

National Indian Health Board



2023 Convening on Tribal Maternal Mortality Review: Full Report





Meeting Background and Overview:

In partnership with the Centers for Disease Control and Prevention (CDC) Maternal Mortality Prevention Team (MMPT), the National Indian Health Board (NIHB) convenes partners to explore the feasibility and development process of Tribal Maternal Mortality Reviews in addressing maternal mortality and morbidity for American Indian and Alaska Native communities. This work is driven by a belief that it would be critical to establish a committee that deeply understands the cultural and historical context of American Indian and Alaska Native persons to develop equitable recommendations for maternal health in Indian Country. Tribal MMRCs do not currently exist, and many states lack Tribal representation on existing MMRCs.

On November 2-3, 2023, the NIHB, in collaboration with the CDC MMPT, hosted the "2023 *Convening on Tribal Maternal Mortality Review*" that was held on the sacred lands of the Santa Ana Pueblo at the Hyatt Regency Tamaya Resort. This meeting aimed to bring partners together to discuss the critical and complex issue of maternal mortality among American Indian and Alaska Native (AI/AN) communities. Attendees engaged in this 1.5-day meeting that provided several key presentations, small group discussions, and roundtable sessions with the following objectives:

- Learn about existing Maternal Mortality Review Committees (MMRCs), foundational and ongoing activities around Tribal Maternal Mortality Review (MMR), and prevention of pregnancy-related deaths among AI/AN communities.
- Learn from peers and share priorities in Maternal Health, lessons learned to date in *Exploring Tribal MMRC* projects, and perspectives to move maternal mortality prevention work forward.
- Provide perspectives on barriers and opportunities in implementing Tribally led MMRCs, accessing data, improving tribal representation, and incorporating a tribal lens in current MMRC processes.

This gathering successfully brought together over 60 maternal health experts, Tribal and Federal partners, representatives from tribal community organizations, and Native advocates from across the nation, including partners from Area Health Boards and Tribal Epidemiology Centers, dedicated to improving the healthcare and well-being of Native communities. Participants from Tribal and Native communities engaged in peer-to-peer learning to shape the future of this work in Indigenous Maternal Mortality Prevention.

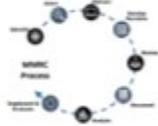
Convening Session Structure and Content

Breakout.Session.Structure

Participants in breakout session discussions represented key sectors in this work, including Tribal Epidemiology Centers, Area Health Boards, state MMRCs, and maternal health community organizations. Each attendee was assigned to a small group breakout session on both Day 1 and Day 2, to ensure perspectives from each key sector were represented across the diversity of attendees, and to build ideas through iterative discussions. Small group discussions were facilitated by a NIHB staff member; CDC staff served as notetakers. While NIHB facilitation was preferred, CDC Foundation supported facilitation for two groups (of the 6 small groups) on Day 1 and one group on Day 2, and notetaking through the duration of the convening.

Facilitators were provided with a facilitation guide containing probing questions and agenda points to ensure structure and productive conversations. However, it is worth noting that facilitators remained flexible to accommodate the natural flow of conversations and priorities of participants. During the discussions, participants were encouraged to document their insights directly on posters or easel pads. Quotes from discussions are included throughout the report in *italics* to provide a richer understanding.

Day.7

How would Tribal Maternal Mortality Review work in your setting?	
<p>Vision</p> <p>What would be the guiding vision for this work in your context? (What does success look like for this work?)</p>	<p>Tribal Maternal Mortality Review Process</p> <p>Thinking through the MMRC data to action process, how do you envision work in a Tribal Maternal Mortality Review? (What key changes would you make based on knowledge or experience with a non-Tribal MMRC? (Note: changes could be cultural, contextual, or other.)</p> 
<p>Scope</p> <p>What would be the optimal population for a review program in your context?</p>	<p>Barriers</p> <p>What are the barriers to moving this work forward?</p>
<p>Staff/Partners</p> <p>What key staff and partners are needed to support this work?</p>	

This first breakout session allowed attendees to discuss “*How would Tribal Maternal Mortality Review work in your setting?*”. The purpose of this session was to encourage participants to envision possibilities beyond current MMRC processes in non-Tribal jurisdictions, stimulating innovative thinking and the exploration of new approaches. Posters were used to help document discussions around various components of MMRC work (i.e., Vision, Scope, Staff/Partners, Process, and Barriers) and capture discussion themes.

Day.8

On Day 2, attendees engaged in discussions covering areas such as Maternal Health priorities, Tribal representation in current MMRC programs, Data Access Issues, and Considerations for the Future of the work.

- "Maternal Health as a Priority," encouraged participants to share insights on existing maternal health priorities, related activities, and the potential benefits of Tribal MMR.
- “Tribal representation in current jurisdictional MMR programs," focused on exploring the status of relationships between Tribes and state public health programs, barriers to Tribal representation, and strategies for improvement.
- "Data access and issues," focused on participants' familiarity with existing data products, anticipated challenges for Tribal MMR, and strategies for overcoming these challenges.

- "The future of the work," included reflections on the ideal model for Tribal MMR, sustainability of partnerships, and the potential for longer-term funding opportunities.

Please see Appendix A for the full Convening Agenda.

Development of the Summary Report

The following summary report aims to provide information and comprehensive insights into the discussions, themes, and key takeaways that took place during this gathering. The report combined the notes from both days and all breakout group sessions into organized highlights of major themes and subthemes that emerged during the breakout sessions and roundtable discussions.

All notes were compiled and organized into major themes by NIHB staff. The thematic areas that emerged from this process include:

- Priorities for Advancing Maternal Health
- Guiding Vision for Tribal MMRs
- Scope for Tribal MMRs
- Partners Needed to Advance Tribal MMRs
- Barriers for Developing Tribal MMRs
- MMRC Models

A detailed inductive coding process was completed by NIHB staff to generate subthemes for each major theme.

While every effort was made to capture all thoughts and perspectives during the gathering, this summary report may not include every idea and insight shared. Therefore, readers are encouraged to interpret the information with awareness of this limitation. However, this report holds significant value and serves as an overview highlighting rich discussions of the identified critical insights.

We thank our partners, attendees, advocates, and contributors for their time and knowledge sharing during this convening.

Priorities for Advancing Maternal Health

Priorities for Advancing Maternal Health was one of the major themes that emerged from discussions during the convening. This section highlights 3 key priority areas that were discussed by participants to improve maternal health outcomes in tribal communities. Subthemes identified in the analysis include A.) Accessing Quality and Culturally Congruent Care B.) Workforce Shortages and C.) Maternal Mental Health and Substance Use Disorders.

A. Accessing Quality and Culturally Congruent Care

Accessing quality health services with providers who offer culturally congruent care emerged as a priority area for Tribal maternal health. With limited or no access to maternity care, especially in rural and remote areas, maternal mortality and morbidity rates continue to rise. Additionally, participants indicated a need for cultural safety and insufficient training and education programs that focus on AI/AN health issues, traditional birthing practices, and community engagement contribute to the shortage of qualified professionals equipped to deliver culturally sensitive and holistic maternal care. Discrimination rooted in historical trauma and unethical medical research practices have contributed to a deep-seated mistrust of healthcare institutions and providers within AI/AN communities. This historical context, coupled with ongoing disparities in access to quality healthcare, language barriers, and lack of cultural competence in healthcare settings, further exacerbates feelings of distrust. Medical mistrust can lead to delays in seeking care, non-adherence to medical recommendations, and reluctance to participate in preventive services. Therefore, it is essential to prioritize access to comprehensive prenatal and postnatal care, emergency obstetric services, and culturally congruent care practices.

“You have to get your care in the office with a provider that may not know anything about you. This model is common with a lot of OB’s and affects the quality of care patients receive. This can lead to [health] complications.”

B. Workforce Shortages

Workforce gaps in maternal care present significant challenges in ensuring quality and accessible healthcare services for pregnant individuals in these communities. Workforce shortages result in even less availability of AI/AN healthcare providers, behavioral health specialists, nutritionists, and Indigenous doulas who understand and respect the unique cultural backgrounds, values, and healthcare needs of AI/AN patients. Mental and behavioral health is another urgent priority for improving maternal health, therefore, it is important to have qualified behavioral health therapists and specialists trained to provide care for AI/AN women training programs, expanding recruitment efforts in Tribal communities, promoting cultural humility in healthcare education, and advocating for policies that support the retention and development Addressing these workforce gaps requires focused strategies, such as increasing investments in AI/AN healthcare of a diverse

maternal care workforce. Closing these gaps is essential to improving maternal health outcomes and addressing disparities.

“Currently we are only staffed with a Maternal & Child Health nurse and doula. We lost our aide due to lack of transportation [to the facility]. The primary need now is an increase in staff. We can’t focus on any other needs due to lack in staff.”

C. Maternal Mental Health and Substance Use Disorders

Prioritizing maternal mental health and substance use disorders (SUDs) is essential for ensuring holistic and effective maternal care. There is a need to expand screening protocols to identify perinatal depression, anxiety, trauma, and other mental health concerns. Providing access to culturally appropriate mental health services, such as counseling, therapy, and peer support programs, is crucial for addressing mental health challenges and promoting maternal well-being. Similarly, addressing SUDs among AI/AN patients requires a comprehensive approach that integrates substance abuse screening, treatment, and recovery support into maternal healthcare services. By prioritizing maternal mental health and SUDs, healthcare providers can improve outcomes for both mothers and babies, reduce the stigma associated with these conditions, and support the overall health and wellness of AI/AN families.

“We just started a home visit program and identified a large portion of moms deal with mental health and SUD.”

“There’s stigma of women going to behavioral health programs because Tribes are close knit and everyone will know what you are doing, so some women would rather avoid that.”

D. Improved Tribal Representation in Current MMRCs

No matter what the future of Tribal MMR looks like, the way states approach MMR will always have an impact on Tribes as well. For this reason, several participants pointed out the importance of ensuring states respect Tribal sovereignty, include sufficient Tribal representation on the committees themselves, operate in a culturally safe way, and coordinate effectively with Tribes and Tribal organizations. Currently, there is limited capacity for Tribal representation on existing MMRCs. As the federal agency responsible for implementing the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) program, CDC has a responsibility to ensure that federally funded state MMRCs are working appropriately with Tribes and that Tribal rights are not trampled during

program implementation. CDC should also ensure Tribes have access to the resources necessary to allow them to fully participate in existing MMRCs.

“CDC has a lever to ensure Tribal representation in MMRCs. Make Tribal representation a requirement. CDC needs to ensure that the programs they are funding respect Tribal sovereignty. Make sure the money shows this!”

“Add more to the existing CDC funding for states to include tribes – add more strings to that funding for states.”

Guiding Vision for Tribal MMRs

Attendees discussed key components for the process of creating and conducting Tribal Maternal Mortality reviews. This section highlights 4 key areas for the guiding vision, that emerged from conversations, for Tribal Maternal Mortality Reviews. Identified subthemes include A.) Grounded in Tribal Sovereignty B.) Holistic Approach to Data and using Interviews as a Source C.) Cultural Considerations for Reviewing Cases.

A. Grounded in Tribal Sovereignty

Respecting Tribal sovereignty in the context of MMRCs involves recognizing and acknowledging the inherent right of Tribal nations to govern themselves and make decisions that affect their communities. It also requires obtaining informed consent from Tribal communities before collecting or using their health data and implementing strict measures to ensure data privacy and confidentiality. Additionally, upholding Tribal sovereignty involves respecting Tribal cultures, traditions, and customs, and incorporating these valued aspects into the review process.

“What resonated for me is the importance of having a framework that’s rooted in cultural values. Before thinking about whether the MMRC process works, we need to think about some of the core things that resonate throughout all Tribal communities so they can see themselves in this work.”

B. Holistic Reviews with Interview Data

Reviewing a variety of data, as available, is crucial to gain a comprehensive understanding of the multifaceted factors contributing to maternal mortality and to develop effective strategies for prevention and improvement. A holistic approach to reviewing deaths, considering both clinical and non-clinical data sources, will enable MMRCs to address the root causes of maternal mortality and recommend interventions that focus on these complex factors. By considering the entirety of a woman's health, environment and surrounding social circumstances, MMRCs can develop more tailored and impactful recommendations, policies, and interventions that address the full spectrum of maternal health needs and promote equity and improved outcomes for all individuals.

There is also a need to humanize the data used to review cases and look at the full story. Family members, healthcare providers, and witnesses, can offer details that may not be captured in medical records or reports, unveiling social, cultural, and systemic factors that could have contributed to the outcome. Their accounts can help identify gaps in care, systemic failures, and areas for improvement to prevent future maternal deaths. In essence, informant interviews humanize the data, putting faces and stories behind the numbers, and play a vital role in creating a more patient-centered and effective maternal healthcare system.

Interviews should be facilitated by trained interviewers and follow Tribe-specific practices, ceremonies, and protocols. Cultural congruency throughout the process is essential for bolstering trust with the interviewer and inviting family members and loved ones to participate. Establishing a trusting relationship with participants fosters a safe and supportive environment where individuals feel comfortable sharing their experiences, perspectives, and insights related to maternal mortality. This is especially critical for cases concerning missing persons or violent deaths. These interviews offer a unique opportunity to gather information directly from individuals closely involved in the circumstances surrounding the birthing person.

“What do we mean/ how do we define data? How do we see a person? Move away from repeated information that perpetuates stereotypes.”

“... Story is sacred should honor the person [in a] responsible and culturally appropriate way.”

C. Cultural Considerations for Reviewing Cases

There are several cultural considerations when developing Tribal MMRCs. Respect for Tribal traditions and customs, such as involving Elders, Grandparents and Traditional Healers in decision-making processes and ceremonies is essential to establish trust and cooperation.

Recognizing the unique healthcare perspectives and practices within each Tribe, including traditional healing methods and spiritual beliefs, is crucial for designing a culturally competent review committee. Incorporating culture-specific training for committee members and providing resources for cultural competency can further enhance the effectiveness of Tribal MMRCs.

“I carry sweetgrass, cedar spray, or sage to cleanse energy after a hard MMRC meeting... just remember these are people and we are honoring their lives. Language is so important.”

“Using simple words in our Native language and understanding the meaning holds power!”

“Having traditional knowledge. Having a traditional healer participating and providing space.”

“There is a need to pay attention to cultural protocols about when you talk about death and how you talk about death... talking about death is taboo in many cultures.”

Scope for Tribal MMRCs

This section highlights 3 key themes identified for the scope of Tribal MMRCs, that were discussed by participants. Subthemes identified in analysis include A.) Address Root Causes and Solutions, B.) Use MMRCs as an Opportunity to Raise Awareness of Intersections with Maternal Morbidity and Child/Infant Health.

A. Address Root Causes and Solutions

Addressing root causes to effectively reduce maternal mortality rates and improve maternal health outcomes will require discussing underlying systemic issues manifested in each individual case. This may include social determinants of health and structural inequalities contributing to maternal mortality. Discussing these aspects of cases will allow for the development of targeted interventions, policies, and initiatives that address the root causes of maternal mortality. Furthermore, by focusing on solutions that address these root causes, MMRCs can develop recommendations that promote health equity, enhance maternal healthcare delivery, and support the overall well-being of pregnant individuals, improving overall population health outcomes. MMRCs also present opportunities to advocate for system-wide reform, community engagement, and multi-sector collaborations. Addressing root causes during the MMRC process leads to comprehensive solutions that pave the way for lasting improvements in maternal health outcomes for AI/AN communities.

“We have to go more upstream to reach the best solution and address the systems change.”

“Focus on root causes and solutions, knowing that there’s an avenue to get to solutions that are focused on addressing root causes.”

B. Use MMRCs to Address Intersections with Maternal Morbidity and Child/Infant Health

Attendees discussed how MMRCs and maternal case reviews can be a piece of an overall programmatic strategy that can be leveraged for broader awareness building on maternal health and family health improvements. Combining analyses from MMRCs with analyses and dissemination of information on severe maternal morbidity could be one strategy to cross-promote maternal health information and provide partners with information for action. Moreover, analyzing morbidity data alongside mortality data fosters a patient-centered perspective, emphasizing the importance of mitigating long-term health consequences and promoting maternal well-being beyond survival. By integrating both mortality and morbidity information and analyses, MMRC programs and partners can enhance their capacity to address maternal health disparities, drive evidence-based practice changes, and ultimately prevent future adverse maternal health outcomes.

In addition, attendees spoke about the importance of using information from maternal case reviews alongside information from other mortality reviews, especially infant or child case review processes. By examining both infant and maternal mortality together during data analyses, dissemination events, or prioritization of 'data to action' with partners, communities and healthcare systems can identify common risk factors, patterns, and systemic issues that may contribute to adverse outcomes for both mother and child. This integrated approach allows for a comprehensive evaluation of the continuum of care during pregnancy, childbirth, and postpartum periods, promoting a more holistic understanding of the complex interplay between maternal and infant health. Additionally, combining information from reviews in partner engagements enables community and healthcare providers to develop coordinated strategies, interventions, and preventive measures that address the health needs of both mothers and infants, leading to more effective care delivery and improved patient safety. Moreover, the synergistic analysis of maternal and infant deaths fosters a culture of collaboration, communication, and multidisciplinary learning within healthcare teams, ultimately driving continuous quality improvement and reducing preventable deaths in vulnerable populations.

“Both maternal & infant death review boards because there are high rates in both populations among our people.”

Partners Needed to Advance Tribal MMRs

This section highlights the 4 key partner groups that emerged in discussions for advancing work around Tribal MMRs. Analysis identified the following partner groups: A.) Tribal Leaders, B.) Elders and Grandparents, C.) TECs and D.) Tribal Members Serving on Existing MMRCs

A. Tribal Epidemiology Centers (TECs)

TECs can support infrastructure and systems development efforts when developing Tribal MMRCs. If given the proper data access and management authority, TECs can intervene and streamline data collection and dissemination for MMRs. Data sharing laws vary state-by-state, therefore, with authority from participating Tribes, housing MMR data with TECs could improve barriers for accessing timely data. TECs are also critical partners, and in some cases leaders, for maintaining reviews in regions or states without a formal MMRC process. TECs create opportunities for Tribes to review cases on their own or in partnership with other Tribes in the same region. Beyond housing and sharing MMR data, TECs can advise on priorities for reducing maternal mortality rates across AI/AN communities.

“Data is power, but for Tribal access of data, there are so many hoops to jump through... give it to the TECs that are representing the Tribes.”

“Data barriers exist for Urban Indian Organizations (UIOs) -TECs are critical.”

“If no state MMRC exists, TECs can take the lead to identify cases and collect data necessary for review and review the cases using an area-wide Tribal MMR model.”

B. Tribal Leaders

Tribal Leaders play a pivotal role in representing and advocating for their communities, especially in matters concerning healthcare. Effectively addressing maternal mortality requires engaging Tribal Leaders in the discussion and decision-making processes. Presenting actionable data that both tells a story and creates opportunities for intervention can also support engagement from Tribal Leaders. Their guidance and partnership can also help address barriers when accessing maternal healthcare services, address social determinants of health specific to Native and Tribal communities, and play a pivotal role in fostering trust between healthcare providers and community members. Collaboration with Tribal Leaders not only promotes Tribal sovereignty and self-determination but also paves the way for sustainable, equitable, and effective solutions for improving community maternal health outcomes.

“When talking to Tribal Leaders, they are less concerned about the data about the case but more on how to prevent this from happening. They are more interested in the data to action piece.”

C. Experts from Non-Traditional Fields, including Elders and Grandparents

Diverse committee membership for MMRCs is crucial for addressing complex issues surrounding maternal mortality. Tribal MMRs offer an opportunity to include experts from non-traditional fields and share recommendations that are both culturally and contextually relevant. For example, there are opportunities for Traditional healers to serve on MMRCs and share Tribe-specific standards of health and well-being. Policy analysts or public health experts may bring expertise in healthcare regulations, ethics, and policymaking, aiding in the identification of systemic factors contributing to maternal mortality. Including members with various and diverse backgrounds relevant to Tribal communities enhances the committee's ability to generate holistic recommendations and implement effective strategies for reducing maternal mortality rates.

In addition, elders and Grandparents hold a sacred and revered position within Native and Tribal communities, embodying wisdom, cultural knowledge, and invaluable life experiences. Elders are revered for their wisdom, and their presence is central to decision-making processes, ceremonies, and community gatherings. They act as teachers, passing down cultural practices, languages, and historical narratives to younger generations, ensuring the continuity of indigenous identities and values. Furthermore, Elders and Grandparents serve as custodians of healing practices, spiritual beliefs, and community cohesion, playing a vital role in maintaining the cultural heritage and social fabric of Native and Tribal societies for generations to come. Developing spaces on MMRCs to integrate the perspectives of Elders and Grandparents allows for an MMRC process guided by their shared wisdom, respected roles in their communities, and diverse cultural and traditional knowledge.

“Protect and integrate traditional practices (like smudging). Bring traditional healers to the table.”

“Nutritionists. A lot of people don’t understand how this plays into their health during pregnancy and fetal health. Also key to mental health...Prioritizing mental health practitioners.”

“Native Approach: ask Elders how to navigate conversations about death/MMRC. Elders are the priority [partners] for preventing maternal mortality.”

Barriers for Developing Tribal MMRs

This section highlights 4 major barriers that were raised in discussions for developing Tribal MMRs. Subthemes identified in analysis include A.) Fragmented Health Systems, B.) Limited Data Sharing Agreements, C.) Insufficient or Unsustainable Funding, and D.) Data Distrust.

A. Fragmented Health Systems

AI/AN women often confront fragmented care when attempting to access maternal health services, reflecting structural deficiencies in the healthcare system. With high rates of referrals and limitations in available facilities, AI/AN communities are more likely to experience fragmented care when seeking maternal health services, leading to gaps in continuity of care and substandard quality of maternal health services. These gaps may create complications with data retrieval and accuracy to prepare case review materials for a committee. There may also be challenges identifying cases for committee review.

“Continuity of care is lacking---systems are not talking to each other –there is no idea where moms are ending up...many women see fragmented care, there is no communication across the medical records, so many missed opportunities.”

B. Limited Data Sharing Agreements

Public health authorities in the United States should honor Tribal sovereignty and fully allow Tribes to have the right to govern their own health data. Potential Tribal MMRCs must ensure data is collected, used, and shared in a way that respects Tribal customs, beliefs, and standards. The process of obtaining proper consent for data collection and sharing can vary across communities, requiring a thoughtful and culturally sensitive approach. These challenges underline the necessity for MMRCs to engage in meaningful dialogue, build trust with Tribes, and adhere to both Federal and Tribal laws and regulations. More resources and tools are needed for the recommendations from MMRCs to reach Tribes in an effective and timely manner. Formal data sharing agreements are helpful for honoring how data can be used to ensure respect for Tribal data sovereignty and confidentiality.

“Strategies of getting the data outside of the current system and getting data to Tribes to make their own decisions – need initial funding to do that, lay the infrastructure and strategies.”

C. Insufficient or Unsustainable Funding

Adequate and sustainable funding is essential to support the vital work of any future Tribal MMRCs. Insufficient or unsustainable funding can limit the resources available for data collection, analysis, and dissemination of findings, thereby hindering the ability of MMRCs to fulfill their mandate effectively. Additionally, funding constraints may impede the recruitment and retention of qualified personnel to serve on committees and impact the ability to use data to inform implementation of recommended interventions. CDC has an important role to play in ensuring that Tribal MMRCs are funded in a sustainable manner and in a way that makes sense for Tribes.

“To sustain partnerships, we need funding to go beyond data collection. Need to fund organizations to build partners and implement recommendations to prevent deaths.”

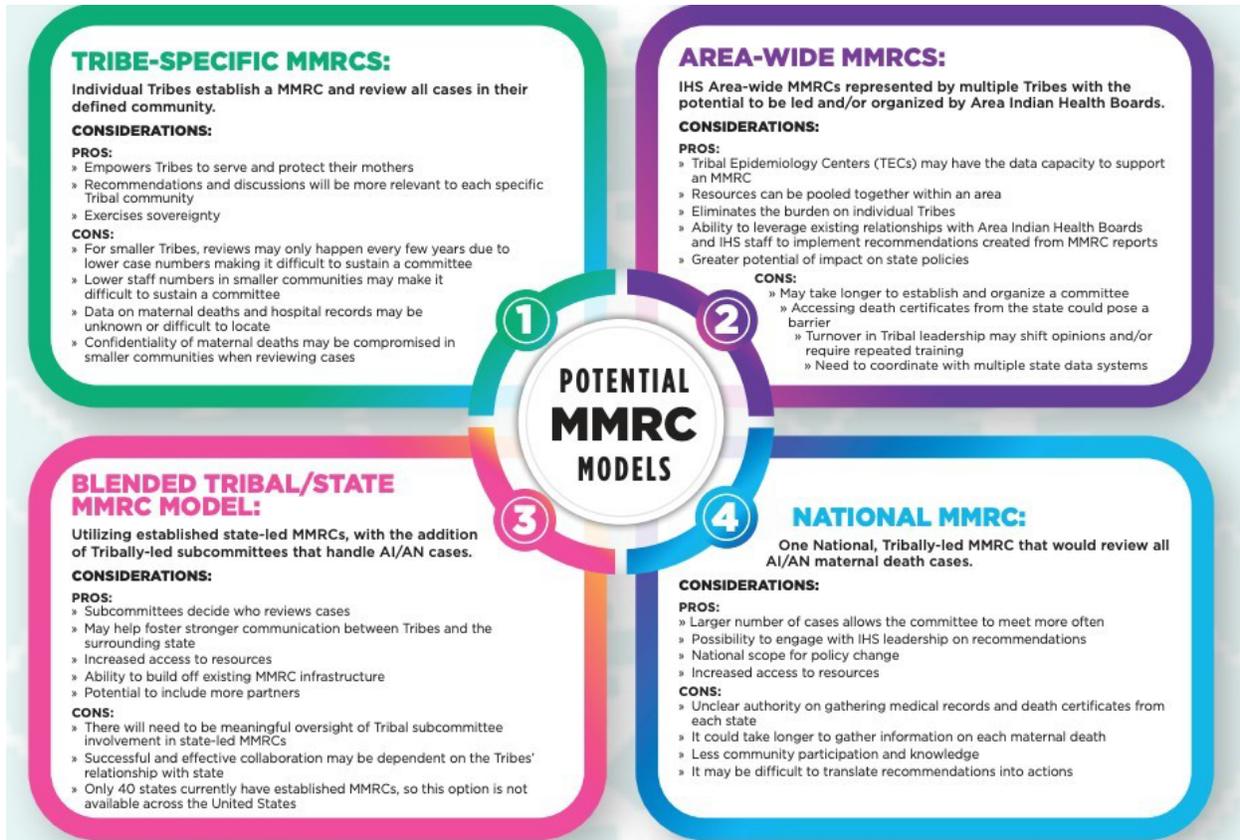
D. Data Distrust

Data distrust among AI/AN communities is a complex issue rooted in systemic discrimination and lack of recognizing data sovereignty laws and regulations. Addressing data distrust among AI/AN people require building trust through culturally sensitive care, meaningful community engagement, and a commitment to honoring Traditional knowledge and sovereignty. When developing a Tribal MMR, it is important to consider structural solutions for protecting AI/AN data. By actively involving AI/AN communities in decision-making processes and prioritizing respectful, collaborative relationships, healthcare providers and institutions can work towards rebuilding trust and improving health outcomes for AI/AN individuals.

“Fear of MMRIA data being weaponized against Tribe...not a lot of trust and not willing to share data because not sure where the data will go.”

MMRC Models

This section summarizes feedback, thoughts, and ideas around existing MMRC models and the four potential Tribal MMR models (see figure below). Overall, participants indicated a single model alone cannot effectively address the complex and diverse considerations for developing Tribal MMRs.



The graphic above depicts four potential models for Tribal MMRCs: Model 1 (Tribe-specific), Model 2 (Area-wide), Model 3 (Blended Tribe/State), and Model 4 (National) that were developed in March 2020 at the Tribal Maternal Mortality Review Committees, Area Indian Health Board Convening hosted by the California Rural Indian Health Board in partnership with the National Indian Health Board. At this meeting, 11 Area Indian Health Board representatives gathered to discuss the need, scope and potential models of Tribal MMRs (shown above). Following this meeting, in 2023 the National Indian Health Board hosted a second convening with Native and Tribal maternal health experts to deepen discussions around the development and need for Tribal MMRCs. Below are comments and feedback given on the four proposed models when they were reviewed at the November 2023 convening in Santa Ana Pueblo, New Mexico.

Feedback and possible revisions to the Potential Tribally led MMRC Models

A. Tribe-specific MMRC Model 1 Feedback:

Participants at this convening indicated concerns over responsible and accurate Tribal data collection, the accessibility of data in Tribes with low maternal mortality rates, and identifying reviewers or healthcare providers in the community. Participants also raised concerns for identifying AI/AN data for non-enrolled members, those living in urban areas or away from the Tribe, and reviewing cases of relatives from another Tribe or non-Natives married into the Tribe.

“For [my] Nation: a lot of it is going to be fear. If we’re just looking at our health system, easy to point fingers at providers [and say] “you didn’t offer this or you didn’t do that.” Also, small numbers – will find relatives, friends, family. [It] gets very personal.”

“But what about not enrolled members? Many live in urban areas and reservations. What about family that’s married in?”

B. Area-wide MMRC Model 2 Feedback:

Participants found elements of this model beneficial, and one participant suggested using this model to review cases for Native birthing people after an initial review was conducted by a non-Tribal, state review. Several other participants indicated their support for a secondary review. Barriers stemming from fragmented care systems arose when discussing this model, such as tracking and accessing hospital data across different facilities, accessing data in states/areas without MMRCs, and building partnerships for effective reviews.

“In thinking about scope, is it regions or traditional lands or by enrolled tribes? Or where people are passing away? Or where they got treatment and care. It gets complicated.”

“Maybe could do a regional review [with a Tribal MMRC for Native birthing people, after initially reviewed by the state].”

“This area Tribal MMRC centers culture, and focuses on prevention, connection to strengths and shares out actionable preventive measures. Ideally, area-wide Tribal MMRCs are supported by National coordination, technical support.”

“If state MMRCs exist, partner with them to identify AI/AN cases and collect necessary data. Then, these cases move to area-wide Tribal MMRC, with representation from medical, grass-roots, Tribal, urban, etc.”

“If no state MMRC exists, TECs take the lead to identify cases and collect data necessary for review and move the cases to the area-wide Tribal MMR.”

C. Blended Tribal/State MMRC Model 3 Feedback:

The Blended Tribal/State Model may increase representation on existing state MMRCs and/or could promote a Tribal-specific subcommittee to review AI/AN case. Tribe/State mistrust was cited as a critical barrier for this model and may be more of a barrier in some regions than others.

“NO TRUST (Blended model).”

“States don't play nice with data, may be giving up power if they give up data to the tribes and how to overcome that with different states that have different relationships with tribes.”

“Working with the data coming out to create meaningful solutions = blended model, but adding in translation component.”

“Blended tribal state model would not work; need to work and get the all tribes together; there's an element of mistrust.”

D. National MMRC Model 4 Feedback:

Comments were made that this model may be best if implemented in combination with another model to provide technical assistance or data/case management support in combination. Some concerns were raised about data availability and accuracy at the national level, particularly considering ongoing challenges with racial misclassification in many datasets. Another potential challenge raised focused on the need for trust between Tribal communities and the MMRC, which may be strained if there is a perception the MMRC is a federal entity.

“Have to get data from state so you can correct misclassification if do a national level; CDC/IHS Cancer national data linkage as an example.”

“If we do the National MMRC model, how would we address mistrust if backed by CDC-are the numbers accurate and representative?”

“National model would work with region-wide groups.”

E. Tribal Consortium MMRC Model (Proposed)

One participant proposed a model that is not currently represented among the Potential Tribally led MMRC models:

“All of the Tribes in the state form a consortium for Native Women's Health Review.”...“Tribes & UIO's serve as pass-through for states to be funded for Tribal abstracting, etc.”

This proposal was highly favored by participants. Some concerns were raised regarding potential barriers due to challenging inter-Tribal relationships, however, participants indicated this review model could support existing structures or other models proposed. Overall, participants thought that this proposal provides opportunities for successful reviews, especially in partnership with another model/process/system (i.e. Tribal Consortium model with a National review).

“Good idea for an MMRC model is that there is a tribal consortium of MMRCs within the state. In other words, a state-based tribal MMRC with all the tribes in the state. Different from the model in which each tribe has an MMRC. And different from area/regional MMRC because there would be less hassle in dealing with multiple state laws instead of just one.”

F. All Additional Comments

“We might need all of the models.”

“A combination tribal and area wide. This is a short term “best idea” - as it's easier to get data.”

“One model at the area level – intertribal. Another model – MMRC translation center. A combination of Models could/should exist: national, regional, tribal with capacity.”

“Hybrid of National and Blended Tribal/State.”

“Including an MMRC “Translation” Center (center to review Tribal case data and recommendations from the MMRC) with one of the models?”

“What if we just add MMRC to TEC statute? And include data sharing.”

“TEC-National Hybrid: Utilize TECT PH Authority, data sharing state relationships w/area for national coordination, guidance, problem-solving & technical support.”

Conclusion

Maternal mortality remains an urgent crisis in Indian Country. It is critical to start at the root causes of these deaths and address urgent maternal health needs. Accessing quality healthcare services, developing culturally congruent workforces, increasing community needs assessment efforts, and addressing maternal mental and behavioral health were all mentioned as priority areas for improving maternal health outcomes. Fostering partnerships between Tribal, Federal, and state entities is crucial for implementing policy changes and resource allocation that address the broader social determinants of health, such as poverty, education, and housing, impacting maternal health outcomes.

MMR is a promising method for further investigating the current challenges and successes Tribes and Tribal-serving organizations face when addressing maternal health. Recognizing and including AI/AN perspectives in current maternal mortality review processes is essential for developing effective healthcare policies and recommendations to improve maternal health outcomes, for all. In general, it is necessary to increase Tribal representation and raise Tribal perspectives at all levels of existing review processes. Additionally, there are opportunities to integrate traditional practices that protect and safeguard Native committee members serving on MMRCs, ensuring they are equipped to conduct effective reviews.

Beyond the existing MMRCs run by state or local governments, Tribal MMRs offer the opportunity to develop models rooted in Tribal sovereignty and data sovereignty with the health and well-being of AI/AN communities at the heart of the review process. Participants of the convening voiced the need to move toward a more holistic, resilience-based process; this is the opportunity of Tribal MMR. Based on the insight shared in this convening, there is likely no “one size fits all” model of Tribal MMR. Rather, different models or components of different models may best suit the needs of Tribes in different places and different circumstances, and so flexibility is key. To develop successful Tribal MMR processes, CDC, Tribes, and Tribal-serving organizations will need to carefully consider potential challenges around data access, data quality, fragmented healthcare systems, and privacy concerns in small communities. In addition, fractured relationships and historical mistrust between Tribal, state, and federal governmental entities can make MMRC more difficult, and these relationships must be navigated with care.

While the convening demonstrated notable momentum in efforts to develop Tribal MMR processes, further work is needed. Moving forward will require dedicated, sustained funding directly to Tribes and Tribal organizations. Additionally, time and space are needed for exploration and planning, as capacity in this area builds. NIHB and CDC MMPT learned they need to continue to engage partners in strategic planning and expand outreach to collaborate with Tribal leaders and Tribal Epidemiology Centers, in particular. These outreach efforts will build on the work done in the convening, which continued conversations to advance the development of Tribal MMR, and strengthen them, by bringing partners together to collaborate on what would work best in and for Tribal communities.

National Indian Health Board



Appendix A – Agenda for the Convening on Tribal MMR

Agenda - Day 1: Thursday, November 2, 2023

Time	Session	Rooms
7:30-8:30am	Breakfast, Networking, and Registration (Breakfast Provided)	Puma
8:30-8:35am	Opening Remarks <ul style="list-style-type: none">• <i>Dr. Jill Jim (Navajo Nation), PhD, MHA, MPH, Public Health Infrastructure & Accreditation Programs Director, NIHB</i>	Eagle
8:35-8:45am	Opening Prayer and Land Acknowledgement <ul style="list-style-type: none">• <i>Governor Nathan K. Garcia, Pueblo of Santa Ana</i>• <i>Lt. Governor R. Michael Lujan, Pueblo of Santa Ana</i>	Eagle
8:45-8:55am	Welcome <ul style="list-style-type: none">• <i>Stacy Bohlen (Sault Ste. Marie Tribe of Chippewa Indians), CEO, NIHB</i>	Eagle
8:55-9:15am	Meeting Overview and Icebreaker <ul style="list-style-type: none">• <i>Lori Garg, MD, MPH, Maternal and Child Health Programs Director, NIHB</i>• <i>Preetha Raj, MPH, Public Health Policy and Programs Project Coordinator, NIHB</i>	Eagle

Time	Session	Rooms
9:15-10:15am	What's Our Story? Thriving and Dying Indigenous Maternal Health <ul style="list-style-type: none"> <i>Janelle Palacios (Salish & Kootenai), PhD, CNM, RN, Founder and Director, Encoded4Story, Nurse Midwife, Associate Research Professor, Montana State University</i> 	Eagle
10:15-10:30am	Break (Snacks Provided)	Puma
10:30-11:30am	MMRC Overview and Tribally Led MMRCs <ul style="list-style-type: none"> <i>Danielle Arellano, MPH, Public Health Advisor, Division of Reproductive Health, CDC</i> <i>Ashley Busacker, PhD, Senior Scientist Maternal Mortality Prevention Team, CDC</i> 	Eagle
11:30-12:15pm	Foundational Work with NIHB in Tribally Led MMRCs <ul style="list-style-type: none"> <i>Lori Garg, MD, MPH, Maternal and Child Health Programs Director, NIHB</i> <i>Carrie Field, MPH, Policy Analyst, NIHB</i> <i>Elisha Sneddy (Navajo Nation), MPH, Public Health Policy and Programs Project Coordinator, NIHB</i> <i>Preetha Raj, MPH, Public Health Policy and Programs Project Coordinator, NIHB</i> 	Eagle
12:15-1:00pm	Lunch (Provided)	Puma
1:00-2:15pm	A Deeper Look: Data MMRCs Create via Committee Deliberations <ul style="list-style-type: none"> <i>Danielle Arellano, MPH, Public Health Advisor, Division of Reproductive Health, CDC</i> <i>Ashley Busacker, PhD, Senior Scientist Maternal Mortality Prevention Team, CDC</i> <i>Tegan Callahan, MPH, Public Health Advisor, Division of Reproductive Health, CDC</i> <i>Mackenzie Leonard, MPH, Project Coordinator, Maternal Mortality Prevention Team, CDC Foundation</i> <p>Large Group Debrief</p> <ul style="list-style-type: none"> Facilitator: <i>Carrie Field, MPH, Policy Analyst, NIHB</i> 	Eagle
2:15-3:15pm	It's in OUR Hands: Improving the Perinatal Health of American Indian and Alaska Native Women Panel Discussion <p>Facilitator:</p> <ul style="list-style-type: none"> <i>Cindy Gamble (Tlingit, Kaax'oos.hittaaan), MPH, CLC, Tribal Community Health Consultant, American Indian Health Commission</i> 	Eagle

Time	Session	Rooms
	<p>Panelists:</p> <ul style="list-style-type: none"> • Abra Patkotak (Iñupiaq), BSW, Birthworker and Doula, Co-founder, Alaska Native Birthworkers Community • Brian Thompson (Oneida Nation), MD, FACOG, Physician, Upstate Medical University • Meghan Curry O'Connell (Cherokee Nation), MD, MPH, Chief Public Health Officer, Great Plains Tribal Leaders' Health Board • Lynn Lane (Navajo Nation), BS, Tribal Maternal Health Innovation Program Manager, Arizona Department of Health Services 	
3:15-3:30pm	Break (Snacks Provided)	Puma
3:30-4:45pm	Small Group Breakouts	Puma
4:45-4:55pm	Day 1 Closing	Puma
4:55-5:15pm	Poster Walk	Puma
6:15pm Arrival	Presentation with Dinner to Follow	Tamaya D
7:15pm Dinner	<p><i>Aunties are a Game Changer: The Protective Role of Indigenous Doulas</i></p> <ul style="list-style-type: none"> • Camie Goldhammer (Sisseton-Wahpeton Oyaté), MSW, LICSW, IBCLC, Founding Executive Director, Doula and Lactation Consultant, Hummingbird Indigenous Family Services 	

Agenda - Day 2: Friday, November 3, 2023

Time	Session	
7:30-8:30am	Breakfast and Networking (Breakfast Provided)	Puma
8:30-8:45am	Opening and Review of Day 1 and Day 2 <ul style="list-style-type: none">• <i>Elisha Sneddy (Navajo Nation), MPH, Public Health Policy and Programs Project Coordinator, NIHB</i>• <i>Preetha Raj, MPH, Public Health Policy and Programs Project Coordinator, NIHB</i>	Eagle
8:45-9:00am	Exercise: Provide Feedback on the Potential Models of Tribally Led MMRCs	Eagle
9:00-11:00am	Roundtable Discussions/Breakout Groups	Puma
9:00-9:25am	Round 1: Maternal Health as a priority.	
9:30-9:55am	Round 2: Tribal representation in current jurisdictional programs.	
10:00-10:25am	Round 3: Data access and issues.	
10:30-10:55am	Round 4: The future of the work.	
11:00-11:15am	Break (Snacks Provided)	Puma
11:15-11:50am	Debrief on Potential Models & Closing Discussion	Eagle
11:50-11:55am	Closing Prayer	Eagle
11:55-12:00pm	Evaluation/Survey	Eagle
12:00pm	Grab and Go Lunch (Provided)	Eagle

National Indian Health Board



Appendix B – Small Group Breakout Sessions Questions

Day 1 – Smaller Group Breakouts

How would Tribal Maternal Mortality Review work in your setting?

Thinking through the MMRC Data to Action process, how do key processes look in a Tribal Maternal Mortality Review? What key changes would you make based on knowledge or experience with a non-Tribal MMRC? (Note: changes could be cultural, contextual, or other.)

What steps/resources are needed to move forward?

Day 2 – Round Table Discussions / Breakout Groups

<p>Topic: Maternal Health as a priority</p> <ul style="list-style-type: none">- What are the maternal health priorities in your settings and what maternal health-related activities currently exist?- What resources and information would be helpful in your mission/work?- How does maternal mortality prevention fit into the current priorities and areas of your work?- What merit or benefit would a Tribal Maternal Mortality Review bring to current priorities and ongoing work in your setting?
<p>Topic: Tribal representation in current jurisdictional MMR programs</p> <ul style="list-style-type: none">- What is the status of relationships generally between tribes and tribal jurisdictions and state public health programs in your context? What has been key to successful partnerships generally for health outcomes, or specifically in MCH topics?- What is your understanding or experience with tribal representation on current jurisdictional (i.e., state run) programs?- How can tribal representation in current jurisdictional MMRCs be ensured or improved in these state-run committees?- What are barriers in your setting that, or generally, may inhibit tribal representation in existing jurisdictional MMR programs (or limit relationships with public health departments more broadly)?- What are strengths in your setting that may promote Tribal representation in existing jurisdictional MMR programs?
<p>Topic: Data access and issues</p> <ul style="list-style-type: none">- Are you familiar with data products that focus on tribal populations from the current (state-run) MMRCs in your context, or national analyses? What challenges or information needs do you still have when it comes these data products?- What data access challenges are anticipated for Tribal Maternal Mortality Review?- What strengths exist? How can we overcome the challenges discussed?
<p>Topic: The future of the work</p> <ul style="list-style-type: none">- What model for tribal MMR do you see best fitting your context (can be one of the four established in formative activities to date with NIHB, or other)? Why does this model resonate with you the most? Could you see multiple models working – how?- What is needed to sustain partnerships over the next 5–10-years? Where do we go next to move activities forward?- Considering potential CDC NOFO development. Is there interest in longer term funding? What types of funding?