From Principles to Practice: Indigenizing Research Ethics for Research Involving Aboriginal Peoples

3rd Seminar on the Ethics of Research with Aboriginal Peoples

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BA (hons); MAHSR; PhD (s)

Inuit – Metis
Irish – English
Teacher – Student
Mentor – mentee
REB member – RAC member
Researcher – participant
Academic - grassroots
Love  Respect  Courage  Honesty  Wisdom  Humility  Truth

Competitive  Egocentric  Curiosity  Analytic  Scientific  Theoretical  Assertive
Policies based on geographical belonging
Policies based on ethnic belonging
Why is it so complicated?
Guiding Principles & Strategies

G.P.S
(Guiding Principles & Strategies)

- The 4 R’s
  - Respect
  - Relevance
  - Reciprocity
  - Responsibility
  - Relationships
Why do we need a GPS?
Research Ethics 101

Basic Research Ethics Documents

Developed to observe the “rules of the road” for research involving human participants.

Ethical Conduct for Research Involving Humans

TRI-COUNCIL POLICY STATEMENT

2010

Canadian Institutes of Health Research
Natural Sciences and Engineering Research Council of Canada
Social Sciences and Humanities Research Council of Canada
Individual

Autonomy
Beneficence
Non-maleficence
Justice
Aboriginal Research Ethics

OCAP
OWNERSHIP, CONTROL, ACCESS AND POSSESSION
FIRST NATIONS INHERENT RIGHT TO GOVERN FIRST NATIONS DATA

Produced by: [Name]
Assembly of First Nations

June 2007

Collective
Collective

Respect
Relevance
Reciprocity
Responsibility

History of research Relations
FN Research Capacity & Interest
Self determination (core)
What are some ways to build relationships between researchers and Aboriginal communities?
Release of Tri Council Policy Statement (TCPS)
Kahnawake Code of Ethics
Manitoulin Guidelines for Ethical Aboriginal Research
Ownership, Control, Access, Possession Principles
Development of Aboriginal Ethics Working Group
Draft CIHR Guidelines for Aboriginal Health Research
Release of CIHR Guidelines
Consultation for TCPS2
Release of TCPS2
“To contribute to community empowerment through research and to ensure proposed research projects focus on ethical and respectful partnerships with Aboriginal communities within the Manitoulin Island District.”

“The self-determination of the Kanien’kehá:ka of Kahnawà:ke to make decisions about research is recognized and respected. The academic researchers’ obligation to contribute to knowledge creation in their discipline is recognized and respected. Research should support the empowerment of Kahnawà:ke to promote healthy lifestyles, wellness, self-esteem, and the Kanien’kehá:ka’s responsibility of caring for the Seven Generations.”
relationships

- 2001: Ownership, Control, Access, Possession Principles, Development of Aboriginal Ethics Working Group
- 2004: Draft CIHR Guidelines for Aboriginal Health Research
- 2010: Consultation for TCPS2, Release of TCPS2
Tri Council Policy Statement

CIHR Guidelines

University of New Brunswick

Nunatsiavut

Labrador Grenfell Health

Sheshatshiu Innu Health Commission

NL Health Research Ethics Authority

NunatuKavut

Mushuau Innu Health Commission

APPROVED
this is your world. shape it or someone else will.
F. Brunger (PI), J. Bull, J. Graham, D. Pullman, D. Wall, C. Weijer

with Darlene Wall
Health and Social Sector Manager, NunatuKavut

*The Labrador Inuit-Métis Research Ethics Project:*
*An experiment in Aboriginal governance of health research in complex communities.*

CIHR Operating Grant, 2010 – 2013, ($180,000).
NunatuKavut Land Claim
+
Provincial Legislation
+
National Policy
=

Goals of project

**Academic goal**
How best to implement and manage a system of Aboriginal governance of health research in communities with complex and multiple political and cultural jurisdictions.

**Community goal**
Set up a rigorous and efficient system for NunatuKavut Community Council oversight of research involving NunatuKavut members or lands.
1. **Explicit “partnership” model:** community partner (Wall) as co-lead

2. **Participant-observation research:**
   Brunger ‘works for’ NCC staff [+interviews; + text-based analysis…]

3. **Two sub-teams**
   i. Community/applied
   ii. Academic/theory

CIHR Guidelines for Health Research Involving Aboriginal People: http://www.cihr-irsc.gc.ca/e/29134.html


NL Health Research Ethics Authority (HREA)

- Proclaimed July 1, 2011
- Responsible for ensuring health research conducted in NL is reviewed by an NL HREA-approved research ethics board

Research Ethics Boards (REBs)

- NL Health Research Ethics Board (HREB)
- MUN’s Interdisciplinary Ethics Committee (ICEHR)
How researchers imagine the process: the “consent” model
[community members as research participant, facilitators, advisors]
How communities imagine the process: The OCAP model
[works if and when community capacity, e.g. “research office”]

relationships
What the REB looks for…

1. Scientific validity, research worth risks?
2. Potential benefits justify the potential risks?
3. Conflicts of interest?
4. Consent informed, voluntary? Coercion?
5. Confidentiality, access to information?
6. Justice in recruitment of subjects?

But the REBs do not know the community-specific information
Therefore, the REBs:

1. Require **review by full committee (not expedited)**: Assume research is not low risk as it may have social/political risks to collective

2. Ensure that researchers provide **account of process** of community engagement

3. **Do not approve until documentation of Aboriginal community approval** has been received by the REB office
What does an Aboriginal research advisory committee (RAC) do?

Aboriginal community review ensures:
• relevance to community needs and priorities
• respect for identities, cultures and knowledge systems
• harms and benefits to community members
• harms and benefits in terms of social, political, economic context

What happens if no community review process exists?

Where no formal review process exists, REBs must rely on:
• **Researcher’s description** of a fair and just process of community engagement
• **Letters of support from individual** community members who may or may not speak on behalf of their community (and may or may not have authority from within the community to speak on behalf of their community)
Can Aboriginal communities form REBs and do ethics review?

- Yes. Any community can form an REB compliant with TCPS2
  - But researchers still have to go to institutional REB and can only conduct research if approved at their own institution (TCPS2 9.9)

- For health research, the REB must demonstrate compliance with TCPS2 and be approved by HREA as a duly constituted health research ethics board (HREA Act)
  - Otherwise, even if do have a community REB, health research still needs to undergo review by an HREA approved REB

Note re: Nunatsiavut and the Inuit land claims agreement: the Inuit can pass ethics review legislation which would supersede the HREA Act (ie, would not have to adhere to bullet 2 above)

What does a health authority / hospital review board do?

For research involving the resources (including staff time) of the health care system:
- Resources available?
- Feasible to do it? (e.g., problems with method or recruitment particular to organizational context?)
- Fits with values of organization?
- Costs & benefits to organization are acceptable?
- Adherence to policies of the health authority?
How do the three types of review fit together?

1. Community Approval

2. REB

3. RHA

Consult with Community

REB approval in principle (for $)

Design research

BEGIN
• Started in 2006
  • Revised and revamped in 2010

• Six members
  • 2 community members
  • 2 academics
  • 2 community members who are also academics

• Reviews 10-15 applications per year
Database registry of research
Research that implicates NunatuKavut

Research involving NunatuKavut
Research in collaboration with NunatuKavut

Research in partnership with NunatuKavut
NunatuKavut initiated partnership

NunatuKavut staff are contracted for research
Continuum of community control: engagement in research

- **Research participant**
- **Research facilitator** [volunteer]
  - Introduce to potential participants
  - Drive researcher to communities
  - Set up town hall meetings
  - Translate
  - Arrange accommodations
- **Research advisor** [volunteer]
  - Sit on advisory board
  - Be informally available to advise, educate, guide researcher
- **Research assistant** [paid and trained]
  - Conduct survey; organize data
- **Contract researcher** [paid contract to NCC]
  - Paid by company (mining, hydro, province) to design and conduct environmental impact assessment
- **Research Initiator** [NCC gets grant, contracts out]
  - Hire a university researcher to work alongside community to conduct research
  - University still controls the purse strings
- **Research Office**
  - Initiate research on behalf of community
  - Hire university researchers to work alongside community to conduct research
  - Full time staff to do all roles above

1. Preliminary discussion with community leaders (can be done by telephone or email)
   - Receive conditional letter of support from community, if required for funding or REB application
2a. Submit application to Aboriginal RAC for review
2b. Submit application to REB for review
3. Once community approval and REB approval are obtained, apply for permissions to access institutions (e.g., health authorities, school boards) or lands (e.g., archaeology permits)
4. Do data collection
   - Ongoing communications; approvals for amendments must be sought from REB and RAC
5. Dissemination, including to the community, in keeping with the terms of application
(Q) Seamless REB – community process

My REB told me I need to get community approval before they will give REB approval, but…

The community told me I need to get REB approval before they will give community approval, but…

(A) REB approval contingent on community approval
[CIHR guidelines]

(Q) Can community request trump REB practice?

My REB says the consent template cannot be altered, but…

The community RAC says I need to change the consent because not appropriate for their membership but…

A. Defer to TCPS2 – in this case, YES. (TCPS2 9.9, 3.2)
[Q]. Can Community RACs insist on approving all materials that have already been approved as ethical, including amendments?

The community RAC got mad at me for putting up recruitment posters that they hadn’t approved, but…

The REB approved my amendment to change my recruitment posters; and I understood I could post them, but…

(A). Yes. Ethics approval is not community approval; community approval is not ethics approval.
Next steps

• Provide practical advice for communities, researchers and REBs on how to implement TCPS2-9;
• Produce policy recommendations for the Newfoundland & Labrador’s provincial Health Research Ethics Authority and its REBs;
• Produce a report for the NunatuKavut on best practices for a rigorous, accountable and community-based system of research review that will work in tandem with other Aboriginal, regional and provincial review bodies; and
• Publish academic papers on the politics of risk and representation related to community-based research review.

Lessons learned
Success

what people think it looks like
relationships
“Science looks for truth, practice looks for what works. What works is true, and what is true works.”

Steuart, 1963
“What do researchers really mean by partnerships? Is this just a way to make sure the research gets through ethics approval?”
G.P.S
(Guiding Principles & Strategies)

• The 5 R’s
  • Respect
  • Relevance
  • Reciprocity
  • Responsibility
  • Relationships
In the end Frank was thinking so far outside of the box, he couldn’t remember what was actually in it.

But, you know... that's the way we've always done it.
They're getting louder!
Nakkumek  Merci  Thank you
To find out more:

