

# 2023 Convening on Tribal Maternal Mortality Review: Meeting Summary



# **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.

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.

The following summary aims to provide information and comprehensive insights into the discussions, themes, and key takeaways that took place during this gathering. The findings summarize 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.

# **Potential Models for Tribal Maternal Mortality Review Committees**

# **TRIBE-SPECIFIC MMRCS:**

Individual Tribes establish a MMRC and review all cases in their defined community.

### CONSIDERATIONS:

#### PROS:

- » Empowers Tribes to serve and protect their mothers
- Recommendations and discussions will be more relevant to each specific Tribal community
- » Exercises sovereignty

### CONS:

- For smaller Tribes, reviews may only happen every few years due to lower case numbers making it difficult to sustain a committee
- Lower staff numbers in smaller communities may make it difficult to sustain a committee
- » Data on maternal deaths and hospital records may be unknown or difficult to locate
- Confidentiality of maternal deaths may be compromised in smaller communities when reviewing cases

# BLENDED TRIBAL/STATE MMRC MODEL:

Utilizing established state-led MMRCs, with the addition of Tribally-led subcommittees that handle AI/AN cases.

### CONSIDERATIONS:

#### PROS:

- » Subcommittees decide who reviews cases
- » May help foster stronger communication between Tribes and the surrounding state
- » Increased access to resources
- » Ability to build off existing MMRC infrastructure
- » Potential to include more partners

#### CONS:

- There will need to be meaningful oversight of Tribal subcommittee involvement in state-led MMRCs
- » Successful and effective collaboration may be dependent on the Tribes' relationship with state
- » Only 40 states currently have established MMRCs, so this option is not available across the United States

# AREA-WIDE MMRCS:

### IHS Area-wide MMRCs represented by multiple Tribes with the potential to be led and/or organized by Area Indian Health Boards.

# CONSIDERATIONS:

### PROS:

- » Tribal Epidemiology Centers (TECs) may have the data capacity to support an MMRC
- » Resources can be pooled together within an area
- » Eliminates the burden on individual Tribes
- » Ability to leverage existing relationships with Area Indian Health Boards and IHS staff to implement recommendations created from MMRC reports
- » Greater potential of impact on state policies

### CONS:

- » May take longer to establish and organize a committee » Accessing death certificates from the state could pose a barrier
  - » Turnover in Tribal leadership may shift opinions and/or require repeated training
    - » Need to coordinate with multiple state data systems

# **NATIONAL MMRC:**

One National, Tribally-led MMRC that would review all Al/AN maternal death cases.

### CONSIDERATIONS:

#### PROS:

POTENTIAL

MMRC

MODELS

3

- » Larger number of cases allows the committee to meet more often
- » Possibility to engage with IHS leadership on recommendations
- » National scope for policy change
- Increased access to resources

### CONS:

- » Unclear authority on gathering medical records and death certificates from each state
- » It could take longer to gather information on each maternal death
- » Less community participation and knowledge
- » It may be difficult to translate recommendations into actions

# Summary of Feedback from the Convening

| Major Theme                                    | Subtheme   | Summary   | Quotes from Participants  |
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| Priorities for<br>Advancing Maternal<br>Health | <ul> <li>Accessing<br/>Quality and<br/>Culturally<br/>Congruent Care</li> <li>Workforce<br/>Shortages</li> <li>Maternal Mental<br/>Health and<br/>Substance Use<br/>Disorders</li> </ul> | Priorities for Advancing Maternal Health was one<br>of the major themes that emerged from<br>discussions during the convening. It is essential<br>to prioritize access to comprehensive prenatal<br>and postnatal care, emergency obstetric services,<br>and culturally congruent care practices.<br>Additionally, workforce gaps in maternal care<br>present significant challenges in ensuring quality<br>and accessible healthcare services for pregnant<br>individuals in these communities. Participants<br>also indicated a need for prioritizing access to<br>care and resources for maternal mental health<br>and substance use disorder. | "You have to get your care in the<br>office with a provider that may not<br>know anything about you. This model<br>is common with a lot of OB's and<br>affects the quality of care patients<br>receive. This can lead to [health]<br>complications."<br>"Currently we are only staffed with a<br>Maternal & Child Health nurse and<br>doula. We lost our aide due to lack of<br>transportation [to the facility]. The<br>primary need now is an increase in<br>staff. We can't focus on any other needs<br>due to lack in staff." |
| Guiding Vision                                 | <ul> <li>Grounded in<br/>Tribal<br/>Sovereignty</li> <li>Holistic Reviews<br/>with Interview<br/>Data</li> <li>Cultural<br/>Considerations</li> </ul>                                    | Attendees discussed key components for the<br>process of creating and conducting Tribal<br>Maternal Mortality reviews. Grounding this work in<br>Tribal sovereignty is essential. Respecting Tribal<br>sovereignty in the context of MMRCs involves<br>recognizing and acknowledging the inherent right<br>of Tribal nations to govern themselves and make<br>decisions that affect their communities.<br>Participants indicated a need to humanize the   | "What resonated for me is the<br>importance of having a framework that's<br>rooted in cultural values. Before thinking<br>about whether the MMRC process works,<br>we need to think about some of the core<br>things that resonate throughout all Tribal<br>communities so they can see themselves  |

|                       | for Reviewing<br>Cases  | data used in the review process. Including<br>interview data provides more context and shares<br>the full story for reviews. Finally, there are several<br>cultural considerations when developing Tribal<br>MMRCs. Respect for Tribal traditions and<br>customs, such as involving Elders, Grandparents<br>and Traditional Healers in decision-making<br>processes and ceremonies is essential to<br>establish trust and cooperation.   | in this work."<br>"What do we mean/ how do we define<br>data? How do we see a person? Move<br>away from repeated information that<br>perpetuates stereotypes."<br>" Story is sacred should honor the<br>person [in a] responsible and culturally<br>appropriate way." |
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| Scope for Tribal MMRs | <ul> <li>Address Root<br/>Causes and<br/>Solutions</li> <li>Intersections<br/>with Maternal<br/>Morbidity and<br/>Infant Mortality</li> </ul> | This section highlights 3 key themes identified for<br>the scope of Tribal MMRCs discussed by<br>participants. MMRCs present opportunities to<br>advocate for system- wide reform, community<br>engagement, and multi-sector collaborations.<br>Addressing root causes during the MMRC process<br>leads to comprehensive solutions that pave the<br>way for lasting improvements in maternal health<br>outcomes for AI/AN communities. Attendees<br>discussed combining analyses from MMRCs with<br>analyses and dissemination of information on<br>severe maternal morbidity as one strategy to<br>cross-promote maternal health information and<br>provide partners with information for action. In<br>addition, attendees spoke to the importance of<br>using information from maternal case reviews<br>alongside information from other mortality<br>reviews, especially infant or child case review<br>processes. | "Focus on root causes and solutions,<br>knowing that there's an avenue to get<br>to solutions that are focused on<br>addressing root causes."<br>"We have to go more upstream to reach<br>the best solution and address the systems<br>change."                       |
| Partners Needed       | <ul> <li>Tribal<br/>Epidemiology<br/>Centers (TECs)</li> <li>Tribal Leaders</li> </ul>  | This section highlights the 4 key partner groups<br>that emerged in discussions for advancing work<br>around Tribal MMRs. TECs can support<br>infrastructure and systems development efforts   | "If no state MMRC exists, TECs can<br>take the lead to identify cases and<br>collect data necessary for review<br>and review the cases using an area-   |

|   | Tribal Members   | when developing Tribal MMRCs. If given the  | wide Tribal MMR model."  |
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|   | <ul> <li>Tribal Members<br/>on Existing<br/>MMRCs</li> <li>Elders and<br/>Grandparents</li> </ul>  | <ul> <li>when developing Tribal MMRCs. If given the proper data access and management authority, TECs can intervene and streamline data collection and dissemination for MMRs.</li> <li>Additionally, 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.</li> <li>When developing Tribal MMRs, it is imperative to engage Tribal members currently serving on MMRCs to learn from their experiences and integrate perspectives on committee member capacity and expertise. Finally, Elders and Grandparents hold a sacred and revered position within Native and Tribal communities. Developing</li> </ul> | wide Tribal MMR model."<br>"Native Approach: ask<br>Elders how to navigate<br>conversations about<br>death/-MMRC. Elders<br>are the priority<br>[partners] for preventing<br>maternal mortality."  |
|   |  | spaces on MMRCs to integrate the perspectives<br>of Elders and Grandparents allows for an MMRC<br>process guided by their shared wisdom,<br>respected roles in their communities, and diverse<br>cultural and traditional knowledge.  |  |
| Barriers for<br>Developing Tribal<br>MMRs | <ul> <li>Fragmented<br/>Health Systems</li> <li>Limited Data<br/>Sharing<br/>Agreements</li> <li>Insufficient or<br/>Unsustainable<br/>Funding</li> <li>Data Distrust</li> </ul> | This section highlights 4 major barriers that were<br>raised in discussions for developing Tribal MMRs.<br>Al/AN women often confront fragmented care<br>when attempting to access maternal health<br>services, reflecting structural deficiencies in the<br>healthcare system. With high rates of referrals<br>and limitations in available facilities, Al/AN<br>communities are more likely to experience<br>fragmented care when seeking maternal health<br>services. The quality and accessibility of data  | "Continuity of care is lacking<br>systems are not talking to each<br>other —there is no idea where<br>moms are ending upmany women<br>see fragmented care, there is no<br>communication across the medical<br>records, so many missed<br>opportunities." |
|   |  | used for reviews is essential for developing<br>effective recommendations. Potential Tribal   | <i>"Strategies of getting the data outside of the current system and getting data to Tribes to make their</i>  |

|             |   | MMRCs must ensure data is collected, used, and<br>shared in a way that respects Tribal sovereignty,<br>customs, beliefs, and standards. Funding also<br>plays a crucial role for sustaining the Tribal MMR<br>process. Insufficient or unsustainable funding<br>can limit the resources available for data<br>collection, analysis, and dissemination of<br>findings, thereby hindering the ability of MMRCs<br>to fulfill their mandate effectively. Data distrust is<br>a complex issue that affects the quality of data<br>used in reviews, however, actively involving AI/AN<br>communities in decision-making processes and<br>prioritizing respectful, collaborative relationships<br>can build trust within communities. | own decisions – need initial funding<br>to do that, lay the infrastructure and<br>strategies."<br>"Fear of MMRIA data being<br>weaponized against Tribenot a<br>lot of trust and not willing to<br>share data because not sure<br>where the data will go."   |
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| MMRC Models | <ul> <li>Model 1: Tribe-<br/>specific MMRCs</li> <li>Model 2: Area-<br/>wide MMRCs</li> <li>Model 3: Blended<br/>Tribal/State</li> <li>Model 4:<br/>National Tribal<br/>MMRC</li> </ul> | Participants shared feedback, thoughts, and<br>ideas around existing MMRC models and the four<br>potential Tribal MMR models (see figure below).<br>Overall, participants indicated a single model<br>alone cannot effectively address the complex and<br>diverse considerations for developing Tribal<br>MMRs.   | Model 1:<br>But what about not enrolled<br>members? Many live in urban areas<br>and reservations. What about family<br>that's married in?<br>For [my] Nation: a lot of it is going<br>to be fear. If we're just looking at<br>our health system, easy to point<br>fingers at providers [and say] "you<br>didn't offer this or you didn't do<br>that." Also, small numbers – will<br>find relatives, friends, family. [It]<br>gets very personal.<br>Model 2:<br>This area Tribal MMRC centers<br>culture, and focuses on prevention,<br>connection to strengths and shares |

|                                |  |   | measures. Ideally, area-wide Tribal<br>MMRCs are supported by National<br>coordination, technical support.<br>If state MMRCs exist, partner with<br>them to identify AI/AN cases and<br>collect necessary data. Then, these<br>cases move to area-wide Tribal<br>MMRC, with representation from<br>medical, grass-roots, Tribal, urban,<br>etc. |
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|                                |  |   | Model 3:  |
|                                |  |   | States don't play nice with data,<br>maybe giving up power if they give<br>up data to the tribes and how to<br>overcome that with different states<br>that have different relationships<br>with tribes.   |
|                                |  |   | Model 4:  |
|                                |  |   | Have to get data from state so you<br>can correct misclassification if do a<br>national level; CDC/IHS Cancer<br>national data linkage as an example.   |
|                                |  |   | National model would work with region-wide groups.  |
| Additional Models/<br>Feedback | <ul> <li>Tribal<br/>Consortium<br/>MMRC</li> </ul> | One participant proposed a model not currently<br>represented among the Potential Tribally led<br>MMRC models. This was favorable and received<br>positive feedback at the convening. | "All of the Tribes in the state form a<br>consortium for Native Women's Health<br>Review.""Tribes & UIO's serve as pass-<br>through for states to be funded for Tribal<br>abstracting, interviewing, etc."  |

# Conclusion

The convening brought partners together that work on funded CDC projects, who are exploring the feasibility of Tribal MMR, and other innovators and experts in Tribal Maternal and Child Health. There is notable momentum in the work. Convening organizers felt the passion and dedication of attendees, and the connections made during our time together resonate. The convening 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. Developing an effective Tribal MMR process requires continued investigation into the current challenges and successes Tribes and Tribal-serving organizations face when addressing maternal health improvements.

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.

NIHB and CDC MMPT learned they need to continue engaging partners in strategic planning and expand outreach to collaborate with Tribal Leaders and Tribal Epidemiology Centers, particularly. To move forward with Tribal MMR development, time and space is needed for exploration and planning, as capacity in this area builds. And we learned that flexibility is needed in terms of the potential Tribally led MMRC models in future work.