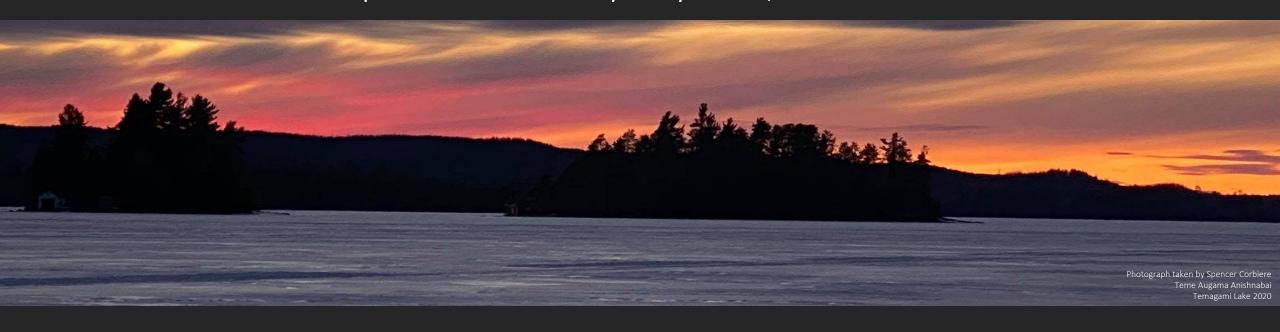




INDIGENOUS RESEARCH ETHICS Enacting Data Sovereignty During COVID-19

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Situating Myself

Commentary in-press:

First Nations' Survivance and Sovereignty in Canada during a Time of COVID-19.

Robyn Rowe, Julia Rowat, & Jennifer Walker



Survivance and Resilience

While ongoing colonial efforts have been exemplified by oppression, land dispossession, geographic isolation, and cultural genocide resulting in systematic discrimination, inequity, and racism across the country, First Nations continue to rewrite the mainstream narrative to one of hope, powered by resistance, resurgence, and survivance.

- Rowe, Rowat, Walker, Releasing in March 2021



(Re)illuminating Systemic Inequities

- While COVID-19 does not discriminate, the social conditions surrounding the pandemic do.
- When applying a biomedical lens, Indigenous nations around the world were already experience significant disparities in health, prior to the pandemic.
- In Canada, the effects of colonialism are evidence in household overcrowding, lack of access to clean water, and inequitable access to healthcare services and primary care providers.

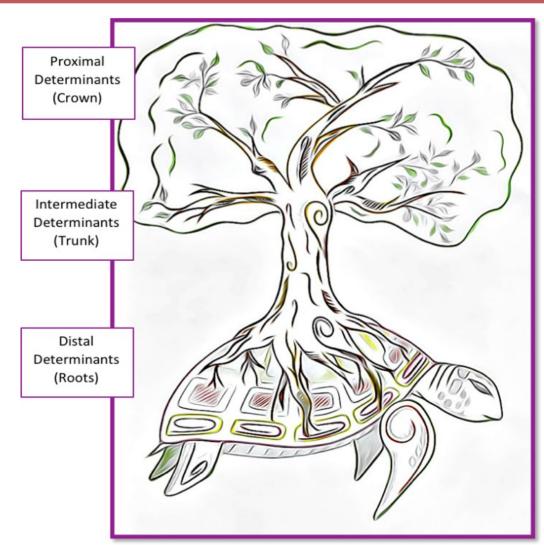
Picture taken by R.Rowe Alderville First Nation Summer 2018

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).

Indigenous Data and their Relationship to COVID-19

- Data has the ability to impact decision-making, influence health policy, leverage funding, and improve health outcomes.
- Data expansions are even more challenging during COVID-19 and Indigenous data are being added toquickly.
- Indigenous nations' interests, values, and priorities are essential to **all** processes data processes that impact 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.

Framework for working with Indigenous Data at IC/ES



- Indigenous research emics
- Community engagement Mutual capacity building

Data Governance

- Formalized data governance and data sharing agreements
- Privacy legislation

Indigenous Data Governance **Principles**

Evidence to Build Policies & Programs

- Cotaborative research Drojects
- Service-model, data requests from continues

Methodology & Approaches

- Indigenous perspectives and models of wellbeing
- Data gapulgually + Contest
- Linkage and analytics

INDIGENOUS DATA AT ICES INCLUDE...



Registries

(e.g., Indian Registry System, Métis Citizenship Registry)



Self-identifiers

(e.g., survey data with identifiers that have been linked at ICES)



Geographic identifiers

(e.g., postal codes or residence codes on First Nations



Indigenousspecific data sets

(e.g., survey or health service delivery data)

https://www.ices.on.ca/About-ICES/Collaborations-and-Partnerships/Indigenous-Portfolio

https://www.ccnsa-nccah.ca/docs/fact%20sheets/cnnc.

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https://fnigc.ca/

Indigenous Sovereignty in a time of COVID

- Indigenous nations, organizations, and leadership are implementing actions to mitigate the spread of the virus and reduce negative outcomes.
- Through the active assertion of sovereignty and autonomy.
- Most communities have pre-existing emergency preparedness plans and have made revisions to respond to the current pandemic.
- Many nations are turning to data to impact COVID-19 related decision-making, leverage community funding, mitigate the spread of the virus, and improve health outcomes.
- Quick actions by First Nations' to incorporate traditional knowledges and practices into some of these revisions, have no doubt mitigated the spread of the virus and saved the lives of many.

Some Data to Ponder...

- 25.5 million reported and confirmed COVID-19 cases in US. 425,000 COVID-related deaths.
- 262,000 reported and confirmed COVID-19 cases in Canada. ~6000 COVID-related deaths
- Two vastly different approaches to COVID management.
- 29,000 total reported and confirmed COVID-19 cases since the pandemic began.
- A third, vastly different approach.



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