Privacy & Security Tiger Team
Draft Transcript
October 6, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director
Good afternoon, everybody, and welcome to the Privacy and Security Tiger Team. This is a federal advisory committee, so there will be opportunity at the close of the meeting for the public to make comment. Just a reminder for Workgroup members to please identify yourselves when speaking.

Let me do a quick roll call. Deven McGraw? Paul Egerman?

Paul Egerman – Software Entrepreneur
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Latanya Sweeney? Gayle Harrell? Carol Diamond? Judy Faulkner? Carol Dvorak?

Carl Dvorak – Epic Systems – EVP
Here.

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

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

Judy Sparrow – Office of the National Coordinator – Executive Director
Neil Calman?

Neil Calman – Institute for Family Health – President & Cofounder
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
David Lansky? Dixie Baker? Micky Tripathi? Rachel Block? Christine Bechtel? John Houston?

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

Judy Sparrow – Office of the National Coordinator – Executive Director
Wes Rishel?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Leslie Francis?

Leslie Francis – NCVHS – Co-Chair
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Joy Pritts?

Joy Pritts – ONC – Chief Privacy Officer
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
We have John Lumpkin from the Governance Workgroup. John Lumpkin.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Thank you.

Judy Sparrow – Office of the National Coordinator – Executive Director
Mary Jo Deering is on from ONC. Did I leave anybody off? Okay. With that I'll turn it over to Deven McGraw.

Deven McGraw – Center for Democracy & Technology – Director
I'm going to turn it over to Paul.

Paul Egerman – Software Entrepreneur
Thank you. This is Paul Egerman. I just wanted to say good afternoon or good morning, whichever is correct for wherever you are. Appreciate your participating in today's call. To remind everybody, we are a Tiger Team that was formed over the summer with a very intense schedule to make some decisions over the summer. I think this group did really an outstanding job. There is a lot that I think this group should be proud of. We were rewarded with some additional challenges to address. Among those challenges is transparency, various issues related to transparency that we'll be talking about today.

Today's agenda really has two topics. The first topic is the discussion from the Governance Group, which will be led by John Lumpkin, Dr. John Lumpkin from the Robert Wood Johnson. The purpose of that discussion is going to be to coordinate our group, our Tiger Team, with the Governance Group and to make sure that if there are any areas that Governance needs some guidance from us on that we understand what we're doing, what they're doing and can give them the guidance that they need and request. So that's the plan and we think that the Governance discussion will last probably about an hour. In the second hour of our call we will be reviewing the transparency document that Deven sent out.

That's the agenda. Did you have anything you wanted to add, Deven, before we ask John to get started?

Deven McGraw – Center for Democracy & Technology – Director
No. That sounded good, Paul. Thank you very much for opening the meeting.

Paul Egerman – Software Entrepreneur
Terrific. So again, I want to thank all of the Tiger Team members for participating. I also, of course, want to thank any members of the public, who might be listening. With those comments, John, why don't you take us through Governance?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Thank you so much for the opportunity to be with you here today, but also looking forward to comments and assistance that you may provide.

The purpose for our workgroup is two-fold. The first being that the HITECH Act has specifically directed the Office of the National Coordinator to develop rules related to governance of what had been at the time called the Nationwide Health Information Network with the asterisk that I'm sure we're all familiar with—that the name will be changing sometime soon—and that this governance ... requirement for the ONC is something that they're moving forward on and created our Workgroup to give them advice.

I think the second reason why our group is in existence has to do with the fact that looking at the scale of the exchange of health information. At the local level, of course, it's the health information exchanges that are creating the environment in which one provider, one holder, one consumer of health information

can then have that information arrive where they want it to be, where it's needed in order to assure that the right decisions are made at the right time between a patient and their provider or by the patient themselves.

Once you begin to move to the national level there needs to be that same level of trust that's created at the local level by the health information exchange. Initially, through grants and contracts with the Office of the National Coordinator the first network came into being and the mechanism by which governance of how that trust environment was maintained was developed through a document called DURSA. I always don't remember what the letters stood for, but basically it's a contractual agreement between those exchanges that are exchanging on the national level. It creates a coordinating committee and mechanisms to determine whether or not entities that will be exchanging will do so in an environment in which there is some trust within exchange that may be across the country.

We're looking at ways that that can be brought to scale, that we can actually look at exchange that extends beyond those partners, who may be under contract or have a grant from the federal government. That is the purpose of our committee.

So when we come to you there's a critical question that basically we're looking for, which is two items that we're going to be asking for the committee. First is I'm going to be providing a high level overview of the approach to the governance that we've developed and then hopefully we'll get some discussion on the privacy and policy components of this governance system. So just to sort of give you a heads up because, as I'm going through, feel free to stop me if you have questions or comments and I think that way we can have the best discussion, but I wanted to give you a heads up ahead of time of what I'll be looking for. First and foremost, have we overlooked any key, high level functions for governance that enables us to create the environment of trust in which providers, patients, individuals would feel comfortable in having their data exchanged across the Internet.

Second: Are there any specific, more granular privacy and security governance issues that need to be addressed? You'll see in that section that I will give you an idea of the level of granularity.

Let's go to the third slide. First of all, just what we've accumulated as what is going to be governed and that is a set of what we call the—we actually start calling it the new name, whatever that will be—for the Nationwide Health Information Network, a set of policies, standards and services that enables the Internet to be used for secure and meaningful exchange of health information to improve health and healthcare. We use ... as a shorthand. I don't know if that will be in the report. We call this the exchange. In other words, there are other ways that people may exchange data; for instance, a doc in one location may send patient data in an e-mail that would not go through an exchange, either a local or regional or national exchange. We're not looking at governance over that. We're looking at what will go through, what will be ultimately the new name of the Nationwide Health Information Network.

Governance is the mechanism that ensures that the necessary policy standards and services are adequately and appropriately established, coordinated, overseen, enforced and maintained over time. You'll see that some of the critical issues for us is recognizing that we're still in the ... area of this nationwide exchange; that we want to encourage innovation without being overly restricted and so the character of governance will change over time.

The governance functions, taken together, must improve health while ensuring public trust and enable interoperability while stimulating innovation. As I mentioned, innovation is a critical component. We want to encourage that to occur. Then finally, the trust and interoperability can only be achieved at the national level with the development of specified information policies—we're going to talk about certain areas for that—and the adoption of some common technical approaches and standards and establishment of clear oversight and enforcement of mechanisms.

So that's what the Committee is going to do. Let me tell you a little bit about the time frame, because you're familiar with very short time frames. We were given equally short time frames. I think we started after you— The first phase of this is that by October 20th, so that's just in a couple of weeks. We will be

identifying the functions and activities and services that require governance and then identifying the minimum elements of each of those functions and activities in order to achieve the objectives of trust and interoperability. We will be reporting to the Policy Committee on October 20th.

We'll then take that insight and feedback from the Policy Committee. By the November 19th meeting of the Policy Committee, we will submit a final report specifying who should be involved and responsible for governance, recognizing that the federal government has a significant role and parts of that role may be achieved through delegation to organizations in the private sector or public/private partnership. So we're looking at both federal public/private partnerships, as well as private organizations that may play some of these roles to identify how and by whom these minimum elements should be governed and identify oversight, enforcement or other means of accountability and how they should apply.

We start off by agreeing to a core set of governance principles. These governance principles that you see are nine: Transparency and openness; that the mechanism of governance needs to be clear and ... trust. There should be inclusive participation and adequate representation. That means as you look at the governance mechanisms that those who are stakeholders in the system and by putting in parentheses including consumers, because we wanted to make that particularly clear; that this governance mechanism should not exclude consumers with the providers. Well, this is too technical for that. We need to find ways for consumers to have meaningful voices in this process. A critical component and it follows throughout is that the form of representation, just as the form of governance, should follow the function that we're trying to achieve.

The third principle is effectiveness and efficiency. The fourth is accountability; that the created environment of trust when one entity in Paducah, Kentucky feels that the same level of accountability occurs in Poughkeepsie, New York when they're exchanging data.

The fifth is that governance should be distributed and should be devolved, as moving from national to state level and recognizing that there is an authority that may be ascribed to the federal government, but that government, that authority may be delegated and recognizing that delegation still does not absolve the federal government of responsibility so that they have some retention of authority even once it's delegated. The sixth principle is that there should be clarity of mission and consistency of actions through the governance process.

There should be fairness and due process for players in there because in order to assure accountability there needs to be some mechanism of enforcement. To assure accountability there needs to be some mechanism of enforcement. That promoting and supporting innovation is a critical component of our principles. Finally, that this needs to be an iterative, ongoing learning process with evaluation, learning and continuous improvement of the governance mechanisms.

The Workgroup identified overarching considerations and also identified four categories, which I will go through; privacy, security and interoperability being the first categorical area. The second one is governance related to technical requirements and then establishing mechanisms for compliance, accountability and enforcement and finally, oversight of the governance mechanisms themselves, in other words, how we assure that this governance mechanism is evaluating itself, learning and engaged in continual quality improvement.

The overarching issues: I'll just highlight a few that are on this slide. First is that we recognize that there's a need for national framework to address the barriers to exchange and that the mechanisms need to be there to determine who may use this brand. That may be one of the enforcement mechanisms, but clearly, individuals, entities will be engaged in exchange through the health information network and how they characterize that involvement is going to be critical in creating the mechanisms for governance and that expectation, the fifth bullet, and process that designate one or more authorized validation bodies.

Right now we're using the term validation bodies. We're recognizing that there is accreditation of entities that's possible. We haven't made a decision on that. It may be certification of some technology or some

other process to validate that those who are engaged in exchange are, in fact, doing it in a way that creates an environment of trust in which interoperability can occur.

In establishing the policies and practices for trust and interoperability we want to assure that there is sufficient privacy protections and safeguards in place to ensure trust within the health information network and thus, enable nationwide interoperability. After a fair bit of discussion we wanted to point out the fact that we came to the conclusion that privacy and security should be addressed separately. They're interrelated. There's a common objective to promote trust and interoperability in exchange, but we also recognize that security is not just focused on supporting privacy, but should also address confidentiality, integrity and the availability of data.

Paul Egerman – Software Entrepreneur
When you say they should be addressed separately are you separating privacy from security or is that one topic together, privacy and security, that is addressed separately?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think that what we would be looking at is looking at privacy and looking at security, but looking at them in two parts of our report. There will be a significant—

W
How about the word distinctly?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think that's probably a better word. Thank you. We'll be looking at them distinctly and they're so interwoven it's hard to pull them apart, but we do want to recognize that there is more to security than just the privacy components.

There should be coordination across state and federal authorities to establish a core, uniform set of privacy and security performance standards to promote trust and interoperability and address obstacles for nationwide exchange and addressing that interplay between the infrastructure that's already in place in states across the nation, most states across the nation, the HIPAA infrastructure that's in place. But for people to play in this space there needs to be some way for them to understand the rules in a more uniform way and that's one of the issues that we believe governance needs to address.

We also believe that there may be a set of best practices or additional requirements that go beyond law; either at the federal or state level and that it's the role of governance to identify what those are and to build them into the nationwide health information network. Finally, that there may be other types of policies and practices needed for adoption of health information on an interoperable and nationwide basis.

So those are the privacy provisions. The next slide goes on into the technical requirements. There the objective is to assure that technical requirements are consistent and cohesive to accomplish interoperability and policy objectives, including a defined security level of assurance. Two areas that I wanted to highlight under this is the need for coordination at the national level, recognizing that there are many entities that have some governance role related to the technical requirements, SCOs and others, and whether a mechanism is needed to deem certain technical resources for use within the health information network, for instance, certification authority registries and provider directories.

The third area is to assure that there are designated, authoritative and trusted mechanisms to validate that conditions for trust and interoperability are met, assure accountability and enforced appropriately. To create that environment of trust, again, going back; if you're in Paducah, Kentucky you have no way of knowing what's going on in Poughkeepsie, New York, but by engaging in the health information network, in the conditions in which the governance authority is engaged in assuring that the accountability and the fact that these requirements and methods and approaches and policies are being utilized in a way that enables trust to be maintained for exchange and interoperability to occur.

That governance should put forward expectations for validation bodies. Again, as I mentioned before, this could be certification, accreditation, use of the brand, enabling someone to exchange without particularly doing either one of those three things. There is a requirement for oversight and mechanisms with mechanisms for accountability and processes for ongoing compliance, complaints, coordinated investigation enforcement, breach notification, resolution of disputes, including alternative dispute resolution, mediation and so forth and ways to redress and identify remedies and also to impose sanctions, whatever those sanctions may be.

The fourth area is to determine how governance processes are performing to adjust to new circumstances. This is recognizing then that this is a young field, that the governance mechanism needs to be able to change over time as more experience is gained in the exchange, as the exchanging organizations grow in size and in number of entities and individuals that are exchanging through this network. We will be learning lessons and we need to make sure that the governance mechanisms are not so carved in stone that they can't change. That means that we have to evaluate the effectiveness of governance.

We need to monitor and track the governance effort. Are complaints being addressed? Are disputes being resolved? Are breaches being addressed? All of these things are components of looking at monitoring. Finally, looking at those items and activities that compliance will be addressing, such as voluntary reporting, routine revalidation and auditing for compliance and so forth.

So these are the rough outline of what we've been addressing as a workgroup as we prepare for our report on October 20th. Again, we would particularly be interested, if we've missed anything, where you think there may be governance issues that we should be addressing that we did not, we did not highlight, or more specifically, looking at the privacy and security governance issues, are there areas where we ought to be more granular in identifying the roles of governance entities.

Paul Egerman – Software Entrepreneur
Thank you very much, John. What comments do people have?

Deven McGraw – Center for Democracy & Technology – Director
John, great presentation. Much appreciated. I have a bunch of questions, but I'll just start with one so I don't monopolize the time here. I thought that I heard you say in the very beginning of the presentation that—and I may have not fully understood, but I just want to get clarity—the recommendations that you have with respect to governance are not intended to apply to sort of what we've been calling directed exchange, the one provider electronically sending, such as by secure e-mail, patient information to another provider versus governance of sort of more formalized networks like what we call an HIO and others call HIE. Did I mishear that or—?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
What we're looking at is exchange that occurs through the health information network. So if you do a directed exchange and it goes through the health information network then that would be something that we would be looking at governance covering. If you send it through Gmail then we probably would not incorporate that within our current scope.

Paul Egerman – Software Entrepreneur
I guess I would challenge that.

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

Paul Egerman – Software Entrepreneur
I would say if you send it through a transport standard that's been established by ONC then it should be included and if e-mail is one of those message transportation standards then it should be included. I mean the NHIN is nothing but a collection of standards and so I think directed exchange is important to be included.

Mary Jo Deering – ONC – Senior Policy Advisor
I will jump in because I think we have a lack of semantic interoperability here. I think John is actually saying the same thing because, by definition, the activities, the specifications and standards that are now being developed under the direct project are going to be moved forward for candidacy as NHIN standards and specifications. So at that point, to the extent that they are accepted and recognized as NHIN or whatever the word may be, standards and specifications, then by definition, they are in scope.

I think one of the ways that we also get a little tangled up here in this is because until in a way governance is done and we know what we're naming this preferred approach to exchanging information, this recognized approach to exchanging information, it almost gets to the point is this mandatory for all manners in which information can flow. I believe that, without wanting to put words in anyone's mouth, there is no presupposition that this covers each and every way that health information ever moves.

Paul Egerman – Software Entrepreneur
I understand the last point, but just to make sure, Mary Jo, that I understand what you're saying, if I hear you right, directed exchange is within the scope of the governance function.

Mary Jo Deering – ONC – Senior Policy Advisor
Well, now remember, one of the things that we have tried to say is that we are not setting up one form of governance for "directed exchange" and another form of governance for the exchange as it currently exists. We're trying to get away from that sort of current dichotomy that we live with right this minute and look at the ways in which the information is flowing and so to the extent that that exchange is taking place and I think John said exactly this—that if, indeed, it is taking place in ways that utilize the standards, services or specifications of what may be called the NHIN then it is in governance. I'll stop there because I don't want to put words in John's mouth.

Paul Egerman – Software Entrepreneur
Yes. Well, I mean the basic purpose of this discussion I think is for us, this Tiger Team, to give feedback to the Governance Group and the feedback that I'm suggesting is that directed exchange needs to be included within this umbrella. That the group can't just say it has to go through one of these HIO organizations. That's the definition of exchange because there's a lot of information exchange going on right now that goes directly from provider A to provider B and that's actually the only thing that's really included in stage one of meaningful use. So it seems like that's got to be part of it, that's got to be within this entire governance structure and—

M
Paul, I think my take away from this is that without specifically mentioning directed exchange we will leave some ambiguity that will confuse folks and so we need to be clear what we're talking about and specifically address directed exchange.

Deven McGraw – Center for Democracy & Technology – Director
Yes. I mean I would recommend that too, although actually, some of the terms that you used to me create an umbrella under which directed exchange clearly fits. It's the creation of some best practices, preferred approach and a brand. To what extent do you get to label your exchange is following this brand, regardless of how you're doing it, because it's meeting the set of standards and services and policies that constitute the nationwide health information network brand, right? That seems to be a better way of explaining it, of course, being clear that it's not limited just to a network of networks approach that characterize the NHIN in previous administration.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
That is in previous iterations.

Deven McGraw – Center for Democracy & Technology – Director
Yes. Yes. ... to say it.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes. Correct.

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

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I would agree with Deven that it may come down to a branding question. The protocols that are specified for NHIN Direct, as well as the protocols that are a part of the current iteration of NHIN are all open protocols that anyone is free to use. They're just open standards and people use those. They use proprietary protocols as well to do information exchange. My assumption is that governance would not apply to people that are doing exchange outside of whatever the brand implies, but that's what I think would need to be clarified.

Deven McGraw – Center for Democracy & Technology – Director
I think ideally you create a brand that people trust and is so strong that the ability to exchange outside of it, while you might theoretically have it unless you are required by law or a spending condition to use the brand, it would be unwise for you to do so, because ideally, people would expect that you would adhere to these.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Right. You'd want the brand to be attractive so that everyone would prefer to do it that way, but the governance would not apply to those people, who weren't trying to be a part of that branded network is my question. It makes sense to me, but it needs clarifying.

Let me put a footnote to the question, which is that, John, you mentioned the states in a number of places in the early part of your slides and it may well be that over time states play a critical role in many areas for establishing the dominant health information player, but I'm pretty sure they'll be more than just state entities that are participating. Some states may have multiple entities. Some regions, like Kansas City, may have things that overlap states. Is state a required part of the governance, the notion of a U.S. state or is it really entities that are participating?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Well, where that comes up is where there are specific state laws and to the extent that federal laws do not preempt those state laws. Then in Kansas City the character of consent, the character of what kind of reporting needs to go to an individual may differ depending on what side of the street you live on. That's the kind of governance issues that we believe need to be addressed in setting up the governance mechanisms. That's looking at states as creators of laws and regulations as opposed to looking at states as facilitators of exchange that may occur in certain situations.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I got you. So you're really focusing on the legal arm of the state, not on the state as the hosting entity.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
That's correct.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Kind of going back to what Paul and Deven were trying to clarify a while ago, I'd like to pose a particular example. If I, as a physician, used an HIE to exchange information with other providers and I myself didn't use NHIN and the HIE didn't advertise itself as an NHIN exchange, but it used the NHIN Connect to exchange with other HIEs would the entities within that HIE be subject to this governance or would it just be the operator of the HIE itself?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Well, I think that the easy answer is yes, they would be subject to governance, but what that governance would be is what would need to be determined and we, as a Workgroup, aren't getting that far down into

the specifics. We're just saying that to the extent that exchange occurs, based upon the policies and procedures, regulations and so forth that that needs to occur; that needs to have some sort of governance mechanism to ensure an environment of trust such that exchange can occur where it needs to occur.

So the example that you use would be one of the things that you would expect the governance mechanism to be specific about. When is it and when is it not under the auspices of the governance process for the NHIN?

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

Leslie Francis – NCVHS – Co-Chair
I have a couple of observations. The first one would be the observation that the overall tone of this is about compliance and enforcement and while improvement is addressed with respect to improving the governance function, I would suggest that a function of governance is working to establish best practices rather than merely identifying bad things that have happened, to encourage best practices and to work in an educate way, prevention rather than oversight after a trust violating event has occurred.

The other thing I would observe is that I think there is reason to think about a little more than maybe slide eight says about what it means to address privacy, both with respect to federal and state legal requirements and also with respect to you did mention best practices and additional requirements beyond law. State law differences may not be barriers. They may actually be privacy and trust enhancing. So, working to try to figure out how to put in some of the more granular controls that might protect the privacy, say, of certain kinds of information may be a governance function.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think we're going to, obviously, have to get into the governance mechanism is going to need to look at a lot of those on a case-by-case basis. When you look at the variances in state law in relationship to handling health information related to mental illness—

Leslie Francis, NCVHS – Co-Chair
You got it.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
There is a huge amount of variability. So the question is if I'm in a state that is fairly restrictive and I am exchanging information with someone who is in a state that's very unrestrictive there needs to be a feeling of trust that I am doing things that are consistent with my, in the case of the physician, requirements that uphold the laws of the state in which I am practicing.

Leslie Francis, NCVHS – Co-Chair
Exactly. I would highlight that. I don't know what to tell you to do about the other point, about having a compliance rather than an improvement of privacy and security and other trust building practices, as well as improving of governance, but I would urge you to try to shift it a little bit. We want to make sure that things go well.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Right. I think that we would agree with you. So it's a word of caution that when we start really getting words down on paper that we look at it from that lens to make sure it has the right balance.

Joy Pritts – ONC – Chief Privacy Officer
As you may know, I've done a lot of work in the state law area and I think that in approaching this topic it's really important to maintain the separation between what law requires and what the group may think is good policy to enable trust, because I think they're very different.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director

Can you maybe elaborate a little bit on that? Because I think what we're looking at is to what extent the mechanism of governance should address it, so I think that we would be looking for something that would be like a sentence we could plug in there that would emphasize the point you just made.

Deven McGraw – Center for Democracy & Technology – Director
Can I just interrupt for a second and see if we can identify where the line is that's creating all of the static? It's getting very hard to hear. It might be mine, in which case I'll dial in from another line.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I can hear fine. I'm not sure.

Paul Egerman – Software Entrepreneur
I don't hear any static.

Mary Jo Deering – ONC – Senior Policy Advisor
I don't hear any static either.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I'm doing pretty good.

Deven McGraw – Center for Democracy & Technology – Director
Never mind. Okay. Never mind. I'll falter on. Go ahead.

Joy Pritts – ONC – Chief Privacy Officer
It's you, Deven.

Deven McGraw – Center for Democracy & Technology – Director
It's me.

Joy Pritts – ONC – Chief Privacy Officer
John, to go back to what you were saying, I think what we have here are a few things that are in place that people may not be happy with, but I think it's what we probably, at least for the time being, need to work within. One is that when Congress addressed this issue of state federalism recently in the HITECH Act it expressly stated that they intended to keep the preemption framework in place, which means that states continue to be free to act independently and in access of the privacy role.

We here at ONC have been trying to identify with some of the state participants in some of our programs exactly what the problem is in this interstate exchange. I think you identified it quite well. When you look at the legal framework the legal framework is that the state in which the data is held is the law which controls the data. So in a paper world or an electronic world, when entity A in state one transmits to entity B in state two, entity B follows state two's laws. That's just how it works.

Now, what I think you were saying though is that in order for health information exchange to be trusted and to work that something additional to that might be required.

Neil Calman – Institute for Family Health – President & Cofounder
For one thing, it means that every state has to know what every other state's law is in order to decide what can be sent legally across from one state to another. Correct?

Joy Pritts – ONC – Chief Privacy Officer
Do you know that now?

Neil Calman – Institute for Family Health – President & Cofounder
No.

Joy Pritts – ONC – Chief Privacy Officer

I guess this will require much longer discussion, so I'm curious to whether ... but I'm curious as to whether by the very nature of health information exchange that that changes the dynamics so much that providers feel like they need to go there; that they would need to know all of that.

Judy Faulkner – Epic Systems – Founder
Isn't it just the sending state is releasing information, who has to follow its rules rather than have to worry about each receiving state?

Joy Pritts – ONC – Chief Privacy Officer
That's why I'm asking.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Well, I don't know. I mean if there's a rule that you can't exchange information on mental health issues or substance abuse without consent and I'm a receiving state and I'm getting all kinds of substance abuse information sent to me without the patient's consent I don't know if people have looked at this yet.

Paul Egerman – Software Entrepreneur
It would seem to me that if I heard what Judy said correctly that might be part of the value this Governance Group could add would be to clarify this issue. Is the rule simply it's according to whatever state that holds the record; that they determine what the rules are for sending?

Joy Pritts – ONC – Chief Privacy Officer
Yes. I think that we need some clarification and some discussion on this. I understand that when you're a single entity that acts in many states that it becomes more difficult, but that's true with any business that operates in many states. No matter what your business is, if you operate in many states you generally have to follow all of those state laws.

Judy Faulkner – Epic Systems – Founder
Some of the state laws, I think, with privacy may be contradictory, but I do think that if you are a sending state and you're following the rules of your sending to go to the receiving, the receiving state must know how to execute the rules for the sending state that the sending state requires.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think that you're actually engaging in the kind of discussion that we would expect would occur within the Governance organization.

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

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
The second point is that we also need to recognize that state laws are not static things. That what we want to do is create an environment of trust and what has existed before has not necessarily been an environment of trust and state legislators are like a carpenter, who only has a hammer. If you see a problem the only thing you have to address it is your hammer and in the case of legislators that means making laws.

On the other hand, those laws can be changed over time and if you create an environment of trust and an infrastructure of how privacy is protected then in some ways state laws may be changed in order to accommodate that kind of exchange if it's seen as a public good. So the first step is to have a governance mechanism, have it begin to address that and within the context of what the state legal structure is, come up with the best possible solution to enable trust to be maintained and exchange to occur.

Neil Calman – Institute for Family Health – President & Cofounder
Good comments.

Deven McGraw – Center for Democracy & Technology – Director
Very good. Getting off of the state law issue and getting back onto the topic of best practices, I think that we've actually outlined some starter ones, important starter ones in our August letter, particularly with respect to the robust adoption of fair information practices by all entities involved in exchange, which we acknowledged that the business associate rules and requirements for business associate agreements provide one mechanism, but probably not the best one for ensuring that all entities adopt fair information practices, which in many respects are really a set of best practices that go above and beyond the law. So between that and also the recommendations on when consent is required and what it ought to look like, it sounds like you've laid a nice framework for how to process some of these issues and identifying privacy and security as an important element. I guess I'm just suggesting here that we've already started to fill in some of those blanks arguably.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Good point.

Paul Egerman – Software Entrepreneur
I also have a comment, John, which is a lot of this discussion was about exchange of information from one state to another, but one of the basic challenges we have is getting information to go like across the street where across the street does not necessarily cross a state boundary. In fact, sometimes it's a problem getting from one floor to another in a doctor's office building. Are you addressing those kinds of governance issues, about what happens when you have one party that doesn't somehow play by the rules, doesn't submit according to technical standards or doesn't comply with security rules?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Well, I think you're asking a coupe of questions. Let me explain how I think I understand what our recommendations will do to address that. The first is that, of course, one way of moving data between floors is through Sneakernet and I don't think we're going to apply to Sneakernet or just transporting paper from one place to another—

Paul Egerman – Software Entrepreneur
No, but you could do directed exchange.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes. But on the more serious side, one of the critical areas that we believe we haven't fully addressed within the committee is how far down into the nodes do we believe that nationwide governance needs to go.

Joy Pritts – ONC – Chief Privacy Officer
Yes.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
So those kinds of issues that are within an exchange, we believe that there's going to need to be room for those exchanges to innovate, but at the same time, in order to create that environment of trust I think that we're going to have to look at how those exchanges are approved or should I say validated. If I am sending information into that regional or local exchange that there's some validation that it is being protected as one would expect that it would be.

Paul Egerman – Software Entrepreneur
Right, but that's an answer that's still, if I heard it right, assumes that there's an HIO in the middle of the transaction. What about directed exchange, where you've got a physician and, say, a hospital or a physician and a laboratory sending information back and forth? Is that an area where you're going to have governance in case one of those players isn't playing by the rules?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think the answer is that we have not yet addressed that.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
That might come back to that branding notion. That if the mechanism used carries the ... that is consistent with whatever the new name is then it would apply.

Paul Egerman – Software Entrepreneur
Not to get ahead—I agree with what you just said, David—not to get ahead of the discussion, there might be other governance issues. I mean if you have a concept of a provider directory or provider certificates or digital credentials one could go so far as to say there are some circumstances under which those would be revoked. The person's right to be listed in the provider directory is eliminated if they don't do certain things. So that would also be a governance kind of an approach.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes. I mean I think as one is working on the pilot phase of the NHIN Direct we are wrestling with those questions right now, so whether it's part or not part of this governance effort it will be part of some governance effort and if it shares the same name and has the ONC ... on it then it would seem to make sense to be part of the same governance model.

Paul Egerman – Software Entrepreneur
It should be.

Deven McGraw – Center for Democracy & Technology – Director
It should be and I think ultimately we don't want multiple governances, which is the point that John made. We want sort of one so that you can exchange through multiple ways and still be required to comply with a basic set of standards and policies if you want to be part of the brand.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Right, but I think the part that we would have to address is that that's not to say that there may not be delegation for validation of the use of that vehicle.

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

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
So there may be, let's say, an accreditation board or body that looks at directed exchange or some certification of the technology and the mechanism by which that occurs, which would be built into this network of governance. It wouldn't necessarily be that the highest level of governance would be directly overseeing that process of exchange.

Gayle Harrell – Florida – Former State Legislator
Who do you anticipate setting those standards?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
That's part of our second phase of the conversation. What we wanted to do to this was a fairly structured approach to talk about what everyone agrees ought to be within the scope of governance and then our report on November 19th would then begin to address who.

Gayle Harrell – Florida – Former State Legislator
Then who holds the stick?

Deven McGraw – Center for Democracy & Technology – Director
The same who.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
The same who. Well, in many instances it will be the same who. It does not necessarily have to be or always be the same who so, for instance, you think about hospital licensing and regulations. Many times there is a deemed status associated with a hospital being licensed, both by Medicare for certification

purposes and by states for licensure purposes. When there are problems with compliance then one of the sanctions is losing that deemed status and undergoing a different kind of review. So there are different kinds of structures and architecture for enforcement that may use a different mechanism once there is a breach that's egregious enough to require special attention.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
To change the subject slightly, have you talked about whether non-provider facing entities would be able to join the network and take part in the governance? Specifically I mean PHRs or other kinds of new age entities that might work on behalf of a consumer with a consumer's authorization to achieve some purpose, but stick to PHRs to keep it simple.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes. That's the reason why we envision that this governance would not be just governance over exchanges, so it's not just a network of networks. It's recognizing that there are other entities out there and PHRs would be ones where, again, the issue of whether or not there would be some accreditation of or certification of PHRs that there are, in fact, meeting and maintaining the infrastructure of trust. So that would be one of the components that we have talked about.

Leslie Francis – NCVHS – Co-Chair
Just a quick observation: If you go back to NCVHS' letter on PHRs there is a huge difference between PHRs that are in some way or another linked, perhaps with business associate agreements, to HIPAA covered entities and an entirely different world as PHRs that are currently not in any way, shape or form linked to HIPAA.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Correct.

Paul Egerman – Software Entrepreneur
I was listening to your comment in response to David's question about PHRs. It's certainly a very interesting question. You said that you yourself was doing governance over exchanges. I guess I would encourage you to view yourself as governance over information exchange over the Internet.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I'm sorry if I wasn't clear. That's what I intended to say.

Paul Egerman – Software Entrepreneur
As far as governance over exchanges because the PHR is not an exchange.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes. No. We're not looking at governance just to be over exchanges, but we're looking at governance over the process of exchange.

Paul Egerman – Software Entrepreneur
It therefore is probably over the process of exchange that uses this brand ... membership agreement.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
That's correct, as per our earlier discussion.

Paul Egerman – Software Entrepreneur
Okay. Just to make sure that we can roll it all into one sentence.

Deven McGraw – Center for Democracy & Technology – Director
I want to go back to the point about sort of including consumer representation in the governance piece. I had the opportunity to attend the hearing and hear a bit from some of the governance examples and how they incorporate consumers into the model. I'm glad to see it on the slides. I think there is room for creative thinking about how you can make consumer representation and I almost hesitate to say it—it's

such an overused word—but meaningful because the consumers from a number's perspective are always going to be smaller than the collective interest of some of the other stakeholders, but there are obviously ways to make sure that the voice at the table is equivalent and maybe that's the wrong word to use, but we saw the models NNQF used to try to balance the fact that they have so many more representatives from industry than consumers.

Similarly on the Health IT Policy Committee I think the numbers of pure consumer representatives may be small, but I think it works because there is a dedication on the part of the Committee members, as well as ONC to be acknowledging a consumer voice. So I'm not suggesting that there's one way to do this, but I guess I'm encouraging more thoughtful development there in sort of later iterations of what you're doing.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I would just add my two bits: That I anticipate, based in some measure, on an ION meeting that was held yesterday that I was part of with maybe some of the other people on the call where the emergence of other kinds of entities that facilitate information exchange, like health record banks or similar, should be anticipated and encouraged by the governance model. I think you've addressed that. I think you've kept that open.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
That, again, goes back to one of our principles that we want this to be tight enough to ensure an environment of trust and interoperability where the exchange can occur, but at the same time, recognize that this field is far from mature and that innovation needs to be supported and not to make it too tight.

Gayle Harrell – Florida – Former State Legislator
Yes. I'd like to offer something also. I think certainly I agree with Deven on the consumer representation, but I think it also needs to have a focus of privacy and security. This is our focus on this Committee certainly, but when we're talking about governance and establishing mechanisms for that and for the exchange of ... that's where the rubber meets the road on privacy and security. When we're talking about consumer representation I think that they really need to have that focus from a consumer, who has their number one concern out there in exchange; it's privacy and security.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I'm not sure I completely agree with that. I think that many of the consumers that may be more vocal in some components are focused on privacy and security. I'm reminded of a hearing where someone raised the issue of consent. That what about the consumer who believes that their provider ought to have them sign a consent for them not to exchange their data. There has been a fairly significantly consumer engagement and push for electronic data exchange, particularly by the disease-focused organizations because they believe that that is so important to better understanding an individual disease and finding cures faster and so forth. So I think there is a broad range of consumer interest.

Judy Faulkner – Epic Systems – Founder
I wonder how many folks have had their data exchanged by going somewhere and their data shows up there. I just had that over the weekend. I had to go to the ED because I was allergic to my allergy meds. It was really fascinating, because my primary care provider sent me over to the university, because they don't have an ED. I went there; walked in. They looked at me and said, "I see you were referred, sent here by Group Health. Do you want your records over?"

I said, "Yes." Click. It was over. It was fascinating, because they put a piece of paper for me to sign and I think there were like three or four lines on a triple space. It couldn't have been easier. I signed and I didn't read it. It's interesting that even though it was so simple I didn't read it. I think the number one issue when people come to get care is their health first, because they want to be healthy and they want to survive. Then within that goes other things.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director

Yes, but the concern for privacy is not about your fear that the good things won't happen, but your fear that the bad things that could happen. Most people want the sharing to occur for the good purposes. They just want some control over the bad purposes.

Judy Faulkner – Epic Systems – Founder
Yes. I'm not disagreeing, but every once in a while, like with so many other things, there becomes a choice you have to make because two clash and then what is the priority. That's, I think, some of the things we're discussing here.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Maybe one of the things we should think about in future iterations of our own consent thinking is a distinction of the kinds of activities that are opted in or opted out of. So, for example, maybe there's an opt-out model for certain kinds of activity, but opt-in for other kinds. We kind of made it all or none at the moment and that might not be granular enough.

Paul Egerman – Software Entrepreneur
Those are good points, David, but I want to make sure that we are using John's time effectively—

Deven McGraw – Center for Democracy & Technology – Director
Yes. Thank you, Paul.

Paul Egerman – Software Entrepreneur
Because our topic is giving guidance, is coordinating. We want to make sure we know what his workgroup is doing and he knows what we're doing and also giving him guidance. So let me ask you a question, John, which is we've asked you a number of questions; do you have any questions you want to ask us?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Well, I think this conversation has been very helpful. I think that the two basic questions and where we have our biggest concern is that we don't want to reinvent the wheel. We know that your Tiger Team has been meeting. You've been doing some good work and we just want to make sure that there's some feeling that what we've been putting into our document is consistent with your thinking.

Paul Egerman – Software Entrepreneur
Do you feel we've given you some guidance on that today?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think so.

Paul Egerman – Software Entrepreneur
Yes. I mean I guess part of the guidance is to include directed exchange in sort of like a level playing field of all of the exchange methodologies. I guess there was a lot of concern I heard and interest about state laws as stuff goes from one state to another. There was also a suggestion that governance does not necessarily just mean somehow finding the evil doers or the bad players; that there might be also an important role for education and best practices.

Was that a good summary or did I miss something there? I'm not just asking you, but asking the group in terms of—

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I think the mention of entities other than just traditional exchange entities.

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

Paul Egerman – Software Entrepreneur

That's right. David's comment too is to consider other entities that are really, I guess, not covered entities, like EHRs that would be involved. That was also, I think, a good suggestion about consumer representation in your efforts.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
One other consideration as I flip through the slides again: A touch point for our discussion has been this notion of Fair Information Practice. I think Carol is on your committee as well. She was the one who brought that up repeatedly for us. I think that that rubric, Fair Information Practice, is a useful way to roll up a bunch of ideas that go beyond just the focus on privacy and security. It might make sense to work that in, although you may have already considered that.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Great.

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

Paul Egerman – Software Entrepreneur
Let's see, Carol and Wes. Is there anybody else that's on both groups?

Deven McGraw – Center for Democracy & Technology – Director
John Houston.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I'm on both.

Paul Egerman – Software Entrepreneur
That's great. It's very helpful to have people who are on both, because then you can participate and help us coordinate. That's very good.

Deven McGraw – Center for Democracy & Technology – Director
Yes. I call it cross pollination.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Great.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Or cross pollution.

Paul Egerman – Software Entrepreneur
That could be. Are there other comments on governance or questions?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
All right. I would just like to thank all of you so much for your time and certainly, hopefully, you will take a look at what we're producing and feel free to give us additional comments as you think of them.

Paul Egerman – Software Entrepreneur
Likewise. I hope that there will be a lot more dialogue. Great presentation, John. We appreciate it. It was very thoughtful.

Deven McGraw – Center for Democracy & Technology – Director
Yes. Thank you very much.

Paul Egerman – Software Entrepreneur
Deven, do you want to start talking about—?

Deven McGraw – Center for Democracy & Technology – Director
] Next on our agenda is to finish up the transparency discussion and transparency recommendations that we are teeing up for the next Policy Committee meeting, which is on October 20th. You'll recall at our last meeting that we had, I think ... around some bigger issues, but didn't really have a lot of time to wordsmith them on our previous call. So Paul and I had circulated a draft articulation of the recommendations that came from the discussion we had on our first meeting; asked for feedback. We got some good feedback and so this morning I circulated to each of you both a clean version with the edits that I received in it, as well as the red lines so you can see where the changes were made.

Paul and I have also teed up what we think are three questions that we still need to resolve or make sure that we have resolved to the comfort level of the Tiger Team members so that this can all get presented. Now again, keeping in mind the rule that we set out when we first started; that we would minimize use of time on these phone calls to wordsmith, but instead to drive consensus on bigger picture issues and use the down time to do the wordsmithing aspect of it. We're not going to spend time here wordsmithing, but instead, to focus on these three big issues that really emanate from the responses that we received from you all in the interim.

We think we've got three overarching questions to discuss here. One is to make sure that the Tiger Team is comfortable with the layered notice approach that we are promoting here. Number two is to talk about when we say that with layered notice what goes out to patients initially should be something that is a short summary. How short is short? Does our concept of short vary at all depending on what we're giving patients notice of, whether it's a consent trigger circumstance or with respect to an OHCA or whether we're talking about the traditional HIPAA privacy notice.

Then the third question is with respect to notice of participation in an OHCA. We received a lot of questions about the draft recommendation in terms of timing of when this notice occurs. This is already well covered in the law and so it's not entirely clear that we need to say anything. We certainly got the most amount of comments back about the draft recommendation, which, in essence said patients should get it ahead of time when that's possible to do so, acknowledging that that's not always the case. But of course, OHCAs are quite different from what we are labeling in this document indirect exchange. Thank you, David McCallie, for that suggested term. I hope you saw that we used it in here to refer to those exchange circumstances that we have already said trigger consent because the physician is no longer in control of disclosures from his or her record.

With that, I think we should address them, try to move on to the first. Does anybody have any questions or concerns about how we're going to proceed before I move into the first question? Okay. Terrific.

The first question is whether folks are on board with the concept of a layered notice approach, which really you see throughout our recommendations. We say that even for the HIPAA Notice of Privacy Practices, ideally that should be done in a layered way so that people aren't presented with eight pages of documents, but get something simple to start out with. We also call for layered notice of an OHCA and we called for layered notice of the use of indirect exchange or trigger type of exchange situation.

Then with respect to OHCA notices and notices of participation in a trigger model, i.e., indirect exchange in our recommendations, that that should ideally be separate from the HIPAA notice so that the patient's attention is drawn to it. Are folks on board with that generally? That was based on discussions that we had in our previous call where folks thought that that was the best way to make sure that people at least have some level of information about the existence of these two types of arrangements without necessarily burying them in the details.

Gayle Harrell – Florida – Former State Legislator
I unfortunately was not on the last call. I'm in the middle of an election, as some of you may know, and was late getting in today. But I want to just make some comments on the layered approach.

I absolutely agree that that is the best way to do it. However, you have to have an education component that is more than what is done in the office or in the emergency room or whatever. I think this is a role

that the ONC needs to play and also the HIOs and a variety of organizations. That if you're going to go with a layered approach to notification then you need to make sure that there is some kind of general understanding in the public out there to what those things are and that they do have the ability to learn more. Most people have no idea what we're talking about. There needs to be more public awareness with this and that layered approach needs to be simple at the very beginning, getting more complex, of course, as you get more into it, but I think that there needs to be some outreach and some education component that we need to make sure gets built into this entire thing.

Paul Egerman – Software Entrepreneur
Good comments, Gayle. The last sentence in the letter, this is item number four, says, "ONC should require federally funded HIOs to develop and implement public education plans." Is that responsive to what you're saying, Gayle? Do you want something a little bit more, to also say ONC has a responsibility to do this?

Gayle Harrell – Florida – Former State Legislator
ONC plays a role in this as well.

Paul Egerman – Software Entrepreneur
Okay. So we need to add like another sentence there, plus ONC needs to. I think we grew that in one of our other recommendations. It probably doesn't hurt to reiterate it here.

Deven McGraw – Center for Democracy & Technology – Director
That's right. There already is, I think, something in HITECH that requires HHS to do more public education. I think it's on privacy and security issues. We can take a look at that. Joy, do you recall?

Joy Pritts – ONC – Chief Privacy Officer
I'm sorry. I was on mute.

Deven McGraw – Center for Democracy & Technology – Director
My question was about there's a HITECH public education mandate on ONC. I just wanted to—

Joy Pritts – ONC – Chief Privacy Officer
The HITECH education, the education requirement I thought was on OCR.

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

Joy Pritts – ONC – Chief Privacy Officer
To inform individuals of their privacy rights. Correct?

Deven McGraw – Center for Democracy & Technology – Director
Okay. That's sounding more familiar. Right.

Joy Pritts – ONC – Chief Privacy Officer
They are working. They're in the midst of working on a campaign to satisfy that requirement. Perhaps you have heard of some. Dr. Blumenthal has mentioned a few times about some listening sessions that we're going to be scheduling in fiscal year 2011 as funds become available.

Deven McGraw – Center for Democracy & Technology – Director
Right. Okay. So in other words it would be appropriate for us to encourage ONC to do some of this public education about these newer exchange arrangements.

Carl Dvorak – Epic Systems – EVP
I wonder if, for the purposes related to transparency around information exchange if we might want to take this a slightly different path and suggest that we recognize OHCAs and ... as HIPAA entities or HIPAA providers under the definitions, provided they're following those standards, which can be defined

elsewhere. We treat them as a HIPAA provider for purposes of this, because I was reading more on it and I think OHCA covers things like a hospital where the anesthesiologist is in a group of anesthesiologists that's not actually owned by the hospital. He might be in an immediate provider group. I'm trying to understand how we would tackle a merger of rules relating to exchange versus rules relating to people who share a common system or a common healthcare provision goal. I wonder if, for information exchange purposes, we should just fall back and say that OHCAs and ... and other HIPAA defined provider variance will be covered under HIPAA rules to treat them as providers for purposes of exchange.

Deven McGraw – Center for Democracy & Technology – Director
So, Carl, I think essentially aside from the question, which we've keyed up as number three on timing, there isn't' really anything that's necessarily different about what we're saying about OHCAs than what would already be required in law. That's question number two. So if you can hold off on that? We are calling them out not because we're suggesting they're the same as trigger consent circumstances, but as a follow on to our August recommendations where we acknowledged that those types of arrangements didn't require patient consent, but that that was more of a transparency issue for patients.

Maybe it's even more important to underscore that patients have that understanding now that we're creating some exchange vehicles that patients are less familiar with and to make sure that patients really understand the distinction. Again, aside from the question that we haven't gotten to yet, but that we will get to on this call about timing, I'm hard pressed to see how what we are asking for with respect to OHCAs is any different than what we're asking for for HIPAA provider notices beyond that we are calling out that it really ought to be separate and distinct from an NPP, from a HIPAA Notice of Privacy Practices.

Carl Dvorak – Epic Systems – EVP
Yes. I think the thing that ... is that ....

M
I said I had trouble hearing you. Could you—?

Carl Dvorak – Epic Systems – EVP
The thing that I noticed when I was reading through the definitions is that HIPAA already has requirements or maybe it's CMS, but there already are requirements for NPP approaches for both, these affiliated, covered entities and as well, the OHCAs. So it seems like there already is a body of definition standards around those things and many of them are built around the notion that they share common systems, it's just under different business entities. It got really confusing as I was trying to map in what we were trying to accomplish here with information exchange onto what is being done with OHCAs and ... and it didn't seem to fit well.

Paul Egerman – Software Entrepreneur
Yes. Carl, the issue here is really an issue of situations where a patient may not understand that their provider, their medical record is involved with the OHCA. That is really the circumstance that we're trying to address with these recommendations.

Carl Dvorak – Epic Systems – EVP
Paul, I think the truth is though that an OHCA that doesn't exchange information at all will still have that issue, right? The patient may not understand regardless of whether they exchange information at all. So it could be a good additional thing to make patients aware of. Maybe if we think about what a patient becomes aware of ... just explain to them what a provider is in the first place, what are all of the definitions ... provider—

Paul Egerman – Software Entrepreneur
There's a lot of static on the line that makes it almost impossible to hear, Carl. Is there a possibility that everybody can make sure they're on mute?

Deven McGraw – Center for Democracy & Technology – Director

Yes. I don't ... that's what it is. Carl, I'm still going to push you as to what it is that's in here that you think conflicts with current law, because, quite frankly, I think it was the consensus of the team, unless you folks want to tell me that I'm wrong about this; that we wanted to say something specific to OHCAs since we raised it in our August letter.

Carl Dvorak – Epic Systems – EVP
I don't know that I can say what is in conflict with the law. What I did notice though is that there seemed to be other definitions around the NPP requirements and the disclosure requirements for both OHCAs and ... that I see we're trying to write into here to some extent. The fact that we're basically expressing an OHCA as almost an exchange model; whereas it's not really an exchange model.

Paul Egerman – Software Entrepreneur
I agree with that. What I don't understand, Carl, is what would you suggest we do.

Carl Dvorak – Epic Systems – EVP
Well, I wonder if what we could do is just define with this transparency document that practice should follow the standard CMS or HIPAA guidelines for disclosures related to being an OHCA or being an .... This policy would basically treat them as a HIPAA provider for purposes of information exchange. They already have disclosure and notice requirements. I think there are certain requirements that they have to put forward so patients know that they're operating as an OHCA or know that they're operating as an ....

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I think HIPAA says that it can be accomplished through a joint notice. I'm not sure whether that requirement is not a firm requirement though, if I'm not mistaken.

Deven McGraw – Center for Democracy & Technology – Director
Yes. It's not a firm requirement.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
As I recall the discussion, I believe there was some concern that data sharing could occur through OHCA or OHCA-like arrangements that would be a surprise to the patient, because it's sharing across the boundary that the patient associates with, where they're getting care, but which would not necessarily involve a well established HIE. So there's an intermediate kind of sharing that we wanted to make sure was called out for transparency just like the, I'll call it, more traditional sharing through an HIE if HIEs could be called traditional. That was a concern, right?

Deven McGraw – Center for Democracy & Technology – Director
Yes. I think that's right. I mean the fact is, Carl, that while that may not be considered external sharing from a legal perspective, I think David's point is well taken; that from the patient's perspective it very well might be. Our primary goal here is just to make sure that patients understand this especially as we move into an environment where there are other exchange entities that are quite different.

Carl Dvorak – Epic Systems – EVP
So maybe we could differentiate OHCAs where there is actual information exchange happening versus OHCAs where it's basically a community hospital, but the anesthesiologist is not on the payroll and the ED doctor is not on the payroll and the attending doctor is not on the payroll? Because that's the situation that I'm struggling to come to grips with, because to try to disclose that as information exchange doesn't seem to fit the model and yet I do respect, like you said, that if three different entities with three different systems start to exchange data on the patient then it seems to make more intuitive sense that the patient should be aware that information is being exchanged among these entities.

Deven McGraw – Center for Democracy & Technology – Director
Carl, I'm going to have to ask you to submit me some language because we actually already worked with this to try to make it clear that not all information sharing in an OHCA necessarily meant exchange and to try to be very clear that I just don't see how what we're asking for here is either confusing or conflicting in the law.

Paul Egerman – Software Entrepreneur
I think if you could send some language, Carl, because I do understand your issue, because I sort of struggle with this too. It's like there are OHCAs and there are OHCAs and we don't want to put together something that requires if you go to a community hospital that you have to learn that the anesthesiologist and the pathologist and the radiologist are separate because you'll find that out anyway when you get your bill. It's not the real issue.

The real issue is more the community physician, the cardiologist, who decides that say since John Houston is on the call, UPMC is going to host his medical record. As a consequence there is sharing of that private practice medical record occurring. That seems like that's just an important thing to disclose. It's not really information exchange if the cardiologist has some relationship with that, with UPMC as they try to do this example, but it would seem like that's important to disclose. So I wasn't too sure of the right way to write that, but if you could suggest something I think you've got a good point.

Carl Dvorak – Epic Systems – EVP
Okay. Well, I'll take Deven's advice and take it off-line and try to follow up with some comments.

Gayle Harrell – Florida – Former State Legislator
Does not the example he's using fall under for purposes of treatment of a patient when you're talking about anesthesiologists or ED doctors? That is direct exchange for treatment.

Paul Egerman – Software Entrepreneur
It's actually not direct exchange. In other words, if you look at a community hospital the way HIPAA treats it is that it is an OHCA and so even though say the anesthesiologist or the radiologist is technically a member of a separate corporate entity in terms of a medical group, to the patient it's all one thing. It's ABC Community Hospital and they share information pretty freely. That organizational structure actually exists because of some of our keen billing situations. They make it better for the physicians to bill themselves as separate entities, but it's not information exchange the way we're talking about it. It's a different topic.

Gayle Harrell – Florida – Former State Legislator
Okay. Thank you for the clarification.

Paul Egerman – Software Entrepreneur
This is a problem we run into a lot, because the organizational structure of healthcare is bizarre ... it's just you've got these things set up that lots of times people have a lot of difficulty understanding what it all means.

Neil Calman – Institute for Family Health – President & Cofounder
There is no organization to healthcare. I have a couple of more serious comments than that one. One of them is you talk about reading level of the average patient. Is that like something that exists somewhere else? Because I wouldn't even know how anybody could operationalize that. Shouldn't we just specify a reading level?

Paul Egerman – Software Entrepreneur
Well, I think what we're trying to do there, Neil, is to actually make it so that each sort of group would handle it differently.

Neil Calman – Institute for Family Health – President & Cofounder
I know, but that I think is a serious problem, because you really don't want it geared to your average patient, which means 50% of the people can't understand it. You really want it geared to the fifth percentile, so 95% of your patients can understand what you're writing.

Paul Egerman – Software Entrepreneur

So maybe that's what we ought to say ... in such a way that it would be understandable to 90% of the patients.

Neil Calman – Institute for Family Health – President & Cofounder
You really don't want your average there. The other question I have is about the separation. Is this separation temporary? Is it separation on two different sides of a piece of paper? Again, I don't really understand and I apologize, because I haven't really seen this before, but what do you really mean by separation?

Deven McGraw – Center for Democracy & Technology – Director
That's a good question, Neil. I think the primary point we were trying to make here is don't bury this in your HIPAA notice. So I think one way to make it separate would be to have it in the HIPAA notice, but have it boxed out and in separate type and with lots of some way to distinguish it so that it doesn't blend in with the rest of the gobbledygook. Another way to do it would be to have it as a separate piece of paper, but once you do have lots of separate pieces of paper you start to overwhelm people in the same way that you do when you have a notice that's seven pages long. So we didn't specify it, but if you have another suggestion I think the primary point we were trying to make is don't bury it.

Neil Calman – Institute for Family Health – President & Cofounder
Right. That's fine. I just think as this stuff comes out people get pretty granular about trying to implement this stuff. I think we need to be as specific as we can about what we mean about it.

The third question I have is I think there's a part in here that's fairly impossible to comply with and that's under 3-A-III, which says that the patient's information should include other participants in the model because the other side of the exchange, especially if you're going through some sort of exchange organizations is constantly evolving. I don't know how you could inform people as to who is potentially on the other side of this. I think up until that point it's fine, but I've always been concerned about this issue. When somebody says to you, "Well, who else can see it?"

You say, "Well, people who you consent," but I don't think it's possible to intelligently inform people about who is on the other side, who else is involved in the exchange, because that's constantly changing.

Deven McGraw – Center for Democracy & Technology – Director
Well, right. Keep in mind that that particular subsection is about what we are calling here indirect exchange models or triggered consent models of which ... centralized in some federated HIOs would be included in that. It's not directed exchange and this is the second level of notice that the provider can rely on the HIO to provide and update that information. So we're not asking providers to identify all of the potential people who might get it. We're asking for HIOs really to have out there for patients who are interested in learning more a mechanism for finding out who was signed up to participate.

Paul Egerman – Software Entrepreneur
I think that's what needs to be clarified, maybe; that it's not the burden on the provider. The HIO should make that available.

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

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I'd like to respond to both of Neil's comments there. Number one, I think that the level of literacy— Well, number zero, I heartily agree with our layered approach. That's really what you asked us about. I think it's the right approach.

Responding to Neil: I think the level of literacy should vary depending upon the layer, because ultimately you're going to get into very specific detail of how information is shared that is almost going to be impossible to reduce to a level where 90% of the people will understand it. I mean that's really what our layering approach is trying to address. So I don't think that we should say that all of the layers need to be

expressed in English or in language that 90% of the recipients will understand. Certainly, at the top level I'd go along with the 90%. With respect to the participants, I do agree that they would change all of the time, but since what we're talking about here is the real notice, I think the notice should point to some public place, like a Website, where they can go at any point and find out who those are, because that is something they could keep current.

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

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Deven, we obviously spoke before about a sample language. You didn't distribute that, did you?

Deven McGraw – Center for Democracy & Technology – Director
No.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I think some of that has good language and maybe addresses some of the things like what Dixie is discussing.

Deven McGraw – Center for Democracy & Technology – Director
Okay. That's fair. We have an anonymous notice that we can share with you all.

M
That will be interesting.

Deven McGraw – Center for Democracy & Technology – Director
Yes. I mean anonymous in terms of who invented it, but it's pretty good. Paul, I thought I sent it to you.

Paul Egerman – Software Entrepreneur
Yes. You may have. Yes. If so, I treated it like all of the other notices and I did what Judy said. I just looked at it and I signed it, because I actually—

Deven McGraw – Center for Democracy & Technology – Director
Actually, I think that's a nice segue. These have been some very good points made that we'll incorporate. You and I can go off-line with Carl to talk about some of the issues that he's raised, but I think that segues nicely into the second point, which is how short is short.

Paul Egerman – Software Entrepreneur
Yes. Perhaps, to phrase it differently, how brief is brief?

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

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I think the focus should be on understandability and accessibility rather than on links. I mean the spirit is that it should be easy to find and easy to understand, not buried deep in a legal document.

Neil Calman – Institute for Family Health – President & Cofounder
Well, another way to look at this question, this came a little bit, I think, from a comment that Judy Faulkner said, which is one page seems like an awful lot for a short summary description. Who's going to read one page? The question is should we say something about that? Should we just say short? I mean what do we want to say about the short summary or do we want to just leave a lot of flexibility on that issue?

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes. Flexibility. I'm looking at the consent, the notice of privacy that I made mention of in the last call, which I said was like 13 pages long. I probably left the impression that that was 13 useless pages. It's

actually extremely well laid out and organized and simple to follow headings. It's not so much the length that's the issue. It's the fact that it's easy to understand. You can flip through it and say, "That's interesting. I didn't know my data was being shared," because there's a big heading on the page that says, "How we disclose and share your medical information outside our institution." There in a bolded paragraph is all of the details. So the length isn't so much the issue as is it accessible and readable and understandable.

Neil Calman – Institute for Family Health – President & Cofounder
Well, the length is an issue if it's delivered as part of a medical visit as opposed to something that somebody can take home and peruse.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes. This was a handout.

Neil Calman – Institute for Family Health – President & Cofounder
Because nobody has the time or is going to sit and wait in an office and do anything, even read one page. I mean I can't imagine that people read those HIPAA privacy notices on their way in to get their x-ray or whatever it is they're getting done. So I think brevity is critical here.

Judy Faulkner – Epic Systems – Founder
The other thing too is if I read what different organizations are going to get the data, but I don't know that that one organization, who has it, is going to sell it, share it or send it out or use it to advertise me, then what good is it knowing who they are if I don't know what their purpose is.

Paul Egerman – Software Entrepreneur
Good point. I'll get to your point in a minute, Judy. I just want to make sure, because what you just said has to do with what I call the detailed information. That's where that kind of stuff should be. But right now I want to think about the short one.

Judy Faulkner – Epic Systems – Founder
Okay.

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

Paul Egerman – Software Entrepreneur
Neil said brevity is important. That's what I heard him say. I don't want to put words in his mouth, but it certainly sounds reasonable. The question is how do we take that comment and change this document as a result? Should we say brevity is important? Should we say 25 words or less? Do we put something really restrictive on it? Do we just say that it's important that—?

Neil Calman – Institute for Family Health – President & Cofounder
I think the content is what's important. It's what should those two sentences or three sentences include. I actually think that what Judy said is very important to include, because it's the most critical question that anybody is going to want to know about their data, which is what's it going to be used for.

Paul Egerman – Software Entrepreneur
You want the short summary to include a summary that says what the data is used for?

Neil Calman – Institute for Family Health – President & Cofounder
Yes. I think that it's got to include that. It's got to include a place where people can go to find out who it's being shared for and a brief statement about the positive part, which is what you're doing, what the purposes are for exchanging the data. That we exchange data through X entity for the purposes of being able to improve your health and that it's not being used. It will not be sold, used for research purposes or whatever and maybe there are one or two other things that need to be included, but to me that's all anybody is going to really be interested in at the upfront part of this.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes, and the pointer to more detail.

Neil Calman – Institute for Family Health – President & Cofounder
Yes and the pointer to where, if you'd like to read more about this and then you probably need some sort of a statement, which I would oppose, but which other people have talked about, which says something like your consent to this or lack of consent will not interfere with your medical care. Not interfere, that's a bad term, but does not affect our ability to treat you today or whatever.

Paul Egerman – Software Entrepreneur
Yes. On that last point, Neil, I want to be clear. This is transparency. It's not consent here. This part is simply informing people, but we're not asking for consent.

Neil Calman – Institute for Family Health – President & Cofounder
I still think it's important to reassure somebody in the information.

Judy Faulkner – Epic Systems – Founder
But, Neil, that's not accurate is it?

Deven McGraw – Center for Democracy & Technology – Director
Well, actually, we did say that already. When consent attaches we said when you have a trigger situation versus use of an OHCA it does need to be meaningful and we said very clearly that in those circumstances that means you shouldn't be discriminated against if you withhold it. We said that already.

Judy Faulkner – Epic Systems – Founder
I understand that and that you shouldn't be discriminated against and you should get care anyway. But I think, Neil, what you mean is that we will take care of you to the best of our ability, but if the best of your ability means that you're going to do something wrong because you didn't know about stuff that was critical to know they won't get as good of care.

Neil Calman – Institute for Family Health – President & Cofounder
I'm not suggesting we say as good of care. It just means that we're not going to refuse to treat you if you refuse to sign this piece of paper.

Judy Faulkner – Epic Systems – Founder
I think that's two different things.

Neil Calman – Institute for Family Health – President & Cofounder
Yes. I wouldn't suggest that they get as good of care, because otherwise we wouldn't be spending all of this time doing this stuff.

Judy Faulkner – Epic Systems – Founder
Absolutely.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
There is a possibility that they can't provide care.

Deven McGraw – Center for Democracy & Technology – Director
Okay. Let's not belabor this, please.

Paul Egerman – Software Entrepreneur
Yes. Also, we're tracking off onto a different issue, which is what happens when a patient doesn't give consent. The topic I want to make sure we sort of wrap up is what's included in this sort of brief summary description. What I'm hearing is it needs to say, as briefly as possible, what is the use of the information. What's it being used for.

Deven McGraw – Center for Democracy & Technology – Director
... purpose.

Judy Faulkner – Epic Systems – Founder
It's almost like a contract, where there are certain things that are bolded. I think that if my data is going to be sold or if it's going to be used in ways that would surprise me, in other words, it's not just for the care of me so I'm cared for, but it's got some other purposes I almost think that should be a bolded statement so I don't miss it.

Paul Egerman – Software Entrepreneur
Okay ... that's into the concept of separation, address that issue. Definitely, we have to put it in positive—

Deven McGraw – Center for Democracy & Technology – Director
Quite frankly, we sort of started with this transparency discussion about the sort of stage one frame without kind of going into secondary uses or data sales where they're permitted—

Paul Egerman – Software Entrepreneur
Yes. So maybe the way to address this issue is because we do have de-identified data as a topic that's coming up I think sometime in November. So for now why don't we just say we're going to talk about the uses? The summary data will describe the uses of the data, so that's broad enough that that could include that de-identified data, but then when we talk about the de-identified data we'll be able to come back to this issue if we want to do something more. Does that sound okay, Judy?

Judy Faulkner – Epic Systems – Founder
Yes, I think it does. I don't know how other people feel; for me personally, the de-identified data for research is something I would want to support.

Deven McGraw – Center for Democracy & Technology – Director
Right. But can we leave that to the de-identification discussion, please?

Judy Faulkner – Epic Systems – Founder
Yes. The other thing is—

Paul Egerman – Software Entrepreneur
... issue.

Judy Faulkner – Epic Systems – Founder
Are we going to get to that last paragraph that says that thing; there was a paragraph there on how you say that I'm part of a community, which is—?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Integrated health systems.

Paul Egerman – Software Entrepreneur
Yes. It's a made-up name of an IDM. Yes.

Deven McGraw – Center for Democracy & Technology – Director
It's just an example, Judy.

Judy Faulkner – Epic Systems – Founder
Yes, but the example can be improved.

Deven McGraw – Center for Democracy & Technology – Director

Yes. Micky had sent some suggested language that looked to me a lot like what you had said, so I didn't incorporate yours because I thought it was hitting the same point, but if you want to take this version and improve it, send it along.

Judy Faulkner – Epic Systems – Founder
Yes, because I don't think this lets me know that people outside of, say, Cleveland Clinic or UPMC may have access to it if the name becomes Cleveland Clinic or UPMC.

Paul Egerman – Software Entrepreneur
Would you prefer that we don't have any examples?

Judy Faulkner – Epic Systems – Founder
I think an example is a good idea. I just think it can be an improved example.

Deven McGraw – Center for Democracy & Technology – Director
Okay. Send us some language, Judy.

Judy Faulkner – Epic Systems – Founder
Okay.

Gayle Harrell – Florida – Former State Legislator
I want to address one thing that is not here. I agree that it needs to be brief, but I think it also needs to be at some point not within the body of HIPAA requirements, within the body of something else. It needs to be—

Deven McGraw – Center for Democracy & Technology – Director
It does that, Gayle.

Paul Egerman – Software Entrepreneur
It's there already.

Deven McGraw – Center for Democracy & Technology – Director
Yes. It's a really good point, but we said that it has to be separate and maybe the better word is distinct, but distinguished, not buried in the notice. Maybe we just ought to say that.

Gayle Harrell – Florida – Former State Legislator
Yes. Please. I would support that.

Deven McGraw – Center for Democracy & Technology – Director
We will do that.

Paul Egerman – Software Entrepreneur
So if I've heard this all right we've had a very good discussion about this, about the transparency document. Let me see if I've got this right. There is consensus around the concept of layered notice. As part of that consensus there was a request to expand item number four about ONC doing the education along with HIOs.

On the issue of OHCAs, Carl is going to send us some suggested wording, because he was a little bit concerned about how that is represented here. On the issue of the brief notice we said how brief the summary notice should be. The summary notice has to describe the uses of the information and it has to be written so that 90% of the patients are able to understand it—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
At layer one.

Deven McGraw – Center for Democracy & Technology – Director

At layer one.

Paul Egerman – Software Entrepreneur
At layer one. That's correct. That also there is going to be some additional wordsmithing of this document. Did I get it all correct or is there something I missed here?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
The only thing I would add is with respect to the education piece. ARRA does give some responsibility to the extension centers to help entities and HIEs on the privacy and security. We may want to consider using that as one avenue of getting that education in.

Paul Egerman – Software Entrepreneur
That's great, although the extension centers are really to help the physicians, the providers, as opposed to the public. I think this educational piece is for the public.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I know, but helping them, giving them examples of educational pieces they may use.

Paul Egerman – Software Entrepreneur
That's a good point. Okay.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
However, they're only available to primary care docs.

Deven McGraw – Center for Democracy & Technology – Director
Yes. I mean there's a limited reach there, but there isn't any reason why they couldn't be a vehicle for help with doctors, who need to do more transparency with their patients about exchange.

Paul Egerman – Software Entrepreneur
Okay. So I think what we'll be doing next is Deven and I will create another draft of this and circulate it to you. Again, we do have some time to wordsmith it, but we don't have a lot of time.

Deven McGraw – Center for Democracy & Technology – Director
Unfortunately, we don't have another call.

Paul Egerman – Software Entrepreneur
Yes. So—

Deven McGraw – Center for Democracy & Technology – Director
I feel like we're really close.

Paul Egerman – Software Entrepreneur
I think we are close. But I want to make sure though that everybody gets a chance to feel comfortable with the final document, because what we want to do is present it in the form of a recommendation on October 20th to the Policy Committee meeting. Is this okay with everybody if we try to do this through e-mail or do you want to see if we could squeeze in an administrative call between now and October 20th or do you think we're pretty close here?

Deven McGraw – Center for Democracy & Technology – Director
I think e-mail works.

W
Yes.

M
I agree.

Paul Egerman – Software Entrepreneur
Okay. That's great. Before we open to public comment let me also say I guess our next topic is going to be provider authentication. That's going to be the next topic that we'll be addressing. We'll send you some information about that in advance. It's a fascinating topic. It could interrelate with some of the governance issues we talked about earlier. Again, before we open to public comment I want to thank everybody for participating. It was really an excellent discussion.

Deven McGraw – Center for Democracy & Technology – Director
Yes. Very good discussion.

Paul Egerman – Software Entrepreneur
Do you have any other comments, Deven, before we—?

Deven McGraw – Center for Democracy & Technology – Director
No. I agree with you. Keep an eye on your e-mail because we'll resolve these and for those, Carl and others, who wanted to make some suggestions, get them in so we can clean up this language and deal with the issues that we talked about today.

Paul Egerman – Software Entrepreneur
Again, does anybody else have any other comments? Okay. Judy Sparrow, if you could open the lines to see if the public would like to say something?

Judy Sparrow – Office of the National Coordinator – Executive Director
Let's see if we have any comments from the public. Operator, can you give instructions? Just a note to the public: Please give me your name and organization. You have a three-minute time limit.

Matt Cover – CNSNews.com
I'm Matt Cover with CNSNews.com. As I was listening in here I just wanted to ask whether or not in these governance regulations that you're beginning to draft whether or not— I've been kind of unclear in asking this of ONC whether or not there is going to be any ability to, I guess, if a diagnosis or a procedure or something like that could be omitted or left off of an EHR. For instance, an HIV diagnosis or a controversial procedure, like an abortion, if there would be an ability to leave that off of an electronic health record.

Deven McGraw – Center for Democracy & Technology – Director
We didn't talk about that issue today.

Judy Sparrow – Office of the National Coordinator – Executive Director
No. Also, we're not really— This Workgroup is an advisory committee to the Office of the National Coordinator, so we're not drafting regulations. We're just forming advice and recommendations to the Office.

Matt Cover – CNSNews.com
Well, in your advice would that be something that you'd consider doing or not?

Deven McGraw – Center for Democracy & Technology – Director
I think this is a time period for public comment on the discussion that occurred today. If you have an official press question that's related to something else on the call you'll need to call us separately.

Judy Sparrow – Office of the National Coordinator – Executive Director
Right, or e-mail me and I can put you in touch with our press person.

Moderator
We do not have any more comments at this time.

Judy Sparrow – Office of the National Coordinator – Executive Director
Thank you, Paul and Deven. Good job.

Paul Egerman – Software Entrepreneur
Thank you to all of the members—

Deven McGraw – Center for Democracy & Technology – Director
Thank you to everybody else. Yes. And you too, Judy.

Judy Faulkner – Epic Systems – Founder
And always to Judy for keeping us organized.

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

Joy Pritts – ONC – Chief Privacy Officer
Crack that whip.

Paul Egerman – Software Entrepreneur
We'll be getting some e-mails out to you shortly. If I've got it right, our next meeting is November 8th. Is that correct?

Judy Sparrow – Office of the National Coordinator – Executive Director
That's correct.

Paul Egerman – Software Entrepreneur
Great. Thank you.

Participants
Good-bye, everybody.

Paul Egerman – Software Entrepreneur
Good-bye. Thank you.

Participants
Good-bye.