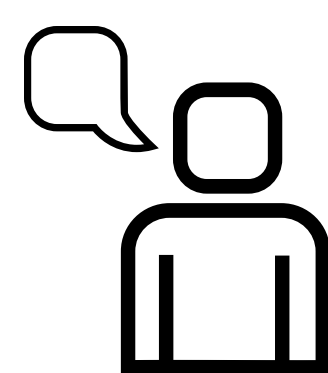


The Northwest Tribal Registry (NTR)



What is the Northwest Tribal Registry?

The Northwest Tribal Registry, often referred to as the NTR or the registry, is a database that contains a small amount of information on American Indian and Alaska Native (AI/AN) people in Idaho, Oregon, and Washington. The NTR was developed in 1999 by the Northwest Portland Area Indian Health Board (NPAIHB) to address the racial misclassification of AI/AN people in health data. The NTR is maintained by NPAIHB with approval from NPAIHB's tribal delegates.



What it is

- A database of AI/AN patients who have received services at Indian Health Service (IHS), tribal, and urban Indian clinics in Idaho, Oregon, and Washington



What it is not

- Tribal enrollment data
- A list of all Northwest AI/AN people

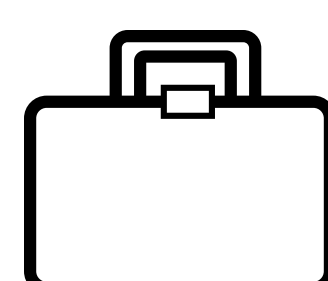


What is Racial Misclassification?

Racial misclassification is an incorrect recording of a person's race in a data system. While this can happen to anyone, it happens more often for AI/AN people. Examples of misclassification include:

- A person who is American Indian is coded as "White" on their death certificate
- A person who is American Indian and Black is recorded as only "Black" on their hospital visit record
- A person who is American Indian is recorded as "Hispanic White" at their doctor's office

When AI/AN are not classified as AI/AN in these data systems, they are not included in health reports, disease rates, or public health statistics for AI/AN, which leads to inaccurate AI/AN health information. This makes it difficult for Tribes to set health priorities and track changes in their communities' health over time.



What is the Northwest Tribal Registry used for?

The Northwest Tribal Registry is used to identify racially misclassified AI/AN people in state health datasets. The race information is then corrected and used to create more accurate health reports for AI/AN communities.



Who provides data for the Northwest Tribal Registry?

The IHS provides NPAIHB with the data used to create the Northwest Tribal Registry. NPAIHB obtains the data under a data sharing agreement with the IHS.



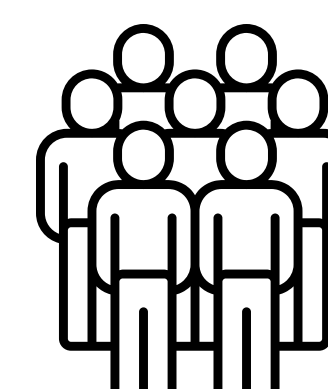
Who does

- The Indian Health Service



Who does not

- Individual Tribes
- Individual Clinics
- State Agencies



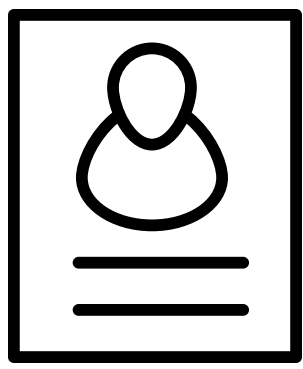
Who is in the Northwest Tribal Registry?

The Northwest Tribal Registry contains information on patients who received services at IHS, tribal, and urban clinics in Idaho, Oregon, and Washington. The NTR includes records of patients from Northwest tribes and from tribes from other areas.



How to end up in the Northwest Tribal Registry

- Be eligible to receive services from the Indian Health Service
- Receive services from an IHS, tribal, or urban clinic in Idaho, Oregon, or Washington



What information is in the Northwest Tribal Registry?

The Northwest Tribal Registry contains personal information for patients included in the registry.



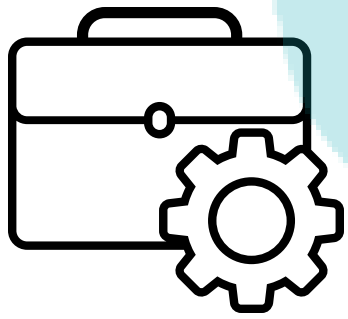
What information is in the Northwest Tribal Registry

- Social Security Number
- Name
- Date of Birth
- Sex
- Address



What information is not in the Northwest Tribal Registry

- Health information



How do we use the Northwest Tribal Registry?

NPAIHB uses the NTR for linkage projects with state health datasets. The linkage projects are used to better identify AI/AN people in state health datasets, and to correct misclassified AI/AN records. Our state partners do not keep any of the personal information from the NTR after the linkage projects are completed.



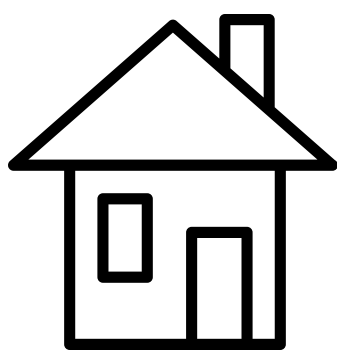
Questions we **could** answer with linkage-corrected data

- How many AI/AN people die in motor vehicle crashes?
- What is the impact of diabetes on AI/AN people in Oregon?
- What are AI/AN cancer rates in Washington?



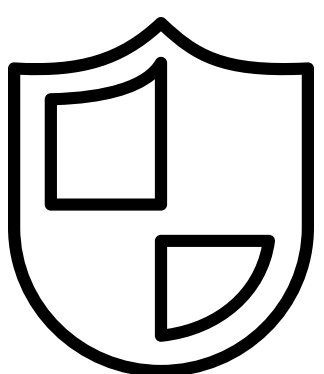
Questions we **could not** answer with linkage-corrected data

- Where does John Doe live?
- Is Jane Smith married?
- What Tribe is Larry Joe enrolled in?
- Does Peggy Sue have breast cancer?



Who owns the Northwest Tribal Registry?

The Northwest Tribal Registry is owned by Northwest Tribes and maintained by the Northwest Portland Area Indian Health Board. NPAIHB has been authorized to maintain the Registry through tribal resolutions from NPAIHB's tribal delegates, and our project protocols have been approved by the Portland Area Institutional Review Board.



How is the Northwest Tribal Registry protected?

The Northwest Tribal Registry is protected according to federal standards for protecting Personally Identifiable Information. This includes encryption, strong passwords, and physical safeguards for protecting the Registry.



How we **protect** the Northwest Tribal Registry

- Encryption of all data and the machine it is housed on
- Very strong passwords
- Safeguards to ensure the physical protection of the Northwest Tribal Registry



The Improving Data and Enhancing Access - Northwest (IDEA-NW) project

The IDEA-NW Project works to reduce AI/AN misclassification in public health data systems and provide Northwest Tribes with local-level health data. The project corrects inaccurate race data for AI/AN through record linkages with state surveillance systems such as cancer registries, vital statistics, hospital discharge systems, trauma registries, and STD/HIV systems. We then analyze and provide tribes with data for use in community health assessments, planning, grant writing, and policy development.



Have questions?

Contact us at IDEANW@NPAIHB.org