

# wellness

**Denise Evans**

*Facilitator, Public Health Educator &  
Truth Racial Healing Circles Lead  
Trainer & Practitioner*

Consult Me, LLC

Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ



# Wellness Moment

ANCESTORS &  
BREATH

A large, irregular pink brushstroke shape with a rough, hand-painted edge, serving as a background for the title text.

# Ancestral Mathematics

In order to be born, you needed:

- 2 parents
- 4 grand parents
- 8 great-grandparents
- 16 second great-grandparents
- 32 third great-grandparents
- 64 forth great-grandparents
- 128 fifth great-grandparents
- 256 sixth great-grandparents
- 512 seventh great-grandparents
- 1,024 eighth great-grandparents
- 2,048 ninth great-grandparents

A large, irregular pink brushstroke shape with a rough, textured edge, serving as a background for the title text.

# Ancestral Mathematics

For you to be born today from 12 previous generations, you needed a total of 4,094 ancestors over the last 400 years.

Think for a moment...

- How many struggles?
- How many battles?
- How many difficulties?
- How much sadness?
- How much happiness?
- How many love stories?
- How many expressions of hope for the future?



A large, horizontal, pink brushstroke graphic that serves as a background for the main text. It has a soft, painterly texture with visible bristles and a slightly irregular, wavy shape.

# *Learning to Breathe*

Slow Down

# Healthy Start Consumer Convening

Day 2: Thursday, May 25  
from 8:45 am-5:00 pm





# Morning Community Circle

**Kenn L. Harris**

*Healthy Start TA & Support Center (TASC)*

*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*







# Welcome!

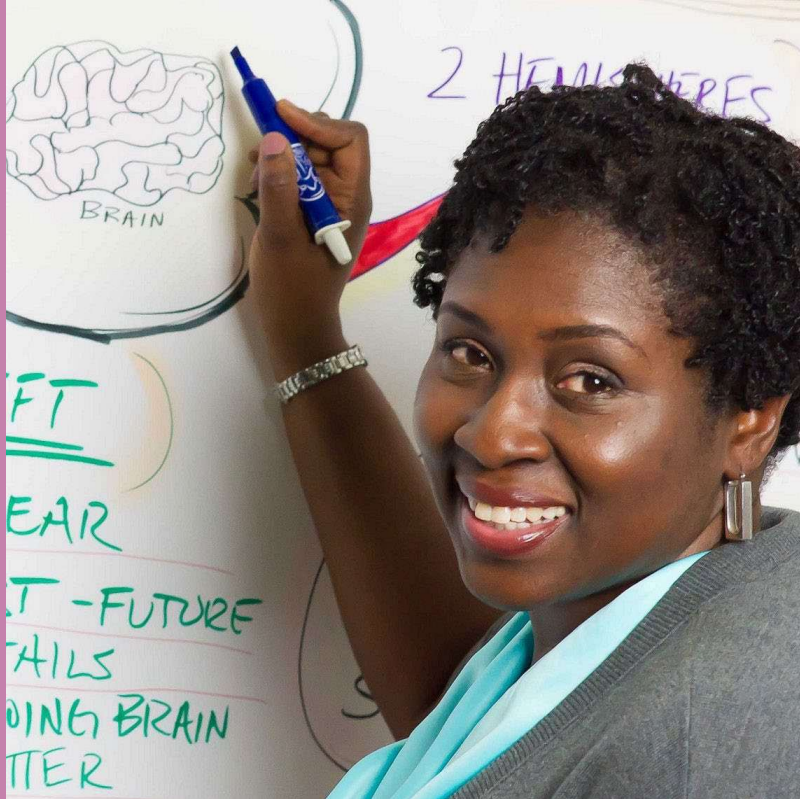
- **Please feel free to:**

- View the agenda in your folder.
- Review the nearby lunch options in your folder and place an order for delivery or pickup in advance.
  - Visa gift cards to cover meal expenses are distributed at registration.
- Take a photo with the photographer!

- **Please also note:**

- The bathrooms are located outside the ballroom to the left.
- We will have the following breaks:
  - Quick break from 10:45-11:00 am
  - Lunch break from 12:30-1:30 pm
  - Quick break from 3:00-3:30 pm
- Coffee and tea will be available in the hall during the quick breaks.
- The TASC team is here to provide support or answer any questions during the meeting.

# See in Colors



**Lisa Nelson,**  
Founder and Creative Director at  
See in Colors



**Sunny Belbenkacem**  
Graphic Recorder at See in Colors



**Plenary Session #1 from 9:00-10:45 am**

**Telling Our Stories**

**Tamela Milan-Alexander  
Dakisha Mitchell  
Amanda Henley**  
*Healthy Start TA & Support Center (TASC)*

**Inequity and Inequality:  
Understanding the State of  
Maternal & Child Health in  
the United States**

**Dr. Divya Mallampati**  
*University of California, San Francisco*

**Division of Healthy Start &  
Perinatal Services (DHSPS)  
Presentation**

**Kristal Dail**  
*DHSPS*

**Break from 10:45-11:00 am**

**Concurrent Skill-building  
Session #1  
11:00 am-12:30 pm**

**Brenda Reyes**  
*HealthConnect One*

**Dr. Linda Henderson-Smith**  
*ATC Consulting*

**Dr. Magda Peck**  
*MP3 Health*

**Stephanye Clarke**  
*SistaCare*

**Lunch & Engagement Activities  
12:30-1:30 pm**





Plenary Session #2  
1:30-3:00 pm

Naming, Recognizing,  
and Reporting Obstetric  
Racism During  
Childbirth  
Hospitalization:  
Consumer Advice for  
Black Birthing  
Communities  
1:30-2:30 pm

Dr. Karen Scott  
*Birthing Cultural Rigor*

Break from 3:00-3:30 pm

Concurrent Skill-  
building Session #2  
3:30-5:00 pm

Same as morning

Adjourn at 5:00 pm



**HRSA**  
Maternal & Child Health

**NICHQ**  
National Institute for  
Children's Health Quality

**HEALTHY  
start**  
TA & SUPPORT CENTER





# Telling Our Stories

**Tamela Milan-Alexander**

**Dakisha Mitchell**

**Amanda Henley**

*TASC Faculty Planning  
Committee*


*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*

 **HRSA**  
Maternal & Child Health

**NICHQ**  
National Institute for  
Children's Health Quality

**HEALTHY**  
**start**   
TA & SUPPORT CENTER





# Inequity and Inequality: Understanding the State of Maternal & Child Health in the United States

**Dr. Divya Mallampati**

*University of California,  
San Francisco*

*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*



# Maternal and Child Health in the United States: 4 Key Messages for Advocates

Divya Mallampati, MD, MPH  
Division of Maternal Fetal Medicine  
Department of Obstetrics, Gynecology, and Reproductive Science  
University of California, San Francisco  
May 25, 2023





### Rural Hospitals Are Shuttering Their Maternity Units

Citing costs, many hospitals are closing labor and delivery wards, expanding so-called maternity care deserts.

PUBLIC HEALTH

[LISTEN & FOLLOW](#)

### Maternal deaths in the U.S. spiked in 2021, CDC reports

March 16, 2023 · 12:02 AM ET  
 Heard on *Morning Edition*  
 By Selena Simmons-Duffin, Carmel Wroth

**TheUpshot**

### Unwanted Epidurals, Untreated Pain: Black Women Tell Their Birth Stories

Regardless of income or education, Black mothers have worse birth outcomes.



### Deaths Among Pregnant Women and New Mothers Rose Sharply During Pandemic

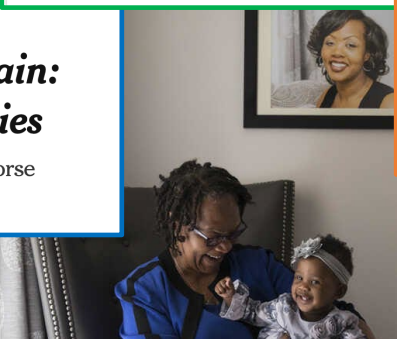
The fatalities, occurring disproportionately among Native American and Black women, were linked not just to medical complications but also to homicides and accidents.



**TheUpshot**

### The Last Person You'd Expect To Die

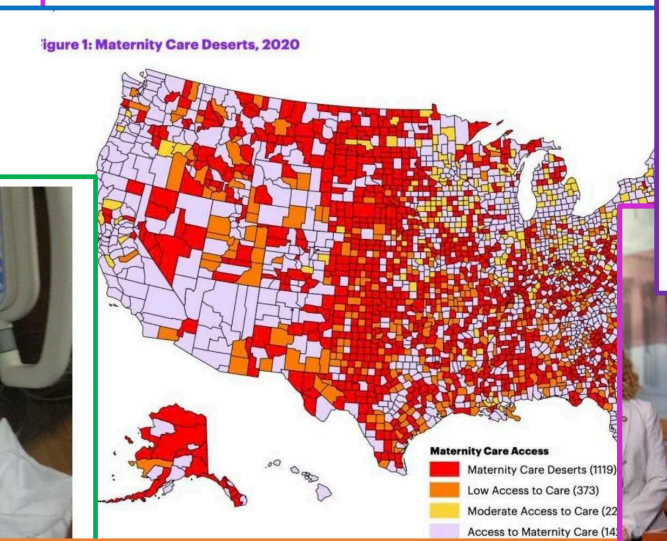
The U.S. has the worst rate of maternal deaths in the world. 700 to 900 deaths each year are preventable, including Bloomstein.



### Millions of Americans are losing access to maternal care. Here's what can be done

October 12, 2022 · 9:37 AM ET  
 By Rachel Treisman

## 'I Don't Want to Die': Fighting Maternal Mortality Among Black Women



**TheUpshot**

### Childbirth Is Deadlier for Black Families Even When They're Rich, Expansive Study Finds

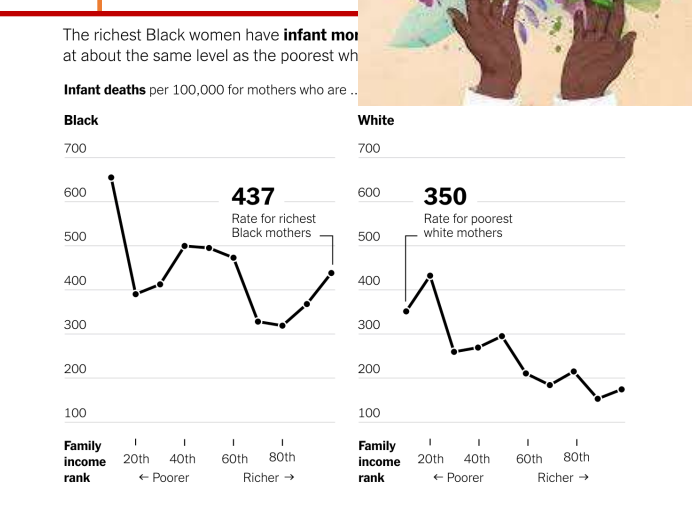
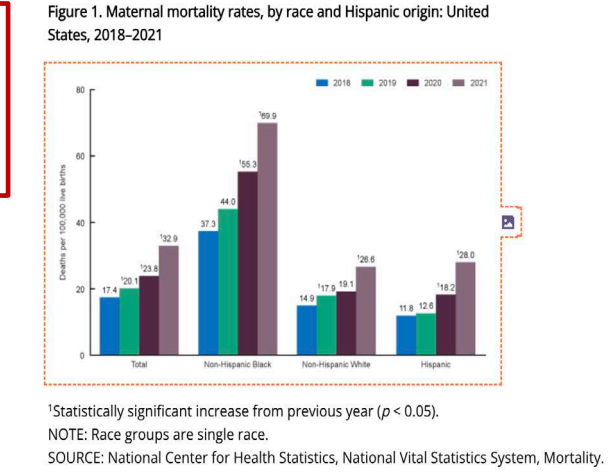
By Claire Cain Miller, Sarah Kliff and Larry Buchanan  
 Produced by Larry Buchanan and Shannon Lin  
 Feb. 2023

**CDC Newsroom**  
 CDC Newsroom Home

#### Four in 5 pregnancy-related deaths in the U.S. are preventable

Data highlight opportunities to better protect moms

Press Release



# Positionality

Cis-gendered South Asian immigrant woman

Have not been a birthing person

Physician and public health professional

Background in Anthropology

Worked in several low -income countries and in the United States, at both public and private institutions



# Definitions

**Maternal mortality** or **pregnancy-related death** is the death of someone during pregnancy or within one year of the end of pregnancy

**Infant mortality** is the death of an infant within one year of life

# Definitions

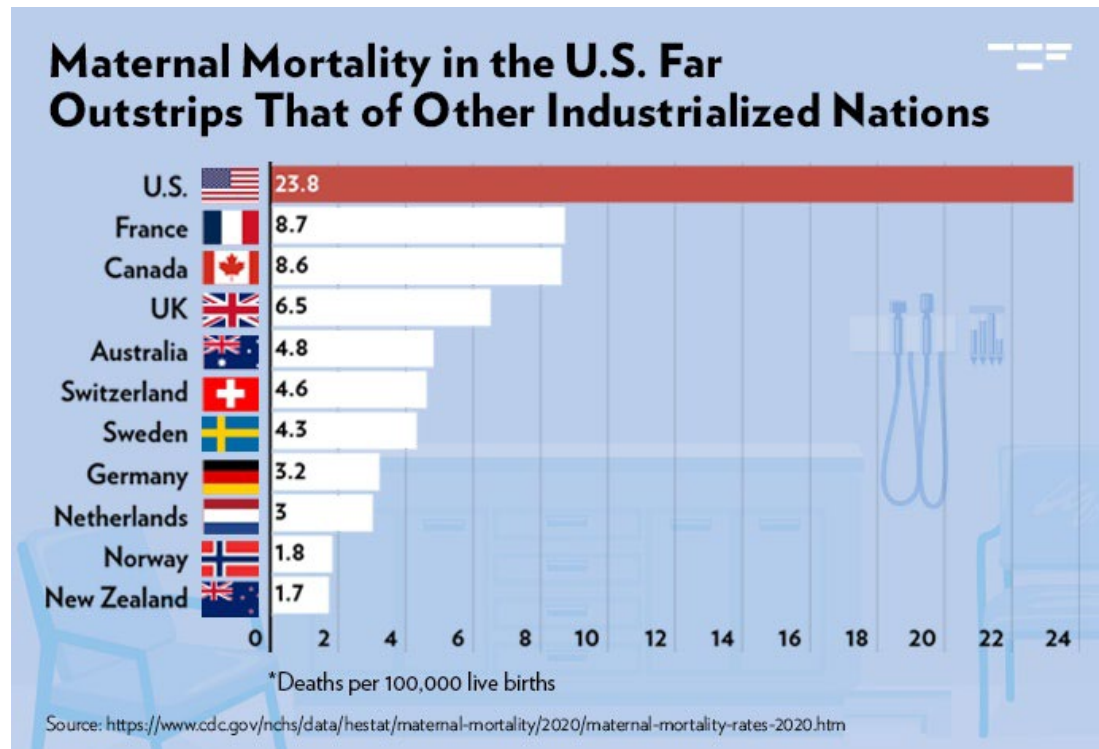
**Maternal morbidity** is any health condition that has a negative impact on a person's well-being or functioning

**Severe Maternal Morbidity (SMM)** is an unexpected outcome of labor and delivery that results in significant short- or long-term consequences to a person's health

1. Acute myocardial infarction*	12. Pulmonary edema / Acute heart failure
2. Aneurysm*	13. Severe anesthesia complications
3. Acute renal failure	14. Sepsis
4. Adult respiratory distress syndrome	15. Shock
5. Amniotic fluid embolism	16. Sickle cell disease with crisis
6. Cardiac arrest/ventricular fibrillation*	17. Air and thrombotic embolism
7. Conversion of cardiac rhythm	18. Blood products transfusion
8. Disseminated intravascular coagulation	19. Hysterectomy*
9. Eclampsia	20. Temporary tracheostomy*
10. Heart failure/arrest during surgery or procedure	21. Ventilation
11. Puerperal cerebrovascular disorders	

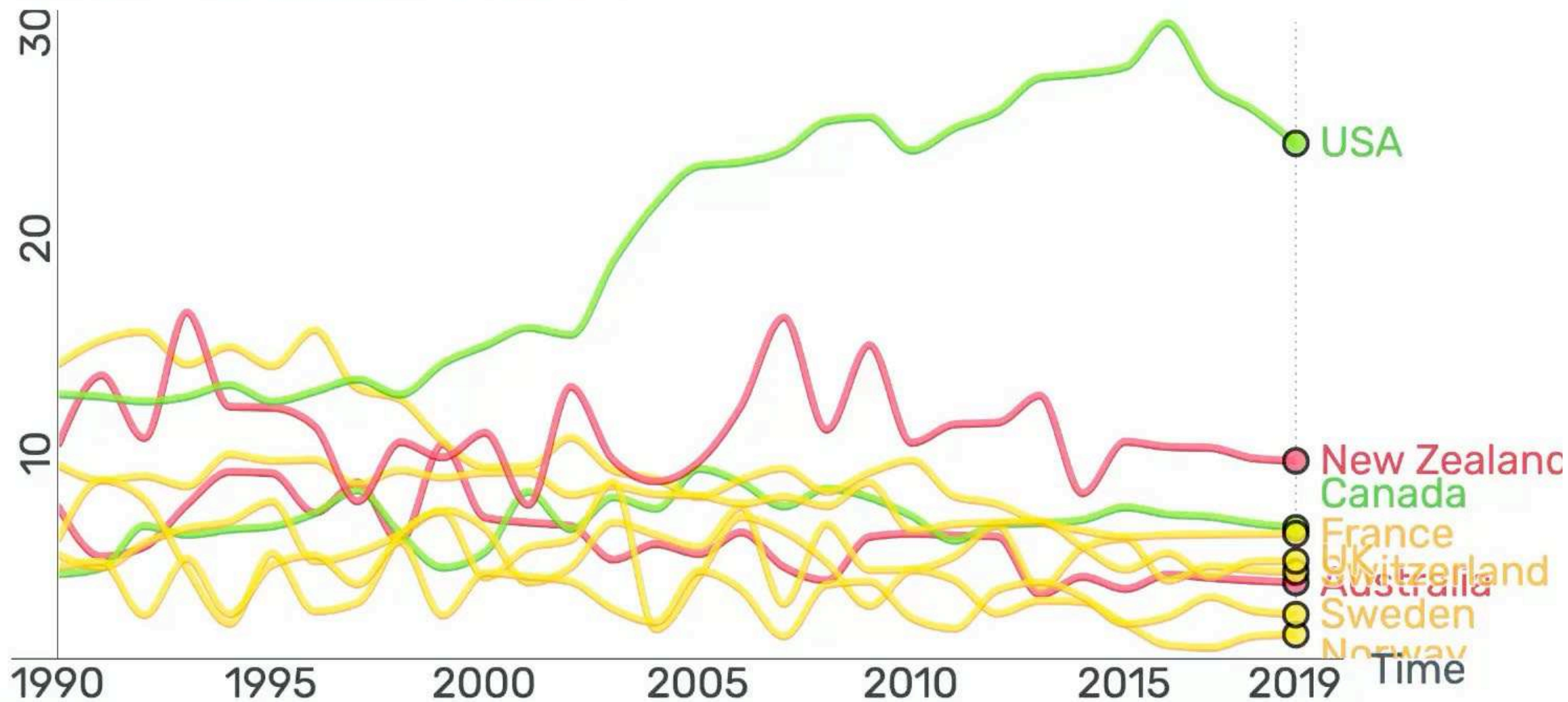
1. Trends in maternal and child health reflect unacceptable outcomes

# Maternal Mortality

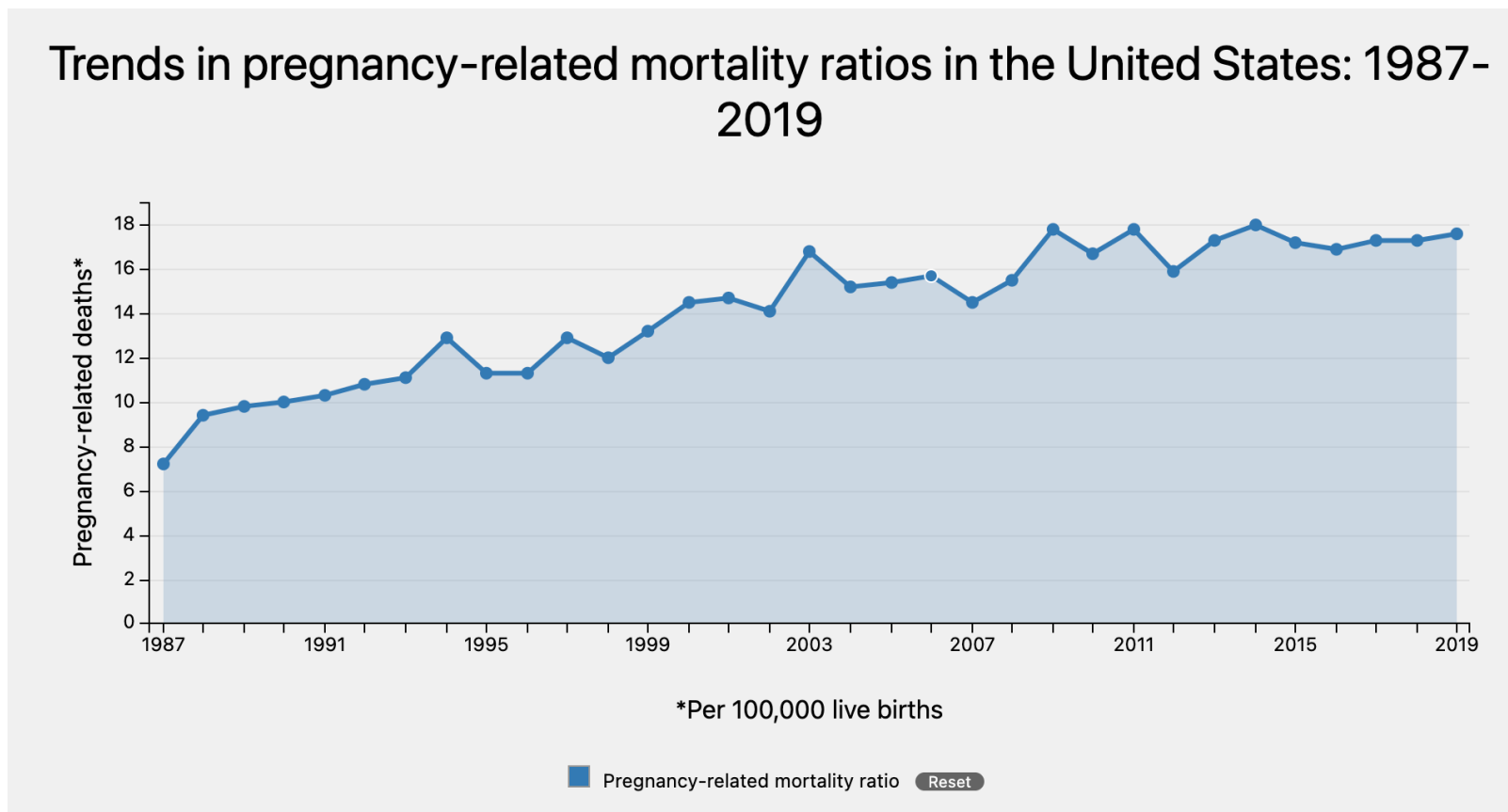


- The United States has **the highest maternal mortality** as compared to other high-income countries
- Our rate is over **three times** higher than our comparable counterparts

## Maternal Mortality Ratio (IHME) ?



# Maternal Mortality over time



Ref: CDC 2023



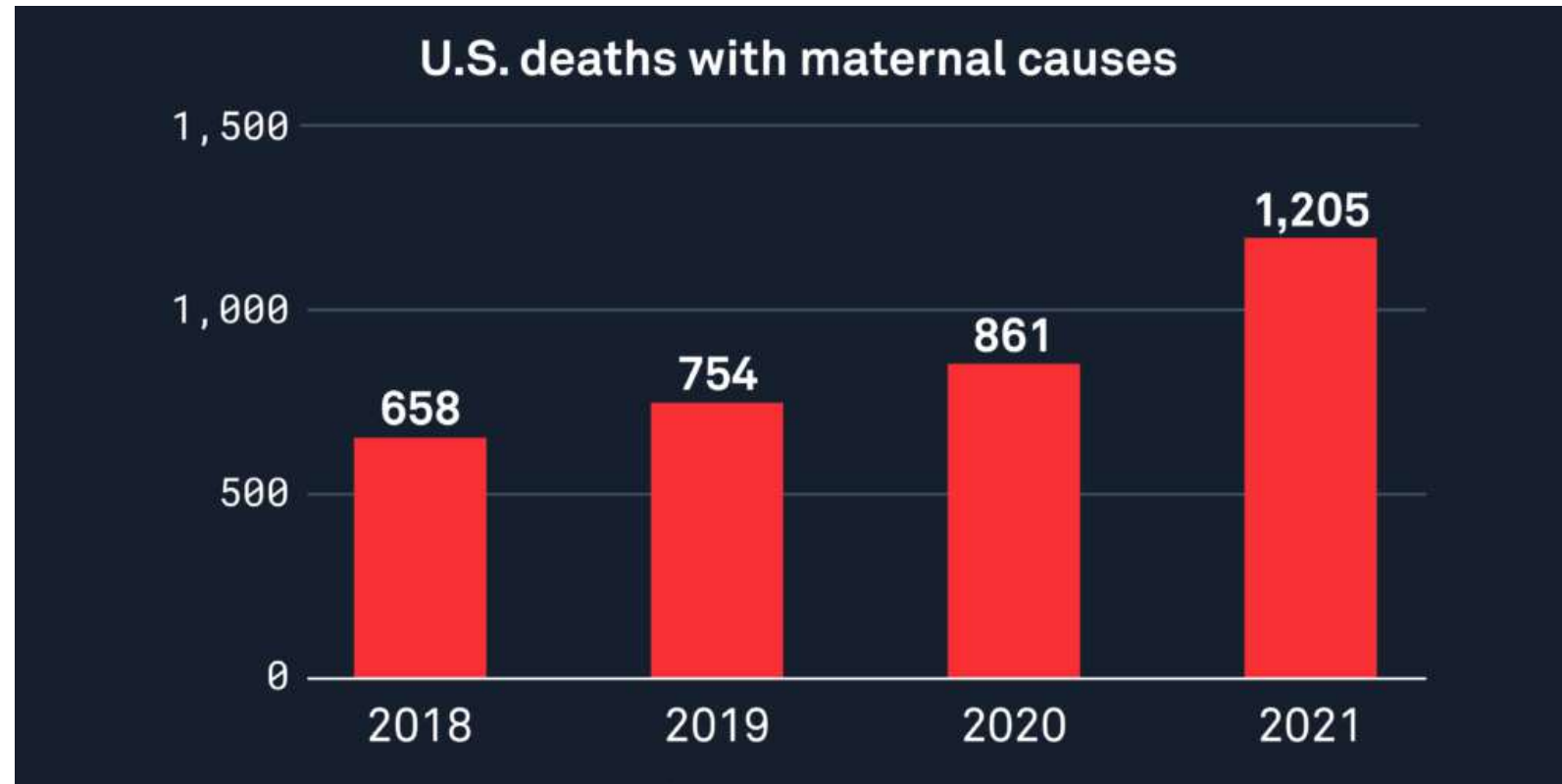
# Maternal Mortality over time

Pregnancy-related mortality rates  
(per 100,000 live births)

20

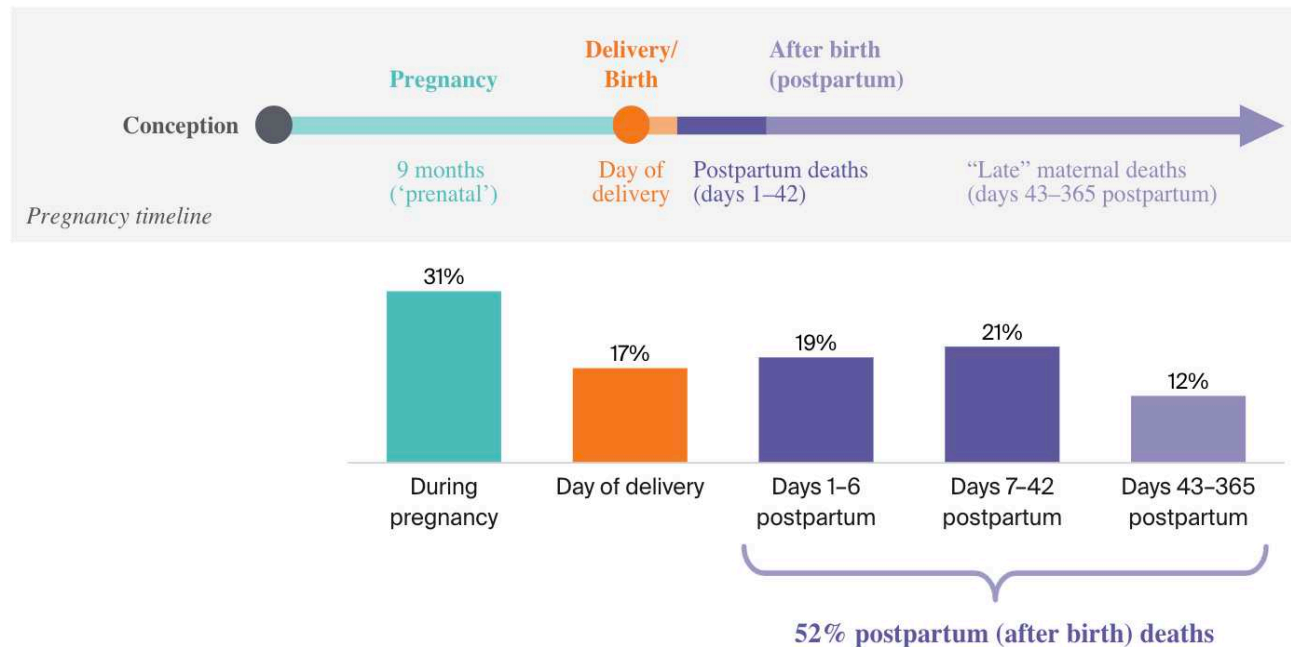
23

32



# The Timing of Maternal Mortality

## Timing of U.S. Maternal and Pregnancy-Related Deaths, 2011–2015



- Over **50%** of maternal deaths occur in the first year postpartum!
- It is estimated that **4 of 5** deaths are preventable

# Causes of Maternal Mortality

The leading causes of death in the United States are:

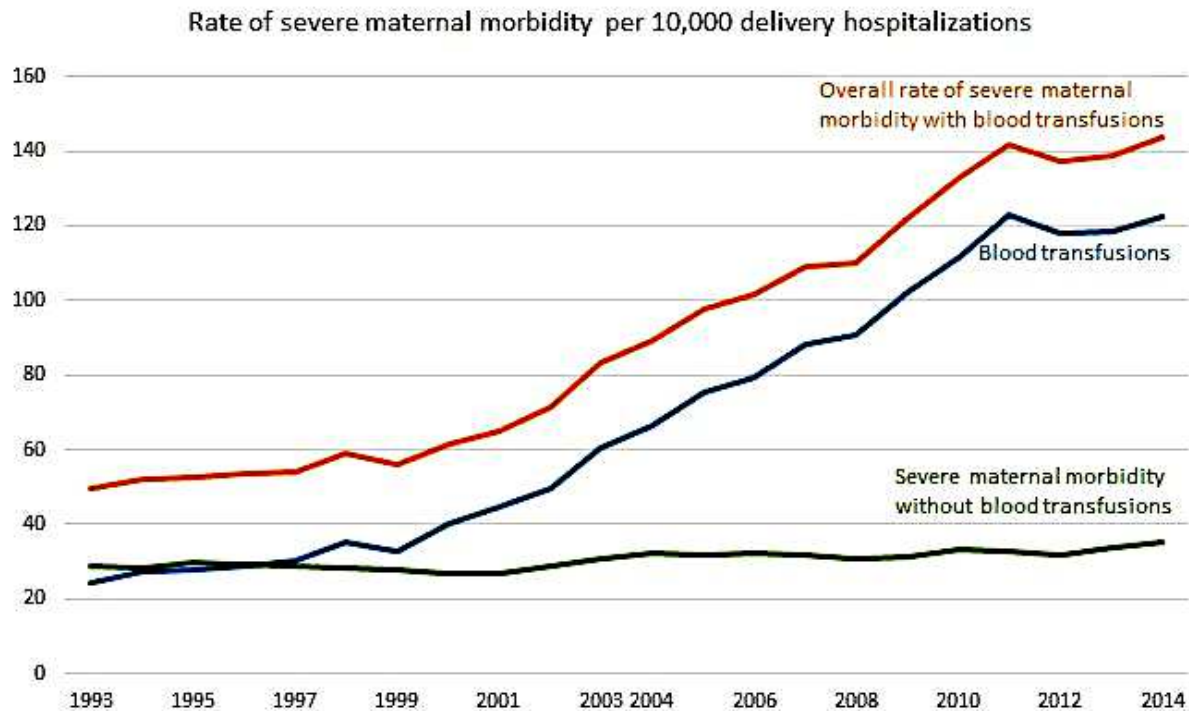
- Cardiovascular disease
- Infection
- Cardiomyopathy
- Hemorrhage
- Embolism (ie blood clot)
- Hypertensive disorders of pregnancy

# Causes of Maternal Mortality

The leading causes of death in the United States are:

- Cardiovascular disease
- Infection
- Cardiomyopathy
- Hemorrhage
- Embolism (ie blood clot)
- Hypertensive disorders of pregnancy

# Severe Maternal Morbidity



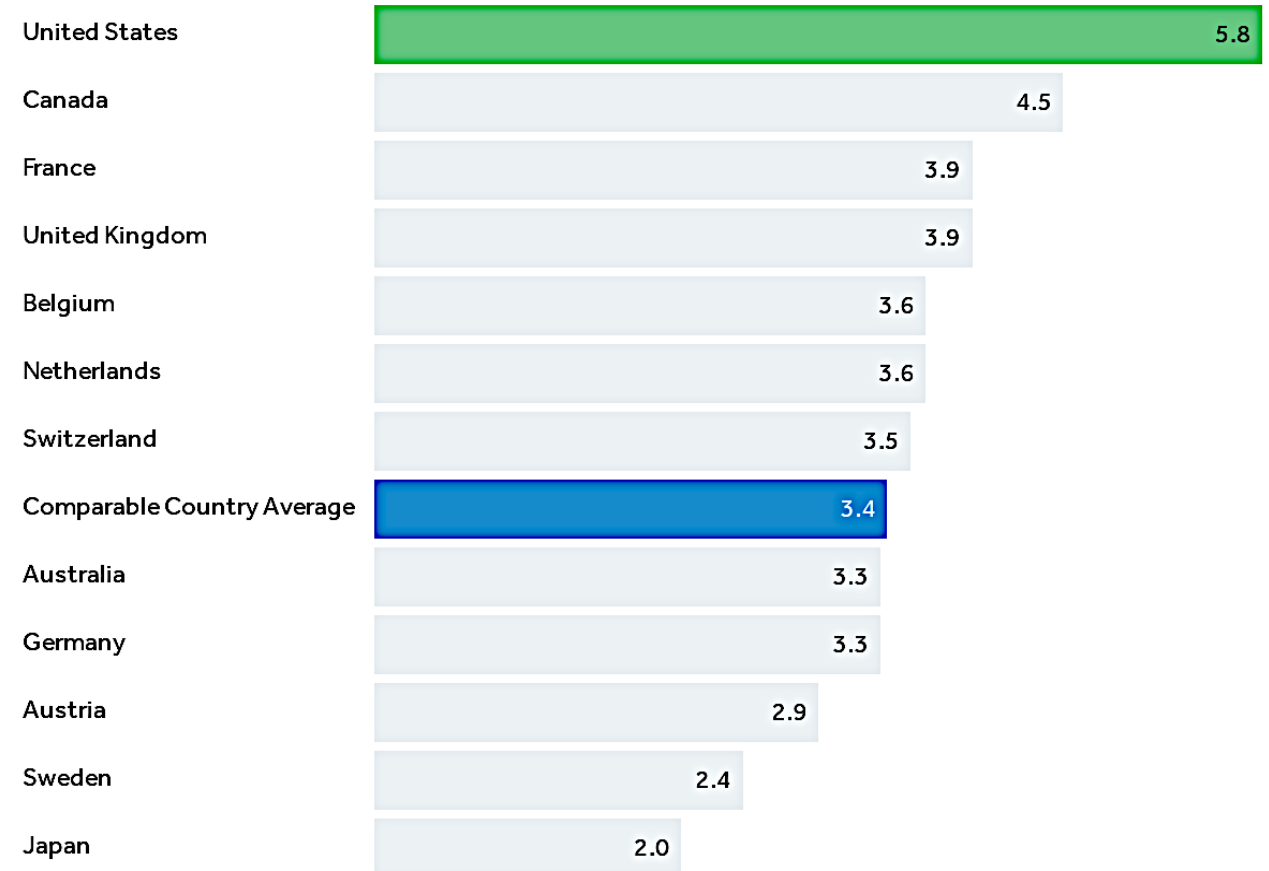
- Severe **maternal morbidity** or “near miss events” have been on the rise in the last two decades

# Neonatal and Infant Mortality

---

- Of high-income countries, the United States has the **highest infant mortality rate**

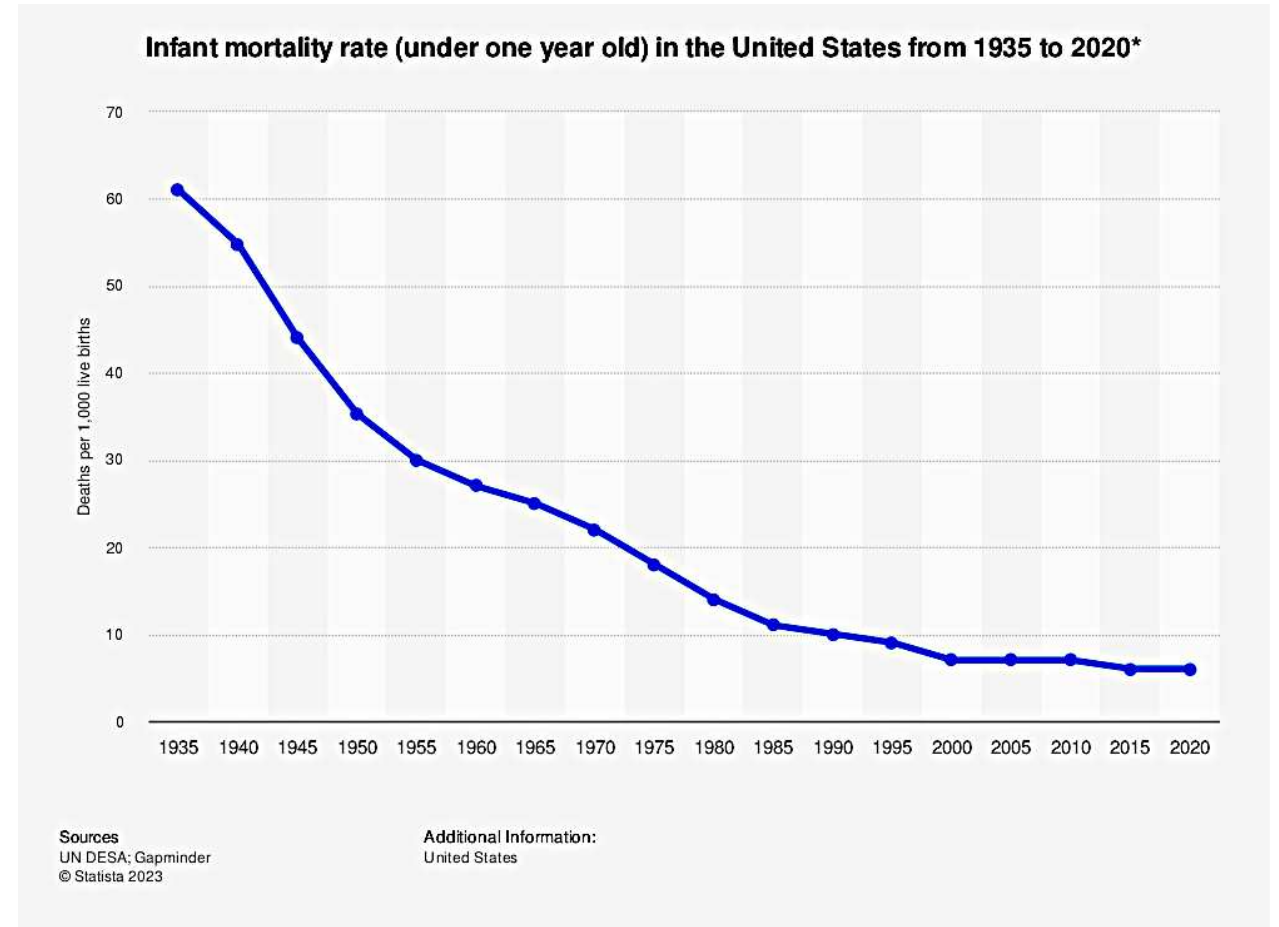
Infant mortality per 1,000 live births, 2017





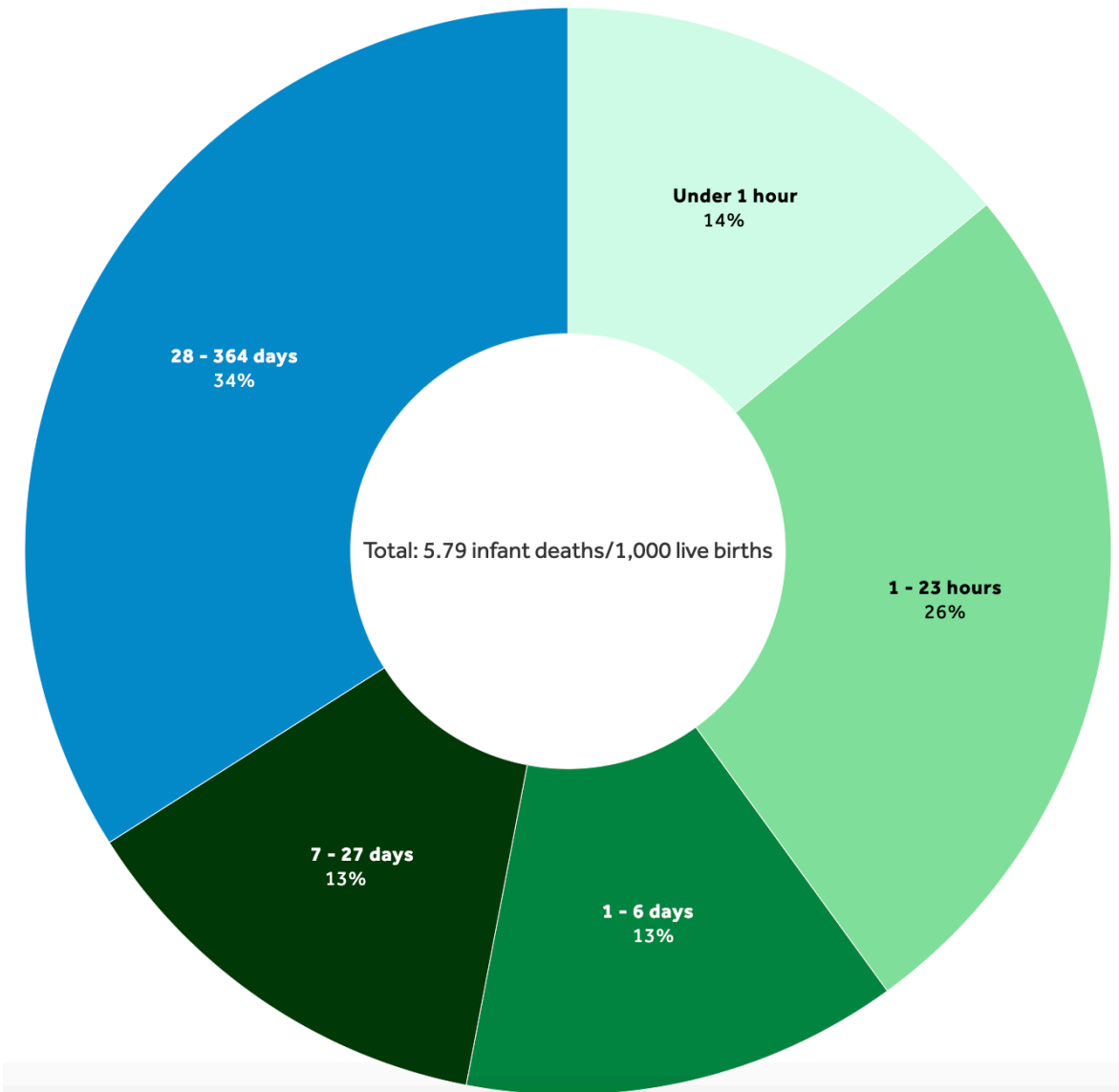
# Neonatal and Infant Mortality

- While infant mortality rates have decreased over the last 90 years, **there is more to be done**



# Neonatal and Infant Mortality

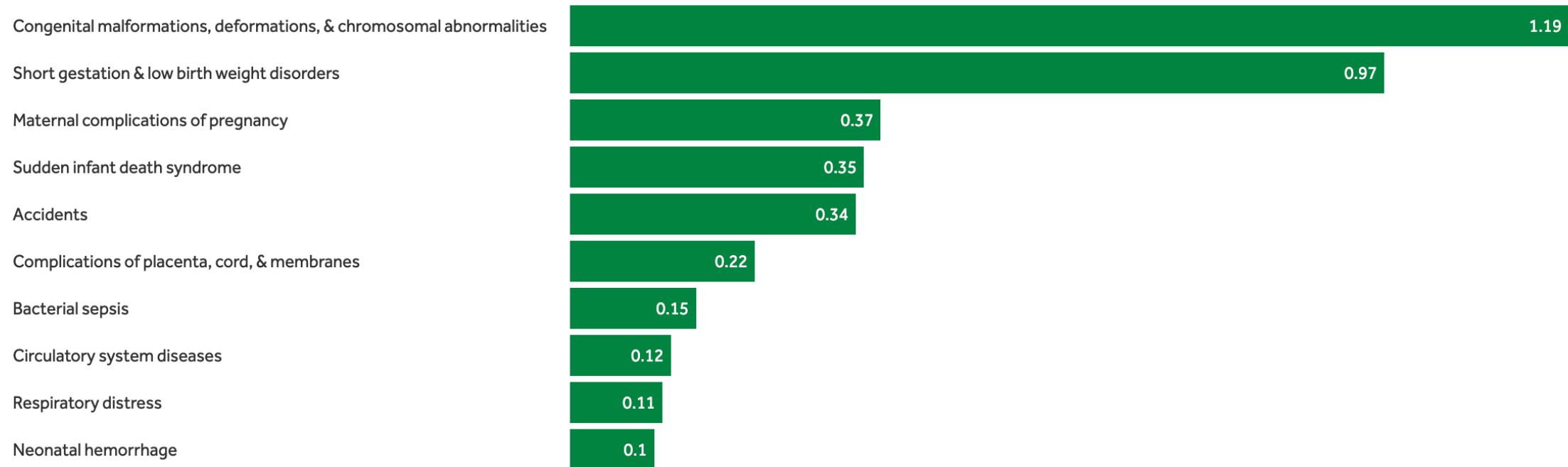
- Of 1000 live births, 5-6 infants will not live to see their 1<sup>st</sup> birthday
- The majority if these infants will die within the first month of life



2. Maternal and child health are  
inextricably linked

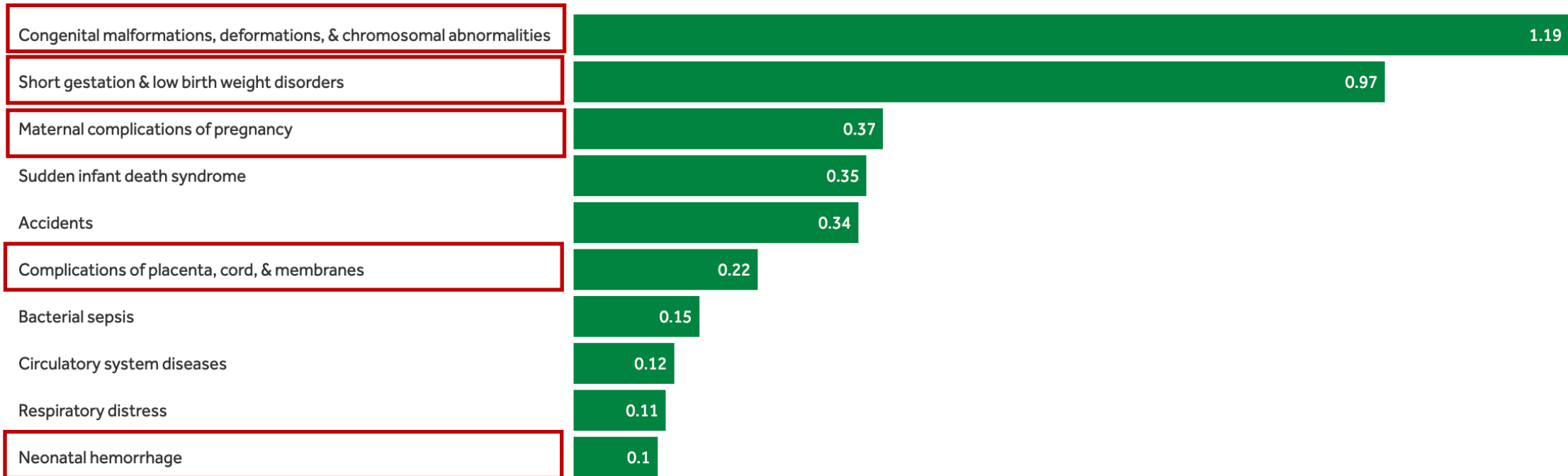
# Causes of Infant Mortality

Infant mortality rates (deaths per 1,000 live births) for the 10 leading causes of death among children 1 year of age or younger



# Causes of Infant Mortality

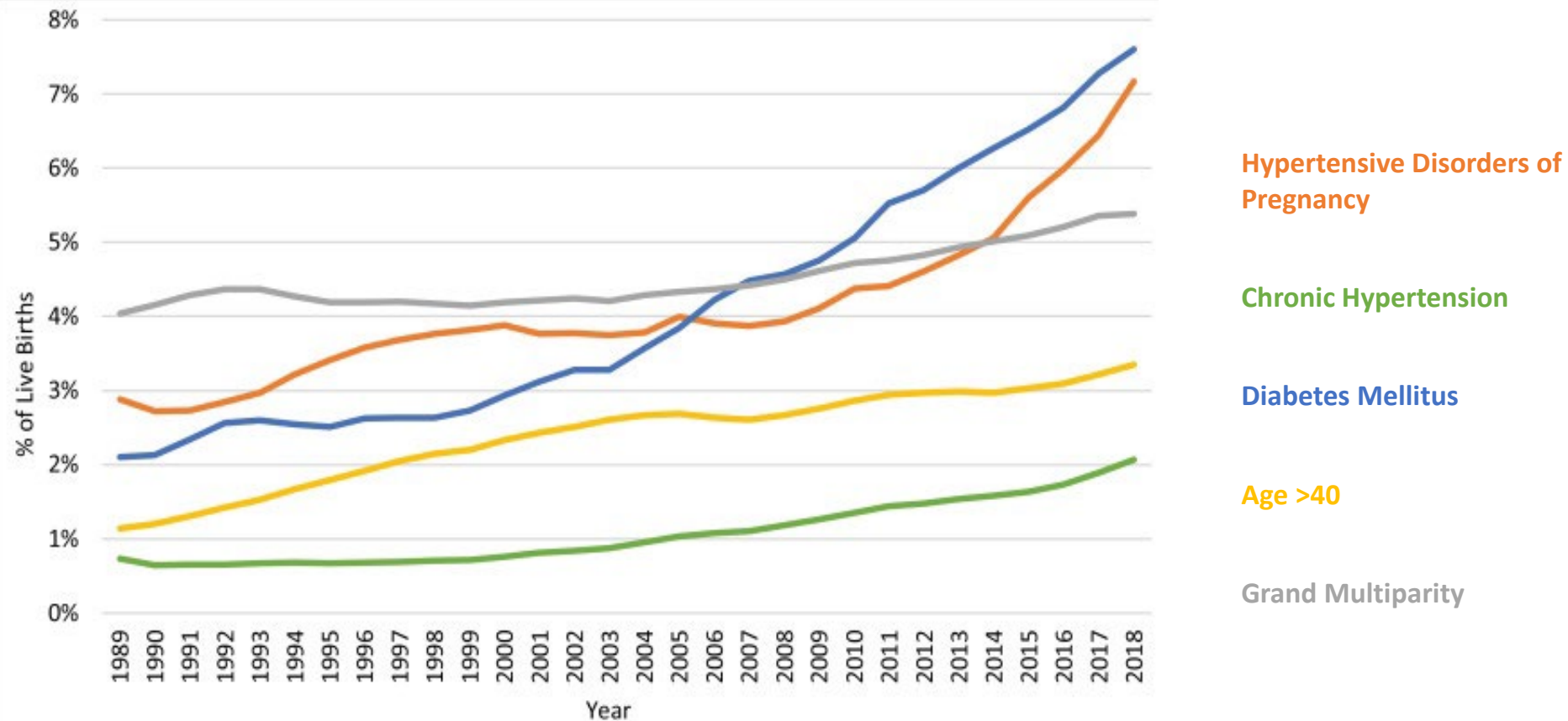
Infant mortality rates (deaths per 1,000 live births) for the 10 leading causes of death among children 1 year of age or younger



The health of a birthing person directly  
affects neonatal and infant health



# Maternal Morbidity





# Maternal mental health and infant health

- Babies of pregnant and birthing people with **mental health and mood disorders** might be at a higher risk of
    - **Preterm birth**
    - **Infant mortality**
    - **Sudden infant death syndrome**
-



# Intergenerational Change in Birthweight

## *Effects of Foreign-born Status and Race/Ethnicity*

*Theresa Andrasfay,<sup>a</sup> and Noreen Goldman<sup>a</sup>*

Foreign-born Black PP

US-born Black PP

Grandmother  
generation



7.8% LBW

11.8% LBW

Mother  
generation



12.1% LBW

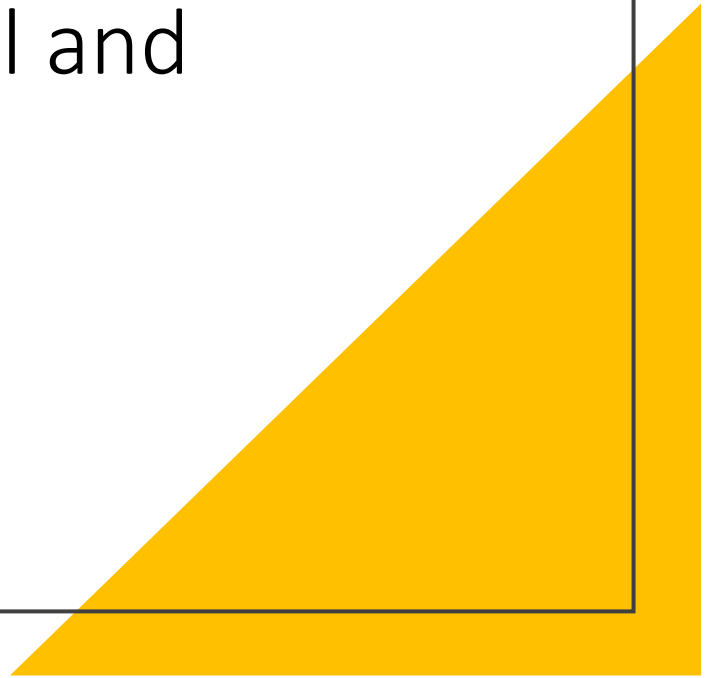
13.1% LBW

Grandchild  
generation



LBW=low birth weight

The **physical, mental, and social health** of a birthing person directly affects neonatal and infant health



3. Disparities in maternal and infant health are **inequities**



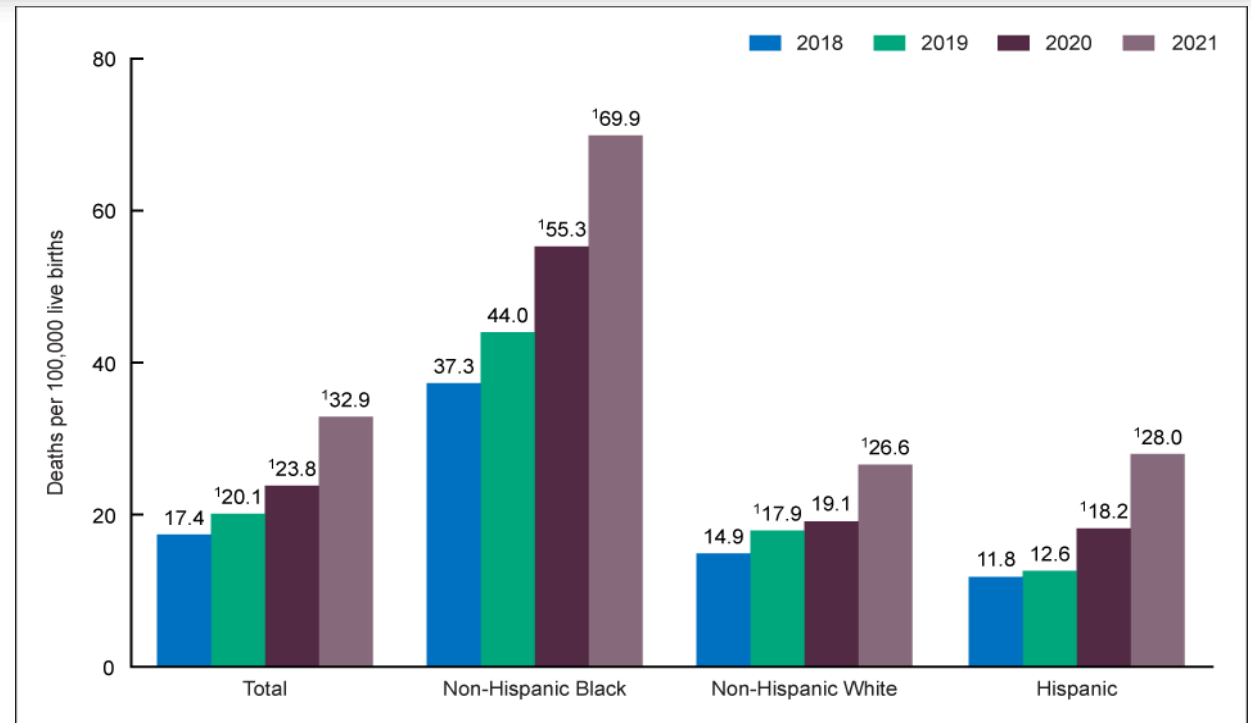
# Inequities in MCH

Inequities in maternal and child health tell a story of  
racism, colonization, structural violence, and historical and systemic  
marginalization

---

# Inequities in Maternal Mortality

- Black birthing people are **three** times more likely to die from pregnancy-related or associated causes than their white counterparts
- American Indian/Alaskan Native people are **two** times as likely to die then their white counterparts

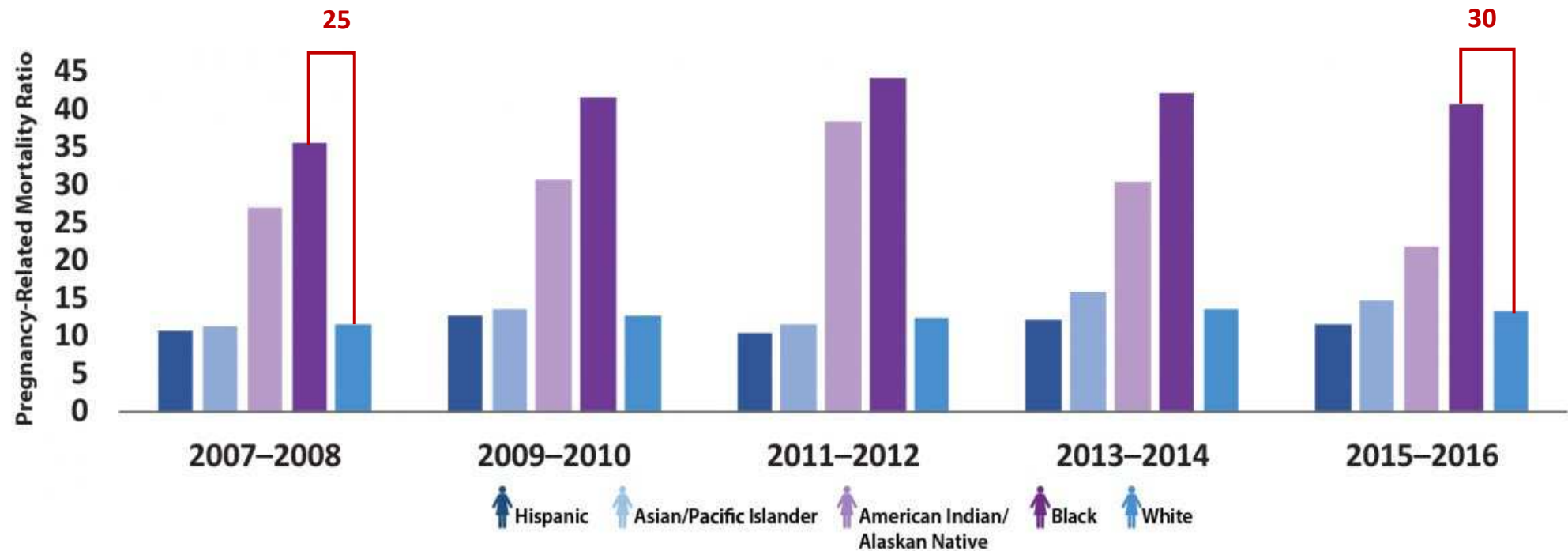


<sup>1</sup>Statistically significant increase from previous year ( $p < 0.05$ ).

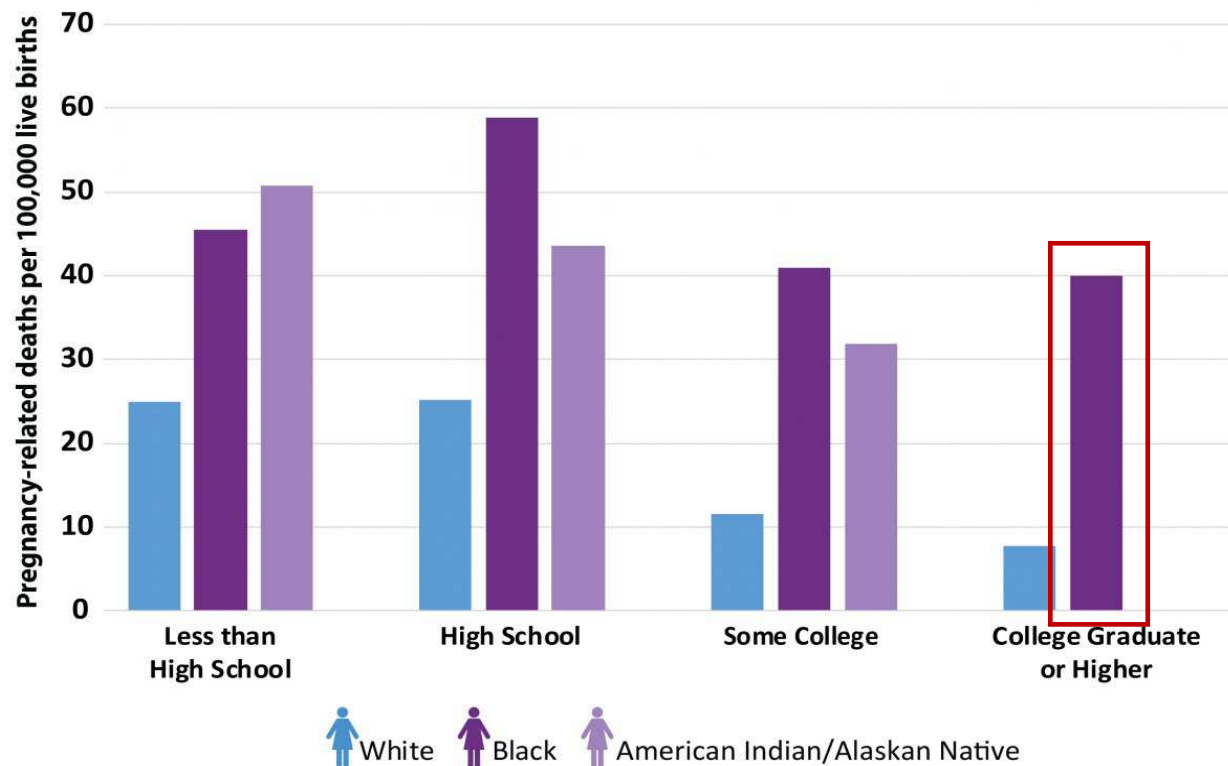
NOTE: Race groups are single race.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

# Inequities in Maternal Mortality

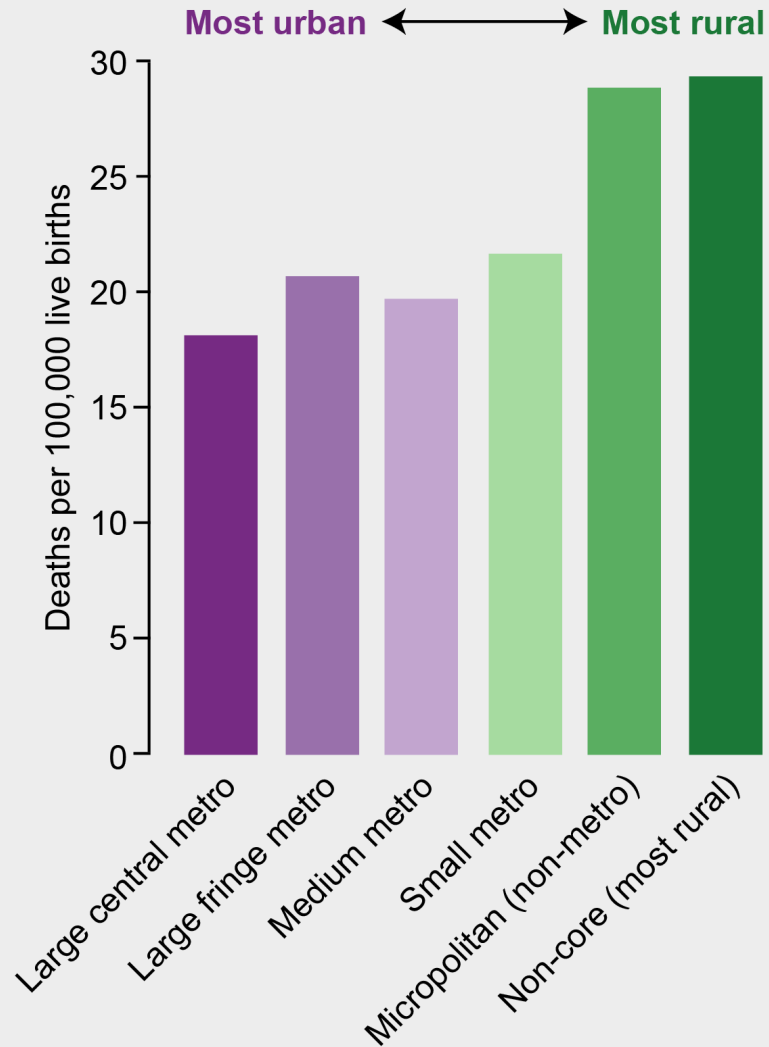


# Inequities in Maternal Mortality



- Black pregnant people with a college degree or more have a higher pregnancy-related mortality rate than their white counterparts at any level of education
- The disparity among mortality rates seems to increase with increasing educational attainment

## Maternal Mortality Rates



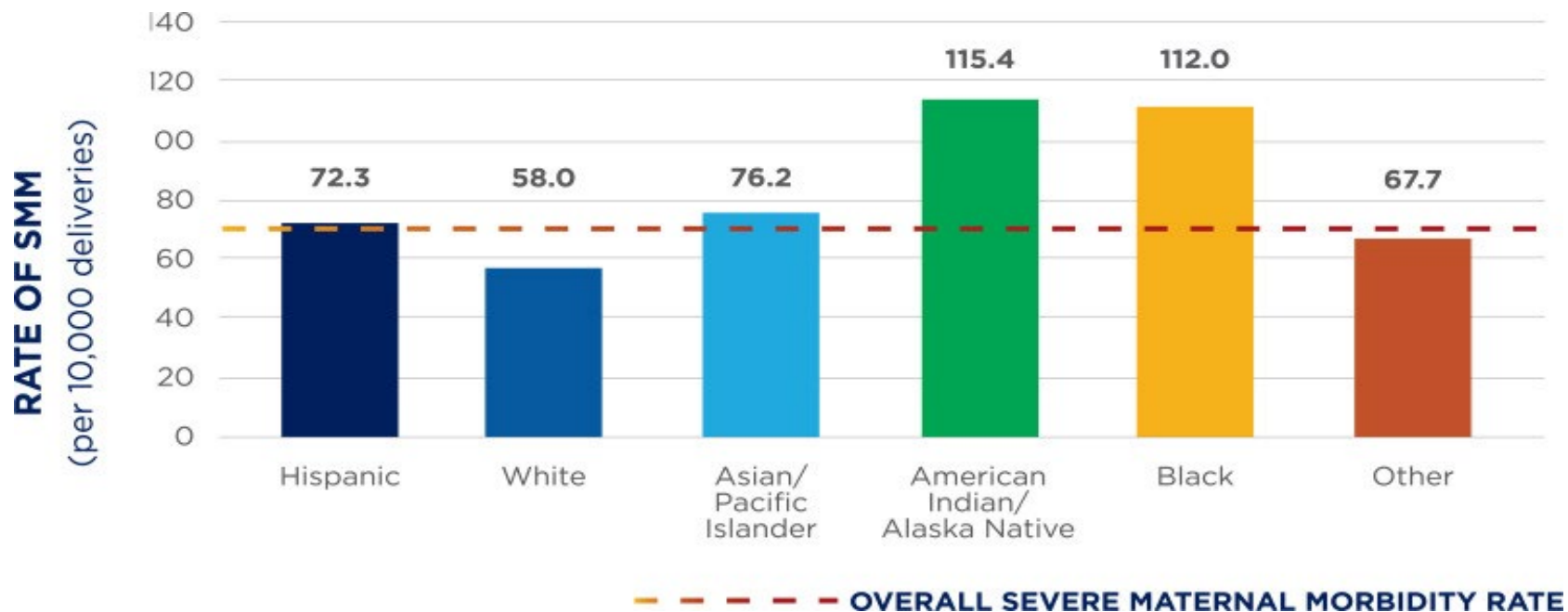
# Inequities in Maternal Mortality

- Rural pregnant people are more likely to experience maternal mortality as compared to those in urban and semi-urban areas
- There are an increasing number of maternity care deserts in the country



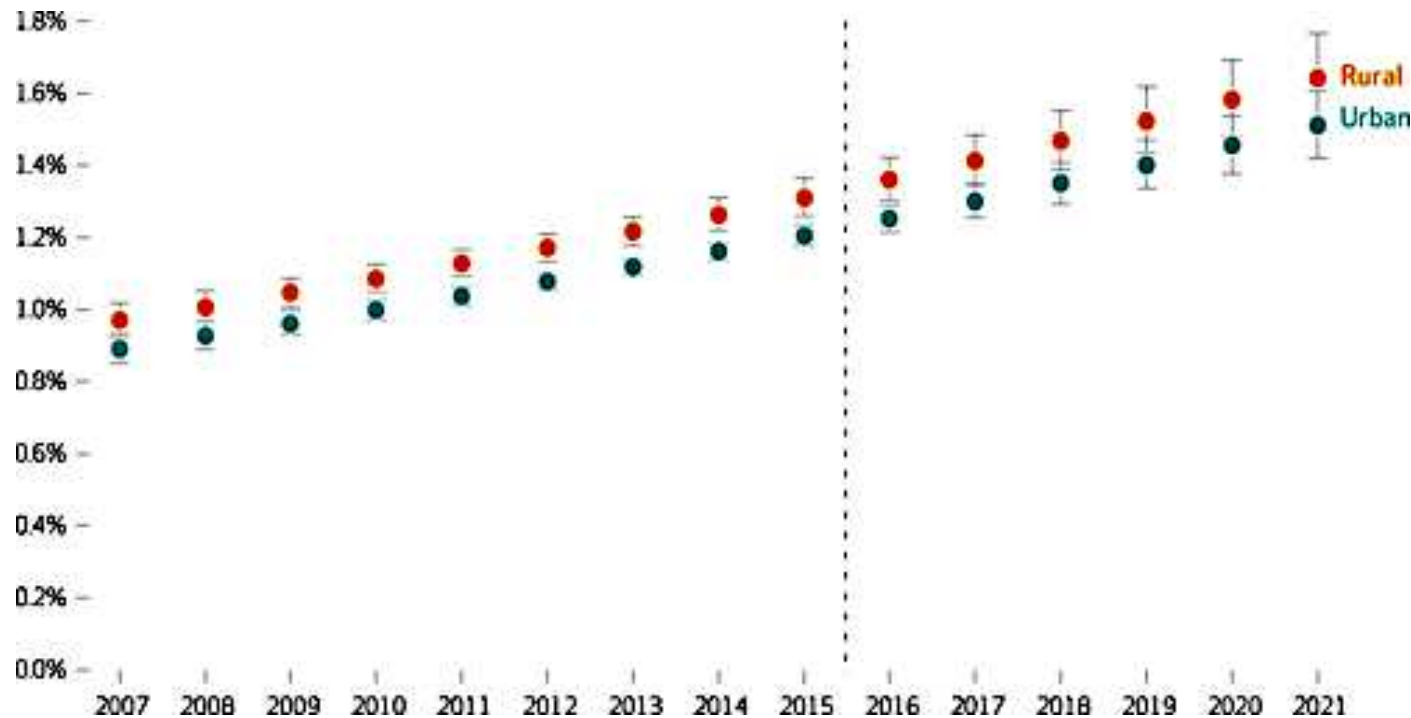
# Inequities in Severe Maternal Morbidity

Non-white birthing people are more likely to experience severe morbidity than their white counterparts



# Disparities in Severe Maternal Morbidity

Probability of SMM and MM Rates Among Rural and Urban birthing people



Ref: Kozhimannil et al 2019

# Pregnancy is a window into our future

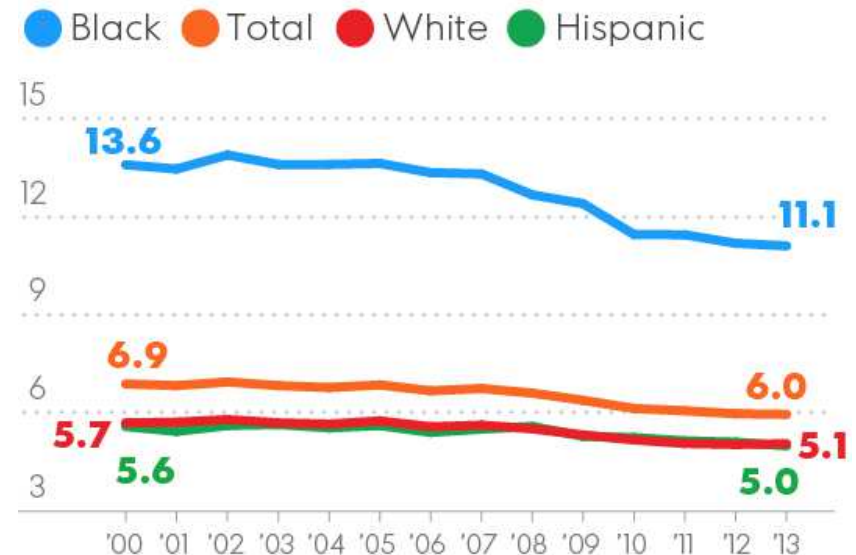
- Particular conditions in pregnancy can both **worsen** existing disease and **predict** our risk of disease in the future
- Disparities in outcomes exist across the entire spectrum of a life course  
→ **what we do in pregnancy matters in ameliorating or exacerbating those outcomes**

# Inequities in Infant Mortality

- Black babies have up to **2.5 times** the risk of dying in infancy
- **Preterm birth** and **low birth weight** are experienced more by black and AI/AN pregnant people

## COMPARING INFANT MORTALITY

U.S. infant mortality rates, by race and Hispanic origin of mother:  
(Rate per 1,000 live births)

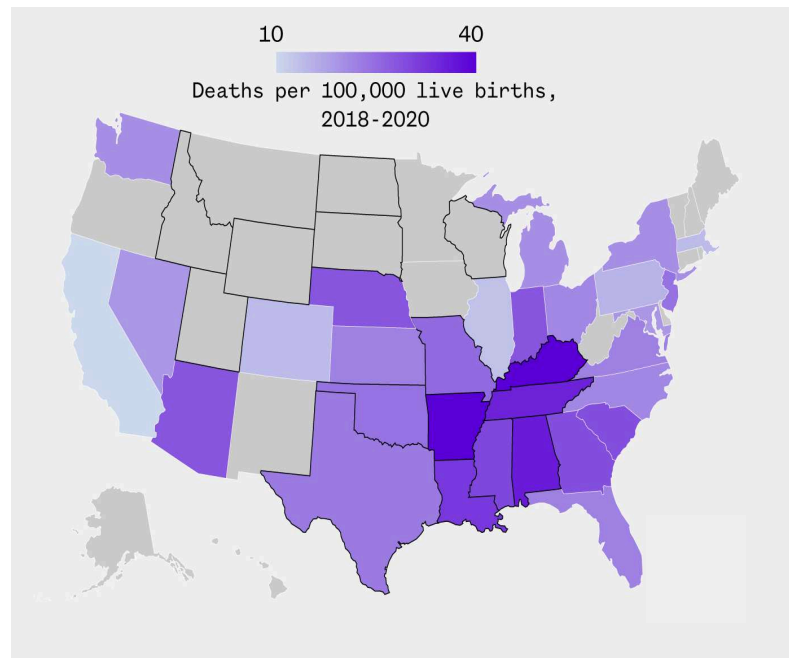




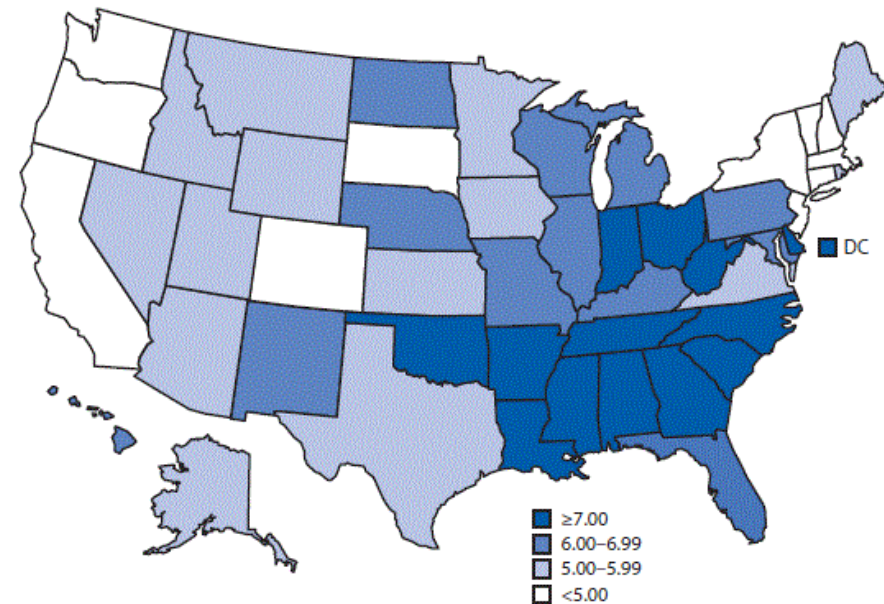
4. The current state of health policy (and politics) will have implications for maternal and child health

# Outcomes are drawn by state lines...

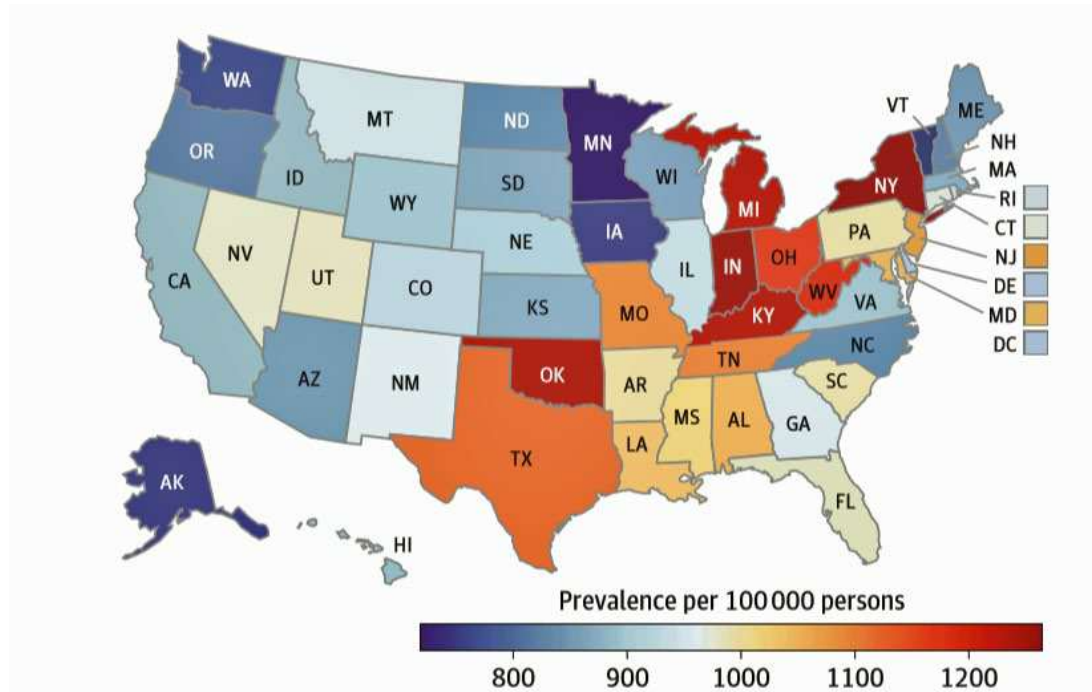
Maternal Mortality Rate



Infant Mortality Rate



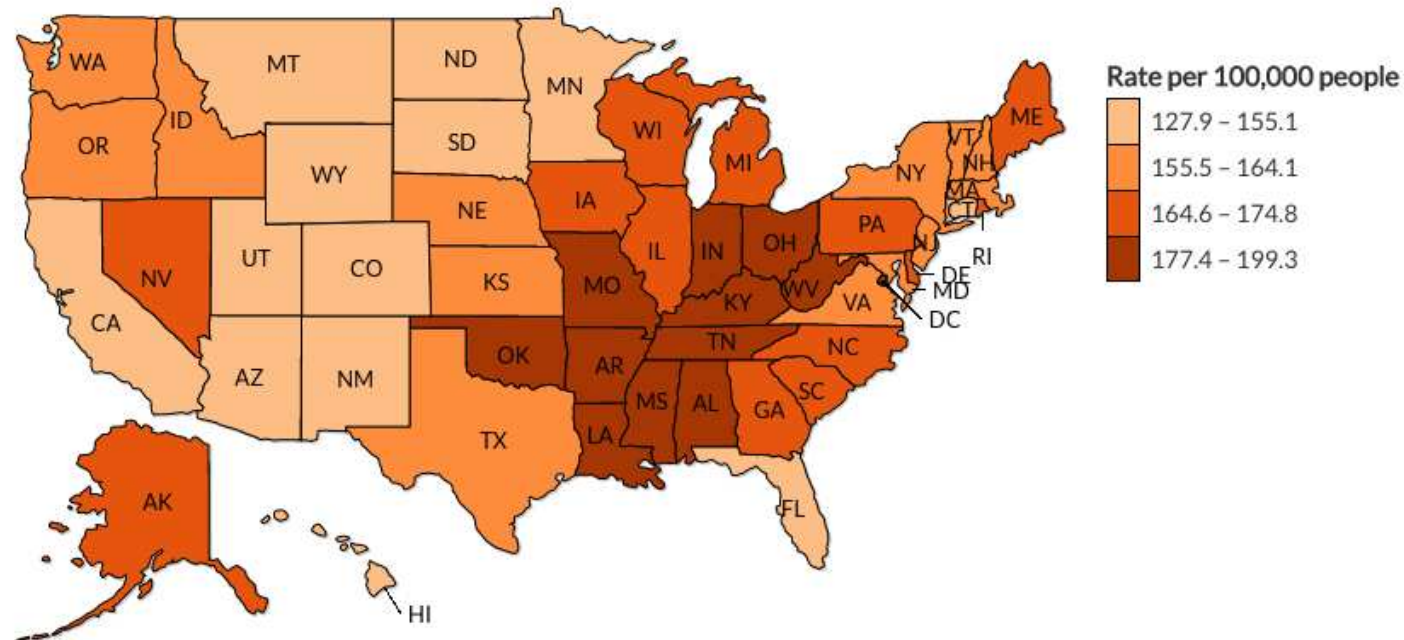
## Heart Failure Prevalence



# Outcomes are drawn by state lines...

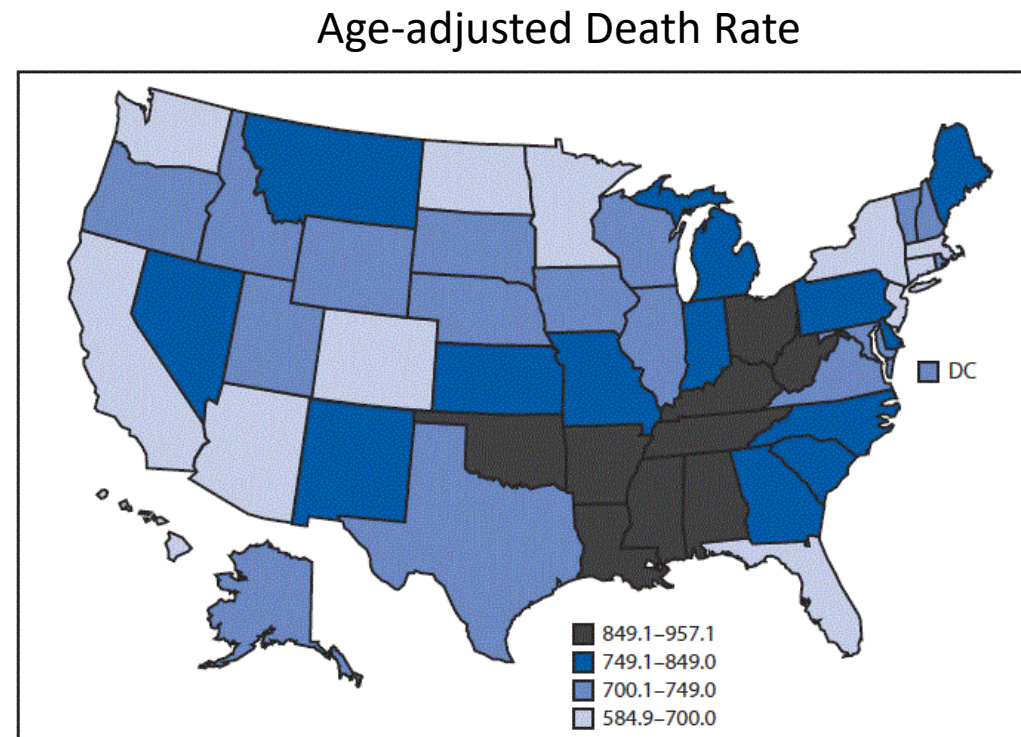
## Rates of Cancer Deaths in the United States

All Types of Cancer, All Ages, All Races/Ethnicities, Both Sexes



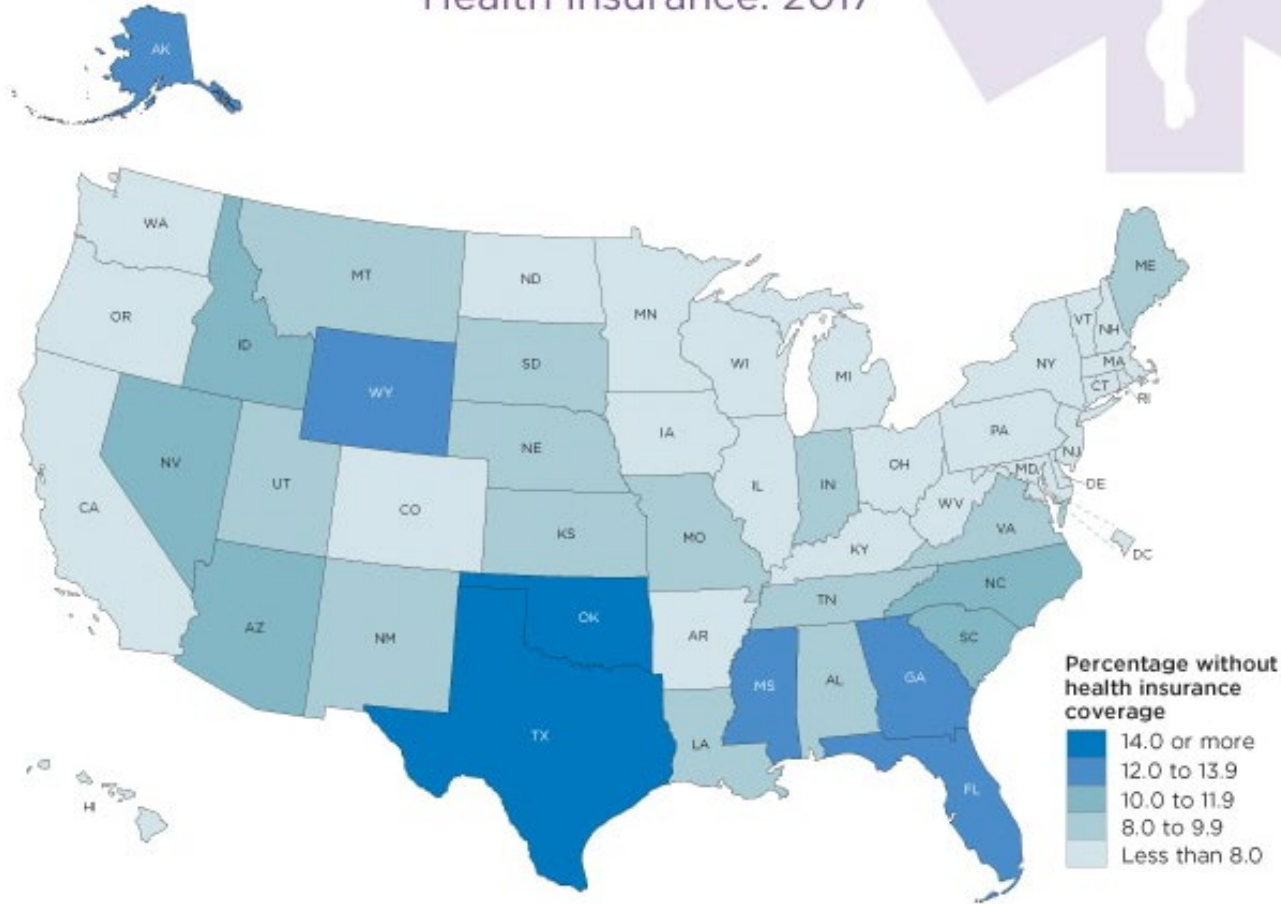


# Outcomes are drawn by state lines...



# Uninsured Rate by State

Percentage of People Without  
Health Insurance: 2017



Outcomes  
are drawn  
by state  
lines...

Thirty-four states are extending pregnancy Medicaid coverage from 60 days to 12 months postpartum. Of the 11 states that have not expanded Medicaid, Mississippi and Wyoming are the only two that have not acted to extend postpartum coverage. Texas has proposed a six-month extension and Wisconsin a 90-day extension.

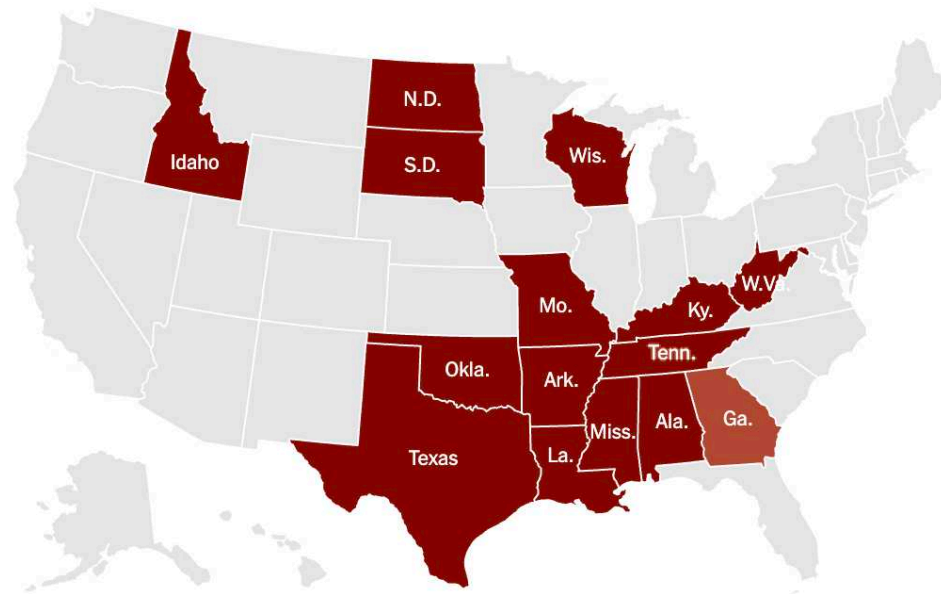
Map: Isabelle Taft • Source: KFF • Created with Datawrapper

# Abortion policy is maternal health policy

## Tracking the States Where Abortion Is Now Banned

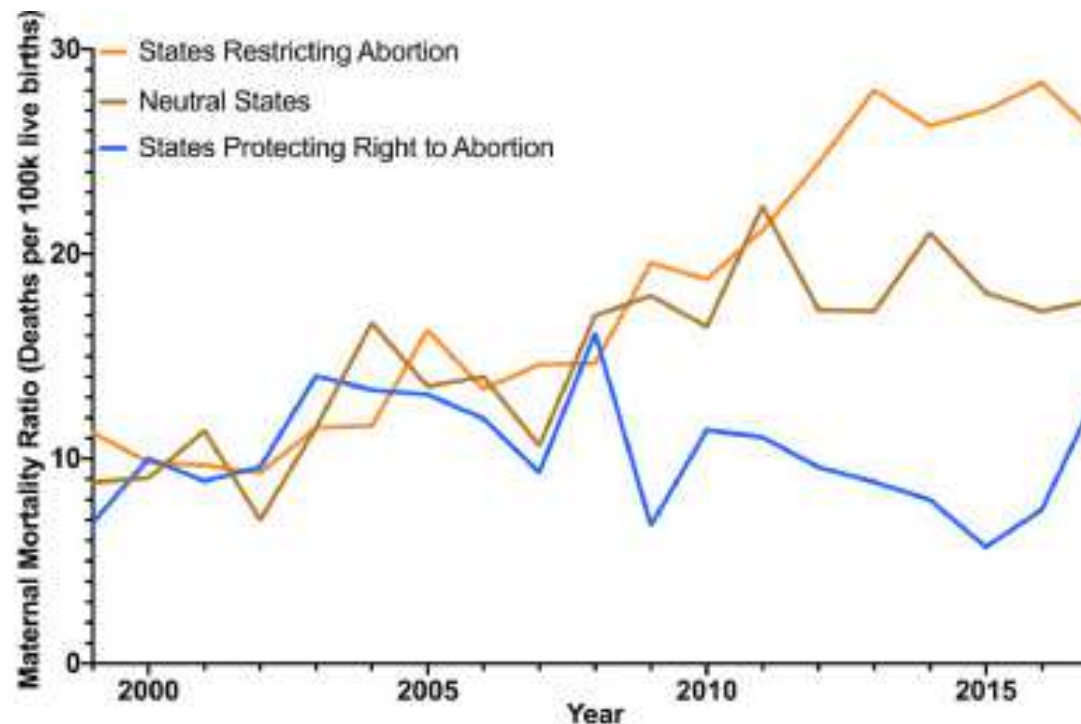
By The New York Times Updated May 18, 3:00 P.M. ET

■ Full ban in effect ■ Six-week ban in effect



# Abortion policy is maternal health policy

States with **restrictive** abortion policies have **higher maternal mortality rates**





POLITICS

# Abortion laws triggered dozens of health complications, new report says

The research is an effort to capture an expansive picture of how health care has been affected by abortion bans



Abortion policy is maternal and child health policy

A final thought ...

Questions? Thoughts?



# DHS Prenatal

Kristal Dail

*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*







# Division of Healthy Start & Perinatal Services

## *Consumer Convening*

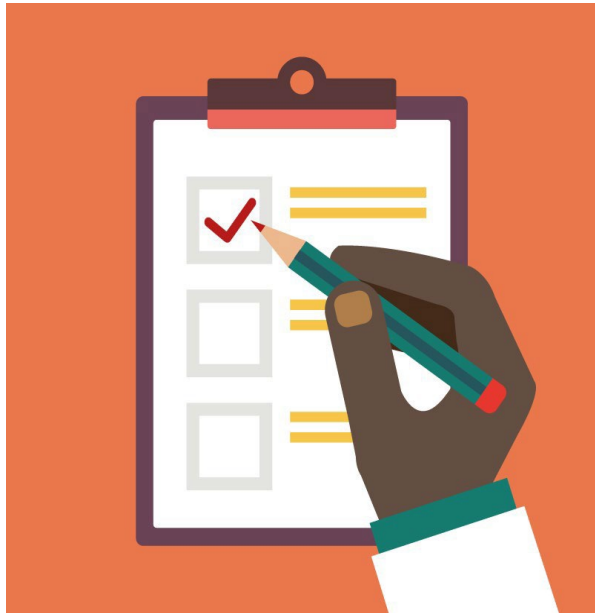
**Kristal Dail, MPH**  
**Public Health Analyst**  
**Division of Healthy Start and Perinatal Services**  
**Maternal and Child Health Bureau (MCHB)**

**Vision: Healthy Communities, Healthy People**





# Agenda



- Healthy Start Overview
- Healthy Start Program Model
- Program Services
- Doula Success Stories

# Healthy Start Overview

## WHAT

Healthy Start is a federally funded, **community driven program** dedicated to reducing disparities in maternal and infant health.

## REACH

As of 2021, HRSA awarded over **\$100 million to 101 Healthy Start Award Recipients** in 35 states, the District of Columbia, and Puerto Rico.

## PURPOSE

**Improve health outcomes** before, during and after pregnancy, and **reduce racial/ethnic differences** and rates of infant death and adverse perinatal outcomes.

## WHERE

Healthy Start works in communities with **infant mortality rates at least 1.5 times the national average**, and high rates of low birth weight, preterm birth, and maternal mortality.



# Healthy Start Program Model

# Current Healthy Start Core Elements

01

## IMPROVE WOMEN'S HEALTH

Access to health insurance & health care, preventative services & health promotion

02

## IMPROVE FAMILY HEALTH & WELLNESS

Comprehensive screenings, parent education, case mgmt, behavioral health support, father/partner involvement

03

## PROMOTE SYSTEMS CHANGE

Community action network; collaboration with local, state, regional, and national government

04

## ASSURE IMPACT & EFFECTIVENESS

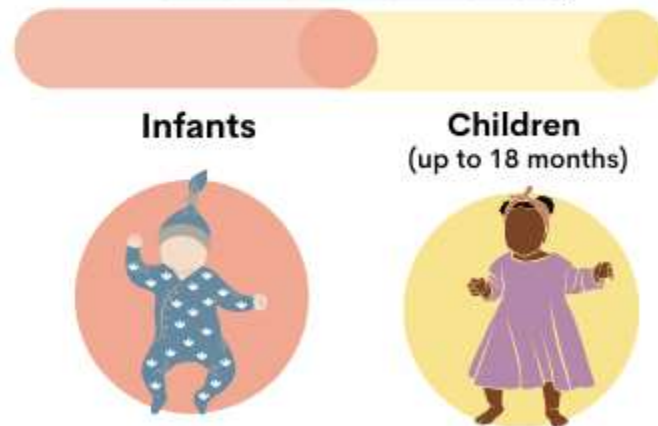
Data collection & evaluation, performance measures, and quality improvement measures

# Who We Serve

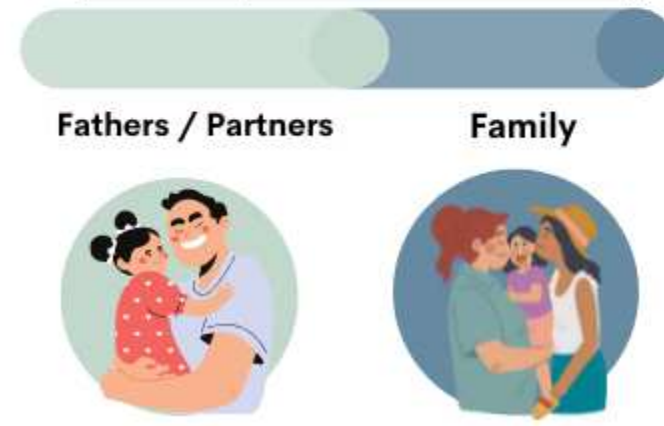
## Birth People



## Infants & Children



## Fathers, Partners & Family





# Healthy Start Program Services

- Home visiting (in-person & virtual)
- Health insurance enrollment assistance
- Care coordination
- Health education
- Parenting education
- Family planning
- Father/Partner engagement
- Doula support\*
- Breastfeeding support
- Nutrition counseling\*
- Childbirth education
- Transportation service\*

\*select program sites only





# National Maternal Mental Health Hotline



**Are you a new parent - or about to be - and feeling sad, worried, overwhelmed, or concerned that you aren't good enough?**

**For emotional support and resources  
CALL OR TEXT 1-833-TLC-MAMA (1-833-852-6262)**

**Free – Confidential – 24/7  
60+ Languages**



# Healthy Start Community-Based Doula Supplements



- **Purpose:** To increase the availability of doula services in Healthy Start service areas
- **Funding:** \$3.125 Million
- 44 Healthy Start grantees

# Black Maternal Health Week 2023

**HRSA is proud to highlight the contributions of HRSA award recipients who create better health outcomes for Black women before, during, and after pregnancy.**  
**#BMHW2023 #HRSAhelpsmoms #TheDoulaDifference**



# *Doulas make the difference*

Breanna & Ms. Linda  
share their story.



**AHA**  
American Hospital Association



# Contact Information

---

## **Kristal Dail**

Public Health Analyst, Division of Healthy Start and Perinatal Services

Maternal and Child Health Bureau (MCHB)

Health Resources and Services Administration (HRSA)

Email: [kdail@hrsa.gov](mailto:kdail@hrsa.gov)

Web: [mchb.hrsa.gov](http://mchb.hrsa.gov)



# Connect with HRSA

Learn more about our agency at:

[www.HRSA.gov](http://www.HRSA.gov)



[Sign up for the HRSA eNews](#)

FOLLOW US:





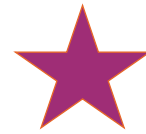


Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ

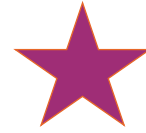
**NICHQ**  
National Institute for  
Children's Health Quality

HEALTHY  
**start**  
TA & SUPPORT CENTER

# Skill-Building Topics



**Birth & Racial Equity Advocate**  
*with Brenda Reyes*



**Putting Your Mask on First**  
*with Dr. Linda Henderson-Smith*



**Powerful Stories, More Powerful  
Storytelling** *with Dr. Magda Peck*



**My Story, My Way**  
*with Stephanye Clarke*

# Here's the plan...

➤ **4 Topics to select from**

➤ **3 Chances to attend**

Session #1 - Thursday @ 11 am

Session #2 - Thursday @ 3:30 pm

Session #3 - Friday @ 10:30 am

➤ **20 Participants per room**

➤ **No Bad Choices**





# Quick Break

*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*







# Naming, Recognizing, and Reporting Obstetric Racism During Childbirth Hospitalization: Consumer Advice for Black Birthing Communities

**Dr. Karen Scott**

Birthing Cultural Rigor

*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*

**HRSA**  
Maternal & Child Health

**NICHQ**  
National Institute for  
Children's Health Quality

**HEALTHY  
start**  
TA & SUPPORT CENTER



*Building Consumer Acts of Resistance:  
Dismantling Harm  
“Anti-Black Gendered Racism in Childbirth Hospitalization”  
& Reclaiming Our Power and Healing*

**Karen A. Scott, MD, MPH, FACOG**  
**Chief Black Feminist Physician Scientist**  
**Founding CEO & Owner**

BCR Gen Info: [info@birthingculturalrigor.org](mailto:info@birthingculturalrigor.org)  
Website: <https://www.birthingculturalrigor.com/>  
Twitter: @RJEpiOBWaarrior @CulturalRigor



# POSITIONALITY – KAREN A. SCOTT, MD, MPH, FACOG



- Southern Black woman from East Nashville before gentrification.
- Daughter of Edith W. Floyd (TN) & the late John Henry Scott, Sr (SC)
- Gratitude: the gift of a formal liberal arts education from 5th grade until completion of medical school.
- Lifelong learner: *This is the way.*
- **Proud Black Feminist, Reproductive Justice Avenger, Wakanda Healer, Yoda Follower, Kare Bear Hugger, Public Health OBGYN, Applied Epidemiologist, And Health Systems Disruptor/Transformer & Architect**
- 21st year anniversary as a community-based trained and serving OBGYN.
- My purpose: To advance **Cultural Rigor through the operationalization of Black Feminism, Reproductive Justice, and Research Justice** in participatory quality improvement and implementation science, practice, and research, and interprofessional education & training





**Childbirth Hospitalization: Outcomes As  
Performance Measures of Quality & Safety**  
*A Black mother and child*

Full Term Pregnancy

Absence of Medical Conditions/Co-morbidities

Optimal Prenatal Care Utilization

Vaginal Birth with a small laceration with repair

Normal weight infant

Healthy infant, no need for NICU care/admission

Infant latched well to breast/chest/body

“High performing, high quality, and safe” birthing hospital

**Is this a SAFE or UNSAFE Black Birth?**

**“Though he put me back together, I still don’t feel WHOLE.”**



Childbirth Hospitalization: Outcomes As  
Performance Measures of Quality & Safety  
*A Black mother and child*

“Though he put me  
back together, I still  
don’t feel WHOLE.”

Is this a SAFE or UNSAFE Black Birth?

Tradition (System Intention)	Reality (Community impact)	Recommendation (Innovation & Disruption)
Outcome measures evaluate hospital performance	Outcome measures evaluate the performance of Black bodies in birth	Experience measures evaluate hospital treatment of Black mothers & birthing people

# BMJ Quality & Safety

Home / Online First

Article Text

Article menu

Editorial

Emotional safety *is* patient safety

FREE

Audrey Lyndon<sup>1</sup>, Dána-Ain Davis<sup>2</sup>, 

Anjana E Sharma<sup>3</sup>, 

Karen A Scott<sup>4</sup>

Correspondence to Dr Audrey Lyndon, Rory Meyers College of Nursing, New York University, New York, NY 10010, USA; [Audrey.Lyndon@nyu.edu](mailto:Audrey.Lyndon@nyu.edu)

**BMJ Quality & Safety** @BMJ\_Qual\_Saf · 3d ...  
Harm is harm. Emotional safety is patient safety. [@audreylyndon](#), [@drdanaaindavis](#), [@AJSharmaMD](#) & [@RJEpiOBWarrior](#) justify a new patient safety paradigm, using obstetric racism as an exemplar.

Helping healthcare teams to debrief effectively

Including equity in quality improvement

Adverse events in paediatric inpatients

Grand rounds in methodology: the realist review

BMJ

QUALITY

[qualitysafety.bmj.com](http://qualitysafety.bmj.com)

Emotional safety is patient safety

BCR

Birthing Cultural Rigor

We need NEW ways of defining and measuring patient safety

“Feeling safe” as defined through patient experience vs  
“being safe” as defined by clinical outcomes selected by  
quality experts and health plans



Power differences and dynamics → degrading  
patient experiences of care as valid patient safety measures.

Minimizes patient experiences as “fake truth”, not related  
to patient safety

Health systems and health insurance plans elevate  
“being safe” over “feeling safe”



 Article Text

Article menu



Editorial

## Emotional safety *is* patient safety



FREE

 Audrey Lyndon<sup>1</sup>, Dána-Ain Davis<sup>2</sup>,  Anjana E  
Sharma<sup>3</sup>,  Karen A Scott<sup>4</sup>

Correspondence to Dr Audrey Lyndon, Rory Meyers  
College of Nursing, New York University, New York, NY  
10010, USA; [Audrey.Lyndon@nyu.edu](mailto:Audrey.Lyndon@nyu.edu)



We need NEW ways of defining and measuring patient safety

“Feeling safe” as defined through patient experience vs  
“being safe” as defined by clinical outcomes selected by  
quality experts and health plans



”Being safe” means we limit the meaning and measure of safety as the absence of physical harm → fails to capture harm as violations of social, cultural, emotional, and psychological safety



 Article Text

Article menu



Editorial

## Emotional safety *is* patient safety

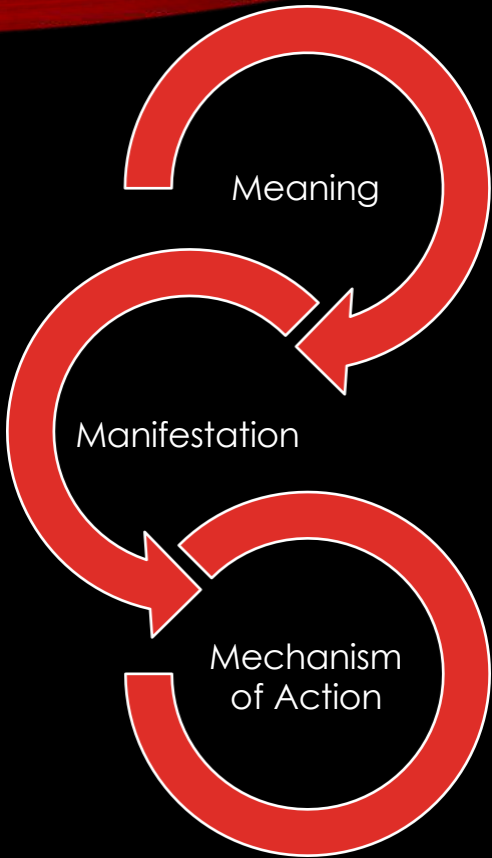


FREE

 Audrey Lyndon<sup>1</sup>, Dána-Ain Davis<sup>2</sup>,  Anjana E Sharma<sup>3</sup>,  Karen A Scott<sup>4</sup>

Correspondence to Dr Audrey Lyndon, Rory Meyers  
College of Nursing, New York University, New York, NY  
10010, USA; [Audrey.Lyndon@nyu.edu](mailto:Audrey.Lyndon@nyu.edu)

# Reproductive and Perinatal Apartheid In The U.S.



Population control programs, practices, and policies

Criminalization of sex, reproduction and motherhood/parenthood

Rapid termination of parental rights for those deemed “unfit” by the state

Environmental degradation with infertility, miscarriages, and other adverse health outcomes

Access to choose from all available birthing spaces, attendants, positions, practices & support persons

Structural stigmatization of Mothers/Fathers/Parents at the Margins

Differential access to Assisted Reproductive Technology

Resistance to expanding definitions of partnering and parenting options and configurations

Maternity/Paternal/Parental leave & affordable childcare

Stable housing and wages

Safe, affordable, and sustainable neighborhoods: clean air, water, food, shelter, and recreation/leisure/play

State sanctioned policy brutality and murders



Context: We limit patient safety meanings and measures to clinical outcomes only AND then we study outcomes data by race.

Result: We see NO difference in outcomes based on race

Conclusion: Racial disparities or racial inequities do NOT exist.

Right? Maybe? **Nope.**



“

**We must call out the lie in QI: The absence of perinatal pathology is the presence of perinatal equity.**

**Karen A. Scott,  
MD, MPH, FACOG**

Chief Black Feminist Physician  
Scientist, Founding CEO, & Owner,  
Birthing Cultural Rigor, LLC







## Karen A. Scott, MD, MPH, FACOG

"Just because you don't see the pathology that you define doesn't mean someone's not being hurt or harmed," said Scott, who created an instrument to measure Black patients' experiences of obstetric racism, capturing what she describes as the misalignment between hospital intentions of providing safe and high-quality care and patients' actual experiences. "

- Washington Post, August 9, 2022

[www.birthingculturalrigor.com](http://www.birthingculturalrigor.com)





"The Ways Anti-Black Racism And Anti-Black Sexism(Misogynistic) Representation Shape Broader Ideas About Black Women, Particularly In Visual Culture And Digital Spaces."

older, fatter,  
sicker

uglier,  
undesirable

hypersexual,  
whore

unfit,  
untrustworthy,  
irresponsible

angry, bitter,  
bossy, b\*tch

controlling

lonely, liar,  
lazy, crazy

drug-seeking,  
drug user,

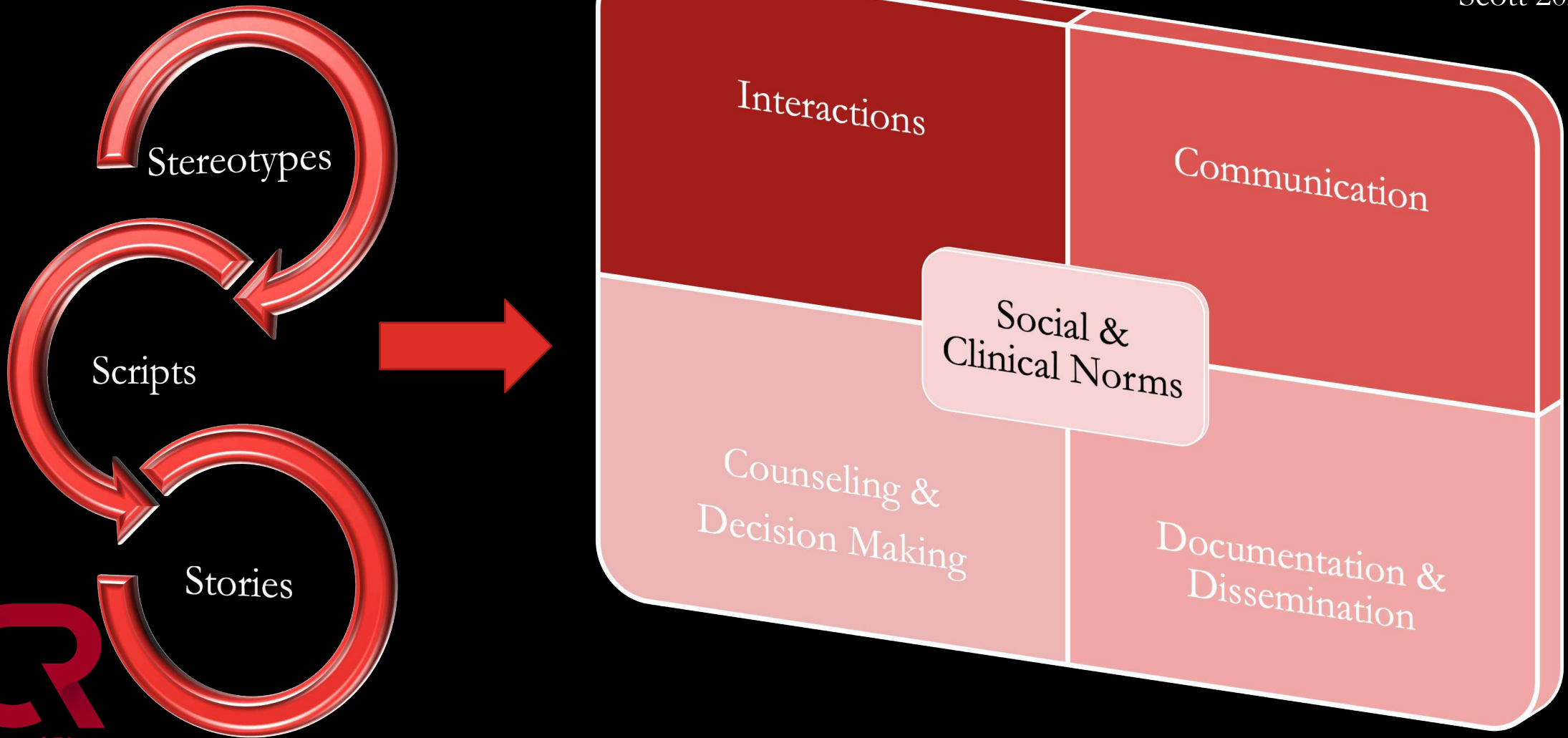
non-  
compliant,  
disruptive,  
hostile

ignorant,  
irresponsible

MISOGYNOIR  
BLACK  
WOMEN'S  
DIGITAL  
RESISTANCE  
MOYA  
BAILEY  
TRANSFORMED

# Consequences of Creating or Sharing Knowledge that is both Anti-Black Racist AND Anti-Black Sexist: Reproducing Misogynoir

Scott 2021





# Weaponizing medical records to perpetuate harm against Black patients & women: Testimonial Injustice

Study sample: 9, 251 notes written by 165 physicians about 3374 unique patients

Original Research | [Published: 22 March 2021](#)

## Testimonial Injustice: Linguistic Bias in the Medical Records of Black Patients and Women

[Mary Catherine Beach MD, MPH](#), [Somnath Saha MD, MPH](#) ✉, [Jenny Park](#), [Janiece Taylor RN, PhD, FAAN](#),  
[Paul Drew PhD](#), [Eve Plank](#), [Lisa A. Cooper MD, MPH](#) &  
[Brant Chee PhD](#) — [Show fewer authors](#)

[Journal of General Internal Medicine](#) **36**, 1708–1714  
(2021) | [Cite this article](#)


- Goal: Name the types of linguistic (“language-producing”) systems of communication used by physicians to show that they doubt or disbelieve patient narratives of their lived experiences (testimonial injustice) and then explore racialized and gendered differences in the use of such language.
- Main measures: 3 linguistic features that create doubt or testimonial injustice by using:
  - quotation marks (e.g., has a “reaction to the medication)
  - specific “judgment words” that suggest doubt (e.g. “claims” or “insists”)
  - Evidential, a sentence made by physicians in which patients’ symptoms or experiences are reported as hearsay

# Weaponizing medical records to perpetuate harm against Black patients & women: Testimonial Injustice

Study sample: 9, 251 notes written by 165 physicians about 3374 unique patients

Original Research | [Published: 22 March 2021](#)

## Testimonial Injustice: Linguistic Bias in the Medical Records of Black Patients and Women

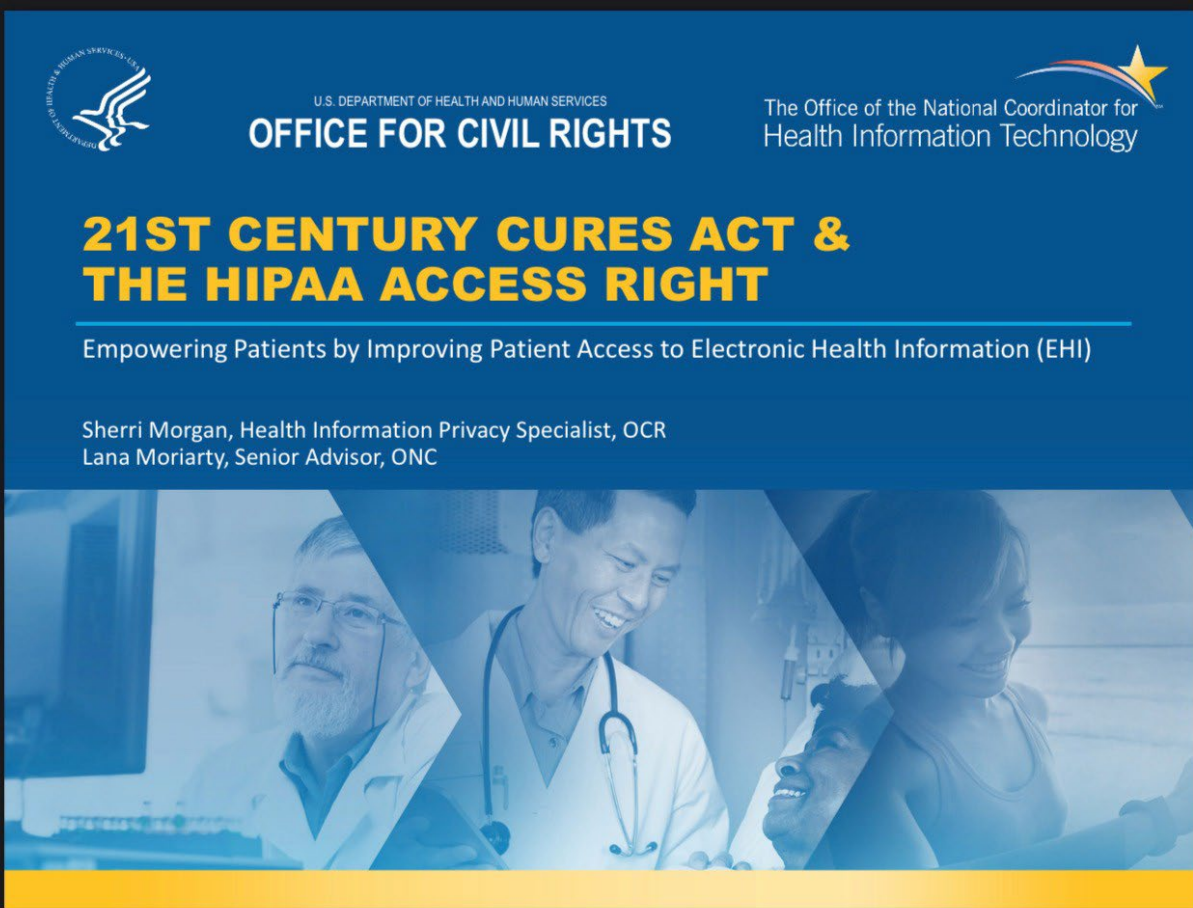
[Mary Catherine Beach MD, MPH](#), [Somnath Saha MD, MPH](#) , [Jenny Park](#), [Janiece Taylor RN, PhD, FAAN](#),  
[Paul Drew PhD](#), [Eve Plank](#), [Lisa A. Cooper MD, MPH](#) &  
[Brant Chee PhD](#) — [Show fewer authors](#)


[Journal of General Internal Medicine](#) **36**, 1708–1714  
(2021) | [Cite this article](#)


- Results:
  - Patient characteristics: 74% Black, 58% female
  - Physicians were more likely to write about Black patients, compared to white patients, using:
    - at least one quote
    - At least one judgment
    - More evidentials
    - written about Black patients had
  - No difference notes based on patient sex (female vs. male) for use of judgment or evidentials
  - Physicians were more likely to use at least one quote to show they doubt female patients



# Correcting the harms against Black patients & women in medical records: Testimonial Justice



 U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
**OFFICE FOR CIVIL RIGHTS**

 The Office of the National Coordinator for Health Information Technology

**21ST CENTURY CURES ACT & THE HIPAA ACCESS RIGHT**

Empowering Patients by Improving Patient Access to Electronic Health Information (EHI)

Sherri Morgan, Health Information Privacy Specialist, OCR  
Lana Moriarty, Senior Advisor, ONC

## Consumer Act of Resistance:

Always ask for a copy of your electronic and paper medical records after ANY clinical visit or encounter with a health care professional, social worker, health system, or hospital

<https://www.healthit.gov/sites/default/files/2018-12/LeveragingHITtoPromotePatientAccess2.pdf>

Patients have the right to request and receive an electronic copy of their electronic Protected Health Information (ePHI) (including medical records) and to have the provider electronically transmit PHI to another person or entity



## The Issue

Hospitals in the U.S. do **NOT** routinely keep Black women, girls, & gender expansive people and their loved ones *safe* during pregnancy, labor, birth, and postpartum.



# Our Vision of SACRED Birth for Black Mothers & Birthing People:

Sacred birth is a radical attitude towards human births, specifically Blackness, Black bodies, and Black births, that regards all birth activities as fundamentally normal, healthy, spiritual, familial, magical, transformative, erotic, communal, emancipatory, and power-activating.

Sacred birth encourages diverse and inclusive birth pleasure, practices, care, spaces, options, partners, communities, and experiences.

The sacred birth movement advocates for safer, respectful, dignified, high quality “participatory” birth care, conditions, experiences, and outcomes, and improved workforce diversification, development, sustainability, and restoration of Black Midwifery care and Black Doula support models as part of its campaign.

# Our Vision of SACRED Birth for Black Mothers & Birthing People:

## Consumer Act of Resistance:

Ask your prenatal health professional and hospital L&D staff/leadership to share their vision of a SACRED Birth for Black Mothers & Birthing People

What truths do they hold about Black bodies, Black Mothers/Parents, Black births, and Black chosen and given families?

What steps are taken to acknowledge, affirm, and amplify the power, potential, promise, and pleasure, not only pathology of laboring, birthing, and living through postpartum?

Scott 2018



## The SACRED Birth Study

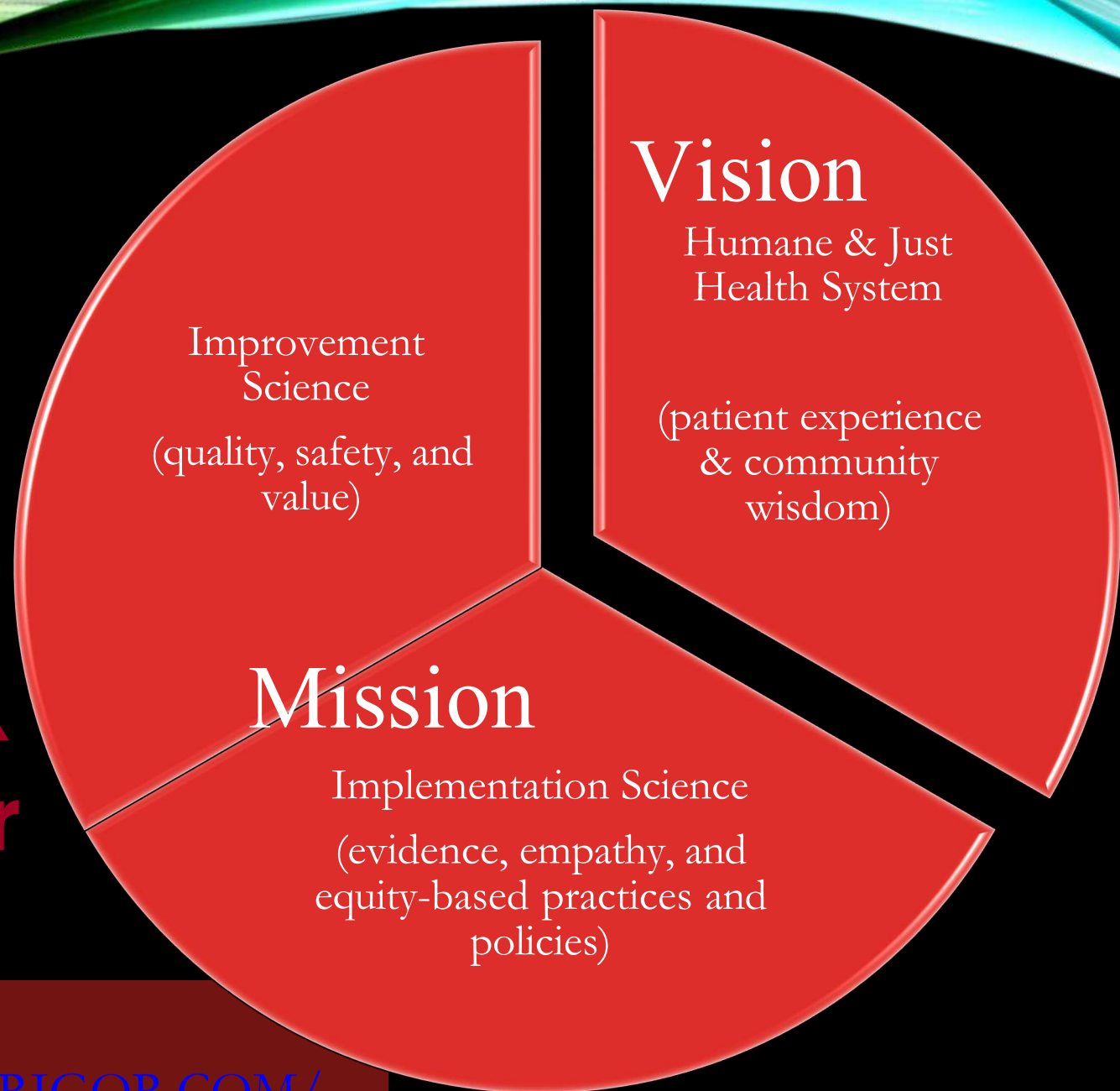
Thank you for this meaningful study. Although I was stressed out due to delivering at the peak of covid-19 in NY, I strongly believe that my experiences were better than most other black women delivering at the same time, simply due to my profession as a pediatrician. I was able to call in many of my friends who were black OB/gyn's working in the hospital to oversee my care and they helped me tremendously! It is very unfortunate that my connections and profession afforded me with these opportunities, despite the fact that overall it was quite traumatic due to the pandemic. I pray that the system changes for the better to accommodate all Black birthing bodies so everyone receives similar special care and attention regardless of their career paths and internal connections.

Scott 2021



# BCR

## Birthing Cultural Rigor



[HTTPS://WWW.BIRTHINGCULTURALRIGOR.COM/](https://www.birthingculturalrigor.com/)

# The Arc of Cultural Rigor in Perinatal Quality Improvement



Reproductive  
&  
Perinatal  
Apartheid

Persistent  
near death  
and death  
gap

Sojourner  
Syndrome

Black Feminist Praxis

Reproductive Justice

Research Justice

Obstetric  
Racism

Black  
Birthing  
Patient  
Experience

Safety &  
Accountability

Autonomy

Communication  
& Information  
Exchange

Anti-Racism/  
Anti-Misogynoir

Empathy &  
Humanity

Dignity in  
Blackness &  
Holistic care

Kinship



Dána-Ain Davis,  
PhD, MPH



**BLACK MATERNAL  
HEALTH WEEK 2019**

#CiteBlackWomen

© Black Mamas Matter Alliance



"Obstetric racism is a threat to maternal life and neonatal outcomes. It includes, but is not limited to, critical lapses in diagnosis; being neglectful, dismissive, or disrespectful; causing pain; and engaging in medical abuse through coercion to perform procedures or performing procedures without consent."

DAVIS, D. (2018). OBSTETRIC RACISM: THE RACIAL POLITICS OF PREGNANCY, LABOR, AND BIRTHING. MEDICAL ANTHROPOLOGY, DOI: 10.1080/01459740.2018.1549389

#BMHW19



## Obstetric Racism: The Racial Politics of Pregnancy, Labor, and Birthing

Dána-Ain Davis. Med Anthropol. 2019 Oct.



### Reproductive Injustice

RACISM, PREGNANCY, AND PREMATURE BIRTH

DÁNA-AIN DAVIS



# MEDICAL RACISM

Health Care  
Profession's response  
to or interpretation  
of a patient's  
race/ethnicity

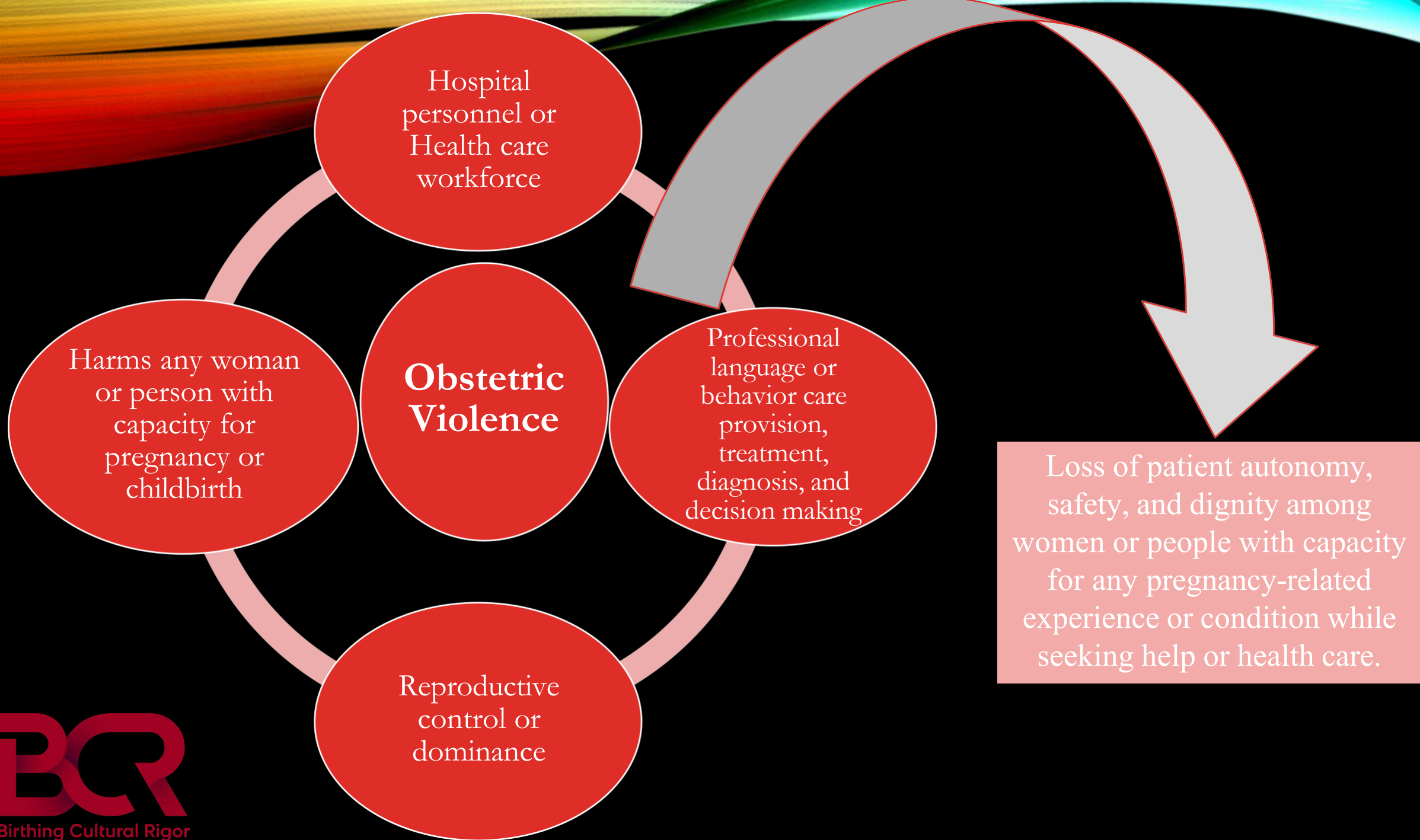
Missed, delayed,  
inappropriate, or  
harmful care and/or  
complications

Racialized Prejudice  
OR discrimination in  
language & behavior

Medical Care  
Provision, Treatment,  
Diagnosis, &  
Decision Making

New or worsening social and clinical  
health inequities that unfairly, uniquely,  
and disproportionately impact Black  
communities, Indigenous communities,  
or communities of color.





# Obstetric Racism = Medical Racism + Obstetric Violence

Framework and event described by Davis 2018 that captures harmful experiences and conditions facilitated by any hospital personnel/health care workforce, that uniquely unfairly harm Black women or people with capacity for pregnancy, birth, and postpartum

## OBSTETRIC RACISM

Dána-Ain Davis, MPH, Ph.D.

Translation from  
Theory to Practice

## PREM-OB SCALE

Karen A. Scott, MD, MPH, FACOG

### DIAGNOSTIC LAPSES

When a clinician's uninterrogated belief that Blackness is pathological leads them to de-emphasize or exaggerate or ignore a patient's symptoms resulting in an inappropriate or lapsed diagnosis.

### NEGLECT, DISMISSIVENESS, OR DISRESPECT

When medical professionals ignore or dismiss a person's expressed need for reproductive help or care and/or treats them with disdain.

### RACIAL RECONNAISSANCE

Describes the Herculean effort made by Black women to avoid or mitigate racist encounters including being hypervigilant about procedures and finding providers.

### INTENTIONALLY CAUSING PAIN

When medical professionals fail to appropriately manage pain, which may be rooted in racialized beliefs about pain immunity and as well as the absence of empathy for Black people's physical suffering, leading to lack of internal motivation to alleviate or reduce Black suffering.

### MEDICAL ABUSE

Can occur when medical professionals engage in experimentation and/or (repetitive) behavior that is motivated not by concern for the patient but serves to validate the clinician's self-worth and upholds their domination over the patient.

### COERCION

When medical professionals perform procedures without consent and/or intimidate patients to make decisions.

### CEREMONIES OF DEGRADATION

The ritualistic ways in which patients are humiliated or shamed and includes a sense of being sized up to determine the worthiness of the patient or their support person(s) who may be viewed as a threat. In response, medical staff may deploy security, police, social services or psychiatry to ensure compliance or to remove the "threatening" person.

### SAFETY & ACCOUNTABILITY

### AUTONOMY & SOCIAL NETWORKS

### DIGNITY IN BLACKNESS & HOLISTIC CARE

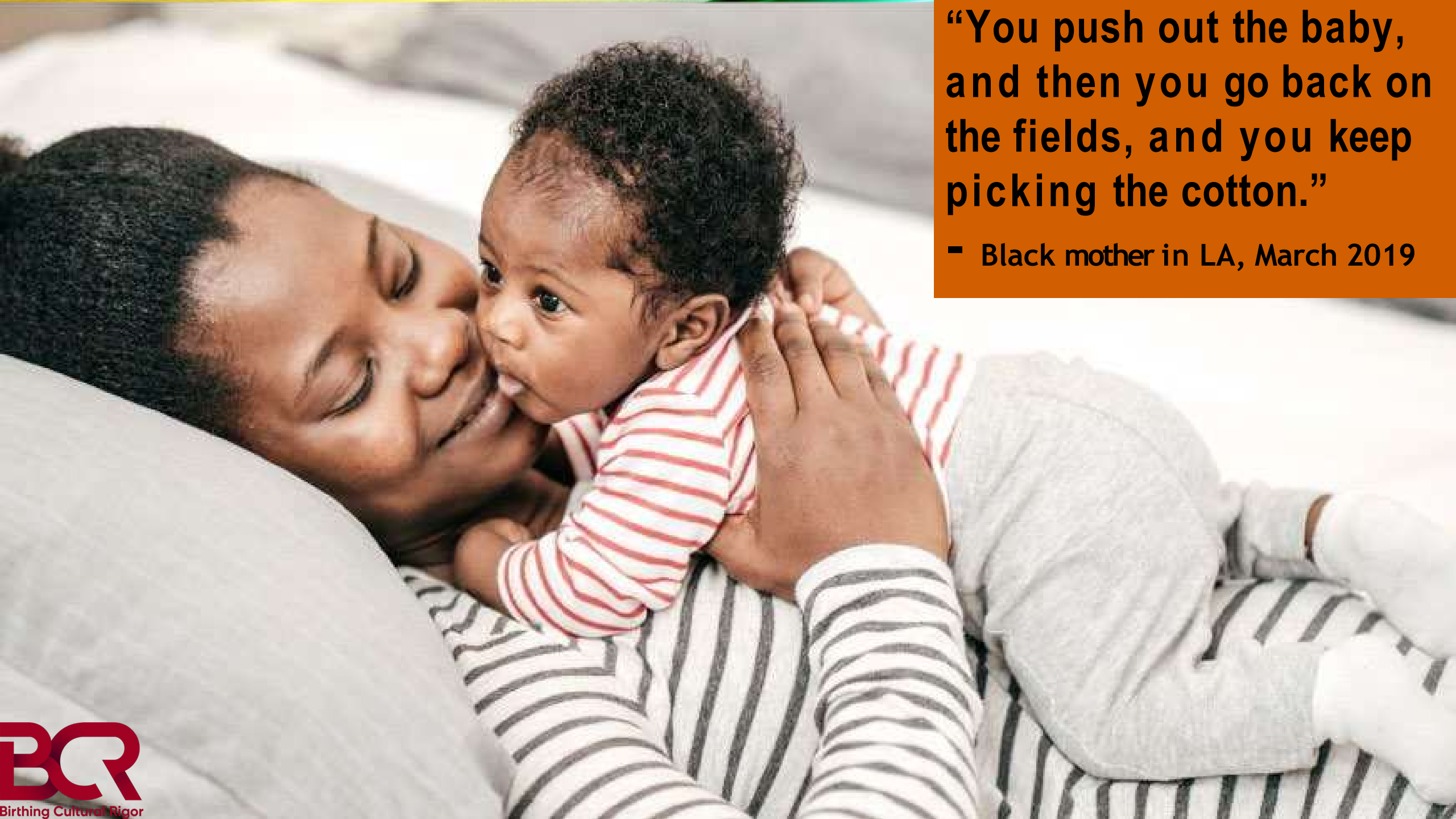
### COMMUNICATION & INFORMATION EXCHANGE

### EMPATHY & HUMANITY

### RACISM

Illustrations © 2020 Cheyenne Varner

Illustrations © 2020 Cheyenne Varner



**“You push out the baby,  
and then you go back on  
the fields, and you keep  
picking the cotton.”**



**– Black mother in LA, March 2019**



Birth / Volume 49, Issue 3 / p. 514-525

ORIGINAL ARTICLE |  Open Access |    

# Psychometric validation of a patient-reported experience measure of obstetric racism© (The PREM-OB Scale™ suite)

Emily White VanGompel MD, MPH , Jin-Shei Lai PhD,  
Dána-Ain Davis PhD, Francesca Carlock MPH,  
Tamentanefer L. Camara MS-HCA, IBCLC, Brianne Taylor,  
Chakiya Clary AA, Ashlee M. McCorkle-Jamieson MD,  
Safyer McKenzie-Sampson MSPH, Caryl Gay PhD,  
Amanda Armijo BA, Lillie Lapeyrolerie BA,  
Lavisha Singh MPH, Karen A. Scott MD, MPH 

First published: 17 March 2022

<https://doi.org/10.1111/birt.12622>

Citations: 7

## Funding information

Financial support for this study was provided by the California Health Care Foundation, the Tara Health Foundation, the Grove Foundation, Dwight and Dr Taya Scott, EdD. Funders had no input or influence on data collection, study design or interpretation, reporting, or decision to submit for publication

PREM-OB  
SCALE

Psychometric validation of a  
patient-reported experience measure  
of obstetric racism©  
(The PREM-OB Scale™ Suite)

Perinatal quality improvement lacks culturally and scientifically rigorous, relevant, and responsive measures of quality and safety as determined and defined for, by, and with Black mothers and birthing people.

The 2020 SACRED Birth study set out to develop a novel and valid measure of patient-reported experiences of obstetric racism during hospital labor, birth, and postpartum.



Karen A. Scott, MD, MPH,  
FACOG (she/her)

The SACRED Birth During COVID-19 study lifted up the voices of over 900 Black women and people, including Black women content experts from different disciplines, generations, and states, Black mothers and birthing people as patient experts, and Black women artists, activists, and advocates from 15 community organizations, and 6 non-Black women scholars.

## The making of a measure:

- 1 Determine theoretical frameworks
- 2 Develop a preliminary conceptual model
- 3 Review existing measures to start developing an item bank
- 4 Design new items if needed
- 5 Revise your item bank with patient, community, and content experts
- 6 Pilot test and perform psychometric analysis

806

Black mothers and birthing people  
participated in the study, representing

348

birthing hospitals across

34

states plus DC



Characteristics of the study participants were similar to the U.S. Black population, with increased representation from individuals with a higher level of education.



1 in 3 households had a total  
income of \$25,000 or less  
(before taxes), despite  
higher levels of education



The PREM-OB Scale™ produces 3 independent scores of obstetric racism: Humanity, Kinship, and Racism. Each score varied significantly by socioeconomic factors previously shown to be associated with experiences of racism, including income and education levels.



Each score did not vary by reported clinical characteristics (including maternal BMI, gestational age, and mode of delivery), demonstrating that the PREM-OB Scale™ measures obstetric racism independent of clinical risk.



Hospital acts of harm as defined by patient-reported experiences of obstetric racism occurred regardless of individual, patient-level characteristics or outcomes.



"The absence of perinatal pathology does not guarantee the presence of perinatal equity. Reducing the numbers of poor clinical outcomes alone will NOT protect Black birthing communities from unsafe, poor quality, inequitable care during childbirth hospitalization." - Dr. Karen A. Scott, MD, MPH, FACOG

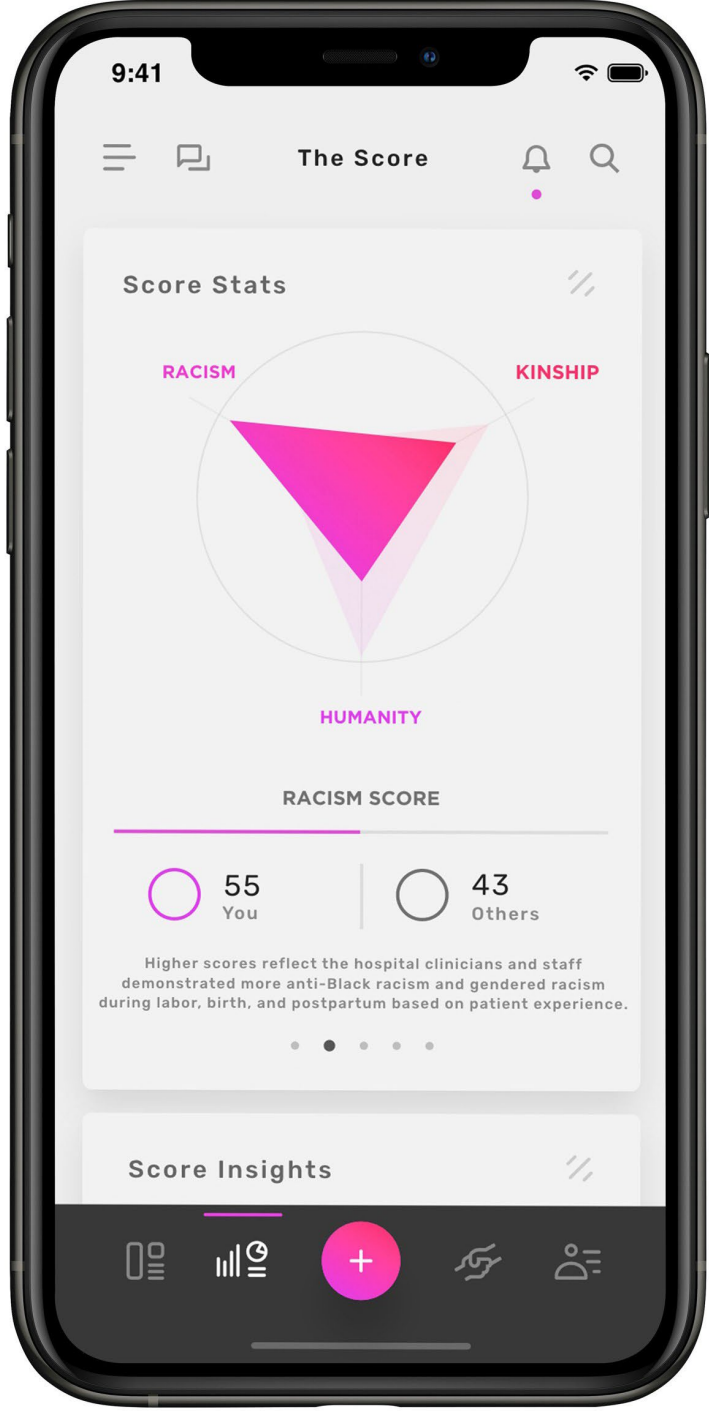


Digital Platform Coming Soon Winter 2023!!

# PREM-@B SCALE

U.S. Geographic Locations include  
South: AL, GA, KY, MS, NC, TN  
Midwest: IN, IL, MI, MN, MO, OH  
East Coast: NJ, NY, Washington DC

Humanity	Kinship	Racism
Safety, accountability, autonomy, communication and empathy	Hospital recognition and involvement of social relationship between mothers/birthing people and their child or support	Anti-Black racism and anti-Black gendered racism (misogynoir) in service provision
31 items, 14 items short form	9 items	12 items



# The PREM-OB Scale™ Suite: An Interpretive Tool for Black Birth Narratives

## Scott Narrative Data Analytic Method



I really appreciated having a black nurse within my labor, birth, postpartum care team. During epidural, a black nurse held my hand during my discomfort. During my postpartum stay another black nurse told me about a financial waiver application for low-income families within Kaiser Permanente Hospital, where if I qualified, I would not have to pay my \$1,500 hospital admission bill. She also discussed belly binding as a cultural technique that some WOC do during postpartum care to provide abdominal support and get back into shape.

# The PREM-OB Scale™ Suite: Interpretative Tool for Black Birthing Narratives

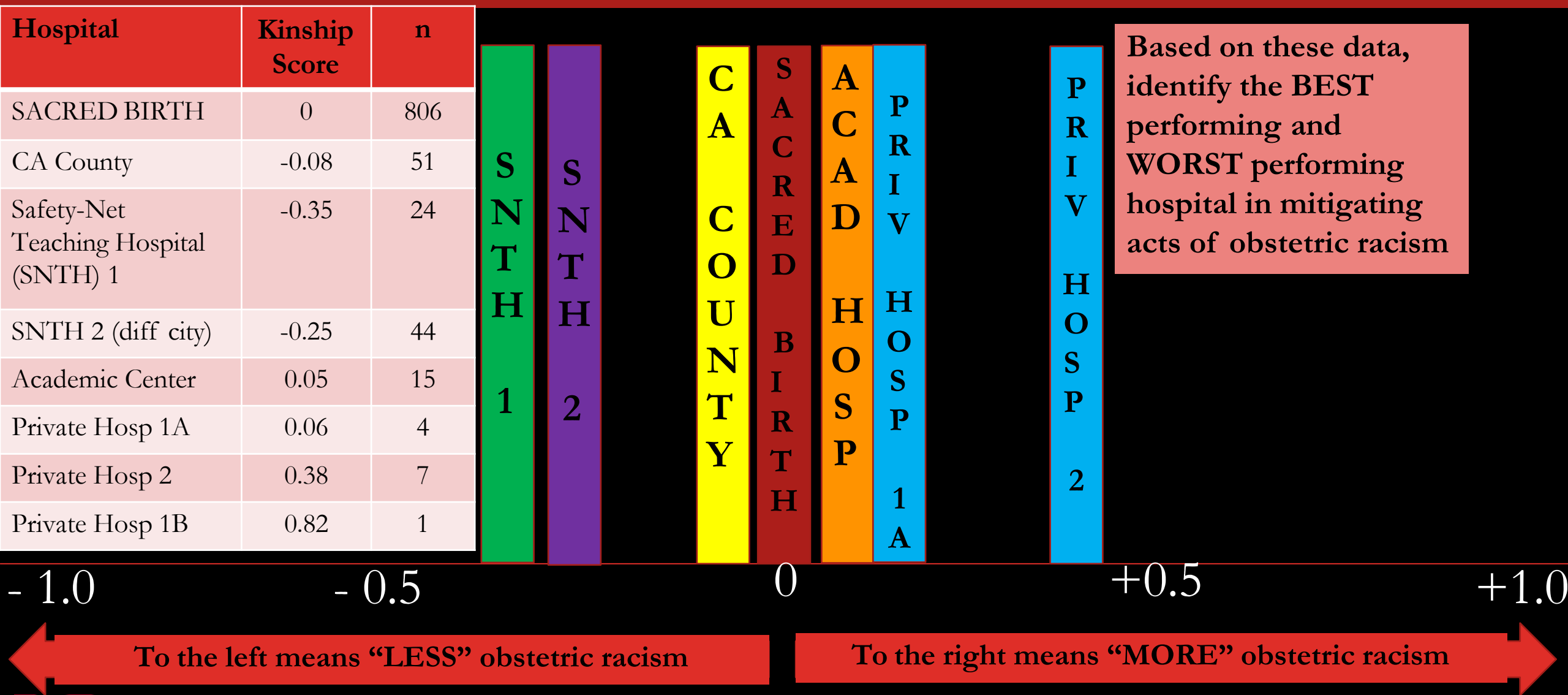
## Scott Narrative Data Analytic Method



Overall, I felt I had a positive experience however, my husband and I felt "in the dark" at times due to lack of communication regarding our baby while he was in the NICU, we were not permitted to have our doula present due to hospital policy, and as a first-time mom, I would have loved to have more explained to me about what to expect. I was upset because my express wishes regarding feeding my baby were not implemented (he was given formula and a pacifier without my knowledge or permission despite my wishes to breastfeed). My husband was reprimanded when going to get water (I believe because he looked "intimidating" to some hospital staff as a 6'4" black man. We received "rushed" and possibly inaccurate discharge information from a staff member who did not seem engaged.



**PREM-OB SCALE™ SUITE: KINSHIP MEASURE**  
**Comparing San Francisco County and Hospital Scores with national data (N=806)**  
(smaller sample sizes in California)







Research Article | Original Research

# Community Support Persons and Mitigating Obstetric Racism During Childbirth

Elle Lett, Marie-Fatima Hyacinthe, Dána-Ain Davis and Karen A. Scott

The Annals of Family Medicine April 2023, 2958; DOI: <https://doi.org/10.1370/afm.2958>

Birthing in community with a support person (CSP) who is not affiliated or aligned with hospital significantly **decreased** hospital acts of obstetric racism based on 3 independent scores of humanity, kinship, and racism

The **decrease** in obstetric racism remained significant even after we controlled for the effect of the relationship status of the Black mother/birthing person.

Marriage or partnership among Black mothers/birthing people does not sufficiently mitigate obstetric racism.

Physical presence of a CSP >>> marriage/partnership as a strategy to prevent or limit the harm of obstetric racism.



Research Article | Original Research

# Community Support Persons and Mitigating Obstetric Racism During Childbirth

Elle Lett, Marie-Fatima Hyacinthe, Dána-Ain Davis and Karen A. Scott

The Annals of Family Medicine April 2023, 2958; DOI: <https://doi.org/10.1370/afm.2958>

Physical presence of a CSP >>> marriage or partnership as an evidence-based strategy to prevent or limit the harm of obstetric racism.

## Consumer Acts of Resistance:

Build an in-person and virtual *birth safety* team of community support persons who are NOT affiliated/aligned with the hospital.

Assign different roles: emotional support, active bystander, notetaker, meal/snack prep, playlist of music and movies/TV shows, aromatherapy & essential oils specialist, posts or shares words of affirmation & whatever you desire & desire.

# Consumer Act of Resistance: Demand application of a postpartum care model defined for, by, and with Black women

[Clin Obstet Gynecol.](#) 2022 Sep; 65(3): 663–675.

Published online 2022 Jun 21.

doi: [10.1097/GRF.0000000000000729](https://doi.org/10.1097/GRF.0000000000000729)

PMCID: PMC9301983 | PMID: [35723647](https://pubmed.ncbi.nlm.nih.gov/35723647/)

Destigmatizing and Democratizing  
Postpartum Care: A “Black Woman-  
Person First” Approach

[KAREN A. SCOTT](#), MD, MPH, FACOG<sup>✉\*</sup> and

[DÁNA-AIN DAVIS](#), MPH, PhD<sup>†</sup>

FIGURE 1

**Building and Bridging Black Futures  
Beyond Birth: A 12-Step Black  
Woman-Person First Approach to  
Optimizing Postpartum Care**





- Home
- Programs/Initiatives
- Office Contacts
- Reports & Resources
- News
- About OCR
- Reading Room
- Frequently Asked Questions
- Careers/Internships
- Blog

## How to File a Discrimination Complaint with the Office for Civil Rights

 [PDF \(205 KB\)](#)



### Introduction

Educational institutions have a responsibility to protect every student's right to learn in a safe

environment free from unlawful discrimination and to prevent unjust deprivations of that right. The Office for Civil Rights enforces several Federal civil rights laws that prohibit discrimination in programs or activities that receive federal financial assistance from the Department of Education. It is the mission of the Office for Civil Rights is

# Consumer Act of Resistance: File a Complaint of Discrimination during Health Care Provision with the Office of Civil Rights (OCR)

### Who Can File a Discrimination Complaint

Anyone may file a complaint. The person or organization filing the complaint need not be a victim of the alleged discrimination but may complain on behalf of another person or group. A complainant filing on behalf of or pertaining to another person(s) is responsible for securing any necessary written consent from that individual, including when a parent files for a student over the age of 18.

### Timeliness

A complaint must ordinarily be filed within 180 days of the last act of discrimination. If your complaint involves matters that occurred longer ago than this and you are requesting a waiver, you will be asked to show good cause why you did not file your complaint within the 180-day period.

OCR will consider ignoring this 180d limit

Explain in your complaint that your legal representative gave you incorrect information

<https://www.hhs.gov/civil-rights/filing-a-complaint/complaint-process/index.html>



## BRIEF

**Subject:** Mobilizing the Office for Civil Rights' Authority to Address Obstetric Violence and Obstetric Racism

**To:** Pamela Barron, Carla Carter & Audrey Wiggins

**From:** Indra Lusero, Anna Reed, et. al.

**Date:** July 25, 2022

### INTRODUCTION

- I. OBSTETRIC VIOLENCE AND OBSTETRIC RACISM ARE WIDESPREAD, AND FORMS OF DISCRIMINATION THAT THE OFFICE FOR CIVIL RIGHTS (OCR) HAS THE AUTHORITY TO ADDRESS.
  - A. Obstetric Violence and Obstetric Racism Happen and are Being Measured and Indicate the Need for Increased Protection and Enforcement of Civil Rights Laws in the Context of Perinatal Healthcare.
  - B. The Office for Civil Rights Has Both the Legal Authority and Procedural Mechanisms Necessary to Address Obstetric Racism and Obstetric Violence.
- II. DISCRIMINATION ON THE BASIS OF RACE, COLOR, AND NATIONAL ORIGIN IS WIDESPREAD IN PERINATAL CARE AND OCR HAS THE AUTHORITY TO ADDRESS IT.
  - A. Obstetric Racism Is Rooted in a Historic Legacy of Oppression and Violence Targeting Black Americans.
  - B. Native Americans Face Significant Civil Rights Violations in Health Care That OCR Has Authority to Address.
  - C. Pregnant Immigrants, Refugees and Migrants Face Unequal Treatment in Violation of Title VI.
- III. DISCRIMINATION ON THE BASIS OF SEX IS WIDESPREAD THROUGHOUT THE PERINATAL PERIOD AND OCR HAS THE AUTHORITY TO ADDRESS IT.
  - A. Mistreatment and Violence During Childbirth are Sex-Based Discrimination that OCR that OCR has Legal Authority Under Title IX to Address.
  - B. Manifestations of Sex-Based Discrimination in Childbirth that OCR Has the Authority to Address
- IV. DISCRIMINATION ON THE BASIS OF AGE IS WIDESPREAD THROUGHOUT THE PERINATAL PERIOD AND OCR HAS THE LEGAL AUTHORITY TO ADDRESS IT.
  - A. Discrimination on the Basis of Age is Widespread in the Context of Pregnancy and Childbirth.
  - B. OCR Can and Should Use its Authority to Address Age-Based Discrimination in the Context of Perinatal Health.
- V. DISCRIMINATION ON THE BASIS OF DISABILITY IS WIDESPREAD THROUGHOUT THE PERINATAL PERIOD AND OCR HAS THE AUTHORITY TO ADDRESS IT.
  - A. Discrimination on the Basis of Disability is Widespread in the Context of Pregnancy and Childbirth.
  - B. OCR Can and Should Use its Authority to Address Discrimination on the Basis of Disability in the Context of Perinatal Health.
  - C. Extreme and Punitive Policies are Increasing and OCR Should Act to Restrict Such Harmful Actions.
- VI. RECOMMENDATIONS
  - A. *Bowen v. American Hosp. Ass'n*, 476 U.S. 610 (1986) is Instructive and Supports Expanded Responsiveness to Obstetric Racism and Obstetric Violence.
  - B. Cooperation and Assistance, Compliance Reports, Access to Sources of Information
  - C. Provide Information to Grantees and Beneficiaries
  - D. Update Processes for Receiving Complaints.

### CONCLUSION

# Consumer Act of Resistance: File a Complaint of Discrimination during Health Care Provision with the Office of Civil Rights (OCR)

### Conclusion

Discrimination on the basis of race,<sup>518</sup> color,<sup>519</sup> national origin,<sup>520</sup> sex,<sup>521</sup> age,<sup>522</sup> or disability<sup>523</sup> while participating in any health program or activity, any part of which is receiving federal financial assistance, is prohibited.<sup>524</sup> OCR also has enforcement authority with respect to a vast array of health programs and activities reaching the majority of pregnant people and infants in the United States.<sup>525</sup> This means that any acts of discrimination that are prohibited under Section 1557 may be investigated and addressed by OCR so long as they occur in any of the healthcare settings enumerated. Tragically, such discrimination is deeply entrenched and widespread. The need for systematic accountability is great and OCR is uniquely positioned to address this need. OCR should immediately begin processing complaints and conducting investigations on individual reports of discrimination while also working prevent and to reduce the prevalence of these harms in collaboration with experts in the field, including the following experts. We look forward to partnering with you to eradicate this discrimination.

### Authors and expert reviewers:

Aarin Michele Williams, JD  
Anna Reed, JD  
Caitlin R. Williams, MSPH, PhD  
Courtney L. Everson, PhD  
Dána-Ain Davis, MPH, PhD  
Dana Sussman, JD, MPH  
Dara Baldwin, MPA  
Deborah Fisch, JD  
Emma Roth, JD  
Farah Diaz-Tello, JD  
Jacqueline Kaye Hammack, JD  
Hermine Hayes-Klein, JD  
Indra Wood Lusero, JD, MA

Jenna Lauter, JD  
Jennifer Mahan, JD  
Karen A. Scott, MD, MPH, FACOG  
Maymangwa Flying Earth, JD  
Nicholas Rubashkin, MD, PhD  
Nila Natarajan, JD  
P. Mimi Niles, PhD, MPH, CNM, LM  
Robyn Powell, PhD, JD  
Samira Seraji, JD  
Saraswathi Vedam, PhD, RM, FACNM,  
Sci D(hc)  
Stephanie Kraft Sheley, JD, MHA  
Zoë C. Miller-Vedam, LLM, MSSc



## The CATCH Pilot:

Community-led Accountability and Transformation  
in Care experiences and Hospital culture

The CATCH Pilot is the first and only community-led childbirth and postpartum quality & patient safety program.

- Developed by Birthing Cultural Rigor, LLC
- Designed to address obstetric racism & advance obstetric patient safety using the PREM-OB Scale™
- Funded by the W.K. Kellogg Foundation with support from NICHQ's Healthy Start TA & Support Center and BCR
- Implemented in select counties throughout Georgia, Michigan, Ohio, and Tennessee\*



Birthing Cultural Rigor



[birthingculturalrigor.com](http://birthingculturalrigor.com)



[info@birthingculturalrigor.org](mailto:info@birthingculturalrigor.org)

\*Implementation in Ohio and Tennessee funded solely by Birthing Cultural Rigor, LLC



Leveraging community storytelling through digital surveys as consumer acts of resistance to *shift* the power of who gets to name, define, measure, monitor, and report “anti-Black gendered racism” during care provision for hospital labor, birth, and postpartum for up to one year.

## Quality & Patient Safety Professionals

Recognition  
Measurement  
Monitoring  
Evaluation  
Reporting  
Prevention  
Mitigation



P  
O  
W  
E  
R

Black Mothers, Black Birthing People &  
Our Given and Chosen Kin





Funded by the W.K. KELLOGG FOUNDATION  
with additional support from NICHQ'S  
HEALTHY START TA & SUPPORT  
CENTER and Birthing Cultural Rigor, LLC



Postpartum Check-Ins for Up to One Year

Patient, Community & Hospital  
Reported Experiences of  
Hospital Acts of Obstetric Racism

Foundational Experiential Learning Modules:  
4 – Part Series on Addressing Obstetric Racism  
In Hospital Settings



### The CATCH Pilot:

Community-led Accountability and Transformation  
in Care experiences and Hospital culture

The CATCH Pilot is the first and only community-led childbirth and postpartum quality & patient safety program.

- Developed by Birthing Cultural Rigor, LLC
- Designed to address obstetric racism & advance obstetric patient safety using the PREM-OB Scale™
- Funded by the W.K. Kellogg Foundation with support from NICHQ's Healthy Start TA & Support Center and BCR
- Implemented in select counties throughout Georgia, Michigan, Ohio, and Tennessee\*

@culturalrigor

Birthing Cultural Rigor



birthingculturalrigor.com

@culturalrigor

info@birthingculturalrigor.org

\*Implementation in Ohio and Tennessee funded solely by Birthing Cultural Rigor, LLC



Community-led Accountability and Transformation  
in Care experiences and Hospital culture

PREM-OB Scale™ Georgia

Join the movement to #EndObstetricRacism!

- Complete The Patient Reported Experience Measure of OBstetric racism© (The PREM-OB Scale™ Suite).
- The PREM-OB Scale™ Suite shows how the hospital team cared for you, your baby, and your support team.
- We will share results with participants, partners, and the public.

## WHO CAN PARTICIPATE?

- Black or African-American people age 18 and older,
- who gave birth on or after January 1, 2021,
- in a birthing hospital located within Bullock, Clayton, Cobb, Dekalb, Douglas, Fulton, and Toombs counties.

## PARTICIPANTS WILL BE ASKED TO COMPLETE THREE STEPS:

1. online screening
2. video call verification
3. online survey (survey will take approximately one hour)

Complete all three steps by July 31, 2023 and  
get a \$50 electronic gift card.

Questions?  [info@birthingculturalrigor.org](mailto:info@birthingculturalrigor.org)

**SIGN UP:**



[redcap.link/CATCHPilot](https://redcap.link/CATCHPilot)



# Consumer Act of Resistance: Join the movement to #EndObstetricRacism

Healthy Start TA & Support will support 500  
participants in select counties in MI and GA

Healthy Start Programs in GA:

Bullock

Clayton

Cobb

Dekalb

Douglas

Fulton

Toombs



# The CATCH Pilot:



Community-led Accountability and Transformation  
in Care experiences and Hospital culture



PREM-OB Scale™ Michigan

Join the movement to #EndObstetricRacism!

- Complete The Patient Reported Experience Measure of OBstetric racism© (The PREM-OB Scale™ Suite).
- The PREM-OB Scale™ Suite shows how the hospital team cared for you, your baby, and your support team.
- We will share results with participants, partners, and the public.

## WHO CAN PARTICIPATE?

- Black or African-American people age 18 and older,
- who gave birth on or after January 1, 2021,
- in a birthing hospital located within Genesee, Ingham, Kalamazoo, Kent, Macomb, Oakland, Washtenaw, and Wayne counties.

## PARTICIPANTS WILL BE ASKED TO COMPLETE THREE STEPS:

1. online screening
2. video call verification
3. online survey (survey will take approximately one hour)

## SIGN UP:



[redcap.link/CATCHPilot](https://redcap.link/CATCHPilot)

Complete all three steps by July 31, 2023 and  
get a \$50 electronic gift card.

Questions?  [info@birthingculturalrigor.org](mailto:info@birthingculturalrigor.org)

# Consumer Act of Resistance: Join the movement to #EndObstetricRacism

Healthy Start TA & Support will support 500  
participants in select counties in MI and GA

## Healthy Start Programs in MI:

Genesee  
Ingham  
Kalamazoo  
Kent  
Macomb  
Oakland  
Washtenaw  
Wayne



## The Community-led Accountability and Transformation in Care experiences and Hospital culture (CATCH Pilot)

### THE PREM-OB SCALE™ SUITE



#### PURPOSE:

To name, measure and monitor patterns, predictors, and perspectives of obstetric racism as an adverse event that violates obstetric patient safety during labor, birth, and immediate postpartum.

### THE PREM-OB SCALE™ SUITE

The Patient-Reported Experience Measure of Obstetric Racism® (The PREM-OB Scale™ Suite) is the first and only validated quality improvement tool to elicit patient definitions of harm and how harm shows up in hospital language, attitude, or behavior during the provision of care during labor, birth, and immediate postpartum.

Participants will complete screening and consent forms before engaging in LIVE video verification.



Next, participants will complete the online survey.

### ANTICIPATED RESULTS

1000 eligible Black mothers and birthing people from selected counties in Georgia, Michigan, Ohio, and Tennessee will share their experiences of obstetric racism and harm during childbirth hospitalization and immediate postpartum.



We will generate scores of humanity, kinship, and racism.



We will characterize the prevalence, patterns, and predictors of obstetric racism as an adverse event and patient safety indicator.



## The Community-led Accountability and Transformation in Care experiences and Hospital culture (CATCH Pilot)

### POSTPARTUM CHECK-INS



#### PURPOSE:

To assess and describe the social, emotional-mental, environmental, and political determinants of Black postpartum health, needs and priorities of Black mothers and birthing people.

To examine the association between patient reported experiences of obstetric racism and postpartum mental health status/conditions over time.

### PROCESS

We will collect and analyze data on Black patients' postpartum expectations, needs, and experiences using online surveys, 1:1 serial interviews, and health record data extraction at 1, 3, 6, 9 and 12 months postpartum.

We will assess baseline and subsequent changes in Black postpartum mental health using validated scales for depression and anxiety.



We will implement a care navigation assessment tool designed by Kay Matthews to determine optimal postpartum mental health support and services, and the Scott-Davis 12-Step Black Woman-Person First Approach to optimize quality of postpartum care services, supports, and experiences.

### ANTICIPATED RESULTS

40 eligible Black mothers and birthing people from selected counties in Georgia and Michigan will share their expectations, needs, and experiences throughout the first year postpartum.

We will develop a Black feminist toolkit to optimize Black postpartum patient/community abilities and preferences for phone, video, home-based, or center-based care, for the first year postpartum.



## The Community-led Accountability and Transformation in Care experiences and Hospital culture (CATCH Pilot)

### FOUNDATIONAL EXPERIENTIAL LEARNING MODULES



#### PURPOSE:

To assess and build systems capacity of health care, public health, and quality/data professional workforce in recognizing, reporting, and responding to obstetric racism.

### PROCESS

We will implement a series of four 90-minute virtual Foundational Experiential Learning Modules (FELMS) to:

assess and transform workforce attitudes, knowledge, and skills...

In the identification, measurement, monitoring, interpretation, and mitigation of acts of obstetric racism...



during interactions, communication, counseling, decision-making, and documentation and dissemination of health care information.



### ANTICIPATED RESULTS

400 health care, public health, and quality professionals will demonstrate improved knowledge and skill in recognizing, reporting, and responding to obstetric racism as an adverse event and patient safety indicator.







**SAVE THE DATE:**

**December 6-9,  
2023**

**Nashville Marriott at  
Vanderbilt University**  
2555 West End Ave.  
Nashville, TN 37203

Join us for  
BCR's Inaugural  
**Obstetric  
Patient  
Safety  
Summit**

Join us at the **first and only** "Black Woman-Person Focused" community-designed and led conference to address obstetric racism as an adverse event that harms Black mothers and birthing people during labor, childbirth, and immediate postpartum in U.S. hospitals.

**Problem:** Clinical outcome measures limit system and community capacity to explain and change the full range of harms enacted against Black birthing communities during childbirth hospitalization.



**Solution:** Build practical knowledge and skills of professionals across disciplines, generations, and geographies using improvement and implementation ethics, theories, meanings, measures, and methodologies grounded in Cultural Rigor.



**REGISTRATION IS NOW OPEN!**

Start the registration process now:

<https://www.surveymonkey.com/r/BCROPSSDec2023>

Be prepared to complete  
registration application in **ONE**  
sitting, ~20-30 minutes.

You must provide short essay  
responses and other req'd info.

Participation in OPSS 2023 is  
by invitation **ONLY**.

Questions? Concerns?  
[events@birthingculturalrigor.org](mailto:events@birthingculturalrigor.org)

<https://www.surveymonkey.com/r/BCROPSSDec2023>



**BCR'S INAUGURAL OBSTETRIC PATIENT SAFETY SUMMIT:  
APPLICATION INFORMATION**

Please choose a time when you can dedicate **20-30 minutes** (in one sitting) to complete the Obstetric Patient Safety Summit (OPSS) registration application.

Every question must be answered to the best of your ability and knowledge.

We understand situations arise that may affect your decision to participate.

OPSS is a **summit**, not a conference or convening, and provides formal, semi-structured opportunities for high-level discussion and idea sharing among a specific group of people. OPSS is created for professionals currently employed in community health, health care, health care financing, health care advocacy, health care law, public health, public policy, quality improvement, implementation science, dissemination science, data science, quality, and patient safety.

As a summit, OPSS 2023 aims to:

- discuss big ideas, tackle big-picture questions, and generate improvement and implementation solutions for U.S. maternal-perinatal industries on a micro-, meso-, or macro-scale.
- invite participants to prepare ahead by studying the predetermined agenda and the problem of obstetric racism.
- encourage registered participants to think of ways to recognize, report, and reconcile with obstetric racism ahead of time, strengthening participation in large and small group breakout sessions.
- build practical knowledge and skills of participants to walk away with cutting-edge, scalable solutions for addressing obstetric racism and advancing obstetric patient safety for Black women, girls, and gender-expansive people, and our given and chosen kin.

We are building summit participation through a rigorous screening process and by invitation only.



If you're interested, **APPLY NOW!**  
Participation in the summit is by invitation only,  
based on a rigorous screening process.

Early registration ends 8/3  
General registration ends 11/3 or sooner

**SPACE IS LIMITED!  
#OPSS2023**



**REGISTRATION IS OPEN!**

Start the registration process now:

<https://www.surveymonkey.com/r/BCROPSSDec2023>





An Emancipated Birth is a SACRED BIRTH

TRAUMA  
INFORMED

PLEASURE  
FOCUSED

POWER  
ACTIVATING

SPIRITUAL

RADICAL

LIBERATORY

INCLUSIVE

PARTICIPATORY



OBSTETRIC RACISM VIOLATES THE SANCTITY AND SAFETY OF BIRTH.





# THANK YOU! QUESTIONS, REFLECTIONS, & DISCUSSION

BCR Gen INFO: [INFO@BirthingCulturalRigor.org](mailto:INFO@BirthingCulturalRigor.org)

#OPSS2023: [Events@birthingculturalrigor.org](mailto:Events@birthingculturalrigor.org)

Website: <https://www.birthingculturalrigor.com/>

Twitter: @RJEpiOBWarrior @CulturalRigor



# The Glossary: From Community to Clinic

**Tamela Milan-Alexander**

TASC Faculty Planning  
Committee

*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*

 **HRSA**  
Maternal & Child Health

**NICHQ**  
National Institute for  
Children's Health Quality

**HEALTHY**  
**start**   
TA & SUPPORT CENTER

# Welcome All and Introductions

## By Tamela Milan-Alexander

### The Glossary: How We Got here





## About CCMH

...we envision a Chicago where all people and all communities thrive and partner with intention to improve maternal health

The Chicago Collaborative for Maternal Health (CCMH) is combatting the maternal mortality and morbidity crisis in Chicago by building awareness in communities and government, fostering collaboration among health and social service providers and driving quality of care in ambulatory care settings.





# CHAMPIONS FOR HEALTH EQUITY

EverThrive Illinois' mission is to achieve reproductive justice in the health care ecosystem through community-driven partnership, policy action, and systems change.

## OUR VISION

A just and affirming health care ecosystem where individuals, families, and communities can thrive.

## OUR VALUES

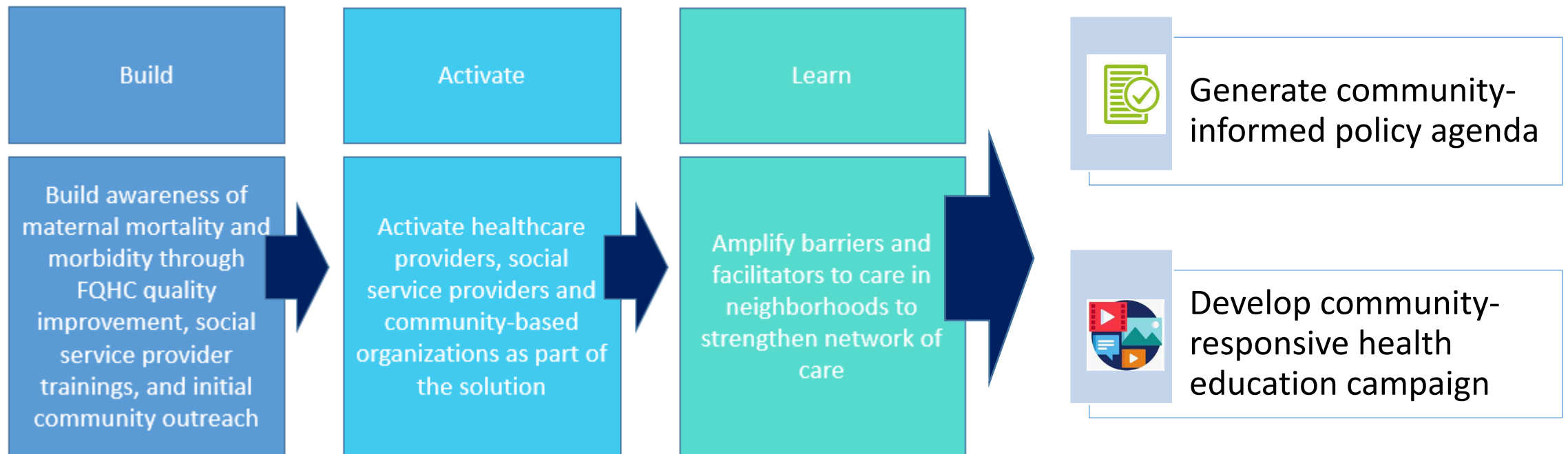
- Reproductive Justice
- Anti-Racism
- Centering the Most Impacted
- Bold Action and Transformation



# CCMH Overview

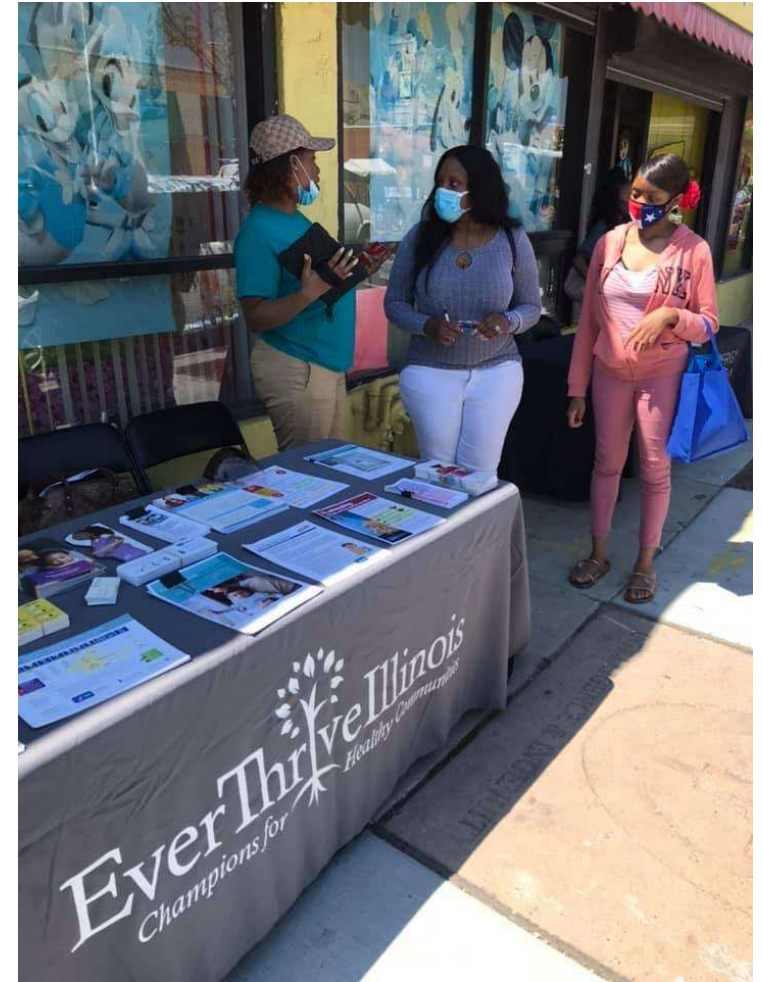
- **Mission:** The Chicago Collaborative for Maternal Health seeks to combat the maternal mortality and morbidity crisis in Chicago by building awareness in communities and government, fostering collaboration among health and social service providers, and driving quality of care in ambulatory care settings.
- **Vision:** The CCMH envisions a Chicago where all people and all communities thrive because healthcare providers, policymakers, community organizations, individuals, and families partner with intention to improve maternal health.
- **Aims**
  - *Aim 1:* Develop a QI collaborative for ambulatory care providers focused on best practices in maternal health for systems and culture change
  - *Aim 2:* Implement a complementary community engagement effort that informs families and community, social service providers about maternal morbidity and mortality prevention
  - *Aim 3:* Determine and advocate for policy recommendations based on the learnings from Aims 1 and 2

# Our Approach



# Activating Stakeholders

- **13 FQHCs** in quality improvement
- **91 Social Service Providers** received foundational training on Maternal Mortality and Morbidity
- **320 total surveys and four focus groups completed** aimed at understanding barriers and facilitators to postpartum care and community understanding of maternal mortality.





# Aim 2 Methods: Focus Group Qualitative Analysis

- Community based participatory research
- Four focus groups facilitated by community health workers (CHW)
- Participants: Black parenting or pregnant individuals who lived in select neighborhoods in the South and West side of Chicago
- Deductive and inductive coding by paired analyst teams
- Thematic analysis

# Aim 2 Methods: Focus Group Qualitative Analysis

- **Objective:** Using focus groups, the pregnancy and postpartum experiences of Black pregnant and parenting people living in economically disadvantaged neighborhoods in Chicago, Illinois.
- **Primary questions**
  - What type of support in the antenatal and postnatal period do women have access to?
  - How do people who are pregnant access healthcare and health information?
  - What are people's perceptions of maternal morbidity and mortality?

# Aim 2 Methods: Focus Group Question Guide

---

## Key Questions

Who do you trust when it comes to health information?

Do you have a healthcare provider who you can go to if you have a health issue?

What are some health issues you know that pregnant people in your community face?

How well do you feel people in your community are supported during pregnancy?

How well do you feel people are supported during postpartum (after pregnancy)?

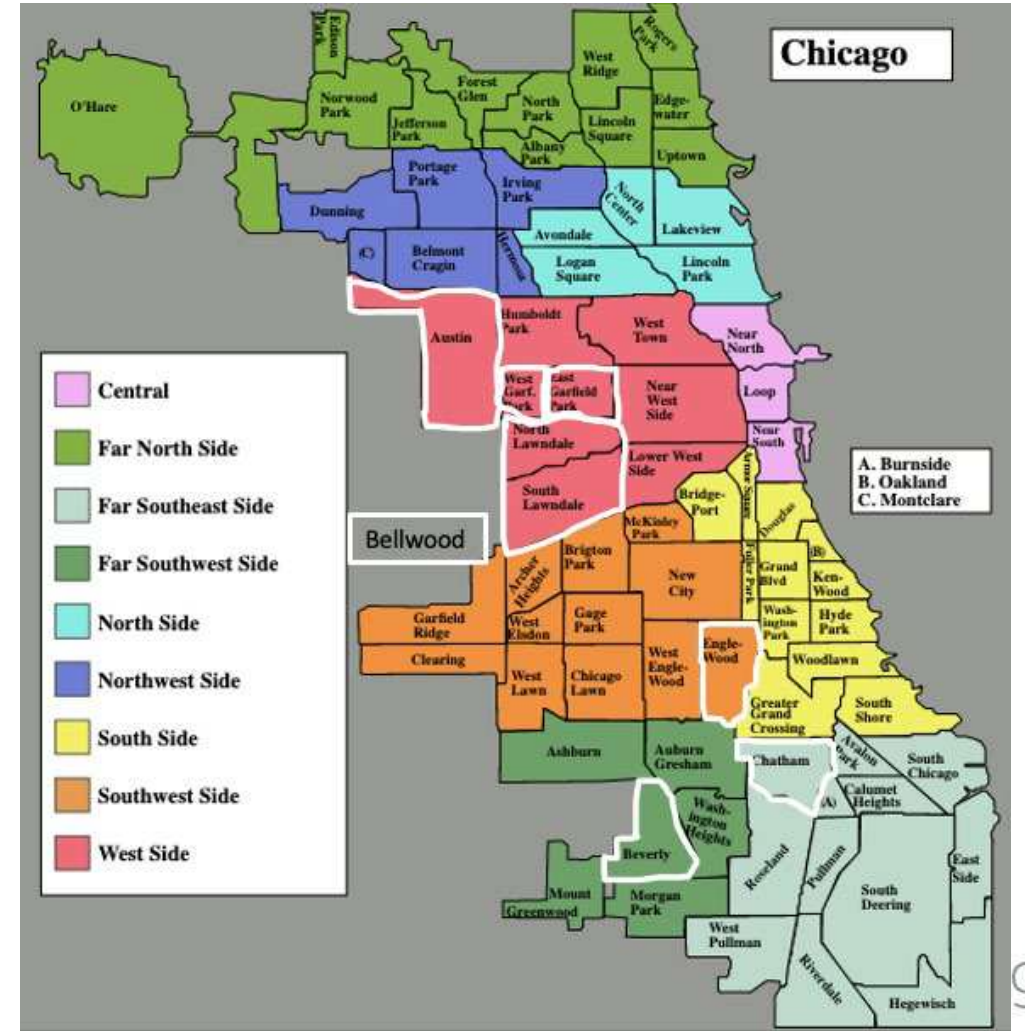
Have you ever heard of maternal mortality? Maternal morbidity?

Do you think this issue is affecting your community? If yes, do you think the community is aware of this issue?

---

# Aim 2 Results: Focus Groups

- 31 participants
- Age range: 23 – 57years old (median=33 years old)
- Self -identified race/ethnicity: African American/Black
- All respondents pregnant or parents
- Neighborhoods
  - Austin
  - West Garfield Park
  - East Garfield Park
  - Lawndale
  - Bellwood
  - Englewood
  - Chatham
  - Beverly





# Activating Stakeholders

66%

Reported not hearing about  
maternal mortality before

70%

Reported maternal  
mortality is not an issue in  
their community

Survey and Focus Group Aims:

- Understand where members of the community receive health care information
- Barriers and facilitators to postpartum care
- Understanding of maternal mortality and morbidity in their communities

# Aim 2 Results: Focus Group Themes

- Need for support outside of medical care
- Sources of health information are varied and not singular
- Need for strengthened connection with medical providers
- Familiarity with the lived experience of the postpartum period and maternal morbidity and mortality, but lack the medical information
- Differences in language and associated gaps in understanding

# Aim 2 Results: Focus Group Themes

## Theme 3: Need for strengthened connection with medical providers

**“They not really seeing what... what part our environment** has to play in it. What our, you know, what our **stress levels, what our life at home** has to do with anything. They just basically, um, **diagnosing us off of textbook definitions.** And I feel like that is not, that’s not doing us no good.”

**“But I think that our healthcare industry isn’t designed to care about people.** And I think **when it comes to Black mothers, that’s where the least care is given.”**

# Aim 2 Results: Focus Group Themes (continued)

## Theme 4: Familiarity with the lived experience of the postpartum period and maternal morbidity and mortality, but lack the medical information

“...we’ve seen perfectly healthy, um, **parents or mothers just don’t make it out of childbirth**... And I’m still clueless about that. I almost lost my sister and **she was perfectly healthy**. She had a C-section, they were able to bring her back, **but like what happened? Like we just don’t know everything.**”

Facilitator: “Okay. Um, **when I say postpartum care**, what was the first thing that popped in your mind?”

Speaker: **“Depression”**



# Aim 2 Results: Focus Group Themes (continued)

## Theme 5: Differences in language and associated gaps in understanding

“We had **these adverse health outcomes**... after we have our children, we liked dang, well, **I had a setback because... they’re not putting the medical terms to it.**”

Speaker 6: **“I haven’t heard of maternal mortality.** I dunno what that is. What is it?”

Speaker 7: **“That doesn’t happen often right?** Or does it happen often?”

# *The Gathering Video*



# The Gathering

A COMMUNITY OF SUPPORT FOR YOUR SELF-CARE DURING PREGNANCY AND AFTER HAVING YOUR BABY



Welcome to The Gathering.  
We are so glad you are here!

Pregnancy, birth, and after birth, and the early years of raising a family can bring incredible joy and memories for a lifetime. These seasons can also be emotional and unpredictable, with more questions than answers, limited help, and most attention going to your little one. As a result, it is typical for everyone involved to be fearful and anxious.

We want you to feel seen, cared for, and supported by joining this community through the following practical tips and simple, actionable steps towards taking care of yourself. At the Gathering, we hope that this season is as memorable and enjoyable as it can be for all involved.

You have a say. Your voice matters.



This can be a tough time. You should not expect to have all the answers, so give yourself permission to reach out for support. Ask questions, voice your concerns, and seek to meet your needs.

- Expressing yourself openly to your family and friends helps them to support you better. Let them know what you need. Delegate to them and let them take care of you. That could be helping you pick your doctor, clinic, or healthcare plan, taking you to your doctor visits, and supporting your choices for self-care.
- When you are having doubts or feeling afraid, spending time with a family member or a friend that has been through pregnancy might give you comfort and peace.
- Knowing where to go in your community for additional support and care can make a huge difference during this time. There might be special events in your neighborhood where you can find other pregnant people and resources to connect with. Seek them out.

## EVERTHRIVE ILLINOIS - THE GATHERING

### After You Give Birth

The period after you give birth to your baby is known as the postpartum period or the time after childbirth. You must take care of your body and state of mind, as you may experience many changes after the birth of your baby. During this time, it is very important that you take care of yourself and pay attention to the physical postpartum warning signs so you can prevent any setbacks. These setbacks could be life-threatening, leading to maternal mortality or death.

So pay attention to any physical and emotional issues you are experiencing and talk to someone in your family or circle of friends, and reach out for support. Call your doctor or healthcare clinic if you are experiencing any of the following postpartum symptoms starting up to one year after giving birth.

#### Physical

- Severe headache.
- Dizziness or fainting.
- Changes in your vision.
- Fever.
- Trouble breathing.
- Overwhelming tiredness.
- Chest pain.
- Severe belly pain.
- Severe nausea and throwing up.
- Severe swelling.
- Heavy bleeding – soaking through one or more pads in an hour.
- Changes in blood pressure.

#### Mental & Emotional

- Feeling overpowering guilt, sadness, or panic.
- Being afraid of staying alone.
- Crying, anxiety, or worrying a lot.
- Feeling hopeless or like you are not good enough.
- No energy and finding it hard to concentrate or pay attention.
- Weight loss, weight gain, or appetite changes.
- Scary thoughts about hurting yourself or your baby.
- Finding it hard to do everyday chores.

## CAMPAIGN GUIDELINES

EverThrive Illinois is inviting organizations to participate in this important campaign called "The Gathering" to address maternal mortality and morbidity in Black communities. Your organization is an integral part of the success of this campaign, and we hope you can participate and help increase healthy outcomes for Black birthing people in Chicago.

The following information contains simple guidelines and examples for EverThrive Illinois' "The Gathering" campaign. Please refer to them as you develop communications in support of this campaign. The more consistent we can be across our communications, the stronger our message will be, allowing us to cut through the clutter.

Thank you for helping make our maternal health campaign a great success!

## THE OVERVIEW

EverThrive Illinois is committed to saving lives as co-lead with Alliances Chicago and our partners through the Chicago Collaboration for Maternal Health (CCMh). Research shows that Black women in Chicago are six times more likely to die while pregnant, having a baby, or in the year after pregnancy than their white counterparts. The vast majority of these deaths are preventable.

We believe that through community-centered education, we can address the root causes of the maternal mortality and morbidity crisis in Chicago, including the systemic racism within the health care ecosystem that breeds mistrust.

## THE FRAMEWORK



Education efforts must help people—during and after pregnancy—lead evidence-based information, practical tips, and simple, actionable steps that should help educate and close the gap between pregnant people, providers.

are and targeted audiences. -based information on identifying postpartum warning signs contributing on-made, user-friendly, and interactive landing page, fact sheets, and education can utilize. ncy and postpartum support need to come from people's own choices, are.

## T & END DATE



# Glossary of Terms

- [22 Everthrive The-Gathering-Glossary Final.pdf \(everthriveil.org\)](#)

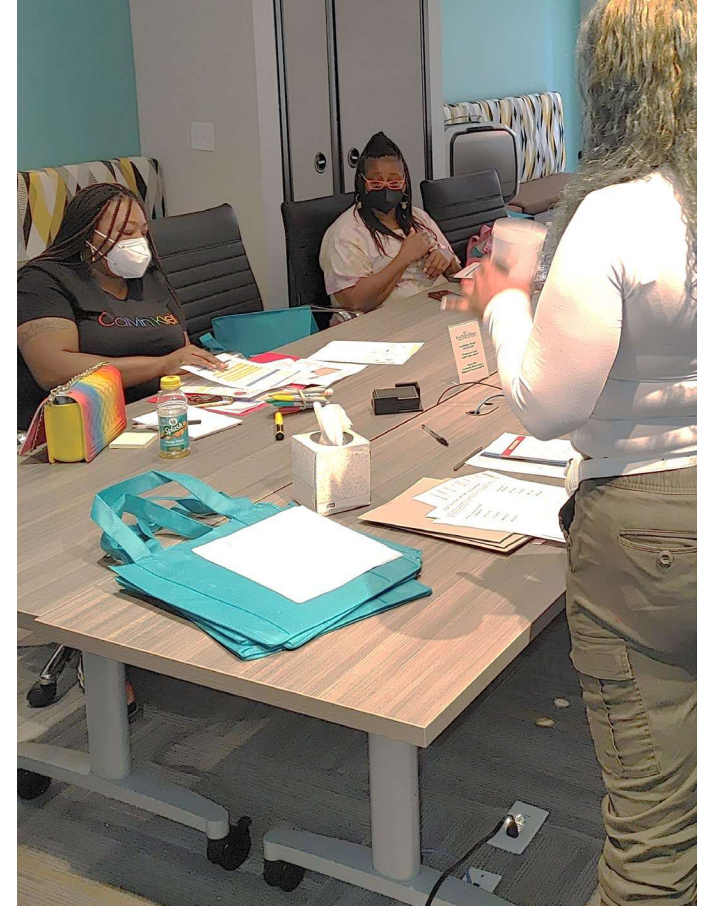


# Key Messages

- You cannot take care of yourself, if you are not well. Real care means increasing awareness about how to take care of yourself after the delivery of a baby
- Maternal mortality refers to the death of a woman from complications of pregnancy. Black women are six times more likely to experience maternal mortality in Chicago
- Know the postpartum warning signs, when to call 911, and how to tell those around you to be an advocate after the birth of a child.
- This is the time to connect to your doctor, clinic or hospital to get access to the healthcare and services you need.

# Join the Gathering!

- **You can help amplify the campaign by:**
  - Using the Campaign Guidelines to amplify the campaign on your own social media channels
  - Share information from our most recent email or [blog](#)
  - Reach out to Tamela Milan-Alexander, Director of Community Engagement [tmilanalexander@everthriveil.org](mailto:tmilanalexander@everthriveil.org)
    - Materials to hand out at health fairs or clinics in our neighborhoods of focus (East and West Garfield Park, Austin, Greater Grand Crossing, Chatham and Englewood)
    - Schedule a short presentation about the campaign at a meeting



# Acknowledgements

**AllianceChicago Project Team:** Dr. Lisa Masinter, Jena Wallander Gemkow, Roxane Padilla, Ta-Yun Yang

**EverThrive Illinois Project Team:** Kirbi Range, Andie Baker, Talibah Johnson, April Thompson, Sheila Sanders, Tamela Milan-Alexander

**Northwestern University Project Team:** Dr. Marquita Lewis-Thames, Dr. Madeline Perry

**University of Illinois At Chicago Project Team:** Dr. Arden Handler, Ashlee Van Schyndel, Renee Odom, Ananya Stoller, Abigail Holicky, Dr. Nadine Peacock

Thank you to the Illinois Perinatal Quality Collaborative and people with lived experience who served as key advisors for this work.

Thank you also to the participating community health centers and social service organizations who participated in this project.

# Celebration And Thank You

[https://www.youtube.com/watch?v=J9rm\\_yrKHTQ](https://www.youtube.com/watch?v=J9rm_yrKHTQ)





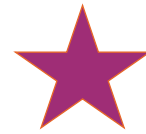


Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ

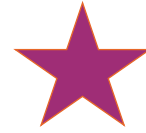
**NICHQ**  
National Institute for  
Children's Health Quality

HEALTHY  
**start**  
TA & SUPPORT CENTER

# Skill-Building Topics



**Birth & Racial Equity Advocate**  
*with Brenda Reyes*



**Putting Your Mask on First**  
*with Dr. Linda Henderson-Smith*



**Powerful Stories, More Powerful  
Storytelling** *with Dr. Magda Peck*



**My Story, My Way**  
*with Stephanye Clarke*

# Here's the plan...

➤ **4 Topics to select from**

➤ **3 Chances to attend**

Session #1 - Thursday @ 11 am

Session #2 - Thursday @ 3:30 pm

Session #3 - Friday @ 10:30 am

➤ **20 Participants per room**

➤ **No Bad Choices**







# Get ready for tomorrow!

*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*

**NICHQ**  
National Institute for  
Children's Health Quality

**HEALTHY**  
**start**  
TA & SUPPORT CENTER

# Day 3

- Optional Wellness Activity @ 8:15 am
- Morning Community Circle @ 9 am
- Morning Plenary @ 9:15 am
- Skill-building Session #3 @ 10:30 am
- Lunch @ 12 pm
- Afternoon Plenary @ 1 pm
- Closing Community Circle @ 2 pm







*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*

**Please take a moment to  
complete the evaluation for  
Days 1 & 2!**

Scan QR code below:



Or visit [link.nichq.org/BostonRMDay2](https://link.nichq.org/BostonRMDay2)

# Quick Break

*We will reconvene at  
3:30 pm*

*Healthy Start Consumer Convening  
Hosted by the Healthy Start TA & Support Center at NICHQ*

