Indigenous Data Sovereignty

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Table of Contents

- Terminology of Indigenous and the distinctions-based approach

- Indigenous self-determination and self-governance

- Constitutional commitments

- What is data sovereignty?

- Foundation of Indigenous data sovereignty

- What is Indigenous data sovereignty?

- Why is data sovereignty important?

- How do we implement this in research?

- Frameworks in Canada that Respect Data Sovereignty in Research

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Indigenous & the Distinctions-Based Approach

- Indigenous is defined as: First Nations, Inuit and Métis Peoples in Canada.

- The Distinctions-based approach was co-developed and implemented by the Government of Canada to recognize and address the reality that First Nations, Inuit and the Métis Nations as the Indigenous Peoples of Canada, consist of distinct, rights-bearing communities with their own histories, including with the Crown.

- A distinctions-based approach ensures that the unique rights, interests and circumstances of First Nations, Inuit and Métis are acknowledged, affirmed and implemented.

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Indigenous Self-Determination & Self-Governance

- Pre-contact Indigenous peoples practiced self-governance that encompassed economic, social and geographic complexities that were culturally appropriate to each community they served.

- Treaties, trade and alliances were foundational for early partnerships between colonial governments with Indigenous nations.

- Over many centuries, these relationships have eroded by racist laws, policies and decisions, such as the 1876 Indian Act, which continues to determine how most First Nations in Canada are governed to this day.

- Self-determination is a means of actualizing reconciliation by putting self-governance back in the hands of the nations and communities they serve.

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Constitutional Commitments

- There are principles recognized by the Government of Canada that speak to the constitutional relationship the Crown has with Indigenous Peoples, the GoC states on their website that:

"This relationship, including existing Aboriginal treaty rights, is recognized and affirmed in section 35 of the Constitution Act, 1982. Section 35 contains a full box of rights, and holds the promise that Indigenous nations will become partners in Confederation on the basis of a fair and just reconciliation between Indigenous peoples and the Crown."

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What is Data Sovereignty?

- In the National Library of Medicine this is defined as:

"Data sovereignty refers to a group or individual's right to control and maintain their own data, which includes the collection, storage, and interpretation of data. Indigenous data sovereignty refers to the ability for Indigenous peoples to control their data and includes autonomy regarding a variety of data types such as oral traditionals, DNA/genomics, community health data, etc. Within the context of transnational indigenous sovereignty and self-determination movements, indigenous data sovereignty can be a powerful tool for those whom the data represents, which claims the rights of Indigenous peoples to use and interpret the data in a way that is accurate and appropriate given their circumstances, customs, and communal way of life."

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Foundation of Indigenous Data Sovereignty

- The foundations for Indigenous data sovereignty rest on Indigenous Peoples' inherent rights to autonomous governance.

- The development and implementation of the United Nations Declaration of Human Rights of Indigenous Peoples (UNDRIP) as mentioned on the website as

"establishing a universal framework of minimum standards for the survival, dignity and well-being of the Indigenous Peoples of the world and it elaborates on existing human rights standards and fundamental freedoms as they apply to the specific situation of Indigenous Peoples."

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What is Indigenous Data Sovereignty?

"Indigenous Data Sovereignty is the ability for Indigenous peoples, communities and Nations to participate, steward and control data that is created with or about themselves. The term sovereignty refers to the fact that Indigenous Nations are sovereign in their governance and that extends to their data and Knowledges as well. It recognizes that Indigenous people are the ultimate authority in their data and Knowledges and aims to redefine Indigenous peoples' relationship to research from being participants or subjects to being meaningful partners and co-researchers"

University of Toronto - Research Guides of Indigenous Studies

Additional resources can be found at Health Data Research Network Canada.

Why is data sovereignty important?

- Indigenous peoples have a history of being "researched to death", and the ethics of doing so have not always been beneficial

- Research has been a colonizing and extractive force upon Indigenous peoples

- Recognizing Indigenous Data Sovereignty places the ownership of Indigenous knowledge and data back in the hands of Indigenous people.

- When thinking of using an Indigenous data sovereignty framework, it is important to utilize a distinction-based approach that is appropriate for you and your research partners

- Good research with Indigenous peoples is aware of the diversity of Indigenous nations, their divergent histories, and lived realities

- (Video)

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How do we implement this in research?

- *Community Research Agreements:* Establish how Indigenous research partners and rightsholders are informed, consulted, involved, and collaborate in the research process from the establishment of research questions through to knowledge mobilization/translation, dissemination of research findings into publications, policies, and interventions.

- *Data Sharing/Stewardship Agreements:* Ensure that Indigenous research partners retain sovereignty over research processes, data analysis, and knowledge mobilization.

- *Ethical Relational Training:* Indigenous Research Level of Engagement Tool, Building Research Relationships with Indigenous Communities and etc.

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Frameworks in Canada that Respect Data Sovereignty in Research

- The tri-agency guides say that projects are required to recognize Indigenous self-determination and self-governance including Indigenous data following the First Nations Principles of OCAP®[1] (Ownership, Control, Access and Possession), the CARE Principles for Indigenous Data Governance, and/or FAIR Principles.

- Additional ones: MDS, ITK NISR (Inuit Tapiriit Kanatami, National Inuit Strategy on Research), Mi'kmaw Ethics Watch, OCAS (Ownership, Control, Access and Stewardship).

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Frameworks in Canada - OCAP®

- Establishes how First Nations data and information will be collected, protected, used, or shared.

- The *de facto* standard for conducting research with First Nations.

- Training in OCAP® is delivered through the First Nations Information Governance Centre and starts at $500 with a variety of discounts offered

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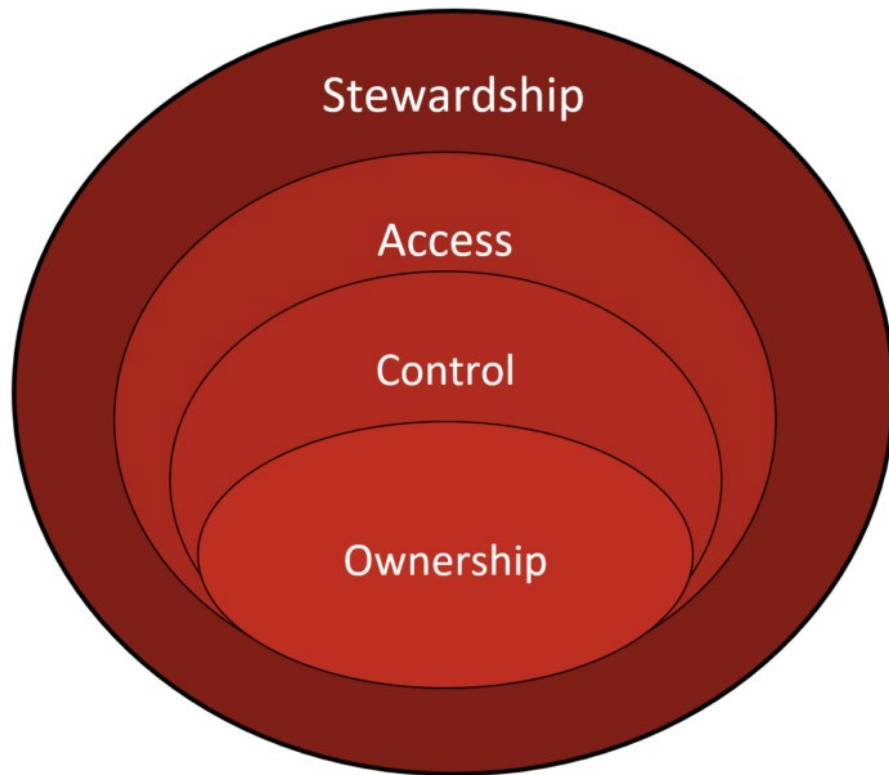
Frameworks in Canada - OCAP®

- **Ownership:** The relationship of a First Nations community to its cultural knowledge/data/information. A First Nations community or group owns information collectively in the same way that an individual owns their personal information.

- **Control:** First Nations people, their communities and representative bodies must control how information about them is collected, used and disclosed.

- **Access:** First Nations must have access to information and data about themselves and their communities, regardless of where it is held. They also have the right to make decisions about who can access their collective information.

- **Possession:** First Nation possession puts data within First Nation jurisdiction and therefore, within First Nation control. Possession is the mechanism to assert and protect ownership and control.

Frameworks in Canada - NAHO

- The National Aboriginal Health Organization (NAHO) identifies six principles of ethical Métis research:

1. Reciprocal Relationships

2. "Respect for"

3. Safe and Inclusive Environments

4. Recognize Diversity

5. "Research Should"

6. Métis Context

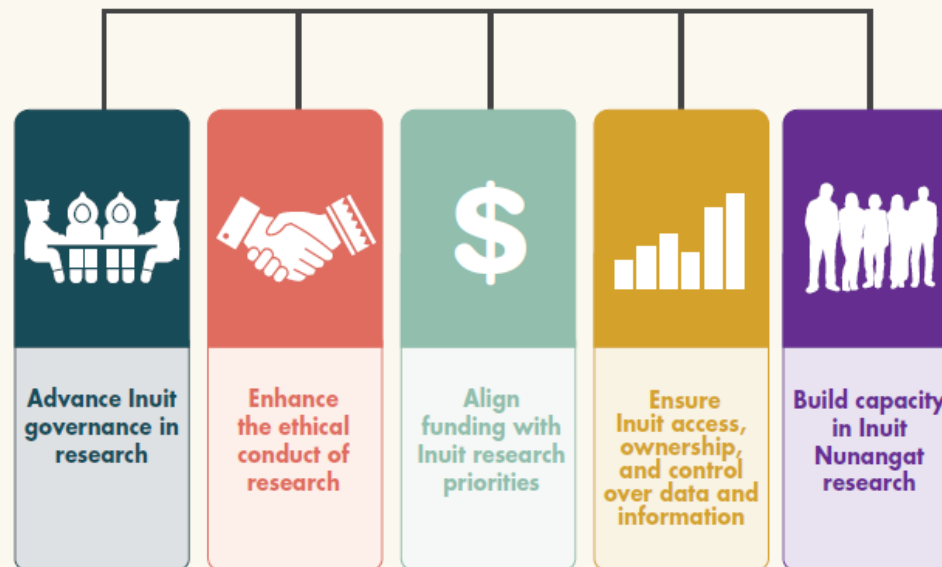**FIRST NATIONS UNIVERSITY OF CANADA**

Métis Data Stewardship - OCAS

- The Manitoba Métis Federation promotes using "OCAS" when working with Métis data

- Métis OCAS and the First Nations OCAP® are similar, but the "S" in OCAS stands for "stewardship" where the "P" in OCAP® stands for "possession."

- **Ownership**

- **Control**

- **Access**

- **Stewardship**

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Frameworks in Canada – Inuit Tapiriit Kanatami National Inuit Strategy on Research

- The Inuit Tapariit Kanatami (ITK) serves as a national voice protecting and advancing the rights and interests of Inuit in Canada

- The National Inuit Strategy on Research (NISR) identifies five priority areas in which coordinated action is necessary to facilitate Inuit Nunangat research that is efficacious, impactful and meaningful to Inuit.

RESPECTFUL AND BENEFICIAL RESEARCH FOR ALL INUIT

5 Priority Areas of National Inuit Strategy on Research

Advance Inuit governance in research

Enhance the ethical conduct of research

Align funding with Inuit research priorities

Ensure Inuit access, ownership, and control over data and information

Build capacity in Inuit Nunangat research

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Frameworks in Canada – Mi'kmaw Ethics Watch

- Mi'kmaw Ethics Watch is a set of standards and processes to ensure Mi'kmaw people are informed of research –were treated fairly and ethically in their participation in any research, understood the research benefits and costs, and were informed of how they or the nation and people would benefit and gain from any research conducted about or among them.

- Mi'kmaw people are the guardians and interpreters of their culture and knowledge system past, present, and future.

- The right and obligation to exercise control to protect their cultural and intellectual properties and knowledge.

- All research, study, or inquiry into Mi'kmaw knowledge, culture, and traditions involving any research partners belongs to the community and must be returned to that community.

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Frameworks in Canada – FAIR Principles

- While the FAIR Principles are not necessarily Indigenous-specific, the intent is that these may act as a guideline for those wishing to enhance the reusability of their data holdings. Distinct from peer initiatives that focus on the human scholar, the FAIR Principles put specific emphasis on enhancing the ability of machines to automatically find and use the data, in addition to supporting its reuse by individuals.

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Frameworks in Canada – FAIR Principles

- **F**indable
  The first step in (re)using data is to find them. Metadata and data should be easy to find for both humans and computers.

- **A**ccessible
  Once the user finds the required data, she/he/they need to know how they can be accessed, possibly including authentication and authorisation.

- **I**nteroperable
  The data usually need to be integrated with other data. In addition, the data need to interoperate with applications or workflows for analysis, storage, and processing.

- **R**eusable
  The ultimate goal of FAIR is to optimise the reuse of data. To achieve this, metadata and data should be well-described so that they can be replicated and/or combined in different settings.

Frameworks in Canada – CARE Principles

- The CARE Principles for Indigenous Data Governance are people and purpose-oriented, reflecting the crucial role of data in advancing Indigenous innovation and self-determination. These principles complement the existing FAIR principles encouraging open and other data movements to consider both people and purpose in their advocacy and pursuits.

Frameworks in Canada – CARE Principles

- **Collective Benefit**
  - For inclusive development and innovation
  - For improved governance and citizen engagement
  - For equitable outcomes

- **Authority to Control**
  - Recognizing rights and interests
  - Data for governance
  - Governance of data

- **Responsibility**
  - For positive relationships
  - For expanding capability and capacity
  - For Indigenous languges and worldviews

- **Ethics**
  - For minimizing harm and maximizing benefit
  - For justice
  - For future use

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Questions?

Additional Resources

- [Learning Module: Indigenous Data Sovereignty](#) (video)

- [Why Indigenous people are fighting for data sovereignty](#) (podcast)

- [Indigenous Peoples Breathing Data Back | Stephanie Russo Carroll | TEDxUArizona](#) (video)

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