



USET

SOVEREIGNTY PROTECTION FUND

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Brian C. Moyer, Ph.D.
Director
National Center for Health Statistics
3311 Toledo Rd. Room 5580
Hyattsville, MD 20782

Dear Dr. Moyer,

On behalf of the United South and Eastern Tribes Sovereignty Protection Fund (USET SPF), we write to provide the Centers for Disease Control and Prevention (CDC) with comments on the Tribal Implementation Center Program. We appreciate this opportunity to provide feedback on the design of the Tribal Implementation Center as data sovereignty and modernization are critical ongoing issues in Indian Country. Tribal Nations and Tribal Epidemiology Centers (TECs), both individually and collaboratively, operate public health programs for our communities that cannot be run effectively without access to robust, timely, and quality public health data. The CDC Tribal Implementation Center has the potential to greatly improve public health data access and use in Indian Country, but time must be taken to ensure the program is not only reflective of the priorities and circumstances of Tribal Nations and TECs, but also addresses the root causes of current data access issues. To create an overall healthier America, Tribal communities must be healthier, and creating healthier Tribal communities requires Tribal Nations and TECs to have access to timely, quality, and robust public health data. The CDC Tribal Implementation Center is an opportunity to invest in the infrastructure and workforce necessary to investigate, analyze, and begin to solve the public health issues that threaten the health status of Tribal communities. Our comments below address each of the questions posed by CDC during the recent listening session.

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 Mexico¹. 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.

¹ USET SPF member Tribal Nations include: Alabama-Coushatta Tribe of Texas (TX), Aroostook Band of Micmac Indians (ME), 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), 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).

What specific community considerations should be integrated into the Tribal Implementation Center program to ensure it respects Tribal sovereignty and supports your community's public health initiatives?

Overall, it is important to remember that the Tribal Implementation Center cannot use a one-size-fits-all approach in its design. The “special considerations” that each Tribal community will require are likely to vary from Tribal Nation to Tribal Nation, just as our public health priorities and initiatives often vary considerably. Therefore, it will be necessary for CDC to develop flexible, responsive systems that honor Tribal sovereignty by facilitating Tribal decision-making and local control.

For example, Tribal Nations should have the authority to define our communities and jurisdictions for data collection, analysis, and response purposes. Our communities are not solely comprised of Tribal citizens – we care for non-Tribal family members and employees, and our enterprises often bring significant numbers of other non-Tribal populations to our communities. In order to effectively respond to public health threats like infectious diseases, Tribal Nations must have the authority to define our community boundaries and demographics, such that we may request and receive public health data from federal, state, and local entities that gives us a more complete perspective of the public health landscape in our communities.

Relatedly, when public health threats are identified, Tribal Nations must be empowered to exercise our right to act as a lead public health authority and coordinate a response in collaboration with the relevant federal, state, or local health authorities. While USET SPF acknowledges that CDC typically does not involve itself in investigations confined within a single state, the Tribal Implementation Center should have a role in providing guidance to state and local governments on Tribal public health authorities and how to work in coordination with Tribal Nations.

However, none of this can be accomplished without first improving data sharing between state and local entities and Tribal health authorities. Without access to quality and timely data, Tribal Nations' ability to effectively respond to public health threats is severely hindered. The Tribal Implementation Center should prioritize the institution of processes that facilitate better data sharing between Tribal Nations and TECs, states, and CDC. Presently, states collect data from/about Tribal Nations and feed that data into CDC systems without sharing that data with Tribal Nations directly. When Tribal entities finally get access to that data, it is often of limited utility due to aggregation and racial misclassification of American Indians and Alaska Natives (AIANs) in datasets. As an agency tasked with fulfilling the federal trust and treaty obligations, CDC has a responsibility to ensure that Tribal Nations can fully exercise our public health authorities. That includes a responsibility to educate states on their duty to share timely, quality data with Tribal Nations, as requests are made. Ensuring data quality will likely require CDC to investigate racial misclassification in datasets and work in close consultation with Tribal Nations to develop a set of definitions/classifications that will provide the granularity that Tribal entities need to monitor community public health.

What does data modernization mean in your role, and how does it support public health initiatives in your community?

Just as our public health priorities vary across Indian Country, data modernization likely has a different meaning for each Tribal Nation or TEC. In the USET SPF region, data modernization ideally means the creation of a fully integrated public health system with seamless, bi-directional data exchange between Tribal Nations, TECs, states, and the federal government. It also includes improved access to line-level data for a community or jurisdiction defined by the Tribal Nation. Working relationships between Tribal Nations and the USET TEC and the 20+ state governments in our region vary widely. Accordingly, the quality of and frequency in which we receive data from state entities can vary widely as well. Data modernization in the USET SPF region must include an investigation into all data pathways from and back into Tribal communities to identify gaps and opportunities to improve data quality and access. Every Tribal Nation must be equally afforded access to relevant information regardless of the states with which we share geography.

USET SPF encourages CDC to use the Tribal Implementation Center as an opportunity to develop a coordinated workflow for data sharing, analysis, and reporting that is consistent, seamless, and ongoing in real time. To achieve this, CDC must invest in building Tribally led, culturally appropriate systems that provide timely and accurate data for decision-making on the federal side while also building interoperable tools and capacity to control and use that data on the Tribal side. Improved access to data is of limited utility if Tribal Nations do not have the infrastructure and workforce necessary to analyze and make use of that data, so modernization efforts through the Tribal Implementation Center must include investment in Tribal capacity building alongside investment in better federal systems.

What steps should be taken to ensure the long-term sustainability of the capacity your Tribal Nation might build through the Tribal Implementation Center?

As discussed above, investments through the Tribal Implementation Center must equally prioritize building Tribal capacity and improving the ways federal and state public health entities work with Indian Country. Federal and state entities must treat Tribal Nations and TECs as equal partners in this effort, while also acknowledging the unique nature of Tribal Nations and our communities. Over many years, states, with significant federal support, have cultivated extensive public health infrastructures that include disease reporting mechanisms, outbreak investigations, contact tracing, and data collection. Tribal public health infrastructures have not historically received the same level of federal investment. As a result, Tribal public health programs do not have the same capacity, infrastructure, or resources as our state counterparts and will likely require more significant investments to update our systems to be compatible and interoperable with state and federal systems.

Further, the Tribal Implementation Center should invest in Tribal workforce development and capacity building. Tribal public health entities should have the expertise necessary to collect and analyze data from our communities so we can create robust, responsive public health programs without having to rely on state and federal partners. Long-term sustainability of Tribal public health programs depends on our ability to increase Tribal capacity in all aspects, from our capacity to receive, store and protect data, to our ability to synthesize and use data created by and for our communities. USET SPF urges CDC to meaningfully invest

in technical assistance, Tribal workforce development and training, and Tribal infrastructure improvements through the Tribal Implementation Center.

Recognizing that data from state and local partners is a problem, what have been some challenges and successes with working with state and local health departments?

Two of the biggest challenges in working with state and local health departments are the variation in relationship quality from state to state, and the time required to work individually with each state.

The USET TEC supports 33 Tribal Nations in 13 states, and the working relationships between states and our member Tribal Nations vary widely. Some states work closely with Tribal Nations and are more willing to engage in data sharing, while other states refuse to work with Tribal Nations. As the USET TEC is tasked with providing public health support and monitoring for all our member Tribal Nations, the variation in these relationships severely hinders our ability to provide equitable services to our membership. This means that some Tribal Nations have significantly less access to information about community health, and the aggregate public health data the USET TEC produces is somewhat skewed, further impacting our ability to respond effectively to public health threats. Tribal Nations and TECs are statutorily designated as public health authorities, so there is no reason that Tribal access to data should vary so widely from state to state.

Additionally, the way many states treat Tribal public health authorities is inappropriate. It takes inordinate amounts of time to negotiate, execute, and maintain the numerous data use agreements required to work with state public health systems. Local public health authorities and other governmental entities are not subjected to the same level of scrutiny as Tribal public health programs. Those entities often have access to real-time data that is not provided to Tribal Nations and TECs despite our designation as public health authorities under law. States also regularly engage in seamless bi-directional data sharing with other governmental entities, and yet it takes weeks or months for Tribal entities to gain access to data that should have been shared from the beginning. As part of its data modernization efforts, CDC and the Tribal Implementation Center must explore ways to compel states to work with Tribal public health authorities in the same way they work with federal and local governments.

Conclusion

USET SPF appreciates this opportunity to provide CDC with recommendations regarding the Tribal Implementation Center. Tribal Nations and TECs have long advocated for improved data quality and access, and the Tribal Implementation Center is a critical opportunity for CDC to make progress on these issues. USET SPF encourages CDC to work in close consultation with Tribal Nations to identify solutions for increasing Tribal capacity to collect, receive, and analyze public health data. Our ability to provide for the health and wellness of our communities depends on our ability to monitor and respond to public health threats. We also urge CDC to educate states on their obligation to provide quality and timely data to Tribal public health entities, and explore opportunities for improving coordination between Tribal, state and federal partners. USET SPF shares this Administration's goal of creating healthier Tribal communities. A key aspect of achieving this goal will be improving Tribal data access and quality such that we may make informed decisions about community health and support public health programs that elevate our health

status. We hope that these comments are helpful as the Tribal Implementation Center design process continues, and we look forward to future opportunities to engage with CDC on this program to ensure it fulfills its full potential 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,

A handwritten signature in black ink, appearing to read 'K. Francis', with a long horizontal stroke extending to the right.

Kirk Francis
President

A handwritten signature in black ink, appearing to read 'K. A. Carroll', with a stylized, flowing script.

Kitcki A. Carroll
Executive Director