
Short Term Follow-Up Technical Assistance Webinar

May 2015

Presentations: Improving Short- and Long-term Follow-up Efficiency through Implementation of an Internet Case Management System—Beth Vogel, MS, CGC

Newborn Screening Short-Term Follow-Up and the INSTEP Application—Steve Scroggins

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

Thalia Wood: OK. Thank you so much everybody for being patient. John has already done the introductions. Beth, you can unmute your phone and we'll go ahead and get started with your presentation.

Beth Vogel: Great. Thank you so much, Thalia, and thank you everyone for joining us today. I'm going to give an overview today of a system that we've implemented in New York newborn screening and also talk a little bit about our plans for the future for what else the system can do and what will hopefully help us improve even further.

This is a short and long term follow-up system that we call Internet Case Management System. Next slide, please, Thalia. Let's talk about the process to build the system. This was not a pre-existing system. We had to work with the vendor to determine what we wanted the functionality of the system to be and then went through a process to implement the system throughout the state. I'll also go through several example cases of where we've used this system and how it's been helpful for us so that you can see things that, maybe in your state, you could do with a system like this as well. Next slide, please.

The process to build the system. We worked with the physicians from specialty care centers. We started with implementing this with cystic fibrosis specialty care centers and we also worked very closely with the software vendor, Natus Neometrics, on developing this system. Really, all 3 of those groups has to come together and say, "What do we need this to do and how can it work," in order to get where we are today. Next ... Thank you.

What we wanted the system to do is make it so that we had an increased ability to interact with providers and to do more targeted phone calls and follow-up calls and letter. You can imagine that each case that comes to us, we have a set system of making phone calls for those cases and sending letters. Those are not based on that individual case, but based on what the baby's test result was. Every case is so different that if we got some feedback from the providers and could use that information, we can target the follow-up and save us time and paper and phone calls and the same for them. That's really what we wanted to get out of using this system is to make ourselves more efficient and also interact better with the different groups that we contact frequently for follow-up.

The system has several different features. One of them, it actually, how the system started is an online diagnosis form. Right now we have a form for cystic fibrosis and SCID. What's turned out to be the most useful of having that online diagnosis form isn't exactly what we intended in the beginning but that it gives the specialists a list of which cases they need to do follow-up on.

They have what's called the referral landing grid. When they go to that, let's say they've got 5 babies waiting for sweat tests, those babies are going to be on their list. It helps because they may think that one of those cases is taken care of but really they haven't sent us the diagnosis form or the results of the sweat test, so we still have it as open. It helps everybody be on the same page with which cases need something done. They'll get in touch with us if they see a case on their list that they don't think should be there so we can figure out what's going on.

It also has an image upload capability. We send out, I alluded to a diagnosis form for some things in paper, still. We also get some test results back in ... For example, our most common one, thyroid function test results, the providers and the hospitals can go into the system and upload an image and it goes right into that baby's case. It's associated with that baby. They can see it, I can see it, versus them faxing it to us and us having to find that baby's case and then get it into the system. It's right there and saves a lot of steps. That's helped us to be a lot more efficient.

The system also has fillable long term follow-up forms. Again, that's useful because a lot of information that you want for long term follow-up also starts in short term follow-up. You want the baby's newborn screen results, you might some demographic information. If they enter that into this system, that's all linked right in our system and nobody has to reenter that information. It saves time.

They are also able to enter case notes remotely so they will ... A lot of what I'll talk about later are those case notes. It's basically like a log between us and them where they can see what we're working on with a case and they can put notes in and let us know what they're doing as well.

They can also view whether the case is open or closed in our system, meaning are we still actively looking for information. We work with ... Each county in New York has an individual, at the county health department, assigned to work on newborn screening. They get a letter when there's a baby who needs follow-up. They can go in and not only read the notes and see what's happened and where they can be useful, but they can also see that sometimes we get a repeat sample in and the case is closed by the time they're looking at it and they can then spend their time and efforts working on cases that really need it. They can also enter new physician information if there's a new provider. Right now, this is what the system is able to do. Next slide, please. There we go. OK, we're good.

One of the goals that we had for the system is to use the infrastructure of our existing case management system. The existing system is not web-based. It's a system that all of our staff here at the newborn screening program uses and we wanted an internet-facing system that integrated with the system being used here by the staff, so that we weren't maintaining two separate systems or people weren't having to check for a case in two different places.

Any time something happens, a letter is ... An image is uploaded or somebody puts a note in, it's going to generate a reviewed action for us in the system that the staff is used to using every single day. Right now, we already had actions in the system. We had letters, we had calls, we had reviews, and then with the implementation of this system, we have emails. The CF [inaudible 00:07:12], when they have a new referral, get an email notification letting them know to log in the system and look at that new referral.

We started with implementing this in August of 2013. So far, we have 60 birth hospitals, newborn coordinators, that are using this system. We have a person at each hospital who's assigned to work with us as well. That person gets our phone calls, follows up if there's a baby who needs a repeat. We reach out to them as frequent users of this system. Also, 34 of our counties are logged on and using and the CF specialty care centers.

From January of 2014 until April of 2015, we had just shy of 3,000 case notes and images put into the system. This is how that has looked over time. It's about 200 actions or case notes per month. That's every time somebody goes in and puts something in, it generates one of those actions for us and I can see how frequently that's happening. As we add more diagnosis forms and get more of our specialists using it, I expect that this number would go up even further. We're also working on getting the rest of our hospitals engaged in using it as well.

I think I already said this, but just to reiterate that each time an image is put in or a notebook is entered, an action is generated in our system and that action serves as a reminder to go look at that and do something with it. It takes about an hour of staff time a day to go in and look in the system and respond to the information that's been put in. Actually, we've been able to split that up a little bit more recently because I can assign them to certain staff so that it comes up on their work list. If they follow CF, they're the person responsible for CF and somebody puts something in a CF case, I can assign that to them. That's actually made using the system even more management for us with our workflow, given that we have disorders assigned to certain staff members.

The system allows us to go in when somebody outside of here works on a case and take a critical look and cancel pending letters or phone calls or adjust the dates and really do individualized follow-up for those cases. Next slide, please.

I'm going to go through several use cases. I recognize everybody's follow-up procedures would be different from state to state in how you would use it, but I wanted to give some examples of how it's worked for us. I'd love to hear, during the ... Any questions or afterwards, if people have other ideas for how this system could be useful or things that they could see working in their state.

A frequently, unfortunately, notification for us from the hospital is that a baby has passed away. What the hospital can do is go into the system and enter a note to let us know that the baby has expired. The system will generate a review action. One of our staff will go in and close the case and cancel any pending follow-up actions for that case. What used to happen is that they would call us and we would require them to send us documentation and we would then go back in the case. In the meantime, that case is still open. This makes a more direct path to closing the case. The last thing we want is to be making phone calls or sending letters on a baby who's expired. The sooner that can happen, the better it is for the baby. This has been useful for that.

Here's another example and one that a lot of the hospitals really like. They will go in the system and enter a note when a repeat has been collected. They receive notification from us that the baby needs a repeat newborn screen. They go into their system, they put a note in that says a repeat sample has been collected once the family has come in and that generates a review action. What that allows us to do is either cancel or delay any actions, and actions can be phone calls or letters, from happening in the meantime. We will leave a review action in so that we make sure the repeat is actually received. Getting to our timeliness issue here. If the sample is delayed or does not arrive, we want to be monitoring for that.

I can't tell you how many times I would get phone calls from hospitals saying, "Oh, I got this letter from you guys saying this baby needs a repeat. They just came in 4 days ago for this. Why did I get this letter?" Well, our system generated the letter and sent it to you while the repeat was in the mail on the way to me and I can't know that that's happening. The system allows me to know, OK, they've collected the repeat. I don't need to keep sending out letters. It's really ... Then, it's saving them getting a letter and looking at it and trying to figure out why they got it. It saves me and my staff that time from having a phone call from them asking why they got the letter. Overall, it makes us be more efficient in following those cases to take just a second to look and see that a repeat has been collected.

OK. Another notebook example. The primary care provider was notified of the need for a repeat sample. This was from the hospital. The hospitals are ultimately responsible for us to notify the provider and the family that a repeat is needed, though the provider does receive letters from us as well. Once they put that in, we can make sure we've got the right primary care provider on file and we can also delay sending a letter to the primary care provider.

Another frequent comment and feedback that we would get previously is that, "I just got a letter saying that this baby needed a repeat. Why am I getting another one?" It was because the hospital was sending it and then we were sending it. They were getting two letters right back to back for the same baby. This way, we can work with the hospital and work out the timing of that notification so that we're not being as duplicative. It's been a useful thing to do that and also gives me and option, when I get those types of calls, to say, "Here's an option to prevent this from happening. Here's something we can do about it."

This next example is an example of how we use this for cystic fibrosis. The specialty care center can go in and put a note in that the baby is scheduled for a sweat test and the date. What the allows us to do is not send them additional letters making sure that the baby's been scheduled. Part of our protocol is to send a letter to the specialist and the pediatrician, saying, "Has this baby been scheduled for a sweat test?" If they put the note in that yes, the baby is scheduled, they're not going to receive that letter from us and they're also not going to receive a follow-up phone call from us until after the date the baby has been scheduled. Instead of every baby in every center now getting a call at a prescribed time, we can look at it and say, "Oh, this baby is scheduled for this day and here's the best time for me to make that additional phone call."

OK. Another example, similar to the pediatrician being notified is if the family was notified of the need for a repeat sample. Again, the newborn screening program sends letters to parents letting them know that the baby needs a repeat and sometimes the hospital sends those letters as well. This allows us to look and say, "OK, the hospital just sent a letter to the parent. We'll send a letter a little bit later so that they're not receiving 2 letters right at the same time." Hopefully be more effective in our follow-up.

Another important notebook for us if the hospital enters that the mother cannot be contacted. This is our cue to additional follow-up for the case. We can go in and check the immunization registry to see if the baby's had any immunizations and where. We can check the birth certificate records and we can also make a call to the county health officer and see if they've had any luck in getting a repeat or can help us with getting in touch with the family. I think because they're using the system, they put that in and sometimes would have picked up the phone to tell us, but not always. That gives us a trigger to go do more follow-up. Also, if we eventually don't end up getting a repeat, it gives us a nice record of everything that's been done and the timing of that from both the hospital side and our side.

Frequently, we send a lot of letters for NICU babies and do a lot of follow-up for NICU babies, as I'm sure is an issue across the board given the likelihood to get from positive screens for those little ones. One of the notebooks that the hospital will put in is if the baby is in the NICU on TPN. We will go in and look at that case and, if appropriate, delay the due date of our calls and letters to follow-up for a repeat sample for that baby. That can be really helpful.

The images. They can enter a diagnosis form or follow-up lab results. Usually, when they're entering that is as an image, we're then able to close the case. As I said, it saves us that step of having to scan it into the system and attach it to that case. It's already right associated with that baby's information. They can ... Some of the hospitals will scan in all of the letters that they send to the mother. Then we have that right in the system and it helps us with 2 things.

We can make sure that we have the right info for the mom and we can also target the timing of the letter that we're going to send to the mom to be the most appropriate timing possible. Also, again, helps us in the unfortunate event that we don't get a repeat in, now we've got a record of the hospital having notified mom, having sent the letter, as well as the follow-up that we've done to show what the efforts have been to get a repeat for that case.

Same thing, this is very similar. Some hospitals will put in the letter that they send to the primary care provider into the system. It allows us to make sure we have the correct info for the primary care provider as well as demographic information for that baby and also to target the timing of the letters.

What else can we do with the system? We can build additional short and long term follow-up forms for all the disorders and engage all of our specialists. We also plan to engage the remaining local health officers, hospitals and specialty care centers. Some of the specialty care centers, even though we only have CF and SKID forms right now in the system, we still gave them access and they will go in the system and still use it for follow-up even if they're not completing electronic forms.

What did we learn from using this system? Our follow-up efforts are often duplicated by what we're doing and what ... Verse hospital and the county and the pediatrician are doing. Using this system, allows us to focus on the cases that really need our attention. The hospitals that are following up and getting repeats and calling mom and sending mom letters don't need as much attention from the newborn screen program and now we can tell those cases apart from the cases where maybe those things wouldn't happen without us making some additional phone calls or sending letters.

Just a few acknowledgments. Natus Neometrics, Tricy E. Thomas and Dan Lagonterie have worked very closely with us on developing the system. Yvette Matos from Mount Sinai Medical Center was willing to test out the system and work through the initial process from the birth hospital perspective. Jane Foley's a local health officer who was willing to work with us. Maria Berdella, Kara Young and Elinor Langfelder-Schwind were at a CF center and willing to test out the system and get it off the ground, so thank you to all of them for that, working and being patient for that.

I'm happy to take any questions and thank you all so much for your time today. I hope that ... As I said, I'd love to hear some suggestions from all of you on other things that you can see this working well with.

Thalia Wood: Thank you, Beth. That was very interesting. I think we'll go ahead and hold questions until after Steve has given his presentation. At that time, when we end, I want to remind people just to star 7 to unmute your phone and ask questions.

Steve, if you've unmuted your phone, we'll go ahead and get started with your presentation.

Steve Scroggins: Absolutely. Hello. Thank you for letting us share this today. As John kind of said in the beginning, our application that we use is definitely home-brewed, so it's nice to be able to share our creation. I am Steve Scroggins from the Indiana State Department of Health and Newborn Screening. Today, I'll be discussing the application we use for follow-up among a few other things. Next slide, please.

The Indiana Newborn Screening and Tracking and Education Program, or what we call INSTEP, we actually developed it in house and it's used by hospitals, physician offices, our newborn screening laboratory, clinical follow-up grantees and other organizations and agencies. As the follow-up coordinator for newborn screening, I use the application daily, specifically to track kids who have missed or are in need of a valid newborn screen. I'll go through how this is done, but first just a little background.

INSTEP was and is developed in-house by our team, maternal and child health. They recognized the need for a single application that could be utilized by everyone who participated in newborn screening, including specific program operators and different stakeholders. INSTEP uses an application program interface, NX, as a middle tier for accessibility depending on user role privileges. That's really on the outside.

On the inside, the application is really a conduit for our data repository and it acts as a single entry point or a dumping ground for our data, then filtering, matching, and making visible whatever you may need to view. We use the term dumper very lovingly. This was the first incantation of this application where data would be dumped in, but there wasn't any kind of real or easily accessibly interface to view that information that you might be looking for. For example, you might be doing secure or personal data that really isn't applicable to whatever it is you're doing, which is never a great thing. You may be doing information on one person, but come to find out you're looking at twins. It was very easy for information to become mingled.

The next version was the extreme in the opposite direction and that database was our ODS. It had an interface that was very easily viewable, compared to the previous one, and it was accessible, but it wasn't capable of showing multiple data point, more than one data point. For example, as anyone who has done follow-up, we all know that people have more than one phone number usually and the ODS was incapable of storing more than one phone number or making viewable more than one phone number. That definitely presented some problems.

Of course, we found somewhere in the middle to be the best and the database we currently use is the IDS. It allows for an easy, accessible view along with multiple data points so you're able to view all the past phone numbers with an individual or a primary care physician, all the addresses, et cetera. As you can imagine, this makes follow-up more efficient, faster, when you have access to more resources to reach out to those people.

In addition, INSTEP also contains ... What's really unique are dashboards, what we call dashboards. They're actually smaller applications inside our bigger application that are program orientated. We have our cystic fibrosis dashboard, long term follow-up dashboard, birth defects and problems registry dashboard along with our newborn screening dashboard. Next slide, please.

Specifically, I think a good example is our CF dashboard. This links actual data with our newborn screen laboratory so anytime we have a positive CF newborn, a case is automatically created within INSTEP, inside the CF dashboard. This allows for quicker follow-up for different specific abnormal newborn screens. I'll go over this more in detail. On this slide right now, this is just kind of an example of what the cystic fibrosis dashboard looks like opening different cases. Next slide, please.

INSTEP is also unique in that it has many different data sources. From vital records to our lab, physician's offices. It's pulling information from multiple places. When it pulls this information, key data points create a unique profile page for each child born. We calls these CHIPs, but it's Child Health Information Profiles. Data associated with that child becomes easily accessible through this page, so being able to pull up demographics like those phone numbers, those addresses, or actual newborn screen results for an individual becomes much simpler using search functions like date of birth or mom's name, birth facility, stuff like that. Next slide, please.

What INSTEP does really well, having using it every day, it definitely allows for faster follow-up time in follow-up. I know, as Beth mentioned before, follow-up means a lot of different things to different stakeholders and program operators. Which every type of follow-up is being pursued, INSTEP, I believe streamlines and organizes the process. The types of follow-ups that I, everyday specifically, use INSTEP for are abnormal follow-up of who has abnormal newborn screens or children who have completely missed a newborn screen. Next slide, please.

In cases of abnormal follow-up, that follow-up is really determined by the specific abnormality, but in general, when a heel stick is sent to the lab, those results are uploaded into INSTEP and linked, as I said before, with that child's profile page. Depending on which abnormality presents itself, a case may be triggered and opened alerting the appropriate stakeholder. As you can see, really the ... In this slide, the efficiency and the flow of INSTEP is something I think that just shortens time on contacting different stakeholders and organizes the whole process by itself. Next slide, please.

Again, with the example of cystic fibrosis, the newborn screen lab will ... Our newborn screen lab will only do analysis on 45 of the most common CF genes. This covers about 95 to 96% of cystic fibrosis cases, but in actuality, there are thousands of CF mutations. Follow-up for a child who has confirmed to have at least one mutation is required and is extremely important. This follow-up requires a clinical test. I think Beth kind of touched on this in her presentation, the sweat chloride test. I think our program goal is that confirmatory test is done within 6 months of life at one of only 4 labs in the state.

Coordinating this with the primary care physician or healthcare provider who has to order that test can be a difficult task. While the goal is 6 months, since using INSTEP, our average follow-up time for a newborn screen, in March, was 25 days to have that confirmatory test. Next slide, please.

Not only does INSTEP allow for that automatic case creation within the CF dashboard for each case, an automatic process chart is also in each case. These steps will trigger complete depending on data received. This automation, an easy accessibly view, allows for organization with not only the PCP but with the clinical lab doing the follow-up testing. In that sense, it really streamlines follow-up and cuts down on kids that may have missed, or data that may not have been received. While certain parts of this process, you can see on this slide, are automatic, certain parts are not and they're manual and I think that really is used as a quality assurance measure to make sure that these kids ... You have of inside each case and make sure that you're clicking on something, that a letter is sent, as a quality assurance measure. Next slide, please.

INSTEP also plays a part in the follow-up with children who may have completely missed the newborn screen. The most common reason for this are early discharge or critical care transfers to other facilities. Follow-up with children who have missed their newborn screen is similar to follow-up with abnormal screens in that cases are created automatically. Next slide, please.

These cases are created from monthly summary reports or what we call MSR. MSR reports are done by all birthing facilities in the state. They're required to submit, through INSTEP, to us, the State Department of Health. The MSR has 2 parts. The first part is really just the list that has numbers of live births and numbers screened, but the second part is really where the follow-up and the case management come in. That second part is the exception so each child who has missed a newborn screen at a birthing facility for different reasons is entered. Again, this usually occurs if the child is in the NICU or if a child has expired. If a child is discharged without a newborn screen, those children are required to be reported to us within 24 hours. It creates an automatic case. Next slide.

When these exceptions are entered and reported, they automatically become open cases in the follow-up dashboard. These cases will automatically close once results from the lab have been uploaded for a child. INSTEP will use key data points to match those lab results with the child's profile page and close the case automatically. Next slide, please.

Once valid results have been uploaded, the case will be closed. This efficiency, again, cuts down on time to concentrate efforts on cases where newborn screens have truly been missed as opposed to children who may have just received a delayed newborn screen. Next slide, please.

Each open case in the follow-up dashboard also has a notes section and I think it's kind of interesting to see Beth talk about the application and the software that they use because it's very similar. With our notes section, it's possible for me, the state follow-up coordinator, to communicate with the birthing hospital or facility on updates and follow-up care. This is especially helpful for hospital employees who might have access or immediate access to email or phone calls or who worked at night, who still need to play a part in the coordination of follow-up. Also, with this notes section, each profile, each child's profile, has a section for attachments so being able to upload images or documentation is something that each birth facility can do. Next slide, please.

In conclusion, INSTEP was very much created with the goal in mind for faster follow-up. This is done through the automation of opening and closing cases. That is very much data dependent along with the versatility of the application to be used by different stakeholders for timely communication while still having those safety nets of manual operations, such as MSR exceptions and abnormal follow-up steps. These manual steps help assure that no child in Indiana is left behind. Next slide.

If anyone has any questions, absolutely feel free. If you don't get to a question, you might think of one after the presentation, feel free to email me. I work with other states on a daily basis, not only in follow-up but brainstorming problems and issues that come up, so absolutely feel free. Thank you very much.

Thalia Wood: Thank you very much, Steve. John and Carol, do you want to see if anybody has any questions and take a lead on this discussion?

Carol Johnson: Sure. Does anybody have any questions for either Beth or Steve? Those were great presentations, by the way. Thank you very much.

Thalia Wood: While people are thinking if they have any questions, don't get off the phone yet because we do have some polling questions we're hoping will lead to some discussion, as well.

Julie: Hi, this is Julie. I have a question.

Carol Johnson: Go ahead, Julie.

Julie: Thank you for those presentations. It was really exciting to see such nice systems and how interactive they are with the hospitals. I realize that each state has it a little different, in terms of who's responsible for follow-up. Primary physician versus hospital and I think, at least, Beth, in New York, you guys have a lot more requirement on the hospital. I thought what a wonderful system in how interactive that is.

I'm wondering, do you have in there something that might alert the hospital for those babies that end up being lost to follow-up? There's always a few and if you have one that shows up at 2 or 3 months and they're coming into the ER or they're being admitted because they're ill. Is that system linked in such the way that it might alert the hospital to say, "Oh my gosh, this baby didn't get their screen completed for whatever reason," or, "They had a positive MCAD and they fell off the face of the earth for while and here they're back." Is there that kind of capacity in that system?

Beth Vogel: Hi Julie. Unfortunately, it's not part of the system right now. There has been discussions at the health department, as a whole, building a system that links the newborn screening information with immunization information with hospital data and linking all those systems together with the idea that you could have some kind of alert system. This system is more contained specifically just to newborn screening and the individuals we work with on newborn screening at the hospital. The staff in the emergency room, for example, are unlikely to be able to go in and see information and check for that.

Julie: I see. It sounds like you have really good potential though with your system. It just looks wonderful. Thanks for sharing.

Thalia Wood: Hi. We do have two questions that were typed into the chat box. They're for both Steve and Beth. The first one is do either system interact with the laboratory data systems or are they standalone?

Steve Scroggins: I can answer that. For Indiana, they are standalone, although our INSTEP, because it was in-house developed and we have a lot of control over it, it's something that the lab does and can use. I think the lab is also using Specimen Gate as well, which is something that we were using before the development, before we developed this application which I really think was why INSTEP was created, to have a one for all application that all the different programs and stakeholders and labs. A lot of our abnormal follow-up in the state is done by grantees, specific grantees, so this is something that they can use, as well to make sure that those kids aren't lost to follow-up and that we're all looking at the same information and have the same data.

Beth Vogel: I can answer as well. Our system is linked to the lab system. The lab side to the Neometrics product is called MSDS and all of the lab data and results are entered into that system and then, if the baby has an abnormal screen, it's automatically transferred into the case management system for further follow-up. It stays linked to the lab results and demographic information from the specimen.

Thalia Wood: OK. Actually ... Questions are coming in right and left here. The next one is for both programs again. Who is the person at the hospital that you communicate with? Nursery staff or medical records staff?

Beth Vogel: Steve, do you want to go first?

Steve Scroggins: Yeah, sorry. In Indiana, it's really dependent and we really leave it up to the birthing facilities to do that. A lot of hospitals will have, we call them the MSR contact person, will be an employee of the facility who might be in health information. It might be ... I know one of our bigger hospitals, has a standalone position who's really responsible for follow-up, who takes the lead on this and does a wonderful job. It really varies from facility to facility and we really leave that responsibility up to them to find the right person to give them the task it is to follow-up with all those kids and enter the information.

Beth Vogel: Yeah. Same here. It varies from facility to facility. Though, I would say mostly they are mostly nursery or NICU staff who end up being assigned to the role of newborn coordinator. Each year, every hospital's CEO gets a form that they have to fill out and sign and designate staff that are responsible for working with the newborn screening program. That's because our health law is written such that the CEO of each hospital is ultimately responsible for ensuring that babies get screened and get appropriate follow-up and so that person decides who they're going to assign to designate to do that role for them. That works out well for us.

Thalia Wood: Thank you. The next question is how are multiple and changing names handled so that efforts aren't duplicated?

Steve Scroggins: In Indiana ... Sorry, Beth. In Indiana, our application uses data points and when a data point has a conflicting last name or first name, because INSTEP allows for multiple data points, it won't override it but it will keep it in context so if baby was born with a different last name, that baby is searchable by that original last name even though that last name might be changed, that baby will still come up. I think the down side that is unavoidable to this is that we do, sometimes, see a mingled record that needs separated. This happens with a lot of cases with twins. I know that ... The good thing about having an application that's developed in house is that we're constantly working with our developers to put safeguards on this and for updates to be able to minimize this as much as possible.

Beth Vogel: Yeah, same. The linking is actually done by the lab when they receive samples, so if they get another sample with a different name but mom's name is the same or the medical record number at hospital, they can link those together and the follow-up for the hospital can also enter an AKA for the baby, so if there's a completely different name, it can be entered in an AKA field so that we see both names in the system.

Thalia Wood: OK. The next question's actually for Steve. It goes back to your first answer, actually. Somebody asks does it mean that Indiana has to enter the demographic data?

Steve Scroggins: No. That information comes from the lab and the information that's on the heel stick card. When the lab gets that heel stick card from the birthing facility, it's mixed with the demographic information that's also put in with the birthing facility. We're actually working on some new updates to try to automate this process because I know no one likes sitting there putting in all that demographic information. We really give this responsibility to the lab to be able to do directly from the heel stick card.

Thalia Wood: Thank you. The last question in the chat box currently is for both of you. How does your system work for out of hospital births, or in particular, for missed screens?

Steve Scroggins: In Indiana, for missed screens ... I can even say that first part first, I guess. For out of hospital births, Indiana does have a large number of midwives. We have a large number of home births. Most of these individuals have access to the internet and the application is web-based, so that's really all it takes. For the very few that don't have access, they're mailing in those monthly summary reports with those exceptions on them. The kids that were missed, they'll mail them in.

If it is a situation where a child has completely missed the newborn screen, it's usually a phone call the next day or that same day that this child was not able to be screened.

Beth Vogel: Yeah. The home births, if we receive a specimen from them, usually the county is more of an integral role in doing follow-up. The county can get into the system. Not that we wouldn't give an account or give access to a midwife and I'm sure there are some that have requested that, but usually the county can really help us in those situations.

For missed screens, we don't have fully integrated tracking yet with our vital records to track missed screens. If we're notified that a sample is lost in transit or damaged in transit, then we can create a case or what we will do is take a blank filter paper that we have here and create a case so that we can track the baby in the system even though we never received a specimen.

Thalia Wood: Thank you. Another question came in for Steve. How do you handle sweat tests by non-accredited centers ... Non-accredited center sweat tests?

Steve Scroggins: It's really our ... It's really written into our project goals that ... That occurs very, very rarely. We're lucky enough to have an accredited center at each corner and in the center of the state, so you're not very far away. If that does occur, we ask that, from a program standpoint, that that's repeated at an accredited lab. We have such a great relationship, I think, with our accredited labs and they have their own follow-up protocols as well. That happens very rarely. So much so that I think a lot of the places that were unaccredited have actually stopped doing sweat chloride tests.

Thalia Wood: OK. That was all the questions in the chat box. Does anybody else have a question that they wanted to ask? One more came in just now. How do you handle reporting of cases missed due to [inaudible 00:45:09], ie. false negatives?

Beth Vogel: If we're notified of a false negative, we document it in our system. We can transfer any case, even if the results are normal, manually from the lab system into the case management side and we have diagnosis codes that we use to indicate that the case was missed by the screen. Usually, at that point that we're being notified as a missed case, we're not doing as much short term follow-up on it because the baby's already had been identified. If we wanted to include that in long term follow-up, we would be able to do that.

Steve Scroggins: Yeah, I think we have it where it's similar. It's really lab-dependent on our side. For something like a false positive, we have certain ... The lab also have follow-up protocols where they would make sure to send out letters and go through their process. We also have our grantees who do specific follow-up. I think it, in Indiana, it's so abnormal and disorder specific, that it would really depend which one it was.

Thalia Wood: OK. We have about 10 minutes left. I'm going to go ahead and start the polling questions. Carol, can you see your computer yet?

Carol Johnson: I cannot, but ...

Thalia Wood: John, do you want to lead? The first polling question is does your state have a written emergency plan that addresses newborn screening? As you can see, I've got the answers coming up here. It looks like most of the states do. We'll go on to the next question. If yes, does it include short term follow-up? It's good to see that most of them do include short term follow-up. If no, what region is your state in? Since there's not very many nos, we're just curious to see which region your state is in if you don't have short term follow-up. Wow. The heartland is doing very well, wouldn't you say, Carol?

Carol Johnson: Yes.

Thalia Wood: OK. This is very interesting. If yes ... If you do have a short term follow-up plan for emergency preparedness, do you have birthing facilities included in your plan? [inaudible 00:49:02] If yes, do you have ... I should say do you have, not doe. Do you have an MOU in place with another state? For follow-up. This is for short term follow-up. I know you can't see this Carol, but John, I think we can use this for some discussion among the group. Do you want to lead the discussion here now? This is where you can invite in a response, but basically, John, if you'd like to start a little discussion here?

John Thompson: I think you started it already.

Thalia Wood: Yeah.

John Thompson: Our work group has had emergency preparedness on the discussion the last couple of times that we've had our meetings and so we wanted to just poll and see who got what out there, if there's a certain region that might need specific help or if you're in one of the regions and you don't have a plan, but your [inaudible 00:50:13] do, then use that as a resource. Is there a general interest out there or can people see ways that our short term follow-up work group could help facilitate learning or sharing information about this type of thing? You have to star 7 if you want to say anything.

Thalia Wood: So far, 12 people put in what they have for definitions. I'm not sure ... Can you see those, the results on your screens?

Female: No.

Thalia Wood: OK. I guess I'm the only one that can see them, then. I can read some of them off or John ... How do you want to deal with this? Do you want to just have a further discussion as we move forward in our work group?

John Thompson: If it's easy for you to read through what people have written then we can throw that out there and the group can chew on that for a bit and then we can get back to the bigger community.

Thalia Wood: OK. The answers have been from collection, screening sample to diagnosis. Assuring that every newborn received both newborn screening and follow-up. To diagnosis to confirmation and into care. From notification of abnormal, unsatisfactory or missed newborn screening until diagnosis is made. Ensuring that infants are followed to the point of diagnosis and treatment. Until child is connected to diagnostic care. Until the baby has been seen by the specialist and received a diagnosis.

I'm not even seeing the full answers right now. I'd have to go into the computer later and look at these. From time of abnormal newborn screen results to diagnosis or exclusion of diagnosis. Follow-up to the point that the baby has a normal result or an affected baby's ... I don't see the rest of that answer right now. Calling out a positive minimum requirement and diagnostic follow-up. Until the child is diagnosed or cleared. Following an infant until diagnosis is confirmed. All activities done to ensure every baby has received a sufficiently reliable care or screening. From collection to diagnosis. Short term follow-up is defined as immediate follow-up to an abnormal critical, missed or ... I can't read the rest of that answer right now. Short term follow-up ...

I can send these out. I will obviously send these out to the short term follow-up work group, but I think ... Why don't you go ahead and tell ... Again, reiterate what our idea is about this, John.

John Thompson: Yeah. I think we'll take a look at this. It sounds like we've got kind of two different ideas across the board of how people define short term follow-up. We will look at this. This is fodder for our discussion. If you have anything that you'd like for us to address in a direction we haven't told you we're going or anything like that, you can certainly feel free to contact me or Carol Johnson or Thalia and we will bring that up. We meet each month for a phone conference and then we have these webinars every other month. We're looking at other opportunities for doing projects that will be helpful for the short term follow-up community, so we're always interested in new ideas.

Thalia Wood: Thank you. I think that was well said. Again, if you have any other questions, if you think of other questions for either of our speakers today, reach out to Carol, John, or myself and we'll make sure that they get answered. We do appreciate the fact that you participated in today's call and thank you again to our speakers. Carol, did you have anything else before we close?

Carol Johnson: No. Just maybe ... Actually, I lied. Yes. Stay tuned for our July webinar and Thalia, do you know the date of the top of your head? Again, I'm out of all my IT here, so I can't see it. We're going to focus on endocrine disorders.

Thalia Wood: Yeah. That will be July 13th.

Carol Johnson: July 13th. Stay tuned and maybe spread the word to any of your endocrine medical consultants or long term follow-up people. I would hope that we have a good representation from them as well as short term follow-up.

Thalia Wood: Absolutely. All right. Thank you so much for joining our call today.

Carol Johnson: Thank you. Bye bye.

Thalia Wood: Bye.