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

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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.

Adaptation of Sex Positivity by Karen A. Scott, MD, MPH, FACOG on April 11, 2018
OUR TRUTHS

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

2. Black people, women, and mothers are worthy.

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

4. 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

Stereotypes

Scripts

Stories

Interactions

Communication

Social & Clinical Norms

Counseling & Decision Making

Documentation & Dissemination
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


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

@SACRED_PREM_OB
https://sacredbirth.ucsf.edu
STUDY DESIGN & METHODS

1. Identify and determine a theoretical framework
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 based on key population, ethics, theory, knowledge, science:
   - Patient experts
   - Community experts
   - Content experts
6. Pilot test and perform psychometric analysis
POPULATIONS STUDIED

Focus groups (patient experts) → Subject matter (content) experts → Cognitive interviewees (patient experts) → Community experts
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

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

Safety
Autonomy
Communication & Information Exchange
Anti-Racism/Anti-Misogynoir
Dignity in Blackness
Empathy & Humanity
Holistic Care
Accountability
Kinship
Research Justice
Reproductive Justice
Black Feminist Praxis
Reproductive & Perinatal Apartheid
Persistent gap in perinatal death & SMM rates

Sojourner Syndrome
Obstetric Racism

The Arc of 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.

CULTURAL RIGOR

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
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

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


Anonymous donor

California Black Women's Health Project

14 Black women-led Community Based Organizations
Danielle Reid, MBA, Executive Director, DR & Associates
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hello@cheyennevarner.com
The SACRED Birth Study
Patient Reported Experience Measure of Obstetric Racism©, PREM-OB Scale™: Methodologies, Meanings, Measures, & Narratives

Translation from Theory to Practice
"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."
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## QUALITY IMPROVEMENT INNOVATIONS
### THE VIRTUAL QUALITY IMPROVEMENT PRIORITIZATION BY AFFECTED COMMUNITIES (V-QPAC) PROTOCOL

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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!

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