

**HIT Policy Committee  
Privacy & Security Tiger Team  
Transcript  
January 13, 2014**

**Presentation**

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Thank you very much. Good afternoon, this is Christianne Williams from the Office of the National Coordinator. This is a meeting of the Health IT Policy Committee's Privacy and Security Tiger Team. This is a public call and there will be time for public comment at the end of the call. As a reminder this meeting is being transcribed and recorded so please state your name before speaking. Also, if you're not the one speaking please mute your line. I will now take roll. Deven McGraw?

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

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Micky Tripathi?

**Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative**

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Dixie Baker?

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Judy Faulkner?

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

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Leslie Francis?

**Leslie P. Francis, JD, PhD – University of Utah College of Law; National Committee on Vital & Health Statistics**

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Larry Garber?

**Lawrence Garber, MD – Internist/Medical Director for Informatics – Reliant Medical Group**

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Gayle Harrell? John Houston?

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

David Kotz? David McCallie?

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Wes Rishel? And Kitt Winter?

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

Here.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Is there anyone from ONC that's on the line?

**Kathryn Marchesini, JD – Policy Analyst – Office of the National Coordinator**

Kathryn Marchesini.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

All righty, anyone else?

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

Wes Rishel.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Wes Rishel thank you for joining.

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

Sure.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

All righty, Deven I'll turn it over to you.

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

All right, great, thank you very much. Happy New Year everyone. I hope you had a terrific holiday season. We're back to work as a Tiger Team with our first meeting of the year and it's kind of exciting. I want to talk a little bit about what we're going to talk about today.

We are going to do a brief de-brief, a short de-brief I should say of the results of the Health IT Policy Committee last month when they considered our recommendations on accounting of disclosures then we're going to spend some time going over our proposed work plan for 2014 and we'll begin to talk about the first issue on that work plan involving access to patient information by the personal representatives of a patient.

And what we're going to try to accomplish on this call is really just to start getting your thoughts about what areas we need to consider and I'm glad that we have a number of you on the phone who have potentially been on the implementation side of this in terms of maybe even so far as to begin Stage 2 of Meaningful Use and making view, download and transmit capabilities available to patients and sort of thinking through how you accomplish both the access by patients and potentially also their personal representatives.

But before we dive into any of that I want to make a couple of announcements in terms of Privacy and Security Tiger Team membership. We have a new co-chair of the Tiger Team I think we – I know that we have talked about this previously because we said our farewells to our previous Co-Chair Paul Egeman towards the end of last year, but we have Micky Tripathi now is the Co-Chair of the Privacy and Security Tiger Team.

He and I are Co-Chairing both the Privacy and Security Tiger Team and the Information Exchange Working Group not necessarily because we're glutens for punishment, although clearly one could say we are, but the idea was to try to eliminate the duplication of effort that was popping up more and more often between those two Working Groups since a number of information exchange issues also trigger privacy and security issues and we were not necessarily conflicting with one another but that required some effort on the part of people who had overlapping membership between the two groups.

So, the way that we intend to reduce that conflict if not eliminate it is to have the same Co-Chairs of both groups and to have a bit more overlap in membership, Dr. Larry Garber, who has been with us for a few months now, also helps us serve in that capacity and he also is a practicing physician replacing a big hole that was left when Neil Calman resigned due to time constraints.

And then we're also being joined by Professor David Kotz who is a Computer Science Professor at Dartmouth College and I'm completely understating his credentials he is really quite accomplished in computer science and in the security field and while I don't think he was able to join us on the call today he was at the Health IT Policy Committee back at its last meeting in December, the first one since his appointment by GAO to the Privacy and Security slot and I'm very much looking forward to having him as a member. So, Micky I don't know if you want to add anything to that?

**Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative**

No, thanks Deven, just wanted to say thanks, I know there are very big shoes to fill I won't even try, but I hopefully can be helpful and also wanted to welcome the new members of the Tiger Team and looking forward to a great year ahead.

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

All right, terrific. So, with that we'll move to a de-brief on the results of the Health IT Policy Committee meeting back in December, we presented the recommendations that we all worked very hard on and they were unanimously adopted by the Health IT Policy Committee with one addition.

There was a suggestion by Christine Bechtel, who is a member of the committee, to add a recommendation that the Office of Civil Rights at HHS further explore whether the patient request for investigations of inappropriate access to their records are being honored and one way that the office could do this is to sort of when they follow up on complaints that come in from consumers they can, you know, get a sense of sort of how well their complaints from individuals are being responded to by these covered entities.

In addition they have audit authority as well and it would certainly be up to them about whether to look into this particular issue further but that certainly was a recommendation that was suggested by Christine and that was endorsed by the Policy Committee.

So, the official transmittal letter is not up on the website yet but it is finished, it basically is a recitation of what was in the slides since they were pretty comprehensive slides and we'll circulate the link to that as soon as it's ready, but I just wanted to, for those of you who are not aware, it got a little bit of press in the trade press but not a huge amount I didn't think and given that it was December and folks were beginning to think of the holidays and not work I wanted to make sure that everyone was aware that all of your hard work was incredibly well received and now it will be up to HHS to decide whether and how to act on those recommendations.

Does anybody have any questions about all of that or want to add any additional information for those of you who were present or were observing the meeting last December?

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Hey Deven this is John Houston.

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

Yes?

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

The point about investigations by OCR, I'm sorry OCR explore whether patient requests for investigations of inappropriate access to their records are being honored.

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

Yes?

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

That's in response to our recommendation about, in lieu of or an alternative to doing accounting of disclosures is if the patient knew of a specific individual that they were concerned about that focused audit would occur, is that where this comes from?

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

Yeah, it's in response to the recommendation of, you know, rather than an access report –

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Right.

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

When patients have concerns about inappropriate access to their records they should ask for an investigation –

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Okay.

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

And the entity should respond to that. So, that's a really good clarification that's what it's about.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Because one of the things that I – you know, I understand that it's nice to have OCR explore this but this part of this already occurs today, you know, if a patient goes to OCR and says today "hey, I think somebody inappropriately accessed my record at UPC" I'm going to get a letter most likely from OCR asking, you know, what we've done.

So, I think this part of it already occurs. I think the real important part of this recommendation was some type of express or task, or approval of the ability of patient to have an audit performed or some, I don't know, some type of guidance about doing focused audits or the like, because that's really I think what the patients find most valuable is the ability to get a focused audit.

So, I'm not sure whether that's part of the – ultimately the recommendation as well and this is just an addition to it or we missed the purpose of it.

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

No, no, I mean, so we did – the other thing that we did was to say that the implementation specifications in the security rule should in fact be more – should include some provisions that would frankly improve the capability of audit trail technology to detect inappropriate access.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Okay.

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

And, you know, so in the context of sort of where that piece of it – so we did have that aspect of it, we do not have, John, a recommendation that says that entities should be given additional guidance on how to investigate these claims largely because I don't think that we got any testimony from anybody as part of this effort that suggested that it wasn't happening.

But in the context of getting the recommendations through the committee, you know, a concern was expressed that, well, you know, if we're relying on these investigations as the mechanism for dealing with inappropriate internal access how do we know that that's actually happening.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Okay.

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

And that was the reason why that was – if you're telling me that you – that from your position as a covered entity that OCR responds to these complaints quite seriously then in essence they will look at this recommendation and say potentially "well, we're already doing that."

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Okay, good. All right, great, I just – thank you.

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

Okay. Any other questions or thoughts? All right, terrific. Again, I just, I can't tell you all enough how much I appreciate all the hard work that you put in to the Tiger Team particularly on issues like the one that we just did with accounting of disclosures that was really, really hard and so hopefully we've provided the kind of guidance that HHS will find useful and I expect or I hope that we will hear in the coming months just how useful they thought our recommendations were.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Deven, can you send us a copy of the transmittal letter when it's finished or is easy to know when it get finished?

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

Yeah, so I offered to circulate the link but there certainly isn't anything that bars us from sending you a copy of it and the link because that's where it will sort of permanently reside on the website. We'll definitely do that. So, thanks for asking.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, yeah, it's just nice to have a local copy sometimes you need to reference it and you can't remember how to find it.

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

Yeah, yeah or it's on the website under the, you know, under the date that the committee approved it and you forget what day that was that's happened to me a lot.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yes.

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

But in the meantime I think the only thing that's holding it back from being posted is actually that we have to get Paul Tang's signature on it, so it will get there.

**Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative**

So, Deven?

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

Yeah?

**Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative**

This is Micky, I got a call from a reporter this morning asking about the Privacy and Security Tiger Team work plan and they asked specifically if we were going to be revisiting AOD and I hope it's okay with you my response was not if we can help it.

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

That sounds good to me. I think you might have a Tiger Team consensus on that one.

**Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative**

Well, I thought the letter was extremely well written, I thought it was terrific.

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

Well, good, yeah, I mean, and again it reflects a lot of work that we put in on wordsmithing and constructing those slides, so, you know, sometimes there is an advantage to being overly detailed in your presentations it makes the letters a little bit easier to put together.

All right, so speaking of work plan. I have it up on your screen now, it's been approved by our Chair, Paul Tang, although I will note a suggestion that he had for us in just a second, but this is a combination of issues that have sort of – some of them have been on a list that we have compiled from time-to-time of issues to deal with and some reflect some specific requests from HHS on areas to focus on or from Paul Tang in terms of sort of where he would ideally like for us to have some additional deliberations and so that's where these come from, you know, they're not picked out of the air.

This is all of the workgroups actually so you can see a little bit, if you can read the fine print, what others are doing. We're going to – in the first quarter of 2014 deal with the implementation issues around personal representatives and I use the term proxy here as well that's typically a state law term, the term personal representative is the term that's used in the HIPAA Privacy Rule.

We had questions around this issue that came up a little bit during our deliberations around the issue of view, download and transmit but we didn't have really sufficient time to sort of tease out those issues a little bit more during our prior view, download and transmit conversations and so we have the time dedicated to do that in the first quarter of 2014.

We've also been asked to look a little bit more into the issue of business associate data practices and maybe even holding a potential hearing on this issue. This issue comes to us from a discussion – you'll remember that we had fairly recently actually, taken on the issue of data intermediaries and how to – you know, and intermediaries subsequent use of data and our recognition that the business associate relationship and business associate agreements, and regulation of business associates was really sort of the vehicle that we currently had for regulating intermediary use of data beyond their sort of – you know, the purposes for which they were engaged by a covered entity.

And we acknowledged write up in our recommendations that the business associate regulations and agreement were probably not sufficient. What didn't constitute sufficient governance for these entities because often there is a power dynamic where the business associate actually holds vaster contracting power in terms of, you know, being able to obtain business associate agreement provisions that allow them to use data for other purposes and then there is the issue of just the ability to manage multiple business associate agreements which John Houston I know that you've brought up as well.

So, we've been – Paul Tang in particular on the Health IT Policy Committee was very interested in having us sort of explore this issue to the extent that we can in a little bit more detail. We've slotted it into quarter two.

The other thing I'll add if you sort of take your eyes up to a couple of rows ahead to what's on deck for the Information Exchange Workgroup, this is a bit of old information for that group, we actually may – we are going to be – electronic health business practice Q2 rather than Q1 which means we'll be sort of dealing with a similar set of issues at around the same time and there might be a way to leverage that in terms of hearing schedules and having some aspects of that hearing be joint depending on how we pull that together. Is that right Micky? And you might be on mute.

**Micky Tripathi, PhD – President & Chief Executive Officer – Massachusetts eHealth Collaborative**

Yeah, I was on mute, sorry. Yes.

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

Okay, that's okay. I didn't tell you it was coming. But, yeah, so we put that – so in Q2 we as a Tiger Team may be taking up the business associate data practices issue at the same time as the Information Exchange Workgroup takes up the business practices of EHRs, which EHRs are business associates so in some respect that maybe a subset, the business practices and the data practices – at any rate there is enough synergy that again there probably will be aspects to a hearing that we might do jointly.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Hey Deven?

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

Yes?

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

This is John Houston again, I'll be more than happy to help out however possible on this since I seem to be the one that has the greatest interest –

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

Okay.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

For this subject, so please feel free to, you know, list me as however you want.

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

We will John have no doubt about that, thank you. And then in the third quarter we're going to take on yet another hard issue which is implementation issues around data access and data sharing with respect to minors. This is another area where there is some significantly challenging, for a number of reasons, not the least of which is the differences in state law around when minors are permitted to consent to receive healthcare services without the consent of their parents, which means that in many cases they're the ones that hold the right to privacy, the right to access information and to be able to not necessarily have that information go to their parents.

But, it's an incredibly complicated issue, another one where we will probably have a hearing. I know we've talked about that although it's not necessarily listed on the work plan, but that is definitely part of what we've been talking about.

And then in Q4 we actually have two issues slotted in there, improving the patient right of access in an electronic environment and security policy issues there was one that at one point was teed up for us to consider regarding the implementation of Blue Button particularly with respect to PHRs and Apps for example being able to pull data from provider systems versus what many of us non-technology folks call the "push" of data that's initiated by the provider at the request of the patient to a patient facing technology.

So, that's not a lightweight agenda by anybody's standards and maybe a bit ambitious given that we also have two issues slotted in Q4 and we're still only going to continue to meet on a twice a month basis, as often as we possibly can, for only 90 minutes a meeting and then of course a couple of – potentially a couple of hearings for the year, which of course take more time. Does anybody have any –

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

Deven?

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

Yes, Judy?

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

Oh, yeah, I have a comment, this is Judy. There seems to be an overlap with Q1 and Q3 because when you look at proxies the biggest issue for proxy is pedes and then in Q3 we're discussing pedes. So, I think if we're going to discuss proxies either we eliminate pedes in Q1 or we jump on it in Q1 because it's those early years of maybe 12-18 those years that are the really difficult ones.

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

Yeah.

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

And the proxies, the others are not nearly as hard. And the other thing I – so I don't know how you want to put them together but there is a huge overlap there.

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

Okay.

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

And the second thing is for pedes I think it would be really good to get some different pediatric groups who have done the same or different things and figure out what is the most common thing that the pediatricians are doing, the different pediatric groups are doing and what seems to work best from what they say.

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

Yeah.

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

We might be able to do some research here and find that out and let you know.

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

Yeah, that would be great.

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

Okay, good, then we'll do that.

**Leslie P. Francis, JD, PhD – University of Utah College of Law; National Committee on Vital & Health Statistics**

Deven, this is Leslie, I wanted to say I've written low view articles about both proxy and about adolescent access to medical records and I've got collections at all the state law variations that I would be happy to share.

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

That's terrific.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Hey, Deven?

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

You know, in light of what Judy's comment I'm almost inclined to say let's just deal with adults on the personal representative issue in Q1 and sort of – and then we'll have a set of recommendations that we can build on to handle the more complicated pediatric/adolescent issues in Q3 and in some cases –

**Leslie P. Francis, JD, PhD – University of Utah College of Law; National Committee on Vital & Health Statistics**

This is Leslie, Deven I think you're exactly right on that because with adolescents one of the issues is separate management of different parts of the record. I mean, you're not going to get that quite the same way although you'll get some of it with adults, but not necessarily the same way.

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

Okay.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Hey, Deven?

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

Yeah?

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

John Houston again, we just went through all of this at UPMC and had an enormous number of meetings about just this issue with respect to adolescents so I'd be more than happy to be involved and discuss this. I'm almost thinking we should have a planning session, because in all candor adult proxy is simple.

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

Yeah.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

I mean, adolescent proxy stuff is really, really difficult and so I – you know, it's almost worthwhile having an hour planning session just to talk about how to tee this issue up.

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

Yeah.

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

Deven, this is Kitt, I wanted to – I did have one question on the first issue dealing with the personal representative, you had mentioned that you were establishing the policies related to view, download and transmit and I was wondering whether you were also including the query response, because what SSA does is the query response?

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

Yeah, we can include the query response piece in here, I mean, I sort of had in my mind that, you know, when the issue has come up previously it's come up in the context of view, download and transmit but now that you mention it I think it also surfaced a bit in our query response discussions and we put it to the side. So, yeah, it should be in there too. Kitt, do you agree that it makes sense for us to deal with adults first and if John's right that it's easy that would be great?

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

Well, I think yes, certainly discussing the adults first, but a lot of the issues that we're going to relate to the adults will also then relate to the children –

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

Yes, yes.

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

And carry forward, but maybe then I don't know if you want to switch Q2 and Q3 so one can just roll into the other?

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

Well, the only thing that keeps us from doing that is the desire to make sure that we are not, again, having the duplicative efforts around the business practices issues with BAs and EHR vendors in particular, and that was something that we were given a request from HHS to prioritize that's the problem.

I mean, I get the sort of let's deal with all the issues that relate to one another in, you know, consecutive months, but I'm hopeful that we can, if in fact the adult issues are not that complicated, which would be great, it won't be that hard to resurrect the discussion around pediatrics where there are many, many more issues to weigh and I'm really glad to have so many of you chime in that you have looked at this, have experience with it or can help us sort of think this through and scheduling some time for planning, absolutely we should do that.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Yeah, I think the planning and actually if you just simply plan on doing some planning in Q2 for the pediatric stuff I think it's going to take you to Q2 to get planning done as well as understand who all the interested stakeholders are so you can tee it up in Q3.

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

Okay.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Deven?

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

Yes, David, hello?

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

This is David, yeah, can we change to a different subject or do you still want to –

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

I think so, does that – that's a good question, do folks sort of feel comfortable with the decision to do all the pediatric and adolescent issues in Q3 to focus the Q1 discussion around personal representatives and/or proxies around adults and to dedicate time, I guess towards the end of Q2 or middle to end of Q2 to do planning for the pediatric piece.

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

Deven, when we do planning for the pedes would that include getting representatives in from other places to –

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

No, it would be our Tiger Team discussion about sort of what issues we need to focus on, who do we need to talk to and there may be more than one planning session, but something, you know, in advance I do think we're going to need to have a hearing.

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

Yes, I agree.

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

And then pulling that together.

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

Okay, so I guess what my question is, I didn't word it well, was are we going to be able to bring in advisors from the different places to ask them how well is what you're doing working?

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

Yeah, well, I would anticipate that we could and should do that as part of the hearing.

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

Okay, good.

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

Okay, great. Any other thoughts on that issue before I'll turn to David and we'll pivot to something else? Okay, David, thanks for your patience, go ahead.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Oh, no problem, I think it's a good discussion. At first I'm a little unclear still on the scope of the Q1 work on the personal representations or proxies and so but let me just ask the specific question, I think there is still some noise and unsettledness out there around consumers getting Direct addresses and/or other means whereby they can participate in the view, download and transmit some trust issues around whether who issues their identities and the like. Do we consider that we've covered all those issues as best we can in our previous discussions or is that something that's likely to need more attention?

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

Well, you know, that's a good question, David, I mean, I sort of – I thought that we had, but if Tiger Team members feel like there is some noise that suggests that's not the case.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

I haven't stuck my toe in that water in recent months but I know at least as of a couple of months ago there is still a fair amount of confusion about it, it seemed to me. I could certainly go find out more and give you a summary of what I think might be going on, maybe that's something I should do to start with.

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

Well, that would be helpful and we can – you know, we can ask folks from ONC too, because that, you know, so I think now that I sort of – now that you're mentioning this David I do think that those issues were sort of nested within this improving patient right of access in an electronic environment that we have now moved all the way to Q4 because of the timing on some of these other issues.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, that's – that was going to be my next question is maybe it's a part of what's in that Q4 category there.

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

I think it is, but if it's a more sort of timing urgent issue that would be helpful to know as well.

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

I think –

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Okay, well, I'll see if the folks that are actively engaged in working through Direct and the DirectTrust consider that there are unanswered policy questions that they would like help on and I'll just give you – I'll summarize whatever I find and you can decide what to do with it.

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

Okay.

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

This is Dixie, I was going to make a comment that sort of relates to what David said, some of these policy issues, for example Direct, are coming out of the Consumer Technology Workgroup. I do see Direct still being mentioned there as well as they've been – they're exploring the whole consumer provided data issues that, you know, there are certainly policy issues around that too.

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

Well, that is absolutely true, Dixie, and one of the other things that we're going to have to work through with ONC is the fact that there is now these two new Workgroups of the Policy Committee and of Standards that are dedicated to consumer empowerment issues.

And so the other set of recommendations that were approved by the Health IT Policy Committee, I believe it was at our December meeting, if it wasn't December it was the month before, dealt with the issue of patient generated data for Meaningful Use Stage 3 and those were approved. I don't want to even attempt to summarize what they were because I haven't looked at them in a month or so and I'm afraid I'll butcher them, but there is now another Workgroup focusing on this issue.

So, what I suggest is that when we sort of see if there are some more of these sort of lingering policy issues around Direct that our next step would then be to sort of talk with ONC to see if in fact those should be triaged to us or in fact they may already be, I don't know, under consideration by these two new Workgroups led by Christine Bechtel on the Policy Committee side and then Leslie Kelly Hall I think on the Standards side.

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

Yeah, they asked me to call in for the taskforce they have on Wednesday morning and that's about all I can tell you about it at this point, but if I hear anything from that I'd be happy to feed it back to you.

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

Okay, well, that would be great too, because right now I think we'll just sort of leave it in Q4 for now, you know, pending, you know, sort of some of these inquiries and what we learn from that and then if we need to make some adjustments we'll come back to you guys and make some adjustments.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Then Deven, I have a – this is David again, I have a second question again.

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

Okay?

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Something that I may just be mis-remembering whether we covered it adequately or maybe it's just not on the radar for 2014 but that's this – the data segmentation for privacy/policy issues – we consider that as either not important for this year or solved?

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

Good question, we – you know, when we took the issue up initially way, way, way back during our original consent discussions in 2010 what we had said at the time was essentially, well there's plenty of policy on the books now but uncertain technical capabilities for being able to implement those existing policies and that we thought that the technologies ought to be piloted and, you know, ONC established the data segmentation for privacy pilots as part of the S&I Framework.

And we've essentially been waiting to sort of hear some of the results from that, but we did not reserve for ourselves any commitment to re-assess those policy issues because we were sort of dealing with an environment where there were existing laws over which we did not have jurisdiction, most of them state law, you know, one obvious federal law in terms of the substance abuse treatment rules, but not the entity that we typically advise, SAMSHA, the mental health agency, substance abuse and mental health administration is part of HHS, but we don't advise them directly, that hasn't stopped us in the past – policy clearly. So, it's not a wall, but we usually try not to tread in that territory unless we're or not heavily into that territory I should say unless we're asked.

And then, you know, we don't have any control over the state laws and we were also – we also acknowledged, as part of that 2010 letter, that NCVHS in fact had already provided policy recommendations to HHS and so we didn't necessarily feel a need to re-tread that territory. So, that's why it's not on the list.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Okay and that makes good sense, this is David again, my concern is that some of us who have looked into the pilots and into the proposed technical solutions are worried that if that is imposed on the average provider there is going to be a lot of trouble, that the technology just can't really match the laws.

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

Yeah, but is that a policy discussion or is that a better technical discussion for standards? Because we can't change those policies.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah.

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

The most that we can do, if we were able to get there from a consensus stand-point, would be to say that the policy ought to be revised, but we don't have control over them.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, well, I'm not sure the technology is going to solve – I mean, I think the policies were written in a paper era and they just don't translate to the technologies that we have at our disposal.

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

And this is Judy and I absolutely agree with David it's a very difficult topic.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, I mean –

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

I mean, undoubtedly it certainly without a doubt has come up in terms of sort of people raising concerns about it on numerous calls but in terms of sort of who is the – which is the right advisory body to review the results of those pilots and sort of determine sort of what that means for direction for ONC, it's honestly – it's not entirely clear to me whether it's, you know, it feels to me more like a technology issue than a policy issue.

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

You know I –

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

That's an interesting thing, because when technology – when policy is made that technology can't do isn't it – it is a technology issue but it's also a policy issue.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Right.

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

I mean, undoubtedly, I mean, the accounting of disclosure recommendations that we just made are proof of that concept in many ways. I mean, we wanted a set of policies that technology could actually accomplish versus the other way around. I think what I'm – the brick wall that I keep bumping my head against is that we actually do not have, you know, most of those policies are vehicles of state law and we don't have the capacity to change them.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

But we do have maybe recommendations about, for example, to the Policy Committee of what should or shouldn't be required for certification.

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

Right, but that's typically what standards does.

**Kathryn Marchesini, JD – Policy Analyst – Office of the National Coordinator**

And Deven, this is Kathryn, just to remind everyone, if I recall correctly the Tiger Team when they were reviewing the request for comment for MU Stage 3 when this question was asked around data segmentation I think the recommendation that the group had was to have the Standards Committee further look into this issue as it relates to the technology. So, I think as far as where the group can help out at this point we kind of really need to wait to see what the Standards Group has to say.

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

Okay, I didn't remember that.

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

Does the Standards Group have any EHR vendors on it?

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, I'm on it Judy.

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

Oh, okay, so you can help with that one?

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

And there are a couple of others and I'll speak out because I think you and I share the same concerns here.

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

Yeah.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

That it's just going to be very difficult to implement that paper, those paper-based laws –

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

Yes.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Into the electronic record where the whole point is to synthesize a record rather than to keep them all segregated. I mean my concern of course –

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

And it would also –

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Is if the Meaningful Use process generates more friction with providers for whatever the reason it hurts our cause for all the good things we're doing.

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

Right.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

And I'm just trying to make sure we minimize as many of those rough edges as possible because just sort of the excuse of "oh, it's the state law" that doesn't cut much – that doesn't give us much slack.

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

Well, I agree with you and I think it also misleads the patients who may think it's doable.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah.

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

The other thing is I know that there was a time where Meaningful Use may – I think it got pulled out, but it said for Meaningful Use that one requirement was that it obeys all the laws of the state and that's where I think we were arguing that it was important to not put that in there and make that a whole different thing, but not put it into a Meaningful Use requirement because of this problem between technology and policy.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, I, Deven, acknowledge the bind that we're in, I just predict, you know, feedback, friction, I mean, rarely have there been hearings when as many providers weighed in with angry comments as the hearing that we had on data segmentation for privacy, it was really stunning.

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

Okay. All right, well, why don't – definitely what I'll do is I'll follow up with ONC, you know, and make – Kathryn is on this call, Michelle's able assistant is helping us out today, we'll follow up to see sort of who gets this, whether a piece of it should come to us, whether it's standards, who sort of starts the discussion, but, you know, clearly it's one that we're going to have to have even with all of its challenges.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yes.

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

Yes.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Maybe a discussion with John Halamka and Jon Perlin would be, you know, to verify that they have it on their agenda as well, that might be something that we can do as just a back channel if necessary.

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

Okay, okay.

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

Deven –

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

I –

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

I'd love to be involved with that if that's possible.

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

It was involved on our – this is Dixie, it was – last time I saw the work plan for 2014 it was on the Standards Privacy and Security Workgroup work plan, but, you know, they're in the process of revising that.

And I brought up, myself, the need for some policy discussion around that and Joy made it really clear that the segmentation for privacy is intended only to – only to provide technology to implement existing law.

So, she in her mind has made a distinct, you know, has put it on the technology side of things because it's for existing law and not for, you know, any other kind of segmentation that one might imagine. So, I think it's on our Standards work plan, I guess we'll find out later this week.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, okay.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Deven, this is Christianne, I'll make sure I get everything out to Michelle as well and highlight these issues to her. So, Ms. Marchesini you won't have to worry about that.

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

Oh, thank you Christianne.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Sure.

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

All right, that's terrific. All right, we'll get follow up on that one too. David you always bring up the hard stuff, that's okay that's why we have you, Judy too.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, you should have learned your lesson, you invited me back.

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

We have a good group I hope we don't – I hope we keep everybody through the year.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

We do it's a good group, it's a great group.

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

Any other thoughts on this schedule? This has been a great discussion so far. All right, well let's try to tease out a little bit, oops, we're not in public comment yet, I didn't mean to do that, let's use some of the remaining time, we don't necessarily, we don't at all really have to go all the way to 3:30, but I want to go back to the Q1 issue around personal representatives and proxies for, you know, at least the two use cases of view, download and transmit and then in a query response type circumstance where the patient is the one or requests for information are being made on a patient's behalf, which would be the case in the Social Security Administration example.

And I've asked Kitt Winter to be prepared to talk a bit about some of the issues that they've encountered when they've obtained medical records in order to process a person's application for social security disability benefits so I'm glad that she was able to make the call, but we won't limit the discussion there.

I just want to sort of try to tee up some of the issues we needed to discuss so that when we have our next discussion on this, which is in a couple of weeks, we can have a more complete agenda and we can ask our folks at MITRE, who help staff us, to do some background research, etcetera. So, Kitt, can I put you on the spot and ask you to sort of share why you thought this was an important issue for us to take up?

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

Certainly, I think I'll just quickly give a little SSA background for that and the main focus that we have is developing the policy for the trust framework. From SSA's perspective we are not a HIPAA covered entity but we require an enormous number of medical records in order to be making disability determinations for a patient and in order to obtain those records we need to obtain a patient authorization. So, we ourselves are that proxy if you will or representative.

What SSA uses is query response and what we have done is develop an authorization, our SSA-827, that a patient signs and that authorization was updated in 2003, approximately then, and covers all of the information that was included in the HIPAA authorization attributes, the requestor, responder, the purpose, the date, the timeframes and is signed.

And SSA then sends that request with patient demographics to a data holder and that data holder in turn requests the patient authorization from SSA and then that data holder reviews the patient demographics and authorization and returns it either in an automated fashion or they pause and review it, the data holder then returns that they have the patient and then SSA requests the medical information from them. So, SSA has become a trusted entity for these organizations.

We also then with Health IT developed and eAuthorization electronic version, there is a click and sign through the Internet that allows a claimant the option to sign and submit the form electronically, and it has different options under there as well as we also do an attestation and what we are doing for those individuals is we are authenticating that that individual is who they say through knowledge-based authentication. We also can take it over the phone or in person. So, that's just a high level quick summary if somebody has a question on what we are doing.

The main question that we continue to put on the table is how does the responding organization know or determine the relationship between that patient and the data requester for us being SSA, being the data requester, are there policies in place that establishes that trust relationship.

So, I think overall an organization needs in place those policies to be comfortable in that trust relationship and that could be an umbrella policy like we use through the eHealth Exchange having the DURSA being that umbrella policy. I know state HIEs have those governance policies. So, that's high level, our first couple of questions in that relationship.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Kitt, this is David, are you asking for the technical means of knowing that it is the SSA who is placing the request or something more generic than that? I didn't quite follow you there.

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

It's either a technical or policy-wise. I mean, since this is the Policy Committee I think what we're putting on the table is policy-wise or there could be a mechanism that through the technology that checks it.

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

And this is a question, this is Deven, about that in fact the Social Security Administration has in fact been designated by the patient as being authorized to ask for these records is that what you're talking about?

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

Yes, for SSA what does happen is the patient comes in they say "we're filing a claim." We say that in order for us to make that determination you have to sign a – we have to obtain your medical records.

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

Right.

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

And then the patient themselves is signing that authorization to us that we then share with the data holder in order to request that information back.

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

Right, but it's almost – but it sounds to me like it's not really – I mean, do the entities consider you a personal representative or is this just a plain old patient authorized it that's what's required to release the data in this circumstance under HIPAA because it's not a TPO disclosure and it's not one of the other disclosures so you meet the HIPAA authorization versus being designated as a personal representative.

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

Right, the patient is giving us the authorization I wouldn't say we're a personal representative, but the patient is giving us the information that – the authorization to then request the information.

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

Okay.

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

We just thought for the big picture this is an issue that can kind of cross barriers not just SSA.

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

Okay.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

This is John Houston we were – I believe we were doing something similar to this with SSA but using Healthway in order to accomplish this, is this something different then or am I confusing the two?

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

It's the same thing.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Okay, thank you.

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

We were just asked to describe how we handled that issue and then also make suggestions. I know that we had discussed before the issue of how does the responding organization know or determine the relationship between the patient and the requester in different situations and the overall high level query response discussion.

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

Yes, we did.

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

So, I think that this is just part of that.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Because, you know, in my opinion, I mean, I think that, you know, again based upon having a DURSA in place and a bunch of other stuff I don't know why there couldn't be some type of trust relationship established where, you know, SSA has to attest to the fact that it has authorizations for those patients for which they're requesting records.

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

Right, what we use now is we have our 827, but we use the umbrella policy of the DURSA when we're requesting through Health IT.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Okay.

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

That is what we use, because under health – under the DURSA there are the different purposes of use and we are covered under one of those purposes of use for actually both coverage and disability eligibility or I mean, eligibility are the two areas of purpose of use. So, we do use that umbrella policy of the DURSA, but in the big picture for this committee going also outside SSA we think that's an issue about having that trust framework when you're talking about representatives.

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

I don't – this is Dixie, Deven why does that not keep treatment, payment – for the reason – associated reason of treat of payment? I mean, there are lots of these intermediaries in payments like –

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

But it's not payment for care, the Social Security Administration is not being asked to substantiate a claim for payment for medical services they're being asked by the patient to determine eligibility for a particular program where then they will subsequently, depending on if in fact they are adjudicated to be a person with a disability, they then may end up under Medicaid or Medicare depending and then that's a payment issue when those claims come in, but the SSA doesn't serve in a payment role.

**Dixie B. Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates**

Right but these...you know, it seems to me like any intermediary who would say "yes that's covered under this – under that guy's insurance policy" and there are others besides SSA, would they all have to establish some sort of similar relationship?

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

Yes and they would and the reason that we're bringing it up is not just for SSA because we have done many of these work-arounds, there are other organizations out there like us where you're really covering the authorized release to a trusted entity which is not covered necessarily under HIPAA and it's not for payment for coverage.

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

But, actually Dixie, your question now makes me wonder whenever do you have complete confidence that there is a treatment relationship for example when a request comes in for a doctor? I mean, we did actually cover, when we did query response some, you know, sort of best practices or reasonable things you could reasonably rely on if you are the disclosing entity to know whether you're sending information in response to a query is doing so in compliance with the law, right?

There are no – in many circumstances there aren't guarantees but there are lots of sort of indicia of reliability of which a trust relationship is one, you know, knowing the patient and knowing who some of her other providers are is another there was a whole list of them, this was all part of our query response recommendations now it's not clear to me whether this relationship existence issue is an issue where we need to do any more work.

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

Right and I think that's where – the whole issue is how do you validate trust and it's not unique to SSA.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

That's a technical question isn't it?

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

No not necessarily, it can be both, but it's not just a technical.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

So where is the policy gap that you see?

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

Yeah, I'm not sure for the existence of the relationship that there necessarily is one and then I think the issue of, you know, how do you determine when a personal representative relationship exists?

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

And that's a much more complicated question that we also work with dealing with what we consider representative payees or people assigned but that's a whole different ballgame that I don't think we want to go down right now.

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

Oh, well, that's interesting because that's exactly the issue that I thought we were.

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

Okay, no, I mean, certainly, yes, I mean that is an issue that SSA addresses too where it – I mean then you can talk about minors or you could talk about people who have that personal representative and we do have that issue as well built in where there are different steps that we go through in order to identify somebody who is viable as a representative and covers that individual and will sign for them and has that authorization.

And it could be – you know, there are ones that are the legal representatives and there are also ones that are just assigned to them that might not have authority over other things but do have authority over either the financial or the medical.

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

Right, right. I think we definitely, again, per our earlier discussion, want to sort of carve the pedes so to speak out of, you know, a discussion that we might have in this first quarter about personal representatives, we want to talk specifically about adults.

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

Right, so we have the issue of people who are not capable of taking care of themselves mentally or physically to handle the financial.

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

Yeah, I mean, there are sort of the category of those where the person isn't capable and then there is another category of, you know, well I might be capable but I just might want my, you know, adult daughter to sort of be in charge, right, or my capabilities are more limited but I want some help like – and how do, you know, provider organizations sort of deal with those requests and then from a technology stand-point.

I mean, this is why I keep going back to view, download and transmit, you know, what do you do about, you know, provisioning account access so that they are directly able to get that data versus, you know, having to hear it third hand or, you know, being able to have discussions with the doctor but not necessarily have the direct access to patient data, those are two different provisions in HIPAA actually.

So, John Houston are you still on the phone? We might have lost him.

**Leslie P. Francis, JD, PhD – University of Utah College of Law; National Committee on Vital & Health Statistics**

This is Leslie, I think going and reviewing the prior recommendations and also looking at the question of whether they are issues that they did not deal with adequately is critical not on the technical side, but on the policy side.

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

Okay, yeah, so definitely getting sort of, David if I can impress upon you, the information about whether there are still some issues to resolve with respect to Direct that would help.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah I'm working on that. I'll try to get a summary to you and you can decide whether it's worth circulating it just one sample anyway.

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

Okay.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

And on Kitt's point I'm still – I'll admit I'm still a little puzzled, but maybe when we just formulate it more – write it down it will make sense to me, because I hear a process that is perfectly legal and for which, you know, there are all – the appropriate laws govern the process and it works on paper and if the question is just how to translate the paper process to electronic systems that seems to me to be a technical problem.

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

Right, right.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

But, obviously I'm in the minority so I'm just missing something.

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

Well, I'm not sure you are, I'm sort of – in trying to sort of shape what an appropriate – you know, what a fulsome discussion might be on this issue I think we're still in the issue spotting phase.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

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**Leslie P. Francis, JD, PhD – University of Utah College of Law; National Committee on Vital & Health Statistics**

I'm also – this is Leslie, I'm also not sure that the translation question is all technical because I think there are going to be questions about what you want to be sure of when you –

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, level –

**Leslie P. Francis, JD, PhD – University of Utah College of Law; National Committee on Vital & Health Statistics**

Yeah.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah, levels of assurance may be the – you know, what's the level of assurance equivalent of a notarized piece of paper or something maybe that's where there is a –

**Leslie P. Francis, JD, PhD – University of Utah College of Law; National Committee on Vital & Health Statistics**

Right.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Policy gap.

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

Okay, well, clearly we have a bit of digging to do to be prepared to really dig into this and any additional input from folks will be helpful. We'll definitely have a summary of what HIPAA provides, we'll make sure that we have someone from the Office for Civil Rights on board, you know, for those of you who work within provider institutions where this personal representative issue comes up from time-to-time it certainly would be helpful to get some input from you all sort of how you handle that and whether you think that there are policy gaps that would sort of help improve – whether it's improving compliance or to make this operationally easier that would be helpful to know.

You know, it's funny, I think Micky told me that he had drop off the call at 3:00, but when we first started talking about this issue as Co-Chairs he said, well, I can tell you how it tends to work, you know, from my perspective as an adult child, you know, the parent provides you with the user name and password of the portal and then you just go in and view it, which I'm sure is generally how it is handled in many cases.

**David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation**

Yeah.

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

That rather than, you know, going through the process of getting, you know, an additional account created for the parent that then also has to be populated there is essentially a family account that gets created that the patient then controls how that account access occurs by giving the user name and password and, you know, if that's functionally –

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

Deven?

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

How it operates, you know, is there something that –

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

Deven, this is something I looked into back in the HealthVault days and they use a very similar model an account is created kind of arbitrarily, it gets, if you will, authenticity by various providers deciding to send data to the account.

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

Right.

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

So, yes, maybe George made up the account for Wes Rishel, but Wes Rishel – the doctor had to be satisfied that it was Wes Rishel sending or telling him to send data to that account and it's sort of the aggregate of these providers decisions that actually gives that account association with an actual person.

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

Well, yes, Wes, thank you, but that wouldn't necessarily be the case for an in house account right? Like the Beth Israel Portal.

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

Well, yeah, so if it's an individual portal – I'm sorry maybe I drifted off the discussion point, but for an individual portal there is not going to be anything that avoids delegation by sharing the password.

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

Right.

**Lawrence Garber, MD – Internist/Medical Director for Informatics – Reliant Medical Group**

Right, this is Larry, yeah, that's exactly how it is. We have a tethered PHR and while I'm diligent about making sure that it's the adult child – account has access, now my wife is also a physician and I actually just spoke to her about this last week and she said most of her patients are just giving their passwords to their kids and call it a day.

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

Yeah.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

This is John Houston, I mean that's fine if that's the practice, but I think that we clearly have to provide a better way and I know at UPMC we, you know, our standard is if you're a parent you have to have an account or we'll create one for you and we will provide that proxy linkage but it really should be a separate account for a lot of reasons and I think that in all candor has to be the standard we take here knowing that there is that side practice that some people choose to avail themselves to.

**Leslie P. Francis, JD, PhD – University of Utah College of Law; National Committee on Vital & Health Statistics**

Yeah, one of the – this is Leslie, one of the things you certainly don't want to encourage is thinking that it's just a great idea to share passwords.

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

Yeah.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Yes.

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

Yeah, I mean –

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

It depends, I mean, my husband has my password, it's just the easiest way to do it.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Hey Judy –

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

No, I think John, this is Wes, I think John made an excellent point that we need to have the provisions for more – for a delegation kind of process and I think it becomes more important as this moves towards gathering input and even perhaps gathering some kind of consent in the far off future that we have the capability of distinguishing between the person and the other person who is the proxy for this person.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

And I might add as well that at UPMC we are already doing eVisits and online physician visits with patients and you certainly don't want to mistake who is making the request simply because somebody has decided to share passwords, because from a liability perspective it could change liability dramatically.

So, I think it is important for where all of this is going to go adding the ability to delineate who is making the request and on whose behalf these accounts are being issued and who has proxy and whatever.

And the other thing I want to say too is Judy we're using your system to do all of this and I'm surprised that you give your password away.

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

I know I shouldn't have said that, my husband is a physician so I didn't really much care.

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

Judy I think you're not the only one, I'm certain you're not the only one.

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

Yeah, thank you.

**Lawrence Garber, MD – Internist/Medical Director for Informatics – Reliant Medical Group**

I'm actually my wife's password vault, so –

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

But just remember where the industry is going and with visits and online care. So, I think that's another reason that we have to keep this all clear.

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

Yeah, yeah, good point, very good point. All right, we may be able to put some good best practice and/or policy recommendations forward on this, very, very helpful. Any other thoughts about issues to uncover with this particular topic? And if you think of anything off line you know where to find us, send an e-mail.

Okay, thank you all. I think that was all that we had teed up for discussion today. Before we move into our period of public comment is there anything else anybody wants to bring up? Okay, hearing none, Christianne if you want to let Altarum know we're ready.

**Christianne Williams – Business Analyst – Office of the National Coordinator**

Yes, I can, operator can you please open the lines?

**Public Comment**

**Ashley Griffin – 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 everybody, talk to you in a couple of weeks.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Great discussion, thank you.

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

Thanks.

**John Houston, JD – Vice President – University of Pittsburgh Medical Center; NCVHS**

Bye-bye.

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

Bye.

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

Bye.