# CDC Listening Session:
# Maternal Health and Tribal Maternal Mortality Review Summary

The CDC Division of Reproductive Health's Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) program supports maternal mortality review committees (MMRCs) to identify and review deaths during and within a year of pregnancy, including documenting prevention opportunities. CDC works with MMRCs to improve review processes that inform recommendations for preventing future deaths.

Existing reviews include deaths that occurred during and within a year of pregnancy among American Indian or Alaska Native women. However, there are no Tribal MMRCs. While citizens of an American Indian or Alaska Native tribe may identify their race as American Indian or Alaska Native, they have a distinct political status as citizens of both the United States and of an American Indian or Alaska Native tribe, which differentiates them from other racial groups. Recognizing this sovereignty, Tribal MMRCs could adapt MMRC processes to reflect community priorities and tribally led approaches to maternal mortality prevention; have direct access to their MMRC's data and determine the use of their data; and provide recommendations relevant to the community made by a tribally appointed committee to prevent pregnancy-related mortality.

A tribal listening session was held by CDC on December 4, 2024, to learn about maternal health and tribal maternal mortality review. Those offering insights were tribal leaders, tribal members, Urban Indian Organizations, tribal health care providers, tribal-serving organizations, and others working in tribal maternal health, to inform a sustainable funding initiative. In total, 291 people registered; 183 attended the virtual event, with approximately 110 representing tribal nations and/or tribal-serving organizations.

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| **Registrants** | 291 |
| **Attendees total** | 183 |
| **Affiliated with a tribe or tribal-serving organization** | 110 |
| **Affiliated with a federal agency (CDC or Indian Health Service (IHS))** | 61 |
| **Others (affiliated with a university, state department of health, etc.)** | 12 |

Session participants shared their perspectives and insights during the listening session via verbal comments and chat box submissions, as well as after the session via the written comment period. Common themes included the importance of community-driven solutions, workforce development, and data improvements. The objective of this summary is to highlight participant feedback and recommendations.

## Areas of Discussion and Participant Feedback

### 1. Maternal Health Initiatives in the Community

Participants shared their experiences promoting maternal health in the communities where they live and/or serve, and opportunities for improving and amplifying their communities' strengths.

Overall, there was a call for solidarity and solutions based in tribal sovereignty. Participants also noted the importance of gathering, virtually or in-person, to discuss approaches — to see one another and connect in this work of maternal mortality prevention by Native communities. Discussion points included the following:

- Health workers who provide maternal care, including nurses, often manage multiple roles, limiting their ability to focus on prenatal care. In some tribal communities, limited workforce capacity is compounded by challenges such as lack of or low Medicaid reimbursements, leading to discontinued services. Also, there is a lack of obstetricians and gynecologists in Native health care systems. Moreover, accessible facilities do not offer specialized care, or specialists like Maternal Fetal Medicine providers.
- Maternity care deserts remain a significant concern. There are reports of low access to prenatal care services and multiple labor and delivery hospitals closing. In certain areas mothers must travel long distances (60 minutes or more) for care. The distance to care is compounded by lack of transportation. Tribal communities could benefit from prenatal care coordination efforts and education around childbirth and increasing awareness of health issues faced by pregnant and postpartum women.
- Other challenges cited include lack of inpatient substance use treatment centers that allow baby to stay with mom, mental health counseling for mothers and their families, and programming to improve maternal chronic health conditions, such as diabetes and hypertension, to prevent preterm birth and other adverse birth outcomes.
- Training Indigenous doulas provides culturally competent support to families and diversifies the maternal and child health (MCH) workforce.
- Integrating culture into maternal health programming engages the community. Culturally tailored prenatal education (e.g. Eagle's Nest program); healthy relationships and good parenting practices (e.g. the Strong Fathers/Azee 'Bidziil Program for Fathers/Father figures); and community events (e.g. baby showers and parent workgroups) are examples.
- Home visiting (e.g. postpartum lactation consulting), implementing adapted Hear Her campaign materials, and providing supplies to families (i.e. diapers, wipes, blood pressure cuffs) improves community engagement, education, and improves prenatal and postpartum health.
- Developing a maternal health strategic plan has focused priorities for Navajo Nation in prenatal care, breastfeeding, nutrition, and mental health.

### 2. Maternal Health Information and Data

The second area of discussion focused on currently used maternal health information and data, and important gaps in this information and data. Participants noted that gaps in data are the most glaring issues in MCH.

- There are gaps in maternal health data, including data on American Indian and Alaska Native women in current MMRC reports, other maternal morbidity data, and data on topics such as pregnancy loss.
- American Indian or Alaska Native women are often misclassified or categorized as "Other," leading to data invisibility in state and federal maternal health data. It is important to educate all relevant professionals about upcoming changes to how race/ethnicity is coded in the Census. This will help ensure all American Indian or Alaska Native women are counted accurately.
- To begin to address racial misclassification in maternal health data, state departments of health can change the way they count American Indian or Alaska Native mothers. Departments can include multiple race and Hispanic ethnicity rather than reporting on a single race variable for American Indian or Alaska Native women (example shared from South Dakota Department of Health). Tribal enrollment data, or other sources, may also be used to correctly identify American Indian and Alaska Native women, via data linkages. There are ways to develop systems/data flows that help states identify when to correct Vital Records data when American Indian and Alaska Native misclassification occurs. This too would improve national-level data.
- While the Pregnancy Risk Assessment Monitoring System (PRAMS) has been a valuable tool, funding constraints have limited its sustainability and reach. PRAMS was cited as useful and the best source for MCH outcome data (South Dakota Tribal 2009 and in Wisconsin, in particular). Participants want to implement PRAMS more consistently, although cost to implement oversampling is a barrier. Participants advocated for tribal-specific PRAMS and oversampling of American Indian or Alaska Native populations, with federally funded support. Pooling PRAMS data, nationally, to achieve a larger American Indian or Alaska Native sample size could also help gather comprehensive information to meet needs and inform data-driven decision-making. Participants requested a call for tribal consultation when opportunities arise to address data limitations such as in PRAMS, or around PRAMS survey updates.
- Data silos, particularly gaps between IHS and tribally owned healthcare facilities, and challenges navigating these systems make it difficult to determine basic statistics such as the live birth rate. These issues are compounded by chronic underfunding, and outdated medical records systems, limiting the capacity to share and receive data. A lack of electronic health records and tracking within IHS leaves gaps in maternal health data, creating limited accountability within systems and programs.
- At the tribal level, there are limited surveillance programs for maternal health; Tribal Epidemiology Centers lack the capacity and staff to implement comprehensive maternal health surveillance.
- Advanced statistical methods may be needed to analyze existing American Indian or Alaska Native data. Dedicated efforts and resources are needed to analyze and interpret American Indian or Alaska Native data. For instance, there is a need for expertise in small sample analysis, merging data sets, using multiple years of data, and missing data analysis. By using information and analyses that include small numbers, it honors data that are collected and creates space to make changes to practice.
- Hiring Indigenous data analysts at agencies like CDC would ensure that American Indian or Alaska Native data are analyzed and interpreted with cultural and contextual understanding.
- MMRCs provide data, but data lags exist.

- Washington state was cited as having a state level MMRC focusing on Indigenous review panel representation and improving racial classification of American Indian or Alaska Native people.
- There are also opportunities to evaluate American Indian or Alaska Native programs to generate data for data driven policy for rural American Indian or Alaska Native pregnant and postpartum women. Evaluations should be timely, ethical, and inclusive of grassroots organizations to determine data measures and drive meaningful change — which may be challenging.

### 3. Considerations for Conducting Maternal Mortality Reviews

Lastly, participants provided input around tribal communities conducting reviews of deaths during or within 1 year of the end of pregnancy. Culturally sensitive, community-centered, and collaborative approaches are recommended.

- A way to humanize the process is to craft narratives for case review by MMRCs that uplift the strengths and humanity of the woman who passed away. The focus should be shifted away from "individual" issues, like substance use disorder, to understand the broader systemic or structural drivers.
- Review committees should have multidisciplinary membership, including people with lived experience who may contribute their stories in safe ways. Tribal members may provide a much-needed voice in the review of cases, advocacy for resources, and promotion of community strengths and culture.
- Incorporate supports for committee members. Supports should include spiritual and mental health with trauma-informed care. Supports should also prioritize traditional grieving practices and cultural timelines when reviewing deaths within tribal communities. Make available ongoing education on historical grief, trauma-informed trainings, and orientations for new MMRC members about these topics.
- Participants emphasized the importance of data sovereignty in death reviews, ensuring that data are used ethically and in ways that protect community privacy.
- Leaders of tribal nations should be consulted on vision, program, and funding, as their decisions impact communities and nations. These leaders represent the people.
- Participants recommended fewer administrative requirements for program funding and longer funding time periods.

The following considerations were contributed by one participant via the chat feature of the listening session. The comments summarized here relate to tribal communities conducting a review of deaths during or within 1 year of the end of pregnancy:

1. **Cultural Sensitivity and Respect**
    - Traditional Practices: Respect and incorporate cultural traditions and beliefs surrounding death, mourning, and maternal health.
    - Community Leadership: Involve tribal leaders, elders, and cultural knowledge keepers to guide the review process.
    - Trauma-Informed Approach: Acknowledge and address historical trauma and systemic inequities that may affect discussions around maternal health.

2. **Tribal Sovereignty**
    - Tribal Oversight: Ensure the review process is led by tribal governments or entities, respecting their sovereignty over health data and decisions.
    - Data Ownership: Establish agreements that clarify tribal ownership of data and how data will be used, shared, or stored.
3. **Community Engagement**
    - Partner Involvement: Engage a broad spectrum of partners, including families, healthcare providers, tribal health departments, and IHS.
    - Family Input: Offer opportunities for families affected by maternal deaths to share their experiences in a safe and supportive environment, if they choose.
4. **Multidisciplinary Review Teams**
    - Include diverse perspectives in the review process, such as: tribal leaders; public health professionals; cultural advisors; mental health experts; clinicians (e.g., OB/GYNs, midwives, doulas); social workers; and community advocates.
5. **Comprehensive Data Collection**
    - Culturally Relevant Metrics: Ensure data collection tools and methods reflect the unique needs and contexts of tribal communities.
    - Holistic Factors: Examine non-medical drivers of health.
    - Respect for Privacy: Protect the confidentiality of persons and families throughout the review process.
6. **Capacity Building**
    - Training: Provide training for reviewers on cultural competency, data analysis, and trauma-informed care.
    - Resources: Support tribal health departments with funding and technical assistance to conduct the reviews.
7. **Systemic Barriers**
    - Identify systemic barriers contributing to maternal mortality, such as:
        - Limited access to prenatal and postpartum care.
        - Provider shortages in rural tribal areas.
        - Implicit bias and discrimination in healthcare settings.
        - Advocate for policy and funding changes to address these barriers.
8. **Dissemination of Findings**
    - Community Reporting: Share findings with tribal communities in a transparent and accessible way, respecting cultural protocols.
    - Action-Oriented Recommendations: Develop actionable recommendations to improve maternal health outcomes based on review findings.
9. **Healing and Support**
    - Grief Support: Offer resources for families and communities to process grief and loss.
    - Community Strengthening: Highlight resilience and strengths within tribal communities to inspire collective action.
10. **Health Program Funding**
    - Sustainable Resources: Identify and secure funding sources to support maternal health programs and ongoing reviews.

- Federal and State Grants: Work with IHS, tribal leaders, and state health departments to apply for maternal health grants.
- Tribal Self-Governance: Explore ways for tribes to manage maternal health program funds directly.
- Equitable Distribution: Ensure funding is allocated equitably to underserved tribal communities.
- Innovation Funding: Support pilot programs, such as culturally tailored doula or midwifery services, with dedicated funds to evaluate their impact.

## Next Steps

In this listening session we heard the collective passion and commitment to tribal maternal health, families, and communities. Those providing input were tribal leaders, tribal members, Urban Indian Organizations, tribal-serving organizations, tribal health care providers, and those working in tribal MCH. The CDC Division of Reproductive Health plans to use listening session feedback to inform a sustainable funding initiative for tribes and tribal organizations that will focus on maternal health and tribal maternal mortality review.

The Division of Reproductive Health is currently working with several tribal partners to explore the feasibility of Tribal MMRCs and build capacity related to maternal health and MMRC processes – to improve the program as it exists and inform future program initiatives. To date, the Division of Reproductive Health investments include 16 tribal partners. This work is informing potential ways for tribal communities to improve maternal health and approaches to public health focused Tribal MMRCs as they deem appropriate. Over time, and with added support for tribal approaches to maternal health data and programs, there is an opportunity to address the larger systemic issues raised during the listening session like workforce development, access to care, and data systems. Maternal mortality data show the disproportionate occurrence of pregnancy-related mortality among American Indian or Alaska Native communities. The work of MMRCs clarifies issues through identifying causes of death, contributing factors, and actionable recommendations to prevent pregnancy-related mortality, and thereby ultimately improves health outcomes among all women. The Maternal Mortality Prevention Team within the Division of Reproductive Health will continue to apply alternate methods for examining pregnancy-related deaths in the Maternal Mortality Review Information Application (MMRIA) among all American Indian or Alaska Native women— regardless of notation of Hispanic origin or another/multiple races—to analyze and disseminate comprehensive information.

Looking ahead, the Division of Reproductive Health plans to engage with tribal leaders via tribal consultation and through other ongoing partner engagements before releasing a Notice of Funding Opportunity. In addition, the Division of Reproductive Health plans continued engagement with tribal partners, through activities and convenings. Such engagement will inform the development of a Notice of Funding Opportunity which reflects tribal needs.