

Privacy and Security Tiger Team
Draft Transcript
September 23, 2011

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 call so there will be an opportunity at the end of the call 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 of members: Deven McGraw?

Deven McGraw – Co-Chair – Center for Democracy and Technology

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Paul Egerman?

Paul Egerman – Co-Chair

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Latanya Sweeney? Gayle Harrell? Carol Diamond?

Carol Diamond. Markle Foundation

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Judy Faulkner? David McCallie?

David McCallie – Cerner Corp.

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Neil Calman? David Lansky? Dixie Baker?

Dixie Baker. SAIC

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Micky Tripathi?

Micky Tripathi. MA eHealth Collaborative

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Dan Callahan?

Dan Callahan. Social Security

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Christine Bechtel or Alice Leiter? Don Houston? Wes Rishel? Richard Elmore?

Richard Elmore. ONC

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Leslie Francis? I know she's on.

Unidentified Woman

Yes, I heard her too.

Judy Sparrow – Office of the National Coordinator – Executive Director

Vern Rinker?

Vern Rinker

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Joy Pritts? Did I leave anyone off?

Alice Leiter

This is Alice Leiter, I just joined.

Judy Sparrow – Office of the National Coordinator – Executive Director

Ok good, thank you Alice. I will turn it over to Deven and Paul.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Go ahead Paul.

Paul Egerman – Co-Chair

Thanks, this is Paul Egerman. Thank you very much Judy Sparrow and I want to thank any members of the public who may be listening to our call over the Internet or over the 800 line. At the end of our call, which will happen somewhere close to 4:00, we will have an opportunity for public comment. So, if you are listening and have some comments we would very much like to hear them. Those comments are very important to us. Also I want to welcome Dan Callahan from Social Security, who is a new member of the Tiger Team. We are very happy to have you Dan and also certainly very happy to have Social Security participating in our discussions.

Dan Callahan. Social Security

Thank you.

Paul Egerman – Co-Chair

So we have a very interesting agenda today. Basically what we are going to do is go through three different topics. First we are going to debrief, which is a fancy way I guess of saying we will tell you what happened at the HIT policy committee meeting on our recommendations related to the ANPRM. Then we have after that Rich Elmore is going to give us a description of a project called, Query Health, that is extremely interesting and then after that we will also get an interesting description of the data segmentation standards initiative from Joy Pritts. So that is the agenda. And unless somebody or anyone has any questions, I will ask Deven to do the debrief.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Ok great thank you very much, Paul. We – for those of you not either present at the policy committee meeting or not on the phone, we had a very successful presentation of our recommendations related to the secondary use of the EHR data as contemplated by the advance notice of proposed rulemaking

issued by HHS and for which there is an open public comment period that we were urging the policy committee to weigh in on. Our recommendations were very well received. We got lots of pats on the back, maybe you can even call it the chest bumping or fist pumping that Wes referred to after our final call where we put the finishing touches on these recommendations. They were – it was very interesting and robust discussion. In essence, the policy committee endorsed our recommendations but gave us some feedback with respect to the wording that they would like to see in the letter. So, since the comment deadline for the ANPRM was extended until October 26 we had an opportunity to continue to refine the text that we would submit as part of the ANPRM in response to the policy committee's comments. So, the plan is for Paul and I to work in the feedback that we got from policy committee into the document which will also we will turn into an actual comment letter. And then, the policy committee will have a chance to look at it one more time to make sure we captured it appropriately and they will do that at their October meeting. And then, we will move that that letter on through the comment process. So, you should all be extremely proud of the hard work that we did on this issue. Again, it was very well received, we just have to do some refinements on language per the policy committee's request and make sure that they are comfortable with the way that we have framed their comments and then the letter will go off. So, we don't have plans to revisit the substance of those recommendations either with the policy committee or with the Tiger Team. However, I think a lot of what we said in our comments and in our recommendations that were endorsed by the policy committee are likely going to be relevant for the discussion we are going to have today on query health. I hope – so does anybody have any questions about my debrief or want to add anything? Paul, I will turn to you first make sure I didn't leave anything out.

Paul Eggerman – Co-Chair

I think Deven you did a good description and it was very interesting presentation in front of the policy committee. One thing that Deven left out, she did like an outstanding job of taking the policy committee through the background information of how the common rule works and what the ANPRM is, how HIPPA handles research. She really did an outstanding job of describing what is a very difficult and complicated topic in a way the provides sort of an easy to understand and brief – somewhat brief summary.

Deven McGraw – Co-Chair – Center for Democracy and Technology

[laughter] That wasn't terribly brief.

Paul Eggerman – Co-Chair

As brief as one could possibly make that is probably a better way of saying that. It was very hard – common rule - HIPPA's View of research and the ANPRM that doesn't lend itself to a three minute talk. I mean that's – to really give the policy committee the background they need to evaluate the recommendation that was really a very – I personally thought that was a great presentation.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Thank you, Paul.

Paul Eggerman – Co-Chair

It was overall though, I think extremely well received and it did prompt some feedback from audience members who sent some e-mails to us, actually to Deven and I afterwards asking questions about how it would impact the research. So it was overall I'd say a well received recommendation. You should feel proud of it and there is some work to do to make sure we clarify some things. It's really almost like a wordsmithing thing to make sure what we write is what we really meant [laughter] that describes it. So there is a little wordsmithing to go. I don't know if anyone else was present and has any other comments they want to make?

Deven McGraw – Co-Chair – Center for Democracy and Technology

Alright, terrific. It's good news all around and I think tees up quite nicely with Rich's presentation on Query Health which for those of you who are policy committee members, you know, it is the presentation that Rich went through really quickly at the policy committee meeting but we actually have an opportunity to ask questions and provide him with more helpful feedback on you know, what they are planning to do and to provide some suggestions around the sort of initial policy guard rails or policy principles that they are intending to put into place and operate under. So for some of you this may be a little bit of a repeat it but again it's not going to be a repeat for everybody so it is important that we all get on the same page. And again, we have the luxury of time and attention and focus on the issue which the policy committee members really did not have when we had this presented to us briefly at the policy committee meeting that took place in September. So, Rich, I think this is your cue; we need to get your slides pulled up, maybe they are and my computer is frozen [laughter]. I will turn it over to you. Thanks a lot.

Richard Elmore. ONC

Thank you, Deven & Paul and members of the Privacy and Security Tiger Team. First of all, congratulations on the work you did on the common rule comments, I thought those were outstanding and assuming that they are picked up on in the rule making process, it's going to make a huge difference in health outcomes in this country and I want to thank you personally for the work you have done. I thought it was just terrific.

Query Health is a project focused on defining the specifications and protocols for distributed population queries hopefully, ultimately, through a process of trying and practices what we come up with eventually resulting in some recommendations for standards as well. So, the presentation we gave to the policy committee is what we will be going through today. I can tell you that generally where we talk about the HIT Policy Committee as part of the feedback mechanism for this project we were also careful to always incorporate in the Privacy and Security Tiger Team as another important source of feedback because in fact those are some of the most important issues we want to make sure we address well. This project is really set up from the get-go to be very very respectful of patient privacy to ensure that patient data is actionable, close the source, and that we want to make sure we stay on the right side of all those questions. So, getting feedback from this group is really the point of today and our conversation as we move forward with the project which just launched on September 6, so it's only a couple of weeks ago. We are grateful for the opportunity to be in front of you early and hopefully that will allow us to make sure that we stay aligned and are working in the best interest of moving the project forward with due regard for privacy and security considerations.

So, what I will try to do is go through the background of this project and for those of you who have been through it before, I apologize. Once we get through that level setting, really the point of this is to present to you some thoughts we've had on a policy sandbox that would guide the initial implementation – the initial pilot of this project. And, it comes out of some conversations we have had internally within ONC, and really want to try to get your feedback and direction for moving this forward. So that's the agenda, those 2 parts.

Now the vision is really tied very closely to the idea of enabling alerting health systems to be able to understand you know, different population measures of health and that can be related to performance, or quality, or disease and so on. You can imagine the various different, kind of aggregate measures that are applied in healthcare while respecting patient privacy and really focusing on being able to improve patient and population health and to be able to reduce cost. And the context – I don't think these questions could have ever been asked before, I mean, I think we needed a certain level of critical mass of deployed electronic health records, with some level of standardization of the information in them to be able to be

used for health information exchange and quality measure reporting. So, in that context, we think the opportunity here is to really improve that community understanding of population health and to enable proactive patient care to be able to deliver insights for local and regional quality improvement. So the idea here is not just you know, some national questions but really being able to more local base to be able to use appropriate tools for being able to get insights into health, disease, a comparative effectiveness as applicable to community [indiscernible]. Not only, I should mention, not only from the perspective of providers to government, but also in private relationships between providers and payers or **Pharma** and providers or any number of combinations of interested parties that would want to be able to share aggregate, de-identified information relevant to answering particular questions related to research, health outcomes and so on. We want you to be able to use something that allows for consistently applied performance measures and payment strategies for the community that are based on the de-identified data and to be able to identify treatments that are most effective for the community. So that's the context and the opportunity.

The challenges today, there aren't any standards for distributed population queries and so, the variation in clinical concept coding even within organizations is extremely challenging. There are, today, computable definitions, standardized computable definitions of type II diabetes or angina, you're talking the meat and potatoes stuff that is driving three quarters of the healthcare cost in this country and we don't have standardized computable definitions. So, those high transaction and plumbing costs are the absence of standards for distributed queries and the lack of an understanding of even how best business practices should be conducted around distributed queries makes it very, very expensive to do this. Further, there is a centralizing tendency which is that, in a number of cases where folks have wanted to try to get information from a variety of data sources, the only way they can really pull that off up to now, was to bring that information together into a centralized database which is moving the data further away from the source, it creates an additional layer of PHI risk exposure, and really limits responsiveness to patient consent preferences and makes it less actionable for us to be able to do anything as patient consent gets better defined through data segmentation initiatives and other forward-looking standards that hopefully we will get to here.

Now, the last point is that because of the cost of doing this, for the most part, distributed population queries today really have only been done by larger health systems or those with larger IT and research budgets. Now, there are notable exceptions to that. There was some terrific work done in New York City, and it's been done with smaller practices, it is actually shown the applicability and the importance of being able to do that for everyone, not just for kind of larger, kind of more well endowed institutions. That is kind of the challenge in which all of this is taking place. And the goal here, really, is to be able to improve the community understanding of patient population health, and to be able to ask the researcher for example, to be able to ask a question of the clinical information that might exist at a practice or might exist in a large institution and to be able to return aggregated results. Those aggregated results might be questions about disease outbreaks, prevention activities, health research, quality measures, and so on, you can imagine the list of aggregated measures.

So let me pause there for a moment before I continue through the discussion to see if there are any questions or comments. I will keep going and feel free to give me the high sign if you do have a question. So the scope and approach for the query health initiative is first of all it's a public-private partnership, it will be guided by the HIT Policy Committee and the Privacy and Security Tiger Team. It will be providing us a policy guidepost for this project. You will not hear, in this project, capital P-policy or capital G-governance as things which we're covering. We expect that we're working within the framework of the law and within the framework of how that law should be interpreted is provided to us by you all. This will be a community driven consensus-based process. For those of you who are familiar with direct or are familiar

with some of the other S&I framework initiatives, the structure is very similar to that. The intent is to be able to apply this to the Electronic Health Records and also potentially to other clinical records. We've seen examples of where distributed population queries have been applied to health information exchanges both in federated approaches or more centralized approaches and being able to get at clinical records on a regional basis has the additive data that you'll be able to deal with some of the challenges such as patient matching and some other considerations about looking at information at an organization level or an EHR level that may be trickier than if it's pulled together regional. So, and then finally the point here is to be able to come up with the recommendations on the standards and services for these distributed population queries. But to get there by starting with a practice, not starting with the standards, so we want to get to [indiscernible] consensus, we want to get to running code of an open source nature, and we want to be able to try that live in a pilot and we want to use that as a way of informing and finalizing our specifications and being able to make recommendations around the standards. Any questions or comments?

Dixie Baker. SAIC

Yes, I have a question, this is Dixie Baker. We had one other experience where standards or a complete model, I'm in the standards committee, and we've had one other sample where a model for service delivery came to the standards committee at a point of time where it was almost too late to have any input into the standards. At what point will this come to the standards committee?

Richard Elmore. ONC

So, I believe that Doug will be talking about it briefly at your next meeting and we will have to discuss that with the leadership of the standards committee, but I think it would probably, you know, subject to what they want to do in terms of agenda, we will probably be ready to have those conversations starting in the following month, but I think as I understood it, the agenda for this month was fairly tight. Does that work from your perspective?

Dixie Baker. SAIC

I think your answer is it hasn't been determined?

Richard Elmore. ONC

It has not been determined but we are interested in having conversations with the standards committee as we are having with the policy committee.

Dixie Baker. SAIC

Ok. Sorry, I haven't looked at the agenda. Thank you.

Richard Elmore. ONC

So, a couple of user stories, these are example user stories. We actually will talk about the workgroups in a minute. But there is a clinical workgroup which is doing a terrific job of ramming out these samples into a set which will inform how we think about architecture and technical approaches to this and will also ultimately result in some [indiscernible] into what will be implemented in a pilot. But just to give you a flavor for what might be included in a Query Health user story. First of all, let me start by saying there is one use case for Query Health, that use case is very simple, right, it's, ask a question against some standardized information and be able to get a result back. There is a lot more to it than that as you know. But that in a nutshell is the basic use case. Now, the user stories that are being looked at in that context of that use case are the two value [indiscernible] present to you are somewhat similar in structure. So, they have a couple of components to them. The first part, this first one is a public health sort of user story and the first element of that is quality compliance and it's looking at the [indiscernible], at the age of 50

you've received the flu vaccine and the second part is more of a surveillance type of activity determining what patients have contracted the flu in the aggregate and then the third is a 2x2 which is actually looking at that intersection between those who have received the vaccine and those who haven't and those who had a flu diagnosis or not. And then one of the things that we do in this user story is to suggest that some of the benefits of having a query approach, you know as was discussed in PCAST, is that ability to be able to get more near time aggregated information in response to what is happening in the rules and our understanding of it, being able to refine a query. For example, for H1N1, to be able to add GI as a condition that needs to be looked for, perhaps being able to specify H1N1 vaccine as a specific vaccine that's being looked for. So, that is one user story. The next one is more of a comparative effectiveness user story and this is looking at case-control and **statin** efficacy so on the quality side looking at the number of patients over the age of 18 who have been diagnosed with high cholesterol or taking a **statin**, and then the surveillance is determining how many of the patients are **hyperlypodemic** or how many are not, and the third element again of the 2x2 looking at **hyperlypodemia**, your cholesterol level, and whether or not you are taking a **statin**, and then you could refine that to be able to look at a couple of **statins** and compare efficacy of those. So, those are some examples of how a population query, an assured population query, might be able to ask a question that returns aggregated de-identified information to the person conducting the research to be able to produce this kind of information back.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Hey Rich, this is Deven. When you say, I just want to clarify, when you say a 2x2 is that looking for a correlation basically? Is that what is meant by a 2x2?

Richard Elmore. ONC

I wouldn't go so far as to say a correlation but it would show – in an observational study you don't necessarily have [indiscernible] but you may see some signals that you want to understand better which would require more rigorous, you know, clinical study for example. But it provides you some information that can be helpful, and being able to get at this some more near time as opposed to clinical trials which can take a lot of time and resources, it can be very helpful to gain insight. In fact I believe some of the information that eventually resulted in the recall of the **cox 2 inhibitor** were based on this kind of observational data out of distributed queries.

Paul Egerman – Co-Chair

2x2 refers to the rows and columns right?

Richard Elmore. ONC

Correct. So in this particular case it is **hyperlypodemic**, yes or no, and taking a **statin**, yes or no, and the prior example it was received a vaccine yes or no and contracted the flu yes or no.

Dixie Baker. SAIC

This is Dixie Baker again. I'm sorry. So it would return a number of patients or would it return a set of de-identified reference?

Richard Elmore. ONC

The idea is, and we will get to this particularly when we talk to the policy sandbox, but the idea is to have a flexible query approach that would allow you to be able to provide aggregated results of the identified information or limited data set type information back to the person asking the question with the appropriate guard rails and all of that. So, it may be more than just patient counts in terms of what is being returned.

Dixie Baker. SAIC

It's basically either a report type thing or a limited data set?

Richard Elmore. ONC

Yes. Does the one case, and we will get to this as we get into the policy sandbox, but the only case where we expect in a pilot to be having any individual identifiable information being provided back would be in the case where there is a permitted public health use case where it's already allowed by you know, state or federal law and regulations.

Dixie Baker. SAIC

Thank you.

Richard Elmore. ONC

Continuing forward, the use case itself is hopefully this simple is really being able to specify patient data and provide patient data that's going to be processed against being able to provide the query or case definition. The sub-comment I think the community is beginning to get clarity around how we should be discussing this is probably more important to mention that information that is going to be processed from the point of view of a query or what results are going to be returned will be under the control of the data owner of the disclosing editing so that information will not be, you know, automatically pulled by an external query that is not without control by the disclosing editing. So, the pub sub was a publication that was prescribed with a common pattern we saw in an environmental scan that we did this summer as one part of a method to ensure some control over the query and the query request for the data owners. And then the third element is being able to provide the results back. So it's really being able to come up with standards and protocols for what data, you know what kinds of questions and what kinds of results.

David McCallie – Cerner Corp.

Rich, this is David McCallie, and to the Tiger Team I should clarify I am helping Rich and volunteers for query health to define query health. So, I am wearing both hats today as a member of the Tiger Team as well as someone involved in Query Health. I just wanted to point a comment out that came up when we had internal discussions about this particular slide, that big box labeled Query Health has misled some people into thinking that there is some kind of repository into which all these results flow and that is not the intent, so the slide could be misleading. The results would go back to the queryer but not to some other aggregating entity called Query Health, is that correct?

Richard Elmore. ONC

Yes, thanks for that clarification David and the team is in the middle of coming up with a new diagram for this which we'll probably have available for the next update.

Deven McGraw – Co-Chair – Center for Democracy and Technology

It's so funny how the diagrams can really throw people off, that's a helpful clarification.

Richard Elmore. ONC

So if you think about this from the perspective of an individual disclosing entity, the entity that is responsible for the data, it is not the person providing the question, you know they have data they're going to have processed against a query or case definition question and then they will be sending some results back, would be a better way to think of this. So, the Query Health organization and timeline, the organization has the initiative group called the implementation group which is driving the overall project progress ensuring that there is coordination across the three working groups and it is also the primary voting group for committed members to make decisions on the project, fully consensus based, if someone doesn't like the work product results, a no vote with actionable recommendation is the path forward and

we are in the middle of working through the charter with the group and are absolutely adhering to that approach the process. There are three work groups, the clinical, the technical and the business work group. The clinical workgroup is both, if you will, the one that steps behind the what, so what questions, what data, what results. The technical workgroup is really the how group, they are figuring out you know, how we're going to get this implemented, the standards that are going to be applied and so on. And the business work group, there has a lot of concerns about the name so we love to get a better name for it, but the idea of it is to really drill into a number of the elements that are supportive of the project that aren't in that in the basic parts of what and how. So it relates to privacy and security and consent and sustainability and data use agreements and best practices and all of the things around the project that are going to be important to ensuring that it is sustainable, that it's extensible, that it stays within you know, within bounds of policy. So, that will be the biggest connection I think to the Privacy and Security Tiger Team and the HIT Policy Committee. A little gold arrow, kind of a, you are here, for mid September leading up to a face-to-face meeting planned for October 17th and 18th, or 18th and 19th, I guess which will really help, I think, the teams to gel and be able to bring to ground the user stories and to make some progress on how we're approaching this technically. So those are some of the next steps in this project.

For community participation, just, it is all recorded, it's all available for public view and you don't have to be a voting member to be able to participate as an observer. All of the work products are visible through the Wiki and we've had some terrific participation with some really just outstanding healthcare stakeholders in each of the workgroups. So, David is a great example of the kind of contributions we're getting from the community.

Goals alignment from an S&I framework perspective, this is an S&I framework project, it is an open government initiative, we are doing our very best to be able to engage providers, patient advocates federal partners, researchers, just anyone that we think could have potential, have a stake in this. Meaningful use and standards, we are focusing on what seem to be signals for stage 2 meaningful use in terms of vocabularies and we will be looking to leverage information models either from the S&I initiatives and from existing distributed query model approaches. Transport approach will leverage the NwHIN. So those are some of the areas where we're trying to ensure that we have alignment for moving forward.

And finally, ONC sponsored an IOM initiative earlier this year to be able to identify the digital infrastructure for learning health system and that went down the list of what those recommendations were. They seemed to align, just about every one, in a significant way with the idea of distributed population queries. I think there is, you know, just a significant benefit that we will be able to bring the country if we can establish those standards and begin the process of being able to get better information, nearer time on population health and all of the other categories of aggregated information. It could be available to us. So, I think there is kind of a strong sense of purpose and mission for the project overall shared by a lot of the community participants.

We had a, what we called a summer concert series this summer, which was an environmental scan that was designed to look at the practices of folks that were actually doing distributed population queries today and there were just some terrific work and feedback from those groups. The value propositions, the ability to really describe, you know, kind of the speed adaptability and patient coverage value statements of having distributed queries were really phenomenal. The work that has been done by these folks is really helping us. We are standing on their shoulders to figure out how to get this done. There were some challenges that were identified out of that summer concert series and a few of them are listed here. And what I really kind of wanted to emphasize was we heard across – the folks that do this talk about this differently than folks that don't, but they talk about it consistently and the one key message was the hardest part of this isn't the technology, it's the policy and governance. So, that is where you all come in.

You know, I think if we want to do this well we need to make sure that we have clarity about our practices, that we've got clarity about you know, what kind of guard rails we need to stay inside of that we have you know, effective and easier mechanisms for folks to be able to engage with each other, to be able to share appropriately within the law and again I think it's important to mention that we are not trying to set law or policy, we are trying to take direction on law and policy to be able to provide distributed population queries and standards for them for the country.

So, how you can help is really in providing that policy guidance and we will make sure we are providing updates and enabling you to be able to monitor progress. The kind of immediate need here is to get your feedback on the project generally of course, but specifically on the policy sandbox for the initial pilot. Now the reference implementation work will start later in 2011 at the earliest, so that provides needed time for review so we're not under the gun in any sense. We feel like we are coming to you early in the process and hopefully that will improve our ability to work together and our ability to be able to respond to the guidance that you come up with. And, the policy sandbox itself has really been modeled after the previous S&I initiative and that's been done in consultation with the privacy office, policy office, the S&I framework office and their staff, so we have gotten terrific input from Joy and the rest of the team. None of this should be new, not foreign to any of you and the idea is to apply to the initial query health pilot. The basic guiding principle has been abundance of caution. So, hopefully you will come to a similar conclusion and if not we will adapt accordingly.

So, here is the policy sandbox and the basic notion is that query requests responses should be implemented in the pilot to use the least identifiable form of health data that is necessary in the aggregate. And then there are three principles within that. The first one of those is one I mentioned earlier which is the idea of a disclosing entity having control of about which queries get processed and which results get returned. So that however that is done, whether its public subscribed or not, may not be the only mechanism for it or may only be a part of a mechanism for it, but the basic idea is the disclosing entity has control of the information that could be processed from a distributed query or it could be returned as a result. The second principle is the idea that the information that will be returned in a result in a pilot would either be first it's kind of a non-interesting case, a mock or test data, so that's no problem, the second is the idea that we would return aggregated information that comes from the data columns you would have typically associate with either de-identified or limited data sets. In either of those cases those would be done in the framework of data use agreements between the parts. Now, it is quite arguable about whether or not de-identified aggregated data use sets, the data use agreements are required but this is an area where [indiscernible] of caution would apply. And then thirdly, the other possibility is that there could be a public health permitted use under state or federal law and regulation where individually identifiable information might be required, perhaps only for the numerator of an aggregated measure but nevertheless might be required in some purposes. So we've left open in that case that there could be the transmission of individual identifiable information. Then the third principle relates to small cell so to the extent that we are sending back aggregated information, we wanted to have a very bright line for which we would blur information. So if we had less, as is stated here, less than five observations in a cell, we would blur the data by methods that reduce the adequacy of the information that's going to be provided. We did a bit of research on this, Ed Larson from our business work group looked into it, there are some CDC data released guidelines which actually recommend limiting cell size to 3 but assume significant large population. Just trying to keep it simple for the pilot, we upped that a bit and also kind of put in a population parameter. But we also found that this was similar to the guidance that is in the guidelines for [indiscernible] that are used by several states. So, let me stop there and see if we can start some conversations.

David McCallie – Cerner Corp.

Rich, this is David again. I never noticed on the slide the use of the phrase limited data set and thought about it from a HIPPA point of view I suspect you do not mean the technical definition of a limited data set as per HIPAA? You just mean limited data. Or what do you mean?

Richard Elmore. ONC

So, the intention was to mean a limited data set per HIPPA. But again, the idea here the way to think about this is these are – this is aggregated data which is coming from data columns that would typically be associated with a limited data set or with de-identified data set.

David McCallie – Cerner Corp.

Maybe Deven or someone that's closer to HIPPA should weigh in but I think there's a – a limited data sets contains considerable PHI essentially again or course whatever the use agreement is this certainly may contain PHI.

Richard Elmore. ONC

So a limited data set can include in addition to the de-identified, could include admissions, discharge and service dates, it can include dates of birth and death and could include age and 5-digit zip code. So, there would have to be some aggregation of that but the idea was again that would be in the context of an appropriate data use agreement.

David McCallie – Cerner Corp.

Ok, thanks.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Rich, this is a Deven. Explain to – in the interest of full disclosure, I participated in a three-person privacy panel that worked on the policies related to the mini-Sentinel pilot. For those of you who don't know what it is, it is a surveillance system that the FDA set up under the authority of Congress that is using sort of a similar model to do post-market safety surveillance on drugs and devices. And in that model, all of the queries are public health related because they are all initiated through the FDA which is a public health authority and so every single one of the sort of queries that go out to the data holders and the responses that come back could in fact be identifiable because they fall under the public health exception. But a decision was made that the public health authority for the safety surveillance activities would not need to know the individual party and so that the data would still come back in the least identifiable form necessary to do the data even though the law permits that data to be disclosed in a fully identifiable form. So I'm questioning a bit the sort of category three in data exchange number two where there seems to be a default to identifiable data anytime the use case is a public health permitted use. So, can you explain to me why you landed there and whether there might be room to sort of clarify that so that certainly if you are responding to a public health reporting requirement where the data needs to be identifiable and there isn't any way to meet the requirement other than through identifiable or in certain circumstances where identifiable data may be needed because you want to alert the patients about a particular problem but otherwise you would default to – I think my preference quite frankly would be to continue to use the least identifiable data notwithstanding the fact that, you know, if you are doing something under public health exception you could use identifiable data for that purpose, you don't always need to.

Richard Elmore. ONC

That's a great clarification and that is really the intent of what we were trying to get at with this policy sandbox. So, we can very easily kind of conform the way this is written to that.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Yeah, and so since part of this is, you know, since the Tiger Team doesn't really have authority to act on its own and we have to bring all of this to the policy committee meeting, we have another meeting before the policy committee meets in October that we could actually have anything that we discussed on this call that sounds like an official suggestion of refinement or modification or clarification I think ideally we would want to bring that to the policy committee but we could work with you all in how to get messaged and we have another Tiger Team call in which to discuss it. That would be one suggestion that I would make that we think about that it not just be, sort of, oh if it's public health and its identifiable but we try to pin that down with a little bit more clarity in a more privacy protective way.

Richard Elmore. ONC

I think that's a good clarification. I think another way to think about this is that there's, you know standard practices out there today, and we probably wouldn't be trying to vary from what that standard practice would be in terms of the information that needs to be provided.

Dixie Baker. SAIC

This is Dixie Baker. Does this work address what the receiver of this data can then do with the data or, do you just reference other existing policy?

Richard Elmore. ONC

So –

Dixie Baker. SAIC

For use of data beyond immediate needs?

Richard Elmore. ONC

The decisions with the idea of trying to keep the project simple, there are certain things that we decided that were kind of outside of the system Dixie, so, examples of that might be, you know, who is an appropriate person to ask a question, what can be done with information that's returned. What addresses are you going to accept a query from and return a result to? They will be decided, you know [Indiscernible] Does that answer your question?

Dixie Baker. SAIC

Yes. This project just sounds like a kind of distributed I2B2 right?

Richard Elmore. ONC

That is one model that was actually part of that summer concert series we referred to, yes. The I2B2 shrine distributed network is one implementation of a distributed population query network.

Deven McGraw – Co-Chair – Center for Democracy and Technology

In other words Rich, so right now with the sort of initial set of pilots the queries are formulated by the clinical workgroup, obviously the government has a role in vetting those since this is a government sponsored pilot. You can correct me if anything I am saying is wrong [laughing] but this is not yet the creation of sort of an open query system that where you sort of really need to decide issues of governance, who gets to ask questions and who is allowed to participate and what are the restrictions on data recipients, although I think per Dixie's question of what do the recipients do with data, I think it's important to understand even in these pilots that are being done who is in fact that query health box that David pointed out who is receiving the results at least in the short-term.

Richard Elmore. ONC

So, this is very early days through the project and is likely, you know that we will learn more as we go through and certainly at this stage we're not at the stage of knowing what the pilot would be. And so, we will have to monitor that as we go forward. But I am hopeful we will be able to come up with something that folks consider to be important, an important problem to be solved, whether that is in the first pilot, solve the mock or test data or whether its solve with live data, let's assume for purposes of this discussion that it is live data. That the questions might ask will in fact be somewhat dynamic that a query that has asked first for flu might get refined based on better knowledge of the actual indications that want to be looking for. The point of the project is to be able to enable questions dynamically to be asked. Now, there are all kinds of requirements around what is allowed and what is not allowed that needs to be decided between the parties. There needs to be control by the disclosing entity which is what that query health box is, is the best way to think of it and we need to make sure they have you know, the control they need to be able to say I am comfortable with the query [indiscernible], questions are being processed and I'm comfortable with results being returned and they want to delete or blur some information before that is returned or I don't want to return anything at all. So, that control needs to stay with that disclosing entity. Our goal is to be able to provide a framework, a technical and standards framework that allows for consenting participants to be able to participate in a variety of different networks where they may be asking questions and returning aggregated information in those networks of consenting organizations could be private in nature, they could be public and private, or there could be a variety of potential models.

David McCallie – Cerner Corp.

This is David. I think that is a really critical point that the query health in the long run really becomes more of an enablement for a variety of different kinds of arrangements exchanging data amongst different partners. There is not a sort of single top down entity that will govern it. Dixie can correct me if I said that wrong but I think that is consistent of what we've been talking about.

Richard Elmore. ONC

That is exactly right, thanks for that David.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Yeah, I don't think I necessarily conceived of it that way. So I would agree, this is Deven, that that is a helpful clarification. Can I ask who is ever typing in the background to please mute your phone? Thank you.

David McCallie – Cerner Corp.

This is David again, just following up on that. I think some of this is still being flushed. I am speaking now as a query health participant rather than as a Tiger Team member, but one sort of way to think of this is by getting an agreement on what the standard is for the kinds of queries that can be supported and for the way that trust can be enforced and authorization can be granted to the right people and denied to the wrong people, by getting agreement on all those standards some of which would be standards, some of which would be profiles and conventions on top of standards, you enable the possibility of loss of new kinds of exposure and use of this data. But you don't do that by creating a central authority, called the query health authority or the ministry of query health or something that has to put up with all the theories and actually issue the theories. That would be up to the individual participant, the queries and the respondents, and to me that makes it much more interesting than it could be otherwise.

Richard Elmore. ONC

So, yes, those are some great examples just to kind of ground it in what's really happening today. I know that which **plat** work you were recently on some projects and part of what he's done with the **pop med net**,

he and [indiscernible] on pop med net is to not only apply to the Sentinel work but also to apply it to an HMO research network, and they actually have participation between payers and providers and the payers have the ability to be able to ask distributed queries of the various providers and the providers who have agreed to participate have gone through appropriate you know, data use agreements with the payer and they have also established an intermediary in this particular case because not only did they not want patient identifiable information to be shared which it wouldn't be you know, with this distributed approach, but they didn't want organizational information to be shared either. And so there is kind of an intermediary that identifies the organization before it's sent back to the payer so there is an interesting example of how this information is being used. The further decisions around health and comparative effectiveness and so on, collaborations between payers and providers and the use of distributed population query. I think the FDA mini-Sentinel example is a terrific example of doing this in a very powerful way. They have been able to use a variety of data providers, some that are very large aggregators in their own right to be able to get access to you know, 100 million patients worth of information, it's claims data, it's not clinical data but nevertheless very, very powerful in terms of being able to get at some important questions with significant advances in terms of turnaround time which are important if you're dealing with concerns about a particular drug interaction or something else that could affect patient safety.

David McCallie – Cerner Corp.

This is David again, connecting dots with what the Tiger Team discussed the last couple of sessions around use of clinical data to identify unexpected adverse events, to monitor for quality to be compared to assessments, I think this would be a potential enablement tool for some of those to be you know, closer to reality than they are today, but it opens also some questions about some of our core principle of when the data is in your control you can do certain things with it but what happens when it's a distributed query and many of the contributors are not in your control and how does that change the balance? Those are the kind of things I think that the query health team is looking for advice on. I just put words in Rich's mouth.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Yeah, so David, I think that is a really interesting way to sort of kick off some of the discussion on this.

This is Deven and one of the – some of the sort of policy assumptions that I've been making in my head about this as I've heard it described and I want to road test a little bit is the following. I'm assuming based on the description that the actual – that in fact each data participant, each entity that decides to participate in a particular query is actually number one, in control of the decision to participate, and to allow its data to be used for that purpose and not only that but they actually have to do the work of taking a look at their data and returning the results that are relevant to the particular question being answered. So whether that is numbers, whether that's a set of de-identified data or a set of data that is a limited data set, it is a sort of behind the firewall analysis where the raw data that is potentially identifiable or may in fact be identifiable is – remains in the control of and does not leave the data holder and what gets shared is only the minimum amount that needs to be shared in order to kind of be able to generate results across multiple settings. So, to me, just because you don't control what another person is doing with its data, you know, the central, the piece that seems to me to be very consistent with what we've said in the past is that the data steward is accountable for activities that it does with data and their ability to say yes or no to participation and to be considering the role they will have with respect to data sharing and the fact that the raw data and identifiable data in particular remains behind the firewall to me seems to be completely consistent with what we've said. So, I guess I am sort of asking, what I do think triggered by Dixie's question that we would probably want to say something about that there be rules on both sides of this exchange right, that the recipient even of the aggregated data you know, be subject to some fair information practice based rules about how they are using the data. But nevertheless, I think to me, there

is a remarkable consistency in what you are proposing with what we've said before. But David, the fact you've asked some questions about this makes me wonder whether there's something I'm missing.

David McCallie – Cerner Corp.

Well, this is David again and since you addressed that question I will answer it. I agree with you totally and just wanted to get the conversation going.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Okay. [laughter]

David McCallie – Cerner Corp.

I think you described it extremely well, I think you described exactly what we have in mind. The holder or the steward of the data remains in complete control and in a sense has to bless each agreement to allow a query to be done and is responsible [indiscernible, low volume] but would be responsible for validating that the responses are consistent with the steward's policies, state law, federal law, so forth. But I just wanted to point out that the kinds of things we conjectured about being able to do with EHR data in our previous meetings are going to be more feasible with the tool like this in place. Albeit considerably against de-identified data in almost all cases I think. You know, we were talking about certain use cases where you do not need to be identified. I don't think those would apply here.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Yeah.

David McCallie – Cerner Corp.

But Rich, I shouldn't be doing the speaking.

Richard Elmore. ONC

David, you are doing a great job [laughter]. The one thing I would add and just again returning to the real world of folks that are doing this. In the pop med net example that we were talking about a minute ago, they have the ability to be able to really control each step along the way. Is this question okay to be asked and you know, the data steward's got the right to be able to say no I don't want to process that question or if they say they do then you know, we will have the technology in place and hopefully some modicum of data standards in place for that to be automatically processed and they will be able to look at result and say I'm okay with this result except there aren't enough observations in the cell and I want to delete that cell. Or maybe some other things they may want so they send it along. So they have the ability to take a look at that information and then pass it back to the person asking the question. And then as they get you know, more comfortable with a particular process, maybe it's with a public health agency, they may turn off the switch that says they have to look at each and every one of those. They have the ability to allow it to flow through and that is something they take responsibility for and is sort of a work flow decision. But they set it up very much to keep it under the data steward's control.

Dixie Baker. SAIC

This is Dixie, there is a slight nuance here that I would really like to better understand and I'm not trying to even express an opinion, I'm just trying to understand. Deven used the term, it stays behind, it stays with the steward, the data don't go anywhere, and in the PCAST model that is really true. Because the PCAST model only returns a URI and then they come back and they get a decryption key, and encryption key that allows them to decrypt the data so that they can use it once, they are not able to keep that encryption key, the data just go away once they have used it. So that is the PCAST model. But I'm not quite hearing you say that here. I am hearing more that the steward, the owner of the data, whatever, no, the steward has – decides whether to participate but once they are a participant the data can be used and

copied – I don't want to say copied, but the result out of that organization can be then flow to another organization.

Richard Elmore. ONC

Yes, with a footnote that even the return of that information is also under the data steward's control to decide that that's an acceptable set of information to send to the requesting organization. But the principle has been yes, to actually send that information.

Dixie Baker. SAIC

Yes, thank you.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Do others have questions? This is Deven. I have another one, but I've really been hogging the floor here. Alright, I'm going to go ahead. In terms of small cell description, that the cells with less than five observations shall be blurred by methods that reduce the accuracy of the information provided. So is that kind of – I want to understand a little bit more about what that means. When the objective is to reduce the accuracy is that to sort of reduce the identifiability or the ability to sort of connect it up and potentially re-identify it? Or are you actually talking about methods that reduce accuracy such that we might be worried that the data is less useful from a research standpoint?

Richard Elmore. ONC

That's a great question. The good practical example of that that we saw this summer came from Sean Murphy's work with I2B2 and he described it as a Gaussian blur. Had to come from Harvard right? [laughter]

Deven McGraw – Co-Chair – Center for Democracy and Technology

They had to get the word Gaussian too. [laughter]

Richard Elmore. ONC

But you know it's a great concept to being able to really set you know, how much of a standard deviation do you want to allow in the blurring of the data and you know there is kind of a science behind that and there's also some considerations about how many times can you ask the question in different ways and get around that for those of you that are statistically inclined. You know this notion of being able to not necessarily send all or nothing for a cell, which was one of pop med net's options, I2B2 had this kind of blurring option so, as opposed to making it all or nothing from the policy sandbox, we thought it would be good to leave open that practice of blurring of data where small cells are involved.

David McCallie – Cerner Corp.

But Deven to your point, this is David, it is to mask, it is to prevent someone from trying [indiscernible] an individual from asking such precise questions that **account yes no one zero** would effectively reveal their identity.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Right, ok, but the data is still actually useful?

David McCallie – Cerner Corp.

Oh, you know some people would argue that any de-identified data is inherently un-useful but only identified data is useful. But yes, it is useful to some degree –

Deven McGraw – Co-Chair – Center for Democracy and Technology

Ok.

David McCallie – Cerner Corp.

Within the constraints of these trade-offs that we constantly have to rethink.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Ok.

David McCallie – Cerner Corp.

This is the way the Census Bureau does census data. You can ask questions about zip codes but only if there is a certain number of people in the zip code will you get an accurate answer.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Got it, ok.

Dixie Baker. SAIC

I'd like to say, this is Dixie, I like the idea of having a data use agreement even for de-identified because the true definition of de-identified is just blurring. And I think that is a really nice precaution that you are taking.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Yeah, I mean – the standard is very low risk of re-identification but that doesn't mean zero risk. So if you've got the parties agreeing to you know certain terms of use and not to re-identify, that's – I would agree with Dixie, that is a good added protection.

Leslie Francis

This is Leslie and I want to apologize, my phone kept going off at the wrong time to say I was here. But I heartily agree with what Dixie just said.

Paul Eggerman – Co-Chair

This is Paul. I agree also. The people need to know what's going on with the data, it's that simple.

Richard Elmore. ONC

If Joy were here I think she would say –

Joy Pritts. ONC

I am here.

Richard Elmore. ONC

Oh, ok. Let me speak on your behalf then. [laughter]

Joy Pritts. ONC

You were talking about me. [laughter]

David McCallie – Cerner Corp.

We take back all that stuff we said.

Joy Pritts. ONC

I know where to find you. [laughter]

Richard Elmore. ONC

I was going to say that a lot of this guidance came from Joy and the privacy team and hopefully it is benefiting from the lessons learned from the work that's already been done by this team.

Paul Eggerman – Co-Chair

This is Paul. This is a great presentation Rich and I especially appreciate the fact you coming in and speaking to us very early in your process so that we understand what you are doing and that just lays all the right groundwork and so I think this is great. Now are you accomplishing what you wanted to accomplish here? To let us know and get –

Richard Elmore. ONC

Yes, I think we have. I mean I appreciate the comments we have gotten so far on the elements of the policy sandbox description. I can already see where there is room for some improvement here and some clarification. You know I guess I would just ask to the extent that you have additional thoughts or want to have you know kind of have some additional recommendations back to us we would very much value that.

Deven McGraw – Co-Chair – Center for Democracy and Technology

I think that – that's really good to hear Rich. I think what I am going to suggest that we do is, I was taking some notes during some of the comments and I think we might just want to write – again since we need to sort of raise this to the level of the policy committee, because we make recommendations to them and they then, when all is going well, say oh good job, that sound like a great idea, [laughter] that we would draw up some of the suggestions that have come through in the discussion and we have an opportunity to sort of make sure we are okay with how they are framed on our next call but it sounds like that would not be terribly difficult. There has not been too much controversy generated on this call today. But, we would just draw that up and I would suggest that it's also would be helpful to frame, for the policy committee, how much of what we have already said on the topic of secondary EHR data, in our last set of recommendations, really matches up very well to you know this sort of proposed policy sandbox that you've got for query health. So we have some consistency here. Does that make sense?

Richard Elmore. ONC

You know it makes a lot of sense. The one thing that – this is kind of a general observation and talking to folks that have been doing this work, they are doing such terrific work and the one thing that has been really hard on them has been dealing with some of the vagaries around this that you just addressed and addressed so well with your comments and recommendations. I think whatever we can do collectively to help make it, within what is allowable, you know easier to be able to conduct research that helps us better understand you know health, health outcomes, and health treatments, it's going to be a big win all the way around.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Alright, terrific. Anything from anybody else before we move on to the next agenda item? Alright, well Joy, are you and your team ready to talk about data segmentation initiative?

Joy Pritts. ONC

Yes. Scott, are you on the phone?

Scott ?

Yes, I am here.

Joy Pritts, ONC

Do you want to give a brief presentation of the project?

Scott ?

Yes, absolutely.

Joy Pritts, ONC

Just very short so people know what we are doing.

Scott ?

No problem. So, what we, with the same initiative, the standards in our operability framework we are doing this project. We have sent out the call for participation that all of you should have received. And we are going to create a community that is going to discuss the standards that are necessary in order to share parts of a medical record. And –

Joy Pritts, ONC

I'm going to jump in. And those are the standards [indiscernible]. Those are the standards, a part of the standards that they are directed to be looking are the standards that were recommended by the standards committee on the privacy of data segmentation – on metadata tags for privacy.

Scott ?

Yes. And, in particular, the use cases that are in the scope of this project are – surround the substance abuse data that has heightened protection under 42CFR part 2, and also potentially, also in the scope of the project would be the insurance for the patients request to withhold insurance to withhold treatment data from their insurance carrier, that data to be segmented as well as part of the use case and those are within the scope and the communities will be developing standards in order to be able to share parts of a record.

David McCallie – Cerner Corp.

This is David, I have a question.

Scott ?

Sure.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Go ahead David.

David McCallie – Cerner Corp.

There is a patchwork quilt of very complicated standards that address this problem none of which are addressing it completely and none of which are easy. I wonder how the S&I process will be able to keep this simple enough to be implemented in a realistic way without getting sucked into the trap of endorsing very complex standards that have failed to address the problem in the past. We have seen – we had that process go on before with even less complicated things like provider directories. This is far more potentially complicated. How do we guarantee that we get something that is implementable out of the process? Maybe this is out of scope for Tiger Team but I'm just registering my concern if nothing else.

Joy Pritts, ONC

David, this is Joy and we would love for you to participate in this initiative and raising those important questions. Is our goal to get something implementable out of this initiative? You bet, it sure is. But it is

also important, given the recommendations that came out of the standards committee that if there are issues with the limited – if there are any issues with the standards that were recommended that we need to be able to know those, if there are any gaps we need to be able to know that. We see this really as a process of moving things forward and you are right we don't want to reinvent the wheel here so to the extent that we have people involved in this initiative that can help avoid that, that would be great.

Scott ?

This is Scott, again and I know our initiative coordinator Jonathan Coleman, would want me to say at this point that the focus is standards harmonization. Not reinventing the wheel, creating new standards but harmonizing existing standards is certainly what they are aiming for.

Paul Eggerman – Co-Chair

This is Paul. Is it part of the goal to find out what is implementable? So actually take what is just written on paper and try to implement it to find out if it works.

Scott ?

Yes. The angle is to develop a pilot, well potentially multiple pilots.

Paul Eggerman – Co-Chair

So there could very well be the conclusions that for one reason or another, some approaches to data segmentation just don't work.

Joy Pritts. ONC

We would hope not but you know you never know how these things turn out.

David McCallie – Cerner Corp.

This is David again. I mean with standards harmonization is a good you know is one very valuable goal but we have seen in the past you can harmonize around standards that don't scale to actual implementation. They may work in a [indiscernible] they may work in a controlled setting but they don't work in the real world. And the healthcare standards process [indiscernible] has made that mistake over and over again.

Joy Pritts. ONC

That is exactly why we are using this process, David. The standards, if you remember, the standards that were recommended by the standards committee were recommended with the proviso that they be tested out and we're trying to, part of the purpose of this project is to exactly do that. So, we wanted to make the Tiger Team aware of this project because obviously it does involve privacy implications. We are trying to make sure that this project does not address policy because – and we are trying to do that by focusing on, our focus is on use cases where the policy has clearly been established as to what rights the patients have so we don't get into the policy debate we just get into the implementation of those policies.

Dixie Baker. SAIC

So the standards recommendations Joy that you are referring to are the metadata?

Joy Pritts. ONC

Yes.

Dixie Baker. SAIC

Okay.

Joy Pritts. ONC

And we really do encourage, I mean as you were talking David, we really do encourage the participation of everybody that is interested in this issue because the more participants the more valuable the outcome.

David McCallie – Cerner Corp.

Yeah, I just have a little ONC fatigue.

Joy Pritts. ONC

I know I can totally understand that [laughter].

Deven McGraw – Co-Chair – Center for Democracy and Technology

David, I just can't imagine why? [laughter]

David McCallie – Cerner Corp.

Let me put you in touch with my boss. [laughter]

Joy Pritts. ONC

I know that. It's really difficult for people. We have all these issues though that we have to simultaneously work on and I also understand this key group of people who have been working on these issues and we are worried we are burning you out but we don't know what else to do, we have to move on this stuff.

Deven McGraw – Co-Chair – Center for Democracy and Technology

It sounds a little bit like that maybe, Scott and Joy, that while you are using the term standards harmonization in order to fend off criticism that you're trying to reinvent the wheel, I think it's still helpful to note that you really are looking for and attempting to test you know standards that will actually work in this space and not just looking to harmonize you know a bunch of standards that don't work.

Joy Pritts. ONC

No, there are clearly definite different parts of this project, you know the development of use cases just like the direct project, development of use cases, the examination of standards, and then pilots. I mean that's to see what works and doesn't work.

Dixie Baker. SAIC

This is Dixie. You probably have already pointed them to this Joy, but I think it would be valuable for the team to see the summary. I think that we wrote it up in a summary that Deven put together of testimony we received from organizations who had technology to support segmentation.

Joy Pritts. ONC

Absolutely. That is – there were 2 springboards for this project. One was the – particularly the conversation at the end of the day and the recommendation – and the summary that the Tiger Team made on the consumer – I can't remember what it was called, the consumer choice technology conference. Then the second piece was the recommendations on the metadata tagging standards that came out of the standards committee. And, those both really flowed into this next step to take up those issues and move it to the next plank.

Dixie Baker. SAIC

Ok, that helps. Thanks.

David McCallie – Cerner Corp.

Dixie, I mean I think our testimony in the upcoming standards committee meeting about our, you know investigation into the inland protocols is a relevant backdrop to this debate. So, it will be – it could be déjà vu all over again if we are not – [[Indiscernible]

Deven McGraw – Co-Chair – Center for Democracy and Technology

Oh dear.

Leslie Francis

This is Leslie. NCVHS heard some testimony on separate management particularly as genetic information and technologies to do it when we were doing – trying to **define** sensitive information categories.

Dixie Baker. SAIC

Yeah we have that. This Tiger Team has that letter.

Leslie Francis

Right, but I was going to say some of the testimony might be relevant.

Dixie Baker. SAIC

Yes.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Alright, well, I know, this is Deven, we are going to be following this really closely at CDT, the organization I occasionally work for when I'm not doing Tiger Team work [laughter]. I suspect that others on the call will be doing so as well and then of course will be, I think it will be good to be able to loop the Tiger Team into that work periodically as it progresses and Joy, I mean we can talk about whether we sort of do that using, you know those participants who where there is sort of overlap in terms of people who are participating in Tiger Team membership or whether we do that in some more formal way with staff I think either way it is going to be, it is obviously a topic of keen interest and one I think we would like to keep up with.

Joy Pritts. ONC

So even though this project is done out of Doug's [indiscernible] because he has that framework, Scott is staffing it for us so we have a direct line there. That's one means, and it seems like you will probably have some overlap in membership. I don't know if that's true we're hoping there is some overlap. But we are keenly aware there are some issues in here. As I said we are trying to steer away from policy but we know how it continues to raise its head.

Deven McGraw – Co-Chair – Center for Democracy and Technology

[laughter] Funny how that happens.

Joy Pritts. ONC

It is funny how that happens.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Ok, anything else? Alright, well we will be able to move into public comment in just a second, but I want to sketch out what I think is, are the marching orders for our next meeting and make sure that I am right about where we are heading. Again, we will take a little bit of time in the beginning of our next call to just go over some, you know a write up of the discussion we had about the query health policy sandbox and

we will get that done and out you in advance of that call so you can look at it. But, I don't think, and sometimes you guys prove me wrong on this, but I don't think it's something that will eat up the entire call and so we may be able to turn to something else. The other thing we had sort of put on a back burner to give ONC some time to do additional work on it, was a security policy or security gap analysis that I think, Joy, am I right that might be – could we maybe move that up in the event to our next meeting in the event that we do in fact sort of finish up with what we have to say on Query Health earlier than the two hours we have for the call?

Joy Pritts. ONC

I don't know about that. Deborah was on the call, did you ask that question, not this call but the last call, did you ask her that directly because she is the one that really has her finger on the pulse of when that will be finished.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Ok, I recall that we did but I tell you what, if we didn't here's how we will leave it. We will keep the call scheduled for two hours. If we are not ready, if we finish up early on Query Health and we are not ready to deal with the security gap analysis until after the October policy committee meeting, we will let everybody go home and do their work, their other work that they get paid to do an end the call early.

Joy Pritts. ONC

Hey, no one has ever complained about that.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Nobody has ever complained about that. [laughter] So, but if that is ready to go and we can start talking about it on our next call we will. How about that?

Joy Pritts. ONC

Okay. Would you mind, or somebody, if Miter is on the line, would you mind pinging Deborah and asking her?

Deven McGraw – Co-Chair – Center for Democracy and Technology

I don't know if – I'm happy to ping her.

Linda ?

Linda's here.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Oh great. That would be terrific, thank you.

Joy Pritts. ONC

Ok great.

Unidentified Man

Deven, do you know the time for the next meeting?

Judy Sparrow – Office of the National Coordinator – Executive Director

October 7, right?

Deven McGraw – Co-Chair – Center for Democracy and Technology

That sounds right to me.

Judy Sparrow – Office of the National Coordinator – Executive Director

October 7, and it's 2 – 4PM.

Deven McGraw – Co-Chair – Center for Democracy and Technology

October 7, 2 – 4 ET.

Paul Eggerman – Co-Chair

That is correct.

Deven McGraw – Co-Chair – Center for Democracy and Technology

Ok, anything else Paul?

Paul Eggerman – Co-Chair

I think that is it before we open ourselves to public comment, open, that means open the lines for public comment. I think this is our last meeting where we get to have Judy Sparrow.

Judy Sparrow – Office of the National Coordinator – Executive Director

That is so sad Paul.

Paul Eggerman – Co-Chair

Yes it is. We want to give you like a virtual hug from all of us. You really did a terrific job Judy.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you. I think I've earned a master's degree in privacy and security.

Deven McGraw – Co-Chair – Center for Democracy and Technology

You have. [laughter]

Paul Eggerman – Co-Chair

Even though it is a privacy and security issue, in case somebody is listening on the internet and doesn't understand why I said it is the last meeting, it's not because anything bad is happening to Judy Sparrow, it's because she is retiring in one week after 20 years of service.

Judy Sparrow – Office of the National Coordinator – Executive Director

Right.

Paul Eggerman – Co-Chair

To the American people to our government.

Joy Pritts. ONC

That's right she started when she was 18.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you.

Paul Eggerman – Co-Chair

That's right. We want to thank you for that and we will miss you.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you. I have enjoyed it all believe me. And you are letting us out a little early.

Deven McGraw – Co-Chair – Center for Democracy and Technology

That is a gift to you Judy. [laughter]

Paul Eggerman – Co-Chair

Let's see if we have any public comments. Do you have anything else, Deven?

Deven McGraw – Co-Chair – Center for Democracy and Technology

No, no, thank you for remembering that Paul.

Paul Eggerman – Co-Chair

So, unless anyone has any comments, let's see if we have any public comments.

Judy Sparrow – Office of the National Coordinator – Executive Director

Ok. Operator, can you check and see please?

Operator

If you would like to make a public and are listening via your computer speakers, please dial 1-877-705-2976 and press *1. Or if you're listening via your telephone you may press *1 at this time and you will be entered into the queue.

We do have one person for public comment.

Judy Sparrow – Office of the National Coordinator – Executive Director

Ok, would you please identify yourself? Hello?

Operator

Actually we no longer have that person.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you everybody. Have a wonderful weekend.

Unidentified Woman

Have a great retirement, Judy!