

NeoQIC Family Engagement Quality Improvement Collaborative Webinar

September 16, 2020
Day 2



Welcome and Roll Call

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

Welcome!

Please chat your name and hospital into the chat box

 **Zoom Group Chat**

From Me to [Everyone](#):
Aviel Peaceman, Boston Medical Center

To: Everyone ▼ ...

Type message here...

Agenda- Day 2

Time	Topic
1:00	Welcome, Introductions, and Roll Call
1:10	Parent Testimonial
1:25	Massachusetts Department of Public Health: Approaches to Family Engagement in MA
1:55	Regulatory Updates
2:15	Introduction to Plan-Do-Study-Act (PDSA) Cycles
2:45	Wrap Up and Next Steps



One word to describe how you're feeling about this work:



Parent Testimonial

Jennifer Gilmete

NICU Parent



Neonatal Quality Improvement Collaborative of Massachusetts

Massachusetts Department of Public Health: Approaches to Family Engagement in MA

Roxanne Hoke-Chandler, MS

Statewide Family Engagement & Collaboration Coordinator, Early
Intervention

Massachusetts Department of Public Health



Neonatal Quality Improvement Collaborative of Massachusetts



150 YEARS
OF ADVANCING
**PUBLIC
HEALTH**

Massachusetts Department of Public Health


FAMILY ENGAGEMENT

NeoQIC Family Engagement Collaborative

September 15, 2020

Roxanne Hoke-Chandler

EIPLP Family Engagement & Collaboration Coordinator



Prenatal through Young Adulthood Family Engagement Framework



Family Engagement Framework

- A three year collaboration among 11 state agencies
- 500+ stakeholders including families, providers, and practitioners
- Led by a planning team – DESE, EEC, DPH
- Built from “the ground up” reflection of the community, their experiences & needs
- Strong focus on Racial Equity with input from Mid-Atlantic Equity Center

Framework Guiding Principles

Guiding Principle

1

Each family is unique, and all families represent diverse structures. Family engagement includes genuine efforts to understand each family's beliefs, values, priorities, goals and aspirations. Families and practitioners make joint decisions and share responsibility in a successful partnership.

Guiding Principle

2

Diversity is expressed and experienced at multiple levels such as (but not limited to) race, religion, ethnicity, culture, language, family structures, ability, sexual orientation, socio-economic status, and educational level. Acknowledging and accepting the need to engage all families is essential for successful engagement of diverse families and includes recognizing the strengths that come from their diverse backgrounds.

Guiding Principle

3

Building a respectful, trusting, and reciprocal relationship is a shared responsibility of families, practitioners, organizations, and systems. This positive relationship has the individual family's strengths and assets at its center.

Guiding Principle

4

Families are their child's first and best advocate. This premier role puts families in a unique position to nurture their children's growth and development and to help practitioners become knowledgeable about their child.

Guiding Principle

5

Equity is the eradication of privilege, oppression, disparities, and disadvantage. Family engagement must be equitable. Equitable family engagement comprises intentional and meaningful engagement activities and systems for all families or groups of families irrespective of families' level of or approach to engagement. Providing equity-based opportunities for family engagement can help family members become effective advocates for their children.

Framework Elements



**Building Positive
Relationships**



**Promoting Family
Well-being**



**Promoting Pathways
for Partnerships
with Families**



**Supporting Child and
Youth Development
and Learning**

State and Local Capacity Building



What did I Google?



Family Engagement

Questions & Discussion

Download the Framework

<http://www.doe.mass.edu/sfs/family-engagement-framework.pdf>

Next Steps

1. An Introduction to the Mass Framework
2. A Deeper Dive into the Mass Framework
3. Culturally Responsive Family Engagement Practices
4. Where Do We Go From Here? Implementing the Mass Framework

Connect with DPH



@MassDPH



Massachusetts Department of Public Health

DPH blog

<https://blog.mass.gov/publichealth>



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150 YEARS
OF ADVANCING
PUBLIC
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Massachusetts Department of Public Health

Thank You!

Roxanne Hoke-Chandler

roxanne.hoke-chandler@mass.gov

When poll is active, respond at **PollEv.com/avielpeacema702**

Text **AVIELPEACEMA702** to **22333** once to join

Does your organization have a formal definition of family engagement?

Yes

No

Not sure

Not yet, but we're working on it



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**Does your SCN/NICU have designated
employee(s) who are leads in family
engagement?**

Yes

No

Not sure



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Regulatory Updates

Meg Parker, MD, MPH

Neonatologist

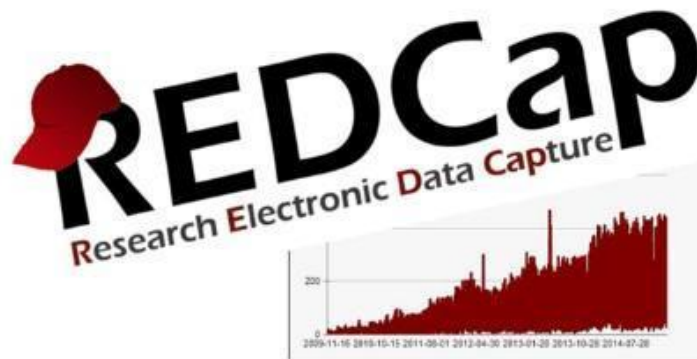
Boston Medical Center



Neonatal Quality Improvement Collaborative of Massachusetts

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



Data Infrastructure- Two Tracks

- Track one: Chart abstracted measures
 - Traditional approach for NeoQIC and most perinatal QI collaboratives
 - Subset of data metrics that are tracked over time by all teams
 - Nearly complete in REDCAP
 - Data is entered into a centralized data base in REDCap at BMC
 - Data use agreement (DUA) needed between sites (more on this soon)
 - IRB depends on the site – we encourage you to reach out to your IRB!



More Track 1:

- Data will be kept at Boston Medical Center (where grant is!)
- All teams will have access to their own data at any time
- Teams will be able to create customized variables if they would like
- You will receive “official” data reports quarterly
- Data will be used to inform on-going improvements!



Data Infrastructure- Two Tracks

- Track two: Chart abstracted measures AND Parent reported measures
 - Because this is a family engagement collaborative, it is crucial to collect information directly from parents
 - We propose to send short, text message queries during the hospitalization and a slightly longer survey (~10 min) around discharge and post-discharge
 - Drafted
 - This will involve asking parents permission to use their phone number and send these messages
 - All families will be informed about the purpose of sharing their contact info privacy protections
 - Whether or not a consent is required may depend on the NICU
 - DUA needed between sites
 - IRB depends on the site – we encourage you to reach out to your IRB!



Data strategies

- Work with institutions to create a single DUA that may include both tracks so that if a team wants to do track 1 to start, they can move to track 2 when they are ready
- Build text-messaging data queries within REDCAP and link the responses easily to the RECAP data
- Text-messaging: short, queries with yes/no responses or simple answer choices to increase parent responsiveness
- Discharge/post-discharge survey elements: goal overlap with data already collected at 3 hospitals understanding post-discharge infant care practices (feeding/sleeping)



- IRB- Track 1
 - Typical of our other QI projects
 - We encourage all teams to reach out to their hospital's IRBs
 - We will help you with this process!
- IRB- Track 2
 - Use of parent-reported measures for QI is novel, but the use of this data is “still” to inform local QI work
 - We do need access to email and phone numbers of parents to administer the surveys and text queries
 - These are identifiers, but will NOT be linked to the final data that is collected
 - These *do* need to be shared with BMC to administer the surveys
 - We encourage all teams to reach out to their hospital IRBs
 - At BMC- this approach was determined to be “QI”. No “informed consent.” But we will explain to parents the purpose and rationale
 - We will help you with the process! We will navigate this together.

Data Use Agreement

- Goal to create a DUA that can be used for both tracks
- Working with BMC legal this month to begin this process
- Need to identify your institutional legal contact

Next Steps on Data

- Track one: Chart Abstracted Measures
 - Measures are in REDCap and close to final now
 - Investigate with local IRBs
 - Move toward securing data use agreements
- Track two: Parent Reported Measures
 - In the process of further defining these measures
 - Investigate with local IRBs
 - Move toward securing data use agreements



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Which track do you think would fit best for your hospital team at this time?

Track 1

Track 2

Not sure



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Track 1

Track 2

Not sure

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Has your hospital team completed a DUA through NeoQIC before?

Yes

No

Not sure



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NeoQIC Human Milk Collaborative Video

<https://www.neoqicma.org/human-milk-educational-videos>



Neonatal Quality Improvement Collaborative of Massachusetts

Hospital Spotlight

South Shore Hospital

Zuzanna Kubicka, MD

Neonatologist

South Shore Hospital



Neonatal Quality Improvement Collaborative of Massachusetts



PEARLS OF IMPLEMENTING FAMILY INTEGRATED CARE MODEL: SSH NICU EXPERIENCE

**ZUZANNA KUBICKA MD
BOSTON CHILDREN'S HOSPITAL, BOSTON, MA AND
SOUTH SHORE HOSPITAL, WEYMOUTH, MA**

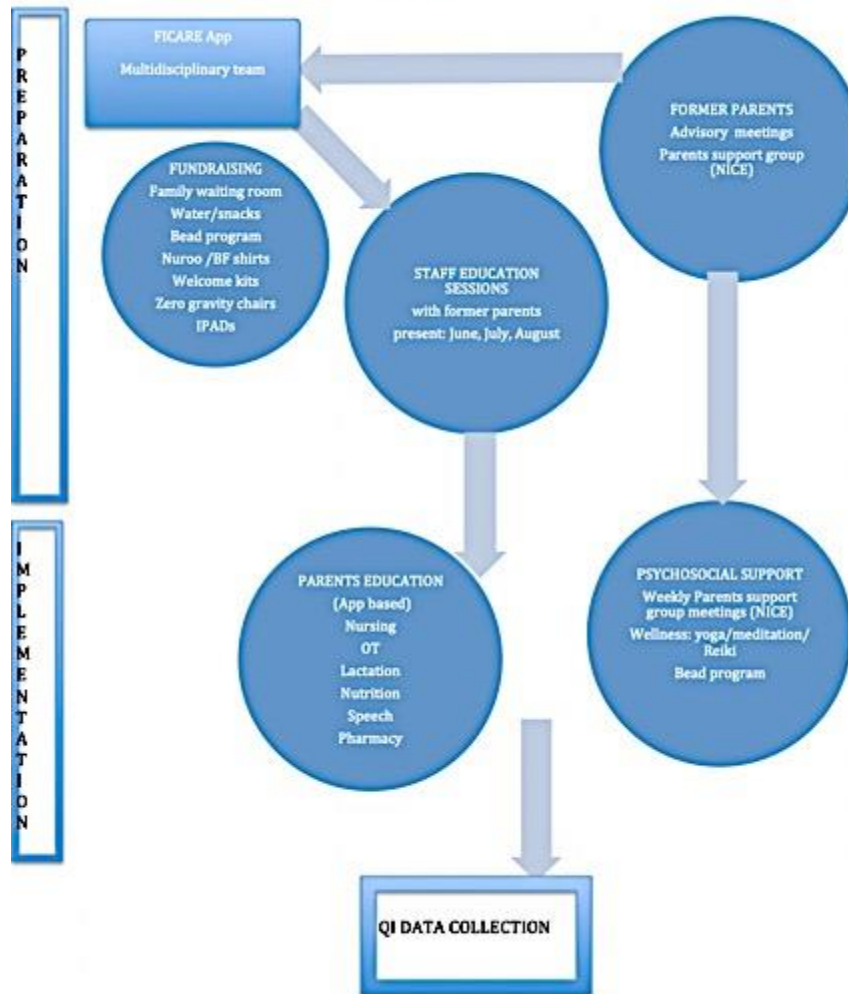
I have no financial
relationships to disclose or
conflicts of interest (COI) to
resolve



Setting: SSH NICU

- ~3600 deliveries and 450 NICU admissions per year.
- 30 beds, ~30 -50 VLBW infant's admissions per year.
- The only level 3 NICU in the state not located in an academic medical center (Division of Newborn Medicine at Boston Children's Hospital).
- 7 neonatologists, 2→5 neonatal nurse practitioners, 8 pediatric/neonatal certified respiratory therapists and 70 nurses.
- No physicians or NNPs in training participating in patient care.
- Excellent OT, speech therapy, lactation, nutritional, pharmacy, social work services
- Angel Eye camera system available for all parents 24/7
- Parental visits allowed 24/7 ; 8am-8pm for 2 parents since Covid

FIcare journey



A group of approximately 12 healthcare professionals, including nurses, therapists, and social workers, are standing in a line in front of a whiteboard. They are dressed in professional attire, including lab coats and scrubs. The whiteboard behind them has some faint, illegible text on it. The overall tone of the image is professional and collaborative.

Our journey

- FICare steering committee formed September 2018, meeting monthly.
- Multidisciplinary work on FICare App with former parent group support.

Disciplines included:

- RNs
- RTs
- Occupational therapy
- Speech Language Pathology
- Lactation consultants
- Nutritional services
- Social work

FICare model implemented September 2019

Our journey

- Parents advisory board monthly meeting
- NICE group =NICU INTEGRATED CARE EXPERTS
- Feedback on App and the FICare
- Fundraising event
- Weekly NICE group support for current NICU parents started September 2019
- Currently parents join via Zoom



Timeframe

- 2018-2019 FICare App built
- Staff education: June 2019. Former parents participated in the teaching sessions to share their story and explain why this approach is so beneficial for parents.
- Sessions included: MDs, NNPs, RTs, Lactation, Nutrition, Pharmacy, OT, Speech, unit coordinators, Nursing Aides, social work
- “GO LIFE” DATE for bedside FICare: September 14 2019
- Additionally
 - Parents support group
 - BEAD PROGRAM



Options for Parents to Participate

- Parents are welcomed to spend as many hours participating in baby's care as they wish.
- No requirement for number of hours
- We understand that every parent has different needs and not everyone is able to spend long hours in the NICU/SCN.
- Many parents must continue to work, travel long distances to the hospital and care for their other children. They will be still able to complete some most important sections: for example "Discharge class"
- FICare is an option, not "a must". Offered to each parent on admission if LOS > 4 days

When to introduce FICare to the parents

- Prenatal consults include the FICare information now and information about access to the App-
parents can start “Introduction” section right away (parents predicted to deliver early)
- App uploaded to personal device/available at our iPads
- “Welcome Package” given to parents close to the day of mom’s d/c home **by the nurse taking care of the baby**

When to introduce the concept to the parents

- “Welcome package” given to the parents upon mom’s discharge home contains:
 - *small gifts including insulated bags for BM
 - *Books about safe sleep



Bedside folder with FICare info given to parents

Parents,

Have you:

- ☐ Received your welcome bag?
- ☐ Uploaded and started to read the SSH NICU app?



- ☐ Started to document the skills you are learning on the baby picture?



- ☐ Been asked if you want to attend daily rounds on your baby?
- ☐ Been told about the support group meeting?
- ☐ Been told about the location of water/snacks?
- ☐ Have you completed the discharge class module?

Ask your team
about

FICARE



Family
Integrated
Care




South Shore
Hospital

Bedside reminders


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FICare baby
placed at
each bedside
(star stickers
once skill is
mastered)

My name is _____

My
Head to Toe
NICU
Journey

Bathing ☐

PG Feeding ☐
PG Medications ☐

Taking Vital Signs ☐

Kangaroo Care ☐

Temperature ☐

Dressing ☐ Swaddling ☐

Double checking PG tube placement ☐

Double checking milk ☐
Warming up milk ☐

Weighing ☐ Diaper Care ☐

DISCHARGE:
Discharge Class/ Module ☐
Safe Sleep Info ☐
Home Feeding plan discussed ☐
Mixing milk ☐
Reinforce giving oral medications ☐
Discuss PCP/appointments ☐

Oral Feeding ☐
Oral Medications ☐

“SSH NICU FICare” App

- Intense, multidisciplinary work since September 2018
- Free, available now from App store
- App uploaded to iPads available at nursing stations
- Parents given information about App during prenatal consult or shortly after admission, upload the App to personal devices



PARENTS' FIC SUPPORT

LACTATION SUPPORT

BABY WEIGHT

DIAPER LOG

PHOTO BOOTH

JOURNAL

FEEDINGS

KANGAROO CARE TIMER

PUMPING



ORIENTATION TO FIGARE

DEVELOPMENTAL CARE

FEEDING YOUR BABY

BASIC SKILLS CARE

DISCHARGE

LACTATION SUPPORT

TAKING CARE OF YOU

TOOLS FOR PARENTS



Parent education

- Nurses providing parents with the knowledge, skills and confidence required to care for their infants in the NICU-“hands on skills” (My head to toe NICU journey tool aka FICare baby).
- Bedside teaching by OT, lactation, nutrition, speech and language pathology, respiratory therapy, pharmacy

What did not work well

- Initial idea: bedside learning by nurses utilizing App, followed by check offs on particular “hands on” skills and quizzes
- Parents prefer self-learning at home, utilize time in the NICU on “hands on” skills
- Parents presenting at rounds(script for rounds was provided)
- Parental flowsheets
- Separate folders for FICare-all in one NICU bedside folder now, information about FICare given to parents prior to mom’s discharge home, “FICare baby” hang by the bedside upon admission

Data capture

- Upon discharge home nurses fill out Ficare survey: number of sections reviewed by parents in the App plus copy of “FICare baby”

Feasibility of utilization of “SSH NICU FICare” App to implement FICare model: pilot results

- During the first 3 months of FICare implementation 132 infants admitted to our NICU/SCN.
- Length of stay (LOS) < 7 days for 79 infants (GA 34.5-41.5 weeks, average LOS 2.4 days). Only 9 parents utilized App in that group.
- LOS was > 7days for 53 infants (GA 23.4-39.2 weeks, average LOS 26 days) and 36 out of 49 parents available for analysis utilized App in this group.
- 12 parents App “users” interviewed close to discharge felt that App made them more confident to care for the baby, helped them to be ready for discharge and information was consistent with daily teaching.
- However parents preferred “**self reading** “ App at home as oppose to using it at the bedside and preferred to utilize time in the hospital for “**hands on**” teaching.

Challenges

- Adjustments in implementation might be needed based on nursing/parental feedback
- Different nurses have different comfort level to change the role from “care giver” to “teacher and supporter”
- Change might not happen overnight
- Frequent reminders to staff might be needed at the beginning

Family engagement collaborative benefits

- Learning from others
- Sharing challenges
- Identifying areas for improvement
- Data capture tools, surveys
- Disparities still exist and might be racial or just a socio-economic! Challenging our mental model is important to make a change...



Thank you!

QUESTIONS?

Wrap Up and Next Steps



TO DO's

- Leadership team:
 - Provide fact sheet on our the project for your IRB and legal department
 - Finalize chart abstracted measures and send
 - Further develop and final parent reported measures
 - Work with BMC legal department to get the DUA ready
- Local Teams
 - Send us a roster of your multi-disciplinary team (if you haven't already!)
 - Decide on track 1 vs. 2
 - Reach out to local IRBs
 - Determine who is the legal contact at your hospital
 - Start monthly meetings
 - Start PDSA cycles!



Next Webinar

- Dates:
 - Wednesday, October 21st from 2-3 pm
 - Wednesday, December 2nd from 2-3 pm
- Topics:
 - Virtual platforms to connect with families
 - Primer on PDSAs



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How confident do you feel in conducting a PDSA cycle at your center?

Confident, I've done this before

Not much experience, but I'm excited to learn

This is completely new, I need to learn more



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Which driver are you most interested in working on first?

1- Inadequate communication regarding infant medical care between NICU staff and families

2- Inadequate services and social supports for families

3- Family engagement in hands-on NICU care

4- Family participation in discharge planning



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Any Questions?



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