FCC Taskforce
January 2023 Webinar

INFANT AND FAMILY CENTERED DEVELOPMENTAL CARE: EVIDENCE FOR PRACTICE

Joy V. Browne, PhD, PCNS, IMH-E (IV)
Clinical Professor, Dept of Pediatrics
University of Colorado Denver School of Medicine
Pronouns: she/her/hers

USING THE EVIDENCE TO GUIDE PARENTS IN OPTIMIZING THE EARLY NICU ENVIRONMENT

Bobbi Pineda, PhD OTR/L, CNT
Assistant Professor, University of Southern California Chan Division of Occupational Science and Occupational Therapy,
Pronouns: she/her/hers

VARIATION IN FAMILY CENTERED CARE METRICS ACROSS CALIFORNIA

Jochen Profit, MD, MPH
Professor of Pediatrics (Neonatology), Stanford School of Medicine
Chief Quality officer at CPQCC
Pronouns: he/him/his

FAMILY-CENTERED CARE
TASK FORCE

FCC Core Team

FAMILY-CENTERED CARE
TASK FORCE

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Caroline Toney-Noland, MSc
Program Manager,
CPQCC

Co-Chairs

Malathi Balasundaram, MD
Clinical Associate Professor
Stanford School of Medicine
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Assistant Professor of Neonatology
University of Rochester Medical Center
Associate Medical Director of Golisano
Children's Hospital NICU

Partners

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TECaN — TRAINEES AND EARLY CAREER NEONATOLOGISTS — est 2009

cpqcc

california perinatal quality care collaborative

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

Section on Neonatal Perinatal Medicine

pac-lac

Perinatal Advisory Council: Leadership, Advocacy and Consultation

NEONATOLOGY TODAY

Peer Reviewed Research, News, and Information in Neonatal and Perinatal Medicine

Grants

FCC Taskforce Phase 3 small group QI efforts on implementing & strengthening Family Centered Care Committes & Family Partnership Councils in 34 centers

“Supported by a grant from Genentech, a member of the Roche Group”
&
“Prolacta Bioscience Foundation”

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Agenda

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Taskforce updates: Colby Day, MD

Speaker: Dr. Joy Browne

Speaker Q&A: Colby Day, MD

Speaker: Dr. Bobbi Pineda

Speaker Q&A: Caroline Toney Noland, MSc

Speaker: Dr. Jochen Profit

Speaker Q&A: Malathi Balasundaram, MD

Closing & Feedback Survey: Malathi Balasundaram, MD

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Executive Council - Family Partners

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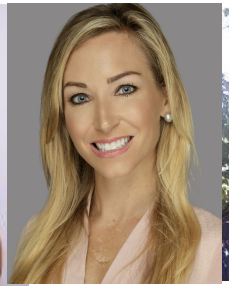
Jennifer Canvasser

Lelis Vernon



Elizabeth Simonton

Necole McRae

Keira Sorrells

Marybeth Fry

Kimberly Novod

Michael Hynan

Morgan Kowalski

Nicholas Hall

Molly Fraust-Wylie

Michelle Wrench

Betsy Pilon

Vishal Kapadia

Katherine Huber

Meegan Snyder

Kristy Love

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Executive Council
Health Care Providers

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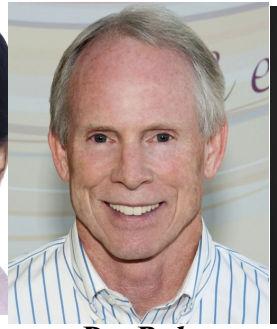
Dr. Dharshi Sivakumar



Dr. Bob White

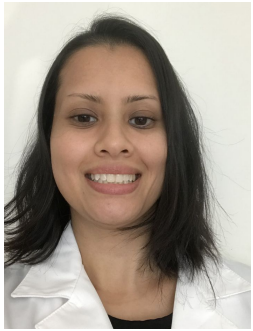
Dr. Emily Whitesel

Dr. Daphna Barbeau

Dr. Robert Cicco

Dr. Kerri Machut

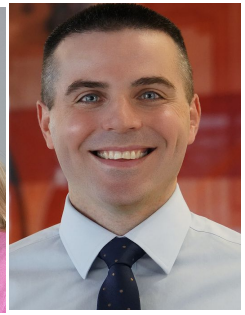
Dr. Jessica Fry



Dr. Vargabi Ghei

Dr. Henry Lee

Dr. Wendy Timpson



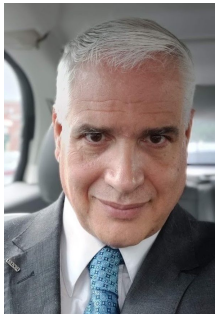
Dr. Jeff Meyers

Dr. Tim Palmer

Dr. Joy Browne

Aida Simonian

Lori Gunther



Dr. Mitchell Goldstein

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One Year Anniversary
FCC Task force

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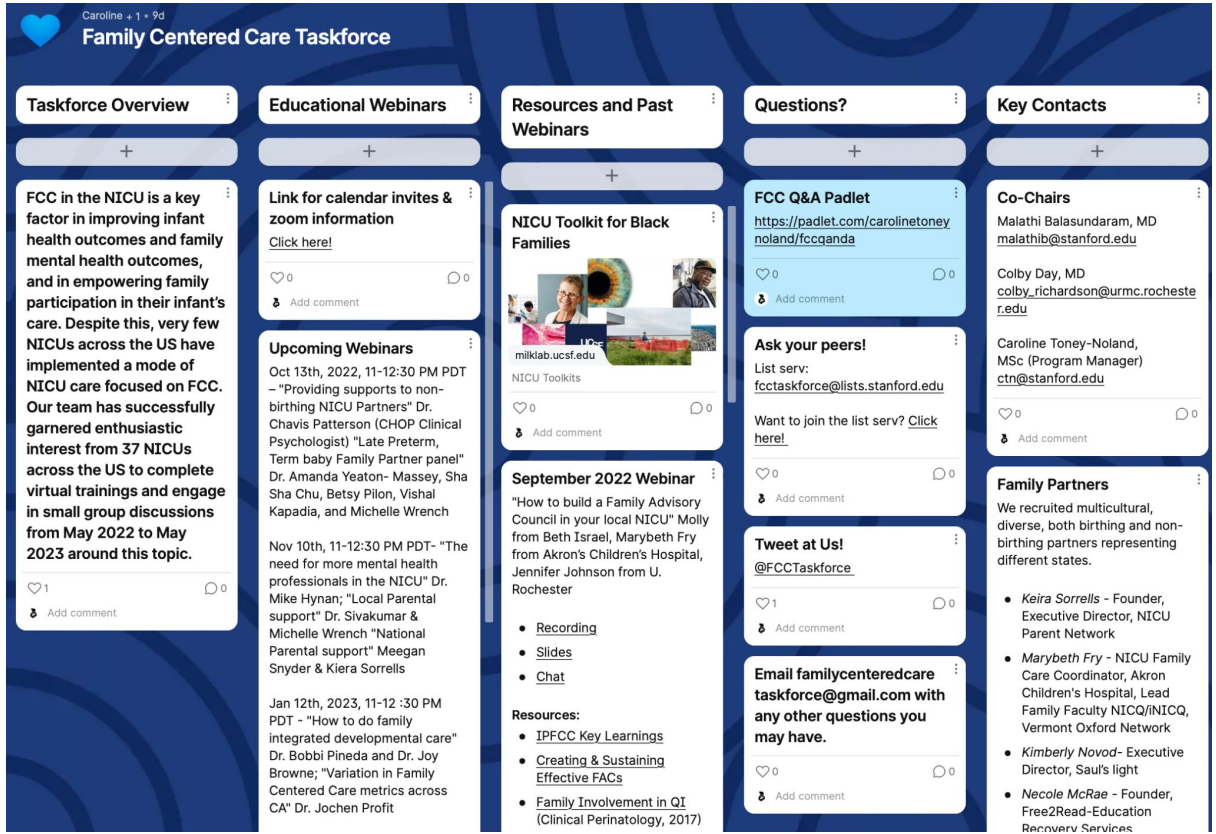
- 340+ listserv members from 90+ hospitals
- UK, Israel, Cambodia, Canada
- FCC Padlet: Scan QR Code



INFANT AND FAMILY CENTERED DEVELOPMENTAL CARE: EVIDENCE FOR PRACTICE

Joy V. Browne, Ph.D., PCNS, IMH-E (IV)

And Carol Jaeger, DNP, RN, NNP-BC

On behalf of the IFCDC Consensus Committee

The Gravens Conference
on the Environment of Care for High Risk Newborns

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Please see slide handouts,
the link is available on padlet.

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Dr. Joy Browne
Speaker Q&A

Family Centered Care Taskforce

Bobbi Pineda PhD, OTR/L, CNT
Assistant Professor
University of Southern California
Chan Division of Occupational Science and Occupational Therapy
Keck School of Medicine
Department of Pediatrics, Neonatology

Occupational Science in the NICU

- Occupational disruption: a disruption to typical patterns of occupation which could be due to environment constraints or health conditions
  - Can lead to changes in identity, routines, and participation in occupations
- Occupational disruption is evident in daily NICU experiences
  - Parental role alteration
  - Infant environmental exposures
  - Experiences that lay the foundation for later development and occupations
  - Engagement in infant occupations: oral feeding and social interactions

Parents in the NICU

- Mental health challenges and low confidence are common
- Parents of low SES have less participation in the NICU
- Parent engagement is relat…nes

> Early Hum Dev. 2018 Feb;117:32-38. doi: 10.1016/j.earlhumdev.2017.12.008. Epub 2017 Dec 21.

Parent participation in the neonatal intensive care unit: Predictors and relationships to neurobehavior and developmental outcomes

Roberta Pineda [1], Joy Bender [2], Bailey Hall [3], Lisa Shabosky [3], Anna Annecca [3], Joan Smith [4]

> Early Hum Dev. 2018 May;120:31-39. doi: 10.1016/j.earlhumdev.2018.03.009. Epub 2018 Apr 4.

Maternal mental health during the neonatal period: Relationships to the occupation of parenting

Rachel Harris [1], Deanna Gibbs [2], Kathryn Mangin-Heimos [3], Roberta Pineda [4]

Published: 14 February 2013

Parental presence and holding in the neonatal intensive care unit and associations with early neurobehavior

L C Reynolds ✉, M M Duncan, G C Smith, A Mathur, J Neil, T Inder & R G Pineda

Journal of Perinatology **33**, 636–641 (2013) | Cite this article

*Parents are the key drivers of their infants' sensory experiences and development

Optimal Programming in the NICU Requires Intention

- Brings infants and parents together to optimize outcome
- Engages parents in achieving their important role
- Optimizes the environment for the infant through interactions with their parents
  - Tailors the intervention to the specific age of the infant
  - Is responsive to the infant's current medical interventions and behavioral cues
- Lays the foundation for future interactions

Overview of the SENSE Program

- Evidence-based: Incorporates what we know to date on sensory experiences in the NICU and packages it in an easy to follow format for parents and health care professionals
- Provides choices of different tactile, auditory, visual, kinesthetic and olfactory/gustatory experiences to provide the infant every day in the NICU
- The amount of time and type of sensory exposures are based on postmenstrual age
  - Sensory development
  - Infant tolerance
  - Behavioral cues
- Intended to be parent-delivered
  - Parent education materials
  - Sensory support team can fill in gaps
- Incorporated into daily life within the NICU
- Typically overseen by a neonatal therapist who does parent education and

SENSE II

Supporting & Enhancing NICU Sensory Experiences

2nd Edition

A Guidebook for Parents in the NICU

USC Chan Division of Occupational Science and Occupational Therapy

Keck Medical Center of USC

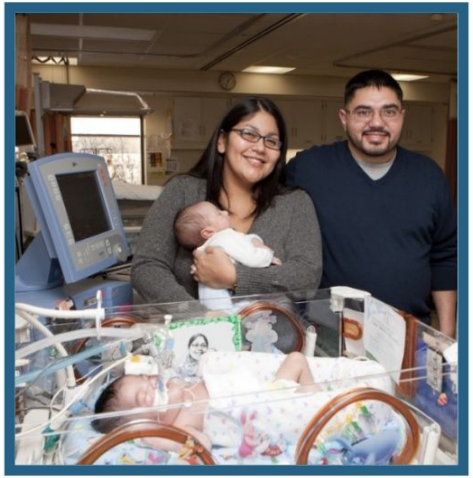
Table of Contents

1 Parenting in the NICU

What You Can Do For Your Baby

Importance of Parents

- The role of the parent is different than any other job on the team and can't be done by anyone else but you.
- You are the most important person in your baby's life.
- You are the person who knows your baby best.
- You taking part in the NICU will help your baby grow and develop.
- Your baby knows you: your voice, your scent, your touch, your heartbeat.



Your Baby's Medical Treatments

- Having a baby in the NICU means that medical treatments are needed.
- Medical treatments are not only helping to keep your little one healthy, but are also helping your baby to grow.
- Because your baby is undergoing medical treatments, you are needed even more.
- **You can help your baby feel more comfortable by talking, touching, or holding your baby before, during, or after needed medical treatments.**

- **You are an important part of your baby's care. Ask the NICU care team questions about anything you don't understand.**

2 Experiencing the World

Our Body's Senses

We Have Seven Basic Senses

1. Touch.
2. Hearing.
3. Smell.
4. Taste.
5. Seeing.
6. Body Awareness (understanding the parts of your body, where they are located, how they feel, and what they can do).
7. Movement.

In the Womb: **Hearing**

- Baby's hearing develops by the 24th week of pregnancy.
- Sounds from the outside world are muted by the body.
- In the womb, your baby can hear the heartbeat, gushes of fluid, blood flowing in the veins, and noises of the stomach.
- Your baby can hear voices from the outside and can also feel vibrations.
- Your baby can recognize parents' voices after birth. **Knowing the parents' voices is important for bonding between parents and the baby.**
- Hearing allows your baby to learn about language and communication.

3 Growing Up in The NICU

Supporting Your Baby's Developing Senses

The NICU Experience

- Premature birth and staying in the NICU changes how your baby experiences the world.
- Your baby no longer has the protection of the parent's body, and your baby experiences all of the noise, light, touch, pain, and gravity that is in the outside world.
- Your baby's senses continue to develop just like they would in the womb, but now those senses are getting different stimulation.
- **It is important to make sure that your baby receives the right kind of stimulation, so that it will support the developing senses.**
- How? By giving sensory experiences that are backed by research, and by spending quality time with parents every day.
- Your health care team can help guide you about the types of sensory experiences that are best for your baby. This may change as your baby grows stronger.
- This guide provides suggested types of activities along with how long to conduct them. All the activities in this book have research that has shown them to benefit you and/or your baby.

Supporting Your Baby's Sense of Touch Through Kangaroo Care and Holding

- **One of a baby's favorite activities in the NICU is kangaroo care, also known as skin-to-skin holding.**
- **While there are different ways to do kangaroo care, it usually involves having your baby (with only a diaper on) placed on your bare chest.**
- Kangaroo care can be done by any parent.
- Holding your baby skin-to-skin helps with bonding with your baby. Your baby can hear your heartbeat, smell you, and feel your touch (much like when they were in the womb).
- Kangaroo care helps your baby keep a stable temperature and makes your baby feel comfortable and secure.
- Kangaroo care helps to steady your baby's vital signs, improve sleep, and decrease stress for both you and your baby.
- Holding your baby in your arms also benefits you and your baby.

Supporting Your Baby's Sense of Hearing

- **Your baby's favorite voice is YOURS. Your voice will provide something familiar, secure, and comfortable.**
- Hearing can help the baby develop language skills later in life.
- The sound level of your singing, reading, or talking should be quiet (that of a whisper), so that your baby does not wake up from sleeping.

4 How Your Baby Talks To You

Watching Baby's Signals

Approach Behaviors: “I’m Ready to Interact”

Focused Attention

Baby will make eye contact with you.

Bright Eyed & Sucking Movements

Regular Breathing Rate

Face, Arms, and Legs Relaxed

Good Color

Awake, Quiet, & Alert

Baby nestled, relaxed, and ready for interaction.

Self-Calming Behaviors: "I'm Doing OK"

Foot Bracing
Babies may put one foot on top of the other or push against your hand or the bed for support.

Sucking
Babies may suck on the breathing tube at times. They also may suck on a pacifier or their fingers. Sucking can be very calming.

Hand Clasping or Finger Grasping
Babies may grasp their own hands or close their fingers around your finger.

Stressed Behaviors: “I Need a Rest”

Hyper-Alert
Wide-Eyed
Staring Gaze

Looking Away

Limp/Flaccid
Unable to respond
to stimulation

Exhausted

5 Your Time With Your Baby

When To Interact

Sleep is Important!

- Sleep is important for your baby, but having positive sensory experiences with you is most important.
- **By planning activities around your baby's sleep, your baby can have both uninterrupted sleep AND positive sensory experiences.**

- Some activities can be done while your baby is sleeping and may help your baby sleep.
- Other activities can be structured around a time when your baby is going to be waking soon.

Things To Do When Baby Is Asleep

- **Some positive sensory experiences can be done during sleep and may even help your baby sleep!**
- Some examples of activities that can be done when your baby is sleeping or to help them sleep include:
  - Giving your baby a pacifier.
  - Giving hand hugs.
  - Doing things for your baby's hearing (like reading, talking, or singing) that are the sound of a whisper.
- All of these things can be done at any time of day, including in between scheduled care times.

Things To Do When Baby Is Asleep

- Activities during sleep are different from activities you may do when your baby is awake.
  - Activities during sleep tend to be low-intensity and often do not involve movement.
- It is important to try only one thing at first, and then you can add another activity as long as your baby stays asleep.
- Here is an example of what you can try while your baby is sleeping:
  - Speak softly to your baby at the sound of a whisper.
  - Wait 30 seconds to one minute. If your baby tolerates it and does not wake up, add one steady hand gently to the forehead.
  - Wait another 30 seconds to one minute. If your baby tolerates it and does not wake up, add your other hand gently onto the stomach.

6 Supporting Your Baby's Senses

Week-By-Week Sensory Plan

Week-By-Week Sensory Plan

Touch
(Tactile)

Hearing
(Auditory)

Smell
(Olfactory)

Seeing
(Visual)

Movement & Body Awareness
(Vestibular & Proprioception)

Each week in the NICU, your baby's senses are developing.

This next section will introduce activities to do with your baby every day. The postmenstrual age at the top of each page will help you find the activities appropriate for your baby's current developmental stage.

The symbols on the left show which sense each activity is for.

You will see recommendations for the amount of time to provide sensory experiences for your baby. These are goals. Some babies will enjoy more or less of an activity, and you might not always be able to do as much as you would like. Do what you can, and follow your baby's lead!

Sensory Support: ≤ 23 Weeks

Here are some things to do with your baby each day this week
(as long as tolerated)

Touch

Do kangaroo care (skin-to-skin) or a hand hug with your baby for at least 1 hour per day.

Hearing

Engage in quiet conversations near the bedside and during diaper changes.

Smell

Provide at least 3 hours per day of parent scent or the smell of breast milk.

Seeing

Protect your baby from direct or bright light.

Movement & Body Awareness

- Unwrap your baby and allow stretching and free movement for at least 2 minutes prior to a diaper change at least 1 time per day.
- Allow your baby to experience being in at least 2 different positions for at least 10 minutes each.

Sensory Support: 32 Weeks*

*Denotes change from previous week

Here are some things to do with your baby each day this week
(as long as tolerated)

Touch

Give at least 2 hours of positive touch each day by doing one or more of these things:

- Provide a hand hug.
- Do kangaroo care (skin-to-skin) for at least 1 hour.
- Hold your baby in a blanket for 15 minutes at a time, or longer if your baby's temperature remains stable.
- Do massage for up to 15 minutes.

Hearing

Give at least 1 ½ hours of positive sound each day by doing one or more of these things:

- Read, sing, and/or speak to your baby (can be broken up into 30 minute periods several times per day).
- Play soft music or recorded voice.

**At the sound of a whisper or quiet conversation.*

Smell

Provide at least 3 hours per day of parent scent or the smell of breast milk.

Seeing

- Cycle light to your baby with natural light (or lights on, when there is no natural light) during the day and dim light or darkness at night.
- Avoid direct and bright lights.

Movement & Body Awareness

- Unwrap your baby and allow stretching and free movement for at least 2 minutes prior to a diaper change at least 3 times per day.
- Allow your baby to experience being in at least 2 different positions for at least 10 minutes each.
- Rock during holding for at least 3 minutes.

Sensory Support: ≥ 40 Weeks

Here are some things to do with your baby each day this week
(as long as tolerated)

Touch

Give at least 3 hours of positive touch each day by doing one or more of these things:

- Provide a hand hug.
- Do kangaroo care (skin-to-skin) for at least 1 hour.
- Hold your baby in a blanket.
- Do massage for up to 15 minutes at a time.

Hearing

Give at least 3 hours of positive sound each day by doing one or more of these things:

- Read, sing, and/or speak to your baby (can be broken up into 30 minute periods several times per day).
- Play soft music or recorded voice.

**At the sound of a whisper or quiet conversation.*

Smell

Provide at least 3 hours per day of parent scent or the smell of breast milk.

Seeing

- Cycle light to your baby with natural light (or lights on, when there is no natural light) during the day and dim light or darkness at night.
- Avoid direct and bright lights.
- While shielding your baby from direct light, have your baby try to focus on or follow your face.

Movement & Body Awareness

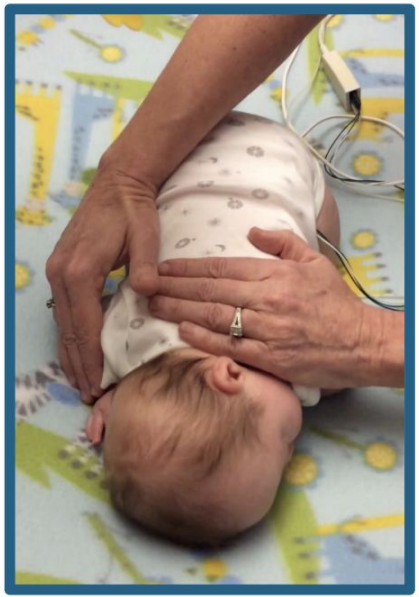
- Unwrap your baby and allow stretching and free movement for at least 2 minutes prior to every diaper change.
- Allow your baby to experience tummy time and being in at least 3 other positions for at least 10 minutes each.
- Rock during holding for at least 7 minutes.

7 Helping Your Baby's Senses

A "How-To" Guide

Massage

- Your care team can help you decide if massage is right for your baby.
- **Do massage only if your baby is showing "I'm Doing OK" or "I'm Ready to Interact" signs.**
- The focus should be on your baby relaxing, rather than the number and type of strokes.
- Apply a hand hug to start.
- Strokes should be done slowly and with gentle pressure.
- Avoid light touch and avoid heavy pressure.
- Up to 15 minutes of massage (at different times of the day) can benefit your baby.



Research Findings

- 400+ hospitals are implementing the SENSE program
- Parents and health care professionals have positive perceptions about the SENSE program
- More parent engagement in the NICU
- Increased parent confidence
- Better infant outcomes

SENSE Program: The Future

- Updated every 5 years to reflect the most current evidence
- Training programs
- Program accessibility through availability as a not-for-profit entity

*Ultimate goal: provide a structured format to aid parents in interacting with their infants in an age-appropriate and individualized manner while in the NICU

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Dr. Bobbi Pineda
Speaker Q&A

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TASK FORCE

VARIATION IN FAMILY CENTERED CARE METRICS ACROSS CALIFORNIA

Jochen Profit, MD, MPH
Professor of Pediatrics (Neonatology), Stanford School of Medicine
Chief Quality officer at CPQCC
Pronouns: he/him/his

Family Centered Care Metrics – Pilot Results

Jochen Profit, MD, MPH
Professor of Pediatrics
Chief Quality Officer, California Perinatal Quality Care Collaborative

Disclosure

Dr. Profit's equity research has been supported by:

- NICHD R01 - HD083368 (PI: J Profit)
- NICHD R01 - HD084667 (PI: J Profit)
- NICHD R01 - HD094847 (Co-PIs: J Profit, E Main)

Dr. Profit's care culture and burnout research has been supported by:

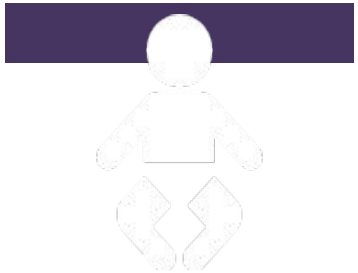
- NICHD R01 - HD083368-01 Co-PIs: J Profit, JB Sexton)

Dr. Profit serves as an unpaid Advisory Board Member of the NEC Society

By the numbers

500K

CMQCC



17K

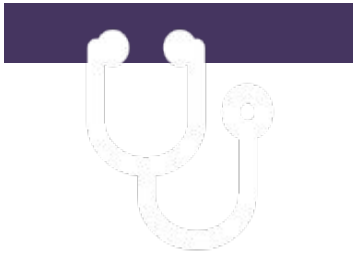
140

CPQCC/CMQCC

7K

ACUTE NEONATAL TRANSPORTS

CPeTS



9K

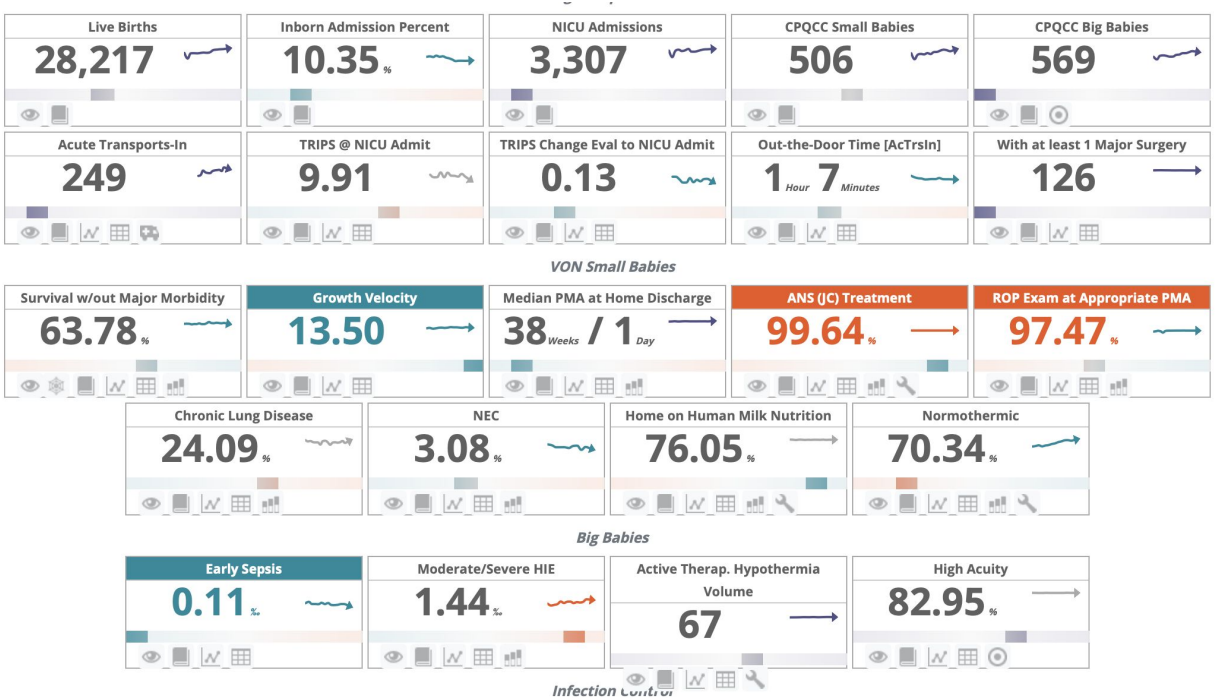
HIGH-RISK INFANTS REGISTERED

HRIF

Our Programs

1. **NICU/HRIF Database**
2. **Quality Improvement**
3. **Education**
4. **QI Research**

NICU/HRIF Database



- Web-based system that analyzes and displays critical information on newborns admitted to and transferred between NICUs across California
- Customizable reports allow for comparison of data across a wide range of parameters
- Individualized member support by a team of knowledgeable analysts
- Linkages with the HRIF program allow for tracking of long-term neurodevelopmental outcomes of high risk infants

Inequities in Perinatal Care

Origins of disparity

SDH

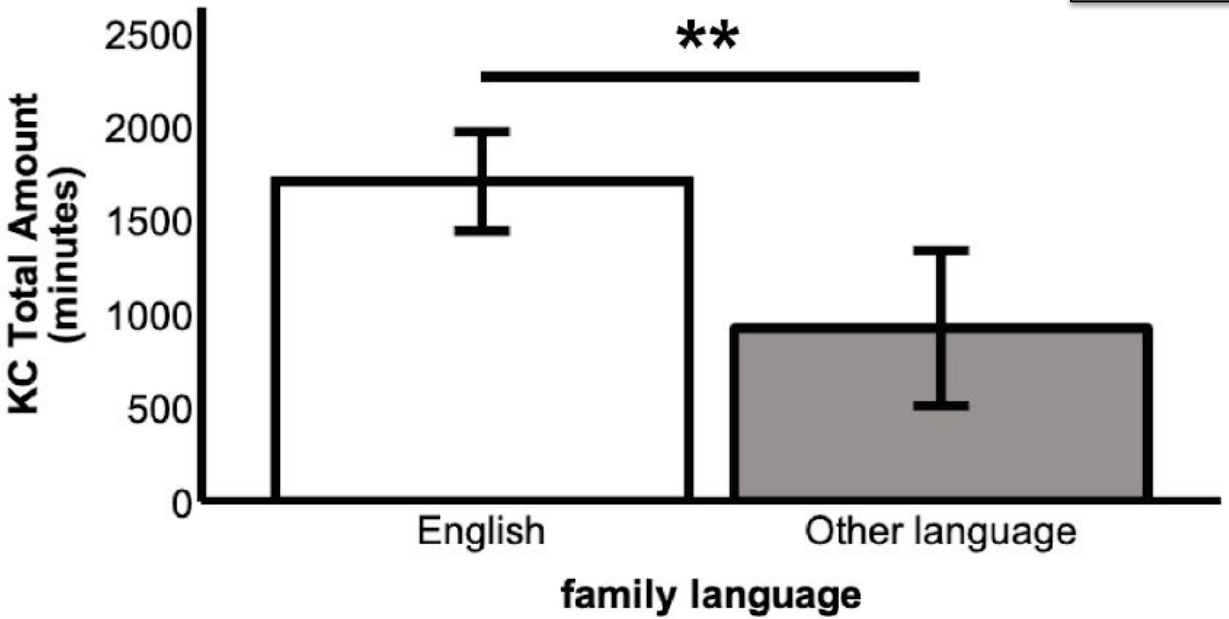
Following THROUGH

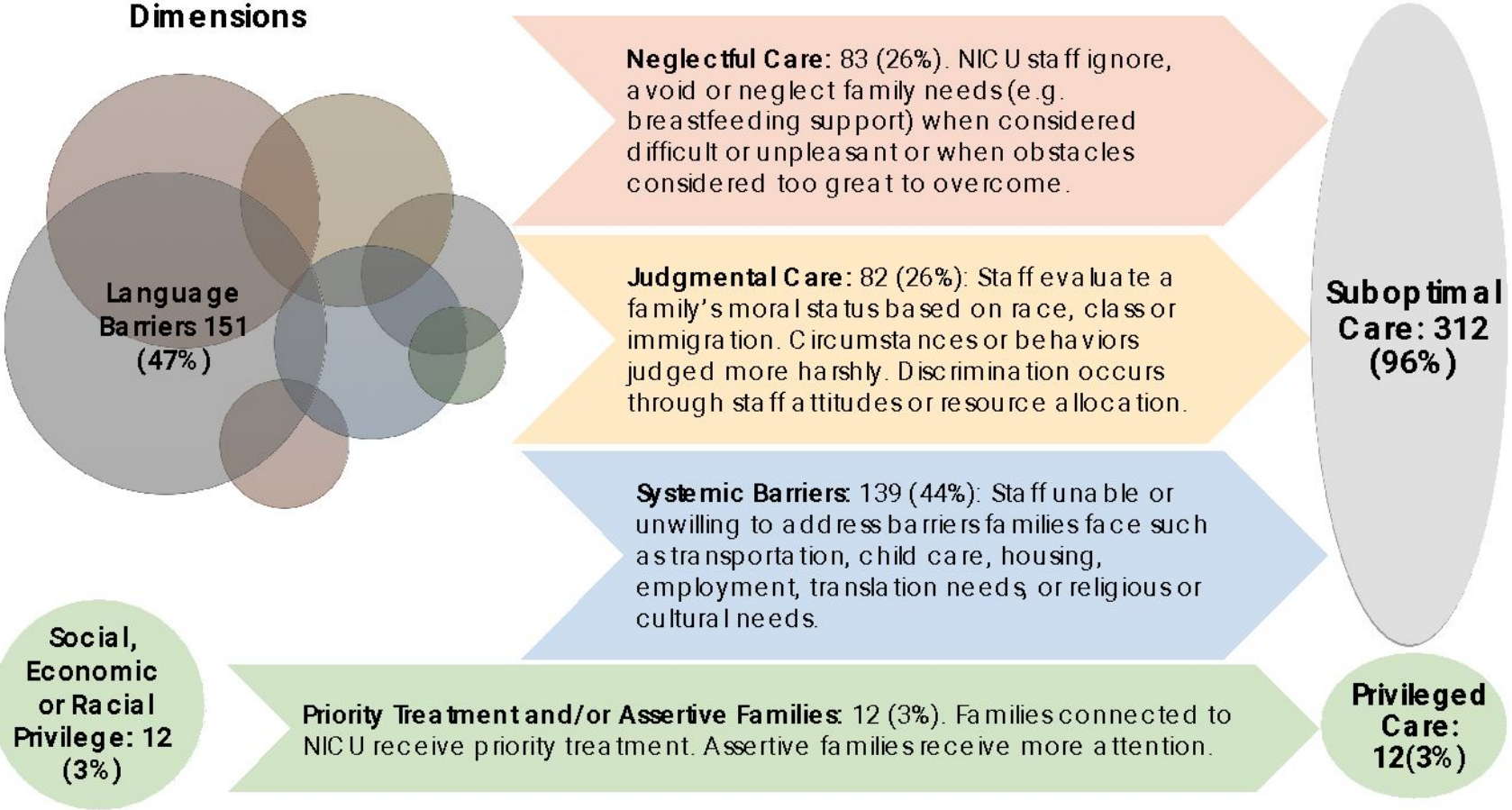
But we treat all patients the same!

Disparities within hospitals – Interpersonal racism

Access to Skin-to-Skin Care

Brignoni-Pérez E et al.
J Dev Behav Pediatr. 2022
Jun-Jul 01;43(5):e304-e311





Sigurdson K, Profit J, et al. Disparities in NICU Quality of Care: A Qualitative Study of Family and Clinician Accounts. *J Perinatol* 2018 May;38(5):600-607

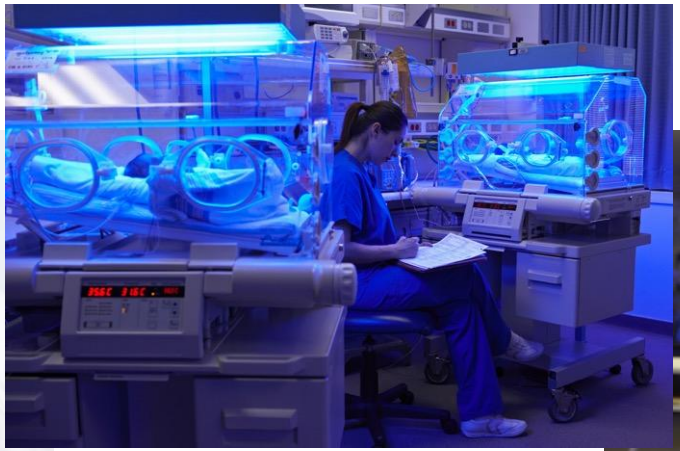
Neglectful care

Just a general observation when I worked as a charge nurse... Nurses tended just to **ignore parents who did not speak their language**. Often the use of a translator didn't occur daily for education and updates. These parents would have to **sit by their baby's bedside and wonder** how they were doing. …these parents did not get the opportunity to interact and bond with their baby as a result.

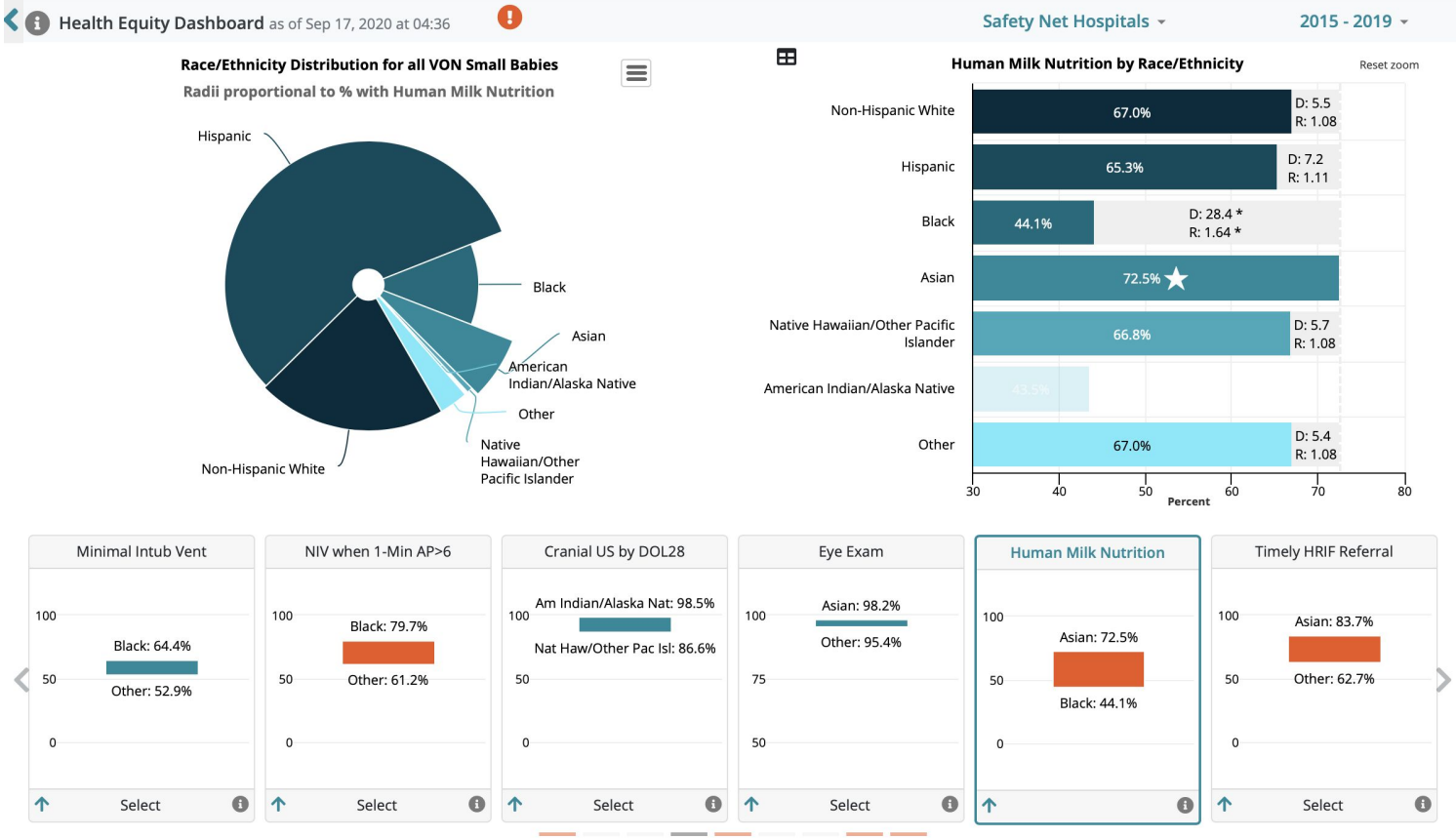
Judgmental care

I see this all the time... the way we treat black moms is definitely different than how we treat white moms. Age plays a factor too - young moms are judged very unfairly. One black mom was judged very harshly for being late for a feeding even though she had a long and challenging transit ride to get to the hospital. A white mother who was late on the same day was greeted with sympathy…

Accounts told of *disparate care of families*, not strictly infants

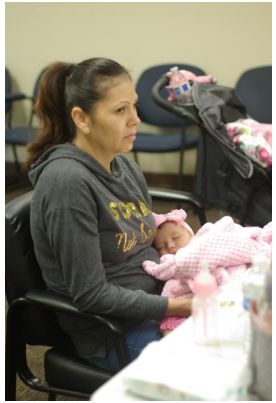


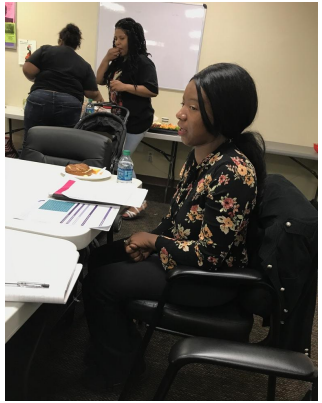
CPQCC EQUITY DASHBOARD



Equity measurement

a. Measuring Family Centered Care





* Expert panel with FAMILY REPRESENTATIVES.
  Focus groups and interviews with minoritized families
* DELPHI METHOD

  Structured method for expert input without need for consensus
  Two rounds of multi-criteria ratings of measures
  SELECTION CRITERIA:
  - Median rating >=7 (scale of 1 (low) – 9 (high)
  - Pass test for agreement (80% of ratings between 7-9)
  - Pass test for disagreement (90% of ratings were between 4-9)
* OVERALL GOAL
  Develop a balanced scorecard of measures across multiple domains

Sigurdson K, Profit J, Dhurjati R, Morton C, Scala M, **Vernon L*, Randolph A*,** Phan JT, Franck LS. **Former NICU Families Describe Gaps in Family-Centered Care.** ***Qual Health Res 2020. *NICU moms***

Three Candidate Measures Selected – 21 NICU Pilot

ENGAGING FAMILIES AS PARTNERS

- Family presence at the bedside
- Family not present at the bedside
- **NICU family advisory council (✓)**

FAMILY PARTICIPATION IN HANDS-ON CARE

started 1/2024

- **Days to first skin-to-skin care (✓)**
- Frequency of skin-to-skin care
- Days to skin-to-skin by two family members

SUPPORT FOR BREASTFEEDING

- NICU lactation consultant availability
- Time to first lactation consult
- **Hours to first oral colostrum (✓)**

PROVIDING SERVICES AND SUPPORTS

- NICU social worker availability
- Time to social worker contact
- **Days to first LISW contact (✓)**
- Frequency of social worker contact

COMMUNICATING WITH FAMILIES

- Frequency of updates to families by MD/NNP/RN
- Frequency of updates to families with limited English proficiency by MD/NNP/RN
- Provision of interpreter services

- Post-discharge care coordination*
- Continuity of care by RN*
- Continuity of care by MD*

*Care coordination measures to be subjected to additional research- Not selected at this time

Measures of Family Centered Car

- **Days to first skin-to-skin care**
- **Days to first social work contact**
- **Hours to first oral colostrum**

Christine Morton[1], Melissa Scala[1], Lelis Vernon[2], Jochen Profit[1], Ravi Dhurjati[1], Ashley Randolph[3], Jessica T. Phan[4], and Linda S. Franck[5]

Abstract

Care and outcomes of infants admitted to neonatal intensive care vary and differences in family-centered care may contribute. The objective of this study was to understand families' experiences of neonatal care within a framework of family-centered care. We conducted focus groups and interviews with 18 family members whose infants were cared for in California neonatal intensive care units (NICUs) using a grounded theory approach and centering the accounts of families of color and/or of low socioeconomic status. Families identified the following challenges that indicated a gap in mutual trust and power sharing: conflict with or lack of knowledge about social work; staff judgment of, or unwillingness to address barriers to family presence at bedside; need for nurse continuity and meaningful relationship with nurses and inconsistent access to translation services. These unmet needs for partnership in care or support were particularly experienced by parents of color or of low socioeconomic status.

Keywords

family-centered care; neonatal care; quality-of-care; grounded theory; patient-and-family engaged research; California; qualitative

A growing body of literature documents parents' critical role in promoting the health outcomes of low birthweight and preterm infants and a variety of models have been promoted toward that end (Franck & O'Brien, 2019). Historically, families were not permitted in the neonatal intensive care unit (NICU) or were only permitted on a limited schedule as "visitors" (White et al., 2013). Family-centered care, as an approach to NICU care, recognizes the strengths and needs of a patient's family and their important role in promoting recovery from illness and long-term health outcomes (Franck & O'Brien, 2019).

The origins of family-centered care can be traced back to British children's hospitals in the 1950s when nurses began to involve parents in the care of their hospitalized children (Jolley & Shields, 2009). The approach came to influence care in the United States over the 1980s, as families gradually came to be seen as active care partners of their children (Brewer et al., 1989). Family-centered care, consisting of interrelated principles and practices that recognize the central importance of family members in an individual's health and well-being, has since been widely applied across the lifespan and in various health care settings (Davidson et al., 2017; Johnson, 2000). It is now understood under the larger umbrella concept of "patient- and family-centered care" in that the principles of working *with* patients and families (rather than doing "to" or "for" them) can be applied to any care setting (Institute for Patient- and Family-Centered Care, 2020). For the purposes of this project involving parents of former NICU patients, we use the term "family-centered care" throughout.

Models of care that explicitly involve families are now considered best practice in the NICU and the implementation of family-centered care promotes mutual respect and shared decision-making between clinicians and families, ensuring timely and quality psychosocial supports and hospital resources that facilitate family well-being and involvement (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012; Franck & O'Brien, 2019). Family-centered care also includes direct care delivered by families to their infants,

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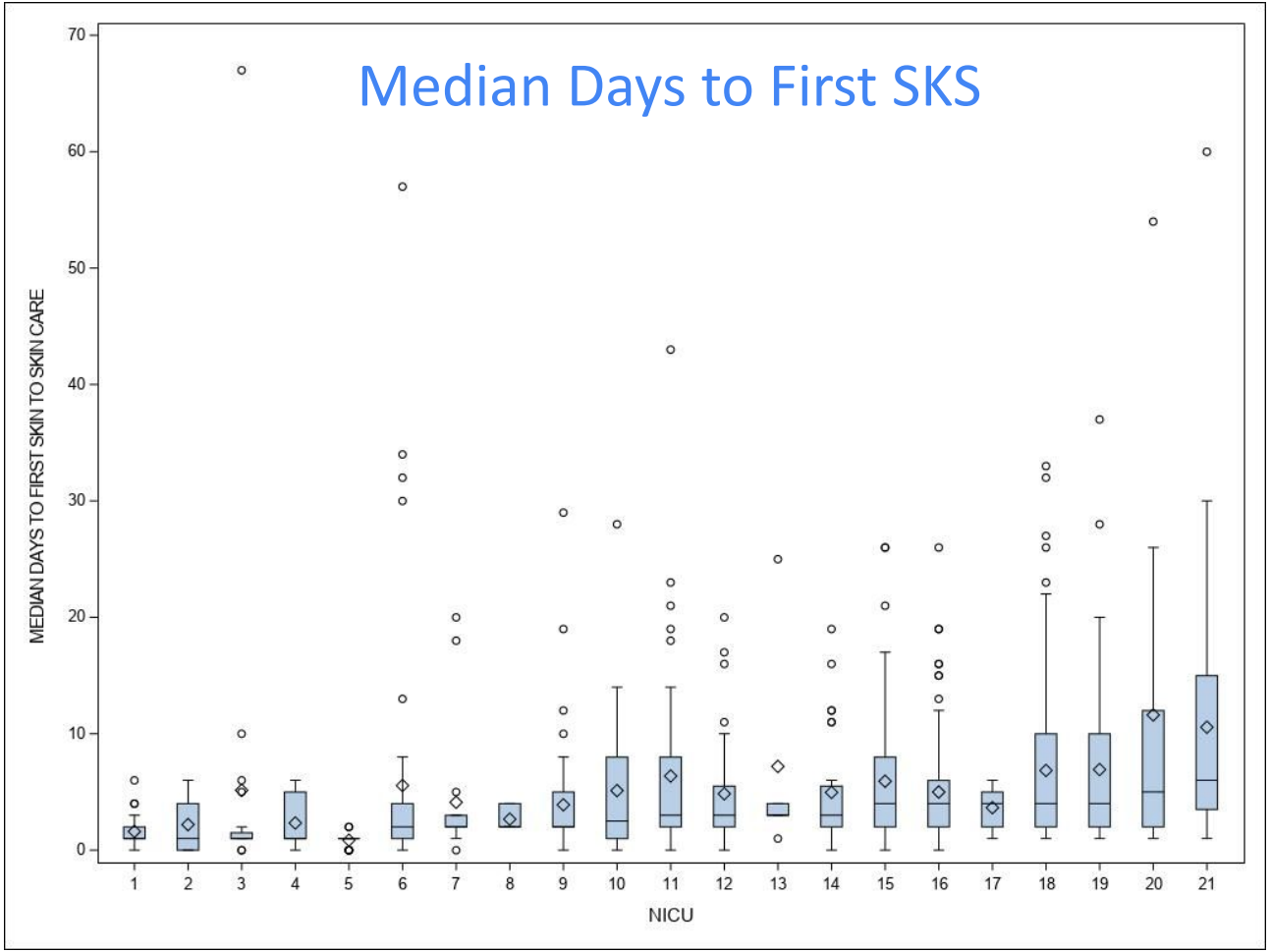
Point-of-care derived measures developed in collaboration with disadvantaged families. Measures selected through a modified Delphi panel that included family representatives.

Family centered care measures among hospitals participating in the FCC Pilot

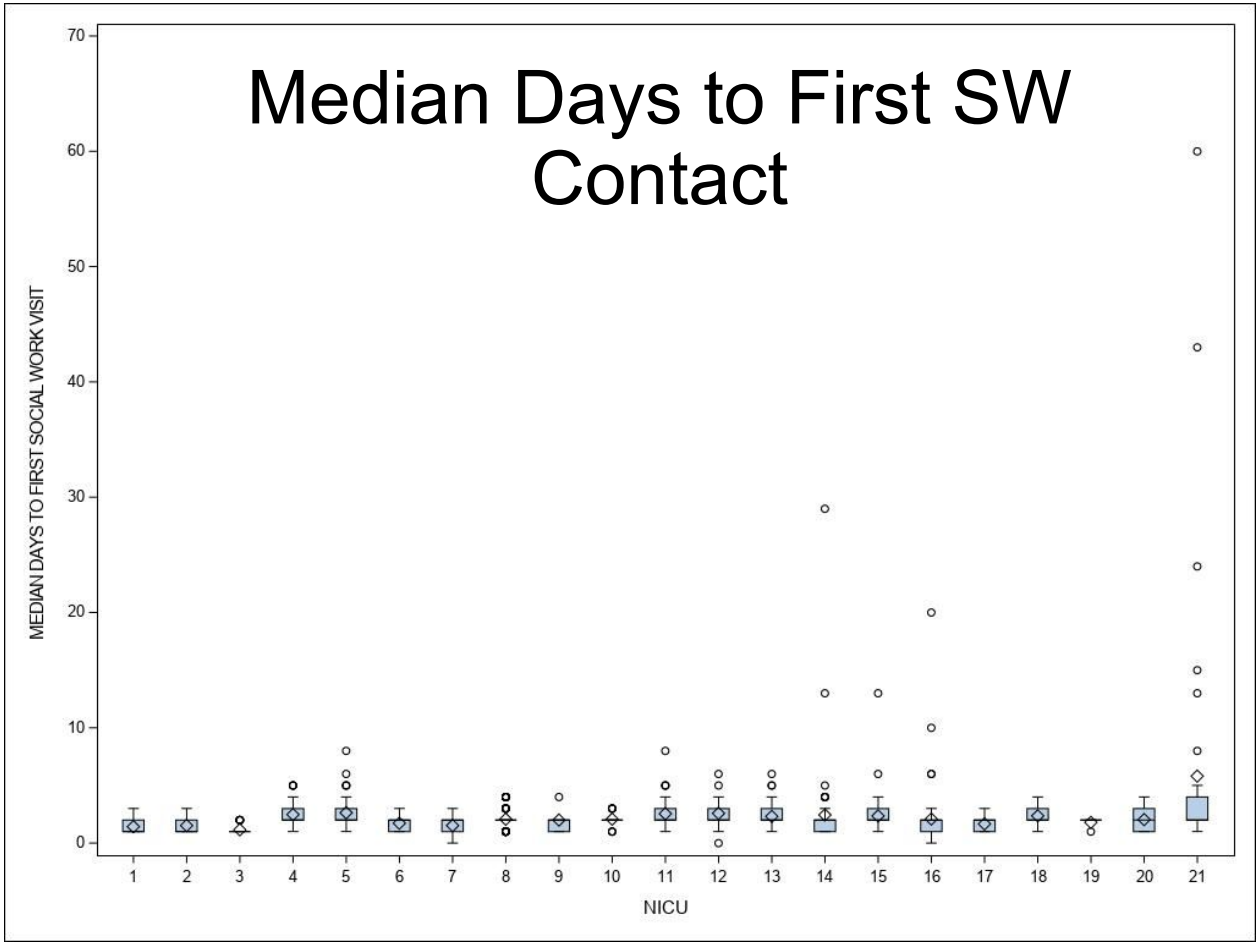
Measure	Mean	(sd)	Median	(IQR)	Range (min-max)
Days to first skin-to-skin care	4.31	4.94	2.54	(1.30-5.51)	(0.18-40)
Days to first SW contact	1.93	0.37	1.98	(1.63-2.17)	(1.15-2.96)
Hours to oral colostrum	31.16	21.61	27.67	(18.0-41.69)	(0.03 - 167.5)

N= 1236 VLBW or high acuity larger infant from 21 NICUs from January 1 to December 31, 2021

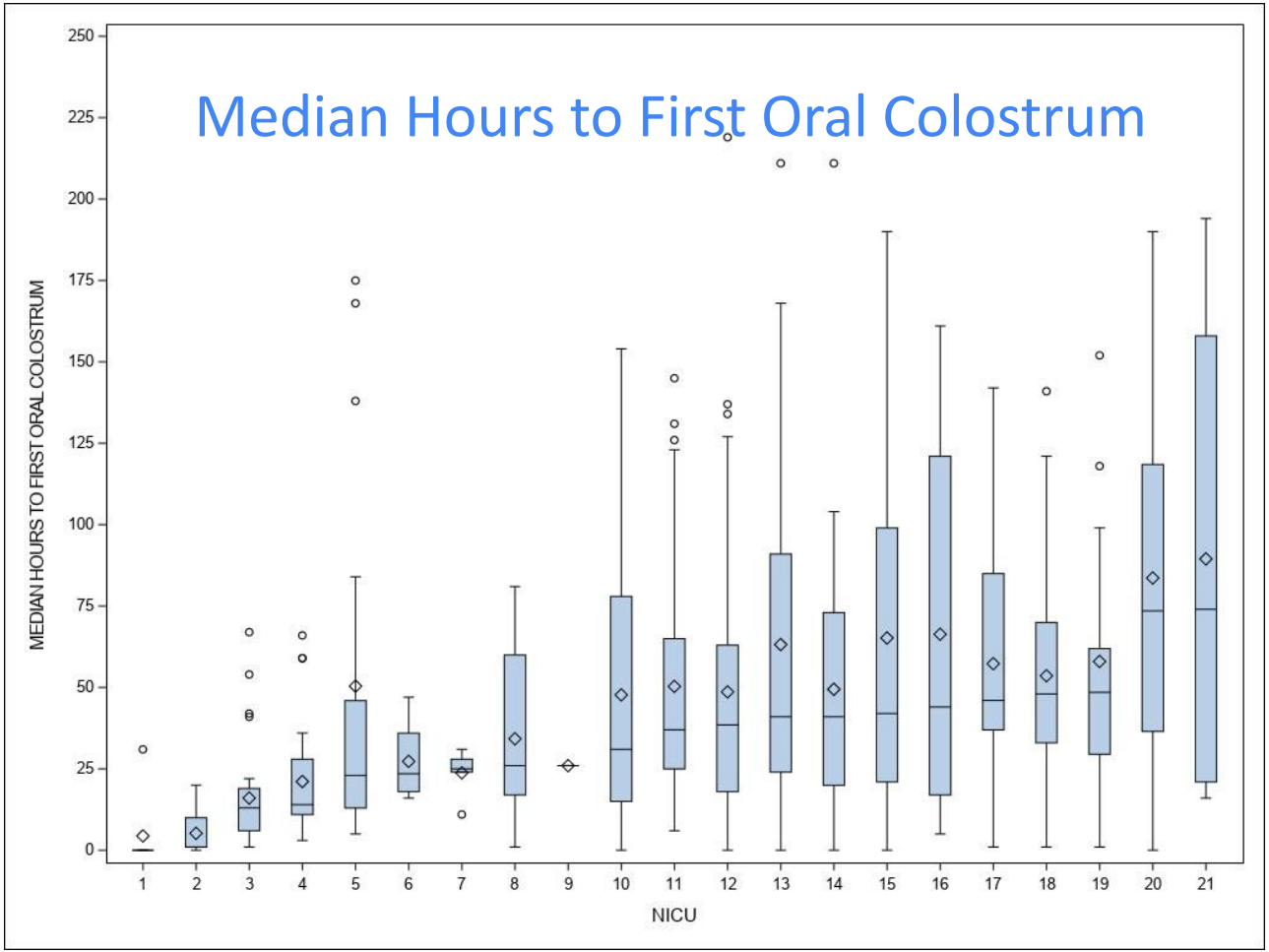
Median Days to First SKS



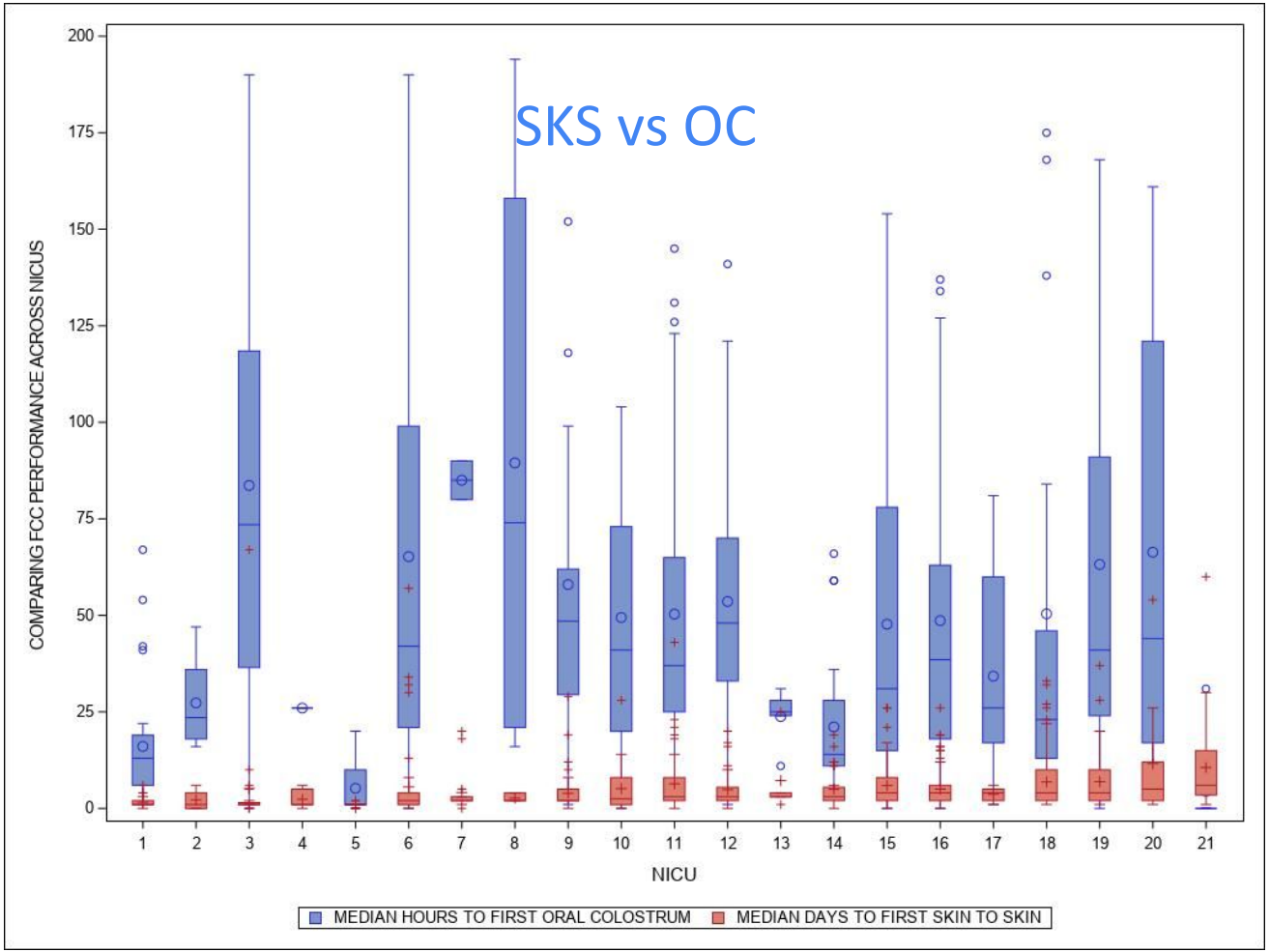
Median Days to First SW Contact



Median Hours to First Oral Colostrum



SKS vs OC


COMPARING FCC PERFORMANCE ACROSS NICUS
200
175
150
125
100
75
50
25
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7
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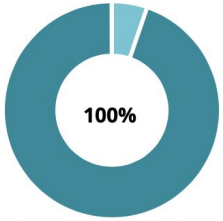
20
21
NICU
MEDIAN HOURS TO FIRST ORAL COLOSTRUM
MEDIAN DAYS TO FIRST SKIN TO SKIN

Family centered care measures among hospitals participating in the FCC Pilot by Safety Net and Ethnicity

	NON SAFETY	SAFETY		WHITE	NON-WHITE	
Measure	Median (IQR)	Median (IQR)	p-value	Median (IQR)	Median (IQR)	p-value
First skin-to-skin care, days	2.1 (3.9)	2.8 (4.3)	<.001	1.8 (2.8)	2.8 (4.4)	<.001
First SW contact, days	2.04 (0.4)	1.9 (0.6)	<.001	2.0 (0.5)	2.0 (0.6)	0.2
First oral colostrum, hours	24.5 (19.8)	32.0 (22.8)	<.001	25.9 (19.7)	29.1 (24.8)	0.002

FCC Focusboard

Priming with Oral Colostrum at this NICU



Percent with Oral Colostrum

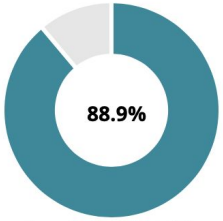
Median Hours to Oral Colostrum

The practice of priming with oral colostrum confers benefits to VLBW infants and signals NICU culture and commitment to use of mother's milk for nutrition.

The percent and median shown are based on all inborn infants who were hospitalized at your hospital for at least 48 hours, who did not have anomalies affecting the ability to prime with oral colostrum, and who were not exposed to maternal substance use during fetal life.

Explore this topic ... Go

Skin-to-Skin at this NICU



Percent with Skin-To-Skin

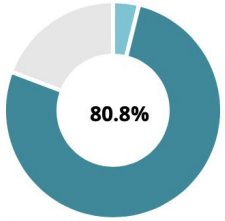
Median Days to Skin-To-Skin

Skin-to-skin care is protective against a variety of adverse neonatal outcomes. SKS requires holding of the infant by a family member. Positive touch is not counted. Infants that are transferred are included.

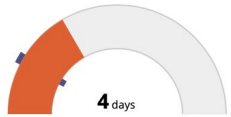
The percent and median shown are based on all inborn infants, who were hospitalized at your hospital for at least 5 days, and who did not have anomalies affecting the ability to provide skin-to-skin admitted to your NICU, and who never experienced high frequency ventilation.

Explore this topic ... Go

Social Worker Visit at this NICU



Percent with Social Worker Visit



Median Days to First Social Worker Visit

Timely social worker assessment is critical to identifying psychosocial and material needs of NICU families and to connect families to appropriate supportive services. Timely social worker contact, within 2 days of NICU admission, is also mandated by CCS regulations in California. The goal of this measure is to examine whether the needs of families are being assessed in a timely manner and to identify opportunities for improvement.

The percent and median shown are based on all inborn and outborn infants who were hospitalized for at least 3 days.

Explore this topic ... Go

Show me ...
- (•) Process Summary
- ( ) NICU Outcomes

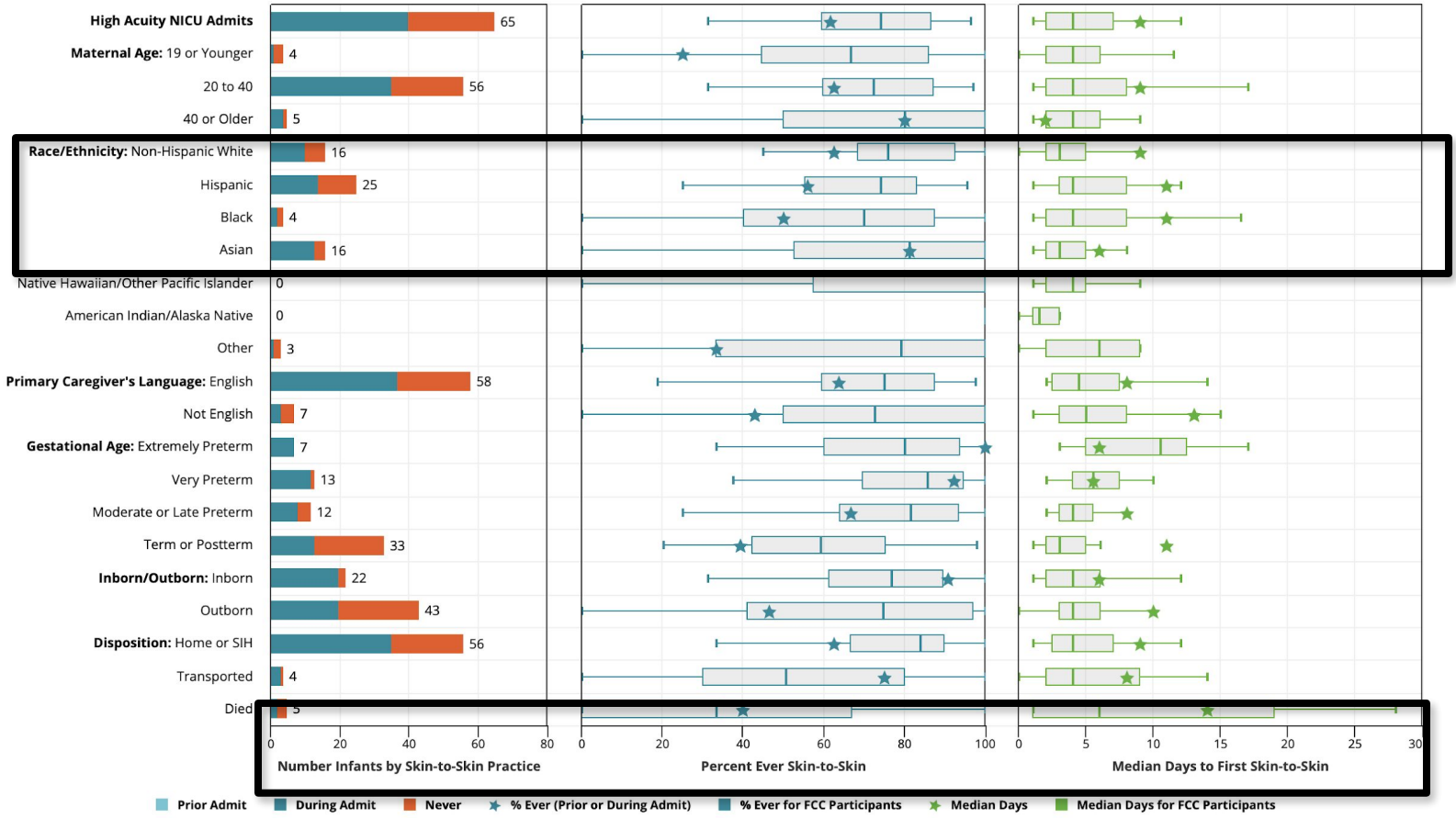
Exclude infants with ...
- [x] Congenital Anomalies
- [x] High Frequency Ventilation
- [ ] Outborn or Transport-Out/Death prior DOL 7
- [ ] GA > 31 weeks

Compare to FCC Participants ...
- (•) All
- ( ) Regional NICUs

Update

Number and Percent of Infants with Skin-to-Skin Ever and Median Days from NICU Admission to First Skin-to-Skin Compared to FCC Participants

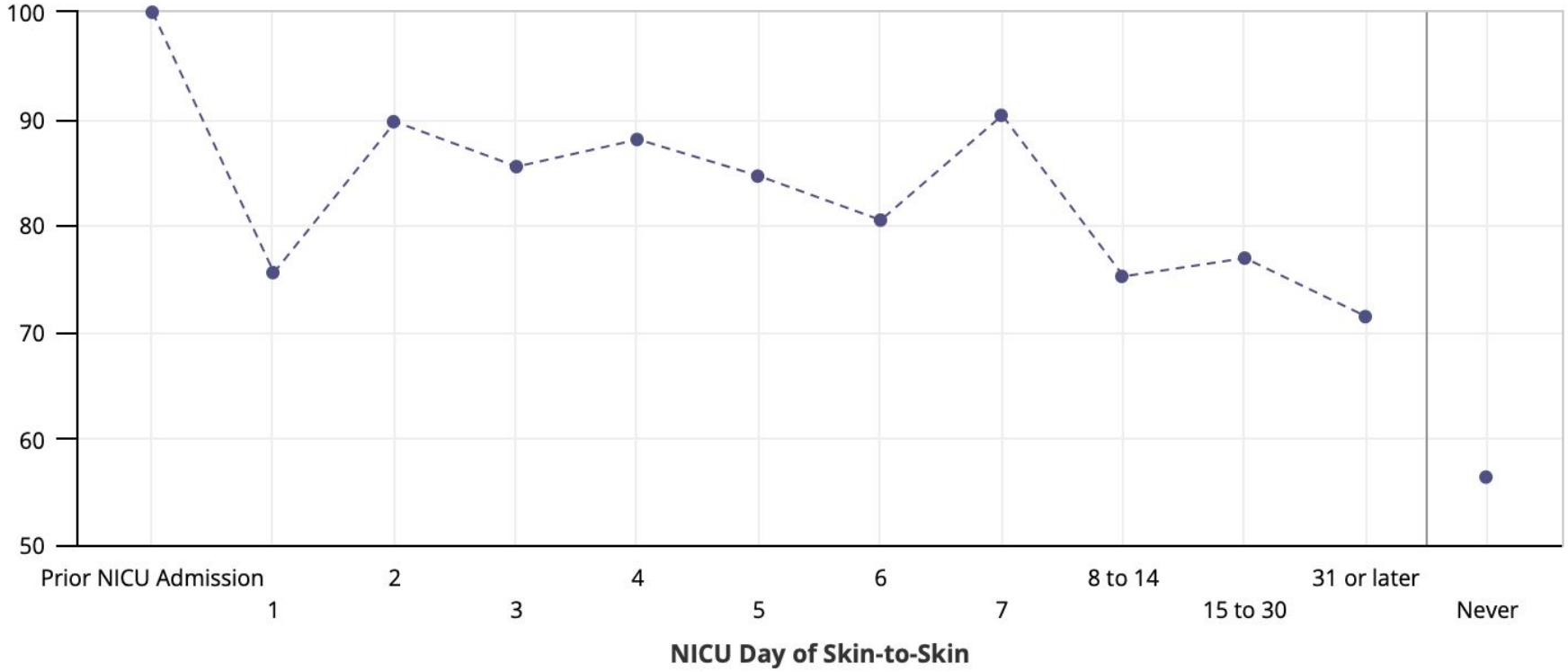
Number of high acuity infants after exclusions: 432. Percent for which skin-to-skin practice is captured as not missing/unknown: 15.0%



CPQCC

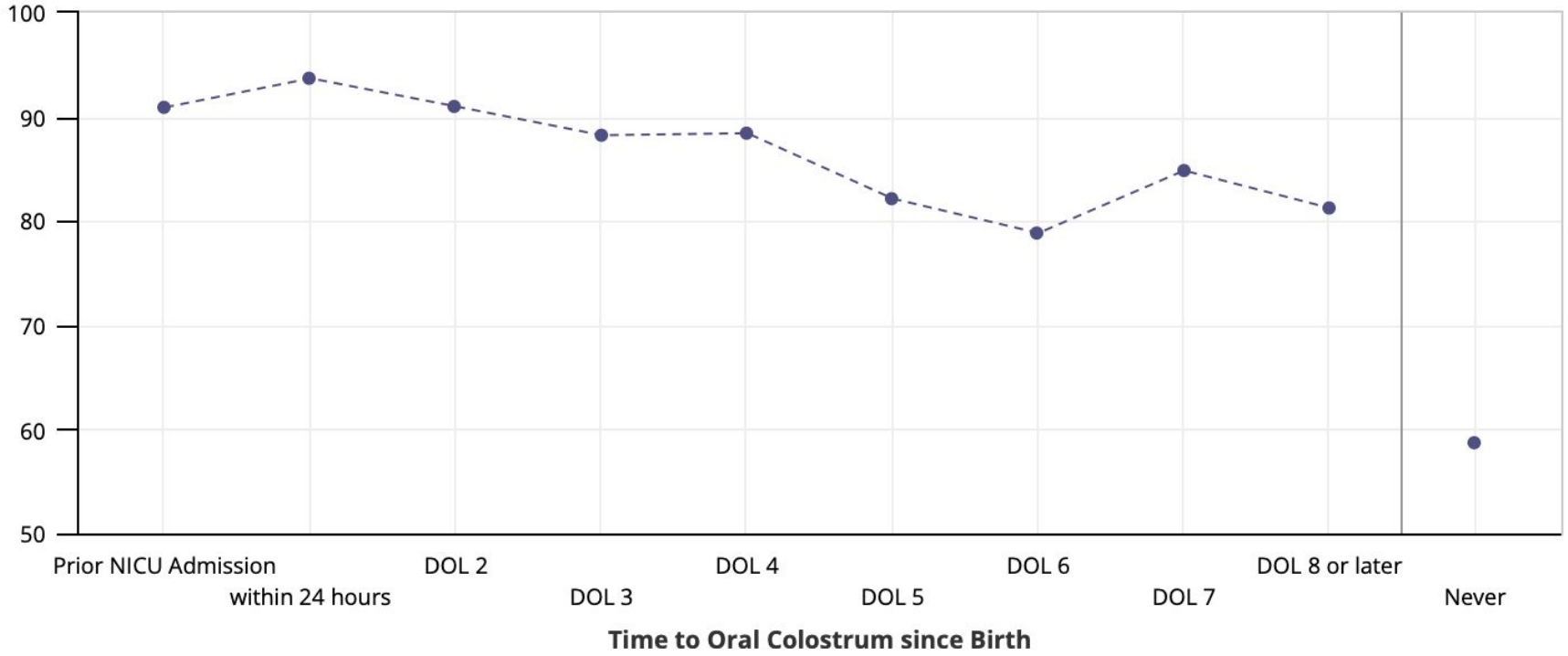
Human Milk Nutrition at Home Discharge by Timing of Skin-to-Skin

The risk-adjusted percent is based on the subset of infants born at 31 weeks gestation or earlier.



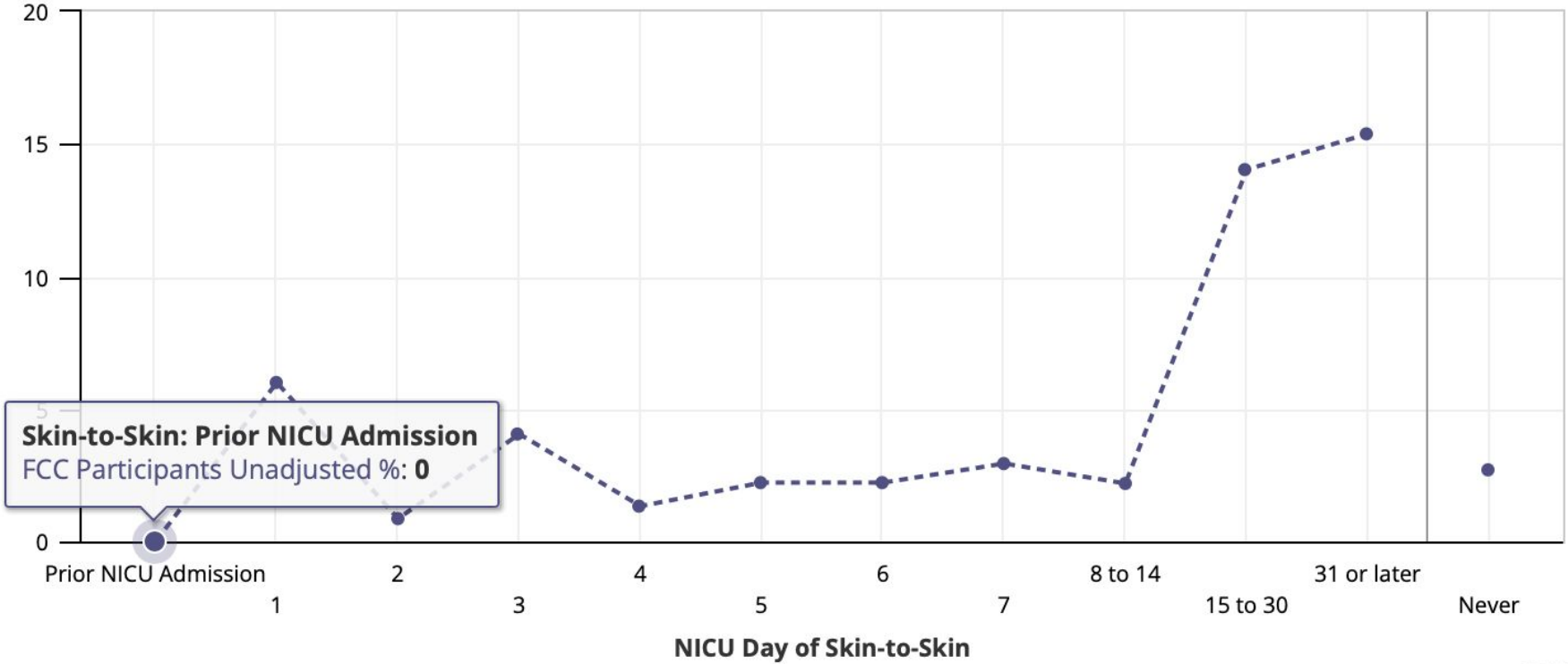
Human Milk Nutrition at Home Discharge by Timing of Priming with Oral Colostrum

The risk-adjusted percent is based on the subset of infants born at 31 weeks gestation or earlier.



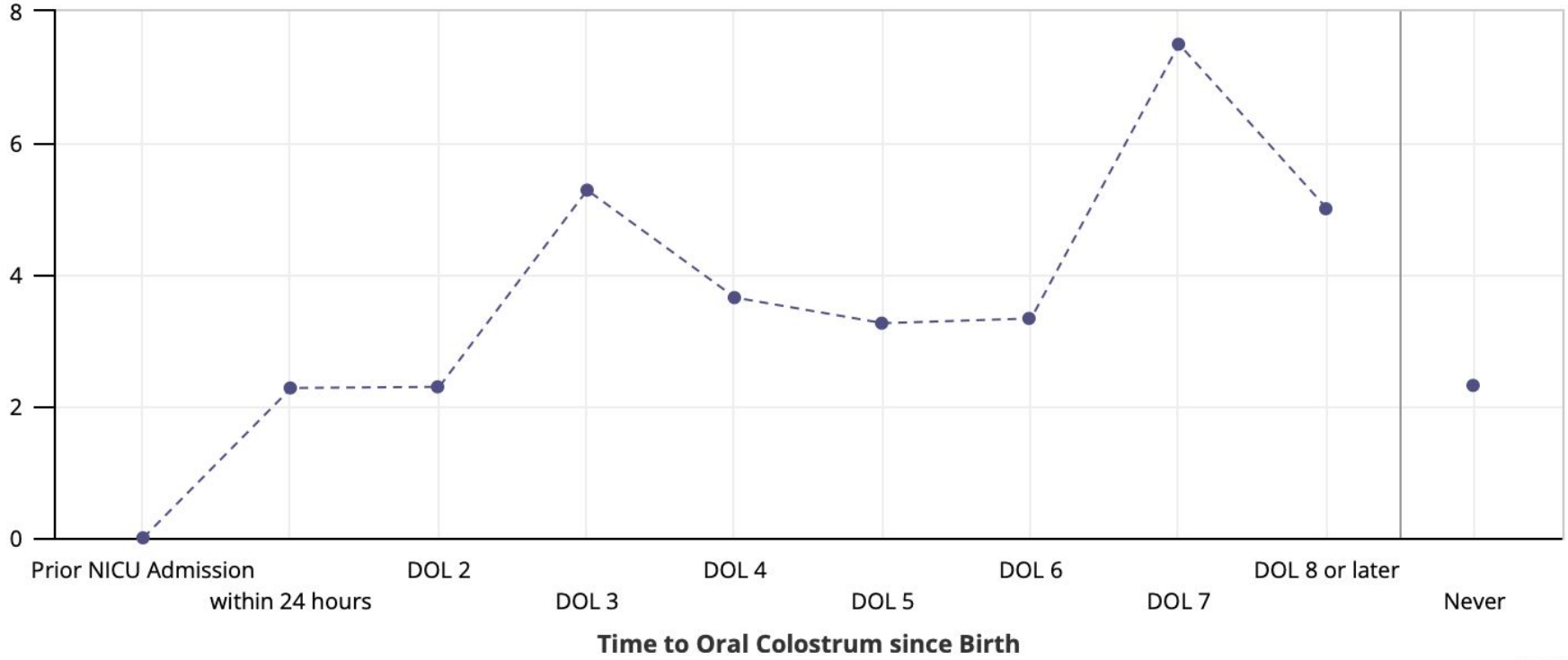
Nosocomial Infection by Timing of Skin-to-Skin

The risk-adjusted percent is based on the subset of infants born at 31 weeks gestation or earlier.



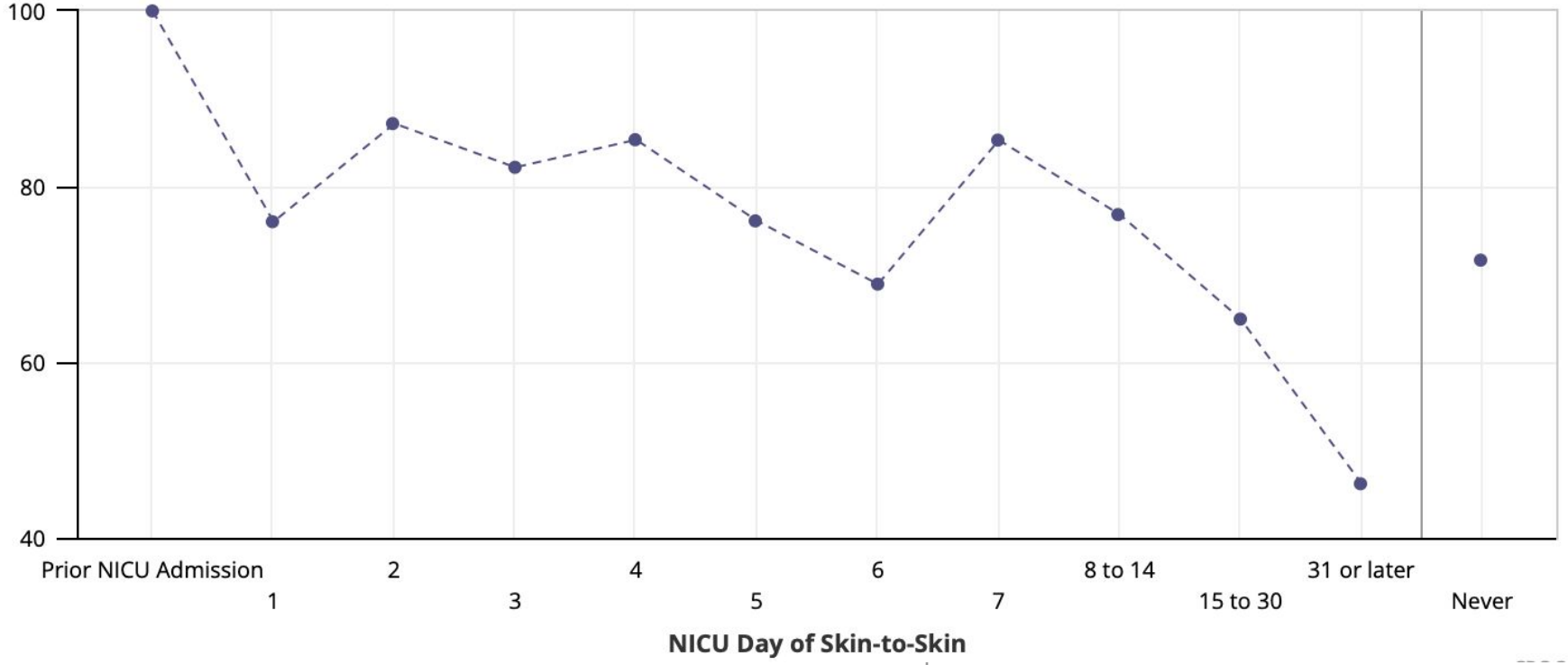
Nosocomial Infection
by Timing of Priming with Oral Colostrum

The risk-adjusted percent is based on the subset of infants born at 31 weeks gestation or earlier.

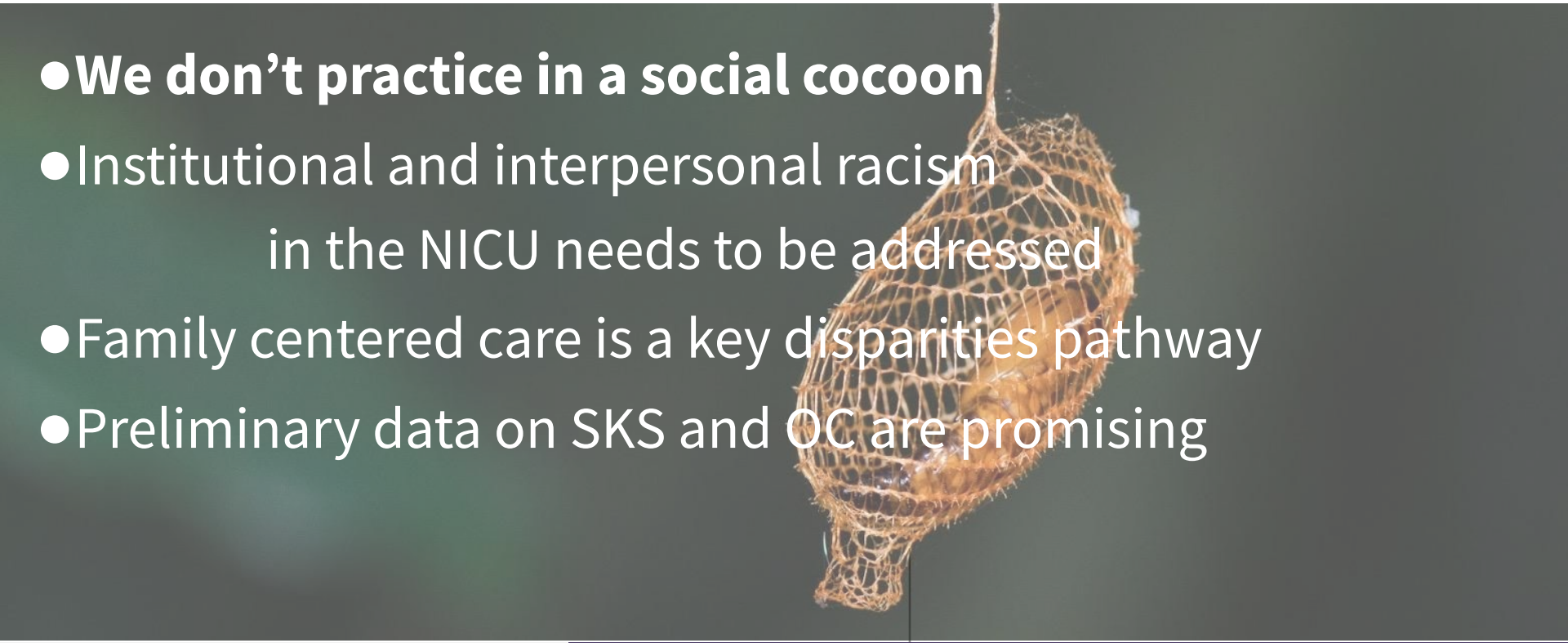


Survival without Major Morbidity by Timing of Skin-to-Skin

The risk-adjusted percent is based on the subset of infants born at 31 weeks gestation or earlier.



Summary



- **We don’t practice in a social cocoon**
- Institutional and interpersonal racism in the NICU needs to be addressed
- Family centered care is a key disparities pathway
- Preliminary data on SKS and OC are promising

Thank you

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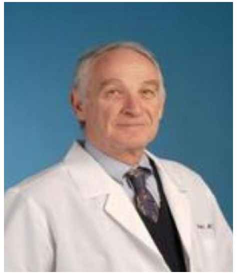


















Days to first skin-to-skin care

Definition	Time in days between NICU admission to the first instance of skin-to-skin care by any member of the family
Numerator	# of days between NICU admission to the first instance of skin-to-skin care by any member of the family
Denominator	-NA-

Days to first skin-to-skin care

Inclusions	All VLWB infants(<1500g) or 22-29 weeks GA
Exclusions	All VLBW infants (<1500g) or 22-29 weeks GA who die within 3 days of NICU admission
Risk Adjustment	Yes

Delayed Social Worker Contact

Definition	% of infants with social worker contact after 3 days from the date of admission
Numerator	Number of VLBW infants with social worker contact after 3 days from date of admission
Denominator	All VLWB infants(<1500g) or 22-29 weeks GA

Delayed Social Worker Contact

Inclusions	All VLWB infants(<1500g) or 22-29 weeks GA
Exclusions	All VLBW infants (<1500g) or 22-29 weeks GA who die within 3 days of NICU admission
Risk Adjustment	None

Time to Priming with Oral Colostrum

Definition	Time (hours) to oral administration (buccal swab) of colostrum to NICU infants
Numerator	Time (hours) to oral administration (buccal swab) of colostrum to NICU infants
Denominator	-NA-

Time to Priming with Oral Colostrum

Inclusions	All VLWB infants(<1500g) or 22-29 weeks GA
Exclusions	All VLBW infants (<1500g) or 22-29 weeks GA who die within 12 hours of NICU admission
Risk Adjustment	None

FAMILY-CENTERED CARE
TASK FORCE

FAMILY-CENTERED CARE
TASK FORCE

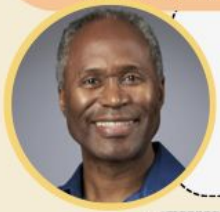
Dr. Jochen Profit
Speaker Q&A

FAMILY-CENTERED CARE
TASK FORCE

FCC Taskforce Webinar

March 16, 11-12:30 PT

Importance of NICU discharge guidelines and standards



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Using technology to provide early and consistent discharge education to NICU Families

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Register using the QR code or the link here

FAMILY-CENTERED CARE
TASK FORCE

Evaluation Link for Today's Webinar