**Example Language for Tribal Resolutions**

This document provides some example language for use in Tribal and organizational resolutions related to data sharing. This language was developed by the Northwest Portland Area Indian Health Board (NPAIHB) to approve NPAIHB’s efforts to obtain data from state and federal agencies, and to emphasize Tribes’ ownership of tribal data. This language can be adapted for use without permission from NPAIHB. To see the full copies of these tribal resolutions, see NPAIHB’s resolution for [**Support for NPAIHB EpiCenter Access and Record Linkages with Health Surveillance Systems in Idaho, Oregon, and Washington**](https://npaihbdata.wpengine.com/wp-content/uploads/2021/10/21-04-03-Linkages-with-NTR.pdf)and [NPAIHB’s resolution for **Tribal Ownership of Health-Related Data**](https://npaihbdata.wpengine.com/wp-content/uploads/2021/10/05-04-04-Tribal-Ownership-of-Data.pdf)**.**

Language for obtaining data from local, state, and federal agencies

**WHEREAS,** the NPAIHB is dedicated to assisting and promoting the health needs and concerns of Indian people; and

**WHEREAS**, the primary goal of the NPAIHB is to improve the health and quality of life of its member Tribes; and

**WHEREAS**, in furtherance of this goal in 1997, NPAIHB established the Northwest Tribal Epidemiology Center (*EpiCenter*) in an effort to improve the quality of American Indian and Alaska Native (AI/AN) public health data; and

**WHEREAS**, AI/AN people in Idaho, Oregon, and Washington experience significant health disparities from many causes; and

**WHEREAS**, the NPAIHB *EpiCenter* has consistently demonstrated adequate measures to ensure the physical security of data and has policies in place to control access to and release of data; and

**WHEREAS**, any dissemination of results to outside audiences will only be done in collaboration with and by approval of NPAIHB, the *EpiCenter*, the Portland Area IHS Institutional Review Board, and member tribes;

**THEREFORE BE IT RESOLVED**, that the NPAIHB endorses and supports efforts by staff of the *EpiCenter,* under the guidance of the Executive Director, to access the following public health surveillance systems in Idaho, Oregon, and Washington to assess the health status of AI/AN people in the Northwest:

* Vital records data, including birth and death records
* Hospital and emergency department surveillance and reporting systems
* Notifiable conditions surveillance systems, including but not limited to COVID-19, HIV, sexually transmitted infections, and Hepatitis B and C surveillance systems
* Disease registries, including but not limited to cancer, trauma, blood lead, stroke, and STEMI registries
* Medicaid claims data
* Prescription Drug Monitoring Program data
* Emergency Medical Services data
* Fatality Analysis Reporting and Motor Vehicle Accident reporting systems
* Violent Death Reporting System data
* Pregnancy Risk Assessment Monitoring System (PRAMS) data
* Adult and youth risk factor surveillance systems

Language regarding tribal ownership of data used for research

**WHEREAS,** the NPAIHB is dedicated to assisting and promoting the health needs and concerns of Indian people; and

**WHEREAS**, the primary goal of the NPAIHB is to improve the health and quality of life of its member Tribes; and

**WHEREAS**, Northwest Tribes have the right to self-determination, and in exercising that right must be recognized as the exclusive owners of indigenous knowledge, cultural and biogenetic resources, and intellectual property; and

**WHEREAS**, these elements have been, and continue to be, damaged, destroyed, stolen, and misappropriated, as Tribal members have been the subjects of research for decades, with virtually no benefits returning back to the community from the research; and

**WHEREAS**, members of the NPAIHB recognize that one way to help safeguard the best interests of Northwest tribal communities is to utilize the Portland Area Indian Health Service Institutional Review Board (PAIHS IRB) to review proposed research protocols and in so doing help prevent research-related abuses of individuals and tribal communities, protect human subjects and traditional knowledge and properties, and to identify research-related benefits and risks to their Tribal communities; and

**WHEREAS**, members of the NPAIHB recognize that it must: (I) protect the people, culture, and natural resources of the NPAIHB from unauthorized scientific research; (2) reduce the adverse effects of research on Tribal communities; (3) ensure that researchers recognize Tribal control of research activities and Tribal ownership of all data and information generated or produced by such research, and; (4) Establish and provide a statutory basis to review and govern any research, collection, database, or publication undertaken on their Reservations; and

**WHEREAS**, any tribe that participates in health-related research must be given possession of the primary data (with the necessary protections taken to protect the rights and privacy and confidentiality of individuals).

**NOW THEREFORE BE IT RESOLVED**, that the Northwest Portland Area Indian Health Board hereby recommends that all health-related research undergo review and approval by the PAIHS-IRB prior to data collection and associated publication of reports; and

**BE IT FURTHER RESOLVED** that the tribe (and the PAIHS IRB, acting as an agent of the interests of American Indian and Alaska Native people, though not speaking for any individual tribe) have the opportunity to review and give input on publications (and presentations to the extent possible) while they are in draft form (NOT after already submitted to a journal or conference).

**BE IT FINALLY RESOLVED**, that there will be a formal process by which tribes and tribal organizations will give input as how data concerning their community is presented, and the following principles are adhered to in research projects concerning Northwest Tribal communities:

1. that investigators will not transfer the data to any other party without formal agreement from the tribe (and oversight by the PAIHS IRB, if involved), and
2. that no secondary analyses are performed on the data that are different than those proposed in the original research protocol without a formal request to the affected tribe (and PAIHS IRB, if involved), and
3. that there are measures taken to meaningfully inform the community of the results of research, and
4. that the tribe has the opportunity to benefit from gains that come out of the research (whether that means monetary profits or benefits in terms of better health), and
5. that the tribe has control over how and when data is disposed of (meaning that the storage of data is explicitly laid out, as are the plans for where and when and how it will be destroyed when no longer needed).