



# 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

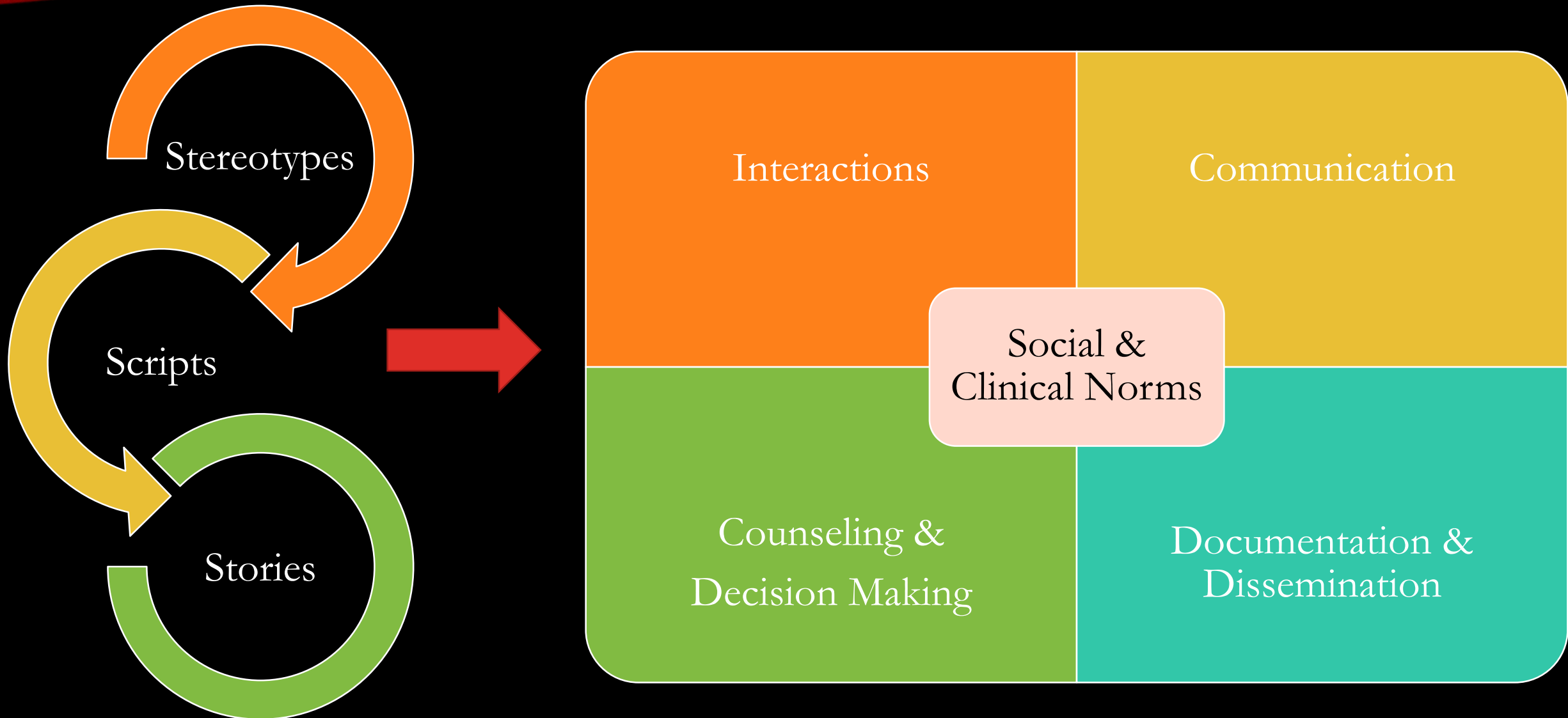
Lack of Trust,  
Truth,  
Transparency, &  
Transformation

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

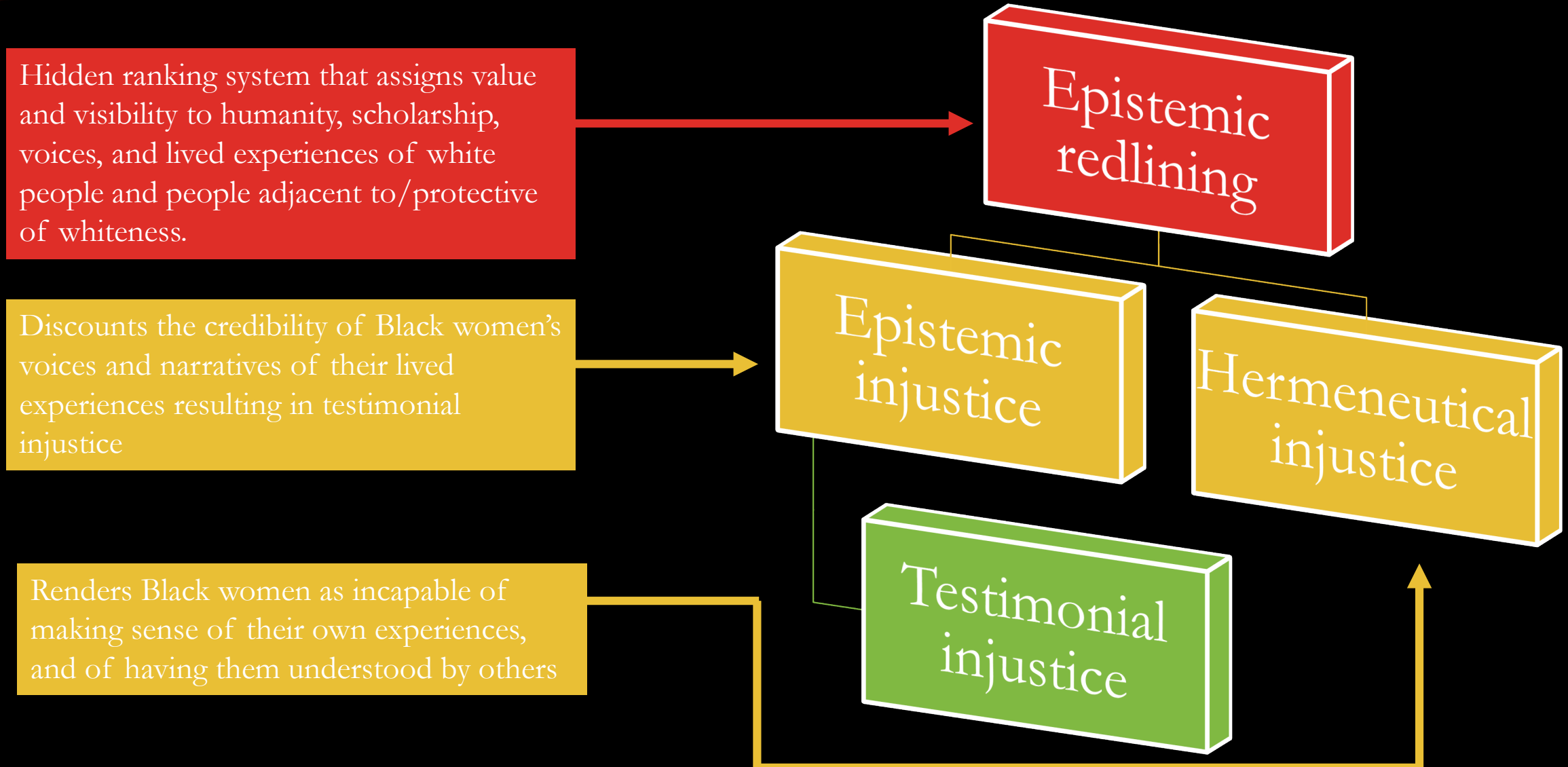
Control, Constraint,  
and Censorship of  
Black women's  
narratives and  
intellectual thought

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*. <https://doi.org/10.1002/FEA2.12045>







## 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™**

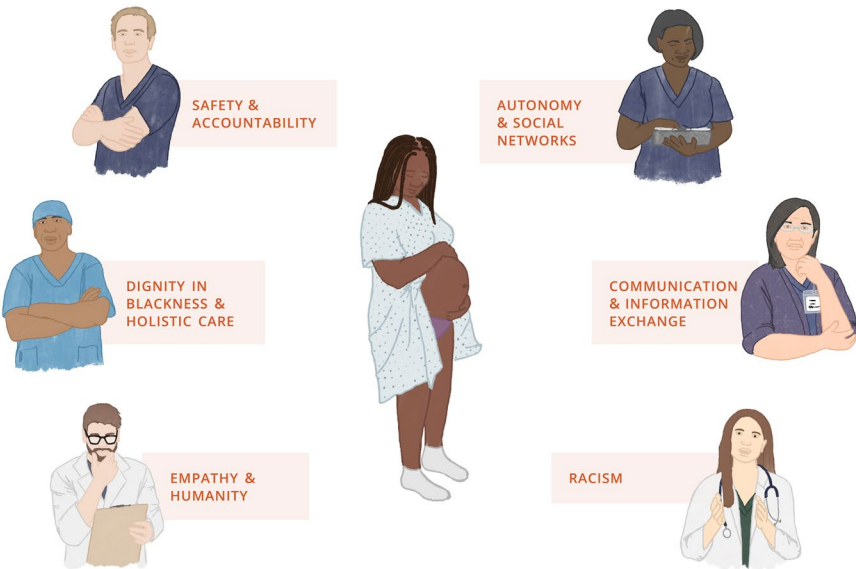
To date, no validated participatory **PREM-OB Scale™** exists that characterizes the “impact” of the quality of hospital-based perinatal care on the patient experience, as defined for, by, and with **Black mothers and birthing people**, in dignified and equitable partnerships with **Black women-led community-based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



# THE SACRED BIRTH STUDY:

## PREM-OB SCALE

Karen A. Scott, MD, MPH, FACOG



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### 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.

@SACRED\_PREM\_OB  
<https://sacredbirth.ucsf.edu>



# 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

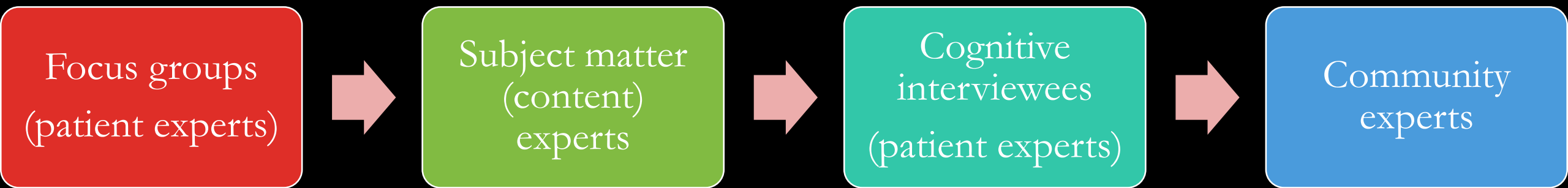
Revise your item bank based on key population, ethics, theory, knowledge, science:

- 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©

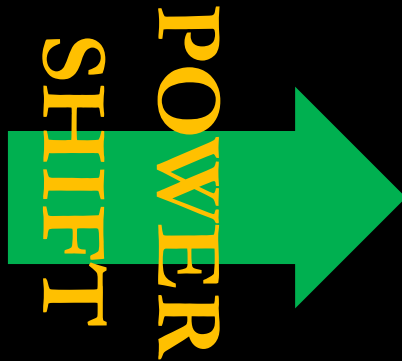
Virtual Community  
Driven  
QI Prioritization



# PARTICIPATORY QUALITY IMPROVEMENT MOVEMENT

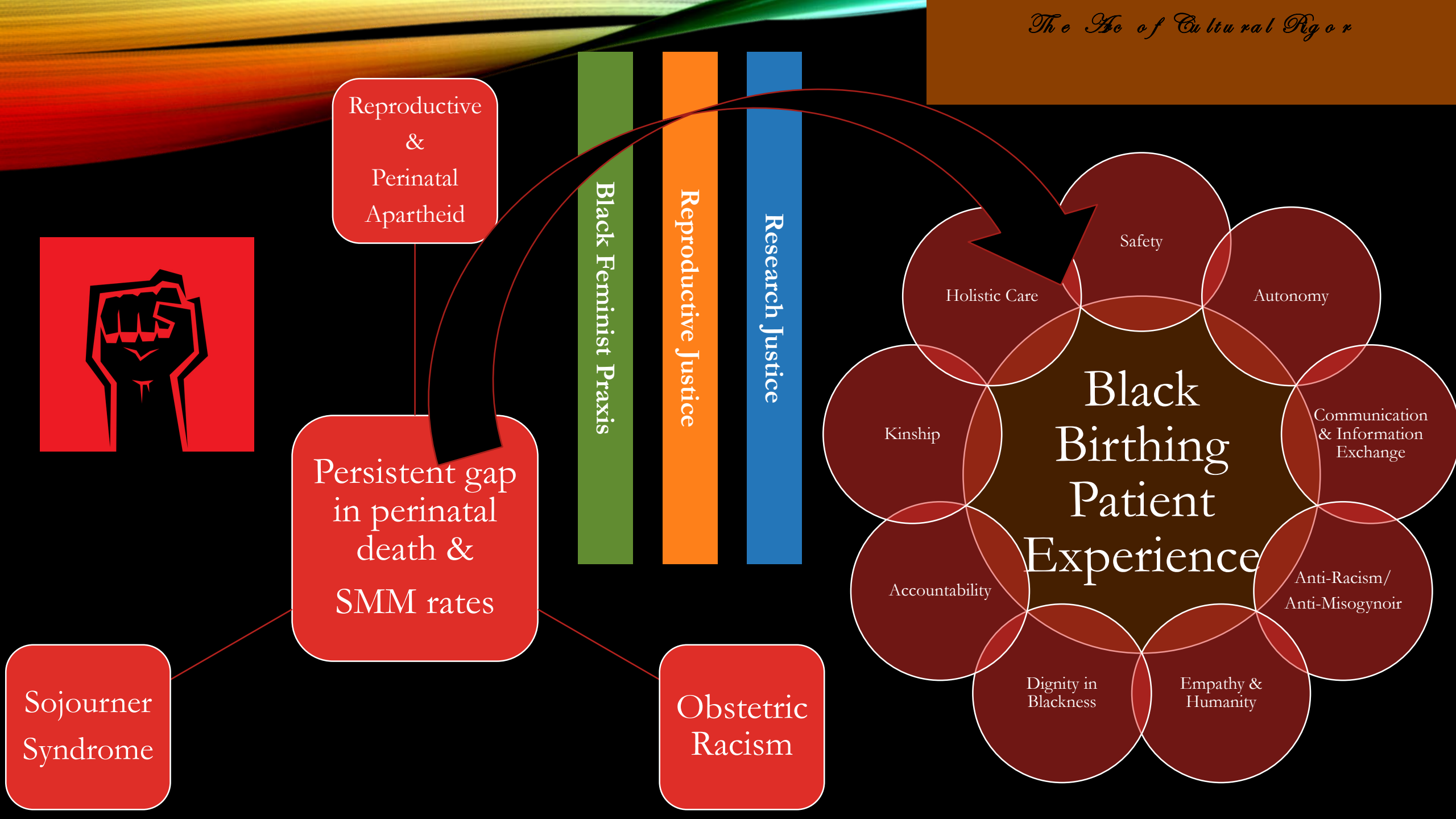
Knowledge Generators, Guardians, Incubators,  
Accelerators & Disseminators

QI Experts  
Clinicians  
Data Scientists  
Hospital  
Administration



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





Reproductive  
&  
Perinatal  
Apartheid

Black Feminist Praxis

Reproductive Justice

Research Justice

Persistent gap  
in perinatal  
death &  
SMM rates

Sojourner  
Syndrome

Obstetric  
Racism

Black  
Birthing  
Patient  
Experience

Holistic Care

Safety

Autonomy

Communication  
& Information  
Exchange

Anti-Racism/  
Anti-Misogynoir

Empathy &  
Humanity

Dignity in  
Blackness

Accountability

Kinship



# 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  
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CALIFORNIA BLACK WOMEN'S  
HEALTH PROJECT



WWW.CABWHP.ORG

14 Black  
women-led  
Community  
Based  
Organizations

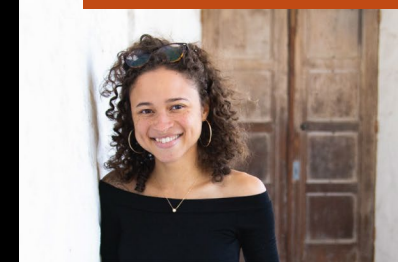




Danielle Reid, MBA, Executive Director, DR & Associates  
Marketing & Communications Lead



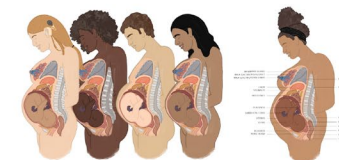
N'Kyenge Ayanna Brown, MFA  
Curator



**CHEYENNE VARNER**  
*professional doula, graphic designer  
founder + owner of*

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EMAIL  
[hello@cheyennevernarner.com](mailto:hello@cheyennevernarner.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.

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.

#### 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.

#### 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.

#### 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.

#### RACIAL RECONNAISSANCE

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

#### SAFETY & ACCOUNTABILITY

#### DIGNITY IN BLACKNESS & HOLISTIC CARE

#### EMPATHY & HUMANITY

#### AUTONOMY & SOCIAL NETWORKS

#### COMMUNICATION & INFORMATION EXCHANGE

#### RACISM

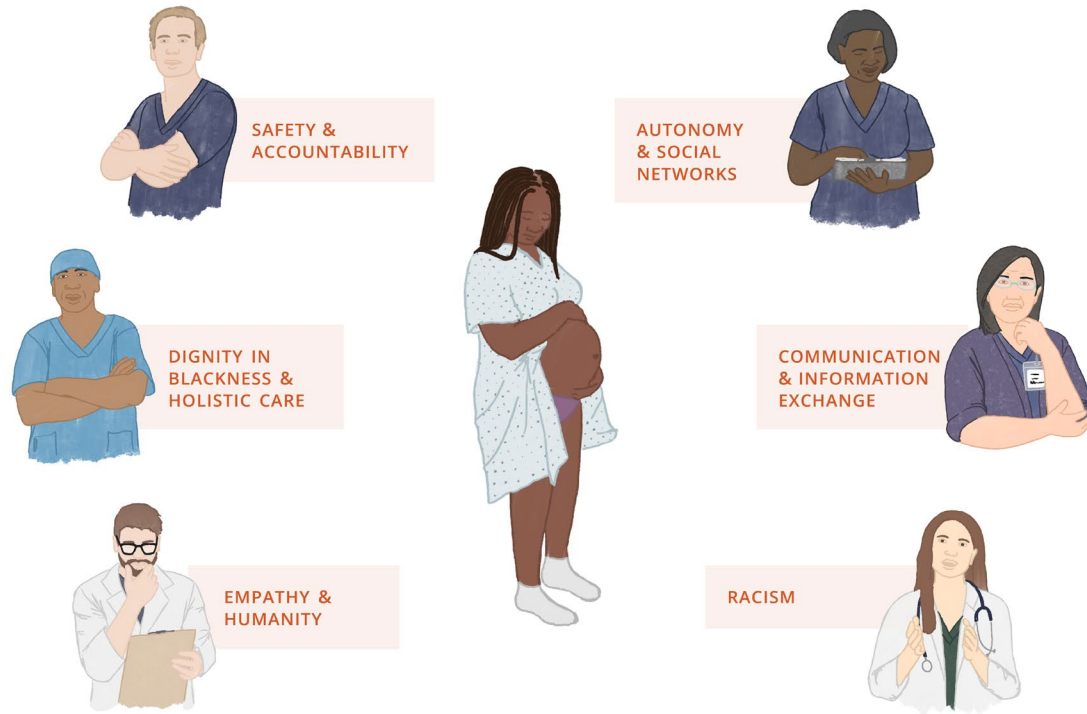


## Black Birthing Narrative & the PREM-OB Scale™

“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



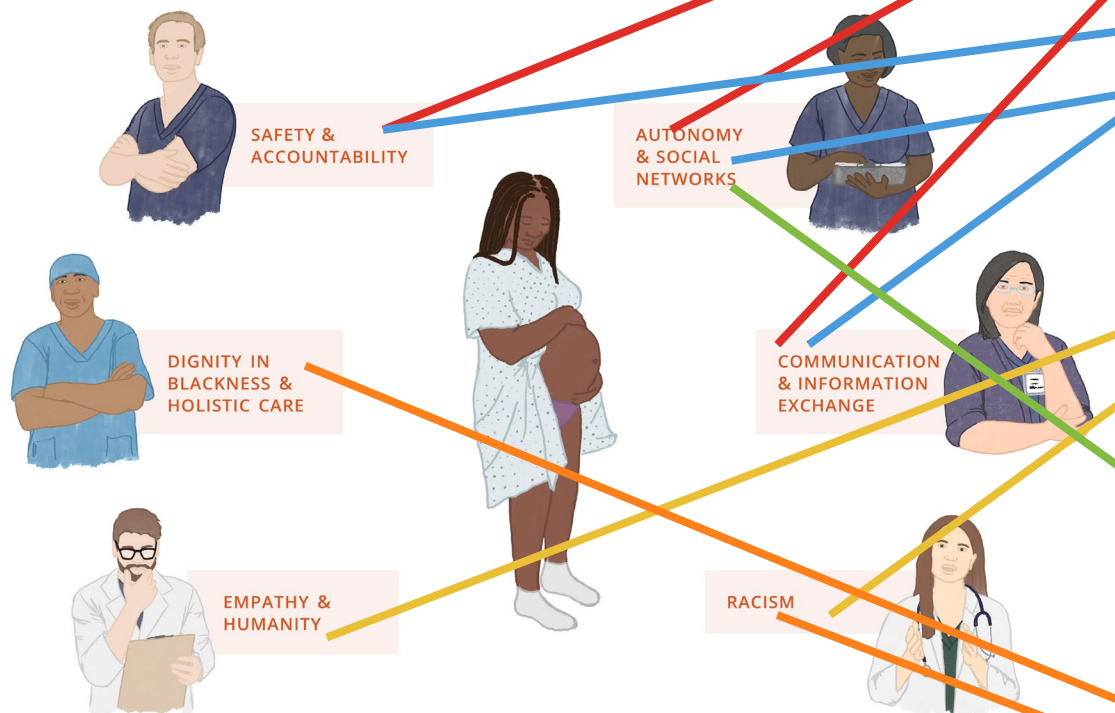


## Black Birthing Narrative & the PREM-OB Scale™

### Scott-Davis Narrative Data Analytic Method

#### PREM-OB SCALE

Karen A. Scott, MD, MPH, FACOG



Illustrations © 2020 Cheyenne Varner

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



**SACRED Birth Community Accountability Partners**





## 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.UCSF.EDU](https://sacredbirth.ucsf.edu)