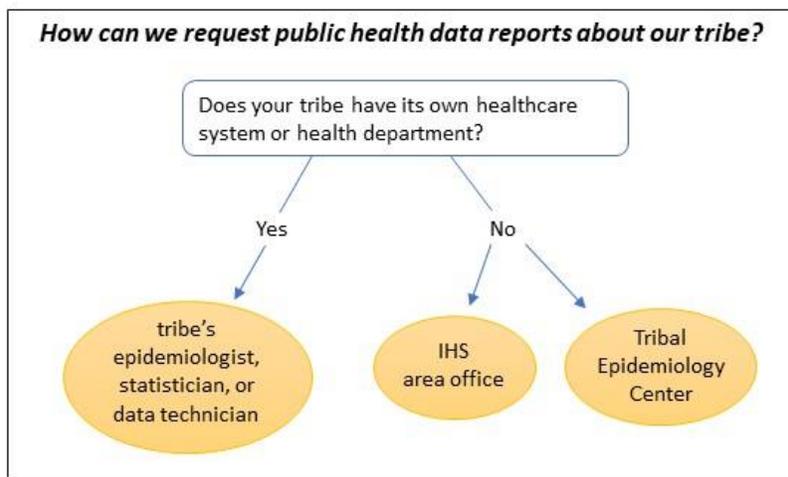


A Guide to Requesting Health Data Reports within a Federally Recognized Tribe

This guide describes how tribal staff in various programs (e.g., environmental, housing, maintenance, etc.) can request health data to better understand and describe the scope of public health issues that affect the tribes they serve. The health data can be used to support grant applications submitted to agencies such as the US Environmental Protection Agency and US Department of Housing and Urban Development. Tribal programs can also use this data to prioritize programmatic activities. This guide is not intended for those doing academic research.

Three ways to access health reports covered in this guide:

- 1) making a request to the tribe's health department or healthcare system
- 2) making a request to the corresponding Indian Health Service (IHS) area office
- 3) contacting the Tribal Epidemiology Center working with the tribe



Tips:

- Be able to clearly communicate your intent when requesting data.
- Be aware of data limitations: e.g. what percent of the community is represented in the data and why?

Does the tribe you serve have a health department or healthcare system?

- **If yes:**
 - The tribe's **epidemiologist, statistician, or data technician** can analyze data and provide customized population health reports about the public health issues of interest.
 - They will either access the tribe's own data system and/or have free access to Indian Health Service's [Resources and Patient Management System \(RPMS\)](#) or the tribe's electronic medical records system to fulfill your query.
 - Alternatively, the tribe's **health director** or **clinic director** may be able to point you to the appropriate staff or reports/assessments on the public health issues of interest that the tribe has completed.
- **If no:**
 - Contact your [IHS area office](#) because almost all IHS offices have a data manager or epidemiologist on staff who can assist you with obtaining health reports. A data sharing agreement may be required.
 - Consult the [Tribal Epidemiology Center \(TEC\)](#) partnering with the tribe you serve. Depending on what kind of data is available to them, some TECs may be able to provide tribe-specific reports, while others may not. See back for more on TECs.

How is the Privacy of Patients and the Tribe Protected?

- Individuals' health data are protected by law, but those laws do not typically apply to general health summaries where it is impossible to link data to specific individuals. The data custodian can help you with this.
- A **data sharing agreement** defines the terms and conditions for data sharing to protect tribal citizens as well as tribes. It can be used when transferring data that is not publicly available. Technical assistance with data sharing agreements may be available through the IHS Area Office or TEC.
- Following [Institutional Review Board \(IRB\)](#) requirements can help ensure that confidentiality of individuals and the community is protected.

What kind of reports could I ask for when I talk to IHS?

- You can ask about various health issues (diagnoses like heart disease, asthma, COPD, etc.), how prevalent these issues are in the community, general characteristics about those who are affected, and trends over time.
 - The RPMS data search function options include query with code, region, zip code, and county.
 - The data specialist can use the program to output data reports in spreadsheets that can be imported into statistical programs like SPSS and SAS for analysis.
- For example, you could ask how many children between 0-18 in last 12 months were hospitalized or seen in the emergency department with asthma. The data specialist would pull up data under specific disease classification codes to answer your question. They may use the code J45.901 in the ICD-10 system for analysis.
- Consider asking your IHS contact about what data they could offer to support your efforts.

Additional Information about Tribal Epidemiology Centers

What are Tribal Epidemiology Centers?

Tribal Epidemiology Centers (TECs) work in partnership with local or area tribes to improve the health and wellbeing of tribal members by offering culturally competent approaches to eliminate health disparities faced by American Indian and Alaska Native (AI/AN) populations. In addition to partnering with tribes, TECs receive funding from and coordinate their activities with federal, state, and local agencies, and academic institutions throughout the country. TECs provide various types of support and services based on organizational structure, tribal populations served, and their mission and goals.

Learn more about the 12 TECs, services unique to each TEC, and each TEC's service areas by consulting:

- The TEC website: <https://tribalepicenters.org/>
- The TEC factsheet: https://www.cdc.gov/tribal/documents/tec_overview.pdf

What do TECs do?

The 7 core functions of TECs are:

- Collecting and monitoring data on the health status objectives of the IHS, Indian tribes, tribal organizations, and urban Indian organizations
- Evaluating delivery and data systems that impact Indian health
- Assisting tribes, tribal organizations, and urban Indian organizations to determine health status objectives and services needed to meet those objectives
- Recommending services to assist Indian communities
- Making recommendations to improve Indian healthcare delivery systems
- Providing technical assistance to tribes, tribal organizations, and urban Indian organizations to develop local health priorities and disease incidence and prevalence rates
- Providing disease surveillance and promoting public health

Each TEC is different because programs and activities may differ. Learn more here:

<https://tribalepicenters.org/7-core-functions/>

Which TEC should I contact?

This map indicates the service areas for each of the 12 TECs and the areas they serve:

<https://tribalepicenters.org/12-tecs/>

Suggestions for improving this document can be sent to
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