Re-storying Research on Research Ethics: Weaving Autoethnography, Poetry, Digital Storytelling, and Narrative Inquiry

Julie Bull
4th Seminar on the ethics of research with Indigenous Peoples, UQAT
Val d’Or, Quebec, November 22, 2018

#DorkSports
#TheJuliestPhD
@julierbull
Nakummek to the Cree and Algonquin Peoples who have cared for this land and to all the Indigenous Peoples who call Val d’Or home today.

“It is a deterrent to researchers and people avoid doing Indigenous research knowing that they have to jump through all of these hoops with all of these different community ethics boards”

-Dr. Anonymous (2018)
The single story creates stereotypes, and the problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story.

— Chimamanda Ngozi Adichie —

“By telling our stories we’re at the same time disrupting dominant notions of intellectual rigor and legitimacy, while also redefining scholarship as a process that begins with the self”

(Sium & Ritskes, 2013, p. IV)
Who Am I?

I am a graduate student
I like to go to coffee shops to think about research methodology
Inuk
Labradorian
Indigenous
Learner
Professor
Researcher
Evaluator
Ethicist
Advocate
Author
Activist
Mentor
"When you follow your heart, you provide that path for others"
From my ancestors who prayed
That one day I'd be here
With who I am
and what they knew
To try anew a different way
The road less travelled
And here I stand
on the blessed land
that takes my hand
To be true to myself
and do the right thing
To examine my life
and the adventures it brings

I ❤ ETHICS
Defining Our Ethical Space: Labrador Innu, Inuit, and Inuit-Métis Perspectives on the Governance of Health Research

Lay Summary

Recent implementation of national guidelines for research involving aboriginal peoples and provincial legislation to constrain requirements for ethical conduct of health research is changing the way in which governance of health research is understood and practiced in aboriginal communities. This study was conceptualized from a partnership between aboriginal communities in Labrador and the researcher as a result of Community Health Research in Labrador: Learning, Listening, and Working Together (CHOICE Lab 2010–2014). 

Research with Aboriginal peoples: authentic relationships as a precursor to ethical research.

But JR1.

Author information

Abstract

Recent ethics guidelines in Canada encourage communities to become involved in governance of research that affects them. Yet very little is known about how communities themselves, communities and research, enact these guidelines within the ethics review process. This article reports on efforts to bring best practices to the ethics review process in Labrador, and to do so in a way that respects and honors the Inuit and Innu cultures as the context for research, and in an Aboriginal context, using the Innu and Innu-Métis research ethics guidelines.

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[Indexed for MEDLINE]

Whose agenda is it? Regulating health research ethics in Labrador

Tam Brunger and Julie Bull

Abstract

In Labrador, the NunatuKavut (formerly Labrador Inuit Métis) have begun to introduce a rigorous community-based research review process. We conducted a study with leaders and health care workers in and beyond the NunatuKavut community of Labrador, asking them what should be emphasised in a community review. We also sought to identify whether and how community review should be directed from the centralised, "institutional" research ethics review that would be the mandate of Newfoundland and Labrador’s impending provincial health research authority. In this article we report on our findings, with the aim of providing strategies and direction for researchers, research ethics boards, and Aboriginal communities dealing with dual-level ethics review. We argue for the adoption and use of a consistent label for community review of research ("Community Research Review Committee") as distinct from research ethics boards. We provide suggestions for the development of separate roles and responsibilities for community review of research to ensure...
Risk and Representation in Research Ethics: The NunatuKavut Experience.

Abstract

This article examines Canadian human research ethics guidelines and their impact on collaborative research. The Inuit Land Claims Agreement Act 1975 has granted Inuit nie-anngitaaq (collective ownership) rights over traditional and unceded lands, including Inuktitut lands in Nunavut. The Inuit74, in turn, also have the right to participate in the decision-making processes that affect their territories. Nevertheless, the Canadian government and research bodies have not co-operated with the Inuit74 to develop research ethics guidelines that reflect their unique circumstances.

The NunatuKavut (NKN) experience offers an alternative approach to research ethics. It proposes a model of collaboration that involves Inuit elders and community members in the design, implementation, and evaluation of research projects. The NunatuKavut model seeks to empower Inuit communities by ensuring that research is conducted in accordance with their values and priorities. The article argues that a more participatory and collaborative approach to research ethics is needed to ensure that Inuit interests are respected and protected.

Key words: NunatuKavut, Inuit74, human research ethics, collective ownership rights, Inuit land claims agreement.

“What Do They Really Mean by Partnerships?” Questioning the Unquestionable Good in Ethics Guidelines Promoting Community Engagement in Indigenous Health Research

F. Brunger, D. Wall,
First Published May 12, 2016 Research Article
https://doi.org/10.1177/1558264615590687

Abstract

This article questions the assumption that community engagement is a good thing in and of itself. It critiques the use of partnerships as a strategy for promoting community engagement in Indigenous health research. The article argues that partnerships can lead to community fatigue and undermine the community’s ability to effectively participate in research. The article also discusses the challenges of implementing participatory research in Indigenous communities and suggests some possible solutions.

Animating the Concept of Ethical Space: The Labrador Aboriginal Health Research Committee Ethics Workshop

Julie Bull

REVISED REFERENCES, 04/13/2016

A Two-Eyed Seeing Approach To Research Ethics Review: An Indigenous Perspective

Julie Bull

THE ETHICS RUPTURE

Edited by
Wil C. van den Hoonsard and Ann Hamilton
Research Ethics Policy Development in Canada

  - Ownership, Control, Access, Possession Principles
- 2001: Kahnawake Code of Ethics
- 2004: Manitoulin Guidelines for Ethical Aboriginal Research
- 2007: Development of Aboriginal Ethics Working Group
- 2007: Draft CIHR Guidelines for Aboriginal Health Research
- 2007: Release of CIHR Guidelines
- 2010: Consultation for TCPS2
- 2010: Release of TCPS2

Context.
Indigenous peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.
Constitution Act 1982, Section 35

PART II
RIGHTS OF THE ABORIGINAL PEOPLES OF CANADA

Recognition of existing aboriginal and treaty rights

35. (1) The existing aboriginal and treaty rights of the aboriginal peoples of Canada are hereby recognized and affirmed.

Definition of “aboriginal peoples of Canada”

(2) In this Act, “aboriginal peoples of Canada” includes the Indian, Inuit and Métis peoples of Canada.

Land claims agreements

(3) For greater certainty, in subsection (1) “treaty rights” includes rights that now exist by way of land claims agreements or may be so acquired.

Aboriginal and treaty rights are guaranteed equally to both sexes

(4) Notwithstanding any other provision of this Act, the aboriginal and treaty rights referred to in subsection (1) are guaranteed equally to male and female persons.
First Nations, Inuit, and Métis are RIGHTS holders, not stake holders
“Community engagement – if done uncritically and in the service of ethical guidelines rather than in service to ethical research – can itself cause harm”

(Brunger & Wall, 2016, p. 1862)
What is Ethical Space?

What do we do as we individually? It's not an "it" - it's a process not a noun.

Two-eyed Seeing

Competitive
Individual
Curiosity
Analytic
Scientific
Theoretical
Assertive

Cooperative
Collective
Courage
Honesty
Wisdom
Humility
Truth
Talk

Walk

Walk
Indigenous Communities

Funders

Researchers

REBs
What are the perspectives and practices of REB members, chairs, and administrators regarding the review and approval of protocols for research with Indigenous Peoples?

Got REB?

I got 9 REB reviews!
“Stories become mediums to unmake colonial borders”  
(Sium & Ritskes, 2013, p. VI)
Conceptual Framework

- Ethical theory
- Epistemology
- Metaphysics
- Pedagogy
- Adult ed.
- Leadership

Indigenous Sciences
- Bioethics
- Health policy
- Health admin
- Critical theory
- Auto-ethnography
- Cross-cultural

Two-Eyed Seeing
- Philosophy
- Education
- Agile/iterative approaches
- Theory of Reflexivity
- Observer World

Decolonizing Methodologies

Reflexive practice

What are the perspectives and practices of REBs regarding the review and approval of protocols for research with Indigenous Peoples?
Recruitment

Canadian Bioethics Society
Société canadienne de bioéthique

+Research Institutes
+Colleges
+Hospitals
+Universities

Participant Contributor Locations

+Dr. Anonymous
findings...
It is about relationships and I think that needs to be highlighted, to get people to pay attention. It's not about forms. So, if people see the application as the beginning of the relationship, that's going to give them the feeling that the application is a hindrance. Whereas if they begin the relationship beforehand, then the application is just the culmination of the relationship.

-Bill
And we have to have the courage, for many reasons, to say “we're just not going to approve this”, or “this can't happen”.

-Karen
People are very epistemologically-centric and until they can really get it, that Indigenous epistemology and ways of understanding the world is fundamentally different, they're not going to understand that that's why research has to be fundamentally different and much more robust, and that's exacerbated by the fact that research history with Indigenous People has been pretty shitty.

-Riley

Ethics is really just based on the values of your community so if we're operating in alignment with those values, then we can't help but be ethical when you get right down to it.

-Gwen
Vulnerability

It's not okay to call me vulnerable anymore, that's not a healing relationship. You can't call me vulnerable unless you're willing to look at your role in my vulnerability, because vulnerability comes in a relationship. And somebody who's supporting that vulnerability instead of supporting your growth and your resilience. And so that's changed the vulnerable people to resilient people.

-Johanne

Ethics is a conversation

And one conversation can change your entire trajectory.

-Riley
all are
teachers,
all are
learners,

context matters
Things REBs can do

- Read CIHR Guidelines for Research Involving Aboriginal People
- Make space to include First Nations, Inuit, Métis on the REB
- Ask the ‘right’ questions in forms and protocols
- Host office hours for Indigenous research
- Require demonstration of community approval prior to granting institutional approval
- Approval in principle to release funds for engagement
- Ongoing and continuing education
Things researchers can do

- Read and study CIHR Guidelines for Research Involving Aboriginal People
- Visit community without collecting data (maybe even volunteer while you're there)
- Ask the community what research they would like to see happen
- Be flexible in methods, approaches, and timelines
- Pass the mic to First Nations, Inuit, Métis partners and collaborators
- Favor Indigenous and decolonizing methodologies
- Ongoing and continuing education

Becoming able humans

To decolonize is to criticize to open our eyes and to question why.
To question what we're told as fact
To look back.
To think critically about history
To question what we think we know
To investigate, not interrogate.
I'M STUCK
IN A DEFICIT-BASED WORLD

Becoming able institutions

IT'S ALL ABOUT RELATIONSHIPS
What's next?

From policies to actions: Promoting and practicing ethical research/review with Indigenous Peoples

Julie Bull

Julie Bull is an award-winning Southern Inuk researcher and educator and is a member of NunatuKavut, Labrador, with more than 15 years of experience in community-based research with Indigenous communities. Her academic background is in Cultural Studies (Philosophy, Psychology, Health Policy Research) and she is recognized for her work and methods for research involving Indigenous Peoples' perspectives.

Julie is a Research Methods Specialist at the University of New Brunswick - Fredericton, professor in the Indigenous Studies Program, and an academic advisor for Indigenous researchers, educators, and learners across the province. She has been an invited lecturer at several institutions across Canada. Among Julie’s many accomplishments, she was awarded the Native Women’s Resource Centre Researcher of the Year Award, the Iona Campagnolo Centre Graduate Scholarship, the Scholarships and Student Aid Secretariat (SSAS) of Health Research - Institute of Aboriginal Peoples’ Scholarship, and the National Aboriginal Health Organizations (NAHO) 2016 National Indigenous Role Model Award from the National Aboriginal Health Organization (NAHO).

Julie is also involved in many academic and grassroots initiatives such as a committee member for education and outreach on the Panel on Responsible Conduct of Research and a member of the NunatuKavut Community Council Research Review Committee.
The Naalak Gathering: A regional dialogue on Indigenous Research Governance

Happy Valley-Goose Bay, NL
March 2019
Save the Date!

May 10-12, 2019

Ethics Rupture II

Native Canadian Centre of Toronto
16 Spadina Road, Toronto, Ontario

For more information and to stay up to date on planning visit http://ethicsrupture.ca

*Ethics Rupture II* (ER2) is a follow-up to the *Ethics Rupture Summit: Alternatives to Research-Ethics Review* (University of New Brunswick, Fredericton, 2012). ER2 seeks to bring together policy makers and researchers in a common pursuit to critically discuss and ameliorate the provisions related to Canada’s TCPS, as a way of enhancing the ethical dimension and addressing the criticisms of prospective ethics review in social sciences and humanities research.
People

Process

- **Research participant**
- **Research facilitator** [volunteer]
  - Introduce to potential participants
  - Drive researcher to communities, Translate
  - Set up town hall meetings, 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 /conduct 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

Continuum of community control: Engagement in research
Research is Reflexive
Research is Relational

“research has to be a marriage, not a one-night stand”

Labrador Inuk Elder

Where the magic happens ...

Your Comfort Zone
"Collective Responsibility"

Nakummek! Marsi! Miigwech!
Niá:wen! Thank you! Merci!

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