to give, in this sort of  
16 privacy in context, I want to give a flip side of  
17 Nick's hospital example. There was a pretty  
18 astonishing article in Business Week that was out  
19 there that talked about -- a couple of years ago  
20 by Chad Terhune -- the use by individual insurers  
21 of pharmacy records and medical credit scores that  
22 were sort of being developed in other ways and

1       these pharmacy records were being used by  
2       individual insurers to figure out if they wanted  
3       to insure people or not. So my worry is all  
4       right, I may think that by and large the personal  
5       health record vendors are quite fine, but where I  
6       get worried about is when you possibly have data  
7       that's gone legitimately from the personal health  
8       record vendor to some other entity that it's been  
9       authorized to share that data with and then maybe  
10      it gets beyond there; there's a lot of literature  
11      out there on privacy now on so-called data  
12      laundering or fourth parties. Lots of rules that  
13      apply to third parties like telecommunication  
14      providers may not apply to fourth parties like  
15      data brokers. My ultimate concern, I guess, is  
16      that this sort of security may involve  
17      watermarking of individual data so we know where  
18      it is, we know who has it and ultimately that's  
19      going to address the concerns that I think a lot  
20      of consumers have about possibly having their data  
21      being used adversely to them and be things like  
22      employer scoring, insurer scoring. And just to

1 give one final example of those sort of brave new  
2 world possibilities. Sharon Hoffman, who's a  
3 really fantastic legal and technical expert in  
4 this area, has brought up the possibility in a  
5 recent article that employers could have access or  
6 somehow have access to these types of records,  
7 that they could develop scores on individuals on  
8 whether they are likely to get sick and that's  
9 very worrisome. I think that because there's the  
10 possibility of that data going out unleashed, we  
11 have to try to build into the technology and  
12 regulation at the beginning of the creation of a  
13 record ways of avoiding those very troubling  
14 scenarios.

15 DR. FRANCIS: Let's turn specifically  
16 now to privacy. I'd like to ask each of you to  
17 pick one -- well I should call it given the way  
18 the terms were set up at the beginning --  
19 confidentiality -- one important issue with  
20 respect to the sharing of information and consumer  
21 knowledge or control so that would be  
22 confidentiality in a technical sense that each of

1 the panelists would like to be sure that gets  
2 talked about. Nick, we'll start with you on the  
3 confidentiality front.

4 MR. TERRY: On the  
5 confidentiality/privacy front, I guess the piece  
6 that worries me the most at the moment is data  
7 scraping from websites. Generally again as Frank  
8 was talking about both The Wall Street Journal and  
9 the Times recently picked up on some fascinating  
10 stories -- PatientsLikeMe is just one of them --  
11 and there's this new complaint that's just been  
12 filed by privacy advocates with the FTC with  
13 regard to some of these activities and I think  
14 that constellation of activities and the  
15 activities of data aggregators generally and what  
16 is happening with this data whether you track it  
17 or not are probably where I'd put my energies.

18 DR. FRANCIS: Could I ask you to  
19 elaborate a little bit for some of the uninitiated  
20 to describe exactly what you mean by data  
21 scraping?

22 MR. TERRY: As I understand it, it is

1 with various levels of consent or conspiring by  
2 those associated with the site, sometimes existing  
3 members, sometimes simply data robots that are  
4 being sent in, that are literally scraping off the  
5 data that people are putting on these websites  
6 with regard to their medical diagnoses, with  
7 regard perhaps to pharmaceuticals that they have  
8 been prescribed and various other pieces of  
9 information, some of which is identifiable  
10 immediately because they may have their own names,  
11 others as I believe was the case with  
12 PatientsLikeMe may not have been directly  
13 identifiable because people posted with  
14 pseudonyms, but because there was linkage or  
15 possible linkage that could be made to social  
16 networking sites, their actual identities could be  
17 discovered. Those are collected along with whole  
18 bunches of other information, such as data from  
19 prescribers and from pharmacies, and are  
20 aggregated in a multibillion-dollar industry and  
21 sold back to health care providers and  
22 pharmaceutical companies, as I understand it.

1 DR. FRANCIS: Thank you. Frank, you want  
2 to comment on a confidentiality issue?

3 MR. PASQUALE: Nick has addressed many  
4 of my deepest concerns here I think in talking  
5 about the scraping issue. I do think that the one  
6 corrective here that I think could help a lot  
7 would be -- I don't necessarily worry all that  
8 much, let's see if I remember PatientsLikeMe if  
9 someone has copied all the data and they have that  
10 data in some vault somewhere that's associated  
11 with that user name, I mean I do start to worry.  
12 But where I really get worried is when that data  
13 becomes actionable and when it gets combined say  
14 with other data and somehow gets used to create a  
15 profile of me and I think that's something that I  
16 was so happy to see the FTC's action on behavioral  
17 advertising now because I think what it's doing is  
18 the agency is trying to make people more aware  
19 that we all have a digital self that's out there,  
20 the sort of digital doppelganger that is  
21 associating various characteristics of past  
22 behavior or past identity or past associations



1 with us. I think to the extent that one way to  
2 make people feel more comfortable about the  
3 inevitable losses of privacy or inevitable sorts  
4 of breaches that may occur is that when this sort  
5 of digital self is created by these new profiling  
6 entities be they online behavioral advertisers or  
7 other profilers that we have some opportunity to  
8 understand what data they're using, how they're  
9 using it -- be more open about it. My nightmare  
10 scenario is that you have a scenario where  
11 reputation scores like credit scores get created  
12 that are black boxes. The worry about the Fair  
13 Credit Reporting Act is yeah, there are lots of  
14 abilities to actually change your report, but how  
15 much does that really mean to the average person  
16 if the only thing that matters is scoring and you  
17 don't know how the score is created? So I think  
18 that's a very important aspect of this is that we  
19 have to be aware of the frontiers of reputation  
20 creation and profiling based on data that may get  
21 out there.

22 DR. FRANCIS: Robert?

1                   MR. HUDOCK: OK. I've been thinking  
2 about this as you've been coming down to me.  
3 There's a legal problem that I see with privacy  
4 and there's a technical problem that I think is a  
5 bigger issue. My biggest legal concern with  
6 privacy is that we have 50 different states with  
7 50 different rules on how to get consent to share  
8 information and what a PHR is, what information  
9 should be shared and in what context. But  
10 ultimately the biggest privacy issue I see is sort  
11 of a consumer interface. They get this  
12 information on the computer and we've mentioned  
13 something about peer-to-peer file sharing before  
14 and a lot of consumers have that on their  
15 machines. So they download some of their medical  
16 information to their personal computer and then  
17 their child installs some peer-to-peer file  
18 sharing software on there, which is automatically  
19 configured to share all sorts of things from your  
20 computer, so all your tax records or whatever get  
21 popped up there. My biggest concern right now is  
22 for the average person being able to protect his

1 or her family as they get this information and I  
2 don't think that that can happen by adding a new  
3 piece of software to their computer. I think that  
4 that has to happen where the internet hits the  
5 house. So my biggest concern is I think that  
6 whatever we wrap around PHRs for security,  
7 wherever we wrap around EHRs, whatever we wrap  
8 around other sensitive information is for naught  
9 because other stuff that's unrelated will end up  
10 leaking the information and it will happen from  
11 the consumer's house and it will be the consumer's  
12 fault because they won't know what to do.

13 DR. FRANCIS: So is it hopeless to think  
14 that -- we've heard a fair amount today about how  
15 consumers don't understand what it is to have a  
16 privacy policy and so do things that they didn't  
17 mean to do or don't read things because they think  
18 they didn't need to read them because they thought  
19 they protected them when in fact they didn't.  
20 What I want to do is ask each of you to comment  
21 moving further on this question of do you see any  
22 hope for the role of the consumer and consumer

1 choice in this or do you think that those  
2 strategies are going to need to be strategies that  
3 say that there are just certain things that  
4 shouldn't happen or is there another way around  
5 this that may be at the actual point of sharing no  
6 matter how it happens, that at that point you have  
7 just-in-time consumer consent? Is that a  
8 strategy? I'll start with Frank and then go to  
9 Nick and back to Robert.

10 MR. PASQUALE: Sure. There are a lot of  
11 challenges here and I think that there is one  
12 thing that I'm glad to see some earlier panelists  
13 talk about was the information overload problem,  
14 that even if the privacy policy could be brought  
15 down from 25 to 12 pages to 10 pages, still there  
16 has got to be prioritization in terms of what are  
17 the most important things in it and what are  
18 really critical to people and I think that's where  
19 these surveys that we had earlier are really  
20 valuable because they can point to us what do  
21 people really value.

22 On a more technological level, there are

1       some ideas out there about the segmentation of  
2       data in the record so that if you really want to  
3       have a segmented record such that part of the  
4       record never gets shared except with your explicit  
5       personal permission for every particular sharing  
6       possibility, you may want to just pre-commit  
7       yourself to that and Viktor Mayer-Schönberger's  
8       book "Delete" talks a lot about the sort of  
9       technical protocols that might be involved in  
10      that, the same with Jonathan Zittrain's book "The  
11      Future of the Internet and How to Stop it" -- he  
12      worries about the future of the Internet -- and he  
13      talks about having a green box and a red box on  
14      your computer, a green zone and a red zone, and  
15      the red zone is where you connect with everybody  
16      but you don't keep really safe things there  
17      because you know it's going to be exposed to the  
18      public internet versus the green part that's more  
19      secure.

20                   Finally, the final technological thought  
21      that I think is somewhat helpful here is what  
22      Jerry Kang's group at UCLA has been dealing with

1       sensor networks and has come out with the idea of  
2       a personal data vault. We heard earlier about  
3       sensor networks being used in health care and I  
4       think that as that type of ubiquitous computing  
5       ends up feeding more and more information about us  
6       or if we sign up for that, we need to have that  
7       option because my final rationale for this would  
8       be opting-in to things like quantifying yourself  
9       or these other things, it may seem like an odd  
10      habit of nerds right now, but I promise that as  
11      wellness programs and other sorts of benefits  
12      become more popular it's not going to be easy to  
13      avoid them. People are going to wonder why aren't  
14      you part of the quantified-self movement? What  
15      are you trying to hide? Are you trying to hide  
16      your cholesterol level from us? I think that even  
17      though they seem that they are the vanguard now,  
18      this privacy phenomenon called unraveling can very  
19      quickly lead a tipping point where everyone feels  
20      not just that it's helpful but that they need to  
21      be part of these things.

22                   DR. FRANCIS: Thanks. Nick?

1                   MR. TERRY: It's a huge surprise that  
2 I'm kind of skeptical with regard to current  
3 privacy policies and so on. I think privacy  
4 policies are like warranties that we saw in the  
5 1960s, that there are actually lists of things  
6 they're taking away from us rather than lists of  
7 things they're going to give us. I think that  
8 what we see today is still the discredited notice  
9 and choice model of privacy, that is, you've been  
10 given notice and that's the health privacy we're  
11 taking away from you and therefore you've been  
12 deemed to have been given a choice. So long as  
13 vendors and suppliers of these websites and PHRs,  
14 untethered non-HIPAA PHRs, as long as the vendors  
15 control the choice architecture then I don't think  
16 we're going to have major improvement.

17                   The other thing I think that the current  
18 phrase that everyone wants to use is trust. Trust  
19 is really big at the moment. We have trust. Our  
20 PHRs have trust. Everyone wants to talk about  
21 trust, but I don't know what they mean by trust  
22 when they talk about it. I think the only people

1       that most of these companies that know the meaning  
2       of trust are their marketing departments and I  
3       think it's a piece of branding. I think trust has  
4       various meanings. I think the meaning of trust  
5       changes as to context. And also I think trust  
6       changes as it scales or that what you're doing  
7       scales, so I don't think anyone should be allowed  
8       to use the word trust in this without defining it  
9       and if they don't define it then we should shout  
10      at them that's not trust, that's as Steven Colbert  
11      would say trustiness.

12                   DR. FRANCIS: Robert?

13                   MR. HUDOCK: Could you specify the  
14      question a little bit more?

15                   DR. FRANCIS: What I want specifically  
16      is a comment on whether more information to  
17      consumers about what their kids might do with file  
18      sharing and what might happen if their kids  
19      install a file-sharing program whether that's at  
20      all likely to be helpful or whether what we ought  
21      to do is have ways that information from PHRs just  
22      can't get on computers that have file sharing. So



1 the question is whether it's consumer consent and  
2 more information to consumers that's a strategy or  
3 whether you see that as hopeless.

4 MR. HUDOCK: I guess I see it as a  
5 little bit of hopeless and the reason why is the  
6 Internet really wasn't designed for the secure  
7 environment that we want to put it into right now.  
8 The basic protocols were designed back in the  
9 1970s where just only a few universities connected  
10 up. I think we have to reengineer how our  
11 Internet works in order to be able to build in  
12 security that actually works because right now, I  
13 just don't know --we can't rely on the methods  
14 that are being provided to us to secure the  
15 information over the Internet as being 100-percent  
16 secure. We can't do layered consent models where  
17 you have different levels of access based on  
18 digital keys and things like that. I think this  
19 technology needs to be developed and it needs to  
20 be pushed out and it will probably take a long  
21 time because we had a problem with the DNS and it  
22 took forever to get a secured DNS system out, so

1 invest in technology to get a better Internet.

2 DR. FRANCIS: Thanks. I have a quick  
3 question for Frank and Nick about models from  
4 elsewhere. We've been mostly talking about what's  
5 going on within the U.S. and there are some  
6 approaches elsewhere and I know Nick knows  
7 something about approaches elsewhere and I think,  
8 Frank, you know something about that.

9 MR. TERRY: You said this would be a  
10 fine 10-day conference. The two pieces that I  
11 think are useful. One, is what is -- the core of  
12 the E.U.

13 Directive -- is privacy and  
14 confidentiality in that it seeks to regulate not  
15 only the dissemination of data, which is primarily  
16 what HIPAA regulates, but also the collection of  
17 data and it puts a proportionality rule with  
18 regard to both of those. It then also layers on  
19 top of that a far stricter rule when you get to  
20 things like medical data as opposed to other types  
21 of data. I think that's the big lesson from there  
22 without getting too technical.

1           The other lesson I think that is worth  
2 looking at, although there is some flux at the  
3 moment as they reorganize, is the Australian model  
4 in two senses. First, they have an identified  
5 privacy curator, a privacy commissioner, someone  
6 who has an independent role and is somewhat  
7 depoliticized and has a role in working with both  
8 industry and consumer organizations to improve  
9 privacy. Those kinds of privacy commissioner  
10 institutions are very good at putting out policies  
11 and practices and fine-tuning and working with  
12 industry and consumers and I think there is some  
13 interesting stuff that could be done there, again  
14 without wanting to get too detailed.

15           DR. FRANCIS: Thanks. Frank?

16           MR. PASQUALE: I'll quickly add onto  
17 that that part of the E.U. Convention on Data  
18 Protection Regarding Individuals says that  
19 personal data including health data can't be  
20 processed automatically unless there are  
21 appropriate safeguards and I think that sort of  
22 model of trying to have some level of reporting

1 and explanation of what's going on with the  
2 processing before it happens might be something  
3 that we should look into.

4 I think also that the French agency CNIL  
5 has a great website that describes a lot of what  
6 they do and as I was looking at the Center for  
7 Democracy and Technology's comments on today's  
8 events, one of the things they mentioned was  
9 people being able to demand or to ask from  
10 personal health record providers or those that  
11 have their data who it was shared with, to be able  
12 to get that type of data. One of the things that  
13 the CNIL has been at the head of the curve on that  
14 is implementing those types of rights of consumers  
15 to understand where their data has been and that  
16 type of auditing capability, so that I think  
17 there's a lot for the U.S. to learn from the CNIL.

18 DR. FRANCIS: Robert has a comment on  
19 that and then I'm going to ask each of the  
20 panelists to give us last thoughts.

21 MR. HUDOCK: Actually, this comment  
22 supports some of the material that we've been

1 presenting and that is the Ponemon study that  
2 actually studied the United States and the cost of  
3 security breaches per record. They actually  
4 studied Australia and the E.U., and the cost of  
5 security breaches per record in Australia and the  
6 E.U. is significantly less than what it is in the  
7 United States so that that may be an indication of  
8 what they're doing is working.

9 DR. FRANCIS: Each of the panelists and  
10 since you have the mic, Robert, I'll start with  
11 you. What do you regard as important last  
12 thoughts as we go forward into this brave new  
13 world where are sort of already somewhere in the  
14 middle of?

15 MR. HUDOCK: I'm a little nervous about,  
16 I'll give you just my 10 cents of advice here and  
17 it really is less about PHRs and more about kids.  
18 I've got three kids and they are little ones, and  
19 I worry about them getting on the Internet so that  
20 my little bit of advice is think about your  
21 security because I think that that's where it's  
22 going to have to happen, whether it's a PHR,

1       whether it's a Facebook or whatever.

2                   DR. FRANCIS: Thank you. Frank and then  
3       Nick.

4                   MR. PASQUALE: I think my very specific  
5       points might be that I do think that there is an  
6       important role for states here where a state like  
7       California, just as led with emission standards,  
8       can lead in other ways and be sort of a lab for  
9       innovation and I think if Google Health and  
10      amazing companies in the Silicon Valley can  
11      survive the California regulatory regime that  
12      others can as well.

13                  I think consumers' private rights of  
14      action really should be looked at and that's a  
15      really interesting way of diversifying authority  
16      to make sure that things are happening correctly.  
17      My final point, the broader point, would be that I  
18      think there is no necessary tradeoff between  
19      privacy, security and innovation if the privacy  
20      and security are done right, and in fact, the  
21      privacy and security goals and standards may be  
22      the real foundation we need to see major

1 innovation here to really get widespread adoption  
2 and diffusion of this innovation. So I would just  
3 caution against the usual tradeoff frame of mind  
4 there and really emphasize how these two things  
5 can be reinforcing.

6 DR. FRANCIS: Thank you. Nick?

7 MR. TERRY: I've been talking about  
8 proportionality and I don't know what that means  
9 to you, but here are three things that I think --  
10 three meanings that it has. You can only collect  
11 data when it's necessary for the announced purpose  
12 for which data is being collected. It's akin to  
13 the minimum necessary rule but on steroids. You  
14 can only use the data that you collect for the  
15 purpose that you say that you're collecting it  
16 for. Third, you can only use, store or process  
17 that data for the time necessary to complete that  
18 purpose and then you have to get rid of that data.  
19 Anything outside of that is a disproportionate use  
20 of someone's private data.

21 In the medical domain we failed I think  
22 in HIPAA by trying to use a surrogate which was

1 TPO, treatment, payment and health care  
2 operations, for that proportionality. And Leslie  
3 and I have bored people with articles in which we  
4 say that a better approach would have been medical  
5 domain or circle of care or something like that  
6 and that's fine by me. Outside of the health care  
7 domain when we're looking at PHRs and unprotected  
8 websites and so on, I would actually take a far  
9 more radical approach to try and get to some  
10 proportionate use and I would use a property rule.  
11 I would say that the data cannot be sold or  
12 bartered if it is medical information data and I  
13 would put a prohibition on that. I would let it  
14 open for nonprofit uses and so on so our outcomes  
15 research folks and our effectiveness researchers  
16 and so on are still in that game. But I would  
17 simply prohibit a market in private medical  
18 information. I think that's consistent with what  
19 GINA is doing, the Genetic Information  
20 Nondiscrimination Act. I think it's consistent  
21 with these new New England Statutes dealing with  
22 prescribing information. I think it's consistent



1 with HITECH's approach to EHR data. And I think  
2 an inalienability rule, a market inalienability  
3 rule as it is called would be a spectacular  
4 approach and a good way of achieving proportional  
5 use of data in this space.

6 DR. FRANCIS: Thank you. Thank you to  
7 everyone on this panel as well as on Panel 4-A.  
8 We need to now turn the microphones over to those  
9 who have been patiently waiting out there in  
10 cyberspace for their turn, so it's time for  
11 visitor input as well, for public comment. Thank  
12 you to Robert, Frank and Nick for wonderful  
13 presentations. [Applause].

14 MS. PRITTS: While we're setting up the  
15 phone, we're also going to be able to take some  
16 comments from people in the audience here.  
17 There's a microphone in the back so that if you  
18 have a comment, please go to the microphone in the  
19 back. We're asking people to limit yourselves to  
20 two minutes and I am going to be very strict about  
21 the two minutes. Anybody who has seen me in  
22 action before knows I mean it, so we'll wait until

1 we are set up here so that everybody can hear  
2 before we start. If we could have our first  
3 commenter from the in-person meeting, please.

4 DR. POTARAZU: I'm Dr. Sreedhar  
5 Potarazu, the CEO for VitalSpring. We are  
6 currently launching in phase one, 15 regional hubs  
7 of integrating every employer to every provider  
8 and we're issuing the report by December 10 of  
9 over 40 of the Fortune 100 companies on  
10 integrating the work health record with the  
11 electronic medical record into a personal health  
12 record. The thing I didn't hear the entire day  
13 today was a practical issue we're dealing with  
14 right now on the integration of coverage data,  
15 nothing to do with clinical data, but coverage  
16 data -- basic financial information that consumers  
17 want to put into a personal health record which is  
18 not feasible in any PHR today. All of the data is  
19 currently unstructured data. There is no means to  
20 pull in structured data and we've spent a lot of  
21 time in terms of talking about clinical  
22 information, but the problem we have right now

1 with hundreds of employers and millions of people  
2 across the country are trying to put in basic  
3 coverage information. The new law around ARRA is  
4 focused on coverage and access and very little on  
5 care and the biggest problem we have right now is  
6 providing consumers transparency on cost and  
7 nothing to do with clinical care and we have no  
8 means of addressing that right now. So the report  
9 that comes out on the 10th is going to address the  
10 immediate challenges that these 50 companies  
11 across the country have.

12 MS. PRITTS: Thank you. Are we ready to  
13 take a call?

14 OPERATOR: The first question comes from  
15 the line of Lester Keeger. Your line is open.

16 MR. KEEGER: The panel was excellent.  
17 Robert talked about the cost of security. This  
18 could be taken care of with proper protocols right  
19 up front.

20 MS. PRITTS: Thank you.

21 MR. KEEGER: The next thing is that  
22 Frank talked about industry investment, the

1       upfront ID, and that means that the -- attached  
2       two actions, properly taken care of can really  
3       make a difference.

4               MS. PRITTS: We're getting an echo in  
5       here - is that from the speaker? Can the speaker  
6       please turn off the webcast?

7               MR. KEEGER: Yes. I apologize.

8               MS. PRITTS: Thank you.

9               MR. KEEVER: Let me say it again.

10              MS. PRITTS: We've heard it I think four  
11       times. If you could move on to your next point  
12       that would be appreciated.

13              MR. KEETER: Are you talking to me?  
14       Sorry.

15              MS. PRITTS: Yes, sir.

16              MR. KEEGER: Frank talked about  
17       safeguards before it happens. This is exactly  
18       right. Robert talked about costs of security --  
19       stopping fraud can be a big payoff and that's  
20       exactly right.

21              Handling data with proper protocols up  
22       front would take care of this. That means that if

1 you can have the proper ID attached to the  
2 specific person with RBAC, your controls attached  
3 to the action, that can make a big difference in  
4 cost and implementation of security and privacy.

5 MS. PRITTS: And by RBAC you mean  
6 role-based access?

7 MR. KEEVER: Yes, ma'am.

8 MS. PRITTS: Thank you very much for  
9 your comment. We are now going to take another  
10 comment from the room and then we'll take our next  
11 comment from the room. Sir?

12 MR. PHELAN: My name is John Phelan and  
13 I'm the CEO and founder of Zweena. It's been  
14 incredibly challenging to be in this room all day  
15 and not ask questions so that I think there is a  
16 missed learning opportunity, quite honestly. I'm  
17 not impressed with my government here today. I  
18 would much rather have an opportunity to ask  
19 organized questions during the panel because I  
20 think there is a communal learning here that  
21 happens from other people's questions, so that's  
22 just a general comment.

1           I have really two things very quickly.  
2       One is CCR/CCD standards. As we digitize discrete  
3       data, which my company does for consumers, we as  
4       the United States need to have one standard. I  
5       didn't hear anybody talk about that today and I  
6       know we're talking about privacy and security, but  
7       quite honestly, consumers want their information  
8       digitized. They're not going to wait for their  
9       doctors, they're not to wait for their hospitals,  
10      and that's what we're doing for consumers in 12  
11      different states today.

12           The second issue really is around  
13      certification. We as a company that's pioneering  
14      a lot of this is having to really talk amongst  
15      ourselves and kind of prop ourselves up and be  
16      good corporate citizens and in many of the  
17      discussions that were talked about today on  
18      privacy and security, we're employing all of  
19      those, and in fact employing more than those. So  
20      we're hoping that somebody like ONC or some  
21      organization within the government is going to be  
22      certifying not only EHRs and EMRs but also PHRs

1 and we're looking forward to being part of that  
2 process.

3 MS. PRITTS: Thank you. Can we get back  
4 to the phone now?

5 MR. MALDONADO: Hello. Thank you to  
6 everyone for a very informative few hours. My  
7 question is about the apparent relative lack of  
8 concern concerning one form of  
9 government-sponsored PHI dissemination versus  
10 another. The one that I'm referring to is the  
11 NHIN Connect platform or model or recipe, and the  
12 NHIN Direct model. The NHIN Connect model is a  
13 model for sharing EHR information among provider  
14 institutions and is very well founded with a lot  
15 of projects rolling out. The NHIN Direct is a  
16 newer model that relies on email, fundamentally as  
17 the protocol, although there is another approach  
18 and seems a much more consumer-oriented, a la the  
19 PHR. I'm interested in your panel's comments on  
20 the relative strengths and weaknesses of those two  
21 dissemination models with respect to  
22 confidentiality.

1 MS. PRITTS: The conference today is  
2 centered on PHRs and we have no panel left to  
3 discuss these issues so we appreciate your  
4 comments and will take them under consideration.  
5 I'll now turn back to comments in the room,  
6 please.

7 MS. WALDO: Hello, I'm Ann Waldo. I'm a  
8 privacy attorney here in Washington and I'm  
9 representing Genetic Alliance today. Genetic  
10 Alliance is a nonprofit health advocacy  
11 organization that serves as a network of over  
12 10,000 patient groups, and government  
13 institutions, and medical researchers and  
14 industry. We support a broad array of health care  
15 goals, improving patient access to care and above  
16 all accelerating breakthrough medicines and new  
17 tests and treatments. We are very much in favor  
18 of PHRs and we're delighted with the changes in  
19 the Stimulus Act that expand patients' rights to  
20 electronic copies of their records and getting  
21 them into their PHRs in a more seamless and  
22 efficient manner.



1                   We do have one small concern that I  
2                   wanted to lay out which has to with a small  
3                   requirement in the HITECH NPRM, the proposed  
4                   regulation, that came out this summer. The  
5                   statute says that patients have a right to have  
6                   records sent to the person or entity of their  
7                   choice provided such choice is clear, conspicuous  
8                   and specific, which we wholeheartedly endorse.  
9                   Unfortunately the NPRM added a further requirement  
10                  that the choice be in writing and signed, and even  
11                  though that could be done electronically, if it is  
12                  done electronically it has to be in conformity  
13                  with the electronic signature requirements of each  
14                  state and I doubt if any of us in the room even  
15                  know what all of those are, much less the average  
16                  provider. So we are greatly troubled at the idea  
17                  that this will serve as an inadvertent impediment  
18                  to patients being granted meaningful access to  
19                  their records through PHRs and we would really  
20                  encourage that policymakers to take a look at the  
21                  part of the NRPM that deals with immunization  
22                  requests where the rule says that if parents in

1 particular have properly authenticated themselves  
2 in the health care setting, then the providers can  
3 honor an oral request to send the immunization  
4 records, for example, to the child's school, so  
5 that I think in the health care setting when the  
6 patient has properly identified themselves,  
7 they've obtained care and so on, that at the point  
8 of perhaps checking out or talking to their  
9 provider if they express an oral request to have  
10 their records sent to a destination of their  
11 choice that we'd like to see that honored in the  
12 interests of advancing patient access to records  
13 through PHRs.

14 MS. PRITTS: Thank you. We'll now turn  
15 back to the phone, please.

16 MR. HOWELL: I'm somewhat disappointed  
17 that our government, as well, is opposed to our  
18 looking at how we are going to scrutinize the  
19 sharing of information in HIEs, the health care  
20 information exchanges between payors, payees,  
21 doctors in their physician practices. We should  
22 have done this upfront-- because a lot of the

1 EHRs, HIEs, have been developed as you very well  
2 know, already, where they're already doing  
3 scrapes, extrapolating information off of a  
4 multitude of websites after the fact. Now they're  
5 trying to do once again after the fact, shoring up  
6 patient information.

7 MS. PRITTS: Thank you for your comment,  
8 and we will now turn back to the gentleman in the  
9 back of the room, please.

10 MR. CARUSO: Hello, I'm Tom Caruso and  
11 I'm building a think tank, a biomedical  
12 informatics think tank. You can find more  
13 information at tpcaruso.com. I wanted to comment  
14 about the lack of conversation concerning clinical  
15 research. The future of medicine is really being  
16 defined by researchers that are in academic  
17 institutions that could very significantly benefit  
18 from access to public health records and to  
19 mechanisms to consent those individuals who are  
20 using those public health records to participate  
21 in studies and to even pay those people to  
22 participate in some way. I would like to see more

1 conversation including clinical researchers and  
2 biomedical researchers who could use this  
3 information very significantly in improving  
4 quality of care in various different ways.

5 MS. PRITTS: Thank you for your comment.  
6 Are there any more comments on the phone, please?  
7 [ no]. Anyone else? [no].

8 I'd like to thank everyone for coming.  
9 I would like especially to thank the people who  
10 managed to stay all day. I know it's been a very  
11 long day. I do understand the desire for  
12 participatory forums. We do strive to have an  
13 open government. We have made great process I  
14 think in this administration in making things much  
15 more transparent in collecting comments in advance  
16 and providing a lot of opportunities for people to  
17 participate in these events, and so we'll take  
18 those comments as we go forward and see what we  
19 can do about that.

20 This may not be appropriate, but I'd  
21 also like to comment back that it's important that  
22 in these forums when you do that, that it's a

1 two-way process so there has to be some respect  
2 for the process also from the participants, so  
3 that one of the difficulties in these kinds of  
4 forums is the lack of adherence to time. We did  
5 not have that today, but I'm sure you've all been  
6 in conferences when people have ignored the time  
7 limits and not adhering to the subject matter of  
8 the calls and things of that manner. So there are  
9 some difficulties with doing that, but I think  
10 this is just a general comment that should be  
11 responded to, that it is a very useful process to  
12 have more open dialogue and useful for us to take  
13 that into consideration, how to make that happen  
14 in a very meaningful way, so I deeply appreciate  
15 that comment and it's something that I think that  
16 we should really think about a lot more.

17           Having said that, I do appreciate  
18 everybody having come and stayed particularly for  
19 our panelists. For me this has been an extremely  
20 informative day and I hope it was for you too.  
21 There were a number of thoughts here today and a  
22 number of things here today, but some of the ones

1       that I think that really came up, I can't possibly  
2       summarize everything that was said today, but the  
3       things that really stick in my mind for the most  
4       part are that the borders are very blurred as  
5       between what health information is and what other  
6       information is, that the mode of holding  
7       information is very blurred between what an  
8       electronic health record might be, a PHR might be  
9       and any other mode, and that it's very difficult  
10      to put boundaries around those different things  
11      and to know how to manage them.

12                 As I started the day, I would like you  
13      leave you all with a quote. This one is not quite  
14      as old as the one I opened with which was from the  
15      1700s. This one was from 1997 and I know in tech  
16      terms that might as well be the 1700s in some  
17      ways. It's from Donna Shalala who was speaking at  
18      the Press Club shortly after HHS issued its report  
19      to Congress when Congress was still trying to pass  
20      a kind of unified health information protection  
21      statute, which as we all know it was unable to do.  
22      The question remains pertinent today as it was

1       then, which is, "When all is said and done, will  
2       our health information be used to heal us or to  
3       reveal us?" And with those kind thoughts, I will  
4       leave you. Thank you very much and have a good  
5       weekend.

6                               (Whereupon, at 4:43 p.m., the  
7       PROCEEDINGS were adjourned.)

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CERTIFICATE OF NOTARY PUBLIC

DISTRICT OF COLUMBIA

I, Irene Gray, notary public in and for the District of Columbia, do hereby certify that the forgoing PROCEEDING was duly recorded and thereafter reduced to print under my direction; that the witnesses were sworn to tell the truth under penalty of perjury; that said transcript is a true record of the testimony given by witnesses; that I am neither counsel for, related to, nor employed by any of the parties to the action in which this proceeding was called; and, furthermore, that I am not a relative or employee of any attorney or counsel employed by the parties hereto, nor financially or otherwise interested in the outcome of this action.

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Notary Public, in and for the District of Columbia  
My Commission Expires: April 14, 2011



