

NeoQIC Family Engagement Quality Improvement Collaborative Webinar

Monday, February 10, 2020



Welcome and Introductions

Meg Parker, MD, MPH

Neonatologist at Boston Medical Center
Associate Chair of the Neonatal Quality Improvement
Collaborative of Massachusetts
Improvement Advisor from the Institute for Healthcare
Improvement



Neonatal Quality Improvement Collaborative of Massachusetts

Agenda

Time	Topic
2:00	Welcome, Introductions, and Roll Call
2:15	NeoQIC and Why Family Engagement Now?
2:25	Testimonial: The Importance of Family Engagement
2:35	Organizational Structure of the Collaborative
2:45	Next Steps
2:55	Questions?



Level 2 and 3 NICUs in Massachusetts

Committed or Interested in Joining

- Baystate Medical Center
- Boston Children's Hospital
- Beverly Hospital
- Beth Israel Deaconess Medical Center
- BIDMC - Plymouth
- Boston Medical Center
- Brigham and Women's Hospital
- Emerson Hospital
- Holy Family Hospital
- Lawrence Hospital
- Lowell General Hospital
- Massachusetts General Hospital
- Metrowest Medical Center
- Mt. Auburn Hospital
- Newton Wellesley Hospital
- Signature Healthcare Brockton Hospital
- South Shore Hospital
- St. Elizabeth's Hospital
- Southcoast- St. Luke's
- UMass Memorial
- Winchester Hospital

Haven't heard yet

- Good Samaritan Hospital
- Melrose Wakefield Hospital
- Metrowest Medical Center
- North Shore Medical Center
- St. Vincent Hospital
- Southcoast - Charlton Memorial
- Southcoast - Tobey Hospital
- Tufts Medical Center



What is NeoQIC?



Meg Parker, MD, MPH

NeoQIC: Neonatal Quality Improvement Collaborative of Massachusetts

PNQIN = Perinatal-Neonatal Quality Improvement Collaborative



NeoQIC History: www.neoqicma.org

- Neonatal quality improvement organization in Massachusetts
- Initiated in ~2006
- Started with level 3s, but now inclusive of level 2s and 1s.
- Since ~2007, the main focus has been the conduct of topic-specific perinatal quality collaboratives
- Virtual
- Intermittent grant funding



NeoQIC Collaboratives

Topic	Year	Care Level	Data Type
CLABSI Reduction <i>Munish Gupta</i>	2007-	Level 3s	Aggregate VON, NHSN, practice surveys
NAS <i>Munish Gupta</i>	2013-current	Level 1,2,3s	VON audits (2013-15), individual-level chart abstraction, practice surveys, staff surveys since 2017
Human Milk <i>Meg Parker</i>	2015-17	Level 3s	Individual-level chart abstraction
Safe Sleep <i>Susan Hwang</i>	2015-19	Level 2,3s	Aggregate “crib” audits
Respiratory Care <i>Helen Healy</i>	2019-current	Level 3s	Aggregate VON and practice surveys
Family Engagement <i>Meg Parker</i>	2020-2022	Level 2s, 3s	Individual-level chart abstraction, *parent-reported*



Why Family Engagement? Why Now?

Meg Parker, MD, MPH



Neonatal Quality Improvement Collaborative of Massachusetts

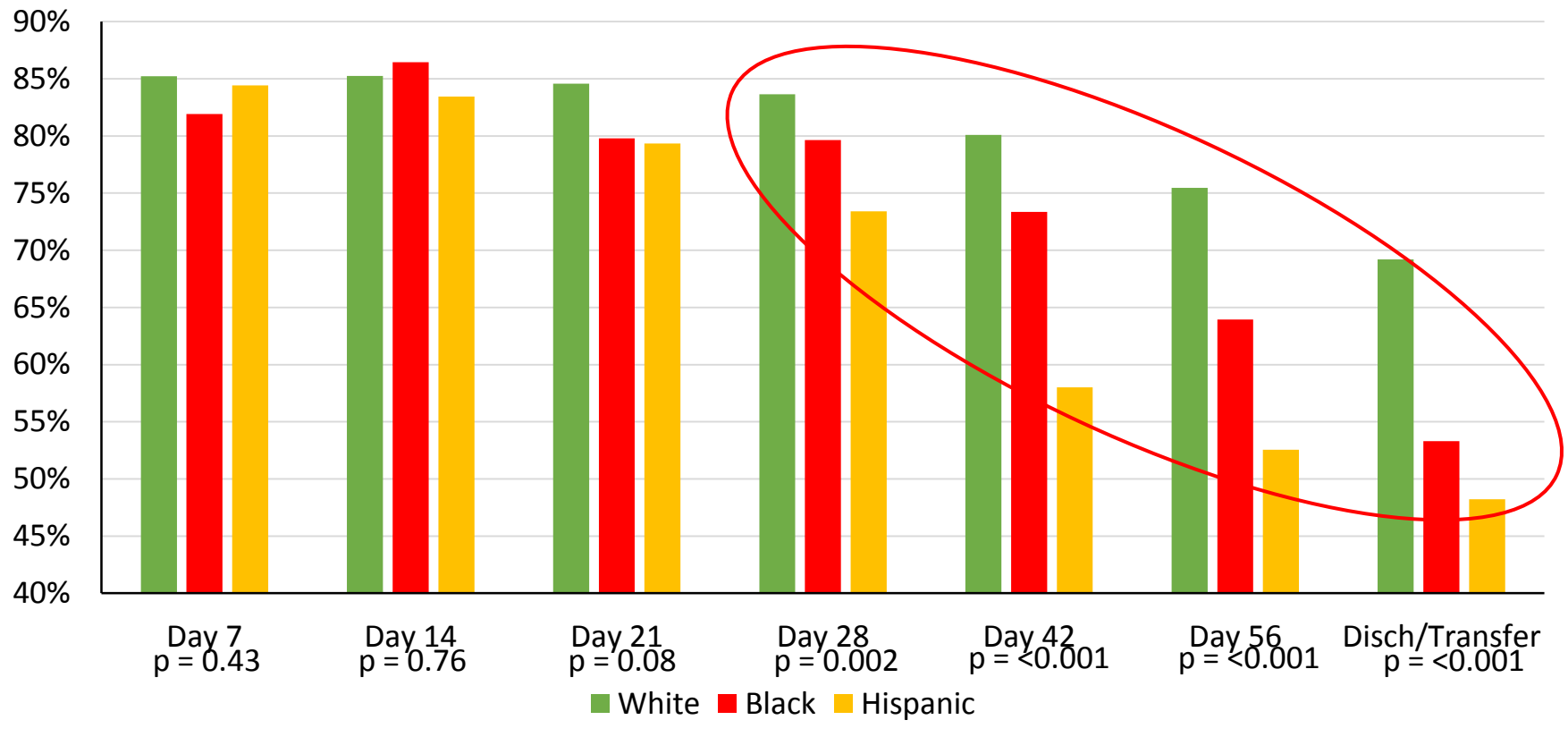
Two Main Reasons for a NeoQIC Family Engagement Collaborative

- 1) This work is a natural segue from the human milk and safe sleep projects
- 2) Increasing evidence on the health benefits for infants and mental health of parents when they are integrated into NICU care



Human Milk Collaborative: Data Collection on >2,200 mother-VLBW Infant Pairs from all 10 Level 3 NICUs

Any Mother's Milk According to Day of Hospitalization



Racial/ethnic disparities emerged after day 21

Family Engagement Practices

- Major variation in:
 - Sibling and non-sibling child visitation
 - Presence of family support meetings
 - (No hospital offered this routinely in Spanish)
 - Presence of paid family support specialists
 - Meals for breastfeeding or non-breastfeeding mothers
 - Parking costs
 - Interpreter services



Qualitative Interviews with non-Hispanic black and Hispanic mothers

“I Felt Like I Was a Part of Trying to Keep My Baby Alive”: Perspectives of Hispanic and Non-Hispanic Black Mothers in Providing Milk for Their Very Preterm Infants

Margaret G. Parker, Adriana M. Lopera, Nikita S. Kalluri, and Caroline J. Kistin

- Hospital providers are an important source of support when:
 - Sufficient time is spent
 - Interactions perceived as unbiased
 - Communication in primary language
- Logistical challenges to mother-infant separation are enormous
 - Transportation



Take Home Message

- We felt that to further tackle reduction in racial/ethnic disparities in NICU breastfeeding, we needed to focus more broadly on family engagement practices

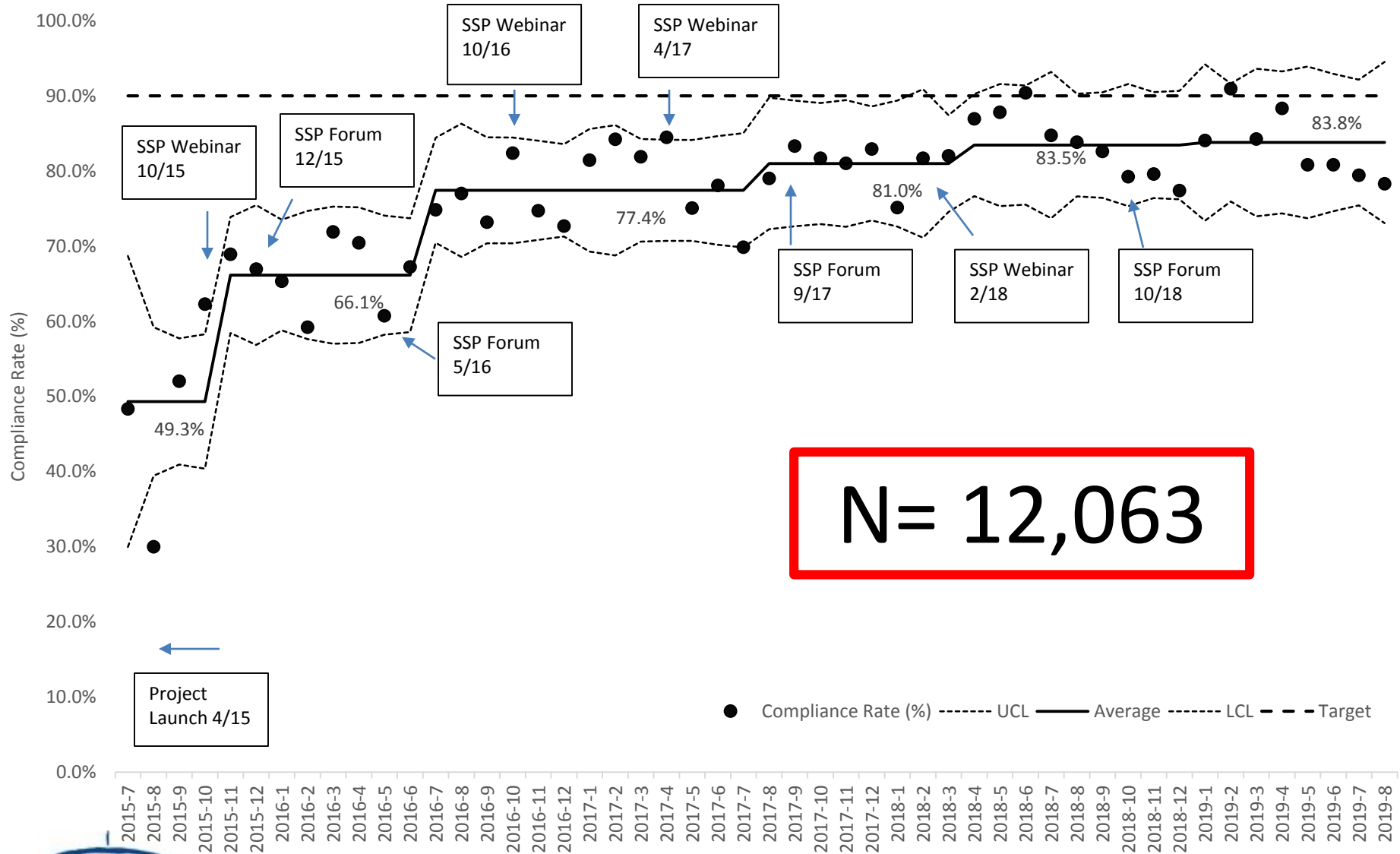
Safe Sleep Collaborative- led by Dr. Susan Hwang

- Initiated based on the need to standardize the infant sleep environment in hospital settings as well as parent education of safe sleep practices
- **Primary aim:** increase the use of safe sleep practices (SSP) among high risk infants discharged from MA NICUs.



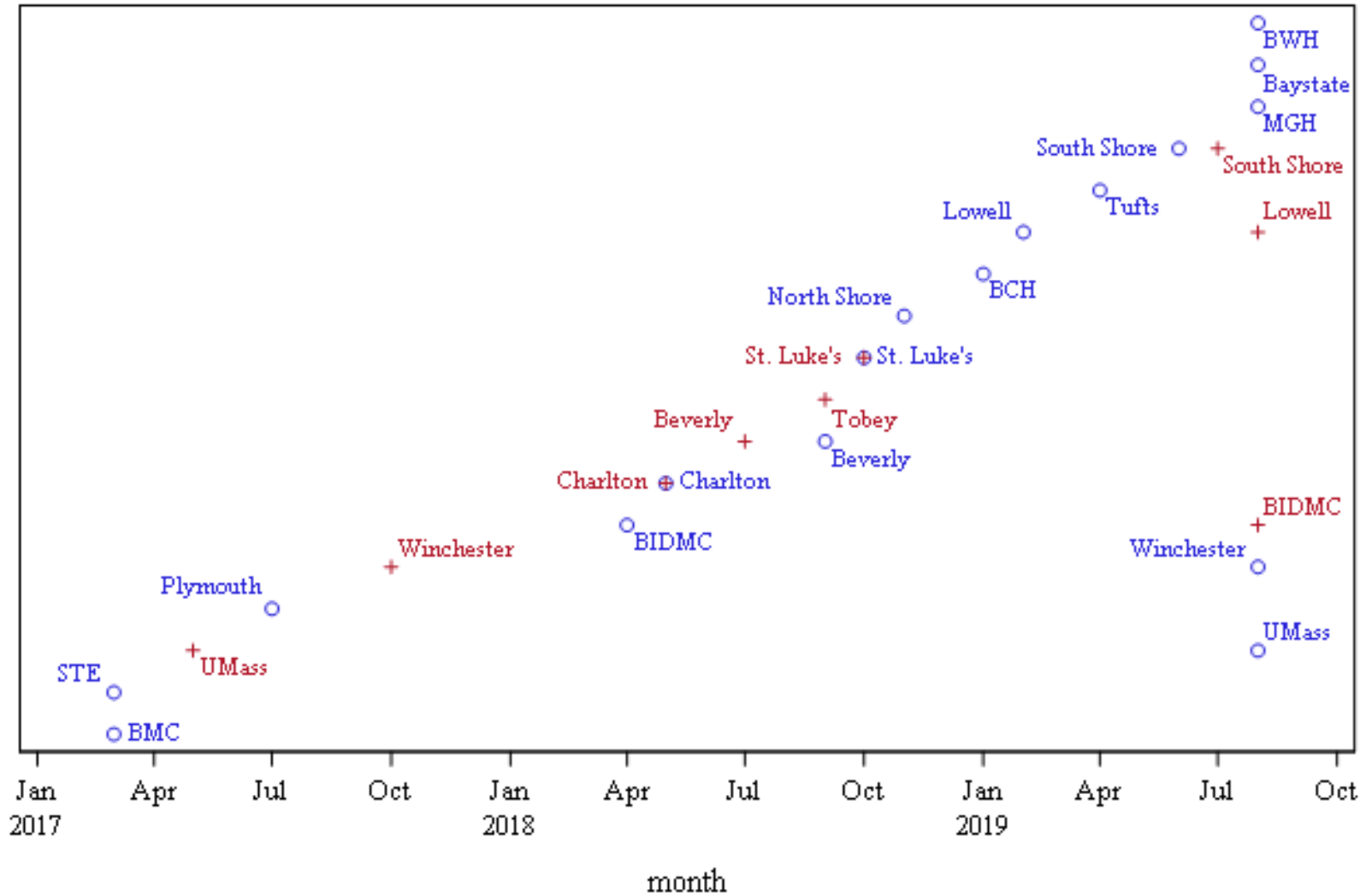
SSP Compliance Over Time (NICU)

Process Changes Nov 15, Jul 16, Aug 17, Apr 18, Jan 19



N= 12,063

Most Recent Audit Month by Hospital



Blue=NICU/ Red=NBN

Take Home Messages


- Safe sleep positioning after discharge is crucial for reduction in sudden unexpected infant death (SUID)
- Strategies to assist families of preterm infants in the NICU in safe sleep practices include both modeling of safe sleep behaviors AND family training/education
- Since family engagement in care is needed for both of the above, a QI collaborative on family engagement is the natural next step

What is “Family Engagement” anyway?

- Great question!

AHRQ:

A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the healthcare team and collaborative partnerships providers and provider organizations




Family centered care
Family integrated care
Families involved in care
Family preparedness
And more!

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And more!

Evidence to Support Family Engagement in NICU Care

- O'Brien, et al. Lancet Child and Adolescent Health, 2018
- Cluster randomized trial of “Family Integrated Care” (FiCare) at 26 NICUs in Canada, Australia, and New Zealand
- Families in the intervention sites were heavily involved in the day-to-day care of their infants and received substantial training by staff
- Benefits in growth, family mental health, and breastfeeding

Evidence to Support Family Engagement in Care

- Family communication-
 - Satisfaction, feeling informed
- Family social support- improvements in maternal mental health
 - Screening for post-partum depression
 - Stress and anxiety
- Participation in caregiving, such as skin-to-skin and breastfeeding
 - Skin-to-skin: physiologic stability, reduce painful stimuli, bonding, milk production
 - Breastfeeding: infections, neurodevelopment
- Discharge planning/preparedness
 - Post-discharge adherence to recommended practices

A Third Practical reason...

- We have the funds now!
- Kellogg Foundation (PI Parker)
 - 2019-2023
- Two goals
 - Support Mississippi and New Orleans in conducting statewide perinatal improvement collaboratives in provision of mother's milk in level 3 NICUs
 - Conduct a MA collaborative to pilot interventions in family engagement



W.K.
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Neonatal Quality Improvement Collaborative of Massachusetts

Family Engagement Testimonial

Molly Fraust Wylie
NICU Family Program Manager
Beth Israel Deaconess Medical Center



Neonatal Quality Improvement Collaborative of Massachusetts



Hello!

I am Molly Fraust Wylie

Former NICU Parent, now NICU Advocate

You can find me at mfwylie@bidmc.harvard.edu

A picture is worth a thousand words

This is the first time I met my first son, Max. He was born at 32 weeks (after 6 weeks of bed rest) and was on the BIDMC NICU.





Then...

Now...

He's 7, a first grader!
Healthy, happy, and a big
brother to Renzo, who is
3. Our experience on the
NICU changed my life and
now I work with other
NICU Families like ours.



“

My experience on the NICU was full of fear, loneliness, confusion, isolation, anxiety, self-doubt... and it was a relatively 'good' NICU stay.



I imagined the alarms when I was at home, away from max.

I struggled to care for myself and accept offers of help.

I didn't feel confident asking **questions-** I **didn't feel like a parent-** I felt like a **visitor.**

— • • —

When we finally got home, I sought out other nicu parents. I needed community. I needed people who understood why we didn't leave our house in the winter and had hand sanitizer everywhere. I needed people who understood my inflexibility with my pumping schedule.

Silver Linings

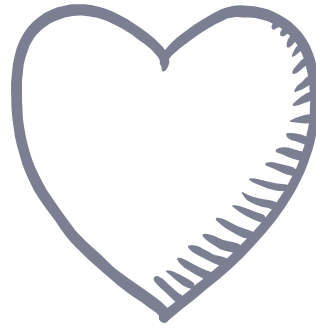
- I went back to work for about a year and quickly realized I could no longer focus on my work. I was lucky enough to be able to start therapy. I realized I wanted to make changes and advocate for NICU families in a more meaningful way.
- I was doing a lot of community building with local NICU Moms, creating support groups online and in person, delivering care packages to NICU families, and reaching out to try and find a way to connect with other NICU Families.
- I connected with a woman who had been in a similar role to mine and stayed close with the social workers on my unit- I got lucky-I was able to turn my passion into a career.

“

In March of 2015, 2 years after Max was born, I attended the Graven's Conference for my first week of work in my new role as NICU Family Program Manager- that was first introduction to Family Centered and Family Integrated Care.

It was life changing.

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My Paid role as A NICU Family Program Manager

The Klarman Family NICU Philosophy of Care

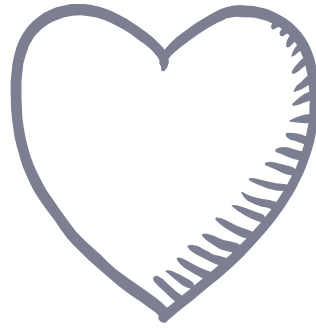
Welcome to the Klarman Family NICU.

Your Family is part of the care team.

Here we:

value families and all the love and knowledge they bring.

support the uniqueness of all families and cultures.



NICU
C.A.R.E.S



**Compassion
Advocacy
Respect
Empathy
Support**

“



— • —



This program develops and coordinates social and informational programs to help families during their baby's hospitalization.



In addition, the NICU C.A.R.E.S. program helps families connect with other parents during and after their hospital stay

Involving Parents During & After Their Stay

- Parents at Rounds
- Parents on NICU Subcommittees
- Craft Nights for Alumni
- Online Facebook Community for Graduate Parents
- Let's Get Together Today
- FICARE
- VON
- MyNICU
- Music Therapy with Berklee College of Music
- LTL Learners Program
- How Can We Help Document
- Alumni Events
- Sibling Support
- Meditation & Relaxation for parents

Strong Community

- Daily Bedside Support
- March of Dimes March for Babies
- NICU Eve of Thanks
- Project Sweet Peas Preemie Plunge
- NICU Craft Nights
- NICU Reunions
- Memorial Service
- Holiday Events & Meals



Family Centered Care

NICU Family Support Here's How You Can Help Us

Dear _____

We appreciate our friends and family asking "What can I do to help?" It can be hard in the moment to think of ways others can help out even though we need it! Here are some things that would be helpful:

Meals

- ☐ Create a schedule of meals so that dinners are taken care of. This might even include using an online resource for help. (mealtrain.com, takethemameal.com, lotsahelpinghands.com, carecalendar.com, mealbaby.com)
- ☐ Coordinate preparation of several frozen meals or casseroles in servings for one or two for easy storage and transport.
- ☐ Ask if you would like me to stop by the hospital for a "cheer me up" lunch, snack, or coffee break.
- ☐ Bake a batch of cookies, or another favorite pick me up food.

Helping Hands

- ☐ Offer to watch siblings so parents can spend time in the NICU, or even coordinate a schedule of willing friends and family.
- ☐ Coordinate play dates for siblings.
- ☐ Offer to help drive children to/from childcare.
- ☐ Walk pets, feed them, or even keep them overnight. Change litter boxes. Organize pet boarding or trips to the veterinarian.
- ☐ Water indoor/outdoor plants, especially in the summer.

Organization

- ☐ Wash and fold parent, baby, and/or sibling laundry, or take it to a laundry service to be done.
- ☐ Pick-up, organize, or even clean the house.
- ☐ Provide and organize a cleaning service to clean house.
- ☐ Offer to act as main contact for information to be shared.
- ☐ Purchase extra cords & chargers for my wireless devices to leave at the hospital bedside.
- ☐ Organize my refrigerator and freezer
- ☐ Pick up and organize my mail by categorizing it in piles: "junk," bills, cards, etc.
- ☐ Run to a store with a list I provide.

Encouragement

- ☐ Provide a daily contact via text or email with a positive "thought for the day." This might include coordinating messages written by several others.

Today I am 56 days old, which is 33 weeks and 4 days adjusted gestational age. I weigh 2000 grams / 4lbs 7oz., which is down 10 grams from yesterday, and 1160 grams more than my birth weight of 840 grams. Remember that babies in the NICU sometimes do lose weight. My care team, including the NICU Nutritionist, are watching my weight closely and making adjustments as they are needed.

Being held yesterday was wonderful!

All of my feedings were by gavage tube. I really appreciate every drop of breast milk you are giving me! Over the day, I had 6 stool(s) and 6 wet diaper(s).

I had 2 episode(s) of apnea, brady, or desaturation. You can get more details from my team. Yesterday, I spent 24 hours on CPAP.

My medications yesterday have included: Iron Sulfate; Caffeine citrate; Vitamin E; Vitamin D (Cholecalciferol).

The people who cared for me yesterday included: Eileen - RN; Christine - RN; Joyce Chan - NNP; Brianna Connolly - Respiratory; Eric Rodriguez - Respiratory; John Zupancic - Attending MD.
Please feel free to ask them your questions at any time.

Thanks for all you do for me.



Family Centered Care



What can I do today?





- Learn how to be a part of your baby's care team
- Access a wealth of information and clinical updates on your baby
- Receive an introduction to the NICU and what to expect
- Take a guided tour
- Receive daily updates on your baby via CribNews
- Track your baby's milestones with a private journal
- Receive lactation support

- Receive NICU Family support & resources
- Access the NICU Educational Video Library
- Familiarize yourself with NICU equipment and language
- Request family meetings
- Learn tips to feed your baby
- Prepare for discharge
- Share photos with family
- View pictures of your baby's care team
- ...And so much more!

Music Therapy



In a partnership with Berklee, our MT's are board certified and trained in research based musical interventions. MT helps target areas such as feeding, sucking, waking, irritability, crying, and of course, parent-infant bonding :)

Research Projects



Collaborative research projects including FICARE, VON, and an ongoing project around NICU care for LGBTQ/non-traditional families

Partnerships

Development Opportunities

Working with the Development team on ongoing opportunities for grateful patients to give back to the NICU via the Family Program

NICU Staff

Partnering with NICU staff to learn more about improving patient care, educate on the family experience, and working together in a stressful environment

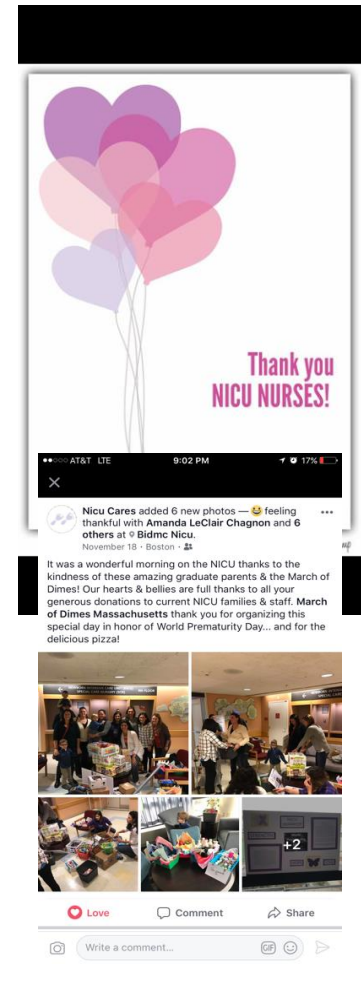
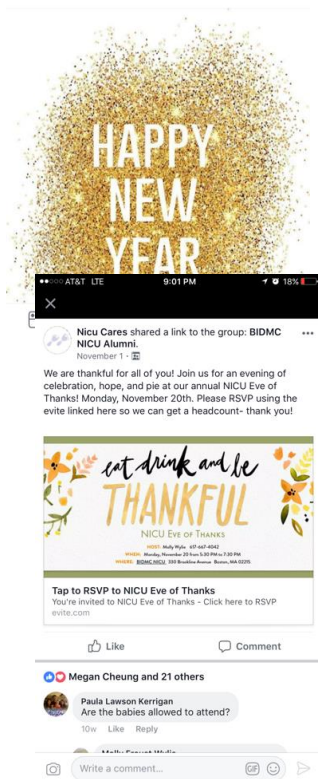
NICU Families

NICU Families want to give back in a variety of meaningful ways. I work with parents of NICU babies to offer multiple ways to stay involved with the NICU and give back

Appreciate!



Express gratitude for our NICU Graduate alumni community and NICU Staff



“

Get & Give Feedback

Focus Groups
Bedside Survey
with NICU Families
Seek Input

Piloting ideas
Crowdsource
Feedback through
Alumni Community
Peer Review
Documents

— • —



THANKS!

Any Questions?

You can find me at mfwylie@bidmc.harvard.edu

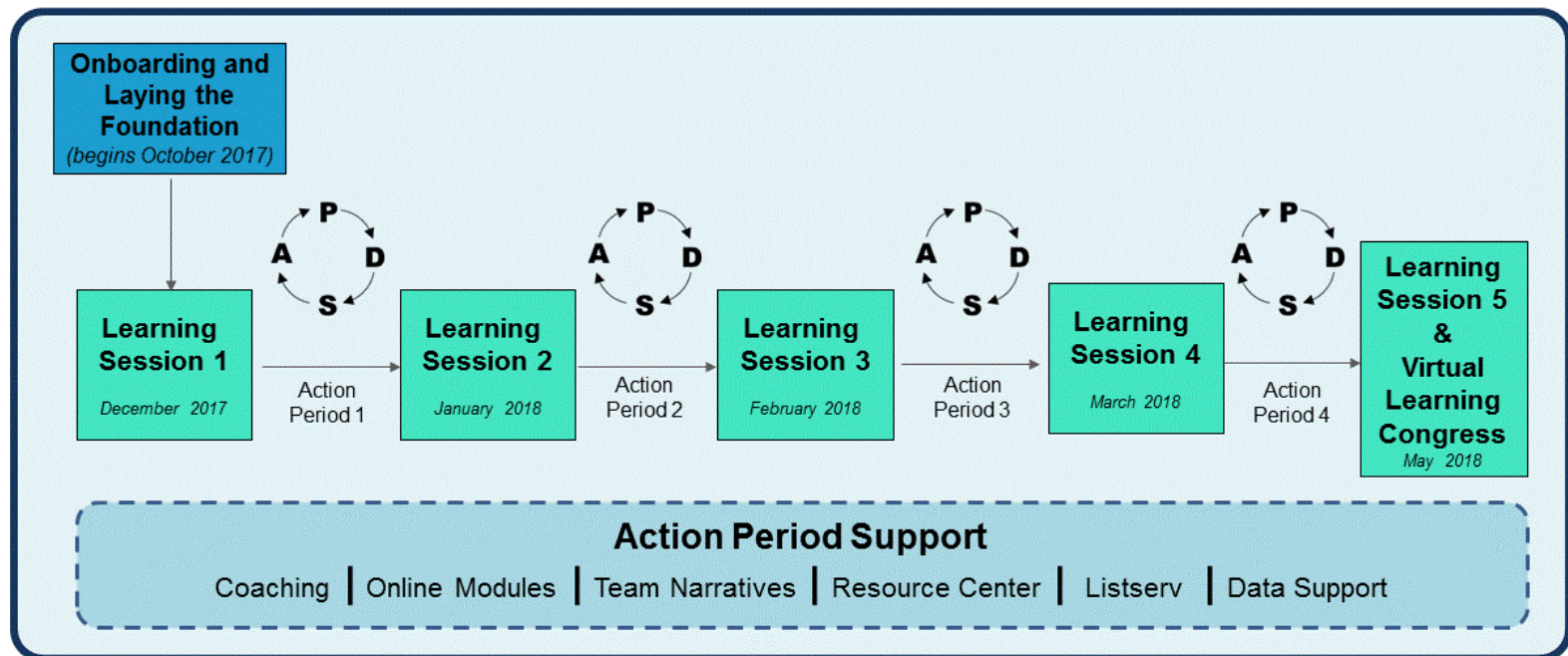
Some Nuts and Bolts of the Collaborative



Meg Parker, MD, MPH

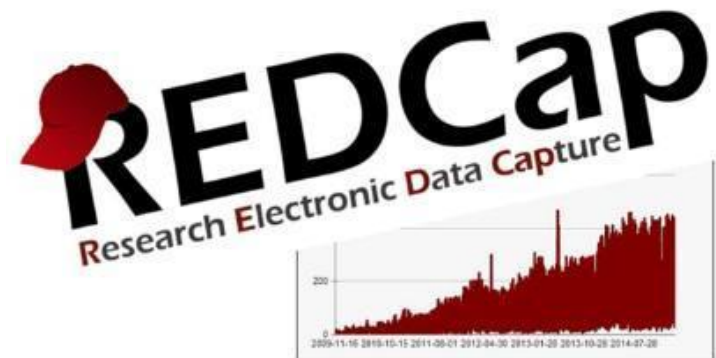
Pillars of Perinatal Quality Improvement Projects

- Institute of Healthcare Improvement Breakthrough Series Model of Improvement



Cornerstones of Perinatal Quality Collaboratives: #1 Data Infrastructure

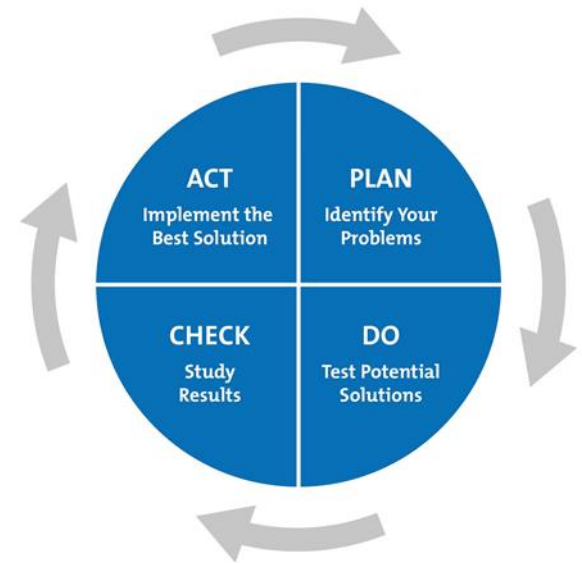
- We decide collaboratively as a group on a key driver diagram and set of metrics
- Teams submit data on core set of metrics
- We examine our data regularly throughout the collaborative to examine our progress
- We share our data openly to learn



Cornerstones of Perinatal Quality Collaboratives: #2 QI Education

- Important goal for NeoQIC leadership
- Critical for sustainment
- Delivered with relevant examples
- Short and high-yield, interactive
- In-person meetings, webinars, site visits, phone calls, monthly homework feedback
- QI educators on our Family Engagement leadership team
 - Meg Parker, Munish Gupta, Wendy Timpson

Figure 1: The Plan-Do-Check-Act Cycle



Cornerstones to Perinatal Quality Collaboratives: #3 Team Work

- Multi-disciplinary teams with parent members
- Goal for monthly meetings
- Conduct Plan-Do-Study-Act (PDSA) cycles with help from the leadership team



Cornerstones to Perinatal Quality Improvement: #4 Time Sharing

- Twice annual in-person conferences
- Quarterly webinars
- Enhances learning and momentum



Leadership Team

- Meg Parker- Project Lead, physician, Boston Medical Center
- Molly Wylie- family support manager, BIDMC
- Wendy Timpson- physician, BIDMC, Leader of VON transitions of care project
- Zuzanna Kubicka- physician, SSH, QI expert and creator of the SSH FiCare app!
- Aviel Peaceman- project manager

- Susan Hwang- from Colorado, physician, leader of the SS project
- Munish Gupta- Chair of NeoQIC

- *If you are interesting in joining- please let us know!!!*

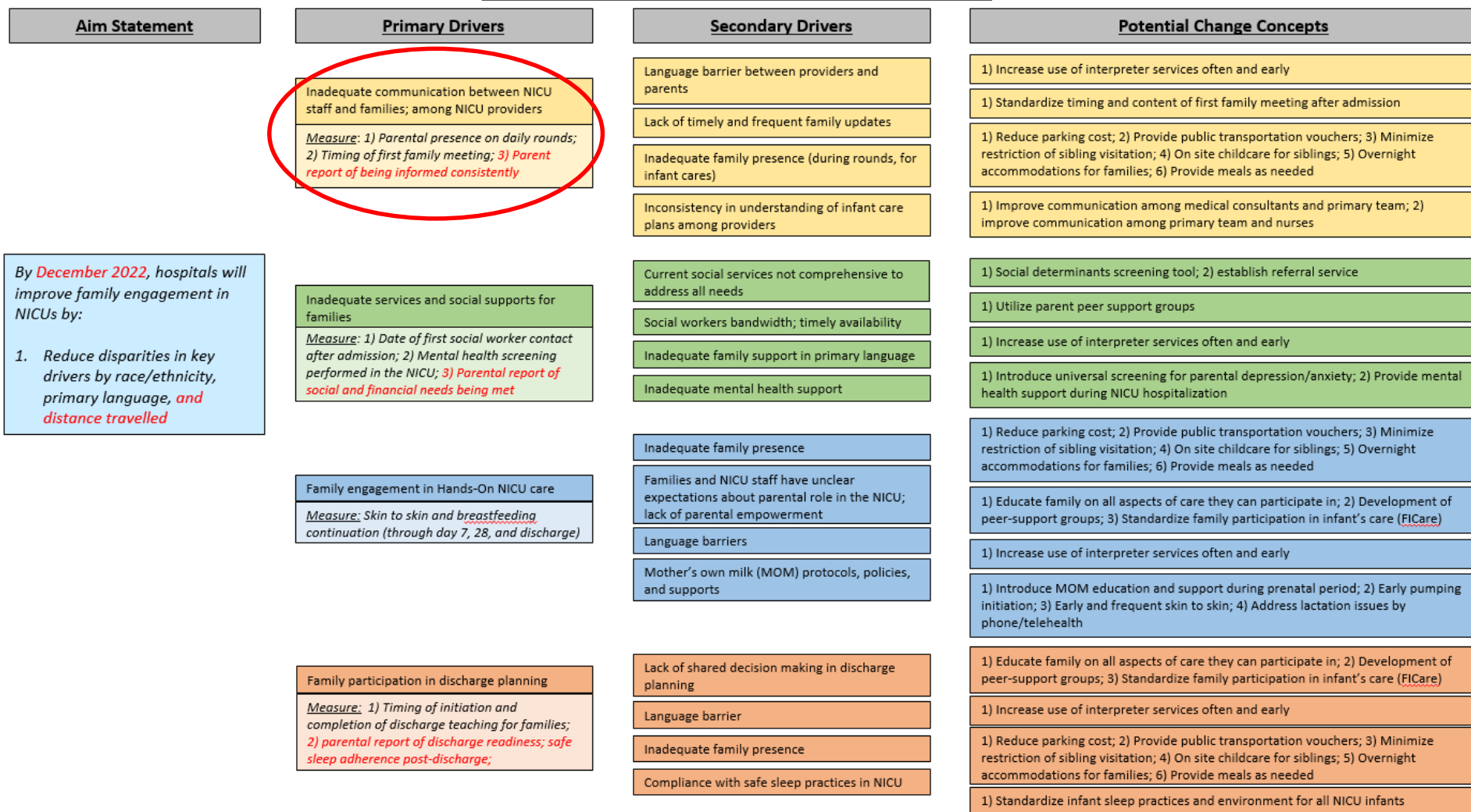


Key Driver Diagram

- Broad array of topics
- We wanted to give teams flexibility to focus on any particular driver that is important to them

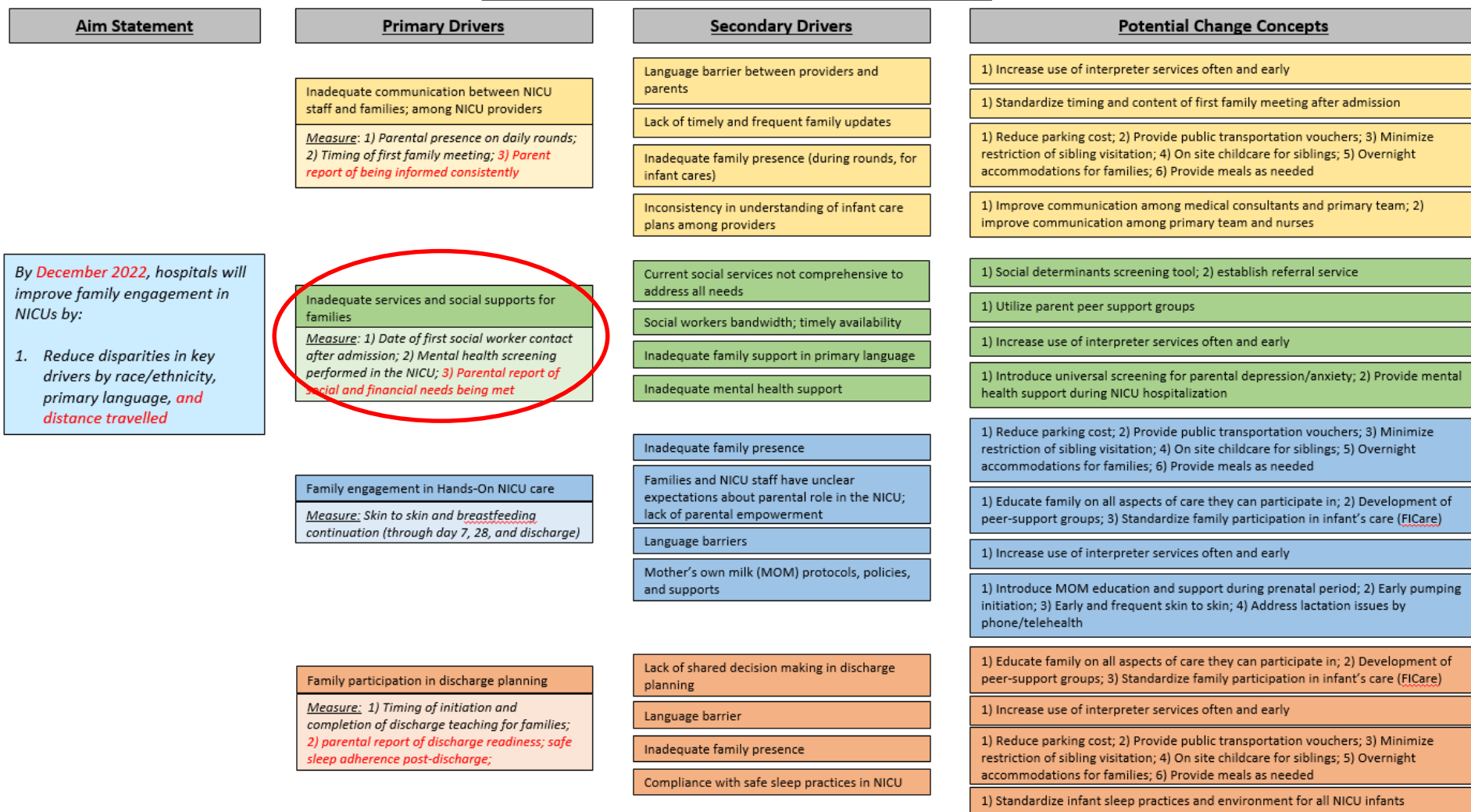
Key Driver Diagram- Family Engagement

Family Engagement QIC Key Driver Diagram



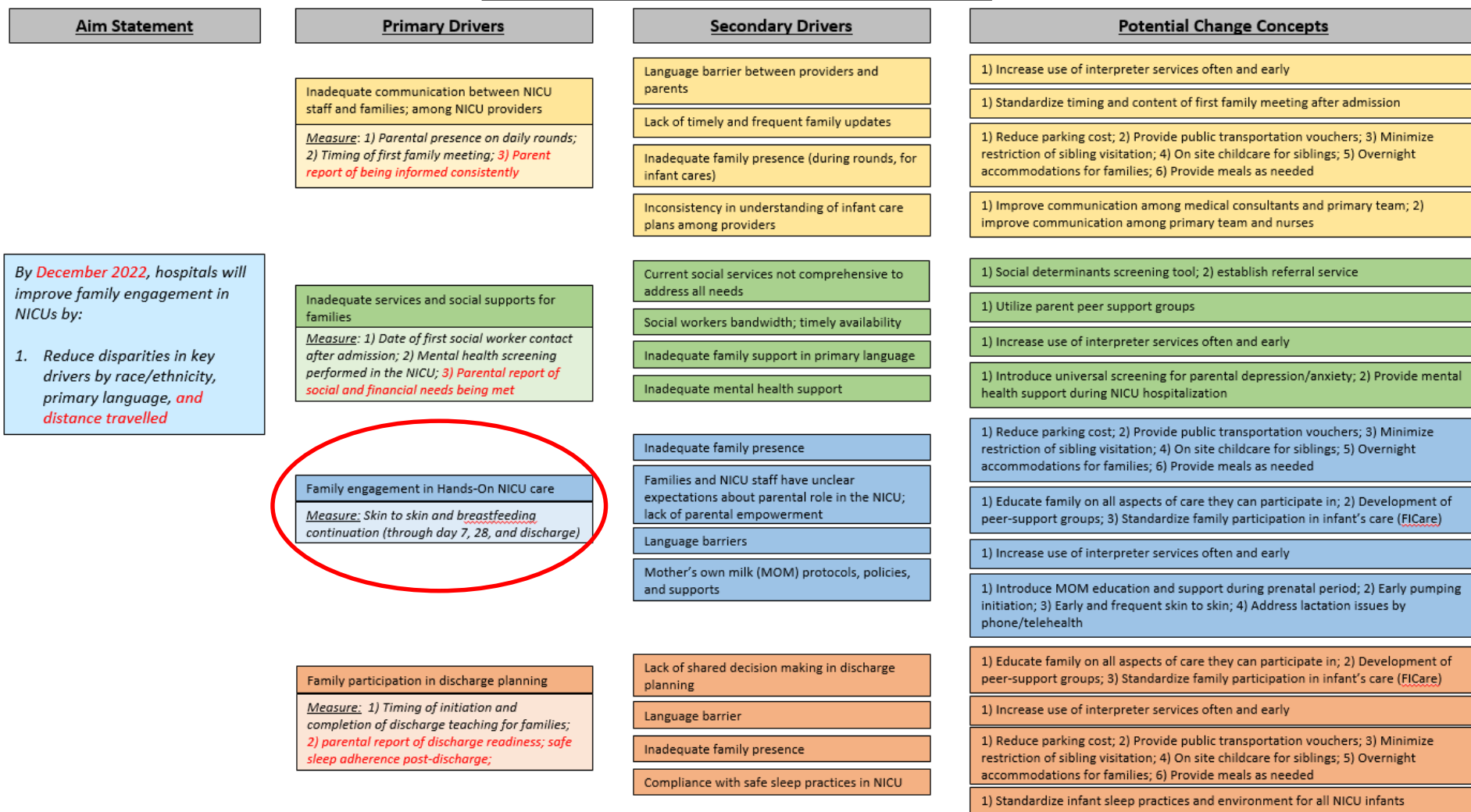
Key Driver Diagram- Family Engagement

Family Engagement QIC Key Driver Diagram



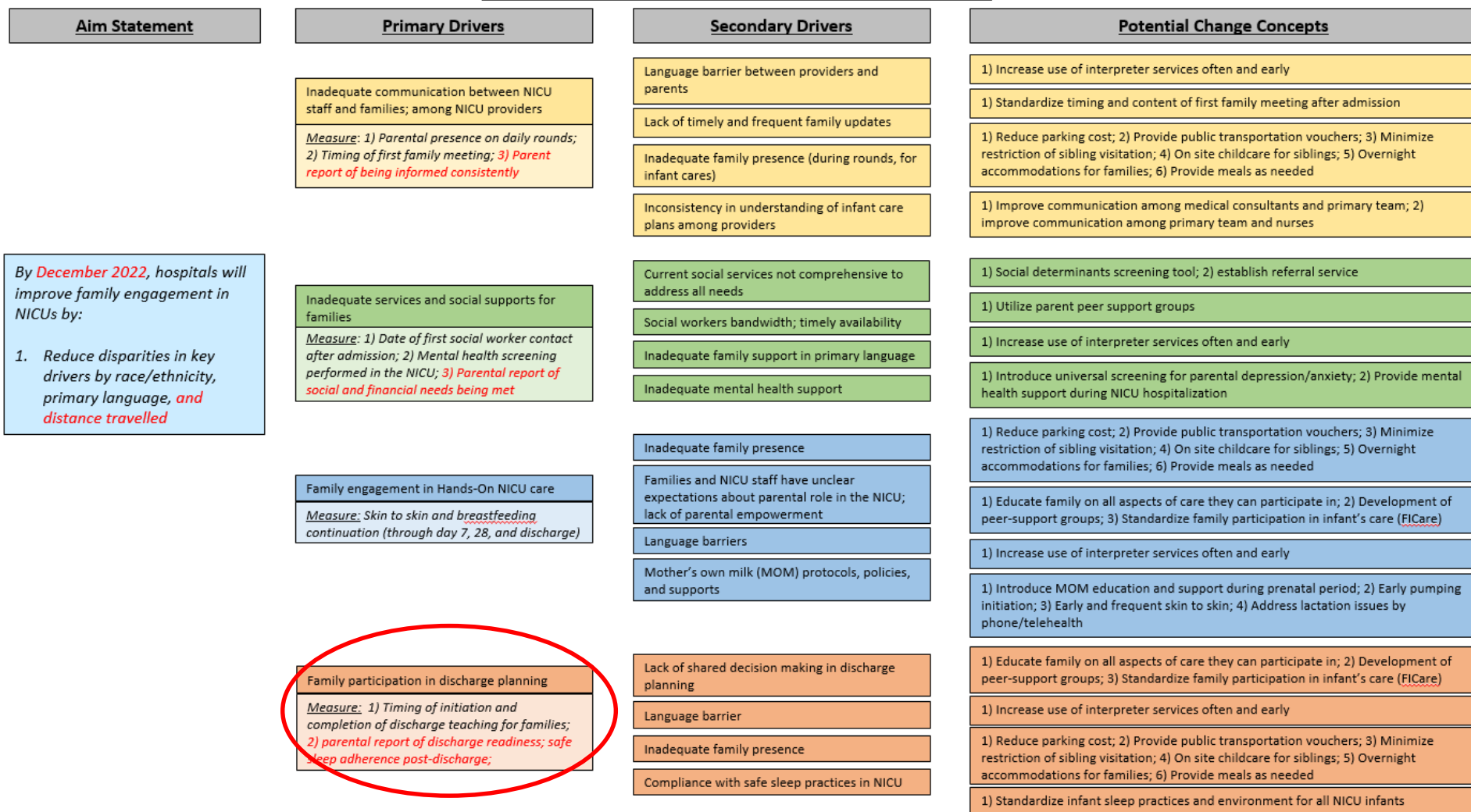
Key Driver Diagram- Family Engagement

Family Engagement QIC Key Driver Diagram



Key Driver Diagram- Family Engagement

Family Engagement QIC Key Driver Diagram



Key Driver Diagram- Family Engagement

Family Engagement QIC Key Driver Diagram

Aim Statement

By **December 2022**, hospitals will improve family engagement in NICUs by:

1. Reduce disparities in key drivers by race/ethnicity, primary language, and distance travelled

Primary Drivers

Inadequate communication between NICU staff and families; among NICU providers

Measure: 1) Parental presence on daily rounds; 2) Timing of first family meeting; 3) Parent report of being informed consistently

Inadequate services and social supports for families

Measure: 1) Date of first social worker contact after admission; 2) Mental health screening performed in the NICU; 3) Parental report of social and financial needs being met

Family engagement in Hands-On NICU care

Measure: Skin to skin and breastfeeding continuation (through day 7, 28, and discharge)

Family participation in discharge planning

Measure: 1) Timing of initiation and completion of discharge teaching for families; 2) parental report of discharge readiness; safe sleep adherence post-discharge;

Secondary Drivers

Language barrier between providers and parents

Lack of timely and frequent family updates

Inadequate family presence (during rounds, for infant cares)

Inconsistency in understanding of infant care plans among providers

Current social services not comprehensive to address all needs

Social workers bandwidth; timely availability

Inadequate family support in primary language

Inadequate mental health support

Inadequate family presence

Families and NICU staff have unclear expectations about parental role in the NICU; lack of parental empowerment

Language barriers

Mother's own milk (MOM) protocols, policies, and supports

Lack of shared decision making in discharge planning

Language barrier

Inadequate family presence

Compliance with safe sleep practices in NICU

Potential Change Concepts

1) Increase use of interpreter services often and early

1) Standardize timing and content of first family meeting after admission

1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed

1) Improve communication among medical consultants and primary team; 2) improve communication among primary team and nurses

1) Social determinants screening tool; 2) establish referral service

1) Utilize parent peer support groups

1) Increase use of interpreter services often and early

1) Introduce universal screening for parental depression/anxiety; 2) Provide mental health support during NICU hospitalization

1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed

1) Educate family on all aspects of care they can participate in; 2) Development of peer-support groups; 3) Standardize family participation in infant's care (FICare)

1) Increase use of interpreter services often and early

1) Introduce MOM education and support during prenatal period; 2) Early pumping initiation; 3) Early and frequent skin to skin; 4) Address lactation issues by phone/telehealth

1) Educate family on all aspects of care they can participate in; 2) Development of peer-support groups; 3) Standardize family participation in infant's care (FICare)

1) Increase use of interpreter services often and early

1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed

1) Standardize infant sleep practices and environment for all NICU infants



Data Collection for this Project

- Individual-level chart abstracted measures
 - Similar to other NeoQIC projects
 - Data use agreement required
 - Sometimes IRB
 - We are considering where to “house” data now
- Parent-reported measures
 - Novel, but we think highly informative for this project
 - Data use agreement
 - Likely IRB and possibly consent by parents to survey them
 - We are considering where to “house” data now



Data Metrics

- Tricky!
- Unlike other topics in NeoQIC, family engagement measures are not well-defined
- We have spent a lot of time considering which data metrics achieve the following:
 - Useful
 - Available in existing EMRs
 - Not too burdensome for teams
 - Overlap with other metrics we collect
- We will probably get down to a few good possibilities for all of our key drivers and vote at our in-person conference



Combining Efforts with Other States

- Colorado Perinatal Quality Improvement Collaborative will be working on this same topic at the same time
- Share key driver diagram and data metrics as much as possible



Project Timeline

	2020				2021				2022			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Develop Data Metrics/Key Driver Diagram	X											
Pilot Data Metrics		X										
Data Use Agreements/IRBs	X	X	X									
Form multi-disciplinary hospital teams	X											
Webinars	X	X	X	X	X	X	X	X	X	X	X	X
In-person meetings	X		X		X		X		X		X	
Data collection and reporting			X	X	X	X	X	X	X	X	X	X
Interventions as PDSA cycles			X	X	X	X	X	X	X	X	X	X

Next Steps for Teams



Building Your Team

- Start to recruit your multi-disciplinary team in your NICU or special care nursery!!!
- Send Aviel (aviel.peaceman@bmc.org) the contact info of all participating team members so that we can add everyone to our contact list
- Recruit family members to your team
 - We will have stipends available for family member participants!



Baseline Practice Survey

- We will send the practice survey to team leads for completion
- Practice survey results will be shared at the in person meeting on March 17th
- Important for understanding baseline variation in family engagement practices



In Person Meeting- Register Now!

- Our first in person meeting will take place on Tuesday, March 17th at the Conference Center at Waltham Woods
- Registration link was sent out yesterday to the current distribution list and we will send out another reminder after today's call
 - If you didn't receive it, contact aviel.peaceman@bmc.org
- Keynote Speaker is **Lelis Vernon**:
 - Faculty Family Leader - Micropreemie Care Team II - Vermont Oxford Network
 - Clinical Advisor, QI Measures - American Academy of Pediatrics, Section of Neonatal Perinatal Medicine
 - Advisory Board Member - Dep. of Perinatal and Neonatal Medicine Research Lab - Stanford University
 - Clinical Guidelines Committee - American College of Physicians
 - Executive Committee - National Network of Perinatal Quality Collaboratives - CDC / QI Family Leader - Florida PQC
 - Leadership Team . - NEC Society / PCORI



Thank you!

Questions?

We look forward to working with all of you on this journey to improve family engagement with NICU families across MA

www.neoqicma.org



Neonatal Quality Improvement Collaborative of Massachusetts