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CONSUMER: CASEY JUDD

EHDI

NARITA A/B – UNIVERSAL NEWBORN HEARING SCREENING

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>> Okay, should I just go ahead and start?
>> No. Okay. So you are here for the universal newborn hearing screening.
>> Warehouse project.
>> Warehouse project. If you are too hot, too cold. Let me know. Or if you need any other support please fill out your evaluation if you're staying through to the next workshop in this same room you can keep your evaluation and just give me both when you believe but if you're leaving just leave your one.
>> I'm going to apologize ahead of time I have a bit of a cold which I woke up with this morning. So if my voice cuts in and out I'm really sorry. Or if I cough a lot even though our lovely interpreter gave me a cough drop to get through it. I'm very grateful. My name is Mallory Minter‑Mohr actually I just got married recently and I'm going to talk about the universal newborn hearing screening warehouse project that we've developed in the state of Ohio.

I work for the EHDI prom there as ‑‑ program there as a researcher.

And we ‑‑ I'm just going to kind of talk about a couple of things like this is just a brief overview. But hopefully I can get through it. We did so much with this project, I could talk about it forever. But we only have like twenty minutes. This project actually started before I even started working for ODH like two years ago like the proposal was made to create this before I even existed in this position so just to give you an idea of how can this process can take I'm still working out bugs with IT as of last week. So these are the working objectives you may or may not have read. I'm going to describe the benefits and the reasons for implementing something similar in your state or jurisdiction and then just kind of describe the project management process and how we went through things and basic steps and what I like to call the ABCs of working with ITS or information technology staff. And kind of describe the method of identifying potential roadblocks for you by going over roadblocks we had throughout our process. Just a little bit of background and for perspective sake in the state of Ohio we are the seventh most populus state in the country. We have 130,000‑140,000 births each year and maybe 130‑140 birthing hospitals in our state.

It's a big state we have a lot of babies born that we have to keep track of too with the EHDI system and a lot of hospitals that we're son constantly trying to give data to.

One of things we currently do regularly is we give them quarterly hospital reports and basically these are just reports that are generated that contain a list of infants born at the hospital and whether or not they were screened. What the screening result was.

And then if they weren't screened the reason for not screening that child was it transferred to a different hospital like a children hospital or ‑‑ did the parent refuse or anything like that. So, and essentially these reports give the hospitals a chance to review the information. And hopefully correct it if it's like any errors or anything missing but there is a lot of limitations to doing this. First of all, it's very time‑consuming, because it is like, potentially 140 hospitals. It takes me just a couple days to generate 140 reports to give to all of these hospitals and then I have to give it to another staff, our audiologist in contact with all our hospital to give them out to all the hospitals and it takes her a few days just to e‑mail them all out and then they are e‑mailing back and forth with her and me and correcting things and it's just, oh my gosh, sorry it just takes a lot of time. So the goal of this project is kind of to eliminate some of these limitations and also include even more hospitals so from the birthing hospital they're generated from our vital statistics records which does not include children's hospitals. Sorry. Because children's hospitals, babies aren't born there so they aren't creating the statistics where that information is coming from. But they still submit screening results to the at a time. But they haven't gotten much feedback on them as far as like compared to the birthing hospitals. So just some of our improvement, yeah, feel free to interrupt, yeah.
>> I just wanted to ask you a question though. Do your hospitals have their own screeners or do they contract out to have a company or other companies screen?
>> From what I understand, it's kind of a mix. Like so some of them do and some of them don't. So.
>> So if some of them do are those screeners keeping the records?
>> So with the birthing facilities they all have access to create birth records and so they usually have an administrative staff create the birth record onsite and then for places like children's hospitals, they submit it through an online data link connected to our data system, Hi\*Track. Yeah, no problem. It's fine, feel free to interrupt. Anyways. So back to our improvement goals. So mostly this is ‑‑ this new project we'd like to give hospitals more autonomy, by allowing them to kind of check and review their own results that they're submitting to us constantly. Everyday they're giving us things. And at any point in time and look at any length of time so the quarterly reports are just three month little snapshots and so with this warehouse they can look at just one day up to like years worth of data at a time if they want to. And then so the other thing too is the data will match hopefully exactly what we have at ODH because we don't just get data from vital statistics, we also get it from paper reports like I said the diagnostic ‑‑ the ‑‑ children's hospital submit through an online links which is the same that diagnostic results come in through Hi\*Track which is our data management system. And then you know people fax and e‑mail us the results sometimes too. It's a big mishmash of things so it's not ‑‑ what's in vital statistics isn't always reflective of reality. And then hopefully the goal is to eventually give hospitals even more information than what they're already getting from these basic vital statistics reports that they're getting now.
>> Do you need some water?
>> I have water. Sorry. Thank you. So with our initial steps, so with one of the things that I would definitely suggest is to use what might already be there in place in your state. So a lot of states already have some kind of public data warehouse system. And we ended up using that to house this data warehouse system for our hospitals so we have a system that already had things like for infant mortality and tobacco use and other things going on in the state but using that system that already existed and just kind of adding to it, really, really helps lower the cost first of all because it's not creating something brand spanking new. But also the IT knowledge base has already increased slightly because they already created it. They already know what's going on and they can just kind of modify it to fit what your needs are and then the other big thing I would suggest is keep it as simple as possible. Of course we have these great ideas and I want we want to give everyone everything and give as much data transparency as possible and we wish we could. But what's simple to us is not simple to like everyone else and definitely not to an IT person. Who has no concept of universal newborn hearing screenings are or EHDI or any of this. They know absolutely nothing. So just make sure you prioritize your list of things that you want and just be prepared to cut things from that list at the bottom. So also in the project beginnings we had our first meeting about this was mostly like our first several meetings was explaining what universal newborn hearing screenings and EHDI is. The entire process from birth to age three. So like the IT people, they don't even know what a hearing screening is. Even if they've had a child, like, and their child had a hearing screening they just don't really know what it is and like what all went into it. What is the diagnostic evaluation. How is that different from the hearing screening? What's early intervention? What is the different types of equipment? Like ‑‑ sorry. What is pass and refer mean. You literally need to explain what does passing mean. What does referral mean. It just doesn't necessarily mean the same thing in our brains as what it means in like a tech person's brain. And then what happens to the baby if they're not screened and like all the different possibilities of where the baby could go and how they end up in places. And just kind of also why all of this matters. So just explaining to them like why you're doing this and why it needs ‑‑ why it's so important to us is also going to make it more important to them. And kind of value it a bit more as well.
>> So also with the project beginnings, after you've explained what EHDI and universal newborn hearing screenings is you are going to want to discuss with the IT people what you're currently doing. Like what your current data system is and they have to learn it from scratch as well. So, for example, in the state of Ohio we use Hi\*Track as our data management system and so we had to teach them and explain to them what Hi\*Track is. Even though we have, like, one IT person essentially this the state of Ohio that knows about Hi\*Track and helps me when Hi\*Track breaks down and everything like that. Now it's a whole team of people coming together that have to learn Hi\*Track. And sometimes it's not the most user‑friendly at times and there's things that can go wrong. And it's just a very specialized program just for EHDI so there's a high probability they've never heard of it before. So a lot of that beginning part too was bringing together this new IT team. Our old, like, IT person, and then the IT from Utah that created Hi\*Track. And then our own program staff here and then occasionally we did have to bring in our legal department for different kinds of reasons on who can see what data. Which I forgot to include in the slide but that's also important as well. Yes. Go ahead. Oh, yeah sorry so Hi\*Track is ‑‑ our data management system so every time a baby is screened at a birth hospital their ‑‑ a birth record is created and goes into our vital statistics program and basically Hi\*Track downloads all the data everyday. And puts it into this, like other program called Hi\*Track. And then it allows us to track the baby if they referred and then we can, like contact them somehow to make sure they see an audiologist and make sure they do that and if they're found to have a loss we can get them referred to EI in an early intervention. Does that help? Yeah. You can ‑‑
>> (Speaker far from mic).
>> We can't use paper anymore. It's been awhile. No with 130,000 births it's a bit difficult and gets overwhelming if you're using paper. Any who, so the other part was creating the current reports we do give hospitals. So those quarterly reports that I was talking about earlier and showing what we're doing right now.

And so the daily process and how it functioned with the IT people is we they did something and I learned since then this is a common practice in IT development is to do things called sprints. And it's basically a two week plan with ITS which is basically what they're going to accomplish for that week. Oh, shoot, okay. So if the planning meetings are at the going of each sprint and a review meeting at the end and we also had fifteen minute daily standup meetings where we basically talked about what we did the day before and they reported to us and it was just kind of, anyone could ask any questions that they wanted to. And so the goal of the sprint is to break things down to the smallest piece as possible of what they're going to work on. For example in sprint one they can be researching how results look in the current program behind the scenes. And then sprint two, they create like a the display for the results of the warehouse and sprint three is getting that data into the display so it could take six weeks for one little box to appear but that's what it is. Sorry. And then just to quickly go over this. We did implement a plan‑do‑study‑act throughout the process with every new change. We planned out our small developments and changes and tested them a bunch of times with IT and on our own. And then discussed possible changes because if you change one thing over here it could change these other four things down the line and you don't know it. Until you actually do it. Which happened last week. And then you just kind of decide on your modifications and move forward. So some roadblocks and thing to think about is regular ‑‑ your regular IT personnel for universal newborn hearing screenings may not be the ones who work on the project. Like I said we only had one person that actually specialized in the system we use and now we have four new people that we had to teach it to. And then also we had some other existing data issues that needed to be cleaned up and fixed before we could actually move on and get this new data system going which they helped with as well which was super nice. And then the other thing that I found out which was a little interesting, is explaining the concept that more than one screening can be done. Was a bit challenging. Like they had created data systems for screenings for like blood tests and other things. Which is usually just like, it's one test. And it's done. It's yes, it's no. And that's not how this works. You can have two tests, you can have three and then there's also diagnostic testing after that and it's just like, oh my gosh, there's so many. So the way it's structured is just going to be different. And you need to kind of help them get their brains wrapped around that. And then also something to consider is that current data might not match the old data as policies and procedures change. What you had back in 2010 is not necessarily what you're getting in 2017. As they're looking at all this old data. And so some of the things that we learned is bring in all of your data. So our IT team equated it to like a giant pipeline so even though you're not going to be using everything that's there right now, bringing it in is going to be easier now. Bringing it all of it over then they can filter it down later on. So we hope to expand this project and include it for our audiologist in the diagnostic pieces as well so even though we're not doing anything with that right now we're just showing hospitals the hearing screening component that diagnostic stuff is all in there and in the base and we build the base for our future plans to expand on it and another thing is always remember that you are the project owner. So that's something we struggled with a little bit. IT people have a way of how they think it should be but if it doesn't make sense to you it's not going to make sense to the hospital and like the hospital staff. So make sure it makes sense to you. And then the other thing is just testing, testing, testing. And patience. Like you cannot have enough patience. I've had to re‑explain what a hearing screening is to our IT staff. Like the same people, the same three people like 50 times even just a couple weeks ago I had to re‑explain it again and it's like, okay this is how it happens.

This is the process and this is how, what happens afterwards. So it's just kind of a lot of repetitive stuff they just have to push through. So our project results which I'm just going to briefly show you which is a data view. A simplified list of the babies that are born or screened at a facility. And then we have developed two initial reports. Really simple ones right now which is just the number of babies that were screened and what the results were and just the breakdown of reasons for not being screened and how many you have for each of those categories. That was our web link if it was going to work. So anyways, after ‑‑ logging in, each hospital will login and this is the first page they will see and this is kind of a descriptive page and right now we have some extra tabs of charts and like reports and downloads in there.

But not everything is activated yet. This is still our test website. That I was like, messing around in. So to see the list of all their babies, they would go to the data view tab. And this is kind of what it looks like. I've already added one little filter because I didn't want to show anyone real data I made fake data based off of characters from the Game of Thrones. All the places and babies are Game of Thrones characters.

Anyway, so when a hospital logs in they'll be able to see a list of all of their babies and they'll have like basic information going there. I'm trying to stay close to the mic. Along with the screenings facility and any other information. But they can always export all of this. As well into an Excel file. But just to show you this is a little bit bigger of what it looks like. It has basic demographics, the screening facility, the screening test date, if a screening was done, if a screening wasn't done the whole line will just be blank. So one thing to point out is that you'll see some duplicate names. That's because those babies had multiple screenings so it's one screening per line if a screening occurred if it didn't occur it's just an empty line. Since I can't scroll over I took a screenshot of what it would look like if you did scroll over and then you can see some of the screening test results and then along with the testers name or the screener's name and then we have, these are all of our standard reasons for not screening. That birth hospitals can checkmark off as potential reasons they didn't screen at the hospital. So equipment malfunction, the parent objected, a physical anomaly, or an early discharge. And then something else that's new that we aren't giving hospitals currently, okay, is also their transfer information. So that's been a big sticking point is like being able to see where the baby went from your hospital if they went to a children's hospital. And these are a list of things facilities can filter by, the different reasons for not screening, the birthday range, if they're look for actually specific child or a specific screener. One extra thing I do want to show you. There's a little button we created in the beginning of each record called show it. And if you click on that it will just show you just a summary of just that baby. So if they want to look at ‑‑ they don't feel like scrolling back and forth because that's like ‑‑ it's time‑consuming and difficult. It can just show a summary of like either the reasons for not screening or the actual screening result itself. And then I did mention that and running out of time. So, the reports. So these are two little reports that we have so far. So the screening results one. This is just a quick version of what it looks like when they open it up. It has some standard things. Screening one for the left and right ear and screening two for the left and right ear. This is what it looks like when you hit the generate button.
>> If you have anymore questions, you can take them out this the hall.
>> That's fine. Sorry. I'm so sorry. Thank you, everyone though, I can show you what it looks like on a piece of paper if you want to see the reports out in the hallway. I have them printed off.