# CARE Data Primer for Ethical Data Stewardship

Medical Institutional Repositories in Libraries

November 2023

# DCN's Data Primer Collection

**DATA CURATION NETWORK**

Ethical. Reusable. Better.

- Collection of introductory peer-reviewed digital resources to support recommended and ethical practices in data curation

- Available as Open Educational Resources (OERs), CC-BY 4.0 License

- Data curator, librarian, archivist audience

- Adoptable and adaptable for instruction

- Result of a DCN Workshop at the University of Minnesota in October 2022

# Methodology

- Sought input from experts in Indigenous data

- Literature search to familiarize and find contacts

  - Native Nations Institute

  - Native Health Database

- Partnered with Network of the National Library of Medicine, Region 3 to provide funding

# Grounding: Tribal Sovereignty

## Tribal Sovereignty

- Right and authority to self- government & self- determination

- Internationally recognized

- Often legally protected

## Data Sovereignty

- Includes data from, about, or involving Indigenous Peoples or their interests

- Often described as Indigenous Data

## Data Governance

- Indigenous Peoples enact Data Sovereignty in different ways

- Control over the collection, use, access, and stewardship of Indigenous Data

# CARE Principles



Be **FAIR** Findable · Accessible · Interoperable · Reusable and **CARE** Collective Benefit · Authority to Control · Responsibility · Ethics

# Pre-Curation

Check the essentials *before* curating.



- Documented contact with Tribal official?

- Clear, explicit permissions for research?

- Are there agreements or obligations that require moderating access to data?

- Acknowledgements, or licensing details that should be included in the metadata?

# Acknowledgement Example

"The Grand Portage Band of Lake Superior Chippewa (GPBLSC) is a sovereign indigenous nation that owns the data shared here. Those data are protected under the principles of data sovereignty and are shared under a data sharing and ownership agreement with the University of Minnesota for analysis and publication of scientific products."

Example https://hdl.handle.net/11299/225296

# CURATE(D)

- **Check the files!**

- **Understand the Data**

- **Request missing information or changes**

- **Augment the metadata**

- **Transform files for reuse**

# CURATE(D), continued

**Evaluate for CARE**

- Harmful language or stereotypes
- Indigenous Peoples portrayed at a deficit
- Consent Process
- Acknowledgments
- Use limitations

*Is this repository the most appropriate home for this data?*

# Supplemental Resources

SAR Guidelines for Collaboration - A collaboration between Native and non-Native museum professionals, cultural leaders. and artists intended to support the understanding, stewardship and care of collections;

Collaboratory for Indigenous Data Governance - List of 32 Indigenous ethics documents developed by Indigenous Nations, communities, and working groups from around the world, used to guide analyses of federal research and Tribal engagement standards;

Global Indigenous Data Alliance (GIDA) - An international network dedicated to advancing Indigenous data sovereignty and governance, assert Indigenous peoples' rights and interests in data, advocate for data for the self-determined wellbeing of Indigenous Peoples, and reinforce the rights to engage in decision-making in accordance with Indigenous values and collective interests;

Native Health Database - The Native Health Database contains bibliographic information and abstracts of health-related articles, reports, surveys, and other resource documents pertaining to the health and health care of American Indians, Alaska Natives, and Canadian First Nations.

Native BioData Consortium - a flagship 501c3 nonprofit research institute initiated and guided by Indigenous scientists and Tribal members. The organization is designed to ensure research and learning on genetics and health benefit all Indigenous Peoples.BioData samples are stored on sovereign native lands of the Cheyenne River Sioux Tribe.

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Data Curation Network
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# CARE Data Principles Primer



**DATA CURATION NETWORK**

## CARE Data Principles, Indigenous data, Data related to Indigenous Peoples and Interest

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