

Making it work:

Operationalizing Principles of Ethical Research in Aboriginal Communities in the Context of Existing Institutional Structures

Background

In 2008, it is estimated that Aboriginal peoples accounted for approximately 8% of persons living with HIV and 12.5% of all new HIV infections in Canada, despite comprising only 3.8% of the total population. To arrive at responsive HIV programs and policies, it is critical that Aboriginal Peoples with HIV and AIDS (APHAs) are engaged as both research participants and team members within research processes. In Canada, policy is being developed by both funders and NGOs that specifically outlines ethical standards for research involving Aboriginal Peoples. The Canadian Aboriginal AIDS Network, our allied academic partners, and community-based membership strive to achieve the highest ethical standards in our research endeavors.

Ethical Research Principles in Practice

The principles of Ownership, Control, Access, and Possession for research in Aboriginal communities were developed as a guideline for establishing self-determination in research processes. Guided by these principles, an initial step undertaken by our Aboriginal community-based research team was ratification of a Principles of Research Collaboration agreement. Examples of our key considerations for conducting ethical research include:

- Reciprocal capacity building for all team members including cultural exchange, training, mentorship, support and evaluation.
- Open discussion about considerations for dissemination of the findings within Aboriginal communities and how authorship in academic publications might best reflect team contributions and support the careers of (especially junior) academic team members.
- Negotiating unconventional funding arrangements so that research team members not employed as researchers or policy-makers may be paid for their work.
- Organize free access to communication technology (use of phone cards, skype, conference calls, online classrooms).
- Anticipate funding to support APHA participation (a budget line designed to eliminate barriers to participation, such as personal care, travelling companions, childcare).
- Make the effort to welcome all team members to the research process and remain aware of the power differences that traditionally exist in Western science and try to not perpetuate them.
- Mindfully schedule meetings to: recognize the needs of those who travel; balance family commitments; and avoid information overload.
- Include opportunities to share meals together and also plan non-work activities to build relationships and get to know each other beyond our roles on the research team.



Our Research

Our team is working on a project entitled "Alcohol Use by Aboriginal Persons Living with HIV/AIDS and its Association with Access to Care and Treatment".

The **purpose** of this project is to explore the association between alcohol use and access to services from the perspectives of APHAs and service providers using a mixed methodology approach.

Although this project is specific to HIV/AIDS, given the disproportionate representation of Aboriginal people with health concerns, considerations regarding access to services could be broadly applied to Aboriginal health research in Canada.

Summary

APHA and community collaboration on Aboriginal HIV/AIDS research projects is critical to developing relevant, nuanced, and principled research, founded on the principles of OCAP. While the philosophy of this process may be easily embraced at a cursory level by academics and community members alike, the practicalities can be difficult to rectify within existing institutional structures.

Despite the layers of complexity involved in achieving parity among all team members; the effort must, and is, being made. We are committed to developing a dynamic process to operationalize the principles and philosophies of ethical HIV/AIDS research by, for and in balance with Aboriginal communities.

RESEARCH TEAM



Contact

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