



# BLACK MATERNAL HEALTH RESEARCH REIMAGINED

Principles for Conducting Research  
in Maternity Care for Black Mamas

## CONTRIBUTORS

Angela Doyinsola Aina, Nia Mitchell, Inas Mahdi, Isabel Morgan, Dr. Monica McLemore, Dr. Ifeyinwa Asiodu, Dr. Karen A. Scott, Caitlin R. Williams, Philicia W. Castillo, Dr. Ayanna Robinson, Nicole Clark, Dr. Jill Denson, Courtney Drayton, Nalini Visvanathan, and Sang Hee Won

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Dr. Joia Crear-Perry, Dr. LeConte Dill, Dr. Shaconna Haley, Dr. Pandora Hardtman, Dr. Fleda Mask Jackson, Dr. Sayida Peprah, Dr. Lynn Roberts, and Charmaine Scarlett

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# Executive Summary



## BACKGROUND

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The United States (U.S.) is experiencing a maternal health crisis. In efforts to meet 2015 Millennium Development Goals, multiple industrial countries decreased their maternal mortality rates (MMR) between 1990 and 2013.<sup>1,2</sup> However, during this time period the MMR in the U.S. increased from 12 per 100,000 live births to 28 per 1000, live births.<sup>1</sup> This increase in MMR is coupled with racial and ethnic disparities where Black women are twice more likely to experience severe maternal morbidity and three to four times more likely to die in childbirth than white women regardless of their socioeconomic status, education level and health risk factors. Data suggest the poor quality of care and mistreatment Black women receive in the U.S. from health care providers are a driver of these disparities. Frameworks like Sojourner Syndrome<sup>3</sup> describe how the intersection of race, class and gender affect the health of Black birthing people across

the life course, and other researchers have shown physiological links between acute stress and chronic strain to poor birth outcomes.<sup>3–5</sup> Tackling the maternal mortality and morbidity crisis among Black women in the U.S. requires strategies grounded in Black women's lived experiences, wisdom and leadership.

This paper, written by the Black Mamas Matter Alliance (BMMA) multidisciplinary Research Working Group,\* presents principles for conducting research on maternal health outcomes for Black Mamas grounded in the Holistic Care principles outlined in BMMA's Black Paper<sup>6</sup> and calls for a reimagining of research that can be conducted with, for and by Black Mamas.

### Research Trauma on Black Bodies and Scholarship

Reimagining research must begin with an acknowledgement of the violence, trauma and experimentation inflicted on Black bodies, families and communities within the fields of science, public health and

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\* In Fall 2017, BMMA's Research Working Group was formed. The group's creation and functioning reflect BMMA's larger goal of leveraging the talent and knowledge that exists in Black communities in order to cultivate innovative research methods that inform policies to improve Black maternal health. Working group members work in different capacities in academia, public health and medicine, and bring an array of knowledge and expertise as it pertains to Black women's health. The focus of the Research Working Group mirrors BMMA's overall aim of Advancing Holistic Care for Black Mamas.

medicine. Researchers must connect that the transgenerational consequences of these traumas inform existing health disparities and provide a foundation for scientific racism. Many Black scholars and activists have called for a dismantling of racism in research which includes the exclusion and omission of research by Black scholars. This exclusion leads to a lack of cultural rigor<sup>7</sup> and has detrimental effects on the integrity and scientific validity of current maternal health research initiatives and methodologies.

## Current Notions of Credible Research

A hierarchy of research methodologies exists in the fields of medicine and public health where randomized controlled trials are universally held as a higher form of evidence than case studies and expert opinion. In order to conduct research with and for Black Mamas, we must use methodologies that are responsive to the needs of the community and that may include quantitative and qualitative components. In addition, expert opinion and case studies from lived experiences must be seen as valid forms of evidence to ensure we are not reproducing social inequalities in research. Subsequently, public entities like the National Institutes of Health (NIH), National Science Foundation (NSF) and Centers for Disease Control and Prevention (CDC) must work to fund the work of Black women research scholars and provide adequate support and mentorship for Black scholars conducting research that is community-based



and focused on social determinants of health. Lastly, all researchers must work to actively Cite Black Women<sup>8</sup> and the research methodologies and tools that have already been created by Black scholars and validated in populations of Black birthing people. Implementing these strategies will help the research community take initial steps to decolonize

current research funding opportunities, interventions and designs and support models of care developed by communities of color in becoming evidence based.

## BMMA's Conceptual Frameworks in Research

In order to decolonize research, BMMA asserts that Black women are experts that produce knowledge that will improve the health of their communities. Thus, Black women's perspectives must be at the center of all research efforts. Therefore, BMMA centers its research and evaluation work in the following

**Reimagining research must begin with an acknowledgement of the violence, trauma and experimentation inflicted on Black bodies, families and communities within the fields of science, public health and medicine.**



frameworks: Birth Justice, Reproductive Justice, Human Rights, Black Feminism, Womanism and Research Justice. Using these frameworks and an internal rubric, BMMA conducted a critical review of select literature on maternal health research focusing on Black Mamas. The literature review was not comprehensive but was designed to critically assess methods and outcomes across studies exploring Black maternal health outcomes.

## PRINCIPLES AND ETHICS OF CONDUCTING RESEARCH WITH AND FOR BLACK MAMAS

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The findings of the critical review of selected literature coupled with the expertise and experiences of the Research Working Group members led to the development of BMMA's Holistic Care Research Principles:

- 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**
- 6. Include Health Equity and Social Justice as Key Themes in Research with Black Mamas**

Black Mamas, regardless of socioeconomic status, education and geographic region, are not thriving and surviving in the current

maternal health care climate. Thus, a reduction in maternal morbidity and mortality centering holistic maternity care practices must be prioritized. Black Mamas need access to respectful and quality holistic maternal care services. Assessment and evaluation tools developed by Black women researchers should be used to inform the design and implementation of maternal health research. Input from Black Mamas must be centered to guide research efforts and the distribution of resources. In order to re-envision Black maternal health research, a paradigm shift toward centering and valuing Black women's scholarship and leadership in and outside of research spaces must occur. BMMA envisions a world where Black Mamas have the right, respect and resources to thrive before, during and after pregnancy. Implementing these research principles will assist the research community in, at minimum, beginning to engage in equitable research with communities and align with our endeavor to advance Black maternal health, rights and justice.



# Black Maternal Mortality



**“Until the lion has his [or her] own storyteller, the hunter will always have the best part of the story.” — AFRICAN PROVERB**

In the 2015 *Trends in Maternal Mortality* report, the World Health Organization (WHO) reported that the global maternal mortality ratio declined by 44% between 1990 to 2015 (from 385 deaths to 216 deaths per 100,000 live births).<sup>2</sup> While the decline in global maternal deaths is noteworthy, it is important to note that “the world did not achieve the Millennium Development Goal of reducing maternal mortality by three quarters between 1990 and 2015.”<sup>2</sup> Disparities in global maternal deaths exist between low, middle and high income countries with women in Sub-Saharan Africa experiencing the highest maternal mortality ratio at 66% (546 maternal deaths per 100,000 live births) each year.<sup>9,10</sup> Despite the declines in the maternal mortality rate across industrialized countries during the same time period of 1990 to 2013, the U.S. maternal mortality rate increased from 12 per 100,000 live births to 28 per 100,000 live births.<sup>1</sup> Further, the racial and ethnic disparities in

maternal mortality and morbidity in the U.S. is significant. Black women are more likely to deliver prematurely, have low birth weight babies, and most shockingly, are three to four times more likely to die in childbirth than white women.<sup>11</sup> This increase occurred despite annual spending of \$111 billion dollars on maternity and infant care, demonstrating that the U.S. is enduring a maternal health crisis.<sup>12</sup>

Due to differences in rate calculations and non-standardized data collection across states, these statistics are likely an underestimation of true mortality ratios for Black women.<sup>13</sup> Data also show that Black women are twice more likely to experience severe maternal morbidity (SMM), or the unanticipated birth and labor complications that lead to substantial long-term maternal health consequences.<sup>14,15</sup> Like maternal mortality, SMM, or “near misses,” have increased over the last 20 years and are closely related to the quality of care provided to the birthing person.<sup>16,17</sup> Data show that Black women have increased risk of pregnancy-related maternal morbidities, including infection, cerebrovascular disorders, and shock.<sup>18</sup> Often, high maternal mortality rates in the U.S. are attributed to Black Mamas having poor health.

But when comparing maternal mortality rates from other developed countries with similarly increased rates of risk factors like obesity and hypertension, data suggest that what differs, is the type of treatment Black women receive from health care providers.<sup>13</sup> Black women report experiencing poor quality of care and mistreatment at higher rates than their white peers across the maternity care continuum in the U.S.<sup>19,20</sup> Such health disparities impact Black women throughout the life course. Surveillance data on Black women's health does not fully describe factors that contribute to health disparities. The Sojourner Syndrome is a framework that examines how the intersection of race, class and gender affect the health outcomes of Black women.<sup>3,21</sup> Mullings found that inequality in the everyday lives of Black women resulting from poor housing, job insecurity, food deserts and environmental toxins serve as sources of chronic stress, which can contribute to negative health effects.<sup>3</sup> Mullings argues that both poor and middle-class Black women's quality of life were affected by systematic neglect.<sup>3</sup> Using the Sojourner Syndrome framework, other researchers have gone on to physiologically link acute stress and chronic strain to premature labor and other negative health outcomes.<sup>3-5</sup> These studies have bolstered Mullings conclusions that "while race may not be biological, racism has biological consequences".<sup>21</sup>

Addressing the maternal mortality and morbidity crisis necessitates strategies grounded in Black women's lived experiences, wisdom and leadership. The Black Mamas

Matters Alliance (BMMA) is a national multi-disciplinary network that consists of individual professionals and Black women-led organizations committed to advancing Black Maternal Health, Rights, and Justice. Our work is grounded in the birth/reproductive justice and human rights frameworks. BMMA advocates for centering Black women researchers, birth workers, clinicians, and addressing the health inequities in maternal health that are afflicting Black Mamas – inclusive of all birthing persons (i.e. *cis*, *trans*, *non-binary*, *queer* and *gender nonconforming individuals*) of African descent (i.e. *Afro-Latinx*, *African-American*, *Afro-Caribbean*, *Black* and *African Immigrants*). We intentionally include the global maternal mortality ratio of Sub-Saharan Africa to connect, in solidarity, with global Black Feminist and maternal rights advocacy to demand the END of structural and systematic violence against Black women and girls.

Addressing the maternal mortality and morbidity crisis necessitates strategies grounded in Black women's lived experiences, wisdom and leadership.

This paper presents principles for conducting research on maternal health outcomes for Black Mamas and summarizes each principle for researching with, for and by Black Mamas. This paper is intended to be used by those who are committed to eliminating preventable maternal deaths and reducing maternal morbidities among Black pregnant and birthing individuals using Holistic Care principles as defined by the BMMA Care Working Group's *Black Paper: Setting the Standard for Holistic Care of and for Black Women*.<sup>6</sup> This includes researchers, funders, policymakers, public health practitioners, community leaders, advocates and all other sectors engaged in maternal and reproductive health.



# Research Trauma on Black Bodies and Scholarship

**“We must acknowledge the juxtaposition of the historical research trauma inflicted on Black women’s bodies and the fact that our [Black women] scholarship and contribution to science and medicine, in this country, is largely ignored...”**

— NIA MITCHELL, MPH

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Reimagining research conducted with, for and by Black Mamas begins with an acknowledgement of the violence and trauma inflicted on Black bodies, families and communities in the interest of science and health care. The justification for this violence was rooted in the racist belief that African people were less than human and resulted in an insurmountable amount of suffering and even death.<sup>22</sup> The subsequent impact of this trauma also has transgenerational consequences for descendants and perpetuates existing health disparities.<sup>23</sup> Although we typically hear about the U.S. Public Health Service Syphilis Study at Tuskegee, a plethora of atrocities are chronicled in *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* by Harriet Washington.<sup>22</sup> Experimentation on Black women’s bodies was also central to the advancement of science and health care and provided the foundation for scientific racism.<sup>23</sup> This includes, but is not limited to, the dissection, study and display of Sarah Baartman’s body; the

experimentation of Anarcha Westcott, Betsey Harris and Lucy Zimmerman by Dr. J. Marion Sims (“father of modern gynecology”) without anesthesia; and the unauthorized use of Henrietta Lacks’ cervical cells for biomedical research.<sup>23</sup>

Fortunately, Black women have sought to reclaim this history by continuing to tell our stories and disrupting the glorification of those that perpetuated our exploitation and suffering. For example, Black Women Birthing Justice published, *Battling Over Birth: Black Women and the Maternal Health Care Crisis*, to highlight and place within a human rights context the stories of over 100 Black women giving birth in California, while the multi-ethnic coalition of community advocates, led by the East Harlem Preservation and Black Youth Project 100 (BYP100), advocated to remove a statue of Dr. Sims from Central Park in New York.<sup>24</sup> Dismantling racism in research and issuing calls to action to address limitations on traditional research practices are not new. Black women research scholars have advocated for innovative research practices and organizations focused on advancing the overall health of Black people.<sup>25</sup> Specifically, Dr. Hope Landrine and her colleagues noted in a 1995 publication that the main consequences of the historical and contemporary exclusion, dilution and omission of Black community knowledge and Black women scholarship in public health and health services research is the absence of cultural rigor and the erosion of scientific validity and integrity in research methodologies.<sup>26</sup> Drs. Landrine and Klonoff called for more studies on Black women’s health that are responsive to and evaluate these contextual variables.<sup>27</sup>

# Current Notions of “Credible” Research



**“To have any research being done on a community, without the direct oversight and collaboration of members of that community, is practicing research with blinders on. There will likely be risk factors not considered, misinterpretations of data, overgeneralizations and often the most harmful aspect will be a narrative that there is something inherently wrong with the population themselves, taking out the full context of the phenomena being examined.” — SAYIDA PEPRAH, PSYD**

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The current taxonomy upheld for establishing evidence in research leads with quantitative research, namely randomized controlled trials, as the gold standard for creating evidence, while qualitative and experiential data are situated at the lower end of the evidence spectrum. In population-based research and public health, differences in health outcomes that are created among and between population groups via an element of discrimination have been described as health inequities. Most data collected by public entities such as the NIH, NSF and the CDC use epidemiologic methods (*studies of illness*

*and disease in groups of people*) to understand how to determine screening, treatment, research and funding priorities. In this context, evidence is tiered by levels, namely ranking from “the gold standard” such as randomized controlled trials (RCTs) to case studies or expert opinion. This taxonomy tends to trend from highly sophisticated quantitative (numeric) data and ends with qualitative (textual) or experiential data. Historically, research on Black Mamas has been defined by evidence specific to Maternal and Child Health (MCH) entities including, but not limited to, state and local health departments, schools and programs in public health, the Association of Maternal Child Health Programs (AMCHP), CityMatCH, and the MCH section of the American Public Health Association (APHA). It should be noted that the contributions of the aforementioned entities are appreciated, most especially with efforts to support and highlight community-based research towards improving maternal health outcomes. Likewise, Jolivet et al asserts that the only type of research to conduct is research that is responsive to the social, legal, economic, cultural and political policy needs, as identified by community, and actively disrupts colonial policies and institutional practices that further (re)produce social inequalities in research and public policy.<sup>28</sup>

Black women research scholars not only develop research questions to directly respond to the needs of Black Mamas but also research methodologies (tools) which data show are less frequently cited in the scientific literature than those developed by white researchers.<sup>29</sup> In academia, these disparities in recognition have implications for funding and tenure track progress. A 2018 analysis identified fewer citations and publishing in journals with lower impact factors as reasons that impacted NIH funding for Black applicants.<sup>30</sup> An R01 grant is one of the oldest research grant types offered by the NIH to support a specified research project in an area representing the investigator's specific interest and competencies.<sup>31</sup> Research shows that between 2000 and 2006, Black women PhDs had a 9.6% lower probability of receiving an R01 Type 1 Award compared with white women, even after controlling for demographic characteristics, education and training, employer characteristics, NIH experience, field, year, and researcher productivity.<sup>30</sup> The gap was even wider for Black women MDs at 12.9%.<sup>32</sup> A 2019 study showed that among R01 applications submitted during 2011–2015, Black scientists were more likely to propose research at the community and population levels which have lower award rates than basic science and clinical research.<sup>32</sup> The implications of the current funding structures indicate that Black researchers are penalized for pursuing research on racial disparities and social determinants of health. Consequently, in addition to the disparity in the probability of Black women with PhDs that receive a R01 award, there is a lack of resources, funding and support for Black women scholars. The comparable funding gap between white women MDs and PhDs and their male counterparts was less than a percentage point, and not statistically significant.<sup>30</sup>

Analysis of current evidence-based practices and maternal health interventions highlight the need for research directed for, by and with Black

women as well as the inclusion of assessment tools and frameworks developed and validated for, by, and with Black Mama populations.<sup>6</sup> Model tools and frameworks that offer guidance include those by Drs. Vijaya Hogan, Diane Rowley, Stephanie Baker White and Yanica Faustin who developed a tool to integrate dimensionality into a health equity framework and address health inequities among African Americans.<sup>33,34</sup> Similarly, the Jackson, Hogue, Phillips Contextualized Stress Measure, a race and gender validated tool was designed to detect stress in Black women populations. Dr. Fleda Mask Jackson and colleagues have published several papers documenting the impact of stress on Black women's health, specifically depression.<sup>35,36</sup> Additionally, the Telephone-Administered Perceived Racism Scale was developed by Dr. Anissa Vines and colleagues to capture various forms and experiences of racism among Black women in epidemiologic research.<sup>37</sup>

Meaningful improvements in the individual and population health outcomes of Black Mamas require recognition of the promise of research led by Black women, as well as reckoning with the structural factors that have hindered Black women researchers' ability to develop and disseminate tools and interventions. Historically, most though not all, Black women were required to train and conduct research in our own institutions of higher education (HBCUs) and publish in our own academic journals such as the Journal of the National Medical Association because of racial segregation.<sup>38</sup> Black women's legacy as researchers, theorists, scholars and intellectuals must be uplifted despite the fact that our intellectual contributions and traditions have been ignored.<sup>39</sup>

# BMMA's Conceptual Frameworks in Research



**“We can decolonize research by interrogating the questions being asked and critiquing the frameworks for comparison. It demands that Black women’s perspectives be included at the center and not in the margins of the creation of questions and the processes for seeking answers as the pathway for equity in Black Maternal Health.”**

— FLEDA M. JACKSON, PHD

Against the backdrop of a maternal health crisis that predominantly and disproportionately impacts Black Mamas across the world, the following frameworks have been integral to the Alliance and inform all of BMMA’s work: Birth Justice, Reproductive Justice, human rights, Black Feminism, Womanism and Research Justice. BMMA recognizes Black Mamas’ bodily autonomy, human right to health and safety, as well as their right to decide whether or not to have children and parent in safe and sustainable

communities.<sup>40</sup> The Alliance also acknowledges multiple forms of oppression that impact Black women’s health outcomes and access to health care services and works to aid Black women scholars and paraprofessionals with the tools to dismantle them. Moreover, the frameworks that inform the work of the Alliance incorporate activist perspectives into research and recognize Black women as experts that produce knowledge and information that will institute changes in their lives and communities.

## Birth Justice

Birth Justice acknowledges that all individuals have the human right to birth and create families. It emphasizes the importance of access to holistic and culturally centered health care during the childbearing years and throughout the pregnancy spectrum, encompassing abortion, miscarriage, perinatal, birth and post-partum care.<sup>41</sup> Birth Justice embraces an individual’s right to make all decisions regarding pregnancy, which includes whether or not to carry a pregnancy; when, where, how and with whom to birth; and whether to access traditional and indigenous healers such as midwives and other birth workers. Moreover, Birth Justice respects an individual’s decision to breastfeed and access



breastfeeding and lactation support.<sup>41</sup> Overall, the Birth Justice framework recognizes the complete range of pregnancy, labor and birth options that should be available to everyone.

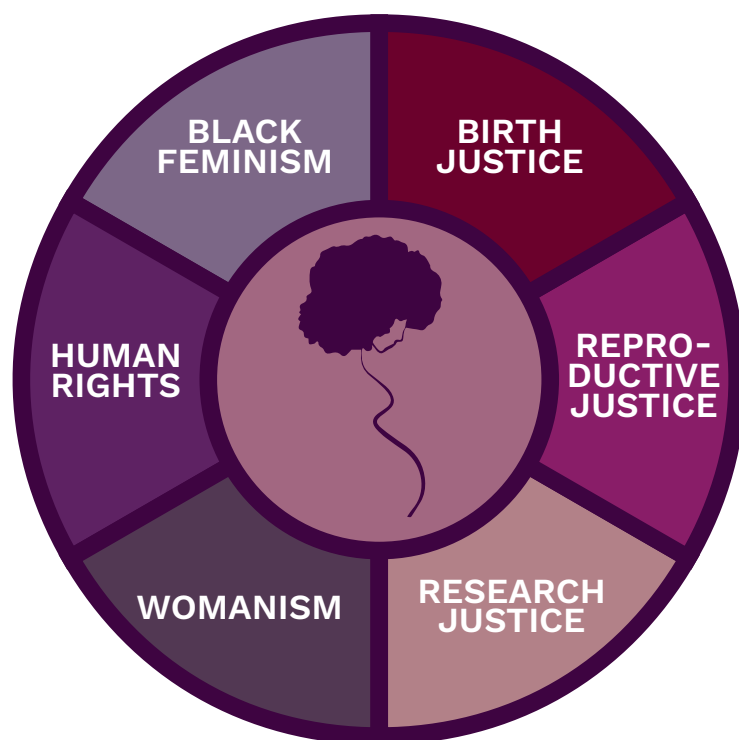
## Reproductive Justice

Reproductive Justice (RJ) is the human right to maintain bodily autonomy, have children, not have children and to parent in safe and sustainable communities.<sup>40,42</sup> Additionally, the Reproductive Justice framework demands gender freedom and sexual autonomy for all human beings.<sup>42</sup> RJ is based on the United Nations internationally accepted Universal Declaration of Human Rights, a comprehensive body of laws that details the individual's rights and responsibilities of the government to protect individual rights.<sup>43</sup> The Universal Declaration of Human Rights indicates that all individuals have the right to control the number of children they have and access to accurate information and education to parent their living and future children. Reproductive Justice integrates reproductive rights and social justice as it emphasizes the impact of oppression on one's reproductive health outcomes. It centers the needs of the most marginalized, pronouncing that reproductive oppression impacts one's access to resources and the human right to live self-determined lives without fear, discrimination or retaliation.

## Human Rights

The human rights framework, as it relates to maternal health, involves integrating pregnant, birthing and postpartum people in the design, implementation and decision-making process of programs and policies intended for their benefit.<sup>44</sup> Maternal health care is an individual right that must be reflected in policies and practice because all individuals should have the right to safe, quality maternal health care that is available and accessible without discrimination.

## BMMA's Conceptual Frameworks in Research



Additionally, the human rights framework acknowledges that all birthing persons should have the right to access maternal health care without experiencing harm, death, morbidity or disrespect and abuse.

## Black Feminism

Black Feminism challenges the assumption that experiences are universal and ubiquitous to both Black and white women due to their intersectional existence. Black Feminist thought emerged as a critical social theory aimed at empowering Black women and furthering social justice for Black women in the U.S. and other oppressed groups.<sup>45</sup> This framework prioritizes the inherent value in African American women's experiences and emphasizes the importance of Black women's health and wellness as an essential component of social justice.<sup>46,47</sup> Black Feminism explores the intersection of race, gender and class and how it impacts

Black women's unique realities. Furthermore, **Black Feminist Health Science Studies** is "... an emergent lens and praxis, built on existing and growing research that demands a multi-pronged approach to ameliorating the health disparities of Black women."<sup>48</sup> This approach unapologetically centers Black women's voices, Black women's experiences with science, medicine and health, and trusts Black women to theorize their own experiences and liberation. It also views the elimination of health inequities and attainment of health and well-being of Black Women as a collaborative and interdisciplinary social justice endeavor.

## Womanism

Womanism embodies Black women's lived experiences and is a celebration of cultural and spiritual traditions. It is a collection of a Black women's history and her story from her emotional, intellectual, spiritual, cultural, personal and political experiences that synergistically combine to elicit a worldview from her perspectives and experiences as a Black woman.<sup>49</sup> Womanism centers the responsibility of Black women to be the change of their health, experiences and overall fate.<sup>50</sup> Womanism includes using spirituality and cultural traditions to change their community.

## Research Justice

Research Justice aims to revolutionize structural inequalities in research. This framework challenges traditional models for conducting social science research by presenting a socially-just and community-centered process to research.<sup>28</sup> Additionally, research justice acknowledges that Black women are knowledge holders and co-researchers that should be involved in the research process. Their perspectives should be at the forefront of the study design process including framing of the research questions, selection of methodologies, analysis of findings

and determination of recommendations that will impact their communities.

The BMMA Research Working Group situates our respective work in research and evaluation using the above frameworks. In order to set the foundation of Black maternal health research, we analyzed and critiqued the current state of "evidence" on the maternity care for, of and by Black Mamas. BMMA's Research Working Group conducted an exploratory review of maternal health literature focusing on Black Mamas by asking:

- How do the accepted definitions of evidence translate to Black Mamas? Are they inclusive of Black Mamas?
- What is the evidence base on the effect of interventions and programs for Black Mamas?
- Who is the authority on determining what is considered evidence for Black Mamas?
- How is the research into evidence-based programs and practices for Black Mamas informed by the needs, desires and preferences of Black Mamas? Is it inclusive of and responsive to their knowledge and lived experience?

Articles were purposively selected to highlight "a best practice or an evidence-based maternal health intervention" within each period along the pre-pregnancy to postpartum continuum. The purpose of the exercise was to critically appraise the design and execution of pre-pregnancy to postpartum interventions for Black Mamas using a rubric that incorporated elements from BMMA's *Black Paper: Setting the Standard for Holistic Care of and for Black Women* and Drs. Moya Bailey and Whitney Peoples' article *Articulating a Black Feminist Health Science Studies*.<sup>6,48</sup> This foundation was important for the Research Working Group to be able to critically examine literature that seeks to improve Black Mama's experiences with pregnancy and childbirth as well as determine what is quality care for them.

# Principles and Ethics of Conducting Research with and for Black Mamas

**“Black women researchers bring a combination of lived experience and research training together to bring a desire for love, justice and applied research principles to the field of maternal health. The research I conduct, I conduct with love and scientific integrity, which expands the potential for a real, meaningful impact to advance Black Mama’s maternal health.” — INAS MAHDI, MPH**

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BMMA’s Research Working Group developed the following holistic care research principles based not only on the findings from the exploratory review, but also as a reflection of the expertise and experiences of all of this paper’s authors and acknowledged contributors who have worked in maternal health and conducted research with and for Black Mamas over the last 30 years. These principles serve as an ethical standard for research and practice which researchers should utilize when engaging Black Mama populations in the development of programs, interventions and research designs.

## I. RECOGNIZE AND RESPECT THE RIGHTS OF BLACK MAMAS

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

## II. UNDERSTAND THE HISTORICAL, SOCIOCULTURAL, POLITICAL AND ECONOMIC CONTEXTS IN WHICH BLACK MAMAS LIVE THEIR LIVES

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The variability of Black Mamas’ lived experiences and needs are often disregarded in the application of research and practice design. Black Mamas’ lived experiences should not be assumed to mirror their white counterparts. Efforts to recognize diversity must contemplate

how these lived experiences, intersecting oppressions and needs will differ among Black Mamas and how responses should be shaped. Consideration of intersecting oppressions (i.e., ability, citizenship, class, education, gender identity and expression, race, sexuality) that cause trauma and impact Black Mama's health at various levels are crucial to developing research and providing care that matches Black Mama's needs. 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, their families and communities. Key to ensuring a humanistic approach to Black Mamas is listening to the voices of Black Mamas about their lives and checking the use of biased language to refer to Black Mamas (i.e., at-risk, disadvantaged, vulnerable, marginalized). 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 ensure that the needs and perspectives of Black Mamas are centered in development of research purported to benefit Black Mama populations.

### III. INVEST IN BLACK WOMEN AS RESEARCHERS

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Institutions should invest in, hire, consult with and adequately compensate Black women scholars at all levels of research. Investments

Efforts to recognize diversity must contemplate how these lived experiences, intersecting oppressions and needs will differ among Black Mamas and how responses should be shaped.

in Black women's development, scholarship and leadership ensure that those close to the issues are in positions where they can continue to transform the narrative of research. As Black women researchers move through the research development pipeline, they can bring along with them Black women's theoretical frameworks (e.g. Black Feminism, Womanism, Reproductive Justice) to inform the development and promotion of community-centered research. Even with their unique perspective and experiences that can enhance the understanding of determinants of health that impact Black women there is disparity in funding, support and resources that Black women researchers receive. There are social, cultural and environmental barriers such as institutional bias in policies, misunderstanding about the specific needs of investigators involved in research with minority communities and lack of institutional support that prevent investment in Black women researchers.<sup>51</sup> These limitations prevent models of care developed by communities of color from becoming evidenced-based.

### IV. FUND AND CONDUCT ETHICAL RESEARCH THAT BENEFITS BLACK MAMAS

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Ensuring that research dollars are equitably spent on studies that truly benefit Black Mama populations is one strategy that can help to build the evidence in Black maternity care. When Black Mamas are centered in research design, research questions shift



from deficit focused to identifying assets and resilience as critical aspects of Black Mama's lived experiences. Research that affirms Black women ensures that confidentiality and health literacy principles are applied throughout the research process, from consenting to sharing 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,<sup>7</sup> both of which expand the lens through which relevant health improvement strategies can be developed.

## **V. HONOR AND COMMIT TO COMMUNITY ENGAGEMENT THROUGH THE ENTIRE RESEARCH PROCESS**

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Conducting research that benefits Black Mamas requires adequately funding researchers and maternal health entities that value Black Mamas. This requires researchers to reject ubiquitous project descriptions that solely frame community deficits and ailments instead of acknowledging the experiences of Black Mamas, families and communities, holistically. Traditionally, community engagement is not always treated as a priority. However, it is a vital component when conducting research with and for Black Mamas and requires researchers to use Community-Based Participatory Practices and additional emancipatory research models.<sup>52–55</sup> The current evidence base is limited and restricts the transformational work required to improve health outcomes of Black Mamas. To improve the current state of Black maternal health, Black Mamas must be respected as experts due to their lived experiences and involved in the research process. Correspondingly, community-based organizations led by Black Mamas and their communities should also be included in the process of analyzing and disseminating data. Moreover, community advisory boards should be created and maintained as they will inform and



actively participate in the research process and ensure community involvement throughout the entire process.

## **VI. INCLUDE HEALTH EQUITY AND SOCIAL JUSTICE AS KEY THEMES IN RESEARCH WITH BLACK MAMAS**

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The research enterprise needs a fundamental shift toward authentic health equity and social justice when conducting research specific to Black Mamas. Funders, both in the private and public sector, should make serious investments in the development of health equity impact assessment tools to evaluate the intended and unintended consequences of community initiatives. Funders need to extensively allocate resources developed by, for and with Black Mamas to ascertain interventions that are most effective in improving health outcomes of Black Mamas. Furthermore, integrating art and spirituality in culturally rigorous<sup>7</sup> scientific research cultivates an environment for community-driven problem solving and authentic partnerships in research, especially within Black Mama populations.

# Black Mama Research Matters

**“Fund Black women researchers, follow their lead in this work, and create opportunities for more Black women researchers to continue this legacy.”**

— COURTNEY S. DRAYTON, MPH

Acknowledging the fact that Black Mamas of all backgrounds, irrespective of socioeconomic status, education and geographic region are not thriving and at times not surviving the journey to motherhood, is critical. This is our **WHY**. Therefore, it is essential to not only address maternal mortality, but to also prioritize reducing severe maternal morbidities by centering holistic maternity care practices. Globally, the work of Black-American, African, Afro-Caribbean and Afro-Latinx scholars, leaders and advocates should be the basis of all initiatives that seek to end maternal mortality, as our collective historical and current experiences with structural and systemic forms of oppression and violence towards our communities that further perpetuates dire health disparities, necessitates investments in our solutions and scholarship. Black Mamas deserve **access** to quality, holistic maternal care services throughout the pre-pregnancy to postpartum continuum. Black Mamas **deserve** to be heard and respected. Assessment and evaluation tools developed by Black women researchers should be employed to inform the design and implementation of maternal health research. Input from Black Mamas should be centered to guide the distribution of resources. Advancing Black maternal health, rights and justice requires a paradigm shift to valuing Black women's scholarship and leadership in and outside of

research spaces. This shift must involve centering care models, tools and innovative research methodologies developed by Black women scholars. We must trust Black women and in doing so, invest in Black women's scholarship.

Centering Black women in research, both as creators of new knowledge and as those who stand to benefit from findings, has tremendous potential to improve maternal health for Black Mamas and other pregnant and parenting individuals. This is exemplified in the work, research and writings of Black women such as Drs. Anna Julia Cooper, Mary Church Terrell, Ida B. Wells-Barnett, Pauli Murray, Zora Neale Hurston, Angela Davis, Audre Lorde, Barbara Smith, Toni Cade Bambara, bell hooks, Diane Rowley, Vijaya Hogan, Fleda Mask Jackson, Dána-Ain Davis, Patricia Hill Collins, Dorothy Roberts, Layli Philips-Maparyan, Leith Mullings and many others.<sup>56–64</sup> We are grateful for and continue this tradition in the research we conduct through BMMA's Research Working Group. Our hope and work are to reclaim and secure the undisputed dignity, value and social worth of Black bodies, Black births, Black life and Black women scholars and activists. We leverage the talent and knowledge that exists in Black communities and cultivate innovative research methods to inform the policy agenda to improve Black maternal health. The public health implications of Black women centered research is the epitome of the Black Mamas Matter Alliance's vision: a world where Black Mamas have the rights, respect and resources to thrive, before, during and after pregnancy. We **owe** this to Black Mamas (from those we've lost to those yet to come).

**THIS is Black maternal health research reimagined.**

# Appendix

FIGURE 1

## BMMA's Conceptual Frameworks in Research

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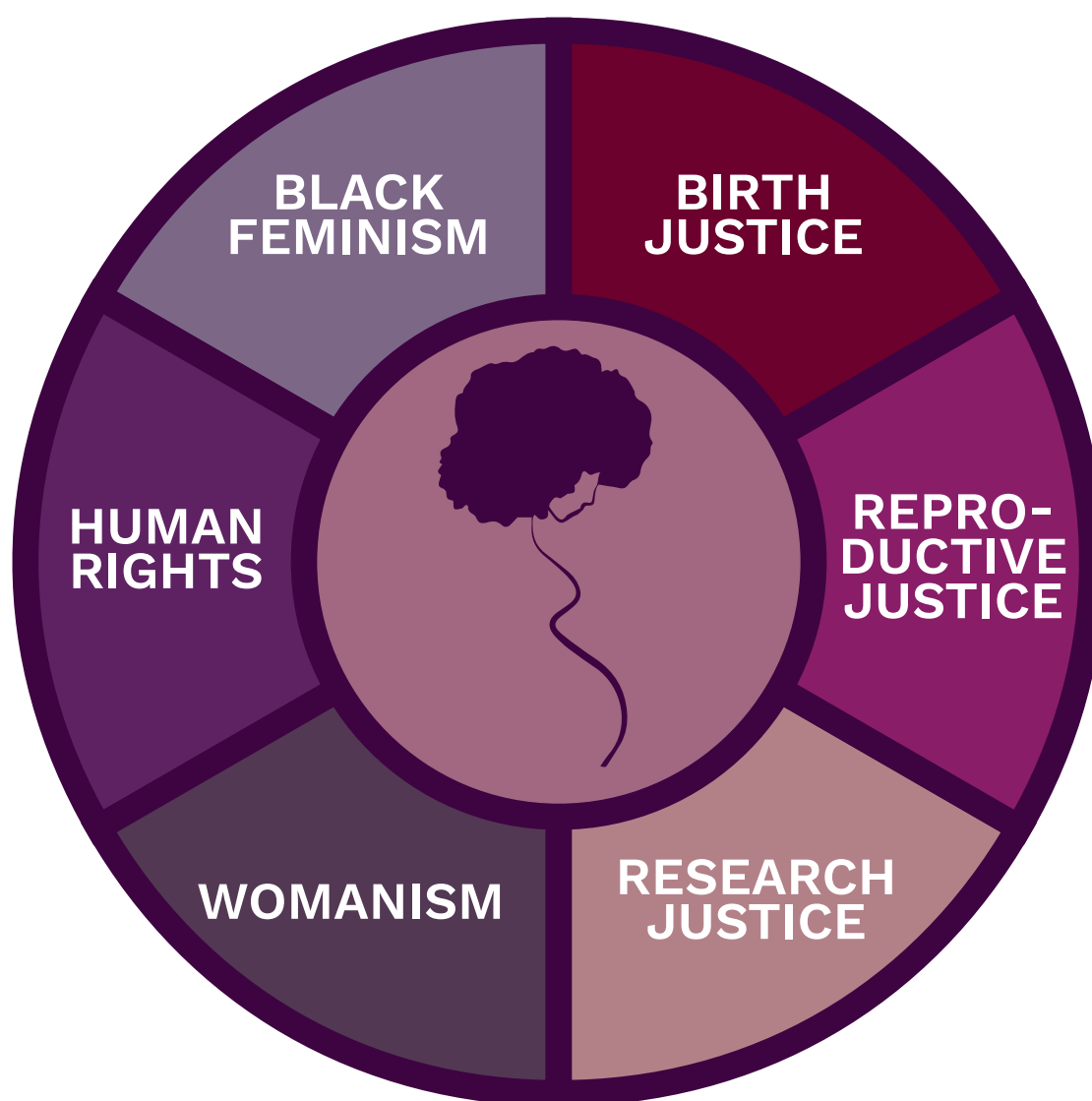


TABLE 1

## Holistic Care Definition and Recommendations from BMMA's *Black Paper: Setting the Standard for Holistic Care of and for Black Women* (2018)

HOLISTIC MATERNITY CARE COMPONENTS	HOLISTIC CARE RECOMMENDATIONS
<ul style="list-style-type: none"> <li>○ Addresses gaps in care and ensures continuity of care</li> <li>○ Is affordable and accessible</li> <li>○ Is confidential, safe, and trauma-informed</li> <li>○ Ensures informed consent</li> <li>○ Is Black Mama-, family-, and parent-centered and patient-led</li> <li>○ Is culturally-informed and includes traditional practices</li> <li>○ Is provided by culturally competent and culturally congruent providers</li> <li>○ Respects spirituality and spiritual health</li> <li>○ Honors and fosters resilience</li> <li>○ Includes the voices of all Black Mamas</li> <li>○ Is responsive to the needs of all genders and family relationships</li> <li>○ Provides wraparound services and connections to social services</li> </ul>	<ul style="list-style-type: none"> <li>→ Listen to Black women</li> <li>→ Recognize the historical experiences and expertise of Black women and families</li> <li>→ Provide care through a reproductive justice framework</li> <li>→ Disentangle care practices from the racist beliefs in modern medicine</li> <li>→ Replace white supremacy and patriarchy with a new care model</li> <li>→ Empower all patients with health literacy and autonomy</li> <li>→ Empower and invest in paraprofessionals</li> <li>→ Recognize that access does not equal quality care</li> </ul>



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## **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. BMMA honors the work and historical contributions of Black women's leadership within their communities and values the need to amplify this work on a national scale. For this reason, BMMA does not have chapters. The alliance is composed of existing organizations and individuals whose work is deeply rooted in reproductive justice, birth justice, and the human rights framework.

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