NORTHERN AND INDIGENOUS HEALTH AND HEALTHCARE

CHAPTER 23.

A NORTHERN AND INDIGENOUS ETHICAL IMPERATIVE FOR WORKING WITH COMMUNITIES

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Indigenous Peoples around the world are mobilizing to (re)assert their inherent right to self-determination, a movement that is being both shaped and reshaped by globally significant developments, such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and the Truth and Reconciliation Commission (TRC) in Canada. Innovations in ethics policies, led by Indigenous peoples, have enhanced guidance and practices in the ethical conduct of research involving Indigenous Peoples. Now, scholars around the world are looking to the Canadian example to learn how they too can begin creating policy in this area. As Northern and Arctic research grows, learning ethical imperatives of these regions and the Indigenous Peoples who live on these lands is essential. Unfortunately, and despite increased documentation about what to do in research involving Indigenous Peoples, there is little description of how to do it – there is a major policy-to-practice gap which this chapter begins to address.

Key Terms: Research Ethics, Human Protection, Governance

Introduction

In *Decolonizing Methodologies,* Maori scholar, Linda Tuhiwai Smith (1999) begins by saying, "the word itself, 'research', is probably one of the dirtiest words in the Indigenous world's vocabulary" (p. 1). To understand this

sentiment in relation to colonialism requires examining shared histories of unequal power relations (between colonizers and the peoples of the lands they invaded) and ongoing colonial constructs and systems, such as how research often privileges researcher interests, needs, and benefits over those of communities. In Canada, a commitment to decolonize research is a commitment to support a process defined and led by Indigenous peoples to identify research priorities and co-create research products that are mutually beneficial. Now, scholars around the world are looking to the Canadian example to learn how they too can begin creating policy in this area.

It is argued that colonial academic culture, which privileges the knowledge acquisition and production of non-Indigenous peoples, results in research (about Indigenous peoples' by non-Indigenous peoples) that is of an exotic (and essentializing) nature (Kovach, 2009). This research often has little or no measured impact on health or social well-being, despite the claims made in funding applications regarding how positive and beneficial the research will be (Brant-Castellano, 2004). As northern and Arctic research grows, learning ethical imperatives of these regions and the Indigenous peoples who live on these lands is essential if the research is to have a positive impact. Unfortunately, and despite increased documentation about *what* to do in research involving Indigenous peoples, there is little description of *how* to do it – there is a major policy-to-practice gap which this chapter begins to address. Specifically, this chapter briefly describes the necessity of and responsibility to ethical research with Northern and Indigenous Peoples by considering self-determination, collective consent, and relational research practices that are essential components for researchers. A short synopsis of the impetus for these research practices lays the foundation for the discussion of Indigenous self-governance in research.

LEARNING FROM THE PAST TO CHANGE THE FUTURE

A pivotal moment in the early 2000s revealed that, nearly two decades after blood samples were taken from members of the Nuu-chah-nulth tribe in British Columbia—who, in the 1980's, consented to DNA research only related to genetic causes of rheumatoid arthritis, the 'residual' samples were being used for research beyond the original intention and was stored in another country. This was never disclosed to the community, and the community did *not* consent to the research or the travelling of their DNA (Atkins, Reuffe, Roddy, Platts, Robinson, & Ward, 1988; Dalton, 2002). Increased dialogue and policy development on Indigenous research ethics emerged alongside this significant and publically reported/known ethical breach.

To safeguard against and learn from situations like those experienced by the Nuu-chah-nulth, many communities formed their own research ethics mechanism1, as part of practicing self-determination in research in their communities (Nuu-Chah-Nulth Tribal Council Research Ethics Committee, 2008). The Nuu-chah-nulth event was significant in that it became a catalyst for reshaping the landscape of Indigenous research ethics. Increasing attention is now focused on Indigenous research ethics and implications of health research on collectives. Today, Indigenous research ethics policies in Canada are explicit about protecting communities and their data, providing self-determination in research, and creating more relevant and rigorous research.

EXERCISING SELF-DETERMINATION IN AND THROUGH RESEARCH

Indigenous peoples' right to self-determination in Canada and elsewhere around the world (Sium & Ritskes, 2013; UNDRIP, 2007) provides the

grounds for Indigenous communities to develop their own research/ethics review processes and procedures. Two of the longest standing Indigenous community-based review systems in Canada can be found in Kahnawake (Code of Ethics, 1996) and Manitoulin Island (Guidelines for Ethical Aboriginal Research, 2001). As well, in 1998, the Steering Committee of the First Nations Regional Longitudinal Health Survey articulated OCAP®: the principles of *Ownership, Control, Access, and Possession* as an expression of self-determination in research. This was explicitly "a political response to tenacious colonial approaches to research and information management" (Schnarch, pp. 80-81). Today, many Indigenous and northern communities assert their self-determination in research as they continue to challenge projects that are based on racist, discriminatory, exploitive, and harmful research practices.

HONOURING SELF-DETERMINATION IN RESEARCH PRACTICE: IT'S ALL ABOUT RELATIONSHIPS

How to support self-determination and establish research governance for health research with Indigenous peoples is a topic long-debated by academics and community members alike; the conclusion is always the same: relationship building is a critical first step (Brant-Castellano, 2004; Kaufert, Commanda, Elias, Grey, Young, & Masazumi, 1999; Kovach, 2009; Martin, 2012; Moore, Castleden, Tirone, & Martin, 2017). Researchers are ethically and culturally obligated to build relationships on a foundation of respect, relevance, reciprocity, and responsibility in an authentic way (Bull, 2010; Kirkness & Barnhart, 1991). This usually begins with a conversation with recognized/recommended/respected 'community authorities'. Community authorities may be Elders, traditional teachers and healers, municipal or tribal leaders, local or regional Indigenous leaders, Chiefs and councils, or someone

else designated to speak for the community. There may be multiple authorities present who are charged with different roles and responsibilities.

Working with Indigenous communities' self-determination (and collective consent) is similar to doing research with schools. School-based researchers are required to get approval from the school board, principal, teacher of the class, parents of children participating, and the children themselves to ensure that the whole community is involved and benefitting. Researchers cannot obtain the students' (or the principal's or the parents') permission *alone* to do the research. While relatively straightforward in certain communities, like schools, this process of ethical community-engaged research does not always align with the realities of authority structures within Indigenous and Northern communities. For example, where there are no active Elders or governing council, or, alternatively, the 'obvious' authorities to approach are precisely those who, because of the power of their role, may block research others deem beneficial.

There is general agreement that in research where an entire community may be negatively implicated even if only few people from the community participate, individual consent is necessary but not sufficient (Burgess & Brunger, 2000; Kaufert et al., 2004; Weijer et al., 1999). Likewise, there is general agreement that individual informed consent is not sufficient for ethical health research involving Indigenous peoples (Brunger & Weijer, 2007; Bull, 2016; Moore, 2015). Given the intimacy of health information, and the small size of some communities, health research in particular can present genuine risks for socially identifiable populations (Weijer et al., 1999). By controlling their own research agenda, Indigenous peoples are able to use their spiritual and philosophical foundations (i.e., ontologies and epistemologies) to guide

the work as a way of mitigating challenges embedded within Western sciences (Smith, 1999).

CONCLUSION

While respect, responsibility, relevance, and reciprocity are all valued characteristics in most social, health, and human research, these qualities are imperative in research with Indigenous and northern peoples as a means to respect and practice self-determination in research. The level and extent to which Indigenous and northern people and communities participate is decided by the community themselves serves to further this self-determination. Researchers do not get to decide when adequate engagement is achieved and must take direction from community partners throughout the duration of a project which is a requirement of the collective consent process. Relationships between researchers and Indigenous peoples facilitate the development of methodologies, conceptual frameworks, and recruitment strategies that are meaningful to communities while maintaining/improving academic rigour, demonstrating the importance of relational approaches to research with Indigenous and northern peoples.

NOTES

1. These may be called a number of names and reflect many different levels of formality from full institutional review processes, to Band Council Resolutions, to Grandmothers Review. The key piece is that the community directs the researcher to what is required *beyond* what the researcher is required to do for the academy.

Additional Resources

Association of Canadian Universities for Northern Studies: Ethical Principles for the Conduct of Research in the North. http://acuns.ca/en/ethical-principles/

Canadian Institute for Health Research: Guidelines for Health Research Involving Aboriginal Peoples: http://www.cihr-irsc.gc.ca/e/29134.html

Toolbox of Principles for Research in Indigenous Contexts: Ethics, Respect, Equity, Reciprocity, Cooperation and Culture. https://centredoc.cssspnql.com/cgi-bin/koha/opac-search.pl?idx=kw&q=toolbox&limit=au%253ACommission%2520de%2520la%2520sant%25C3%25A9%2520et%2520des%2520services%2520sociaux%2520des%2520Premi%25C3%25A8res%2520Nations%2520du%2520Qu%25C3%25A9bec%2520et%2520du%2520Labrador&sort_by=relevance_dsc&limit=itype:LIVR

Tri-Council Policy Statement for Research Involving Humans: Research Involving First Nations, Inuit, Métis. http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/

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