



Critical Congenital Heart Disease Technical Assistance Webinar

March 14, 2014

Presentations:

- Legislative/Implementation Challenges—Kimberly Noble Piper, RN, BS, CPH, CPHG
- Data Collection—Rachael Montgomery, BSN, RN
- Quality Improvement/Quality Control—Marci Sontag, PhD presenting for Debra Doyle

Moderators:

- Thalia Wood, MPH, Specialist, NewSTEPS
- Marci Sontag, PhD, Associate Director, NewSTEPS

Please direct all comments/questions pertaining to this presentation to Thalia Wood at Thalia.Wood@aphl.org or 240-485-2701.

Thalia: Welcome, everyone. This is Thalia Wood with the Association of Public Health Laboratories. This is the March Critical Congenital Heart Disease Technical Assistance Webinar. We'll get started here in a moment. I'm probably going to go ahead and mute everyone. For those of you who are speaking, Kim, just do star, 7, so that you can speak.

I also just want to let you know that Deb Doyle will not be available on the call for today. She's had a family emergency, so that will be [inaudible 00:00:31] by Marci. I'm going to go ahead and mute. It's star, 7.

Marci: Thank you, Thalia. Can you hear us? Can you hear me, Thalia?

Thalia: I can hear you.

Marci: Okay, perfect. Thalia, I'm just going to go ahead and give a brief overview before we introduce Kim. Looking at who's on the call, it looks like that many of you who were at the meeting last month are on the call. I just wanted to give you a quick overview of what happened at the meeting for those of you who weren't there, and then our speakers today will be going into more detail.



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The meeting was held February 27 and 28, in Silver Spring, Maryland, at the APHL office. We had a fabulous attendance. There were over 80 people there, really a nice mix of people from state health departments, from other federal organizations. We had members representing family organizations and advocacy groups, really a great mix of people. We had a format in which we had presented first the grantee and other states who are well along their way in implementing, then short 15-minute presentations of what has happened across several different areas CCHD implementation within their state. What were their challenges? What were their successes, here's some things to think about.

We did that for two or three speakers for each group, and then broke into small groups to have discussions. I really want to commend you who attended this meeting, that the small group discussions were incredibly fruitful. It was great getting to listen to all of the discussion that were happening, the idea sharing, the networking, and we heard feedback from people who have been implemented for quite a while, saying, "I was really able to learn from this, from other states that have implemented, and from states that are in that new process." New idea, how do you problem solve, how do you get things done?

I think overall it was a very successful meeting. The participation was just overwhelming, with how everyone really rolled up their sleeves and engaged. I think we all went home exhausted, but with lots of ideas.

From this meeting, to answer [Laura Terra's 00:02:52] question from a little bit earlier, there will be several products that will be coming out. One of the first things is we are working with the presenters, so if we haven't already reached out to you, presenters, we will be shortly, to make sure that it's okay to share their slides on our website of what they presented. We're putting together a brief summary of those presentations as well.

The goal of this, we talked about whether this should be a tool kit, and we don't want to duplicate tool kits that have already been in existence that are really being used well. What our long-term goal here is to have this meeting be the birth of a CCHD resource center that will exist on the NewSTEPS website. We're going to take the resources that were here, the ideas, organize them in a way that is really very useful for all of you to be able to access. Here's what was happening, here's the discussion that happened related to data sharing and data collection, and then provide those resources you can click through so you can find what they're doing in various states. What's New Jersey doing? What's Michigan doing? How can I find out what other people are doing?

That is under development. We are working with that to put that up on our NewSTEPS webpage. We're also working on a lessons learned from state implementation paper that we'll be writing this summer. We've already talked to a couple of people of the speakers who are interested in helping us with that manuscript preparation. This will be a nice follow up to the paper that was presented last summer, where Dr. [Gerard 00:04:26] Martin [inaudible 00:04:26] will be the



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author talking about implementation and really some guidelines and thoughts to consider. Now we're going to have a nice companion to that to say here's what's happening in some of the states, how some of the things are working, and what are some of the lessons learned from that.

We've really view our overall resource center as a growing resource that we will be looking back at all of you to help us. We'll be adding to that. This meeting will give us the foundation to have a really strong start at it, and then adding resources as more and more of us are implementing CCHD screening.

With that, today, what we would like to do is open it up. We've got three speakers to present. They were people who attended the meeting and were very actively involved in the meeting, not actually speakers at the meeting, but people who identified as leaders. I asked them to present across three different topic areas, the legislative and implementation challenges, then data collection, and then quality improvement and quality control. We'll talk about these, giving you a brief overview of what was discussed and some of the lessons learned. Next month, we'll talk about the other three issues which were NICU challenges, homebirths, first at a distance, and telemedicine challenges, and then education solutions. With that, I'd like to introduce Kimberly Noble-Piper, who's going to be talking with us today about legislative and implementation challenges.

Kimberly: Hi, this is Kim. Thanks, Marci. Can everybody hear me?

Marci: We can hear you.

Kimberly: You guys can hear me. I guess I won't hear from everybody. Yeah, it was a great meeting. First of all, I'd just like to start off by thanking APHL and NewSTEPS and [inaudible 00:06:14] for holding this meeting. I was wondering what Iowa representatives would get from the meeting because while we have legislation that mandates screening is done, that's it. A lot of states, I felt, were way ahead of us as far as data collection and monitoring, and what their legislative authority allowed them to do. It turns out the meeting was very helpful, very useful for me, and the two other Iowa folks that were there. It has given us a lot of stuff to think about and great direction on how to move forward with this. Thank you again for doing this.

I participated in small workgroups. As Marci said, we started off with presentations from [inaudible 00:07:04] grantees already and other people that were involved with [PHD 00:07:09] screening, farther along in the process. Then we broke up into small groups, and we talked about the presentations. We talked about what issues were affecting us in our state level, and came up with some challenges and some potential solutions to those challenges. That's what you see on the first slide here.



The challenges, the first one is pretty obvious. You probably have a template of challenges that starts out with funding, for about any project you're working on. Obviously funding is a challenge for states. A lot of us have unfunded mandates. Some potential solutions that were suggested for that were integrating parent advocates and the legislative activities, and taking some non-traditional approaches to funding.

The advocate conversation focused on how advocates were very concerned with getting screening mandated first of all. That was our priority. They wanted universal screening for every baby. They weren't concerned with the funding as maybe the public health departments and the institutions would have to work with mandates were. They didn't necessarily understand the implications of unfunded mandates. We thought it was important to connect early with those advocates to establish some common goals and to have an understanding that while everybody agrees, I think, that this was the right thing to do and that it should happen, there are resources necessary to make sure that this happens the right way.

As far as some unconventional or non-traditional approaches to funding, first is we suggested the cigarette tax, birth certificate or marriage license fees, on the registrations, potentially newborn screening fees. If you guys work with newborn screening fees, that's how your programs are supported. That may be a good one to look at, increasing the fee to cover the administrative costs of that.

Another challenge was the lack of public health authority. Existing legislation might not give public health authority to add conditions to their screening panel, to mandate screening, to collect data, or to monitor the screening. What was suggested was that we work with advocates to revise policies to [inaudible 00:09:37] authorizations for administration fees [inaudible 00:09:42] screening to the public health department, or some statewide entity to assist with that. That authority is there.

Another challenge was the reluctance of hospitals to report for the state. It's important to establish reporting systems through collaboration with the providers. Some ways would be centralized reporting systems, setting that up so everybody's reporting to one place, having a uniform, very minimal data set. If you're expecting your providers to submit data to you in hardcopy, filling out forms and submitting those to you on a regular basis, so that you're getting some kind of idea of what's happening out there, that could be pretty cumbersome. If you could make it a minimal of a data set as you can, that would be helpful. If reporting is automated, then you could maybe expand what you're requesting for data. Legislation or administrative rules would require reporting, would definitely help to increase the recording and data collected by the centralized supporting system.

Another challenge is a lack of dedicated staff to build the infrastructure for these. That is another resource there's not enough of to go around. The suggestion was made to work with existing contractors, starting with a small amount and then expand as resources become



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available, and use your existing referral networks such as regionalized perinatal care systems that some states have for referral purposes, and work with those agencies that already have some similar infrastructure in place. Partner up with them.

[Discordant 00:11:39] messaging is also another challenge. Again, I really recommend that you join forces early with stakeholders to develop a common message, and obtain cohesive support for that. The stakeholders are the advocates. Most of them are parents. Their main goal is to make sure that other babies don't suffer the same consequences that happened with their children, and that every baby has the opportunity to have this condition caught early. The other pieces to a uniform newborn treating system maybe aren't as important to them to promote as everything else, whereas from the state side, we're concerned with having resources available to do a quality program, newborn screening program. The earlier you can get together and all be on the same page, the better.

Sustainability, that's always another issue that could be on a template for challenges. We recommend coordinating sustainability with third-part insurers, your funders, and advocates. Then we hope that the American Medical Association comes up with a CPT code sooner rather than later so that hospitals can bill for doing the CCHD screening.

That was the extent of the conversations summarized from the break-out workgroups. It was great discussion and a lot of good ideas were put out from that. Thanks.

Thalia: Thanks, Kim. Marci, what's your thought? Should we open up for questions in between each speaker, or wait until the end?

Marci: I would say maybe wait until the end because I think some of the questions that Kim brought up might be addressed by some of the other speakers later on. We'll get more detail about the data, and we can have a nice discussion at the end.

Thalia: Okay. Rachel, I see that you're on the phone. You'll need to do star, 7, to unmute your line. This first slide was some of the bullets for the data collection, and Rachel's going to expand on that. Did you unmute your phone, Rachel?

Rachel: Yes, can you hear me?

Thalia: Yeah. Do you want me to go on the next slide?

Rachel: Sure.

Thalia: Okay. There we go.



Rachel: We had some good discussions as well. I just wanted to say that I really enjoyed the meeting, and it was very helpful. This part of the discussion was particularly more important for my state because this has been our biggest challenge, data collection.

One of the main challenges that we face is the resistance to report results, getting the hospitals to buy in. There were some suggestions made during that discussion which was to meet with the hospitals. We actually, through our [Eddie 00:14:39] program have encouraged some of our hospitals to create forms within their electronic medical record in a format that we'd requested. We [inaudible 00:14:51] those hospitals are providing that information to us every day. It has improved the reporting for our hearing screening results. That would be probably a good way for those hospitals that do have those electronic medical records to get them to report because it's very easy and less time for staff to have to send in information.

Another suggestion was to offer stipends to hospitals. I've added also to recognize those hospitals that meet or exceed reporting standards. This is something that we also do with our hearing screening results that are reported. We do recognize hospitals in the state that meet or exceed the [JCIH 00:15:41] standards. We either recognize them on our website or in a newsletter, and we found that that really encourages them to report those results in a timely manner.

Also getting IT involved, they would better know technology available for sharing data, and that is very important to have them involved, especially with the move to reporting electronically. Again, as was mentioned before, mandating reporting of the screening data.

Another challenge was identifying the data to collect. I know many states are collecting data and the use of certain tools to collect that data. Our state is looking to utilize the blood spot cards to collect data, and we realized that's limited data that can be placed on those cards because of the space that's available. There were other suggestions to add modules to existing systems to collect data, such as out of hospital data, integrating the HL7 messaging, linking the newborn screening data to birth defects surveillance systems.

Unfortunately, in my state we do not have a birth defect surveillance system, but I know that was highly recommended by New Jersey. That would be great if we could have that in place to collect that data. Linking the system with another state system, I know one of the states in our group mentioned that they were in the process of doing this because a lot of their babies were transferred out of state for services.

Then someone else in our group had mentioned that [STS 00:17:33] database, and mentioned that you would need an IRB to pull data, and it was challenging to match the data with the newborn screening data. They also mentioned the [Impact 00:17:50] system, which is a cardiac [CAS 00:17:51] database, I believe. But they said it wasn't as robust and not everyone participates, so that data would be limited. Someone also mentioned pulling claim status from



Medicaid, but that also represented, I believe, challenges with matching data with the newborn screening system.

Another challenge is the false negatives and collecting that information. Babies that pass the screen, we may not get information on those babies. It was suggested that collaborating with the tertiary care centers. We've actually had two babies in our state that did pass our [inaudible 00:18:40] screen that we later were notified by one of our pediatric cardiologists. We realize how important it is to establish those good relationships with the pediatric cardiologists in the state. Also, the birth defects registry, for those states who have that available, we did include all the infants identified with a heart defect even if they passed the [inaudible 00:19:07] screen.

Then funding, of course, is an issue, a big challenge for surveillance. I also added to the lack of staff to perform that surveillance. Some of the suggestions during discussion included an increase in the cost and fee increases, link to existing electronic systems to save money, not duplicating that information. In our state, again, we use graduate students to help with some of our hearing data surveillance, and we have [MIUs 00:19:50] for the local university. We have two students that help us. They come in once a week and help us with that data collection.

Lastly, lack of uniform terminology. It was noticed to plan ahead when establishing reporting fields, utilize existing standards. One I added, to learn from other states and adopt what they are using. It may be easier if you're sharing data, especially with those border states where babies may be transferred for services. There was some great information and a lot of people had shared a lot of good information, and it was very helpful.

Thalia: Thank you so much, Rachel. That was a great overview of the data collection piece. Marci, I'm going to original main slide for QI/QC, and then will go ahead and use Deb's slide if you want me to, for your discussion.

Marci: Sure. Thanks, Thalia. For those who may have joined late, just a disclaimer that Deb [inaudible 00:21:03] Doyle had a family emergency, so she's unable to join us this morning. I'm going to do my best to fill in for her. This dovetails nicely into what Rachel just presented that once you have collected the data, what are we going to do with the data? Actually, this slide that you're looking at now is the overview of the challenges and potential solutions. I'm actually going to move forward to Deborah's slide first, and then we can come back to those high-level issues because Deborah did a very nice job of summarizing it for us.

When we're thinking of QI/QC for critical congenital heart disease newborn screening, what are the questions of interest? The first one that Deborah outlined is every baby screened. That's critical. We need to know how well we're doing. She had several points of discussion that came up from the conversations. The first is using the dry blood spot cards to document the minimal CCHD data and link with the birth certificates.



This is an option that is available in a lot of states. Many states are modifying their dry blood spot collection cards to have very minimal data, pass, fail, and not done. Taking that and linking it to the electronic birth certificate or other birth certificate data to say, yes, we know which babies were screened and which weren't screened. Using the birth certificate themselves to capture the CCHD data, again, an option that's available in many states to modify the electronic birth certificate and have people entering data, the clerks or other people at the hospital, entering that data possibly at that very simple level, pass, fail, not done.

As was mentioned by Kimberly at the beginning, that type of data entry is much easier if it's not automated. If there's some way to automate it, can you do something that's more complex and entering more data, the actual values that are collected on the baby? If they didn't pass, did they have a second screen? What were their values on the second screen, et cetera?

Another point of discussion was to designate specific staff to follow up on those missed screens. Why wasn't the baby screened? Having staff at the state level to then reach out to the hospitals and say, we know in this unit, 5% of your babies on CCHD screening. What happened? Having someone whose that's their job to really be able to follow up on that, identify what happened, and then make note of it. Are there ways we could use that for better education? Or is there a certain subset of the babies that weren't screened and it's the NICU babies, and maybe we need to change how we record that data. But having someone dedicated to doing that is helpful.

The border issues. I think all of us have challenges with border issues, maybe most of us. Maybe Hawaii and Alaska are the two states who don't have the border issues of babies being born in one states, and actually residing in another state, or having their long-term follow up in another state. These are very important issues. How we determine if a baby was screened if they're moving back and forth, or were born in one state and were identified immediately, and gone to another state for their tertiary care. Consider interstate MOUs for data sharing. We also talked with the birth defect registry from the nation level, from the CDC, people who were at the meeting, and talked about other ways we could work on the national system to improve that to help us support state-to-state baby border challenges.

The out-of-hospital births, how do you determine if out-of-hospital births are screened? Is it mandated within your state that they are screened? We talked about working with the state and what ways and different organizations to think about. How can we really train the midwives? How we could get the right equipment? They know what they're doing, and how do they report that back? Is that through the previous mechanisms? That's one of the biggest challenges, identifying are those babies being screened, and are they be screened appropriately?

Then another question of interest, what is the quality and completeness of the data? Now that we've determined, yes, the babies are being screened appropriately, we have data on these babies, is the data being collected in a quality manner, and is it complete? The review of the



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number of hospitals with documented policies and procedures. What are the systems in place to say, yes, all of the hospitals have the procedure? Yes, they're training people appropriately. They have the right procedures, all of those pieces are in place. How are we tracking that at the public health level?

They've suggested that we can perform site visits to witness screening, so going out to the nurseries and seeing how the hospitals are actually performing screening. For dry blood spot screening, we have the evidence of how well it's happening by looking at the dry blood spot card, but we don't have any evidence if the hospital or at the state level or at the public health level to know how it's happening at each hospital. Could we perform some site visits?

Then from the data that is collected, one thing we can do is look at what are the missing fields? Did we receive the screening results? Was the newborn screening delayed? Do we know that it happened between the recommended 24- to 48-hour period, or is consistently in a specific hospital happening at 48 to 72 hours? Is it happening early? What's going on? Are those data missing? Are we collecting the actual [inaudible 00:26:51] values, preferably though some automated data transfer for collecting those values? We can look at that and say, look at this. They tended to be lower at this specific hospital, or they tend to have fewer failures than other cases. Are they really interpreting this algorithm correctly?

There were several presentations on how algorithms aren't always interpreted correctly. It seems pretty straight forward, and then when you get into the nuts and bolts, it can be challenging to remember if the difference is 4 or greater, is that a failure for the national algorithm? And the [inaudible 00:27:29] states have adopted their algorithms. Are people interpreting that correctly? All of those challenges. We really need to have that data to be able to look at that and make those interpretations.

That leads very well into what's the long-term outcome of this? Are we finding actual reduced morbidity and mortality? Is this cost effective? In order to be able to do that, we really do need to be able to collect that data. Collecting additional data on the screened positive infants, partnering with the birth defects registries in order to be able to identify those screened positive and those screened negative infants that actually turned out to be false negatives. Collecting that data and a long-term follow up [manner 00:28:12] so we can see what are the long-term outcomes. Linking it with the birth defects registry, as I mentioned, and having designated staff to follow up on the screened positive infants. Again, this is a financial commitment, but having that staff to be able to say, yes, we are needing what we're needing. These babies are being followed appropriately. They're getting the right services. They're getting the right surgeries. We can see what's happening with them, and having a record that yes, our public health program made a difference in the life of these babies.

We can work with the pediatric cardiac surgeons to collect data. They collect data that is submitted to national databases we can find out and partner with them to identify how those



babies from our specific programs are doing. Cross the screen positive infants with hospital abstract reporting systems. All that inpatient data. Partnering with the birth defects registry as available, or with other groups. For most of us, there's a very small number of hospitals that are performing those surgeries. We can partner with those tertiary care centers to find out who is doing those surgeries, what surgeries are being done, and collect information on them, similar to what we would do for dry blood spot newborn screening.

I'm just going to take a step back. That was from Deb's notes, which were more detailed than what we had presented in our high-level notes. These high-level notes are already on the NewSTEPS website for these three topics, as well as the other three topics. I'm just going to see if there's any other QI things that we should bring up here that we haven't already discussed.

The unique aspect of the point of care screening I think is very important here. Identifying those engagement partners and partnering hospitals together so that they can help each other, hospitals of similar size. One of the challenges that I think [inaudible 00:30:17] has seen is that hospitals who aren't having many births don't perform a lot of [inaudible 00:30:23] screening. While we think from the surface, this looks very straight forward, we've seen in many different places that the more you do it, the better you get it, the more you see these really truly are a true positive. Here's how we need to follow up on them, so partnering hospitals together so they can share that information.

There's a lot of variation between states that really having sheer numbers will help us to identify some of the challenges that we see. Having a centralized data system, and this is something that we are developing, and have really developed within NewSTEPS to capture the diagnosis, the [pulse ox 00:31:08] time. This is some discussion about collecting that zip code so we can look at altitude to see if there's variations among altitude and who's being identified where.

The disparate terminology is a challenge when we're looking at quality improvement and quality control. Creating definitions that are standard across all programs and across all states. We talked about creating a collaborative to attack this. We are as NewSTEPS going to be looking into developing case definitions, based on other case definitions that are currently in existence, including the CDC's birth defects registry case definitions. They're for a different purpose and used in different ways, but how can we learn from them, partner with them to build case definitions? We're gathering a group of volunteers to work on those in the near future coming up this summer.

An important thing that we all can remember is lessons learned from [Eddie 00:32:06]. There's a manuscript that will be coming out from Chris [inaudible 00:32:01] from New York, has worked with a long-term follow up subcommittee of the secretary's advisory committee, I guess now, the discretionary advisory committee of inheritable disorders in newborns and children. They have written a paper of lessons learned from [Eddie 00:32:24]. What can we learn from what has happened in [Eddie 00:32:25] that could be applicable to CCHD? We have some basic



information about that available now, and as soon as that manuscript is available, we will make sure that all of you are made aware of that.

One of the things that we did spend a lot of time on and thought about what are the challenges, are getting the hospitals to report data electronically. What are the options that are available for electronic data collection, so that we can have that data centrally, and use it for all these QI/QC activities? Michigan gave a very nice example. They're really giving options to their hospitals. Some hospitals will be using HL7 messaging. Some will be doing data transfer through other mechanisms, through a module that [Perkin Elmer 00:33:13] has helped them to develop. Some places are using spreadsheets to enter data weekly and transmitting that data to them.

Really, we need to give them benefits of reporting. This is an additional piece of work that we're giving to the hospitals. How do we give them something back for what they can do? I think Rachel mentioned the report cards. How do we provide those report cards back to the hospitals to allow them to say, we're doing great and we're right along the same track as everyone else. Or, we need to improve. Giving them those report cards, and then mechanisms for improvement so they see that their data entry makes it worth it. We have to give them something back to incentivize them to want to continue participating in entering good quality data.

With that, I think that's the 75-mile-an-hour summary of the quality improvement/quality control. Now we have some time for question.

Thalia: As I open up the line, Marci, could you explain what the STS database is for people? I'm going to go ahead and unmute everybody here. Now everybody should be unmuted. Marci, can you explain what the STS database is? People, if you're not going to talk, mute your phones please?

Marci: Yeah, the best option might be just to mute everyone and have everybody to use that star, 7, option when they want to ...

Thalia: I can do that. I'll go ahead and do that. Okay, now everybody's muted again. If you want to ask a question, just star, 7, and you can speak. Please explain what the STS database is. I don't think everybody knows.

Marci: Yes, sorry. I was muted, and now I think I'm not. I wanted John [Hokenson 00:35:25] could explain a little more details about it. I think I saw him on the call. Can I put John on the spot?

Thalia: Dr. [Hokenson 00:35:42] if you could push star, 7, and unmute your phone?

Marci: I don't know the details of it. It's a database used by I think it's the Society of Thoracic Surgeons to collect information about cardiac surgeries that have occurred, that all of the cardiac surgeons are entering data into. I don't have a lot of detail about how or when that happens.



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- Thalia: Dr. [Hokenson 00:36:17] is on the computer, so he isn't on the phone. Please use star, 7, to unmute your phone to have any discussion or questions for our presenters.
- Marci: He says it is the Society of Thoracic Surgeons database weighted on post-op complications. Thank you, John. He just typed that into the conversation window.
- Thalia: Are there other thoughts or questions from the meeting, or any additional information that you would like to have? Or anything that we've missed from someone who was at the meeting?
- Rachel: Is there any way we can get copies of those handouts presented, those new slides?
- Marci: Yes. We can take these new slides that have gone into a little bit more depth than our initial slides and put them up on our website. It will probably be early next week when we're doing that. We'll see if we get that done this afternoon. If not, we can do that early next week.
- Rachel: Great. Good overview for all the presenters, and yourself, Marci.
- Marci: Thank you.
- Thalia: There's a question. Have any of the states or systems posted model policies for facilities?
- Kimberly: I'm thinking that this question is directed towards model policies for hospital facilities. I don't think I've seen that yet. But I think that's a very good question. If anybody has anything available, if you'd like to speak up now? We can reach out to various places and see if we can identify model policies.
- Thalia: All right. For a group that was hard to quiet down just a couple of weeks ago, I'm a little surprised by the silence on the phone. Maybe we just wore you all out. Here's some example of what you would consider, model policies would be great. This is [Jay Massin 00:38:46] who asked this question online.
- I am going to speak for the questioner because I'm not entirely sure what the intent of the question was with the model policies, but I think it would be great to have some, what types of information do we want back from the hospitals? How are training the hospitals? What are the best policies and procedures at the hospital level for performing CCHD newborn screening? What's a public health facility able to give to the hospital facility to help them facilitate newborn screening?
- Marci, you see the next question. Where are the next steps determined at the national meeting on CCHD?



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Marci: Yes. For those of you who joined a little late, there are some next steps. We're going to be developing a resource center on our webpage that's going to incorporate all of these resources that we have gathered from all of the states. It was really amazing, all of the resources that were presented and shared, either in oral presentations or among the small groups. We will be developing that in the coming weeks and months to birth of a national resource center for CCHD newborn screening, within the NewSTEPS webpage.

We're also working on a manuscript from this meeting, so the lessons learned from state implementation type of manuscript that will be a nice partner to the paper that [Gerard 00:40:31] Martin [inaudible 00:40:32] that came out last summer.

We'd like to continue to support the networks that were made. It was great to see people meeting across different regions, from different places, different disciplines, and I would like to continue to support that network. We're brainstorming internally on how we can help to keep this discussion going, whether it be on these webinars, but also virtual conversations and other ways we can continue to share information on our website, on the listserv, and other ways. If any of you have any ideas, we are very much open to partnering and sharing ideas across our different groups.

Thalia: Okay, a couple more comments have been made here. Although individual level data collection is ideal, some states may be able to implement aggregate reporting. I didn't see this on the summary.

Marci: Absolutely. Gina, I'm sorry. I think we might have missed that somewhere because many states really don't have the public health authority to implement aggregate, or implement baby level reporting, or the resources to be able to do that. There were some very nice presentations on if you can do only aggregate level reporting, what can you do with that, and how do you facilitate that? Gina, I don't know if you're on the phone, you've been able to collect some very nice data from within New Jersey about aggregate level successes at each hospital.

Thalia: The next question will actually probably be addressed next month, but I'll go ahead and read it out anyway. What types of arrangements have nurse midwives that perform homebirths made to implement CCHD screenings? This will be covered, of course, in the April webinar, but do you want to talk about that for a minute, Marci?

Marci: I don't mean to be the one speaking all the time, so I'm trying to ... It's hard to know who has phone access versus who has computer access. If anyone else would like to help answer this question, related to nurse midwives specifically?

Thalia: Be sure to push star, 7, to unmute your phone if you would like to talk about this.



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Marci: I'm not hearing anyone jump in. Right now, there's not an easy solution that's come up. People have really been in that developmental stage of talking with the nurse midwives, talking with those associations, making those partnerships. If you could help me, I'm trying to think of the state that had a model practice for homebirths for CCHD screening?

Thalia: That was spoken about from the Wisconsin model, and again, I know we'll be covering more on that next month.

Liz: Yeah, this is Liz [inaudible 00:43:40] in Wisconsin, and we do have a form that the midwives fill out. Then that data is entered into a module that we added to our [Eddie's 00:43:50] screening application.

Thalia: Thank you.

Liz: They actually do put in some additional information, the actual numbers for the [pulse ox 00:44:04] screening and some additional demographic information.

Marci: Great. Thank you.

Chris: Hi, this is Chris [inaudible 00:44:18]. Can you hear me?

Marci: We can. Hi, Chris.

Chris: Hi. I just wanted to, Marci, comment on the question about the aggregate data. You mentioned the lessons learned. Just to highlight to folks, one of the lessons learned from [Eddie 00:44:34] was in our recommendation that screening programs should require child level data for quality improvement efforts, and really would emphasize to programs to work to do that. Sometimes people say they don't have legislative responsibility, and I think you need to take a look since you're doing a newborn screening program on a state level, a major part of that is to follow up and be able to collect that data.

Being from a state that initially did hearing screening aggregate-wise, and now we've moved to individual, when we compare our data now with individual, you can see there's discrepancies in terms of the numbers screened, which generally would go down. But it gives you at least better data. Then in terms of doing quality follow up and making sure, particularly when you're dealing, actually this is a little different for newborns, hearing screenings, in terms of a loss, to follow up, but being able to report on an individual basis I think is critical for any newborn screening program. We particularly emphasize that for point of care screening.

Kimberly: Thank you, Chris. Very important point. It goes back to the first slide that Kim presented on partnering early with legislative authority, when people are writing those bills, when you're talking about what the mandate is within your state, to really make sure that verbiage is in there



early on. I know New Jersey has had to now go back and try to modify how they're collecting data, and how they would get all that in because their legislation passed so quickly. But for those of us who are still in the developmental processes to think prospectively to be able to collect that data is important.

Thalia: Yes, thank you. That's right. We've had a couple of more questions about NICU and homebirths, and I want to keep everybody interested, so tune in next month which is when we'll be covering those topics. Rather than answer your questions right now, I think those will be answered on the April webinar.

Marci: Thank you, Thalia. That's a good teaser for next time because if the questions are related to NICU and homebirths, these are the challenges that we face with this population. Tune in next month. We'll talk about the challenges that we had identified, and what some of the state-level solutions were.

Thalia: All right. Are there any other questions or thoughts?

Ellie: Marci, this is Ellie [inaudible 00:47:26]. Can you hear me?

Marci: I can. Hi, Ellie.

Ellie: Hi. I just wanted to share that the statute in Maine for both [Eddie 00:47:35] and CCHD specifies that hospitals will provide the following the information, but not limited to that, and it has aggregate data points. In our rules, we have been able to put in a statement saying that information will be reported with enough detail for us to be able to assure that we don't duplicate count. That's where we get baby level data because of that statement in our rules.

Thalia: Thank you, Ellie.

Ellie: We also have related to homebirths, in Maine, certified nurse midwives do not attend homebirths. They are certified professional midwives that are not nurses. That group of individuals has really expressed an interest in being trained to be able to do CCHD screening. They have a unique relationship with their clients and really want to be able to do that. There are a couple of them that have purchased equipment. I don't know specifically what they purchased, so I don't know whether it's FDA approved for use in neonates, but we are going to continue to work with them to see that they have appropriate equipment and training. They also will need to be reporting to us when those rules go through.

Marci: Great. Thank you, Ellie.

Ellie: You're welcome.



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- Marci: All right. Again, I want to thank you all of you for calling in today, and thank all of you who participated last month in our meeting. We will be getting more details of that meeting out to you in the coming months of what was found in the discussions that happened. It was a very fruitful meeting, and I'm hoping that you've all taken things home to your states and regions that you can implement.
- Thalia: Thanks so much both to Kimberly and Rachel for giving us your thoughts today as well.
- Marci: Absolutely, and to Deborah who shared her thoughts with us via slide that I hope I was able to present well for her.
- Thalia: Absolutely.
- Marci: Questions, we really request suggestions for future calls. For next month, we have identified that we're going to finish up our debrief on this CCHD meetings, but please let us on other calls. Thalia will be sending a short survey to list ideas for those calls, as well as feedback on thi