

**Privacy and Security Tiger Team  
Draft Transcript  
July 8, 2011**

**Presentation**

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Good afternoon everybody and welcome to the Privacy and Security Tiger Team. This is a Federal Advisory call which will be 2 hours and there will be an opportunity at the end of the call for the public to make comment.

Let me do a quick roll call of members: Deven McGraw?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Latanya Sweeney? Gayle Harrell? Paul Egerman?

**Paul Egerman – Co-Chair and Software Entrepreneur**

Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Carol Diamond? Judy Faulkner? David McCallie? I know he's on. Neil Calman?

**Neil Calman – Institute for Family Health**

Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

David Lansky? Dixie Baker? Micky Tripathi? Christine Bechtel? John Houston?

**John Houston – University of Pittsburgh Medical Center; NCVHS**

Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Wes Richel? Leslie Francis? Vern Rinker?

**Vern Rinker**

Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

And Linda Koontz is on from Miter. Did I leave anyone off?

**Joy Pritts**

Joy Pritts is on the phone.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Thank you Joy.

**David McCallie – Cerner Corp.**

And David McCallie is back.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

And with that, I will turn it over to Deven McGraw and Paul Egerman.

**Josh LaMeau – Markle Foundation**

Josh LaMeau is standing in for Carol Diamond today. She is on vacation.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Great, thank you.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Anyone else need to weigh in and present themselves before we get started? Alright, terrific, we're going to – we've got a topic on our agenda today, view and download transparency, but we're going to start with a little overview and discussion of what happened at the Policy Committee on Wednesday where we presented our recommendations on amendments and corrections. The recommendations were approved by the policy committee. I think it's important for those of you who were either not present in the room or on the phone to hear the discussion, the Policy Committee really felt like the work was incredibly important, both from a patient safety standpoint as well as on the consumer engagement side given the patient right to request an amendment and having the capability of systems to be able to appropriately make amendments and to propagate them forward. It was obviously a critical piece of the puzzle. We got a lot of praise for the work done on this, we got a lot of praise for the simplicity of what we were proposing. I think people got it and understood it quickly which was nice. We are not always able to do that with some of the complicated topics that we take on, but it's always nice when we're able to distill sometimes complicated issues into recommendations that make sense, that make progress and that people can really understand and grasp.

I want to pause and make sure that Paul has his input and others who were present or on the phone during the call. We have one lingering issue that we do need to resolve that we had acknowledged in our last Tiger Team call and that the Policy Committee also weighed in on as being important and that is the role of HIO's and at a minimum transmitting amendments forward. That was the bulk of the discussion that took place on the call. But I want to pause and turn to Paul and then to others to sort of chime in on their thoughts on the outcome of the Policy Committee meeting on our issue.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Yes, Deven, I think you did a good job summarizing the call. It's always hard to predict what people would be interested in. There was a fair amount of interest in this topic and there was that issues on the HIO's really in response to a comment that Neil made that we want to talk some more about.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Anyone else who was present or who listened in? Or even if you didn't and wants to add anything?

**Neil Calman – Institute for Family Health**

This is Neil and I was present and I thought that the presentation was incredibly well done and well received by the group. I think it's a credit to all the work that you guys have commandeered through this process. These are some really complicated issues and when you can present them to a group of people that really haven't heard them before and have them basically agree as readily as they did with all the issues that you've presented, I think that's really terrific.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Well we couldn't have done any of this without the dedication of everybody getting on these calls and spending time responding to emails in the interim when we're trying to clean issues up and we're doing really good work and I think it's really starting to pay off. All the time we've spent on these phone calls together. So –

We do have this issue of the role of Health Information Organizations (HIOs) and propagating corrections and then the other stream of discussion that took place in our last Tiger Team meeting that was less emphasized in the policy committee was circumstances where the HIO is the actual data steward or is performing functions with data and could potentially itself be a source of error in some circumstances and

what the obligations in those circumstances are to either make corrections and/or propagate them forward.

One of the pieces of information that we don't have yet but I think we do need to help us answer this question is, what are the HIOs that are in existence and working today, what have been their policies and approach to this issue? And so one thought that I had and wanted to raise for discussion is whether this topic would be one that would benefit from joint expertise of Tiger Team and the information exchange work group given the presence of so many persons from state level HIOs on that working group. I wanted to sort of gauge what people thought of – I don't know if that means setting up a small task force like we did for the digital certificate issue quite recently or whether it makes sense to try to just add some additional folks or on to a call where we discuss this. So I wanted to open that up for discussion to see what people think. It feels like we need a little bit more information will help us resolve this issue with a concrete set of recommendations.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I think we have a fair amount of anecdotal evidence to this issue. I think it would be very helpful to get a sense of what the empirical data is – incidence data quality. I think this all ties back into what we talked about before with respect to data – to patient matching and – how do people err either of the side of simply not matching the data if there's some question versus potentially trying to force the data together. That may resolve in higher error rates. So I think it will be very important to sort of as a range of questions along these lines.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Right and along those lines John, we actually did have something to say about the role of HIOs and patient matching as part of that collection of recommendations.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

Oh yes, that's my point. We talked about that – I agree with you but this is an area – patient matching sort of flows back into this particular issue in my mind to some degree.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes, definitely there is a connection there. I would agree with that. Not all errors are ones of matching but there's definitely a connection there. In fact, I had the reason to go back and look at our patient matching recommendations fairly recently and had noticed that we had expressly in our recommendation letter reserved the issue of amendments and corrections for later discussion. So, and here we are.

So what do folks think in terms of sort of processing this forward about either having some participation from i.e. workgroup and maybe sort of dividing this up or should we do it in a central Tiger Team meeting and just invite some other folks to join us with some expertise? Another option would be just to do some background research and have it present in our discussion which was our original plan.

**Neil Calman – Institute for Family Health**

I think either would be ok. I think it would be helpful to have a few of the exchange folks working with us on this. One of the things that I discovered in some research after I left the meeting on Wednesday and this was troubling me was that our electronic health record does not record access by outside entities in the same way it records access by inside entities. I can see anything that anybody in our organization has accessed but I can't see it if our RIO has accessed information. So, the reason I asked about that question was because – one of the points you guys made which was really wonderful was if there is already sort of an obligation for good practice to do something, to let people know about changed information, well that should cover some of this. So I thought if I could go into my electronic health record and just see whether or not this information that's changed has been accessed by anybody, I could then know whether I have some responsibility or need to transmit that forward. But, there's nothing in there which also brought up for me the bigger question that patients who want to see an audit record of their electronic health record are going to need to go both to the electronic health record, at least now, and to the exchanges that might have accessed that electronic health record. Because they can't get that all from one place. I don't know if we've ever dealt with that issue but that had never really occurred to me

previously that a patient might ask to see who accessed their record wouldn't include any information from outside accessed.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

This all goes back to some of what's really important being asked of an NPRM as well.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

So Neil and others may be aware that right now there's an open comment period on a proposed rule of changes to the HIPAA accounting of disclosure requirement. There are lots of pieces to this but one set of provisions gives patients the right for the first time to ask for an access report to the designated record set which is the sections of the electronic health record that are relied on for treatment purposes. That's a really rough summary of a designated record set. But at any rate, it's an open comment period where I know a lot of entities and consumer groups are commenting. Ordinarily, you otherwise wouldn't have a legal right to an audit trail. I guess some institutions are providing that as a matter of practice. But in the proposed rule, the business associate, which is the role that the HIOs play, they are responsible for providing, if the patient were to ask for an access report, they have to provide that access report to the covered entity which provides it to the patient under the proposed rule. Again it's subject to open comment, but it is a topic on which the Office of Civil Rights is now gathering input.

**Paul Egerman – Co-Chair and Software Entrepreneur**

This is a good discussion. What it says to me is one way to get started is to do our best to frame the questions or frame the discussion. In which case the NPRM might be some of the background material.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes.

**Paul Egerman – Co-Chair and Software Entrepreneur**

But we have to be very clear on what our focus is. I think that ought to be our first step and maybe what we do is with our good friends at Miter we try to frame that discussion and then we run it by John and Neil to make sure we've got it right because Neil is experiencing this right now. Then I think we can figure out the best format to address those questions, either a task force or an entire committee. I view that more as a procedural detail. In either case we probably want to include some representatives from the exchange organizations who have a different perspective but also have some experience with some of these issues.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Neil, I thought your comments were really interesting about the difference in what you can see when you look at the audit trails. So what I'm going to try to find out is that simply because people program things differently? Or is it actually because technology for accessing it through the RIO is different than otherwise and it is a technological challenge? I don't know which it is.

**Neil Calman – Institute for Family Health**

I think the point that Paul made – it's like – if you just knew and it was in bullet #1 of the discussion items at the Policy Committee meeting, if you just knew who accessed it and there was a change of information, you'd be able to go there and keeping with just good clinical practice. Just like if you sent the report to a specialist before, you could at least know that somebody else needed to have that information updated. I was actually shocked to find out that the system didn't record that. I don't think I've ever asked that question before.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Yes, it's interesting. The example you gave with radiology is an interesting sample. Because one of the things that happen in inpatient studies is sometimes it's the flip side where the Radiologist recognizes there is something very serious going on and they want to immediately contact people and they can't figure out who to contact or how to get to them. There are definitely interesting workflow challenges in this entire process.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

But are you thinking of the Radiologist getting to the patient or the Radiologist getting to the patient's Primary Care Physician?

**Paul Egerman – Co-Chair and Software Entrepreneur**

Yes, the Primary Care Physician or the attending or whoever they need to contact.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Oh, ok.

**Paul Egerman – Co-Chair and Software Entrepreneur**

It's not always clear who that is because the workflow is such that the person who orders the exam, there shift may have ended by the time the exam is actually read. But also may not be the right person to contact when there is a problem or a challenge. But rather than get into the weeds of the workflow, to summarize where we are, I think we agree that this is a very interesting topic. The first step should be to frame the discussion, to write down the questions we are going to try to address and see if we can get a consensus around the framing and then we can expand our group so that we have the right set of people to address the issues. Does that sound right?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

It does to me Paul. It's a good summation.

**Neil Calman – Institute for Family Health**

And I think you've framed it pretty well in your 2 bullet slide there. Because basically I think what you are saying there was if there is a mechanism that allows people to have access to this information that's consistent with just good clinical practice, I would almost see that as phase 1 or I guess at this point phase 2. And then its phase 3, a way to automate those kinds of things but right now we don't have either of them and I think the way to frame it is to say well at least let's make sure the providers have access to where the information went so that they can follow up with it and then figure out a way to automate that process as a later discussion. So, I think you've already framed it in some sense but we'll start there.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

That's a very helpful way to think about it.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Your comments are excellent Neil, but as we think about this, we have to keep in mind a comment that Judy made on Wednesday, which is we make sure as part of our framing and understanding this problem, that we don't end up with a solution because so many annoying false positive messages because there are minor changes going on and you end up with a system that's not useful.

**Neil Calman – Institute for Family Health**

Yes.

**Paul Egerman – Co-Chair and Software Entrepreneur**

There is an interesting challenge here.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Alright, terrific discussion. Paul, you and I have some work to do with our folks from Miter but all this feedback was really helpful; one more important issue for us to tackle, among many.

So with that, I think we'll move on into the slides that we distributed for the meeting today. I do have control over them – excellent – and no frozen computer today. What we're going to talk about is transparency with respect to the view and download meaningful use criteria that are in the proposed stage 2 recommendations that were included in the policy committee letter. Now of course we don't know whether these recommendations will necessarily be accepted, that's up to CMS and ONC, but we have already put some recommendations related to privacy and security before the policy committee on the view and download functionality in the event that it does get accepted by the agencies and put into place

and we want to similarly that we make sure we've dotted all the I's and crossed all the T's on that capability at least with respect to the privacy and security issues that are in our purview.

This slide summarizes the obligations on hospitals and eligible providers with respect to the view and download capability and in the actual policy committee letter is a bit of a placeholder for us to consider whether a privacy and security (P&S) warning should be put into the standards and certification criteria, should be part of what is certified. For example, in an EHR, or that needs to be present in a certified EHR, some sort of warning and we actually have a number of slides here that will give a little bit of background about what some kind of warning might look like.

So our objective here again is focusing on the transparency implications, risks from a privacy and security standpoint of a patient's ability to view and download their own electronic health information. We have a couple of quotes here from work done by the Markle Foundation and Josh, I'm really glad that you were able to join us with Carol on vacation. They have done a fair amount of work through a multi-stakeholder process in developing a set of model policies for a view and download capability, which came to be known as the blue button among the persons who worked on it. Full disclosure – I was one of those people who did and I think there are a number of people on the call who are either familiar with or who helped participate in that work. So, to provide you with an example, part of transparency is helping people make informed choices in a circumstance where their choice to download their data means they are taking on the risk for the privacy and security of that information and needing to make sure that consumers are at least at a baseline level aware that when they download the data the stewardship responsibility for that data really passes to them. But you really do so that it doesn't overwhelm them or scare the crap out of them but that also provides them the opportunity to get more information if they want it. Essentially, as its covered in the slide it provides a clear and concise explanation of what a download capability is and its fundamental implications, provides links for people to view more details about the download process and some basic security protections that they can take on their own and who to contact if they think for example, there's an error in their information, who they can contact if they have further questions, and then ultimately the purpose of the notice is to get independent confirmation that the individual, having been notified of the potential risks, really wants to download a copy of their health information. Hopefully you can see on your screen and if you can't, I think it's pretty well summarized at another point, but it's pretty basic information here. If you download sensitive information to a shared or unsecured computer or device others might see it. You're responsible for protecting the information you download and for deciding with whom to share it. Are you sure in fact that you want to do this? There is an option to say yes, no, or tell me more. I want to know more before I decide to do this.

Now, on subsequent slides we actually have examples on how this concept of a simple notice with links to more additional information is being deployed both by the Veterans Administration with respect to the download functionality in my healthy vet which is called the blue button and in Medicare with respect to the My Medicare portal for Medicare beneficiaries, Here the screen is not all that easy to see but I think you can see that there are links to security tips and we have a slide that we explain in more detail, very clear written language that the patient is on notice, that in fact once they download the information, they are responsible for it from this point forward and there is also a warning notice at the bottom. You should be protecting your information and really only sending to safe sites, devices or persons that you trust. The next slide the Miter folks sort of teed up a summary of what the security tips are on the My Healthy site that you can link to. They are pretty common sense but its making sure people are aware of it. Download your information to a safe and secured location; treat your health information like any other confidential information. If you think somebody is accessed your account check your history because your able to check a trail of who's accessed it and making very clear that patient or the person appropriately accessing the account is in control once the data is downloaded. And then similarly, there's a similar set of language that's included with the Medicare blue button initiative. So what we have are some examples of both what the Markle Foundation has done in putting forward a set of simple and deployable policies to allow this to happen and to provide for openness and transparency to individuals in simple way but with a prospect of getting more information. You see an example of how the VA and Medicare have done this for their view and download functionalities that are in practice today. With that I want to turn it over to Paul who is going to lead us into – we've framed some questions for you to consider what some recommendations in this area might look like and Paul take it away.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Sure. We have 2 or 3 questions.

First one is: **Should the Tiger Team recommend transparency requirements related to patients ability to view and download and if so what are those requirements?**

The second question is: **Should those transparency requirements be made a part of the certification rule?**

Another words, you could say that there are going to be some transparency requirements but it's not necessarily part of certification. It could be like best practices or perhaps be part of some other function. So those are the two questions and in responding to those two questions I think Deven did a great job talking about what the Veterans Administration is doing and what the Markle blue button is all about. On the next slide we have some background about the previous recommendations on transparencies. These were not limited to the patients you download which used to be called portal, these are just general comments that we've made in the past. The first bullet is that these recommendations really focused on exchange but it's just helpful background that may be useful to these discussions. We have these core values that we had before. One was patients should not be surprised to what happens to their health information. The second core value was the foundation of trust in health information exchanges still the patient provider relationship. The third core value we had was is that transparency about information exchange practices is a necessary component in establishing credibility with patients. So those are core values that hopefully will guide our discussions. We also made these previous recommendations that may be relevant. One is providers are responsible for being open and transparent with their patients and that also the concept of providers should be providing layered notices. The idea that you can provide some very general notice and a link to a place where one could get more information. I think we saw an example of that actually in the Health EVet notice. So if we go back to the previous slide, these are our questions. The first question is this:

**Should the Tiger Team recommend transparency requirements related to patients ability to view and download?** What is our response to that first question?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

I'll start. I believe so and I think the policy committee has actually teed it up for us to do so. A number of people including folks on this call who are on the policy committee who have expressed concern that patients who download their information don't or may not understand necessarily that in doing so they are sort of moving the data from an environment where its covered by HIPAA and the doctor or hospital or other institution is responsible for protecting the privacy in moving it into an environment where a patient is carrying more of that load and in many respects it's a very different environment. But to do so in a way that isn't intended to discourage people from using it but to make sure that they are aware. And so it seems like it would be – I'm trying to figure out a reason why we wouldn't want to do it because I think it's really consistent with fair information practices.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I agree that these are things that we should be delving into. The key in my mind is if we are going to provide recommendations, I that from an operational perspective to implement these types of things, to make sure that we provide adequate guidance. That may be the wrong way to say it. I almost say we need to make recommendations which are very specific about the substance, the content of what needs to be part of the transparency requirement. I will give you an example: we are finding it more and more that business associate agreements are all over the map because they tell you what needs to be in a business associate agreement, sort of, but then it's up to the interpretation of the covered entity that decides the substance of it. I think it's becoming more and more problematic so I think the more detailed guidance the better off we are.

**David McCallie – Cerner Corp.**

Just for the sake of good discussion, I'll take the opposite point of view. I think any institution is going to do this anyway but they are going to use their own language consistent with their own approach to how

they relate to their patients. I can't see why we need to be so paternalistic as to tell them what common sense is.

**Paul Egerman – Co-Chair and Software Entrepreneur**

David, when you say you take the opposite point of view, are you taking the opposite point of view to the part of what John just said about we should be specific or the opposite point of view to the fact that Deven says we should just not make a comment on this topic?

**David McCallie – Cerner Corp.**

Good question, I wasn't trying to be so precise. I have no objection to a recommendation of best practice along the lines of the granularity of the slides you showed a few minutes ago about our general approach we said to information sharing, no surprises and providers responsible. Other words, that's high level, good common sense written down and forces an institution to think through the issues, I don't have an objection to that. I would object, at least at this stage of my thinking which may change as this call may go on, to the notion that this should be something as a requirement or certification.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So the way we're trying to frame this, and maybe this is too – I don't know what the right word is, but maybe its stifling the discussion, we're saying there are three questions. They are: should we say anything at all? If so, what are we going to say? Is what we're going to say part of the certification? Those are three different questions. So you're answering the third one right now which says you're saying it shouldn't be part of the certification.

**David McCallie – Cerner Corp.**

Right.

**Paul Egerman – Co-Chair and Software Entrepreneur**

If I'm hearing you right. You're agreeing on the first question with Deven that we should say something.

**David McCallie – Cerner Corp.**

I have no objection to saying something. I'm not going to go to the mat to fight for the need to say something but I would not object to that. I think reminding people –

**Paul Egerman – Co-Chair and Software Entrepreneur**

You just might want it to be guidance or best practices.

**David McCallie – Cerner Corp.**

Guidance and best practices, yes, I like those words.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So, I just want to say, is there anyone that thinks we shouldn't say anything at all on this subject? Ok, that means we have an opportunity to continue this discussion. Let's focus in on what we want to say. And then let's talk about what if anything we want to say – what is the public policy level we want to apply to that. So what is it that we want to say? Do we want to just stick with what appears to be in the Markle and Health EVet documents which sort of says you should try to link to security tips, you should provide written language that shifts responsibility, and you should provide some sense of warning. Do we want to say something like that? What should we be saying?

**Neil Calman – Institute for Family Health**

I don't like the shift responsibility piece because I don't think we are actually shifting responsibility. We are not taking any responsibility away from the providers. Basically, we are just adding a responsibility to the patient. Another words, there could still be a breach on the providers side; we haven't shifted that over to the patient side. I don't think you should use the word shift responsibility.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yea, I think the issue is that once you've downloaded it, you deal with it from that point forward as your responsibility. It certainly doesn't minimize or lessen to any degree the providers responsibilities over the data that they steward.

### **Josh LaMeau – Markle Foundation**

The simple mental model here is like somebody giving you a copy of a record that they keep. They still keep their copy but they are giving you a new one. Now, the new one that you have is your responsibility and it's your choice how to protect it, use it, and share it and such like that. So, I guess a couple points on Deven's introduction on why it's a good idea to say something, it sounds like we have consensus on that, one extension that point has already been made, this is something that any sensible organization is going to want to do anyway. There is a transaction happening here, they're going to want to be transparent about what is happening so that the individual making the choice knows what they're doing. It's also something whether we go the best practices route and some statement on that or say that this should be a certification requirement it's a fairly easy thing to implement and certify. I just wanted to mention that the scope of this in terms of certification requirements should be a fairly easy hurdle. I am in agreement to say something like it should address these basic things such as those in the Markle disclosure statement. We actually spent quite a bit of time with lots of different organizations to do this type of thing, refining. It should address points in that but not necessarily that it says the exact same thing verbatim of course because different circumstances are going to be required.

### **Paul Egerman – Co-Chair and Software Entrepreneur**

Very helpful comments Josh. And picking up what you all said, shifting responsibility, that's the expression used in the slides is probably not the right expression because the provider doesn't lose any responsibility just that the patient has some responsibility now. And so the issue that you say is there might be two, three, or four basic things that we want to summarize. So what are those basic things? Unfortunately I don't have control over the slides.

### **Deven McGraw – Co-Chair – Center for Democracy and Technology**

Where do you want to go Paul?

### **Paul Egerman – Co-Chair and Software Entrepreneur**

We'll start with the blue button.

### **Neil Calman – Institute for Family Health**

Paul, before you jump to that, can I throw out another thing that I thought of on this issue that I don't know if this is a sideline or whether it's helpful at all. There are two kinds of things that one would be concerned about if you downloaded your information. One would be that you would leave it on the kitchen table and somebody who knows you would see it and find it. I think if people have confidential stuff, they are probably clearer about safeguarding that stuff. The other is you leave it on the bus or subway or drop it somewhere and someone picks it up and knows all about you. So in thinking about the second part, a major protection comes from just not having someone's name on the information or any identifying demographics. If I'm downloading the record and I know it's about me and I'm concerned about the possibility of leaving it somewhere unnoted, maybe one of the ways of helping people not just understand more about it but actually doing something to protect it at least against the second type of loss would be to give people the option to download information without any identifying information on it. Then if they passed it off to somebody through an email or something, they could add that back on if wanted. But that would cover a lot – who cares if you find something on a subway if it's got a whole lot of information on it if there's no way to identify who it belongs to. It's like finding an ATM passcode but you don't have the card and you don't know who it belongs to. I was just thinking about that and whether or not that's not an option that a vendor would be required to put forward for people that are worried about having their identification on it. They can opt to download the information without any identification on the information that was downloaded.

### **Paul Egerman – Co-Chair and Software Entrepreneur**

That's an interesting idea. Let me put that idea on the side for a moment. As you said, there are two kinds of things you would be concerned about. What I really want to do first is to find out what are the lists of

things we want to be concerned about. What do we want to say about that? And then we can try to address this identification issue. So if you look at the screen here on the slide My Health EVet blue button. They seem to have three categories. They have a links to security tip so that's like a layered notice. This is where some of your comments that Neil just made occur.

**Neil Calman – Institute for Family Health**

Right.

**Paul Egerman – Co-Chair and Software Entrepreneur**

It would be helpful in terms of identification material. It says here, written language shifting responsibility, we want to use different terminology, probably written language perhaps informing the patient of their new responsibilities and they have some sort of a warning. So those are the three types of things that the My Health EVet blue button has. This is a summary of it on the next slide. It says download your data to a safe and secure location – let's go back one. I do have this now Deven.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Ok sorry.

**Paul Egerman – Co-Chair and Software Entrepreneur**

That's ok. Download your data to a safe and secure location, treat your confidential information and this is a warning, remember you are in control of access to your personal health information. The Markle Foundation, I guess it's similar, here are the buttons, download your data to a safe and secure location –

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

This is Medicare.

**Paul Egerman – Co-Chair and Software Entrepreneur**

I'm sorry, this is Medicare. This is all about keeping stuff in a secure place. Where was the Markle one?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

It was before My Healthy Vet.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Ok. There's a provide a quick and clear explanation, prominent links to provide more details, so that's what My Healthy Vet does, independent information that the patient wants to download a copy after presenting a minimum information about the sensitive data. Are there categories of information here that we want to bring forward and say here's the minimum stuff that we want to have happen? Do we want to use the Markle Foundation's? Do we have our own comments about this?

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Can I comment on whether the fact the name be included? Is that ok right now?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Can we hold off on that Judy until we get through the notice?

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Ok, that's fine.

**Paul Egerman – Co-Chair and Software Entrepreneur**

The first part is the notice. What do we want to say if anything? We said we want to say something in this notice. What do we want to say? What are the major categories?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

It sounds like you were describing the ones – there's definitely similarity in all of these. One is a clear statement that the patient is going to be in control of the information once they download it.

**Josh LaMeau – Markle Foundation**

Their copy. I think that copy part is critical.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Their copy. Once it's downloaded it's their copy they are responsible for it. A second category is that includes a link to more information about how best to protect your information. That either tells people that they ought to keep their information confidential and share it only with people they trust or entities they trust that then has a link to additional data. Then maybe the difference in the Markle one is that it actually requires people to take the affirmative step of saying "yes, I really want to do this" and I read the notice or "no, I don't" or "I'd like more information." I don't really see that option as clearly in the My Healthy Vet or Medicare but both of them really include provisions that again make it clear to people that they are taking a copy of their data that is in their control. To some extent they do talk about how it's your responsibility to keep your copy confidential with links to tips. I'm inclined to agree with David that we don't want to specify the actual terms of the notice and say, we must use this particular type of notice. I think it's important to give people some flexibility but I do like the idea of describing a set of required topics that ought to be covered and that the initial notice should be short with links to more information.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So, if I heard you right Deven, I wrote down three bullet points:

- A clear statement that the patient is in control of their copy
- A link to where they could get more information about how they can protect it, steps and tips or something like that
- A clear warning – I'm not sure how its different from the first one – but some sort of a warning perhaps requiring a yes/no answer before download

**Josh LaMeau – Markle Foundation**

I think that's right, that there is sort of a confirmation. Just as your purchasing something on-line and there is a last step that gives you a review. This is what you're doing/do you want to do it/submit. That's the third bullet point that I think Deven was going with.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So, we have this clear statement - #1, #2 – a link where you get more information, and #3 – a warning/confirmation step asking is this what you want to do and I understand this/I want to do this.

**David McCallie – Cerner Corp.**

I'm comfortable with the first two, the third one seems to me to be overly prescriptive and might preclude certain models where the consumer perhaps requests establishment of an automatic channel that might be made available at some point in the future. Like as encountered data about my meetings with my providers are available please automatically send a copy via secure direct email to my PHR and here's my address, I authorize this, click. I don't think we want to put prescriptions in how a user interface behaves. We are just arguing for a reminder to the patient that they are now responsible for protecting the confidentiality of their copy of the data. Then, let's let innovation figure out the best way to make this a pleasant experience for consumers to do in large volumes.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Ok, so I want to make sure I understand what you just said David. In terms of the clear warning and confirmation, would you say that should be a best practice that should be something that shouldn't be there at all? That should be a clear warning without a confirmation?

**David McCallie – Cerner Corp.**

I like a best practice statement and is suggested that the consumer confirm at least once. I think I would say something like that.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes.

**David McCallie – Cerner Corp.**

That they are accepting responsibility for protecting the confidentiality of their copy of the data. But I wouldn't want the notion that every time you download something you have to go through something like the iTunes [ula](#), all 75 pages of it to download the latest version.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Well, that's a good point. So, the comment is to confirm at least once and – I'm trying to understand – you view the clear warning as redundant with the first two statements? Or do you think it's a clear warning and a confirmation at least once? Do those two things come together?

**David McCallie – Cerner Corp.**

Well, I hate to even require the at least once. I'm taking the people – the lawyers of the institution's employing these services will ensure that appropriate confirmation is captured no matter what we say. I'm just saying no more than once would we even think of requiring confirmation as a policy level statement. Individual institutions can make it as tortuous or as easy as they want. Our goal in the long run is to make this easy and useful so that more consumers will in fact leverage their health data to improve their health.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes.

**David McCallie – Cerner Corp.**

We don't want to make this scary or odious.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes, and I think that –

**Paul Egerman – Co-Chair and Software Entrepreneur**

The comment about at least once is very interesting. Do you want to apply that to only the clear warning? The third one or is that the first two bullets also?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

On that point can I ask Josh a question? I feel like this came up...

**Josh LaMeau – Markle Foundation**

Yes, many times.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

I can't remember how it got resolved. It might be helpful allowing us to resolve this.

**Josh LaMeau – Markle Foundation**

Great points by David and they did come up when we went over this. The VA and CMS were part of our collaboration when we put out the recommendation they implemented. We avoided the term warning. We basically said independent confirmation for the most part. We definitely didn't intend it to be each and every time. The point is at the decision making moment the person has a concise explanation of the implications of the choice they are making. The choice could be a onetime download or it could be setting up automatic downloads that happen subsequently until changed. The idea here, like any on-line transaction of import, you usually have a confirmation step and I agree that we don't have to be too prescriptive about it, but it seems like having a general policy statement or even a certification criteria that there is a transparent process that by which the individual confirms the transaction or transactions if something that the supplier of the download out to be able to show. And certainly any institutions transactions this data is going to want to consummate online in an easy way. So I agree that maybe there is some combination here where there is some basic criteria along these three bullet points if that's what we agree to that are part of certification criteria and then there could be some supplemental statement on best practices organizations could consider things like some of the other ideas we –

**Paul Egerman – Co-Chair and Software Entrepreneur**

I want to make sure I understand this. What I've got in my notes and tell me if I've got this correct Josh, David and Deven, is:

#1 – a clear statement that patient is in control of their copy

#2 – links to where they can get more information

#3 –

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

#3 – independent confirmation of the transaction or transactions being authorized

**Paul Egerman – Co-Chair and Software Entrepreneur**

Now, what do you think of those three?

**David McCallie – Cerner Corp.**

I really get concerned when we talk about taking these three to be something that missed then has to go right certification –

**Paul Egerman – Co-Chair and Software Entrepreneur**

We're not at that point yet.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes, we're not at that point yet. We don't want to do that. I think we do need to have a discussion about how we policy forward. I agree.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Where we are right now, I just want to say what do we think our recommendation ought to be? The next question is going to be how much muscle do we want to put behind that recommendation?

**David McCallie – Cerner Corp.**

So let me play devil's advocate. Wouldn't it be equally important to have a bullet point that says this information that you are about to receive is very powerful, please use it to improve your health by making sure your other providers have a copy of the data, making sure that you understand the implications of your health plan. Another words it sounds like we're trying to be the nanny here. The goal is to get this information liquid. Why are we putting all these fearful things in there instead of putting all the good things that this data can do for you.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I think the answer to that question is you don't know what you don't know and I think for all of us doing this for the right motive and the right intent are there going to be circumstances where organizations or individuals aren't completely transparent with respect to everything that they might use the data for or issues associated with the proposed download. I can't give you a specific example but are there things we need to be fearful of that maybe we haven't thought about?

**Paul Egerman – Co-Chair and Software Entrepreneur**

Your comment David is interesting with compare to several months ago I had a very minor medical procedure and I had to sign like three pages of what's called informed consent. It told me about all the infections and all the things I could get from this procedure. Nowhere in it did it say why this would be good for me to do this thing and that's unfortunately the way our health care system works these days.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

I also don't think there's anything that we would do to stop an institution from promoting this but since we are the Privacy and Security Tiger Team, we do understand in fact we are talking about two different policy environments in terms the one that governs the health care institutions where these patients will be getting data and the one that governs the world they share it with outside of the health care system. Essentially the idea here is not to scare people and maybe that needs to be part of our recommendation to make it clear that it isn't about scaring people but about making sure they understand that when they get a copy of their record, that there's a transfer of some responsibility in terms of when it's in your

possession its really up to you how private and secure you want to keep that data. I totally agree and so if creating a notice an entity put a positive spin on it, I think that would be great.

**David McCallie – Cerner Corp.**

I like the fact that the Markle thing is in a nice friendly green color instead of a red color.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Right, with a skull and crossbones on it.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So, here's the way I'm trying to incorporate this comment. To say in our recommendation there should be an introductory sentence that says the purpose is not to frighten people, it's not to dissuade people, it's simply to be transparent so people understand the responsibilities and that we should make that clear statement of an introductory statement and then we have these three things. We have a clear statement that the patient is in control of their own copy, there are links to where the patients get more information and there is an independent confirmation of the transaction or transactions.

**Neil Calman – Institute for Family Health**

Can I throw in my two cents? I think we are looking at it like lawyers instead of life providers. To me it should be one sentence. It should say by downloading this information, please protect this information; it has important information about you personally. Boom! End of story. We don't have to do a whole disclaimer when someone gets an ATM code. There's a certain amount of logic here. If someone is printing something or holding it in their hand, they know that its vulnerable and basically what we're doing is putting one sentence out there saying just remember that you have it. I think this whole business about your responsibility, my responsibility, that's all the legal stuff that's not what we should be doing putting out there for people. I think we should just be telling people that this information you're getting on a device or printing is only as secure as you keep it. Please be careful with your health information. Period. It shouldn't be a legal document and I don't think it should require somebody to do an electronic signature that they've received it. I don't think we need all kinds of disclaimers and everything. I think we are just trying to be friendly to people and remind them that this is sensitive information.

**Josh LaMeau – Markle Foundation**

I agree with that and one of the reasons we spent some time in our collaborations with about 40 different organizations to show that we could come up with some examples and fairly friendly language, but at the same time we do have to recognize there are a lot of web users out there that have no idea the difference between the desktop and the web is. Really, they really don't. So, it's sort of a balance, the spirit is that you're not trying to scare them but at the same time you want them to know the implications of the transaction; what is actually happening. To the comment about we should be promoting this, I think we should look no further than the implementation of the blue button by the VA. In order to get to the screen where you do confirm the transaction, you view the advantages of why you'd want to do this; what's the advantage. It's certainly not mutually exclusive. It's simply the question, can we make a reasonable policy statement that makes sure that implementers think about this issue that they are going to want to do anyway and keep it simple and not use words like warning or use long scary -

**Paul Egerman – Co-Chair and Software Entrepreneur**

I think we all agree what we don't want to do. We don't want to have one of these things where we all know. When you're trying to do something on the internet or I have a car that does this on the GPS system or you get [indiscernible] and you've got to punch I agree before you can move forward. You hit the I agree button because you don't have time to read the damn thing. Right? It's frustrating and you see that all the time. That's what we don't want to do. I think we all know that and I think Neil's comment is excellent and I think Josh you are agreeing with that and what we want is simple non legal language. I don't think we can do it all in one sentence, but if we opt for three sentences, it's something short and brief and its gives us information in a non-legalistic way.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

I agree with you Paul that that should be our example. But our experience as patients download their information is, almost all of our – even though we send what we think is reasonable standardized text out, most of the health care organizations do rewrite it in their own words. So, keeping that flexibility that David mentioned earlier is still important.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Well, I think that's right. That feedback is also critically important. It might help us seg-way into the format of this recommendation. In other words, how descriptive are we going to be? How much muscle are we going to put behind our recommendation? But first I want to find out at least if there is – I think we are spiraling in on something. I'm not sure we are but the sense is we are not trying to scare patients, we want to have a brief statement and it should include the three components that we just described. The statement that patients are in control of their copy, that there is some link or place they can go to to get more information so it's a layered notice, and there's an independent confirmation of the transaction or transactions. All of that done in a simple fashion. Does that work? Are we in agreement on that?

**David McCallie – Cerner Corp.**

I think that's workable and I would like to see the words.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes, we'll have to work with the Miter folks to work it up but I think conceptually we are starting to coalesce less around a workable idea.

**Paul Egerman – Co-Chair and Software Entrepreneur**

If that's our workable idea, and I'm eventually get to the comment that Neil and Judy want to talk about, about ID, but first I want to talk about what I call how much muscle do we want to put behind this workable idea? Is this a best practice, is this guidance, is this certification criteria? Where do we want to put this?

**David McCallie – Cerner Corp.**

I'll come back in since I inadvertently jumped ahead before and restate after thinking about it now some more that certification of the download capability itself may in fact be very desirable but certification of language cautioning the consumer is probably going too far.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

I'm not disagreeing with you at all because it has felt to me from my initial thoughts on this issue that it makes no sense to ask people or to require vendors to certify to a specific statement. I'm wondering whether – and maybe the answer to this is no – but I'm wondering if there is a demonstrated capability of showing a notice to patients that meet this criteria is something we could ask for and/or whether an additional way to get through this is maybe through the meaningful use avenue that as part of this view and download capability you have to attest that you have employed a mechanism of transparency to patients that meets this following criteria.

**Paul Egerman – Co-Chair and Software Entrepreneur**

The other alternative could be – I was picking up on what Judy said – that her experience is that the providers alter whatever the message is.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Right.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Maybe the idea is to say well the certification criteria should be that there's a message and the provider's can alter the message. So the providers can write their own message. There is a starting point language but providers can change it where they see fit.

**David McCallie – Cerner Corp.**

What I worry about is 10 pages of federal registered small print defining what this notice is, what font it has to be in, how many times it has to be showed, whether it's on the same page or a separate page. I mean you just know how many questions will come back of, does this qualify, is this sufficient?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes.

**David McCallie – Cerner Corp.**

I just think our institutions are going to do this and there's no way they wouldn't do this. This is releasing of PHI and they are going to bend over backwards to be incredibly careful about how they do it and I just think we're going to be telling them stuff we already know but will now put it in 10 pages of fine print.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So, what I'm saying is maybe another way to approach it is maybe you can have best practices or guidance and what a notice should look like. The certification criteria could be that providers could insert their own notice.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

That's what it should be.

**David McCallie – Cerner Corp.**

If we go even that far maybe. Cause then you'll say where does the notice have to be? Is it once or every time they download; is it every item they download? Somebody will ask those questions and somebody will have to write certification criteria to answer those questions and then we'll have 10 more pages that won't add value to the enterprise of what meaningful use is about.

**Paul Egerman – Co-Chair and Software Entrepreneur**

What do you think Judy?

**Judy Sparrow – Office of the National Coordinator – Executive Director**

It makes me think of the pharmaceutical ads on magazines where you have the ads on the front page and back page and you have a whole page.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes, we don't want that.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

I think that's what we're really trying to avoid.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Yes.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I hate to play devil's advocate and you can tell me if I'm crazy because Deven does periodically.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

I'm not the only one.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I think all of us and I agree in principal that we all want to do the right thing and all of us are in good faith trying to do the right thing and I'm trying to think of the scenarios where things go wrong. The one story I could think of where something could go wrong is when you end up with some type of intermediary, third party that's going to do this on behalf of a covered entity and they end up inserting or compelling some type of compliance with a set of terms that they have developed which allow them then to use the data for some other purpose or god only knows what they might try to interject. I think from my perspective, there's a defensive component to this for the provider so that we can find a third party that might get

involved in this transaction, allow them to insert themselves into the transaction in a way that either compels the patient to do something or does something that the patient doesn't even understand it's happening. I see so many scenarios where this type of stuff happens or vendors try to do things. I'm a little cynical, I hate to say it.

**Paul Egerman – Co-Chair and Software Entrepreneur**

John, that cynicism, does that translate that you want to be more prescriptive with these warnings? I'm just trying to understand. I hear the cynicism but where I missed you was what does that cynicism lead to in terms of this discussion?

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I guess I would think that as long as David's point, as long as you're within a certain sort of bounds. I think we need to try to engage our patients in a way we think is appropriate and to the extent that we think is appropriate, I'm just worried about once you get outside this certain set of bounds, should there be an additional set of requirements associated with disclosure and downloading of information. I'm not sure other than that – once you go over bounds there has to be something else there. I just see more and more some of the vendors that are out there, not Judy's epic reigning, but in general, they try to impose upon the providers additional criteria that providers frankly doesn't want to obligate themselves to but they're almost compelled to in a way.

**Paul Egerman – Co-Chair and Software Entrepreneur**

What you're doing there is you're reflecting your experience with the business associate agreements.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

Yes, I am but I also see other contexts too and the business associate agreement is just one of them. As much as I want to make this transparent and easy for the user, I also want to make sure that we don't end up in an environment where by things happen or that are unintended and that this ends up causing more bad press –

**Paul Egerman – Co-Chair and Software Entrepreneur**

So do you fear that if we aren't prescriptive here some vendor will put in something that will allow activity that you think is inappropriate?

**John Houston – University of Pittsburgh Medical Center; NCVHS**

That's correct and then again maybe if we stay within a particular set of boundaries, everything can be as simple as what we discussed but if you get beyond the boundaries then that's where there has to be much more active communication, more description of what these other potential secondary uses and the like might occur as part of these processes.

**David McCallie – Cerner Corp.**

You're actually looking for a proscription against other actions happening to the data rather than strengthening the warning to the consumer. You're saying that the delivery of this download shall not be diverted to purposes other than giving the consumer a copy.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

Yes, thank you for saying something I couldn't figure out how to say.

**David McCallie – Cerner Corp.**

I wonder if that's within our scope.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Yea, I don't know how you do that.

**David McCallie – Cerner Corp.**

That's a HIPAA violation of some other kind or –

**John Houston – University of Pittsburgh Medical Center; NCVHS**

The patient authorizes it not knowing any better isn't a HIPAA violation.

**David McCallie – Cerner Corp.**

I see what you're saying. I got you. Sneak a covert operation into the download.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Yea, like the 73 pages you have to click I agree to.

**David McCallie – Cerner Corp.**

Yes, that's a very interesting point John.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

John I actually agree with you that there are some risks here. Along the lines of the point that someone just made, there's so much discussion I lost who said it, that dealing with this should not necessarily be in the notice to individuals although maybe in some of the detail about the potential risks but as we discussed when we went over transparency as a separate topic not related to view and download, but transparency in general, the longer a notice gets in terms of its level of its comprehension and covering risks, the less effective it is. So, on the secondary point of whether we want to say something about not allowing the view and download capability to become the portal through uses and disclosures that ought not to be permitted end up occurring because the individual has authorized them through a single authorization that isn't really well understood, I think there's a couple of things we could say.

1. Authorization to download should be limited to downloading the information. Quite frankly what the patient does with the information from that point forward is another kettle of fish.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I'll give you an example I'm just thinking of –

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

John, I'm not done.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I'm sorry....

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

2. Secondly, we have already said that the providers are responsible with how they share their data. They can use intermediaries or other entities in some circumstances to do this if they do so in a trustworthy way. This goes back to our summer letter that dealt with consent that had all these really good statements in it as well. And then ultimately the provider if they're going to delegate functions to another entity really does have to do so in a way that is really trustworthy. I'm not in disagreement with you that the business associate agreement creates a power dynamic that always doesn't put the provider in the right amount of control. But quite frankly, I'm not sure we have a better vehicle for dealing with this right now.

**Paul Egerman – Co-Chair and Software Entrepreneur**

I think those are all really good comments. I think we also need to stay focused. We're simply talking about view and download. We're talking about the download capability. This is really the patient's ability to download their own data. That's what we're limiting ourselves to at this point and time.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

On the provider side, I guess that does leave very little risk and maybe the scenario that occurs like, go buy myself a new iPhone and there's a new app that allows me to download my E-Healthy Vet record to my iPhone, not realizing when I click on it, by doing that I am now exposing all of my data to whoever developed that application.

**Josh LaMeau – Markle Foundation**

It seems like we don't want to preclude the ability for people to share their data with their iPhones. They might derive a great deal of value from something like that. It's more that when the individual is at a decision making step that they understand what the decision is.

**Unidentified Individual**

I agree.

**Josh LaMeau – Markle Foundation**

It's readily available and not hidden. That's basically the general policy guidance it seems like we want to make. That applies to one transaction or setting up on-going transactions or it applies to transactions for the information going from the covered entity going to the individual or to the covered entity to a third party. The basic principles of consent are there and they apply to the download. To get at John's point, the idea was raised earlier, should the vendor that's providing this functionality be able to show that they have the mechanism to provide the information to the individual and I think our wording should be flexible enough so if they want to show it in video as opposed to or in addition to brief text, that should be fine. The question was should the provider be able to customize that? -

**Paul Egerman – Co-Chair and Software Entrepreneur**

Well, there was a question before that which is what is the format of our recommendation? Is it just guidance or is it best practices? Is it certification? Is it certification with the ability for the provider to customize? But we need to decide if we're going to use certification or meaningful use public policy levers around this recommendation.

**David McCallie – Cerner Corp.**

As we sit here and talk about these things, I'm thinking of several alternate ways than just a quote unquote download. I wonder if the notion of download itself is too prescriptive.

**Paul Egerman – Co-Chair and Software Entrepreneur**

But we have to focus on the download right now because we're under the assumption that that will be included in stage 2.

**David McCallie – Cerner Corp.**

Yes.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

I'm going to agree with David. Another way to do it is not download it but simply have a view that to the reader they can't tell the difference between whether it's downloaded or it's residential to their iPhone. It's a view, it's the same thing but much safer. To say that you have to download it when in fact when there are other alternatives that may be safer might be a mistake.

**Josh LaMeau – Markle Foundation**

I used Kaiser's PHR and I would have liked to be able to easily download what was in it when I left Kaiser before I left because I can't get in there anymore and get my immunization history.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

You should be able to Josh. It's called Lucy.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Yes, and in response to what you're saying Judy is, yes, the way stage 2 meaningful use is being proposed there's two functions: a view and an optional download.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Yes, I like that as an optional because the view doesn't –

**Paul Egerman – Co-Chair and Software Entrepreneur**

And to be clear, what we are talking about is what messages would occur related to that optional download.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

The download will not be a requirement. You can get around it as David suggested with other ways.

**Paul Egerman – Co-Chair and Software Entrepreneur**

That's correct. So, if you optionally choose to download, then what is the messaging that occurs?

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Ok.

**Paul Egerman – Co-Chair and Software Entrepreneur**

And so we have this concept that the messaging is clear and simple and has three categories statement that if you download you're responsible for your future there are some links to get more information and there are some independent confirmation of transaction or transactions. But it's only for the optional download. So the question I have is if we're going to do certification around the optional download to make sure that that option exists, so we also want to do certification around this message? Another words do we want to make sure that there is a confirmation step? Do we want to make sure that providers can edit the statement? Or do we want to say nothing about that from a certification standpoint and just do this like best practices and guidance?

**David McCallie – Cerner Corp.**

Given this is such an unexplored territory; I would again come back to guidance at this level. We risk over specifying if we put it into language of certification.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

David, suddenly my mind went back to interactions when you made your comment about how requiring certifications so often gets turned into pages and pages of specs reminded me of some of the minimal interactions I've had in that context. From a technology side it feels like the need to specify is almost like in the genes. I certainly want to avoid that but let me just ask one question before we let this go. Is there a possibility that a provider would want to create such a notice but the lack of a certification requirement for their EHRs might result in their not being able to do so because the technology can't accommodate it? Is that a possibility that we potentially have to address?

**Paul Egerman – Co-Chair and Software Entrepreneur**

What your question suggests would be, should we say simply that there should be a certification criteria that allows a provider to write their own notice whatever it might be? And it so happens to give guidance on one way of doing that.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

I think there should be a criteria that the software needs to be able to support the provision of a notice as well as tracking of the users acceptance of the notice.

**David McCallie – Cerner Corp.**

Oh, now you've got another –

**Paul Egerman – Co-Chair and Software Entrepreneur**

Let's do it one at a time. Should there be certification criteria that says just a notice without saying what the content of it is in order to accommodate what Deven suggested?

**David McCallie – Cerner Corp.**

I'd say best practice.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So you'd say no to that then David.

**David McCallie – Cerner Corp.**

Correct, I would say no.

**Unidentified Individual**

Yes, I would say no also.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Anyone want to say yes?

**Unidentified Individual**

Ask the question again?

**Paul Egerman – Co-Chair and Software Entrepreneur**

The question is, should the certification criteria say a notice has to be provided prior to this optional download and the provider can write the text of that notice? That doesn't say what the content is but just says there has to be a notice and the provider can write the text.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Are people going to get confused as to what a notice means?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Well we've laid down some specifications. It comes with the entire package of what we've been talking about but my only concern and maybe this is best addressed by you and David as vendors, are providers going to have an issue if they want to provide a notice, given that we leaning towards best practice, and then have a vendor potentially tell them, well we can't technically make that happen?

**Paul Egerman – Co-Chair and Software Entrepreneur**

I'm a vendor, I implemented it and if the patient wants to download, they push this button and the data downloads and that's that.

**David McCallie – Cerner Corp.**

Vendors don't respond to client requests like that by consulting certification criteria. It's not very likely that that would happen. In this case something as trivial as this, I don't think it's really likely. Judy may feel differently but –

**Judy Sparrow – Office of the National Coordinator – Executive Director**

I agree with you David. I think it's pretty trivial. I mean there's a possibility a vendor may say either it's too hard or I don't have the time. It's pretty trivial.

**David McCallie – Cerner Corp.**

There are other vendors to pick from.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So it's sounds to me that we are coming to a conclusion that we defined this notice as best practices and guidance and does not require certification. Am I understanding the consensus correctly? Anybody disagree?

**Josh LaMeau – Markle Foundation**

We're describing this as trivial which I think everybody agrees to but the concern about the certification criteria is will the people writing it go crazy and get over specified? That's the general concern I'm hearing. Is it still trivial if all the certification criteria said is that the provider providing this patient portal view option to download is able to customize a transparency message for the decision making point the patient to download? David and Judy it sounds like what you're saying is they could take that little idea and run with it too far and become overly prescriptive. Is that the concern?

**Judy Sparrow – Office of the National Coordinator – Executive Director**

I don't have a concern that way. I think that they will be reasonable.

**David McCallie – Cerner Corp.**

My concern is what we're describing here is we are calling it download but it's really export. The different ways in which one could set up a process to export your record from a provider system into your designated target which might not be your PC, it may be a service is complicated enough that once somebody's starts writing certification about where they expect to see that notice, it's going to get all tangled up in legalese that doesn't achieve much. No provider system is going to allow something like that to happen without an appropriate notice displayed in an appropriate place in the workflow anyway. So I don't think we need to go out of our way to certify that they are going to do something that we know they are going to do. What we have done is to give them a reminder that best practice says that somewhere along the way the consumer should be reminded that the fact that they are now responsible to protecting this health information, this copy of the health information. That seems reasonable as a best practice but to go beyond that just invites more rounds of questions with ONC authorities and clarification sessions and the like on a subject which isn't as important as many of the other areas where we should be spending our time.

**Josh LaMeau – Markle Foundation**

Thank you, that's a really articulate response. I appreciate that.

**David McCallie – Cerner Corp.**

Thanks, I thought that was inarticulate.

**Josh LaMeau – Markle Foundation**

It made a lot of sense.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

The other thing that occurred to me in that explanation where you were more articulate than you thought you were is that often times when we make a specific ask in certification it's because we want things to look the same. We have some very specific interoperability criteria and that's not always the case but we really don't necessarily want to create that kind of an expectation here and so maybe best practice is the way to go. One option we have is to say – we're not that close to the end of the call, but we're getting there, is to sort of sit on this, but assume we're heading in the direction of best practice because we're not looking for a one size fits all notice and we think that in general providers will want to do this and that the vendors will respond to this in kind particularly as we put out best practice recommendations that scope out what we think it ought to look like and their certainly are examples in the marketplace from Markle to My HealthyVet to my Medicare to whatever Kaiser does with their PHR that can be helpful to people creating their own.

**Paul Egerman – Co-Chair and Software Entrepreneur**

I think that's fine. It seems like we have one of these rare moments of agreement. So what we need to do here is write it up to find out if we really have agreement and circulate that to everybody and then if we do we'll present it to the Policy Committee. I want to get to Neil's last issue. Does that sound right in terms of what we're supposed to do with slides and everything?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

We would take time on the next call which is July 22 to go through the wording –

**Paul Egerman – Co-Chair and Software Entrepreneur**

And that could also give us another chance to look at it as a whole to see if – because sometimes when you look at these things as a whole there's a total picture and you start to view it a little bit differently. I think that's fine. I'd also turn because we have a few minutes, to the topic that Neil raised about the patient identification in the download. Judy, do you have a comment on that?

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Yes, just a couple comments. One is that what the Healthy Vet uses I believe is just a text download. What vendors may want to use is the CCD download. It's useful because it's both standard and it is up loadable. CCD does require a name. As we talk about this we should – if we think about removing the name we have to realize it isn't part of the CCD requirements.

**Paul Egerman – Co-Chair and Software Entrepreneur**

What will be part of the certification criteria probably will be the exact format of what this download will be and it will probably be CCD. It might be CCD with what I would call a P-cast style wrapper. Meta-data that describes the patient and describes providence also.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

I think it would also include the CCR right?

**Paul Egerman – Co-Chair and Software Entrepreneur**

It might. It's hard to predict. Most likely there will be a specific format or maybe more than one format and most likely I think that format will include the ID because it has to.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

My point is just to keep that in mind as we talk about that. The second point I'm thinking if you have a few kids, you as an adult – ok here's my record without my name on it but I can see danger if you have a few kids and you get mixed up on which one is whose. You bring that into the next doctor thinking you have the right thing on that kid and you have the wrong handout.

**David McCallie – Cerner Corp.**

I'll weigh in to. I don't like the idea of stripping the name out for the simple reason that the power of these documents downstream will come from the trustability that it is in fact an unforged document. If you have excerpted the name, no one is going to trust it. That's what provinaunce is all about and the digital signature and the P-cast header is to validate that it hasn't been tampered with which would include of course the names being there. I think in the long run the name is better. What I would suggest as an alternative might be, and I'm not saying this should be a certification point but, you could provide the consumer with the option of downloading an encrypted version of it. The consumer just puts in a password to the blue button site and its encrypted before it even hits the hard drive of the PC with the consumer selected password. Options like that are possible if we want to –

**Paul Egerman – Co-Chair and Software Entrepreneur**

That's a good comment but as I think about this discussion haven't we actually changed topics a little bit? Our topic really was this transparency notice when you do this optional download. And what we're really talking about now is different techniques to make the download a little more secure. That's an interesting topic but that's a different topic.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Right and in many respects we may have already teed up that issue for the Standards Committee because we do have a recommendation that patients be able to download securely.

**John Houston – University of Pittsburgh Medical Center; NCVHS**

Those topics are almost surrogates for what you need to put in a notice because if you can do it secured maybe you don't need to provide such notification.

**Paul Egerman – Co-Chair and Software Entrepreneur**

So the subtotal here Neil is I don't hear a lot of enthusiasm for what you're suggesting. Do you have any comments?

**Neil Calman – Institute for Family Health**

No, I don't have a vested interest in pursuing it any further if people don't think it's a good idea.

**Paul Egerman – Co-Chair and Software Entrepreneur**

I don't necessarily want to say it's not a good idea but I do think it's a different category. It's trying to make the download more secure and I think there are some ways one might be able to do that but it turns out to be tricky. It's one of these things when you start doing it whatever you suggested it was a good idea there are 20 different reasons why it's not a good idea.

**Josh LaMeau – Markle Foundation**

It may be a good idea in some circumstances and not a good idea in others. Among the many things that people consider to make this secure that could be on the list of things that they consider. One quick aside on the question of what format the download should be in. I know if Carol were on the line she would jump in now so I'll try to impersonate her. Our working groups at Markle have a lot of people participating are recommending fairly strongly that the download format be human readable text, not necessarily CCR or CCD. If it's available in CCR or CCD then the individual ought to have the option to download it in that format. Human readable text I'm sure is one of the standard committee rules.

**Paul Egerman – Co-Chair and Software Entrepreneur**

And to be clear Josh the wording that's in the proposed stage 2 is view and download. The view is human readable. The download is what the standards committee has to describe so it could be text it could be CCD it could be CCR. I don't know what it's going to be. That's not within our scope right now to define that.

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

I think the letter from the policy committee on the view and download capability actually had some human readable – I think they addressed this already but we can double check it. I don't have it in front of me right now. I think that was part of the recommendations that have already gone through on the view and download that came through the policy committee through the meaningful use workgroup.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Let's circle back to the questions on the screen for the view and optional download. Do we feel we've answered these questions? Does anybody have any other comments?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

I think we need to wordsmith for folks to feel comfortable but again it feels like we coalesced around some consensus concepts.

**Paul Egerman – Co-Chair and Software Entrepreneur**

Terrific. Unless anyone else has to say maybe we should see if the public has anything to say.

## **Public Comment Received During the Meeting**

No comment at this time.

**Judy Sparrow – Office of the National Coordinator – Executive Director**

Thank you operator. Now Deven and Paul?

**Paul Egerman – Co-Chair and Software Entrepreneur**

Thank you very much Judy Sparrow as always your help in organizing this call and thank you to all the members on the workgroup for a terrific and articulate discussion on a Friday afternoon. Before we shuttle off to our weekend activities Deven do you have anything else you want to add?

**Deven McGraw – Co-Chair – Center for Democracy and Technology**

Nice closing Paul and everyone enjoy your weekend and chat with you in a couple of weeks.