STRENGTHENING SYNDROMIC SURVEILLANCE DATA SHARING

with Tribes & Tribal Epidemiology Centers

REPORT AND RECOMMENDATIONS

FEBRUARY 2026

National Indian Health Board

About NIHB

MISSION STATEMENT

Established by the Tribes to advocate as the united voice of federally recognized American Indian and Alaska Native (AI/AN) Tribes, the National Indian Health Board seeks to reinforce Tribal sovereignty, strengthen Tribal health systems, secure resources, and build capacity to achieve the highest level of health and well-being for our People.

THE NATIONAL INDIAN HEALTH BOARD (NIHB) represents Tribal governments — both those that operate their own health care delivery systems through contracting and compacting, and those receiving health care directly from the Indian Health Service (IHS).

Located in Washington, DC on Capitol Hill, the NIHB, a non-profit organization, provides a variety of services to Tribes, Area Health Boards, Tribal organizations, federal agencies, and private foundations, including:

- **Advocacy**
- **Policy Formation and Analysis**
- **Legislative and Regulatory Tracking**
- **Direct and Timely Communication with Tribes**
- **Research on Indian Health Issues**
- **Program Development and Assessment**
- **Training and Technical Assistance Programs**
- **Project Management**

The NIHB continually presents the Tribal perspective while monitoring federal legislation and opening opportunities to network with other national health care organizations, to engage their support on Indian health care issues. The NIHB is the only organization of its kind; dedicated to strengthening healthcare for all American Indians and Alaska Natives (AI/ANs) and works to strengthen Tribal sovereignty.

CONTACT INFORMATION

National Indian Health Board

50 F St NW, Suite 600

Washington, DC 20001

MAIN PHONE: 202-507-4070

FAX: 202-507-4071

ACKNOWLEDGEMENTS

The NIHB respectfully acknowledges the crucial partnerships from Tribal health organizations, Tribal Epidemiology Centers, and state health departments, who provided the information necessary to develop this report and recommendations. NIHB also acknowledges the Council of State and Territorial Epidemiologists (CSTE), specifically the Syndromic Surveillance Team, for their financial support, guidance, and technical assistance in developing this report, and their ongoing commitment to strengthening Tribal data sovereignty.

NIHB would also like to acknowledge the work and support of the following staff towards this report:

- **SOPHIE SEMBAJWE** **Project Lead** ..... *Tribal Public Health Programs*
- **SARAH PRICE** **Associate Director** ..... *Tribal Public Health Programs*
- **TYRONE PETERSON** **Project Coordinator** ..... *Tribal Public Health Programs*
- **JEANNIE LE** **Project Lead** ..... *Tribal Health Data*
- **LUKE LAYMAN** **Tribal Health and Sustainability Scholar**

FUNDING

This report was supported by Cooperative Agreement number NU38OT000297 from the Centers for Disease Control and Prevention (CDC) and CSTE and does not necessarily represent the views of CDC and CSTE.

Executive Summary

Introduction

SYNDROMIC SURVEILLANCE provides public health officials with a timely system for detecting, understanding, and monitoring health threats. By tracking symptoms of patients in EDs and other settings—before and after a diagnosis is confirmed, all in near real-time—public health can detect unusual levels of illness to determine whether a response is needed. Public health also uses syndromic data to monitor disease trends. Syndromic data can serve as an early warning system to protect populations from respiratory viruses, environmental threats, avoidable injuries, emerging diseases, and more. Syndromic surveillance is a collaborative effort among local and state health departments, CDC, and partners.[1]

While Tribes and Tribal Epidemiology Centers (TECs) have inherent and designated public health authority, respectively, challenges to accessing public health data, including for syndromic surveillance, exist. This report explores prevailing data sharing practices around syndromic surveillance between states, Tribes, and TECs, and successes and barriers related to effective data sharing. This report also offers recommendations for systematic changes by federal, state, and local governments that can provide real-world solutions to supporting Tribes and TECs in participating in syndromic surveillance.

Methods

NIHB gathered information on current syndromic surveillance data sharing practices with Tribes and TECs using a mixed methods research approach, including:

1. An assessment conducted with state health departments on how states engage in syndromic surveillance data sharing with Tribal health organizations and TECs
2. Key informant interviews with a selection of states, Tribes, and TECs on syndromic surveillance practices, successes, and barriers; and
3. A legal scan of relevant state and Tribal laws related to syndromic surveillance.

Key Findings

Assessment Findings

Eighty-two percent of state health departments that responded to the assessment (32/39) reported that they do not share syndromic surveillance data with Tribes and/or TECs. Eighty-three percent of states that do share syndromic surveillance data (5/6) provide line level data or direct system access to their TEC(s), while only 33% reported that they share data with Tribes (2/6). All states that share data require formal data use agreements.

Findings from the State Key Informant Interviews

1. States want to work with Tribes and TECs more effectively
2. States differ widely in the level of data access they grant Tribes and TECs
3. States cite significant barriers to their ability to work with Tribes and/or TECs
4. Many states are new to syndromic surveillance or have limited infrastructure
5. Poor syndromic surveillance data quality and/or completeness impacts the ability to share data
6. States that partner closely with Tribes and/or TECs have found collaborative solutions that these states view as successful

Findings from Tribal Health Organization and TEC Key Informant Interviews

1 Tribes and TECs face challenges in accessing data in large part due to data-sharing policies and procedure limitations at the state level

2 Data quality and completeness is often insufficient for the needs of Tribes and TECs

3 States do not all recognize Tribal and TEC public health authority

4 Tribes and TECs have limited capacity to use syndromic surveillance data

5 Tribes and TECs are creating their own models and partnerships to access data

6 Tribes face competing priorities and staffing limitations

7 Tribal leadership and health officials are still deciding the role that Tribes and TECs should play in syndromic surveillance

Recommendations

General Recommendations

1 Encourage stronger understanding of Tribal and TEC public health authority to strengthen partnerships among state and local health departments with Tribal health organizations and TECs.

2 Improve the quality of data collected on American Indian/Alaska Native patients and Tribal community members at the healthcare facility level.

3 Increase the knowledge of state and local public health professionals on Tribal health systems and cultural safety.

Recommendations for Federal Agencies

1 Federal government agencies should work with Tribal public health authorities to develop models for syndromic surveillance that recognize the lawful status of Tribes and TECs as public health authorities.

2 Federal government agencies should support and invest in Tribes and TECs to strengthen their capacity to conduct and/or receive Tribal syndromic surveillance data, as well as disease surveillance more broadly.

3 Federal agencies, including CDC and IHS, should support Tribes by developing and/or updating national systems for syndromic surveillance to be more conducive to Tribal data sovereignty and to ensure Tribal contribution and participation in public health processes and data sharing practices.

A. Update National Systems for Syndromic Surveillance

B. Require and Incentivize States to Share Public Health Data

4 Ensure inclusion of national standards for collection of Tribal affiliation in future HL7 Syndromic Surveillance Implementation Guides and better enforce demographic standards used by the National Syndromic Surveillance Program (NSSP) and participating states.

Recommendations for State and Local Governments

1 Consult with Tribes and TECs early and often when developing syndromic surveillance systems.

2 Consider hiring and retaining Tribal liaisons and Tribally-focused epidemiologists at state and local government agencies.

3 Consider and share lessons learned from successful state, local and Tribal partnerships.

Table of Contents

Introduction

Background on Tribal Data Sharing

Tribal Nations, as sovereign nations, are inherent public health authorities with the rights and responsibility to protect the health of their people. With this authority comes the ability to gather, share, analyze and use public health data, including protected health information. This includes the right for Tribes to set the rules and regulations for surveillance and reporting within their jurisdiction and allows them to access information they deem necessary to protect Tribal citizens. Tribal Epidemiology Centers (TECs) are also designated by federal law as public health authorities[2] for the purpose of accessing protected health information covered by the Health Insurance Portability and Accountability Act (HIPAA) data, at the request of, and in consultation with Tribes[3].

Tribes have historically been unable to fully exercise their sovereign right to public health data due to significant data access barriers. TECs have faced similar challenges when accessing data on behalf of Tribes[4]. Historically, states have been the de facto holders of public health data, and surveillance systems have been designed without consideration for the unique structure of the Tribal health system. Tribes, despite having the same sovereign powers as states in relation to data reporting, have had to rely on data sharing arrangements with states without having the ability to collect their own data directly.[5]

Similar requirements are in place for their TEC partners. However, the ability to receive data has often relied on the varied relationship between each Tribe and/or TEC and their surrounding states and has been limited by state laws that govern data sharing, misunderstandings of Tribal data sovereignty, and systematic barriers in transmitting data across systems.[6] Tribes and TECs also often overlap with multiple states, and each state may have different practices for data sharing.[7] An additional barrier is that state agencies often contribute to the erasure of reportable data on American Indians and Alaska Natives (AI/AN), whether due to small sample size leading to data suppression, or due to poor demographic information being collected around race and ethnicity for AI/AN. Moreover, tribal affiliation has not traditionally been a required field in data collection efforts which poses additional challenges, affecting the completeness of data associated with enrolled Tribal members.

Because of these limitations, Tribes and TECs have often settled for aggregate data, or in many cases, no data at all. Without this data, Tribes and TECs have faced challenges in responding in real time to emerging public health threats and setting priorities for improving the health of their communities.

Background on Syndromic Surveillance

What is syndromic surveillance, and how is it different from other forms of disease surveillance?

Syndromic surveillance is an early warning public health surveillance system that assists health departments and other public health authorities in detecting, understanding, and monitoring health threats and disease trends in near-real time. In syndromic surveillance, emergency department (ED) data are collected and automatically reported daily to health departments. Some jurisdictions also collect data from urgent care, primary care, and in-patient hospital settings, while others may

also collect data from other sources including commercial laboratory, mortality, and behavioral health data.

Historical Overview of Syndromic Surveillance

At the core of syndromic surveillance is the use of pre-diagnostic information for early detection of public health events such as chief complaints, symptoms, and clinical findings. Since the early beginnings of syndromic surveillance in the 1990s — when it mainly targeted threats like bioterrorism and flu outbreaks — the practice has seen significant development. After the terrorist attacks of 9/11, its use grew rapidly and now covers a wider range of public health crises as well as regular health monitoring.[8]

Why is Syndromic Surveillance Important?

Syndromic surveillance is important for early detection of disease clusters and public health threats to facilitate and mobilize rapid response mechanisms with the aim of decreasing morbidity and mortality in target populations.

Brief Overview of Tribal Access to Syndromic Surveillance Data

TECs in some regions have managed to gain varying levels of access to syndromic surveillance data systems operated and managed at the state level, and through this mechanism can serve as a gateway for Tribes to access syndromic surveillance data on their Tribal citizens with varying levels of granularity.[9]

At the same time, the Indian Health Service (IHS), the federal agency charged with delivering direct health care and public health services to federally recognized Tribes and Urban Indians, operates health facilities across the country that use a separate syndromic surveillance reporting system that does not feed into the Electronic Surveillance System for the Early Notification of Community-based Epidemics (ESSENCE) system which is housed and managed by CDC's National Syndromic Surveillance Program (NSSP). At the time of this report, the IHS syndromic surveillance system and processes are still not integrated with any of the state instances of ESSENCE and other state-level syndromic surveillance systems. This poses challenges to the completeness of syndromic surveillance data reported to states, and by extension, the data received by Tribes and TECs. Tribes and TECs have to gain access to IHS syndromic surveillance data separately through other IHS-facilitated mechanisms.[10]

Goals of this Report

The National Indian Health Board (NIHB), in partnership with the Council of State and Territorial Epidemiologists (CSTE), conducted this project to understand current practices related to sharing and usage of syndromic surveillance data for federally recognized Tribes and TECs.

GOAL To strengthen Tribal capacity to receive and use syndromic surveillance data

OBJECTIVES OF THIS REPORT

1. Understand current Tribal and TEC participation in syndromic surveillance and access to syndromic surveillance data
2. Determine common barriers to data sharing between States, Tribes, and TECs
3. Propose recommendations to improve Tribal and TEC access to syndromic surveillance data and strengthen Tribal data sovereignty

Findings

State Assessment Results

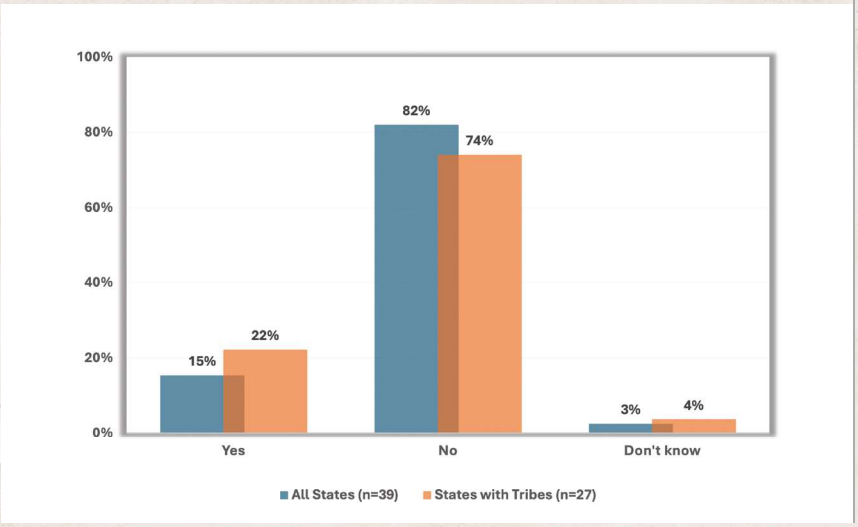
NIHB staff, with support from CSTE, administered a survey to representatives of all 50 state health departments. The purpose of the survey was to identify how states engage in data sharing with Tribal health organizations and TECs, with a focus on syndromic surveillance practices and procedures, and highlighting existing successes and barriers to data sharing. The survey was sent to CSTE's syndromic surveillance state listserv.

Thirty-nine states responded to NIHB's state health department assessment. Twenty-seven (69%) of these respondents represented state health departments that have at least one Tribal jurisdiction within their state boundaries. The state respondents represented all twelve IHS Areas

Figure 1 The Twelve IHS Service Areas [11]

Eighty-two percent of (32/39) state health departments reported that they do not share syndromic surveillance data with Tribes and/or TECs, with 74% (20/27) of states with at least one Tribe in their jurisdiction reporting that they do not share any syndromic surveillance data with Tribes and/or TECs. On the flip side, fewer than a quarter (6/27) (22%) of states with Tribal jurisdictions located within their borders reported that they provide non-publicly available syndromic surveillance data to Tribes and/or TECs in their geographical area ***(Figure 2)***.

Figure 2 Does the state engage in data sharing practices with Tribes and/or TECs for syndromic surveillance purposes (aside from sharing publicly available data)?



Practices for Sharing Syndromic Surveillance Data with Tribes and TECs

As stated above, six states (22%) with at least one Tribal jurisdiction within their borders reported sharing syndromic data with Tribes and/or TECs. The following two questions were asked of these six states ***(see Figure 3)***.

Five of the six states (83%) reported that they either shared line-level data or provided direct access to syndromic surveillance data to their corresponding TEC(s), with two also providing the TEC(s) non-public aggregate data. The remaining one state only provided their corresponding TEC(s) with non-public, aggregate data ***(Figure 3)***.

Only two states shared syndromic surveillance data with Tribes. One state reported providing line level or direct access to at least one Tribe, while the other provided both line level or direct access and non-public aggregate data to at least one Tribe ***(Figure 3)***.

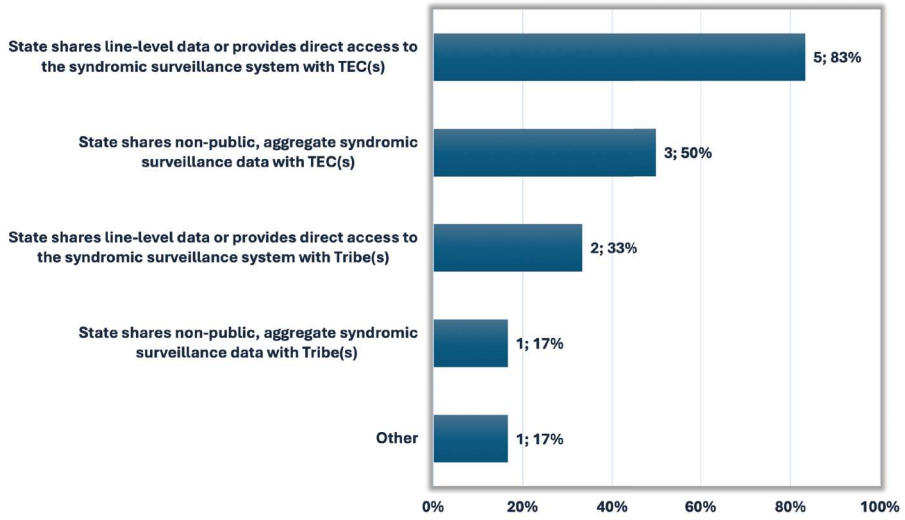


Figure 3 Current syndromic surveillance data sharing practices with the Tribe(s) and/or TEC(s) in each state's area (n=6)

All six states reported that neither Tribal health organizations nor TECs share syndromic surveillance data with the state, although one state noted that Tribal healthcare facilities contribute data directly to the state's syndromic surveillance platform.

Four of the states (67%) stated that they had formal agreements with the Tribe(s) and/or TEC(s) with whom they shared syndromic surveillance data. Additionally, one state reported that individual staff members from the TEC(s) they partner with are required to sign annual user confidentiality agreements ***(Figure 4)***. All five of these states share line level/direct data with their corresponding TEC(s).

One state reported using only informal agreements. This state provided only non-public aggregate data with their TEC.

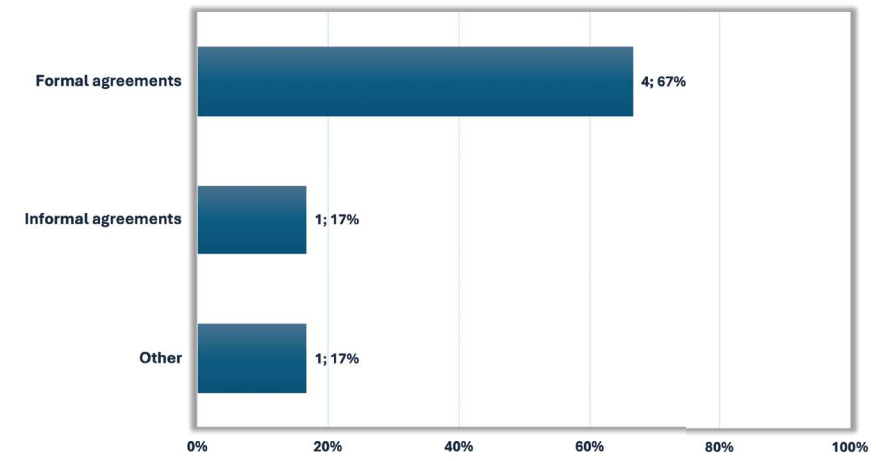


Figure 4 Type of data use agreements states have with Tribe(s) and/or TEC(s) with which they share syndromic surveillance data? (n=6)

Barriers to Syndromic Surveillance Data Sharing with Tribes and TECs

States that do not share syndromic surveillance data with Tribes and/or TECs in their area were asked about why they do not share data, including barriers they face in doing so.

Several themes emerged from the responses.

LIMITED STATE CAPACITY RELATED TO SYNDROMIC SURVEILLANCE: Many states noted that they faced capacity issues in conducting their own syndromic surveillance practices that significantly reduced their ability to partner with Tribes and/or TECs. This included limited funding and staff knowledge. Several states indicated that they are very early in the process of developing their syndromic surveillance practices.

STATE LIMITATIONS ON DATA SHARING: States indicated that broad limits on their data sharing with Tribes and TECs impacted their ability to partner. They suggested that the current syndromic surveillance system was heavily geared towards state and local health department access as opposed to Tribes and TECs. Several indicated that they did not have data use agreements in place with Tribal or TEC partners. Others indicated that, based on their understanding, they would only be allowed to share aggregate data with Tribes and TECs. One state indicated concerns about Tribes/TECs having access to all state data.

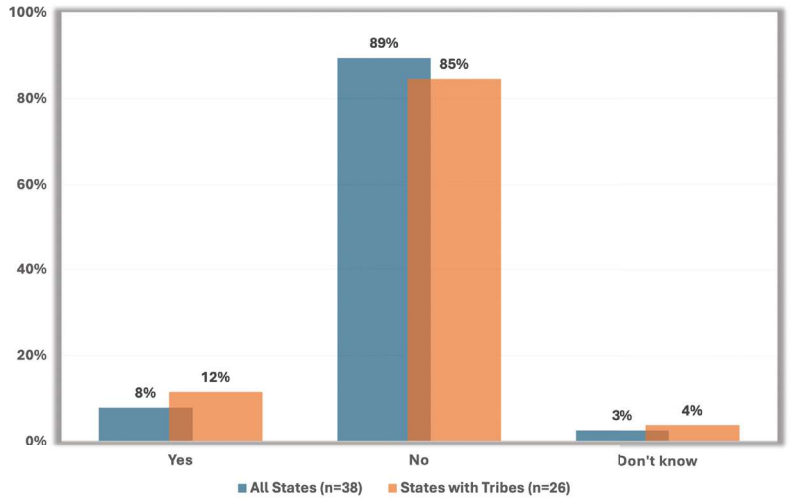
Several states indicated that there was a lack of knowledge around Tribal and TEC public health authority, and the requirements for data sharing with Tribal entities. Some indicated that they do not know much about the Tribal health system in general. Others stated that data sharing with Tribes was not a priority at their health department.

STATE PERCEPTIONS OF TRIBAL PRIORITIES AND CAPACITY: Several states indicated that, based on their perception, Tribes either do not have capacity or do not prioritize syndromic surveillance. States reported that Tribal data is not reported into the state's syndromic surveillance system, Tribes have not asked for their data in relation to syndromic surveillance, and/or the Tribes in their area have not demonstrated the capacity to use syndromic data.

THE NATIONAL SYSTEM FOR REPORTING IS NOT BUILT WITH CONSIDERATION FOR TRIBAL LAND BOUNDARIES

CHALLENGES FOR STATES IN IDENTIFYING DATA RELEVANT TO TRIBES: States reported several challenges related to identifying what data applies to or would be meaningfully relevant for Tribes and TECs to receive. Some states specifically pointed out that the data collected on race and ethnicity through syndromic surveillance was of poor quality, and due to the relatively small population size of Tribal communities in their region, their state's data sharing rules required the suppression of Tribal data in reports. This presented barriers to syndromic surveillance data sharing with Tribes and TECs. An additional barrier highlighted was the fact that Tribal affiliation, which could assist in identifying subsets of data relevant to Tribal communities, is not a field included in syndromic surveillance reports. Furthermore, some state respondents reported that since Tribal members often live and/or seek health care outside their Tribal lands, there is no clear mechanism to determine what criteria to use to share data or grant surveillance system access to Tribal public health authorities, in the same ways that county and state government entities access the data based on the state/county location of the healthcare facility or the patient's residence. The national system for syndromic surveillance reporting is not built with consideration for Tribal land boundaries.

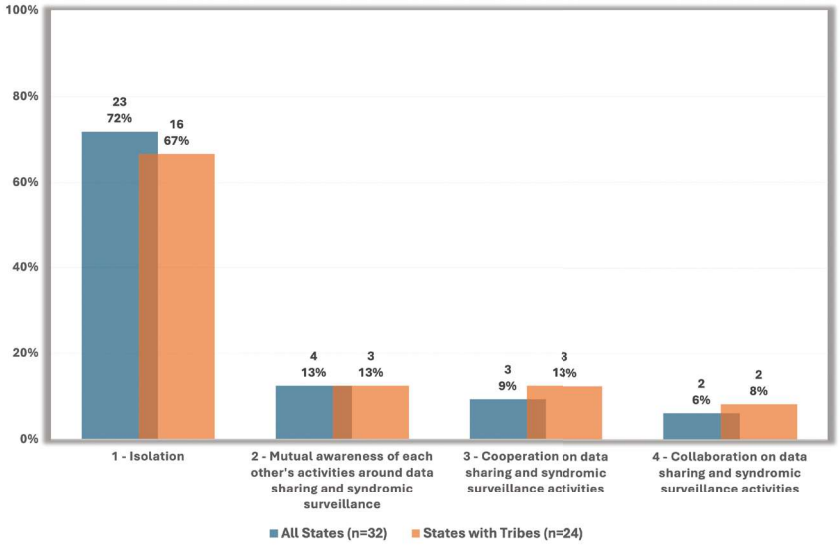
Figure 5 Does the state share any tools or resources related to syndromic surveillance with Tribe(s) and/or TEC(s)?



Tools and Resources Shared with Tribes and/or TECs

89% of states (34/38) reported that they did not share tools or resources related to syndromic surveillance with Tribes or TECs, with only three states stating they do share tools or resources ***(Figure 5)***. The types of tools and resources shared included trainings, guidebooks, toolkits, technical assistance, shared methods and queries (such as R scripts), and data dashboards.

Figure 6 State's characterization of the overall level of partnership and collaboration with the Tribe(s)/TEC(s) related to syndromic surveillance data



Overall Level of Partnership with Tribes and/or TECs

Overall, states characterized their level of partnership with Tribes and/or TECs related to syndromic surveillance as low, with the majority (72% of all states and 67% of states with Tribes) reporting "Isolation". Five states, all of which contain Tribal jurisdictions within their boundaries reported either cooperation or collaboration on data sharing and syndromic surveillance activities ***(Figure 6)***.

Key Informant Interview Findings

NIHB identified key state health departments, Tribal health organizations, and TEC partners to participate in Key Informant Interviews (KIIs). For states, these KIIs were intended to increase understanding of broad syndromic surveillance practices, if and how data and resource sharing occurs with Tribes and/or TECs, and explore any barriers or successes to working with Tribes and/or TECs on syndromic surveillance from the state's perspective.

For Tribes and TECs, these KIIs were intended to explore and better understand each Tribal public health authority's level of participation in syndromic surveillance, their ability to access data and foster data partnerships, and allow them to share related successes and challenges. Additionally, questions were asked to understand each Tribe and TEC's ideal role in syndromic surveillance, and how far they are currently from achieving this role.

NIHB identified and interviewed key state & tribal health groups and TEC partners

NIHB interviewed 21 respondents, including nine state health departments, five Tribal health organizations (defined as Tribal governmental public health departments or other Tribal entities performing public health services), and seven TECs. One state was excluded from the final analysis due to not completing a consent form for the KII. Respondents to the KIIs represented health organizations across seven out of the 12 IHS areas.

State Health Department Findings

NIHB staff analyzed the findings from the state health department KII responses to better understand how states shared data with Tribes, and their barriers in doing so. Several key themes emerged across the states interviewed.

1 States want to work with Tribes and TECs more effectively.

While states did not always share data in practice, all the participating state health departments acknowledged Tribal sovereignty and/or Tribal public health authority when discussing their syndromic surveillance data sharing practices. A common theme across many states was the desire to work with Tribes and/or TECs more appropriately, collaboratively, and effectively. States suggested several initiatives they felt would strengthen these relationships, including forming state-level workgroups with Tribes and TECs, opening up more dialogue, and developing national-level, standardized data use agreements that could be used to streamline formal partnerships between states, Tribes, and TECs. States acknowledged the need for improvement, with one state sharing that it is not the current or historical reality that Tribal data access is honored even if the state knows they have the right to receive this data.

2 States differ widely in the level of data access they grant Tribes and TECs.

Tribal and/or TEC access to syndromic surveillance data varied widely by state. One state was willing to provide direct access to Tribes, although they do not currently do so. In some other states, Tribes had no access to data or could only access publicly available, aggregate reports. One state

indicated that they were unauthorized to send data to non-state entities.

Several states made it clear that Tribes can access data, but only upon request. One state indicated that Tribes can request specific data or can collaborate on outbreak response activities but did not refer to the existence of more general, ongoing data sharing processes with Tribes.

Five out of the nine states that participated in the KIIs discussed having data use agreements in place to share syndromic surveillance data with TECs, with some sharing data through direct system access while others shared data indirectly.

3 States cite significant barriers to their ability to work with Tribes and/or TECs.

The states that participated in the KIIs reported several significant barriers that prevent them from working with Tribes and TECs on syndromic surveillance.

- Six states cited communication challenges and delays.
- Five states cited bureaucratic hurdles such as the federal government or states limiting the data.
- Four states cited distrust between Tribes, TECs, and state health departments as a major barrier.

Several states also indicated that their perceptions of Tribal capacity and prioritization of syndromic surveillance was low. States shared that Tribes had little knowledge of syndromic surveillance, that many Tribes considered syndromic surveillance low in priority, and that Tribal staffing levels were a challenge. One state shared that, while Tribes sometimes asked for data, what they really needed was assistance with analysis and interpretation of the data, so more work was needed to understand the needs within Tribal partnerships.

4 Many states are new to syndromic surveillance or have limited infrastructure.

Half the participating states reported that there were limitations in the state's syndromic surveillance infrastructure that limited the state's ability to support Tribes and/or TECs. There were reported challenges with limited funding, staffing, unclear roles when working with Tribes on data sharing, and competing priorities.

5 Limitations in quality and/or completeness of healthcare facility data impacts the ability to share data with Tribal entities.

Six states indicated that data quality and completeness is a large barrier to data sharing. Facilities did not collect complete data on race and ethnicity, and Tribal affiliation is not an option in reporting forms, nor is it mandated for healthcare organizations reporting to the state. Because of this, there are challenges identifying who is AI/AN, and what their Tribal affiliation may be, which limits the degree the syndromic surveillance data received at the state can be associated with Tribal jurisdictional areas and what parameters can be used for syndromic surveillance data sharing beyond the use of available zip code.

Adding to this challenge is that, in some states, Tribal healthcare facilities are not part of CDC's national syndromic surveillance reporting system because they use RPMS the primary electronic health record system under IHS, which does not currently have electronic reporting capability to participate in NSSP. Furthermore, many Tribes do not have health facilities that operate emergency departments, which are the primary contributors to syndromic surveillance data at the healthcare facility level nationwide.

6 States that partner closely with Tribes and/or TECs have found collaborative solutions that these states view as successful.

Several states shared successes they had experienced when partnering with Tribes and/or TECs to develop collaborative solutions. Some examples included:

- Working with Tribes to help them receive hospital data directly
- Working with TECs to collaboratively support hospitals in collecting better race, ethnicity, and Tribal affiliation data
- Using workarounds to find proxies for Tribal affiliation (i.e. geographic location) to better refine the most relevant data for Tribes and/or TECs
- Advocating for Tribes to have direct access to syndromic surveillance data
- Having a Tribal epidemiologist and Tribal liaison at the state to ensure collaboration
- Establishing office hours for Tribes to receive technical assistance
- Seeking Tribal approval before publishing data on Tribal citizens

FINDINGS ACROSS TRIBAL HEALTH ORGANIZATIONS AND TRIBAL EPIDEMIOLOGY CENTERS

NIHB staff analyzed and consolidated the findings from the Tribal health organization and

TEC KII responses to better understand how they engaged with syndromic surveillance. Several key themes emerged across both the Tribes and TECs interviewed.

Barriers to Syndromic Surveillance Data Sharing

1 Tribes and TECs face challenges in accessing data due to state limitations.

All five Tribal health organizations and seven TECs that were interviewed reported that states serve as the primary holders and stewards of syndromic surveillance data. Respondents also noted that states conduct syndromic surveillance activities within and around Tribal jurisdictions. However, data from Tribal health facilities is not always consistently reported to state systems.

Three out of the five Tribes and six out of the seven TECs who participated reported that state limitations created barriers to their ability to receive data. Data use agreements were commonly needed to facilitate data sharing. Three of the Tribes and four of the TECs stated that they currently had a data use agreement with at least one state.

All Tribes interviewed only overlapped with one state. TECs, however, could overlap with multiple states. Some TECs shared that there were differences across the various states they worked with, with some states not currently providing data use agreements. Both Tribes and TECs also shared that some data use agreements with states were mutually beneficial and collaborative, while others were paternalistic, not designed for Tribal needs, or actively limited the type of data Tribal public health authorities could access. One TEC also shared that developing data use agreements with one state was a lengthy process that presented delays in accessing, analyzing and reporting data.

The TEC suggested that the process be improved by including Tribal organizations at the onset of the data use agreement process and instating an

automatic renewal process thereafter.

Overall, access to syndromic surveillance data varied widely by state, and ranged from productive data sharing partnerships to no data being shared. Two TECs shared that at least one of the states they overlapped with designed their data-sharing processes collaboratively with Tribes. However, other states have imposed barriers on data sharing. In some cases, state laws were perceived as a barrier to data sharing; as an example, one Tribe reported that the state shared data with local health departments, but not Tribal public health authorities.

Tribes and TECs also reported that distrust played a role in limited data sharing partnerships. Respondents from the TECs also shared several systematic barriers, including:

- Lack of real-time data due to indirect access to surveillance system(s) and lags in receiving data. Six TECs shared that they must specifically make formal data requests to gain access to data they need.
- State protocols limiting access to data, such as states requiring minimum case thresholds to share data.
- Data collected by the state being mismatched or aggregated inappropriately. Four TECs shared that the data they receive is often not useful for Tribal and/or TEC needs.

Access to syndromic surveillance data varied widely by state

2 Data quality and completeness is often insufficient for the needs of Tribes and TECs.

Tribes and TECs both reported challenges using the data that is shared or available to them due to the quality and completeness of the data. Syndromic surveillance relies on data being timely and accurate. Several Tribes and TECs reported that the data they received from the states and other external agencies was not in real-time and was only accessed indirectly with inconvenient time lags. Moreover, two Tribes and four TECS stated that they faced major challenges in identifying Tribal members or Tribally-relevant associations in the data they received. Demographic information was often incomplete or inaccurate, and Tribal affiliation was not collected. Tribes and TECs that overlapped with multiple state jurisdictions reported facing additional barriers based on the different data-sharing protocols employed from one state to another.

Three Tribes reported that, while they received data from the state, this data did not coincide with their Tribal needs. One Tribe specifically stated that while they could access data directly from the state surveillance system, this did not prove very useful to them. This is because their Tribal clinics do not report data into any of the state surveillance systems, but instead report to IHS through a separate system, from which the Tribe does not routinely receive data. Some TECs also shared that data received in aggregate from the state was often not specific enough to make it actionable to them.

Several Tribes and TECs shared some solutions they use to adapt to these data sharing challenges. One Tribe shared that they receive data from the county rather than the state, as they can partner more closely at the county level than the state level to identify Tribal members and receive data that is more Tribally relevant. One TEC reported that they have linked syndromic surveillance data from one state health department with IHS data they periodically receive, to try to correct for racial misclassification in their data. However, this method has been used on historical data sets, rather than on near real-time surveillance data.

3 Not all states recognize Tribal and TEC public health authority.

Tribes and TECs reported that states did not demonstrate an understanding of Tribal or TEC public health authority, or how the Tribal public health system functions in general. Five of the TECs interviewed, and one Tribal health organization stated that the role of Tribes and TECs is not well understood by their state partners. Current data ownership practices prioritize state rights over that of Tribes or TECs. Because of this, states are set up as gatekeepers, and Tribes and TECs often cannot get direct access to their data the way states do, despite the fact that Tribes, like states, have inherent public health authority, and that TECs have been granted public health authority for the purposes of accessing protected health information in consultation with Tribes. One TEC also shared that Tribes and TECs are not seen as equals to state and local public health authorities, and therefore even when a state offers to share data, they create additional barriers such as training, or have undue suspicions due to Tribe and TEC's lack of staffing, funding, and infrastructure

TRIBES REPORT THAT STATES HAVE NOT DEMONSTRATED AN UNDERSTANDING OF TRIBAL PUBLIC HEALTH

4 Tribes and TECs have limited capacity to use syndromic surveillance data.

Tribes and TECs both discussed their limited capacity in relation to syndromic surveillance and data usage in general. Both discussed lack of training for staff, with four of the five Tribes and five out of seven TECs identifying staffing as a barrier. Additionally, funding was a barrier for five of the participating TECs. Tribes stated that not all Tribes were prepared to manage or act on data, even if shared by the state, while TECs highlighted system capacity challenges, including data storage and analysis software limitations.

Opportunities for Syndromic Surveillance Data Sharing

Tribes and TECs are creating their own models and partnerships to access data.

Tribes and TECs are innovating to address data challenges and have been creating their own models and partnerships to better access syndromic surveillance data in their communities.

TRIBAL MODELS AND EXAMPLES OF SUCCESS:

Tribes have reported success with several models for receiving data including:

- Accessing clinical data directly from their own Tribal clinic and healthcare organizations
- Developing partnerships with their surrounding counties, where the county gets data from the state syndromic surveillance system, and collaborates with the Tribe, sharing the data via phone or email.

Several Tribes felt that they were able to develop strong, collaborative relationships with state and local health departments, even if the Tribe did not access syndromic surveillance data.

One Tribe also discussed that the Tribes in their state had considered developing a state- wide Tribal surveillance system that Tribes could directly access, and that partners with (but can limit) state access to Tribal data.

TEC-SPECIFIC MODELS AND EXAMPLES OF SUCCESS:

A number of TECs are still in the early stages of their syndromic surveillance capacity and processes. Others who do not currently participate in syndromic surveillance have expressed considerable interest in eventually participating in this form of surveillance.

While none of the TECs believed that they had complete access to the data they wanted, six of the seven TECs reported having some access to syndromic surveillance data. TECs gained access to this data using various mechanisms, including adopting solutions designed to circumvent limitations imposed on them by the state.

Three TECs reported having direct access to some form of syndromic surveillance system while four reported indirect access. Syndromic surveillance access options that were cited included:

- Direct access to subsets of the state's syndromic surveillance system
- Receiving aggregate data from the state
- Directly receiving data from Tribal healthcare facilities through data use agreements (DUAs)
- Requesting data from IHS (although this is not in real-time posing a major limitation)
- Using data from Medicaid on Tribal patients

Some TECs are using alternate approaches to support their syndromic and disease surveillance capacity to provide them with greater access and autonomy over their data. These approaches include working directly with CDC, and with companies such as Google and Amazon to build out their internal data systems.

Findings Specific to Tribal Health Organizations

Several additional themes emerged that were specific to the interviews conducted with Tribal health organizations. This section focuses on the perspectives of Tribal health organizations, defined in this report as Tribal governmental health departments and other Tribally-led governmental entities that perform public health activities and that are distinct from the existing network of TECs. Importantly, Tribes are the decision makers for how data should be received and analyzed for their communities. As the governing authority behind TECs, Tribes have additional decision making around their public health roles and capacity, and around their policies and preferences on how to engage with TECs, and on how TECs should be partnering with Tribes, states, and local health departments. Additionally, as Tribes vary widely in size, location, population, and other characteristics, they may face different capacity challenges and varying levels of interest in collecting certain types of data compared to TECs, which have a clear mandate to build capacity for Tribal data collection and analysis.

1 Tribes face competing priorities and staffing limitations.

Syndromic surveillance is not necessarily a priority when it comes to the types of surveillance data Tribes want to pursue.

Only one Tribe that was interviewed currently has access to syndromic surveillance data, although several pull data from their clinics but not specifically for syndromic surveillance. Two Tribes could have access but choose not to at this time due to data infrastructure and capacity limitations, and poor data quality in relation to Tribal patients.

2 Tribal leadership and health officials are still deciding the role that Tribes and TECs should play in syndromic surveillance.

ROLE OF TRIBES IN SYNDROMIC SURVEILLANCE: Tribal public health officials have limited knowledge about syndromic surveillance and in many cases Tribes are newly navigating their roles as public health authorities and what that means for them in regard to syndromic surveillance.

ROLE OF TECS IN SYNDROMIC SURVEILLANCE: Several TECs reported that they share data with Tribes in the form of reports or dashboards which can be perceived as a success for Tribal access to syndromic surveillance data. Two Tribes specifically indicated that the TECs in their region are the data hub for their syndromic surveillance work. In this light, TECs play the role of facilitators for data access for the Tribes in their region. However, it is important to note that the syndromic surveillance data directly accessed by the TECs is often limited and controlled at the state level. Most, if not all TECs, do not receive state-wide or regional data.

Reported Findings by Region

NIHB cross-referenced the responses of state health departments, Tribal health organizations, and TECs by region to summarize data and determine commonalities and disagreements across responses. The names of each region are confidential to protect the identity of the respondents.

PROJECT REGION 1: The TEC staff in Project Region 1 expressed a very clear desire to share syndromic surveillance and other public health data with Tribes in their region. They are in the very early stages of gaining access to the national ESSENCE system and are still in the process of putting mechanisms in place to ensure their ability to share syndromic surveillance data with Tribes that want to receive it. Two states in this project region have not historically shared syndromic surveillance data with Tribes, but there was interest at the state level in sharing public health data with Tribes through greater collaboration in the future. There was explicit interest from one Tribal health organization in this project region to formalize the syndromic surveillance data sharing processes with their regional TEC, to eventually begin receiving syndromic surveillance data for their public health activities.

One state and one tribe in this project region mentioned distrust between Tribes and the state as being a strong barrier to adequate data sharing. The participating Tribe and state also expressed interest in partnerships across states, the Tribes and the TEC in the region.

PROJECT REGION 2: One of the states in this project region believed they were doing a good job of partnering with the TEC and that there were not many barriers to data sharing. On the other hand, the TEC staff in the region reported that one state's prevailing approach to the TEC was very paternalistic. The TEC staff felt that there was inadequate recognition of the TEC's public health authority at the state level, and that it is common practice at the state level to make unilateral decisions on the type of data and format the TEC should receive. The TEC staff expressed that at times they could only access data aggregated by the state in ways that were not optimal for use by the TEC and Tribes in the region. There is a strong feeling at the TEC level that the states hold themselves as de-facto holders of public health data for the Tribes in their region.

One Tribe in the region reported that the state grants them direct access to ESSENCE, which is used at the state-level for syndromic surveillance. A second Tribe reported limited partnership with this state, and preferred working with the county health department in their area. For this second Tribe, partnering to receive data from the state would present a lot more barriers as it would be harder to identify Tribal citizens in the state-level data.

Whereas, the local county and Tribal jurisdiction overlap with one another, making the sharing of public health data between the county and Tribe much easier.

PROJECT REGION 3: One state in the region actively shares indirect syndromic surveillance data with their regional TEC. They formalize this process through data use agreements between the state and TEC which have to be renewed periodically. The process for renewal of these DUAs can be relatively lengthy and pose significant barriers to the ability of the TEC, and by extension, the Tribes in the region to receive syndromic surveillance data in a timely fashion. Most Tribes in the region

do not operate emergency department facilities, so to obtain syndromic surveillance data for their Tribal members, it is imperative that they coordinate with the states and federal agencies who serve as gatekeepers for this data. IHS serves as a key partner in the coordination.

PROJECT REGION 4: The TEC staff in this project region expressed some difficulties with receiving syndromic surveillance data from IHS for the facilities in their area. The data they receive from IHS is not in real time and is received every several months. There is no real- time direct access to syndromic surveillance from either the state or IHS. The state staff in this project region expressed real interest in engaging more with Tribal entities in their region. They did allude to a potential data sharing partnership with one Tribe in their area to receive syndromic surveillance data directly; however, that collaboration was stalled due to competing priorities at the Tribal level.

PROJECT REGION 5: The state in this project region does not share any data directly or indirectly with Tribal entities in their area including the TEC in their region. The TEC staff in this region expressed frustration with how existing state laws can be interpreted in ways that can hamper the sharing of public health data with the TEC and other Tribal entities in the area. The staff at one Tribal health organization expressed only being able to receive some form of syndromic surveillance data from their Tribal health facility but not from the county, state, or TEC in their area. The state and Tribal public health authorities in the region do want to establish formal data use agreements, but effectively operationalizing data sharing across these entities is needed to address the real-world barriers that exist which include the understaffed, underfunded and under-resourced Tribal institutions.

PROJECT REGION 6: The TEC in this project region accesses syndromic surveillance data from the state and funnels this to Tribes in their region who want to receive it. The TEC specifically has direct access to a subset of the syndromic surveillance data at the state- level and is able to provide tailored reports to Tribal entities in their region. However, the TEC staff report that they lack formal recognition or authority from states. This limits their ability to act on behalf of Tribes and interrupts data sharing and workflows. Two states enforce protocols, such as minimum case thresholds (e.g. 10+) for reporting data out and require state review before releasing data products to Tribes. The third state in the region requires state review before releasing data externally but has been comparatively faster and more responsive to TEC and Tribal data requests. One Tribal health organization in the region expressed difficulty in using the data received from their TEC for syndromic surveillance purposes due to gaps in Tribal-specific information in the data. The Tribal organization stated that they receive data that can be used for syndromic surveillance purposes from their Tribal health center only. They emphasized that data from the IHS electronic medical record can be challenging to compile into reports because of how outdated and piecemeal the data from IHS can be.

PROJECT REGION 7: State-level and TEC-level public health collaboration and syndromic surveillance data sharing in this project region remain relatively strong. The TEC in the region has direct access to the state-level syndromic surveillance system providing them with the subset of data associated with the Tribal jurisdictions in the region. The existence of strong partnerships between the state-level and TEC-level epidemiologists has been a great facilitator for collaborative public health partnerships in the region. There is a strong culture of respect for Tribal public health authority and data sovereignty that is lacking in some of the other project regions. TEC staff in this region pointed out that nationwide there is a prevailing distrust between states and Tribes, and existing prejudices originating from non-Tribal government personnel (federal, state, and local) toward Tribes and TECs that hampers productive collaboration and public health data sharing across the country.

Scan of Syndromic Surveillance Laws

Jurisdictional public health laws can play a role in determining the level of data access provided to Tribes and TECs. To determine the potential impact of public health laws and legal requirements on syndromic surveillance data access for Tribes and TECs, NIHB identified relevant laws, statutes, policies, codes, protocols, ordinances, regulations, resolutions, guidance, and other legal documents that govern data sharing between states, Tribes, and/or TECs for all states that participated in the KIIs.

All documents included in this legal scan were required to be publicly available. NIHB used the following methods to identify documents for review and inclusion in the scan:

1 Directly reached out to staff in each state jurisdiction interviewed to request any legal documentation pertinent to their syndromic surveillance and public health data sharing and reporting.

2 Conducted an online search for publicly available legal documents on public health data sharing pertaining to each participating jurisdiction.

3 Utilized legal documents previously identified and systematically reviewed by CSTE that were found to be relevant to public health data sharing in several states of interest.

State laws often enable or prohibit data sharing with Tribes, whether explicitly (by including Tribal entities in the text specific to the law) or implicitly (by enforcing laws with no mention of Tribal entities that may still impact data sharing practice with Tribes). NIHB reviewed state laws to understand:

1 If syndromic surveillance reporting is mandated by the state;

2 If syndromic surveillance reporting guidance or laws require, allow, or prohibit sharing data with Tribes and/or TECs;

3 If general surveillance data reporting guidance or laws require, allow, or prohibit sharing with Tribes and/or TECs**[12];

4 If state guidance or laws recognize Tribal and/or TEC public health authority, role in data collection, data sovereignty, etc.;

5 If state guidance or laws actively encourage or have policies to facilitate better data sharing with Tribes and/or TECs;

6 If race, ethnicity, and/or Tribal affiliation are required to be reported for syndromic surveillance data and /or general data surveillance data.

These laws were then cross-referenced with the state assessment and KII results to understand the potential impact of these laws on public health practice.

***In the absence of specific syndromic surveillance laws, a state's existing authority to conduct public health surveillance is generally recognized as providing support for voluntary syndromic surveillance systems.*

Therefore, it is expected that general surveillance laws will govern data sharing with Tribes and TECs where syndromic surveillance is not mandated.

SOURCE: *Purtle, J., et al. (2018). The Impact of Law on Syndromic Disease Surveillance Implementation.* **J Public Health Manag Pract**. *24(1): 9–17. doi:10.1097/PHH.0000000000000508.*

Tribes, as sovereign nations, have jurisdictional authority, and can establish public health reporting requirements within their jurisdiction. To this end, NIHB reviewed the Tribal laws for all the Tribes that participated in the KIIs to determine if they had formal, publicly facing statutes related to their public health authority and/or health reporting requirements, which may include syndromic surveillance.

NIHB did not review legal documents for TECs, as TECs are not "governmental" entities in the strict legal sense. Moreover, TEC public health practices are governed by their Tribal member organizations, often through data use agreements, many of which may not be publicly available, and by federal law authorizing them as public health authorities.[13]

All states and Tribes selected for the legal scan will remain confidential to protect the

identity of the jurisdictions and public health staff that participated in the KIIs.

RESULTS

Of the eight states included in the law review, three had legal documents requiring syndromic surveillance reporting in their jurisdiction.

Table 1: Legal Language for Sharing Syndromic Surveillance Data and Current Data Sharing Practice for States that Require Syndromic Surveillance Reporting in their Jurisdiction

State	Legal Language for Sharing Syndromic Data	Current Data Sharing Practices
STATE 1	Legal documents allow sharing of syndromic surveillance data with Tribal governments with data use agreements.	Allow Tribes and TECs direct access to syndromic surveillance data.
STATE 2	No legal documents allowing or prohibiting syndromic surveillance data sharing with Tribes or TECs.	Does not currently share syndromic surveillance data but indicated in KIIs and state assessment that they are willing and able to share data. Law was not mentioned as a barrier.
STATE 3	Legal documents state that syndromic surveillance data can only be shared with state government entities, local health departments, the healthcare organizations that provided the data (when limited to data collected by that entity), and researchers in certain circumstances.	Does not currently share syndromic surveillance data with Tribes or TECs, and indicated they are not allowed to share data with externalentities beyond local health departments with data use agreements at this time.

Five states do not require syndromic surveillance reporting in their jurisdiction, although one has legal documents authorizing an incentive program for healthcare facilities. This program echoes the national Medicare Promoting Interoperability Program which incentivizes hospitals to report syndromic surveillance data.[14]

Table 2: Legal Language for Sharing Epidemiological Data and Current Data Sharing Practice for States that do not Require Syndromic Surveillance Reporting in their Jurisdiction

State	Legal Language for Sharing Syndromic Data	Current Data Sharing Practices
STATE 4	Epidemiological data can be shared with Tribes during declared public health emergencies. Required to collaborate with Tribal organizations, but no specific mention of data sharing in general.	Provides direct access or line level (non-aggregate) syndromic surveillance data to the TEC(s).
STATE 5	Disclosure laws allow reporting from health care providers and state entities only to federal, state, or local public health authorities. However, other legal documents state there are no restrictions in sharing data, including protected health information w/ Tribal public health organizations where a case resides.	Does not currently provide syndromic surveillance data to Tribes and/or TECs but stated that Tribes are allowed access. Due to competing priorities, no Tribe has successfully completed the full onboarding process. Law was not mentioned as a barrier.
STATE 6	A state statute promotes cooperation and formal agreements, including for data sharing with Tribes located in the state.	Provides direct access or line level (non-aggregate) syndromic surveillance data to the TEC(s).
STATE 7	The state may enter into agreements with Tribes or the TEC(s) allowing them to receive and investigate reportable diseases and access other Tribal data.	Provides direct access or line level (non-aggregate) syndromic surveillance data to the TEC(s).
STATE 8	One administrative code says that state agencies and federal agencies may access data with the state's approval. No others may access non-aggregate data. However other state laws allow the state to enter into agreements with Tribes, although data sharing is not specified.	Provides direct access or line level (non-aggregate) syndromic surveillance data to Tribes and the TEC(s).

Overall, in the states selected for review, in most states legal documents are not the major barrier to syndromic surveillance access for Tribes and TECs. The exception to this is State 3, where state laws limit access. However, it should be noted that the level of access was provided by states, and Tribes and/or TECs may have differing perceptions regarding their levels of data access. Future surveys of Tribal health organizations and TECs would benefit from closely cross-referencing laws against real-world data access challenges. Additionally, a review of additional state laws would be valuable beyond this subset of states.

GENERAL DATA SHARING: 88% of responding states have at least one legal document that contains language actively encouraging data sharing with Tribal organizations. Fewer states formally recognize Tribes (38%) or TECs (25%) as public health authorities in legal documents.

DEMOGRAPHIC DATA COLLECTION: 88% of responding states require demographic data to be reported as part of their general reporting guidelines. Of the states that require syndromic surveillance reporting in their jurisdiction, however, only one of three has separate requirements to report demographics as part of syndromic surveillance reporting.

TRIBAL LAWS: Tribes are inherent public health authorities due to their sovereign status, and as reinforced by federal law. Like state and local health departments, Tribes may choose to formally assign their authority to a specific Tribal entity and may choose to define their role through legal documentation.

Table 3: Tribal Legal Documents Formally Defining the Tribe's Public Health Authority/ Role and Current Data Sharing Practice for Tribes

Tribe	Do Tribal Legal Documents Formally Define the Tribe's Public Health Authority/ Role?	Current Data Sharing Practices
TRIBE 1	Formal definition of public health authority	Do not receive syndromic surveillance data by choice (no legal barrier cited)
TRIBE 2	Formal definition of public health authority	Do not receive syndromic surveillance data by choice (no legal barrier cited)
TRIBE 3	Formal definition of public health authority	Do not receive syndromic surveillance data due to internal and external legal barriers- state limits data and Tribe is not sure if their current authority documents include syndromic surveillance
TRIBE 4	No formal definition of public health authority, but provide information on reporting through the Tribe in guidance documents	Receive syndromic surveillance data
TRIBE 5	No formal definition of public health authority	Do not receive syndromic surveillance data

Due to the role of states as the de-facto holders of public health data, particularly syndromic data, Tribal ability to access data is often more impacted by non-public data use agreements rather than just legal documents.

Discussion and Recommendations

The aim of this section is to provide recommendations that can be operationalized by state, local and federal governments, with the ultimate goal of strengthening public health data sharing between states, local and federal government agencies and Tribal public health authorities. It is important to note that Tribal governments are structured differently from one another, each having varying needs, resources and capacity. Considering this reality, we do not seek to provide recommendations specific to Tribes and TECs, rather we have provided through this report examples of how some Tribes are navigating existing barriers and limitations in their access to syndromic surveillance and public health data.

General Recommendations

1 Encourage stronger understanding of Tribal and TEC public health authority to strengthen partnerships among state and local health departments with Tribal health organizations and TECs.

It is important to recognize differences in capacity across Tribes and TECs in conducting syndromic surveillance. Partnership is key to a strong, resilient public health system, and Tribes and TECs often rely on and benefit from partnerships with their state or local counterparts. Many states have expressed a strong interest and willingness to partner more closely with Tribes to support Tribal access to data and public health capacity.

To strengthen this partnership, it is important that states recognize the lawful status of Tribes and TECs as public health authorities. As such, Tribal organizations and TECs have the right to access data, including disaggregated data and protected health information, for the purposes of protecting public health.

States, as the main holders of public health data, need additional assistance and resources to help them understand the lawful status of Tribes and TECs as public health authorities and to reduce barriers hindering public health data sharing across federal, state, local and Tribal jurisdictions.

States should also be discouraged from requiring lengthy approval process for individual Tribal and TEC requests for public health data. Public health surveillance is most effective when data is sent across public health agencies in real time, and lengthy approval processes slow down the ability of Tribal public health authorities to take public health action on behalf of their communities. Like all public health authorities, Tribes, and TECs in consultation with their member Tribes, can determine the "minimum necessary" information needed to protect the health of their communities. States must recognize that Tribes and TECs, in consultation with their members, do not need to explain or justify how they are using their own data.

Syndromic surveillance works best when Tribes and states design systems for data sharing together with a strong understanding of the rights and responsibilities of each jurisdiction.

2 Improve the quality of data collected on American Indian/Alaska Native patients and Tribal community members at the healthcare facility level.

A major barrier to determining which data is associated with Tribes and Tribal communities is ongoing challenges with identifying who is AI/AN in a data set, and if any are Tribally affiliated. Moreover, AI/AN patients may seek care outside of Tribal health services or even across state lines and many Tribes need data from outside their jurisdiction (often defined by zip code) to fully identify the health status in and around their communities.

For syndromic surveillance reports, race and ethnicity data is often incomplete or incorrect. Tribal affiliation is also not mandated or included in syndromic surveillance reports. This poses difficulties for Tribal organizations in identifying which data is relevant to their communities, and gaining access to the full picture is often difficult since accessing or receiving public health data for those receiving healthcare services outside of their Tribal boundaries is often restricted. Improving the quality of data on AI/AN race and Tribal affiliation would require a concerted effort from all levels of government from the federal, Tribal, state, and local levels as well as buy-in and support from healthcare professionals and leadership. States may be well-positioned to hold healthcare organizations accountable in improving the accuracy of data collected and reported on race and ethnicity in their facilities. However, these mechanisms would need to consider the existing governmental, public health and healthcare ecosystem in each state. It is very important to emphasize that states should not use the inability to identify individuals of AI/AN race or Tribal affiliation in the data as a barrier to share data with Tribal public health authorities.

Syndromic surveillance works best when Tribes & states have a strong understanding of respective rights & responsibilites

In addition to collecting better demographic information, more Tribal healthcare facility participation is needed in syndromic surveillance to ensure more complete data sets. Currently, many states, TECs, and Tribes reported that Tribal healthcare facilities do not report syndromic data, making accessing syndromic surveillance data a low priority for these organizations. Onboarding these clinics is most successful when efforts are collaborative across all levels of government. These efforts would emulate the early success of efforts in Alaska, where deep-rooted partnerships between the state and TEC led to joint efforts to onboard Tribal hospitals to the ESSENCE platform hosted by CDC's NSSP. Their effort led to the majority of Tribal hospitals onboarding, with visibility for the Alaska Native Epidemiology Center. This drastically improved data quality by reducing missingness for AI/AN patients[15].

TO LEARN MORE about the collaborative efforts in syndromic surveillance between Alaska and the Alaska Native Epidemiology Center, and two other TECs experiences, please refer to the following report: **Syndromic Surveillance in Tribal Health: Perspectives from Three Tribal Epidemiology Centers on Access and Utilization** published in the International Journal of Environmental Research and Public Health. (https://doi.org/10.3390/ijerph22050664).

3 Increase the knowledge of state and local public health professionals on Tribal health systems and cultural safety.

Public health professionals who have not worked in the Tribal health system often don't understand the role Tribes and TECs play in public health. Federal agencies and national public health organizations can support a stronger understanding by having clear guidance and policies supporting data sharing with Tribes, and by linking state and local public health agencies to Tribally created and approved resources for understanding the Tribal health system. This goes beyond workgroups and committees and requires full government agency and organizational support for Tribes and TECs. State and local agencies should also incorporate policies that require staff to learn about the Tribal health system, particularly for programs that might impact Tribes or TECs. Finally, academic institutions are also key players and should include information on Tribal health systems in their public health degree and training programs.

Recommendations for Federal Agencies

1 Federal government agencies should work with Tribal public health authorities to develop models for syndromic surveillance that recognize the lawful status of Tribes and TECs as public health authorities.

Tribes are sovereign nations with a government-to-government relationship with the federal government. Despite overlapping jurisdictions, Tribes do not report to states and should not need to rely on partnerships with states to carry out their core rights and responsibilities as government entities. However, the current syndromic surveillance system sets states as the de-facto holders of data and does not recognize or adapt to the unique structure of Tribal health systems. Tribes, through necessity, must navigate relationships with states in their region to access data, and are subject to the priorities, policies, and state-imposed limitations of each state they overlap with.

Tribes vary in size, capacity, and desire to carry out data-related public health activities. Tribes may approach public health surveillance activities in various ways, including through their own formal or informal Tribal health department, through Tribal Consortiums, and/or through partnerships with TECs, states, and local governments. The Indian Health Service (IHS), a federal agency primarily providing healthcare services to Tribal and urban Indian populations, also plays a key role in public health activities in Indian Country.

Designing a system that allows Tribes to collect and use syndromic surveillance using their existing and/or preferred infrastructure is a core component of Tribal data sovereignty and will support the existing public health authority of Tribes.

Systems adopted or developed by Tribes should be locally driven or locally supported. Because of the varying structure, capacity and resources that exist across Tribal public health authorities, one syndromic surveillance model will not fit all. It is important that the systems and processes used by Tribes and TECs (in consultation with Tribes) for syndromic surveillance have the support of Tribal leadership, Tribal health professionals, and Tribal members.

2 Federal government agencies should support and invest in Tribes and TECs to strengthen their capacity to conduct and/or receive Tribal syndromic surveillance data, as well as disease surveillance data more broadly.

Tribes and TECs have faced disparities in public health infrastructure compared to their state and local counterparts due to a lack of investment. The Tribal public health system is capable of conducting surveillance and/or using data, but more resources are needed to strengthen Tribal health organizations and TECs.

To be successful in syndromic surveillance, Tribes and TECs require investment in Tribal health systems. This includes providing more

federal funding to Tribal entities for surveillance, providing Tribal staff with pertinent training and other resources to build Tribal capacity, and supporting them in improving their own Tribal infrastructure, including supporting access to modern data storage and analysis systems to better engage in syndromic surveillance and public health activities directly.

3 Federal agencies, including CDC and IHS, should support Tribes by developing and/or updating national systems for syndromic surveillance to be more conducive to Tribal data sovereignty and to ensure Tribal contribution and participation in public health processes and data sharing practices.

Federal support could include the development of a national system that is conducive to Tribal data sovereignty and Tribal contribution to public health data and practice. For example, federal agencies could work with Tribes to explore how to give Tribes direct access to the syndromic surveillance platforms as well as tools and training to create their own mechanisms for syndromic surveillance that would reduce reliance on states, while allowing Tribes the flexibility to decide who (for example the Tribe, a partnering TEC, or both) receives the data. The following proposed mechanisms are ways Federal agencies can enable Tribes to take ownership of their syndromic surveillance processes in ways that they think best. The following are several mechanisms federal agencies can implement toward achieving this goal:

Update National Systems for Syndromic Surveillance

CENTERS FOR DISEASE CONTROL AND PREVENTION: CDC, through their National Syndromic Surveillance Program (NSSP) can develop an updated version of the ESSENCE system used nationally and by various state public health agencies to create jurisdictional data fields that are more conducive to Tribal geographies and jurisdictions. In this effort, geographic information systems (GIS) can be used to geocode the locations of Tribal lands that can be incorporated into the national ESSENCE system and can further serve as a model that states can use in their state-level syndromic surveillance systems to collaborate more easily with Tribes in their syndromic surveillance practices. Moreover, such tailoring of the national syndromic surveillance system would facilitate the onboarding of Tribal public health authorities for direct access to ESSENCE and state-level, real-time surveillance systems. It would also allow Tribes and TECs the opportunity to create custom-made syndromic surveillance systems for their own purposes, if desired, based on the national Tribal-friendly model.

INDIAN HEALTH SERVICE: While IHS provides direct healthcare services to Tribes and collects syndromic surveillance data from facilities serving Indian Country, there are many challenges that the agency experiences in reporting this data back to Tribal health facilities, and by extension Tribes. There is currently no real-time, overarching mechanism for IHS to feed syndromic surveillance data back to IHS facilities on a large scale. At the time of this report, IHS is in the process of updating the IHS-supported electronic medical record (EMR) Resource and Patient Management System (RPMS)[4], which is an outdated system that does not support the electronic, real-time transfer of syndromic surveillance data to and from IHS facilities. Once IHS has updated to a newer EMR and a more modernized mechanism of reporting health information, this will provide multiple opportunities for IHS to offer more up-to-date syndromic and overall surveillance data to IHS-supported health facilities, and, by extension, Tribes and TECs with the need and desire to receive it.

Require and Incentivize States to Share Public Health Data

Facilitating the recognition of Tribes and TECs as public health authorities is paramount. One way to facilitate recognition of Tribes and TECs as authorities of public health data is to incorpo-

rate partnerships and data sharing with Tribes as a standard requirement of federal grants for state and local governments.

States should be incentivized and trained in developing meaningful, mutually beneficial partnerships with Tribes and TECs. Tribes have repeatedly indicated that Tribal data access has not improved since the COVID-19 pandemic. Requiring state and local health departments to hold data use agreements with Tribes and TECs as a component of receiving federal grants could incentivize states to re-prioritize and engage in more meaningful relationships with their Tribal partners. It would also increase equitable access to data, as states can generally access Tribal data without agreements through current surveillance infrastructure, but Tribes cannot do the same with state data.

Syndromic surveillance works best when Tribes and states design systems for data sharing together with a strong understanding of the rights and responsibilities of each jurisdiction.

4 Ensure inclusion of national standards for collection of race demographics and Tribal affiliation in future HL7 Syndromic Surveillance Implementation Guides and better enforce demographic standards used by NSSP and participating states.

The inclusion of more complete demographic information as a requirement in the National Syndromic Surveillance Program's (NSSP) ESSENCE system is necessary in the long-term. To this end, working with health professionals at the healthcare facility level will be critical to better collect information on race/ethnicity on AI/AN and by extension, Tribal members and residents. Efforts like the Office of Management and Budget's Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD15) are a good example of a national initiative on standards to improve the quality and completeness of demographic data collection in healthcare facilities, and could serve as a leveraging point to coordinate and improve on data collected on AI/AN and Tribally-affiliated individuals at the healthcare facility level.

Improved collection on AI/AN race and more accurate data on patient Tribal affiliation would increase the accuracy of overall public health surveillance data being routed to Tribes and TECs and increase their ability to predict and respond to patterns of illness that may be exhibiting in or around their communities.

An important note regarding the collection of data on Tribal affiliation: There are concerns for some Tribal jurisdictions about information on Tribal affiliation being available to state health departments to use and report on at their own discretion. Tribes and their leadership need to be consulted on whether this method would be acceptable to them and their communities for public health data collection and reporting purposes.

Another strategy at the federal level to improve the capture of demographic information would be to support Tribes and/or TECs in strengthening their capacity to match their internal Tribal affiliation/enrollment data against separate health data sources including IHS and other syndromic surveillance and public health data, to enhance their ability to track syndromes and other illnesses in their communities. These decisions should be made in consultation with Tribes, recognizing that data-matching solutions are not a one-size-fits all strategy.

A crucial point to consider is that syndromic surveillance data, unlike other automated case reporting systems, generally is not electronically routed across state jurisdictional boundaries. Routing of syndromic surveillance data for reporting purposes is based on the state where care is received, unless there are specific data use agreements that have been established across state lines. Therefore, collecting Tribal affiliation information alone has its reporting limitations for Tribal members receiving care across state lines, unless this information is combined with supplemental data sources, data use agreements or other data routing mechanisms. Similarly, Tribal organi-

zations engaged in data matching may need datasets routed to them from several states, and it may be challenging to determine the most appropriate geographical boundaries to include in a dataset to have optimal Tribal public health impact.

Recommendations for State and Local Governments

1 Consult with Tribes and TECs early and often when developing syndromic surveillance systems.

Many states are early in their adoption of syndromic surveillance for their public health systems. Furthermore, many are still in the capacity assessment and planning stages in relation to syndromic surveillance. Consequently, this presents a critical time for various state health departments to initiate and incorporate Tribal participation in the continued development in their state syndromic surveillance systems and processes. Tribes and TECs report that systems work best when developed collaboratively. States should work closely with Tribal partners, consult with Tribes regularly, and pursue meaningful, two-way relationships with Tribal jurisdictions.

2 Consider hiring and retaining Tribal liaisons and Tribally focused epidemiologists at state and local government agencies.

Findings from the KIIs revealed that state public health agencies with formalized Tribal liaisons and/or Tribally focused epidemiologists among their staff were significant facilitators for greater collaboration and public health data sharing between states, Tribes and TECs. States and local health departments should strongly consider hiring and retaining Tribal liaisons and epidemiologists with Tribally focused job responsibilities. Staff in such designated positions can better focus their attention on fostering Tribal partnerships built on trust and respect, strengthening state and Tribal collaboration, and connecting Tribal public health authorities with the resources they deem necessary to participate in syndromic surveillance and other public health activities that benefit their communities.

3 Consider and share lessons learned from successful state, local & Tribal partnerships.

Many states, locals, Tribes, and TECs are developing their own solutions to improve the way data is collected and shared to strengthen the ability of all entities to improve the health of their people. Showcasing examples of successful relationships can help states with less experience understand how they can better build relationships with their Tribal and TEC partners. Several examples of successful relationships were identified through this project.

CASE STUDY A: One Tribe reported having an excellent relationship with their local health department. The entities have historically shared communicable disease data and worked together to ensure the correct jurisdiction conducted each case investigations. This has facilitated a smooth transition into sharing syndromic surveillance data and ensured the Tribe had access to this data despite having limited capacity to conduct syndromic surveillance themselves. The Tribe reported that this partnership is more beneficial than one with the state because of the close jurisdictional overlap and the ability to better identify who is a Tribal citizen.

CASE STUDY B: One state reported that they are working together with the TEC in their region to improve the type of data collected by health facilities in their area. Currently, data is not comprehensive enough to disaggregate by race and ethnicity. The state and TEC are working with facilities to collect better data related to Tribal affiliation, race, and ethnicity so that the state can more easily share relevant data on AI/AN and Tribal members with the TEC.

CASE STUDY C: One TEC reported that they worked collaboratively with a state in their region to set up a data use agreement. This early partnership and spirit of collaboration has enabled the TEC to successfully and routinely access data from this state as needed.

Conclusion

Syndromic surveillance is a promising public health system that provides relevant and timely real-time data to health agencies. However, Tribes and TECs have had limited access and participation in syndromic surveillance for strengthening their own public health efforts due to ongoing challenges with accessing real-time and complete data, a lack of investment in Tribal public health infrastructure, and systematic issues that favor state and local data access over Tribes and TECs.

Yet promising solutions are emerging, with Tribes setting up direct connections with their health clinics, TECs taking steps to support Tribes in conducting syndromic surveillance, and states expressing the desire to work more closely with Tribal and TEC partners. Federal agencies, national partners, state and local governments, and Tribal organizations need to come together to find productive, and collaborative solutions to the real-world, systematic issues that Tribes and TECs face in accessing data.

Public health threats do not happen in a vacuum or respect jurisdictional boundaries. However, Tribes are the best authorities when it comes to using data in Tribally led ways, understanding the connection between their data and their people, and keeping their communities safe. When Tribes cannot access and use their own data, the entire public health system is weakened, and Tribal sovereignty is degraded.

By working together, state, local, and Tribal governments and TECs can better meet challenges and effectively strengthen the health of all their communities, while centering Tribal organizations in developing Tribally driven and data informed solutions to emerging public health challenges.

DESPITE ONGOING CHALLENGES, PROMISING SOLUTIONS ARE EMERGING

Methods

State Health Department Assessment on Syndromic Surveillance Data Sharing Practices

Assessment Design

NIHB developed an assessment instrument to collect information about how states engage in data sharing with Tribal health organizations, with a focus on syndromic surveillance practices and procedures. The assessment was developed by a team of five NIHB staff members with expertise in Tribal disease surveillance, data modernization, evaluation, infectious disease, and other related subject matters. The assessment was informed by prior information gathered through NIHB and Tribal efforts and guidance from Tribal listening sessions. CSTE staff with expertise in syndromic surveillance reviewed and provided feedback on the questions. This feedback was incorporated into the final assessment.

The assessment consisted of six questions, with up to four additional sub-questions that appeared based on responses. These questions included demographics and contact information, and questions on whether and how states engaged in data sharing practices with Tribes or TECs. Questions also addressed barriers to data sharing and asked respondents to characterize their overall level of partnership with Tribes or TECs.

The final assessment was created using the Qualtrics assessment software and could be completed by participants online.

Data Collection

NIHB and CSTE determined that the assessment should be administered to experts at all 50 state health departments, including those with no Tribal health jurisdictions within the state boundaries to ensure the most comprehensive information was received. CSTE identified the appropriate syndromic surveillance representatives at each state health department using CSTE's State Health Department Syndromic Surveillance Contacts Listserv.

The assessment link was shared by CSTE syndromic surveillance staff with representatives from the syndromic surveillance teams at all 50 states via email on January 29, 2025. CSTE provided several follow-up communications. The assessment closed on May 30, 2025.

Assessments were collected from 43 respondents. Several state health departments submitted multiple responses. For quantitative data, the most complete response was retained. For qualitative data, responses were combined. After removing duplicates, responses were recorded from 39 state health departments, a response rate of 78%.

Analysis

All quantitative data analysis was conducted in SAS 9.4 and graphs were created in Microsoft Excel. Descriptive statistics were conducted for all quantitative assessment questions. Qualitative data was analyzed using inductive thematic analysis techniques.

To ensure data was both comprehensive and relevant, NIHB analyzed data at two levels: 1) all state health departments and 2) excluding state health departments that do not have Tribal health jurisdictions within the state's boundaries. 36 states are identified as having Tribal jurisdictions within their boundaries nationwide.

All 39 state respondents were included at Level 1. 27 state respondents were included in Level 2, a response rate of 75% of states identified as having Tribal jurisdictions within their boundaries.

State, Tribal, and TEC Key Informant Interviews

Key Informant Interview Protocol Design

NIHB staff with expertise in data modernization, epidemiology, and qualitative evaluation, in consultation with CSTE, developed three sets of KII protocols to gather information from state health departments, Tribal health organizations, and TECs.

State Health Department KIIs

The state health department KII protocols were developed to expand on the questions asked during the state health department assessment. The state protocols were further broken down into two categories of questions: 1) "State Respondents Sharing Syndromic Surveillance Data with Tribes and/or TECs", and 2) "State Respondents NOT Sharing Syndromic Surveillance Data with Tribes and/or TECs". For both categories, the assessment consisted of 14 questions intended to understand broad syndromic surveillance practices, if and how data and resource sharing occurs with Tribes and/or TECs, and any barriers or successes in working with Tribes and/or TECs on syndromic surveillance from the state's perspective.

Tribal Health Organization KIIs

The Tribal Health Organization KII protocols were developed to understand Tribal participation in syndromic surveillance, ability to access data, data partnerships, successes, and barriers. In recognition of Tribal Sovereignty, differences in Tribal capacity, and differences in the desire to conduct data activities, questions also assessed the Tribe's ideal role in syndromic surveillance, and how far they are currently from achieving this role. The protocols consisted of 13 questions. Tribes who receive or have direct access to syndromic surveillance data completed all 13, while those who did not have access answered five questions.

TEC KIIs

The TEC focused KII protocols were developed to understand TEC participation in syndromic surveillance, ability to access data, data partnerships, successes, and barriers. In recognition of differences in capacity, desire to conduct data activities, and Tribal Sovereignty to determine their role of their TEC, questions also assessed the TEC's ideal role in syndromic surveillance, and how far they are currently from achieving this role. The protocols consisted of 14 questions. TECs who receive or have direct access to syndromic surveillance data completed all 14, while those who did not have access answered six questions.

Data Collection

Overall, NIHB aimed to interview approximately 20 public health organizations across states, Tribes, and TECs.

NIHB selected potential state KII participants from the 27 states that responded to the initial state assessment who had Tribal health jurisdictions within their state boundaries. States were selected based on geographic diversity and diversity in the level of data sharing with Tribes based on the results of the initial assessment. NIHB reached out to 12 priority states.

Tribes and TECs were selected to align with the states that participated in the KIIs. This was cross-referenced with NIHB data related to data sharing and access for these Tribes and TECs. NIHB contacted 11 Tribes, and nine TECs.

State, Tribal, and TEC Key Informant Interviews, continued

NIHB contacted all selected potential participants by email to request their participation. If contact information was not available, NIHB staff followed up by phone to determine the best contact.

Those who agreed to participate were interviewed by trained KII facilitators using the KII protocols via Zoom. Interviews were scheduled for 45 minutes, and participants were invited to bring several experts to the interview to offer perspectives. All interviews were recorded and transcribed unless the participant opted out of recording, in which case a note-taker transcribed the meeting. NIHB offered a $20 incentive to each participating group. All participants were required to complete consent forms allowing their data to be included in the final analysis.

NIHB interviewed 21 respondents in total - nine state health departments, five Tribal health organizations, and seven TECs. One state was excluded from the final analysis due to not completing a consent form for the KII.

Analysis

NIHB staff conducted an inductive thematic analysis process to identify, analyze, and report patterns within KII data. Two lead reviewers developed a codebook based on preliminary reviews of a subset of transcripts. This codebook was regularly updated by all reviewers.

Five reviewers analyzed the KII's using shared codes. All reviewers received structured training to ensure standardization in the application of codes. Each reviewer was assigned to review state, Tribal, and local KII's by region.

Following the completion of all reviews, each reviewer conducted a comparison of responses across their assigned region(s) for commonalities and conflicts in information provided by different entities.

The lead reviewers reviewed all final themes and grouped the data into larger, more specific themes to develop final findings.

Notes

[1] For more details on syndromic surveillance and its use in public health, you can refer to the following webpage: About NSSP | National Syndromic Surveillance Program (NSSP) | CDC (https://www.cdc.gov/nssp/php/about/index.html)

[2] For more details, access NIHB's eCR Roadmap for Tribes and TECs, Supplement I: Understanding Tribal Public Health Authority at https://www.nihb.org/wp-content/uploads/2025/01/eCR-Roadmap-FINAL-12.13.24.pdf

[3] Hoss, A. (2015, April 16). Tribal Epidemiology Centers Designated as Public Health Authorities Under the Health Insurance Portability and Accountability Act. Public Health Law; Centers for Disease Control and Prevention. Retrieved 1/31/2023 from https://www.cdc.gov/phlp/docs/tec-issuebrief.pdf

[4] For more details, access NIHB's eCR Roadmap for Tribes and TECs, Supplement I: Understanding Tribal Public Health Authority at https://www.nihb.org/wp-content/uploads/2025/01/eCR-Roadmap-FINAL-12.13.24.pdf

[5] Field C, Price S, Locklear AC. (2024). Barriers and Opportunities for Tribal Access to Public Health Data to Advance Health Equity. Journal of Law, Medicine & Ethics. 52(S1):39-42. doi:10.1017/jme.2024.45.

[6] United States Government Accountability Office. (2022, March). Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access. GAO. Retrieved 2/23/2023 from https://www.gao.gov/assets/gao-22-104698.pdf

[7] Field C, Price S, Locklear AC. (2024). Barriers and Opportunities for Tribal Access to Public Health Data to Advance Health Equity. Journal of Law, Medicine & Ethics. 52(S1):39-42. doi:10.1017/jme.2024.45.

[8] Smith GE, Elliot AJ, Lake I, et al. (2019). Syndromic surveillance: two decades experience of sustainable systems - its people not just data!. Epidemiol Infect.147:e101. doi:10.1017/S0950268819000074.

[9] Purtle, J., et al. (2018). The Impact of Law on Syndromic Disease Surveillance Implementation. J Public Health Manag Pract. 24(1): 9–17. doi:10.1097/PHH.0000000000000508..

[10] Indian Health Service (N.D.) IHS Health IT Modernization Program. Retrieved 10/31/2024 from https://www.ihs.gov/hit/

[11] Indian Health Service. (N.D.). Where We Work. Retrieved 12/15/2025 from https://www.ihs.gov/careeropps/where-we-work/

[12] Purtle, J., et al. (2018). The Impact of Law on Syndromic Disease Surveillance Implementation. J Public Health Manag Pract. 24(1): 9–17. doi:10.1097/PHH.0000000000000508.

[13] Hoss, A. (2015, April 16). Tribal Epidemiology Centers Designated as Public Health Authorities Under the Health Insurance Portability and Accountability Act. Public Health Law; Centers for Disease Control and Prevention. Retrieved 1/31/2023 from https://www.cdc.gov/phlp/docs/tec-issuebrief.pdf

[14] For more information, on the Medicare Promoting Interoperability Program, access documentation at https://www.qualityreportingcenter.com/globalassets/2025/01/iqr/pi_infographic_cy-2025-requirements_jan2025_vfinal_508.pdf

[15] Wang, C., Ward, L., & Smith, N. H. (2025). Syndromic Surveillance in Tribal Health: Perspectives from Three Tribal Epidemiology Centers on Access and Utilization. International Journal of Environmental Research and Public Health, 22(5), 664. https://doi.org/10.3390/ijerph22050664

References

Centers for Disease Control and Prevention. (n.d.). About NSSP | National Syndromic Surveillance Program (NSSP). https://www.cdc.gov/nssp/php/about/index.html

Field, C., Price, S., & Locklear, A. C. (2024). Barriers and opportunities for tribal access to public health data to advance health equity. Journal of Law, Medicine & Ethics, 52(S1), 39–42. https://doi.org/10.1017/jme.2024.45

Hoss, A. (2015, April 16). Tribal Epidemiology Centers designated as public health authorities under the Health Insurance Portability and Accountability Act. Centers for Disease Control and Prevention, Public Health Law Program. https://www.cdc.gov/phlp/docs/tec-issuebrief.pdf

Indian Health Service. (n.d.). IHS health IT modernization program. https://www.ihs.gov/hit/

Indian Health Service. (n.d.). Where we work. https://www.ihs.gov/careeropps/where-we-work/

National Indian Health Board. (2024). NIHB's eCR roadmap for tribes and TECs, Supplement I: Understanding tribal public health authority. https://www.nihb.org/wp-content/uploads/2025/01/eCR-Roadmap-FINAL-12.13.24.pdf

Purtle, J., et al. (2018). The impact of law on syndromic disease surveillance implementation. Journal of Public Health Management and Practice, 24(1), 9–17. https://doi.org/10.1097/PHH.0000000000000508

Smith, G. E., Elliot, A. J., Lake, I., et al. (2019). Syndromic surveillance: Two decades' experience of sustainable systems—It's people, not just data! Epidemiology & Infection, 147, e101. https://doi.org/10.1017/S0950268819000074

United States Government Accountability Office. (2022, March). Tribal Epidemiology Centers: HHS actions needed to enhance data access (GAO-22-104698). https://www.gao.gov/assets/gao-22-104698.pdf

Wang, C., Ward, L., & Smith, N. H. (2025). Syndromic surveillance in tribal health: Perspectives from three Tribal Epidemiology Centers on access and utilization. International Journal of Environmental Research and Public Health, 22(5), 664. https://doi.org/10.3390/ijerph22050664

Centers for Disease Control and Prevention. (2023, June 16). Implementation guides. National Syndromic Surveillance Program. https://www.cdc.gov/nssp/php/onboarding-resources/implementation-guides.html

Office of the National Coordinator for Health Information Technology. (n.d.). FHIR. U.S. Department of Health and Human Services. Retrieved April 20, 2026, from https://healthit.gov/interoperability/investments/fhir/

Centers for Disease Control and Prevention. (n.d.). Public health data strategy: PHP—public health data strategy milestones 2025 and 2026. Retrieved April 20, 2026, from https://www.cdc.gov/public-health-data-strategy/php/about/phds-milestones-2025-and-2026.html

National Indian Health Board

National Indian Health Board

NIHB.ORG

SOVEREIGNTY. STRENGTH. HEALTH.