

An Overview of Models for Community Based Aboriginal HIV/AIDS Research



Healing Our Spirit Research Logo – by Gordon Dick

**Prepared for Healing Our Spirit BC Aboriginal HIV/AIDS Society
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August, 2002**

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Introduction

This paper was written to provide a general overview of models for Aboriginal HIV/AIDS community based research. This is a new and expanding area that is gaining more visibility in Aboriginal communities and among Aboriginal people working the area of health and research. This introduction to models currently being utilized is intended for anyone with an interest in this emerging area – students, health researchers, Aboriginal health professionals and workers, Aboriginal communities and organizations.

The paper provides an overview of the current situation in Canada, vis a vis Aboriginal health research; a vision of a model for community based research that can be implemented as Aboriginal institutional development continues; and point form discussion of models that are currently being used to conduct Aboriginal HIV/AIDS research. Simply speaking, this overview of research models looks at, where we are now, where we are going, and how we plan on getting there.

We encourage you to utilize and credit appropriately the models that are included. Website links are also provided to facilitate access to samples and existing models of community controlled research. There are many in depth and more comprehensive community based research and methodology resources, most can be found through Aboriginal AIDS service organizations and academic institutions. Contact information is provided for further information and resources.

Community Based HIV/AIDS Research

Community based HIV/AIDS research in Canada is in continuous evolution, and has posed challenges to traditional structures and methods for conducting health research, particularly with marginalized populations affected by HIV/AIDS. The movement for community based research has provided both new models for AIDS service organizations to assess their effectiveness with clients, and ways to identify and share information about new trends emerging in an quickly changing field of health. Community based HIV/AIDS researchers have posed challenges to academic institutions, and funders about the way that HIV/AIDS research is conducted, and how research priorities are set for HIV/AIDS research in Canada.

At the same time that community based research has gained strength within more mainstream AIDS organizations, Aboriginal AIDS organizations have also achieved

significant gains in community based research. Aboriginal AIDS regional and national service organizations have linked with national Aboriginal health research and funding institutions to build Aboriginal community research capacity, and take greater control over research that affects Aboriginal peoples.

OCAP – Ownership, Control, Access and Possession

There are not many discussions today about research in Aboriginal communities that do not involve the OCAP principles. OCAP is an acronym that has grown in popularity in Aboriginal communities, and particularly among First Nations communities, where the term originated.

OCAP stands for ownership, access and control, and possession. The concept behind the acronym denotes the movement of some individuals and communities to seek control over research in, and with Aboriginal communities and individuals.

At this point there are many that advocate for full implementation of these principles, which could involve more control located in Aboriginal academic and funding institutions, and creation of separate structures that would perform Aboriginal ethical and peer review. Of course, there is still much work to be accomplished in this area, in particular, development and coordination yet to take place at the national and regional levels. In the meantime, communities can take control of research that takes place in their communities, and with their community members.

A discussion follows of governance issues, how they relate to the development and coordination of OCAP principles, and how they can be incorporated into the further development Aboriginal HIV/AIDS community based research.

Health Governance Structures and Aboriginal Community Based Research

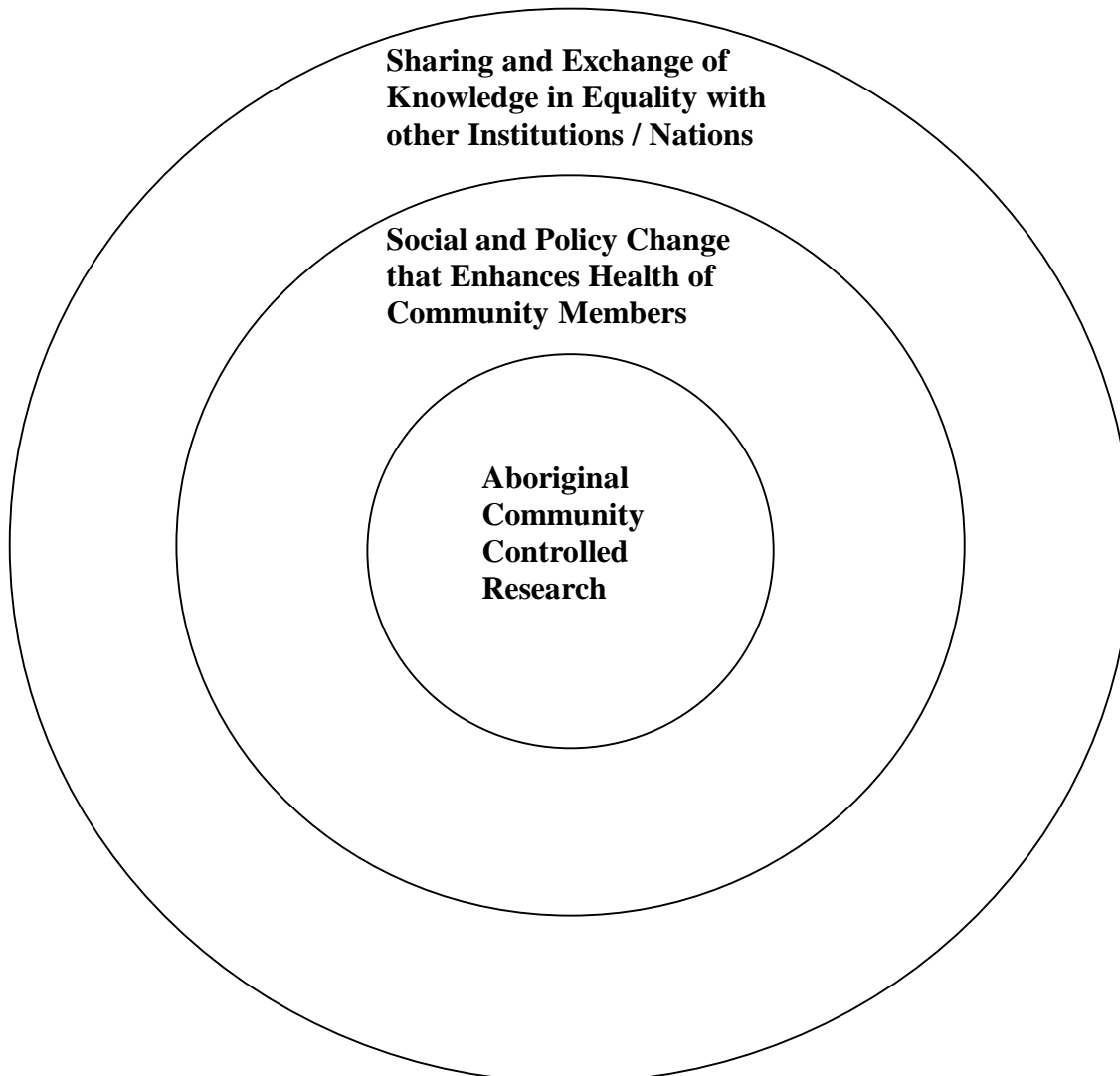
The creation of NAHO – the National Aboriginal Health Organization marked a new era of partnership among political organizations to collaborate in health research, resource development and service coordination at the national level. While research is a part of their mandate, there is currently no overall coordination of the research in Aboriginal communities at the national level.

The Aboriginal Health Institute, of the Canadian Institutes of Health Research (CIHR) has a mandate to fund health research with Aboriginal communities. Community based researchers can apply for funding, but must have a minimum of a PhD to apply. This requirement is a barrier to many communities conducting their own health research. This model, while it does shift some power to communities, some may argue, it must go farther in empowering communities to conduct their own research, without re-enforcing the existing barriers posed to community based research by academic institutions.

While these recent national initiatives in Aboriginal health have opened new avenues of development and collaboration between traditionally politically dichotomous groups; there still remains a gap in the coordination of research that takes place in Aboriginal communities. Institutional development at the national level has not yet meaningfully addressed some of the very basic issues of control of traditional knowledge, control of researcher's access to Aboriginal research participants, and communities, and intellectual property issues in research. Such an ambitious effort, which would involve the considerable consultation and collaboration between the Aboriginal peoples in Canada – the many First Nations, Metis, and Inuit peoples.

Aboriginal community based governance structures may can develop mechanisms for controlling among their community members. There are website links provided in this document to assist communities in developing their own model/s.

A Vision Model of Aboriginal Community Based Research



- This model was developed to provide a visual example of the direction that Aboriginal HIV/AIDS community based research is moving in, by enhancing Aboriginal community control and involvement in HIV/AIDS research. Substantial changes are required in institutional change and development to realize this goal, and current power imbalances must also be rectified.
- This example is meant to be inclusive at every level of - research partners, academic institutions, funders, mainstream and Aboriginal HIV/AIDS service organizations, other Indigenous peoples, Aboriginal research institutions, and partners in Aboriginal community health and wellness.

Aboriginal Community Based HIV/AIDS Research Models

At the local level community organizations have been innovative in creating health research projects that will work in their specific community. These approaches are often developed to address barriers to community controlled research, and involve various levels of concession of community control. As Aboriginal HIV/AIDS community based research continues to change and evolve, research models will evolve and reflect Aboriginal advances in self governance.

Some community based and participatory researchers advocate less for rigid models and methods and more for adherence to guiding principles and values of research that benefits communities. Ideally, cultural values and guiding principles inform the development of the models for Aboriginal community based research. The Canadian Aboriginal AIDS Network (CAAN) has been at the forefront of developing Aboriginal HIV/AIDS community based research guiding principles. The CAAN Research Capacity Building Program Guiding Principles include:

- Inclusion of Aboriginal people living with and affected by HIV/AIDS (APHAs)
- Aboriginal participation is demonstrated at all stages of the research process
- Diversity of Aboriginal communities, and ‘communities within communities’ will be honoured
- Balance between traditional Aboriginal methods, and scientific, or methodologically sound research methods
- Inclusion of OCAP principles
- Provide guidance to the academic community about Aboriginal peoples needs in regards to community based HIV/AIDS research

While these principles are specific to the CAAN Aboriginal HIV/AIDS Capacity Building Program, they are broad and can be specified to fit with specific community based HIV/AIDS research initiatives.

The following list of five community based HIV/AIDS research models includes a brief discussion of the benefits and challenges for each approach. This list is not meant to be an exhaustive list, but one that illustrates the broad approaches Aboriginal peoples have utilized to conduct much needed health research in their communities.

Academic and Aboriginal HIV/AIDS community partnership model

- This model really falls within three categories – academic initiated, community initiated, and joint project initiation. There are differences between the three approaches, as the location and control of the research influences how the research is conducted, and how the results are disseminated.
- This model is currently utilized frequently because community agencies at this point in time access funding that requires a university housed researcher, and because Aboriginal organizations often do not have the resources and/or capacity to conduct the research on their own.
- Logistical barriers related to ethical review, which is required by some funders, can also be resolved in this model.

Community Aboriginal HIV/AIDS agency and Aboriginal community partnership model

- This model has been utilized in the development of partnership projects, and in education initiatives across the country. There is currently not an existing model that has been developed specifically for a research partnership initiative. In BC, this partnership model is being developed by the creation of research agreements and memorandums of understanding between Aboriginal communities, academic institutions, and Aboriginal AIDS service organizations.
- Scarcity of resources allocated to development of partnerships impact the success of this model. Currently, jurisdictional funding issues may pose barriers to the development of partnerships between on and off-reserve organizations. Issues with non-status, Inuit and Metis participation also pose challenges to how this model is developed, particularly in urban or off-reserve locations.
- Research initiated in Aboriginal communities that does not include partnerships with community based Aboriginal HIV/AIDS agencies can negatively impact the health and opportunities of Aboriginal people that access services primarily through Aboriginal AIDS service organizations. Unfortunately, those who may be particularly impacted by a lack of cooperative partnerships, may be the people the research is intended to help - Aboriginal people living with and affected by HIV/AIDS. This aspect of this particular model requires further development, and the sharing of best practices developed in this area.

Student researcher model

- This model can be utilized with undergraduate, graduate and post-graduate students as is required with the level and complexity required for the research.
- The Canadian Aboriginal AIDS Network (CAAN) Summer Student Award Program provides a model for achieving balance of benefit to the host Aboriginal HIV/AIDS agency, to the academic institution that works with the individual student, and to the Aboriginal community in the research takes place.
- At the graduate and post graduate level, academic institutions require copyright for research conducted by their students. Aboriginal organizations and communities should be aware of institutional restrictions that students must comply with, and be involved in decision making for the publishing and results dissemination process.
- The strong benefit to this model is the result that trained community based researchers with experience in Aboriginal HIV/AIDS students are created through this approach. Support for Aboriginal students and Aboriginal AIDS service organizations is another benefit to this approach.

Community Aboriginal HIV/AIDS agency based research

- While AIDS organizations are often the applicants for Aboriginal community based HIV/AIDS research funding, other Aboriginal organizations with HIV/AIDS as a part of their mandate are often eligible to apply for certain funding.
- Often funding for small community based research initiatives is made available at the regional level. Nationally funded initiatives often require complex scientific methodological proposals, and university based research team leaders. Health Canada's Aboriginal community based HIV/AIDS Research Program is an exception to this – principal investigators/applicants can be a community based organization manager, or community based researcher.
- Often community based HIV/AIDS research that is agency based will examine aspects of program delivery, populations accessing the service, and effectiveness of HIV/AIDS programs for specific populations infected/affected by HIV/AIDS.
- A challenge for community and agency based researchers, is that their research may not be valued to the same degree as other more 'rigorous' or 'scientific' research.

National Models

- The First Nations Health Survey was conducted with significant control of the process by First Nations communities and governance structures. The research was First Nations, and on-reserve specific, and therefore information generated through the research does not represent the needs of non-status, Metis, Inuit, or off-reserve First Nations populations. Its community based model of training and data gathering is useful in adapting for use in rural and other small communities. However, the model relies upon the existence of health service delivery structures, and therefore may not be directly transferable to all urban or off reserve Aboriginal, or Metis communities at this time.
- The launch of the Aboriginal Institute, of the Canadian Institutes of Health Research (CIHR), presents an opportunity and challenge to create health research initiatives that meet a broad range of needs, diversity, communities; and integrate Aboriginal traditions, beliefs, culture and methodology with Western scientific models. At the present time, the funding structure supports control of community based health research by academic institutions.
- CAAN has been involved with a number of national HIV/AIDS research initiatives, and have initiated Aboriginal research initiatives. Their work and research in the area of harm reduction led to the development of an Aboriginal Harm Reduction Model, that is currently in its second phase of development.
- The National Aboriginal Working Group for Research and Surveillance, was formed to provide an advisory function to the Laboratory Centre for Disease Control, in their tracking of the HIV/AIDS epidemic among Aboriginal peoples. National advisory working groups and committees are common mechanisms for government bodies to seek input from Aboriginal communities, in their research with Aboriginal peoples.

Aboriginal Control of Research in the Community - Examples

There are specific examples of communities that have asserted control over research that takes place with their community members. In addition to communities that have taken control of research in their community, there are Indigenous organizations that provide samples of agreements, statements, protocols and tribal research codes that individual communities can modify to meet their needs. While these models and tools do ensure that the power imbalance shifts, Aboriginal communities still require the development of complementary regional or national structures that will reflect the needs, and aspirations, of Aboriginal peoples. And, more importantly, the development of Aboriginal research institution/s will help to ensure the accountability of researchers to communities, and that benefits flow to the communities that have approved the research to take place.

Please note, that samples of agreements, protocols and position statements are not included in the text of this report. Please see the websites listed at the end of the document to download a copy of the samples.

Please note also that these samples have been developed by specific Indigenous nations, organizations and groups. Use of references to samples in this report is to facilitate access to existing models developed by Indigenous peoples. Please directly credit the appropriate Nation, or organization if you wish to use them in your community.

Websites – Samples of Indigenous Research Protocols, Agreements

Aboriginal Community Based Research Capacity Building Program, Canadian Aboriginal AIDS Network

http://www.caan.ca/CBR_Background.htm

Akwesasne Task Force on the Environment Protocol for Review of Environmental and Scientific Research Proposals

<http://www.slic.com/atfe/Prot.htm>

Compilation of Statements with Reference to Indigenous Knowledge by the Arctic Council Indigenous Peoples Secretariat

<http://www.arcticpeoples.org/knowledge/statements-agreements.htm>

Guidelines for Respecting Cultural Knowledge – Alaska Native Knowledge Network

<http://www.ankn.uaf.edu/standards/culturaldoc.html>

Hopi Cultural Policy Office Protocol for Research, Publications and Recordings: Motion, visual, sound, multi media and other mechanical devices

<http://www.nau.edu/hcpo/hcpo/index.html> and follow link from Site Index

Inuit Guidelines Research Guidelines – Research Principles for community controlled research with the Inuit Tapirisat of Canada

AND

Dene Cultural Institute guidelines

<http://www.idrc.ca/books/847/7-App1.html>

Indigenous Research Protection Act – Sample Created by the Indigenous Peoples Council on Biocolonialism

<http://www.ipcb.org/pub/irpa.doc>

International Indigenous Resolutions on Traditional Knowledge, Intellectual Property and Against Gene Patenting, Compiled by the Indigenous People's Council on Biocolonialism

<http://www.ipcb.org/resolutions/index.htm>

Portland Area Indian Health Service Institutional Board Guidelines for Researchers
AND
Model Research Protocol Submission Letter

http://www.npaihb.org/epi/irb/guidelines_fr.doc

http://www.npaihb.org/epi/irb/Samples_fr.doc

Portland Area Indian Health Service Institutional Review Board – Index of All Sample Research Documents

<http://www.npaihb.org/epi/irb.html>

Protocols & Principles for Conducting Research in an Indigenous Context, Indigenous Governance Program, Faculty of Human and Social Development, University of Victoria

<http://www.uvic.ca/igov/research> and follow link to download PDF file

The Australian Institute for Aboriginal and Torres Strait Islander Studies – Guidelines for Ethical Research in Indigenous Studies

<http://www.aiatsis.gov.au/corp/docs/EthicsGuideA4.pdf>

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Organizations to Contact for Further Resources

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Vancouver, BC

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Toll Free: 1-800-336-9726

Tel: 604-879-8884

Fax: 604-879-9926

Website <http://www.healingourspirit.org>

Chee Mamuk Aboriginal Program

STD/AIDS Control, BC Centre for Disease Control

655 West 12th Avenue

Vancouver, BC

V5Z 4R4

Tel: 604-660-2088/ 660-2087

Fax: 604-775-0808

Website <http://www.bccdc.org/stdaids/stdeducation/BCAAAP/BCAAAPindex.shtml>

The Red Road HIV/AIDS Network Society

Suite 804-100 Park Royal South

West Vancouver, BC

V7T 1A2

Tel: 604-913-3332

Fax: 604-913-3352

Website <http://www.red-road.org>

Canadian Aboriginal AIDS Network

602-251 Bank Street

Ottawa, ON

K2P 1X3

Toll Free: 1-888-285-2226

Tel: 613-567-1817

Fax: 613-567-4652

Website <http://www.caan.ca>