INSTITUTE FOR WOMEN'S POLICY RESEARCH

Data in Danger: The Disappearing Infrastructure of Maternal Health Research

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Birthing While Black: The Urgent Fight for Maternal Health Reform Series

Introduction

In recent decades, federally funded and supported research has shined a light on the state of US maternal health outcomes and the extent to which Black women disproportionately experience maternal mortality and morbidity. Researchers have recently raised concerns about data collection, citing instances of overreporting,[1] underreporting,[2] and a general lack of uniformity that makes interstate comparison difficult and can obscure circumstances on the ground. **Regardless of these complexities, racial disparities are a clear and constant through line in the research.** More in-depth qualitative and quantitative research is needed to address this enduring health inequity.

Researchers have made efforts in recent years to address the flaws in data collection. However, current political developments threaten advancements made on this critical research and on efforts to address maternal mortality more broadly. Maternal health research sits at the intersections of the current administration's multipronged policy attacks on grants or programs considered "diversity, equity, and inclusion" in nature[3] and on the public health infrastructure writ large. This means the systems that have long been in place to shed light on a range of health outcomes—systems which public health experts have been working to strengthen—are forced to go dark at the very time they are most needed.

> *Accurate public health data is critical to solving the maternal health crisis. It illustrates the real-world impact of policy choices, reveals how different communities experience negative maternal health outcomes, and shows us which programs and interventions are effective and where resources should be channeled.*

In addition to the loss of surveillance and data, cuts to public programs such as Title X and Medicaid, among others, threaten to exacerbate negative outcomes and worsen disparities. Making matters worse, some states have intentionally disbanded or weakened their maternal mortality review committees (MMRCs), eliminating one of the few pathways states have to understanding the individual and community impact of maternal mortality.[4]

This brief is the sixth and final in IWPR's series *Birthing While Black: The Urgent Fight for Maternal Health Reform*. It reviews the historical and current mechanisms for collecting and disseminating maternal health data, describes the flaws and complexities that have emerged in those systems, and details the current-day threats to our ability to understand and address the United States' maternal health crisis.

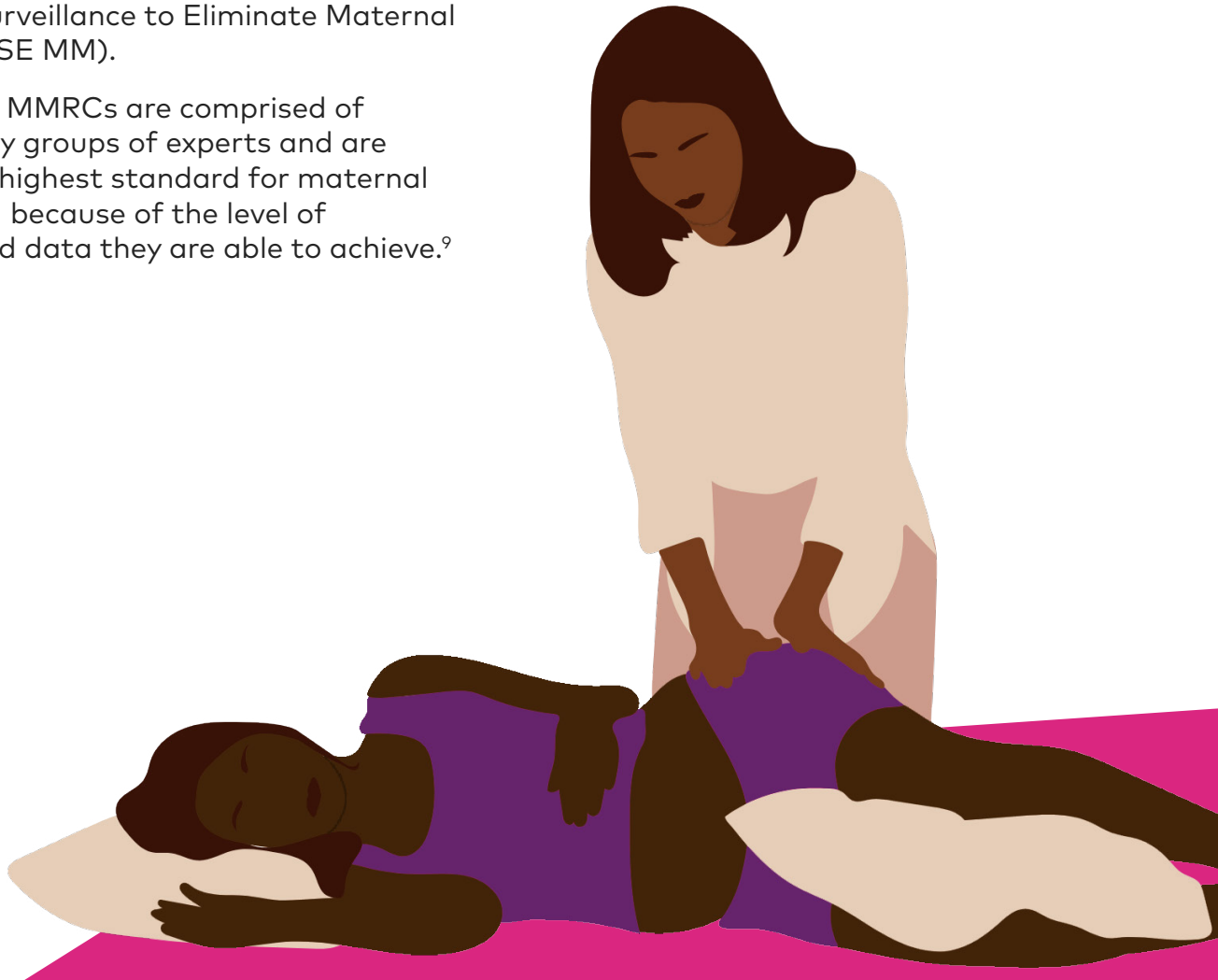
Collecting maternal health data.

In the United States, maternal mortality data is collected and reported through a complex and interdependent network of research bodies: national vital statistics systems,[5] surveillance programs, and state-level MMRCs.

At the national level, the Centers for Disease Control and Prevention (CDC) houses the two main sources of maternal mortality information: the national vital statistics system (NVSS),[6] compiled annually by the National Center for Health Statistics (NCHS) and the Pregnancy Mortality Surveillance System (PMSS),[7] run by the Division of Reproductive Health at the National Center for Chronic Disease Prevention and Health Promotion.[8] The CDC also houses other critical research efforts, such as the Pregnancy Risk Assessment Monitoring System (PRAMS) and Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM).

State and local MMRCs are comprised of multidisciplinary groups of experts and are considered the highest standard for maternal health research because of the level of accuracy around data they are able to achieve.[9]

These life-saving research efforts—like much public health research—are often invisible to the general public. The broader public does not have a window into the unseen labor of researchers and the critical role it plays in fueling interventions that save lives: extending postpartum Medicaid coverage, providing insurance coverage for doulas, improving hospital protocols, and identifying the impact of maternal health deserts. We can't fix what we can't see or measure.



Opportunities to strengthen maternal mortality data collection.

The lack of historical research on pregnancy-related mortality and morbidity means that collecting accurate data on maternal health outcomes is a relatively new endeavor that needs improvement. It requires careful coordination between federal, state, and local bodies across multiple sources of information. Recent efforts to improve the quality and accuracy of maternal health data has attempted to address ongoing challenges.

Different Definitions of Maternal Mortality

The foundation of US maternal mortality statistics is a patchwork of surveillance systems that operate with different definitions of maternal death. For instance, the NVSS only looks at deaths that occur within 42 days after a pregnancy ends, while PMSS considers deaths for a full year, allowing them to track conditions like cardiomyopathy and thromboembolism that often develop months after delivery. MMRCs also track deaths for a full year, but their data is intended for short-term actions vs. long-term trends. The use of different definitions undermines the accuracy, comparability, and consistency of maternal health data.

State-Level Variability

Vital statistical information is the pillar of national maternal mortality estimates, and for many decades has suffered from misclassification problems.[10] In 2003, experts acknowledged the prevalence of these problems over previous decades and implemented a "pregnancy checkbox" on death certificates. This effort was an attempt to identify missed cases but also led to the reporting of many false positives, particularly in women over 45 whose deaths were erroneously classified as pregnancy-related.

Not all states adopted the new pregnancy question at the same time, which made comparisons across states very difficult, and prevented the CDC from publishing a national maternal mortality rate for many years.[11] Additionally, inconsistencies with the way the checkbox was filled out skewed national ratios and led to confusion. Official national numbers are often two years old by the time they are released, leaving policymakers to respond to outdated data.[12]

Timely research and real-time data is essential. It allows policymakers, advocates, and health care providers to design effective interventions, allocate resources, and hold systems accountable. Without it, policymakers might respond to conditions in ways that are no longer the most relevant or effective or might be delayed in addressing urgent shifts in conditions on the ground. To effectively reduce maternal deaths and improve reproductive health outcomes overall, public health research must be both rigorous and responsive to current conditions.

Challenges Facing MMRCs

Maternal mortality review committees play an unmatched role in maternal mortality research but face several challenges. Their work is resource-intensive and often underfunded. They require a broad group of stakeholders to access and review data across multiple, inconsistent, and sometimes incomplete sources.[13] MMRCs can also be impacted by a lack of available training, limited diversity of team members, the time and cost required to process records, and providers' final decisions on the patient's cause of death.[14] Legal authority, scope of work, data systems, and funding can all differ significantly across states, making it difficult to compare data across borders.

Limitations to PRAMS

PRAMS surveys are updated every three to five years, making it difficult for researchers to address current or pressing issues through those surveys. Data is aggregated or truncated for specific variables to protect confidentiality and is released roughly 8–12 months after the end of a calendar year, so there is a significant lag between collection and dissemination of the data.[15] Additionally, as with other self-reported data, validity and reliability varies among participants.[16]

Additional Limitations

Current mechanisms for collecting data are limited and inconsistent in terms of identifying early pregnancy losses and terminations, linking mother-child records, and identifying gestational ages for critical events in pregnancy.[17]

Lack of Qualitative Data

The vast majority of maternal mortality research in the United States is gleaned from quantitative sources; there is a dearth of studies that reflect women's lived experiences in their own voices.[18] This research is critical to understanding patient experiences, particularly those of women who are most impacted by health disparities, and to developing solutions to addressing the inequities of their experiences.[19] **Quantitative data alone does not provide a detailed window into pregnant women's experiences with a range of drivers of negative health outcomes such as racism, encounters with providers, and the logistics of accessing care.**

In addition to conducting qualitative research that sheds light on women's birthing experiences, it is also critical that we better understand the longer-term impacts of maternal mortality and morbidity. Amid the current state of research, much remains unknown or only partially understood. As we described in our previous brief "When Care Fails, Generations Suffer: The Ripple Effect of the Black Maternal Health Crisis," what little research that does exist on the long-term impacts has largely focused on the economic impact of maternal mortality and morbidity. However, there are much deeper cascading consequences we must consider. What are the immediate economic impacts on children and families left behind? How does maternal mortality compound wealth inequities across generations? What are the physical and mental health impacts of parental loss on children?

The pathways to these potential outcomes are numerous, including the impact of the loss of the mother on her immediate family and surviving children, and the impact on Black women who are left shouldering the responsibility resulting from the loss of a Black mother. **We must understand not only how to *prevent* maternal mortality from occurring, but also how to *support* the families who experience it.** Rich qualitative data is critical to these efforts.

Recent threats to maternal mortality research.

Like many other areas of research, maternal mortality research has come under serious threat from the Trump administration.[20] Cuts to federal grants and the evisceration of public programs and employment, in addition to state-based attacks on MMRCs, have all rapidly shifted the reproductive health research environment.[21]

Funding and Staffing Cuts

The current administration has taken direct aim at surveillance and research on women's pregnancy-related deaths by banning from its grant-making processes the very language used to describe those deaths. As of May 2025, the administration has urged federal employees to not approve any grants that include the words women, Black, minority, race, LGBTQ, trans, bias, abortion, science-based, barrier, cultural sensitivity, discrimination, equity, gender-based violence, health disparity, and injustice, among hundreds of others.[22] Organizations and individuals working on pre-approved grants that included such language have lost funding.[23] **Halting this research puts efforts to improve the nation's understanding of conditions that predominantly affect women—including endometriosis, menopause, infectious diseases contracted in pregnancy, and pregnancy-related deaths—at stake.**[24]

In March 2025, as part of its effort to radically reshape federal public health programs,[25] the CDC hollowed out the Division of Reproductive Health, essentially taking an ax to PRAMS and PMSS. The entire PRAMS team was laid off and PRAMS data collection was stopped on the spot. As of the publication of this brief, access to PRAMS data was suspended[26] and there was no mechanism by which to collect information about 2025 cases.[27] As one CDC staffer anonymously told *Rolling Stone*, "We cannot understand factors associated with poor pregnancy outcomes without surveillance like PRAMS. . . . If we don't understand those factors, US maternal morbidity and mortality will continue to worsen. This means more women will die."[28]

Because data from PRAMS was the backbone of much of the research on maternal health, the loss of the program and its information will have far-reaching impacts on research conducted across academia and public health. Experts have explained how the loss of research and surveillance tools will completely hamstring policymakers and health care providers, rendering invisible a number of issues such as barriers to prenatal care, trends in postpartum depression, and other systemic issues that indicate the contours of the maternal health crisis."[29]

As part of cuts to the CDC, the entire staff that worked on PMSS—analysts responsible for compiling and vetting that data—was let go. As a result, the CDC has not published any recent briefs, and it is unclear what is happening with pregnancy-related death information from 2023–2024.

The limited information available suggests the MMRCs and perinatal quality collaboratives will not be part of the new structure of the Department of Health and Human Services (HHS), leaving hospitals and providers without the information required to implement lifesaving solutions. As Dr. Veronica Gillispie-Bell wrote, "These programs are not bureaucratic add-ons, but the main reason our nation has made progress in reducing maternal deaths."[30]

These sweeping cuts have essentially made maternal health research go dark. From banning future research efforts to eliminating funding and staff for current programs and freezing the very infrastructure used to collect and disseminate data, the efforts of policymakers, advocates, and medical

professionals will be significantly hindered. **The federal government has done an about face just as the research community was making progress in improving research systems and garnering support and resources needed to meaningfully address the ongoing maternal mortality crisis.**

State-Based Attacks on MMRCs

While the work of some states' MMRCs is sure to be hampered by the federal funding environment, other states have eliminated or reorganized their MMRCs as a political response to maternal deaths related to abortion bans.[31] In the wake of a report that two women in Georgia died as a result of that state's abortion ban,[32] lawmakers dismissed all 32 members of its MMRC. In March, it reconstituted the group but will not make the list of new members public.[33] Idaho let its MMRC expire in 2023 and took more than a year to reactivate it.[34] In late 2024, Texas lawmakers announced they would not review pregnancy-related death cases from the years immediately following the implementation of the 2022 abortion ban, delaying a report that was otherwise supposed to be released during an election year.[35]

The work of MMRCs was critical before the *Dobbs* decision. However, in the wake of the Supreme Court eliminating the federal right to abortion, and given the rapidly changing maternal health landscape, the need for a clear window into the current and evolving state of reproductive health access and outcomes has never been more critical. And that is precisely why certain states are erecting barriers to collecting this data. **We cannot identify or measure a problem—or hold policymakers accountable—if we do not have evidence that it is occurring.**

Federal Cuts to Adjacent Programs

In addition to the direct attacks on maternal health research, there have been vast cuts to maternal health-adjacent programs. Funding and staffing cuts have impacted the Teen Pregnancy Prevention Program, the Title V Maternal and Child Health Services Block Grant, and the National Maternal Mental Health Hotline.[36] The CDC's Assisted Reproductive Technology (ART) team was eliminated a week after the president coined himself the "fertilization president." That team tracked IVF outcomes and provided critical information to the public on a wide range of fertility issues.[37] The CDC team focusing on emergency preparedness for pregnant and postpartum women and infants—the group responsible for how pandemics can impact pregnant women—suffered significant cuts.[38]

And there's more. The CDC team that oversaw contraceptive guidelines, making recommendations in an app that allowed doctors to quickly reference the most up-to-date guidance on contraception for their patients, was fully shut down. The Intimate Partner Violence Prevention team was dismantled, and all employees working on rape prevention education were laid off.[39]

Additionally, the administration froze roughly $35 million in Title X funding,[40] a move that the Guttmacher Institute estimates will force at least 834,000 people to lose access to reproductive health care.[41] If not reversed, that funding freeze would fully eliminate Title X care in California, Hawaii, Maine, Mississippi, Missouri, Montana, and Utah.[42]

The administration also erased all online information deemed in violation of its executive orders. The ReproductiveRights.gov website established by the Biden administration in the wake of the *Dobbs* decision is no longer online.[43] Lastly, significant cuts to the National Institutes of Health (NIH) have impacted a wide array of reproductive health research that was being conducted at universities around the country.[44]

Conclusion

Federally funded research has always been the backbone of maternal health research. While imperfect, this research has shed light on an ongoing maternal health crisis in the United States that peer countries do not experience, and it has illustrated how US trends have been moving in the wrong direction while other countries have seen significant improvements in maternal health outcomes. It has told us much about the enduring racial disparities in maternal mortality and given advocates, policymakers, and medical experts a basis upon which they have proposed interventions that could start moving the needle in the right direction.

In recent years, there have been growing efforts to improve the gaps and inaccuracies that have been common with maternal mortality research. Those national efforts have largely been ground to a halt because of the Trump administration's gutting of major pillars of our public health system, particularly those created to identify and address maternal health inequities. Those pillars are being dismantled at the very time that cuts to other government programs threaten the health and well-being of women and families.

Black women, who are already at greater risk of maternal morbidity and mortality because of historical and ongoing inequities, will shoulder the heaviest burdens of these changes. Shifts in economic and social policies that are changing labor market opportunities,[45] health care coverage and access,[46] the cost of everyday goods, and stability for rural communities[47] will also have an outsized impact on Black communities and will only exacerbate the acute risks to Black women's reproductive health outcomes. We must remember that research is the very tool that allows us to clearly see problems, to understand their root causes, and to formulate effective responses.

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To see more from IWPR's *Birthing While Black: The Urgent Fight for Maternal Health Reform Series*, visit iwpr.org/birthingwhileblack/.

To learn more about IWPR's federal policy recommendations on maternal health, visit iwpr.org/maternal-health.

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