



Family Medicine

# Research involving Indigenous communities

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# Project Overview

- Indigenous Forum
- While First Nations, Inuit and Metis people comprise 3.8% of the Canadian population, **they account for over 30% of the total federally incarcerated population (OCI).**
- While those incarcerated already experience inadequate health care, **these inequalities have been found to be even more significant for the incarcerated Indigenous population.**



# Lack of Trust

- Indian agents establishing reservations
- Western 'science' has justified and sustained colonization and racist policies of subjugation (Kovach, 2010).
- Data collection through government agencies has been used against communities to **pathologize** and **take action against them**
- e.g. **used to extract children** from their families in the **residential school system** and the **'60's scoop**
- Sharing personal information with government systems had led to **deep communal and personal loss**, solidifying mistrust.

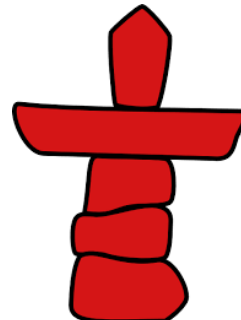


# Historical Issues

- **Exclusion from Process:** Indigenous communities often excluded from the interpretation and presentation of data findings → misinterpretation and pathologizing of communities
  - Researchers often fail to factor historical trauma & Indigenous worldviews → key elements or indicators excluded
- **Harmful Use of Data:** many communities have been subject to studies on diabetes, HIV, and alcohol consumption -> focusing on individual decision-making, rather than presenting the health and social challenges in a broader social context → research not furthering community well-being
- **Privacy & Informed Consent:** There are many examples of studies on First Nations people being published by research teams without community approval of the interpretation or presentation of findings

# Data quality

- **Lack of high quality data** → main data sources (census, vital registration, health surveys, health services utilization, and surveillance systems), do not identify First Nations populations → inadequate sampling → misrepresentation → **limits utility for communities & policy makers**
- **Determining First Nations identity within a data set has to happen at the data collection level; that information has to be collected at the same time as other data**
- Even when Indigenous identity collected, **rarely disaggregated to adequate level**
  - Problematic because there are differences in health determinants and health status outcomes between First Nations, Inuit, and Metis



# Data Quality Solutions

- **Develop a First Nations identifier:** Essentially, a question within the data collection process that asks if a respondent is Indigenous
- **Alternative data sources:** improved participation in data collection with the implementation of the Regional Health Survey (RHS). The RHS is a survey that closely aligns to the Canadian Community Health Survey and is owned, managed, and facilitated by the FNIGC
- **Data Linkages:** Data sets that don't contain First Nations identifiers could have that info added to the data set through a process called 'linking.'
  - E.g. cases in a data set can be identified as FN by linking to the Indian Register if there is a variable in each set that is identically shared (wouldn't identify non-status FN who are not listed in the Indian Registry.)

# FNIGC - Principles of OCAP

**Ownership**

**Control**

**Access**

**Possession**



# Respectful & Meaningful Relationships

- Prioritize the **development of respectful and trusting relationships** with communities
  - If data work is done in deference to self-determination, **solutions will naturally present themselves** and data will address community needs, support community capacity, and further community well-being.
- **It is the right of First Nations to “construct knowledge in accordance with self-determined definitions of what is real and what is valuable”** (Brant Castellano, 2004).
- Indigenous worldviews take a **holistic approach** to understanding well-being. **If an Indigenous worldview is not incorporated** into research activities from the outset, the **findings will be incomplete** and may even be unacceptable to First Nation communities.





# Traditional & Cultural Customs

- Honorarium customary to give to those sharing knowledge as a show of **reciprocity**
- Respecting cultural traditions, **particularly when discussing difficult topics**
  - Importance of having Elders, smudge or other ceremony



# Our Project

- Engagement with Indigenous communities **starting with formulation** of project plan (without burdening)
- Including Indigenous community members **in both quality improvement & official research** + knowledge translators
- Member checking **throughout project** implementation
- Still addressing barriers with CSC concerning OCAP



# Closing Questions

- Are you collecting Indigenous identifiers in your work?
- Are you being mindful of Indigenous worldviews and cultures?
- How is the data you are collecting beneficial to Indigenous communities?



# References

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