

**HIT Policy Committee
Privacy & Security Tiger Team
Hearing: Non-Targeted Query
Transcript
June 24, 2013**

Attendance

The following Workgroup members attended this meeting:

- Deven McGraw
- Paul Egerman
- Dixie Baker
- Gayle B. Harrell
- Judith Faulkner
- Leslie Francis
- John Houston
- David McCallie Jr.
- Wes Rishel
- Kitt Winter

The following Workgroup members did not attend this meeting:

- Micky Tripathi

Presentation

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

Thank you. Good afternoon everybody, this is a MacKenzie Robertson in the Office of the National Coordinator for Health IT. This is a meeting of the HIT Policy Committee's Privacy & Security Tiger Team; it is a virtual hearing on non-targeted query. It is a public hearing and there is time for public comment on the agenda. The hearing is also being recorded and transcribed, so please make sure you identify yourself for the transcript. A few other reminders that since this is a virtual hearing, I just want to remind all of our participants not to put your phone on hold, the hold music will come through the speakers and will interrupt the presenters, so please just disconnect your phone to take another call if you have to. Also, if you're listening through your computer speakers, if you can please make sure you either turn your speakers off or just keep your phone on mute, so we don't get any background noise for the presenters. With that, I will now take roll call. Deven McGraw?

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

Here.

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

Thanks Deven. Paul Egerman?

Paul Egerman – Businessman/Software Entrepreneur

Here.

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

Thanks Paul. Dixie Baker?

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

I'm here.

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

Thanks Dixie. Judy Faulkner?

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

Here.

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

Thanks Judy. Leslie Francis? Gayle Harrell? I know Gayle is on.

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

I'm on.

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

Thanks Gayle. John Houston?

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

Here.

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

Thanks John. David McCallie?

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

Here.

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

Thanks David. Wes Rishel?

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

Here.

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

Thanks Wes. Micky Tripathi? Kitt Winter?

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

Here.

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

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

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

Joy Pritts.

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

Thanks Joy.

Kathryn Marchesini, JD – Policy Analyst – Office of the National Coordinator

Kathryn Marchesini.

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

Thanks Kathryn. Okay, I will turn the agenda back over to you Deven.

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

Thank you very much MacKenzie and thanks to all of the members of the Tiger Team, members of the public and the presenters that we have presenting to us today. I want to thank all of you for taking the time to join us on this virtual hearing on non-targeted query. I'm going to start by setting the stage for the day, to talk a little bit more about what we're hoping to explore in the hearing today, an overview of our agenda and our presenters, as well as the questions that we hope we will get answered in the three hours that we have together today. And then I'm going to turn it over to my co-chair, Paul Egerman, for some additional remarks from him. And he's also going to tee up the first panel of questioners, introducing them, and I will monitor the time.

So with that, I'm going to start by trying to be very clear about why we're gathered here today, the purpose of this virtual hearing. It is an effort to understand what policies are deployed to ensure that a non-targeted query for a patient record is appropriate, legal and authorized. And in just a minute, we'll talk about what we mean when we say non-targeted query. The focus of this hearing is on policy, we are a working group of the Health IT Policy Committee. So we're interested at digging through policies that have been deployed on non-targeted query. It is not on security methodologies and it is not on identity management issues, not that those are not important, but we're trying to spend the hearing today to try to get an understanding of and some examples of policies that have been adopted in this area.

Some of these policies might include limitations on who can conduct the query or the purposes for which a query can be conducted. Geographic or any other limits or parameters, that again, that are intended to help assure proper access when there is a query and also intended to help demonstrate that the requester is in fact authorized to access a patient's records. We're particularly interested in environments where there are limitations placed on access to the record via a query, and again, this is non-targeted query. Examples include, but are not necessarily limited to partial access to the record, again geographic limits, purpose limits, for example limiting queries to those for direct treatment. Some health information exchanges or HIEs may have inherent limitations based on factors such as geography, in the case of a regional HIE. We're also interested in hearing of instances where limiting policies were considered, but ultimately not adopted. And we also want to understand more about the thought processes behind the development of any such policies. Why? If you adopted some limitations, why did you do it or if you declined to adopt some limitations, what was the reason why you rejected those policies?

We are focusing on queries between disparate entities, not queries within an integrated delivery system or organized healthcare organization. Not that query may not be a challenge within those organizations, but given the focus of Stage 2 of Meaningful Use and our desire to facilitate the exchange of patient data across disparate entities, we are really hoping to focus this virtual hearing on queries between and among disparate entities. What do we mean when we say non-targeted query? Well, what we're talking about is a scenario where the patient's other providers are not known in advance of the query. And so as a result, the non-targeted query involves looking for the patient's record, using information about the patient versus a scenario where you are looking for a patient's record by asking one or more specific provider organizations.

It's typical – it's going to involve the use of an aggregator and an example of an aggregator could be a record locator service or a data element access service or even a health information exchange. But again, you're looking for the record based on patient information; there is an aggregator that is designed to help find that information. And when we – when the Tiger Team began deliberating on the issue of query and response to queries, we really did focus our use cases on those involving queries for direct treatment, treatment of that patient. But we are interested in hearing about how non-targeted queries might be used for other purposes, it's one of the nice things about having a hearing is that we actually get to open up the aperture a little bit and get a more full picture of what might be going on in the field on the issue of non-targeted query.

So here's a snapshot of our agenda. We have two panels today; we have not divided the generous entities who have agreed to present testimony before us today. They're not divided based on any particular type or subject matter, but just an effort to try to organize the day a little bit better. We'll hear from four testifiers in the first panel and then there will be a Q&A period and then we will hear from four testifiers in the second panel, and then there will be another Q&A period. And then there will be a short period to sort of do a little bit of wrap up and a period for comment from the public, and then we will adjourn the hearing.

Here's the list of the entities that we are going to hear from in panel one. Each entity will have five minutes to give us a presentation on the questions we have asked, which I will get to in a minute. Some of the entities have multiple people listed, that doesn't mean they each get five minutes, what it means is that they have more than one representative on the call to help assist in either the presentation or in answering the questions or both. So this is panel one, with the Nebraska Health Information Initiative, Healthway, the Rochester Regional Health Information Organization and the Indiana Health Information Exchange. And then on panel two, we have Rhode Island Quality Institutes CurrentCare, we have Surescripts, we have ClinicalConnect and we have SMRTNet.

So now I'm just going to provide for each of you, and also for members of the public who may be seeing this for the first time, the questions that we asked the presenters to focus on in their five-minute presentations. How long have you operationalized non-targeted queries and please describe the process? How long have you been operational with your approach and how many patients are involved? Is there an inherent scope limitation associated with your entity that affects provider's ability to perform non-targeted queries, for example, geography? What limits are placed on non-targeted queries such as, who can query, for what purpose and the scope of the query? What roles to patients have in limiting queries? Are there circumstances in which patient preferences are overridden, and if so, how does that process work and have there been any problems? How to patients exercise meaningful choice as to whether the records are included in your aggregator or aggregator service? Does this extend to the release of the data or does that require additional consent?

How do you address exchange of sensitive information in a Non-targeted query model? What information is returned to a requester as a result of a non-targeted query? And if you exchange sensitive information is there a difference in what is returned when such information is involved? In what environment and for what providers have non-targeted queries proven to be most effective? Please provide appropriate metrics if they're available. What challenges or problems have been created by your approach and what adjustments have you or do you plan to make? Would having widely applicable policy or guidance on providers ability to perform non-targeted queries helpful and if so, what should those policies be?

So with that, before we jump into the first panel I want to turn it over to Paul Egerman, my co-chair for any further remarks that he has and to get us started.

Paul Egerman – Businessman/Software Entrepreneur

Great. Thank you very much Deven and I just want to say this is an exciting hearing that we're about to go through, some very important and valuable information. To briefly reiterate a couple points of what Deven just said, in this discussion this afternoon or this morning, but this discussion today, we are focusing on exchanges of information between separate healthcare organizations. We are not focusing today on information exchange at all within an organization. So sometimes in healthcare, it's hard to know what an organization is, but you may have some very large organizations that exist that are regional or possibly even national and we are not looking at what happens within those large organizations. It's really between completely separate healthcare entities, so that's one thing I wanted to emphasize. The second is that this is query response, and we call it non-targeted, where you go to some we call it aggregator, some service that you tell them this is the name of the patient, it's say Deven McGraw. And it gives you some response, either it says it has no data or it says here are the places where the data might be located or actually gives you the data, there's lots of different models. So that's what we're looking at is non-targeted query response between separate healthcare organizations.

And we're about to get started with our panels. What I want to tell the panel, the people who are presenting, this is a little bit difficult to do over the telephone because we can't see you and I want to make sure I tell you in advance we appreciate what you are doing. But we also want to tell you in advance that we are going to be pretty rigid about the five-minute limit because we have a number of people on the call and we want to spend the most amount of time doing question-and-answer. So Deven has a timer and the way the timer will work is I think it'll give you like approximately a 30 second notice that your five minutes is about to be up. And so that's to help you wrap up and when you get to the end of the five minutes, either Deven or I will actually stop you. And when we stop you again, it's not our intention to be rude, it's our intention to be understanding of all the other people on the call. So I want to explain that that's how the process works and if you are a presenter and you complete your presentation in less than five minutes, we will all consider you an absolute paragon of virtue and whatever you said is most likely to make it into federal regulations. So I just want to make sure I put that out. So our very first presentation is from Nebraska Health Information Initiative.

Deb Bass – CEO – Nebraska Health Information Initiative

Great. Can you all hear me okay?

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

Yup.

Deb Bass – CEO – Nebraska Health Information Initiative

Next slide then please. I'm going through the recognition. And we can just click right onto that next slide. I'm going to go over some of this beginning information very quickly; it just gives you some general background. Again, we are one of the first statewide HIEs and started exchanging data in March of 2009, and you can see our URL there for the website if you want to look for additional information. Next slide please. We have – we are a 501(c) 3, we're managed by the board of directors and we had C capital that came in prior to ARRA and HITECH. Next slide please. We have 2.3 million lives, people say Nebraska is 1.8 million in population and that just speaks to our geographic limitations. We actually have individual – 26 percent of our MPI have addresses outside the state of Nebraska. We have about a third of the providers participating in the state and we're connected to 51 percent of the beds.

Next slide. Just some history on the privacy and security efforts here; we started talking about this in 2008 and we were one of the first states that had a payer at the table from the beginning. So we developed our policies based on treatment and payment. As we progressed on into 2012, we added limited public health reporting to support meaningful use and also allowed direct payer access, that they could logon and view the information. And now, of course, we're currently reviewing the policies for HIPAA, HITECH Revision and of course, the DURSA Agreement.

Next slide. Way back in the beginning, so we were fortunate in that Nebraska law is not as prescriptive as other states. So we based our policies primarily on the HIPAA reg, and as I said, we had that payer at the table. But much of our conversation centered around what was currently then happening in the paper world was the entire chart was being faxed. So we talked about how we could minimally limit that information and track and auditing – and tracking and the auditing was the next major consideration. Next slide please. So with that, our consent management, we are an opt-out platform, less than 3 percent of the individuals in Nebraska have opted out over the entire history, in fact it's 2.8 right now. We do have a support desk that's available 7 x 24 and individuals can opt-in and opt-out pretty quickly using that. And we have no break the glass. We've talked about this twice and every time we thought that the odds of that happening are minimal, so we are not going to be concerned about break the glass. So we also have – we are an opt-out and so because of that, we scrub the 42 CFR Part 2 data from the medical records. And we also use direct services for the exchange of that information.

Next slide please. As far as the query scope limitations, it's pretty much Nebraska, Iowa, neighboring states, there must be a direct treating relationship. It is role based for certain information depending upon the level of the healthcare professional and we abide by the minimum necessary and episode of care. Next slide please. We quickly arrived at this use case approach because when we were talking about just a broad specific method of choice, we decided it was too difficult to try to understand just exactly what that meant, so we developed some very specific user – use cases that we presented to the Privacy and Security Committee.

Next slide please. And here's the list of the use cases that we developed for the payer access centering around utilization management, hospital acquired conditions and quality reporting. And again, very specific and we brought those to the Privacy and Security Policy Committee and next slide please. And with the payer access, we talked about there would be several sorts that would occur. First of all, we sorted the information based upon their current eligibility files. And then we applied a secondary date range customization so that we only sorted on the date range so that we can make certain that we hit that minimum necessary episode of care requirement. And that we added a secondary audit on top of the primary audit. Next slide please.

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

Okay Deb, you have about 15 seconds. The rooster was your 30 second –

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Ah, okay. Great. Well you can see these are just – there's the date range, they put that in. Next slide. Then the information is populated once they do the date range. Next slide. These are just the first audit. Next slide. The secondary audit that happens according to that individual and the last slide please. Then we also use the same approach for our public health use cases, and you can see those listed there. And that's it.

Paul Egerman – Businessman/Software Entrepreneur

Deb, thank you so much. That was very helpful and thank you for putting up the contact information. That was great and I also always feel that we're not doing justice to the presenters, because we're not telling you anything about their titles and their background, so that was a very good and significant presentation. Next we have I think Mariann Yeager from Healtheway.

Mariann Yeager, MBA – Executive Director – Healtheway

Thank you. I'm Mariann Yeager, Executive Director of Healtheway that is the nonprofit public-private collaborative supporting the eHealth exchange and thank you for inviting us to speak today. So the eHealth Exchange has 40 participants connecting hundreds of hospitals, tens of thousands of physician practices and hundreds of millions of patients across all 50 states. It supports a range of healthcare transactions including query retrieve as well as document submission or push, as well as publish, subscribe. And so in that respect it supports a variety of use cases and enables exchange among private sector participants as well as between private sector and governmental participants.

So first we'd like to explain how large-scale query-based exchange is working. So the eHealth Exchange has been initially deployed to date in geographic clusters around the US that are largely bound by region. So by default, queries have generally been based upon or limited based upon geography and service area. It's really important to note that the eHealth Exchange was never intended to promote unbound broadcast queries. But now that participation in the eHealth Exchange is reaching critical mass, we're developing additional guidance and would welcome other work to help provider's narrow queries to the relevant circumstances and the most likely places where a patient's records are expected to be found. We actually have seen success in using constrained or non-targeted queries universally across a variety of environments and use cases, for example request for records to support the Social Security Administration's Disability program where the beneficiary indicates where they've received care, enabling a more narrow query. We also see that request for records for treatment purposes, care coordination and referrals across care settings, where providers generally anticipate the most likely places where their patients may have been treated in a respective area and this is based upon the prior experience based upon where they typically refer for care. So the general rule by default, the providers tend to limit the scope of their queries to the most likely places where they anticipate their patients may been treated based upon their current experience.

We'd also like to describe how robust query functionality is implemented in the eHealth Exchange. First participants include policy statements or assertions with the message that enables a responder to determine whether or how to respond to a request. This includes information about the user, their authentication and the role that that user place. It includes information about the organization as well as the purpose for the query, which are limited in the eHealth Exchange to a narrowly defined set of permitted purposes. In addition, participants must provide accurate and true assertions as a condition of the trust agreement. The assertion is also signed, digitally signed, to support integrity authentication and non-repudiation of the assertion. In addition to the assertion, there are axis consent policies, which may be also included with the message that provide more granular information about the requester's policy related to the disclosure of information.

Now it's important to know without these policy statements provided up front, providers would be forced to manually verify the role, the purpose of the use, the user of the request before responding. So this actually enables some level of automation. In addition to standards and policies employed in the eHealth Exchange, we're also designed to enable the requester to further narrow the scope of the inquiry, for instance, based on dates of service and to reflect the type of information that they actually need. And finally, only participants and users who have the requisite authority under applicable law are permitted to request or release data.

In closing, the eHealth Exchange has largely limited queries based upon service area and the specific circumstances and use cases at hand. We do, however, believe additional guidance and shared services may be needed to offer enhanced functionality to support more automation and to promote narrowly scoped queries as connectivity grows. The eHealth Exchange framework overall is robust and it can support that additional level of segmentation of query purpose and process, and we'll certainly look to national level guidance as available to inform our work. And we definitely look forward to the recommendations of this group.

We do encourage the Tiger Team to be as specific as possible when studying the matter further; sometimes posing very general questions can lead to maybe solutions that aren't as salient in the implementation level. For instance, we suggest the Tiger Team may be informed by studying how frequently providers are unaware of where their patient's data reside and may also beneficial to engage the implementation community more broadly, since they have already developed and implemented policies and approaches locally. But overall we hope that these discussions more fully distinguish the differences in inquiry circumstances and the specific issues that need to be addressed nationally before national policies are advanced. Thank you.

Paul Eggerman – Businessman/Software Entrepreneur

Thank you very much, Mariann. And a great presentation and thank you for operating entirely within the five minutes, I very much appreciate that. And next we have, Ted Kremer, I hope I'm pronouncing your name correctly, from the Rochester Regional Health Information Organization.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Everyone in my family pronounces it differently, so you did fine. Our initial efforts to operationalize our regional query services really required establishing the policies, legal frameworks to ensure community trust of a network query environment. The data-sharing agreements included business associate agreement terms, privacy policies and operational procedures for all the participating organizations; that had to get established first. Subsequently most of the operational work involved technical and deployment efforts. Technical work was needed to establish the interfaces for data providers to connect and build our HIE over time. The data supporting our query services builds over time, so significant data was necessary for promoting our services.

Deployment efforts then included marketing, outreach, training necessary to both set up and implement query services in a variety of settings and workflows. Rochester RHIO was formed in 2006 and has been providing patient-centric query services since around 2008. Our services include support for 1.4 million patients and to date, over 880,000 patients have provided consent for their care providers to use our query services. Of those, 96 percent of the patients signed an affirmative consent. Our scope is limited currently to a geographic region across 13 counties in the Finger Lakes Region of Western New York. The area is predominantly rural with Rochester serving as the region's urban hub. Query services are currently available to care providers for treatment and operations, and only to those organizations and types of organizations as approved by our RHIO Management Committee and that have signed data-sharing agreements with the RHIO and completed required training.

User roles are limited to health professionals and medical support or clinical staff members that have a demonstrated need to access the clinical data to perform their job duties. We use what's called a per covered entity consent to view model. In this model patients have to provide consent for each participating organization in order for them to view their information through the HIE. As such, many of our patients will sign multiple consents, but once the patient has indicated their preference, any changes to those preferences have to be submitted in writing back to the RHIO to change their consent status. Where a patient hasn't made those preferences known to us though, their information can only be accessed in a true medical emergency under what we consider a break the glass event. And all those events are audited 100 percent by RHIO compliance and privacy officers. And additionally, each month we audit five practices for general consent compliance.

Meaningful choice. So as a consent to view model, patients have to approve each covered entity's access to their information. But the RHIO, similar to hospital's transcription services or lab services or hosted IT service providers, we've got a business associate agreement where their data flows to us and as such, the patient's choice is really to allow or deny viewing of their care information to their care providers. But it doesn't allow them to control where their information is stored. Consent forms, educational materials and consumer facing websites detail how their information will be used and the sources of information included in the RHIO.

Through conversations with our regional data providers, this is sort of on the whole segmentation piece. It became apparent that a lot of our data sources were not confident in their ability to either segment or exclude all types of sensitive information 100 percent of the time, or in the ability of HL7 interfaces to record and persist such flags across data systems. So based on that, we erred on the side of inclusion and patient education and made it clear to patients that sensitive information may be available through our query services. We publish all the sources of data that are available through our services and our consent form clearly indicates that all data will be available through the HIE and it enumerates all the types of sensitive information that may be included. Having said that some of our data providers any that are providing SAMHSA 42 CFR Part two data were able to filter that data from the data source, based on the location of testing and treatment. So that is not included in our exchange.

In terms of data, currently 70 sources of data flow through the RHIO including lab, path, radiology reports and images, hospital reports, medications, emergency medical service information, which is pre-hospital care information and social services or elder care information. We do not display sensitive information differently when responding to a patient query. As regards to what settings of who – important, we're fortunate that the a University Consortium led by Cornell Weill was able to demonstrate significant savings. The research demonstrated reduction in ED admissions by some 30 percent, reduction in post discharge readmission rates by some 55 percent and a reduction in duplicate imaging by about 35 percent.

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

So Ted, you've got about 10 seconds. The reason –

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Well, I think I'll hold right there, I think those savings are a good story.

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

They are.

Paul Egerman – Businessman/Software Entrepreneur

They are a good story. Thank you very much Ted, great presentation. And in this panel, and I should have said this at the beginning, we somewhat arbitrarily put panels of four together. This panel, the final presenter is Indiana Health Information Exchange, John Kansky.

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

Are you on mute John?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

Can you hear me?

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

Now we can –

Paul Egerman – Businessman/Software Entrepreneur

Yes, we hear you now.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

Okay, apologies.

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

No problem, we haven't started your timing yet, so you're good.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

Okay, thank goodness. Thanks for the opportunity today. I have just two slides, the first one's going to help me a little bit with the what we have and the second slide with the kind of how and how long and how often question. So, the first slide please. So, one of the services of the – next slide please.

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

I'm stopping your time. Do we have those slides?

Paul Egerman – Businessman/Software Entrepreneur

Yes, here it is.

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

Great.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

Yes. So the Indiana Network for Patient Care is a service of the Indiana Health Information Exchange and it is an inter-organizational system of clinical data repositories. And we consider it centrally managed but federated, which means that all the data is in a common data center but continues – we're hosting a silo of data for each of our participating members, more on that on page 2. It's used every day in hospital Emergency Departments, in inpatient settings and in outpatient settings. And one of its primary functions is to enable non-targeted queries. And its purpose is to enable clinicians to discover relevant clinical information at the point of care, so non-targeted query to us is synonymous with enabling clinicians to discover clinical information at the point of care. Access is strictly controlled and data use is governed, and I'll talk a little but that in a minute.

So next slide please. The picture on the left is Indiana and all the blue Hs are participating hospitals; there are 94 of them from 34 different systems. We also have participation from large medical groups and clinics, some payers, some freestanding labs, imaging centers and public health agencies. Believe it or not, this has been around, thanks to the Regenstrief Institute, from the early to mid-90s and has grown steadily since then. Data is pushed to or pulled at the point of care in response to an automated query; it's usually an automated query. So let me spend about 40 seconds explaining this. I call this system, when I explain it, I call it the jigsaw puzzle assembler and what I mean by that is for an individual patient whose clinical jigsaw puzzle pieces are scattered across the health care system, for every participating organization, at the point of care, we're able to assemble the patient's jigsaw puzzle. But it's always, always triggered by some event electronically, that's how it's automated, an ED admission, a hospital admission, a doctor's visit is always the trigger to establish patient provider relationship. We do not enable break the glass, we have considered it; you can ask about that if you want to.

The access is tightly controlled, don't really have time to go into a lot of detail except to say that there's always a patient provider relationship, there's always a time window that's appropriate for that setting, for example, it's 24 hours for an ED visit and then the access is closed. The user using the system or receiving the information is always within a specific role and if they're accessing via a device, the device is matched via the IP number of the facility where the query is coming from. There are about 5000 queries per day, per day, from the 52 or so live hospital emergency departments. There are about 5000 or 6000 queries per day from other settings. I'd have to explain a little about the difference between an access and whether you want to count that as a non-targeted query or not.

And I want to focus on the word membership in the bottom half of the slide. Everybody who participates in the Indiana Network for Patient Care is a member, they have signed a contract, they have agreed to access rules, and they participate in a governing entity that sets the policies for the sharing of data across the network. And many of them join in part to benefit specifically from this non-targeted query, from the ability to discover patient data at the point of care. And with that, I'm going to close and I haven't even heard a rooster.

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

No, you're good.

Paul Egerman – Businessman/Software Entrepreneur

Totally impressive, thank you so much and great presentations from everybody. Let me explain how we're going to do the question-and-answer period now. We're going to do a question-and-answer period for these four presenters. Questions should come from Tiger Team members only, and if you look on your screen, there is an icon for raising your hand. And so if you can use that to raise your hand, so that we will know that you would like to ask a question, then we will call on you. If you are a Tiger Team participant and you are not at a computer system, we will give some time towards the end of our Q&A for you to try to break in and make sure that you get a chance to answer your questions.

For the participants, what I want to also tell you is answering the questions, we're less interested in situations where you agree with each other, we're more interested in situations where you've chosen to take a different approach for some reason. We're also, as Devon said, very interested to know why you made various decisions that you've made, so not just the decision but sort of like what was the thought process behind it is also interesting to that...to us. So, do we have any questions?

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

I see John's hand raised.

Paul Egerman – Businessman/Software Entrepreneur

Is that what that says? Okay.

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

Yup.

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

Thank you. Great testimony, I thought that was all very informative so I appreciate that. I guess the one question that I do have is, to what extent have any of the individuals or their organizations established prospective methods to ensure that a query is only being made for a patient or a consumer that has an active relationship with the organization that's requesting the information?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

This is John Kansky, I can respond to some of our trigger rules.

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

Go ahead.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

So if I understand the question, so for example, we – the governing body discusses and agrees upon access triggers. In other words, the data is not available unless the following occurs, everybody in the network agrees to those triggers. So for example, it might be the hospital emergency department – the hospital sends an ADT stream in real-time and if we don't see the patient's information in that ADT stream, their data access to that organization is not turned on. We have similar access rules for inpatient and outpatient settings.

Mariann Yeager, MBA – Executive Director – Healtheway

This is Mariann Yeager. From a Healtheway perspective and looking at it as a network of networks building upon local policy, the permitted purposes are narrowly constrained, even for treatment purposes. And they're asserting when they send a message whether it's a requester responding to a message that – and if it's related to treatment, that the provider has a treatment relationship with the individual who is the subject of the message. If that's at all helpful.

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

Yeah.

Paul Egerman – Businessman/Software Entrepreneur

That is helpful. Great. I see also that Dixie Baker is asking a question.

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

Thank you. Thank you all for your excellent testimony, it went by very, very quickly. So, I hope I didn't miss something, I probably did. I have a specific question to John Kansky. In that last slide that you showed, you said that access to information – by a number of systems – and then one of the things listed was device-facility match. I would like to hear more explanation about what that means and how do you measure it, how do you determine – how do you make that device-facility match?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

Sure. So, as you know, security and convenience are opposites. So the device-facility match and I realize that wasn't well defined, so let's talk about emergency department. In addition to pushing data in response to an automated query, we also open up access to a web-based system and the device that would be accessing that system, for example an Internet connected computer in the emergency department, would have to be in an IP range that we knew to be at the querying facility. Now, when we get into mobile devices and the desire to have this access be more ubiquitous, we're going to be challenged to continue to find innovative ways to secure access.

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

Yeah, that's exactly what I was thinking. Thank you. I appreciate that, thanks.

Paul Egerman – Businessman/Software Entrepreneur

Terrific. And next we have a question from Wes Rishel.

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

Thanks. Several of you mentioned having in your governance the ability to do basically role-based authorization for queries. I wonder how many roles you have define, is it like two or like twenty or what? Because two is easy, twenty is bordering on nuclear mass there.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

John Kansky from IHIE, ours is closer to two than twenty.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Ted Kremer in Rochester, ours is at three, so yes, much closer to the two than twenty.

Paul Egerman – Businessman/Software Entrepreneur

And can you tell us what the two or the three are?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

So we have a clinical user and we have an administrative user that cannot see all the clinical data, but they can do basic patient summary information. And then we have another role where the person can just set consent.

Paul Egerman – Businessman/Software Entrepreneur

Okay. Anybody else? Terrific. Thank you. Next question is from David McCallie.

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

Yes, hi, David here. Thanks for really fast-paced presentations, hard to keep notes as fast as you guys talked. One thing that jumped out at me from the Nebraska group was the early and active involvement of the payer in terms of roles, maybe parlaying a little bit on the role question from before. I was wondering do any of the other of the panelists have payer access as part of their authorized roles.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

This is John Kansky from IHIE. We have payers that contribute data to the INTC, the system of repositories and they benefit from information from the repository, but they do not have the ability to do non-targeted queries.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Ted Kramer in Rochester. We have a provider – or a payer role for case and disease management, but they have struggled mightily to get patient consent, so it is not very often used.

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

Hmmm.

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

Yeah, that – this is David again. That should have been the second part my question, which was how well the patients receive that idea, and feel free to elaborate on that if you'd like.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Well I think the challenges at least we've heard from the payers could be a reception from the employees. I think the other piece is where in the workflow process they get those consent forms signed. I think from a – if it's a disease management program, it's more understood by a patient where they've tried to upstream getting those consents more in say something like an enrollment process. That's I think where you hit more of the patient angst issues. It's also a challenge because your enrollment forms are signed by a subscriber typically and not all the members of a family.

Sara Juster, JD – Vice President, Compliance – Nebraska Methodist Health System; Privacy Officer – Nebraska Health Information Initiative

This is Sarah Juster with Nebraska. I just have to say that I've really received very few inquiries from patients expressing much concern over payer access. I think they all know that their payers are getting information through the more traditional channels of paper or fax or otherwise, this is a different method of the payer getting that same information. So, luckily again, we just haven't had much patient angst over the issue.

Paul Egerman – Businessman/Software Entrepreneur

So to what extent are patients aware even that you exist? Or the entire process?

Sara Juster, JD – Vice President, Compliance – Nebraska Methodist Health System; Privacy Officer – Nebraska Health Information Initiative

Well the patients all receive information when they check-in or access healthcare from a participating provider that explains who has access to their information through NeHII and for what purposes. And I think it's pretty clearly spelled out the payers do have access for certain purposes in that information.

Paul Egerman – Businessman/Software Entrepreneur

Interesting.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

In New York –

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

We also have a consumer – this is Deb...we also have a consumer micro site that we refer individuals to that talks about this. So we – it's the – when they sign that authorization for treatment, they're releasing their information to their payers for payment. So, it's the same concept.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

I think in New York it gets a little more problematic because we have a specific payer consent form, and it's not durable, it's only good for a year. So again, the workflow issues become, I think, the biggest problem for them.

Sara Juster, JD – Vice President, Compliance – Nebraska Methodist Health System; Privacy Officer – Nebraska Health Information Initiative

And actually it's interesting that you mention that one year consent because that's one of the reasons that Nebraska went to an opt-out process, because Nebraska state law initially limited consents to only six months. A lot changed after NeHII was formed, but it still is only a one-year period as well, which made administratively just an absolute nightmare to try and get opt-in as opposed to opt-out.

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

Mariann Yeager does – this is Dave again on the payer access role. Is that a common role in the Healthway settings or is it accommodated at all?

Mariann Yeager, MBA – Executive Director – Healthway

I would say it's not a role per se. The function of payers. I would say is addressed as a permitted purposes, which are defined very narrowly. So a good example is the definition of payment and operations are really limited to the payment and operation of the healthcare provider as it relates to obtaining payment for the services rendered for the individual subject of the message. So, it's – payers are not currently participants in the eHealth Exchange except to the extent to receive data to substantiate a provider's payment.

Paul Egerman – Businessman/Software Entrepreneur

Actually I have one more question on the payer's side, which is, if the patient self-pays for a particular episode of service, is there a way to make sure that the payer does not have access to that information?

Sara Juster, JD – Vice President, Compliance – Nebraska Methodist Health System; Privacy Officer – Nebraska Health Information Initiative

This is Sara Juster at Nebraska. Unfortunately we don't have any way to segregate that data, so we recommend to patients who want to make sure the payer doesn't see any information, to simply opt-out.

Paul Egerman – Businessman/Software Entrepreneur

Okay.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

I will also add to that, that we are not going to start working to get self-pay in for a med query data because we also use the HIE for the prescription drug monitoring program for the state. And we do have a way technically that we can sort out the self-pay med data. But for the rest of the data, we defer to the process Sara defined.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

This is John Kansky, I'd like to comment on the self-pay issue in that I think that was – it's very operationally difficult to implement and I think one of the maybe unintended byproducts of that federal policy, we're having to – we've implemented some clunky, but I think effective ways of dealing with that in that any of our participants that are faced with that restriction inform us and then we basically have to opt-out that patient's data. But I just wanted to communicate that that has thrown a bit of a curveball and wrench into a lot of these efforts.

Sara Juster, JD – Vice President, Compliance – Nebraska Methodist Health System; Privacy Officer – Nebraska Health Information Initiative

This is Sara Juster with Nebraska again. I just want to also make the Tiger Team aware; this is a problem not only in health information exchange, but for individual providers having the ability to segregate the data for self-pay patients.

Paul Egerman – Businessman/Software Entrepreneur

That's very helpful. I need to make sure we give everybody a chance to ask questions and I have in the queue next Gayle Harrell. Gayle, would you like to – do you have a question?

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

Thanks so much and I'm going down the same road that you all have been going down on this patient's – how much does a patient know about what is exactly happening. And since you do have opt-in and opt-out entities seem to be involved, for the patient, this is very problematic if they can get a hold of information they really didn't want them to, a payer or another facility or another doctor. And, what – how much information do you really impart to patients when they make these decisions? And

who does that, is it up to the provider to do it? What does the HIE do in the way of informing patients as to what actually happens to their information?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Ted Kremer in Rochester. We have educational materials for patients, trifolds, handouts, we've paid for radio spots, movie theater spots, we've got a website, and so we spent a fair amount of money actually informing patients. And I think that's why our opt-in consent rate are as high as they are, because they kind of understand the landscape.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

This is Deb in Nebraska, we also use the YouTube video that when the hospitals are going live they play that in their waiting rooms, other areas where there's TV access, and have a full media campaign.

Paul Egerman – Businessman/Software Entrepreneur

That's very useful. Could you send us the URL for that YouTube video Deb? That would be interesting to see.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Sure, connectnebraska.net. And that's that consumer micro site and there's a link right on the site.

Paul Egerman – Businessman/Software Entrepreneur

Terrific, thank you. That was a great question Gayle; it's great to have the responses. I'm going to go on to the next person, which is Wes Rishel.

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

Thanks Paul. One of you, I think it might have been Deb, said that you have a filter for SAMHSA data and I'm wondering how you detect SAMHSA data in order to filter it?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

So I think that was me in Rochester, Ted Kremer, and it's actually at the testing facilities. Their data is segmented on their side.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Same thing happens in Nebraska where we test it.

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

So you're saying the sender is required not to know that they have SAMHSA data and not to send it to you and in your testing facility, you look at a data stream and determine there was no – and Gronk if there was data in there, SAMHSA data in there? Is that right?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

It's back on – well, it's back on the sender's responsibility not to send us the data.

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

Yeah, and I understand that, although that's just kicking the can down the street, but what – you both said something about your testing facility. And I'm just not understanding what the relationship is between that and the requirement of the providers to restrict sending SAMHSA data.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

So in our region, there are only one or two facilities – there are only a few facilities that actually do SAMHSA testing, so we're able to isolate it that way with them.

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

Wes, he meant testing in a different sense. He meant provider source of data.

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

Oh, I see, okay.

Paul Egerman – Businessman/Software Entrepreneur

Yeah, that's the way I understood that also.

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

All right, all right. Geek I am.

Paul Egerman – Businessman/Software Entrepreneur

Are you all set Wes? Great and Deven, you have a question?

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

Yeah, I do. I was hoping to get each of the panelists to elaborate a little bit on what exactly a person or entity who queries gets in response. Do they get the location of the patient records and then they need to make a second query? Do they get the actual data? And if they get data, what kind of data do they get, is it read-only? Is it data that can be absorbed into their own EMR? How does that work?

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

This is Deb. I can start if you'd like. They get the patient information tab and of that, they can see the lab results, the radiology results, the transcription reports, but they have to click on each one of those high-level items to get additional information. So there are several clicks involved, but they get a summary report on the first screen.

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

Got it, but they don't have to submit additional queries in order to get at that underlying information? They can make – sounds like they can make choices and sort of open the envelopes they need to open.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Correct.

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

Yeah, I'd love to hear from Healthway and Rochester and Indiana about that, too.

Mariann Yeager, MBA – Executive Director – Healthway

Sure. Well this is Mariann Yeager, Healthway. The first step is to send an inquiry and discover if that participant has records for the patient and then if so, then they can make the query and again it's – they'll put parameters around the dates of service and the types of records that they're looking for. So if there are no records found or no patients found or if, for instance, the patient does not permit the disclosure of the information, there's a generic response that comes back, information not found. And then if the data are returned, their participants generally receive them in usually one of the standardized formats. So that it'll be return the records in a format that can be digested and consumed by the recipient system, although there's also the ability to send unstructured data. But I have Marty Prah on the line, Marty do you want to step it here, because I know you are closer to the details of this.

Martin Prah – Health IT Consultant, Accenture, Social Security Agency

Sure, thanks Mariann. Yeah, as Mariann described, if a patient is matched, the responding system will send back the correlated patient demographic and patient identifier information, along with their own identifying information from that organization. And it possibly may even be further granularity at what we call an assignment authority or the facility level that will be responded. But as Mariann described, the subsequent queries for the documentation with other meta-attributes such as data range of service would follow the initial patient discovery query.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Rochester uses a model similar to Nebraska's.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

This is John Kansky from Indiana. I'm going to use the emergency department as the most compelling and easiest to explain. Remember that the query is automated, so the registration of the patient in the registration system generates a query automatically. The responding information is the patient's information, meds, allergies, recent hospitalizations, labs, radiology, etcetera, some of the similar stuff the other ones are providing. I want to comment though that we have low to high tech ways of sending the information, ranging from a pushed piece of paper to a dedicated printer in the emergency department that has the relevant clinical information arranged as a doctor would like to see it. The most high-tech thing that we do is send the information directly into the hospital's electronic health record system as structured data, which requires a pretty sophisticated hospital system to work with us to do that.

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

Thank you very much. Very helpful. Interesting.

Paul Egerman – Businessman/Software Entrepreneur

Great. So I've got David McCallie and Dixie Baker in the queue. Before I ask them for – give them a chance to ask questions, are there any Tiger Team members on the phone that don't have access to a computer who would like to ask a question, who hasn't asked one yet? Okay, then we'll go to David McCallie.

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

Yeah, I hope I can make this question make sense. We are talking about non-targeted queries here in contrast to the notion of a targeted query where the provider knows exactly where the data is that he needs to go get through some mechanism. It sounds like to me the descriptions at least of three of you, maybe Healthway might be slightly different, that providers don't ever restrict the location of the data, either you've got data about that patient or not. And I guess I want to make sure I got that correct, is there ever a case with those of you that are sort of repository-based where the provider could say I don't want to see it unless it comes from a specific named site or source. Do you give that capability and if so, do people use it?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

We don't do that in Rochester.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Nor in Nebraska.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

Nor in Indiana and I'm curious, do you – is that a – is that functionality that – how would that be used?

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

Well I think in the, and maybe Mariann can comment on this, but in the broader non-regional HIE settings where you have a larger domain of coverage, we've been, in the Tiger Team anyway, debating the notion that you might need to put some restriction on where you thought the data might be. And in your models, as you all three confirmed, you either have the patient or you don't and you've already assembled the view of what you've got. In a more federated model, it might make sense to restrict to a certain location, that's one of the reasons we're having this hearing. So, I was just trying to pull out the fact that in your regional models you don't do that, you don't need to.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

And this is John Kansky again. I see more of a, it might be relevant to limit by data type. So for example if you're a pharmacist or a nurse during medication reconciliation, you might only be interested in medication information and we do that sort of by allowing the users to configure their view of the data within the system, but it's by data type or arrangement, not by geographical query.

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

Great. Thank you.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

And this is Deb from Nebraska. I'd like to add that our patient lives come from that ADT admission, discharge, transfer data that's one of the feeds that we get when a hospital goes live. So they have to have access care at the facility in order for us to have the name in our system. Does that make sense?

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

Yes, no. That's how I assumed it worked, but I appreciate your confirming that. Thank you.

Paul Egerman – Businessman/Software Entrepreneur

So I just want to make sure I heard that correctly. So, is it the case that the only people who can access a patient's record is people who have already submitted data on that patient?

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

No. I was just commenting about how patient's lives become accessible in the health information exchange is that they have received treatment from one of the data provider facilities.

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

Could – let me ask – this is John Houston. To clarify that though, is it more accurate to say there's a registration for the patient so they are potentially receiving treatment even for the first time through your facility?

Paul Egerman – Businessman/Software Entrepreneur

Yeah.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning-Indiana Health Information Exchange

– in Indiana.

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

Yeah, but I don't think – saying that you can't query unless you already have data on the patient, although she –

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

Right, but I'm saying you might have a registration but no data yet. If you register a new patient, you may be looking for data.

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

I think she was saying that they'll know there's data there, because that's the only way that patient's record would have made it in.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Yeah, there's very seldom a time when we enter a patient's name that there is not information because we received those records from the data providers or the hospitals.

Paul Egerman – Businessman/Software Entrepreneur

But I'm still a little confused. So, if I'm a healthcare organization, can I do an inquiry on a patient or do I have to first have sent you some ADT feed before I can do an inquiry on that patient?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

This is John Kansky from Indiana. In our case, the answer is yes and yes. The ADT feed is what gives you the access to the data. So whether you've treated this patient prior or not, okay, so in the emergency department, a patient you've never seen before walks in, you register them, that tells us, that establishes the provider relationship and gives you the data.

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

John, this is Wes Rishel. I hear you saying that you don't do a query in the more conventional sense, that the ADT, I'm registering a patient for today is in effect a query. Is that right?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

That's absolutely correct.

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

So it's no – there – it's a natural conjunction of registering the pa – although you may do it the day before the patient actually comes in, right?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

In the outpatient case, yes.

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

Yeah, thanks.

Paul Egerman – Businessman/Software Entrepreneur

That's very helpful.

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

Interesting.

Paul Egerman – Businessman/Software Entrepreneur

Perfect. I have on the list, Dixie Baker.

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

I'm trying to figure out the data flows that are involved here. It sounds to me like Nebraska brings all the. Let me start there, Nebraska brings all the data to a central repository and there's an opt-out. Does the opt

out occur before the data are brought together or is it an opt-out of use of the data once they are brought together?

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

In Nebraska we're a hybrid federated model so each data provider, which is basically the hospitals, have their own separate edge server. And then we use a Master Patient Index and record locator service to identify the matches and then bring that into view on that information summary tab. But there is a screen that happens before they can get to that information summary tab and it's the patient consent and it says yes or no. And if the individual has opted out, then that consent page comes up as "no" and they cannot go further into that system.

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

Well that's very helpful, thank you so much. Now my understanding is Healthway leaves the data in place, right.

Mariann Yeager, MBA – Executive Director – Healthway

Right.

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

And Rochester said it's a purview – it's a per covered entity consent to view. Now a view – you can do a view without moving the data. Are the data brought together in the Rochester model?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

The data model that we use is similar to Nebraska's; it's got federated edge servers.

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

Okay.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

The only difference is that we're requiring consent per covered entity versus RHIO-wide consent.

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

Dixie, can I piggyback on your question, just to make sure I understood –

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

Please – I want to – let me go through the last one, Indiana.

Paul Egerman – Businessman/Software Entrepreneur

Yeah, let's – Indiana first.

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

And it was inter-organizational, federated and it sounds almost like they brought the data together in a data center, but different databases. I'd like a – just for completeness, to get that one as well.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

Sure, so – this is John Kansky. In our case, the data is in a data center, all members have their data in their own dedicated repository, logically separated in the database. But the data does flow and then any patient restriction, whether it's requested at the time when they present for service or whether it's submitted via their HIPAA request for restriction later on, then we constrain the outflow of the data.

Paul Eggerman – Businessman/Software Entrepreneur

But what patient constraints do you allow?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

It's not – okay, so two comments. Today, as we have it implemented, it's a very blunt instrument. If the patient doesn't want to share a piece of their data, we basically have to opt them out entirely. However, the Regenstrief Institute, who developed the software that our repository is based on, has a federal grant to look at ways to, in a similar system, make that choice more granular.

Paul Eggerman – Businessman/Software Entrepreneur

Okay, but right now, it's all or nothing, so if I don't want somebody to see something about me, I have to agree that they can't see anything about me. Is that correct?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

That is correct.

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

I thank you guys and Paul, I did cut off David, so –

Paul Eggerman – Businessman/Software Entrepreneur

Yes, I know that. David?

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

Okay, thanks. Thank you all.

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

Yeah, and I just was – I just want to make sure I understood correctly, and maybe I'll start with Deb in Nebraska. It sounds like your model lets the MPI matching and the record locator work proceed even before consent. But then if a patient opts out, then you don't necessarily take them out of the system, but you just prevent anyone from using that data that's in the MPI and record locator. Is that correct or close?

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

That's correct, we don't want to penalize the patient because we do allow them, through our consent help desk, that we can change that back and forth pretty quickly, and they can – they have the right to change their consent status as frequently as they want. So we don't want to penalize them by removing that data, so we configure it so that it's blocked from view and the consent to access comes up as a "no." And we've had situations where individuals, particularly with the transplants, we do a lot of transplants here in the state, they go back to their PCP and they've opted out. And the PCP explains to the patient how important it is that he has this information, they'll call the help desk and we can reconfigure the system so that they can access that information, because the physician can verify the identity of the patient sitting there in his office.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Okay, that's extremely helpful, thank you, perfect clarification.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Thank you.

Paul Egerman – Businessman/Software Entrepreneur

That's great. So I have a – this is Paul, I have a question for Ted Kremer at Rochester. It's interesting to me that your model appears to be different in that you have sort of much more of an opt-in model; the other presenters seem to have much more of an opt-out model. But your model allows a patient to decide what healthcare providers can have access to the information and I'm curious to know why you are different. Is it because of a state law, is it because of some decision you made, what caused you to come to that conclusion?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

I think a lot of it was New York State policy has privacy issues sort of buried in a bunch of different regulations. So as we looked at that, it needed to be a little more granular. We had policies that extend beyond HIPAA and education law and all over the place.

Paul Egerman – Businessman/Software Entrepreneur

But it wasn't like the state required you to do it; it was more like responding to what appeared to be a privacy culture? Is that what I'm understanding or is there a state law that says this is what you have to do?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

It was really both, our community conversations started leaning in that direction and then the state policy endorsed that approach.

Paul Egerman – Businessman/Software Entrepreneur

Okay. And then you also said there's a break the glass capability, in the form of, if I heard you right, you said, a true emergency. Can you tell me a little but more about that, how that works?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

So the statuses that a patient can have, they can either say "yes" to a covered entity or "no" or it can be an unknown status. So if they haven't set consent yet and there's a true medical emergency, someone in an ED can basically access their information. It then says they don't have consent, but it's a medical emergency and then we audit 100 percent of all those break the glass events. Typically we get about 25 of those a month.

Paul Egerman – Businessman/Software Entrepreneur

That's a high number.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Well, again – yeah, I mean we have to go out to emerg – we focus on a lot on the emergency department use case and so that's where most of those happen.

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

Just curious, does break the glass prevent acc – supersede a "no" or does the "no" trump?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

No it does not. Once the patient said "no," it's a "no."

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

Got it, thanks.

Paul Egerman – Businessman/Software Entrepreneur

But can a patient say specifically "no" to any emergency?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Right now it's per covered entity so no, they can't sort of say blank-wide "no."

Paul Egerman – Businessman/Software Entrepreneur

Okay. And I still don't understand, what is the definition of a true emergency, if the patient's like conscious and can talk, can you still break the glass or do you have ask them for permission?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

It is under the definition as the treating physician has made and so when we do each individual audit, we want medical necessity sort of proved to us, but it's under the discretion of the treating provider.

Paul Egerman – Businessman/Software Entrepreneur

That's interesting. And without necessarily telling the patient?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Without necessarily telling the patient, well, that could be if they're unconscious and they break the glass, they haven't told the patient, that's correct.

Paul Egerman – Businessman/Software Entrepreneur

And what does your audit show, when you say you audit every one of them and it's 25 a month. Are there any that you think – you've come to the conclusion were inappropriate?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

We've hit a few that were inappropriate, where a physician was treating their own patient and the question of whether their inhaler was actually life-threatening or not was somewhat debatable. But again, they were the treating provider and they really just didn't want to go through the consent process and saw that it might cause harm to the patient, somewhat debatable at that point.

Paul Egerman – Businessman/Software Entrepreneur

And you also have a process of auditing in general beyond the emergency department, the consent?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Absolutely. Each month we go out and audit for just general consent, five practices each month.

Paul Egerman – Businessman/Software Entrepreneur

And I assume the purpose of that is to establish compliance. Have you found any problems?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

We again still have an occasion where we have to – it's usually physicians and it's usually primary care physicians or specialists who wonder why through a RHIO they need consent where through a hospital portal they would not. And so we have to walk through an educational process, but none of the accesses have risen to sort of inappropriate access or breach.

Paul Egerman – Businessman/Software Entrepreneur

And I'm curious; do any of the other groups do any kind of audit around compliance with consent rules?

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

In Nebraska we do, yes.

Paul Egerman – Businessman/Software Entrepreneur

And can you tell us a little about how that works and what you discover?

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

We – each one of the facilities and providers there, we make certain that they – that we review their audit report on an annual basis at a minimum, and we're – we leave that somewhat up to them if they'd like it more frequent, but we're now talking about that minimal requirement more frequent.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

Just a point of clarification, on the sort of self-audit piece, we do something similar to what Deb does where we provide each entity a monthly report as well, to show the usage.

W

Oh, that's a good idea.

Paul Egerman – Businessman/Software Entrepreneur

I'm sorry, who was the last speaker who said that?

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

That's Rochester.

Paul Egerman – Businessman/Software Entrepreneur

Rochester, great. Thank you, Ted. That's great. Do we have any other questions from –

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

Yeah Paul, I have my hand raised.

Paul Egerman – Businessman/Software Entrepreneur

I'm sorry, Deven?

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

Yeah, it's Deven.

Paul Egerman – Businessman/Software Entrepreneur

Ah, okay go ahead. I don't see on the list, but, go ahead.

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

I see myself. So I – so given – what's been – this has been a fascinating discussion for a whole lot of reasons. But one of them being that each of you went through the process of looking at whatever state law might be relevant, working with your members to sort of determine what are the circumstances under which the non-targeted query could be utilized for what purposes, defining some use cases. I imagine you probably also have a process for determining when use cases get added. What you've done with patients on meaningful choice and there are differences among you. So what would you suggest to us in terms of creating national policy here? Are we best not to tinker with the good work you've already done? Do you need us to set some parameters so that somebody else doesn't have to go through the pain that you all went through or what would you say?

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

This is John Kansky from IHIE. I think it would be helpful to get to a uniform privacy guidelines and standards laws nationwide using HIPAA, if you could, as the benchmark. I'm saying that with a degree of nervousness, because we've worked very hard for literally a couple of decades to implement what we think is a very good system and wouldn't want to – like you said, we wouldn't look forward to being with tinkered with. But I know that as a country, as we try to support healthcare efficiency, quality and safety, having uniformity of laws would be helpful.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

I would counter that and say I would support the grassroots efforts. This is Deb in Nebraska. As you know we've shared our policies with more than 20 different states and RHIOs helping to help build on that uniformity concept. But it is a challenge with all of us having different state laws. What I would see as more beneficial is some kind of standardization and data sharing across state lines. That's truly – right now we're looking at three different data sharing agreements with our neighboring states, and the time and the energy that goes into that to review these agreements costs – adds a lot of burden to all of our systems, and that seems to be where the real challenge is. I would also add that the Privacy and Security

Committee is the most engaged committee that we have a NeHII. We have great other ones, but our Privacy and Security Council, they are on top of things and they're very involved. And I think that we need to let them continue to take that leadership as they are the individuals that are on the frontlines trying to manage this.

Sara Juster, JD – Vice President, Compliance – Nebraska Methodist Health System; Privacy Officer – Nebraska Health Information Initiative

This is Sarah Juster from Nebraska also. I would just encourage the Tiger Team to be very careful in putting into place or suggesting any additional restrictions on the use of exchange that go beyond the ability or what's permitted under HIPAA. And what I mean by that is, we are only exchanging information for purposes for which patient authorization or consent is not needed under HIPAA and I'm very concerned if there are additional restrictions put in place that that will hamper the ability of us to exchange information electronically, even though we could exchange the very same information through other means.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

This is John Kansky. I want to echo that last comment. We want more exchange done more securely.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

So from Rochester's perspective, I think what we've heard from physicians is, well policy constructs were helpful in general to move us forward. Wherever those policies start minimizing the clinical integrity of the information, and we start getting into detailed segmentation or patients ability to flag particular segments, the physician community starts to really question the integrity of HIE sponsored data versus requiring everyone to log into separate hospital portals. So I would just advise, as we look at policies to think about the broader workflow implications and the clinical issues and the cost considerations as well.

Mariann Yeager, MBA – Executive Director – Healtheway

And this is Marianne Yeager. From a Healtheway perspective, since the eHealth Exchange is a federated network, we already rely on local policy and I think you've heard today that there are important differences in how the work – how these types of constraints are implemented. And so that's one of the reasons that we just have really embraced the concept of local autonomy is to allow the communities, the regions, the states to implement the policies and workflows that make sense for their communities.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

This is Deb again. I wanted to touch on something that Deven raised about whether or not we can share the information the physician can pull from the HIE back into the EHR. And it's not necessarily a policy requirement, it's a financial consideration because the interface fees that are being charged by EHRs are many times prohibitive in making that data transfer happen. So that's another piece to keep in mind.

Paul Eggerman – Businessman/Software Entrepreneur

That's a valuable observation.

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

Yeah, thank you. That was a really helpful answer to my question. Thank you.

Paul Eggerman – Businessman/Software Entrepreneur

Yup. Do we have any Tiger Team members who have any other questions?

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

Paul, I'd like to follow on that last question if you don't mind. I didn't know whether we had time.

Paul Eggerman – Businessman/Software Entrepreneur

We do.

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

This is Dixie. The – Deb mentioned, well several of you mentioned about sharing information across state lines. Do you actually report non-targeted queries that goes across the HIEs or across state lines?

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Right now we're just limiting it to direct point-to-point in Nebraska.

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

No, I mean, if you would receive a query from Indiana, could you handle it?

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

No. There's no data sharing agreement in place.

Mariann Yeager, MBA – Executive Director – Healthway

This is Marianne Yeager from Healthway. With respect to the eHealth Exchange, it was designed to enable information, if appropriate, to be shared across state lines using a consistent and cohesive common trust agreement. And really the shared platform and trust framework we've been talking about. And so we see that data typically cross state lines where there is an adjacent treatment area that just happens to be over the state, so it's still what I would call regional, but our approach certainly traverses technology platforms, geographies and the like.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

And this is John Kansky. The only non-targeted queries we support that come from outside our state that we respond to are via the eHealth Exchange and it's with federal agencies like SSA.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

And this is Deb, I do want to –

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

In Rochester – .

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

Oh, I'm sorry, go ahead.

Ted Kremer, MPH – Executive Director – Rochester Regional Health Information Organization

No, I was just saying in Rochester we just work across regions.

Deb Bass – Chief Executive Officer – Nebraska Health Information Initiative

I do want to clarify, we do have hospitals in Nebraska from outside of the state that they're member of the health systems and they have signed the data participation sharing agreement. So, those – they do conduct queries and they are outside of the state of Nebraska, but they're a member of a health system or have signed our data sharing agreement.

Sara Juster, JD – Vice President, Compliance – Nebraska Methodist Health System; Privacy Officer – Nebraska Health Information Initiative

And those are primarily and Iowa.

John P. Kansky, MBA, MSE, CPHIMSS, FHIMSS – Vice President of Strategy and Planning – Indiana Health Information Exchange

John Kansky from IHIE. One more comment. We do have interstate sharing between HIEs, but it's not non-targeted query, it's supporting other specific use cases like results delivery.

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

Thank you.

Paul Egerman – Businessman/Software Entrepreneur

That's very helpful. Any other questions? Let me thank our panelists and invite you to remain if you would like to listen to our second group of panelists and also to participate in the question-and-answer that will come after the second group. And Deven's going to introduce the second group.

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

Are we doing a break or are we just going straight into this one?

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

We had planned to go straight through, that's what was on the agenda. So given that we've asked for people's time, I think we are going to go as planned. If you obviously need to take a bio break you should feel free to do so, but we're going to proceed.

Paul Egerman – Businessman/Software Entrepreneur

And just know that Deven does not give that normally, so that's a positive thing to – permission.

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

Doesn't give what normally?

Paul Egerman – Businessman/Software Entrepreneur

Permission to leave for a bio break, so this is really...

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

Paul, that's only because I can't – Paul, so what I'm I supposed to do? Yeah, so I will – I'm going to go ahead and be the bus driver for the second panel, but I also am still using this alarm, which comes off as a rooster. I haven't quite figured out on my phone how to fix that. But it does ring – it sounds at four minutes and 30 seconds, so when you hear it, it actually means you have 30 more seconds to go, in case that wasn't clear. And some folks have made it in even before the rooster starts to crow. But everyone did super – did spectacularly in terms of time management on panel number one. So, we've had a good pattern set here. So we'll move to the presentation from Rhode Island's Quality Institute's CurrentCare. And I don't know who's starting, whether it's Laura Adams the CEO and President or Charlie Hewitt the Director of HIE Program Management. But either way, we're looking forward to hearing about how Rhode Island has dealt with non-targeted query.

Laura Adams – President & Chief Executive Officer - Rhode Island Quality Institute

Hi, it'll be Laura Adams.

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

Hi Laura, thank – go ahead.

Laura L. Adams – President & Chief Executive Officer – Rhode Island Quality Institute

I want to thank the members of the Tiger Team for the opportunity to respond to your questions today. Our CurrentCare is Rhode Island's statewide HIE operated by the Rhode Island Quality Institute, a 501 c3 and the state designated RHIO. CurrentCare viewer enables providers to access patient level clinical information through these non-targeted queries. The viewer, which has been operational since April 2012, provides access to 90 percent of the med history, 85 percent of lab reports and over 80 percent of hospital admissions and discharges generated in the state. CurrentCare operates within a pretty well defined privacy and security policy framework, which is the product of an ongoing community-based process.

Over nearly a decade and diverse stakeholder group that includes consumers, has collaborated in developing the framework, which provides for the privacy, security and integrity of the CurrentCare information. An important outcome of this process is the legislation on this Rhode Island HIE Act of 2008. Key provisions in this Act include participation in the HIE have to be voluntary opt-in, for both patients and providers. The HIE can only collect information about consented patients, collect information from providers which have agreed to be data sharing partners and can only disclose information to providers which are authorized data users, to the Department of Health or those authorized by them or to the RHIO.

The HIEs information must only be used for treatment and coordination of care, for purposes of public health and for the RHIO. For consented patients, the HIE can collect all confidential health information and make it all available for authorized uses. Upon the patient's request, the RHIO has to provide a copy of the patient's information and a disclosure report. The Department of Health regulates the HIE and in addition, the community has overseen the development of numerous other policies such as disclosure of PHI of minors, the collection and disclosure of substance abuse treatment information, the revocation of patient consent and the response in the event of a breach.

Prior to receiving authorization to view, providers sign a data use agreement obligating them to use the information responsibly. Prior to each session, the provider has to enter their unique user ID and password and attest to a treating relationship with the patients being viewed. The system maintains a log of each user's interaction with CurrentCare and is continuously monitored to detect threats and to report operational performance. Frequent audits assure that all these controls are working properly. Only authorized data sharing partners may send in information and they determine what information is sent. Only information of consented patients may be sent and substance abuse treatment programs subject to 42 CFR Part 2 must have an additional consent prior to sending their information.

In giving consent, patients agree to allow access to all their data. This was the preference of Rhode Island community in order to maximize quality and safety. Only licensed practitioners may view the patient's clinical information. Others who support the practitioners in a clerical role, only have access to demographic information. In an emergency, only practitioners who are licensed to prescribe treatment are authorized to access information without the patient's consent, that's break the glass. In this case, CurrentCare documents that the patient's consent preferences have been recognized and the patient is informed of the access.

In compliance with 42 CFR Part 2, information sent from a substance abuse treatment program is not displayed until the provider specifically requests it. Before viewing this information, a provider must again attest to a treating relationship and agree to obtain the patient's written consent before disclosing this information to anyone else. Patients may limit their consent to emergencies only or by specifying providers by name. Otherwise consent is given to all providers involved in their care. Over 94 percent of patients select all providers, 5 percent emergencies only and less than 1 percent only these providers.

The greatest challenge has been balancing privacy and security concerns, quality and safety and the practical considerations to make exchange happen. Practicality has been really critical for us, as it would have been so easy to make HIE impossible technically and operationally without compromise on some sort of an ideal. Some of our compromises include opt-in, but with all the data, simple granularity regarding who can see the data, the process for confirming a treating relationship with the provider and the process for dealing with new uses of data through advisory group review and approval, rather than sort of trying to exhaustively figure it out up front.

The fact that CurrentCare is operational today I think is a credit to a policymaking process that we believe listened and responded to the many and sometimes conflicting concerns of our entire community. Thank you.

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

Perfect. Thank you very much Laura, it was a great testimony. Next up we have Paul Uhrig, the Executive Vice President, Chief Administrative and Legal Officer and Chief Privacy Officer of Surescripts. Go ahead Paul – you may be on mute.

Paul Uhrig, JD - Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer - Surescripts

Sorry, I am. Thank you, Deven.

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

That's okay.

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer - Surescripts

So to frame the discussion, Surescripts ePrescribing service in the ambulatory setting puts eligibility and formulary information and medication history at a prescriber's fingertips at the time of prescribing. So these are non-targeted queries, as you've defined the term and the system's been in place for 12 years now. Today we connect over 520,000 prescribers with 93 percent of the nation's retail pharmacies, mail-order pharmacies and all major PBMs throughout the United States. So last year, just by example, we delivered almost 600 million medication histories throughout the United States.

So for purposes of this discussion, I'm going to describe for you our medication history ePrescribing Service, which is our predominant non-targeted query service at this time. So in its most simplistic terms, an authorized prescriber, under applicable law who is using an EHR or ePrescribing application that has been certified by us, may send a request to Surescripts to obtain a patient's medication history and formulary information. So an integral part of our operation is to ability to identify and match patients to their insurance eligibility, benefit and formulary records and respond to the requesting healthcare provider. At a high-level prescribers submit patient identifying information in a medication history request. In order to facilitate the proper and correct response to that request, we utilize demographic information provided in the request to match the individual to his or her pharmacy and PBM records by searching a Master Patient Index.

We don't keep databases of patient information. What we do is retrieve the data from PBMs, payers and pharmacies and deliver that information on their behalf. We are able to send and use that data only as permitted by the data source with a pharmacy, PBM or payer. So we have access to approximately 260 million lives through the MPI. This information's updated on a daily basis by the data sources with updates on 20 to 30 million lives per day during high enrollment periods. When a request for medication history is made, the MPI returns either a patient "found" or a patient "not found" response. If the patient's found, then in the case of an eligibility request, the MPI matches the patient with their payer- assigned unique ID number, for payer information. And the PBM uses the patient demographics and the payer signed ID to confirm that coverage exists and to retrieve and return that benefit coverage.

In the case of a medication history request, if a patient is found, the MPI matches the patient with database keys that are used to retrieve medication history records from the pharmacy. Records that are permitted to be disclosed are then transmitted back to the requesting treating provider. If a patient is not found or if no records are to be transmitted, then a message is sent back to the requesting provider stating that the patient was not found and no data is available. All this happens, from the time of the request to a response being returned, in a sub-second to 1-2 second timeframes.

So we require that all participants, whether data requesters or the data sources, comply with all applicable laws. The fact that they deliver information in this manner electronically does not alter their obligations to comply with the law. We also impose obligations through our contracts with the EHRs. So for instance, EHRs must require that both its healthcare provider customers and physicians will comply with applicable law including HIPAA and state law. They must contractually require that each prescribing physician will obtain the consent of a patient prior to requesting the medication history of the patient. They must comply with the provisions of their business associate agreements. They must require the healthcare provider to have appropriate – physical – and physical safeguards. And they must request medication history only in connection with the treatment of a specific patient in a scheduled or walk-in outpatient visit or another specific treatment event. And finally they must conduct or have conducted ID proofing that meets regulatory requirements and require healthcare provider customers to do the same in order to ensure that only appropriate persons transmit messages to the network.

So you ask about patient involvement. As indicated, requesting prescribers are required to obtain the consent of the patient to request medication history. And the checkbox that I mentioned, that is in every request, constitutes their acknowledgment that they have obtained the consent of the patient. Also data sources must comply with applicable law, so they can't disclose any information that they are not permitted to disclose or if they have agreed with the patient to not disclose any information.

So I heard the alarm go off. I guess I'd just say is, from a policy perspective, my final comment would be that it's always important that the patient not be surprised. And so that's why the CMS standard as well as our own rules contemplate that the requestor get the patient's consent. Thank you.

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

Great. Thank you very much Paul. Do we have Christian Carmody from Clinical Connect and/or Tracy Crawford?

Christian Carmody, MBA, MS, IT – President - ClinicalConnect HIE and Vice President - UPMC Enterprise Infrastructure Services

Yes.

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

Oh terrific. You are – we are ready for you if you are ready.

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

Great. Thank you for the opportunity to present today. ClinicalConnect is Western Pennsylvania's first health information exchange. It's a partnership of nine regional health systems, which include 30 acute-care hospitals, and over 3000 physicians. We have some recent participants that include a post-acute care pediatric rehabilitation organization, three post-acute skill nursing facilities and an independent 50 member private pediatric physician group. ClinicalConnect has been operational since June 2012. We have 8.2 million patient records and 1.8 million patients have consented through our registration processes.

Access to information in ClinicalConnect is coordinated through a participant's EHR. In order for a participant to make a request to ClinicalConnect for a patient's information, the patient must be registered in the participant's EHR. If not, then they request cannot be made to ClinicalConnect. Further, since the request is initiated through the participant's HER, the individual requester must be registered as a user of the participant's EHR. Once the user is logged in to the participant's EHR and a patient has been selected, the EHR can make a request to ClinicalConnect for information related to that patient. If there is information related to patient, ClinicalConnect provides the information.

The ClinicalConnect model has a number of advantages, most notably by requiring the participant to utilize its EHR to front-end request to ClinicalConnect, there is a high level of assurance that the patient has a current relationship with the provider, the patient has been informed of ClinicalConnect and has had the opportunity to opt-out, based upon Pennsylvania law. The user has the need to access the information in question, since a user must first access the patient's record with an EHR, consistent with the role-based access controls already implemented by the provider. The EHR, other monitoring systems and processes implemented by the participant can monitor access to ensure that it is appropriate, based on the controls already developed by the provider.

With respect to the questions that were posed, I wanted to address a number of them that I feel are particularly germane to how ClinicalConnect operates. I'll start with number four, what additional limits are placed on non-targeted queries? As I've discussed, who can query ClinicalConnect is controlled at the participant level based on a user having the appropriate security to view that patient record within the participant's EHR. Purpose and scope are defined in the ClinicalConnect data exchange agreement as limited to treatment, payment and operations, public health activities and reporting as permitted by HIPAA and reporting on quality measures as defined by Meaningful Use under ARRA and HIPAA.

Number five, what roles do patients have in limiting queries? Under Pennsylvania Act 121, Pennsylvania is an opt-out state. A patient is given an opportunity to opt-out when he or she registers for services at a provider's facility. The patient's preference is then passed electronically to ClinicalConnect and managed centrally. Access to patient information within ClinicalConnect is then blocked until or unless the patient later chooses to opt back in. Number six, how do patients exercise meaningful choice as to whether their patient – I'm sorry, their records are included in your aggregator service and does this extend to the release of data or does that require additional consent? ClinicalConnect requires that each participant make a standard notice of privacy practices addendum available to its patients. This addendum describes ClinicalConnect and how the patient's information will be managed and exchanged. And regardless of whether the patient has opted out, the patient's information is sent by each participant to ClinicalConnect. However, if the patient has opted out, ClinicalConnect will not provide the patient's information in the event of a query. And this model is based on ClinicalConnect being a business associate of each participant. This model is designed to ensure that patient information can be made quickly available should the patient choose to opt-in after having previously opted out.

And lastly number seven, how do you address exchange of sensitive information in a non-targeted query model? Currently, technical capability and standards within the industry that support the exchange of sensitive information are limited. As a result, ClinicalConnect instructs its participants not to send sensitive data to ClinicalConnect, especially where statutes impose additional restrictions on the disclosure of information. In light of these limitations, where the patient has concerns regarding access to their information, including sensitive information, the patient is advised of his or her ability to opt-out. Thank you.

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

Great, thank you very, very much. Much appreciated. We'll move to the last presenter in our panel, Joanna Pardee-Walkingstick of SMRTNet. I hope I didn't butcher your last name Joanna.

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

No, that's perfect. Thank you. Good afternoon everyone. SMRTNet originated as a grantee of the AHRQ Transforming Communities Through Healthcare Information Technology grant series. We've been supporting non-targeted queries since 2007. SMRTNet began with a network-driven provider identity verification process employing role-based access controls through basically a secured website web access. Currently, we have four clinical provider roles with one clerical role that excludes all clinical data. The role-based access controls limit the information provided by the exchange to the member healthcare provider, based on their assigned role and HIE access is only provided to SMRTNet members who share a common data governance structure and legal agreement.

Starting in 2011, we have since deployed automated query functionality. These queries are initiated from within the patient record, within the native EMR of the member provider and do require the registration of the patient prior to executing a query. Currently SMRTNet is covering 2.5 million patients, 87 percent of whom report addresses from within the state of Oklahoma. Provider queries are limited to treatment and operations functions, as well is limited by the geography of SMRTNet membership. So that being said, we are a hybrid network, as a centralized data repository as well as federated data sources. So the query access to the federated data sources can be turned on or off by the web access providers using click boxes.

Whereas for the providers using automated queries, those federated member sources are automatically included within the retrieval of that patient information, per the source aggregation for that particular patient within our MPI.

As far as additional limits being placed, we have automated alerts for anomalous usage in place. Alert parameters are based on typical usage parameters analysis and so when an alert is triggered, an audit of that user activity is automatically performed to verify legitimate access. So far we have not instituted any break the glass functionality. As far as patient's roles in limiting queries, we are an opt-out state and network. Opt-out materials are provided to each of our member facilities, as well as on our public website. Patient participation is global per our clinical task force within the governance structure. We do not allow micromanaging of source data on the patient's part at this time. Periodic audits are performed of our opt-outs to ensure ongoing compliance. And patients who have previously opted out can opt back in should they change their mind about SMRTNet participation at any time. And to date we've received less than a 1000 opt-out requests.

As far as meaningful choice, SMRTNet members start by amending their notice of privacy policies to include sharing data with SMRTNet prior to going live with the data exchange. Additionally members have the opportunity to exclude information based on restrictions applied by their facilities internal policy. Our members also provide educational materials and collaterals to their patients about HIE participation; however, with our diverse membership, each member has a high degree of flexibility as to the content and delivery models for those informational materials.

Sensitive information is filtered at the data source level and never sent to that exchange. We also have the technical capacity to mute specific data codes or elements at the network level to prevent mistakes in release. We do offer direct secure messaging as a method for exchanging sensitive data as an alternative to the general exchange. A clinical summary or CCD of the patient from the data in SMRTNet is presented to the requesting provider. The full display is restricted and determined by role-based access controls or the internal controls within the EMR. Emergency department usage has been most critical, especially addressing the challenges between inpatient primary care and probably the biggest – our biggest learning point has been the automated query approach from within the EMR, has been absolutely pivotal to provider engagement and usage through improved workflow. And currently over 90 percent of our queries into SMRTNet are initiated through an automatic query process.

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

Terrific Joanna, you are right on time. Everyone was right on time, everyone did a super job with that. All right, so I'll ask – I see John Houston's hand in the queue. And I remind other Tiger Team members who are listening online that they should go ahead and get in the queue. And I'll also do, as Paul did, after everyone has had a – everyone with their hands raised has had a chance to ask at least one question, or have a chance at asking questions, we'll make sure that anybody who's on the phone has a chance to answer questions. And then we'll just keep going back through the queue until we have exhausted our time. So go ahead John.

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

Great. This is a question to Laura Adams. You spoke briefly about how you manage information associated with drug and alcohol treatment and I'm just sort of interested to get a better understanding of how that information is managed and segregated within your environment. This is one of the areas I know that a lot of organizations struggle with, especially since there really aren't great ways to necessarily differentiate the information at a data level. So, could you sort of speak just briefly as to what you guys do to really try to ensure that that information is not inappropriately accessed or shared?

Laura Adams – President and CEO – Rhode Island Quality Institute

Absolutely. The way that we segregate that data is when it comes from one of those Part 2 protected centers, so we have patients signing the general current care consent to have their information sent in. And then once it's sent to CurrentCare, if it's coming from one of those that are protected 42 CFR, a second layer of consent has to be obtained from the patient to send in data from those centers. Once it comes to into our HIE, that data's partitioned behind something that's hidden from the viewer – provider viewer, unless the provider viewer asks is there any of this information available. If it is, it will say yes the information's available, and a screen comes up where there's a second layer of attestation, if you have a treating relationship with the patient. And also it reminds people that they are not to disclose this information without direct consent from the patient. Does that answer the question?

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

It does. Does this – have you extended this to psychiatric data or do you handle that differently or is it handled generally with the other types of data that you store within your HIE.

Laura Adams – President and CEO – Rhode Island Quality Institute

Again, it's based on the entity – the submitting entity. Now we have obviously primary care doctors that are treating depression and that sort of thing that information flows up along with hemoglobin A1cs and all others just because there isn't the ability to segregate. And when we put this consent model in place years ago, we were looking ahead to this time when we wanted that information to all be there. Our community felt very strongly it didn't want and HIE full of clinical data holes.

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

But let's just say, for instance, I know in the state of Pennsylvania, psychiatric – licensed psychiatric providers, we have to handle their information differently, than as you'd indicated, a PCP that might be treating a patient for depression. We don't have to treat that depression information in the same manner. So I guess I'm just verbally thinking but – so you could in theory then, for those licensed psychiatric providers, set up a similar environment as you would for your drug and alcohol treatment providers and then segregate that data?

Laura Adams – President and CEO – Rhode Island Quality Institute

If they fall under 42 CFR.

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

Oh, you do – all – okay.

Laura Adams – President and CEO – Rhode Island Quality Institute

That's what makes the decision is whether or not that provider is a 42 CFR provider.

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

Okay. That's helpful. Thank you.

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

David McCallie?

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

Yes. My thanks also to all the participants. Terrific job of summarizing so quickly and thoroughly. I just want to confirm what I think I've heard from all of you and this is the same question that we asked the first panel, that the data about the existence of the patient's record and the locations of the query is preserved, even if the patient has opted out of deeper access. And I think several of you actually made the point that that allows the patient to opt back in fairly quickly. Could you each confirm that that's how you do it or not, either way?

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

This is Chris Carmody from ClinicalConnect and I can confirm that we do receive the data from our participants and store that data regardless of whether the patient has opted in or opted out. In order to have that flexibility to quickly flip the switch and enable access to that patient data.

Laura Adams – President and CEO – Rhode Island Quality Institute

It's Laura in Rhode Island and here, no data can leave the source without a patient having opted in. Now a patient can opt-in and opt-out at will, but every time they opt-out, there is no data collected during the opt-out period and we have no ability to go back and retrieve any data during the opt-out period.

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

Just Laura, while I have you speaking, if they opt-out after some data has already been collected you just restrict access or do you actually purge it out?

Laura Adams – President and CEO – Rhode Island Quality Institute

We restrict access to that data, we don't purge it out, and we just restrict the access.

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

Okay. Great.

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

So this is Paul. So on the incoming side, if the message does not indicate that the requester obtained the patient's consent, the request cannot get through the network and ever get to a data source. On the data source side, they manage patients who do not want their data shared, so that data would never come to us and we would just return a patient not found message.

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

This is Joanna Walkingstick. We continue to receive the patient data for patients that have declined participation. We leave that as needed, then that enables us to display a this the patient has opted to not participate in SMRTNet that also facilitates them opting back in at a later date, without having essentially a hole in their global record.

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

Okay thank you all. That was all very clear.

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

Thank you. Gayle?

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

Thank you Deven. I'm very interested again in the patient's participation in the whole model, and we have both opt-in and opt-out present in this segment as well. And I'm interested to know what ability the patient has to get a copy, an audit record of what has transpired and who has accessed their information. If each one would comment on that and then if each one would also comment on if they've had any breaches or any complaints from patients.

Laura Adams – President and CEO – Rhode Island Quality Institute

This is Laura Adams and we have never had a breach before and complaints from patients. And I'm sorry, I focused on that and forgot your first half of the question, it was –

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

Audit logs and how much – does the patient have to get the information as to who has accessed their records.

Laura Adams – President and CEO – Rhode Island Quality Institute

That was part of a Rhode Island HIE Act of 2008 that mandated that patients would be able to get copies of all the information contained in their record and an audit log of who accessed it.

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

Paul, you want to answer next?

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

Sure. So in terms of audit rights, we are a business associate of the covered entity so if we were to receive a request for an audit, we would refer that to the covered entities and we would cooperate with them obviously in complying with that request. In terms of patient – well, there's never been a breach. In terms of patient, over the 10 years I've probably received maybe a dozen, two dozen phone calls from patients, they fall into three buckets. Just how does the system work? The second bucket would be, who can I call so that I don't want my information shared? And a handful of people who evidently either I guess were surprised that it occurred and we walked them through the process and obviously then worked with the vendor and the physicians to figure out why the patient was surprised. I will say just that I've never received a call that said, jeez, how did my internist have access to medication history or I was in the ER on the verge of death and how did the doctor get my medication history? In those few times where I received a question, it tended to be the podiatrist or someone like that who had access to medication history for treatment purposes, and that seems to be when the patient had some questions shall we say.

Paul Egerman – Businessman/Software Entrepreneur

But Paul, do you have a method to where a patient can say I don't want you to collect my data at all as opposed to share it? Say, I don't want you to store it?

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

Well we don't collect it, again.

Paul Egerman – Businessman/Software Entrepreneur

Right.

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

So what we do is refer them to the applicable payers and pharmacies so that they can request, at the data source, that that data not be shared and that's how it's managed. So we have a policy and a process to handle that.

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

I think there were a couple of presenters who didn't have a chance yet to answer Gayle's question, Christian and Joanna, if I'm –

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

Sure, this is Chris. Our process at ClinicalConnect is similar to Surescripts where if a patient had a question about who accessed their record, we would direct them back to their provider and work with the provider to ensure that we could present the complete view of who accessed their record pertaining to that particular patient. I'm sorry, and I forgot to answer the first question as well. We haven't had a breach or any patient complaints over the past year that we've been operational.

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

And Joanna?

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

We also lean on our participating members to provide – basically be that go between. If a patient requests an audit, we do send them to a participating provider to then request that audit and then discuss that within the context of their patient care. And we have also not had a breach, but we've received a number of questions from patients as far as the administrative or the governance type questions, we handle those. If it's anything clinical-based, we send that back to the member.

Laura Adams – President and CEO – Rhode Island Quality Institute

This is Laura Adams. I want to just check in quickly with Charlie Hewitt, who runs our HIE. Charlie, did I speak too soon about the no complaints, I want to be sure that we've correctly answered that question. Do have anything to add on that?

Charles Hewitt, MBA – Director of HIE Program Management – Rhode Island Quality Institute

Laura, that's correct, we haven't received any complaints about that my data's being used inappropriately or things like that. We've had a few patients who want to see their record and we've had a few patients who wanted to know who's seen my record.

Laura Adams – President and CEO – Rhode Island Quality Institute

Thank you, I just – I thought as the CEO, sometimes complaints don't get to me. A lot of times they don't get to me.

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

All right. Great, Dixie, you're next.

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

Oh good, because in addition to – I actually tuned in for, I'd like to ask Christian another question about his answer he just gave. You said you refer – if a patient requests an audit of access, you refer them back to the covered entity, right?

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

That's correct.

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

But if you release the data to another entity, the original covered entity who provided you the data, since you're a central repository, wouldn't necessarily know whether you released it to the second person, right?

M

Work with them –

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

Yeah, we work directly with both sides in our network to know who requested that data, who viewed the data and who provided the data, so we can provide that trail. And we also capture through the EHR access, the specific user account that accessed that record and all the other logistics around data and time of that access.

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

Right, that's not the covered entity, that's what – that's data that you collect, right?

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

That is data that we collect but we are still that – the central hub or central database. We still receive the data and the record from all the patient records from our participating members and make that available through our end-user tool, our viewer for our system.

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

Right. So if you let provider "B" view the record that was provided to you by provider "A," how does provider "A" know that provider "B" viewed it?

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

We would tell them.

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

Oh, okay.

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

Yes, we capture that flow of the users accessing the records and obviously where the record's coming from.

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

Okay, okay, that's helpful. And also want to thank you Christian for your written testimony because it answers a lot of questions that I would have had otherwise, so, I appreciate it. I have a question for Joanna. Joanna, you mentioned that you had received less than – fewer than 1000 opt-out requests –

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

Yes.

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

– which kind of raised the question in my mind, do patient have to initiate an opt-out request or are they given the opportunity to opt-out before you ever get your data?

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

Actually, that's a point that we give the flexibility to the member. Some of our members notify the patient and then tell them that they can opt-out if they are uncomfortable. And some of our members actually provide that form with their other encounter information, if they want to sign it. So there's a high degree of flexibility with our membership as far as how they want to present that option and anyone in the

world can get the paperwork for opting out through our public website as well.

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

But you will have received the patient's data most likely before they get the opportunity to opt-out probably, right?

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

Yes.

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

Interesting. Okay, thank you.

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

Okay, so we're – David, since I see your hand raised, it looks like we are into the second round of questions, at least for some folks. So I want to pause for a moment and see if there are any Tiger Team members who are just on the phone who would like to ask a question.

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

Okay. Hearing none, you're up David.

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

Yeah, this is on the data – sensitive data question and specifically for Paul Uhrig and Surescripts, but anyone else who wants to chime in, feel free to. And the question is whether or not you restrict certain medications based on their potential tight association with a sensitive illness or whether your consent allows essentially all the medicines to flow through.

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

Well the theory is again, that the consent would allow that, although that is managed at the data source, where they have filtering mechanisms in place to filter for what would be viewed as a sensitive or where they've agreed with the patient not to share information. So all of that is handled at the data source.

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

Is it common that data sources do that or is that a theoretical capability that doesn't get exercised much? It obviously would be cumbersome for pharmacies to have to manage that for every patient. What happens in practice?

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

Yeah, my understanding is that most handle it that way, I can't speak to the specifics of every relationship but most to handle it that way.

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

Are any of the other participants aware of filtering medication profiles based on sensitive association of the drugs?

Laura Adams – President and CEO – Rhode Island Quality Institute

We don't do that in Rhode Island, it's all in.

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

For ClinicalConnect, we do not filter on medication, we do filter on specific locations that are known to produce that sensitive information, for instance, we have a psychiatric hospital that we do not take their data in.

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

Okay. But not specifically after that by the drug list themselves?

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

No, we don't. We accept all.

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

Great. Thank you.

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

This is Joanna. We do not as a network filter medications; however, some of our members have opted to exclude certain medications.

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

And how does that work Joanna, because that's actually related to the question I was going to ask you about the sort of filtering capabilities that you mentioned in your remarks. Can you talk a little bit more about how that has worked?

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

They filter it at the source level generally and it is never sent to the network.

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

Right. But didn't you also mentioned that you have the capability to block certain codes in case –

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

Yes, we do.

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

– they made a mistake. And how long have you had that capability, have you deployed it? How well does it work?

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

Well we've had that capability on our new platform since 2011. We have not deployed it, but we've been kind of exploring if it needs to be and how would we go about deploying it.

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

Okay. Great, that was my question.

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

It's a nice thing to have in the tool bag though.

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

Interesting. Paul, you want to go ahead?

Paul Egerman – Businessman/Software Entrepreneur

Sure. I have a question for Laura Adams in Rhode Island. As I understand your model it's basically sort of an opt-in situation, and could you explain a little bit more about how that works for emergency care?

Laura Adams – President and CEO – Rhode Island Quality Institute

Yes. There's no information available in the HIE whatsoever unless someone is opted in. So it can be an emergency, but if you haven't given your consent, there won't be any data to flow into the system, so there's nothing that's sort of hidden and we can reveal in the sense of an emergency, we can't.

Paul Egerman – Businessman/Software Entrepreneur

And does the patient say, when they opt-in, that they want it made available to emergency departments, so is that like a patient choice?

Laura Adams – President and CEO – Rhode Island Quality Institute

Any opt-in at all means that will be available in emergencies and then patients have three levels of granularity around their selection of who sees their data. They can say, this is for emergencies only, no other time can my data be accessed. The can, at the second level, say look I just want this provider and maybe this hospital to have access, but nobody else. So they can do it by specific provider name or they can opt-in and everyone involved in their care. And I think I mentioned that more than 95 percent opt-in for all involved in my care, about 94 percent, 5 percent opt in for the emergency only and then 1 percent designate specific providers.

Paul Egerman – Businessman/Software Entrepreneur

And what's the definition of an emergency?

Laura Adams – President and CEO – Rhode Island Quality Institute

We have a legal definition here in the state of Rhode Island, so that's on the law books what that – and I don't have that on the top of my – but we can get that for you if you'd like to have it.

Paul Egerman – Businessman/Software Entrepreneur

So that's the same definition that's used like if a patient's like in a traffic accident or something like that, and a physicians has to treat them?

Laura Adams – President and CEO – Rhode Island Quality Institute

I'm sorry, yes.

Paul Egerman – Businessman/Software Entrepreneur

Okay. And I'm also interested, your approach is an approach where unless a patient opts in, you really don't have any data on that patient at all, which seems a little bit different. And I'm curious how did you come to that conclusion or why are you doing that differently than other people are doing that?

Laura Adams – President and CEO – Rhode Island Quality Institute

We did that some years ago because we knew that with Rhode Island state law, we weren't going to be able to upload behavioral health information, let alone substance abuse and the alcohol treatment information if we didn't have consent before the patient's data leaves the source. So we did that with an eye towards the future, because we put this model back in place, like we said, 2008 and the system went live in 2012. So we set the policy framework before we ever shared any data, of course, and our sense at that time was that first of all, with a really strong sense in our state that patients needed to have control over the information. So, it was – they wanted it all in, but they also wanted the ability for people to have to say yes before any data flows. So that was for "two reasons," for patients to be able to not have any data flowing anywhere without saying "yes" and secondly, for us to enable a comprehensive record for that patient when they do say "yes."

Paul Egerman – Businessman/Software Entrepreneur

Okay, and that's helpful. And what some of the other panelists have said is the advantage of keeping the data is the patient can change their mind a lot. Are you having any problems with patients changing their mind that they originally decide not to participate, then they choose to? Is that a problem?

Laura Adams – President and CEO – Rhode Island Quality Institute

No it hasn't been, not too many people are changing their consent preferences. Of course, as long as they are consented, the data flows into the HIE and it stays there, even if they revoke their consent. Now we don't reveal that data if they revoke their consent and no other data flows in during the time that their consent is revoked, and we'll never be able to go back and capture that data from the time that their consent was revoked. But we can start the data spigot flowing again as soon as they opt back into the system. So, we haven't had any problems with people doing a lot of changing of their consent back and forth.

Paul Egerman – Businessman/Software Entrepreneur

All right, so that's very helpful. And the question I have for basically all the panelists is, one of the things that's clearly in the news right now is this whole situation with this individual who leaked the NSA information, who appeared to be a system administrator. And I'm just curious, do you all have system administrators who have similarly have access to all patient data?

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

This is Chris Carmody from ClinicalConnect. Yes our systems administrators would have access, but we have security tools and mechanisms in place that audit their access and alert us and if there are certain triggers, like if they were looking up their – like a record that had their same last name or different scenarios like that, as well as just all their accesses are captured and logged and reviewed.

Laura Adams – President and CEO – Rhode Island Quality Institute

Same is true for Rhode Island.

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

Same is true for SMRTNet.

Paul Uhrig, JD – Executive Vice President Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

So same would be true for us. Obviously we're a federated model, but the same would be true.

Paul Egerman – Businessman/Software Entrepreneur

Great, thank you.

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

Great. So I'm going to ask you all the same question that I asked of the other panel in terms of sort of some of the variability in the policies that you all have enacted, some of which is in response to state law mandates, but other policies were responsive to the needs of your stakeholders. What would you suggest that we do, if anything, from a national policy standpoint on this issue given even what you heard in the first panel, if you were able to listen in, as well as your own experiences in deploying non-targeted query models? How can we help you and how can we not hurt you, I guess might be another way to frame the question.

Laura Adams – President and CEO – Rhode Island Quality Institute

Well I would – this is Laura again from Rhode Island. I would echo the person's earlier comment that said, we of course would not like a lot of things going on that would get in the middle of what we've done here. This has been an extraordinarily thoughtful process, the HIE has earned significant credibility and trust in the community because of the way we've gone about it. I can tell you opt-in is not fun and opt-in is not cheap. And we took that high road for all the what we think were the right reasons, with the view down the road and so forth, right reasons for our community. And we recognize that other communities chose different pathways because it was right for their community.

So our concern is that we also are very, very interested in the data flow across state lines. I mean, we've got people from all 50 states represented in our each HIE right now. A lot of that has to do with an Ivy League college in the city of Providence and so forth, but we are interested in recognizing that a situation like Rhode Island is going to present some complications ensuring that data, because we are stricter in many ways than lots of other states. So there's a – we think there's a lot of thinking through to do, but we want to see data exchange enabled, just because we believe so strongly that patients deserve this and really need it, and our healthcare system really needs the access to reduction of waste and the efficiency boost that we get.

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

So Deven, this is Paul. Here's my perspective is one policy, one does not fit all theme, and certainly I think any policies need to do a couple of things. They need to encourage innovation and they need to meet the needs of patients and providers. And so to me, I think a fundamental question is education, not only of patients which is key I believe, but those who I'll call innovators and who may not necessarily be those who are on the committees and testify often. We live in an age where college kids in their dorms are coming up with apps, right. And so how are the policies, how are the standards really promulgated so that everybody in the industry at least knows some of the baselines, if that makes sense.

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

Yup. Chris or Joanna?

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

This is Chris again. I really concur and echo Laura's comments about looking for ways and opportunities that this team can help foster the relationships between states. That's some of our bigger hurdles right now being in Western Pennsylvania and trying to work with providers and patients even that are in Ohio or West Virginia or New York is definitely a challenge and a pretty big hurdle that we haven't yet solved. So, that would be extremely helpful to have that type of focus from this team.

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

This is Joanna. I would second especially the commentary from the first group around the state to state connections. We're currently working with, in testing with connecting to HIOs in Kansas and Missouri. And any standardization or guidance that could come at that level would be extremely helpful. However saying that, I know that at the inception one of our biggest policy changes at the very beginning was the convoluted and confusing nature of our own state law in Oklahoma that even seemed to contradict itself in certain areas of how to handle certain types of data. And the lack of consistency between the state law and the federal law and the true opportunity to electronically implement exchange for 42 CFR classified patients has been an ongoing challenge for us since 2006.

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

So I want to, if there's time, as follow up on the remarks that you all just made in terms of how we might be helpful in facilitating more state to state exchange, but I see that David McCallie has his hand raised, so I'm going to hold off until –

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

Deven, actually can I jump in. This is Chris Carmody.

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

Yeah.

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

Just before you leave this, I think the one other aspect besides the state to state really, and I think I heard this from the first group of panelists and now our group, is how we – where we could use some extra guidance in terms of that managing and handling of sensitive information. I think that's – I don't want to lose sight of that. So, I just wanted to bring up that because that's an important point as well. Sorry to interrupt.

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

No, you didn't interrupt at all, you were – it was entirely appropriate. Thank you. All right, I'm going to – David, I see your hand raised, so I'm going to go to you and I'm hoping there will be more time to sort of go back on these sort of two issues that you want us to explore. So go ahead, David.

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

Thanks, Deven. And good news, I'm going to explore one of those issues with my question, I hope, or I think I am. And that is, the question about the complexities of state to state movement of the data. It seems fairly dramatically to be different with Surescripts in that I didn't hear anything, perhaps Paul can clarify, about state specific limits. I think my assumption is that Surescripts would say they have the declaration that it's a treatment relationship, they have the declaration that the patient has consented to the fetch of the medical prescribing history and then that's broadcast to the appropriate source. And it's up to the source to make a decision of whether to release or not and that's that. My question, Paul, do I have that right and the if that is correct, why would that not apply to the broader query model where if you have the consent of the patient at the point of care conveyed through the system to the responding system, why isn't that sufficient? So Paul, do I have the Surescripts model right?

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

Correct. Yes you do.

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

And that works pretty well, you go – I mean, you don't care which state the pharmacy is in or the PBMs headquarters are in.

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

That's correct, right, and deal with the – whether it's Laura's example of students or the people who spend their winters in Florida. There's all kinds of examples where someone may be treated one day in one location, but their records are located in a different location.

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

I wonder if any of the other HIEs, particularly the ones that are wrestling with cross-state issues, what's to prohibit a declaration from the patient at the point of care transmitted through the system to the responder that says please release my data. Is that a model that you've explored and doesn't work or is it just too complicated with legal structures in place or – ?

Laura Adams – President and CEO – Rhode Island Quality Institute

For us – go ahead please.

Joanna Pardee-Walkingstick – Director of Member Services – SMRTNet

Oh, I was just going to say – this is Joanna. The nuances between state specific regulations around handling patient data have provided some stumbling blocks.

Laura Adams – President and CEO – Rhode Island Quality Institute

I think one of the issues for us in Rhode Island is that we've started to – held our participants in the HIE that their – anybody receiving the data has signed a data user agreement. And so without that signature on that data user agreement, we don't know that they have agreed to handle the data in the way that we have expected. So I think there will be some work to deal with that.

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

That's a good point and I guess in the case of Surescripts, you mentioned Paul, there's contract language between the EHR vendor, Surescripts and the providers themselves that obligate them to certain standards.

Paul Uhrig, JD – Executive Vice President, Chief Administrative and Legal Officer, Chief Privacy Officer – Surescripts

That's correct, we would have contacts with each of the EHRs and we have flow-down provisions that they are supposed to impose upon their ultimate customers. That's correct, that speak to the things that I talked about in terms of having the treatment relationship, when the information can be provided, or the requirement to obtain the consents, the need to have HIPAA compliance security and privacy policies in place, etcetera.

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

Great. Thank you.

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

Thanks, David. So I don't see other hands raised in the queue so I'm going to continue along this line of thinking that I teed up and that David continued to tee up. If we don't sort of – I'm not suggesting that patient consent isn't may be the vehicle for facilitating exchange across state borders, it may be, even though it's complicated. Are there other sort of avenues that we should explore? I also heard that another complicating issue is having people be signing on to the agreement or agreeing to abide by policies, is there an avenue there to sort of explore some sort of national set of terms and conditions or models? Or does that make no sense at all. Given, again we're trying to preserve the flexibility here, right, but what is it that we can do to smooth the pathway for states with their own community models to nevertheless be able to share with one another?

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

Devon, this is Dixie. Could I add to that?

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

Yeah.

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

What forms such – guidance or whatever would it be is most useful to them, whether it be guidelines, whether it be policy that comes through and regulations, what's most likely to get their attention? Because some of the topics that have come up we've actually spoken about before and I think maybe our messages need a better way to get out there.

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

Or a better policy vehicle even, I sort of feel like – I mean I've got a lot of you folks who are expressing these issues, participated in the HISPC project of – that feels like a lifetime ago but wasn't really that long ago. But was aimed at attempting to sort of reduce these cross state barriers, and yet we still have them. So what, if anything, can we be doing differently to try to crack this nut.

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

Good. Yeah, good.

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

And this is a hard question, or else if someone had the answer I guess we wouldn't be here talking about it.

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

Yeah, I was going to say, do you want answers from our panelists only or do you want opinions from others?

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

Well we'll have a chance at the Tiger Team to sort of talk about this in our deliberation, so I sort of would like for the presenters to have a chance to provide their input on it. Having said that, it's not like it's a question that we surfaced to them in advance, so, it may require some additional thinking.

Laura Adams – President and CEO – Rhode Island Quality Institute

You know I think there are several ways – this is Rhode Island again. I think there are several ways we could go with this. We have always appreciated when there has been a need to do something that crosses geographic boundaries when there's been a national level agreement on the minimum standards of things. I think that's been helpful in so many different venues, so I think this would be something that we would look toward again. I mean I can see a circumstance where they might find something for their information to flow around in Rhode Island and there be something else that they sign for, an interstate sort of transmission of that. I wouldn't hope for that because obviously we've got one consent, everybody's got to opt-in and then secondly, if you're sharing 42 CFR Part 2 data, you've got a second consent, so we can consent them to death here and consent is challenging, it's very challenging.

So, I wouldn't hope for that, but I can see where in circumstance like Rhode Island, we can take a lot of data in, what we can't do is give it out, because of the consent type thing. I'm not sure that we could even share with an opt-out state, for example. So for me, the minimum standards, I mean probably we could with this direct, but I think we'd certainly have to talk a few with our community and understand the

implications and what it means. So please don't take that as the gospel, the community has not had that conversation to date, so I don't want to represent that as our position.

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

Okay.

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

This is Chris Carmody again from ClinicalConnect and I agree. I think the opt-in/opt-out dilemma and again, this is something that we face inside of Pennsylvania. We've been talking with the Keystone HIE, which is Geisinger's led health information exchange about how we can work together. And they were operational at least five years ago and moved forward with an opt-in approach. And again ClinicalConnect is the opt-out model and the state of Pennsylvania passed Act 121 that established Pennsylvania is been an opt-out state. And we're having again issues in terms of how we handle the passing of data just between two organizations, two HIEs within Pennsylvania. So some guidance from this Tiger Team whether it's in the form of policy or maybe in the recommendations that we either figure out how to solve that interoperable question between an opt-in and opt-out or we pick one, as a nation and move forward that way would be beneficial – would help simplify things I would think.

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

Anybody else want to respond? Okay, I'll – Gayle, I see your hand up. Do you want to go ahead and ask a question?

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

My question again is related to the opt-in and opt-out and how the different states of view it. So – states have chosen a model for it, individual HIEs perhaps have done that, but I think it was pretty well discussed, so I think that's a whole discussion the Policy Committee will have to have, and the Tiger Team will have to have for various things. One point I do want to offer though is that it's not just mental health, it's also a lot of laws that deal with HIV and sexually transmitted diseases and abortions.

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

Anybody else – oh, go ahead.

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

Devon, this is David. Can I pursue Christian's statement just with the follow-up question?

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

Oh yes, go right ahead.

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

So Christian you described two HIEs within the same state, so that removes one variable. Admittedly they are – they have different opt statuses, but I'm just curious sort of in principle, if a patient is needing his data. he's with a provider in one HIE and he needs data, the provider needs the data that's in the other HIE in the state, and the patient says, I give you my permission to go get it. So you have consent, even if technically you don't need it, maybe under HIPAA, you have opted in, which would trump the most restrictive constraints, what's to stop that data from flowing? Is it just the contractual and business arrangements that are in place or is there some belief that that shouldn't happen? I'm not sure I –

Christian Carmody, MBA, MS, IT – President – ClinicalConnect HIE and Vice President – UPMC Enterprise Infrastructure Services

In that scenario where the patient has opted in, let's just say for example for purposes, KeHI and their HIE, the patient opts in and we have a connection between KeHI and ClinicalConnect, the data's going to flow. If the scenario where a patient has – let's just say a patient has opted out at KeHI, they come to Pittsburgh and they decide to opt-in to our health information exchange. Well we would only have our information about the patient locally, we wouldn't have the information from KeHI because they chose to opt-out there and they never collected any information and passed it on to us from that perspective. So that would be the scenario where it would cause issue in terms of having the discrepancy between the opt-in and opt-out models.

And I think beyond that, from the state to state level, some of the things that we've experienced is just, I think there's a lack of understanding from a true clear perspective what the different states, what their laws are first of all, and then how that – what are the discrepancies? What are the differences between the states and how you would deal with that in terms of the passing of that data.

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

Good. Thank you.

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

Anybody else have any other questions for our presenters? Okay, I think we'll go ahead. We're a little ahead of schedule, which is nice, especially for those of you who wanted a bathroom break earlier and didn't get a chance to get one. We can move to next steps. I will say we thought that we were going to have – (Indiscernible) not enough time to begin to have a discussion among the Tiger Team members about where we might head with this. And it's still quite possible that even though we do have a bit more time than we thought we would that people will need some time to really digest what we heard, have a chance to read through the transcript. I know I certainly am looking at my notes right now and thinking they don't look so good in terms of getting in all of the very rich detail that we got from both panels.

We will be beginning to discuss this in earnest at our next Tiger Team meeting, which is on July 10th from 1:00 p.m. to 2:30 p.m. Eastern time. And we invite our panelists to attend that meeting because we'll be talking about the testimony that we have received and we're going to leave more time than usual in that during that discussion to gather information from the public. I think the call would be too big if we sort of had everyone actively participating in the dialogue. But what we can do is to open up the ability for you all to give us feedback on the discussion at other times in the call than just at the end. So that we – and certainly to give more time at the end. So for those of you who want to continue to engage with us on this, we want to find a way for you to do that outside of the context of just this virtual hearing. And so we wanted to put that on your calendars and more details will be forthcoming about sort of the agenda and times for public comment in the near future.

And I suspect that this may also take us more than one Tiger Team call to wrap up recommendations on this. We're clearly not going to present recommendations on this at the July Health IT Policy Committee meeting, because that's on July 9th we don't even meet again until July 10th. I think we're initially aiming at August, but again, depending on how robust the conversation is, we may in fact, need some additional time. But we're certainly aiming to present this at the August Policy Committee meeting and hope we will be able to do that. Gayle, now I see your hand raised. I'm sorry if I missed you earlier. Do you have a question or was that from the earlier one?

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

No, I do have a question.

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

Okay.

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

I would request – more of request is that in looking at the information that was sent out, we only I believe have the website or the URL for one or two of the presenters. If we could have each one – if you could send us the website so before our next meeting we could take a look at their websites and really kind of familiarize ourselves a little bit more with that particular HIE. It would perhaps answer some of our questions or really give us more insight and understanding for conversation in talking about various alternatives.

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

Well that – it sounds like a great idea, Gayle. So, we'll ask each of the panelists in both of the panels, I think we have the one for Nebraska from the slides and also Indiana. But we'll certainly go back and gather the others.

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

Thanks so much.

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

That's really helpful. I mean, in addition to sort of, we'll have the transcript available for folks as well.

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

Does anybody else want to add some thoughts before we open it up for public comment? Okay, so – Paul Egerman, do you want to – I know that I want to say some extremely wonderful things about the folks who joined us on this hearing today. We couldn't thank you more for taking the time, for sharing with us your experiences and being so candid with us about both the challenges and successes that you have experienced. It was enormously helpful and we look forward to continuing the dialogue with any of you who want to remain engaged in the conversation, it's been extremely helpful.

Paul Egerman – Businessman/Software Entrepreneur

Yes, and this is Paul Egerman. I just wanted echo what Deven just said. Thank you so much for your participation. I know it was a lot of work to present when we put you under pressure and said you can only talk for five minutes that makes it all that much harder. So I just want to thank you for participating today and hope that you will listen in to our next Tiger Team meeting. And also hope that if you have additional thoughts on our work that you will let us know. We very much appreciate your comments. And I also, of course, want to thank the Tiger Team and the members of the public. I think we have an opportunity now for public comment to see if they have any.

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

Yup.

Public Comment

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

Operator, can you please open the lines for public comment? And I'll notify everyone that public comments will be limited to three minutes. Thanks.

Caitlin Collins – Altarum Institute

If you are on the phone and would like to make a public comment please press *1 at this time. If you are listening via your computer speakers you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. We have no comment at this time.

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

All right, thanks to everyone again and we look forward to discussing this topic on our next call.

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

Thank you, Deven. Thanks Paul.

Paul Egerman – Businessman/Software Entrepreneur

Thank you.

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

Thanks everybody.