

Improving the Accessibility of Research Ethics Boards for HIV Community-Based Research in Canada

HIV CBR ETHICS

Community consent in Aboriginal communities



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HIV CBR Ethics Fact Sheet Series:

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- 3 Managing multiple roles and boundaries
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We are a group of Canadian HIV researchers interested in community-based research (CBR) and research ethics. We conducted interviews with over 50 academic researchers and community service providers from across Canada involved in HIV CBR. They told us about the ethical issues they encounter in their daily work with communities affected by HIV. They also described how they work with their research ethics boards (REBs) to ensure participants will be protected from research related harms. In this series of 10 evidence-based fact sheets, we identify key ethical considerations when designing HIV CBR projects and seeking ethics review. We encourage HIV CBR teams to use these fact sheets to assist in project planning. They may also be useful for engaging REBs in a dialogue about the range of strategies employed by Canadian researchers for ensuring the protection of diverse individual and community needs.

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In this brief, we discuss four key issues:

- Indigenous knowledge, ethical frameworks, and ethics review
- Community consent
- The role of elected leaders and other designated community representatives
- Integrating culturally appropriate practices

Background

Globally, Indigenous peoples have a complex history with research because it has been used as a tool for colonization and has negatively affected their communities (Smith, 1999). In Canada, Aboriginal¹ peoples' practices have been documented without community knowledge, shared without community input, and used to benefit researchers and academic institutions at the expense of Aboriginal peoples (Dyck & Waldram, 1993). In some cases, knowledge collected from Aboriginal people was taken under false pretenses, without informed consent (or any form of consent at all), failed to produce promised benefits, and was even used to stigmatize Aboriginal communities (Schnarch, 2004). In the past, research ethics boards (REBs) emphasized aspects of consent that were at best out-of-sync with, and at worst in conflict with, elements of Aboriginal cultures, customs, values, worldview, and preference for relational approaches to ethics (Castellano, 2004). Many standard practices enforced by REBs (e.g., emphasis on autonomy and individual consent) conflict with notions of respect and consent in Aboriginal communities (Ellis & Earley, 2008).

In response to this history, the new Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans has dedicated chapter 9 to discussing ethical issues related to research involving the First Nations, Inuit and Métis peoples of Canada (TCPS-2, 2010). The document recognizes the unique status and treaty rights of the Aboriginal peoples of Canada and outlines a framework for respectful and ethical partnerships. The guidelines outline the ethical imperatives of meaningful community engagement, respect for First Nations, Inuit and Métis governing authorities, customs and cultures, and honouring the role of Elders as keepers of knowledge.

While change is a slow process, things are getting better. Across Turtle Island,² Aboriginal-led health research is addressing the over-representation of HIV among Aboriginal people. The Canadian Aboriginal AIDS Network has been at the forefront of this mobilization effort. It provides support, resources, models and leadership for research teams across Canada.

In community-based research (CBR), the historical legacy of research with Aboriginal communities is often recognized and steps are taken to redress past wrongs. This entails engaging in research that puts Aboriginal knowledge and community needs at the forefront. CBR with Aboriginal communities always involves a process of relationship building and consultation before any data collection is conducted. This process is primarily about being present and respectfully engaged. It may involve attending community events, participating in cultural ceremonies, or both. It often starts with humble introductions and sharing where you and your family are from. Usually, this process leads to the drafting of a formal Principles of Research Collaboration contract to act as a guide for the work ahead.³

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Part of enacting a community engagement strategy (as outlined in the TCPS 2) is the process of garnering community consent. Despite recognition of the importance of these procedures, many REBs still lack an understanding and appreciation for some of these practices and the potential challenges of their implementation. In this brief, we identify various approaches to thinking about community consent with Aboriginal peoples and describe the strategies employed by Canadian HIV CBR teams to balance these competing viewpoints.

1 We use the term "Aboriginal" to describe Indigenous Peoples in Canada, including Inuit, Métis and First Nations who are status or non-status, on or off-reserve.

2 Turtle Island is another way of referring to North America that honors an Aboriginal creation story.

3 See for example, CAAN's template http://depts.washington.edu/ccph/pdf_files/Principles_of_Research_Collaboration_Template.doc.pdf.

Issue 1: Indigenous knowledge, ethical frameworks and ethics review

For many Indigenous peoples, traditional knowledge is sacred. It is usually experientially acquired through watching and participating in life and ceremony. Its transmission is sometimes facilitated by Elders who are considered knowledge keepers. They will often pass on gifts of ancestral knowledge when they feel you are ready to receive them. In this way, knowledge can be shared from one generation to the next. In contrast to Western ways of knowing, knowledge is not individually owned. It is often held in trust; those who possess it take on additional stewardship responsibilities. Knowing something does not necessarily give one the right to share it.

Aboriginal communities have specific beliefs about the power of knowledge, ownership of knowledge, and ethical uses of their knowledge (Castellano, 2004). Because of earlier examples of researchers taking knowledge, Aboriginal communities are sensitive to such questions as: Who owns the data? Who has publication rights? How do dissenting views get represented in publications? (Glass & Kaufert, 2007). First Nations people have developed their own research ethics framework based on the principles of ownership, control, access, and possession (OCAP™)⁴:

- a) **Ownership** – recognizes that First Nations own information collectively in the same way that an individual owns their personal information.
- b) **Control** – recognizes the rights of First Nations Peoples to maintain and regain control of all aspects of their lives and institutions extend to research, information and data.
- c) **Access** – recognizes that First Nations Peoples must have access to information and data about themselves and their communities.
- d) **Possession** – recognizes that First Nations Peoples have a right to possess data about them, or determine how it is stored, as a means to assert ownership and preclude misuse.

OCAP™ is becoming increasingly expected as a guiding framework by First Nations communities and is gaining recognition by REBs. However, researchers may need to explain the concepts and how basic research ethics protections will be ensured. For example, REBs will want to know how possession will be handled (i.e., who will actually manage the data?). REBs may not be aware that many Aboriginal organizations have the capacity and resources to manage and protect data. In cases where the infrastructure is not currently in place, they may partner with another Aboriginal organization to steward the data for them. In this way the principle of possession and REB requirements can both be met. Many of the researchers we heard from used the OCAP principles and worked

“The ethics review board said, ‘You can’t share your data with the community. It belongs to you; you have to keep it separate.’ So I met with, like, the director of the ethics and explained to them the sort of Aboriginal 101 and the notion of the community ownership.”

with their community partners to operationalize them in a way that met the community’s, researcher’s, and REB’s needs. Many participants reported that some REBs have become more aware of OCAP because of ongoing efforts by Aboriginal communities and researchers to educate them.

In addition to the OCAP principles governing First Nations Research, there are also a number of frameworks for researchers working with Metis and Inuit communities, including the *Principles of Ethical Métis Research*,⁵ *Ethical Principles for Conduct of Research in the North*⁶ and *Negotiating Research Relationships with Inuit Communities, a Guide for Researchers*.⁷

4 The OCAP principles are trademarked by the First Nations Information Governance Centre <http://www.rhs-ers.ca/node/2>

5 http://www.naho.ca/documents/metiscentre/english/PrinciplesofEthicalMetisResearch-descriptive_001.pdf

6 <http://acuns.ca/website/ethical-principles/>

7 <https://www.itk.ca/publication/negotiating-research-relationships-inuit-communities-guide-researchers>

Issue 2: Community consent

When researching with Aboriginal communities, consent may need to be sought first from Aboriginal community leaders and then from all individual participants (McGrath & Phillips, 2008). Whereas Western conceptions of informed consent are based on individual self-determination and autonomy, many Indigenous perspectives include the family and community in decision-making (Flicker & Worthington, 2011; Glass & Kaufert, 2007; McGrath & Phillips, 2008). Obtaining community consent prior to individual consent may be a requirement of funders, and an ethical and legal requirement in some jurisdictions (e.g., in the Canadian Territories) (Castellano, 2004). Community consent may require undergoing an ethics review or obtaining a licence from an Aboriginal community in addition to the REB of the researcher's home institution

(Flicker & Worthington, 2011; Glass & Kaufert, 2007). If community consent is not obtained, researchers may need to stop or modify their research should the community decide not to proceed (Castellano, 2004; Davison, Brown, & Moffitt, 2008; Schnarch, 2004). Many of the researchers we heard from described the processes they took to develop relationships with communities to ensure from the beginning that the research was reflective of community needs and interests.

Some of the researchers we heard from participate in research with Aboriginal communities only when they are invited, in order to ensure that they do not impose an unwelcome project or research agenda on the community.

“It’s so extensive because it’s not just the workshop itself, it’s the interviews, it’s the community readiness and community consent to do this and their involvement in so many other little projects that have taken off in partnership or as a result of this happening. So it was also putting all of that stuff together. So it’s funny because throughout the last three years I have to keep reminding myself that this is a research project. Because it has so many other impacts than what I think other mainstream research looks like.”

Issue 3: Elected leaders and other designated community representatives

When researching with Aboriginal communities, exactly who can provide consent or speak on behalf of the community is not always clear. Researchers need to take the time to ascertain who the appropriate consent-givers are and to ensure they are effectively informed about the research (McGrath & Phillips, 2008). Where there is a designated band council or elected leadership (e.g., on a reserve or settlement), researchers are expected to approach them and negotiate community consent as part of a formal process. However, they may suggest that someone else in the community review the research and provide consent. Some communities have established their own ethics review committees or licencing boards, or both. In other cases, consent may be given by grandparents or Elders who ultimately decide consent with other family input (McGrath & Phillips, 2008). As with any group, there may be different or competing interests and the consultation process should be as open as possible to ensure that tensions are not

heightened and conflict not created (Davison et al., 2008; Flicker & Worthington, 2011; Glass & Kaufert, 2007). For example, Reid and Brief (2009) found themselves in a conflict between Elders in the community and the Band Council. Elected officials are often very busy and have many responsibilities; research may not be on top of their list. This may mean researchers will have to wait. Finding appropriate representatives can be challenging in an urban context where there is no designated community decision-making process and the Aboriginal population may comprise diverse groups (Glass & Kaufert, 2007). In these cases, researchers may want to consult with Aboriginal service organizations to ensure the research meets their needs. Some of the researchers we heard from explained that they target some of their research on reserve and some off-reserve to avoid creating possible tensions within reserve communities about very sensitive research.

“[The institution] has on their ethics form... a whole section, are you working with Aboriginal people? ...If so, have you received band approval? If not, we need to see a copy of the letter that you're sending and basically ethical approval isn't given until the community has signed on and it has to be band council or someone designated with the authority to speak for the community. It can't just be like a community member.”

Issue 4: Culturally appropriate practices

Many researchers working with Aboriginal communities have adopted culturally appropriate and decolonizing research practices to inform methods, data analysis, and the dissemination of findings (Flicker & Worthington, 2011). When weighing the “benefits” and “risks” of any approach, research teams need to take cultural considerations into account: 1) What are the practices of this community? 2) Is it appropriate to include these practices in the research process? and 3) Who should be involved? REBs may not be aware of Indigenous practices and customs. Researchers will need to explain why they are being used and in what ways (Glass & Kaufert, 2007; McGrath & Phillips, 2008). Below we discuss some cultural practices that were used by the researchers we heard from:

“Someone explained to me that research could provide cultural retention, so that as an Aboriginal youth, that it was up to me to make sure that Indigenous knowledge was being sustained because it was always at the point of being erased...[What] we have noticed is that this community-based research done by the community is a really great way to hang on and find this information that is... at the risk of being gone.”

- a) **Offering tobacco or other medicines (or culturally relevant gifts):** Some First Nations and Métis communities exchange tobacco in traditional ceremonies as part of prayers, giving thanks, communicating with the spirits; and self-purification. Researchers may be expected to exchange tobacco, sage, or other ceremonial gifts to show respect for and an understanding of local Aboriginal culture and customs (Ellis & Earley, 2008).
- b) **Oral consent:** The use of written consent may be considered inappropriate and even insulting by some Aboriginal persons and communities. As well, most Aboriginal cultures are based on oral traditions, and English may be a second or third language. Researchers should avoid overly formal, legal-sounding language to ensure accessibility and comfort (Davison et al., 2008).

c) **Identifying individuals and communities:** Enforcing confidentiality may be considered disrespectful because it erases the source of the knowledge and privileges the researcher(s) (Davison et al., 2008). Some communities insist on being identified and are proud research participants.

d) **Involving Elders:** Elders are considered important sources of traditional knowledge in Aboriginal communities. A number of the projects we heard from involved Elders in several ways:

- a. Consulting on the project and providing feedback on design and questions
- b. Opening and closing data collection or analysis sessions with prayers and ceremonies
- c. Providing support to participants and researchers throughout the life of a project, including when participants become upset or when conflict arises, and possibly as a resource to follow up with.

Some REBs may be unfamiliar with the role of Elders and how they fit into a project—are they participants or project staff? Researchers should explain how the Elder(s) will be involved and what their role on the project will be.

The researchers we heard from stressed the importance of conducting research that builds community capacity and cultural retention, and addresses community priorities. Researchers should discuss these issues within their teams and how best to achieve these goals (Glass & Kaufert, 2007). Finally, it is important to remember that there is not a single “Aboriginal community” and to consider diversity within and across geographic communities, participants, and even research teams. Not all participants who are Aboriginal will want their culture mixed with research, and no single approach will always be appropriate or relevant.

Questions for consideration:

The following questions may be useful for HIV CBR teams to reflect on when working with Aboriginal communities to conduct research. Thinking about these issues in advance may help facilitate the research process and maintain positive relations with individual participants and the community.

- 1) Humility check point: Are you the right person to be doing this work? How can you demonstrate trustworthiness? How can you continue to build better relationships? Is your team ready to proceed?
- 2) How might being a researcher affect your existing and future relationships in the community? How do you feel about those changes?
- 3) What do you need to know about the local community history, culture and customs in order to respectfully proceed?
- 4) Is there a community engagement plan in place? How have Elders or organizations been involved? Is the investment of community energy and time commensurate with needs and wants?
- 5) How will your team incorporate Indigenous worldviews into the way they work together? How will you make decisions? How will you represent and share your work? How will you ensure the process is "culturally safe" (NAHO, 2006)?
- 6) What ethical guidelines, frameworks, or processes should you learn about?

Further recommended reading:

Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – Chapter 9 Research Involving the First Nations, Inuit and Métis Peoples of Canada: <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/>

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 http://www.naho.ca/documents/fnc/english/FNC_OCAPCriticalAnalysis.pdf

Principles of Ethical Métis Research: http://www.naho.ca/documents/metiscentre/english/PrinciplesofEthicalMetisResearch-descriptive_001.pdf

Guidelines for Research Involving Inuit: http://www.naho.ca/documents/it/2010_Ethics_FactSheet9.pdf

Australian Institute of Aboriginal and Torres Strait Islander Studies' guidelines for ethical research in Indigenous Studies: <http://www.aiatsis.gov.au/research/ethics/gerais.html>

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