

# Reflections on Indigenous Data Sovereignty, the Global Indigenous Data Alliance, and the CARE Principles for Indigenous Data Governance

April 23<sup>rd</sup>, 2021

Robyn Rowe, Ph.D. Candidate



Photograph taken by Spencer Corbiere  
Teme Augama Anishnabai  
Temagami Lake 2020

*Rethinking the Responsibilities of the Social Sciences Researcher in Supporting the Advancement of Indigenous Data Sovereignty*

# Situating Myself



# Introduction

- Data has the ability to **impact decision-making, influence health policy, leverage funding, and improve health outcomes.**
- Data expansions within the age of digitization are happening quicker than we can keep up.
- In turn, Indigenous data are being added to and Indigenous knowledge(s) are being (re)produced, renewed, and revitalized.
- Indigenous Peoples' interests, values, and priorities are essential to **all** processes involving information and knowledges (aka DATA) about Indigenous lives.
- Historically, Indigenous Peoples and priorities were excluded from the decision-making processes- as Indigenous groups around the world take back their autonomy, there is a global shift in the ways in which Indigenous data are managed, owned, shared, stored, and controlled.

# Indigenous Data

**INDIGENOUS DATA** include any information in any format that affects Indigenous lives at the individual or collective levels (Information on land, resources, people, and nations).

# Sovereignty

**INDIGENOUS DATA SOVEREIGNTY (ID-SOV)** is the right of Indigenous Peoples to govern the collection, application, and ownership of Indigenous data and information.

# Governance

**INDIGENOUS DATA GOVERNANCE (ID-GOV)** is the mechanisms by which ID-SOV is activated

# Advancing ID-SOV on Globally

Indigenous Peoples all around the world have inherent, collective rights. In order to provide research outcomes that are relevant to Indigenous populations, there is an important role for mainstream and settler organizations within this space. It is important to recognize that Indigenous Peoples have inherent rights to self-determination, sovereignty, and self-governance that are not earned or granted; they simply exist.

As Indigenous Peoples continue to assert our inherent rights, the primary goals are nation rebuilding through self-determination and self-government.

Non-Indigenous organizations can contribute by working *with* Indigenous nations towards accomplishing those goals. By helping to eliminate obstacles/barriers and advocating for changes to oppressive systemic policies and practices.

Globally, initiatives are advancing their collective rights by instilling Indigenous-based protocols for how Indigenous data are defined, owned, access, and controlled.



# The UN Declaration on the Rights of Indigenous Peoples

- Article 3 – right to **self determination**
- Article 4 – right to **autonomy and self-government**
- Article 5 – right to maintain and strengthen **distinct** political, legal, economic, social and cultural institutions
- Article 15 (i) – right to **dignity** and **diversity** of cultures traditions, histories and aspirations which shall be appropriately reflected in education and public information
- Article 18 – right to **participate in decision-making** in matters that would affect rights...and to develop indigenous decision-making institutions
- Article 19 – States shall... obtain free, prior and informed **consent** before adopting and implementing legislative or administrative measures that may affect them
- Article 23 – right to **determine** and **develop** priorities and strategies...and to administer programs through their own institutions if possible
- Article 31 – right to **maintain, control, protect** and **develop** intellectual property
- Article 33 – right to **determine** their own identity or membership. Right to determine structures and select membership of their institutions

# GIDA

## Global Indigenous Data Alliance

*Promoting Indigenous Control of Indigenous Data*



## WHAT DOES THIS MEAN IN CANADA?

- Over 30 years of work has been done that have laid not only the foundation but provided a structure for successful nation-to-nation rebuilding for Indigenous Peoples across the country.
  - The Report of the Royal Commission on Aboriginal Peoples (RCAP formed in 1991 and report released in 1996)
  - The Truth and Reconciliation Commission of Canada (Calls for Action in the TRC, 2015)
  - The Final Report from the National Inquiry into Missing and Murdered Indigenous Women and Girls (Calls for Justice for MMIWG, 2019).





# Truth and Reconciliation Commission (TRC)

## **TRC CALL TO ACTION #18**

“acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools”

## **TRC CALL TO ACTION # 19**

“establish measurable goals to identify and close the gaps in health outcomes”

## **TRC CALL TO ACTION #20**

“recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples”

## **TRC CALL TO ACTION #43**

“to fully adopt and implement the *United Nations Declaration on the Rights of Indigenous Peoples* as the framework for for reconciliation”

# In Canada: Advancing Indigenous Data Governance

- Must be reflective of the interests of the three distinct Indigenous groups in Canada: First Nations, Inuit, and Métis
- Within those three groups, must also recognize the diversity in languages, cultures, traditions, and nations.
- Means honouring traditional relationships and treaties.



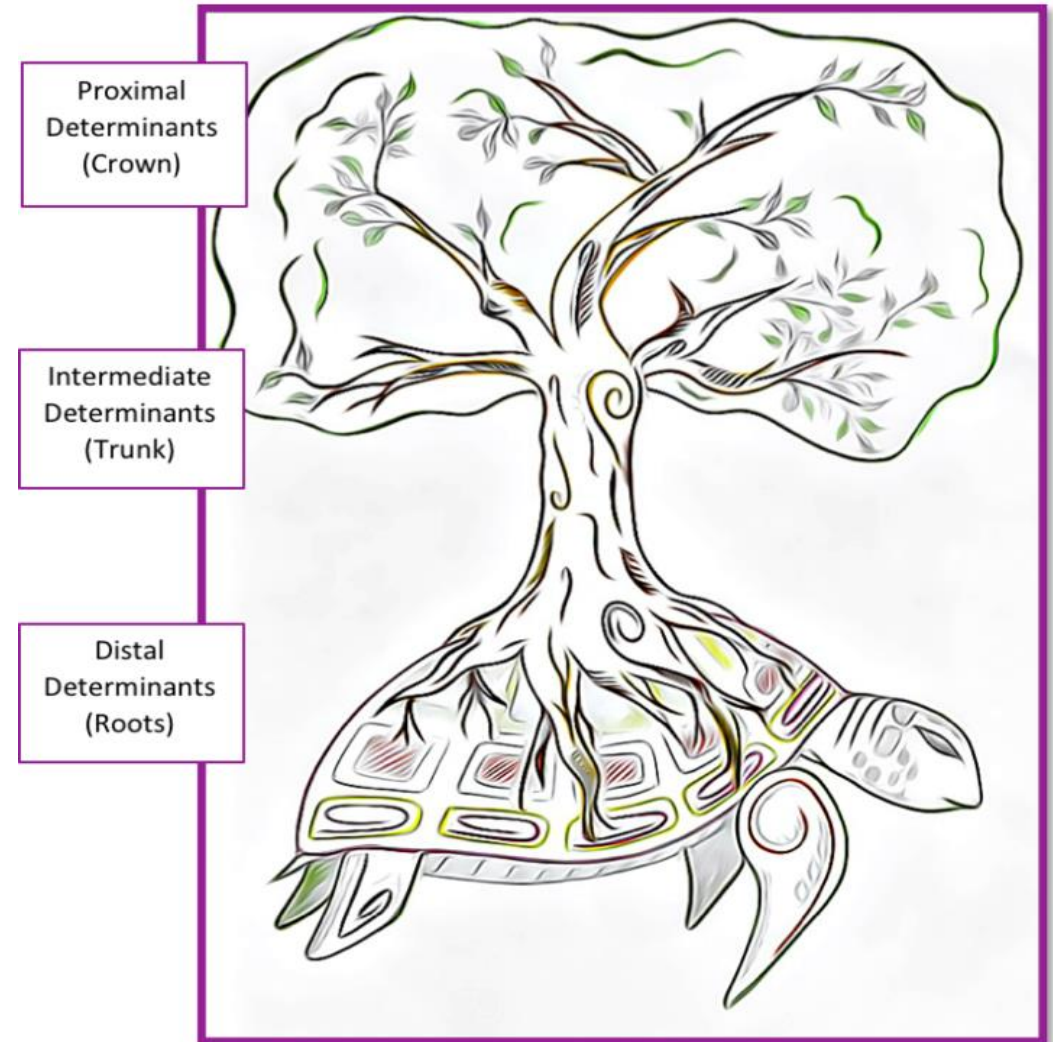
Kayaking with my sister  
on Lake Temagami,  
Summer 2020

# Advancing Indigenous Data Governance

**Proximal Determinants:** early child development, income, social status, education, employment, and food security

**Intermediate determinates:** health care systems, education systems, community infrastructure, governments, and social supports

**DISTAL:** Deeply Rooted Factors such as historical, political, economic, and social factors that can impact the mental, emotional, spiritual, and physical of individuals and community wellness



Wholistic [whole health] Framework Tree Adaptation by  
Robyn Rowe (with permission) ©

## The Role of non-Indigenous allies

- The **foundations** of ID-SOV and ID-Gov are Indigenous leadership and Indigenous decision making
- The primary role of Non-Indigenous Allies in ID-Sov and ID-Gov is to support Indigenous leadership/decision making.

- 1. Step back – Let us Lead**
- 2. Use your privilege to advocate for ID-Sov and ID-Gov**
- 3. Openly adopt ID-Sov and ID-Gov Principles**
- 4. Enable Indigenous Data Leadership/ Decision Making**

# Open-Access Data Learning

## Links:

- [Indigenous Data Sovereignty](#), 2016
- [The State of Open Data](#), 2019
- [Good Data](#), 2019
- [Indigenous Data Sovereignty and Policy](#), 2020



# REFERENCES

- Carroll, S.R., Rodriguez-Lonebear, D., & Martinez, A. (2019). Indigenous Data Governance: Strategies from United States Native Nations. *Data Science Journal*, 18(1).
- First Nations Information Governance Centre. (2019). The First Nations principles of OCAP®. Retrieved on December 2, 2019 from <https://fnigc.ca/ocap>
- Lovett, R., Vanessa L., Kukutai, T., Rainie, S.R., & Walker, J. (2019). Good data practices for Indigenous data sovereignty. In A. Daly, K. Devitt, & M. Mann (Eds.), *Good Data*. Amsterdam: Institute of Network Cultures Inc. ISBN 978-94-92302-27-4.
- Rainie, S.C, Rodriguez-Lonebear, D., & Martinez, A. (2017) Policy Brief (Version 2): Data Governance for Native Nation Rebuilding. [http://usindigenousdata.arizona.edu/sites/usindigenousdata/files/spotlight/files/policy\\_brief\\_data\\_governance\\_for\\_native\\_nation\\_rebuilding\\_v0.5\\_1.pdf](http://usindigenousdata.arizona.edu/sites/usindigenousdata/files/spotlight/files/policy_brief_data_governance_for_native_nation_rebuilding_v0.5_1.pdf).
- Rainie, S.C., Schultz, J.L., Briggs, E., Riggs, P., & Palmanteer-Holder, N.L. (2017). Data as a strategic resource: Self-determination, Governance, and the data challenge for Indigenous nations in the United States. *The International Indigenous Policy Journal* 8 (2). doi: 10.18584/iipj.2017.8.2.1.
- Rainie, S.C, Kukutai, T., Walter, M., Figueroa-Rodriguez, O.L., Walker, J., & Axelsson, P. (2019). Issues in Open Data: Indigenous Data 21 Sovereignty. In T. Davies, S. Walker, M. Rubinstein & F. Perini (Eds.), *The State of Open Data: Histories and Horizons* (pp. 300-319). Cape Town and Ottawa: African Minds and International Development Research Centre.
- Research Data Alliance International Indigenous Data Sovereignty Interest Group. (2019). CARE principles for Indigenous data governance. [Global Indigenous Data Alliance]. <https://www.gida-global.org/care>.
- Schultz, J. L., & Rainie, S. C. (2014). The strategic power of data: A key aspect of sovereignty. *International Indigenous Policy Journal*, 5(4).
- Smylie, J., & Firestone, M. (2015). Back to the basics: Identifying and addressing underlying challenges in achieving high quality and relevant health statistics for indigenous populations in Canada. *Statistical Journal of the IAOS*, 31(1), 67-87.
- United Nations. (2016a). Historical overview. <https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples/historical-overview.html>.
- United Nations. (2016b). United nations declaration on the rights of Indigenous peoples. <https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html>.

INFORMATION, DATA, AND RESEARCH ABOUT OUR PEOPLES  
—COLLECTED ABOUT US, WITH US, OR BY US—  
BELONG TO US AND MUST BE CARED FOR BY US.  
- LIZ LA QUEN NÁAY KAT SAAS MEDICINE CROW

# CHI-MIIGWETCH



@RobynKRowe



rrowe@laurentian.ca

**ROBYN ROWE**

PhD Candidate & Research Associate  
School of Rural and Northern Health  
Laurentian University

**Indigenous Data Team Lead**  
Health Data Research Network Canada