

Black Maternal Health Research Re-Envisioned: Best Practices for the Conduct of Research With, For, and By Black Mamas

*Black Women Scholars and the Research Working Group of
the Black Mamas Matter Alliance**

The purpose of this article is to provide an overview of a forthcoming report entitled Black Maternal Health Research Re-Envisioned: Recommendations for Improving Research on Maternity Care for Black Mamas¹ which provides principles that should underpin the ethical design of clinical, epidemiological, health services, and public health research, specifically, with, for, and by Black Mamas. This article supplements the research rubric developed by the Research Working Group of the Black Mamas Matter Alliance. The full report presents recommendations for improving research on maternal health outcomes for Black Mamas and integrates the BMMA Care Working Group’s Black Paper: Setting the Standard for Holistic Care of and for Black Women. This article begins by defining the problem and the inherent assumptions necessary to determine the positionality of the research rubric and report. Fundamentally, we believe the conduct of research has historically been unethical and inhumane specific to Black Mamas. We then turn to historical perspectives and the conceptual framework used to develop the research rubric. The framework includes Birth Justice, Reproductive Justice, Human Rights, Black Feminism, Womanism, and Research Justice. Next, we synthesize the intersections of the holistic care report and use those principles to outline how they apply to research. Finally, we present the re-envisioning of research from the perspective of reproductive justice and why this approach is optimal in the current landscape of health services provision, law, policy, and science.

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¹ The term Black Mamas is inclusive of all birthing persons (e.g., cis, trans, non-binary, queer and gender nonconforming individuals) of African descent (e.g., Afro-Latinx, African-American, Afro-Caribbean, Black, and African Immigrants living in the United States).

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INTRODUCTION

In 1906, the national black leader W. E. B. Du Bois challenged [the] bleak forecast [of Black health and life expectancy] and countered arguments of inherent black inferiority in *The Health Physique of the Negro American*, proceedings drawn from an Atlanta conference on black health. The conference findings pointed to the impact of environmental and social conditions on black morbidity and mortality rates. Commenting on the higher black rates, Du Bois noted that ‘the present differences in mortality seem to be sufficiently explained by conditions of life.’²

In the last decade, there has been increased awareness of research injustice³ and the need for reproductive justice⁴ in the context of advocacy and policy. Research injustice, is a situation or circumstance where community voices and experiences are dismissed or ignored, information is inaccessible (whether through jargon, cost, money, hidden in databases, behind paywalls, lack of translations), narratives exclude or misrepresent community experiences; and communities lack control over the production, documentation, possession, and dissemination of their own data or stories.⁵

Conversely, reproductive justice is a theory, practice, and strategy that is grounded in four principles.⁶ Simply put, reproductive justice posits that: (1) every person has the right to decide if and when to become pregnant, and to determine the conditions under which they will birth and create family; (2) every person has the right to decide they will not become pregnant or have a baby, as well as have accessible and available options to prevent or end pregnancy; (3) individuals have the right to parent children they already have with dignity, with the necessary social supports, in safe environments and

² SUSAN L. SMITH, *SICK AND TIRED OF BEING SICK AND TIRED: BLACK WOMEN’S HEALTH ACTIVISM IN AMERICA, 1890–1950*, at 8 (1995).

³ See generally Research Justice: Methodologies for Social Change (Andrew J. Jolivet ed., 2015).

⁴ See generally LORETTA J. ROSS & RICKIE SOLINGER, *REPRODUCTIVE JUSTICE: AN INTRODUCTION* (2017).

⁵ See Andrew J. Jolivet et al., *Part One* of RESEARCH JUSTICE, *supra* note 3, at 1, 1.

⁶ See ROSS & SOLINGER, *supra* note 4, at 9–10.

healthy communities, and without fear of violence from individuals or the government; and (4) individuals have the right to disassociate sex from reproduction as healthy sexuality and pleasure are essential components to whole and full human life.

While some clinicians and educators have prioritized incorporating reproductive justice into curriculums,⁷ this prioritization is severely lacking within the research enterprise, the results of which constitute the foundation of clinical care and education. Many all-White teams and funders are attempting to retrofit their mission, vision, and values in attempts to address poor health outcomes.⁸ However, the research working group of Black Mamas Matter Alliance believes it is important to invoke a scientific revolution that centers Black Mamas and communities to determine which research questions are most important to them, what research questions should be prioritized, and what methods and analytic procedures should be used to provide meaningful data that should inform policy, funding decisions, and health services provision.

A forthcoming report entitled *Black Maternal Health Research Re-Envisioned: Recommendations for Improving Research on Maternity Care for Black Mamas*⁹ is one recent attempt to fill this gap and remedy the lack of citable principles that should underpin the ethical design of clinical, epidemiological, health services, and public health research, specifically, with, for, and by Black Mamas. The term Black Mamas is inclusive of all birthing persons (e.g., cis, trans, non-binary, queer and gender nonconforming individuals) of African descent (e.g., Afro-Latinx, African-American, Afro-Caribbean, Black, and African Immigrants).

The Black Mamas Matter Alliance (BMMA) is a national network of Black women-led organizations and multi-disciplinary professionals who work to ensure that all Black Mamas have the rights, respect, and resources to thrive before, during, and after pregnancy. The alliance grew out of an initial partnership project between the Center for Reproductive Rights and SisterSong Women of Color Reproductive Justice Collective called the Black Mamas Matter Project. In its initial form, BMMA was made up of four working groups (Care, Policy, Research, and Culture Shift) that served

⁷ See generally Dázon Dixon Diallo, *HIV Prevention and Reproductive Justice: A Framework for Saving Women's Lives*, in RADICAL REPRODUCTIVE JUSTICE: FOUNDATIONS, THEORY, PRACTICE, CRITIQUE 340 (Loretta J. Ross et al. eds, 2017); Loretta J. Ross, *Conceptualizing Reproductive Justice Theory: A Manifesto for Activism*, in RADICAL REPRODUCTIVE JUSTICE, *supra*, at 170; Andrea Smith, *Beyond Pro-Choice Versus Pro-Life: Women of Color and Reproductive Justice*, in RADICAL REPRODUCTIVE JUSTICE, *supra*, at 151; Rachel R. Hardeman et al., *Structural Racism and Supporting Black Lives—The Role of Health Professionals*, 375 NEW ENGL. J. MED. 2113 (2016); Brenda Pereda & Margaret Montoya, *Addressing Implicit Bias to Improve Cross-Cultural Care*, 61 CLINICAL OBSTETRICS & GYNECOLOGY 2 (2018).

⁸ See, e.g., Vanessa Daniel, *Opinion, Philanthropists Bench Women of Color, the M.V.P.s of Social Change*, N.Y. TIMES (Nov. 19, 2019), <https://www.nytimes.com/2019/11/19/opinion/philanthropy-black-women.html> [<https://perma.cc/Q7P6-M2AH>].

⁹ BLACK MAMAS MATTER ALLIANCE, BLACK MATERNAL HEALTH RESEARCH RE-ENVISIONED: RECOMMENDATIONS FOR IMPROVING RESEARCH ON MATERNITY CARE FOR BLACK MAMAS (forthcoming 2020).

to develop the alliance's perspective and foundation as it related to its goals around culture shift, policy, service provision, and research in maternal health. The Research Working Group was composed of entry- and mid-level public health and clinical practitioners, researchers, and doctoral students, who were guided by experienced and senior-level academic and community-based researchers, clinicians, midwives, and reproductive justice advocates and authors.

The purpose of this Article is to provide an overview of the full research report and to supplement the research rubric developed by the Research Working Group of the Black Mamas Matter Alliance. The full report written by the Research Working Group presents recommendations for improving research on maternal health outcomes for Black Mamas and integrates the BMMA Care Working Group holistic care principles defined by the Care Working Group's *Black Paper: Setting the Standard for Holistic Care of and for Black Women*¹⁰ for conducting research with, for, and by Black Mamas. The target audience for this Article and the full report is researchers, funders, law students, lawyers, policy makers, public health practitioners, community leaders, advocates, and all others engaged in maternal and reproductive health.

This Article begins with defining the problem and the inherent assumptions necessary to determine the positionality of the research rubric and report. We then turn to historical perspectives and the conceptual framework used to develop the research rubric. Next, we synthesize the intersections of the holistic care report and use those principles to outline how they apply to research. Finally, we present the re-envisioning of research from the perspective of reproductive justice and why this approach is optimal in the current landscape of health services provision, law, policy, and science.

I. ASSUMPTIONS AND TRANSPARENCY

All scientific inquiry emerges from certain foundational assumptions. The present article is no different. The BMMA Research Working Group is committed to transparency in enumerating the assumptions that underpin research we conduct and envision. Transparency and replicability are two hallmarks of science and, therefore, we believe they should be illuminated when reporting best practices, principles, and guidelines that inform research with, for, and by Black Mamas.

The three major assumptions of the BMMA Research Working Group relative to this analysis are: (1) there are no solutions or interventions for improved Black maternal health that Black women themselves do not al-

¹⁰ See BLACK MAMAS MATTER ALLIANCE, <https://blackmasmatter.org/> [<https://perma.cc/4A4M-5WJX>].

ready possess;¹¹ (2) the “shame and blame” narratives that dominate much of the discourse about data on Black Mamas is not insightful or helpful and perpetuates a dangerous myth that White people serve as a default standard for the rest of the population;¹² and (3) current conduct of research—specifically the dissociation of social and clinical determinants of health—is both problematic and unethical.

The first assumption is grounded in a gold standard of clinical care provision: that people who experience a health condition are the experts of their own experience. Patient history has long served as a gold standard in algorithmic management of symptoms, health assessments, diagnostics, and treatments. We believe that the same standard should exist when conducting research with, for, and by communities most burdened by a condition. Additionally, if communities are trusted to recognize, diagnose, and communicate changes in their health status, they too possess particular insights into the interventions necessary to ameliorate these conditions.

The second assumption is grounded in a methodological problem that has been driven by research methods. Epidemiologic methods have contributed to a methodological problem. This is best manifested in the notion that “Black race” is a risk factor that is associated with many poor health outcomes across the reproductive spectrum.¹³ Race is not the risk factor—racism is.¹⁴ Black race is an exposure variable—in other words, it is a characteristic of a population; however, it has been used in statistical models as an independent variable; meaning it can be manipulated in a scientific experiment like temperature or feedings.¹⁵ There is nothing inherent about Black skin that is physiologically different from any other type of skin except its capacity to overexpose those who have it to racism. This is a methodological problem—driven by research methods.

The third factor that contributes to unjust methodological approaches in the conduct of research is the dissociation of social and clinical determi-

¹¹ BLACK MAMAS MATTER ALLIANCE, SETTING THE STANDARD FOR HOLISTIC CARE OF AND FOR BLACK WOMEN (2018), http://blackmamasmatter.org/wp-content/uploads/2018/04/BMMA_BlackPaper_April-2018.pdf [<https://perma.cc/NX27-AYEK>].

¹² See Karen A. Scott et al., *An Inconvenient Truth: You Have No Answer That Black Women Don't Already Possess*, BLACK WOMEN BIRTHING JUSTICE (Oct. 31, 2018), <https://www.blackwomenbirthingjustice.org/single-post/2018/10/31/An-inconvenient-truth-You-have-no-answer-that-Black-women-don%E2%80%99t-already-possess> [<https://perma.cc/88JE-L4BN>].

¹³ See Karen A. Scott et al., *The Ethics of Perinatal Care for Black Women: Dismantling the Structural Racism in “Mother Blame” Narratives*, 33 J. PERINATAL & NEONATAL NURSING 108, 109 (2019).

¹⁴ For an example of this notion, see *Peripartum Cardiomyopathy (PPCM)*, AM. HEART ASS'N (last reviewed Jul. 31, 2015), <https://www.heart.org/en/health-topics/cardiomyopathy/what-is-cardiomyopathy-in-adults/peripartum-cardiomyopathy-ppcm#.W50pE62ZPBK> [<https://perma.cc/UD6W-953M>].

¹⁵ See Monica R. McLemore, *To Prevent Women from Dying in Childbirth, First Stop Blaming Them*, SCI. AM. (May 1, 2019), <https://www.scientificamerican.com/article/to-prevent-women-from-dying-in-childbirth-first-stop-blaming-them/> [<https://perma.cc/QJ97-UAN4>].

nants of health. Despite robust theory that social and clinical determinants of health are intimately related, there is a functional separation of the two in research, publications, and guidelines. The work of epidemiologists such as Professors Nancy Krieger¹⁶ and David Williams¹⁷ have shown that eco-social theory and critical race theory are essential to understanding the distributions of health and disease in populations. In other words, the lack of consideration of structural factors leads to systematic underestimation or misappraisal of Black Mamas' clinical risk factors and the lack of consideration of structural factors increases said risks. For example, access to health insurance, transportation, childcare, housing, education, food insecurity, carceral involvement, and other social determinants have been described and associated with poorer health outcomes.

Compounding these issues are proposed fixes to so-called "health disparities" that focus on quality improvement without equity, such as those centered on individuals that fail to acknowledge that structures of power are often out of reach for marginalized communities. All of these problems are reinforced by silos that exist in the provision of clinical health services where much of the research that drives interventions for improved health outcomes is conducted. The divestment of the social safety net has resulted in increased investment in individual risk stratification and responsiveness strategies¹⁸ because of an absence of system recognition and responsiveness to structural factors.

Enumerating these assumptions is a part of ensuring transparency. Distinguishing methods—tools and procedures used to conduct research—from methodology—the justification and rationalization about why those methods are appropriate—is just one component of transparency. The second component of transparency is determining an epistemological stance. Epistemology is the theory of knowledge production; specific to science, it is the methods, plus validity, scope, depth, and reporting of findings.¹⁹ This concept is important because early science was conducted using a positivist perspective, a belief that science could unlock discoveries and provide insight to a single truth.²⁰ Currently, we scientifically recognize the capacity for multiple truths (i.e., a post-positivist perspective)²¹ that acknowledges that there are multiple ways of knowing and that truth is underpinned by the fact that

¹⁶ See Julia B. Ward et al., Commentary, *How Do We Assess a Racial Disparity in Health? Distribution, Interaction, and Interpretation in Epidemiological Studies*, 29 ANNALS OF EPIDEMIOLOGY 1, 3 (2019).

¹⁷ See NANCY KRIEGER, EPIDEMIOLOGY AND THE PEOPLE'S HEALTH: THEORY AND CONTEXT 202–35 (2011).

¹⁸ See David R. Williams et al., *Racism and Health: Evidence and Needed Research*, 40 ANN. REV. PUB. HEALTH 105, 105–25 (2019).

¹⁹ See Elizabeth A. Howell et al., *Reduction of Peripartum Racial and Ethnic Disparities: A Conceptual Framework and Maternal Safety Consensus Bundle*, 131 OBSTETRICS & GYNECOLOGY 770, 773 (2018).

²⁰ See RESEARCH JUSTICE, *supra* note 3, at 6–7.

²¹ See Eric F. Tanlaka et al., *Postpositivist Critical Multiplism: Its Value for Nursing Research*, 6 NURSING OPEN 740, 740–41 (2019).

such truth is conditional, dynamic, and contingent upon positionality, lived experience, and perspective. Naming these assumptions allows for a broader visualization of how research could and should be conducted differently. However, prior to presenting the best practices and guidelines for the conduct of research with, for, and by Black Mamas, it is important to understand the historical perspectives that have contributed to research injustice and why the research enterprise must shift to improve health outcomes and resolve health inequities.

II. HISTORICAL PERSPECTIVES

Reimagining research conducted with, for, and by Black Mamas begins with an acknowledgement of the violence and trauma inflicted—and that which continues to be inflicted—on Black bodies, families, and communities by those who invoked the progression of science.²² The justification for this violence has been rooted in the racist belief that African people were less than human.²³ Although recent attention has focused on ethical violations in health services provision, including the United States (U.S.) Public Health Service Syphilis Study at Tuskegee, a plethora of atrocities have been well chronicled.²⁴ Experimentation on the bodies of Black women was central to the advancement of science and healthcare, and provided the foundation for scientific racism.²⁵ This experimentation included, but was not limited, to the dissection, study, and display of Sarah Baartman's body; the experimentation by Dr. J. Marion Sims (the “father of modern gynecology”) on Anarcha Westcott, Betsey Harris, and Lucy Zimmerman without anesthesia; and the unauthorized use of Henrietta Lacks' cervical cells for biomedical research.²⁶

As egregious as these examples are, it is necessary to point out why these studies are unethical since several core issues remain unaddressed and are still occurring in research conducted today. The discrimination, mistreatment, and racism experienced by Black Mamas in the clinical environment—documented by BMMA and other researchers—extends to participation in research. Specifically, the lack of informed consent (e.g., Tuskegee),²⁷ lack of acknowledgment or compensation for scientific awards

²² See *id.*

²³ See generally Marcella Alsan et al., *The Tuskegee Study of Untreated Syphilis: A Case Study in Peripheral Trauma with Implications for Health Professionals*, 35 J. GEN. INTERNAL MED. 322 (2019).

²⁴ See IBRAM X. KENDI, STAMPED FROM THE BEGINNING: THE DEFINITIVE HISTORY OF RACIST IDEAS IN AMERICA 38–39 (2016).

²⁵ HARRIET A. WASHINGTON, MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICAN FROM COLONIAL TIMES TO THE PRESENT 25–51 (2006).

²⁶ See, e.g., Zinzi D. Bailey et al., *Structural Racism and Health Inequities in the USA: Evidence and Interventions*, 389 LANCET 1453 (2017).

²⁷ See DEIRDRE COOPER OWENS, MEDICAL BONDAGE: RACE, GENDER, AND THE ORIGINS OF AMERICAN GYNECOLOGY 35–37 (2017); see also Deirdre Cooper Owens & Sharla

and discoveries (e.g., Henrietta Lacks),²⁸ explicit coercion of communities of color and inflicted harm (e.g., Puerto Rico Birth Control Pill Studies),²⁹ criminalization of pregnant people and punitive uses of various contraceptive methods, and involuntary sterilization (e.g., Norplant).³⁰

A. Lack of Informed Consent

In many studies, researchers have manipulated ethical principles, specifically informed consent.³¹ Many historical and current studies have assumptions rooted in racism, classism, sexism, heterosexism, and transphobia, particularly those that assume there is something inherently wrong with Black people or that there are essential differences among and between people that are rooted in erroneous biological conceptions of race.³² More specifically, when researchers misrepresent study purpose, methodology, or misappropriate community support, trust, and goodwill—as measured by the proximity of funders³³ and research teams to Black people and institutions—gatekeeping occurs and harm (specifically peripheral trauma such as increases in all-cause mortality in the impacted populations)³⁴ can result. Special attention must be paid to funders in the conduct of clinical research and healthcare provision. As noted in her work *The Price of Civil Rights: Black Lives, White Funding, and Movement Capture*, Megan Ming Francis outlines the impact that funders had during the civil rights mobilization of the legal community.³⁵ The interactions between funders and social movement organizations influenced the direction of the movement and ultimately steered the campaigns away from the priorities of community activists. A similar dynamic exists in clinical research and healthcare provision. One glaring example is the Tuskegee Study of Untreated Syphilis in the Male Negro, which began as a Public Health Service funded study, using tax dollars in 1932. In addition to funder exploitation, the study researchers exploited the notion that “bad blood” resulted in several illnesses, including anemia, fatigue, and syphilis.³⁶ The researchers did not provide the available treatment

M. Fett, *Black Maternal and Infant Health: Historical Legacies of Slavery*, 109 AM. J. PUB. HEALTH 1342, 1343 (2019).

²⁸ See Otis W. Brawley, *The Study of Untreated Syphilis in the Negro Male*, 40 INT’L J. RADIATION ONCOLOGY BIOLOGY PHYSICS 5, 5-8 (1998).

²⁹ See generally REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* (2010).

³⁰ See generally Gregory Pincus et. al., *Effectiveness of an oral contraceptive; effects of a progestin-estrogen combination upon fertility, menstrual phenomena, and health*, 130 SCIENCE 83 (1959).

³¹ See DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY* 104-112 (1997).

³² See, e.g., WASHINGTON, *supra* note 25, at 55, 140, 232, 396-404.

³³ See KENDI, *supra* note 24, at 9, 19; ROBERTS, *supra* note 31, at 2, 250-52, WASHINGTON, *supra* note 25, at 32-33.

³⁴ See Megan Ming Francis, *The Price of Civil Rights: Black Lives, White Funding, and Movement Capture*, 53 L. & SOC’Y REV. 275, 275-309 (2019).

³⁵ See Alsan et al., *supra* note 23, at 323-24.

³⁶ See Francis, *supra* note 34.

for syphilis at that time, rather using the study as a natural history experiment to understand the progressive phases of the infection. The only remuneration the men received was free medical exams, meals, and burial insurance.

Research and reproductive injustice were committed by the sheer omission of Black women, wives, other sexual partners, and daughters in the study. After the study ended, forty years after it began, the U.S. government still failed to recognize that the women sexual partners “directly impacted but not married to the male participants of the study, and the children manifesting congenital syphilis but borne out of wedlock” received little to no remedy from the government.³⁷ The lack of attention to the communities impacted by the conduct of unethical research contributes to mistrust and harm. Research across the reproductive spectrum should be community centered.

B. Lack of Acknowledgment or Compensation

The story of Henrietta Lacks, now immortalized by a book and film, provides an exemplar of how scientific discoveries exploit research participants and serves as a reminder of why informed consent is essential. The Office on Science Policy of the National Institutes of Health (NIH) highlights the advances made using cells named for Ms. Lacks (e.g., HeLa—using the first two letters of her first and last name),³⁸ but there is no acknowledgement that the cells were taken from her cervix without her informed consent. After her death at age 31, her family received no compensation or recognition until after public attention was raised about her story in 2013, when the NIH developed guidelines about HeLa cell line use.³⁹ Communities and individuals need true informed refusal, informed consent, and compensation when participating in research.

C. Explicit Coercion of Communities of Color

The birth control pill in the U.S. has been cited as the reproductive technology that “changed everything”⁴⁰—from allowing more women to enter the workforce to resolving many vexing conditions that inhibit women from functioning as full citizens in society. At the same time, the Puerto Rico Birth Control Pill Clinical Trials exploited community members who were not told they were participants of a clinical trial, who suffered severe

³⁷ See *id.*

³⁸ Deleso Alford Washington, *Examining the “Stick” of Accreditation for Medical Schools through Reproductive Justice Lens: A Transformative Remedy for Teaching the Tuskegee Syphilis Study*, 26 J. CIV. RTS. AND ECON. DEV. 153 (2011).

³⁹ See *Significant Research Advances Enabled by HeLa Cells*, NIH OFF. SCI. POL’Y, <https://osp.od.nih.gov/scientific-sharing/hela-cells-timeline/> [<https://perma.cc/5ZW5-5JL4>].

⁴⁰ See *NIH, Lacks Family Reach Understanding to Share Genomic Data of HeLa Cells*, NAT’L INSTS. HEALTH (Aug. 7, 2013), <https://www.nih.gov/news-events/news-releases/nih-lacks-family-reach-understanding-share-genomic-data-hela-cells> [<https://perma.cc/DH2Y-YPFV>].

side effects, and received no remuneration or compensation for their participation.⁴¹ Poor and undereducated women were subject to manipulation by the researchers and clinicians who conducted the study, including those who led study from Harvard University.⁴²

A more recent example of reproductive coercion is involuntary sterilization and the overuse of the Long Acting Reversible Contraception (LARC) in the United States. Involuntary sterilization overuse in communities of color was documented in the 1927 decision of *Buck v. Bell*.⁴³ The use of sterilization and controlled fertility of people of color has occurred as recently as 2010 by the carceral system in the State of California.⁴⁴ The loss of fertility is a glaring example of reproductive injustice, and the control of fertility of Black Mamas continues to this day. The overuse of LARC with Black Mamas warranted a response from the SisterSong Women of Color Reproductive Justice Collective and the National Women's Health Network in 2016 entitled the LARC Statement of Principles.⁴⁵ Excitement about newer and longer acting contraception spawned two regional clinical trials that showed increased uptake of LARC despite the reality that other contraceptive methods were preferred by participants and few providers were trained or willing to remove the LARC devices once placed.⁴⁶

D. Criminalization of Pregnant People

The criminalization of pregnant people is not new. Recent attention has focused on issues such as the shackling of pregnant people, giving birth in prisons, the prosecution of pregnant people for experiencing miscarriages, and the criminal penalties facing those who use drugs or alcohol during pregnancy. Professor Dorothy Roberts documents this long history in her seminal book, *Killing the Black Body*.⁴⁷ However, it is essential to highlight how research has specifically contributed to the criminalization of pregnant

⁴¹ Lily Rothman, *50 Years Ago This Week: How Birth Control Changed Everything*, TIME MAGAZINE (Apr. 3, 2017), <https://time.com/4713875/1967-birth-control-pill/> [<https://perma.cc/WC89-E94B>].

⁴² See Drew C. Pendergrass & Michelle Y. Raji, *The Bitter Pill: Harvard and the Dark History of Birth Control*, HARV. CRIMSON (Sept. 28, 2017), <https://www.thecrimson.com/article/2017/9/28/the-bitter-pill/> [<https://perma.cc/MP6J-Q75Y>].

⁴³ See *id.*

⁴⁴ 274 U.S. 200 (1927).

⁴⁵ See Corey G. Johnson, *Female Inmates Sterilized in California Prisons Without Approval*, NBC (Jul. 8, 2013, 11:27 AM), <https://www.nbcbayarea.com/news/california/Female-Inmates-Sterilized-in-California-Prisons-Without-Approval-214634341.html> [<https://perma.cc/H3VK-A8TQ>].

⁴⁶ See generally SISTERSONG WOMEN OF COLOR REPROD. JUSTICE COLLECTIVE & NAT'L WOMEN'S HEALTH NETWORK, LONG-ACTING REVERSIBLE CONTRACEPTION: STATEMENT OF PRINCIPLES (2019), <https://nwhn.org/wp-content/uploads/2019/03/LARC-Statement-of-Principles-1-1.pdf> [<https://perma.cc/M5PK-DNSX>].

⁴⁷ See generally NICOLE DUBE, CONN. GEN. ASSEMBLY, OFFICE OF LEGISLATIVE RESEARCH, COLORADO'S FAMILY PLANNING INITIATIVE (2015); Gina M. Secura et al., *The Contraceptive CHOICE Project: Reducing Barriers to Long-Acting Reversible Contraception*, 203 AM. J. OBSTETRIC GYNECOLOGY 115.e1, 115.e3–115.e6 (2010).

people. Recently, Developmental Origins of Health and Disease (DOHaD) has emerged as a frame to understand human health and disease.⁴⁸ The definition of DOHaD has changed over time, but the concept essential has remained the same; the conditions of fetal life and development set the stage for adult disease.⁴⁹ In other words, the first 1,000 days are essential for optimum growth and development, disease prevention, and health promotion.⁵⁰ However, one shortcoming of this framework is the assumption that the pregnant person is the only environment which should be considered when determining environmental conditions that impact health and disease. Because many DOHaD studies are not contextualized by adverse childhood life events, as well as other social and structural determinants of health, one unintended consequence of establishing DOHaD as a reference point for interventions is that it can lead to placing blame on the mother and the community.⁵¹ Additionally, fetal personhood laws and the establishment of unique rights (or lack thereof) for pregnant people create circumstances that lead to the criminalization of pregnant people.⁵² The most obvious is the loss of bodily autonomy many pregnant people experience when they use drugs or alcohol during pregnancy. Fortunately, important scholarship from Black women has elucidated these harms, again, providing a much-needed perspective that is grounded in Birth Justice,⁵³ Reproductive Justice,⁵⁴ Human Rights,⁵⁵ Black Feminism,⁵⁶ Womanism,⁵⁷ and Research Justice.⁵⁸ These conceptual frameworks are essential to understanding the best practices for the conduct of research with, for, and by Black Mamas. Research Justice is the opposite of the earlier defined Research Injustice, centered by community voices and experiences, as well as community control over the production, documentation, possession, and dissemination of data and stories. Birth

⁴⁸ See generally ROBERTS, *supra* note 31, at 150–201.

⁴⁹ See D.J.P. Barker & C. Osmond, *Infant Mortality, Childhood Nutrition, and Ischaemic Heart Disease in England and Wales*, 327 LANCET 1077, 1077–81 (1986).

⁵⁰ See, e.g., K. Suzuki, *The Developing World of DOHaD*, 9 J. DEVELOPMENTAL ORIGINS OF HEALTH & DISEASE 266 (2017); Liana Winett et al., *A Framework to Address Challenges in Communicating the Developmental Origins of Health and Disease*, 3 CURRENT ENVTL. HEALTH REP. 169, 172 (2016).

⁵¹ See LUCY M. SULLIVAN & CARA BRUMFELD, 1,000 DAYS, THE FIRST 1,000 DAYS: NOURISHING AMERICA'S FUTURE 5–7 (2016), https://fhop.ucsf.edu/sites/fhop.ucsf.edu/files/custom_download/1000Days-NourishingAmericasFuture-Report-FINAL-WEBVERSION-SINGLES_0.pdf [<https://perma.cc/E52B-2LJ6>]; see also *Why 1,000 Days*, 1,000 DAYS (2019), <https://thousanddays.org> [<https://perma.cc/N88M-SWN4>].

⁵² See Winett et al., *supra* note 50, at 170–72.

⁵³ See ORISHA A. BOWERS ET AL., SISTERREACH, TENNESSEE'S FETAL ASSAULT LAW: UNDERSTANDING ITS IMPACT ON MARGINALIZED WOMEN 30 (2019).

⁵⁴ See, e.g., BIRTHING JUSTICE: BLACK WOMEN, PREGNANCY AND CHILDBIRTH (Julia Chinyere Oparah & Alicia D. Bonaparte eds., 2015).

⁵⁵ See, e.g., ROSS & SOLINGER, *supra* note 4; RADICAL REPRODUCTIVE JUSTICE, *supra* note 7.

⁵⁶ See, e.g., Jael Silliman et al., UNDIVIDED RIGHTS: WOMEN OF COLOR ORGANIZE FOR REPRODUCTIVE JUSTICE (2004).

⁵⁷ See, e.g., PATRICIA HILL COLLINS, BLACK FEMINIST THOUGHT: KNOWLEDGE, CONSCIOUSNESS, AND THE POLITICS OF EMPOWERMENT (1990).

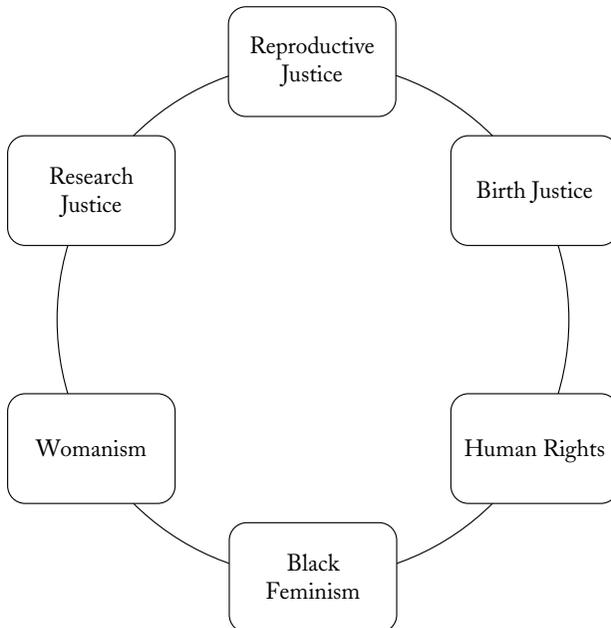
⁵⁸ See, e.g., ALICE WALKER, IN SEARCH OF OUR MOTHERS' GARDENS: WOMANIST PROSE (1983).

Justice is specific to pregnancy, labor, and childbirth, whereas Reproductive Justice—grounded in Human Rights—covers the entire sexual and reproductive spectrum. Black Feminism, popularized by Dr. Patricia Hill Collins, is grounded in the experiential knowledge and wisdom of Black women and their conceptualization of equity among and between the sexes, irrespective of gender. Womanism, coined by Alice Walker, is a framework unique from feminism and is an attempt to highlight the essential contributions to society by women, external to any other sex or gender.

III. CONCEPTUAL FRAMEWORKS

Several overlapping conceptual frameworks, shown in Figure I, guide the development of this summary, as well as the work of the BMMA Research Working Group.⁵⁹ These frameworks inform both the process and the content of the work and are essential to the ethical conduct of research. Birth Justice, Reproductive Justice, Human Rights, Black Feminism, Womanism, and Research Justice, are infused within the work of the research working group⁶⁰ and the combination of these concepts is essential for the conduct of any research with, for, and by Black Mamas.

FIGURE 1: RESEARCH WORKING GROUP CONCEPTUAL MODEL



⁵⁹ See, e.g., RESEARCH JUSTICE, *supra* note 3, at 13–25.

⁶⁰ See, e.g., SETTING THE STANDARD FOR HOLISTIC CARE OF AND FOR BLACK WOMEN, *supra* note 11.

Research teams and funders need to deeply interrogate the capacity for and the presence of these conceptual frameworks in work they propose, conduct, or fund. The implications for research are important given the role that evidence plays in the allocation of resources. Basic science, public health, and clinical research should be grounded in multiple conceptual frameworks specific to the composition of research teams, the relationship of teams with existing community organizations and leaders, data use agreements, dissemination of data, and the long-term ideas, theories, and narratives that are developed from the research findings. The cumulative nature of science requires careful consideration of the effect of research findings on researched communities and should be directly linked to principles of holistic and respectful care.

IV. INTERSECTION OF HOLISTIC CARE AND RESEARCH

The BMMA Research Working Group developed the following holistic care research principles based not only on a forthcoming literature review,⁶¹ but also a reflection of the expertise and experiences of the collaborators of and advisors in the group who have worked in maternal health and conducted research with and for Black Mamas for decades. The principles of holistic care are outlined in Table 1 below and are integrated into the research best practices that provide a foundation from which to approach Black Mama populations in the development of programs, interventions, and ethical research design.

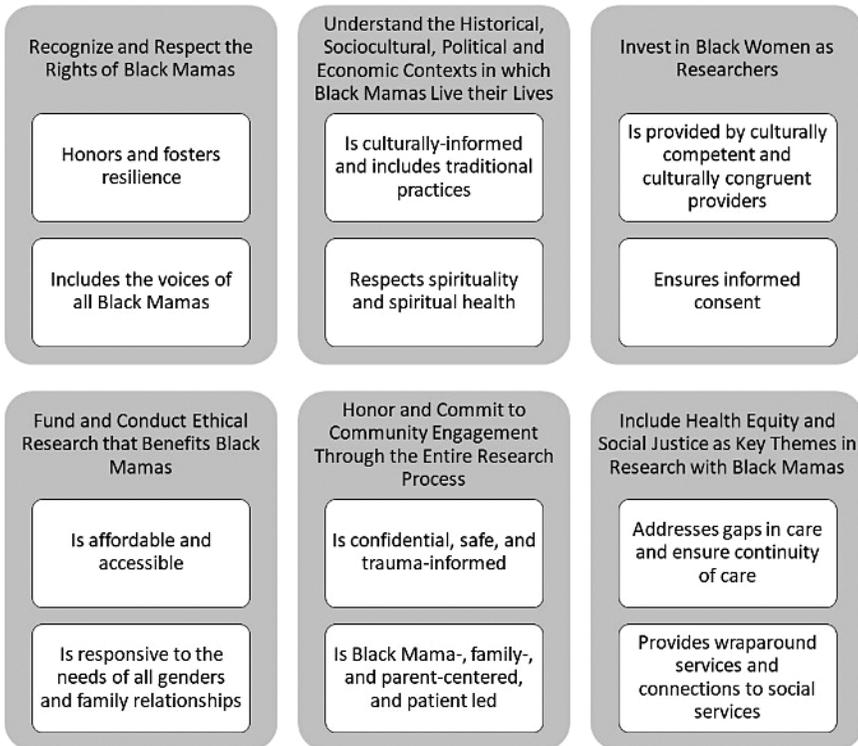
TABLE 1: BLACK MAMAS MATTER ALLIANCE
HOLISTIC CARE PRINCIPLES

<p>Holistic care:</p> <ul style="list-style-type: none"> ▪ Addresses gaps in care and ensures continuity of care ▪ Is affordable and accessible ▪ Is confidential, safe, and trauma-informed ▪ Ensures informed consent ▪ Is Black Mama-, family-, and parent-centered, and patient led ▪ Is culturally-informed and includes traditional practices ▪ Is provided by culturally competent and culturally congruent providers ▪ Respects spirituality and spiritual health ▪ Honors and fosters resilience ▪ Includes the voices of all Black Mamas ▪ Is responsive to the needs of all genders and family relationships ▪ Provides wraparound services and connections to social services

⁶¹ See, e.g., *id.*

The following six domains comprise what we believe are the best practices and guidelines for the conduct of research with, for, and by Black Mamas. These principles are not comprehensive and are meant to serve as a minimum to equitably engage communities as partners in research. These domains are intentionally, deeply intertwined with the BMMA Care Working Group Holistic Care Principles (Table 1). The domains are: (1) Recognize and Respect the Rights of Black Mamas; (2) Understand the Historical, Sociocultural, Political and Economic Contexts in which Black Mamas Live their Lives; (3) Invest in Black Women as Researchers; (4) Fund and Conduct Ethical Research that Benefits Black Mamas; (5) Honor and Commit to Community Engagement Through the Entire Research Process; and (6) Include Health Equity and Social Justice as Key Themes in Research with Black Mamas. Each domain is presented with descriptors and guidelines necessary to achieve research justice. We believe all six need to be operationalized within research and that none can be omitted. These domains also cannot be retrofitted to existing research projects without careful consideration to ensure the appropriate expertise is fully represented.

FIGURE 2: BEST PRACTICES AND GUIDELINES FOR HOLISTIC CARE



We present a contemporary research example to apply the best practices and guidelines for the conduct of research with, for, and by Black Mamas. The ARRIVE trial (A Randomized Trial of Induction Versus Expectant Management)⁶² was funded by public research dollars and conducted by investigators across forty-four different institutions to determine if infant outcomes during labor and birth could be improved. One underlying element of this study design was removing the unpredictable variable, namely the time when labor and birth starts, hoping that healthcare teams could be more prepared to support births in a systemized manner. The primary design of the study was to randomize healthy pregnant people to an induction of labor at thirty-nine weeks gestation to determine if maternal or fetal outcomes could be improved.⁶³ A secondary aim was to determine the impact of induction on surgical birth or cesarean section rates.⁶⁴ The study found a lower rate of C-section in the group who were induced as opposed to those who had a naturally initiated labor without intervention.⁶⁵ These findings were used to suggest that induction of labor (one intervention) could be used to avoid a second intervention without demonstrating the benefit to pregnant people or fetuses.⁶⁶ Further, the evidence taxonomy prioritizes “objective” knowledge as the only legitimate source of truth at the exclusion and delegitimization of experiential, cultural, spiritual, and public knowledge, despite the fundamental roles of such knowledge in meaning-making and interpersonal relation.

V. BEST PRACTICES FOR THE CONDUCT OF RESEARCH WITH, FOR, AND BY BLACK MAMAS

A. *Recognize and Respect the Rights of Black Mamas*

Integral to the first domain is recognizing the human right to health and safety for Black Mamas and their families. Providers must utilize and recognize the reproductive justice framework which asserts that Black Mamas have the rights to maintain personal bodily autonomy, to have or not have children, and parent their children in safe and sustainable communities. Respecting the rights of Black Mamas includes acknowledging that Black Mamas have unique expertise, skills, and perspectives that should be the center of all research questions, methods, and analyses of data—and data dissemination—specific to Black people. In this domain, it is essential that

⁶² BMMA RESEARCH WORKING GROUP, A CRITICAL APPRAISAL OF THE LITERATURE ON MATERNITY CARE INTERVENTIONS: IMPLICATIONS FOR STUDIES WITH, FOR AND BY BLACK MAMAS, (forthcoming 2020).

⁶³ See W.A. Grobman et al., *Labor Induction Versus Expectant Management in Low-Risk Nulliparous Women*, 379 NEW ENG. J. MED. 513, 514 (2018).

⁶⁴ See *id.* at 513.

⁶⁵ See *id.* at 514.

⁶⁶ See *id.* at 519.

the strengths of Black Mamas be investigated, as well as their resilience and resistance.

This domain is currently missing from the conduct of research, the bedrock of clinical and health services provision. For example, this domain was violated in the ARRIVE trial as it was already known that Black birthing people prefer unmedicated and normal physiologic birth and suffer from an unmet need for midwifery care.⁶⁷ Additionally, it was already known that first-time Black birthing people are more likely to experience surgical birth or cesarean section, which creates future risk categorization in subsequent pregnancies.⁶⁸ Any cursory analysis prior to the conduct of this study would have shown that Black birthing people would not be inclined to participate, and this is reflected in the overall percentage of eligible individuals (seventy-three percent) who declined to participate.⁶⁹ There were 22,533 eligible participants and only 6,106 signed (twenty-seven percent) an informed consent.⁷⁰

Historically, the conduct of research and science more broadly has excluded Black Mamas due the inaccurate and harmful notion that there are default humans—White men—that serve as the standard for the rest of the human population. The myth of the default human is deeply rooted in the need for homogeneity among research participants that is a hallmark of quantitative research studies. People with the capacity for pregnancy historically have been excluded from clinical research funded by public tax dollars.⁷¹ Steps have been taken to correct this unfortunate exclusion, however studies that are not aligned with existing data regarding research participation should not be considered when funding and designing large scale clinical research studies like the ARRIVE trial.

B. Understand the Historical, Sociocultural, Political and Economic Contexts in Which Black Mamas Live Their Lives

The variability of Black Mamas' lived experiences and needs are often disregarded in the application of research and practice design, such as in the design of the ARRIVE trial. Black Mamas' lived experiences should not be assumed to mirror their white counterparts. For example, Black birthing people have long known that births to younger individuals have better outcomes than older individuals. Unfortunately, teen pregnancy prevention programs have been universally targeted at age without attention to race. Efforts to recognize diversity must contemplate how these lived experiences, inter-

⁶⁷ See *id.*

⁶⁸ JULIA CHINYERE OPARAH ET. AL., *BATTLING OVER BIRTH: BLACK WOMEN AND THE MATERNAL HEALTHCARE CRISIS* 128-45 (2017).

⁶⁹ See generally Marco Huesch & Jason Doctor, *Factors associated with increased cesarean risk among African American women: evidence from California*, 105 AM. J. PUB. HEALTH 956 (2010).

⁷⁰ See Grobman et al., *supra* note 63, at 516.

⁷¹ See *id.*

secting oppressions and needs will differ among Black Mamas and how responses should be shaped. Consideration of intersecting oppressions (e.g., ability, citizenship, class, education, gender identity and expression, race, sexuality) that cause trauma and impact Black Mamas' health at various levels is crucial to developing research and providing care that matches the needs of Black Mamas.

Application of this principle will require researchers and providers to challenge the default model of whiteness in medicine and confront racist and sexist stereotypes about Black Mamas, as well as their families and communities. Key to ensuring a humanistic approach to Black Mamas is listening to the voices of Black Mamas and checking the use of biased language to refer to Black Mamas (e.g., at-risk, disadvantaged, vulnerable, marginalized, underserved). Committing to the broader understanding of the unique lived experiences of Black Mamas and the incorporation of interdisciplinary and transdisciplinary research teams will propel researchers to both challenge traditional research approaches and allow Black Mamas' needs to be centered in the development of research purported to benefit Black Mama populations.

C. *Invest in Black Women as Researchers*

Institutions should invest in, hire, consult with, and adequately compensate Black women as researchers at all levels. Using public funding from the NIH as an exemplar, Black scientists are less likely to be funded as Primary Investigators.⁷² Data from the non-profit sector show that seven to eight percent of funding goes to people of color and only 2.3 percent to Black communities.⁷³ Investments in Black women leaders and development assures that those close to the issues are in positions to transform the narrative of research. As Black women researchers move through the research development pipeline, they can bring with them Black women's theoretical frameworks (e.g. Black feminism, womanism, reproductive justice) to inform the development and promotion of community centered research. This canon of evidence was informed by additional contributors and advisors to the BMMA Research Working Group, including Dr. Fleda Mask Jackson, Dr. Lynn Roberts, Dr. Dana-Ain Davis, Dr. Joia Crear-Perry, Dr. Karen A. Scott, Dr. Ifeyinwa Asoidu, Dr. Rachel Hardeman, Dr. Kemi Doll and many others.⁷⁴ Ideally, Black researchers should never be hired alone or be

⁷² See Shradha Chakradhar, *Seeking Reform, a Neuroscientist Argues Against 'Sexist' Beliefs That Keep Research Focused on Male Animals*, STATNEWS (May 30, 2019), <https://www.statnews.com/2019/05/30/scientist-calls-for-end-to-outdated-gender-stereotypes-experiments/> [<https://perma.cc/N7F3-8EL3>].

⁷³ See Michael Lauer, *Delving Further into the Funding Gap Between White and Black Researchers*, NIH EXTRAMURAL NEXUS (Oct. 10, 2019), <https://nexus.od.nih.gov/all/2019/10/10/delving-further-into-the-funding-gap-between-white-and-black-researchers/> [<https://perma.cc/AAS9-VZ9F>].

⁷⁴ See CHRISTIAN GONZÁLEZ-RIVERA ET AL., THE GREENLINING INST., FUNDING THE NEW MAJORITY: PHILANTHROPIC INVESTMENT IN MINORITY-LED NONPROFITS 7-9

alone on any research team. This is essential to sustainability, as well as retention of Black expertise in the research enterprise. Despite the public funding of the ARRIVE trial it is impossible to know if any of research investigators participated in the collection of data were Black Mamas or Black women researchers. The publication record is equally ambiguous.

D. Fund and Conduct Ethical Research that Benefits Black Mamas

Moving towards research that benefits Black women requires substantive funding for work that centers and directly benefits Black Mamas. This requires researchers to reject standard project descriptions that solely frame community deficits and ailments, and instead view Black Mamas, as well as their families and communities, holistically. When Black Mamas are centered in research design, research questions shift from deficit focused to identifying assets and resilience as critical aspects of Black Mamas' lived experiences. Had ARRIVE investigators consulted Black Mamas and people with the capacity for pregnancy, they would have heard about the need for more providers who provide vaginal birth after cesarean (VBAC) or at least, a trial of labor. Patient preference research has shown that most participants favor these options.⁷⁵

Research that affirms Black women ensures that confidentiality, health, and research literacy principles are applied throughout the research process, from obtaining consent to participate to sharing, analyzing, and publishing data. Relatedly, the selection of study design must also evolve to elevate mixed methods and emancipatory methodologies that capture data with cultural rigor, both of which expand the lens through which relevant health improvement strategies can be developed. A current study that has been designed to highlight these methods is the Supporting Our Ladies and Reducing Stress to Prevent Preterm Birth study (SOLARS) that is both community informed and engaged.⁷⁶

E. Honor and Commit to Community Engagement Through the Entire Research Process

Currently, a large proportion of data collected and/or funded by public entities such as the National Institutes of Health, National Science Foundation, and Centers for Disease Control and Prevention use epidemiologic methods (studies of illness and disease in groups of people) to determine screening, treatment, research, and funding priorities.⁷⁷ In this context, ran-

(2008), <http://greenlining.org/wp-content/uploads/2013/02/FundingtheNewMajority.pdf> [<https://perma.cc/9HM3-5CFZ>].

⁷⁵ See *Our Partners*, BLACK MAMAS MATTER ALLIANCE, <https://blackmamasmatter.org/our-partners/> [<https://perma.cc/56CZ-JRRN>].

⁷⁶ See Anjali J. Kaimal et al., *The Association of Patient Preferences and Attitudes with Trial of Labor After Cesarean*, 39 J. PERINATOLOGY 1340, 1340 (2019).

⁷⁷ See SOLARS, <https://solars.ucsf.edu/> [<https://perma.cc/57ML-98ZL>].

domized clinical trials are often viewed as the gold standard, while qualitative or experiential data is viewed as less credible.⁷⁸ However, study quality matters and the evidence taxonomy has increasingly come under scrutiny from methodologists concerned about blind faith in the randomized controlled trial.

Generally, community engagement has been an afterthought despite the importance of Community Based Participatory Research (CBPR),⁷⁹ Participatory Action Research (PAR),⁸⁰ and other Emancipatory Research Models (ERM)⁸¹ in ethically conducting research with, for, and by Black Mamas. Recent attention has been paid to CBPR as a potential powerful research method to support collaborative science, bringing together researchers and community members. There have been different methods to bring together researchers and community members, but CBPR is defined by three major principles: (1) research priority is jointly developed with research teams and community members; (2) community are engaged in all levels of the research process; and (3) dissemination and utilization of research findings are jointly determined by research teams and community members. Another iteration of CBPR is PAR, which emphasizes community participation and action and was developed as part of public health research because the intent of PAR is to understand and improve science by changing it. ERM are not exclusive to any discipline but have been effectively deployed in nursing. Grounded in the work of Paulo Freire, this research framework highlights praxis, a term defined as simultaneous reflection and action in order to transform the world.⁸² The evidence base that currently exists is not sufficient for the transformative work necessary to improve health outcomes for Black Mamas and, given the transparent assumption that researchers do not possess any solution to Black maternal health that Black women do not already know, it is necessary to center Black Mamas as research experts by experience.

Similarly, research procurement is an essential principle necessary for the ethical conduct of research. Contracting for space, food, childcare, research tools, measures, and other essentials necessary for the conduct of research must include partnerships with local community leaders, Community-Based Organizations (CBOs) and Businesses led by Black Mamas, their families and communities. Analysis and dissemination of data

⁷⁸ See, e.g., Linda S. Franck et al., *Research priorities of women at risk for preterm birth: findings and a call to action*, 20 BMC PREGNANCY AND CHILDBIRTH 10 (2020).

⁷⁹ See Tom Frieden, Opinion, *Why the "Gold Standard" of Medical Research Is No Longer Enough*, STATNEWS (Aug. 2, 2017), <https://www.statnews.com/2017/08/02/randomized-controlled-trials-medical-research/> [<https://perma.cc/V8PW-Z8UK>].

⁸⁰ See generally Barbara A. Israel et al., *Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health*, 19 ANN. REV. PUB. HEALTH 173 (1998).

⁸¹ See generally Julia Chinyere Oparah et al., *By Us, Not for Us: Black Women Researching Pregnancy and Childbirth*, in RESEARCH JUSTICE, *supra* note 3.

⁸² See Paula N. Kagan et al., *Introduction to PHILOSOPHIES AND PRACTICES OF EMANCIPATORY NURSING: SOCIAL JUSTICE AS PRAXIS 1–11* (Paula N. Kagan et al. eds., 2007).

also need to center these entities. At the study design phase, research teams need to create and maintain community advisory boards and community research review boards to advise and inform the entire research process. Development of a community institutional review board to protect communities (as opposed to participants in research) should be an additional goal of all research programs.

F. Include Health Equity and Social Justice as Key Themes in Research with Black Mamas

The research enterprise needs a fundamental shift toward authentic health equity and social justice when conducting research specific to Black Mamas. Significant investments need to be made in the development of health equity impact assessment tools to evaluate the intended and unintended consequences of community initiatives. Similar to the human genome project and the precision medicine cohort initiative All of Us, federal funders need to allocate resources to determine interventions that are most effective in improving health outcomes for Black Mamas, developed with, for, and by Black Mamas. An essential component of this principle is the development and innovation of research dissemination tools in media and fora that are convenient for communities but are novel, bold, and innovative such as infographics, theatrical readings and enactment of qualitative research findings, tweetchats to expand community advisory boards, and dance interpretations of research findings. Integration of art and spirituality in both cultural and scientific rigor should allow for novel public health and community driven problem solving and interventions for testing in authentic partnership.⁸³

VI. REFLECTIONS ON SCIENTIFIC REVOLUTIONS

This summary of the groundbreaking research report would be incomplete without a final reflection on the current moment in space and time. The *politics of pregnancy* requires an understanding that a scientific revolution is required to resolve health inequities.⁸⁴ One framework that has been useful in understanding the current environment is the work from Thomas S. Kuhn outlined in his groundbreaking book *The Structure of Scientific Revolutions*. Kuhn's book has been recognized as one of the most influential aca-

⁸³ See generally PAULO FREIRE, PEDAGOGY OF THE OPPRESSED (1970).

⁸⁴ One such example is the work being done by the UCSF Preterm Birth Initiative, which focuses on both California and East Africa. See, e.g., *Annual Symposium on Preterm Birth*, CAL. PRETERM BIRTH INITIATIVE, <https://pretermbirthca.ucsf.edu/symposium-preterm-birth> [<https://perma.cc/F72X-NU97>] (describing the Initiative's annual preterm birth symposiums); UCSF Cal. Preterm Birth Initiative, *Collaboratories: Transdisciplinary Monthly Discussion Series on Preterm Birth*, YOUTUBE (Oct. 30, 2018), https://www.youtube.com/watch?v=UH_Soutkfr0 (highlighting the Initiative's monthly meetings).

democratic books of all time and is routinely taught in doctoral programs.⁸⁵ Using the basic principles outlined by Kuhn (Table 2), we believe that the ongoing scientific revolution is in a moment of transition and that we are currently in phase III, crisis period. It is important to recognize several critiques and shortcomings of this framework, as well as where we have modified the concepts as they are applied to our analysis.

TABLE 2: THE PHASES OF SCIENTIFIC REVOLUTIONS,
ADAPTED FROM KUHN

Phase	Descriptor	Characteristics	Important Considerations
I. Pre-paradigm	No consensus on any given theory	Incompatible and/or Incomplete theories	Scholars move to one theory—great insights can be learned
II. “Normal” Science	Consensus in a discipline	When facts are difficult to explain in existing paradigm—weaknesses in old paradigm are shown	Anomalies in science are consistently hard to resolve
III. Crisis Period	Anomalies in science are chronic	Can be resolved in context of “normal science”	If not resolved in “normal science” move to next phase.
IV. Paradigm Shift	Scientific Revolution	Underlying assumptions are re-examined	A new paradigm is established
V. Post-Revolution	New paradigm dominance is established	“Normal science resumes”	New paradigm becomes primary frame

According to Kuhn, the pre-paradigm phase only happens once, and we believe it has occurred. Our rationale for this belief comes from the notion that biomedical science has been built on concepts normalized and embedded in scientific racism.⁸⁶ However, recent attention to health disparities, differences among and between groups in health-related outcomes, and social epidemiology, defined as “a branch of epidemiology that focuses particu-

⁸⁵ See THOMAS S. KUHN, *THE STRUCTURE OF SCIENTIFIC REVOLUTIONS* 23–32, 52–61 (3d ed. 1996).

⁸⁶ See *Thomas Kuhn*, STAN. ENCYCLOPEDIA PHILOSOPHY (last updated Oct. 31, 2018), <https://plato.stanford.edu/entries/thomas-kuhn/> [<https://perma.cc/5BV4-FJWP>].

larly on the effects of social-structural factors on states of health” have elucidated the need for focus on structures—not individuals—to achieve optimal health.⁸⁷ Other research has shown that “blame the mother” narratives and mistreatment during pregnancy, labor, and birth have been rampant and this foundational pivot from pregnant people being exclusively responsible for pregnancy outcomes has shifted to include the environments, conditions, and individuals who support them during the perinatal period.⁸⁸ Communities have had this understanding long before science has reached this “pre-paradigm” shift. In the twenty years since health disparities have been described and rigorously researched, many scholars have published seminal work to include racism, sexism, and gender oppression as important contexts to understand conditions that impact Black Mamas and stifle their capacity to achieve optimal health and wellness.⁸⁹

The “normal science” phase 2 is unfortunately deficit focused, a function of attempting to retrofit health equity approaches to a system inherently built to identify problems. Birth historically has been inaccurately framed as a clinical or medical condition, as opposed to a normal physiological process.⁹⁰ Additionally, important advocacy work led by BMMA, such as highlighting the Black maternal health crisis, has resulted in a paradigm shift based on the recognition that exposure to racism, rather than race, is the risk factor for poor health outcomes.⁹¹ This shift has allowed for “normal science” to begin collecting data that describes and predicts the impact of interpersonal, internalized, and structural racism on health outcomes. We believe this shift has brought us to the current “crisis” in science, where we now sit. Evidence of the current crisis includes the lack of attention to the problem of maternal morbidity and mortality at the federal level and within philanthropy communities, specifically the lack of funding to design and test interventions to mitigate the burden of Black birthing people.

⁸⁷ See KENDI, *supra* note 24, at 210-11; DOROTHY ROBERTS, FATAL INVENTION: HOW SCIENCE, POLITICS, AND BIG BUSINESS RE-CREATE RACE IN THE TWENTY-FIRST CENTURY 81-103 (2001); ROBERTS, *supra* note 31, at 9, 61; WASHINGTON; Owens & Fett, *supra* note 27, at 1342. See generally Nancy Krieger, *Methods for the Scientific Study of Discrimination and Health: An Ecosocial Approach*, 102 AM. J. PUB. HEALTH 936 (2012).

⁸⁸ Kaori Honjo, *Social Epidemiology: Definition, History, and Research Examples*, 9 ENVTL. HEALTH & PREVENTATIVE MED. 193, 193 (2004); see also KRIEGER, *supra* note 17, at 193.

⁸⁹ See ROBERTS, *supra* note 31, at 175-81; Monica R. McLemore, *How to Reduce Maternal Mortality*, 320 SCI. AM. 48, 48-51 (2019); Scott et al., *supra* note 13, at 108-15; Saraswathi Vedam et al., *The Giving Voice to Mothers Study: Inequity and Mistreatment During Pregnancy and Childbirth in the United States*, 16 REPROD. HEALTH 77 (2019).

⁹⁰ A repository of the work of these researchers is documented in the full BMMA Research Working Group report. See BLACK MAMAS MATTER ALLIANCE, *supra* note 9 (forthcoming 2020). For an example of such work, see Dána-Ain Davis, *Obstetric Racism: The Racial Politics of Pregnancy, Labor, and Birthing*, 38 MED. ANTHROPOLOGY 560 (2019).

⁹¹ See Am. Coll. of Nurse-Midwives et al., *Supporting Healthy and Normal Physiologic Childbirth: A Consensus Statement by ACNM, MANA, and NACPM*, 22 J. PERINATAL EDUC. 14, 14-18 (2013).

CONCLUSION

It is now time to move from a crisis period where many all-White teams and funders are attempting to retrofit their mission, vision, and values to address poor health outcomes and invoke a scientific revolution that centers Black Mamas and communities to determine which research questions are most important, what research questions should be prioritized, and what methods, and analytic procedures are necessary to conduct science that provides meaningful data to inform policy, funding decisions, and health services provision. Respectful care, diversification of the healthcare workforce, public investment in insurance and communities are all goals that are consistent with reproductive justice. One of the fortunate realities of being in a crisis period is that it allows for deep reflections on what is known and what is possible.

In addition to re-envisioning research, we can introduce bold and most innovative approaches to improving health across the reproductive life course, building on existing health data contextualized by the Black Futures Lab and the Black Census,⁹² to develop a comprehensive reproductive justice agenda. Such an agenda could include paid family leave; universal basic income; a cessation of the criminalization of pregnancy and pregnant people; comprehensive health coverage; the provision of doulas and midwives to communities ill-served by the current healthcare system; and, finally, envisioning the patients and communities we work with as ideal participants in the current and future healthcare workforce. We must finally stop making pipeline excuses and realize that the pipeline we have does not work because of a lack of courage or the political will to disrupt how we train the healthcare workforce.

The research process and rubric housed within the *Black Maternal Health Research Re-envisioned: Recommendations for Improving Research on Maternity Care for Black Mamas*⁹³ outlines a clear path to establishing the paradigm shift that is necessary to dismantle the current paradigm and establish sustainable community engagement in research toward health equity.

⁹² See generally BLACK FUTURES LAB, MORE BLACK THAN BLUE: POLITICS AND POWER IN THE 2019 BLACK CENSUS (2009).

⁹³ See Kacey Y. Eichelberger, et al., *Black Lives Matter: Claiming a Space for Evidence-Based Outrage in Obstetrics and Gynecology* 106 AM. J. PUB. HEALTH 1171, 1171–72 (2016); see generally BLACK MAMAS MATTER ALLIANCE, POLICY WORKING GROUP, ADVANCING HOLISTIC MATERNAL CARE FOR BLACK WOMEN THROUGH POLICY (2018) (highlighting the crisis and noting “a recent increase in media attention” to the issue).

