

**Centers for Disease Control and Prevention Tribal Listening Session on Facilitating
Data Sharing for HIV, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis
Programs - March 31, 2026**

Summary

The Centers for Disease Control and Prevention (CDC) National Center for HIV, Viral Hepatitis, STD, and Tuberculosis Prevention (NCHHSTP) advances public health by strengthening collaboration across sectors and partnering with communities to address HIV, viral hepatitis, STDs, and TB by examining the specific social and health factors that affect disease spread through populations. Central to this mission is the effective use of surveillance and program data, along with strong governance and protections that ensure data are maintained securely and used responsibly to support prevention goals.

NCHHSTP is updating its 2011 *Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, STD, and TB*¹ programs to reflect new and evolving data systems and technologies and to better address partner needs. To support this effort, CDC convened a virtual Tribal Listening Session on March 31, 2026, to collect feedback directly from tribal nations, tribal epidemiology centers (TECs), and tribal-serving organizations, that is, organizations that provide assistance and resources to tribes, about their experiences with data sharing. The feedback provided by respondents focused on practical challenges, effective engagement practices, tribal governance considerations, and factors influencing decisions to participate in data-sharing arrangements. Insights from this discussion will guide updates to the revised guidance that acknowledge tribal sovereignty and strengthen public health partnerships.

The listening session was hosted by Dr. Renata Ellington, Acting Director for NCHHSTP, and facilitated by Anes Aref, Associate Director for Informatics, and the Systems Security and Privacy Officer at NCHHSTP, and Dr. Sharon Stanphill, Chief Health Officer of Government Affairs for the Cow Creek Umpqua Tribe of Indians Nation. In total, 213 people registered and 143 attended the virtual event. Participants included 35 tribal leaders, tribal members, tribal health organization members, tribal health care providers, and tribal-serving organization representatives. In addition, 67 CDC or Indian Health Services (IHS) and 16 state and local health department staff members attended. Finally, others in attendance included 25 members of other organizations representing various nonprofit, academic, and

¹ <https://www.cdc.gov/sti/media/pdfs/PCSIDataSecurityGuidelines.pdf>

federal partner organizations that support public health through technical assistance, research, workforce development, and health systems improvement.

The goal of the listening session was to give attendees the opportunity to share their experiences with two tribal data-sharing pathways on NCHHSTP data: 1) Data-sharing between a state or local health department and a tribe, and 2) Data-sharing between a state or local health department and a TEC.

To guide discussion, participants were invited to offer comments on four framing questions:

1. What have been your experiences with requesting or sharing data with state or local health departments?
2. What engagement practices have been helpful when state and local health departments request or use data involving tribal communities?
3. Which tribal governance or decision-making processes (e.g., consultation, approval, Institutional Review Board (IRB) review, tribal council involvement, TEC coordination) should be recognized when requesting or sharing data?
4. Under what circumstances might tribes or TECs choose not to participate in a data-sharing arrangement, and what approaches support respectful communication in those situations?

Approximately 15 attendees provided responses to the framing questions, either verbally or through the virtual session chat. Respondents included representatives of tribes, tribal-serving organizations, TECs, and IHS. Responses to these framing questions have been summarized into the key themes presented below.

Overview of Key Themes and Insights from the Tribal Listening Session

The listening session revealed consistent themes across tribal, TECs, and other tribal partners regarding the realities of public health data sharing. Respondents described current data-sharing conditions as influenced by long-standing relationships, staffing and information systems capacity constraints, evolving data systems, and the central importance of tribal sovereignty in all data-related decisions. Their insights highlight both progress and persistent challenges that could inform revisions to future guidance documents.

Data Sharing Experiences

Respondents described a range of experiences with requesting and sharing data with state and local health departments. Several respondents reported long-standing, trusted relationships that support effective data exchange. Others highlighted persistent challenges, such as staff turnover, inconsistent practices across states, limited access to detailed source/line-level data, and reliance on dashboards that do not provide enough detailed information on American Indian/Alaskan Native (AI/AN) populations. These inconsistencies and data gaps impede timely tribal public health action, limit outbreak response, and reduce the accuracy of tribal-specific public health insights. Specific comments included:

Relationship Building

Trust and clear communication emerged as critical components of successful data sharing. Examples included longstanding partnerships that have enabled rapid data exchange during outbreaks and formal agreements that affirm tribal ownership and control. Respondents emphasized that relationships require sustained investment, regular engagement, and mutual respect.

Software Integration

Several respondents noted efforts to modernize data systems, including joint implementation of platforms like Maven² to streamline investigations and improve seamless data flow between tribes and states.

Challenges in Data Access

Barriers included inconsistent data sharing processes, state-level variation in policy interpretation, staff turnover and shortages at state and local health departments, and information systems that categorize data by race/ethnicity rather than tribal affiliation, which do not meet tribal data needs.

Barriers for Tribal Epicenters

Several TEC respondents described substantial obstacles in obtaining data across multiple states. Limited access to detailed source data and differing state requirements complicate their ability to produce accurate tribe-specific reports and fulfill core functions.

Internal Tribal Data Processes

² Maven is public health information system used by some health departments to manage and track infectious disease cases, outbreaks, and related public health activities.

Many tribes are building internal data capacity, including developing dashboards and strengthening data infrastructure. While state websites and TEC partnership data reporting and analysis are commonly used, tribal data systems are still evolving. Current limitations may constrain data use, but future capacity growth will allow more detailed analysis.

Service Gaps and Data Infrastructure

Respondents described how gaps in local public health services, such as the absence of a public health nurse division, affect access to complete Sexually Transmitted Infection (STI) or STI treatment data and complicate coordinated response efforts.

Staff Capacity and Data Definitions

Capacity limitations at state and tribal levels—combined with dashboards lacking AI/AN-specific detail—pose challenges for timely, actionable data use. Differences in data definitions and structures further complicate data interpretation.

Effective Engagement Practices for Data Sharing

Respondents discussed engagement practices that facilitate respectful and productive data sharing between tribes and state/local health departments. They emphasized the role of tribal liaisons, regular meetings, understanding tribal sovereignty, and clearly communicating how data will be used. Collectively, these practices demonstrate that respectful engagement and clear communication are foundational to successful data sharing. Specific examples include:

Role of Tribal Liaisons

Dedicated state tribal liaisons were identified as essential for supporting respectful communication, ensuring consultation before data use, and helping navigate varying approval processes.

Regular Collaborative Meetings

Standing meetings across state, tribal, and TEC partners support relationship building, improve coordination, and enhance shared response to outbreaks and routine public health concerns.

Internal Approval Processes

Respondents indicated that data requests often require tribal council or IRB review. Transparency about how data will be used is necessary to build trust and facilitate timely approval.

Understanding Sovereignty and Authority

A deep understanding of tribal sovereignty, and explicit recognition within state policies, agreements, and processes, is essential for successful engagement. Lack of recognition remains a major barrier.

Staff Capacity

Staff limitations at tribes and health departments, combined with administrative requirements such as leadership letters or multiple approval steps, can delay data requests. Respondents suggested that streamlined agreements could reduce burden.

New Tribal Health Programs

Tribes establishing new public health divisions highlighted the importance of initial engagement meetings, community assessments, and ongoing communication to establish roles and expectations.

Tribal Governance and Decision-Making in Data Sharing

Overall, governance requirements must be central and considerate of tribal sovereignty. Respondents emphasized that there are several decision-making processes that must be recognized when requesting or sharing data, including consultation, IRB review, and tribal council involvement. They also highlighted the administrative burden of data sharing agreements and the need for flexibility and respect for tribal sovereignty in these agreements. Key themes included:

Consultation and Approval Processes

Data requests must align with tribal governance structures, which vary by tribe and may include review by tribal liaisons, IRB, executive directors, or tribal leadership. Respondents emphasized the need for clarity, relationships, and face-to-face communication.

Data Sharing Agreements

Respondents noted that negotiating multiple agreements across states creates administrative burden for the tribes. They recommend using umbrella agreements

that recognize tribal ownership, clarify authority, and allow flexibility across jurisdictions.

Flexibility and Sovereignty

Tribes emphasized that agreements must be adaptable, explicitly recognize tribal sovereignty, and should be tailored to tribal needs rather than standardized across jurisdictions.

Secondary Data Use and Biospecimens

Tribes require clear processes for approving any secondary data use and expect ongoing involvement in decisions regarding biospecimens.

Privacy and Data Protections

Concerns about privacy, especially for small populations, may lead tribes to decline agreements if protections are insufficient.

Recognition of Sovereignty

Tribes may choose not to participate when states fail to recognize sovereignty recognition, use unclear data-ownership language, or maintain strained relationships.

Administrative Burden and Data Quality

High administrative effort, combined with insufficiently granular or relevant data, can make agreements impractical for tribes and TECs.

Data Modernization

Respondents expressed interest in federal efforts to streamline tribal data access, modernize systems, and reduce the burden on tribes in navigating state processes.

Further Opportunities for Tribal Feedback

NCHHSTP encouraged continued input from tribal partners and invited written comments within two weeks (by April 14, 2026) to ensure all perspectives could be fully considered in the ongoing refinement of the updated Data Security and Confidentiality Guidance. CDC is also committed to reviewing and addressing any unanswered questions as part of the final session report.

Additional Comment or Follow-up Questions

CDC received one written comment from a TEC during the two-week response period. This comment was consistent with feedback given during the live listening session.

The quality of data sharing relationships between state health departments and TECs or tribes can vary. However, these relationships are most effective when states recognize TECs and tribes as equal public health partners. State health departments should engage with the tribes early and clearly communicate what data are being shared and their intended use. They should also ensure tribes have meaningful access to and control over how their data are used. Routine data sharing outside of public health emergencies can strengthen data-sharing relationships between states and tribes.

The TECs themselves are public health authorities, and tribes have sovereignty over their public health data. Tribes may rely on tribal council discussion or approval, tribal IRB or research review, and coordination through the TEC. They may choose not to accept data sharing agreements if there are any concerns, such as those related data quality, data misclassification, lack of tribal consent, unclear data use parameters, or data-sharing frameworks that do not recognize tribal public health authority. State health departments should respect a tribe's decision without applying pressure or criticism but also maintain open dialogue.

Next Steps

CDC NCHHSTP will carefully consider the lessons learned during this listening session when preparing the forthcoming revised Data Security and Confidentiality Guidance and tribal data sharing scenario. CDC will continue working with tribal partners, health departments, and funding recipients to help ensure that data are adequately protected and responsibly used. These insights will also serve as a resource for CDC's broader data modernization initiatives, informing ongoing efforts to improve data exchange security and efficiency. Continued engagement with tribal partners will remain central as NCHHSTP implements the revised guidance and supports data sharing across funded programs for HIV, viral hepatitis, STD, and TB. Together, these actions reaffirm CDC's commitment to tribal sovereignty and to supporting data sharing approaches that are responsive to tribal needs and priorities.