PAIRED Mid-Initiative Meeting: *Getting Ready to Deliver*

FPQC

FPQC's Vision & Values

*"**All** of Florida's mothers, infants & families will have the **best health outcomes** possible through receiving **respectful, equitable, high quality, evidence-based** perinatal **care**."*

- Voluntary
- Data-Driven
- Population-Based
- Evidence-Based
- Equity-Centered
- Value-Added

FPQC Partners & Funders

Florida HEALTH

CDC
Centers for Disease Control and Prevention

Agency for Health Care Administration

AIM
Alliance for Innovation on Maternal Health

USF Health
College of Public Health

The American College of Obstetricians and Gynecologists
Women's Health Care Physicians

AWHONN
Florida
Promoting the Health of Women and Newborns

Florida Affiliate of the American College of Nurse-Midwives
With women, for a lifetime®

Florida Association of Healthy Start Coalitions, Inc.
Every baby deserves a healthy start

Florida Society of Neonatologists
Advancing the Care of Neonates in the Sunshine State

Florida Academy of Family Physicians
Support Florida's Family Physicians

Florida Hospital Association
Mission to Care. Vision to Lead.

Florida Alliance for Healthcare Value

Preeclampsia Foundation

March of Dimes

Florida Blue

United Healthcare Community Plan

FPQC

New Hospital Perinatal QI Participation Parameters

Florida Statute	All Florida maternity hospitals are required to participate in two FPQC quality improvement initiatives at all times.
CMS QI Reporting	All hospitals participating in Medicare are required to report whether they are participating in a national and state perinatal quality collaborative and implementing their safety bundles.
Joint Comm. Requirement	TJC accredited hospitals must select one hospital QI health equity issue and present a series of QI steps performed to address this issue.

PAIRED Mid-Initiative Meeting: *Getting Ready to Deliver*

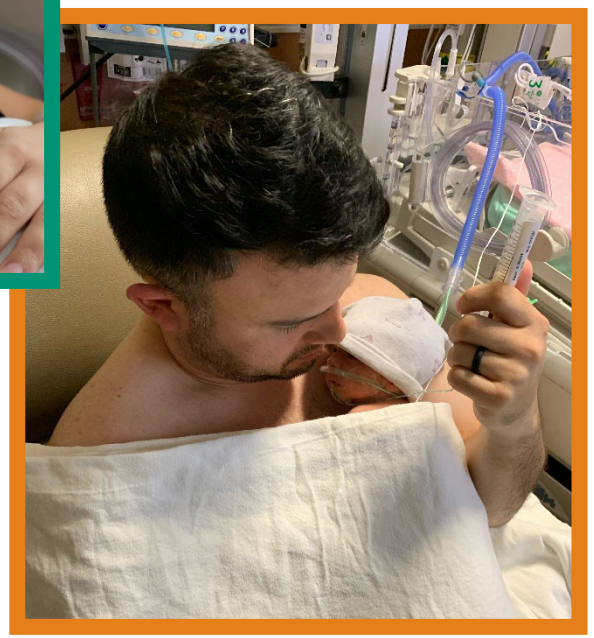
- Less than 9 month to deliver
- Family Center Care has never been needed more than now

COVID-19

Staff Turnover

Family Stress

- Today is the day to get ready



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PAIRED Leadership Team

Nurse Consultant

Sue Bowles

Clinical Co-Leads

Mark Hudak

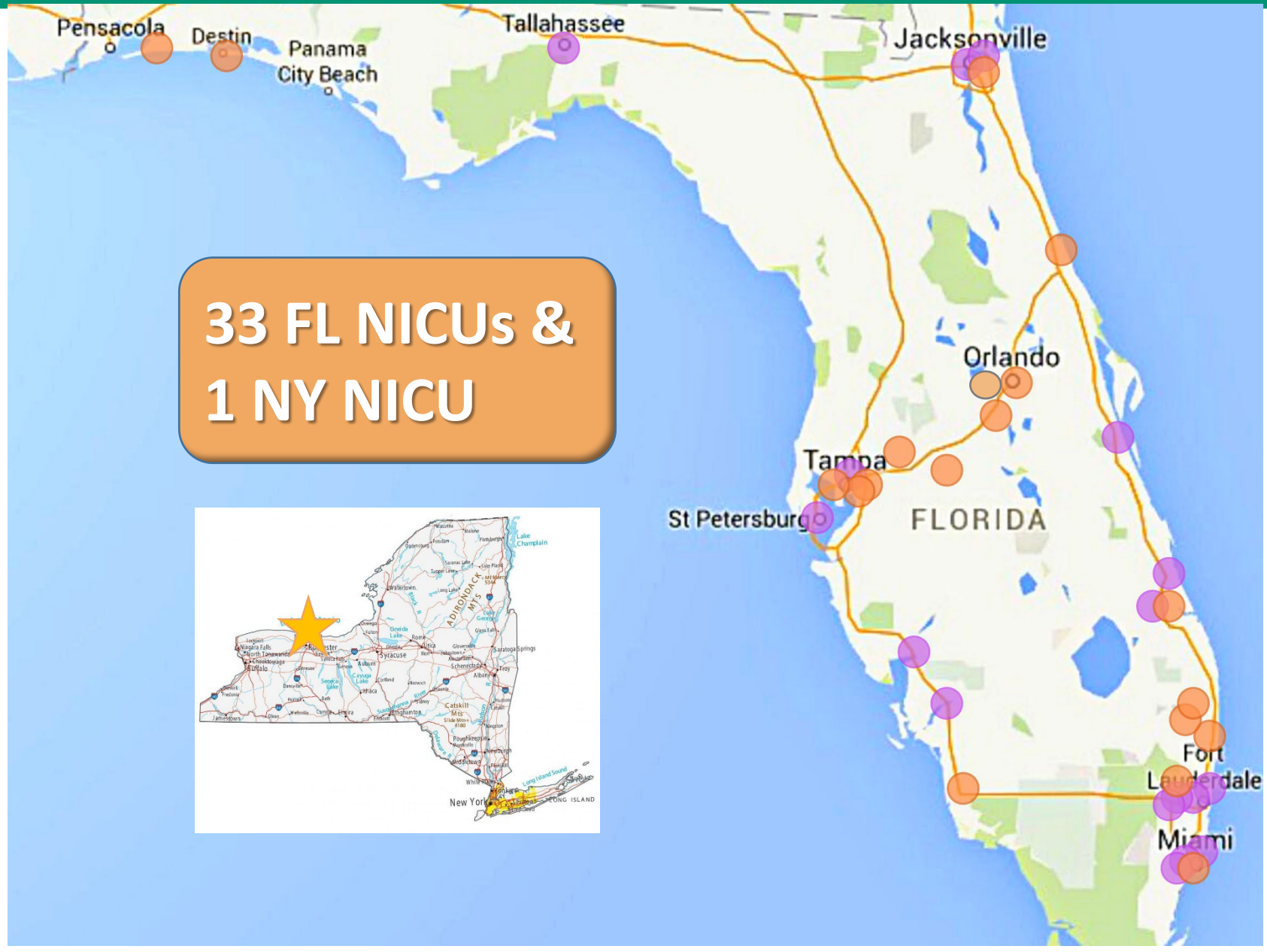
Samarth Shukla

Parent Consultant

Lelis Vernon

FPQC

Pilot & New PAIRED Hospitals



What would you like to get out of today?

- Continue to see improvements; more engagement and continue to grow
- Feedback from hospitals regarding parent education and CGS
- Revamping PAIRED Initiative w/in their hospital system
- Documentation of SSC
- Increase SSC engagement, engage travelers, best way to implement CGS
- Increase staff comfort level with infants who are more critical
- Staff engagement and getting new hires up to speed on initiative
- Knowing what similar challenges other hospitals are having
- Employee turn over and staff engagement in SSC
- Working on sustainability and getting numbers back up after the kangaroo-a-thon
- Getting new graduates comfortable with standing transfers; increasing survey numbers
- Engaging new grads and central line infections/infection control
- Staff engagement and educating parents
- Learning to maintain the initiative after the initiative ends
- Motivating staff to encourage parents to do SSC; implementing CGS w/in hospital
- How to teach FCC to staff?
- Maintaining the importance of SCC among staff over time
- How to move the needle forward and sustain

You Are the Best!

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@TheFPQC

Join our mailing list at FPQC.org

E-mail: FPQC@usf.edu

Where We Are on the PAIRED Initiative

Drs. Mark Hudak & Estefania Rubio

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MAJOR AIMS

By 6/2023, each NICU will achieve:

A 20% increase from baseline in the % of infants who receive skin-to-skin care from at least one family caregiver within 3 days of clinical eligibility as defined by individual unit protocols

SUPPLEMENTAL

By 6/2023, family caregiver surveys will demonstrate a 20% improvement from baseline in the perception of the culture of family-centered care in each NICU as averaged across all 4 domains.

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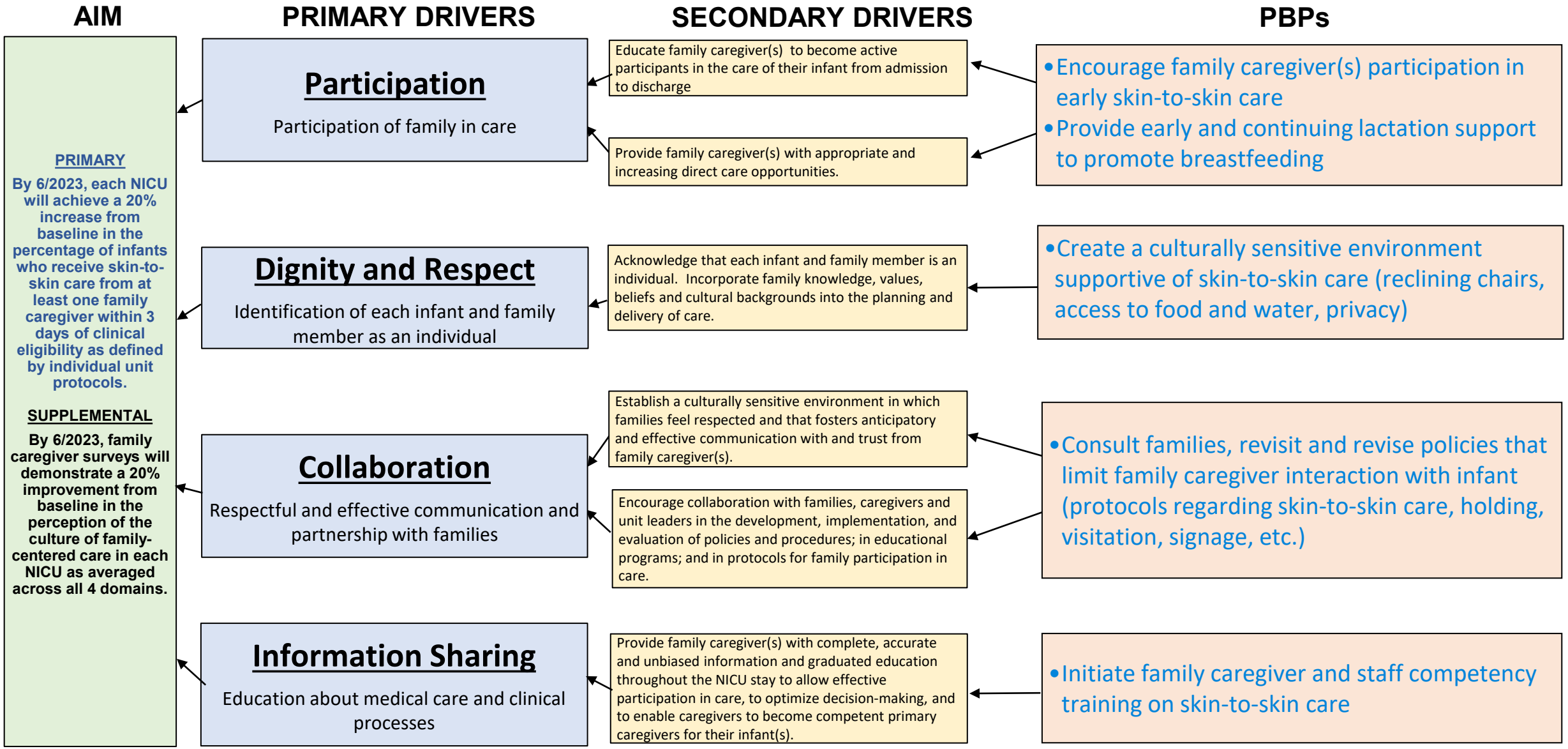
PAIRED—Family-Centered Care

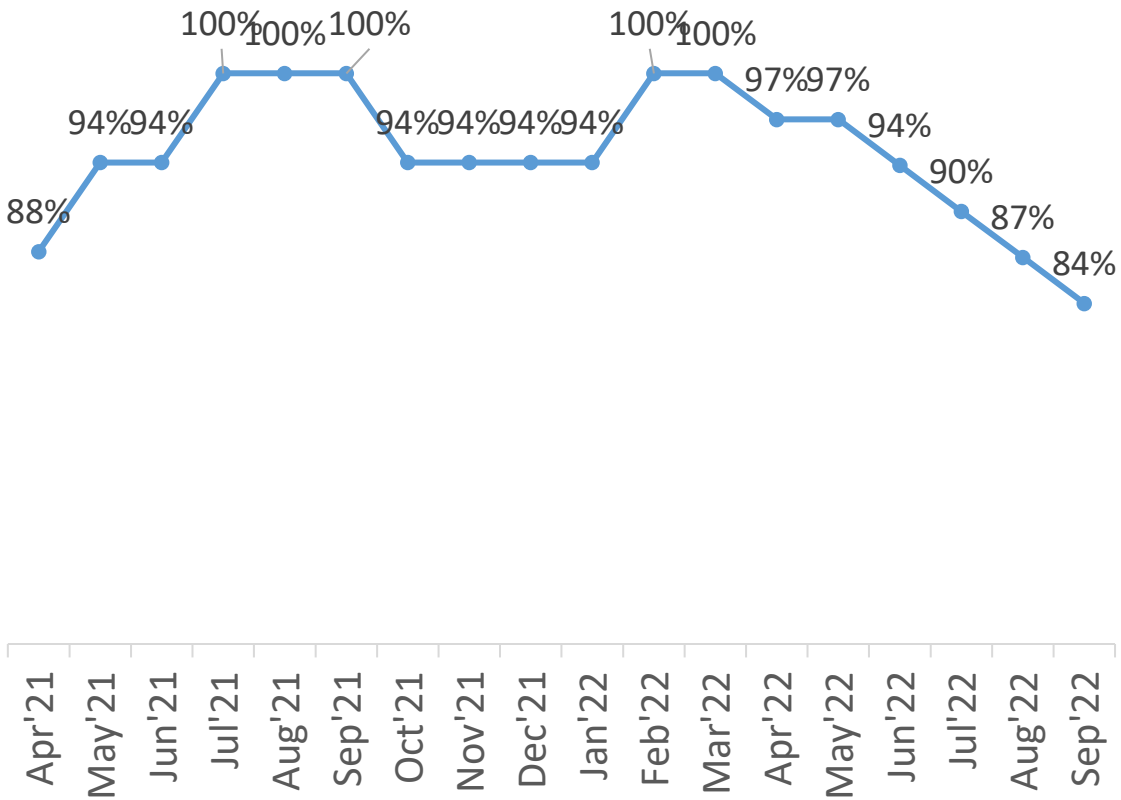
Date: 10/9/2020



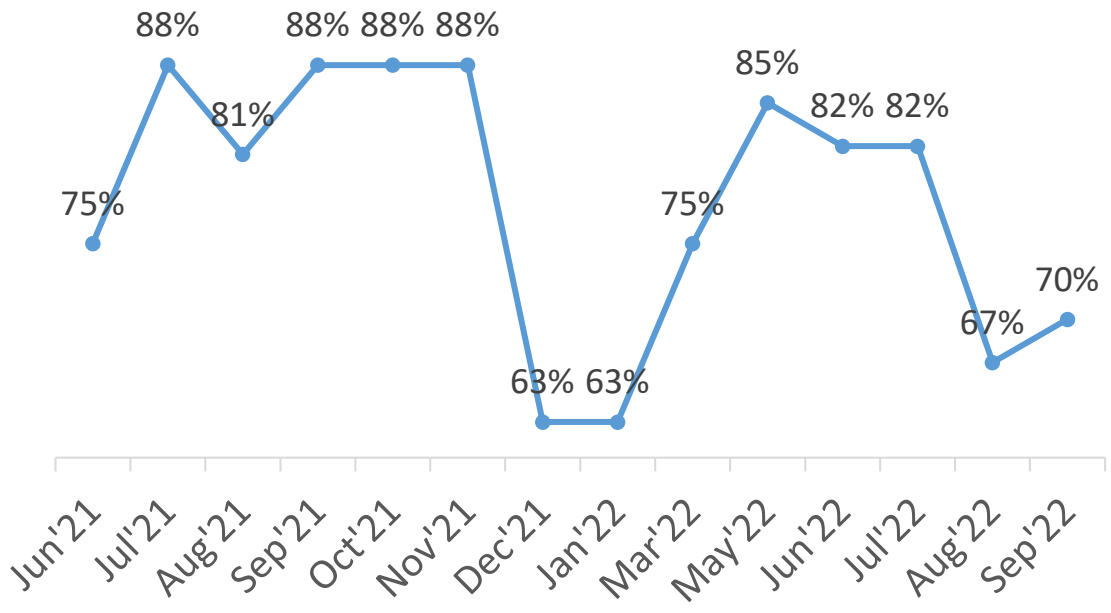
Family-centered care is defined as a shared approach to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and family caregiver(s). There are four essential domains of FCC: 1) family participation in care, 2) dignity and respect, 3) family collaboration, and 4) information sharing.

HOSPITAL PARTICIPATION AND ENGAGEMENT

% HOSPITALS SUBMITTING MONTHLY QI DATA



% HOSPITALS ATTENDING MONTHLY COACHING CALLS



PAIRED DATA

Patient-level data – 10 infants per month

- Skin-to-skin care and adverse events during SSC
- Mother's own milk
- Primary caregiver education

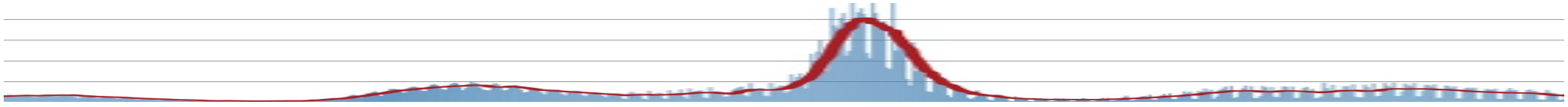
Hospital-level data

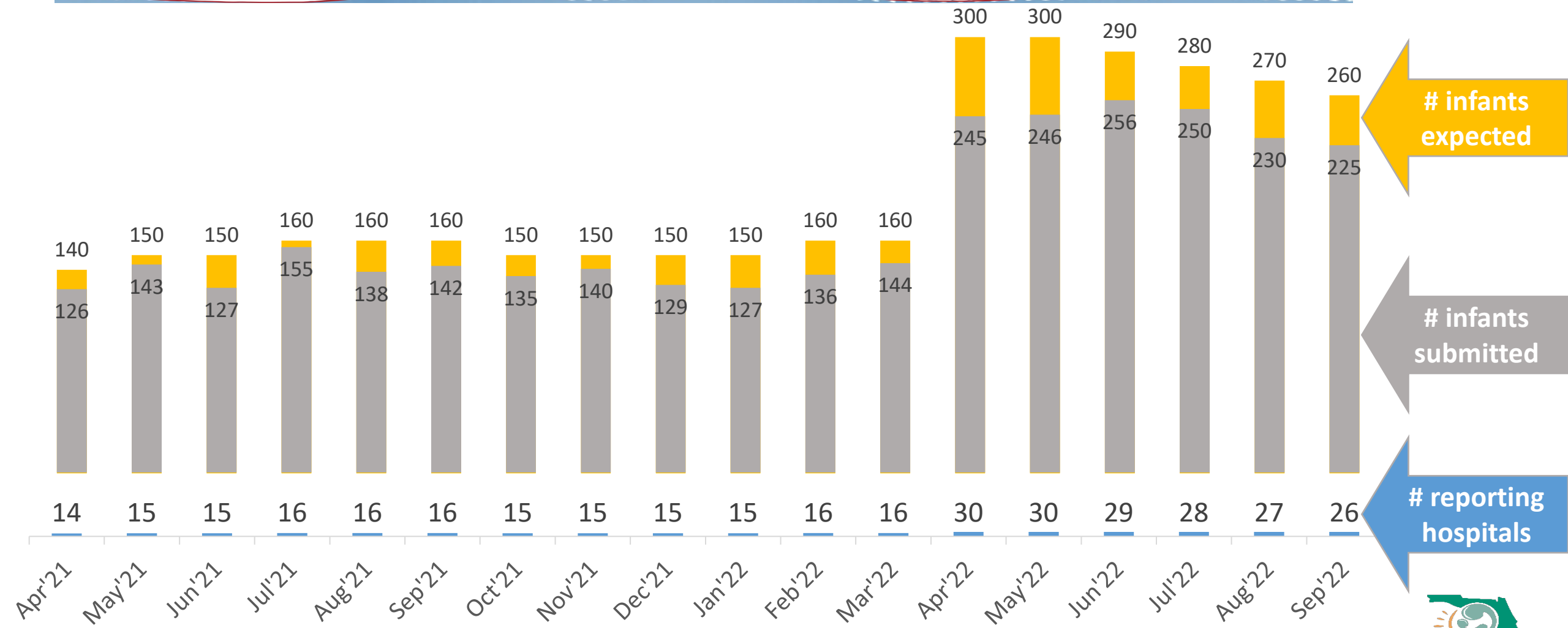
- Staff education
- SSC policy
- Standardized documentation

Auto-submission – 48 hours prior to discharge

- Family caregiver survey

MONTHLY DATA SUBMISSION





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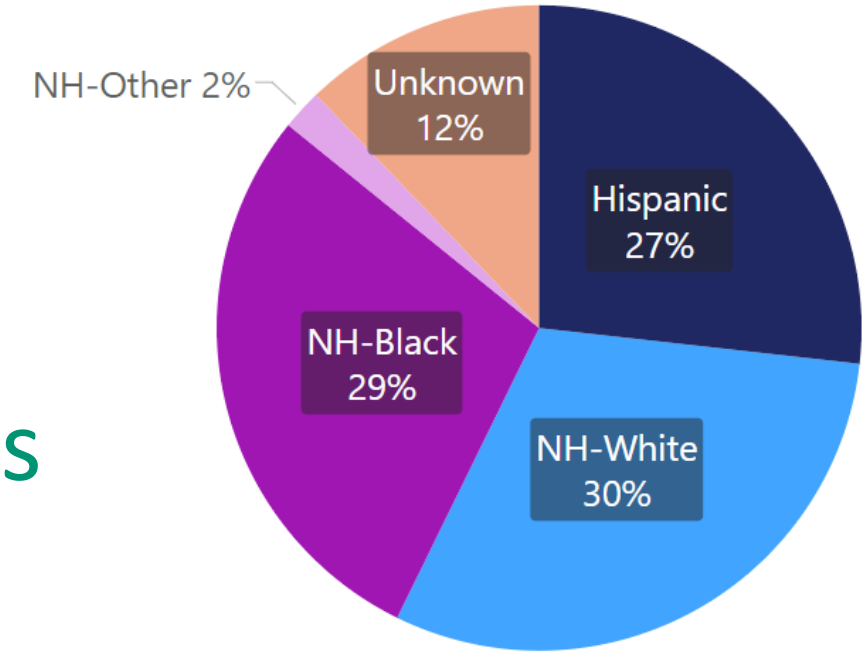
PATIENT CHARACTERISTICS

3011 infants
BW (mean): 2242 g
GA (mean): 34 wks.
NICU LOS (mean): 28 days
PC - Spanish: 9%



SSC PRACTICE

Improvement in documentation

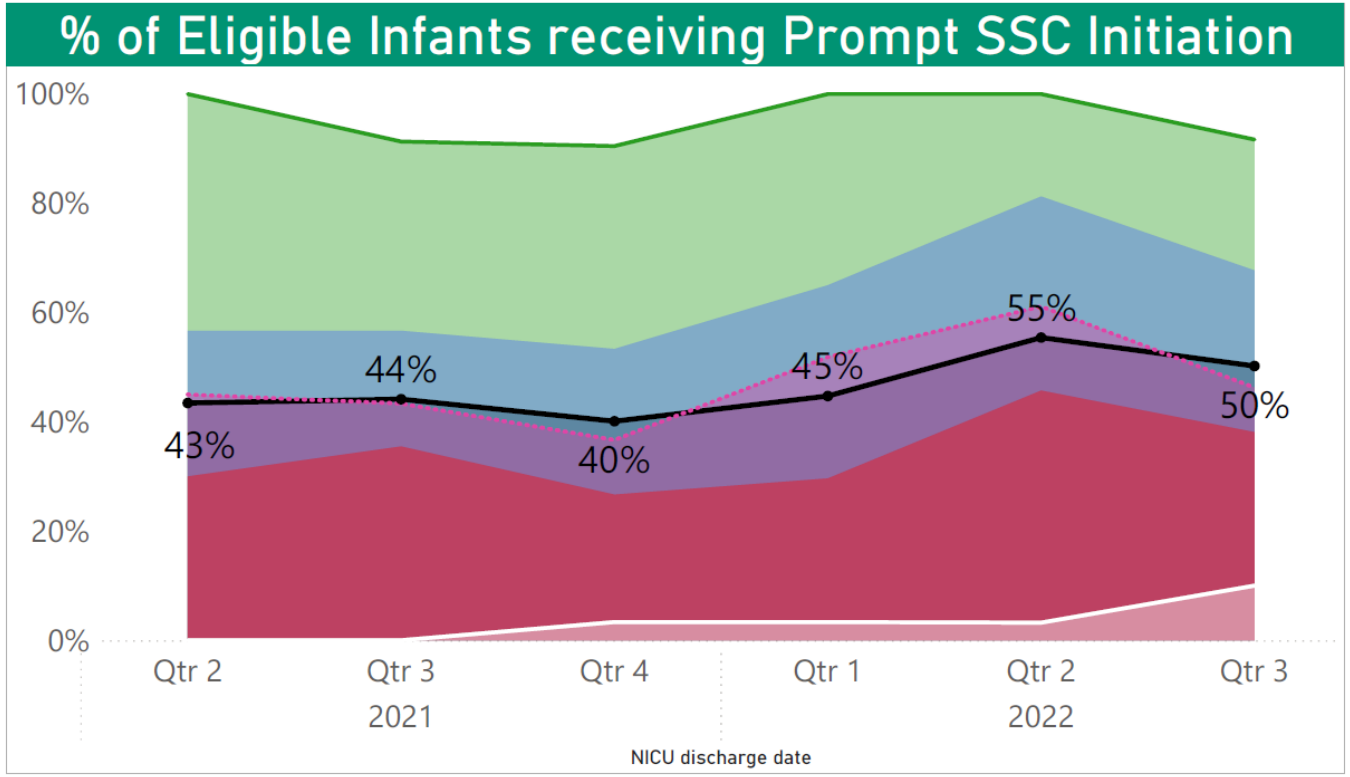
No SSC documentation: 40% in Q2-21 to 30% in Q3-22

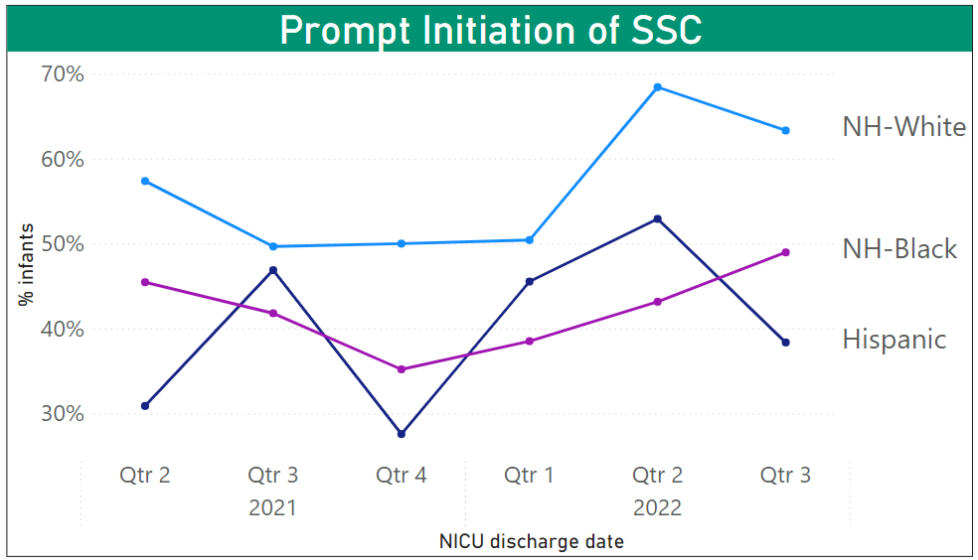
Father engagement in SSC

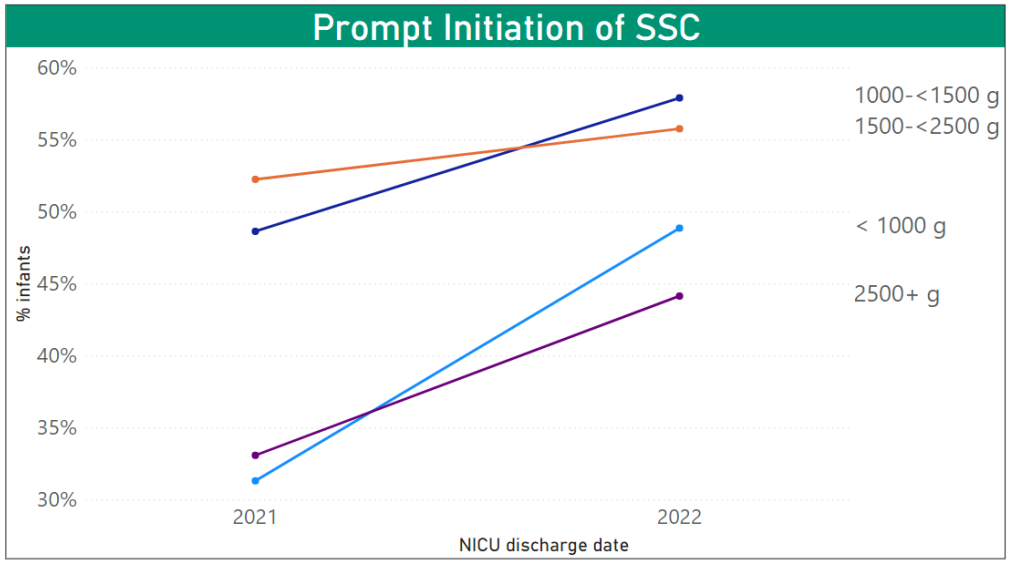
16% in Q2-21 to 21% in Q3-22

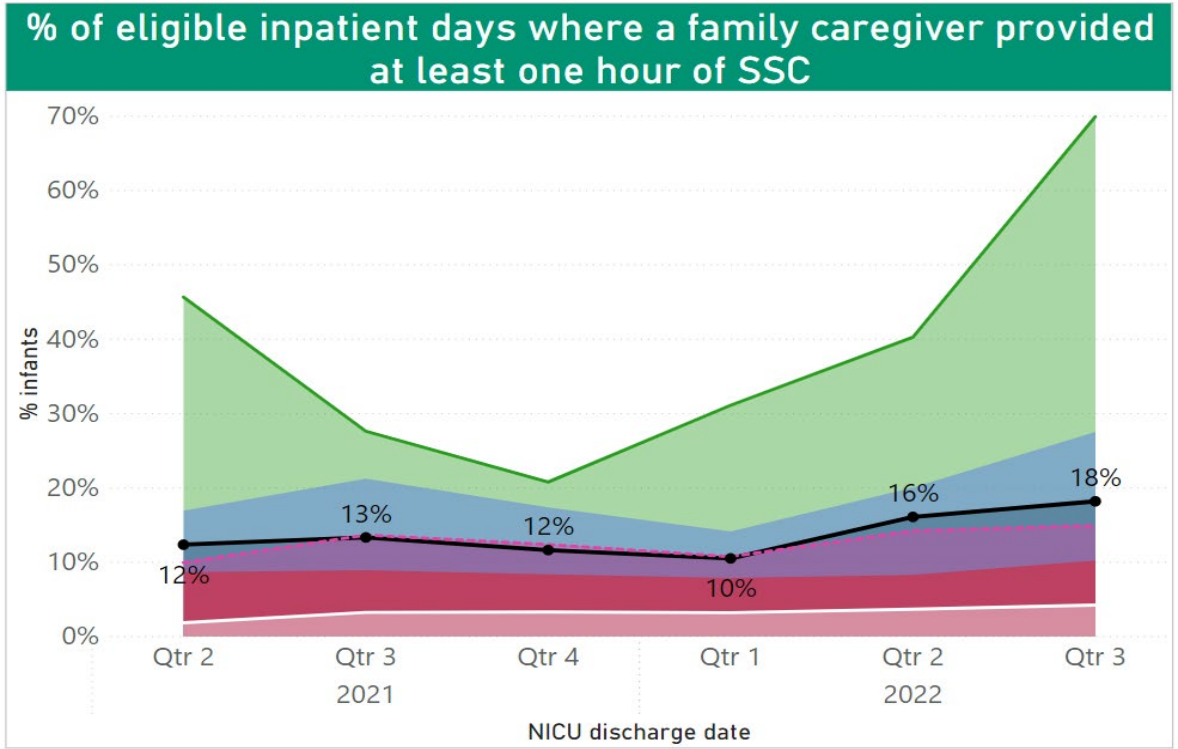
SSC PRACTICE

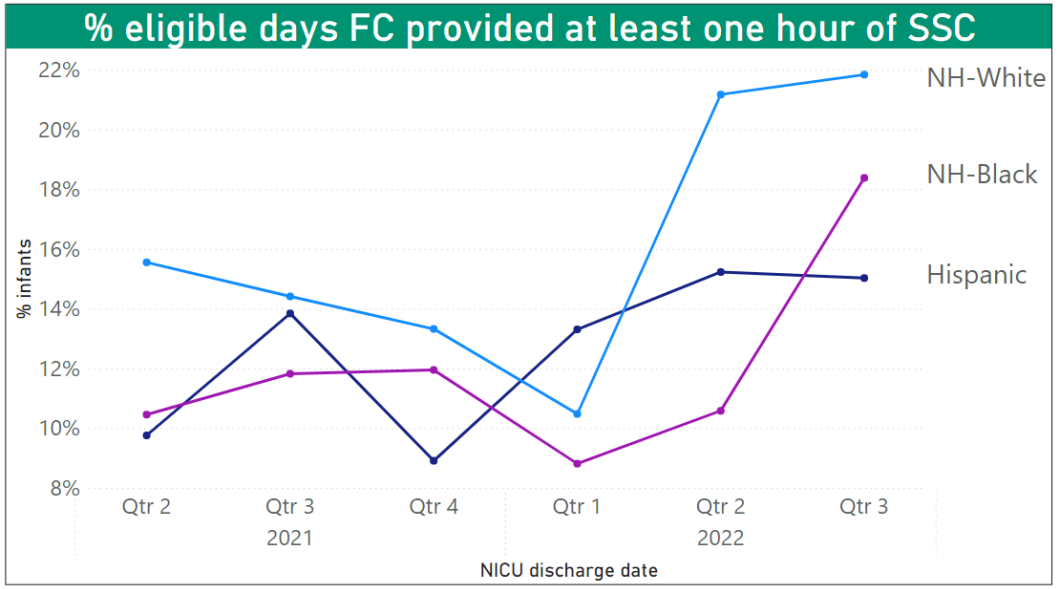
	Q2-2021	Q3-2022
# SSC episodes/hospital	78	102
# SSC hours/hospital	97	147
Average SSC duration/episode	75 min	90 min

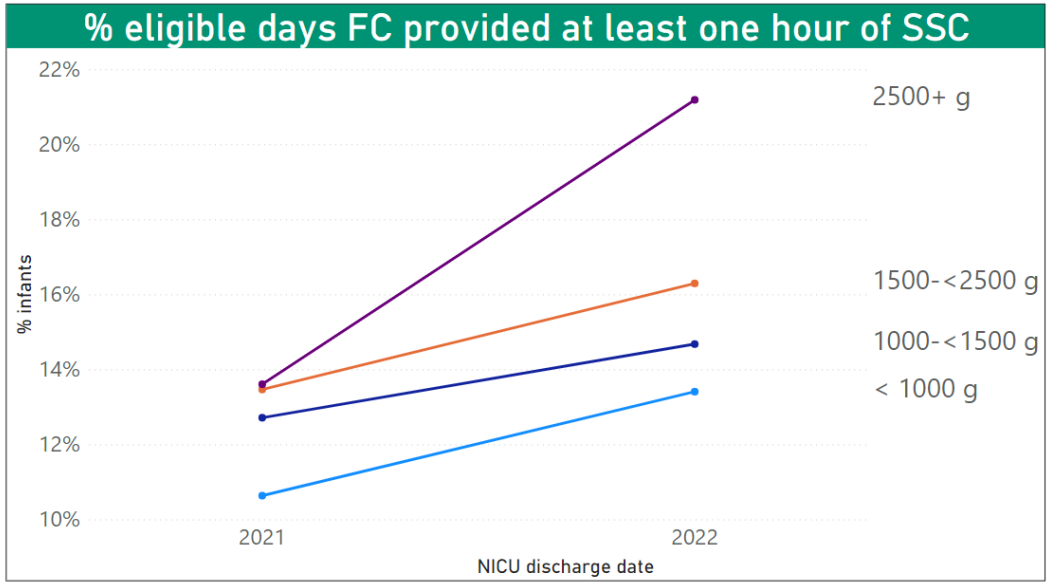

% of Eligible Infants receiving Prompt SSC Initiation
100%
80%
60%
40%
20%
0%
44%
45%
55%
43%
40%
50%
Qtr 2
Qtr 3
2021
Qtr 4
Qtr 1
Qtr 2
2022
Qtr 3
NICU discharge date

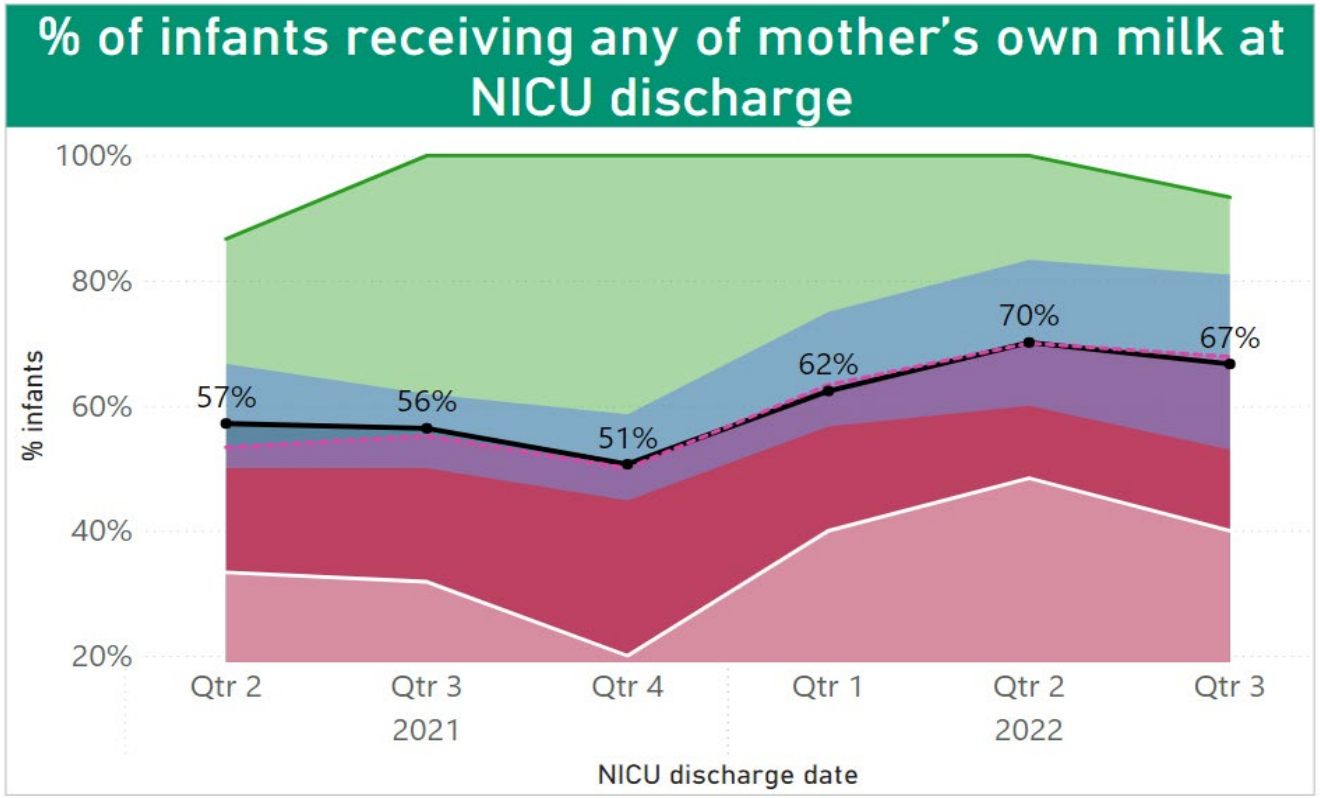

Prompt Initiation of SSC
70%
60%
50%
40%
30%
% infants
NH-White
NH-Black
Hispanic
Qtr 2
Qtr 3
2021
Qtr 4
Qtr 1
Qtr 2
2022
Qtr 3
NICU discharge date

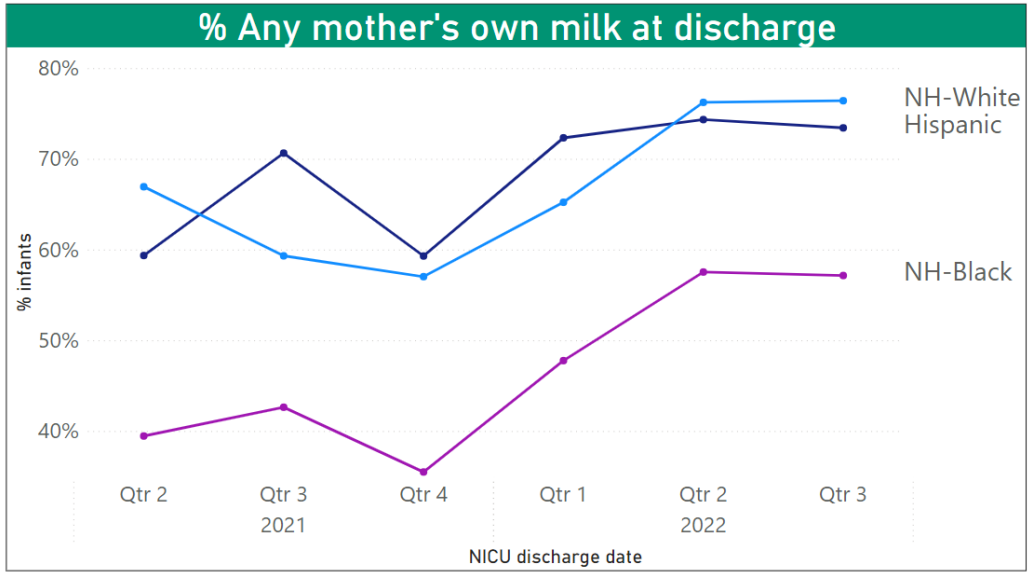

Prompt Initiation of SSC
60%
55%
50%
45%
40%
35%
30%
% infants
1000-<1500 g
1500-<2500 g
< 1000 g
2500+ g
2021
2022
NICU discharge date

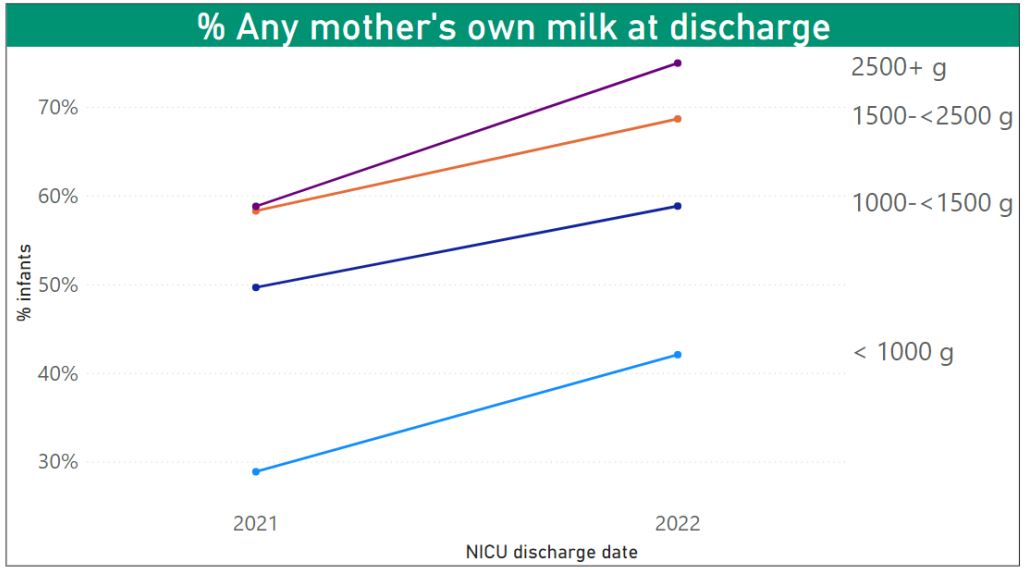

% of eligible inpatient days where a family caregiver provided at least one hour of SSC
70%
60%
50%
40%
30%
20%
10%
0%
% infants
12%
13%
12%
10%
16%
18%
Qtr 2
Qtr 3
2021
Qtr 4
Qtr 1
Qtr 2
2022
Qtr 3
NICU discharge date


% eligible days FC provided at least one hour of SSC
22%
20%
18%
16%
14%
12%
10%
8%
% infants
NH-White
NH-Black
Hispanic
Qtr 2
Qtr 3
2021
Qtr 4
Qtr 1
Qtr 2
2022
Qtr 3
NICU discharge date

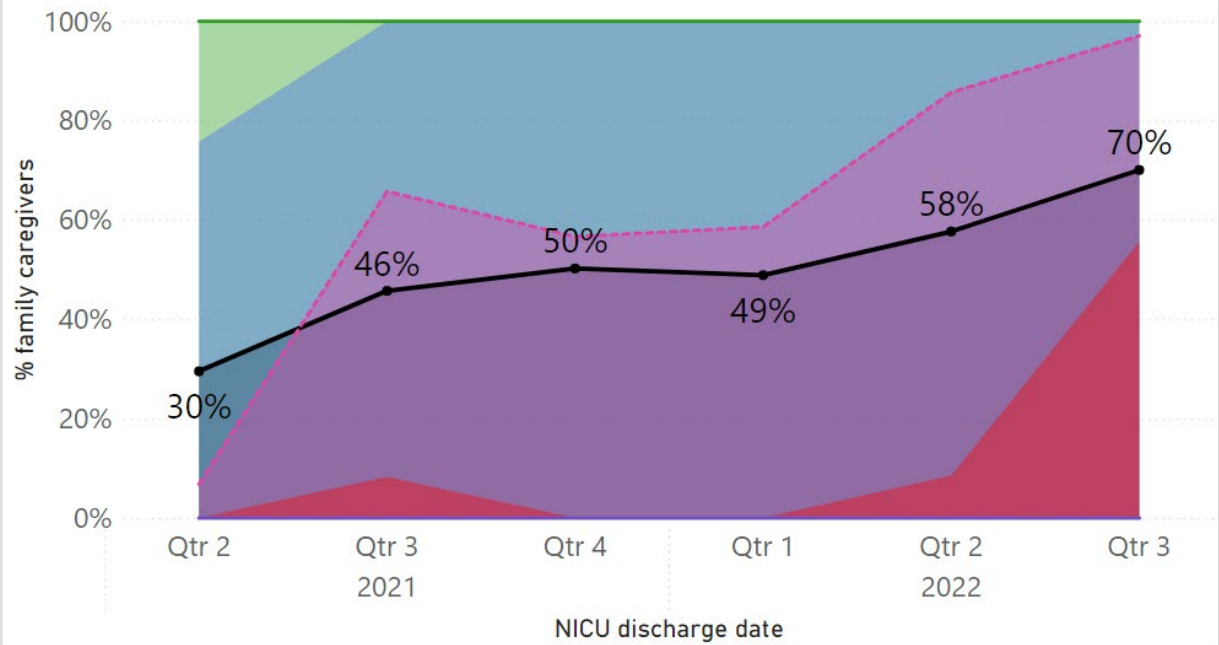

% eligible days FC provided at least one hour of SSC
22%
20%
18%
16%
14%
12%
10%
% infants
2500+ g
1500-<2500 g
1000-<1500 g
< 1000 g
2021
2022
NICU discharge date


% of infants receiving any of mother's own milk at NICU discharge
100%
80%
60%
40%
20%
% infants
57%
56%
51%
62%
70%
67%
Qtr 2
Qtr 3
2021
Qtr 4
Qtr 1
Qtr 2
2022
Qtr 3
NICU discharge date

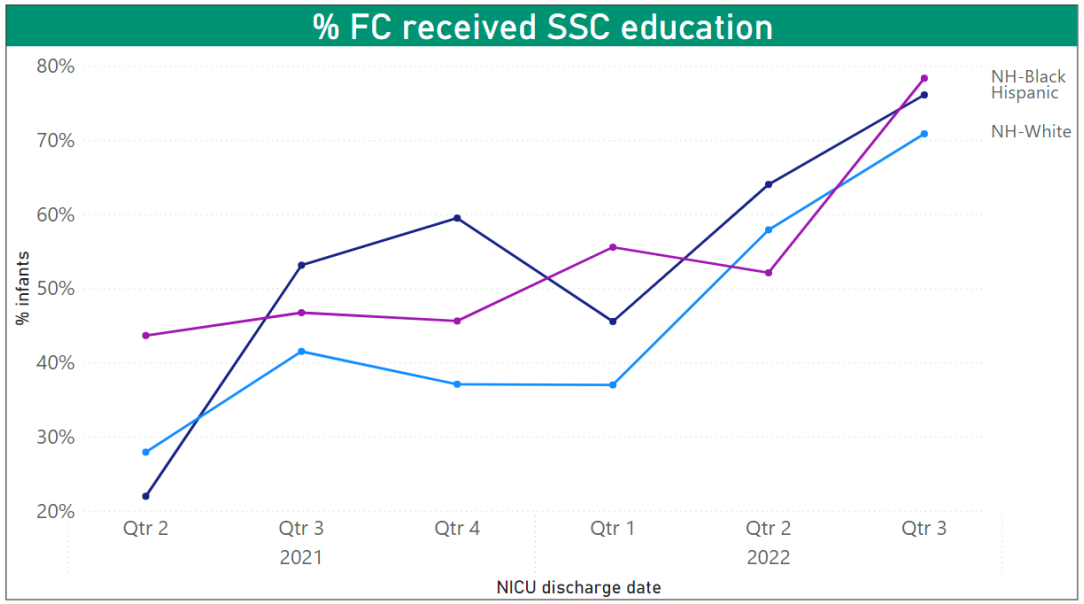

% Any mother's own milk at discharge
80%
70%
60%
50%
40%
% infants
NH-White Hispanic
NH-Black
Qtr 2
Qtr 3
2021
Qtr 4
Qtr 1
Qtr 2
2022
Qtr 3
NICU discharge date


% Any mother's own milk at discharge
70%
60%
50%
40%
30%
% infants
2500+ g
1500-<2500 g
1000-<1500 g
< 1000 g
2021
2022
NICU discharge date

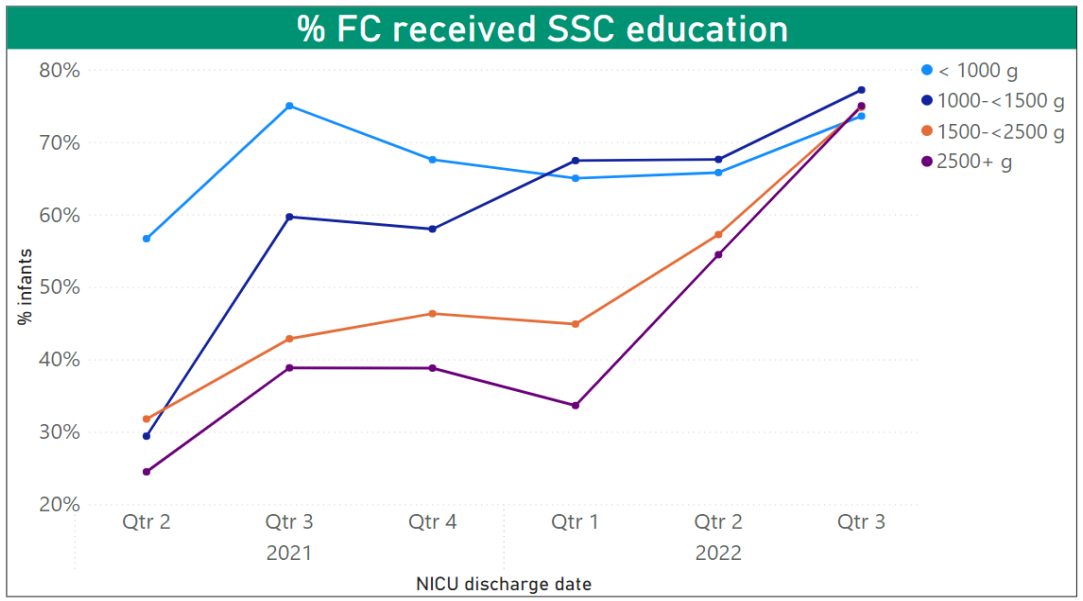
% of family caregivers who received education about and competency training in SSC

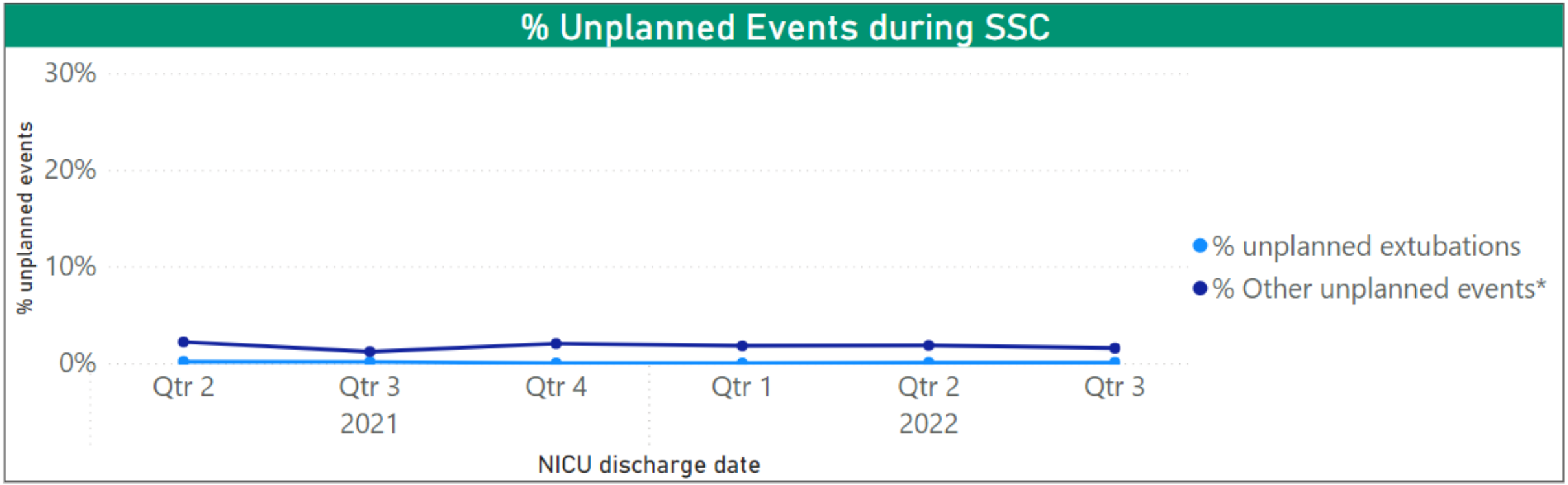


% FC received SSC education



% FC received SSC education





* Other unplanned events include: Significant apnea/bradycardia/desaturation (ABD), Hypothermia and Line dislodgement

	2021	2022
# SSC episodes	4097	7207
# unintended extubations	4	4
# line dislodgements	3	8
# significant ABD	40	89
# hypothermia	29	26
# Total unplanned events	76	127

PAIRED DATA

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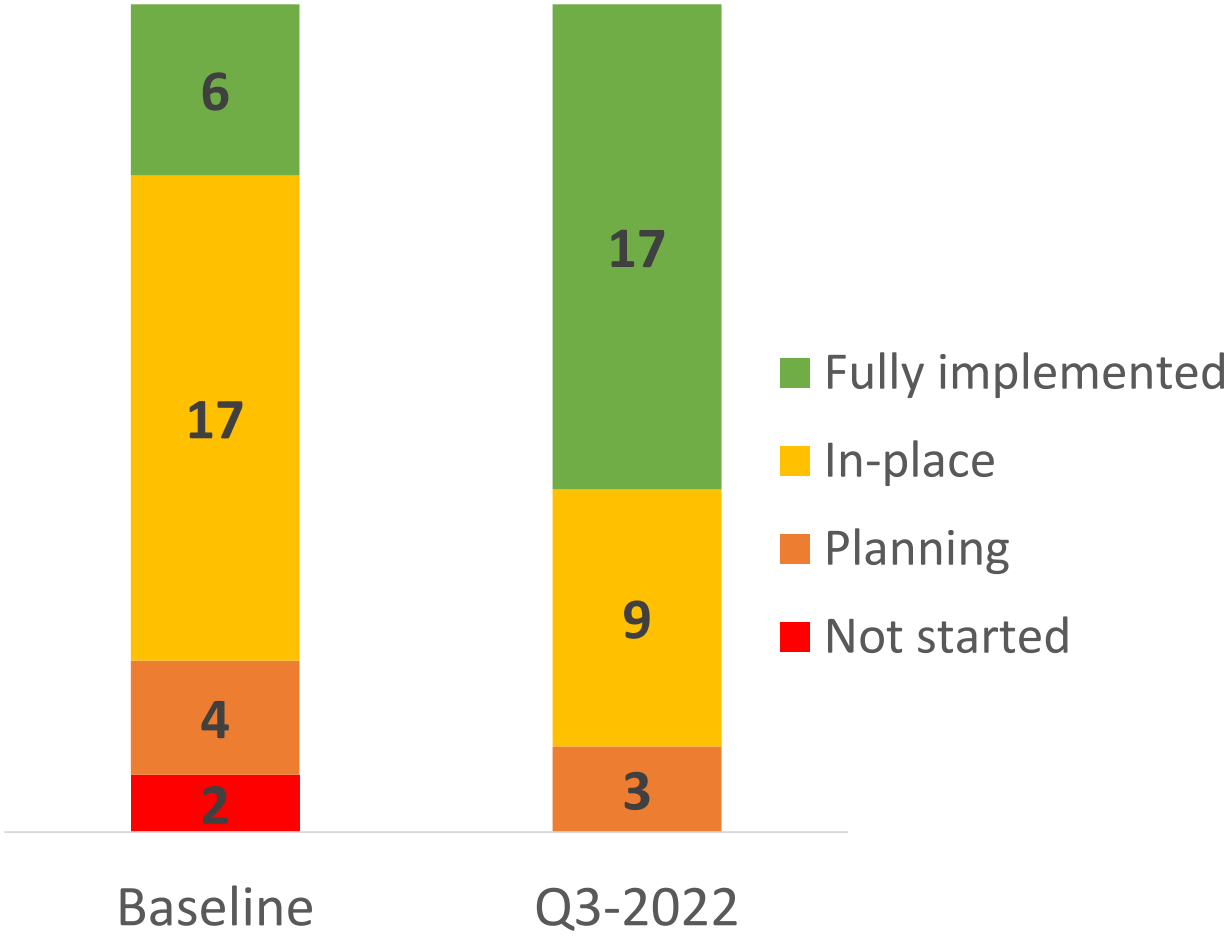
Hospital-level data

- Staff education
- SSC policy
- Standardized documentation

Auto-submission – 48 hours prior to discharge

- Family caregiver survey

NICU policy promoting SSC for all eligible infants and family caregivers



Staff educated about SSC to date:

66%

% Doctors, NP, PA

69%

% Nurses

52%

% Respiratory Therapist

PAIRED DATA

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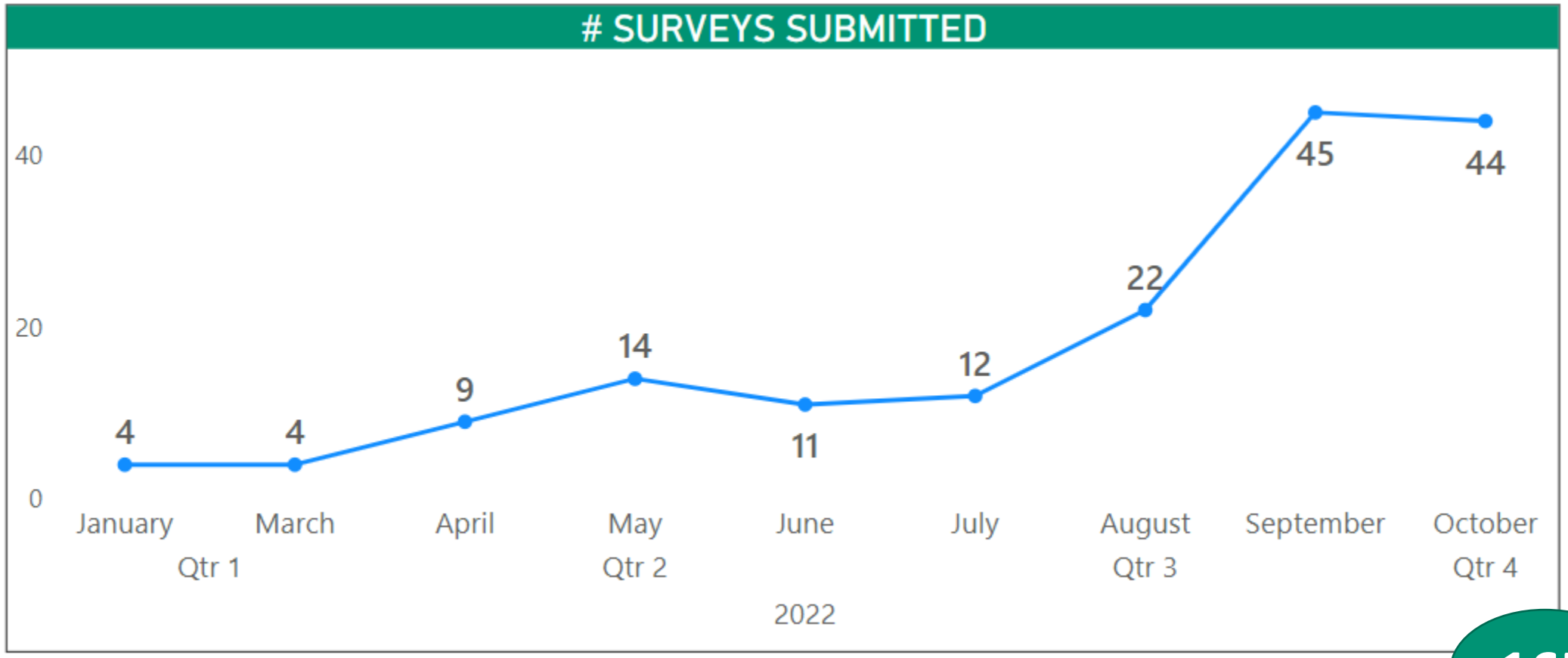
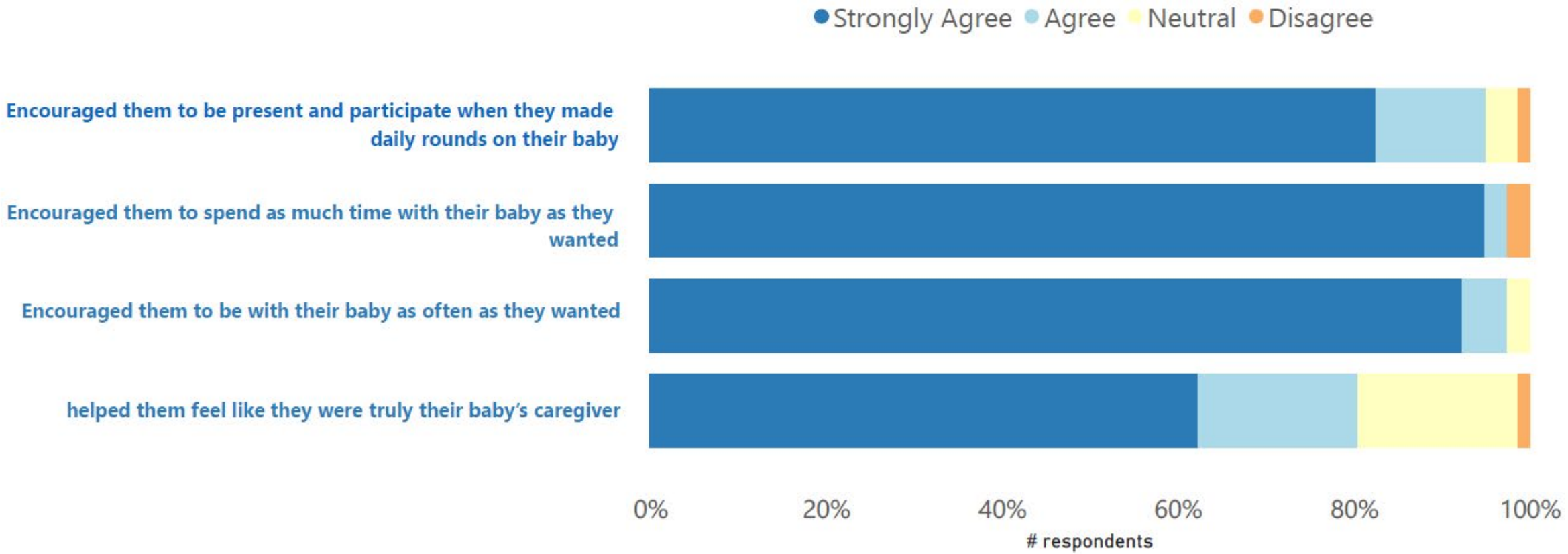

SURVEYS SUBMITTED
40
20
0
4
4
9
14
11
12
22
45
44
January
March
April
May
June
July
August
September
October
Qtr 1
Qtr 2
Qtr 3
Qtr 4
2022

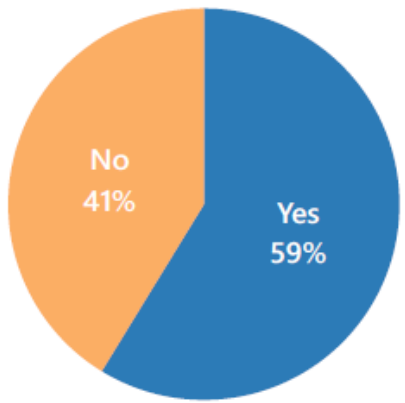
165

The family caregiver felt that the NICU team....



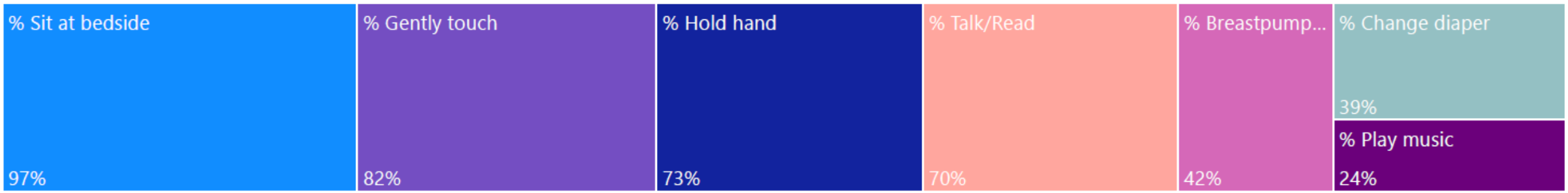
PARTICIPATION - First NICU encounter

% that held their baby the first time they saw their baby in the NICU



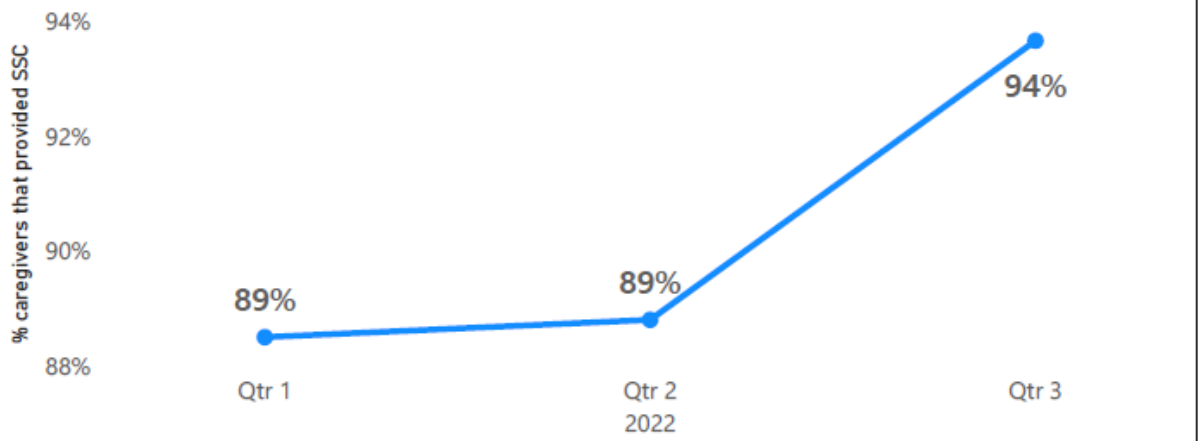
Of those that did not hold their baby in their first NICU encounter, reason for not holding:

Activities done by the caregiver when unable to hold baby

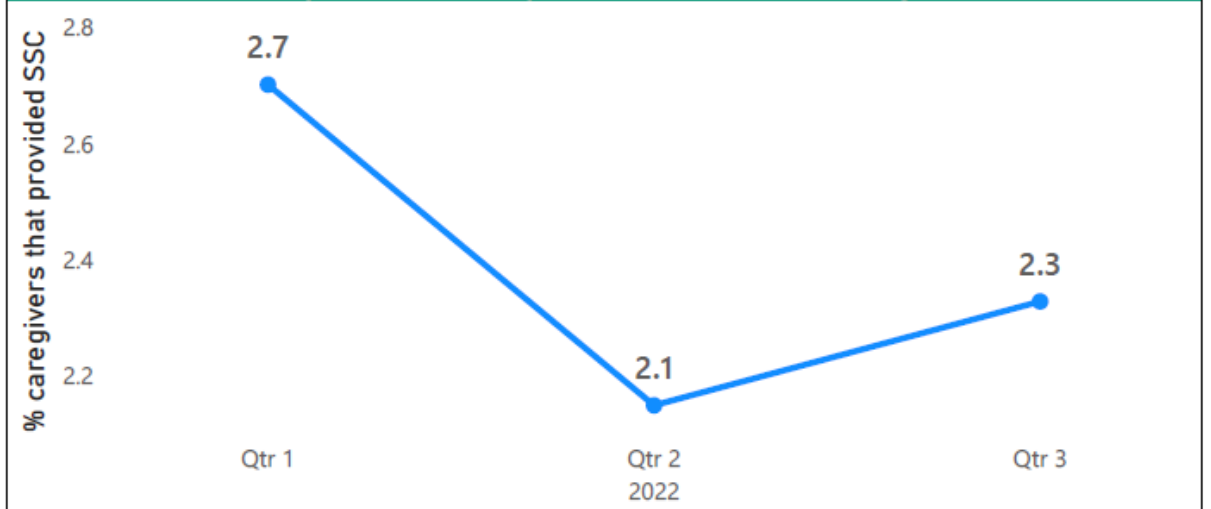


PARTICIPATION - SKIN-TO-SKIN CARE

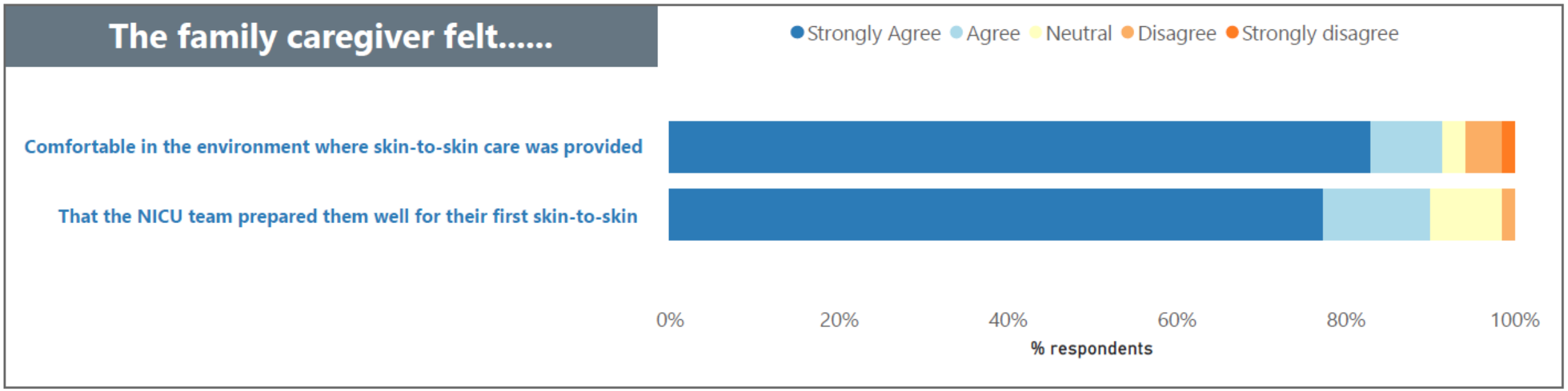
% of caregivers that provided skin-to-skin care in the hospital



Average # of days to first SSC episode

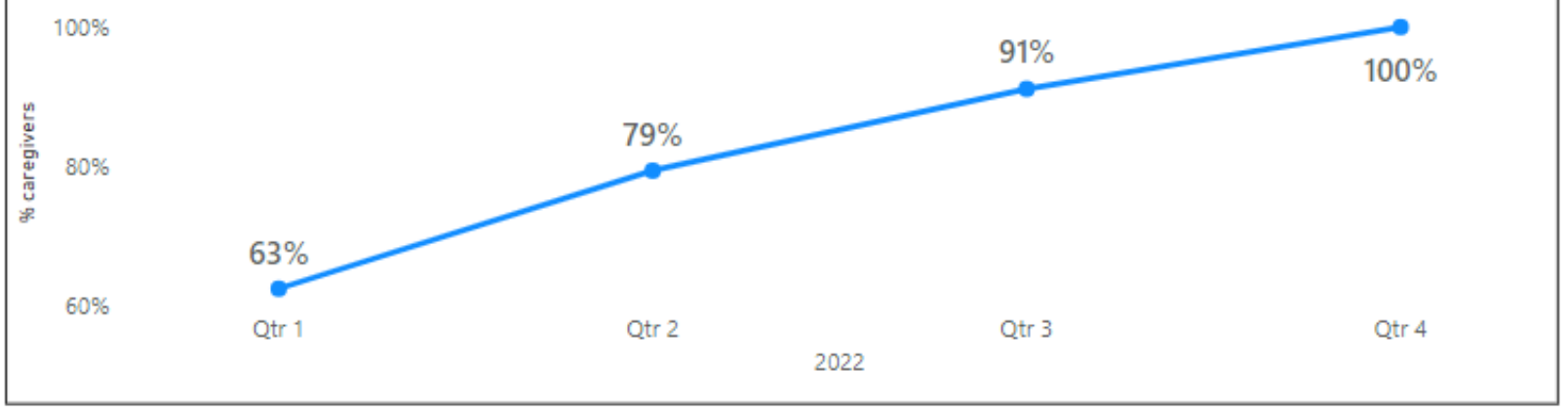


The family caregiver felt.....

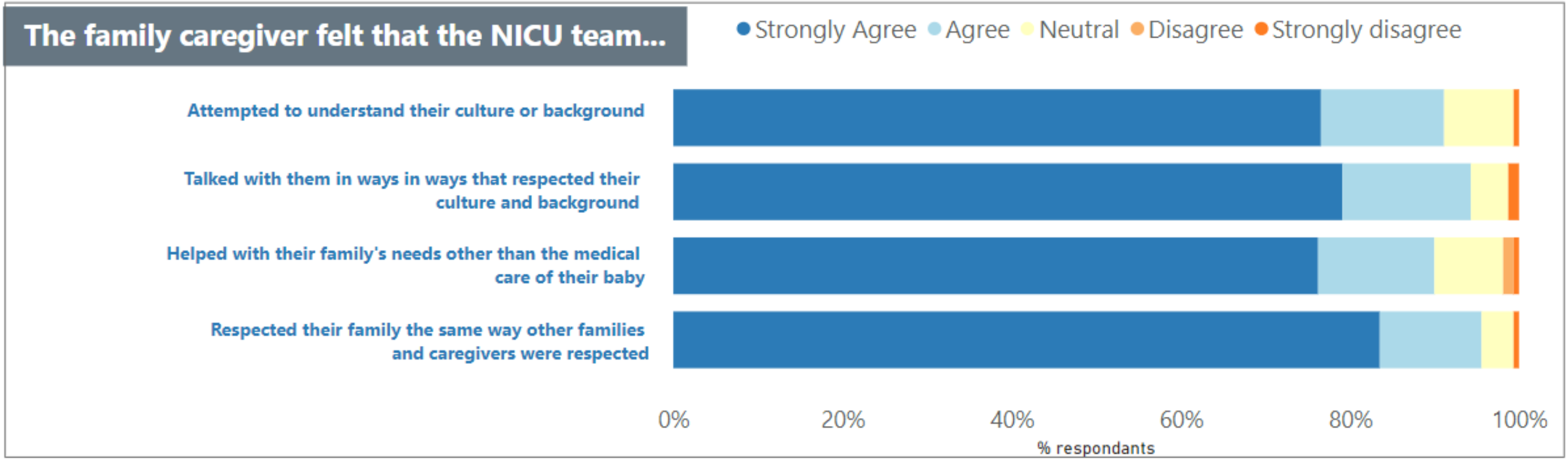


DIGNITY AND RESPECT

% of caregivers that reported talking to the NICU team in detail about what to expect while in the NICU

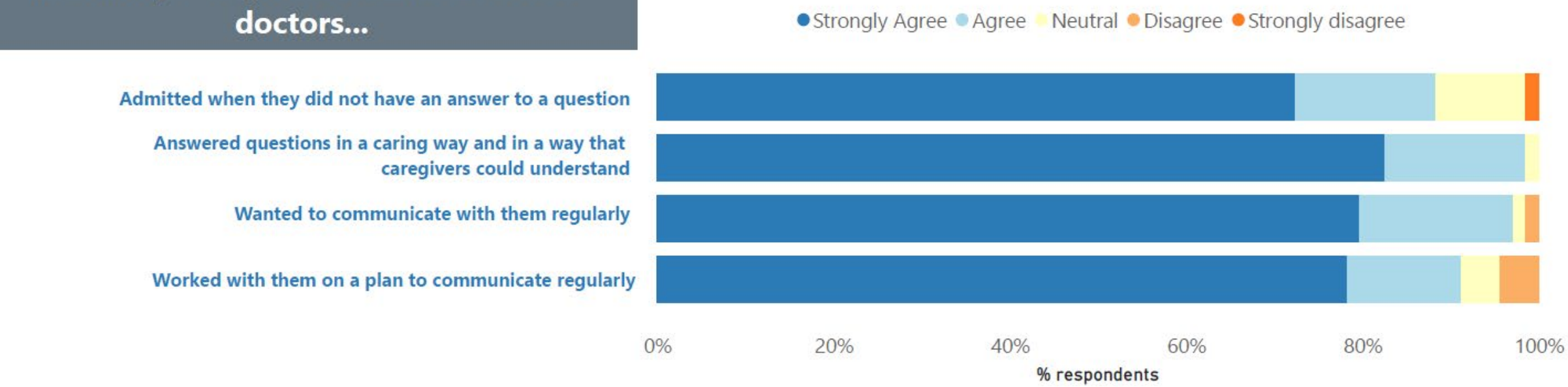


The family caregiver felt that the NICU team...

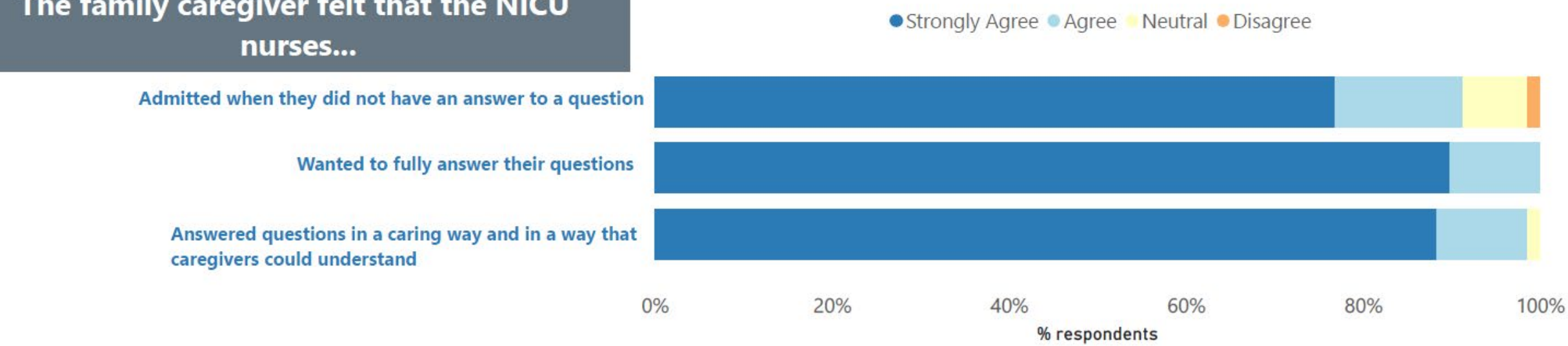


COMMUNICATION

The family caregiver felt that the NICU doctors...



The family caregiver felt that the NICU nurses...



PREPAREDNESS

Average of caregiver s' rating of how well prepared they felt about...

Year	2022			
	Qtr 1	Qtr 2	Qtr 3	Qtr 4
% Taking care of baby at home	100	98	97	97
% Breastfeeding	73	87	96	93
% Bottle feeding	100	96	96	98
% Providing general newborn care	100	98	97	97
% Giving medications	100	91	93	83
% Managing equipment	90	94	91	90
% Baby is medically ready to go home	100	97	98	97
% Know what to do in an emergency	100	93	98	92

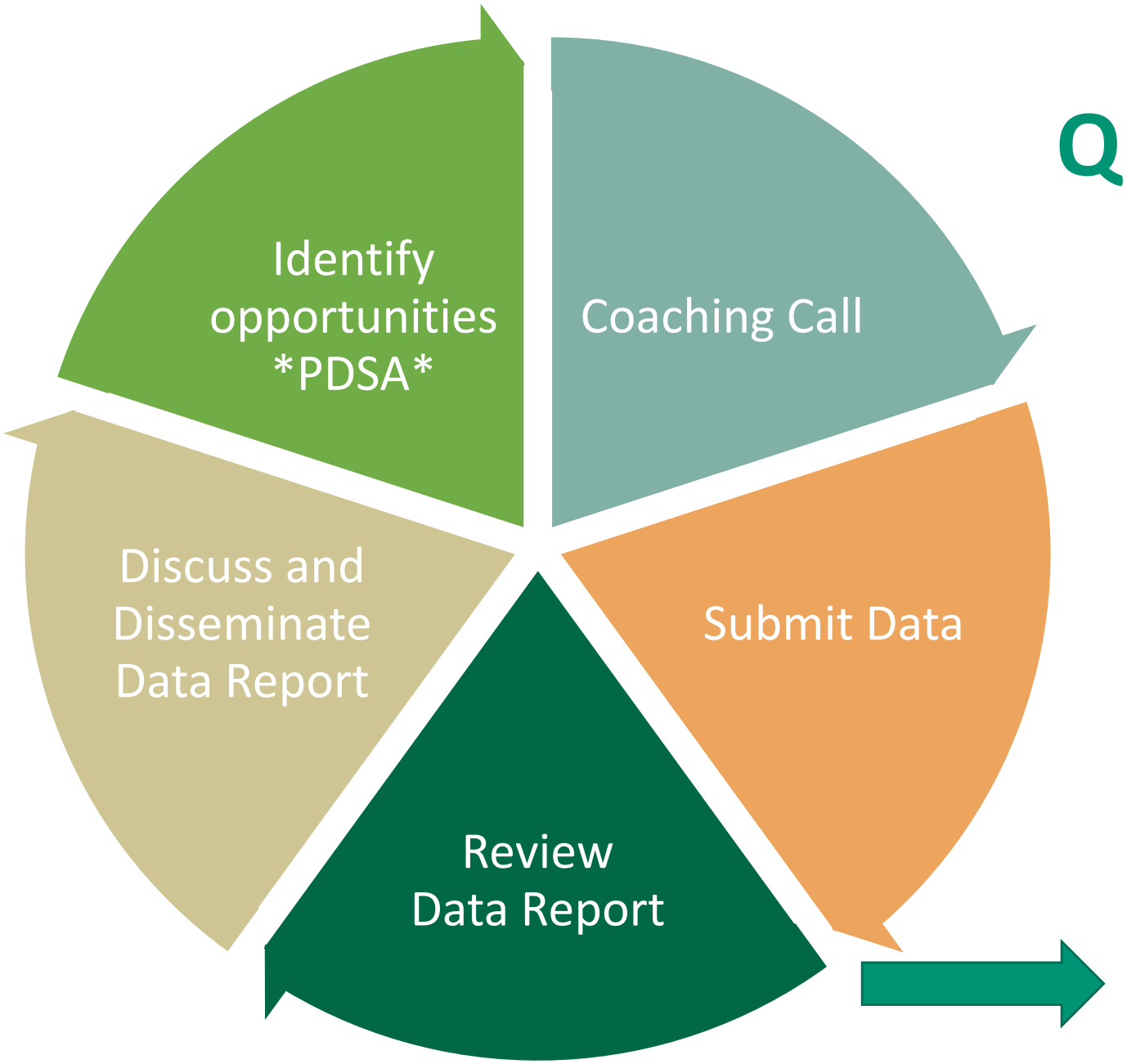
PAIRED—Family-Centered Care

Date: 10/9/2020

AIM	PRIMARY DRIVERS	SECONDARY DRIVERS	PBPs	
PRIMARY **By 6/2023, each NICU will achieve a 20% increase from baseline in the percentage of infants who receive skin-to-skin care from at least one family caregiver within 3 days of clinical eligibility as defined by individual unit protocols.** **SUPPLEMENTAL** **By 6/2023, family caregiver surveys will demonstrate a 20% improvement from baseline in the perception of the culture of family-centered care in each NICU as averaged across all 4 domains.**	**Participation** Participation of family in care	Educate family caregiver(s) to become active participants in the care of their infant from admission to discharge Provide family caregiver(s) with appropriate and increasing direct care opportunities.	• Encourage family caregiver(s) participation in early skin-to-skin care • Provide early and continuing lactation support to promote breastfeeding	16% 18%
	Dignity and Respect Identification of each infant and family member as an individual	Acknowledge that each infant and family member is an individual. Incorporate family knowledge, values, beliefs and cultural backgrounds into the planning and delivery of care.	• Create a culturally sensitive environment supportive of skin-to-skin care (reclining chairs, access to food and water, privacy)	?
	Collaboration Respectful and effective communication and partnership with families	Establish a culturally sensitive environment in which families feel respected and that fosters anticipatory and effective communication with and trust from family caregiver(s). Encourage collaboration with families, caregivers and unit leaders in the development, implementation, and evaluation of policies and procedures; in educational programs; and in protocols for family participation in care.	• Consult families, revisit and revise policies that limit family caregiver interaction with infant (protocols regarding skin-to-skin care, holding, visitation, signage, etc.)	180%
	Information Sharing Education about medical care and clinical processes	Provide family caregiver(s) with complete, accurate and unbiased information and graduated education throughout the NICU stay to allow effective participation in care, to optimize decision-making, and to enable caregivers to become competent primary caregivers for their infant(s).	• Initiate family caregiver and staff competency training on skin-to-skin care	75% 25%

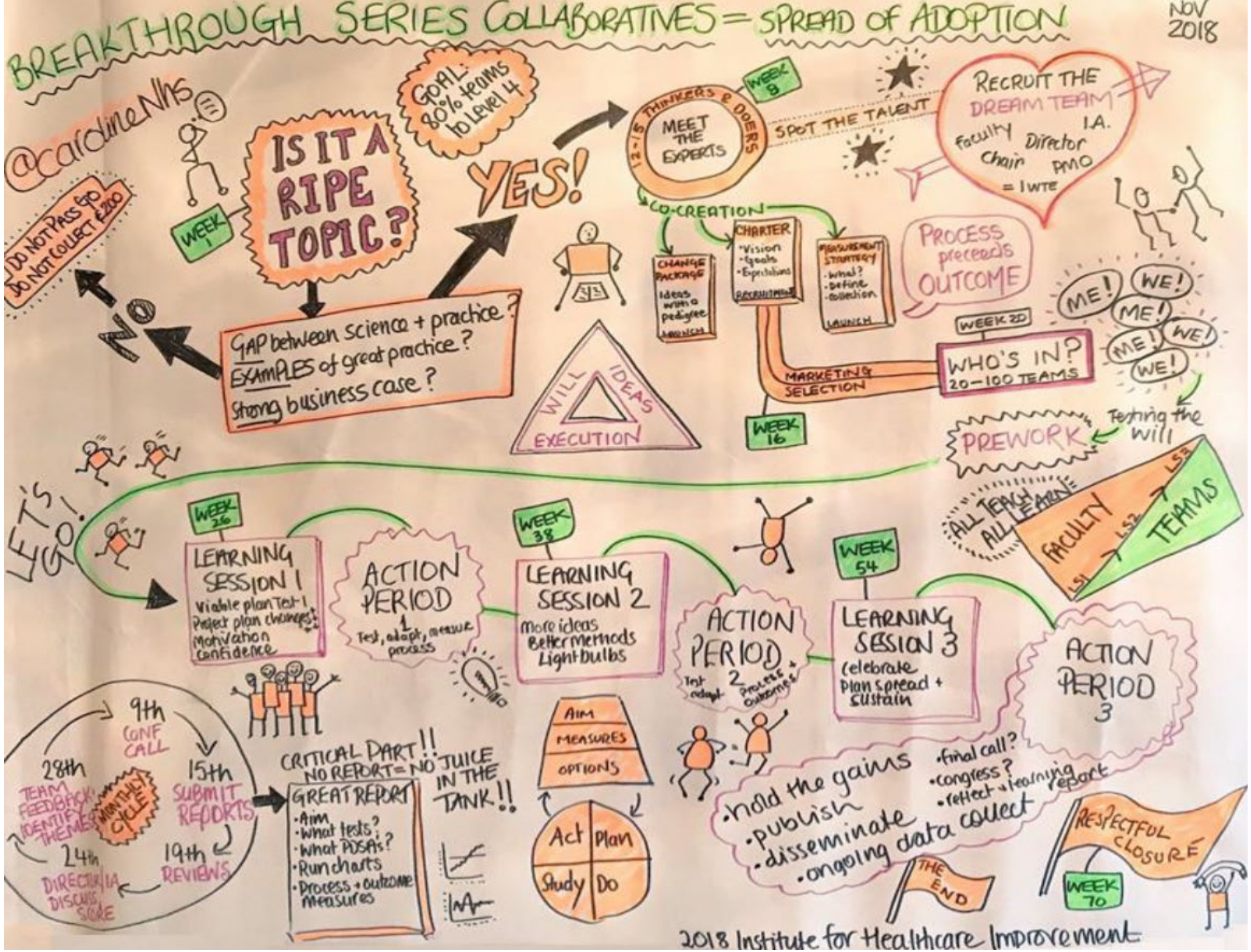
Family-centered care is defined as a shared approach to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and family caregiver(s). There are four essential domains of FCC: 1) family participation in care, 2) dignity and respect, 3) family collaboration, and 4) information sharing.

QI MONTHLY CYCLE



QI REPORTS

- Aim
- Run Charts
- Tracks Process, Structural and Outcome Measures
- Add your PDSAs


BREAKTHROUGH SERIES COLLABORATIVES = SPREAD of ADOPTION
NOV 2018
@carolineNHS
GOAL: 80% teams to Level 4
IS IT A RIPE TOPIC?
YES!
NO
DO NOT PASS GO DO NOT COLLECT £200
WEEK 1
GAP between science + practice?
EXAMPLES of great practice?
Strong business case?
12-15 THINKERS & DOERS
MEET THE EXPERTS
WEEK 8
SPOT THE TALENT
RECRUIT THE DREAM TEAM
Faculty Director I.A.
Chair PMO
= 1 WTE
CO-CREATION
CHANGE PACKAGE
Ideas with a pedigree
CHARTER
•Vision
•Goals
•Expectations
MEASUREMENT STRATEGY
•what?
•define
•collection
PROCESS precedes OUTCOME
WEEK 20
WHO'S IN? 20–100 TEAMS
MARKETING & SELECTION
WEEK 16
WILL IDEAS EXECUTION
ME! WE! ME! ME! WE! WE!
Testing the will
PREWORK
ALL TEACH ALL LEARN
FACULTY LS1 LS2
TEAMS LS3
LET'S GO!
WEEK 26
LEARNING SESSION 1
Viable plan Test-1
Perfect plan changes
Motivation confidence
ACTION PERIOD 1
Test, adapt, measure process
WEEK 38
LEARNING SESSION 2
More ideas
Better Methods
Lightbulbs
ACTION PERIOD 2
Test adapt Practice + Outcomes
WEEK 54
LEARNING SESSION 3
Celebrate
Plan spread + sustain
ACTION PERIOD 3
9th CONF CALL
15th SUBMIT REPORTS
19th REVIEWS
24th DIRECTOR/IA DISCUSS SCORE
28th TEAM FEEDBACK IDENTIFY THEMES
MONTHLY CYCLE
CRITICAL PART!!
NO REPORT = NO JUICE IN THE TANK!!
GREAT REPORT
•Aim
•What tests?
•What PDSAs?
•Run charts
•Process + outcome measures
Aim
Measures
Options
Act Plan Study Do
•hold the gains
•publish
•disseminate
•ongoing data collect
•final call?
•congress?
•reflect + learning report
THE END
RESPECTFUL CLOSURE
WEEK 70
2018 Institute for Healthcare Improvement

Questions?

fpqc@usf.edu

www.fpqc.org

"To improve the health and health care of all Florida mothers & babies"

Conducting Neonatal Quality Improvement with a Health Equity Lens

Meg Parker, MD MPH

Professor of Pediatrics

Academic Chief of Neonatology, UMass Memorial Medical Center

Co-Director- Neonatal Side

Perinatal Neonatal Quality Improvement Collaborative of Massachusetts

Florida PQC PAIRED Initiative

November 3, 2022

Child Health Equity Center

UMass Chan Medical School

PN QIN Perinatal-Neonatal Quality Improvement Network

Disclosures

- I have no conflicts of interest.

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Topics

- Quality Improvement and Equity
- Using a health equity lens in neonatal QI
  - Data measures
  - Family members as partners
  - Standardized and non-standardized approaches
- Equity in skin to skin care in the NICU setting

Seminars in Perinatology 2021

Six Domains of Health Care Quality

- Institute of Medicine
  - Safe
  - Effective
  - Patient-centered
  - Timely
  - Efficient
  - Equitable

https://www.ahrq.gov/talkingquality/measures/six-domains.html

Six Domains of Health Care Quality

- Institute of Medicine
  - Safe
  - Effective
  - Patient-centered
  - Timely
  - Efficient
  - Equitable: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location and socioeconomic status

https://www.ahrq.gov/talkingquality/measures/six-domains.html

AHRQ: 2018 National Healthcare Quality and Disparities Report

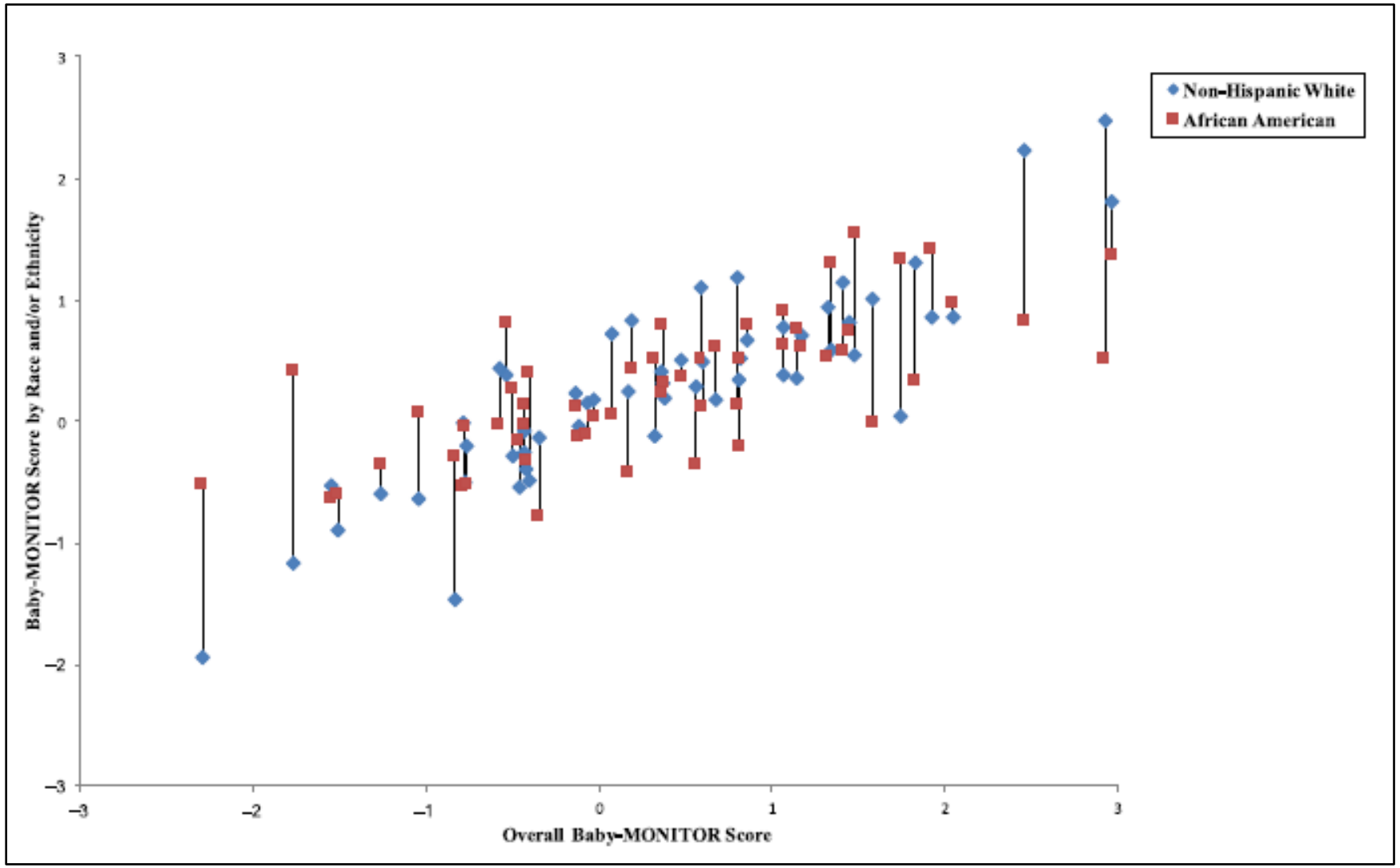
- When reviewing racial and ethnic disparities in quality measures, most have persisted or worsened since 2000
- This occurs with pediatric and adult healthcare quality measures

Racial/Ethnic Disparities in Neonatal Care Quality

- Examination of “Baby-MONITOR” NICU quality measure score among California NICUs according to race/ethnicity
- Stark racial/ethnic disparities in Baby-MONITOR scores, which varied dramatically by center

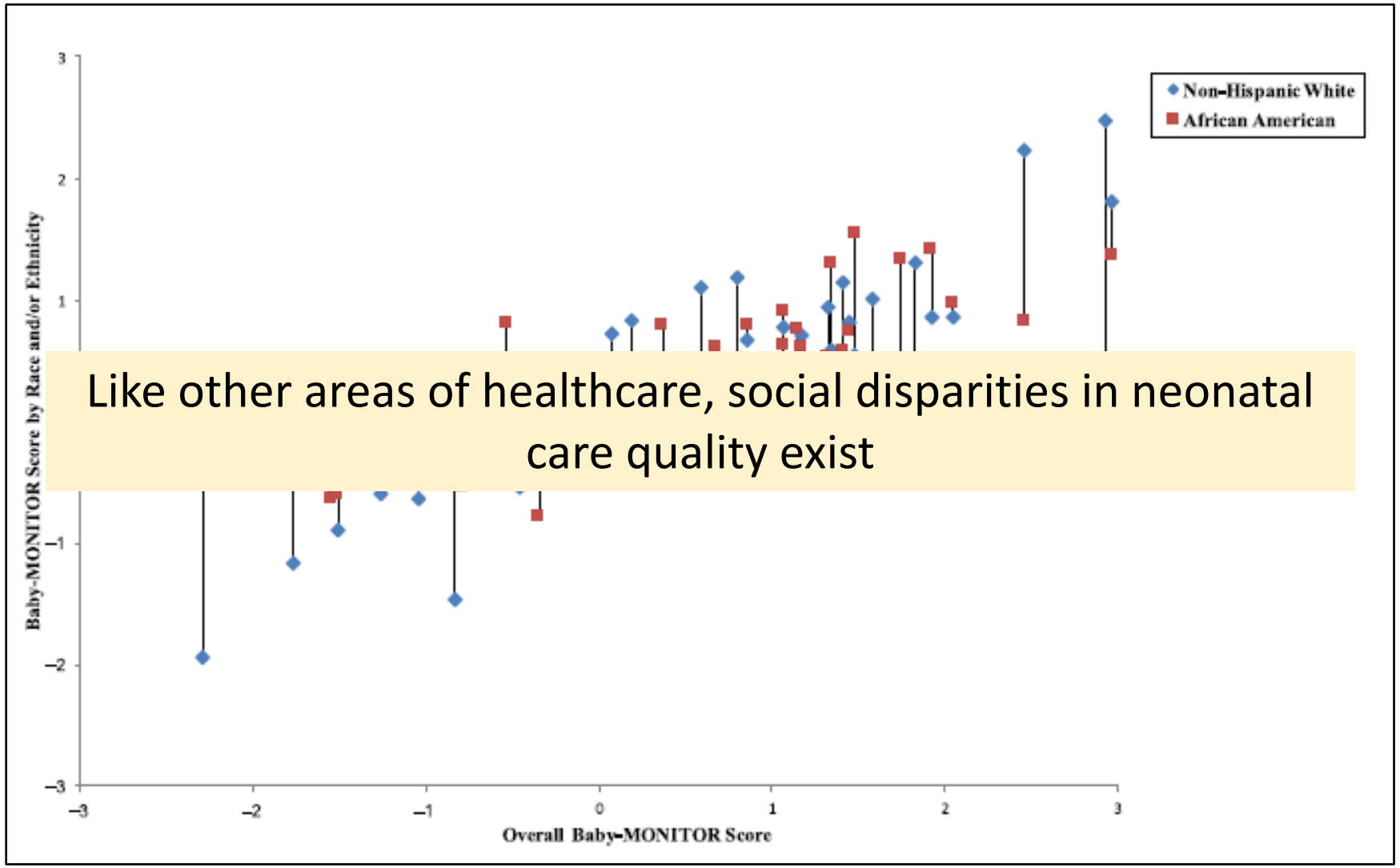
Proft et al. *Pediatrics* 2017; Sigurdson et al. *Pediatrics* 2019; Edwards et al. *Pediatrics*, 2021

Black/White Disparities in Neonatal Care Quality by Center



Proft et al. *Pediatrics* 2017; Sigurdson et al. *Pediatrics* 2019

Black/White Disparities in Neonatal Care Quality by Center



Like other areas of healthcare, social disparities in neonatal care quality exist

Proft et al. *Pediatrics* 2017; Sigurdson et al. *Pediatrics* 2019

1) NICU care quality contributes to NICU outcomes

2) NICUs vary in the *degree* of social disparities in care quality and subsequent outcomes. This means that there are there are things we can do better in the NICU to address this

1) NICU care quality contributes to NICU outcomes

2) NICUs vary in the *degree* of social disparities in care quality and subsequent outcomes. This means that there are there are things we can do better in the NICU to address this

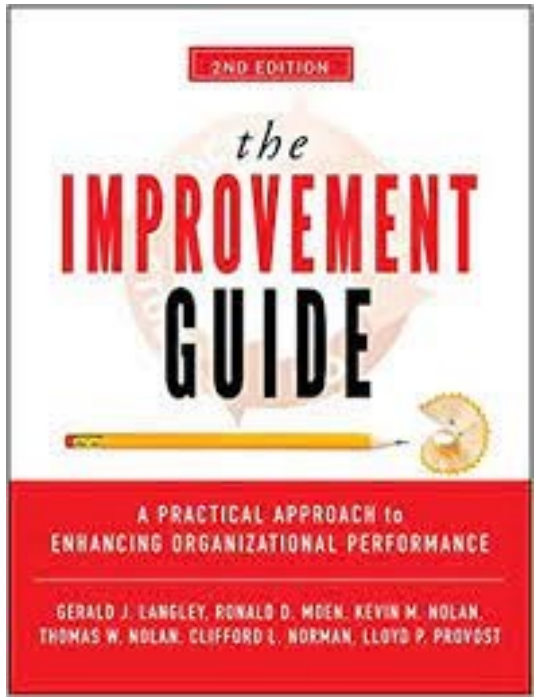
Use QI Methods!!

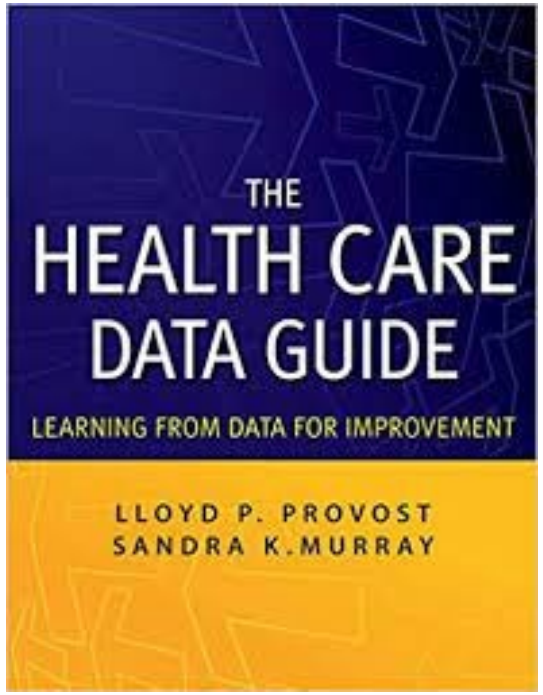
What is the Role of Quality Improvement?

- Quality improvement is the framework to systematically improve care.
- Quality improvement seeks to standardize processes and structure to reduce variation, achieve predictable results, and improve outcomes for patients, healthcare systems, and organizations.

- Key elements:
  - Track changes over time
  - Systematically trial interventions
  - Usually involves multidisciplinary teams

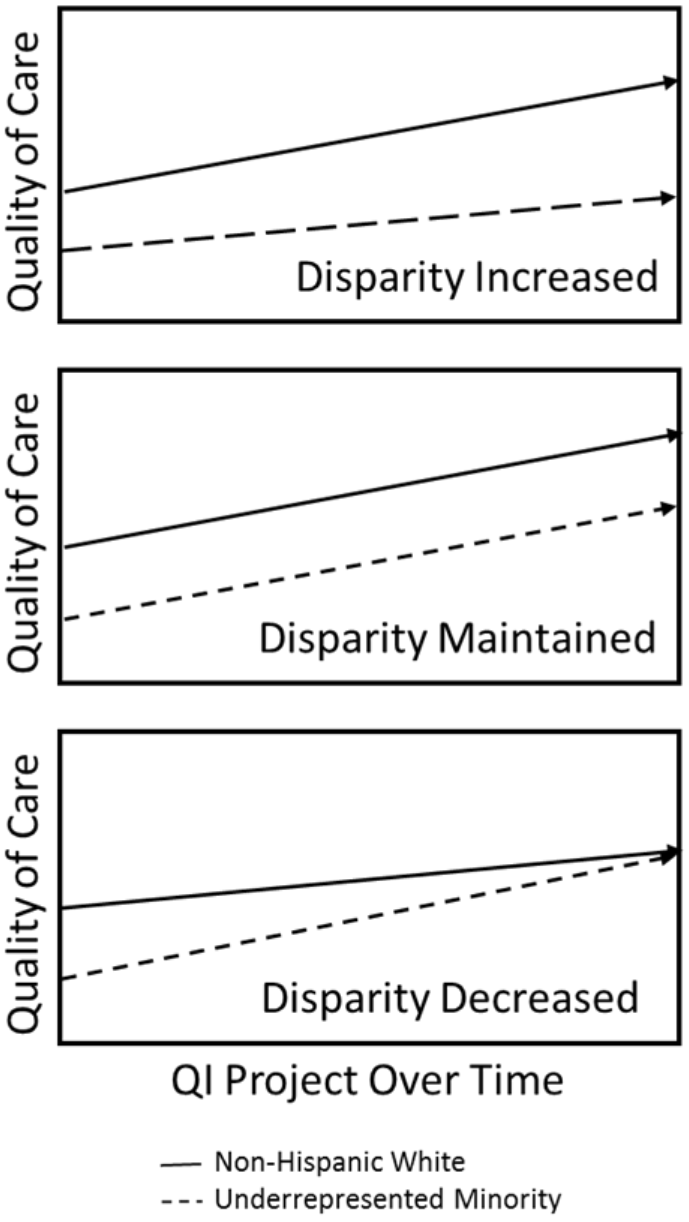
What Impact Does QI Have on Social Disparities in Care Delivery?





MISSING!!!

Three Scenarios



Adapted from Green et al, The Joint Commission Journal on Quality and Patient Safety, 2010.

Quality Improvement is a Very Powerful Framework!

How Do You Address Health Equity Using Quality Improvement?

Available online at www.sciencedirect.com

Seminars in Perinatology

www.seminperinat.com

Quality improvement approaches to reduce racial/ethnic disparities in the neonatal intensive care unit

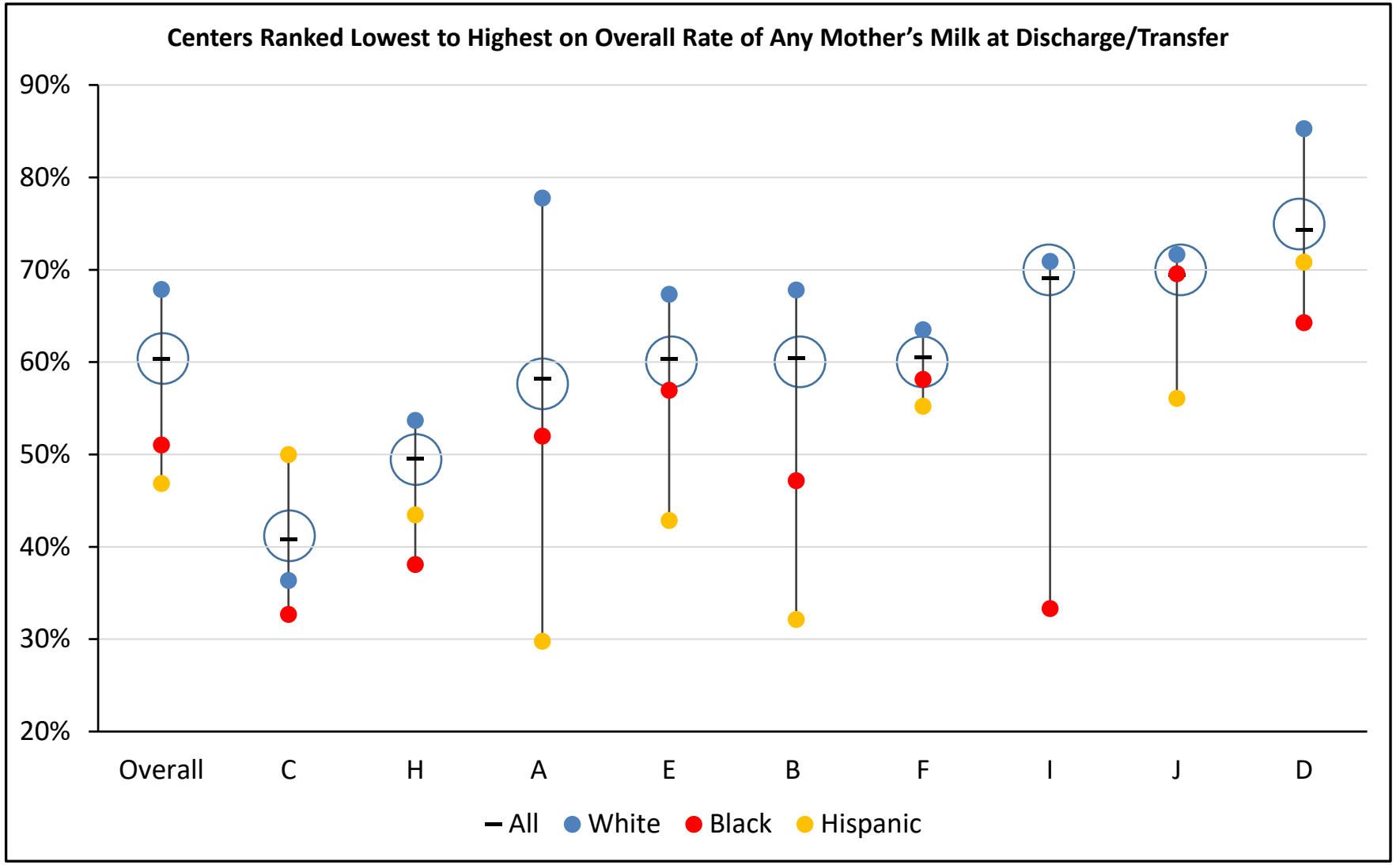
Margaret G. Parker[a,*], *and Sunah S. Hwang*[b]

1) Data Measurement Selection

- Many times people don’t know that social disparities exist because measurement of social factors is lacking
- You can’t address disparities unless you know they exist!
- When you find out, it can be incredibly revealing!
- Example: MA Human Milk Project 2015-2017

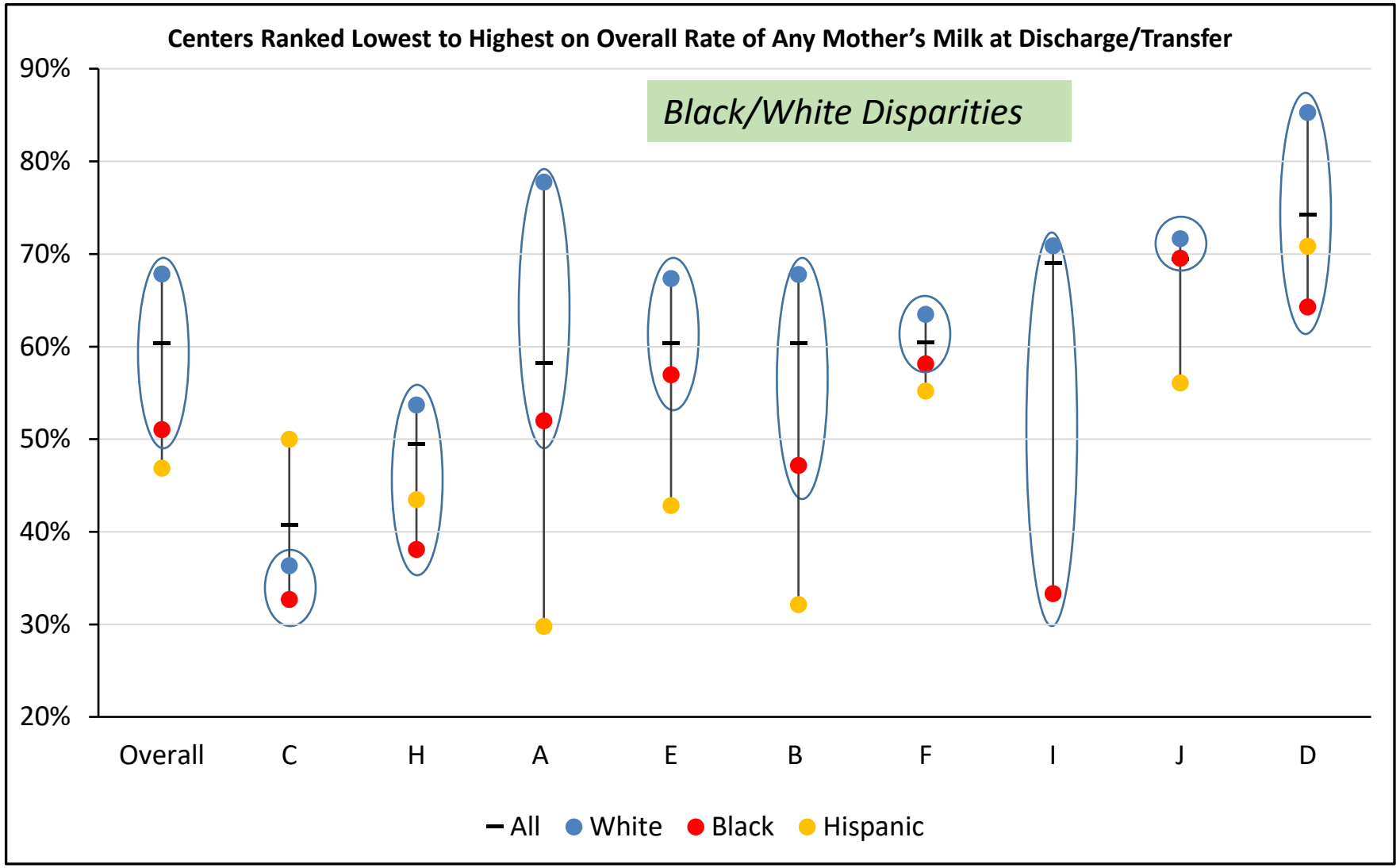
Example of Hospital-Level Racial/Ethnic Disparities

MA Human Milk QI Project 2015-2017



Parker et al, *Pediatrics 2019*

Hospital Variation in Disparities



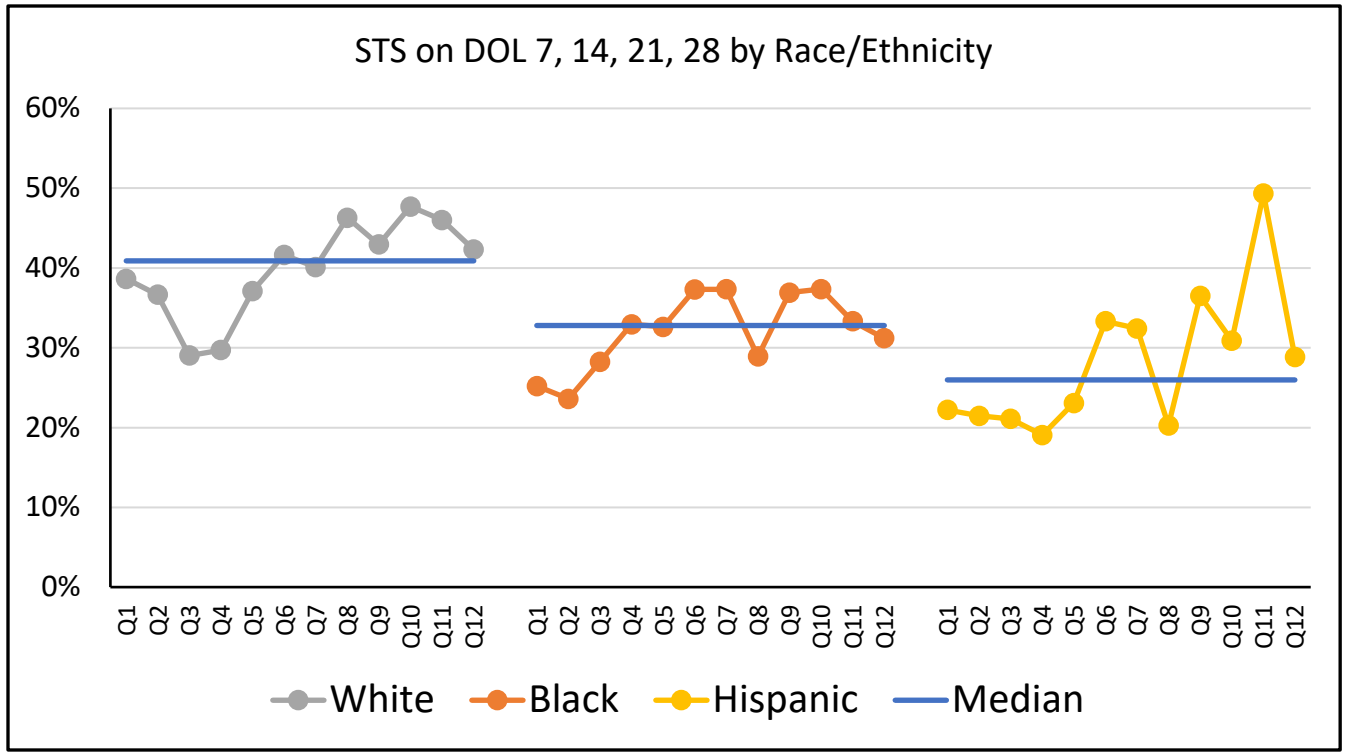
Parker et al, *Pediatrics 2019*

Barriers to QI Project Data Collection that Enable Tracking by Social Factors

- Data reporting by social factors is burdensome
  - Can be time intensive
    - Individual-level data collection
  - More intense data regulatory requirements

- Measures of social factors are inaccurate or missing
  - Example: Limited English Proficiency

STS on Chart Audit Days According to Race/Ethnicity
MA Human Milk Collaborative 2015-2017



2) Include Family Perspectives

- Even though everyone agrees that family member perspectives are important, they are often left out of multidisciplinary teams

Survey to MA NICU Teams in March 2020 to 15 hospitals: Only 20% routinely involve family members on their QI teams

How to Involve Family Partners

- Zoom
- Compensation
- Diverse family types
- Make accommodations for schedules

3) Intervention Approach

- Standardized Approach: "One-size-fits-all" model: introduce a standardized set of interventions to all groups

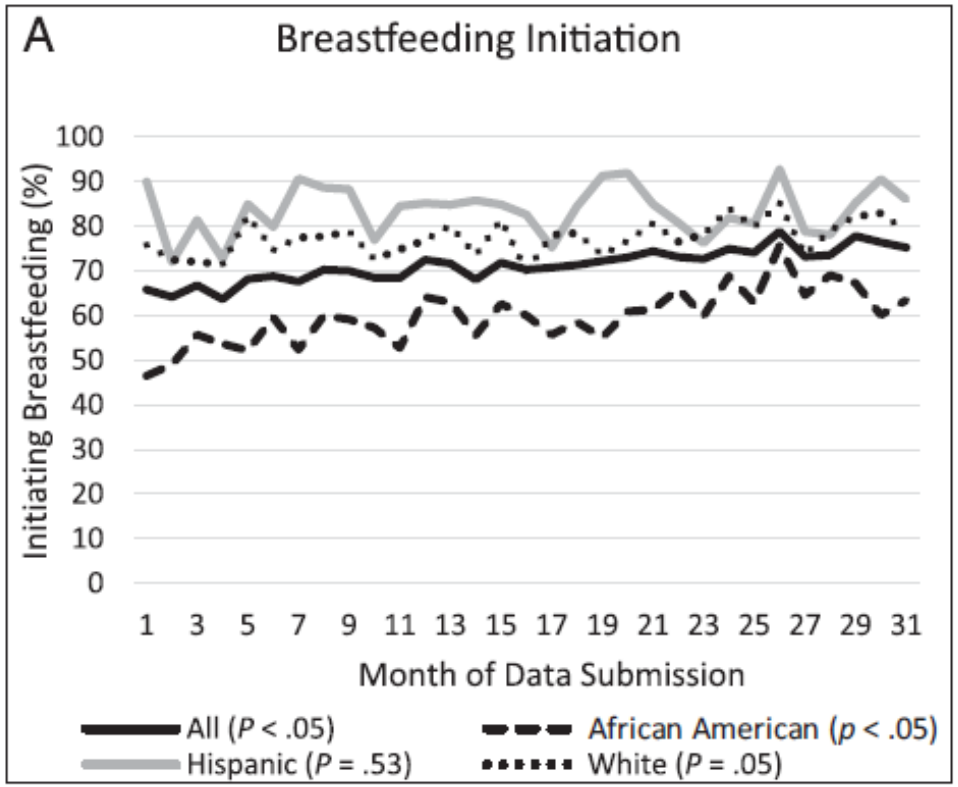
- Non-standardized Approach: "Culturally competent QI" model: introduce interventions that are tailored to the particular needs of a given group

Green et al, The Joint Commission Journal on Quality and Patient Safety, 2010.

Standardized Approaches to Care

- This can be highly successful
- Reduces variation
- Example: CHAMPS

Baby-Friendly Ten Steps introduced in Southern US maternity hospitals



Merewood et al, 2019

Skin to Skin Care: Standardized Approaches

- Consistent guidelines for eligibility within a center
- AAP guidance
  - STS can be safety performed for infants with secured umbilical lines, ventilated infants, and those receiving positive pressure ventilation

Baley J; Skin to skin care for term and preterm infants in the neonatal ICU; AAP COFN; *Pediatrics* 2015

Survey to 15 MA NICU/SCNs in 2020:
What is your approach to skin to skin in the following clinical scenarios?

Scenario	Prohibited	Discouraged	Encouraged	N/A
ELBWs in the first 72 hours of life	0	2	5	8
Infant on a regular ventilator	0	1	6	7
Infant on a high-frequency ventilator	3	3	1	8
Infant on CPAP	0	1	9	5
Infant with UAC	4	1	6	4
Infant with UVC	2	3	7	3
"Feeder and grower" maintaining temperature in an open crib	0	0	15	0
Infant with symptoms of NAS	0	0	15	0

Survey to 15 MA NICU/SCNs in 2020:
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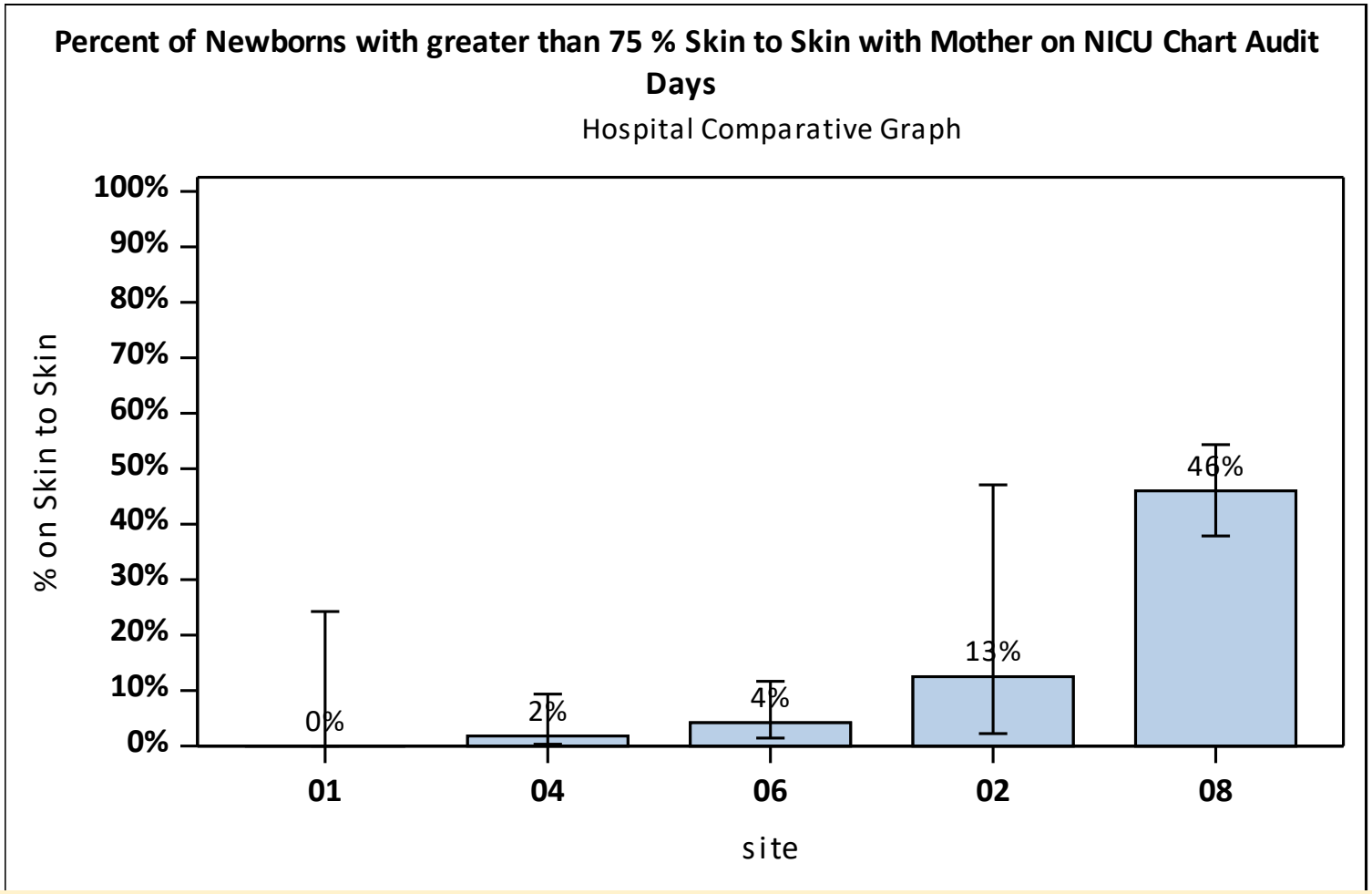
Infant				
Infant				
Infant with UVC	2	3	7	3
"Feeder and grower" maintaining temperature in an open crib	0	0	15	0
Infant with symptoms of NAS	0	0	15	0

There isn't a consistent approach and in many cases care does not align with AAP guidance

MA Family Engagement Project: STS by Center 2020-2022



Large variation among centers indicates more standardized approaches are needed

PDSAs to Standardize Approach to STS

- Update guidelines or consistently use guidelines
- Prompts in daily rounds or nursing hand-offs
- Prompts in patient facing materials (crib cards)
- Document STS
- Standardize approach to help transfer infants into STS position
- Kangaroo-a-thon

Crib Card

I'm eligible for Skin-to-Skin Care!

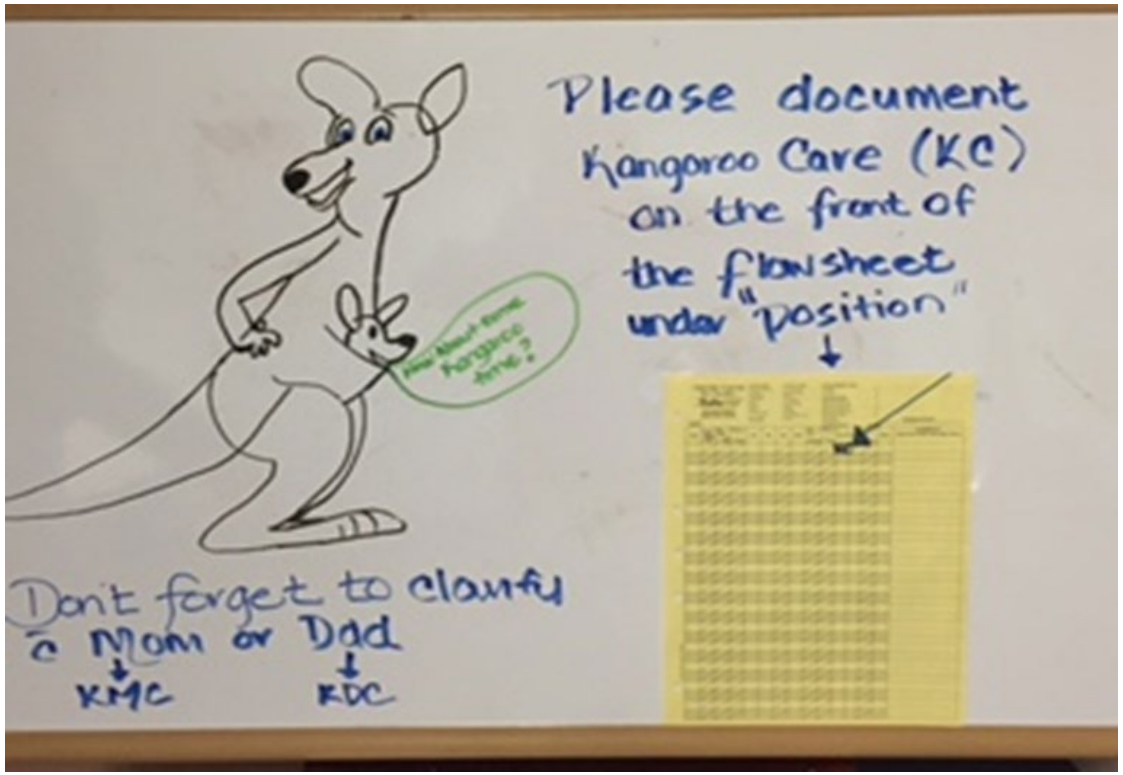
- Skin-to-Skin Care is when you hold your baby when he or she is naked, with only a diaper, on your bare chest
- Skin to Skin Care can help premature babies keep the right body temperature, breathe and sleep better and help mothers make more breast milk

Ask your medical team for more information

Goal population: premature infants < 44 weeks corrected gestational age

Kangaroo-a-thon

Documentation of STS



Skin to Skin Care: Standardized Approaches

- Consistent education to families

- Benefits
  - Breast milk
  - Bonding
  - Physiologic stability
- Practical aspects
  - Clothing
  - Length of time

Educational Materials

- https://www.neoqicma.org/educational-materials

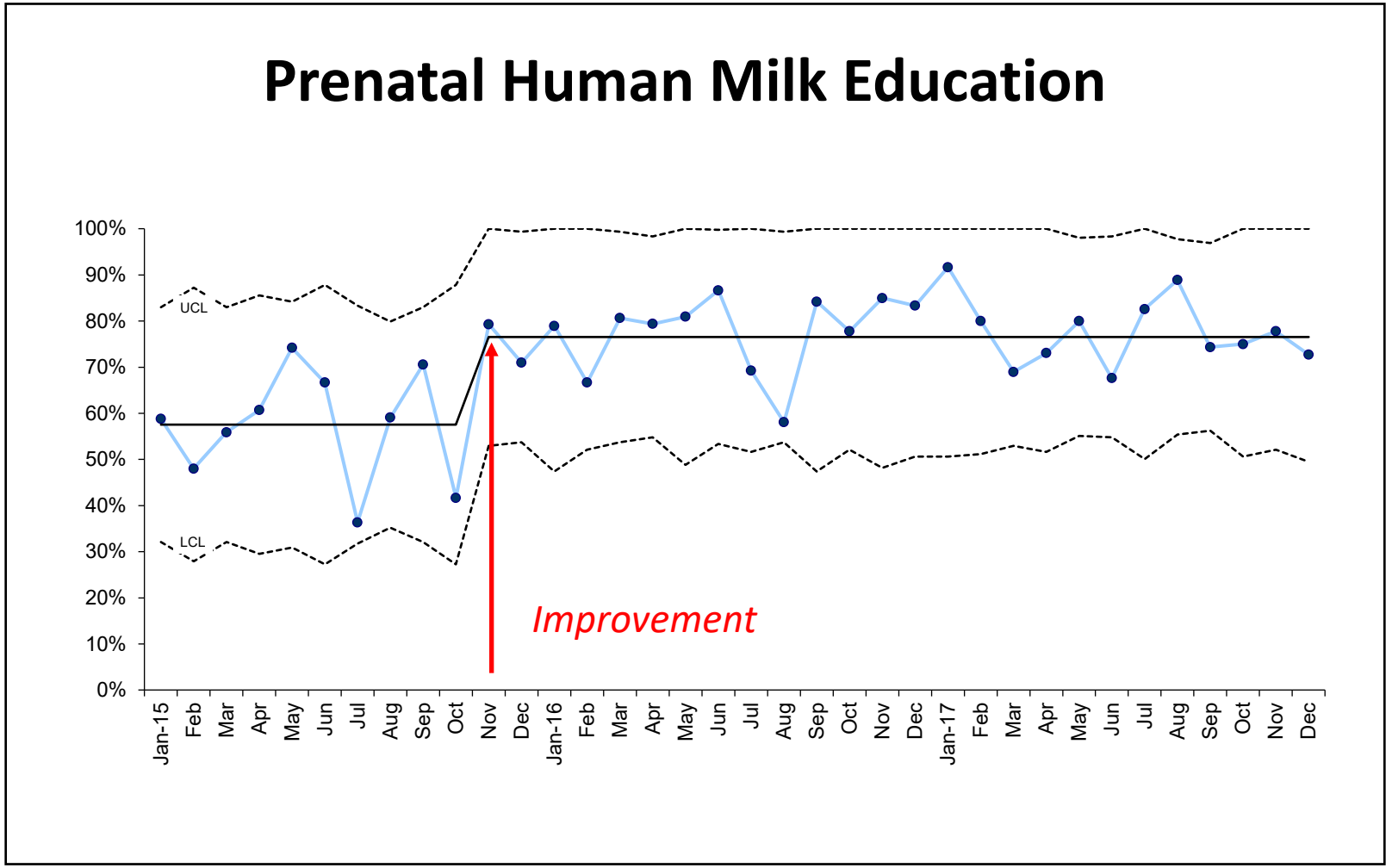
But sometimes standardized approaches aren't enough. . .

MA Human Milk Project 2015-2017

Goals: *Among VLBW infants in MA:*
1) Increase any/exclusive mother's milk at discharge
2) Reduce racial/ethnic disparities in provision of mother's milk

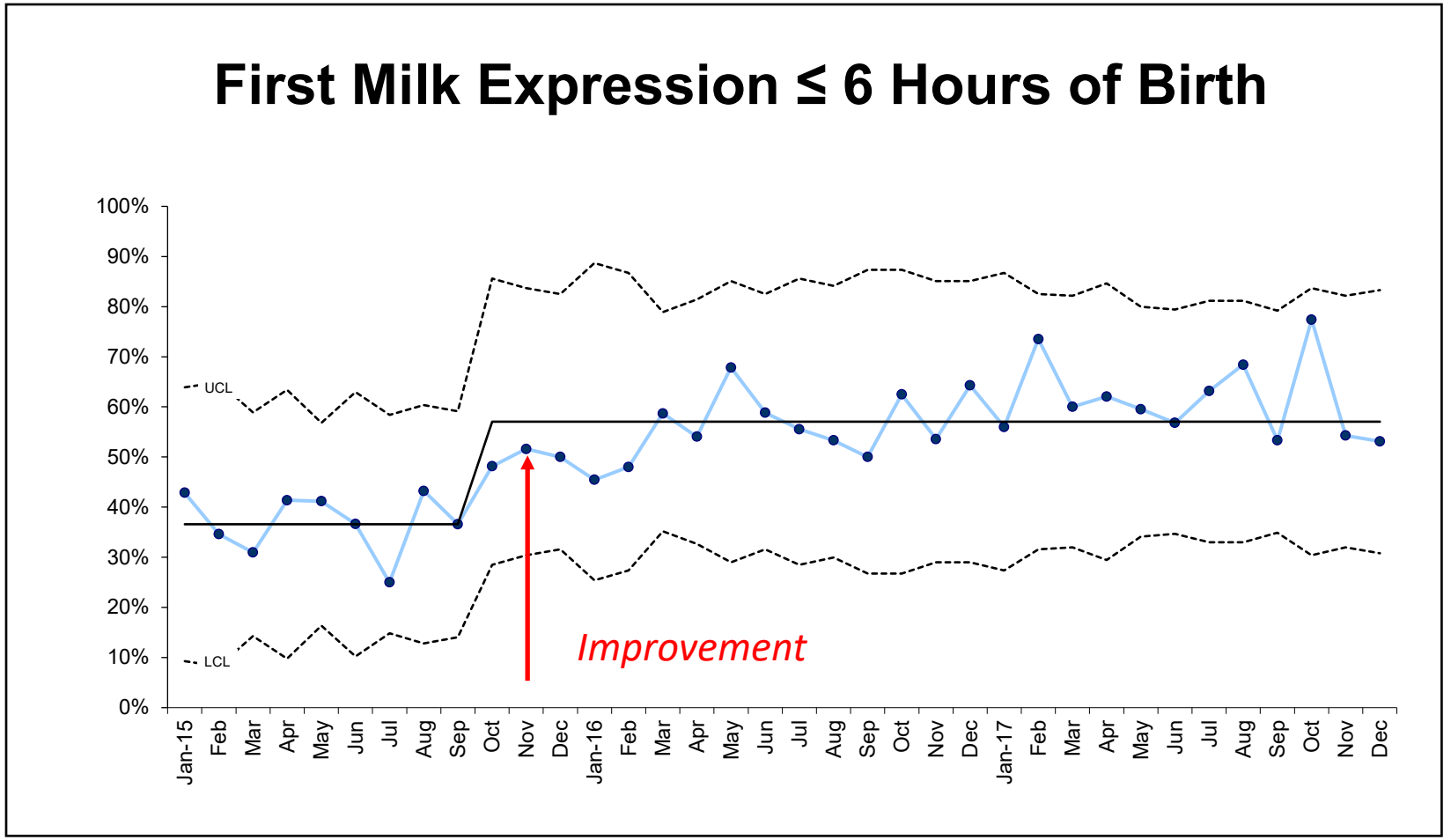
www.neoqicma.org

Process Measures



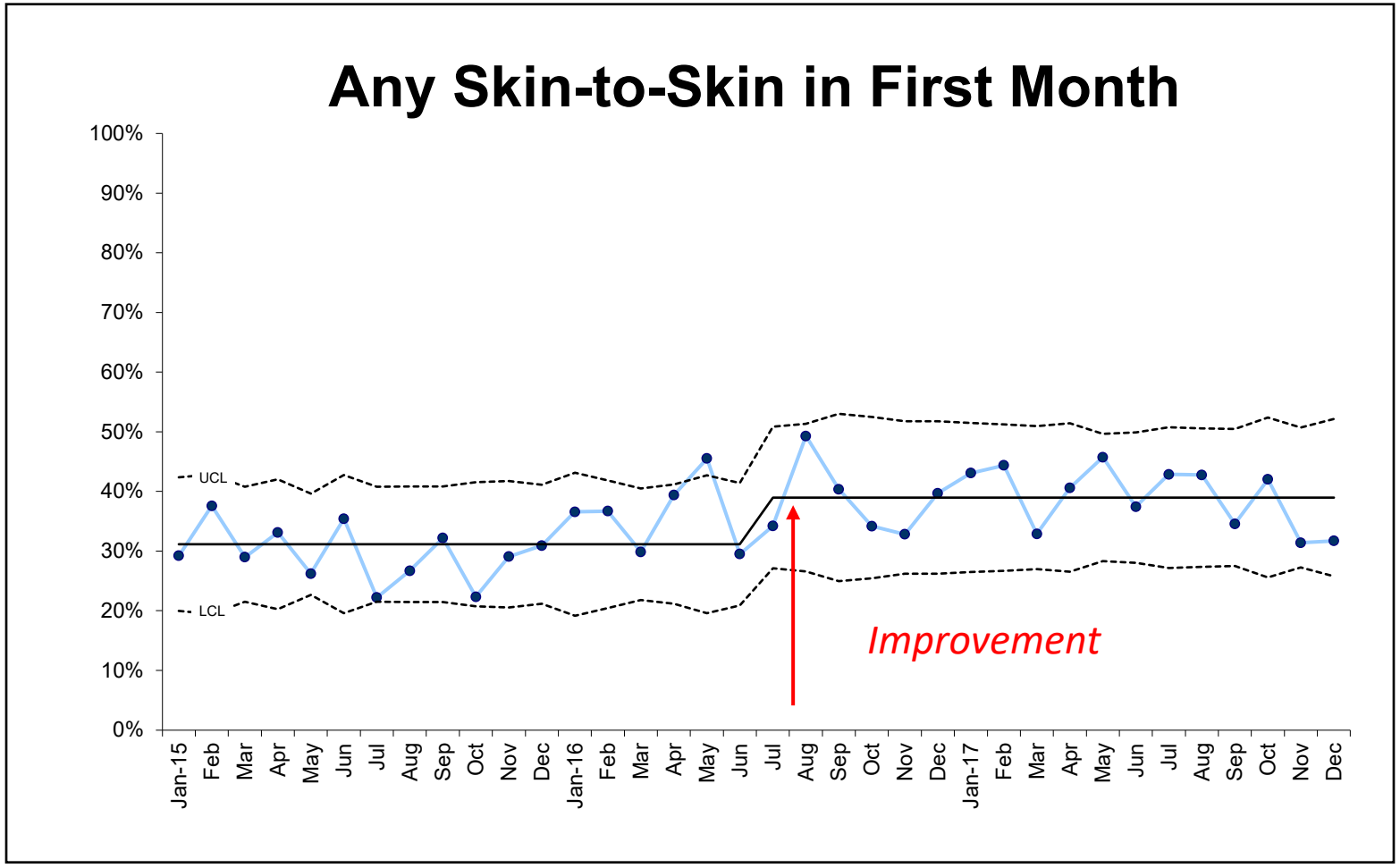
Parker et al, *Pediatrics* 2019

Process Measures



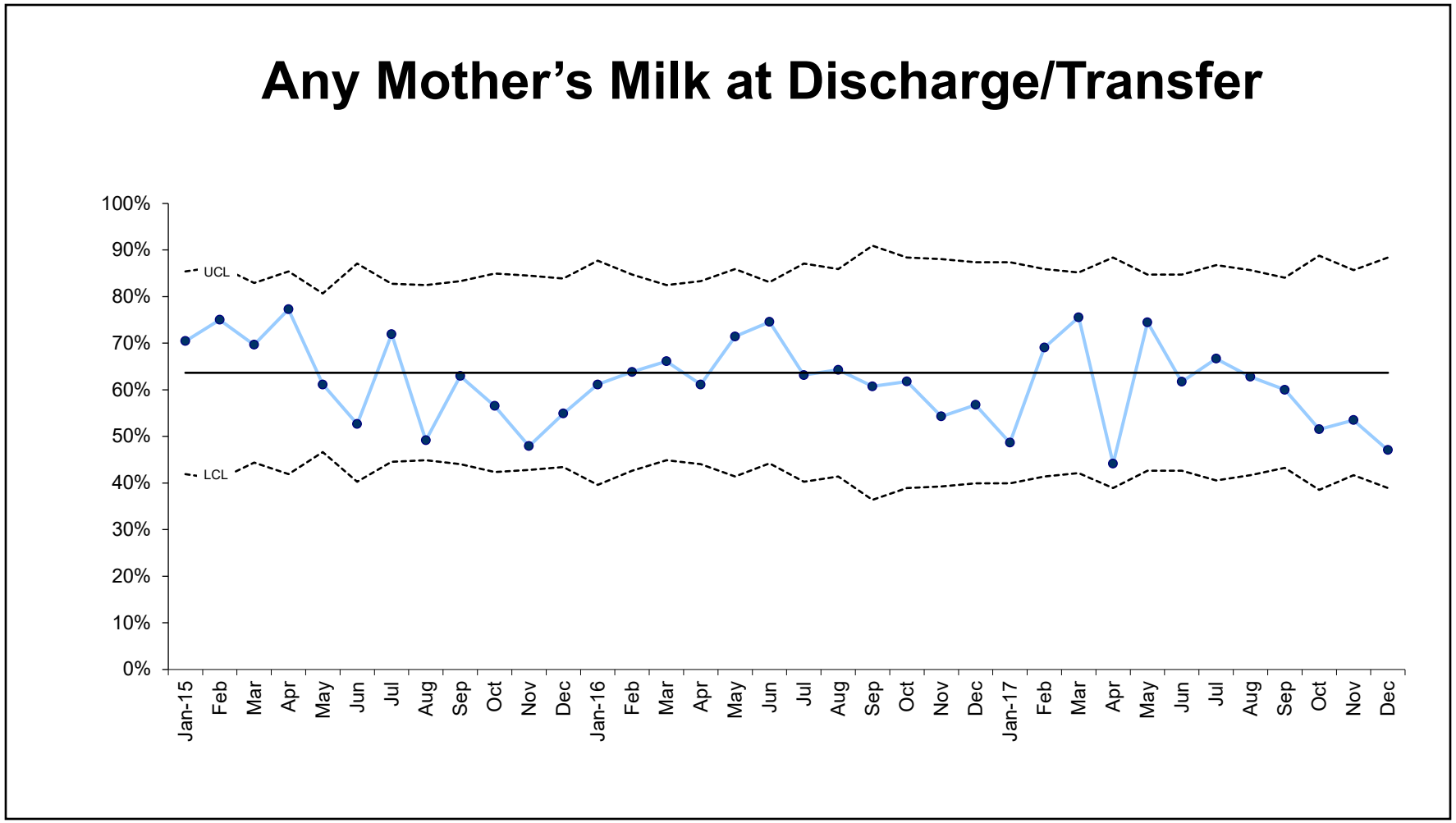
Parker et al, *Pediatrics* 2019

Process measures



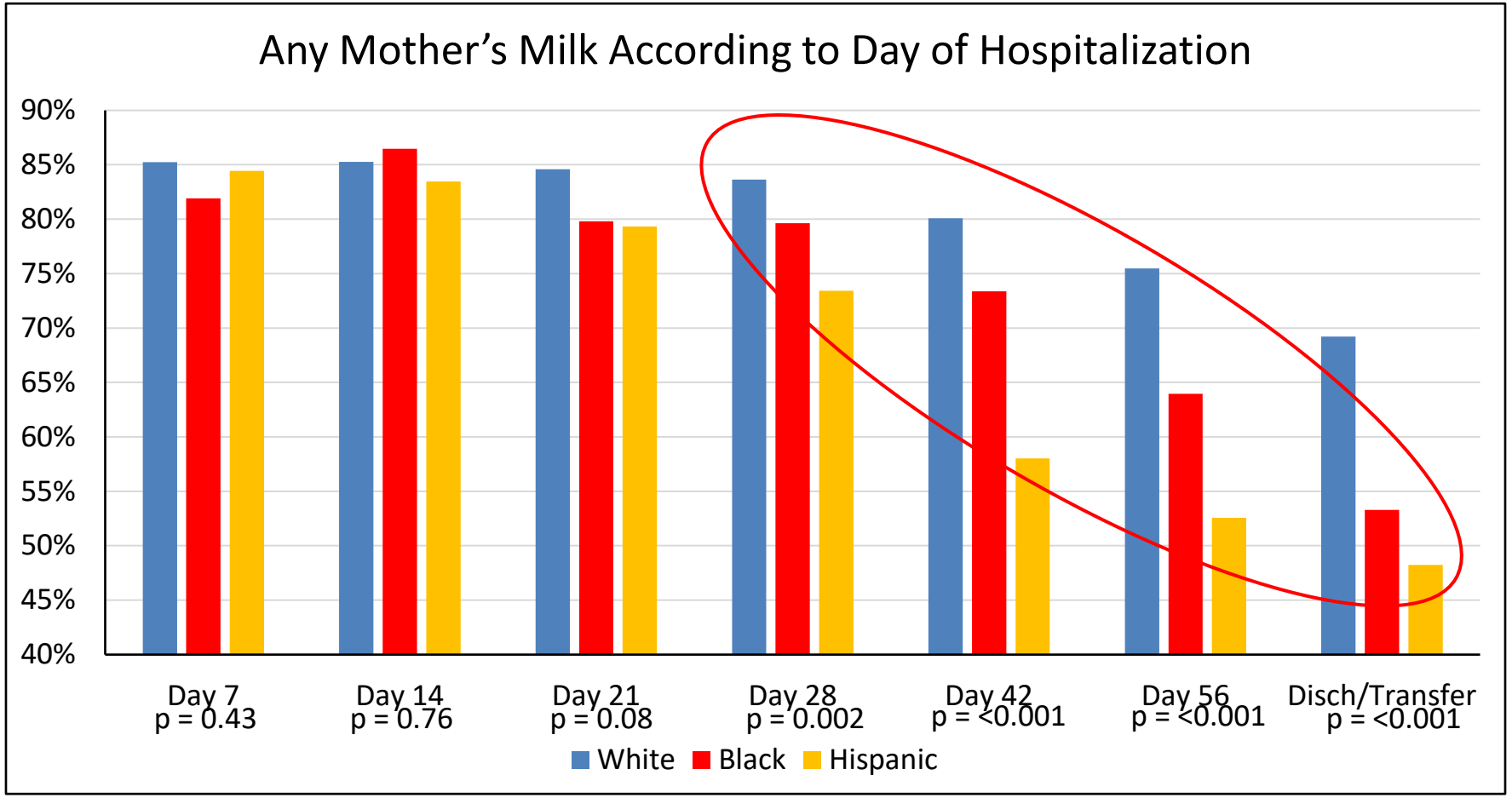
Parker et al, *Pediatrics* 2019

Main Outcome



Parker et al, *Pediatrics* 2019

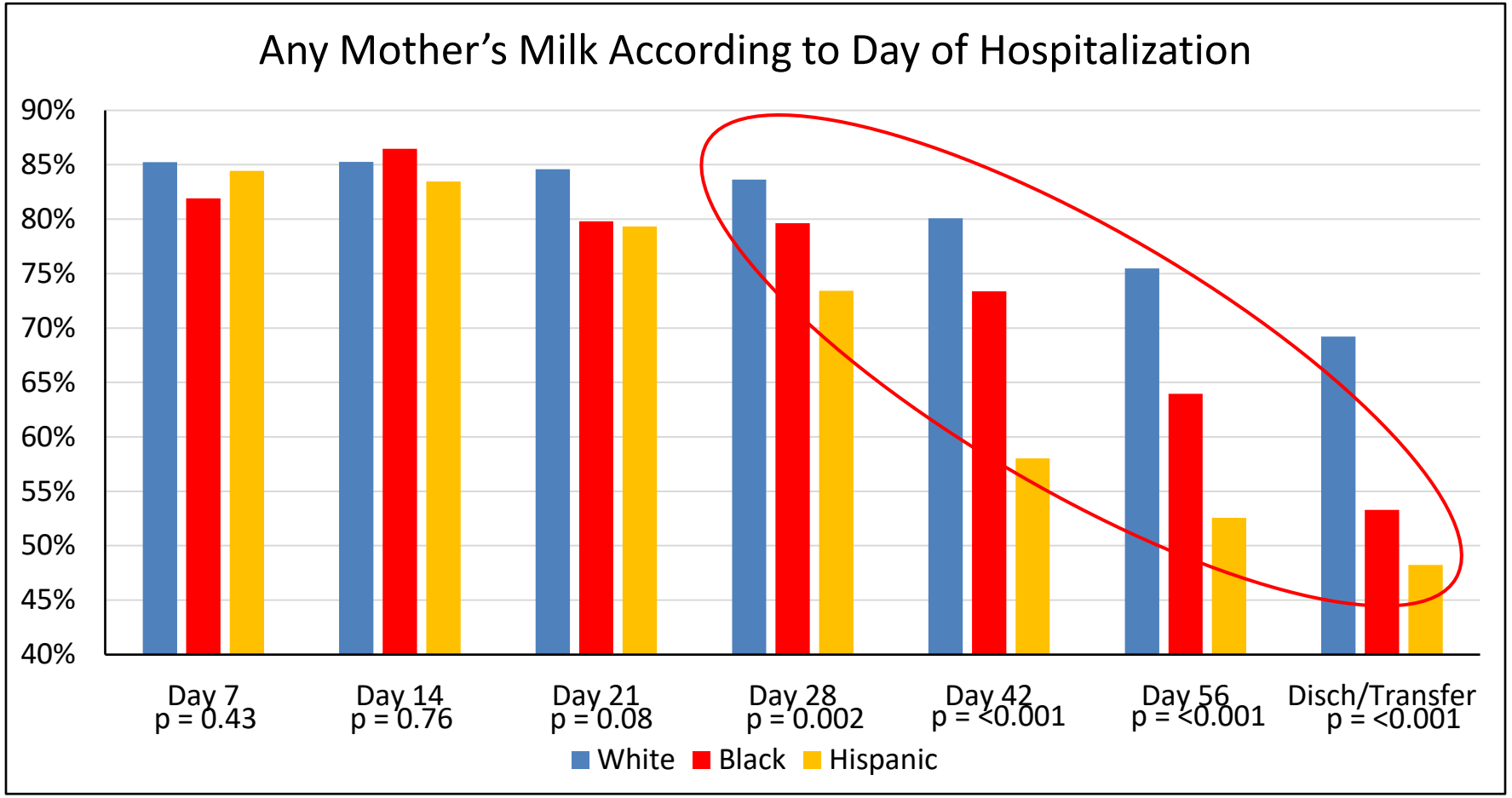
MA PQC Human Milk Project



Racial/ethnic disparities emerged after day 21

Parker et al, *Pediatrics 2019*

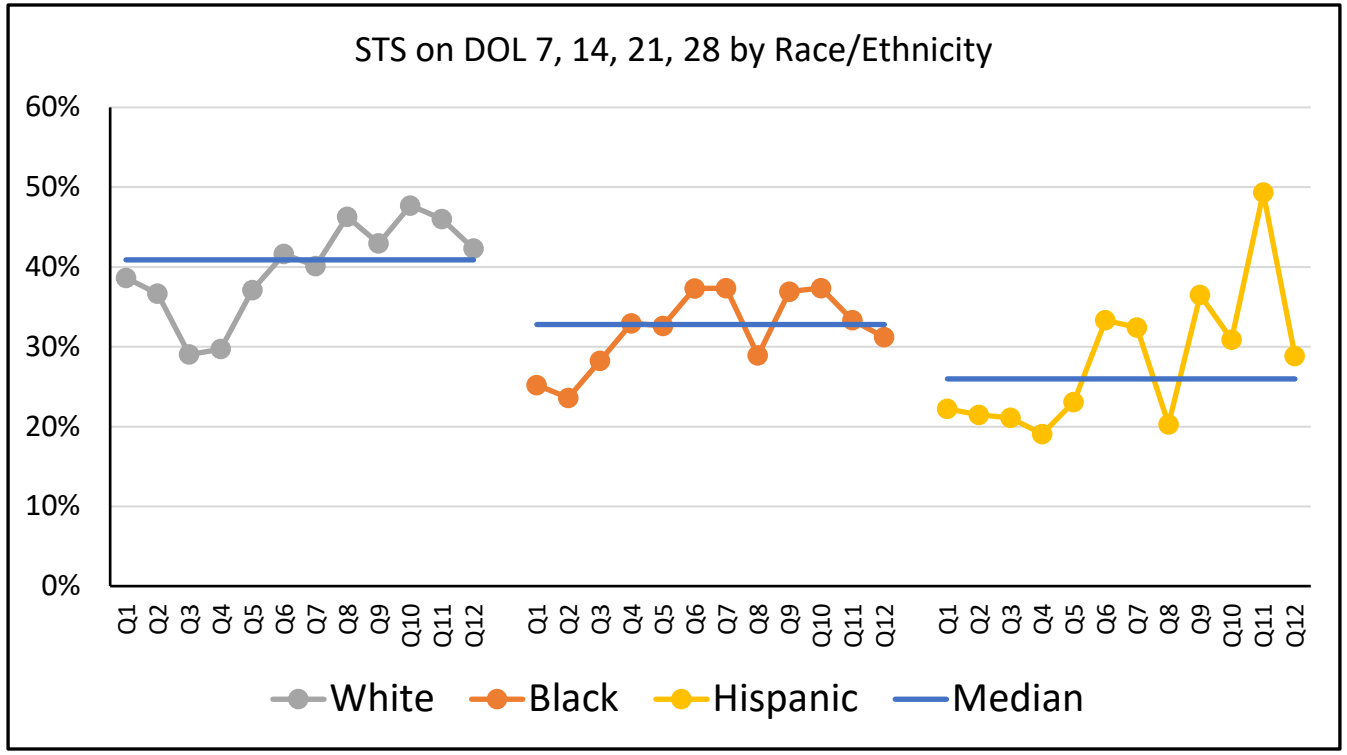
MA PQC Human Milk Project



Our "standardized" approaches early the hospitalization did not lead to reductions in racial/ethnic disparities

Parker et al, *Pediatrics 2019*

STS on Chart Audit Days According to Race/Ethnicity
MA Human Milk Collaborative 2015-2017



Different rates of STS according to race/ethnicity

What did we do next?

- We knew we needed to pursue non-standardized approaches to STS care and provision of MOM

- Qualitative interviews of Black and Hispanic mothers
- Examination of family engagement practices across centers
- Review existing literature

Qualitative Interviews with 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

Logistical challenges to mother-infant separation are enormous

- Transportation, parking

Hospital providers are an important source of support when:

- Sufficient time is spent
- Interactions perceived as unbiased
- Communication in primary language

Parker et al. *Breastfeeding Medicine*, 2018

Adverse Social Determinants of Health Impact NICU Visitation among Black and Hispanic Mothers

"If you run out of money because you are not working so that you can be with your baby you have to make sacrifices, sometimes that means not buying a meal"

"The hospital isn't far from where I live, but I couldn't go back and forth.. Because I don't have a car."

"I live only 12 minutes away so I tried to be there as much as I could but I also had to take care of other children at home."

"The hardest thing was the transportation. I went every day, but sometimes it was difficult because I didn't have money for gas or I couldn't spend a lot of time at the hospital because I couldn't afford the parking; sometimes I didn't eat in order to go to the hospital."

Cordova Ramos, *in progress*

Social Disparities in NICU Visitation

- Families need to physically visit the NICU to do STS, pump milk and directly breastfeed

- Household income <$50,000 vs. >$100,00 was associated with less frequent NICU visitation. Bourque et al. *Hospital Pediatrics* 2021

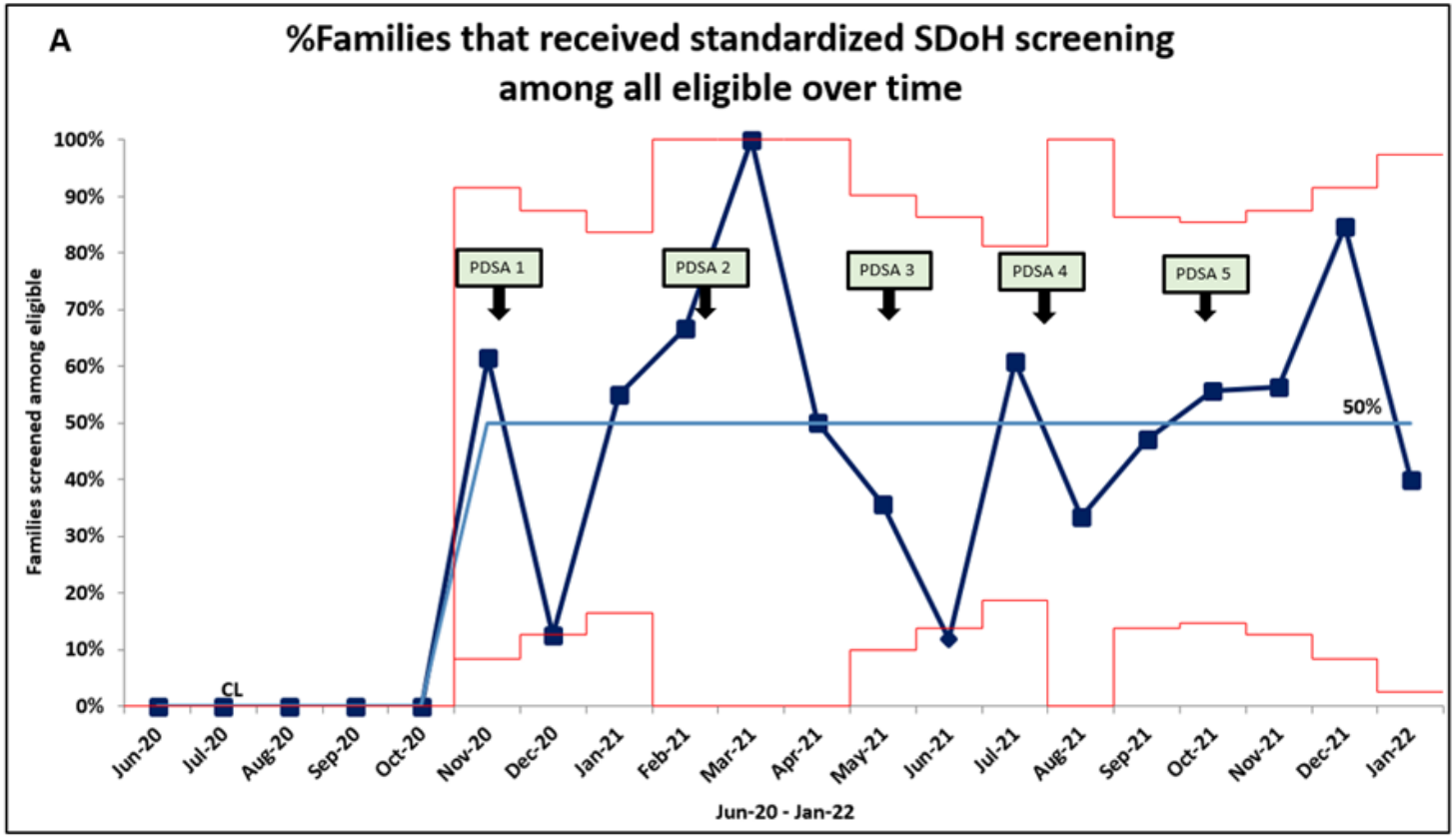
Family Engagement Practice Survey to MA QI NICU Teams

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

Non-Standardized Approaches to Addressing Social Disparities in STS

- Screening and referral for social determinants of health
- Support for food, parking, transportation for families with hospitalized infants
- Cash assistance

Boston Medical Center Example: Standardized Screening and Referral



Results: Adverse SDH Identified

1+ unmet need: 74/91 (81%)

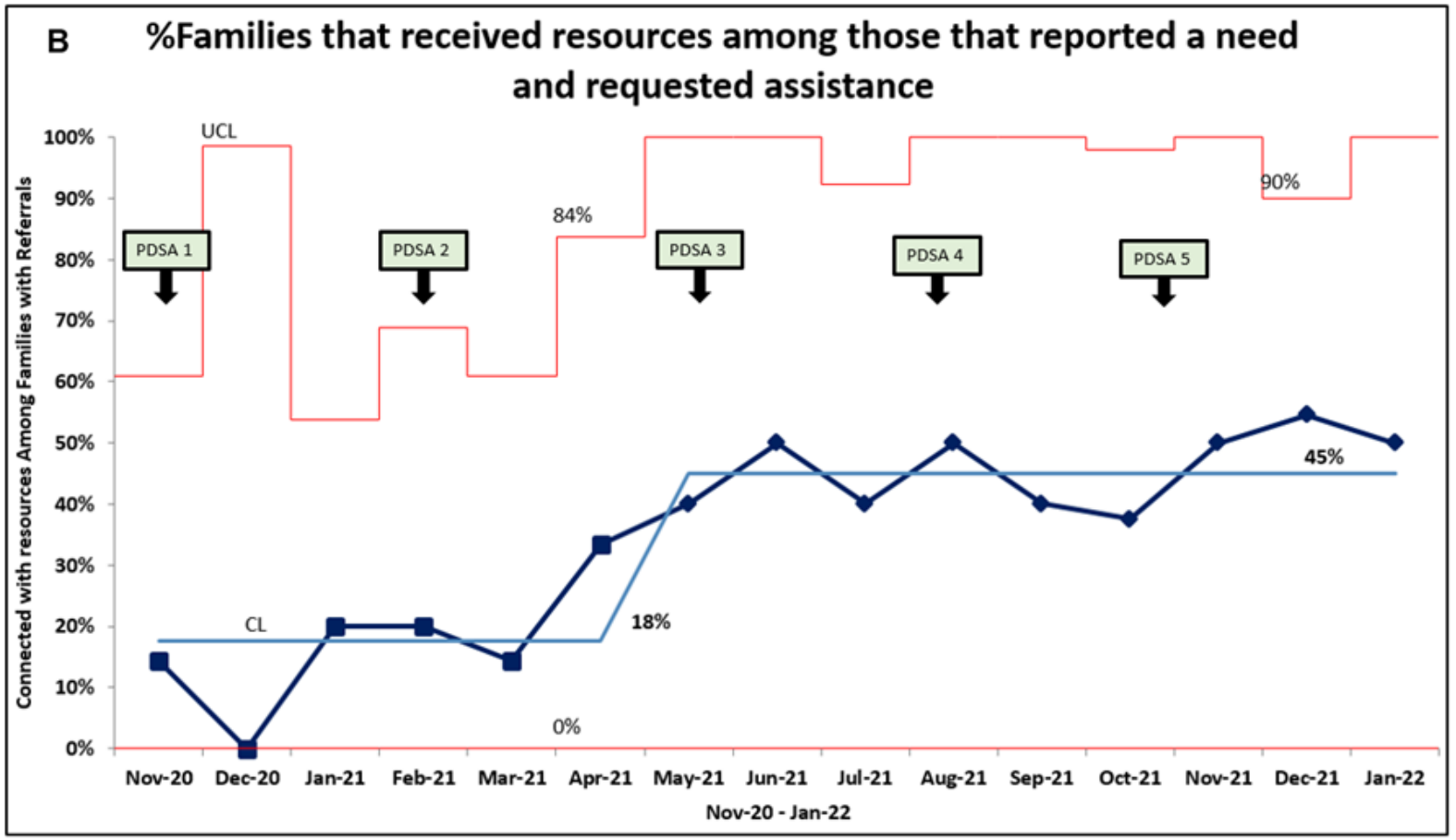
2+ unmet needs: 55/91 (60%) (range 2 to 5)

Total unmet needs: 173

Desired assistance for need: 146/173 (84%)

Unmet need	n (%)	want assistance
Education	53	41 (77)
Employment	24	17 (70)
Utilities	20	17 (85)
Food	22	22 (100)
Housing	14	14 (100)
Transportation	23	23 (100)
Caregiving	10	8 (80)
Medications	7	4 (57)

Results: Connection with Resources

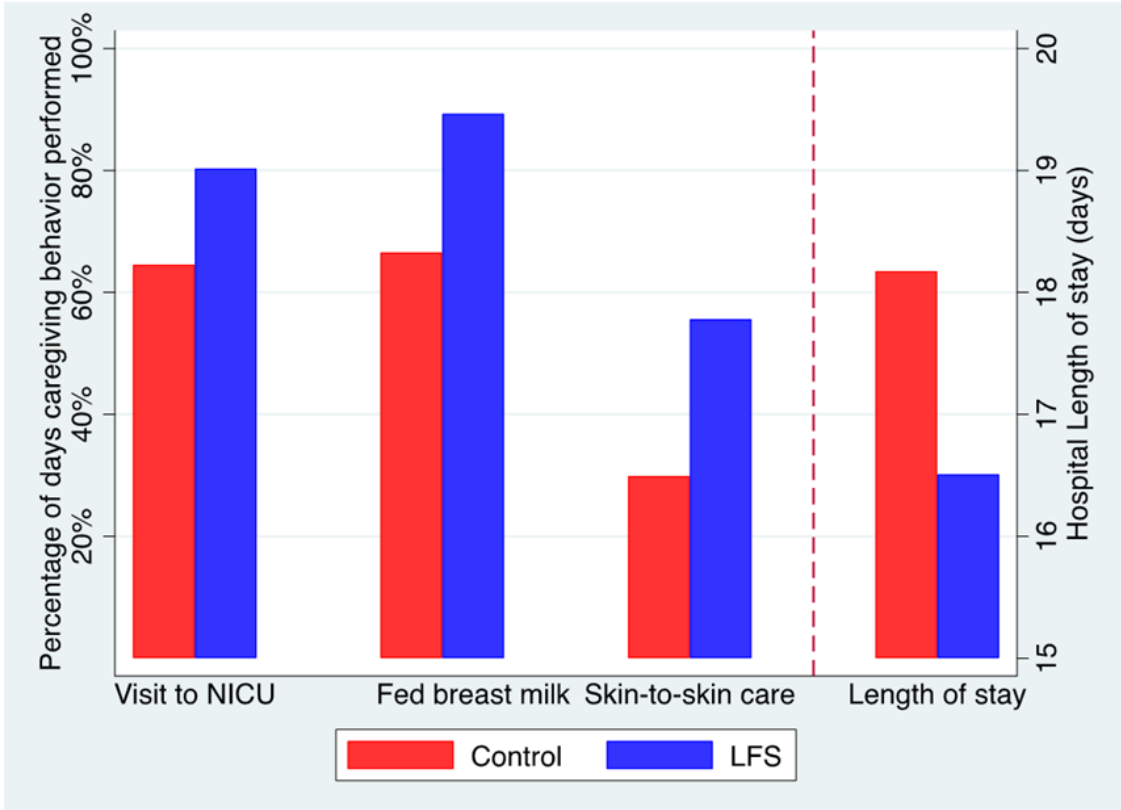


Cash Transfer RCT of Medicaid-Eligible Mothers with Hospitalized Preterm Infants (n= 46)

- 2017-2018; Tufts Medical Center
- Mothers randomized to receive $200 a week x 3 weeks maximum vs. control (usual care)
- Intervention group received a one time “label” stating that cash was intended to help mothers visit the NICU

Andrews KG et al. *Maternal Child Health J*, 2020

RCT of Labelled Financial Transfers to Medicaid-eligible NICU Mothers, n = 46



Daily NICU caregiving behaviors among the control and financial transfer group shown; estimates are adjusted for baseline maternal and infant characteristics

Cash Transfer RCT continued

- What did mothers use the money for?
  - Food 45%
  - Transportation 35%
  - Infant related expenses (e.g. car seats, formula) 30%
  - Other (e.g. rent) 20%
- In summary, provision of $200 a week for a maximum of 3 weeks led to significant differences in breastfeeding, skin-to-skin, and NICU visitation
- *This is dramatically less than the cost of a typical NICU hospitalization (~$2,000 a day for a <32 weeker)*
- New grant: NIH R01 (MPI Parker/McConnell): Effect of Support for Low-Income Mothers of Preterm Infants on Parental Caregiving in the Neonatal Intensive Care Unit (NICU)" (HD109293)
  - RCT of cash transfers of $160/week to mothers with hospitalized preterm infants to examine impact on breastfeeding and skin-to-skin care

Next Steps in MA

- Family engagement and social disparities collaborative
  - Addressing social disparities in hands on care and visitation
- CDC PQC grant- SDH screening/referral in the NICU setting
  - Year 1 is starting in 5 NICUs/SCNs serving large proportions of low-income families
- (Outside MA) Larger R01 (Parker/Garg/Drainoni): Implementation-effectiveness grant to study SDH screening/referral in the NICU Setting

Using QI with an Equity Lens Pearls

Approach	Example
Make reducing disparities a main aim of the project	“We aim to reduce black/white differences in breastfeeding by 10% at our hospital within a year”
Include diverse perspectives on your multi-disciplinary team, especially family members	A team holds multi-disciplinary QI meetings by zoom to enable increased attendance by family members
Track outcome, process, and balancing measures by social factors of interest (e.g. language status or r/e)	A team conducts a project to promote earlier discharge and tracks the extent that English and non-English speaking families perform similarly
Conduct PDSAs that enables standardized care	A team sets up a process to ensure families are updated daily, even if they are not present on rounds
Conduct PDSAs specifically targeted at socially vulnerable groups	A team implements a screening and referral system for unmet basic needs

Acknowledgements

PNQIN

MA PNQIN Hospital Teams

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Nicole Lomerson

Kevin

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Tami May

Judy Burke

Chadni Jain

Erica Dota

Bharati Sinha

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-NICHD R01HD104772 (PI Parker/Garg/Drainoni)

-NICHD R01HD109293 (Parker/McConnell)

Break

Collaborating on Ideas and Solutions: Round Robin Session

Lunch

Round Robin Report Out

Infant Eligibility for SSC

Successes	Challenges

• Visual reminders
  • Color coordinated bed cards
  • Post pictures in hallways
  • Tags on badges: “Ask me about kangaroo care”
  • Milestone keepsakes: “Beads of Bravery”, “Tides of Hope”
• Staff prepared
  • Established protocol; 2-4 am/pm quiet hours
  • SSC during touch time/cluster care
  • Care rounding: ask about SSC
• Family prepared
  • Info in parent scrub in area
  • Classes for families; empower to speakup
  • Push dad involvement
	• **Staff turnover**
	
	• Nurse/RT resistance and divergent comfort levels
	  • Recommend: education, discover their barriers; know your staff and enlist resisters
	
	• Logistics with dads not wanting to remove shirt
	  • Thin shirt is better than not doing SSC
	  • Plan for next day with suggestions on what to wear

SSC Education of Staff and Parents

Successes	Challenges

• Having a champion
  • Making time to be involved
  • Physician involvement
• Utilizing support staff: occupational therapists, social workers, etc.
• Mandatory education for parents
	• Not having a standard practice
	  • Buy-in, inconsistency, generational differences
	  • Getting families to visit and stay a while
	• Cultural differences regarding privacy
	• Staff shortage
	
	• **Recommendations:**
	  • Daily rounds
	  • Use of equipment: Boppy/borrowing
	  • Empowering the fathers
	  • Including siblings
	• Decreasing emotional anxiety

Length of SSC

Successes	Challenges

• Cards with STS tips for families
• Rewards system for nurses and caregivers
• Ensure that personal needs are attended to first
	• Competing and conflicting priorities
	• Workflow barriers
	• Differences between ELBW and LBW perceptions of care needs
	
	  • Scheduling times to STS to address limited space
	  • Bedside huddles
	  • Pictureboard for increased visibility

Race, Ethnicity, Birth Weight Considerations for SSC

Successes	Challenges

• Language services: translating documents, using interpreters, best in-person or tablets, convenience of interpreter services from staff phones; certify and incentivize bi/multilingual staff
 	
• Providing resources (bus passes, gift cards, waiver for discounted transportation services)
	• Funding to address issues with SDOH
	  • Grants, in-house resources (case managers), Cerner → "Find Help"
	
	• Literacy - Health literacy
	  • Use more videos; take advantage of PNQIN materials
	
	• Cultural barriers, dialects
	  • Connect families with staff with similar backgrounds (language, country of origin)

Caregiver Surveys

Successes	Challenges
• Ask the family to complete the survey as part of discharge rounds. • Have the doctors ask and share the QR code during rounds. • Add the QR card to the discharge packet.	• Have/ask the caregivers to complete at the time QR code is given • Challenges with discharge planning process, content and timing. • More than one person responsible for asking, reminding, and following up about the survey. • No follow up on survey completion. • Discharge phone call and text follow up • Incomplete caregiver survey.

PDSA and Small Tests of Change

Susan M. Bowles, DNP,APRN-CNS,RNC-NIC,CBC
Nurse Consultant PAIRED Initiative
Florida Perinatal Quality Collaborative

FPQC

Disclosures

- Nurse Consultant for Educational Projects, WaterWipes
- Nurse Consultant for Quality Projects, AngelEye Health
- Member Speakers' Bureau Abbott Labs

Model for Improvement

https://usf.box.com/s/wdha0afm8252hh08s43my7k1rrfzdnuz

Maya Balakrishnan, MD, CSSBB
FPQC Director of Quality
Director, Quality & Safety, USF GME
Professor, College of Medicine

Principles for Small Tests of Change

The Goal:

Test potential improvements to the unit's care processes that have the potential to transform care in large and small ways

Why is this important?

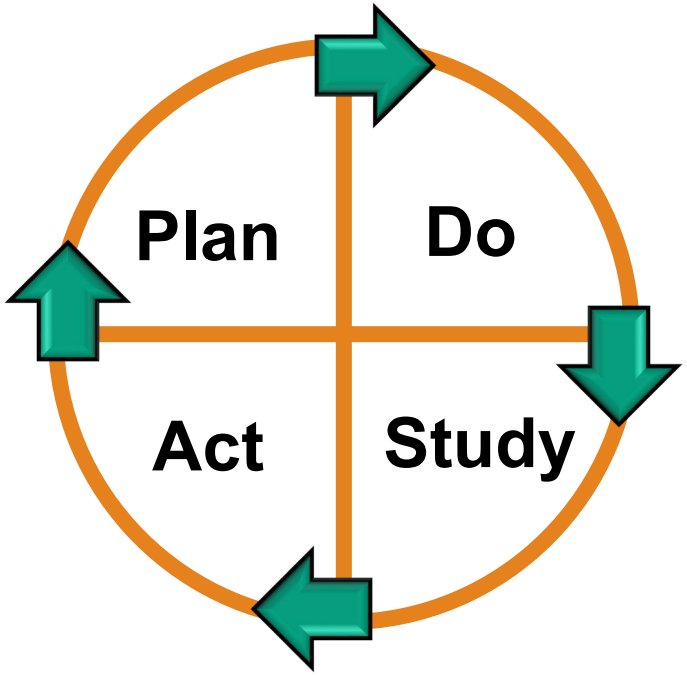
Small-scale tests of change help determine whether an idea could result in sustainable improvement. Changes should be tested under multiple conditions and with a variety of staff before being implemented

Example: *Babies on ventilators*

Principles for Test of Change

How To Do It:

1. Understand the testing process—PDSA
2. Determine which staff will be involved
3. Predict the outcome
4. Be specific
5. Be forward thinking and flexible



Tip

- Make sure tests of change are very defined and limited in scope, particularly when first implementing.
- 1 patient, 1 nurse, 1 day is an acceptable way to begin a test of change.

How to keep it simple?

Ask yourself:

- What is one thing that we are not doing that the evidence suggests we should be doing to improve our performance?
- How can we test ideas about this one thing?

Research vs. Quality Improvement

	Quality Improvement Used to learn	Research Used to Evaluate
Purpose	Bring learning into daily practice	Discover new knowledge
Tests	Many cycles sequential and observable	One large “blind” test
Biases	Stabilize biases from test to test	Control for as many as possible
Data	Just enough	Just in case
Duration	Small tests of significant changes accelerates rate of improvement	Can take a long time

Test—Implement—Spread

Test

Implement

Spread

Why Test?

- To see if the idea will work in your setting
- To understand if the test results in the desired outcome
- Learn how to adapt the change to conditions in the local environment
- Evaluate costs and side-effects of the change
- Minimize resistance upon implementation

What not to do!

- ✓ Write a policy and procedure
- ✓ Take many months to get it approved
- ✓ Train your staff
- ✓ Go live

PDSA Examples

- Pilot standing transfers with two stable ventilated babies
- Review five 34-week infants and assess how often they go S2S
- Pilot the S2S competency with one RN bedside care provider and one RT bedside care provider and assess performance

Preparation

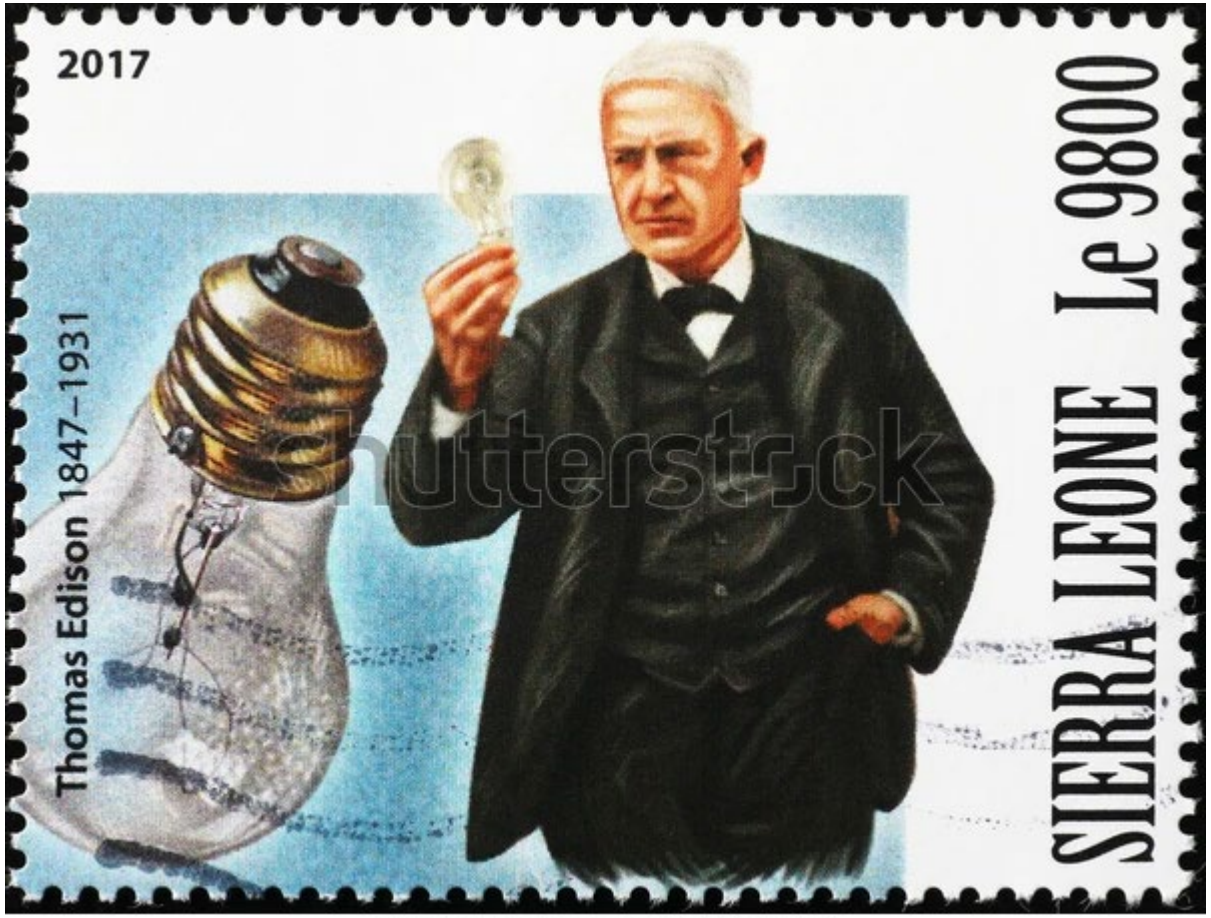
1. What are you testing?
2. Who is doing the test?
3. When will the test occur?
4. Where will it occur?

5. What do you think will happen?
6. What would make this test successful?
7. What else do you need to conduct this test?
8. When are you going to evaluate the results?

Common Traps

- Plan Do, Plan Do
- Do Act, Do Act
- No testing, only data collection
- No ramps of tests, random PDSAs
- Undisciplined PDSAs, no documentation
- No Prediction – what are we going to learn
- Beware of cycles longer than 30 days

Failure is an Option



"I did not fail one thousand times; I found one thousand ways how not to make a light bulb."

Applying Lessons Learned

Table Exercise

Review the case study on your table. Discuss the PDSA example as a group and answer these questions.

1. What is being tested?
2. Is the scale of the test as small as possible for the first cycle?
3. What does the team predict with be the outcome of the test?
4. How will data/feedback be collected? Is this specific enough?
5. How will the data/feedback collected be used to plan the next cycle?
6. What is your recommendation for the next cycle?
    - How large?
    - What should be kept, changed or abandoned?

Linking Tests of Changes

- Testing changes is a continuous process: Completion of a PDSA cycle leads directly to the start of the next cycle ➡ RAPID CYCLES
- A team learns from the test:
  - What worked and what didn't work?
  - What should be kept, changed, or abandoned?
  - Uses the new knowledge to plan the next test.
  - The team continues linking tests in this way, refining the change until it is ready for broader implementation.

Next Steps

- Look at your data! Where should you focus your efforts?
- Revisit the FPQC Family-Centered Care PAIRED Toolkit and driver diagram to identify potential opportunities for improvement
- Plan your next PDSA Cycle
- www.fpqc/paired/toolbox

Questions?

FPQC

Break

| Parent Power |

Elizabeth Simonton | Co-Founder & CEO of ICU baby

| Parent Power | the POWER of empowering parents to be active participants in their baby's NICU care.

Successful NICU Outcomes Occasioned by Clinical Care

NICU Healthcare Teams' Clinical Outcomes

+

Parental Involvement


ICU baby
> Emotional Support
> Financial Support
> Informational Support

Agenda

- How I Got Here
- Learning of a NICU Admission
- Common Phases Parents Go Through
- 3 Truths for (Almost!) Every Family
- What Parents Have to Say [Video!]
- 10 Parent Pro Tips
- Q & A
- Feedback

Receiving the news ...

“Your baby is being sent to the NICU.”

- I was shocked and couldn’t breath.
- I was devastated.
- I thought my baby was going to die.
- My Husband called for a priest.
- I felt guilty.

Common Stages for Parents in the NICU

| Credits to ICU baby's Leah MG Jayanetti & Valerie Hernandez |

NICU Newbie

NICU Navigator

NICU Homebound

3 Truths for (Almost!) Every NICU Family

1. All Families Have A Story ... & It's Complicated
2. Life Outside of the NICU is Complicated
3. Life Inside of the NICU is Complicated

Truth
No. 1

All Families Have A Story ... & It's Complicated

- Pregnancy Losses
- Infertility & Infertility Treatments
- Bedrest
- A condition diagnosed early on
- Several “false starts” and visits to triage
- Unexpected delivery
- Etc.

Quick Tip

Acknowledge that there is a story, both in your reaction to their reactions & in your interactions with them.

Truth No.2

Life Outside of the NICU is Complicated

- Sibling Care
- Transportation
- Work and/or School Commitments
- Emotional Wellness
- Financial Stressors
- Safety
- Access to Care
- Etc.

Quick Tip

→ Avoid Assumptions.

Truth No.3

Life Inside of the NICU is Complicated

- Teams
- Terms
- Sights, Sounds, Smells
- Routines
- Other Babies & Other Parents
- The Hospital
- Etc.

Quick Tip

Recognize that they are in a foreign land that has a different culture, language & dynamic.

How Are We Going to Empower Our Parents?

| Question Asked |

What do the doctors and nurses do to make you feel like you are part of your baby's care?

https://youtu.be/PeH56elDnZU

10 Parent Pro Tips | Parents Want to ...

1. Feel Informed
2. Feel Heard
3. Feel Like a Partner
4. Feel Needed
5. Feel Included
6. Feel Able
7. Feel Successful
8. Feel Healthy
9. Feel Well
10. Feel United




The Power of Information

- Regularly communicate … even if there is nothing to say
- Be clear about possible set-backs
- Make sure they understand what you are telling them
  - linguistically accessible information
  - comprehensible words
- Often, it’s not what you say, it’s how you say it
- Consider parents’ emotional state, language, culture & education

PARENT PRO TIP

No. 1 | Feeling Informed

The Power of a Voice

- Some will not speak up without an invitation
- Can't always make decisions ...
- Can be involved in the decision making process
- Invite questions
- Encourage conversation

PARENT PRO TIP

No. 2 | Feeling Heard

The Power of Your Power

- Afraid to speak up
- Fear of retaliation
- Want to be liked

.....

- Be aware of elevated role
- Practice humility & approachability

PARENT PRO TIP

No. 3 | Feeling Like a Partner

The Power of Parents' Presence

- Parents don't know what they don't know
- We know the benefits of their presence, they don't
- Tell them how important their presence is
- Encourage them to be there by engaging them when they do come

PARENT PRO TIP

No. 4 | Feeling Needed

Barriers

- Geographics - 100 miles away
- Social determinants of health
- Zip codes with generational poverty
- Work, sibling care, transportation, emotional health & poor health

Mitigating the Barriers

- Utilize social worker & community resources
- Connect with a mentor
- Integrate technology
- Leverage family & friend support

The Power of a Purpose

- Give parents a developmentally appropriate role
- Parents are uniquely positioned to do things, healthcare teams cannot

Voice
Smell
Touch During Touch Times
Skin-to-Skin Care
Provide Breastmilk

PARENT PRO TIP

No. 5 | Feeling Included

Importance of including the non-birthing parent

The Power of Learning New Skills

- Parents have the opportunity to learn
- They will model your good care
- Encourage behaviors that will help them when their baby is released
- Write down the baby's progress, questions and information.
- Information, communication, engagement

PARENT PRO TIP

No. 6 | Feeling Able

The Power of Feeling Effective

- Set them up for success
- Prepare them for set-backs
- Manage expectations
- Celebrate small victories
- Mark milestones*
- Caution milestone mania

PARENT PRO TIP

No. 7 | Feeling Successful

The Power of Self-Care

- Self-care can feel selfish or self centered
- Self-care so they can be emotionally & physically well
- Maintain their stamina for the NICU journey

...

- Get into a rhythm for predictability
- Allow a support system to help
- Eat well, rest & breathe

PARENT PRO TIP

No. 8 | Feeling Well

Your unique ability to deliver the message so it's heard.

The Power of Emotional Wellness

- Social worker to bridge to services
- Mentor group
- Hand-to-Hold - https://handtohold.org
- MAMMHA - https://www.mammha.com
    - universal screening, referral & care coordination
- Healthy Start

PARENT PRO TIP

No. 9 | Feeling Well

The Power of People

- Humanize what is a foreign world
- It's never a routine case for parents
- Body language talks
- Put on the lens of a parent
- Highlight gifts from the community

PARENT PRO TIP

No. 10 | Feeling United

Parent Satisfaction

Parent Readiness

Parent Success

Improved NICU Outcomes

Improved Transition to Home

Improved Long Term Outcomes for Family Unit

P	Participate with your baby's healthcare team.
A	Ask questions. Allow yourself time to adjust to the NICU.Advocate for your baby and your family's needs.
R	Read (or sing) to your baby.Ready yourself for creating a NICU routine.
E	Educate yourself by asking your healthcare team questions and using NEST resources.Embrace all resources available to help you and your baby.
N	Nurture yourself so that you can be there for your baby.
T	Touch times can help you bond with your baby. Talk with your baby's healthcare team frequently to get more information.
S	Show up, Speak up, and Stand up for your baby and your family - you are their voice.

ICU baby

- Ideas are only as good as your ~~executive.~~ execution
- What's your Unit's philosophy of care? Does it mention inclusion of parents in care? Is it posted in your Unit?
- Questions & Comments

ICU baby

Thank you for making parents a priority!

elizabeth@icubaby.org

icubaby.org

@icubaby_org

www.facebook.com/icubaby.org/

elizabethsimonton

Integrating Families Beyond Skin to Skin: PAIRED Plus

Samarth Shukla, MD
Physician co-lead
PAIRED Initiative, FPQC
Assistant Professor
Division of Neonatology
University of Florida college of Medicine, Jacksonville

PAIRED aims to improve family-centered care across the four domains of:

PA rticipation in care and decisionmaking

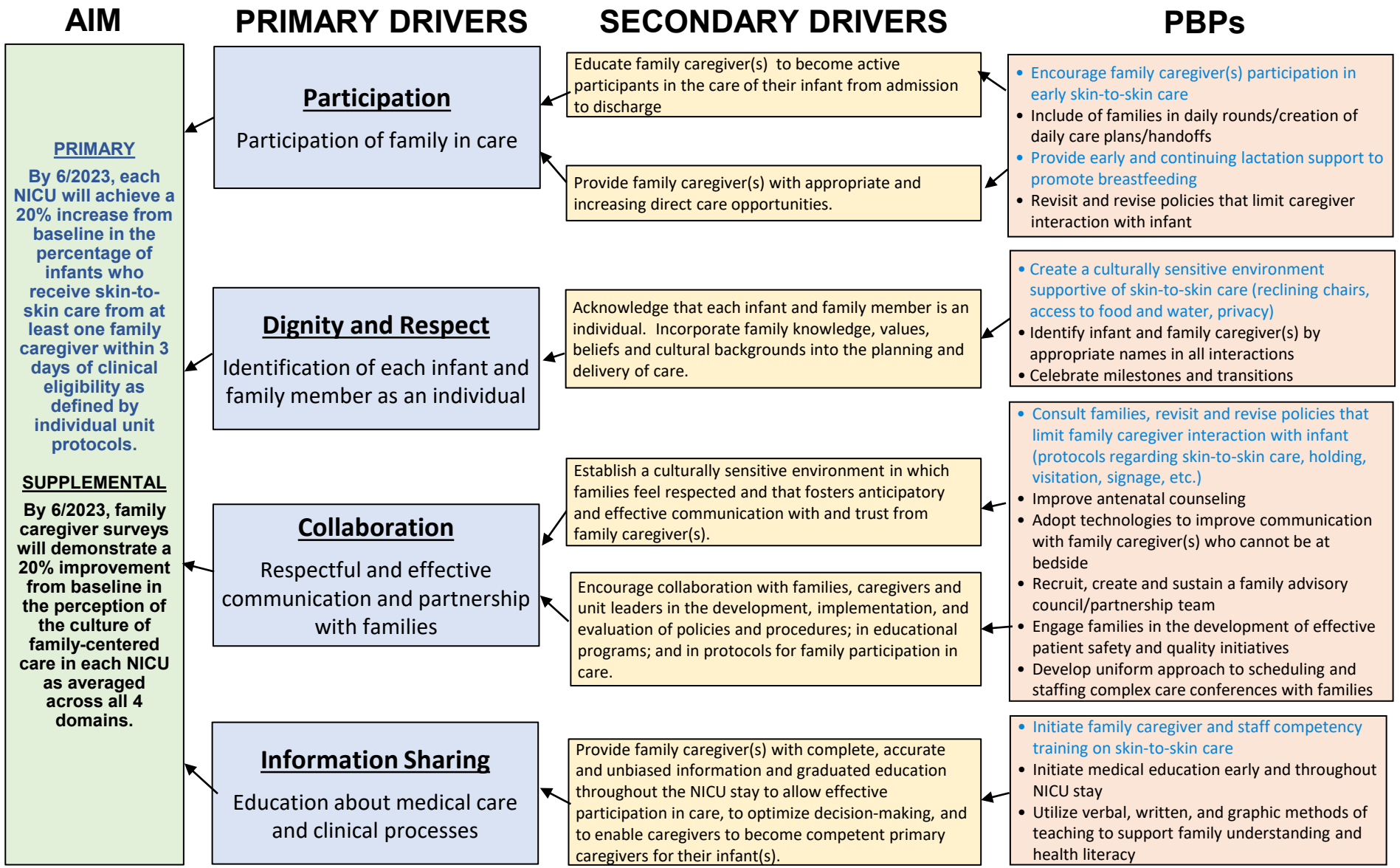
I ndividual recognition of each infant and family

R espectful collaboration with families

ED ucation for families about care after discharge

PAIRED—Family-Centered Care

Date: 10/9/2020



Family-centered care is defined as a shared approach to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and family caregiver(s). There are four essential domains of FCC: 1) family participation in care, 2) dignity and respect, 3) family collaboration, and 4) information sharing.

PAIRED Plus

PAIRED Plus is the title given to the other PBPs that also contribute to FCC

- Inclusion of families in daily rounds
- Identifying infants and families by name
- Complex care conferences and early medical education

PAIRED Plus

- Components may overlap and affect each other
- Units may already be working on certain PBPs to improve skin to skin care, which will also improve medical knowledge, family presence at rounds, etc
- Helps to integrate families in infant's care beyond skin to skin
- FPQC will not collect data on outcome measures for these additional components
- Units are expected to work on these projects and monitor their own data

Why to integrate families?

- NICU has the most extended length of stay among all other hospital units
- One of the very few units where patients always need surrogates for medical decision making
- Our patients always rely on families for post-discharge care (for medical needs as well as development)
- It is prudent to keep families updated, informed, and involved in all aspects of care
- NICU families experience anxiety, depression, and grief to a significant proportion
- Families' long term mental health requires to be addressed

How Do We Achieve This?

Pochard, F., & et al. (2001). Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision-making capacity. Critical Care Medicine, 29, 1893–1897

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Care Conferences

Care Conferences

- **Communication!!!!**
- **Most important concern raised by families**
- **Interpersonal and informational communication has been found to be the most effective approach**
- **Interdisciplinary conferences are great for addressing family concerns and making shared decisions**
- **Helps with unbiased and unprompted disclosure of child's health**

**Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.*
**Khalaila, R, et al., Meeting the needs of patients' families in intensive care units. Nursing Standard. 2014*
***Altimier, L. Compassionate Family Care Framework: A new collaborative compassionate care model for NICU families and caregivers. Newborn and Infant Nursing Reviews, 2015*

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Care conferences

- Established benefits of early, frequent and effective communication between care providers and families
- Family meetings fail to occur as needed in most ICUs
- In a large multicenter study of 1500 patients who were treated for more than 2 weeks in ICUs, <40% reported discussion with their doctor about prognosis or treatment preferences
- Gap between what we know and what we practice

** Teno JM, et al. Decision-making and outcomes of prolonged ICU stays in seriously ill patients. J Am Geriatr Soc. 2000 May*

Barriers to Care Conferences

Time

- Average ICU in USA cares for 10 patients/day
- Number is much larger for NICUs
- Physician:Patient ratio
- Other than patient care, physician is responsible for documentation, teaching and administrative tasks
- Most parents visit later in the day

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

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Barriers to Care Conferences

Turnover of Caregivers

- Caregivers work in shifts at most ICUs.
- Day and night time physicians/nurses are different
- Day to day physicians/nurses may be different
- Transfer of care among caregivers on days/nights/weekends

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Barriers to Care Conferences

Skills

- Effective communication with ICU families is complex
- Explain physiology in understandable terms, provide information on prognosis and treatment options
- Listen with patience and sympathy
- Address emotions like anger, grief, guilt, and work on conflict resolution
- Inadequate training of providers on communication skills

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

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Barriers to Care Conferences

Cultural Sensitivity & Language Barrier

- Multicultural society
- Where is the training on cultural sensitivity?
- Country of immigrants->Different backgrounds and languages
- Interpreters may not be readily available, time consuming
- Arranging family meetings around these barriers becomes challenging

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Barriers to Care Conferences

Space

- Lack of dedicated space for family meetings
- Many NICUs are open floor concept or have too small private patient rooms
- Not enough space around the patient for several care givers
- Noisy and lack of privacy
- Providers may feel uncomfortable to discuss sensitive issues and avoid the topic altogether

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

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Strategies to Improve Care Conferences

Maximize Time Efficiency

- Identify days and times that would be most convenient
- Start with something less frequent (may be once a week)
- Make the feasible times available to the families
- Gives framework for scheduling and gives appropriate notice to all stake holders

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Strategies to Improve Care Conferences

Maximize Time Efficiency

- Use printed informational material for common medical topics
- Not every care giver needs to be present for entire meeting
- Inform families of the physician/nurses' role in the meeting and that the remaining discussion can happen with case management/lactation specialists/pastoral care/palliative care teams
- Physician time is a major barrier for care conferences. Making it less onerous for physicians, will make it happen more frequent

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Strategies to Improve Care Conferences

Use Reminder Tools

- NICU is a complex and high intensity work place
- Simple reminders and triggers will improve practice of care conferences
- Add “Family meeting” to daily checklist, include the scheduled meeting date and time
- “Daily goals” form for families/nurses

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Strategies to Improve Care Conferences

Clarify Goals at Every Meeting

- Every task is easier if appropriate goals are defined in advance
- Cannot discuss each and every topic at all meetings
- Care givers may appear lost if they are unaware of family expectations: Treatment/Prognosis/Surgical procedure, etc.
- Helps to identify appropriate priorities for discussion and have the appropriate participants

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Strategies to Improve Care Conferences

Engage Nurses

- Bedside nurses are closest to the families, constantly present
- Engaging the bedside nurse reduces time burden on physician and improves family satisfaction
- Consistency of information provided to the family
- Nurses should include the topic of Family communication on daily rounds and their list of “daily goals”
- They can help arranging the time and goals for the meeting
- Focus the team’s attention on family needs

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Strategies to Improve Care Conferences

Involve Other Professionals

- Case management/Social worker for family dynamics, emotional counselling, financial support, transition of care!!!!
- Pastoral care for spiritual support
- Palliative care/Ethics support, depending on the goals of the meeting
- Sub-specialty support

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Strategies to Improve Care Conferences

Training in Communication Skills

- Caregivers who are confident in communication skills are more likely to conduct care conferences
- Various educational programs like End-of-life education for physicians, End of life nursing education consortium, programs from National Palliative care research center, etc

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Strategies to Improve Care Conferences

Relax Restrictions

- Patients and the families want to be with each other
- Presence of family members can be comforting to the patient and reassuring to the families
- Restrictions may be necessary during procedures/emergencies especially in open floor NICUs
- Ease of restrictions will keep families readily available for updates and family meetings
- Trainees will learn the improved communication skills

Gay, E. B., et al., The intensive care unit family meeting: making it happen. Journal of critical care, 2009.

Performance Measurement & Feedback

- Define “family meeting” or “care conference”
- Document when a meeting is conducted
- Define the timeline. (e.g. Within 5 or 7 days of NICU admission)
- Monitor the data and obtain feedback from families/staff
- Share the data and feedback with staff

Medical Education

Medical Education

- Central to family centered care
- Several barriers: busy life, lack of accommodation, transportation, language/knowledge barrier, stress/anxiety, lack of knowledge and skills to take care of a sick infant
- Empowers the families and makes them feel involved and confident as primary care givers

Medical Education

- Medical education for families can start before or soon after the birth
- Can be in-person sessions or virtual
- Verbal/audio-visual aids, printed or PDF handouts
- Involve families to decide what they would like to learn
- Intensity of education can vary from relaxed to a rigorous approach

Medical Education

Relaxed Approach

- HUGG group from Glasgow, UK
- Implemented family integrated care and parent education was a core component of the model
- Daily family awareness sessions on topics suggested by parents
- Led by nurses, physicians, therapists, pharmacists, dieticians, phycologists and graduated parents!!
- Informal sessions with time for Q&A
- Text reminders regarding the sessions and links to online resources

Patel N, et al; Helping Us Grow Group (HUGG). Family Integrated Care: changing the culture in the neonatal unit. Arch Dis Child. 2018 May

Medical Education

NICU Level 1 Seminar Room **FAMILY AWARENESS SESSIONS** **2-3pm**

Next to Waiting Area **AUGUST**

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
31st OUR FAMILY'S TEA AND COFFEE AFTERNOON	1st	2nd	3rd  "Memory Making"	4th  "Positive Touch""	5th  CPR	6th
7th OUR FAMILY'S TEA AND COFFEE AFTERNOON	8th  "Babies and Oxygen"	9th  "Helping My Baby to Develop"	10th  "Parents Together"	11th  "Bathing, Sterilising and Making up Feeds"	12th	13th
14th OUR FAMILY'S TEA AND COFFEE AFTERNOON	15th  "Help Us Prevent Infection"	16th  "What can parents be involved in?"	17th  "Getting Ready for Home"	18th  "Bathing, Sterilising and Making up Feeds"	19th  CPR	20th
21st OUR FAMILY'S TEA AND COFFEE AFTERNOON	22nd  "Transition to Breastfeeding"	23rd  "Take Time Out"	24th Glasgow Children's Hospital Charity	25th  "Parents Participate in Ward Rounds!"	26th  CPR	27th
28th OUR FAMILY'S TEA AND COFFEE AFTERNOON	29th  "Coping with Stress"	30th Bliss for babies born premature or sick	31st  "Expressing Milk"	1st  "How to help comfort your baby"	2nd	3rd

Patel N, et al; Helping Us Grow Group (HUGG). Family Integrated Care: changing the culture in the neonatal unit. Arch Dis Child. 2018 May

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Medical Education

Intensive Approach

- Implemented family integrated model in Madrid, Spain
- Family education included structure of NICU, family self care, learning infant's behavior, taking part in baby's care, preparation for home
- Content was given in printed and electronic formats

Inclusion Criteria for Parents:

✓Willing to spend at least 6hrs a day in NICU

✓Active involvement in care for at least 21 days

✓No language barriers

✓Informed consent to participate

Moreno-Sanz B, et al. Scaling Up the Family Integrated Care Model in a Level IIIC Neonatal Intensive Care Unit: A Systematic Approach to the Methods and Effort Taken for Implementation. Front Pediatr. 2021 Jun

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Medical Education

Tasks Included in Educational Sessions

- Hand hygiene
- Physiology and monitors
- IV lines
- Bathing
- Breast and other types of feeding techniques
- Kangaroo care
- Diaper changing
- Oral medication
- Mouth and skin care
- Stress and Pain response
- Interaction
- Invasive and non invasive respiratory support
- Care for NG/OG tube, ostomy, urinary catheters

Moreno-Sanz B, et al. Scaling Up the Family Integrated Care Model in a Level IIIC Neonatal Intensive Care Unit: A Systematic Approach to the Methods and Effort Taken for Implementation. Front Pediatr. 2021 Jun

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Medical Education

“My answer is yes, a thousand times yes. This program was determinant to learn how to deliver the care that my baby needs. The program allowed us to behave as real parents and not mere observers of our baby’s life.”

Moreno-Sanz B, et al. Scaling Up the Family Integrated Care Model in a Level IIIC Neonatal Intensive Care Unit: A Systematic Approach to the Methods and Effort Taken for Implementation. Front Pediatr. 2021 Jun

Antenatal Counseling

Antenatal Counseling

- Another component for family centered care approach
- Having an infant in NICU is extremely stressful for families
- Extreme preterm births present a medical and ethical challenge for providers and families
- No universal agreement on approach and management
- Family decision making is of utmost importance, but depends on quality of communication and counseling by providers

Antenatal Counseling

- Multiple opportunities to meet with the providers to share information and develop a care plan
- Reports where parents expressed disconnect between information provided and what they recall
- Information provided must be consistent and accurate
- Clear documentation
- Learning opportunity for trainees

Lemyre B, Moore G., Counselling and management for anticipated extremely preterm birth, Paediatrics & Child Health, September 2017

Strategies—Antenatal Counseling

Preparation

- Obtain all the relevant information
- Plan to have an interpreter if needed
- Have both parents available if feasible
- Avoid disturbance- Turn the pager off, close the door, etc
- Introduce yourself clearly
- Ask/address them by their names (including infant's)
- Include trainees/less experienced staff in the discussion

Daboval T, et al., Neonatal Ethics Teaching Program—Scenario-Oriented Learning in Ethics: Antenatal Consultation at the Limit of Viability. MedEdPORTAL Publications. 2015

FPQC

Strategies—Antenatal Counseling

During Consultation

- Assess their knowledge
- Understand their cultural/social background, beliefs
- Provide accurate and most up to date medical information
- Present the choices clearly, include pros and cons
- Disclose the uncertainty
- Offer time to think
- Ask how you can help them

Daboval T, et al., Neonatal Ethics Teaching Program—Scenario-Oriented Learning in Ethics: Antenatal Consultation at the Limit of Viability. MedEdPORTAL Publications. 2015

FPQC

Strategies—Antenatal Counseling

After Consultation

- Validate their difficult situation
- Provide support that they are not alone
- Provide any written information for parents to refer to
- Meet with them again, if possible, to resolve any questions

Daboval T, et al., Neonatal Ethics Teaching Program—Scenario-Oriented Learning in Ethics: Antenatal Consultation at the Limit of Viability. MedEdPORTAL Publications. 2015

FPQC

Summary

- PAIRED plus helps to integrate families in patient care
- Different drivers of PAIRED plus interact with each other
- Successful implementation of PBPs for one driver will likely improve outcome measures for other drivers

- Improved family satisfaction
- Improved family readiness for infant care at home
- Improved quality of care and long term outcomes

Together we care!!

Thank you!!

Stump the PAIRED Advisors

Adjourn