

CENTERING DATA EQUITY IN THE BLACK MATERNAL HEALTH CRISIS IS A PUBLIC HEALTH IMPERATIVE

April 2024

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INTRODUCTION

There is a deeply troubling, well-documented, and ongoing maternal health crisis in the United States (U.S.). According to the World Health Organization, the U.S. has the worst outcomes for maternal death in the developing world, with 17 deaths per every 100,000 births.¹ The overall rate is ten times the estimated rates of other high-income countries, such as Australia, Japan, and Spain. In 2023, the Centers for Disease Control and Prevention reported that Black women are 2-3 times more likely to die because of childbirth [the brief uses the term Black women and Black birthing people to represent all bodies across the gender spectrum which can give birth].²

In 2022, the United States experienced one of the worst rates of maternal mortality in history, with a 40% increase from the previous year, likely aggravated by the COVID-19 pandemic. A recent report by the New York Times highlighted that not only are the rates for Black maternal health persistently rising in the U.S., but that even “wealthy” Black women continue to have poorer birth outcomes than “poor” White women.³ In other words, even when Black women achieve the highest levels of wealth and education, outcomes of maternal death remain consistent in comparison to other racial groups.

Public health policy remains at a crossroads with respect to the maternal health crisis in the US. The data that continuously tells policymakers and industry stakeholders that there is a problem must not be ignored. Trends for maternal health outcomes in the United States for Black women have defied current trends and have no biological explanation for the dire health outcomes experienced by Black women. The unexplained outcomes are likely a result of historical biases and racism linked to a strained public health system.⁴

Data Equity is a Public Health Imperative

The worrisome trends in Black maternal health are important reflections on how data equity principles and the need for quality data can tell a story about the challenges in an overwhelmed healthcare system. The data illuminate facts and directs epidemiological information toward solutions that can inform the reduction of our current public health crisis.

Background

Established in 1977, the Office of Management and Budget Directive (OMB) Statistical Policy Directive No. 15 (Directive No. 15) promotes uniformity and comparability for data on race and ethnicity across all federal programs and fund initiatives, including monitoring compliance with civil rights laws inclusive of equal access to housing, education, and employment.⁵ The directive was revised in March 2024, with the expansion of categories for race and ethnicity, as enumerated below.

1. Tikkanen, R., Gunja, M., FitzGerald, M., (2020, November 18). Maternal Mortality and Maternity Care in the United States Compared to 10 Other Developed Countries. The Common Wealth Fund. <https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/maternal-mortality-maternity-care-us-compared-10-countries>
2. Hoyert, D. (2023, March). Maternal mortality rates in the United States, 2021. National Center for Health Statistics. DOI: <https://dx.doi.org/10.15620/cdc:124678>
3. Miller, C., Kliff, S., Buchanan, L. (2023, February 12). Childbirth Is Deadlier for Black Families Even When They're Rich, Expansive Study Finds. *The New York Times*. <https://www.nytimes.com/interactive/2023/02/12/upshot/child-maternal-mortality-rich-poor.html>
4. Geronimus, A. (2001). Understanding and eliminating racial inequalities in women's health in the United States: The role of the weathering conceptual framework. *Journal of the American Medical Women's Association*, 56(4), 133–136, 149–150.

- American Indian or Alaska Native;
- Asian;
- Black or African American;
- Hispanic or Latino;
- Middle Eastern or North African;
- Native Hawaiian or Pacific Islander; and
- White

The inclusion of Middle Eastern or North African (MENA)⁶ and the expansion to sub-categorical racial and ethnic identification are ground-breaking, as individuals are also able to self-identify through a write-in option.

While the expanded definitions demonstrate progress, OMB still does not have a standardized method for collecting important demographic data regarding gender identity, a gap which is outlined in the issue brief jointly published by the Blue Cross Blue Shield Association (BCBSA) and the National Minority Quality Forum (NMQF), *Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy*.⁷ Thus, the Black Women’s Health Imperative (BWHI) supports the recommendations outlined with respect to increasing race and gender data equity for inclusion in future updates to Directive No. 15:

- Directive No. 15 should provide clear and consistent requirements for the collection of Race, Ethnicity, and Language (REL) and sexual orientation and gender identity (SOGI) data that include a minimum standard for disaggregated Race/Ethnicity collection and are consistent with industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards);
- OMB should incorporate the current data standards promulgated by the U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No. 15 and require that the policy be the minimum standard for collecting disaggregated REL data; and
- OMB should intentionally and proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization in the Directive No.15 update.

BWHI is a national organization in its 40th year, whose work is centered to advocate and implement policy, program, and strategic health systems recommendations to address the deep disparities in health impacting Black women and girls. As part of the mission to lead the effort to solve the most pressing health issues that affect Black women and girls, we are certain that comprehensive data informs evidence-based driven solutions to address the health needs of our constituency. Our perspective is to advance an imperative for federal government and health care industry stakeholders to ensure a full representation of individual identity, including who is being counted and impacted by public health disparities in the US. As change

5. Blue Cross Blue Shield Association, National Minority Quality Forum. (2023, March 28). Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy. Data Equity Coalition. https://dataequitycoalition.com/wp-content/uploads/2023/07/NMQF_Brief_Paper.pdf

6. Federal Register Volume 89, Number 62. (2024, March 29). Revisions to OMB’s Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, Pages 22182-22196. U.S. Government Publishing Office. <https://www.govinfo.gov/content/pkg/FR-2024-03-29/pdf/2024-06469.pdf>

7. Blue Cross Blue Shield Association, National Minority Quality Forum. (2023, March 28). Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy. Data Equity Coalition. https://dataequitycoalition.com/wp-content/uploads/2023/07/NMQF_Brief_Paper.pdf

agents, we coalesce with a multi-sectoral group of partners within the Data Equity Coalition as equity advocates for inclusive health policy and health systems change work.

BWHI core principles of data equity as they impact public health outcomes for Black women’s health:

- Data collection is for data utilization, the improvement of policy which impacts the health of women and girls and their families;
- Accelerated research and technological advancement in support of women and their primary health concerns as a defined public health priority;
- Identification of structural inequities, as data can address and name deficits that impact Black and Brown women. By way of evidence, the maternal health crisis is a primary example of how data calls out the story and clear need to improve women’s health in the United States; and
- Systematizing processes and training within health access and infrastructure from care providers, payers, and the private sector, including expanded coverage options.

The Persistent Lack and Use of Comprehensive Data and Its Impact to Maternal Health is Systemic

There is evidence to suggest why our health systems continue to struggle in the face of closing the gaps in maternal health. Recent reports from The Health Management Academy note that hospital systems continue to have limited dedicated analytic support for routine data collection to address and identify maternal health disparities.⁸ This lack of capacity and support in our health systems highlight the importance of data equity as a primary tool for impacting public health outcomes and how the lack of data equity exacerbates the gaps in maternal health outcomes in systems of care. The workforce dynamic creates a lack of positive health outcomes over time. Therefore, the lack of staff creates barriers to quality care due to the inconsistent monitoring and accessibility of data.

Furthermore, there needs to be more timeliness of state-level population data related to maternal health (i.e., perinatal quality collaboratives, health departments, etc.). This lag does not support healthcare systems’ ability to make forward-looking strategic decisions on resourcing, care models, or responding to patient needs in real time. The lack of real-time data infrastructure systems makes it nearly impossible to surface and act on rolling trends.

Due to current infrastructure gaps, working within a data equity approach means we must ask different questions to engage Black women in systems of care that support their needs holistically. Industry stakeholders should advance data equity to address maternal morbidity in the U.S. by understanding that Black women have a myriad of historical socio-structural concerns that impact their ability to birth free from harm. Methodologically, interrogations are not solely about statistics but quality of life and reducing harm.

8. The Health Management Academy (THMA). (2023, April). Case Study Compendium: Maternal Health [PowerPoint slides]. THMA. <https://hmacademy.com/insights-and-resources/?resource-topic=digital-health>

The demographic indicators collected in OMB Directive No. 15 are instructive for policymakers to understand the maternal health crisis better. Embedded in the data equity approach is a need for more systemic storytelling. Thus, linking to clear and disaggregated demographic data will begin a path forward to address the U.S. maternal health crisis.

Examples of equity informed standardized questions to ask birthing Black women as part of standard of care:

“Did I answer all of your concerns today?”

“Is there something I missed in my understanding of your health needs today, including those of you and your family?”

“I want to leave here knowing I understand you and how you are feeling about your pregnancy. Is there something you think I have not clearly addressed or understood?”

Furthering the Work: Policy Recommendations to Advance Data Equity in Black Maternal Health

The national Black maternal health crisis in the US is not a crisis which has “snuck” up on our health systems. The US is having a reckoning moment. The issue of maternal mortality has gained acknowledgement and understanding within a diverse array of community leaders, activists, researchers, and social media influencers who have been amplifying the need for immediate corrective action within systems of care. There are well-documented stories of Black women experiencing racism in their health care engagement, or simply not being “heard” by their providers when in pain.⁹

According to a report by the California Department of Public Health, a local southern California hospital, failed to properly treat a pregnant Black woman who complained of discomfort in her legs. Unfortunately, the physician’s unwillingness to listen to the woman’s concerns led to her death.¹⁰ Here is an example of what happens when health practitioners ignore a Black woman’s concern about their own maternal health. Occurrences like this happen far too often, and despite being well-loved, or a wealthy celebrity, many Black women are experiencing difficult birthing processes.¹¹

Maternal Health Data Equity

The maternal health data equity story reinforces how Black women, while comprising merely 11% of the total U.S. population, hold disparately high rates of exposure to the experiences of inequitable access to treatment

9. *Ibid.*

10. Reyes, E. (2023, August 7). Inglewood hospital fined \$75,000 for failures that led to maternal death. *The Los Angeles Times*. <https://www.latimes.com/california/story/2023-08-07/inglewood-hospital-fined-75-000-for-failures-patient-dying-childbirth-maternal-death>

11. Danielle, B. (2020, October 24). Serena Williams Says Black Women Are Dying During Childbirth Because ‘Doctors Aren’t Listening To Us. *Essence*. <https://www.essence.com/news/serena-williams-doctors-listening-black-women-during-pregnancy/>

and care.¹² Hospitals and care systems have capacity issues to receive, analyze, and address data promptly. Another pointed issue is a stressed health infrastructure with documented provider shortages and managed care silos which often lack the time to incorporate the lived experience of patients as instructive to achieve equitable and concordant care.

The disparities seen in health outcomes of Black women may also be attributed to the environmental and structural stressors of racism, sexism, and the lack of belief in the care system. Black women deserve the same level of care as their White counterparts. There are monumental changes that must be engaged to ensure positive and impactful outcomes for Black maternal health and would, in turn, support all maternal health outcomes in the United States.

Therefore, in addition to alignment with the recommendations in the inaugural BCBSA and NMQF issue brief, the scope of the revised OMB Directive No.15. should also include:

- The expansion and enforcement of a set *pre and post-natal (up to 12 months postpartum)* national quality measures across regional, public, and private health systems
 - Including a subset of routinized maternal mental health outcomes;
- Data collection, analysis, and utilization for improving care is integrated as part of learning practices into maternal care systems through dedicated data team members who work closely with care providers (OBs, nurses, MAs, etc.) as an overall part of care teams; and
- Indicators for REL and SOGI captured and routinely monitored for maternal outcomes to ensure that care systems, public and private, are timely aware of ongoing disparities, intending to drive interventions and positive health outcomes.

CONCLUSION

Creating data equity principles that govern the Black maternal health crisis is necessary to prevent maternal deaths. The National Center for Chronic Disease Prevention and Health Promotion reported that 80% of pregnancy deaths are preventable.¹³ Pregnancy-related deaths for Black women most often occur within the span of a Black woman's pregnancy through one year postpartum. Applying routine principles of data equity as comprehensive policy interventions is crucial for the improvement of the delivery of safe maternal health care.

12. Chinn, J., Martin, I., & Redmond, N. (2021). Health Equity Among Black Women in the United States. *Journal of Women's Health* (2002), 30(2), 212–219. <https://doi.org/10.1089/jwh.2020.8868>

13. Trost, S., Beauregard, J., Chandra, G., et al. (2022). Pregnancy-Related Deaths: Data from Maternal Mortality Review Committees in 36 U.S. States, 2017–2019. Centers for Disease Control and Prevention. <https://www.cdc.gov/reproductivehealth/maternal-mortality/docs/pdf/Pregnancy-Related-Deaths-Data-MMRCs-2017-2019-H.pdf>