



# Addressing Disparities in Perinatal Care Delivery

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# Are there Disparities in Perinatal Care?





# She Was Pregnant With Twins During Covid. Why Did Only One Survive?

Why being Black and giving birth in New York during the pandemic is so dangerous.



*Delivery people are among the essential workers who must expose themselves and their families to the virus every day. Photograph by Matt Rouken / AP / Shutterstock*



## For Latinos and Covid-19, Doctors Are Seeing an 'Alarming' Disparity

The outsized infection rate among Hispanics in some states could hobble efforts to quash the spread of Covid-19, prompting states like Oregon to step up testing and take emergency measures.



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California perinatal quality care collaborative

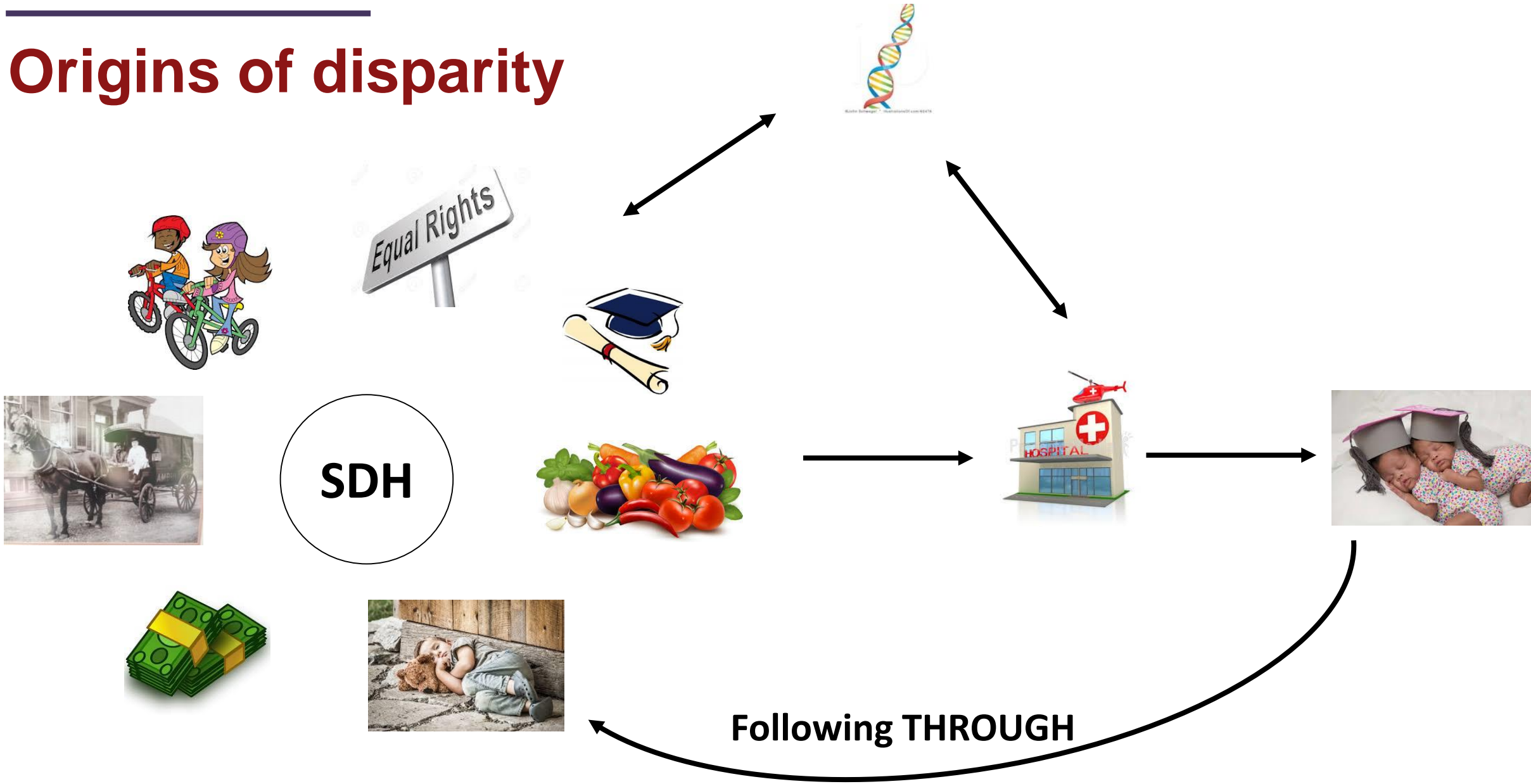
CPQCC



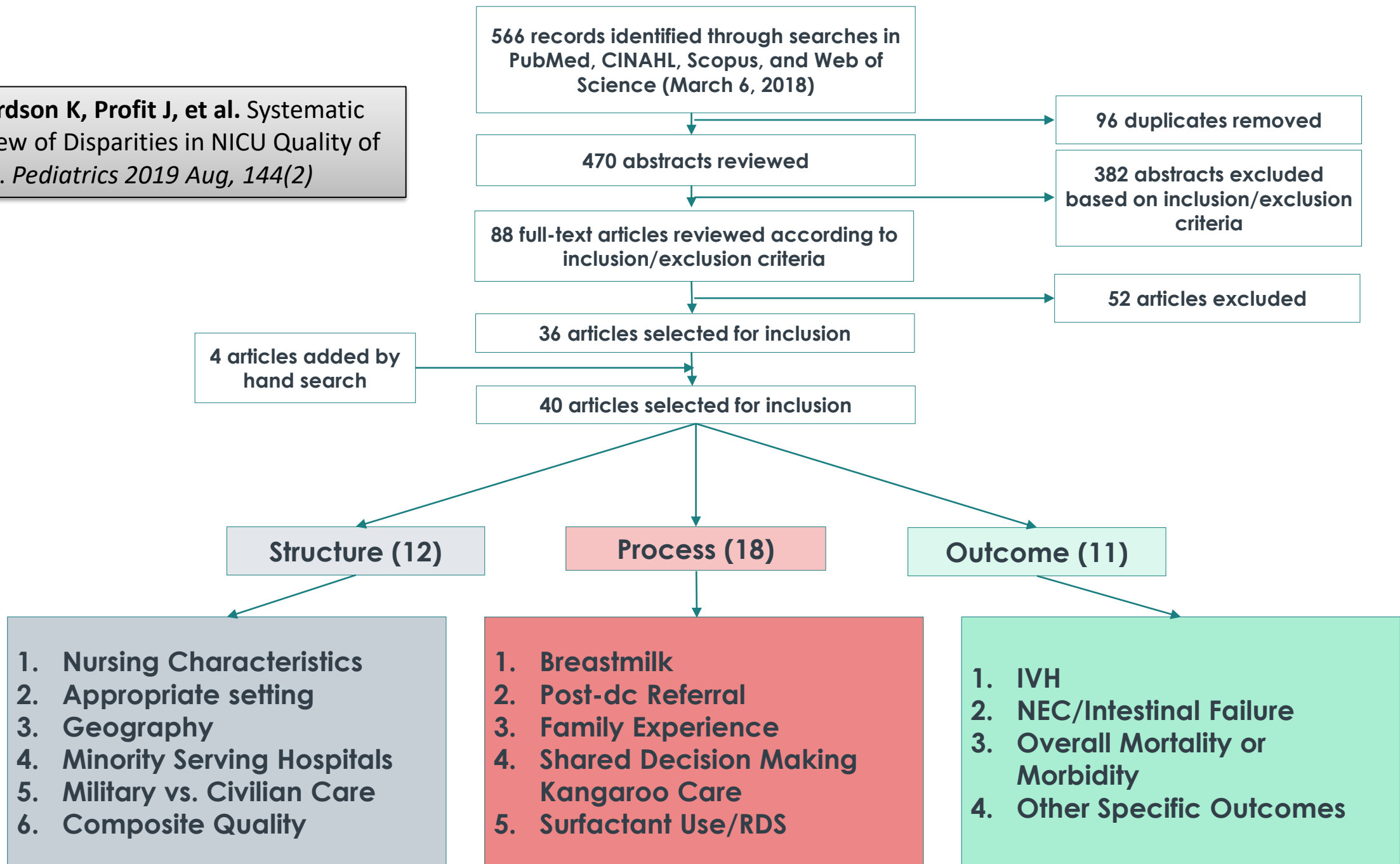
# Context matters – always exposed to bias



# Origins of disparity



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



# What are the mechanisms for disparities in NICU Care?



# Mechanisms for Disparity

Minority mothers and neonates can have worse outcomes than whites because

1. Receive care from facilities that treat patients with poor quality of care (*BETWEEN*),
2. Receive worse quality of care than white mothers in the same facility (*WITHIN*)

Opinion

EDITORIAL

## Racial Segregation and Inequality of Care in Neonatal Intensive Care Units Is Unacceptable

Elizabeth A. Howell, MD, MPP; Paul L. Hebert, PhD; Jennifer Zeitlin, DSc, MA

Despite significant improvements in the survival of very preterm newborns in neonatal intensive care units (NICUs) over the last decade, significant racial and ethnic disparities exist for very preterm infants.<sup>1-3</sup> While these disparities are rooted in a complex web of factors, a growing body of evidence has documented the role of quality of care in creating disparities. Black and Hispanic very preterm infants are more likely to be born in hospitals with worse outcomes than white infants after adjustment for risk factors, and differences in hospital of birth explain a significant proportion of the black-white and Hispanic-white disparities for these vulnerable infants.<sup>2</sup> Additional research has documented that racial and ethnic disparities in quality exist between and within NICUs for very low-birth-weight infants.<sup>4</sup>

In this issue of *JAMA Pediatrics*, Horbar et al<sup>5</sup> explore the extent of segregation and inequality for very low-birth-weight and very preterm infants in NICUs across the United States. They developed indices at the hospital level to measure segregation (ie, uneven distribution of racial and ethnic groups across NICUs) and inequality (ie, concentration of racial or ethnic groups in lower-quality NICUs). Using data from the Vermont Oxford Network and a cohort of more than 117 000 infants born at 401 g to 1500 g or 22 to 29 weeks' gestation from 2014 to 2016, they measured segregation and inequality at the hospital level for black, Hispanic, and Asian infants relative to white infants. They found significant segregation across NICUs in the United States for all 3 racial and ethnic groups and regional variation in quality of care. Compared with white infants, black infants received care at lower-quality NICUs; Asian and Hispanic infants received care at higher-quality NICUs. Region of residence explained differences for Hispanic but not Asian or black infants.

This article has a number of strengths in relation to previous studies. First, Horbar et al<sup>5</sup> used a comprehensive measure of quality, the composite Baby-MONITOR (Measure of Neonatal Intensive Care Outcomes Research) score, rather than solely relying on risk-adjusted mortality or morbidity to assess hospital performance. The Baby-MONITOR score includes 9 infant-level process and outcome measures (eg, antenatal steroid exposure, hypothermia on admission, health care associated infection, and mortality) that have been used to measure quality in California NICUs.<sup>4,6</sup> Much of the previous literature on the contribution of quality of care to neonatal disparities has relied on measures of risk-adjusted neonatal morbidity and mortality ascertained through the use of administrative data. While morbidity and mortality are direct measures of health and of most importance to families, they are indirect measures of quality, and comparisons between hospitals are more strongly reliant on the ability to carry out risk adjustment than process measures. Furthermore, they do not identify specific areas that can be targeted in the NICU to improve outcomes. While the use of administrative data, such as state discharge abstract data linked with birth certificate data, allow for population-based estimates, these administrative data lack many of the data elements necessary to measure quality more directly (eg, receipt of medications, vital signs, and growth).

Another strength is the use of a national data set that includes nearly 90% of very low-birth-weight and very preterm infants born annually in the United States, making it possible to confirm that previous findings from specific regions apply more broadly to the US population. Horbar et al<sup>5</sup> also propose an interesting index for inequality. In our previous research, we ranked hospitals by risk-adjusted morbidity and mortality and examined where black and Hispanic very preterm infants were born.<sup>2</sup> In this article, Horbar et al<sup>5</sup> rank NICUs by a direct measure of quality and examine the proportion of white infants in those NICUs. Their index of inequality has the potential to be used in future research investigating disparities. Future research would benefit from more granular data on race and ethnicity to measure disparities in care for specific subgroups of black, Hispanic, and Asian infants.

Patient-level quantitative measures of quality, such as those used in the study by Horbar et al,<sup>5</sup> are critical to solving disparities in the NICU because these measures have the potential to illuminate the pathways by which racial disparities in outcomes are realized. Minority mothers and their neonates can have worse outcomes than white mothers because (1) they receive care from facilities that treat all mothers with poor quality of care, (2) they receive worse quality of care than white mothers in the same facility, or (3) they have health and social risks that are beyond the control of the hospital.<sup>7</sup> Without patient-level measures of quality, we cannot distinguish the effects of the latter 2 pathways and therefore cannot say whether the solution lies within the hospital or not. Furthermore, this composite measure builds on previous work to identify evidence-based interventions in neonatology and illustrates the health impact of failure to implement them in current practice. This approach offers an opportunity for future research to identify which components of care contribute most to disparities. Although each component is weighted equally in the score, the authors point out that changing these weights would likely affect estimates of inequalities.

jmapediatrics.com

JAMA Pediatrics Published online March 25, 2019

E1

Howell E, et al. *JAMA Pediatr* 2019



# Disparities between hospitals – Institutional 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 Zeitlin, DSc, MA

**IMPORTANCE** Substantial quality improvements in neonatal care have been achieved in the past decade yet racial and ethnic disparities in morbidity and mortality persist. We examined whether disparate patterns of care by race and ethnicity explain these outcomes.

**OBJECTIVES** To examine differences in neonatal morbidity and mortality among non-Hispanic black (black), Hispanic, and non-Hispanic white (white) very preterm 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 intercept for hospital was used to generate risk-adjusted neonatal morbidity and mortality rates for infants in 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, retinopathy of prematurity stage 3 or greater, or intraventricular hemorrhage grade 3 or greater).

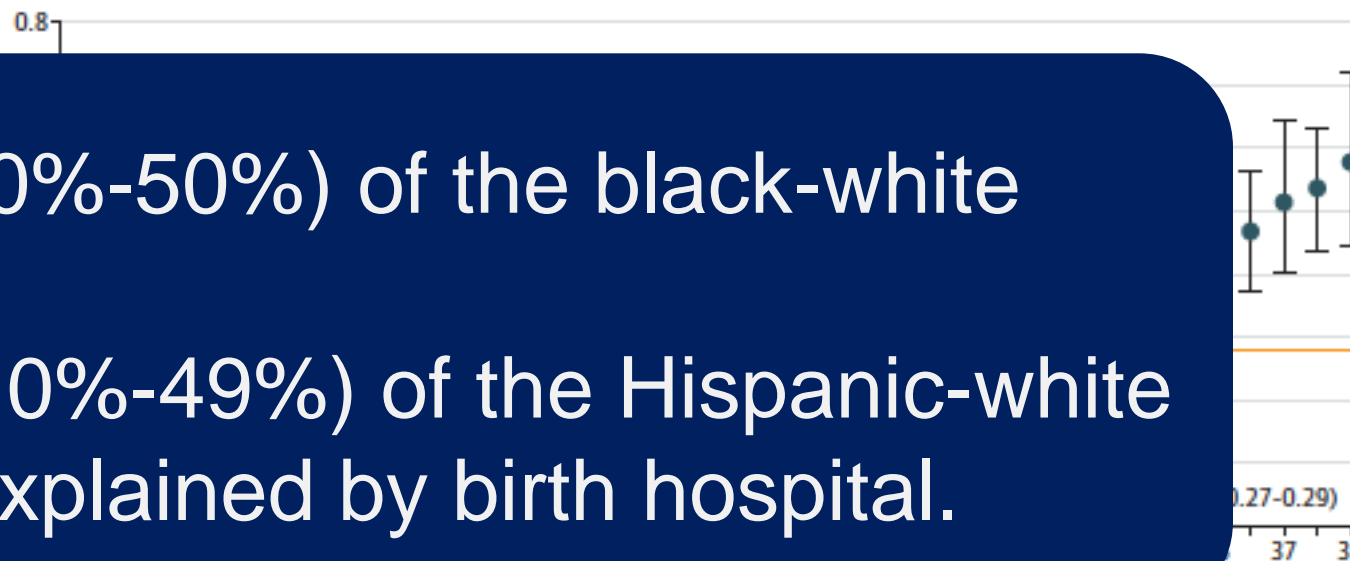
**RESULTS** Among 7177 very preterm births (VPTBs), mortality was higher among black (893 [32.2%]) and Hispanic (722 [22.5%]) VPTBs (2-tailed  $P < .001$ ). The risk-standardized mortality rate was twice as great for VPTB infants born in hospitals in the highest mortality tertile (0.40; 95% CI, 0.38–0.41) as for those born in the lowest tertile (0.14; 95% CI, 0.14–0.18). Black (1204 of 2775 [43.4%]) and Hispanic (1204 of 2775 [43.4%]) 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, however, 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. Differences in care by hospital and differences contribute to excess morbidity and mortality among black and Hispanic infants.

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

Editorial

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

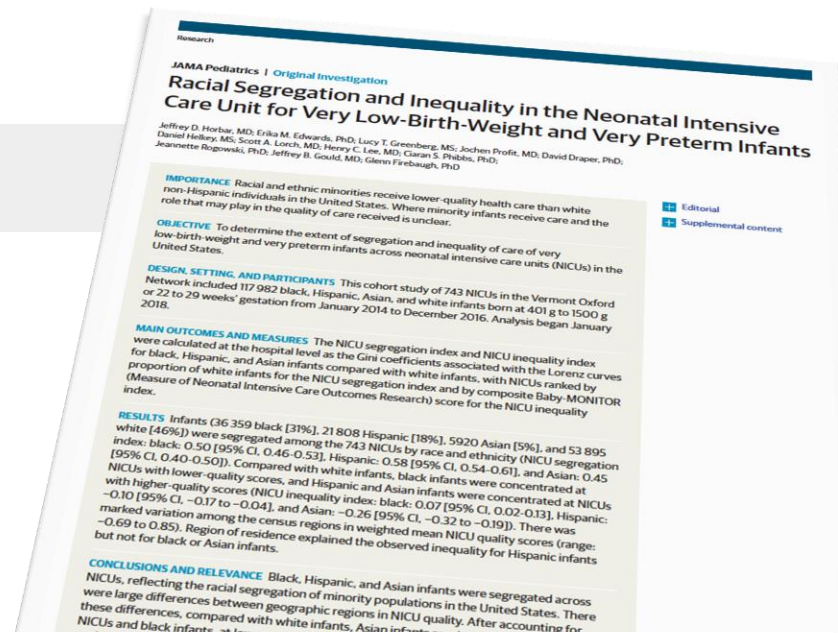
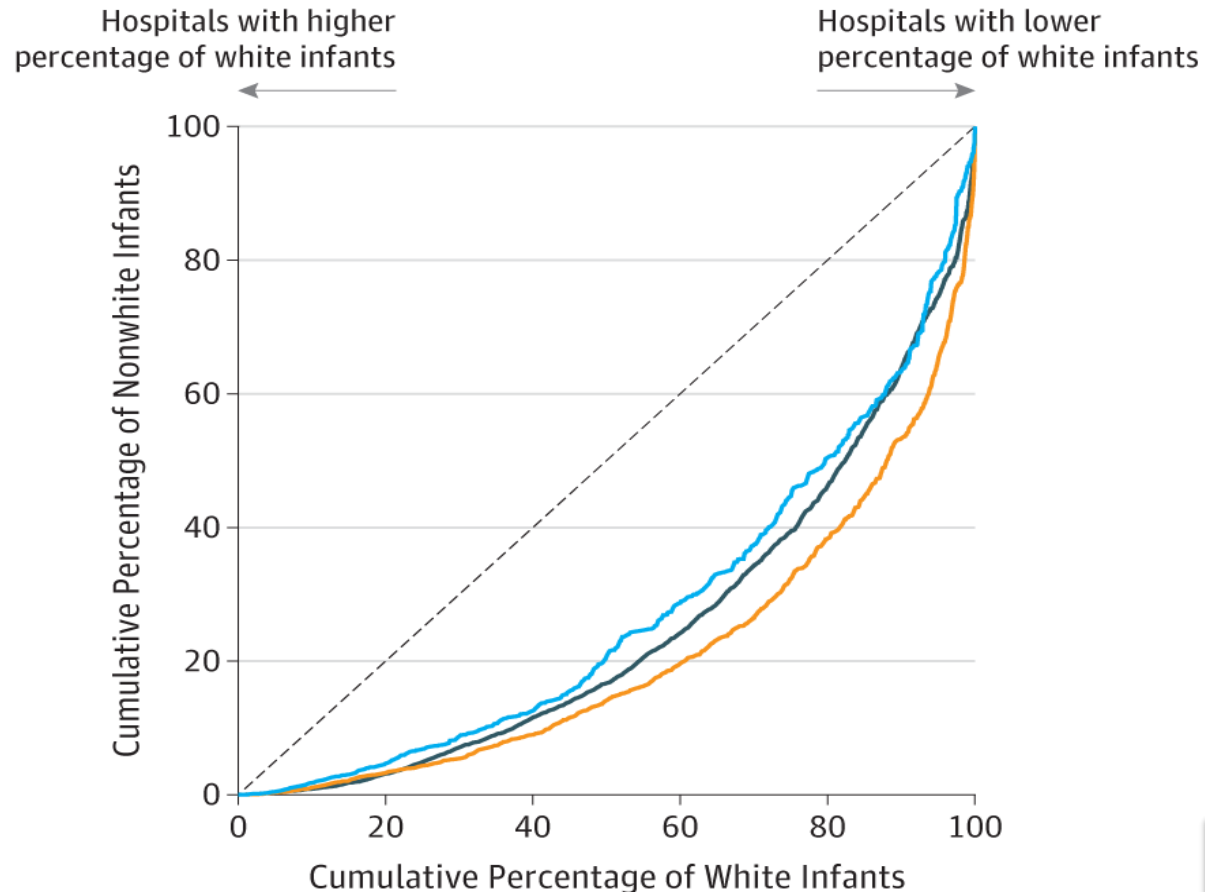


Howell et al. JAMA Pediatr 2018

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@mssm.org).

# Racial Segregation in the NICU

	NICU Segregation Index (95% CI)
Black	0.50 (0.46-0.53)
Hispanic	0.58 (0.54-0.61)
Asian	0.45 (0.40-0.50)



Lorenz Curves for **Segregation** by Race/Ethnicity in US NICUs ranked by the proportion of white infants from highest to lowest, and the cumulative population percentages of white and minority infants were plotted on the x- and y-axes. If all NICUs had the same racial distribution as the overall population, the curves would fall on the diagonal.

Edwards, Horbar, Profit et al. *JAMA Pediatr* 2019

# Disparities in Health Care–Associated Infections in the NICU

Jessica Liu, PhD, MPH<sup>1,2</sup> Charlotte Sakarovich, PhD<sup>1,2</sup>  
Henry C. Lee, MD, MS<sup>1,2</sup> Jochen Profit, MD, MPH<sup>1,2</sup>

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<sup>2</sup>California Perinatal Quality Care Collaborative, Palo Alto, California

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Am J Perinatol

## Abstract

**Objectives** This study

associated infection (HAI)

race/ethnicity and its

**Study Design** This is

between 2011 and 2015

**Results** Risk-adjusted

units (NICUs), ranging

higher odds of HAI

Non-Hispanic black

tertile of infection

ethnicities suffered sim

**Conclusion** Hispanic in

variation in infection across

with infection.

## Keywords

- infant
- health care–associated infection
- disparity
- risk factors

Health care–associated infection (HAI) is a serious complication among very low birth weight (VLBW; <1,500 g) preterm infants hospitalized in the neonatal intensive care unit (NICU), and infection rates in these infants have ranged from 21 to 30%.<sup>1–4</sup> VLBW infants are especially susceptible to HAI. They are immune-incompetent hosts, require prolonged hospitalization, undergo frequent invasive procedures, and receive prolonged broad-spectrum antibiotics and intravenous nutrition.<sup>1,5–7</sup> In addition, infection risk is conveyed by a combination of maternal health and clinical practice-related factors.<sup>1–3,5,6,8–11</sup>

HAIs are associated with increases in neurodevelopmental impairment, mortality, length of stay, and as a result, increased financial costs of care.<sup>3,6,12–17</sup> Payne et al reported that the occurrence of just one single type of HAI would increase costs of treating VLBW infants by \$100 million.<sup>12</sup> Reducing HAI has been a priority in recent years, and successful efforts have been reported from individual NICUs and through collaborative networks, such as the Vermont Oxford Network and the California Perinatal Quality Care Collaborative (CPQCC).<sup>7,18–20</sup>

Vulnerable populations may be differentially affected by HAI because they may receive care in challenged hospitals, which provide lower quality of care,<sup>21–23</sup> or differential treatment within hospitals.<sup>24</sup> HAI is more dependent on

<sup>1</sup> At the time of this research, Dr. Sakarovich was a senior statistician at the quantitative sciences unit.

Original Article

Figure 2A  
**A**



Blacks more likely cared for in hospitals with higher HAI rates

Hispanics more likely to have a HAI

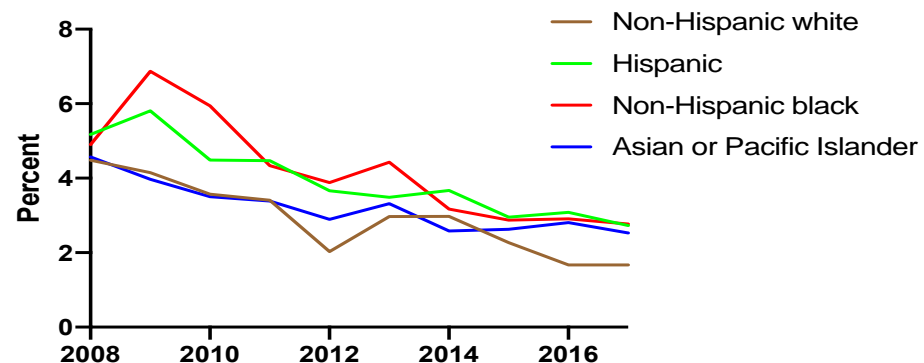
Liu et al. Am J Perinat 2019; Apr 30



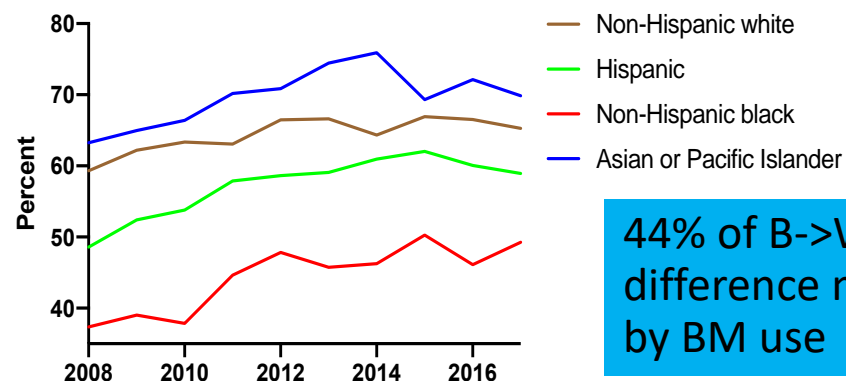
# Disparities between or within hospitals

## NEC

NEC Incidence by Race/Ethnicity

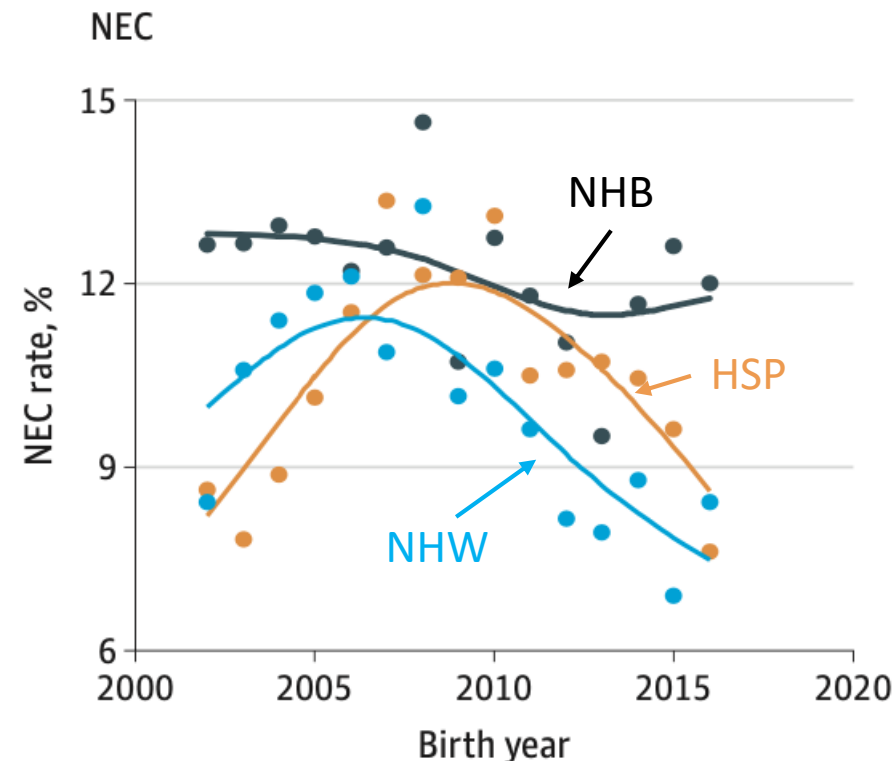


Breast Milk Use at NICU Discharge by Race/Ethnicity



44% of B->W  
difference mediated  
by BM use

Goldstein, Profit et al. *Pediatr Res.*  
2020 Aug;88(Suppl 1):3-9

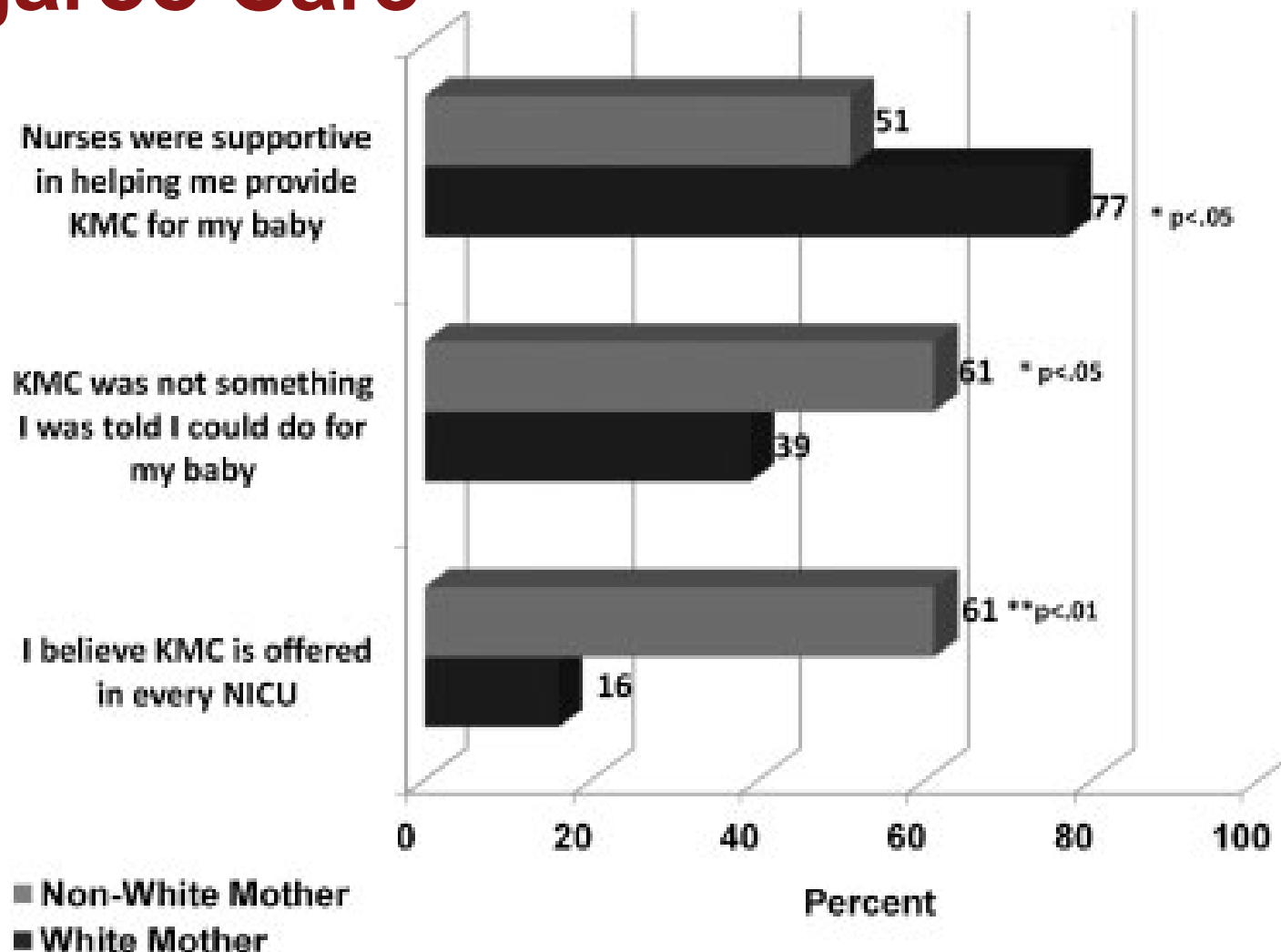


Travers, Profit et al. *JAMA Netw*  
Open. 2020;3(6):e206757

## Disparities within hospitals – Interpersonal racism

# Access to Kangaroo Care

Hendricks-Muñoz et al.  
Am J Perinatol 2013

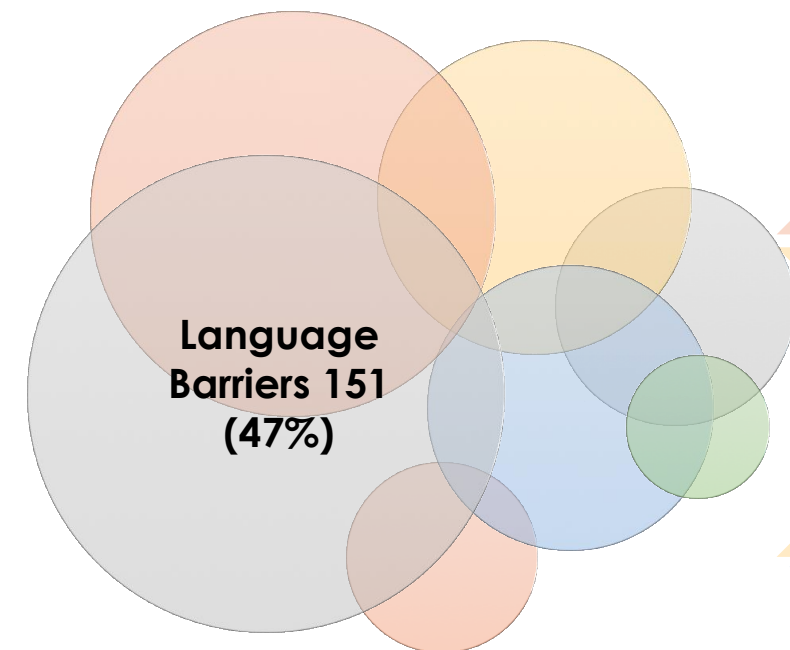


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**But we treat all  
patients the  
same!**



## 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.

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## Neglectful care

A family in the NICU was from the Middle East... with a language barrier for the mom. The dad was very demanding and in extreme denial of his baby's outcome. **Staff avoided going to the room, especially when dad was present...The medical team avoided rounding at the bedside when dad was present and this just widened the gap in care for this baby.**

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# Judgmental care

We are in a rural area setup. Mostly White. There was this one mom, drug addicted, low social economic status who would visit briefly. The baby was not going home with her and was held very little...Some nurses would encourage her to hold and treat her with respect...**Others would not allow her to hold and you could see mom shut down and put up barriers. This was not in the best interest of infant and may have done harm. Personal biases were very apparent.**



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# Systemic barriers to care

A hispanic 24 week baby born outside the hospital with young parents with another former 25 weeker. **Parents didn't have transportation and had irregular working conditions. Child Protective Services** was called because the medical team was concerned about **infrequent visits and infants medical needs at discharge.**

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



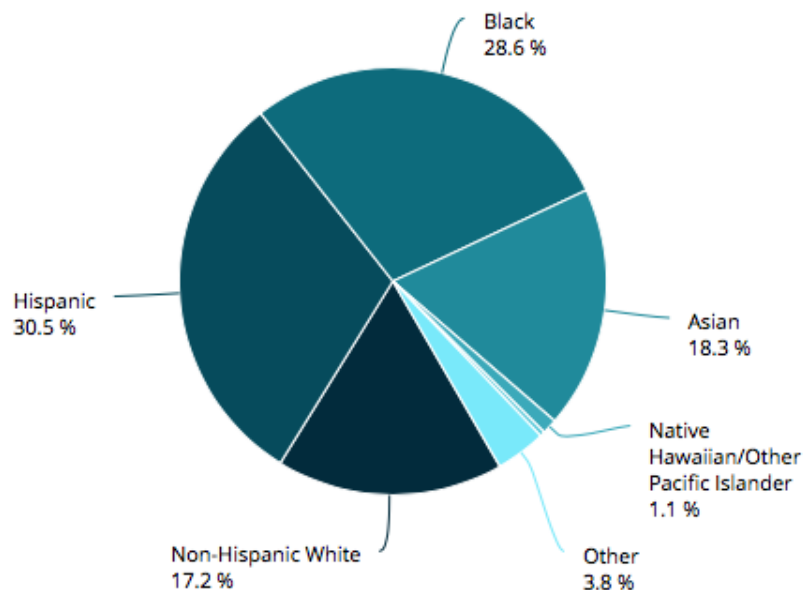
# CPQCC EQUITY DASHBOARD

Health Equity Dashboard as of Sep 30, 2019 at 06:36



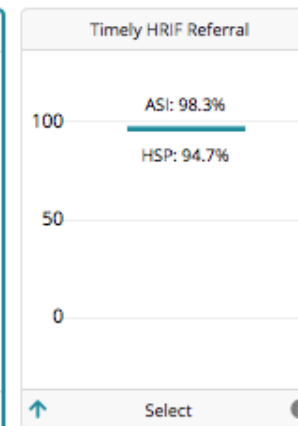
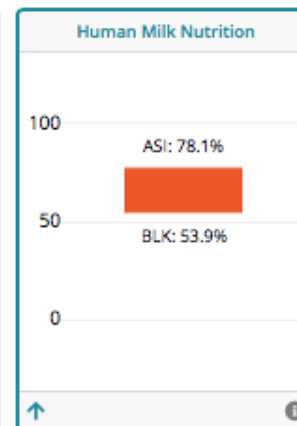
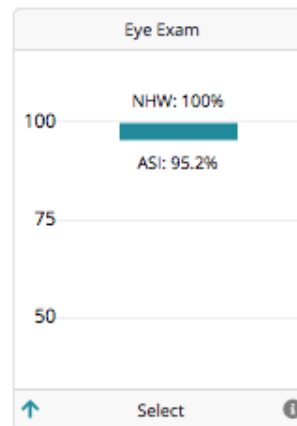
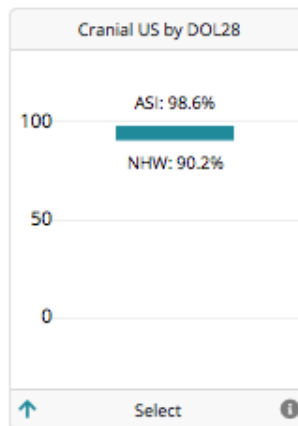
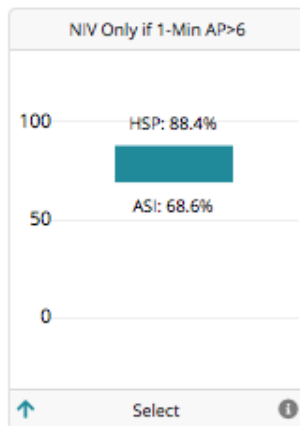
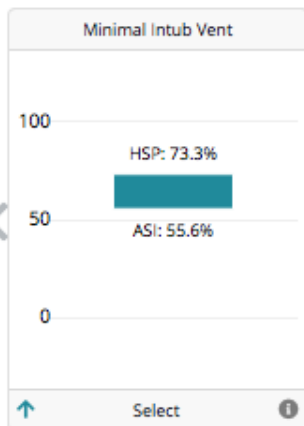
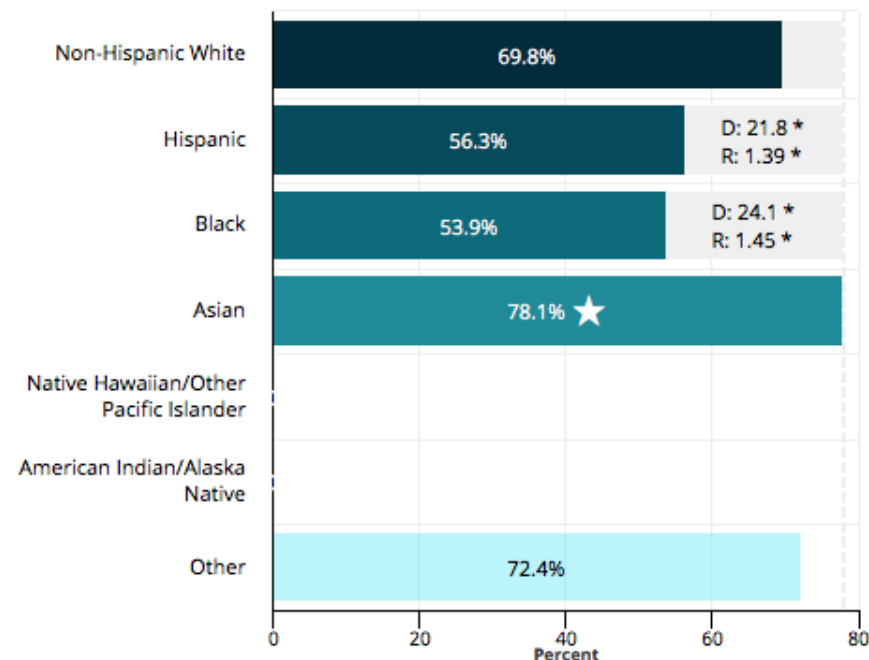
2016 - 2018

Race/Ethnicity Distribution for all VON Small Babies



Human Milk Nutrition by Race/Ethnicity

Reset zoom





# Measures of Family Centered Care

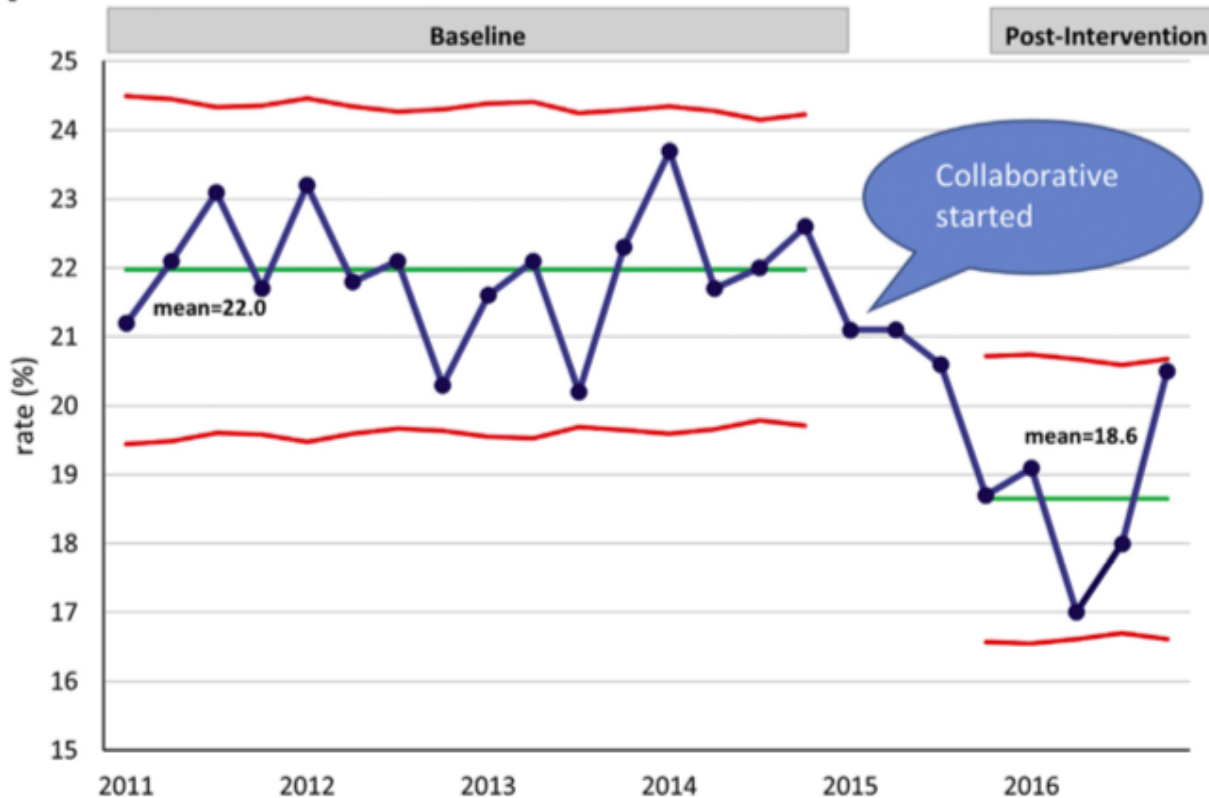
- NICU family advisory council
- Days to first skin-to-skin care
- Time to priming with oral colostrum
- Delayed social worker encounter



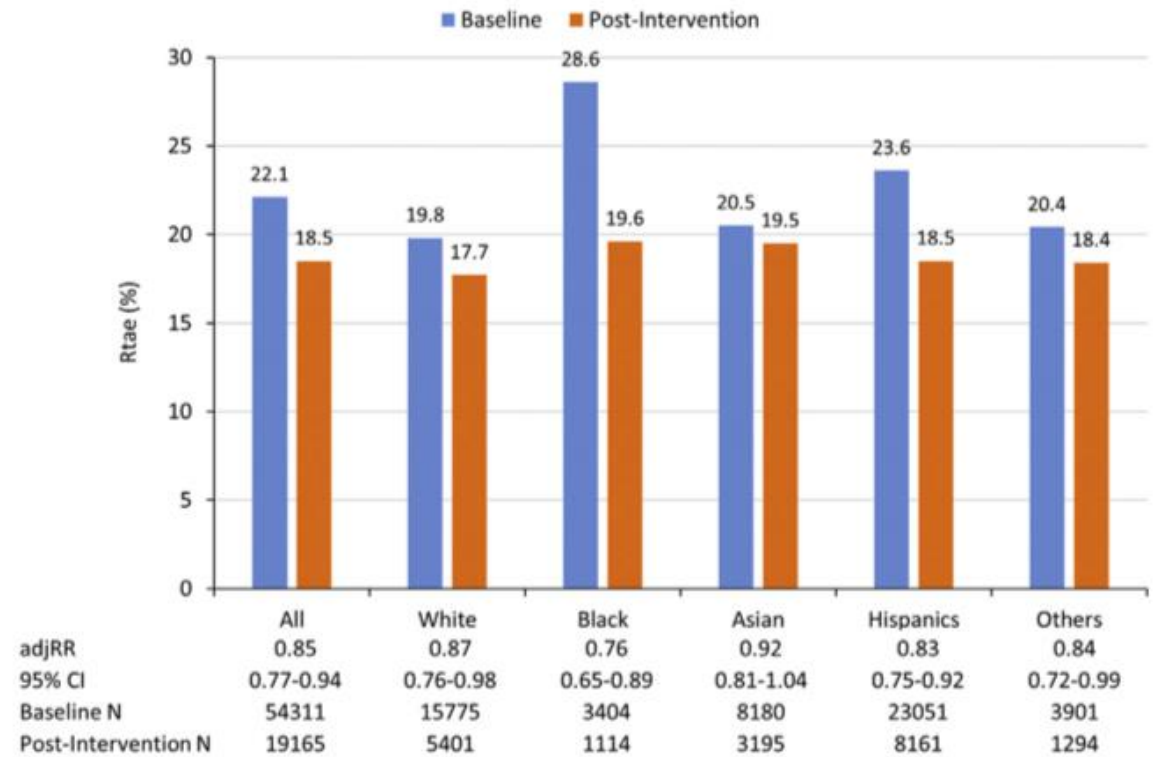
*Point-of-care derived measures developed in collaboration with disadvantaged families. Measures selected through a modified Delphi panel that included family representatives.*

# Disparity reduction through technical QI

**A** Severe maternal morbidity

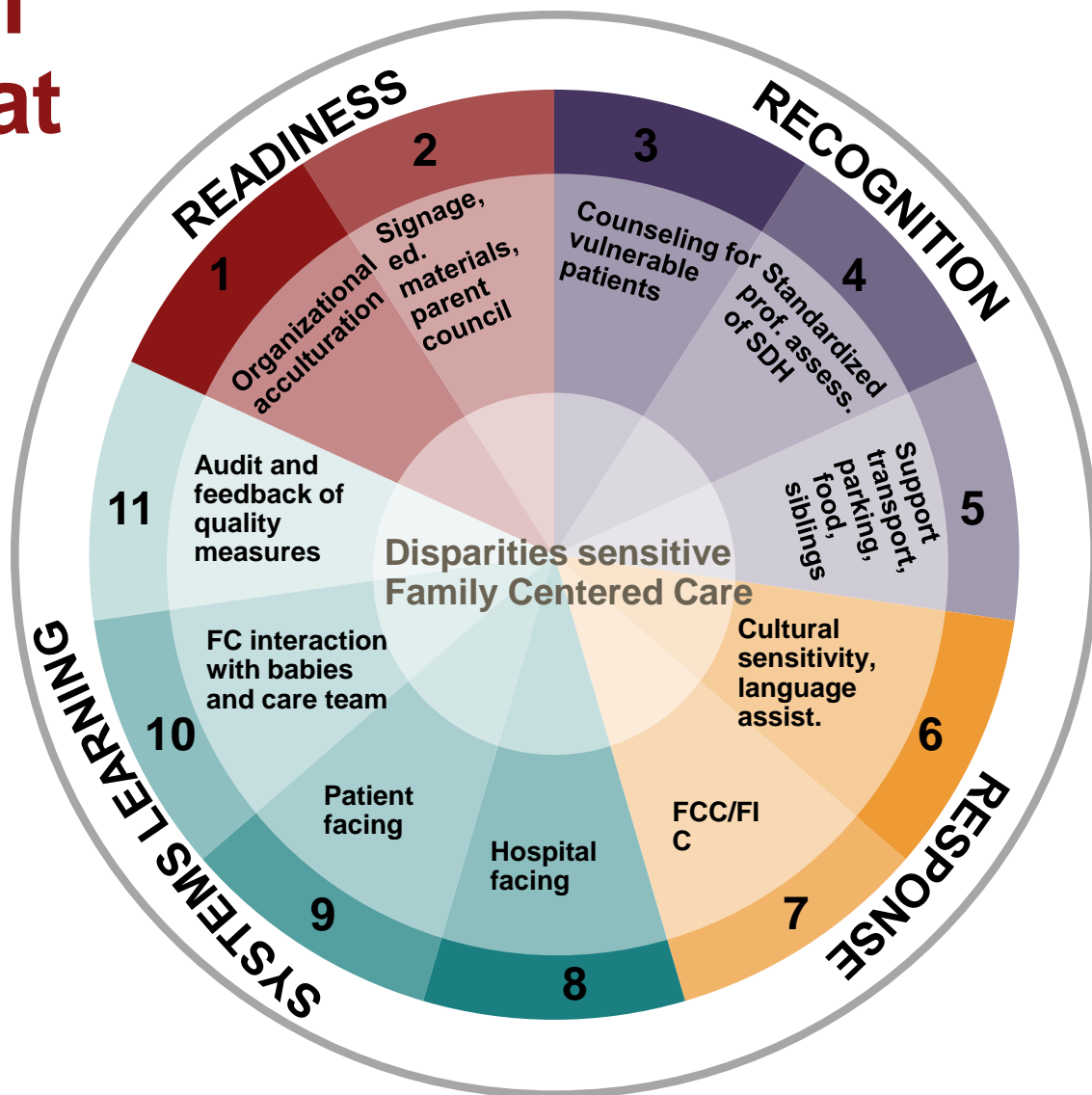


**A** Severe maternal morbidity



Main, Profit et al. AJOG 2020

# Changing what we do in the NICU



**FCC or Family Integrated Care**

**Audit and feedback of quality measures babies and by care team**

**race/ethnicity/language phone/video**

- **Language concordance**

REVIEW ARTICLE **OPEN**

# The color of health: how racism, segregation, and inequality affect the health and well-being of preterm infants and their families

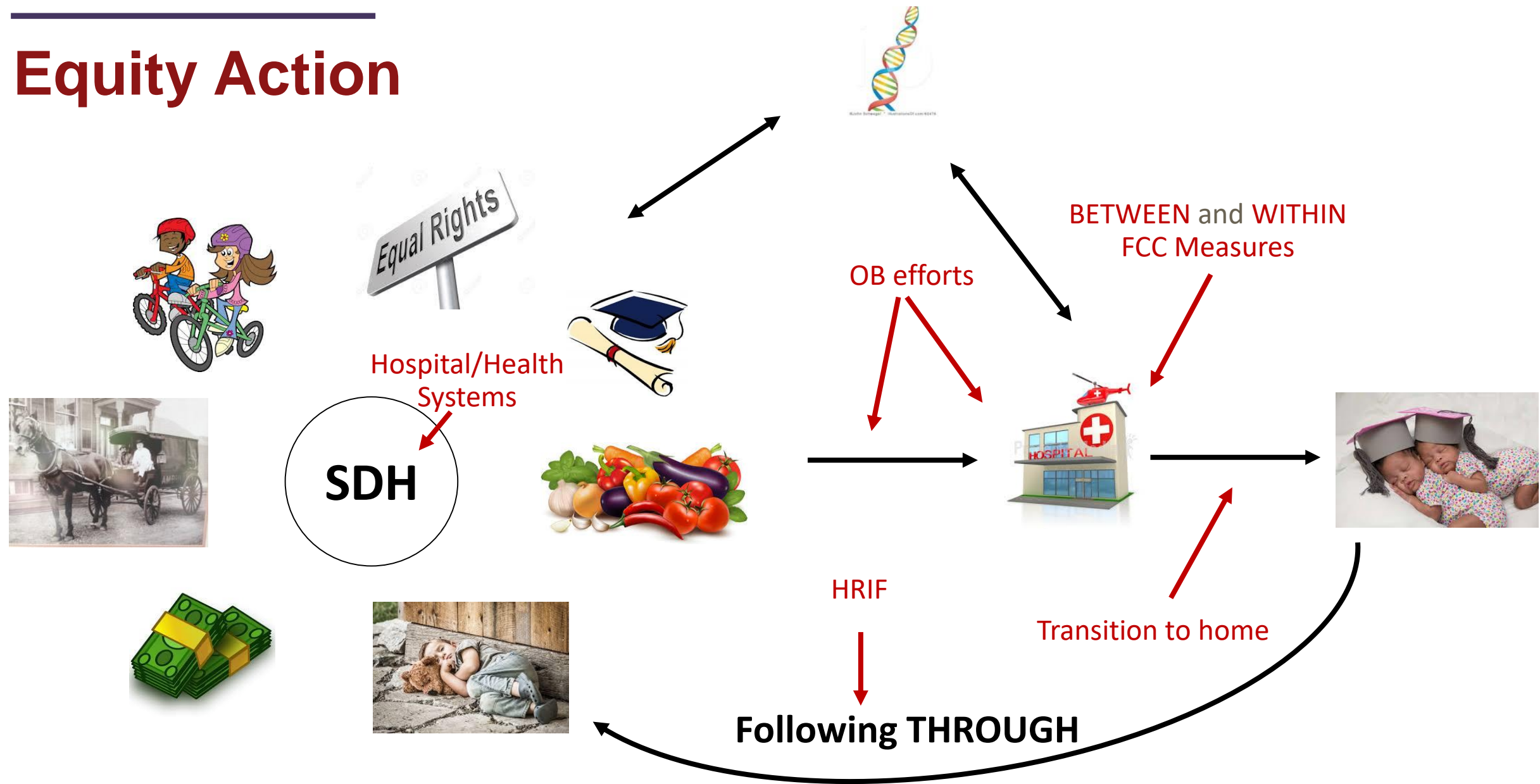
Andrew F. Beck<sup>1,2</sup>, Erika M. Edwards<sup>3,4,5</sup>, Jeffrey D. Horbar<sup>3,4</sup>, Elizabeth A. Howell<sup>6,7,8</sup>, Marie C. McCormick<sup>9,10,11</sup> and DeWayne M. Pursley<sup>9,11</sup>

# 62

1. Identify, prevent, and mitigate social risks
2. Recognize our responsibility does not end at NICU discharge
3. Develop robust quality improvement efforts to ensure equitable, high-quality NICU care
4. Advocate for social justice at the local, state, and national level



# Equity Action



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# Summary

- **We don't practice in a social cocoon**
- Disparities in NICU care exist within and between NICUs
- Prioritize disparities
- Routinely measure processes and outcomes by race/ethnicity
- Incorporate disparities into all QI efforts
- Engage your family advisors
- Try Something Tomorrow!!



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**PROFIT LAB**

**@ProfitJochen**

**@CPQCC**

**@ RDhurjati**



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

**- Dr. Martin Luther King, Jr.**