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APHL Newborn Screening Health Information Technology Webinar

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Presentations:

- Kentucky State Profile— Darrin Sevier
- Washington State Profile— Ashleigh Ragsdale & Amy Liu

Moderator:

- Careema Yusuf, MPH, Senior Specialist, NewSTEPS

Please direct all comments/questions pertaining to this presentation to Careema Yusuf at careema.yusuf@aphl.org or 240-485-2761.

Careema Yusuf: Great. Again, thank you so much for joining us this afternoon. Today we are going to have two states present on their Newborn Screening Health Information Technology Program experiences. First up on the docket will be Darrin Sevier from the Kentucky Department of Public Health Division of Laboratory Services and followed by him would be Ashleigh Ragsdale and Amy Liu from the Washington Department of Health Newborn Screening Program.

Darrin, why you are pressing star seven to unmute, I'm going to bring up your slide and you may begin when you're ready.

Darrin Sevier: Okay, thank you, Careema. My name's Darrin Sevier and I'm one of the Newborn Screening Supervisors for the Kentucky Division of Laboratory Services and I was brought in on our Kentucky Health Information Exchange late in our project as part of a validation they needed from someone with laboratory experience. I'll give you a little bit of an overview of our program and where we're at so far.

Go ahead with the next slide. As a bit of a history, we implemented our current LIMS system in 2008 and in 2009 we implemented electronic data entry at birthing centers then in 2010 the State went forward with the Health Information Exchange and there was planning that began for that and then from 2010 to 2012 was we were working on implementation, mapping link codes, testing it, HL7 messages, working with our vendors and so forth. Then in 2012 to



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2013, we did go live with the ... On a Health Information Exchange with our Non-Newborn Screening tests at the State lab and we're still testing the NBS Health Information Exchange information.

Next slide. Our current status, as I said, we're still in a holding pattern. We ran into some issues and I'll talk about that a little bit later with our Newborn Screening Results and Exchange. Well, we are still using our electronic data entry by the processing center and recently we added CCHD Result Collection to our existing demographic entry and hearing result entry.

Nest slide. First, I want to talk a little bit about our electronic data entry system. It's a web based portal which we refer to as KYChild. It was originally conceived for use in birth registry and vital statistics. The hospitals have to enter in the information into the KYChild system in order to get birth certificates. This is the way get buy in from the hospitals. We've been very successful with that.

The portal also has a place for entering the Newborn Hearing results. Now like some other states we don't use those results in the laboratory. They do not go on a Newborn Screening Report. Those get reported to our EHDI program and then as I said, recently we started collecting critical congenital heart defects results and those were reported to the Division of Adult and Child Health, again those don't go on to our Newborn Screening Results and, finally, we have the electronic data entry for newborn screening.

Next slide. However the problem with that is none of this data that's collected is associated with LOINC codes. This was begun before we started going the HL7 path and so it was never conceived with LOINC codes in mind. There has been some discussion as to whether or not we might add LOINC codes to it in the future. I think it would be a great idea but where we've already gone down this path, it'll be a little difficult at this point to up and change but the way this works is the web based portal collects the data. That file is then exported and it's picked up by our LIMS System and it's populated into a holding table.

On the next slide. This is a picture of our KYChild information screen. You can see here there's infant's name, date of birth, some information about the status of the infant at birth, stuff that you would find on a New Born Screening Form. Also on the panel on the left hand side, you've got a place for entering the hearing information, the CCHD information and more information for the user of KYChild. Once the user enters all the information for this child then they can create the order.



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Next slide. Once they do that, it creates a label which is then applied to the top of the Newborn Screening Form and it actually looks just like our Newborn Screening Form, however, up at the top, you can see a big bar code with a number underneath it. That is our KYChild number or our KY Unique ID Number. That allows us to tie those results back to that baby when it comes in to our lab.

Next slide. Once the form is received in our lab, we add our own accession number.

Go ahead to the next slide. What happens after they get accessioned, they go to our demographic entry person. That person will then scan the accession number bar code that we generated in the lab and that creates the record in the system or it pulls up the record if the accession's already been punched and the system already knows there's an accession number there.

Then our demographic entry person scans the KYChild bar code. That will then pull all of the demographic end data that was in that holding table that I mentioned and will populate all the demographic entry fields in our LIMS System. Then our data entry personnel just simply checks a few fields to make sure that it imported the correct patient. They save the bar code or they save the specimen and move on to the next accession bar code and they can go through several cards very, very quickly.

Next slide. One of the downsides is this is only used by birthing hospitals and we have pretty much a 100% usage from our birthing hospitals but any repeat specimens that are collected at the doctor's office or especially when it was collected by a midwife or a health department, those are still hand written.

It usually takes about two hours for one demographic entry person to enter all the demographics. Our average daily load is about 200 to 250 samples and about 10% of those are hand written. This portal was developed by the Commonwealth of Kentucky office of information technology. They did all the web design, all the back end work we did not contract that with a vendor for this.

Okay, so on the next slide, we'll switch gears a little bit and we'll talk about the Kentucky Health Information Exchange or KHIE. In 2009, Governor Bashir signed an executive order creating the Governor's Office of Electronic Health Information (GOEHI). GOEHI then received funding from the Centers for Medicare and Medicaid Services and from the American Recovery and



Reinvestment Act and they use those funds to use incentives for doctor's offices to meet new for use criteria.

They also used it to purchase the exchange software that operates our exchange system. The laboratory itself, we received funding through the CDC Epidemiology Lab Connector Grant, the ELCACA, we used that money to pay for the new upgrades for our land system so that they would be able to create the HL7 message and transmit that into the exchange.

The next slide. We began working toward the implementation of HL7 messaging to KHIE in 2010. Part of that was we established key contacts with our multiple vendors and here in the Newborn Screening Lab we have our Specimen Gate LIMS System from PerkinElmer but the rest of the lab has another LIMS from a different vendor. We had to have both of those vendors on board. We had the vendor for the exchange software and then we also have personnel from the Governor's Office of Electronic Health Information. They provided input. They said how the message should look and they talked about what all needed to be included.

The next slide. What did we do? We held meetings with all the parties involved. Kind of a get together to try and figure out what all needed to be done. Our LIMS vendors began work on the HL7 messages. They worked very closely with the exchange software vendor because the exchange software vendor basically said, "This is the format that we're expecting." Then the LIMS vendors had to work out a way of making the HL7 message fit with what the vendor was working with.

However, there was some back and forth there. There are some things that the vendor had to change to accept what the data was coming out of our LIMS systems. As the implementation progressed, we started having weekly teleconferences and these were great because during our testing, we would come up with an issue so we could always bring it up in our Monday teleconference and say, "Hey, look, we're having this issue. This is not coming across right. What's going on here?"

Then both the vendors were online and they could say, "Okay, well, you know, we're seeing this. Why is this coming through? Well, looks like it's a problem with the HL7 message." One thing that's different in Kentucky than it seemed to be from a lot of different states is our LIMS vendors were the ones who were



responsible for mapping the Link codes. We really did not have very much input on that and our LIMS vendors did most of the heavy lifting with that.

The only issue was if there was a problem with a ... a test kind of through was they weren't sure which code to use or we didn't, there wasn't really a good code out there to use. Then we were consulted for our input.

The next slide. How did it all work out? Well, we generally received excellent support from our LIMS vendors. As I said, they did most of the heavy lifting. We did do a lot of consultation with them but they really did a great job with getting everything up and running. That being said, it's difficult getting everybody on the same page. The old saying, "Too many cooks spoil the broth," well, when you have so many different people that you're having to deal with, sometimes it was hard.

You would have your exchange vendor blaming the LIMS vendor, the LIMS vendor blaming the exchange vendor and we had to act as liaisons to kind of coach them along and say, "Okay, well, is this working? Well, maybe it could be this?" Then also, it's just difficult to run schedules. If we did come in with a problem, maybe the exchange vendor was on vacation that week. Our representative for the exchange vendor was on vacation this week. Those were some of the difficulties that we ran into.

On the next slide. The goal was that non-NBS HL7 messaging; we've had that live in the exchange since 2003. Granted the HL7 message you're seeing there is Newborn Screening, not the non-NBS but I had a user access to the NBS.

The next slide. The Newborn Screening part of it though created some unique challenges and that has slowed us down quite a bit. One thing, we have a lot of free text comments. Most of our mass spec, if it's not normal, is some sort of free text comment and when we started working on this, we really had no way of putting that in there. We didn't have a really good LOINC code, so we had a see additional notes LOINC code added.

Same thing with hemoglobin and now as I understand it there's a much better way of dealing with hemoglobin in the HL7 message. When we started we didn't really have that so we did the same thing. We did see additional notes code and then the pattern itself is entered as a free text comment.



The other issue we ran into was how to map the results in the exchange. Our exchange report has the overall interpretations, work narrative summary, positive markers, equivocal markers and we had to work very closely with our LIMS vendors to say, “This should go in a positive marker. This should go in equivocal marker. This should show up in the short narrative summary,” and that required a lot of testing and a lot of back and forth with them to get that to work.

The next slide. Part of that back and forth was we did have our NBS LIMS vendor came on site and they worked through all of those issues with getting the reports to look the way they should and I’ve got some examples here. We do report values for all of our CAH, IRT, T4 and TSH results so I’ve included an example of what our IRT results look like in the exchange.

On the next slide. For the MSMS, we only report values for positive disorders. This is an amino acid panel and it’s normal. If it were abnormal, if they had PKU, you’d have the phenylalanine and the phenylalanine tyrosine and their values.

The next slide. Hemoglobin pattern and this is what it looks like. This is a normal, so you see the value has ‘see additional notes.’ The notes says “Normal FA.” If it were FAS, the value would say, still say ‘see additional notes.’ The note would then say “See note for ...” whatever note number we were up to in the message, and then below this will be a ‘see note for’ and it would ... or it would have ‘note for’ and it would say FAS and have our interpretation of requires follow up testing or whatever it says.

Next Slide. We’re currently not live and that is mostly due to issues with unnamed babies and this was something that came up late in the testing phase. The problem is we were sending out reports to the exchange or to the test version of the exchange and we were expecting these to show up immediately or within a day, because we were doing our validation, we would pull the reports off of the exchange and compare them to our regular report but sometimes we would come up with ones that were missing.

After some back and forth, we discovered that it was because these babies were unnamed. They would be like Baby Girl Doe or Unnamed, Unknown Boy, so that’s creating difficulties because the Governor’s Office of Electronic Health Information only wants one record for each patient in the exchange.



They were having an issue with these who were coming through, they were not able to match them to another patient in the exchange and so they were holding them until they got more information for the birth certificate or some other test, the lab report from the hospital. The workaround for that is going to be adding the medical record number from the hospital to the HL7 message which we did not have to begin with.

The question that we're working on now is which field to put it in. The Governor's Office of Electronic Health Information originally wanted us to remove our accession number and place a medical record number in there instead but we of course want to keep our accession number, so now they're working on a way of us having both of them in there.

On the next slide. What were our lessons learned? Having adequate vendor support is crucial as I said, they did most of the heavy lifting for us we really couldn't have done it or couldn't have been this far if we hadn't had a very good vendor support. It's important to establish a good collaboration between party early on and with us being able to have the weekly teleconferences, with everybody involved and so they could talk with each other and we could be a liaison between them, that really, really helped and if you don't have that cooperation, if it's email exchanges back and forth then that just kind of bogs down everything.

Also important is try to make sure that everyone's expectations of desired functionality are clear from the beginning. This goes back to the unnamed baby thing. GOEHI was never expecting these results to show up immediately. The laboratory here is expecting them to show up immediately so we were not quite on the same page there and so we weren't aware of how these things were going across if they were unnamed and they were showing up in this unnamed queue. As I said, we did not find out until later so talking about the expected functionality at the beginning of the process would have save a lot of bit time.

Then finally, planning and testing of all this takes an enormous amount of time. We've been working on this for a couple of years and we're still not there yet. Validations take time, looking at all this stuff and then having to coordinate with everybody to get changes made is not always an easy process and does take time as well, and I believe that's my last slide.

I thank you for your attention and if you have any questions, feel free to let me know. Thank you.



Careema Yusuf: Thank you so much, Darrin. That was great. We do have time for some questions, if you would like to ask a question on the phone. You can press star seven to unmeet your line or if you choose, you can write your question in the chat box and I'd be happy to read it out and have Darrin answer it for you if he can.

Does anybody have any questions? Okay, maybe you are thinking of them. Maybe we can move on to the next presentation. Next up would be ...

Robin: Hello, can you hear me?

Careema Yusuf: Oh, yes, yes.

Robin: I'm sorry. This is Robin Lusk. I'm having extraordinary technical difficulty so I apologize for ...

Careema Yusuf: Sure, no problem go ahead.

Robin: I do have several questions and, unfortunately, because I'm having technical difficulty, I wasn't able to see the slide presentation. Maybe some of that was answered there but I do have some questions and that mostly have to do with the vendor for data exchange. Number one: Who is the vendor for data exchange?

Darrin Sevier: That to me is kind of a good question, because their name has changed about 12 different times, I think. It started out being ACS and its actual [inaudible 00:19:13] then it's XEROX, and it's Optimum Insight. The EHR, when we log into that, it says Optimum Insight, so who the owner of that is, I'm not sure at the moment.

Robin: Okay. Your ... inside ...

Darrin Sevier: Say that again?

Robin: Was it insight or inside?

Darrin Sevier: Insight. Optimum O-P-T... U-M Insight.

Robin: Okay, now when you say that ... Number one let me ask you, what version of specimen that you have? Do you have Life Cycle or Screening Center?



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- Darrin Sevier: We have Life Cycle.
- Robin: Okay, you do have Life Cycle and NH ... PerkinElmer is creating HL7 messages on the export for you to the integration [crosstalk 00:20:01].
- Darrin Sevier: Yes.
- Robin: They are doing that?
- Darrin Sevier: Yes. They pretty much did everything. They created the entire message. Now, like I said the exchange kind of dictated what they wanted to see.
- Robin: Right but they are making you an HL7 ... It's not a flat file export; it's an actual HL7 message.
- Darrin Sevier: Yeah, well, the ... Well, you couldn't see the slide. I had a portion of our HL7 message. I mean it is a file. I mean I can go onto our [inaudible 00:20:31] drive and pull it.
- Robin: Okay, so okay, I see and I can see now. It did get connected. I see a slide.
- Darrin Sevier: Yeah.
- Robin: Okay, great. That answers that question and now I have another ... Now when you say that the vendor is sending HL7 results back to someone, I assume the birthing centers?
- Darrin Sevier: No, no, we are only submitting ... The LIMS is only submitting HL7 to an exchange, a Health Information Exchange, and right now those data are sitting in the Health Information Exchange.
- Robin: What happens to them? I mean what do they ... What happens there?
- Darrin Sevier: As of right now, anybody that has ... Which we're only on test for newborn but any doctor's office that wants to can sign up for access to the exchange and then they can log in and look at the EHR or VHR on the exchange.
- Robin: Okay, so [crosstalk 00:21:27] ...
- Darrin Sevier: Say that again?



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- Robin: It's a web interface?
- Darrin Sevier: Yes, now there is a capability of doing the CCD, the Continuity of Care Document, where the exchange is not set up for that just yet but they are working toward that.
- Robin: Okay, and now early on you said, we're talking about a file export or data exported from the birthing centers.
- Darrin Sevier: Yes.
- Robin: That exported data, how is that coming from the birthing centers? Is that a web interface that they go on and enter the information into or into the ...
- Darrin Sevier: Yes.
- Robin: File or is it in HL7?
- Darrin Sevier: It's a web portal. They enter it. I'm not sure what the file export type is from that but it goes straight from the web portal into Specimen Gate Database.
- Robin: All right, great. Thank you.
- Darrin Sevier: You're welcome.
- Careema Yusuf: I do have two questions, Darrin. Do you have any privacy issues of the data being sent to the exchange?
- Darrin Sevier: We haven't run into any privacy issues there. The exchange is very, very ... I'm trying to think of the word, very privacy orient though. When you go to log in, there's a big HIPAA Statement right there and it does track who all logs in, what they do when they're logged, and anytime you try and pull up a specific report, you also get the big long hairy disclaimer that says "This is protected health information. You're only should be looking at this if you are caring for this patient blah, blah, blah," and you have to click accept or decline, and it does track all of that.
- Careema Yusuf: Okay, great, and the other question is how is your message delivered back to the hospital or PCP?



- Darrin Sevier: Well, that one we're not delivering those out yet. It's going to the exchange and that's up to the doctor's office or hospital, if they were wanting to look at this report, they would have to get an account with the exchange and will look at it there and as far as I understand it, they don't have any way of pulling that data out of the exchange, other than just looking at it as a web based portal at this point. That is something that we're headed toward but we're not there yet.
- Careema Yusuf: Go ahead.
- Robin: Well, I'm just going to say, that leads me to one more question. Are you sending paper reports back to the birthing centers?
- Darrin Sevier: Yes, we're all doing paper reports. We're looking into an e-reporting system in the meantime, but I don't know if we'll get there or not, but it is all paper so far.
- Robin: Okay, thanks. I apologize for interrupting.
- Careema Yusuf: Not a problem at all and kind of a question related to the exchange and privacy. Do you have consent or dissent from the patient to send data to the exchange? Is there some sort of process there?
- Darrin Sevier: Not for us here.
- Careema Yusuf: Okay.
- Darrin Sevier: We don't have anything. We don't have anything on our form for consent or dissent.
- Careema Yusuf: Okay, and then I do have one more question. It says you mention exchange only one record per baby. Do you send only initial specimen results or do you in fact send a record for each specimen?
- Darrin Sevier: We send a record for each specimen, they, when the account goes there, they'll link it together somehow, and that was where we ran into the problem with the unnamed babies. If it's got the medical record number, of course, that's going to match up and so they can match that automatically but if it doesn't then someone, some actual person has to go through there and say, "Okay, this is the same baby as this," and then link them together so that it all has one exchange account number basically.



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Careema Yusuf: Okay, great. Those are the questions that I see for now and we ... If you have any more please go ahead and write them in the chat box or ask them at the end of the next presentation. We're going to move on. Next up, we have presentation from the State of Washington. I am going to share my desktop to share the PowerPoint Presentation before we begin. Please bear with me.

Okay, Ashley, press star seven to unmeet your line and you can take it away.

Ashleigh Ragsdale: Hello, can you hear me?

Careema Yusuf: Yes.

Ashleigh Ragsdale: Excellent. Okay, so I am Ashleigh Ragsdale, formerly Fleischman, and I work in the Newborn Screening Program in the sort or follow up and I was the Product Coordinator for implementing HIE for the Newborn Screening Program.

Amy Liu: I'm Amy Liu. I'm the HL7 Rhapsody Specialist for this project and I'll be helping out and kind of a second phased more of a project which we'll talk about in the presentation.

Ashleigh Ragsdale: Okay, next slide. Okay, just a little background, in Washington, similar to kind of what Kentucky was just talking about, we have a centralized statewide Health Information Exchange so all of our messages will be going to that exchange and then each of the vendor's hospital, they're clinics will connect to that exchange and get the information from them.

Back in mid-2011, we received some grant funds that started this project for us and that got us going and now we all operate on an in kind contribution. Our project started with the focus on doing electronic reporting of our lab results. We focused on that because we had a lot of stakeholder interest in receiving our reports electronically. A lot of places do, they transcribe these messages or they scan them into their medical records so we had a lot of interest in wanting to receive them electronically into their medical record systems

So far, the project has involved two parts of Department of Health, which is us the Newborn Screening Program and then our Department of Information Resources Management, our software vendor NeoMetrics and then one Health Port which is the State HIE provider.

Next slide.



Amy Liu:

I'll just give a quick overview of what the current workflow looks like and talk about what we're planning to do in the future. Right now, DOH is sending all of the Newborn Screening Results via mail or fax and these results are generated through NeoMetrics and that's how hospitals are currently receiving the results.

Next. This is the diagram kind of shows where we want to go with this project. In the future we want these results to be sent electronically via HL7251 messages to hospitals that are connected to the statewide HIE and there's kind of two different components within this work.

The first one would be NeoMetrics sending or generating the raw HL7 messages. Those will then be picked up by Rhapsody. Rhapsody will be doing some filtering of the messages which Ashleigh will talk about in a little more detail later on, and then this filter messages will then be sent to our statewide HIE and the hospitals will then be pulling these messages from the HIE.

This new automated workflow will significantly decrease amount of time and resources needed to send out the current paper results and additionally it will be able to send out these results quicker to hospitals and once we have this interface in place, adding additional hospitals to the routes will be a lot easier as well.

Next slide. I wanted to spend a few minutes just talking about how we've connected with our HIE, in case other sites were interested. One whole part is the organization that runs our HIE and in order to connect to the HIE, every organization needs to install what we call an activator and the activator is what actually communicates with the statewide HIE.

All the messages that are sent to the HIE are secure through doctor authentication and one of the main concerns of our security officer was ensuring that us, the state, initiates all communications. We're the ones that push up our messages and we're the ones that pull inbound messages and that was an important factor in connecting to our statewide HIE and so this diagram here, we can talk about the Newborn Screen example.

DOH would be sending the Newborn Screening results to the HIE via the blue lines and the hospitals would then receive these messages by pulling them from the secure mailbox in the HIE via the red and green lines.



Ashleigh Ragsdale: Next slide. Okay, we've kind of divided our project into two phases because it takes a long time to get this all up and running. The first phase was our kind of internal development and that was creating the HL7 message for reporting the results. It was getting our system up and running and ready to connect to the HIE.

From a Newborn Screening perspective the goals of that first phase were, one, standard message format using the most current HL7 Link and SNOMED codes and we did want to just make one standard message that all the hospitals would then learn how to read and then we also wanted to follow the NLM Implementation Guide as closely as possible and we really wanted to focus on maintaining the integrity of our current paper reports. We didn't want to lose any of our reporting by going to electronic messaging.

Next. Next. Thanks. The resources we use, these are some of the resources, they can all be found on the NLM-NBS Coding and Technology Guide website. We were following them as close as possible. We also worked a fair amount with Swapna Abhyankar at NLM to help us find codes or get codes that we didn't have. She was a great resource for us on how to kind of map the link. We did have to do all the mapping ourselves or I did most of it and worked with NeoMetrics and in our experience there was a lot of ... There's a big learning curve, it took a lot longer than we expected.

We actually just pushed this all into our live system that's not so very excited to have that kind of completed. One of the main things we learned was to meet weekly and we spent a lot of time working with NeoMetrics and I even had the opportunity to go to New York and work with them there in person and that face to face communication was really helpful because this is such a complex project. I feel we got months of work done in that one week that I spent up there. We had a lot of work to do, it took a long time but we're almost done.

Next slide. I'm going to show you a couple of examples of what our messages looked like. We followed the Implementation Guide really closely but we did deviate in a few places and one of them is in the mass spec panel because we really didn't want to lose some of the integrity that we already had in our reporting.

For those of you who aren't familiar with HL7 or LOINC, these next couple of slides might be a little confusing but I tried to highlight the important parts and the basic structure of the message for the disorder reporting, it's divided into



sections and then there's OBR statement is kind of a section header and those are followed by OBX statements and they're individual statements that pertain to that section.

Next slide or next ... Okay, so the mass spec is divided into panels. In Washington we divided it into three panels the fatty acid, organic acid, and amino acid panel. Each of the panels has its own OBR statement or header that denotes that we're going to start talking about the fatty acid in word screening panel.

Next, and then within each panel there's a disorder group interpretation and this is where you can denote if the disorders that are part of that panel are all in range or out of range. In this example, there's a condition that has an out of range result that requires additional testing.

Next. Then there's an opportunity to say what condition is [inaudible 00:34:26] based on whatever might have been out of range. In this example there's the CUD is the condition that was suspected because of the out of range results.

Next. Then we are able to put in our comments or discussion section using the panel code and this is where we have the opportunity to really explain what the abnormal results mean and what we recommend to happen for this. We have really long and detailed notes on our mailers. I know not everybody does that but this is where we were able to kind of pull those in and put them right into that profile so that people know what they need to do because of those abnormal results.

Next. This is just an example of what the first part of a mass spec panel looks like in our message and it's the same for amino acids, fatty acids, and organic acids.

Next. Okay, then this is where we start to deviate from the implementation guide and one of the reasons why we did that was because we wanted to really, clearly be able to state what condition was out of range. We felt that just stating that a fatty acid oxidation disorder was out of range wasn't necessarily clear enough for what our purposes were so we use a condition specific interpretation.

Next, we have these for all the conditions on our the mass spec panel and here you can see, this is an MCAD New Born Screening interpretation and it says that the MCAD Task was in range and below it, you list all of the acylcarnitines that are associated with MCAD and what we're using Rhapsody for is Rhapsody will



be able to filter out all of these values for disorders where the interpretation is in range.

Next. We did this so that on our paper mailers we don't report the values if the condition is normal and so we wanted to maintain that as well and these disorder interpretations do include the reference range for each condition so they're able to see that within range and what the cut off value for that is, with just this one line.

Next. Now if one of the conditions is abnormal like this example here where we have the carnitine, the CUD was abnormal. We would retain the acylcarnitine, the individual acylcarnitine values and they would show what the C0 result was. What the C0 or acylcarnitine to citriline ration was for them to put into their records.

Next. This is the second half of one of our mass spec panel messages, including the MCAD, the CUDs, and LCAD which were normal.

Next, thank you. One of the other really complicated sections of the message that took us quite a while to figure out is the hemoglobinopathy panel, and so I just wanted to show kind of how we figured out doing that and it starts the same OBR statement for the hemoglobin screening panel.

Next. Then it has the same interpretation and condition suspected codes that you would find in the mass spec panel. For this example, it's normal so it's in range and there is no hemoglobinopathy condition suspected.

Next, where hemoglobins differ is that they actually even have a separate OBR statement so there's another section pertaining to the hemoglobin and that is where you have your observations.

Next, and we use the new predominance coding that NLM came out with not too long ago and this allows us to say which hemoglobins were found and in what order. In this example, it's a normal hemoglobin so we found the most hemoglobin F in this and second most hemoglobin A.

Next. This is what a normal hemoglobinopathy message would look like. Next. Okay, oops. Next. I miss-grouped my animation. Okay, then if you look into an abnormal message it's very similar.



Next. You have same interpretation and conditions suspected but here, you say something is out of range and then you can say what the condition is that was suspected. In this case it's a sickle carrier. You can actually repeat this condition suspected line as many times as you need to. There are some combined conditions, suspected codes but you might have a sickle carrier as well as an alpha-thal carrier, so you're able to do multiple conditions suspected depending on what the hemoglobin result was.

Next, and then similar to the mass spec, there is a commons discussion code that would populate if the result was abnormal and we wanted to add some more information or tell them what recommended follow up there was to expand on what the link and per code says.

Next. Then the predominance here, you see there's multiple, there's more predominant hemoglobin so you can do these and there's up to five I believe and so that's an example of an abnormal hemoglobin message.

Next. Then unidentified variances get a little complicated as well. There's not much different here in the first section of the hemoglobin message. It's very similar.

Next, and then in your observations, you start out the same way with the predominancies and the hemoglobin F/A and then a hemoglobin unidentified.

Next, but what's different is that whenever there's that hemoglobin unidentified code, you need to designate what it isn't.

Next, here you actually have to list out all of the hemoglobins that can be identified by your lab and basically you're telling them, we ruled out hemoglobin A, we've ruled out hemoglobin F. It's not any of these on our list and our list is actually, I think, twice a long but it didn't all fit on this slide so that, it gets really long and complicated but that's the way that it works and we have over 250 hemoglobin codes in our system and we found that this has worked really well for almost all of them. There's a few that get complicated but I think it's a really great way to try to convey what you've found in your hemoglobins.

Next.

Amy Liu:

As you can see from the examples that Ashleigh just went through, it took quite a bit of time to work with NeoMetrics to get these messages correct and



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Ashleigh did a lot of testing and working with NeoMetrics. We are very excited that we are done with the HL7 piece of the project and so now we're moving to our Phase Two which is working with our partners.

The next step that we're planning to do is preparing a package of guidance documents to send out to hospitals and in this document we're planning to have the NLM Implementation Guide, some documents talking about the specific deviations that Washington has made and then some sample messages so that the hospitals can send those along to their vendors so the vendors can make any necessary changes to their EHR.

We're planning to send out these documents to hospitals that have identified being interested in this project and it's been a little interesting in terms of our communication with the hospitals.

Early on when we first started the project, there was a lot of interest in this project but due to ... I mean full use and the fact that this project requires hospitals to connect to the HIE, I think, some of that interest faded but now that we have required ... Washington State has required all eligible, Medicaid eligible hospitals to send EOR messages for meaningful use via IHIE and a lot of hospitals have connected the HIE.

I think more and more hospitals are expressing interest again and so we've been communicating with hospitals, who have recently talked to us, saying that they're interested and we'll be working with them soon.

The first step for the hospitals is to make sure that they're connected to the statewide HIE and then after that we'll talk with the hospitals and see if the vendors ... If we need to talk to vendors to see if there needs to be any additional communications in terms of trainers for their EHR. After this stop then we're planning to through kind of our own validation process.

Next slide, since we haven't gone through our validation process just as kind of our proposed procedures. Once the hospitals are connected to the statewide HIEE, we want to see how these messages are being digested and parsed in their EHR system and so one of the ways would be to take screen shots of their EHR system and compare them to the paper mailers, what we're currently sending out.



If we see any discrepancies or anything that needs to be changed, we'll work with the hospital to make those changes on their EHR side and once the messages start looking pretty good in their system, we'll start sending live data for a period of time during this validation process and there's a ... Though after a period of time because it depends on every hospital and the volume of births that come through those hospitals so that that will determine how long the validation process will be.

After this validation process and once the hospitals are good with what they're seeing in their EHR system, we'll have the hospitals sign off on electronic messages and then DOH will stop sending the paper mailers.

Next.

Ashleigh Ragsdale: Okay, I'm talk about some of our successes and challenges and this is all pretty much related to Phase One but one of our big successes is we really feel like we maintained the integrity of our paper mailers and maybe even were able to include additional information that we aren't currently sending.

We did have some great collaboration within Department of Health as well as with our external vendor, with NeoMetrics and then our staff was trained and educated in new technical skills, like HL7, LOINC, and the NeoMetric system and we now have more resources within DOH to serve as a liaison for these kinds of projects as well as working with the lab and the vendors and eventually the hospitals when we get them up and running and working on this project.

Next slide. Some of our challenges, there were some competing priorities within the Department of Health. This definitely did not rank as high on our priority list as we would like. There was some staff turnover. Here, we had a really big learning curve for us or at least myself and DOH and then I know that even NeoMetrics had to learn some more about HL7 and LOINC and getting on the same page and there was the competing with the Meaningful Use with the hospitals, that's slowing down some of our Phase Two implementation.

Next, Lessons Learned, so a big one, do not get lost in the translation. This is a new language so either learn the language or find someone who knows it. It will really help out. I think this next one is the biggest one is identify someone with an understanding of both what Newborn Screening is, what it does, and what our reports mean as well as someone who can read that HL7 or read the LOINC



codes and can bridge that gap between these two worlds. It will really save some time.

Definitely partner with your IT department for message transport. I have no idea how that works, Amy does, so it really helps to have someone handle that part of it and it's not my responsibility. Keeping on track, I think one of the big things that really helped keep us moving was meeting weekly. We had weekly meetings with NeoMetrics, NBS and then bringing in to the IT department here. We did a in person meeting in New York and then we have conference calls and then don't underestimate the complexity of the message, kind of like what Kentucky said, this complicated, it takes a long time, so just be prepared for that.

Next.

Amy Liu:

Kind of our future goals and next steps. Once we start sending messages electronically to hospitals, we also want to start expanding that and be able to report electronically to clinics and primary care providers as well. In the future, we also want to be able to utilize and maximize the HIE and be able to receive inbound messages. Meaning, receiving lab orders from the birth facilities themselves and then, lastly, being able to integrate the Newborn Screening results with other databases within DOH or external partners.

Next.

Careema Yusuf:

Great, thank you so much. I'm just going to slip back to the ready talk webinar and if anybody has any questions for Washington?

Robin:

Hi, this Robin again, can you hear me?

Careema Yusuf:

Yes, we can hear you. Go ahead.

Robin:

I have a couple of questions. One has to do ... First let me say, I'm very impressed, especially with the way you stayed faithfully committed to the NLM Message Guide, bravo, but I have a question about where you felt that there was a discrepancy with the MSMS reporting because there's like 20 different disorders for fatty acid disorders in that NLM Message Guide and I'm wondering did you have more than that 20 or what was the issue there?

Ashleigh Ragsdale:

What we did that was different was we added those disorder specific interpretations. In the NLM Guide, they just have ... It's just the fatty acids in



range, conditions suspected, non ... and then it'll list all of the [inaudible 00:49:47] Carnitine. We wanted to add in a place that we could say MCADD tab, normal; ELCADD normal; CUD, abnormal. We wanted to be able to really clearly state that for each disorder rather than relying on just saying all the fatty acids were normal so that's just where that was something that we added in that was not part of the Implementation Guide.

Robin: When you're reporting ... Do you report all the analytes under each condition?

Ashleigh Ragsdale: They are in the message. NeoMetrics will ... The message that comes out of NeoMetrics has all the analyzed but if the result is normal, we use Rhapsody to take the analyzed out. We will only have the analyzed there if the result is abnormal.

Robin: Okay, so you are stripping out all the normal.

Ashleigh Ragsdale: Yes, we are.

Robin: Results ... Okay, so if you left all the normal analytes in, wouldn't that kind of do the same thing that you're doing with the ... having the specific statement saying that this ...

Ashleigh Ragsdale: It could, it could definitely do that but what we wouldn't want to do is have someone try to interpret the results for us. We want to be able to interpret them and tell them this is abnormal and here's your reference ranges whereas if they just had the acylcarnitines and it said everything was normal but maybe one of your secondary ratios is actually abnormal, they might be concerned about that and say, "Well, the C2 to C0 ratio is abnormal then why is this normal?" We really wanted to be really clear and have that control over the interpretation of the results.

Robin: Okay, yeah, that's makes sense. Okay, I have a question about your state ... I mean your Health Information Exchange, your state charges hospitals a fee to participate?

Amy Liu: For meaningful use, specifically for ELR, we've asked Medicaid eligible hospitals to be required to use the HIE and so in terms of charging an RHIE charges, there's a fee schedule that they give to hospitals depending on, I believe their revenue and so it starts off from \$600 to \$12,000 a year.



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- Robin: Do you know whether or not that's because of the DPN connection?
- Amy Liu: That I do not know.
- Careema Yusuf: Ashleigh and Amy ... Oh, I'm sorry, are you done Robin ...
- Robin: Well, I just had a ... Just one question.
- Careema Yusuf: Oh, go ahead.
- Amy Liu: As for the HIE, in terms of the protocol, they actually use a AS2 protocol for sending out messages.
- Robin: They pay a fee also to do a normal condition reporting? To your Bureau of Epidemiology?
- Ashleigh Ragsdale: Yeah, they pay for connections. Maybe it's the connections.
- Amy Liu: For connections, basically, we, DOH, we pay the fee in order to connect to the HIE and so once we pay the fee, basically all the services that the HIE could provide is included in that fee.
- Robin: To the hospitals.
- Amy Liu: Right, for everyone, anyone that's connected to the HIE for both DOH and hospitals or whoever else wants to connect.
- Robin: Okay, you pay the fee, why is the hospital being asked to pay a fee.
- Amy Liu: Because the hospitals are connecting to the HIE, so the HIE is essentially, they're the ones that are hosting ... One health part, they're hosting HIE and they're the ones that are routing messages through the different connections
- Robin: They're charging Department of Health and then they're also charging the hospitals.
- Amy Liu: Yes, so they charge anyone that connects to them.
- Robin: Okay.



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- Amy Liu: They're providing a service for those who are connecting to them by routing these messages, providing these encryptions for these messages.
- Careema Yusuf: I do have two more questions. One is asking, how does the HIE match the Newborn Screening messages with their baby records? What are the identifiers? Do you have any?
- Ashleigh Ragsdale: Currently, our HIE doesn't serve as ... Kind of it doesn't store that information or view that information the way Kentucky does. It's more of a pass through so the intent will be that our messages will go into the hospital medical record or the electronic health records at each individual hospital. The HIE doesn't read the messages, except for the header, so that it knows where to send it and then it's on the hospital end that their EHR will digest and parse the message and we intend to use probably the medical record number or the bar code number of the message for them to be able to match it to their medical record system.
- Careema Yusuf: Okay, thank you, and I think that answers the next one, which is asking does your HIE change or modify the message at all or is it just a pass through and then does it store results at all, in for example, a community health record?
- Ashleigh Ragsdale: No, currently our HIE does not have ... It's not a repository, so it's not storing any information. It's purely, you can see it as a post office. It's just passing messages through to the receiver.
- Careema Yusuf: Okay, great. Does anybody else have any other questions? Who is your HIE vendor? Do you know?
- Ashleigh Ragsdale: OneHealthPort.
- Careema Yusuf: Okay. Any other questions? Okay, if not, I would like to say thank you so much to all the presenters. I think that was a great presentation. You will be receiving an email from me after the webinar. We'll have a post webinar survey just to get your thoughts and any feedback you may have and also this will be available in the next couple of weeks online, in case you wanted to revisit it. Thank you again, everybody, and have a great afternoon.