



# SAVING LIVES: OPPORTUNITIES FROM THE DATA-DRIVEN SUMMIT TO IMPROVE MATERNAL HEALTH

January 2022

**HEALTHY  
MOMS.  
STRONG  
BABIES.**



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## A Call to Action

The United States is the only developed country with an increasing maternal mortality rate, disproportionately impacting historically marginalized communities. With more than 60 percent of these deaths are preventable, we must do better for pregnant people and their families. In response to this disturbing trend, the Biden-Harris Administration recently issued a nationwide [Call to Action](#) to both the public and private sectors to help improve maternal health outcomes. This report describes actionable opportunities that can support the nation's commitment to improving the lives of pregnant people and their families.

The [MITRE Corporation](#), a not-for-profit organization with a mission to solve problems for a safer world, and [March of Dimes](#), a leader in research to improve the health of mothers and babies, came together through a common vision to help improve data reporting and quality and promote data-driven decision making by states and localities to improve maternal health outcomes. For more than two years, MITRE and March of Dimes have elevated essential conversations and promoted collaborations to spark change while developing tools that assist states and localities with data-driven decision making. Though the collaboration shows promising results, there is still more work to do in maternal health data collection, analysis, sharing, and reporting.

As identified in MITRE's April 2021 policy paper [Saving Women's Lives: A Data-Driven Approach to Reduce Maternal Mortality](#), addressing the multiple layers of maternal health challenges and inequities requires collaboration among all levels of government with industry, academia, community organizations, providers, and pregnant people. To identify areas for collaboration to improve maternal health data, MITRE and March of Dimes convened federal

and state agencies, leading academic researchers, industry-leading nonprofits, and other maternal health stakeholders at [Saving Lives: A Data-Driven Summit to Improve Maternal Health](#), a virtual meeting on November 3, 2021. The following is a detailed report of those discussions including Summit participant-identified opportunities to improve maternal health data collection, analysis, sharing, and reporting.



While we use “pregnant and postpartum people” where possible in this report to recognize that not all pregnant people identify as women, we use “women” and “maternal” to reflect terminology used in federal, state, and local data.



## About the Summit

### Summit Structure

Key stakeholders in maternal health data led three keynote panels: federal and state data challenges; the role data plays in national, state, and community-level decision making; and how collaboration and innovation are essential to improve maternal health outcomes. All Summit participants were encouraged to actively participate at the Summit through question-and-answer sessions, small breakout discussions after each panel, and follow up discussions using an online platform. In addition to discussing opportunities to improve data collection, analysis, and reporting, the Summit provided an opportunity to build partnerships for continued engagement and collaboration on data-driven strategies to improve maternal health outcomes. Continued collaboration can help reduce silos and sharing best practices will further our nation's work towards positive change and impact.

### Summit Participants

The Summit operated under the Chatham House Rule—participants are free to use the information discussed during the Summit but may not identify the speakers or participants without express permission. While this report reflects challenges and opportunities presented on panels and discussed during breakout sessions, the authors analyzed comments to find common themes but have not attributed information to specific organizations or individuals. More than 100 individuals from government agencies, academic institutions, and nonprofits participated in this event, representing organizations and agencies including but not limited to: the U.S. Department of Health and Human Services' Administration for Children and Families, the Assistant Secretary for Planning and Evaluation, Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), and the Health Resources & Services Administration; the U.S. Department of Veterans Affairs (VA); the Federal Communications Commission; State and/or Maternal Mortality Review Committees (MMRCs) representation from Baltimore, Washington, D.C., Illinois, Missouri, New Jersey, North Carolina, and Ohio; AcademyHealth; American College of Obstetricians and Gynecologists (ACOG); Association of Maternal & Child Health Professionals (AMCHP); Association of Women's Health, Obstetric and Neonatal (AWHONN); and the National Academy for State Health Policy (NASHP).

## Key Summit Themes

Maternal health data at the national, state, and local levels is vital for decision making. Data informs policies, resources, programs, and interventions to help improve maternal health outcomes. How data is collected, analyzed, and reported is critical to provide the best foundation for these important decisions. We must ensure data is more complete, accurate, and timely.

Summit discussions frequently referenced the following themes, which should be considered as opportunities for the maternal health community to address.

### Health Equity

Maternal health disparities among races and ethnicities are not explained by differences in health behaviors and only partially explained by differences in education and socioeconomic status. These disparities are also reflective of implicit bias, racial residential segregation, and discrimination in the healthcare system. As we consider improvements in data collection and analysis, advancing health equity must be a pillar in this work to improve maternal health outcomes.

### Communication and Collaboration

While existing tools are continuously being improved to collect and report data, there is an ongoing need for communication and collaboration across and among federal, state, and local agencies to ensure all parties are aware of available resources and actively engaged in using current tools and best practices.

### Data Consistency

Data and variable definitions, being able to appropriately merge data sets, and detailing which data elements are included in “complete” data sets can all impact how data is collected, stored, shared, and analyzed.

### Data Access

The data needed to make decisions that impact policy and local interventions exists but is often out of reach to the teams and researchers that need it most. Access, sharing, and privacy must be key considerations as data sets are evaluated for improvement.

**“ We cannot improve what we cannot measure. ”**

*– Summit Participant*

### Barriers

Technology limitations, state and local policies, and funding for appropriate workforce expertise were identified as the main barriers to solving maternal health data challenges.



## Opportunities to Improve Maternal Health Data

Summit participants described maternal health data collection, analysis, sharing, and reporting challenges and identified potential steps forward. The table below summarizes opportunities to improve maternal health as discussed at the Summit.

Opportunities Identified by Summit Participants	
<i>Improve Data Collection Practices</i>	
1	<a href="#">Balance Consistency and Flexibility</a> : Define a minimum required core set of measures for state collection with standard guidelines for collection and analysis to help eliminate confusion and inconsistencies.
2	<a href="#">Include Race and Ethnicity Data</a> : Incentivize collecting and segmenting race and ethnicity data consistently using a national standardized set of measures to minimize reporting burden and facilitate system-wide collaboration through payment requirements.
3	<a href="#">Look Beyond Clinical Data</a> : Create a multifaceted approach that contextually and holistically considers factors beyond clinical elements.
4	<a href="#">Include Pregnant People in Research Trials</a> : Follow <a href="#">Recommendations for Common Data Elements for COVID-19 Studies Including Pregnant Participants</a> when developing data elements and measures for future infectious disease studies.
<i>Enable Data Sharing and Remove Barriers to Access</i>	
5	<a href="#">Prioritize Interoperability</a> : Standardize data and data exchange to improve the ability to abstract data and follow a pregnant person’s care journey and empower the individual to take charge of their own health care choices with access to their data.
6	<a href="#">Connect VA and Community Veteran Data</a> : Improve training and communication on the Veterans Health Information Exchange (VHIE) to promote sharing of pregnant and postpartum Veterans’ electronic health information between VA and non-VA providers.
7	<a href="#">Expand Medicaid Coverage</a> : Expand Medicaid postpartum coverage in each state to one year to eliminate the data collection disruption currently experienced when coverage ends at 60 days.
8	<a href="#">Improve Comprehension of Maternal Event Timelines</a> : Link birth certificates to hospital discharge data to calculate the timing of maternal events and help improve investigations of poor outcomes.
9	<a href="#">Create Rapid Cycle Review for Quality Improvement Efforts</a> : Ensure states and localities have the tools, training, and support needed to effectively conduct process evaluation on federal maternal health quality improvement efforts and adjust maternal health programs in progress.
10	<a href="#">Flag Data to Prevent Morbidity from Turning into Mortality</a> : Add a pregnancy flag in the electronic health record (EHR) and train on how to use it to improve the ability to identify emergency conditions related to pregnancy and help prevent or treat severe maternal morbidity while also improving EHR coding.
11	<a href="#">Share Data Between Agencies and Across Jurisdictions</a> : Identify additional data needed in each state to evaluate maternal mortality and severe maternal morbidity and work to advance legislative changes or develop advance data use agreements (DUAs) to provide access to data.
<i>Elevate and Support State and Locality-Based Data</i>	
12	<a href="#">Include Diverse Perspectives and Provide Clear Guidance for MMRCs</a> : Create interdisciplinary state MMRC teams to expand beyond clinical expertise to ensure well-rounded data analysis and interpretation.
13	<a href="#">Expand MMRC Support to Effectively Use MMRIA</a> : Expand support for states’ use of Maternal Mortality Review Information Application (MMRIA), create opportunities for collaboration among states to share best practices, and enhance opportunities to assign a CDC epidemiologist to each MMRC.
14	<a href="#">Improve Collaboration Between PQCs and MMRCs</a> : Ensure Perinatal Quality Collaboratives (PQCs) have access to MMRC data to prioritize intervention efforts; create MMRC and PQC liaisons to share updates between the two teams.

## Improve Data Collection Practices

Because priorities, policies, and challenges vary across municipalities, there are very few maternal health indicators that are reported consistently across all counties, let alone state or national levels. The variance of data elements and measures based on community needs makes it difficult to determine national or regional connections that can drive change. Summit participants discussed several specific challenges in data collection practices and recommended solutions to help bridge the gap between data and practice to contribute to improved outcomes.

### 1. Balance Consistency and Flexibility

Consistency and uniformity in state data collection is critical to provide a national picture of maternal mortality and enable consistent comparison across states. While state data collection efforts, term [definitions](#), and measurements are currently at each state's discretion, state-level Summit participants requested uniform guidelines to effectively compare data across states. Summit participants want to compare data to help evaluate their programs and inform future interventions while also having the flexibility to collect and analyze data specific to their community. Clear guidance is needed on how to manage consistency and uniformity with flexibility in relation to data collection and analysis. Without this, data consistency cannot be achieved.

#### *Opportunities Identified by Summit Participants:*

Require core set of measures for state collection through MMRIA with standard guidelines for collection and analysis to help eliminate confusion and inconsistencies. Although MMRIA highlights core data fields identified by review committees and subject matter experts, users are not required to complete these fields and only date of death is a required entry.

Ideally, MMRIA could also provide standardized definitions for additional elements that states could choose to collect as relevant to their community to help in their decision making. Quarterly training events are available for abstractors, along with self-paced [training materials and job-aids](#) that provide reinforcement of consistent abstraction approaches within and across states.

“**Maternal deaths have a lot of judgement—infant deaths are cut and dry—birth and death date. Maternal deaths have a lifetime of history to consider and has to be determined if it is pregnancy related or not.**”

– Summit Participant



The [Maternal Mortality Review Information Application](#) (MMRIA) is a data system and a data strategy designed to facilitate the functions of MMRCs through common abstraction and committee review processes, development of prevention recommendations, and overall data language.

“**It is hard to see discrimination through an individual medical record—it is crucial to collect this data to highlight disparities in outcomes or procedures when separated by race or ethnicity.**”

– Summit Participant

## 2. Include Race and Ethnicity Data

While [self-reporting or medical staff observations](#) are preferred means of obtaining information about an individual's race and ethnicity, the response rates vary. This can result in missing or conflicting information in documenting key demographics within EHRs. This limits states and localities in effectively separating [data by race and ethnicity](#). Without this information it is difficult to identify, track, and address disparities to inform equitable care and service delivery.

*Opportunities Identified by Summit Participants:* Incentivize collecting and segmenting race and ethnicity data consistently using a national standardized set of measures to minimize reporting burden and facilitate system-wide collaboration through payment requirements. Make necessary improvements in state health information technology (IT) systems to capture race and ethnicity data to help identify disparities through across-the-board comparisons.

When conducting any collection or analysis on race and ethnicity data, it is important to keep in mind the following considerations:

- Oversampling these populations is not a solution—there is a need to work with stakeholders to find better data collection methods. A partial solution is to pull race and ethnicity data from birth certificates.
- There is value in small datasets—important findings can still be gleaned from a small sample to inform recommendations without oversampling.
- Provide information in a way that is accessible to others but does not lead to unfair repercussions or perceptions of the system providing the data.

In the interim, national programs can use geocoding to compute race and ethnicity over populations and use this data as a proxy, but this is a stop gap, not a substitute. These efforts will help address racial and cultural bias across the network of care that serves pregnant and postpartum people as well as the institutions that influence or coordinate within that network (including public health agencies, Medicaid, and coroners).

## 3. Look Beyond Clinical Data

Current maternal health data collection is heavily focused on clinical and biological elements with limited emphasis on other factors that may influence maternal health outcomes. Data elements like insurance coverage, access to care, housing, neighborhood, intimate partner violence, broadband availability, and other social determinants of health improve our understanding of why maternal deaths may occur. There are also other



A 2019 [report from the U.S. Government Accountability Office](#) noted an opportunity to conduct an assessment to determine how to address weaknesses identified with the completeness and accuracy of race and ethnicity data in the electronic health record, and implement corrective actions as necessary.

**“ Don’t collect data just to collect data—you need to have an impact and identify what needs to be changed and identify what is working. ”**

– Summit Participant



qualitative aspects of what pregnant people are experiencing in their interactions with healthcare systems (including non-pregnancy related visits), such as [disrespectful care](#), which may not be incorporated into the causality of a poor outcome. A consistent mechanism is needed to collect this information from all patients to prevent bias by limited sampling. These factors are essential in determining interventions to prevent death and morbidity and need to be considered when analyzing data related to maternal health outcomes.

*Opportunities Identified by Summit Participants:*

Create a multifaceted approach that contextually and holistically considers factors beyond clinical data elements. Identify non-traditional data sources that will help understand and improve surveillance of factors contributing to maternal health outcomes. Home and community factors can influence death or severe maternal morbidity and are crucial when determining if a death was pregnancy-related or pregnancy-associated. When MMRCs design this multifaceted approach, it should be tailored to the communities they represent and include community members in the conversation from the beginning. This will contribute to finding the root cause and can deepen understanding and lead to more robust recommendations to improve maternal health outcomes in the community.

#### 4. Include Pregnant People in Research Trials

As COVID-19 research trials quickly took off, there was little time to standardize measures, and many trials excluded pregnant people. This caused a delayed understanding of how COVID-19 impacts pregnant people and may have contributed to the public confusion and discomfort of pregnant people becoming vaccinated. Recent reports show pregnant people who contract COVID-19 are [70% more likely to die from the virus](#) than non-pregnant people and are at increased risk for adverse pregnancy complications and outcomes. However, [only 31% of pregnant people](#) are getting vaccinated, which may be somewhat related to delayed evidence on guidance for pregnant people regarding vaccines.

*Opportunities Identified by Summit Participants:* Researchers should follow [Recommendations for Common Data Elements for COVID-19 Studies Including Pregnant Participants](#) when developing data elements and measures for future infectious disease studies. To help incorporate this data into national, state, and local decision making, we need to develop a data consortium for maternal health during public health emergencies that includes high informatics security yet allows stakeholders to easily access the information. It is also important to bring data and recommendations to pregnant people in a way that they can understand. Healthcare providers should also be respectful of their patients' culture and language to address any potential distrust of science and medicine.

“ **Add a section to MMRIA on the investigation and what (if any) information was lacking. So often we don't know many data points because we cannot locate medical records and the investigators do not ask questions about the decedent's mental health, relationships with partners/family, etc.** ”

– Summit Participant

## Enable Data Sharing and Remove Barriers to Access

Health departments and other health services do not have consistent access to interoperable maternal health data. There are gaps in existing systems to capture longitudinal data or cross-sectional hospital and discharge data. The data can be locked within the different provider systems, leaving patients, providers, and researchers with an incomplete picture of a pregnant person's history, potentially leading to poor outcomes and incomplete analysis. Early prevention and treatments of maternal morbidities require a continuation of a person's health data before, during, and after pregnancy. Despite the nationwide and statewide incentives to increase use of health IT and EHRs, data are still fragmented.

Summit participants described an urgent need for integrated perinatal health data at the individual level to allow researchers and clinicians to make timely decisions. If a pregnant or postpartum person dies, integrated records are critical to identify whether the death was preventable and how to amend processes and resources to prevent future deaths.

## 5. Prioritize Interoperability

The lack of interoperability between electronic systems used in the delivery of healthcare and social care makes it difficult to track and assess maternal health outcomes over time. Data sharing is challenging in fragmented care environments, particularly in rural communities where hospital obstetric services are not available, requiring people to travel long distances to obtain care. A pregnant person might also obtain care at multiple facilities over the course of their pregnancy and postpartum experience. Despite increased investment in EHRs and the development of Health Level Seven International® (HL7) Fast Healthcare Interoperability Resources® (FHIR), much work remains to define the data elements and standards to enable the exchange and use of maternal and infant health data to inform research and design of proper interventions.

*Opportunities Identified by Summit Participants:* Improve interoperability among individual healthcare facilities and systems to contribute data to health information exchanges. Standardized data and data exchange would improve the ability to abstract data and follow a pregnant person's care journey and empower the individual to take charge of their own health care choices with access to their data. The federal government is leading efforts to improve the use of EHR data and interoperability through multiple agencies, including CDC, CMS, Office of the National Coordinator for Health Information Technology, and National Institutes of Health. With the development and adoption of HL7 Implementation Guides, researchers will have increasing access to clinical and social care data to analyze conditions, treatments, and procedures related to pregnancy. This infrastructure on the national level will enable clinicians and researchers to longitudinally link



In 2019-2021, The National Quality Forum (NQF) convened a Maternal Morbidity and Mortality Committee to propose [improvements for maternal morbidity and mortality measurements](#). The resulting measurement frameworks in morbidity and mortality can be used to identify gaps in maternal morbidity and mortality measurement and guide the development of key measurements.

**“ There is richness in data, but states can't access that data. ”**

– Summit Participant

maternal and infant data, review medical history and socioeconomic factors, and identify a full range of risk factors for pregnancy on both the birthing person and baby.

## 6. Connect VA and Community Veteran Data

The demand for Veteran maternity care continues to increase, with the number of deliveries that VA paid for increasing [14-fold since 2000](#). Although [maternity care services are fully covered](#), the services are not provided at VA facilities but outsourced to the community. VA employs maternity care coordinators to provide warm handoffs between pregnant people and community providers and resources, noting these handoffs in the pregnant person's VA EHR. However, that's where the data stops—the VA often does not receive data back to add to the EHR. Furthermore, many Veterans are dual or tri-eligible (e.g., VA and CMS, VA and Indian Health Service). This can result in Veterans picking and choosing where to receive certain services, subsequently leading to poor care coordination and potential adverse maternal health outcomes and significant gaps in data.

*Opportunities Identified by Summit Participants:* Although VA and non-VA providers have access to the [Veterans Health Information Exchange \(VHIE\)](#) to share electronic health information of their pregnant and postpartum Veteran patients, there is limited use of the system. A [2020 OIG report](#) noted costs, technology, and training issues as barriers to adoption. With further support from VA on training and communication, non-VA providers are more likely to use VHIE. Since all maternity care is outsourced from VA, data sharing between VA and non-VA providers through VHIE is essential to ensure a comprehensive understanding of care provided to Veterans. This will be particularly helpful for minority Veterans, who are at increased susceptibility for poor maternal health outcomes.

## 7. Expand Medicaid Coverage

Medicaid beneficiaries account for [42% of births in the U.S.](#) One challenge to assessing the outcomes for people receiving pregnancy-linked Medicaid is that in most states Medicaid coverage ends on the last day of the month in which the 60-day postpartum period ends. This means individuals may delay care, forgo care, or seek emergency treatment after their pregnancy-linked Medicaid coverage ends. Consequently, their data is not typically connected back to Medicaid or to their delivery providers. Maternal health experts advocate for a full year of coverage after birth, as 33% of all maternal deaths occur between one week and one year postpartum.



The 2021 [Protecting Moms Who Served Act](#) requires that the VA must provide training and support to community maternity care providers so they can address the needs of pregnant and postpartum veterans. Furthermore, the U.S. Government Accountability Office must report on maternal mortality and severe maternal morbidity among pregnant and postpartum Veterans, with a focus on racial and ethnic disparities in Veterans' maternal health outcomes. The data from the Protecting Moms Who Served Act could provide insights into why Veterans have higher rates of maternal mortality and morbidity as well as the unique disparities among this unique population.

*Opportunities Identified by Summit Participants:* Section 9812 of the [American Rescue Plan Act](#) of 2021 gives states a new state plan option to [extend](#) Medicaid state plan coverage beyond the required 60-day postpartum period through the end of the month in which a 12-month postpartum period ends. In addition to [improving care and outcomes](#), [expanding the Medicaid coverage](#) to the optional 12-month coverage period would help prevent the currently experienced data collection disruption in Medicaid. This would allow Medicaid to collect data on the deaths that occur between 60 days and one-year postpartum for individuals with births covered by Medicaid. Linking this data with other sources will enable further analysis to understand the causality of these deaths, helping inform interventions to reduce similar circumstances and deaths in the future.

**“ Free the data. ”**

– Summit Participant

## 8. Improve Comprehension of Maternal Event Timelines

The identification of maternal deaths is complicated and often results in analysis and reporting delays. For example, many MMRC reports are published two to three years after the deaths occurred (see MMRC reports on the [Review to Action website](#).) This delay affects the [timeline of maternal events](#) that can be lost, destroyed, or misinterpreted along the way. When a person dies while pregnant or within a year of pregnancy, the pregnancy checkbox on the death certificate does not indicate at what point during that period the death occurred. It requires investigation to determine the timeline of the death, often skewing interpretation of events.

*Opportunities Identified by Summit Participants:* Link birth certificates to hospital discharge data to calculate the timing of maternal events and help improve investigations of poor outcomes. This longitudinal data can help determine what happened at different points in time. For example, a back calculation of the theoretical time of conception can be determined, which can help decipher the timing of events. The calculation or model would need to account for non-birth outcomes, such as in cases of maternal or infant death resulting in no birth certificate.

When linking records, a Summit panelist identified these important factors to consider as identified in recent state reports:

- Around 2% of births do not occur in hospitals
- Maternal deaths are increasingly occurring in the postpartum period (30-40%) and in the period just before birth
- Records do not always include the clinical detail to truly understand the care provided
- There are incomplete outpatient maternal data systems to complement inpatient data

**“ There is a need to push states to change rules to share and release preliminary data. ”**

– Summit Participant

## 9. Create Rapid Cycle Review for Quality Improvement Efforts

There is a need for rapid cycle review of data for federal quality improvement efforts. Data is often not shared quickly enough to impact maternal health outcomes. Federal programs intended to improve maternal health outcomes often do not receive program data until the program is complete, leaving no time for in-the-moment evaluation or changes to help improve outcomes through the program.

*Opportunities Identified by Summit Participants:* Ensure states and localities have the tools, training, and support needed to effectively conduct process evaluation on federal maternal health quality improvement efforts and adjust maternal health programs in progress. Timely data is important to ensure implementation plans are current and consistent. Legislation and federal funding are needed to support these efforts. Beyond maternal health, many other programs struggle with this same challenge. Approaches to solve this data challenge for maternal health programs could be tested and applied more broadly.

## 10. Flag Data to Prevent Morbidity from Turning into Mortality

When the general population experiences leg swelling or high blood pressure, these are often not emergencies. The same symptoms when experienced in the postpartum period are dangerous and may require immediate medical attention. When a postpartum person receives care in an emergency department, medical staff could be unaware of the recent pregnancy. This can result in poor health outcomes, including death. This may happen because the available medical record data may not show the pregnancy, or the triage nurse may not ask. Further complicating the challenge, after the incident occurs, it may not be linked or coded to pregnancy.

*Opportunities Identified by Summit Participants:* Add a pregnancy flag in the EHR and train on how to use it to improve the ability to identify emergency conditions related to pregnancy and help prevent or treat severe maternal morbidity while also improving EHR coding. With this data, we can better understand trends in severe maternal morbidity and subsequently design interventions to prevent death or “near misses” from happening in the future.



The California Maternal Quality Care Collaborative’s [Maternal Data Center](#) instantaneously links discharge data to birth certificate or clinical data, which supplements quality improvement efforts. Examples of QI metrics at the hospital, regional and state levels include risk adjusted severe maternal morbidity (SMM), SMM among patients with hypertension or hemorrhage, low-risk first-birth (NTSV) cesarean rate, unexpected newborn complications (among term uncomplicated infants), and exclusive breast milk feeding.

**“ While there is richness in maternal health data, it is worthless if it remains inaccessible. ”**

– Summit Participant



## 11. Share Data Between Agencies and Across Jurisdictions

Many Summit participants from states and localities noted common barriers to accessing data (e.g., unable to access Medicaid claims and VA records) as well as unique challenges (e.g., departments in the same state not sharing data, or state and local laws prohibiting MMRCs from accessing or sharing critical data). Lack of state-to-state data sharing presents a problem when perinatal care, birth, or maternal death happen in different states, preventing the resident's state from accessing that data. Information sharing is crucial to help inform policies, programs, and interventions. Overall, maternal health data on maternal mortality is not available on a sub-national level.

*Opportunities Identified by Summit Participants:* Since states have different laws and policies governing sharing of relevant data, each state should identify additional data they need to evaluate maternal mortality and severe maternal morbidity and work to advance legislative changes or develop DUAs between departments, organizations, or states to provide access to data. Some states have shown success at developing and executing DUAs—they should share their strategies broadly to assist other states in making similar improvements in data access. Integrating data and IT systems is an important consideration and an integration strategy should be developed in advance of executing DUAs. The federal government should provide more information detailing how states can access Medicaid and VA data and to develop promising practices such as DUAs, or model legislation that may be helpful across states. When considering data merges from multiple sources, it is important to consider the different collection, analysis, and sharing requirements and to ensure data quality and consistency.

### Elevate and Support State and Locality-Based Data

Tailoring technical assistance and resources to meet the needs of each state, territory, and tribal entity takes time and resources. Differences in services, data, staffing, and even specialized medical equipment requires innovative approaches to meet each state and locality where they are to build capacity, evaluate, and report data. Summit participants explained the value MMRCs provide in making data-driven decisions to reduce maternal mortality and improve maternal health outcomes. Summit participants recommended elevating and promoting the role of MMRCs through national engagement and support.



Through funding from HRSA's [State Maternal Health Innovation Program](#), New Jersey is developing an IT infrastructure (Maternal Data Center) to create real-time data processing and linkage of electronic birth certificate, death certificate, and hospital discharge data with findings on key maternal health indicators to be shared with subscribed birthing hospitals to make timely changes to recently implanted or in progress strategies. With earlier access to data, it could allow for analysis of real-time data. There is opportunity for this best practice to be leveraged for other states.

“*It would be incredibly helpful for MMRC’s to have a document that describes where federal and typical state data could be accessed to assist in abstraction and ultimately MMRC discussion and recommendation formulation. Having this listing at the local, state, and federal level with someone to oversee updates would also help when determining priorities for state and local initiatives.*”

– Summit Participant

## 12. Include Diverse Perspectives and Provide Clear Guidance for MMRCs

MMRC membership composition matters and can impact committee discussions and decisions. When discussing cases, answers to the question “was this death preventable?” vary on a members’ background and experience. It is important to include community members with lived experiences but states often shy away from including these members to avoid potential emotional harm.

*Opportunities Identified by Summit Participants:* States should create an interdisciplinary MMRC team to expand beyond their clinical expertise to ensure well-rounded data analysis and interpretation. Committee members should be provided with resources to understand factors in determining preventability and identifying intervention points, as well as emotional support for difficult cases, especially for members with lived experience in maternal morbidity.

## 13. Expand MMRC Support to Effectively Use MMRIA

Several Summit participants commented that federally funding state work in data collection, analysis, and reporting has resulted in more complete and consistent reporting. Currently, [31 states receive federal funding](#) that directly supports MMRC coordination and management to help identify, review, and characterize maternal deaths and identify prevention opportunities. Using MMRIA provides consistent data in one repository and is integral to effective decision making. However, not every state has the funding to appropriately staff an MMRC often resulting in a lag of collecting data and entering results in MMRIA.

*Opportunities Identified by Summit Participants:* Expand support for states’ use of MMRIA to ensure consistent reporting across states. With states as the key holders to essential data, it is crucial that they receive proper support to review and extract data for analysis. Create opportunities for collaboration among states to share best practices. Summit participants representing MMRCs with a [CDC assigned epidemiologist](#) reported that their understanding and use of MMRIA improved greatly with this “epidemiologist lifeline.” Enhance opportunities to assign a CDC epidemiologist to each MMRC. Many Summit participants were not aware of the resources on [Review to Action](#) and expressed interest in learning more.

## 14. Improve Collaboration Between PQCs and MMRCs

PQCs help to implement the recommendations from MMRCs, including reduction in deliveries for induction before 39 weeks without medical reason and reduction in maternal morbidity from hypertension and hemorrhage. Lack of funding and data coordination create a snowball effect—without timely data MMRCs cannot provide timely recommendations, and PQCs cannot implement recommendations in a timely manner.

*Opportunities Identified by Summit Participants:* MMRC data should be made available to each PQC to prioritize intervention efforts. Each state should have liaisons that belong to both the MMRC and PQC to share updates between the two teams. The shared membership and structures as well as consistent communication can improve health equity and turn the data from the MMRCs into action. Although the CDC does [directly fund 13 PQCs](#) and supports the National Network of Perinatal Quality Collaboratives (NNPQC), additional, sustained funding and support would help PQCs nationwide make measurable improvements.



[Perinatal Quality Collaboratives](#) (PQCs) are state or multistate networks of teams working to improve the quality of care for mothers and babies.

## Conclusion

Federal, state, and local government agencies and maternal health organizations face similar challenges with data collection, analysis, and reporting both in regard to maternal mortality and program impact. There are several areas of overlap yet limited collaboration among organizations and agencies working with maternal health data. Now is the time to remove silos and collaborate to spur action.

It will take communication and collaboration to ensure maternal health data is complete, accurate, and timely and that this vital asset for decision making is available, accessible, and easily understood.

## Participant Identified Next Steps

- Form federal interagency committee to advance action on maternal health data and outcomes. Communication and coordination across agencies can help with definitional and alignment issues, even if data are collected at different levels (e.g., national, state, local program).
- Federal agencies should regularly share best practices, lessons learned, available support, and the latest instruction for collecting, analyzing, and reporting maternal health data across the federal government and with states and localities through conversations and interactive meetings.
- Continue to meet as a community of practice to share best practices and “replicate what works,” but involve more representation from MMRCs, state health departments, and federal and state decision makers. Suggestions for future meetings include:
  - Improving data availability, linkages, and communication across agencies and organizations
  - Conducting assessments on understudied population groups
  - Improving transparency and timely availability of maternal health data more broadly beyond healthcare providers

“*There are many people working on the same issue but a lot of silos. There is limited collaboration across all players. Who is and who is not at the table when these decisions are being made is very important.*”

– *Summit Participant*

## Shared Participant Resources

### Models for Maternal Health Data Consortium

The [National Institute of Child Health and Human Development \(NICHD\)](#) leads several consortiums for shared learning and collaboration. These collaborative methods could be expanded to include more projects.

- [MAT-LINK](#): MATernal and Infant Network to Understand Outcomes Associated with Medication for Opioid Use Disorder during Pregnancy
- [National Ambulatory Medical Care Survey](#)
- [Implementing a Maternal health and PRegnancy Outcomes Vision for Everyone \(IMPROVE\) Initiative](#)
- [Data and Specimen Hub \(DASH\)](#) is a centralized resource that allows researchers to share and access de-identified data from NICHD-funded studies. It includes 158 studies related to labor and delivery. DASH also serves as a portal for requesting biospecimens from selected DASH studies.

### Data Consistency Best Practices

The [Transformed Medicaid Statistics Informational System \(T-MSIS\)](#) collects utilization and claims data as well as other key Medicaid and CHIP program information to keep pace with the data needed to improve beneficiary quality of care. It requires that all 56 state Medicaid agencies submit data in the same way to TMSIS, allowing consistent comparisons across all agencies. It includes enhanced information about beneficiary eligibility, beneficiary and provider enrollment, service utilizations, claims and managed care, and expenditures for Medicaid and CHIP.

### Data-Driven Decision Making

The [MITRE Maternal Mortality and Morbidity Interactive Dashboard \(3MID\)](#), a microsimulation and policy simulator, allows users to analyze how budgeting, social determinants of health, medical interventions, and policy could reduce rates of maternal morbidity and mortality across the U.S. It incorporates local factors, including state-specific demographics and resources to enhance outcomes for priority populations, e.g., rural residents, racial and ethnic groups, and groups that have been economically marginalized. This tool will empower users to make data-driven decisions and reduce maternal morbidity and mortality rates within their states.

### Maternal Vulnerability Index (MVI)

The [U.S. Maternal Vulnerability Index](#) is an open-source tool that provides national-, state-, or county-level views of a range of 43 indicators associated with maternal health outcomes across the personal, clinical, and environmental context in which mothers live, work, carry pregnancies, deliver, and raise their children.

### MMRC Guidance and Resources

[Review to Action](#) provides resources to MMRCs to enhance the quality and comprehensiveness of their process. They connect states with an MMRC to national-level support and their peers to build capacity to conduct maternal mortality review and translate findings into action; assist states without an MMRC in

gathering resources, tools, and support to build political and social will to establish a committee; and raise awareness of the critical role MMRCs play in supporting the elimination of preventable maternal deaths and promoting the health and wellness of birthing people.

This resource is supported through a partnership between AMCHP and the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality administered by the CDC.

## HRSA Programs for Improving Data Efforts

There have been several efforts at HRSA to identify needs and data gaps in maternal health and to improve data capacity, including the development and maintenance of an infrastructure to collect and analyze maternal health data:

- [Title V](#) – *Example:* State Systems Development Initiative (SSDI) aims to develop, enhance, and expand state and jurisdictional Title V MCH data capacity to needs assessment and performance measure reporting in the Title V MCH Block Grant Program.
- [Alliance for Innovation on Maternal Health \(AIM\)](#) – *Example:* Works through state-based teams to align national, state, facility-level QI efforts to implement patient safety bundles. There is a forecasted supplemental grant for SSDI recipients focused on improving maternal health care by expanding state data capacity for AIM.
- [State Maternal Health Innovation Program](#) – *Example:* Supports nine states through to address disparities in maternal health and improve maternal health outcomes by identifying activities that improved surveillance, included collaboration, and focused on some innovative changes to improve maternal health outcomes.

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