



USET

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March 5, 2024

Jess Smith
Acting Director
Office of Intergovernmental and External Affairs
Hubert Humphrey Building
200 Independence Ave. SW
Mail Stop: 620E
Washington, DC 20201

Dear Acting Director Smith,

On behalf of the United South and Eastern Tribes Sovereignty Protection Fund (USET SPF), we write in response to the Department of Health and Human Service's (HHS) request for comment on the [Draft HHS Tribal and Tribal Epidemiology Center Data Access Policy](#). USET SPF appreciates this opportunity to comment on the draft policy, as Tribal Nations and Tribal Epidemiology Centers (TECs) continue to experience frequent challenges in accessing public health data at all levels. Despite HHS conducting extensive Tribal consultation on this topic over two years, as well as receiving direct [recommendations from the Government Accountability Office](#) (GAO), this draft policy is exceedingly inadequate. The draft policy fails to address the GAO's recommendations, and even fails to accomplish the goals set forth in the policy's own scope and purpose section. USET SPF [commented to HHS](#) during a previous round of consultation urging the agency to establish a policy that fully recognizes the status of Tribal Nations and TECs as public health authorities (PHAs). This draft policy fails to do this in a meaningful way, and indeed stands to diminish the authority of Tribal Nations and TECs to access public health data if implemented in its current form. USET SPF believes that HHS should overhaul the draft entirely in close consultation with Tribal Nations, but we offer the following comments and recommendations in the hope that they will strengthen and improve the policy to a point that it may be useful to Tribal Nations and TECs.

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), 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

Adhere to Statutory and Regulatory Requirements

Under the 2010 reauthorization of the Indian Health Care Improvement Act (IHCIA) as part of the enactment of the Affordable Care Act, TECs were designated as public health authorities (PHA) under the Health Insurance Portability and Accountability Act (HIPAA). Further, Tribal Nations themselves are designated as PHAs under [federal law](#) and [regulation](#). As PHAs, Tribal Nations and TECs have the legal right to access protected health information. Further, the statute designating TECs as PHAs also states that the HHS Secretary “shall grant to [TECs]...access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary.” These legal frameworks create a clear obligation for HHS to share data with Tribal Nations and TECs, and that obligation is not conditioned on any action by or policy of Tribal Nations, TECs or HHS itself. Yet, this draft policy conditions the sharing of data with Tribal Nations and TECs on “feasibility,” regulations, and other existing agreements, and contains numerous caveats that would serve to limit the data that HHS will share with Tribal Nations and TECs.

In the Objectives section of the draft policy, HHS states its intention to establish a policy for Tribal and TEC data access “to the extent feasible and permitted by federal law, regulation and any existing agreements in place between HHS and third parties.” The draft policy also states that the policy does not supersede or modify any other statutes, regulations, or data use agreements that govern the sharing of data and goes so far as to say that in the event of a conflict between this policy and HHS Operating Division-specific authorities and agreements, “the latter will prevail.” Further, the draft policy states that “other authorities or mechanisms not included in this policy may exist when the data cannot be disclosed to the TEC or a Tribe as a PHA.” HHS’s repeated references to these caveats in the draft policy is in clear violation of its statutory obligations and renders the policy nearly useless.

To correct this, HHS must remove the language throughout the policy that limits or diminishes the rights and authorities that Tribal Nations and TECs have as PHAs. Prior to and through this new policy, HHS and its Operating Divisions have imposed separate standards for Tribal data requests, which are often more burdensome than those imposed on other PHAs and have cited HIPAA and privacy concerns as their reasons for doing so. However, HIPAA does not require the levels of diligence and investigation currently imposed on Tribal health entities. HIPAA simply requires that the covered agency, in this case HHS, only verify the identity and authority of the data requestor, and HIPAA contains broad flexibility for verification. Further, according to a frequently asked questions document on the HHS website, the HIPAA Privacy Rule states that “to the extent a [PHA] is authorized by law to collect or receive information for the public health purposes...covered entities may disclose protected health information to such [PHAs] without authorization pursuant to the public health provision.”

Even the definitions that HHS has proposed for “data” and “data sharing” are unnecessarily and wrongfully limiting. Within the definition of data, HHS should include “but not limited to” following the word “including” and preceding the list of data types to be made available and should eliminate the phrase “can feasibly be disclosed,” as the statute does not limit the definition of data nor places the condition of feasibility on the

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).

obligation to share data with Tribal Nations and TECs. Additionally, the definition of “data sharing” states that the act is subject to “applicable laws, existing agreements, regulations, reasonable technical constraints, and the availability of appropriations.” Again, the statute requiring HHS to share data with Tribal Nations and TECs supersedes existing agreements and regulations, and certainly does not hinge the action on technical capacity or funding. As a federal agency charged with trust and treaty obligations to Tribal Nations, it is HHS’s responsibility as trustee to make the data requested by Tribal Nations and TECs in their capacity as PHAs available, and any limiting factors such as technical capacity or funding constraints are HHS’s responsibility to address in order to make the data available.

Therefore, HHS’s repeated attempts in this policy to limit what and how data should be shared with Tribal Nations and TECs, both through the consistent use of qualifying language and deference to HHS Operating Divisions to create further requirements, must be removed and corrected. The right of Tribal Nations and TECs to access data from HHS is enshrined in statute and regulation, and neither narrowly restrict that access in the way that HHS is attempting in this policy.

Meaningfully Address the GAO Report Recommendations

As part of its report titled “Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access,” the GAO issued 5 recommendations for HHS. GAO’s first recommendation was for HHS to develop a policy clarifying the data that are to be made available to TECs as required by federal law. As currently written, the draft policy delegates the responsibility to determine types of data to be made available to Tribal Nations and TECs to the HHS Operating Divisions, which are charged with developing their own protocols to provide “further specificity regarding access to and categories of data.” While it may be necessary for each Operating Division to develop protocols for sharing data that are specific to their operating systems, Operating Divisions should neither be given the discretion to further limit or restrict the types of data to be made available, nor impose additional conditions for Tribal Nation/TEC access to said data. In addition, the delegation of these efforts to the Operating Divisions creates further delays for an already critically necessary policy. Tribal Nations and TECs have struggled consistently to secure access to HHS data, a fact that has not improved in the two years since HHS began consulting on this policy.

As things currently stand, this draft policy does nothing to advance Tribal Nation/TEC access to HHS data, as it neither clarifies the data to be shared nor sets out any concrete guidance or best practices. USET SPF urges HHS to consider how it might more meaningfully implement the GAO’s recommendations.

Incorporate Enforceability and Eliminate Double Standards

A significant issue with this draft policy is the lack of enforceable standards. Within the draft policy, HHS Operating Divisions are directed to develop protocols and guidance that include procedures for requesting data, timelines for processing requests, review procedures and procedures for ensuring timely access to data. USET SPF agrees with the sentiment of these minimum requirements for Operating Division policies but urges HHS to require strict timelines for the acknowledgement of a Tribal data request as well as the processing of requests, particularly given the issues Tribal Nations and TECs have experienced thus far in accessing HHS data.

The GAO report reflects issues a vast majority of TECs have experienced with delayed or nonexistent responses from HHS Operating Divisions to their data requests, including the statement from multiple TEC

officials who reported that they had stopped making new requests for HHS data due to the agencies' delayed responses to prior requests. One of GAO's findings was that the HHS's lack of policies, guidance and procedures hinders access to data, and the recommendations center on the creation of guidance that includes information on how to request data and time frames for agency response to those requests. The Indian Health Service (IHS), in response to the GAO recommendations, has developed an initial policy that includes specific timelines for responding to different data requests. USET SPF supports the incorporation of timelines, but we maintain that they will remain ineffectual if enforceability measures are not also present.

In addition, the HHS draft policy and all Operating Division policies should include consideration and procedures for emergency situations, such as global pandemics, for example, when expedited access to public health data is required. A 30- or 60-day timeline to receive infectious disease data is entirely unhelpful.

HHS must also address the inappropriate double standards regarding opting out of data disclosures. While USET SPF unequivocally supports Tribal Nations' sovereign right to own and make decisions for their own data, the provision allowing Tribal Nations to opt out of data sharing with TECs through a request to HHS must be reconsidered. Tribal Nations and TECs are not afforded the ability to opt out of sharing their data with states and federal entities, so it is inappropriate to give such broad discretion to Operating Divisions to decide whether or not to share data. The draft policy also states that even with an opt-out in effect, Operating Divisions may still share that data with TECs. Further, the data currently accessed by Tribal Nations/TECs is of limited utility, particularly in the USET region where our member Tribal Nations are small and often racially misclassified. An opt-out policy in our region would likely further complicate the USET TEC's ability to provide specific health information and data to our member Tribal Nations who have already granted us permission to access and use their data.

Definition of Tribe-Specific Data

HHS must also reconsider the definition of Tribe-Specific Data within this policy. The definition hinges largely on the data being identifiable within the data set, but this is complicated by the nature of Tribal Nations. The policy goes on to say that "data pertaining to a specific Tribe or concerning Tribal Members is not considered Tribe-Specific Data...when data is not identifiable or attributable to a single Tribe." However, even in aggregate form and de-identified, the geographic locations of many of our member Tribal Nations and their small populations that often share genetic markers have the potential to expose Tribal Nations within the datasets. USET SPF suggests that HHS conduct further consultation on this definition and the guidance that will govern the sharing of Tribe-Specific Data.

Conclusion

Despite being statutorily recognized as public health authorities, Tribal Nations and TECs have struggled to secure parity in access to federal public health data for far too long. Lack of data hinders Tribal Nations' ability to identify and address public health priorities in our communities. HHS has taken nearly two years to develop a data sharing policy, and USET SPF is disappointed that this draft policy makes no meaningful progress toward improving data sharing between HHS and Tribal entities. Indeed, we are concerned that this policy may stand to further diminish Tribal Nations' and TECs ability to carry out the public health

activities with which we are charged. HHS has a dual obligation to correct these issues – both as an arm of the federal government tasked with fulfilling trust and treaty obligations, and as the covered entity tasked with sharing data and information with public health authorities. USET SPF urges HHS to reconsider this policy and its potential impacts and revise it with a better understanding and acknowledgement of Tribal sovereignty and the Department’s own legal obligations. 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,

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 'Kitcki A. Carroll', written in a cursive style.

Kitcki A. Carroll
Executive Director