SAVING WOMEN'S LIVES:
A DATA-DRIVEN APPROACH TO REDUCE MATERNAL MORTALITY

By Rachel Mayer, Sarah Kinling, and Alison Dingwall

OUR MOTHERS ARE DYING AT AN UNPRECEDENTED RATE.
The United States is the only country in the developed world to <u>see an increase in women dying as a result of pregnancy</u>. Our maternal mortality rate has doubled in the last two decades— the worst rate among wealthy nations and <u>55th</u> among all countries when last compared in 2017.

While the United States is known for its advances in science and medicine, nearly 1,000 women will die this year of pregnancy-related complications (e.g., hemorrhage, heart failure, eclampsia). More than half of these deaths, postmortem findings show, could have been prevented with timely and proper interventions. There are also near misses—more than 50,000 women each year barely survive these complications, and many face significant short- or long-term consequences to their health.

These preventable tragedies impact minority women at greater rates. Non-Hispanic Black women are almost three times as likely to suffer a pregnancy-related death than White women. Native American women are two to three times as likely than White women to die from pregnancy-related causes. Inequities increase with age—minority women over the age of 30 die at four to five times that of White women of the same age. These disparities exist in communities across the country, regardless of other socioeconomic factors.

It May Be Worse Than We Know

The current approach to determining the U.S. maternal mortality rate is potentially undercounting actual pregnancy-related deaths. The national rate, last estimated in 2018 by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS) to be 17.4 maternal deaths per 100,000 live births, only includes women that died during pregnancy through 42 days postpartum to align with the World Health Organization's (WHO) definition. Yet the CDC notes that 24% of maternal deaths occur 43 days to one year postpartum.

Further complicating an accurate maternal mortality rate are the inconsistencies and barriers in data collection, analysis, and reporting. Death certificates are the primary data collection method at the national level, yet there are noted inaccuracies in how pregnancy-related deaths are documented. Localities and states collect data on maternal deaths but lack specific national guidance on what data to collect and how to analyze it, leading to reporting inconsistencies across states. These collection issues coupled with only some states reporting complete data to CDC's Pregnancy Mortality Surveillance System (PMSS), make it nearly impossible to capture the full national picture of our maternal health crisis. Without consistent state data standards and required reporting, PMSS is comparing apples to oranges, and in many cases, comparing apples to nothing.

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Benefits of National Maternal Mortality Data Standards

The wheels of change are in motion. In December 2020, the U.S. Department of Health and Human Services (HHS) published the Action Plan to Improve Maternal Health in America, and the Surgeon General issued a complementary Call to Action to Improve Maternal Health. While both advocate for improving data quality, future planning must consider the importance of creating national standards for data collection, analysis, and reporting.

President Biden's agenda for women advocates applying California's strategy to reduce maternal mortality nationwide. After a rigorous data collection process to understand the leading causes of preventable pregnancy-related deaths within the state, California successfully cut its maternal death rate in half by applying impactful interventions. **The key to California's success was implementing data-driven interventions based on the state's population demographics.** The other 49 states in the United States need to follow this same strategy—collect standardized, comprehensive data, and then design and implement programming to reduce maternal deaths based on the specific needs of their populations. In many states and localities, data collection and analysis already exist, but it occurs in silos. Each state has different collection parameters and analysis procedures—some better than others—and collaboration and coordination between states and with the federal government is limited.

Understanding the full and true extent of why women are dying in pregnancy, childbirth, and the postpartum recovery period—and how this can be prevented—is a necessary first step in reducing maternal mortality and improving maternal health. From the limited data we have, there appears to be layer-upon-layer of contributing factors to maternal mortality including social determinants of health, racial disparities, ignoring patient concerns, and a lack of standardized approaches to obstetric emergencies.

CURRENT U.S. MATERNAL MORTALITY DATA SOURCES

NATIONAL CENTER FOR HEALTH STATISTICS (NCHS)

Entity: Center within the CDC

Maternal Death Definition: Pregnancy through 42 days postpartum

Process: Statisticians identify maternal deaths through death records (pregnancy checkbox and maternal mortality ICD-10 codes)

State Data-Sharing to Federal Government: Contractual obligation through Vital Statistics Cooperative Program

PREGNANCY MORTALITY SURVEILLANCE SYSTEM (PMSS)

Entity: Surveillance system within CDC's Office of Reproductive Health

Maternal Death Definition: Pregnancy through one year postpartum

Process: Medical epidemiologists review and analyze death records, linked birth records, fetal death records, and additional available data from all 50 states, New York City, and Washington, DC

State Data-Sharing to Federal Government: Voluntary

MATERNAL MORTALITY REVIEW COMMITTEES (MMRC)

Entity: State or local level; some states receive federal funding

Maternal Death Definition: Vary by state

Process: Multi-disciplinary teams perform comprehensive reviews of deaths using information beyond what is available in vital records, including medical and non-medical data sources

State Data-Sharing to Federal Government: Voluntary

To get there, the United States needs standardized, comprehensive data from every state. This would allow us to understand why women are dying and inform our actions to reduce maternal mortality. Consistent, annual reporting from states would enable preventive action—identifying areas of concern and emerging trends to inform new or updated policies and procedures—to make positive changes.

It All Starts with Data: Recommendations for Data Collection, Analysis, and Reporting Policies

Improving maternal health data collection, analysis, and reporting is a fundamental first step toward a national commitment to reducing maternal mortality and eliminating preventable deaths. To reduce maternal deaths and reduce racial disparities in maternal health, we need high-quality data. When MITRE created

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a data-driven decision-making tool to help states determine which interventions could have the most impact, our team quickly realized that data quality among states was drastically different and impossible to compare state-to-state. Only states with high-quality data can benefit from the use of this or other decision-making tools—without high-quality data, the resulting decision is not quality either. The more states with consistent high-quality data available, the better we are able to address maternal mortality with national interventions and policies.

For the last three years, as MITRE navigated data quality issues in maternal health, our team shared lessons learned with the maternal health community to fill the literature gap and help raise awareness of these data quality issues. Collaboration from federal, state, and local entities is essential to improve data standards. **The following recommendations can guide policymakers in shaping national data standards to inform what actions and policies are needed to reduce maternal mortality and improve maternal health.**

Create a common language to classify and review maternal mortality rates. The NCHS and WHO define maternal death as the death of a woman while pregnant or within 42 days postpartum from any cause related to or aggravated by the pregnancy or its management. CDC advocates extending this definition through one year postpartum to capture additional pregnancy-related deaths. CDC's PMSS uses a more comprehensive term—pregnancy-associated death, defined as the death of a woman while pregnant or up to one year postpartum, with two subcategories separating pregnancy-related deaths and deaths unrelated to the pregnancy. With CDC using two different definitions and timelines, states have several options to consider in their data collection, making national analysis or state-by-state comparisons cumbersome. Standardized definitions in state data collection and reporting will allow CDC to compare apples-to-apples data and report clearly and accurately on the national picture. HHS, the U.S. Department of Veterans Affairs (VA), and state maternal mortality review committees (MMRCs) must follow the CDC-recommended pregnancy-related

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death definition (death of a woman while pregnant or within one year postpartum). Federal action is encouraged to mandate this definition usage to ensure consistency in all data collection, analysis, and reporting. By collecting information through one year postpartum, agencies can still report 42 days postpartum data to WHO for data for global comparison.

Ensure the pregnancy checkbox on death certificates is applied correctly. In 2018, all 50 states implemented a pregnancy checkbox to indicate whether the cause of death listed on the death certificate is a maternal death. The NCHS uses this data to determine the national maternal mortality rate. Unfortunately, insufficient training in death certification has resulted in improperly completed death certificates. Physicians, nurses, and medical examiners can complete death certificates, yet few have formal training on how to do so, with most learning through on-the-job experience. Formal death certification training requires a multipronged approach and must be prioritized within each state. This includes hospitals and residency programs making death certificate training a requirement and the Association of American Medical Colleges (AAMC) mandating training for medical programs while offering it as a continued medical education course for current practitioners.

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Provide guidelines for MMRCs. MMRCs identify, review, and analyze maternal deaths to act on findings to reduce maternal mortality in their state. The Preventing Maternal Deaths Act of 2018 provides funding for states to create MMRCs but does not offer guidance on review and reporting procedures. This has led to each MMRC defining maternal death differently (e.g., time period of pregnancy through 42 days vs. through one year, and pregnancy-associated vs. pregnancy-related) as well as discrepancies in scope of cases reviewed, documentation of preventability, and frequency and format of reporting. This results in vastly different data. Federal guidance in coordination with stakeholders on how MMRCs can standardize review and reporting procedures, including a standard reporting template, will improve data quality, timeliness, and consistency across states.

Develop data collection policies. Localities and states need to collect the same types of data for a true national comparison. Providing data collection requirements would remove the guesswork for states. All states must collect information on pregnancy-related deaths and the related medical condition from pregnancy through one year postpartum. Correlating these deaths with the following data points will allow for comprehensive national analysis and bring to light the relationships among these factors. This list is not prohibitive—additional information and factors valuable for the particular state to capture are encouraged.

Race and ethnicity: Given what we know historically about both disproportionate outcomes in minority communities and more severe outcomes in minority pregnant women, race and ethnicity data (e.g., non-Hispanic White, non-Hispanic Black, Asian, American Indian/Alaska Native, Hispanic, other) is vital information in maternal mortality data collection.

Preventability calculations by condition and race: Localities and states also analyze the data in different ways. Some states have a general preventability rate, while others break down preventability by condition (e.g., hemorrhage, eclampsia) or race. Preventability based on condition and race are important when determining the most impactful intervention.

Health insurance coverage: Knowing what type of insurance (e.g., Medicaid, private, Marketplace, no insurance) a woman had will help determine if updates are needed to national policies. For example, if a state demonstrates a higher rate of maternal mortality among women without insurance, an outreach effort is initiated.

Hospital or licensed birthing center information: Where and how a woman received obstetric care is important to show the full picture of what may have led to a woman's death. Documenting the maternal health quality (e.g., rates of cesarean section,

episiotomy) of the hospital, whether it is located in rural or urban setting, if the delivery provider was an emergency physician, family physician, or obstetrician, and even the distance from the woman's residence to the hospital could reveal provider issues and disparities.

Comorbidities and co-occurring diagnoses: Tracking a woman's overall health status during pregnancy is necessary for providers to adjust treatment plans, but it also provides a window into potential correlations in the event of a maternal death. This data will allow public health professionals to understand critical trends in comorbidities and manner of death, leading to better tools to prevent and treat pregnant women with the same comorbidity or co-occurring diagnoses (e.g., smoking, obesity, diabetes).

Conduct and share comprehensive maternal mortality and morbidity assessments on understudied population groups (e.g., Veterans, indigenous people and tribal nations, and incarcerated mothers). These populations have shown an increased risk of maternal death but lack current and comprehensive data needed to derive impactful interventions. The Black Maternal Health Momnibus Act of 2021 highlights the importance of these assessments but should be expanded to also address the issue of coordination and reporting. If the bill passes, VA, Indian Health Services, and the Federal Bureau of Prisons must coordinate on data collection and share results with CDC for national reporting and comparing to the general population.

Require and support states to share maternal mortality data with CDC. States have autonomy over the frequency (e.g., continuous, yearly) and form (e.g., physical death certificates, electronic versions, or screenshots of relevant sections) in which they share maternal mortality data with NCHS. For PMSS and MMRCs, some states share nothing, some only share the number of maternal deaths, some share a little more and may include condition, and other states are more forthcoming with comprehensive data. Privacy is an often-cited concern because of the low incidence of maternal mortality in certain states, with some

states aggregating the data they share to the point that it is hard to draw conclusions. De-identifying the data before sharing and storing it limits privacy risks. MMRCs must be the primary vehicle to collect, analyze, and report this data to CDC's PMSS to create a true national picture of the maternal mortality crisis. It is important to note that to date, 45 states have established an MMRC, but many have yet to produce a report.

Working Together to Improve Maternal Health

Addressing the multiple layers of maternal health challenges and inequities will require collaboration on all levels of government, industry, academia, and community organizations, as well as the participation of providers and patients. Consistent and reliable data are the foundation that this collaborative effort depends on. We know building this foundation is possible—CDC's Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) program is halfway there—it includes 25 states collecting standardized data. While this is a good starting point, we still have a long way to go in reducing maternal mortality.

Concurrent top-down and bottom-up approaches are necessary. We must provide a national data collection standard and support all 50 states, the District of Columbia, territories, and tribal nations in standing up MMRCs to ensure the state-level data is accurately feeding into a national report. A yearly report from MMRCs would enable CDC to produce a national report every two years, allowing us to understand the full extent of the problem and establish a benchmark to measure our progress. The ultimate achievement would be to create a national dashboard for states to compile MMRC report data, providing quick access and state-by-state comparisons, eliminating the time-consuming process of creating hundred-page reports.

With accurate and complete data, maternal health professionals and policy makers can identify national priorities to reduce maternal mortality—a data-driven approach to reverse this disturbing trend and ultimately help the United States become a world leader in maternal health.

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MITRE Publications

Harvard Maternal Health Task Force (May 2020): Accuracy of Maternal Mortality Rates and Updated NCHS Methodologies: Data Quality Matters

MITRE (August 2019): Can Data Modeling and Analytics Help Reduce Pregnancy-Related Deaths?

The Baltimore Sun (April 2019): Tackling Racial Disparities in Maternal Health

Health Affairs (February 2019): The United States Maternal Mortality Rate Will Continue to Increase Without Access to Data

Proceedings of the 2020 Spring Simulation Conference (SpringSim 2020): The MITRE Maternal Mortality Interactive Dashboard (3MID): A Tool for Assessing the Effectiveness and Equity of Quality Improvement Toolkits on Maternal Care

Journal of Public Health Management and Practice (November 2020): Let COVID-19 Serve as a Catalyst to Fix National Crisis of Poor Maternal Mortality Data

Women's Health Issues (January 2021): Documenting Maternal Deaths: Implications for National Statistics and Research