



Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Objectives:

Upon completion of this module you will be able to:

- understand that there are diverse perspectives on research involving First Nations, Inuit and Métis communities;
- interpret the Ethics framework in the context of First Nations, Inuit and Métis communities;
- recognize and respect the cultural norms, governance structures and needs of different **Aboriginal** communities involved in research.

The term “Aboriginal” refers to the three major Indigenous groups in Canada of First Nations, Inuit and Métis peoples. These groups are recognized under Canada’s Constitution Act, 1982.

TCPS 2
Ch. 9





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Panel on Research Ethics
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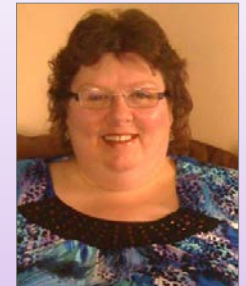
Introduction

Chapter 9: Research Involving First Nations, Inuit and Métis Peoples of Canada was developed in keeping with the diverse worldviews of Aboriginal communities. It is designed to serve as a framework for the ethical conduct of research involving Aboriginal peoples. It is offered in a spirit of respect and is not intended to override or replace ethical guidance offered by Aboriginal peoples themselves.

To put this in historical context, research involving Aboriginal peoples in Canada has been defined and carried out primarily by researchers who are not Aboriginal. Generally, the approaches have neither benefited Aboriginal peoples nor reflected Aboriginal world views and priorities. Research results did not necessarily reflect an Aboriginal perspective as the communities were not engaged.

TCPS 2
Ch. 9

See the stories contributed by these four people about their experiences with First Nations, Inuit and Métis research projects on the following pages.





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Panel on Research Ethics

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Take the Time to Learn Community Norms

Hello, my name is **Dr. John Kelly**.

Part of my research has been to work with First Peoples communities to help develop their language programs. Importantly, Aboriginal People's perspective of ownership is different from Canadian copyright law. The law protects authors of songs, stories and other materials for life plus 50 years beyond the calendar year of the creators' deaths. From an Aboriginal perspective this law does not go far enough. Our people hold that ownership remains with the authors' families and clans perpetually. Researchers who do not learn about community practices, including family and clan ownership, can create severe problems within a community.

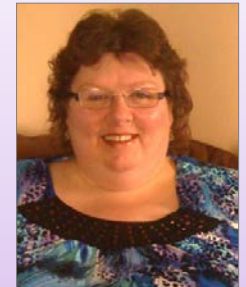


Years ago, a researcher who was collecting Aboriginal stories and songs was documenting the origin and meaning of a particular song. This song and its history belonged to a particular family but it was a non-family member who told the researcher a story about the song. This source said that the song was about the best friend of a dying man. According to the source, the friend wanted the man's wife and took advantage of his death. The researcher published this version of the story with the song without verifying if the story was true. A family member would have been able to tell the researcher that this version was false.

In the true version of the story, the dying man asked his closest friend to take care of his wife and family. He wrote a song that sealed and signified the agreement. After the ancestor passed on, his dear friend married the wife and thus fulfilled his commitment. This was a highly honourable action within that culture. Years later, the owners of the song found out about the published falsehoods. This caused great pain to the family. After an Elder of the family made their objections known, a museum curator allowed the misinformation to be removed during a CD digitization. The damage, however, had already been done. In real ways, cultural misappropriation cannot be taken back.

If the researcher had sought out the traditional owners for permission to use the song, they could also have provided an accurate interpretation. This would have honoured the family and the community's traditional values. Also, it would have enhanced the research. It is incidents such as this one that have led to a lack of trust in researchers by Aboriginal communities. My advice to researchers is to take the time to learn all they can about the ethical values and practices within an Aboriginal community before they conduct their research.

See the stories contributed by these four people about their experiences with First Nations, Inuit and Métis research projects on the following pages.





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Panel on Research Ethics

www.pre.ethics.gc.ca

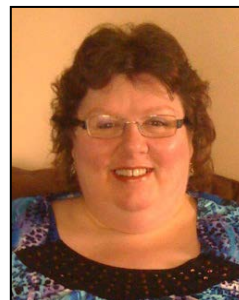
Respect Community Knowledge and Contributions

My name is **Darlene Wall** and I am the Social Sector Manager for NunatuKavut. Over the past few years, we have become more actively involved in health and social research. Our communities have had both positive and negative experience with research and researchers.

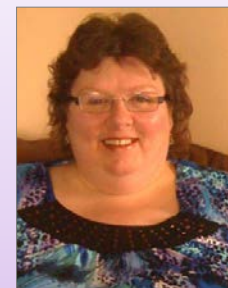
I remember one study a few years ago where part way through the project a new researcher became involved and he decided that because he was co-investigator he was “boss”. He showed very little (if any) respect for what research team members from the community offered. This led many of our team members to stop coming to our meetings altogether. In the end it did work out ok, but it left me feeling a little frustrated and not eager to work with the person again.

Then we’ve had the complete opposite with two of our current research projects. Right from the outset we have been a part of every decision and the researchers have respected all communication. Of course, we don’t always agree with each other on everything but we always discuss things until we come to a consensus. Having a true give and take relationship with researchers makes us want to be involved in even more projects.

As a result of a research partnership starting in 2006, NunatuKavut partnered with Memorial University of Newfoundland on a CIHR-funded project to investigate and implement a community research review mechanism. As a community we have been working on this for a few years and are excited to have relationships with researchers who listen to and value the needs we have. Together we truly are making a difference.



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Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Panel on Research Ethics

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Build Trust through Reciprocity

My name is **Heather Castleden** and as a researcher I believe trust between communities and researchers is established when researchers work in an open, honest, and transparent manner.

Regular communication with community leaders is critical -- not just by submitting written updates or final reports but also actively seeking feedback and guidance on research processes, cultural norms and protocols, budget spending, and interpretation of results.

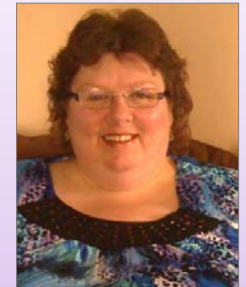


Trust is further built when researchers become involved in the community's activities and events, listen to and address community partners' research needs, and reciprocate in some way. This reciprocity could be through shared authorship on final research results or it could be through cutting and stacking wood for a community Elder. The point is, researchers need to be willing to spend the time to learn -- through watching, listening, and asking -- what doing research 'in a good (trustworthy, respectful) way' means for a particular community.

Click on the link below to view Heather Castleden's 'thank you' story to the Huu-ay-aht First Nation for teaching her to be a 'good' researcher:

<http://www.youtube.com/watch?v=Jz6l-I-Td6k>

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Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Panel on Research Ethics www.pre.ethics.gc.ca

Communicate, Collaborate and Tailor Research to Community Needs

My name is **Frances Chartrand** and I am a Métis woman from Duck Bay, Manitoba. As Director of the Manitoba Métis Federation (MMF) Métis Community Liaison Department (MCLD), I have been involved in research for the past few years. My department plays a key role in Métis specific health research as community engagement leaders. This experience has been very positive and helpful.

When we are involved in a research project, we make use of "Knowledge Networks"-- a series of discussions involving researchers, our MMF Region offices, the MCLD staff and the regional provincial health system.

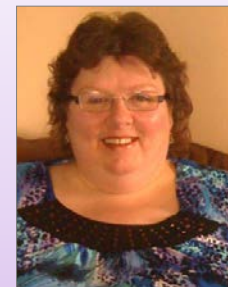
These inclusive discussions help us ensure that research outcomes are useful in improving programs and services to better serve the needs of Métis citizens. They have also helped us to better clarify everyone's roles and responsibilities, as well as where we can work collaboratively with the health system.

Our Knowledge Networks use a Métis holistic approach and are very involved in interpreting research outcomes within a community context. We benefitted from a capacity building research project in which the researchers provided training modules such as: Use of the Métis Life Promotion Framework© and Wellness Areas©; how to read charts/graphs of aggregate data; how to integrate new knowledge with community context; and how to analyze comprehensive shared knowledge for use in health planning. We also attended a 'Métis Community-Based Research and Proposal Development Institute' to learn more about what community based research is and about the roles of community collaborators and researchers. By the end of the week, my staff was able to develop a research idea into a full community-based research proposal.

It's really important for communities to have an understanding of what happens in the research process. We have found that the combination of the Métis experience with spiritual and emotional aspects of health and the health service data representing physical and intellectual aspects of the knowledge has increased our ability to contribute to better health system planning and decision-making by the regional health system. We also identify and participate in new areas of research that are important to our Métis citizens.



See the stories contributed by these four people about their experiences with First Nations, Inuit and Métis research projects on the following pages.





The Ethics Framework in the Context of Chapter 9

Because TCPS 2 acknowledges the unique status of Aboriginal peoples of Canada, it provides the context of each core principle in relation to research involving First Nations, Inuit and Métis participants.

See how each core principle is interpreted in the context of Chapter 9 on the following pages:

- Respect for Persons
- Concern for Welfare
- Justice

TCPS 2
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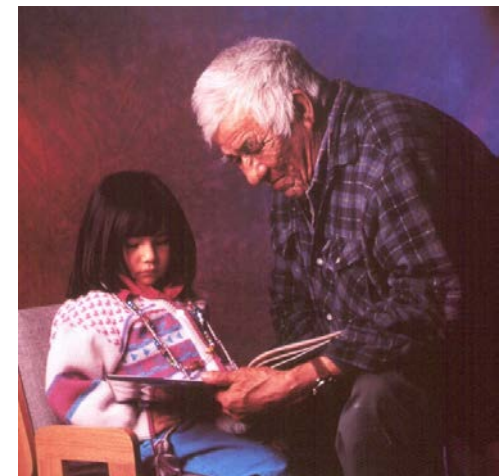
The Ethics Framework in the Context of Chapter 9

The principle of **Respect for persons** means to honour every individual's and community's capacity and autonomy to make free and informed decisions. This includes the freedom to refuse to participate.

Aboriginal cultures and identities are distinct from other Canadian perspectives. Ethical protections, therefore, extend beyond the individual participants and include obligations and responsibilities to the natural world, knowledge received from ancestors, and future generations.

TCPS 2
9 : B

- Respect for Persons
- Concern for Welfare
- Justice





The Ethics Framework in the Context of Chapter 9

The principle of **Concern for Welfare** protects the interests of the individual. This is balanced with care for participants' physical, social, economic and cultural environments.

Additionally, TCPS 2 acknowledges concerns for the broader role of Aboriginal communities to promote their collective rights, interests and responsibilities. Whenever possible, appropriate and desired, involvement in research should enhance the capacity of First Nations, Inuit and Métis peoples. This may support their efforts to maintain their cultures, languages and identities while at the same time respecting the community's research priorities.

TCPS 2
9 : B

- Respect for Persons
- Concern for Welfare
- Justice





The Ethics Framework in the Context of Chapter 9

The principle of **Justice** is concerned with the balance of power between researchers and participants. For example, a community that is relying on sponsorship for a research project, might find that the research sponsor controls important decisions that affect their community.

Justice also requires that the risks and benefits of research are equitably distributed – with no one group inappropriately included or unfairly excluded. Women, for example, should not be excluded from a survey of community issues (e.g., substance abuse, political campaigns, domestic violence).

Another area of great sensitivity is the misappropriation of cultural or ceremonial elements by researchers. Justice and fairness requires respect for each community's traditions.

Fairness and equity is best achieved through early engagement with communities. This allows time to establish relationships based on mutual trust and communication, as well as to define the research parameters, responsibility for decision-making and level of community engagement.

TCPS 2
9 : B

- Respect for Persons
- Concern for Welfare
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See the next page for an example of a community-based research project that helped give voice to marginalized Aboriginal women.





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

From Stilettos to Moccasins

A national research project examining the healing journeys of Aboriginal women in treatment for substance abuse brought together a large team of researchers and community collaborators. The collaborators included women with a history of treatment for drug abuse, Elders, academic researchers and treatment providers.

The community engagement process ensured that the research was done “by, for and in balance with” the research participants and not “on” them. The goal, as expressed in multiple publications, was to conduct research with respect,



Painting by team member, Pauline Young

“...which we defined as carrying out research with people who have been traditionally excluded from the production of knowledge and considering the rights, beliefs, values and practices of everyone involved in the research process.” (Dell et al, 2014)

Visit the study website (links below) for a video of a song written by Aboriginal women to represent their journey in treatment as they worked to reclaim their identities.

Study: [Aboriginal women drug-users in conflict with the law](#)

Video: [From Stilettos to Moccasins](#)

- Respect for Persons
- Concern for Welfare
- Justice





Benefits of Research for Aboriginal Groups

Benefits of research may be direct (affecting the individual participants) or indirect (affecting the community or society in general). Each community will need to weigh the relevance of potential benefits of a research project against its foreseeable risks.

More and more Aboriginal communities are asserting their right to be active partners in research. These partnerships are based on mutual trust and cooperation. This helps the research proceed in a manner that is relevant, respectful, equitable and reciprocal with regard to shared power, decision-making and benefits derived from the research outcomes.

Research should engage Aboriginal people in any project that affects them. However, communities may choose varying **levels of involvement**.

Levels of Involvement:

Some communities may choose to be equal participants in all stages of a research project that involves their communities. Others may choose to strengthen the research capacity of their members through local training that enhances skills in research methods, and project management. Still other communities may be satisfied with recognition for their contributions, or the return of results. Others may choose simply to monitor the research.



TCPS 2
9:12

TCPS 2
9:13

TCPS 2
9:14



Community Capacity Building

Other opportunities for communities to benefit from being involved in research can occur through capacity building efforts. An assessment of the current capacity of the community needs to be considered along with the level of capacity the community wishes to achieve. For example, some communities may begin their capacity-building efforts with data entry while others may be able to assist with project design, and/or the interpretation and analysis of findings.

Research projects should support capacity building in Aboriginal communities where possible. Involving community members in various stages of the research process provides the opportunity for skill development. Different communities may have differing needs for capacity building. The best way to determine what level of capacity building is desired by communities is to ask them.

Once the researcher and the community agree upon involvement and expectations, these details can be included in the research agreement.

TCPS 2
9:14

Learn about the experience of two researchers who conducted research in an Inuit community (next page).





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Panel on Research Ethics

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Community-Driven Capacity Building



My name is Julie Bull and my name is Debbie Martin. Our research focused on the health and wellbeing of Aboriginal peoples. We were involved in a community health needs assessment. The design of the study called for a community-based participatory approach. Working with key community leaders, we looked at our areas of expertise and what each person on the research team could contribute to the project.



We then divided up tasks, based on our expertise. Our community wanted to become involved in many aspects of the interpretation of the data, so we agreed to share our initial results with the community, to get their feedback and to use the feedback to assist with our ongoing analysis of the data. This worked really well. We presented our findings to our research team, the community council, and at a community meeting and received useful advice on our interpretations.

Through this experience, we have learned the importance of providing communities with the opportunity to decide the degree to which they wish to be involved. For this particular community, being involved in the interpretation of the findings was the degree of capacity building they wanted for this study.

We believe the key point for researchers is to make sure the community you are working with is aware of the processes necessary to conduct the research so they can make an informed decision about their involvement. Lastly, make sure that the extent of capacity building opportunities you have agreed to is clearly outlined in a research agreement.

Learn about the experience of two researchers conducting research in an Inuit community (next page).



TCPS 2
9:14



Community Engagement

Community engagement is a process that establishes a respectful relationship between a researcher or research team, and an Aboriginal community. It can facilitate collaboration between researchers and communities. The degree of collaboration may vary depending on the community context and the nature of the research.

Engagement with communities may take many forms, including:

- meeting informally with community members;
- consulting with Elders and/or knowledge keepers;
- negotiating a **research agreement** with the formal leadership;
- working with a community advisory group or review body.

A community's involvement in a research project may range from information sharing to active participation and collaboration, to shared or sole leadership of the research project. Communities may also choose not to engage actively in a research project, but simply acknowledge it and indicate that they have no objection to it.

TCPS 2
9.1

- Community Engagement Examples
- Requirements of Engagement
- Nature & Extent of Engagement
- Engagement with Communities of Interest



Research agreements should clarify and confirm details of what researchers and communities expect and are willing to commit. An agreement may outline the sharing of benefits and who makes decisions. Also, it may specify how researchers will obtain informed consent from the community and its individuals. The agreement could formalize the community's engagement, as well as its role in interpreting the research and disseminating the outcomes.

TCPS 2
9.11



Community Engagement Examples

Community engagement takes time but it is time well spent. Community involvement often leads to better research design, greater participation and more valid and useful results. The knowledge that community members bring to the research enterprise can be invaluable.

To see an example of how traditional knowledge can inform academic research, view a [CBC report](#) about a collaboration between Inuit Elders and climate change researchers. To find out more, view the film: '[Inuit and Knowledge and Climate Change](#)'.



For good advice about how to engage communities with respect, view "[Seeing Evidence, Sharing Truths](#)", a video produced to promote sensitive and effective research partnerships with First Nations, Métis and Inuit people in Canada.

- Community Engagement Examples
- Requirements of Engagement
- Nature & Extent of Engagement
- Engagement with Communities of Interest



TCPS 2
9.1



Requirements of Engagement

The requirements of engagement will vary depending upon the type of research and whether the project affects the welfare of a First Nations, Inuit or Métis community. For example, research investigating mould levels in reserve homes may require extensive community engagement. However, a project that investigates urban unemployment may require a different level of engagement, depending on the community's role, its desire to be a partner, or the nature of the project.

When research involves any Aboriginal community, **organization or community of interest**, researchers are required to document their engagement strategy and/or practices for their REB.

Organizations or communities of interest may be formal or informal, temporary or permanent. They generally exist to represent or advocate for a particular group on identified issues. They are varied and may include political organizations, friendship centres, housing associations, health centres or other groups designed to enhance the welfare of their memberships.

TCPS 2
9.10

TCPS 2
9.4

- Community Engagement Examples
- Requirements of Engagement
- Nature & Extent of Engagement
- Engagement with Communities of Interest





Nature and Extent of Engagement

The nature and extent of engagement depends on the type of research and the degree to which it is focused on Aboriginal people. Researchers need to work with communities to determine the level of engagement that meets the communities' priorities and respects their culture.

Communities and researchers need to reach an understanding of how the norms of the community and the needs of the research interrelate (e.g., privacy, confidentiality, consent, etc.). It is important that both the researcher and the community are aware of each other's expectations before the research begins.

Community engagement is not always required. For example, research that relies on publicly available information such as blogs or census data may not require community collaboration. However, if the data can identify a community, an REB may recommend contacting the community.

TCPS 2
9.2

- Community Engagement Examples
- Requirements of Engagement
- Nature & Extent of Engagement
- Engagement with Communities of Interest





Engagement with Communities of Interest

Within communities there may be diverse interests represented by specific individuals or groups. Researchers must be sensitive to when these interests conflict or overlap and engage with the appropriate, organizations and communities of interest.

For example, an issue that affects Aboriginal youth living in an urban centre may give rise to a temporary community of interest seeking to have its voice heard. This community may seek research partnerships to gather information or present evidence to influence city policies or laws. A community of interest may grow and develop into a permanent organization that seeks active research involvement.

TCPS 2
9.6

- Community Engagement Examples
- Requirements of Engagement
- Nature & Extent of Engagement
- Engagement with Communities of Interest





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Types of Communities

First Nations, Inuit and Métis communities have distinct histories, cultures and traditions. Researchers should be aware that each of these groups have representative bodies and service organizations that are also considered an extension of their communities. To find out more about different types of organizations listed below, see the following pages.

- Friendship Centres
- Health Centre
- Political Organizations
- Communities with Complex Authority Structures
- Urban Communities



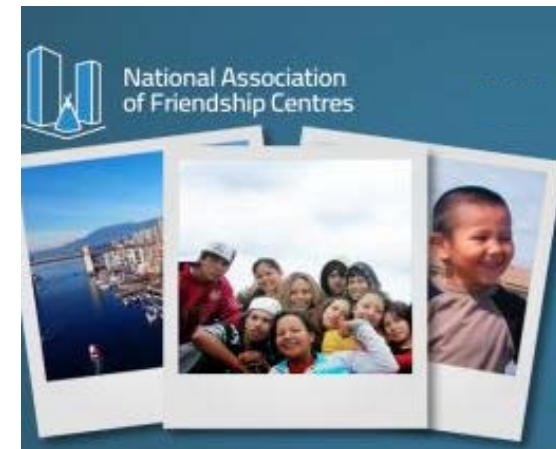


Friendship Centres

Friendship Centres are normally non-profit facilities that offer meeting space, workshops, support groups and other services. A friendship centre may be a main support system in a metropolitan area. They can also provide project opportunities. For example, researchers may contact a friendship centre to investigate how life for their members has improved or declined since migrating from Aboriginal territories. The board and staff may choose to participate in research that focuses on its members.

To find out more about friendship centres, visit the website of the [National Association of Friendship Centres](http://www.nafc.ca).

TCPS 2
9.4





Aboriginal Health Centres and Programs

Across the country there are a variety of Aboriginal community-led health organizations that provide primary health care services to First Nations, Inuit and Métis people. The services provided by these organizations may include clinical care, traditional healing, health promotion, illness prevention and community development programs. Some are part of a provincial network like the Ontario [Aboriginal Health Access Centres](#). Some form a part of a government health services program like the Winnipeg Regional Health Authority – [Aboriginal Health Programs](#). Some serve a particular group, city or region such as the [B.C. First Nations Health Authority](#) or the [Mi'kmaq Confederacy of PEI Health Program](#).

Researchers may build trusting relationships with participants by first engaging health organization staff as cultural consultants. Careful collaboration could help researchers engage the community in a respectful manner.

TCPS 2
9.4





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Panel on Research Ethics
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Political Organizations

A political organization is a body that advocates on behalf of its membership regarding various social and political issues. Aboriginal political organizations often can facilitate research of interest to their members.

Prospective participants however, might not recognize existing political, organizations or communities of interest as representing their priorities. Therefore, researchers and REBs must not assume that approval of a project by any particular group is the only avenue for endorsing a project.

Researchers should work proactively to ensure that parties with vested interests are engaged in the research. This could include, for example, traditional chiefs, band councils, community councils, Aboriginal REBs and national organizations.

TCPS 2
9.3



Sisters in Spirit
**HONOUR THE LIVES OF
MISSING AND MURDERED
ABORIGINAL WOMEN**

Friday October 4
Broadway Campus
Health Sciences Building (Building B)
Event Space
11:30-12:30



www.suvcc.ca



www.vccw.ca/vcc-project



www.nwacc.ca



www.ch-fce.ca



Communities with Complex Authority Structures

Every community has its own authority structure. Some authority structures are more complex than others, involving formal and informal mechanisms within communities to guide decision-making. Within a single community there may be an elected leadership body, respected elders, advisory bodies and specialized knowledge-keepers.

Researchers should learn about these multiple structures because projects that engage community participants may need other approvals in addition to that of the formal leadership. For example, in a First Nations community, an Elders' Council may be the correct body to review traditional knowledge in a research project. In many cases however, the band, tribal or hamlet council must be included as part of the decision-making process.

TCPS 2
9.5





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Urban Communities

Urban communities are established outside of traditional Aboriginal territories and within the limits of municipalities. Neighbourhood groups, social groups, support groups and communities formed by common interests are all types of urban Aboriginal communities. Some communities may seek research partnerships to learn more about their needs and how to address them.

Researchers should consult the various organizations that represent urban populations as a starting point to identify community codes of research practice. Aboriginal urban populations may be comprised of many communities. Individuals may identify with more than one community. Researchers will need to show their REBs a community engagement plan suitable to the complexity and diversity of the population they wish to engage.

TCPS 2
9.2

TCPS 2
9.4



Photo credit: BC Métis Federation



Authority and Governance

Researchers interested in doing research with a First Nations, Inuit or Métis community should seek a genuine collaboration with its formal leaders. In addition to a community's formal leadership, researchers must also consider diverse interests and complex community authority structures.

For some research projects such as those including critical inquiry, engagement with formal leadership may not be required.

When dealing with authority and governance structures in the context of research it is important to remember that individual consent of participants must still be sought.

For more on diverse interests and critical inquiry, see the following pages.

TCPS 2
9.3

TCPS 2
9.5

TCPS 2
Ch. 3





Diverse Interests within a Community

The formal leadership of a community may not represent all the diverse interests of that community. Researchers need to be aware of other perspectives and other needs.

Special measures may be necessary to ensure inclusion of people who may not have a voice in the current governance structure. For example, people who may be marginalized within a community (e.g., women, people living with HIV/AIDS, street youth) may not be consulted by the established authority.

Researchers should ensure that all groups within a community that are relevant to the research project, or may be affected by the research outcomes, have an opportunity to have their voices heard and to be involved.

TCPS 2
9.6





Critical Inquiry

Critical Inquiry is research that may include criticism of a public institution, a policy or in this context, governance of an Aboriginal community, or other social phenomena.

In the consent process for a critical inquiry project, researchers must ensure that prospective participants are aware of foreseeable risks. For example, community members who become participants may be at risk of economic and social penalties imposed by the formal leadership or their peers.

It is important that researchers do all they can to protect the privacy and confidentiality of participants in critical inquiry research.





Research Agreements

Once a researcher and a community have agreed to work together on a research project, a **research agreement** is a good way to clarify and confirm mutual expectations. Whether there is a formal research agreement or not, the REB will require documentation detailing how researchers have engaged the community.

Negotiation of a research agreement typically includes a discussion of how community customs and codes of practice will be respected. As well, the role of Elders and other knowledge keepers and how they will be recognized in the research process may also be discussed. Other issues that need to be addressed include privacy and confidentiality, intellectual property rights and collection and storage of human biological materials.

For examples of research agreements, see the following documents in the Appendix :

- 1. Centre for Indigenous Peoples' Nutrition and Environment (CINE): Sample Agreement**
- 2. Research Partnership Agreement: An Exploratory Study of the Contribution of Equine Assisted Learning in the Treatment and Wellbeing of First Nations Youth Who Abuse Solvents**

TCPS 2
9.11

See the following pages for more information about typical elements of a research agreement:

- Community Customs & Codes of Practice
- Recognizing the Role of Elders & Other Knowledge Keepers
- Privacy & Confidentiality
- Intellectual Property Rights
- Collection of Human Biological Materials





Community Customs and Codes of Practice

Community customs and codes of practice derive from traditions from predominately oral cultures. Research agreements may be written or oral as long as they are documented. Researchers should become informed about the cultural norms and codes of research practice of the community they wish to engage.

For example, many First Nations communities have adopted the code of research practice known as the [OCAP Principles](#) of Ownership, Control, Access and Possession in the context of research. However, Inuit and Métis may have different procedures to address similar issues. For example, the [Inuit Research and Research Ethics Fact Sheet Series](#), or the [Six Principles of Métis Research](#). Researchers should make themselves aware of all relevant community-based research guidelines.

Issues raised by differences between policies, codes and community customs need to be addressed before the research can begin.

- Community Customs & Codes of Practice
- Recognizing the Role of Elders & Other Knowledge Keepers
- Privacy & Confidentiality
- Intellectual Property Rights
- Collection of Human Biological Materials

TCPS 2
9.8



Recognizing Elders and Knowledge Keepers

Recognizing the role of Elders and other knowledge keepers is a vital step to ensuring an inclusive research approach because they are respected persons in the community who are able to provide cultural context in all stages of research (e.g., design, conduct, interpretation and dissemination). Researchers must take care to work with the community and identify Elders, Métis senators, and other recognized knowledge keepers.

Appropriate recognition of Elders' and knowledge keepers' unique advisory role and contributions should be part of the research agreement. For example, this could include honoraria or published acknowledgment of their contributions.

TCPS 2
9.8

- Community Customs & Codes of Practice
- Recognizing the Role of Elders & Other Knowledge Keepers
- Privacy & Confidentiality
- Intellectual Property Rights
- Collection of Human Biological Materials





Privacy and Confidentiality

Any issues related to privacy and confidentiality should be addressed early in the community engagement process. One frequent concern for individual Aboriginal participants is how their privacy and confidentiality can be safeguarded given the small size of their communities.

Each of the examples of research activity below raises concerns about privacy and confidentiality. See the following pages for more information about how these concerns can be addressed:

- **Recruitment by sign up sheet**
- **Focus group in a small community**
- **Data entry by community members**
- **Dissemination of results concerning a specific community**

TCPS 2
9.16

Note: Guidance regarding privacy and confidentiality that applies to all research involving humans is more thoroughly covered in TCPS 2 Chapter 5.

TCPS 2
Ch.5

- Community Customs & Codes of Practice
- Recognizing the Role of Elders & Other Knowledge Keepers
- Privacy & Confidentiality
- Intellectual Property Rights
- Collection of Human Biological Materials





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Privacy and Confidentiality

Any issues related to privacy and confidentiality should be addressed early in the community engagement process. One frequent concern for individual Aboriginal participants is how their privacy and confidentiality can be safeguarded given the small size of their communities.

Each of the examples of research activity confidentiality. See the following pages for concerns can be addressed:

- **Recruitment by sign up sheet**
- **Focus group in a small community**
- **Data entry by community members**
- **Dissemination of results concerning a specific community**

Recruitment by sign-up sheet:

A better way to do this is to allow people to contact the researcher privately to find out more about the study. You may distribute a flyer with contact information rather than a sign-up sheet where participation interest is no longer private.

TCPS 2
9.16

Note: Guidance regarding privacy and confidentiality that applies to all research involving humans is more thoroughly covered in Chapter 5 of TCPS 2.

TCPS 2
Ch.5

- Community Customs & Codes of Practice
- Recognizing the Role of Elders & Other Knowledge Keepers
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Privacy and Confidentiality

Any issues related to privacy and confidentiality should be addressed early in the community engagement process. One frequent concern for individual Aboriginal participants is how their privacy and confidentiality can be safeguarded given the small size of their communities.

Each of the examples of research activity below addresses confidentiality. See the following pages for more concerns that can be addressed:

- **Recruitment by sign up sheet**
- **Focus group in a small community**
- **Data entry by community members**
- **Dissemination of results concerning a specific community**

Focus group in a small community:

Participants in a focus group may be assured that the researcher will keep their comments confidential but the researcher cannot guarantee that each member of the focus group will do the same. Limitations on the safeguarding of privacy and confidentiality need to be made clear in the consent process.

Note: Guidance regarding privacy and confidentiality that applies to all research involving humans is more thoroughly covered in Chapter 5 of TCPS 2.

TCPS 2
Ch.5

- Community Customs & Codes of Practice
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Privacy and Confidentiality

Any issues related to privacy and confidentiality should be addressed early in the community engagement process. One frequent concern for individual Aboriginal participants is how their privacy and confidentiality can be safeguarded given the small size of their communities.

Each of the examples of research activity below addresses privacy and confidentiality. See the following pages for more details on how these concerns can be addressed:

- **Recruitment by sign up sheet**
- **Focus group in a small community**
- **Data entry by community members**
- **Dissemination of results concerning a specific community**

Data entry by community members:

One way to safeguard privacy is to strip data of personal identifiers and replace them with a code (e.g., 01AA) prior to making records available to those doing data entry. However, coding is often not sufficient to conceal identities. Indirect identifiers or linking to another data set can inadvertently identify participants. Care must be taken to safeguard community members' personal information. In some cases it may not be appropriate for community members to be involved in data entry.

- Community Customs & Codes of Practice
- Recognizing the Role of Elders & Other Knowledge Keepers

Note: Guidance regarding privacy and confidentiality that applies to all research involving humans is more thoroughly covered in Chapter 5 of TCPS 2.

TCPS 2
Ch.5





Module 9: Research Involving First Nations, Inuit & Métis Peoples of Canada

Panel on Research Ethics

www.pre.ethics.gc.ca

Privacy and Confidentiality

Any issues related to privacy and confidentiality should be addressed early in the community engagement process. One frequent concern for individual Aboriginal participants is how their privacy and confidentiality can be safeguarded given the small size of their communities.

Each of the examples of research activity below raises concerns about privacy and confidentiality. See the following pages for more information about how these concerns can be addressed:

- **Recruitment by sign up sheet**
- **Focus group in a small community**
- **Data entry by community members**
- **Dissemination of results concerning a specific community**

Note: Guidance regarding privacy and confidentiality that applies to all research involving humans is more thoroughly covered in Chapter 5 of TCPS 2.

Dissemination of results:

When results of a study may have an impact on the reputation or well-being of a community, there may be a need to protect the identity of the community as well as the individual participants. For example, publishing a study of reproductive health among sex workers in several communities could draw unwanted attention to those communities. Names and locations of these communities may need to be disguised and any indirect identifying information about them removed.

- **Community Customs & Codes of Practice**

Role of Elders & Knowledge Keepers

Confidentiality

Community Rights

Human Rights



TCPS 2
Ch.5



Intellectual Property Rights

Intellectual property rights related to doing collaborative research should be a point of discussion between the researchers, the community and the institution. The discussion should include what qualifies as intellectual property for the purposes of research. A clear understanding of the criteria and any relevant law that may apply is a joint responsibility of researchers, the community and the institutions.

Intellectual property rights may include community access to data and involvement in interpretation and dissemination (e.g., co-authorship).

If commercial application of the research is possible, the research agreement should address the expectations of the community, the researchers and the institution.

TCPS 2
9.17

TCPS 2
9.18

- Community Customs & Codes of Practice
- Recognizing the Role of Elders & Other Knowledge Keepers
- Privacy & Confidentiality
- Intellectual Property Rights
- Collection of Human Biological Materials



Collection of Human Biological Materials

When research involves the collection of human biological materials, the rights and propriety interests of participants and communities must be specified in a research agreement. The roles and responsibilities regarding custodianship, collection of data, storage and usage should also be noted.

For example, First Nations, Inuit and Métis people may request control over, and access to, data and human biological materials collected for research. The research agreement should specify exactly how and when the human biological materials will be destroyed, or returned to the community, and at what date this will happen.

In some cases, biological materials collected for other purposes (e.g., diagnostic tests) may later be found to have a secondary use. If researchers expect that there will be another purpose for biological materials, this secondary use should be discussed in the research agreement. Secondary use of biological materials is addressed in Chapter 12 of TCPS 2.

TCPS 2
Ch.12

TCPS 2
9.19

TCPS 2
9.20

- Community Customs & Codes of Practice
- Recognizing the Role of Elders & Other Knowledge Keepers
- Privacy & Confidentiality
- Intellectual Property Rights
- Collection of Human Biological Materials





Requirements of REB Review

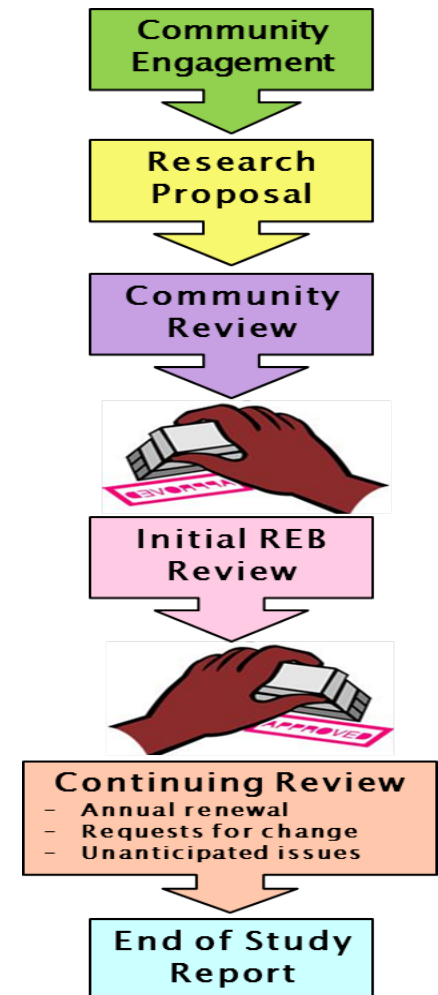
For research that is conducted under the auspices of an institution that receives research funding from the Canadian Institutes of Health Research ([CIHR](#)), the Natural Sciences and Engineering Research Council ([NSERC](#)) or the Social Sciences and Humanities Research Council ([SSHRC](#)), REB Review from that institution is required. This is true even if research ethics review has already been done by community REBs or other responsible bodies.

Researchers must advise their REB on how they plan to engage the community before research begins. The REB will want to know the details of the community engagement plan and whether there will be a research agreement. If the nature of the research does not require community engagement, researchers must provide a rationale acceptable to the REB.

TCPS 2
6.1

TCPS 2
9.9

TCPS 2
9.10





What's in a Research Agreement?

Apply what you have learned so far. Read the case studies involving one or more First Nations, Inuit or Métis communities on the following pages.

The researcher is seeking advice about community engagement and research agreements. Your task is to identify issues related to community engagement and research agreements, cite the TCPS 2 articles that apply and make a recommendation as to how each issue could be addressed. This is an exercise you can do on your own or with a group.

Make sure you have access to [TCPS 2](#). Then see if you can find the guidance in TCPS 2 that would apply. What changes would you make to each study plan to make it consistent with the core principles of TCPS 2 (2014)?

- **Exploring an urban HIV/AIDS prevention strategy**
- **The impact of generational knowledge translation on cohesion in an Inuit community**
- **Do organically-based diets improve health status for First Nations communities?**





What's in a Research Agreement?

Exploring an Urban HIV/AIDS Prevention Strategy

A public health research team plans to assess the health service needs of urban Aboriginal people living with HIV and AIDS. Previous research shows that this community of interest is not being served by standard intervention strategies. The focus will be on urban Aboriginal people who may be in vulnerable circumstances for several reasons. They might migrate often between rural, urban and territorial locations. They may have personal circumstances that prevent access to effective interventions. Those who are homeless, work in the sex trades, or are addicted to drugs often fall outside the network of readily available services.

Participants will be recruited from the population of Métis, Inuit and First Nations individuals over 14 years of age who currently live on the streets in Montreal and Ottawa. Recruitment and participation will take place at community drop-in centres and friendship centres. All participants will be interviewed about their personal, health and migration history. At the end of each interview, each participant will get an appointment with a health team affiliated with the study for a medical examination – a complete physical. A follow-up appointment will be scheduled to discuss the results. At the follow-up appointment, each participant will be invited to attend a focus group meeting to share experiences accessing services and support networks and to discuss possible interventions and health management strategies.

The study's goal is to determine the extent to which participants currently access services and/or support networks, what effects these services have on the incidence of HIV and AIDS, and how access to services could be improved.

What are the ethical issues that would need to be addressed in the context of community engagement and research agreements in this case study?

Consult [TCPS 2](#) online to see what guidance would apply to these issues.

What changes would you recommend to make the plan consistent with TCPS 2?



What's in a Research Agreement?

Exploring an Urban HIV/AIDS Prevention Strategy	
Ethical Issues	TCPS 2 Guidance
Determination of community authorities	9.1, 9.2, 9.3, 9.4, 9.5, 9.15
Privacy and confidentiality	Chapter 5 and 9.16
Consent issues	3.1, 3.2, 3.9, 3.10, 3.12, 4.6
Use of human biological materials	3.2, 9.19, 9.20 and Chapters 12 & 13
Incidental findings	3.4

Review the list of issues and relevant articles. Did you consult the same articles in [TCPS 2](#) ? Did you find other issues?

Discuss how applying TCPS 2 guidance from the beginning of the project could affect community engagement, research design and research ethics review.

Were there questions unresolved by the guidance? Refer back to the [core principles](#) in Chapter 9 to help resolve outstanding issues.



What's in a Research Agreement?

Impact of Generational Knowledge Translation on Cohesion in an Inuit Community

A musicologist proposes to spend several years working with an Inuit community to document the traditions of passing musical heritage and stories to the younger generations. She is also interested in the possible effects of the transmission of cultural heritage on community cohesion. She intends to transcribe accounts of this process from conversations with the community's Elders. In addition she will include previously published accounts of this community's cultural traditions from the work of the researchers who have come before her.

As a frequent visitor the musicologist will observe the life of the community. She will interview residents to assess their mental and emotional well-being, the extent of their participation in cultural transmission opportunities, and their community engagement. Once her data collection is complete, she plans to curate a collection of the songs and stories for an exhibit on the effects of cultural transmission on community cohesion. The musicologist will also publish her findings in a peer-reviewed journal.

What are the ethical issues that would need to be addressed in the context of community engagement and research agreements in this case study?

Consult [TCPS 2](#) online to see what guidance would apply to these issues.

What changes would you recommend to make the plan consistent with TCPS 2?



What's in a Research Agreement?

Generational Knowledge Translation and Cohesion in an Inuit Community	
Ethical Issues	TCPS 2 Guidance
Intellectual property	9.18
Identification and involvement of Elders	9.15
Permission of formal and informal authorities	9.3
Consideration of diverse interests within the Community	9.6
Risks and responsibilities of observational research	2.3, 9.8, 10.3

Review the list of issues and relevant articles. Did you consult the same articles in [TCPS 2](#) ? Did you find other issues?

Discuss how applying TCPS 2 guidance from the beginning of the project could affect community engagement, research design and research ethics review.

Were there questions unresolved by the guidance? Refer back to the [core principles](#) in Chapter 9 to help resolve outstanding issues.



What's in a Research Agreement?

Do Organically-Based Diets Improve Health in First Nations Communities?

An environmental soil and plant scientist and a multi-disciplinary research team want to study the effect of organic farming practices on health in First Nations communities over 3 to 5 years. The team's hypothesis is that communities trained to produce and consume food using traditional and organic farming practices will be healthier than those whose food is produced using pesticides.

Members of four communities that have high rates of chronic illnesses (e.g., diabetes, hypertension, asthma) will be invited to participate. Participants will be assigned to one of two groups. Participants who are willing to be involved in a sustainable nutrition training program will be assigned to the group that receives training from Elders and members of the research team in traditional organic gardening, agro-ecology and organic food entrepreneurship. Participants who prefer to maintain their conventional/processed food choices will be in the group that will be invited to attend workshops on healthy meals using the commercially available foods they prefer. Once each year, participants will be interviewed about their food preferences and knowledge of the nutritional value of their food.

Baseline measures of blood sugar, glycemic index, cholesterol levels and red and white blood cell counts will be taken to assess each participant's health in both groups. Samples of the foods participants eat will be analyzed for nutritional value and chemical content. These measures will be repeated periodically during the project. The team expects to produce presentations and papers in the areas of environmental science, nutrition and health, as well as education and training.

What are the ethical issues that would need to be addressed in the context of community engagement and research agreements in this case study?

Consult [TCPS 2](#) online to see what guidance would apply to these issues.

What changes would you recommend to make the plan consistent with TCPS 2?



What's in a Research Agreement?

Do Organically-Based Diets Improve Health in First Nations Communities?

Ethical Issues	TCPS 2 Guidance
Mutual benefits in research	9.11, 9.13
Respect for community codes and practices	9.8, 9.19 and Chapter 12
Scholarly review: Methodological issues	2.7
Secondary use of data and biological materials	2.4, 5.5, 5.6, 9.20, 9.22, 12.3, 12.4
Privacy and confidentiality	5.1, 5.2, 9.16
Interpretation and dissemination of research results	9.7, 9.8

Review the list of issues and relevant articles. Did you consult the same articles in [TCPS 2](#)? Did you find other issues?

Discuss how applying TCPS 2 guidance from the beginning of the project could affect community engagement, research design and research ethics review.

Were there questions unresolved by the guidance? Refer back to the [core principles](#) in Chapter 9 to help resolve outstanding issues.



Summary

- The core principles of TCPS 2 centre around respect for human dignity and are interpreted in Aboriginal contexts in Chapter 9: Research Involving First Nations, Inuit and Métis Peoples of Canada.
- Benefits of research should be equitable and reciprocal; decision-making is shared between communities and researchers.
- Community engagement is a key element of research involving First Nations, Inuit and Métis Peoples.

Additional resources:



[Toolbox of research principles in an aboriginal context – First Nations of Quebec and Labrador Health and Social Services Commission](#)



[Negotiating Research Relationships with Inuit Communities - A Guide for Researchers](#)



[CIHR Guidelines for Health Research Involving Aboriginal People](#)





Acknowledgements

The [Panel on Research Ethics](http://www.pre.ethics.gc.ca) (PRE) would like to thank the Advisory Committee on TCPS 2 Chapter 9: Research Involving First Nations, Inuit & Métis Peoples of Canada. Members of the committee included:

- Judith Bartlett
- Julie Bull
- Heather Castleden
- Joyce Helmer
- Julien Hountin
- John (Cle-alls) Medicine Horse Kelly
- Lucie Levesque
- Debra Martin
- Amy Nahwegahbow
- Cynthia Stirbys
- Debra Webster



Appendices

SAMPLE AGREEMENT
Provided by the Centre for Indigenous Peoples'
Nutrition and Environment (CINE)

Project Title

Research Agreement

Date

(Name of organization)_____ agrees to conduct the named research project with the following understandings:

1. The purpose of this research project, as discussed with and understood in the community of _____, is:

2. The scope of this research project (that is, what issue, events or activities are to be involved, and the degree of participation by community residents), as discussed with and understood in this community, is: _____
3. The methods to be used, as agreed by the researchers and the community, are: _____
4. Community training and participation, as agreed, are to include:

The development of this project is based on sincere communication between community members and researchers. All efforts will be made to incorporate and address local concerns and recommendations at each step of the project.

At the end of the project, the researchers will participate in community meetings to discuss the results of the analysis with community members.

5. Information collected is to be shared, distributed, and stored in these agreed ways: _____

The data collected is confidential and no name is attached to a record. Copies will be kept at CINE where the data will be

converted to an electronic form. The data will be kept on diskettes in the community, at CINE. The researchers and CINE will be available to answer questions and assist community members should community members decide to use the data for different purposes; a final report will be distributed after approval from the community members.

6. Informed consent of individual participants is to be obtained in these agreed ways: _____

An individual consent form will be read by the interviewer to the respondent. A copy of the consent form will be left with the respondent where the address of each researcher can be used at any time, should the respondent wish to contact the researcher(s) for additional information.

7. The names of participants and of the community are to be protected in these agreed ways: _____

As mentioned on the consent form, the interviews are confidential. In no instance will the name of a respondent be attached to a record.

Before distribution of the final report, or any publication or contact with the media, the community will be consulted once again as to whether the community agrees to share this data in that particular way.

8. Project progress will be communicated to the community in these agreed ways: _____
9. Communication with the media and other parties (including funding agencies) outside the named researchers and the community will be handled in these agreed ways: _____

Funding, benefits and commitments

Funding

The main researchers have received funding and other forms of support for this research project from: _____

The funding agency has imposed the following criteria, disclosures, limitations, and reporting responsibilities on the main researchers.

Benefits

The main researchers wish to use this research project for their benefit in the following ways (for instance, by publishing the report and articles about it): _____

The researchers will submit a final report to the funding agency in 20XX. Scientific presentations in peer-reviewed publications and conferences will be made. The final report will be reviewed by community members prior to publication. Scientific presentations will be made and articles published after discussion with the respective community leaders.

The benefits likely to be gained by the community through this research project are:

- Educational
- Informational
- Financial

Commitments

The community's commitment to the researchers is to:

- Recommend capable and reliable community members to collaborate or to be employed in this project.
- Keep informed about the progress of the project, and help in leading the project toward meaningful results.

The researchers' main commitment to the community is to:

- Inform the community about the progress of the project in a clear, specific, and timely manner.
- Act as a resource to the community on nutrition-related questions.

The researchers agree to interrupt the research project in the following circumstances: _____

- If community leaders decide to withdraw their participation.
- If the researchers believe that the project will no-longer benefit the community.

Signed by:

Date:

Date:

Community:

(Signature of Main
Researcher)

(Signature of Community Contact
Person)

Name:

Name:

Position:

Position:

RESEARCH PROJECT PARTNERSHIP AGREEMENT
An Exploratory Study of the Contribution of Equine-Assisted Learning
in the Treatment and Wellbeing of First Nations Youth
Who Abuse Solvents

Research Team Members

- Ernie Sauve, Executive Director, White Buffalo Youth Inhalant Treatment Centre
- Tamara Mackinnon, Program Director, Cartier Equine Learning Centre
- Colleen Anne Dell, Department of Sociology & School of Public Health, University of Saskatchewan
- Debra Dell, Coordinator, Youth Solvent Addiction Committee
- Darlene Chalmers, Faculty of Social Work, University of Regina
- Cindy Adams, Faculty of Veterinary Medicine, University of Calgary

The researchers, as named above and identified as “the partners”, agree to conduct the above named research project with the following understanding:

- 1. The purpose of this research project, as discussed with and understood by the university and community partners, is to answer the question: *Does EAL contribute to the residential treatment and the bio-psycho-social-spiritual healing of First Nations youth from solvent abuse, and if so, to what extent and how?* In answering this question, the aim of this research is:**
 - to examine the contribution of Cartier’s equine-assisted learning formula to the bio-psycho-social-spiritual wellbeing of First Nations youth from White Buffalo who participate in Cartier’s program, and
 - to develop and apply culturally competent EAL measures.
- 2. The approach and principles guiding the research project as discussed with and understood by “the partners” are that:**
 - the study will be carried out in active partnership by a community-based research team.
 - the study will involve the development of an Advisory Group (National Native Addictions Partnership Foundation, Siksika First Nation) and Research Assistants.
 - the approach to our study is rooted in Western and Indigenous knowledge systems (including YSAC’s culture-based model of resiliency)
 - we share the concepts of hope and inspiration, and understand the reciprocal intentions of our work together.
 - decision-making power will be shared by all partners in all stages of the study.
 - the study is relevant to everyone involved.

- that the *CIHR Guidelines for Health Research Involving Aboriginal Peoples* (2008) and the OCAP principles (ownership, control, access, possession) will direct the study.

-

3. The scope of this research project (e.g., issues, events, and/or activities that are to be involved), and the degree of participation by “the partners” as discussed with and understood by “the partners” are:

- outlined in the proposal submitted to the Alberta Centre for Child, Family & Community Research.
- that White Buffalo will provide designated in-kind resources (e.g., staff time) to facilitate data collection at the treatment centre. This will include providing program and school time for the youth to journal, staff recording in client files the youths’ attitudes and behaviors, and participation of youth and staff in interviews post EAL program.
- that Cartier will provide resources (e.g., staff time) to facilitate data collection at the EAL program site. This will include participating in interviews post EAL program.
- that the university researchers and YSAC coordinator will contribute their time to carry out the research project with no remuneration apart from their current university/YSAC salary.
- that at the design, conducting and analysis phase of the research project, all partners will provide input and feedback on the emerging themes from the data that the university researchers will take the lead on analyzing.

4. Methods to be used, as agreed by the research partners, are:

- an exploratory study capturing the lived experiences of the participants. Of critical importance is capturing in their own words the youths’ experience of participating in the EAL program, White Buffalo staff, and Cartier EAL facilitators.
- multiple, triangulated methods that will be used to collect the data and will include interviews with the youth, client written and video journaling, interviews with the Cartier EAL program facilitators, interviews with White Buffalo staff, and White Buffalo staff recordings in client files and video reflections.
- psychological tools will include, for example, the Harter Self-Perception Scale and the Jewel Equestrian Scale.

5. Community training and participation, as agreed, is to include:

- a capacity building and knowledge exchange workshop between the members of the research team and the staff of White Buffalo will be organized at the start of the project. This workshop which will initiate the project is for the purpose of information sharing related to research methods generally and this study more specifically.

- the staff and Elders of White Buffalo will serve in an advisory capacity on the cultural competency and youth solvent abuse population appropriateness of the Western-originated outcome measures. An Advisory Committee will be developed to provide expert guidance to the project and will be asked for input when required by the research team.

6. Information collected is to be shared, distributed, and stored in these agreed ways:

- any information gathered cannot be made public without agreement and consent of all research team members.
- any data recommending changes in the service delivery of the program(s) will: (1) be shared with the programs, and (2) will not be made public without the program(s) consent.
- information will be stored according to University of Saskatchewan Ethics, University of Calgary Ethics, and University of Regina Ethics guidelines according to the respective Human Ethics Review Boards.
- collection of information for purposes beyond the scope of this research project will not occur without discussion, approval, and consent of the research team.

7. Informed consent of individual participants is to be obtained in these agreed ways:

- that this study is required to receive university ethics board (University of Saskatchewan, University of Calgary, University of Regina) approval to ensure that no harm will be done to the participants (e.g. informed consent).
- that this study will also ensure that no harm will come to the horses through the Cartier Equine Learning Centre's adherence to industry standards
 - i. that this study adhere to White Buffalo's accreditation standards for research (which is typically fulfilled by acquiring University research ethics board approval for a study): there is an external review for all research projects conducted at the Centre
 - ii. risks and benefits of the study are clearly outlined
 - iii. the research process is clearly outlined
 - iv. the research design is adequate
 - v. the impact on organizational resources are identified upfront
 - vi. there is a process for informed consent in the study.

8. The names of participants are to be protected in these agreed ways:

- as stated in (7) above, this study is required to receive university ethics board approval (University of Saskatchewan, University of Calgary, University of Regina) to ensure that anonymity and confidentiality are maintained related to the participants and staff.
- the data collected are confidential and no name is attached to a record outside of the programs.
- confidentiality is adhered to as per the policies and procedures of the White Buffalo and Cartier programs.

9. Project progress will be communicated amongst the partners in these agreed ways:

- face-to-face, conference calls, and electronic updates (i.e., email) will be scheduled at regular intervals as set out and agreed to by the team at the start of the project.

10. Communication with the media and other parties (including funding agencies) will be handled in these agreed ways:

- a team member, as agreed to by the partners, will be designated as the initial media contact person: Colleen Anne Dell for research specific questions; Ernie Sauve for White Buffalo specific questions; Tamara Mackinnon for Cartier specific questions.
- a team member, as agreed to by the partners, will be designated as the funding agency(s) contact person: Darlene Chalmers for the Alberta Centre for Child, Family & Community Research.
- requests by the public to any of the partners for information related to the project that is not yet in the public domain in terms of research findings will be forwarded to the team for discussion and approval.

Benefits

The study will be of notable significance in the two areas under investigation: First Nations youth solvent abuse residential treatment and EAL. The research partners wish to use this research project for benefit in these ways:

- a published final report* to the funding agency as per the funding requirements (*authorship order to be determined at start of any product)
- presentations at peer-reviewed conferences (*)
- peer-reviewed and grey literature publications (*)
- media awareness and other venues as agreed upon by the research team.

Commitments

The partners' commitment to the research project is to:

- keep informed on the project progress, and help in leading the project toward meaningful results
- maintain communication that is timely and respectful
- consult with the team on any circumstances or conditions that may require discontinuation of the research project (i.e., if it is determined and agreed to by the team that the project will no longer be of benefit to either program)
- incorporate recommendations from the findings that will contribute to improving the efficacy of the respective programs.

This research partnership agreement is not legally binding and is agreed to in the spirit of conducting a mutually respectful, co-operative research project.

Partner Signature**Date**

Ernie Sauve, Executive Director, White Buffalo Youth Inhalant Treatment Centre

Tamara Mackinnon, Program Director, Cartier Equine Learning Centre

Debra Dell, Coordinator, Youth Solvent Addiction Committee

Colleen Anne Dell, Department of Sociology & School of Public Health,
University of Saskatchewan

Darlene Chalmers, Faculty of Social Work, University of Regina

Cindy Adams, Faculty of Veterinary Medicine, University of Calgary

Partnership agreement signing ceremony June 30, 2010

Partnership Developed to Study Equine-Assisted Learning (EAL)

On June 30, 2010 a two-year research project was launched to study the effects of equine-assisted learning in the treatment of First Nations youth solvent abuse. The project began officially with an Elder ceremony and signing of a Research Partnership Agreement. The study represents a unique collaboration between the White Buffalo Youth Inhalant Treatment Center, a non-profit organization located at Sturgeon Lake First Nation and the Cartier Equine Learning Centre, a full service equine facility located north of Prince Albert Saskatchewan. Cartier provides a nationally recognized EAL Certification Program through its Academy of Equine-Assisted Learning. The signing ceremony for the research partnership is symbolic of the research team's approach to knowledge building and collective understanding in this area.

The research team involves the partnering of researchers from three universities (University of Calgary, University of Saskatchewan, University of Regina) and national representation from the Youth Solvent Addiction Committee, the National Native Addictions Partnership Foundation, and the Canadian Centre on Substance Abuse. The project is guided by an advisory team including an Elder and a youth treatment graduate from Saskatchewan, as well as representation from Siksika Medicine Lodge located in Southern Alberta. Principle Investigator, Dr. Colleen Dell comments that "active partnership is vital to ensuring that the study is owned and directed by the community and that the research outcomes are relevant to the partners involved".

The purpose of the study is to explore how the use of equine-assisted learning in youth solvent abuse treatment may contribute to youth behavioral change and increased physical, psychological, emotional and spiritual wellbeing. The linkage between what is commonly termed 'horse therapy' or equine guided interventions and treating individuals who problematically use substances has gained increased attention in Canada over the past several years. Tamara Mackinnon, Program Director at Cartier Equine Learning Center describes their EAL approach as "complementary with the existing program at the White Buffalo Inhalant Treatment Centre, bringing two strong programs together to reinforce and influence positive change in young lives".

The University of Calgary, Faculty of Veterinary Medicine's co-principle investigator Dr. Cindy Adams, explains that "an important aspect of the study's partnership model also emphasizes understanding the effect of the human-equine partnership in the lives of the youth". The White Buffalo Inhalant Treatment Centre has incorporated the Cartier Equine-Assisted Learning Program as a treatment adjunct for more than five years. White Buffalo Executive Director Ernest Sauve explains, "this approach is not entirely new, but is a return or reintroduction to what is already known about the horse within a cultural context". However, research on the potential benefits of including the

horse within educational and life skills programs with this population is limited and highlights the importance of undertaking the research study.

Plans for a Horse Dance, a culturally significant ceremony, will bring community and research partners together again in the fall.

This project is funded by the Alberta Centre for Child, Family and Community Research, an innovative Alberta-based resource that supports the development of research evidence and policy for child youth and family health and wellbeing.

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