

GOAL 3

**WHITE HOUSE
BLUEPRINT
EVIDENCE TO
ACTION BRIEFS**

**Advance Data Collection,
Standardization, Harmonization,
Transparency, Research, and
Analysis**



Maternal Health
Learning & Innovation Center™
MaternalHealthLearning.org

**THE WHITE HOUSE BLUEPRINT
FOR ADDRESSING THE
MATERNAL HEALTH CRISIS**





The White House Blueprint for Addressing the Maternal Health Crisis (White House Blueprint) has identified goals and actions to reduce the rates of maternal mortality and morbidity, eliminate disparities in maternal health outcomes, and improve the overall experience of pregnancy, birth, and the postpartum period for people across the United States.

The following Evidence to Action Brief highlights Goal 3 of the White House Blueprint.

Maternal Health Goal 3

Advance data collection, standardization, harmonization, transparency, research, and analysis.

CONTRIBUTION TO QUALITY OF LIFE

The [White House Blueprint](#) is a “whole-of-government approach to combating maternal mortality and morbidity” so that all people in the United States who are capable of becoming pregnant and giving birth are healthy and safe.

“Data collection on maternal health risks, services, and outcomes in the US continue to be fragmented,”^{1.pg.7} thus leaving the health care system, communities, and federal, state, and local entities without the information they need to make informed decisions to address maternal mortality and morbidity.^{1.pg.7} This gap can be mitigated through increased efforts to bolster data linkages and data-sharing mandates for the main sources of maternal health data in the US, including federal data sources, state health departments, and health care systems.

BASIC FACTS

Several disparate federal, state, and local data sources, including the Centers for Disease Control and Prevention (CDC), state health departments, and health care systems, are responsible for collecting, analyzing, and sharing maternal mortality data. Leveraging and linking these data systems can provide a more holistic evaluation of maternal and infant health outcomes within and outside of health care settings.^{1.pg.36} These data systems are optimal when data is collected and shared in a way that identifies health disparities, thereby driving development of more equitable policies that improve maternal health outcomes for underserved populations.^{1.pg.39} It is important that collected data supports the analyses of factors that have been determined to have a major impact on maternal health: the social determinants of health, environmental stressors, mental health status, substance use disorders, and chronic diseases.

The [White House Blueprint](#) highlights several innovations that have the potential to create data-driven, equitable system change. One such innovation is Maternal Mortality Review Committees (MMRCs; for a more detailed description of MMRCs, see the Goal 1 Evidence



to Action Brief). MMRCs review data related to maternal morbidity and mortality utilizing both quantitative data (e.g., vital records, billing data, birth/death certificates) and qualitative data (e.g., hospital records, social service records).² Thirty-six states have voluntarily shared their MMRC data with the CDC to allow further analysis.^{1.pg.38}

MMRCs comprise multidisciplinary representatives who lead a review process that informs recommendations for preventing future maternal deaths. Experts such as the Black Mamas Matter Alliance recommend that multidisciplinary representatives include members from various fields such as maternal-fetal medicine, midwifery, mental health, and behavioral health, along with social workers and patient advocates. MMRCs also should involve communities in developing their recommendations.³ Collaboration between communities and MMRCs can lead to a plan of accountability that determines who is responsible for implementing MMRC recommendations.

The [Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#) is another innovation highlighted in the White House Blueprint. PRAMS is a national data source that seeks to collect data around factors that have a major impact on maternal health, including data related to the social determinants of health. PRAMS collects self-reported population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. Forty-six states as well as the District of Columbia, Puerto Rico, New York City, and the Northern Mariana Islands participate in PRAMS and represent 81% of all live births in the US.^{2,4} PRAMS data fills a research gap by providing data to researchers who investigate emerging issues in the reproductive health field.

Maternal health data is most useful when it is timely, accurate, standardized, comprehensive, equitable, and actionable. When it is collected with these standards in mind, new maternal health research insights are acquired, which can lead to improved treatment options and enhanced quality of care.^{1.pg.37} To bridge gaps in data collection and invest in research that translates into equitable system change, the [White House Blueprint](#) commits to the following actions:

Action 3.1. Improve data collection by enhancing MMRC data to inform maternal health interventions, supporting PRAMS data collection improvements, working with hospitals in the Maternal Morbidity and Mortality Data and Analysis Initiative to identify drivers of poor outcomes, coordinating with Health Center Program participants to report deidentified data that will help address disparities, working with FEHB [Federal Employee Health Benefits] carriers to capture race and ethnicity data, requiring reporting of perinatal, behavioral health, and child health measures under Medicaid/CHIP [Children's Health Insurance Program], and including maternity metrics in the public Medicaid and CHIP Scorecard.

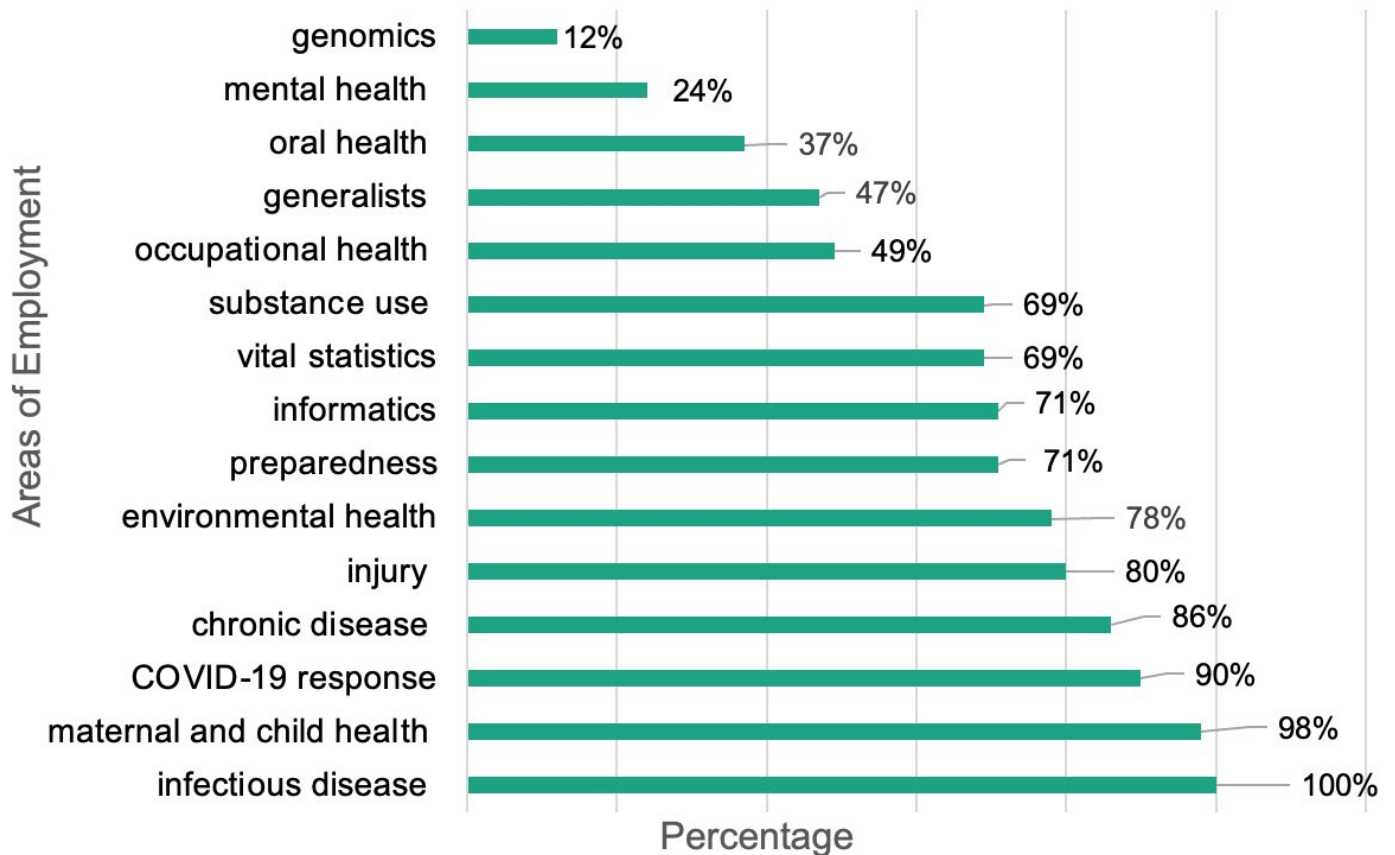
Action 3.2. Bolster research and build the next generation of maternal health researchers by funding opportunities for research under the Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone (IMPROVE) initiative, identifying research gaps to inform future research to improve health outcomes, and enhancing HHS research on rural maternal health.

Action 3.3. Better understand conditions that impact pregnancy through a systematic review of risk factors for poor pregnancy outcomes, funding demonstration sites that seek to address endometriosis and other issues that increase the risk of pregnancy complications, a systemic review studying Women, Infants, and Children (WIC) participation and maternal outcomes, linking housing and health data to understand contributors to maternal mortality, and advancing research on environmental stressors and pregnancy.

HOW ARE WE DOING?

Below we highlight data related to Goal 3. Racial, ethnic, geographic, and socioeconomic disparities emphasize where efforts should focus to improve health outcomes related to the goal.

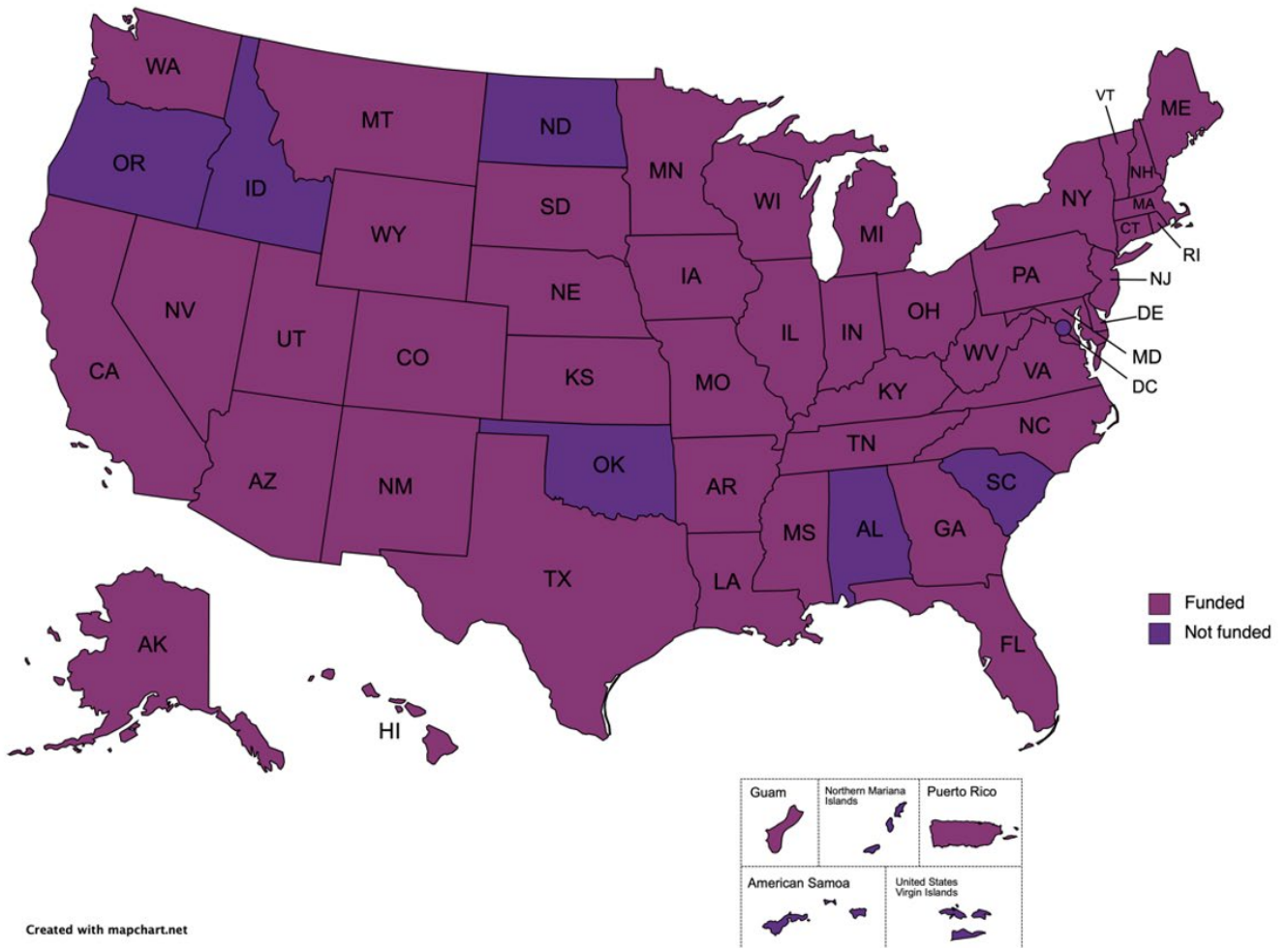
Figure 1: Presence of Lead Epidemiologist by State and Program Area in 50 States and Washington, DC, 2021



Epidemiologists are critical to data development, collection, and analysis. In 2021, there were an estimated 4,135 epidemiologists employed at the state and jurisdiction levels—a 23% increase from previous years. However, this number does not meet the demand of data needs at the state level. Further, epidemiologists need additional skills to meet the information needs of new and emerging MCH challenges, such as collection and use of big data, informatics, research, and evaluation.

Source: Council of State and Territorial Epidemiologists. Workforce Capacity Assessment. [Epidemiologist Capacity Assessment](#). 2021. Accessed September 11, 2023.

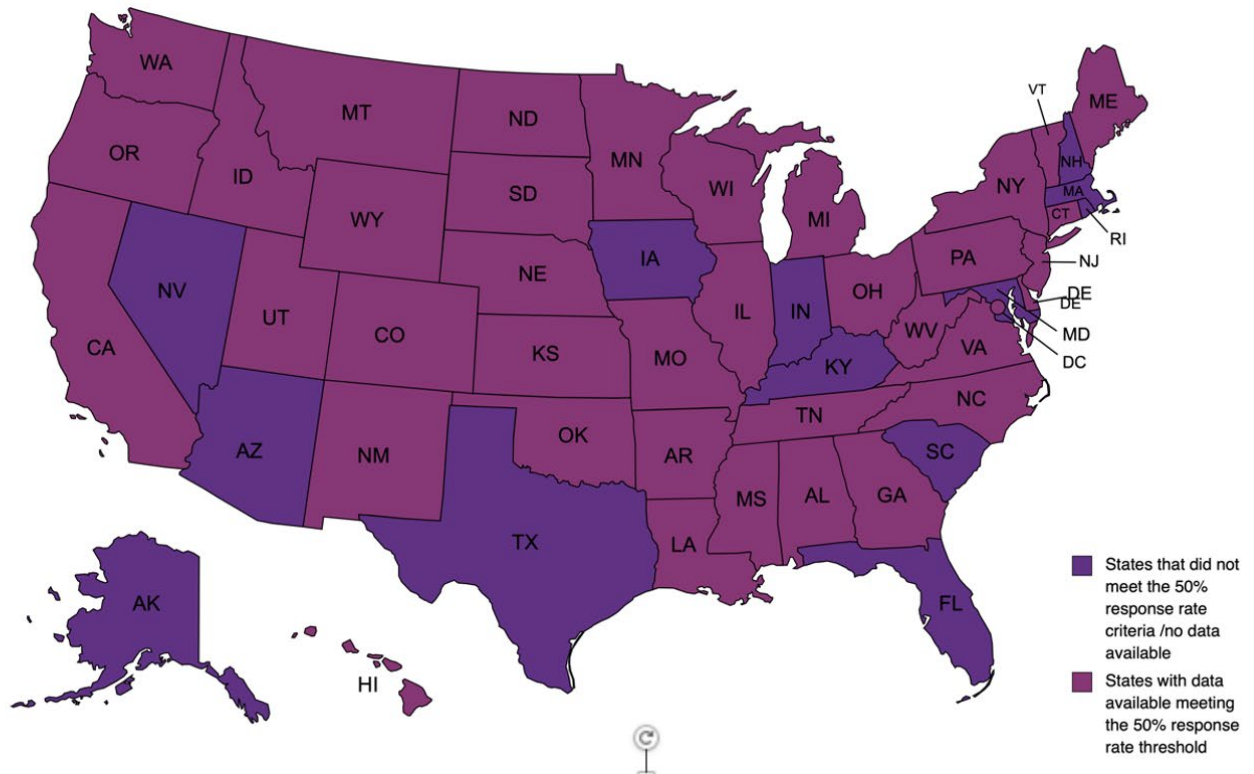
Figure 2: Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE)



Through the ERASE MM program, the CDC funds 46 states and US territories. “This funding directly supports agencies and organizations that coordinate and manage Maternal Mortality Review Committees to identify, review, and characterize pregnancy-related deaths; and identify prevention opportunities.” ([CDC ERASE MM](#))

Source: Centers for Disease Control and Prevention. [Enhancing Reviews and Surveillance to Eliminate Maternal Mortality \(ERASE MM\)](#). Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion. Accessed July 20, 2023.

Figure 3: Pregnancy Risk Assessment Monitoring System (PRAMS) Data Availability by State, 2021



PRAMS monitors maternal attitudes and experiences before, during, and after pregnancy. Not all states participate in PRAMS (and they may or may not have their own state version of PRAMS). This annual data is critical for identifying the needs of the perinatal populations in the US. Currently has a minimum overall response rate threshold policy for the release of data for each year. For 2021, the threshold was 50%. In 2021 it varied from a low of 32% in South Carolina to a high of 80% in Puerto Rico.

Source: Centers for Disease Control and Prevention. [Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#). Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion. Accessed July 20, 2023.

CALL TO ACTION

Foundational to combating the maternal mortality crisis in a way that eliminates inequities is standardized, transparent, equitable, and actionable maternal health research and data. Data is useful only if it leads to action—the result of data collection and research improvement efforts must be equitable system change that leads to improved maternal and infant health. Federal, state, and health system actors must collaborate, partner, and share data with a commitment to equity.

STORY BEHIND THE DATA: FACTORS AFFECTING PROGRESS

Over the years, the gap in data related to maternal health has widened across the US. There are many factors that hinder advancing data collection, standardization, harmonization, transparency, and research. Although there are numerous examples of data collected in the provision of care for women and their infants (e.g., birth and death certificates, hospital billing data, and public programs such as WIC), this data often is not combined and used for research, evaluation, or quality improvement purposes.^{1,pg.38}

Data often lags, making it difficult for researchers to understand recent trends. There also is no legislative mandate for data collection in the US, which results in a lack of standardization across maternal health data points. Without formal mandates, data definitions, collection methodologies, and analysis differ from state to state and program to program, making harmonization and transparency about recording adverse outcomes difficult.⁶ Moreover, there is disparity among states' capacities to collect, link, and surveil relevant data.⁷

Another gap relates to the type of data collected. Analyses have not focused enough on key drivers of poor maternal health outcomes such as mental health, violence, and environmental stressors.^{1,pg.37} There has been incomplete and inconsistent collection of race, ethnicity, and other demographic information in many maternal health data sources. For example, there is a severe lack of data on maternal morbidity and mortality for Native American/American Indian (Indigenous) people in the US. As recently as 2018, maternal mortality racial disparities data did not disaggregate data for the Native American/American Indian population.⁸ To



address the lack of data for Indigenous people, it is critical to collect, report, and disaggregate all data.⁸ Failure to include pregnant people who do not identify as cisgender in research trials has resulted in a gap in information about health and disease among pregnant people.⁹

Finally, data initiatives often fail to include the voices of the individuals most affected by the maternal health crisis. MMRCs, for example, have struggled to meaningfully include diverse community members who can speak to the needs of the communities they represent.³ In an environmental scan conducted by the Black Mamas Matter Alliance in 9 state MMRCs, participants described barriers to joining their local MMRC that included lack of transparency in the recruitment process and legislative barriers pertaining to compensation and background checks, as well as the number of seats available for community members on MMRCs.

WHAT COULD BE DONE TO ADDRESS THE ISSUE?

The [White House Blueprint](#) identifies actionable steps to address Goal 3. In addition, experts from the maternal and child health (MCH) field have identified innovative, evidence-informed strategies from several databases and national repositories.

Maternal & Child Health Innovations

MCH experts selected the following resources for action after a review that included: the [MCHbest Database](#), a database developed to aggregate evidence-based strategies that can be used as is or adapted to fit local and state-level contexts; the [Association of Maternal and Child Health Program's Innovation Hub](#) (AMCHP), a searchable repository of local and state practices, policies, and community-based innovations considered to be “what’s working” in the MCH field; the [Robert Wood Johnson Foundation's What Works for Health](#) (RWJ) database, a tool that helps local communities to identify policies and programs that fit within their context and match their priorities; the [Maternal Health Learning & Innovation Center](#), a national resource for improving maternal health inequities; and a search of leading organizations and agencies working in this field.

- [Alliance for Innovation on Maternal Health \(AIM\)](#). AIM is a national maternal safety and quality improvement initiative that provides implementation and data support for the adoption of evidence-based patient safety bundles. AIM works through state teams and health systems to align national, state, and hospital-level efforts to improve overall maternal health outcomes. AIM can provide technical assistance and implementation support for states implementing the safety bundles.
- [Centers for Disease Control and Prevention, Reproductive Health Data](#). The CDC's Division of Reproductive Health monitors data from the 50 states and other jurisdictions.
- [Maternal Mortality Review Committees \(MMRCs\)](#). Black Mamas Matter Alliance (BMMA) developed a comprehensive report on how to share power with communities within the state MMRCs. These multidisciplinary committees conduct reviews of pregnancy-related deaths to prevent future deaths. BMMA provides guidance that helps to identify, engage, and meaningfully include diverse community members in MMRCs.
- [National Institute for Children's Health Quality](#). NICHQ is a national organization with a repository of resources to support Perinatal Quality Collaboratives (PQCs) and quality improvement in health care systems.
- [Outreach Using a Data Collection System](#). There is emerging evidence that developing a data collection system can support monitoring and evaluation of the effectiveness and success of enrollment and retention efforts. (MCHbest)
- [Public Reporting of Health Care Quality Performance](#). There is moderate evidence that displaying quality scores alongside insurance plans or options supports consumers to choose better plans. (MCHbest)
- [Recommendation Tools to Align Fatality Review Programs to Improve Maternal and Infant Health Outcomes](#). These tools are part of a cutting-edge practice that can support local Fetal and Infant Mortality Review (FIMR) recommendations being written, collected, sorted, and elevated to local and state MCH leaders. (AMCHP)

State Maternal Health Innovations from the Health Resources & Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) Grantees

The [State Maternal Health Innovations \(MHI\)](#) initiative, funded by [HRSA's MCHB](#), currently provides funding to 18 states to develop, implement, and evaluate state-level equity-centered innovations. Below we highlight innovations that address Goal 3 from the MHI cohorts (2019–2024):

- [Illinois](#). Innovations to ImPROVe Maternal Outcomes in Illinois (I-Promote-IL) is developing a statewide system to improve collection of maternal health data at the [county](#) and state levels. The state [PQC](#) is implementing several quality improvement and equity-focused data initiatives. In addition, Illinois has used [qualitative digital storytelling](#) as a method of data collection.
- [Maryland](#). MDMoms, the MHI initiative, is developing and implementing a statewide data system to capture data on severe maternal morbidity by working with hospital systems and communities. Each of the [dashboards](#) identifies specific hospital data and ensures access for community to see and understand the data. Additional information can be found at: mdmom.org/resources and mdmom.org/maternal-morbidity-surveillance.
- [Massachusetts](#). The Massachusetts Department of Health established the [Public Health Data Warehouse \(PHD\)](#) in 2017 as a way to link inter- and intra-agency data to address the state's growing opioid crisis. This tool provides access to timely, linked, multiyear data for analysis of fatal and non-fatal opioid overdoses as well as other health priorities and trends aimed at reducing morbidity and mortality in the Commonwealth. Using the All-Payer Claims Data database as its spine, the PHD links datasets at the individual level for all medical encounters, which generates billing data submitted to insurance or the state for payment. To this core dataset, PHD links 29 datasets from multiple agencies and state

programs, allowing examination of more complex interactions between the social determinants and health outcomes. In addition, the Division of MCH Research and Analysis maintains the [Pregnancy to Early Life Longitudinal Data System \(PELL\)](#) at the Department of Public Health. A population-based data system that links delivery records to hospital discharge records for both mother and baby, PELL uniquely identifies deliveries and children born to the same mother and multiple hospitalization records belonging to the same woman or children. The longitudinal nature of PELL allows mothers and children to be followed over time, and its core data includes vital records (births, fetal deaths, and deaths of people who give birth and their children), hospital discharges, observational stays, and emergency department visits. More than 99% of Massachusetts deliveries from 1998 to 2020 were linked in PELL.

- [New Jersey](#). The New Jersey Department of Health uses the [NJ Maternal Data Center](#) to improve data collection and reporting.
- [Multiple MHI States](#). Arizona, Arkansas, Iowa, and Minnesota are working to develop data dashboards that highlight maternal mortality and severe maternal morbidity data at the hospital, state, and county levels.

Resources from the [MCH Evidence Center's Digital Library](#)

The [MCH Digital Library](#) is a digital repository of evidence-based and -informed toolkits, briefs, white papers, and more with seminal and historic resources. The following may support Goal 3.

- Bannon J, et al. Agency for Healthcare Research and Quality. [Obtaining and Using Data in Practice Improvement: A Handbook for Health IT Advisors and Practice Facilitators](#). 2022. Accessed September 11, 2023.
- Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion. [Social Determinants of Health Data Exchange for Chronic Disease Prevention Initiative: Public Health Use Case Package \(Version 1.2\)](#). 2022.

Accessed September 11, 2023.

- National Association of County and City Health Officials. [Compendium of NACCHO Policy Recommendations](#). 2018. Accessed September 11, 2023.
- U.S. Maternal and Child Health Bureau. [Federally Available Data \(FAD\) Resource Document \(rev. ed.\)](#). 2022. Accessed September 11, 2023.

Strategy Development Criteria to Consider for State and Local Implementation

To select impactful strategies for local implementation, an organization may consider using the following criteria, based on the Results-Based Accountability framework outlined in the book *Trying Hard Is Not Good Enough* by Mark Friedman.

- **Specificity:** Ensure strategies are clearly defined, including responsible parties and timelines.
- **Leverage:** Evaluate how strategies can improve data quality and reliability.
- **Values:** Assess alignment with community and organizational values.
- **Reach:** Consider feasibility and affordability at the required scale.

Using these criteria can aid in developing feasible and impactful strategies. Visit maternalhealthlearning.org/blueprint for more details.



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8. Kozhimannil KB. [Indigenous Maternal Health—A Crisis Demanding Attention](#). JAMA Health Forum. 2020;1(5):e200517.





The MHLIC is available for consultation, coaching, and technical assistance to support your implementation of any innovations to improve maternal mortality and morbidity. For more information, visit

<https://maternalhealthlearning.org/connect>.

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