



NativeDATA

A Data Sharing Resource for
Native Peoples and Organizations

Making a Request for Data – Example Worksheet

This document shows an example of how to fill out the Making a Request for Data Worksheet. The example shows how the Northwest Tribal Epidemiology Center would complete this worksheet to request cancer data from the Oregon State Cancer Registry. Note that this worksheet is for illustrative purposes only.

Purpose, Definitions, and Authority

1. Describe what data you are requesting and why.

The Northwest Tribal Epidemiology Center (NWTEC) is requesting cancer incidence data from the Oregon State Cancer Registry (OSCaR) in order to monitor trends in cancer burden among American Indian/Alaska Native (AI/AN) residents of Oregon. The data will be used to inform health care planning and disease prevention efforts among the Tribes in Oregon.

2. Explain your general legal authority and, if appropriate, your legal authority to obtain the data.

The Northwest Tribal Epidemiology Center is authorized to receive this data under Oregon Administrative Rule 333-010-0050(2)(b)(c) and its status as a public health authority pursuant to 25 CRF §1621m(e)(1).

Duration You Will Use The Data For

3. Describe how long you will use the data. Sometimes this is called the “period of performance.” The time period should include a start and end date.

We will use the cancer registry data over the period August 2021-July 2026. After the initial data pull in 2021, we will request annual updates to the data.

Description of Data Use, Data Elements, and Scope of Data Request

4. Describe how the data will be used.

Tip: Be specific. This will help ensure that data are being used appropriately to benefit your community.

The Northwest Tribal Epidemiology Center will use the Oregon State Cancer Registry data to measure the burden of all cancers and specific cancers among AI/AN residents in Oregon, and to understand disparities in cancer burden compared to the non-Hispanic White (NHW) population in Oregon. Specifically, we will calculate the following:

- Counts of incident cancers by site for AI/AN in Oregon for the most recent years to determine leading cancer sites
- Counts of incident cancers by site for AI/AN in Oregon over the past 5 years by age group
- 5-year age-adjusted incidence rates and rate ratios for AI/AN and NHW for all cancers and top 10 leading cancer sites broken out by sex
- 3-year rolling averages (during 1996-the most recent year available) for all cancers and top 10 leading cancer sites to determine trends in cancer incidence among AI/AN residents in Oregon
- Stage at diagnosis for screen-able cancer sites (breast cancer, cervical cancer, colorectal cancer, prostate cancer)

5. Describe the specific data you want. Make sure to include:

a) Specific data variables that will be obtained

Tip: Data dictionaries, which list the names and definitions of different data variables, can help you understand what data is available.

Unique record ID

Address at diagnosis – State

Address at diagnosis – County

Sex

Age at diagnosis

Race 1

Race 2

Race 3

Race 4

Race 5

Ethnicity

Primary Site

Stage at diagnosis variables: SEER Summary Stage 1977, SEER Summary Stage 2000, Derived Summary Stage 2000, Summary Stage Best

Date of diagnosis – year

Histologic Type ICD-O-3

Behavior Code ICD-O-3

b) The data time frame

All years of data from 1996 (the year the registry started) to the most recent full year of data available. We request for annual updates to the data as new years of data are finalized.

c) The geographic area the data will cover

All records of cancer cases diagnosed among Oregon residents

d) Who the data will include

We request all available records of cancer cases diagnosed among Oregon residents. We will use the race1-race5 and ethnicity variables to identify AI/AN and NHW cancer cases.

Data Access, Transfer, Storage, and Destruction

6. Outline how (and how often) data will be accessed or transferred.

Tip: When you request to access data, you can ask for different kinds of access.

“Live access” means you get to directly access the database and obtain new data as needed. “Static access” means you obtain a “snapshot” of the data from the database at one point in time.

Following the initial data pull in 2021, NWTEC will request annual data pulls of the same variables that include the most recent full year of data (when these data are available). For each data pull, OSCaR will transfer the data file to NWTEC using a secure file transfer protocol (SFTP) site. OSCaR will password protect the file prior to uploading to the SFTP site. A designated contact at NWTEC will receive the link to the SFTP site from OSCaR through an encrypted email message. Once the NWTEC contact has saved the file to a restricted folder on NWTEC’s server, they will call the designated contact at OSCaR for the password to open the file.

7. Describe who will have access to the data from your Tribe or organization.

Access to OSCaR data will be limited to the following NWTEC staff:

Sujata Joshi, Epidemiologist

Andrea Sifuentes, Epidemiologist

Joseph Smith, Biostatistician

8. Describe how the data will be stored and kept safe.

Tip: Mention any specific trainings staff will need to go through to be able to access the data.

The dataset will be stored in a restricted access folder on NWTEC's secure server. Only the staff members listed in the agreement will be able to access this folder. Authorized NWTEC staff will need to use a strong password to log on to NWTEC's secure file server. All files on the server are backed up to tape every 30 days, and the tapes are stored in a bank vault in Portland, OR.

Staff with access to the data are required to undergo annual Information Systems Security Awareness training and annually sign confidentiality pledges for handling confidential data.

9. Detail how the data will be destroyed.

Once the project period is completed, the data files will be deleted from NWTEC's server. Server back-up tapes are re-written approximately every 30 days, so that all back-up copies of a deleted file will be written over and become unrecoverable within 30 days of deleting the files from the server.

Data Protection and Security

10. Describe the way that data will be protected while being:

- a) Accessed or transferred – OSCaR will transfer the data file to NWTEC using a secure file transfer protocol (SFTP) site. OSCaR will password protect the file prior to uploading to the SFTP site. A designated contact at NWTEC will receive the link to the SFTP site from OSCaR through an encrypted email message. Once the NWTEC contact has saved the file to a restricted folder on NWTEC's server, they will call the designated contact at OSCaR for the password to open the file.
- b) Analyzed – Access to the data file on NWTEC's server will be restricted to users specified in this agreement. These users will be required to use a strong password to access the server. Staff with access to the data are required to undergo annual Information Systems Security Awareness training and annually sign confidentiality pledges for handling confidential data. Data read into any statistical analysis software must be accessed through the server folder. Data will not be saved to an individual user's hard drive, unless the hard drive has whole disk encryption that uses an AES 256-bit encryption algorithm with FIPS 140-2 Operational and Integrity checks enabled.
- c) Stored – The data will be stored in a restricted access folder on NWTEC's secure server. Authorized users must use a strong password to access the server folder.
- d) Reported – To protect the privacy of individuals, NWTEC will only report results in aggregate, and will not release findings where non-zero numerator cell sizes are less than 5 (i.e., data will be suppressed for cell sizes of 1-4). A higher threshold may be used if there is any risk of identifying an individual patient. To protect the confidentiality of Tribes, no Tribe-specific data will be made publicly available. Tribe-specific data will only be released to authorized individuals from a specific Tribe, unless NWTEC receives written permission to release data to a third party. At all times, staff will exercise caution when interpreting any statistics where the number of events is small.
- e) Destroyed - Once the project period is completed, the data files will be deleted from NWTEC's server. Server back-up tapes are re-written approximately every 30 days, so that all back-up copies of a deleted file will be written over and become unrecoverable within 30 days of deleting the files from the server. Any copies of data files that are temporarily stored on encrypted hard drives during analysis will be destroyed using a secure shred function.

11. Indicate how people with access to the data will protect the data.

Tip: Require people with access to the data to sign confidentiality agreements or pledges.

Only the staff members listed in the agreement will be able to access data files provided under this agreement. Authorized NWTEC staff will need to use a strong password to log on to NWTEC's secure file server to access the data files. Staff with access to the data are required to undergo annual Information Systems Security Awareness training and annually sign confidentiality pledges for handling confidential data.

12. Detail who should be notified if data is lost, stolen, or accessed by someone who should not have access.

In case of a loss or unauthorized access to data, the NWTEC Director will be notified immediately. The NWTEC Director will then notify the Executive Director of the Northwest Portland Area Indian Health Board and points of contact listed on this data sharing agreement.

Release and Publication of Data

13. Indicate what requirements will need to be met for review, approval, and authorship of any reports, presentations, and publications that use the data.

For any published manuscripts that utilize data obtained under this agreement, NWTEC will send drafts of the manuscripts to OSCaR staff and to the Portland Area Indian Health Service Institutional Review Board for approval before publication.

References:

This handout was adapted from the Network for Public Health Law's Checklist of Information Needed to Address Proposed Data Collection, Access and Sharing. <https://networkforphl.org/wp-content/uploads/2020/01/Checklist-of-Information-Needed-to-Address-Proposed-Data-Collection-Access-and-Sharing-final.docx>



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Got questions? Contact us at ideanw@npaihb.org or visit NativeDATA.npaihb.org.

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