

Ethical Engagement, Indigenous Research Methodologies and Implications for TB Research

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**End TB
2022 TB Conference**

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LAND ACKNOWLEDGMENT

As a visitor here today, from Tkaronto, I am grateful for the opportunity to speak to you from the traditional territories of the Blackfoot Confederacy (Siksika, Kainai, Piikani), the Tsuut'ina, the Îyâxe Nakoda Nations, the Métis Nation (Region 3), and all people who make their homes in the Treaty 7 region of Southern Alberta.

My co-presenter and colleague, Tina Campbell would like to acknowledge that she is speaking to you today from Treaty 6, the traditional Territory of the Cree and the homeland of the Metis people.

READ

Truth & Reconciliation Report
<https://nctr.ca/records/reports/>

LEARN

Indigenous Community Research Partnerships

<https://www.queensu.ca/indigenous/decolonizing-and-indigenizing/community-research-partnerships-training>

OACAP Governance Principles
<https://fnigc.ca/what-we-do/education-and-training/>

TAKE ACTION

Write your MP and ask for clean drinking water for First Nations, Inuit and Metis communities.
https://davidsuzuki.org/wp-content/uploads/2018/02/reconciling_promises_reality_clean_drinking_water_first_nations.pdf

An imbalance of power

"The history of research demonstrates an imbalance of power between Western-oriented researches and their academic institutions, and the individuals and communities who attempt to engage in the research process. **Such power imbalances in mainstream academic research systems typically characterize research as a process done 'on' people, which is described as distorting Indigenous knowledge,** and viewed as "inquiry conducted by outsiders, harvesting information that is translated into distorted representations"

If we are unable to foster inclusivity in partnered knowledge development, we will continue to fail to adequately explore and address Indigenous health and wellness knowledge and to understand the health needs of Indigenous people in society."

Wise Practices in Indigenous Health

- Recognizing, respecting and supporting the rights of Indigenous communities to self-determination in research.
- Prioritizing, establishing and facilitating engagement and partnerships, with communities, throughout the research cycle.
- Recognizing and addressing the limited resources and inequities faced by community partners and facilitates capacity strengthening and systems changes necessary to redress it.
- Recognizing, respecting and supporting Indigenous/community-led oversight policies.
- Recognizing and respecting 'cultural safety'.
- Facilitating knowledge translation in a respectful, reciprocal and meaningful manner

Reconciliation of Ethical Space

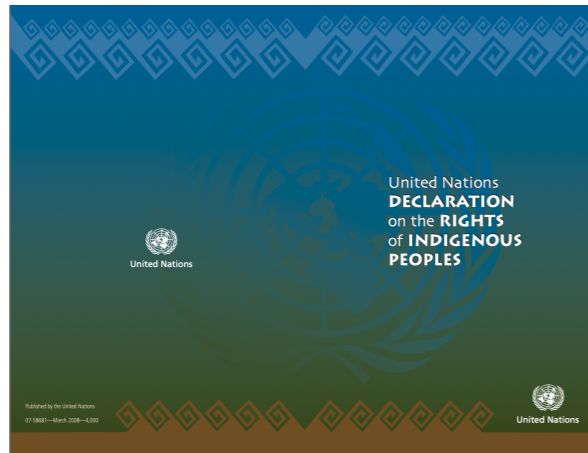
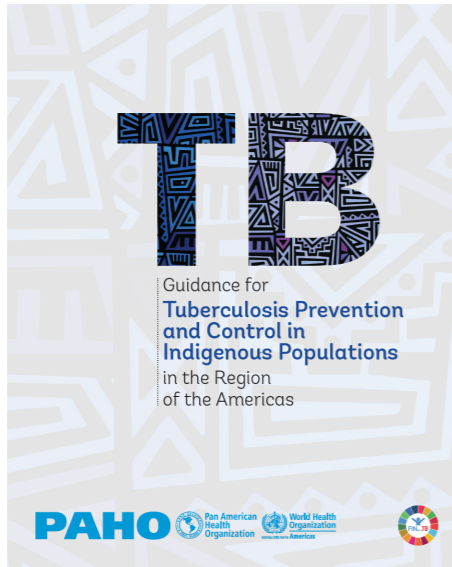
- Ethical space is the totality of a community's principles, values and beliefs
- Within health research there are divergences between the ethical spaces of aboriginal and western communities
- Protecting ethical space involves dialogue on the design of the research through to the dissemination of the results

"Fundamental to this process is an ongoing respect for both parties' ethical spaces and a continual questioning of "is this ethical". This requires a dialogue about intentions, values, assumptions throughout the research process."

Willie Ermine - What is Ethical Space

<https://www.youtube.com/watch?v=85PPdUE8Mb0>

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2.2 Engagement of communities, civil society organizations and public and private sector health services providers.

Ethical goals of community engagement

- Identifying and managing non-obvious risks
- Extending respect to the stakeholder community
- Building legitimacy for the research project

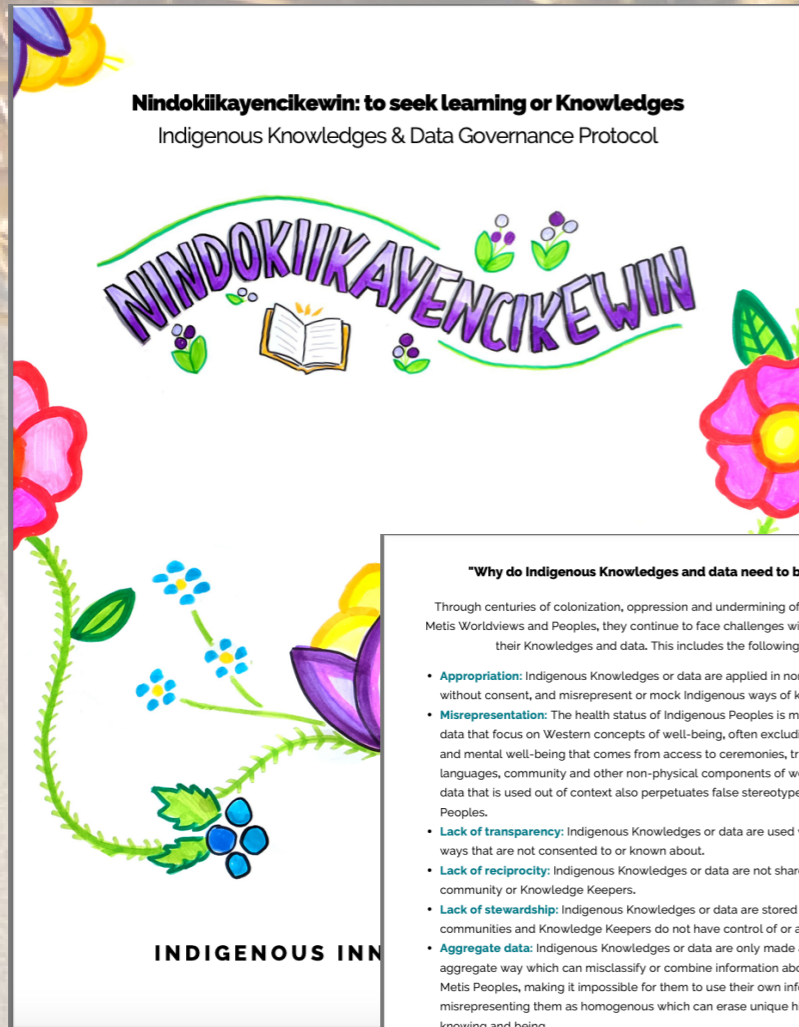
“Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable.”

King et al., 2014
Castellano MB., 2004

Indigenous Data Sovereignty

"Data sovereignty is not just about First Nation, Inuit and Metis Peoples stewarding their own Knowledges and data - it is about improving their capacity and well-being through meaningful, self-determined and self-governed processes that support their visions and sustainability as communities.

Data sovereignty is also about empowering First Nation, Inuit and Metis communities to choose when and how to allow others to reciprocally apply their Knowledges and data in ways that benefit non-Indigenous people - for example, applying Indigenous environmental stewardship practices more broadly."

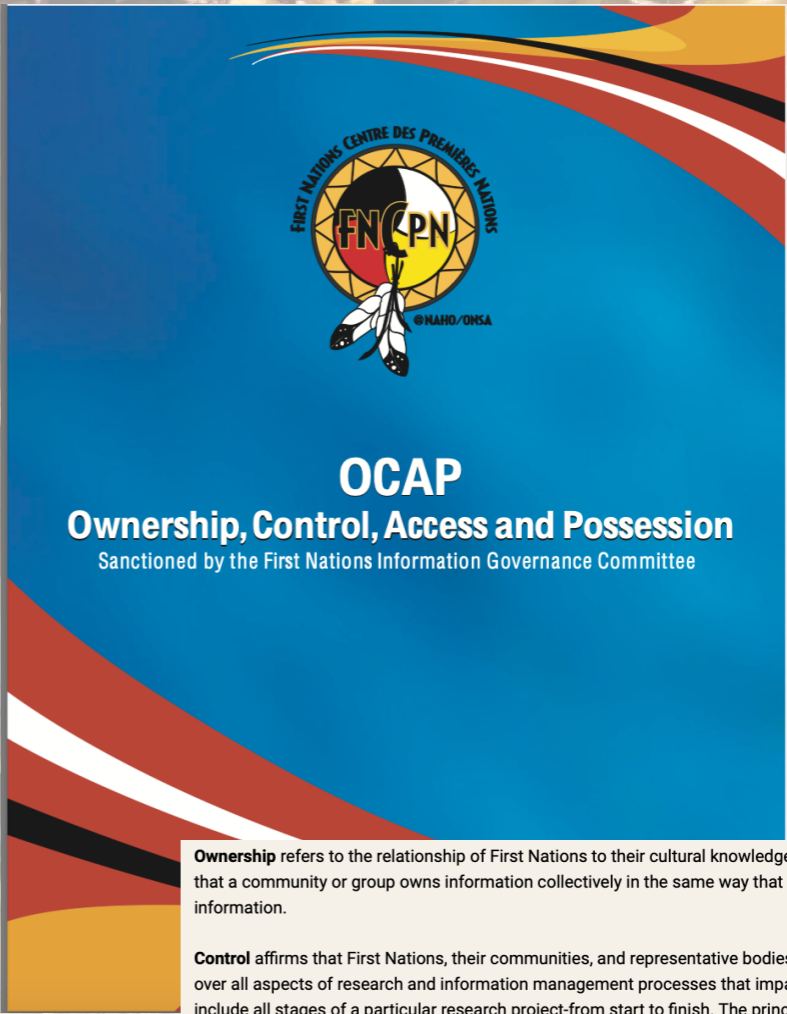


"Why do Indigenous Knowledges and data need to be protected?"

Through centuries of colonization, oppression and undermining of First Nation, Inuit and Metis Worldviews and Peoples, they continue to face challenges with collection and use of their Knowledges and data. This includes the following examples:

- **Appropriation:** Indigenous Knowledges or data are applied in non-Indigenous contexts without consent, and misrepresent or mock indigenous ways of knowing and being.
- **Misrepresentation:** The health status of Indigenous Peoples is misrepresented through data that focus on Western concepts of well-being, often excluding spiritual, emotional and mental well-being that comes from access to ceremonies, traditional medicine and languages, community and other non-physical components of well-being. Indigenous data that is used out of context also perpetuates false stereotypes about Indigenous Peoples.
- **Lack of transparency:** Indigenous Knowledges or data are used without consent or in ways that are not consented to or known about.
- **Lack of reciprocity:** Indigenous Knowledges or data are not shared back with the community or Knowledge Keepers.
- **Lack of stewardship:** Indigenous Knowledges or data are stored in databases that communities and Knowledge Keepers do not have control of or access to.
- **Aggregate data:** Indigenous Knowledges or data are only made available in an aggregate way which can misclassify or combine information about First Nation, Inuit and Metis Peoples, making it impossible for them to use their own information and misrepresenting them as homogenous which can erase unique histories and ways of knowing and being.
- **Legislation:** Indigenous Knowledges or data collected by publicly-funded work is property of the government and can be made public through privacy, access and archival laws without consent. As well, once a non-Indigenous person receives rights to use Indigenous Knowledges, terminology, intellectual property etc., for example as the name of a product, this information no longer belongs to or can be protected by Indigenous Peoples.
- **Patriarchy:** Patriarchal systems have replaced traditional governance systems in many communities, and the traditional role of women, Two Spirit, queer, trans and gender diverse people as leaders and decision makers has been threatened or lost entirely.
- **Imposition:** Data collection requirements are imposed on communities through funding agreements, and the resulting data are not relevant to or mutually supportive of their planning and decision-making needs.

INDIGENOUS INNOVATION INITIATIVE (2021). Indigenous Knowledges and Data Governance Protocol. Toronto: Indigenous Innovation Initiative. Available from: www.indigenouinnovate.org



Ownership refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

Control affirms that First Nations, their communities, and representative bodies are within their rights in seeking to control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project-from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.

Access refers to the fact that First Nations must have access to information and data about themselves and their communities regardless of where it is held. The principle of access also refers to the right of First Nations' communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

Possession While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: it refers to the physical control of data. Possession is the mechanism by which ownership can be asserted and protected.

https://fnigc.ca/wp-content/uploads/2020/09/5776c4ee9387f966e6771aa93a04f389_ocap_path_to_fn_information_governance_en_final.pdf

Indigenous Data Sovereignty

Indigenous

New report finds critical gap in data about Toronto's urban Indigenous community



Our Health Counts report compiles 4 years of research and data about Toronto's urban Indigenous communities

[Rhiannon Johnson](#) · CBC News · Posted: Feb 28, 2018 9:18 PM ET | Last U

KEY FINDINGS

The report found that there are two to four times more Indigenous people within the city than Statistics Canada counted in 2011.

Statistics Canada's 2011 National Household Survey found Toronto had an Indigenous population of 19,265. The Our Health Count study's interim 2016 estimate was a population of between 34,000 and 69,000.



Research, Data & Publication Agreements

Research Agreements are contracts between one or more organizations that are cooperating in the conduct of a research program. The agreement describes the actions that each organization has agreed to undertake, and defines the obligations each party has to the others participating in the collaborative research effort.

Research Agreements may include terms governing the following:

- Roles and Responsibilities
- Schedules and deliverables
- Publication of the research results
- Intellectual property arising from the research collaboration
- Care of data and confidential information exchanged during the research
- Transfer of materials among the collaborating organizations
- Compliance with export control and other laws and regulations
- Rights and procedures to terminate the project

'Nothing about us, without us'

The research process for our FN communities is near and dear to our organizations hearts.

- We ensure that we follow a very detailed code of research ethics.
- We ensure that the agenda is community driven, providing the research team do a community scan to identify the needs of the communities.
- We ensure that we hold a very high standard of ethics given the historical events between Indigenous people and others.

'Nothing about us, without us'

Creating an Ethical space where western perspective and Indigenous perspectives are equally understood is very important as well.

- ethical space will be attained by encouraging teamwork and equality among all research partners and this should include cultural awareness (information) and competence (application of information)
- incorporating and accommodating elder involvement throughout the duration of the project is encouraged as well

10 important ethical research guidelines to follow

1. Transparent Engagement of Community
2. Community Control
3. OCAP principles
4. Culturally appropriate
5. Benefits of Research
6. Active Participation and Capacity Development
7. Consultation and Negotiation
8. Informed Consent
9. Protection
10. Transfer of knowledge

A vibrant, sunlit hillside covered in dense green and yellow vegetation under a clear blue sky. The text is overlaid in the upper center of the image.

Mahsi Cho!
Tiniki!
Thank you!