



“A Fact Sheet on Aboriginal Health Research Governance”

Written by Darlene Sanderson (PhD Candidate) for the Aboriginal Women's Health and Healing Research Group*

Background and Purpose:

This fact sheet will focus on a section of a larger comprehensive review of the literature on Aboriginal health research governance. In addition, it will:

- Examine Aboriginal research ethics review processes, research agreements and models for ensuring that research is directed by and accountable to Aboriginal communities.
- Provide the basis for the analysis of the standards and guidelines for ethical and appropriate research, as well as the mechanisms for ensuring Aboriginal communities have control of the research.

Governance may be defined as self-determination, or decision-making for social, spiritual, political, and economic order; thus, Aboriginal health research governance would mean that Aboriginal people define the meaning of health within their social/cultural/spiritual contexts.

Implicit in this is the ability to define the key determinants of health and well-being; issues of ethics, protocols, ownership, control, possession and dissemination must all be examined.

A literature review was conducted that included a library search on the following key words: *aboriginal, governance, health research, Indigenous health research governance, aboriginal health research governance, native health research governance*. University libraries, the internet and other sources were approached for recent journals and proceedings.

Indigenous scholars have articulated traditional epistemologies. Ermine et al (2004) calls for an ethical space to be recognized in all interactions between Indigenous and non-Indigenous worlds, including health research governance.

Lavoie (2004) noted there are several gaps in Canada's health service delivery system due to jurisdictional issues and the fact that the federal government sets the specific services to be transferred. There is a significant difference between the services transferred to Aboriginal people and full control. This may be translated to health research governance, in that full control ought to address the needs and gaps identified by the communities.

The research process needs to have the Indigenous peoples involved at all levels of development. It would be useful here to analyze the process of decision-making in a research program, and will illuminate why ethics, as Ermine so clearly states, is a critical component to all research projects.

Health Research Governance- and Emergent Themes:

- **Government funding bodies that address Aboriginal health research look at the structure of their organization. There needs to be a critical examination of the structures of decision-making and Indigenous peoples' participation of policy development and its implementation.**



To achieve equity, there should be an equitable percentage of funding to Aboriginal health research initiatives that are governed by boards that have Aboriginal peoples, especially women, at the table that makes health research decisions.

- **Ethical space, funding allocation and equity all need to be considerations in Aboriginal health research governance.**

Equity is a looming issue, in health research and health delivery, and access to health care. There is a need for culturally appropriate health services and access. The Canadian Public Health Association's mission statement calls for disease prevention, health promotion and protection and a healthy public policy. Funding should be equitable to all Aboriginal people, no matter how isolated the communities are, and there should be long-term strategies. If Aboriginal women are in position to make effective decisions, control of Aboriginal health research will lead to culturally relevant Aboriginal health policies that will address the needs of the communities.

In order to improve the health status of Indigenous people, Indigenous health policy-makers and health policies that are designed, developed and offered by Indigenous people are needed. Cultural safety or sensitivity programs need adequate funding so that western education systems and social structures have an understanding and respect for Indigenous worldviews.

- **There is a need for a shift in power structures to have better representation of Aboriginal women and marginalized groups on boards and decision-making bodies, including those that govern health research.**

It also highlights the importance of language, culture, cultural diversity and protocols, as it relates to Aboriginal health research governance. Funding and control are inter-related, as the funding decisions, the criteria set for meeting the funding reviews should be governed by Aboriginal women in their own health research. The sharing of experience through Aboriginal women researchers in the context of conferences and appropriate training is also a need identified.

- **Resources for research programs need to be adequate to meet the community needs. Limited funding for many needs create competitiveness between communities, and many times, the funding is short term. There is a need to ensure adequate and appropriate follow-up to the research.**

Government programs and funders all have criteria to be met for programs to be carried out. Most government funding has a committee that holds the decision-making power about programs to be funded and Indigenous women must be represented on these committees.

- **Aboriginal health research needs to be respectful of protocols and relevant to community needs.**

Many communities are now establishing their own code of ethics for all research that may be conducted in their community. There is an urgent need to build community capacity to do community based research that will address the needs articulated by community members, such as honoring the health and building on strengths and



resiliency, instead of conducting research that highlights the “dis-ease” within communities, which often do not heed the significance of the spiritual aspect of life.

- **The process of decision-making should be community-based, and guided by Elders who are knowledgeable in health.**
- **Follow-up should be well resourced.**
- **Access to good health care is a basic human right and is one of the tenets of the Canada Health Act.**

Canada must adhere to the fiduciary responsibility for Indigenous peoples’ right to enjoy good health. Every child has a right to her or his own spiritual, cultural and language and religious traditions. Every person has a right to practice her or his religion or faith. Spirituality is fundamental to good health. Adequate resources are needed for language and cultural restoration.

- **Language and cultural practices are the foundation of traditional laws, health and identity; therefore, health policies should reflect this.**
- **Jurisdiction, responsibilities, and accountability all need clarity when research is conducted.**

Indigenous principles of governance are transmitted through language and in traditional cultural practices. It is through the recognition of our spiritual connection with the land and waterways that defines our identities that are fundamental to good health. Therefore, the principles of governance are defined by place and culture, and need to come from the communities themselves.

- **Indigenous peoples’ health is interconnected with education, law and environmental policies.**

There should be coordination between health, education and environment ministries to support Aboriginal health research governance.

- **Health concepts may be defined by the local people. The need for education about the traditional connections to the land and a recovery of the language is essential for good health.**

Ideally, health determinants are culturally defined. There are traditional concepts of health, education, laws and relationship with the environment and correlation with health.

- **Elders are our living treasures.**

There are a few who carry the real traditional knowledge of health and well-being. Listening to those keepers of knowledge can provide the guidance from the past for future generations, and for guides in formalized aboriginal health policy development.

- **The jurisdiction and responsibilities of communities, universities and governments needs clarification.**



There is too much fragmentation in policy-making and health care delivery, and it is suggested that there be a consolidation in the creation of health policy. Health policies need to reflect the culture and aspirations of the people involved. As a result, health policies ought to be reflective of the results of community-based health research. There is a need to foster partnerships and collaboration between Aboriginal and non-Aboriginal organizations.

- **Universities have a responsibility to set aside equitable funding for Indigenous research; to educate themselves about the Indigenous Peoples' protocols for the protection of Indigenous knowledge; to provide the resources for Indigenous ethics review boards.**
- **There is a trend for both the federal government and the provincial government to divest themselves of providing basic health services to First Nations.**

There needs to be a clarification of roles and responsibilities of communities, and both levels of governments. Also, with the interactions of academics in research, this is a position of power and control, in terms of voice, decision-making and policy development. Researchers must take care that they are not perceived to be another level of colonialism.

- **The value of traditional medicines needs to be reflected in health policies and the urgent need to protect them. There is today, little reflection of Indigenous peoples' spiritual relationship with the land reflected in health policy, or recognition of spirituality as a fundamental part of healthy living.**

Fundamental tenets of Aboriginal health research governance

These suggested tenets span research ethics, self-determination/self governance discourse, and discourse on Aboriginal women's health.

1. Language and cultural education is fundamental to achieving good health, as women, families, and communities. Health research processes and methodologies could include the reclaiming of language and cultural practices.
2. Health research should recognize local Indigenous protocols and the Elders who have the traditional knowledge and community recognition as carriers of that knowledge. Indigenous protocols need to be recognized and respected by all educational institutions, and all levels of government.
3. Health research needs to benefit Indigenous peoples directly, and these benefits may be ensured by the participation of Indigenous peoples, especially women, as decision-makers in their own health research governance.
4. The findings of the health research need to be accessible to community members. Culturally-appropriate follow-up to the research should be well resourced.
5. Communities should be supported in developing their own health research protocols, and universities and other tertiary educational institutions should examine the international declarations that protect Indigenous peoples' health, education and



knowledge (Coolangata Declaration, Mata Atua Declaration of intellectual Property Rights).

6. Funding agencies should demonstrate equity in accessing adequate resources for Indigenous peoples' health initiatives by establishing oversight/steering committees that are at least 50% Indigenous, and with adequate representation from Aboriginal women, so that marginalization is no longer an issue.

Indigenous values and principles to consider in the development of Aboriginal Health Research Governance:

- Respect, relevance, reciprocity in the research process (B.C. Aboriginal Community Capacity and Developmental Research Environments, 2004 <http://www.health-disciplines.ubc.ca/iah/acadre/>).
- Protecting Indigenous Knowledge.
Although funding agencies often request the research data, it is an inherent right to protect traditional knowledge.
- Sharing, caring, strength and honesty.



References Cited

Ermine, W., Sinclair, S., Jeffrey, B., (2004). "The Ethics of Research Involving Indigenous Peoples" Report of the Indigenous Peoples' Health Research centre to the Interagency Panel on Research Ethics. Indigenous Peoples' Health Research Centre, July 2004 Saskatoon, Saskatchewan

Lavoie, J. (2005) 'Governed by Contracts: The Development of Indigenous Primary Health Services in Canada, Australia, and New Zealand'. National Aboriginal Health Organization Journal of Aboriginal Health 1(1):6-24. Ottawa, Ontario.

*Edited by members of the Aboriginal Women's Health and Healing Research Group Planning Committee Members and Executive Director.

Note: The views expressed in this document are not necessarily reflective of all members of the Aboriginal Women's Health and Healing Research Group Planning Committee.