



WA DOH Tribal DSA Consultation Roundtable #2

DECEMBER 19, 2024 | Virtual - Zoom

Agenda

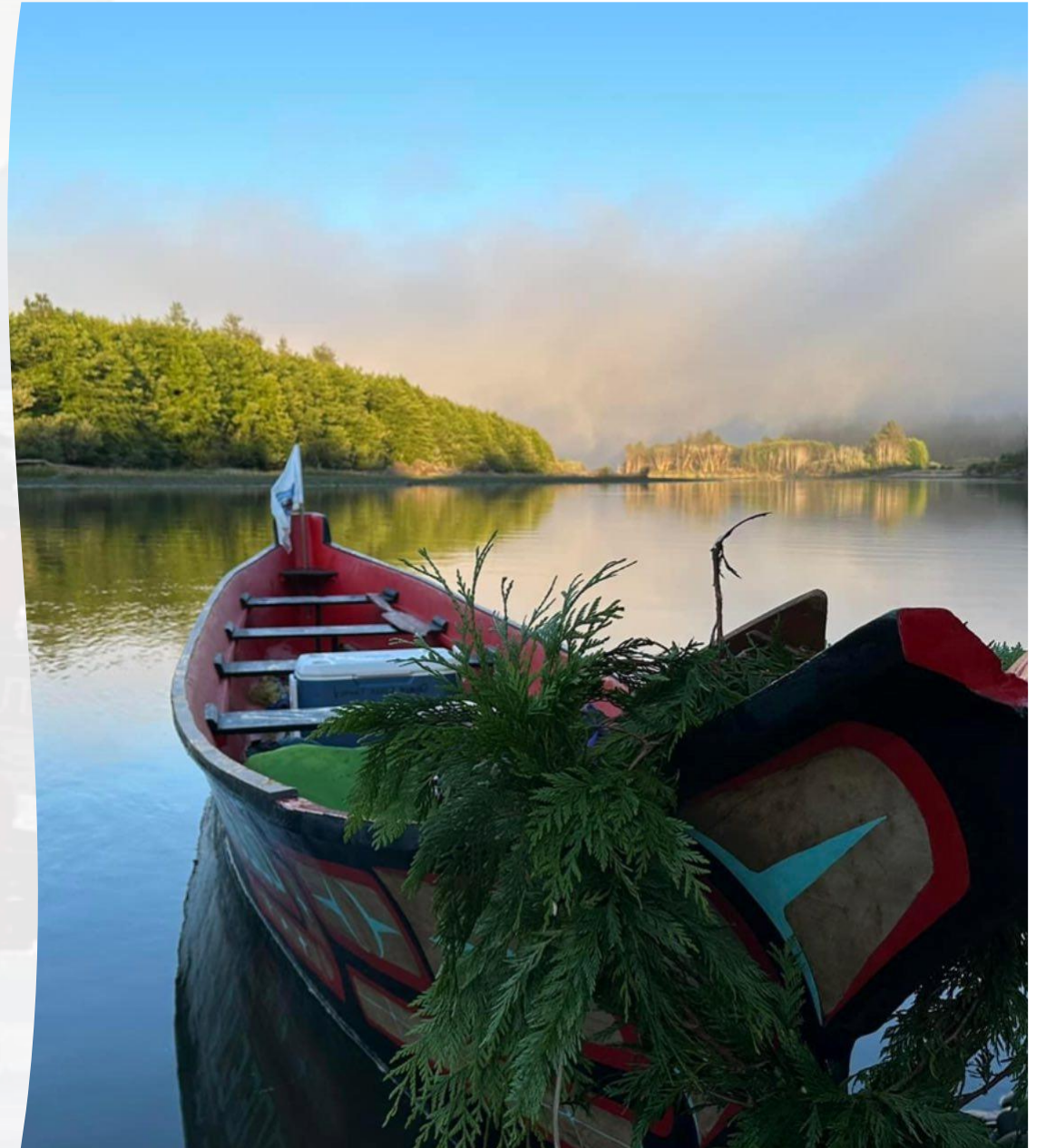
Welcome & Introductions

Recap of Roundtable #1

Systems Review

TDSA Template

Next Steps



Overview

TDSA Executive Consultation

On June 21, 2021, WA-DOH entered into consultation with Tribes through the AIHC to create an umbrella TDSA. Consultation ended without resolution on March 24, 2023. Since this time, WA-DOH's work continued and GIHAC established the Tribal Data Sovereignty Workgroup to help guide this process through the development of guiding principles, the Tribal DSA Checklist, which GIHAC adopted on December 3, 2024. With this vote, consultation was requested for the finalization of a WA-DOH TDSA template based on GIHAC's work.



@WaDeptHealth
@WaHealthSec



December 9, 2024

Re: Executive Consultation- Tribal Data Sharing Agreement

Greetings Honorable Tribal Leaders, Partners, and Professionals:

Respectfully, the Washington State Department of Health (WA-DOH) is hosting a consultation on a draft template Tribal Data Sovereignty Agreement presented by WA-DOH and guided by the Governor's Indian Health Advisory Council (GIHAC)'s Tribal Data Sovereignty Workgroup.

In accordance with chapter 43.376 RCW, the [Washington State Centennial Accord of 1989](#), and the [DOH Consultation and Collaboration Procedure](#), we are inviting Tribes and partners to work with us on finalizing a Tribal Data Sharing Agreement (TDSA) template for availability and use by Tribes.

A TDSA is a data sharing agreement (DSA) with a Tribal Nation that goes beyond WA-DOH's standard DSA to acknowledge Tribal sovereignty. The TDSA identifies the Tribal Nation as an owner of the Tribal data that DOH holds, creating a mechanism for the Tribal Nation to govern the use of their data, and expanding access to WA-DOH held data.

On June 21, 2021, WA-DOH entered into consultation with Tribes, through the American Indian Health Commission, to create an umbrella TDSA that could be utilized by all Tribes within Washington State. Consultation ended without resolution on March 24, 2023. Since this time, GIHAC established the Tribal Data Sovereignty Workgroup to help guide this process through the development of guiding principles, which GIHAC adopted on December 3, 2024.

With GIHAC's vote on December 3, 2024, it was requested that we move into consultation for the finalization of a WA-DOH TDSA template based on GIHAC's work. We invite you to join us for the following dates and times:

Meeting Type	Date and Time	Zoom Information
Roundtable #1	Thursday, December 12 th , 2024 from 2 pm – 3:30 pm	847 9211 8164 Passcode: 085267
Roundtable #2	Thursday, December 19 th , 2024 from 2 pm – 3:30 pm	824 0953 7124 Passcode: 000133
Consultation	Thursday, January 9 th , 2025 from 2 pm – 3:30 pm	842 0394 4304 Passcode: 130674

Roundtable #1 Recap

- Summary of Roundtable #1
 - Side-by-side of Checklist and draft TDSA Template; Kristin walked us through the template summarizing each component.
 - Refined Roundtable #2 agenda based on feedback from participants in first session.



TDSA Checklist approved and Dr. Shah blanketed at AIHC Delegates on 12/3/24

DOH Systems Overview

❖ WA DOH Data Systems Website:

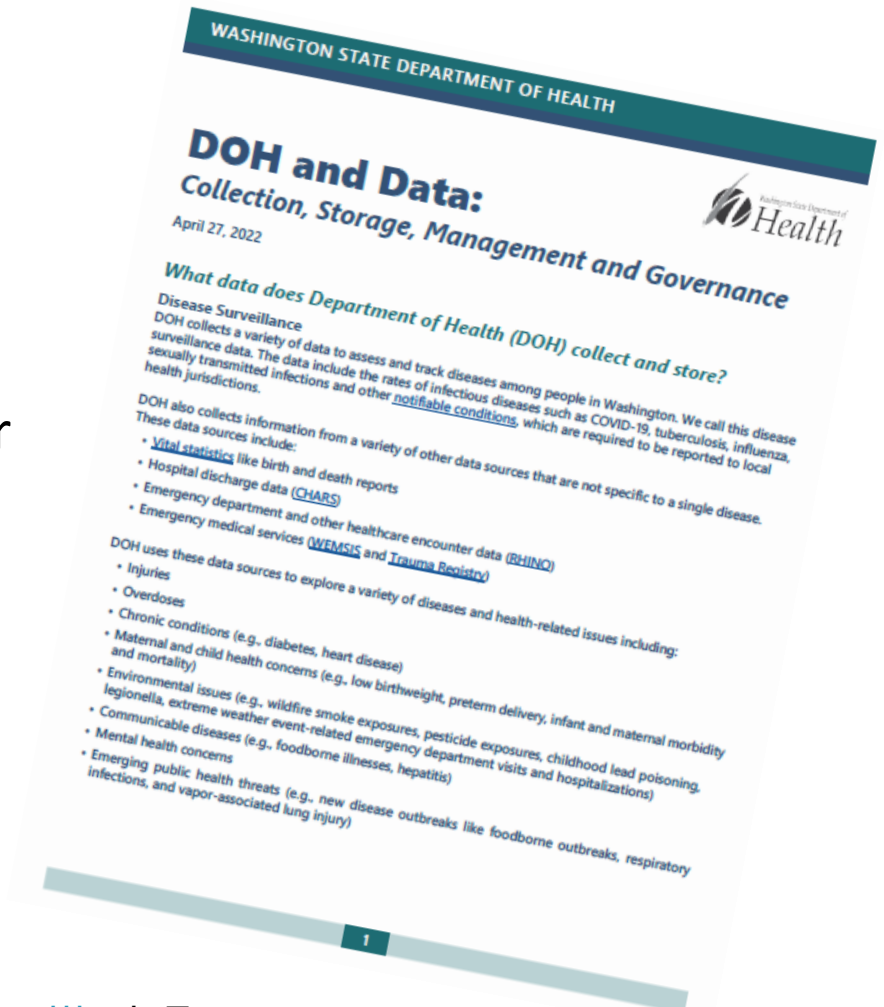
[Data Systems | Washington State Department of Health](#)

- 🕒 Request from Roundtable #1: review process for new data systems and the system access inclusions: "The [TRIBE] can choose to request access to additional DOH datasets and databases, and any access provided to additional datasets and databases will be added in the form of an Exhibit and Appendices attached to this Agreement and executed by both parties."

Data Set or System	Description
Washington Disease Reporting System (WDRS)	The Washington Disease Reporting System (WDRS) is an electronic disease surveillance system that allows public health staff in Washington State to receive, enter, manage, process, track and analyze disease-related data. WDRS includes some of our notifiable conditions.
Public Health Issue Management System (PHIMS)	The Public Health Issue Management System (PHIMS) is Washington State's standardized internet reporting system for notifiable conditions data. Department of Health and local public health agencies work together in Washington State to collect information and conduct investigations into the causes, spread and containment of certain chronic and contagious diseases.
Rapid Health Information Network (RHINO)	The RHINO program is responsible for syndromic surveillance data collection, analysis, and distribution at the department. Syndromic surveillance data is collected in near real-time from hospitals and clinics from across the state. Key data elements reported include patient demographic information, chief complaint, and coded diagnoses.
Washington Health and Life Events Systems (WHALES)	WHALES is the web application the Department of Health (DOH) uses to register vital life events, amend vital records, and issue certified copies of vital records in Washington State. It stores information about the births, deaths, fetal deaths, marriages, and divorces that occur in Washington State.
Comprehensive Hospital Abstract Reporting System (CHARS)	The Comprehensive Hospital Abstract Reporting System (CHARS) is a Department of Health system which collects record level information on inpatient and observation patient community hospital stays.
Washington State Immunization Information System (WA IIS)	The Washington IIS is a lifetime immunization registry with records for Washington residents.
Behavioral Risk Factor Surveillance System (BRFSS)	The BRFSS is a yearly survey that measures changes in the health of people in our state. It is the longest continuously running phone survey in the world. This survey is an important source of health-related data. It is the only survey that collects information on certain health factors like tobacco use and insurance coverage.
Healthy Youth Survey (HYS)	The Healthy Youth Survey (HYS) is a biennial, cross-sectional survey of 6th–12th graders that measures adolescent health and wellbeing in Washington state administered since 2002.
Pregnancy Risk Assessment Monitoring System (PRAMS)	WA PRAMS is a survey of new mothers conducted by Washington State Department of Health and the Centers for Disease Control and Prevention (CDC). PRAMS gathers information from mothers about their experiences before, during, and after their most recent pregnancy.
Cancer Registry	All healthcare providers and entities that diagnose or provide the first course of treatment to a patient must report cancer case information to the state cancer registry in accordance with state and federal law.

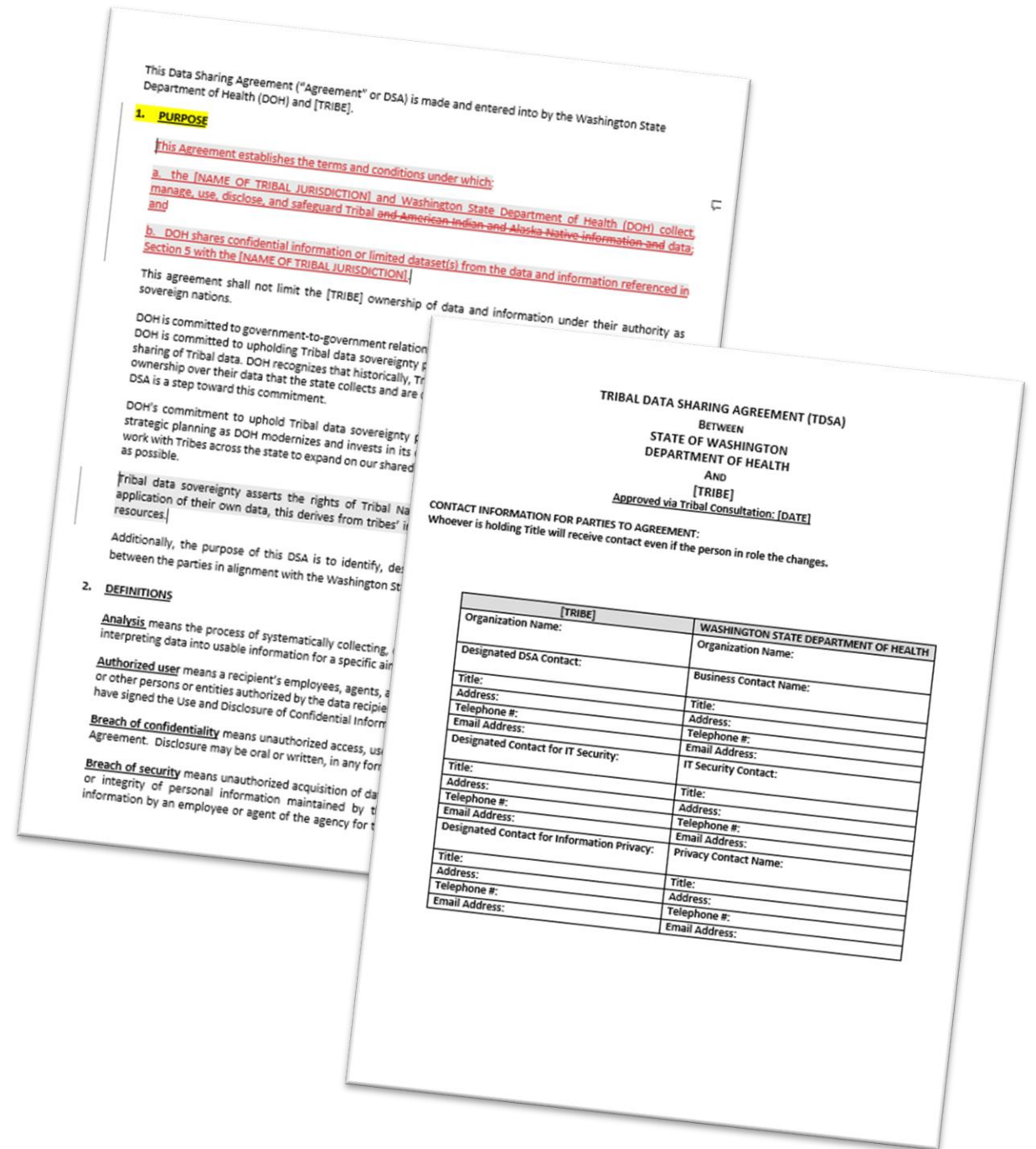
DOH Resources

- ❖ WA DOH Data Systems Website:
[Data Systems | Washington State Department of Health](#)
- ❖ [DOH and Data: Collection, Storage, Management, and Governance Fact Sheet](#)
- ❖ Additional resources coming soon through the Partner Hub



WA-DOH TDSA Template

Utilizing the approved Tribal DSA [checklist](#), prior work on the umbrella DSA and continued refinement, WA-DOH has created a draft TDSA template. We strongly believe, that as public health authorities, a Tribe's access to data is imperative to carrying out their public health authority. This effort is new, we will continue to learn best practices as we implement the DSA, adjust our efforts, and work together to honor tribal data sovereignty principles.





TRIBAL DATA SHARING AGREEMENT CHECKLIST For use by State and Tribal Nations

Checklist Purpose: This document provides recommended items for Washington State agencies to include when developing their data sharing agreements with Tribal nations.

What is a Tribal Data Sharing Agreement? A Tribal data sharing agreement provides terms and conditions under which a state agency (1) provides a Tribal jurisdiction informed consent on how Tribal data, including sensitive communicable disease data about their Tribe and their Tribal members, are used or shared with third parties; and (2) treats a Tribal jurisdiction as a sovereign government with equitable access to public health data to protect the health and safety of their community members. These agreements should be developed in consultation with Tribal governments. Below is a list of basic components of a Tribal data sharing agreement.

This document was developed in collaboration with representatives from Tribes through the Washington Governor’s Indian Advisory Council Data Sovereignty Committee.

Basic Tribal Data Sharing Agreement Components

- 1. PURPOSE.....2
- 2. DEFINITIONS (Specific to Tribes).....2
- 3. TRIBAL DATA SOVEREIGNTY PRINCIPLES3
- 4. RECOGNITION OF TRIBES AS TRIBAL HEALTH JURISDICTIONS AND PUBLIC HEALTH AUTHORITIES.....6
- 5. OWNERSHIP OF DATA.....6
- 6. INFORMED CONSENT AND PROTECTION OF A TRIBE’S DATA AND INFORMATION7
- 7. ACCESS TO STATE AGENCY DATASETS/DATABASES.....10
- 8. COMPLIANCE WITH DSA11
- APPENDIX A: TRIBAL NATION DATA USE FORM11

WA-DOH TDSA Template

Checklist	Template
Purpose	Sections 1, 4, 5, 6, 10
Principles 1-8	Section 1. A and B, 10, 13
THJ/PHA	Section 3.
Ownership	Section 4.
Informed Consent	Section 5.
Access	Section 6.
Compliance	Section 17.
Data Use Form	Section 5. A; Appendix E

Tribal Nation Data Use Form

The intent of the data use form is to provide information to [TRIBE] to process the data request. [TRIBE] may require additional information from the Department of Health Contact to determine if the form will be approved.

PART 1 – To be completed by Department of Health (DOH)

I. DOH Contact

Name: Title:
Program: Department:
Email: Phone:

II. DATA USE APPROVAL REQUEST OR TYPE OF NOTIFICATION

Is DOH requesting [TRIBE] approval to use the Tribal Nation's data? Or is DOH notifying the Tribal Nation of an exception use that is exempt from prior express written permission under Section 5E of the Tribal Data Sharing Agreement Between State of Washington Department of Health and [TRIBE]?

Data Use Approval Request (If this is an approval request, skip to Description of Data Use Request or Exempted Data Use Notification)

Notification of Exceptions – Exempted Data Use

Tribal Data Use Form Exceptions: Please specify the type of exempted use this notification qualifies for.

A request under the Public Records Act (RCW 42.56.520).

A WA State or federal statute or regulation prohibits or limits DOH compliance with Section 5 of the Tribal Data Sharing Agreement between State of Washington Department of Health and [TRIBE].

A compulsory legal process, court order, a settlement, or a consent decree prohibits or limits DOH compliance with Section 5 of the Tribal Data Sharing Agreement between State of Washington Department of Health and [TRIBE].

A contract, cooperative agreement, or grant agreement that predates this agreement that prohibits or limits DOH compliance with Section 5 of the Tribal Data Sharing Agreement between State of Washington Department of Health and [TRIBE].

Sharing with a state agency, federal agency, local health jurisdiction, or Tribe when DOH receives notification that a Tribal citizen or American Indian or Alaska Native individual is suspected of having been exposed or having exposed other persons, or has been diagnosed with a notifiable condition listed under WAC 246-101-101 within that agency's jurisdiction, a local health jurisdiction, or Tribal jurisdiction in alignment with current public health tribal/local/state practice.

Data Use Form

The data use form is a mechanism for DOH to respect Tribal data sovereignty and meaningfully partner with Tribes on the use of their data.

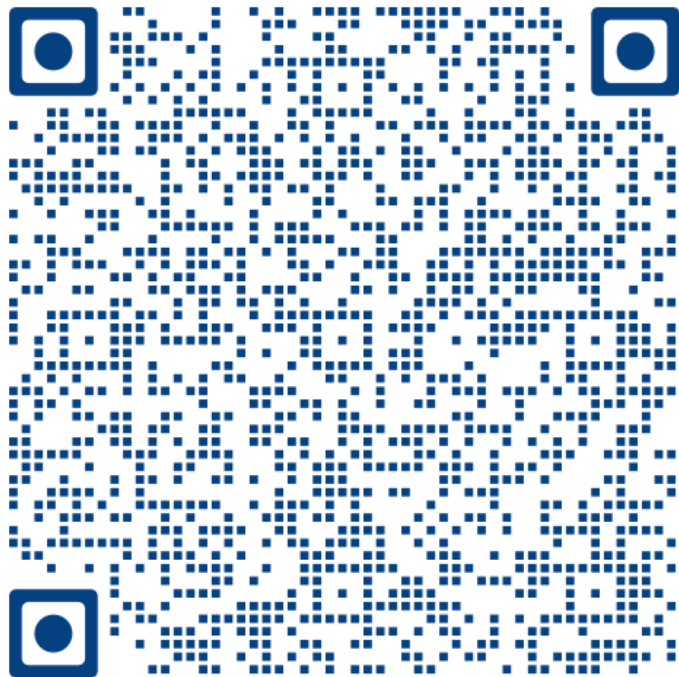
Appendix E in [Draft TDSA Template](#)

Next Steps: Consultation

Meeting Type	Date and Time	Link
Consultation	Thursday, January 9th, 2025 2 pm – 3:30 pm	842 0394 4304 Passcode: 130674

For additional information, please contact Amanda Tjemslund, Senior Tribal Epidemiologist, Office of Health and Science, at amanda.tjemslund@doh.wa.gov or 360-995-3324, or Candice Wilson, Executive Director, Office of Tribal Public Health and Relations (OTPHR), at candice.wilson@doh.wa.gov or 360-819-7626.

Office of Tribal Public Health and Relations



OTPHR



Washington State Department of
HEALTH

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