



USET

SOVEREIGNTY PROTECTION FUND

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Diana W. Bianchi, M.D.
Dr. Courtney Aklin, Ph.D.
Dr. Janine Clayton, M.D.,
Co-chairs, IMPROVE Initiative
National Institutes of Health (NIH)
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Drs. Bianchi, Aklin, and Clayton,

We write on behalf of the United South and Eastern Tribes Sovereignty Protection Fund (USET SPF) in response to the National Institutes of Health's (NIH) virtual rapid-response Tribal Consultation on the NIH Implementing a Maternal health and Pregnancy Outcomes Vision for Everyone (IMPROVE) Initiative Maternal Health Research Centers of Excellence. While we strongly agree that there must be a focus on maternal health and mortality in Indian Country, we urge NIH to tailor this effort to the unique circumstances facing Tribal Nations throughout the United States, as well as ensure it is upholding its trust and treaty obligations to support Tribal sovereignty and self-determination in all areas of its work. With this in mind, we question the necessity and value of a rapid consultation and encourage NIH to take the time to ensure this initiative better reflects Tribal Nation guidance and priorities. Toward that end, we offer the following responses to NIH's framing questions.

USET SPF is a non-profit, inter-tribal organization advocating on behalf of thirty-three (33) federally recognized Tribal Nations from the Northeastern Woodlands to the Everglades and across the Gulf of Mexico.¹ USET SPF is dedicated to promoting, protecting, and advancing the inherent sovereign rights and authorities of Tribal Nations and in assisting its membership in dealing effectively with public policy issues.

How can the goals and objectives of the Centers of Excellence be inclusive of the needs of Tribal communities?

USET SPF suggests that NIH reconsider this question. Prior to attempting to implement Maternal Health Research Centers of Excellence in Indian Country, NIH must first consult with Tribal Nations on

¹ USET SPF member Tribal Nations include: Alabama-Coushatta Tribe of Texas (TX), Catawba Indian Nation (SC), Cayuga Nation (NY), Chickahominy Indian Tribe (VA), Chickahominy Indian Tribe–Eastern Division (VA), Chitimacha Tribe of Louisiana (LA), Coushatta Tribe of Louisiana (LA), Eastern Band of Cherokee Indians (NC), Houlton Band of Maliseet Indians (ME), Jena Band of Choctaw Indians (LA), Mashantucket Pequot Indian Tribe (CT), Mashpee Wampanoag Tribe (MA), Miccosukee Tribe of Indians of Florida (FL), Mi'kmaq Nation (ME), Mississippi Band of Choctaw Indians (MS), Mohegan Tribe of Indians of Connecticut (CT), Monacan Indian Nation (VA), Nansemond Indian Nation (VA), Narragansett Indian Tribe (RI), Oneida Indian Nation (NY), Pamunkey Indian Tribe (VA), Passamaquoddy Tribe at Indian Township (ME), Passamaquoddy Tribe at Pleasant Point (ME), Penobscot Indian Nation (ME), Poarch Band of Creek Indians (AL), Rappahannock Tribe (VA), Saint Regis Mohawk Tribe (NY), Seminole Tribe of Florida (FL), Seneca Nation of Indians (NY), Shinnecock Indian Nation (NY), Tunica-Biloxi Tribe of Louisiana (LA), Upper Mattaponi Indian Tribe (VA) and the Wampanoag Tribe of Gay Head (Aquinnah) (MA).

Because there is Strength in Unity

this issue of maternal health and family outcomes within our communities and honor Tribal guidance as to whether these Research Centers are the most appropriate or best model for Indian Country. Given federal trust and treaty obligations, Tribal sovereignty, and our complicated history with research, perhaps another model would be more fitting or effective. However, only the guidance obtained via Tribal consultation can answer this question. Attempting to replicate a model that has worked in other communities without an understanding of our circumstances and Tribal leader direction, is inappropriate.

Regardless of how maternal health and other initiatives move forward in Indian Country, NIH must always utilize a Community-Based Participatory Research model. As NIH learned during its June 30th consultation, community trust, support, and consent is critical to conducting ethical research that reflects Tribal Nation priorities and circumstances. This includes ensuring that Tribal Nations are overseeing and facilitating all research that takes place on our lands and with our people.

Are there research priorities or types/areas of research, e.g., culturally-based practices, that should be included to specifically address the needs of expectant mothers and their families in tribal communities?

Tribal Nations and Indian Country are not monolithic. Each individual Tribal Nation should determine what and whether culturally-based practices are utilized in this space. This is another reason why early consultation and Community-Based Participatory Research are so important. What is a cultural tradition for one Tribal Nation may not be appropriate for another. Tribal Nations are the only arbiters of culture and practitioners of Indigenous Knowledge. We should determine, guide, and administer any culturally-based practices in maternal health and other research.

How can we better encourage and facilitate research partnerships with tribal communities on maternal health topics?

Tribal-designated Institutional Review Board Review (IRB) must be a requirement before any research commences within any Tribal community, unless expressly waived by Tribal Nation leadership. This review process must include informed-consent procedures that outline publication permission, as well as community protection informed consent and procedures.

We further recommend that NIH prioritize research that places the community, not the research partner, at the center. This includes funding existing Tribal community infrastructure and assisting Tribal Nations and our preferred partners, including Tribal colleges, with developing our own research questions, processes, and methods. NIH should facilitate the provision of training to communities on how to do this, as well as how to draft research applications. Finally, outside partners should be required to complete training on Tribal sovereignty, community research, and how to honor Indigenous Knowledge.

What special considerations for Tribes should be in place as we develop funding opportunities?

Any research in Indian Country must clearly outline how the research will benefit Tribal communities in both the short- and long-term, particularly if the research yields significant results. USET SPF continues to underscore that Tribal Nations must see direct benefits from any research conducted in our communities, as “Helicopter research,” where non-Tribal researchers gather data/samples then depart the community, has been practiced in Indian Country for too long. In addition, all researchers **must** have documented consent of the Tribal Nation in any research application, including where research is to be conducted off of Tribal lands on Native people. Further, Tribal Nations **must** retain data sovereignty and must have assurances of data protection.

Further, Tribal Nations have been left out of the decision-making process within federal programs affecting Indian Country for far too long, including those within NIH. NIH must include requirements for formal coordination with Tribal Nations such as a Tribal appointment or membership within any coordinating entity overseeing those initiatives. NIH must make Tribal consent, including Tribal Institutional Review Boards (IRB), a non-negotiable element of all research applications involving Indian Country.

Finally, while Native researchers are applying for NIH-funded programs, these applications are not being funded. Scoring priority needs to be given to Native researchers, as well as university partners with letters of support from Tribal Nations. In addition, NIH should assist in obtaining funding for translational research to improve sustainability instead of defunding existing projects. For example, Healthy Native Babies, the only existing maternal-child health project developed by Native people for Native people was recently defunded. We feel as though NIH should have consulted on integrating this project into the IMPROVE initiative.

How should the data hub for the Centers of Excellence be established to incorporate and sustain Tribal sovereignty for data collected and stored?

As we have stated repeatedly to NIH in the past, all research in Tribal communities and with Native individuals must contain protocols for integrating Tribal consent and oversight, as well as protections for Tribal data ownership and Native participants. Tribal Nations must have absolute ownership of our data, and any data from this initiative should be held by Tribal Nations themselves or stored on a central hub with express permission from each Tribal Nation and under parameters negotiated by Tribal Nations. Data may only be shared or utilized with the express consent of a Tribal Nation. Without these protections in place, NIH-facilitated or funded research should not occur in our communities or with our people.

Conclusion

While USET SPF recognizes the importance and necessity of maternal health initiatives, NIH has a legal and moral trust obligation to uphold the sovereign status of Tribal Nations that supersedes all other interests. With this in mind, it is critical that NIH seek Tribal guidance *before* implementing new initiatives or models in Indian Country, as well as to implement policies and protections that will prevent ethical violations against our communities and our people. Tribal Nations must direct and oversee any research that occurs on our homelands or with our citizens and NIH must ensure necessary policies are in place to protect the sovereignty, ownership, privacy, and use of our data. In the absence of these policies and guidance, NIH-funded research should not be conducted in Indian Country. Should you have any questions or require further information, please contact Ms. Liz Malerba, USET SPF Director of Policy and Legislative Affairs, at LMalerba@usetinc.org or 615-838-5906.

Sincerely,



Kirk Francis
President



Kitcki A. Carroll
Executive Director