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Xavier Becerra
Secretary
U.S. Department of Health and Human Services
200 Independence Ave. SW
Washington, DC 20201

Dear Secretary Becerra,

On behalf of the United South and Eastern Tribes Sovereignty Protection Fund (USET SPF), we submit these comments to the Department of Health and Human Services (HHS) in response to its request for comment on the draft Tribal Data Access Policy (TDA) and the draft Tribal Epidemiology Center (TEC) Data Access Policy (TECDA).While we appreciate the prior recommendations that HHS incorporated into these new drafts, USET SPF believes there is much more work to be done to make these drafts workable for Tribal Nations and TECs and continues to be disappointed by the attempts to restrict data access and sharing through the inappropriately-limiting language in these policies. Federal statute clearly directs HHS to share the data in its possession with Tribal Nations and TECs, yet these new draft policies still contain numerous caveats and possible loopholes that have the potential to limit the authority of Tribal Nations and TECs to access public health data.

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.

To offer a holistic view of USET SPF's recommendations, we have provided both a redlined copy of the TECDA policy and this comment document detailing our concerns with the draft policies. While USET SPF greatly understands the need to finalize and implement these policies, we believe that there are numerous

[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).

revisions necessary to bring these draft policies in line with federal law and make them appropriate for Tribal Nations and TECs.

**Federal Statute Requires HHS to Share Data with Tribal Nations and TECs**

Tribal Nations and TECs have an unambiguous statutory authority to request and access data in HHS's possession. 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 ourselves are designated as PHAs under federal law and regulation. The statute designating TECs as PHAs 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 both an unquestionable legal right for Tribal Nations and TECs to access protected health information and a clear obligation for HHS to share data with Tribal Nations and TECs.

Most importantly, that obligation is not conditioned on any action by or policy of Tribal Nations, TECs or HHS itself. Yet, this draft policy, like the previous draft, continues to condition data sharing with Tribal Nations and TECs on "feasibility," regulations, and existing agreements, and contains numerous other caveats that would serve to limit the data that HHS will share with Tribal Nations and TECs. Prior to and through these new draft policies, HHS and its Divisions have imposed separate standards for Tribal data requests, which are often more burdensome than those imposed on other PHAs and have cited federal law, regulations, existing agreements, technical constraints, HIPAA and other privacy concerns as their reasons for doing so. However, neither HHS as a whole nor its Divisions have the right to limit data sharing with Tribal Nations and TECs for any reason outside of federal law. Specifically in the case of HIPAA, that law 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. 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." Other federal laws, such as those governing the sharing of mental health and substance use data, may limit data sharing with Tribal entities on some occasions, but those federal laws are the only justification appropriate for limiting Tribal access to HHS data. The statute is exceedingly clear – Tribal Nations and TECs, as PHAs, have the right to access data in HHS's possession without the many caveats that HHS has created in these draft policies.

Beyond the fact that imposing these additional requirements and claiming internal HHS limitations as justification for limiting data sharing with Tribal Nations and TECs violates the statute governing our right to data sharing, to do so is also a violation of HHS's responsibilities under the federal trust and treaty obligations. As a federal entity, HHS is charged with upholding and honoring these obligations to Tribal Nations, and those obligations extend to the issue of data sharing. Constraints like technical capacity, available appropriations, or contradicting agreements with states are all HHS's responsibility to address in order to ensure that data requests from Tribal Nations are fulfilled.

Additionally, there are a few examples of other unnecessarily limiting language within the policies that must also be removed. The reference in the sections titled "Minimum Data Access" to "potentially accessible"

datasets must be removed for the reasons of superseding federal law and HHS's obligations as a trustee of the federal trust and treaty obligations discussed previously. The words "of likely interest" must also be removed, as HHS does not have the right to determine what data may be of "likely interest" to Tribal Nations and TECs. HHS must direct the Divisions to maintain lists of all existing data sets and defer to Tribal Nations and TECs to determine what is of interest. As we will discuss later in our comments, Tribal Nations have the sovereign right to determine our health priorities, and that right extends to the authority to determine what information is necessary for governance and operation of our health programs.

HHS's repeated attempts in this policy to limit what and how data should be shared with Tribal Nations and TECs must be removed and corrected. USET SPF identified many of these instances in the redline we provided, and our comments below discuss additional examples and reasons why these policies must be heavily modified to properly account for Tribal Nations's sovereign rights and the authorities Tribal Nations and TECs have as PHAs.

**Current Drafts Grant Inappropriate Discretion and Deference to Divisions**

While USET SPF acknowledges the necessity of Division-specific Tribal and TEC data sharing policies, the current HHS-wide draft policies grant far too much discretion and deference to the Divisions and their respective policies, procedures, authorities and agreements. Both the TDA and TECDA policies state that these HHS-wide policies do not "supersede or modify any other statutes, regulations, or data use or other agreements that govern HHS's or a Division's collection, handling, disposing of, or sharing of data" and that "[i]n the event of a conflict between this policy and Division specific authorities and agreements, the latter shall prevail." To allow Division specific agreements or regulations to prevail over this policy is inappropriate and would violate the clear statutory directives to share all data in the possession of the Secretary. Further, the draft policies currently state that Divisions shall provide Tribal Nations and TECs with the same level of data access as other PHAs "to the greatest extent possible." Tribal Nations and TECs are PHAs as affirmed under federal law and regulation, and there is no reason that a Division should ever not provide data access to the same level of other PHAs. As is the case with many provisions of these draft policies, these provisions are an example of overreaching language that stand to diminish and undermine the authority of Tribal Nations and TECs to access this data under federal law.

By employing overly broad and ambiguous language and deferring to the Divisions to detail "further specificity regarding access to and categories of Data" in their respective policies, the HHS-wide policies fail to realize their own goals and create additional potential opportunities to limit Tribal and TEC data access. The statute requiring data sharing with Tribal Nations and TECs does not include caveats for Division-specific policies or procedures, and therefore, Divisions must not be granted the authority to limit Tribal Nations' or TECs's access to data or the types of data that are covered under Division-specific policies. The Division-specific policies should simply detail the exact logistical procedures for requesting data in that Division's possession, the relevant points of contact, explicit and workable deadlines for acknowledging, processing and fulfilling Tribal Nation and TEC data requests, a clear appeal process for denied claims, and a list of data, data sets, monitoring systems, delivery systems and other protected health information in the Division's possession. These policies and their implementation should be simple because the only authorities against which the Divisions would need to check Tribal Nation and TEC data requests would be the Tribal entity's statutory authority to act as a PHA and other federal laws such as those governing the sharing of protected mental health and substance use information.

As written, a Division would have the broad authority to claim any number of reasons why it cannot facilitate data sharing, from its own regulations to technical restraints, to the availability of appropriations, or other yet-undefined "standards." For example, the sections on "Data Privacy and Security Protections" state that individual data use agreements (DUAs) with Divisions might include more stringent security protocols and defers to the Divisions to determine the level of protection appropriate "based on the sensitivity of the data and generally applicable standards." However, Divisions do not have the authority to impose additional requirements or limitations on Tribal data sharing for any reason outside of federal law. The federal laws governing Tribal and TEC data access and the inherent authority of Tribal Nations to act as PHAs supersede HHS regulations as well as any agreements between HHS, its Divisions, the states or any other third parties. To impose stricter security requirements based on subjective judgements about sensitivity both undermines Tribal Nations's and TEC's statutory right to data sharing and calls into question Tribal Nations's ability and authority to make decisions for our communities. And while USET SPF acknowledges that certain issues like a lack of available appropriations might present as a barrier for HHS and its Divisions, those issues do not override HHS's obligation to provide requested data to Tribal Nations and TECs and must not be referenced in these policies as justification for limiting Tribal and TEC data sharing and access. As stated previously, HHS's trust and treaty obligations to Tribal Nations as a federal entity require the agency to make the data requested by Tribal Nations and TECs in their capacities as PHAs available, and any limiting factors outside of federal law are HHS's responsibility to address in order to make the data available.

USET strongly opposes HHS's deference to the Divisions. It is inappropriate to defer this level of decision-making and policy drafting to the Divisions without requiring additional, extensive Tribal consultation. Tribal Nations and TECs have consulted on these draft policies for over two years, but as it stands, many crucial decisions about process are being left to the Divisions without explicit requirements to consult with TECs and Tribal Nations. In the event that HHS continues to defer to Divisions to establish their own policies, HHS must also require the Divisions to consult with Tribal Nations and TECs as they develop their Division-specific policies, and language in certain sections, like the sections on "Data Collection" must be revised better account for Tribal decision making regarding how data on our communities is collected, and none of proposed Divisional policies should exceed what the TDA already inappropriately limits. In the "Data Collection" sections, HHS encourages Divisions to evaluate their data collection and management methodologies as they relate to Tribal citizens and identity, and USET SPF strongly believes that this is a broader discussion that must happen in close consultation with Tribal Nations. How Tribal citizens and community members and their information are defined and collected is a sensitive topic with broad implications, and Divisions must not make these crucial decisions in the absence of Tribal consultation.

Ultimately, the policies as written fail to fulfill the stated purpose of these documents to create HHS-wide standards for Tribal and TEC data sharing and access. If the intent of these documents is to create a Department-wide policy for "how" HHS will provide Tribal Nations and TECs with data, "including the scope of Data available, the process to obtain Data, and the expected timelines for processing Tribal requests for Data," that intent is not realized in these draft policies. In the section titled "Interagency, Intergovernmental and Similar Agreements", HHS states that "as applicable and feasible," Divisions are "encouraged" to incorporate provisions into their relevant agreements that are consistent with these Tribal data access policies but are not required to do so. Language like this example that would allow Divisions to circumvent these HHS-wide Tribal data access policies completely undermines the intent to create Department-wide standards for Tribal data sharing. HHS must remove this and other instances where Division policies, regulations, agreements or actions are given the authority to supersede this policy and, by extension, the federal laws that require HHS to share the data in is possession with Tribal Nations and TECs.

**Tribal Nations Have the Sovereign Right to Define Our Communities and Priorities**

Within the TDA and TECDA policies, there are several mentions of "area" or "jurisdiction" that must be removed to account for Tribal Nations' inherent rights to define our own communities and data priorities. Language referring to a Tribal Nation's jurisdiction or a TEC's area creates the potential for overly-limiting data sharing decisions. For example, how a Tribal Nation may define its population for the purposes of determining cancer rates within its population may be tied more to geography, while its defined population for the purposes of tracking infectious diseases may be different and broader. Further, in the case of infectious disease tracking, a Tribal Nation may require access to data from surrounding areas, and language in these policies that refer to jurisdiction may undermine Tribal Nations's abilities to access critical public health data.

Therefore, HHS must remove all references to "area" or "jurisdiction" from the TDA and TECDA policies. As it stands, these clauses create the potential for HHS or Divisions to deny Tribal Nation or TEC data requests on the grounds that the request is outside our "area" or "jurisdiction" or otherwise not relevant to our communities. Tribal Nations have the sovereign right to self-governance, and this includes the right to determine what information is pertinent to our communities.

**Definitions of Data Must be Revised**

As currently written, the definitions of data in both the TDA and TECDA policies are insufficient and inappropriate. In both definitions, references to feasibility, regulations, and existing agreements must all be removed. In addition, the definitions must include not only the data contained within data monitoring systems, but access to the monitoring systems themselves. The statute governing access to data states that the Secretary shall share "data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary," and the definitions must account for this broad range of available information. The prior draft of this policy included "monitoring systems" in the definition, but the updated drafts only reference the data contained within those monitoring systems. HHS must comply with federal law and revert to the broader definition of data that is inclusive of monitoring systems.

Further, USET SPF believes, as discussed previously, any reference in the definitions to "area" or "jurisdiction" must be removed from the definitions of data and data access.

**HHS Must Reinstate the Provisions Requiring Tribal Consultation and Training for Federal Employees**

In the initial draft of these policies, HHS had included sections requiring Tribal consultation and training on Tribal data sovereignty and Tribal data sharing laws for federal employees, but those requirements have been removed from these drafts and must be reinstated. Tribal consultation must be required for Divisions as they develop their Division-specific policies, and there must be a requirement for ongoing Tribal consultation on the implementation of the HHS-wide policies and all Division-specific policies. The requirement for Tribal consultation is enshrined in federal law, regulations and Executive orders, and HHS must acknowledge and fulfill that requirement at all times, but especially when considering policies of this importance. HHS must also include the requirement of training for federal employees on Tribal data sharing

practices, Tribal sovereignty and Tribal self-governance. Many of the issues Tribal Nations encounter with federal officials stem from a lack of understanding of our inherent rights and the obligations that HHS as a federal entity have to Tribal Nations. Further, data sharing with Tribal Nations and TECs up to now has been heavily impacted by widespread lack of understanding within HHS Divisions when it comes to the legal right of Tribal Nations and TECs to access data within HHS's possession.

In addition, this draft removed the requirement that HHS create a "data governance board" and advisory boards that would have brought together Tribal officials and subject matter experts to improve data sharing and access at HHS and across Indian Country. This requirement should be reinstated in the final draft policies.

**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 over two years to develop these new draft policies, and USET SPF is disappointed that these updated drafts continue to make no meaningful progress toward improving data sharing between HHS and Tribal entities. Indeed, we are concerned that these policies 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 these policies and their potential impacts and revise them 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,

Kirk Francis
President

Kitcki A. Carroll
Executive Director