



USET

SOVEREIGNTY PROTECTION FUND

1730 Rhode Island Avenue, NW
Suite 210
Washington, DC 20036
P: (615) 872-7900
F: (615) 872-7417
www.usetinc.org

Transmitted Electronically to:
consultation@hhs.gov

October 27, 2022

Marvin Figueroa
Director – Intergovernmental and External Affairs
U.S. Department of Health and Human Services
200 Independence Ave. SW
Washington, DC 20201

Dear Mr. Figueroa,

The United South and Eastern Tribes Sovereignty Protection Fund (USET SPF) is pleased to submit comments to the Department of Health and Human Services (HHS) regarding the agency's request for comment on the development of a Tribal Data Sharing Policy. USET SPF acknowledges HHS for initiating consultation to respond to the recommendations in the Government Accountability Office (GAO) report "[Tribal Epidemiology Centers, HHS Actions Needed to Enhance Data Access.](#)" USET SPF recognizes that sharing data among the scientific community is an integral part of scientific discovery and progress, but it must include protections for Tribal Nations. USET SPF also cautions HHS against developing a blanket policy that restricts access to data for Tribal Epidemiology Centers (TECs.) TECs are an integral part of the Indian Health System and must maintain access to timely and accurate health data for the Tribal Nations they serve. It is our hope that the long-standing data access issues can be resolved for TECs while upholding Tribal sovereignty, including data sovereignty.

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.

Introduction

Over the years, states have cultivated extensive public health infrastructure. This includes the establishment of reportable disease and vital statistics reporting mechanisms, outbreak investigation,

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

contact tracing, data collection, and quarantine measures for all residents, including Native American people. This data is then shared with the federal government through cooperative agreements. However, Tribal Nations and TECs continue to experience frequent challenges in accessing not just public health data on both the federal and state level, but Tribal data as well, which often is not reported back to the Tribal Nation. This includes vital COVID-19 data. This lack of access to quality public health data has hindered the ability of Indian Country to respond to the public health emergencies in our communities, including COVID-19.

Despite a legal imperative for HHS to share federal public health data, USET's TEC has long struggled with access to data at both the federal and state levels. Prior to the COVID-19 pandemic, the only HHS dataset that TECs could access was the Epi Data Mart, a subset of data from the Resource and Patient Management System (RPMS) from the Indian Health Service (IHS). We have historically not had any datasets held by the Centers for Disease Control and Prevention (CDC). USET's TEC finally received access to HHS Protect (limited to COVID-19 data ONLY) over a year and a half after the onset of the pandemic. This has significantly impeded the work of TECs, both prior to and during the COVID-19 pandemic. We have long advocated for the access to which we are entitled as Public Health Authorities but have faced frequent barriers and delays. Toward more robust public health infrastructure in Indian Country and improvements in epidemiology for our populations, it is critical that HHS establish a data-sharing policy that fully recognizes our status as Public Health Authorities.

Data Sharing Policies must not hinder ongoing, on-the-ground work between Tribal Nations and Tribal Epidemiology Centers (TECs)

USET SPF strongly supports the creation of a Tribal Data Sharing policy, as parity in data access among the TECs and codification of data sovereignty is long overdue. However, the policy must not increase administrative burdens on Tribal Nations, nor should it disempower the work of TECs. In line with our continued position regarding data sovereignty, USET SPF agrees that no Tribal Nation-specific data should be included in any level of access without explicit consent from Tribal Nations. This includes the data shared with TECs. However, this consent may take many forms, and may vary among the regions and TECs. As was stated during the October 19th Tribal consultation, this requires the development of a flexible policy, rather than a one-size-fits-all approach. In addition, toward a final policy that does not overly burden Tribal Nations or TECs, we would like to highlight the USET TEC's current model for gaining Tribal Nation authorization to access data and ensuring the appropriate protections for this data.

USET has operated a TEC since 1996 and has implemented a number of protocols to protect the data entrusted to us by the Tribal Nations we serve. Since its inception, the USET TEC has maintained its mission and charge from the Tribal Nations we serve to provide Tribal Nation-specific information to Tribal Leaders, health directors and public health professionals. In order to fulfill this directive, most Tribal Nations that have Tribally operated health clinics have granted TEC staff access into their Resource and Patient Management Systems (RPMS.) In order to obtain access, USET TEC staff fill out an Information Technology Access Control (ITAC) form requesting access to specific packages in RPMS. These forms are submitted to the Tribal Nations for consideration and signature. Once we have Tribal approval, we then reach out to the clinical site manager to set up our access. For Tribally operated facilities, permission and access is always at the discretion of the clinic and can be revoked at any time. Tribal Nations have provided the USET TEC with this level of access because we keep all protected health information pulled from RPMS for analysis behind the IHS firewall on a separate server only accessible to select TEC staff. Once RPMS data has been analyzed and summarized, Tribal Nation-specific reports are released only to Tribal Nation health officials and Tribal leaders. Any Tribal Nation-specific educational materials that are produced from this data must have the approval from Tribal health officials prior to broader distribution.

USET's policy is that Tribal Nation data belongs to the Tribal Nation and may not be used except with the Tribal Nation's express consent. We do, however, make USET area aggregate reports publicly available. Occasionally, we are called upon to produce regional statistics (for example, diabetes burden in the northeast). We can get these requests from an outside entity or from a Tribal Nation(s). In these instances, we require permission from each participating Tribal Nation in the region of interest before releasing to a third party or the requesting Tribal Nation.

We offer this context on our work with the Tribal Nations we serve as an example of informed, prior consent. The consent element of this policy should be negotiated at the regional level between TECs and the Tribal Nations they serve, and any Tribal Data Sharing policy should include a consent requirement. However, this must be balanced with the need for timeliness. Too often, gaining access to critical data is a lengthy and complicated process, and instituting a one-size-fits-all approach to consent may further complicate access for TECs and Tribal Nations. While we uphold the necessity of informed and prior consent, USET SPF cautions against requiring time-limited data sharing resolutions from each individual Tribal Nation (as was suggested during the October 19th consultation), as this could hinder real-time response to pressing issues or emergencies, as well as create administrative burdens for Tribal Nations and TECs, alike.

TECs are valuable partners to Tribal Nations, and require access to HHS data to function properly

Additionally, many TECs serve smaller Tribal Nations that lack the capacity to maintain their own public health workforce. For these Nations, TECs provide critical services at all times, but particularly during public health emergencies. In order to maintain the level of service they provide to the Tribal Nations they serve, TECs must have timely and accurate data.

It is also important to note that as far as we know, the vast majority of federally held Public Health (HHS) datasets do not contain identifiable data and are relying on the race/ethnicity field to identify AI/AN data. This is of limited utility to us, as some of our Member Tribal Nations are small and often racially misclassified within the data sets, leading to inaccurate and insufficiently detailed data. Data in this form restricts the ability of the USET TEC to provide specific health information and data to our Member Tribal Nations, as is our charge.

For example, the Centers for Disease Control and Prevention (CDC) has asked TECs on numerous occasions which datasets we would like to access. When we don't know which data the CDC has in its possession (and its accompanying data dictionary), it makes it impossible to prioritize data requests with our limited capacity. We reiterate our request for the CDC to share with TECs all information regarding the datasets in its possession. While access to federally datasets is critical to the work of the TEC's in general, we must also note that state access may also be needed. For that reason, the USET TEC would like to see a provision written into cooperative agreements between states and federal HHS entities requiring a data sharing plan between states and TECs.

Under the present system, there is no way of ascertaining which data is "Tribal data" and which is not. To remedy this, a more specific data sharing scheme would have to be negotiated by the states, who feed the federal datasets. From a public health perspective, it would be ideal for all states to institute uniform fields in which citizens of federally recognized Tribal Nations are identified, as well as identifying the Nation of citizenship. Because of the potential for implications beyond public health, this is an item for further consultation between HHS and Tribal Nations.

Incorporate Protections in the policy for data shared on an interagency basis or with external entities

USET SPF has consistently advocated for increased data protections when data is shared between agencies or with external entities. It is important to remember the historic relationship between scientific study and Tribal Nations, which has led to increased distrust of the scientific and healthcare systems. However, there is a distinction between data sharing amongst federal agencies and external entities, and data sharing between Tribal Nations and TECs. TECs are incredibly valuable institutions who operate in close cooperation and coordination with the Tribal Nations they serve. They do not carry as much of the historical trauma and distrust as their federal or external scientific counterparts. USET SPF strongly supports TECs and their work but does not support extending their level of data access to other entities without further negotiation and consent from Tribal Nations.

USET SPF understands the value of scientific inquiry in its myriad forms, but Tribal Data Sovereignty must remain paramount in consideration of a Tribal Data Sharing policy. Under all circumstances, the data produced by, for and of Tribal Nations belongs to those Nations, and must remain protected.

Conclusion

As statutorily recognized Public Health Authorities, TEC in parity access to federal public health data is long overdue. Although TECs continue to provide invaluable support and services to Tribal Nations, the lack of data provided to TECs has led to severe gaps in understanding and addressing public health issues in our communities. Once and for all, HHS must ensure that TECs have access to critical public health data from federal and state governments. While we unequivocally maintain that Tribal Data Sovereignty and Self-Determination are upheld and respected throughout the creation of a Tribal Data Sharing Policy, we urge HHS to ensure the Tribal Nations served by each TEC have the opportunity to determine how this occurs. USET SPF requests that HHS conduct further Tribal Consultation on these issues and look forward to continuing to work with you on the development of this important policy. Should you have any questions or require further information, please contact Ms. Liz Malerba, USET SPF Director of Policy and Legislative Affairs, at (615) 838-5906 or by email at lmalerba@ustinc.org.

Sincerely,



Kirk Francis
President



Kitcki A. Carroll
Executive Director