

Family Centered Care Taskforce March Webinar: Improving Discharge Planning

Vincent Smith MD, MPH, Malathi Balasundaram MD, Colby Day MD, Caroline Toney Noland MSc, Kari McCallie MD, Kristy Love

Colby Day: I think if you advance, it shows our core team. Caroline, who we could not do any of this without. We have Malathi and myself, and then we also have quite a few partners. Now, as you can see, the slide has grown over time, which is pretty exciting. And so we're very grateful to have such wonderful partners as we start to grow this Family Centered Taskforce even further. And we also have a few grants that we're very grateful for as well. We're supported by Genentech and ProLacta, and then we also had a Gravens lunch session sponsored. And today we have 2 exciting presentations that you'll get to hear from Dr. Smith and Kristy Love initially, and I will speak in a little more detail about that in a couple of minutes to introduce them, and then our very own, Dr. Balasundaram, is going to be able to give us a talk as well. We will have specific questions and answers after each of these sessions, and so please definitely chat in questions and comments as our speakers are presenting, and then we will have some time set aside after each presentation to be able to talk through some of those questions.

We could not do this without our family partners. We have 17 family partners who are very active with our organization, and then we also have our health care partners as well that we see on the next slide, who are 16 very dedicated individuals that are contributing to the task force. And we have a couple of exciting updates to tell you since our last webinar. Most of these are related to the recent Gravens Conference that was in Florida. I hope that many of you were able to attend it either in person or virtually. We were able to support five Family Partners to attend the Gravens Conference virtually and four Family Partner Small Group Leaders, as well as three Health Care Partners Small Group Leaders to attend the conference in person. In collaboration with the National NICU Parent Network, we are able to hold a Taskforce luncheon that had 70 Gravens attendees and provide CME/CEUs for this attendance. And we also shared a much of our taskforce work

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with the general attendees at Gravens on Friday in the form of a workshop, which was very interactive and a great way to hear how other people are doing things in their institutions, and to share what our actual members are doing as well. And this last bullet point is really exciting. So, a year ago we have 50 individuals that were involved in this taskforce, and over the last year, we've been able to expand to over 415 individuals, who represent over 200 NICUs from 36 states and 14 countries, all of whom are committed to learning more about family-centered care, and really trying to advance this culture in their units and globally.

And so now, it is my pleasure to introduce our first two speakers. Dr. Vincent Smith is the Division Chief of Newborn Medicine at Boston Medical Center and a Professor of Pediatrics. He's a graduate of Texas A&M University, Stanford University School of Medicine, and the Harvard School of Public Health. He trained in pediatrics at Children's Hospital and Boston Medical Center in the Boston Combined Pediatric Residency program. He then completed a fellowship in Neonatal-Perinatal Medicine

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through the Harvard-wide program, a collaboration of Beth Israel Deaconess Medical Center, Brigham and Women's Hospital, Massachusetts General Hospital, and Boston Children's Hospital.

He completed a fellowship and health services research at Children's Hospital and serves as the medical director for the AAP Fetal Alcohol Spectrum Disorders Program. He is an active member of the Massachusetts Medical Society and Society for Pediatric Research. And he is also a former member of the National Perinatal Association Board of Directors. In addition to parental NICU discharge readiness, his professional interests include families affected by substance use and medical care for LGBTQIA-headed families.

“Dr. Vincent Smith is the Division Chief of Newborn Medicine at Boston Medical Center and a Professor of Pediatrics... Kristy Love...is a mother of two premies. For over 20 years, Kristy has worked in the nonprofit community, providing health education, advocating for NICU families and the high-risk population.”

Along with Dr. Smith, we have Kristy Love, who is a mother of two premies. For over 20 years, Kristy has worked in the nonprofit community, providing health education, advocating for NICU families and the high-risk population. She's collaborated with community groups, corporations, national organizations, and universities to improve outcomes for families of premature infants, babies formed with special needs and developmental needs. So please join me in welcoming our speakers and remember to chat in your questions.

Vincent Smith: Excellent. All right. So, first of all, thank you all for having us, and for your interest in this topic, because it's pretty near and dear to my heart and to Christy's heart. It's hard for me to see the chat while I'm sharing my screen, so somebody else will have to kind of keep an eye on the chat for me.

I'm going to do most of the talking for the presentation part, and Christy is going to jump in to add extra detail and also when there are questions that come up.

And I also want to acknowledge Erika Goyer from National Perinatal Association who helped make all of our slides look so much more beautiful than the slides that I initially created. So, thank you for that.

I have no financial disclosures that are relevant, and Kristy has no financial disclosures that are relevant.

We would like to acknowledge that the publication of the discharge guidelines supplements was sponsored by the National Perinatal Association, and the funding for the publication was provided to the National Perinatal Association by private donations and supported by an educational grant by Sobi. The funding for the implementation portion of the project was provided to National Perinatal Association by our partners and AngelEye, who've been helping us on the second part of our journey.

So, during our time together a couple of things I want to kind of explain the importance of discharge preparation, which I'm not going to spend too much time on, because I feel like I'm preaching

to the choir when it comes to that. I do want to spend it describing the creation of the guidelines and what the guidelines cover. And then I also want to talk a little bit about some steps for a successful implementation of the guidelines. I want to spend just a little bit of time and give a kind of high-level view of that. And then if you want more information about the successful implementation, we're going to have to invite Cuyler (Romeo) back because she's amazing, and she does a great presentation for those who were at Gravens, you kind of heard it.

So, this is going to be kind of the flow of the talk for today. We're going to start off with some definitions and the creation of the guidelines. And then we're going to review the topics that the guidelines cover, and there are like 200 plus guidelines. We're not going to be able to go through each individual guideline in that kind of way. So, what I want to give you is more of kind of a bit of a flavor for what the guidelines cover as opposed to specific guidelines themselves. And I'll tell you how you can get the guidelines and then also about some supporting material that goes with the guidelines. Then the last piece we'll talk a little bit about implementation, and hopefully, we'll make it not seem quite as scary or as a big of a task, as it sometimes can seem when you're trying to implement something new.

So, the importance of NICU discharge preparation and transition planning. Normally, I spend a good amount of this part of the time convincing you that it's really important to have discharge planning for the families and for providers. But given the audience, we're going to skip that part, and we're going to just jump right into assuming we all agree that it's an important thing.

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And if we're talking about discharge readiness specifically, what we're talking about is the attainment of technical skills and knowledge, emotional comfort, and confidence with infant care. And this is by the primary caregivers at the time of discharge, and anybody who's ever heard a talk from me in the last 10 years knows that I use this definition all the time. I think this is really important. Discharge readiness is the goal. Discharge preparation is the process, and so it's the process of facilitating discharge readiness to successfully make the transition for home. So, with that in mind, we're going to transition to the discharge preparation guidelines. When we start to think about the guidelines where they came from in the ether and all of this, the original guidance came from the AAP. And what the AAP (the American Academy of Pediatrics) did was they described basically infant physiologic maturity in pretty reasonable detail. What they said was that in order for an infant to transition from the NICU to home, the infant needs to achieve physiologic maturity, meaning that they can coordinate breathing and oral feedings; they can ingest adequate volumes and gain weight; and they can maintain normal body temperature; and thus they demonstrate stability. And so that's

all pretty clear and pretty straightforward. And then the AAP said the parents should participate in a program for care of the infant at home. But what the AAP didn't do was give more detail about what the program should involve, how it should be implemented, or any of (those) things. They just said this needs to happen, and then they just left it kind of open. And the AAP suggested that former NICU infants need to be followed in a medical home that is familiar with taking care of former NICU infants. And they said in this medical home, they need to be followed by a pediatric provider, and they need a program that's going to track the infant's growth and development. And so all of that is actually really good, but they don't talk about the transition from the NICU piece to this medical home piece or any support services that come around the families after they're already discharged.

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So with that in mind, that's kind of what brings us to how the National Perinatal Association got into the discharge planning game. The National Perinatal Association developed these guidelines over many years, and they were using the best available evidence. I think everybody's familiar with the National Perinatal Association. But for those who don't know, NPA is an interdisciplinary organization and is one of the leading voices in perinatal care, and one of their missions is to bring parents and professionals together to advocate for better policies and care practices. The way the guidelines came about is around 2017, the NPA convened a work group with the goal of creating a comprehensive set of guidelines that reflected the best available evidence from across disciplines. And it's also informed by families' experiences, and so families were always a part of this process from the very beginning all the way through.

And so the process of creating these guidelines started with what's called an environmental scan, which is basically reviewing all existing standards and literature, and also the work group collected and collated existing standards and had a literature review of published medical and nursing literature that were related to this particular topic. And then, using that environmental scan, that became the basis for the first draft of the evidence-based, multidisciplinary consensus guidelines. And then the work

group determined where consensus existed, recognizing that there were some differences in practices, and then they also tried to identify gaps with no guidelines available and then created a course of action to be able to address what the gaps were.

Then, in 2019, the National Perinatal Association hosted a summit of content experts whose express purpose was to review the draft of the guidelines that the work group had created. Prior to the conference, the content experts were divided into 4 groups based on topics—family and home assessment, special circumstances, support systems, and/or transfer and/or coordination of care. And each of those groups was given the questions: is this content appropriate; is this content complete; or is there missing information; and also are the recommendations appropriate, practical and actionable? Are the recommendations clear and concise, and are the recommendations comprehensive and complete? So that was the pre-work that folks had to do coming into the summit. During the summit, which consisted of 16 multidisciplinary experts, representing 14 different organizations, they reviewed their assigned sections of the guidelines. At the end of the summit, each of the groups produced a report and devised next steps for their draft of the guidelines. Then a select group of content experts went back and verified each of the references associated with the guidelines from the original article or guidance and assessed the level of evidence for each of the items.

And then in January of 2021, NPA hosted a second national summit. After all the work was done between the first summit and the second summit, and this national summit consisted of experts that reviewed the revised version of the guidelines. That summit consisted of 22 multidisciplinary experts that represented 19 different organizations. Similar to the first summit, the content experts were assigned this time 5 different topic areas instead of 4, and during the summit, the content experts reviewed their assigned sections of the guidelines with the same questions that we have from the first summit. At the end of the summit, the group of experts produced a report and devised next steps for the draft of the guidelines. So that report is what was used to make the final form of the guidelines which were created and published. And that's where we are today.

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So, the goal of these guidelines is to support the families and to assure that they have the skills, knowledge, and confidence that they need to be able to transition successfully from the NICU to home. You should know that these guidelines are free, and they're open access. You can just come and claim them. You can use them. And in addition to the guidelines themselves, there is a companion website which we're going to talk about. But you'll notice on the slides, NICUtohome.org, and we're going to talk a little bit about that after I run you through the guidelines.

So, when we're thinking about the guidelines, they're divided up into the topic areas: basic information, anticipatory guidance,

family and home needs assessment, and the transition and coordination of care. And as I mentioned a couple of times, there are over 200 of these guidelines, so there's no way we're going to be able to go through all of them, and I'm not sure it'd be worth your time for us to sit here and do that together, and so instead, what I'm going to try to do is give you a flavor for what each of the sections cover, and then from there we can talk a little bit more about how to use these guidelines.



The first section of the guidelines is what we call basic information, and what we covered in this particular area are things that every family in the NICU should know, regardless of if they're in the NICU for 3 days or 3 months. And so it covers things like goals and timelines, like when things need to happen during the course of your NICU journey and a curriculum for what the skills and the knowledge that the families need to acquire to help them make the transition. Then it discusses discharge education, strategy, which is going to be your approach to helping the family with the education curriculum. And then it also talks a little bit about supplemental material, because in most instances, bedside teaching is going to be the number one method of commanding information. But then, in addition to the bedside teaching, there's going to be potential websites. There can be digital teaching. There can be videos. Sometimes there are papers, folders, binders. So, there are a lot of other ways to get supplemental material to reinforce the information that's given right at the bedside. And then, in addition, basic information also covers infant care, skills, demonstration, and that goes into a little bit of detail when you're actually doing the teaching and the teach back and confirming understanding, and it discusses safer sleep practices, car seat/car bed installation and safety. And then, understanding what some typical and atypical infant behaviors are because sometimes, especially former premies—their behaviors may be slightly different than what you'd expect for term babies that are the same age.

The next section of the guidelines covers home and family needs assessment, and this gives individuals an idea about the family structure, the family support, the family's learning, style, and other factors that could impact how your discharge preparation process is going to go. In this section they look at family assessment, which is looking at who's in the family, who are going to be the care providers, who are going to be the primary providers, who are going to be the other support systems. It looks at caregiver mental health, both at the time of discharge planning, taking into account past mental health issues, and also raising awareness that potential mental health issues for both the caregivers and for the infant that may come up later, and also it has a little bit of anticipatory guidance. But there's a whole anticipatory guidance section that we're going to talk about independent of this particular section.

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The next section of the guidelines. We talk a little bit about, transfer and coordination of care, and what we found in our in our work is that traditionally, this has been an area of really pretty significant weakness and or challenge when it comes to the discharge planning process because oftentimes people think, okay, when they leave the NICU, you cut the cord, the end, and our work here is all done. For a family, though, that's not how they experience any of this. What we strive for is to have basically a continuum from NICU to home and have it be a seamless transition between both the providers that are taking care of the infant and the family, and for the family, so that they don't feel like they're just dumped by the NICU, which is often how families feel.

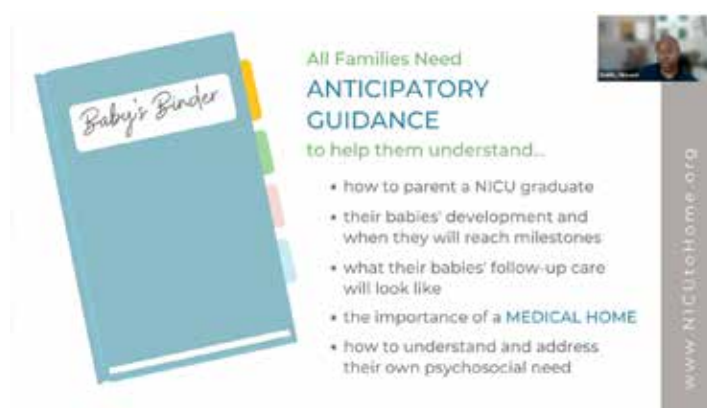
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And so in this section, we talk a little bit about the importance of primary care, pediatric primary care providers and the medical home, and we also help the family to understand the role that the medical home will play—kind of an ongoing care and with care coordination. And we talk a little bit about use of navigators and navigating the hospital system for appointments and things that follow up after NICU discharge. In this section, we make some recommendations about communication among NICU providers and community providers, as well as communication between families after discharge and the NICU.

We strongly encourage more integration of the NICU and community providers in ongoing care together. In this section here, we also explain the potential for subspecialty needs and how to talk with families about that. We talk about things like routine home visiting. We talk about follow up problems, like early intervention, and then we talk about ways to communicate information to the medical home and to subspecialty providers, and one of those methods is the discharge summary where we talk about some specific components that the discharge summary should include for clarity and for the sake of transition.

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The next section of the guidelines talks a little bit of understanding what the family support systems are, so you can help the families to get in place any types of support that they’re going to need to be able to successfully make this transition. Some of the systems that we look at are peer to peer programs and how to safely use technology. So the role of social worker and potential social worker involvement, because for some families, social work is almost like a bad word, and we try to not have it be framed in that kind of way and not have social work interaction be in that kind of way. We talk a little bit about mental health support because sometimes mental health issues can arise, especially for fathers and partners in a very different way than what they would for postpartum birthing people. And we talk about communication, post-discharge, mostly communication between families and NICU providers. And then we talk about use of community programs for potential support for families.



And then the next section of the guidelines—we talk about anticipatory guidance, and the goal for this whole section is to give the families a more realistic idea of what their life is going to be like with their new addition—and this is both in the short term, like in the days and weeks that follow discharge, and more in the long term over the course of the next couple of years as the infant grows and develops—the kind of things that they look for. And part of the goal of this section of the guidelines is to help families understand how they parent the NICU graduate, and it may be slightly different than parenting a non-NICU graduate. We talk about helping them to understand their baby’s development and when they’re going to reach their milestones and what their baby’s follow-up care will look like. How many appointments are they going to have? And are there going to be providers coming to the house? Are they going to have to go to our offices? And then we really stress the importance of a medical home to help the families, not just with the direct medical care but also with coordination of care, especially if subspecialties are involved, if the baby has any kind of complex medical needs or any kind of ongoing medical needs or any medical equipment.

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And so those things sometimes people don’t understand the role that medical homes can play and the help the medical homes can provide. And then the last part we also want families to understand and address their own psychosocial needs, because many times these things never actually get addressed, or even mentioned, and especially for husbands or partners or for fathers or partners, regardless of the marital status. Sometimes this isn’t even addressed.

In addition to all of these big pillars that we’ve just talked about, there are also some other circumstances that have to be taken into account as part of your discharge planning process.

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And so, because these things you need to be aware of and because they may affect what you do during the discharge planning process. One of the first ones is families who prefer speaking other languages. And in this section of the guidelines, we talk a little bit about interpreter use. We specifically address when it’s appropriate to use family members as interpreters and when it’s not. We talk about using computer and things like Google translator without specifically naming Google. And then we talk about in-hospital navigation when the preferred language for the family is not the prevailing language of the area that they’re in. And then we talk about the importance of social support and also primary care options for families with limited English proficiency.

And then for military families, we talk a little bit in this section about follow up considerations. How follow up happens? We talk about the moves that are often inherently part of being a military family. We talk about Tricare insurances and some of the pros and cons that come with that, considering a lot of military families, or the majority of military families, are on the Tricare insurance. We talk about home visitation and what that looks like for military families compared to non-military families, and then we talk about information sharing because it matters quite a bit if you’re a military family in a military hospital, or a military family in a civilian hospital, or if you go back and forth between different types of facilities, which oftentimes military families do.

“So, all of those are important considerations that you need to take into account when you’re doing your kind of discharge planning. What the ultimate goal for the guidelines is—because we cover a lot of territory and there’s kind of 200 of them—it really boils down to what every family is going to need to know, what families are going to need to be ready for having an idea what their day-to-day life will look like, and who’s going to be part of the team.”

And then for LGBTQIA plus-headed families, we talk about the importance of designating who the caregivers are, understanding what parental roles are, and understanding parental rights and

acceptable terminology and acceptable questions versus non-acceptable questions.

Then for parents with disabilities, in this section we talk a little bit about some family literacy, accessibility issues, both in the hospital and in the NICU and home as well as home environment preparation, meaning getting the home ready to be able to successfully parent an infant at home and some factors that need to be taken into account, like possibly an OT assessment of the home to make sure that it’s appropriate, and then also an assessment of caregiver ability.

And then in the section where we talk about families with distinct cultural and or philosophical expectations, we talk a little bit about family belief systems. We talk about family support people. We talk about cultural practices and then community resources and how community resources may interact in a way that’s culturally sensitive.

So, all of those are important considerations that you need to take into account when you’re doing your kind of discharge planning. What the ultimate goal for the guidelines is—because we cover a lot of territory and there’s kind of 200 of them—it really boils down to what every family is going to need to know, what families are going to need to be ready for having an idea what their day-to-day life will look like, and who’s going to be part of the team. And so that’s a summary of what all the guidelines cover without specifically looking at the individual guidelines.

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Alright, so this is what I promised you earlier in the talk. There is also a companion website. So, you can write this down and check it out. It’s the nicutohome.org. And what’s really cool about this website is it’s created by the National Perinatal Association. It’s kind of a living place, and it’s intended to be a place, a repository for tools and resources and a community of experts, who are all interested in NICU discharge planning and discharge preparation. It’s a place where you can come and look for information. Or if you have some suggestions or ideas or things that work for you, you can come and share those, so then they become available to other people. It’s our way of making this whole implementation of the guidelines a little bit easier because if one person has figured out one part, they can help with, and then another person figures out another part, and you put them all together, then it makes it easier for the next group to come along and to be able to implement what these guidelines say. There’s no reason to reinvent the wheel every single time.

But what do we do next? So the guidelines were finished, the guidelines were published. The website was created, tools were put up on the website, and then, as one of our work group members, Julia E., says, “We did not create these guidelines so

they can sit on a shelf.” And so what we really want is for people to be able to get these guidelines into the hands of people who actually have an ability to make a difference in the lives of families because we really do believe that these guidelines can help, and for anyone who’s been through the NICU who didn’t have really specific guidelines, the journey, probably the transition, probably wasn’t as ideal as it could be.

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And so that leads us to talking about implementation of the guidelines. And so, when we think about this, what do we do to turn these recommendations into actions? And what do we do next?

And this can be a pretty daunting task, and we acknowledge that. So, our work group, once the guidelines were created, turned to focusing on how we can help with the implementation and understanding. The guidelines are written in such a way that they’re general, meaning that they can apply to a bunch of different circumstances because the personnel available in any given NICU, the patient population, and the types of providers, and the types of patients, the number of patients—those are going to vary quite a bit across NICUs, and there’s no way we could do just one stop shopping, like push the “if this, then do this.” So, what’s going to be required in order to be able to implement these guidelines locally, you’re going to have to look at and adapt them for whatever your resources are available to you. But that can seem scary. And so anybody at Gravens, there was a mom there named Mia Malcolm, and one of her quotes was “We’re not asking you to boil the ocean. We just want you to start with the pot.”

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And so the truth is, everybody has a pot that they can start with. For these guidelines, even though there’s a bunch of them, you can pick one that you’re passionate about, one that you care about, and start with that. And then, once you’re able to successfully and sustainably implement that, move on to the next, and move on to the next, and before you know it, you have a whole package of discharge planning that you’ve kind of kind of built up. I’m going to talk a little bit about just one person’s implementation journey, and it’s Cuyler Romeo,

and she’s just an excellent of the work group, and she’s just an excellent example of what one person who’s motivated can do. She’s an OT (Occupational Therapist), and she works with feeding, feeding matters, and she’s at Banner in Arizona. I want to talk a little bit about that.

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And so a couple of important pieces about her. You know she’s a former NICU mom. She’s an OT, a feeding specialist, and has years of working in the NICU. But what she didn’t have is a background in implementation, science, or health care, quality and improvement. And so she was a motivated person who thought that this was a really good idea and thought there was potential benefit to her unit in doing this and to the families that she takes care of. So she relied on open access tools for health care quality and improvement, and dissemination science, and she was able to do quite a bit with just those open access tools.

And so, just before we jump into to what exactly she did and how she did it. Let’s talk a little bit about what her unit is like. She’s at Banner, in Arizona, which I told you before is a community hospital. It’s a level 3. It’s got 42 beds at present, and it serves Southern Arizona and several rural communities, and she describes her population way better than I’m ever going to be able to describe it, but you name it, they have it in that unit. People travel for hours sometimes to get there. They have really complex patients. And so all of those things are kind of really important. And the way she kind of began this was she put together a group of invested stakeholders, and she used already existing infrastructure and relationships, meaning that she didn’t come in and try to create something brand new. She had a parent group who was already interested in (being) active. She had a group of nurses and therapists who are already interested in (being) active. She found a neonatologist who was willing to come on board and believed in what she was trying to accomplish. She pulled all of these people together, and they form kind of a think tank.

And then she said, okay, with this group of stakeholders, with this group of guidelines, can we pick one, maybe two things which are really important to our patient population, maybe something that we’re not doing as well as what we would like to do, and let’s try to focus on those, and what things would make a meaningful difference to our population. And then what kind of metrics will we use to measure our success so that we can know, not just for ourselves, but for others and people who are clinically at the

bedside, people who are in administration, people who are going through the program who are experiencing it as families. And so, what kind of outcomes are going to be important? What kind of metrics are going to be important for us to be able to show that we're being successful with these things?

“And then she said, okay, with this group of stakeholders, with this group of guidelines, can we pick one, maybe two things which are really important to our patient population, maybe something that we're not doing as well as what we would like to do, and let's try to focus on those, and what things would make a meaningful difference to our population.”

What she chose was access to early intervention services because what she was finding—as a place to start with—a lot of families are leaving the NICU but not connecting with early intervention services. And it's including people who would qualify for early intervention services. Then given that she's an OT and feeding matters in her organization, identify feeding needs and risk factors. And she chose to implement these things because they're related to topics that her unit cared about, and they had metrics that they could measure, that they could track for success with early intervention, referral and assessing services and assessing feeding risk and documenting the assessment of the feeding risk and using that for early intervention. Just to prove the power that one person can have—when she decided that these were the things that she was going to focus on. She was able to make a few phone calls to local agencies, and it's amazing how making one phone call suddenly removes barriers. She discovered that there was an individual who could help with referrals to earlier intervention, both making them and following them up, and that person wasn't getting the referrals, and so just connecting her unit with that particular individual, referrals went up from like 10% to maybe 40%. It was an order of magnitude of change to that huge degree. And then she found out that many kids who met requirements for services—meaning they've been evaluated by a therapist and found to have a challenge that they would qualify for early intervention services—they just weren't getting referred because people weren't aware that the feeding challenges that were coming up qualify people for services. So, I'm not saying that this is what you need to do in your specific unit, but I said sometimes just having one person making one phone call and having one discussion can really change outcomes in a huge way for folks and for individuals.

So then, what Cuyler was able to do was to go online—again, I told you she didn't have any training in dissemination or implementation models—but she was able to go to this website dissemination-implementation.org. And what she found was that there are a bunch of free tools that she could put in the things that she was trying to measure, what she was trying to do, and it, in a really simple and straightforward way, walked her through the processes that she would need for a successful implementation and use to be able to assess how the implementation is going, thus helping to maintain a sustainable program.

“What she chose was access to early intervention services because what she was finding...a lot of families are leaving the NICU but not connecting with early intervention services...including people who would qualify for early intervention services...She discovered that there was an individual who could help with referrals to earlier intervention, both making them and following them up, and that person wasn't getting the referrals, and so just connecting her unit with that particular individual, referrals went up from like 10% to maybe 40%.”

And so, this is an example of some of the tools that she was able to access that help with the planning. This was one of her challenges. Infants are referred to community services NICU developmental clinic, (which) could follow, but the service is often not rendered. And why? Using these tools, she could kind of help trouble-(shoot). Why this? Even if the referrals are happening—not that all the referrals were happening—but first to get the referral to happen, and then, when they did happen, how come the services are not getting rendered? And then there are tools to understand the needs. And in this particular instance, the tools were divided up into three different categories—processes, providers and parents. And we'll talk about those on this slide.

“Cuyler was able to do was to go online...to this website dissemination-implementation.org. And what she found was that there are a bunch of free tools that she could put in the things that she was trying to measure, what she was trying to do, and it, in a really simple and straightforward way, walked her through the processes that she would need for a successful implementation and use to be able to assess how the implementation is going, thus helping to maintain a sustainable program.”

So in relation to what the guidelines were and what their goals were, processes were things like discharge summary, approved assessments, and education. Provider information were things

like medical records, point of contact, referral pathways, and follow up. And then the parent piece was parent education and advocacy with education, integration, and advocacy. And so those are ways that they kind of translated the guidelines that they were working with into these tools that they were using and how they could help with their implementation.

So what was your greatest worry? I think that in starting this work that they were really intimidated because it was doing something new, and they were worried about what was going to be their ability to be successful. And then in doing this, they were, I think, pleasantly surprised at how much one person could actually do and how much change could come about with one particular person. This again was a pilot study, meaning that they decided they were going to pick one or two guidelines to start with, using these resources that are already available, and then supplementing with the online materials that were free and readily available to them, and working towards goals that were already kind of important to them.

For them, their next step is they're going to refine the pilot a little bit more. They're going to continue to collect data with the pilot, and then they want to expand the pilot. Because again, as I said, they started with two things, and there are over 200 guidelines, and they want to expand it because, as they noted, they were able to make success and make measurable, meaningful success with the things that they were doing. Then, people became excited about the success, and people became excited about the potential success, and so that got people on board to want to do more, and then they want to assess what their outcomes look like and to make sure that what they're doing really is as sustainable as what they hope it is. And then, they made the one partnership which was hugely key to being able to connect with outpatient services, which was one of their goals. And so, they're looking for other partnerships in other ways and making use of other resources which could be underutilized because people may not be aware of them or know how to use them.

So anyway that was not meant to be a course on how to do implementation but just an example of what the power of one person who's motivated can do, and I say that so you could feel empowered to do things and know that you aren't alone in necessarily doing this. There are other ways to help, and National Perinatal Association is one of those.

“And so, they’re looking for other partnerships in other ways and making use of other resources which could be underutilized because people may not be aware of them or know how to use them.”

So I'm going to stop talking because I was supposed to only talk for 30 minutes, and I think I went over just a little bit, and I want to thank all of the steering committee who worked on these guidelines, who produced the guidelines and all the content experts who contributed to being able to make this work happen. And I want to thank you for listening for your attention, and Kristy and I are happy to take some questions.

Colby Day: Thank you so much for that fantastic talk. We have had a few things in the chat that have come up while

you've been showing us your slides and talking through Zoom. One of the things that has come up is when is the correct time to measure parental readiness for discharge and whether parents really know that they're ready for discharge prior to going home, or whether it might be a better idea to evaluate that after they've been home and are able to actually assess that they've been made ready. I love to hear your thoughts on that.

Vincent Smith: So, I love how they frame a question as being simple when it's actually really, really complicated. I would say, there are a couple of ways to do it, and I'm going to preface it. Kristy, you should unmute and jump in here too if I'm messing up or leaving something out. I don't know that there is a magic correct time or a magic incorrect time, I think, for sake of ease, oftentimes it's easier to assess their discharge readiness right before they go home while they're still in the NICU—and ideally, after all the discharge teaching has been done, which means that you can't wait till the last minute to do all the discharge teaching, otherwise there's no time to get it in and assess and have them leave.

And so ideally, you'll have a timeline. You'll get the discharge education pieces done early enough and skills demonstrations done early enough and signed off on all these things early enough that you get assessed right before they go home, because that's the time when you're most likely get most of them. But it is true that, at the moment, right before they go home, they're probably at a bit of a high. They're excited. They're nervous because they're leaving, but they're also excited because they're going to be going home, and it's really kind of a mixed thing. But they haven't been at home primarily providing all the care for the infant. Yeah. And so sometimes how you feel in the moment and how you feel after a week of doing that is a little different. And in that regard, assessing what the discharge readiness is like a week or two after discharge, then you probably get a more realistic idea of how people feel about their discharge preparation at that time. The problem is people are really busy at that time taking care of their infant, adjusting to the addition to the family. And so your response rate is probably going to be a little bit lower, and you could make the argument that if you assessed 4 to 6 weeks after discharge after people get over the initial shock and awe of being at home and like oh, I can't believe I'm actually home and I'm doing it. And so, I think that then they've had a chance to kind of settle in, re-establish a routine, and they kind of figured out a lot of the initial challenges that are kind of a little bumpy a few days right after discharge, and so that could give you a better idea of long term what it meant. And then, if you assess them at 6 to 8 months afterwards, you can get an idea of what the retention of the information really is like.

And so that was a really, really, really, really really long answer to say there's not really a magic number, and there's pluses and minuses with whichever way you decide to do the assessment. I think it's probably more important to do an assessment in a consistent way. And that way you get relative comparisons again and again and again. And whichever time period you pick, there are good arguments for either time period. So, Kristy, did you want to add anything to that?

Kristin Love: I think you covered the majority of it, I will just share as a NICU parent. No matter how much education and preparation we have, or we think that, or the staff feels that we have, we really don't. Because once we walk out those doors, we're leaving our support system and knowledge back in the NICU. So, community resources is a huge piece that I think a lot of institutions are missing, communities are missing, because

having your community resources is going to help that transition.

“I will just share as a NICU parent. No matter how much education and preparation we have, or we think that, or the staff feels that we have, we really don’t. Because once we walk out those doors, we’re leaving our support system and knowledge back in the NICU. So, community resources is a huge piece that I think a lot of institutions are missing, communities are missing, because having your community resources is going to help that transition.”

Colby Day: And I would definitely recommend to those of you that haven’t been reading through the chat, and we’ll make this available as well. We had some really great examples and stories that have been shared from our family partners that are on the call, and at least in perusing them as they’ve been coming through, I have to say there are probably a lot of areas we can improve. There’s been a few that have stated they had a good experience but maybe still had some issues with things like feeding supply companies and whatnot, but certainly sounds like we have some room for improvement with discharge readiness.

Another thing I would love for you to speak about is you really emphasize that medical home. And I wonder if you could define a little bit what you mean by that because I feel like medical home could be a different group of individuals, depending on resources in the community and where people are being discharged and how maybe they could bridge this support gap that we’re talking about of parents leaving the NICU and kind of feeling that they are addressed at that point.

Vincent Smith: Alright, so when we’re thinking about medical home, we’re thinking about a place that serves kind of multi functions. I mean, it’s a place that you have to feel comfortable asking just general questions because especially when you’re home with a former NICU baby, there are some things that you’re just not sure if they’re going to be normal or abnormal, and it’s going to take a while to know that. So, you do need a place that you can get that baseline level of “is this okay,” “is this not okay?” And then you want to have a place that’s going to consistently monitor your growth and development of the infant and be able to know when they need to do interventions. And so, because there can be ongoing issues, specifically feeding issues and specifically growth-related issues. And then, as the kid gets a little bit older, sometimes there are behavioral challenges and learning difficulties to come along.

And so you want a place that’s going to kind of understand that and be your partner and working with that and can also help with you if you need that for advocacy for services—whether it’s early intervention services or if the kid is a little bit older, school

system services, and then also a lot of former NICU babies have complex medical care, meaning it’s not just their primary care that they’re seeing. They see Endocrine, or they see Renal, or they see Cardiology, or they see Infectious, or speech and OT—they see all these other litany of services, and as a parent, it can be kind of hard to keep track of all of those things and to make sure that all the referrals are in place and that all the recommendations are being implemented. In theory, your medical home should be able to help you with that, because you shouldn’t have to kind of manage all of that stuff by yourself. They should help you track appointments, and when there’s feedback from the appointments, how to implement that and make sure that that’s getting taken care of and making sure that all of the infant and the family’s needs are getting met. And so sometimes, a new need will come up that hadn’t been anticipated, and you’ll need referrals, and the medical home should in theory be able to help you make the referrals and help follow the recommendations from the referral.

“...when we’re thinking about medical home, we’re thinking about a place that... you have to feel comfortable asking just general questions because...there are some things that you’re just not sure if they’re going to be normal or abnormal, and it’s going to take a while to know that. So, you do need a place that you can get that baseline level of “is this okay,” “is this not okay?” And then you want to have a place that’s going to consistently monitor your growth and development of the infant and be able to know when they need to do interventions...And so you want a place that’s going to kind of understand that and be your partner and working with that and can also help with you if you need that for advocacy for services”

And so the whole point with the medical home is what that looks like can vary a little bit. There’s no like this is only what a medical home looks like. I mean it can be a pediatric provider. It can be a pediatric practice. It can be oftentimes, though it’s more than just the pediatrician, because sometimes you have some of the nurses who are discharge coordinators or case managers or social workers or psychologists or therapists or all these other people who can help with some of the other health heavy lifting and help when questions or challenges arise. And so it could just be your pediatrician. But sometimes it’s more than just the pediatrician. I feel like I’m giving really long answers to these questions.

Colby Day: Well, it’s because we aren’t asking simple questions. Right? No, that answered my portion of the

question definitely. We have about 2 minutes before we're going to go to Dr. Balasundaram. And we just had a question come through on how we build out a medical home for underserved areas and rural areas. So, I'm going to challenge you to try to answer that because it's important.

“I think whether it’s an underserved area, whether it’s a rural area, whether it’s an affluent area, realistically, what you’ll have to do is an assessment of what the resources are that are available at that given (area),”

Vincent Smith: So, I think whether it's an underserved area, whether it's a rural area, whether it's an affluent area, realistically, what you'll have to do is an assessment of what the resources are that are available at that given (area), and that's going to vary quite a bit—like a lot, depending on where you are and what that place is. And then you have to map that out to what the specific needs are, and then, regardless of what's available, if it's not going to be available to you locally, then you have to look at what are other ways through maybe telemedicine or remote health, that you can get some of these other needs met and what are the supports that are available to you. And I say that because sometimes there are national things that are available and accessible to supplement, and it may not be as robust as being able to go to a place that's right across the street from you, but if that place is not available to you, it's better than nothing. That makes sense, like consultation with the developmental pediatrician 200 miles away over telemedicine is probably better than not having any consultation at all. I mean, although it'd be preferable for you to be able to go across the street to your developmental pediatrician and have them see you and your baby and to make the assessments and form a natural relationship with you that way. Sometimes it's not going to be available.

I think the thing that matters the most is having somebody who really cares and who's willing to get in there and help. Because I think that makes a huge difference.

Colby Day: Absolutely. Well, thank you so much, Dr. Smith, and also Kristy for this talk, and I'm going to pass things over to Dr. Balasundaram.

Vincent Smith: Thank you so much for having us.

Malathi Balasundaram: Hi, everyone. Thanks, Vincent and Kristy, for sharing your wonderful resources to our community. And Vince and I use many of your publications while building this program. So thank you for all your work and the discharge planning and the preparation. So that's wonderful. I'm going to talk about our local unit-based program that we have built for our NICU families... I'm going to start from our journey, which began in 2017, and we completed our journey in 2019 and (show) how we are sustaining the program, and I can give you a demo of our education activities under the MyChart Bedside. Okay. So this is the picture of me. I'm with Doctor Kari McCallie, and she is my partner at the time, and so she is a neonatologist, an Epic Physician Builder, and she is supposed to be on sabbatical. And she said she wouldn't make it to this meeting, but lucky for us she joined. And so, if you have any specific questions related to the Epic (an electronic health record system) and MyChart Bedside,

here is our contact information, and she is available for you to ask any questions if you are thinking of implementing this program in your unit.



El Camino Health is the 20-bed community level 3 NICU, and we provide care for any infants 23 weeks and on, and we are an open bay unit with approximate delivery volume of 4,500 newborns that average 400 NICU admissions per year.

We are staffed by Stanford neonatologists and nurses and ancillary staff, and we do have Stanford residents and medical students there (going) through our unit. We don't have any fellows or advanced practice providers in our unit.

So I don't want to spend more time here, and I think Dr. Smith clearly described why we needed to focus on this, and we heard about our multiple family partners, about how they felt about the discharge planning and post discharge. I just wanted to briefly talk about if you are not adequately preparing families, that contributes to poor infant outcomes and heightened family anxiety and increase in the healthcare utilization after discharge.

As Dr. Smith mentioned in his talk, quality of discharge teaching is the strongest predictor of discharge readiness. With this in mind, this will be built into our program as a part of the Family Center Care committee. So we built our family-centered care program in 2016, and in the beginning phase, we actually looked at improving the discharge education. So we looked at our Press-Ganey (patient satisfaction surveys), and some of you are familiar with this. But if you have international colleagues, I just wanted to share what is the Press-Ganey. So this is the patient satisfaction survey the families usually get after discharge, and we have our really specific survey that goes out to the families by mail, and we are actually working on making that an electronic form. So (in) this survey, we looked at our Prepare for Discharge top box responses—that is the response that reflects the highest possible rating. So we looked at (it), and our rating was 47% in 2017, so we looked at the other categories. We were scoring (around) 70%. So, this is the lowest of 47%. So, we wanted to improve by using technology and providing consistent discharge teaching, and the goal is to start this process closer to the admission time and not waiting until the last few days of hospitalization.

So this is just a screenshot of our NICU survey (Figure 1). We used a four page document in the beginning of the journey, and then I consolidated, worked with the present patient experience. We consolidated this into 2 pages. It focuses on different categories—nurses, doctors, and discharge, an overall assessment, some specific to our center. So this survey is usually sent out within a month time period to the NICU families.

So this is a flow diagram (Figure 2). And it focuses on multiple interventions that we followed in this incremental journey. The first intervention we formed a committee—we formed the task force—it's called, a comprehensive discharge teaching task force.

We have a wide range of providers—bedside nurses, nurse practitioners, nurse manager, neonatologists—and families are members of this task force. Once we formed the committee, we wanted to work on the unit-specific discharge teaching. So, the team members actually wrote a unit-specific discharge teaching. We have some old discharge teaching also, so we just modified that, and we created a video for important discharge teaching sections, like how to use the bulb syringe and how to measure the temperature and (using the) car seat and mixing the formula. So, we just to ask the families what they wanted to hear from us. We included their feedback, and we created a video, and we created the El Camino NICU gmail account, and we uploaded that into YouTube, and we linked that YouTube into the e-book content. So we've been through several revisions, and we accommodated the Family Advisory Board that we are now calling a Family Partnership Council.

“The first intervention, we formed the task force—it’s called a comprehensive discharge teaching task force. We have a wide range of providers—bedside nurses, nurse practitioners, nurse manager, neonatologists—and families are members of this task force.”

Originally we thought, we can build this as a Word document, and then with the Word document, it's not easy to navigate the table of contents. So I just converted that into an e-book using a iBook author application. Now it's called the Apple Pages. So in this day it has a table of content, and parents can review this, and then so they can go back and review the content at their own pace. So we had a 3 iPads donated by our family advisory board. That's how we started this project in the beginning, using the three iPads.

The next intervention. Once we wrote that e-book, then we wanted to implement that e-book, and then how (to) make sure it reaches every family—we focused on that as a second intervention.

“Once we wrote that e-book, then we wanted to implement that e-book, and then how (to) make sure it reaches every family—we focused on that as a second intervention.”

So here you can see the content (Figure 3). On the picture on the left is the discharge teaching on the e-book and iPad. So it does (have) a table of contents. We matched the content to the electronic health record (of) what the nurses are looking on their end. So, we match the content with the order (of) how it appears, and we created a paper checklist. So the paper checklist was based at the bedside, and it matched the content of the e-book, too. So whenever the parents review this information, they can actually sign off on the paper checklist, and the nursing staff kind of add that information into electronic health record. So it was manually transferred by nursing staff into Epic.

So the next intervention is like, okay, (with) the previous one, the nursing staff manually needed to input that information. (With) a paper checklist, we did an audit, making sure it (was) reaching every patient. But still we were not able to achieve that. So the next intervention.

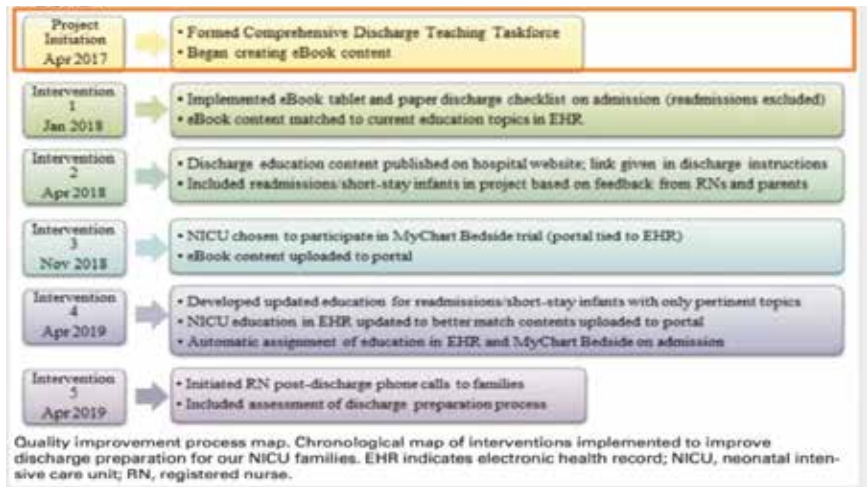
We had only 3 iPads in the unit, and (there are) 20 patients there. We don't have access for (all of) them to use it. So, what we did is we actually created the PDF of our discharge education and uploaded it into our hospital website, and so that way, the patients' families can have access to this information, so they can review this information at their home.

So when they are here, they can just focus on providing care to the babies, and instead of sitting and then reading the information, we uploaded that on the website with the help of our marketing team. And so, they can review that information and come to the unit and then check off on the paper checklist.

Figure 1. Press-Ganey Survey

The image shows two pages of a Press-Ganey Survey form. The left page is titled "NICU SURVEY" and includes sections for "NURSES" and "DOCTORS" with Likert scale questions. The right page is titled "DISCHARGE" and "OVERALL ASSESSMENT" with similar Likert scale questions. A large "PREVIEW" watermark is overlaid on the form.

Figure 2 Flow Diagram of Interventions



“we actually created the PDF of our discharge education and uploaded it into our hospital website, and so that way, the patients’ families can have access to this information, so they can review this information at their home... also, we created a Homecoming Checklist”

And during this intervention also, we created a Homecoming Checklist. So what it is—we usually give this information a few

Figure 3 E-book on Tablets

El Camino Health

Electronic Book on Tablets

- Content written by interdisciplinary Discharge Teaching Taskforce
- E-book chapters matched Epic education topics
- Paper checklists at bedside -- nurses transferred to Epic

NICU 1

Discharge Teaching

Discharge teaching checklist

Education (Read Only)

days before the discharge. It has a checklist for the families to go through. What are the things they need to buy or bring in on the day of discharge. So just to help them prepare, bring in the car seat and installing the car seat, information and all those things. It was created by one of our nurses, Michelle Ranch. It’s really useful to give this information just a few days before the discharge so the parents can prepare.

So, the next intervention is—so there’s always room for improvement, right? From the previous intervention, the nursing staff has to manually enter into Epic, and it’s only the three iPads at the bedside, so the iPads are not available frequently for some of the families. So lucky for us at our hospital—actually, I did the pilot study to include the MyChart Bedside as a part of the pilot to the NICU—we received 20 iPads, so each baby gets their own iPad.

So we actually pilot that MyChart Bedside, integrating the

Figure 4. MyChart Bedside



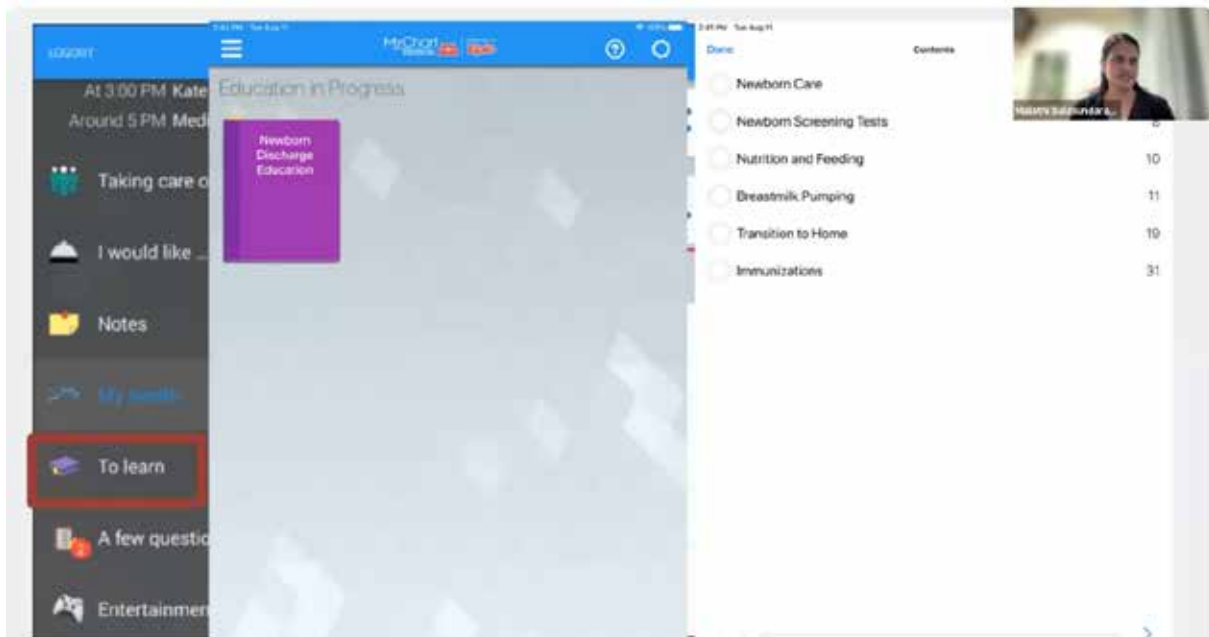
e-book content to the MyChart portal. This is a MyChart Bedside screenshot (Figure 4). Basically it's a tablet-based application that gives the admitted patients and their families more information about the patient's condition and hospital stay. As you can see, they can review their treatment team, who's taking care of their babies, and they can look at the vital signs and lab work and problem list and what medications the baby's on. All this information is available on their iPad and the MyChart Bedside.

and the page opens (like) this for each chapter. Once they open the chapter, this is what they are seeing on their end. So, each chapter has the reading material, and also if applicable, there is some picture. And also, there's a video incorporated. I can just play this video hopefully. [video does not play in this article]

Under MyChart Bedside, there's a section called "To Learn" (Figure 5). That's where we uploaded all of our e-book discharge education into that To Learn section.

So this is where the families look at this information on the iPad, and under To Learn, it opens as a e-book. It's a newborn discharge education. It has different chapters, divided into 6 categories,

Figure 5. MyChart Bedside Newborn Discharge Education Interface - "To Learn"





Nurse (on video): To bulb suction your baby, you're going to take your bulb suction, gently press down with your thumb, put it in your baby's mouth on the side, release, and then put any mucus or secretions on a cloth to the side. You're always going to do the mouth before you do the nose. So, to do the nose, you'll do the same thing, one nostril at a time. Gently insert the bulb suction, release, and then put any mucus or secretions to the side.

Malathi Balasundaram: Okay. (The parents are looking at) MyChart Bedside while they are in the NICU because they can't take that iPad home. But if they wanted to see this information on their own mobile, they can use this as a MyChart mobile app (through) the app store. They can download the MyChart app, and they can pick the organization, and ours is El Camino Health, and they can log into the mother's MyCare account, and it's a proxy. Then switch to the baby. They can select the menu and type education so they can just look at the education. All the material that is on their MyChart Bedside is available for them to review on their phone. That way, if they wanted to review this on their phone, they can do that, and they don't have to use bedside MyChart Bedside. If they have an iPad or laptop, they can bring that, and we can actually use their device to scan the QR code and activate the MyChart Bedside so they can keep that account active even after the discharge, so all the information will be saved. And they have full access to their baby's information, labs,

vital signs and everything, and now they can even look at our notes. Once we sign it, it just flows to MyChart Bedside, and so they can review and read our notes.

Once we received these 20 iPads, we wanted to take this as a pilot project. So, what we did is (take) the e-book content and transfer to the "To Learn" section of the MyChart Bedside. The discharge education checklist (Figure 6) was manually assigned to patients by nurses, so you could have imagined that...it was time consuming for nurses. I can show the data on how we did this pilot phase, and so we wanted to make it better. We wanted to improve. So this is how it works. What they do is the patient reviews this information, (for) example, taking a temperature. (There are) two boxes on the bottom. One is "I understand"; the other one is "I have a question." So, if they understand the concept, they can just click "I understand." So that flows directly to the Epic electronic health record, and the nurses can review that information. And if they have any questions, they can put "I have questions," so that it flows, and then it's (recorded as) not complete. (The orange circles turn green when the concept is completed.)

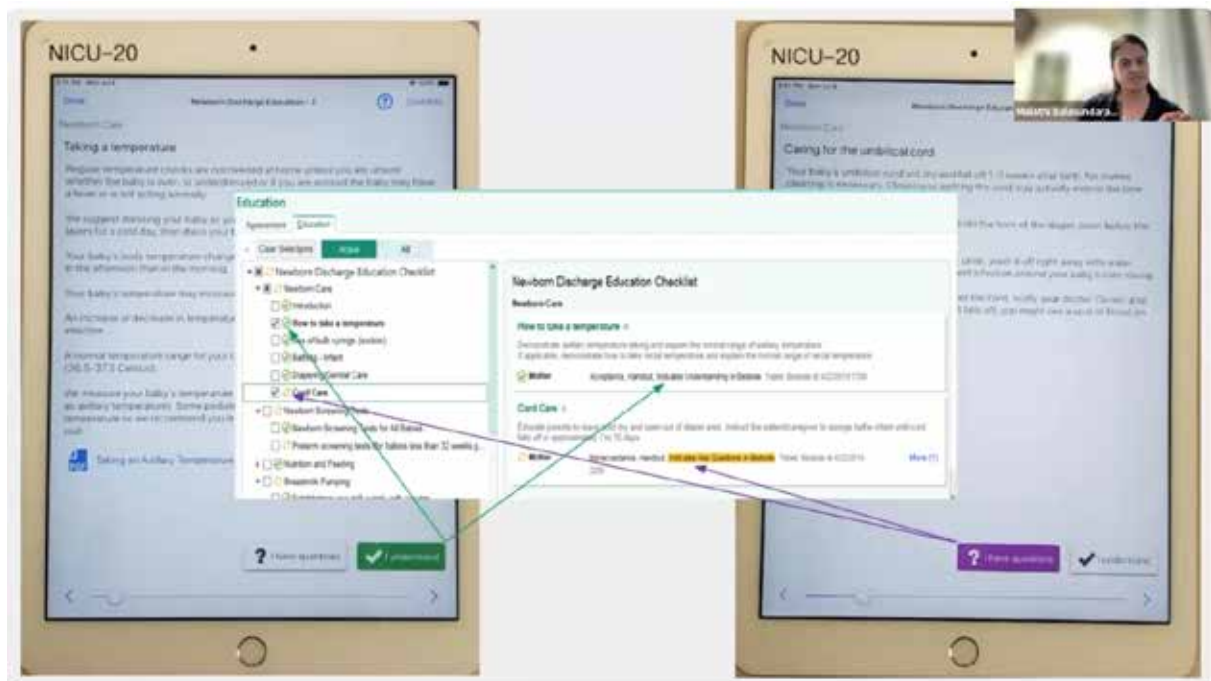
So, (to) this day the nurses can see whether this family participated in the education, how far they are behind or how far they (have) completed, and so they can just gently remind them to complete that education to be in advance and so not on the day of discharge. That's the beauty of this space that they are able to look at this and then communicate with the families.

So the next intervention, as I mentioned, the nurses actually need to assign the checklist in order for them to get the families to see this information on the MyChart Bedside, which is just painful, so we just wanted to get it better, so we optimized that MyChart Bedside portal.

This optimization is where our Epic Physician Builder, Dr. McCallie, did a beautiful job of creating this content of what are the information (written) in the e-book. So, each education section (was) given a point, and so we have full discharge education points.

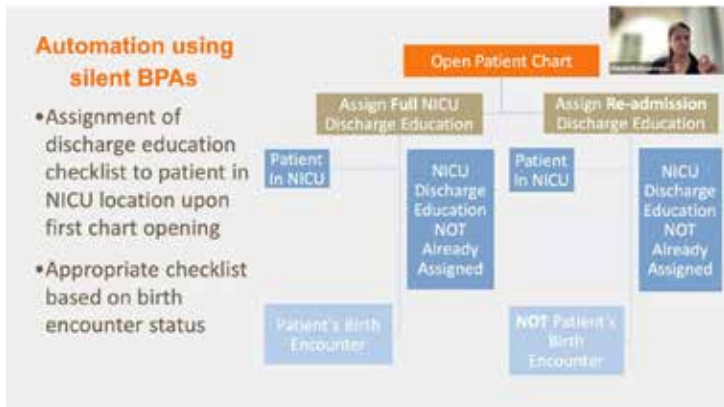
There's a separate section for the readmission discharge education points (since) we don't want the readmission families

Figure 6. MyChart Bedside Newborn Discharge Education Checklist Interface



or short stay families to look at the entire discharge education. So we created a consolidated version for the readmission families.

So this way, using the BPA, the Best Practice Advisory, (the discharge education is) actually automatically assigned to the patient at the time of any NICU admission. So this is what the flow diagram is showing.



The silent Best Practice Advisory you can use. But if you open the patient chart based on their birth encounter—if the baby was born to that encounter, they actually get this full discharge education. But if they are re-admitted, it's not a birth encounter, then they will get this small version of the re-admission discharge education (instead of the full discharge education)... So then we focused on this. We focused on the full education. Then we had a consolidation education version.

This slide actually shows our demographics of maternal language, and what proportion we have of non-English language preference families, and, as you can see, we have a majority 89% who speak English and 4% Spanish.

But we wanted to include everyone, so we actually included a specific for the Spanish speaking families. So in this version, the Spanish-speaking doctors with the help of a unit clerk and Google Translator translated all the material into Spanish. Then we can

“All the material that is on their MyChart Bedside is available for them to review on their phone. That way, if they wanted to review this on their phone, they can do that, and they don’t have to use bedside MyChart Bedside. If they have an iPad or laptop, they can bring that, and we can actually use their device to scan the QR code and activate the MyChart Bedside so they can keep that account active even after the discharge, so all the information will be saved. And they have full access to their baby’s information, labs, vital signs and everything, and now they can even look at our notes. Once we sign it, it just flows to MyChart Bedside, and so they can review and read our notes.”

Figure 7. Full NICU Discharge Education Points

MyChart Bedside (MCB) Optimization

- Content re-vamped to better match e-book content
- Short-stay checklist created for re-admissions
- Appropriate checklist **automatically assigned** to patients on NICU admission

Topic	Points
Newborn Care Introduction How to take a temperature Use of Bulb syringe (suction) Bathing – Infant Diapering/Genital Care Cord Care	Newborn Care How to take a temp Use of Bulb syringe Bathing – Infant
Newborn Screening Tests Newborn screening tests for all babies Preterm screening tests (for babies < 32 weeks gestation or < 1500 grams at birth)	
Nutrition and Feeding Feeding Your Baby	Nutrition and Feeding Feeding Your Baby
Breastmilk Pumping Establishing your milk supply with a pump Collection of breastmilk Cleaning a breast pump Storing, labeling, and transporting breastmilk Appropriate breastmilk volumes Maintaining a healthy pumping routine Maintaining full milk production Thawing and warming stored breastmilk	
Transition to Home Easing the Transition to Home Tips and Tricks for Transition to Home Circumcision Care Back to Sleep – Positioning for Sleep Tummy Time Comforting your baby Infant CPR Pets at home NICU Discharge Medications Follow-up appointments When to call the pediatrician Safety tips	Transition to Home Tips and Tricks for Transition to Home Back to Sleep – Positioning for Sleep Tummy Time Comforting your baby When to call the pediatrician Safety tips
Immunizations Why vaccinate? Hepatitis B Vaccine	

assign this based on the family's language preference. If they speak Spanish, they will be assigned to the Spanish discharge education. I will show you the screenshot of how the families review that information in the next few slides.

So this is what the family sees.



So they actually see this information in Spanish, and they have a e-book, and then they have a chapter, and then each chapter has the same information and videos. We actually have a subtitle, and the subtitle will be translated into Spanish, so they can just read that subtitle. And so that's the one modification we did. And so then they can check off the same way that the other families do—to understand or they have a question.

The nurses, and on the other end of Epic, they actually see the information as Spanish in parentheses, and then they just (see) all the information in English (Figure 8). But once they try and sign off, they can see all the completion, everything, all the circles are completed and green. That gives us the information that education was completed for this family.

We do have a PDF printout for the families if they don't have any electronic access, or they don't know how to download on their phone...so they can take this home and then review that information and come to the bedside, and then they can check off that they understand or they have a question.

So we try to capture every level as possible as we can.

“...we actually asked 159 families how they feel about the MyChart Bedside education, and 70% used it...(and of those) 92% said they liked it, and 6%... preferred one-on-one education with the nurses”

So this is how (we continued) the optimization then—we created this Consolidated Education point, and we translated into Spanish, and then we automatically assigned the education based on their birth encounter or readmission.

Then we wanted to hear from the families. Okay, so is it really working, or how we are doing? Lucky for us, we actually have the follow up phone call. As a part of the family centered care program, you have a follow up a phone call program for nurses. Right now we have four nurses. They actually call the families within a week or two after discharge and check in with them—how the home transition went and how we can improve and is there any way that we can provide better care for the future families. And so that's the way we wanted to hear from them.

So, during that implementation phase, we actually asked 159 families how they feel about the MyChart Bedside education, and 70% used it, and 30% haven't used it, and because they were short stay—they stayed only less than 48 h, like admitted for rule out sepsis—and so they are not able to access those MyChart Bedside. But whoever had access to that, 92% said they liked it, and in 6%, they preferred one-on-one education with the nurses, and 2% declined to rate. The MyChart Bedside Education—a majority of them actually like this program, and they wanted this to continue; they actually gave it good feedback. I just want to read a couple of them: “It's very good informative material, and it answered most of our questions”; “appreciated the simplicity of the iPad”; very convenient refresher for experienced parents”; and “smooth, easy to navigate and self-paced.”

Figure 8. The Nurse Sees Progress in English of Spanish-language Discharge Education Checklist



“We wanted to hear from the nurses also because it's a workflow change. So we asked them how they feel about this program, and the majority of them, 92%, actually liked it—'improved the workflow on the day of discharge'; 'making teaching easier for parents, as they had seen content previously and were able to ask better informed questions'; consistent teaching content'; 'and easy to keep track.'”

We wanted to hear from the nurses also because it's a workflow change. So we asked them how they feel about this program, and the majority of them, 92%, actually liked it—“improved the workflow on the day of discharge”; and “making teaching easier for parents, as they had seen content previously and were able to ask better informed questions”; consistent teaching content”; “and easy to keep track.”

So any quality improvement work that we do, along with the process, we have to look at the outcome, and so the next slide shows our outcome focused on MyChart Bedside usage (Figure 9). As you can see, the yellow line is usage. We separated into two different time periods. The pilot period is the one where the nursing staff had to manually enter the checklist. As you can see, the usage is very, very, very low, so it's 22% average in the pilot phase, the yellow bar. But then you see the optimization where automatically everything is assigned. So, it improved to 60%. The parents viewed the MyChart Bedside more frequently and then responded, improving from 29% to 85% on the green line. The Red Bar is actually the nursing time. So we assumed 5 min of nursing time per education point. So then, how much saved by

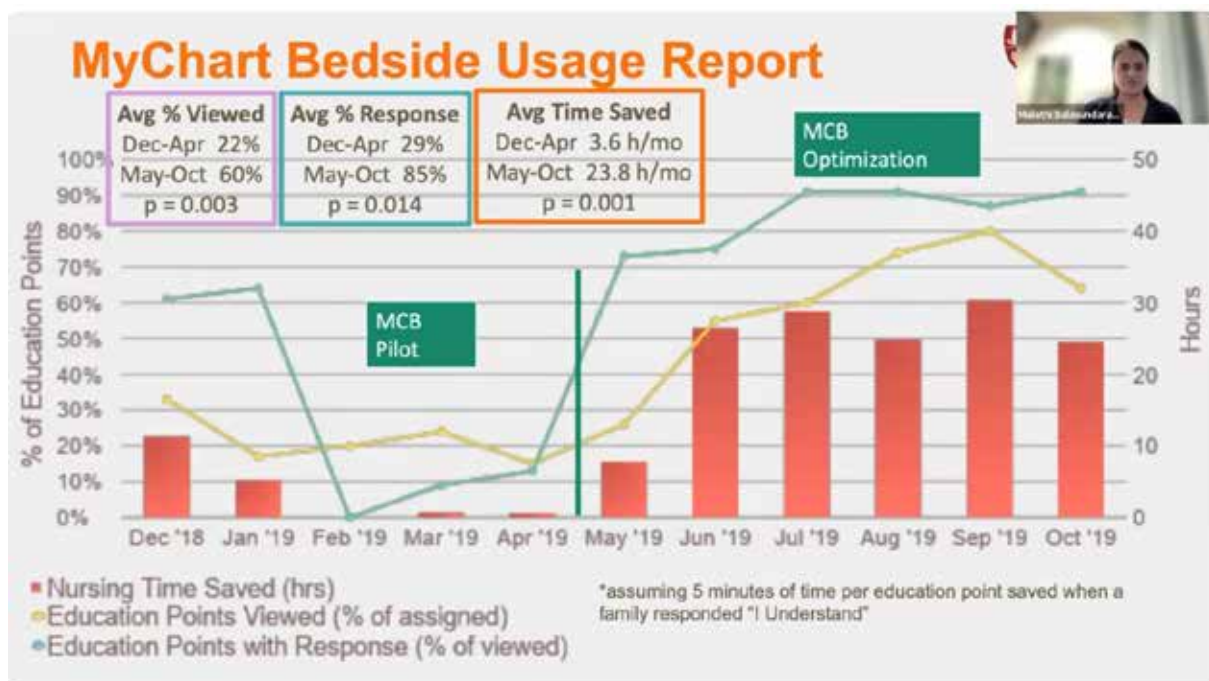
using MyChart Bedside when a family responded “I understand”? You can see from 3 h per month average, you're able to increase to 24 h per month average, and in the sustainability period, we are actually doing a fantastic job of saving 55 h per month. So, it's better response from the families and nursing staff and decreases the burnout. There's a lot of advantages of using this platform, and it's not easy and is time consuming, but we can make it work.

“...how much saved by using MyChart Bedside when a family responded “I understand”? You can see from 3 h per month average, you're able to increase to 24 h per month average, and in the sustainability period, we are actually doing a fantastic job of saving 55 h per month.”

So then as you may recall what our original aim was. We looked at the Prepared for Discharge Press-Ganey survey, and the top box for analysis. So our average was 47% pre-intervention, and we are able to improve that to 70% (after optimization). So, our return response rate for our Press-Ganey is around 20%. I actually look at this quarterly prior to feedback to the leadership team. With that return rate, we were able to show the improvement Just fantastic. Thank you.

So the sustainability period. Yes, we've completed this intervention in 2019, and so we wanted to see how we are doing. So, this is two years later, and, as you can see the amazing unit clerks—they are the one to actually activate the iPad at the time after the admission, they actually activate scanning the QR code and then leave it at the bedside. The parents need to put in the PIN. So then they can have full access to their account, and we were able to improve our average view and our average response. And so our average is around 83 to 94%. Last year we looked at our

Figure 9. MyChart Bedside Usage Report with Time and Optimization



data, still we are consistently doing a 92 to 95% of the time they were able to review and then answer the question they are able to understand.

Also, we looked at our report for discharge top box responses, and then we were still consistently in the 70s and so, which is great.

So, we were able to show that the impact with this project is the family receive(s) consistent information. So, it's not based on who's on and who's discharging the baby. If some nurses are really good with the discharge education, they do a great job. It's not like that. So consistent information was given and prepared well before discharge, and (families) ask the questions based on the knowledge that they received or read.

And you've saved the nurses time, and I've also included the family satisfaction scores about (being) "prepared for discharge." Also, it's easy to update the content. It's kind of easy, and with the help of Epic Physician Builder, we can just update the content and the Epic. We actually did that in the division twice, and we changed our breast pump from one company to another one, so we had to update everything. So it's just a little bit easy to update the content based on feedback and changes in the unit. And we included every disciplinary staff wanting to provide better care—nurses, MDs, Lactation consultant, unit clerk, marketing, IT and families. So it's just a multidisciplinary way of showing that improvement. And the families have access to this education post discharge by accessing the website, or if they activated the MyChart Bedside on their iPad, then they have a full access to that.

“And what if the families are technologically challenged? It could be that everyone uses a smartphone, and it's easy to teach them, so they can overcome all those barriers.”



El Camino Health Challenges/Solution

- Physicians time Commitment (Volunteer)
 - Write eBook, format, upload
 - Building EHR BPA (Best Practice Advisory)
- IT security concern, losing iPads
 - Shared family voices
- Staff/rotating Trainees education
 - Yearly refresher FCC orientation list
 - Trainee one on one orientation by FCC Chair
- Delay in updating the website content

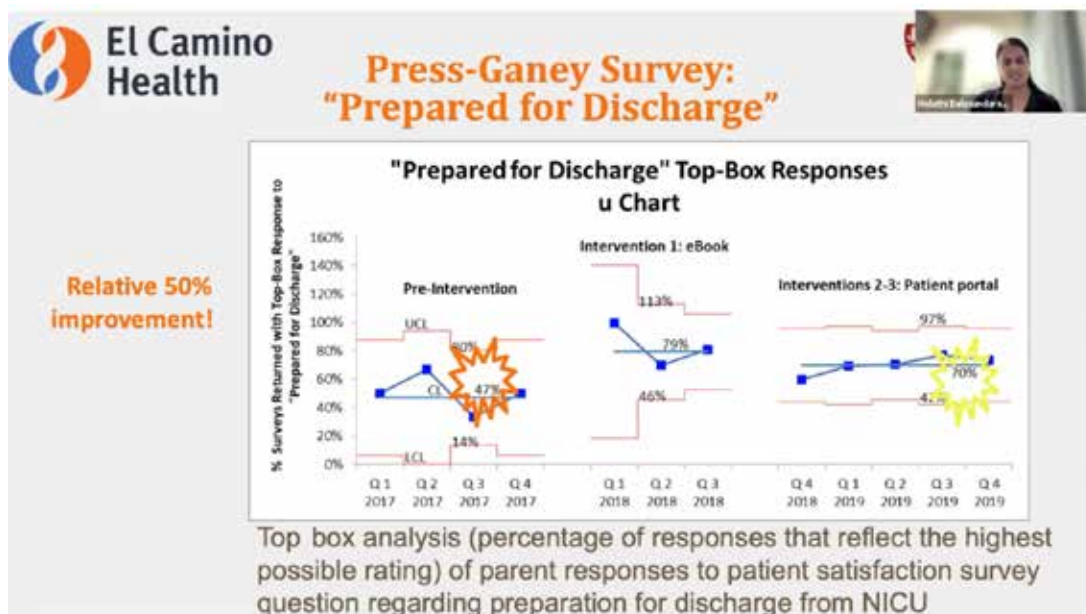
Every project has challenges, and I share some potential solutions here. Physician time commitment—so we did volunteer, and I wrote the e-book, formatted and uploaded in the iPad all those things. And then Epic Physician Builder affected my colleague the same way, building the EHR BPA—all those things is a time commitment, but we are proud to do that because we were able to show this big impact.

IT (Information Technology) security—the original meeting with IT was that they were concerned about security issues on losing the iPads, and we actually shared the family voices on how stressful the discharge planning (was), and they were able to change their mind. (Now,) they (the families) were able to have full access. And in this, 6–7 years now, they haven't lost a single iPad.

So, we have all of our 20 iPads and 5 iPads that were donated from the family advisory board—we still have it in every unit. As the staff are rotating trainings and education, we have several travelers, and then we have new trainees and new hires in the nursing staff. So what I did is we had a yearly refresher FCC (Family Centered Care) Orientation list. So, I actually do the one-on-one orientation with the trainees. It's just to go through the FCC Activities. Same goes with the early refresher for our nursing staff, the orientation list.

The other challenge is website content updating. So it (has to)

Figure 10. Press-Ganey Survey Results after Implementation and Optimization of MyChart Bedside



go through Marketing. So there's a delay in updating. We still have the old version on our website, and it's time to update that information.

“And in this, 6–7 years now, they haven't lost a single iPad”

This is the screenshot of our FCC Orientation checklist (Figure 11). It just covers the entire topic under the FCC umbrella, so we include the discharge teaching as a part of that. So all the nursing staff get their training.

So, the limitation of this project: I know it was done in the 20-bed community NICU. So, you may have a concern about taking this to the Children's Hospital, or an acute unit and all those things, but it's still possible they can once the baby is stable. You're not giving this information when they're on ECMO, but maybe when they come off of it...or when they are stable, you can still assign this education.

“It's not a replacement for direct bedside teaching. We still want bedside teaching to happen, so we included that as a part of the education as well.”

Finding champions to run the program, and if you already have the unit specific content, you can just translate or just convert them into the e-book or maybe it's a great medical student project, so they can, or you can, use the NPA Guidelines or whatever you want to use. So, you can just to change the cover and then use the e-book as a platform.

These (are) not available in other languages, so we have only English and Spanish, but you can request a fund, and you can translate the material on your own. And iPads—you can make sure if someone is willing to give a foundation funds or something, so you can add this: the MyChart website pilot project, or you can use the MyCare on Mom's phone as a proxy to access this education.

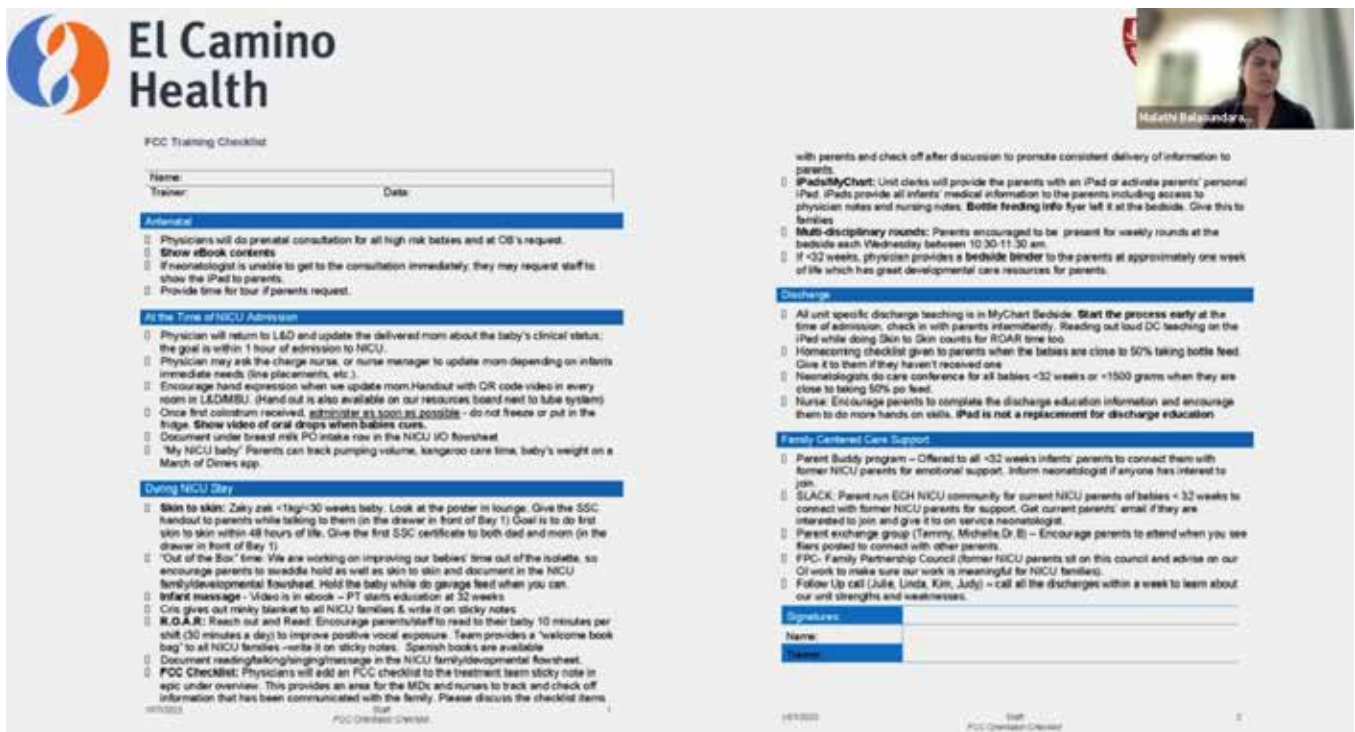
And what if the families are technologically challenged? It could be that everyone uses a smartphone, and it's easy to teach them, so they can overcome all those barriers.

It's not a replacement for direct bedside teaching. We still want bedside teaching to happen, so we included that as a part of the education as well.

“That was an e-book for discharge education. We have an e-book for diagnoses, and what it does is it pulls directly from the patient's problem list. So, if the patient has jaundice on their problem (list), it assigns them the handout for jaundice from the NICU PET website. It's also nice because it will assign it. It gives the handouts in all of the languages, so English, Spanish, and Chinese.”

We added the Spanish discharge education, as I mentioned. But you can go and then actually change the preferred language on your own. So that's why the instruction lists are here. You can

Figure 11. Family Centered Care (FCC)Orientation Checklist



do it under demographics. And once you do that, then you can delete all the English discharge education, and then you can just add the Spanish.

We added infant massage into this part of the discharge education, so they will get this information at 32 weeks. It's just a video and then a short description of benefits. And then families can review this information (about) it.

We added the new Breast Milk Pumping e-book because we changed our breast milk pumping company. So we just added that information.

This is my acknowledgment slide, and I think this is the end of our talk, so I just wanted to acknowledge everyone, and there's three references. That's it.

Caroline Toney-Noland: Great. Thank you so much for sharing it. There was a lot of good chatter happening in the chat. So someone asked, and Carrie started to answer, how much of the discharge teaching is child- as well as NICU unit-specific? Could these be used in different locations across the country or the world?

“We did want to show you our new website. So, if you go to FCCTaskforce.org, you'll be taken here. You've seen our padlet in the past. This is our brand new website. So, you can see under webinars all of their recordings and slide decks under resources. These are things that we've linked to or that presenters have linked to, or that things that you all have shared, that you have found really valuable as part of the listserve.”

Malathi Balasundaram: Oh, I think they could if they have their discharge education unique for their population, so they can just convert this into whatever format they want. They just start with the e-book. They can do it. They can just convert that in the format, or if they want it to go to MyChart, but they can have full access. They can. It's just they need content. Kari, just jump in if you have any thoughts about this.

Caroline Toney-Noland: ...to answer questions people with just wonderful questions. So keep them coming.

Caroline Toney-Noland: I think Betsy had mentioned this in Vincent's presentation about the importance of diagnosis-specific discharge education. It seems like you've automatically sent most of these to NICU families. Do you have videos or education that are more diagnosis-specific yet? Or is that perhaps in the next intervention?

Malathi Balasundaram: We actually have it. We don't, we don't cool the babies in our units, so we actually transfer them out. But if you are a cooling center, you can actually add a problem-specific discharge education. So we actually have three problem-specific information for the families using the NICU PET, the parent education material website. So, we actually put that information on our education area. So, for ROP and RDS—and there's one

more diagnosis—we actually have the parent and our chart link to that education section. Yes, so you can make it diagnosis-specific. That's easy to make if you have the material. Yes.

Kari McCallie: Yeah, we have just like you saw (for) the e-book. That was an e-book for discharge education. We have an e-book for diagnoses, and what it does is it pulls directly from the patient's problem list. So, if the patient has jaundice on their problem (list), it assigns them the handout for jaundice from the NICU PET website. It's also nice because it will assign it. It gives the handouts in all of the languages, so English, Spanish, and Chinese. So we don't even have to know what the parents preferred languages, necessarily. We can just go ahead and give them all the handouts.

Caroline Toney-Noland: That's fantastic. Thank you so much. Thank you, Malathi. I know that it's really encouraging to hear from someone, especially since you didn't have funding, and so to have this, I think, is a really wonderful opportunity that you asked for what you needed, and your family Partnership council was able to help you with that and your administration. So thank you so much for sharing that. In our last couple of minutes, if you have other questions, drop them in the chat and Malathi can respond. We did want to show you our new website. So, if you go to FCCTaskforce.org, you'll be taken here. You've seen our padlet in the past. This is our brand new website. So, you can see under webinars all of their recordings and slide decks under resources. These are things that we've linked to or that presenters have linked to, or that things that you all have shared, that you have found really valuable as part of the listserve. So please make sure you check that out. If you have any feedback, let us know. And then I want to just sort of show you a wonderful video that features some of our family partners, and we can have this to end our session today.

Video (Mother 1): I came into my premie experience already having gone through the trauma of infertility, and already having that, you know. At first, I thought it was guilt, but it was shame. It was I am not a good mother—I am not. I can't even get pregnant first of all. Now I can't stay pregnant. Now I don't know my babies.

Video (Mother 2): You know the trauma. It begins at delivery, and then it just continues throughout until you get to discharge. And then you're processing.

Video (NICU provider): As NICU providers, you know, to take on all that emotion, you know. You just be fried by the end of the day, right? But leave it absent and not addressing it does not allow for very good family-centered care, and I think a lot of it relies on communication.

Video (Mother 3): Personally, after I gave birth at 24 weeks, I felt such a guilt that I failed with the voice that I was like “Now they're in the NICU—that's where they belong. They're with the people who know how to treat them, and they don't need me.” I was lucky enough to be in a hospital that had a very strong family-centered care plan, who, before I could even verbalize that, said to me, “You're going to change diapers. You're going to take the temperature. You're going to feed them. You're going to hold them. They need you.” And I needed that—to know that, you know, I was supposed to be there.

Video (Mom 4): After that first month, one of the nurses— she said I was going to hold Avery today, and I haven't held Avery ever. And she said, “Oh, well, we're just going to make that happen today,” and I was like “Oh, I don't know if I can do that.” But she said, “We can do it. We're going to do it together.”

Video (Mom 5): Simply asking how my day was or having a conversation with me that has nothing to do with the NICU or

babies or monitors meant the world to me.

Video (Mom 6): In any kind of an ICU situation, your relationship with your partner is—that is the most fragile, because you're both going from the hardest time of your life, together with your child, that you both love more than anything.

Video (Mom 7): and I think another concrete thing that's super important that often gets left out that our family experienced is not having adequate discharge planning. You go from having this like super high intensity experience to sometimes from having had a one-on-one nurse to be with your child to just saying, "Okay, it's a big change to go home. If you have questions, this is where you call. You're going to have questions. That's okay. You know how to do this, and it's scary." So I think you know just kind of naming that for families involving people understand that you can be a good parent and be scared.

Video (NICU Provider): For NICU parents, you know, this is again a life altering event—that in the NICU, we are there because we have to because that's our kid. We are resilient, not because we want to, but because we have to. At the end of the day as NICU providers, you and your teams could go home. You could change jobs. You could do whatever you can. And again, not to say you don't care, because I know you absolutely care about your families and you and your kid. For us, that's our full life.

Caroline Toney-Noland: Thank you so much to all of the family partners who are part of that video for allowing us to share it to hopefully amplify your voice in this. We do have a couple of upcoming webinars. You'll be receiving calendar invites for these if you're part of the listserve.

We have some amazing content coming at you, and this is all a reflection of things that you have named, or that our family partners or health care partners have named, are absolutely vital to providing this work, and so thank you so much for all that you do. You know we've all been inspired to say, I think, by so many different wonderful options and resources. Start small. Pick something that you're going to work on in the next week and try to find a way to make it happen.

So thank you so much, and we will see you all in May.

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*Vincent Smith, MD, MPH
Division Chief of Newborn Medicine
Professor of Pediatrics
Boston Medical Center
Boston, Massachusetts, United States*



*Malathi Balasundaram, MD
Clinical Associate Professor
Stanford School of Medicine
FCC Committee Chair
El Camino Hospital
Mountain View, CA, United States*



*Colby Day Richardson
Associate Medical Director of Golisano Children's Hospital NICU
Assistant Professor of Pediatrics
Division of Neonatology
University of Rochester School of Medicine
Rochester, NY, United States*



Caroline Toney-Noland, MSc
Program Manager
CPQCC (California Perinatal Quality Care Collaborative)



Kari McCallie
Clinical Associate Professor of Pediatrics
Lucille Packard Children's Hospital
Stanford University
Palo Alto, CA, United States



Kristy Love
Director of Operations
National Perinatal Association

