Short Term Follow-Up Technical Assistance Webinar

March 2016

Presentations: Jami Kiesling, RN, BSN, Missouri State NBS Profile

Jacob Rosalez, APHL, Senior Specialist, Institutional Research

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Carol:	Well welcome everybody to our March Short Term Followup Webinar. Today's topic are going to be about using infographics in your program. Before we go into our two main speakers, we are very happy to have Jami Kiesling with us today from the state of Missouri to do the Missouri state profile. Go ahead Jami, and thank you for agreeing to present to us today.
Jami:	Okay, can you guys hear me?
Ruth Anne:	Yes, we can hear you.
Jamie:	Okay, great. Like Carol said, my name's Jami Kiesling and I'm the Program Manager for Missouri's Newborn Bloodspot Screening Program. I will be providing a state profile for Missouri today. Just for fun this first slide has some of our lovely state symbols on it. You can go ahead and progress to the next slide. Here's a map of Missouri, and in 2014 we had a population of a little over 6 million. We have a 115 counties, and our state capital, Jefferson City, is centrally located in the middle of the state. Four of our five largest cities are located along the I-70 corridor, which runs East and West through the state. We have 4 children's hospitals, one in Kansas City, one in Columbia, two in St. Louis. We have 8 border states, which I think ties us with Tennessee for the most neighborly states. We have the 7th largest Amish population in Missouri, so that's always something we take into consideration, trying to make sure we get all the babies screened, as many as possible. We have a poverty rate of 15.5,

which is a little higher than the national average of 14.8. We have 87 people per square mile. Next slide.

Here are some of our 2014 statistics. Because the fact that we have a large number of border states, we do have babies that are born in Missouri, and then screened out of state. It's difficult to know exactly how many Missouri babies are screened out of state, but we do know ... We have at least 755 out of state babies that are born, that are screened in Missouri. Some of those babies have initial screens in other states, and then get transferred in to some of our children's hospitals that have screens in Missouri, too. We really try to coordinate with our neighboring states and make sure that all the babies are getting [followed 00:03:17] appropriately. Next slide.

These are the core conditions that we've identified in 2014. Missouri screens for 32 of the 34 core conditions. We do not yet screen for [SCID 00:03:34] or X-ALD. Next. These are the secondary and other conditions detected in 2014. Of note, in addition to Pompe we also screen for Krabbe, Fabry, and Gaucher, and LSD disorders. Next slide. I want to give an idea of our program structure here in Missouri. In addition to our internal program staff, we also contract with four children's hospitals to coordinate and provide followup services for all babies found to have a [inaudible 00:04:16] positive newborn screen. We have four genetics contracts, four cystic fibrosis contracts, and three Hemoglobinopathy contracts. Next.

This slide outlines some of the new and exciting developments here in Missouri. We were able to add holiday courier pickup in January, 2014. Then Sunday courier pickup was added July, 2015, and Saturday and holiday testing began October, 2015. We now have over 3 years of LSD screening under our belts. We went live with Pompe, Fabry, Hurler, and Gaucher on August 1st. We plan to go live with Krabbe screening in April, and then we hope to start piloting Niemann-Pick in June. We have a SCID bill that has been introduced during the 716 legislative session, and seems to moving along nicely. House Bill 1387 has passed the House, and it is currently in the Senate, so we're hopeful that the legislation will pass with year, and allow us to move on with implementing screening for SCID in Missouri. All of our initial hearing screenings are now being reported through the electronic health record. We're working toward implementing a similar reporting process for CCHD as well. Next slide.

This is a nice graphic to show our sample transit time improvement due to the addition of holiday and Sunday couriers, and Saturday and holiday testing. As you can see the changes that have been implemented over the last couple of years have really helped improve our timeliness. Next slide. Here's my contact information, and I've also included Patrick's contact information. That's the state's public health lab. Thank you.

Carol:	Thank you, Jami. That was an excellent presentation. I took a lot of notes. Thank you.
Jami:	Thanks.
Carol:	Next up, we have Jacob Rosalez. He's a Senior Specialist in APHL and Institutional Research. He's going to show how infographics can be used in newborn screening data. Thank you, Jacob.
Jacob Rosalez:	Good afternoon, everyone. I was already introduced, so I'm Jacob. What I'm going to show you is kind of like a whipped together, this quick and easy interactive data visualization here. The software that I utilize is Tableau. Tableau is ,one of the things when it comes to like interactive data visualization data dashboard, I think some people might be a little, maybe a little, I don't know, I don't want to say scared, but have concerns because maybe they don't have a background in data science or computer science. One of the useful things with the software Tableau is that it's a very, I would say, if you understand how to use Excel and make like graphs and whatnot in Excel, than you should be able to transfer those skills over to the Tableau. Tableau has a graphic user interface, so it's all kind of drag and drop, point and click. At times there's need to actually put like some formulas together, but for the most part, it's just drag and drop stuff. There's no coding or programming involved, so it's something that someone who doesn't have a background in data science or computer programming, they can do rather easily.
	This dashboard that I put together here, obviously to [fix 00:08:05] initial newborn screening fees for MDS program of the United States. The data, I collected data from the New Steps Data Repository for the initial [fee 00:08:15] data. Essentially, this has three data points. I have the state, their initial fee, and also their NCC region. Right now, when you look at it this table here shows aggregate results for initial screening fees. You have the average, you have the minimum, and you have the 25th percentile, the median, the 75th percentile, and the maximum. As you hover over a state, you'll get some information. California, it'll tell you what NCC region it is, and what the initial screen fee is. If I were to click on California in the table down here. Oh no, sorry. If I click on California, the table down here gives me their screen fee down here, so I can kind of have a quick way to compare. Also, on my legend here I have it so I can actually filter this aggregate table, instead of be the national, I can filter for the region that California is in.
	This is all pretty quick and easy. Like I said there's three data points in this. You don't need to have a plethora of data. You don't need to have a CDC survey or anything like that with hundreds of data points. If you have anything from like [birth 00:09:38] spinal data, and you just want to put together an interactive dashboard with that, you can do that with just a few data points. There's no, you

don't really need to have an understanding of JIF, even though this is kind of a core plus math with the polygon. There's no ... You don't have to put any [inaudible 00:09:55] shape files or anything. You just need to make sure that you have the state name in there, and then it'll actually locate those states and plug that data in on those states that you want.

Some things with Tableau that I always like to point out to folks that are really interested in it, is that if you have data that is extremely sensitive, you can use Tableau. However, with regards to sharing it with other folks on the internet, you need to have a Tableau online license, or a Tableau server license, which is we're talking like in the thousands of dollars. It's pretty expensive to have, to use that. But if it's just data that you have from say like the birth data that is sent out every year. Or just data on like if you want to include some information about your area with regards to what the census population data is, anything that is readily accessible publicly, Tableau is a really good tool. When you load it into what is called Tableau public, it's online and can get like [embed 00:11:04], so you get an [embed 00:11:06] code for your dashboard. Then you can throw it on your blog, on your Facebook, or if you're organization has a website, you can take that [embed 00:11:17] code, give it to your folks in your center in your information systems, and they can display that on the page for you.

For me, I love doing JIFs maps, and a lot of times, you probably see it. Sometimes you see a static maps, and it looks like a Christmas tree, because they're trying to present too much data at one time. The benefits of using an interactive visualization for maps is that you can just hover over. If I have like, say I have 15 different data points, I can hover this, and see what's going in with regards to any information about the demographics, or that geography. Other things that you can use Tableau for is you can develop [beyond just 00:12:01] maps. You can have charts and figures, so you could have a bar graph, a histogram, a line graph. You could create filters, so you could filter by different criteria of your data. That's about it. It think I'll probably stay on if you have questions afterwards. Thanks for your time.

Carol: Thank you, Jacob, and yes, it'd be great if you wouldn't mind staying till the end, because we will do questions at the end of that. Great, thank you, Jacob. I also took a lot of notes from your presentation. Next we have Amy Gaviglio. Sorry, I can't talk very well today. I'm going to blame the Daylight Savings time issue on my lack of speaking ability. Today we have Amy Gaviglio from the Minnesota Newborn Screening Program. She's going to talk to us about using infographics to educate parents about newborn screening and parental options. Next, Amy it's to you.

Amy Gaviglio: All right, thank you, Carol. Can you hear me?

Carol: I can.

Amy Gaviglio: Perfect. Well, thank you very much for letting me share our experience with creating an infographic. Next slide. Perfect, thank you. The idea for creating an infographic, really for us, stemmed from a few places. Basically we were identifying largely through observation some problems in understanding what is becoming a very complex topic as far as both newborn screening, but all of the parental options that are available to parents. We had reported both from parents and providers that there was some confusion about parental options. What parental options were available, and how to exercise those options. In addition, particularly in Minnesota, our parental options have changed many times over the course of a relatively short period of time. I think a lot of our providers, and quite frankly even us in the program, were having a hard time keeping track of all of the different options, and again how to exercise those options. The third kind of problem we identified was that newborn screening itself was really not being seen as the true process that it is, or that it now was encompassing three different components: the bloodspot, the hearing, and the CCHD.

With that problem in mind, I ... Next slide, sorry. Oh, it's not going to let you do the animation. Okay. Underneath these infographics, what I did was I pulled one of our health educators who had done graphic design work, and also had taken some plain language training. We kind of brainstormed how we thought might be the best way to try and convey the parental options, as well as the process of newborn screening. After looking up quite a bit of information, it was determined that an infographic probably was the best way to try to draw people in, not only to read the document, but to better understand the complexity. Honestly, our first step was to go to Google images, and that's what I'm showing here. We basically just looked up different type of health information infographics for design ideas and flow. You can see some of our favorites here. Next slide.

Oh. I need to remember we can't do animation on here. Shoot. If you remember from the last slide, you probably saw a roadmap concept was pretty common within not only health care, but particularly during ... Or infographics related to pregnancy and birth, so we decided to go with the roadmap idea. Then from there, after we kind of had at least our general of what we're going for as far as look and feel, we identified what our key messages were. What were the main pieces of information we wanted providers and parents to be able to take home from them by just looking at the sheets. Once we identified our key messages, we went to the plain language website, which is shown here. This is a really great way to take your team messages and use some of their dictionaries, thesauruses to find better ways to convey the information. Really, what is another word for a heel poke, what is another word for punching the [inaudible 00:17:02]. Those types of things we spent a lot of time on trying to bring the reading level down as far as possible. Next slide.

After we have those kind of key components in place, we designed several variations. I, for the interest of time, I'm not going to go through all of them, but I can say there were at least 10. We sent out [four 00:17:27] reviews to kind of a wide variety of audiences. We targeted obstetric and labor and delivery nurses who we felt were likely to be the ones having the conversation with parents, and going through the fact sheets, or the infographics. Our midwifery population, hospital education specialists, and then expecting and new moms. We took their feedback and incorporated it into multiple derivations of a draft. Next slide.

Another component of the infographic that we felt was really important was to try to obtain quote unquote endorsements from state and national organizations. For us, we just felt because of kind of all the attention, relatively negative attention that newborn screening had been getting in Minnesota, that we really wanted to add extra validity to the documents, so that it wasn't just coming from us at the Department of Health, but it was supported and endorsed by several really well-known organizations. We sent it HPHL, and New Steps, the Minnesota Chapter of the American Academy of Pediatrics, the March of Dimes, the Minnesota Chapter and Save Babies Through Screening and allowed them to review both at the local level, and I know for March of Dimes in particular it did go up to the national level as well, so they could look at it, provide any input before kind of giving their stamp of approval, and allowing us to put their logo on the document. Next slide.

This is our final product. I will go through kind of each component in a little bit more detail, but you can see the general look and feel is a roadmap. The first side is really focused on the newborn screening process, and how it works, and where things go. The second part is really those parental options that are available to parents after newborn screening. We were able to get it down to a 5.2 reading level, which I was really happy with, because it can be very difficult to convey this information in that low of a reading level. Next slide. Now that we had our product, we really spent awhile thinking about the best to roll it out. I know I have mentioned this many times, and I know all of understand that we just spent so much time putting together this great product, but if it isn't used properly it really ends up being kind of a waste of our time. The roll out in implementation is really just as important as creating the document.

We started by sending a letter announcing the availability of the infographic, and that we would be hosting webinars to walk through the infographic and what our expectation was for how to use the document. The letter was sent to nurse managers, lab managers, quality control or quality assurance specialist at the hospitals, safety risk managers, midwives, I think that pretty well covers where we sent it. Then we hosted several training webinars for hospital staff and midwives. We hosted them over a two week period and we have them multiple days in the morning over lunch and in the evening to try and get as many people

as possible. Then we also recorded the webinar for future availability and sent that link out to all of our nurse managers to encourage them to put it into their training curriculum. Then after we felt pretty good that our providers were comfortable with the infographic, and we're ready to use it, we began sending it out, along with our general fact sheet, with each specimen kit. Now whenever someone gets a specimen cart, they also get both the infographic and our fact sheet with each order. Next slide.

In terms of our webinar, and how we framed it was, we really wanted to inform and educate, I guess, the providers on why education is so important in newborn screening, and why maybe it hasn't been in the past. Why is this focus on education? We really talked about some of fairly numerous studies that indicated that parents really want to be talked to about newborn screening, and want to know what's going on. Then we talked about how it facilitates followup if there's a borderline, or abnormal, [unsat 00:22:09] result. It really helped parents to know what happened so they know if they need to do a followup. We added several quotes that we provided to hospital staff. Next slide. We also talked how in this day and age newborn screening information, and really all healthcare information, you can find it everywhere. You can find in online, you can find it on Facebook, you can find it on Twitter, but that's not always accurate. That part of their role in talking with parents is to really dispel myths, and make sure that the information that they were getting was truly accurate, and making sure that they weren't making decisions based on things they were hearing in the media, or [work 00:22:58] blogs, or word of mouth. Next slide.

Here's a close-up of our infographic. I'll go through these pretty quickly. We started with very basic your baby is born, and then the three tests that will be done: hearing, heart, and bloodspot. We put the time 12-40 hours, 12 is mostly for hearing screening, it can be done as early as 12 hours. Just getting them, again, a timeline for when this is going to happen. Next slide. Then talking about that the hearing screening and heart screening would be done in the hospital, and they should get the results before they leave hospital, and that the bloodspot screening was sent to us at the Minnesota Department of Health. Again, kind of putting it into context of where things are happening, and where it's going. Next slide.

Then we spoke focused more on the bloodspot, and so we talk about that the bloodspots are sent to us, and that we punch them into smaller little pieces to do the testing. Then what they could expect if the results were negative, and what they could expect if the results were positive. Next slide. The best side, this is the top of the back side, which really talks about after newborn screening and the parental options. It was important for us to have the front side talk about newborn screening so that they could put the testing and the bloodspots into some sort of context. We showed them what the bloodspot would look like, and

how small it was, and what was done [early 00:24:44] leftover. Then we talk a little bit about why they are stored. You can go to the next slide.

We talk about their first option, and I'm sorry this looks like it got cut off but ... Which is basically the [default 00:25:00] option for us in Minnesota so that they don't have to do anything to exercise this option. That's the [default 00:25:08] would be that the bloodspot from results go into storage, and that they can only be used for program operations. Next slide. Here is where we talk a little bit more about why we would we want to store them, and what program operations, at least defined by Minnesota state statues, means. What might they be used for if you chose option A? Next slide. Then we moved to the second option, which is not only are you allowing them to be stored and used for program operations, but that you would also be allowing research use of the bloodspots and test results. To exercise this option you would need to sign a consent form, and then just reiterating that if you don't sign this consent form that they would never be used for research. Next slide.

Then we talk about the final parental option after screening, which is that you can ask for the bloodspot and test results to get destroyed. We also talk about that this too requires completion of a form, and that if you complete this form that we would destroy them, and they would no longer be available as well. Next slide. In general, both in terms of the feedback after webinar and feedback since they've been regularly disseminated, these are some quotes that we've gotten back from both parents and providers. Overall, the feedback has been really great. I think both providers ... I think the nurses really feel much more comfortable talking about the options, and the parents, I think, are much better in understanding what their options are, and what they have to either do or not do to select different options. Certainly since rolling this out, we have seen an increase in receiving both of our forms, so both the consent forms and the destruction forms. It's good to see that parents are at least more aware of their options, and are exercising them accordingly.

I won't go through all of the feedback, but again I'm happy to share anything. I'm happy to share our raw data, or our raw infographic file if anyone wants to play with it themselves. We'd be happy to share with you for that as well. With that, I think I'll just, next slide wrap up. There's only [inaudible 00:27:51] the webinar. If you want to watch the full webinar that was provided to our hospital staff on how to communicate this information to parents. That's available there, as well as my email address should you want a copy of anything that I just showed. Thank you.

Carol: Thank you, Amy. That was excellent. Ruth Anne, do we have another presenter at this time? Or are we ready for questions?

Ruth Anne: Looks like we do have some time for another presentation. Ashleigh, are you on the line? If you are, please press star 7 to unmute yourself.

Ashleigh: Hi, Ruth Anne, I am here.

Ruth Anne: Okay, awesome.

Carol: Next, since we have time, we have Ashleigh Ragsdale from the Washington State Newborn Screening Program. She is going to talk to us about infographics in a different way, about using report cards. Ashleigh, please go ahead, and thank you.

Ashleigh: Great, thanks Carol. Like they said, I'm Ashleigh, I'm from Washington, and I'm just going to talk a little bit about some of our reports that we've been doing. Go ahead and go to the next slide. First thing we do, is we do a quarterly hospital report that's sent out to the lab manager, the nurse manager, and the hospital administrator every quarter. Next slide. It contains, we have a section on hospital compliance, which is [inaudible 00:29:30] with our newborn screening logs and regulations, a section on their quality, which is unsatisfactory specimens and demographic errors. Then we also send them a bulletin, and that kind of gives an overview of the disorders we've detected in that quarter. Program updates or kudos is a section for us to give them some just additional information that might worthwhile for them to know. Next slide.

                  Just a little bit of a background. We, our law was revised in June of 2014, and it did make some changes for compliance. The first one is that the first screen [constantly 00:30:07] collected by 48 hours of age, and that we must receive that specimen within 72 hours of collection at the laboratory. It also requires that healthcare providers notify the Department of Health when they notify parents of recommendations for diagnostic testing, and then we're also required to publish this information online in a public forum every year. Next slide. I'm going to go over the compliance section of our report first. Basically, this looks at all of the infants that are born in their facility, whether the facility collected the screening specimen or not, they are the responsible party for that. It covers any baby born in their hospital, and kind of did they improve over the next quarter, or how they're doing against the statewide rate. Next slide.

                  This is an example of our overall compliance report. In the very top section we do give them the law and the requirements they're supposed to meet, especially because it's kind of a newer thing, we want to make sure that they know what they're being measured against. Next slide. Oh my animations aren't working like Amy's. On the top half in the purple box we start off with just how many infants that were born in their facility, what their hospital birth volume is, and how many of those babies were eligible for screening. In the green boxes below, we show them where they were compliant with the law, so the collection within 48

hours, and the specimen being received within 72 hours. The middle column shows them if they made a positive or negative change over the last quarter, and we code it so that it's, if they did better it's in green, and if they did worse it's in red. Then we also give them how the overall state hospitals are doing. Then in the red boxes on the bottom, it shows all of the specimens that were non-compliant. Then we break them down into various reason for non-compliance. Then all of the specimens that are in those red boxes, we give them a detailed list. Next slide.

This is a detailed list for collection timing errors, and we [inaudible 00:32:32] what was wrong with it. On this one, Bart Simpson he didn't get a first screen, because the first screen we got for him was after 7 days of age, where Stewie Griffin he had one, but it was collected at 69 hours, so he didn't make that 48 time frame. Then we also have the unknown collection timing, which is where they aren't filling in either birth date and time or collection date and time, and so we can't accurately calculate the age that infant, the age at which they were screened. Next slide. Then also get a list of all of their transit errors. These lists can be kind of long, because there's a lot more transit errors than collection errors. Once again, we break it out into those categories, the first one being this was, the specimen was so old, it was invalid for testing. Then the rest of them are mostly just delayed transit, and there's also a section on unknown transit, because we couldn't calculate that, again, because they're missing usually the collection time or collection date. Okay, next slide.

This is, you don't have to read this, but this is the logic that we put behind in our system in order to calculate those. The compliance, go ahead and do the next slide, and then we categorize them. If anybody is interested in kind of how we made those determinations in our system, I'm happy to share that. Go ahead and go to the next slide. Okay, the other quarterly one we do is the quality report. The quality report is different because it's looking at all of the specimens that they submitted regardless of whether that baby was born in their facility or not. It also will include second screens, as Washington is a two screen state. We look at their overall unsatisfactory rate, their demographic errors, how they do on transit time for all specimens, and once again we then compare that to their previous performance and statewide performance that quarter. Next slide.

Here's a screenshot of the quarterly report. I apologize for the blue boxes, they're supposed to be animated. Right on top we give them just how many screens they submitted, what their volume is, how many were first screens, how many were second screens, and the number of parental refusals that they sent it. How many specimens they received that did not have an error, and then their overall performance rate, which is the number [of specimens 00:35:01] that didn't have any errors at all. We don't get a lot very good hospitals with that. Most of them are around this 70% mark for those. The top section details their unsatisfactory specimens. On the left hand side it'll list each of the types of

unsatisfactory specimens, how many there were. Then this chart in the blue and green, the blue is their facility, and the green is statewide, and it shows their unsatisfactory error rate over the past year and the current quarter. Then in middle is the demographic errors on the specimen cards, and that's the same setup where they list out all of the errors they had. Compare, you have the chart that goes over the past year, and then also the state [red 00:35:46] error rate for them to compare to.

Then on bottom, we do their specimen transit time. Is there a difference in their average transit time for first or second screen? How many specimens are making that 72 hour transit time, and it's broken down by less than 24 hours, 25 to 48 hours, and then 48 to 72 hours, and then anything over 72 is in the red in the chart. Next slide. These are also accompanied by those detailed lists, similar to the compliance report. This list of all of their specimens that were unsatisfactory, we group out why they were unsatisfactory. We find that the hospitals really appreciate this, because then they can go back and look at those particular cases and see what went wrong. Maybe there's a particular individual who's collecting specimens, and they're not doing a very good job of it. It allows them to kind of do some education with their staff. Next slide.

This detailed list is on demographic errors. We list off the demographic errors along the top, and then on the bottom there's each specimen that had a demographic error broken down by initial specimen versus subsequent specimens. There also a NICU category for places that have a NICU. We do that so that they're, a lot of hospitals have different locations where first screens are collected versus second screens. This way they can also look at the unit that might be filling out the cards incorrectly. We [do 00:37:18] categorize them into three different things. You can have a missing piece of information, just [patient 00:37:24][inaudible 00:37:24] just not there, wasn't provided. It can incorrect, which means for some reason we had to go in and edit that. Or it could be invalid, which often happens with the time, or the collection time might be before the date of birth or the birth time, so you can't have that collection time. Or maybe the submitter ID that they put in is a submitter ID that wasn't in our system. We break that out into what kind of error that was. Next slide.

This is just the snapshot of quarterly bulletin, [breaks out 00:37:59] all of the newborn screening conditions. What they were identified, or how many of them identified that quarter and the year to date, as well as how many babies we've been screening, and how many tests we've done. Next slide. This is an example of the bottom of our bulletin. It's a place where we like to give some kudos. These are hospitals that have done a good job of collecting or sending specimens to us on time, as well as those hospitals that maybe made significant improvement over the last quarter. We have had a few hospitals come up to us and say we're going to get on that list, we want to be one of those 100% hospitals every quarter. We find that they like this motivating factor. Next slide.

Then we're also required to do an annual report. The annual report contains a lot of the same information as our quarterly report. This is published annually on our website, so it is public. We'll putting out our 2015 report very soon. It does list the hospitals and their individual compliance with the law. Then in our 2015 annual report, we'll also be listing out each hospital with their unsatisfactory error rates and their demographic error rates. In 2014, we just did it in aggregate, so we're looking forward to putting that out there publicly so that they can see how they're doing compared to other hospitals. Then, like I mentioned, it does kind of include this extra report on timeliness of parent notifications. Next slide. This slide isn't going to work. Behind this is a list of, but I'll show you what it looks like on the next slide. The report contains each hospital, and then on the right hand side there's a list of their transit compliance, and their collection compliance. That's the one that I couldn't show you. But here we've broken them out by their volume, so it has all the high volume hospitals, medium volume, and low volume [for 00:40:03] hospitals to see kind of how they do compare to other hospitals of their same size. Next slide.

Also does it by region, but that was also hidden on the previous slide, so I'm sorry about that. We break it out by their location within the state, so that they can see how they're doing against their neighboring hospital. This one here is actually the unsatisfactory demographic overall error report. We just show them also broken out by volume, as well as the other submitter, so the birth center and midwife submitters as well as the clinic and laboratory. In the chart below, you can that are birth centers, and our clinic, and laboratory are definitely our biggest hitters with our demographic errors. Next slide. Then we do it again here. We break it out by what their most common unsatisfactory specimens are as well as by who's submitting them. Low volume hospitals have a much bigger problem with layered specimens, whereas midwives and birth centers seems to have issues incompletely saturated specimens. Then all of this will be done by individual hospital in the 2015 report. Next slide.

Here again demographic errors by who's the submitter group. Submitter ID is something that's often not included on our hospital [inaudible 00:41:30], whereas clinics have trouble putting in birth time and collection time on their card. Next slide. Then this is our report on timeliness of parent notification by the healthcare provider. We broke it out by standard referral, so a referral that we would want the parent to be notified within one day, or on the same day as the referral was made. Then a non-urgent referral, so something where notifying the parent in a few days is acceptable because they don't need to come in immediately for diagnostic testing. Next slide. This is just a, to show you guys the regional breakdown of our specimen collection compliance. We get pretty good compliance across the state. Next slide. When we do it for transit, we can see that there's a lot of issues with some of our regions that are a little bit farther away from our laboratory. Our lab is in the green section right there in the

middle in North Puget Sound. The regions farther away have a much harder time with that transit compliance. Next slide.

Then this is what happens when we break it down by our hospital volume for each of those, and the low volume hospitals definitely struggle with our transit much more than the high volume ones do. Also with collection they have a little bit harder time with getting on-time collections. Next slide. That is it. Thank you for your time. If you guys have any questions about our reports or want copies or anything that ... The annual report is on our website, but we're happy to share those quarterly reports or anything like that. Thank you.

Carol: Thank you, Ashley. That was fantastic. Now we will open it up for questions. You can either type the question in the chat box, or press star 7 to unmute to ask your question, so ahead everybody.

Ruth Anne: All right, we have our first question for the Washington presenter, Ashleigh. What software program do you use to produce your report cards? Are your report cards populated entirely by your LIMS system? Who was involved in the development of your report card, and what costs were associated with the development of your report card?

Ashleigh: Hello, can you hear me?

Ruth Anne: Yes, we can hear you.

Ashleigh: Okay, great. Thanks. Right now the report cards are built in Access, Microsoft Access. We are working on building into our [inaudible 00:44:16]metrics which is our LIMS system with SSRS, which Sequel Server Reporting Services. We just got access to that, and so I'll be transferring the layout of the report into the LIMS system. The data that's coming out for the compliance report is completely, 100% coming out of our LIMS system. I worked with them to help develop the logic and the queries behind that. Then the quality report about half of it is coming directly out of the LIMS system, and then the other half is the raw data coming out, and then we have to do some extra calculations kind of on the side to get it to populate into those reports the way that we want them to. The plan is to get it all coming out of our LIMS system. We did not have an additional budget for this, it's just something that I have been working on with some support from my team to design these reports. That's it. Thanks.

Ruth Anne: Thank you, Ashleigh. We have another question. What would ... Would each state comment on how they report newborn screening results to hospitals and providers?

Amy Gaviglio: This is Amy, can you hear me?

Ruth Anne:	Yes, we can hear you.
Amy Gaviglio:	Perfect. As far as negative newborn screening results in the state of Minnesota, those get sent back to the submitting facility. We ask that they send them on to the patient's primary care provider. We're kind of in the process of transitioning our lens, and so eventually the negatives will also be able to be viewed remotely. For positive or borderline, or unsatisfactory results. For positive and borderline, those, a genetic counselor calls the primary care physician. One, make sure that they are indeed the child's primary care physician, and then give them the results over the phone and then we fax a packet of information, so the report and some fact sheets, and some specialist contact list. Those get sent to the primary care provider. Then we also we do a notification to our specialty centers shortly after calling the primary care provider to let them know that we have a new case, and any clinical information that we've been able to gain from the primary care provider. Just letting them know that they should expect a call from the primary care provide to set up further labs. Unsats also get called, but those get called back to the submitting facility.
Ashleigh:	This is Ashleigh in Washington. We have a very similar process to Minnesota on calling out abnormal results, where the [inaudible 00:47:47] to the baby's primary care provider. Then are unsat go back to the submitter as well. Because we are a two screen state, we have a more passive followup for those where we wait for that routine second screen. If that doesn't come in a timely fashion, then we will be calling for a second screen for those kids that had an unsat result. I don't know if John wants to say anything else on the followup for Washington, but it's a very similar process to Minnesota.
Carol:	Any other questions?
Jacob Rosalez:	This is Jacob. I'm curious about the infographics from Minnesota. What software did you use to create those?
Amy Gaviglio:	We use ... Can you hear me?
Jacob Rosalez:	Yes.
Amy Gaviglio:	Okay, sorry. We use a combination of Photoshop to create some of the graphics, but it was largely built in InDesign.
Ruth Anne:	Great, thanks. We just received a couple of more comments. One is a comment that says excellent presentations. Great work. Then we have a question for Jacob. Is there additional costs associated with linking graphics developed in Tableau to a website? Can you talk a little more about what Tableau provides? Or Tableau public?

Jacob Rosalez: Okay, so it depends on the type of Tableau that you're using in [cost 00:49:45]. If you use Tableau public, it is completely free. The caveats of that are it is public, so if it's like extremely super sensitive like patient data, then you're obviously not going to use it. But if it's just ... If you're using stuff that you and your team are, whomever feels like this is okay to have it publicly released, it's a very cost-effective. It's a free way of developing interactive data visualization. Essentially, all you do is if you go the Tableau public route, you develop dashboards. It's called Tableau desktop for like the paid version, but there's also a free version of Tableau desktop that you can use. Some of the bells and whistles with regards to linking to data aren't as ... Tableau desktop you have a lot of ... Tableau desktop [inaudible 00:50:41] costs roughly, I want to say $1200, and with that you can connect to a plethora of data. Access, Sequel Server, a lot of stuff. Whereas if you use the Tableau public desktop, you're limited to, I think you can link to Access, you can link to like CSV and Excel files.

You're kind of limited with your data connections, but with regards to creating your dashboard, it has essentially the same power as desktop, just limited data connection capabilities. If you were doing the free route on public, you develop your dashboard in the Tableau desktop, you know make it, and then you have an option to upload to Tableau create. You create a Tableau public account for yourself, I think the data limitation on that is I want to say 10 Gigabytes. It's pretty ... It's not that bad. You upload it in there, and then you have a link, and like it's, I don't if any of you are familiar with the good all days of MySpace, when you found a really cool YouTube video, and you captured it in [inaudible 00:51:47]. It's similar to that. That doesn't cost anything with regards to having hosted there. The only caveat is that it's going to be publicly available for other folks to view, and they can download your dashboard workout.

If it's very private and sensitive data, then you want to purchase desktop, and either get a license for Tableau online. I think they charge, I want to say it's either $50 or $100 per login. It's pretty pricey, so I guess it depends on like how many people you need to view your dashboard. Then there's also called Tableau Server, which again you have to pay like ... Tableau Server connects to like, if you have a server in your organization, it would connect to that server, but you have to pay like a maintenance few. Where Tableau online you're using the Tableau servers to host your dashboard that you developed. I hope that helps. Feel free to contact me if you have any other questions about that. I know it can be a little confusing.

Ruth Anne: Thank you, Jacob. Do we have any other questions? Please feel free to press star 7 or to write them in the comment box. That box on the bottom left. All right. I'm not hearing anything. I wanted to thank you all for joining us today. This was a wonderful webinar. We all learned a lot. We look forward to seeing you at our next webinar.

Carol: Thank you everyone.

Ruth Anne: Sorry, just wanted to see if there's anything else you wanted to add, Carol.

Carol: No, I think that's great. It was ... Yeah, I agree, it was a great webinar. Stay tuned for our May webinar.

Ruth Anne: Great, thank you. Have a great day, everyone.