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On April 1, 2009, AHS brought together 12 formerly separate health entities in the province: nine geographically based health authorities (Chinook Health, Palliser Health Region, Calgary Health Region, David Thompson Health Region, East Central Health, Capital Health, Aspen Regional Health, Peace Country Health and Northern Lights Health Region) and three provincial entities working specifically in the areas of mental health (Alberta Mental Health Board), addiction (Alberta Alcohol and Drug Abuse Commission) and cancer (Alberta Cancer Board).



ABORIGINAL RESEARCH PROTOCOLS

Healthy Aboriginal People in Healthy Communities



A M H B

ALBERTA MENTAL HEALTH BOARD

... Advancing Mental Health

ACKNOWLEDGEMENTS

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AMHB Wisdom Committee

Geraldine Cardinal
Jim Cardinal
Alex Crowchild
Alma Desjarlais
Albert Desjarlais
George Goodstriker
Bessie Joy
Gloria Laird
Ron Neufeld
Percy Potts
Rose Potts
Sykes Powderface
Patty Wells

AMHB Past and Current Staff

Elsie Bastien
Laurie Beverley
Jeannine Carriere
Brenda Desjarlais
Brian Fayant
Lorita Ichikawa
Chris LaForge
Marty Landrie
Wilma Spear Chief
Trudi Thew

Advisors

Andy Black Water
Dr. Joe Couture
Carol Carifelle-Brezicki

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INTRODUCTION

The Aboriginal Research Protocols sub-committee was tasked with producing a set of ethical research practices with Aboriginal communities for the Alberta Mental Health Board in the area of mental health services.

The sub-committee, facilitated by Jeannine Carriere (Consultant), comprised of Andy Black Water (Standoff), Dr. Joe Couture (Wetaskiwin), Carol Carifelle-Brezicki (Métis Settlements General Council), and Elsie Bastien (Aboriginal Mental Health Coordinator, AMHB).



ABORIGINAL RESEARCH PROTOCOLS

The Aboriginal Research Protocols sub-committee determined that it is important to:

- Acknowledge who the grandparents are in Aboriginal families and communities.
- Understand the extended family to understand the community.
- Clarify and establish links amongst existing services in the community such as Elders, leaders and service providers.
- Be clear on how this will improve existing conditions and make this clear to communities involved.
- Consider how terminology may be different in different cultural groups – Example is the word *mental health* – going to a psychologist suggests there is something wrong with you – use different terms to reduce misunderstanding in communities.
- Address people in the language they understand whether it is local language or in English.
- Gather the Elders, as they are an important source of knowledge - bring the project to them and they will give support.
- Be knowledgeable and respectful of existing spiritual and cultural protocols and follow these when working with diverse communities.
- Recognize mental health is a central piece of health from a holistic perspective – to have a strong mind is a definition used in some Aboriginal communities as being in balance with physical, emotional and spiritual self.
- Understand it is not important to believe what other people believe but it is important to know what they believe – everyone's reality differs.
- Give communities the right to refuse or stop the research they are engaged in if protocols and respectful research practices are not followed.

WHAT THE ELDERS SAID

Within the Aboriginal Research Protocols sub-committee, two Elders, Andy Black Water and Dr. Joe Couture, provided some insights into mental health and Aboriginal communities that need to be honored. The following is a summary of these teachings.

Andy Black Water

You hear about someone being sick. The first question is: "Is that person eating well?" "Are they having food or drink?" The response is to establish the degree of illness. There is a lifeline from the mouth to the kidney for example and if your kidney functions well, it will flush out and you're doing well. Examining the intake of food and liquid is still our way of determining that holistic health is still intact. We use habits of people. When we look for anxiety or stress, do they breathe easy or are they breathing fast? This tells us how their mental health is.

There are other signs of individual behavior such as the older you are the more space you need. Older men for example don't like to be handled. Maturity can apply to an older or younger person. It depends on their degree of connectedness. As your consciousness develops your perception of your maker becomes clearer. Reverting the process of how we came to be is to recognize the force of how we came to be. We all come from a "maker", a life giving force. We are put to the test with obstacles. The strongest test is to have something taken away like our children. In order to survive we have often adapted to the ways of the white man.

We must translate documentation for example to acknowledge ways of being and understanding and comparison. Our logic is different as based on our life force. First Nation communities and urban communities differ. Some say land-based equates nationhood. Land base allows for ceremonial ways of life. Not knowing who you are can affect the transition to help us know who we are. Lack of resources prevents us from changing norms. We have adapted some norms that are negative – i.e. we are killing ourselves and each other.

How do we prepare ourselves to cope with change? We must allow for self-expression and diversity. As we're exposed to more and more people, we need to change with time and environment. For example, Elders wait until people come to them. Now we're going to have to go to the people if we want to help, young people for example. We are born reverencing life and we can help young people by helping them to connect to ceremonies.

Dr. Joe Couture

As we turn into the 21st century, there are a great number of people healing themselves. Dreams instruct us, guide us and teach us. We need to use humor in developing our identity. Using our extended family systems to address issues such as the Hollow Water project in Manitoba. We need to look at disease differently as something to learn from. When people still have something or lessons to learn, they may develop disease. We may see sadness and terminal illnesses that stem from this. There are theories of personality in mental health work and 456 religions in the world – religions that define meanings. All indigenous people who are connected to the earth however have relational beliefs about creation.

The challenge is to have the right attitude and to train people to have the right skills to work with Aboriginal people. Getting to know the people you work with is time-consuming. There is diversity in the community – i.e. pan Indians – taking the best of both worlds. The mixed blood people, weekend Indians who attend ceremonies on weekends, traditionalists, etc. We have two spirited people who have been misjudged. Not every tribe has positive views about this.

Several years ago, there were gatherings of Elders across the country who provided teachings to their audience as they camped in different places. They addressed several issues. One Elder, Abe Burnstick talked about being an Indian person, “in the heart”. We may be different in many ways but that is part of our strength, but when we come from the heart, we can’t go wrong.

ANNOTATED BIBLIOGRAPHY ON PROTOCOLS IN RESEARCH IN ABORIGINAL COMMUNITIES

American Association for the Advancement of Science (AAAS). (2003).

Traditional Knowledge and Intellectual Property: A Handbook On Issues and Options for Traditional Knowledge Holders in Protecting their Intellectual Property and Maintaining Biological Diversity. AAAS. Washington.

This handbook outlines several issues that pertain to the importance of conducting respectful research in Aboriginal communities from a global perspective. The personal authors, Stephen Hansen and Justin Van Fleet begin their discussion by citing the International Human Rights Instruments Addressing Intellectual Property (1948) in that;

“Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits” and secondly, “everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which is the author” (UDHR, 1948). Furthermore under Article 29 of the International Human Rights Instruments, it is stated “Indigenous peoples are entitled to the recognition of the full ownership, control and protection of their cultural and intellectual property. They have the right to special measures to control, develop and protect their sciences, technologies and cultural manifestations, including human and other genetic resources, seeds, medicines, literatures, designs and visual and performing arts” (2003).

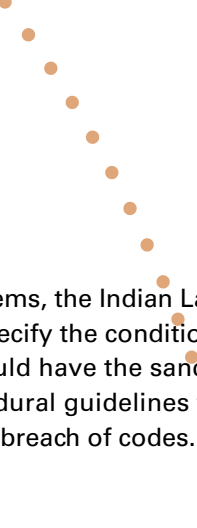
The AAAS handbook also states that documenting traditional knowledge is “fundamental to both preserving this knowledge for current and future generations” (p.35). It is also recommended that local words and terms be used in documenting traditional knowledge “should the community decide to share its knowledge” (p.35). If this occurs, the authors strongly suggest that informed consent be consistent and clear in every instance of collecting information from Aboriginal communities. (p.25).

American Indian Law Center, Inc. (1999). Model Tribal Research Code.

American Indian Law Center Inc. New Mexico.

This document describes a number of problems and issues in American Indian communities who were involved in research projects. Some of the complaints in a lengthy list from various tribes include:

- Individual Indian people have been persuaded to participate in research in which they did not fully understand the risk to their health and safety.
- Research was conducted which did not respect the basic human dignity of the individual participants or their religious and cultural beliefs.
- Researchers have not respected the confidentiality of Indian people to the same degree than they would have of non-Indian people.
- Researchers have pursued issues of importance to the larger society but of marginal interest to Indian people, and have been uninterested in problems of more urgent concern to the Indian community.
- Researchers have violated promises of secrecy regarding sensitive religious or cultural materials and information (p.2).



In order to prevent or avoid these problems, the Indian Law Center advocates for the development of tribal research “codes” which clearly specify the conditions under which research is to be conducted in tribal communities. These codes should have the sanction of tribal leaders in each community to protect jurisdictions and provide procedural guidelines for conducting research. Codes should also state what sanctions will be used in the breach of codes.

Aboriginal Healing Foundation. (2000). Ethics Guidelines for Research.

AHF. Ottawa.

These guidelines have been formulated to represent standards set out in the Royal Commission on Aboriginal Peoples. These include principles of research such as the importance of using local language, the importance of oral knowledge and protocol, honoring diversity amongst Aboriginal people and the obligation to professional and ethical research practices. What is also valuable are the guidelines for research which are formulated as the following questions:

- Are there perspectives on the subject of inquiry that are distinctively Aboriginal?
- What Aboriginal sources are appropriate to shed light on those perspectives?
- Is proficiency in an Aboriginal language required to explore these perspectives and sources?
- Are there particular protocols or approaches required to access the relevant knowledge?
- Does Aboriginal knowledge challenge, in any way, assumptions brought to the subject from previous research?
- How will Aboriginal knowledge or perspectives portrayed in research products be validated?

These questions are supported by a discussion on informed consent and collaborative strategies that promote the involvement of research teams or community representation in research projects in Aboriginal communities. Most important is the acknowledgement that the community needs to benefit from any research conducted within it.

American Indian Rehabilitation Research and Training Center. (2002).

Symposium on Research and Evaluation Methodology.

Work Group on American Indian Research and Program Evaluation Methodology. Washington.

This extensive document provides a numbers of recommendations for what they describe as “overcoming a history of exclusion from control of research” (p.22). in Indian country. The following is a summary of those recommendations:

- Hire tribal members to assist in the process of research.
- Demonstrate how the research findings will benefit the tribe and tribal members.
- Guarantee that the research activity does no harm to the tribe, tribal members and the environment.
- Guarantee confidentiality or anonymity of research participants, tribal communities and the tribe.
- Publish results only after review and approval of the manuscript by tribal representatives (p.25).

The organization suggests that involving a community advisory committee in any research project assures that “local level evaluation protocols, cultural assessment instruments, community focus groups, cultural protocols for interviewing families and other qualitative and quantitative tribally developed measures are all excellent examples of the outcomes that are possible when tribal communities are empowered” in the research process (p.47).

Australian Institute of Aboriginal and Torres Strait Islander Studies. (2000).

Guidelines for Ethical Research in Indigenous Studies.

Australia.

The institute conducted workshops in Aboriginal communities to develop these guidelines or Principles of Ethical Research:

- Consultation, negotiation and free and informed consent are the foundations for research with or about Indigenous peoples.
- The responsibility for consultation and negotiation is ongoing.
- Consultation and negotiation should achieve mutual understanding about the proposed research.
- Indigenous knowledge systems and processes must be respected.
- There must be recognition of the diversity and uniqueness of peoples as well as of individuals.
- The intellectual and cultural property rights of the Indigenous peoples must be respected and preserved.
- Indigenous researchers, individuals and communities should be involved in research as collaborators.
- The use of, and access to, research results should be agreed.
- A researched community should benefit from and not be disadvantaged by the research project.
- The negotiation of outcomes should include results specific to the needs of the researched community.
- Negotiation should result in a formal agreement for the conduct of a research project, based on good faith and free and informed consent (p.4).

Castellano, M.B. (2004). Ethics of Aboriginal Research in Journal of Aboriginal Health. January, 2004.

Castellano describes Aboriginal research as “research that touches the life and well-being of Aboriginal peoples” (p.99). Ethical research with Aboriginal people means a code of conduct that reinforces the cultural and social values of a community (ibid). The author states that traditional teachings “are conveyed through examples, through stories and songs, in ceremonies and most important, through engagement with the natural world which is governed by the laws of life”(p.100). She also states that the persons who have the most knowledge about these principles are Elders (p.101) and that ethics and rules governing relationships must be in place for research in order to undo the colonial underpinnings of research which is under the control of outsiders to the Aboriginal community (p.102). She cites the Tri-Council Policy Statement on Aboriginal research that states that standards for research in Aboriginal communities must be developed when:

- Property of private information belonging to the group as a whole is studied or used.
- Leaders of the group are involved in the identification of potential participants.
- The research is designed to analyze or describe characteristics of the group.
- Individuals are selected to speak on behalf of, or otherwise represent the group (p.105).

Castellano also cites a number of studies and reports which identify the need for protocols in conducting research in Aboriginal communities and summarizes these in five major themes:

- Consultation with communities involved when developing protocols for research.
- Informed consent from community leaders prior to research being conducted.
- Community involvement in conducting research.
- A clear definition of what sampling may look like and not to add to a sample without checking with community first.
- Advance drafts of research reports distributed to community.

She concludes her article by framing the need for ethical research within the context of self-government in Aboriginal communities. She states “establishing and enforcing ethical practice in Aboriginal research will require a continuing commitment to implementing protective legislation, administrative infrastructure and education of the many participants in research” (p.113).

Kral, Michael. (2003). Researcher Studies Inuit Suicide Rate. In Hartford Courant. August 3rd, 2003.

This article features the work of Michael Kral who has engaged in an eight month study of suicide in the territory of Nunavut. Kral states that this area has one of the largest rates of suicide in the world, described in the article as “an epidemic.” Kral says that Inuit youths exhibit similar characteristics as youth in Sri Lanka, which had a rate of 47 per 100,000 in 1991. These factors are risk factors such as alcohol abuse, depression, family problems and rapid cultural change. Kral has conducted extensive research in Inuit communities and recommends that research in this area needs to be focused on family and community involvement. He also discusses the importance of attending to other matters such as opportunities to debrief and to let people tell their story instead of looking immediately for solutions.

Nechi Training, Research and Health Promotions Institute. (2002).
Healing Together Our Sacred Journey. Edmonton.

Within this report some principles of research are addressed by a community advisory committee which view the research function as:

- non-intrusive to the community
- relevant to the program development
- reflective of Aboriginal cultural values
- in consultation with stakeholders
- in liaison with staff and host communities (p.2).

Although these principles were developed in research addressing sexual abuse, they are transferable to other issues in the Aboriginal community.

