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Issues and Options for Revisions to the  
*Tri-Council Policy Statement on Ethical Conduct of Research  
Involving Humans (TCPS):*  
Section 6: Research Involving Aboriginal Peoples

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**Aboriginal Research Ethics Initiative (AREI)**  
of the Interagency Advisory Panel on Research Ethics (PRE)

Report prepared with the Assistance of

*PRE's Technical Advisory Committee on Aboriginal Research  
(PRE-TACAR)*

and the

*Guiding Consortium for the Development of TCPS Guidelines for  
Research Involving Aboriginal Peoples*



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## TABLE OF CONTENTS

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|   |           |
|---|-----------|
| <b>PURPOSE OF THIS DOCUMENT .....</b>   | <b>1</b>  |
| <b>Part 1:BACKGROUND .....</b>  | <b>1</b>  |
| <b>1.1 The Tri-Council Policy Statement: Ethical Conduct for Research<br/>        Involving Humans (TCPS) .....</b> | <b>1</b>  |
| <b>1.2 PRE’s Aboriginal Research Ethics Initiative and Parallel Initiatives .....</b>                               | <b>3</b>  |
| <b>Part 2:REDEFINING RESEARCH RELATIONSHIPS .....</b>   | <b>5</b>  |
| <b>2.1 Aboriginal Peoples’ Participation in Research .....</b>  | <b>5</b>  |
| <b>2.2 An Evolving Culture of Research and Ethics .....</b>   | <b>6</b>  |
| <b>2.3 Scope of Community Codes and the TCPS .....</b>  | <b>7</b>  |
| <b>Part 3:KEY CONSIDERATIONS IN RESEARCH INVOLVING<br/>        ABORIGINAL PEOPLES .....</b>                         | <b>8</b>  |
| <b>3.1 Respect for Human Dignity: A Core Ethical Value .....</b>  | <b>8</b>  |
| <b>3.2 Respect for Aboriginal Diversity .....</b>   | <b>9</b>  |
| <b>3.3 Respect for Indigenous Knowledge Systems .....</b>   | <b>10</b> |
| <b>3.4 Respect for Cultural Heritage .....</b>  | <b>11</b> |
| <b>Part 4:APPLYING ETHICAL PRINCIPLES IN ABORIGINAL CONTEXTS .....</b>  | <b>12</b> |
| <b>4.1 Types of Community and Modes of Representation .....</b>   | <b>12</b> |
| <b>4.2 Communities Within Communities .....</b>   | <b>14</b> |
| <b>4.3 Research Agreements .....</b>  | <b>15</b> |
| <b>4.4 OCAP Principles .....</b>  | <b>16</b> |
| <b>4.5 Cultural and Intellectual Property .....</b>   | <b>17</b> |
| <b>4.6 Privacy and Confidentiality .....</b>  | <b>18</b> |
| <b>4.7 Equitable Distribution of Risks and Benefits .....</b>   | <b>19</b> |
| <b>Part 5:ETHICS REVIEW PROCESSES .....</b>   | <b>20</b> |
| <b>5.1 Parallel Ethics Review Processes .....</b>   | <b>20</b> |
| <b>Part 6:RECOMMENDATIONS FOR PRE’S CONSIDERATION .....</b>   | <b>21</b> |
| <b>6.1 Recommendation for TCPS Revisions .....</b>  | <b>21</b> |
| <b>APPENDIX A – First Nations .....</b>   | <b>25</b> |
| <b>APPENDIX B – Inuit .....</b>   | <b>32</b> |
| <b>APPENDIX C – Métis .....</b>   | <b>40</b> |
| <b>APPENDIX D – Urban Aboriginals .....</b>   | <b>47</b> |





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## **PURPOSE OF THIS DOCUMENT**

This paper seeks to

- 1) To set out the context of ethics in research involving Aboriginal peoples, communities and individuals;
- 2) To identify prospective revisions to Section 6 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS);
- 3) To build on existing guidelines as appropriate, including current provisions of the TCPS and Canadian Institutes of Health Research (CIHR) *Guidelines for Health Research Involving Aboriginal People* (2007);
- 4) To clarify the application of the TCPS in relation to parallel codes of ethics, including codes and protocols adopted by Aboriginal organizations and communities.

The paper is a report to the Interagency Advisory Panel on Research Ethics (PRE) based on the work of various committees under PRE's Aboriginal Research Ethics Initiative. It will inform further deliberations by PRE on ethics of research involving Aboriginal peoples. Comments on this report and recommendations contained herein will assist PRE in drafting revisions to the TCPS, including the current Section 6.

Consultations on a draft 2<sup>nd</sup> edition of the TCPS will take place in the Fall of 2008 with a view to finalizing PRE's recommendations on a 2<sup>nd</sup> edition to be presented to CIHR, SSHRC and NSERC in mid-2009.

Comments from Aboriginal communities and organizations and the research community at large on the present report are welcome and may be forwarded to [arei@pre.ethics.gc.ca](mailto:arei@pre.ethics.gc.ca)

### **Part 1: BACKGROUND**

#### **1.1 The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)**

The TCPS<sup>1</sup> was adopted in 1998 as a joint policy of the three federal granting Agencies: Canadian Institutes of Health Research (CIHR)<sup>2</sup>, Natural Sciences and Engineering Research Council (NSERC) and Social Sciences and Humanities Research Council (SSHRC).

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<sup>1</sup> <http://www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm>

<sup>2</sup> The Canadian Institutes of Health Research replaced the Medical Research Council which was dissolved in 2000.



The TCPS consists of an ethics framework and 10 sections. Consistent with and inspired by international norms, it outlines guiding ethical principles and covers standards and procedures for research ethics review, informed consent, privacy and confidentiality, conflict of interest, and justice and inclusion in research. It addresses issues in particular fields such as research with Aboriginal peoples, clinical trials, and genetic research.

All researchers and institutions who are eligible to receive or administer funding from the Agencies are required to adhere to the guidelines set out in the TCPS. A number of federal and provincial government departments and other research entities also refer to the TCPS as a standard of ethical practice.

In Section 6 of the TCPS the Agencies affirm that “aboriginal peoples have rights and interests which deserve recognition and respect by the research community”<sup>3</sup>. The TCPS describes some best practices in research involving Aboriginal people but refrains from elaborating guidelines on the ground that sufficient consultation with Aboriginal peoples had not yet been carried out at the time of writing.

The Good Practices are as follows:

### ***B. Good Practices***

*Researchers and REBs involved with Aboriginal communities should consider the following "good practices," which have been drawn from the documents referred to above:*

- *To respect the culture, traditions and knowledge of the Aboriginal group;*
- *To conceptualize and conduct research with Aboriginal group as a partnership;*
- *To consult members of the group who have relevant expertise;*
- *To involve the group in the design of the project;*
- *To examine how the research may be shaped to address the needs and concerns of the group;*
- *To make best efforts to ensure that the emphasis of the research, and the ways chosen to conduct it, respect the many viewpoints of different segments of the group in question;*
- *To provide the group with information respecting the following:*
  - *Protection of the Aboriginal group's cultural estate and other property;*
  - *The availability of a preliminary report for comment;*
  - *The potential employment by researchers of members of the community appropriate and without prejudice;*
  - *Researchers' willingness to cooperate with community institutions;*
  - *Researchers' willingness to deposit data, working papers and related materials in an agreed-upon repository.*

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<sup>3</sup> TCPS, 6.1

- *To acknowledge in the publication of the research results the various viewpoints of the community on the topics researched; and*
- *To afford the community an opportunity to react and respond to the research findings before the completion of the final report, in the final report or even in all relevant publications (see Section 2 on information disclosure).*

*Aboriginal Peoples may wish to react to research findings. It is inappropriate for researchers to dismiss matters of disagreement with the group without giving such matters due consideration. If disagreement persists, researchers should afford the group an opportunity to make its views known, or they should accurately report any disagreement about the interpretation of the data in their reports or publications.*

## **1.2 PRE's Aboriginal Research Ethics Initiative and Parallel Initiatives**

On release of the TCPS in 1998, the Agencies committed to regular updates of the document to respond to ongoing changes in social values, research practice and law. The Interagency Advisory Panel on Research Ethics (PRE)<sup>4</sup> was created in late 2001 with a mandate from the three federal Agencies to provide independent, interdisciplinary reflection and advice on the evolution, use and interpretation of the TCPS.

PRE has set a high priority on developing robust guidelines on Aboriginal research for inclusion in the TCPS through its Aboriginal Research Ethics Initiative (AREI) which is further described below. PRE, in concert with the Agencies, designated Aboriginal research ethics a priority in 2003. Following a public call for nominations an Aboriginal member was added to PRE<sup>5</sup>. A Consortium to provide policy advice was convened in 2004<sup>6</sup>, including representation from five national Aboriginal organizations<sup>7</sup>, the three granting Agencies and federal departments with an interest in the TCPS and Aboriginal research.

The Consortium has adopted PRE's guiding principles of adhering to open, inclusive and participatory public processes. To respect Aboriginal viewpoints in the policy dialogue, PRE has made a commitment that consensus advice from the Consortium will be reflected in PRE's recommendations to the Agencies on revisions to the TCPS. If consensus is not achieved on an issue, either it will be carried forward for further work or the dissenting views and their underlying rationale will be noted for the Agencies.

A Technical Advisory Committee on Aboriginal Research, PRE-TACAR, has also been convened, to provide broad advice from the perspectives of diverse academic disciplines as well as community researchers. Deliberations of PRE-TACAR and the Consortium

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<sup>4</sup> [www.pre.ethics.gc.ca](http://www.pre.ethics.gc.ca)

<sup>5</sup> Marlene Brant Castellano, Professor Emeritus of Trent University and former Co-Director of Research with the Royal Commission on Aboriginal Peoples was appointed to PRE in June 2003. She chairs the Aboriginal Research Ethics Initiative (AREI).

<sup>6</sup> <http://www.pre.ethics.gc.ca/english/workgroups/aboriginal/torgc.cfm>

<sup>7</sup> Assembly of First Nations, Métis National Council, Inuit Tapiriit Kanatami, Congress of Aboriginal Peoples, Native Women's Association of Canada

draw on public input, PRE's commissioned background papers, and insights from parallel initiatives.

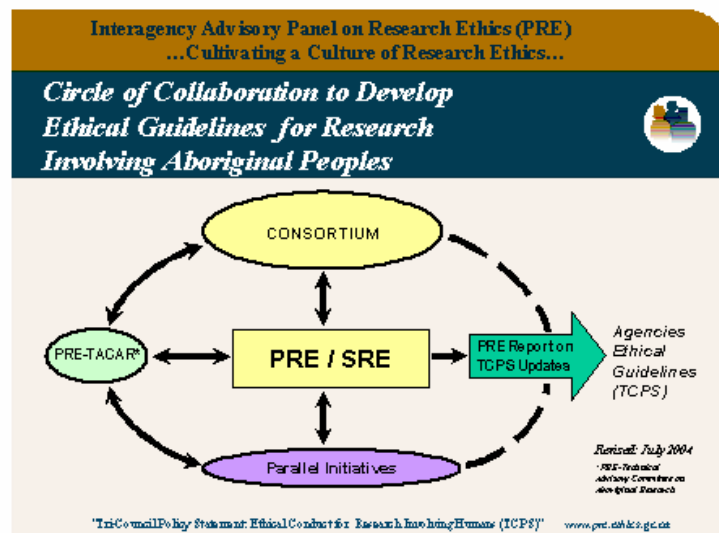
Since the release of the TCPS in 1998 there have been important developments in Aboriginal research and research ethics. First Nations, Inuit and Métis peoples and communities are asserting a more active role in directing research affecting them. Communities, organizations and research institutions have formulated a number of ethical codes to guide research practice.

In May 2007 the Canadian Institutes of Health Research (CIHR) released *Guidelines for Health Research Involving Aboriginal People*,<sup>8</sup> a document developed under the leadership of CIHR Ethics Office and the Institute of Aboriginal Peoples' Health, one of the thirteen CIHR institutes. The CIHR guidelines establish an important benchmark as the first Canada-wide policy on research ethics that recognizes the cultural distinctiveness of Aboriginal peoples, the need for safeguards in light of past ethical violations, and the importance of partnerships between researchers and Aboriginal communities involved in research.

The next phase in developing tri-council policy on Aboriginal research involves expanding the dialogue to engage the social sciences and humanities and the natural sciences and engineering research communities, incorporating input from the broad Aboriginal community, and developing content for an updated version of the TCPS that provides guidelines for researchers and institutions seeking to respect varying codes and perspectives.

Figure 1, below, displays the relationships among participants in PRE's Circle of Collaboration. Terms of Reference for the Consortium and PRE-TACAR can be viewed at <http://www.pre.ethics.gc.ca/english/workgroups/aboriginal/torgc.cfm>.

Figure 1



<sup>8</sup> Canadian Institutes of Health Research (2007) CIHR *Guidelines for Health Research Involving Aboriginal People*, <http://www.cihr-irsc.gc.ca/e/29134.html>

## Part 2: REDEFINING RESEARCH RELATIONSHIPS

PRE's initiative to develop ethical guidelines for research involving Aboriginal peoples is situated in a broader movement transforming the relationship between Aboriginal peoples and Canadian society. Research has a critical role to play in creating the knowledge base for mutually respectful relationships and full participation in Canadian life, with all its responsibilities and benefits.

In this section we affirm the distinct place that Aboriginal peoples occupy in Canadian society and note the diversity among First Nations, Inuit and Métis and their approaches to research participation and ethical safeguards. Complementary developments in ethics and research practice endorsed by the federal granting Agencies, universities and some federal government departments are cited. This section also clarifies the application of the TCPS in relation to parallel codes of ethics, including codes and protocols adopted by Aboriginal organizations and communities.

Generic provisions for the TCPS are proposed later in the document, in Section 6 below.

### 2.1 Aboriginal Peoples' Participation in Research

First Nations, Inuit and Métis peoples occupy a distinct place in Canadian society. Aboriginal and treaty rights of Aboriginal peoples were recognized and protected in the Constitution Act of 1982. The content and impact of those rights have been debated and litigated over the past 25 years, resulting in some clarifications and leaving many questions unresolved.

Many First Nation communities, in concert with their representative organizations, have adopted protocols and ethical codes as an expression of their inherent right to self-government.<sup>9</sup> Land claims organizations in Inuit territories are mandated to review and approve research carried out in affected territories.<sup>10</sup> Research has been pivotal in giving substance to constitutional recognition of the Métis, and their representative organizations are working to increase capacity for research under their own direction. Native women have taken the lead in research on violence against Aboriginal women, countering the

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<sup>9</sup> See: First Nations Centre (2007). *OCAP: Ownership, Control, Access and Possession*. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization; and Kahnawake Schools Diabetes Prevention Project (2007) *Code of Research Ethics*. Kahnawake, Quebec. Accessed at [http://www.ksdpp.org/elder/code\\_ethics.html](http://www.ksdpp.org/elder/code_ethics.html) October 16, 2007.

<sup>10</sup> See: ITK and NRI (2007). *Negotiating Research Relationships with Inuit communities: A Guide for Researchers*. Scot Nickels, Jamal Shirley and Gita Laidler (eds), Inuit Tapiriit Kanatami and Nunavut Research Institute: Ottawa and Iqaluit; and Section 17.13.1(f) and (k) of the *Land Claims Agreement Between the Inuit of Labrador and Her Majesty the Queen in Right of Newfoundland and Labrador and Her Majesty the Queen in Right of Canada* (2005), which states:

The Nunatsiavut Government may make laws in Labrador Inuit lands and the Inuit communities in relation to ... health related research involving Inuit, including establishment of ethical standards for and the ethical review of medical research involving Inuit ... and the creation of boards, authorities and other entities to establish, manage and operate health care and research programs, services and related facilities.

neglect of issues of critical importance to their safety. Pan-Aboriginal and urban organizations are similarly seeking a more influential role in research affecting their lives.

Despite the diversity among First Nations, Inuit and Métis communities and the different approaches to asserting agency in research, Aboriginal peoples have common goals. They act collectively to ensure that research does no harm. They maintain that when research is undertaken by outside institutions and researchers, equitable participation of affected communities is necessary to ensure that research is relevant to their needs and priorities, that it respects local culture and knowledge systems, and that it is rigorous in terms of Aboriginal methods of inquiry and means of validating findings.

## 2.2 An Evolving Culture of Research and Ethics

The initiatives of Aboriginal peoples and communities to influence or direct research affecting their lives have been complemented by developments in the research and ethics communities. The TCPS (1998) recognized particular ethical obligations in the conduct of research involving Aboriginal peoples, in particular with respect to group interests and the risk of doing harm due to misunderstanding of cultural norms. International instruments, such as UNESCO's *Universal Declaration on Bioethics and Human Rights* (2005), have recognized the particular impacts unethical scientific conduct has had on indigenous and local communities and have endorsed the balancing of group and individual interests.<sup>11</sup> Qualitative and participatory methods that authentically represent the perspectives and voice of participants have gained greater recognition in social science and health sciences research, and patient groups have become more vocal in advocating for involvement in review and monitoring of ethical practice.

SSHRC in 2004 launched a strategic grants pilot program which specifically embraces a shift from research *on* and *about* Aboriginal peoples to research *with* and *by* Aboriginal peoples. NSERC for some years has recognized sensitive aspects of northern research particularly in relation to the environment and has collaborated with northern agencies to develop and implement research guidelines.<sup>12</sup> In 2007, following extensive dialogue with health researchers and Aboriginal communities through Aboriginal Capacity and Developmental Research Environments (ACADRE)<sup>13</sup>, CIHR released *Guidelines for Health Research Involving Aboriginal People*<sup>14</sup> endorsing agreements between researchers and Aboriginal communities and providing a sample agreement and protocol for developing the content of such agreements.

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<sup>11</sup> United Nations Educational, Scientific and Cultural Organization (2005). *Universal Declaration on Bioethics and Human Rights*. Adopted 19 October 2005 by the 334d session of the General Conference of Unesco. See,

[http://portal.unesco.org/shs/en/ev.php-URL\\_ID=9049&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/shs/en/ev.php-URL_ID=9049&URL_DO=DO_TOPIC&URL_SECTION=201.html)

<sup>12</sup> [http://www.nserc.gc.ca/northern\\_research/About\\_e.asp](http://www.nserc.gc.ca/northern_research/About_e.asp)

<sup>13</sup> Aboriginal Capacity and Developmental Research Environments (ACADREs) are eight centres supported by CIHR and the Institute of Aboriginal Peoples' Health, attached to universities across Canada.

<sup>14</sup> See Canadian Institutes of Health Research. Note 5 above.

A number of universities adhering to the TCPS and engaged in research involving Aboriginal peoples have developed ethics codes that complement and supplement institutional ethics policies and provisions of the TCPS. Codes that apply in the Indigenous Governance Program at the University of Victoria<sup>15</sup> and the Centre for Indigenous Peoples' Nutrition and Environment (CINE) at McGill University<sup>16</sup> are two examples.

While federal government departments have not formally adopted ethical codes governing research with Aboriginal peoples several of them have reference to the TCPS and its statement of good practices.<sup>17</sup> The Northern Contaminants Program of Indian and Northern Affairs Canada (NCP) has produced "The NCP Approach to Research" which incorporates many of the ethical principles and practices being advanced by Aboriginal communities and organizations.<sup>18</sup>

### 2.3 Scope of Community Codes and the TCPS

Research in the broadest terms is an undertaking which involves inquiry or systematic investigation to extend knowledge. The Tri-Council Policy Statement sets out minimum ethical obligations of institutions and researchers receiving funds from the three federal granting Agencies for "research involving humans." Based on a subject-centred perspective, the scope of the TCPS thus covers research that engages individuals in reporting, observing or reflecting on their experience or environment. Aboriginal research within this definition is an activity that engages Aboriginal persons in research activity.

Aboriginal peoples consistently present a broader view of research. Codes of ethics developed by communities draw on cultural understandings of responsibilities of humans to one another, to the natural environment, to ancestors and coming generations and often to the spirit world. They are particularly concerned with research that will enable them to maintain their cultures, languages and identities as distinct peoples and facilitate their full participation in Canadian society.

Research guidelines developed by First Nations and Inuit organizations address participation in all research that impacts their communities. Involvement at all levels is generally sought, from concept, to project design, through data collection, analysis and dissemination of findings. The degree of involvement in a particular project will be

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<sup>15</sup> University of Victoria, Indigenous Governance Programs, *Protocols and Principles for Conducting Research in an Indigenous Context* (June, 2000)

<sup>16</sup> McGill University, Centre for Indigenous Peoples' Nutrition and Environment (CINE). *Indigenous Peoples & Participatory Health Research*. 2003. (Online). Available: [http://www.mcgill.ca/files/cine/partreresearch\\_english.pdf](http://www.mcgill.ca/files/cine/partreresearch_english.pdf) [February 28, 2005],

<sup>17</sup> For a fuller treatment of government and institutional initiatives, see: Chabot, Cecil and Brent Faulkner. (2005) "Review and Analysis of Ethical Principles and Best Practices for Research involving Aboriginal Communities, of Federal Departments and Agencies, Canadian Universities, Colleges, Provinces and Territories". Research report prepared for Interagency Secretariat on Research Ethics.

<sup>18</sup> Northern Contaminants Program (2003). *Canadian Arctic Contaminants Assessment Report II: Knowledge in Action*, Chapter 3, The NCP Approach to Research. Ottawa: Indian and Northern Affairs Canada. Accessed at: [http://www.ainc-inac.gc.ca/nep/pub/pdf/kno/kno\\_e.pdf](http://www.ainc-inac.gc.ca/nep/pub/pdf/kno/kno_e.pdf) October 16, 2007.

affected by scientific and technical skill requirements and local capacity to manage and contribute to the activity.

The TCPS provides guidance to institutions and researchers to respect and protect the dignity of individuals in research involving humans. Protocols and ethical codes established by First Nations, Inuit and Métis communities and organizations are typically broader, covering the interests of the community, all types of research and all stages of research development, implementation and dissemination of results. The overlap or divergence of the TCPS and community codes and mutual clarification of expectations should be considered by all parties in advance of launching a particular project.

### **Part 3: KEY CONSIDERATIONS IN RESEARCH INVOLVING ABORIGINAL PEOPLES**

The value of collaborative practice in research involving Aboriginal peoples and communities is well established. Meaningful collaborative practice derives from the core ethical principle of the respect for human dignity. With regard to Aboriginal research this implies respect for Aboriginal diversity, respect for Indigenous knowledge systems, and respect for cultural heritage. These elements in turn will require the adoption and consideration of norms and practices that respect the particular cultural context in which the research is undertaken.

#### **3.1 Respect for Human Dignity: A Core Ethical Value**

Respect for human dignity is a core principle of research ethics codes. The TCPS (1998) acknowledges that while much research has been respectful and beneficial, the human dignity of Aboriginal peoples has been violated when research has stigmatized them, when researchers have taken possession of cultural property and human remains without legitimate consent, and when groups have been treated merely as sources of data.

The TCPS (1998) sets out criteria for assessing when group interests are implicated in research and summarizes, for the consideration of Research Ethics Boards and researchers, good practices that embody respect for culture, traditions and knowledge of Aboriginal groups. The good practices proposed are consistent with the kind of involvement now being sought by Aboriginal peoples, incorporating partnership, community participation in design, relevance to community concerns, access to data and representation of community views in publications.

Initiatives of both First Nations and Inuit peoples to establish ethical guidelines and protocols for consultation and partnership are grounded in Aboriginal rights to self-governance. Local and regional codes and agreements that flow from them help to ensure that the culture, traditions and knowledge of the community are accorded respect on a par with the culture, traditions and knowledge of external researchers and institutions.

Many First Nations communities, and bodies that include the First Nations Information Governance Committee of the Assembly of First Nations and the First Nations Centre of



the National Aboriginal Health Organization, have adopted research codes and protocols based on principles of Ownership, Control, Access and Possession of research processes and data (OCAP).<sup>19</sup> While nationally representative bodies have assumed leadership in developing statements of principles, they maintain the position that the adoption, interpretation and application of the principles remains the prerogative of the First Nation community engaged in research. OCAP is an expression of the overarching goal of First Nations self-determination in research. The templates provided for ethical practices at the community level recognize that participatory methods and collaborative research agreements are practical ways of bringing together community priorities and external research expertise.

Representative Inuit organizations, which have mandates under land claims agreements to review, approve and monitor research, also defer to local community authority to endorse research proposals. Scientific research on the environment as well as social science research involving human participants is covered in guidelines for consultation and community participation. The guidelines anticipate that researchers and communities will collaborate to achieve high quality research and mutual benefit.

Métis communities, women's groups and pan-Aboriginal organizations aspire to assume a larger role in research affecting their members but development of research protocols is at an earlier stage of development. Without a land base or official recognition of service entitlements these sectors of the Aboriginal community generally are limited to project-based funding for research and similarly limited opportunities to develop policy on research.

First Nations and Inuit communities and their representative organizations are changing the dynamic of relations with institutional researchers. The language may speak of community control or consultation. In ethical terms, community initiatives in research are enabling the practice of respect for human dignity in Aboriginal contexts, a value that has been endorsed in principle for many years. Respect for human dignity also implies respect for diversity within and among communities, for Indigenous knowledge systems, and for cultural heritage.

### **3.2 Respect for Aboriginal Diversity**

Aboriginal peoples include First Nations, Inuit and Métis who have distinct histories, identities, languages and experience, and urban Aboriginal communities that derive predominantly from one nation such as the Mi'kmaq in Halifax or include a multiplicity of Aboriginal identities as in Toronto. Varied communities have inherited or developed diverse organizational structures.

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<sup>19</sup> See: First Nations Centre (2007). *OCAP: Ownership, Control, Access and Possession*. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization; and First Nations Centre (2007). *Considerations and Templates for Ethical Research Practices*. Ottawa: National Aboriginal Health Organization. Accessed at: <http://www.naho.ca/firstnations/english/resources.php> October 16, 2007.



Local communities have governing bodies that may be specific to the Aboriginal population, such as band councils on First Nations reserves or councils in Métis settlements. Most Inuit and Métis people are represented in public governments that include all local residents. Multiple communities may come together in tribal councils, treaty organizations or Inuit land claims organizations, delegating some governing authority to these bodies. Aboriginal people living in urban settings may retain their primary attachment to communities of origin or express their voice through voluntary associations including pan-Aboriginal political organizations, women's groups, friendship centres, social service and economic development bodies. National political organizations<sup>20</sup> represent diverse sectors of the Aboriginal community in public and intergovernmental forums but do not assume governance responsibilities.

In each geographical community or community of interest there is significant and growing internal diversity. Distinctions between individuals who have the status of Indians under the *Indian Act* or beneficiaries under Inuit land claims agreements and those who self-identify as First Nation or Inuit are becoming more complex. Some individuals move off traditional territory and back again; they intermarry with non-status persons; they have varying degrees of fluency in Aboriginal languages, with younger generations generally having less fluency. There are substantial differences in socio-economic status within and among communities. In many communities, including urban settings, there is a strong move to revitalize traditional forms of ceremony and cultural expression which may have become diffused or obscured as economies and lifestyles have undergone change.

A pan-Aboriginal approach to research design and research ethics review therefore does not reflect respect for diversity among and within Aboriginal communities.

### **3.3 Respect for Indigenous Knowledge Systems**

The term "Indigenous knowledge" as used here is roughly interchangeable with Aboriginal knowledge, to connect with developments in the international sphere. Over the past 30 years, in parallel with change in the recognition of Aboriginal rights in Canada, Indigenous knowledge has gained recognition around the world as a resource of potential benefit to modern society, although it still struggles for legitimacy in many quarters.

Traditional techniques of sustaining environmental systems in balance with human usage are attracting interest, as is knowledge of plant life for agricultural, medicinal and cosmetic purposes. Commercial exploitation of Indigenous knowledge has prompted efforts to protect the interests of holders of Indigenous knowledge through instruments such as state legislation in Peru and the international *Convention on Biodiversity* (1992).

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<sup>20</sup> National political organizations are frequently consulted on issues of public policy affecting their membership. Five prominent organizations: The Assembly of First Nations, Inuit Tapiriit Kanatami, Métis National Council, Native Women's Association of Canada and Congress of Aboriginal Peoples have participated in the development of PRE's approach to developing research ethics policy. See below, Section 2.3.

Indigenous scholars in recent years have attempted to map the contours of Indigenous knowledge in terms that are comprehensible in western knowledge systems.<sup>21</sup> A common theme in these expositions is the dynamic nature of Indigenous knowledge as a way of engaging with reality. Indigenous knowledge is holistic, involving body, mind, feelings and spirit. Knowledge is specific to place, usually transmitted orally and rooted in the experience of multiple generations. Indigenous knowledge is expressed in symbols, arts, ceremonial and everyday practices, narratives and, most especially, in relationships. A recurring theme in Indigenous knowledge of diverse peoples is relationship with the land as a living entity that reveals the way of right living.

Aboriginal peoples continue to value their ways of knowing, looking to Elders as the keepers of oral tradition and sources of wise counsel. Today they are affirming their right to conserve elaborate and transmit their knowledge using culture-based methodologies. They maintain that this knowledge base is essential to resolution of the range of problems that confront them. They affirm further that Aboriginal knowledge when shared appropriately can contribute to well being in Canada and the world at large,

The desire to conserve and develop Indigenous knowledge and to benefit from modern applications of such knowledge is a motivating force in community initiatives to assume a decisive role in research.

Respect for Indigenous knowledge is implemented by ensuring that world view and protocols are represented in planning and decisions from the earliest stages of conception and design of projects through to analysis and dissemination of results. Dialogue between researchers and communities at the outset should not be impeded by Research Ethics Boards' expectations that contact should be initiated only after ethics review.

### **3.4 Respect for Cultural Heritage**

Cultural heritage that Aboriginal people seek to protect may include artefacts, cultural property, collective knowledge and skills, and other intangibles that are transmitted from one generation to the next, such as folklore, customs, representations or practices.<sup>22</sup> The precise duties implicated in respect for cultural heritage are still in process of evolution and definition in Canada and internationally.

Canadian research ethics standards, Government of Canada policy, legislation in other

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<sup>21</sup> Leroy Little Bear. "Jagged Worldviews Colliding" in Marie Battiste (ed.), *Reclaiming Indigenous Voice and Vision*, Vancouver: UBC Press, 2000; Clare C. Brant, "Native Ethics and Rules of Behaviour," *Canadian Journal of Psychiatry*, Vol. 35, August 1990.; Gregory Cajete, *Native Science, Natural Laws of Interdependence*. Sante Fe, New Mexico: Clear Light Publishers, 2000.; Marie Battiste and James (Sakej) Youngblood Henderson. *Protecting Indigenous Knowledge and Heritage, A Global Challenge*. Saskatoon: Purich Publishing Ltd., 2000.; Marlene Brant Castellano. "Updating Aboriginal Traditions of Knowledge." In *Indigenous Knowledges In Global Contexts*. Edited by George J. Dei, Budd L. Hall, and Dorothy Goldin Rosenberg. Toronto: University of Toronto Press, 2000.; Marlene Brant Castellano. *Ethics of Aboriginal Research*. *Journal of Aboriginal Health*, 1(1): 2004.

<sup>22</sup> Convention for the Safeguarding of the Intangible Cultural Heritage, UNESCO, Paris, 17 October 2003

countries, and international treaties recognize the duty to respect cultural heritage. For example, the 1998 TCPS statement on Good Practices on Research Involving Aboriginal Peoples encourage researchers to provide to communities “information respecting...[p]rotection of the Aboriginal group’s cultural estate and other property.” (Section 6.3). Other nations have addressed the issue. Peru, for instance, has enacted legislation on research that provides a definition of Indigenous peoples’ collective knowledge and specifies standards and procedures that researchers must respect in research involving indigenous cultural competence and expertise.<sup>23</sup>

Conventions in the international sphere also articulate standards to implement the duty of respect for cultural heritage, for example, UNESCO’s 1970 *Convention on the Means of Prohibiting and Preventing the Illicit Import, Export and Transfer of Cultural Property*. UNESCO’s 2003 *Convention on Safeguarding of the Intangible Cultural Heritage* calls for respect of the cultural heritage of communities, groups and individuals.

A Government of Canada statement on Aboriginal policy affirms that “the Aboriginal peoples of Canada have the right to govern themselves in relation to matters that are internal to their communities, integral to their unique cultures, identities, traditions, languages and institutions.”<sup>24</sup>

Ethical, national, regional and international norms thus speak to the spirit, substance and contours of the duty of respect for cultural heritage. Implementation of the duty entails obligations to safeguard, preserve and not misappropriate cultural heritage, and implicates corresponding duties to consult and seek the informed consent of affected communities.

## **Part 4: APPLYING ETHICAL PRINCIPLES IN ABORIGINAL CONTEXTS**

This section addresses issues that are likely to arise in applying principles of respect set out in Section 3 by researchers and institutions adhering to the TCPS who are engaged in research involving Aboriginal people and communities. Since community codes of ethics and the TCPS have evolved from different cultures and histories, interpretation, negotiation and flexibility will often be needed to reach agreement on ethical practice.

### **4.1 Types of Community and Modes of Representation**

The TCPS statement of best practices proposes that “researchers should consider the interests of the Aboriginal group when any of the following considerations applies:

- (a) Property or private information belonging to the group as a whole is studied or used;

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<sup>23</sup> Law No. 27811 Resources (2002) cited in Nicholls, Donald. A Comparative analysis of Research Ethics (2005). Research report prepared for the Secretariat on Research Ethics. Ottawa. p. 18.

<sup>24</sup> [http://www.ainc-inac.gc.ca/pr/pub/sg/plcy\\_e.html](http://www.ainc-inac.gc.ca/pr/pub/sg/plcy_e.html) accessed 03 May 2006.

- (b) Leaders of the group are involved in the identification of potential participants;
- (c) The research is designed to analyze or describe characteristics of the group; or
- (d) Individuals are selected to speak on behalf of, or otherwise represent, the group.”<sup>25</sup>

Where an identifiable group is the subject of study or assists in the conduct of research, the TCPS criteria are helpful.

The 2007 CIHR Guidelines provide a useful analysis of a continuum of research situations involving groups or communities where Aboriginal-specific guidelines apply or where exemptions are appropriate.<sup>26</sup> The situations range from a First Nation geographically distinct community as the primary focus to a neighbourhood which includes Aboriginal residents who are not singled out as subjects of study.

However, there are other situations where a group or community is not readily identifiable but the interests of Aboriginal people are implicated. Census data indicate that more than 50 per cent of the population that identifies as First Nation, Inuit or Métis lives off reserve. Aboriginal people assert that any research that identifies participants as Aboriginal is likely to have implications for the group. Ethical issues arise in two types of situation: where the interests of identifiable groups are likely to be affected and where the cultural characteristics of Aboriginal individuals not affiliated with a group place them at greater risk of harm.

For example: a proposal to study the experience of homeless occupants of a tent city that ignores the high representation of Aboriginal occupants in the project design may later find that Aboriginality is a significant variable. If the principal investigator or team members are not conversant with Aboriginal cultures, their methods of inquiry may offend the dignity of Aboriginal participants and their interpretations of data may reinforce negative stereotypes that reflect on the larger Aboriginal community.

Urban Aboriginal people, and Métis who are distributed in urban and rural settings and non-status Indians not included in federal registries receive relatively few benefits of research. If they are included in clinical trials or general surveys on service needs, their Aboriginal identity is not noted and thus does not elicit cultural accommodations.

In the United States, to promote identification and inclusion of minorities in research so that they can potentially share in the benefits, it is policy of the National Institutes of Health that all grant applications describe the extent to which they are including women, children, and minorities in their research.<sup>27</sup> In New Zealand, the Health Research Council requires that research proposals contain a clear description of responsiveness to Maori

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<sup>25</sup> TCPS section 6.A

<sup>26</sup> *CIHR*, op. cit. Section 1.5a at p. 13.

<sup>27</sup> Birman, Dina. (2006) “Ethical Issues in Research With Immigrants and Refugees” in Joseph B. Trimble and Celia B. Fisher, *The Handbook of Ethical Research With Ethnocultural Populations & Communities*, Thousand Oaks CA, Sage Publications, Inc., 160.

needs and priorities, based on prior consultation.<sup>28</sup> The provinces of Ontario and British Columbia are now making provisions for self-identification of Aboriginal students in provincial schools as a basis for developing appropriate services.

On a practical level, the degree of community involvement in a project may vary from a formal agreement and co-management to verbal approval of the proposed research in a group setting, which should be recorded, to informal advice from an ad hoc committee. Where a researcher has an ongoing relationship with a community, ethical approval may be signalled by a letter or equivalent evidence of endorsement by a relevant leader or authority.

Without being exhaustive or restrictive, the following bodies or individuals might be mandatory and/or legitimate channels for seeking an expression of acceptance of community participation:

- a) governing authorities in First Nations and Inuit communities, self-governing jurisdictions and Inuit land claims regions;
- b) ethics oversight bodies designated by formal leadership;
- c) organizations participating in the research project;
- d) organizations designated by the research participants;
- e) advisors designated by the research participants;
- f) advisors identified by the researcher or research institution.

## **4.2 Communities Within Communities**

Researchers have pointed out that diverse communities of interest often co-exist within geographic communities and that formal leaders may not be the appropriate persons to act on their behalf. Examples are traditional governance bodies such as the Confederacy Council of the Haudenosaunee whose authority derives from the Great Law of the Iroquois rather than the *Indian Act*, or sacred societies of the Blackfoot, which are recognized as the authorities with respect to their knowledge. Women taking action against domestic violence have encountered opposition from some community leaders and so may not have access to their formal approval of research, for example, to improve the women's safety. Alienated youth may not trust that their voices will be respected if official leadership is involved in approving the research.

In the case of traditional leadership structures or sacred knowledge, legitimate channels for group consent exist and should be respected. In the case of vulnerable groups, alternative avenues for engaging participation may be more appropriate.

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<sup>28</sup> Kaufert, Joseph M., Kathleen Cranley Glass, William L. Freeman, with Lisa LaBine. *Background Paper on Issues of Group community or first Nations Consent in Health Research. (2004)* Working paper prepared for the Aboriginal Ethics Policy Development Project of CIHR-Ethics Office and the Institute for Aboriginal Peoples' Health, 70.

Where divergent group interests within a community appear to be in conflict, problem-solving on site will be required to avoid deepening divisions or increasing the vulnerability of groups and individuals. The good offices of trustworthy persons who have moral authority in the community can often be enlisted to find ways to proceed with research that preserves respect for all parties. However, in some cases the risks involved simply outweigh the benefits to be derived from proceeding.

### 4.3 Research Agreements

Agreement between researchers and community representatives on the terms and conditions of collaboration can be viewed as community consent, paving the way for informed consent of participating individuals, which is also required. Consent provisions of the TCPS (1998) imply that giving consent is a process that begins before the start of the research activity and is maintained throughout the subject's participation in the research.<sup>29</sup> This is consistent with Aboriginal views that see consent as a relationship maintained by dynamic interaction throughout a project.

Research agreements serve as a primary means of clarifying and confirming mutual expectations and commitments between researchers and communities. Expanding on information normally provided to a individual participants (see TCPS, article 2.4), agreements typically set out the purpose of the research and detail mutual responsibilities in project design, data collection and management, analysis and interpretation, production of reports and dissemination of results. The level of community involvement sought and achieved will depend on the organizational infrastructure in place in the community or group and the willingness and capacity of both partners to develop the necessary supports for shared authority and responsibility.

Particularly in First Nation and Inuit communities, collective endorsement of research initiatives has become a standard requirement. Regional organizations such as the First Nations of Quebec and Labrador have developed protocols and sample agreements to give guidance to their constituent communities.<sup>30</sup> The National Aboriginal Health Organization (NAHO) has developed toolkits for ethics education to advance the understanding of research ethics among community participants and researchers in Aboriginal contexts.<sup>31</sup>

The CIHR *Guidelines for Health Research Involving Aboriginal People (2007)* recommend that researchers conclude research agreements with Aboriginal communities. (Articles 5,6,8) They set out a detailed list of elements to consider, a step-by-step process and a sample agreement provided by the Centre for Indigenous Peoples' Nutrition and Environment (CINE).

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<sup>29</sup> TCPS (1998) Article 2.1

<sup>30</sup> Assembly of the First Nations of Quebec and Labrador: First Nations of Quebec and Labrador Research Protocol, June 2005, p. 19. Accessed at [www.iddpnql.ca/an/protocole1an.html](http://www.iddpnql.ca/an/protocole1an.html) May 7, 2006.

<sup>31</sup> Castellano, Marlene Brant. "Ethics of Aboriginal Research" (2004). *Journal of Aboriginal Health, Vol 1, No. 1*. Ottawa. National Aboriginal Health Organization. 98-114; Henderson and First Nations Centre, NAHO. Cited in note 4.

Because research agreements are a relatively new practice, it is not clear how effective they will be in preventing violations of human dignity or providing avenues of redress when ethical violations occur. U.S. sources indicate that such agreements do not have the force and effect of contracts.

Such agreements are increasingly being recognized by academic institutions and the researchers associated with them as providing reference points for ethics review and approval on such items as consent and confidentiality. Agreements that specify procedures for community ethics review, included as part of the institutional ethics application, can provide contextual information and guidance for Research Ethics Boards conducting initial review of applications and continuing ethics review throughout the project.

#### **4.4 OCAP Principles**

OCAP principles were developed by the National Steering Committee of the First Nations and Inuit Regional Health Survey (1998). OCAP principles were refined and applied by First Nation parties in the second Regional Health Survey (2002-3). They are now being extended to shape the conduct of various types of research in First Nation communities.

The principle of ownership asserts that a community or group owns information collectively in the same way that an individual owns personal information and that the community or group can therefore choose to share it (or not) under conditions that they specify. The principle of control asserts that First Nations Peoples, their communities and representative bodies have a right to control all aspects of research and information management processes, which affect them. Control can extend to all stages of a particular research project, from conception to completion. The principle of access asserts that First Nations Peoples must have access to data about themselves and their communities collected in the course of research and they have a right to make decisions regarding access by others to their collective information. Possession of data in the case of the Regional Health Survey is exercised by mandating as a data steward a regional organization that has adequate infrastructure to manage sensitive data. OCAP principles together represent assertion of self-determination applied to research.<sup>32</sup>

The language of control can arouse concern among academic researchers that the integrity of research will be compromised by “political” interference. First Nations representatives consistently affirm that high quality research is in the best interests of their communities as well as the external agencies seeking valid data and conclusions. They also maintain that high levels of quality and validity can best be achieved through collaboration and involvement of community members and application of culturally appropriate research methods. The risks and benefits to all parties can be balanced most

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<sup>32</sup> First Nations Centre (2007). *OCAP: Ownership, Control, Access and Possession*. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization; and First Nations Centre (2007).

effectively by applying knowledge of the local context. Advocates for compliance with OCAP also argue that critical inquiry is possible in the context of collective decision-making.

Academic researchers and institutions across Canada in many cases already share decision-making with Aboriginal communities. For example, university based Aboriginal Capacity and Developmental Research Environments (ACADREs) and their associated community networks spearheaded the development of the new CIHR guidelines.

Negotiation of research agreements permits Aboriginal parties and academic researchers to explore the practical implications of OCAP, or comparable principles operative in Inuit and Métis communities, to reach mutual accommodations. It must be acknowledged also that sharp differences in ideology, tenaciously held, will probably not promote collaborative effort.

#### **4.5 Cultural and Intellectual Property**

The definitions of tangible and intangible cultural property over which Indigenous peoples arguably have rights are broader than the definitions of intellectual property protected under national law and international agreements. Intangible cultural property such as traditional knowledge of the medicinal properties of plants or traditional clothing design that is collectively held, is often regarded as “folk knowledge” which is available in the public domain and which may be adapted through commercial processes to produce marketable commodities without consent of the originators,. Data gathered and published in violation of Indigenous community ethics may become the basis of secondary research despite challenges from the communities that were the original sources of information. Contracts involving secondary use of data originally collected and published in violation of Indigenous community ethics may be regarded as legitimate by research institutions.

Indigenous knowledge often does not fit the criteria of sole ownership, innovation and representation in a tangible work that are necessary to claim protection for intellectual property rights. National laws and international consensus on these issues are evolving.

Community protocols for research partnerships typically contain provisions for reporting results in a format and language accessible to community members. Research reports are regarded as a product of both community and researcher contributions rather than the sole property of the researcher. Communities consider that their review and approval of reports and academic publications is essential to validate findings, protect against misinterpretation and maintain respect for Indigenous knowledge which may entail limitations on its disclosure. Differing positions on interpretation of results have been resolved in some communities by agreement to include dissenting positions in publications.



Research agreements may specify how protection and respect of cultural knowledge will be facilitated through review processes and how intellectual property rights will be assigned, whether to community sources, to researchers or to both on a shared basis.

#### **4.6 Privacy and Confidentiality**

The privacy of individual subjects in research is normally protected by removing information that would identify them personally. Anonymized data are added to a data pool and are available for analysis and sometimes for secondary use. Longitudinal studies require access to data banks in which consent for additional studies may not have been obtained from original informants and may not be obtainable subsequently. Such secondary usage requires REB review and the REB may allow a waiver of consent under certain conditions (see TCPS, 2.1.c).

Misrepresentation of Aboriginal peoples, unauthorized use of data and lack of reporting to communities on research outcomes have created ongoing sensitivity about the potential use of data collected for approved purposes. There are additional fears that general consent to collect personal data will facilitate unauthorized government surveillance.

Many Aboriginal communities are small and characterized by dense networks of relationships, with the result that anonymizing individual data is often not sufficient to mask identities. Some Aboriginal research subjects are reluctant to speak to interviewers from their own community because of privacy concerns. Other subjects, in qualitative studies or life histories, may wish to be acknowledged individually for their contributions. Communities themselves have distinguishing characteristics, which in some cases have compromised efforts to disguise the site of research and has led to stigmatizing the communities.

The Regional Health Survey administered by regional First Nations organizations has addressed the problem of balancing confidentiality and access by having communities designate a regional organization to hold data, while local authorities make decisions on who can access the data and under what conditions. In practice, the organization that serves as data steward evaluates requests for information and its recommendations to community authorities have considerable influence.

Privacy protections within the research context are evolving within the federal granting Agencies with attention to harmonization with federal, provincial and territorial legislation. CIHR has published *Best Practices for Protecting Privacy in Health Research*.<sup>33</sup>

Accommodation of Aboriginal initiatives to maintain access to data for community use, applying principles such as OCAP, will be situated within the larger framework of law and policy to protect privacy.

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<sup>33</sup> CIHR. *Best Practices for Protecting Privacy in Health Research* (September 2005), accessed at [www.cihr-irsc.gc.ca/e/29072.html](http://www.cihr-irsc.gc.ca/e/29072.html), May 10, 2006.

## 4.7 Equitable Distribution of Risks and Benefits

Aboriginal communities have participated in the past in research to advance the frontiers of knowledge as defined by external experts. They have done so in the midst of pressing social, economic and environmental problems. They are now demanding more respectful attention to community realities and priorities.

Community benefit may include relevant knowledge, evidence-based policy and social interventions, and increased capacity to conduct partnered or autonomous research. In most research relationships a primary benefit sought by communities is increased capacity to conduct autonomous research that can more readily be conducted in Aboriginal languages and oral modes. Autonomous research would enhance the exploration, articulation and application of Indigenous knowledge in its own context, with translation to other contexts following a parallel process. Communities recognize the importance, in the present environment, of meeting standards of excellence in both Aboriginal and academic universes.

Aboriginal people also seek to share in the benefits of research activities themselves in the form of research grants, overhead levies and commercialization of research discoveries. In recent times community-based projects have made provisions for sharing grant resources. Employing Aboriginal research assistants and translators is already common practice in community-based projects. Implementing a rational program of training to enhance autonomous research initiatives is less common.

Under the SSHRC Strategic Program introduced in 2004 funding can flow to a community organization provided the research team includes both members of the Aboriginal or community organization and university- or college-based scholars.<sup>34</sup> The National Institutes of Health in the United States has gone further in supporting research capacity building in Native American tribes. Through Native American Research Centers for Health (NARCH), tribes or tribal consortia are eligible to receive grants to establish research partnerships and are required to use at least 30% of all funds within the tribal structure.<sup>35</sup>

Equitable benefit from research activities implies revised funding guidelines to cover project overhead costs, management time commitments, and expert consultation, including honoraria for Elders.

Genetic researchers and their sponsors demonstrate a high level of interest in research among Indigenous populations, especially those that are socially isolated and homogeneous. This is a field where ethics and the assessment of risks and benefits are rapidly evolving. Genetic research has potentially important implications for Aboriginal communities and warrants specific attention in continuing policy development.

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<sup>34</sup> [www.sshrc.ca](http://www.sshrc.ca)

<sup>35</sup> Kaufert et al. cited in note 29

## **Part 5: ETHICS REVIEW PROCESSES**

### **5.1 Parallel Ethics Review Processes**

Ethical review of all research involving humans, undertaken in institutions eligible to administer funds of the federal granting Agencies, is required to adhere to ethical guidelines in the TCPS. Reviews are normally conducted by research ethics boards (REBs) in the researcher's institution. The TCPS provides that such institutional review is required "in addition to review by any agency having jurisdiction over the site of the research"<sup>36</sup>, which could include an ethics committee mandated by a First Nation or Inuit government or other Aboriginal authority. Proposals described above go beyond involvement of mandated authorities, to include agencies or persons designated by participants and participant groups to represent their interests.

Bodies created by communities to review research proposals or oversee research activities will not necessarily duplicate the makeup of institutional REBs and the scope of the TCPS. In the context of scarce resources in community organizations the same personnel may be involved in reviewing the ethics of a proposal and co-managing the research. An expectation that conflict of interest will be managed by separating ethics review and project management functions may impose unsupportable demands on small communities. Community protocols may apply to research beyond the scope of REB responsibilities, for example research on the interface between environmental and human systems that does not involve individual participants.

For the foregoing reasons, community review of research will not replace REB review within institutions supporting particular projects. The guidelines envisaged for the TCPS are intended to provide avenues for filling gaps, accommodating overlap and resolving conflicts between community and institutional ethical codes.

Where CIHR, SSHRC or NSERC grants are made directly to community agencies the application of standards and procedures under the TCPS should be clarified with recipients in advance.

In accordance with the TCPS, an REB should have provisions for membership such that when context-specific expertise is lacking for the review of particular research proposals, ad hoc members are appointed. In cases where review of Aboriginal research is regularly required, the REB membership should be modified to ensure cultural expertise within its regular complement.

Experience with structures to promote cultural responsiveness to Indigenous peoples in other jurisdictions can provide references points for evolving policy of the federal

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<sup>36</sup> TCPS (1998) article 1.14

granting Agencies in Canada. In the United States, tribal interests are accommodated through Institutional Review Boards at national and tribal levels. In New Zealand the Health Research Council requires that two Maori members be appointed to each regional review board and that “responsiveness to Maori” in research proposals be validated by local assessments. In Australia the National Health and Medical Research Council has published *Values and Ethics in Aboriginal and Torres Strait Islander Health Research (2003)* as a complement to national ethics codes. A companion document, *Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics (2005)* has been released in 2005 “for Aboriginal and Torres Strait Islander people to refer to when making decisions about health research in their communities.”

The foregoing discussion on translating ethical duties into practice has emphasized sharing of responsibility between communities and researchers to facilitate the ethical conduct of research. Having reference to parallel codes and protocols in institutions and communities is likely to pose questions of which code should prevail when expectations and/or requirements diverge.

High quality, socially beneficial research involving Aboriginal peoples can best be carried out through equitable partnerships. It would be counterproductive to assert the primacy of one party in the relationship. Maintaining respectful relationships will be dependent on each partner being prepared to reflect on what is essential to achieving common goals and what degree of flexibility is consistent with their core values.

## **Part 6: RECOMMENDATIONS FOR PRE’S CONSIDERATION**

Given the diversity of Aboriginal identities, interests and circumstances it is proposed that it would be counter-productive for the TCPS to make rigid prescriptions of how researchers based in western institutions should interpret and apply the ethical principle of respect for human dignity in First Nation, Inuit and Métis contexts. Instead, Research Ethics Boards and researchers should assess the ethical protections incorporated in each research project involving Aboriginal participants and communities in relation to the following.

### **6.1 Recommendation for TCPS Revisions**

#### **TCPS Ethics Framework**

The value of collaborative practice in research involving Aboriginal peoples and communities is well established. The introductory ethics framework of the TCPS should affirm such practice by incorporating the following provisions:

Protections for human research participants set out in the TCPS apply to research involving Aboriginal peoples with the provision that application of the principles and requirements may require interpretation or adaptation in Aboriginal contexts.

Respect for the dignity of Aboriginal people is due to them as members of distinct communities who value their culture and heritage. Particular obligations are created by the protections of Aboriginal and treaty rights entrenched in the *Constitution Act* (1982), such rights being still in process of definition.

Because of the importance that Aboriginal people and communities attach to their collective identity as peoples, their representative bodies, whether governmental or organizational, will normally establish the appropriate form of consultation required to authorize research involving their members and sponsored by external institutions.

In no case is community or organizational agreement a substitute for individuals' informed consent to participate in a research project.

The TCPS provides guidance to institutions and researchers to respect and protect the dignity of individuals in research involving humans. Protocols and ethical codes established by First Nations, Inuit and Métis communities and organizations are typically broader, covering the interests of the community, all types of research and all stages of research development, implementation and dissemination of results. The overlap or divergence of the TCPS and community codes and mutual clarification of expectations should be considered by all parties in advance of launching a particular project.

### **Key Implications for Researchers and REBs**

Researchers and REBs should consider key questions in assessing ethical protections in proposed research involving Aboriginal communities, including communities of interest:

- Researchers and REBs should consider whether respect for human dignity of Aboriginal peoples requires adaptation of standard TCPS principles and procedures in this project.
- Researchers should determine early in the design of the research whether a First Nations, Inuit or Métis code of ethics or a protocol is operative in the participant community and how the code or protocol will be accommodated in the design and implementation of the proposed research.
- REBs should review what measures have been put in place by the researchers to recognize and protect Indigenous or local knowledge in the conduct of the project and the dissemination of findings.
- Researchers should consider, and REBs should review, whether tangible or intangible cultural property of Aboriginal persons or communities is at risk of misuse or misappropriation. Researchers should include measures to mitigate such risks of misuse or misappropriation in the research ethics review proposal.
- REB should review the research process to ensure it is respectful and inclusive of the diversity within and among communities.

- Researchers should consider entering into research agreements with Aboriginal communities who have adopted them as a means to clarify and confirm mutual expectations and commitments between researchers and communities. Particularly in First Nations and Inuit communities, collective endorsement of research initiatives has become a standard requirement.

### **Consultation and Representation**

Where prospective participants in a research activity are members of an Aboriginal community or organization with identifiable leadership, researchers shall consult with such leaders and shall take into consideration protocols and ethical codes operative in the community or organization.

Notwithstanding the previous statement, self-identified Aboriginal individuals who wish to participate in a research project which is unlikely to affect group interests, or reflect on a community or organization, will not be excluded from participation on the basis of their Aboriginal identity.

Where prospective participants in a research activity self-identify as Aboriginal and do not signify membership in a community or organization having identifiable leaders, researchers shall take reasonable efforts to ensure protection of cultural interests, if any, as appropriate.

In research proposals involving one or more Aboriginal communities or a significant number of Aboriginal participants, researchers shall report on how they have secured or intend to secure community participation to proceed with the project. Engaging community support may include consulting and/or obtaining permission of

- a) governing authorities in First Nations and Inuit communities, self-governing jurisdictions and Inuit land claims regions;
- b) ethics oversight bodies designated by formal leadership;
- c) organizations participating in the research project;
- d) organizations designated by the research participants;
- e) advisors designated by the research participants;
- f) advisors designated by the researcher or research institution.

Where alternatives to community, regional or organization protocols are deemed necessary to ensure the inclusion or safety of participants, some of whom may be at greater risk of harm, the researcher shall describe such alternatives and provide a rationale to the REB for pursuing them.

### **Privacy, Ownership and Access to Data**

Researchers should negotiate with communities mutual understandings of appropriate respect for cultural and intellectual property, how to proceed with community review of

findings, terms of ownership of research products and any limits on publication of materials.

Researchers should inform communities and individuals what arrangements are made in partnered research to respect privacy of individuals and communities and agree on access by communities to data important to their own planning and development processes.

### **Sharing of Costs and Benefits**

Researchers should endeavour where appropriate and possible to share costs and benefits of research more equitably between researchers, institutions and Aboriginal communities.

## **The First Nations Regional Longitudinal Health Survey as an Example of Collaboration Involving First Nation on-reserve Communities, Participants and Researchers**

### **1. Project Description**

The First Nations Regional Longitudinal Health Survey (RHS) is the only large-scale health survey exclusively governed and administered by First Nations at the National, Regional and Community levels. The RHS uses Participatory research methods to incorporate both Western and Traditional understandings of health, wellbeing and governance.

The Inuit participated in the 1997 pilot survey however, given the disproportionate participation by First Nations and the challenges in meeting the needs of both First Nations and Inuit within this project, the Inuit declined to participate further.

### **2. Description of Engaged Parties**

This RHS is a multi-level, participatory research project with extensive engagement from all parties from the Community to the National level. First Nations, in keeping with their principles of OCAP (Ownership, Control, Access and Possession),<sup>37</sup> act as the governing bodies and administrators of this extensive survey. The First Nations Information Governance Committee (FNIGC), a standing committee of the Assembly of First Nations (AFN) Chiefs Committee of Health (CCOH) provides overall guidance for the project. The FNIGC is made up of individuals appointed by their respective regional First Nations organizations.

The National RHS team is responsible for administering the survey from the National perspective, taking their direction directly from the FNIGC through regular teleconferences and face-to-face meetings. The National RHS team was initially and is currently hosted by the AFN while the First Nations Centre at NAHO (FNC) hosted Phase 1. Regardless of organizational host, the National RHS team always takes their direction from the FNIGC.

At the Regional level First Nations Provincial and Territorial organizations host the survey guided by Regional steering committees primarily consisting of individuals appointed by the participating communities. A Regional Coordinator manages the regional level activities in collaboration with the participating communities. The Regional Coordinator takes their direction from their respective Regional Steering Committees.

At the community level, designated individuals collaborate with the Regional Coordinator to ensure their specific community requirements are met. As often as

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<sup>37</sup> [http://www.naho.ca/firstnations/english/documents/toolkits/FNC\\_OCAPInformationResource.pdf](http://www.naho.ca/firstnations/english/documents/toolkits/FNC_OCAPInformationResource.pdf)



possible the community assists in the hiring of data collectors from within their communities.

Health Canada's, First Nations and Inuit Health Branch (FNIHB), formerly the Medical Services Branch (MSB), has been the sole provider of funds for survey specific activities. The FNIHB has also been instrumental in advocating on behalf of the RHS within other federal departments. The RHS has subsequently received funding for data dissemination projects from Indian and Northern Affairs Canada (INAC) and there have been ongoing discussions with respect to negotiating more direct financial support for ongoing survey and analysis activities.

Finally, there is an extensive list of outside experts from academia and elsewhere providing specific advice when requested. Outside experts have provided assistance in survey development, sampling frameworks, development of a First Nations specific Code of Ethics<sup>38</sup> and Privacy and Consent issues. A significant outside contribution to the work of the RHS has been an independent evaluation of the RHS in the context of data quality and respect for the First Nations principles of OCAP by Harvard University<sup>39</sup>. This report has provided valuable external validation for the work of the RHS while providing objective advice for improvements for future iterations of the survey.

### **3. Where/How did the Research Initiative Originate?**

The first RHS took place in 1997 and involved First Nations and Inuit from across Canada. At the time, reliable information on the health and wellbeing of First Nations and Inuit was severely lacking due to the exclusion of First Nations and Inuit from major national health surveys. RHS 1997 was implemented to address these deficiencies while acknowledging the need for First Nations and Inuit to control their own health information. The Inuit discontinued their support for the process due to difficulties of the RHS in addressing both First Nations and Inuit requirements.

### **4. Planning and Implementation**

The pilot phase of the RHS had its beginnings in January of 1994, as a result of a study commissioned by Health Canada, Human Resources Development Canada, and (INAC) to examine the feasibility of a national level, aboriginal health survey. The study found that there was a lack of quality data on Aboriginal communities for program planning, health service delivery and informing public policy. A recommendation was made for a series of regional health surveys to be administered under complete Aboriginal control, respecting regional and community processes while building Aboriginal capacity in research. The First Nations and Inuit Regional Health Survey was founded in 1995 with funding from the Medical Services Branch of Health Canada.

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<sup>38</sup> <http://rhs-ers.ca/english/pdf/rhs-code-of-research-ethics-2007.pdf>

<sup>39</sup> Review of the First Nations Regional Longitudinal Health Survey (RHS) 2002/2003 Prepared by the Harvard Project on American Indian Economic Development.  
[http://rhs-ers.ca/english/pdf/rhs2002-03reports/rhs\\_harvard\\_independent\\_review.pdf](http://rhs-ers.ca/english/pdf/rhs2002-03reports/rhs_harvard_independent_review.pdf)

Planning for data collection including the development of the survey questionnaire and other research processes along with the development and adoption of the RHS Code of Research was completed in 1997. Following data collection, a final report with all thematic areas finally presented to the general public at the National Aboriginal Information and Research Conference in Ottawa, March 28–31, 1998.<sup>40</sup>

Phase 1 was initiated after the pilot phase and followed an even more rigorous process. The survey instrument was developed over a two-year period and data collection occurred over the period of one year with the final results being presented publicly November 13-15, 2005 at the First Nations Research Conference where the RHS celebrated its ten year anniversary.<sup>41</sup>

The second phase has been in the planning process for approximately a year and a half with data collection for this phase anticipated to commence in Spring 2008.

Funding for the RHS has been a continuous challenge with no guaranteed multi-year funding to date. Funding is negotiated with Health Canada's First Nations Inuit Health Branch on an as required basis. It is hoped that the RHS will be able to secure multi-year funding agreements prior to the end of the current phase.

Funding is expected to continue to be an ongoing challenge as the RHS is excluded from traditional funding sources, such as from the Canadian Institute of Health Research (CIHR), as First Nations do not meet government and academic criteria requiring Principle Investigators to be directly associated with an academic institution.

For each phase of the surveys there have been National and Regional reports generated and distributed. There have been ongoing challenges to analyze and disseminate the data primarily arising from a lack of resources. Some recent progress made as a result of the November 2005 Memorandum of Understanding between the FNIGC and CIHR resulted in a Request for Applications by the Institute of Aboriginal Peoples Health (IAPH) for submissions to analyze RHS data. Applications under this initiative are screened according to CIHR guidelines and the OCAP principles through a joint peer review committee consisting of CIHR and FNIGC members.

Significant to this process was a one-time funding opportunity provided by INAC that enabled the National RHS team to set up an electronic data system to facilitate online data access by FNIGC approved researchers. This system is expected to increase First Nations capacity to control use of the data while being able to make it more readily accessible by interested parties for analysis.

## **5. Governance and Methodology**

Under the multi-layered governance structure, designated community members are

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<sup>40</sup> [http://rhs-ers.ca/english/pdf/rhs1997/rhs\\_1997\\_final\\_report.pdf](http://rhs-ers.ca/english/pdf/rhs1997/rhs_1997_final_report.pdf)

<sup>41</sup> <http://rhs-ers.ca/english/phase1.asp>

responsible for working in collaboration with their respective regional coordinators to ensure accommodation of local language, culture and protocols. This responsibility is facilitated most often through the employment of local community members to serve as data collectors. These community members may also work through their regional steering committee to resolve conflicts. These conflicts may require external consultation by 'experts' for subject specific areas such as Privacy Law and scientific methodology. The external advisors provide their services by contract and make only recommendations.

For example a noted Privacy expert was contracted on several occasions to provide feedback regarding consent, ensuring privacy as well as feedback on reconciling issues between Privacy law which focuses on the individual and OCAP which focuses on the collective.

The challenge of reconciling OCAP with individual privacy laws is ongoing. For example, in British Columbia where there are many communities with small populations not all communities were able to have record level data returned to them due to Privacy legislation. One option would be to have the community organization take on the responsibility of data steward from the outset of the survey process placing the legal responsibility for maintaining Privacy and Confidentiality at the community level. This however would require a significant infusion of resources and training not currently available. To address this issue, Regional Coordinators now must ensure that each of their community partners is fully informed of what level of access to their community data they may have, given that it may be limited. In order to facilitate community level OCAP in this difficult situation these communities may collaborate with the Regional Coordinator to have the data analyzed and disseminated back to the community through the regional office thereby ensuring legal obligations are met while providing the highest level of access to the data legally possible.

The development of research questions and methods was an extensive process,<sup>42</sup> in brief, beginning with assessments provided by the participating communities as to their health priorities and data requirements. The development was further informed by way of expert advisors either contracted out or who provided their services voluntarily and/or as an extension to work that they were already involved with (i.e. academic partner).

In response to stated needs, themed reports have been generated at the National level inclusive of housing, older First Nations adults, homecare and selected indicators by gender.<sup>43</sup>

The RHS questions and methodology continue to develop in keeping with the initial objectives as set out in the pilot survey. For example, in recognition of the wholistic nature of health and well being an Ecological survey was undertaken in parallel to Phase 1 as a pilot to provide some preliminary assessments of the impact of natural and built environments on health.<sup>44</sup> The results of this survey have not yet been released and

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<sup>42</sup> [http://rhs-ers.ca/english/pdf/rhs2002-03reports/rhs2002-03-report\\_on\\_process\\_and\\_methods.pdf](http://rhs-ers.ca/english/pdf/rhs2002-03reports/rhs2002-03-report_on_process_and_methods.pdf)

<sup>43</sup> <http://rhs-ers.ca/english/phase1.asp>

<sup>44</sup> <http://rhs-ers.ca/english/pdf/rhs2002-03reports/rhs-community-ecological-survey.pdf>

the impact on the current Phase of the RHS is unknown however it is anticipated that a version of the Ecological survey will be streamlined into the current and future phases of the RHS.

## **6. First Nations Ethical Principles**

The general ethical principles as defined in the TCPS appear to be reflected throughout the RHS beginning with the recognition of the need to have First Nations specific ethical concerns addressed through the development of the RHS Code of Research Ethics. This Code provides the framework of principles and procedures outlining the responsibilities of each participant through all aspects and phases of the surveys and potential spin-off research from beginning to end<sup>45</sup>.

The foundations for the RHS Code of Ethics are the First Nations principles of OCAP (Ownership, Control, Access and Possession). Fundamentally, these principles put into plain language and provide a mechanism to express First Nations inherent rights. OCAP expresses the inherent rights and provides guidelines for action by First Nations who are working to regain control over their lives, specifically with respect to information belonging to them.

A common sentiment, still heard today in many First Nations communities is that of being 'Researched to Death.' Conversely the RHS speaks of 'Researching ourselves back to life' reflecting First Nations demand to be treated with dignity and recognition of the value of quality research.

By taking ownership over research involving them, First Nations ensure that they are protecting themselves from harm resulting from disregard for Free and Informed Consent. The RHS Code of Ethics also serves to ensure that the RHS National and Regional teams are respectful of the communities with which they have entered into a trust relationship.

The RHS takes issues of Privacy and Confidentiality seriously and has even been faulted for having an overly complex consent form, the direct result of taking consent seriously. Despite the complexity of the consent form, the data collectors, who were often community members, are specifically trained to ensure the participants are completely informed of their rights prior to obtaining consent.

The RHS has also contributed greatly to the debate and development of Privacy and Confidentiality in the context of collective societies. At the time of this writing, in recognition of data ownership issues beyond research, the AFN is in the process of releasing a position paper on OCAP as it relates to First Nations collective data outside of research processes. The foundation for this paper was built on experiences learned through the RHS process such as how to appropriately address collective and individual consent.

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<sup>45</sup> RHS Code of Ethics - <http://www.rhs-ers.ca/english/pdf/rhs-code-of-research-ethics-2007.pdf>

Justice and inclusiveness could be said to be the driving force behind the RHS. A lack of justice both real and perceived along with the issues of inclusiveness in mainstream surveys was THE catalyst for the RHS. There are criticisms held against the RHS for not representing the off-reserve population however, while justified this is an issue of capacity as the inclusion of the off-reserve First Nations population would necessitate significantly greater levels of funding and support to properly engage all the relevant stakeholders. In recognition of this criticism the RHS has and continues to seek support from federal departments for capacity to extend the survey to the off-reserve population.

The RHS seeks to balance the potential Harms and Benefits resulting from the research by way of thorough consultation processes inclusive of participating communities and where necessary informed by outside experts. To date, a real and tangible benefit of the RHS is proof of First Nations abilities to successfully take control over major initiatives that involve themselves providing a sense of accomplishment.

## **7. Community-Based Participatory Processes**

This project can be described as a *Community-Based Participatory* research project where the First Nations as a community have chosen to take control over their own health information. The most valuable aspects of this ongoing project have been the development of a Code of Research Ethics relevant to the participating communities and most importantly the defining and refinement of the First Nations principles of OCAP (Ownership, Control, Access and Possession). The principles of OCAP have become the foundation for all discussions about First Nations health data moving well beyond the original scope of research to include all data relevant to First Nations communities and individuals.

The RHS has also been able to hold up to external scrutiny. To alleviate external concerns about the processes of the RHS, Harvard University was contracted to provide an independent assessment of the quality of the research design and consistency of the research process with OCAP. The results were positive.

*In summary, the review team was impressed with the overall quality of the 2002/2003 RHS, consistency with previously validated survey research practices and its innovations with respect to the involvement of First Nations communities and their representatives in the research process. The 2002/2003 RHS used information gained from the first round of data collection (1997 RHS) to develop more refined methodology and protocols. Compared to other national surveys of Indigenous people from around the world, the 2002/2003 RHS was unique in First Nations ownership of the research process, its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people and their representatives at each stage of the research process. All of this was accomplished under considerable resource constraints.*<sup>46</sup>

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<sup>46</sup> Review of the First Nations Regional Longitudinal Health Survey (RHS) 2002/2003 Prepared by the Harvard Project on American Indian Economic Development.

The RHS provides an excellent example of research involving First Nations, for First Nations by First Nations, using Participatory methods to ensure that their research meets the highest ethical standards as defined by First Nations.

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[http://rhs-ers.ca/english/pdf/rhs2002-03reports/rhs\\_harvard\\_independent\\_review.pdf](http://rhs-ers.ca/english/pdf/rhs2002-03reports/rhs_harvard_independent_review.pdf)

*Iglutaq*  
**The Implications of Homelessness for Inuit**  
**A Case Study of Housing and Homelessness in Kinngait, Nunavut Territory**  
**28 April 2008**

## Foreword

This example of research involving Inuit has been prepared by the Secretariat on Research Ethics based on the publicly available report (2006) produced by both the Harvest Society of Kinngait (Nunavut Territory) and Dr. Frank Tester. Excerpts of the report are quoted. The Secretariat benefited from Dr. Tester's input and comments.

### 1. Project Overview

The study was initiated by Inuit of Kinngait, Nunavut Territory and the Harvest Society of Kinngait – an organization concerned with food security, shelter and other social issues in the community. The organization has members who are youth, adults and elders. They were given assistance and encouragement by Michel Petit who was, at the time, Director of Social Work in the community. They invited Frank Tester, from the School of Social Work and Family Studies at the University of British Columbia (UBC), to coordinate the research.

Using a participatory action research approach, the study details residents' experience of living in overcrowded conditions and compares objective measures of overcrowding with their perceptions of living conditions, consequences for their daily lives and physical and mental health. Released in 2006 the report is available at:

[http://www.swfs.ubc.ca/fileadmin/template/main/images/departments/social\\_work/faculty/IGLU\\_TAO\\_in\\_my\\_room.pdf](http://www.swfs.ubc.ca/fileadmin/template/main/images/departments/social_work/faculty/IGLU_TAO_in_my_room.pdf).

The shortage of housing in Nunavut Territory is well known. In every community, there are long lists of individuals and families waiting for accommodation. Despite being Aboriginal people, Inuit are not governed by the *Indian Act*. Inuit are full tax payers but they are not eligible for many of the special programs that from time to time are devised to meet the needs of First Nations people living on reserves in the rest of the country. The Nunavut government is a public government, and not an Aboriginal government. Funds for housing are allocated from its operating budget, as would be true of any provincial government. Responsibility for housing lies with the Nunavut Housing Corporation. Social housing accounts for the greater part of its responsibilities, and 98% of social housing in Nunavut is occupied by Inuit.

The growing Inuit population and the lack of adequate housing has created a situation of serious overcrowding where as many as three to four generations can sometimes find themselves living under the same roof. Rooms may be occupied by many different people

of different genders and ages living within the same family. People sleep on couches, as well as mattresses on the floor. This situation contributes to a long list of social and personal problems experienced by Inuit. The lack of funds to address the housing needs of Inuit has, consequently, contributed significantly to other health and social service-related costs. The report, for example, found that in Kinngait, using nationally accepted formula for calculating rates of overcrowding, approximately 47% of the homes were overcrowded compared to 7% at the national level.

Inuit are constantly frustrated by cross-cultural differences in communicating about and dealing with such problems. Historically, problems were dealt with by direct, open and honest communication. What the mainstream Canadian culture requires in order to 'make a point' is evidence; and that means 'scientific' evidence, conceptualized and as practiced within western European cultures. Inuit traditional knowledge —*Inuit Qaujimagatuqangit* — struggles to find a place in this 'way of doing things'.

In this case, Inuit recognized the need to speak to decision makers in a language that they would understand and take seriously. At the same time, *Inuit Qaujimagatuqangit* was practiced in conceptualizing the research, conducting training workshops and in developing the instrument used to collect information. The research is therefore an attempt to combine different ways of doing the research with the overall objective of having an impact on the understanding of people in positions of authority with the capacity to change things. The Harvest Society of Kinngait initiated development of the project because it "wanted to have an impact on Inuit housing and overcrowding" using language that non-Inuit (*Qallunaat*) would understand.

The project took a year. The training workshops took place in May 2005. The field work was done by Inuit youth, and two students who worked with them in the summer. Frank Tester then processed the data and wrote up the report in the fall of 2005. The report was published in 2006. In the case of this project, Frank did not have previous experience working with this community. His only prior experience was interviewing some Elders in Kinngait in relation to another research project.

## **2. Designing, Developing and Implementing the Project**

Participatory action research (PAR) was the chosen approach because research was only part of what was to be accomplished. PAR seeks to engage people in social change. Partners agreed to a phenomenological approach that involved "surveying the community using a questionnaire designed in and with the community, the result of an exchange between the researchers and youth in the community, employed as trainees and as researchers".

The four objectives of the project were to: "(a) document the extent of the problem statistically; (b) document the social and personal implications of the problem phenomenologically through interviews with youth, parents, adults and public officials in the community; (c) train and actively involve a number of Kinngait youth in learning about, doing and using the research in addressing the problem of overcrowding; (d)



through the use of film, document the stories of households, the material circumstances of housing in the community, and through a series of interviews with public officials and professionals provide background on current circumstances.”

Inuit Elders Mangitak Kellypalik and Makituk Ingwartuk assisted by Simega Suvega, and members of the Harvest Society were active advisors, “lending strength and wisdom to the work that was done”. The project involved Inuit youth in the various components of the research, providing employment as well as opportunities for capacity building in the conduct of research but also for “acquiring an interest and concern in social conditions.” Six Inuit youth contributed to the development and administration of the survey questionnaire used for the in-depth interviews of residents. A seventh individual contributed primarily to the questionnaire development. Other contributors and participants were parents, relatives and partners. Two students from UBC spent time in the community and assisted with the research. A dedicated community liaison facilitated logistics, organizational assistance and advice where needed. The project also benefited from support from the Mayor and the Council of Kinngait. It was funded by the National Homelessness Initiative of the federal government and the Social Sciences and Humanities Research Council (2005).

The development of the survey sought to accommodate community language, culture and protocols. Survey questionnaires were available in English and Inuktitut. To prepare the questionnaire for in-depth interviews, a two-week design and training workshop was organized with seven Inuit youth selected by the Elders. The workshop was lead by Frank Tester as the co-investigator and two non-Inuit assistants, both of whom were students at the University of British Columbia. The questionnaire was professionally designed, and ideas and concepts were translated into Inuktitut. Inuit youth played an essential role in that ideas, observations and questions arising from the design process were taken home by the students who discussed them with parents and relatives, returning with suggestions and ideas for changes to the questionnaire. Professor Tester then revised the instrument every evening after input from the students during the days the workshops were held. The result of this iterative process was many revisions to the questionnaire, allowing for inclusion of “what constituted reasonable and important questions” to better understand housing and overcrowding issues in the community. The instrument reflected community realities, asked questions important to the community and did so in a way respectful of Inuit culture and language.

Elders participated at various points in the workshop. They provided youth with initial background, insights and stories about past and current housing practices. Later in the development process, they were informed by the Inuit youth and researchers about historical documents and the research project itself.

Capacity building occurred when students acquired skills related to research design, questionnaire development, interviewing, understanding of the consent process, dealing with content, and the rationale for saying things or for organizing questions in a certain way. They considered the use of film, other images and stories in the conduct of research. Attention was paid to ethical issues that might arise during interviews. The workshop and

development process occurred over two very intense weeks of learning and development.

The researchers hoped to interview 100 individuals. The stratified sample paid attention to age and status, single Inuit, couples, female and male participants. It used housing lists and house numbers, lists of Elders, and listed individuals registered on a house-waiting list. Youth under 15 represent 38% of the population. Given the rapid growth of the population and the number of young people in need of accommodation, the research project sought to ensure appropriate representation of youth, for whom access to housing is a rapidly growing problem. Therefore, the sample had more youth representation than what would normally be the case in a random survey of the population. Otherwise, sampling was done randomly within each of the categories (youth, adults, Elders, etc.,) identified as important to the research. No household was sampled more than once. For example, if a youth was interviewed in a home that home was then removed from the sample available for further interviews. The knowledge Inuit youth had of their own community was essential to this process. In the end, over 90 questionnaires were completed.

The sample required the development of both assent and consent forms. Prospective interviewers studied and discussed the consent forms during the two-week design workshop in order to ensure that assent/consent process and content were understood, as well as the rationale behind the process. Consent and assent forms were available in both English and Inuktitut.

The forms indicated that participation was voluntary and that withdrawal from the study had no implications for the individual in question. Within the context of PAR, community members' participation in the study is essential for achieving the common goal of the study. To show appreciation for participation and providing information to the study, a small token was offered to participants, and specified as such in the consent form. Researchers ensured that interviewees understood that they were not being paid to participate in the study.

The form provided contact information to answer any questions about the project. A community contact was provided as well a way of getting in touch with Professor Tester if necessary. Concerns about the rights of the interviewees as research subject were to be addressed either by calling the UBC Research Subject Information Line or a local entity, *Nunaqyummi Qaujisqtulirijikkut*, the latter being recognized as a more appropriate body for Inuit to contact. The form asked prospective participants to indicate, with their signature, whether they agreed (a) to participate, (b) to be interviewed, (c) whether the interview could be audio-taped or videotaped and (d) whether their home might be videotaped as well. The interviewer was requested to sign this form too. However, if someone did not wish to sign but wanted to participate, a taped verbal agreement was also accepted.

It was anticipated that participants might have some questions or that something might bother them during or after the interviews. Provisions for follow-up were outlined in the forms. These included participants contacting the resources identified in the forms or the

researchers, who would try to assist participants. Requests for further conversations with the social worker or *Qallunaat* researchers, in private, would be accommodated.

The forms outlined the purpose of the research, who initiated and would conduct the study, why individuals were asked to participate, how data would be collected, who would conduct the interview and that a non-Inuit researcher would be present during the interview. Prospective participants could express their preferences regarding audio-taping or not. The forms also clarified that agreeing to being filmed could result in the community knowing what the interviewee thinks and/or what his or her housing conditions are. It was explained that the audio tapes would be made anonymous through coding and that Inuit interviewers would have access to these tapes for a limited period (five months after the interview). Tapes and notes would be kept in a locked cabinet by Frank Tester and destroyed after five years. The consent and assent process and forms also clarified the limits of confidentiality. Interviewees were made aware that if information related to child abuse was communicated to the interviewer, the interviewer would then be under obligation to report this. It was made clear that the tape recorder could be turned off at any point, if requested by the interviewee.

Ethics review was done by the University of British Columbia's Behavioral Research Ethics Board. The proposal was also reviewed and approved by the Nunavut Research Board.

No interviewees are identified in the report, but contributors to the research team such as Elders, the Inuit youth and university-based research assistants are identified. The report clearly identifies the community in which homelessness and overcrowding occur and the perceived impacts by residents on their daily lives, well-being and security. The use of the report is on-going, publicizing in written form the documented problems of overcrowding, homelessness and related problems affecting residents of Kinngait and other Inuit communities. Filming of the current housing situation was not totally achieved, but what has been done constitutes a basis for future undertakings. Professor Tester used the experience to inform a documentary film on Inuit housing, shot in another Inuit community, and which is currently under production.

The Inuit youth and Frank Tester reported back to the community after the report was completed. They kept in mind the audience, what people might want to know about and what they might benefit from. In a community where there is much poverty and a constant struggle to put food on the table, holding a community feast as part of a report back made a lot of sense. The youth arranged and advertised the gathering on the community radio and by word of mouth. After the meal, Frank presented the results - pictures of the training sessions and some of the information collected. The research team answered questions. The Inuit interviewers received a certificate of accomplishment and a hoodie from UBC.

One of the youth traveled with Frank to Iqaluit to do interviews with CBC radio and the press. Local and national media outlets reported on the research results. The student

spoke for the project and was the one interviewed. Frank restricted his role to one of moral support and answered any questions that the student thought would be better directed to him.

### **3. Considerations and Challenges**

Some of the considerations and challenges arising when working in Aboriginal communities are remarkably similar to the problems that arise working in other (and what some people call 'third world') countries, where western European academics have sometimes gotten themselves into serious trouble exporting their ideas and ideals about how certain social problems should be addressed. This is why taking direction from local people is important. A collaborative approach such as participatory action research allows for such "taking direction". It is an iterative approach, involving residents from the beginning, and at all levels, over the life of the project—including communication.

Lack of understanding and appreciation of community and cultural settings by *Qallunaat* researchers, and by student researchers, may have implications for the research. Guidance and taking direction from local community members is essential for ensuring the use of appropriate research processes, maximizing participation of local people and producing meaningful research results. In particular, guidance and orientation of students participating in field work is essential. Most academics feel that it is important for students to benefit from their research. Taking students into the field (in this case, Nunavut and a very different cultural experience) has its own challenges. Many students have never been on an Indian reserve or in an Inuit community. Students can be quite idealistic and their idealism is sometimes shattered by coming face to face with realities that a seasoned researcher has come to 'take for granted'. They may have the best of intentions, but a lack of experience and insight into the workings of other cultures and communities can sometimes lead to conflicts between what they think is the right or 'necessary' thing to do and what, in fact, makes sense. Orienting students to what they can expect in the field is difficult, as the best way to learn is to be there. But being there and doing things without orientation can cause problems. Taking direction from local people is therefore important.

However, 'taking direction' can, in itself, be complicated. People often see academics and others as 'experts' and defer to them with ease. This is a case of the 'yes' that sometimes means 'no'. If a researcher is not sensitive to the fear, respect and deference that people have toward 'experts', for historical and personal reasons, consultations and the best intentions to take direction from a community can lead to directions and outcomes that, in fact, have little or no support. This is compounded by the desire of the researcher to 'get on with it'; for the sake of time and budget, to get the research underway. Researchers who are new to Aboriginal settings need time to 'hang out' - to just be there and to have no pressing agenda so that they can become familiar with people, settings, develop relationships and gain the trust and respect of people. Few research grants afford a researcher - including students - this luxury.

A third challenge is related to the collection of information and how to recognize the participation of people. In participatory action research the person being interviewed should be an integral part of the research. The research and the research product are thus the property of the community and the researcher. A token of appreciation, monetary or in other forms, does not constitute 'compensation' and being seen to pay individuals for information is a problem for all forms of research, but especially for PAR. The challenge resides in information and cultural insights being considered as a commodity, with implications for what gets produced, who comes forward and the results. When one purchases information, the information becomes the property of the person paying for it. It can be argued that paying for interviews has proprietary implications that contradict the idea of participatory research. This is a subject that requires ongoing debate and consideration within academic as well as Inuit communities.

Finally, the design and development of questionnaires and other instruments for research purposes is an art; one that is sometimes badly practiced. The number of seemingly minor technical details that can affect the utility of an instrument are many. Researchers working with Inuit and other Aboriginal communities don't always take the development of instruments seriously. This is particularly true where conventional social science research needs to be combined with cultural considerations and traditional knowledge. Wording and designing things so that they can be translated easily is important. And there are other cultural realities that are often overlooked. For example, in the research project presented here, the question of what constitutes 'truth' arose — and whether the truths expressed by some respondents might be 'more true' than those expressed by others. The concept of truth and matters of first hand, versus second hand, information is very different in Inuit culture than in western-European cultures. Participatory research permits the research to access these kinds of insights and to learn from the community. The research is hopefully enriched accordingly. Universities compound the problem of doing good research by often asking that instruments be developed and submitted as part of the ethical review process. In fact, a good instrument is designed in the field as part of the research undertaking.

There are situations where the consent and assent forms required by university ethics review boards are not appropriate. This is particularly the case in working internationally and with populations that have been oppressed, where, for example, signing something has historically meant identifying oneself in such a way that one becomes a target for abuse — and even death. In many situations, verbal consent is adequate. Professor Tester has worked in situations where communities didn't want anything to do with the paper work (consent forms, information sheets, etc.) required by ethics review committees and, in effect said: "If we know you and trust you, we will work with you. Signing a lot of paper that talks about things we might not understand or care about, won't change that".

Respecting other ways of doing things can often lead to conflicts between what is required by officialdom and what best suits others. This experience points to the tendency of bureaucracies to build and grow in attempts to deal with every possible aspect of what should be considered. Forms, rules and regulations proliferate accordingly. Then one encounters a community or individuals that, perhaps recognizing a cultural habit that is

not theirs, in a simple statement such as the one above, dispense with all of it. These situations working across cultures make for important and ongoing discussions that should include academic and other researchers, as well as Inuit and other Aboriginal communities.

**Michif Language Learning and Documentation**  
**Camperville, Manitoba**  
**A Case Study of Research Sponsored by The Métis Centre at the National**  
**Aboriginal Health Organization<sup>47</sup>**

## 1. Project Description

This is one of many examples of research within Métis communities. As there are different forms of research, there are many types and forms of Métis communities. What may have worked in this example, may not work in other situations.

During the month of July, 2007 the Métis Centre at NAHO conducted a research project, exploring the efficacy of immersion language instruction as a method of teaching the Michif language. Researcher and Michif student, Tricia Logan lived in Camperville, Manitoba with her two generous hosts and Michif speaker-instructors, Rita Flamand and Grace Zoldy. In addition two other students, community members from Camperville sat in on the Michif lessons and were asked to help evaluate some of the research activities and efficacy of Michif immersion. These students were Ramona Guiboche and Helen Lafreniere.

Principle participants included; the Métis Centre at the National Aboriginal Health Organization, (NAHO) ([www.naho.ca/metiscentre](http://www.naho.ca/metiscentre)), Rita Flamand and Grace Zoldy, principal researcher and Michif language student, Tricia Logan, Métis Centre at NAHO Research Officer, Michael Fisher and additional students; Ramona Guiboche and Helen Lafreniere. Camperville, Manitoba was selected as the location for Michif immersion study because it is home to Rita and Grace as well, it is a community with a generally high Michif speaker concentration.

Activities of the Michif immersion segment of the project were modeled after the Master-Apprentice language revitalization program.<sup>48</sup> Michif students in the immersion program live with Michif speaker-instructors, in their homes for time periods that last from several weeks, up to a month or longer. Rita and Grace adapted the Master-Apprenticeship program after hosting two students prior to the Métis Centre students. In the present version of the program, Tricia lived in Rita's cabin, at her home for the month of July. She spent mornings with Rita, in her home and the afternoons with Grace, in hers. Tricia was there as a researcher, as well as a Michif student. While she attended immersion classes each day, she kept a journal of the progress and compiled reports on the efficacy of immersion for Michif language transmission. She conducted interviews with speaker-instructors and other students as well as former students of the Master Apprentice program. All interviews were used for research purposes and all the audio or video tapes

<sup>47</sup> National Aboriginal Health Organization – [www.naho.ca/metiscentre](http://www.naho.ca/metiscentre)

<sup>48</sup> Hinton, Leanne, Matt Vera and Nancy Steele, *Keeping Your Language Alive: A Commonsense approach to one-on-one language learning*, Heyday: Berkeley, 2002

of Michif language were compiled to create a traditional knowledge archive of Michif, an endangered language, including stories and oral histories in Michif. Research objectives evolved over the month of Michif immersion in order to account for the gradual addition of different lessons and methods of teaching. As medicinal herbs, oral histories or new speakers were added to the lessons, research methods and protocols were revisited as per the ongoing changes.

## **2. Origins of the Project**

These research activities originated in July 2006 and were in response to proceedings from a Métis gathering on Métis health. Both Rita and Grace when asked about health in meeting interviews drew connections between the retention of their Michif language and their physical, mental, emotional and spiritual health. At that time, both Elders invited the Métis Centre to come live and learn Michif with them. This invitation was important to the research process and it is noted as the initiation of the project and an unwritten Michif research agreement.

Speaker-instructors Rita and Grace extended an invitation to the Métis Centre and up to four students to come to their homes for the month of July for Michif immersion. Four students initially volunteered to come to Camperville and at the start of July 2007 three of four were able to secure time in order to attend ‘classes’. Tricia was sent by the Métis Centre and she was the only person from outside Camperville to attend. Tricia met and worked with Rita and Grace during Métis Centre Elders Gatherings and built a relationship with them over two years leading up to this study. Even though there are few to no formally written Métis ethical guidelines, the Métis Centre adapted organizational standards, which were commonly understood from mainstream and academic research experiences, and what the Centre knew or was learning about regarding Métis research expectations from Rita and Grace.

Funding for this Michif immersion project was provided by the Métis Centre at NAHO. Access to the funding was contingent on several different circumstances. Initially, there was not a great deal of buy-in for this project from the Métis Centre, because of concern of whether it aligned within the Métis Centre mandate. The Métis Centre did approve funding after a year of re-framing the purpose of the project and particular terms were established. The terms that had to be met in order to gain approval for funding were; that the culture/language component of the Manitoba Métis Federation (The Louis Riel Institute) was aware of the project and would be willing to accept results from the project, that the results were compiled in a way that would aid language programs for any Métis language in any Métis community interested in language revitalization and that Rita and Grace, as speaker-instructors, were willing to become research partners and participate in research activities as well as the Michif lessons.

Research affiliations were created with the Louis Riel Institute and Gabriel Dumont Institute. The Gabriel Dumont Institute is a Métis-governed educational institute and resource in Saskatchewan that houses a large volume of Métis material culture, historical items and is host to large Michif language files on their virtual museum. They provided



support for the start and follow-up stages of the study. The Gabriel Dumont Institute provides support for Michif immersion and is contributing invaluable advice and support on how to manage the volumes of Michif language archives and Traditional Knowledge collected over the month of July 2007.

It should be noted that the letters of support required by the Métis Centre from the Manitoba Métis Federation via the Louis Riel Institute were not directly connected to Camperville or the speaker-instructors. The connection to the Manitoba Métis Federation was to assure that Métis organizations were interested in receiving results from this research. The speaker-instructors were engaged with the Métis Centre in the research agreement as individuals, and even though they represented an undefined community of Michif speakers, they did not enter into the research as part of any other organization or geographically or politically defined community. In this case, the individual speaker-instructors did not require community approval and they preferred to conduct the project as individuals.

Before the Métis Centre entered the community and Rita and Grace's homes they ensured that a research agreement was drafted, approved and signed via a joint effort from the speakers and the Métis Centre. Métis Centre staff members, Tricia Logan and Michael Fisher traveled to Camperville in November 2006 and June 2007 to gather information and to help reach an agreement on what was required by both parties to complete a project of this nature.

While the Métis Centre maintained phone contact over the months leading up to the start of the project, the face-to-face meetings between Tricia, Michael, Rita and Grace were critical to build a trusting relationship and to ensure both parties were satisfied with the terms of the proposed research. The Métis Centre maintained contact with Rita and Grace from July 2006 until start of the project in July 2007. Contact and informal activities connected to this project continue today, between Tricia, Rita and Grace. Even after the formal written requirements of the project have been fulfilled, the relationship between the speaker-instructors and Tricia will continue. Conceptually, there is no end date for this case of research since it includes a long-term, un-definable commitment to the Elders and the language by the researcher.

### **3. Research Agreement**

The research agreement, developed in partnership between the Métis Centre, Rita Flamand and Grace Zoldy covered general aspects of research activities. Lessons and terms of conducting Michif instruction were left to the discretion of Rita and Grace. Their adaptations and style of teaching Michif would be part of the findings of the final report but were not part of the original research agreement. The agreement included; project objectives, an outline of which parts of Michif immersion would be reported on, collection of information, consent, privacy, ownership and voluntary withdrawal. It was agreed that Michif lessons would be audio recorded on a daily basis, some lessons might be video recorded and a daily journal would be kept by Tricia, for research purposes. Rita and Grace had control when and for how long the audio recordings would be

retained. Edited audio and video copies of lessons and interviews are held at the Métis Centre and will be, at the request of the speaker-instructors, in a permanent archive at the Gabriel Dumont Institute and copies of all complete audio recordings by each speaker-instructor were left with each speaker, respectively. Rita and Grace reserved the right to recall any or all recordings at any time. None have been recalled, to date.

Consent was provided by the speaker-instructors to the Métis Centre, written in English and spoken in both English and Michif. Initial terms of consent were agreed upon in the research agreement and additional consent obtained from the speaker-instructors orally before the start of every video recorded interview.

When interviews were conducted with other students and community members, they were asked to sign a written consent form, they all complied with the terms and their interviews were video and/or audio recorded.

Spontaneous activities that resulted from the month of Michif instruction, such as the transmission of oral histories, traditional knowledge or personal information were dealt with by the researcher on a case-by-case basis. The researcher, in all cases asked if continuing with audio or video taping was appropriate or desired, if the information in the lessons could be shared with others and if so how and in what format should the lessons be shared. Protocols were applied and adapted over the course of the month. These changes were not specifically recorded in the research agreement, but the agreement was initially developed with these anticipated adaptations in mind.

#### **4. Implementation**

Rita and Grace monitored the program daily. They measured Tricia and the other students' progress with the language. The three or four interviews monitoring interviews for the Métis Centre conducted during the project also gave Rita and Grace the formal opportunity to address any problems with the project. Both the Métis Centre staff and the speaker-instructors ensured the terms of the research agreement were adhered to, over the course of the month.

Each one of Rita's classes involved rote memorization, learning a writing style and pronunciation guide, cooking and learning from stories and oral histories. Her views on the language emphasized her requests for what was to be done with them. She was concerned for how the language was learned; who it was shared with and in what format it would be shared in. Rita also wanted to be informed about who would be able to access her language lessons and information. Rita is very open and accommodating with her language. She truly believes in dedicating her life to teaching and sharing Michif.

In Grace's home, language lessons were different. Tricia was the only student and the lessons were much less 'structured'. Michif transmission was done primarily through conversations and experiential learning. There were discussions about every day activities, there were Michif recipes, learning about Michif medicines and herbs, work in the garden and many stories of Métis holidays. Lessons were audio taped and some extra

lessons were recorded on small cassettes, by Grace herself, after Tricia left. From Grace's perspective, she was less concerned how or where the lessons ended up, but just that it was being passed on.

Evaluation of project process was also done in two segments, to be later merged as one set of findings. Rita and Grace monitored their Michif students' progress with the language lessons. They would increase or decrease their pace in lessons according to how all of the students; Tricia, Ramona and Helen were picking up new words or concepts. The Métis Centre coordinated a portion of their evaluation scheme with linguist, Dr. Nicole Rosen. Dr. Rosen visited Camperville near the end of July and participated in some of the Michif lessons. She spoke with speaker-instructors, students and community members in order to evaluate the efficacy of this Michif language program.

Michif language lessons were treated with care and ethical consideration, not only because they were sacred and rare, but because the words and stories were just as precious as the language itself. For instance, when Grace taught about the herbs and medicines, there was a whole set of different considerations used than those used during the conversational times. Procedures for handling medicines and sacred items had to be adhered to. Some of the methods were unknown, but Grace, as speaker and Elder, helped Tricia learn what to touch, to listen to and ask about as the herbs and medicines were introduced to the lessons. The ethical actions and findings of this report were not completed out of necessity per se, but also out of a personal commitment made to the speaker-instructors, as they have trusted you with their ancestral and endangered language.

Protocols used during the Michif and English language interviews varied. There was a general sentiment that lessons and interviews spoken in Michif are presented as lessons and something to be kept and held by Michif people, for Michif people. The interviews or lessons conducted in English were perceived as being for Michif people but also for a larger, possibly non-Métis audience and the research report. What was shared in Michif was always viewed in a different light than what was shared in English since the audience for the findings would be either Michif, and or English language speakers.

## **5. Applying Ethical Principles to Michif Language Research**

### **5.1 Communicating potential harms and benefits of the research**

Rita and Grace's prior research experience helped to create a fair and a mutually beneficial partnership with the Métis Centre. This was the first time, in their experience with research, that the speaker-instructors were approached prior to entering their homes and that they were asked to help define the terms of the research that they would be partnering on. In this case, potential harm was noted and based on prior experience, but not all Métis and Michif Elders have these years of experience. In those cases, Elders may not be informed or acutely aware as Rita and Grace are on how proper referencing; Elder approval of texts, collaborative approaches and ethical project design can protect their personal interests.

## **5.2. Confidentiality of personal and cultural information**

Privacy and anonymity were addressed in the research agreement. The speaker-instructors agreed to discretionary terms that gave them the option to keep any or all of their identifying information confidential if they so chose. They were also given the option to withdraw from any or all parts of the research. Presently, they have not indicated that they wanted any information kept confidential.

Even though Rita and Grace did not request that their information and stories in the reporting process be attributed to anyone else, there is still an implied presence of ancestral wisdom. In some cases, Métis Elders have and will ask that the stories and traditional knowledge be sharing be referenced not particularly to them, but to what could be referred to as an 'accumulation of ancestral wisdom', since they do not feel they 'own' the knowledge. In the case of this study, the references in the final report will still be attributed to Rita and Grace but their families and ancestors will be acknowledged through an acknowledgements page and or the preface to the piece.

During Rita's classes, since the students were using her own personally-designed writing system for Michif, the consent was conditional and it had to be accompanied by an explanation of where the information would end up. Rita has spent decades developing her own writing system for Michif and sharing her language with quite a few students and researchers.

In this study, the instructors would help by indicating when they were sharing rare or ancestral knowledge. They would not state outright, that what they were speaking about, in English or Michif, should be treated with care, but they would at times present "rules" or suggestions on how their discussions should be used. For example, when a lesson-conversation on different medicinal herbs and teas was held between Grace and Tricia, there was new way of recording and listening for the Michif lessons. In Grace's opinion, she collected all of these herbs to share them and she wanted people to have them. She felt that it was not necessarily her place to put too many restrictions on who can touch or handle the teas and herbs. She felt that if many people need this medicinal knowledge, they could have access to them. There were rules for using the herbs and sacred items, but these rules seemed to have originated out of respect and necessity rather than purely spiritual reasons. Use of family and community photos, records and stories was also considered the same as some of the material culture.

## **6. Observations Regarding Further Research With Métis People**

### **6.1 Developing research questions and methods**

A major objective of this project was to test the efficacy of Michif language immersion. Research was designed to be beneficial and effective for other communities, who hoped to create a project similar to this one, for their own Michif, Métis language or community.

Research methods were created and adapted to take both western and Indigenous

methods and apply them to a Métis setting. Creating ethical guidelines for a Michif setting was done in coordination with the creation of Michif research methods. Selecting effective definitions of 'community', understanding the unique jurisdictional struggles of Métis communities and having a comprehensive understanding of Michif language and Michif life before entering the community were essential to the methods development.

## **6.2 Resolving differences in expectations, approaches or obligations between community partners and researchers or their organization/institution**

The majority of the differences in expectations that existed in this project involved the relationship between the incoming researcher and the established Métis community. The researcher entered as an outsider, never having been raised in this community and not related to anyone in the community. Remaining neutral as possible in matters of social, regional and familial politics was essential to project management.

Métis communities do not operate with the same formal boundaries and jurisdictions, in so much as many First Nations communities do. While there are socially, politically and geographically defined Métis communities, recognized by Métis and non-Métis, many Métis are still considered 'unaffiliated' with any formal community. Access and involvement of Métis individuals is not necessarily connected to involvement of community, in all cases. Including a community or group in project design, or terms of the research project such as privacy, confidentiality, ownership or control should be considered in light of the local situation and the preference of participants. There are many benefits that can arise from involving a larger community but those should be mutually beneficial to individuals and community.

## Native Counselling Services of Alberta & University of Alberta Collaborative Research Example

### 1. Project Overview

As Director of Research at Native Counselling Services of Alberta (NCSA), Patti LaBoucane-Benson partnered with Dr. Brenda Munro, Professor, Department of Human Ecology at the University of Alberta, to undertake a collaborative, community-based research project in Edmonton, Alberta on homeless youth. NCSA (incorporated in 1970) is an Aboriginal not-for-profit organization that provides a wide range of social and restorative justice services throughout Alberta. In addition, BearPaw Media, Research and the Aboriginal Resource Centre are a part of BearPaw Communications, which is a department of NCSA.

The impetus for the LINKS Program Development and Research Project (hereafter referred to as the LINKS research project) came from NCSA's experience in providing homeless prevention programs, and in operating Cunningham Place, a 52-bed, transitional youth housing project. In partnership with Dr. Munro, NCSA had also completed two earlier surveys in Edmonton with homeless people (adult Aboriginal and youth populations). Based on this foundation, a proposal was sent to the IAPH (CIHR) to conduct further research that would create a better understanding of the realities of homelessness for youth — including the barriers experienced while engaged in transitioning out of homelessness and what characteristics youth require to successfully make the transition. As well, we also envisioned using this information to develop a program that would assist homeless youth to initiate positive health-seeking behaviours. Dr. Munro received the IAPH grant, and NCSA acquired additional funds from the Urban Aboriginal Strategy (UAS) in Edmonton for the two-year program pilot.

The purpose of the LINKS project was twofold: first, to develop and pilot the LINKS program, which is a community-based initiative that brought university students and homeless youth together over a twelve week period to exchange information as two distinct cultural groups. For students, the program provided opportunities to gain a better understanding of the realities of homelessness from same age peers and to challenge personal stereotypes through constructive interaction. For the street/homeless/transitioning youth, the program provided opportunities to interact with same-age peers who would provide healthy role modeling, positive health seeking behaviour and inspiration in their lives. The program was developed on the tenet that the sharing of information and life experiences between students and youth in a safe, fun and encouraging environment would foster supportive, empathic connections between these two groups. The program was developed with funds from the CIHR and offered for two years at NCSA with funds acquired from the UAS.

The second purpose of the project was to conduct a community-based research project with young women for a period of two years that identified internal and external assets that facilitated survival on the streets, and enabled the process of transitioning out of

homelessness. A qualitative and longitudinal approach was used to explore the life experiences and development of 18 young women; while several young women completed ten or eleven interviews, the average number of interviews conducted was six over the two year period. In addition, two focus groups were conducted at the beginning of the project.

## 2. Participants

The following chart details the partners, organizations, researchers and participants that were involved in the research project.

|                             |   |
|-----------------------------|---|
| Funding Partners            | The research project was funded by the Canadian Institutes for Health Research: Institute for Aboriginal People's Health. The LINKS program pilot was funded by the Urban Aboriginal Strategy in Edmonton.  |
| Administering Organizations | The project funds were held by the Principle Investigator, Dr. Brenda Munro at the University of Alberta, Department of Human Ecology. The project staff were employed by BearPaw Research at Native Counselling Services of Alberta and supervised by Co-Investigator Patti LaBoucane-Benson, Director of Research and Communications.   |
| Partnering Organizations    | NCSA and the University of Alberta partnered with many key organizations in Edmonton for both the LINKS program development/implementation and the recruitment/retention of longitudinal research participants. These organizations delivered services and provided resources to the population that we wanted to recruit into the LINKS program, as well as become participants in the research study. |
| Advisory Committee          | The advisory committee comprised of representatives from the partnering organizations. They were recruited specifically for their expertise in the area of homelessness, youth and the barriers youth face in transitioning back to homefulness. Representatives included a combination of Aboriginal and non-Aboriginal people, who brought diverse perspectives on homelessness to the discussions.   |
| Research & Program Staff    | This project employed one Research Coordinator/LINKS Program Facilitator, a LINKS program co-facilitator, several research assistants (two assistants that were with the longitudinal research project for two years) and two researchers who assisted in data analysis and writing.  |

|                                 |   |
|---------------------------------|---|
| Research & Program Participants | Research participants were young women who were currently or in the recent past homeless. LINKS program participants were recruited from Cunningham Place (a youth transitional housing project). |
|---------------------------------|---|

### 3. Timeline

The collaborative, community-based approach employed for the LINKS Research Project required extensive time spent on pre-research activities; specifically, time for relationship building with other service providers in the community, the development of a community advisory committee and time for research assistants to become grounded in both the homeless youth literature, community-based research methods and to develop a rapport with service providers for the recruitment of research participants.

This research project was initially proposed in 2002; permission was sought first within NCSA to pursue the research project, as it would involve the NCSA programs that provide services to homeless individuals. Next, the proposal was developed and submitted to the IAPH for funding. Funding was secured in November of 2003, after which university ethics approval was acquired. In June 2004, a project coordinator/facilitator and research assistants were hired. The first six months were spent building relationships with numerous service providers in Edmonton and drawing them into the project in one of three roles: as advisory committee members; in providing a location where research participants could be recruited for the longitudinal project; and as a part of the learning process in the LINKS program (program participants visited different services in Edmonton to better understand the services provided to homeless youth). The community advisory committee was instrumental in assisting the research team in problem solving throughout the program development and data collection phases.

Data collection for the longitudinal project started considerably later, as the recruitment process within this population was difficult and it required many visits to the partnering agencies and relying on a 'word of mouth' recruitment process. NCSA staff and service provider partners were essential in this process as researchers relied on their knowledge of the population to find women who would be interested. The advisory committee met on a regular basis at the beginning of the project, and less frequently after data collection was underway for approximately one year (make this clearer).

The LINKS program was offered by NCSA and drew program participants from the resident population of Cunningham Place, and students from the University of Alberta (who received course credit for their participation in the program). Both the data collection for the longitudinal research and the LINKS program concluded in April 2007. The final evaluation of the LINKS project was completed in May and disseminated shortly after to the UAS and was published online for partners as well (to ensure on-going accessibility). The coding and analysis of longitudinal data from the qualitative interviews was completed in approximately 4 months; one article has been published another submitted for peer review, 2 additional submissions for peer-reviewed publications of the findings will be completed in April 2008; and dissemination of



information to research partners will be completed in Spring 2008 as well. The Investigators plan to carry out multiple methods of dissemination of the findings from both the evaluation and the longitudinal study including at the local service level and in larger policy contexts. In addition, efforts will be made to locate the young women who participated in the longitudinal study to let them know what has become of the information they shared – this will be done one-on-one, as each participant is located.

It is important to ensure that the findings are shared with the advisory committee, the staff at Cunningham Place who interfaced regularly with the LINKS program, as well as for articles that focus on informing our understanding of homelessness for women, Aboriginal people and implications for effective programming. Publications will also be prepared that focus on policy recommendations that could have a positive effect for agencies such as those that participated in the project as well as this and other similar communities.

#### **4. Special Considerations**

Conducting a longitudinal study, in terms of access and retention, is often difficult because the homeless youth population is typically transient, moving regularly between communities and cities. Further, as their well-being and personal situations fluctuate they can be more or less easy to contact over time. These factors became important barriers to overcome. While contact was lost with a few of the young women, participants were asked at the outset to make a commitment to this longitudinal study. Many of the young women were excited about being involved, and most were motivated by the opportunity to help other youth. Research assistants managed to maintain connection with participants by forming positive, respectful relationships with them and by regular communication with service providers assisting the participants. While the bi-monthly guideline for interviews was not always met those participants that temporarily “disappeared” usually reappeared and were once more quite interested in involvement.

Participants recruited were 18-years-old or older, and were in the early stages of transitioning out of homelessness. Initially, young men were also sought as participants, but their inclusion was not feasible due to problems in the recruitment of both male interviewers and participants. Half of the participants were of Aboriginal descent, a direct reflection of the homeless population in Edmonton, which is approximately 50 per cent Aboriginal.

During the first meeting, participants received an information sheet and a verbal overview of the project. Following agreement to participate, interviews were conducted in local coffee shops or fast-food restaurants of the participants’ choice and a meal was provided. Researchers strove to ensure confidentiality of the participants; participants were asked to choose their own pseudonym during the informed consent granting process; this ensured that they understood how their identity would be protected when the findings were presented.

Interviews were held approximately every two months; they addressed not only current

successes and challenges in transition, but also questions related to their background, paths towards homelessness, and how they maintained themselves while homeless. The successive interviews built trust over time and helped to collect more in-depth information. The research assistants employed a variety of instruments that would assist participants in speaking about their experiences and ensure that participant voice could be included explicitly in the findings; for example, a printed time line was used, whereby participants could place important events within the chronology of their lives, creating a visual picture of their experience. Also, each successive interview would provide time for catching up on current events in their lives, but then also focus on a particular and unique aspect of their lives, which they could speak to in detail (both historically and currently). These topics, which were chosen according to the asset charts that were developed and revised throughout the project, guided the participants to speak about important, but sometimes difficult, aspects of their lives in a respectful way. A respectful approach to how to address often difficult issues with interviewees and to ensure they left the interview in good shape was used. Finally, participants were invited to submit a creative work that would further illustrate their lived experiences; these could include poetry, rants, narratives or works of art.

Interviews were tape recorded unless the participant indicated she was not comfortable with doing so. Detailed summaries of each interview, transcripts of specific interviews, charts recording assets and final summaries on each participant's background and experience during the research period were completed by the interviewers. The interviewers were given opportunities to debrief as needed and also kept journals detailing their own personal reactions and thoughts regarding the interviews.

## **5. Addressing Challenges**

Typically, community-based research (CBR) can take a great deal of time for grounding-in and for the research staff to build relationships with the partners who have expertise in the research area. For this project, NCSA was a full partner and initiator of the research project; the Director of Research had significant applied experience in working within this field and represented an organization that was actively engaged in the addressing the needs of homeless (or at risk of being homeless) youth in the city of Edmonton. The research staff were able to use the NCSA network and expertise to facilitate the building of relationships with the University and with other agencies in Edmonton, as well as use Cunningham Place for the delivery of the LINKS program. In addition, program staff (or -the research team) worked out of an NCSA office, which further facilitated their immersion in the field. Therefore, the leadership NCSA provided was significant in the development of relationships that facilitated efficient and effective research activities.

In addition, the Investigators strove to include both an Aboriginal and non-Aboriginal population in this project, in all aspects of participation; the Investigators, the advisory board, the research staff and the participants. Again, working with NCSA facilitated this endeavour; NCSA has an extensive network of employees and clients, most of whom are Aboriginal. In addition, programs like Cunningham Place provide services to Aboriginal and non-Aboriginal clients, which provided an excellent population to draw from for the

LINKS program. Further, the collaborating partners that participated in the project also had extensive experience in working with Aboriginal and non-Aboriginal clients, as well as employing Aboriginal people in their programs. This background provided grounding in sound research practices with Aboriginal community members. Within the excellent community of agencies that took part in the project, meeting the goal of including specific populations of people was readily achieved.