U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
TRIBAL DATA ACCESS POLICY

DECEMBER 6, 2024

SECTION 1
PURPOSE AND SCOPE

The United States Constitution recognizes the political relationship that exists between the federal government and Tribal sovereigns. This government-to-government relationship has been given form and substance by numerous treaties, laws, federal judicial precedent, and Executive Orders. Tribal sovereigns exercise their rights of self-determination and self-governance over their members, territory, and resources. Tribal sovereigns may also elect to exercise authority over public health matters impacting their Tribal Members, including emerging threats and other health-related needs in their communities.

Agencies and authorities of a Tribe responsible for public health matters as part of their official mandate, as well as those acting under a grant of authority from or contract with that public health agency, are public health authorities (PHAs) for purposes of the Privacy Rule promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). It is critical that agencies and authorities of a Tribe, acting in their capacities as PHAs, have timely access to appropriate data for their public health activities. As sovereign governments, Tribes also have important goals beyond public health, including the promotion of individual, family, and community wellbeing. These goals may also require data access, which is important for HHS to address to the fullest extent possible.

The purpose of this Tribal Data Access (TDA) Policy is to establish a U.S. Department of Health and Human Services (HHS or Department) wide policy for how HHS will provide Tribes with data (both in general and when acting in their capacities as PHAs), including the scope of data available, the process to obtain data, and the expected timelines for processing Tribal requests for data. It also establishes an HHS-wide expectation for responding to requests from Tribes for data in the custody and control of HHS and its Staff and Operating Divisions (collectively referred to as "Divisions").

By improving and clarifying how the Department will provide data to Tribes, HHS seeks to advance health equity for American Indians and Alaska Natives (AI/AN people) and eliminate data disparities facing Tribes. This policy will help ensure the Department is sharing data with Tribes to the maximum extent permissible under federal laws, regulations, and existing

agreements, and enhance the social, physical, spiritual, economic, and health status of AI/AN people.

This TDA Policy is applicable to all of HHS. It provides expectations and best practices for HHS to manage and respond to tribal data requests. Divisions with data covered by this policy shall develop or modify their implementation protocols for managing and responding to Tribal requests for data administered by or held under that Division's custody and control that are consistent with this policy, including but not limited to Section 6.

SECTION 2
OBJECTIVES

- To affirm Tribal sovereignty to support and promote public health and well-being in Indian Country; and improve health and human services and their outcomes for AI/AN individuals, families, and communities.
- To support the work of Tribes in the protection and promotion of the well-being of AI/AN people and the non-AI/AN community members Tribes also serve.
- To support the work of Tribal PHAs in the protection and promotion of the well-being of AI/AN people and the non-AI/AN community members Tribes also serve.
- To advance the Administration's priorities of achieving health equity, increasing transparency, and providing support for underserved communities, through the provision of data that will enable Tribes to better identify public health issues, allocate healthcare resources, and tailor actions to improve public health in Indian Country.
- To establish an HHS-wide policy with respect to data access for Tribes, while maintaining the necessary flexibility for Divisions to develop implementation protocols specific to their internal operations, data systems, applicable authorities, and existing agreements. Further specificity regarding access to and categories of data covered by this policy shall be identified in the Division-specific protocols and guidance to be developed in accordance with this policy, as detailed in Section 4.
- To recognize HHS's partnership with and support the work of Tribes in helping to meet the public health data needs of Tribes and Tribal organizations; and to support Divisions in their work to provide appropriate data to Tribes.
- To provide clear points of contact and protocols across HHS for tribal requests.
- To support Tribal capacity building as it relates to public health activities and specifically in the context of data access, security, analysis, and application.
- To charge and hold HHS accountable for the implementation of this TDA Policy.

SECTION 3
DATA AVAILABLE TO TRIBES

SECTION 3.1 TRIBAL DATA ACCESS AUTHORITIES, ACCESS TO PROTECTED HEALTH INFORMATION

HHS recognizes that Tribes are sovereign nations and the HIPAA Privacy Rule definition of PHA provides that Tribes may be PHAs, establish PHAs, or grant their PHA authority to another individual or organization. This policy does not alter the HIPAA Privacy Rule definition of PHA, nor impose additional requirements on the formation of a PHA; individuals or organizations serving as Tribal PHAs need only provide appropriate documentation to HHS that they have been authorized by the Tribe to serve in that capacity (for example, through a letter or email from the Tribal chair). Upon request for protected health information (PHI) by a Tribal PHA, PHI should be disclosed by HHS to that Tribal PHA for public health activities in accordance with the HIPAA Privacy Rule. Furthermore, PHI beyond that requested for public health activities may be provided to Tribes consistent with the HIPAA Privacy Rule and on par with the access provided to other government entities (e.g., state and local agencies). Data should be provided to Tribes in accordance with this policy, and without additional cost or process requirements to request or obtain data beyond what is expected of other government entities.

If Tribes or Tribal PHAs request PHI from HHS, HHS is permitted to rely on a statement from the requesting official that the requested information is the minimum necessary for the stated purpose(s), consistent with 45 C.F.R. § 164.514(d)(3)(iii)(A). To the greatest extent possible, Divisions shall provide Tribal PHAs with the same level of data access as other PHAs, without additional cost or process requirements to request or obtain data beyond what is expected of other PHAs.

SECTION 3.2 DATA PRIVACY AND SECURITY PROTECTIONS

The Department shall not provide data to any requestor, including Tribes, that cannot meet relevant privacy and security standards and requirements. Division-specific data guides shall include information about any general data security requirements related to disclosure of PHI, other personally identifiable information (PII), and sensitive or otherwise statutorily protected data in their possession. Individual data use agreements (DUAs) for specific data requests shall include more detailed information about security protocols required for access, when applicable. At a minimum, this shall include written assurance of data protection to the level determined appropriate by the Division disclosing the data, based upon the sensitivity of the data and generally applicable standards. Individual consent for the data to be disclosed may be required depending on the nature of the data, applicable federal law or regulation, such as "Confidentiality of Substance Use Disorder Patient Records" under 42 C.F.R. Part 2, Section 301(d) of the Public

Health Service Act, the Privacy Act of 1974, 5 U.S.C. 552a, the HIPAA Privacy Rule, and agreements between HHS and third parties, such as informed consent documents. Division-specific guides shall outline further process requirements, restrictions, or limitations to releasing such data, as applicable. Tribes shall not be subjected to higher levels of control than apply to other government entities or PHAs.

SECTION 3.3 MINIMUM DATA ACCESS

In addition to requests made as a PHA, a Tribe may also request datasets that can be made available to another government entity in furtherance of carrying out health and human services functions and promoting the health and well-being of its population. This includes, but is not limited to, datasets that contain aggregate data or individual-level data about the Tribe, general datasets pertaining to public health events impacting the Tribe, and datasets containing information about the health, public health, and human services delivery systems serving the Tribe, consistent with Section 6.

As described below, HHS will direct Divisions to maintain lists of potentially accessible existing datasets of likely interest to Tribes. HHS can only provide access to existing data that is under HHS stewardship. Divisions are expected to provide the same type of existing in response to a Tribe's request that may be made available to another government entity.

SECTION 3.4 COMPLIANCE AND GOVERNANCE

The HHS Chief Data Officer (CDO) shall oversee the implementation of this policy in collaboration and consultation with HHS Division CDOs and the Office of Intergovernmental & External Affairs (IEA). The HHS CDO shall manage and update a public access website that facilitates access to this policy, as well as the Division-level operating protocols, available datasets, points of contact, and guidance as described below.

SECTION 3.5 PERIODIC TRIBAL INPUT AND DATA FORUM

HHS shall stand up a data forum to periodically, but not less than once annually, solicit individual feedback and individual input from Tribal officials and Tribal subject matter experts regarding Tribal data access, which may include but not be limited to issues such as the efficacy and efficiency of Division operating protocols and guidance, as well as gaps in data practices, collection, and reporting methods as they relate to tribal data requests. These communications will not be in the form of consensus advice or recommendations. At the forums, HHS will also share updates, highlight relevant datasets and projects, and provide relevant information about Tribal data. HHS may also convene periodic Tribal listening sessions and Tribal consultations.

SECTION 3.6 SHARE BACK PROVISION

When a Tribe requests Tribe-specific data that it has submitted previously to a Division, every effort should be made to share back those data submitted directly by the Tribe in a timely manner (as defined in Section 4.1) by the recipient Division, consistent with Section 6.

SECTION 4
HHS DIVISIONS

SECTION 4.1 DIVISION PROTOCOLS AND GUIDANCE

Each Division with data covered by this policy shall develop operating protocols and guidance for responding to data requests from Tribes that are specific to each Division's internal operations, data systems, and legal authorities. Such Division protocols and guidance must comply with this TDA policy. Such protocols and guidance shall ensure data is secure and sufficiently available, consistent with this TDA Policy. Such protocols and guidance shall ensure access to data, datasets, monitoring systems, evaluation systems, delivery systems in possession of the Divisions are provided to the maximum extent permitted by applicable law, regulation, existing agreements, and Division privacy and security policies without the imposition of administrative conditions that are not otherwise generally applicable to PHAs or other government entities.

Division protocols and guidance shall include the components necessary for efficient and effective review, evaluation, and fulfillment of data requests from Tribes. Division protocols and guidance shall include at a minimum:

1) Procedures for submitting data requests, including the identification of any associated documents that may be required (e.g., standard forms, templates); this shall include any additional details regarding PHI requests, such as the minimum necessary standard under the HIPAA Privacy Rule.
2) Procedures for ensuring timely access by Tribes to requested data, including specific deadlines for processing data requests, with a maximum of 15 business days to acknowledge receipt of a request and 90 calendar days to grant or deny the request, and provide a description of steps necessary for the Tribe to take in order to receive such data (such as completing a data sharing agreement or credentialing users). In fulfilling approved data requests, all divisions must respond to Tribal correspondence within 5 business days to help ensure timely access to approved data.
3) Procedures for internal review of data requests, including for assessing and tracking compliance with Section 6.
4) A list of existing potentially available datasets that are of likely interest to Tribes.

5) Procedures for handling denials that include issuing a written notice to the requestor with a reason for the denial.
6) Procedures for expediting data requests, where possible, in the event of an emergency (whether a formally declared Public Health Emergency or other urgent response scenario). This shall include a process for the requestor to inform the relevant Division of the nature of the emergency.
7) Procedures to access technical assistance resources, if any, that can potentially assist Tribes with requesting data and complying with data security requirements.

Each Division with data covered by this policy should consider how best to securely transmit responses to tribal data requests to facilitate greater accessibility when possible and appropriate for public health activities, e.g., through machine-readable datasets, summary tables, graphs, and narratives. HIPAA-covered Divisions are encouraged to consider use of the HHS HIPAA Public Health Authority Disclosure Request Checklist as part of developing their operating protocols and guidance.[1]

Each Division shall complete the requirements of this section within twelve (12) months of this policy's Effective Date.

SECTION 4.2 POINT(S) OF CONTACT

Each Division with data covered by this policy shall designate an official point of contact or points of contact (PoCs), which may be a general inbox or inboxes and/or specified personnel position(s), for external correspondence related to Tribal data requests. The HHS CDO shall make the master list of PoCs available on the public data access website and keep the website updated. Division CDOs will notify HHS CDO of any updates and changes impacting accuracy of information on the HHS CDO public website within 5 business days of said changes.

SECTION 5
IMPROVING DATA

SECTION 5.1 INTERAGENCY, INTERGOVERNMENTAL, AND SIMILAR AGREEMENTS

It is HHS's intent that the best practices for Tribal data access set forth in this TDA Policy be advanced through relevant agreements that Divisions enter into on an interagency, intergovernmental (i.e., state, Tribal, local governments), or similar basis. As applicable and feasible, Divisions are encouraged to incorporate provisions into their relevant agreements that are

[1] HIPAA: Public Health Authority Disclosure Request Checklist

consistent with the purposes and objectives of this TDA Policy (including in DUAs, grants, funding agreements, etc.) that will further adherence to these principles.

SECTION 5.2 DATA COLLECTION

Underlying this TDA Policy, HHS acknowledges that the efficacy of data access and sharing rests on the foundational collection of accurate, quality data and data integrity. Accurate data collection, particularly in regard to the identification of AI/AN individuals, when possible, must be an HHS-wide priority to advance the purposes of this TDA Policy and public health investigations, actions, interventions, and health outcomes in Indian Country. HHS encourages all Divisions to evaluate their internal data collection, management methodologies. and metrics related to AI/AN information, including Tribal membership and multi-racial/ethnic identifying individuals.

SECTION 5.3 DATA GOVERNANCE BOARDS AND ADVISORY BODIES

To the extent possible, Divisions are encouraged to solicit the participation of elected Tribal officials and Tribal subject matter experts on federal-public data governance boards and other data advisory bodies, if permitted by applicable law. Where none exist, Divisions may consider establishing such advisory bodies, including Tribal specific data advisory bodies, if permitted in accordance with applicable law. Divisions are also encouraged to solicit input on data related matters through their respective Tribal advisory committees, as applicable.

SECTION 6
LIMITATIONS

This TDA Policy is not intended to waive or create any Tribal governmental rights or authorities, including treaty rights, sovereign immunity, or jurisdiction. Nor does this TDA Policy affect any rights or protections afforded to AI/AN individuals or others in regard to PHI and other PII under applicable authorities, such as HIPAA and 42 C.F.R. Part 2.

HHS also recognizes that the collection, management, use, analysis, disposal of, and sharing of data is subject to federal laws, policies, regulations, and, at times, by legal agreements under which data are collected that can vary by data type and dataset; therefore, careful consideration of the interplay of these laws and applicable agreements must be factored into data activities conducted in connection with the implementation of this policy. For this reason, the provision of data and data access under this policy are subject to all applicable laws, existing agreements, regulations, reasonable technical constraints, and the availability of appropriations.

This policy does not supersede or modify the statutory responsibilities set forth under the United States Code that pertain to Divisions or the Secretary. Nor does it 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. In the event of a conflict between this policy and Division-specific authorities and agreements, the latter shall prevail.

Other authorities or mechanisms not covered in this policy may exist that may prohibit, prevent, or limit the disclosure of data, such as, but not limited to, "Confidentiality of Substance Use Disorder Patient Records" under 42 C.F.R. Part 2, Section 301(d) and Section 308(d) of the Public Health Service Act, the Privacy Act of 1974, 5 U.S.C. 552a, and the Common Rule, 45 C.F.R. Part 46, Subpart A.

In all circumstances, data shall only be provided to the extent permitted by federal law, regulation, and federal agreements in place with the underlying data source, including contracts, Certificates of Confidentiality, and notices (e.g., privacy notices and consent agreements) with individuals from whom the data is collected.

SECTION 7
DEFINITIONS

For the purposes of this policy, terms are defined as follows:

Aggregate Data means, in general, the numerical or non-numerical information that is (1) collected from multiple sources and/or on multiple measures, variables, or individuals, and (2) compiled into deidentified data summaries or summary reports, typically for the purposes of public reporting or statistical analysis. The specific content and extent to which data is aggregated varies by dataset. Aggregate data may be disclosed using de-identified summary statistics and other appropriate forms of data transmission and must comply with applicable data protection requirements. Where aggregate data cannot be de-identified in accordance with all applicable authorities, such as reportable data containing less than a threshold of a specific population needed to maintain data protections, it shall not be released except as permitted by federal law, regulation, and existing data use or other agreements.

Data means information relevant to health and human services, including but not limited to information needed for public health purposes, that: is under the custody and control of HHS; can feasibly be disclosed to other government entities and public health authorities for use in activities advancing the health and wellbeing of Tribal members and related populations pursuant to and consistent with applicable law, regulation, and existing Division agreements; and is inclusive of data included in monitoring systems, delivery systems, PHI and other PII, including, unless specified otherwise, information at the individual and aggregate levels relevant to a specific Tribe.

Data Access means the act of providing data that is in HHS custody and control, including data maintained in monitoring systems and delivery systems, available for use by Tribes in their

capacities as public health authorities and sovereign governments. Direct access to monitoring systems and delivery systems may only be provided when permitted by all applicable authorities.

Department of Health and Human Services (HHS or Department) means the Cabinet-level department of the Executive branch whose mission is to enhance the health and well-being of all Americans by providing for effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services.

Division means the thirteen HHS Operating Divisions (OpDivs) that have responsibility for administering a wide variety of health and human services and conducting life-saving research for the Nation, and the seventeen Staff Divisions (StaffDivs) that provide leadership, direction and management guidance to the Secretary and the Department. OpDivs and Staff Divs are collectively referred to as Divisions.

Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law that, among other things, required HHS to adopt national standards to protect the privacy and security of certain health information. The implementing rules for these standards are the HIPAA Privacy, Security, Breach Notification, and Enforcement Rules (45 C.F.R. Parts 160 and 164).

Personally Identifiable Information (PII) means information that can be used to distinguish or trace an individual's identity, either alone or when combined with other information, that is linked or linkable to a specific individual.

Protected Health Information (PHI) has the same meaning as in 45 C.F.R. § 160.103.

Public Health Authority (PHA) means an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian Tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate. *See* 45 C.F.R. § 164.501.

Secretary means the lead federal official for the U.S. Department of Health and Human Services.

Tribal Epidemiology Center (TEC) means an epidemiology center established under Section 214 of the Indian Health Care Improvement Act, as codified at 25 U.S.C. § 1621m. A list of currently funded TECs is available at https://www.ihs.gov/epi/tecs/currently-funded-tec/. Per 25 U.S.C. § 1621m(b), TEC functions are specified as "(1) collect data relating to, and monitor progress made toward meeting, each of the health status objectives of the Service, the Indian tribes, tribal organizations, and urban Indian organizations in the Service area; (2) evaluate existing delivery systems, data systems, and other systems that impact the improvement of Indian health; (3) assist Indian tribes, tribal organizations, and urban Indian organizations in identifying highest-priority

health status objectives and the services needed to achieve those objectives, based on epidemiological data; (4) make recommendations for the targeting of services needed by the populations served; (5) make recommendations to improve health care delivery systems for Indians and urban Indians; (6) provide requested technical assistance to Indian tribes, tribal organizations, and urban Indian organizations in the development of local health service priorities and incidence and prevalence rates of disease and other illness in the community; and (7) provide disease surveillance and assist Indian tribes, tribal organizations, and urban Indian communities to promote public health."

Tribe means an Indian or Alaska Native tribe, band, nation, pueblo, village, or community that the Secretary of the Interior acknowledges to exist as an Indian Tribe pursuant to the Federally Recognized Indian Tribe List Act of 1994, 25 U.S.C. §§ 5130-31. Throughout this TDA Policy, Tribe is synonymous with Tribal government.

Tribal Member means an individual recognized by a Tribal government as a member, citizen, enrollee, or other term signifying formal political association of that respective Tribe according to the criteria established by that Tribe.

SECTION 8
EFFECTIVE DATE

This HHS Tribal Data Access Policy shall be effective immediately upon the signature of the HHS Secretary (Effective Date). There shall be a twelve (12) month implementation period, following the Effective Date, for Divisions to comply with Section 4. HHS shall review and consider updates to this policy, at a minimum, every three years.