

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 <u>informed consent</u> 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 <u>equitable access to public health data</u> 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
	DEFINITIONS (Specific to Tribes)	
3.	TRIBAL DATA SOVEREIGNTY PRINCIPLES	3
	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 INFORMATION	7
7.	ACCESS TO STATE AGENCY DATASETS/DATABASES	10
8.	COMPLIANCE WITH DSA	11
ΛDD	PENDIX A: TRIBAL NATION DATA LISE FORM	11

1. PURPOSE

1.	1. Protection of Tribal Data. This Agreement establishes the terms and conditions under which the [NAME OF TRIBAL JURISDICTION] and [NAME OF STATE AGENCY] collect, manage, use, disclose, and safeguard Tribal and American Indian and Alaska Native information and data.	
2.	Granting the Tribe Access to Data About Their Community. This Agreement establishes the terms and conditions under which the [NAME OF STATE AGENCY] shares data and information with the [NAME OF TRIBAL JURISDICTION] .	

2. **DEFINITIONS** (Specific to Tribes)

1.		ird Party. Third Party means any person or entity (this includes, but is not limited to, ner state agencies) who is not a signatory to this Agreement.
2.	2. Tribal data means data or information that is specific to an individual Tribe and includes public or private data or information on or about a Tribe or its people subject to Tribal rights of ownership and control. Tribal data also includes, but is not limited to, Tribe of membership, Tribe of affiliation, events and conditions within the Tribe's jurisdiction and lands, information about Tribal members and any persons living within the Tribe's jurisdiction, Tribal census tract, Tribal land, and identification of Tribal facilities, entities, and enterprises and any individuals they serve.	
3.	Tri	bal data sovereignty means the inherent legal authority of Tribes to:
	1.	☐ manage the collection, ownership, application and interpretation of Tribal data or information even if it is collected by federal, state, or local governments and/or other third parties regardless of where data is collected;
	2.	\Box have the right to informed consent on how their data, including, but not limited to, protected health information about their Tribal members, are used or shared with third parties;
	3.	$\hfill\square$ have the same or additional access to state data as other public health jurisdictions in order to carry out their governmental duties; and
	4.	\Box be notified by other entities holding Tribal data of data breaches and be informed of any policies regarding data disposition, security, confidentiality, storage, and human subjects research limitations.

3. TRIBAL DATA SOVEREIGNTY PRINCIPLES

	 Inherent Authority to Manage Data. Tribes hold the sovereign authority to manage the collection, ownership, application and interpretation of their own data even when it is collected by federal, state, or local governments and/or other third parties. Demonstration of Commitment: 	
		 The jurisdiction will formally recognize and respect this inherent authority by involving Tribes in all stages of data collection, analysis, interpretation, and use, ensuring their administration over the process.
		 Tangible policies will be developed to ensure that Tribal oversight is in place whenever Tribal data is collected or utilized by external entities.
	2.	Ownership of and Authority Over Tribal Data. Tribes retain an ownership interest in data and authority even when the Tribe's data are located in a state, federal or other datasets. This interest remains when the Tribe's data are aggregated with other data.
	Demonstration of Commitment:	
		 Jurisdictions will explicitly recognize Tribal ownership and authority over their data and will establish clear mechanisms to safeguard this ownership in cases of aggregation or third-party handling.
		 Continuous monitoring and formal agreements will be implemented to ensure that ownership and authority rights are respected across all data storage platforms.
		 Jurisdictions will not utilize data sets in a manner that drives down to a specific Tribe's data without their permission.
	3.	Informed Consent. Tribes have the right to informed consent on how their data, including protected health information about Tribal members, are used or shared with third parties. Third parties include entities that are not signatories to the agreement, including other state agencies.
		Demonstration of Commitment:
		 Jurisdictions will develop and enforce consent policies that require Tribal approval before sharing or using Tribal data.
		• Jurisdictions will provide the Tribe informed consent procedures in plain language.

• Transparent consent processes will be established, and clear documentation will be required to ensure the Tribe is fully informed before their data is utilized by external entities including how the Tribe's data will be used by external entities. 4. Equitable Access to Data. Tribes have the right to exercise their Tribal data sovereignty and П must have the same or enhanced access to state data as other public health jurisdictions to effectively carry out their governmental duties. Jurisdictions will ensure that Tribes are provided with timely and equitable access to all relevant datasets and will establish access pathways that are either equal to or greater than those provided to other public health jurisdictions. • Dedicated processes for data access, along with technical assistance and necessary training, will be developed to facilitate Tribal access and use of data for governance and policymaking. 5. Equal Partners in Data Projects. Tribes must be equal partners in the design and implementation of data projects that involve their data or interests. Jurisdictions and Tribes will work collaboratively to develop and identify population-based projects to support public health functions of the Tribe and the state. Demonstration of Commitment: • Jurisdictions will ensure that Tribes are full collaborators in any data project, from inception to execution, with equal decision-making power. Joint planning committees will be established to involve Tribes in project design, implementation, analysis, reporting, and interpretation. • Jurisdictions will work collaboratively with Tribes and third parties to identify state and foundational resources. 6. Consulting with Tribes on Use of their Data. Jurisdictions must meaningfully consult and П partner with Tribes on how and when a jurisdiction shares Tribal data with third parties, and how it analyzes, reports, or interprets Tribal data. **Demonstration of Commitment:** • Formal consultation processes will be implemented to ensure that Tribal input is sought and integrated whenever their data is shared, analyzed, interpreted, or reported. A structured feedback loop will be developed so that Tribes are continuously informed and able to provide direction on the use of their data throughout all stages of the data lifecycle.

• Update existing data sharing agreements with third parties to include this requirement. 7. Privacy and Security Protections. Jurisdictions and Tribes will collaboratively strengthen privacy and security, including cybersecurity protections, by focusing on the following key elements: data access controls, encryption standards, data sharing agreements, data storage, retention, and destruction, and ongoing risk assessments. Demonstration of Commitment: • Joint Planning and Collaboration: Jurisdictions will ensure the inclusion of the Tribes in both existing and future planning efforts to enhance data privacy and security measures that impact both parties. • Tangible Instruments and Policies: Concrete tools and policies will be developed and implemented to safeguard data, ensuring transparency and clarity in how privacy and security are maintained. • Ongoing Monitoring and Evaluation: Continuous oversight will be provided through regular monitoring and evaluation of privacy and security measures, with established timelines for reviewing and updating protections. • Breach notification: Develop mutually agreed upon policy for providing timely notice of a breach of data by the parties to the agreement. "Timely" means as soon as possible but no later than 10 days. The jurisdiction will require breach notification requirements for third parties who have the Tribe's data. • Legislative Collaboration (would apply to all principles): When necessary, the jurisdiction and Tribes will work together to propose legislation aimed at further enhancing data privacy and security protections. 8. Tribal Data Sovereignty Supersedes Third Party Access and Use of Tribal Data. Jurisdictions must treat a Tribal government's rights to data as superior to access and use of data by third parties (entities who are not signatories to the agreement) in the following manner: Ensuring Tribes give consent to their data being shared with third parties. This includes: o regularly reviewing third-party agreements to ensure compliance and informed consent has been maintained; o ensuring Tribes have the ability to revoke consent at any time regardless of prior authorizations; o providing Tribes with priority access to their data and involvement in reporting

efforts; and

- o implementing releases of information, data sharing agreements, Tribal research review processes up to and including, Tribally approved Institutional Review Board (IRB) review.
- Implementing a third-party agreement renewal process that aligns with this principle with a specified timeline
- Including requirement in third-party agreements that the third party shall honor a Tribe's request to discontinue use of their data

4. RECOGNITION OF TRIBES AS TRIBAL HEALTH JURISDICTIONS AND PUBLIC HEALTH AUTHORITIES

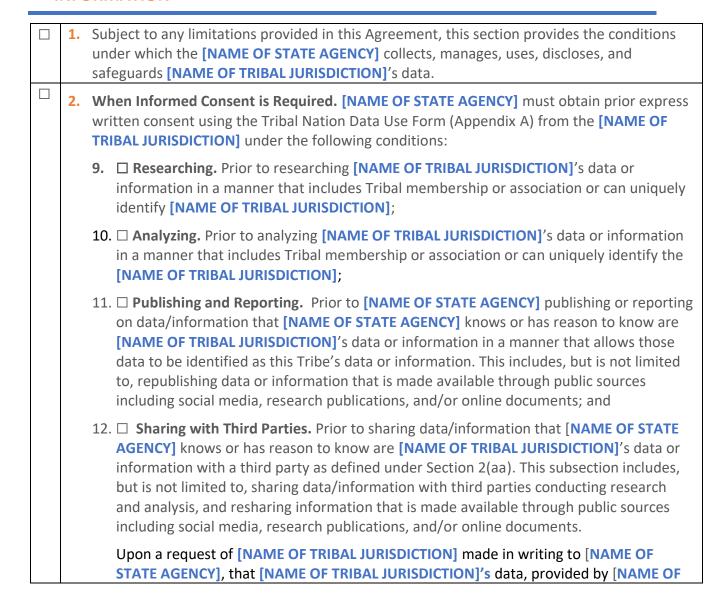
1.	Tribes are Public Health Authorities. In implementing this Agreement, [NAME OF STATE AGENCY] , shall, in accordance with the law, honor and treat Tribes as both health jurisdictions and public health authorities as recognized under 45 CFR § 164.501 and WAC 246-101-010(38).
2.	Tribes are Public Health Jurisdictions. In implementing this Agreement, [NAME OF STATE AGENCY] shall, in accordance with the law, honor and treat Tribes as public health jurisdictions with all the public health powers that exceed those of non-governmental public health authorities.

5. OWNERSHIP OF DATA

1.		ta ownership remains with and is not transferred to those authorized to receive and use e data and information subject to the following conditions:
	5.	☐ The [NAME OF TRIBAL JURISDICTION] and [NAME OF STATE AGENCY] shall have joint ownership in data and information in [NAME OF STATE AGENCY] data systems regarding the Tribe, its Tribal citizens, and persons who reside within the Tribe's jurisdiction, under this Agreement;
	6.	☐ This Agreement shall not limit the [NAME OF TRIBAL JURISDICTION] 's ownership of data and information under their authority as sovereign nations; and
	7.	\square This Agreement shall not transfer data ownership to third parties.
	8.	☐ When [NAME OF STATE AGENCY] conducts research that includes Tribal data, the following requirement shall apply:

[NAME OF TRIBAL JURISDICTION] has sole ownership and control or co-ownership and co-control of its data and information regarding the Tribe, its Tribal citizens, and persons who reside within the Tribe's jurisdiction.

6. INFORMED CONSENT AND PROTECTION OF A TRIBE'S DATA AND **INFORMATION**



	STATE AGENCY] to a third party, is being used in a manner that violates Tribal Data Sovereignty principles.
3.	Collaboration on Publishing and Reporting. The [NAME OF STATE AGENCY] will provide [NAME OF TRIBAL JURISDICTION] the opportunity to collaborate with [NAME OF TRIBAL JURISDICTION] prior to publishing and reporting on Tribal data.
	13. Tribal Research. If [NAME OF STATE AGENCY] or a third party wants to use [NAME OF TRIBAL JURISDICTION] 's data for research, the [NAME OF STATE AGENCY] must ensure through internal polices and/or third-party agreements that Tribes have the authority to determine if research is happening and to ensure that the request should go through the Tribe's internal research review process and to decide whether to participate or not. A Tribe's internal research review process could include an entity selected by a Tribe that reviews research to protect the interests of Tribal members and the Tribal community, like a Tribal Institutional Review Board. The [NAME OF STATE AGENCY] will require all third parties where applicable to comply with IRB processes required by the Tribe, in addition to any third-party IRB.
4.	Updating existing agreements. [NAME OF STATE AGENCY] will update all data sharing agreements with third parties to reflect the requirements of this section. The [NAME OF STATE AGENCY] will terminate agreements with third parties who fail to comply with these requirements as well as applicable federal laws.
	Update template agreements. [NAME OF STATE AGENCY] will update template agreements with third parties to reflect the requirements of this section. Template agreements should include termination provisions for failure to comply with these requirements as well as applicable federal laws.
	14. Timelines for submitting Tribal Nation data use form. The Tribe will respond no later than 30 days after receipt of the Tribal Nation Data Use Form. If the Tribe does not respond within 30 days of receiving [NAME OF STATE AGENCY]'s request, the [NAME OF STATE AGENCY] will make reasonable efforts to contact the Tribal contact listed in Section [INSERT SECTION NUMBER].
	Expedited Requests. [NAME OF STATE AGENCY] can request approval prior to 30 days by providing justification for an expedited process.
	Existing IRB. If a Tribal Research Review of record exists, the [NAME OF TRIBAL JURISDICTION] may indicate on the Tribal Nation Data Use Form that the Tribe defers approval to the Tribal Research Review.
	15. Prohibited Sharing of Potentially Identifiable Information Belonging to AI/AN Individuals. The [NAME OF STATE AGENCY] will not share potentially identifiable information (including, but not limited to, protect health information e.g. sexually

	transmitted infections, pregnancy, behavioral health treatment etc.) or data belonging to American Indians and Alaska Native (AI/AN) individuals with third parties.
5.	Exceptions. This section provides exceptions for when [NAME OF STATE AGENCY] shall not be required to seek prior express written permission under Section 6.2 or be prohibited from sharing information under Section 6.7. Unless otherwise stated, [NAME OF STATE AGENCY] shall still be required to provide notification to the [NAME OF TRIBAL JURISDICTION] utilizing the Tribal Nation Data Use Form (Appendix A) as soon as [NAME OF STATE AGENCY] has reason to know whether the data or information involves Tribal data or information. The [NAME OF STATE AGENCY] will consult with the Tribe regarding any legal objections the Tribe may have and shall share only the minimum necessary information. The exceptions include the following:
	16. ☐ A request under the [INSERT STATE PUBLIC RECORDS LAW]. The [INSERT STATE PUBLIC RECORDS LAW] requires release of the data or information with a minimum of [INSERT NUMBER OF DAYS] notice as per [NAME OF STATE AGENCY] Public Records Policy and Procedure unless and until amendment of the Public Records Act exempts Tribal data from public disclosure;
	17. A state or federal statute or regulation that prohibits or limits [NAME OF STATE AGENCY] compliance with Section 6. The [NAME OF STATE AGENCY] will identify which statutes and regulations prohibits or limits such compliance.
	18. ☐ Compulsory legal process, court order, or a settlement or a consent decree which prohibits or limits [NAME OF STATE AGENCY] compliance with Section 6;
	19. An existing contract, cooperative agreement or grant that the [NAME OF STATE AGENCY]'s compliance with Section 6. The [NAME OF STATE AGENCY] shall include the specific language from the contract, agreement, or grant that requires [NAME OF STATE AGENCY] to share Tribal data on the Tribal Nation Data Use Form (Appendix A). This subsection is subject to Section 6.5 which requires [NAME OF STATE AGENCY] to update all data sharing agreements with third parties to reflect the requirements of this section and discontinue future use of data under this Agreement in a manner that violates Section 6;
	20. ☐ Data reports and data visualizations published prior to execution of this Agreement. No Tribal Nation Data Use Form is required. This subsection shall not include updates to prior reports and data visualizations after execution of this Agreement;
	21. Data analyses that are (1) conducted to understand and correct data collection interruptions or problems; and/or (2) undertaken to address data quality concerns, such as to identify invalid data or missing or incomplete data. [NAME OF STATE AGENCY]

must follow requirements of Section 6 if [NAME OF STATE AGENCY] shares data analysis with a third party;

22. □ Whenever an individual is requesting [NAME OF STATE AGENCY] information or records that relate to them or the provision of health care services to them. No Tribal Nation Data Use Form is required.

7. ACCESS TO STATE AGENCY DATASETS/DATABASES

1.	Current database/dataset access. Access to the following [NAME OF STATE AGENCY] data by [NAME OF TRIBAL JURISDICTION], including but not limited to upgraded systems to those datasets, is provided for the purposes outlined in Section 1 of this Agreement (Access to checked boxes only. If necessary, attach exhibit with additional requirements specific to dataset): • Statewide notifiable disease reporting system	
	• Linked Immunization Administration Data in state notifiable disease reporting system	
	Linked Death Data in state notifiable disease reporting system	
	Linked syndromic surveillance data in state notifiable disease reporting system	
	Linked case and contact investigation data in state notifiable disease reporting system	
	State case and contact investigation system (case and contact investigation data)	
	State Immunization Information System	
	NONDISCRIMINATION IN ACCESS. The [NAME OF TRIBAL JURISDICTION] shall have the same or additional access to [NAME OF STATE AGENCY DATASETS/DATABASES] as other public health jurisdictions.	
2.	same or additional access to [NAME OF STATE AGENCY DATASETS/DATABASES] as other	
	same or additional access to [NAME OF STATE AGENCY DATASETS/DATABASES] as other	
	same or additional access to [NAME OF STATE AGENCY DATASETS/DATABASES] as other public health jurisdictions. Extent of Access. Subject to subsection (b), the [NAME OF TRIBAL JURISDICTION]'s access	

4. Future dataset/database access. [NAME OF TRIBAL JURISDICTION] can choose to request access to additional [NAME OF STATE AGENCY] 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.

8. COMPLIANCE WITH DSA

1.	[NAME OF STATE AGENCY] will collaborate with Tribes to establish written Tribal data sharing policies and procedures that implement the requirements under this Agreement.
2.	[NAME OF STATE AGENCY] will provide regular, project, and temporary staff orientations and training on the policies and procedures referenced in subsection (a) under this section. Orientations and training shall include the education and information on protecting Tribal and AI/AN Population Data and Information and use of the Tribal Nation Data Use Form. Training shall occur annually and within 90 days of hire.
3.	[NAME OF STATE AGENCY] will work to ensure staff compliance with Tribal data sharing policies and address any violations in accordance with the [NAME OF STATE AGENCY] Tribal data sharing policies and procedures and [NAME OF STATE AGENCY] human resources policies and procedures.
4.	Breach Notification. The [NAME OF TRIBAL JURISDICTION] shall notify the [NAME OF STATE AGENCY] Chief Information Security Officer at [INSERT EMAIL ADDRESS] within ten (10) business days of any suspected or actual breach of security or confidentiality of information covered by the Agreement.
	The [NAME OF STATE AGENCY] Chief Information Security Officer shall notify the [NAME OF TRIBAL JURISDICTION] at [INSERT EMAIL ADDRESS] within ten (10) business days of any suspected or actual breach of security or confidentiality of information pertaining to Tribal data/information or American Indian/Alaska Native data/information covered by the Agreement.

APPENDIX A: TRIBAL NATION DATA USE FORM

Parties shall refer to the Tribal Data Sharing Agreement for when and how this form should be utilized.

PART I – To be completed by [NAME OF STATE AGENCY] requesting/notifying entity.

		TO BE COMPLETED BY [NAME OF STATE AGENCY]
1.	Date of Request	
2.	Date for Tribe to Respond	
3.	Name of Contact Person, Title, Program, and Department	
4.	Email and Phone	
5.	Is this a request for the Tribe's Approval to use the Tribe's data or is this a notification to the Tribe?	
6.	If this is a notification only, please specify the type of exempted use this notification qualifies for under Section 6 of the Tribal Data Sharing Agreement.	
7.	If an existing contract, cooperative agreement or grant prohibits or limits [NAME OF STATE AGENCY]'s ability to comply with the Tribal informed consent requirements of the Tribal Data Sharing Agreement, please provide an explanation including specific language from the contract, agreement, or grant that requires [NAME OF STATE AGENCY] to share Tribal data.	
8.	If [NAME OF STATE AGENCY] is conducting data analysis that is exempt from the requirements of Tribal informed consent under the Tribal Data Sharing Agreement, please address the following questions:	

A. What data analysis is being conducted?	
B. Does this analysis include corrections for identifying AI/AN or Tribal enrollment?	
Brief title for data use approval request or notification of exempted data use.	
Date approval is needed (N/A, if this is a notification of exempted data use).	
11. Expedited approval is needed. Please provide justification for expedited approval (N/A, if this is a notification of exempted data use).	
12. One-time use or a recurring use?	
13. If this is for research, list any and all institutional review boards that will complete a review.	
14. Anticipated frequency of use (e.g., daily, monthly, annually, etc.)	
15. Tribal data to which this request or notification applies	
16. How the data will be used (published, analyzed, shared, or used in research or other applications, etc.) and why it is necessary	
17. Who will gain access to these data or to products that include or are derived from this request or notification?	
18. How will data collection occur (e.g., a field in WDRS)	

19. Potential benefits to the Tribal Nation, AI/AN and/or other Tribes	
20. Potential risks or harm to the Tribal Nation, AI/AN and/or other Tribes	
21. Any additional information that will be useful to the Tribal Nation in reviewing this request or notification	

PART II – To be completed by the Tribal Jurisdiction.

		TO BE COMPLETED BY TRIBAL JURISDICTION
1.	Date of Response	
2.	Name of Contact Person, Title, Program, and Department	
3.	Email and Phone	
4.	If this is a request for approval by the Tribe, does the Tribe approve or disapprove of the request above?	 □ Approve □ Disapprove □ There is an existing Tribal IRB. The Tribe defers to the IRB for approval. List name of IRB to review for approval □ N/A – This is a notification only
5.	Potential benefits of this request (e.g., consistent with Tribal sovereignty, respects Tribal culture, will help improve health of AI/AN, will help dispel negative racial stereotypes, supports strengthening Tribal public health capabilities)	(OPTIONAL)
6.	Potential risks or negatives associated with this request (e.g., inconsistent with Tribal sovereignty, not respectful of Tribal culture, perpetuates negative racial stereotypes,	(OPTIONAL)

v. 5 10-4-24

v. 4 9-26-24

v.3 9-6-24

v.2 8-23-24

v.1 7-12-24

	does not support improving health status of AI/AN, may not be sufficient information to prevent incorrect conclusions, does not support strengthening Tribal public health capabilities)	
7.	Please explain whether the benefits of this request or notification will outweigh the potential risks or harm.	(OPTIONAL)