Reconciling Research with Métis, Inuit and First Nations Communities

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Honouring the Traditional Territory

Mississaugas of the New Credit First Nations and the Toronto Purchase

Haudenosaunee

Huron-Wendat

Métis
INTRODUCTIONS

- Lynn Lavallee
- Janet Smylie
- Real Carriere
- Katherine Minich
Overview

- Overview of Chapter 9 Articles – Lynn
- Implementation of Chapter 9 and Lessons – Réal
- From Intention to Impact: Clearing the Pathway to Social Value in Indigenous Research – Janet
- Ethical tensions from Inuit Qaujimajatuqangit (Inuit Traditional Knowledge perspective) - Katherine
- Relating back to research ethics review – Lynn
- Questions/comments
Community Responses – Pre-Chapter 9

- National Aboriginal Health Organization
  - Ownership
  - Control
  - Access
  - Possession (Schnarch, 2004)

- Five R’s from First Nations education +
  - Respect
  - Reciprocity
  - Relationships
  - Responsibility (Kirness & Barnhardt, 2001)
  - Relevance (Lorilee McGregor)
Six Principles of Métis Research (NAHO)

- Reciprocal relationships
- Respect for individual and collective, autonomy, identity, personal values, gender, confidentiality, practice and protocols
- Safe and inclusive environments
- Recognize diversity within and between Métis
- Relevant, benefit all, accurate, accountable, responsible, acknowledge contribution, protect Métis cultural knowledge
- Métis context – history, values, knowledge, etc.
Research in the North/Inuit


Tri Council Policy Statement 2010

Tenure and Promotion

www.pre.ethics.gc.ca
TCPS Chapter 9

- Research Involving the Inuit, Métis and First Nations Peoples of Canada
- 2014
- 22 Articles to help guide researchers and research ethics boards in reviewing research protocols
- Application across universities and provinces varies
TCPS Chapter 9

- Defines who Aboriginal people are
  - Inuit, Métis and First Nations
  - Inherent political identity
  - Political identity as a determinant of health

- Requirement of Community Engagement in Aboriginal Research
  - On lands
  - Recruitment criteria including Aboriginal identity
  - Cultural heritage, artifacts, traditional knowledge
  - Interpretation of results will refer to
  - Aboriginal as a variable
Chapter 9

- Demonstrating engagement
  - Research agreements (9.11)
  - Letter of approval
  - Token Indians/Advisories and such
- Respect for Governing Authorities
- Complexes Authority Structures
- Diverse Interests
- Collaborative Research (9.12)
  - Respectful relationships
  - Participatory designs
Agenda

- Chapter 9 Implementation
- Chapter 9 Assessment
- Lessons for Researchers
Chapter 9 Implementation

How did I implement chapter 9?
- Respectful Engagement
- Community Research Agreements
- Indigenous Research Protocol
- Indigenous Knowledge Ownership
Chapter 9 Assessment

- Chapter 9 vital to protect Indigenous knowledge and ethical research.
- More work needs to be done to promote knowledge of ethics in Indigenous communities.
  - So research outside of university also ethical
Lessons for Researchers

- Chapter 9 is critical research framework, but still need to...
- Understand diversity of Indigenous people.
  - Diverse Indigenous nations, Diverse Indigenous research protocols.
  - Work with communities to empower their research processes.
- The non-indigenous researchers that had done this best have
  - Personally gone to communities.
  - Clearly explained the intentions of their research.
  - Asked for input of community.
  - And LISTENED to input.
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- **AEC**
  - Research Support to conduct interviews
  - Attend Conferences to present research

- **Tapwe Kichi**
From Intention to Impact: Clearing the Pathway to Social Value in Indigenous Research

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CIHR Applied Public Health Research Chair in Indigenous Health Knowledge and Information
The Well Living House is an action research centre that’s focused on Indigenous infant, child and family health and well-being. Our long term vision is that every Indigenous infant will be born into a context that promotes health and wellbeing – at the individual, family and community levels.
WLH - SMH Governance relationship

- Two accountability routes:
  - Counsel of Grandparents: Indigenous communities
  - St. Michael’s Hospital (SMH)

- Memorandum of understanding (MOU)
  - acknowledge collaborative governance
  - define equal partnership
  - acknowledge principle of Indigenous collective and self-determined research management and governance
  - detail the terms
Today’s Presentation

- 3 Cases involving Barriers and Bridges
  - Respecting Indigenous Intellectual Property
  - Reconciling Voice in Academic Publications
  - Examining the Ethical Alignment of Existing Research Funding Policies and Processes
Epistemic Racism
Reconciliation
Article 31: Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.

From the UN Declaration on the Rights of Indigenous Peoples
Hospital/University X shall own all intellectual property arising under this Agreement and all work products provided hereunder. Service Provider shall cause its employees and agents to waive their moral rights and to sign the Undertaking attached in Schedule B. Service Provider shall execute such documentation as may be required by Hospital/University X, including without limitation, assignments.
Not just justice: inquiry into missing and murdered Aboriginal women needs public health input from the start

Kirsten Patrick MB BCh DA

On Dec. 8, 2015, the Government of Canada announced its plan for a national inquiry into murdered and missing indigenous women and girls, in response to a specific call to action from the Truth and Reconciliation Commission.1 On Jan. 5, 2016, a pre-inquiry online survey was launched to “allow ... [stakeholders an] opportunity to provide input into who should conduct the inquiry, ... who should be heard as part of the inquiry process, and what issues should be considered.”2 We urge the federal government to be cognizant of the substantial knowledge, skill and advocacy of those who work in public health when deciding who should be consulted as part of this important inquiry.

A recent report from the Royal Canadian Mounted Police3 confirmed that rates of missing person reports and homicide are disproportionately higher among Aboriginal women and girls than in the non-Aboriginal female population. As rates of female homicide have declined in Canada overall, the rate among Aboriginal women remains unchanged from year to year. This is troubling, and the need to seek testimony from survivors of family violence should not be surprising, especially given the overlapping determinants of health and justice. There is also substantial overlap with identified determinants of poor health in Aboriginal communities both in Canada and elsewhere.4,5 These are the factors associated with higher rates of youth suicide, adverse birth outcomes and tuberculosis, and poorer child health. It’s clear that a common web — woven of a legacy of colonization and cultural genocide, and a cumulative history of societal neglect, discrimination and injustice — underlies both endemic interpersonal violence and health disparities in Canada’s indigenous populations. There is no conversation to be had about one without a conversation about the other — if the aim is healing — because the root causes are the same.

The World Health Organization (WHO) is currently engaged in developing a global plan of action to strengthen the role of health systems in addressing interpersonal violence, particularly that involving women and girls.6 A draft report by the WHO acknowledges interpersonal violence as a strongly health-related issue that nevertheless requires a multisectoral response tailored to the specific context. Evidence from Aboriginal community models in Canada also demonstrated...
Pathways to Health Equity for Aboriginal Peoples: Overview

The root causes of poor health are well understood. Factors such as income, education, employment, living conditions, social class, social support, and access to health services are all part of determining whether or not people are healthy. Aboriginal peoples' health is also affected by culture loss, racism and stigmatization, loss of language and connection to the land, environmental deprivation, and feeling spiritually, emotionally, and mentally disconnected from their Indigenous identity. Being disconnected from their Indigenous identity can damage Aboriginal peoples' health. Just as important to acknowledge and understand; however, are the factors that have positive effects on Aboriginal health, such as personal and community resilience, restoring and promoting Aboriginal identity, keeping cultures and languages alive, and self-governance.

Promising practices to address these health inequities are occurring today in urban settings, First Nation reserves, and Inuit and Métis communities throughout Canada. Through Pathways research, we will learn how best to have these promising approaches adapted and adopted by communities across the country.

CIHR and its partners will contribute to the creation of better preventive health services, healthier communities and health equity for First Nations, Métis and Inuit peoples in Canada in four priority areas:

- Suicide Prevention
- Diabetes/Obesity
- Tuberculosis
- Oral Health
Today’s Presentation

3 Cases involving Barriers and Bridges
- Respecting Indigenous Intellectual Property
- Reconciling Voice in Academic Publications
- Examining the Ethical Alignment of Existing Research Funding Policies and Processes
Ethical tensions
Inuit Qaujimajatuqangit (Inuit Traditional Knowledge) and science applied in Nunavut, Canada

Katherine Minich
IN THE BACKGROUND

- acculturation policies
- settlements
- all day English schooling
- wage economy
- relocations
- residential school
- missionaries
- medical evacuation
- depleting natural resources
EXTERNAL DEPENDENCY

- Cross cultural research
- Non-Indigenous researchers
- Conflicting knowledge bases
- Land claim organizations
- Federal involvement
- High cost
- Existing high social needs
- Demographic pressure
- Early Inuit research standards
COMMUNITY BENEFIT

- Match to IQ principles
- Political influence in self-government
- Keeping animals and the environment healthy
- Elders sharing
- Community activities (workshops)
- Business opportunities
Where do we go from here?

- Communities are developing their own research ethics guidelines!
Where do we go from here?

- We are here!
- Infiltrate to Transformate the Colonial System
Questions?
Miigwetch

Tapwe Kichi

Thank you
Practical Suggestions for REBs

- Ask the questions
  - Modify protocol forms
  - Engagement, research agreement, dissemination, intellectual property, mutual benefit, building capacity

- Does the researcher/s know the community?
  - Political and cultural identity
  - Ontario – COO, independents, Métis, Native Women’s (ONWA), Inuit Tapiriit Kanatami

- Build capacity in REB
  - How does your REB ensure this expertise?
Chapter 9

- Community REBs
- 9.10 – Requirement to Advise on Plan for Community Engagement
  - Where engagement is not being proposed researchers shall provide a rationale acceptable to the REB
  - REB member must understand the political identity of specific communities
- Mutual benefits (9.13)
Chapter 9

- Capacity building and strengthen research capacity (9.14)
  - Hire? Aboriginal people
  - Does your REB assess this?

- Recognition of the role of Elders (9.15)
  - Provide ethical guidance
  - Paying honoraria – consultant fees!
Chapter 9

- Interpretation and dissemination of research results (9.17)
  - Disagreement accurately reported

- Intellectual property (9.18)
  - Significant challenges
  - Ideologically different
    - Indigenous knowledge cannot be intellectual property
  - REB reviewers look for this in the research agreement!
Chapter 9

- Biological materials and secondary use (9.19-22)
- Secondary use of information or bio materials identifiable as originating from Aboriginal peoples
- Linking two or more anonymous datasets or human bio material (avoid another Dr. Ward)