INDIGENOUS DATA GOVERNANCE AND RESEARCH ETHICS

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ETHICAL RESEARCH USING INDIGENOUS DATA

• Grounding in Indigenous paradigms and knowledge
• Grounding in a shared understanding of colonization in Canada
  • TRC Calls to Action; MMIWG Inquiry Calls for Justice
• Grounding in Indigenous sovereignty and rights (UNDRIP)
INDIGENOUS PARADIGMS

- Wholism
- Interconnection
- Strengths-based
- Importance of stories
- Collective benefit
- Community-centred and driven
- Respect, Reciprocity, Responsibility, Relevance
- Relational Accountability
• Historical and ongoing colonization and its impacts
• Disruption of knowledge, governance, family and language systems
• Intergenerational trauma and resilience
"THE GREAT AIM OF OUR LEGISLATION HAS BEEN TO DO AWAY WITH THE TRIBAL SYSTEM AND ASSIMILATE THE INDIAN PEOPLE IN ALL RESPECTS WITH THE OTHER INHABITANTS OF THE DOMINION AS SPEEDILY AS THEY ARE FIT TO CHANGE."

- John A Macdonald, 1887
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”
INDIGENOUS SOVEREIGNTY AND RIGHTS

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
Indigenous governance of Indigenous data

Nation building ↔ Data building

Use of Indigenous data for governance

First Nations Information Governance Centre

refers to the rights of First Nations communities to own, protect and control how their information is used for research and other purposes.
Example: Framework for working with Indigenous data at ICES

Initially developed with the Chiefs of Ontario for working with First Nations data
Data governance agreements require a re-imagining of our current research process and our relationship to it.

- Institutional support and capacity
  - From researchers to human resources
- Community support and capacity
  - Meaningful and active governance and involvement
Data governance agreements require strong, established relationships.

- Partnership and/or relationship agreements
- Ethical and ongoing communication
- Mutual capacity building
- Processes to support community-led analysis of data
Examples of Data Governance Agreements

MNO signs new data governance and partnership agreement with the ICES

On July 13, the Institute for Clinical Evaluative Sciences (ICES) welcomed members of the Métis Nation of Ontario (MNO) for a meeting at the Sunnybrook Health Sciences Centre in Toronto to sign a new data governance and partnership agreement.

In attendance were Provisional Council of the Métis Nation of Ontario (PCMNO) Senator Joseph Petras, who opened the proceedings with a prayer and MNO President Margaret Froh, who signed the agreement. Also speaking were Dr. Storm Russell, MNO Senior Policy and Research Analyst and Dr. Jennifer Walker, an ICES core scientist who together with Dr. David Henry and Saba Khan have been instrumental in guiding this research.

MNO President Margaret Froh and ICES President and CEO Michael Schull sign a new data governance and partnership agreement.
Data governance agreements require the **right people** to be having **the right conversation**

- Overall system must allow for diverse Indigenous perspectives and governance
- The system has to be built so that it doesn’t interfere with existing Indigenous governance/relations
Example of a data governance agreement process
Example project:
Diabetes in Ontario First Nations

COMMENTARY  ●  VULNERABLE POPULATIONS

Describing the process of ethical conduct of research in an Ontario-wide First Nations diabetes research project

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ABSTRACT

BACKGROUND: Diabetes mellitus is an established health concern in First Nations communities and is associated with complex influences of colonization. This study, a partnership between First Nations communities and other people in Ontario. We also examined age and sex-specific crude diabetes prevalence.

RESULTS: Between 1995 and 2014, the Ontario (57.0%, 95% confidence interval [CI] 56.3%, 57.8% vs. 44.5%, 95% CI 44.4%, 44.5%). Over time, all-cause mortality for those with diabetes declined but remained consistently
When I look at this information it reminds me of the wisdom and knowledge that our elders and ancestors have passed down to us. I see this information as one more way that our ancestors are able to provide us with important lessons about how we can live a good and healthy life.

Caroline Lidstone-Jones,
Batchewana First Nation & Founding Member of the Mamow Ahyamowen Steering Committee

Enacting sovereignty during COVID-19
Weekly new COVID-19 positive results (rolling average of current and previous week)

All First Nation
Beyond the data...

- Story-based methodology is a powerful methodology for humanizing experiences of both suffering and resilience.
- The historic and enduring legacy of colonialism. COVID-19 has magnified existing inequities.
- Relational worldview social, spiritual and land-based relationships.
- Indigenous resilience during the pandemic should not be misinterpreted by the federal government as a waiver of its fiduciary and other responsibilities toward Indigenous peoples.
Lessons

• Sovereignty is foundational. Relationships are key.
• Where relationships to support Indigenous data sovereignty are not established, a global pandemic has not proven to be a good time to start the process.
• Where relationships are strong, information can flow more easily to support decision-making and determination.
Resources – Learning more

• Cancer Care Ontario: Indigenous Relationship and Cultural Safety Courses
  https://www.cancercareontario.ca/en/resources-first-nations-inuit-metis/first-nations-inuit-metis-courses

• Indigenous Community Research Partnerships Training Resource
  https://www.queensu.ca/indigenous/decolonizing-and-indigenizing/community-research-partnerships-training

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