

**Privacy & Security Tiger Team**  
**Draft Transcript**  
**October 7, 2011**

**Operator**

All lines are bridged.

**Erin Poetter – Office of the National Coordinator**

Great. Thank you. Good afternoon everyone. This is the Privacy and Security Tiger Team call. As a reminder to folks on the lines this is a public call so there will be an opportunity at the end for the public to make comments. So I'm quickly going to run through the role call and if I don't call your name but you're on the line you'll have an opportunity at the end to let us know that you're there. Deven McGraw?

**Deven McGraw – Center for Democracy & Technology – Director**

Here.

**Erin Poetter – Office of the National Coordinator**

Paul Ergerman?

**Paul Eggerman – Businessman/Entrepreneur**

Here.

**Erin Poetter – Office of the National Coordinator**

Neil Calman?

**Neil Calman – The Institute for Family Health – President and Cofounder**

Here.

**Erin Poetter – Office of the National Coordinator**

Dixie Baker?

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

I'm here.

**Erin Poetter – Office of the National Coordinator**

Christine Bechtel?

**Alice Slater - National Partnership for Women & Families**

This is Alice Slater on for her.

**Erin Poetter – Office of the National Coordinator**

Oh great. Hi Alice.

**Alice Slater - National Partnership for Women & Families**

Hi.

**Erin Poetter – Office of the National Coordinator**

Rachel Block? Carol Diamond? Judy Faulkner?

**Judy Faulkner – EPIC Systems Corporation**

Here.

**Erin Poetter – Office of the National Coordinator**

Gayle Harrell? John Houston?

**John Houston - University of Pittsburgh Medical Center; National Committee on Vital & Health Statistics**

Here.

**Erin Poetter – Office of the National Coordinator**

David Lansky? David McCallie?

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

Here.

**Erin Poetter – Office of the National Coordinator**

Wes?

**Wes Rishel – Gartner, Incorporated**

Here.

**Eva Powell – National Partnership for Women & Families**

Micky Tripathi? Latanya Sweeney? Leslie Francis?

**Leslie Francis – National Committee on Vital & Health Statistics**

Here.

**Eva Powell – National Partnership for Women & Families**

Verne Rinker?

**Verne Rinker – Office for Civil Rights**

Here.

**Erin Poetter – Office of the National Coordinator**

Rich Elmore?

**Richard Elmore – Office of the National Coordinator – Query Health**

Here.

**Erin Poetter – Office of the National Coordinator**

Scott Weinstein?

**Scott Weinstein**

Here.

**Eva Powell – National Partnership for Women & Families**

And is there anyone I didn't mention who is on the line?

**Micky Tripathi - Massachusetts eHealth Collaborative**

Yeah hi this is Micky Tripathi.

**Erin Poetter – Office of the National Coordinator**

Thank you.

**Dan Callahan – Social Security**

This is Dan Callahan from Social Security.

**Eva Powell – National Partnership for Women & Families**

Great. Hi Dan.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah he should be on the list Erin.

**Erin Poetter – Office of the National Coordinator**

Yeah I'm not sure I have the latest list.

**Deven McGraw – Center for Democracy & Technology – Director**

Yes it seems like it might be a little outdated.

**Erin Poetter – Office of the National Coordinator**

Okay we'll make sure to get that fixed.

**Deven McGraw – Center for Democracy & Technology – Director**

Thanks.

**Erin Poetter – Office of the National Coordinator**

Anybody else?

**Carol Diamond – Markle Foundation**

Carol Diamond is here.

**Erin Poetter – Office of the National Coordinator**

Great. Hi Carol. And there was one other individual?

**John Moehrke – Health Information Technology Standards Panel (HITSP)**

John Moehrke.

**Erin Poetter – Office of the National Coordinator**

Great. Hi. Okay I'll turn it over.

**Deven McGraw – Center for Democracy & Technology – Director**

John are you sitting in for somebody?

**John Moehrke – Health Information Technology Standards Panel (HITSP)**

Ah, no I've been on this committee since the start.

**Deven McGraw – Center for Democracy & Technology – Director**

John, on the Privacy Security and Tiger Team?

**John Moehrke – Health Information Technology Standards Panel (HITSP)**

Oh, yeah, HIT Standards.

**Eva Powell – National Partnership for Women & Families**

No this is the policy one.

**John Moehrke – Health Information Technology Standards Panel (HITSP)**

Oh. Then no I'm not on that one.

**Deven McGraw – Center for Democracy & Technology – Director**

And you're on the call so you're welcome to stay, but we'd appreciate it if you would chime in during the public portion of the call.

**John Moehrke – Health Information Technology Standards Panel (HITSP)**

Fair enough.

**Deven McGraw – Center for Democracy & Technology – Director**

Okay. Thanks John.

### **Eva Powell – National Partnership for Women & Families**

Great. So now I'll turn it over to Deven and Paul.

### **Paul Egerman – Businessman/Entrepreneur**

Great. Thank you very much Erin. This is Paul Egerman I want to welcome everybody on this beautiful Friday afternoon or for some people on the west coast perhaps Friday morning, late morning, but welcome you to our call. The Privacy and Security Tiger Team is a Workgroup of the HIT Policy Committee, so we make recommendations to the HIT Policy Committee which in turn considers them and then makes recommendations usually to the National Coordinator. At the end of our call there will be an opportunity for public comment so I wanted to especially welcome any members of the public who are listening to this call either over the internet or over the 800 number, we very much appreciate your interest in our work, and we are especially interested in any comments that you might have, so if you have any comments or suggestions at the end of the call please be sure to give them.

Today, in this call, we are going to be working on discussing some recommendations on what's called the policy sandbox for ONCs Query Health Project, that is actually the entire agenda and this was a project that was discussed at our last meeting and as a result of the meeting Deven, and the good people at MITRE put together this series of slides that sort of summarizes that discussion and so the purpose of this call is to review that to see if there is a consensus that these are reasonable recommendations, and if there is a consensus then Deven and I will present it at next Wednesday's HIT Policy Committee meeting and ask for Policy Committee approval of these recommendations. So with those comments, Deven do you want to get us started?

### **Deven McGraw – Center for Democracy & Technology – Director**

Okay, sure, thanks a lot Paul I appreciate it. So we had, both at the last Policy Committee meeting, as well as at the last Tiger Team call a description of the Query Health Project that was led by Rich Elmore who is now with ONC and is the Director of that project, and we don't want to repeat that presentation because I think most of you have seen it, but I think some relevant facts to keep in mind for our discussion are the following.

The model of Query Health is what is frequently called bringing the questions to the data rather than collecting copies of the data centrally to answer a particular question. So as a result, the data holder retains control of the raw data and typically performs the analysis, and reports back either aggregate or deidentified results. The initial set of queries are going to be developed by the clinical workgroup of the Query Health Project but the individual data holders will decide whether or not they would like to participate in a particular query. So those are some sort of central facts that we wanted to highlight for you as we talk about a set of policy recommendations that Rich originally brought to us that ONC had really developed on policy for Query Health but they wanted to get our opinion about it and so much of what you'll see in the next slide that Paul's going to start to take us through are sort of discussions about those recommendations, which they call the policy sandbox. Discussion of those recommendations and some additional thoughts that we had about those recommendations that were tee'd up during our last phone call. So with that, Paul?

### **Paul Egerman – Businessman/Entrepreneur**

Sure and before I go onto the next slide does anybody have any questions or comments about what Deven just said? Okay, so these are now the actual proposed policies and our recommendations on them. So the very first one relates to the disclosing entity, the data holder, and basically says whether or not to participate, in effect to participate, whether or not to run a particular query and to release any results will be under the control of the disclosing entity or the data holder, and so basically what we are saying is that the Tiger Team is recommending that the Policy Committee endorse this policy, basically it's consistent with our core value that patients trust their providers and, you know, the whole concept of trust between patient and provider, so the provider should be able to control, decide whether or not to participate in a particular query or query request, but it's also consistent with the most recent recommendations that we made regarding secondary uses of EHR data, which also said that the provider

entities should be accountable for all access use and disclosure of that information. So, do we have any comments on this?

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

This is David.

**Paul Egerman – Businessman/Entrepreneur**

Go ahead.

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

I totally agree with this. The only complicating factor is the potential that the disclosing entity could be itself an indirect entity like an HIE. I don't think that's contemplated as something that would occur in the early stages of Query Health, but in order to achieve a longitudinal view of a patient, even after they've been de-identified, it may be necessary to have other entities that create that longitudinal view across separate care delivery entities, so it could complicate in the long run.

**Paul Egerman – Businessman/Entrepreneur**

Yeah and that's a good comment and if I recall correctly David you're involved with Query Health is that right.

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

Yes. I'm, you know, one of many people who have been contributing.

**Paul Egerman – Businessman/Entrepreneur**

Yeah, which is very helpful to have people on sort of like, what I'd call, like both sides. And my reaction, I don't know if other people have any reaction to that is, that is an interesting complicating issue but fortunately it's not one we have to deal with right now. So unless somebody would look at it differently I would say, you know, we should just focus on the Query Health project which does not involve the HIEs right now.

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

I'm comfortable with that, this is David again, I just wanted to raise the question.

**Paul Egerman – Businessman/Entrepreneur**

Yeah, that's helpful.

**Richard Elmore – Office of the National Coordinator – Query Health**

Hey Paul this is Rich. Just a clarifying point in the last clinical workgroup call we had some feedback from Chris Chute who is an epidemiologist who was saying, you know, look I don't care about inpatient versus outpatient so much as I care about that longitudinal view and actually out of that conversation in the clinical workgroup we did talk about the need for, or potential for, you know, a Query Health application querying against the clinical record of an HIE, so depending on how you want to move this forward we could elect to come back to you if that becomes a prioritized user story.

**Paul Egerman – Businessman/Entrepreneur**

If that's okay with everybody else I would prefer that and one of the reasons I would prefer that is there are so many HIE models it's really, what you just said it's possible in some but it may not be possible with other models.

**Deven McGraw – Center for Democracy & Technology – Director**

That's right.

**Paul Egerman – Businessman/Entrepreneur**

And what I'd like, it seemed to me it would be better if you came back to us and said this is specifically what our ideas and what we want to do, and then we could comment on it.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

This is John Houston. I apologize for having missed the last meeting. Real quick question though about, is this intended to be for research quality assurance, comparative, you know, activities like comparative research activities at a provider level, I mean what, at what level, or is there no sense of what this is going to be used for yet?

**Paul Egerman – Businessman/Entrepreneur**

Rich do you want to respond to that?

**Richard Elmore – Office of the National Coordinator – Query Health**

There are a broad range of potential applications, the ones that we see today are primarily around post market surveillance comparative effectiveness, public health kinds of applications, disease outbreak, disease prevalence, and so on, quality measures, performance measures or others, so there's a fairly long list, and we are trying to develop a generalized architecture and tool to the policy that will apply will certainly, to some extent, depend on the specific domain that's involved.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

You didn't really, I guess you did mention research in one context, is there some thought that this would extend to things like, as far as like research recruitment or other things of that sort?

**Richard Elmore – Office of the National Coordinator – Query Health**

Yeah. We've seen some good practical applications of research for aggregated measures. As to recruitment it would probably be, kind of, maybe a step in a process of getting to recruitment, it wouldn't generally in research go down to the identifiable level, it's kind of an outside of the system, between participating parts.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

Thank you.

**Paul Egerman – Businessman/Entrepreneur**

Great. So, getting back to what we see on the screen here the idea of the provider entity maintaining control, it was helpful to hear David's comment that the HIEs might eventually be sort of like an interesting change or sort of almost like a curve ball to what we have here, but based on the initially proposed policy about Query Health the sense I have is that this group agrees with what's on this slide and so we'll go onto the next slide. I think you're going to take us through this Deven?

**Deven McGraw – Center for Democracy & Technology – Director**

Yes. Paul can I ask you to take the reins on this one because I don't know if you can hear the truck backing up in the background.

**Paul Egerman – Businessman/Entrepreneur**

Okay, yes. Okay.

**Deven McGraw – Center for Democracy & Technology – Director**

Thank you.

**Paul Egerman – Businessman/Entrepreneur**

So what Query Health said was that the data that actually is going to be exchanged in this sort of initial, I don't know if pilot is the right word, project will be either mock or test data number one, or will be aggregate de-identified data sets, so that sort of means like totals like 17, or aggregate limited data sets each with data use agreements or number three a public health permitted use. So that's what they proposed and our recommendation was to simply say that we agree with that, that the data should either be de-identified or aggregated limited data sets with a data use agreement in place even for de-identified data. And then we also said the data use agreement should, at a minimum, restrict the use of the data to facilitating Query Health and prohibit the recipient from de-identifying, re-identifying the data. So, comments about what's on this slide?

**Leslie Francis – National Committee on Vital & Health Statistics**

Has anybody, this is Leslie Francis, has anybody thought through what the extent of the public health exception would look like there with some of the state public health.

**Deven McGraw – Center for Democracy & Technology – Director**

Leslie we have some subsequent slides on that question.

**Leslie Francis – National Committee on Vital & Health Statistics**

Oh, thank you.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

This is John Houston, regarding the data use agreement aspect of it, I'm not sure whether that in and of itself might require some subtle changes to HIPPA, because as I recollect, and I don't have the HIPPA Privacy Rule in front me, but I thought that the data use agreement was something that had to be executed by the covered entity in each case and was within the domain and control of the covered entity itself, and whomever was going to use it for the limited data set, and I don't know whether this would necessitate some change to that, that data use agreement or structure.

**Paul Egerman – Businessman/Entrepreneur**

It's a good question.

**Deven McGraw – Center for Democracy & Technology – Director**

Why would it though? Why would it though, John?

**Paul Egerman – Businessman/Entrepreneur**

...I'm sorry did you say something Deven?

**Deven McGraw – Center for Democracy & Technology – Director**

Well I just, I don't understand why it would if in fact, you know, I mean first of all we don't know what they're trying, I don't think Richard is suggesting, and he should of course respond to this, that there would be sort of a one size fits all data use agreement for any query of Query Health. I suspect it will be a process of you know, setting it up for the particular query at hand and then the entities who may or may not want to participate might negotiate that or if they don't like the terms of it they don't have to participate, I mean nobody's being forced into this. I'm not sure I understand where HIPPA would need to be changed.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

Well my only thought on this and it might be a new one more than anything is that that data use agreements, as I understand them at least under HIPPA, were intended to be something that on an individual basis the covered entity would have to execute with anybody who'd be a recipient of it, so I guess what you'd have to do is have a structure that would support the notion that each individual covered entity would have to sign a data use agreement, there couldn't be a standing data use agreement I guess or that would be, and again I may be wrong, I just was thinking that there might be some nuance that would have to be...

**Paul Egerman – Businessman/Entrepreneur**

I think, John, this is Paul, I think I understand where you're heading with this, but I think you're a little bit ahead of where Query Health is because Query Health is sort of like a project that ONC is running.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

Right.

**Paul Egerman – Businessman/Entrepreneur**

And really the participants only have to sign one data use agreement to participate in the project. What I think you're suggesting is a broader almost governance issue as to how this would work if it were in the.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

Yeah. I maybe.

**Paul Egerman – Businessman/Entrepreneur**

Robust implementation.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

I may be getting into the weeds or getting far beyond the scope of things. I just think, I think about this in a practical sense and once this thing really gets going I would imagine it would be a high volume potentially of queries and I think it's fundamentally a really good thing.

**Paul Egerman – Businessman/Entrepreneur**

Yeah.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

But if there is some change to the structure of a data use agreement and how HIPPA contemplates it, I'm just teeing it up as something somebody might want to investigate and make sure there isn't an issue.

**Paul Egerman – Businessman/Entrepreneur**

Yeah and I think that's a good comment and if I recall the presentation that Rich Elmore had done earlier or one of the presentations indeed they did talk about a number of what I think, I don't know if I'm putting it in the right category, of governance issues in terms of how we would operationalize what's in Query Health. But right now our scope is simply to comment on the proposed policies of the Query Health Project so that they can be comfortable getting it launched but also hopefully launching it in a way that does lay a foundation for future.

**Richard Elmore – Office of the National Coordinator – Query Health**

Hey Paul this is Rich, may I help with a clarification?

**Paul Egerman – Businessman/Entrepreneur**

Sure.

**Richard Elmore – Office of the National Coordinator – Query Health**

So the idea of the data use agreement is that there would be one between the requestor and the recipient and it would almost have to be, we think, done at kind of a domain level, and this is something that really needs to be worked out in more detail because we get into the specifics of the domain and understand how, you know, specific policy is going to apply. Alice Slater, who is also on this call is leading the operations workgroup which will be looking at that question so that we can come back to the Tiger Team as we get better insight into it. My guess is, and Alice I'd ask you to weigh in on this, is that we may assist with templates for data use agreements but ultimately those will be, you know, established between the parties in terms of what they require, it will be voluntary as those things...

**Paul Egerman – Businessman/Entrepreneur**

And some of this...

**Alice Slater - National Partnership for Women & Families**

This is Alice, thanks Rich, I was just about to say a similar thing is we had some discussion on our workgroup call yesterday about the extent to which we just want to set things like required policies or required elements or how much actual drafting of what something might look like would be and it seemed like the group was leaning toward the latter that it would be nice to get at least some templates or some model notices in place so we can start to really, as Rich said, see what this would look like operationally, that said we're in such early stages of this that we haven't started thinking about how we might go about doing that or what the actual elements would be to go into those sorts of agreements.

**Paul Egerman – Businessman/Entrepreneur**

Very helpful comments.

**W**

This is...sorry.

**Paul Egerman – Businessman/Entrepreneur**

I was going to say I think some of this is also covered on the next slide, but were you trying to say something Carol?

**Carol Diamond – Markle Foundation**

Yeah. I just wanted to I guess ask a question and I'm a little confused about the conversation moving to data use agreements because I guess I was under the impression that the whole point of Query Health is that the data isn't harnessed or moved as much as the analysis gets pushed to the data, so there's not an issue of creating a new custodian or an new holder of the data. So I was just confused about why we're having so much discussion about data use?

**Richard Elmore – Office of the National Coordinator – Query Health**

Yeah. I think that's right it's more of an abundance of caution for the ONC sponsored pilot so I think that one of the important roles that the Policy Committee and the Tiger Team could play in this as we get further into it is to consider ways in which without deviating from what's law and policy, and regulation, to figure out if there are ways that we can more effective and efficient, you know, lowering the transaction costs of being able to participate in these queries.

**Paul Egerman – Businessman/Entrepreneur**

That's right and also a comment I wanted to make, I probably should have made, this is Paul, I should have made this comment when I got started, is I really want to compliment ONC and Rich Elmore for getting us involved so early in this process, you know, because lots of times it sort of seems like the policy is the things that are decided like after the fact when the technical people think they figured it all out, so they're getting us involved very early in the process and so that's why perhaps there's some things that may appear to be an abundance of caution, but I think overall the discussion at this point in their entire process is healthy and helpful for everybody. So, on this issue.

**W**

...

**Paul Egerman – Businessman/Entrepreneur**

I'm sorry somebody else was trying to say something?

**Micky Tripathi - Massachusetts eHealth Collaborative**

Yeah this is Micky. I just have a question about, so on number two, it says that it should be a de-identified or limited data set, unless number three it's a public health permitted use. I'm wondering why we're sort of, you know, having both of those, because it seems to me that if it's a permitted use, meaning that there is a data use agreement between two parties why wouldn't we allow that or say that we don't think that for the pilot it should be identified in any way. You see what I'm getting at? So for example, we have a, in my...a data warehouse. If there was a Query Health participant and we get patient identified data now as part of health care operations for a particular customer like a hospital system, does this, this would suggest that an organization like ours couldn't participate in Query Health whereas public health can receive the identified data. It seems to me that from a Tiger Team perspective we either ought to be concerned about, you know, about identified data going at all, and if it does should be for any permitted use not just public health, or on the other side, you know, come down on saying we don't think that any patient identified data should go in this pilot.

**Carol Diamond – Markle Foundation**

So this is Carol again. I really, I'm very confused by this conversation because different kinds of research require different information and identifiers, and I think it's wrong to say research is either all identified or

all unidentified, there is a ton of, I would argue, including surveillance work, that could be done in an unidentified way.

**W**

Right.

### **Carol Diamond – Markle Foundation**

In the public health arena. So the question should not be is it identified or de-identified. In addition, I think the whole point, of again, Query Health is not to give a new name to the old way of doing things, which from what I understand is to actually talk about developing the research methodologies to truly send the question to the data, not collect the data, and that's a very different paradigm, which is to say if I'm interested in doing flu surveillance for example, I might ask every hospital in my jurisdiction to tell me their numerators and denominators for flu counts, and I might aggregate the results of that, and that maybe all that I need to do for flu surveillance. And then for something more complex where more information is required it may look differently. So I don't think it's constructive to try to pigeonhole any of these, what I would consider to be population health questions into either a certain kind of data requirement or a certain kind of, you know, analytic methodology.

### **Deven McGraw – Center for Democracy & Technology – Director**

So, this is Deven, sorry...Rich do you want...at first. I have some thoughts on it but I wanted to get...

### **Paul Egerman – Businessman/Entrepreneur**

Yeah. I want to hear what Rich has to say. Agree.

### **Richard Elmore – Office of the National Coordinator – Query Health**

So the concept here was to first of all make sure that we were being very careful with information which, the idea was to be very careful in terms of what it was that we were going to be doing during the ONC sponsored pilot, so that was the idea even in the aggregate that, and you know, where we'd be aggregating, you know, de-identified columns or limited data set columns that we would still have data use agreements in place. The public health exception was that we'd see a number of applications for public health where we may send a numerator and a denominator in because it's, you know, appropriate to the public health agency to then have a follow up call with a specific list of patients who are at risk of something, to provide the facility to be able to provide that more identifiable level as would normally be done today.

And so there are other uses like IRB and so on. Each of those have particular policy and security considerations that need to be taken into account and so our thought was, in the interest of trying to keep it simple and keep a bright line here, and an abundance of caution, that this is what we were trying to do for the sandbox. If in the process of getting to the prioritized user's story we start deviating from what would be supported by these standards here for data exchange, then we would ask if we could come back to you. And there's also a question of course what happens beyond that and more, you know, general use in the wild, but this was specifically targeted towards the ONC sponsored pilots.

### **Paul Egerman – Businessman/Entrepreneur**

Okay so the ONC sponsored pilot is either mock data or it's, number two it's aggregate of de-identified data or limited data sets, or it's number three, which is public health permitted use under federal state law, which is intended to be, you tried to make that like as narrow as you could.

### **Deven McGraw – Center for Democracy & Technology – Director**

Well that's right, but keep in mind we haven't gotten, this is Deven, and my apologies for having to be absent from the call for a couple of minutes. We did talk a little bit about this public health issue on our last call and therefore there is, there are essentially 3 recommendations associated with this data exchange policy and you all are kind of skipping ahead to the third one, which is fine, which basically said that there shouldn't be a blanket public health exception in this policy, that instead it ought to really be not all public health activities, and Carol put her finger on one, which is flu surveillance necessarily requires the reporting of identifiable data, and that the policy in Query Health really ought to be disclosures should

be in the least identifiable form necessary to address the particular query. So limited data sets and de-identified data should be disclosed for public health purposes in circumstances where that is a sufficient amount of data to meet the question unless the greater identifiability of data is specifically needed and of course, you know, permitted under applicable law.

**Leslie Francis – National Committee on Vital & Health Statistics**

Deven, this is Leslie again, but that, I'd really like clarity about what that might actually mean in certain circumstances because, I mean that's a large type of secondary use potentially with needed data that involves identifiable and there's some real, yeah, that's to me the one big privacy open question with this.

**Deven McGraw – Center for Democracy & Technology – Director**

The public health one?

**Leslie Francis – National Committee on Vital & Health Statistics**

The public health one where law permits and where there is need for identifiable data, possibly not because you want to follow up with patients who need treatment or because you're looking for an index patient in contagion or whatever, but possibly because you're trying to link records and you need identifiable information in order to do that.

**Neil Calman – The Institute for Family Health – President and Cofounder**

Well this is Neil, or you're trying to use geographic information on, you know, where they live and whatever to track down some epidemic.

**Judy Faulkner – EPIC Systems Corporation**

This is Judy. What about things such as sex and age is that considered personal information that can be included?

**Deven McGraw – Center for Democracy & Technology – Director**

No sex can, age in a limited data set can be included, I don't have it in front me, I think you might have to just have month and year versus actually the specific date.

**Judy Faulkner – EPIC Systems Corporation**

Okay, because they'll need that for supporting an awful lot of research.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah, no absolutely, I mean this why a limited data set was created in HIPPA Judy was to accommodate a lot of secondary data use needs where dates and certain information that might otherwise be potentially identifiable is needed to accomplish the purpose.

**W**

But the age is not, age is not one of things you have to strip out in the HIPPA de-identified data set unless age would identify the person.

**Deven McGraw – Center for Democracy & Technology – Director**

As a birth date, right.

**Neil Calman – The Institute for Family Health – President and Cofounder**

So, what about geo coding of addresses?

**Deven McGraw – Center for Democracy & Technology – Director**

The standard is tied to, you know, we have Verne on the phone we should ask him to answer this question. Do you remember off the top of your head Verne what the specification is on zip codes.

**Verne Rinker – Office for Civil Rights**

For the de-identified or for limited data sets?

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah either, both actually.

**Verne Rinker – Office for Civil Rights**

The limited data set is a postal address other than, what must be removed is the postal address other than town, city, state or zip. And the other I believe is de-identified I think is restricted to zip codes with the exception of needing to have at least the 10 or 25,000 in a given unit.

**Deven McGraw – Center for Democracy & Technology – Director**

In the particular zip code area.

**Verne Rinker – Office for Civil Rights**

Right.

**Deven McGraw – Center for Democracy & Technology – Director**

Right. Okay. So there are some restrictions on that but it's not completely out of the ballpark.

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

So this is David with a question. Just, I mean obviously Query Health or any other equivalent service shouldn't do anything that is against the law and it's kind of redundant to say that so are we trying to carve out a subset out of the complete space of legal uses of a service like this, a subset for the pilots and is that what we're debating or, I mean we're not debating changing the rules of HIPPA.

**Deven McGraw – Center for Democracy & Technology – Director**

I think what we're debating, David, is creating a set of policies that take the law as the baseline, but that are the policies that will build trust and allow organizations to feel like this is an enterprise that they can participate in, because there are certain up front policies that everyone whose participating has agreed to that take the law as a given, but answer some questions maybe that law doesn't answer. So for example, in this particular point that we're discussing today, you know, obviously you are permitted to use a limited data set and/or de-identified data to meet probably any Query Health question that comes up, but often identifiable data is permitted to be used, but often, in cases where it's not needed. So permitting identifiable data to be used doesn't necessarily mean that that's the most privacy protective way of getting the sufficient amount of data to address the question.

So, it is, I think a layer of policies that are more specific and in many respects arguably tighter from a privacy standpoint than what would otherwise be permissible under current law, but it certainly doesn't go below the legal threshold. So, yes, we are saying if you, you should participate in Query Health because here's a set of policies that we have built in order to create a trustworthy ecosystem where you are contributing some of your data to answer some really important questions and.

**Paul Egerman – Businessman/Entrepreneur**

Let's get back; this is a very helpful discussion, but I'd like to get back to the slide number 5 that's on the screen and I don't understand where we are with this, I think people are...

**Deven McGraw – Center for Democracy & Technology – Director**

I think we've been a little all over the place, yes.

**Paul Egerman – Businessman/Entrepreneur**

Item number 1 and 2 under data exchange, there proposed policy says public health permitted use under state or federal law, which is also, I mean there's certainly nothing, to pick up what David McCallie said, is that if it's already permitted under law, they're saying that that's what they're proposing to do, things that might be already permitted under law. And all we said in response to that was basically.

**Deven McGraw – Center for Democracy & Technology – Director**

No it's not all we said in response to it Paul, we have 3 slides in response to that.

**Paul Egerman – Businessman/Entrepreneur**

Yeah. I understand so let's go through them.

**Deven McGraw – Center for Democracy & Technology – Director**

Okay. Okay.

**Paul Egerman – Businessman/Entrepreneur**

So the first slide says this, it says the Tiger Team agrees that the data being exchanged should be de-identified or aggregated limited data sets, so we agree with that, with the data use in place even for de-identified data, so first we're agreeing with that part, then we're saying the data use agreement should, at a minimum restrict the use of the data to facilitate Query Health and prohibit the recipient from re-identifying the data, I didn't hear anybody saying anything that was like disagreeing with that sentence.

Then the next slide relates to some of the comments that were already made, right? We say during the initial pilot phase of Query Health ONC should implement clear policies restricting the data recipient for using the shared, information shared for Query Health for purposes other than to address the particular research question, in other words you have restate, you can only use the information for the question involved.

And then we also said that should be part of the data use agreement but as Query Health scales beyond the pilot phase ONC should consider the need for a governance structure that can enforce compliance, right. And then there's a third slide, right?

**Deven McGraw – Center for Democracy & Technology – Director**

Yep.

**Paul Egerman – Businessman/Entrepreneur**

Which says, I don't know if you want to take us through this?

**Deven McGraw – Center for Democracy & Technology – Director**

No, no go ahead, go ahead Paul you're doing well.

**Paul Egerman – Businessman/Entrepreneur**

Okay, basically addresses this issue, right, it say although HIPPA allows identifiable data to be disclosed for public health purposes not all public health activities require identifiable data, which is exactly I think one of the points that Carol was trying to make.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah.

**Paul Egerman – Businessman/Entrepreneur**

And so Query Health policy should be that disclosures are in the least identifiable form necessary to address the particular use in query, in other words, you shouldn't ask for identifiable data unless you, like really need it. And so basically it just says that in the next sentence, in other words limited data sets and de-identified data should also be disclosed for public health purposes unless greater identifiable data is specifically needed. So, my question is, is do these recommendations, are we comfortable with these recommendations, I mean, I almost feel like we're re-discussing this issue, but I thought these recommendations came from the discussion we had with the same issue last time. Do these recommendations cover people's concerns?

**Leslie Francis – National Committee on Vital & Health Statistics**

Those recommendations, as far as they go are great, but I think there should also be monitoring or some effort to at least try to be careful to see what Query Health on the public health side is actually doing with identifiable data. So, I mean I was just proposing an additional thought on that point.

**Paul Egerman – Businessman/Entrepreneur**

And so say, again, what the additional thought is, in other words, you're saying this is fine but you would like to do, take it one step further, what is the one step further you would, could you please.

**Leslie Francis – National Committee on Vital & Health Statistics**

Well the one step further I was suggesting was not to prohibit what's legally okay at the public health level with respect to identifiable data when needed, rather, I think there should be very careful monitoring of when Query Health is actually involving the use of identifiable data through public health and the privacy implications thereof. So we're extremely careful to get a good picture of what's going on there.

**Paul Egerman – Businessman/Entrepreneur**

And you say monitoring, who is monitoring it?

**Leslie Francis – National Committee on Vital & Health Statistics**

Well whoever is watching Query Health.

**Paul Egerman – Businessman/Entrepreneur**

Sure is it...ONC should monitor.

**Leslie Francis – National Committee on Vital & Health Statistics**

Sure.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah, well if certainly in the pilot phase ONC is going to be monitoring this, but if I understand the sort of long-term aims and Rich you can step in and correct me if I'm wrong, that this is sort of starting an infrastructure that is not expected to necessarily be government managed, which is one of the reasons why one of the recommendations says that, you know, when you scale this up beyond the pilot phase there's going to need to be a governance structure.

**Leslie Francis – National Committee on Vital & Health Statistics**

Right, and, but I would want specific information or, you know, attention given during the pilot phase to what's going on, on the public health side, so that we would know what kind of governance structure would make sense.

**Richard Elmore – Office of the National Coordinator – Query Health**

I think that we can probably find some ways to accommodate that. I would be very concerned if there was any thought that anyone who is participating in the project from ONC actually knew what data was going back and forth, you know, the idea here I think is that we want to be able to provide an infrastructure that can be used in a variety of networks where people come together because it's permitted by law or because they agree and consent to participate and we may need to figure out ways in which they can do that monitoring and that we figure out some, you know, best practice for what that monitoring should be like in the case of identifiable information.

**Leslie Francis – National Committee on Vital & Health Statistics**

Right, you know, I'm not taking a position about that, I'm just calling this out as an efficacy that I'd like to see sensibly addressed.

**Paul Egerman – Businessman/Entrepreneur**

So, I'm trying to understand, would you like to see some statement that says something like ONC should monitor the ways.

**Leslie Francis – National Committee on Vital & Health Statistics**

Yeah.

**Paul Egerman – Businessman/Entrepreneur**

In which identifiable data is used with an intention of learning information that might be helpful in subsequently developing governance policies.

**Leslie Francis – National Committee on Vital & Health Statistics**

That sounds perfect to me.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

This is Dixie. I have one comment, two comments actually, about this one and I agree with Leslie, and first I'd like to say that this slide that shows like 7, HIPPA not only allows, it does allow identifiable data to be disclosed for public health purposes but it does say that it should be the minimum necessary, and so I think that that should be incorporated in there, but I think Leslie's right in that, yeah HIPPA says that but OCR I don't think monitors or has a role in overseeing public health use of data, so I.

**Deven McGraw – Center for Democracy & Technology – Director**

They don't. We would be asking ONC to do it as part of their Query Health pilot.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

Yeah, yeah, but I think it's an issue beyond just Query Health even and I agree with her. I agree with her comment. The other comment I had is this last sentence here I think needs to be a little wordsmithed a bit because it sounds like we're saying that these data should be disclosed and what we're really saying is that when data are disclosed to public health that the data should be limited to a limited data set or de-identified data.

**Deven McGraw – Center for Democracy & Technology – Director**

Unless greater identified data, okay that makes sense Dixie, thank you.

**Deven McGraw – Center for Democracy & Technology – Director**

Okay, thank you.

**Joy Pritts – Office of the National Coordinator for Health Information Technology – Chief Privacy Officer**

Okay Deven this is Joy and I apologize for joining late, but I'm not sure exactly what role you had in mind for ONC to be monitoring the public health piece.

**Deven McGraw – Center for Democracy & Technology – Director**

Well, if I understood Leslie correctly, as ONC is rolling this out as a pilot, I think we want to understand a little bit more when public health queries that it is determined require the disclosure of identifiable data, we want to understand a little bit more about when those occur and the circumstances.

**Joy Pritts – Office of the National Coordinator for Health Information Technology – Chief Privacy Officer**

So are you asking, are you.

**Deven McGraw – Center for Democracy & Technology – Director**

Within the context just of Query Health when ONC is still at, you know, at the phase of launching it as a pilot at a minimum.

**Paul Egerman – Businessman/Entrepreneur**

Yeah.

**Joy Pritts – Office of the National Coordinator for Health Information Technology – Chief Privacy Officer**

Are you asking for, I mean it's a very broad request on trying to identify exactly what it is, so are you looking for information on what kinds of queries are coming in, or are you looking for monitoring what the end user is doing with the information.

**Leslie Francis – National Committee on Vital & Health Statistics**

No, no, no what kinds of queries so that there's a sense of the scope of what's actually being done with respect to Query Health, not, I mean monitor is not meant to be, at least in my sense, I was not suggesting evaluation or anything like that, but what I was suggesting was gathering some general information about the types of queries that are thought to require identifiable information because that, and how frequent they are, because that would give some sense of what sort of governance is likely to be most helpful. It seems to me that's the right kind of thing to be thinking about with a pilot that's all.

**Joy Pritts – Office of the National Coordinator for Health Information Technology – Chief Privacy Officer**

Okay, so then my next question goes to Rich. Does that seem like something that's doable?

**Richard Elmore – Office of the National Coordinator – Query Health**

I think that we'll have an enough visibility about what kinds of questions are being asked in the ONC sponsored pilots. We will, I believe, I don't believe it would be right for us to be in the actual loop of, you know, I think that we don't belong in the actual loop of, we would have to do it through interviews or some other mechanisms. I don't think we should be looking at the data or looking at the queries directly. I think that's up to the organizations that will be using the technology and the standards. The other thing that I would just mention is that in the ONC sponsored pilots it will cover, you know, a small percentage of the potential uses of this. I don't know that it would be representative from the point of view of policy making purposes.

**Paul Egerman – Businessman/Entrepreneur**

Yeah, but, this is Paul, there is that risk. I mean, if I understood Leslie's suggestion correctly, maybe I didn't, is the purpose of, one of the purposes of monitoring is simply to learn things to help us decide, to help ONC decide how governance issues should be addressed in the future.

**Leslie Francis – National Committee on Vital & Health Statistics**

Yep.

**Paul Egerman – Businessman/Entrepreneur**

And, but if I pick up on what you said Rich, there's also the risk of gee what's done in Query Health may not necessarily be representative of how it might be used if it were used operationally. So that your suggestion that we may not learn as much as we could which is always a problem with any kind of a pilot project.

**Joy Pritts – Office of the National Coordinator for Health Information Technology – Chief Privacy Officer**

Well, right, that's particularly true given the constraints that we're placing on the participants at the outset I think.

**Paul Egerman – Businessman/Entrepreneur**

Yeah.

**Joy Pritts – Office of the National Coordinator for Health Information Technology – Chief Privacy Officer**

I think it's just something that we need to recognize and I don't know that I would necessarily call it monitoring, I think we need to find another term, because monitoring does make it sound like we're sitting in the middle watching the queries go by, and we will not be doing that.

**Paul Egerman – Businessman/Entrepreneur**

So maybe the way to address this issue is, I want to go back to the previous slide, we have this sentence at the end that says ONC should consider the need for a governance structure that can enforce compliance with data use agreements and other policies and maybe we just need to broaden that to simply say, you know, based on the learning experience of Query Health and, you know, the types of queries that seem to be most useful that somehow that needs to somehow impact the ultimate governance structure that ONC needs to consider. Does that, if we do it that way does that respond to your concerns Leslie and is that.

**Leslie Francis – National Committee on Vital & Health Statistics**

Yeah, I mean, that way you'd be actually looking at across the board.

**Paul Egerman – Businessman/Entrepreneur**

Yeah, it's not just identifiable data, in other words, but fundamentally that's what a pilot project is, right, I mean we're going to learn things and I think, if I remember it right, I may not remember right, but I believe the presentation on Query Health clearly called out that governance was like a big future challenge. So this is something that clearly the pilot needs to be an opportunity to learn information how to address that.

**Leslie Francis – National Committee on Vital & Health Statistics**

Absolutely. My only sort of last comment on this would be that because the public health one is the one where identifiable data is actually at issue, that is the risk here, despite the constraints that of course exist legally on public health departments.

**Paul Egerman – Businessman/Entrepreneur**

Okay, well that's a good observation, but what I'm suggesting is we have the three slides on the issue of data exchange that we broaden a little bit the governance sentence to indicate that, you know, the pilot will be used as a methodology to learn information that ONC will consider when it considers governance and other policies, and so my question is, is with that expansion, are these three slides acceptable?

**Deven McGraw – Center for Democracy & Technology – Director**

Yes.

**M**

Yes.

**Deven McGraw – Center for Democracy & Technology – Director**

I vote yes. This is Deven.

**Leslie Francis – National Committee on Vital & Health Statistics**

Yeah. I'm okay with that.

**Paul Egerman – Businessman/Entrepreneur**

Okay.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

This is John; I think this is a win, really a win/win.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah.

**Paul Egerman – Businessman/Entrepreneur**

Yes I agree and I, you know, want to reiterate what I said before, I think, you know, Rich Elmore and ONC, you know, they should be commended, which is positive thing, commended for bringing this whole thing to this discussion point to us so early in the process.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah.

**Paul Egerman – Businessman/Entrepreneur**

Because, you know, I mean there's some challenges when you're doing something so early, because you have no idea how it's going to end up, right. You know, everybody remember what Einstein said about research, which was if we knew what we were doing we couldn't call it research, and so we don't really know how this is going to turn out.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

I'll be, this is John, I think, you know, if you think about this, this really diffuses a lot of the concern that the public has over these types of activities.

**Paul Egerman – Businessman/Entrepreneur**

Oh absolutely.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah.

**John Houston – University of Pittsburgh Medical Center – NCVHS**

I mean it's really a very, a very, it almost seems simple after-the-fact that this makes a lot of sense.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah.

**Paul Egerman – Businessman/Entrepreneur**

It has a lot of benefits.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah.

**Paul Egerman – Businessman/Entrepreneur**

A lot of potential benefits. There's also a lot of challenges associated with it. This is not easy technically and there's clearly going to be governance things, but I agree. So let's go onto the last area, which is.

**Verne Rinker – Office for Civil Rights**

Paul?

**Paul Egerman – Businessman/Entrepreneur**

Pardon me?

**Verne Rinker – Office for Civil Rights**

This is Verne; can I ask two questions on this?

**Paul Egerman – Businessman/Entrepreneur**

Sure.

**Verne Rinker – Office for Civil Rights**

The first is what's the rationale behind the data use agreement for de-identified data? I mean, from my.

**Deven McGraw – Center for Democracy & Technology – Director**

To prevent, to prohibit re-identification, there's no functionality in the law for that.

**Verne Rinker – Office for Civil Rights**

Okay, so that's, is that something to note, I guess a data use agreement is fairly broad and that's one element of it, is there a need to narrow that, is this a burden issue? Will it be a burden issue?

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah it could, who is this again?

**Verne Rinker – Office for Civil Rights**

This is Verne.

**Deven McGraw – Center for Democracy & Technology – Director**

Okay, thanks Verne. Yeah, I mean I think it's both, we have a couple of expressed policy desires here, one is to say, if you're getting it as a, you know, from Query Health you should use it for, you know, for Query Health and not just sort of, you know, absorb it and then use it for other things. I'm not sure how much subsequent value de-identified data might have, but you know, many people make a lot of money off of it. So, if you're getting it de-identified you sign agreement that says that's what you're going to use it for and you also agree not to re-identify it. So Rich, is that sort of what you were thinking of in terms of the data use agreement terms?

**Richard Elmore – Office of the National Coordinator – Query Health**

I would pass on that at this point. I don't think we're far enough into it unless Alice you have any thoughts.

**Deven McGraw – Center for Democracy & Technology – Director**

Okay. Well that's certainly, I mean that's certainly what we, you know, what we as a Tiger Team have thought were the two things that we would want to see in an agreement and maybe it's wrong to call it a data use agreement since those typically have other items in it. If you want to, if you suggest that we use some different terminology I think we'd be amenable to that.

**Alice Slater - National Partnership for Women & Families**

This is Alice, I think this is just a really helpful discussion because as Rich said we're so early in this and we haven't started talking about anything related to that specific privacy and security requirements yet, but it's really helpful to see this thinking and we can bring these as elements to the workgroup and hopefully make some more progress, and come back at you with some more specifics.

**Richard Elmore – Office of the National Coordinator – Query Health**

I guess, just one immediate reaction is that re-identification absolutely that one goes without saying. The one that I'm not sure about is, you know, what kind of relationships might exist between parties and how they might use the data, whether or not we said that there were restrictions on those activities required in the data use agreement, it's not obvious to me what's an appropriate role for us in that.

**Deven McGraw – Center for Democracy & Technology – Director**

And so when you say us are you talking the Policy Committee or are you talking OCR or HSS?

**Richard Elmore – Office of the National Coordinator – Query Health**

Assuming that this is related to the question of what kind of governance would be established by ONC?

**Deven McGraw – Center for Democracy & Technology – Director**

Right.

**Richard Elmore – Office of the National Coordinator – Query Health**

Yeah the question would be one of, you know, how far should ONC be going in terms of specifying what are acceptable uses as part of a data use agreement.

**Deven McGraw – Center for Democracy & Technology – Director**

Right.

**Richard Elmore – Office of the National Coordinator – Query Health**

I'm clear about the re-identification part; it's the other part of your comments that I'm just not sure about now.

**Deven McGraw – Center for Democracy & Technology – Director**

Well, so here was my thought about restricting sort of what you're able to do with the data once you get it and it came out of some Tiger Team discussions that we had on our the last call where you don't want Query Health to be the door through which data comes into an entity that they otherwise might not get that they then utilize for other purposes that might not be consistent with the purposes of Query Health or it might be totally different from the purposes of Query Health and, you know, when you're sort of opening patient data up to a pipeline of secondary uses that we think are valuable, I think it's reasonable, at least at the pilot stage, to say you're getting this data for purposes of answering a query that you brought to Query Health and you should use it to answer your query. So that it's not again, it doesn't become the open door through which, you know, that data then is sort of part of the organizations database and then they can use it for other things.

You know, this is not, it's not inconsistent with the model that the many sentinel pilot projects follows where, you know, the recipients of the data uses, commits to using it to answer the question but not, you know, for other purposes, so. I mean we had a lot of discussion on our last Tiger Team call about, okay, you know, we've got some policies regarding the data holders and their ability to control data and decide whether or not they're participating, but at the end of the day they're giving up some of their data and trusting that someone else will hold it and use it responsibly. What do we have in terms of commitments on the other end of that question, and so that's why, you know, there's recommendations in here that say, you know, a data use agreement should restrict the use of that data to, you know, the purpose for which it was gathered, and that's also consistent with fair information practices, and people should commit not to re-identifying it when it's shared in limited data set or de-identified form, which we hope will be the case most of the time.

**Richard Elmore – Office of the National Coordinator – Query Health**

So, would it make sense to say then that the recipient of the data would not use the data for purposes outside of those that are agreed to in the data use agreement?

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

Well, this is David, it seems to me that what we are offering is advice about what should be in a good data use agreement.

**Paul Egerman – Businessman/Entrepreneur**

That's right.

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

And the enforcement of that is contractual law and other laws.

**Paul Egerman – Businessman/Entrepreneur**

That's right.

**Deven McGraw – Center for Democracy & Technology – Director**

Right.

**Deven McGraw – Center for Democracy & Technology – Director**

I think, when you think of it that way, it makes a lot more sense to me.

**Paul Egerman – Businessman/Entrepreneur**

Yeah, I mean if you have a data use agreement you're assuming that both sides agree with whatever is in the agreement, both sides do whatever is in the agreement.

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

And we're making suggested recommendations about some minimums that ought to be in all those data use agreements.

**Deven McGraw – Center for Democracy & Technology – Director**

Yep.

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

That makes sense. And it's less about governance and more about what's an appropriate data use agreement.

**Deven McGraw – Center for Democracy & Technology – Director**

Right.

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

In other words it's not active monitor; it's really just a statement of what makes sense to be captured in an appropriate data use agreement for Query Health, some of which may go strictly beyond the letter of the law.

**Deven McGraw – Center for Democracy & Technology – Director**

Right. That's right.

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

Increase trust and likewise.

**Verne Rinker – Office for Civil Rights**

This is Verne, so that's helpful. The second question I had was on slide seven, talking through the least identifiable and minimum necessary, what you're trying to evoke there, the actual language kind of, it starts with public health, it then suggests the least identifiable without really drawing that to public health only, which HIPPA would operate in the background anyway, but then it wraps up again with public health. So I wasn't sure if you were intending an overall minimum necessary type suggestion here. When I think of identifiable or least identifiable, I think of a choice between limited data set and de-identified, and whichever one of those, as opposed to something that might be iteratively, what we really try to get to when we say minimum necessary, which is among two different sets of, if you will, de-identified data you might have less elements in the data you would release because some other elements, even though it would be de-identifiable, would not be useful for the disclosure purpose.

**Deven McGraw – Center for Democracy & Technology – Director**

Right. Well the, Verne the recommendation is framed the way it is because we are reacting to the set of initial policies that ONC initially drew up and brought to us for our reaction and thoughts and so, you know, it sort of cues off of the, I'm just going to move the slides back to remind us of what was there, cues off of that, the initial policy, which was worded to say, when we exchange data it's either going to be mock or test data or it's going to be what I sometimes group into the lesser identified or anatomized category, which is de-identified data or a limited data set, or it's public health which may require identifiable information. So they had identifiable three categories and that's the reason why slide seven is really framed as, well, you know, you've set up this category of public health and singled it out for possibly needing identifiable data, but we essentially think you don't really need to do that, and should instead have a policy that says, you know, disclose in the least identifiable form necessary, i.e., minimum necessary to address the query, and, you know, use identifiable information only when you need to, and of course when you're permitted by public law, which is the case often in public health.

So, that's the reason for the wording there. I think if we were probably starting from scratch, we would have sort of started from a slightly different framework, but aside from the wording that Dixie suggested in the recommendation on slide seven, which I think it was a very good point, is there another way that you would suggest rewording this to make this more clear?

**Verne Rinker – Office for Civil Rights**

Other than potentially looking at the, whether you're intending the minimum necessary versus least, which was a suggestion already, I think I'd just go back to if I contrast this to the Non-Query Health operation, it seems that either all of these are playing in the background or you're adding stuff to a disclosure that already happens and you're adding, it's almost like making Query Health an additional burden when

somebody can do that otherwise. For example, in the public health context, I mean why go through Query Health when in fact you can just go straight to the entity. I think I'm just struggling with...

**Deven McGraw – Center for Democracy & Technology – Director**

Well, I think maybe we may be identifying a place in the law where we think maybe there ought to be room for some clarity about when the minimum necessary standard applies to a public health disclosure that, you know, and one part of the rule says it can be identifiable and another part of the rule says it's, you know, it's minimum necessary, and we don't have a lot of guidance on the extent to which minimum necessary applies to the level of identifiability of data. Having said that, I think we're also perfectly comfortable as a Tiger Team saying, you know, we are doing something above the baseline of HIPAA or that clarifies some, you know, what we might see as unanswered questions from HIPAA for this research network that we want people to have a high degree of trust in.

**Verne Rinker – Office for Civil Rights**

Okay.

**Deven McGraw – Center for Democracy & Technology – Director**

We're not just trying to interpret HIPAA.

**Verne Rinker – Office for Civil Rights**

Sure, absolutely. Sure, that's helpful. Thank you.

**Deven McGraw – Center for Democracy & Technology – Director**

No thanks Verne, I appreciate the feedback.

**Paul Egerman – Businessman/Entrepreneur**

So are we ready to go onto slide eight then?

**Deven McGraw – Center for Democracy & Technology – Director**

I think so.

**Paul Egerman – Businessman/Entrepreneur**

Okay. So the last slide, which I think might be an easier issue, because I think the issues that we just discussed in the data use are the hardest part, relates to just a proposed policy involving, it says small cells, but it's really not the cell I guess that's small it's the number of observations contained in the cell, but basically it says when there are cells with less than 5 observations in the cell there is apparently a message that blur the accuracy of the information that is provided and it cites a specific, a data release guideline that already exist, and as I understand this issue it's in place so that you don't ask like it's an iterative series of questions that are so specific that you can find out information about an individual through a process like this. And so what we simply said there is we agree with that policy and recommend the Policy Committee endorse it. So do we have any comments about this? I assume silence means acceptance and so the next question is, do we have any other comments about Query Health? Or is this like a full and complete series now with a bit of wordsmithing and expansion around the concept of governance that we're able to present to the HIT policy committee on Wednesday?

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

You know, this is Dixie, on that last one I think the reason you heard silence is I don't fully, I for one, don't fully understand what they mean by, well I know what they mean by blurring, but if you, it says you blur, you'll reduce the accuracy of the information provided but you really don't say that you're going to reduce the likelihood that these individuals will be identified.

**Paul Egerman – Businessman/Entrepreneur**

I don't know if you want to respond to that Rich. My understanding was this is a technique that is used to, it's sort of like de-identifying data, it's a technique that is used to try to minimize that possibility.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

Yeah, that's my understanding too; I just don't think the words that are on the slide say that.

**Richard Elmore – Office of the National Coordinator – Query Health**

Yes, I think Dixie's correct that there is a risk around re-identification if the question is asked multiple times and all we've done is to blur the data, and the person who has done a lot of really good work on this is Shawn Murphy at Harvard in connection with i2b2, and the way he does it is to establish a distribution and he uses a...distribution, you can set how many, you know, how many standard deviations you want the data to be able to stray from normal and that's the way in which he creates the blur, but his own analysis indicates that, ask enough times and you can probably reconstruct what the actual data should have been in the cell. So there is a risk associated with that.

**Paul Egerman – Businessman/Entrepreneur**

Okay, but getting back to what you're saying Dixie, is there some recommendation you want in terms of how we could word this differently? I mean, I don't.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

I think what we're trying to say there, and I may be wrong, but I think what we're trying to say is that blurred by methods that reduce the likelihood that the identities will be disclosed or whatever like that, rather than reduce the accuracy of the information. You know, I.

**Paul Egerman – Businessman/Entrepreneur**

Oh, I see. I see what you're saying.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

Okay.

**Paul Egerman – Businessman/Entrepreneur**

So, in other words reduce the likelihood that identifiable information will be provided.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

Yes. Yes. I mean you could reduce the accuracy of the date of the information, as we say here, and make it, you know, no less likely that the person would be identified.

**Paul Egerman – Businessman/Entrepreneur**

But I thought one of the things they did when they did this is they actually did change the accuracy though. So if the number was two they might change it to three. Did I misunderstand that Rich?

**Richard Elmore – Office of the National Coordinator – Query Health**

That's correct.

**Paul Egerman – Businessman/Entrepreneur**

So it does change the accuracy Dixie, in other words.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

But the purpose is really to make it less likely that the individual will be identified, right?

**Richard Elmore – Office of the National Coordinator – Query Health**

That's correct without completely eliminating that risk.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

Right. Right, but the purpose is, that we care about, I mean, you know, we don't care if you want to change all the accuracy you want, but the data elements we most care about are those that disclose the identity of individuals.

**Paul Egerman – Businessman/Entrepreneur**

So, the best way, I think, to respond, is, because what is written here is correct, it does reduce the accuracy of the information. There is a method of doing that, but you would probably just need to put in a sentence that says, explains that this is being done to minimize the potential that this data could be used to identify an individual.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

Yes.

**Paul Egerman – Businessman/Entrepreneur**

Okay. Terrific.

**Richard Elmore – Office of the National Coordinator – Query Health**

If I can just ask would the Tiger Team be comfortable or opposed to using the word minimize in that sentence too to reduce.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

Yes.

**Richard Elmore – Office of the National Coordinator – Query Health**

The difference is pretty significant in terms what we would have to do.

**Paul Egerman – Businessman/Entrepreneur**

Yes, I think that's a better way of doing it, that's much better. Thank you.

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

You know some universities actually run some algorithms to see, that test the likelihood that individuals will be identified. I know Vanderbilt is one that does that. Has Query Health considered doing that?

**Paul Egerman – Businessman/Entrepreneur**

That's a question I guess to Rich Elmore?

**Dixie Baker – Science Applications International Corporation – CTO, Health & Life Sciences**

Yes.

**Richard Elmore – Office of the National Coordinator – Query Health**

We're not that far along but we'll certainly take that question and see what we can do with it.

**Paul Egerman – Businessman/Entrepreneur**

Great. So on the next slide there is just this question, are there any policy recommendations that people want to make relative to Query Health, in other words do we think we covered it in the previous eight slides or does anybody have any other comments they want to make? So, I will assume silence means that we are happy campers with the slides that we've done so far.

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah, I think I agree.

**Paul Egerman – Businessman/Entrepreneur**

So, Deven and I will adjust them and present them on Wednesday and before we talk about public comment, Deven do you have anything you want to talk about? Do you want to...

**Deven McGraw – Center for Democracy & Technology – Director**

Yeah, yeah, yeah I only, yeah I only want to let folks know that the next, that assuming all goes well at the Policy Committee meeting next Wednesday, the next topic that we have keyed up for you is a gap analysis of the HIPPA security rule that ONC has been working on, but it won't quite be ready for the next call that we have, which is on October the 20th. So we're going to hold off on canceling that call until we know for sure that we don't have any follow-ups to these recommendations that the Policy Committee

asks us to do next Wednesday, but you should keep your eyes peeled for a notice because we may be able to give you your time back on October the 20th. So, and then I guess the only other thing is, you know, for all of those who are honoring a holy day today, or the Jewish holiday of Yom Kippur, I just wanted to, I don't know whether you really celebrate a day of atonement, but I wanted to recognize it since it starts shortly for some.

**Paul Egerman – Businessman/Entrepreneur**

Well thank you, that's very nice of you. So.

**Richard Elmore – Office of the National Coordinator – Query Health**

Paul, may I just say briefly, thanks to you and Deven and to the Tiger Team and the MITRE folks, everybody who has contributed to this, it's really going to be helpful as we go down the line, so thanks a lot.

**Paul Egerman – Businessman/Entrepreneur**

Oh, great, Rich, it's off to a, as far as I can tell, it's off to a great start, so thank you for your efforts on this and thank you Joy, and thank you Erin, but let's also see if we have any public comment? Erin if we could ask for, open ourselves to public comment please?

**Erin Poetter – Office of the National Coordinator**

Yes, operator can you check to see if there's anyone that wishes to make a public comment and just a reminder to the public to please keep your comments to less than three minutes each.

**Caitlin Collins – 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 you computer you may dial 1-877-705-2976 and press \*1 to be placed into the comment queue. We do not have any comments at this time.

**Paul Egerman – Businessman/Entrepreneur**

Great. Thank you very much Erin and thank you very much to all the members.

**Deven McGraw – Center for Democracy & Technology – Director**

Thank you Paul for doing such a great job of leading us through these, much appreciated.

**Paul Egerman – Businessman/Entrepreneur**

Terrific and thank you for doing all the work and presenting them. Have a good weekend.

**M**

Thanks.

**Paul Egerman – Businessman/Entrepreneur**

Bye-bye.

**W**

Bye everybody.

**W**

Thanks everyone.

**Judy Faulkner – EPIC Systems Corporation**

Good-bye.