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APHL Newborn Screening Health Information Technology Webinar

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Presentations:

- Meaningful Use 101— Wes Kennemore
- Rhode Island's KIDSNET— Ellen Amore & Christelle Farrow

Moderator:

- Guisou Piñeyro, Senior Specialist, Newborn Screening and Genetics, APHL

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Please note that the recording begins after the presentation started.

Wes Kennemore: The first of those is that any individual eligible provider or eligible hospital had to use a certified electronic health record and there were a number of stipulations around what constituted a certified health record.

Then, we have to be able to connect those health records to improve the exchange of information and ultimately the quality of care. Finally, it dictated a number of clinical quality measures that had to be reported in order to demonstrate compliance with Meaningful Use.

Now, there are actually two separate ways and two separate programs under which a hospital or a provider might be able to dictate. Many people believe that you sign up for Meaningful Use, you're eligible, you comply with requirements and you get paid. That's not entirely true.

There actually are two separate ways you can be paid. One of those is under Medicare and the second one is under Medicaid. Obviously, you have to select which program you're going to be compliant with and which program you are going to be paid under. If it's Medicare, those funds are administered by the federal government. If it's under Medicaid, those funds are administered locally, the state Medicaid agency.

There's also a difference in how much money you're eligible to get which we'll talk about in just a minute. Under the federal program, Medicare program, you have to bill at least as much as they reimburse you in order to be reimbursed where under Medicaid, they don't really care how many dollars they reimburse you. It's more based on the percentage of your patient population.

For an average Medicaid provider, 30% of their encounters need to be Medicaid, paid in some capacity by Medicaid in order for them to qualify for reimbursements where for pediatric practitioner, that number drops only 20%.

You have to choose again one program or the other and you can't double dip. That's kind of true. That's kind of not true because hospitals have an option where they can double dip but that's a long and complex process that we won't talk about today but we could talk about it later if you'd like.

Basically, the whole goal of Meaningful Use was to incentivize hospitals and providers. If you look at what could a provider be reimbursed, under Medicare, they could make up to $44,000 and this was money that would be reimbursed to the provider to help subsidize and incentivize them to institute quality and electronic health record.

If they could qualify under the Medicaid program, those number of dollars could go up actually $63,000 and all this assumes that they were qualified in either 2011 or 2012. If you didn't qualify in 2011 or '12, there were some reductions and unavailability and step wise reductions. Again, that's a formula that we could talk about at another time if you wish to.

That bottom bullet is actually very key which is any hospital that qualified under either program qualified for a base of $2 million of incentives and could qualify for additional incentives based on some formulas and there was no maximums. It really was beneficial for hospitals to think about getting involved in the program.

Essentially, Meaningful Use has three phases. Phase one which began in 2011 was really focused on the concept of let's institute an electronic

health record and let's begin to capture information. In stage two, we're saying that we want to begin to exchange that information in meaningful way. In stage three, we're now looking more toward how we can utilize that information to improve the quality of care.

Stage one, obviously has already been enacted. The regulations are in place to pursue that. The stage two regulations have been published and they're in place for certain providers now and certain providers have gotten an extension where they don't have to comply with stage two just yet. The stage three regulations are actually just now in development and have not yet been published.

If you look at that in pictorial format, because I put a lot of words on those previous slides, pictorially, you look at this and say this slide, we actually built this slide back in 2011. We've used it in a number of presentations since then. This is the way Meaningful Use was originally laid out, that 2011 and '12 were all about data capture. '13 and '14 was about data aggregation. Then '15 and on was about how to you use that to impact outcomes. Basically, what you're seeing is stages two and three. There's a shift of one to two years before those stages actually get fully implemented.

If you go all the way back and you look at how is Meaningful Use being driven to the healthcare community, first off, there were five very specific priorities that were identified as part of the Meaningful Use program. Without reading the model, you can see the model list there on the slides. Basically, we want to improve the quality and safety. We want to engage our patients. We want to improve care coordination. We want to ensure privacy. Then we want to start looking at population health.

We accomplished that through the requirement that a certain set of core objectives have to be implemented by everyone pursuing Meaningful Use dollars. There are menu set of objectives and you have to choose some subset of those objectives in order to fully comply.

Again, I realized all of this is still very high level. Again, we could dive into all kinds of detail at any point if you wanted to. Basically, if you look at stage one, for hospitals and critical access hospitals, there were 14 core

objectives that every hospital had to meet. There were 15 core objectives that every eligible provider had to meet.

If you notice the public health and population requirements were not part of the core but then you went to the menu set and there were about ten objectives there and you had to implement about five of them and at least one of those had to be a public health objective. You could choose one out of any one of the three.

As stage two moves on, we're basically moving most of the public health objectives into the core. Everyone is going to have to be able to comply with all the public health objectives.

Then you look at those and say, "What are those public health objectives and what does that really mean for us?" Well, in the public health world, it means a couple of things. Basically, what we're trying to focus on is the capability to submit electronic data regarding our immunizations, electronic data regarding syndromic surveillance and the capability to submit electronic laboratory results.

Now, the big debate that's going on in public health or in Meaningful Use right now today is should an automated and electronic case report be part of the Meaningful Use objectives. To date, we have not mandated the case report as part of the Meaningful Use objectives not because we think it's unimportant but because technologically, there had been a number of hurdles in getting that implemented and defining the requirements fully but there are some pilot projects to try to move forward with the idea of a case report as well.

Again, just a quick clarification on a public health agency, I think you all know what a public health agency is but it is actually defined in the Meaningful Use regulations just to make sure there was no confusion.

Now, the Meaningful Use objectives that we tend to focus on most heavily in the Informatics Group at APHL obviously is the report of a lab results objective. I think this is the objective that would apply more to the newborn screening group than the others. You think about this, it's basically the capability to submit an electronic data on a reportable result

but a reportable result is dictated by state and local law more than federal law.

Under stage one, all you really had to do was submit a test transaction. If that test transaction failed, you are done. You could theoretically submit a test transaction that you knew was wrong and you knew would fail and you would still have met the Meaningful Use objective for stage one. If that submission was successful, that test transaction, then you had to engage an ongoing submission.

For stage two, we've obviously lost those exemptions and we have to participate in ongoing submission in order to qualify for our Meaningful Use reimbursements.

Just a quick overview, immunization registries and under stage two, we've actually increased immunization registries to include what we think, quotation marks says specialized registries. Again, it's basically the idea that we are submitting to some registry the concept that an individual has been immunized against a particular condition.

Syndromic surveillance by and large has been restricted to emergency departments. We are really looking more at emergency departments submitting syndromic surveillance data. There had been a number of issues around trying to have providers or even inpatient hospitals submit syndromic surveillance. There are of course exceptions to that all across the country but by and large, syndromic has been applied more to emergency departments.

What does that really mean for newborn screening? Now, those first two bullets in particular, really do shock a lot of people when we say them but they are true. The first one is, Meaningful Use applies to eligible hospitals and eligible providers. Public health laboratories are neither eligible providers nor eligible hospitals.

Therefore, technically, a public health lab is not required to comply with Meaningful Use. Likewise, a commercial lab, a LabCorp or Quest or panel, technically, they also are not required to comply with public health with

Meaningful Use because they are not eligible hospitals or eligible providers.

Thirdly, large labs and public health labs have received no incentive payments under Meaningful Use. There could be an argument that there's minimal incentive for public health to comply with these rules.

There are a couple of exemptions here. Here's where we run up against some of the gray areas. Specifically, as it applies to newborn screening, if some newborn screening test would qualify as a reportable condition, in other words, if it is required to be reported to a particular jurisdiction in which you operate and if the lab performing that test is performing it as an agent of an eligible hospital, then, that test or that report must be submitted to the public health agency utilizing Meaningful Use compliant technology and rules or the hospital would lose its ability to claim its Meaningful Use dollars.

There's a little bit of a circuitous logic here and I fully recognize that. We've discussed it at length in a number of our meetings and it's just not something we've done a good resolution to yet. The key point there is that all of those issues are very clearly jurisdictionally dependent.

Having said that we may not be required as public health entities or public health labs or even newborn screening labs, we may not be required to comply with Meaningful Use. Realistically, what are our best practices?

Here is the simple truth and I said this actually for the very first time in a presentation I made at the APHL annual meeting in 2011. We in public health have, at least at the beginning of Meaningful Use, turned our heads the other way and said the rules don't apply to us and we're not incentivized to comply.

My comment is that may be true but if we in public health don't get ahead of the curve and if we in public health don't try to lead the way, we will be left behind and we will later become overwhelmed by requirements that hit us on the back end. It behooves us to look ahead

and it behooves us to try to be on the leading edge of these requirements.

What do we really need to do? Well, we really need to look at our business processes and we need to say, "As we begin to move forward, how are we going to implement various types of reporting?" The answer is we really need to be looking at the Office of the National Coordinator (ONC) and the standards that have been issued by Centers for Medicare & Medicaid Services (CMS) and ONC and people like that. We need to leverage those technologies that we have available today but we still need to keep in mind that there's a future out there and there are requirements that are going to hit us in the future.

A great example that is the integration with Health Information Exchanges (HIEs) and that's a whole separate presentation that we could spend several hours on so I won't dive into it. The reality is we are going to have to be integrating with HIEs more and more as we move forward.

We also need to establish partnerships. We can't look at any of this is in a vacuum. We have to be reaching out to the hospitals that we interact with. We have to be reaching out to the public health agencies that we report to and that we interact with. We need to be looking inside the public health laboratory community to form collaborations in how can we share and reuse components in order to make everyone's hurdle for compliance lower. These are all of our best practices that we really need to be thinking about.

Even down to the point of what is the best practices systems architecture. I've laid one out here. Please don't try to read it in detail. This is really just a flowchart that we developed as part of one of our projects in which we're assisting with Meaningful Use in the public health community. There's an architecture that makes sense and makes it easier to comply with the Meaningful Use requirements.

Finally, I'd really like to say, if you're looking for help, if you're looking for more information, if you want to know more about this, there is a program in Meaningful Use, there is a program at APHL where we are

actually funded by CDC to help stimulate compliance with Meaningful Use in the public health community.

It's one of the programs that I happen to run so we're available to talk to you at any point in time. We'd love to help you out. We are funded by CDC grant. There's a very simple one page application that you send in to CDC to say, "Hey, I'd like some help and here's what I'd like you to help me do." They review that and if they approve it, then they may dump it over the fence to my team and then we move forward with helping to implement those solutions.

Again, conclusion, Meaningful Use, we will be able to respond faster. I actually have a very interesting little scenario that's a true life scenario about how we were actually able to decrease our response time to help tie this outbreak by about four days through the use of Meaningful Use compliant electronic laboratory reporting. It really does make a huge difference in our impact in the public health community.

Finally, there's my contact information. If you don't have time to copy that down, feel free to reach out to the people that you're aware of in the newborn screening group. They have the strange ability to find me wherever I am in the country. We'll be happy to talk to you at any point in the future. With that, I will turn it back over and happy to answer any questions.

Guisou Piñeyro: Thank you so much, Wes. That was really great. We'll pause here for a couple of minutes. If in case anyone has any question, if you would like to ask a question, please press star 7 to unmute your line.

Male: Hi. There will be an opportunity to ask more questions later on after the presentation. I guess we can move to the next one.

Guisou Piñeyro: With that ...

Brendan Reilly: Actually, sorry.

Guisou Piñeyro: Yeah, go ahead.

Brendan Reilly: This is Brendan in Texas. If I could just summarize a little bit and ask a bit of a question here. I think with a lot of folks who are interested more specifically, and I think we kind of touched on this but I'm not quite clear on it is in newborn screening, we're attempting to establish, receiving test orders from hospitals and then reporting results back to them. There's a lot of talk about that hospitals need to show compliance to show that they can report to a public health agency.

I guess from my perspective, we're reporting results back to them. One thing we're wondering is how we can leverage the requirements on them to motivate them to create these connections with us.

Wes Kennemore: That's actually an excellent question and it's a $64,000 question because we've been working trying to resolve that exact issue for quite some time. Here's a kind of interesting little nuance of the rules. You get around it. There is a requirement around how you report laboratory results but there is no requirement on how you submit those orders. Many times, the electronic order side is not compliant because there really is no regulation for them to comply with.

Having said that, over on our informatics team, we've been doing some work around the concept of electronic test order and result for quite some time and we have some pilot projects over on that area, to tell you that I have a magic bullet that says, "Here's how you get them to comply or to agree to work with you," I don't have a magic answer there.

What I can tell you, is that when I talked to Chief Information Officers (CIOs) in the hospitals, even as a doctor, it used to be I could call a CIO. If I said I'm Dr. Kennemore, they would talk to me all day long. In nowadays, if I say I'm Dr. Kennemore, they say, "Who cares? I'm too busy to talk to you."

That really is an issue. The way that we are influencing hospitals, CIOs and technology departments today is by being able to basically tell them, "Look, we understand that you're overburdened. We understand you have more way to do. Let us just come in and take the ball and run with it so that your staff has to have very minimal involvement. We will help you

put the tools in place to make this happen." Still not a perfect answer but it's the best answer I've got for you today.

Brendan Reilly: All right, thanks.

Guisou Piñeyro: Thank you for that question. I think we'll move on to the second presentation.

Operator: The conference has been muted.

Guisou Piñeyro: Next up, we have a presentation from Rhode Island KIDSNETt Program. Christelle Farrow and Ellen Amore will be presenting. Ellen is the KIDSNET manager and Christelle is Rhode Island's newborn screening program manager. If you could press star 7 to unmute your line, then please let me know when to advance the slides and I'll be happy to do that for you.

Ellen Amore: Okay, we have unmuted our line hopefully. Can you hear me?

Guisou Piñeyro: Yes, loud and clear. Thank you.

Ellen: Okay. Hi everybody. This is Ellen Amore. Thank you for the opportunity to share with you how Rhode Island has integrated three of our newborn screenings. The blood spot, the laboratory data, the newborn hearing data and we're actually working now on critical congenital heart disease data, how we pulled that into our childhood preventive health information system that's called KIDSNET. Next slide please.

Just to let you know briefly what KIDSNET is, KIDSNET is really a public health program. It's not full electronic medical records that has all information on a child. We have pulled together in one information system data related to maternal and child health program. We're very focused on maternal and child health and supporting those programs in our health department that serve those populations.

What our mission and function is, is we facilitate the collection and sharing of this public health data by obviously authorized users in order to help facilitate timely and appropriate follow up to preventive health

services including of course the newborn screening services that we provide.

KIDSNET is also actually incidentally an immunization registry. We have been working with providers on Meaningful Use. We're familiar with the topic you just had and we'd love to see the public health menu items expanded beyond immunization to include some of the newborn screening functions as well. Next slide please.

The way that we capture data in KIDSNET, we began a long, long time ago. January 1st 1997, we began collecting all births in the state and we have continued to do so since then. Right from the beginning, the newborn hearing screening data system sent us data right into KIDSNET. We started getting blood spot data. We have it going back to the year 2000. We're hoping to implement our CCHD data flowing into KIDSNET by next summer.

Initially, records are opened in KIDSNET as result of getting feeds, electronic feeds from our electronic birth certificate system. For those children who aren't born in Rhode Island, we can also open records when we get data from one of the participating programs. It's a hybrid data modeled, meaning that some of the programs, we just warehouse certain key pieces of information into KIDSNET. Other programs, we are their entire data system.

For example, we are the immunization registry. We are a home visiting data system. For newborn, we really just warehouse key pieces of information. We have a separate lab system. We have a separate newborn hearing screening system, et cetera.

Once we get an initial load, the services may be updated again. Either we may get direct data entry in some cases but for the most part, we just get electronic file feeds from various programs and healthcare providers. Next slide please.

This is a slide that shows you the partner programs that we collect information and integrate Information from. We have a growing number

of programs that are sharing data through KIDSNET. All of the newborn screening programs send data.

The thing that is important to note is the standards that have been developed, the HL7 standards to share data and to exchange data were developed actually after we started doing this. All of our file exchange doesn't use the modern world of HL7 data exchange with the exception of now, the immunization piece because providers need that for Meaningful Use.

Really, we just have flat files going back and forth. We customize the import process. It worked okay because we have a small number of data sets that we're pulling from so it's really been okay but if you have a lot, you probably need to go with national standards. Next slide please.

We also have a growing number of users that, authorized users that can use the system. We have primary care providers and specialists, audiologists, head start child care, EI, WIC. CEDARR's is a Medicaid case management program in Rhode Island. All of those programs can help us with care coordination and follow-up needs for newborn screening. They're very important partners.

Also, it helps our KIDSNET staff show what newborn screening follow-up is needed and which programs a child might be participating in, who their primary care provider is. All those things help track them down and find other partners out in the community who might be able to assist us with newborn screening follow-up. Next slide please.

This gives you an idea of how the data flows. Within the birthing hospitals, they're filling out their birth certificate worksheets. The lab slips are going up to the lab, newborn hearing screening goes into the screening equipment and they're also performing critical congenital heart disease screening. We're actually not going live officially till next summer but all the hospitals are, for the most part, already doing that. They're putting that information into their electronic health record.

Each of these types of data are collected in different ways. The birth certificate information goes into the electronic birth certificate. That

opens a record in KIDSNET. The lab data comes in directly. We get a feed from the ... We use the regional laboratory in Massachusetts. The hearing data comes from a system, we call it Right Track. The hospitals have their own electronic health records.

Not all the hospitals are going to be able to send those critical congenital heart disease data from an electronic health record especially and not initially. We've also built in a way to get that information directly from the electronic birth certificate system. There's going to be two options on that at least initially. All right, next slide please.

Because the data is integrated, we've been able to create several reports that helps support our newborn screening follow-up. We have, we call the six-day report which is basically a report that runs and tells us every birth in the state who has not ... Who has, we have no evidence that a blood spot specimen has been received by the laboratory.

We have a similar report for newborn hearing screening, who is missing the newborn hearing screen and hasn't been done at all and then of course we follow up with the hospitals and the primary care providers on that. We have various diagnostic tracking reports so if we have an abnormal newborn blood spot result and we're trying to figure out who still hasn't had diagnostics, those all run on a regular basis.

We have several different reports that can be run directly out of KIDSNET that allow our partners out in the community to see who needs follow-up from newborn hearing screening. Primary care providers can run report, early intervention and WIC. We know who is in early intervention, who is in WIC and they can see which of their clients need diagnostic audiology or a re-screen or something like that. We will do the same thing as soon as we start collecting the critical congenital heart disease. We'll do a similar type of report to see who has been missed on that.

Actually, I'm sure many of you do the same thing where you connect you birth certificate data with the laboratory data but that is very, very powerful. When we first started running that six-day report and told the hospitals, we were actually a little bit disturbed to find out how frequently kids had been missed. It was really eye-opening to see how

many times, how many bullets had been dodged and kids not getting the proper screening. Initially, the hospitals said, "How do you know that we didn't screen them?" We told them that we've integrated the data.

We went from that to ... They started calling us saying, "We know we missed this child. We missed this baby. We've already been in touch with the primary care doctors. They're coming back in. They're going to have it done." It really became much more proactive on their part. It was really great. Now, it's very rare.

We also have found things like one ... Always a holiday weekend is when things go awry. All of a sudden, our six-day report was very long and when we followed-up, we found out that somebody different at the hospital who's filling in on a holiday weekend had put the envelope, overnight mail envelope that got sent to lab up on top of a file cabinet. It was just sitting there and so it had a large number of specimens in it. We were able to track that down and very quickly. We didn't end having to recall all of those babies in.

Christelle is going to now walk you through the data system to show you what it looks like and to talk a little bit about that. Next slide please.

Christelle: Okay. Authorized users in KIDSNET can see a summary of the newborn screening services. In KIDSNET, this is what we call the newborn summary screen. As you see, there's the birth, weight of that infant, the hospital they were born in. We also had immunization data, the hearing assessment information, the data testing was performed, the results, as well as the audiological recommendation.

We also have the newborn development risk assessment information and any child with a risk that showed a positive result, they're referred to home visiting. The next is the home visiting program that that child was referred to as well as blood spot information where we have a Guthrie number.

Each specimen has its own unique Guthrie number. We also have the blood drawn date, the results of that screening and the specimen

received date is the date that the lab received the specimen. Next slide please.

You can also see more specific information about each program. Here's what the newborn hearing page would look like. As you can see, the top portion was the same information you've viewed in the summary page. Now, we have more detailed information that the audiologist completed regarding that child. You'll see the date tested, who that audiologist is, the type of testing that was performed, as well as the confirmed diagnosis for that child. The audiologist also has the capacity to enter comments within KIDSNET and that's displayed as well. Next slide please.

For newborn blood spot screening, this is the page that would be displayed. As you can also see, the newborn blood spot ... The first top of the portion was shown in the summary page. For a baby who had an abnormal newborn screening, the results would say call newborn screening program and the provider will then have to call the newborn screening coordinator to get more detailed information.

This slide also lists all the conditions we're testing for. In Rhode Island, we test the 29 conditions. Starting August 1st of 2014, we recently added severe combined immunodeficiency, if this this child has more than one newborn screening specimen that was done, all of them would be shown on this page but in chronological order. Next slide please.

For the instance that have an abnormal newborn screening that needs to have diagnostic follow-up performed, our newborn screening coordinator would go into KIDSNET and make a referral to one of the five clinics whether that's the metabolic endocrine, cystic fibrosis, hemoglobin immunology clinic and then that clinic would then go on to KIDSNET, they would get a list of kids that were referred to them by the newborn screening coordinator in their drop down list.

Once they would complete the follow-up information on that child, that child would then disappear from their drop down menu. This is an example. All these information that we're showing you right now is not a real child. This is all in the play environment. They would click, for example, Sneezy, once they click that child's name on the demographic

information, it would automatically be pre-populated. As you can see, the name of the child, the date of birth, what primary care physician that child is being seen for by, we also have the parent and the date of birth of the parent.

The next is the data that child was referred to the independent clinic and that is the date that the newborn screening coordinator made that referral to KIDSNET. We also have the first date of that child's appointment within a clinic. The clinic would also enter the confirmed diagnosis, where that child was diagnosed, prenatal information is also entered. The clinic also has the ability to enter comments within KIDSNET within these specific categories. That would also be displayed. Next slide please.

Also, we have the diagnostic testing that was performed, any comments that was entered and then the diagnostic treatment whether that child was enrolled into that counseling. That clinic would then hit submit, and then that information would automatically be sent to KIDSNET and when a provider goes into KIDSNET, they would see all these information that was displayed within the diagnostic reporting page. Next slide please.

For critical congenital heart disease, currently we have six birthing hospitals and all the birthing hospitals are screening for critical congenital heart disease. Now, we're working on getting the data from these hospitals to this date because as of July 2015, all hospitals will not only be required to screen but they'll also be required to submit data so we can do tracking and follow-up.

Currently, there are two hospitals with electronic health records currently exporting the flat files to KIDSNET and these are our two largest birthing hospitals in Rhode Island. They deliver about 80% of our births. Hospitals, we have about two hospitals that have no EHR system. They're all on paper.

Like Ellen stated before, they would have the ability to enter CCHD results into our electronic birth certificate data system. The data elements that were developed within the file listed below, we have the mom's name, date of birth, medical record number, the same for the

baby, the birth hospital, the date of the final screening, the confirmed diagnosis, and what the failure you attribute it to. Next slide.

Instead of creating a whole new system to have that diagnostic file of information entered for babies who do not pass their critical congenital heart disease, we are just using our existing system known as the birth defects reporting page. Cardiologists will have the ability to go into our birth defects page and enter that follow-up information on that child who did not pass their critical congenital heart disease screening.

This is just an overview of what our current birth defects supporting page looks like. We're going to be enhancing that so we can make sure that we're able to enter information regarding critical congenital heart disease so that child, the birth defects, whatever type of critical congenital heart disease form they have would be entered and then the test results, the echocardiogram. We are just building off of the current system we have for that for the follow-up information. Next page please.

The next step with CCHD is we are going to develop electronic interfaces with other hospitals, EHR system. We are working to complete the development of data entry capacity into the electronic birth certificate system. That will go live ... We're switching to a new birth certificate system and we're going live with that January 1st of 2015, as well as develop CCHD display in KIDSNET.

As you remember, we have pages for providers to view newborn blood spot data as well as hearing data. We're going to also be building that same module for CCHD so when a provider goes in, they can see the test results of that child. Like the other two screenings, we're also going to develop a six-day report so we can track and follow up on kids who do not receive a critical congenital heart disease screening within the first six days of life. That completes our presentation.

Guisou Piñeyro: Thank you so much. That was really great. I think we're all really excited to hear more once your CCHD and EDI results become fully integrated in KIDSNET. That's really exciting.

Ellen Amore: EHDI results have been there since 1997. We've always had those. Those are fully up and running. CCHD is the new one.

Guisou Piñeyro: Great. Thank you.

Ellen Amore: We will be happy to answer any questions. Does anyone have anything?

Guisou Piñeyro: Please press star 7 if anyone has a question.

Guisou Piñeyro: We did get one question in to the chat box. The question is with so many agencies with access to your data, how do you ensure that health information stays in private?

Ellen Amore: The access to the system is what they call role-based access. The information that you're able to see in the system is dependent on your role. If you are a primary care provider, you're able to see pretty much all of the information although not entirely because you need that to do your job. An audiologist would not be able to see, for example, the critical congenital heart disease results because they probably don't need to know that. It's role-based access.

We, as a program, don't allow information to go out to a new role without the permission of the program. It's their responsibility to work with the legal staff to decide if we have legal authority to release that information to a particular user group. Of course, you have login IDs and passwords just like any secure system.

We also, in Rhode Island have a fairly permissive state law in terms of we are allowed to share information for the purpose of care coordination so that allows us to do quite a bit. I know in other states, it's a little bit more difficult because of state laws.

Guisou Piñeyro: Thank you. Any other questions?

Brendan Reilly: Hi. This is Brendan Reilly in Texas. If I could jump in, I wanted to follow up on a question. I had a similar question. If I could just drill down a little bit more in terms of, for these different external providers, what kind of

process do you have for them to sign up basically? What do they need to do in order to gain access to the system?

Ellen Amore: They have an annual agreement that they sign. It's actually ... It's a little hard to explain. Their access is determined for the most part by participation in our state supplied vaccine program. When they sign up to get state supplied vaccines, they do that annually.

There's an online registration system that they have to go in and fill out and include their medical ... I believe it includes their medical license number. It's tied in with that. It has to be somebody who's participating for the most part in the state supplied vaccine program because those are the people in the state who see children. People who don't see children don't need to have access to the system.

They go in. They do an online thing and they have an agreement that they agree to protect privacy, abide by HIPAA and other state confidentiality laws that has language about if they have to keep being secure, that people have to ... I don't have the language right in front of me but basically that they ask every user that is assigned a user name and password has to sign a confidentiality agreement and those have to be available on file for audit purposes. They're pretty strict about who they sign up.

We also have a staff of what we call provider liaisons who got out and do training in every office. As part of the training, they discuss confidentiality and security. When you first log in to KIDSNET, there's a disclaimer that says it's against state law to basically look at people who are not your patients.

We also do audits. We look for unusual activity. We have uncovered unusual activity and followed up on that. In some cases, it seemed legitimate. In some cases, it's been problematic and has been addressed.

Guisou Piñeyro: Hi, everyone. This is APHL. Our phone dropped the call. I'm sorry about that. The question was specifically for EHDI data. Is there any validation of the data submitted and how do you do quality control of the data since so many providers are submitting information?

Ellen Amore: Right. Rhode Island is very, very different from other states when it comes to our EHDI data. As Christelle mentioned, some of you may have been chuckling that we only have six hospitals in our entire state that deliver babies. It's almost like a small city. That's it. We really are not dealing with a lot of hospitals. We have all of our EHDI data is centralized so we, as a state, contact with one of the hospitals to be responsible for the entire state. They do go out. They train all the screeners. The screeners are putting the results and sending the results. They have somebody that does QA at the point of entry into the newborn hearing screening database called Right Track.

We're assuming that that is all been done by the program and by the time it gets to kids, it's already been cleaned and it's fairly accurate. I know that probably doesn't help you because it's very different from other states where the hospitals are sending the data themselves. There's less QA on it.

The only data that we actually get from healthcare providers, from doctors per se is the immunization data. Quality assurance is a constant effort.

Guisou Piñeyro: Great. Thank you. Any other questions for the last few minutes that we have? Feel free to use the chat box as well. Okay. Hearing none, I appreciate everyone being on the webinar today. Thank you especially to our presenters, Christelle and Ellen and Wes Kennemore for your great presentation.

If anyone does think of any additional questions, feel free to send them to myself or to Careema and we'll be sure to forward those on to the presenters and get you some answers. With that, I will end the webinar. Thank you so much everyone.

Ellen Amore: Thank you.