



Prioritizing Patient Narratives & Community Wisdom in Quality Improvement & Implementation Science

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

Public Health OBGYN, Applied Epidemiologist, & Systems Disruptor
Associate Professor

Obstetrics, Gynecology, & Reproductive Sciences
Humanities & Social Sciences
University of California, San Francisco



OUR VISION: SACRED BIRTH FOR BLACK MOTHERS & BIRTHING PEOPLE

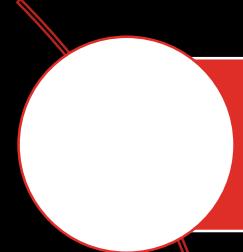
Sacred birth is a radical attitude towards human births, specifically Blackness, Black bodies, and Black births, that regards all birth activities as fundamentally normal, healthy, spiritual, familial, magical, transformative, erotic, communal, emancipatory, and power-activating.

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

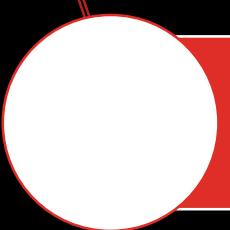
The sacred birth movement advocates for safer, respectful, dignified, high quality “participatory” birth care, conditions, experiences, and outcomes, and improved workforce diversification, development, sustainability, and restoration of Black Midwifery care and Black Doula support models as part of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



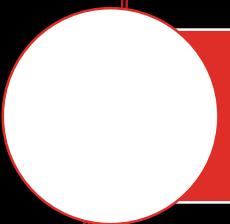
OUR TRUTHS



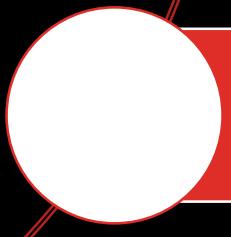
We believe, trust, value, and adore Black people, women, & mothers.



Black people, women, and mothers are worthy.



We protect, prioritize, cite, and amplify Black women's/people's voices, intellectual thoughts, lived experiences, and political activism.



We activate and advance the power and potential, not pathology, of Black people, women, and mothers and our given and chosen kin

BACKGROUND

Follow the Data

Persistent
Death/Near
Death Gap

Primary Drivers

Ethics

Knowledge

Leadership

Secondary Drivers

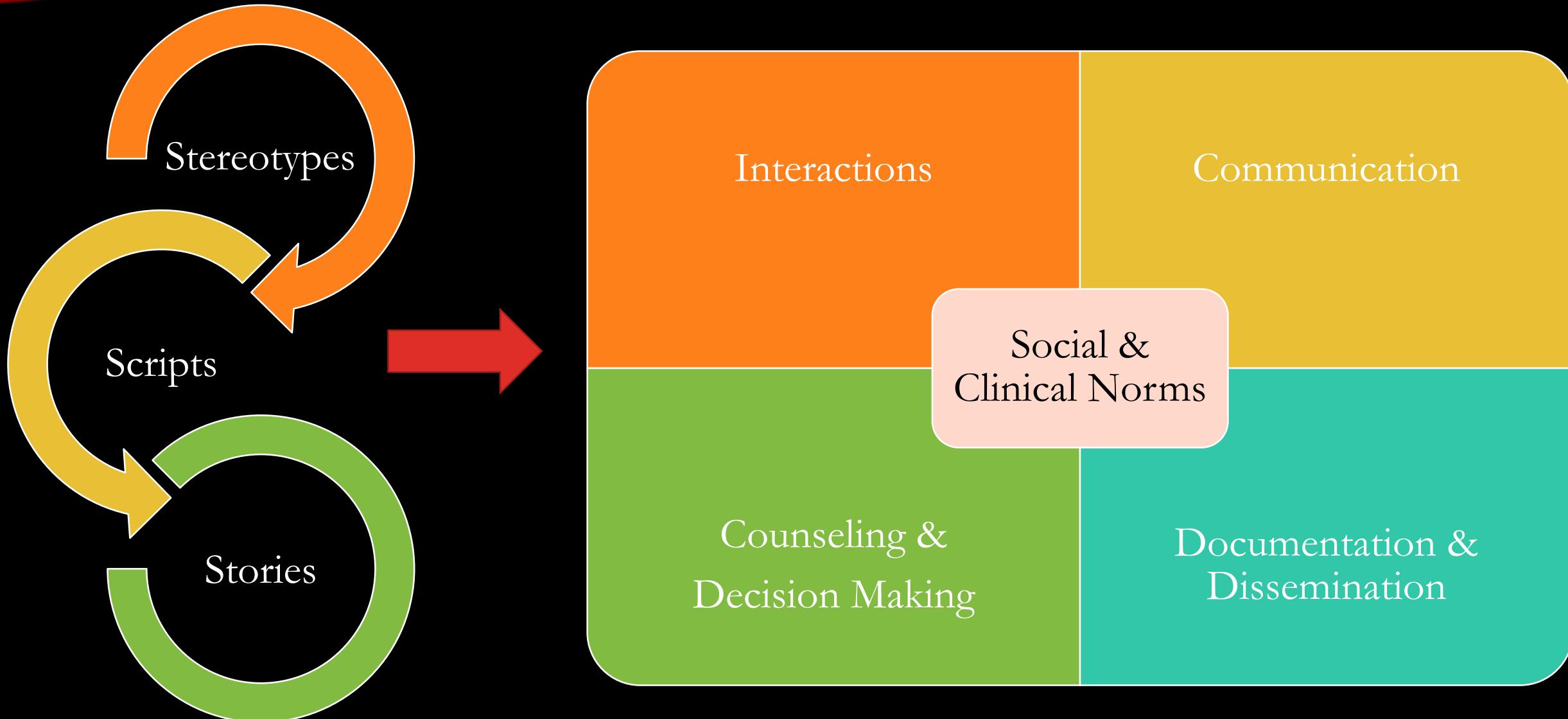
Poor
Science

Lack of Trust,
Truth,
Transparency, &
Transformation

Outcome>>>
Experience

Lack of
Community
Participation

Consequences of Perinatal QI Epistemology: Willful Reproduction of Racism





Consequences of Perinatal QI Epistemology: Willful Reproduction of Racism

Hypervisibility of
Black women as
victims

Structural exclusion
and erasure of Black
women as patient,
community & content
experts

Control, Constraint,
and Censorship of
Black women's
narratives and
intellectual thought

Lack of accountability

Consequences of Perinatal QI Epistemology: Lack of legal or ethical oversight → Separate but equal

SCOTT, K.A. (2021), The Rise of Black Feminist Intellectual Thought and Political Activism in Perinatal Quality Improvement: A Righteous Rage about Racism, Resistance, Resilience, and Rigor.
Feminist Anthropology. DOI.ORG/10.1002/FFA.212045

Hidden ranking system that assigns value and visibility to humanity, scholarship, voices, and lived experiences of white people and people adjacent to/protective of whiteness.

Discounts the credibility of Black women's voices and narratives of their lived experiences resulting in testimonial injustice

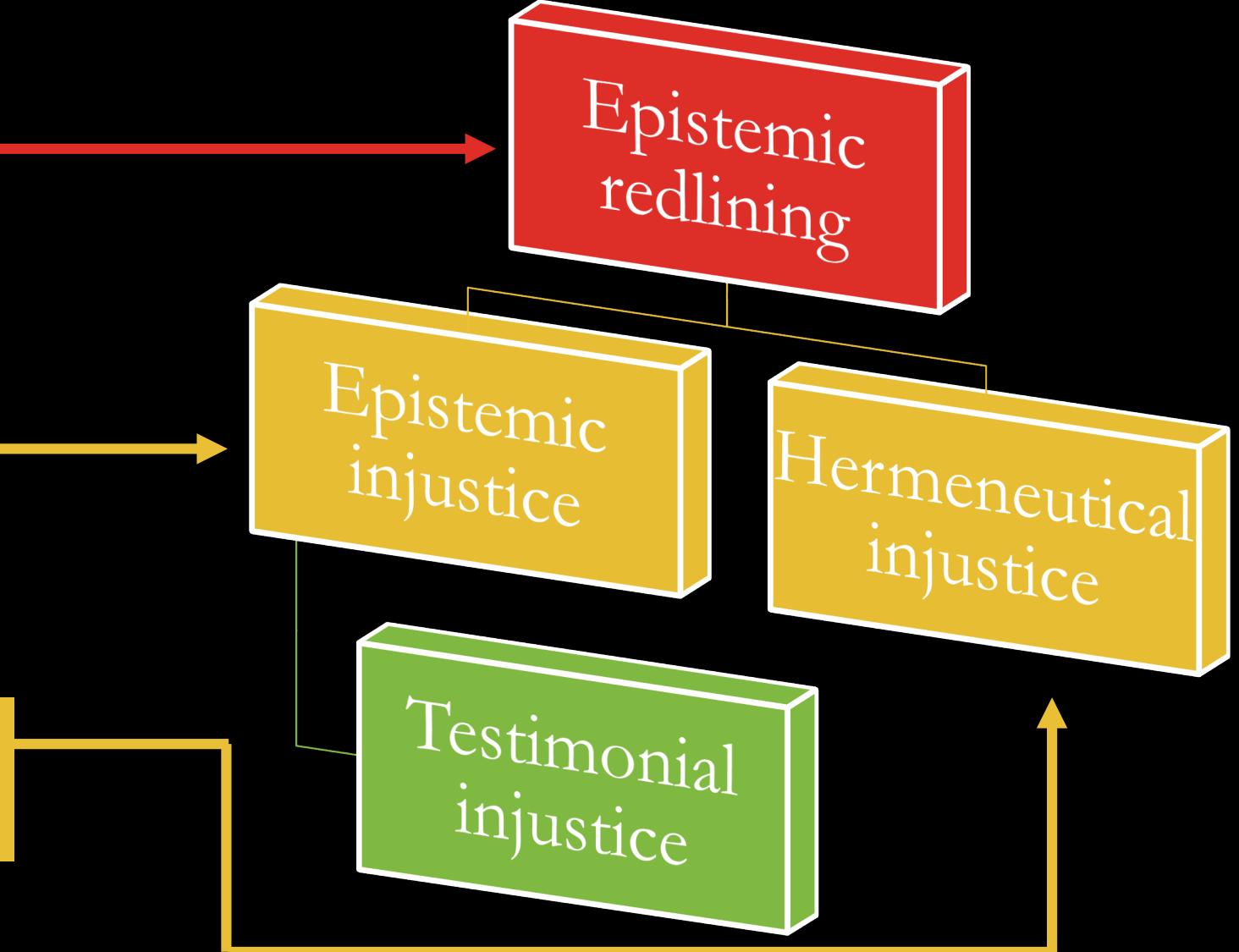
Renders Black women as incapable of making sense of their own experiences, and of having them understood by others

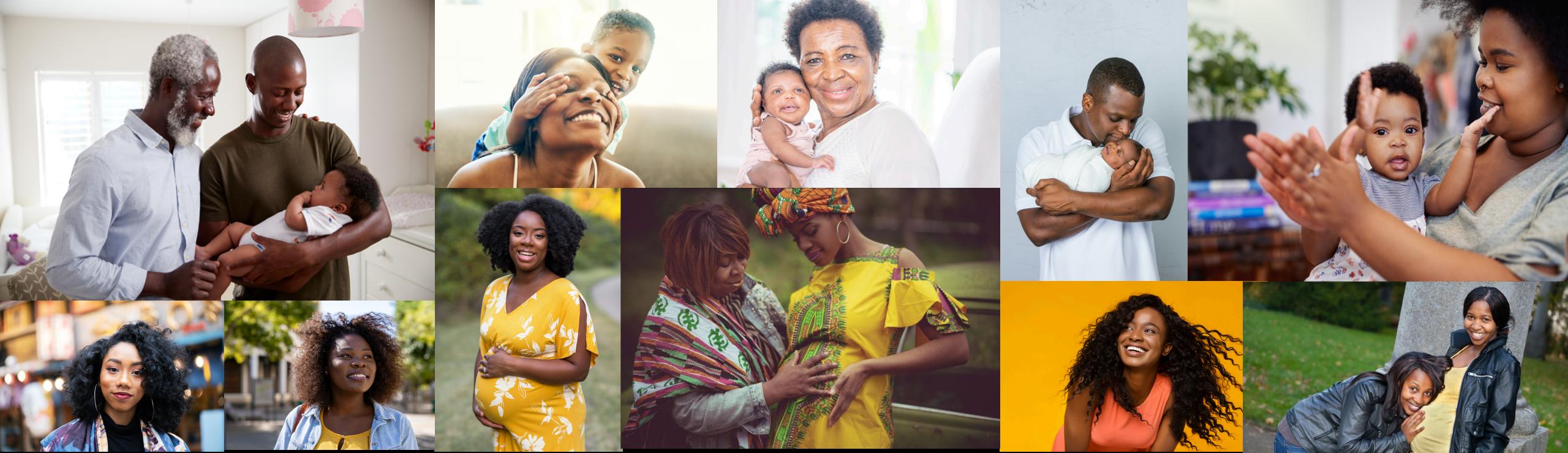
Epistemic redlining

Epistemic injustice

Hermeneutical injustice

Testimonial injustice





Problem Statement

Perinatal Quality Improvement Epistemology reproduces racialized and gendered misconceptions about Blackness, Black womanhood, and Black birthing people that undermine our humanity and justice.



Rationale

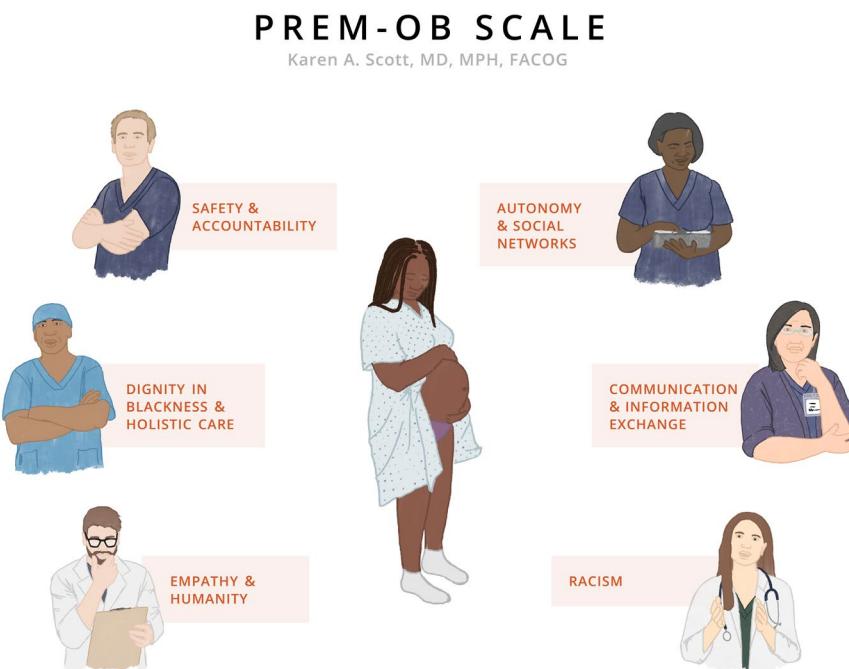
Application of Black feminist anthropological theories and methodologies activate an unapologetic and fierce authority to declare two truths of resistance: (1) the lives of Black women and people with the capacity for reproduction and pregnancy-related experiences are worthy; and (2) Black women and people with the capacity for reproduction and pregnancy-related experiences deserve high-quality care experiences that honor the full expression of our humanity, power, and potential.



THE SACRED BIRTH STUDY: VALIDATION OF A PATIENT-REPORTED EXPERIENCE MEASURE OF OBSTETRIC RACISM®, PREM-OB SCALE™

To date, no validated participatory **PREM-OB Scale™** exists that characterizes the “impact” of the quality of hospital-based perinatal care on the patient experience, as defined for, by, and with **Black mothers and birthing people**, in dignified and equitable partnerships with **Black women-led community-based organizations & Black women scholars**.

THE SACRED BIRTH STUDY:



Aim 1

Validate a patient reported experience measure of obstetric racism, the PREM-OB Scale™, through field testing among 1000 Black mothers and birthing people.

Aim 2

Develop a community centered-people focused hospital-based QI toolkit with Black women-led CBOs.

Aim 3

Examine the association between the PREM-OB scale™, COVID-19 pandemic hospital responses, and birth outcomes and experiences.

STUDY DESIGN & METHODS

Identify and determine a theoretical framework

Develop a preliminary conceptual model

Review existing measures to start developing an item bank

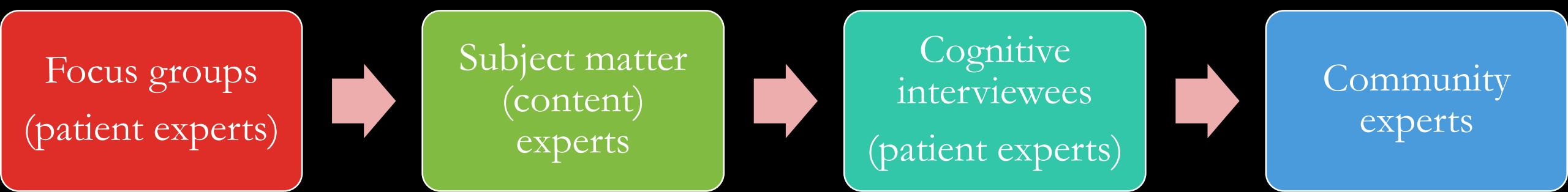
Design new items if needed

Revise your item bank based on key population, ethics, theory, knowledge, science:

- Patient experts
- Community experts
- Content experts

Pilot test and perform psychometric analysis

POPULATIONS STUDIED



MODEL OF PARTICIPATORY QI SCIENCE, PRACTICE, & RESEARCH

Name the problem

Persistent Death/
Near Death Gap

Define and contextualize the
problem through Black Feminist
Intellectual Thought & Political
Activism

Reproductive &
Perinatal
Apartheid

Sojourner
Syndrome

Obstetric
Racism

Propose methods to measure,
monitor, & modify the problem

Black Women-
Led/Serving
CBOs

Transdisciplinary
Transgenerational
Scholarship of
Black Women

Patient-Reported
Experience
Measure of
Obstetric Racism©

Virtual Community
Driven
QI Prioritization

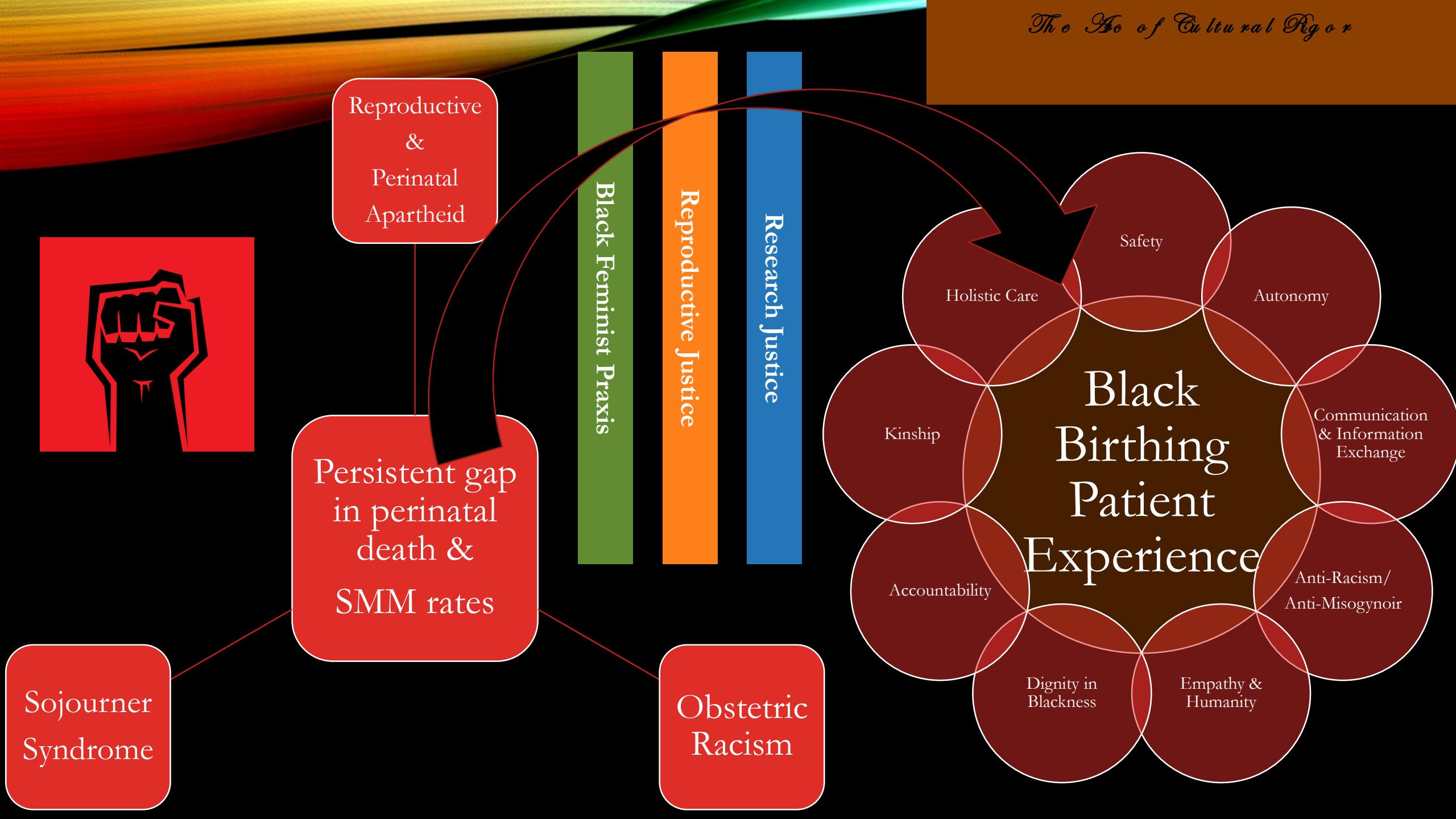
PARTICIPATORY QUALITY IMPROVEMENT MOVEMENT

**Knowledge Generators, Guardians, Incubators,
Accelerators & Disseminators**

QI Experts
Clinicians
Data Scientists
Hospital
Administration

SHIFT
POWER

Black mothers & birthing people
Black community leaders
Black women activists
Black women artists
Black women scholars
In Social Sciences & Public Health



CULTURAL RIGOR

SCOTT KA, BRAY S, MCLEMORE MR. FIRST, DO NO HARM: WHY PHILANTHROPY NEEDS TO RE-EXAMINE ITS ROLE IN REPRODUCTIVE EQUITY AND RACIAL JUSTICE. *HEALTH EQUITY* 2020;4:17-22.



SOCIAL MOVEMENT:

Black Feminist Intellectual Thought & Political Activist in Participatory Perinatal QI



ANALYTIC FRAMEWORK:

Reproductive & Perinatal Apartheid, Sojourner Syndrome, Obstetric Racism



PRAXIS:

Participatory QI Science, Practice , & Research
PREM-OB Scale™, & Community Driven Virtual QI
Prioritization Protocol



VISION:

#SACREDBirth Movement to
#EndObstetricRacism in Hospital Settings

Advancing Cultural Rigor in Perinatal QI Science, Practice, & Research

American Anthropologist / Early View

COMMENTARY

Obstetric Racism: Naming and Identifying a Way Out of Black Women's Adverse Medical Experiences

Karen A. Scott , Dána-Ain Davis 

First published: 14 March 2021

<https://doi.org/10.1111/aman.13559>

Feminist Anthropology / Early View

Situating Research

The Rise of Black Feminist Intellectual Thought and Political Activism in Perinatal Quality Improvement: A Righteous Rage about Racism, Resistance, Resilience, and Rigor

Karen A. Scott

First published: 11 April 2021

<https://doi.org/10.1002/fea2.12045>

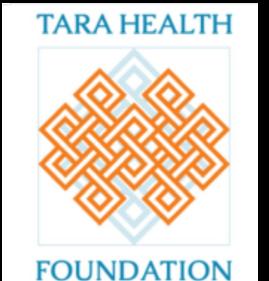


SACRED Birth in the Time of COVID-19

Examining Safety, Autonomy & Kinship, Communication, Racism, Empathy, & Dignity in Blackness
during hospital births in 2020 during COVID-19 Pandemic



California
Health Care
Foundation



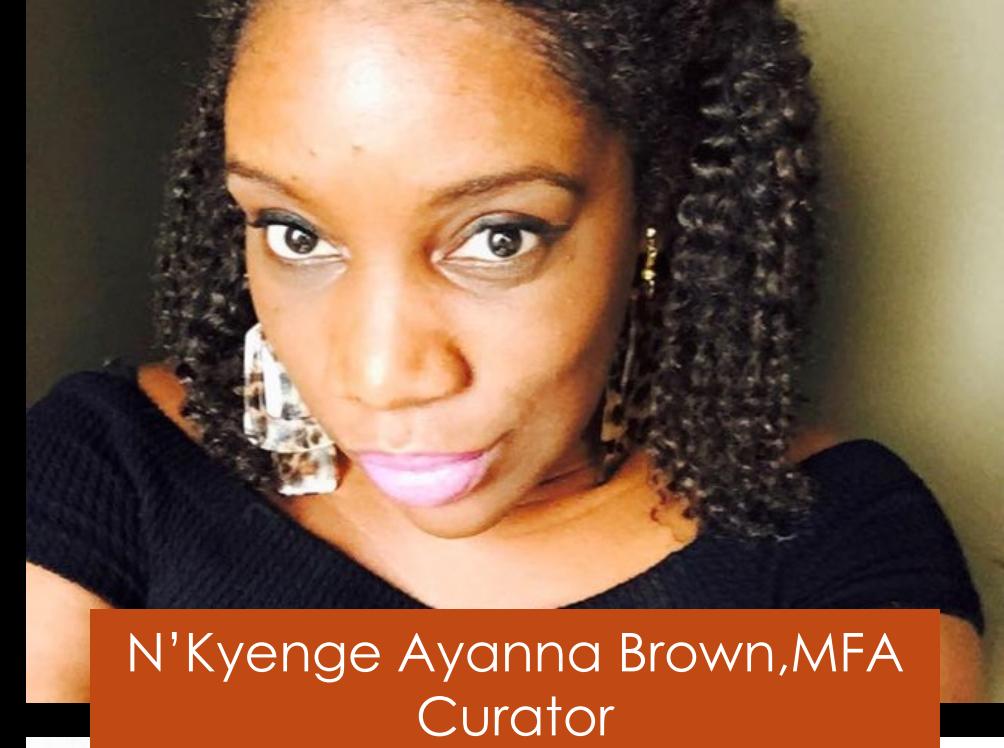
Anonymous
donor



14 Black
women-led
Community
Based
Organizations



Danielle Reid, MBA, Executive Director, DR & Associates
Marketing & Communications Lead



N'Kyenge Ayanna Brown, MFA
Curator



CHEYENNE VARNER
professional doula, graphic designer
founder + owner of

The Educated Birth
www.theeducatedbirth.com
[@TheEducatedBirth](https://www.instagram.com/TheEducatedBirth)

Everyday Birth Magazine
www.everydaybirth.com
[@EverydayBirth](https://www.instagram.com/EverydayBirth)

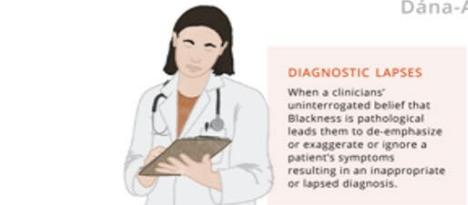
EMAIL
hello@cheyennevarner.com

The SACRED Birth Study

Patient Reported Experience Measure of Obstetric Racism©, PREM-OB Scale™: Methodologies, Meanings, Measures, & Narratives

OBSTETRIC RACISM

Dána-Ain Davis, MPH, Ph.D.



DIAGNOSTIC LAPSES

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



RACIAL RECONNAISSANCE

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



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.



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.

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.



Translation from Theory to Practice



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.



COERCION

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

PREM-OB SCALE

Karen A. Scott, MD, MPH, FACOG



SAFETY & ACCOUNTABILITY



AUTONOMY & SOCIAL NETWORKS



COMMUNICATION & INFORMATION EXCHANGE



RACISM

Illustrations © 2020 Cheyenne Varner

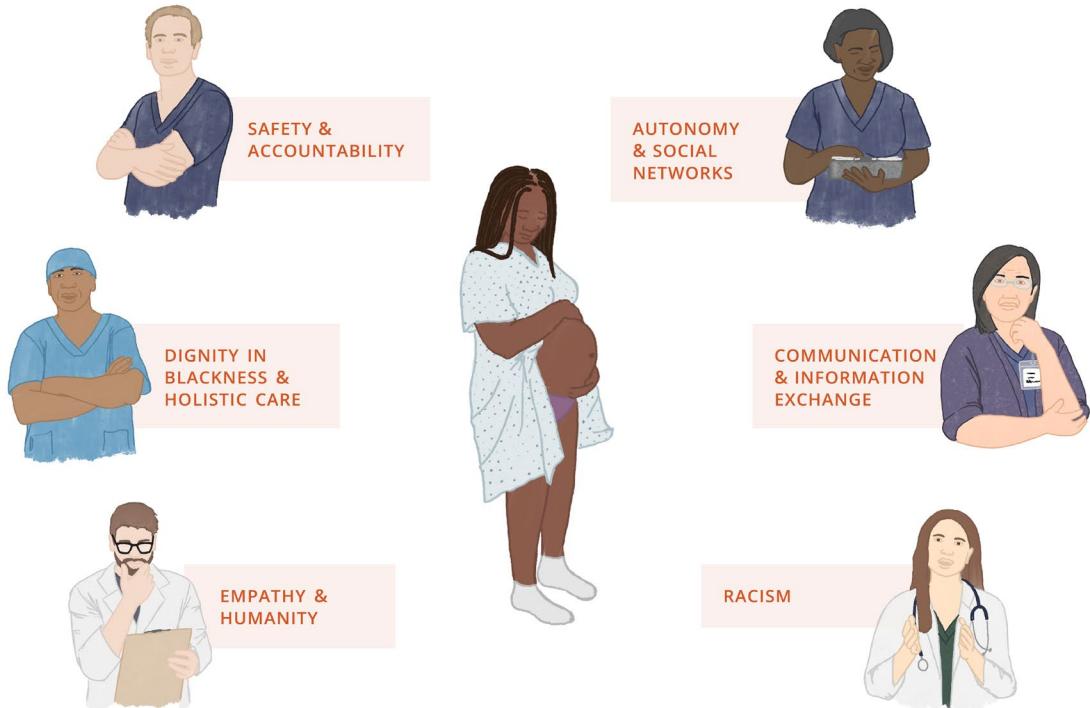
Illustrations © 2020 Cheyenne Varner

Black Birthing Narrative & the PREM-OB Scale™

“The biggest issue I had with my labor and delivery experience is the fact that I developed a birthing plan in writing prior to delivery that was in my chart regarding pain control yet it was not honored. I expressed my need and want for an epidural to anyone who would listen, that cared for me during my time at the hospital, yet somehow I was forced to deliver naturally without any pain medication. This was not because I had a quick labor either. I got to the hospital at 7:00 pm they started my induction at about 10:00 pm and I did not deliver until 6:06 am, so they had ample amount of time to fulfill my need for an epidural. There was a point where my husband was asleep and I could not yell loud enough to wake him due to the amount of pain I was in but I could reach the nurse's button but nobody would respond. I felt like I was in pure hell and it was the worst, most painful, most traumatic experience I have had to endure when it comes to labor and delivery and this is my 4th child.”

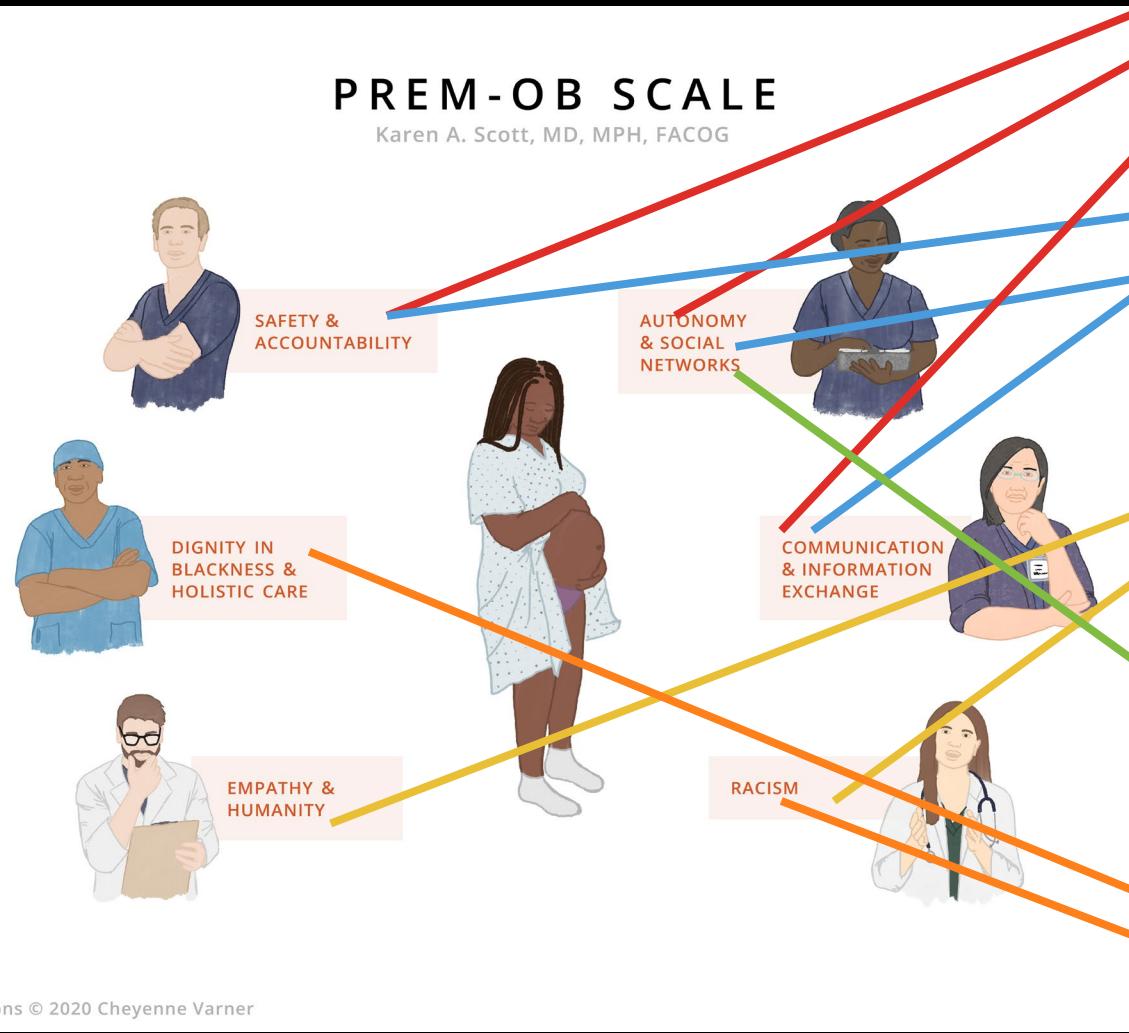
PREM-OB SCALE

Karen A. Scott, MD, MPH, FACOG



Black Birthing Narrative & the PREM-OB Scale™

Scott-Davis Narrative Data Analytic Method



“The biggest issue I had with my labor and delivery experience is the fact that I developed a birthing plan in writing prior to delivery that was in my chart regarding pain control yet it was not honored.

I expressed my need and want for an epidural to anyone who would listen, that cared for me during my time at the hospital, yet somehow I was forced to deliver naturally without any pain medication.

This was not because I had a quick labor either. I got to the hospital at 7:00 pm they started my induction at about 10:00 pm and I did not deliver until 6:06 am, so they had ample amount of time to fulfill my need for an epidural.

There was a point where my husband was asleep and I could not yell loud enough to wake him due to the amount of pain I was in but I could reach the nurse's button but nobody would respond.

I felt like I was in pure hell and it was the worst, most painful, most traumatic experience I have had to endure when it comes to labor and delivery and this is my 4th child.”

QUALITY IMPROVEMENT INNOVATIONS

THE VIRTUAL QUALITY IMPROVEMENT PRIORITIZATION BY AFFECTED COMMUNITIES (V-QPAC) PROTOCOL

PREM-OB Scale™ Domains	Perinatal QI Priorities and Mitigations
Safety & Accountability	<p>Shame, Stigma, Love, Grace, and Dignity: Birthing While Black</p> <p>Patient/Community Feedback in EHR Language and Patient Handoff</p>
Autonomy & Social Capital/Kinship	<p>Black Birthing Rights in Hospital Settings</p> <p>Black Women's/People's Autonomy: Asset vs Threat</p>
Communication & Information Exchange	<p>Pre-Escalation Steps Prior to Calling Hospital Security</p> <p>Use of Mediation with a Professional and Community Representative External to Hospital</p>
Racism	<p>Redesign and Expansion of care team</p> <p>Anti-Racism Community Advisory & Accountability Board/Taskforce</p>
Empathy & Humanity	<p>Human Resources Accountability Metric: What is your Why? and Empathy-specific Competency Based Screening/Interviews</p> <p>SACRED Birth Assessment/Checklist for Black People Focused Care</p>
Dignity in Blackness & Holistic Care	<p>Explicit Informed Consent/Refusal for Every Cervical Exam</p> <p>Racial Equity Caucus for Restoration of Dignity in Blackness for patients, community, clinicians, staff, and physicians with hospital privileges</p>



2021 VISION & BEYOND:

Advancing the **#SACREDBirth QI Movement** to **#EndObstetricRacism** through **#HumanCenteredDesign** approaches, grounded in **#CulturalRigor**, focusing on the South and Midwest
(Where the Data Reside....Follow the Data)

360° Cultural Shifts™: Community-Staff-Nurse-Physician Influencers

Large group trainings

Small group coaching sessions

Illustrated Clinical Narratives

Animated Video Clinical Narratives

Effective Clinical Practice Techniques

Mixed Methods Assessment & Evaluation



Building Hospital and Community Capacity & Capability of **#DiagnosingNDismantlingObstetricRacism** using the first & only validated PREM-OB Scale™ and other novel QI tools, trainings, & techniques

For more information about the SACRED Birth QI Implementation program, visit <https://sacredbirth.ucsf.edu/hospitals-health-centers-and-health-plans>.



THANK YOU!

EMAIL: KAREN.SCOTT2@UCSF.EDU

FOLLOW ME ON TWITTER OR IG: @RJEPIOBWARRIOR @SACRED_PREM_OB

[HTTPS://SACREDBIRTH.UCSE.EDU](https://sacredbirth.ucsf.edu)