

Research governance in NunatuKavut: engagement, expectations and evolution

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ABSTRACT

Some of the world's most southern Inuit populations live along central and the southeastern coast of Labrador in the territory of NunatuKavut and are represented by the NunatuKavut Community Council (NCC). Southern Inuit and NCC staff have been actively collaborating with researchers and research ethics boards since 2006 on research ethics and the governance of research in NunatuKavut. As self-determining peoples, Southern Inuit, like many Indigenous communities, are reclaiming control of research through a number of highly effective community consent contracts and ethical review processes and protocols. These community-driven research agreements have both shaped, and been shaped by, academic writings on the issue of collective consent to research. This case report describes the evolution of NCC research governance from 2006 to 2018, emphasising the ethics and engagement that is required to conduct research with Southern Inuit or within the territory of NunatuKavut.

ARTICLE HISTORY

Received 15 April 2018
Revised 18 November 2018
Accepted 21 November 2018

KEYWORDS

Inuit governance;
Indigenous research ethics;
engagement; community-
driven

Introduction

A paradigm shift is occurring in health research involving Indigenous Peoples from research *with* Indigenous Peoples instead of research *on* them [1,2]. Over the last 20 years, this paradigm shift has been shaped by political, social, intellectual and institutional movements within Indigenous communities and academia, which has led to the development of policy on research ethics for research with First Nations, Inuit and Métis Peoples [3–6]. As more guiding documents and policies emerged, increasingly more Indigenous academics started writing about the ethical tensions and dilemmas they experienced when working in academic institutions [7–12]. A notable shift occurred when their emphasis was no longer on the tensions of working in communities, but rather the tensions of doing community research in academic institutions.

As self-determining peoples, many Indigenous communities are reclaiming control of research through a number of highly effective community consent contracts and ethical review processes and protocols. Like many Indigenous communities, the NunatuKavut Community Council (NCC) is mitigating unethical research practices and is asserting its inherent right to determine research with its people and on its territory. This case report describes research governance initiatives at the NCC from 2006 to 2018 emphasising the ethics and engagement that is required to conduct research with Southern Inuit or within the territory of NunatuKavut.

Location

NunatuKavut means *Our Ancient Land* and refers to Southern Inuit territory in southeast and central Labrador. Southern Inuit have lived and subsisted upon these lands prior to the arrival of Europeans to their territory and have always lived off the land, sea and ice, and continue to occupy their traditional territory today. NunatuKavut communities are spread out over a vast territory with rugged terrain and access to some communities are fly in/out and seasonal ferry service only. Several communities are connected by road (mostly dirt roads but increasingly more are paved). The NCC is the representative governing organisation of approximately 6000 Southern Inuit of NunatuKavut. The NCC, including a President and Vice-President, is elected by its membership to govern and is comprised of council members representing 6 regions across NunatuKavut territory. The primary function of the NCC is to ensure the land, ice and water rights and titles of its people are recognised and respected. After decades of effort, on 12 July 2018 the NCC entered into official dialogue with the federal government to negotiate an agreement on their Indigenous rights and self-determination.

An inherent part of self-determination relates to decision-making in research. That is, Southern Inuit are to decide the research that occurs with them or on their lands and the research is to be guided, informed and prioritised by Southern Inuit. NCC staff, partners and

collaborators have been working for many years to advance opportunities for community self-determination in research in NunatuKavut, with a vision towards research that is beneficial to community, of priority and accurately representative of Southern Inuit in their place.

Research policy context

Since the early 2000s, several Indigenous communities and nations in Canada have created their own research/ethics review structures because they “have distinct legal and constitutional rights and thus, have political legitimacy to make decisions about issues, including health research projects, which directly affect [them]” [13, p. 20]. The 2007 release of the *United Nations Declaration on the Rights of Indigenous Peoples* – UNDRIP [14] aligned with the other foundational documents grounding Indigenous research ethics in Canada at the time, such as the Tri-Council Policy Statement for Research Involving Humans (1998, 2010). More recently, in 2015, the Truth and Reconciliation Commission of Canada (TRC) released their *TRC: Calls to Action* which outline many ways to begin valuing and integrating Indigenous worldviews and knowledges [15].

Researchers and research ethics boards are required to know the ethical and legal dimensions of research with Indigenous Peoples. Indigenous communities have created a number of highly effective community consent contracts (eg, research agreements, research partnerships, etc.) and ethical review processes and protocols (eg, community Research Ethics Boards, Research Advisory Committees (RACs), Elders councils’ directives, Band Council resolutions, etc.). These community-driven research agreements have both shaped, and been shaped by, academic writings on the issue of collective consent to research [1,6,13,16,17]. It is a complex ethical, legal, political and cultural landscape in which Indigenous Peoples operate to ensure Indigenous sovereignty over the research that happens on Indigenous territories. For NunatuKavut, like many other Indigenous Nations and governing councils, the first stage of any research project is engagement. Whether one is a seasoned researcher – known or unknown to the specific community – or a novice just beginning a research career, and whether or not they are Indigenous to another territory, permission to conduct research in any Indigenous Nation is required and community consent is an ongoing conversation.

Early developments in research governance

NCC has been actively engaged in research ethics since 2006, positioning itself as a leader active in local, provincial, regional and national conversations that examine the

governance of research with Indigenous Peoples. NCC’s initial ethics review process was basic and included a simple 1-page application form (2006). The impetus for initiating that process was the amount of research being done in natural resources and NCC wanted to ensure that Southern Inuit values, culture and land were being protected and represented accurately in these projects. During that same time, a conference was held in Happy Valley-Goose Bay called *Listening, Learning, and Working Together* (2006), where community members and leaders met with researchers and policy makers to discuss research generally and Labrador priorities specifically. The governance of research was a common theme at the conference and NCC took an active role in advancing its research ethics processes and policies in the years since.

From the 2006 conference, the NCC, a community member and graduate student and a research ethics scholar formed a new relationship and plan to develop research governance in NunatuKavut [10]. This conversation helped NCC and Southern Inuit start to conceptualise and define the *ethical space* in research. This *ethical space* has been articulated by Cree Elder and scholar, Willie Ermine, to denote this space of engagement that is essential in health research involving Indigenous Peoples [18]. This builds on work from Roger Poole [19] which examined the space between 2 opposing societies when they are required to work together to address an issue. Essentially it is a framework for human dialogue that Ermine adapted to conceptualise the relationship between Indigenous and non-Indigenous Peoples, highlighting the necessity of integration.

Then, in 2009, a pivotal moment occurred in NCC research: the initiation of the *Community Health Needs Assessment* (CHNA) [20]. The marked difference in the CHNA was that NCC held the funds and that the research was among the first major studies in NunatuKavut to be done *by, with, and for* Southern Inuit. In 2010, NCC led a federally funded project research project that aimed to revise and implement a robust research governance structure and to examine the nuances of research governance in complex communities. From 2010 to 2013, NCC developed a rigorous structure of research review [21] and disseminated the processes and outcomes in various places [16,22–25] (Figure 1). These efforts culminated in the formation of the NCC RAC which is currently comprised of 6 members: 2 community members, 2 academics and 2 community members who are also academics. Research applications are submitted on an ongoing basis and are reviewed by available members of the RAC. Discussion and deliberation between RAC members occur as needed and researchers are asked to provide additional information as required to ensure adequate and ethical considerations have been reflected.

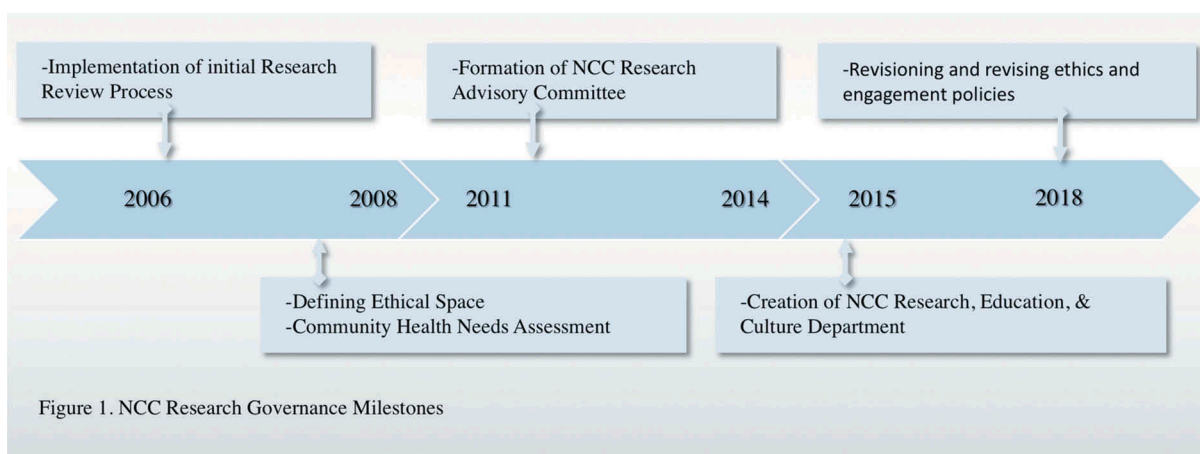


Figure 1. NCC research governance milestone.

Strengthening Nunatukavut's research policy

Since 2013, the research capacity and related interests at NCC has grown and has been met with an increased attention on research involving Southern Inuit. The NCC RAC reviews between 25 and 30 projects per year (and is continuously increasing). The creation of the Research, Education and Culture (REC) department (of which co-author Hudson is the manager), in 2016, further strengthened NCC's commitment to and leadership role in policy and process pertaining to research in Nunatukavut. In a short time, REC has begun to initiate, lead and collaborate in pertinent research areas such as Inuit governance and sustainability, Inuit education, cultural revitalisation, renewable energies, and research ethics and community engagement.

As Indigenous researchers and community people, we (the authors) often find ourselves entrenched in relationships (as participants, partners, collaborators), and processes that many Indigenous scholars have argued were initially designed to dispossess us of our lands, waters, knowledge and culture in the name of western knowledge production and truth seeking. An integral shift that is required is "to meaningfully acknowledge Indigenous partners as *nations*, not stakeholder groups – with jurisdiction over research in their communities and on their traditional lands" [26, p. 4]. NCC continues to assert its inherent right to determine the research that happens with Southern Inuit and throughout Nunatukavut by enhancing the ethics and engagement policies and practices for research.

Closing thoughts

There has been substantial movement within Indigenous nations since NCC began its research governance initiatives in 2006. Now there are Indigenous

Data Sovereignty Networks in New Zealand, Australia and the USA contributing to the global movement to ensure that Indigenous People determine and decide the ways in which data is collected, analysed, interpreted, managed and reported [27]. As NCC visions towards a future of research sovereignty in Nunatukavut, we go back to our roots, to our ancestors, to the land, water and ice to guide us in the direction that will protect Nunatukavut Peoples and lands for generations to come. To do that, NCC is currently undertaking a year-long process of engagement with its staff and citizens to strengthen its research policies.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

The authors have not received any funding.

References

- [1] Riddell JK, Salamanca A, Pepler DJ, et al. Laying the groundwork: a practical guide for ethical research with Indigenous communities. *Int Indig Policy J.* 2017;8(2):1–20.
- [2] Smith LT. *Decolonizing methodologies: research and Indigenous peoples.* New York: Zed Books; 1999.
- [3] Canadian Institutes of Health Research (CIHR). CIHR guidelines for health research involving Aboriginal people (20-7-2010); 2007. Available from: <http://www.cihr-irsc.gc.ca/e/29134.htm>
- [4] Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), & Social Sciences and Humanities Research Council of Canada (SSHRC). Tri-Council policy statement: ethical conduct for research involving humans (TCPS 2). Ottawa, ON: Government of Canada Panel on Research

- Ethics; 2014. Available from: <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-epc2/Default/>
- [5] Moore C. Implementing Chapter 9 of the Tri-Council Policy Statement on the ethics of research involving Aboriginal Peoples in Canada: how's that going? [Unpublished doctoral dissertation]. Halifax, NS: Dalhousie University; 2015.
- [6] Schnarch B. Ownership, control, access, and possession (OCAP) or self-determination applied to research, a critical analysis of contemporary First Nations research and some options for First Nations communities. *J Aborig Health*. 2004;14(16):80–95.
- [7] Brant-Castellano M. Ethics of aboriginal research. *J Aborig Health*. 2004;1(1):98–114.
- [8] Wilson S. *Research is ceremony: indigenous research methods*. Black Point, NS: Fernwood Publishing; 2008.
- [9] Kovach M. *Indigenous methodologies: characteristics, conversations and contexts*. Toronto, ON: University of Toronto; 2009.
- [10] Bull JR. Research with Aboriginal Peoples: authentic relationships as a precursor to ethical research. *J Empir Res Hum Res Ethics*. 2010;5(4):13–22.
- [11] Martin DH. Two-eyed seeing: a framework for understanding Indigenous and non-Indigenous approaches to Indigenous health research. *Can J Nurs Res*. 2012;44(2):20–42.
- [12] Bird-Naytwohow K, Hatala AR, Pearl T, et al. Ceremonies of relationship: engaging urban Indigenous youth in community-based research. *Int J Qual Methods*. 2017;16(1):1–14.
- [13] Kaufert JM, Commanda B, Eilias R, et al. Evolving participation of aboriginal communities in health research ethics review: the impact of the Inuvik workshop. *Int J Circumpolar Health*. 1999;58:134–144.
- [14] United Nations. Declaration on the rights of Indigenous peoples; 2007. Available from: www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf
- [15] Truth and Reconciliation Commission of Canada. *Truth and reconciliation commission: calls to action*. Winnipeg, MB: Truth and Reconciliation Commission of Canada; 2015. Available from: http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls_to_Action_English2.pdf
- [16] Brunger F, Russell T. Risk and representation in research ethics: the NunatuKavut experience. *J Empir Res Hum Res Ethics*. 2015;10(4):368–379.
- [17] Weijer C, Goldsand G, Emanuel EJ. Protecting communities in research: current guidelines and limits of extrapolation. *Nat Genet*. 1999;23:275–280.
- [18] Ermine W. The ethical space of engagement. *Indig Law J*. 2007;6(1):194–201.
- [19] Poole R. *Towards deep subjectivity*. New York: Harper Torch Books; 1972.
- [20] Martin DH, Valcour JE, Bull JR, et al. NunatuKavut community health needs assessment: a community-based research project. Happy Valley-Goose Bay: NunatuKavut Community Council Inc; 2012.
- [21] NunatuKavut Community Council (NCC). Application for research with NunatuKavut; 2013. Available from: http://www.nunatukavut.ca/home/files/pg/application_for_research_with_nunatukavut_january_2013-2.pdf
- [22] Brunger F, Bull J, Wall D. The NunatuKavut model of research oversight: innovation through collaboration. In: Gros-Louis McHugh N, Gentelet K, Basile S, editors. *Toolbox of principles for research in Indigenous contexts: ethics, respect, equity, reciprocity, cooperation and culture*. Wendake, QC: First Nations of Quebec and Labrador Health and Social Services Commission; 2015. p. 51–59.
- [23] Brunger F, Bull J. Whose agenda is it? Regulating health research ethics in Labrador. *Etud Inuit*. 2011;35(1–2):127–142.
- [24] Brunger F, Wall D. 'What do they really mean by partnerships?' Questioning the unquestionable good in ethics guidelines promoting community engagement in Indigenous health research. *Qual Health Res*. 2016;26(13):1862–1877.
- [25] Bull J. A Two-eyed seeing approach to research ethics review: an Indigenous perspective. In: Van Den Hoonaard WC, Hamilton A, editors. *The ethics rupture: exploring alternatives to formal research ethics review*. Toronto: University of Toronto Press; 2016. p. 167–186.
- [26] Stiegman M, Castleden H. Leashes and lies: navigating the colonial tensions of institutional ethics of research involving Indigenous peoples in Canada. *Int Indig Policy J*. 2015;6(3):1–10.
- [27] Walter M, Lovett R, Bodkin Andrews G, et al. *Indigenous Data Sovereignty Briefing Paper 1*. Miam nayri Wingara Data Sovereignty Group and the Australian Indigenous Governance Institute; 2018.