



NewSTEPS

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Short Term Follow-Up Technical Assistance Webinar

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Presentations: Thalia Wood for Yvockeea Monteiro, District of Columbia NBS Profile

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Thalia Wood: Good afternoon, everyone. This is Thalia Wood with APHL. I have muted your phones, so once we get started, I just want to remind the speakers, to do *7 to unmute your phone so you can speak. We'll get started here in just one more minute. Thank you.

Okay, I do have 3:01, so I think we'll go ahead get started. I'm going to put up the first slide here so you know who our presenters are today. I will actually be presenting for Yvockeea, but John, if you want to go ahead and get us started, and we'll get rolling.

John Thompson: Great. Welcome, everyone, to our Short-Term Follow Up webinar today. As Thalia mentioned, we're starting off with our State Highlight, and this time it will be the District of Columbia. So, unfortunately Yvockeea is not able to present, but Thalia is going to be sharing her slides that she prepared for this purpose. Once again, the intent of having a little highlight, spotlight, at the beginning of these webinars is just to show what great work that everybody's doing, and that there are unique things about each of our programs, and ideas of how to do things that we can learn from one another. So, she'll start off, and then today we'll be talking about the CoLIN initiative, which is the ... it's an acronym, stands for the Collaborative Improvement and Innovation Network. So, Yvonne Kellar-Gunther from New STEPs, and also Colorado School of Public Health will speak first, and then we'll hear from Robin Thomas from California's newborn screening program, and then Carol Johnson from Iowa's newborn screening program. Thank you so much, and Thalia it's your turn.

Thalia Wood:

Great. Thank you so much John. So, as John mentioned, we're going to have the profile about the District of Columbia today. As you probably are aware, the District of Columbia, of course, is not a state. It's considered to be a city. It has a population of about 658,000. It does have a mayor and a 13-member council. It's interesting, though, be their laws can actually be overturned by Congress. They are under Congress's preview because they are not a state, and of course, if you lived in this areas you'd see on their license plates that they have taxation without representation, which is, kind of, a sore spot with them. They do have a neural network-voting at-large person who sits in the House of Representative. So, I'm not sure exactly what that person can do since she's non-voting.

I just wanted to also let you know, the newborn screening program for the District of Columbia does use PerkinElmer for their screening purposes. As far as the current births, they have approximately 10,000-15,000 a year. It's really hard to get a good, accurate number for the births of the district because so many of the residence of the District are not in the District. They're in Virginia or Maryland, and also Virginia and Maryland people come to the District to deliver, so it's very hard to calculate exactly how many are actually district residents, and so every year it's, kind of, a floating number, and I don't have an actual, good number for 2013 or 2014.

For 2014, this is what I got from Yvockeea. She sent me some information. She said that in 2014 they identified five acylcarnitines. She didn't specify which acylcarnitines they were or which of the amino acid disorders, but one was there. They had one congenital adrenal hyperplasia, two cystic fibrosis, six congenital hypothyroidisms, one Galactosemia, one SCID, which is quite interesting because I believe they just started screening for SCID last year. Is that correct? Do you know?

They had 19 sickle-cell disease. They had 996 traits, and those were mostly sickle cell trait, and other identified traits but predominately sickle cell. And 424 G6PD, which I thought was quite interesting as most of you are aware, the G6PD is not screened for everywhere. So I thought that ... even Yvockeea thought that was a relatively high number, but they were all confirmed.

I did want to share with you Yvockeea's contact information. If you want more information about the D.C. program, I encourage you to go ahead and contact here. I'm sure she wouldn't mind answering your questions. She did apologize for not being here today, but she has a report due tomorrow, so I told her I would provide this information. Before we move forward with the COIIN presenters, I just real quickly wanted to share another slide here with you from Alabama. They had a conference in September, and they have posted the presentations to their website, which you can see here on the slide right now. As noted, Dr. Harvey Levy said he thought some of the family's presentations were the best he'd heard, and as you know, he's been around newborn screening for a very long time, so I encourage you to go to the Alabama website

and check that out. So, without further ado, I will turn this over to the COIIN group. Yvonne, are you on the phone? Yvonne, *7.

Y Kellar-Guenther: Sorry, I had to ... yeah, I just did *7. Can you hear me?

Thalia Wood: Okay. Yes, thank you very much.

Y Kellar-Guenther: Sorry. My name's Yvonne, and I guess I know many of you, is my guess, but I am with NewSTEPs, and I'm out of the Colorado School of Public Health, and I have the pleasure of actually leading the COIIN initiative from the NewSTEPs side. It's been a really great experience. Thalia, could you advance the slide for me, please?

As John said, COIIN is an acronym, it stands for the Collaborative Improvement and Innovation Network. Before I heard of that what we used to talk about was [inaudible 00:06:22] and collaborative. So, what it is is a group of eight states who have come together, and in their states they're making changes, and they have state teams, which I'll get to in a minute, but then there's also this sharing that goes across states. We learn by talking to each other, we learn ... When I talk to people sometimes I'll connect with another state that I know is having a similar struggle, or has created something that they might be interested in. The emphasis is really on coming together, sharing resources, sharing lessons learned, and getting education to try to help move the timeliness needle, if you want to call it that, in their states.

So, NewSTEPs put out a call and asked people who were interested, and we have eight states who, again, are actually in the COIIN. Arizona joined us a little late, and then we have one team that's actually two states, which is Colorado and Wyoming. What we asked from them is that they put together teams within their state, and we wanted them to have someone from Lab, someone from Follow-Up, and someone who was either representing a hospital, a hospital point of view, or a hospital association. Then, the teams are five or more in some states, so they try to bring on the people that were unique to what they were facing, or what they wanted to do to try to make the impact that they wanted to have around timeliness.

This is voluntary, which I think is really important, so there's no money going to the states, and they show up. They show up every month, much like you guys, to have a discussion, and then in between they're meeting, and they're working, and they're doing things, so they're very dedicated. Again, they've just been an amazing group of people. So, can you forward?

When we first met, we asked them to come up with goals, and so these are the different goals by the states. I'm not going to go over the goals, but at the bottom I have in a nutshell, what people are really interested in is increasing the number of specimens collected and received in the lab in a timely manner. So, in quality indicator speak, we are focusing on quality indicator five, and the

emphasis of this CoIIN was on Quality Indicator 5A, 5B, and 5C, and then we amended Quality Indicator 5 to have a 5D. So, what those get at is birth to collection, birth to receipt by lab, then birth to call out, received by lab to call out. So, that's, kind of, the emphasis, is what they're looking at.

You can see that there's a range as to where they're targeting. So, you've got [inaudible 00:09:24] recommendations but some of the states are aiming for 85%, some are at 95%, and they started also at different levels. So, this is the goals that they're working towards. They've done these in a variety of ways. So that's ... actually, I don't think I have... Will you give me the next slide, please, Thalia?

Just to give you an overview, there's a variety of ways that the states are actually working to get this stuff done. So, some of them have added courier, some have increased their hours that the lab is working. There's a lot of education to hospitals, which I'm not going to go into a lot of detail because Carol and Robin are going to talk about their efforts, but those are the three big ways. A lot of that is combination that the states are doing to actually make the impact.

What we do as part of CoIIN, is we provide some support, and again, the states come together. We had a kickoff meeting last January, almost a year ago, where we met and we really talked through the continuous quality improvement cycle, and helped everyone think through the goals and creating SMART goals, so they're measurable, they're specific, they're time bound, they're all those things that we look for in SMART goals. Then, we asked for education needs but then I also talk to states on a regular basis and try to identify education needs. So, we've had calls where we've learned how to do data visualization, so we brought in someone from outside newborn screening who could speak to us about data visualization.

At one point there was a need to talk to midwives because that a group that was, maybe, having some difficulty with timeliness. So, we connected with a midwifery association and a midwife in one of the states who then came and talked about their process, and helped understand what they were going through, and then we could think through the timeliness piece and where we could, kind of make an impact. The states also give updates, much like what you guys just did for the D.C. area. That states will talk about what's going on, where they're at, the impact they've made, and perhaps more importantly to me is then we have discussion about, hey I'm stuck here can I get some input, how have you all been able to move this because we did this change, we're up to 70% which is not what we wanted, we really want to be at 90. So, there's the sharing of ideas that happens on these calls, which is really great.

Then sometimes, as I said, we'll connect people together. It's like, wow Colorado's got this great tool, let's get that on SharePoint so other states can use that great tool. Finally, because it is quality improvement, and part of the

PDSA cycle, we have created a tool to help them track their data. So, what you see, you see a graph with a lot of colors on the right side of the screen. Those are tools that we've provided to them, and states go in and put in the numbers for each of the quality indicators, and then you get the chart, which is the little thing in gray that you see, which helps show movement.

It's good because you can look and you can say, wow you had a huge increase in July, what happened? Then we can understand the impact of those changes, what happened, or you were doing well and there's a little bump down, what happened there, and what are the barriers that we're facing? That's really how CoIIN moves across. To date, I can say that the states have had improvement in their timeliness, all of the states have, which has been great, especially at quality indicator 5B. They're doing a great job, they're continuing to move along, and that's mostly what I want to say because I would like to hear from California and Iowa about what they're doing specifically with regards to things that we thought would interest you as a Short-Term Follow Up audience. So, that's it. Thank you.

Thalia Wood: Thanks, Yvonne. Do we have California ready to talk? Robin, are you there?

Robin Thomas: Yes. Hi everyone. This is Robin Thomas. I'm a Nurse Consultant with the California Newborn Screening Program. We'll just talk a little bit about three of the activities we've been involved with the CoIIN project. We're very happy to be a part of the CoIIN collaborative. Starting with our educational objectives, we have, over the past year, made timeliness part of our quarterly area service centers director's meetings, and also at our annual staff meeting that we hold once a year. One of the things we've done is just make sure that we have the topic of timeliness on each agenda, and we've shared our participation in the CoIIN project, and we got feedback and buy-in from all of the other area service centers.

We had two area service centers out of the seven that we part of the CoIIN team. What we've done for this fiscal year is everyone has agreed to a unified educational plan for all seven of our area service centers, and that educational plan is the same gals that we identified for our CoIIN project, and that is that 85% of our initial specimens from collection to the lab would happen within two calendar days. Our baseline in 2014 was 76.3%. So, we have a lofty goal to get to 85%.

Our other objective is that 95% of all of our initial specimens would be collected within 12 and 48 hours by March of 2016, and our baseline for that goal for 2014 was 90.6%. Also, from the state, overall we are working on our state newsletter to also have a message about timeliness in our state newsletter. The next thing we did was revise some of our hospital reports. We have a hospital report we call the Hospital Evaluation Performance Profile, HEPP. You can go to the next slide. This is an example of our HEPP report, and what we did was split the report into two pages. For July 1st we have a revised HEPP report.

The first page is focusing on the timeliness factors of collection and transit time. The hospitals are now starting to receive the format of the report with a letter explaining the changes, and they receive these reports quarterly. So, you'll see on this report we have ... This is a monthly report from one hospital that had 278 births, and we have the areas that are grayed out if they are outside of the desired goals that we have for them, hospital. If they are within the goals it'll just stay yellow. So, any numbers that they have outside of the goal will show gray on their report, and we also have their average age of collection and their average transit days for that. They usually receive the quarterly report, and we drill down monthly. The area service centers review the reports monthly in case there's a particular problem that needs to be followed up.

The next page shows the second page of the report, and this is the same hospital's report for September. This one, we focus on the TRF completion, and the number of inadequate specimens. If there are no areas that were on the TRF, it shows yellow. We can see for this month, this particular hospital did a really great job with completing the forms. They had no inadequate specimens. It's just a method for them to see how their staff is doing, and also for our area service centers to see what educational efforts they need to focus on.

We also have ... You'll see a couple of numbers there for the medical license number, missing the medical license number, but we're not shading that as a deficit because right now we can't accept the provider's MPI number, so we're not dinging the hospitals for that.

You can go to the next slide. One of the things we did starting late in 2014 was add Saturday pickup service. We use Golden State Overnight, which we call GSO, which is a carrier that provides standard overnight service in California, and also in a few neighboring states. So, they agreed to add Saturday pickup service for newborn screening. It's not a service that they typically offer. They are basically a Monday through Friday pickup service, but because we are a large customer for them, they agreed to add Saturday pickup for newborn screening.

Despite us having the GSO pickup for Saturdays, we still have some areas that only receive Monday through Friday service, or if there's a pickup it can only be delivered within two days. These are some of our remote areas in the far north of the state, and also some in the far south of the state. So, we have ... Basically, one of our lessons learned is that we have a very complex, multi-system state, because if you can see the very top where it says Monday through Sunday, we have our Kaiser hospitals that have ... Kaiser has a courier service that provides Monday through Sunday pickup, and GSO covers most of our state with Monday through Saturday, but we still have 10% of our specimens that are Monday through Friday only. Even though 10% is a small number, it's still almost 50,000 babies for us here in California. So, we are still trying to figure out how we can improve the service so that those 50,000 can be a little better served.

You can go to the next slide. This slide is very busy, but basically this slide is designed to show the difference between the NICUs and the regular nursery. This slide reflects 42 hospitals in one of our area service centers. Each of them have a group of hospitals that they're responsible to do the education and site visits for, and we have almost 300 hospitals in the state and over 200 midwives, but this is just reflecting the hospitals. You can see on the left side, the NICUs have a ... their collection times are a little bit more delayed than the regular nursery. You can see that for the same hospital, if there's a NICU, their specimen may not be collected until a little bit later.

We also have, if you see some of the red lines, these reflect some of the hospitals that are very reluctant to change their practice until our regulations are changed. Currently, our regulations give a much longer time to collect, by six days or prior to discharge, and some of them will not change their procedures until our regulations are finalized. So, we have had success in getting some of the NICU staff and the nursery staff together to just, sort of, walk through their procedures, and they've been able to identify a way that they can get the specimens to the lab faster so that they can be picked up by the courier, or just different ways that they could improve, by having a conversation, finding out what each other are doing. That's basically our update for California.

Y Kellar-Guenther: Can you hear me?

Robin Thomas: Yes.

Y Kellar-Guenther: When we put this together we'd put in discussion questions, and if we have time I would still like to have discussion questions at the end, but one of the takeaways that we've learned from COIIN is that monitoring your courier is really important. Some of the small changes that people have been able to find is there's a contract with the courier but it's not, maybe, being executed in the way that it was written, and you don't notice those shifts over time. Thinking through where in the hospital the pickup happens has had an impact, having someone go to the lab versus going up to the floor where the babies are born can change the timeliness.

So, one of the questions ... Robin, Carol, and I sat down and came up with discussion questions, and one of the questions we have is for people to think about how they're monitoring their courier. If we get a chance, we'll come back to that. The other question ties back into the slide that Robin just showed, which is, how are people working with hospitals that have a nursery and a NICU, and are you computing timeliness differently? We hope the answer is to that question, but if we have time, we would like to come back to that. So, I will let Carol go, but if we have time we have this slide and another discussion slide. Thank you.

Thalia Wood: I do have one question that was put in the chat box for Robin, real quickly before we go onto Carol. Somebody wanted to know, what is TRF?

Robin Thomas: TRF is our Test Request Forms. That's what we call our newborn screening form that they give the blood spots on.

Thalia Wood: Okay, great. Thank you, Robin. Okay, Carol, are you ready to go?

Carol Johnson: I am. Good afternoon, everyone. Welcome to our CoIIN presentation. I am first going to start with an overview of our CoIIN project. We initially formed our CoIIN team. It had five individuals, Kim Piper from our Department of Health, Stan Berberich from our lab, and myself representing Follow Up. We also asked a Nurse Educator in our largest birthing center in Iowa to join us as well as a representative from the Iowa Hospital Association. We then quickly added three more team members as we identified a need, and we now have a Lab Manager from the birthing center as part of our CoIIN team, and labs are key here. We'll talk about that. We also added a midwife to our team, and Ashley Comer from our Newborn Screening Lab, who now has become the primary liaison for our CoIIN project with birthing centers. We, accidentally I should say, formed two partnerships that I'll talk about in a minute.

Then we had to identify what birthing centers we wanted to participate in our CoIIN activities, and it ended up that we chose seven, which were diverse in both the healthcare systems that they were a part of, where they were located in our state, and the number of births that they had. Then we went on and developed and perfected our info graphic, we pinpointed next steps, and we began to provide education to facilities. This education was about general newborn screening things, but very specifically we talked about time-critical disorders, timeliness of newborn screening, and our CoIIN project. We're very happy to report that out of those hospitals that we went and talked to, three have formed their own local CoIIN teams, and we've already provided technical assistance to two out of those three teams.

Next slide, please. This is our info graphic. You'll see in the upper right that our goal is there in red, which states that by March 2016 we want 95% of our specimens to our newborn screening lab within 60 hours after birth. Again, we're using birth as our data point versus collection. Then, you look at the form and you see that in the middle there is a horizontal bar graph. We use the red, yellow, green colors here on purpose because I think we all can identify with green is good, green means go, red is stop, or bad, or critical. So, we use those on purpose. This horizontal bar graph, the green represents which percentage of births where the cards got to our newborn screening lab in equal to or less than 60 hours after birth. The yellow is 60.1 to 80 hours after birth, and the red is greater than 80 hours.

Those first two horizontal bars are for the facility, and the bottom two bars are for the state. I want to say here that this is real data, and this is one of our pilot hospitals that we're working with. You can note here that only 46% of this facility's samples were getting to the lab within 60 hours after birth, which needs improvement. Also, over 30% of their samples were not arriving until 80

hours after birth. Compare that to the state average. Again, this facility was 46. In April the state average was 70% were getting there within 60 hours after birth. And 30% in this facility it was 80 or more hours, whereas the state average was 9%.

Another way to look at this data is that vertical bar graph at the bottom. Each one of those bar graphs represents a birthing facility in Iowa. The blue bar represents the state average and the yellow bar represents the facility. It's just another easy way to look at the data. So, keep those numbers in mind as we go to the next slide please, Thalia.

Huge, huge improvements. They went from 46% in April to 80% of their samples arriving in the lab within 60 hours after birth in September of this year, and they reduced that 30% that were 80 hours or older down to 2%. If you look at that vertical bar graph, you remember how far they were over to the right, you can see how far they've come over to the left and that they are now surpassing the state average. So, if you don't remember anything else that I say today, look at this data and realize that when you work with your facilities, timeliness and newborn screening absolutely can improve. We're proud of this facility, and they are pretty proud of themselves, too.

Next slide, please. So, besides the benefits that you just saw from a birthing facility point of view, we have found the benefits to our program participating in CoIIN to be priceless. It has opened up the floodgates of communication between our program and birthing centers that just really didn't exist before, and it's made the program step back and reevaluate our communication and our educational strategies, as well as our entire QI system.

Next slide, please. What are the lessons that we've learned so far? First and foremost, education is key. We have found that when we go out, and do education, and make people aware of the importance of timeliness in newborn screening, they absolutely want to do the right thing. The other lesson today is, it is incumbent upon us as a newborn screening program to provide our birthing facilities with this information. We also realized that we need a dedicated QI person in our program, and so we're working on establishing a person outline right now. We partnered with a risk manager and with our state perinatal program.

A few words about our state perinatal program is that they travel to nearly every birthing center in the state of Iowa. They're a long-existing program, and they have great relationships with birthing centers. So, what we did is we sat down with our perinatal team, we provided them newborn screening education and specific CoIIN education, and now when they go out to facilities they have that timeliness data, that info graphic you saw, with them. They have other educational materials, including the report card for that facility with them, and they reinforce our message about timeliness and newborn screening. I think this

is important because they get to hear it from another source and it isn't just the newborn screening program that keeps pushing and pounding on them.

We also realized that even though we've had a courier in Iowa seven days a week since 2006, we were not monitoring the utilization of that courier very effectively, so we're working on that now and hope to see improvement in that area. Then, we have a web portal access in our program, where birthing centers can go in and look up newborn screening results, and what we're finding with our pilot hospitals is that not necessarily the right people have access to that web portal, meaning that you want people who can do research about delayed samples to have access, and you want people who can actually affect change to have access to that data. So, I believe as we move forward that's going to be a big improvement that we can make in our program, and I think it'll be a little bit of work as well.

Then, another lesson is to be prepared. So, talking about that relationship with the risk manager that we formed. She's a risk manager for the largest healthcare system in Iowa. She had two hospitals participating as our pilot hospitals, but she soon wanted data for all of her hospitals. So, our pilot essentially went from the seven birthing center pilot to about a 20-hospital pilot simply because of this relationship with this risk manager, and we weren't really prepared for that. Now, it is absolutely worth it, but I'm just telling you, form the relationship but be prepared for the data that you're going to be asked for. The other thing is that people talk, and we're finding that facilities are calling us and saying, hey we want our CoIN data, can you get it to us? So again, be prepared.

Last but not least here, the lessons that we've learned from the other states participating in this CoIN project have been invaluable, and they're great partners, and I want to say a big thank you to all of them. Next slide please. Next steps include a webinar. We will invite all of the stakeholders in timeliness for newborn screening to participate, and once we do that we're going to open up the CoIN project to all of the birthing facilities in Iowa. Initially they'll be able to see their info graphic on that web portal that I mentioned. They'll only be able to see their own data for about six to nine months. We want to give them time to see their data, and do improvements, and have time for the program to work with them as well.

Then after that, our plan is to publish this data. Hospitals will be able to see how each other is doing, and the public will also be able to see that. We also realized we need to enhance our state report card and our facility report, to not only include QI data points like quality and some of the things that Robin showed, but also, again using Robin's as an example, things like what other barriers to timeliness are there, like missing information on the card, gestational age, etc. So, we're going to work on that.

We also have a [list serve 00:35:49] that we use already to communicate with birthing facilities, but we're thinking about perhaps expanding that to maybe

make a provider-specific list serve, and looking at other modes of communication as well. We're going to partner with our midwife who's on our CoIIN team to work with those midwives who are not affiliated with a birthing center in Iowa, because they've been identified as a provider subset where we need to work on some timeliness goals. Of course, we'll continue to monitor timeliness data, and barriers to timeliness in our state even after this CoIIN project is finished. Next slide. That is the end of my presentation, and we'll open it up to questions.

Thalia Wood: Thank you so much, Carol. Yvonne, did you want me to go on to the next slide where you have some discussion questions?

Y Kellar-Guenther: If there are no questions right now. I would say, we would invite you guys to unmute yourselves and ask questions if you ...

Thalia Wood: I can go ahead and unmute the lines. If we have too much feedback I'll re-mute them I'll. But I'll unmute them for right now.

Y Kellar-Guenther: Okay. I don't know if people have questions for Carol. I'm not [inaudible 00:37:10] so I'd probably just ask. Does anyone have any questions for Carol?

Alright, so we have the initial question of, like, how do you monitor your courier? We have the initial question of, are people computing timeliness differently for NICUs versus the ... I'm going to say the regular hospital, which is wrong. Carol, what's the term we want?

Carol Johnson: B Unit.

Y Kellar-Guenther: B Unit, thank you. Then we've got these as well. She put it back up. I don't know where you guys want to go, but I don't know if you've heard something that surprises you, or if you want to talk through more. The courier has been an interesting thing for us, and Carol talked about this in her presentation. Just because you have a contract doesn't mean that it's being carried out the way that it was originally written. So let's just start with that. How are people monitoring their carriers? John, you're the only other person I actually know for sure is on the call. How does Washington monitor their couriers?

Female WA: Washington State doesn't have their own state courier system. Not applicable.

Y Kellar-Guenther: Well, it might be because then you still have contract with outside people to provide that, right?

Female WA: That's incorrect. The hospitals are responsible for getting the specimens directly.

Y Kellar-Guenther: Okay, so then as a state it's all on the hospital?

Female WA: Yep.

Y Kellar-Guenther: Okay. That's interesting. What about your timeliness then? Do you do it differently for hospitals with NICUs versus the birthing units?

Female WA: We send all the birthing hospitals in the state a quarterly report that tells them how their timeliness is, and we give them a list of all the specimens that came late, and we do on our specimen cards, if they mark the NICU box on the card, then that will show up in the report so they can, kind of, itemize it out how you like.

Y Kellar-Guenther: Okay, and is that what other states are doing?

Cecilia: Hello?

Y Kellar-Guenther: Hi.

Cecilia: Hi, this is Cecilia [inaudible 00:39:41] with New England Newborn Screening. How are you doing today?

Y Kellar-Guenther: I'm well, thanks.

Cecilia: Can you hear me okay?

Y Kellar-Guenther: Yes.

Cecilia: What we do here in Massachusetts is we contract with UPS courier services for most of our locations, and we have pickups, and then next day air delivery, so we'll get everything within the next morning. We also have a checklist. So, if any given hospital, if we don't receive specimens from any one hospital on a given day, our staff will call them. We have a list of contact people for newborn screening at the hospital. So, we'll call and say, we didn't get anything today, did you send us something? That's very helpful, and they'll tell us whether they had specimens or they didn't. Sometimes we'll find that they actually did send something, and we can get the tracking number for them, and track it to determine if something's been delayed, or mis-routed, or perhaps even lost by our courier.

We have a few hospitals that use their own private courier service, that are local in Boston here, that deliver to us every day. Same thing. We have contact people there, if on any given day that they don't deliver we will call them. It works very well. We're right on top of it if it's not here.

Y Kellar-Guenther: When you instituted that, did you see an increase in your timeliness? How long has that been in practice?

Cecilia: We've been doing this for a very long time, so it's pretty effective.

Y Kellar-Guenther: How many ... like, California, Robin's probably thinking, how many hospitals do you have in Massachusetts?

Cecilia: We have about 57 that deliver to us. 57 different locations every day.

Y Kellar-Guenther: How long does it take for the calls? If I'm thinking I want to do this, is it quick, is it a couple hours?

Cecilia: It's very quick. If I get ... Say we have ten hospitals today that did not deliver, it would probably take one of our staff members just a few minutes to make each phone call because we've already established our key contact people. We'll also find out, if we were to, say, call the nursery where the pickup is supposed to be, they might say, oh I don't know, we brought it down to the shipping and receiving area. So we can so, no that's not supposed to happen, the contract is the driver's supposed to go to the nursery. So, we can fix that on this end.

Y Kellar-Guenther: That's great. I love your system. Thank you for sharing that.

Cindy, Vermont: This is Cindy in Vermont, and I have, sort of, a corollary to what Cecilia just said. The Vermont specimens are shipped overnight during working days to Massachusetts, so they're received there, and then every day, mid-morning I'd say, the newborn screening lab in Massachusetts faxes us a list of all of the hospitals, we have 12 hospitals in Vermont, that submitted [UPS 00:42:44] envelopes that day. I'm thinking about this now that I'm listening to you all. We don't normally call a hospital that hasn't sent in a UPS, because being a rural state, many hospitals don't have a delivery every single day. What we do do is keep a very close eye on birth certificates and census lists, so if we see that a baby born in Hospital X should have had a filter paper submitted, then we'll call and hear, hey we shipped that UPS out, here's the tracking number. There is a delay, and I think we could probably tighten that up more than we have been. So, I appreciate Carol's excellent presentation and all of these thoughts for how we can improve things.

Y Kellar-Guenther: Great, thank you. That's what I was going to ask, is what the delay is. It's conversations like this that I think that's where CoIN is really helpful. So, I guess we can maximize the benefits here. How are other people tracking the samples received and making sure they're getting what should be coming?

Erica, Colorado: Hey Yvonne, this is Erica from Colorado.

Y Kellar-Guenther: Hi Erica.

Erica, Colorado: We have some things we've been doing to better closely monitor our courier. We've been encouraging hospitals to submit daily manifests that tell us what specimens are supposed to be in that particular envelope, and we also have a login here for our courier. We use a state-provided courier, so we have a login here in our mail room so that we can keep track of what's been received from

each facility by that courier. One of the things that really has been helpful, and it's something that we piloted a few years back was our chain of custody form, which kind of tracks that particular envelope of specimens each step of the way. That really has been vital when there's been a he-said-she-said kind of issue, where maybe the hospital said, the courier hasn't been coming by, and the courier says no we've been coming, we weren't able to get in.

So, we've used to chain of custody, first as a pilot and then in cases where we're struggling with hospitals with their timeliness to just make sure that each step of the way is documented. We're in the process of having that chain custody pre-printed on manila envelopes that we will use for all hospitals across the state. On there, we've decided to add a box that says no specimens available for packaging. So the courier will still go to that hospital daily, and bring us an empty envelope, which will indicate to us that there was nothing available. Then, if we get no envelope it'll be a reminder that we need to check and see what's going on at the hospital to ensure they're not holding onto specimens longer than they should have.

Cecilia: Do you have to pay for those empty envelopes?

Erica, Colorado: So, our courier's going there anyway. We do have to pay for the printing of those empty envelopes, so we're going to encourage that every hospital submit an envelope that day, and that's really important for some of our smaller facilities where we might go three or four days without specimens because they might only be birthing, you know, 50, 100 babies a year. But the courier's going there anyway, so we're already paying the courier to go to that facility six days a week. So, at least then we'll have documentation that the courier went there, went into the lab, tried to pick up something, and if there's nothing available that's fine. What we envision is when all the envelopes get here that morning from the courier, we'll run through our checklist and make sure there's no facilities missing.

In the past we've had facilities where the person on send-outs is on vacation, and a day or two will go by and nobody thought to send out the newborn screen specimens. Those are the stories we hear all the time. At least then we'll have, kind of, a daily mechanism for ensuring that the courier went there and that the hospital was ready, whether it's an empty envelope, or an envelope full of dried specimens. At least then we can track with our 55 birth facilities a day what's going on.

Y Kellar-Guenther: Any other questions for Erica? Thank you for sharing that. Erica, do you have a sneeze of what the cost is going to be for ... I mean, I understand that you're using the courier, but for the envelopes?

Erica, Colorado: We actually have gone a little bigger in the last few weeks of dreaming up our chain of custody. So, we actually are getting a cost right now of what it'll look like to be color on all those manila envelopes. Initially, for 20,000 envelopes it

was about 4,000 a year to have them printed, but we just decided to try to print them in color on the envelope to make it stand out better, so we're waiting for the cost to come back.

Y Kellar-Guenther: Interesting, okay.

Erica, Colorado: We still have to see what that is, but we also like the idea of having a universal-type package that the courier's looking for because you never know who the courier driver's going to be, whether they're new, whether they're not familiar with the facility. We see specimens coming in plastic bags, paper bags, envelopes, bio-specimen bags. We really just wanted to have more of a uniform manner that specimens are all coming to as well. That way, when the courier gets to that particular site they look for the envelope that they should be looking for. It helps the probably run a little bit more smoothly.

Y Kellar-Guenther: I'm actually going to put you on the spot a little bit more, because Erica is one of our amazing sites. I know that you've been working with class here in Colorado for your reports, right, for hospitals? You've got that design class?

Erica, Colorado: Oh, the poster. Thank you. So, we have a poster that we're in the final design stage, where we're creating a new poster for hospitals that run through the important steps of newborn screening specimen collection, couriers, and transport. What we did is we reached out to one of our local graphic design classes at a local college, and we were accepted as one of their community projects for the fall, and we went in, and we met with the class, explained the importance of newborn screening, and the ideas that we had for this new poster that's really designed for hospital staff. Then, they just got back with to us a few weeks ago with the first round of concept designs, and we went back to them, picked one of their concept designs, and we're currently refining the text and the pictures. In the coming days, we'll have a final copy. They basically just asked for a small donation to be made to their graphic design class, which was about 10% of what it would cost us if we went to a commercial graphic design company.

Y Kellar-Guenther: Erica shared that story with us with CoIIN. It was nice because that's just a different way of partnering and thinking through how to get the information at the level that you want. So, I just wanted to make sure she could share that with all of you. So, thank you.

Erica, Colorado: We'll be happy to share it with the newborn screening community once we get our final poster design done, so that everybody could use it. We tried to keep it along the national recommendations for collection and transport so that not only could we use it here in Colorado but anybody could use it if they're looking for an educational material to get it to their hospital.

Y Kellar-Guenther: Great. John and Thalia, I don't know how much time I'm still allowed to take. Do you guys [inaudible 00:50:13] time?

Thalia Wood: We still have ten minutes. That's fine. We did have one questions in the chat box. Hang on a second. I'm not sure what was ... Any negative feedback from hospitals? I'm not really sure what that was referring to.

Speaker 10: I do. That was earlier in the talk when the program was being discussed. Not so much the couriers.

Y Kellar-Guenther: That's fine. We can go to that. I think the hospital reports, one of the things that people are worried about is that-

Speaker 10: That's what I was asking about. The reports.

Y Kellar-Guenther:er I think that's a great discussion to have [Luke 00:50:46]. Robin, you guys are not ... and Carol, I think you don't ... you're not transparent with hospital names yet, right? But California is thinking about it, is that right, Robin?

Robin Thomas: We don't share with the hospitals the other hospital reports. They only receive their data. We are considering adding something to our website in the future, we haven't done that yet, to show how everyone is doing. Some of the ACEs do, on their newsletters, sort of, compare the hospitals. They, sort of, show the hospitals how they're doing in comparison to the others. So, it's a mix of, some get it and some don't, but when we send the reports to the hospital they only receive their own reports.

Y Kellar-Guenther: Have h you had any negative feedback from any of that?

Robin Thomas: Usually the negative feedback is that they don't believe the data is their hospital, so we have a supplemental report where we can actually drill down to each specimen so we can show them which specimens are theirs so that they can see.

Y Kellar-Guenther: Great. How about you, Carol?

Carol Johnson: Again, our plan is to make this transparent, but we're six or nine months away from doing that. We want to give the hospitals enough time to make improvements. The only negative comment that I've heard, and I wouldn't even say it's negative, is that the question that's coming up is for those midwives who deliver at home and then bring their samples to a birthing center to catch up with the courier to get to the lab, those hospitals are not wanting that midwife data to count in their data.

Robin Thomas: I would say that's the same for California, too. We separate the midwives, and we'll have a report for the midwives separate from the hospital.

Y Kellar-Guenther: Right, and I think Colorado does the same thing, right? You look at the midwife data differently, the timeliness? Erica?

Erica, Colorado: Sorry, Yvonne. I was sitting in the back of the room. No, we give the midwives exactly the same report card that we give to the hospital birthing centers.

Y Kellar-Guenther: But it's just their data, and so they ...

Erica, Colorado: [crosstalk 00:53:16]. We do not post the data anywhere, nor do we tell hospitals how other hospitals are doing. We're not one of those states that has been onboard with transparency, and that decision is pretty much coming down from the top at our health department, so we just work with that.

Y Kellar-Guenther: We do have ... One of our CoIIN states is doing transparency, and that is Tennessee. They have not ever reported out that there has been negativity, but that doesn't mean that there hasn't. We just haven't heard. Then, Arizona, of course, is also on our CoIIN, and it's really interesting having Arizona because, of course, they were a little farther along. They'd been doing that transparency, and working on this, and they've gotten an award for it. What they talked to us about is that next phase of keeping it at the top of the radar so people are still aware of it and still care about it. So, they've getting a little bit of backsliding. So, they're now doing things to make sure that this remains important. Overall, the state is doing really well but they have a few facilities that it's becoming a little less important to, but they still have those transparent reports. I don't know if they get used to them or what's going on ...

Female Arizona: Yvonne, it's Sondi. I'm on.

Y Kellar-Guenther: Oh, great.

Female Arizona: Sorry, I didn't want to interject. Yeah, I mean, as most of you know we've been doing the transparent reports, both individual hospitals as well as their perinatal peer level for almost two years now. Truly, it was much ado about nothing. We trained them, we prepared, them, we gave them an opportunity to comment on style, context, everything on who should get them, when should they go out, and the truth is it has really driven the change and created that level of ... you know, that transparency is doing what it's designed to do. So, we do, as I think one of the other states mentioned, have to be prepared to look at all of the data for each site because anyone that has an outlier, I'm going to send them back that medical record number and ask them to look at it and try to fix it.

So you know, for us it's been pretty good. I think what Yvonne said is, after a while though, the ones that are at 95% or above, they don't really care about 20 or 30 that aren't making it. If there's a holiday problem, or a system issue, or a person on vacation, because they feel like they're making the goal, what's the problem? So, I think as Yvonne, said, we're looking at some additional strategy to keep them motivated, and keep that going, and figuring out on this next CoIIN project how we're going to drill down and look a little closer at some of those variability.

Y Kellar-Guenther: Your insight has been very helpful for all of us, so thank you. I think we have two minutes left, Thalia and John. Do you want to ...

Thalia Wood: Yvonne, did you want to go to any of the other slides with other questions? There's some slides at the end here.

Y Kellar-Guenther: No, those are ones I just haven't taken out. At the very end, you might have a contact. Do you have a contact information?

Thalia Wood: I do. I'm putting that up now.

Y Kellar-Guenther: This is just, if you have other questions, or you want to know more about it, you can reach out to any of us. I can talk about ColIN very generally, but your real experts, of course, are Robin and Carol. I would be happy to get an email and respond, but thank you, and thank you for letting us share what we're doing. We appreciate it.

Thalia Wood: Thank you, we appreciate it too. John, do you have some final words before we get off the phone today?

John Thompson: I do have some final words. I want to thank everybody for their participation today. Thanks especially to Yvonne, Robin, and Carol for great presentations. It's a good thing our phone was on mute because we've got six people here in the room and we were listening to all the good ideas, and talking about how it works in Washington. So, we're grateful for your sharing, and for the people who have comments and questions. Thanks so much. I believe Thalia will be sending out an email request for filling out a little, short survey. Our work group really pays attention to comments and things from the community, so please let us know if you have ideas of things that you want to see addressed or ways that we can do better. Thanks, everybody.

Thalia Wood: Thank you. We'll be back in two months.