

Tribal Data Sovereignty: A Summary of Structures, Systems, Principles, Laws, and Related Resources – A Global Perspective.

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Abstract

- This systematic review explores Tribal data sovereignty, focusing on the structures, systems, principles, laws, and related resources globally.
- Working with a medical librarian (Olson), search phrases were developed to ensure comprehensive and relevant results from existing literature through 2024.
- Databases such as PubMed, CINAHL, LISTA, SocINDEX, and Academic Search Complete were selected based on their subject coverage and accessibility through the authors' institutional library.
- The findings from this review will serve as a valuable resource for Tribal rightsholders, non-Tribal rightsholders, and policymakers, providing insights to inform ongoing Tribal data sovereignty efforts.

Background

- This project examines available scholarship and identifies key concepts, frameworks, and mechanisms that have been developed and are central to the creation of partnerships between Tribal and state public health professionals.
- Public health professionals, both on and off Tribal lands, need data to inform decision making for health and education, funding, and resource allocation. Effective collection and use of data that includes best practices for data stewardship and protection, recognizing the embedded biases of frameworks and theory, while finding mechanisms to enable public health actions and policy making in real time.
- Data sovereignty is related not just to the ownership of datasets, but also rights related to control over data collection, use, and dissemination, including arrangements for sharing and protection of information. This sovereignty is an inherent right of Tribal nations and is based in both self-governance principles and treaty rights.
- It is critical to recognize that identification of variables, what may be considered data, and the interpretation of meaning are all grounded in the worldview of the person asking the question, and "science" is neither unbiased nor objective for this reason.
- There are best practices that can be employed to support interoperability and data sharing while preserving the sovereignty of Tribal groups and ensuring ethical management of data.

Methods

- Identify the Research Question:** The review aimed to explore studies related to Indigenous data sovereignty.
- Define the Inclusion and Exclusion Criteria:** Articles were included if they discussed Indigenous data sovereignty.
- Search for Studies:** Search phrases were developed to ensure maximum relevant results from existing literature through 2024. Databases including PubMed, CINAHL, LISTA, SocINDEX, and Academic Search Complete were selected based on their subject coverage and accessibility via the authors' institutional library on February 22nd, 2025. **Search phrases included**
- Selection Criteria:** Eligible articles were selected based on the defined inclusion and exclusion criteria including "academic journals only" criteria.
- Extract Data:** Key data will be extracted from each study, focusing on relevant findings related to Indigenous data sovereignty.
- Assess Quality:** Each study was evaluated for quality based on predefined criteria.
- Synthesize and Present Results:** The results will be synthesized and presented, highlighting key trends and findings related to Indigenous data sovereignty.

Results

- Results are ongoing:** We expect to synthesize relevant studies to support the development of a global framework for Tribal data sovereignty.
- Resource Development:** The findings from this review will serve as a valuable resource for Tribal rightsholders, non-Tribal rightsholders, and policymakers, providing insights to inform ongoing Tribal data sovereignty efforts.

(indigenous OR DE "Indigenous peoples" OR aborigin* OR maori OR "torres strait islander*" OR "first nation*" OR "metis" OR "alaskan native*" OR "alaska native*" OR "american indian*" OR "inuit*" OR sami OR). Select Studies:

Discussion

- Indigenous Data Sovereignty emphasizes the right of Indigenous communities to control and govern their data, ensuring it aligns with their laws and cultural values.
- Data should be governed by the laws of the Indigenous community from which it originates, ensuring communities control their own data and to prevent exploitation.

Discussion (cont.)

- Building trust between researchers and Indigenous communities fosters ethical, respectful relationships and ensures data is shared and used responsibly.
- Protecting Indigenous data is essential to prevent misuse, ensuring data is used ethically and remains within the control of the Indigenous community.
- Ensuring accurate and reliable data collection helps maintain respect for Indigenous knowledge and integrates it into decision-making processes that benefit the Indigenous community.
- Developing Indigenous-led data infrastructure enables self-determination in managing and analyzing data, with ownership belonging to Indigenous communities to protect their information.

Conclusions

- This review highlights the growing global efforts to strengthen Indigenous data sovereignty through robust governance structures, legal protections, and collaborative data-sharing initiatives.
- While progress has been made, challenges remain in ensuring consistent implementation and support across regions.
- Continued development of resources and partnerships will be crucial for empowering Indigenous communities to manage and protect their data effectively, ultimately contributing to more equitable and culturally respectful research outcomes.

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Figure 1. Search Results

