

**HIT Policy Committee
Privacy & Security Tiger Team
Transcript
January 27, 2014**

Presentation

Operator

All lines are bridged with the public.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Thank you. Good afternoon everyone, this is Michelle Consolazio with the Office of the National Coordinator. This is a meeting of the Health IT Policy Committee's Privacy & Security Tiger Team. This is a public call and there will be time for public comment at the end of today's call. As a reminder, please state your name before speaking as this meeting is being transcribed and recorded. I'll now take roll. Deven McGraw?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Micky Tripathi? Dixie Baker?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

I'm here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Hi Dixie. Judy Faulkner?

Judy Faulkner, MS – Founder and Chief Executive Officer – EPIC Systems Corporation

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Hi Judy. Leslie Francis?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Leslie is on, she's on mute and driving.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Thank you. Gayle Harrell? Larry Garber? John Houston?

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Hi John. David Kotz?

David F. Kotz, PhD – Associate Dean of the Faculty for the Sciences – Dartmouth College

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Hi David. David McCallie? Wes Rishel?

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Hi Wes. Kitt Winter?

Kitt Winter – eHealth Exchange Coordinating Committee Chair – Social Security Administration

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

And are there any ONC – hi Kitt. Are there any OCR staff members on the line? And are there any ONC staff members on the line? Okay. And with that, I'll turn it back to you Deven.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Okay, terrific. Well, in terms of the agenda, we had originally planned to have Joy take us through what would be our first annual summary of Privacy & Security Tiger Team activities, which – since this is the first one we've ever had, it was actually going to cover more than a year. It would have been really a summary of our entire body of work together as a Tiger Team. This was something that Joy very much wanted to do in order to demonstrate to all of you who have really hung in for many years with the work that we've done, as well as to members of the public, what our recommendations have been and, where appropriate, what actions have been taken in response to those recommendations. And this – when I say where appropriate, that means to the extent that HHS has had sufficient time to act on them, because many of our recommendations have, in fact, been incorporated into policies out of HHS, mostly from ONC, some from CMS through meaningful use.

So, I think that that'll be a really interesting presentation when we're able to have it. Joy is – we – so instead of starting the call with this discussion, we hope that she'll be able to join us about midway through. And if that's the case, then we'll just turn to that summary when she's able to join us. So instead we will start with – okay – I'm going to have to skip through a lot of slides here. I wonder if Altarum is able to just get us to the other part of the presentation, which beg – the discussion on personal representatives. Ah, perfect, thank you guys very much.

So we'll come back to this discussion, which we began a bit on our last call, which is the issue of personal representatives of a patient and access to their health information. And what we're going to do this time, which we were not prepared to do on the last call, is to provide some of the legal background around personal representatives and their access to information, as well as what HIPAA says about sharing with family members generally. One thing I will say right at the start, we've got this on a later slide, but it's worth mentioning right up front is that we are not going to be discussing minors. We – Judy, that was a very good suggestion that everyone seemed to agree with, that we should deal with all of the minor's access issues separately and try to at least initially take on this issue of personal representatives for adults. So try to keep that in mind as we have the discussion. And it's not – there are actually, I think, a number of twists and turns, even to the adult access.

So I'm going to go through a bit of background, and this is from the HIPAA Privacy Rule. HHS already recognizes that there are times when individuals are either legally or otherwise incapable of exercising their rights under the Privacy Rule. Or they may simply want to designate another person to act on their behalf, with respect to those rights. And specifically, under the Privacy Rule, a person who is authorized under state or other applicable law to act on behalf of the individual in making healthcare related decisions is that person's personal representative. What's in your backup slides are some material from some frequently asked questions about this, that's on the Office for Civil Rights website, and what you'll see from reading that is that this Privacy Rule language is quite specific that personal representatives need to be legally authorized to make healthcare decisions on behalf of a person. This is not a situation where I just say, well, I want my mother to also have access to my information as well. You're not a personal representative unless you have been legally authorized to make healthcare decisions for that person.

And this is relevant because there's another set of provisions, which I'll get to in a minute, that are about sharing information just with family members where there's not a situation where somebody has been under some authority of law, designated to act on a patient's behalf. So with some exceptions, which we'll get to in a second, the Privacy Rule actually requires covered entities to treat a personal representative as the individual with respect to uses and disclosures of an individual's protected health information, that's the identifiable health information, as well as with respect to their exercise of the individual rights under the HIPAA Privacy Rule.

So that means that under the Privacy Rule, a covered entity must provide an individual's personal representative with an accounting of disclosures, if they ask for it. Provide the personal representative access to the individual's PHI and in addition, if there are circumstances where the individual's authorization is required under the HIPAA Privacy Rule before the information can be disclosed, then the personal representative is in the position to authorize those disclosures. Again, it's not a change in the Privacy Rule in terms of what does require authorization and what does not for disclosure, but what it says is, if you're a personal representative of an individual, you have the right to exercise those authorizations.

Now, the covered entity does have some discretion here, and they can elect not to treat a person as though they are a personal representative, even if legally they are, if the individual has been or may be subjected to domestic violence, abuse or neglect by that person, or treating the person as a personal representative could endanger the individual. And the covered entity, in the exercise of professional judgment, decides it's not in the best interest of the individual to treat the person as that individual's personal representative. So, if the covered entity has some concerns in some – they have the legal authority under the HIPAA Privacy Rule, to not treat someone as a personal representative, if those concerns fall under these particular categories.

Now, this is different, as I mentioned earlier, from the capability to just share information with family members or other persons who are either involved in helping to care for the individual who is the patient or are involved in payment for their care. And here the Privacy Rule permits disclosures of some PHI, some protected health information, with those members, again, friends or family who are involved in the individual's care or payment for care, without the need to get authorization, without the need for some sort of legal process to designate that person as a personal representative. This is the friends and family sharing provision, as a lot of us tend to call it. But the personal health information that is allowed to be disclosed is only that information that's directly relevant to their involvement with the individual's care or their payment for that care. And the individual has the right to object to such disclosures and in the case where there has been an objection, then the covered entity has to basically defer to the patient in that regard, and not disclose information to family members or friends.

Now, there are also some provisions in the Privacy Rule that if it's an emergency and in certain other circumstances, a covered entity – where – particularly where an objection has not been articulated and is not known, the covered entity does – is able to make reasonable inferences about what the patient would want and act in the best interest of the individual, with respect to disclosures to friends and family. But again the scope of the protected health information that's involved is, what's relevant to the care of the individual, or in the case of payment information, what's relevant to payment for care as opposed to what the personal representative has a right to access is any information that the individual herself could access under HIPAA's individual access rights.

So here are some suggested ways that Micky and I came up with for framing this, but this is all, as always, subject to Tiger Team discussion. Again, as I mentioned earlier, we've already made a decision, and so unless we want to change our minds, we want to try to limit this to adults. And then we will be able to build on whatever we come up with for adults, assuming that there are additional policy recommendations that are needed in this space, we can build on that when we have our discussion about children and teens.

We've also suggested that we could have a use case here, which is access to protected health information through the Stage 2 view, download and transmit capability as opposed to thinking about sort of the entire universe of personal representative access to information. And the issues here really involve are you authorized to access the PHI? Not authentication, we – to some degree we've dealt with the issues of what's reasonable for covered entities covered by HIPAA with respect to proving that the individual is who he or she says they are. Not that those issues don't necessarily arise here, but the meatier issues are likely to be those related to how do you know that someone is, in fact, a personal representative and to what extent is that necessary before they can access information through view, download and transmit, for example. And then we just put an "other" caveat down here in case we forgot something, which could in fact be the case, we wanted to have a robust discussion and not necessarily confine it, but provide some direction of where we thought we could go with all of this.

So, in sort of teeing up an initial set of issues for discussion. We – it is likely the case today, and I certainly have heard anecdotal stories for people who do have patient portals or other ways to online access their health information from their provider, the patients may in fact be sharing user ID and password information with the person whom they wish to be involved in their care. And this probably happens a fair amount with adult children who are actively involved in the care of their aging parents.

Current rules on portals or current rules as applied to portals, may not necessarily easily allow for family and friends to have their own credentials to a patient's account. In part because if the personal representative relationship doesn't exist, then the PHI that a family or friend is permitted to have under HIPAA absent specific authorization from the patient, is limited to what's relevant to current care. So depending on what is populated in the portal and how long the information remains there, that could potentially be problematic, although we talk about whether that's a problem that's more theoretical than in reality. Do we think that unique credentials or accounts would be needed for a personal representative? And are there policy issues that need to be resolved with respect to distinguishing between patients and personal representatives? It's not clear to me from reading the Privacy Rule that you would need to make that distinction, if in fact the personal representative relationship exists.

And the other thing we wanted to make a note of is that the policy decisions on this issue are likely impacted by the debates that have surfaced more than periodically in our conversations, both with respect to technology and policy, regarding data segmentation. Under HIPAA, a personal representative has access to everything the individual would be able to access, which is essentially all data except psychotherapy notes. Having said that, if the relationship is not one of a personal representative, but it is instead friends and family, and an objection has been raised by the patient with respect to some data, but not all data. Or you have the circumstance where the – what the patient is able to view online is more than just the information that's relevant to current care, the segmentation issues may be relevant here. And I don't want us to get too wrapped up in discussing deeply the segmentation policy issues, because it is still the case that ONC is working to figure out how to – which committee, either the Policy Committee or the Standards Committee will sort of deal with what the results have been of those pilots. So I don't think it would be a productive use of our time at this juncture to go deeply into that issue, but it's fair and important to acknowledge that it likely is a factor here.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

I have a question, Deven.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Yes Dixie.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

Not relating to segmentation, but –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

That's okay. Go ahead.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

You said that a personal representative has access to all your data except psychotherapy notes. Is there like a separate authorization required for that?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Patients don't get them, that's why the personal representative can't get them.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

Oh, oh, I see, except for the psychotherapy notes that the psychotherapist chooses not to disclose to the patient, they also wouldn't disclose to –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

That's right.

Leslie Francis, JD, PhD – University of Utah College of Law – National Committee on Vital and Health Statistics

Deven?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Yes.

Leslie Francis, JD, PhD – University of Utah College of Law – National Committee on Vital and Health Statistics

This is Leslie. I have a Law Review article I wrote a couple of years ago on the segmentation issues and personal representatives –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Ahh.

Leslie Francis, JD, PhD – University of Utah College of Law – National Committee on Vital and Health Statistics

– and I will send that around.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Perfect. Thank you.

Leslie Francis, JD, PhD – University of Utah College of Law – National Committee on Vital and Health Statistics

It does express some of the policy concerns, anyway.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

That will be very helpful, thank you Leslie. We'd appreciate getting that.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Hey Deven?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Yes.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

John Houston. One of the things I think doesn't come through in what you've said so far, which is important, at least important to me, is that even though HIPAA defines what a personal representative is, and certainly HIPAA invests certain rights in those personal representatives. A lot of organizations including my own deal with situations where somebody's less than a personal representative. A great example is somebody – if a patient wants somebody else to have access to the medical record via our portal, they can see – an account can be set up for that individual. The patient can link – make the decision to link that person to their – that portal between accounts so that that – but it's within the control of the patient.

But there are also a variety of other situations, which are less than true personal representative situations where the patient has expressed some limited interest in having somebody doing something on their behalf, and it might include certain access to the medical record. Other things that they might do, unrelated to this, might be they want them to be able to take them to appointments or get their prescriptions for them, or things like that. But it's less than the defined personal representative under HIPAA and sometimes it does include access to certain parts of the medical record or rights with respect to accessing the medical record.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Right.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

I just want to bring that out as being sort of a subset –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

No, I'm glad John, because you are experienced at managing this for a large institution is going to be very helpful because it's one thing for us to sort of read what's in the rulebook about what people can and can't do, but I'm certain that there are all kinds of permutations about what patients and family members ask for. And how does that get handled and is there a need for additional federal policy on that, even if just for clarification. Or are people handling this just fine.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Right and I think what we have found is that there's some lesser, what's the word, level of not necessarily access, but some individual that yeah, they have some involvement in the patient's care, but it isn't everything and it – the patient doesn't necessarily want them to have rights to everything. But they want them to have things like access to their medical record, or aspects of their medical record –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Right.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

– in order to facilitate or aide the patient in their care. And so, I don't know how you bifurcate this – how you de – how these – the status of these individuals, but it can't be or shouldn't be all or nothing and I think that unfortunately that's sometimes the way it's viewed.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Right.

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

Question, question.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Sure.

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

John, are you currently doing all or nothing or do you have some divisions now of levels of access.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

We have divisions. We have divisions of access –

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

(Indiscernible)

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

, as well as – not just access to medical records, but a whole variety of things that the patient might want somebody to do on their behalf. So –

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

And you then control access through the portal, according to this set of divisions that you're describing?

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

I hate to – the answer is that we're working towards that and recognize it gets to be somewhat difficult with adolescents. But the point is that somebody maybe might just have the right to access the record via the portal and nothing more. And I know that's sort of an odd nuance, but we – I'm just speaking, we need to think in terms of granularity in terms of what those representatives can do on behalf of a patient. And it shouldn't be everything including making medical decisions on their behalf, because the patient very well might want them to be very limited in the types of activities they perform or have the right to do on their behalf.

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

I think I would, and I imagine other committee members would like it if you could share –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Yeah.

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

– those divisions, so that we see kind of how it's conceptualized and practiced, and then you can advise us on levels or implementation you have for that.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Sure.

Judy Faulkner, MS – Founder and Chief Executive Officer – EPIC Systems Corporation

This is Judy and we do the same thing. We have different levels that patients can choose among.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

That would be – that's incredibly helpful information to have as examples about how people navigate this. Does anybody else have – I mean, I didn't hear Larry Garber chime in when – during roll call, but we can reach out to him in terms of, he's now our practicing physician representative on the Tiger Team. Are there others who are aware of or would be willing to do a little bit of digging about how their own institutions handle this? Because I think in addition to having some examples, I'm just – I'm still struggling with whether there are lingering policy issues where we need to resolve anything. And if there are and folks are sort of kind of accustomed or growing accustomed to dealing with this, and maybe this is a best practices situation where we provide a bunch of examples that we've learned but then ultimately say, there's not really need for any new policy on this. That could be what's going on here, but –

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

And it might – again, I think we also need to be forward thinking about where the state of this needs to go, and I will defer to Judy with respect, because we – our portal's largely based upon what EPIC provides.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Okay.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

And she can probably provide us the totality of what they do now and where they're going. But again, I think I'm just thinking more broadly in the context of what a patient would have an individual do on their behalf, not just with respect to information, but in their care. Because again I think there's a lot of different levels of things that patients want individuals to do for them.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

This is Dixie. John is that documented in the legal authorization or is that something your hospital layers over the legal authorization?

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

They layer over top of it. We have actually something we call the personal representative form, which it sort of sounds like more – basically it says, this person can do certain limited things on your behalf. One of them is not medical decision making, it's something less than that though; it might be picking up prescriptions or involved in discussions about the patient's care; however, it doesn't go that full way to things like medical decision making authority. And they're really – they're rights are really at the luxury of the patient. And yes, if it goes – it can go further than that, but typical – often it's that we would have the courts involved if we had to have somebody who has legal, medical decision making authority, especially if somebody's not competent.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

So John, this is Joy Pritts.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Yes, Joy?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Yeah, we're sheltering in place in my office at the moment.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

That's good.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Yes, we had to move. So I'm curious about this, because it seems to me like – this is kind of in response to what Dixie said, that it sounds like you're working under the §164.510, permitted uses and disclosures for individuals involved in the patient's care. So, is that where you're doing that and you're going a step further and getting the patient to actually do it in writing and stuff? Is that what I'm hearing?

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

No actually, I think that it might be sort of – that probably goes further. I mean, individuals may not necessarily; again, in the context of making decisions about the patient's care, it maybe doesn't even go that far though.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Okay.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

The patient has simply made the decision that they want to have that individual be able to access their record, maybe they want to have that person help interpret what their record means, but they fully want to have full control over the care that they're receiving.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Okay, so it sounds like it's a third category, which is really –

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

It is –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

– now.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Yeah, it is a third category.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

But it sounds like a regular HIPAA authorization.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

It could be –

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Yeah, it could be.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

– what I was thinking, too.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Yeah, it could be, I'm just thinking, and I'm less thinking in terms of what HIPAA provides – more in terms of functionally what we see. And it's not all or nothing, there are levels of – there are different levels of access and permissions and the like, and I just think we want to be cognizant of that as we think about these types of things.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

No, I think that's really good.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

No, that is good. And I think it's going to be incredibly useful to have more information from you all and from Judy about sort of what are the options that you can currently provide. And maybe David McCallie couldn't make it on this call, but maybe he can chime in from the technical perspective for Cerner, and we can ping Larry and the others who were not able to make it on this call, to see what other evidence we can gather. I mean, I ha – I don't want to preliminarily decide that there's not a policy issue to resolve, based on UPMC's experience because we may be able to dig up some more and we may hear from some folks during our public comment. But, my own preliminary thinking is that there may not be a policy issue to resolve. But there may be some acknowledgments of sort of the state of the world and that best practices, so the rest of the provider community who may be struggling a little bit with some of these issues, having not had to deal with them previously, could learn.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

And I think this – again, this is John Houston. I think there is an opportunity to also help serve the patient because I'm sure some patients are much more comfortable knowing that these individuals have limited access. Or that those types – those limits can reasonably be introduced so that maybe a patient otherwise wouldn't want somebody to have access to parts of their record or be involved in their care, they would become comfortable because it's something lesser than that, so it's not all or nothing.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

I'm confused at this point, Deven – and this is Dixie, I'm sorry. I don't think – it doesn't sound to me like what John is talking about is a personal representative in the sense of what the topic is, but rather what people can do with respect to just normal HIPAA authorize – HIPAA access. Because to – for a patient to allow set individuals to say, well okay, you can give them the result of my lab tests or you can work with them to schedule an appointment, that's not – that doesn't require a legal –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

No, it –

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

– document and I think it's really important for us to make that clear distinction.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

I agree with that. I absolutely agree with that, and I apologize, I tried to get out of the HIPAA realm. I'm just thinking practically about what we try to do to accommodate patients and give them options and choices about how much or how little they want people to be able to do on their behalf.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

And so that suggests that really, I mean, we were not told necessarily that we had to limit our consideration of this issue to just the personal representative circumstance, so I – now I'm looking at the title of the slides, because I printed them out, and it says personal representative. This whole issue came up because we were – it came out of discussions that we were having months ago, maybe even more than a year ago, about policies related to view, download and transmit. And at some point, questions arose about, well what if – what about access by others to a patient's view, download and transmit account? And – for lack of a better way of framing it, and we put those issues to the side. So I think you raise an important point Dixie, that we – that this is not a discussion that should necessarily be confined to personal representatives and that maybe it's about access by designated others –

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

Um hmm.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

– to a VDT – to view, download and transmit on a patient’s behalf or with the patient’s permission; however, we choose to frame it. But it does occur to me that we don’t want to leave the personal representative issue just to the side, right, because at the end of the day, if in fact you do have a personal representative situation, arguably that representative should be granted access to the patient’s view, download and transmit. One could make that argument, but there might be a separate set of issues, because they’ve got that legal authority that distinguishes that circumstance from some of the others.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

We might recommend policy on what level of authorization would be required to give them access via view, download and transmit.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Agreed.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Okay.

Judy Faulkner, MS – Founder and Chief Executive Officer – EPIC Systems Corporation

Deven, could I bring up a slightly diff – this is Judy.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Sure.

Judy Faulkner, MS – Founder and Chief Executive Officer – EPIC Systems Corporation

Could I bring up a slightly different issue? And that is, what should the rules be for the patient to authorize it? Should the patient authorize it, some of our customers require a handwritten signature –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Um hmm.

Judy Faulkner, MS – Founder and Chief Executive Officer – EPIC Systems Corporation

– that be required, should it be required that you go to the healthcare organization to set up or change something? Should it be allowed that you can do it over the computer? How do you do that?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

Um hmm, yeah.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Good point.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Very good point.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

I think it’s probably a ra – I suspect there’s probably a range of practices out there, because all HIPAA says is that you’re permitted to share information with friends and family members, as long as the patient hasn’t objected. But there isn’t anything that would prevent an organization in an abundance of caution to ask that there be sort of some sort of designation in writing of that.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Yes, but I'll tell you, this is – this is John Houston. And I think though, as technology progresses, one of the things we do, again based upon what Judy's product provides, is you can proxy anybody, as long as they have an account, to your record. And so that's the most powerful way to do it is you give – especial – as long as the patient has their own fa – has – are in control of their faculties, you give them the right to decide if and when and how you want them to have – somebody to have access to the record. And it doesn't have to be a – it could be a friend, it could be family, it could be whomever, but you put that within the patient's control. So I think that's another piece of all this, too, is how do you – are you giving them better tools if you allow them to do that themselves independent of even the provider?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Hmmm.

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

This is Wes. This may be redundant, but, one of the things that really rang out was the stuff that John said about there being a level of access that you want to grant who could be giving you medical advice or advice on which of the options your physician is offering to choose or things like that. I mean, many people rely on a friend who happens to be a clinician –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Right.

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

– in those situations and if we do nothing else but create a differentiated level of access for that particular role, I think we will have accomplished a lot. We may find there are other distinctions as well, or we could drive ourselves crazy coming up with the different roles, but I think the very specific one that John mentioned as a typical use case is really critical.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Huh. I had not thought of that Wes and you know what, I must have been focusing on another part of John's comments that was – because I didn't catch that, but I just made note of it.

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

We're having some personal experience with a relative right now, so we're sensitive to these issues.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Ah. Okay. Great. Well, we know we have Joy back on the phone, which is great, and we're coming up on the halfway point to our call, so I'm inclined to make a right turn and allow her to present the summary. But I wanted to just do a gut check on when our next call is and to see if folks who have agreed to provide us with some additional information on how they handle this, John and Judy with respect to what EPIC allows. We'll do some outreach to David McCallie and to Larry Garber and others who were not able to make the call today. Leslie will have a chance to get her paper around. I'm just eyeballing when our next Tiger Team call is, does somebody know off the top of their heads who's on the phone. I have February 10 on my calendar.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

That's the next one.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

All right, between now and February 10, hopefully we can do some more information gathering here. Because I'm pleased at the level of interest in this topic from everyone today, it's great. But it's just – it sounds like in order for us to really be productive in coming up with some recommendations or thoughts, we're going to have to do a little more digging – digging beyond the law. Does that sound good to folks?

Judy Faulkner, MS – Founder and Chief Executive Officer – EPIC Systems Corporation

Sure.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Yes.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Okay. Joy, are you ready?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

I'm ready, are you all ready?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

We are ready, we just – I'll ask our friends at Altarum to bring us back to the beginning of the deck for your presentation –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Okay.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

– since we skipped over it. Ah, perfect.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Know what, I'm not ready.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

You're not? Like seriously?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

I didn't have it – I don't have it up on my – I have to get back on my website here.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Oh, okay. All right, we'll give you a moment to do that. In the meantime, I'll say as a public service announcement, all of you should have received, from the folks who send out all our Tiger Team mailings, the link to the transmittal letter for the accounting of disclosure recommendations. They're up on the web, the letter has gone through its entire process and we are officially finished with that issue.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Okay.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

If you didn't get your link, let me know.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

So am I driving this bus or is Altarum driving?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Umm, do down to the arrow and see if it –

Caitlin Collins – Project Coordinator, Altarum Institute

Just let us know when you want – when you need to move to the next slide and we will do so.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Okay, good enough. All right, well welcome back everybody, happy belated New Year. I'm sorry I missed the first call, but I was on vacation and I am now back. And as a – the beginning of the new year, what we wanted to do is we wanted to start giving you all an annual summary of the privacy and security activities that you've engaged in in the prior year, so that you can see the progress that you all are making. But we had to start somewhere and so our first annual summary of Privacy & Security Tiger Team activities will actually be a multi-year summary. Because we think that it's really important for you all to see just how much progress we've made in a relatively short amount of time that you – I know that sometimes it probably seems that it's been forever, but the relatively short amount of time that the Tiger Team has been in effect. Next slide please.

So you all are members of the Privacy & Security Tiger Team and I really don't need to remind you of who you are, but we – not all of you have been on the Tiger Team forever. So, it's good to know that the Tiger Team was formed in 2010, shortly after this office, the office of the Chief Privacy Officer was created. And it was originally called the Tiger Team because at the time, that was the term – in the consulting world – I'm sorry, I'm going to have to put you on mute for just a moment.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Oh dear.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

While Joy does that, if for some reason we aren't able to hear the entirety of the presentation, Joy is also going to do this same presentation at the Policy Committee on February 4, so maybe we'll check in with her when she gets back and see if it might just be better to defer to the Policy Committee meeting.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Okay, although not all the members of the Tiger Team are on the Committee. It doesn't mean they couldn't listen in, but obviously, if it's going to keep getting interrupted, I don't want to waste everyone's time.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

No, we're back, we're back. We have been told that they have it under control and we don't have to leave the building.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Oh, very good.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Good.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

That's excellent news.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

That is excellent news, and so I will proceed with all due haste. So originally there were a lot of issues that were really on fire and that's why this was called the Tiger Team and it still is that way in a lot. There is so much going on in this area, and this team has done so much work, that it still is a Tiger Team. It addresses issues; it gets thrown a lot of things from a lot of different offices in ONC. And so these are still very critical privacy and security issues, so, I think that the name still remains very important. Next slide please. These are the members as of September 30, 2013, which is when we had to have a cutoff date, so we used the fiscal year, the end of the fiscal year 2013. Next slide please. And as you can see, there's also a lot of contributors from former Tiger Team members. Next slide please.

As you all know, the Fair Information Practice Principles have really been a foundation for the Tiger Team recommendations. And it's been something that the co-chairs insisted on from the start is that there be some framework. A basic framework that you could go back to and look at and measure against as to whether the work that the group was doing met what have often been seen as the gold standard for privacy in the IT world, and that's the Fair Information Practice Principles. And you can see them listed here on this slide, and I'm sure most of you are very familiar with them, such individual acts as correction, individual choice as to how information is used, collection, use and disclosure limitations, safeguards, the quality and integrity, openness and transparency and accountability. Next slide please.

And the Tiger Team has addressed these – has used – addressed these Fair Information Practices from a very specific perspective, and that's what they call the core values. That when you all are looking privacy and security in the terms of health information technology, you're looking at it in a way to make sure that the relationship between the patient and his or her healthcare provider remains the foundation of trust in health information exchange. So that is a very important concept and we really appreciate the fact that you return to that to make sure that that trust is not something that – is something that's really preserved as we move into health information technology. That the providers who have the most contact with the patient are responsible for maintaining the privacy and security of their patient's records that the patients are pretty much at the center, which is something ONC believes. That you consider the patient needs and expectations and what we've often articul – heard articulated as a "no surprises rule," that a patient shouldn't be surprised about or harmed by the collections, uses or disclosures of information. And underlying all of this, of course, is a theme that runs through so many of your conversations, which is that as we are working on this, we need to make sure that we earn and maintain the trust of both the consumers and the physicians. Next slide please.

In carrying out these investigations and examining information, we've had a number of what I would call very major public hearings, which are listed on this slide. Starting with the Consumer Choice Technology back in June of 2010, Addressing Patient Matching, which is a topic we continue to come back to, Trusted Identity of Physicians in Cyberspace and Patients in Cyberspace, both ongoing issues that we continue to address, Non-Targeted Query and Accounting of disclosures. And all of these public hearings have really then made deliberations very transparent to the public, so people understand where the recommendations are coming from. We have, over the years, attempted to make these more publically available in the sense that we've introduced the concept of having portals where people could – where just the general public could also give – who are not – of course we can't have everybody testify, but finding new creative ways of getting more input from the general public to make sure that everybody has a chance to be heard. Next slide please.

So I don't want this to be – we often, particularly us in the government, have a way of establishing metrics that are based just on numbers. We don't want this to be just on numbers, but we do think it's important to realize that the Tiger Team has made a total of 160 recommendations. This is a lot of work. And it's a lot of information, and a lot of suggestions as to the way – the areas in which ONC should head. Of those recommendations that were – 154 of those were approved by the HIT Policy Committee and transmitted to ONC, sometimes after a little back and forth between the Policy Committee and the Tiger Team and 6 recommendations were withdrawn as no longer relevant due to ONC actions that we've taken. Next slide please.

The Tiger Team recommendations cover all aspects of the Fair Information Practices. As you can see, safeguards, which is kind of in the security area, has been an area where there have been a lot of recommendations, as have individual choice is probably the next highest one. You can see that there have been a number of different areas that have been addressed and again, I wouldn't focus too much on the numbers, that just demonstrates – is mainly to demonstrate that the Tiger Team has addressed all aspects of the FIPPs. Because some of these recommendations are quite detailed and some of them are more general and we, of course, appreciate the substance more than the numbers. Next slide please.

The Policy Committee has adopted, here are the ones that the Policy Committee has adopted and forwarded to ONC, which again you can see how things break down a little bit. Next slide please. And we've adopted over 50% of the Policy Committee Tiger Team recommendations that were forwarded to us. Now there are a number of categories that are listed here, and I want to just describe a little bit about what they mean, and I – as I'm discussing this, I would say that we do have a matrix that tracks all of these recommendations and where they ended up. And the categories can be a little bit fuzzy as to whether they're solely adopted or partially adopted, but I think you'll get the general gist that we list – when the Tiger Team makes a recommendation and the Policy Committee adopts it and forwards it, these are things that HHS considers and does some action with respect to.

Now that doesn't mean we always accept everything, but it does mean that we do adopt it. And that's one thing that I really did – do feel like we made a commitment to the Tiger Team when they first started that we were going to make this a valuable experience for you and for us, and that we were going to make this – act on recommendations that we received. Because we think that it's very important that when you have a Federal Advisory Committee, that – they are created for a purpose and it's not just to make recommendations that will sit up on a shelf, it's something that should be at least considered and if possible, acted on.

So a brief explanation of these categories, the one is – the first category there is solely adopted, and that's where HHS has implemented the recommendation, either in federal rulemaking or we directly initiated action to act on either the recommendation or to implement the recommendation in a practical fashion. A good example of this is the recommendation that we had that we should make clear in the final rule that meaningful use criteria regarding uses of health information do not override existing state or federal law, setting parameters around access, use and disclosure of health information. And then ONC, when the final rule was – MU Stage 1 final rule was released, it specifically states that nothing required in this final rule should be construed as affecting existing legal requirements under other federal laws. That while the capability provided by certified EHR technology may assist in the compliance of certain legal requirements, they do not in any way remove or alter those requirements. So, those are some of – that's an example of a recommendation that we received and that was really what we – we have used the term solely adopted, that it was not altered, it was just recommended and we said, okay, we're going to run with that one.

We have partially adopted where we adopted – implemented the recommendation in a final rule or indirectly initiated action to act on the recommendation or implement the recommendation. And in these it – this is where adopted, solely adopted, partially adopted, you can maybe quibble about some of them and I don't know that it really matters that much. But an example of this would be, for example, the Tiger Team recommended that the attestation for doing a security risk assessment should be reinforced through audit. And then CMS, when it issued its final rule stated that they were developing an audit strategy to avoid fraud and abuse caused by false attestation. So, it isn't necessarily a direct adoption, but you can see that it clearly reflects the thought process behind the Tiger Team and the Policy Committee.

There is also the category of action pending, and those are recommendations that we've received, that we're considering what, if any actions to take. And some of these recommendations were made as recently as September 2013 and so, some of these are still under consideration. Because, I know September might sound a long time for folks on the line, but given the fact that we were out for the first couple of weeks in the new fiscal year, and we're still digging out, to us it seems like yesterday, so some of those are still under consideration for just timing purposes. And then some of those are under consideration because we're still, in some ways, in some circumstances, waiting to see what the market is doing. And it's always a little bit of a challenge to determine when, if – when and if federal intervention is necessary. Timing can be everything.

And then there's the last category, which is in process where we've taken some action in response to the recommendation, but we may be taking additional action. So one of these issues is, for example, identity-proofing policies with respect to when clinical providers access information data remotely, so we've taken some action in that area, we've recognized that this is an area that was of concern to the Tiger Team that it presented a greater risk to security than onsite access. And was partial – was part of the reason why HHS conducted the mobile device roundtable to find out what people were actually doing in this area, and then subsequently held a 30-day public comment period to identify other areas and issued its – a practical advice on that topic. Next slide please.

So as you can see, there was a lot of the recommendations have come in, we've thought about them, we've taken a lot of action on them. And in particular, of interest I think to many of you is how do these – how did some of these recommendations – where did they end up in the rulemaking process? And, as you can see from this current slide, to know surprise to you, Meaningful Use Stage 1, Meaningful Use Stage 2 are two areas where Tiger Team recommendations have clearly been adopted. The recommendations went into the Common Rule Advanced Notice of Proposed Rulemaking, so they have been taken into consideration with all the other comments as that continuous rulemaking process advances.

And then we also use these as, ONC itself has fairly limited rulemaking authority, but what OCPO does is we – ONC does, and in particular my office, is we are involved in the clearance process for many federal rules, and most federal rules involving privacy of health information. Hopefully all of them, but we're realistic and we realize we aren't put on the distribution list for all of them, but a lot of them. And so when we have received in rules from other HHS offices and even from other agencies, we, when we are making our comments on those rules, look to the recommendations we've received from the Policy Committee as guidance for how we respond to those proposals, the proposed rules, for example. And I think that you will even note that when you read some of these rules that have been issued, that the Policy Committee's recommendations have been used as a basis for the privacy provisions that have been adopted. Next slide please.

One of the – I wanted to give you a walk through, very briefly, a sample implementation where the Tiger Team made a recommendation to the Policy Committee, which sent it on to us and how we acted on it. And so one of those was this recommendation that originated in the Tiger Team and came over from the Policy Committee, that said include in Meaningful Use Stage 1 the requirement that eligible professionals and hospitals conduct a security risk assessment under HIPAA and that we should provide appropriate guidance. And we did two things with that, the first thing we did is that we adopted that recommendation and professionals and hospitals are required to attest that they have actually done this part of the Security Rule, that we all know that they were required to do anyway. Yet this has given a tremendous amount of priority to conducting a security risk assessment that had not been there before. We have heard more about security than need to perform a security risk assessment since this was put in this rule, than you probably heard in the last 5-10 years. So it has made people aware of something that they probably needed to do for a long time, and now they understand that they need to do it in order to receive payment.

In addition to that, so that's the policy piece, but we also recognize that we did need to provide some assistance to providers to carry through with this requirement. So we released a security risk assessment tool to the Regional Extension Centers, providing technical assistance to professionals back in February 2011. And although it's kind of a new a little bit – a new thing, we will be releasing – we've been working with OCR very closely on releasing a second version of the security risk assessment tool, which is more to the – that will be able to be released to the general public, which is more geared towards a non-health IT professional, which is a kind of difficult – it's a delicate balance to walk to make sure that it's legally sufficient yet still understandable by the general public. Next slide please.

We've also issued program guidance that has been influenced by the Tiger Team recommendations. Our first program guidance was released to the health – both of the program guidance examples were released to health information exchange grantees. And in particular, the one that's designated as 3 three on the slide, which is the privacy and security framework requirements and guidance. It provides directions to states and state designa – and designated entities on the suggested approaches for ensuring private, secure health information exchange of individually identifiable health information. So, we took the recommendations and although we did not have the authority – the jurisdiction to draft a regulation on this, we did tie some federal funding to saying to people, you receive federal funds, this is where we think that you – how we would like you to see that you protect health information. Next slide please.

We've also initiated a number of privacy and security projects, some of which you can see – some of which the projects started before the Tiger Team got involved. And many of them, which actually originated very much as a result of recommendations that were made by the Tiger Team. And one I would like to in particular point to, recent ones that I would like to point out are the Notice of Privacy Practices Project, which we received recommendations on transparency and we worked very closely with OCR in developing a layered model notice of privacy practice, which was recently released. In addition, there were recommendations that were related to the Query Response Model for health information exchange including how we – there was recognition from the Tiger Team that this may be somewhat time consuming for providers. And they were looking for some kind of exploration on how you could do this, how you could educate patients and make it meaningful choice, and we explored that through this eConsent Trial Project with the Western District of New York. Next slide please.

So as you can see a lot of the Tiger Team and the Policy Committee's recommendations have ended up in policy, they've ended up through practical what I would call technical assistance. They've ended up in demo projects and in pursuit of potential standards. We have tried to look at different potential levers that we can use as ONC, in order to move forward the recommendations that we have agreed to take on. So our next steps with this is there will be a – we will share this briefing with the Policy Committee on February 4, so they can see a lot of the hard work that you all have done. We are establishing an info graphic, which will give a visual overview of your work and as well as an executive summary, a 2-page narrative that we can use.

And you might wonder why we did this. One of the reasons we have – we've done this for a number of reasons. One is for what I would call a somewhat selfish reason is, we have received a number of inquiries from our oversight entity saying, well how do you designate – how do you prioritize the work that you do? And when you hear, what are you doing about it? And it's been very useful for us to go through this and, I'm sorry, but I'm not leaving.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

You can't say that on a public call.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

I'm not leaving.

W

All clear.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

All clear, there we go, I don't have to leave. I'm sorry, where was I?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Why are you doing this, Joy?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Why are we doing this? Well some of it is for an ONC kind of selfish perspective which is, we receive inquiries from our oversight body saying how do you prioritize work? And it's been very useful for us to go back and look at these recommendations and say, we prioritize work and we do these projects because actually, we've received recommendations from our body of stakeholders, the Federal Advisory Committee that has recommended we do this work. And it's been very helpful that way.

But we also wanted to do this for you, the Tiger Team and the Policy Committee, to show you how much work you've done and how useful it has been. And to give you a really big thank you for all of the work and all of the time that you had put in over the last several years, and to tell you, it really does make a difference. So, I would like to end with a big thank you to you, the Policy Committee as well to MITRE, without whom we couldn't have all of these meetings and we would not have this Executive Summary. Any questions?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck and Associates

I just want to thank you Joy, this was so informative and it really was encouraging to see what's happened to all our work. So I think you've done a great job with the summary and so has MITRE, so thank you.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

This is John Houston, I follow up, I agree and to be a little tiny bit selfish, when are these things going to be available, like the Executive Summary and the briefing and the like. Because I – when my boss asks me what the heck do I do on these calls, it's always great to have something to give him in return.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Good point, John.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

The presentation itself is public, but when will these be – this spring. The other items I'm hearing will be sometime this spring. So, the sooner the better, we understand, but soon.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

If you could distribute them and make sure they get out, it would be greatly – much appreciated and then the Executive 2-page narrative or even – it would be great. I do want to be able to provide that to my boss.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

So when we are ready to release this, we will make sure that we distribute it directly to all the members of the Policy Committee and the Tiger Team, directly.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Great.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

That's great, Joy, thank you. Does anybody else have any questions? All right, well Joy, thank you very much, I'm going to be eager to hear the reactions of the other members of the Policy Committee whom we don't have on our Tiger Team to this. Just, it's helpful to have, it's not at all satisfying to be on an Advisory Board when you sort of feel like your recommendations are going into a black hole, so it's always nice to have it reinforced that in fact, you do care what we have to say –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Oh we –

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

– and we appreciate it very much.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

We do and we have found it extremely useful and I think the fact that when you – a lot of the HHS recom – notice of proposed rulemakings and the preamble to final rules, you will see references to the Policy Committee recommendations on privacy and security.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Yup, I have seen them, so – because they're usually rules I'm trying to comment on, so –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

I was going to say, you usually have to – search – to find it, but they are in there.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Well and honestly, there have been occasions where I've been sitting down to write a comment on behalf of my own organization and had very little difficulty writing it because I basically say, I agree with what the Policy Committee recommended.

Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated

This is Wes. I think we wouldn't be complete without acknowledging Deven and Paul, particularly those of us that have been on the team since the start that recall we were dealing with some organizational and perhaps leadership difficulties in getting this work addressed before. So, for Paul and Deven and Joy, I'd just like to say, for she's a jolly good fellow, for she's a jolly good fellow – ”

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Thank you Wes. I'm glad that this is going to go before the Policy Committee so Paul can see it, because certainly, and I give kudos to all of you. We have retained a significant number of our original members for the entire 3-year period, which is really a bit unprecedented among other workgroups that have had a lot more turnover. And so for all of you who are new to this process, welcome to what is already a really good team.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

So I don't know if everybody saw this, but the Tiger Team essentially was named to – by Health Info Security as one of the most influential people for 2014.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Yes, they're projecting us to be among the most influential on security issues.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Yeah.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

And I said, has to be based on past work.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

When did – I didn't see that. When and where do we see – find that information out at?

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

Oh, if that – we should get that link circulated.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

This is Michelle; we can circulate it to the workgroup.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

That would be great.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

That would be great.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

All right with that, I think we have some prep work to do for our next call so we can dig deeper into this personal – not personal representative, friends and family and others access to health information through view, download and transmit, including personal representatives, but not limiting to them. So if you volunteered to provide us with information, we will be following up with you. I think we should be able to make much more progress on this and either be close to finishing or finishing by the next call. We'll just sort of see how much digging we can do between now and then. But I thank all of you for your really helpful input on the discussion that we were able to have today. Is there anything else anybody would like to chime in on before we go ahead and open to public comment a little bit early? Okay, Michelle, we're ready to hear from the public.

Public Comment

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology

Operator, can you please open the lines?

Ashley Griffin – Management Assistant – Altarum Institute

If you are on the phone and would like to make a public comment, please press *1 at this time. If you are listening via your computer speakers, you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. We have no public comments at this time.

Deven McGraw, JD, MPH, LLM – Director – Center for Democracy & Technology

All right, terrific. Thank you Joy for that summary, thanks to all the members of the Tiger Team for joining today and thanks to members of the public for listening in, I'll talk to you all in a couple of weeks.

John Houston, JD – Vice President – University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics

Thank you.