

**HIT Policy Committee's
Privacy & Security Tiger Team
Transcript
July 10, 2013**

Presentation

Operator

Ms. Robertson, all lines are bridged.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thank you. Good afternoon everybody. This is MacKenzie Robertson in the Office of the National Coordinator for Health IT. This is a meeting of the HIT Policy Committee's Privacy & Security Tiger Team. This is a public call and there is time for public comment on the agenda. The call is also being recorded, so please make sure you identify yourself when speaking. I'll now go through the roll call. Deven McGraw?

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

Here.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks Deven. Paul Egerman?

Paul Egerman – Businessman/Software Entrepreneur

Here.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks Paul. Dixie Baker?

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

I'm here.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks Dixie. Judy Faulkner?

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

Here.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks Judy. Leslie Francis? Gayle Harrell? John Houston?

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

Here.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks John. David McCallie?

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

Here.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks David. Wes Rishel?

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

Here.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks Wes. Micky Tripathi? Kitt Winter?

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

Here.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thanks Kitt. And any ONC staff members on the line, if you could identify yourself please.

Kathryn Marchesini, JD – Policy Analyst – Office of the National Coordinator for Health Information Technology

Kathryn Marchesini.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Great. Thanks Kathryn.

Gayle Harrell, MA – Florida State Representative – Florida State Legislator

Gayle Harrell just joined.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Ah, thanks Gayle.

David Holtzman, JD, CIPP/G – US Department of Health & Human Services, Office of Civil Rights

And David Holtzman from OCR.

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Perfect. Thank you. I'll turn the agenda back to you Deven.

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

All right, terrific. Thank you very much MacKenzie. What we're going to be doing today is to debrief on the virtual hearing that we held about a week and a half ago on non-targeted query and response, and really sort of just begin a discussion of any potential policy recommendations that we might want to make, based on what we heard from the hearing, and any other considerations that we have. One thing I want to note is that I want to— we're going to do this meeting a little bit differently. We're going to have two periods of public comment, one in the middle of the conversation and one at the end. So at about 1:45, which is halfway through our call, we'll do a break and MacKenzie and her team will do what they usually do at the end of the meeting, which is to invite any members of the public to call in.

The reason why we're doing it this way is because we didn't really have a chance at our virtual hearing to have a discussion with the persons who testified for us, or who presented to us, to sort of have a back and forth with them beyond the Q&A period, where we sort of— we really felt that we needed to have a chance to sort of digest what was said at the hearing and ideally, in that context, be able to get some feedback from them about some of our thinking. And so they all were provided with the information for calling in to this call, but they're on the public line. So when we open it up, of course, we will want to hear from them, if they're interested in responding to what they've heard in the first half or the second half of the call today. But of course, any members of the public who are on the line, but that also want to make comment, we're interested in hearing from them, too.

We don't typically get folks during our public comment period to provide comment, although I certainly know that there are lots of people listening in, which we appreciate. And maybe doing the meeting this way, which is in some ways consistent with the way that we've done a lot of the recent Policy Committee meetings, at least the in-person one, where we have been starting to break for public comment in the middle of the day versus waiting all until the end. So hopefully this will give us a chance to get some feedback as we're having the discussion, as opposed to just at the end. And I think the other thing that I'll note is that we actually have three meetings scheduled in the month of July. I'm not sure how that happened, but I think it's going to be helpful to us in being able to finish a set of recommendations on the issue of non-targeted query response by— in time for the August Policy Committee meeting.

So this is not the only opportunity that we will have to talk about this issue, which is probably going to be really helpful for those of you who haven't really had a chance yet to digest the hearing transcript or to take a look at the materials that the MITRE team helped pull together to prepare us for today. It was a bit rushed, we apologize that you did not get these materials until this morning, at least the comparison chart and the slides that MITRE helped develop, and that really is a circumstance of not having the transcript available immediately. I mean it was actually quite prompt, but we never get them on the day after a hearing and then we had the holiday last week. So this is not our last bite at this apple by any stretch of the imagination, but it's good to be able to get the conversation started today and hopefully to have some feedback from some of the folks who presented to us, as well as members of the public. Paul, is there anything that you want to add before we sort of dive in to the material?

Paul Egerman – Businessman/Software Entrepreneur

Well I just want to add that— I don't know if any of the people who testified, the HIEs and the other organizations who testified are on the line, but they were just terrific to give us so much of their time. It was a very useful hearing that we had. And it's also, I'm sort of both interested and amused that Deven you mentioned that we will have three meetings in July. What we are doing in our summer vacation, the Tiger Team is working very hard on giving advice on privacy and security; so, appreciate the dedication of the Tiger Team members.

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

Thank you, another summer of Tiger Team. Okay, does anybody have any questions before we dive in? Okay, so what I wanted to do is just remind people a little bit of how we got to this point of considering non-targeted query situations. And recall that we really began this effort through an investigation of query and response generally where we laid out what the existing obligations would typically be in a query response situation, both with respect to the data holder, who's going to ultimately be receiving a query and providing some response, and the responsibilities of the entity or person making the query. This is all material that you guys have seen before so I offer it to refresh your memory.

We came up with some recommendations on query and response and these recommendations were considering the use case of what we called targeted query, where you are querying records from a particular provider or from specific providers, but you're looking for records on a patient, so it is still a query. And our recommendations really sort of matched what was the sort of set of existing obligations that we really saw existed on both— on each end of that transaction. And these next two slides are really— well, next three slides, really are just a categorical summary of the areas that we hit in our particular recommendations on these issues. The actual text of the recommendations can be found in the summary material, the background material in your slides. I didn't want to load them all up in the front of the slide deck because it would actually be quite long and our purpose here is not to rethink or reword those recommendations, because they've actually already had the assent of the Policy Committee. But to remind ourselves of what we have already said about query and response, before we launch into a discussion about non-targeted query.

So some of the areas that we— all of the areas really that we have previously covered include what would support reasonable reliance by the data holder that the requester is who they say they are. This is an identity issue. What supports reasonable reliance by the data holder that the requester either has or will have a direct treatment relationship with the patient, and with respect to direct treatment scenarios, which was the use case we were considering, therefore has legal authority and is otherwise authorized to obtain the data? Does it matter if the data holder makes a decision to disclose or if the data holder's response is automated? To what extent does automation trigger our previous recommendations on the need for meaningful choice by patients? What patient identifying information should be presented as part of the query? And what should be the response?

Data holders should respond to queries consistent with their professional and legal obligations. And should there be a requirement to account for and log the query and/or disclosure and to share the log with the patient upon request. And with respect to sensitive data, as a best practice and to assist providers in complying with their own applicable law and policies, the parties to a query and response should ideally have a technical way to communicate applicable consent authorization needs or requirements and be able to maintain a log of such transactions. Again, this is a categorical summary of the recommendations that— or the areas of recommendation that we already made on query and response transactions in the background slides, specifically slides 20 through 33, you can actually see more of the text of those recommendations.

So then in looking through the transcript of the hearing, and I'm— and I have had a chance to look through it at least once. I still want to type up my notes, but I— the following sort of thoughts occurred to me, and I put these on slides not to dictate that this is where the discussion should go, but to maybe provide some help to folks who haven't had a chance to read it yet and to refresh our recollection about what we heard at the hearing. But these are all subject to further discussion and challenge, but I offer them as a mechanism for kicking off the conversation. Again, all of these were sort of, having read through the transcript, my sort of overarching thoughts.

Access to each of the networks who presented to us is controlled in some way and limited really to members who have executed some sort of participation or business associate agreement, which binds them to abide by any specific query limitation or other— limitations or other network policies. And in the case of Surescripts, the agreements are executed with the data holders and then with each prescribers EHR vendor. The network policies provide patients with some choice, most are opt-out of the ones that we heard from, but some in fact are opt-in and many adopt a model where the data is held by the network, but is accessible only for those patients who have either opted in or have not opted out. Rhode Island was the only network that I believe we heard from where the data does not move into the network without opt-in consent. And actually, on second thought, one could put Surescripts in that category, too. The data won't get released by the data holder unless the patient has said yes. For sensitive...

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

Yeah...

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

Yeah, I just— do you mind if I get through these and then we can launch into a discussion Wes?

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

Sure.

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

Okay, thanks. For sensitive data, most of the testifiers or presenters depended really on the data partner to withhold any data that might require additional consent or some other type of sensitive data. Rhode Island seemed to be the only model where Part 2 data, which is the data that's covered by federal substance abuse treatment rules, was made available in the HIE, but even then, it was only to providers who specifically requested it, it was subject to a second consent from the patient and then subject to a second attestation of treatment relationship and accompanied by a reminder about the re-disclosure limits that are part of those regulations. In many networks the patients who had concerns about access to sensitive data in the HIE were counseled to either opt-out or to not opt-in. Many of the networks do have role-based access levels for participants, which I have to admit was somewhat of a surprise to me, it was very interesting.

All networks do audits of access and disclosures, but only some made them directly available to patients on request. None of them appeared to do an override of patient consent, although some stated that they had emergency break the glass in circumstances where the patient had not yet provided any form of consent. All networks limit access to certain purposes. Treatment was common to all, many others also allow for operations and public health reporting purposes and a couple or maybe a few allow for payer payment access. All but Surescripts have some either inherent or express geographic limits. Testifiers expressed some concern about potentially having federal policy disrupting the arrangements that they had carefully implemented, but most expressed a desire for some guidance, common agreement or terms, that would help facilitate network-to-network or HIE-to-HIE exchange, and additional guidance on how to handle sensitive data.

So if we launch into our discussion of this, and you guys, as I said, can feel free to just completely reject my key themes. Previous recommendations were considered – I want to remind us again that the previous recommendations that we had on the topic of query response were considered in the context of a targeted query where you know the provider or the providers whose records you are querying. We have previously, I think, presumed that at a minimum these would also apply to non-targeted query and that our exercise here was to determine whether there would be additional criteria that might apply in the context of a non-targeted query. But it occurred to me in preparing for this discussion, that it's worth asking the question, after this hearing, do we still think that those recommendations that we made on query that applied in the targeted context do they also apply to non-targeted query? And would we add or make modifications to those recommendations in light of this hearing, and if so, would those be modifications that would apply to any query or just in the context of a non-targeted query?

So with that, I'd like to open this up for discussion. Again, I'm going to reiterate, there's no need to wordsmith the key themes, they're not conclusions or recommendations other than some thoughts that I offer for us to get started. But I'm much more interested in having more of a free flow of discussion about what we heard, what we think from a policy standpoint needs to be said, either in addition to what we've said already, as a modification to what we've said previously, on the issue of query.

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

So Deven, I'll – your interest in a comment when you're ready.

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

Yes, go for it David.

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

Okay. First, I think you did a great job of summarizing the key themes, I think this is terrific. And my comment is really pretty picky detail, really two comments. One is, the slide that says all but Surescripts have some – no, no I'm sorry, the geographic limits are correct. Anyway, I'll just make the comment and not reference it to the slide. I think that Surescripts, it's true that they don't release the medication history data until the provider asks for it, but they do preload the MPI data from the PBMs as part of the formulary service, so there is knowledge of who the patients are and where they – what their insurance coverage is, is available before consent. So, it's just a technicality around the fact that I think that's sort of a two-stage model.

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

Okay.

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

And then the second comment about the inherent regional limitations of everyone other than Surescripts, I think HealthWay, as I understand the way their network of network models work is that the networks themselves that you might connect to are typically regional, although there's nothing that requires them to be regional, but that you could connect to any region. So the – it's not quite the same as that there's only a regional restriction, because you could pick anywhere in the country that happens to be on the network and then connect to it. And there's nothing in their charter or their DURSA that I'm aware of that requires that the networks they connect to be regional. I think that's just the way it has evolved so far.

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

Yeah, I – that’s a much more accurate statement David. I actually, after I had sort of created those sort of initial thoughts, I went back to that particular part of Mariann Yeager’s testimony, and it’s on page 6 in the actual transcript, and it was very interesting about how at least initially the way that it’s been deployed is the queries have largely ended up being bound by region, but it’s funny – and so I’m almost quoting her – I am quoting the transcript here, “it’s really important to note that eHealth Exchange was never intended to promote unbounded broadcast query, but now that participation in eHealth Exchange is reaching critical mass, we’re developing additional guidance and would welcome other work to help providers narrow queries to the relevant circumstances, and most likely places where a patient’s record is to be found.”

But then she goes on to say that they’ve had success in having queries across a variety of environments and use cases and the Social Security Administration Disability Program and queries to providers to be able to make sure that those Social Security Disability determinations can move forward is an example of this. But in that case, and we have Kitt on the phone to help remind us about how this works, they actually do query specific providers and that generally they find that providers tend to limit the scope of their queries to the most likely places where they anticipate their patients may have been treated, based on their current experience, which is to me very interesting. So while the national capability might be there, I thought that sort of level of detail about how it ends up being actually deployed is very interesting.

(Multiple speakers talking, indiscernible)

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

Hang on a second; I think that’s Kitt...

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

Yes.

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

Let me make sure that I haven’t misarticulated any of that incorrectly, since we have Kitt Winter from the Social Security Administration on the phone.

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

Right and I can just quickly add, what we do for our patient authorization allows us to access sensitive data as well, but we see many data holders placing organizational policy restrictions on sensitive information. So in other instances, data holders will release that sensitive data to us, based on our patient authorization that we would provide to the responder. But we do a targeted request back and forth. And in our cases, many responders who consider our patient authorization acting as the requester in the realm of the data holder patient consent. I don’t know if that clarifies it a little bit more.

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

Thanks Kitt. So I thought I heard a combination of Wes and David, but I’m not sure I was right.

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

This is David. I just want to finish the thought and then I’ll relinquish the floor to Wes. Just on Mariann’s comments. She also noted in that context that they are investigating the creation of what she called “shared services,” which is their language to describe MPI and record locator capability that would give the physician some guidance about where to look, which of the networks to connect to. She didn’t go into that, but she did register that they’re investigating that. So I think they understand that you don’t– you can’t do a broadcast query for technical reasons, if nothing else, but that helping the physician find the data may turn out to be an important capability, as Surescripts does with the PBM input. And then I’ll stop there.

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

Yeah.

Paul Egerman – Businessman/Software Entrepreneur

Yeah. And this is Paul. I mean, I’d also just add to your comments David. I mean the basic reality today is physicians are like extraordinarily busy; they don’t have time to do the data equivalent of a fishing trip.

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

Yeah.

Paul Eggerman – Businessman/Software Entrepreneur

They're really – their major concern with these kinds of things is how fast they can get the data so it's not surprising that that's...

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

This is Wes. Just a couple of questions, I'll try to work backwards. For HealthNet – I'm sorry, HealthWay, they definitely have participants who are not geographically limited in scope, the IDNs, integrated delivery networks or who have limitations in geographical scope that are based on where their business is and could cross multiple states. But they have this fundamental limitation of scaling, which Paul has described, and I think part of why we're here is recognizing that that limitation is a technology limitation and that there are technologies that would remove that inhibition against the broad searching based on the difficulty of doing it, so we have to anticipate that with the policy. I think it's worth noting, and Kitt may want to confirm this, that the Social Security Administration (SSA) actually sends a copy of the patient consent form with the inquiry, and that the way it does it is one that right now implies a person would deal with evaluating that further response, but I think that's important, based on other things we've noted already.

And in key things, one of four, there's in the first bullet, there's a statement for Surescripts these agreements are executed with the data holders and with the prescriber's EHR vendors. It's clear that the agreement with the EHR vendor requires the vendor to flow down that agreement to their clients, so there's no implication that their clients are not somehow participating in a participation agreement, because they go through Surescripts.

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

Okay. Thank you – thanks, that's helpful. Are there any other thoughts? As we're sitting here, the other thing that I'm recalling that was among numerous interesting things in the testimony, was the capability that some of the networks had to almost to automate the query based on say, that it was triggered by registration in the system, for example. Or by the scheduling of a visit, I remember that coming up for a couple of networks, and as I was going back through the materials of what we thought was sort of reasonable reliance on issues of identity and treatment relationship, I think we mentioned that capacity as sort of one element that could support reasonable reliance. If there's some way, from a technology standpoint, to be able to confirm that it's actually a patient who's in the system.

Paul Eggerman – Businessman/Software Entrepreneur

This is Paul. I mean that's the way I had interpreted that information is that they were using basically; I think somebody referred to the ADT feed, basically registration information, as a vehicle to indicate that the entity had some relationship with the patient, a treatment relationship with the patient presumably. And so I thought that was interesting. I did want to quickly go back to David's – and the previous discussion about geography and make the observation that we had made the previous recommendation that we didn't think that there was a need for any policy, an issue of limiting things like on a geographic basis for this query response – non-targeted query response and certainly going through that last discussion, what we heard in the hearing, I don't see any reason to alter that recommendation. It seems like that seemed to be confirmed that while these things are happening regionally anyway, but even ones that aren't there's reasons why it just certainly hasn't been a problem. It seems to work and the systems seem to be able to create their own processes to handle those kinds of queries.

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

And this is David. I certainly agree with that Paul, thank you for being more articulate.

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

Yeah, although I have to say, that's probably one of the issues that I feel like when we presented this to the Policy Committee that we got a little pushback on. There was, and Paul you can help refresh my memory, but there was this sort of level of discomfort with the idea that you could sort of have a query that originated in Maryland coming to a provider in Colorado, where the two don't know each other and that there would be the sort of capacity to discover the patient's record without any sort of limitations whatsoever. And I'm still scratching my head as to why that would be problematic. But one of the things that does occur to me is that maybe we didn't do a good enough job of reminding the Committee that in fact all of the other recommendations that we made on targeted query would apply here as well. And that ultimately if that provider in Colorado, keeping my example on the table for a minute, was not comfortable that they knew— that they were comfortable that they could be reasonably assured of the identity of the queried or that they knew that there was a treatment relationship, that the likelihood that they would respond might be lower than it would be if the query came from a known provider or some person within their network or some— there was some degree of comfort or it was accompanied by patient consent.

Paul Egerman – Businessman/Software Entrepreneur

Yeah, and— this is Paul again. And again, the way I would respond to that is to offer simply comment as to how these things work right now. I mean, a provider in Maryland can telephone a provider in Colorado, can send a fax or make a phone call to the medical records department of the organization in Colorado and ask for something— ask for patient data. And this happens all the time, and the organizations have policies as to how they handle it. They will either answer the question or they won't, and they usually do try to be helpful as best as they can. And so, I just don't see that it's that hard and this issue of they don't know who— the providers don't know each other, well again, they actually do have a way to determine whether or not they know each other, there are just lots of vehicles for that.

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

This is Dixie.

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

And this is Kitt. For the discussion, I mean I'm thinking that the targeted query recommendations also apply to the non-targeted query.

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

Yeah.

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

As long as the data holder has confidence and knows the identity of the requester and that they are who they say they are, and that the data holder has a reasonable reliance that the requester has a direct treatment relationship with the patient, are the key factors. And they're both really common to both targeted and non-targeted queries.

Paul Egerman – Businessman/Software Entrepreneur

And what we're saying with the non-targeted, I don't think we said this with the targeted, we're saying with the non-targeted is the data holder does not have to give the data if they don't want to, for any reason.

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

Yeah, I mean that's basically...

Paul Egerman – Businessman/Software Entrepreneur

They just need to respond in some way, they can say no I'm not going to tell you...

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

Yeah.

Paul Egerman – Businessman/Software Entrepreneur

The answer to your question, but they don't have to say anything if they have some reason that they don't know who that other side is or if they just plain don't want to give data.

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

The other question...

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

It's the paradigm...

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

Okay, hold on a minute let me let Kitt finish and then we'll open it up to other voices that I've heard.

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

Sorry, I was just going to say, and if we are going to separate out the recommendations between targeted and non-targeted, does then the requester need to inform the data holder or the responder of which type of query they are initiating?

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

Yeah.

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

I mean, that would add a whole other factor of what they would have to provide.

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

Yes, that would be a little odd. Umm, so I heard a bunch of voices, was that...

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

Yeah, this is John Houston. I just– I think that that's the wrong paradigm though. The requester doesn't have to send– I'm sorry, the responder doesn't have to send the data, but I think every provider in the United States frankly wants to see a trust fabric in place where they don't have to worry about whether the request is bona fide. They want to be able to rely upon the fact that there's a trust fabric in place that simply allows them to be assured and have a high degree of confidence that in fact any request we made is appropriate and that there's some bona fide treatment relationship or purpose behind the request that allows them to release the data.

Paul Eggerman – Businessman/Software Entrepreneur

(Indiscernible)

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

This is David and I think one of the things that makes the Surescripts model work across state boundaries and at the scale that it works is that there is, in fact, a pretty explicit and strongly, carefully worded contract that all those providers know everyone has signed. And I think that's a part of the solution and the DURSA for eHealth Exchange is moving in that direction as well. It's everyone signs that, in addition to having technical trust capabilities underneath.

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

And I agree– this is Judy and I agree with both David and, oh sorry, my...

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

John.

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

John.

Paul Eggerman – Businessman/Software Entrepreneur

John.

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

Yeah and my worry when we say that is, I am agreeable that if there is a reason where there isn't trust, and what David said is that there should be trust, we should create it in such a way that there is. If there is a reason that there isn't trust, then that makes sense. But our experience has been that the biggest reason is I just don't want to share with you because I don't want you to take my patient. And should we figure out a way to say that if there is a legitimate trust reason it's okay, but just refusing to share because you don't want someone else to have your patient is not a good reason.

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

Indeed it's not.

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

Well remember at one of the other meetings that we had a number of months earlier I asked the question of the people there, do you ever see any reason not to share, and every single one of them on the panel there said, "There is no reason." But the reason that we see, and this we have to be very careful of, the reason that we see is just what I said, a) I don't want them to have my patient because I don't want them to steal my patient away or b) They're going to charge me, I'm already covering that patient, I don't want to have to pay their charge. Those are the two problems we run into.

Paul Egerman – Businessman/Software Entrepreneur

Right and I think Judy those are really excellent points. I think we have to be careful, however a little nervous as a policy group that we are not acting like we're in— like elementary school teachers and grading healthcare providers and saying how good a job they do on works and plays well with others. That's not...

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

Yeah.

Paul Egerman – Businessman/Software Entrepreneur

We've just got to be very careful about it. And to get back to the basic policy discussion, and to get back to the hearing, what I heard in the hearing was there are some inherent geographic limitations. There are some situations where the geographic— there was one national example, there have been some examples of multiple states, but there was just a general feeling that there wasn't a need for a policy that limited geography in any way.

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

Yeah.

Paul Egerman – Businessman/Software Entrepreneur

That that didn't seem to be necessary, and that was a conclusion we came to before in a previous discussion and I just felt it was...

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

Yeah.

Paul Egerman – Businessman/Software Entrepreneur

It was just— there was just some evidence here that that was the right thing, that we had made the right decision that even though I guess some of the Policy Committee people were a little bit reluctant and from there we went to an interesting discussion about that John Houston called the trust fabric, and that's really an important concept, but that's actually not what we're talking about. The assumption is that there is a trust fabric in place, and we sort of dealt with that once before. So if there's a trust fabric in place, we're saying, there really isn't a reason to limit on the scope, in terms of whether or not it's national and the number of inquiries that are being performed.

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

But then, what I don't get Paul is you're saying no need to limit the scope geographically, but my recommendation that we don't say you can just deny because if there is trust, and if you're assuming there is a trust fabric there, why should they deny?

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

Well, but here's the thing Judy. Here's how we tried to handle that, which was much more delicately acknowledging that the law that puts the data holders and provides them with the legal responsibility to protect that data, also vests with them the responsibility to make ethical and legal judgment calls about when that information will be disclosed. And we frankly don't have a vehicle to say, as a policy matter, you are required to disclose and in fact, the law doesn't require disclosure, except in certain circumstances, to the patient when she asks for a copy of her record, to the government when they're investigating you, under certain other public health disclosure laws. Something I just learned recently, for national security purposes, but generally the discretion is up to the record holder and I don't think we're going to change that. But we have good statements in here that presume that providers in a query situation will do the right thing by their patients and disclose in accordance with their ethical and legal obligation.

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

(Indiscernible)

Paul Egerman – Businessman/Software Entrepreneur

Yeah, and what we could do perhaps Deven– I'm listening to what Judy is saying, I'm wondering if it almost fits in different category, simply to say that you look at things like accountable care organizations and healthcare providers and have some financial responsibility for a patient's treatment, that in some cases those financial arrangements might represent motivations to not...

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

Exactly.

Paul Egerman – Businessman/Software Entrepreneur

To not share data and it's an interesting discussion; I view it as a separate category though...

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

Well, yeah...

Paul Egerman – Businessman/Software Entrepreneur

And that's something that perhaps we should– I'd kind of suggest we put to the side and talk about, but I think some of those things might create incentives that are different from what we're hoping for, in terms of free flow of information.

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

Yeah, I...

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

And can I just add one more thing before we put it aside?

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

Go ahead Judy.

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

And that is, what I went through here– what we went through, was about 2 years before we could release interoperability of our customers saying they would only exchange with certain ones, and not with others, for the financial reasons. And it was– when you say, Deven, that they will do it for the ethical and healthcare purposes, and legal, we didn't find that to be true, and that was the problem. And it took us two years of just saying; listen, wherever the patient goes is where the record needs to go.

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

Right.

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

And if you find that in fact something is wrong, there is a committee who will judge that and remove that group whose doing wrong from the ability to interoperate, if they don't deal with the records correctly and they violate the rules. But other than that, where the patient goes is where the record has to go and I think you are– would be surprised by how much this won't happen then.

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

Yeah.

Woman

(Indiscernible)

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

I'd like to suggest that we have a way of sort of dividing...

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

Go ahead Wes.

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

Yeah, this is Wes, I'm sorry. I'd like to suggest we have a way of sort of dividing this issue; one is sort of a general recognition and a comment that there is a concern about providers using financial reasoning and deciding when to reply, but no other. And then effectively for us to be very sure that they have no reason, in terms of the implementation of the policy we control to justify that behavior.

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

Right.

Gayle Harrell, MA – Florida State Representative – Florida State Legislator

This is Gayle, I'd like to...

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

Go ahead Gayle.

Gayle Harrell, MA – Florida State Representative – Florida State Legislator

I don't know that within the bounds of the legislation that empowers this committee to make recommendations, that we have the ability to really determine that. These are financial decisions that are outside—truly outside the purview of what we are to be looking at. So, although it's a very valid conversation and payment models are changing, which is going to change incentive and HIT and electronic health records are part of that whole process. That there's going to be an evolution, but I don't know that it's really—we do not, I don't think, have the ability to say, you must exchange information if—with a trust fabric established.

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

Yeah. I'm not sure that that's what—thank you Gayle this is Deven again. I'm going to try out some language for you all, that does what Wes suggests, and tries to address Judy's point that it is our belief that the records should go where the patient goes. But we've acknowledged that it really is the record holders who will ultimately make the decision and our hope is that they will in fact send the records where the patients are, in order to facilitate good patient care, but that ultimately we rely on them to make the right judgment call.

Paul Egerman – Businessman/Software Entrepreneur

That's right. And this is a good discussion and I like that summary Deven and I like it also as it relates to the clock. Because we said at 1:45 we would pause in the middle and allow, if there's any members—any of the HIE—any of the presenters at our hearing or any other members of the public, who might want to insert a comment at this point. Is that right Deven?

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

Yes, it is Paul, thank you. I would—MacKenzie, can you take care of that?

Public Comment

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Sure. Operator, can you please open the lines for public comment?

Caitlin Collins – Project Coordinator, Altarum Institute

Yes. If you are on the phone and would like to make a public comment please press *1 at this time. If you are listening via your computer speakers you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. We do not have any comment at this time.

Paul Egerman – Businessman/Software Entrepreneur

Okay. So I'm going to assume that that means that there are thousands of people listening to our call and every one of them agrees with everything we've said so far.

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

Or they're going to hopefully send us some comments after the fact, if they didn't get an opportunity to chime in. I liked pausing in the middle, it interrupted our conversation a little bit, but it sort of felt like we could have an opportunity for people to contribute to exactly where we were in the conversation.

Paul Egerman – Businessman/Software Entrepreneur

Well again, we are very much appreciative of the commitment also of the individuals who gave testimony and if they were on the call, we wanted to make sure they had a chance to put in their views, too. So that's why we did that.

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

Right, Wes, I think I cut you off before we moved to public comment, but maybe I didn't. Am I wrong about that?

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

No, I don't feel cut off.

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

Okay. One of the other thoughts that I had related to sort of the conversation that we had with both panels about sort of what would be helpful to them from a policy standpoint, besides not mucking the good works that they had already done, and that involved, I thought, issues involving sort of the capacity to exchange with entities with whom they might not have participation agreements. We heard at least from a couple of them that when they got a query or a request for data from somebody who was outside of their network, they were reluctant or they did not share the data because those entities had not signed the participation agreement. And is there a reason to pursue sort of some common agreement, for example, and I'll just throw that out there for discussion.

And then, of course, the other issue that continues to be vexing for a lot of entities is the sensitive data issue. But of course, we're still sort of waiting to get at least some results from the data segmentation pilots that might give us some clue as to how we can deal with a circumstance where the sensitive data is just not being included in a lot of these networks because of the additional constraints around sharing and concerns about its sensitivity. So, I'm not sure how much more progress at this point we can or should try to make on the sensitive data question, given that the pilots are still pending. But I am definitely interested in hearing thoughts about the point about sort of how do you scale, given the sort of reliance on trust agreements for many of these networks?

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

I have something to say about that, Deven.

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

Okay, go ahead Dixie.

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

This is Dixie. And it really relates back to what John said about trust fabric and then David mentioned about Surescripts and I was thinking at the time, well Surescripts really does work very well, but I think it's because everybody can— everybody has knowledge about that agreement, because each participant has the same agreement. And although I'm not fond of having— forcing regulations that require everybody to have some common agreement, a trust fabric can't exist unless there's something that people can presume to be there. And in the cases we heard and the HIEs that exist today, that doesn't exist. So I think there is— that it's worthwhile at least to consider some form of minimum common agreement.

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

This is David. I mean, I kind of agree with that in principle, but in practice, it's just so incredibly hard to do...

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

Yeah, I know, but how do you get this trust fabric– how else...

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

Yeah. Well, I mean I think you can look at what's happening in the direct community and the difficulty even with a fairly simplified set of privacy issues in direct, I mean, it is by design a limited subset of capabilities push– direct treatment push. But even in that limited set of cases, it has been harder than anyone expected to get a universal understanding of how the trust model should work. And one of the things that I look back on the early work in direct and regret is that we used the word trust to mean a whole lot of different things. And we should have been much more precise and talked about technical assurances, which were different from clinical assurances, which were different than legal obligations under HIPAA and so forth. So, it really...

Paul Egerman – Businessman/Software Entrepreneur

This is Paul, I'm listening to all this and I hear what you just said Dixie about Surescripts and I have just a couple of observations about Surescripts. On the one hand it certainly illustrates that there is– technically, one can do this on a national basis. On the other hand, I also want to make the observation that Surescripts is dealing with medications and basically a prescription profile. And while that's a critically important part of the entire healthcare record in terms of the total quantity of data, it's a small percentage and so if you really look at everything being– look at scalability, it's encouraging but it's not necessarily– information that's not necessarily definitive, but that says that you can do this on a national basis. As it relates to the trust fabric itself, I also kind of worry a little bit that when we start thinking about this on a national basis; it's sort of like creating the cart before the horse. Because even though we always seem to want to do an example of somebody in Florida getting information from somebody in like Seattle, Washington or something, it's like 98% of this stuff is still we can't get the healthcare provider to get information from another provider who might be located across the street. And so I'm just not personally convinced that the trust fabric is the biggest obstacle we have beginning a query response– an effective query response system in place.

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

Well I think...

Paul Egerman – Businessman/Software Entrepreneur

Figure out the trust exists between the providers across the street, their problems are, they just don't have the– to get it done.

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

This is Wes. I think there are several issues that cause problems with interoperability, most of which are being addressed by other workgroups.

Paul Egerman – Businessman/Software Entrepreneur

That's right.

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

I think this workgroup, I see it, and this is just a personal view, but I see us as creating the requirement specifications for the trust technology and creating a basis for action in regulation to provide whatever safe harbor or pseudo-safe harbor or whatever you want to call it, to help reduce the reluctance of stakeholders to play the interoperability– I don't want to call it a game, to be interoperable.

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

Right.

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

A lot of the guidance that comes out of this process, I think, helps that tremendously, and even that hearing, putting all of the approaches on the table so people can see what's working and what's not working will facilitate it a lot.

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

Yeah.

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

That's all part of the trust fabric, if you take the broadest definition of trust.

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

Right, this is Deven. The idea that this is happening and can happen and that the set of conditions don't in many ways have to be one size fits all, but do have to address the concerns of the community, be it patients and providers. But ultimately it can be pulled off and it can happen.

Paul Egerman – Businessman/Software Entrepreneur

Yeah and this is Paul. I look at, I think, back at the hearing. Indeed one of the things that the regional HIEs were doing that was extremely important was they were somehow creating this trust fabric, they were creating the relationships and they were doing something more, they were doing audits to make sure things were going correctly. And we heard one example, I believe it was in Rochester, where they talked about somebody who had done something inappropriate perhaps, just the way they had accessed data, and so that's sort of like a governance function also, and they're doing those functions locally, and that seemed like there was a great deal of value there.

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

But they said they weren't really doing it across state lines. I totally agree with you– this is Dixie. I totally agree with you within their network, but they acknowledged that exchanging across state lines, they basically weren't doing that.

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

Well, with entities not already in their network. So some of them do exist and have coverage beyond state lines...

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

Right.

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

But...

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

And those ones– this is David, the ones that have signed common agreements, common contracts like in Surescripts case or in the HealthWay DURSA case, do exchange across state lines.

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

Yup.

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

It's those contracts that make it possible.

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

That goes back to what Deven brought up at the beginning of this conversation.

Gayle Harrell, MA – Florida State Representative – Florida State Legislator

And this is Gayle and I want to jump in here, too. I think part of it also in developing that– has to be if we can identify some common standards for trust that then we can make that basis for the DURSA or a document so that it's not reinvented in every little town in America. And that you have a framework that you can start with that if you have a regional HIE setting up, here are some basic parameters that these are the accepted principles under which you do this, and here is a DURSA that works. And that if you can– and that here are some governance models– comes down to governance in many, many situations. Otherwise– public confidence if they don't see some concrete examples and kind of a framework that they know. It's kind of like the Good Housekeeping seal of approval, yes this meets the standard, and I know I can trust my records to be– I can give consent or whatever.

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

There is– this is David. There is a process under way ONC has sponsored called the National Governance Forum.

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

Yeah.

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

It has 20 or 30 different HIE stakeholders trying to do, I think, pretty much exactly what Gayle's just suggested, create some framework documents.

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

Yes, I'm aware of that, but I also think that our recommendations in many ways contribute...

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

Oh yeah, yeah, yeah.

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

As you suggested, David, and I also thought it was interesting that at least I think a number of folks are aware of the DURSA because eHealth Exchange, operated by HealthWay, however we want to call it, HealthWay eHealth Exchange, the DURSA is pretty well known. But even Deb Bass from Nebraska said that they've provided their model agreements and sketches of their governance structure to at least 20 different organizations. So I suspect and hope that there's sort of a lot of sharing of knowledge out there. I know the eHealth Initiative has the HIE communities, as does the National eHealth Collaborative. So in many respects while the communities may be crafting solutions that are– that have some differences to them based on their own needs and expectations, they're probably are likely some commonalities, at least to the issues that they cover and to how they deal with this. That may have just simply happened organically.

Paul Egerman – Businessman/Software Entrepreneur

And Deven, I just also want to do a check. This interesting discussion about governance and the trust fabric, but is this consistent with our discussion about limitations on non-targeted query?

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

Well, that's a good question Paul. So I'm trying in some ways to be responsive to the suggestions of the entities who presented to us, about what would be sort of helpful to them.

Paul Egerman – Businessman/Software Entrepreneur

Okay. And so that's important and so that could be a good outcome, I just want to make sure that we sort of like not get afield and find we're all on the same page. It seems like we did make previous recommendations on non-targeted queries and the most controversial one was we sort of said, we didn't see any reason to like put limits on it, that people could make as many of these queries as they want over whatever geographic region that they wanted to. And that's where we got the most resistance from the Policy Committee and so we did the hearing and based on the hearing and based on this discussion, I get the sense we should be going back to the Policy Committee and saying, we think we got it right the first time and perhaps say it a little more diplomatically than that. But, reiterate what we said before, and say, here are our reasons and here's our evidence for that.

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

Yeah, yeah, that's...

Paul Egerman – Businessman/Software Entrepreneur

Are we all on the same page on that issue?

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

I'm comfortable with that. This is David. I think, well no, never mind, it'll just take us on another thread.

Paul Egerman – Businessman/Software Entrepreneur

So if we're comfortable with that, I just wanted to make sure. So it seems to me we did the hearing and we— based on the hearing, we're not changing any of our previous recommendations, but now we're moving on to the answer to the question that we gave which is sort of like, what would you like us to do from a policy standpoint?

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

Right.

Paul Egerman – Businessman/Software Entrepreneur

Is that right Deven?

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

Yeah, yes. Although you're right Paul, we really should sort of at least close the loop on the issue of...

Paul Egerman – Businessman/Software Entrepreneur

Close the loop, yes.

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

Whether we would have any policies to recommend that would limit, in some way, the use of non-targeted query. And we're sticking with our previous answer, but we have— we can at least present to the Policy Committee that we explored this further, provide them with some flavor of what we learned at the hearing, maybe to try to get some general consensus on the articulation of the key themes. So additional feedback from folks on those would be helpful, we got some during this call. And then— then, I think we can consider whether we move to putting on our agenda specifically looking at a way to sort of scale query network beyond where they are today and what would be helpful to do that. But I do think you're right, that that's a separate topic than the one that we took on.

Paul Egerman – Businessman/Software Entrepreneur

And with— for this discussion to is the reason for discomfort with the sort of like the no— the policy of no policy on the inquiries is people are concerned about well what if the trust fabric isn't fair, and what we're simply saying is, well that's a different topic, and it's a good topic, but that's a different one.

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

Yup. Yup. So that's what we'll definitely do to prepare for the next Tiger Team call, which I believe is on Monday, this coming Monday. So we can at least close the loop on that set of recommendations. We can spend some time remaining on this call talking about how much we might want to pursue these other matters that were laid— that the presenters suggested to us. The other thing, I'll take a moment to note now, before I forget is that I was actually mistaken about how many full Tiger Team calls we have in the month of July. We have the one we're on today; we have a full Tiger Team call that is designated to be on this query issue next Monday. But the call that's on the 29th is actually a call that any Tiger Team member can attend, but it's designed to be for the subgroup in order to close the loop on recommendations related to Meaningful Use Stage 3 and whether we have additional recommendations to make on how to ensure that security risk assessments get done. So that's what that call is designed for, so my apologies for being unclear earlier. I think we are likely to be able to wrap up the non-targeted query work by our next call, probably relatively quickly. Again, whether we want to— we'll also talk about whether we want to move on to some of these other issues. But that meeting on the 29th is about Meaningful Use Stage 3 and the risk assessment attestation.

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

Deven this is Dixie. There's one more thing I think that you should capture in the reiteration of our previous recommendations and that is the summary that you gave a little earlier about our belief is that the record should go where the patient goes.

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

Yeah. Yes.

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

I think that's an important statement to add.

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

Yes. Yes, we're going to add that and everyone will be able to look at how that gets articulated in the framing.

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

Thank you.

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

So I'm going to move– I'm going to– does anybody else have any further comment to make to influence the preparation of the final set of materials for query? And then we'll spend a little bit of time talking about whether we want to move to this other– spend some time as a Tiger Team talking about what the presenters thought would be helpful. The other thing that occurs to me that they thought would be helpful is clarity around the different state laws. I thought it was very interesting actually that the SMRTNet person talked about how yes, it would be easier if there weren't these differences in state law, but often times some of the problem is that even within your own state, it's not clear what– are.

Paul Egerman – Businessman/Software Entrepreneur

This is Paul. I mean, that's a huge problem with the state laws. I mean, you look at HIPAA, basically one of the nice things about HIPAA is for the most part it's like all there in one package for you, and there are people you can ask who know a lot about it. But you go to any state in this country and I've got a state legislator on the line, and it seems like they all have 200 different laws related to privacy and security and it's very difficult to find anybody who can tell you and explain to you how it works in any state. I don't know if Gayle wants to respond to that, but I think it's a universal problem.

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

This is Judy and I spoke to the Chief Justice of Wisconsin who said that there's no way that anybody could really follow the privacy laws of Wisconsin since there are so many of them and they're contradictory.

Paul Egerman – Businessman/Software Entrepreneur

And, I mean as a vendor– as a former vendor, the way I would always do this was I would rely on my customers and they would sort of tell anecdotally here are the laws in this state. And you get more and more customers in a state and they tell you two or three or four different things, you kind of shrug your shoulders and you do your best. I mean that's what I always did, because it was just– I mean, I'm just very sympathetic, but it's a problem that's created on the state side and so what you just said Judy, makes sense. It's like there's– it's a huge problem, I don't know how we can solve it.

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

Yeah, its federalism right, I mean it goes all the way back to the Constitution, so states have those rights reserved.

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

Yup. And in enacting HIPAA, Congress made very clear that stronger state laws would be— on privacy would be allowed to remain in place. One of the things that we could do, in terms of sort of making a complete presentation to the Policy Committee about the hearing, and that in addition to closing the loop on our query recommendations and getting them finalized by the Policy Committee, we could actually note for them some of these issues that presenters brought up and get some feedback from the Committee itself about whether this is an avenue that we should explore. Or whether— I mean, to a certain extent we do have, as Gayle mentioned, sort of limited capacity to change some of these things, but— and it's a reality that people have to operate in. So what are some mechanisms that might make it easier or might make things more clear? I'm not sure.

I mean, there are only so many things that we can possibly take on, but it does— I do have a great deal of sympathy for these folks on how long it took each of them to be able to really get operations off the ground. Because there are a lot of issues that you have to deal with, of which privacy and security is only one, but it's a big one. And kind of easing the path forward does feel like a worthwhile goal on the one hand, on the other hand, there's probably only so much we can do to make that happen.

Paul Egerman – Businessman/Software Entrepreneur

Yeah. And this is Paul, not to make the matter even worse, but I think there may also be jurisdictional issues and I think that there are some city and county governments that also established privacy laws, especially since they may own hospitals. I mean, so they may establish their own— through city council meetings or county meetings, they establish their own privacy and security regulations. But I think it's important for us to somehow put at least a paragraph or two to describe this was some of the feedback and it's just an issue. And I think the sense I have from the vendors on the phone that they kind of agree; this is just a problem, probably understanding what the state's rules are.

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

This is David. I thought it was really interesting the Surescripts approach to dealing with the state line issue, which is to capture patient assent that the request is what they want to happen right now, regardless of the source of the material being queried. So not just relying on the right that raw HIPAA gives you, but actively capturing patient consent, and considering that that is adequate in most states to allow for the release of information, in the limited context that they're in.

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

And that's how Social Security does it as well, because we're not covered under HIPAA.

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

Yeah. And I think that's a work around for at least some subsets of the problem we're trying to solve.

Gayle Harrell, MA – Florida State Representative – Florida State Legislator

This is Gayle. I would totally agree with that, most state laws with consent— the patient's specific content, I think can be exchanged and— released. The only thing is with STDs and HIV status; sometimes you need a secondary consent.

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

Yeah.

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

Yeah, no I think the sensitive information is still an issue in some locations, which is why all of these panelists told us that they push that burden out to the edge node to follow their own local rules about what they actually release, so...

Paul Egerman – Businessman/Software Entrepreneur

Yeah but that — this is Paul — but that structure, David, strikes me as problematic from a standpoint of, I don't think you need to make patient's provide an authorization— an approval for absolutely every visit.

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

Yeah.

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

Yeah, and...

Paul Egerman – Businessman/Software Entrepreneur

You don't want people to have to mindlessly– you don't want people that check in and sign the damn form absolutely every single time, because that's the easiest way to get around whatever the rules are, because nobody knows what the rules are, because that's just a paperwork– that's just expensive.

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

Yeah.

Paul Egerman – Businessman/Software Entrepreneur

It's expensive to the healthcare organization and it annoys the patient, so it seems like a bad combination.

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

I want to echo that Paul. We hear a lot of customers say that the process of not only signing it, collecting it, filing it, retrieving it, etcetera.

Paul Egerman – Businessman/Software Entrepreneur

Yeah, there's a whole– I mean, you can't just sign the thing and forget it, you've got to do something with the...

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

Exactly.

Paul Egerman – Businessman/Software Entrepreneur

Piece of paper after it's signed, and if you create an environment where you have to do it at absolutely every visit, that's a ton of paperwork to keep track of. And it's not a good privacy policy because after a while people will just sign the things without reading it and be annoyed by it, but that's not really authorization in any way.

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

I think in practice people don't do it at every visit, they do it yearly or they do it at some interval and make it clear that it has a standing consent for the duration of the treatment of the episode of care. There are ways to make it less odious, but yes, it is odious, although we are making a big point about consumer choice here, so if you want to give people choice, you have to give them choice.

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

Yeah, but we have selectively applied choice in certain circumstances, number one. And number two, all of our consent recommendations came within a framework of expectations that people adopt other fair information practices as well, so that the burden wouldn't be on the patient and with an understanding that you wouldn't and shouldn't need to get consent each and every time.

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

Right, it would be great if everybody followed HIPAA, I don't think any of us would argue with that. I'm just pointing out that one way to avoid having to literally build into your software different rules for every state is to get proactive consent.

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

Well, although I guess with my legal hat on David, given that I've seen some of these consent laws, and if you've seen one consent law, you've seen one consent law, they usually have different specifics attached to them. The general consents usually don't– won't fit the bill, so even though in theory one could presume just get consent on the front end and save yourself some time on the back end, and that there's some way to sort of program this in a one size fits all way, or even a ten sizes fit ten common models way, I'm not sure that's possible.

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

Well, I think we've heard in several meetings– this is Wes. We've heard in several meetings that there is a goal of finding the common denominator that can be handled routinely, making that as large as possible and also providing the information about the request necessary to allow the non-automatic response to be made for the exceptions.

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

Right.

Gayle Harrell, MA – Florida State Representative – Florida State Legislator

Agree to get to the 90:10 rule, where 90% of the time it is a relatively routine type of thing and 10% you may need further clarity on. And if you can get a system that works functionally at that level, I think you've got a system that's going to work.

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

Yeah. Judy were you...

Paul Egerman – Businessman/Software Entrepreneur

So Gayle, we only have to work for 45 of the 50 states, is that what you're saying? That was the 90:10 rule.

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

I don't think this is...

Gayle Harrell, MA – Florida State Representative – Florida State Legislator

Nation's laws on consent.

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

I think lots of luck on that one Paul.

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

I don't think this will fly but if you really...

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

Judy's already said that Wisconsin laws are all but impossible, so, there's one...

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

Well the other thing is that if you really wanted to reduce the work overhead and you look at the statistics that at least we see with patients signing for consent to their entire record, it's about a 99% sign yes for the entire record, 1% says no. The way to do it from a practical point of view would be to have the 1% sign that they don't want it and the 99% would be assumed, and that would really reduce the burden of work effort.

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

So you're talking about an opt-out plan rather than an opt-in plan.

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

Sure.

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

I think that actually– this is Wes. I think that really complicates the matter of trusting the requesting entity. I mean it's one thing to trust them to convey what's been gathered, it's another thing to trust them to gather anything in an opt out situation. You've got no– you've got to trust that their interpretation of opt out is consistent with your state and things like that. I think that it complicates the issue.

Gayle Harrell, MA – Florida State Representative – Florida State Legislator

I agree.

Paul Egerman – Businessman/Software Entrepreneur

Right, it complicates– this is Paul. It complicates the issue plus I think we already talked about it, we had a spirited discussion on opt in, opt out, we ended up with meaningful choice and I have a feeling that if we started talking about it again, we'd have another spirited discussion. Because it is something that people feel really strongly about. I mean I'm listening to all this discussion and it's like, I don't if I'm getting this right, I'm getting like two different treads, one is getting back to John Houston's comment on the trust fabric that there should perhaps be a discussion about some sort of like generic or best practices or recommended trust document or trust terms that might help facilitate all of that process. And then I'm also– on this discussion about the patient approval, whether or not we also want to make some– if that's a topic we want to tee up if we want to at least have some general concepts, which is the patient should not have to do this every visit. And there might be some general concepts there that might be helpful, too.

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

Well, frankly I think we have dealt with the issue of meaningful choice pretty clearly. I'm not sure that we need to go down a road we've already traveled. That is, I agree with Paul, it's like reopening a wound.

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

I didn't mean it to be that, it was said more tongue-in-cheek.

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

Right, I added that color to it Judy, it's hard, it's very hard and people feel very strongly about it. So we're sort of reaching the time for our last public comment period and the end of our call. What we're going to endeavor to do, Paul and I and the folks at MITRE who support us and ONC staff, to work up some language that would be the basis of the slides that we would present to the Policy Committee that will put a bow around our recommendations on query and add some additional thoughts about what the presenters said at the hearing that will potentially be helpful, but that we'll be able to look over again on our next call again, which is Monday. It also gives those of you who haven't had time to read through the transcript a chance to do so. But that's what we'll aim for in the following Monday. We've had a really interesting discussion that was teed up by the terrific presenters at our hearing, and so many of you joining us today to participate as well. Are there any other closing thoughts, Paul?

Paul Egerman – Businessman/Software Entrepreneur

No, I agree, it's a great discussion. Let's see if we have any public comment.

Public Comment

MacKenzie Robertson – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Operator, can you please open the line for our second public comment session?

Caitlin Collins – Project Coordinator, Altarum Institute

If you are on the phone and would like to make a public comment please press *1 at this time. If you are listening via your computer speakers you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. We do not have any comment at this time.

Paul Egerman – Businessman/Software Entrepreneur

Terrific. Well thank you very much and our next call is on Monday.

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

Thank you folks.

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

Thank you.