



Improving Care and Outcomes for Vulnerable Infants and Families

Jochen Profit, MD, MPH

Associate Professor of Pediatrics

Chief Quality Officer, California Perinatal Quality Care Collaborative

Agenda

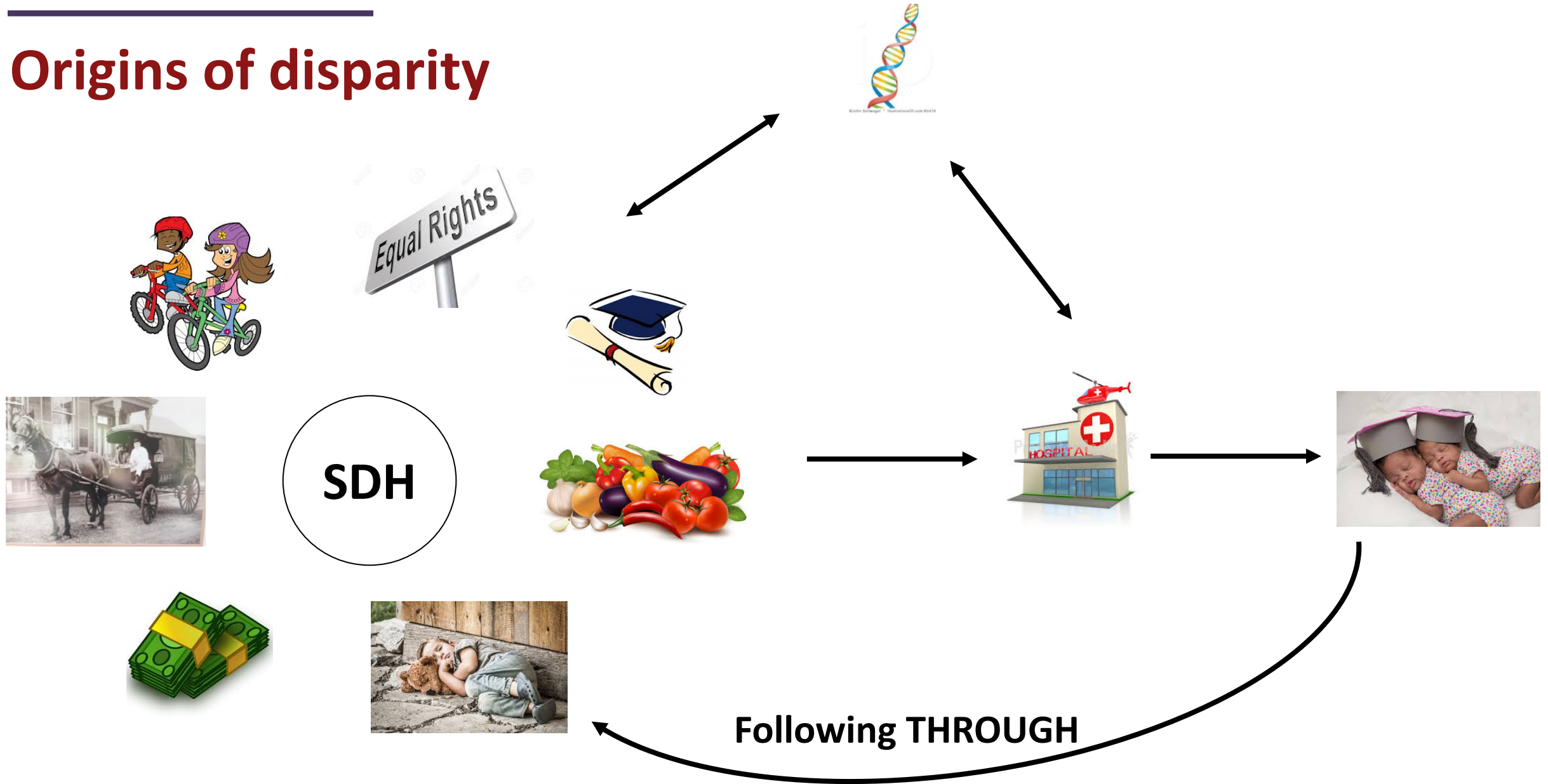
- ***Introduction: Context for Measurement, Project goals*** 12:00--12:15p
Jochen Profit, MD, MPH, Principal Investigator
- ***Description of Measures*** 12:15--12:25p
Ravi Dhurjati, MS, PhD
- ***Data Collection: Best Practices, Q&A Session*** 12:25--12:40p
Beate Danielsen, PhD, Director, Health Information Solutions
Fulani Davis, BS, Program Manager, CPQCC
Janella Parucha, BS, Program Manager, CPQCC
- **Discussion** 12:40—1:00p
Jochen Profit, Ravi Dhurjati, Beate Danielsen, Fulani Davis, Janella Parucha

Context for Measurement

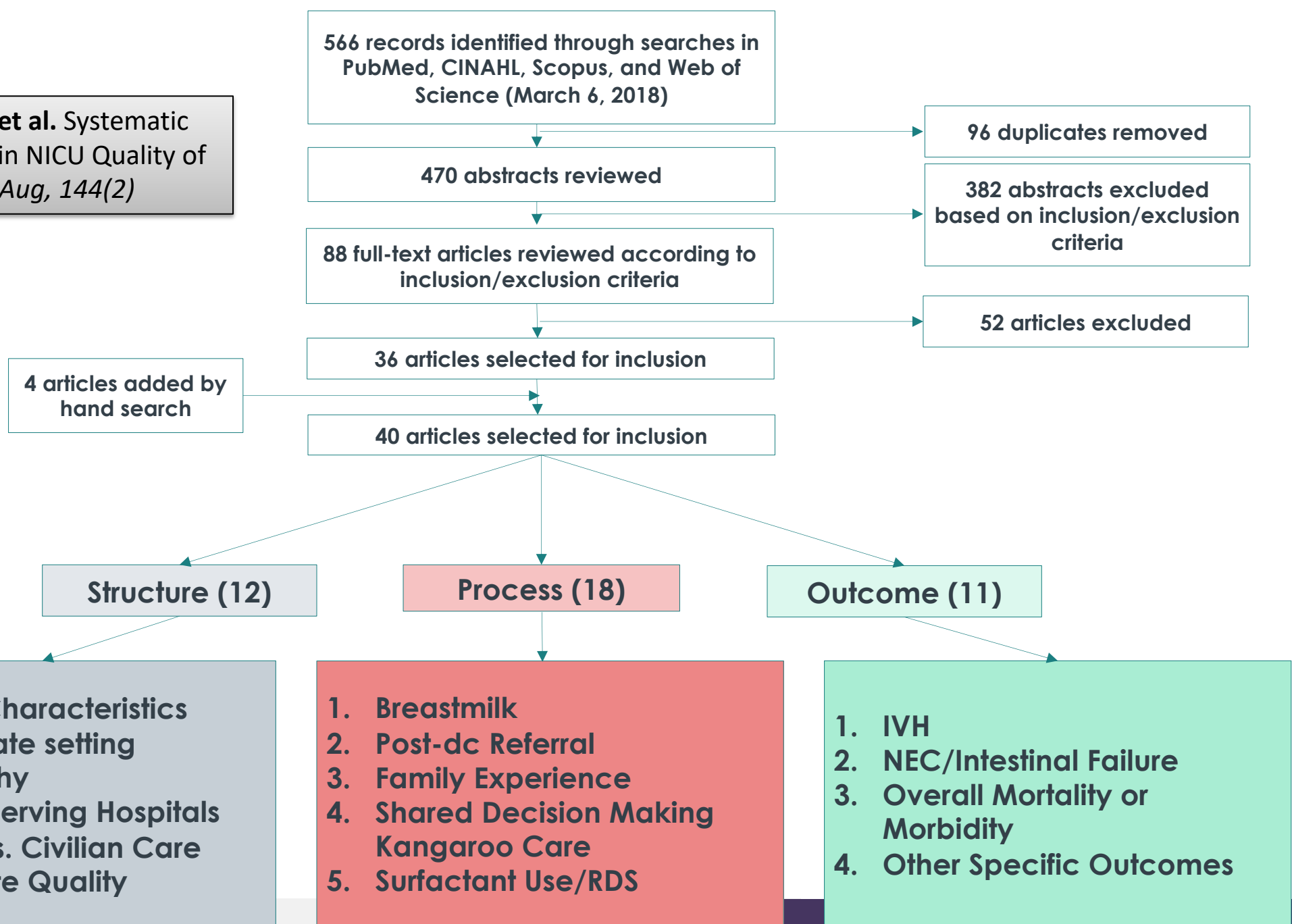
With your partnership, CPQCC is committed to and highly engaged in addressing disparities in care delivery



Origins of disparity



Sigurdson K, Profit J, et al. Systematic Review of Disparities in NICU Quality of Care. *Pediatrics* 2019 Aug, 144(2)



Disparities between hospitals – Structural racism

Neonatal mortality by hospital in NYC

JAMA Pediatrics | Original Investigation

Differences in Morbidity and Mortality Rates in Black, White, and Hispanic Very Preterm Infants Among New York City Hospitals

Elizabeth A. Howell, MD, MPP; Teresa Janevic, PhD, MPH; Paul L. Hebert, PhD; Natalia N. Egorova, PhD, MPH; Amy Balbierz, MPH; Jennifer Zetlin, DSc, MA

IMPORTANCE Substantial quality improvements in neonatal care have occurred over the past decade yet racial and ethnic disparities in morbidity and mortality persist. We examined whether disparate patterns of care by race and ethnicity contribute to these disparities in outcomes.

OBJECTIVES To examine differences in neonatal morbidity and mortality among non-Hispanic black (black), Hispanic, and non-Hispanic white (white) very preterm (VPT) infants and to determine whether these differences are explained by birth hospital.

DESIGN, SETTING, AND PARTICIPANTS Population-based study of nonanomalous infants born between 24 and 31 completed weeks of gestation in New York City hospitals using linked 2010 to 2014 New York City data sets. Mixed-effects logistic regression with a random-effects term for hospital was used to generate risk-adjusted neonatal morbidity and mortality rates for each hospital. Hospitals were ranked using the distribution of black, Hispanic, and white very preterm infants. The statistical analysis was performed in 2017.

EXPOSURE Race/ethnicity.

MAIN OUTCOMES AND MEASURES Composite of mortality or severe neonatal morbidity (bronchopulmonary dysplasia, intraventricular hemorrhage, or retinopathy of prematurity stage 3 or greater, or intraventricular hemorrhage stage 3 or greater).

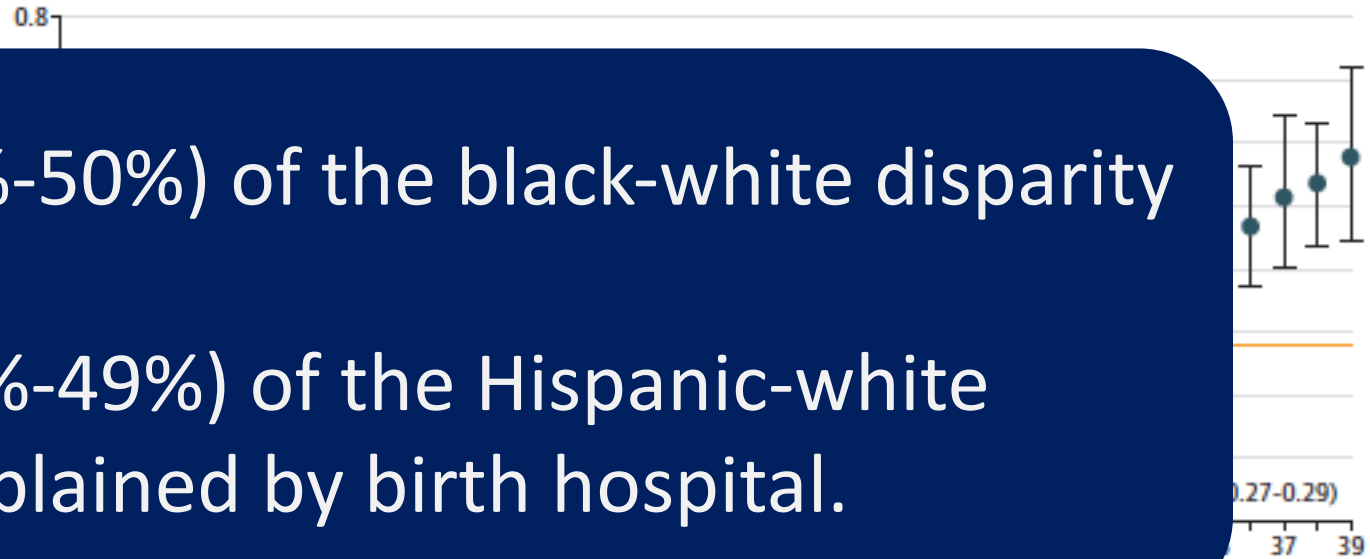
RESULTS Among 7177 very preterm births (VPTBs), mortality was higher among black (893 [32.2%] and 22.5% VPTBs (2-tailed $P < .001$). The risk-standardized mortality rate was twice as great for VPTB infants born in hospitals in the highest mortality tertile (0.40; 95% CI, 0.38-0.41) as for those born in the lowest mortality tertile (0.20; 95% CI, 0.14-0.18). Black (1204 of 2775 [43.4%]) and Hispanic (1024 of 2775 [36.9%]) infants were more likely than white (325 of 1418 [22.9%]) infants to be born in the highest morbidity and mortality tertile (2-tailed $P < .001$). Among black, Hispanic, and white VPTB infants, 40% (95% CI, 30%-50%) of the black-white disparity and 30% (95% CI, 10%-49%) of the Hispanic-white disparity was explained by birth hospital.

CONCLUSIONS AND RELEVANCE Black and Hispanic VPTB infants are more likely than white infants to be born in hospitals with higher risk-adjusted neonatal morbidity and mortality rates. These differences contribute to excess morbidity and mortality among black and Hispanic infants.

Corresponding Author: Elizabeth A. Howell, MD, MPP, Icahn School of Medicine at Mount Sinai, One Gustave L. Levy Place, Box 1077, New York, New York 10029 (elizabeth.howell@mountsinai.org).

JAMA Pediatr. doi:10.1001/jamapediatrics.2017.4402
Published online January 2, 2018.

Figure. Hospital Rankings for Risk-Adjusted Neonatal Morbidity and Mortality, New York City, NY, 2010-2014

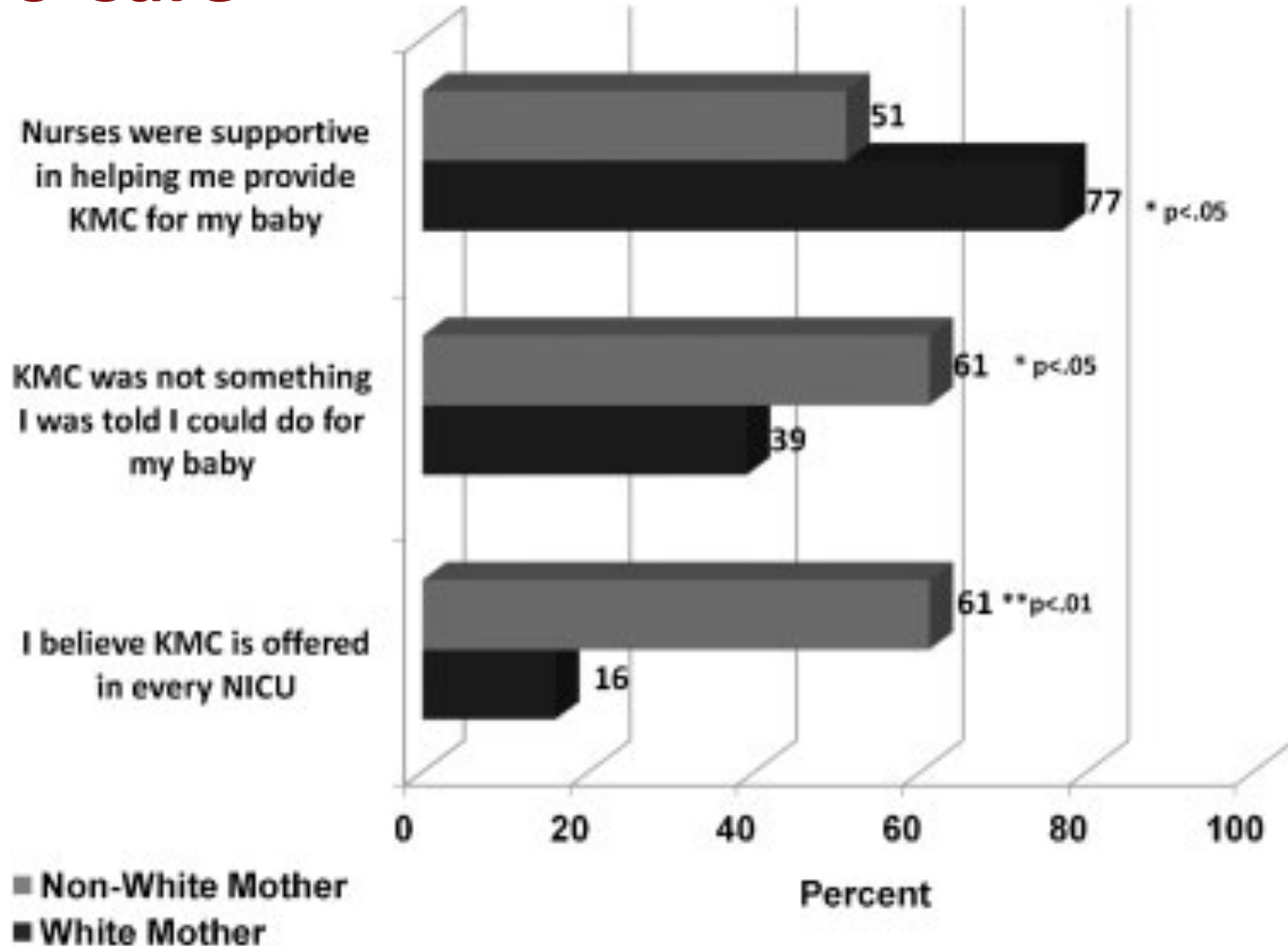


Howell et al. JAMA Pediatr 2018

Disparities within hospitals – Interpersonal racism

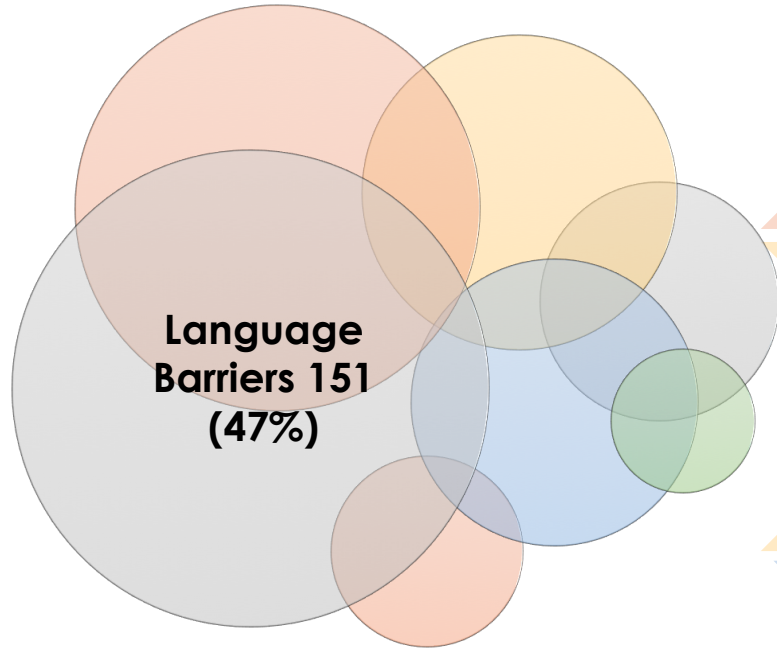
Access to Kangaroo Care

Hendricks-Muñoz et al.
Am J Perinatol 2013



**But we treat all
patients the same!**

Overlapping Dimensions



Language Barriers 151 (47%)

Social, Economic or Racial Privilege: 12 (3%)

Types of Disparate Care

Neglectful Care: 83 (26%). NICU staff ignore, avoid or neglect family needs (e.g. breastfeeding support) when considered difficult or unpleasant or when obstacles considered too great to overcome.

Judgmental Care: 82 (26%): Staff evaluate a family's moral status based on race, class or immigration. Circumstances or behaviors judged more harshly. Discrimination occurs through staff attitudes or resource allocation.

Systemic Barriers: 139 (44%): Staff unable or unwilling to address barriers families face such as transportation, child care, housing, employment, translation needs, or religious or cultural needs.

Priority Treatment and/or Assertive Families: 12 (3%). Families connected to NICU receive priority treatment. Assertive families receive more attention.

Suboptimal Care: 312 (96%)

Privileged Care: 12 (3%)

Sigurdson K, Profit J, et al. Disparities in NICU Quality of Care: A Qualitative Study of Family and Clinician Accounts. *J Perinatol* 2018 Apr 5.

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... – **Family advocate regarding family identified as black or African American**

Accounts told of disparate care of families, not strictly infants



CPQCC Equity Action

1. Audit and Feedback, Benchmarking

- a. Development of new disparity sensitive metrics (FCC measure pilot)
- b. Equity Dashboard

2. QI focus

- a. Health Equity Taskforce – interpersonal racism, structural racism, care transitions
- b. Collaborative of safety net NICUs focused on breastfeeding
- c. Use of disparity aim in QICs

3. Education

- a. CPQCC annual meeting focus on equity, now for 3rd year
- b. Disparity Tip Sheet

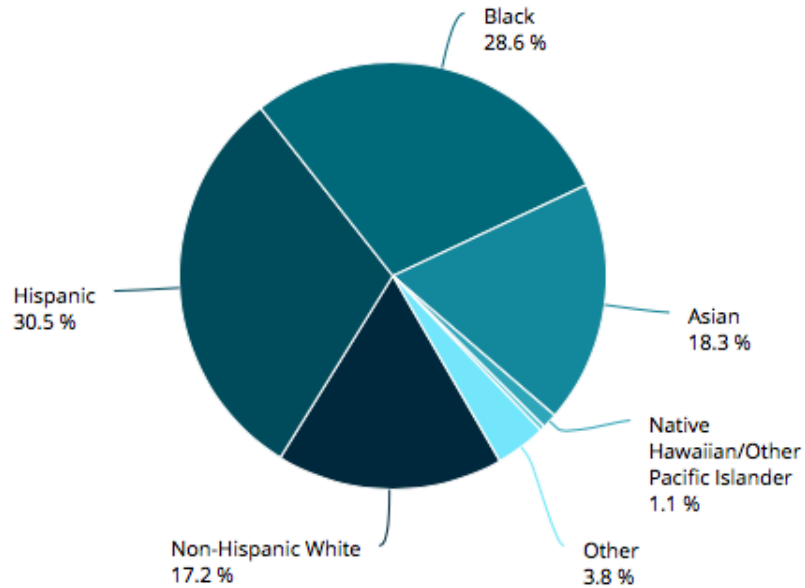
4. Research

- a. Various efforts and collaborations

Ib. CPQCC EQUITY DASHBOARD

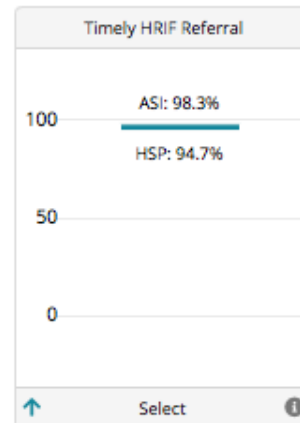
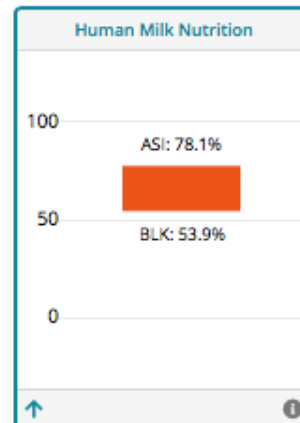
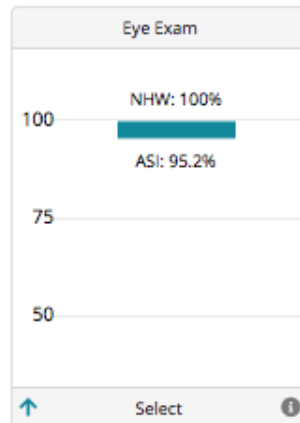
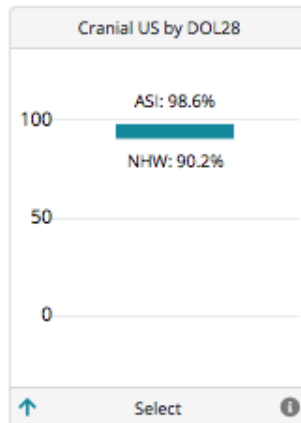
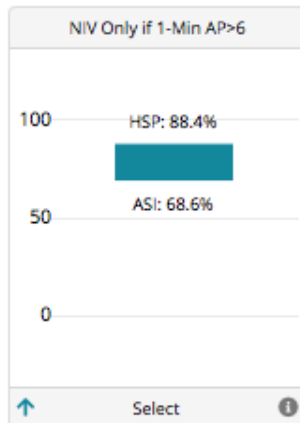
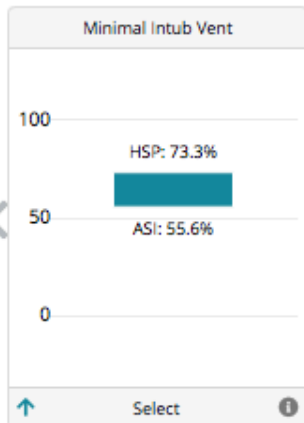
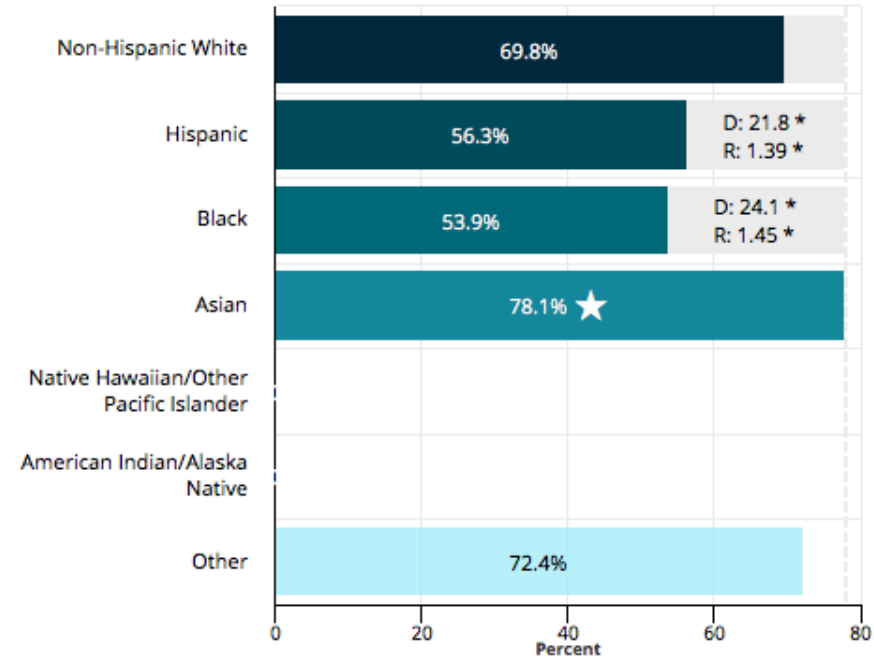


Race/Ethnicity Distribution for all VON Small Babies

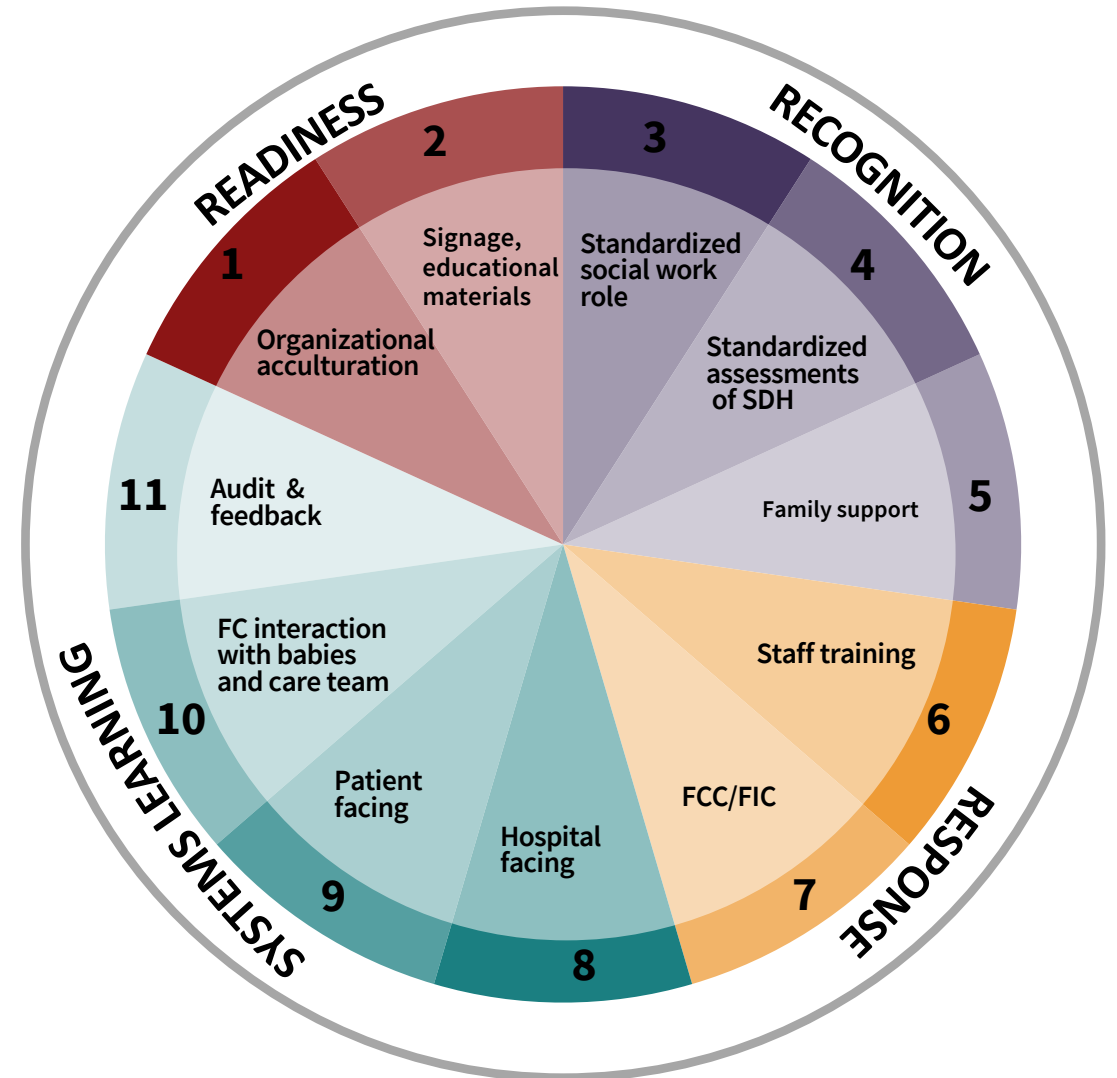
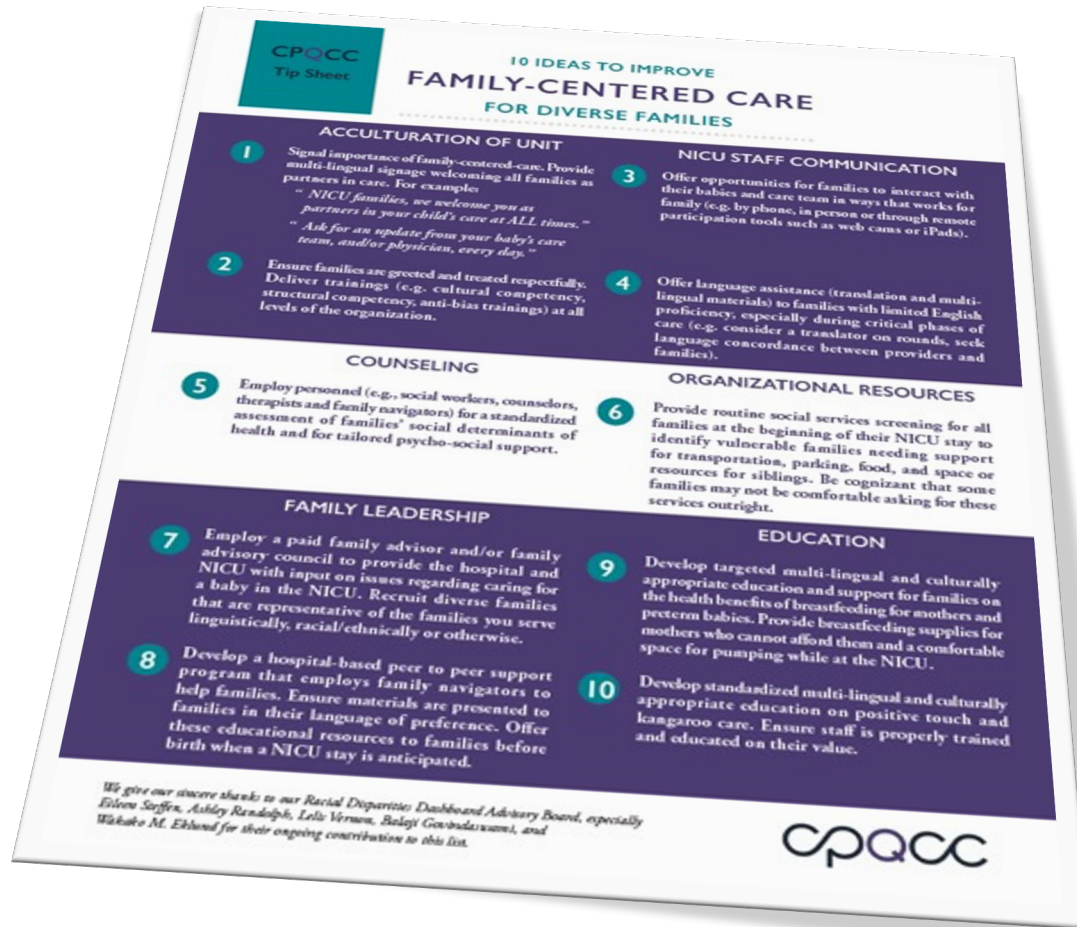


Human Milk Nutrition by Race/Ethnicity

Reset zoom



Education - Disparity Tip Sheet and Organizational Change Framework



profit@stanford.edu

@ProfitJochen

@CPQCC



**"OF ALL THE
FORMS OF INEQUALITY,
INJUSTICE IN HEALTH
CARE IS THE
MOST SHOCKING AND
INHUMANE."**

- Dr. Martin Luther King, Jr.



MEASURING FAMILY CENTERED CARE

Ravi Dhurjati | Krista Sigurdson | Ashley Randolph | Lelis Vernon | Linda Franck | Jochen Profit

Project Goals

- Routine measurement of processes of family centered care to inform improvement
- Design data collection to reduce measurement burden
- Results will be used to establish partnerships with families to improve key care delivery processes

Family Centered Care is Critical to Long-term Outcomes

NICU

TRANSITION AND FOLLOW THROUGH



HIGH QUALITY CLINICAL CARE



FAMILY ENGAGEMENT AND INVOLVEMENT IN CARE

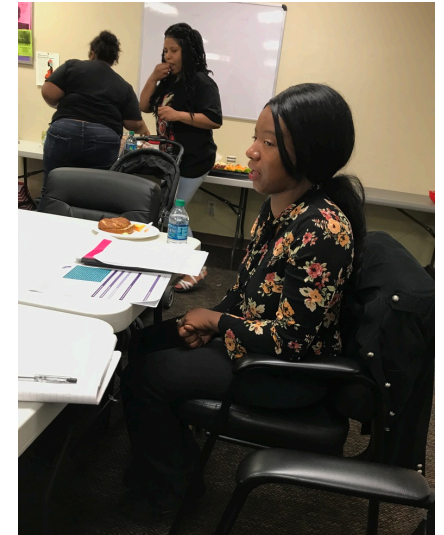


INTEGRATION OF THE INFANT INTO THE FAMILY UNIT

*Gaps in family centered care contribute to variation in care and outcomes
Minority families are particularly vulnerable*

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. *Former NICU moms**

Four Candidate Measures Selected – 30 NICU Pilot starting 1/2021

ENGAGING FAMILIES AS PARTNERS

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

PROVIDING SERVICES AND SUPPORTS

- NICU social worker availability
- Time to social worker contact
- **Delayed social worker encounter (✓)**
- Frequency of social worker contact

FAMILY PARTICIPATION IN HANDS-ON CARE

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

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

SUPPORT FOR BREASTFEEDING

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

CARE COORDINATION

- 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 Care

- Days to first skin-to-skin care
- Time to priming with oral colostrum
- Delayed social worker encounter



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



Days to first skin-to-skin care

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



Time to priming with oral colostrum

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

Delayed social worker contact



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

Thank you

Ashley Randolph, Family Representative,

Lelis B. Vernon, Family Representative, Chair Parent Advisory Council, NICU Baptist Children's Hospital of Miami

Marybeth Fry, M. Ed., Family Representative, Akron Children's Hospital

Balaji Govindaswamy, MBBS, MPH, Division Chief, Neonatology, Santa Clara Valley Medical Center

Jeffrey B. Gould, MD, MPH, Robert L. Hess Professor in Pediatrics, Stanford University

Vincent C. Smith, MD, MPH, Assistant Professor of Pediatrics, Harvard Medical School

Eileen Steffen, RNC-NIC, NICU Quality and Research Coordinator, Saint Barnabas Medical Center

Sangeetha Malik, PhD, Santa Clara Valley Medical Center

Jean Raphael MD, MPH, Associate Professor, Baylor College of Medicine

Wakako Eklund, DNP, NNP-BC, Pediatrix Medical Group of Tennessee and Vanderbilt University

James W. Collins, MD, MPH, Professor of Pediatrics(Neonatology), Northwestern University

Waldemar A. Carlo, MD, Edwin M. Dixon Endowed Chair in Neonatology, University of Alabama

Yolanda Ogbulu, PhD, CRNP, FAAN, Assistant Professor, University of Maryland School of Nursing

Donald A. Goldman, MD, Professor of Pediatrics, Harvard Medical School

Q and A Session

Data Collection: Best Practices

Beate Danielsen, PhD, Director, Health Information Solutions

Fulani Davis, BS, Program Manager, CPQCC

Janella Parucha, BS, Program Manager, CPQCC

Q and A Session

Data Collection: Best Practices

NICU ID: 0000 Record ID: 01602 Birth Year: 2021 DOB: 01-01-2021 BW: 2100 GA: 34/2 NICU Data Eligible Infant

Demographics Items 1-8	Maternal HX Items 9-18	DR Items 19-23	Respiratory Items 24-39	Infections Items 40-42	Other DX/PX Items 43-47	Neurological Items 48-51	Anom. / Bili Items 52-55	Disposition Items 56-60
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Initial Disposition

Note that responses in this section will be ignored if you do **not** answer item 57, initial disposition from your center!

56. Enteral Feeding at Discharge
57. Initial Disposition from your Center
58. Weight at Initial Disposition grams Unknown
59. Head Circumference at Initial Disposition (cm) cm Not Done Unknown
60. Initial Discharge Date Unknown

Initial length of stay: TBD

Family Centered Care (FCC) Items:

- Days from NICU Admission to First Skin-to-Skin Care at Your Hospital Days, or Enter Date Prior to NICU Admission Never Done Here Unknown
- Days from NICU Admission to First Social Worker Contact at Your Hospital Days, or Enter Date Prior to NICU Admission Never Done Here Unknown
- Hours from Birth to Administering Oral Colostrum at Your Hospital Hours, or Enter Date and Time at Never Done Here Unknown

Comment:

Discussion

Jochen Profit, MD, MPH

Ravi Dhurjati, MS, PhD

Beate Danielsen, PhD, Director, Health Information Solutions

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