



## Critical Congenital Heart Disease/Health Information Technology Technical Assistance Webinar

March 2015

### Presentations:

- Kate Tullis and Jerry Hendrickson on the Delaware Integration Experience
- Karen Andruszewski and Kristy Tomasko on the Michigan Integration Experience
- Andrew Richardson and Eduardo Gonzalez-Loumiet on the Florida Integration Experience

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Careema: Good afternoon everybody. This is Careema Yusuf of APHL and the NewSTEPS program. I'd like to welcome you all to today's webinar. I will go ahead turn it over to Lisa Hom who will begin the webinar and do the speaker introductions.

Lisa: Careema thanks so much. Are you able to hear me?

Careema: Yes, I am.

Lisa: Wonderful. Thank you all for joining us this afternoon for part two of our Health Information Technology Critical Congenital Heart Disease joint webinar series. This is the second part of a 3 part series dealing with Health Information Technology.

Today's topic will be the state experiences with integration of reporting newborn training results. Four Critical Congenital Heart Disease and/or early hearing detection and intervention in the Newborn Screening Program. Program Specialists and IT Specialists from Delaware, Michigan and Florida will be presenting on this call this afternoon. We will also have a brief discussion section at the end when all of our speakers have finished speaking.

To introduce myself, I am the one the co-chairs of the NewSTEPS Critical Congenital Heart Disease Technical Assistance work group along with Amy Gaviglio who will be leading our discussion section at the end of the

presentation. Amy is a genetic counselor at the Minnesota Department of Health. I'm a nurse at Children's National.

We'll be hearing from Delaware. Our first speaker is Jerry Hendrickson. He is an Information Assistance Support Specialist working in Public Health for Delaware. He supports the Newborn Screening Program in a business analyst role. Jerry, I will go ahead and turn it over to you. Are these your slides?

Kate: Hi. This is Kate Tullis and yes, these are our slides. I will be speaking first and Jerry will be finishing out the talk.

Lisa: I'm so sorry Kate. I had the order switched. I'll go ahead and introduce you Kate. [crosstalk 02:15] I apologize for that. Kate Tullis is the Director of Children and Youth Services and Special Care Health Care Needs for the State of Delaware. In that role, she oversees the Newborn Screening Program. Kate has been actively involved in the follow-up aspects of newborn screening in Delaware through NYMAC and with the division of Delaware Public Health.

Kate: Terrific. Thank you so much.

Lisa: I'm sorry about that.

Kate: First, I want to thank everybody for inviting us to share what we've been working on for over two years now. If you could go advance the slides. Do I, Careema? Thanks.

Today we're going to provide an overview of the work we've been doing toward the electronic incorporation of our EDHI data from birth facilities into the Public Health database. We want to illustrate how our hearing data is incorporated into our newborn screenings results [mailer 03:18] and our reporting protocol.

I'd just like to start with Delaware stats. We're a small state. Usually, I have a picture of where we are in the United States because I didn't know when I moved here where Delaware was. Delaware has 11,500 births a year on average. We have 7 birth facilities and 1 midwife that serves our Amish population. For our blood-spot people, we are a 2 screen state. The first screen is prior to discharge at the hospital. Our second screen we like to receive between 7 and 28 days of age.

As far as our hearing information goes, in 2014, I use the word mandated here but that's a little strong. Our EDHI Advisory Board recommended that the ABR be the preferred method of screen here in the state on all our babies. That's been widely adopted. Only our midwife is now currently only screening with OAEs. We do have strong EHDI legislation which mandates screening and reporting.

However, it says reporting must occur between 10 days of the screen. If I could go back in time to 2012 when this legislation was being passed, I would've changed that. The legislation does not address how reporting should be done. However, there is space for hearing on our blood-spot card, which you can see here. This is what Delaware's challenge was.

In 2012, we had over 5,600 blood-spot cards received without the hearing data reported. We have a wide variety of reporting methods. Some of the hospitals would send us fax logs from the device. They would send us emails of results. Things came to us via the postal service. I have a picture of one of our best results. One hospital sent us a handwritten log they copied and faxed whenever I tried to remind them. One hospital, I gave access to their hearing screening database and said, "If you want the results, you need to look up the individual instance." I always say we got them every way except smoke signals.

We want to take a step back. Why are we doing this? Why are we trying to get this data? I'm probably preaching to the choir. We all know the EHDI mantra, we want to screen by 1 month of age in order to have a diagnostic exam completed by 3 months of age so by 6 months of age, the appropriate intervention can take place. We all know the earlier the hearing loss is detected, the earlier appropriate intervention can take place. That results in the best outcome for the child.

We began this road working with Pat Scott in 2013 with some ARRA funding. The Delaware Newborn Screening Program began working with our state mandated Health Information Exchange. Which we call it our Delaware Health Information Network (DHIN). We wanted to achieve the bidirectional transfer of our newborn screening data to and from Public Health, our birth facilities and PCPs.

Our database vendor is Natus. Natus was also the vendor we worked with at our Birth Facilities. We surveyed and upgraded all screeners in the state so they would have the electronic data transfer capabilities.

This is what we were working from in 2013. On the left you see the hospital. Our vision was the blood-spot cards, as it always has, comes from the hospital to our Public Health lab where its data entry for all the demographics is done. We wanted in parallel our EHDI data to come over from the hospital into Public Health. That would be through our DHIN. That's the health information exchange where the data would be matched and merged with our blood-spot data. We would be able to convert that data to an HL7 message that could go back out to our hospitals and providers. I always like an adorable baby picture after seeing one of those blows.

Then reality sets in. Our goal when we started this was to have the hospitals provide the State electronically on a daily basis to public health through our HIE, through the DHIN. This would have been a win-win for us. We thought for our nurse too. We thought this would be able to happen automatically. We could just program it to happen at 2 in the morning every night. Unfortunately, what we ran into was our hospitals had concerns about connecting their screeners directly to their networks, making that automated transfer of data really problematic. We had to work hard to get some nurse manager buy-in.

What we've achieved. One hospital which luckily is our largest birth facility, with almost 50% of our births, transfers the data on a daily basis. Two hospitals, because the nurses felt it was too much to ask to do a manual transfer on a daily basis, are submitting their data on a weekly basis. We have one hospital in test. We hope by the end of this month, we'll have over two thirds of our birth coming in electronically. Our largest hospital that's transferring on a daily basis is doing this because it's hearing screening database rests outside of the hospital information network. It's able to get an export out directly every night that way.

I'm going to let Jerry drive from here on out. He's going to explain how it happens. Jerry's our Support System Specialist for our program.

Jerry:

Hi everyone! What happens is depending on the hearing machines that the hospital has, they will export and it'll be either a high track or an XML file that will be downloaded from the scanner to a flash drive. The file is exported to the flash drive to the hospital network. There was a little bit of an issue there because the machines didn't have any anti-virus on them. They didn't want the machines hooked up directly to the networks. Once the file is on the hospital network they're exported from the network into the DHIN. From the DHIN, they are delivered immediately to us.

The file is uploaded to Natus' MSDS System database via Neolink. The file is then matched on the number of criteria to data from blood-spot cards. If the hearing results indicate a missed or referred record, a record is created in our case management system. The screen below shows what we see when we go into Neolink. I took out all the names and numbers and put in some generic stuff. You can see the OAE result on one. When you scroll further to the right on the screen, you see the labs of ABR results.

That shows the whole thing. Over on the right you see a lot of pass, pass. A couple refers, the zeros were where they were not able to successfully complete a test. That's in the file for each kid coming in.

This is a snapshot of our MSDS System before we upload that file. Here we have, test patient Rick Grimes. Right now you can see there's some demographic data; date of birth. Where I have the arrow on the right side, "blank hearing results."

Now we go back into NeoLink and we do matches. Like Kate said, there's a number of matching criteria. If you'll look at the bottom portion of the screen, we see Rick Grimes, they found a match down here in the MSDS system. We go ahead apply the match, go to the next screen and we're back in the MSDS. There we have a pass, pass from the ABR with the hearing results done on March 18th 2015. As I said before, if there's refers our CMS system, the case management, has a record created so we know that there needs to be follow-up.

That is it. Are questions at the end or at the end of each presentation?

Lisa: Hi thanks Jerry and Kate. We were going to go ahead and save the discussion after all of the presenters had had a chance. That way we can talk about each of the states. If you are able to, it would be great if you and Kate could stay on the call.

Kate: Sure, thanks so much!

Jerry: Absolutely.

Lisa: Okay, thank you! Next we'll hear from Michigan. The team from Michigan is made up of Karen Andruszewski. She's the Quality Assurance Coordinator for the Newborn Screening Follow-up Program. Among her many responsibilities as a coordinator, she works directly as the liaison for birthing hospitals in regards to their CCHD submissions.

We'll also hear from Kristy Tomasko from Michigan. Kristy is the Newborn Screening Data Analyst for the Newborn Screening Data Program. She's the point person for the Health Information Technology Initiative and helps implement HIT from the Newborn Screening program. Thank you very much. We'll go ahead and start with your slides.

Kristy: Hi, could every one hear me? [crosstalk 15:33] Thank you. Hi, my name is Kristy and I'm here with Karen to talk about Michigan's experience with HL7 reporting of CCHD results.

I'll begin with a little background of Michigan's CCHDs screening history. On June 1st 2012, we received a HRSA grant for a CCHD Demonstration program. The program was to look at two goals; to increase the number of Michigan newborns screened for CCHD using a validated screening protocol and to develop infrastructure to collect CCHD screening data through electronic health

information exchanges to enable effective Public Health follow-up, quality assurance and evaluation. On April 1st 2014, the screening was mandated for all Michigan newborns as well as a mandate on electronic reporting of results to the State Newborn Screening Program.

We offer three different electronic reporting options. First, Perkin Elmer e-reports for individual case reporting. Second is a batch file reporting from the EHR system that's uploaded to the secure State FTP site. Our third is the direct HL7 messaging via the Michigan Health Information Network and that's what we're going to focus today's talk on.

The HL7 development and implementation project required a lot of collaboration across the State of Michigan Departments. The Michigan Department of Community Health Newborn Screening Program, the MDCH Office of Medicaid Health Information Technology and the Department of Technology Management and Budget. The Office of Medicaid Health Information Technology was identifying programs across the health department that were interested in investing and implementing in HL7 technology and messaging. We were able to access Medicaid Management Information Systems and HIT Advanced Planning document funding to help support our project. The APD funding is available for state systems to make system improvements.

The next stage in development was working on the implementation guide. Newborn Screening worked the DTMB to develop the guide. The implementation guide details specifications for; developing and mapping hospital messages to the Newborn Screening database, describe ways to handle errors in the data and messages and provide descriptions about reporting fields including the proper codes for the messages. Hospital IT uses the implementation to guide to build the CCHD fields into their EHR and develop the HL7 message. Once these messages are final, then they are sent nearly instantaneously from the hospital EHR directly to the MDCH data hub which then filters into the Perkin Elmer e-reports for follow-up. I'll show you a picture of that later.

Once the implementation guide is finalized and complete, the next step is the pilot on boarding process. In Michigan it started with the implementation guide and requirements being available on Michiganhealthit.org. Next, there was an onboarding kick off meeting to welcome hospitals to begin working on the HL7 development. Once hospitals were on board and developed the message, they could be sent for testing and validation. Once messages are finalized and good with validation, transports established through the Michigan Health Information Network and finally the messages can be sent to production to our system.

During the testing and validation process, hospitals submit test messages that are evaluated and then returned to them with feedback for improvement.

Hospitals then resend these messages and go through the process again until it's perfected and they reach a message with no errors. Currently we have 5 birthing hospitals submitting test messages for data quality validation. We have seen a reduction in errors throughout multiple submissions over time but still we have no messages being sent in with no errors.

This is a little description and image of how HL7 reporting works in Michigan. First, a baby is screened. Second, the results are then entered into the EHR by hospital staff. Then that creates and generates the HL7 message. This message then goes to the HIE (the Health Information Exchange) which is sent through the Michigan Health Information Network State shared services. Which is received at the State and validated. Then parsed into the CCHD screening database and application which is the Perkin Elmer e-reports, in our case.

Next Karen is going to talk about details on the hospital submissions.

Karen: As Kristy said, I'm going to give a little bit more detail on the electronic reporting options. To date we have 18 hospitals submitting their CCHD data using the web-based Perkin Elmer e-reports. With this system, each record is entered individually. There are 65 hospitals are submitting files to the secure state FTP site. The majority of these files are pulled by the hospitals IT departments from their EHR. A few hospitals are entering the results into an Excel spreadsheet that we've provided and they are submitting that to the FTP website. Of these 65 hospitals, 5 are working toward submitting their data by HL7 messaging. One hospital is working on the HL7 implementation. To date they have not submitted any data by either of the other options.

Hospitals have showed interest in the HL7 implementation for several reasons. One is fewer data submissions errors with the HL7 and through file uploads to the state FTP site. We have been able to give many grants. They've been made available to the hospitals to implement HL7 technology. Future transmission of the newborn screening blood-spot card [demographic 21:26] fields by HL7 a newborn screening laboratory reports back to the hospitals are projects that are currently in progress. This should be a great savings on staff time in the hospitals. For our midwives, they have options of reporting by e-reports or faxing or mailing a paper format. Several of our midwives are doing it but they aren't all quite on board yet.

For challenges. These are some of the challenges we've had with submitting the CCHD data. The data quality of FTP submissions, when we were originally setting this up we had wanted our newborn screening kit numbers, a bar code on the card, to be required field. But too many of our hospitals said they could not provide this. We had to make the decision to use mothers first and last name

and the baby's birth date as required fields. Within our Perkin Elmer system they were able to set up two quarries for us. One of the technical error quarry.

An example of this would be missing data, such as the mothers first or last name. This would generate an error. Another example would be incorrect data. The other quarry is for linking errors. An example of this would be the date of birth in the file submitted does not match date of birth hospital staff reported on the newborn screening blood-spot card. All errors are sent back to the hospitals to make corrections. Corrected records can be submitted in a file directly to the FTP site or through e-reports.

The challenges with hospital IT HL7 methods development are the CCHD messages currently not a meaningful use requirement. This in turn makes it hard to get the hospitals to join in. The priority for hospital IT staff are meaningful use tasks. Most of the hospitals we talked to, the nursing staff would love it if their hospitals go to the HL7 submissions now. Unfortunately, that's not the case.

Another challenge has been some unforeseen issues with multiple submission options. Regarding functionality, our web-based e-reports module has functionality built into it. If a user makes a mistake, they will get a user error message and they are able to make the corrections. The FTP files are flat files. There is only one record per infant but up to 3 pulse oximetry readings to be recorded which follows our CCHD screening algorithm.

There's a potential issue if a second record is submitted for an infant, it could override a previous record. Sometimes you want this if a hospital is correcting a mistake but that's not always the case. Sometimes a hospital is submitting a second or third pulse ox reading on a baby and as long as they record the reading in the appropriate fields, the first reading is going to be preserved. Some hospitals initially say they would be submitting their data by HL7 so they were not submitting any data at all while we thought they were in development. For most of them, once they reviewed the HL7 and implementation guide, they realized that they were not ready at the present to go forward with this. The decision then had to be made by the hospitals to submit the data by either e-reports or file submission to the FTP site.

An additional challenge is the LOINC currently does not define CCHD long term follow-up data elements. This will be a future project for us.

Kristy: Finally, we have some helpful tips for states interested in implementing HL7. First provide feedback to hospitals. Currently our state reporting goal for CCHD is to receive more than 90% of CCHD records. We provide quarterly reports to help hospitals gauge where they are in comparison to the State average.

Another idea is for states to investigate Medicaid APD opportunities. Your state may have funding available to help your programs implement this technology and the money really does help. Newborn Screening results and EHDl reporting are meaningful use requirements. If possible, wait to implement CCHD HL7 reporting alongside these requirements to increase hospital interest and willingness to work on CCHD at the same time.

Lastly, if you do plan to use multiple submission options, be aware of issues with delays in data submissions, babies transferring one hospital to another and problems with untimely FTP batching which causes problems with newborn screening follow-up.

Use our contact information if you have questions.

Lisa: Thank you Karen and Kristy. That was really fantastic. We all learned a lot from your experience in Michigan. I particularly liked the last two slides which will give us plenty of fodder for discussion at the end.

The next state that we'll hear from is Florida. Our two speakers from Florida are Andrew Richardson. Andrew has 16 years of healthcare related IT experience. He has served as an IT Project Manager for two laboratory web-coded system implementations. A laboratory information system migration and has been the Project Manager and subject matter expert for the electronic laboratory ordering, electronic laboratory reporting project in the state of Florida for the past 3 years.

Joining him from Florida, will be Eduardo "Eddie" Gonzalez Loumiet. He is one of the owners of Uber Operations, a health technology company. He is a Project Manager for several public health organizations including the Florida Department of Health and the APhL. He's a graduate of Loyola University and Miami University. He's also a professor of House and Schematics at FAMU in North Florida. Thank you very much. Gentlemen, I'll let you go ahead and begin your presentations. You might need to hit star 7 to be un-muted.

Andrew: Hello?

Lisa: Hi is this Andrew or Eddie?

Andrew: This is Andrew Richardson. I'm going to go ahead and start off with our presentation. A few slides in I'll hand it over to Eddie. Similar to the other states.

First, I want to start with our project summary, what's the HL7 project in the state of Florida. For us, we're tackling CCHD hearing and all the demographic data for the blood-spot all in one. There are a lot of similarities we've noticed

from the other two states presentations earlier today. You can see how we had to combine in the history of how we got to where we are today with this project.

My current project for HL7, I'm going to read the project summary right here is, to develop and maintain a bidirectional electronic laboratory ordering and electronic laboratory reporting interface between Florida's Hospital Laboratory Information Management Systems and the Florida Department of Health's Bureau of Laboratories for Newborn Screening tests.

We all understand all the benefits of these sort of projects and prove the efficiency and timeliness for Newborn Screening test result reporting. Not only for our bureau of Laboratories but also for Florida's hospitals. Both our private and public partners stand to gain efficiency gains from these projects and everybody wins is the way we look at it.

I'm going to go over our historic profile with regard to hearing and CCHD data. We have 220,000 births last year, 2014. That number has been hovering between 215,000-240,000 over the last 5-6 years. We implemented Universal Newborn Hearing Screening initially in 2000. We adopted Critical Congenital Heart Disease in June of 2014. It's quite a gap between the two. Which should be for most states.

A real quick rundown of our Universal Newborn Hearing Screening reporting. We initially started with aggregate reporting of refer results; quantities per hospital. We were able to get refer reporting on a record level. We had the refers for individual babies. That was a little bit better. After that we started recording the results on the blood-card which gave us individual record reporting of passes and fails. Then we got the whole complete picture. From there we moved onto a web-based reporting system that's currently still running. We use the e-reports product from Perkin Elmer as well. A lot of similarities between us and Michigan.

Right now, we're working on getting the state of the HL7 electronic file. CCHD being that it was a little bit newer, we initially added some space on the blood-card to get that record level reporting on the card. We're moving into HL7 with that now as well.

This is the amount of breakdown of our hearing report history, the years and what we received. Those images there at the bottom are our web-based web portal where results can be reported to us individually. That's the e-report system that Michigan uses as well. Our HL7 is in progress here. Once I get down to that part, that's when I'll hand it over to Eddie and he'll start talking a little bit more about that.

Our CCHD reporting system. This is another little break down. In January of 2014, we added a section on the blood-card for reporting. It takes some time for those blood-cards to age out, time out and hospitals get them. We had the foresight to change our cards before CCHD was implemented. We didn't turn it on until June.

We can do CCHD reporting through that same e-reports web portal. We have not turned that on yet due to efforts being put into the HL7 process. We do have the capability to have that web portal turned on for CCHD reporting. It's just not done for right now.

This is not the entirety of Florida's blood-card. This is just the CCHD and Hearing Screening Section. I'm not going to go through and read all these fields. I'm sure some of these fields are identical to what the rest of you all are reporting. I wanted to put these on the slide so you could see what all data we collected on a blood-card.

As we're going through all our variations of reporting and trying to improve. We bounce these ideas off of our hospitals. We're trying to find out how we can make this process more efficient. We landed on the discussion of, if we could get the hospital systems that have this data to talk to our systems, that would be the most efficient method of doing this. We don't have people writing on the blood-card. We don't have people doing data entry on the card. There's a myriad of benefits from this process.

I ended up getting touch with the Florida's State Department of Health, they're contracted with our Data Integration Team, which is Eddie's team. We started talking about how we could do this. We found out very quickly that this has been going on for a long time with a lot of other different data sets. Just not specific to CCHD Hearing and Newborn Screening. It's newer in our arena. There was nothing in our arena that should prevent this from happening. We made the decision to forge ahead. At that point, I'm going go to go ahead and hand this over to Eddie. Take it on from here.

Eddie: Great. Can you hear me?

Careema: Yes we can. Thank you.

Eddie: Great. Thanks HPL for organizing and thanks Drew for the intro.

One of the first questions we asked when Drew first approached the Data Integration Team here in the state of Florida was, "What are was talking about here? What type of data?" Naturally, we have a ton of experience with ELR, Immunizations and [inaudible 34:09], things of that nature. That first introduction to the Newborn Screening world and specifically the Post Oximetry

data was key for our integration engineers to know what we're talking about and to know what kind of data we're working with. Also, to be able to ask the right questions when working with our trading partners; the hospitals, for example.

How we plan to get to Hearing and Post Oximetry data is what we're going to be talking about over the next few minutes. A little history. In the state of Florida the Integration Team was founded in 1998 by a group of Integration Engineers. A lady name Janice [Farse 43:47] is someone you may know. The first request was for ELR for surveillance systems. Over the years, we have created a tool belt. It's almost like a center of competency where different program areas can come to the Enterprise Integration Team, as Drew came from the Newborn Screening area and request for us to assist them in projects like this, of state-wide significance.

Naturally, we're extremely busy with meaningful use but our IT area understood the benefits, the impact in a positive way this would have not only for the residents, the citizens, the visitors of the State of Florida but also for the children. Some of the stats that we have at the bottom really laid the foundation for our capabilities. We're naturally a large state but we're talking millions and millions of files through one area. We've got a data policy and all data coming in and out of the agencies including the newborn screening area, needs to come through this Data Integration Team. We'll talk about what the means now. Did it flip?

Careema: We seem to have lost Eddie.

Eddie: I'm here. Did you do next slide? Because for some reason [crosstalk 36:17] There you go. All right. No problem.

I'm going to geek out a little bit here and explain some of the tools that we have. Our foundation from an infrastructure perspective; big into open sores. A lot of the stuff we work on, we can share with other jurisdictions in other states. Some of the solutions that we use like Track, Subversion to really organize and manage the different interfaces and requests that we had. Today we're working with 15 hospitals and just in the Newborn Screening project. A lot of this is streamlined and share-able not only within our own organization but others like folks on call, for example.

This is our tool belt. From a transport perspective, we all know the first step. How are we going to get the data from the hospital to the State of Florida and specifically the Lab? What we've done over the years is rebuild that tool belt from a protocol stand point [Cinnemex 37:20] which is mentioned in the first talk. The direct project SSTP web services more recently a service called Move-it which we were very, very impressed with. Over the last two years we have

something like 2,000 users of the Move-It application and an internal movement, a file movement solution called File Mover.

Once you have the data arriving to the State of Florida and having the capability to send back the result to the hospital, for example. Once that data gets here, we're asking for HL7 messages. Everyone on the phone knows that every EMR/EHR is different. Every hospital lab system is different even though they may be the same vendor. From a localization and configuration stand point, we have to be prepared to expect something different even though we advise to use a certain message guide. The tools that we have from an integration perspective is Coral Reef, the integration engine which is very popular in hospitals. Which gives us a little bit of an advantage where we're receiving data from a hospital and there is a big chance they're also using Coral Reef. That helps tremendously. Merth is the other integration tool that we're using and then Rhapsody from the Orion Health team.

Our people are certified in these tools and have years of experience not only does that help ... Training is mandatory for sure. Not only does that help us internally here in terms here in the State of Florida but from a technical systems perspective. Where an Orlando based hospital, for example, may need some assistance with their integration tool. We're in a position where we can assist them from a technical perspective and give them some guidance, share some documents with them. Whether it's mapping documentation or channels and conformance profiles, things of that nature.

Why reinvent the wheel? We're [beating 39:13] at the standards. One of the reasons we're part of this core group and on this call, we listen to the experts. For this project, PHII, the NLM message guide and LOINC. Luckily on our staff we've got a young lady named Robin [last name 39:30] who's extremely fluent in LOINC and Snomed and she's been a tremendous help. Whereas in other organizations that may be a stumbling block. National organizations like APHL provide vocab assistance and technical assistance which is a big plus.

This is a high level diagram. As I look at it, I see I have to update something. The complexity of having a center of competency or an integration team that will control, monitor and provide that translation transformation services throughout the state and with our national partners. From a project perspective, we plugged in the Newborn Screening project from ELO and ELR perspective into our integration process using standard operating procedures and our support infrastructure to support our interfaces post go-alive.

I mentioned foundation and our experience since 1998. One of the things that does take time but has helped us tremendously is collaboration with organizations like APHL, the CDC and different projects. Whether it's the Flip

Project, the E-Tore Project with the CDC on salmonella, reading the ELC high tech grant where we upgraded our messages to April 7251, participating in projects like the R&R Hub, the [Limeside 41:00] Bi-Terrorism project. They do take time and in some cases funds to participate in these collaborations. Its allowed us to create those friendships, relationships and those experiences that put us in a position to be able to answer to the call when Drew calls up and said, "I need help with Newborn Screening."

Standard. As mentioned, we are using the Public Health Informatics Institute of National Library of Medicine message guide. One of the recommendations we always say when we're on boarding a trading partner or hospital is, "Please read this first." When they receive the PDF, they're a little overwhelmed. We've worked around that and you'll see in the next slide.

We don't just hand them a message guide or an implementation guide. We go through an onboarding process. The onboarding process ... By the way we can share this with the folks on the call, explains what the projects about. Not only that, it lists the advantage or the benefits of being involved in this project. As we've encountered, we've been working with hospitals as mentioned with the [inaudible 42:11] speakers, there are competitive initiatives. Whether that's the ICD10 conversion, ELR, Immunizations, cost cutting, cloud computing and security, we've got to sneak in there. We've got to get in the queue. We got to convince the CFO and the CIO of that hospital that this is important. We've made their lives easier by providing that list of benefits of why getting engaged in this project helps. Not only about saving babies lives potentially but also cost benefits, process benefits, mistakes, things to that nature. We provide that for them in the onboarding documentation where they can hand that to their decision makers and get them on the queue to engage with us on this project.

I mentioned the implementation guide. If you've received that and you're new to newborn screening, you're a hospital employee that's extremely busy or Project Manager from the IT team that has no clue what HL7 means, it can be overwhelming. What we did is, our team member that I mentioned earlier Robin [last name 43:12] who we created an addendum or almost like a constraint profile. Which says, "In the state of Florida, these are the 100 fields that we need. By the way, this is where it should come from in the HL7 message." We not only did that with the ordering piece but we also did that with the resulting piece. Really constraining what they're required to do. Constraining that message guide to make their lives easier and reduce some of that burden with the goal of getting that data to the State of Florida as soon as possible.

Some of the challenges. You see sit with a Project Manager from a hospital and they're extremely busy people. Why is this important? Part of that has been a little bit of a challenge. Part of it has been an education process for not only us

but the hospitals. That onboarding registration document or package helps with that "ammunition." The other challenge we've experienced that, where is the data sitting in the hospital? They may have multiple systems. There are some hospitals that may not have a integration team on their end or may not have to tools or the bandwidth to be able to compile that data and be able to send one HL7 order. We've been able to work around them. We've provided some flexibility. We try to go beyond what is expected. We want to be able to get that data and reduce some of those challenges.

Some of the success. One of the major helps during the last couple years now has been partnering with some of the large EHR vendors. Some that have their on "hubs." For example, let's profile Cerner. Cerner has their reference lab network. The State of Florida has one connection. With Cerner, we use VPN. We have one connection with Cerner. But Cerner has created one connection with us that connects us to half a dozen to a dozen hospitals. Those hospitals are already on their "hub." From an connectivity perspective it reduces the amount of time from an onboarding steps, for example. Which has been a tremendous help for us. Conversations and arranges with organizations like Pediatrics is another one that has really helped us get going at a faster clip with these different interfaces.

Partnerships that I've mentioned. These are some of the hospitals that we're working with. One of the recommendations we have is tracking each hospital whether is a spreadsheet or using a solution like a base camp or some sort of data base. After a while when you've got weekly calls with a lot of these hospitals, it can be a challenge. Who's using VPN, SFTP? What type of data, vendors are they using? Tracking this from the beginning is a huge help because when you get into 10, 15, 20 hospitals, it can get a little bit out of control. Being able to be organized and having a dedicated Project Manager or two is definitely a big suggestion.

Collaboration. These are the organizations that are all-in that have been helping us tremendously over the last couple years. The dedication has been outstanding. Whether it's a vendor or non-profit organization or even the federal government has been tremendous. Buy-in from our organization in the State of Florida has been key as well from upper management. For example, if we want to get a VPN connection sped up, the upper management folks know, "This is important. This is about children. This is a high priority. Let's make it happen." That's been a tremendous help. It's helped Drew and I move these interface forward.

Careema: I think that's your last slide.

Eddie: Excellent. Thank you very much for the time.

Lisa: Thanks so much Andrew and Eddie. That was fantastic. We did have time purposely for a few questions and for some discussions for our excellent expert presenters. Amy if you want to go ahead and start with a few of our questions. I don't know if any folks have typed any in.

Careema: Yes they have. Hi Amy, this is Careema. There are two questions that folks have typed in. I don't know if you want me to read those out or want [crosstalk 47:38].

Amy: Yes. Let's start with those and then we'll open it up. A reminder to star 7 to unmute yourself if you do have questions.

Careema: Thank you. The first question is, "Could the speaker address quality assurance in terms of evaluating the accuracy of the screening results against the approved [inaudible 48:00]." Hello?

Kristy: Hi, this is Kristy from Michigan. If you're talking about once we have data, then looking at validating the screen protocol. We have planned to look at that in the future because we are getting individual baby level data for all the babies in Michigan. We do plan to look into that once we have more information, more data coming in.

Amy: Along the same lines, "Is there a way to determine quickly if babies were discharged without getting screened?"

Karen: This is Karen from Michigan. I don't know if I would say "quickly." It depends on how the hospitals submits their data. It's really up to that.

Jeff: This is Jeff [Schoff 49:03] from Michigan. I haven't been introduced but I'm on the IT side in Michigan. There is a way for the hospital to tell us that in the HL7 message. There's a "reason not performed" and it's because the baby's been discharged. Obviously, it's difficult for the hospital to predict when they're going to discharge a baby before the screenings. We don't always get that message.

Amy: Thank you.

Careema: All right. Are there any questions from people on the call?

Amy: I have another one that's been typed in. It's for Delaware-

Careema: Okay, go ahead.

Amy: It's for Delaware and Michigan. "How many of the Pulse Oximetry results are being recorded? Is it one test or the final test or for each and every test in the process?"

Kate: I'll just say for Delaware, we're not doing CCHD having that coming in electronically yet. But it is recorded on our card and we're asking for the final results. Delaware has [inaudible 50:05] asking for pass, fail or not performed.

Karen: This is Karen from Michigan, again. With our algorithm, they can submit up to three readings. If the first one is a pass that's it. If the first one is a rescreen, we ask for another screen. If that would be a rescreen yet, then we would ask for a third. If that one was still a rescreen, that would be considered a positive at that point.

Kate: Do you require reporting of all three of those screens then?

Karen: If it follows the algorithm, yes.

Andrew: To answer for Florida, we're doing the same thing as Delaware right now. We're just recording the final. There might be a move toward recording more of the results then similar to Michigan. I don't know if three would be the cap. That's how many are in our protocol. We generally have them go through a screening protocol and record the final screen after they manually go through the protocol. I'd just like to make a comment that I think the way Michigan is doing it is great.

Amy: I have another question typed in. It's specifically for Delaware. "How long did the project take to implement? What is the percent match with Neo?"

Kate: It seemed like it took forever to implement. From the time we really started working it, I'd say about 18 months. Our percent match is quite high. Definitely greater than 95%. I want to say 98% but at least 95% for sure. The ones that don't match, it's pretty easy to figure out who those kids are.

Jerry: Like somebody else was talking before. Sometimes you have a little bit of data entry where a number is transposed. Once you go in and look you see, "Oh, that's who they match with." We match them that way.

Kate: We're a little humble. It's hard to be on a call with Florida and Michigan with your numbers. For us, looking at 3% or 5% of 11,500 births is a lot easier.

Careema: Does anyone else have any questions?

Tony: This is Tony from Minnesota. I have two questions; one for Delaware, one for Michigan. Can I ask both of them?

Careema: Yes, go ahead

Tony: The first question is for Delaware. If I understood correctly, you're transferring data from the screening device to the EHR using a flash drive. Is that correct?

Jerry: Yes. Basically what happens is they put it on the flash drive then they transfer it to the hospital network. The hospital network already has a direct SFTP or VPN set up with the Delaware Health Information Network. That's how it's transferred to them which turns right around and sends it to us into our system. Through another VPN [inaudible 53:54]

Tony: In terms of using the flash drive, did anyone at the birth facilities in IT express any concerns over the security of having a physical flash drive that needs to be moved from screening device to the EHR? How is that being dealt with?

Kate: Yes it did. It turns out some of the nurses carry these flash drives on their badges. They're encrypted, HIPPA compliant flash drives. They use it for other things. My question to everyone. We are really struggling with the fact that the screeners cannot be hooked up directly to ... Our hospitals don't want the screeners hooked up directly to their system in any way. This stopped our project dead in the water for a couple of months while we came up with the compromise of having these special flash drives. I buy them for the hospitals. Compared to our regular \$10 flash drives, they're \$50 HIPPA compliant flash drives.

Jerry: Right. They're encrypted so if somebody else got ahold of it, they wouldn't know how to get into it. The data is protected. The reason we hit that road block in the first place was the hearing machines themselves were FDA approved and warrantied. That was without any kind of anti-virus on it. The hospitals were afraid if they put that on the devices, that would void the warranty as it were. That's why they didn't want them hooked up directly to their networks.

Tony: Thanks. In Minnesota we've had little bit of a different experience where at least with the facilities that are using Epic want to have the screen devices hooked up directly to their EHRs so that the data can stream straight from the screening device to the EHR using the EHR as a single source of truth. From what I understand, and Amy probably has some better insight into this, the security folks at those facilities felt a lot better about having a direct connection between the screening device and their EHR. I think they have some anti-viral software loaded on the front end of their EHR so they can assure some data security and integrity right there.

Kate: That's really great to know. I have Amy's contact. Amy, I may be getting in touch with you.

Amy: That would be great. It was interesting because Tony's right. We've looked at an idea of a flat file option as a way to get results as quickly as possible. I would say by in large, most facilities have said, "No. We do not want to go that route. We do not want to have our nursing staff carrying these things around and moving the data themselves. Please can we go straight to a streaming HL7 messaging model." Which is where we wanted to end up anyway. It's fine. I would be happy to touch base with you. Great.

Careema: Any other questions?

Tony: Yes, I had a really quick other question and this is for Michigan. When you [inaudible 58:01] your implementation guide for the facilities, did you base your implementation guide on the HL7 2.6 CCHD implementation guide that's available?

Jeff: Yes, this is Jeff Shaw again from the technology side of Michigan. We did. We did allowed the hospitals to submit using version 2.5.1. We initially got a lot of push back trying to force the hospitals to go to 2.6. There's basically almost no difference between the two versions. There's one field that changes slightly between the two versions. We allow both 251 and 2.6.

Tony: Perfect, thank you.

Careema: We may have time for one other question, not from Tony. Anyone else?

Amy: I will ask one quick question it's for Delaware. You mentioned very briefly that part of the way you were funding your initiatives for reporting was through ARRA funding. I was wondering if you want to speak a little bit more to that. As I know that funding for building something like this is something that's always a concern for states.

Kate: [crosstalk 59:28] I can only briefly speak on that. It was happening way above my level here in Public Health. It was money that was allocated for our HIE entity. That's all I can say about that, Amy. I'm sorry. But there was some money and it was going to expire. We had a brief window of time where we could jump on it and we did. Funding for this is tough.

Amy: My understanding of the ARRA funding is that it's from the American Recovery and Reinvestment Act to promote HIT. I'm not sure if those state grants are still available or not.

Kate: No. I have been able to use some money from my CDC EHDI grants.

Amy: Perfect. I know that's been something we've been looking at too. Which is a good option.

In the interest of time we will close out. I want to thank everyone from Delaware, Michigan and Florida. These are great presentations showing a very nice wide diversity of ways to go about this. As a reminder, there is our part 3 of this HIT/CCHD combo will be Friday April 24th when we'll hear from Lura Dausat and John Eichwald on integrating Newborn Screening reporting for both EHDl and CCHD again.

Careema: Thanks everyone. Have a good afternoon.