

Accessing Data About Suicidal Behavior Among American Indians and Alaska Natives

Data can be valuable to American Indian and Alaska Native (AI/AN) communities in understanding the problem of suicide in specific communities; helping develop policies, practices, and services to address suicide; applying for funding; and allocating resources. This resource sheet describes key local, state, and regional sources of data on suicide (deaths, attempts, other behavior, and thoughts) in AI/AN populations. It also briefly discusses ways to improve access to AI/AN data.

Historical Issues Related to Data

Locating current, reliable, and useful data on specific AI/AN populations is a challenge. Historically, many Native communities have experienced research that violated tribal norms and which was used in ways that benefited others instead of the tribe. Cheryl Crazy Bull described it this way:

Since the Native people of this hemisphere came into contact with Europeans, we have been the subjects of intense scrutiny. Sometimes this scrutiny is for financial gain, sometimes it is for the sake of knowledge, and at other times it is for the sake of dominance. In response to this misuse and abuse, tribal people recently have begun to appropriate the research process for ourselves. Today more and more Native people are conducting research and scholarship in our communities and in the institutions with which we work...¹

Keeping in mind the history of data collection in AI/AN communities is useful when considering both the limitations of current data systems and the opportunities for improving access to quality data for suicide prevention in the future.

Sources of Data

There are a number of different sources of suicide-related data on AI/AN populations, each with some limitations. They may be categorized as follows:

National sources: National sources include databases such as WISQARS, NVDRS, and YRBSS (which are discussed in the online part of this course). These sources can provide useful perspectives on the needs of the larger AI/AN population.

Local, state, and regional sources: These sources are valuable because they are likely to have data that is specific to local, state, and tribal communities and therefore can more accurately portray the needs of each unique Native community. They also may have more recent data than the national sources.

“Local statistics should be used whenever possible to increase relevancy and impact and to eliminate the perception that all Tribes and Villages can be viewed as one culture or community. . . . The circumstances of each Tribe or Village are shaped by its own unique location, culture, economy, social services, and history.”²

¹ Crazy Bull, C. (1997). A Native conversation about research and scholarship, p.17. *Tribal College Journal of American Indian Higher Education*, 9(1), 17–23.

² U.S. Department of Health and Human Services. (2010). *To Live To See the Great Day That Dawns: Preventing Suicide by American Indian and Alaska Native Youth and Young Adults* (p. 113). [DHHS Publication SMA (10)-4480, CMHS-NSPL-0196]. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

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Indian Health Service (IHS) Resource and Patient Management System (RPMS)

Description: RPMS is the health information system used by many IHS federal, tribal and urban (I/T/U) health care facilities.

Suicide-related data: The Suicide Reporting Form (SRF) in RPMS includes data on:

- Incidents of suicide ideation with intent and plan, attempts, and deaths
- Age and gender
- Method and substances involved
- Other relevant information

The SRF is completed at the point of care when the health care provider becomes aware of an incident. Suicide data is also captured by diagnostic codes documented in the medical record. Reports can be generated from RPMS that contain de-identified patient data.

Populations covered: This data is representative of only those AI/AN who receive care at I/T/U health care facilities that use RPMS. In some communities this may be the majority of AI/AN people and in others a smaller percentage.

Limitations:

- Data from RPMS is not U.S. general population data. It is specific only to those AI/AN patients who get their care at I/T/U facilities.
- Use of the SRFs varies in the 12 IHS areas. In some areas, it is used extensively; in others, it is significantly underused.
- This data is not published. It is available at the local health care facility level or area level and only by those who have been granted access to the RPMS database(s).

Access: Contact the clinical director at the local I/T/U healthcare facility or the IHS area behavioral health consultant.

Tribal Epidemiology Centers (TECs)

Description: Tribal epidemiology centers (TECs) are funded by IHS and the Centers for Disease Control and Prevention (CDC). They work with local or area tribes providing various types of support and services related to tribal health data and surveillance systems, including collecting, analyzing and managing data. There are 11 TECs.

Suicide-related data: Available data varies with each TEC. Some TECs provide up-to-date community health data profiles that are specific to their tribes. If they do not have local data, they may be able to suggest how to find it.

Populations covered: Each TEC covers the needs of a specific group of tribal communities.

Limitations:

- Many, but not all, states and AI/AN tribes in the U.S. are covered by the TECs.

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- The TECs differ in the amount and types of data they collect, which is dependent on the TEC's organizational structure, divisions, tribal populations, mission, and goals.

Access: For information on all 11 TECs, go to

http://www.nihb.org/docs/10162009/Tribal%20Epi%20Centers%20Fact%20Sheet_2009.pdf

Urban Indian Health Institute (UIHI)

Description: The Urban Indian Health Institute (UIHI) focuses on American Indians and Alaska Natives across the U.S. who live in cities. It comprises 34 Urban Indian Health Organizations (UIHOs).

Suicide-related data:

- Suicide data come from the National Vital Statistics System (NVSS), which gets its data from death certificates.
- Mental health data come from the Behavioral Risk Factor Surveillance System (BRFSS).
- Area-specific data about counties are available when a county is served by an Urban Indian Health Organization (UIHO). Types of data include demographics, health care access, mortality, and behavioral health.
- Data is collected from specific communities to create community health profiles.
- UIHI has developed a number of surveys and needs assessments that are specific to the health of urban AI/AN people.

Populations covered: The UIHI covers AI/AN populations served by the 34 UIHOs in select cities across the U.S.

Limitations:

- Data from the NVSS and BRFSS are available for the 100 counties in the 19 states where the 34 UIHOs are located **only if** the numbers for those areas are large enough: 10 or more suicides for the time period and in the location(s) requested.
- Suicide data often exists in such limited numbers that UIHI can only report nationally aggregated data.
- Data generated by the 34 UIHOs are only available for specific projects and not available to the general public.

Access: Contact UIHI at <http://www.uihi.org/resources/how-to-request-data/>.

State Health Departments

Suicide-related data: Varies by state, but usually at least deaths and attempts.

Populations covered: All AI/AN in the state who have had suicide-related incidents.

Limitations: See section below on general challenges with local and state data sources.

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Access: At the state health department, contact the suicide prevention program and/or the office that deals with health statistics.

General Challenges with Local, State, and Regional Data Sources

Developing a unified data system for AI/AN populations is complicated because many Native people live within multiple, overlapping governmental jurisdictions of states, counties, tribes, and reservations. Tribes and reservations, which have their own sovereign governing bodies, may be located within or across counties and states, and they may or may not be served by the Indian Health Service. To obtain accurate data on suicidal behavior for specific tribes or reservations, it may be necessary to collect data across these jurisdictions and health care systems, which are usually not connected.

Due to these overlapping boundaries, some suicide deaths may be counted more than once, while others may not be captured at all. For example, the death of a person living on a reservation may be counted by both the reservation and the county coroner.

There are also challenges with data collection within individual government and health systems. For example, medical examiners or coroners responsible for death certificate classification may mistakenly list AI/AN people as another race or ethnicity.

To obtain the most complete data available on a particular population, use as many of the sources listed above that are relevant since they may have different gaps. For information about comparing records across data sets to supplement or validate data, visit the [Tribal Data Linkage Toolkit](#) hosted by the Council of State and Territorial Epidemiologists.

Ways to Improve Access to AI/AN Data

Working Collaboratively

Given the multiple governmental jurisdictions and agencies that may be involved in serving AI/AN populations, it is valuable for tribes and others working with them to develop ways of collaborating that accept the tribe's rights and powers in order to improve data collection, access, and sharing. Partnering can help maximize resources as well as facilitate sharing of information.

In some situations, collaboration may be enhanced by inviting individuals from different agencies and organizations to participate in local coalitions or task forces working on suicide prevention or related issues. For example, inviting the local county coroner to join in the coalition's work might enable the coalition to engage the coroner in improving and expanding collection of data related to suicide deaths. In addition, once local agencies and organizations are working together, it may be easier to educate each other about key issues. For example, it may be possible for representatives of tribes and suicide prevention projects to work with local coroners and medical examiners on how to more accurately identify and record the race and ethnicity of people who have died.

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Developing Data-Sharing Agreements

Access to data can also be improved when formal agreements to share data are developed between one or more agencies or organizations that collect suicide-related data. A formal agreement can help minimize concerns related to sharing data and establish systems to make it easier to access data. Below are a few examples relevant to local communities and tribes.

- Data-sharing agreements can be developed between several agencies in the same tribal community. For example, the Fort Peck Tribes in Montana developed a data-sharing agreement aimed at facilitating access to data on suicide deaths and attempts between the Tribal Health Department, IHS, private hospitals and clinics on the reservation, the Bureau of Indian Affairs, the Department of Social Services, a local treatment center, and the Department of Justice. These agencies are all HIPAA-certified, so they can share data with the assurance that confidentiality will be protected. Due to this agreement, the local suicide prevention project, housed in the Tribal Health Department, can regularly access and compile comprehensive data on suicide deaths and attempts for program planning.
- Some tribal governments have passed tribal resolutions mandating data sharing across all or some agencies and organizations in their tribal jurisdiction.
- Different tribes can develop data-sharing agreements with each other and with county and state data sources. This can be helpful particularly in determining where deaths should be recorded to avoid double counting.

Guidelines for data-sharing can be created through the development of a protocol, tribal resolution, policy statement, Memorandum of Agreement (MOA), or Data Use Agreement (DUA), which discusses the obligations of all parties involved. Several information sheets produced by UIHI provide basic guidance on developing partnerships and writing MOAs and DUAs. See <http://www.uihi.org/projects/health-equity/partnership/>.

Developing Tribal Data Systems

Some tribes have made efforts to improve their own surveillance and data systems in order to improve accuracy, increase program reach to suicidal individuals, and enhance program planning. A tribe can start by simply centralizing the data that its community organizations are already collecting, and then later require additional organizations to report data and expand the types of data reported.

A more complex system, developed in 2001 by the White Mountain Apache Tribe, was the first tribally mandated youth suicide surveillance and follow-up system. It requires all tribal service providers and community members to report all suicidal behaviors, including ideation and attempts, to a central tribal surveillance system. For information on the White Mountain Apache system, see the article at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2741522>.

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