

**Addressing Disparities in Perinatal Care Delivery** 

Jochen Profit, MD, MPH

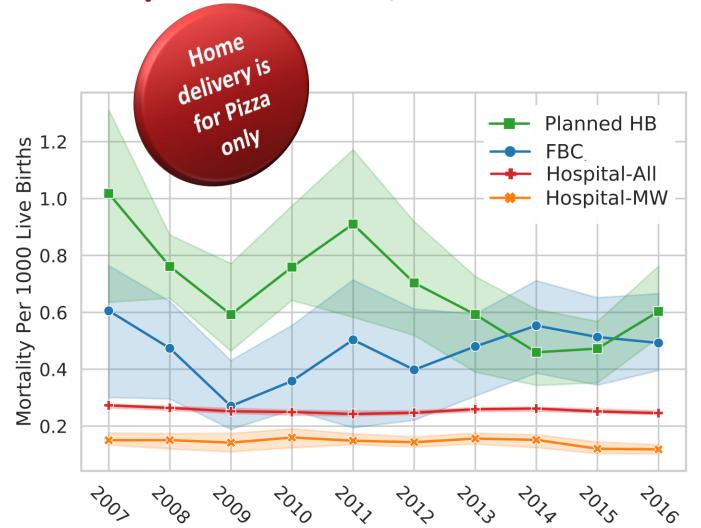
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## L. Joseph Butterfield, MD









#### **Disclosure**

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





# By the numbers



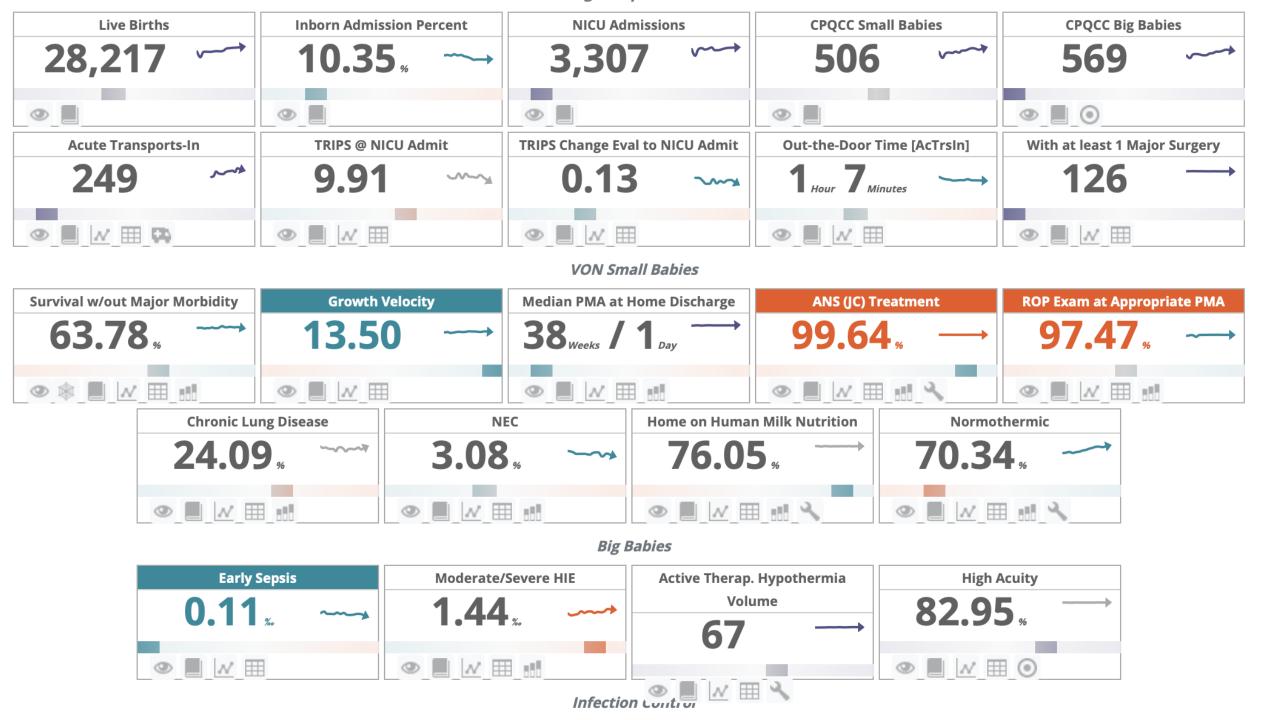








CPQCC CPeTS HRIF CMQCC

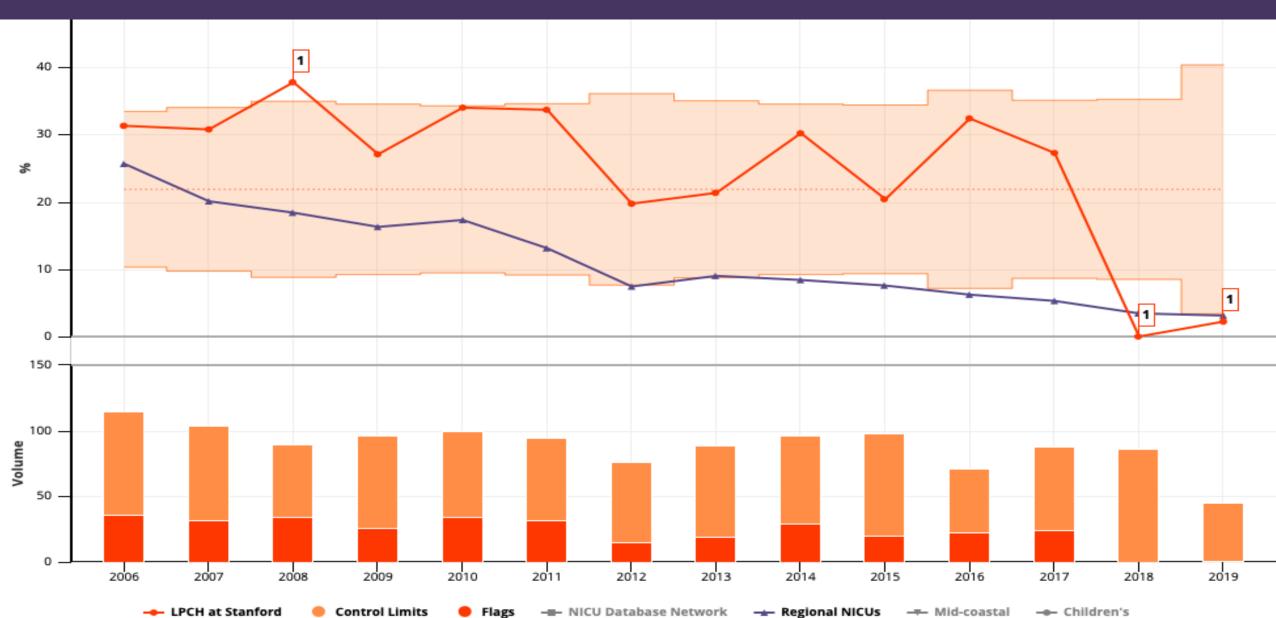


#### Hypothermic Newborns (Body temperature at NICU admission <36°C)

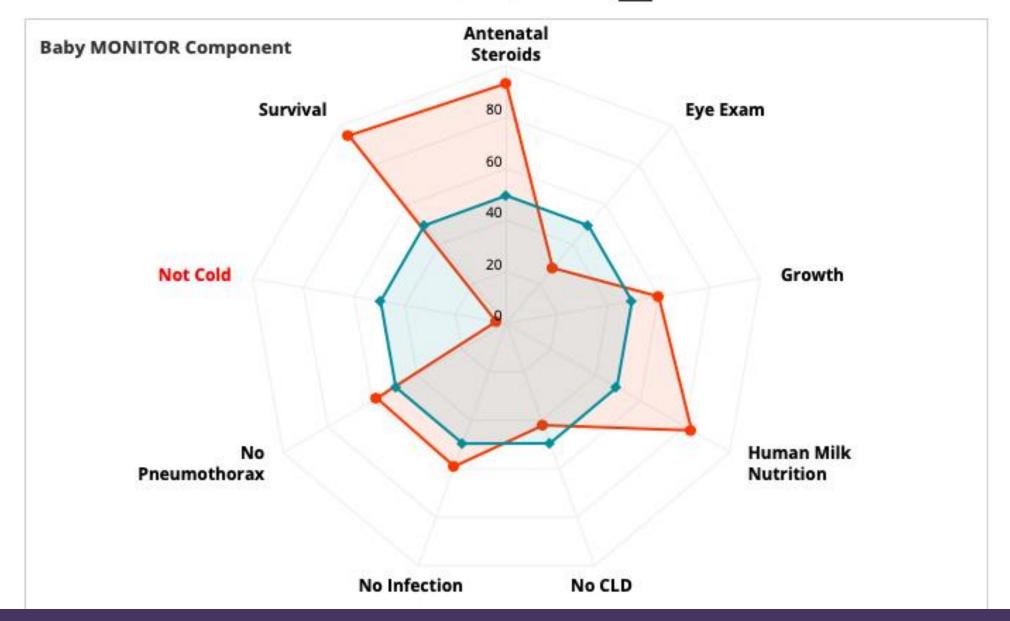
Inborn Infants 401 to 1500 grams or 22 to 29 Completed Weeks Gestation Born in 2006-2019







Demo NICU: Composite Score: 69



# CPQCC BABY-MONITOR

# By The Numbers NICU level improvements between 2008-2017

Member hospitals reduced mortality rates for VLBW infants by

15%

An additional

8.5%

of babies were discharged without major morbidities like severe ROP, NEC, CLD, and severe IVH And the rate of Necrotizing enterocolitis (NEC) decreased by

45%

# By The Numbers NICU level improvements between 2008-2017

Member hospitals reduced severe intraventricular hemorrhage by

19%

There were

36%

fewer cases of severe retinopathy of prematurity (ROP) or ROP surgery

And the rates of nosocomial infection declined by

44%

Lee, Liu, Profit, Hintz, Gould.
J Perinatol. 2020 Jul;146(1):e20193865





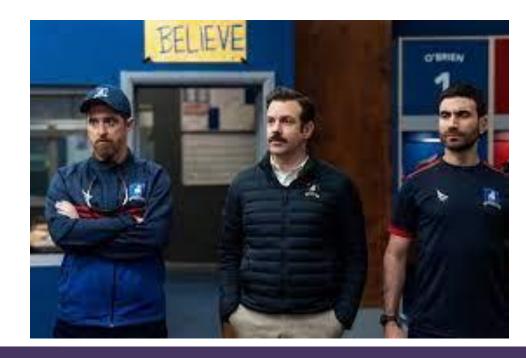
# **Best Hospitals for Neonatology**

Fifty pediatric centers were ranked for care of fragile newborns. Taking breast milk at discharge, the hospital's level of experience taking care of newborns, infection rates in the NICU, availability of ECMO for fragile heart-lung patients, advanced technologies and family support services accounted for most of each hospital's score.

**HOW WE RANK AND RATE HOSPITALS »** 



- #2 Children's Hospital Los Angeles
- #3 Lucile Packard Children's Hospital Stanford
- #4 University of California San Francisco
- #5 Racy Children's San Diego







# 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.



#### THE ESSENTIAL WORKERS FILLING NEW YORK'S CORONAVIRUS WARDS

By Dhruv Khull



Delivery people are among the essential workers who must expose themselves and their families to the v



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.





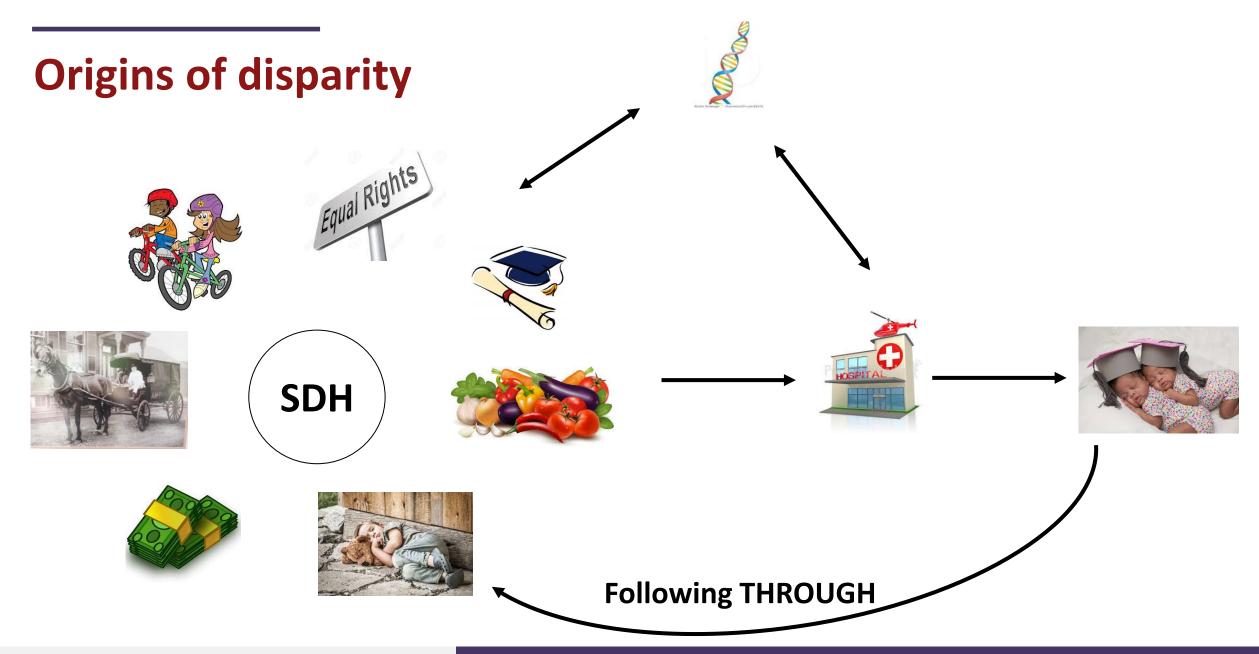
# Context matters – always exposed to bias





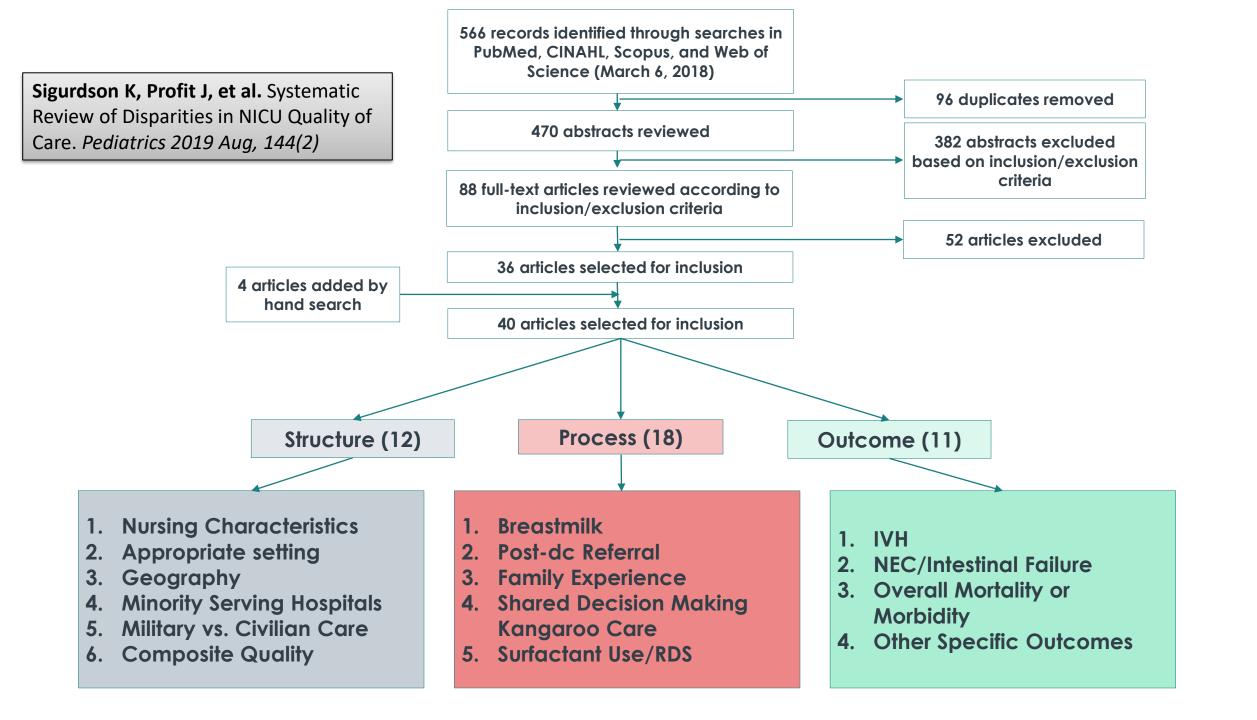












# What are the mechanisms for disparities in NICU Care?





#### **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)

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

a growing body of evidence

preterm infants are more likely to be born in hospitals with factors, and differences in hospital of birth explain a signifi-signs, and growth). cant proportion of the black-white and Hispanic-white disbetween and within NICUs for very low-birth-weight infants.4

extent of segregation and inequality for very low-birth- an interesting index for inequality. In our previous research, weight and very preterm infants in NICUs across the United we ranked hospitals by risk-adjusted morbidity and mortality States. They developed indices at the hospital level to mea- and examined where black and Hispanic very preterm insure segregation (ie, uneven distribution of racial and ethnic fants were born.2 In this article, Horbar et al5 rank NICUs by a groups across NICUs) and inequality (ie. concentration of racial or ethnic groups in lower-quality NICUs). Using data from infants in those NICUs. Their index of inequality has the pothe Vermont Oxford Network and a cohort of more than 117 000 tential to be used in future research investigating disparities. infants born at 401 g to 1500 g or 22 to 29 weeks' gestation from Future research would benefit from more granular data on race 2014 to 2016, they measured segregation and inequality at the and ethnicity to measure disparities in care for specific sub hospital level for black. Hispanic, and Asian infants relative to groups of black. Hispanic, and Asian infants. 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 tential to illuminate the pathways by which racial disparities and Hispanic infants received care at higher-quality NICUs. Region of residence explained differences for Hispanic but not a nates can have worse outcomes than white mothers because

care associated infection, and mortality) that have been used ous literature on the contribution of quality of care to neonaadministrative data. While morbidity and mortality are direct would likely affect estimates of inequalities.

Howell E, et al. JAMA Pediatr 2019

Despite significant improvements in the survival of very preterm newborns in neonatal intensive care units (NICUs) over are indirect measures of quality, and comparisons between hosthe last decade, significant racial and ethnic disparities exist pitals are more strongly reliant on the ability to carry out risk for very preterm infants. 1-3 While these disparities are rooted adjustment than process measures. Furthermore, they do not in a complex web of factors, identify specific areas that can be targeted in the NICU to improve outcomes. While the use of administrative data, such has documented the role of as state discharge abstract data linked with birth certificate quality of care in creating disparities. Black and Hispanic very data, allow for population-based estimates, these administrative data lack many of the data elements necessary to mea worse outcomes than white infants after adjustment for risk sure quality more directly (eg, receipt of medications, vital

Another strength is the use of a national data set that in parities for these vulnerable infants. Additional research has cludes nearly 90% of very low-birth-weight and very preterm documented that racial and ethnic disparities in quality exist infants born annually in the United States, making it possible to confirm that previous findings from specific regions apply In this issue of JAMA Pediatrics, Horbar et al<sup>5</sup> explore the more broadly to the US population. Horbar et al<sup>5</sup> also propose

Patient-level quantitative measures of quality, such as those used in the study by Horbar et al.5 are critical to solving (1) they receive care from facilities that treat all mothers with This article has a number of strengths in relation to pre- poor quality of care, (2) they receive worse quality of care than vious studies. First. Horbar et al5 used a comprehensive measure of quality, the composite Baby-MONITOR (Measure of Neoscial risks that are beyond the control of the hospital. Withnatal Intensive Care Outcomes Research) score, rather than out patient-level measures of quality, we cannot distinguish 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, an more, this composite measure builds on previous work to identenatal steroid exposure, hypothermia on admission, health tify evidence-based interventions in neonatology and illus trates the health impact of failure to implement them in current to measure quality in California NICUs. 4.6 Much of the previsearch to identify which components of care contribute most tal disparities has relied on measures of risk-adjusted neonato disparities. Although each component is weighted equally tal morbidity and mortality ascertained through the use of in the score, the authors point out that changing these weights

IAMA Pediatrics Published online March 25, 2019 E1





#### Disparities between hospitals – Structural racism

Howell, MD, MPP, Icahn School of Medicine at Mount Sinai. One

York New York 10029 (elizabeth

## **Neonatal mortality by hospital in NYC**

JAMA Pediatrics | Original Investigation Differences in Morbidity and Mortality Rates in Black, White, and Hispanic Very Preterm Infants Figure. Hospital Rankings for Risk-Adjusted Neonatal Morbidity and Mortality, New York City, NY, 2010-2014 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  $0.8 \cdot$ MPORTANCE Substantial quality improvements in neonatal care decade yet racial and ethnic disparities in morbidity and mo whether disparate patterns of care by race and ethnicity **OBJECTIVES** To examine differences in neonatal mor 40%(95%CI, 30%-50%) of the black-white disparity non-Hispanic black (black), Hispanic, and non-Hispan City hospitals using linked 2010 to 2014 New York Cit data sets. Mixed-effects logistic regression with a ran used to generate risk-adjusted neonatal morbidity and and infants in each hospital. Hospitals were ranked using t distribution of black, Hispanic, and white very pretern hospitals. The statistical analysis was performed in 20 **30%** (95%CI, 10%-49%) of the Hispanic-white MAIN OUTCOMES AND MEASURES Composite of mort or severe neonatal morbidity (bronchopulmonary dys retinopathy of prematurity stage 3 or greater, or intra disparity was explained by birth hospital. (28%) and was higher among black (893 [32,2%]) and .27-0.29) [22.5%]) VPTBs (2-tailed P < .001). The risk-standard (0.40: 95% CI, 0.38-0.41) as for those born in the low 95% Ct. 0.14-0.18), Black (1204 of 2775 [43,4%]) and in the highest morbidity and mortality tertile (2-tailed P proportion of the explained disparities can be attributed to diff among black. Hispanic, and white VPTB infants. However, 40% (95% CL 30%-50%) of the black-white disparity and 30% (95% CI, 10%-49%) of the Hispanic-white disparity was

Howell et al. JAMA Pedatr 2018



hospitals with higher risk-adjusted neonatal morbidity ar

JAMA Padiatr: doi:10.1001/jamanediatrics.2017.4402

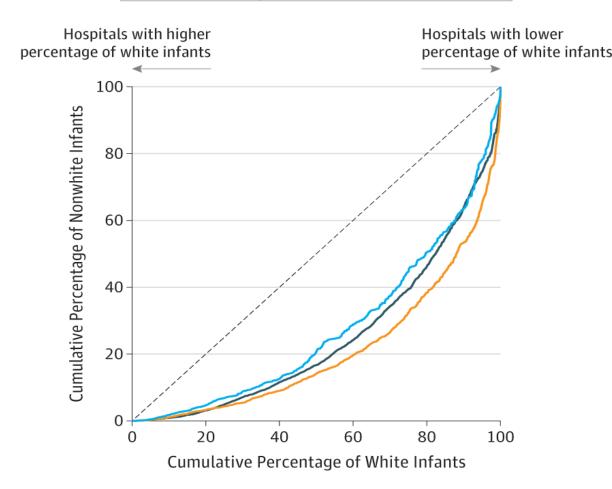
Published online January 2, 2018

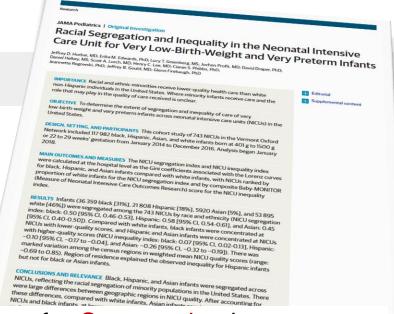




#### Racial Segregation in the NICU

	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)

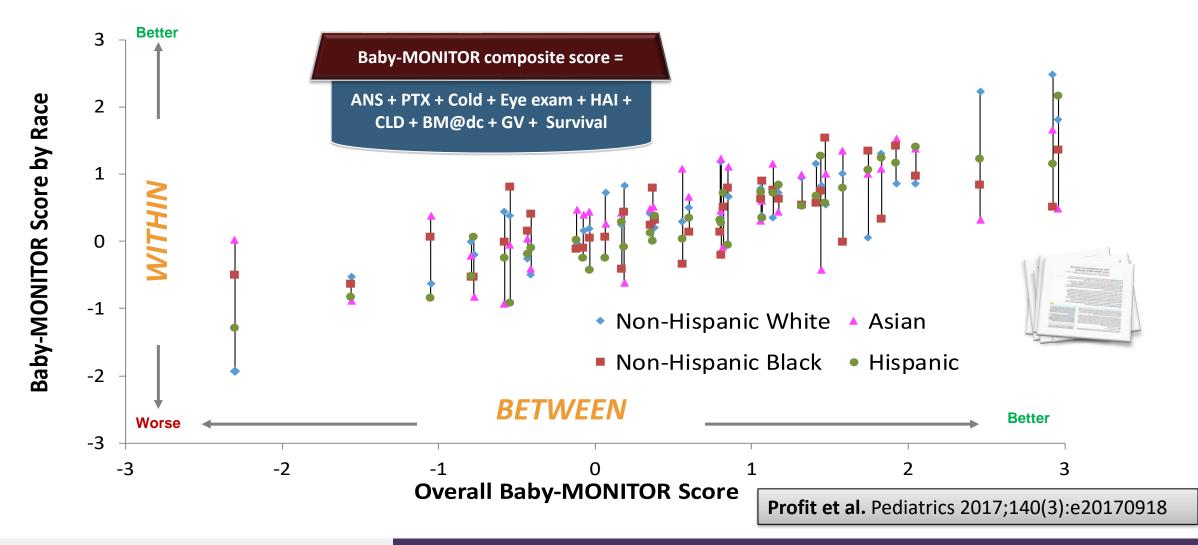




Lorenz Curves for Segregation by Race/Ethnicity in US NICUs ranked by the proportion of white infants from highest to lowest, and the cumulative population percentages of white and minority infants were plotted on the x- and y-axes. If all NICUs had the same racial distribution as the overall population,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

Edwards, Horbar, Profit et al. JAMA Pediatr 2019

## Variation in Quality of Care by R/E WITHIN and BETWEEN NICUs







rigure ZA Non-hispanic Black Non-hispanic White Original Article Low-infection Tertile Med-infection Tertile Disparities in Health Care-Associated Infections in the NICU Jessica Liu, Ph.D, MPH1,2 Charlotte Sakarovitch, Blacks more likely cared for in Henry C. Lee, MD, MS1,2 Jochen Profit, MD, MP Perinatal Epidemiology and Health Outcomes Research Unit, Division

Ne cnatclogy, Department of Pediatrics, Jucile Packard Children's Hospital, Stanford University School of Medicine, Palo Alto, Californ <sup>2</sup>California Perinatal Quality Care Collaborative, Palo Alto, Calif <sup>3</sup>Division of Biomedical Informatics Research, Department of Medicine, Stanford University, Stanford, California

<sup>4</sup>Medical Data Lab. Université Côte d'Azur, Nice, France

Am J Perinatol

Abstract

Objectives This stud associated infection (H race/ethnicity and its Study Design This is between 2011 and : Results Risk-adjus units (NICUs), rang higher odds of HA Non-Hispanic bla tertile of infect ethnicities suff

Keywords → infant

► health care-

 disparity risk factors

associated infection Conclusion variation in infection acre with infection.

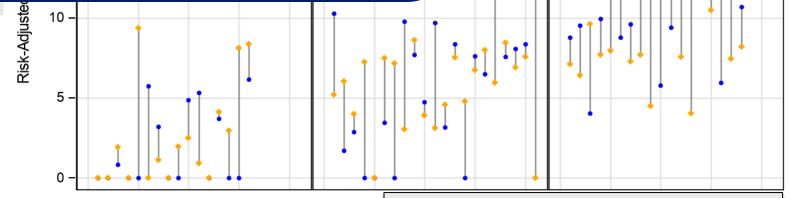
Health care-associated infection (HAI) is a serious complication among very low birth weight (VLBW; < 1,500 g) preterm infants hospitalized in the neonatal intensive care unit (NICU), and infection rates in these infants have ranged from 21 to 30%. 1-4 VIBW infants are especially susceptible to HAI.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

hospitals with higher HAI rates

**Hispanics** more likely to have a HAI

HAIs are associated with increases in neurodevelopmental impairment, mortality, length of stay, and as a result, increased financial costs of care 3.6,12-17 Payne et al reported that the occurrence of just one single type of HAI would increase costs of treating VLBW infants by \$100 million.12 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), 7,18-20

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



Liu, Profit, et al.

Am J Perinat 2020 Jan; 37(2):166-173





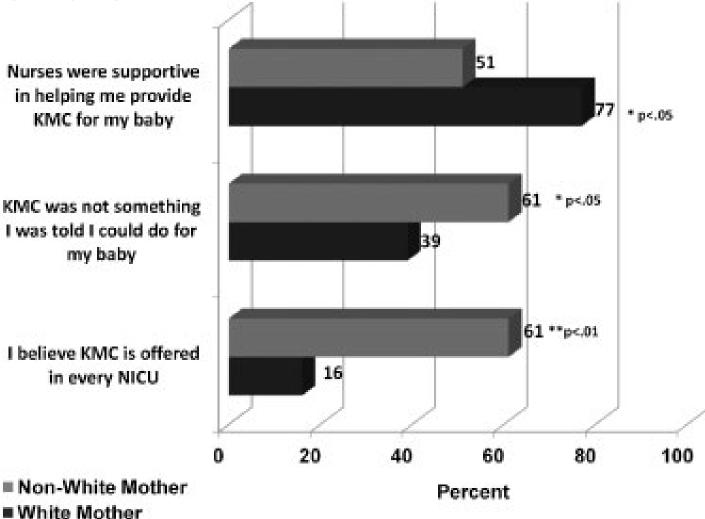
High-infection Tertile

<sup>&#</sup>x27; At the time of this research, Dr. Sakarovitch was a senior statistician at the quantitative sciences unit

#### Disparities within hospitals – Interpersonal racism

**Access to Kangaroo Care** 

Hendricks-Muñoz et al. Am J Perinatol 2013



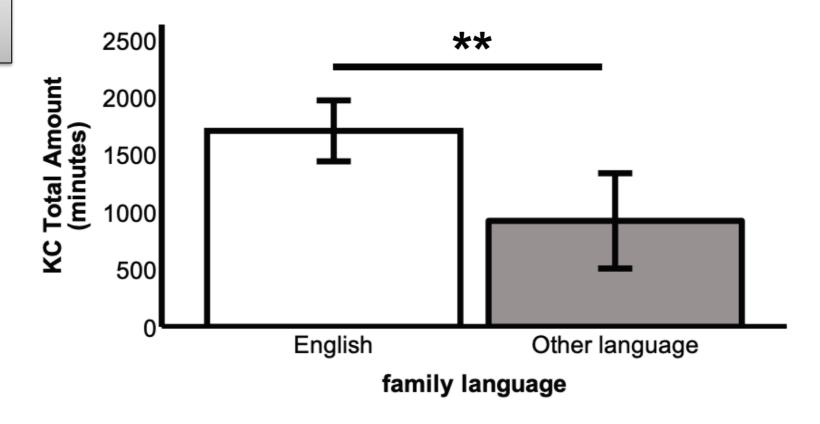




#### Disparities within hospitals – Interpersonal racism

#### **Access to Skin-to-Skin Care**

Brignoni-Pérez E et al. www.medrxiv.org/content /10.1101/2020.11.09.202 24766v1

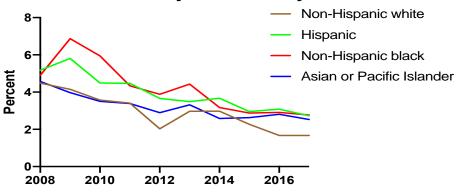




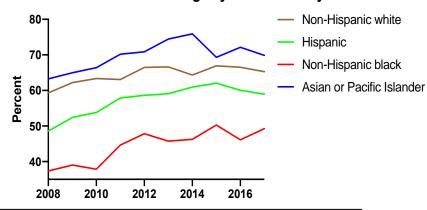
#### Are disparities improving?

#### **NEC**

#### **NEC Incidence by Race/Ethnicity**

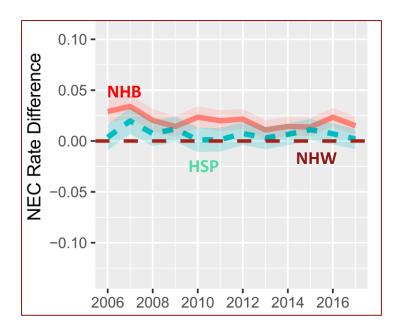


#### Breast Milk Use at NICU Discharge by Race/Ethnicity

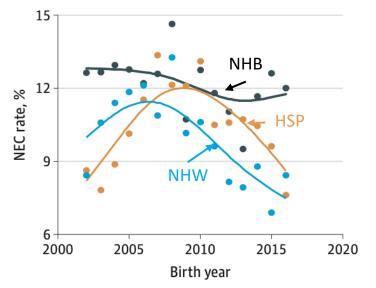


Goldstein, Profit et al.

Pediatr Res. 2020 Aug;88(Suppl 1):3-9



Boghossian et al. Pediatrics. 2019; 144(3):e20191106



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





# But we treat all patients the same!



#### Overlapping **Dimensions**

# Types of Disparate Care

Language **Barriers 151** (47%)

or Racial

Privilege: 12

(3%)

**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.

Suboptimal **Care: 312** (96%)

Social, Economic **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.

**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 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...



# 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 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
- c. Use of disparity aim in QICs

#### 3. Education

- a. CPQCC annual meeting focus on equity and anti-racism
- b. Disparity Tip Sheet

#### 4. Research

a. Various efforts and collaborations





# 1. Audit and Feedback 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:



- 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 started 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
- 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

NICU lactation consultant availability

SUPPORT FOR BREASTFEEDING

- Time to first lactation consult
- Time to priming with oral colostrum (√)

#### **COMMUNICATING WITH FAMILIES**

- Frequency of updates to families by MD/NNP/RN
- Delayed social worker encounter (✓)
   Frequency of updates to families with limited English proficiency by MD/NNP/RN
  - Provision of interpreter services

#### **CARE COORDINATION**

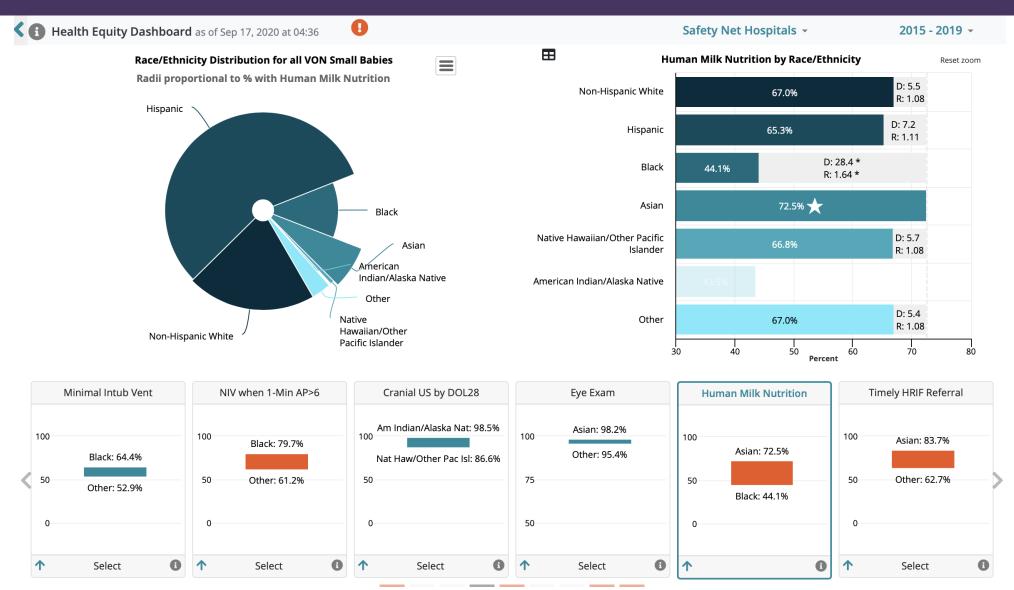
- Post-discharge care coordination\*
- Continuity of care by RN\*
- Continuity of care by MD\*

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





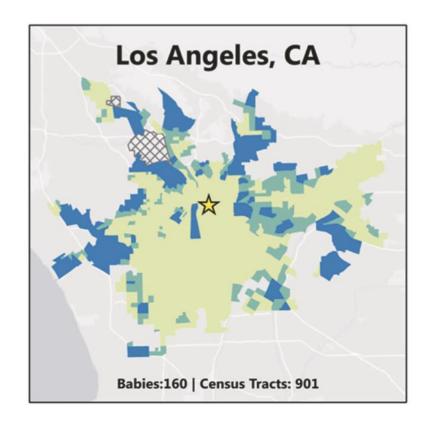
## 1b. CPQCC EQUITY DASHBOARD

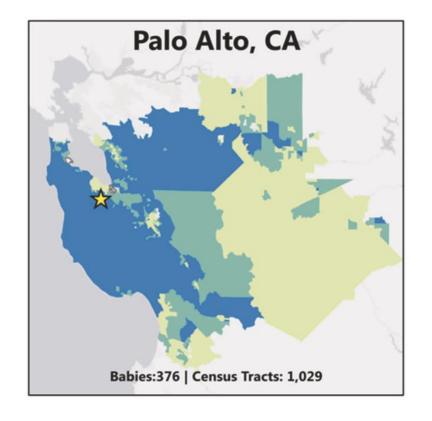






#### **NICU** catchment areas

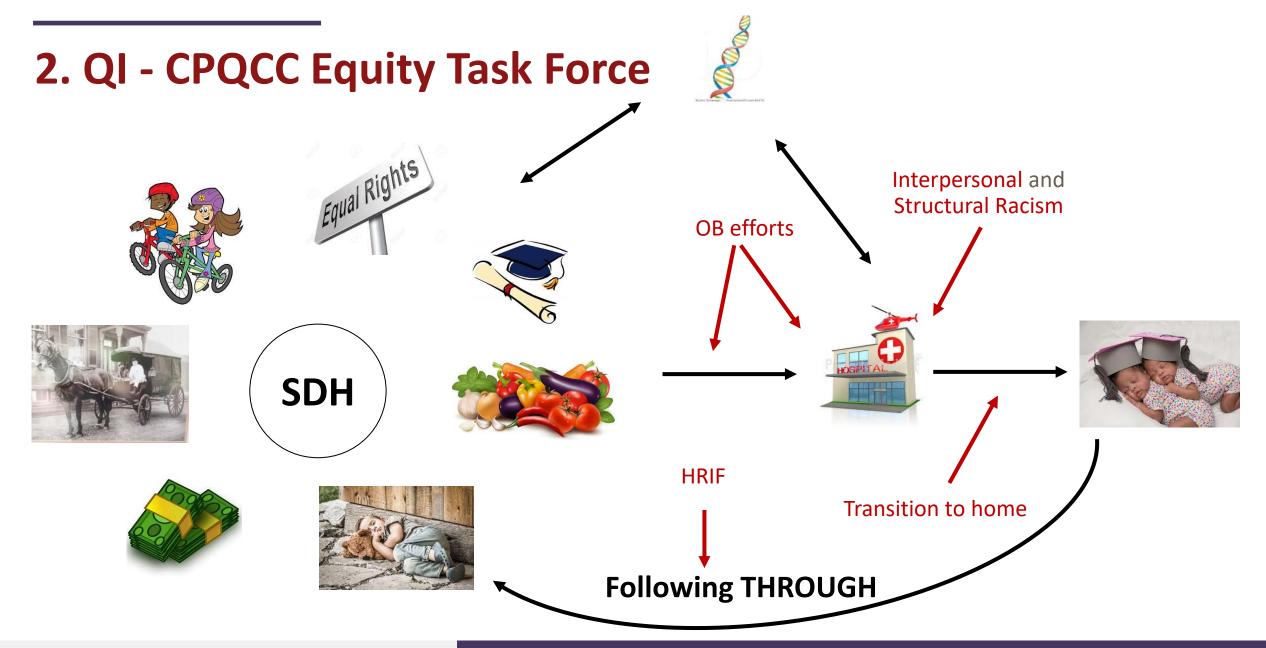














#### 3. Education – Call to Action

#### Friday, March 5, 2021

#### 2021 CPQCC Improvement Palooza

Advancing Anti-Racism in the NICU Through Teamwork and Family Centeredness

#### **2021 CPQCC Improvement Palooza**

- 8:00 Opening and Welcome Elizabeth Rogers, MD
- 8:15 Practicing Anti-Racism to Improve Outcomes for Black Infants

Moderator: Carmin Powell, MD Rachel R. Hardeman, PhD, MPH & Tamorah Lewis, MD, PhD

- 9:25 How to Build and Make the Most of Your QI Team: CPQCC Leadership
- 9:55 Break
- 10:05 NICU Partnerships: Respect, Trust & Collaboration Moderator: Ashley Randolph Jochen Profit, MD, MPH, Necole McRae & Jenne' Johns. MPH
- 11:15 How to use the CPQCC Health Equity Dashboard to
  Advance Equity in Your NICU: Center Work with PQIP
  Ambassadors
- 12:00 Lunch (team lunch with personal reflection)
- 1:00 Access, Equity and the California Latinx Experience Cristina Gamboa, MD, Ashwini Lakshmanan, MD, MS, MPH & Marina Persoglia Bell, MA

- 2:00 Brave Spaces: Restoring Right Relationships
  Amber McZeal, MA, Elizabeth Rogers, MD,
  Cloteal Franklin & Mark Burns
- 2:45 Break
- 2:55 QUALITY IMPROVEMENT SUCCESSES FROM CPOCC MEMBERS

Mother And Baby Substance Exposure Initiative (MBSEI) Collaborative: UC Irvine

Pam Aron-Johnson, RN, Robin Koeppel, DNP, CNS & Alexandra lacob, MD

Reducing Hypothermia in ELBW Infants: Kaiser Permanente Fontana

Dilip R. Bhatt MD, FAAP, FACC, FACMQ, Rangasamy Ramanathan, MD, Nirupa Reddy, MD, V. Reinaldo Ruiz, MD, FACOG & Sunjeeve Weerasinghe, MSN, NNP-BC, CNS

Grow, Babies, Grow: Mercy San Juan Medical Center Laura Dennis, RD, MAS, Carolyn Getman, MD, Sofie De Nardi, MD & Gale Schmaltz, NNP

- 3:50 Closing Remarks
- 4:00 Adjourn

17 You Retweeted



Christine Morton @christinemorton · Mar 5

Really looking forward to talking about hard things with @carminmari @tamorahlewisMD @RRHDr #antiracistNICU building on the work of so many important scholars Thank you @CPQCC for this session

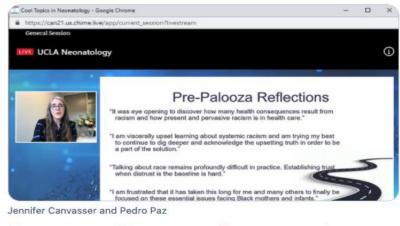


↑ You Retweeted



Henry Lee @henryleeneo · Mar 5

Thank you to @eerogersmd and @cpqcc planning committee for Improvement Palooza - 'not one day event, but a journey that we are embarking on together - to dismantle racism'











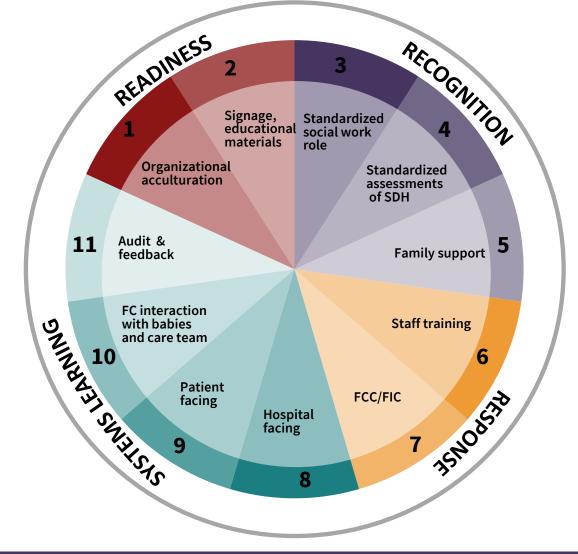






**3b. Education** - Disparity Tip Sheet and Organizational Change Framework

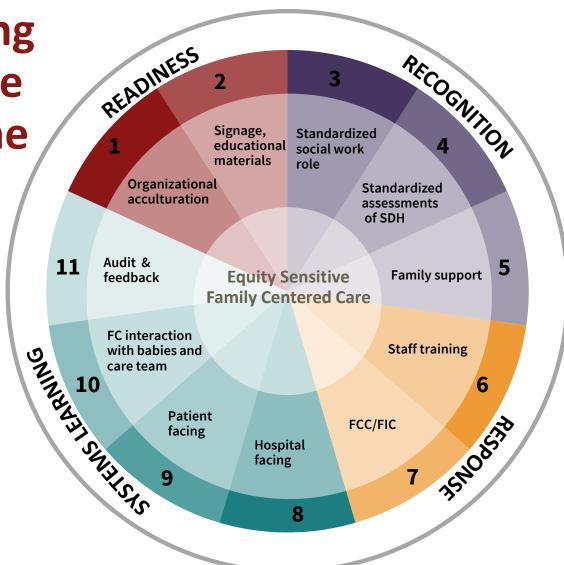








Changing what we do in the NICU



FCC or Family
Signage Fod Caron

Audigand feedback of inflealithmeasures bes the construction of the cone/video

Language concordances."



Our Responsibility to Follow Through for NICU Infants and Their Families

REVIEW ARTICLE OPEN

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

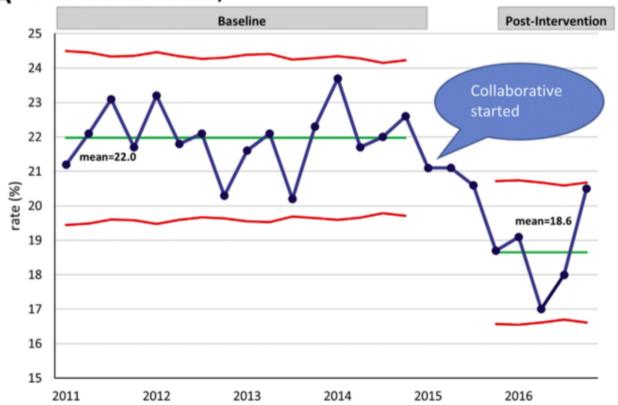
Andrew F. Beck<sup>1,2</sup>, Erika M. Edwards<sup>3,4,5</sup>, Jeffrey D. Horbar<sup>3,4</sup>, Elizabeth A. Howell<sup>6,7,8</sup>, Marie C. McCormick<sup>9,10,11</sup> and DeWayne M. Pursley<sup>9,11</sup>



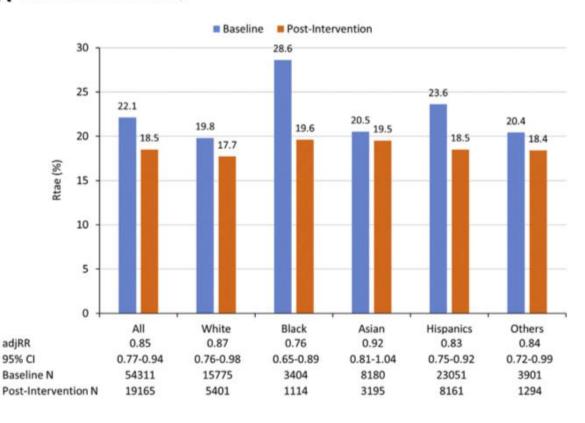
- 1. Identify, prevent, and mitigate social risks
- 2. Recognize our responsibility does not end at NICU discharge
- 3. Develop robust QI efforts to ensure equitable, high-quality NICU care
- 4. Advocate for social justice at the local, state, and national level

## 4. Research – Technical Versus Adaptive Disparity Solutions QI

#### A Severe maternal morbidity



#### ▲ Severe maternal morbidity

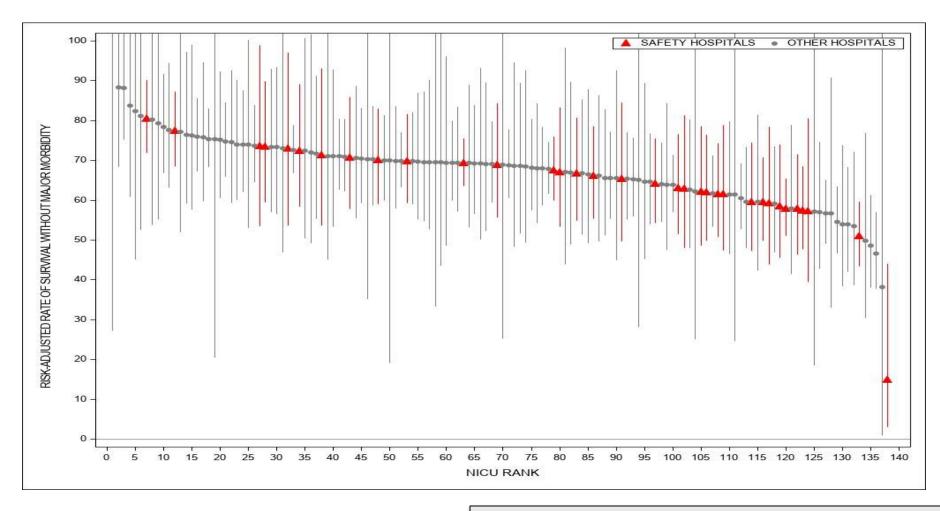


Main, Profit et al. AJOG 2020





#### 4. Research



Liu J, Pang E, Iacob A, Profit J, et al., *under review* 





# **Summary**

- We don't practice in a social cocoon
- Institutional and interpersonal racism in the NICU exists and needs to be addressed
- Education is necessary but not sufficient, trust in QI methods
- Families know best
- Try Something Tomorrow!!

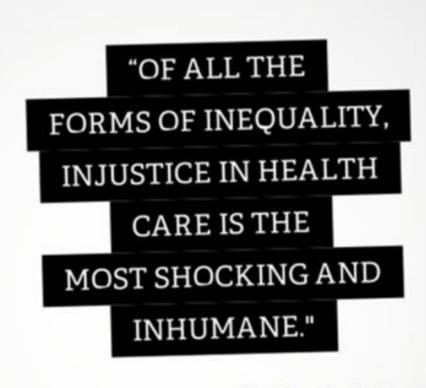


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- Dr. Martin Luther King, Jr.



