National Indian Health Board

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# TRIBAL MATERNAL MORTALITY REVIEW LAW AND POLICY CONSIDERATIONS



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Maternal mortality review is a public health tool that commonly has three goals: 1) to document more accurate data on incidents of deaths that occur during or within one year of pregnancy; 2) to identify factors that contribute to preventable deaths; and 3) to publish recommendations for policies, systems changes, and strategies to address the contributing factors and improve maternal health outcomes.

Over the past five years, in partnership with the Centers for Disease Control and Prevention (CDC), the National Indian Health Board has held several national convenings to explore Tribal maternal mortality review. These included participation from Tribal maternal health experts. Tribal and federal partners. representatives from Tribal community organizations, and Native advocates from across the nation, including partners from Area Indian Health Boards and Tribal Epidemiology Centers. Several themes consistently emerged from these convenings:1 1) the importance of ensuring the effort is grounded in Tribal sovereignty and cultural values; 2) the urgency of making changes at multiple levels to save lives amidst this maternal mortality crisis, and

https://www.nihb.org/resources/2023%20Tribal%2 OMMR%20Convening%20Report-%20PUBLIC.pdf <sup>2</sup> Centers for Disease Control and Prevention.

(2024, August 7). Enhancing reviews and surveillance to eliminate maternal mortality. Maternal Mortality Prevention.

https://www.cdc.gov/maternal-

mortality/php/erase-mm/index.html

<sup>3</sup> Only 4 states require any Tribal representation on their MMRC (Guttmacher Institute. (2024, February 13). *Maternal mortality review committees*.

https://www.guttmacher.org/state-

policy/explore/maternal-mortality-review-

<u>committees</u>.) A handful of others may incidentally include some Tribal representation.

3) the need to ensure the process maintains a holistic, culturally congruent approach to data and case review – including careful consideration of cultural protocols around how to appropriately collect data, conduct interviews, talk about death, and use data. In addition, participants recommended improving Tribal representation on existing maternal mortality review committees (MMRCs).

An approach to maternal mortality review based on these principles would be a significant departure from current MMRC programs. To start with, Tribal MMRC does not yet exist. All current MMRCs are run by states, territories, or cities. <sup>2</sup> and most large lack Tribal representation.<sup>3</sup> Additionally, while MMRCs are distinct from hospital peer review committees or complaint investigations, 4 the CDC frames maternal mortality review as essentially a part of the continuous quality improvement cycle for health care systems. 5 MMRCs have traditionally focused on medical causes of maternal 6 and mortality. resulting recommendations have focused on changes in hospital-level policies and practices.

https://www.cdc.gov/maternal-

mortality/php/mmrc/key-components.html <sup>5</sup> Centers for Disease Control and Prevention. (2024, May 15). *Maternal Mortality Review Committee Logic model*. Maternal Mortality Prevention. https://www.cdc.gov/maternalmortality/php/mmrc-logic-model/index.html <sup>6</sup> See e.g. Thumm, E. B., Rees, R., Nacht, A., Heyborne, K., & Kahn, B. (2022). The Association Between Maternal Mortality, Adverse Childhood Experiences, and Social Determinant of Health: Where is the Evidence? *Maternal and Child Health Journal*, 26(11), 2169–2178. https://doi.org/10.1007/s10995-022-03509-z

<sup>&</sup>lt;sup>1</sup> National Indian Health Board. (2024, November). 2023 convening on Tribal maternal mortality review: Meeting summary.

<sup>&</sup>lt;sup>4</sup> CDC. (2024, May 15). *Authorities and protections to support maternal mortality review*. Maternal Mortality Prevention.

Some MMRCs have begun to look at nonmedical causes of maternal deaths, like unintentional overdose. There has also been some movement toward more discussion of root causes of poor maternal health outcomes, including examining social drivers of health. However, most MMRCs maintain a healthcare focus in their recommendations, rather than a public health or holistic perspective. Furthermore, current MMRCs do not consider Indigenous Determinants of Health when conducting maternal death reviews, despite the disproportionately high rates of pregnancyrelated deaths among American Indians and Alaska Natives (Al/AN). The Indigenous Determinants of Health provide a model for considering the combined positive and negative forces - both historical and current - that powerfully influence health outcomes for Native peoples. <sup>7</sup> Without understanding these Indigenous-specific factors, recommendations intended to reduce maternal mortality will be insufficient for advancing equity for AI/AN birth givers.8

Since 2018, the United States has invested heavily in MMRCs as a primary strategy for improving maternal health. However, rates of maternal deaths continue to worsen, <sup>9</sup> particularly among Al/AN birth givers. In 2021, the Al/AN rate of pregnancy-related deaths was nearly 5 times the rate for White birth givers.<sup>10</sup> These staggering outcomes suggest that this strategy is falling short of accomplishing its

https://www.nihb.org/resources/Tribal%20PN3%20 Policy%20Agenda.pdf aims. The current MMRC models (and recommendations produced from state-centric, hospital-focused MMRCs) are not meeting the needs of Tribes and Tribal communities. Establishing Tribal maternal mortality review programs that deeply understand the cultural and historical context of American Indian and Alaska Native persons could substantially improve development of effective recommendations for improving maternal health outcomes in Indian Country.

However, the uniqueness of Tribal maternal mortality review also means that questions around legal authorities and necessary policy supports will also be distinct, and sometimes more complex, compared to state MMRC programs. This white paper serves as an introduction to some of the law and policy issues that a Tribe or Tribal organization may need to consider when beginning maternal mortality review. As such, it will not be exhaustive, does not constitute legal advice, and does not feasibility. Tribes and Tribal evaluate organizations are encouraged to use this resource as a starting point for discussions with their own leadership and legal counsel when seeking to establish Tribal maternal mortality review.

For a condensed overview of law and policy issues to consider while developing a Tribal MMRC, see Appendix A.

For a glossary of key terms, see Appendix B.

https://www.cdc.gov/maternalmortality/php/pregnancy-mortalitysurveillance/index.html

<sup>10</sup> Centers for Disease Control and Prevention. (2024, November 14). *Pregnancy mortality surveillance system: Pregnancy-related mortality ratio by race-ethnicity: 2017–2019, 2020, and 2021*. Maternal Mortality Prevention.

https://www.cdc.gov/maternalmortality/php/pregnancy-mortalitysurveillance/index.html

<sup>&</sup>lt;sup>7</sup> United Nations Economic and Social Council: Permanent Forum on Indigenous Issues. (2023, January 13). *Indigenous determinants of health in the 2030 Agenda for Sustainable Development*. <u>https://www.nihb.org/resources/IDH%20UNPFII%2</u> OReport%20-%202023.pdf

<sup>&</sup>lt;sup>8</sup> National Indian Health Board. (2024, November). 2024 Tribal prenatal-to-three policy agenda: Charting a path to good health and wellbeing for American Indians and Alaska Natives, prenatal to age 3.(p. 6-8).

<sup>&</sup>lt;sup>9</sup> Centers for Disease Control and Prevention. (2024, November 14). *Pregnancy mortality* 

surveillance system: Pregnancy-related mortality ratio in the United States: 1987-2021. Maternal Mortality Prevention.

# 2.1 TRIBAL SOVEREIGNTY

Tribal nations have inherent sovereignty. 11 Sovereignty is the right and the power to selfgovern, and Tribal sovereignty has been repeatedly affirmed by the United States Supreme Court, the US Constitution, and hundreds of Indian treaties and federal statutes.<sup>12</sup> Tribal sovereignty is a foundational principle of federal Indian law, the body of law that defines the rights, relationships and responsibilities between Tribes, states, and the federal government. A Tribe's sovereignty includes an inherent authority or plenary and exclusive power over their members and their territory, subject only to limitations imposed by federal law.<sup>13</sup> Under their sovereignty, Tribes establish their own government structure, define their own citizenship, make and enforce laws about Tribal lands. environment. education, culture, and health, and manage associated data through their own systems. Executive Order 14112 is a recent example recognizing Tribal sovereignty and outlining the federal government's trust responsibilities. 14 Respecting Tribal sovereignty in the context of MMRCs means that federal and state programs supporting MMRCs recognize and acknowledge the inherent right of Tribal nations to govern themselves and make decisions that affect their communities. It means that non-Tribal MMRCs must obtain informed consent from Tribes before collecting or using the health data of Tribal citizens and should implement 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.

## 2.1.1 Public Health Authority

One of the legal foundations undergirding MMRCs is public health authority. Public health authority refers to the legal authority of a sovereign government to engage in public health activities to promote and protect the health of the people within its jurisdiction.<sup>15</sup> Tribal nations' inherent sovereignty is the legal basis for the status of Tribes as public health authorities.<sup>16</sup> A Tribe's public health authority exists regardless of whether a Tribe has established a public health department or has previously conducted public health activities.17 Tribes always have this authority. Tribes also do not depend on federal law or the United States government for their public health authority. It is an inherent function of their own sovereignty.

http://dx.doi.org/10.2139/ssrn.3759311

<sup>&</sup>lt;sup>11</sup> Cohen's Handbook of Federal Indian Law, §
4.01[1][a] (Nell Jessup Newton et al. eds., 2012).
<sup>12</sup> Getches, D. H., Wilkinson, C. F., Carpenter, K. A.,
Williams, R. A., & Fletcher, M. L. M. (2017). Cases

and Materials on Federal Indian Law (7th ed.). West Academic Publishing.

<sup>&</sup>lt;sup>13</sup> Tribes maintain "inherent powers of limited sovereignty which has never been extinguished." United States v. Wheeler, 435 U.S. 313, 322–3 (1978) (quoting F. Cohen, HANDBOOK OF FEDERAL INDIAN LAW 122 (1945)).

<sup>&</sup>lt;sup>14</sup> 14112: Reforming Federal Funding and Support for Tribal Nations To Better Embrace Our Trust Responsibilities and Promote the Next Era of Tribal

Self-Determination, Dec 6, 2023. Federal Register, 88 FR 86021.

<sup>&</sup>lt;sup>15</sup> Gostin, L. O., & Wiley, L. F. (2016). *Public Health Law: Power, Duty, Restraint* (3rd ed.). University of California Press.

<sup>&</sup>lt;sup>16</sup> Hoss, A. (2019). *A Framework for Tribal Public Health Law.* Nevada Law Journal: Vol. 20: Iss. 1, Article 4.

https://scholars.law.unlv.edu/nlj/vol20/iss1/4

<sup>&</sup>lt;sup>17</sup> Hoss, A. (2021, January 4). Tribes are public health authorities: Protecting Tribal sovereignty in times of public health crisis.

Tribal public health authority is, however, acknowledged by federal law.

Tribal organizations that are not governmental entities cannot claim sovereignty, and do not have public health authority, unless certain authorities have been granted to them by a government. For example, the 12 Tribal Epidemiology Centers (TECs) are designated by federal law as public health authorities for the purposes of the Health Insurance Portability and Accountability Act (HIPAA), which is an important federal law that governs data sharing of protected health information. <sup>18</sup> In the Indian Health Care Improvement Act (IHCIA), Congress further specifies the activities that fall under a TEC's congressionally authorized scope of work, including certain public health activities. 19 Several of these align closely with the purposes of maternal mortality review, including:

- collecting data related to the health objectives of Tribes
- assisting Tribes and Tribal organizations in identifying high priority health objectives and the services needed to achieve those objectives
- making recommendations to improve healthcare delivery systems

While TECs do not have the same broad, inherent public health authority as sovereign Tribal nations, this federal statute grants TECs authority to carry out these specified public health activities and to be treated as public health authorities for the purposes of accessing protected health information covered by HIPAA. IHCIA also states that when carrying out these activities, TECs must work at the request of and in consultation with Tribes.

https://www.ihs.gov/epi/tecs/public-healthauthority-tec/ Tribal governments also have the option to grant other entities, like inter-Tribal organizations, authority to carry out public health activities on behalf of the Tribe.

# 2.2 THREE SOVEREIGNS;

# INTERSECTING JURISDICTIONS

American Indians and Alaska Natives are simultaneously citizens of three sovereigns: the United States; their state of residence; and the Tribe in which they're enrolled. Understanding the roles, relationships, authorities, and jurisdictions of these three governments is critical for unraveling the complications that may come into play during Tribal maternal mortality review. At different points in the review process, the laws of any of these three jurisdictions may be relevant. In some cases, the jurisdiction or applicable law may be disputable until adjudicated by a court. As others have noted about the complexity of the Tribal context, "In practice, the potential for real conflicts of law and competing jurisdiction can exist, and there is limited case law on how civil jurisdictional principles may be applied in public health contexts."20

Additional complications exist for Tribal maternal mortality review because the public health infrastructure in the United States was developed with states at the center, with strong deference to state public health authority. So, although Tribes are sovereign nations with legal rights to conduct their own public health activities, carry out maternal mortality review, and access public health data, many federal and state systems and structures create substantial barriers preventing Tribes from exercising these rights as a practical matter.<sup>21</sup>

<sup>&</sup>lt;sup>18</sup> Indian Health Service. (n.d.). *Public Health Authority and TECs.* Division of Epidemiology and Disease Prevention.

<sup>&</sup>lt;sup>19</sup> Indian Health Care Improvement Reauthorization and Extension Act of 2009, 25 U.S.C. §1621m. (2009).

<sup>&</sup>lt;sup>20</sup> Hoss, "A Framework for Tribal Public Health Law," supra note 16

<sup>&</sup>lt;sup>21</sup> Field, C., Price, S., & Locklear, A. (2024). Barriers and opportunities for tribal access to public health data to advance health equity. *The Journal of Law Medicine & Ethics*, 52(S1), 39–42. https://doi.org/10.1017/jme.2024.45

# 2.3 PREVENTING MATERNAL DEATHS ACT OF 2018

Passage of the Preventing Maternal Deaths Act of 2018 (PMDA)<sup>22</sup> launched a renewed national effort to establish sustainable, standardized MMRCs. As stated in the Act, its purpose is "to establish or continue a [f]ederal initiative to support [s]tate and [T]ribal maternal mortality review committees, to improve data collection and reporting around maternal mortality, and to develop or support surveillance systems at the local, State, and national level to better understand the burden maternal of complications and mortality and to decrease the disparities among populations at risk of death and severe complications from pregnancy."

PMDA states that a federally funded MMRC program may be started by a state, a Tribe, or a Tribal organization, and lays out the minimal requirements to be eligible for this funding. (Tribes, under their own sovereignty, can create their own maternal mortality review programs that do not adhere to the requirements in PMDA if they are using alternative funding sources.)

Among other requirements, PMDA requires that federally funded MMRCs "demonstrate to the Centers for Disease Control and Prevention that such maternal mortality review committee's methods and processes for data collection and review...use best practices to reliably determine and include all pregnancy-associated deaths and pregnancy-related deaths, regardless of the outcome of the pregnancy." However, what constitutes "best practices" is not clearly defined, particularly for Tribes. The broad language of the statute leaves open the

https://www.congress.gov/bill/115thcongress/house-bill/1318/text

possibility that, as long as a Tribal maternal mortality review program is working towards the stated purpose "to better understand the burden of maternal complications and mortality and to decrease the disparities among populations at risk of death and severe complications for pregnancy," then there may be flexibility around how that goal is achieved. Tribes could potentially create maternal mortality review programs that include a variety of activities and may not look like state maternal mortality review models, but still adhere to all requirements in the authorizing language of the PMDA. Tribal flexibility will to some extent hinge on how CDC defines "best practices" 23 in this context.24

The Act includes additional flexibility for Tribes and Tribal organizations. It includes several references to the Secretary of the Department of Health and Human Services (HHS) or the implementing agency (CDC) cooperating with Tribes and Tribal organizations to develop the maternal mortality review program and requires consultation with Indian Tribes to establish and identify appropriate mechanisms for Tribes and Tribal organizations to be included in MMRC programs.

## 2.3.1 Policies Contained in a Notice of Funding Opportunity

CDC leads implementation of the PDMA and provision of associated appropriated funds, which are distributed through a Notice of Funding Opportunity (NOFO). A NOFO may include additional restrictions or requirements to be eligible for funding, beyond those in the PMDA. For example, the CDC NOFO issued in

<sup>24</sup> CDC's current guidance on best practices for MMRC can be found at <u>CDC.gov/erasemm</u>, although to date there is little mention of Tribes.

<sup>&</sup>lt;sup>22</sup> Preventing Maternal Deaths Act of 2018. 42 U.S. Code § 247b–12.

<sup>&</sup>lt;sup>23</sup> Tribes frequently express concerns that federal agencies often define "best practices" in ways that discount the value and legitimacy of Indigenous Ways of Knowing and Traditional Knowledges, privileging instead Western epistemologies and academic literature that has historically neglected and excluded Tribes. Tribal leaders point out that

<sup>&</sup>quot;best practices" designed by outsiders for use with other populations are unlikely to be the most effective or culturally appropriate practices for Tribes. Tribes are then left with the choice of either forgoing federal funding, or submitting to "best practices" that were not designed by, for, or with their Tribal communities.

2019 <sup>25</sup> for the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) program added requirements that applicants must (among other things):

- "Abstract and enter comprehensive information about all deaths potentially related to pregnancy...into the Maternal Mortality Review Information Application (MMRIA)" data system created by CDC.
- Provide "evidence of the ability to share data with CDC through MMRIA" and allow for "CDC examinations of recipient MMRIA data on a routine basis."
- "Document committee decisions about a reviewed death in MMRIA consistent with [CDC] guidance"
- Provide documentation of collaboration (e.g. a Memorandum of Understanding) with certain state agencies, including

State Vital Records Offices; State Medicaid Offices; State Medical Examiner/Coroner Offices; and State Public Health Agencies. (Note: state applicants were not required to demonstrate any such collaboration with Tribes.)

NOFO also describes the funding The instrument type as a Cooperative Agreement, meaning it requires "CDC's substantial involvement in this program" throughout the period. entire funding While specific requirements may be different in future NOFOs, requirements like those used in 2019<sup>26</sup> may raise significant sovereignty concerns for Tribes (particularly by limiting Tribes' ability to protect sensitive data), in addition to reducing Tribes' flexibility to use the funds in ways that may be most culturally appropriate and effective for achieving the PMDA's stated goal: "to better understand the burden of maternal complications and mortality."

# **3** MATERNAL MORTALITY REVIEW TO ACTION CYCLE

Based on PMDA authorizing language and associated appropriations, CDC's ERASE MM program has developed a specific model for standardized MMRCs and a systematic process. To facilitate MMRC functions and support centralized reporting, CDC has also developed the Maternal Mortality Review Information Application (MMRIA, pronounced "Maria"), a CDC-hosted data system designed to provide "a common data language." The CDC MMRC model and data system were originally designed for non-Tribal programs (primarily states), without input from Tribes. While this paper focuses on the CDC-recommended process, Tribes, under their own authority, may choose to conduct their own maternal mortality review using a different model or process. Tribes should obtain legal counsel to understand possible legal complexities of any alternative maternal mortality review process they wish to pursue,

<sup>&</sup>lt;sup>25</sup> Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion (2019). Notice of Funding Opportunity (NOFO) Title: "<u>Preventing Maternal</u> <u>Deaths: Supporting Maternal Mortality Review</u> <u>Committees</u>." Agency NOFO Number: CDC-RFA-DP19-1908.

<sup>&</sup>lt;sup>26</sup> Similar requirements also appeared in the 2024 NOFO for the same program. Centers for Disease

Control and Prevention, National Center For Chronic Disease Prevention And Health Promotion. (2024, May 23). Notice of Funding Opportunity: Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (CDC-RFA-DP-24-0053).

https://www.grants.gov/search-resultsdetail/349738

particularly concerning data ownership, confidentiality, and privacy.

Before beginning, it is worth noting that according to CDC's logic model for how the activities of an MMRC lead to improved population health, success relies on these two assumptions: 1) Jurisdictions have a task force, perinatal quality collaborative, or other MMRC infrastructure to implement recommendations; and 2) Jurisdictions have a funded, functioning system for conducting quality autopsies. In addition, CDC's logic model cites geography and political will and support as significant contextual factors that can impact the operation and success of an MMRC. These factors will be especially important for Tribes to consider when embarking on maternal mortality review.

The following sections will follow the steps within CDC's action cycle for Maternal Mortality Review Committees. <sup>27</sup> For each step of the action cycle, we will discuss the laws and policies that may become relevant for a Tribe or Tribal organization leading maternal mortality review.

# 3.1 ESTABLISHING MATERNAL MORTALITY REVIEW

Before launching the action cycle, the first step is the formation of an MMRC. What laws or policies may be important to consider to establish maternal mortality review? Efforts to establish or strengthen a MMRC should include a review of what protections and authorities are already in place. Careful consideration of the laws and policies needed to clarify authorities and protections can reinforce MMRCs' role as a public health surveillance process.

A Tribe may launch any form of maternal mortality review under their own sovereignty and

inherent public health authority. A specific Tribal law or resolution establishing the MMRC will provide the strongest policy support and ensure sustainability and clarity. States commonly pass MMRC authorizing legislation to provide structure, clarity, authorities, and protections. A Tribe would similarly benefit from creating a Tribal maternal mortality review law that could preemptively address many of the legal issues that could arise throughout the action cycle. One well-designed authorizing law can be effective in preventing many potential legal complications.

On the other hand, to clarify authority to operate on behalf of one or more Tribes, **a Tribal organization** may need a resolution from each Tribe in the covered area stating support for this activity. This is necessary to clarify legal authorities, respect Tribal sovereignty, and to be eligible for federal funding under the ERASE MM program. This is also true of a Tribal organization planning to create a national MMRC: a resolution from every Tribe stating support and clarifying authorities or permissions may be necessary.

Tribal resolutions establishing an MMRC can also provide certain legal protections for the committee to ensure the sustainability of the program and promote cooperation from others who may be involved, like healthcare providers <sup>28</sup> who hold important medical records. CDC recommends that the authorizing law for an MMRC also include clarification or protections related to confidentiality and immunity, <sup>29</sup> and has in the past required funding applicants to provide evidence of "legal immunity or other mechanisms used to protect review committee members from subpoena and personal liability based on activities during and within the scope of participation in the MMRC

 <sup>&</sup>lt;sup>27</sup> CDC. (2024, August 7). Enhancing reviews and surveillance to eliminate maternal mortality.
 Maternal Mortality Prevention. <u>CDC.gov/erasemm</u>
 <sup>28</sup> In this context, like most legal contexts,

<sup>&</sup>quot;healthcare provider" is an umbrella term that

refers to any person, facility, or organization that provides healthcare.

<sup>&</sup>lt;sup>29</sup> CDC, "Authorities and protections," supra note 4

review process." <sup>30</sup> These concepts are described more in following sections.

## 3.1.1 Scope

For clearest authority, the scope of the review committee should be clearly defined in the authorizing law. Establishing the scope begins with clarifying the definition of "maternal mortality" that will be used to identify cases to be reviewed. Many state MMRC laws include language similar to CDC's definition of pregnancy-associated deaths: "deaths during or within a year of pregnancy."

Questions of scope are particularly important to clarify for Tribal MMRCs because, unlike for states, geographic residency may not align with citizenship. For example, will the MMRC review cases only of Tribal members? Or all Al/AN cases within a geographic area? Or all residents within a certain jurisdiction (like a reservation), regardless of Al/AN status?

When establishing the scope, a Tribe or Tribal organization will need to carefully consider both the purpose of the MMRC and the feasibility of the desired or proposed scope. Considering purpose includes consideration of a Tribe's sphere of influence for implementing (or advocating for implementation of) any recommendations that result from the maternal mortality review process. Feasibility may be closely tied to legal authorities accessible to the MMRC, based on how it was founded. Feasibility may also be influenced by the laws, policies, and willingness to collaborate of surrounding jurisdictions. A Tribal MMRC also has the option to specify that cases with related pending litigation or criminal allegations will be excluded from review.

A Tribe may also decide to expand the scope beyond maternal mortality. A Tribe may, for example, determine that it is more culturally appropriate, feasible, or effective to include fetal and infant death reviews under the same committee.<sup>31</sup> A Tribe may also be interested in examining or tracking instances of maternal morbidity (sometimes also called 'severe maternal injury'). According to the Guttmacher Institute, MMRC laws in 12 states include reviewing or tracking maternal morbidity cases within the committee's scope of work.<sup>32</sup> In some cases, these laws allow but do not mandate reviewing maternal morbidity cases or tracking trends in maternal morbidity. While CDC considers MMRC to be programmatically distinct and a wholly separate process from either maternal morbidity review <sup>33</sup> or fetal/infant death review, Tribes may choose their own approach.

## 3.1.2 Empaneling

The next important question related to establishing an MMRC is deciding who will sit on the committee. The legal term for establishing the members of a committee is "empaneling." According to the Preventing Maternal Deaths Act, a federally funded MMRC must include "multidisciplinary and diverse membership that

<sup>&</sup>lt;sup>30</sup> CDC, National Center for Chronic Disease Prevention and Health Promotion (2019). Notice of Funding Opportunity (NOFO) Title: "<u>Preventing</u> <u>Maternal Deaths: Supporting Maternal Mortality</u> <u>Review Committees</u>." Agency NOFO Number: CDC-RFA-DP19-1908.

<sup>&</sup>lt;sup>31</sup> For an example from state law, see Maine's MMRC authorizing law (22 MRSA : §261) which established a "Maternal, Fetal, and Infant Mortality Review Panel" which must "review the deaths of all women during pregnancy or within one year of giving birth, the majority of cases in which a fetal death occurs after 28 weeks of gestation and the majority of deaths of infants under one year of age."

<sup>&</sup>lt;sup>32</sup> Guttmacher Institute. (2024, February 13). Maternal mortality review committees. https://www.guttmacher.org/statepolicy/explore/maternal-mortality-reviewcommittees. (This helpful resource includes a comprehensive review of state MMRC laws.)
<sup>33</sup> To learn more about what maternal morbidity review can look like from an obstetric hospital perspective, see: American College of Obstetricians and Gynecologists. (2016, September). Severe maternal morbidity: Screening and review. https://www.acog.org/clinical/clinicalguidance/obstetric-careconsensus/articles/2016/09/severe-maternalmorbidity-screening-and-review

represents a variety of clinical specialties, state, Tribal or local public health officials, epidemiologists, statisticians, community organizations... and... organizations that represent the populations... that are most affected by pregnancy-related deaths."

A Tribal MMRC could further specify who must be on the committee through the authorizing Tribal law or a committee charter. A committee charter does not have the force of law, but can clarify how the committee will be run.<sup>34</sup>

When considering provisions around empaneling, these questions may be helpful to consider:

- How many people will serve on the MMRC?
- How will members be chosen?
- What subject matter expertise, professional disciplines, or perspectives will be represented in committee membership to ensure holistic and culturally congruent reviews?
- Will committee membership include any requirements for specific demographic or geographic representation?
- Will committee membership specifically include elders, traditional healers, or other community leaders or knowledgekeepers?

## 3.1.3 Confidentiality Protections

Confidentiality protections are important to support the functioning of an MMRC by safeguarding participation and data sharing. The term "confidentiality" can be used to refer to two different types of protections.

One type of confidentiality protection has to do with ensuring that committee members do not disclose identifying information or inappropriate information about committee activities to anyone outside the committee. This type of protection is required to be eligible for federal MMRC funding. As stated in the Preventing Maternal Deaths Act, "States, Indian tribes, and tribal organizations participating in [federally funded MMRC] shall establish confidentiality protections to ensure, at a minimum," that there is "no disclosure by the maternal mortality review committee, including any individual members of the Committee" and that "no information from committee proceedings, including deliberation or records, is made public unless specifically authorized under State and Federal law ."

Many state MMRC laws also include another form of confidentiality, which prohibits MMRC data, proceedings, and findings from being subject to subpoena or discovery, or admissible as evidence, for civil or criminal court cases. This second definition of confidentiality ensures the MMRC doesn't get enmeshed in cases like medical malpractice lawsuits or criminal allegations of illegal abortion, and instead can focus on its mission of preventing pregnancyrelated deaths. Tribal MMRCs would similarly benefit from such protections.

Unfortunately, the matter is more complicated for Tribes, since a lawsuit or criminal case connected in some way with an Al/AN pregnancy-related death is most likely to be filed in a state or federal court (not a Tribal court).<sup>35</sup> An MMRC or its members, although not involved as a party, could potentially be subpoenaed for

<sup>&</sup>lt;sup>34</sup> For a state example, see Minnesota Department of Health. (2022, May). *Maternal Mortality Review Committee Charter.* 

https://www.health.state.mn.us/people/womeninfa nts/maternalmort/committee.html (Website

includes the state law authorizing and establishing MMRC, the committee charter, and additional details on MMRC operation.)

<sup>&</sup>lt;sup>35</sup> This is both because the majority of Al/AN births take place in non-Tribal healthcare facilities, and

because Tribal healthcare providers operating under a P.L. 93-638 contract/compact are covered by the Federal Tort Claims Act, so allegations of negligent medical care from a "638" Tribal provider would be filed against the United States, not the Tribe. See Indian Health Service. (2018, August). *The Federal Tort Claims Act.* Risk Management Manual: A Manual for Indian Health Service and Tribal Health Care Professionals. (3<sup>rd</sup> ed.).

records, documents, or depositions related to the case and thereby drawn into the court proceedings involuntarily. Although some appellate court decisions have, on the basis of Tribal sovereign immunity, supported Tribes' motions to quash third-party subpoenas in private civil suits, 36 the courts have also reiterated that "the answer to this issue is far from clear." 37 The issue of whether Tribal sovereign immunity applies gets even murkier if the subpoena is directed to Tribal employees (rather than the Tribe itself), <sup>38</sup> committee members who are not Tribal government officials at all, or an MMRC that may not be indisputably "an arm of the Tribe" 39 (for example, this may be disputed if the MMRC is run by a non-governmental Tribal organization). Assertion of Tribal sovereign immunity from third-party subpoenas is also uncertain in criminal cases, in which courts must balance any claims of sovereign immunity against a defendant's constitutional rights to due process.40

To strengthen protections for the MMRC, Tribes can explicitly state in the authorizing law that it is the Tribe's intent to extend Tribal sovereign immunity to the MMRC; that the MMRC acts as an "arm of the Tribe"; and that the MMRC is exempt from subpoena, discovery, etc. in Tribal courts for all civil and criminal cases. It is unclear whether these protections would be

https://www.ihs.gov/riskmanagement/manual/ma nualsection07/

 <sup>36</sup> Kiowa Tribe of Okla. v. Manufacturing Technologies, Inc. (1998) 523 U.S. 751, 754-758 [140 L.Ed.2d 981, 118 S.Ct. 1700]
 <sup>37</sup> Bonnet v. Harvest (U.S.) Holdings, Inc., 741 F.3d 1155, 1159 (10th Cir. 2014), quoting *Alltel Commc'ns, LLC v. DeJordy*, <u>675 F.3d 1100</u> (8th Cir.2012)

<sup>38</sup> <u>People ex rel. Owen v. Miami Nation Enterprises</u> (Cal: Supreme Court 2016)

<sup>39</sup> Compare, for example: <u>Breakthrough</u> <u>Management Group, Inc. v. Chukchansi Gold Casino</u> <u>and Resort (10th Cir. 2010) 629 F.3d 1173;</u> Runyon ex rel. B.R. v. AVCP, 84 P.3d 437, sufficient in all cases to keep a Tribal MMRC from third-party involvement in court proceedings. Additional protection to the Tribal MMRC could come from state laws exempting MMRC proceedings from subpoena and discovery in state courts.<sup>41</sup>

### 3.1.4 Immunity

According to CDC, immunity provisions can protect "MMRC members, as well as any witnesses or others providing information from personal liability based on activities during the review process."42 Because it reduces potential risk for those involved, like committee members or healthcare facilities who provide medical records, immunity facilitates full participation in the review process. But again, while a Tribal resolution can guarantee immunity from liability under Tribal law, it may not be able to provide sufficient protection for potential liability under state law (if, for example, a case involves non-Tribal healthcare providers). Like confidentiality protections, additional protection to the Tribal MMRC could come from state laws providing immunity to those involved in MMRC.

# 3.2 CASE IDENTIFICATION

Identifying cases requires access to data about deaths (e.g., vital records, hospital discharge data, and/or other clinical records where a death may be recorded). To facilitate this

2d 1163, 1171-72 (D.S.D. 2012) (US Dist. Court of South Dakota); <u>Gavle v. Little Six, Inc. (Minn. 1996)</u> <u>555 N.W.2d 284, 294</u>. See also: <u>People ex rel.</u> <u>Owen v. Miami Nation Enterprises</u> (Cal.2016), which states "The jurisprudence over how to apply the arm-of-the-state doctrine is, at best, confused" (quoting Mancuso v. New York State Thruway Authority (2d Cir. 1996))

<sup>40</sup> United States v. R. Enterprises, 498 U.S. 292, 301 (1991)

<sup>440 (</sup>Alaska 2004); J.L. Ward Assocs. Inc. v. Great Plains Tribal Chairmen's Health Bd., 842 F. Supp.

<sup>&</sup>lt;sup>41</sup> Existing state laws that provide confidentiality and immunity protections for MMRCs may be sufficient to protect future Tribal MMRCs operating in the state, depending on the specific language of the state law

<sup>&</sup>lt;sup>42</sup> CDC, "Authorities and protections," supra note 4

access, Tribes can use the Tribal law or resolution that created the MMRC to also specify that the MMRC has authority to access clinical and non-clinical records. This policy support not only ensures access to data held by entities under the Tribe's jurisdiction, but can also support data requests to non-Tribal entities and may be required for federal funding applications.<sup>43</sup> Data<sup>44</sup> access is one of the most important and potentially challenging areas of law for Tribal MMRCs, not only in this stage of the process, but throughout.

In this stage of the process, MMRC case identification is most reliant on access to accurate vital records, including data from registration of births, fetal deaths, and death reporting systems. Guidance shared by CDC to improve case identification states that, "Improved ascertainment of pregnancyassociated deaths may occur by linking death records of female decedents ages 10-60 years to pregnancy outcome information (birth or fetal death)." 45 As CDC explains, these records are linked by common information that is found on both the death certificate of the woman and an infant birth certificate or fetal death certificate. "using either deterministic or probabilistic linkage". Previous NOFOs for MMRCs have included a requirement to provide "evidence of

#### https://www.grants.gov/search-resultsdetail/349738

access to vital records", including death certificates, birth certificates, and fetal death certificates.<sup>46</sup>

## 3.2.1 Legal Authority to Access Data for Public Health Purposes

The source of the authority to access data – including vital records and medical records – will depend on whether the MMRC is run by a Tribe, a TEC, or another kind of Tribal organization.

**Tribes** have the authority to request and receive any data on their members from any source, Tribal or non-Tribal.<sup>47</sup> However, Tribes do not have the power to compel a non-Tribal entity to provide data, and so in those cases Data Use Agreements (DUAs) are useful tools for clarifying data sharing relationships and to ensure timely access to data. Access to data held by Tribal government agencies and Tribal healthcare facilities may be simpler, as Tribes can pass a law or resolution requiring certain Tribal entities to report pregnancy-related deaths directly to the MMRC.

**Non-governmental Tribal organizations** do not have inherent authority to access data, but they can be authorized to request and receive data with the support of Tribal resolutions, or in the case of TECs, other federal laws. DUAs and

<sup>&</sup>lt;sup>43</sup> E.g. The 2024 NOFO included the requirement that "Applicants must submit evidence of authority that provides the MMRC access to clinical and nonclinical records." Centers for Disease Control and Prevention, National Center For Chronic Disease Prevention And Health Promotion. (2024, May 23). Notice of Funding Opportunity: Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (CDC-RFA-DP-24-0053).

<sup>&</sup>lt;sup>44</sup> "Data" includes any and all types of clinical or non-clinical records that may be used or collected during the course of maternal mortality review, potentially including medical records; death, birth, and fetal death records; legal records; social services records; Medicaid claims data; and other data sources.

<sup>&</sup>lt;sup>45</sup> CDC. (2024, May 15). Reference Guide for Pregnancy-Associated Death Identification.

Maternal Mortality Prevention.

https://www.cdc.gov/maternal-

mortality/php/mmc/reference-guide.html <sup>46</sup> CDC, National Center For Chronic Disease Prevention And Health Promotion. (2024, May 23). Notice of Funding Opportunity: Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (CDC-RFA-DP-24-0053).

https://www.grants.gov/search-resultsdetail/349738

<sup>&</sup>lt;sup>47</sup> See: Substance Abuse and Mental Health Services Administration. (2024, May). Understand Unique Data Concerns When Working with Tribes. https://store.samhsa.gov/sites/default/files/cfribest-practices-tribal-considerations-pep24-07-006.pdf and U.S. Department of Health and Human Services. (2024, September 3). Draft Tribal Data Access Policy. https://cdo.hhs.gov/s/tribal-data

Memoranda of Understanding are important tools for these organizations as well, and may include the Tribal organization, the Tribes they are serving, and the state agency or healthcare entity holding the data.

## 3.2.2 Challenges in Data Access for Tribes and Tribal Organizations

Unfortunately, having authority to access the data does not always translate to data access in practice. Despite clear public health authority, Tribes and TECs have documented frequent, substantial barriers to accessing data that has been reported through multiple Tribal and federal reports.<sup>48</sup> Because most public health data (like vital records) are held in systems governed by states, states become the de facto gatekeepers of data access. As a 2013 report from the TECs describes, "Some states respond promptly to data requests, easily facilitate data sharing agreements to protect misuse of public data and do not charge a fee. Other states are limited in response and/or charge expensive fees to acquire public data. Access to AI/AN data across the U.S. is highly variable from one region to another."49

In addition to fees and unresponsiveness, three other types of barriers are common when Tribes seek data from a state: <sup>50</sup> 1) the state is purposefully uncooperative (often due to bias against Tribes or a long history of tense state-Tribal relations); 2) state privacy laws restrict data sharing with Tribes; <sup>51</sup> and 3) state officials and/or state legal counsel mistakenly believe Tribes do not have the authority to access the data or that sharing health data with the Tribe would be a violation of HIPAA.<sup>52</sup> (HIPAA is not a barrier to sharing protected health information with public health authorities; see further discussion under "Case Abstraction.")

These barriers can create extra difficulties for Tribal MMRCs attempting to meet the PMDA requirement for federally funded programs to establish processes "for confidential case pregnancy-associated reporting of and pregnancy-related deaths to the appropriate State or tribal health agency, including such reporting by: (i) health care professionals; (ii) health care facilities; (iii) any individual responsible for completing death records, including medical examiners and medical coroners; and (iv) other appropriate individuals or entities." The policies or agreements necessary for establishing such processes will further vary based on whether the reporting Tribal. federal. entity is state. or nongovernmental. Because reports relevant to Tribes may be coming from so many different types of entities, this step in the action cycle can become complex for Tribes. Table 1 explores the authorities and agreements that may be needed to access data from various sources depending on whether the MMRC is based in a Tribe, TEC, or other Tribal organization.

content/uploads/2016/03/TEC-Best-Practices-Book-2013.pdf

<sup>51</sup> See, for example, the impact of <u>California</u> <u>Invasion of Privacy Act</u> (CIPA) on public health data

access for California Tribes. <sup>52</sup> National Indian Health Board, Public Health in Indian Country Capacity Scan Report 2019, (2020).

<sup>&</sup>lt;sup>48</sup> See, for example, U.S. Government Accountability Office, "Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access," Report to Congressional Addressees, GAO-22-104698 (March 2022). <u>https://www.gao.gov/assets/gao-22-104698.pdf</u>

<sup>&</sup>lt;sup>49</sup> Best practices in American Indian & Alaska Native public health: A report from the Tribal Epidemiology Centers. (2013). <u>https://tribalepicenters.org/wp-</u>

<sup>&</sup>lt;sup>50</sup> Field, et al. (2024), s*upra* note 21

#### Table 1: What authorities & agreements are needed for Tribal MMRCs to access data? The MMRC requesting data is situated in a... Data Source Other Tribal Tribal Epidemiology Tribe Center (TEC) Organization Direct report Inherent Public Health Need: Data Use Need: DUA with each from Tribal Authority (PHA) includes Agreement (DUA) with Tribe served. medical right to data access. each Tribe served. Recommended: examiners. Recommended: Tribal Recommended: Tribal Tribal resolutions to coroners. resolution to require resolutions to require require reporting to health care Data Held By Tribal Entity reporting. reporting to MMRC. MMRC. providers Inherent PHA includes right to data access. Tribal Vital Need: DUA with each Need: DUA with each **Recommended:** Policies **Records office** Tribe served. Tribe served. clarifying how MMRC will access vital records. Referrals from Inherent PHA & data sovereignty means a state MMRCs Within statutory Need: Tribal function of TEC. right to data access. resolutions or MOU Tribal PHA is recognized to provide authority State Vital Recommended: Tribal under federal law. to access data. Records or resolutions or MOU other non-Recommended: Data Recommended: DUA supporting TEC data Data Held by Non-Tribal Entity clinical state Use Agreement (DUA) access; DUA with state. with state. sources with state. Federal law includes Inherent PHA & data TECs as PHA for the Need: Tribal Direct report sovereignty means a right purposes of HIPAA. resolutions or MOU from nonto data access. Tribal PHA Tribal health to provide authority Recommended: Tribal is recognized under federal

resolutions supporting

TEC data access.

to access data.

care providers

law.

# **3.3 CASE SELECTION**

The next phase of the action cycle is case selection. The criteria for which cases will be reviewed is set by the authorizing law or by the committee charter and reflects the defined scope of the MMRC (as discussed previously under "Scope").

A Tribal MMRC will have the most complete data if it is able to perform data linkages between vital records and either Tribal enrollment lists or a list of users of the Indian Health Service (depending on how the scope of MMRC was defined). This extra step is recommended due to the well documented and widespread issue of racial misclassification in data. which particularly affects American Indians and Alaska Natives. 53 (This is different from, and in addition to, the data linkage process described earlier to link death certificates with infant birth certificates/fetal death certificates.)

Tribes inherently have access to their own enrollment data to be able to perform such a linkage, but Tribal organizations would need explicit permission and a data use agreement with every Tribe and its service area to access enrollment data, which is very sensitive and protected data. Both a Tribe and a Tribal organization would likely need a data use agreement with the Indian Health Service (IHS) to access an up-to-date IHS user list.

# **3.4 CASE ABSTRACTION**

The next phase, case abstraction, is largely concerned with gathering all the relevant records and data to provide the necessary context and facts about what may have led to the death. According to CDC, "Case abstractors should be able to collect at a minimum vital records, hospitalization and prenatal care records, and autopsy reports."<sup>54</sup> CDC also notes that pointing to clear authority in law (like a Tribal resolution) "can facilitate compliance with data requests." However, as discussed previously, Tribal authority to request data may not always result in receiving all the data needed. The nuances based on data requester and data holder described in Table 1 apply for this phase as well.

## 3.4.1 HIPAA & Other Perceived Legal Barriers for Tribal Data Access

Data needed for the case abstraction phase include medical records and other protected health information. HIPAA, the law that governs the circumstances under which a covered entity may disclose protected health information, is sometimes mistakenly perceived to be a barrier to sharing data with Tribal public health authorities. However, HIPAA provides specific permission for covered entities to share data with all public health authorities, including Tribes and TECs.

Additionally, only health care providers, health plans, and health care clearinghouses are covered entities,<sup>55</sup> so HIPAA does not apply to data held by most government agencies (with some exceptions, e.g. Medicaid programs and programs providing clinical services are still covered entities). This is why HIPAA generally does not apply to non-clinical state records like vital records. Instead, other state or federal privacy laws may be relevant, depending on the type of data and the data source. Tribal sovereignty exists regardless of state law and should supersede state law. However, without enforcement mechanisms, states may still not cooperate with Tribal data requests. If records are needed from non-Tribal entities, familiarity with state privacy laws will be important for

<sup>&</sup>lt;sup>53</sup> Hoss, A. (August 19, 2019). Exploring Legal Issues in Tribal Public Health Data and Surveillance.
Southern Illinois University Law Journal, Vol. 44, 2019, Available at

SSRN: <u>https://ssrn.com/abstract=3439719</u> or <u>http:</u> //dx.doi.org/10.2139/ssrn.3439719

<sup>&</sup>lt;sup>54</sup> CDC, "Authorities and protections," supra note 4 <sup>55</sup> U.S. Department of Health and Human Services, Office for Civil Rights. (2024, August 21). Health information privacy: Covered entities and business associates. <u>https://www.hhs.gov/hipaa/forprofessionals/covered-entities/index.html</u>

establishing necessary DUAs or data sharing processes.

## 3.4.2 Subpoena Power for Data Access

Subpoena power can be another legal tool to support access to the data needed for case abstraction. Tribal law may be used to authorize a specified Tribal government official to subpoena records not provided voluntarily. <sup>56</sup> Challenges may still arise, however, if the entity holding the needed records is outside the Tribe's jurisdiction.

# 3.4.3 Informant Interviews

Another policy issue that may be relevant in this phase pertains to any informant interviews (e.g. of family members of the deceased) that may be conducted for further information about the case. The 2024 NOFO for ERASE MM programs<sup>57</sup> includes a requirement for involving informant interviews in the MMRC process. utilizing CDC guidance.<sup>58</sup> This guidance explains that interview data, "when obtained through qualitative. participant-centered research methods, can provide multi-faceted perspectives on the woman's care experiences before and surrounding her death." An MMRC seeking to use these kinds of research methods with AI/AN people must take extreme care, particularly with a topic as sensitive as maternal deaths. Tribes are frequently hesitant to allow this kind of research, due to the welldocumented and lengthy "history of governmental and researcher misuse of American Indian and Alaska Native data."59 To respect Tribal sovereignty and ensure all ethical protocols are met, anyone wanting to interview Tribal citizens will need explicit permission from

all relevant Tribes to do so, and must also verify whether additional processes (like Tribal Institutional Review Board (IRB) approval<sup>60</sup>) are needed. Critically, MMRC staff must obtain informed consent from both the Tribe and the interviewee. As the CDC guidance observes, the MMRC must also understand the laws/resolutions/agreements "governing their process to ensure confidentiality and legal immunity to potential informants; as well as when confidentiality may be legally required to be broken, such as when domestic violence is reported...Strong confidentiality protections can facilitate participation and disclosure in interviews."

For a Tribal MMRC to include interviews as part of their regular work, the law establishing the MMRC should clearly authorize the MMRC to conduct informant interviews and extend confidentiality and immunity protections to interviewees. Additionally, cultural competence and Tribal specific approaches to dealing with grief and maternal deaths in the community may necessitate diverging from CDC guidance for interview methods and protocols; Tribal participants in ERASE MM funding may need to seek special permission from CDC to implement culturally appropriate interview methods.

# 3.5 CASE REVIEW

The case review stage is when the committee reviews the abstract and evidence and discusses the factors that may have contributed to the death. The committee will also discuss whether and how the death might have been prevented. The structure, process, and agenda

https://www.cdc.gov/maternal-

mortality/media/pdfs/MMRC\_Informant\_Interview\_ Guide\_v1\_1\_tagged\_508.pdf

<sup>&</sup>lt;sup>56</sup> For an example from state law, see <u>Oklahoma</u> <u>Enrolled House Bill No. 2334</u>: "In any investigation relating to the functions of the Maternal Mortality Review Committee, the State Commissioner of Health may require production of, by subpoena, any records, including books, papers, documents, and other tangible things which constitute or contain evidence which the Committee finds relevant to the investigation and review, if the Committee has been unable to obtain the necessary information by requesting it. The production of records may be

required from any place in the state to be forwarded to the Committee."

<sup>&</sup>lt;sup>57</sup> CDC, "2024 NOFO" supra note 26

<sup>&</sup>lt;sup>58</sup> CDC. (2020, May 22). Informant interview guide for maternal mortality review committees.

 <sup>&</sup>lt;sup>59</sup> Hoss, "Exploring Legal Issues" supra note 51
 <sup>60</sup> CDC, "Informant interview guide" supra note 56

for the discussion may be outlined in the committee's charter or committee policies and procedures.

# 3.6 **R**EPORTING

After the committee has finished its deliberations and made determinations for each case (i.e., relatedness. preventability. contributing factors, and recommendations for prevention), the next step is to produce reports and data products. In this phase, it will be important to be mindful of data sovereignty and privacy protections. The authorizing law can provide important clarifications for reporting, including with whom data. findings. recommendations or reports may/must be shared, how often reports will be made, methods of dissemination. etc.

Privacy protections are also important, since Tribal MMRCs are likely to be working with extremely small case counts. The MMRC should include protocols in the committee's policies for how patient privacy will be protected and ensure deidentified information cannot be re-identified.

Any Tribe or Tribal organization considering applying for federal funding for MMRC should also be aware that the PMDA (and subsequent NOFOs) includes requirements related to sharing reports and data with CDC. Tribes should consider carefully if there may be any objections to these requirements related to concerns about data sovereignty.

# 3.7 RELEASE AND BEYOND

One of the primary purposes of MMRCs is to create policy and strategy recommendations to prevent future pregnancy-related deaths. Before beginning maternal mortality review, then, a Tribe or Tribal organization may find it useful to consider at what level or jurisdiction those policy changes and program strategies are likely to be needed. Part of this consideration will relate to where birth givers within the MMRC's population of focus receive care (e.g. Tribal, IHS, Urban Indian, or private healthcare providers; on or off Tribal lands; etc.). This will help to determine which policymakers and program partners are needed to implement the MMRC's recommendations. In this case, policymakers could refer to government officials at any level, or leadership within healthcare organizations, professional associations, and related systems.

In the case of state MMRCs, CDC recommends including those partners on the committee itself, as well as working before the release of a report to partner with decision makers, community organizations, and communities disproportionately impacted by maternal mortality to engage in implementation of MMRC recommendations. But because some of these key partners and decision makers are frequently non-Tribal, a Tribal MMRC may decide it would be inappropriate to include them on the committee itself, and may instead want to explore other options for partnership. For devising additional example. policy recommendations could be the role of a separate advisory committee or task force made up of MMRC members, Tribal community members, and non-Tribal decision makers with the power to influence recommended policy changes.61

# 4 CONCLUSION

By right and by necessity, Tribal maternal mortality review may look very different from current CDC recommendations for state MMRCs. When establishing a Tribal MMRC,

morbidity." New York also maintains a <u>Taskforce on</u> <u>Maternal Mortality and Disparate Racial Outcomes</u>.

<sup>&</sup>lt;sup>61</sup> For an example from state law, see <u>New York</u> <u>Public Health Law Section 2509</u>, which establishes "an advisory council on maternal mortality and morbidity," in addition to a Maternal mortality review board, "to review the findings of the board"

and "develop recommendations on policies, best practices, and strategies to prevent maternal mortality and

familiarity with state laws is essential, and legal counsel will be needed to address potential complications and jurisdiction issues. As described throughout this white paper, a variety of law and policy supports are necessary tools for creating and sustaining effective maternal mortality review.

# **5** APPENDIX A: OVERVIEW OF KEY CONSIDERATIONS

# 5.1 COMPONENTS TO PROVIDE CLARITY FOR TRIBAL MMRC

Depending on the structure of the Tribal MMRC, the clarifying elements in the table below may be included in these or other law/policy documents: Tribal law/resolution; Memorandum of Understanding between Tribes and/or Tribal organizations; MMR Committee Charter; DUA with state(s); DUA with healthcare providers/facilities; intergovernmental agreements/compacts; etc.

Component	Examples of Questions to Consider
Authority & Charge	<ul> <li>What activities are within the MMRC's authority to carry out?</li> <li>Will the MMRC reside within a government agency? Or within a different type of organization (e.g. a TEC or an inter-Tribal organization operating as a 501(c)3 non-profit) and conduct MMR on a Tribal government's behalf?</li> <li>What is the designated purpose(s) of the MMRC?</li> <li>Will the committee be charged with investigating every pregnancy-associated death (within the scope of the committee)?</li> <li>Will the MMRC be charged with determining preventability of deaths?</li> <li>Will the committee be mandated to investigate or consider racial or other health inequities?</li> </ul>
Funding & Staffing	<ul> <li>Will the MMRC rely on federal MMRC funding through CDC? (If yes, what additional restrictions &amp; requirements are included in the Notice of Funding Opportunity?)</li> <li>What staffing will be needed to support the committee's work?</li> </ul>
Process & Protocols	<ul> <li>What model will be used for conducting maternal mortality review?</li> <li>How will you ensure the MMR process will be culturally congruent?</li> <li>Will the MMRC use CDC's standardized process for MMRCs?</li> <li>Will the MMRC use the CDC-developed MMRIA data system?</li> </ul>
Committee Governance	<ul> <li>Who establishes the committee convening schedule?</li> <li>How are voting and decision-making procedures established?</li> <li>What are the protections against potential conflicts of interest?</li> </ul>
Defined Scope	<ul> <li>Which cases will this MMRC review? For example:</li> <li>What geographic scope will the committee cover?</li> <li>Will the MMRC review cases only of Tribal members? All Al/AN cases within a geographic area? All residents within a certain jurisdiction (regardless of Al/AN status)?</li> <li>Will the MMRC also be required or permitted to review cases of severe maternal morbidity or to track maternal morbidity data?</li> <li>Will the MMRC function in coordination with or in conjunction with other types of death reviews, like fetal and infant death reviews?</li> </ul>
Authority to Access Data and Records	<ul> <li>What data sources will be used in reviewing cases? (e.g. vital records, hospitalization and prenatal care records, autopsy reports, social service records, medical transport records, Medicaid data, etc.)</li> </ul>

	<ul> <li>What entities collect the data that will be needed for a holistic case review? (e.g. Tribal government, Tribal health facilities, Indian Health Service, private or nonprofit healthcare entities, state agencies)</li> <li>What is the basis of your MMRC's authority to request data?</li> <li>Does your MMRC have authority to mandate (and enforce) data sharing? Under this authority, which entities can be mandated to share data?</li> <li>What data use agreements (DUA) or memoranda of understanding (MOU) will you need to have in place to ensure efficient access to records and data?</li> <li>Are there any state privacy laws that may stymie necessary data access?</li> </ul>
Case Identification	How will the committee identify or be notified about cases?
and Notification Processes	<ul> <li>Does your MMRC have authority to mandate case reporting? From which entities?</li> </ul>
	<ul> <li>What DUAs or MOUs will you need to have in place to ensure timely identification/ notification of deaths?</li> </ul>
	<ul> <li>Do the relevant Tribe(s) and state(s) have funded, functioning systems for conducting quality autopsies?</li> </ul>
Committee	Where will the committee be situated organizationally? Who oversees
Organization &	the MMRC program?
Membership	How many people will serve on the MMRC?
(Empaneling)	<ul> <li>What subject matter expertise, professional disciplines, or perspectives can/must be represented in committee membership to ensure holistic and culturally congruent reviews?</li> </ul>
	<ul> <li>Will committee membership include any requirements for specific demographic or geographic representation?</li> </ul>
	How will members be chosen?
Confidentiality Protections for Members, Data, and Review Process	• Will committee members and staff be required to sign confidentiality agreements (i.e. agree not to disclose data, information, or committee activities outside of official reports)?
	<ul> <li>Do relevant states have laws providing confidentiality protections for MMRCs, so that data, information, and findings from MMRCs cannot be subject to subpoena or discovery, or introduced as evidence in civil or criminal court proceedings?</li> </ul>
	• Do relevant Tribes have laws/resolutions providing confidentiality protections for MMRCs, so that data, information, and findings from MMRCs cannot be subject to subpoenaed or discovery, or introduced as evidence in civil or criminal court proceedings?
	<ul> <li>Are confidentiality protections in place to protect witnesses (participants in informant interviews)?</li> </ul>
Immunity for Committee Members, Witnesses, and Record Providers	• Do relevant states have laws providing immunity for committee members and witnesses from being questioned in any civil or criminal proceeding or being held personally liable?
	<ul> <li>Do relevant states have laws providing immunity to ensure healthcare providers, health care facilities, and pharmacies are not held liable for civil damages or subject to any criminal or disciplinary action resulting from providing records to the MMRC?</li> </ul>

	<ul> <li>Do relevant Tribes have laws/resolutions providing immunity for committee members and witnesses from being questioned in any civil or criminal proceeding or being held personally liable?</li> <li>Do relevant Tribes have laws/resolutions providing immunity to ensure healthcare providers, health care facilities, and pharmacies are not held liable for civil damages or be subject to any criminal or disciplinary action resulting from providing records to the MMRC?</li> </ul>
Authorities for sharing de-identified data, findings, and/or recommendations	<ul> <li>Will the MMRC be permitted or required to share de-identified data and/or findings with the CDC?</li> <li>Have all Tribes involved agreed to the data sharing or reporting required as a condition of receiving federal MMRC funding?</li> <li>What protections are in place to protect Tribal data sovereignty?</li> <li>Is the MMRC authorized to share data with MMRCs or public health authorities in other jurisdictions?</li> <li>Have all relevant Tribes provided clear written authorization for specifying the MMRC data and information that is permitted to be shared, and with whom it may be shared?</li> </ul>
Standards for types of findings and recommendations to report; dissemination of findings; and frequency of reporting	<ul> <li>If the MMRC is under a Tribal organization or involves multiple Tribes, how will data, findings, and recommendations be shared back with all relevant Tribes?</li> <li>How often will the MMRC be required to publish reports?</li> <li>With whom is the MMRC required to share reports?</li> <li>What should MMRC reports include?</li> <li>What standards for privacy protections will be put in place regarding reporting with small case counts?</li> <li>Will the MMRC be charged with creating policy or strategy recommendations for reducing maternal mortality?</li> <li>Will the MMRC share findings with an advisory council or specialized task force charged with making recommendations to address health inequities?</li> <li>Do the relevant Tribe(s) and state(s) have a task force, perinatal quality collaborative or other infrastructure to implement MMRC recommendations?</li> <li>Does the MMRC or wider organization have written agreements or policies to support implementation of MMRC recommendations by the relevant agencies or organizations?</li> </ul>

# 6 APPENDIX B: GLOSSARY OF KEY TERMS

Data Sovereignty Grounded in Tribal nations' inherent sovereignty and Indigenous Peoples' inherent rights to self-determination, Tribal Data Sovereignty asserts Tribes' rights to govern the collection, ownership, and application of both their own data and data that are collected by external entities about them. (<u>Carroll, Rodriguez-Lonebear, and Martinez 2019; National Congress of American</u> Indians 2018). International and settler-state legal frameworks such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) reaffirm Indigenous Peoples' rights to control and access their data (<u>UNDRIP</u> 2007). See Indigenous Data Network. (2024, April). Indigenous data governance brief: US Indigenous data sovereignty and governance summit. <u>https://usindigenousdatanetwork.org/wpcontent/uploads/2024/10/Indigenous-Data-Governance-Brief-FINAL.pdf</u>

DUA Data Use Agreement. A DUA) is a legal contract that outlines how data can be used and shared between two parties and can facilitate an MMRC's access to data essential for case identification and review.

Federal Indian Law Federal Indian law is the complex body of law (including statutes, regulations, policies, case law, etc.) that governs the relationship between the American Indian and Alaska Native Tribes and the United States and state governments. It covers a wide range of topics, including Tribal sovereignty and the federal trust responsibility.

#### Indigenous Determinants of Health

A model developed by the United Nations Permanent Forum on Indigenous Issues that describes Indigeneity as an overarching determinant of health for Indigenous peoples, and 33 additional positive and negative forces – both historical and current – that can powerfully influence health outcomes for Native peoples.

### Maternal Mortality Review

Maternal mortality review is a public health tool that commonly has three goals: 1) to document more accurate data on incidents of deaths that occur during or within one year of pregnancy; 2) to identify factors that contribute to preventable deaths; and 3) to publish recommendations for policies, systems changes, and strategies to address the contributing factors and improve maternal health outcomes.

#### Maternal Mortality Review Committees

Maternal mortality review committees (MMRCs) are multidisciplinary groups that convene at the state or local level to comprehensively review deaths that occur during or within 1 year of the end of pregnancy.

MOU A memorandum of understanding (MOU) is a written agreement between two or more parties that outlines their intentions, roles, and objectives and guides their working relationship. MOUs can be useful for clarifying relationships and commitments between Tribes and entities like state agencies and promote more effective cross-jurisdictional cooperation.

#### Pregnancy-Associated Deaths

Deaths that occur during pregnancy or within one year of the end of the pregnancy, regardless of cause.

#### **Pregnancy-Related Deaths**

One responsibility of MMRCs is to determine "pregnancy relatedness" of a maternal death under review. A death is considered "pregnancy-related" if it occurred during pregnancy or within 1 year of the end of pregnancy *and* is determined to have been caused by a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy. In addition to having a temporal relationship to pregnancy, these deaths are causally related to pregnancy or its management.

### Preventability

One responsibility of MMRCs is to determine "preventability" of a maternal death under review. A death is considered preventable if the committee determines that there was at least some chance of the death being averted by one or more reasonable changes to patient, community, provider, facility, and/or systems factors. MMRIA allows MMRCs to document preventability decisions in two ways: (1) determining preventability as a "yes" or "no", and/or (2) determining the chance to alter the outcome by using a scale that indicates "no chance", "some chance", or "good chance." Any death with a "yes" response or a response that there was "some chance" or a "good chance" to alter the outcome was considered "preventable."

#### **Public Health Authority**

Public health authority refers to the legal authority of a sovereign government to engage in public health activities to promote and protect the health of the people within its jurisdiction. "A public health authority" can also refer to an entity (like a Tribe or government health department) that uses public health authority to carry out public health activities. Public health authorities have special powers and permissions under the law.

#### Severe Maternal Morbidity

Severe maternal morbidity (SMM) can be thought of as unintended complications or outcomes of the process of labor and delivery that result in significant short-term or long-term harm to a pregnant person's health.

#### Social Determinants/Drivers of Health

Social determinants of health (SDOH) are non-medical factors that affect health outcomes. They include the conditions in which people are born, grow, work, live, and age, as well as the broader forces and systems that shape everyday life.

### **Tribal Epidemiology Centers**

The 12 Tribal Epidemiology Centers (TECs) offer epidemiologic and public health support to American Indian and Alaska Native (AIAN) communities, Tribes, Tribal Organizations, and urban Indian organizations (T/TO/UIOs). Funded in part by the Indian Health Service, TECs manage public health information systems, investigate diseases of concern, manage disease prevention and control programs, and respond to public health emergencies. The TECs provide services to an estimated 574 Tribes, 41 UIOs, and 9.7 million AI/AN people across all 12 IHS Areas.

#### Tribal Sovereignty

Tribal sovereignty is the inherent authority of Tribal nations to govern themselves, which includes the right to establish their own governments, create laws, determine citizenship, and protect the health and welfare of their people.