

	Number	Level	Effective Date
	2026.04.V1.1	I	04/01/2026
Title: INDIGENOUS DATA SOVEREIGNTY POLICY			
Supersedes:			
Primary Responsibility: Division of Planning & Operations			
Review Cycle: Annually		Reference Code:	

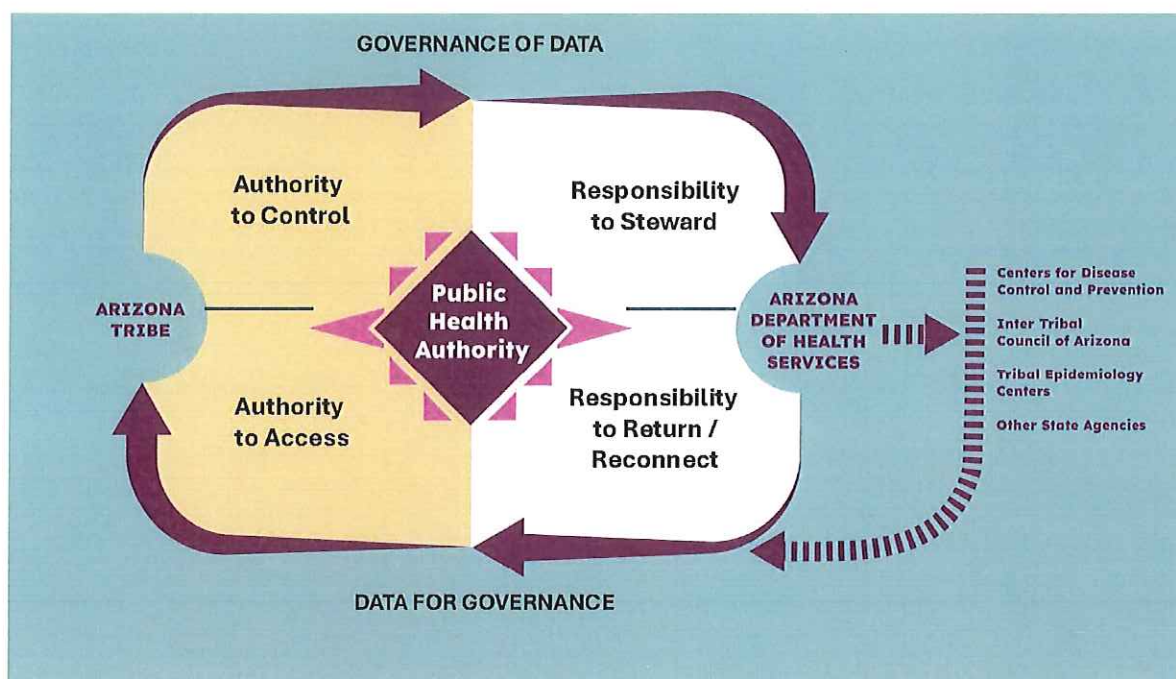
Purpose/Scope

The Indigenous Data Sovereignty (IDSov) Policy (hereinafter “Policy”), reaffirms the rights of the Tribes in the State of Arizona to govern Tribal health data. This Policy describes and acknowledges the rights of the Tribes, as well as the responsibilities and expectations of the Arizona Department of Health Services (ADHS), its contractors, and other data actors who interact with Tribal health data. Interaction includes control, collection, use, storage, management, stewardship, analysis, processing, reporting, protecting, sharing, returning, and disposition. The Policy upholds Tribal sovereignty and self-determination by setting forth the guiding principles, recommendations, and procedural standards to ensure that ADHS data activities are conducted in an ethical and culturally informed manner.

Context

This Policy describes and implements a sovereign-to-sovereign relationship between ADHS and each Tribe that shares geography with the State of Arizona. Each sovereign Tribe has the authority to carry out its public health authority within its territory and among its citizens. The Policy lays out a collaborative and relational framework (see Figure 1) for ensuring that data collected to support the State’s public health mission are used, shared, and stored in ways that respect each Tribe’s sovereignty and corresponding public health authority within its territory and among its citizens.

Figure 1. Tribal Data Governance Framework for ADHS



This policy was created in partnership between ADHS and Tribes in the State of Arizona with guided engagement from the University of Arizona’s Native Nations Institute and the Collaboratory for Indigenous Data Governance. Foundational steps were taken starting in Fall 2023 which included in-person visits with Tribes in Arizona and leadership meetings with Tribal government to strengthen partnership. These conversations had the common theme of reconnecting Tribes with their data to ensure Tribal access to data for their own governance priorities and Tribal governance of how others steward Tribal data. These important meetings resulted in establishing an internal ADHS Tribal Data Sharing Workgroup, co-creating a Tribal Data Sharing Agreement between ADHS and a Tribal Nation, hiring an ADHS Tribal Health Epidemiologist to liaise with Tribes, and partnering with Native Nations Institute and the Collaboratory to provide expertise in Indigenous Data Sovereignty and relationship governance.

An inaugural two-day meeting was held in August 2024 with Tribes in the State of Arizona to co-develop the policy principles and priorities using democratic deliberation. The participant-led, facilitator-guided process created a safe space for Tribes to articulate values, define governance needs, and build consensus free from external influence. This approach reflects a transformative sovereign-to-sovereign partnership model, aligning state health data systems with Indigenous governance

values and the CARE Principles for Indigenous Data Governance (Collective benefit, Authority to control, Responsibility, Ethics). Once trust was built, an additional two meetings were held with the State, collaborators, and the Tribes in Spring 2025.

Applicability

This Policy applies to:

1. All ADHS Workforce Members, contractors, and other data actors who work with data or repositories of data while executing business functions, activities, or services for or on behalf of ADHS or its customers;
2. Both previously generated data and all new data that the ADHS interacts with; and
3. Indigenous Peoples' data at the ADHS includes any data defined by Tribes in the State of Arizona as Tribal data and including but not limited to:
 - a. Writings (e.g., a report, language transcriptions for marketing communication);
 - b. Documentation of Indigenous Peoples' heritage in all forms of media (e.g., reports, photography, films, sound recordings);
 - c. Specimens (e.g., human tissue, plant, soil, living or non living organisms, etc.);
 - d. Individual level socioeconomic data and all health-related data and specimens;
 - Arizona Vital Records Birth Data
 - Arizona Vital Records Death Data
 - Arizona Vital Records Fetal Death Data
 - Arizona Hospital Discharge Data
 - MEDSIS (Infectious Diseases, Blood Lead, Opioid Overdose, Birth Defects)
 - MEDSIS Environmental Exposure Data
 - Sexually Transmitted Diseases Data (PRISM) Surveillance
 - Arizona Immunization Information System (ASIIS)
 - Immunization Data Registry (IDR)
 - HIV/AIDS Surveillance Data (eHARS)
 - Arizona State Trauma Registry Data
 - Tuberculosis Surveillance Case Data
 - Arizona Pregnancy Risk Assessment Monitoring System
 - Cancer Registry
 - State Unintentional Drug Overdose Reporting System (SUDORS)
 - Community Profiles
 - Data Dashboards
 - Arizona Behavioral Risk Factor Surveillance System
 - Visual analytics (charts, graphs, GIS mapping, etc.)
 - Arizona Department of Licensing Facilities (AzCareCheck.com)
 - Arizona State Public Health Laboratory Samples
 - Environmental Health

- Administrative data from various governmental agencies, nations organizations; and
- Environmental data
 - Heat Maps
 - Particulate Matter
 - Precipitation
 - Wind

Exceptions

There are no exemptions.

Policy

The following Foundational Indigenous Data Sovereignty standards shall serve as guiding principles for how Tribes and the ADHS collaborate on data governance:

1. Respecting *Tribal Sovereignty* means ensuring equal partnership in all decision-making processes to uphold Tribal self-determination and authority.
2. Nurturing *Trust* requires sustained relationships, ongoing communication, and transparency in decision making, with clear recognition of each Tribe's distinct governance structures and protocols.
3. Applying local, national, and international *Indigenous Data Governance Standards* necessitates following the guidance and protocols of the Tribe to which data relates. Therefore, Tribes define their data, geographies and populations of interest.
4. *Any Interaction with Tribal Data* must occur under agreements co-developed with Tribes that specify purposes, timelines, conditions, and review processes, ensuring that all data access and use happens according to a Tribe's terms.
5. Ensuring *Data Integrity* involves ADHS interacting with Tribal data using culturally aligned practices, with Tribal oversight to safeguard context, prevent misuse, and validate findings.
6. *Building and Sustaining Capacity* requires investing in Tribal data infrastructure, training, and resources so that Tribes can independently govern and interact with their data.
7. Applying *Data Governance Principles* such as FAIR (Findable, Accessible, Interoperable, Reusable) must always operate within the boundaries defined by the Tribe, and in alignment with CARE (Collective Benefit, Authority to Control, Responsibility, Ethics) to ensure ethical, sovereign, and culturally informed use of data.
8. *Documenting and Managing Metadata* means ensuring that all information related to Tribal health data is accurately recorded, maintained, and governed in alignment with Indigenous Data Sovereignty principles.

9. *Release of Tribal data* requires explicit permission from the Tribe. The ADHS Minimum Data Suppression Standards Policy is the base practice and Tribes may further suppress data at local or county level.
10. *Reporting or publishing data* requires ADHS Workforce Members, contractors, and other data actors, including counties, educational institutions, and corporations to aggregate any Indigenous data to report by American Indian and Alaskan Native race/ethnicity. ADHS Workforce Members, contractors, and other data actors are prohibited from reporting or publishing data disaggregated by Tribal identifiers (e.g., community name, zipcode, geographies, locations, Tribal affiliations) without permission from the Tribe. ADHS Workforce Members, contractors, and other data actors must partner with Tribes and follow Tribal authority when publishing disaggregated Tribal data.

Recommendations for Policy Adherence

1. Education and Training: Develop and deliver regular training sessions on the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), the FAIR and CARE Principles for Indigenous Data Governance, and cultural responsiveness.¹ These sessions shall emphasize how data policies must uphold Tribal sovereignty, cultural beliefs, traditional knowledge systems, and community priorities. The FAIR Principles ensure that data and resulting research are **F**indable, **A**ccessible, **I**nteroperable, and **R**eusable, while the CARE Principles ensure that data serves the **C**ollective benefit, remains under the **A**uthority to control by the Tribe, and is handled **R**esponsibly and **E**thically.²
2. Regular Communication and Meetings with Tribes as Outlined in the Tribal Consultation Policy: The ADHS will engage in regular consultation with Tribes on matters related to Indigenous Data Sovereignty issues that may impact Tribal communities. Communication may occur through formal Tribal Consultation, Leader-to-Leader Meetings, meetings conducted by the ADHS Tribal Liaison or at the request of a Tribe for formal or informal meetings. These meetings provide opportunities to review data governance issues, share updates, and address concerns.
3. Annual Review of this Policy by Tribes and ADHS: ADHS shall review this Policy at least every 3 years with Tribes at a Tribal Consultation. A 45-day open comment period will be provided if any text changes are recommended.
4. Implementation and Oversight: The ADHS, through the Tribal Liaison and Tribal Health Epidemiologist, shall provide assistance in the implementation and oversight of this Policy, data request and data sharing agreements; provide

annual reporting through the Governor's Annual Report, create and work with advisory groups if needed.

5. **Enforcement and Accountability:** If there is a suspected or actual violation of this Policy, the concerned employees or their manager must promptly contact the Enterprise Data Manager Office and the Review Committee for Indigenous Data Sovereignty. These entities will assess the nature of the concern and determine next steps using techniques outlined in this Policy. Resolution efforts may include education, facilitated dialogue, policy clarification, and other culturally informed compliance techniques. If an issue cannot be resolved through internal processes, it may be escalated in accordance with ADHS policies and procedures. Staff, contractors, and other data actors should be aware that Tribes retain sovereign authority and must pursue legal or formal action independently, particularly in cases involving misuse of Tribal data. In addition, the ADHS is subject to Arizona's data breach notification law (A.R.S. § 18-552), which outlines requirements for responding to breaches involving unencrypted personal information.
6. **Accessible Language:** All descriptions of datasets and data policies must be accessible and written in jargon-free language.
7. **Enhance Tribal Legal Expertise:** Support the development of legal and policy expertise within Tribal communities through capacity and capability-building programs, agreements, and access to Indigenous Data Sovereignty resources.

Roles

1. The ADHS Director, or designee, shall be responsible for ensuring the effective implementation of the Policy within the ADHS.
2. ADHS Supervisors or management shall be responsible for ensuring their ADHS employees and contractors adhere to the Policy standards. If clarifications, exemptions, or guidance is needed, the employee or managers can ask for guidance from the Enterprise Data Management Office and Review Committee for Indigenous Data Sovereignty. For managers seeking guidance on employee adherence to this Policy, please contact the Enterprise Data Management Office at edmo@azdhs.gov and Review Committee for Indigenous Data Sovereignty at TribalRelations@azdhs.gov.
3. Employees shall review the Policy contents with their manager. If there are any additional clarifications, employees or managers can reach out to the Enterprise Data Management Office or Review Committee for Indigenous Data Sovereignty. It is recommended that this Policy be included in the onboarding materials for new ADHS Workforce Members, contractors, and data actors.

4. A committee for reviewing IDSov standards will be established consisting of the state epidemiologist, representative of Tribal Leaders or Tribal Health Directors, Tribal liaison, Tribal health epidemiologist, deputy state epidemiologist, a representative from the enterprise data management office, the ADHS HIPAA Privacy Officer, and other subject matter experts within the ADHS identified by the state or deputy state epidemiologist with experience in Tribal sovereignty and Indigenous data. Legal consultation with the General Counsel and the Chief Administrative Counsel is available if needed to ensure legal and administrative compliance. The committee can be contacted by emailing TribalRelations@azdhs.gov and will review and respond to inquiries ad hoc.

Responsibilities

1. Recognition and Respect: All Tribes data use must align with UNDRIP and the ADHS Tribal consultation policy, including the right to self-determination and ongoing FPIC and in accordance with A.R.S. § 41-2051(C). All ADHS Workforce Members, contractors, and other data actors who interact with data must:
 - a. Understand and apply the principles of Tribal self-determination from the UNDRIP and ADHS Tribal consultation policy when interacting with Tribal data.
 - b. Recognize and respect individual, collective, and community rights to data rights, ownership, access, and governance.
 - c. Ensure data use upholds individual rights, freedoms, and dignity.
 - d. Indigenous knowledges, practices, and cultural data must be respected, protected, and maintained. This includes ADHS, its contractors, and other data actors who have a responsibility to comprehend all Indigenous knowledge systems, cultural expressions, and intellectual property.
2. Engagement and Collaboration: At every stage, interaction with Tribal data must be based on a process of meaningful and respectful engagement and continue throughout the process.
 - a. Methods and levels of engagement should align with data goals and reflect the priorities and interests of the Tribes.
 - b. All Tribes may have or develop their own data and research protocols and processes for reaching decisions about how other data actors interact with Tribal data.
 - c. ADHS Workforce Members, contractors, and other data actors should be open to changing and developing their practices to respond to and accommodate Tribal data protocols.

3. **Collective Privacy and Confidentiality:** ADHS Workforce Members, contractors, and other data actors shall safeguard all Tribal data entrusted to them and not misuse or wrongfully disclose it. This commitment includes the following responsibilities:
 - a. Respect the collective privacy of the Tribes by safeguarding collective Tribal identities, cultures, histories, knowledges, geographies, languages, and relationships from harm.
 - b. Confidentiality must be maintained at all times. Data actors must ensure they interact with Tribal in ways that prevent unauthorized access, disclosure, and misuse.
 - c. Address privacy and confidentiality with communities and individuals early on in the engagement process. This should be established to ensure transparency, accountability, and adherence to Tribal protocol.
 - d. Handling of Tribal data must be cautious with meaningful, informed, and dynamic consent.
 - e. Any breach of confidentiality or misuse of Tribal data must be reported promptly to the ADHS and Tribes affected.
4. **Cultural Capability and Learning:** ADHS Workforce Members, contractors, and other data actors are responsible for their own professional development and ongoing cultural learning, should demonstrate appropriate cultural competency, including self-awareness, understanding of Indigenous cultural property, laws, and protocols, and shall communicate respectfully and effectively.
 - a. ADHS Workforce Members, contractors, and other data actors shall be responsible for developing their cultural capabilities and providing an environment that supports the Tribes in meeting the standards expressed in this IDSov Policy, including:
 - b. Train ADHS Workforce Members, contractors, and other data actors on Indigenous data ethics and methods and ensure employees have the requisite skills to interact with Tribal data.

Challenges and Considerations

1. **Data Delegation of Authority:** Tribal employees who are initially granted access to data through a Data Sharing Agreement within a specific program, office, bureau or division, may change roles or transfer departments. This shift can create confusion regarding continued data access and may lead to unauthorized use of Indigenous data. Tribes may set up their own policy or process for external data requests or a Data Delegation Form can be

implemented to clearly outline who is authorized to access and manage specific datasets.

2. Informed Consent and Permission: Ensuring that all interactions with Tribal data are governed by clear and culturally appropriate consent mechanisms is foundational. However, challenges persist in applying and maintaining Free, Prior, and Informed Consent (FPIC) across diverse data contexts. This Policy affirms that ADHS Workforce Members, contractors, and other data actors will not interact with Tribal data without the express, documented consent of affected communities and individuals, in alignment with the principles of FPIC as recognized by UNDRIP. Documented consent can include written, verbal, and digital. Dynamic consent should be considered as a process to support ongoing relationships around consent, especially for human tissue biospecimens.

Authority:

1. A.R.S. § 41-2051, Governor's office on Tribal relations; director; responsibilities of state agencies; report.

Feedback

1. Staff may provide policy feedback by sending an email to: [ADHS Policy Feedback](#)

Figure 1. Tribal Data Governance Framework for ADHS

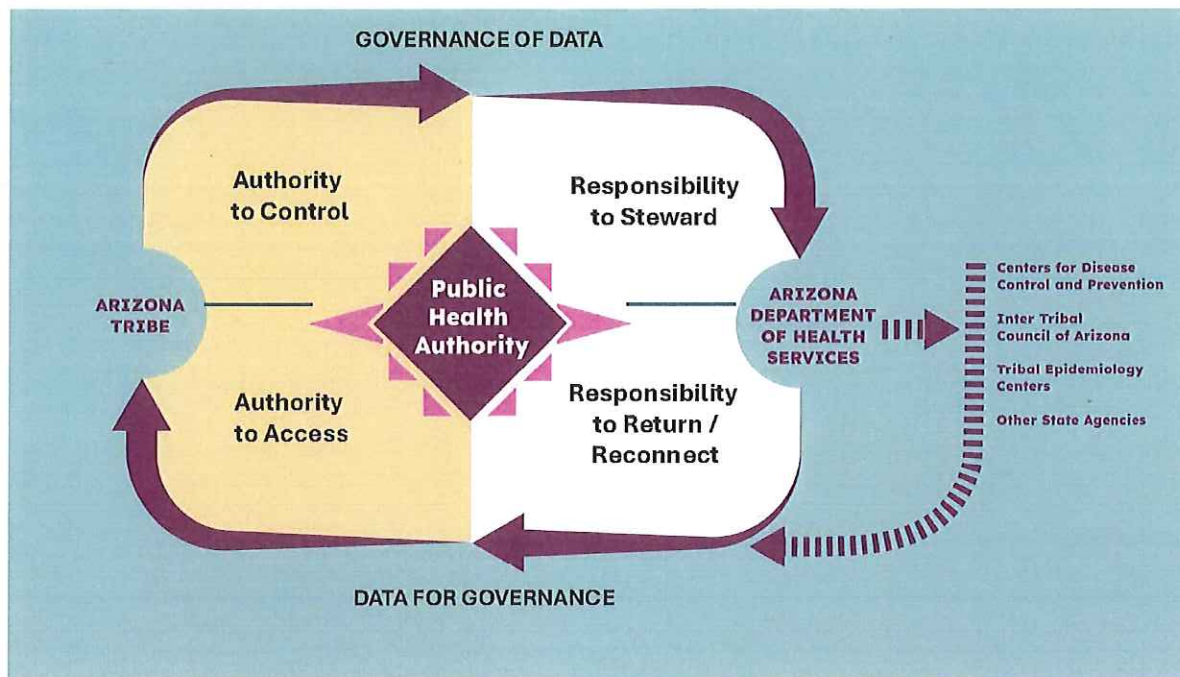


Figure 1 illustrates key principles of Indigenous Data Sovereignty by distinguishing between the governance of data and the use of data for governance. The top half of the model emphasizes the authority and control Indigenous Peoples retain over data collected about their communities, including the right to define data and determine how data is collected, accessed, and used. ADHS Workforce Members, contractors, and other data actors have a corresponding responsibility to steward all Indigenous data in ways that align with Tribal rights and requirements. The bottom half focuses on how data, once collected, is stewarded and used, raising critical questions about whether such stewardship and use supports Tribal self-determination or focuses primarily on the needs and priorities of ADHS Workforce Members, contractors, and other data actors. Data actors have a responsibility to ensure that ADHS data is accessible and protected in ways that preserve a meaningful connection to Tribes. The flow of data, represented by directional arrows, highlights the importance of tracking decision points to ensure data returns to communities in beneficial and equitable ways. The Tribal Data Governance Framework for ADHS provides a foundation for policies that respect Indigenous sovereignty, ensure ethical data practices, and support community capacity-building. This framework was developed by Tribal leaders and staff in the State of Arizona in collaboration with ADHS, the Native Nations Institute, and the Collaboratory for Indigenous Data Governance.

Glossary

1. **Biospecimen:** A sample of material, such as urine, blood, tissue, cells, DNA, RNA, or protein, from humans, animals, or plants. Biospecimens may be used for a laboratory test or stored in a biorepository to be used for research.¹
2. **Business Function, Activity, or Service:** Public health programs such as Arizona State public health laboratory services, disease control activities, preparedness activities, prevention activities, any other areas or programs interacting with Tribes.
3. **Data Actors:** A person, device, application, system, or organization that communicates, generates, uses, or stores information or data. The definition of data actor applies equally to public, private, governmental, administrative, commercial, and non-commercial actors.²
4. **Data Suppression:** Is the intentional omission or modification of data in reports to prevent the identification of individuals and protect their privacy, and ensures that protected health information is not disclosed in a manner that could comprise confidentiality.³
5. **Dynamic Consent:** An approach that allows for bi-directional engagement and communication between communities and/or participants and researchers. This method can provide a foundation for Indigenous Peoples' choices as collectives and allows them to change their decisions over time which further enhances transparency, communication, trust and accountability in research.⁴
6. **Indigenous Peoples' or Indigenous Data:** Refers to data, information, and knowledges recorded on any medium and in any format generated by Indigenous Peoples, as well as by governments, the private sector, and other institutions or individuals, on and about Indigenous Peoples, their governments, or their more-than-human relations. Indigenous Peoples' data is comprised of, but not limited to, information, specimens, and knowledges about more than humans with which they have relations; information about Indigenous individuals; and information and knowledges about Indigenous Peoples as collectives.²
7. **Indigenous Data Governance:** Refers to mechanisms through which Indigenous Data Sovereignty is upheld. It involves applying Indigenous Peoples' cultures, values, principles, and processes to the management and control of Indigenous data—both Indigenous governance of Indigenous data and non-Indigenous stewardship of Indigenous data.⁵
8. **Indigenous Data Sovereignty:** Refers to the rights of Indigenous Peoples to exercise self-determination and governance over Indigenous data.⁵

9. **Indigenous Health Data:** refers to the data, information, knowledges, and specimens about Indigenous Peoples' health and wellbeing.
10. **Indigenous Peoples:** In the United States refers to federal, state, and unrecognized Tribes, and peoples of Hawai'i, Guam, Puerto Rico, Northern Mariana Islands, American Samoa, and the US Virgin Islands in affirmation of their political rights and rights-based statuses.⁵
11. **Institute of Electrical and Electronic Engineers (IEEE) Recommended Practice for the Provenance of Indigenous People's Data:** Establishes a common set of parameters for the provenance of Indigenous People's data.²
12. **Public Health Authority:** Refers to an agency or authority of the United States, a state, a territory, a political subdivision of a state or territory, an Indian tribe, or a person acting under a grant of authority from or a contract with such an agency, that is responsible for public health matters as part of the agency or authority's legal mandate.⁶
13. **Tribal Consultation:** Two-way, government-to-government exchange of information and dialogue between official representatives of the State and Tribal Nations regarding state agency actions or policies before the state agency makes decisions on those actions or policies.⁷
14. **Tribal Data:** Refers to data, information, knowledges, and specimens recorded on any medium and in any format generated by the Tribe as well as by governments, private sector, and other institutions or individuals on and about the Tribe, their government, or more than human relations, and as further defined by the Tribe.
15. **Tribal Data Governance:** Operationalizes Tribal data sovereignty by incorporating a Tribe's specific values, culture, and governance mechanisms to manage and control that Tribe's data ecosystem. It determines how and when a Tribe's data can be appropriately gathered, analyzed, accessed, and used. Tribes can exercise data governance by implementing data principles, policies, procedures, and/or laws.¹
16. **Tribal Data Sovereignty:** Refers to the notion that in accordance with rights under Tribal sovereignty, Tribal self-determination, and the reserved rights doctrine, unless

expressly ceded through a valid agreement, Tribes inherently retain the authority to govern the ownership, collection, application, and control of their data.^{1 2}

17. **Tribal Individual:** People who relate to the Tribe as defined by the Tribe, possibly including enrolled citizens, descendants, self-identified individuals, and community members.
18. **Tribal Sovereignty:** The inherent authority to govern and to protect and enhance the health, safety, and welfare of Tribal communities and citizens.⁵
19. **Tribal Health Data:** Refers to health-related information specific to a Tribe, including clinical data, community data, and environmental data.
20. **Tribes/Tribal Nation:** Refers to federally and state recognized Tribes in the contiguous US and Alaska.
21. **Institute of Electrical and Electronic Engineers (IEEE) Recommended Practice for the Provenance of Indigenous People's Data:** Establishes a common set of parameters for the provenance of Indigenous Peoples' data.²

Endnotes

1. [National Institute of Health, National Cancer Institute](#)
2. See ["IEEE Recommended Practice for Provenance of Indigenous Peoples' Data," in IEEE Std 2890-2025 , vol., no., pp.1-25, 14 Nov. 2025, doi: 10.1109/IEEESTD.2025.11302960](#)
3. Arizona Department of Health Services. (2026). ADHS Minimum Suppression Policy. www.adhs.gov
4. [See Entwined processes: rescripting consent and strengthening governance in genomics research with indigenous communities. The Journal of Law, Medicine & Ethics.](#)
5. [See "Indigenous Data Governance Brief." United States Indigenous Data Sovereignty Network.](#)
6. U.S. Government (2024). Code of Federal Regulations (45 CFR § 164.501). eCFR (Electronic Code of Federal Regulations) website (eCFR.gov). Retrieved January 16, 2026, from eCFR (Electronic Code of Federal Regulations) website (eCFR.gov).
7. Presidential Memorandum for the Heads of Executive Departments and Agencies, [Uniform Standards for Tribal Consultation](#), Nov. 30, 2022, 87 Fed. Reg. 74479 (2022)

¹ This definition was created as part of a data initiative project in which Indigenous Data Alliance was contracted by the Chickasaw Nation Department of Health (CNDH) to advance Tribal data modernization and public health accreditation readiness within CNDH.

² See United States v. Winans, 198 U.S. 371, 381 (1905); Winters v. United States, 207 U.S. 564 (1908); Cohen's Handbook of Federal Indian Law n.2, § 2.02[2] (Nell Jessup Newton ed., 2012); Rebecca Tsosie, Tribal Data Governance and Informational Privacy: Constructing "Indigenous Data Sovereignty," 80 Mont. L. Rev. 229, 242-243 (2019).

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ITS120 - Data Governance Data Operations Policy

ITS117 - Data Governance Organization Policy

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3. Carroll, S. R., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., Lovett, R., Materechera, S., ... Hudson, M. (2020). "The CARE Principles for Indigenous Data Governance." *Data Science Journal*, 19(1), 43.
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6. National Congress of American Indians. (2020). Tribal Nations and the United States: An Introduction. Washington, D.C., February 2020.
7. Taitingfong, R., Martinez, A., Carroll, S. R., Hudson, M., Anderson, J. (2023). "Indigenous Metadata Bundle Communiqué." Collaboratory for Indigenous Data Governance, ENRICH: Equity for Indigenous Research and Innovation Coordinating Hub, and Tikanga in Technology. DOI: [10.6084/m9.figshare.24353743](https://doi.org/10.6084/m9.figshare.24353743)
8. Garrison, N. A., Carroll, S. R., & Hudson, M. (2020). Entwined processes: rescripting consent and strengthening governance in genomics research with indigenous communities. *The Journal of Law, Medicine & Ethics*, 48(1), 218-220.
9. Australian Institute of Aboriginal and Torres Strait Islander Studies. (2020). *AIATSIS code of ethics for Aboriginal and Torres Strait Islander research*.
<https://aiatsis.gov.au/sites/default/files/2020-10/aiatsis-code-ethics.pdf>



Standard Work: Indigenous Data Sovereignty Policy

Bookmarks: [Instructions](#) | [Process Flow Chart](#) | [FAQ](#) | Owner: Tribal Relations | Questions: Tribalrelations@azdhs.gov



PURPOSE: This standard work describes the internal process for adhering to the Indigenous Data Sovereignty (IDSov) Policy and upholding the rights of the Tribes in the State Arizona to govern the collection, use, storage, and sharing of their health data.



AUDIENCE: This Policy applies to all ADHS Workforce Members, contractors, and other data actors who work with data or repositories of data while executing business functions, activities, or services for or on behalf of ADHS or its customers.



DEFINITIONS: See Glossary.

Step-by-step instructions:

Guidance for Policy Adherence

Purpose: To ensure the practice of following and enforcing established policy within ADHS to ensure consistency, compliance, risk management, and operational efficiency.

Procedure: The ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist will work in collaboration with ADHS Staff for policy compliance.

1. **Education and Training:** Develop and deliver regular training sessions on the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), the FAIR and CARE Principles for Indigenous Data Governance, and cultural responsiveness.¹ These sessions shall emphasize how data policies must uphold Tribal sovereignty, cultural beliefs, traditional knowledge systems, and community priorities. The FAIR Principles ensure that data and resulting research are Findable, Accessible, Interoperable, and Reusable, while the CARE Principles ensure that data serves the Collective benefit, remains under the Authority to control by the Tribe, and is handled Responsibly and Ethically.²
2. **Regular Communication and Meetings with Tribes as Outlined in the Tribal Consultation Policy:** The ADHS will engage in regular consultation with Tribes on matters related to Indigenous Data Sovereignty issues that may impact Tribal communities. Communication may occur through formal Tribal Consultation, Leader-to-Leader Meetings, meetings conducted by the ADHS Tribal Liaison or at the request of a Tribe for formal or informal meetings. These meetings provide opportunities to review data governance issues, share updates, and address concerns.

3. **Annual Review of this Policy by Tribes and ADHS:** ADHS shall review this Policy at least every 3 years with Tribes at a Tribal Consultation. A 45-day open comment period will be provided if any text changes are recommended.
4. **Implementation and Oversight:** The ADHS, through the Tribal Liaison and Tribal Health Epidemiologist, shall provide assistance in the implementation and oversight of this Policy, data request and data sharing agreements; provide annual reporting through the Governor's Annual Report, create and work with advisory groups if needed.
5. **Enforcement and Accountability:** If there is a suspected or actual violation of this Policy, the concerned employees or their manager must promptly contact the Enterprise Data Manager Office and the Review Committee for Indigenous Data Sovereignty. These entities will assess the nature of the concern and determine next steps using techniques outlined in this Policy. Resolution efforts may include education, facilitated dialogue, policy clarification, and other culturally informed compliance techniques. If an issue cannot be resolved through internal processes, it may be escalated in accordance with ADHS policies and procedures. Staff, contractors, and other data actors should be aware that Tribes retain sovereign authority and must pursue legal or formal action independently, particularly in cases involving misuse of Tribal data. In addition, the ADHS is subject to Arizona's data breach notification law (A.R.S. § 18-552), which outlines requirements for responding to breaches involving unencrypted personal information.

Recommendations for Consideration:

1. **Accessible Language:** All descriptions of datasets and data policies must be accessible and written in jargon-free language.
2. **Enhance Tribal Legal Expertise:** Support the development of legal and policy expertise within Tribal communities through capacity and capability-building programs, agreements, and access to Indigenous Data Sovereignty resources.

Process Flow Chart

Establishing a Data Sharing Agreement with Tribal Nation in Arizona

Purpose: To outline the process for initiating, reviewing, and executing Data Sharing Agreement between the Arizona Department of Health Services and a Tribal Nation(s).

Procedure:

1. Request for DSA Template
 - a. The Tribal Nation's health department or designated health office submits a request for a Data Sharing Agreement template.
2. Template Distribution

- a. The ADHS Tribal Liaison or ADHS Tribal Health Epidemiologist provides the Tribe with a word document version of the Tribal Data Sharing Agreement template.
 - b. The document outlines the type(s) of data to be shared by ADHS.
3. Internal Review and Feedback
 - a. Upon receipt of the completed template or comments from the Tribe, the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist reviews the document in coordination with the internal ADHS Tribal Data Sharing Workgroup.
4. Meeting for Review and Feedback
 - a. A meeting is scheduled with the Tribe to review outstanding questions and obtain feedback on the revised DSA.
5. Submission for Procurement
 - a. Once the DSA has been updated and agreed upon, the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist submits the finalized agreement through the Procurement Request System.
6. Contract Execution
 - a. The ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist coordinates with the assigned Procurement Office to execute the DSA with the Tribal Nation.
7. Notification and Next Steps
 - a. After execution of the DSA, the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist sends an email notification to the Tribe confirming completion.
 - b. The notification includes information about upcoming introductory emails and meeting coordination with relevant ADHS data owners for each requested dataset. The assigned ADHS Procurement Office works collaboratively with ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist.

Establishing a Data Sharing Agreement with Inter Tribal Council of Arizona, Tribal Epidemiology Center, Urban Indian Organization, Indian Health Service, Tribally Operated 638 Health Care Facilities, or other organizations

Purpose: To outline the process for initiating, reviewing, and executing a Data Sharing Agreement (DSA) between the Arizona Department of Health Services (ADHS) and organizations such as the Inter Tribal Council of Arizona (ITCA), Tribal Epidemiology Centers (TEC), Urban Indian Organizations (UIOs), or Indian Health Service (IHS).

Procedure:

1. Tribal Approval Letter Requirement
 - a. The requesting organization must obtain and submit an official approval letter from the designated Tribal Nation(s).
 - b. The approved letter/Tribal resolution must include a clear description of the data requested and confirmation that the Tribe supports the request.
2. Drafting the Memorandum of Understanding (MOU)
 - a. Upon receipt of the approval letter, the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist prepares a draft MOU outlining:

- i. The type of data requested,
 - ii. The requesting organization's role,
 - iii. Purpose and use of the data.
3. Internal Review and Feedback
 - a. Upon receipt of the completed template or comments from the Tribe, the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist reviews the document in coordination with the internal Tribal Data Sharing Workgroup.
4. Meeting for Review and Feedback
 - a. A meeting is scheduled with the Tribe to review outstanding questions and obtain feedback on the revised DSA.
5. Submission for Procurement
 - a. Once the DSA has been updated and agreed upon, the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist submits the finalized agreement through the ADHS Procurement Request System.
6. Contract Execution
 - a. The ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist coordinates with the assigned ADHS Procurement Office to execute the DSA with the Tribal Nation.
7. Notification and Next Steps
 - a. After execution of the DSA, the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist sends an email notification to the Tribe confirming completion.
 - b. The notification includes information about upcoming introductory emails and meeting coordination with relevant ADHS data owners for each requested dataset. The assigned ADHS Procurement Office works collaboratively with ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist.

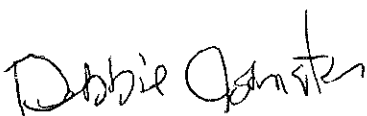
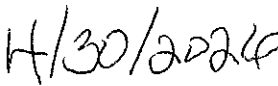
Routing Tribal Data Requests

Purpose: To outline the process for reviewing, routing, and fulfilling the different types of Tribal data requests.

Procedure: ADHS categorized Tribal data requests into three different types of requests. These are submitted through the [ADHS Data Request Submission Form](#) and involve thorough review and approval by the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist, as well as collaboration with the Tribal Nations.

1. Requests from a Tribal Nation for their own data.
 - a. When ADHS receives a data request from a Tribal Nation for their own data, the request is routed simultaneously to the appropriate program and to the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist. The ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist confirms the request directly with the Tribal Nation, while the program begins preparing to fulfill the request. This parallel process helps ensure timely completion of the request. However, the program will not share any data until the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist communicates approval from the Tribal Nation.
2. Requests for Tribal data that do not come from the Tribal Nations (i.e. ITCA, TECs, Counties, Institutions).

- a. When ADHS receives a request for Tribal data that does not originate from the Tribal Nation, it is simultaneously routed to the appropriate program and to the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist. The program is included to ensure awareness of the pending request; however, the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist works closely with the Tribal Nation to obtain and relay express permission to share any data. Programs are asked not to release any data until the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist communicates approval from the Tribal Nation.
3. Requests for Tribal data from the Media or the Public.
 - a. Tribal data requests from members of the media or the public are initially routed to Administrative Counsel and Rules (ACR). ACR then collaborates with the ADHS Tribal Liaison and/or ADHS Tribal Health Epidemiologist to determine the most appropriate way to handle each request.

	
Debbie Johnston Director, Arizona Department of Health Services	Date