

**HIT Policy Committee
Privacy & Security Tiger Team
Transcript
October 21, 2013**

Presentation

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thank you, good afternoon everyone 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, 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

Paul Egerman?

Paul Egerman – Businessman/Software Entrepreneur

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Dave McCallie?

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

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Dixie Baker?

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

I'm here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Gayle Harrell?

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

John Houston?

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

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Judy Faulkner? Leslie Francis?

Leslie P. Francis, JD, PhD – University of Utah College of Law

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Micky Tripathi? Wes Rishel? Larry Garber? 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

David Holtzman?

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

Staff for OCR.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

And are there any ONC staff members on the line?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Joy Pritts.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks, Joy, and with that I'll turn it over to you Deven.

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

Great, thank you very much Michelle, it is nice to be back. We had a virtual hearing on accounting of disclosures on September 30th which was the day before the most recent government shutdown so we were not able to – we missed our initial call in October where we had scheduled some time to debrief from that hearing and begin thinking about what possible recommendations might be, but thankfully we are back in business and we already had this call on the schedule.

We'll continue to remain with our schedule – I don't know what that was. We'll continue with our scheduled calls with the hope of being able to wrap up this issue in time for the December Policy Committee meeting hopefully. So, let's go to the next slide which I might actually have, see we're so out of practice.

Paul Egerman – Businessman/Software Entrepreneur

There it is.

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

So, on the agenda today is really to sort of have an open discussion with Tiger Team members about that virtual hearing. At some point, maybe midway or three quarters of the way from the discussion we'll do a little review of some of our previous recommendations that might be relevant to recommendations that we might make on this issue or at least might be helpful in orienting some of our thinking and then, you know, again depending on how the discussion is going if we're sort of landing on some potential areas of consensus we'll begin discussing those, but we really want to spend the bulk of the time that we have on the call today just giving people a chance to share their impressions from the hearing and begin a discussion about the issues and potentially where we might be able to land.

Paul, I want to pause for a moment and invite you to share any remarks that you might have before we start diving in.

Paul Egerman – Businessman/Software Entrepreneur

Sure, well, I just want to say this topic, accounting for disclosures, is a controversial topic with a lot of interest in the topic. When we held the hearing we were not able to accommodate on the Internet everybody who wanted to sign on, perhaps that was a prediction of future Internet challenges that HHS was going to have, I don't know, but that was certainly an indication that there was a lot of interest.

And so if there are any members of the public on the phone I just want to thank you for your interest in our conversation this afternoon and also want to tell you we will have public comments at the end, a little before 3:30, and so if you would like to make a public comment please do so.

The public comments are important and also moving to the next slide Deven showing that we do have a blog in place, the Health IT Buzz Blog, and that is also a place where anybody can be making comments, it will remain open through this Friday, so that would be another alternative for any members of the public who would like to make a comment on this topic would be to sign onto the blog site and that is the URL on your screen, it's a fairly long one, and then we will also ask the Tiger Team members after Friday to read through all of the public comments.

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

Thank you, Paul and there are already, at least as of Sunday, there were, and actually as of last Friday, there were 18 sets of public comments that had been filed on this blog and we sent the link around to Tiger Team members with the materials that we distributed for this hearing so that everybody would be aware that in fact those comments had been posted.

The blog was not really live during the shutdown but everything that had been submitted previous to the shutdown that had been essentially queued up and waiting I believe is now up. Of course if you have already submitted something prior to last Friday and you don't see it up yet you might want to go ahead and just resubmit it just to make sure that we get it. But through this Friday we'll be accepting comments through that vehicle in addition to opportunities for people to make public comments on the end of our calls.

All right, so just next slide please. Okay, this is – the next series of slides, and Gayle we're on the slide with the number three on bottom of it and for anybody who doesn't have Internet access we're on the slide entitled hearing goals. So, this is just a reminder, again it's been several weeks since we had our heads in this and Paul and I just wanted to refresh everyone's recollection about where we left off.

We had five distinct hearing goals we wanted to understand more about what patients would like to know about uses and disclosures of electronic protected health information, the capabilities of technology that could be leveraged to give patients this greater transparency, how such technologies are currently being deployed by providers, plans and their business associates, other issues that were raised as part of the initial proposed rule to implement, the changes that were in HITECH to the current HIPAA Privacy Rule requirements regarding accounting of disclosures and difficulty in making the distinction between uses and disclosures both from a policy and a technology context. Next slide.

The next couple of slides essentially remind us of the people who were kind enough to share their testimony with us during the hearing. We had a panel of patient perspectives that started us off, we followed that with a panel on vendors and business associates. Next slide. And then we heard from a host of healthcare providers and we closed the day with impressions from the payer community.

So, we really had tremendous participation in this hearing. We again thank the individuals who were willing to share their time with us on that long but incredibly productive afternoon we very much appreciate you taking the time and also the time that people have taken to respond to the blog and to provide us with additional thoughts on this complicated issue.

Paul and I also prepared, with the materials that we sent to the Tiger Team, just a few thoughts that both of us had after the transparency hearing, you know, relevant to the goals and we did not put an account of these – of our thoughts on the slides because we felt that it was sort of too early to, on the one hand be drawing conclusions in advance of the Tiger Team, we wanted to have a fulsome discussion, but we also wanted to kick start the conversation with some thoughts about, you know, whether the proposed access report, for example in its current form, would really be workable and if not why not.

What might be some avenues of opportunity for moving forward? What about providing information to patients about who has accessed their record down to the level of individual person? And so, again, I hope – it's only a two-page document, it's part of the downloads that you'll see on the screen, thoughts from the hearing.

We offered these really just to kick start the discussion but we really hope to have an open dialogue with members of the Tiger Team about what their impressions were of the hearing both in terms of what you think is likely not workable as well as hopefully what you think might be workable. Paul, do you want to add anything as we kick this off?

Paul Eggerman – Businessman/Software Entrepreneur

No, I think you did a great summary, Deven, thank you for doing that. So, the real issue is, you know, what are the Tiger Team member's impressions from the hearing and one way to do that is to think through the panels very briefly like, sort of back up one slide to panel number one patient perspectives, do people have any reactions to what was said in patient perspectives in terms of the three patient advocacy groups who presented?

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

This is Gayle, you know, if I may kind of jump in and start things off, I think from a patient's perspective the three presenters made or at least two of them made a very, very clear case for the need for patients being able to have access to this information. The question really is "is the technology at the stage where that is feasible" and their perspective was "well if you don't demand it the technology will never be there."

So, what I got out of that was that the technology probably isn't totally ready to do this but that the patients are demanding it and that competition and public pressure will really push the development of it whether it is within the record itself or whether it comes from outside sources that patients then have access and can use that by, you know, maybe go on a website and get the information through a paid source. But it was – certainly the patient perspective from the hearing is this is an absolute must.

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

This is Wes Rishel –

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

Let me say – this is John Houston.

Paul Eggerman – Businessman/Software Entrepreneur

Okay, go ahead Wes, first Wes then John.

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

So, first, hello, I'm sorry I missed roll call. One of the things that Gayle brings up, which I think is very true, is that throughout the day and certainly in the first panel we heard a lot about the patient's need for access to their own healthcare information and we heard a lot about the patient's need to know who accessed their healthcare information but those are two different topics and I would argue that certainly the technology is a lot more prepared to support the patient's need to see their healthcare information than it is for the patient's need to see a detailed list of who accessed their healthcare information. Thanks.

Paul Eggerman – Businessman/Software Entrepreneur

Great, John?

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

Yeah, I think there's a difference – I wouldn't say that there is a need, I really don't, I mean, I think that working for a large health system we see these types of requests very rarely and so I think for some people there is a desire to have this functionality but I really – I'm unsure personally, based upon, again, my own experience and hearing from other people that this is something for which there is a significant demand for.

So, I just think we need to temper what a number of people of said as what they would desire in a perfect world to have against the fact that evidence in the last 10 years of HIPAA really has not manifested the need to have these technologies to the degree that I think some people had expressed in this testimony. And so I just think we have to be very careful about, you know, this is a recommendation.

Leslie P. Francis, JD, PhD – University of Utah College of Law

So, this is Leslie Francis, a couple of quick things, one I think there was emphasis on having whatever it is that happens be understandable or presented in a way that a wide variety of people can access.

A second thing that I think was interesting was the suggestion that the technological development may actually come away from the EHR that there may be folks who develop the kind of interpreted software that can help people understand it.

And I think a third thing is that – and this kind of cuts against what John was saying a minute ago, while everybody agrees that the level of actual demand has been low it isn't clear that that's a good measure of the usefulness of the information or the importance of making it available to people.

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

This is Dixie, I'd like to –

Paul Egerman – Businessman/Software Entrepreneur

Go ahead Dixie?

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

Thank you, thank you, from the patient panel one of the things – there are two points I'd like to make number one is there seemed to be a misunderstanding about what an audit log provides. An audit log typically provides a record of system events they aren't at all, you know, user oriented. So, I think that there was a misunderstanding there.

I think, overall, from the whole day we kept – and especially in the fourth – at the end of the fourth panel, at the end of the day, it became clear to me that what patients really are more strongly asking for is the ability to request and receive an investigation when they suspect inappropriate access more than a complete accounting of all accesses.

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

This is John Houston, by the way, Dixie hit the nail on the head that's what we deal with 99% of the time and we're able to satisfy that very effectively using the tools that we personally have implemented and I agree that is really to me the focus.

Paul Egerman – Businessman/Software Entrepreneur

Right, and this is Paul, I just want to say Dixie's point about the audit log is also important. There was some – when we get to the vendor panel there was some discussion about that topic.

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

Yeah.

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

This is David, I'll weigh in too when it's time.

Paul Egerman – Businessman/Software Entrepreneur

Go ahead, David?

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

I like what Dixie said. I think that what disappointed me about the consumer panel was the – not that I expected to hear this, but a lack of very much give and take around what would be the right amount of information, it was presented as everything or nothing and I think the questions from our committees focusing on, you know, the amount of – the overwhelming amount of data weren't really responded to very well. So, it seems to me it would have been great if we had some process that could lead us to sort of what's the right granularity, what's the right level of information?

Second is, I think that the distinction between I'm interested in knowing who is accessing my record versus I'm interested in knowing who is abusing my record was not brought forward very clearly and I think that's something that we ought to think about. We all know of many abuses of access to health data even if there aren't very many consumers asking for just the facts on who has accessed their records. So, we clearly need to detect the abuses and to be able to deal with those. So, you can't stop auditing as Dixie pointed out.

And then third, just a, you know, sort of common sense point that even if it's a fairly rare request if it's important we as a society often support those kinds of things. So, we don't get rid of fire departments because there aren't very many fires anymore we believe that it's important to maintain that capability.

So, I think somewhere in that spectrum between detecting and reporting on abusive access to the data from that spectrum over to comprehensible meaningful summaries of how your data is being used in support of your care and associated processes there is some set of capabilities that we should support. Clearly, dumping everything out is not the right answer to me, it just doesn't – no one would be able to interpret it and it would be a massive amount of wasted data.

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

This is Wes, a couple of points. One, I think that there was an assumption in the law, in the HITECH Act that HIPAA required collecting of all of the information – called every system that falls under HIPAA to collect information on which user accessed which data that could lead a person to conclude that a) the industry was fully compliant and b) the only thing left to do was to collate that information and then the report that's described in the law could be met, collate and cross match identities of users and that went into the estimate of the cost of implementing the legislation.

I think we are dealing with a couple of realities. One is that the analytic problem is to deal with too much data and ill/poorly governed data in the sense that the data may be coming from different systems but it's in different formats, different content levels, different definitions of events, a whole number of things that aren't standardized.

And to get to the point that most of the providers and technology vendors made which is that when an investigation is undertaken an awful lot of time is spent sorting the wheat from the chaff in data logs determining, you know, avoiding false positives, avoiding false negatives, doing a bunch of things and the argument is really an economic one, what is the cost of putting all that effort in for every patient all the time, can it be so automated that the cost is even hypothetically considerable versus what is the cost of doing it on a complaint.

The relevant arguments about the frequency of complaints then go to the cost issue, because if there is an investment of the size that people are talking about, which the technology vendors who had the most to gain by selling their products to do this argued wasn't practical then we do have to look at the frequency of complaints to measure the costs. Thanks.

Paul Egerman – Businessman/Software Entrepreneur

Those are good comments Wes and that also is a good segue to our second panel. So, I wonder if people have any comments about what the vendors had to say?

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

Yeah, Paul and team it's Deven, I agree I thought it was interesting that in fact the vendors who might be able to benefit by potentially asking for more robust report requirement so that they could build and potentially sell expensive technology were in fact part of the team of folks who were saying, you know, this is not doable. Although, I do, you know, recall hearing from a couple of them that, you know, that they actually might be able to – they had technology or could have technology if in fact what they needed to account for was very carefully limited to actual sort of disclosures out of the institution or the term OHCA was also used and that I thought was intriguing.

Then of course there was some discussion about whether there would even be further limitations between sort of machine mediated actual disclosures and of course we'd have to define what we thought that meant versus those that are done by humans.

Paul Egerman – Businessman/Software Entrepreneur

Right, although the way I understood the machine mediated there was a lot of concern about that in terms of, you know, basically like laboratory devices and fax machines and that maybe those were not useful – that was not necessarily useful especially if the goal is to determine what are inappropriate accesses or who is accessing the data, it's sort of hard to understand why you need to know whether or not your blood sample was put in a culture machine.

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

Right, right, right but in terms of –

Paul Egerman – Businessman/Software Entrepreneur

So, it just seemed like there was a – a better way to say it, what I heard was there was a – including those perhaps on such a broad basis was problematic that we may need to do a discussion about a narrower definition.

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

Right, right, I mean, it sort of runs into the, you know, both the goal number five, right, which is potentially problematic from both a policy and a technology perspective. What's an access versus what's a disclosure and, you know, currently, from a policy context there are lots of things that fall into the category of disclosures where in fact, you know, the – I think a lot of us would still consider it to be an internal access to information such as for example the accessing of a record by a member of the medical staff to check on a patient at the hospital, accessing at the hospital record.

You know, when you contrast that with the sharing of information from one integrated delivery system to another for treatment purposes where, you know, the term disclosure sort of has more intuitive meaning I think for folks. I just had the sense from a couple of the vendor testimony, and it will be helpful of course when we have a transcript ready to take a look at this, that, you know, if in fact we had a more narrow definition of what might constitute a disclosure that it might be something that might be more technically feasible. I don't know if other folks grabbed onto that too. I was looking for –

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

Yeah, this is Wes again, I was actually astounded when Joy mentioned that an attending physician as a community physician in a hospital accessing the EHR is in fact a disclosure and not just an access that effectively means that for most institutions there is no distinction between disclosures and access, because if you can do some amount of logging and produce a report for all of the physicians who aren't employees who are legally accessing the record then you can do it for almost all EHR users without much more difficulty.

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

Yeah, I mean, I think to Wes's point, this is John Houston, I mean, you know, when I look at a physician who is on my medical staff, you know, we sort of lump them under sort of the workforce membership idea, you know, if you're on our medical staff in order to treat our patients in the hospital even though they are your patients as well, you know, you need to have access and that's all part of sort of an integrated approach to caring for the patient and in that context a physician is as much serving the hospital as anything.

Paul Egerman – Businessman/Software Entrepreneur

Yes, those are all excellent comments. I just want to turn back a minute to think through the vendor panel. Are there other observations about things that the vendors said that – I mean, that did seem exactly as both Dave McCallie I think and Deven said that the vendors who might benefit from this were still saying that it was impractical, but are there other observations that we want to point out that are important to keep in mind?

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

This is Dixie, the Kurt Lang, from FairWarning.

Paul Egerman – Businessman/Software Entrepreneur

Long.

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

Now I know that's his product, but he seemed to, you know, think it was a lot easier than other vendors and I like Wes's comment on panel one that, you know, it might be possible to do or certainly beneficial to do a cost analysis that shows, that compares the cost of generating these data like FairWarning seems to do with the cost that it takes to investigate a suspected misuse, you know, I think that that's a good recommendation.

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

And I have to say my interpretation of Kurt was he started out saying how well his software worked and he ended up saying it was impractical to use it to meet the requirement, we can go back and check the transcript, but I thought he definitely wanted to distinguish between the raw capability of software and the application for the specific use.

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

Can I –

Paul Egerman – Businessman/Software Entrepreneur

And the other point that was made, I think it was Eric Cooper at Epic made it, was is the way the logs are oriented that, you know, a simple thing like just looking up some piece of information on a patient could actually end up having like 6 different entries in the log and that going through the logs in a detailed way by itself was possibly confusing, which I think is part of what Dixie was saying earlier that logs were not really intended for this purpose. Was somebody else trying to say something?

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

Yes, this is John, yeah, this is John Houston and I was listening to this panel and since I use FairWarning, I use Cerner, I use Epic believe me I was listening to all of that very intently because they're absolutely correct the data formats are totally different, what they have in them is totally different. FairWarning as a tool is great for doing internal investigations. Could we generate a user log report, yeah, but it's ugly and when you have to normalize data between, you know, in our case 30 or 40 different systems it is really a difficult thing to do. So, I'm hearing all of this testimony and I think it is much more difficult than it might first appear.

Paul Egerman – Businessman/Software Entrepreneur

Right, now the other comment that I heard at the vendor panel from both Eric Cooper and from John Travis from Cerner was not everything is in these logs that there are distribution reports and data that are basically put, in effect pushed to various people that it's not directly in these logs. So, another way of reiterating what Dixie said is the logs themselves were not set up for this purpose.

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

This is David, one additional comment in attempts to balance with my criticism of the first group is I didn't sense a lot of – I didn't hear anything from the vendors about a compromise of what's the right level of granularity.

Paul Egerman – Businessman/Software Entrepreneur

Yeah.

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

Clearly dumping everything is too much and clearly that wouldn't actually be of benefit to the consumer, but what's that middle ground, unfortunately nobody brought forward a good idea as to what that was, which seems to me to be an opportunity for ONC, hint, hint, hint.

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

This is Gayle, I'd like to jump in on that too and one of the questions I asked was, you know, all we heard was negative, negative, negative what are the positive things and I didn't hear very many positive things come out as to what that right level would be and this is going to take quite a bit of discussion I think to come to that understanding of what the right level should be because patients do expect to be able to have some kind of understanding of who is accessing their information.

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

This is Wes, I think we're kind of jumping around on the panels, but the written testimony that accompanied the submission from Intermountain Healthcare was one of the few I thought that went into some important issues one of them was what are the rights of the employee for privacy considering that the worst case scenario, which is quite feasible involves physical danger to employees.

And second, as far as I can tell, looking at Gartner resources, and as far as they could tell looking at their resources, there is no industry that has ever been required to release this level of information before anywhere in the world or at least anywhere in an industrialized country. So, that might give us some pause in terms of the feasibility of what's – one of the great points about an investigation is there is an allegation at hand, there is some reason to be providing the information as opposed to dumping it all or making it all available to the public with no understanding of whether there is any culpability.

Paul Egerman – Businessman/Software Entrepreneur

So, those are great comments and since you mentioned Intermountain I advanced the slide to look at panel three.

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

Good job.

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

So, can I –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Paul, this is Joy, may I just insert one very brief comment here?

Paul Egerman – Businessman/Software Entrepreneur

Absolutely.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Wes, I am not familiar with – intimately familiar with the Gartner's company's research, but I will say that the overall principle of a patient having, knowing who has – of a person knowing who has accessed their information is generally founded in the OECD fair information practices and I believe that, just as a very high level, is where that came from.

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

Yeah, but to an individual named person, Joy?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Deven, what I'm saying was that at a high level that is where that principle came from it does not necessarily come from the – this discussion has been really focused on a patient's right to know how their information has been misused. The OECD principle is broader than that, right?

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

And this is David; I'll chime in and agree with Joy in that, you know, the Fair Credit Reporting Act requires disclosure of access to your credit record –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Yes.

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

Albeit not nearly at the level of granularity that we're talking about here for healthcare records.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Right.

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

But the –

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

But it doesn't focus on individual employees, right?

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

No, no.

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

I mean, the issue here is that the employee is a person too –

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

Yeah, no that's my point.

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

Who has rights, right?

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

Yeah, well –

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

And I don't know does the OECD principle really focus on identifying individuals who are in the workforce?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

No, Wes, I just – I was just saying that from a high level that is where the principle stems from, because this discussion has focused on a patient's – you know, the patients want to know this information because they want to point the finger at somebody and blame them for a misuse whereas the OECD principle is broader than that, it's not just a right to know who has misused your information, it's a right to generally know who has had access.

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

I guess I'm just – and I haven't read the principles, but I'm just asking the question –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

It's a broad principle; it doesn't go to this level of –

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

Is who – what does "who" mean? What does "who" mean in that statement?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Yeah.

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

Does it mean what corporation or does it mean what individual?

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

We will – I will uncover the relevant principle for you.

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

Okay.

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

The Fair Credit Reporting Act will also uncover that as well, it is – what you get to know is what organization accessed your credit report and the date.

Paul Egerman – Businessman/Software Entrepreneur

Right.

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

This is Gayle; I'd like to jump in.

Paul Egerman – Businessman/Software Entrepreneur

Yeah, before you do that Gayle, just, if I could just make a comment, this is a useful discussion, I just want to be clear though it was part of the feedback that we got at the hearing that I think the people at Intermountain, perhaps one or two of the other providers were concerned about employee safety issues.

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

Yeah, Kaiser was –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

–

Paul Egerman – Businessman/Software Entrepreneur

So, that was simply part of the feedback and there is a difference between having the concern about who has access to your record because you're concerned about disclosure versus who has access to your record perhaps because you're concerned about the outcome.

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

This is Gayle and I –

Paul Egerman – Businessman/Software Entrepreneur

You know, that's just an observation. Go ahead, Gayle.

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

Thank you, thank you. I think the whole question of having access to the name of a person comes from the great fear that people do have that individuals would get a hold of their personal private health information – in cases of using it for political purposes, using it for blackmail or any kind of disclosure of private health information and yes the person is relevant and I am sure the public would feel that they would want to know who did what.

Paul Egerman – Businessman/Software Entrepreneur

Okay, so again, I'm thinking about the panel three the provider perspective, so do we have any other observations in terms of what we heard from the healthcare providers?

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

You know, the healthcare provider panel, this is Deven, was the first place where somebody raised the issue that they were not, potentially not or should be not covered by the HITECH Law and that came from I believe Kevin Nicholson from the Chain Drug Stores.

Paul Egerman – Businessman/Software Entrepreneur

That's right.

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

Because what HITECH – it was emphasized I think a bit more in the payer panel, but it was the first place where we heard somebody say this was intended to be EHRs and if you don't have an EHR this should not apply.

Paul Egerman – Businessman/Software Entrepreneur

And we got that same information from the written comments from, I can't remember it was an association of clinical laboratories.

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

Yes.

Paul Egerman – Businessman/Software Entrepreneur

Where it basically said – and again for segue into the payer perspectives that basically said we're not an EHR therefore the law doesn't apply to us.

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

Cop out.

Paul Egerman – Businessman/Software Entrepreneur

Well, whatever it is, I'm just saying that's what we heard.

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

Yes, no, I –

Paul Egerman – Businessman/Software Entrepreneur

I think that's what we heard from the laboratory guy and I think that's what we heard from the payers.

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

Yeah, we heard that.

Leslie P. Francis, JD, PhD – University of Utah College of Law

This is Leslie, can I interject just quickly, I think some of that goes back to the point Joy was making which is that one way to construe the law is that medical information that's been entered for treatment purposes I should be able to know if it's been re-purposed. So, if for example it was used for research I should be able to know that even though the use for research might have been entirely proper.

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

This is Dixie, in my notes AHIMA was the second organization and Kaiser Permanente was the third that pointed out the concern for the safety risk of their workforce, just FYI.

Paul Egerman – Businessman/Software Entrepreneur

Okay and so let's move quickly onto the payer perspectives. I think that Deven raised one of the fundamental issues that was raised there was again they were saying "well payers aren't EHR systems so therefore we don't count." At least that's one of the things I heard. Were there other observations?

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

Well, Kaiser didn't say that. Kaiser was in that payer panel and they didn't say that.

Paul Egerman – Businessman/Software Entrepreneur

I thought they did actually. I thought they said that the payer side doesn't count.

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

The payer side doesn't but they didn't discount their whole organization.

Paul Egerman – Businessman/Software Entrepreneur

Yeah, no that's right. They said the payer side is not part of their EHR.

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

I thought that they were – that Kaiser was a really good example of the impact of this – what Wes saw, you know, astounding, I too was astounded to learn that when a provider who is not an employee of a hospital accesses the hospital's EHR there it's a disclosure. So, that was really eye-opening to me too and I thought Kaiser was a good example because it's primarily in California where by law a provider cannot be employed by a hospital. So, that's a huge issue.

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

Well, I would say – I would guess, you know, I'm not a lawyer therefore I can speak with perfect assurance that an OHCA, that the Kaiser Permanente Organization and the Kaiser Healthcare Delivery Organization are in fact an OHCA. However, Joy may be able to help us here, but as I recall the regulation went beyond the law in establishing the requirement for gathering this information from every electronic designated record set rather than just from the electronic health record. If that's true wouldn't the payers be involved because they have electronic designated record sets?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

David are you on the phone? David Holtzman? If you are answering you're on mute.

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

Sorry, what was the question?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

The question had to deal with – I know the answer, but I was diverting to you so maybe I'll just answer it, no I'm kidding, the question had to deal with, you know, the statutes that EHR, if the regulation expanded to designated record sets?

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

Electronic, yeah.

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

Well, I think in this proposal OCR was aligning it with the scope of the privacy rule which applies to all designated record sets and it was OCRs belief that it would be inappropriate and very difficult to limit the scope of the information to only that found in EHRs.

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

David, I think the question that brought this up is whether payers are exempt from this regulation, some of them stated in the testimony that because they don't have an EHR they're exempt and we're wondering if the change of the scope of the regulation to include electronic designated record sets didn't bring payers back into the need to comply with the regulation.

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

Well, by its own terms the privacy rule applies to covered entities and in some limited respect or in some respects to their business associates. In this particular case there was no limitation in this particular standard to only those users who used EHRs. However, you'll notice that we did provide a limit or some change to the scope of the application of the rule based on whether the practice used or maintained their information in an electronic record as opposed to information that was maintained in paper.

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

Now, I know how my wife feels when I talk to her about technology. Could you get that down to a pretty simple answer David? Is it possible? Are payers –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Could I jump in David?

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

Are payers, yeah –

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

Well, the bottom line here is that, that was an interesting perspective that was introduced by a panelist. We are not going to be able to provide an analysis of that position, it would be something that we would look at and evaluate and, you know, with further study and discussion we may be able to provide, you know, a response to that. But –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

David, can I jump in and then you can tell me when I'm wrong?

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

No, I'm never going to tell you you're wrong.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Sure, you can kick me even though you're not across the table from me, but I think what – yeah, there was some perspective raised at the hearing but what it came from, I believe, was that the statute –

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

Yes.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

The provision in the statute was limited – stated, it wasn't limited, the statute expressly said that the accounting of disclosures, the right to an electronic accounting of disclosures was limited to, I'm sorry, was limited, was directed specifically to electronic health records and in the NPRM OCR used its general rulemaking authority to expand that beyond EHRs to include all information in a designated record set and so what the participants in the panel were doing were saying, well, essentially were saying "we think you should just stick to the statute and not expand it beyond that."

And I think what David is saying is that when you, you know, if you wanted to make this provision consistent with the rest of HIPAA that you would apply it the same across covered entities. How's that? Does that make more sense Wes?

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

Well, I think, you know, what I hear is that there is enough ambiguity at least for the layman to not know whether it was the intention in the regulation to enforce it against the payers that have electronic designated record sets.

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

Well, Wes, no actually the Reg is – the proposed regulation –

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

Yeah.

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

Which is the only stage of regulatory activity that's taken place.

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

Right, yeah.

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

Is very clear about to whom it applies there is no doubt about that. I think Joy is right. I think what some of our testifiers were arguing is "oh, just do what the statute says" which means we would be out.

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

Okay, well, I think that's fine if that's the way you heard it. What I heard was a little different. I heard that there is substantial misinformation that there are payers who just don't believe that the proposed regulation applies to them. I mean, obviously, you know, ignorance of the law is no excuse, but nonetheless the fact that there is misinformation may cause some unexpected constraints in the level of feedback that's coming back with regards to the –

Paul Egerman – Businessman/Software Entrepreneur

Yeah and this is Paul.

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

Feasibility of the proposed regulation.

Paul Egerman – Businessman/Software Entrepreneur

This is Paul, what I heard was closer to what Deven said that basically the way I interpreted it was both in the provider and in the payer panels people did not want to do this and for the payers and for at least one of the provider participants they were trying to hang their hat on this concept although the law only says one thing and we're not part of that. But the real issue was not so much whether or not they're an EHR; the real issue is they didn't want to do it.

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

Agreed.

Paul Egerman – Businessman/Software Entrepreneur

That's what they said. So, anyway this is an interesting discussion that we've had and we've talked about a number of topics and so now the next question is, you know, how are we going to sort of like bridge this gap where we talk about the patients and the patient perspectives and comments that Joy says and also Gayle says, well, you know, there are some reasonable expectations on the part of the patient to get certain information and some of the very clear and consistent feedback that we got from the vendors and the providers and so there is an interesting challenge as to how to bridge the gap.

And I think the way that we want to first approach this is to briefly review some of the other things that we've said in the past, is that right, Deven?

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

Yeah, no that's true. We thought that it might be helpful to talk about a couple – to resurface and remind everybody about a couple of recommendations that we've made directly on the topic of transparency to patients that might be relevant and helpful for us to draw on and then another set of recommendations that's not directly related to this issue but for which some of the reasoning that led us to draw some of the conclusions we did might be helpful in getting us to a set of recommendations on this issue.

So, just quickly going over those and Gayle we are back to the slides and for others who are following along the slides on paper we're on the slide that is slide number six at the bottom and it says "Example of Previous Recommendation, re: Patient access."

So, I want to remind everyone that we had a recommendation that was adopted by the Policy Committee and made part of certification for 2014 that the portal, the view, download and transmit capability be able to deploy audit trails and be able to provide them to a patient on request and in fact in the 2014 certification criteria certified EHRs have to be able to, in the patient's portal, record an activity history log which monitors when the information is viewed, downloaded and transmitted to a third-party and then to make this available to the patient upon request. Again, this is related to the portal one area where we sort of opinioned on this issue and applied it to a particular circumstance.

I'm going to skip the next few slides, my apologies, because I want to go to another example of a recommendation that's more directly on point and that's slide nine which is another example, again, of a recommendation where we addressed this transparency issue and it's with respect to targeted query so it's fairly recent.

With respect to targeted queries for direct treatment we asked ourselves the question if there should be a requirement to account for and log the query under the disclosures and then – and the disclosures and then share the log with the patient upon request and our answer was that "yes, the data holder should both log the query from an outside organization and the response regardless of its content and the requester should also log the query, and that this information on both the query and the response should be available to the patient upon request." And we asked that this be considered in terms of sort of technology requirements potentially for the next stage of certification which would be whenever the Stage 3 rules come out.

Paul Eggerman – Businessman/Software Entrepreneur

Yes –

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

So, now we're going to go to a couple of recommendations that –

Paul Eggerman – Businessman/Software Entrepreneur

Deven, Deven?

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

Yes?

Paul Eggerman – Businessman/Software Entrepreneur

I don't mean to interrupt, but the key phrase in that last slide I just want to point out –

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

Okay.

Paul Eggerman – Businessman/Software Entrepreneur

In the query response was from an outside organization.

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

That's right, that's right.

Paul Eggerman – Businessman/Software Entrepreneur

And these were queries and responses outside of the OHCA that's what we were commenting on then.

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

Yes that's correct, Paul, thank you, good point.

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

Deven, this is Larry Garber, I've been on the call, I missed the roll call.

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

Oh, hi, Larry.

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

Hello, so what about the scenario where, you know, our organization is being attacked by people in China randomly trying to query and we, you know, we deny the queries as they come in because we know that they are not legitimate queries? Is that something we're supposed to log and disclose to the patient?

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

No I don't think so Larry, although admittedly we did not discuss that particular use case. But I think we were envisioning completed targeted queries. A query comes in and there is a response to the querier that gets logged and provided to the patient.

Paul Eggerman – Businessman/Software Entrepreneur

That's right.

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

Okay. But there are some – cases where someone is querying from a legitimate organization but they don't have consent so that one we also don't reply to.

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

Right, keep in mind we're not re-reviewing this recommendation.

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

Okay.

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

We are providing it as context for where we have been previously on a similar issue.

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

Deven?

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

Yes?

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

This is Dixie, I think I've heard Wes mention OHCA and I've heard Paul mention OHCA and I'd like to put forth a clarification that Kaiser Permanente had in their written testimony that I think is important and I assume it's right, but Joy – I'm sure Joy and David will correct me, but Kaiser said that the privacy rule designates exchanges of PHI between OHCA participants as disclosures, but because HIPAA exempts TPO from the accounting disclosures it hasn't been a problem. But they made it clear that exchanges between OHCA participants are disclosures. Right, Joy, David?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

David?

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

Sorry, I have to get out my quarter and start flipping for heads or tails. I believe that is correct and that in fact they are uses – I'm sorry, they are disclosures for which an authorization is not required.

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

Right that's what they said.

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

That's correct, yes.

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

Okay, so just to close the circle on the recommendations that we wanted to sort of resurface for everyone, again, these are recommendations that we have already come to. We're going to go back really pretty far in our history to September 2010 and again these are meant to not be – these are meant to potentially be helpful in enabling us to come to some recommendations with respect to accounting of disclosures.

This next set of recommendations, which I'm on slide seven, the core values are less directly related to the issue of transparency to patients about disclosures or about access or about appropriate use of a record and transparency but it might help to remind ourselves about our thinking about sort of a set of disclosures that we thought raised sufficient privacy concerns for patients that we would put another protection on them and that's consent.

So, here, you know, again, just going back to some of the core values that drove our work on privacy issues way back when we really first started as a Tiger Team was to recognize that the relationship between the patient and the provider is really the foundation for trust in health information exchange and that as key agents of trust for patients providers are the ones who are responsible for maintaining privacy and security of their patient records and that we need to consider patient needs and expectations, and that patients should not be surprised about or harmed by collections, uses or disclosures of that information.

And that ultimately to be successful in using health information exchange to improve health and healthcare that we would need to earn the trust of both consumers and patients. And with these core values in mind, and I'm on slide eight now Gayle and others who are following along, when the decision to disclose or exchange the patient's identifiable health information from the record is not in the control, that decision is not in the control of the provider or that provider's OHCA, this maybe the first time when we used the OHCA term in our recommendations, patients should be able to exercise meaningful consent to their participation.

And so in essence we recognized that disclosures that are out of the control of the provider or the OHCA then the providers that's the patient's foundation of trust that triggers heightened concern and in that particular set of circumstances we said meaningful choice should apply.

Again, different issue on the table but nevertheless our reasoning for how we got to the recommendations that we ultimately put before the Policy Committee and had adopted might be helpful in allowing us to work our way through a set of recommendations on this issue and what do we need to be more transparent about with patients, etcetera. So, we just wanted to offer those to help focus the discussion and inform the discussion really.

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

Deven, this is John Houston, I mean, I don't think anything that you put in these last number of slides, to me, you know, is contrary to I think what we're talking about. I think there is a – simply it's a matter, in my opinion, of the amount of detail that's involved in an accounting of disclosures and, you know, I think that all the testimony and personal experience and otherwise I think that's really the issue here, is how much detail is necessary, how involved does it need to be in order to provide the patient with that meaningful information.

And I think what I heard, and again my personal experience is, is that the patient typically doesn't really want or is not able to really appreciate when we give them a large amount of data and to Dixie's earlier point, which is, is that when there is an issue if the patient typically already has a pretty good understanding of who has probably looked at their record and so – I know when we do audits and we provide information it's often very focused.

So, again, I would just say that trying to be practical about what we're proposing here versus what we have recommended in the past, I just think that we just have to worry about the level of granularity and detail and I think what I'm hearing and what I'm sensing is that, you know, less is not a bad thing in terms of level of detail as long as it gets the patient the basic information that 99% of the patients really are interested in.

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

Thank you, John.

Paul Egerman – Businessman/Software Entrepreneur

That's –

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

This is David –

Paul Egerman – Businessman/Software Entrepreneur

Go ahead David?

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

This is David, I just would endorse what John said, I think that was a great summary, it's just a question of the right events that should trigger it and the right amount of detail, and unfortunately we're not hearing anybody propose a good answer to that question.

Paul Egerman – Businessman/Software Entrepreneur

So, at least at a high level, might a recommendation or a comment that could come from us would be that the level of detail proposed in the NPRM is not practical and also appears to be not likely to be useful to patients and less – an approach involving less detail would be good?

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

This is David, I think that's the direction that we – one of the directions we can head in.

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

And I think –

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

You know, and what the right triggers are –

Paul Egerman – Businessman/Software Entrepreneur

Yeah, I mean, I don't know what that means less detail, but we could add that.

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

Yeah.

Paul Egerman – Businessman/Software Entrepreneur

We have to roll up our sleeves and think about that a little bit, but –

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

Yeah.

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

And this is John Houston, I think that, you know, our practice has always been if you start with less detail and the patient has concerns we very quickly get into an investigation that still is able to dig into more detail, but, you know, it's a question of how much do you give up front, how much is really meaningful, how much can we do in an automated fashion which, you know, again allows the patient to get information more quickly and with less effort, and how much do we reserve for when there really is some question and we have to dig into it deeper to understand whether there was some issue.

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

This is Gayle; I'd like to jump in if I can too?

Paul Egerman – Businessman/Software Entrepreneur

Go ahead.

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

You know, I really think that we need to define actually how much information that we want, at least at that first level, that should begin the discussion, let us define, you know, how much, what information would be given out at what level and also in what format, it needs to be useable to the patient. So, just providing them with a bunch of coding and, you know, who's accessed a whole humungous bunch of information isn't going to help them. So, I think we need to define the format that that limited set of information comes to the patient in.

And then we also need to provide for further information to come forward in that investigative stage should the patient not be satisfied with at least an initial brush and if you set levels, and perhaps our recommendation needs to be refined is to leveling and being more defining into what information is available to the patient and the format would be a good place to start with retooling our recommendations.

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

This is Wes; I want to agree very strongly with Gayle with one caveat. I think that sort of a fundamental issue here is whether the patient should have a right to know the names of employees that have accessed their data without going through a process that creates an allegation and I realize that goes back to the law rather than to a proposed regulation but nonetheless I think that a great deal of what we're going to be up against is going to come back to this issue even if we say, they don't get to know what nursing unit they were on when they accessed or they don't get to know whether they accessed my STD history or not.

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

Hi it's David, can I interject something here?

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

Yeah.

David Holtzman, JD, CIPP/G – Senior Health Information Technology & Privacy Policy Specialist – Office for Civil Rights

There is nothing in the rule that proposed or there has not been any proposal that says that an employee's name must be disclosed to the individual. What the rule proposes is that the user ID be provided and, you know, there is no requirement in statute or regulation which requires an organization to use an employee's name as the user ID.

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

So, then it's also the case that if the same employee uses the same user ID in eight different systems it's okay to provide eight different identities and if like my ID is WRishel that's pretty clear who the person is, is it okay to change that ID to be one that's less apparent?

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

Yeah, this is John Houston, I always read HIPAA to mean that if an accounting of disclosures really ultimately required that we provide a name.

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

I mean, I don't have the proposed regulation open in front of me right now, but boy I sure thought it said you had to provide the identity of the employee.

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

I mean, core HIPAA I think requires a name. I don't – that's what the accounting of disclosures was all about.

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

But that was about corporate disclosures, we're talking here about access reports.

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

But if somebody inappropriately looked at a record internally is that an access or disclosure? I've always viewed it as being a disclosure.

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

It depends on who they work for apparently, if they're a community physician it's a disclosure, which I don't think many of us understood, but even if it's a nurse who is more typically employed it's an access.

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

But is it – access assumes that there is appropriate action. I mean, to me I've always viewed access as saying there is an appropriate purpose behind why that would – the "access" occurred and once there was an inappropriate purpose it became a disclosure, that's the way I've always interpreted it myself and I'd love to be wrong about it, but I've always sort of taken that view on it. I'd love to hear other people's perspectives on this.

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

Oh, that's interesting, yeah, I hadn't thought about that.

Paul Egerman – Businessman/Software Entrepreneur

Well, let's – we're drifting a little bit, although it's an important discussion, we need to understand and have common terminology when we talk about access or disclosure we have to each mean the same thing, but the comment that I had made earlier which was to try to summarize this discussion which was to say the level of detail that is included in the NPRM is too great that it causes a system that the technical feasibility and concern is that it may not be understandable or usable to the patient and approach needs to be found that involves less detail.

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

Well, not –

Paul Egerman – Businessman/Software Entrepreneur

And then Gayle wanted to expand that to describe possibly that there might be a staged approach which is also useful, but let's just do the first step, is do we have an agreement on that first comment? I mean, Deven, go ahead.

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

Well, all I'm saying is I think the term less detail in a way is a little confining. I sort of got the impression that where the discussion was headed is more of a sort of less is more both in terms of what should trigger the need for a report as well as what would be required to be captured in a report, and less is more – you know, so and maybe less detail with respect to the transparency point overall. But I worry that confining it to, well, just less detail just addressed sort of one of those less factors, right?

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

This is Dixie, I think, you know, I was just looking at HIPAA and it – you know, HIPAA actually prescribes exactly what you include in the disclosure. It seems to me that this conversation, and I totally agree with what Deven said, less detail really doesn't grab it, but the difference between post HITECH and pre HITECH is that treatment payment and healthcare operations are no longer excluded from the accounting of disclosures. So, I don't think we should address the level of detail that should be in the accounting but rather perhaps focus in on, how can we capture some level of transparency of disclosures for treatment, payment and healthcare operations without having to get the level of detail that might be – that's required by law for other disclosures.

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

Well, I just have to – this is Wes; I just have to ask the question are we talking about the HITECH law or are we talking about a proposed regulation? Because if we're talking about a proposed regulation it calls for an accounting of access to information in situations that are clearly not a disclosure, it doesn't call for saying, only show me the user's who illegitimately accessed my data and therefore might have converted to a disclosure by John's reasoning, it calls for a list of all the users who had access to my data.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

This is Joy, I really feel like I need to interject, I should have earlier –

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

Yes?

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

That assumption is not correct, the term access, David jump in if you disagree, the term access, disclosure and use are all neutral, none of them assume that the use or the viewing or the sharing of that information is appropriate or inappropriate they're all neutral.

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

Yeah, Joy, that was my point that the proposed regulation –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

–

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

Calls for access, a list of accesses not – it's not limited to inappropriate accesses.

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

Right.

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

Right.

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

All right and that therefore those accesses are not disclosures along the lines that John had proposed. So, the proposed regulation is about access. The law, the HITECH Act was about disclosure. Those are overlapping but different concepts and I think it's important to know which are we commenting on?

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

Well, we're not – we are putting forth, Wes, and I hope this will be helpful, we are trying to put forth recommendations to HHS, so this also involves ONC, because there is a technical component here, as well as the policy arms within HHS, which is, I think for the most part for this issue the Office for Civil Rights, but, you know, given what we know is in the statute, given what we know is then, at least initially proposed, how would we advise HHS to be able to move forward.

I do not think we are limited by what's been proposed. We also need, I think, to be mindful that OCR has to write rules for an entirety of covered entities and not just those who technically use EHRs, and we have to decide I think in our recommendations how or if we're going to address that or whether we would sort of limit it to just what the statute requires.

I mean, you know, we've been asked to provide a set of recommendations on this issue, I think all of what came before us needs to be taken into context, but I think that we need to, based on what we've heard from testimony, what we know from our own experiences provide the best set of recommendations we know of to enable forward movement on this, because, you know, it's a difficult issue and they've asked us for help.

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

That's very helpful, in particular I think as we're taking into account the whole context including the proposed regulation we have to be clear in what we write when we're talking about accounting of disclosures and when we're talking about access. We may only address one or the other, but we need to be clear what it is we're speaking about.

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

This is Dixie, I have a starter thought is I like – I think that Kaiser's recommendation made sense that if accesses between participants in an OHCA should not be considered disclosures. I think that really, if you think about OHCA's that would be really disruptive if all of those were considered disclosures.

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

So, in terms of maybe if we're sticking with the less is more theme, at least to start, less would include thinking through some more narrow universe.

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

Yes.

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

Would be included, not, you know, so focusing more on what's genuinely sent outside of an institution or an OHCA.

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

I think that's what I was trying to capture by the trigger word.

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

Yeah.

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

I mean, what are the –

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

Yes.

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

What kind of access to data triggers exposure to the requirement that it be called a disclosure and therefore reportable or whatever.

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

And if – I don't know the words but somehow capture the idea that if a doctor is, you know, is accessing a hospital's EHR, you know, as a practicing doctor in that – and maybe not necessarily an employee but, you know, practicing within the hospital somehow that has to be excluded as well.

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

But, again, I think if we are talking about accounting of disclosures then I agree with this commentary. I think however that – I think you can find language in the commentary especially with the proposed regulation that says one of the reasons that OCR decided to go towards access rather than accounting of disclosures was the difficulty that industry faced in identifying all disclosures and I mean I'm here not talking about a community physician member doing an access and having disclosure, I'm just talking about all the different paths by which data for TPO goes from one corporate entity to another one and so we need to somehow keep feasibility in mind as well.

Maybe the argument is there is no choice we really need accounting of disclosures for the patient's benefit full stop, maybe the argument is there is a misperception of what patients really need, maybe it is that they really need some sort of graded series of steps to pursue the possibility of misuse by a member of the workforce, but I think we have to decide that, it's a decision of high consequence no matter which way we go or whether we take some third position.

Paul Egerman – Businessman/Software Entrepreneur

That's right, you know, and this is Paul, in listening to what you just had to say Wes that was very helpful and I'd make the observation we had a situation before where we're faced with a challenge where there is a clear idea of what patient's wanted and there was a clear description of something that in the law as to what patient's deserve to have on the one hand, on the other hand there was some also clear technology feasibility issues and that had to do with that whole issue of segmentation of the record. The reason I bring that up is what we recommended in part under that circumstance was some tests and some trials to find out what could actually be delivered and so it's just an observation as to whether or not we want to make any recommendations on that type of an approach.

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

This is David, I mentioned this in the hearing as a question form I think but I've been thinking about it since, is there any way to tie the notion of what's a disclosable event to the things that are required to be in a notice of privacy practice? Is there some sense of what needs to be mentioned in the notice of privacy practice? Is there a way to say that's a starting point for being a disclosure?

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

Well, David, I think you would find that that doesn't probably hit the less is more except in terms of the level of generality. HHS recently released some very good models.

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

Right.

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

Model notices of privacy practices, I'm happy to distribute those to folks and see if it triggers ideas.

Gayle B. Harrell, MA – Florida State Representative – Florida State Legislature

That would be good Deven.

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

Yes.

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

Yeah, we can do that, we can do that –

Joy Pritts, JD – Chief Privacy Officer – Office of the National Coordinator

I would note that those were produced at the recommendation of the Tiger Team.

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

Really?

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

Yeah, they're very good; I was very impressed I looked at them. My thought was at the level of – the high level things that are enumerated there you could use as an organizing principle for deciding what level of granularity below that would be appropriate. In other words, if you're already telling the patient about it and they're supposedly understanding what they read –

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

Yeah.

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

Then the ability to pursue that and say "well, what actually did happen with the local HIE, because it says here that my data might be disclosed to the HIE" that would seem like a reasonable consumer request.

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

Well, let's get those out to folks and see what that stimulates in terms of conversation. So, I'm mindful Paul of where we are timing-wise.

Paul Eggerman – Businessman/Software Entrepreneur

Yes and it does seem to me like we've made very good progress on this call and that we have reviewed the hearing and seem to have some sense of consensus about what we heard during the hearing and we also have a number of ideas that have been thrown out as to how we might react and so that might be also a very good point to pause and to see if we have any members of the public who would like to make a comment.

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

Go ahead Michelle.

Public Comment

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Sorry, I was getting off of mute. Operator can you please open the line?

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 comment at this time.

Paul Egerman – Businessman/Software Entrepreneur

Okay, thank you Michelle and let me just say before we close this is not an easy issue, there are some really important issues here and this is an opportunity for us to think through these issues and see if we can come up with some good ideas that might be helpful to OCR and ONC, and HHS. Our next meeting is when Deven?

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

Yeah, good question, November, hold on, November 5th it's a Tuesday from 11:00 a.m. Eastern Time to 12:30, so a little on the early side for our Westcoasters, but not too bad.

Paul Egerman – Businessman/Software Entrepreneur

So, in between meetings we'll hopefully get some more comments on the blog so that will be useful to read and we'll have this material that Joy is talking about to distribute and we'll have a chance on November 5th to have an interesting discussion to see if we can come up with some concepts of what we might recommend.

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

Thank you all very much, good call.

Paul Egerman – Businessman/Software Entrepreneur

Thank you.

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

Thank you.