# Privacy and Security Tiger Team
# Draft Transcript
# July 22, 2011

## Presentation

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Thank you very much. Good afternoon, everybody and welcome to the Privacy and Security Tiger Team. This is a federal advisory committee call, so there will be opportunity at the end of the call for the public to make comments. Let me do a quick roll call. Deven McGraw?

**Deven McGraw – Center for Democracy & Technology – Director**
Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Paul Egerman?

**Paul Egerman – Software Entrepreneur**
Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Tony Sweeney? Gail Harrell?

**Gayle Harrell – Florida – House of Representatives**
Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Carol Diamond? Judy Faulkner?

**Judy Faulkner – Epic Systems – Founder**
Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
David McCallie?

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Neil Calman? David Lansky? Dixie Baker?

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Micky Tripathi? Rachel Bloch? Alice Lighter or Christine Bechtel?

**W**

Alice is coming on. She's going to be late.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Right. John Houston?

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Wes Rishel? Leslie Francis couldn't make it today. Lisa Tutterow?

**Lisa Tutterow – Office of the National Coordinator – popHealth Principal**
Here.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Vern Rinker? Did I leave anyone off? Okay. With that, I'll turn it over to Devin McGraw and Paul Egerman.

**Paul Egerman – Software Entrepreneur**
Well, thank you very much Judy, and thank you everybody for participating in our call. We are the Privacy and Security Tiger Team, which is organized under the HIT Policy Committee to address certain, specific privacy and security topics. And what we're going to be talking about will be completing our discussion about view and download transparency recommendations. And we sent out to the Tiger Team members a written document, and I think we also have a PowerPoint presentation that has the same materials in it.

Deven, did you want to say anything, or do you want me to go through the Power Point presentation?

**Deven McGraw – Center for Democracy & Technology – Director**
Yes. Why don't we go ahead and go through the PowerPoint. The letter provides the framing about why we're coming to the decision that we're coming to. The slides really drill down on what are the specific recommendations that we're teeing up, given the discussion that we had last week about moving to best practices versus a certification standard.

And we just need to wordsmith those best practices. So I think what we want to do is get through that wordsmithing today, and then we'll be good to go for the August meeting.

**Paul Egerman – Software Entrepreneur**
That looks good.

**Deven McGraw – Center for Democracy & Technology – Director**
Again, we do have in the letter some text, which I didn't put on the slide, but of course we certainly can tale about any and all of it, but the letter really does lay out nicely the background, including the view and download recommendations from the Meaningful Use Workgroup that were the catalyst to our having this discussion in the first place.

And we also talk a bit about the nationwide privacy and security framework principles that apply here, as well as some of the core values and recommendations we've identified in the past that are relevant to the approach we would take here.

And the letter also notes that we reviewed the policy brief on the Blue Button initiative that was prepared by the Markel Foundation, and that we also looked at examples provided by the VA for the My HealtheVet view and download capability, as well as Medicare's capability. We took a look at how that was handled.

And ultimately again, we spent some time discussing whether there ought to be a certification requirement, and the letter identifies that we understood the appeal of a requirement, but we really thought that providers would want some flexibility with respect to the type of guidance that they would provide, and that requiring a standard might result in some over specification or create an unintended inflexibility.

And so the best practice guidance, as you'll see on your slide, is what we've tried to wordsmith here. And essentially, we're asking for providers who are participating in the Meaningful Use program—want them to offer patients clear and simple guidance regarding the use of the view and download functionality that is in stage 2. Such guidance should be offered at the time the patient indicates a desire to download the electronic health information, and at a minimum should address, really, the following three items—and we could also say three categories it occurs to me.

So reminding patients that they'll be in control of the copy of their medical information that they've downloaded and that they should take steps to protect it in the same way that they protect other types sensitive information. Including a link or links to resources with more information on such topics such as the download process, and then how the patient can best protect information after the download. We saw that in all three examples that we viewed. And then obtaining independent confirmation that the patient in fact wants to complete the download transaction or a series of transactions, if in fact there are a number of them that can be accomplished at once.

And then we also are suggesting that providers could review the Markle Foundation policy brief and the guidance provided to patients as part of the My HealtheVet Blue Button and Medicare Blue Button for examples of guidance provided to patients using view and download capabilities.

So that, again, was our attempt to capture what we thought we had reached consensus on our Tiger Team call of just a couple of weeks ago. And so with that, I want to open it up for discussion.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Deven, I have a question.

**Deven McGraw – Center for Democracy & Technology – Director**
Yes. Hi Dixie.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
And I'm sorry I didn't make that last meeting. I was having a little vacation. There is also risk in viewing the information from your desk at work or something like that. What was the basis for deciding not to give these kind guidance until they choose to download it versus when they choose to view it?

**Deven McGraw – Center for Democracy & Technology – Director**
You know, that's interesting. And it may be just the way that we've framed—that's an interesting question, Dixie, and it may just be the way that we framed it, and we may need to wordsmith that. In each of the examples that we saw from Markle—I'm trying to think of when the information popped up. Certainly when the patient is taking control of the information through the download, that's when the responsibility—there's a responsibility shift that occurs there, whereas if the patient is logging in to a view

and download where that information is still behind the firewall of the institution who's offering the capability, or the healthcare provider who is offering the capability, that transaction hasn't really occurred.

And so we have focused, now that I think about it, on the download. I'm not sure I understand—given that the patient is going to be identity-proofed and authenticated into a view and download when the data is still in the EHR—what the risks are.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Well the risk—and we actually encountered this way back in the Picasso Project—is that people need to understand that when they choose to view it, it's their responsibility to make sure that, for example, they don't leave it on their laptops where … come by, or they don't view it at work and then—you know, it's their responsibility if other people see it as well.

**Paul Egerman – Software Entrepreneur**
That's interesting. Do other people have any comments about this?

**Gayle Harrell – Florida – House of Representatives**
I would absolutely agree with Dixie that the warning needs to be actually before they open the package and look at the package.

**Paul Egerman – Software Entrepreneur**
One of the things that was pointed out after we did our letters—one of the people at MITRE pointed this out—was the Markel recommendations actually suggested warnings every step in the process, and I wonder if this was the reason why?

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Yes. That's a good idea, actually.

**Paul Egerman – Software Entrepreneur**
Yes. So that you could say a best practice is to provide some warning if you're viewing and a separate warning if you're about to commence the download. Because Dixie's comment is correct. The way I understood our discussions, we really focused on the download. And we viewed downloading as not meaning the same thing as view, where you're view is a separate function.

And so what Dixie is suggesting is that there should be some best practice notice about the view also.

**Judy Faulkner – Epic Systems – Founder**
Well, and I think that anybody who has e-mail already knows that you don't bring an e-mail up that you know is going to have something on it that you don't want everybody to see—and leave it there. So I'm wondering if we're at a stage now where it's more like being told how to put on your seatbelt. Pretty much most of us know that, then it's going to be a little irritating for people because it goes back to alert fatigue.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
I'm not so sure that I agree with Judy with respect to everybody knowing that. I think a lot of people don't recognize how a computer is configured and whether it's caching information or not. And this is an issue that I think can be very transparent to the user. From a technical perspective, you can set your computer up so that it deletes the cache—whatever is in the Internet Explorer whenever you exit Internet Explorer—and would wipe out stuff that had been viewed.

But there's also the capability to store the cache and not to delete the cache. So if somebody logs out, inadvertently leaving information on the computer because even though they just viewed it, it's still sitting there in the cache. And I think maybe the more appropriate way to address this issue would be through criteria for PHRs, whereby they had to be designed so that they by default would wipe out any remnants of information in the cache on the user exiting the PHR.

**Paul Egerman – Software Entrepreneur**
Good comments, John. But to be clear, we're not talking about PHRs. We're talking about this view and download functionality that is really part of the EHR.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
Okay. I'm sorry. Then I should say EHR then, but it still applies. The exact same thing still applies. My apologies.

**Paul Egerman – Software Entrepreneur**
And this is one way to look at this issue, is also to remember that the way that we have described our recommendations for this topic is that there—it's like best practice or guidance from the HHS. A letter basically suggesting it's not certain certification criteria. So if I hear what Judy Faulkner is saying, she's saying maybe for some patients this is overreaching—that they don't need it. Here what Gail is saying is maybe for some patients, they do need this. Maybe the provider is the one who needs to make that decision based on their knowledge of their population. But the fact is that we're just providing guidance as to what to do—doesn't mean that they necessarily have to do what our guidance is.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
But I think the best and easiest guidance is simply to have the provider and/or the technology vendor be able to ensure that there aren't remnants of data left on the computer after the person is done viewing it.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Well, I wasn't even suggesting that, but that's a really good point, John. I think that most people could use an additional reminder that when they bring this information up on their computer, they should make sure that wherever they are—in the airport or whatever—that it's their responsibility and not the provider's to make sure that other people can't see it.

**Paul Egerman – Software Entrepreneur**
So what you're suggesting, Dixie—let me make sure I understand it right—you're suggesting that in addition to what we've already written here, what you would suggest is for the view function that there be a best practice warning that says—somehow cautions people—about viewing sensitive patient data on computer devices that might be publicly visible?

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Yes. Yes. It sounds to me like what I'm suggesting is similar to what Markle has suggested, although I haven't looked at this.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
Just to weigh in—I'm more inclined to think like Judy here and give the consumer more credit for understanding whether somebody's looking over their shoulder or not. Most people don't need to be told that. On the other hand, I think John does raise an interesting point that it is possible to configure, at least Web pages, with headers that prevent the browser from caching, or at least instruct the browser not to cache the Web page. There's Pragma headers that can be set up that way, so that is something that we conceivably could issue as a best practice.

I'd be hesitant to think of it as something that you'd certify because there will be so many devices in the future where information could be displayed that aren't going to fall into the traditional browser category. So an iPad or a cell phone, the caching logic may be completely different on a personally controlled device, so I'm hesitant to think of that as a certification criteria. But certainly for a designer, it would be a best practice to set flags to instruct the display device that cache should not be maintained.

**Paul Egerman – Software Entrepreneur**
Good comments, but we've got two different topics that we're talking about right now. They're a little bit interrelated, but I would like to make sure that we do them one at a time. So the first one is like the question is, should there be some best practice warning just if you're viewing the data. And the second one is, should there be a best practice issue about caching Web pages. I view those as two different topics.

So what I'd like to do is first, look at the very first one which is, should there be any kind of a warning about viewing the data on a publicly accessible device. Because what I'm hearing on that is two different things: Some people say yes, and some people say not. So what do we want to do? We could talk about it some more, or we could …

**Deven McGraw – Center for Democracy & Technology – Director**
I have a suggestion, which is to say that to raise this before the policy committee in terms of whether we focused on the download function and had consensus around the areas that would need to be addressed, and that some members of the Tiger Team suggested that, in fact, it would be good to provide some guidance to people, even with respect to the view function even if they don't download. Others thought that that might be overkill. Want to see what the Policy Committee thinks about that.

We don't have very many people on the call today, and my personal view is that the provider probably knows his patient community well enough to determine whether that kind of guidance, just upon access is important or not. And maybe that's a way to flesh it out some more, which is the providers need to use their judgment about whether, in fact, we're warning upon access. Their patient population may not be Web-savvy enough to understand that even access carries some risk.

**Paul Egerman – Software Entrepreneur**
And so, just to understand what you just said, Devin, what we would do is we'd just, in effect, report back his discussion, that some people felt that it was important to give this warning; others were concerned that it might be annoying because it's stating something that a lot of people think is obvious.

**Deven McGraw – Center for Democracy & Technology – Director**
Yes.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
I agree with Judy about in terms of just viewing information that you're going to get this fatigue from doing it. But I don't think the first issue is much of an issue. And I agree with Judy that I don't think we need to make that suggestion.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
I think we need to make sure the providers are aware and, as Debbie said, put it into the whole policy framework so that they are aware that perhaps they may want to advise their patients. Different populations have different levels of computer ability and knowledge, and we have a huge digital divide in this country.

And if this is the first time somebody is looking at something like this, they might not even realize the potential of what they're doing. I always err on the side of caution in a situation like this, where you want to make sure that people are as knowledgeable as possible as to the risks that they are facing when they do something.

**Deven McGraw – Center for Democracy & Technology – Director**
So maybe the way to do it—this is Devin again—is to say providers should also consider whether, given their patient population, it makes sense to also provide some (I've avoided using the term warning, but I'm just going to use it here because it's a nice shortcut. It sounds scary to me) providing some guidance or warning to people even just upon the view. Particularly if the there's a patient population that may not necessarily understand that there are risks associated with viewing information from a public computer or a computer that they're using in a public space where people might see or be able to see it after they've walked away if they don't turn it off.

**Alice Lighter**
I agree with that, and I think there's a way to raise it in our letter without saying that it should be required, or that it should necessarily be a best practice, but we should still raise the issue.

**Deven McGraw – Center for Democracy & Technology – Director**
Are people comfortable with that.

**Paul Egerman – Software Entrepreneur**
As a best practice, in other words, Devin?

**Deven McGraw – Center for Democracy & Technology – Director**
In other words, so it would be listed not necessarily as a best practice providers should also, but it would be framed more as providers should consider offering guidance, even to patient who are just viewing the record, depending on whether they believe their patient population understands the risks that can be associated with simply viewing data, such as viewing from public computers or viewing in public spaces or not closing out of the account before you leave.

**Alice Lighter**
Exactly.

**Paul Egerman – Software Entrepreneur**
So do we have a consensus about that approach?

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
You know, either one of those is fine with me.

**Paul Egerman – Software Entrepreneur**
Because I think, Dixie and Gail, you were the ones who were most interested in this area. Are you comfortable with this?

**Gayle Harrell – Florida – House of Representatives**
Yes. I'd be comfortable with that.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Yes. That sounds fine. I think we also need to address the cache issue because ….

**Gayle Harrell – Florida – House of Representatives**
We will.

**Paul Egerman – Software Entrepreneur**
Yes, that's an excellent comment. Gail, that's exactly what we will do next. So the issue that was raised by John and David and now Gail is also in the context of the best practice. Let me see if I'm saying this right—I don't want to put words in somebody's mouth— but as a best practice recommendation, those people who are displaying data using Web pages, and that may not be the mechanism for everybody, but those who are using Web pages should do so in a manner that the data is not cached. Am I describing that correctly.

**David Lansky – Pacific Business Group on Health – President & CEO**
Yes. That's the intent of what I was saying, absolutely.

**Paul Egerman – Software Entrepreneur**
Okay. And so David, John, and I guess Gail, if I'm hearing you right, you three think that's a good thing to do? You want that as part of our recommendations. Is that correct.

**Gayle Harrell – Florida – House of Representatives**
Correct.

**Paul Egerman – Software Entrepreneur**
Okay. Does anybody disagree with that?

**W**
I'm not disagreeing, Paul, I'm just asking. I'm just clarifying that it would be a best practice recommendation that a provider would seek this functionality from a vendor?

**Paul Egerman – Software Entrepreneur**
I think it would be a best practice recommendation. I suspect vendors and developers, if they're using Web pages to display this information, that they should use functionality that prevents caching of the data.

**M**
Could I suggest we be a little more precise? I know we think it's a matter of using Web pages. If they're using a technology that caches information that they should, if at all possible, be able to flush the cache or remove the data from the device after viewing is completed.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
I agree. I wouldn't restrict it to Web pages because there are other technologies that cache as well.

**David Lansky – Pacific Business Group on Health – President & CEO**
I'm okay with that as long as we don't try to turn it into a certification test.

**Paul Egerman – Software Entrepreneur**
Yes. And in my opinion, it'd be hard to do this as certification because not all vendors would use that kind of technology. And so it's sort of unfair to have certain vendors have certain tasks that other vendors might not. It's hard to figure out, although I suppose there's a way of doing it.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**

I will tell you one thing though. I've dealt with working in security with vendors who don't even realize that they've left data on the computer—not cleaning out caches. And you have to go back to them and literally tell them they need to design their software in order to delete it. The people didn't even realize information was being left on the computers.

**Paul Egerman – Software Entrepreneur**
That's helpful. That's extremely helpful. Are you saying though that this should be more than best practice? We should try for certification.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
No. We can leave it as a best practice, but I just want to get the point across that even vendors in their programming aren't necessarily doing something that I think is just good hygiene.

**Gayle Harrell – Florida – House of Representatives**
Good vendor hygiene. How about that.

**Paul Egerman – Software Entrepreneur**
It's an interesting topic because I can remember back in the good old days when I was a vendor, sometimes I got frustrated that I was doing my best to do what you call good hygiene, but my competitors weren't. It was very hard to explain that sometimes to users.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
Even if this is a best practice, it's something that customers can point to and say this is a best practice. This is what we need you to develop to.

**Deven McGraw – Center for Democracy & Technology – Director**
And it's also alerting industry that we think this is a good idea—and providers potentially too. So if ONC were to accept this recommendation and include it in materials provided to providers, this would get out there.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
I think it's an excellent point, and I would like to see it as a recommendation that's not restricted to just the patient download of their records because as a lot of vendors offer software as a service, a lot of the services will be accessed through browser, and they'll have the same issue.

**Paul Egerman – Software Entrepreneur**
That's right because you have this issue, Dixie, where if the user is not a patient, the user is a clinician accessing data—say from a laptop or a computer at a hotel or something—there might be an issue there. Although, what we are focused on right now is the view and download.

**Deven McGraw – Center for Democracy & Technology – Director**
For the patient, right.

**Paul Egerman – Software Entrepreneur**
For the patient. I think it's a lot more complicated when you get into the provider's workflow because if you strictly prevent all local caching, the performance of most Web applications would come to a screeching halt.

**Deven McGraw – Center for Democracy & Technology – Director**
That's right.

**Paul Egerman – Software Entrepreneur**
I just don't think we want to go that far, but as a best practice to remind vendors that it is possible to minimize the amount of caching—that makes sense to me. I get leery of trying to actually certify against it given how much variation there is in the browsers and how the Pragmas that have to be followed are not mandatory, and the browser maker may can choose to ignore them. And you can't force that on the vendor—I don't think.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
And the technology changes so fast.

**Paul Egerman – Software Entrepreneur**
And the technology is changing all the time, yes. So tell me—I just want to understand. I think we got a consensus on this, and I want to make sure I understand how to phrase it. So it basically says if the application uses technology that creates a local cache of data, then the best practice is that that technology avoid retention of that local cache.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
Once the application is closed, that's David's point.

**Paul Egerman – Software Entrepreneur**
Avoid retention of the cache when the application is closed?

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
Terminated. Yes.

**Paul Egerman – Software Entrepreneur**
On devices that display consumer protected health information should be configured such that no cached copies are retained if possible. Something like that.

**Deven McGraw – Center for Democracy & Technology – Director**
Yes. I like that.

**Paul Egerman – Software Entrepreneur**
That's a better description. Let me see if I've got it. Devices that display consumer protected health information should be configured—something like that—in such a way…

**Deven McGraw – Center for Democracy & Technology – Director**
So no cached copies are retained upon termination.

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
That way you don't have to—Dave's point is you're cleaning the cache out as the application is running, and you don't want to degrade performance.

**Paul Egerman – Software Entrepreneur**
Okay. And that's also a best practice?

**John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security**
Yes.

**Paul Egerman – Software Entrepreneur**
Sounds great. So we started this discussion with view and download. Dixie correctly pointed out that we had only done the download piece—that we hadn't done the view piece, so is there anything more we want to say on the view piece before I go back to the download piece again? You think we've completed the view piece then?

**Deven McGraw – Center for Democracy & Technology – Director**
I think we have.

**Paul Egerman – Software Entrepreneur**
Okay.

**Deven McGraw – Center for Democracy & Technology – Director**
We'll get language around to folks just to make sure, but when we were talking about providers giving consideration to offering patients guidance also when they're just viewing.

**Paul Egerman – Software Entrepreneur**
Great. These are excellent improvements to our recommendation. Then what you see on the screen is the draft recommendation on what I'm now calling the download piece. Again, it's still a best practice; it's still sort of like guidance. It's not certification. It says that we will offer patients, as Deven said, a clear and simple guidance. This was a suggestion that a number of people have made to make sure this is not legalistic. It's clear and simple, and it has these three different components: remind patients that they will be in control of their copy of their medical information; include links or resources with more information if they need it—the concept of a layered notice; and then the third thing it says obtain independent confirmation that the patient wants to complete the download transaction or transactions. So this is a sometimes frustrating notice that says, "Are you sure you want to do this?"

So this is the recommendation. Are we all comfortable with this? Does this correctly describe our previous discussions?

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Yes.

**Gayle Harrell – Florida – House of Representatives**
Yes.

**Deven McGraw – Center for Democracy & Technology – Director**
Excellent. I always hold my breath at that moment, Paul. I don't know if you do.

**Paul Egerman – Software Entrepreneur**
Well actually, whenever that happens, I almost wonder if something has gone wrong because I'm not used to everybody agreeing.

**David Lansky – Pacific Business Group on Health – President & CEO**
I think it's why you moved the calls to Friday afternoon.

**Deven McGraw – Center for Democracy & Technology – Director**
You caught us.

**Paul Egerman – Software Entrepreneur**

You're on to us. David is amazing. But I think we have a good set of recommendations on this topic, and I feel pretty good about it.

**Deven McGraw – Center for Democracy & Technology – Director**
I do too. I do too. So we have some time left on the schedule, so wanted to bring to your attention where we are—yes Dixie?

**Carol Diamond – Markle Foundation – Managing Director Healthcare Program**
No, it's Carol. I just wanted to let you know I've been on. I just waited for a time to let you know. Sorry.

**Deven McGraw – Center for Democracy & Technology – Director**
Oh, okay. Thanks, Carol.

**Paul Egerman – Software Entrepreneur**
Yes, thank you Carol. I don't know when you joined the call, but hopefully you see that we were significantly influenced by the great work that you and your team did at the Markle Foundation.

**Carol Diamond – Markle Foundation – Managing Director Healthcare Program**
Great. I'm glad it was helpful. Thank you.

**Paul Egerman – Software Entrepreneur**
I'm sorry. Go ahead, Deven.

**Deven McGraw – Center for Democracy & Technology – Director**
Yes. I just wanted to give everyone an update on where we are with the HIO question that arose when we presented our recommendations on amendments and corrections to the Policy Committee last month.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
Deven? Can I interrupt before you change to that subject? I just remembered I have a tangential question to the download question.

**Deven McGraw – Center for Democracy & Technology – Director**
Okay.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
And I'm not trying to take us off topic. Because I think we've settled the download question that was on the table. This is tangential.

**Deven McGraw – Center for Democracy & Technology – Director**
Okay

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
A recent discussion came up here when some of my colleagues were asking me what the right answer was with respect to the timing between the data being made available to the patient and the physician's opportunity to interact with the patient first if there's sensitive or difficult material that could be downloaded.

**Deven McGraw – Center for Democracy & Technology – Director**
Yes.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
And the way that your little summary is worded here, it says within 24 hours of an encounter or four days after the information is available to the EP.

**Deven McGraw – Center for Democracy & Technology – Director**
That's right.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
Is that four days allowed there so that the EP has a chance to communicate with the patient first?

**Deven McGraw – Center for Democracy & Technology – Director**
Yes.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
That's what the spirit of that was?

**Deven McGraw – Center for Democracy & Technology – Director**
Yes.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
That wasn't just a technology lag?

**Deven McGraw – Center for Democracy & Technology – Director**
No. It wasn't a technology issue. It was to allow the provider time to contact the patient so that the patient didn't see the item for the first time when he or she logs onto the view and download.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
Okay. That's what I wanted to confirm. That was the advice I gave, but I wasn't sure about that.

**Deven McGraw – Center for Democracy & Technology – Director**
No. You are exactly right.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
In some states, for instance, laboratory results have to be reviewed by the physician first and, in fact, actually have to have face to face communication on very specific types of lab tests—for instance, HIV screen.

**Deven McGraw – Center for Democracy & Technology – Director**
Right.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
So there's adequate time for all that to happen.

**Deven McGraw – Center for Democracy & Technology – Director**
Right.

**Paul Egerman – Software Entrepreneur**
And I think in making those comments, Deven, I think you're probably reflecting your participation in the Meaningful Use workgroup, but what we're doing in our letter is simply repeating what the Policy Committee's recommendations for stage 2. Right?

**Deven McGraw – Center for Democracy & Technology – Director**
Yes. That's correct.

**Paul Egerman – Software Entrepreneur**
In other words, this is not a topic that this group discussed or is not really a topic for us to necessarily comment on. It's not a privacy and security issue, but it's really very important and reasonable workflow issue, so it's not a surprise that people would be curious about it.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
The reason it occurred to me to ask it in this context was—it was one of our clients. And what they were doing was actually giving consumer access to a subset of the CCD, from which they had extracted everything that could conceivably be sensitive. And I said, "I don't think that's the spirit of the download." And it got into this question of how do we do this if the doctor hasn't had a chance to talk to the patient yet.

So it does have a little bit of bearing on privacy and security, only in the sense that that's a technique people use to address the sensitive issues is withhold them. And again, that's not the spirit of what we're trying to accomplish here with liquidity, but it's a workaround that this client felt necessary.

**Deven McGraw – Center for Democracy & Technology – Director**
And Paul is right, we're not presenting it. You didn't ask the question I assume, David, because you were presenting it for discussion. You just wanted clarity on what the Meaningful Use Workgroup had already said, which the Policy Committee endorsed.

**David McCallie – Cerner Corporation – Vice President of Medical Informatics**
That's correct. I blur these committees together.

**Gayle Harrell – Florida – House of Representatives**
Well there's a lot of common membership among them, so that's understandable.

**Deven McGraw – Center for Democracy & Technology – Director**
Anything else? Any other tangential issues? Okay. Well what I was beginning to give you all an update on, which is largely just to update you that we haven't forgotten that this issue was out there to be resolved, is the question about the role of HIOs in amendments and corrections that came up at the last Policy Committee meeting.

And we have not forgotten that issue, but we are trying to get some agreement with Micky Tripathi and David Lansky, who are the co-chairs of the Information Exchange Workgroup about how best to proceed forward given that this issue has implications both for the work that they do with the HIO folks who populate that workgroup and the work that we do here on the Tiger Team, and what might be the best way—since it has a bit of a cross-jurisdictional aspect to it—to be able to move it forward.

And there's been vacation that's gotten in the way, darn it. So we haven't forgotten it. It's on deck, but there isn't a process yet that's been proposed for how we want to move it. So just wanted to update you on that. Does anybody have any questions about that at all?

Okay, so I think we wanted to take a little bit of time with—we are perilously close to being able to end early, which is really nice, and I'd love to give you the time back. But one of the things that Paul and I

have been talking about in terms of teeing up some issues for our discussions in the very near future is a potential focus on research uses of data.

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
And this is Joy.

**Deven McGraw – Center for Democracy & Technology – Director**
Okay, Joy.

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
Secondary uses have been a topic that this group has been, quite frankly, biting at the chomp or whatever they call it. Chomping at the bit.

**Deven McGraw – Center for Democracy & Technology – Director**
Chomping at the bit. Right.

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
To address some of the secondary uses there has been some activity going on in HHS, particularly on the research issue. And there was released today an advance notice of proposed rulemaking on what are called the Common Rule. The Common Rule is the federal regulations on human subjects research.

And the ANPRM does include—what an ANPRM is it's before a notice of proposed rulemaking. It's a little different from a request for information. It's asking for more than information. What it does is it says we're thinking of heading in a certain direction, and we're not sure that's exactly the direction we should be headed. Here are some issues we'd like you, the public, to comment on.

And there are sections in this ANPRM that expressly address privacy and security, and particularly you can see the way that it is structured that it would be utilized in a health IT context. So I put that out there as a way of perhaps framing the discussion that this group has expressed a desire to have on research. That it may be a way of framing your discussion would be to look at this ANPRM and the way it addresses privacy and security for research.

And it is at a very high-level policy level, and so where things might be headed. I would also say that given that it is only an advanced notice of proposed rulemaking, the people tend to be, I guess, freer with the proposal that goes out because it's only in the very initiative stages. So don't think that anything that is in here is locked down. Nothing is locked down. All of this is on the table.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Joy, this is Dixie. What was the overall intent of it? It sounds like privacy was one tangential area. What was the central purpose of it?

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
Well, privacy and security are a—it's one of the areas addressed. I wouldn't just call it tangential necessarily, but there are a number of different issues addressed. And the goal here was to simplify some of the requirements for the Common Rule, and also to make them more protective of patients in some way because there is some thought that the way things operate right now and rules that are in place, they're applied sometimes mechanically, maybe. There's a lot of paperwork filled out that isn't necessarily benefiting the individual.

So the overall idea is to focus on risks to make this process when you're looking at research, focusing on the areas that are really risky and not focus a lot of effort on areas that may be able to handle in a more uniform fashion so that the IRBs aren't getting all twisted up about it.

There's also—with privacy and security in particular as anybody who's been involved in this issue knows—there has been a lot of struggle with how to deal with the differences between the Common Rule and the Privacy Rule over the years. And there is some effort in here to kind of harmonize those and make them more—not only making them more compatible, but also making it a little bit more useful for the individual.

**Gayle Harrell – Florida – House of Representatives**
Joy, for those of us who are not familiar with the Common Rule, could you send us a link or something that we could take a look at this?

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
Sure. We will have somebody send out the link to the ANPRM.

**Deven McGraw – Center for Democracy & Technology – Director**
That would be great. I think also…

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
I'm sorry. I'm going to jump in here and tell you one more thing I'm going to send you a link to. And I don't mean to be tooting my own horn too much about this, but I worked with an Institute of Medicine panel a few years ago as a consultant on the Privacy Rule and the Common Rule, and I wrote a paper that the core of which explains how these two different rules evolved, and how one was based on information privacy, and the other is really focused on physical safety.

It explains a little bit of why they evolved, and how they evolved, and what the current differences of them are. So if anybody really wants to dive into it, I think that it might be useful.

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Send that also to me.

**Deven McGraw – Center for Democracy & Technology – Director**
Yes. Absolutely. So just to clarify, we're not asking you all to make decisions about this now because we would never spring on you on the day of the call, "Are we going to do this, or are we going to do that." But Joy, I saw that come out today, and I had similar thoughts that this might be a way for us to at least begin a discussion on policy around secondary uses of data from EHRs because it's a really large topic, and you would hate to not have some direction that you're heading in on that issue before starting to dive in.

So I like the idea of potentially having a focus for at least the initial issues that we would want to discuss. I'm not saying that we would necessarily limit taking on research to just looking at this rule, but it does potentially provide a vehicle.

I think the other thing that I find appealing about having the Tiger Team and subsequently the Policy Committee weighing in on something like this if we decide to do it is that we haven't been able to do that on some other comment opportunities that are on issues of privacy that are related to some work that we've done, because of timing.

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
Right.

**Deven McGraw – Center for Democracy & Technology – Director**
And here, we might actually have some good timing for once.

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
Like I said, it's been a lengthy process. Since literally the day I walked in here, this has been under the works. But it's not something that we could really discuss with people. That was probably the reason why I didn't want you really to take up the research issue when there's this whole other initiative going on. But this way, at least you can see where some of the thought process has been up to now.

**Deven McGraw – Center for Democracy & Technology – Director**
So it sounds like what we would probably need to do is to get folks the Advanced Notice of—the actual document and to send it to—I do think I agree with Gail that you should circulate your paper for those who are interested in learning more about the background.

And then we can make a better decision about whether the team agrees that this is something that we want to weigh in on when we meet next. Does that make sense?

**Joy Keeler – MITRE Corporation – Health IT Program Manager**
Yes.

**Gayle Harrell – Florida – House of Representatives**
I think so.

**Deven McGraw – Center for Democracy & Technology – Director**
Paul, what do you think?

**Paul Egerman – Software Entrepreneur**
I think it makes great sense, and I'm excited about the opportunity to work on it. It sounds like an extremely interesting topic.

**Deven McGraw – Center for Democracy & Technology – Director**
I think Joy is right about the chomping at the bit. I can remember when we were having those consent discussions, really almost a year to the day ago, and people not being terribly happy about confining the discussion just to the uses of data that were under stage 1 of meaningful use, which are extremely limited. They don't really mention secondary uses beyond some public health reporting and quality reporting at all.

But we know that these uses of data are not only contemplated but are actually happening. So I agree. Anybody else have any thoughts?

**Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences**
Sounds like a wonderful opportunity. The timing couldn't be better. How often does that happen?

**Deven McGraw – Center for Democracy & Technology – Director**
Exactly.

**Joy Keeler – MITRE Corporation – Health IT Program Manager**

You make the timing happen. No, it's usually totally out of our hands. Who should I send this material to for distribution?

**Deven McGraw – Center for Democracy & Technology – Director**
Judy, are you still on?

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Yes. You can send it to me, Joy. I'll get it out.

**Deven McGraw – Center for Democracy & Technology – Director**
Alright, and in the meantime, Paul and I will do the wordsmithing with team MITRE, our trusty sidekicks, to wordsmith the two other points that we wanted to add to these recommendations to get them around for any last minute thoughts because we don't have another call before the Policy Committee meeting.

And if there's nothing else—Paul, do you have anything else?

**Paul Egerman – Software Entrepreneur**
Well, I think we have to be sure we do public comment first.

**Deven McGraw – Center for Democracy & Technology – Director**
Yes, of course.

**Paul Egerman – Software Entrepreneur**
But this was a great discussion, and I very much appreciate everybody's dedication on the Friday afternoon in the summer. It's really quite impressive. Let's see if there are members of the public who would like to make comments.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Operator, can you check and see if anybody wishes to comment please.

**Operator**
Yes. We have no comments at this time.

**Judy Sparrow – Office of the National Coordinator – Executive Director**
Okay, well thank you. And thank you all.

**Paul Egerman – Software Entrepreneur**
Thank you Judy Sparrow and thank you Joy. Our next call is two o'clock eastern time on Friday August 5th.

## Public Comment Received During the Meeting

1. There are Beneficiary PHI warnings and disclaimer information on mymedicare.gov site regarding downloads

2. Part of the mymedicare.gov beneficiary portal registration process includes privacy and security information and warnings of EMR (inside institution) and PHI (in Patients possession).

3. Privacy and security best practices educational scripts and a privacy and a security technical framework (from providers)

4. Good Afternoon: In support of the points regarding browser settings and warnings for viewing information. Patients and Providers should bear the risk of using Public Computers for viewing patient information. As to additional protection, once in the portal the user could set additional parameters to prompt them when they are on a public computer - such as online banking. Finally a simple warning on the portal that the information is best viewed on a private PC. Thank you.