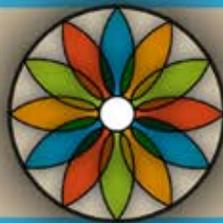


TOOLBOX OF RESEARCH PRINCIPLES



IN AN ABORIGINAL CONTEXT

ETHICS • RESPECT • FAIRNESS • RECIPROCITY • COLLABORATION • CULTURE

## 2018 Edition

### Editorial committee

Karine Gentelet, Université du Québec en Outaouais  
Suzy Basile, Université du Québec en Abitibi-Témiscamingue  
Nancy Gros-Louis McHugh, First Nations of Quebec and Labrador Health and Social Services Commission

### Science committee

Carole Lévesque, Director, DIALOG  
Marlene Brant Castellano, Professor Emeritus

### Other contributors

Jean-Noé Landry, Executive Director, OpenNorth  
Geneviève Beauchemin, Master's student, UQO  
Joannie Gray Roussel, First Nations of Quebec and Labrador Health and Social Services Commission  
Èva-Marie Nadon Legault, Université du Québec en Abitibi-Témiscamingue



### Institutional contributors

First Nations of Quebec and Labrador Health and Social Services Commission  
Université du Québec en Abitibi-Témiscamingue  
Université du Québec en Outaouais  
DIALOG – The Aboriginal Peoples Research and Knowledge Network (financial contribution for linguistic revision and translation)

The 2018 edition was made possible thanks to a SSHRC grant.

### Coordination of linguistic revision

Chantale Picard, First Nations of Quebec and Labrador Health and Social Services Commission

### French revision

Isabelle Capmas, Caractère

### English translation

Èva-Marie Nadon Legault, étudiante à la maîtrise, Université du Québec en Abitibi-Témiscamingue

### Graphic design and lay-out

Code jaune, design et créativité  
Mireille Gagnon, First Nations of Quebec and Labrador Health and Social Services Commission

### Peer-reviewed contributions.

The content of this publication may be reproduced, in whole or in part and by any means, provided that the intended use is entirely for private or public non-commercial purposes, without charge or further permission, unless specified otherwise.

We only ask that:

- the text and materials be reproduced accurately;
- the complete title of the text, tool, video or material reproduced be indicated;
- the authors be indicated as follows: author (LAST NAME, given name), "Title," Toolbox of research principles in an aboriginal context: ethics, respect, fairness, reciprocity, collaboration and culture, First Nations of Quebec and Labrador Health and Social Services Commission, Université du Québec en Abitibi-Témiscamingue, Université du Québec en Outaouais, 2018.

Commercial reproduction and distribution are prohibited.

The content of the articles in the Toolbox of research principles in an aboriginal context reflect only the views of their authors and do not necessarily reflect the opinions of the committees or those of the contributors or institutions. The authors are responsible for their ideas and the final versions of the texts that they validated—in both languages where possible.

Masculine pronouns are used in this document to lighten the text, and do not intend any discrimination against women.

© DIALOG Network, UQO, UQAT and FNQLHSSC, 2018  
ISBN: 978-1-77315-218-9

Legal Deposit – 2018  
Bibliothèque et Archives nationales du Québec / Library and Archives Canada

## 2015 Edition

### Editorial committee

Karine Gentelet, Université du Québec en Outaouais  
Suzy Basile, Université du Québec en Abitibi-Témiscamingue  
Nancy Gros-Louis McHugh, First Nations of Quebec and Labrador  
Health and Social Services Commission

### Advisory Committee

Jane Gray, Assembly of First Nations Quebec-Labrador  
Pierre Noreau, Université de Montréal  
Hugo Asselin, Université du Québec en Abitibi-Témiscamingue

### Other contributors

Nadine Gros-Louis, First Nations of Quebec and Labrador Health and  
Social Services Commission  
Patricia Montambault, First Nations of Quebec and Labrador Health and  
Social Services Commission  
Jean-Denis Gill, First Nations of Quebec and Labrador Health and Social  
Services Commission

### Institutional contributors

First Nations of Quebec and Labrador Health and Social Services  
Commission  
Université de Montréal - Centre de recherche en droit public  
Université du Québec en Abitibi-Témiscamingue  
DIALOG- Aboriginal Peoples Research and Knowledge Network  
(financial participation in the revision and translation of texts)

### Linguistic revision coordination

Chantale Picard, First Nations of Quebec and Labrador Health and  
Social Services Commission

### French revisers

Isabelle Capmas  
Diane Saint-Pierre  
Sematos

### English revisers

Janet Brownlee  
Meaghan Girard  
Ken Hay  
Greg Kelm  
Casey Roberts

### French translators

France Chouinard  
Nathalie Desmeules  
Nicolas Girard  
Sylvain Jobin  
Diane Saint-Pierre

### English translators

Ken Hay  
Pierre Lalonde  
Chad O'Brien  
Natalie Pavey  
Casey Roberts

### Graphic design and page layout

Code jaune, design et créativité

The contents of this publication may be reproduced in whole or in part,  
provided that it is done solely for personal or public non-commercial  
purposes,  
without charge or further permission, unless otherwise specified.

We ask only that:

- the text and material be reproduced accurately;
- the complete title of the text, tool, video or material be indicated;
- authors be indicated as follows: author (LAST NAME, given name),  
" title", Toolbox on the Research Principles in an Aboriginal Context:  
Ethics, Respect, Equity, Reciprocity, Collaboration and Culture, First  
Nations of Quebec and Labrador Health and Social Services Commission,  
Centre de recherche en droit public, Université du Québec en Abitibi-  
Témiscamingue, 2014.

Commercial reproduction and distribution are prohibited.

The contents of articles in the Toolbox on the Research Principles in an  
Aboriginal Context reflect only the views of their authors and do not  
necessarily reflect the opinions of the committees or those of the  
contributors or institutions. The authors are responsible for their ideas  
and the final versions of the texts that they validated, where possible, in  
both languages.

The masculine gender is used in this document simply to make the text  
easier to read, with no intention of discrimination against women.

© FNQLHSSC, UQATn CRDP and DIALOG Network, 2015  
ISBN: 978-1-926528-67-0  
Legal deposit – 2015

Bibliothèque et Archives nationales du Québec / Library and Archives  
Canada

### Peer-reviewed contributions.



# INTRODUCTION

From the start, the *Toolbox of Research Principles in an Aboriginal Context: ethics, respect, fairness, reciprocity, collaboration and culture* was designed to evolve. We wanted this tool to be durable and to adapt to the needs of the different communities affected by ethical issues (First Nations, academics, students, researchers and public administrators). We will therefore regularly update this tool.

Two years after the publication of the first edition of the Toolbox, the editorial committee has decided to enhance documentation on issues of increasing concern for Indigenous organizations. These include the ethics of protecting material and immaterial cultural heritage and of open data. The context in which knowledge and heritage are disseminated is in full technological effervescence. It would therefore appear important to offer both food for thought and tools to support the communities in making informed decisions and to help identify major issues calling for reflection. This update contains two new tabs specifically devoted to these subjects.

We also took advantage of this update to integrate the modifications suggested by certain users. Among other changes, we mention "peer review" in the "Articles and Contributions" tab. We also overhauled the Toolbox's web platform so that articles and other documents are easier to find online.

The update of the Toolbox was made possible thanks to support from the Social Sciences and Humanities Research Council (SSHRC). This grant allowed us to develop educational materials on the ethics of research in an Aboriginal context for workshops provided on-request to First Nations authorities and academics, students, researchers and public administrators.

For more information about the workshops, please consult the training section of the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) service offer at [www.cssspnql.com](http://www.cssspnql.com).

# TOOLBOX ON THE RESEARCH PRINCIPLES



## IN AN ABORIGINAL CONTEXT

### **Karine Gentelet**

The issue of ethics of research in an Aboriginal context constitutes a subject that I have reflected on for several years now. This reflection goes well beyond the institutional procedures that have been implemented by universities and funding agencies to regulate the use of research funding.

The ethics that I am concerned with are those that guide human relations and those that enable us to respect each other and reach a common understanding on how to work. For me, ethics ultimately represent a long-term relationship and commitment between researchers, individuals and communities.

The story behind this toolkit is first and foremost a story of meetings – a meeting that is first of all professional in the context of a special issue of the *Éthique publique* journal that focuses on the ethical issues that have an impact on Aboriginal peoples, and secondly a meeting that is based on friendship with the co-editors of this toolbox, Nancy Gros-Louis-Mchugh and Suzy Basile.

Finally, it also involves meeting with researchers, both women and men, Aboriginal and non-Aboriginal, who were asking the same questions regarding the ethics and difficulties related to communicating, collaborating,

sometimes working together or even identifying their own needs, not because of a lack of will or integrity, but because of the fact that it is difficult to streamline two work concepts or two visions of life. Research, we know, often imposes a number of imperatives (grants, publishing deadlines, etc.). However, not only are these imperatives sometimes difficult to measure, they can also be intolerable for peoples who have decided to take control of their own search tools.

Moreover, even though reflection constitutes a fundamental element in my career path, action constitutes an equally determining stake. It was therefore important for me to associate an action with this reflection, one that offers tools so that, whether you are a researcher or someone who will take part in the research, one can have sufficient information in order to initiate a respectful, or ethical, collaborative relationship. Research must first and foremost remain a human experience, which is perhaps the main message of this toolbox.

### **Suzy Basile**

It was when I discovered a photo of my grandparents, which was taken behind their backs and published in a book without their consent, that my concerns regarding ethical issues appeared for the first time. Since then, I have often questioned the approach taken

by certain authors whose writings, in my opinion, do not reflect the realities of my people, the Atikamekw Nation. It was while reading various books such as *The Jesuit Relations* that I realized that there was room for interpretation and that the observations made on Aboriginal peoples could sometimes be wrong or even distorted by the authors' interpretations. I quickly found that it was possible to publish only one version of the story without taking into consideration the points of view of the interested parties or validating with them what would be published about them. Moreover, certain texts of this type are subsequently widely cited and used as references. As part of my studies in anthropology and my functions among various institutions, I had the opportunity to discuss and collaborate with many professors, researchers and students who were interested in Aboriginal issues. The main question remains "How can contact be established with...?" It's all about relationships and mutual respect. In the early 2000s, the development work on a research protocol was set to begin at the request of several Aboriginal communities in Quebec which had been studied without ever having been informed of the results and also without having had the opportunity to validate those results. During the consultation processes on the subject, I had the opportunity to come to the realization that, just like researchers, the Aboriginal communities



also needed to be informed of their rights and their ability to impose limits on the many research projects that concern them. I also had the opportunity to apply the principles of the research protocol in the course of my PhD project in the field of environmental science. This was certainly beneficial, not only for a successful data collection and results interpretation process, but also for the establishment and maintenance of a relationship based on trust and mutual respect that is essential to the sound governance of research projects. In their quest for self-determination, Aboriginal peoples need relevant research on their past, present and future. To ensure that such research is conducted under the right conditions, tools related to the ethics of research involving Aboriginal peoples must be gathered and made available to as many people as possible. This was the primary objective that we had in mind when we established the project focused on creating a toolbox on the research principles in an Aboriginal context: ethics, respect, fairness, reciprocity, collaboration and culture.

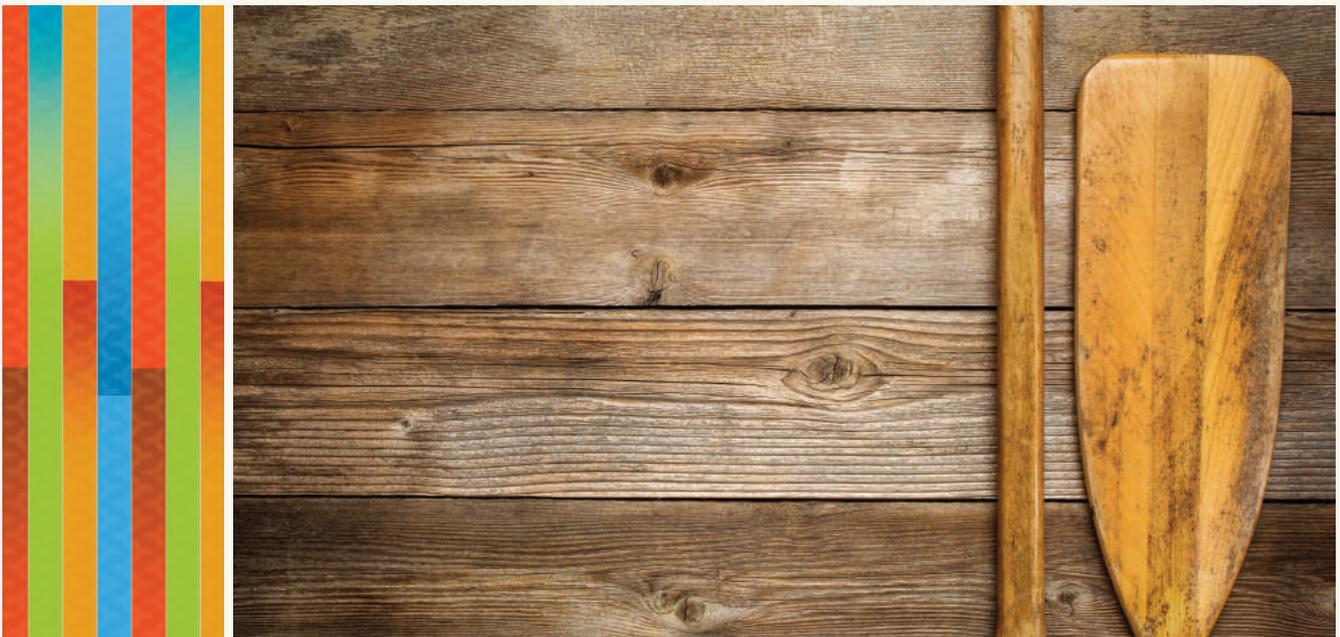
### **Nancy Gros-Louis Mchugh**

The imminent need to have information, which is scientifically and culturally validated, on the health status of the First Nations in Quebec has always been present and expressed within the First Nation of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) and among the First Nations in the region of Quebec.

For this purpose, the FNQLHSSC initiated a reflective process focused on research and the ethical context in 1995 during the creation of the First Nations Regional Longitudinal Health Survey (RHS). This trailblazing survey brought forth the following First Nations principles: Ownership, Control, Access and Possession (OCAPTAM). My familiarization with these ethical issues in 2002 during my involvement with the RHS and particularly with the principles of self-determination in the area of research has allowed me to shape my way of thinking regarding these issues.

The disparities between the expectations of the communities and those of the scientific community have turned out to be very revealing in terms of my actions within the FNQLHSSC. In this vein, I had the opportunity to contribute to the creation of the First Nations of Quebec and Labrador Research Protocol (AFNQL, 2005) in addition to its revision and publication in 2014. Through this work, I met people and mentors who were instrumental in advancing these ethical issues and driving the reflection focused on the decolonization of research.

The FNQLHSSC's involvement in the development of the toolbox on the research principles in an Aboriginal context: ethics, respect, fairness, reciprocity, collaboration and culture will allow it to continue, among other things, its mission to support First Nations with respect to information governance and the research that is taking place among their populations. Furthermore, this tool will be able to serve as educational material in order to influence future researchers in terms of the development of respectful and lasting relationships with First Nations.



# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### MEMORANDUM OF UNDERSTANDING (MOU) - PROTOCOLS

CANADA  
AUSTRALIA

### GUIDELINES

CANADA  
Alberta  
British Columbia  
Prince Edward Island  
Manitoba  
New-Brunswick  
Nova Scotia  
Nunavik and Nunavut  
Ontario  
Quebec  
Saskatchewan  
Newfoundland And Labrador  
Northwest Territories

UNITED STATES

AUSTRALIA

NEW ZEALAND

NORWAY

AFRICA

### OPEN DATA

CANADA  
ÉTATS-UNIS  
AUSTRALIA  
EUROPE  
AFRICA

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### MEMORANDUM OF UNDERSTANDING - PROTOCOLS

#### CANADA

**ASSEMBLY OF FIRST NATIONS, AND INDIGENOUS AND NORTHERN AFFAIRS CANADA.**  
Memorandum of Understanding between the Assembly of First Nations and Indigenous and Northern Affairs Canada, [Online], 2016.

**FIRST NATIONS OF ALBERTA.**  
Memorandum of Understanding for First Nations Education in Alberta: Long Term Strategic Action Plan, [Online], 2013. Alberta.

**ABORIGINAL AFFAIRS AND NORTHERN DEVELOPMENT CANADA AND MINISTER OF EDUCATION OF ONTARIO.**  
Memorandum of Understanding, [Online], 2013. Ontario.

**ST. MICHAEL'S HOSPITAL, AND THE COUNSEL OF GRANDPARENTS.**  
Well Living House at the Centre of Research for Inner City Health: Memorandum of Understanding (MOU) with St. Michael's Hospital, [Online], 2012. Ontario.

**UNIVERSITY OF LETHBRIDGE & RED CROW COMMUNITY COLLEGE.**  
Establishing the Blackfoot Digital Library: Memorandum of Understanding between the University of Lethbridge and Red Crow Community College, [Online], 2008. Alberta.

#### AUSTRALIA

**ABORIGINAL HEALTH AND MEDICAL RESEARCH COUNCIL OF NEW SOUTH WALES, AND MENTAL HEALTH COMMISSION OF NEW SOUTH WALES.**  
Memorandum of Understanding between Aboriginal Health & Medical Research Council of NSW and the Mental Health Commission of NSW, [Online], 2017. New South Wales.

**AUSTRALIAN COLLEGE OF RURAL AND REMOTE MEDICINE (ACRRM), AND NATIONAL ABORIGINAL COMMUNITY CONTROLLED HEALTH ORGANISATION (NACCHO).**  
Agreement: ACRRM and NACCHO, [Online], 2011. Queensland and Territoire de la Capitale Nationale.

**DEPARTMENT OF THE PREMIER AND CABINET.**  
Aboriginal and Torres Strait Islander Protocol – Acknowledgement of Traditional Owners, [Online], 2017. Strategic Engagement and Protocol, Protocol Queensland, Queensland Government.

## TABLE OF CONTENTS

### EXISTING PROTOCOLS AND INITIATIVES

## MEMORANDUM OF UNDERSTANDING - PROTOCOLS

**KAURNA WARRA PINTYANTHI, AND THE UNIVERSITY OF ADELAIDE.**

Memorandum of understanding, [Online], 2013. South Australia.

**MID NORTH COAST LOCAL HEALTH DISTRICT (MNCLHD).**

Memorandum of understanding for Health Research Collaboration, [Online], 2014. New South Wales.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES



#### **INDIGENOUS HEALTH ADAPTATION TO CLIMATE CHANGE.**

Ethics, [Online], [s.d.].

#### **CANADIAN INSTITUTES OF HEALTH RESEARCH (CIHR). ETHICS OFFICE.**

CIHR Guidelines for Health Research Involving Aboriginal Peoples: Draft for consultation, [Online], 2006. Government of Canada.

#### **MÉTIS NATION GATEWAY.**

"Ethical Protocols", Métis Nation Environment Knowledge Place, [Online], 2011.

#### **DEPARTMENT OF TOURISME AND CULTURE. CULTURAL SERVICES BRANCH.**

Guidebook on Scientific Research in the Yukon, [Online], 2013. Government of Yukon.

### **ALBERTA**

#### **ALBERTA MENTAL HEALTH SERVICES (AHS).**

Aboriginal Research Protocols: Healthy Aboriginal People in Healthy Communities, [Online], 2006. Alberta Health Board, AHS.

#### **BAYDALA, LOLA.**

Community Based Participatory Research in Aboriginal Communities; Creating an Ethical Space, [Online Video], 2016.

#### **STEVENSON, MARC G.**

Ethics and Research with Aboriginal Communities, [Online], 2010. Edmonton, Sustainable Forest Management Network, 18 p.

#### **UNIVERSITY OF CALGARY.**

Cultural Protocol Guidelines: Recommended Practices for First Nations, Métis and Inuit Cultural Engagement, [Online], [s.d.].

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### BRITISH COLUMBIA

##### **CANADIAN ABORIGINAL AIDS NETWORK.**

Principles of Research Collaboration, [Online], 2013.

##### **DEVELOPING URBAN ABORIGINAL PROTOCOLS.**

Urban Aboriginal Research Charter Template: A Guide to Building Research Relationships, [Online], 2016. Okanagan Campus, Institute for Community Engaged Research Press, University of British Columbia.

##### **FIRST NATIONS HEALTH AUTHORITY.**

Researcher Guides, [Online], 2017. Vancouver.

##### **HEILTSUK INTEGRATED RESOURCE MANAGEMENT DEPARTMENT (HIRMD).**

HIRMD Research Application, [Online], 2015. Bella Bella, HIRMD Research Advisory Committee.

##### **INTER TRIBAL HEALTH AUTHORITY.**

Research Protocol, [Online], 2005.

##### **MCGILL, DRU, DAVINA TWO BEARS, JULIE WOODS, THE RESEARCH ETHICS AND IP WORKING GROUP.**

“Collaborative Projects and Memoranda of Agreement (MOA)”, The Intellectual Property Issues in Cultural Heritage Project (Éd.), Simon Fraser University and Social Sciences and Humanities Research Council of Canada. [Online], 2015.

##### **SCOTT, GRAHAM.**

Building Bridges Together a Resource Guide for Intercultural Work between Aboriginal and Non-Aboriginal Peoples, [Online], 2008. Vancouver, Social Planning and Research Council of British Columbia.

##### **THE UNIVERSITY OF BRITISH COLUMBIA.**

Indigenous Research Methodologies: Research Ethics, [Online], [s.d.].

#### PRINCE EDWARD ISLAND

##### **NATIVE COUNCIL OF PRINCE EDWARD ISLAND.**

“Research Advisory Committee: Guidance for Researchers”, Research Ethics, [Online], 2014.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### MANITOBA

**BERNACKI JONK, LUELLA.**

“Research Practices Involving Canadian Aboriginal Communities: Ethical Considerations”, *Research in Canadian Aboriginal Communities*, [Online], 2007. Winnipeg, University of Manitoba.

**CANADIAN CENTRE FOR POLICY ALTERNATIVES MANITOBA.**

“Na-gah mo Waabishkizi Ojijaak Bimise Keetwaatino: Singing While Crane Flying North”, *Gathering a Bundle for Indigenous Evaluation*, [Online], 2018.

**FACULTY OF KINESIOLOGY AND RECREATION MANAGEMENT.**

*Reconciling Ethical Research with Métis, Inuit, and First Nations People*, [Online Video], 2016. Winnipeg, University of Manitoba.

**FIRST NATIONS CENTRE.**

*Considerations and Templates for Ethical Research Practices*, [Online], 2007. Ottawa, National Aboriginal Health Organization.

**MANITOBA FIRST NATIONS EDUCATION RESOURCE CENTRE (MNFREC).**

*Guidelines for Ethical Research in Manitoba First Nations: Principles, Practices, and Templates*, [Online], 2014.

#### NEW-BRUNSWICK

**BULL, JULIE.**

*The intersection of people, policies, and priorities in Indigenous research ethics*, [Online Video], 2017.

#### NOVA SCOTIA

**HUNKA, ROGER, AND JOSHUA MCNEELY.**

*Implementation of the Nagoya Protocol within Canada*, [Online], 2011. Maritime Aboriginal Peoples Council, Ikanawtiket Environmental Incorporated, Native Council of Nova Scotia, Native Council of Prince Edward Island, New Brunswick Aboriginal Peoples Council, Congress of Aboriginal Peoples.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### NUNAVIK AND NUNAVUT

**INUIT TAPIIRIT KANATAMI (ITK), AND NUNAVUT RESEARCH INSTITUTE (NRI).**

Negotiating Research Relationships with Inuit Communities: A Guide for Researchers, [Online], 2006. Scot Nickels, Jamal Shirley and Gita Laidler, Inuit Tapiriit Kanatami (Éd.), ITK, NRI.

**INUIT TAPIIRIT KANATAMI (ITK), AND NUNAVUT RESEARCH INSTITUTE (NRI).**

“Negotiating Research Relationships: A Guide for Communities”, Pimatziwin: A Journal of Aboriginal and Indigenous Community Health, [Online], [s.d.].

**INUIT TAPIIRIT KANATAMI (ITK).**

National Inuit Strategy on Research, [Online], 2018.

**NUNAVUT RESEARCH INSTITUTE (NRI).**

Research Licencing Applications, [Online], 2015. Iqaluit.

#### ONTARIO

**ABORIGINAL HEALTH RESEARCH REVIEW COMMITTEE, AND MANITOULIN FIRST NATIONS LEADERSHIP AND COMMUNITY AGENCIES.**

Guidelines for Ethical Aboriginal Research: A Resource Manual for the Development of Ethical and Culturally Appropriate Community-based Research within the First Nations Communities in the Manitoulin Area, [Online], 2003. Little Current.

**ANAQUOT, KISHK, JENELLE POWER AND HARRIET KUHNLEIN.**

Collaborative Research: an “Indigenous Lens” Perspective, [Online], 2008. Canadian Coalition for Global Health Research.

**ASSEMBLY OF FIRST NATIONS.**

First Nations Ethics Guide on Research and Aboriginal Traditional Knowledge, [Online], [s.d.]. Ottawa.

**ASSEMBLY OF FIRST NATIONS.**

Ethics in First Nations Research, [Online], 2009. Ottawa, Environmental Stewardship Unit, AFN.

**FIRST NATIONS CENTRE.**

Health Information and Research Planning, [Online], 2009. Ottawa, National Aboriginal Health Organization.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### **FIRST NATIONS CENTRE.**

Health Governance Models e-Workbook, [Online], 2010. Ottawa, National Aboriginal Health Organization.

#### **FIRST NATIONS CENTRE.**

Understanding Health Indicators, [Online], 2007. Ottawa, National Aboriginal Health Organization.

#### **FIRST NATIONS CENTRE.**

Template for a code of Research Ethics, [Online], 2007. Ottawa.

#### **FIRST NATIONS ENVIRONMENTAL HEALTH INNOVATION NETWORK (FNEHIN).**

Research Ethics Protocols & Guidelines, [Online], [s.d.]. Ottawa.

#### **INDIGENOUS HEALTH RESEARCH DEVELOPMENT PROGRAM.**

Ethical Guidelines for Aboriginal Research Elders and Healers Roundtable, [Online], [s.d.].

#### **INDIGENOUS RESEARCH ETHICS INSTITUTE.**

Resources, [Online], 2017. Ottawa, Carleton University.

#### **KELLY, JOHN. M. H., AND LAURA-LEE BALKWILL.**

Research Involving First Nations, Inuit and Métis Peoples of Canada, [Online Video], 2012.

#### **THE FIRST NATIONS INFORMATION GOVERNANCE CENTRE.**

First Nations Regional Health Survey (RHS): Best Practice Tools for OCAP Compliant Research, [Online], 2011. Ottawa.

#### **THE FIRST NATIONS INFORMATION GOVERNANCE CENTRE.**

First Nations Regional Longitudinal Health Survey (RHS) – Code of Research Ethics, [Online], 2007. Ottawa.

#### **MÉTIS CENTRE.**

Principles of Ethical Métis Research, [Online], 2017. Ottawa, National Aboriginal Health Organization.

#### **NOOJMOWIN TEG HEALTH CENTRE.**

Guidelines for Ethical Aboriginal Research (GEAR), [Online], 2011. Little Current.

#### **NATIONAL ABORIGINAL HEALTH ORGANIZATION (NAHO).**

Interviewing Elders: Guidelines from the National Aboriginal Health Organization, [Online], 2005. Ottawa.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### **URBAN ABORIGINAL KNOWLEDGE NETWORK (UAKN).**

Guiding Ethical Principles, [Online], 2013.

#### **ROYAL COMMISSION ON ABORIGINAL PEOPLES.**

Integrated Research Plan, [Online], 1993. Government of Canada.

#### **ROYAL COMMISSION ON ABORIGINAL PEOPLES.**

Ethical Guidelines for Research, [Online], 1993. Government of Canada.

#### **SIX NATIONS COUNCIL.**

Six Nations Council Research Ethics Committee Protocol, [Online], [s.d.]. Ohsweken.

#### **SIX NATIONS COUNCIL.**

Conducting Research at Six Nations, [Online], 2015. Ohsweken.

#### **FIRST NATIONS CHILD AND FAMILY CARING SOCIETY.**

First Nations Children's Action Research and Education Service: Guidelines for Ethical Research, [Online], [s.d.]. Ottawa.

#### **FIRST NATIONS CHILD AND FAMILY CARING SOCIETY.**

Guidelines for Ethical Research, [Online], 2016. Ottawa.

#### **TEMAGAMI FIRST NATION (TFN), AND TEME-AUGAMA ANISHNABAI (TAA).**

Exploration Memorandum of Understanding (Draft), [Online], 2013.

#### **TRENT UNIVERSITY.**

Research Ethics, [Online], 2004. Peterborough, Indigenous Studies Ph.D.

#### **YORK UNIVERSITY.**

Guidelines for Research Involving Aboriginal/Indigenous Peoples, [Online], [s.d.]. Toronto.

### QUEBEC

#### **ASSEMBLY OF FIRST NATIONS QUEBEC-LABRADOR.**

First Nations in Quebec and Labrador's Research Protocol, [Online], 2014. Wendake.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### **ASSEMBLY OF FIRST NATIONS QUEBEC-LABRADOR.**

Consultation Protocol of First Nations of Quebec and Labrador, [Online], 2005. Wendake.

#### **CREE BOARD OF HEALTH AND SOCIAL SERVICES OF JAMES BAY.**

Get the Toolkit, the Social Participation of Indigenous Elders Toolkit [Online], 2018. Montréal.

#### **QUEBEC NATIVE WOMEN INC.**

Guidelines for Research with Aboriginal Women, [Online], 2012. Kahnawake.

#### **FIRST PEOPLES WORKING GROUP.**

Research Guidelines, [Online], 2017. Québec, Laval University, Institut nordique du Québec.

#### **KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT (KSDPP).**

Code of Research Ethics, [Online], 2007. Kahnawake.

#### **PEARCE, MARGARITA, CATHERINE POTVIN AND JORGE VENTOCILLA.**

Protocol for Research in Panama's Indigenous Guideline, [Online], 2006. Consortium of Canadian Universities in Panama (McGill, Université Laval, UQAM).

### SASKATCHEWAN

#### **THE INDIGENOUS PEOPLES' HEALTH RESEARCH CENTRE (IPHRC).**

Our Research, [Online], 2017. Regina.

#### **SASKATOON ABORIGINAL WOMEN'S HEALTH RESEARCH COMMITTEE.**

Ethical Guidelines for Aboriginal Women's Health Research, [Online], 2004. Winnipeg, Prairie Women's Health Centre of Excellence.

### NEWFOUNDLAND AND LABRADOR

#### **LABRADOR HEALTH RESEARCH ADVISORY COMMITTEE (LAHRC) AND NL HEALTH RESEARCH ETHICS BOARD (HREB).**

Guidelines for research involving Aboriginal communities in Newfoundland and Labrador, [Online], 2013.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### NORTHWEST TERRITORIES

##### **THE AURORA RESEARCH INSTITUTE.**

Doing Research in the Northwest Territories: A Guide for Researchers Applying for a Scientific Research Licence, [Online], 2011. Inuvik.



#### UNITED STATES

##### **AKWESASNE TASK FORCE ON THE ENVIRONMENT (ATFE), AND RESEARCH ADVISORY COMMITTEE (RAC).**

Protocol for Review of Environmental and Scientific Research Proposals, [Online], 1996. Indigenous Peoples Council on Biocolonialism.

##### **AMERICAN INDIAN LAW CENTER INC.**

Model Tribal Research Code: With Materials for Tribal Regulation for Research and Checklist for Indian Health Boards, [Online], 1999. Albuquerque, NM.

##### **COLLABORATIVE RESEARCH CENTER FOR AMERICAN INDIAN HEALTH (CRCAIH).**

CRCAIH Tribal IRB Toolkit, [Online], 2015.

##### **COLLABORATIVE RESEARCH CENTER FOR AMERICAN INDIAN HEALTH (CRCAIH).**

Template Investigator Submission Forms for Tribal Institutional Review Boards (IRBs), [Online], [s.d.].

##### **COLLABORATIVE RESEARCH CENTER FOR AMERICAN INDIAN HEALTH (CRCAIH).**

Stronger Ethics, Stronger Research: Tribal Governance as a Key Community Health Speaker, [Online Video], 2015.

##### **FIRST ARCHIVISTS CIRCLE.**

Protocols for Native American Archival Materials. [Online], 2007.

##### **HOPÍ CULTURAL PRESERVATION OFFICE (HCPO).**

Protocol for Research, Publication and Recordings: Motion, Visual, Sound, Multimedia and other Mechanical Devices, [Online], [s.d.]. Kykotsmovi, AZ. []

##### **INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM.**

Indigenous Research Protection Act, [Online], [s.d.]. Nixon, NV.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### **NATIONAL CONGRESS OF AMERICAN INDIANS (NCAI).**

“Research Regulation”, NCAI Policy Research Center: Supporting Indian Country in Shaping its Own Future, [Online], 2017. Washington, DC.

#### **NATIONAL SCIENCE FOUNDATION.**

Principles for the Conduct of Research in the Arctic, [Online]. Alexandria, VA, NSF.

#### **NCAI POLICY RESEARCH CENTER, AND MSU CENTER FOR NATIVE HEALTH PARTNERSHIPS.**

‘Walk softly and listen carefully’: Building Research Relationships with Tribal Communities, [Online], 2012. Washington, DC, and Bozeman, MT.

#### **PURDUE AGRICULTURE.**

What is an IRB?, [Online Video], 2014. West Lafayette, IN, College of Agriculture, Purdue University.

#### **SAHOTA, PUNEET CHAWLA.**

Research Regulation Toolkit: Research Review Checklist for American Indian and Alaska Native Communities, [Online], [s.d.]. Washington, DC, NCAI Policy Research Center.

#### **SAHOTA, PUNEET CHAWLA.**

Research Regulation in American Indian/Alaska Native Communities: Policy and Practice Considerations, [Online], [s.d.]. Washington, DC, NCAI Policy Research Center.

#### **SAHOTA, PUNEET CHAWLA.**

Research Regulation in American Indian/Alaska Native Communities: A Guide to Reviewing Research Studies, [Online], [s.d.]. Washington, DC, NCAI Policy Research Center.

#### **SAHOTA, PUNEET CHAWLA.**

Research Regulation Options for American Indian/Alaska Native Communities, [Online], [s.d.]. Washington, DC, NCAI Policy Research Center.

#### **SMITHSONIAN NATIONAL MUSEUM OF THE AMERICAN INDIAN.**

Native Peoples and Genetic Research 11: Dr. Shane Doyle, [Online Video], 2014.

#### **THE UNIVERSITY OF ARIZONA.**

AZ Tribes: Governance & Research Policies, [Online]. Tucson, AZ.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### AUSTRALIA

**AUSTRALIAN CATHOLIC UNIVERSITY (ACU).**

Ethical Review for Research Involving Indigenous People – IREAP Guidelines – ACU Human Research Ethics Committee, [Online], 2016.

**AUSTRALIAN HERITAGE COMMISSION.**

Ask First: A guide to respecting Indigenous heritage places and values, [Online], 2002. Australian Government.

**AUSTRALIAN INSTITUTE OF ABORIGINAL AND TORRES STRAIT ISLANDER STUDIES (AIATSIS).**

Guidelines for Ethical Research in Australian Indigenous Studies, [Online], 2012. Australian Government.

**AUSTRALIAN INSTITUTE OF ABORIGINAL AND TORRES STRAIT ISLANDER STUDIES (AIATSIS).**

Ethical research, [Online], 2018. Australian Government.

**AUSTRALIAN INSTITUTE OF ABORIGINAL AND TORRES STRAIT ISLANDER STUDIES (AIATSIS).**

AIATSIS Research Ethics Committee Charter, [Online], 2016. Australian Government.

**AUSTRALIA. NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL (NHMRC).**

Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, [Online], 2003. Canberra, ACT, Australian Government.

**CARLSON, BRONWYN.**

Social Media Research and Indigenous Communities, [Online Video], 2016. Australasian Research Management Society.

**DAVIS, MICHAEL.**

Undertaking projects and research in Central Australia: CLC protocols and the development of protocols for projects and research in the CLC region, [Online], 2005. Alice Springs, Central Land Council and Desert Knowledge Cooperative Research Center.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### **DEPARTMENT OF ABORIGINAL AND TORRES STRAIT ISLANDER POLICY AND DEVELOPMENT.**

Protocols for Consultation and Negotiation with Aboriginal People, [Online], 1998. Brisbane, Queensland Government.

#### **DESERT KNOWLEDGE COOPERATIVE RESEARCH CENTRE.**

Aboriginal Research Engagement Protocol, [Online], 2007. Fitzroy North, VIC.

#### **EIDOS.**

Ethical Principles and Guidelines for Indigenous Research, [Online], 2007.

#### **FEDERATION OF ABORIGINAL & TORRES STRAIT ISLANDER LANGUAGES CORPORATION (FATSIL).**

FATSIL Guide to Community Protocols for Indigenous Language Projects, [Online], 2004.

#### **INDIGENOUS JUSTICE CLEARINGHOUSE.**

Conducting research with Indigenous people and communities: A series of Research Briefs designed to bring research findings to policy makers, [Online], 2013. Australian Government.

#### **INDIGENOUS LEADERSHIP CHARLES DARWIN UNIVERSITY.**

Aboriginal researchers needed for change, [Online Video], 2016.

#### **INDIGENOUS LEADERSHIP CHARLES DARWIN UNIVERSITY.**

Cultural protocols when researching with Australian Aboriginal communities, [Online Video], 2016.

#### **INDIGENOUS LEADERSHIP CHARLES DARWIN UNIVERSITY.**

Research with Indigenous people – procedural and practical ethical consent, [Online Video], 2016.

#### **KIMBERLEY LAND COUNCIL.**

Kimberley Land Council Research Protocol, [Online], 2011. Broome, WA.

#### **LAYCOCK, ALISON, DIANE WALKER, NEA HARRISON AND JENNY BRANDS.**

Researching Indigenous Health: A Practical Guide for Researchers, [Online], 2011. Melbourne, The Lowitja Institute., ou [Online].

#### **MCAULLAY, DANIEL, AND COLLEEN HAYWARD.**

The Aboriginal Research and Study Protocols, [Online], 2012. Joondalup, WA, Edith Cowan University (ECU).

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### **NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL (NHMRC).**

Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics, [Online], 2003. Canberra, ACT, Australian Government.

#### **NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL (NHMRC).**

National Statement on Ethical Conduct in Human Research, [Online], 2015. Canberra, ACT, Australian Government.

#### **NINTI ONE LIMITED.**

Aboriginal and Torres Strait Islander Research Engagement Protocol, [Online]. Alice Springs, NT.

#### **NORTH AUSTRALIAN INDIGENOUS LAND AND SEA MANAGEMENT ALLIANCE (NAILSMA).**

Guidelines and Protocols for the Conduct of Research, [Online], 2007. Brinkin, NT.

#### **NORTH SYDNEY COUNCIL.**

Aboriginal & Torres Strait Islander Cultural Protocol Guidelines, [Online], 2014. North Sydney, NSW.

#### **OXFAM AUSTRALIA.**

Aboriginal and Torres Strait Islander Cultural Protocols, [Online], [s.d.].

#### **QUEENSLAND STUDIES AUTHORITY.**

Aboriginal and Torres Strait Islander Studies Handbook, [Online], 2010. Spring Hill, QLD, Queensland Government.

#### **QUEENSLAND STUDIES AUTHORITY. GUIDELINES: INDIGENOUS PERSPECTIVES.**

Ethical Research in Indigenous Studies, [Online], 2007. Spring Hill, QLD, Australian Institute Of Aboriginal And Torres Strait Islander Studies (AIATSIS).

#### **ROYAL AUSTRALASIAN COLLEGE OF PHYSICIANS (RACP).**

AFPHM webinar - Aboriginal health ethics and research, [Online Video], 2015. Webinar was presented by Ms Victoria Jones, Aboriginal Health & Medical Research Council Ethics Committee.

#### **THE FRED HOLLOWES FOUNDATION. INDIGENOUS AUSTRALIA PROGRAM.**

A Cultural Protocol for Evaluation: A guide for the Indigenous Australia Program team and external consultants to support and encourage good practice, [Online], [s.d.]. Sydney, NSW.

#### **THE ROYAL AUSTRALIAN AND NEW ZEALAND COLLEGE OF PSYCHIATRISTS (RANZCP).**

Ethical Guideline 11: Principles and Guidelines for Aboriginal and Torres Strait Islander Mental Health, [Online], 2014. Melbourne, VIC.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### GUIDELINES

#### **WALANGA MURU.**

Aboriginal Cultural Protocols, [Online], [s.d.]. North Ryde, NSW, Macquarie University.



#### **NEW ZEALAND**

#### **HEALTH RESEARCH COUNCIL OF NEW ZEALAND.**

Guidelines for Researchers on Health Research Involving Māori, [Online], 2010. Auckland.

#### **KATOA LTD.**

Kaupapa Māori Research: Research Ethics, [Online], 2012. Auckland.

#### **PŪTAIORA WRITING GROUP.**

Te Ara Tika – Guidelines for Māori research ethics: A framework for researchers and ethics committee members, [Online], [s.d.]. Auckland, Health Research Council of New Zealand.

#### **THE NATIONAL ETHICS ADVISORY COMMITTEE – KĀHUI MATATIKA O TE MOTU (NEAC).**

Māori Research Ethics: An overview, [Online], 2012. Wellington.



#### **NORWAY**

#### **ARBON, VERONICA.**

Indigenous Research: Elders & knowledgeable others in higher education, [Online], 2010. Kautokeino, WINHEC Journal 2011, Sámi University College.



#### **AFRICA**

#### **TRUST PROJECT GLOBAL RESEARCH ETHICS.**

Protecting San Indigenous Knowledge - From a Research Contract to a San Code of Ethics, [Online Video], 2016.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### OPEN DATA



**NATIONAL COLLABORATING CENTRE FOR ABORIGINAL HEALTH.**  
NCCAH Webinars, [Online], [s.d.].

**FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION.**  
Summary report pre-annual general assembly, [Online], 2017. Wendake.

**NATIONAL RESEARCH COUNCIL CANADA.**  
"The Uqailaut Project", Inuktitut Computing, [Online], [s.d.].

"Grants: PEG/Atikamekw knowledge, culture and language in Wikimedia projects", [Online], Meta-Wiki, Wikimedia Canada, this page was last edited on 11 April 2018, at 17:11.

**INDIGITIZATION.**  
Indigitization – Toolkit for the Digitization of First Nations Knowledge, [Online], [s.d.].

**MACODRUM LIBRARY.**  
Indigenous Studies GIS resources, [Online], [s.d.]. Ottawa, Carleton University.

**OPEN GOVERNMENT PORTAL.**  
Aboriginal Lands, [Online], [s.d.]. Government of Canada

**OPEN GOVERNMENT PORTAL.**  
Aboriginal Peoples, [Online], [s.d.]. Government of Canada.

**OPEN GOVERNMENT PORTAL.**  
First Nations, [Online], [s.d.]. Government of Canada.

**CITY OF EDMONTON.**  
Indigenous Place Names of Edmonton, [Online], 2017.

**CITY OF WINNIPEG.**  
Census – Aboriginal People, [Online], 2017.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### OPEN DATA



#### UNITED STATES

##### **BLACKFOOT DIGITAL LIBRARY.**

Welcome to the Blackfoot Digital Library, [Online].

##### **NATIVE NATIONS INSTITUTE.**

“Indigenous Traditional Ecological Knowledge in Agroforestry”, US Indigenous Data Sovereignty Network, [Online], 2017. Tucson, Native Nations Institute at the University of Arizona.



#### AUSTRALIA

##### **AUSTRALIAN INSTITUTE OF ABORIGINAL AND TORRES STRAIT ISLANDER STUDIES (AIATSIS).**

Guides and resources, [Online], [s.d.].

##### **AUSTRALIAN INSTITUTE OF ABORIGINAL AND TORRES STRAIT ISLANDER STUDIES (AIATSIS).**

“Databases and indexes”, Guides and resources, [Online], [s.d.].

##### **AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE AND AUSTRALIAN BUREAU OF STATISTICS.**

“Values and ethics in Aboriginal and Torres Strait Islander research”, National best practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people. 2012. AIHW Cat. No. IHW 74. Canberra: AIHW. 17-21.

##### **DEPARTMENT OF THE ENVIRONMENT, WATER, HERITAGE AND THE ARTS.**

Indigenous Knowledge Management Systems (databases): Guide for Indigenous Communities, [Online], [s.d.]. Australian Government.

##### **DE SOUZA, POPPY, FRAN EDMONDS, SCOTT MCQUIRE, MICHELLE EVANS AND RICHARD CHENHALL.**

Aboriginal Knowledge, Digital Technologies and Cultural Collections: Policy, Protocols, Practice, [Online], 2016. Melbourne, Melbourne Networked Society Institute, The University of Melbourne.

##### **GARVEY, GAIL, NIKKI PERCIVAL, LIZ IZQUIERDO, DAVID MOODIE AND SUZANNE MOORE.**

“Big Data in an Indigenous Health Context: Opportunities and Obstacles”, Ethics in Cancer, [Online], 2016. Sydney, Cancer Forum, vol. 40, n° 2.

# TABLE OF CONTENTS

## EXISTING PROTOCOLS AND INITIATIVES

### OPEN DATA

#### **JACKSON, JEN.**

Indigenous education: Why 'big data' tells only part of the story, [Online], 2015. Melbourne, Mitchell Institute at Victoria University.

#### **NAKATA, MARTIN, AND MARCIA LANGTON.**

Australian Indigenous Knowledge and Libraries, [Online], 2017. Sydney, UTSePress.

#### EUROPE

#### **OPEN KNOWLEDGE INTERNATIONAL.**

The Open Data Handbook, [Online], [s.d.].

#### **EUROPEAN DATA PORTAL.**

Training Companion, [Online], [s.d.].

#### **SIMPLESHOW FOUNDATION.**

Open Data – explained in a nutshell, [Online Video], 2016.

#### AFRICA

#### **TANZANIA DEVELOPMENT GATEWAY.**

About Tanzania Indigenous Knowledge Database, [Online], 2002. Dar es Salaam, Tanzania.

# TABLE OF CONTENTS

## ISSUES OF RESEARCH ETHICS – ARTICLES AND CONTRIBUTIONS:

### PEER REVIEW EVALUATIONS



**DE-CENTERING THE UNIVERSITY FROM COMMUNITY-BASED RESEARCH :  
A FRAMEWORK FOR ENGAGEMENT BETWEEN ACADEMIC AND INDIGENOUS  
COLLABORATORS IN NATURAL RESOURCE AND CONSERVATION RESEARCH.**

Megan S. Adams, Christina N. Service, Jennifer Walkus, Jennifer Carpenter, Jess A. Housty,  
Douglass Neasloss, Paul C. Paquet and Chris T. Darimont



**EXPANDING THE TOOLBOX : EPISTEMOLOGICAL STRETCHING  
AND ETHICAL ENGAGEMENT.**

M. J. Barrett, Matt Harmin, Karonhiakta'tie Bryan Maracle and Christie Thomson



**DOCUMENTING THE HOMEWORK SUPPORT PROGRAM : ELEMENTS OF A  
SUCCESSFUL COMMUNITY-UNIVERSITY RESEARCH PARTNERSHIP.**

Natasha Blanchet-Cohen and Amélie Lainé



**WAY OF BEING TO PROMOTE A SHARED PROCESS.**

La Boîte Rouge vif



**FAQ : A TOOL FOR UNDERSTANDING THE ETHICAL CONDUCT OF RESEARCH  
AND THE RIGHTS OF ABORIGINAL PARTICIPANTS.**

Marie-Pierre Bousquet and Bryn Williams-Jones



**THE NUNATUKAVUT MODEL OF RESEARCH OVERSIGHT :  
INNOVATION THROUGH COLLABORATION.**

Fern Brunger, Jullie Bull and Darlene Wall



**KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT CODE OF  
RESEARCH ETHICS : DEVELOPMENT AND APPLICATION.**

Treena Delormier, Ph. D., Alex M. McComber, M.Ed., and Ann C. Macaulay, CM MD FCFP



**WE SHOULDN'T BE AFRAID TO THINK SMALL : ENGAGED ACCLIMATIZATION  
AS A RESEARCH IN AN ABORIGINAL CONTEXT.**

Caroline Desbiens, Irène Hirt and Pekuakamiulnuatsh Takuhikan –  
Comité patrimoine ilnu, Mashteuiatsh

# TABLE OF CONTENTS

## ISSUES OF RESEARCH ETHICS – ARTICLES AND CONTRIBUTIONS:



**ETHICS OF PUBLIC CONSULTATIONS IN HEALTHCARE – LESSONS LEARNED FROM ILYUU AHTAAWIN HEALTH PLANNING WITH THE JAMES BAY CREE.**  
Adelina Feo



**A CHECKLIST OF SKILLS, KNOWLEDGE AND CONSIDERATIONS FOR UNIVERSITY-BASED RESEARCHERS AND INDIGENOUS COMMUNITIES.**  
Audrey R. Giles, Tricia McGuire-Adams and Francine E. Darroch



**APPROACHING RESEARCH IN INDIGENOUS SETTINGS : NINE GUIDELINES.**  
RDK Herman



**KAPATAKANA/PORTAGE TRAILS COLLABORATION: NEGOTIATING THE PASSAGE FROM INTENT TO ACTUALIZATION**  
Louise Lachapelle et Shan dak Puana - Mamu minu-tutamutau



**METHODOLOGICAL AND CONCEPTUAL GUIDELINES FOR THE ANALYSIS OF CASES OF DISCRIMINATION AGAINST ABORIGINAL WOMEN.**  
Marie Léger



**THE STORY OF A SUCCESSFUL PARTNERSHIP BETWEEN ABORIGINAL LEADERS, PRACTITIONERS AND RESEARCHERS ENGAGED IN A KNOWLEDGE COPRODUCTION APPROACH : THE CREATION, IMPLEMENTATION AND ACHIEVEMENTS OF THE ODENA RESEARCH ALLIANCE.**  
Carole Lévesque, Édith Cloutier, Tanya Sirois, Ioana Radu and Rolando Labrana.



**MIYUPIMAATISIUN IN EYYOU ISTCHEE : INDIGENOUS HEALING AND COMMUNITY ENGAGEMENT IN HEALTH AND SOCIAL SERVICES DELIVERY.**  
Ioana Radu, DIALOG and Larry House



**COMMUNITY FILMMAKING AND TERRITORIAL RESEARCH : DEVELOPING NEW RESEARCH FROM A MAPUCHE PERSPECTIVE.**  
Juan Rain, Roberto Contreras, Fresia Paineñil, Gerardo Berrocal, Ariella Orbach, Thora Martina Herrmann and Manon Barbeau



**DOCUMENTING KNOWLEDGE ON THE TERRITORY FOR TRANSMISSION PURPOSES : MECHANISMS FOR COLLABORATION AND RESEARCH ETHICS AMONG THE PEKUAKAMIULNUATSH.**  
Sükran Tipi, Hélène Boivin and Marlène Tremblay

# DE-CENTERING THE UNIVERSITY FROM COMMUNITY-BASED RESEARCH: A FRAMEWORK FOR ENGAGEMENT BETWEEN ACADEMIC AND INDIGENOUS COLLABORATORS IN NATURAL RESOURCE AND CONSERVATION RESEARCH

**MEGAN S. ADAMS**<sup>1,2,3</sup>  
**CHRISTINA N. SERVICE**<sup>1,2,3,4</sup>  
**JENNIFER WALKUS**<sup>5,6</sup>  
**JENNIFER CARPENTER**<sup>7</sup>  
**JESS A. HOUSTY**<sup>8</sup>  
**DOUGLASS NEASLOSS**<sup>4,9</sup>  
**PAUL C. PAQUET**<sup>1,2</sup>  
**CHRIS T. DARIMONT**<sup>1,2,3,\*</sup>

<sup>1</sup> Department of Geography, University of Victoria.

<sup>2</sup> Raincoast Conservation Foundation.

<sup>3</sup> Hakai Institute.

<sup>4</sup> Spirit Bear Research Foundation.

<sup>5</sup> Wuikinuxv Nation Fisheries.

<sup>6</sup> School of Resource and Environmental Management, Simon Fraser University.

<sup>7</sup> Heiltsuk Integrated Resource Management Department.

<sup>8</sup> Qqs Projects Society.

<sup>9</sup> KITASOO/XAI-XAIS Integrated Resource Authority.

\* Corresponding author: Chris Darimont (darimont@uvic.ca)

“The unexamined assumptions of the scientist both determine and limit what he or she will discover...Most people do not fully realize to what extent the spirit of scientific research and the lessons learned from it depend upon the personal viewpoints of the discoverers.”  
H. Selye, *The Stress of Life* [1].

Complementing indigenous knowledge, First Nations communities may draw upon ecological, geographical and associated scientific research as sources of information in local decision-making about land and resource stewardship. Such research can affirm local and traditional ecological knowledge and empower its application. Moreover, as decision-making agency is shifted increasingly (back) to indigenous governments in what is now known as Canada, abundant opportunity exists for applied research at the community level. Academic scientists can provide capacity for such research. Community-engaged research offers a process by which these opportunities between indigenous communities and academics can be realized. We present here a short-

ened and modified version of a framework we recently developed [2] and illustrate it with real-world examples.

True community-engaged research occurs when members of communities and research-based institutions collaborate throughout the research process towards shared outcomes. In the context of First Nation communities, this process can be built upon the foundation of indigenous knowledge, or local or traditional ecological knowledge (LEK/TEK), held within communities. This knowledge incorporates adaptively evolving practice and belief with knowledge of natural systems, which is transmitted culturally through generations over millennia [3-5]. It can inform an understanding of local and interconnected patterns and processes of resources embedded within socio-ecological systems over large spatial and temporal scales [6-8]. In systems in which we live and study, local people hold knowledge about the interrelationships among bears, salmon and people. For example, at watersheds important to local people, knowledge holders understand and can predict areas in which bears will be feeding on different runs of salmon.

Academic collaborators in engaged research can build upon this foundation, synchronizing their capacities with local knowledge towards relevant deliverables for the community. This process requires that each party seek to enhance individual strengths and cultivate benefits from research by respecting and working together throughout the process. In the bear-salmon-human systems work, the scientific participants bring knowledge about how to apply molecular genetics approaches that provide complementary information to existing knowledge about bear activity (e.g. the genetic identity and gender of individual bears detected via our non-invasive hair-snagging [9]). We acknowledge that academics can be part of communities, just as community members can be researchers. Although we recognize significant crossover, for these purposes we have framed the research process through the binary roles of academic and community collaborators.

Despite potential opportunities, current approaches to academic research in conservation science may not recognize opportunities for truly collaborative engagement with indigenous communities [2, 10]. Without careful consideration, collaborations can recreate problems of the past in which research is extractive, rather than valuable to indigenous communities [11]. In our experience, visiting scientists may not involve communities in the conception of the research, respect cultural protocols when operating on the landscape, consider the potential costs or benefits of their research in and

around the community, or communicate information and research outcomes in a manner that is accessible or applicable for First Nations governments [12, 13]. In addition, numerous cultural differences stemming from different values and beliefs, methodologies and reward systems exist in how academic and indigenous experts conduct what is considered “research”. Finally, these limitations of academic research are further – and ultimately – compounded by a broader lack of trust between indigenous and non-indigenous peoples. This stems from a history of imposed assimilation practices subsequent to European contact (e.g., residential schools in Canada). Violence, oppression and discrimination towards indigenous peoples in the past and present may have strong repercussions for research collaborations [14]. Identifying these limitations humbly and openly can build understanding and compassion between collaborators. Indeed, this writing process, and the discussions underlying it, aided us in this process. While formal efforts like this are not required, we see this sort of effort as an essential early step in the engagement process.

Engaged research benefits when academic institutions and their scholars can de-center themselves from the universities to which they ‘belong’ by localizing their responsibilities, intentions, and time in communities [11, 15 and 16]. In other words, ecologists can seek direction from their host communities about how to participate in an engaged research process. Individual leaders and

local protocols within communities [e.g. 4] can provide guidance. Other academic disciplines, like geography, anthropology and health, that provide training and experience in contemporary social science practices and that endeavor towards an ethic of community engagement can also be important sources of guidance [e.g. 17-19]. In our relationships, we spend time together socializing at children’s camps and cultural events, and jarring salmon together. Opportunities like this would present themselves in any community.

Shaped with input and shared experience from applied scholars and leaders within First Nations communities, we offer here reflections on our process of academic-community engagement in three communities in coastal British Columbia, Canada: Bella Bella, Klemtu and Wuikinuxv village [2]. Acknowledging that contexts differ among communities, we present a generalizable framework to help enable future efforts. Although always a work-in-progress for both scientists and communities, we consider it essential that communities have tangible input to the research process and that outcomes are jointly determined. Although not in any sense unflawed, rigid or a finished product, in our experience this approach can yield sincere, productive, and enduring relationships among academics and community members for locally driven research.

## FOUNDATIONAL PRINCIPLES

Fundamentally, an engaged research process can be built upon a consideration of: i) how research questions are framed, ii) the consequences of research outcomes at local scales and iii) respect for place. Several local dimensions, such as local and traditional knowledge or the needs of legally entitled community management, can provide context for the foundation and direction of framing the research question(s) and process. Academics have a responsibility to understand how their short-term research efforts can fall into the broader framework of the community's requirements. For example, Service et al. (2014) used a multi-method approach of conventional science and local knowledge interview data to document a recent distribution shift of grizzly bears in coastal British Columbia [9]. While wildlife distribution shifts are of scholarly interest, they also have direct implications for ecotourism and logging operations in the region. This research was done under the direction of two indigenous government offices: the Heiltsuk Integrated Resource Management Department and the Kitasoo/Xai-Xais Integrated Resource Authority, ensuring results could be directly applicable to local land-use planning. By respecting and operating within the communities' requirements, the authors framed their research through a local resource management context.

This responsibility extends more broadly to respect for the place-based setting and authority of the community as part of a complex socio-ecological system, where the landscapes and resources are integral aspects of a community's experience and knowledge systems [4, 21]. This respect can be demonstrated simply through word choice (e.g. academic partners avoid possessive pronouns in phrases like "my study area").

We also recognize that consideration must be given to whose voices are heard and whose are potentially excluded within the community throughout this process [21]. This consideration extends among communities as well; research with one Nation (and not with others) occurring in a territory with overlapping claims can have far reaching and unintended implications for resource management and potential land claims processes that should be carefully considered and discussed.



## STAGE-BY-STAGE FRAMEWORK OF THE RESEARCH PROCESS

To support these core principles, we offer a generalizable framework for engagement at each stage of the collaborative research process. While we recognize that engagement does not

always follow a simple chronology, our model addresses what we believe is a collaborative experience at each stage (Table 1). We identify the contributions that academics and indigenous community members can provide, offer examples of collaborative actions within these stages, and suggest the process

benefits that can be cultivated at each stage. The latter include: respect, trust, co-capacity building, and sincere relationships (Figure 1). We emerge with the framework based on our collective experiences and goals for an engaged research process, enhanced with insight from the literature.

### Table 1. (p. 4)

Roles, contributions, and examples of the process by community and academic collaborators in the stages of conception, design, implementation and dissemination of community-engaged research. We list a non-exclusive suite of possible roles; in practice, collaborations might take different forms. We also recognize that community members may themselves be academics, but for simplicity we identify binary roles. We list examples of actions that could occur within each stage of the research process. Adapted from Adams et al. 2014 [2].



**Table 1.**  
**Roles, contributions, and examples of the process by community and academic collaborators**

Research Stage	Community Collaborators	Academic Collaborators	Process Examples
<b>Conception</b> - Identify research focus - Examine assumptions - Establish research questions beneficial to all parties	- Formulate research questions within local context of TEK/LEK and research goals	- Situate local context into scholarly framework to shape research focus	- Share understandings and qualify assumptions about the study system from all perspectives - State research objectives transparently - Examine potential benefits and costs of the research
<b>Design</b> - Select appropriate scope and methods - Organize local logistics - Craft data sharing agreements	- Ensure methodology respects local protocols - Provide clear expectations on research goals and data sharing agreements - Suggest if current project can build from/contribute to other local research	- Provide design expertise in scientific methods - Contribute to shared vision for project goals and data sharing agreements	- Ensure an understanding of the potential implications (e.g., cultural, safety) of research on the land or in the community, and the importance of respecting existing protocols - Ensure academic rigour is adequately maintained, but is dynamic if required to embrace changing research goals or local operations - State potential applications, protections, and storage of data in a transparent manner
<b>Implementation</b> - Assemble research team - Engage in collaborative fieldwork - Consult frequently on progress and challenges	- Ensure logistically safe and culturally respectful research operations - Contribute local experts on research teams - Share local knowledge - Provide feedback on research process	- Share technical expertise - Respect local protocols - Consult regarding project progress with community - Provide feedback on process	- Share capacity and respect among team members - Provide support for the integration among various assumptions, goals, and relationships to place - Create space for collaborators and community members to engage with the research process
<b>Knowledge dissemination</b> - Respect both access to and confidentiality of knowledge - Communicate research outcomes	- Respect data sharing protocols - Make knowledge accessible to the community - Use information for resource management decisions, as appropriate - Participate in scholarly publications, if appropriate	- Respect data sharing protocols - Make knowledge accessible to the community - Craft academic publications - Offer information for resource management, if appropriate	- Manage and distribute information at community and academic levels, as per previously agreed upon data protocols - Collaborate on authorship of reports and /or scholarly publications - Extend research findings beyond collaborators into the community - Solicit process feedback, for ongoing activities and future collaborations

### STAGE 1: CONCEPTION OF RESEARCH FOCUS AND QUESTIONS

The process for community-engaged research begins with transparently identifying desired approaches to and outcomes in the application of research. Both academic and community stakeholders need to qualify their assumptions and expectations prior to identifying specific research questions. Desired outcomes are often derived through local requirements and informed by local and/or traditional knowledge, typically with applications for resource management or conservation [e.g. 9, 19 and 22]. The collaborative perspectives of academics and communities can yield productive research questions that reflect local and complex socio-ecological circumstances [4, 22]. From our perspective, the most mutually beneficial collaborations could fulfill the resource management needs of the communities and their governments while simultaneously providing scholarly opportunity for academics [e.g. 9, 19 and 22]. Recognizing and articulating these overlapping opportunities may require time and reflection. Once potential collaborations have been identified, jointly prepared funding can be sought to increase research support and engagement capacities of both parties [4]. For example, funds can be allocated for local wages and sampling costs while also supporting travel costs of researchers and post-sampling analytical fees.

In conceptualizing specific research objectives, respect for each other's context and process can be demonstrated by

considering the various approaches, needs, and capacities of each party. The process and outcomes of research will impact both academic and community collaborators depending on the scope. For example, each party has to be flexible with how the collaboration might affect timelines, reward systems, and future decisions. Openly and thoughtfully entered into and navigated, this early stage of the research process can begin to build mutually informed respect and acceptance, which can cultivate trust between collaborators.

### STAGE 2: RESEARCH DESIGN

Once the focus of the research has been identified, collaborators can craft a project plan and select appropriate methods for the scope of the project. Scholarly collaborators may provide methodological expertise with regard to data collection, by nesting data within a study design that adheres to local protocols and guiding principles for operating within the focal community as well as its neighboring communities [e.g. 4, 12]. Collaborators could do this by soliciting not only the capacity within the research team, but also through processes that involve the broader community, such as workshops or information sessions. Community collaborators may also suggest how the current research could build from or contribute to concurrent local research. Open negotiation of data sharing, communication, and storage protocols at the onset of the project is critical to building clear expectations about ownership, control, access and possession of information for collaborators [13, 23].

A thoughtful research design can ensure an understanding of the potential implications of carrying out research within local protocols and a suitable methodology. Throughout the learning and observation of scientific and cultural protocols, these steps encourage and maintain acceptance and respect for both guiding principles and research approaches between collaborators. As capacity is shared and built into the design of research, so too is trust in the engagement process.

### STAGE 3: IMPLEMENTATION

A collaborative team of community experts and scholars can implement the research. Engaging local people in research opportunities can increase logistical safety, enrich the experience, and ensure local protocols are respected. Similarly, Nations that drive their own research agendas may hire scientists and technicians for methodological and analytical abilities. These capacities can be taught and shared between the collaborators, and beyond to the community [24]. For example, community team members may learn how a sampling design or methodology could be implemented in a different study system. Academic team members may learn about the cultural context and broader natural history of the research focus. In other words, just as local capacity can be built via collaboration, so too can the capacity of academics; indeed, they have much to learn about being participants in community-engaged work. Individuals may bridge both worlds as academically trained practitioners or scholars and members of indigenous communities (such as authors that lead [22, 25 and 26]).

During implementation, partners can develop one another's capacity while also building collaborative personal and professional relationships. Such relationships would be sincere and respectful; without condescension and/or ulterior agendas in forming the relationship. Research partners may also acknowledge various assumptions and backgrounds, motivations to do research, and relationship to place among team members. The mutual trust and respect further built during co-capacity building can allow for a dynamic process that works towards shared, desired outcomes and a sense of involvement in the research.

#### STAGE 4: USE AND DISSEMINATION OF KNOWLEDGE

Research produces information that may have scholarly value and applications to community-based needs. Information should be disseminated through means that respect both the access to and confidentiality of knowledge as negotiated in data sharing protocols [13, 21]. The synthesis of research information and outcomes for communities can be crafted to be accessible, informative and sensitive to confidentiality [11]. Communities may apply research outcomes to local governance strategies or an increased understanding of local socio-ecological systems [21; e.g. 19, 22]. Scholars may apply information towards the development or testing of theory through the peer-reviewed publication process. Community and academic partners may collaborate in the authorship or review process of communicating

research outcomes. For scholarly publications, this inclusion is expected if community contributions are consistent with typical publishing expectations [20]. Communicating research outcomes involves careful consideration of authorship ethics through respect for data protocols and acknowledgement of the contributions and intellectual property of knowledge holders and community members [27]. Importantly, any information gathered from knowledge holders remains their property and does not become 'intellectual property' of universities. Academics should consider building in safeguards against such demands from their institutions.

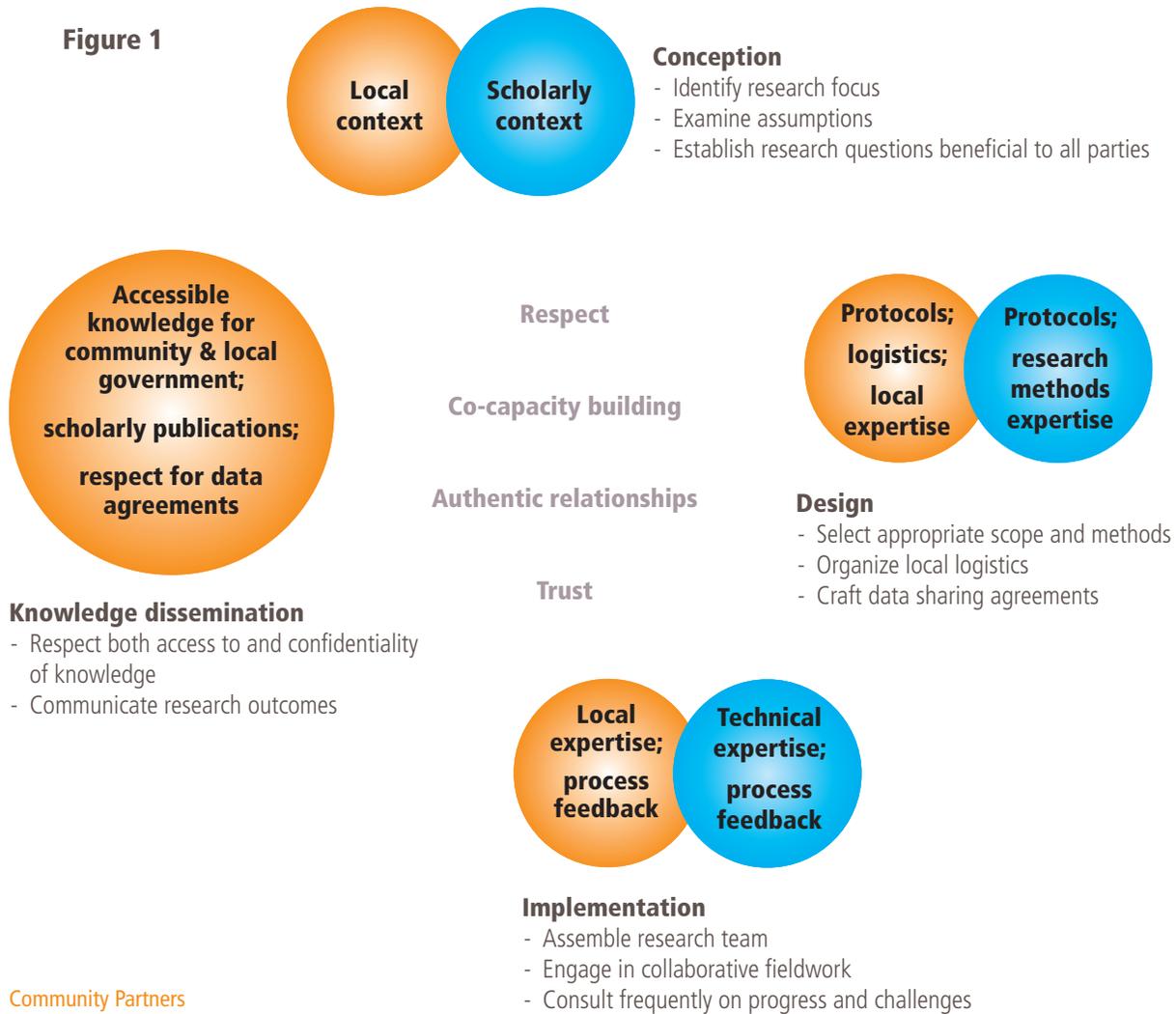
The partnerships formed over these stages can cultivate enduring relationships and potential future collaborations among partners (Figure 1). In particular, respect and acknowledgement of the validity of knowledge contributions, clear boundaries of possession, ownership and/or confidentiality of data, and an understanding of the implications of benefits and detriments of the research, all provide a strong foundation for enduring research partnerships [13, 28].

Academic collaborators can go beyond these best practices within the research process, and engage with other aspects of the community within and outside of the research timeframe. For example, as part of the multi-Nation bear-monitoring program, we focus a component of sampling directly in and around Wuikinuv village so the school students and community members can visit sampling sites and collect data

during weekly "village bear walks". As another example, many of the concepts that shape the study design, as well as dissemination and application of this project, are forged with youth, elders and other community members over the preparation and sharing of local foods, or during time spent in communities and on the land. Community guests commonly accompany the research team during fieldwork throughout the territory. Additionally, ideas are exchanged while walking, cooking or camping when research is done for the day. And importantly, our professional and personal relationships naturally extend over the "off-season". The relationships cultivated and maintained become part of the lives of academics and community members. For example, communities may invite academic collaborators to meet during the "off-season" or to witness and/or participate in cultural events, while academics can welcome community collaborators to their university space and to conferences, or invite them to be on supervisory committees. In urban environments, where academics and community members may cross paths, we also connect to socialize and exchange concepts. These examples of exchanges are central to engaged research with and within communities (Figure 1, p. 8).



**Figure 1**



Community Partners  
 Academic Partners  
 Research process  
 Dynamic Feedback

Research outcomes, potential collaborative roles, and reciprocal process benefits generated through an engaged research process. Although there will be shared experience among collaborators in the roles (denoted by overlap among circles in figure), knowledge base, and capacity throughout these stages, much of the engaged research process occurs through collaborators working beside one another from their own worldview, knowledge base, and method of inquiry (denoted by non-overlap) towards shared outcomes. Throughout each stage, community and academic partners can cultivate process benefits including respect, trust, co-capacity building, as well as open and enduring authentic relationships. The research process can lead to future collaborations, demonstrated by the continuous arrows. Process stages can revisit a previous stage if feedback from within the team or the community suggests that the scope, design, implementation, or dissemination of the process requires modification. Adapted from Adams et al. 2014 [2].

## CONCLUSION

Openly and honestly facing current challenges to indigenous community engagement through collaborative research approaches can lead to valuable knowledge production with applications for conservation, resource management and applied scholarship. This dynamic process involves the scholarly community de-centering themselves from academic institutions towards situating the research process from a community context [11, 15 and 16]. Academics, including the authors of this work, have much to learn. The journey also entails direction from First Nation communities regarding their desired involvement and the capacity they can both offer and require. Ultimately, writing pieces such as this one is relatively simple compared to the humbling realization of respectful and open collaboration through our choices and actions as peoples from diverse worldviews and knowledge bases. While this presents challenges, in our experience, engaged research affords inspiring opportunities for effective research outcomes accompanied by sincere, productive, and enduring relationships.

## ACKNOWLEDGEMENTS

We acknowledge and thank colleagues, mentors and friends from the Heiltsuk, Kitasoo/Xai'Xais and Wuikinuxv Nations as well as the University of Victoria for sharing their knowledge, friendship and ideas with us, and for helping to foster authentic connections with place and people. The support of the Hakai Beach Institute, National Sciences and Engineering Research Council, Raincoast Conservation Foundation, Tula Foundation, and Spirit Bear Research Foundation has been integral to this work. We extend special thanks to Jeff Cortassel for sharing with us the elegant and powerful concept of 'de-centering the university' from community-based research.

## LITERATURE CITED

- [1] SELYE, H. 1956. *The Stress of Life*. (New York, New York: McGraw-Hill).
- [2] ADAMS, M., J. CARPENTER, J.A. HOUSTY, D. NEASLOSS, PAUL C. PAQUET, C.N. SERVICE, J. WALKUS, and C.T. DARIMONT. 2014. Towards increased engagement between academic and indigenous community partners in ecological research. *Ecology & Society* 19(3): 5.
- [3] JOHNSON, M. and R. RUTTAN. 1993. *Traditional Dene Environmental Knowledge, a Pilot Project Conducted in Ft. Good Hope and Colville Lake N.W.T. 1989-1993*. (Hay River, Northwest Territories: Dene Cultural Institute).
- [4] HEILTSUK TRIBAL COUNCIL. 2001. *Guiding Principles for Scientific Research in Heiltsuk Territory*. (Bella Bella, British Columbia: Heiltsuk Tribal Council).
- [5] BERKES, F. 2008. *Sacred Ecology*. (New York, New York: Taylor & Francis).
- [6] HAGGAN, N., N. J. TURNER, J. CARPENTER, J. T. JONES, Q. MACKIE, and C. MENZIES. 2006. *12,000+ years of change: Linking traditional and modern ecosystem science in the Pacific Northwest*. (Vancouver, British Columbia: Fisheries Centre, University of British Columbia).
- [7] TURNER, N. J. and F. BERKES. 2006. "Coming to Understanding: Developing Conservation through Incremental Learning in the Pacific Northwest." *Human Ecology* 34(4): 495–513.
- [8] TROSPER, R. L., F. CLARK, P. GEREZ-FERNANDEZ, F. LAKE, D. MCGREGOR, C. M. PETERS, S. PURATA, T. RYAN, A. THOMSON, and A. E. WATSON. 2012. "North America." In *Traditional Forest-Related Knowledge*, edited by R.L. Trospers and J.A. Parrotta. (Springer Netherlands), p. 157–201. (<http://www.springerlink.com/index/H5173718K205R527.pdf>).
- [9] SERVICE, C. N., M. S. ADAMS, K. A. ARTELLE, P. PAQUET, L. V. GRANT, and C. T. DARIMONT. 2014. "Indigenous knowledge and science unite to reveal spatial and temporal dimensions of distributional shift in wildlife conservation concern." *PLOS ONE* 9(7): e101595.
- [10] HUNTINGTON, H. P., S. GEAREHEARD, A. R. MAHONEY, and A. K. SALOMON. 2011. "Integrating Traditional and Scientific Knowledge through Collaborative Natural Science Field Research: Identifying Elements for Success." *ARCTIC* 64(4): 437–45.
- [11] GAUDRY, A. 2011. Insurgent Research. *Wicazo Sa Review* 26(1): 113–136.
- [12] TOBIAS, T. 2000. *Chief Kerry's Moose: A Guidebook to Land Use and Occupancy Mapping, Research Design and Data Collection*. (Vancouver, British Columbia: Union of BC Indian Chiefs & Ecotrust Canada).
- [13] SCHNARCH, B. 2004. "Ownership, Control, Access, and Possession (OCAPT) or Self-Determination Applied to Research." *Journal of Aboriginal Health* 1(1): 80–95.
- [14] SMITH, L. T. 1999. *Decolonizing Methodologies: Research and Indigenous Peoples*. Zed books.
- [15] CORNTASSEL, J. and R. C. WITMER. 2008. *Forced Federalism: Contemporary Challenges to Indigenous Nationhood*. University of Oklahoma Press.
- [16] CORNTASSEL, J. Panel member: *Decolonizing Community Engagement*. Community-Engaged Scholarship at UVic, a conversation series. February 19, 2014.
- [17] COCHRAN, P. A. L., C. A. MARSHALL, C. GARCIA-DOWNING, E. KENDALL, D. COOK, L. MCCUBBIN, and R. M. S. GOVER. 2008. "Indigenous Ways of Knowing: Implications for Participatory Research and Community." *American Journal of Public Health* 98(1): 22–27.
- [18] BULL, J. R. 2010. "Research with Aboriginal Peoples: Authentic Relationships as a Precursor to Ethical Research." *Journal of Empirical Research on Human Research Ethics* 5(4): 13–22.
- [19] CASTLEDEN, H., V. S. MORGAN, and C. LAMB. 2012. "'I Spent the First Year Drinking Tea': Exploring Canadian University Researchers' Perspectives on Community-Based Participatory Research Involving Indigenous Peoples." *The Canadian Geographer / Le Géographe Canadien* 56(2): 160–79.

[20] CASTLEDEN, H., V. S. MORGAN, and A. NEIMANIS. 2010. "Researchers' Perspectives on Collective/Community Co-Authorship in Community-Based Participatory Indigenous Research." *Journal of Empirical Research on Human Research Ethics: An International Journal* 5(4): 23–32.

[21] TOBIAS, T. 2010. *Living Proof: The Essential Data-Collection Guide for Indigenous Use-and-Occupancy Map Surveys*. (Vancouver, British Columbia: Union of BC Indian Chiefs and Ecotrust Canada).

[22] HOUSTY, W.G., NOSON, A., SCOVILLE, G.W., BOULANGER, J., DARI-MONT, C.T., and C. E. FILARDI. 2014. "Grizzly Bear Monitoring by the Heiltsuk People as a Scientific Crucible for First Nation Conservation Practice." *Ecology and Society* 9(2): 70.

[23] TOBIAS, J. K., C. A. M. RICHMOND, and I. LUGINAAH. 2013. Community-Based Participatory Research (CBPR) with Indigenous Communities: Producing Respectful and Reciprocal Research. *Journal of Empirical Research on Human Research Ethics: An International Journal* 8(2): 129-140.

[24] DREW, J. A. 2005. Use of Traditional Ecological Knowledge in Marine Conservation. *Conservation Biology* 19(4): 1286–93.

[25] MOODY, M. 2008. *Eulachon past and present*. Dissertation. (Vancouver, British Columbia: University of British Columbia).

[26] WHITE, X. E. A. F. 2006. *Heiltsuk stone fish traps: products of my ancestor's labour*. Dissertation. (Burnaby, British Columbia: Simon Fraser University).

[27] CANADIAN INSTITUTES OF HEALTH RESEARCH. (2007). *CIHR Guidelines for Health Research Involving Aboriginal People*. (Ottawa, Ontario: Canadian Institutes of Health Research).

[28] TURNER, N. J., M. B. IGNACE, and R. IGNACE. 2000. Traditional Ecological Knowledge and Wisdom of Aboriginal Peoples in British Columbia. *Ecological Applications* 10(5): 1275–87.

## EXPANDING THE TOOLBOX: EPISTEMOLOGICAL STRETCHING AND ETHICAL ENGAGEMENT

**M. J. BARRETT**  
University of Saskatchewan

**MATT HARMIN**  
University of Saskatchewan

**KARONHIAKTA'TIE BRYAN  
MARACLE**  
Independent researcher

**CHRISTIE THOMSON**  
University of Saskatchewan

Even though the importance of Indigenous knowledge (IK) has been recognized, and in many instances its inclusion has been legally mandated, the lack of comprehension about epistemology (the manner in which knowledge is acquired) and ontology (the manner in which the nature of reality is understood) is an impediment to open dialogue and co-operation among the parties involved. This, in particular, holds true when spiritual aspects of knowledge are vital for respectful engagement and/or to accomplish research tasks. In order to effectively and ethically conduct research with Indigenous peoples, the wide range of human abilities to know must be at the very least respected, and ideally, both understood and engaged by those involved in any collaborative effort. We talk about this as "epistemological stretching," the expansion of the ways of knowing that one respects, understands and/or uses. In concrete terms, this means that those who do not subscribe to traditional Indigenous ways of knowing must have some experience and understanding of concepts such as transrational (spiritual) forms of intuition. Without such an understanding,

Indigenous knowledge will continue to be 'scientized' (Simpson, 2004) and respected only for its empirical contributions, a situation that occurs far too frequently.

Epistemological stretching enables all parties to at least appreciate, if not directly access, the kinds of insight and wisdom that emerges from a shifted consciousness that includes intuitive, affective and embodied ways of knowing. This shifted consciousness is a state of being in which the individual is deeply connected not only to his inner wisdom, but also to spiritual forms of knowing as well. It supports access to knowledge and knowing in diverse forms, including intuition, dream knowledge and information obtained by communicating with plants, animals and spirit beings.

Effectively accessing and interpreting these diverse epistemologies requires practice and skill. Understanding and respecting their existence is a first crucial step for effective and ethically appropriate engagement with Indigenous peoples and inclusion of their knowledge in consultation, decision-making and research processes.



## THERE ARE MANY WAYS OF KNOWING

Research supported by a Social Sciences and Humanities Research Council of Canada research project identified three key conceptual gateways<sup>1</sup> to epistemological stretching. They are:

1. There are many different ways of knowing, some which are perceived as more or less “normal” (e.g. accepted) within one’s culture;
2. One’s experience and understanding of the world is constrained by one’s worldview; and
3. Habitual forms of thought, talk and action (discourse) can support, undermine, make difficult and/or challenge the dismissal, ridicule, absence, usefulness or appreciation of particular ways of knowing.

To address the first three threshold concepts, we provide introductory activities that can serve as workshop activities or educational tools prior to gathering a group for consultation. Two of these activities focus on the first concept. The third activity supports all three concepts.

### Activity 1 : (10–40 minutes, depending on discussion).

**Goal:** To have participants identify where and how they dismiss or not even consider certain ways of knowing. This activity can be held with a group of any size and is especially valuable as an ice breaker. Participants are asked to graph the relative frequency of various ways of knowing in order to paint a portrait of how often they use different ways of knowing.

1. Provide participants with the graphs on the ways of knowing (Appendix 1; feel free to revise as needed for your group).
2. Ask participants to complete the graphs to represent the relative frequency with which they use each way of knowing. They should start by completing the graph for their professional professional life, and then proceed with the graph for their personal life.
3. Facilitate group discussion about the key learnings in completing these graphs. Questions to ask include:
  - What did you notice once you completed the graphs?
  - Were you surprised by the results? If so, how?
  - What are the implications of the differences/similarities in how you acquire knowledge in different settings?
  - What does this mean? (Indigenous knowledge is holistic. When people are better at using all their capacities for knowing, they are allowing themselves to be whole and tap into inner, embodied and/or spiritual knowing.)

**Note :** The development of this activity was prompted by a young female engineer who, in a class discussion similar to the next activity, stated, “I use intuition a lot and very effectively in my personal life; I never thought to bring it into my professional life.”

**Possible extension:** Compile all of the graphs completed by participants and create a visual representation of the data you collected. Potential questions include:

- What have you noticed?
- Why do you think these particular results were obtained?
- Are there any trends? What do these trends tell us? How can they help us work ethically across cultures?
- Does anything need to change?
- What (if any) impacts would such changes have on your work? On your personal life?
- What ways of knowing were not listed on the graph, but would be worth considering?

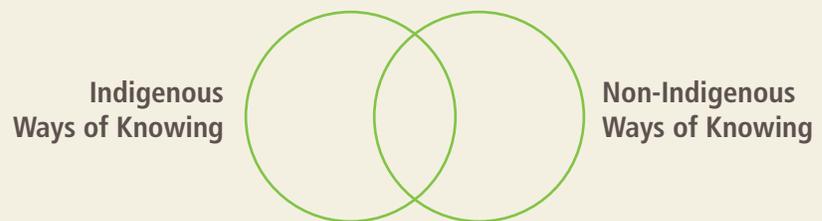
1. Land and Meyer (2006) call these ‘threshold concepts’ gateways “that lead to previously inaccessible, and initially perhaps ‘troublesome,’ ways of thinking about something” (n.p.).

### Activity 2 (45 minutes) :

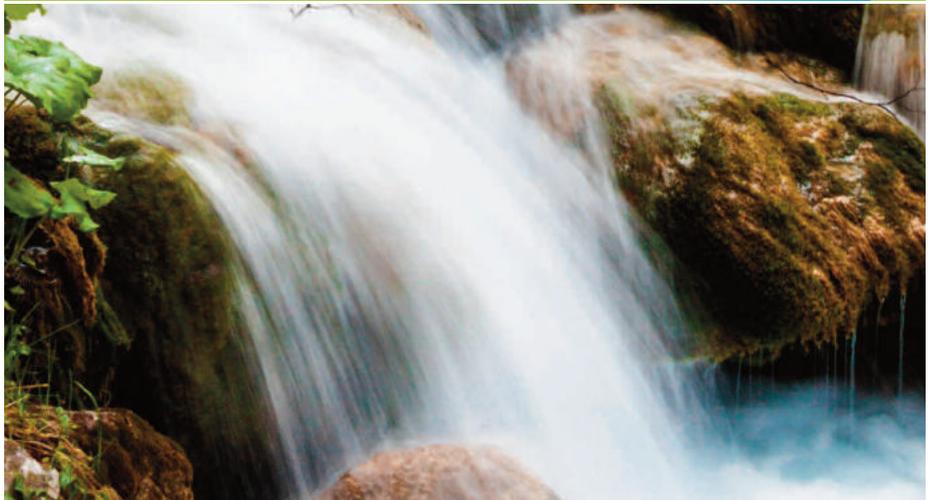
This activity challenges the conception that Indigenous and non-Indigenous ways of knowing may not, as is often assumed, be incommensurable.

1. Create a long list of ways people acquire knowledge (feel free to draw on the results of the graphing activity, if desired).

Using a Venn diagram, place all the ways of knowing that are shared by Indigenous and non-Indigenous people in the area where the circles overlap. In the outside sections, label one circle Indigenous Ways of Knowing and the other Non-Indigenous Ways of Knowing. Put ways of knowing that belong to only one group in the appropriate section. The size of the area of overlap represents how many of the ways of knowing are recognized by both groups (e.g. dreams, intuition).



**Summary point:** The degree of overlap (or lack thereof) depends on what ways of knowing non-Indigenous and Indigenous peoples accept as legitimate. See Barrett (2013) for background reading and Barnhardt & Kawagley (2005) for one example of a Venn diagram.



### Activity 3 (30–90 minutes) :

This series of activities/discussion supports participants' understanding of how particular ways of knowing are dismissed, ridiculed or ignored, as well as enhances their ability to observe and effect change. Start by showing the participants the video featuring examples of students who have undergone epistemological stretching to encourage them to accept other ways of knowing: *Multiple Ways of Knowing in Environmental Decision-Making* <http://www.youtube.com/watch?v=WMSK3v6iJu0>

#### The following definitions are important for this exercise:

1. In this context, discourse refers to habitual forms of thought and the ways in which they are reproduced. We are focusing on identifying discourses which reproduce some ways of knowing as dominant and others as marginalized. Dominant discourses are embedded in and reproduced through everyday speech, action and physical spaces. It is difficult to think and act outside of discourse (Foucault, 1995);
2. Modern Western culture: We have all come to learn and accept the frameworks of Western culture, which focuses on the centrality of the individual and places humans above everything else (Beeman & Blenkinsop, 2008). These ideas can also be described as "Eurocentric"

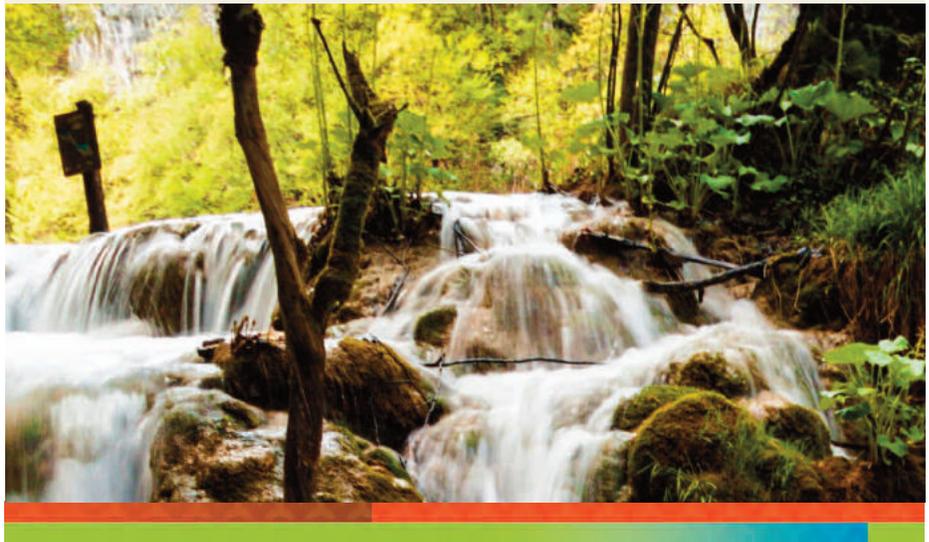
**Overview:** Through presentation and discussion, describe the idea of "discourse" as a way to talk about how the stories we tell ourselves determine what is or is not appropriate, desirable or even possible. Using the steps below, emphasize how some discourses are dominant and relate this to the core assumptions of modern culture. Follow up with a short discussion, focusing on how these discourses are reproduced in modern Western culture, and how discourse constrains our ability to relate to nature and Indigenous knowledge holders.

1. The facilitator tells a story about a local encounter with discourse. Two examples follow (feel free to use these examples or create your own). Example 1: I recently received an e-mail from a colleague, who is also a graduate student. In this e-mail, she stated that many people she has talked to have received telepathic communications from their pets or other animals, but very few are willing to talk about them. Using the chart below, identify the discourse, what kind of thinking and action made possible (or impossible or very difficult), as well as some alternative discourses.
2. Example 2: When I was writing my doctoral dissertation, I continually received wisdom from trees along a particular street. I never spoke of this to my professors while I was a student. The interesting thing is that although some of my doctoral committee members may have had similar experiences, none of them, except the person of Cree ancestry, openly talked about receiving wisdom from Nature.
3. To help participants develop skill in identifying how discourse works, spend a significant amount of time discussing more examples, and explore the effects, using the chart below, to demonstrate how discourse limits thinking and action.

4. Ask participants to reflect on the discourses in their lives and how they are affected by or resistant to them. Participants should consider the source of these discourses and whether they might want to reconsider some of them. Note that most discourses are culturally specific.

How does discourse limit the kinds of relationship one can have with the natural world? How does it limit our ability to accept the full scope of Indigenous knowledge, which, according to Marlene Brandt Castellano<sup>2</sup> (2002), includes three main sources:

1. Traditional knowledge, [which] has been handed down more or less intact from previous generations...
2. Empirical knowledge, [which] is gained through careful observation...[and] created by many people over extended time periods...[and]
3. Revealed knowledge, [which] is acquired through dreams, visions and intuition that is understood to be spiritual in origin (pp. 23–24).



2. Marlene Brandt Castellano is a Mohawk Professor Emeritus at Trent University and past co-director of research for the Royal Commission on Aboriginal Peoples in Canada.

## 5. DISCOURSE CHART

What is the discourse?	Thought: What kind of thinking does the discourse promote?	Action: What kind of action does the discourse promote?	What is impossible or difficult to say/think or do (given this discourse)?	Possible alternative discourse
<p><b>Example 1:</b></p> <p>Animals cannot communicate with humans; they do not have agency.</p>	<p>Animals have nothing to contribute to resource management decisions; those who think otherwise are deluded.</p>	<p>Science is the only way to know about animals. This includes measurement, observation and theory. We will only use this kind of knowledge.</p>	<p>I asked the (insert animal name/or spirit of that animal/or head spirit of that animal group) and this is what was communicated. We need to consider this advice in our decision-making.</p>	<p>Animals have the ability to contribute and should be asked to do so.</p>
<p><b>Example 2:</b></p> <p>Trees cannot communicate with humans.</p>	<p>Trees do not have a spirit.</p>	<p>No one listens to trees.</p>	<p>I received wisdom from a tree.</p>	<p>Trees are wise; Trees have a spirit; Spending quiet time with trees can provide knowledge and wisdom.</p>
<p><b>Additional local examples</b></p>				

For a possible alternative approach, see Barrett, M.J. (2012). Decentering norms: Teaching multiple ways of knowing in environmental decision-making. *Collected Essays on Learning and Teaching*, 5, 103–108. Retrieved from: <http://celt.uwindsor.ca/ojs/leddy/index.php/CELT/article/view/3405>.

## CONCLUSION

Despite ongoing attempts to bring Indigenous knowledges into environmental and other decision-making processes, effective engagement with IK will remain elusive until the parties involved come to a deeper understanding of the many different forms of knowledge and the many legitimate ways there are to acquire knowledge. These activities demonstrate some introductory ways to introduce the notion of “epistemological stretching” as an essential component to ethical engagement with traditional knowledge keepers and Indigenous knowledge. For a more extensive set of educational modules or a published paper on this topic, visit Dr. M.J. Barrett’s website at the School of Environment and Sustainability, University of Saskatchewan at: [http://www.usask.ca/sens/our-people/faculty-profile/Core/MJ\\_Barrett.php](http://www.usask.ca/sens/our-people/faculty-profile/Core/MJ_Barrett.php)

## SUPPORTING REFERENCES

BARRETT, M.J. (2013). A hybrid space: Epistemological diversity in socio-ecological problem-solving. *Policy Sciences*, 46(2), 179–197.

BARNHARDT, R. & A.O. KAWAGLEY. (2005). Indigenous knowledge systems and Alaska Native ways of knowing. *Anthropology and Education Quarterly*, 36(1), 8–23.

CASTELLANO, M. (2002). Updating aboriginal traditions of knowledge. In J. Dei, B. Hall, & D. Rosenberg (Eds.), *Indigenous knowledges in global contexts: Multiple readings of our world* (pp. 21–36). Toronto, ON: University of Toronto Press.

FOUCAULT, M. (1995). *Discipline and punish: The birth of a prison* (A. Sheridan Trans.). New York: Vintage Books.

MEYER, R. & J. LAND. (2006). *Overcoming barriers to student understanding: Threshold concepts and troublesome knowledge*. New York: Routledge. See also <http://www.ee.ucl.ac.uk/~mflanagan/thresholds.html>

SIMPSON, L. (2004). Anticolonial strategies for the recovery and maintenance of Indigenous knowledge. *The American Indian Quarterly*, 28(3 & 4), 373–385. Retrieved from <http://muse.jhu.edu/journals/aiq/summary/v028/28.3simpson.html>

YouTube video: Barrett et al. (2013). *Multiple Ways of Knowing in Environmental Decision-Making* <http://www.youtube.com/watch?v=WMsK3v6iJu0>

## ACKNOWLEDGEMENTS

Attributions: To all our relations, we give thanks. To those that have shared knowledge of their ancestors and experience we give special thanks. Doug Clark, Harold Gatensby (Tingit), Carolyn Hossler, Colleen Jones (Tingit/English), Alysa Loring, Danny Musqua (Ojibwe/Sauteaux), Sheryl Mills, Aimee Schmidt, Kiri Staples, Randall Tetlich (Vuntut Gwich’in) and all the students of ENVS 811: *Multiple Ways of Knowing in Environmental Decision-Making*, University of Saskatchewan, Graduate School of Environment and Sustainability.

Research completed at University of Saskatchewan, School of Environment and Sustainability. Funded by:

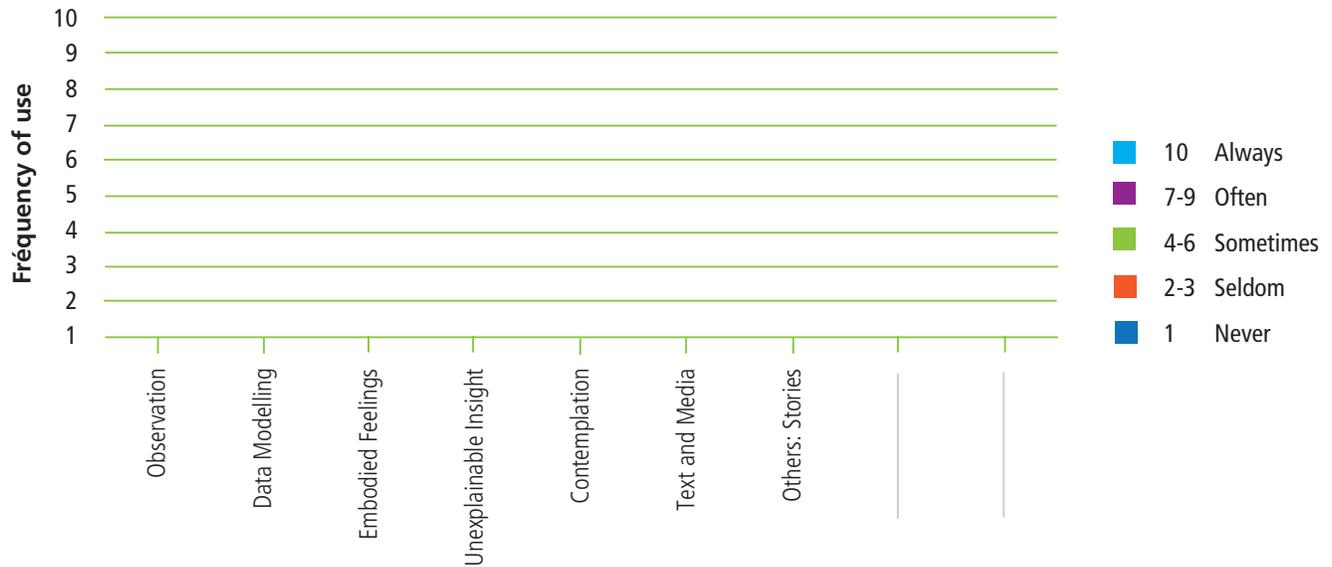


## APPENDIX 1

### PROFESSIONAL CONTEXT

The purpose of this activity is to create a bar graph identifying ways you come to know things in your professional work. Please write in any category you feel is important, but does not appear below.

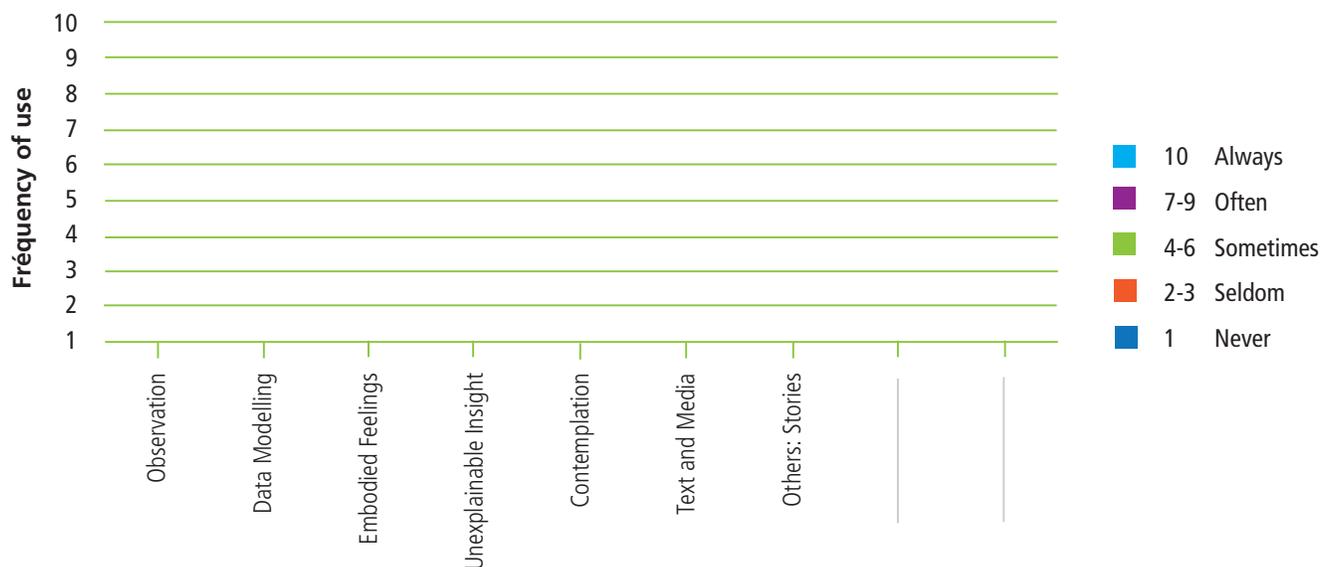
In my professional work, I come to know things through



### PERSONAL CONTEXT

The purpose of this activity is to create a bar graph identifying ways you come to know things in your personal life. Please write in any category you feel is important, but does not appear below.

In my personal life, I come to know things through



# DOCUMENTING THE HOMEWORK SUPPORT PROGRAM: ELEMENTS OF A SUCCESSFUL COMMUNITY-UNIVERSITY RESEARCH PARTNERSHIP

**NATASHA BLANCHET-COHEN**  
Associate Professor, Concordia University

**AMÉLIE LAINÉ**  
Regroupement des Centres d'amitié  
autochtones du Québec

## INTRODUCTION

Collaborations between Aboriginal communities and the universities can be beneficial if they involve respect and equality. Universities and society are finding common grounds for co-production of knowledge by working "in collaboration with society on social issues of shared concern" (Lévesque 2012: 291).

After decades of research marked by an unequal division of powers between university researchers and Aboriginal communities (Smith, 2012), the terms of this relationship need to be redefined. Marked by both success and errors, and in the face of well-established organizational cultures, new guidelines for researcher/community relations must be developed. It is therefore important to gain a better understanding of what makes positive collaborations possible.

In Canada, the Community-University Research Alliances (CURA) have enabled partnerships between the Aboriginal communities and the universities, resulting in collaborative work on various issues such as language, natural resources management, protection of culture, and health. These partnerships have provi-

ded an opportunity to redefine the terms of the production of scientific knowledge and to come up with new ways of doing things, including initiatives that reflect the questioning of conventional ways of doing things in the social sciences, where researchers where researchers strive for objectivity, in dissociating themselves from the context of their research (Guay and Thibault 2010).

In Québec, the ODENA – Aboriginal Peoples in Quebec Cities, which is a Quebec research alliance headed jointly by the Regroupement des Centres d'amitié autochtones du Québec (RCAAQ) and DIALOG- Aboriginal Peoples Research and Knowledge Network, adopted a charter setting out shared ethical values: 1) respect; 2) fairness; 3) sharing; 4) engagement; and 5) trust (see the contribution by Lévesque et al. in the toolbox). All researchers and partners of the ODENA Alliance who request internal grants for funding of their projects must include "provisions for the co-construction of knowledge." As Basile et al. (2012) emphasize, it is high time that Aboriginal organizations become an integral part of the process of redefining ethical approaches to research that concerns them.



### THE ISSUE: THE HOMEWORK SUPPORT PROGRAM

The Homework Support program that we have chosen to document is an initiative that stems from a collaboration between the RCAAQ and ODENA Alliance. This program is part of the numerous programs and services offered by the Friendship Centres throughout Quebec to meet the specific needs of urban Aboriginal children. Thanks to a commitment made at the First Nations Socio-Economic Forum by the RCAAQ with the Ministère de l'Éducation, du Sport et du Loisir (MELS), six Native Friendship Centres have been offering the program since 2006: Lanaudière, Quebec City, La Tuque, Saguenay, Chibougamau and Val-d'Or.

An integral part of the friendship Centres' programming for almost a decade, the Homework Support had never been documented, beyond a descriptive summary of the project and the activity reports written for the funding agencies. But every year close to 140 children register in the Homework Support program, and it is one of the approaches highlighted by the MELS (2008) to encourage academic success and to prevent school dropout.

We note that the high school graduation rate among Quebec First Nations members over 18 years old stood at 76% in 2012, compared to 87% among the non-Aboriginal population in Quebec (Statistics Canada 2012). According to the First Nations Regional Health Survey, 39.9% of First Nations adults had less than high school compared with 24% for the Canadian population at

large (FNIGG, 2008). In addition, Aboriginal people face specific school-related difficulties. Aboriginal children are often confronted by an education system presenting barriers that are difficult to overcome, such as language, prejudice and the lack of understanding about Aboriginal realities and Aboriginal culture (Lainé 2014). Quebec's Commission des droits de la personne et de la jeunesse accordingly considers Aboriginal youths to be among the groups most likely to be subjected to discrimination or racial profiling in Quebec (Eid *et al.* 2011).

### THE BENEFITS OF THIS RESEARCH: A SUMMARY

This research partnership allowed us to document the relevance of the Homework Support program offered by the Friendship Centres (Blanchet-Cohen *et al.* 2014). The Centres' willingness and interest that 130 people were able to participate, making up three target groups: 1) elementary and secondary school students who are currently receiving or have previously received Homework support program; 2) families; and 3) the Centres' employees directly involved in the service. Between November and February, discussion groups and individual interviews took place and a questionnaire was completed by more than one-third of the children participating in the program. The Centres presented the project orally to the parents. A consent form was sent home for the parents/guardians to sign. Phone call were made to remind parents/guardians to return the form, but none refused that their child participate.

The information collected clearly brought out the holistic approach underpinning the program offered by the Centres. Beyond the concrete help with learning provided by the Homework Support staff, the service offers a context conducive to the acquisition of new knowledge and development of self-esteem among the students. It gives them the desire and motivation to learn, by providing positive reinforcement combined with diversified learning strategies and the creation of intergenerational and inter-community links. This approach helps students' adopt a more positive attitude towards school, to persevere more in the face of difficulties and failure, and ultimately, continue their studies. The service also encourages families to provide the children with appropriate supervision to promote their success.

With the submission of the research and evaluation report, the Centres offering the program saw that the research brought out the scope of their programming. The questions raised by the discussion groups or interviews led to wider reflection on these issues by the program's staff at the Centres. The research also served to define and articulate the winning conditions of the Homework Support program, including:

- **A culturally safe supervision and accompaniment approach:** Flexibility in an Aboriginal context, positive reinforcement and recognition increases the children's motivation and helps them adopt a more positive attitude towards school, their schoolwork and the difficulties they encounter.

- **Staff's profile:** Having staff who speak the children's first language or who belong to their nation considerably helps the children to understand their homework and creates a relationship of trust with the staff.
- **Transportation service for students:** In areas where there is poor public transit, where the schools and Aboriginal communities are isolated and where parents do not have a vehicle, the transportation service of the Homework Support program ensures that as many children as possible can participate.
- **Continual adaptation of the service:** Annual evaluations and constant adaptation of the Homework Support service are key elements in an ongoing process of improvement.

The documentation of the program fostered a questioning of the Friendship Centres role. In light of the growth of the urban Aboriginal population (Comat *et al.* 2014) and the difficulties children have in adapting to their arrival at school, there is indeed an increase need for adequate school support of Aboriginal children. The friendship Centres could thus play the role of an intermediary between the student, his or her family, and school. By establishing solid relations for collaboration and joint action within the community, the Native Friendship Centres are able to work together with the schools and other resources (police services, health services, social workers, etc.) to combat the racism and social exclusion that young Aboriginal people may experience. These

collaborations can therefore help to ensure better support for Aboriginal families whose socio-economic, family and health conditions constitute obstacles to their children's academic perseverance and success.

These reflections allowed the RCAAQ to explore new avenues for solutions with the MELS and to propose the recruitment of a liaison officer. Based at the Native Friendship Centre of Val-d'Or (NFCVD), this pilot project will promote collaboration and coordination of actions between the NFCVD and the city's elementary and secondary schools that take in Aboriginal students.

Four elements that contributed to the success of this research partnership are described below. By research partnership we mean the "pairing of different kinds of expertise between the universities and civil society organizations" (Fontan 2010: 3), which serves to coproduce new knowledge from a perspective of social change or transformation. These elements reflect the principles for "good research practice" identified by the Assembly of First Nations of Quebec and Labrador (APNQL, 2005, page 3).

### 1. A NEED DEFINED BY THE LOCAL ENVIRONMENT

The first element of this collaboration is the fact that it emerged from the people directly involved at the community level, through the RCAAQ. Since its creation, the RCAAQ has been an incubator of initiatives for urban Aboriginal people and has successfully developed innova-

tive and proactive strategies (Lainé 2014). Collaboration with researchers from the ODENA Alliance came out of a reflection from the RCAAQ, which saw that the Homework Support program had not yet been the subject of any study, despite its popularity. Furthermore, an external evaluation of the Homework Support program by the MELS in 2008 had not taken account of the activities implemented by the Native Friendship Centres. The RCAAQ thereupon obtained funding from the MELS to conduct an independent evaluation; this funding was enhanced by a contribution from the ODENA Alliance.

From the outset, the RCAAQ expressed an interest in documenting the Homework Support experience to make known its importance, scope and benefits. The research question was clear: What is the relevance of the Homework Support program? Three meetings were held with RCAAQ representatives to develop the research plan and to define the approach taken to document this program. This involved the following:

- To target the family and the community, not just the child, in recognition of the fact that the program goes beyond the individual;
- To understand the environment/context in which the child lives, because that influences the child's life at school;
- To emphasize school perseverance, not just academic success;
- To produce an inventory of the tools developed by the Centres to use Aboriginal culture as a means of facilitating the children's learning.



This plan served as the basis for defining the methodology and the approach used to obtain data. As Fontan has noted, “research that is defined jointly seeks to meet objectives that incorporate concerns which are not necessarily the researcher’s own concerns” (2010: 10). The framework provided by the local environment, where there is knowledge of the program and its specific nature, served to develop a culturally appropriate methodology.

## 2. TOOLS SELECTED AND VALIDATED BY THE LOCAL ENVIRONMENT

First of all, the RCAAQ took part in the selection and validation of the research tools. Further to identifying the study’s goals and including parents and extended families along with the participating children, the RCAAQ determined the type of data collection. A survey would not be appropriate in this context, so we opted instead for discussion groups/roundtables. This method allowed us to identify good practices, to explore what was or was not working well, and to facilitate sharing among the Centres. The joint development of the methodology allows for an equitable and respectful research (APNQL, 2005).

Based on the guidelines provided by the local context, the research team developed interview questions and discussion groups to encourage a conversation with the participants. The questions were then reviewed and reformulated to make sure they were expressed in clear and straightforward language.

The research team contributed to the project through its knowledge about research with children, which was its main area of expertise (Blanchet-Cohen 2014). A play-based approach was used. This involved first playing a ball game and then using drawings to create an atmosphere where the children could express orally, in writing or in their drawings what they liked about the Homework Support service and the Native

Friendship Centre, and what they would like to see improved. The children were asked to draw what they liked about Homework Support on one side of a sheet of paper and what they liked about school on the other side. The children then explained their drawings. The social and personal relations aspect of the Homework Support emerged strongly from their drawings (see Figure 1).

**Figure 1. Drawing by 9 year old Attikamekw, Centre d’amitié autochtone de Lanaudière**



The discussion groups and the interviews with the families took place after the period devoted to the program. In keeping with the Centres' practice, a meal was provided before holding the discussion groups, which helped to establish an atmosphere of sharing. These meetings lasted 90 minutes on average and always included the Centre's employees, essential for creating a bridge to the research team and for transferring information to other employees. In the discussion groups for families, the employees were observers; they asked a number of questions to improve their ways of doing things.

The discussion groups with the Friendship Centres' employees were held during working hours and lasted about 90 minutes. They provided an opportunity for the staff to reflect on their work and to articulate their approach and the kinds of learning involved.

### 3. RELATIONAL AND INSTITUTIONAL ETHICS

As with all university research, this project was approved by the Ethics Committee at Concordia University. Following the standards set out in chapter 9 of the *Tri-Council Policy Statement*, the letter presented by the RCAAQ with the submission of the project to Concordia's Ethics Committee recognized the requirement to ensure "community engagement and collaboration in research undertakings" (2010: 128).

Further to the letters of consent (those signed at the start of each work session and those signed by the parents for their

children), the ethics of this research were founded on human relationships. The engagement of the researchers allowed the RCAAQ to make the decision to carry out a research partnership on this topic. Accordingly, the RCAAQ proposed conducting this research following a conference presentation on the approach and work experience required for researchers working with Aboriginal youths (Blanchet-Cohen 2014). Aside from the need for the research, developing good relations between the researcher and the milieu proved to be essential.

Regarding the discussion groups, we saw that some participants had first chosen to observe the activity and decided to participate in the discussion only after a relationship of trust had been established. For example, even though he had a letter of consent, one child chose to withdraw from the activity, only to return later. The way that the researcher team presented themselves helped to forge this atmosphere of trust (Kovach 2010). The RCAAQ members thus appreciated the language used by the research team, and their way of engaging in conversations, including a non-imposing presence and a soft tone of voice.

As noted by Basile *et al.*, ethics "is above all a matter of people's relationships with and engagement towards one another" (2012: 3). The large number of children and parents who participated illustrates the engagement of the researchers and the local environment.

### 4. OWNERSHIP OF THE RESULTS BY THE LOCAL ENVIRONMENT

Throughout this research activity, a dialogue between the research team and the local environment made it possible to validate the data analysis and effective appropriation of the results by the community.

Halfway, the research team prepared a PowerPoint presentation, which was given to the RCAAQ board of directors. This preliminary draft of the results was based on the fieldwork carried out at four Centres, giving food for thought to the RCAAQ and contributing to its programming. Following submission of the report, a joint presentation was made at the ACFAS Conference in 2014, as well as to the RCAAQ board at its quarterly meeting. These presentations were not only an opportunity for the Centres to discuss the Homework Support programming, but they also led to a proposal for creating a liaison officer between the schools and the urban Aboriginal community.

## CONCLUSION

We have learned that a research partnership depends on the desire of each party to pool their complementary expertise. One must be both intentional and flexible, in order to effectively combine the wealth of each type of expertise and to get the most out of the partnership at every stage.

In respecting the roles and functions of each party, this partnership was beneficial. This type of research not only led to the production of knowledge concerning the relevance of the Homework Support program in the Aboriginal communities (a topic hitherto largely unstudied), but also brought immediate benefits for the community, in terms of their thinking about the programs offered and in terms of identifying new

needs, such as the liaison officer position. It is essential to establish a good relationship between researchers and Aboriginal organizations in order to create bidirectional benefits (Asselin and Basile 2012: 5). Care must be taken from start to finish of a research project to maintain that relationship, with trust as an integral part, in order to meet the real needs of Aboriginal people.



## BIBLIOGRAPHY

ASSEMBLÉE DES PREMIÈRES NATIONS DU QUÉBEC ET DU LABRADOR [APNQL]. 2005. *Protocole de recherche des Premières Nations du Québec et du Labrador*. APNQL.

ASSELIN, HUGO and SUZY BASILE. 2012. Éthique de la recherche avec les peuples autochtones. Qu'en pensent les principaux intéressés ?, *Éthique publique* 14 (1) : 1-9.

BASILE SUZY, KARINE GENTELET, ALLISON MARCHILDON and FLORENCE PIRON. 2012. Présentation du dossier « Peuples autochtones et enjeux d'éthique publique », *Éthique publique* 14 (1): 1-5.

BLANCHET-COHEN NATASHA (in press). Indigenous Children's Rights: Opportunities in Appropriation and Transformation, in W. Vandenhole, E. Desmet, D. Reynaert et S. Lembrechts (dir.), *International Handbook of Children's Rights: Disciplinary and Critical Approaches*. London: Routledge.

BLANCHET-COHEN NATASHA, P. GEOFFROY and M. TRUDEL. 2014. *Evaluation Report on the Homework Support Program*. Submitted to the Regroupement des Centres d'amitié autochtones du Québec, Montreal.

COMAT IOANA, CAROLE LÉVESQUE, NATHALIE Fiset, STÉPHANIE CHIASSON *et al.* 2014. *Aboriginal people in Quebec cities: Issues, challenges and solutions in Val-d'Or and Senneterre*. ODENA, no. 2014-01, INRS-UCS, Montreal and Val-d'Or.

SOCIAL SCIENCES AND HUMANITIES RESEARCH COUNCIL OF CANADA, NATURAL SCIENCES AND ENGINEERING RESEARCH COUNCIL OF CANADA AND CANADIAN INSTITUTES OF HEALTH RESEARCH. 2010. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Government of Canada, Ottawa.

EID PAUL, JOHANNE MAGLOIRE and MICHÈLE TURENNE. 2011. *Profilage racial et discrimination systémique des jeunes racisés: rapport de la consultation sur le profilage racial et ses conséquences*. Commission des droits de la personne et des droits de la jeunesse du Québec, Québec.

FIRST NATIONS INFORMATION GOVERNANCE CENTER (FNIGC). First Nations Regional Health Survey. Available on line <http://data.fnigc.ca/online> Consulted 2014-10-15.

FONTAN JEAN-MARC. 2010. Recherche partenariale en économie sociale: analyse d'une expérience novatrice de coproduction des connaissances, *La revue de l'innovation dans le secteur public* 15(3): en ligne. <http://www.innovation.cc/> Consulted 2014-08-28.

KOVACH MARGARET. 2010. *Indigenous methodologies: Characteristics, conversations, and contexts*. Toronto: University of Toronto Press.

LAINÉ AMÉLIE. 2014. *Homework Support: An example of community support for Aboriginal children and their families initiated by the Regroupement des Centres d'amitié autochtone du Québec*. Oral presentation made at Université du Québec à Chicoutimi, March 2014.

LÉVESQUE CAROLE. 2012. La coproduction des connaissances en sciences sociales, in Miriam Fahmy (dir.), *L'État du Québec 2012*: 290-296. Montréal: Boréal.

SMITH LINDA TUHIWAI. 2012. *Decolonizing methodologies. Research and Indigenous Peoples* (2<sup>nd</sup> ed.). Londres : Zed Books.



# Way of being

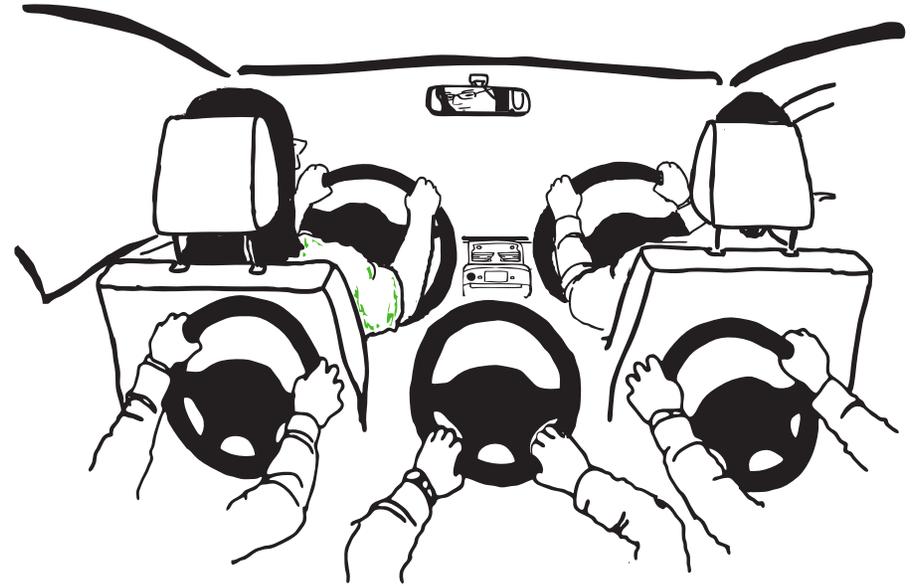
## To promote a shared process

To ensure success in terms of collaborative work, certain moral postures, values, principles and behaviours should be encouraged while others should be avoided. This guide's premise is clear: the team that was tasked with undertaking the concerted approach must create a framework for the inventory and cultural transmission project while facilitating the involvement and engagement of the participants. Their priority must be to promote the expression and creativity of others.

### Interpersonal attitudes: openness, flexibility, listening

When it comes to developing and implementing a project, it is essential to keep in mind that it will be subjected to many adjustments and clarifications, major changes, and even dramatic shifts. It is not uncommon when one proposes to «do something» on a personal and individual basis, to change one's mind because a better solution was found along the way. This possibility is even more likely when a project involves several people. When trying to reach a consensus, it is important to keep an open mind with respect to the positions of others and to make an effort to understand and contextualize their thought processes.

As so eloquently stated by the poet in French: "Camarade, le chemin n'existe pas, il se fait en marchant" (Comrade, the path does not exist, it is made by walking). In other words, each project is discovered progressively as each step is taken; that is why it is important to move forward and adapt constantly, even in the face of uncertainties, areas that are unclear and doubt.



Demonstrating an ability to adapt also means being able to bounce back; sometimes, things don't go the way they were initially planned. Once we are in the field, we may come to realize that we cannot achieve what was anticipated. Also, many opportunities can arise and it can be difficult to take advantage of them within the context of a pre-established and inflexible program. All of these factors can be destabilizing, which is why it is important to demonstrate creativity, tenacity and trust (in yourself and others) in order to overcome these challenges and reverse the situation to everyone's benefit.

### Adaptation: of the process and the activities

The activities presented in this guide should not be perceived as recipes, but rather as suggestions relating to working methods and general attitude. Adapting these methods to something that is suitable to everyone is highly recommended, and even necessary. The project is based on the particularities inherent to its context. In a meeting of cultures, it is important to make an effort to understand the characteristics of the others' culture and adapt the working methods to these characteristics to the extent possible rather than imposing one's point of view and one's own cultural mechanisms.



**Gathering together on equal footing in order to establish and project a common vision.** The moments of discussion and sharing are very important to ensure the good participation of each stakeholder. Here, the collaborative team and the key collaborators are gathered in one of the Nation's communities. This is an opportunity to discuss what has been done in terms of collaboration, what needs to be done and the way to do it. This sharing fosters a sense of belonging to the project among each of the stakeholders.



**Interpersonal reconciliation to build relationships and strengthen the connections between the stakeholders.** Togetherness in a project also means getting to know each other, gaining a mutual appreciation for each other and developing the desire to work together and gather around a shared process. Here, the consultation team and designers from several Aboriginal Nations are meeting around a friendly meal. Deliberately, the consultation team has dispersed around the table in order to avoid sitting side by side. This promotes meeting people, easy introductions, reconciliation and group cohesion and the partners quickly become friends!

### **Togetherness: being proactive in the relationship**

"Togetherness" first of all means sharing a forward thinking vision which is reflected in the shared project. That is why collaborative processes often involve a meeting of different cultures as well as different ways of living and thinking. The consultation team often finds itself in an unfamiliar environment; it will therefore have to get out of its comfort and safety zone consisting of sticking with people who know each other. "Togetherness" means knowing how to approach others, having the desire to make contact, starting up conversations, being present, making yourself visible and showing initiative in terms of interpersonal relationships. Beyond making contacts, it is important to maintain the relationships and embody this willingness to work together and make it a reality. This process of coming together avoids the perception of a rift between experts and fosters openness to discussion, sharing, getting to know each other better and building a trusting relationship and the emergence of opportunities. Basically, it refers to the rules of politeness, friendliness and respect.

### **Togetherness: sharing the information and the decisions**

Ensuring that collaborative projects take place smoothly involves sharing a common vision, greater transparency and good communication between stakeholders. It is therefore essential to organize information sharing sessions on a regular basis to ensure that everyone is aware of the project's progress and so that they can share in the challenges or successes. That way, everyone will be able to improve their own work and put their own participation into perspective in terms of the overall tasks to be carried out. These sharing sessions can take place on different levels (consultation team, all partners or all stakeholders). Obviously, the more people there are to bring together, the more worthwhile it is to wait until there are substantial points to discuss. But, in the case of small projects, meetings are simpler and it is better to get together or communicate on a regular basis.



Sometimes, it can be difficult to get everyone together, namely because of a lack of availability among the members or due to physical distance. In this situation, other strategies can facilitate sharing sessions such as telephone calls, videoconferencing or blogs. It is therefore necessary to determine together the right solution that will ensure smooth communication between the main players of the project.



Even though each member of the team, because of their expertise, may have specific tasks to perform, this does not necessarily mean that they are detached from the group or that they are involved in an independent process. It is necessary to constantly keep in mind that the project is larger than the individual and that sharing is synonymous with synergy.

### **Togetherhness:** aiming for consensus

"Togetherhness" implies that several different positions and strategies must be applied constantly. When working collaboratively, it is not enough to simply approve a decision. The decision must be made by the group on a consensual basis. It is negotiated within a fluctuating context between recognition for the expertise of each and respect for each person's point of view. It is necessary to build on empirical knowledge (knowledge developed through experience; expertise which is based on a practice), but within a spirit of openness and relative respect for the perceptions of each. However, this respect for the positions of each individual must not impede the progress of the group project. It is important to avoid censoring expression while rallying to the decisions made by consensus. Each stage of the work has its own world of expertise and each expertise has its own margin of authority.

### **Verification and validation:** review of the objectives and evaluation of the process and its results

The inventory and cultural transmission processes generally take place in several stages. During each of these stages, it is important to review the objectives of the project. These objectives can be defined at the outset of the project, or they can evolve along the way. At each stage (or turning point of the project), it is also important to carry out a validation exercise. This validation process can be more or less extensive in terms of scope. For each stage of the work, an activity report must be produced so that it can feed into the subsequent stage. Within a collaborative context, this can be an opportunity to obtain information from the participants regarding its validity and the collaboration method. How do the participants perceive their contributions to the project? Are all partners satisfied with their participation and the group dynamic? It is important to always allow for improving the contents and products while remaining open to changing the way things are done, making adjustments and taking the opinions of each into consideration before moving on to the next stage.

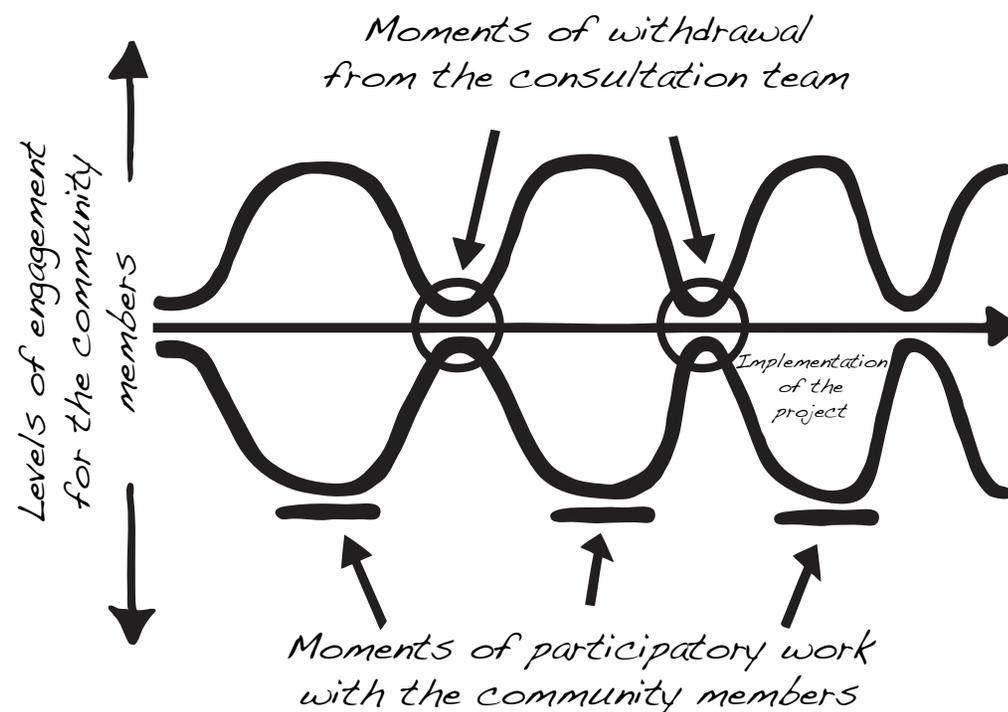


**The pleasure of gathering around shared passions.** In the same spirit of togetherness, a contemporary artist and designer participates in the activities of the community with whom she collaborated on a project. On a regular basis, the women of the *Cercle des fermières* (farmers' circle) gather at one of their homes in order to share a good time, enjoy a special treat prepared by the host, focus on and talk about their personal production techniques and participate in a few relevant activities. Here, the group is watching NFB documentaries on traditional techniques that the *Cercle* practices.

"Togetherhness" can simply mean meeting with the person instead of sending them an email, but it can even mean living together in an isolated place for the time it takes to carry out a stage of the work. It is important to know how to arrange times to get to know each other to ensure that the team can grow together around the project.



**Intensive work on behalf of the consultation team in order to present to the community the content collected over the course of a week of collaborative activities.** Moments of withdrawal from the consultation team are sometimes necessary to ensure that the collaborative activities take place more smoothly. As part of a week-long visit for consultation in a community, the team works to prepare the public evening validation session. This consists of gathering a maximum amount of content elements while making sure that they can be clearly presented in order to allow everyone to quickly take them into account and have the opportunity to react to them.



### **Fluctuation:** between moments of participatory work and withdrawal from the consultation team

In a collaborative process, there are different possible levels of engagement for the community members. As for the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC), it encourages participation as much as possible. Even though this attitude aims to encourage the community to carry out an inventory and cultural transmission project by and for itself, it is not possible to achieve everything using a participatory approach. The role that the consultation team must play is precisely to enable and facilitate the engagement of the greatest possible amount of people in a project. A consultation process implies certain moments of participatory work, but it also implies moments of withdrawal from the consultation team which are needed to process the acquired material and ensure the continuation of the process. The larger the scope of the project and the more participants are involved, the more these moments of withdrawal are necessary to ensure the integration of individual contributions into the overall process.

# Behaviour

Ethical protocol, diplomacy, informed commitment and responsibility of representation



It can sometimes seem difficult to participate in dialogue with representatives of the governance structures. Those in positions of authority are often very busy and the hierarchal levels are well-defined and must be respected, which makes it so that the "machine" is cumbersome and slow to respond. As things develop, someone will eventually end up passing off the consultation team to someone else, and the project will have to be presented once again to an appointed delegate who, in turn, will end up finding another replacement because they themselves are too busy. Thus, sometimes the person with whom the consultation team eventually ends up working is far removed from the first person to be contacted. However, while this approach may seem long, unnecessarily complex and actually a mere formality, it is actually of paramount importance; it should not be neglected, and all correspondences should be tracked in order to be able to demonstrate that the ethical and diplomatic protocols were observed.

A community consultation process often involves visiting a community and the participation of its members in various activities. Also, regardless of the nature or context of the project, it is important to constantly keep the diplomatic and ethical concerns in mind and act accordingly. In any society, structures of representation, authority and governance are in place; they must be respected. These concerns also apply to each participant in response to a history of oppression or negligence with respect to minorities. If a community's participation is desired, it is necessary to honour and respect this participation and definitely not take it for granted, while considering them as partners.

## Respect and collaboration: receiving the community's approval and working with a delegate

A collaborative project involves the collaboration of multiple stakeholders who probably each have their own governance structure. Also, from the start of the project, it is essential to properly identify and respect these governing bodies including those in positions of authority (elected representatives, administrative councils, etc.). The first step therefore consists of making contact with these authorities in order to, on the one hand, present the project and obtain their approval to continue and, on the other hand, to foster a collaborative relationship based on the delegation of a cultural representative by the community. Close collaboration with this "delegate", who is legitimately recognized within the sphere of governance, will ensure a stronger footing in the community as well as a better adaptation of the activities to the context.

## Spirit of the collaboration: the interests of each

Certain points are important to emphasize in order to ensure good participation on behalf of the participants in the consultation activities. In a collaborative approach, each stakeholder should find beneficial to apply the process, which can result from a local initiative as well as external pressure. In the latter case, it is essential that all participants adhere to the process and make it their own. To that end, the "initiators" of the project must make every effort to demonstrate to each stakeholder the merits of the collective process as well as the advantages and benefits that may derive from it. The participants must not be there to "serve" or "do a favour" for the consultation team. The process, facilitated by the consultation team, must be rewarding for all parties involved while being beneficial to everyone.



## FAQ: A TOOL FOR UNDERSTANDING THE ETHICAL CONDUCT OF RESEARCH AND THE RIGHTS OF ABORIGINAL PARTICIPANTS

### MARIE-PIERRE BOUSQUET

Associate Professor  
Department of Anthropology  
Université de Montréal  
marie-pierre.bousquet@umontreal.ca

### BRYN WILLIAMS-JONES

Associate Professor  
Bioethics Program  
Department of Social and Preventive  
Medicine  
Université de Montréal  
bryn.williams-jones@umontreal.ca

Research involving humans in Canada is governed by a number of guidelines, including the 2<sup>nd</sup> edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2, 2014) and the *First Nations of Quebec and Labrador Research Protocol* (2005). These documents are intended to protect research participants and promote good research practices. The first includes a chapter on research with Aboriginal peoples. These documents are intended to guide the practice of researchers and to ensure the good research of conduct. They are therefore directed primarily at researchers rather than research participants.

It is thus likely that most members of First Nations are not familiar with these documents. As a result, they are not aware of their rights as research participants or of the obligations that researchers have towards them.

They also do not necessarily know what the objectives of research are; for example, that not all research is intended to benefit participants. Often, the main benefit of research is the acquisition of new knowledge for the scientific com-

munity and, more broadly, for society. Finally, members of First Nations do not always know, like most non-academics, how research is constructed. It usually starts with a research question asked by a professor or a student, and then a research project is developed, that is to say, a document that includes a literature review, a description of the methods, a justification of the relevance of the issue, the schedule, the expected benefits, as well as ethical considerations regarding the participants and their communities. To conduct the proposed research, researchers usually apply for public funding (they enrol in competitions where only a small percentage of the projects will actually be funded).

Research takes time, is expensive and largely financed by public funds. It is subject to ethical, academic and administrative regulations. First, from the standpoint of ethics, any project involving human beings (whether in the social sciences, health sciences or life sciences) and conducted by researchers at Canadian universities must be evaluated by a research ethics board (REB) before the research can begin. A REB is composed of a member knowledgeable in ethics, a member knowledgeable in



law, public representatives and members with relevant expertise in relation to the projects being evaluated. REBs are required to follow the TCPS2, which guides their evaluation<sup>1</sup>. The purpose of a REB is to ensure that the research is properly conducted and that the participants are protected. The members must take into consideration the particularities of the project, its context, as well as the participants and communities involved. For the project to be properly evaluated, it is the researcher's responsibility to submit – in addition to his or her research project – a description of the methods used to find the participants, to inform them as best as possible (in plain language) what will be required of them, and to obtain their consent. After the evaluation, if everything is correct, the REB issues a certificate of ethics approval that authorizes the researcher to begin the research. Ethics certificates first appeared in the 1990s in Canada and gradually became mandatory. Today, no research with human participants may be conducted by a Canadian researcher without a certificate of ethics approval, whether the research is conducted in Canada or in another country.

From the scientific point of view, researchers also have obligations that involve the rigor of their analysis, the relevance of their methods (consultation group, interviews, biological samples, statistics, etc.) and the neutrality of their starting position: they should not decide in advance what they will find or be influenced by political or ideological

considerations. They have an obligation to disseminate their research results through means such as oral presentations, publication in scientific journals and, increasingly, more popular forms of communication such as movies, blogs, video clips, leaflets, etc.

Finally, from an administrative point of view, funds are managed through the financial services of academic institutions (a relatively stringent bureaucracy). Research rarely yields direct financial benefits to researchers outside the wages paid by their institution (excluding students who, at best, receive scholarships, and at worst, use funds they themselves have accumulated). Collaboration between researchers from different departments and different institutions is becoming more common; working in a team can facilitate the creation of innovative projects but also makes managing time, finances and personnel more complex.

Research with members of First Nations falls within the general context of academic research, but also has features that are recognized by the TCPS2 and researchers. Such research was born in a colonial context, but has evolved in recent decades towards a more collaborative and participatory model. First Nations participants are no longer mere subjects. If they wish, they can become more involved than in the past and in some contexts, participate in all phases of the research, from its beginning until its completion, in consultation and collaboration with the researchers. To be

involved to the full extent of their interest, Aboriginal people must be knowledgeable about their rights, the way research is conducted and the obligations of researchers.

In this document, we offer a simple and effective tool for transferring knowledge about research, in the familiar form of Frequently Asked Questions (FAQ). Each answer to a question takes into account the codes of politeness and ethics specific to First Nations as well as those of researchers, and is supported by references to relevant sources for further information, in particular the key sections of the TCPS2.

The choice of questions is based on the field research experience of Marie-Pierre Bousquet from working with Algonquin populations (particularly Anicinabek)<sup>2</sup> and the specialization in research ethics of Bryn Williams-Jones. The goal is not to try to anticipate every possible question, but rather to address those that most frequently arose during our research and activities as REB members.

1. This does not prevent researchers working with Aboriginal people who submit research projects to REBs from consulting and following the *First Nations of Quebec and Labrador Research Protocol*.
2. M.-P. Bousquet is an anthropologist. She lived for a year in an Anicinabek community (Algonquin) in 1996, and has since made numerous research trips to Anicinabek, Innu and Abenaki communities.

## FAQ

### Question

#### **1. I didn't really understand what the research project is about. What can I do?**

Researchers have an obligation to inform you of all the elements necessary for you to make an "informed" decision about whether or not you will participate in the project. They must tell you what the risks and benefits associated with the project are for your First Nation in general and for you personally.

Researchers often use words that are specialized or complicated, but they must inform you using language that everyone can understand.

You must have the time to reflect and be able to ask the researchers any questions you have before you make your decision. If questions remain that are still not clear to you, your decision cannot be "informed." In short, researchers must make it possible for you to understand what they are researching.

If you feel more comfortable in the language of your nation, you can ask researchers to translate all their documents into your language and you can even request an interpreter.

#### **2. I don't dare to withdraw from the research because I gave my word or my consent, but I've changed my mind since then. What can I do?**

Giving your word is very important in Aboriginal communities. Changing your mind does not mean that you're not a person of your word. Giving consent to research is not a question of giving your word. You agree to participate in a research activity voluntarily and nobody will think that it is a question of honour.

You have the right to withdraw in the middle of the research project without having to justify yourself. You do not need to give your reasons. Nobody has the right to harm you because you have changed your mind.

#### **3. I do not see how the research project will serve the community. Does the researcher have an obligation to do research that will be useful? Are there going to be personal benefits?**

In Aboriginal communities, it is often said "we cannot know where we're going if we do not know where we came from." Generating knowledge that looks, at first, to be of no use, can help us know either where we are going or where we came from, or both. In other words, knowledge is rarely useless.

### References

**Chapter 3**, Art. 3.2, TCPS2

**Chapter 3**, Art. 3.1 and 3.3, TCPS2

**Chapter 9**, Art. 9.13, TCPS2

## Question

## References

Often, research has a potential for benefits down the road: you do not necessarily see the consequences. However, it also happens that research is initiated for more immediate or direct benefits: for example, professional training, development of research capacity, hiring people locally, or even documenting community needs so that politicians take these into account.

Researchers do not have an obligation to do research that will benefit you or your community. You can tell them about what research you would like to see conducted, but they do not have to take this into account. If their research doesn't interest you or if you feel that it will be a waste of your time, you are not required to participate.

### **4. Who must give permission for research to be conducted in the community?**

Researchers must contact the community's authorities, that is to say, the people that most people consider to be authorities, official representatives or the most competent people. It may be the tribal council, band council, elders council or a religious congregation (if the research involves a group of believers). It depends on the subject and the research context. The best for researchers is when everyone knows that they want to do some research. The researchers need to be mindful of how things work in the community.

**Chapter 9**, Art. 9.1 to 9.3,  
TCPS2

### **5. I would like to participate in the research project, but my council doesn't want to. Can I go against their opinion?**

In Innu traditional cultures, Atikamekw, Eeyou, Anicinabek, etc., leaders had no right to force anyone to do anything. The principle of letting the band members be independent in their decisions was very important. Also, individuals were first of all responsible for themselves: you had to be able to take care of yourself, to make personal decisions, to be able to stand in solidarity with others. People should respect the decisions of others.

**Chapter 9**, Art. 9.1 to 9.7,  
TCPS2

Canadian law also protects your freedom, which is a fundamental principle of the state and society.

Researchers have an obligation, where possible, to seek the participation of the community in general. Research conducted in collaboration with the community has the best chance of succeeding and meeting the standards of First Nations. When researchers arrive in communities where there are divisions, they must take into account the views of all groups, who often have different interests.

Any decision to participate in a research project, even if it has implications for the community, remains an individual responsibility.

## Question

### **6. I'm already participating in a research project. Can I talk to another researcher?**

Yes, you can talk to another researcher. Your participation in a research project is voluntary. Nothing binds you to a project; you may decide to stop participating in a project whenever you want. Researchers cannot blame you: you have to feel free.

## References

**Chapter 3**, Art. 3.1, TCPS2

### **7. I received a gift for participating in the research. If I want to withdraw, do I have to give it back?**

No, you do not have to return gifts or compensation offered by researchers. These gifts are a way of recognizing your participation and thanking you for the time spent with them. Sometimes these gifts are a way to repay the costs of your participation in the project (travel, meals, etc.). Normally, all of this should have been explained to you in the consent form.

**Chapter 3** and **Chapter 7**, TCPS2

The researcher should not put you in a situation where you feel obliged to participate because it would be in the interest of the community. This would create a real conflict of interest for the individual and the community. However, this conflict of interest can be managed through an agreement with the community where the benefit is explained before the participants are recruited. There should not be an imbalance between the person who has the resources and those who need them. For example, if a community has been extensively studied for a medical condition like diabetes, but received nothing in return, people will not necessarily want to participate in a new research project on the subject. The researcher may be tempted to ask people if there would be something they would like, for instance, a new school. If the construction of the school is conditional on participation in the research, it is improper influence. On the other hand, if construction of the school has begun before the start of the research and is included in an agreement, it constitutes a legitimate sharing of benefits.

Researchers are not supposed to offer gifts (or other benefits) that could unduly influence a person's choice to accept or continue to participate in research. In addition, strongly influencing participants can skew the research results or encourage behaviours that are known to be problematic. For example, if a researcher is interested in online gambling, he or she would not offer scratch cards or launch a competition to win something that connects to the Internet (tablet, computer). It is legitimate to recognize a participant's contribution with a gift, in cash or other form: gift card, object, etc. If the researcher is interested in eating behaviours or sports, he or she could encourage healthy lifestyles by giving participants a fruit basket or a bicycle. Certainly, a bicycle is expensive and can be seen as a way to influence the participant, but considering the health benefit to the individual, this gift can be justified.

## Question

## References

### 8. How does it work if I live in town? What happens if I don't have ties to my community anymore?

When researchers want to do research in an urban area, it is recommended that they contact the communities to which the people they are targeting belong, or Aboriginal organizations present in the city, such as a friendship centre, a centre for the development of Aboriginal human resources, etc. The aim is to ensure that recruitment is handled properly and in a way that takes into account cultural differences. The goal is not that band councils or other agencies decide instead of individuals.

Ultimately, each person is responsible for making their own choice. If you find that a research project is interesting, you can agree to participate without needing approval from anyone. It is up to the researcher to pay attention and see what may be the extent of the participation of the community.

**Chapter 9**, Art. 9.1 and 9.2, TCPS2

### 9. Do I have to sign a form to give my consent?

Usually, signing a consent form is required, because it is a way of documenting the informed consent of a participant. The form also provides the participant with a summary of the project, a description of what he or she is being asked to do as part of the project, the risks and benefits associated with participation as well as phone numbers and email addresses for contacting the researcher or his or her institution. Lastly, it reaffirms the participant's right to withdraw.

However, the signing of a document can be seen as offensive in certain contexts. In many Aboriginal communities, the giving of one's word is already a form of agreement that respects the rules of courtesy and ethics. Signing a paper may also be evocative of the colonial past, when contracts imposed obligations on the participants. Trying to get someone to sign can be offensive when the participant does not master reading and writing. Finally, among people with an oral tradition, the required consent may be given orally, out of respect for the community's customs and practices. The researcher will then present the contents of the document orally and leave a written copy in case the participant would like to verify the content of the consent given, or have a phone number or email.

It is important to note that a consent form is in no way a contract. It is a way to keep a written record. Remember that participants may change their minds whenever they wish, even though they earlier agreed to be part of the research project.

**Chapter 9**, Art. 9.8 and **Chapter 3**, Art. 3.12, TCPS2

### 10. If I'm having a hard time because the questions have stirred up bad memories, what can the researcher do for me?

The core values of research ethics include respect for people and concern for the well-being of participants. Respect is a core value in Aboriginal societies, which makes it even more important to the researchers.

**Chapter 2**, section B and **Chapter 9**, section B, TCPS2

## Question

## References

The researcher has an obligation to anticipate the risk of consequences to the participants, including the possibility that bad memories may be stirred up. These risks should be prevented, as much as possible, and specialized support should be provided to participants if needed. This could take the form of a hotline for psychological help, contact numbers for social workers, the presence of a family member who will ensure that everything is ok with you, etc.

Researchers do not have an obligation to be the person to provide support since they are not necessarily skilled in this area. Some researchers, such as psychologists and social workers, have been trained to help people, but this is not always the case.

That research can bring out emotions is not always bad; sometimes it helps when we are able to tell someone what is in our hearts and thus share something that we've been keeping inside. As a participant, you can ask to speak to someone from outside the community (e.g., a research assistant you do not know) if you do not want to say some things out loud in front of people you know. You can also ask to speak to someone in the community, if you feel more comfortable with someone who is part of your entourage.

### **11. What will be done with my contribution to the research (e.g., words, biological data)?**

The researchers will use your contribution to conduct their research. The information you provide will be kept for several years. It can be analyzed by various methods, depending on the project, the research subject and the discipline of the researcher.

Suppose that the researcher interviews you, asks you questions, gets you to talk about a certain subject or fill out a questionnaire. After that, the researcher might identify sub-themes you touched on, see what words you used or count the number of times you spoke about a specific topic, etc. Since there are many ways to analyze what someone says, if the researcher is working with a team, other people who have different perspectives might analyze what you said. Ultimately, your words will appear in the research results as exact quotes or in statistical form. They may also be included in generalizations made in comparison to what other people may have said. At all times, the researcher is committed to protecting your privacy. The researcher may not divulge your name or other things that identify you without your permission.

You might participate in health research where you give a biological sample: saliva, blood, etc. In general, this kind of research also collects medical information that provides a context for the analysis of your sample. In this situation, as in all others, the protection of confidentiality is taken very seriously. In the vast majority of cases, your data will be anonymized and generalized.

## Chapter 2, TCPS2

## 12. Who owns the results of the research?

Your experience of participating in research will go a lot better if you feel from the outset that you can trust the researcher and that your data will be treated in a respectful and appropriate manner. If you do not trust the researcher, do not participate, since all the ethical principles governing the relationship between researcher and participant (respect, autonomy, justice, etc.) are thereby called into question.

The researcher must use your data for the purpose that was indicated in the informed consent document. This includes commercial uses (patents, new technology, etc.). If another use is conceived of, the researcher must ask permission from the research ethics board and, in some cases, the participants (when people are alive and can be contacted, that is, when the data has not been made anonymous).

Research generates a lot of data that may be useful to researchers, but that can also create certain problems for participants if the data comes from the community. Consider these examples:

- A researcher is interested in rituals. If he or she publishes a description of a ritual, non-Aboriginal people could possibly try to use this knowledge for their own financial gain. Canadian law on intellectual property would not protect such information. How can abuses be avoided? It becomes essential to establish an agreement with the researcher that explicitly indicates who owns the intellectual property rights to the rituals, what information can be shared and with whom (e.g., some information is communicated only within the community, other information can be communicated to a wider audience).
- A researcher is interested in elders' hunting songs. This is personal knowledge (and may even belong to a family). A hunter is usually selective about who he gives his songs to. The researcher and the participant must agree on how this knowledge can be shared: does the hunter agree that his songs will be recorded? If so, is it only the researcher who can listen to the recording, or can it be broadcast? Who gets copies of the recordings?
- A researcher is interested in medicinal plants. Sharing knowledge about these plants may give rise to legitimate fears: large-scale exploitation, habitat destruction, and application for pharmaceutical patents on the active molecules of the plants without sharing royalties with the community. In this context it is important to establish clear agreements on the use and transmission of knowledge. For example, precise knowledge about the plants (i.e., where they grow) might be prohibited from being published. If there is the possibility of developing a drug, the researcher can negotiate with the community a contract that explicitly documents the sharing of future benefits (royalties, training, infrastructure, etc.).

The issue of data sharing and ownership is complex and there is not unanimity either among First Nations or among researchers about how to approach the issue. It is up to you to decide what you want to do. Some communities are demanding the application of the OCAPT<sup>TM</sup> principles (ownership, control, access and possession), which are approved by the First Nations Information Governance Centre. These principles might apply to your situation, but they are general formulations and do not deal with specifics. In practice, there are many kinds of studies to which they

**Chapter 9**, Art. 9.13, 9.18 to 9.20, TCPS2; OCAP<sup>TM</sup>

do not apply very well (e.g., in social sciences where people talk about their personal lives). In some contexts, if applied to the letter, these principles may work against the idea of respect for the participant, especially by challenging the protection of confidentiality. As well, they may impose responsibilities on the communities that are unsustainable (e.g., active participation in all phases of research), which may prevent them from participating in research that could benefit them (due to lack of resources, staff, knowledge or resources). However, the spirit of the document is important and valid, and is outlined in Chapter 9 of the TCPS2, specifically that the researcher must ensure that the community is involved to the full extent that they wish to be in research that concerns them.

**13. I would like to know the results of the research project. Does the researcher have an obligation to show them to me?**

It depends on what is meant by “results.” The researcher collects data, which then must be analyzed and interpreted. The results provided before the end of the analysis are considered preliminary. They may be communicated in progress reports that summarize the main lines of the data already collected, but this depends on the agreements that have been concluded with the researcher, which can be negotiated individually or by communities.

It is very rare that the researcher will reveal the raw data, as there is normally a commitment to protect the anonymity of participants. However, with the approval of the participants, personal information may be shared as long as it does not harm anyone.

Before the end of the project, a researcher who works with a community is committed to providing an opportunity for community representatives to participate in the interpretation of research results and their public presentation.

At the end of a project, it has become increasingly the norm that the researcher submits a final report to the community. The results can also be communicated in various forms: websites, oral presentations, scientific papers, etc. It is important that the researcher presents the results in the clearest language possible.

It is very important to know that research takes time: it may be several years between data collection, analysis and final presentation of results.

**Chapter 9**, Art. 9.17, TCPS2

**14. Researchers from other countries do not always know what an ethics certificate is. They don't ask our consent. Are they required to comply with ethical principles of research in Quebec?**

The TCPS2 applies to all Canadian researchers working in institutions subject to this policy (such as universities). Canadian researchers, even when their research is conducted in other countries, must respect the TCPS2.

**Chapter 2**, section A, TCPS2

## Question

## References

However, foreign researchers are not subject to the guidelines of the TCPS2. You can demand that these researchers appear before a research ethics board before agreeing to participate in their project (either you indicate which board, or they must find one for themselves). You can also require them to read and comply with the *First Nations of Quebec and Labrador Research Protocol* (2005).

Researchers, regardless of their nationality, must in all cases comply with the provincial and federal laws in force.

### **15. I find that the researcher does not understand our way of thinking. In my culture, it's not appropriate to say so. I don't want to be rude, so how can I make him understand?**

**Chapter 9**, Art. 9.8,  
TCPS2

Western researchers do not always understand Aboriginal codes of conduct because their values or ways of communicating differ from those of Aboriginal people. For example, they do not necessarily understand that cancelling an appointment, postponing a meeting several times or not responding to emails can be a way of telling them that you do not want to participate in their research project. Some may think that Aboriginal people are not trustworthy. Similarly, in the standards of Western behaviour, it can be considered disrespectful not to look someone in the eye. In addition, within a research context, it is common that the researcher will have prepared a lot of questions. However, in many Aboriginal codes of conduct it is considered rude to look someone in the eyes or ask a lot of questions.

Therefore, you have two choices:

1. You want them to understand your ways of doing things and you explain the difference between their behaviour and yours. The researcher will then adapt;
2. You adopt their ways of being and you tell them things directly.

It is important to ensure that both parties understand each other and work to avoid misunderstandings in order to establish a good collaboration.

## CONCLUSION

Research in Canada is governed by principles directly related to the values of Aboriginal communities: respect for the autonomy of the individual (whose research participation should always be voluntary), concern for their well-being and justice. The key document in Canada is the TCPS2, which contains an entire chapter (Chapter 9) on the particular considerations relevant to Aboriginal participants and communities. Researchers and REBs have an obligation to read this entire document. It was developed in the tradition of the great international documents that provide guidelines for the conduct of all research with humans (e.g., the Declaration of Helsinki, adopted in 1964, which is an official document of the World Medical Association). The TCPS2 is an excellent starting point for researchers and communities who want to conduct successful and mutually beneficial collaborative projects.

If the will of the community is to act as a true partner in the research project, it is essential to understand the nature of research in all its complexity: research takes time, money, highly qualified staff, administrative tasks, etc. It is therefore important to recognize that the interests of researchers and communities are not always the same. You can, a priori, trust the institutions that employ researchers,

but that trust should not be blind. It is your responsibility to ensure that the research project has an ethics certificate, to be critical, to ask good questions and to ensure that they all receive satisfactory and clear answers. It is also your responsibility to negotiate the terms of your collaboration and participation. If you want your community to participate more actively in the research that concerns it, it must invest resources. It will take a research office and qualified personnel who can both evaluate projects and negotiate agreements to ensure that research is conducted for the well-being of the community and in accordance with its customs and values.

To ensure the proper conduct of research in an Aboriginal community or with Aboriginal participants, it is essential that the interests and values of each party are transparent. Dialogue is a very effective way to arrive at a common understanding and to avoid misunderstandings. These understandings are strengthened by written agreements, a recommended step. Implementing these ethical principles encourages more collaborative research and avoids reproducing colonial models of conducting research. Ultimately, the goal of research is to advance knowledge for the common good by respecting the interests of participants and communities.



## RECOMMENDED READINGS

ASSEMBLY OF FIRST NATIONS OF QUEBEC AND LABRADOR. June 2005. *First Nations of Quebec and Labrador Research Protocol*. [http://www.cdrhpnq.qc.ca/afnql\\_research\\_protocol/full/protocol\\_en\\_full.pdf](http://www.cdrhpnq.qc.ca/afnql_research_protocol/full/protocol_en_full.pdf)

CARON, N. 2006. "Soigner les patients autochtones: offrir des services culturellement appropriés," *Perspectives du Collège royal*, 3(2): 19-23. [http://www.med.uottawa.ca/sim/data/Images/Aboriginal\\_care\\_Caron\\_f.pdf](http://www.med.uottawa.ca/sim/data/Images/Aboriginal_care_Caron_f.pdf)

OTTAWA, P.-É. 2012. "L'éthique comme outil de respect de soi-même et des autres (entrevue)," *Éthique publique*, 14(1) (<http://ethiquepublique.revues.org/981>).

PANEL ON RESEARCH ETHICS. 2014. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), Ottawa. (<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/>)

MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX DU QUÉBEC. 2012. "Formation en éthique de la recherche," Tutorial. (<http://didacticiel.ethique.msss.gouv.qc.ca/>)

ZIMMERMAN, S. 2012. "La Recherche visant les Premières Nations, les Inuits ou les Métis du Canada." Webinar, Groupe en éthique de la recherche. (<http://sshrc.adobeconnect.com/p7s2iartnqg/>)

## MORE ON THIS SUBJECT: SCIENTIFIC TEXTS

ASSELIN, H. and S. BASILE. 2012. "Éthique de la recherche avec les peuples autochtones," *Éthique publique*, 14(1) (<http://ethiquepublique.revues.org/959>).

BRANT CASTELLANO, M. 2004. "Ethics of Aboriginal Research," *Journal of Aboriginal Health*, January: 98-114. ([http://archives.algomau.ca/main/sites/default/files/2012-25\\_003\\_007.pdf](http://archives.algomau.ca/main/sites/default/files/2012-25_003_007.pdf))

CHAREST, P. 2005. "Les assistants de recherche amérindiens en tant que médiateurs culturels : expériences en milieux innu et atikamekw du Québec," *Études/Inuit/Studies*, 29(1-2): 115-129. ([http://classiques.uqac.ca/contemporains/charest\\_paul/assistants\\_de\\_recherche/assistants\\_de\\_recherche\\_texte.html](http://classiques.uqac.ca/contemporains/charest_paul/assistants_de_recherche/assistants_de_recherche_texte.html))

DESMARAIS, F. 2006. "Consentement préalable, libre et éclairé des Peuples autochtones en droit international: la nécessaire redéfinition de son cadre conceptuel," *Revue québécoise de droit international* 19(1): 161-209. ([http://rs.sqdi.org/volumes/19.1\\_desmarais.pdf](http://rs.sqdi.org/volumes/19.1_desmarais.pdf))

ETHIER, B. 2010. "Terrain de recherche en milieu autochtone: la participation radicale du chercheur à l'ère de la recherche collaborative," *Altérités* 7(2): 118-135. ([http://www.alterites.ca/vol7no2/pdf/72\\_Ethier\\_2010.pdf](http://www.alterites.ca/vol7no2/pdf/72_Ethier_2010.pdf))

JÉRÔME, L. 2008. "L'anthropologie à l'épreuve de la décolonisation de la recherche dans les études autochtones: Un terrain politique en contexte atikamekw," *Anthropologie et Sociétés* 32(3): 179-196. (<http://www.erudit.org/revue/as/2008/v32/n3/029723ar.html>)

INUIT TAPIIRIT KANATAMI (ITK) and NUNAVUT RESEARCH INSTITUTE (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. 38 p.

ROSENTHAL, J. 2006. "Politics, Culture, and Governance in the Development of Prior Informed Consent in Indigenous Communities," *Current Anthropology* 47(1): 119-128. (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3619215/>)

# THE NUNATUKAVUT MODEL OF RESEARCH OVERSIGHT: INNOVATION THROUGH COLLABORATION

## FERN BRUNGER

Associate Professor of Health Care Ethics, Division of Community Health and Humanities, Faculty of Medicine, Memorial University, 300 Prince Philip Drive, St. John's, Newfoundland, A1B 3V6, Canada, fbrunger@mun.ca.

## JULIE BULL

PhD student, Interdisciplinary Studies, University of New Brunswick; Member of NunatuKavut, julierbull@gmail.com.

## DARLENE WALL

Social Sector Manager and Member, NunatuKavut, dwall@nunatukavut.ca.

The goal of our research was to determine the best approach for implementing and managing a system of Indigenous governance of health research in communities with complex and multiple political and cultural jurisdictions.<sup>1</sup> To that end, we set up a system of research oversight for the NunatuKavut Community Council (NCC), an organization representing the southern Inuit of Labrador, and performed a critical examination of that process to make recommendations for best practices.

This paper presents the policies and procedures developed specifically for NunatuKavut. Through our background research and findings, we illustrate the complexities of navigating the research review system in a context of multiple jurisdictions and types of review. We furthermore provide clear explanations and justification for the 'researcher roadmap' we developed. We conclude by reflecting on our methodological strategies, which placed the focus on the knowledge of community members and resulted in a model for innovation in researcher-community collaboration.

## 1. CONTEXT

NunatuKavut means "our ancient land." It is the territory of the 6,000 southern Inuit of Labrador. The southern Inuit (formerly known as the Labrador Métis) are a people of mixed European and Inuit ancestry who live in the small communities along the coast of central and southern Labrador, from Lake Melville to the Strait of Belle Isle.

A combination of three events culminating in 2010 produced a unique context for research, allowing us to 'experiment' with best practices. First, the NCC—then the Labrador Métis Nation—began to mobilize politically, re-emphasizing the community's Inuit identity and seeking a land claims agreement. As part of that process, the NCC also sought to adopt a more proactive role for identifying health research needs and engaging researchers within the community. Second, in the province of Newfoundland and Labrador, legislation was enacted to establish a provincial Health Research Ethics Authority (Government of Newfoundland and Labrador, 2011). Until then, the Labrador-Grenfell regional health authority's research ethics board,



1. This research is supported by the Canadian Institutes of Health Research (#106542) Brunger (PI), J. Bull, J. Graham, D. Pullman, D. Wall, C. Weijer (Co-Investigators), *The Labrador Inuit-Métis Research Ethics Project: An experiment in Aboriginal governance of health research in complex communities.*

which included representation from the Innu, Inuit and Métis groups, had been responsible for ensuring that research was appropriate to the region. The creation of the provincial Health Research Ethics Authority meant that the research ethics board no longer conducted ethics reviews; that work was relegated to a centralized provincial Health Research Ethics Board (HREB). This put an end to the formal local (Labrador-based) ethics review of health research, thus placing a greater onus of responsibility on the Indigenous communities for determining whether the research being proposed on their territory and with their membership was acceptable to the community. Moreover, the Health Research Ethics Authority's centralized HREB required community review and approval prior to granting ethics clearance. This mobilized the community to seek ways to develop a more rigorous system of research review and oversight. Third, the Tri Council Policy Statement was revised to include a new chapter on guidelines for research involving Canada's Indigenous communities (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010) that also required that communities be consulted before research could be approved by a research ethics board. The three changes together both enabled and justified NunatuKavut's efforts to create a more rigorous system of research oversight.

## 2. METHOD

Our research to re-design and implement NunatuKavut's system of research review and oversight was innovative in three ways. First, we created an explicit division of labour into two research sub-teams: a community-based team and an academic team. Both teams conducted their work separately and sequentially such that the community work was prioritized and the academic work was driven by the community team. Key to that process was Bull's position as both a member of NunatuKavut and an academic. Second, the PI (Brunger) worked on behalf of the NCC (under Wall) to set up the ethics review process; in her capacity as anthropologist, she researched the process, and in her capacity as ethicist and Chair of the provincial HREB, she navigated between the needs of the two systems. Third, we employed and simultaneously researched a partnership model that privileged the authority of community "lay" members as knowledge producers. This decolonizing approach (Smith, 1999) felt very natural for us. The project idea had been inspired by Bull, then an upper-level undergraduate student, during a 2006 Indigenous community-led workshop in Labrador, in which communities addressed researchers, explained their health research needs, and engaged researchers in potential collaborations.<sup>2</sup> Subsequently, Brunger applied for funding to support Bull's Master's thesis, the pilot research for and foundation of the current study (Brunger & Bull, 2011). Wall had been engaged since the earlier pilot study and gradually assumed

more responsibility during the writing of the grant application that led to this project. Brunger, who had no desire to become a non-Aboriginal "expert" in Aboriginal studies, happily took full direction from Wall with regard to NCC needs and perspectives throughout the project. Working together, we assessed requirements for and designed the process; implemented, monitored and evaluated the system; put recommendations in place; and implemented the final process.

## 3. THE NUNATUKAVUT RESEARCH ADVISORY COMMITTEE PROCESS

The NunatuKavut Community Council's Research Advisory Committee (NCC-RAC) was established in 2006. It is responsible for the review of all research involving the membership of NunatuKavut or conducted on NunatuKavut lands. The NCC-RAC was established by the NunatuKavut Community Council and is accountable to the NCC executive. Between 2010 and 2013, the committee reviewed approximately 10 to 15 applications per year.

The revised NCC-RAC process that resulted from this research was introduced in January 2013. The application is divided into three sections: (A) information about the study, which is a brief form to be submitted by the researcher to determine or confirm that NCC-RAC review is necessary; (B) the application

2. *Community Health Research in Labrador: Listening, Learning, and Working Together*, Labrador Aboriginal Health Research Committee sponsored workshop, Happy Valley-Goose Bay, Labrador, 2006.

itself; and (C) the community-specific application detailing the expectations for each community engaged in the research. The application includes the types of questions that normally appear on typical REB applications, but places a greater emphasis on the anticipated demands on community's economic, social and cultural resources, including the specific expectations of community collaborators and community-based participants (NunatuKavut Community Council Research Advisory Committee, 2013a).

### 3.1 WHICH REVIEW COMES FIRST?

Navigating multiple reviews was described as a confusing experience by researchers. They were receiving conflicting messages from various communities and REBs about which review should happen first. For example, was REB approval required in order to approach an Aboriginal community for review and approval, or was Aboriginal community review and approval a prerequisite for REB review?

While it made sense in theory for the REB to hold off on its review and approval until it received confirmation of community support for the research, early analysis of this approach made it clear that it was unjust, as it removed some of the burden from the REB only to place it squarely on the community. Indeed, we (the NunatuKavut Research Advisory Committee and the HREB) had

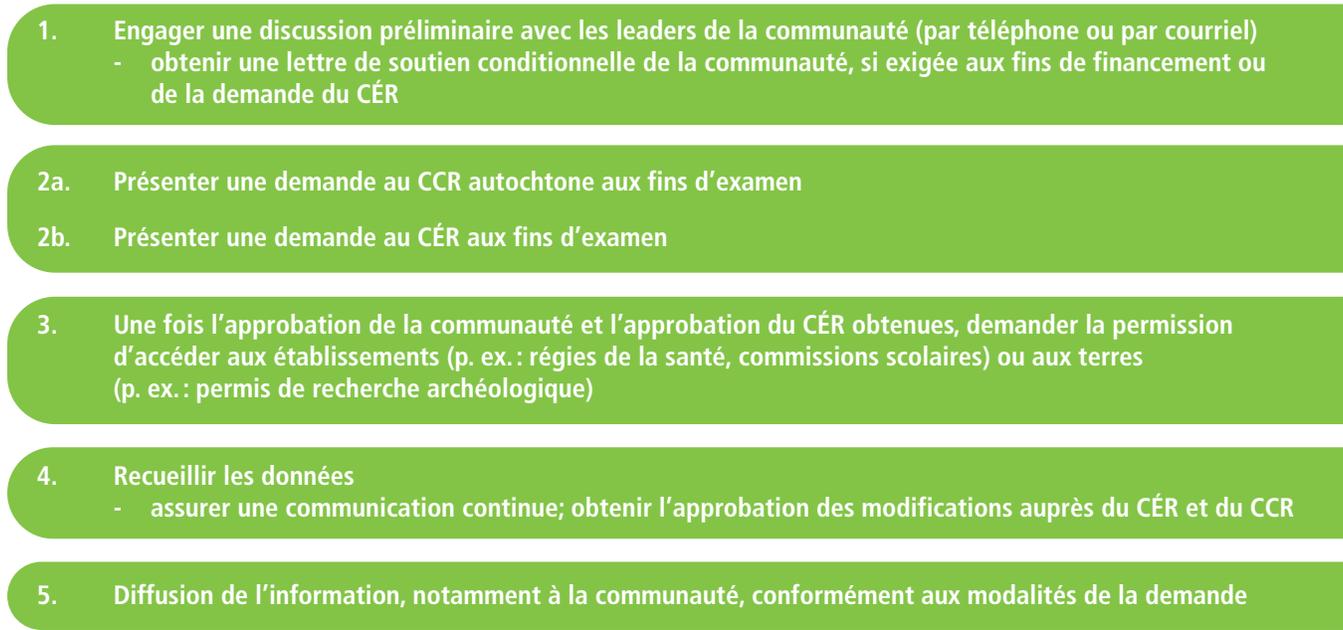
begun with the approach of applying what intuitively—and in keeping with the 2006 Canadian Institutes of Health Research guidelines (Canadian Institutes of Health Research, 2010)—seemed to be a “gold standard” of having community review and approval in place before ethics approval was granted. However, this inadvertently served to place the burden of rigorous ethics review on the under-resourced community review committee. The community was suddenly responsible for picking up on the potential risks (which the researcher would subsequently minimize by making alterations to the methods prior to submission to the REB), a task that normally would have fallen to the REB. In other words, the heaviest lifting, normally assumed by the REB, was being done by the community research advisory committee (RAC). To remedy the situation, we switched the order; we

had the REB do its work and had the researcher address the changes before the submission to the community RAC. This significantly reduced the workload of the community RAC, but introduced a new problem: With this approach, any changes requested by the community then had to be returned to the REB as an amendment for review and approval, adding an additional step for the researcher and the REB. However, as the priority lay with lightening the burden for the community RAC, and given the minimal additional effort required of the REB and researcher, this approach was felt to be the most appropriate.<sup>3</sup> A researcher guidance document was created and posted on the NCC website next to the application form, and presented instructions using a “roadmap” diagram (Figure 1, p.4) (NunatuKavut Community Council Research Advisory Committee, 2013b).



3. For the provincial HREB and for researchers, this process does introduce some confusion since not all Aboriginal community RACs share that approach; some require their own review to be conducted with approval in place prior to the researcher submitting to the REB. For researchers whose studies involve multiple Aboriginal RACs, this means that the REB itself must be flexible and ready to accommodate different (sometimes contradictory) approaches to which review comes first within a single application to the REB.

**Figure 1. NunatuKavut Research Advisory Committee process for community review and approval**



### 3.2 THE DISTINCTION BETWEEN ETHICS REVIEW AND COMMUNITY REVIEW

Determining which review comes first hinges on the distinction between community review and REB review. We created terms of reference for the NCC-RAC that clearly established the role of the RAC and the parameters of its work (NunatuKavut Community Council Research Advisory Committee, 2013c).

#### Excerpt from NCC-RAC Terms of Reference:

The powers of the NCC-RAC

To ensure that research involving the NunatuKavut peoples and lands is:

- 1) Conducted in a manner that is appropriate to the spiritual, cultural, social and environmental context of the NunatuKavut people
- 2) In keeping with the needs, expectations and values of the NunatuKavut

- 3) Conducted in keeping with the principles of OCAP (ownership, control, access and possession) (First Nations Information Governance Centre, 2013; Schnarch, 2004); and
- 4) Approved by a research ethics board, when required OR by funders

The tasks of the NCC-RAC

#### 1. Review of academic research proposals

- To review research for its acceptability and determine whether the proposed research: (a) is appropriate as submitted, (b) requires revision, or (c) is inappropriate for or harmful to the NunatuKavut community
- To assist researchers with developing a proposal, by commenting on and making recommendation for modification of research projects to meet community appropriateness

#### 2. Liaison between researchers and NunatuKavut membership

- To negotiate researcher-community agreements
- To collaborate in research, with the level and type of collaboration varying depending on the researcher-community agreement
- To assist researchers, for example by identifying potential communities and individuals for participation, with the level and type of assistance varying depending on the nature of the collaboration
- To provide information and advice to researchers and community members
- To identify research needs and priorities and make that the information available to researchers

### 3. Assistance to NCC staff researchers

- To review NCC research proposals and research contracts for appropriateness to NunatuKavut membership

### 4. Administration of research

- To maintain a registry of research
- To liaise with HREA and research ethics boards
- To liaise with other Aboriginal research review committees and other research approval bodies

### 3.3 THE DISTINCTION BETWEEN COMMUNITY SUPPORT AND COMMUNITY APPROVAL

The processes surrounding the RAC and the REB have been a source of confusion for researchers conducting research engaging Indigenous communities in Newfoundland and Labrador in general (that is, beyond NunatuKavut). For the REB to proceed with the review and approval stage, how does one determine *whose* authority constitutes community “support?” An elected official of one particular community within the Aboriginal community? A community-based research collaborator? A member of the governing body representing the broader Aboriginal community? Or must it be a formal approval letter from the RAC itself?

Researchers and REBs understandably do not always appreciate the distinction between a community collaborator’s letter of support-in-principle, a letter of support from an Aboriginal appointed official, and a letter of RAC approval following a formal community review and

approval process. Within the jurisdiction of NunatuKavut, the process was very straightforward and easy to navigate. The NCC-RAC had, from its early days, clearly defined and conveyed lines of authority and accountability. The NunatuKavut Council does not give letters of support for research, but directs the RAC Chair to provide those letters. Community members who are approached by researchers to collaborate communicate informally with the RAC Chair. All research goes through a formal review process by the RAC. So for the southern Inuit, in all research (not just that related to health and social issues), the system has worked efficiently.

Under the revamped NCC-RAC, this standard of practice was established as formal process for NunatuKavut. Our novel idea was the introduction of a formalized RAC consultation and ‘support-in-principle’ process—a process separate from the approval itself—at the design stage. Researchers are directed to telephone or email the NCC-RAC Chair early on in the design of their research in order to determine with whom to speak within the community and how to collaborate on the design of the study. By designating the community’s RAC as the explicit entry point into the community, the researcher has a greater ease of access to collaborators and resources within the community early in the design phase (NunatuKavut Community Council Research Advisory Committee, 2013b).

### Excerpt from NCC-RAC Guidelines for Community Engagement with NunatuKavut:

Steps in the process of community engagement

#### i) Preliminary discussion

The preliminary discussion is an informal email or telephone call by the researcher to the RAC Chair, to introduce the possibility of a research application. The purpose of the preliminary discussion is for the researcher to:

- a. Introduce the researcher and the project to the NCC-RAC Chair
- b. Ensure that a proposed topic is appropriate for submission
- c. Have an opportunity to ask questions and clarify any steps in the process of review
- d. Receive help with identifying communities or research support persons, as part of the early design phase of the research

Following that discussion, the researcher is invited to complete the form “Initial Application – Section A.”

### 3.4 THE DISTINCTION BETWEEN COMMUNITY COLLABORATION WITH RESEARCHERS AND COMMUNITY REVIEW OF FORMAL (ALREADY DESIGNED) PROPOSALS

The confusion over RAC review compared to community collaboration poses unique challenges for graduate students conducting research engaging Indigenous communities. We heard heart-breaking stories of students who approached communities, preliminary proposal in hand, ready to begin the process of discussing community needs

in order to co-design a study, only to be given a flat out “no.”

Indeed, in the case of the students we interviewed, a complete proposal was required early in their academic program. Students therefore submitted what they considered to be tentative proposals (developed to meet academic requirements) to the community RAC to receive feedback on the community needs/wants in order to develop a “real” proposal for submission to the RAC. In other words, the students submitted their proposals not as a formal submission to the RAC for an ethics review, but rather as a means for initiating dialogue; their proposals were meant to generate community support, cultivate a relationship and serve as a springboard for collaboration on the research, for instance in the development of the final proposal based on the community’s input. However, from the community RAC perspective, the submission of a proposal by a researcher with no prior contact or relationship was an affront to the principle of collaborative research, resulting in the project’s outright rejection.

The problem never occurred with NunatuKavut because the research review process was understood to function as a relationship building process as well, rather than solely exist for research approval purposes. Our research, by demonstrating that such an approach avoided situations where researchers were turned down because of the lack of prior contact, highlighted this process of relationship building and explicitly built it into the review process (as indicated in the terms of reference excerpt, above).

### 3.5 REMOTE COMMUNITY MEMBERS VS CENTRAL COMMUNITY OFFICIALS

Who represents or speaks for community perspectives (in the municipal sense) in cases where communities represented by the RAC are scattered across remote geographical areas? Two concerns were expressed by community members situated geographically far from the NCC-RAC site. First, the RAC may not be aware of particular social, economic, geographic, or political factors specific to the local community, which could affect the appropriateness of the research in that community. Second, community members may form solid research collaborations important to their own community that may be deemed unimportant or inappropriate by the central RAC and declined for official approval. Although this issue was not encountered on NunatuKavut territory, it was reported to have occurred in another Aboriginal jurisdiction.

We addressed this problem by creating a “Community” attachment to the RAC application (NunatuKavut Community Council Research Advisory Committee, 2013a).

#### Excerpt from *Application to Conduct Research and Consultations in the Territory of NunatuKavut*:

#### Section C – Community Specific Application

(only applicable to research that is community-based and conducted in communities other than Happy Valley-Goose Bay)

The Community Specific Application should be completed for each commu-

nity that will be involved with the research. The information should be specific to members of that community, and contain information tailored specifically for them. Think of this as an opportunity to get the community as excited about your research as you are! Please remember to keep this information readable for a layperson (grade 6 or lower is appropriate).

*Length: 1-2 pages.*

Information required:

- Title of research
- Layperson abstract
- Description of how community members will be asked to participate. Possibilities include but are not limited to:
  - Research participant
  - Research facilitator [volunteer]
  - Possible duties: Introduce potential participants; drive researcher to communities; set up town hall meetings; translate; arrange accommodations
  - Research advisor [volunteer]
- Possible duties: Sit on advisory board; be informally available to advise, educate, and guide researcher
  - Research assistant [paid and trained]
- Possible duties: Conduct survey; organize data
  - Contract researcher [paid contract to NCC]
  - Possible duties: Paid by company (mining, hydro, province) to design and conduct environmental impact assessment
  - Research initiator [NCC receives grant, recruits academic researcher]

### 3.6 WHEN IS AN INSIDER CONSIDERED A GENUINE INSIDER FOR PURPOSES OF BEING EXEMPT FROM REB REVIEW?

If a project is conceived, designed, and conducted by the NCC *for its own purposes*, then this constitutes quality improvement or program evaluation and is not 'research' requiring review by an REB (TCPS2). While our research was underway, a large number of environmental impact assessments and one major health needs assessment were conducted by the NCC. This led to the question of whether the NCC-RAC should review its own research. The Council determined that given the high volume of environmental impact assessments being conducted at the request of mining companies, government departments and others, the review and approval of internal research was key to ensuring high standards and avoiding conflicts of interest in relation to remuneration by the stakeholders requesting the assessments.

Moreover, in debating whether to submit local research to RAC review, we faced an additional problem: university researchers who had been invited in by the community as partners in community-initiated research (as was the case for the health needs assessment) would need to submit to REB review and approval as academics; and their own REB review and approval is contingent on RAC approval (because it constitutes research involving an Aboriginal community). The practice of having all community-initiated internal research undergo RAC review resolved this conundrum as well.

### 3.7 THE COMPLEXITIES OF WHETHER AND WHEN COMMUNITY REVIEW IS NEEDED FOR RESEARCH THAT IS NOT SPECIFICALLY ABOUT ITS MEMBERSHIP

If research is conducted on the lands or with the membership of a particular Aboriginal government or territory, then that Aboriginal RAC must review and approve the research. In the case of NunatuKavut, however, there is not yet a formal recognition of the lands as being southern Inuit lands; moreover, communities are often mixed demographically, and may include southern Inuit, northern Inuit, people of Innu descent, and non-Indigenous families. Therefore, for research conducted on NunatuKavut land that does not specifically collect information about the southern Inuit (e.g., health research with no demographic information being collected), there would be no expectation of or obligation for researchers to obtain approval from the NCC-RAC.

The related question of whether RAC review is required when research may impact a particular community but falls outside of the Aboriginal RAC's jurisdiction—that is, where research may inadvertently reveal information about a particular Aboriginal community but the research does not specifically or intentionally target Aboriginal peoples—was also raised. Labrador's largest city, Happy Valley-Goose Bay, is home to Innu, Inuit, southern Inuit and non-Aboriginals. It is also the site of much of the health research conducted in the region. Some research includes demographic questions such as ancestry and thus may have implications for Aboriginal

communities; some research has no implications for specific Aboriginal communities; and other research specifically targets particular Aboriginal communities. The question of when, how, and whom to consult about the acceptability of the research from the perspective of a particular Aboriginal community is, then, particularly at play in the context of that town.

Given these complexities, the NCC-RAC introduced a "Notification of Research" option in order to manage potentially ambiguous research in terms of the resulting implications for NunatuKavut (NunatuKavut Community Council Research Advisory Committee, 2013d).

#### Excerpt from *Procedures for NCC-RAC Office Staff*:

Process for review:

The Chair reviews the submission and determines whether the proposed research is:

- (1) An inappropriate submission (no review required)
- (2) A notification of research (no review required)
- (3) An appropriate submission (review required)

#### (1) Inappropriate submission

**Used when:** Research does not involve NunatuKavut (inappropriate submission)

**Example:** Research is with Innu, not NunatuKavut

**Action:** Email from NCC-RAC Chair notifying researcher that no review is required by NCC-RAC. Notification will be sent within 2 weeks.

## (2) Notification of research

**Used when:** Research implicates NunatuKavut but does not involve NunatuKavut directly (see Appendix A, “Type 1 – Research that may implicate NunatuKavut”)

**Example:** A social worker is conducting research on family violence in Happy Valley-Goose Bay. She is not specifically focusing on NunatuKavut, but demographic information is being collected such that results may yield results that may have implications for NunatuKavut as a community.

**Action:** Email from NCC-RAC Chair notifying researcher that no review is required by NCC-RAC. Notification will be sent within 2 weeks. The researcher is expected to submit a final report as a courtesy. If circumstances change such that the research process or its results do involve NunatuKavut directly, then the researcher must inform the NCC-RAC in writing.

## (3) Appropriate Submission

**Action:** NCC-RAC Chair will email researcher with an invitation to submit the **Full Application – Section B**. Email invitation to submit full application will be sent to researcher within 2 weeks.

## 3.8 THE QUESTION OF COMMUNITY MONITORING AND OVERSIGHT

For the NunatuKavut RAC, an important missing piece in the review process was oversight of, and a proactive stance toward, what research is being done in the community. To respond to the need for direct oversight, a Database registry was designed with the help of the Health Systems Information and Management Service (HSIMS) of the Faculty of Medicine at Memorial University.

The intent of the registry was to capture the range and type of ongoing research as well as to identify whether and how the research was reviewed for ethics and community agenda/appropriateness, and whether and how the research outcome and dissemination was known to, and deemed to affect, the community. The registry is populated with previous research that has been reviewed by the NCC-RAC, and all new studies are inputted into the registry. The registry was designed so that NunatuKavut staff can perform annual statistical analyses of the data to determine what types of research are being conducted, by what types of researchers, who is controlling the purse strings, and whether the OCAP™ principles are being followed. Over time, the database will also be used to generate a portrait of existing gaps in research, information that can then be shared with researchers.<sup>4</sup> Moreover, the registry enables the NCC and researchers to clearly address and apply the OCAP™ principles. The registry contains a line item

that reads, “Access and Possession: Describe precisely what de-identified information is being retained for access by NCC and where NCC can access that information once the study is complete.”

## 4. CONCLUSION

We produced a strong evidence base for implementing an innovative and efficient community RAC process. Our novel idea was the introduction of a formalized RAC consultation and ‘support-in-principle’ process—a process separate from the approval itself—at the design stage. Our methodological strategies placed the focus on the knowledge of community members. This approach was key to our success. The use of the anthropologist/ethicist as both insider (co-developing and working with the system as a member of the RAC working under the authority of Wall) and outsider (researcher, academic, HREB Chair) enabled us to ensure that the NCC process segued with the provincial process. Bull, as both a member of NunatuKavut and an academic with expertise in Indigenous theory applied to research ethics, provided a critical gaze that encouraged us to remain faithful to a decolonizing approach to research collaboration. While Bull’s position effectively blurred the standard boundaries of academic vs community member, Wall’s position as co-Investigator and lead in the community-based sub-team successfully reversed that standard dichotomy. We attribute the success of our venture to that reversal.

4. Phase 2 of the database project involves HSIMS constructing a separate level of access, such that researchers applying to NCC will complete the on-line form to input their information directly to the database (in progress). A Phase 3 (under discussion with all parties) has been proposed by LAHRC. The database will become a pan-Labrador Aboriginal research database, managed by LAHRC with the infrastructural support of the Labrador Institute.

## REFERENCES

- BRUNGER, F., & BULL, J. (2011). Whose agenda is it? Regulating research ethics in the Labrador context. *Etudes/Inuit/Studies*, 35(1-2), 127-15.
- CANADIAN INSTITUTES OF HEALTH RESEARCH. (2010). *Guidelines for health research involving Aboriginal people*. Retrieved 03/31, 2013, from <http://www.cihr-irsc.gc.ca/e/29134.html>.
- CANADIAN INSTITUTES OF HEALTH RESEARCH, NATURAL SCIENCES AND ENGINEERING RESEARCH COUNCIL OF CANADA, AND SOCIAL SCIENCES AND HUMANITIES RESEARCH COUNCIL OF CANADA. (2010). *Tri-Council Policy Statement: Ethical conduct for research involving humans*, December 2010.
- FIRST NATIONS INFORMATION GOVERNANCE CENTRE. (2013). *The First Nations principles of OCAP™*. Retrieved 07/03, 2014, from <http://fnigc.ca/ocap>.
- NEWFOUNDLAND AND LABRADOR, *Health Research Ethics Authority Act*, SNL2006 CHAPTER H-1.2 (2011).
- NUNATUKAVUT COMMUNITY COUNCIL RESEARCH ADVISORY COMMITTEE. (2013a). *Application to conduct research and consultations in the territory of NunatuKavut*. Retrieved 03/31, 2014, from [http://www.nunatukavut.ca/home/files/pg/application\\_for\\_research\\_with\\_nunatukavut\\_january\\_2013-1.pdf](http://www.nunatukavut.ca/home/files/pg/application_for_research_with_nunatukavut_january_2013-1.pdf).
- NUNATUKAVUT COMMUNITY COUNCIL RESEARCH ADVISORY COMMITTEE. (2013b). *Guidelines for community engagement with NunatuKavut*. Retrieved 03/31, 2014, from [http://www.nunatukavut.ca/home/files/pg/guide\\_for\\_researchers.pdf](http://www.nunatukavut.ca/home/files/pg/guide_for_researchers.pdf).
- NUNATUKAVUT COMMUNITY COUNCIL RESEARCH ADVISORY COMMITTEE. (2013c). *NunatuKavut community council research advisory committee terms of reference*.
- NUNATUKAVUT COMMUNITY COUNCIL RESEARCH ADVISORY COMMITTEE. (2013d). *Procedures for NCC RAC office staff*.
- SCHNARCH, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research. *Journal of Aboriginal Health*, 1(1), 80-15.
- SMITH, L. T. (1999). *Decolonizing methodologies: Research and Indigenous peoples*. London: Zed Books.

# KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT CODE OF RESEARCH ETHICS: DEVELOPMENT AND APPLICATION

## TREENA DELORMIER

Ph.D., Alex M. McComber, M.Ed.,  
Ann C. Macaulay, CM MD FCFP

*“Research should support the empowerment of Kahnawá:ke to promote healthy lifestyles, wellness, self-esteem, and the Kanien’kehá:ka’s responsibility of caring for the Seven Generations.” (KSDPP Code of Research Ethics Policy Statement, 2007)*



## BACKGROUND

The Kahnawake Schools Diabetes Prevention Project Code of Research Ethics<sup>1</sup> was first developed in 1994-1995 to guide the then new Kahnawake Schools Diabetes Prevention Project (KSDPP) which is a partnership between the Kanien’kehá:ka (Mohawk) community of Kahnawà:ke, Quebec and academic researchers from neighbouring universities. In this community-based participatory research (M. Cargo & Mercer, 2008; Jagosh et al., 2012; LaVeaux & Christopher, 2009) partnership the community of Kahnawà:ke is represented through the KSDPP Community Advisory Board (CAB) whose membership comprises volunteers from community organizations, the community at large and an elder. The objective of KSDPP is to increase healthy lifestyles through healthy eating and physical activity among children and youth with the long term goal of preventing obesity and reducing the high prevalence of type 2 diabetes [www.ksdpp.org](http://www.ksdpp.org).

## CREATING THE KSDPP CODE OF RESEARCH ETHICS 1994-1995

In 1994-1995, when there were no national guidelines addressing ethical research with Indigenous communities, KSDPP recognized the need to ensure research would respect the community’s aspirations. At that time general conversations on community participation in research ethics were occurring among Indigenous communities particularly in the circumpolar north, and being echoed by other Indigenous organizations internationally (Kaufert et al., 1999). Many researchers also recognized the past injustices of ‘helicopter research’ when researchers had not involved communities in decision-making processes and communities had been stigmatized by the publication of negative results, to which they had no recourse (Brant-Castellano, 2004; Montour & Macaulay, 1988).

KSDPP recognized that the obligations of academic researchers and community members to this participatory health promotion research project were distinct and needed to be clearly laid out. The overarching goal was that ethical research principles should reflect traditional Kanien’kehá:ka governance and decision-making and be firmly rooted in

1. More information on KSDPP and the full KSDPP Code of Research Ethics document can be downloaded at [http://www.ksdpp.org/media/ksdpp\\_code\\_of\\_research\\_ethics2007.pdf](http://www.ksdpp.org/media/ksdpp_code_of_research_ethics2007.pdf)

the notion that knowledge created for Kahnawà:ke should also support the self-determination of the Kahnawakero:non (people of Kahnawà:ke).

Through an eight month process, community members and academic researchers discussed and learned about their mutual responsibilities, goals and aspirations while negotiating the principles to guide KSDPP research. This process was inspired by a Haudenosaunee (Iroquois) consensus-building model that strives for collective decision-making through mutual respect, listening and understanding differing perspectives. The resulting draft KSDPP Code of Research Ethics was reviewed by CAB members during a half-day workshop before being approved.

The KSDPP Code of Research Ethics guides the entire research process. This includes agreeing on the purpose of the research, defining research questions and objectives, deciding how data will be collected, managed, analyzed and interpreted, and how research findings are disseminated first within Kahnawà:ke and then externally at Indigenous and scientific conferences and in scientific journals (Macaulay et al., 1998).

### KSDPP CODE OF RESEARCH ETHICS REVISED 2007

*"The self-determination of the Kanien'kehá:ka of Kahnawà:ke to make decisions about research is recognized and respected. The academic researchers' obligation to contribute to knowledge creation in their discipline is recognized and respected." (KSDPP Code of Research Ethics Policy Statement, 2007)*

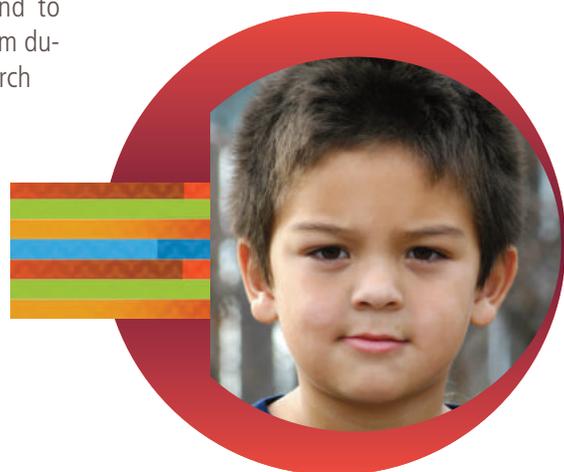
From 1994 through 2007, KSDPP conducted several significant research projects, brought new researchers to the project and had many post-graduate students conduct independent projects related to KSDPP topics in health promotion. The KSDPP Code of Research Ethics was referred to extensively to guide these new research partnerships and projects. As a result of these experiences, gaps in the KSDPP Code of Research Ethics were identified. To address the gaps, it was agreed by researchers and the CAB that the Code should be reviewed and updated. Modifications brought to the KSDPP Code of Research Ethics addressed the changing context of KSDPP including the accelerating revitalization of Kanien'kehá:ka culture and language within Kahnawà:ke, newly evolving ethical research guidelines (Assembly of First Nations of Quebec and Labrador, 2005; Brant-Castellano, 2004; Canadian Institute of Health Research, 2007; First Nations Centre, 2007; Schnarch, 2004), scholarship on Indigenous philosophy (Ermine 2007; Smylie et al., 2004), decolonizing methodologies

(L. Smith, 1999; 2012) and the developing emphasis on Indigenous knowledge translation (Estey, Smylie, & Macaulay, 2009) in research. The review was conducted by a team of community researchers with postgraduate research training, CAB members including an elder, and academic researchers. The committee met on a regular basis for eighteen months from 2005 to 2007 and the final draft was reviewed by the research team and reviewed and approved by the CAB.

The review and update resulted in strengthening the KSDPP Code of Research Ethics and the reaffirmation of the relevance of the principles. The new section linking Indigenous methodologies and Haudenosaunee philosophy with decolonizing methodologies (L. Smith, 1999; 2012) clearly explains these foundations for KSDPP research. The obligations of all the partners—the community researchers, the academic researchers and community members—were reviewed and reaffirmed. The collective rights of the community, in addition to the rights of individuals were emphasized. The review and approval process for ethically responsible research was expanded to outline the steps and key decision-making points to ensure that research was undertaken to benefit the community and to promote community capacity building. Procedures for the consent process for individuals, data collection, ownership and management (Schnarch, 2004), dissemination and publication of research results, and authorship guidelines were also expanded.

New sections added details for appointing an ombudsperson for each research project, the process for using secondary data, knowledge translation (Estey, Kmetc, & Reading, 2010; Smylie et al., 2004), multi-site research agreements, and included a researcher checklist outlining all the steps needed from beginning to end and a glossary of terms. In addition the revised Code included seven appendices outlining how the principles will be operationalized throughout the research process. The modifi-

cations addressed areas where more guidance was needed to respond to KSDPP’s evolving research program during the previous decade of research in Kahnawà:ke, in new partnerships with other Indigenous communities, and in training the numerous Indigenous and non-Indigenous postgraduate research students and fellows.



**Table 1. Highlighted Content from the KSDPP Code of Research Ethics**

Section	Relevance
Indigenous Methodologies and Haudenosaunee Philosophy (Appendix A)	This explains that ethical research uses respectful protocols, values Haudenosaunee ways of knowing in research, and outlines decolonizing methodologies.
Review and Approval Process for Ethically Responsible Research (Appendix B)	This is a multistage process that requires community consultation and community involvement. Ongoing consultation ensures that the research supports the principles of community based participatory research and respects the KSDPP Code of Research Ethics. It reiterates the need for all proposed research to be reviewed and approved by the KSDPP Research Team, the CAB and the appropriate University Institutional Review Board (IRB).
The Consent Process (Appendix C)	This recognizes that research must respect the rights and dignity of the community at a collective level and the people as individuals involved in the research.
KSDPP Ombudsperson	An ombudsperson is someone who can be contacted regarding questions by participants or community members about their rights, or any concerns arising in relation to a research project. The ombudsperson is usually a voluntary KSDPP CAB member.
Data Collection and Management	This reflects KSDPP’s responsibility for ensuring respect of Kahnawà:ke’s intellectual and cultural integrity; to ensure ownership, access, possession and control of data; and to ensure quality data management procedures.
Secondary Data Analysis	This section explained that researchers must always seek community approval for all secondary data analysis even in situations where, as outlined in the Code, researchers would not have to seek university IRB approval. The rationale for this was to ensure that the community is always aware of local research being undertaken and has the opportunity to discuss if and how secondary data analysis would likely result in beneficial findings for the community.





**Table 1. Highlighted Content from the KSDPP Code of Research Ethics (suite)**

Section	Relevance
Dissemination and Publication of Research Results (Appendix D)	This ensures that all research results and knowledge generated by KSDPP are presented, discussed and approved by any groups, organizations and/or communities participating in the research and the CAB, before the results are disseminated externally to the general public via local community media, scientific publications and conferences. KSDPP provides quarterly research updates to the Onkwata'karihtahtshera Health and Social Services Research Council (OHSSRC), the local body with the mandate to oversee all health and social services research in Kahnawà:ke. KSDPP and the KSDPP Code of Research Ethics existed prior to OHSSRC's creation in 1999. The OHSSRC recognizes the capacity and leadership of the KSDPP Community Advisory Board (CAB) to conduct ethical and respectful research in Kahnawake guided by the KSDPP Code of Research Ethics. The OHSSRC actually sought guidance from KSDPP's Code of Research Ethics when they developed their OHSSRC Regulations for Research in Kahnawake. A number of KSDPP community based researchers, including the first author, have been members of the OHSSRC. OHSSRC agreed that their approval is not required for KSDPP research proposals and projects.
Knowledge Translation (Appendix E)	This reflects the new thinking on knowledge translation, writings of Indigenous scholars on how Indigenous knowledge translation occurs and the goals of granting agencies that research should benefit health and health systems.
KSDPP Authorship Guidelines (Appendix F)	This is a combination of standard authorship requirements as set out by academic journals with an added category that allows authors to also be someone who "can provide essential expertise" (e.g., academic, indigenous knowledge, historical clarification, cultural relevancy, etc.)
Multi-site Research and Multi-site Research Agreement	This new section reflected KSDPP experiences in research partnerships with other Indigenous communities.
Researcher Checklist (Appendix G)	This outlines the specific items that a new researcher must fulfill in order to do research in the community. These include the review and approval process, dissemination process and return of data to KSDPP and the community.
Glossary of Terms	This assists everyone involved with any aspect of a research project to understand the technical terms that are commonly used in ethical guidelines and key words of the Kanien'keha (Mohawk) language.



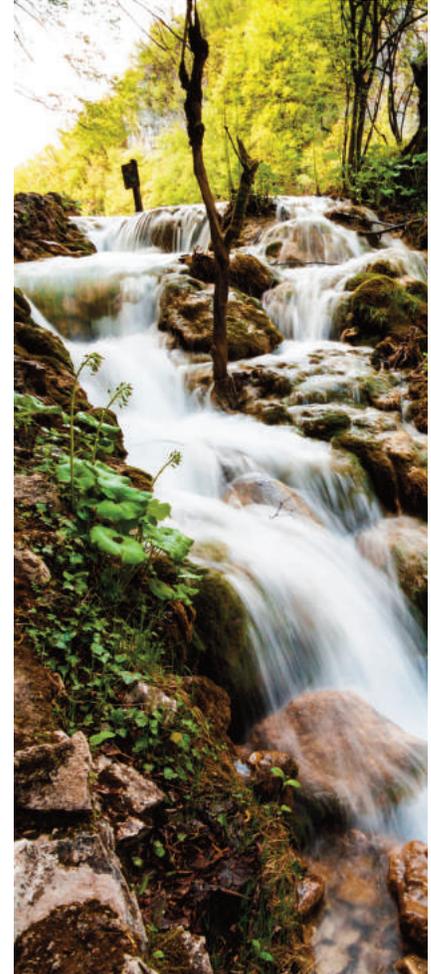
## IMPACT OF THE KSDPP CRE AND ETHICAL RESEARCH PRACTICE

The KSDPP Code of Research Ethics has been a critical guide over the last twenty years of KSDPP research. It has been adopted and adapted by many other Indigenous and non-Indigenous communities and organizations. We believe it has also contributed to the community ownership of KSDPP (M. Cargo et al., 2008; M. Cargo, Delormier, Lévesque, McComber, & Macaulay, 2011). National recognition came in 2010 when the Canadian Institutes of Health Research (CIHR) Partnership Award was given to KSDPP in recognition of a project that combined scientific rigor with cultural relevance and for its contribution to Indigenous research ethics. The Code of Research Ethics was also acknowledged by the CIHR Guidelines for Health Research Involving Aboriginal People (<http://www.cihr-irsc.gc.ca/e/29134.html>) (Canadian Institute of Health Research, 2007). These guidelines were developed under the leadership of the CIHR Institute of Aboriginal Peoples Health to guide Indigenous Research from 2007 to 2010. Since then all research with Indigenous Peoples that is funded by the three main Canadian granting agencies is guided by the Tri Council Policy Statement on the Ethical Conduct of Research Involving Humans with Chapter 9 dedicated to Research Involving the First Nations, Inuit and Métis People of Canada. This chapter outlines how researchers should partner with Indigenous communities, but does not prescribe the operationalized details that characterize the KSDPP Code of Research.

Ethics (<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/>)(CIHR, NSERC and SSHRC, 2014).

## CONCLUSION

Based on our experiences we recommend that Indigenous community-university partnerships develop written guidelines or codes of research ethics, as the discussions necessary to come to agreement bring increased clarity of the expertise, obligations, expectations and goals and also help to develop trust between the community and the researchers. Once research activities commence, guidelines provide all the partners with the principles and a clear, thorough, mutually-acceptable process for conducting the research and disseminating the results for the benefit of community and academia.



## REFERENCES

- ASSEMBLY OF FIRST NATIONS OF QUEBEC AND LABRADOR. (2005). First Nations of Quebec and Labrador Research Protocol.
- BRANT-CASTELLANO, M. (2004). Ethics of Aboriginal Research. *Journal of Aboriginal Health*(January), 98-114. Canadian Institute of Health Research. (2007). CIHR Guidelines for Health Research Involving Aboriginal People. Retrieved 15 April, 2013, from <http://www.cihr-irsc.gc.ca/e/29134.html>
- CARGO, M., DELORMIER, T., LEVESQUE, L., HORN-MILLER, K., MCCOMBER, A., & MACAULAY, A. C. (2008). Can the democratic ideal of participatory research be achieved? An inside look at an academic-indigenous community partnership. *Health Educ Res*, 23(4), 904-914.
- CARGO, M., DELORMIER, T., LÉVESQUE, L., MCCOMBER, A. M., & MACAULAY, A. C. (2011). Community Capacity as an "Inside Job": Evolution of Perceived Ownership Within a University-Aboriginal Community Partnership. *American Journal of Health Promotion*, 26(2), 96-100.
- CARGO, M., & MERCER, S. L. (2008). The value and challenges of participatory research: strengthening its practice. *Annu Rev Public Health*, 29, 325-350. doi: 10.1146/annurev.publhealth.29.091307.083824
- CIHR, NSERC And SSHRC (2014). *Tri-Council Policy Statement 2: Research Involving the First Nations, Inuit and Metis Peoples of Canada*. Government of Canada Retrieved from <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/>.
- ESTEY, E., KMETIC, A., & READING, J. (2010). Thinking about Aboriginal KT: Learning from the Network Environments for Aboriginal health Research British Columbia (NEARBC). *Canadian Journal of Public Health*, 101(1), 83-86.
- ESTEY, E., SMYLIE, J., & MACAULAY, A. C. (2009). Aboriginal Knowledge Translation Understanding and Respecting the Distinct Needs of Aboriginal Communities in Research. Retrieved June 2010, 2010, from <http://www.cihr-irsc.gc.ca/e/41392.html>
- FIRST NATIONS CENTRE. (2007). OCAP: Ownership, Access, Control & Possession. In A. o. F. N. Sanctioned by the First Nations Information Governance Committee (Ed.). Ottawa: National Aboriginal Health Organization.
- JAGOSH, J., MACAULAY, A. C., PLUYE, P., SALSBERG, J., BUSH, P. L., HENDERSON, J., . . . GREENHALGH, T. (2012). Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice. *Milbank Q*, 90(2), 311-346. doi: 10.1111/j.1468-0009.2012.00665.x
- KAUFERT, J., COMMANDA, L., ELIAS, B., GREY, R., YOUNG, T. K., & MASUZUMI, B. (1999). Evolving Participation of Aboriginal Communities in Health Research Ethics Review: The Impact of the Inuvik Workshop. *International Journal of Circumpolar Health*, 58(2), 134-144.
- LAVEAUX, D., & CHRISTOPHER, S. (2009). Contextualizing CBPR: Key principles of CBPR and the Indigenous research context. *Pimatisiwin*, 7(1), 1.
- MACAULAY, A. C., DELORMIER, T., MCCOMBER, A. M., CROSS, E. J., POTVIN, L. P., & PARADIS, G., E. A. (1998). Participatory research with native community of Kahnawake creates innovative Code of Research Ethics. *Can J Public Health*, 89(2), 105-108.
- MONTOUR, L. T., & MACAULAY, A. C. (1988). Returning research results to the Mohawk community. *Canadian Medical Association Journal*, 139, 201-202.
- SCHNARCH, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research. *Journal of Aboriginal Health*, 1(1), 80-95.
- SMITH, L. (1999). *Decolonizing Methodologies: Research and Indigenous peoples* (Vol. Zed Books).
- SMITH, L. (2012). *Decolonizing Methodologies: Research and Indigenous Peoples* (2 ed.). London; New York: Zed Books.
- SMYLIE, J., MARTIN, C. M., KAPLAN-MYRTH, N., STEELE, L., TAIT, C., & W., H. (2004). Knowledge translation and indigenous knowledge. *Int J Circumpolar Health*, 63(Suppl 2), 139-143.

# “WE SHOULDN’T BE AFRAID TO THINK SMALL”: ENGAGED ACCLIMATIZATION AS A RESEARCH PRINCIPLE IN AN ABORIGINAL CONTEXT

## CAROLINE DESBIENS

Professor  
Geography Department, Université Laval /  
caroline.desbiens@ggr.ulaval.ca

## IRÈNE HIRT

Researcher, Department of Geography  
and Environment  
University of Geneva / irene.hirt@unige.ch

## COMITÉ PATRIMOINE ILNU

(Innu Heritage Committee),  
Pekuakamiulnuatsh Takuhikan  
Mashteuiatsh, Québec (Canada) /  
stacy.bossum@mashteuiatsh.ca

## INTRODUCTION

In an article published in 2012, Grimwood et al. proposed the concept of “engaged acclimatization” to describe a participatory research approach that is intended to be gradual in nature, highly practical, and based on the step-by-step building of a research relationship where academic and community partners find it of mutual interest to pool their efforts. We tested this approach in the context of a research project entitled “Tshishipiminu : occupation ilnu de la rivière Péribonka et développement hydroélectrique” (Tshishipiminu: Innu occupation of the Peribonka River and hydroelectric development). During their initial meeting, the partners—a Université Laval professor, a researcher from the University of Geneva, and members of the Comité patrimoine ilnu (Innu Heritage Committee) of Pekuakamiulnuatsh Takuhikan reflected on the nature and scope of the data collection. They came to the conclusion that—as opposed to the academic trend where research projects tend to keep growing in terms of the size of the teams and the amount of money invested—they shouldn’t be afraid to buck this trend, and to

“think small” instead. It seemed that, in order to implement an ethical and participatory approach, they had to reverse the usual order by beginning with some fairly modest and applied research which, if the partnership proved to be satisfactory, could potentially be expanded into a larger project. It was also a question of reducing the size of the research team while attempting to increase the number of people affected by the project’s spin-offs. In order to enact these principles, the partners pursued a common objective: that of producing an exhibition in the form of information panels in a relatively short period of time, that is, within two years. The text that follows summarizes our experience so as to identify and describe the practices that were found to be effective in terms of both the scientific quality of the results and the building of an equitable partnership.

## TSHISHIPIMINU: THE CONTEXT

In the language of the people of Mashteuiatsh, *nehlueun* (a dialect of the Innu language), Tshishipiminu means “our river.” The watercourse at the heart of this research project has its source in the Otish mountains and crosses more than 450 kilometres before draining into Lac Saint-Jean. Whereas the river as a whole



is officially called the Peribonka, the Pekuakamiulnuatsh refer to it as Peli-paukau shipi (“where the water is cloudy”); several other place names stretching from its source to its mouth reflect the great variety of places and features that make up this living environment. The Peribonka is one of Québec’s most important heritage rivers: covering a surface area of 28,200 km<sup>2</sup>, its drainage basin structures the practices and culture associated with the use of the canoe, and the language and economy of the Pekuakamiulnuatsh.

Despite its occupation by several generations of Pekuakamiulnuatsh, in the twentieth century the river became the central axis of a vast network of hydroelectric energy production on which the aluminium industry, among others, and thus a large part of the Saguenay-Lac-Saint-Jean region’s economic development were based (Girard and Perron 1995; Massell 2011). The first hydroelectric installations (Lac Manouane and the Passes-Dangereuses reservoir, which were the property of the Alcan corporation) date from the 1940s, while the latest dam (Péribonka IV, built by Hydro-Québec) was put into service in 2008. Consequently, the impact of hydroelectric development has extended over several generations and follows other phases of territorial appropriation, including those linked to the fur monopoly, the establishment of the townships, agricultural colonization, the creation of the Mashteuatsh reserve and, more recently, the emergence of regional county municipalities (RCMs).

Placing the rights and interests of Aboriginal peoples at the forefront, the goal of the Tshishipiminu research project is to document and publicize the way that the Pekuakamiulnuatsh have occupied the territory of the Peribonka River, and how, after the building of the hydroelectric dams and their associated infrastructures, the Pekuakamiulnuatsh adapted their territorial practices in order to maintain and revitalize them. Even though our research is based on other studies carried out over the past several decades (Brassard 1983; CAM 1979; Charest 1980), such a task may seem enormous; this is why, by scaling down the work, the members of the team were able to take it on.

### RUSSIAN NESTING DOLLS

The first stage was to develop a smaller space of collaboration within an extended research structure. The Tshishipiminu project was in fact initially part of a much larger research context: that of the Tetawan CURA (Community-University Research Alliance) “Habiter le Nitassinan Mak Innu Assi – Paysages culturels, aménagement et gouvernance des milieux bâtis des collectivités innues du Québec” (Living in Nitassinan Mak Innu Assi—Cultural landscapes, development and governance of built environments in Québec Innu communities), which brought together regional land-use planning and development specialists and practitioners in the fields of architecture, planning, geography, anthropology, etc., coming from Innu communities and from a number of postsecondary institutions. The goal of the work connected with the Tetawan CURA was “to design a sustainable and

culturally appropriate built environment that is also oriented towards an increased autonomy in the development and management of housing”<sup>1</sup> [*our translation*]. Starting from the fact that hydroelectric development represents an entry point for understanding the spatial dynamics of reduction (Aboriginal) and expansion (non-Aboriginal)—as well as Aboriginal strategies to counter this destructuring of their ancestral lands—our work was part of the CURA research theme entitled “Cultural landscapes and representation.” The objective was to develop a multidimensional profile of the evolution of Innu cultural landscapes.

In both Québec and Canada, anyone involved in research in the Aboriginal context would have been quite familiar with the Community-University Research Alliance (CURA) program offered by the Social Sciences and Humanities Research Council of Canada (SSHRC), which was designed to encourage closer ties between community and practice milieus and academic and research spheres. Based on a knowledge mobilization approach, the aim of the program was to link up various local-scale actors possessing an in-depth understanding of their communities’ needs and priorities with academic researchers, who are generally associated with extensive knowledge production and transfer networks. So, by linking up various milieus and scales of analysis, the objective of the CURA program was to foster the development of innovative approaches, strategies and solutions to questions and issues connected with very specific contexts. Despite the fact that, after

1. Tetawan CURA: <http://www.tetawan.org/a-propos>. Accessed August 18, 2014.

roughly a decade of existence, the CURA program is no longer part of the SSHRC's programming, it did help to set up a partnership-oriented research culture in many social science disciplines: its spirit and methods can still be found in the funding opportunities offered today, which testifies to the paradigm shift that has gradually been developing in Canada.

Although the CURA program clearly represented an advance from the viewpoint of the implementation of research ethics, many researchers have encountered stumbling blocks in the practical application of this program. With regards to our own experience, one of these issues was that of a real democratization of the research process: a very difficult task, given the size of the Tetauan CURA. For the past several years, and in the course of reflection on the ethics of research in the Aboriginal milieu—and especially, in Québec, the ethics highlighted with the publication of the *First Nations of Quebec and Labrador Research Protocol* (APNQL 2014)—it has become apparent that this democratization might be perceived differently by academic and community milieus. Whereas many academic researchers have often focused on developing better strategies for the dissemination and appropriation of research results by potential “users” at the end of the data collection and analysis process, community milieus generally perceive their involvement as the starting point, and not the end point, of any research process that concerns them.

Without denying the advances that have been made in the ethics of research in the Aboriginal context, many inconsistencies still remain in this area: while most social science researchers now adhere to the principles of “Ownership, control, access and possession” (OCAP) (Schnarch 2004), we need to be aware that applying these principles requires that local partners be involved at every stage of a research project, from its design to dissemination of the findings. Indeed, how can a community control an approach that it has not helped to define, based on its own tools and priorities, or supported in the various phases of its implementation? We ourselves quickly found that such an approach could not be achieved without close ties established, developed and maintained by a small team of people with the professional capacities and personal desire to commit to a common path, and for a sufficient period of time (Desbiens 2010).

Such a commitment cannot be shared in the same way by all of the people and institutions associated with a structure as vast as a CURA. Indeed, by nature, a CURA—or any other research structure based on the model of a network—often tends toward a widening of the circle, somewhat akin to the image of the waves generated by a stone thrown into a body of water. There are many advantages to such an outward reach of the network: the coming into contact with new actors; the multiplication of viewpoints; the diversification of knowledge; the raising of the awareness of a wider public; etc. However, such a strategy can sometimes lead to the weake-

ning of the interpersonal and human ties that are in fact at the basis of a research project, if the project is envisioned as a relationship first and foremost. In order to counter the problem of the weakening of ties between too many or too many different types of actors in a structure that could potentially grow indefinitely, the Tshishipiminu project opted for the drawing of a smaller circle. Although porous in nature, this circle proved to be a space of action that was just large enough to act in a direct and effective manner. The image of Russian nesting dolls describes this strategy quite well: as part of a potentially expandable whole, we formed a much smaller circle of people, places and approaches and thus regained the closeness needed for building and maintaining a good research relationship.

### A SMALL PROJECT WITH EXPANSIVE INTERFACES

Working with a small team and fewer means clearly affected the way that the research was performed, especially in terms of the data collection. The Tshishipiminu project did not claim to carry out “exhaustive” research but rather sought to find “expressive” ways of presenting the experience of the transformation of the land through hydroelectric development, as experienced by members of the Mashteuiatsh community. In order to go beyond the simple collecting of data and to instead see the collection/appropriation/dissemination activities as a “wheel in motion,” the primary objective of the research was to produce a “panel” exhibition. The archival research began in the spring of 2011; the interviews were conducted in the

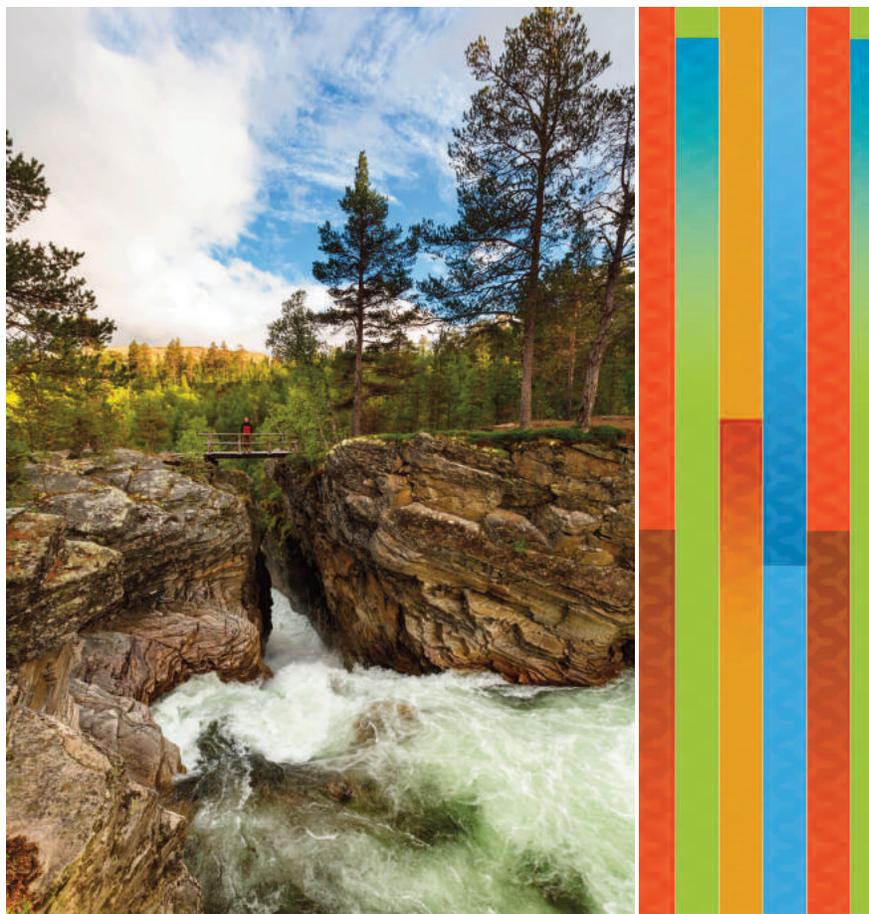


summers of 2011 and 2012; and the data analysis occurred in the fall of 2012 and winter of 2013 and continued with the designing of the panels from March to October 2013, culminating with the presentation of the exhibition *Tshishipiminu : occupation ilnu de la rivière Péribonka et développement hydroélectrique* (Tshishipiminu: Innu occupation of the Peribonka River and hydroelectric development) at the Mash-teuiatsh Native Museum from November 2013 to March 2014.

The interview process was conceived and planned together with the various partners, with the idea of involving people in the community who wanted to learn about interview techniques. Since an Aboriginal candidate could not be found at the time, this role was ultimately taken on by one of the researchers. In terms of the production of the exhibition, it is important to mention that it was designed as a fully-fledged research “method”—that is, a working approach—before being simply a means of dissemination. There were several reasons for adopting this approach. First, the exhibition made it possible to establish a very concrete frame of reference for the data collection, in order to curb the researchers’ undoubtedly professionally-conditioned tendency to accumulate data without regard for the constraints of data processing or dissemination to publics other than academic ones. Secondly, the exhibition acted as a filter and a common thread for selecting the appropriate themes, and hierarchizing and formatting the information. In this approach,

the reception of the work by the people of Mash-teuiatsh was necessarily at the forefront of the choices made in terms of how to represent the information: for example, who is speaking in this exhibition?<sup>2</sup> Which topics are likely to appeal to people? How can a proper balance be maintained between what is included and what is not included? Which themes should be avoided, and so on? In this regard, we soon learned, for example, that some aspects of the research might carry a heavy emotional

load for some members of the Mash-teuiatsh community, especially for families who lost their hunting and trapping territories when the most recent dam became operational in 2008 (Péribonka IV). Moreover, some aspects, such as people’s spiritual relationship with the land, might be of an intimate and private nature. It was therefore necessary to look together at which aspects could or could not be presented in the exhibition and, as the case may be, find the best ways of presenting the material.



2. We are grateful to Élisabeth Kaine, a professor and researcher at the Université du Québec à Chicoutimi, for having made us aware of the importance of this question.

Thirdly, the exhibition served as an end point, a mandatory rendez-vous, as it were, for work that—like any research—could have gone on indefinitely. It allowed us to rapidly disseminate the preliminary findings and, based on community members' comments and reactions, to determine the next stages of the project. This exercise also allowed us to clarify the roles of the various actors involved in the research (academic and community researchers, knowledge holders, heritage specialists, administrators, linguists, an archivist, a museologist, a cartographer, etc.) in order to define and consolidate the best possible structure for the pursuit of the partnership. The engaged acclimatization stage indeed proved to be a positive one, and the partners expressed the desire to continue with the work.

Ultimately, this small project nonetheless enabled us to determine the most promising interfaces for the future growth of the project. The toponymy of the Peribonka River in particular emerged as a theme that should be prioritized and linked up with work already under way in Mashteuiatsh. In this respect, participatory map-making could be another fruitful means of data collection. Similarly, the highlighting of heritage sites could lead to other initiatives, including heritage sites visits and discussions with the authorities in charge of the dams in order to increase access to the river for the Pekuakamiulnuatsh. In documenting another episode of the territorial appropriation of the Nitassinan (territory) of Mashteuiatsh, the project also adds other

perspectives on the evolution and development of the areas that are currently the focus of the territorial negotiations that have been under way since the signing of the Entente de principe d'ordre général (EPOG (Agreement-in-Principle of a General Nature) in 2004.

Another important lead that should be pursued is the promotion of the cultural visibility of the people of Mashteuiatsh on their Nitassinan. A brochure of the exhibition is currently being prepared, and the panels will be exhibited in other innu communities and regional museums, in parallel with the holding of various educational activities and events aimed at the sharing of information and exchanges with the general public. The work accomplished could also serve as the basis for the production of other information panels to be installed in strategic locations on the territory or to ultimately become part of viewing areas (belvederes) integrated into the hydroelectric facilities. Although a new application for funding from the SSHRC is planned, it should be noted that if there were to be no further funding, all of these extensions of the Tshishipiminu project could be carried out by using the means already available, and a little creativity, of course. This leads us to believe that, beyond the sums invested and the infrastructures mobilized, the time and personal investment of the researchers involved undoubtedly represent the most important capital for the continuation of the work (Desbiens 2012).

## CONCLUSION: ON THE SOCIAL AND SCIENTIFIC VALUE OF COLLABORATION BETWEEN RESEARCHERS AND COMMUNITIES

A few years before the widespread critical reflection on the role of the researcher and the ethics of research involving humans, the American science philosopher Donna Haraway warned us about the illusion of objectivity, which she referred to as the "god trick" often deployed by academic researchers: that is, the aspiration to see and know everything "from nowhere," in other words, without being observed oneself. Also noting the excesses of radical relativism, she proposed a middle ground, interwoven with connections: "We don't want to theorize the world, much less act within it, in terms of Global Systems, but we do need an earthwide network of connections, including the ability partially to translate knowledges among very different—and power-differentiated—communities" (Haraway 1988: 580). Haraway goes on to specify that: "The alternative to relativism is partial, locatable, critical knowledges sustaining the possibility of *webs of connections called solidarity in politics and shared conversations in epistemology*" (Haraway 1988: 584, our italics). In emphasizing the concept of "situated knowledge," all of Haraway's work asks a very pertinent question, which is: "How should one be positioned in order to see?" (1988: 588). In the context of the Tshishipiminu project, there is no doubt that it is the academic researchers' positioning within the social universe of Mashteuiatsh, at all stages of



the project, that fostered not only the positive reception of the research, but also the quality of the data produced. Our experience testifies to the fact that, as well as applying the principles of ethics, respect, equity, reciprocity and collaboration, participatory research is a structured method that enhances the scientific value of a project.

For her part, Québec anthropologist Carole Lévesque underlines another fundamental aspect of any collaborative research process, which is the idea of “living together”: “Research activities [are] a component of the idea of living together. From this perspective, one can talk about the co-production of knowledge as a tool for social change” (Lévesque 2012: 294) [our translation]. But she is careful to note that one needs to be able to distinguish between two current tendencies:

*Two main stances seem to be currently emerging from this new dynamics of interaction between academia and society: the first, more deterministic, position is tied to the objective of demonstrating the relevance of academic research based on its findings, and of promoting these findings. The second, more integrated, stance proposes that we review the very process of creating scientific knowledge. The terms of the rapprochement vary, depending on whether academia wants to inform and instruct society about its own accomplishments, or whether, on the contrary, it works together with society on shared and socially grounded issues. (Lévesque 2012: 291) [our translation]*

With regards to the ethics of Aboriginal research, what stands out here is the importance of putting researchers back in their place, as it were: that is, of acknowledging their (often very fictitious) hold over the modes of production and validation of knowledge, and putting them back into the social, political and cultural universe of which their knowledge is a part. Having the courage to “think small” represents one more step towards democratizing research and the products of this research. This enables a “collective intelligence” (Lévy 2003) to emerge, which, because it is the fruit of everyone’s contributions, belongs, by this very fact, to a greater number of people.

## REFERENCES

ASSEMBLÉE DES PREMIÈRES NATIONS DU QUÉBEC ET DU LABRADOR (APNQL). 2014. *Protocole de recherche des Premières Nations au Québec et au Labrador*. Online :

[https://www.cssspnql.com/docs/default-source/centre-de-documentation /francais\\_web.pdf?sfvrsn=2](https://www.cssspnql.com/docs/default-source/centre-de-documentation /francais_web.pdf?sfvrsn=2).

BRASSARD DENIS. 1983. *Nitassinan : Occupation et utilisation du territoire par les Montagnais de Pointe-Bleue*. Report submitted to the Atikamekw-Montagnais Council, Wendake.

CHAREST PAUL. 1980. Les barrages hydro-électriques en territoire montagnais et leurs effets sur les communautés amérindiennes, *Recherches amérindiennes au Québec* 9(4): 323-337.

CONSEIL ATTIKAMEK-MONTAGNAIS (CAM). 1979. Nishastanan Nitasinan (Notre terre, nous l'aimons et nous y tenons), *Recherches amérindiennes au Québec* 9(3): 171-182.

DESBIENS CAROLINE. 2012. Dix idées pour le Nord : un manifeste pour la nordicité, *Cahiers de Géographie du Québec* 56(159): 643-659.

DESBIENS CAROLINE. 2010. Step lightly, then move forward: exploring feminist directions for Northern research, *The Canadian Geographer/Le Géographe canadien* 54(4): 410-416.

EPOG 2004. *Entente de principe d'ordre général entre les premières nations de Mamuitun et de Nutashkuan et le gouvernement du Québec et le gouvernement du Canada*. En ligne :

<http://www.versuntraite.com/documentation/publications/EntentePrincipeInnus.pdf> (dernier accès 11 décembre 2014).

GIRARD CAMIL and NORMAND PERRON. 1995. *Histoire du Saguenay-Lac-Saint-Jean*. Montréal: Institut québécois de recherche sur la culture.

GRIMWOOD BRIAN, NANCY DOUBLE-  
DAY, GITA LAIDLER, SHAWN DONALD-  
SON and SYLVIE BLANGY. 2012. Engaged acclimatization: Towards responsible community-based research in Nunavut, *The Canadian Geographer/Le Géographe canadien* 56(2): 211-230.

HARAWAY DONNA. 1988. Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective, *Feminist Studies* 14(3): 575-599.

LÉVESQUE CAROLE. 2008. Cinq défis pour bâtir le rapprochement entre la recherche et la société, *Découvrir* (juin-juillet): 5.

LÉVESQUE CAROLE. 2012. La coproduction des connaissances en sciences sociales, in Miriam Fahmy (ed.), *L'État du Québec 2012*: 290-296. Montréal: Boréal.

LÉVY PIERRE. 2003. Le jeu de l'intelligence collective, *Sociétés* 79: 105-122.

MASSELL DAVID. 2011. Quebec hydro-politics: the Peribonka concessions of the Second World War. Montréal: McGill-Queen's University Press.

SCHNARCH BRIAN. 2004. Propriété, contrôle, accès et possession (PCAP) ou l'autodétermination appliquée à la recherche, *Journal de la santé autochtone* 1(1): 80-95.

# ETHICS OF PUBLIC CONSULTATIONS IN HEALTHCARE – LESSONS LEARNED FROM IYUUA AHTAAWIN HEALTH PLANNING WITH THE JAMES BAY CREE

## ADELINA FEO

Erg, MA Bioethics Program (candidate),  
Université de Montréal

### Acknowledgement to

Bryn Williams-Jones, Director  
of Bioethics Programs, Université  
de Montréal and Jill Elaine Torrie,  
Assistant Director of Public Health,  
Cree Board of Health and Social  
Services of James Bay, for revision  
and suggestions for improvement  
of the manuscript.

## INTRODUCTION

Citizen involvement in healthcare policy planning and resource allocation has been a standard in Canada since the mid-1990s (Mitton et al., 2009). Public consultation is a form of participation in decision making that allows members of the public to express their viewpoints, have their contributions listened to, and receive information on decisions for which they are not directly responsible (Litva et al., 2002). Public consultations are varied in scope – from private companies that inform the public about the impact of urban development – to public commissions that attempt to understand the public view on ethical issues or patient focus groups that relate the experience of healthcare delivery. In terms of healthcare, citizens are usually consulted to identify basic community values, help guide decisions on resource allocation and participate in the restructuring of services and governance (Abelson et al., 2003). Although the literature on public consultation is quite extensive regarding techniques and design, there seems to be no consensus on the when and how of public consultation or how the information gathered should be incorporated into public policy (Mitton et al. 2009, Shipley and Utz, 2012, Abelson et al. 2003).

The discussion on the ethics of how public consultation takes place, in practice, is virtually absent from the scientific literature. It is usually assumed that the act of seeking public opinion is an act of openness and benevolence. However, it may be construed that the act of speaking publicly about an issue can put participants at risk and that an ethical framework is necessary to protect them. Then, the question that arises is whether research ethics principles might offer some direction on how public consultations can and should be designed and conducted. The present article will ask the following questions:

- 1) Are research ethics principles appropriate for public consultations?
- 2) If they are, what principles apply specifically to public consultation?
- 3) What impact do such principles have on the planning and delivery of a public consultation?

To support this reflection, the Iiyuu Ahtaawin Health Planning (IAHP) process will be used. In 2011, the Grand Council of the Cree began a negotiation process with the First Nation and Inuit Branch of Health Canada. The purpose was to enter into a block-funding type of agreement that would allow more flexibility in allocating funds according to local health priorities. Health Canada agreed, conditional to a regional health



planning exercise taking place. The exercise would identify community assets, population health indicators and health concerns of the residents of the territory. This health planning exercise is scheduled to take place in the Cree territory of James Bay, Quebec, from 2013 to 2015. The goals of IAHP are to:

- 1) collaborate with existing regional initiatives by sharing information to prevent consultation fatigue;
- 2) partner with the communities and support local efforts to develop comprehensive Miyupimaatisiun (Health) Plans;
- 3) partner with regional entities to support community health plans; and,
- 4) support regional and local entities in creating a regional strategic plan for health.

In September 2013, a small working group met to identify the ethical considerations that would steer the process. This working group was made up of the Assistant Director of Public Health responsible for Surveillance, Evaluation, Research and Communications for the Cree Board of Health and Social Services of James Bay (CBHSSJB), a lawyer with experience in teaching bioethics and participating in ethics committees, as well as the author of the present article as Director of Allied Health Services and Quality Assurance for the CBHSSJB, due in part to her concurrent studies in bioethics. It was felt that the initial ethical basis for the IAHP did not reflect the reality of the Cree territory and was lacking in some dimensions. The reflection that occurred is the basis for this article.

## PUBLIC CONSULTATIONS AS RESEARCH

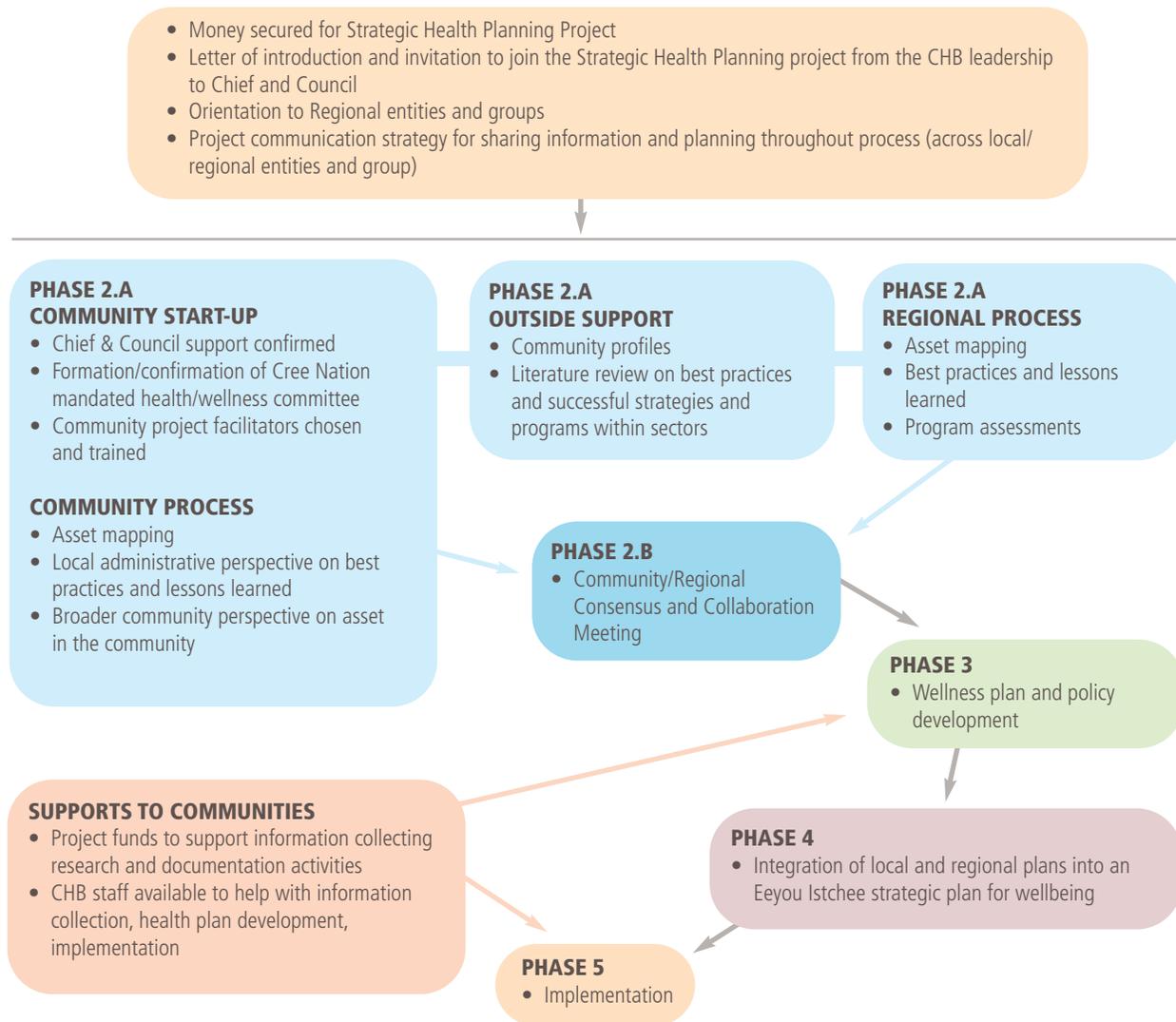
The first question that arises is whether there are enough similarities between public consultations and research to apply research ethics principles. Can we consider public consultations as research? It is difficult to really debate the question without delving deeply into the complex relationship between information, knowledge and science. One could write a whole thesis (in fact, one could write many!) on this very subject. What is science? What is the pursuit of knowledge and how does it differ from the simple gathering of information? These are all valid questions far beyond the scope of this article. *The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS-2) (2010) outlines the ethical principles applicable to most research conducted in Canada involving human participants. It defines research simply as: "... an undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation" (Ch.1, p.7).

Within this framework, two conditions must be met for a public consultation to qualify as research: the "extension of knowledge" and a "disciplined inquiry." The goal of IAHP as a health consultation is to have regional and local entities and groups collaborate to create a Cree regional strategic plan for *Miyupimaatisiun* (Health) based on community needs and assets, while engaging and supporting communities in the development of local health work plans and support structures. Public consultation can help health administrators gain

more information on an issue for which information is lacking. (Thurston et al. 2005) Public consultations are also an important source of information on possible solutions for health problems and of lessons learned in the past. Previous CBHSSJB consultations have outlined perceptions of health services (CBHSSJB, 2008), impacts of climate change (Foro et al., 2013) and the experience of people living with cancer (CBHSSJB, 2014 unpublished). It is an important way to obtain public opinions on services that should receive funding allocation, on the functioning of programs and on specific criteria for eligibility to services (Mitton et al. 2009). It can be stated, with some degree of confidence, that public consultations do extend knowledge on the healthcare concerns of a target population.

With the second criteria of "disciplined inquiry," public consultations are usually a labour-intensive process involving logistics and planning. A number of methods can be used to promote public involvement: surveys, focus groups, regular public meetings, visioning exercises, citizen juries and organized agency structures such as Regional Health councils (Thurston et al, 2005, Quantz & Thurston, 2006). These techniques are described quite extensively by these authors and are similar to, if not the same as, those used in the conduct of research. Most agree that a number of techniques are preferable to address any one question in public consultations and that the method used must be responsive to the population and the political context in which the

## Brief outline of the liyuu Ahtaawin Health Planning (IAHP) initiative (2013 to 2016)



discussion takes place (Shiple & Utz, 2012). Take the example of liyuu Ahtaawin: in Figure 1, we can see that it is a multi-step process involving many actors, a systematic collection of information through consultation of different target groups and the use of epidemiological data and asset mapping of community resources. A process like IAHP arguably satisfies the two requirements

of extension of knowledge and systematic inquiry. A structured approach can help in documenting the population's perceived causes of disease or use of health services. Through this, attention may be directed at addressing these issues not obtainable through an epidemiological or strictly expert approach. For example, public consultation might reveal that the disappearance of the tra-

ditional way of life is perceived as the main cause of chronic disease. It would then follow that interventions geared towards improving medical frontline services might not garner the same measure of success as a more culturally adapted approach. This is the type of tangible knowledge that can be acquired through public consultation.

Consultations use research-type methods, but the overall purpose of the action differs from that of research, which tends towards generalization and the quest for knowledge for its own sake. Not all public consultations can be described as having a research-type goal. Regular town hall meetings that discuss urban planning projects allow citizen concerns to be voiced; however, their purpose is not to learn more about the population itself. The IAHP uses a focus group approach to gain insight on health matters as they are perceived by the population. Focus groups have been identified as good means to obtain a broader range of citizen perceptions instead of surveys (Vogt, King & King, 2004). Vogt, King and King (2004) argue that “at their most effective, focus groups generate qualitative data that complements the current knowledge base on most subjects,” supporting structured information collection that a focus group-based public consultation like IAHP can generate. The information gathered through public consultation complements the information gathered through the rigours of the research process.

The other source of unease with regard to qualifying public consultations as research is the question of dissemination to the scientific community. Properly conducted research tends to be the “property” of academic circles. There is a clear academic structure at work: there is a principal investigator, usually with a university centre affiliation, whose main goal is to publish in scien-

tific journals for the advancement of knowledge; the information is disseminated in academic conferences and through university lectures, passed on to graduate students and so on. The question of inclusion of the new knowledge within the scientific community is one of the key features of this pursuit.

Conversely, the outcomes of public consultations rarely end up in scientific journals. They are usually transcribed and published in the form of consultation or commission reports and published on the web by the organizations (private or public) responsible for them (e.g., Foro et al., 2013). In the case of IAHP, a plain language report is planned for distribution at the end of the consultation. It will be sent to all participants and possibly disseminated on local media. Ensuing reports and health plans will also be available on the web sites of the Cree Board of Health and Social Services of James Bay, as well as the Cree Nation Government. This is not the standard method of distribution for what is usually termed research. However, it is highly conceivable that a researcher interested in the perception of health in First Nation populations could have access to this information for use in his own research. For all these reasons, I argue that there is enough of a parallel between public consultations and research as defined by the TCPS-2 to allow us to delve further into the evaluation of whether research ethics principles are suitable for this type of process.

## ETHICAL PRINCIPLES OF PUBLIC CONSULTATIONS

The literature on the ethics of conducting public consultation is virtually non-existent. None of the scoping reviews or theoretical frameworks researched identified or questioned which ethical principles would be at work in the design of public consultations. This is not to say that there are no ethical considerations in the public consultation literature. For example, some of the ethical principles outlined in the TCPS-2 are mentioned explicitly in the public consultation literature and are present to some degree: concerns for informed consent (Thurston et al. 2005), the inclusion of vulnerable populations (Quantz & Thurston, 2006, Maar et al, 2011, Mitton et al., 2009, Shipley & Utz, 2012, Abelson, 2001) and the protection of personal information. However, they are not identified as ethical considerations and there is no overt discussion of ethics in the development of a study design. Two exceptions would be the question of time investment (Maar et al, 2011, Buetow, 2003, Shipley & Utz, 2012) and loss of trust in public institutions (Mitton et al., 2009, Maar et al, 2011, Buetow, 2003, Shipley & Utz, 2012), but there is no overt mention of potential risks to the participants.

Similarly, Health Canada's *Policy Toolkit for Public Involvement in Decision Making* (2000) does not recommend that its departmental employees conduct a formal ethics evaluation of their consultation process. The word “ethics” is present only four times in the document,

always referring to the goal of the public consultation (such as seeking public opinion on an issue that requires an ethical debate) and never as part of the planning process. This document does, however, address some ethical considerations also outlined in the TCPS-2, such as the notion of consent and the involvement of vulnerable populations. While it does not speak of “consent” per se, the Health Canada document does stress the need to inform participants of the mandate of the public consultation, the process, the issues that will be discussed and the overall objectives of the consultation process. The document also encourages organizers to facilitate the participation of vulnerable populations as much as possible, and to make an effort to ensure a certain representation. Similarly, the Commissaire à la santé et au bien-être du Québec (2012) places the emphasis on ethics as the finality of the debate, as opposed to being part of the design. It does, however, include a section based on principles of deliberative democracy that outlines the principles that should be considered in a public consultation process. The section outlines the main principles of inclusion, deliberation and consensus, as well as liberty and equality. Conventions must be established at the onset of the public debate to ensure that all participants can voice their opinion regardless of social status or association, while respecting the differences and particularities of different groups.

The ethical principles outlined by the TCPS-2 take on a particular meaning in the public consultation process. Specifically, while the principles remain important and valid, their application and the questions that arise around each principle may differ from standard research protocols.

**Consent:** The Health Canada Toolkit (2000) and Thurston et al. (2005) stress the importance of giving clear information to participants of public consultations. Making the desired outcome clear may dictate whether someone will invest his or her time in the initiative. Consent to participate in a public consultation is seldom documented through a written consent form, as is normally the case for participation in a clinical trial. Instead, a person’s presence in a consultation event or process is an explicit expression of their consent to participate. When a person consents to participating in a clinical trial, the process is clearly explained and he or she basically knows what to expect. During a public consultation, a great deal remains unknown; the participant may know the general topic of the consultation, but not necessarily the questions that will be asked. This is even more the case in a focus-group approach, like the IAHP, where participants may feel added pressure to contribute due to the small group size. The process may unearth very sensitive issues related to lifestyles and social conditions that may be difficult to keep private. At the other end of the spectrum, the lack of clear know-

ledge of the specifics that will be addressed can lead to the process being futile for some, and even a complete waste of their time.

**Vulnerable populations:** The TCPS-2 makes an important point of ensuring that vulnerable populations benefit from the fruits of research. The literature on public consultation also supports the inclusion of marginalized populations (CSBE, 2012). While research and reviews support the inclusion of these populations, one review showed that only 38% of public consultations in health-care made the effort to solicit input from disadvantaged groups. (Mitton et al. 2009) Mitton et al. go on to say that “When participation is open to all it often becomes unequal,” referring to the need for special measures to include and recruit people belonging to disenfranchised groups who do not have a voice in regular public proceedings. These could be people with various types of disabilities, low-income families and individuals struggling with dependencies or mental health conditions. Marginalized and vulnerable people often have more difficulty expressing their needs and are less likely to participate and be heard in public consultation. They have the most interests in the outcome of public consultations on health matters, yet have the least voice. This can be compensated by acting on the number of representatives from a group, the time allotted for expressing opinions and the number of interventions allowed. (CSBE, 2012)

**Conflicts of interest:** Conflicts of interest can be a confounding factor in the outcome of public consultations. There are many lobby groups that can hijack a consultation process for their own purposes. There can also be community members who have secondary gains linked to the outcome of the process (Shipley & Utz, 2012). For example, the shortage of housing in certain communities may be identified as a major concern for populational health, leading to overcrowding, social issues and other health concerns. However, if half of the people participating in the consultation are gainfully employed by a local construction company, it is possible that this issue will receive more importance than necessary. While housing may be a valid concern, mechanisms are often inadequate to assess divergent interests that can infiltrate the consultation process. The consultation organizers should also disclose the possible conflicts of interest inherent in the consultation to ensure a transparent process. (Buetow, 2003)

**Risk assessment:** The TCPS-2 stresses the responsibility of researchers in ensuring that participants in research are not subjected to undue risk. Measures in place to mitigate risk must be proportional to the risk to the participant, which implies that a reflection on potential risks take place. This may sound obvious. The reality is that a focus group where people discuss their health concerns does not seem more risky than an afternoon chat with friends. However, when the reflection takes place,

risks do emerge that warrant intervention. Some are innocuous, such as wasting the participant's time. Others can be important, such as being ostracized by your community for voicing an unpopular opinion or for being exposed with a particular health or social condition. The Health Canada Toolkit (2000) mentions, in a bulleted list, that a risk assessment must take place. It does not, however, proceed to explain how to conduct such an assessment or determine potential risks. The important point is that a reflection takes place to ensure that adequate measures are taken.

**First Nations context:** Research in a First Nations context must meet specific guidelines included in the TCPS2 (chapter 9). The main points outlined are that research should be conducted with the participation of the community as a whole. To conduct research, researchers must have proper authorization from community leaders (Henderson et al. 2002, Maar et al. 2011). Traditional and cultural values must be taken into account in the research design in order to ensure cultural safety and respect for practices that have too often been oppressed. Cultural safety is a framework for understanding and approaching working with communities and populations who are traditionally silenced and marginalized due to systemic and colonial oppression, including Aboriginal communities (Papps & Ramsden, 1996) and particularly Aboriginal women who hold specific knowledge and need equal representation in decision making (QNW, 2012). In the context of health

consultations, this translates into seeking the support of the Chief and Council before starting a consultation process, as supported by the TCPS-2 (Art. 9.3). This guidance is echoed by a number of authors and organizations (Maar et al., 2011, NAHO, 2005, QNW, 2012, TCPS-2) that advocate a local definition of the research question, as well as research designs developed in collaboration with the communities. The First Nations context will also have an impact on the methodology chosen. Appropriate questionnaires and written material can be complicated to develop (and may be difficult and costly to translate), and sometimes even inappropriate in communities where an oral tradition remains alive and well (Maar et al. 2011). It also means giving serious thought to the values that surround health. What does it mean for this community to be healthy? What are their concepts of distributive justice and equality? How do they define a "good life?" For someone outside the community, this means talking to local people and learning about the culture, communication styles, customs and power differentials inherent to the community and traditional structures. It is also about being aware of the historical impositions that have occurred, especially from governments, the trauma of post-colonialism and the struggle for empowerment that these communities face on a daily basis (Maar et al. 2011, QNW, 2012).

## IMPLICATIONS FOR THE IYUU AHTAAWIN HEALTH PLANNING PROCESS

As the community start-up phase approached in September 2013, the ethics working group got together to review the ethics section of the planning proposal. There was concern that the ethics principles and approach chosen had a very academic feel to them. The ethical points initially selected by the IAHP organizer were outlined in the planning document as “recruitment, implementation, analysis, reporting and handling of information” (CBHSSJB internal document, unpublished). Of these points, most of the emphasis was placed on free and informed consent and protection of personal information. The ethics portion of the proposal outlined how information was going to be collected, transcribed and destroyed after being summarized and denominalized. The recruiters were instructed to make lists of people in their communities who “have personal or employment experience, knowledge, and/or skill in the purpose and topic of the planning you are recruiting for” and to avoid using pressure to push people to participate. The ethics section then went on with two and half pages of text to be read to participants before the beginning of the focus groups. It explained the goals of the IAHP process, who was responsible for the process, what would happen in the discussion group, that participation was voluntary and that all information heard should remain confidential. This approach is supported by First Nations literature on ethical research, particu-

larly the need to explain the purpose of the consultation, in language that is clear and culturally appropriate to the context in which the consultations take place (NAHO, 2005, QNW, 2012, AFNQL, 2005). The treatment process applied to the information collected was explained, i.e., the information gathered in the discussion group would be added to other information gathered in the community (such as asset mapping and epidemiological data). From this information, Miyupimaatsiun plans (health plans) would be developed for each community. The proposal went on to explain that the sessions would be recorded and transcribed with identifying information removed. A process report and a plain language report would be written based on the analysis of the information to ensure accountability to the participants (NAHO, 2005). The recordings and the transcripts would be destroyed at the end of the IAHP process. Once all of this had been explained to the participants, they would be asked: “Are you okay with these points about our discussion today?” From that point on, the people who decided to stay would be considered as having consented to the process.

## ETHICAL REFLECTION OUTCOMES

The research ethics principles outlined in the previous section – namely informed consent, involvement of vulnerable populations, management of conflict of interest and risk assessment – were used to look at the IAHP process in order to see whether there were consi-

derations that had been overlooked. Aside from the overly academic and sometimes contractual style, the ethics section supported the concerns to ensure informed consent and the protection of personal information (Health Canada, 2000, QNW, 2012, NAHO, 2005, TCPS-2), which also echoed the guidelines described in the Health Canada Toolkit (2000). However, in using research ethics principles, the working group brought the reflection further. One critical aspect had not been considered: the assessment of risk to participants. This is not surprising. Since public consultations are not included in the TCPS-2 guidelines, it is not customary to consider them in research terms. Looking at the process through that lens, however, identified four areas of potential risk to participants, in increasing order of importance:

- 1) misuse of participants’ time,
- 2) mistrust in public institutions,
- 3) misrepresentation of vulnerable populations and
- 4) intimidation.

Once these potential risks were identified, it became important to recommend to the IAHP planning committee measures to mitigate these risks.

### Misuse of participants’ time:

Although this is considered more of an annoyance than a risk in the true sense, participants in the process would be spending several hours of their valuable time in consultation. Therefore, it is important to show that people’s time is valued. Maar et al. (2011) considered

incentives, such as small gifts or a prize draw, as “a culturally necessary acknowledgement of participants’ contribution.” The consultation process should be well rehearsed, with experienced and trained personnel, and held in a convenient location comfortable for all. Under-preparation can lead to a poorly developed process that does not allow optimal use of participants’ time and expertise (Buetow, 2003). Some measure of gratitude, such as refreshments and snacks might be appreciated. Another way to ensure that the participants’ time is well spent is to ensure that the process makes sense to them. Particularly, in a First Nations context, it is important that the process reflects the culture and traditions (NAHO, 2005, QNW, 2012, TCPS-2, Ch.9). The IAHP has to pay particular attention to the culture of the Cree and ask questions that pertain to the Cree perspective of health. If a facilitator comes with questions stemming from a very medical model of health, some concepts of the particular view of health held by the Cree might be lost. For example, focusing on exercise and diet as management for diabetes would seem appropriate in a western model, but the inclusion of a mental health component might seem essential to the specific population. Without this component, the participants might walk away from the process feeling that it was not tailored to their needs and reality.

**Mistrust in public institutions:** Historically, consultative processes have been largely unsatisfactory in the context of First Nations, particularly with

regard to resource allocation and development projects (AFNQL, 2005). This has left people feeling ignored and manipulated by government officials. The IAHP process is a partnership between the Cree Board of Health and Social Services of James Bay and the Cree Nation Government, in association with Health Canada. The band councils of each of the nine Cree communities of the region will be approached for their support in this process. This implies that the main actors in health and social services in the region have a shared responsibility in the proper unfolding of the consultation process. They have the responsibility of ensuring a clear and transparent process. They also have a responsibility to the population to deliver on their promises. A participant in a study by Maar et al. (2011) expressed this well:

*One thing you want to avoid is having your project become just another survey that is going to sit on the backburner, so feedback to the community is really important, not just to Chief and Council, but to everyone including all participants. Prepare a report based on results. Give back to the community in a presentation.*

This means that the facilitators have to ensure that they receive the population’s concerns without judgment or bias and that the population does not feel like the facilitators have come with a pre-determined agenda (Buetow, 2003). Furthermore, all pertinent recommendations must be included into the final report, regardless of whether or not they meet the various stakeholders’ political agendas and established

strategic plans. It is also crucial to make the purpose of the consultation very clear from the onset, because governmental agencies’ goals often differ from those of participants, who usually want some operational, practical outcome to emerge from public consultation (Thurston et al. 2005), such as improved access to care or better infrastructures.

Institutions may consult to obtain general orientations from the public, whereas the public may want a more definitive say on policies (Shipley & Utz, 2012). Failure to deliver concrete action can lead to total mistrust in the decisional and healthcare institutions that serve the people. In small communities, the impact can be very real. Someone who has lost faith in their health provider may not seek regular preventive medical care, feeling that healthcare providers do not understand their particular reality. In a context where chronic diseases and psychosocial concerns are a harsh reality, as is the case in many First Nations communities, this may mean that a person’s condition may deteriorate beyond repair very quickly. A measure to mitigate this risk is a clear and continuous communication plan between the IAHP planning committee, band councils and the directors of the health facilities. The plain language report for each community should be aired on the local radio. The Miyupimaatisiun plans that ensue from the consultations could also be the object of resolutions by the Cree Nation Government to show the commitment of the region and its institutions to follow through on the concerns brought to light by the population. The

transparency of the consultation process is of utmost importance; if people perceive the process as fair, they will tend to perceive the outcomes as fair as well (Lauber and Knuth, 1999).

**Misrepresentation of vulnerable populations:** The recruitment method chosen by the planning committee – i.e., a focus group approach – is one that makes logistical sense. In small communities where everyone knows each other, there are obvious names that pop up when we think of health planning. The people selected will most likely be the people who hold positions of influence in the community, or have healthcare experience. Recruitment of people with health care experience (e.g., such as nurses) is seen often in healthcare consultations. This has the unfortunate effect of projecting an elitist view on health concerns (Abelson, 2001, Quantz & Thurston, 2006). Target participants may also be Elders who hold traditional and historical knowledge and are well respected in the community. Some of the most vulnerable people in the community are likely not to figure on this list. As mentioned previously, these are people who may be struggling with mental health problems and addictions, low income families, people living in situations of violence or people with limited mobility who cannot easily attend public gatherings. This might also apply to youths, who might be overlooked if an explicit effort is not made to include them in public consultation processes. The recruitment method and the focus group approach are not particularly well suited to facilitating the participation of such vulnerable groups of

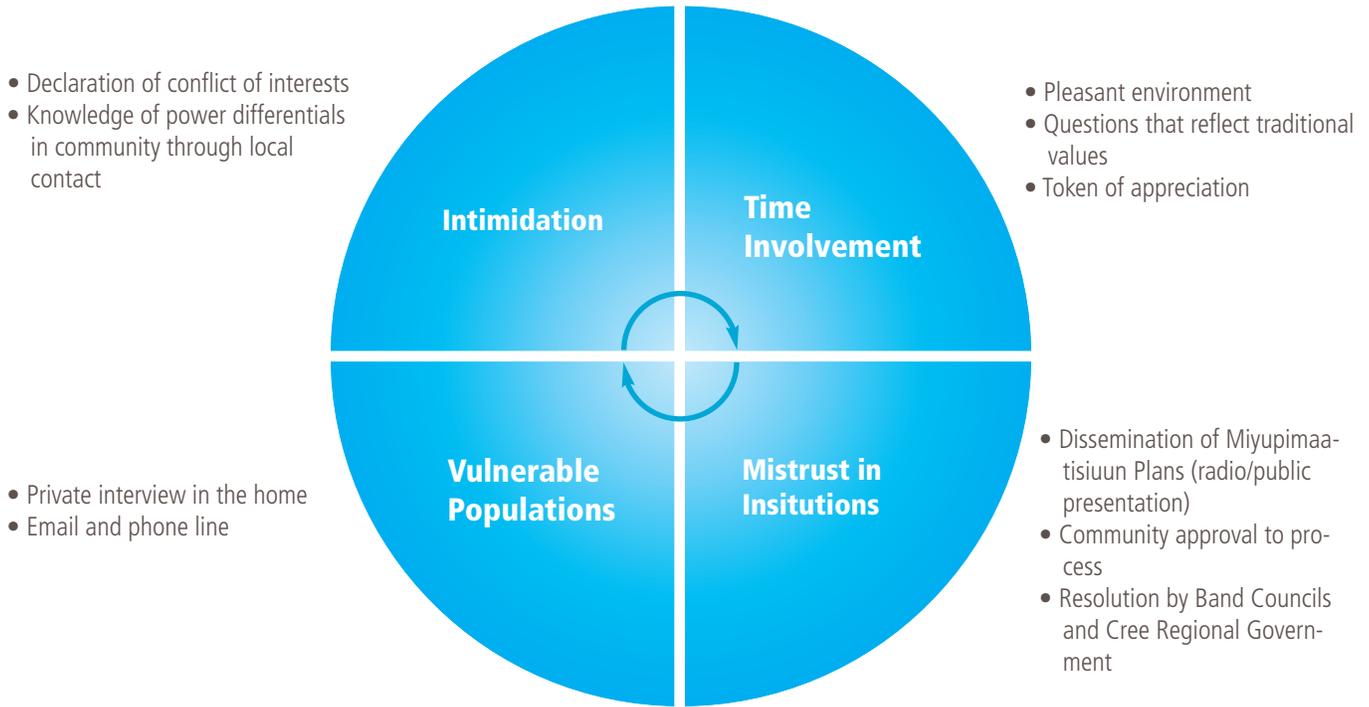
the population. While focus group recruitment through a selected list may still be the most functional way to achieve the goals set by IAHP, other methods to reach vulnerable people are recommended (Mitton et al. 2009). This may include a call to the population on the local radio for a public open microphone forum or a phone/email line available to receive people's health concerns on specific questions. It may also be possible for an interviewer to visit people interested in participating in their home setting, as suggested by Maar et al. (2011). Although this would allow a more equitable access to all, it might be cost-prohibitive and should be assessed from a cost-benefit perspective.

**Intimidation:** The highest risk situation is the risk of intimidation. This can translate into the perceived inability to speak openly due to power differentials related to clan membership, age, social or political standing, gender or disability. We can imagine a scenario where someone may bring up a situation that has occurred that incriminates a health service. This may have repercussions on employment in the future, questionable service when visiting the clinic or all-around discontent and marginalization by certain people within the community. A caregiver who may mention very candidly that she feels she is not getting sufficient support from the local institutions regarding care, home adaptations and adapted transportation could see her services affected if the service providers perceive her comments as a complaint with regard to their work. A more subtle impact of power differentials may simply be the social convention that

some people in the community must not be contradicted. It might be a healthcare provider or an Elder who is perceived as having authoritative knowledge (Abelson, 2001). Power differentials can exist due to educational levels and cultural or religious views. (Abelson, 2001) Group dynamics, pressure to conform and social desirability also shape the responses that may emerge in a group setting, and it is common for public consultation organizers to overlook the power differentials that can occur in diverse groups within the community (Shiple & Utz, 2012).

The sum of all these pressures can skew the process and recommendations that ensue. It can cause distress among the participants who want to express their personal views. A measure to mitigate this risk may be to provide an email address and phone number and inform participants that if there are things that they hear that they do not agree with, or information they would like to add that they feel, for whatever reason, unable to divulge in public, that they can do so in private after the end of the proceedings. Prior to the consultation process, all participants could complete a conflict of interest form. In small communities where people know a fair amount about everyone's daily business, it might be unnecessary (or outright awkward) to hold a public declaration of conflicts of interest. However, it may still be pertinent for the person who will analyze the data to be aware of recurrent comments by an individual that align and support a personal interest, and thus might bias the subsequent data analysis.

**Figure 2: Risk assessment and proposed measures**



## CONCLUSION

Public consultations occur within a political space with many actors – internal and external to the process – who shape policy and outcomes (Thurston et al 2005). Part of the political space is the reality and legacy of colonialism: “The struggle over who speaks for whom, and when, is inherently a political or power struggle. For Aboriginal people this is embedded within a struggle to overcome the results and constraints of colonialism” (Quantz & Thurston, 2006). Failing to recognize cultural differences can cause harm (Maar et al. 2011). A key point in ensu-

ring cultural safety is the importance of community involvement (TCPS-2, Maar et al. 2011), something that is at the very core of the IAHP process. The first step in the process is to visit the local chiefs and councils to obtain their support. The process must also reflect the values of the Cree people regarding health and be respectful of traditional proceedings, since the values of the group has an impact on the proceedings and outcomes (Abelson, 2001). Communication should be translated into Cree, with priority given to the oral form and open-ended questions (Maar et al, 2011) Although it can be argued that

this would not be an ethics proposition per se, one working group recommendation was to start each group with a short reflection on the values underlying Miyupimaatisiun (health or well-being) and the values that participants want to see reflected in the discussions. It was felt that many of the values of respect, free participation and confidentiality, empowerment and beneficence would be brought up this way in words and concepts that made sense to the participants, rather than imposed by an outside view of health and proper conduct of academic proceedings.

At its most basic, the concept of public participation is a foundational tenant of the modern idea of democracy (Shiple & Utz, 2012). Numerous authors advocate a better way of evaluating both the process and outcome of public consultation in healthcare. But as Shiple and Utz (2012) state: "We still cannot determine, definitively, that we are doing it right." Looking at ethical principles that guide the design of public consultations might be a first step in that direction. While one may argue that public consultations differ from more usual forms of research, the application of research ethics principles adds the important dimension of risk assessment to the planning process.

In the context of public consultations in a First Nations setting, questions of cultural safety and community involvement are crucial. The TCPS-2 framework is supportive of this reflection as well. This is not to say that public consultations need to be regulated and supervised with the same normative provisions as is currently the case with research funded by the three federal granting councils. Submitting public consultation protocols to research ethics boards may only lengthen and complicate the process, and may be unwarranted given the types of risks involved. In a First Nations context in particular, the process may lose its organic grass-roots quality. Nevertheless, a reflection based on research ethics is crucial in identifying all factors that may cause discomfort or harm to the participants and to the community. The principles of informed consent, respect of autonomy, protection of privacy, inclu-

sion of vulnerable populations and harm reduction are essential in planning an efficient, empowering, collaborative public consultation. The ethical reflection stimulated by the Iiyuu Ahtaawin Health Planning process demonstrates that research ethics principles can be applied effectively to public consultations.

Recommendations have been made to the IAHP planning committee by the ethics working group. Follow-up on these recommendations with the planning committee will be necessary to ascertain whether they were implemented as proposed, and to evaluate the perceived impact of these recommendations on the process. It was beyond the mandate of the working group to determine whether the measures proposed were feasible with regards to available funding, manpower and timelines. However, the exercise was valuable in identifying key ethical issues in public consultations, particularly in a First Nations context, which is clearly an area where more ethics research is warranted.



## REFERENCES

- ABELSON, J. (2001) Understanding the role of contextual influences on local health-care decision making: case study results from Ontario, Canada, *Social Science & Medicine* 53: 777-793.
- ABELSON, J. FOREST, P-G., EYLES, J., SMITH, P., MARTIN, E., GAUVIN, P. (2003) Deliberations about deliberative methods: issues in the design and evaluation of public participation processes, *Social Science & Medicine* 57: 239-251.
- Assembly of First Nations of Quebec and Labrador. (2005). *Consultations Protocol of First Nations of Quebec and Labrador*. Wende: First Nations of Quebec and Labrador Sustainable Development Institute.
- BUETOW, STEPHEN, (2003) The Ethics of Public Consultation in Health Care: An Orthodox Jewish Perspective *Health Care Analysis*, 11 (2)
- Commissaire à la santé et au bien-être. *L'importance du débat public et les conditions qui y sont propices. Un guide du commissaire à la santé et au bien-être* – version détaillée. (2012) [www.csbe.gouv.qc.ca](http://www.csbe.gouv.qc.ca)
- FORO, A., BÉZIERS, L. ROBINSON, E., TORRIE, J. (2013) Perceptions des leaders et des professionnels d'Eeyou Istchee quant aux changements climatiques et à leurs effets sur la santé humaine : rapport des consultations <http://www.creehealth.org/sites/default/files/Climate%20Change%20-%20Fr%20-%202014-14.pdf>
- Health Canada. *Health Canada Policy Toolkit for Public Involvement in Decision Making*. Ottawa: Health Canada. 2000.
- HENDERSON, R. SIMMONS, D., BOURKE, L., MUIR, J. Development of guidelines for non-Indigenous people undertaking research among the Indigenous population of north-east Victoria (2002) *Medical Journal of Australia*, 176: 482-485.
- LAUBER, T. BRUCE, AND BARBARA A. KNUTH. 1999. Measuring Fairness in Citizen Participation: A Case Study of Moose Management." *Society and Natural Resources* 12:19–37.
- LITVA, A., COAST, J., DONOVAN, J., EYLES, J. SHEPHERD, M., TACCHI, J., ABELSON, J. MORGAN, K. (2002) 'The public is too subjective': public involvement at different levels of health-care decision making, *Social Science in Medicine* 54: 1825-1837.
- MAAR, M.A., LIGHTFOOT N.E., SUTHERLAND M.E., STRASSER, R.P., WILSON, K.J. LIDSTONE-JONES, C.M., GRAHAM, D.G., BEAUDIN, R., DAYBUTCH, G.A., DOKIS, B.R., LESAGE, M.T., RAYMOND, M., WILLIAMSON, P. (2011) Thinking outside the box: Aboriginal people's suggestions for conducting health studies with Aboriginal communities, *Public Health* 125: 747-753.
- MITTON, C., SMITH, C., PEACOCK, N., EVOY, S. ABELSON, J. (2009) Public participation in health care priority setting: A scoping review, *Health Policy* 91: 219-228.
- National Aboriginal Health Organisation. (2007). OCAP: Ownership, Control, Access and Possession. Approved by the PCAP: Propriété, contrôle, accès et possession - Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization.
- PAPPS, E., & RAMSDEN, I. (1996). Cultural safety in nursing: The New Zealand experience. *International Journal for Quality in Health Care*, 8(5), 491-497.
- QUANTZ, DARRYL, THURSTON, WILFREDA E. (2006) Representation strategies in public participation in health policy: The Aboriginal Community Health Council. *Health Policy* 75 : 243-250.
- QNW. (2012). Guidelines for Research with Aboriginal Women. Quebec: Quebec Native Women, inc. [http://www.faq-qnw.org/sites/default/files/publications/Guidelines\\_for\\_Research.pdf](http://www.faq-qnw.org/sites/default/files/publications/Guidelines_for_Research.pdf)
- SHIPLEY, R., UTZ, S. (2012) Making it Count: A Review of the Value and Techniques for Public Consultation, *Journal of Planning Literature* 27(22)
- TCPS v.2 Canadian Research Institutes: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans: <http://www.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/>
- THURSTON, W.E., MACKEAN, G., VOLLMAN, A., CASEBEER, A., WEBER, M., MALOFF, B., BADER, J. (2005) Public participation in regional health policy: a theoretical framework, *Health Policy* 73: 237-252.
- VOGT, DAWNE S., DANIEL W. KING, AND LYNDA A. KING. 2004. "Focus Groups in Psychological Assessment: Enhancing Content Validity by Consulting Members of the Target Population." *Psychological Assessment* 16:231–43.

# A CHECKLIST OF SKILLS, KNOWLEDGE AND CONSIDERATIONS FOR UNIVERSITY-BASED RESEARCHERS AND INDIGENOUS COMMUNITIES

**AUDREY R. GILES**  
**TRICIA MCGUIRE-ADAMS**  
**FRANCINE E. DARROCH**

School of Human Kinetics, University of Ottawa

Corresponding author: [agiles@uottawa.ca](mailto:agiles@uottawa.ca)

## INTRODUCTION

The literature on ethical research with Indigenous communities has typically assumed that Indigenous community members needed to learn specific skills from university-based researchers in order to fully participate in collaborative community-based research. Though a great deal of lip-service has been paid to the need for true collaboration between community members and university-based researchers, this deficit-based approach continues to dominate training considerations. The need for university-based researchers to be trained by community members is often overlooked.

We believe that university-based researchers and Indigenous community members interested in conducting community-based research

will, by going through the attached checklist, be better equipped to identify their capacities and training needs, as well as form a more equitable and respectful partnership. The checklist is a starting point for both university-based researchers and community members to engage in early discussions as they jointly develop research projects. Ultimately, we hope that the exercise below will respect the knowledge and expertise of Indigenous communities and universities, contribute to preventing research fatigue and facilitate the co-creation of meaningful research that will benefit all those involved. We encourage you to adapt this resource to your own specific research context. A list of additional resources has been appended to this document.



# AN INVENTORY OF SKILLS, KNOWLEDGE AND CONSIDERATIONS FOR UNIVERSITY-BASED RESEARCHERS WHO WANT TO CONDUCT RESEARCH WITH INDIGENOUS COMMUNITIES

## Research Foundations

Check all that are relevant to your work/discussion

- How would you build a relationship with the community prior to commencing any research?
- How would you build a relationship with a researcher prior to commencing any research?
- Is there an existing organization or group that facilitates community-based research with this particular community?
- Does the community have a policy on its degree of participation in the development of a research question?
- Who will attend the initial meeting to discuss the possible research?
- What funding opportunities are available for this research? For communities? For researchers? For both?
- What are the potential benefits of the research to the community?
- How do your goals align with those of the community?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Thoughts, questions, concerns:**

---

---

---

---

## Community Protocols

### Check all that are relevant to your work/discussion

- Do you know how to approach community leaders?
- Is there a community contact person who will educate university-based researchers about cultural practices within the community?
- Do you know how to approach an elder?
- How do you invite a community member to participate in the research?
- Is there a preference for the manner in which to collect data (e.g., sharing circles or storytelling)?
- What forms of compensation are appropriate? When should it be given? By whom?
- What are the research ethics protocols?
- What are the data management/storage/access requirements?
- Who will be responsible for the community/university research agreement?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Thoughts, questions, concerns:

---

---

---

---



## Knowledge Dissemination

### Check all that are relevant to your work/discussion

- What is the process for gaining approval from community members prior to initiating knowledge dissemination activities?
- What are the community's knowledge sharing practices?
- Who will participate in the knowledge dissemination activities?
- What forms of knowledge dissemination are favoured by community members?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Thoughts, questions, concerns:

---

---

---

---

**What existing knowledge/skills would you like community members to bring to the project?**

**Check all that are relevant to your work/discussion**

- Participant recruitment
- Translation
- Interpretation
- Data collection
- Transcription
- Data analysis
- Proposal and report writing
- Project management
- Knowledge dissemination
- Project-specific skills
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Thoughts, questions, concerns:**

---

---

---

---

### What existing skills can university-based researchers bring to the project?

Check all that are relevant to your work/discussion

- Participant recruitment
- Translation
- Interpretation
- Data collection
- Transcription
- Data analysis
- Proposal and report writing
- Project management
- Knowledge dissemination
- Project-specific skills
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

#### Thoughts, questions, concerns:

---

---

---

---

**What existing skills would you like to have further developed on your university-based research team?**

**Check all that are relevant to your work/discussion**

- Participant recruitment
- Translation
- Interpretation
- Data collection
- Transcription
- Data analysis
- Proposal and report writing
- Project management
- Project-specific skills
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Thoughts, questions, concerns:**

---

---

---

---

## Advisory Committee

### Check all that are relevant to your work/discussion

- Membership: identify who will represent the university and community to ensure selected individuals are research stakeholders
- What time commitment can committee members expect?
- At what frequency will meetings be held?
- What conflict resolution process will be used?
- Have confidentiality agreements been prepared for committee members?
- What is the role of the advisory committee? (Give specific advice? Be fully involved in the project?)
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Thoughts, questions, concerns:

---

---

---

---

## Project Evaluation

### Check all that are relevant to your work/discussion

- How will you know if the research objectives were met?
- What forms of evaluation will be used?
- How and at what intervals will there be an opportunity for all partners to evaluate the progress of the project?
- How and at what intervals will there be an opportunity for all project partners to assess their contribution to the research process? Their level of involvement in the research process? The quality of the relationships/partnerships in the research process?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Thoughts, questions, concerns:

---

---

---

---

## AN INVENTORY OF SKILLS, KNOWLEDGE AND CONSIDERATIONS FOR INDIGENOUS COMMUNITIES INVOLVED IN COMMUNITY-BASED RESEARCH

### Research Foundations

Check all that are relevant to your work/discussion

- How would you build a relationship with a researcher prior to commencing any research?
- Is there an existing organization or group that facilitates community-based research with this particular university or researcher?
- Does the university or researcher have a policy on its degree of participation in the development of a research question?
- Who will attend the initial meeting to discuss the possible research?
- What funding opportunities are available for this research? For communities? For researchers? For both?
- What are the potential benefits of the research to the researchers?
- How do your goals align with those of the researchers?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Thoughts, questions, concerns:**

---

---

---

---

## University Protocols

### Check all that are relevant to your work/discussion

- Who is the applicant of the research grant (if applicable)?
- Who is the main contact person?
- What forms of compensation are allowed?
- What are the research ethics protocols?
- What are the data management/storage/access requirements?
- Who will be responsible for the community/university research agreement?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Thoughts, questions, concerns:

---

---

---

---

## Knowledge Dissemination

### Check all that are relevant to your work/discussion

- What is the process for gaining approval from university-based researchers prior to initiating knowledge dissemination activities?
- What are the university's knowledge sharing practices?
- Who will participate in the knowledge dissemination activities?
- What forms of knowledge dissemination are favoured by university-based researchers?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Thoughts, questions, concerns:

---

---

---

---

**What existing knowledge/skills can community members bring to the project?**

**Check all that are relevant to your work/discussion**

- Participant recruitment
- Translation
- Interpretation
- Data collection
- Transcription
- Data analysis
- Proposal and report writing
- Project management
- Knowledge dissemination
- Project-specific skills
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Thoughts, questions, concerns:**

---

---

---

---

**What skills would you like to have further developed in your community?**

**Check all that are relevant to your work/discussion**

- Participant recruitment
- Translation
- Interpretation
- Data collection
- Transcription
- Data analysis
- Proposal and report writing
- Project management
- Project-specific skills

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Thoughts, questions, concerns:**

---

---

---

---

## Advisory Committee

### Check all that are relevant to your work/discussion

- Membership: identify who will represent the university and community to ensure selected individuals are research stakeholders
- What time commitment can committee members expect?
- At what frequency will meetings be held?
- What conflict resolution process will be used?
- Have confidentiality agreements been prepared for committee members?
- What is the role of the advisory committee? (Give specific advice? Be fully involved in the project?)
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Thoughts, questions, concerns:

---

---

---

---

## Project Evaluation

### Check all that are relevant to your work/discussion

- How will you know if the research objectives were met?
- What evaluation methods will be used?
- How and at what intervals will there be an opportunity for all partners to evaluate the progress of the project?
- How and at what intervals will there be an opportunity for all project partners to assess their contribution to the research process? Their level of involvement in the research process? The quality of the relationships/partnerships in the research process?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### Thoughts, questions, concerns:

---

---

---

---

It is our hope that the above checklist of skills, knowledge and considerations for university-based researchers and Indigenous communities is used as a tool by partners engaged in collaborative community-based research. To create this checklist, we have drawn on our collective experience as university-based researchers involved in community-based research. This tool can serve to initiate dialogue about developing meaningful research relationships between Indigenous communities and university-based researchers; as such, it may be adapted to align with specific research contexts.

Associate professor Dr. Audrey Giles is an applied cultural anthropologist who has the pleasure of leading a dynamic team of emerging researchers from the School of Human Kinetics at the University of Ottawa. Her research is conduc-

ted in partnership with Indigenous peoples living in the NWT, Nunavut and Northern Alberta; non-governmental organizations; and different levels of government. Her research examines the intersections between ethnicity, gender, physical practices and injury prevention

Tricia McGuire-Adams is a second-year human kinetics Ph.D. student at the University of Ottawa being supervised by Audrey. She is the former director of the Urban Aboriginal Knowledge Network Secretariat for the National Association of Friendship Centres. An Anishinaabe from Bingwi Neyaashi Anishinaabek, Tricia has worked with a variety of Aboriginal organizations in such areas as community-based research, community justice, post-secondary education and women's issues. Her doctoral research focuses on decolonizing physical activity among First Nation women.

Francine Darroch is a fourth-year human kinetics Ph.D. candidate at the University of Ottawa who is also being supervised by Audrey. Francine was an obesity research project director at Brown University and previously worked with the World Health Organization and non-profit groups in Canada, India and the USA. Her doctoral research involves identifying the factors influencing weight gain and physical activity among pregnant urban Aboriginal women, with a view to developing a culturally appropriate community-based resource.



## ADDITIONAL RESOURCES

BORDEAUX, B. C., WILEY, C., TANDON, S. D., and HOROWITZ, C. R. (2007). Guidelines for Writing About Community-Based Participatory Research for Peer-Reviewed Journals. *Progress in Community Health Partnerships: Research, Education, and Action*, 1(3), 281-288.  
[https://www.press.jhu.edu/journals/progress\\_in\\_community\\_health\\_partnerships/1.3bordeaux.pdf](https://www.press.jhu.edu/journals/progress_in_community_health_partnerships/1.3bordeaux.pdf)

COMMUNITY-BASED RESEARCH CANADA  
<http://communityresearchcanada.ca/resources>

DEVELOPING AND SUSTAINING COMMUNITY-BASED PARTICIPATORY RESEARCH PARTNERSHIPS: A SKILL BUILDING CURRICULUM.  
<http://depts.washington.edu/ccph/cbpr/index.php>

OCAP - OWNERSHIP, CONTROL, ACCESS AND POSSESSION  
<http://cahr.uvic.ca/nearbc/documents/2009/FNC-OCAP.pdf>

PACIFIC AIDS NETWORK – RESEARCH AGREEMENT CHECKLIST  
<http://pacificaidnetwork.org/wp-content/uploads/2011/10/PAN-RESEARCH-AGREEMENT-CHECKLIST.pdf>

PARTICIPATORY RESEARCH AT MCGILL (PRAM)'S PARRY, D., SALSBERG, J., & MACAULAY, A.C.  
<http://communityresearchcanada.ca/res/download.php?id=4225>

REITSMA-STREET, M. (2002). Processes of Community Action Research: Putting Poverty on the Policy Agenda of a Rich Region. *Canadian Review of Social Policy*, 49(50), 69-92.  
<http://web.uvic.ca/spp/documents/process-commaction.pdf>

TRI-COUNCIL POLICY STATEMENT: Ethical Conduct for Research Involving Humans  
[http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPs\\_2\\_FINAL\\_Web.pdf](http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPs_2_FINAL_Web.pdf)

URBAN ABORIGINAL KNOWLEDGE NETWORK: Guiding Ethical Principles  
<http://uakn.org/wp-content/uploads/2013/01/UAKN-Atlantic-Appendix-A-Guiding-Ethical-Principles-February-13-2013.pdf>

USAI: Utility Self-Voicing Access Inter-Relationality Research Framework  
<http://ofifc.agiledudes.com/sites/default/files/docs/USAI%20Research%20Framework%20Booklet%202012.pdf>

UNIVERSITY OF BRITISH COLUMBIA. Community-Based Research  
<http://communitybasedresearch.ubc.ca/>  
[http://communitybasedresearch.sites.olt.ubc.ca/files/2014/03/Summary-CBR-Faculty-Forum-2014\\_March\\_5-with-images.pdf](http://communitybasedresearch.sites.olt.ubc.ca/files/2014/03/Summary-CBR-Faculty-Forum-2014_March_5-with-images.pdf)

UNIVERSITY OF TORONTO. Community-Based Participatory Research: A Training Manual for Community-Based Researchers  
<http://individual.utoronto.ca/sadaf/resources/cbpr2007.pdf>

WENGER, L. & MACINNIS, A. (2011). Inventory of tools for Assessing University Capacity, Support for, and Outcomes of Community/Civic Engagement and Community-Engaged Scholarship. Campus Community Partnerships for Health and the Institute for Community Engaged Scholarship, University of Guelph.  
[http://cescholarship.ca/wp-content/uploads/2013/06/Assessment-Tool-Inventory\\_June-29\\_2011\\_with-cover.pdf](http://cescholarship.ca/wp-content/uploads/2013/06/Assessment-Tool-Inventory_June-29_2011_with-cover.pdf)

## APPROACHING RESEARCH IN INDIGENOUS SETTINGS: NINE GUIDELINES

### RDK HERMAN

Senior Geographer  
Smithsonian National Museum of the  
American Indian

Conducting research with Indigenous peoples poses a number of issues and challenges beyond the usual framework of human subjects research. This is true even for oral history research that may be exempt from institutional oversight, and regardless of whether the research is conducted by non-Indigenous or Indigenous researchers. Indigenous peoples have experienced colonization, cultural hegemony, and many forms of exploitation, in which they have had little or no role in representing their own self-understandings or world views. They have had researchers and institutions conduct research on them from which the people themselves have benefited not at all, while their traditional knowledge has been exploited for the profits and advancement of others.

Consequently, guidelines for research with Indigenous peoples have been put into place at national, institutional and community levels to ensure that such research is both non-exploitative and not harmful to the community, and in the hope that such research will promote Indigenous values and understandings. The aim of such guidelines is three-fold. The first aim is to decolonize research **methodologically**: to use research methods

that are collaborative and reciprocal rather than exploitative and authoritative. The second is to decolonize research **epistemologically**: to understand Indigenous cultures on their own terms, via their own worldview, without imposing Western knowledge structures on them. The third is to ensure **protection of Indigenous intellectual properties**.

In many countries and institutions, regulations governing research with human subjects are already subject to policies and guidelines. In the United States, most research institutions, funding agencies and federal government agencies abide by the Federal Policy for the Protection of Human Subjects, often referred to as the "Common Rule." Under this policy, all human-subjects research must be reviewed and approved by an Institutional Review Board (IRB). However, the Common Rule does not take into account the particular circumstances regarding Indigenous peoples, nor does it cover certain types of oral data collection. This essay is one of many attempts to fill these gaps, and to provide a general tool for those conducting any kind of research in Indigenous settings. It supplements statements of ethical research produced by disciplinary organizations such as the American



Historical Association, the Oral History Association, the American Anthropological Association, the Association of American Geographers, and others.

Researchers need to manifest respect, reciprocity, and mutual benefit wherein the research (a) is informed by the viewpoints of Indigenous peoples involved in open negotiation; (b) benefits the community; and (c) results in a product that is shared with the community, and in which the community's participation is clearly acknowledged. Research with Indigenous peoples should be conducted with foreknowledge of appropriate protocols and the social, cultural and even legal pitfalls that may arise. Working with Indigenous peoples requires patience, diligence, and personal integrity. It is all about building relationships. Following appropriate protocols may slow the research timetable considerably, which may clash with research guidelines and schedules imposed by research institutions and funding organizations. However, it is important that such institutions come to recognize the need for appropriate methodology in regard to work with Indigenous peoples.

It is also often the case that Indigenous knowledge does not follow the same formats and structures as does Western approaches to knowledge. While it is impossible to generalize across all Indigenous societies, Indigenous knowledge tends to be (a) largely oral, manifested in storytelling, song, dance, ritual, and ceremony; (b) controlled by the communities' rules regarding who has access to information and when; (c) holistic,

understanding the world as a unified web of relationships across natural, human, and spiritual realms; and (d) subjective and experiential. Because these characteristics contrast with the principles of knowledge derived from Western scientific method, Indigenous knowledge has historically been deemed non-scientific, and even discounted as myth or superstition.

Today it is recognized that Indigenous knowledge, derived through millennia of informal observation and experimentation and transmitted in oral and ritual forms, constitutes a valid and important wealth of human knowledge and understanding of the world. Contemporary research on Indigenous issues that engage with Indigenous knowledge and understandings should seek to promote and enhance the status of Indigenous knowledge, and to allow Indigenous epistemologies to inform new ways of looking at topics.

The following guidelines are based on a review of about 25 documents on Indigenous research ethics, protocols and guidelines from the United States, Canada, New Zealand and Australia, and internationally. Many of the documents share strong consistencies that we have summarized below. But there are also variations, and in some cases, elaboration and details worth examining. The literature relevant to the peoples with whom one is working is worthy of attention. This essay, however, provides a general introduction and orientation to the major considerations. A bibliography is included at the end.

In any given research situation, specific steps should be negotiated between the researcher(s) and the community. Even defining what constitutes a "community" can be difficult and problematic, and researchers need to tread mindfully and respectfully. The guidelines developed here thus reflect underlying principles for ethical conduct of which the lead researcher should be fully knowledgeable prior to going into the field, and which should fully inform the conduct of that research. They are not merely intellectual precepts, but *guides to action*.

These guidelines are specific to research in the humanities and social sciences, and are not sufficient for those wishing to conduct research in health sciences or natural-resource exploration. Research conducted by government agencies is further delimited by relevant laws and regulations. In all cases, researchers should be informed of and aware of applicable laws from all levels of government—including those of the Indigenous nation itself—that have jurisdiction.

## NINE GUIDELINES FOR RESEARCH WITH INDIGENOUS PEOPLES

### INTEGRITY:

**Open consultation:** All aspects of the research project, its aims, methodology, and sponsors should be openly discussed and negotiated with the community or its representatives before the project begins.

**Values:** Research should be conducted within the values framework of the Indigenous peoples involved, and should reflect and support those values rather than reframing them into a Western context.

**Respect:** Cultural protocols and traditions appropriate to the community, the local area and the research participants should be respected.

### RESPONSIBILITY:

**Consent:** Full and informed consent from those participating in the research and those affected by it must be secured. Depending on the context, such consent may be individual or collective, or both.

**Confidentiality:** Confidentiality, anonymity and public recognition of participants are delicate if not dangerous matters for many Indigenous peoples, and must be clearly and carefully negotiated before any project materials are made public.

**Protection:** Indigenous knowledge and the intellectual property of traditional knowledge holders and Nations must be safeguarded within the bounds agreed to in negotiation with the community.

### RECIPROCITY:

**Partnership:** Research partnerships with Indigenous individuals, communities or organizations should be pursued, to the extent that they are desired. Collaborative work in full partnership with the community is often preferred.

**Review:** Research participants and community leaders should have the opportunity to review and revise drafts of the study, and should receive copies of the final study. They should receive acknowledgement, fair return and royalties where appropriate.

**Benefit-sharing:** Every effort must be made to ensure that benefits flow to Indigenous peoples from research, and that any potential negative impacts are minimized.

### I. INTEGRITY:

**1. Open consultation: All aspects of the research project, its aims, methodology, and sponsors should be openly discussed and negotiated with the community or its representatives before the project begins.**

Working with Indigenous communities is about building relationships. Trust, honesty, openness and integrity on the part of the researcher are essential from the start. This requires meeting with the community or its representatives, possibly several times, to negotiate the project. That is, coming in with a project fully framed out and trying to “sell” it to the community might not work so well. The community wants to buy-in: to know what the project is, how it will benefit them, its aims and intent, the methods and people involved, anticipated outcomes, how the results will be

used (including any spin-off projects), all sponsors and sources of financial support, and all personnel and investigators responsible for the research. This information must be conveyed in a clear, concise and appropriate way. It may take several times for the information to be digested, as the community is taking in a lot at once—especially in cultures that are more traditional, less exposed to the ways of Western research, and/or have lower formal education and literacy rates. They are rightly cautious and circumspect, and want to be sure they fully understand the project and its potential implications. It is very important to allocate the necessary time for this. A dialogue may result which reshapes the study to better suit the needs and conditions of the community.

Open consultation should, of course, take place throughout the entire project as necessary, not merely at the outset. Communication should be adapted to the standards and conditions of the community and participants, and accord with their protocols. How do you know whether the participants really understand? This process cannot be rushed, and it can be a good idea to work with a respected facilitator who is fluent in the local culture. Appreciate silence, as it may mean people are figuring things out. Show humility and respect for their thoughts.

As with informed-consent processes, the positive and negative implications and potential impacts of the research should be discussed. The community might see potential impacts of which you are unaware. In addition, the people participating have an absolute right to know, as



far as can be anticipated, what will become of the information they have volunteered as well as its possible uses and applications. If the community has no research board, it is advisable to have the community's political and spiritual leadership review and approve the research proposal.

Sponsorship in particular can be a major issue: it is not uncommon for a community to be opposed to work that has been sponsored by a particular organization because of the organization's past history, political stance, etc. It is very much to the researcher's benefit to make sure that all of this information is well understood in advance. Similarly, it is important in the initial consultation stage to delineate who will own the raw data and the end result of the research—from community ownership of materials to copyrighted academic papers—and whether any royalties derived from the research will be shared with or given to the community.

Negotiating a research project can take months or even a year, after which the researchers will work closely with community members. Researchers should understand that these relationships do not end once the study is completed.

**2. Values: Research should be conducted within the values framework of the Indigenous peoples involved, and should reflect and support those values rather than reframing them into a Western context.**

Research in Indigenous settings often involves a clash of value systems between the individualist dominant culture of private property and competition, and cultures in which the values of respect, reciprocity, honesty, kindness, caring and sharing are commonly held. Indigenous cultures also have their own appropriate protocols for engaging with different members of the community. This can be tricky to negotiate, so you should do your homework on this so as to better conduct your behaviour and your research relationships in a manner that is consistent with the values of the participating community. At the same time, you need to be sensitive to the social, economic, physical, psychological, and religious contexts, beliefs and practices of the people involved. Encroachments on values and principles that are subtle or even unintended can violate the trust that is necessary to conduct research in the community.

Ideally, Indigenous values should be acknowledged by incorporating them into the research design and methodology of a project, rather than using Western terms and constructs to define the project. Best to ensure that relevant aspects of Indigenous worldviews are understood, acknowledged and upheld. One way to accomplish this is to include Indigenous perspectives in the final study. Acknowledging and respecting Indigenous knowledge systems and processes is not only a matter of courtesy but also recognition that such knowledge can make a significant contribution to the research process and results.

**3. Respect: Cultural protocols and traditions appropriate to the community, the local area and the research participants should be respected.**

Respect is fundamental to the relationship between the researcher and the community. Not only respect for the people, but also for the ancestors, the land, the other nations of beings, and the generations to come. All of that constitutes the community.

Many Indigenous jurisdictions have established research protocols that they expect researchers to follow. These include protocols for establishing relationships and for sharing knowledge. Researchers should familiarize themselves with these and follow local cultural protocols and traditions.

Contrary to Western scientific notions of unrestricted access to information, in Indigenous communities receiving certain knowledge is a privilege rather than a right. Hence it is important not to approach research in Native communities as a process of "mining data." Researchers must at all times be conscious of their responsibility for the information they receive, as that information is the property of the community and its members, and shared only for specific purposes. This differs from the Western academic approach of putting knowledge out into the public sphere. A collaborative research method can ensure that this guideline is followed.

In this vein, the researcher should be especially cautious in regard to collecting sensitive data, and avoid pursuing “restricted” data or subjects. People have the right to retain certain cultural knowledge as secret or sacred, and researchers should never try to overstep that boundary once it has been made clear. It is up to the community to decide what they are and are not willing to share, and this decision should be respected at all times. Information pertaining to traditional medicines, ceremonies, songs, rituals and other sacred cultural traditions is particularly sensitive, and in some cases there is gender-specific knowledge as well that is inappropriate to share with anyone of the opposite gender. When such knowledge is shared in the course of a study, there must be open and clear discussions about the extent to which such knowledge can be shared outside the community. You need to strictly observe any limitations imposed.

Using cameras and recording devices—capturing images and voices—can also be a sensitive issue, and you should seek permission first. The informants should understand clearly what you plan to do with the pictures or recordings. Publishing pictures of people without their permission can be offensive. Additionally, participants may be concerned about how their recorded voices will be used, and may not want such recordings archived. In some cases, Indigenous communities may confiscate recording devices if they are abused.

You must at all times bear in mind that you have earned the privilege of receiving any knowledge that has been sha-

red with you, and that responsibility for the use of the knowledge comes with that privilege. It is not a commodity, it is a trust.

## II. PROTECTION:

### **4. Consent: Full and informed consent from those participating in the research or those affected by it must be secured. Depending on the context, such consent may be individual or collective, or both.**

The principle of “informed consent” should be practiced regardless of whether the study constitutes “research” under IRB standards. All participants should be fully informed that they are involved in a research study before the study begins. Informed consent is a fundamental principle of the Common Rule and is monitored by IRBs. In the United States, informed-consent principles are clearly stated in the Common Rule (see <http://ohsr.od.nih.gov/info/sheet6.html>). Informed Consent is an important principle, not just a legal requirement. Such consent should be confirmed before the research commences and, if necessary or advisable, reaffirmed on an ongoing basis.

The consent of the Indigenous jurisdiction or collectivity may be required. Depending upon the context, there may be a readily identifiable governing body (e.g. Band Council, Tribal or Nation Council, Metis Settlement Council, organization board of directors) that is the natural point of contact for collective permission to undertake research. Where there are no identifiable persons or groups, then an Indigenous mentor or advisory group might be established

for cases where community information or knowledge is cited.

As with the principle of open consultation, making sure that the community and participants are truly informed and really understand what they are getting into may take time. A once-only statement or document may serve Western academic or legal requirements, but does not necessarily mean that consent has been either given or informed, especially in the case of more traditional peoples who operate under a different set of principles. See Tindana et al. (2006) and Miller et al. (2007) for case studies of obtaining informed consent in traditional settings.

The researcher should determine what the conditions of the informed consent will be, but leave latitude for those who agree to some conditions but not others. Signed informed-consent forms are useful, but researchers should be aware that Indigenous peoples can be sceptical about signing forms, and it is essential to build a relationship of openness and trust. Recording verbal consent is another option.

The process of informed consent may include traditional protocols such as the presentation of tobacco to Elders or other practices that are appropriate in the tradition of those agreeing to participate in the research. Traditional knowledge holders should be approached in culturally appropriate manners. At the same time, the informed-consent process can be presented as a matter of the researcher’s own cultural protocol. Just as the researcher is asked to respect and participate in the protocols of the com-

munity, so in turn the researcher can ask community members to respect the protocols of the academic world.

Where children are involved in the research, special attention should be given to ensuring that appropriate consent is obtained, including that of a parent or guardian and of other parties where appropriate; and where practical, of the children themselves. Research with children receives special consideration from the IRB approving the research.

In keeping with collaborative methods, it is strongly advised that research participants have the opportunity to check transcripts for accuracy and approve the use of quoted material before it appears in the research products. While not necessarily recognized as such, they are in effect, co-authors.

**5. Confidentiality: Confidentiality, anonymity and public recognition of participants are delicate if not dangerous matters for many Indigenous peoples, and must be clearly and carefully negotiated before any project materials are made public.**

The degree to which participants will be identified in the study and its related materials (including records, tapes and transcripts) or their words made available to other persons must be clearly negotiated as part of establishing informed consent. This includes three areas: confidentiality (control over publication or release of their statements to other persons), anonymity (whether or not they can or will be identified as the sources of information) and recognition

(whether or not they will be identified as participating in or facilitating the study).

Decisions on these matters should be made in consultation with the individuals to ensure that the individual will not be jeopardized in any way through public acknowledgement of their contribution to the research.

In politically volatile situations, even simple oral-history gathering can endanger peoples' lives. Therefore it is essential that the researchers work closely with Indigenous advisors to determine where and how any such material will be made public, and what levels of privacy and confidentiality need to be ensured.

In the case of historical studies involving archival or documentary materials, respect should be shown to the relatives and descendants and communities who may be affected by the research. The researcher should determine where identities may be disguised or where consultation with various parties may be needed.

**6. Protection: Indigenous knowledge and the intellectual property of traditional knowledge holders and Nations must be safeguarded within the bounds agreed to in negotiation with the community.**

Past negative experiences with researchers have created understandable concerns regarding the protection of Indigenous knowledge and traditional

intellectual property. How these will be protected should be discussed with research participants and Indigenous jurisdictions as part of the preliminary discussions regarding the research.

Regardless of the copyright of the published results, acknowledgement should be carefully undertaken to ensure that the intellectual property of Indigenous communities, Nations and traditional knowledge holders are shown the appropriate respect and afforded protection. Indigenous knowledge does not become the property of the researcher, and if third-party permission is requested of the researcher for further use of the materials produced, the researcher should refer that question to the person or community from whom that information originated.

In communities where research protocols have already been established, such protocols will likely address issues such as ownership of data, use of research materials and publication issues. As part of their preliminary research, researchers should determine whether there are local protocols that relate to their research.



If there is no local research protocol, researchers should establish a research agreement with the community. This ensures that the principle of openness is adhered to, and that guidelines for the ownership and use of information are clearly delineated.

Information provided by participants is their intellectual property, and they have the absolute right to exercise control over the use of the information they have volunteered. This includes the right to restrict access to it, or to withdraw part or all of the information from the actual research project findings. It is the researcher's responsibility to clarify with research participants how this control might be exercised.

The researcher must ensure the protection of Indigenous participants and Indigenous resources in the research process, including (as far as possible) protection from any negative impact that might result from the findings of the project being made public. This may include placing a moratorium on the research material for an agreed period of time or on keeping certain material confidential.

### III. RECIPROCITY

#### **7. Partnership: Research partnerships with Indigenous individuals, communities or organizations should be pursued, to the extent that they are desired. Collaborative work in full partnership with the community is often preferred.**

Using a collaborative approach, such as Community-Based Participatory Research (CBPR), ensures that the viewpoints and perspectives of the community or participants are fully integrated into every aspect of the project. Research partnerships ought to be developed in a way that meets the needs of both parties. The hiring and training of community members for the research project can further the transfer of knowledge skills to that community. As part of a collaborative process, the researcher would take responsibility for sharing and co-developing research skills with research participants.

Most importantly, partnership and collaborative methods serve to ensure many of the other principles listed here: open consultation, incorporation of Indigenous values, and that relationships are conducted with respect. Collaboration gives the community a sense of ownership in the project and helps ensure that the community benefits.

#### **8. Review: Research participants and community leaders should have the opportunity to review and revise drafts of the study, and should receive copies of the final study. They should receive acknowledgement, fair return and royalties where appropriate.**

Research participants, traditional knowledge holders and Indigenous jurisdictions should be afforded the opportunity to review proposed uses of Indigenous or traditional knowledge they have shared, and they have the right to decide whether their knowledge will be included in the final product. Before any form of distribution or publication takes place, the results and outcomes of any research based on materials contributed by Indigenous individuals or groups should be presented in draft form to those participants, and/or to the community's leaders or research advisory board.

It is important that the participants and the community leadership have the opportunity to comment on and provide feedback on interpretations of data, to review transcripts of their words and interpretations to confirm that any words attributed to them reflect their meaning, and to ensure that sensitive or inappropriate information is not published. Participants should have the right of veto or censure over their contributions. Revisions to draft materials should be made that respect the feedback given. This ensures the integrity of the final product and protects the intellectual property of the community.

Where possible, it is recommended that the research findings be presented at community forums as well as in written and/or visual forms, particularly to those who provided the basis for the research findings. Non-technical language and easily understandable formats should be used as much as possible to convey the results.



In some instances, translation into Indigenous languages may be necessary to ensure that those affected by the research have access to the results. Publication of the research findings in Indigenous forums (in addition to other venues) is strongly encouraged.

A summary of the final research report should be made available to any individual or group who provided information used in the final research report, and copies of the published study should be provided to the community.

**Benefit-sharing: Every effort must be made to ensure that benefits flow to Indigenous peoples from research, and that any potential negative impacts are minimized.**

Before undertaking research with an Indigenous community—or for that matter, with anyone—it is always good to ask yourself, “Who does this benefit?” If the research does not benefit the community, but perhaps only uses them to achieve some other end, then the project should be reconsidered. Whether the research is community-based, literary, philosophical or historical, it should at the minimum do no harm. But better, it should make a positive contribution to the needs, aims and aspirations as defined by the participating Indigenous community and should lead to the enhancement of the lives of its members. Research might be directly useful to an Indigenous jurisdiction or to individuals, or it may be beneficial by pushing the boundaries of Indigenous scholarship, or by contributing to scho-

larship in a more general sense. In all cases, the research ought to make a positive contribution to the lives of Indigenous peoples and/or to Indigenous or general scholarship, while doing no harm. And for the most part, it will be the community that decides what benefit they want from the project.

Where possible and appropriate, fair return should be given for participants’ help and services, which should be acknowledged in the final output. The contribution of any individual or group consulted should be acknowledged in the final research report, while recognizing that any individuals or groups taking part in the research have a right to remain anonymous.

If the information gathered will be used for any commercial purpose, a formal agreement should be made that considers the protection of the Indigenous community’s and individuals’ cultural and intellectual property as well as rights-in-data, and for any royalties to be derived from the study.

Beyond these formal types of benefits, researchers might want to engage in other acts of reciprocity (gifts, money, aid, etc.), with the people who have facilitated or contributed to their work, and possibly fed them as well. Reciprocity is a normal part of most Indigenous cultures, and it is good to participate in it by giving something back. At the same time, one must be mindful of cultural protocols and relations within the community, so that such gifts do not cause problems.



## INDIGENOUS RESEARCH PROTOCOL LINKS AND DO- CUMENTS

The following materials are organized geographically, as certain issues are specific to certain countries. However, all of these documents assist the researcher in gaining a deeper understanding of the legal and ethical issues.

**Note:** the interchangeable terms "Indigenous," "Aboriginal," "Native," "Indian," and "First Nations" (or, "First Peoples") are used by different countries and different organizations.

### WORLD:

World Intellectual Property Organization. "WIPO and Indigenous Peoples." <http://www.ohchr.org/Documents/Publications/GuideIPleaflet12en.pdf>.

Indigenous Peoples Council on Biocolonialism (IPCB). "Indigenous Research Protection Act." <http://www.ipcb.org/publications/policy/files/irpa.html>.

UN Commission on Human Rights, Working Group on Indigenous Populations. "The Mataatua Declaration on Cultural & Intellectual Property Rights of Indigenous Peoples." <http://www.ankn.uaf.edu/IKS/mataatua.html>

UN Human Rights Council. 1995. "Principles & Guidelines for the Protection of the Heritage of Indigenous People." <http://www.ankn.uaf.edu/IKS/protect.html>.

World Health Organization. "Indigenous Peoples & Participatory Health Research." [http://www.who.int/ethics/indigenous\\_peoples/en/index1.html](http://www.who.int/ethics/indigenous_peoples/en/index1.html).

### UNITED STATES:

U.S. Department of Health and Human Services: Research Involving Human Subjects.

<http://grants2.nih.gov/grants/policy/hs/>. This site provides, in one place, HHS and NIH requirements and resources for the extramural community involved in human subjects research in their roles as:

Applicants/Grantees, Offerers/Contractors, Peer Reviewers and Institutional Officials.

American Indian Law Center, Inc. 1999. "Model Tribal Research Code, Third Edition," Albuquerque. <http://www.npta.arizona.edu/research/NPTAOResearchProtocolsWebPage/AllLawCenterModelCode.pdf>

Austin, Diane, Sherri Gerlak, and Carolyn Smith. 2000. "Building Partnerships with Native Americans in Climate-Related Research and Outreach" -- CLIMAS Report Series CL2-00. Institute for the Study of Planet Earth, The University of Arizona. <http://www.climas.arizona.edu/files/climas/pubs/cl2-00.pdf>.

"Ethics of Research Involving Indigenous Peoples and Vulnerable Populations." Report of the Global Forum on Bioethics in Research Ninth Annual Meeting. Auckland, 2008.

Hopi Cultural Preservation Office. "Protocol for Research, Publications and Recordings." <http://www.nau.edu/%7Ehcpcp-p/hcpcp>. Mihesuah, Devon A. 1993. "Suggested Guidelines for Institutions with Scholars Who Conduct Research on American Indians." *American Indian Culture and Research Journal* 17(3): 131-139.

Nason, James D. 1996. "Tribal Models for Controlling Research." *Tribal College Journal*, 8(2): 17-20.

National Endowment for the Humanities. "Code of Ethics Related to Native Americans." <http://www.neh.gov/grants/manage/code-ethics-related-native-americans>

NCAI Policy Research Center. "Research Tools." <http://www.ncaiprc.org/tools>. Contains the following documents: "Research Regulation in American Indian/Alaska Native Communities: Policy and Practice Considerations." "Research Regulation in American Indian/Alaska Native Communities: A Guide to Reviewing Research Studies." "Sample Memorandum of Understanding." "Sample Memorandum of Cooperative Agreement."

U.S. Interagency Arctic Research Policy Committee. 1995. "Principles for the Conduct of Research in the Arctic." <http://arcticcircle.uconn.edu/SEEJ/ethics.html>

### CANADA:

Assembly of First Nations Environmental Stewardship Unit. 2009. "Ethics in First Nations Research." [http://www.afn.ca/uploads/files/rp-research\\_ethics\\_final.pdf](http://www.afn.ca/uploads/files/rp-research_ethics_final.pdf).

Association of Canadian Universities for Northern Studies. 2003. "Ethical Principles for the Conduct of Research in the North." <http://www.nri.nu.ca/pdf/EthicsEnglishmarch2003.pdf>.

Canadian Institutes of Health Research. 2007. "CIHR Guidelines for Health Research Involving Aboriginal People." <http://www.cahr.uvic.ca/nearbc/documents/2009/aboriginal/CIHR-IAPH%20Guidelines%20for%20Health%20Research%20Involving%20Aboriginal%20People.pdf>.

First Nations Centre, National Aboriginal Health Organization. 2005. "Sacred Ways of Life: Traditional Knowledge Toolkit." [http://www.naho.ca/documents/fnc/english/2005\\_traditional\\_knowledge\\_toolkit.pdf](http://www.naho.ca/documents/fnc/english/2005_traditional_knowledge_toolkit.pdf)

First Nations Centre. 2007. "Considerations and Templates for Ethical Research Practices." Ottawa: National Aboriginal Health Organization. [http://www.naho.ca/documents/fnc/english/FNC\\_ConsiderationsandTemplate-InformationResource.pdf](http://www.naho.ca/documents/fnc/english/FNC_ConsiderationsandTemplate-InformationResource.pdf)

Indigenous Peoples Health Research Centre (IPHRC). 2005. "Kwayask Itôtamowin: Indigenous Research Ethics." [http://iphrc.ca/assets/Documents/IPHRC\\_ACADRE\\_Ethics\\_Report\\_final.pdf](http://iphrc.ca/assets/Documents/IPHRC_ACADRE_Ethics_Report_final.pdf)

Trent University. 2004. "Ethics Guidelines for Ph.D. Program in Indigenous Studies." <https://www.trentu.ca/indigenousstudiesphd/ethicsguidelines.php>

Tri-Council Policy Statement, Government of Canada. 2006. "Research Involving Aboriginal Peoples" Section 6 of "Ethical Conduct for Research Involving Humans" <http://www.pre.ethics.gc.ca/english/policystatement/section6.cfm>

University of Victoria Faculty of Human and Social Development. 2003. "Protocols & Principles for Conducting Research in an Indigenous Context." <http://www.uvic.ca/hsd/assets/docs/pdf/policies/igovprotocol.pdf>.

### NEW ZEALAND & PACIFIC ISLANDS

Auckland Uniservices Ltd. 2001. "Pasifika Education Research Guidelines." New Zealand Ministry of Education. [http://www.educationcounts.govt.nz/\\_data/assets/pdf\\_file/0010/7669/pacsrc-h--guide.pdf](http://www.educationcounts.govt.nz/_data/assets/pdf_file/0010/7669/pacsrc-h--guide.pdf)

Cram, Fiona. 1997. "Developing Partnerships in Research: Pākehā Researchers and Māori Research." *SITES* 35: 44-63

Pūtaiora Writing Group. 2010. "Te Ara Tika: Guidelines for Māori Research Ethics: A Framework for Researchers and Ethics Committee Members." Health Research Council of New Zealand. <http://www.hrc.govt.nz/sites/default/files/Te%20Ara%20Tika%20Guidelines%20for%20Maori%20Research%20Ethics.pdf>.

University of Otago. 2011. "Pacific Research Protocols." <http://www.otago.ac.nz/research/otago028669.pdf>.

### AUSTRALIA:

The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). 2012. "Guidelines for Ethical Research in Indigenous Studies." [http://www.aiatsis.gov.au/\\_files/research/ethics/GERAIS.pdf](http://www.aiatsis.gov.au/_files/research/ethics/GERAIS.pdf). [This is an ex-

tremely good source, very detailed with advice on actually implementing the guidelines]

Queensland Department of Aboriginal & Torres Strait Islander Policy and Development. 1999. "Protocols for Consultation and Negotiation with Aboriginal People" <http://www.datsima.qld.gov.au/resources/atsis/everybodys-business/protocols-aboriginal/protocols-for-consultation.pdf>.

### OTHER READING:

Caine, V., C. Davis, T. Jacobs, and A. Letendre. 2004. "Ethics in the Context of Research and Indigenous Peoples: A Bibliography." *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 2(1): 91-120.

Cajete, Gregory. 2000. *Native Science: Natural Laws of Interdependence*. Clear Light Books.

Ferreira, Maria Pontes and Fidji Gendron. 2011. "Community-Based Participatory Research with Traditional and Indigenous Communities of the Americas: Historical Context and Future Directions." *International Journal of Critical Pedagogy*, 3(3): 153-168.

Hart, Michael Anthony "Indigenous Worldviews, Knowledge, and Research: The Development of an Indigenous Research Paradigm." *Journal of Indigenous Voices in Social Work*, 1(1): 1-16.

Miller Suellen, Phuoc V. Le, Sienna Craig, Vincanne Adams, Carrie Tudor, Sonam, Nyima, Droyoung, Mingkyi Tshomo, Lhakpen, and Michael Varner. 2007. "How to Make Consent Informed: Possible Lessons from Tibet" *IRB: Ethics and Human Research*, Vol. 29, No. 6: 7-14.

Smith, Linda Tuhiwai. 1999. *Decolonizing Methodologies: Research and Indigenous Peoples*. Zed Books, London

Sahota, Puneet Chawla. 2010. "Community-Based Participatory Research in American Indian and Alaska Native Communities." NCAI Policy Research Center.  
<http://www.ncaiprc.org/files/CBPR%20Paper%20FINAL.pdf>.

Tindana, Paulina Onvomaha, Nancy Kass, and Patricia Akweongo. 2006. "The Informed Consent Process in a Rural African Setting: A Case Study of the Kassena-Nankana District of Northern Ghana" *IRB: Ethics and Human Research*, Vol. 28, No. 3: 1-6.

# KAPATAKANA/PORTAGE TRAILS

COLLABORATION: NEGOTIATING THE PASSAGE FROM INTENT TO ACTUALIZATION



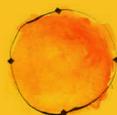
## **Mamu minu-tutamutau**

Louise Lachapelle and Shan dak Puana  
Co-leads

## **THE TOOLBOX**

**RESEARCH PRINCIPLES IN ABORIGINAL SETTINGS:  
ETHICS, RESPECT, FAIRNESS, RECIPROCITY, COLLABORATION AND CULTURE**

Suzy Basile, Karine Gentelet and Nancy Gros-Louis Mchugh, eds.



2015

# KAPATAKANA/PORTAGE TRAILS

## COLLABORATION: NEGOTIATING THE PASSAGE FROM INTENT TO ACTUALIZATION

### **Mamu minu-tutamutau**

Louise Lachapelle and Shan dak Puana  
Co-leads

**Doing well together** in a collaborative context – what does that mean? This is the question raised by **Mamu minu-tutamutau** from the point of view of the different partners in a collaborative research project in Aboriginal communities.

**Mamu minu-tutamutau** is an experiential and evolutionary approach rooted in a friendship between two women, both researchers and artists, who discovered the complementarity of their skills and activist commitments. For several years, this critical and creative complicity has deepened and grown even stronger, enabling us to combine our efforts and knowledge to work together in an intercultural perspective for the decolonization and democratization of the research relationship between Aboriginal and non-Aboriginal collaborators.

Collaborative ethics develop as we negotiate the passage from the intent to the actualization of collaboration.

Learning to work together requires respect, time, a mutual commitment, adjustments and demanding learning processes. Each collaborator is repeatedly faced with the issues, challenges, conflicts and solidarity specific to power dynamics and collaborative processes.

To illustrate these crucial stages, moments of fluidity and stormy passages that punctuate the individual and collective paths travelled by collaborators, **Mamu minu-tutamutau** draws inspiration from **portage trails** or **kapatakana** (an Innu-Aimun term). These vital trails allow us to journey along Nitassinan rivers and provide rest areas along the shore and in the forest.

## KAPATAKANA/PORTAGE TRAILS

How can we collaborate to do research in Aboriginal communities?

And work together to do what? How, and for what purpose?

On the concrete yet fragile ground of collaborative research in Aboriginal communities, the Aboriginal and non-Aboriginal partners from universities and communities begin to move together to reconcile a diversity of objectives and ways of doing things by carrying out common projects.

Meeting the challenge of **Doing well together** in a collaborative context requires creating and maintaining conditions favourable to respectful, safe and healthy dialogue; reflexivity; reciprocal relationships; concerted action; collaborative governance; and cultural exchange.

However, one of the biggest challenges facing these collaborators remains the reconciliation of their respective ethical spaces so that the outcome of collaborative work and of the collaboration itself become the expression of a shared vision of **Doing well together** in a collaborative context.

# MAMU MINU-TUTAMUTAU

## APPROACH RESEARCH COLLABORATION

**Research collaboration** between Aboriginal and non-Aboriginal partners is a political, ethical and scientific project.

On the concrete ground of research collaboration in Aboriginal communities, Aboriginal and non-Aboriginal partners challenge themselves to work together to transform the research relationship and the (inter) cultural conditions that tend to maintain historical, structural and socioeconomic inequalities.

**Mamu minu-tutamutau** seeks to foster conditions more favourable to respectful, fair and negotiated collaboration for research conducted in Aboriginal communities, as well as form reciprocal and responsible relationships among collaborators (Aboriginal and non-Aboriginal researchers, organizations and communities).

## KAPATAKANA/PORTAGE TRAILS

### Issues and challenges of research collaboration in Aboriginal communities

- ◆ Respect the well-being and interrelationships among individuals, communities, ecosystems and knowledge.
- ◆ Make research more relevant to all partners and increase its social and scientific integrity.
- ◆ Promote the appropriation and implementation of a shared ethical outlook and culturally adapted governance and self-regulation processes.
- ◆ Develop common language, points of reference and inclusive and consistent ethical practices to guide concerted action (individual and collective).
- ◆ Contribute to the self-determination and increased research capacity of Aboriginal communities and organizations and boost their participation in all stages of research, including the choice of research topic and questions; research methodology, conduct and evaluation; intellectual property rights; and the mobilization of knowledge, with respect to the level of involvement desired by each party.
- ◆ Encourage mutual healing, social justice and peaceful coexistence.

#### Imagine a common vision of coexistence arising from our different perspectives

The intercultural research relationship between Aboriginals and non-Aboriginals remains fundamentally unequal. When the research process does not question the power structures and the systemic and persistent socioeconomic and cultural inequalities in Canada, it runs the risk of continuing to reproduce them, simply because these inequalities serve (and sometimes reinforce) the established culture and power, academic hierarchy and academic freedom, as well as the dominant methods for producing and sharing knowledge.

Aboriginal peoples and colonizing peoples have a “different historical consciousness” (Sioui Durand, 2009) and are still struggling to imagine a common vision of their coexistence. These are necessary and critical findings in light of the possibilities as well as the current limitations of collaborative research between Aboriginal and non-Aboriginal partners. (SOURCE: Lachapelle and Puana, 2012)

# MAMU MINU-TUTAMUTAU

## APPROACH COLLABORATIVE ETHICS

**Collaborative ethics** situate the research relationship within a holistic approach to self-determination, self-regulation, individual and collective healing and social justice.

The issues and challenges related to the establishment of an equitable research partnership and the creation of conditions for a mutually beneficial collaborative approach impact, in a concrete and comprehensive manner, the implementation of **collaborative ethics** and working methods that are explicit, egalitarian and negotiated in the context of research in Aboriginal communities. In other words, they are influenced by the various interpersonal and organizational relationships that develop among community and Aboriginal and non-Aboriginal academic partners, including the informal relationships and collaboration maintained beyond a specific research project.

**Mamu minu-tutamutau** values the critical and transformational power of collaboration and develops a creative and performative approach to **collaborative ethics** in Aboriginal communities.

## KAPATAKANA/PORTAGE TRAILS

### Collaborative ethics issues and challenges in Aboriginal communities

- ◆ Recognize the ethnocentric and discriminatory nature of colonial history and cultural heritage and, in particular, of its research tradition whose values and practices still define, to a large extent, the academic system.
- ◆ Take a critical look at “our own” culture in its relationship to that of the “other” and give voice to this critique (despite the risk of loyalty conflicts and marginalization).
- ◆ Know the history and present context of the communities with which we work.
- ◆ Situate ourselves as subject and analyze the power relations that we have with others: colleagues, partners and research participants.
- ◆ Challenge the epistemological foundations of Western research and consequently transform the values and practices that are embedded in institutional and disciplinary traditions, as well as in professional, community and personal cultures.
- ◆ Put into practice forms of reflexivity (personal and collective, disciplinary and institutional) that introduce ethical and methodological changes adapted from an intercultural point of view and that transform the relationship to knowledge.

#### How can we do research and live together?

Over the course of the ongoing negotiations that consolidate the collaborative efforts of research partners, including the choice of research topic and questions; research methodology, conduct and evaluation; intellectual property rights; and the mobilization of knowledge, the first challenge is probably the creation of a language and ethics that respond collectively to common and pressing socioeconomic and (inter) cultural issues, the recognition of the essentially relational aspect of the research process. This is both an ethical, political and scientific responsibility and project: the establishment of the conditions making collaboration possible between Aboriginals and non-Aboriginals, the development of different research relationships and an intercultural approach to decolonization. How to be in a relationship rather than in opposition, how do we do research (and live) together? (SOURCE: Lachapelle and Puana, 2012)

# MAMU MINU-TUTAMUTAU

## APPROACH COLLABORATION AGREEMENT

The collective development of a **collaboration agreement** is a pragmatic strategy for establishing a mutually satisfactory definition of conditions for collaboration and forms of self-regulation necessary for a negotiated research partnership.

**The research collaboration agreement** should explicitly state how the partners have agreed to work together and clearly summarize their mutual decisions and commitments, for example regarding their roles and responsibilities, the exercise of powers and decision-making, control over the research conduct framework, the sharing of anticipated benefits and the prevention of inappropriate practices, such as the exploitation and marketing of Aboriginal knowledge.

**The collaboration agreement** is a formal document signed by the parties involved that should also include the research plan, a document that describes the scientific objectives of the research and methodologies, identifies the sources of funding and sets out the expected results. Additionally, it should include a formal protocol on how data and findings are to be shared in the context of research in Aboriginal communities.

**Mamu minu-tutamutau** considers the negotiation and development of a **collaboration agreement** as a creative, performative and transformational process that fosters the sharing, reconciliation and intercultural learnings essential for the research partners to develop **collaborative ethics**. **The collaboration agreement** thus serves as a vision statement, a tool for research and governance, and a space for ethical dialogue. The resulting document, along with the process that led to its creation, forms an integral part of the collaborative research and is one of the main findings.

## KAPATAKANA/PORTAGE TRAILS

Among the issues and challenges specific to the collaboration agreement:  
to act according to a different vision of research in Aboriginal communities

**A creative process** The partners use their imaginations to reconcile a variety of objectives and ways of doing things (methodologies, protocols and other cultural practices) and their respective ethical spaces. They transform the research's relational dynamic, how research is conducted and its impacts, as well as our relationship to knowledge.

**A performative process** Individually and collectively through their words and actions, the collaborators jointly define and implement the equitable and culturally adapted conditions of a mutually satisfying and beneficial research partnership based on reciprocal relationships.

**An iterative process** The negotiated development and revision of a collaboration agreement is a process that continues throughout the research. This dialogue is ongoing as the research is defined, conducted and evaluated. It demonstrates the transformational power of collaboration and collaborative ethics.

"The strength and usefulness of a research agreement is directly related to the quality of the research relationship among the research partners. A respectful relationship is developed on the same basis as an effective agreement. Elements of both include good communication, honesty, transparency and trust." (SOURCE: CIHR, 2007)

# MAMU MINU-TUTAMUTAU

## ACTIVITIES

### Training and exchange workshops

#### Research projects and collaboration

Meeting the challenge of **Doing well together** in a collaborative context means creating and maintaining conditions favourable to respect and dialogue, reciprocal relationships conducive to the achievement of concerted actions, collaborative governance and the crossroads of cultures.

The **training and exchange workshops** offered by **Mamu minu-tutamutau**, as well as its research **projects and collaboration**, help participants to identify and better understand the diversity of these conditions and develop culturally appropriate collaborative ethics through concrete actions with the principal actors in a spirit of creative exchange and mutual training.

**Mamu minu-tutamutau** contributes to this vast movement of affirmation and empowerment of the traditional ethics and protocols of Aboriginal peoples, the collective knowledge embodied by the Elders and by the custodians of ethics in Aboriginal communities.

### WEB platform

<http://mamuminututamutau.wordpress.com/>

#### Interactive and evolving archives on research ethics and practices in Aboriginal communities

Hosted on the **Mamu minu-tutamutau web platform**, the **archives** contain more than sixty resources and tools on ethics and research practices in Aboriginal communities. This annotated bibliography offers a continuous and interactive review of numerous guides and guidelines on ethics and research practices developed by Aboriginal communities and organizations.

The purpose of these **archives** is to increase awareness of this abundant documentation and make it more accessible. It is particularly important to promote the circulation and ownership of these diverse tools by Aboriginal communities and organizations.

Suggestions for additions to the **archives** and comments on the documents already posted are welcome.

### Publications and conferences

The **publications and conferences** of **Mamu minu-tutamutau**, like its other activities in Aboriginal communities, play a role in developing pragmatic practices and strategies and actively search for solutions addressing some of the needs identified by the communities and Aboriginal and non-Aboriginal researchers.

The dissemination activities of **Mamu minu-tutamutau** also aim to inform the actors working in Aboriginal and research communities and raise their awareness about certain issues and challenges specific to collaborative research in intercultural and interdisciplinary contexts.

#### The collaboration agreement: a creative, performative and iterative process

**Mamu minu-tutamutau** is also developing a research and governance tool inspired by Aboriginal protocols that will support the efforts of communities in their negotiations with researchers.

Negotiating the terms and conditions of research collaboration facilitates the **passage from the intent to the actualization of collaboration** and determines the partners' **collaborative ethics**.

The collective development of a **collaboration agreement** is a pragmatic strategy for establishing:

- ◆ Respectful relationships.
- ◆ Favourable conditions for intercultural ethical dialogue.
- ◆ A mutually satisfactory definition of the conditions for collaboration and the forms of self-regulation necessary for a negotiated research partnership.

## KAPATAKANA/PORTAGE TRAILS

# THE COLLABORATION AGREEMENT OR SEARCHING FOR WAYS OF DOING WELL TOGETHER

**Collaborating in research** requires developing a language and ethics that respond collectively to common socioeconomic and (inter) cultural issues. The ongoing development of a collaboration agreement is a pragmatic strategy to facilitate the passage from the intent to the actualization of collaboration. These **collaborative ethics** supports the partners' creative and performative approach in all phases of research on any subject or area.

The **collaboration agreement** is a tool for research and governance that guides the collaborators in the negotiation, definition and realization of their research, as well as in the appropriation and implementation of their **collaborative ethics**. This concerted effort takes place prior to starting the initial research activities, or better yet, prior to submitting funding applications. It's worth remembering that the first contact sets the stage! Everyone is responsible for these **collaborative ethics**. The collaborators' individual and collective capacity to demonstrate respect and openness when entering into this dialogue is a significant indicator of the specific challenges and potential of their partnership.

The **collaboration agreement** explicitly documents the terms of reference and working methods on which a research partnership is built. It is periodically evaluated and adapted to the context, activities and the evolution of the research relationship. In summarizing the nature, objectives and terms of the collaboration, the **collaboration agreement** reflects a shared understanding of **Doing** and **Doing together** in a collaborative context. Such an agreement is the basis on which **collaborating in research** and **collaborative ethics** can become the expression of a shared vision of **Doing well together** in a collaborative context that takes into consideration the different points of view of these collaborative partners.

## KAPATAKANA/PORTAGE TRAILS

### The collaboration agreement: meeting the challenge of Doing well together

**What do we mean by Doing in a collaborative context?** Reconciling the partners' diverse scientific and community objectives and agree on the subject of the collaboration, as well as on the objectives of the collaborative effort.

**What do we mean by Doing together in a collaborative context?** Reconciling the different ways of doing things (methodologies, protocols and other cultural practices), as well as agree on a common vision of collaboration and the practical ways of working together.

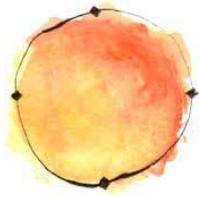
**What do we mean by Doing well together in a collaborative context?** Reconciling ethical spaces and agreeing on the terms and goals of the collaboration, the self-regulatory processes and a way to evaluate the collaboration and its outcome that satisfies the different actors.

### Strategic collaborations and participatory approaches to collaboration

According to research ethics policies, researchers now find themselves obligated to encourage Aboriginal communities affected by their research to participate. In addition, the policy and research program orientations are such that researchers must secure part of the financing for their activities in the form of strategic partnerships in Aboriginal communities supported by various governments.

The concerns of Aboriginal organizations and representatives (social justice, political objectives or a desire to access funds unavailable to Aboriginal communities other than through association with a university) are sometimes the reason for becoming involved in research funding applications, research activities or strategic collaborations (of variable usefulness) with researchers.

(SOURCE: Lachapelle and Puana, 2012)



## KAPATAKANA/PORTAGE TRAILS

# WHAT DOES **DOING** MEAN IN A COLLABORATIVE CONTEXT ?

A **collaboration agreement** requires a concerted and shared definition of the subject of the collaboration and the objectives of the collaborative efforts in the specific context of a research partnership.

### Why work together? To do what? And for what purpose?

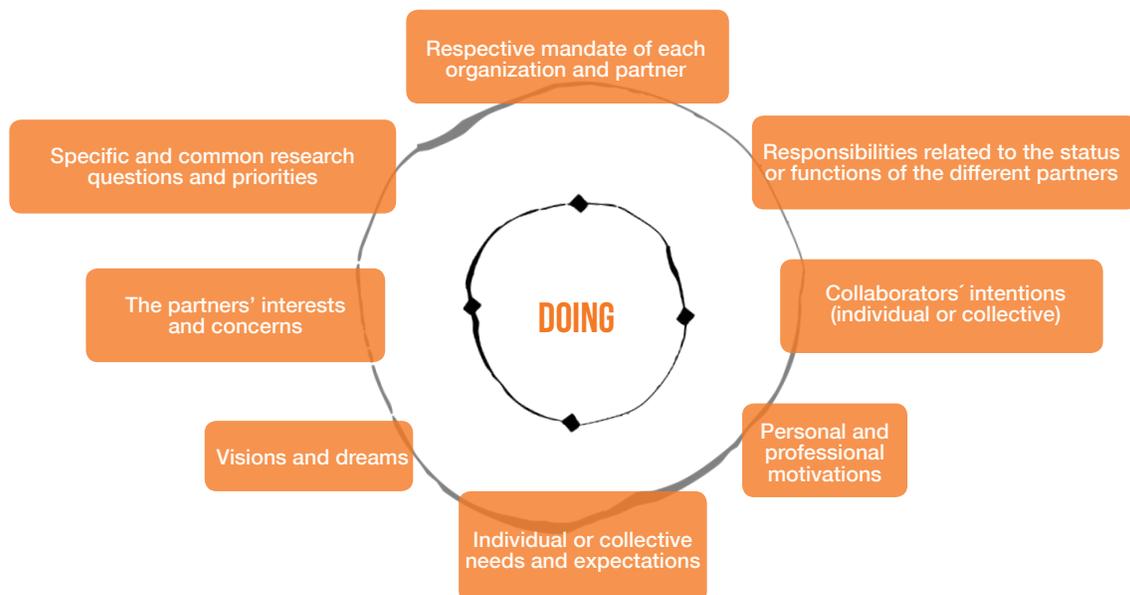
Aboriginal organizations, communities and representatives do not necessarily get involved in community-based research projects for the same reasons Aboriginal and non-Aboriginal researchers do. Their needs, intentions and scientific or community objectives may differ. Aboriginal and non-Aboriginal partners undertake a collaborative approach developed from positions, experiences and practices that are extremely different from one another. This reality might seem obvious.

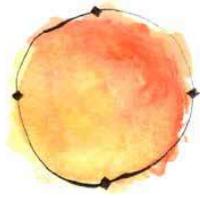
However, collaborators rarely assess these differences as they enter into their research partnership. It is nevertheless their responsibility to manage this diversity positively by addressing the challenges of increasing the relevance of the research for all the parties involved.

Favourable conditions for the emergence of a common definition and a shared understanding of the purpose and objectives of the research collaboration are created in order to ensure that the collaboration will produce high-quality ethical research because it is more responsible and mutually beneficial.

Collaborative research recognizes that partners need to show respect for the social and scientific integrity of the research. Each partner has obligations to the other partners, communities and research participants.

Reconciling the diverse motivations and objectives (scientific and community, personal and professional, individual and collective) of the partners involved in a process of doing in a collaborative context that mobilizes the people, organizations and communities concerned.





## KAPATAKANA/PORTAGE TRAILS

# WHAT DOES **DOING TOGETHER** MEAN IN A COLLABORATIVE CONTEXT ?

**Collaborating in research** is based on the negotiation and ongoing evaluation of the collaboration conditions. The partnership restores the balance in the research relationship and increases the relevance of the research for all partners.

How can we do together in a collaborative context?

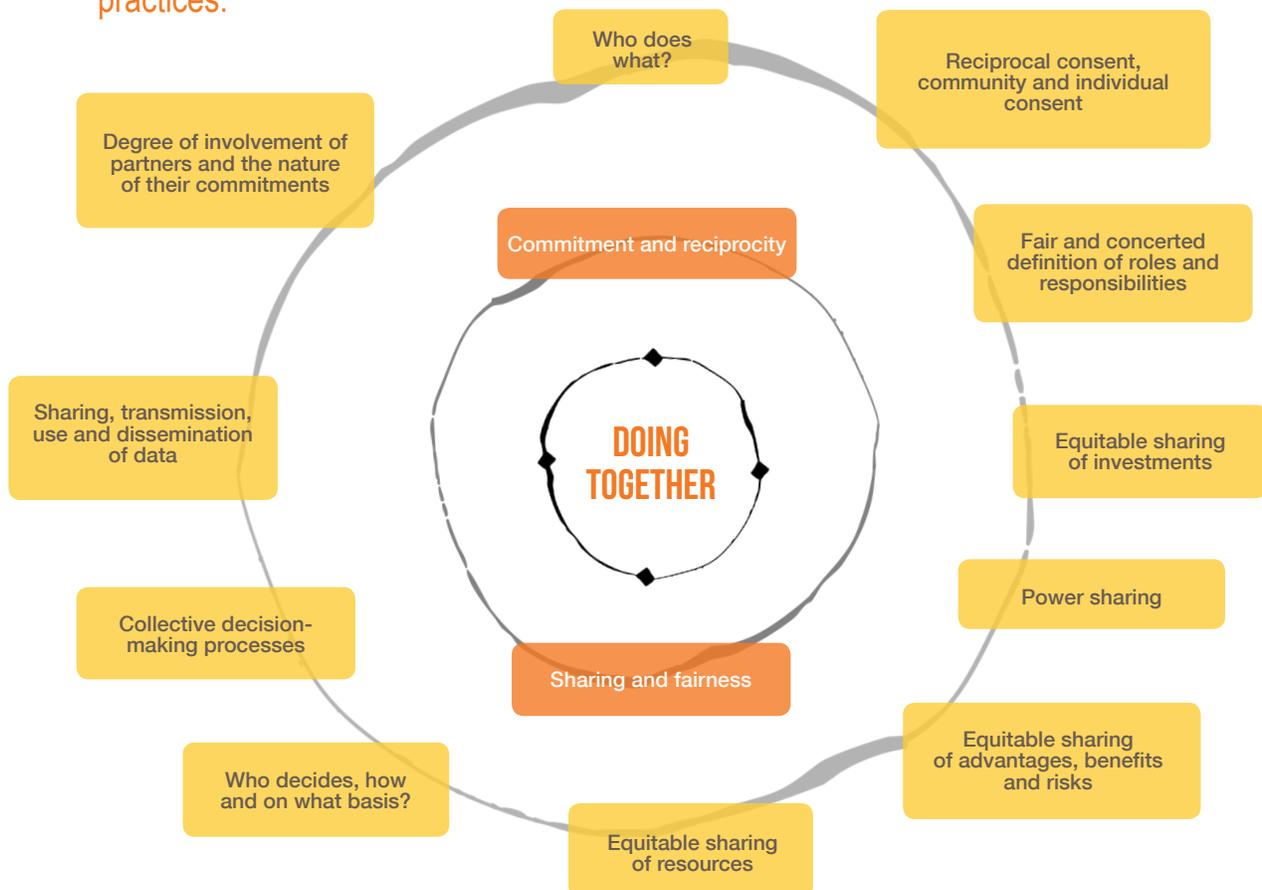
What is collaboration from the perspective of the various partners collaborating on a research project in Aboriginal communities?

How will we work together?

The **collaboration agreement** is intended to guide and establish a fair, reciprocal and mutually beneficial relational process that ensures all partners (community and university, Aboriginal and non-Aboriginal) share the responsibility for the manner in which the various phases of the research project are conducted and self-regulated to the degree of involvement desired by each actor.

The development of a **collaboration agreement** leads to an ethical dialogue where partners can openly discuss the concrete problem of equitable and culturally adapted conditions under which to conduct research and collaborate in Aboriginal communities.

Reconciling ways of doing things, methodologies, protocols and other cultural practices.



## Commitment and reciprocity

### Fair and concerted definition of roles and responsibilities

#### Partners' degree of involvement and the nature of their reciprocal commitments

##### *Who does what?*

The partners jointly negotiate the nature and degree of appropriate involvement in each stage of research. They define a satisfactory and mutually beneficial level of commitment and reciprocal obligations. The collaboration agreement enables mechanisms to be set up to operationalize these commitments and the active participation in the research

### Reciprocal consent and commitments

#### Collaboration agreement

#### Community and individual consent

##### *Who does what?*

Collaborative ethics tends to adopt a relational understanding of community and individual consent. This is an ongoing process and a reciprocal commitment in which the collaborators (partners or participants), under the collaboration agreement, are mutually accountable throughout the research project.

## Sharing and fairness

### Power sharing

#### Collective decision-making processes

##### *Who has what powers (authority and capacity)? Who decides what, in whose name, how and on what basis?*

Collaborative research is the responsibility of all partners. This involves a concerted and adapted definition of the respective roles and responsibilities of the collaborators, the planning phase and power sharing mechanisms.

Collective decision-making processes that are transparent, democratic and inclusive enable partners and participants to share control of the manner in which research is conducted (project design, formulation of research questions, planning, management, collection, analysis and interpretation, dissemination, evaluation and monitoring of research) and the management of resources, data and findings.

For example, decision-making processes based on some Aboriginal consensus models can develop a spirit of solidarity between the partners and affirm the strength of collective decisions.

### Equitable sharing of resources, benefits, risks and investment

##### *Who pays? Who contributes? Who benefits?*

"Benefit sharing in research is an essential concern of Aboriginal communities. A research project should lead to outcomes that are beneficial to the participating Aboriginal community and/or individual community members. Benefit sharing vis-à-vis a community should be interpreted from the community's perspective. . . . Benefit sharing involves fair reward for investments in research." (SOURCE: CIHR, 2007)

To ensure fairness and reciprocity, the allocation of financial resources should go beyond simply reimbursing expenses and be used to compensate partners for the costs of the participation of Aboriginal communities and organizations involved in the research project.

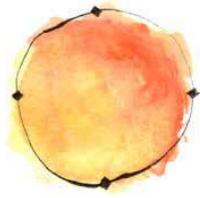
Sufficient resources (funding, services, time and training) should be made available to partners for ongoing learning.

### Sharing, transmission, use and dissemination of data

##### *Fair trade? Reciprocity? Circularity of knowledge?*

A formal protocol, negotiated locally and, if necessary, adapted to the different activities specific to the project, complements the collaboration agreement by defining the ethical guidelines for:

- ◆ The manner in which the First Nations OPAC Principles™ will be applied: What are the obligations of the partners with respect to the Ownership, Control, Access and Possession of information, data, results and other deliverables of the research project.
- ◆ Respect for local protocols and practices regarding traditional knowledge (TK).
- ◆ Intellectual property rights (IPR) and co-ownership of intellectual property.
- ◆ The official name and signature, as well as the use of such, to identify any coproduction or knowledge mobilization activity, thereby ensuring the partners and participants' contribution is formally recognized, if they so desire.



## KAPATAKANA/PORTAGE TRAILS

# WHAT DOES **DOING WELL TOGETHER** MEAN IN A COLLABORATIVE CONTEXT ?

The **collaboration agreement** sets out the manner in which the partners' different practices and skills, the diversity of people, opinions and voices (including dissenting and divergent opinions), and the diversity of cultures, traditions and knowledge systems will be recognized, respected and valued.

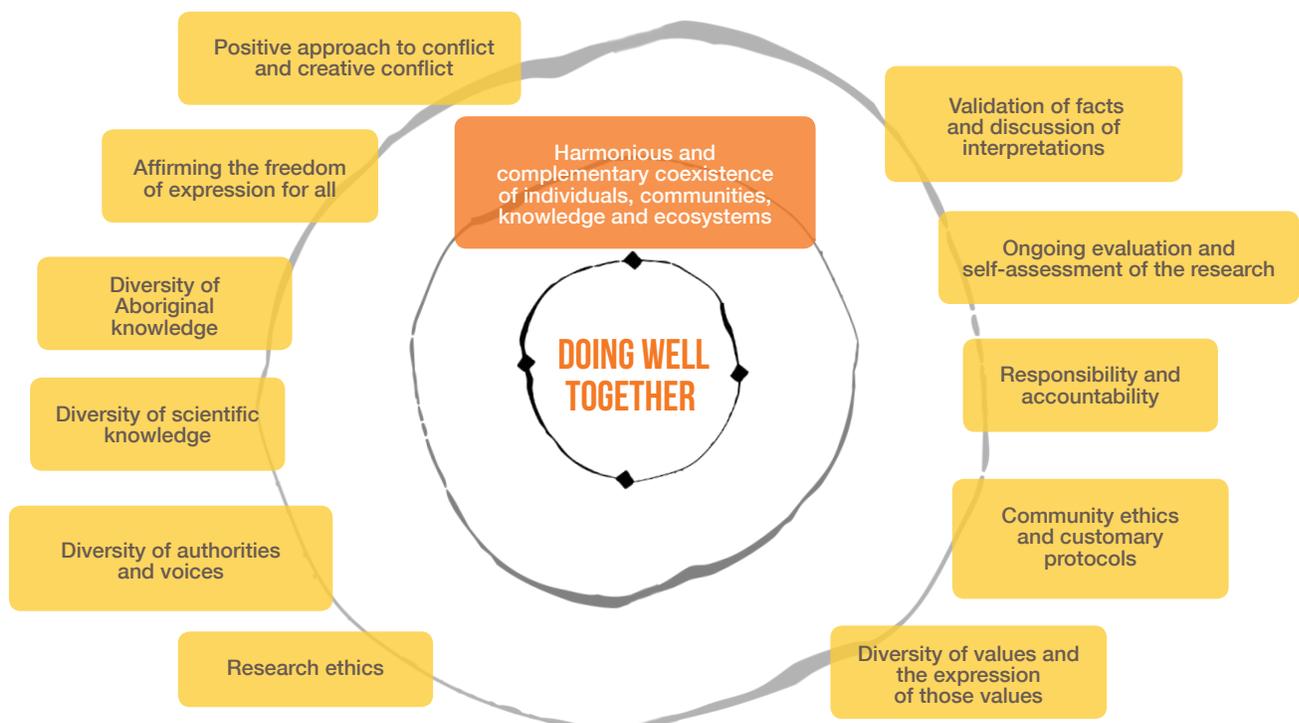
It also defines the main principles, ethical guidelines, self-regulatory processes and core values the collaborators will adhere to in creating a research partnership that is egalitarian, equitable, sustainable and viable, and whose diverse outcomes are mutually beneficial.

How can people Do well together in a collaborative context?  
And they will Do well together according to what perspectives and criteria?  
According to which intentions, values, needs and goals?

Personal motivations, worldviews and value systems all have a significant impact on how people approach collaborative research and on how they manage to situate themselves in a relational dynamic where differences emerge in a state of tension that is potentially creative or conflictual. This tends to accentuate the need for self-reflection, dialogue and conciliatory processes of intercultural ethics.

The evolutionary nature of a **collaboration agreement** stems from the fact that the negotiation, development and evaluation of the structure of the **collaborating in research** and **collaborative ethics** themselves constitute a process that is continuously unfolding throughout the research project. The agreement therefore constitutes a space for dialogue and a continuous evaluation and self-assessment tool of the research process and its impacts, as well as the collaborative ethics from the different partners' perspective.

Reconciling the ethical spaces, the cultural, social and spiritual values of Aboriginal communities, and the research communities.



## Harmonious and complementary coexistence of individuals, communities, knowledge and ecosystems

### Validating facts and discussing interpretations

*Who's talking about what? To whom? In whose name? In what language and for what purpose? From what position/culture?*

The collaboration agreement sets out procedures for reviewing interpretations and validating facts that are viable and fully integrated into research activities. The aim is to gather input from various actors in order to:

- ◆ Correct factual errors.
- ◆ Discuss interpretations, conclusions and research findings.
- ◆ Contextualize interpretations and conclusions.
- ◆ Disclose research limitations.

### Affirmation of freedom of expression for all

The collaboration agreement explicitly sets out that the diversity of experiences and viewpoints, freedom of conscience and the right to dissent and disagree are to be respected by creating:

- ◆ Favourable conditions for safe and healthy dialogue among collaborators and all those involved (partners and participants).
- ◆ Appropriate means to communicate, listen to and document the diversity of views and voices, including divergent opinions.
- ◆ Prevention, mediation and conflict management procedures.
- ◆ Opportunities to develop individual and collective skills for critical dialogue and the sound management of conflict and dissenting views.

### Positive approach to conflict

#### Creative conflict

Various situations and dynamics can disrupt collaborative research in which conflicts are inevitable and potentially creative insofar as they also carry the potential for change and innovation.

The aims of the collaboration agreement is to:

- ◆ Anticipate potentially conflicting values, loyalties or interests.
- ◆ Identify appropriate strategies that can be used to develop the collective capacity for safely managing conflict.
- ◆ Develop a positive approach to conflict and thus realize the potential of transformation that flows from appropriate conflict resolution.

### Continuous evaluation and self-assessment of research

#### Responsibility and accountability

The collaboration agreement identifies:

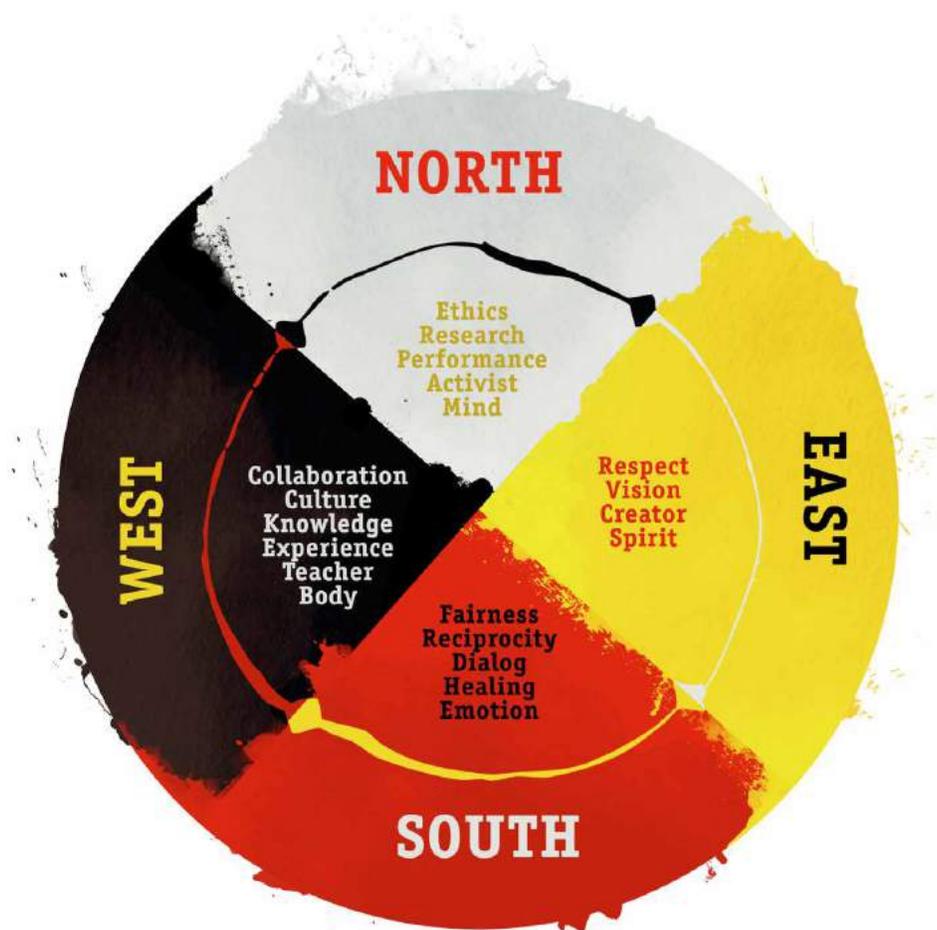
- ◆ Favourable moments for conducting individual and collective evaluations during different phases of the research project.
- ◆ The manner in which collaborative ethics, the efficiency and effectiveness of the collaboration, and the relationship between research intentions, objectives, actions and outcomes will be evaluated from the perspective of each actor.
- ◆ Appropriate forms of accountability: between partners (each in relation to the others), to research participants, and to the communities and organizations involved (including granting agencies).

# MAMU MINU-TUTAMUTAU

## KAPATAKANA

In **Mamu minu-tutamutau** and from our respective positions as researchers, activists and artists, each of us maintains an empathetic and critical view of our own culture in relation to the other. We explore collaborative and intercultural ethics in the context of research in Aboriginal communities through reflexive actions and inclusive performative processes based on the recognition of the diversity of knowledge and the appreciation of Aboriginal knowledge.

**Mamu minu-tutamutau** furthers the process by focusing attention on governance methods and customary protocols that guide relationships and ethics in Aboriginal communities and by gratefully drawing inspiration from certain Aboriginal concepts and languages. We look respectfully to the medicine wheel to illustrate the current state of our approach.



The medicine wheel is associated with the traditions of many Aboriginal peoples. It represents the circle of life divided into four quadrants, each of which is associated with a colour, cardinal point, phase, path and sphere.

The circle represents the main principles and spiritual values. We have indicated the principles put forward by this Toolbox: ethics, respect, fairness, reciprocity, collaboration and culture, and the Mamu minu-tutamutau identity circle. The different colors of the quadrants of the circle and the cardinal points, as well as the words inscribed in them, emphasize the interrelationships and unity among the phases of the cycle.

**East** The introspective phase, the vision quest.

The mind becomes engaged during this phase of the cycle, when new ideas are sought and new projects prepared, Mamu minu-tutamutau takes the path of creation.

**South** The dialogue and reciprocity phase.

We are in a position of active listening and constructive exchange. Mamu minu-tutamutau takes the path of healing.

**West** The experiential phase of our process.

Active in the concrete practice of our research, this is the path of teaching through sharing and exchanging what we have learned.

**North** The performative phase.

Our intellect analyzes and evaluates our experience. A moment of rest before repeating the cycle, this is the path of activism that reflects, and then plans its next action.

The collaborative ethics of **Mamu minu-tutamutau** and its holistic, experiential and transformational approach are based on the medicine wheel that teaches us to live in harmony with ourselves and others, to take the kapatakana that gives us insight into the cycles of life and to follow the path of individual and collective healing.

**Louise Lachapelle and Shan dak Puana**  
Co-leads, **Mamu minu-tutamutau**

## REFERENCES

This contribution to The Toolbox drew inspiration from the diversity of **Mamu minu-tutamutau** activities and materials, which are available at <http://mamuminututamutau.wordpress.com/>

We also quoted directly from the following:

CANADIAN INSTITUTES OF HEALTH RESEARCH (CIHR), (2007). CIHR Guidelines for Health Research Involving Aboriginal People. Ottawa, <http://www.cihr-irsc.gc.ca/e/29134.html>.

LACHAPELLE, Louise and Shan dak Puana, (2012). "Mamu minu-tutamutau/Bien faire ensemble: L'éthique collaborative et la relation de recherche," *Éthique publique* vol. 14, no. 1: Peuples autochtones et enjeux d'éthique publique, Suzy Basile and Karine Gentelet, eds. [<http://ethiquepublique.revues.org/951>].

SIOUI DURAND, Guy, (2009). "Insoumission," in *La Loi sur les Indiens revisitée/The Indian Act Revisited*, Louis-Karl Picard-Sioui (dir.), Huron-Wendat Museum, Quebec, pp. 5–8 and 29–36.



Photo : Fatou Diop



## **Mamu minu-tutamutau**

Co-leads

**Louise Lachapelle** Ph.D.  
Professor and artist-researcher  
Collège de Maisonneuve  
Centre Figura, Université du Québec à Montréal  
lachapelle.louise@aces.com

**Shan dak Puana** (Jeanne d'Arc Vollant) M. Sc.  
Researcher  
jdvollant@globetrotter.net

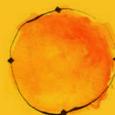
Graphics: Alexandre Huot

Cover photo: Louise Lachapelle

The authors would like to thank Dominic Bizot and Claudia Maltais Thériault of the Université du Québec at Chicoutimi and recognize their contribution to **Mamu minu-tutamutau** following their recent collaboration in a research project. The authors also acknowledge support from Fonds de recherche du Québec - Société et culture

# KAPATAKANA/PORTAGE TRAILS

COLLABORATION: NEGOTIATING THE PASSAGE FROM INTENT TO ACTUALIZATION



2015

# METHODOLOGICAL AND CONCEPTUAL GUIDELINES FOR THE ANALYSIS OF CASES OF DISCRIMINATION AGAINST ABORIGINAL WOMEN

MARIE LEGER

## 1-INTRODUCTION

Native women are both female and Aboriginal. Despite this obvious fact, one or the other of these aspects is sometimes overlooked when it comes to fighting discrimination or developing public policies. For example, there are policies intended to help women regardless of their origin or, conversely, policies that target native persons without taking their gender into account. As this was the case in the legal sphere until recently, there are very few policies that encompass both of these realities. This is why crafting specific tools is essential in order to make both identities visible and clear.

The goal of the project "Ethnic and gender-based discrimination in the Americas: the case of indigenous women," which is the result of the work of native organizations and human rights groups in Argentina (Council of Indigenous Organizations of Jujuy [COAJ], Colombia [National Indigenous Organization of Colombia], Mexico [Mixe People's Services and Lawyers for Justice and Human Rights] and Quebec [Quebec Native Women]), is to tackle this issue so as to facilitate access

to justice for Aboriginal women. We will present the conclusions of years of work with native communities in our respective countries and with the Inter-American Commission on Human Rights from the Organization of American States (OAS).

The text that follows is a summary of our shared publication from 2014 written in English and Spanish and entitled, *Methodological and Conceptual Guidelines to Confront Situations of Multiple Discrimination*.<sup>1</sup> It is a condensed version of what we learned together over the course of more than three years, mainly within the communities and by discussing the results we each obtained.

## II-TOOLS FOR ANALYSIS

To gain a grasp on the reality faced by a native woman, it is important to understand that she belongs to a specific native people with its own worldview and idea of justice. Her sense of belonging also means that she is a member of a community and that she generally conceives of herself as a community being. All of these factors must be taken into consideration if we wish for native women to have true access to justice.



1. "Indigenous Women of the Americas, *Methodological and Conceptual Guidelines to Confront Situations of Multiple Discrimination*," available in English and Spanish at the address: <http://www.forestpeoples.org/topics/gender-issues/publication/2014/indigenous-women-americas-methodological-and-conceptual-guide>

This is why we think that Aboriginal principles are always at issue when we address native women's issues, whether in the form of a research project, when going to court or when analyzing or proposing adequate public policies.

### 2-1 Aboriginal principles: Duality, respect, reciprocity, harmony, spirituality

- **Duality and complementarity:** Males and females, and humans and nature are complementary. One is not superior to the other. This principle is ever present in the Aboriginal worldview. In the Andes mountains in Latin America, there are rituals that celebrate the man/woman and human/nature duality. In Argentina, we observed that many rituals that honour the male/female duality are starting to disappear.
- **Respect and reciprocity:** "Do not give others that which is superfluous to you; give them what they need. Give and receive with all your heart." This means that we do not go into communities to interview women without giving them something in return: training, tools, and the opportunity to participate in our project.
- **Integrity and spirituality:** Spirituality is integral to life, knowledge and understanding the world. The world as a whole is made of emotions, spirituality and knowledge. Of course, all peoples do not share the same forms of spirituality, but all have one and it must be acknowledged.
- **Harmony:** A state of harmony between the community, nature, and the cosmos is what people seek.

### 2-2 The Aboriginal view of law and Aboriginal rights

Aboriginal peoples do not all have the same institutions to bring people to justice, but all peoples have rules, a way of seeing and managing human and social relations, and a way of resolving conflict.

The Aboriginal view of law (Derecho Propio), or customary law, is not the same as laws referring to indigenous by the majority society. The latter is recorded in constitutional or international documents. While it generally recognizes the existence of indigenous rights themselves, it is not inherently Aboriginal. The intrinsic right of Aboriginal peoples fits into a unique worldview. If we wish to understand violations of the rights of Aboriginal women, we must above all understand what this means within the context of their own cultures and norms.

#### **Territory, autonomy, and culture:**

These elements are essential to the survival of Aboriginal peoples and it is important to understand what they mean to Aboriginal women. Earth is female and our mother. She is a living being who must be respected. Attacking sacred sites or the ways in which women practice their rituals causes spiritual violence to women. This type of spiritual violence is generally not taken into account by mechanisms and laws that are intended to protect women from

violence. For Colombian native women, violence is not only physical or psychological; it can also be spiritual.

It is important that our account of what we understand by territorial rights, autonomy and culture, as well as living without violence or any other right, incorporates the perspectives and priorities of Aboriginal women.

### 2-3 Additional tools: Intersectionality, multiple

#### **discrimination, trifocals**

Discrimination does not only occur when a person with the same rights is treated differently. It also occurs when a person with different needs is treated the same way. There are two types of discrimination: direct discrimination such as in Canada where it is inscribed in the law (Aboriginal women cannot pass on their Aboriginal status in the same way that non-Aboriginal women pass on their citizenship), and indirect discrimination where discrimination is not intended, but it manifests itself regardless. While working with Aboriginal women in Argentina and Mexico, we also noticed that public policies that apply equally to all lead to discrimination toward Aboriginal women in the sense that governments did not think about taking their specific situations into account. This could be considered discrimination by lack of differentiation.

The following are the concepts that helped us to address situations of discrimination:

- **Intersectionality:** In general, an Aboriginal woman does not experience discrimination because she is a woman, Aboriginal, or poor, nor due to her age or a handicap. Rather, she experiences discrimination for all of these reasons simultaneously. This is a specific form of discrimination that is different from all other types of discrimination taken separately. To clearly understand "intersectional" discrimination, we must consider the multi-faceted reality that the woman faces. We must also consider the context in which discrimination has arisen, such as the history of colonization of Aboriginal peoples and the history of domination over women. Intersectional analysis, whose goal is to understand the new type of discrimination produced by the "intersection" of multiple forms of discrimination, can be applied to all cases where more than one form of discrimination exists (Ontario Human Rights Commission). With regards to Aboriginal women, we must not forget that they are members of different nations within the dominant nation of the country in which they live. Consequently, Aboriginal peoples have rights both as their own people and as communities. The respect or non-respect of these rights influences the women's daily lives and the forms of discrimination to which they are subject.
- **Multiple discrimination:** At the beginning of the project, we used the term "double discrimination." Aboriginal women face discrimination not only because they are

women, but also because they are Aboriginal. These two characteristics are immutable (or nearly) and they are protected by specific international doctrines: ILO Convention 169 and the United Nations Declaration on the Rights of Indigenous Peoples, the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and the Inter-American Convention on the Prevention, Punishment and Eradication of Violence Against Women, also known as the "Convention of Belem Do Para" for women.

In a statement delivered during the World Conference on Women in Beijing in 1995, Aboriginal women spoke of triple discrimination as they believed that, in addition to their status as both female and Aboriginal, they were also subject to discrimination because they were poor (social status). To this we can add that they can also be victims of discrimination against age, sexual orientation or a handicap. This is what is referred to as multiple discrimination.

- **Trifocals:** The Mexican team for the project developed this analysis tool by studying the Mexican government's policy against poverty (*Programa Oportunidades*). This policy, which is now applied in countries across the continent, aims to provide women with an income supplement in exchange for attendance at trainings on health and hygiene. In Mexico, nearly all native communities are poor and benefit from the program. It is often the case in other places that governments provide the

only source of cash income for women. Nevertheless, by examining this program through trifocal lenses, the team realized that the program also created forms of discrimination that specifically affected Aboriginal women.

Trifocals allow us to examine the situation from the perspective of human rights, gender and Aboriginal peoples.

These lenses also make it possible for us to see, for example, that Aboriginal women were not receiving services in their language. It was clear that neither they nor their communities had been consulted during the development of the policy. We noticed that, in order to be entitled to the monthly sum provided by the program, they were required to attend mandatory training workshops that were often given in a language that was different from their own. Missing a workshop was consequently prohibited or the allocation was reduced. However, members of Mexican native communities have community obligations (for example, volunteer work for the community) and this was not considered a valid reason for missing a workshop by the program administrators. The women therefore found themselves in a situation where they had to choose between an income that they could not do without and fulfilling their responsibilities as community members.

A policy that is, at first sight, positive for women since they receive financial support can hide a number of violations when we take a closer look at what this support actually means for Aboriginal



women. An analysis conducted from the triple perspective of rights, women and Aboriginals allows us to see the effects of discrimination.

### 2-4 The community and the intersection of individual and collective rights

In general, Aboriginal women construct their identity based on their community as they are most often community beings. Understanding their reality means comprehending whether or not their communities and peoples are able to exercise their rights.

Individual rights are conferred upon individuals by the sole fact that they are human. Likewise, collective rights are granted to communities so as to protect their integrity and dignity as a community. We often contrast individual and collective rights, and yet it is clear that they should not be dissociated from each other. The simple reason is that they are contingent on each other.

The worlds in which Aboriginal women live require us to note that these two types of rights are intimately linked. When territorial rights are attacked, it necessarily has an impact on women in their daily and personal lives. If militias or megaprojects overrun an Aboriginal territory, women are subject to prostitution or rape by foreigners. Conversely, if a woman in a community is raped or subject to sterilization without her consent, the entire community must suffer the consequences. Removing a woman from her community to protect her after rape amounts to fighting one act of violence with another. Separating her from her commu-

nity, her family, and her land is not only emotionally challenging, it also makes her more vulnerable to future acts of violence or discrimination.

As a result, we believe it is crucial to work with Aboriginal women as well as with community authorities and the men of which they are comprised. Access to justice and change for women requires battling on these two fronts.

We can develop multiple tools to reflect the situation of discrimination facing Aboriginal women according to the context and objectives. **However, we must always consider the perspective of the women themselves and the peoples to which they belong while taking into account their internationally-recognized rights. These include human rights, specifically women's rights (primarily individual rights) and the rights of Aboriginal peoples (primarily collective rights).**

## III-IMPLEMENTATION OF TOOLS DURING RESEARCH OR THE PRESENTATION OF CASES IN COURT

Aboriginal principles must be present in every action that is undertaken, as well as in the attitudes of those who work with Aboriginal women and the data that is retained for analysis.

### 3-1 Women as the focus of research and analysis

Too often, Aboriginal women are viewed as research subjects or victims who

need defending, whereas they are above all the subjects of their own lives and the only ones who can change their situation. In other words, they are the experts.

The project teams had different ways of taking this fact into account. In the Mixe de Jaltepec de Candayoc (Oaxaca) community in Mexico, women in the community were trained to fulfil the role of community researchers and to understand the health system in their community. They conducted interviews in their language and spoke with researchers to share the knowledge they had acquired. In each region of the Jujuy province in Argentina, there was a "promoter" whose role was to speak with the women from different communities about various cases of discrimination and ways of denouncing it. In Colombia, women used the workshops to define what it means to have a right to life without violence. This experience became the basis on which lawyers were able to base their argument.

Awareness-raising and training sessions about women's rights are very important and must be designed in such a way as to be compatible with the culture. They allow women to speak out without fear and to realize that they can react to certain situations that they believe to be unavoidable and even "natural." Once this realization has taken root, the women must not be forgotten. We must find the means to help them to change their situation or equip them with tools that allow them to find solutions themselves. For example, we can provide them with relevant information so that they can take action

themselves or find organizations to act on their behalf. We can ask Aboriginal women to speak about violence or discrimination that they have experienced without concentrating on the pain it has caused and their determination to find a solution.

### 3-2 Avoid revictimization

Revictimization occurs when victims find themselves in situations that make them relive the pain of an act of violence previously experienced, or when the conditions they are denouncing or for which they wish to receive justice put them face to face with another violent situation. Aboriginal women have lived through a long history of depreciation due to a colonial background that has made them sensitive to behaviors that remind them of the situation. It is also important to work with communities to improve the situation of women so that they do not feel like they are being judged when they speak about acts of violence or discrimination that they have experienced.

Both within the framework of research and legal action, obtaining prior, free and informed consent is important. This consent must be liable to annulment at

any time, which means that the person must be constantly informed about the purpose of the research and the steps leading to the denunciation of a violation of rights before the court. Women must receive respectful support in their maternal language and the right to withdraw at any time.

The question of confidentiality is equally important. Most often, Aboriginal cultures are extremely communitarian. If we wish for members of the community to support women in their demand for justice, it is important to involve them in the process. However, victims are also entitled to confidentiality of personal information that they do not wish to share. This is a challenge that must be discussed with women and authorities so as to accommodate the need for both confidentiality and a sharing of information with the community.

### 3-3 Finding healing and enacting change

During our discussions on revictimization, we asked ourselves what we should do once women become willing to speak out about their past and current personal wounds. How did our grandmothers and predecessors deal with this pain? How do you transform pain into strength? Argentinian women chose to take a cross-cultural approach, employing methods that were rooted in the Aboriginal tradition while receiving support from broad-minded psychologists. Their aim was to begin a healing process within the community that was focused on spirituality and

rituals that celebrate duality and the importance of women. The healing spaces thus created highlight the strength and value of women and their ability to generate change.

### 3-4 Legal and political process

Aboriginal women must overcome many obstacles in order to obtain justice. In addition to community isolation and a scarcity of services, native women face a number of challenges.

#### "Naturalization of violations:"

Women often believe that their situation cannot be changed, and they do not realize that they are the victims of violence or discrimination. Even if they do not like the indifferent or hostile treatment they receive when they go out of their communities, they have never thought about how it could be different. This is why raising awareness about the problem is essential. However, reinforcement is needed once the groundwork has been laid. We must develop methods of accompanying women through the process and provide ways to take action. For example, when we look for cases in Argentina in which the right to education was denied, cases of discrimination in the health field come up. Even if this was not what we were looking for, we couldn't close our eyes to such an important subject. We must give women the means to face their situation, and provide them with references and information that will help them improve their lot.



**Fear of making criminal charges:**

For many reasons, even when they are aware that they are victims of violence or discrimination, Aboriginal women are often afraid of denouncing these violations of their rights in court.

Sometimes they may be personal reasons. A woman may be afraid that her husband or her community will retaliate. Unfortunately, these are not unfounded fears. As a case in point, a Mexican Aboriginal woman named Valentina Rosendo Cantu was raped by military men and after she denounced the fact, her husband divorced her. She was subsequently required to leave her community. Although she won the case in the Inter-American Court of Human Rights, she now lives outside of her community with her daughter.

Being forced to leave one's community is often a difficult situation. To prevent it from happening, it seemed essential to us to not only work with the women, but also with the men and the authorities in the communities. Reinforcing the place of women in their communities while simultaneously strengthening the communities themselves is crucial. Women agree that Aboriginal peoples have the right to self-determination and they want to participate. People sometimes use situations of discrimination toward women within communities to argue that Aboriginal peoples are unable to govern themselves. We think that we must instead reinforce the internal capabilities of native peoples to take initiative in protecting women in their nations.

Within the framework of our project, working with a Mexican Aboriginal community proved to be a fruitful endeavour. At the end of a period of consultation and awareness-raising amongst authorities, the latter decided to support women and even file appeals in court with them. Collectively filing an appeal is a way of emphasizing the collective nature of certain violations and protecting the person who is pressing charges. Without support, the complainant is much more vulnerable.

Some reasons for not pressing charges are related to the justice system itself and its often discriminatory manner of treating Aboriginals, specifically native women. Pressing charges is not easy in an environment that is both hostile and completely foreign to Aboriginal cultures. The complainant may even find the experience equally traumatizing as the original act. Although promoting awareness of a justice system designed for and by others is not easy, it is essential.

**The limits of justice:** Filing and winning cases of discrimination or violation of the rights of Aboriginal women is not always possible. The reasons are multiple: there may not be a sufficient amount of information, the proof may have been destroyed or the deadline may have been missed. In addition, the justice process is generally very long, which discourages many women from pressing charges. In the judicial process, receiving acknowledgement of the harm done and possible reparations is a major challenge. Accompaniment and training are essential ingredients.

**Demonstrating discrimination:** Discrimination is illegal and the right to non-discrimination applies immediately. However, proving that someone was truly subject to discrimination is not always easy since contextual proof is necessary in all cases. How do you explain that an Aboriginal woman is a victim of discrimination because she is a native woman, and that this situation would not have arisen if the victim was not Aboriginal? We must explain what has happened from the perspective of the Aboriginal woman and then elucidate the reasons for the situation, such as a history of oppression.

The main tools used to prove the existence of discrimination include testimonies from the victim(s), which must be gathered in their maternal language in a location where they feel safe. The person collecting the information must also be familiar with their culture. Women must be able to speak about what they want to share and what they want to keep to themselves. Testimonies deal with the facts, as well as personal and community discrimination, and the goal is to demonstrate the moral and cultural damages that have been committed. Statistics show that systemic discrimination is also a factor (poverty, education, access to services, etc.). Unfortunately, statistics on Aboriginal women are rare and not easily accessed, and so we must sometimes create databases ourselves.

One way of demonstrating discrimination is to show the "road to discrimination." For example, in the field of education, we could show the path that

a person has taken to reach the university level and draw a parallel between all of the obstacles that an Aboriginal woman must overcome to attain the same level of education. This explains why women rarely succeed in this regard.

Proving that discrimination has occurred also requires expertise. Nationally-recognized experts lend legitimacy to Aboriginal realities before an unyielding magistrate, while Aboriginal experts provide testimony from an Aboriginal perspective.

Lastly, legal precedents, international cases (Special Rapporteurs, thematic reports, the Treaty Surveillance Committee, etc.), as well as conclusions and recommendations made by the court can also constitute substantive arguments.

Throughout the research and documentation process of multiple discrimination cases, having a framework for analysis and specific tools is essential. These are necessary in order to know which pieces of evidence must be found, which questions to ask to bring out the fact that Aboriginal women are at the same time Aboriginal AND women, and that both of these aspects must be documented. The relationship between collective rights and individual rights, the Aboriginal perspective and its worldview, the gender perspective and views on oppression and discrimination must guide our data collection and analysis.

The same goes for public policies. It was only by studying the policy against poverty in Mexico from the perspective of Aboriginal women that it was found that it engendered discrimination. This analysis allowed the Aboriginal organization ONIC in Colombia to intervene so that the law concerning the protection of victims of armed conflict took into account the specific situation of native women. At COAJ in Argentina, this facilitated understanding of the educational situation of women in order to propose a strategy and solution. Quebec Native Women Inc. was able to understand and explain how the combined effect of various laws in Canada and Quebec made life difficult for Aboriginal women who wished to denounce the violence to which they are subject.

## V-CONCLUSIONS

We wish to demonstrate the importance of developing a specific methodology that respects Aboriginal principles. Constructing a conceptual framework is also necessary in order to link Aboriginal rights, collective rights, and the rights of women, putting women at the centre of research and the actions taken. A lot of work remains to be done, but we hope that our experience will contribute to improving the lot of Aboriginal women.



## APPENDIX:

### Summary of the "protocol" for the treatment of cases of violation of Aboriginal women's rights, written by COAJ (Board of Indigenous Organizations of Jujuy , in Argentina).

- Situations of discrimination must be considered from the viewpoint of women, and the context surrounding situations of equality that has been constructed over a long period of time.
- We must recognize our own prejudices in order to clearly understand the issues and to make intercultural dialogue possible.
- The communitarian context must also be considered, specifically the worldview and philosophy of community members. To do so, we must engage in a process of identity reconstruction based on the history of the community and the women who live in them, both unspoken and forgotten memories, and internal tensions within the community such as difficulties recognizing the role of women.
- Concerns about diversity have increased over the past several years, but public policies consistently fail to take them into account.
- Individual and collective rights are interdependent.
- Spiritual principles are important in constructing an identity and they permeate the lives of communities and peoples. They serve to ensure harmony between men, women and nature.
- Aboriginal women are instrumental in recuperating spiritual principles.
- There is a difference between certain "cultural" practices that can sometimes harm women and the philosophical vision of the Aboriginal world where the principles of duality and the right to a life without violence exist.
- We must underscore the damages that result from discrimination and the disrespect of the rights of Aboriginal women. This creates healing spaces so that balance can be restored between the cosmos in the same way as their ancestors once did.
- These healing spaces prevent new suffering by treating old wounds with words.
- Healing spaces must be holistic so as to re-establish the balance between women and nature. To be healthy is to live a balanced life.

## BIBLIOGRAPHY

- ONTARIO HUMAN RIGHTS COMMISSION (2001), "An intersectional approach to discrimination: *Addressing multiple grounds in human rights claims.*"
- CRENSHAW, KIMBERLÉ (1989), "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics" U. Chi. Legal F. 139, <<http://heinonline.org/HOL/LandingPage?handle=hein.journals/uchclf1989&div=10&id=&page=>>(consulted March 31, 2014).
- CRENSHAW, KIMBERLÉ (1991), "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color" 43 *Stanford Law Review*, 1241.
- QUEBEC NATIVE WOMEN INC., "Guidelines for Research with Aboriginal Women," June 2012.
- INDÍGENAS, FIMI (2006), "*Maiwin Iranka Waya. A Companion Report to the United Nations Secretary General's Study on Violence Against Women,*" <<http://www.fimi-iiwf.org/archivos/7ffd8ee2807b42a0df93d25d70c9cfdb.pdf>> (consulted March 31, 2014).
- HERNÁNDEZ CASTILLO, AIDA (2010), Presentation to the Inter-American Court of Human Rights, < <http://justiciaporinesyvalentina.wordpress.com/category/6-material-audiovisual/>> (consulted August 8, 2013).
- HERRERA CARMEN and SUÁREZ JULIA (2011), "*El programa Oportunidades y los derechos de las mujeres indígenas en México*" Nostramo ediciones, Mexico.
- INTER-AMERICAN COURT OF HUMAN RIGHTS (2010), "Rosendo Cantú and Al. Vs. Mexico, Judgment of August 30, 2010, (*Preliminary Objections, Merits, Reparations and Costs*)" Available at the address: [http://www.corteidh.or.cr/docs/casos/articulos/seriec\\_216\\_ing.pdf](http://www.corteidh.or.cr/docs/casos/articulos/seriec_216_ing.pdf).
- INTERNATIONAL LABOUR ORGANIZATION (ILO), Convention 169, Indigenous and Tribal Peoples Convention, 1989, available in several languages: [http://www.ilo.org/dyn/normlex/fr/f?p=NORMLEXPUB:12100:0::NO::P12100\\_ILO\\_CODE:C169](http://www.ilo.org/dyn/normlex/fr/f?p=NORMLEXPUB:12100:0::NO::P12100_ILO_CODE:C169).
- UNITED NATIONS, Declaration on the Rights of Indigenous Peoples, adopted by the General Assembly on September 13, 2007. Available at the address: [http://www.un.org/esa/socdev/unpfii/documents/DRIPS\\_en.pdf](http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf).

# THE STORY OF A SUCCESSFUL PARTNERSHIP BETWEEN ABORIGINAL LEADERS, PRACTITIONERS AND RESEARCHERS ENGAGED IN A KNOWLEDGE COPRODUCTION APPROACH: THE CREATION, IMPLEMENTATION AND ACHIEVEMENTS OF THE ODENA RESEARCH ALLIANCE

## CAROLE LÉVESQUE

Professor, Institut national de la recherche scientifique. Co-director of the ODENA Research Alliance  
carole.levésque@ucs.inrs.ca

## ÉDITH CLOUTIER

Director, Val-d'Or Friendship Centre. Co-director of the ODENA Research Alliance /edith.cloutier@caavd.ca

## TANYA SIROIS

Executive Director, Regroupement des centres d'amitié autochtones du Québec tanya.sirois@rcaaqaq.info

## IOANA RADU

Doctoral Candidate, Concordia University oanarw@gmail.com

## ROLANDO LABRANA

Research Assistant, INRS, Centre Urbanisation Culture Société /rolando.labrana@ucs.inrs.ca

## INTRODUCTION

Over the past twenty years, research partnerships between universities and Aboriginal organisations and communities<sup>1</sup> have flourished across both Québec and Canada (see especially Asselin and Basile 2012; Cook 2013; Hanson and Smylie 2006; Lachapelle and Puana 2012; Lévesque 2009; Lévesque, Aparicio et al. 2012; Smithers Graeme 2013). Whether they are inspired by the premises of collaborative or participatory research, emphasise the voices and knowledge of Aboriginal people themselves, aim for a well-grounded and situated understanding of Aboriginal realities, or seek to document Aboriginal approaches and perspectives in the areas of education, the environment or health, these partnerships necessarily lead to new joint research practices that often have tremendous potential for social change. It was in this context that the ODENA Research Alliance<sup>2</sup> (www.odena.ca) was set up in 2009,

thanks to a grant from the Social Sciences and Humanities Research Council of Canada (SSHRC) under the Community-University Research Alliance (CURA) program (www.sshrc-crsh.gc.ca/funding-financement/programmes-programmes/cura-aruc-fra.aspx).

Bringing together representatives of ten organisations of the Québec Native Friendship Centres<sup>3</sup> movement, Aboriginal intellectuals from various backgrounds, researchers from seven universities as well as fifteen students, ODENA aimed, from the very beginning of its activities, to develop new knowledge bases derived from the meeting of scientific and Aboriginal knowledge, expertise, practices and cultures, in order to: 1) offer alternative and innovative avenues to understanding and responding to the individual and societal challenges faced by Aboriginal peoples in cities in the Province of Quebec (whether affiliated with First Nations, Métis

1. In Québec, the expression "Aboriginal community" refers to a place designated as an Indian reserve or northern Aboriginal village.
2. The term ODENA means "the city" in the Anishnabe language. The ODENA Research Alliance focuses on Aboriginal people in Québec cities. It has been headed, between 2009 and 2014, by the Regroupement des centres d'amitié autochtones du Québec (RCAAQ), an umbrella organization for the Québec Native friendship centre movement, and Institut national de la recherche scientifique (Université du Québec).
3. Native Friendship Centres are community-based service organisations established in a number of Québec and Canadian cities. The first Native Friendship Centre was established in Winnipeg in 1951, and the first in Québec was the Chibougamau centre, created in 1969. There are now some 120 Friendship Centres across Canada, including 10 in Québec. Their activities are targeted to Aboriginal people living in urban areas. Initially, when Aboriginal people left their communities of origin (reserves), they very often found themselves isolated and without adequate services or support. Today, Native Friendship Centres have become "key catalysts of action and solidarity for urban Aboriginal people, places for learning and training, and meeting points where help is given in areas such as housing, health care, education, the fight against poverty, assistance with homework, and elder support" (Lévesque and Cloutier 2011) [our translation]. They act as incubators of social economy and human development, for the benefit of a growing Aboriginal population.

or Inuit); 2) support their social, economic, political and cultural development; and 3) highlight the collective action of the Native Friendship Centres.

To accomplish this, it was necessary to create an integrated and joint mediation, governance, and research structure. This strategic work preceded the actual establishment of ODENA, as the relationships between several researchers, leaders, and Aboriginal representatives concerned had been formed since 2005 and had developed on a number of occasions, in both the academic and Aboriginal milieus, before the grant was obtained in 2009. Thus, the ODENA Alliance is the result of an existing collaborative process, which led the members to jointly identify, well before they had decided on which research activities to undertake, the knowledge sharing issues, the ways in which the partnership would function and common values.

When the ODENA Alliance began its work, an important lack of knowledge existed in Québec regarding the Aboriginal population living either temporarily or permanently in the province's cities: a rapidly growing population whose needs and challenges are complex, varied, and increasing (Environics Institute 2010; Lévesque and Cloutier 2013). Even with some sectoral studies in the 1990s and 2000s, no overall assessment had yet to determine the scope of existing knowledge and little or no studies proposed concrete actions or interventions. The lack of knowledge was thus combined with a lack of tools

and mechanisms that would allow research findings reaching academics from various disciplines, as well as Aboriginal practitioners, actors, and decision makers. Even fewer studies incorporated Aboriginal knowledge, approaches, practices and perspectives into their design and methodology. Moreover, the human development, social reconstruction and decolonization initiatives launched over the preceding decades by the various Québec Native Friendship Centres, had not been characterised or given a summary description. Thus, it was important to document these initiatives, to define the practices that had facilitated their implementation, to recognize and value them at the local, regional, national and international levels, to draw lessons from them, and to identify avenues for future work and action.

If the earlier collaborations had enabled academic and Aboriginal partners to share, discuss and exchange different types of knowledge during study or training days, talking circles and workshops and seminars, the creation of a new alliance would now call for an increased pace of activities, including forging constructive relations and a new epistemic environment where ideas and questions could be jointly debated, and developed. Conditions also needed to be created that would further these relations in the long-term, as well as the partners' agreement on a process that would allow the ethical and respectful nature of the partnership to be preserved in all circumstances. Therefore, it was important that the existing colla-

borative relationships be transformed into bonds of knowledge coproduction and co-creation. In addition, the Alliance members also shared other concerns, such as a common will to work together, a desire to enter into relations of reciprocity and mutual trust, and a genuine wish to enjoy collegial and amicable relations.

The ODENA Alliance was thus built on solid and well-established foundations. But despite this particular and, in a way favorable context, it was still important for us to develop a governance structure that would clearly be joint in nature but also dynamic and flexible in order to meet the requirements of the partnership, face the challenges and obstacles unavoidable in any partnership experience, and fulfil our commitments in the areas of research and knowledge mobilisation, as proposed and encouraged under the SSHRCCURA program. In the next few pages, we will present an overview of our vision and governance structure. We will then give two examples of knowledge co-creation projects carried out under the aegis of ODENA: 1) the Québec-wide provincial survey of 1,000 urban Aboriginal people; and 2) the scientific watch and monitoring project at the Minowé Clinic.

Each of these projects resulted from a specific combination of knowledge, research questions and expertise of the Alliance members. Each was also organised differently given the nature of the knowledge issues identified, the partnership approaches implemented, the leadership exercised, the members

concerned, the relevant disciplines and expertise, the methods used and the impacts. There is clearly no magic formula for a partnered knowledge coproduction research project in an Aboriginal context (or indeed in any other context). One must often innovate, overcome certain obstacles, re-examine established approaches, constantly meet new challenges, and even change one's strategy along the way. Nor is there one single model that applies in every situation (Lechner 2013; Lévesque 2012). Each of the projects implemented under the ODENA Alliance has in fact evolved in its own way, even though certain common founding principles were shared by all participants.

## 1. A SHARED GOVERNANCE STRUCTURE AND COMMON PRINCIPLES

Between 2009 and 2014, the ODENA Research Alliance brought together nearly 50 people from various academic disciplines, with diverse expertise and experiences, and with different types of knowledge. It was therefore crucial, right from the start, to create conditions that would encourage the expression of everyone's points of view, aspirations and concerns in regard to the partnership's governance and operation. During the 2009 ODENA start-up general assembly,<sup>4</sup> a temporary working committee was set up to define a charter of values and determine the governance bodies that would provide a solid foundation for future activities. This working committee met on several occasions in the first year in order to present an operating structure that would rally all participants. From the onset, it was decided that all representative bodies of the ODENA Alliance would be equal and joint in nature (in terms of both academic and Aboriginal representation) and would participate in decision making at all operational levels of the partnership, from the leadership jointly shared between an academic leader and an Aboriginal leader, to the composition of the different committees. It was also agreed that an Aboriginal elder and an Aboriginal youth representative would sit on the Steering Committee, which replaced the temporary working committee in the second year and became the decision-

making body for the Alliance in the areas of ethics, research, training and knowledge mobilisation. In this regard, the concern of Aboriginal partners was to ensure that the voice of all segments of the Aboriginal population in Québec cities could be heard through these representatives. For the researchers it was important that a seat on the Steering Committee also be reserved for a student.

This governance structure reflected the composition and diversity of the Alliance, and was an expression of the importance given to the development of trust, even before undertaking the actual research work. This planning step proved to be essential to identify the respective expectations of researchers and Aboriginal partners, to clarify member status and roles, to determine research needs and approaches, and to decide mechanisms and tools likely to ensure cohesion, liaison and communication within the Alliance. It also allowed the identification of common values on which the ethical responsibility of the Alliance was based and that reflected the desire of the participants for equality and harmony on all occasions.

4. A record of this founding general assembly is available in French- (Lévesque, Cloutier et al. 2009a) and English (Lévesque, Cloutier et al. 2009b). Both documents are available online: [www.odena.ca](http://www.odena.ca)

These values are as follows:

<b>Respect</b>	Respect is based on the full recognition of each individual's knowledge and expertise, be it scientific knowledge, Aboriginal knowledge, spiritual knowledge or experiential knowledge.
<b>Equity</b>	Equity is manifested in the importance of taking into account and valuing the respective contribution of each individual to the collective production by jointly signing, for example, works accomplished, whether in the form of research documents, collections of texts, presentations or even scientific articles.
<b>Sharing</b>	Sharing emphasizes the importance of pooling everyone's experiences and expertise, and of increasing the opportunities for meeting and exchange by creating favorable conditions encouraging a space for everyone to speak, in both the academic and Aboriginal milieus.
<b>Reciprocity</b>	Reciprocity translates in belonging to a collective project, where the benefits are collective and have an impact in both the academic and Aboriginal milieus and take different written or oral forms, unlike a solely individual appropriation.
<b>Trust</b>	Trust is evidenced in adherence to a joint infrastructure and in the desire to preserve the quality of the relations and ties formed through the activities and initiatives implemented.

Once the governance structure and charter of values had been defined, there was still a need to develop the tools and mechanisms that would allow these different parameters to be concretely embodied and for our common principles to be expressed in specific actions and initiatives. How then do you make sure that this common vision can be verified in the choice of future actions and activities in the context of such a broad research alliance? The Steering Committee played a major role in this regard by making the decision to support only research projects and public dissemination activities that necessarily brought together researchers, Aboriginal representatives or intellectuals, and students. Whether in the case of a university seminar, a training day in an

Aboriginal organization, a knowledge sharing workshop or the participation of an ODENA delegation to a national or international scientific conference, the presence of the three main groups of actors was essential to the intellectual and financial involvement of the Alliance. In our view, equity, sharing, and reciprocity must be embodied on all fronts to avoid reproducing divisions between Québec society and Aboriginal societies, between researchers and other knowledge holders.<sup>5</sup>

Rather than curtailing the activities of members, the implementation of this provision led to some 40 distinct events held over a five-year period and to more than 200 presentations or contributions of various kinds. Overall, these activities

reached more than a thousand people and mobilised, in one capacity or another—organiser, commentator, facilitator, mentor, speaker, expert, researcher, student, resource person—almost all the members of the Alliance. Similarly, the sectoral grants obtained by the members out of the general funding envelope could only be allocated if the team included both researchers and Aboriginal partners. The request for financial assistance could come from either researchers or partners, but in all cases had to reflect convergence and collaboration between the academic and Aboriginal milieus and had to be consistent with the common scientific programming.

5. This represents a small contribution to a much larger social phenomenon, but it is likely to bear fruit over the longer term and to help change attitudes and mentalities, especially in universities where elitist behaviours still too often predominate over socially engaged research initiatives with an objective of solidarity.

The ODENA Alliance also innovated by setting up collective research projects in parallel with the sectoral research activities. There is a large distinction to be made in this regard. The aim of the collective projects was to coproduce knowledge regarding federative, interdisciplinary and interinstitutional issues, in contrast to the sectoral projects that focused on a specific theme. The collective projects mobilised several dozen people over a number of years on issues jointly identified by the researchers and partners. The impact of these projects was the creation of knowledge bases which became reference tools for all Alliance members (an example of such a project will be given in the next section). The sectoral projects were in turn developed by teams of at least three individuals and expressly targeted public policy issues such as poverty, community justice, health, homelessness, racism, security and education. This resulted in reflection or analysis papers which recorded various types of knowledge and approaches, and were made available to all members.

By committing ODENA to a path where collective knowledge sharing initiatives went hand-in-hand with sectoral initiatives, the values shared by the Alliance members were reflected in the scientific programming, in the choice of an integrated knowledge coproduction approach, in the identification of the issues to be studied and in the nature of the anticipated impacts. It was indeed essential that the research topics chosen could be linked to societal challenges. It was also essential that the new knowledge be based on an equal relationship between the participants and that these initiatives also cover the entire spectrum of the partnership experience. We did not in fact separate the research activities from its other underlying activities and that ensure both its scientific and social relevance. The creation of new data and their processing and analysis were carried out in synchronicity with, and were complementary to, the dissemination, transmission and reciprocal learning activities.

In the area of community-partnered research there is often the hope that the results obtained can meet the needs identified by the partners or practitioners (to use the terms employed in academic discourse). This way of understanding the partnership, where some participants have research skills and others, research needs, did not suit the Alliance members, as it points to a relationship that is more instrumental and mechanical than constructive and organic.

Aboriginal partners may of course want to learn more about a particular research topic or research sector—just as researchers do—but their concerns are also linked to their practices, experiences, knowledge, skills and aspirations. In our view, reducing the Aboriginal contribution to the question of their needs for knowledge which researchers are being called upon to meet introduces an unequal dimension into the relationship and, indeed, a hierarchy in the relations that people entertain with the sphere of knowledge, whether scientific or other.

By linking research questions and societal challenges, that is, challenges reflecting the problems and issues that the partners are faced with in the context of their work, researchers are able to clarify their research questions and renew them in light of the concrete realities and manifestations that they hope to circumscribe, while also increasing the social and citizen impact of their work. At this point the terms of the relationship change as the researchers come to recognise that their partners also hold knowledge and are able to identify collective avenues for solutions to the challenges that they face. Moreover, by combining research activities and knowledge transmission mechanisms, partners become part of a dynamic and interactive relationship. In an additional measure, this relationship focuses on the high points of the research: the implementation, analysis steps, dissemination, transmission and mobilisation in the relevant areas, both academic and Aboriginal. These are the bases on which the two following examples rest.



## 2. AN UNPRECEDENTED PROVINCIAL SURVEY OF THE ABORIGINAL POPULATION IN QUÉBEC CITIES

### 2.1 CONTEXT

As previously stated in this document, the Aboriginal population in Quebec cities, despite a marked growth since the early 1990s, had received little attention from researchers prior to the creation of the ODENA Alliance. More specifically, most of the existing studies had concerned the city of Montréal and, to a lesser extent, the city of Val-d'Or (see Dugré and Thomas 2012; Jaccoud and Brasard 2003; Laplante and Potvin 1991; Lévesque 2003; Montpetit 1989). The project to conduct a provincial survey of a representative sample of the Aboriginal population had been discussed from the start by ODENA members, and the Steering Committee quickly assumed the responsibility for the survey's characterisation and implementation. Not only had such a survey, at such a scale, never been conducted in Québec, but the lack of information on the living conditions of this population also made the work of local actors more difficult and made it harder for practitioners to effectively target their actions, expand their initiatives and more adequately respond to the growing and increasingly diverse needs of this population. From the perspective of actual research, this lack of data prevented exploring new ways of understanding and explain-

ing the urban and citizen realities experienced by a growing proportion of the province's Aboriginal population.

After numerous discussions on the most appropriate methodological tool to employ, it was agreed that the survey would be structured around a semi-open questionnaire (rather than, for example, a single quantitative tool with closed questions) and would be addressed to Aboriginal people, both men and women, over 18 years of age. The survey was administered to the target population in urban areas where Friendship Centres are present and expanded its concept of residence to include long-term, short-term and transit contexts influenced by personal, family, work or study circumstances. From the onset, we were aiming for a sample of 500 to 750 people in order to obtain a large enough initial profile of the realities and living conditions of the population and a methodological representativeness for each of the cities targeted. Ultimately, thanks to the support and availability of the staff at the Friendship Centres and several other public organisations, 1,000 people were surveyed over a period of three years. The questionnaire included approximately a hundred main questions<sup>6</sup> and covered a wide range of topics and themes, such as: identity; mobility; marital and family status; housing and living conditions; schooling; traditional knowledge; occupational activities; ties with the land and communities of origin; relations with Aboriginal people and other citizens; and community life. These were jointly identified by

researchers and Aboriginal partners during fifteen work sessions extending over a six-month period and involving several actors, including members of the Steering Committee, the survey scientific committee and participants from the Regroupement des centres d'amitié autochtones du Québec and the various Friendship Centres.

Even the questionnaire design required several stages of definition, selection of variables, organisation of content and validation. We wanted to gather quantitative information, but also hear the people met share their concerns and aspirations. Before being conducted on a provincial scale, the questionnaire was tested on roughly a hundred people living in Val-d'Or and Sept-Îles. This first field test helped improve the content, rephrase some of the questions and add sub-questions of a qualitative type in several sections. For example, it wasn't enough to broach the issue of schooling without acknowledging traditional teachings; it wasn't enough to discuss the person's family, without considering its extended members; it wasn't enough to talk about urban living conditions without asking the person about his or her ties with Aboriginal communities and territories. In short, apart from the usual categories found in a sociological survey, we added other categories reflecting the shared realities, values, trajectories, heritages, experiences and visions existing within the Aboriginal world. This was in addition to the ethical procedures implemented to ensure both the anonymity and confidentiality of the

6. To be sure to cover as many situations as possible (men, women, youth, elders, workers, students, entrepreneurs, unemployed persons, trainees, etc.), we introduced certain distinctions in the questionnaire based on a person's life trajectory or experience. Important documentation work was carried out in parallel in order to design not only the actual questionnaire but also the data entry and processing tools that would allow for in-depth analysis of the data collected.

data collected, including an information letter and a consent form. No problems were encountered in this regard during the provincial tour.

## 2.2 CONDUCTING THE SURVEY

More than a hundred people from diverse backgrounds, both Aboriginal and non-Aboriginal, including professionals and practitioners, were mobilised throughout the course of the survey to ensure that it was carried out under the best possible conditions. Many of these people represented different Aboriginal organisations, as well as community or educational organisations interacting with Aboriginal populations in the context of their mandates. They all played an essential role in each of the cities or towns concerned by the survey and in the various locations visited. The staff at all of the Native Friendship Centres in Québec also played a major and significant role in organising field visits as well as providing resources, office space and their own communication networks to the team. But more than this, the different Centres created the appropriate environment for administering a large number of questionnaires by holding ongoing discussions with the team of interviewers and arranging for the participants to be accompanied when necessary.<sup>7</sup> As for the Regroupement, in addition to being involved in the design and validation of the questionnaire, also developed specific communication tools that proved indispensable in promoting the survey and channeling the interest that it generated across the province. Among

these tools were public invitation posters, messages posted on social media and Aboriginal communication channels.

Although the questionnaire was mainly administered to Aboriginal people that frequented Friendship Centres, the survey also enabled us to gather data on people that did not have particular ties with the Centres. Through this methodological choice, we wanted to ensure that we were reaching as many urban Aboriginal people as possible so that we could document a wide range of experiences. The questionnaire had in fact been designed with this in mind.

## 2.3 IMPACTS

Throughout the data collection period, considerable importance was placed on monitoring and regular dissemination of information resulting from the survey or regarding its implementation. Presentation of the methodological and organisational characteristics used in the survey, during each field visit—more than 30 visits in twelve cities—was ongoing as part of the regular meetings held by the Regroupement with its board of directors or with the Centres under its banner, during the ODENA Alliance general assemblies and during seminars or colloquiums held in either the academic or Aboriginal milieu, or during national and international conferences where an ODENA Alliance delegation was present. Synthesis texts, fact sheets, posters and PowerPoint presentations, were regularly made available to the members during these meetings or online on the Alliance website

(Labrana and Abitbol 2013; Labrana et al. 2014; www.odena.ca).

Data collection for this vast provincial survey ended in the spring of 2014. Since then, preliminary results have been brought to light and a more in-depth qualitative, statistical and spatial analysis is currently ongoing for each of the cities concerned as well as for the province. Sophisticated tools (analytical software such as SAS, SPSS and NVivo) have been developed to ensure an adequate and rigorous treatment of the quantitative and qualitative data, and to preserve the confidentiality and anonymity of the survey participants. Ultimately, these results will be reproduced in an interactive public atlas allowing for consultation through various electronic features, the choice of which will be the result of joint decisions. A tool will also be developed so that each Friendship Centre may access the relevant data; similarly, the Regroupement will have access to all the data. For the moment, the raw survey data are being stored in a relational database for processing and analysis. Publications resulting from this work, including the present text, will be acknowledged and will recognise the contributions of the various participants.

Some of these preliminary results have already enabled us either to confirm certain already known trends or to identify several new realities. For example, we found that in the sample comprised of more than 82% members of First Nations,<sup>8</sup> the majority of the Aboriginal population in the cities and towns studied were women (65%). It was also a

7. Measures had in fact been taken from the very beginning of the survey to plan for the possibility that some of the people to whom the questionnaire was being administered might need special support.

8. The sample contains a small proportion of Métis individuals (6%), as well as a small proportion of Inuit (4%). The remaining 8% includes people with multiple identities.

young population (with 40% of the individuals under 30 years of age). Of the 1,000 people surveyed, a small proportion (17%) owns a single-family home, with the most widespread form of housing being an apartment. In terms of languages, the mother tongue of more than 60% of the sample is an Aboriginal language; and this language is still largely spoken by the families living in urban areas (Labrana et al. 2014).

Aside from this socio-demographic information, one of the main sections of the survey as we have already mentioned concerned the mobility patterns of the Aboriginal population. A topic that Québec researchers had given little consideration to date, but that particularly interested the CURA Aboriginal partners. In general, it is believed that for the most part Aboriginal people in cities come from communities/reserves. The results brought to light have allowed us to qualify this observation and to see differently the ties and interaction dynamics between communities and cities. Indeed for far too long, communities and cities were seen in a distinct and even opposing fashion, as though a geographical, social and cultural boundary existed between these two worlds.

Our survey has opened up new avenues of understanding on this subject. For example, 29% of the sample grew up, between 0 and 18 years of age, in both a community and an urban area.<sup>9</sup> So, we are seeing the emergence of charac-

teristics of a way of life that is not only linked to the reserve or, on the contrary, to the city, but is effectively in symbiosis between these spaces and the places that one finds there. Although there are some variations in this combination of “reserve vs. city” in the different locations where the survey was carried out, the fact remains that, on the provincial level, it can be seen in nearly a third of the cases studied. An identical proportion was also found for people that had been born and had lived, between the ages of 0 and 18, in an urban area.<sup>10</sup> Ultimately, only two fifths of the people questioned (42%) had lived out their childhood and adolescence in an Aboriginal community exclusively.

In line with this new picture of the mobility patterns of Aboriginal people in Québec cities—an analysis of which will enable us to document the phenomenon in greater depth over the next few months—another aspect is worth mentioning, as we round out this part of the article. We observed another little known phenomenon, which has been briefly identified in the Canadian scientific literature but has not yet been studied in Québec. It is a form of residential or work alternating between a city and a reserve. This form of alternating means that a person may reside in an Aboriginal community and work in a city, or vice versa, when the person’s home is in the city and he or she works in the community. This form of alternating may be daily, weekly, or even monthly. In certain cities, up to 25% of the individuals met practised this form of mobility. It is no

longer a marginal situation, but is instead the reflection of a new social and economic configuration, the manifestations and consequences of which need to be more closely examined in the near future.

### 3. IMPLEMENTATION OF A SCIENTIFIC WATCH AT THE MINOWÉ CLINIC

#### 3.1 CONTEXT

This second example of a knowledge co-construction approach under the aegis of ODENA is quite different from the survey, in that it is an intervention project to which a scientific watch was added and that it was implemented at the Val-d’Or Native Friendship Centre. In this instance, the researchers were partners in the context of a local initiative headed and managed by an Aboriginal organisation. The Minowé Clinic was created in 2011 in response to a need expressed by many Aboriginal people in the region to have access to culturally appropriate psychosocial and health care services: in other words, services that take into account their particular cultural, social, economic as well as historical circumstances. Too often, these circumstances are not known to the practitioners involved and are not considered when making a diagnosis or assessing a situation. The types of interactions between practitioners and Aboriginal peoples may also be affected by misunderstandings, given the different cultural markers and cultural codes.

9. In order for us to quantitatively record this combination of community vs. city, we specified that the participant must have lived for at least nine years in one or the other location between the ages of 0 and 18.

10. In this case, the person must have lived in an urban area for at least fifteen years between the ages of 0 and 18.

Although many health and social services programs are now based, right from their very definition, on a broad acceptance of the role of social and economic determinants in deteriorations or improvements in an individual's physical or mental state of health, much still remains to be done in this area, when working with Aboriginal people both on reserves and in cities.

It is well known that the living conditions and the health status of Aboriginal peoples rank far below those of the Canadian population: a higher incidence of chronic illnesses; major psychosocial problems; obesity; legacy of residential schools; intergenerational trauma; and a lower life expectancy (CCDP 2013). Right from birth, Aboriginal children are exposed to greater health risks in all current categories (MacDonald and Wilson 2013; Smylie and Adomako 2009). In urban areas, the situation becomes more complex, as health problems are combined with other major difficulties: lack of appropriate care and resources; social isolation; increasing level of child placement; overrepresentation of Aboriginal people in both the homeless and prison populations; insalubrious and unsafe housing conditions; food insecurity; repeated situations of racism and discrimination; chronic unemployment. It has also been confirmed that many Aboriginal people do not trust the Québec or Canadian health care system, a situation that leads to other serious problems, including delayed diagnosis, more complex treatments, lack of support, lack of follow-up or preventive measures (Martin and Diotte 2010, 2011). Such a situation had been

observed in the field in Val-d'Or since at least the early 2000s, and had gradually led to the adoption of concrete measures relating to health and social services.

During the First Nations Socioeconomic Forum in Mashteuiatsh in 2006, the Québec government and First Nations authorities had agreed to implement actions to reduce the health and social services discrepancies between the Aboriginal and non-Aboriginal populations in Quebec (APNQL 2007). One of the commitments made at the Forum by the Health and Social Services Minister was to establish a partnership with the Regroupement des centres d'amitié autochtones du Québec to foster "the transfer of knowledge and expertise between the Friendship Centres and health and social services providers in the Québec system and to identify areas of complementarity in the services for Aboriginal people in urban areas" (Ouellette and Cloutier 2010: 7) [our translation]. It was in the wake of these commitments that the Minowé Clinic, which was in the planning phase, was implemented.

The main objective of this initiative was to renew the service offer in the region by emphasising culturally appropriate care, renewing the nature of the relationship between the patient

and specialised staff, and creating a welcoming and supportive space for care on the premises of the Val-d'Or Native Friendship Centre. This was made possible through a partnership with the *Centre de santé et de services sociaux de la Vallée-de-l'Or* (Vallée-de-l'Or Health and Social Services Centre) and the *Centre jeunesse de l'Abitibi-Témiscamingue* (Abitibi-Témiscamingue Youth Centre) (Ouellette and Cloutier 2010; Lainé and Lainé 2011). From the beginning, leadership and staff at the Friendship Centre (which was already an integral part of ODENA) wished to include ODENA researchers and students in their project in order to: monitor developments and achievements at the Clinic; expand the scope of the project by documenting similar experiences and initiatives at national and international levels; encourage the transfer and appropriation of knowledge in various milieus and with different types of clientele; and to increase the project's impacts in both the Aboriginal world and scientific community. The scientific watch grouped these analytical elements into five main areas: statistical monitoring of interventions; knowledge documentation and synthesis; design of knowledge tools; dissemination; and transmission and appropriation of knowledge.



### 3.2 CONDUCTING THE SCIENTIFIC WATCH

These five scientific monitoring areas were carried out simultaneously starting in 2009 mutually sustaining and complementing one another. A team of five comprised of three Friendship Centre professionals and two researchers—occasionally assisted by students—interacted regularly in order to prepare reference documentation to monitor interventions taking place at the Clinic, to identify the Clinic’s achievements and orientations, and to position the latter in relation to similar experiences in Québec, Canada or internationally. This interaction also allowed for dialogue to be maintained and for knowledge and skills to be shared during all stages of implementation at the Clinic.

- **Statistical monitoring of interventions**

In order to measure and evaluate the impact of the new service offer at the Clinic, data had to be compiled on a monthly and annual basis relating to the interventions carried out and construct a patient and, in some cases, family registry. Statistical files were used to record information based on current variables such as: type of intervention; gender; age; reason for consultation. These records were kept by the Friendship Centre staff and the researchers were responsible for processing and analysis.

- **Knowledge documentation and synthesis**

This component of the scientific watch aimed to gather the opinions and aspirations of the main partners: Aboriginal, government and academic; to document similar initiatives developed in the Aboriginal context in Canada or elsewhere; and to explore various approaches likely to inform the actions and decisions taken in terms of implementation. It was in this context that an initial discussion and knowledge sharing day was organised in 2009 in close collaboration with ODENA to: 1) assess the current situation of health and social services in the region; and 2) identify the needs of the Val-d’Or Aboriginal community in order to develop culturally appropriate services. The results of the presentations and discussions were reported on, summarised and analysed in an ODENA Alliance Cahier (Cloutier, Dugré et al. 2009) in order to keep a written record of the discussions and note the various partner expectations in this regard. It was on this occasion that the theme of social perinatal care emerged, which became one of the Clinic’s leading orientations in the coming years. In addition to this first activity, researchers regularly met their Friendship Centre collaborators in order to effectively circumscribe empirical and theoretical advances that everyone could learn from. As of 2012, the team’s concerns also converged on an approach that was still quite unknown in Québec, that

of cultural safety.<sup>11</sup> (see Lévesque and Radu 2014; Lévesque, Radu and Sokoloff 2014). The objective was to develop a documentary reference tool on the subject and build an analytical grid in order to define the Clinic’s experience on a continuous scale. This was done and the information was shared during the regular meetings of researchers and Aboriginal partners.

- **Design of knowledge tools**

The information recorded was also processed and reproduced in various products to further its circulation and discussion. Factsheets, statistical profiles, case studies and PowerPoint presentations were gradually developed in order for results to be accessible and available. These tools also highlighted the results of other work carried out in the ODENA Alliance context, whether within the framework of the abovementioned provincial survey or that of another collective research project that led to the production of a new social and economic mapping of the Aboriginal population in Québec cities (Lévesque, Apparicio et al. 2011; Lévesque, Apparicio and Cloutier 2013).

- **Dissemination and transfer**

The fourth component of the scientific watch was to emphasise the Clinic’s experience in a number of forums, whether in Aboriginal, government, or academic milieus. Between 2009 and 2014, approximately thirty talks or public pre-

11. The notion of “cultural safety” was developed in New Zealand in the 1980s, in the context of nursing care for the Maori. Nursing educator Irihapeti Ramsden, a Maori herself, wrote extensively on the subject and publicized it internationally (Ramsden 2002). She documented this concept in her 2002 PhD thesis based on her own experience as a nurse and educator and in response to alarming concerns about Maori health and their dissatisfaction with health services that were considered to be culturally unsafe. According to the Health Council of Canada (2012), the aim of cultural safety is “building trust with Aboriginal patients [in] recognizing the role of socioeconomic conditions, history and politics in health.” Cultural safety differs from cultural competency, the goal of which is instead to create “a health care environment that is free of racism and stereotypes, where Aboriginal people are treated with empathy, dignity and respect.” A cultural safety approach in turn aims for real social change by proposing a re-examination of public policies targeted to Indigenous populations and a renewal of existing practices, in a perspective of decolonization and self-determination. The Val-d’Or Native Friendship Centre, in collaboration with several ODENA Alliance researchers, made a firm commitment as of 2012 to work towards achieving culturally safe services, by focusing their action and intervention strategies in this direction and by launching an ongoing process of reflection and planning in this regard.

sentations on the experience of the Minowé Clinic were given before a wide range of audiences: in the context of the ODENA activities on the national or international scene or during colloquiums, seminars or round tables organised in the Québec and Canadian scientific communities. Each of these presentations, by either Aboriginal leaders and practitioners or researchers and students, where applicable, was supported by documentation collected in the context of the scientific watch. Especially noteworthy in this regard was the presentation given during the May 2012 consultation carried out in Montréal by the Health Council of Canada, which led to a synthesis text published in December of the same year (CCS 2012). In this report, the Minowé Clinic was singled-out as one of the most exemplary practices in Canada in the area of cultural safety. This is in addition to the presentations in Toronto (2010), Vienna (2012) and Austin, Texas (2014), to name but a few. A series of presentations was also given in the context of the ongoing activities of the Regroupement at the provincial, regional and local levels. The information was widely circulated, both to promote the Clinic's successes and to identify lessons likely to inspire the development of clinics in other Québec Friendship Centres.

- **Transmission and appropriation of knowledge**

The last task of the scientific watch relates to the transmission and appropriation of knowledge and skills by the practitioners following the opening of

the Clinic. These were activities of a wider scope and impact that can only take place after a certain amount of time has passed as the practices tested and implemented have to be collected, defined and documented over time, and appropriate transmission and evaluation mechanisms have to be designed. This part began in the spring of 2014 and has already resulted in a 7-hour intensive cultural safety training session offered at the Val-d'Or Native Friendship Centre in the fall of 2014. This first experience will be followed by others and will include a training booklet and teaching guide in 2015.

### 3.3 IMPACTS

The relationship that developed between the Val-d'Or Native Friendship Centre professionals and the ODENA Alliance researchers in the context of this scientific watch can be described as a "win-win" situation. In fact, the results provided different solutions to shared concerns, for the simple reason that the expectations of the actors in the field differed from those of the researchers, as is, of course, perfectly legitimate.

The common objective here was to document the achievements of the Minowé Clinic while incorporating them within the major national and international trends in this regard. For the researchers, the challenge was to bring to light information that would inform both the procedures and approaches adopted, and the actions taken in the national and international Aboriginal contexts. For the Val-d'Or Native

Friendship Centre professionals, the challenge was to take ownership of this information and to integrate it into the strategic and operational orientations of the Clinic. These challenges were overcome in different ways, so that the researchers' skills and knowledge were channeled into the production of various analysis and synthesis products—case study collections; thematic files; statistical profiles; research reports—whereas the Native Friendship Centre professionals' skills and knowledge helped to change the Centre's organisational culture. In general, if researchers are able to circumscribe, categorise and analyse the parameters of the desired changes required to "achieve the provision of culturally appropriate and culturally safe services, it is the actors in the field who hold the key to integrating these services into an approach aimed at social change over the short and medium term.

The example of the partnership forged in the context of the Minowé Clinic clearly shows the importance of the Aboriginal and non-Aboriginal partners working together, and, in this case, the importance of renewing the service offer in the health and social services field in order to strengthen the relationship between the members of the Val-d'Or urban Aboriginal community and the Québec health care system. The work undertaken within the scientific watch helped build bridges of knowledge between the local and the global, between interests located at the level of a city or of a Native Friendship Centre, including explanatory frameworks whose scope reaches a broader scale.

## CONCLUSION

What lessons, in regard to the research ethics with Aboriginal peoples, can we draw from these two very different examples and, more broadly, from the ODENA partnership experience? There are indeed clearly many lessons. For the purposes of the present document, we have identified five: 1) the importance of creating consensus on knowledge sharing issues; 2) the need for collaboration on all levels; 3) the recognition of the skills and knowledge of all participants; 4) the necessity of mutual learning; and 5) a commitment towards a more just and equitable society.

- **The importance of creating consensus on knowledge sharing issues**

We are not the first to note (Cochran, Marshall and Gover 2008; Kidman 2007; Lachapelle and Puana 2012; Lafrenière, Diallo et al. 2005) that the relationship of collaboration between the academic and Aboriginal worlds must first be built around common issues and concerns. It is not “research” as such at the heart of this relationship; it is in fact “knowledge.” The consensus created in the context of ODENA finds its source in knowledge sharing issues. In keeping with this perspective, it was people’s relationships to knowledge, modulated differently depending on whether these individuals were researchers or Aboriginal leaders or intellectuals, which was given priority. A stance of this kind is directly in line with the questioning that has recently emerged regarding the knowledge society: a society based on different knowledge

systems, whether it is scientific knowledge or, as in the present case, knowledge held by Aboriginal peoples (Lévesque 2009).

- **The need for collaboration on all levels**

The research activities in the context of the ODENA Alliance, which were essentially based on approaches aimed at knowledge coproduction and co-creation, were not isolated from other social dimensions related to knowledge: that is, its transmission, sharing, circulation, dissemination and mobilisation. All of these dimensions were activated simultaneously in order to cover the full spectrum of the various phases of knowledge creation. If the endeavour to create such knowledge is fundamental, so is its social and scientific integration. This way of working within ODENA led the members to explore several avenues of collaboration, as was the case with the scientific watch, which was carried out starting from the field of intervention, and not, as often tends to be done, from a strictly theoretical understanding of social phenomena.

- **Recognition of the skills and knowledge of all participants**

The appropriation of a collaborative project is the concern of all who agree to work together, and who know that they will have to innovate as they go along and sometimes even take a few steps back before starting again on more solid ground. It is on this level that the main challenges encountered within ODENA arose. Indeed, even if the idea of a part-

nership and of collaboration was taken for granted, albeit hoped for, this needed to be embodied in concrete actions. For a few of the Alliance members, both researchers and actors, this was not entirely self-evident. For the researchers, the challenge laid in accepting (or refusing to accept, in some cases) the demands of working in continual interaction, as well as in recognising and valuing knowledge approaches other than the scientific one. For the local actors, the fear that their own knowledge and skills would not be respected, or that the researchers “were coming to tell us how to do our job” was expressed on several occasions. We did not try to resolve these difficulties or ignore them or pretend that they did not exist; instead, we encouraged the expression of these concerns so that they remained open and present, thus obliging us to continue our vigilance, and to maintain in all circumstances the consensus and trust that framed the Alliance. As we stressed at the beginning of this document, there is no ideal recipe for success or single way of working in partnership. One has to recognise that the relationship developed is sustained by both its achievements and its difficulties; it is forged over time, and is constantly evolving; it calls for innovation and creation, and requires that we recognise the differences in the voices engaged in the exchange—those of both the researchers from various disciplines and the collaborators and partners from the Aboriginal world:

In order to be effective, dialogue must fulfil two requirements. On the one hand, it must recognise the differences in the voices engaged in the discussion and not establish beforehand that one of them is the norm and that the other can be said to be a deviation or backwardness, or to be showing ill will. If one is unwilling to question one's own certainties and evidences or to temporarily see things from the other person's perspective—and be ready to acknowledge that, from this point of view, the other person is right—dialogue cannot take place. On the other hand, the dialogue cannot end in any satisfying way if the participants do not agree on a common formal framework for their discussion, if they do not agree on the type of arguments that are acceptable and on the very possibility of seeking truth and justice together. (Todorov 2008: 285) [our translation]

- **The necessity of mutual learning**

This common ground is built around shared knowledge issues and is as well a space for collaboration and learning. It is in this regard that the value of reciprocity that we emphasised from the beginning is best embodied. The impacts of joint projects must be able to satisfy everyone's expectations, as well as their respective needs to understand the phenomena under consideration. In the same way, it is quite legitimate that some of these impacts also have a collective scope that extends beyond the project itself. So, with the provincial survey, we attempted to lay the foundations for a new body of knowledge

relating to the Aboriginal population in Québec cities; and, in the case of the Minowé Clinic, we took every opportunity to promote this innovative project in order to raise awareness and ultimately affect policy regarding cultural safety in regards to health and social services targeted to Aboriginal peoples. This is why there cannot only be one type of impact or a single way of working. One needs to explore a number of different avenues as well as develop tools to create and re-create the conditions likely to foster partnership work.

- **A commitment towards a more just and equitable society**

Aside from the favorable views we share on knowledge, it is a broader commitment that defines the ODENA Alliance experience which has led us towards social transformation. Our contribution is a modest one, but it is important because through our continuous interaction, we have contributed to an increased visibility and recognition of Aboriginal realities and issues in order that their potential for change and achievement may be reflected in public policy and strategies geared towards the urban Aboriginal population, as well as territorial communities (reserves and Aboriginal Nordic villages). From a different point of view, we also participate in raising awareness within Quebec society, the academic community and media, by sharing our methods and joint productions. Also, the impact of our works and experiences are not solely reflected in Aboriginal contexts or regarding Aboriginal realities. They are manifested in many other knowledge or

study areas in the field of partnership research, knowledge coproduction and social innovation.

From a reconciliation perspective, the Alliance has created opportunities for harmonious relations between Aboriginal and non-Aboriginal people based on joint approaches and achievements. Finally, the scientific community operating within the vast sphere of community-partnered research, knowledge coproduction and social innovation can learn from the lessons and adapt the tools developed by the ODENA Research Alliance. Whether one is located within an Aboriginal context or not, the foundational values of respect, equity, sharing, reciprocity and trust are key to successful research collaborations.



## REFERENCES

- ASSEMBLÉE DES PREMIÈRES NATIONS DU QUÉBEC ET DU LABRADOR (APNQL). 2007. *Forum socio-économique des premières Nations. Rapport final. Agir maintenant...pour l'avenir*. APNQL, Wendake.
- ASSELIN HUGO and SUZY BASILE. 2012. "Éthique de la recherche avec les Peuples autochtones : qu'en pensent les principaux intéressés ?," *Éthique publique* 14 (1): 333-346.
- CLOUTIER ÉDITH, DUGRÉ SUZANNE, SALÉE DANIEL, COMAT IOANA and CAROLE LÉVESQUE. 2009. *Enjeux et défis en santé et services sociaux pour les Autochtones en milieu urbain*. Cahiers ODENA n° 2009-04. Synthèse de l'atelier. DIALOG. Réseau de recherche et de connaissances relatives aux peuples autochtones et Regroupement des centres d'amitié autochtones du Québec, Montréal.
- COCHRAN PATRICIA, MARSHALL CATHERINE and REVA MARIAH S. GOVER. 2008. "Indigenous Ways of Knowing: Implications for Participatory Research and Community," *American Journal of Public Health* 98 (1): 22-27.
- CONSEIL CANADIEN DE LA SANTÉ (CCS). 2012. *Empathie, dignité et respect : Créer la sécurisation culturelle pour les Autochtones dans les systèmes de santé en milieu urbain*. Toronto, Conseil canadien de la santé. Online: [http://www.conseilcanadiendela-sante.ca/rpt\\_det.php?id=437](http://www.conseilcanadiendela-sante.ca/rpt_det.php?id=437), Consulted 15/05/2013.
- COMMISSION CANADIENNE DES DROITS DE LA PERSONNE (CCDP). 2013. *Rapports sur les droits à l'égalité des Autochtones*. Ottawa: Commission canadienne des droits de la personne.
- COOK SAMUEL R. 2013. "Collaborative Destinies in American Indian and Indigenous Studies," *Anthropology News*. Consulted 2013-10-18. <http://www.anthropology-news.org/index.php/2013/10/15/collaborative-destinies-in-american-indian-and-indigenous-studies/>
- DUGRÉ SUZANNE and DANIEL THOMAS 2010. "Politiques sociales, identité et relations entre Autochtones et Québécois: le cas de la ville de Val-d'Or (Québec)," in Jerry P. White and Jodi Bruhn (Editors), *Aboriginal Policy Research Volume VIII. Exploring the Urban Landscape*: 67-85. Toronto: Thompson Educational Publishers.
- ENVIRONICS INSTITUTE. 2010. *Urban Aboriginal Peoples Study*. Online: <http://uaps.twg.ca/wp-content/uploads/2010/04/UAPS-FULL-REPORT.pdf>.
- JACCOUD MYLÈNE and RENÉE BRASSARD. 2003. "La marginalisation des femmes autochtones à Montréal," in D. Newhouse et E. Peters (sous la direction de) : *Des gens d'ici. Les Autochtones en milieu urbain*. Ottawa: Programme de Recherche sur les politiques, p. 25-37.
- HANSON P. GAYE and JANET SMYLIE. 2006. *Knowledge Translation for Indigenous Communities. Policy Making Toolkit*. Prepared for Indigenous KT Summit Steering Committee.
- KIDMAN JOANNA. 2007. *Engaging with Maori Communities: An Exploration of Some Tensions in the Mediation of Social Sciences Research*. Produced in the Tihei Oreore Series for Nga Pae o te Maramatanga, University of Wellington, Victoria.
- LABRANA ROLANDO and JONATHAN ABITBOL. 2013. *La tournée provinciale de l'Alliance de recherche ODENA. Bilan de la Phase 1*. Cahier ODENA no. 2013-01. Alliance de recherche ODENA, Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG) et Regroupement des centres d'amitié autochtones du Québec, Montréal.
- LABRANA ROLANDO, LÉVESQUE CAROLE, CLOUTIER ÉDITH and TANYA SIROIS. 2014. *Les Autochtones des villes au Québec : conditions socioéconomiques et dynamiques de mobilité. Première série de résultats de l'enquête provinciale ODENA*. Cahiers ODENA 2014-03. Alliance de recherche ODENA, Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG) et Regroupement des centres d'amitié autochtones du Québec, Montréal.
- LACHAPELLE LOUISE and SHAN DAK PUANA. 2012. "Mamu minu-tutamutau – bien faire ensemble. L'éthique collaborative et la relation de recherche," *Éthique publique* 14 (1) : 1-26.
- LAFRENIÈRE GINETTE, DIALLO P. LAMINE, DUBIE DONNA and LOU HENRY. 2005. "Can University/Community Collaboration Create Spaces for Aboriginal Reconciliation," *The First Peoples Child & Family Review* 2 (1) : 53-66.

LAINÉ AMÉLIE and MATHIEU-JOFFRE LAINÉ. 2011. La clinique Minowé: un modèle de services de santé et de services sociaux en milieu urbain pour les autochtones de la Vallée-de-l'Or, in A. Maire et M. Faye (dir.), *Le bien-être et la santé autochtones*: 87-93. Québec: CIÉRA, Université Laval. [Cahiers du CIÉRA no 8].

LAPLANTE MONIQUE and MICHELINE POTVIN 1991. Les Autochtones de Val d'Or. *Étude sur les Autochtones vivant en milieu urbain*, Centre d'amitié autochtone de Val-d'Or, Val-d'Or.

LECHNER ELSA 2013. Walking the Talk of Collaborative Research with Participants", *Anthropology News*, <http://www.anthropology-news.org/index.php/2013/10/07/walking-the-talk-of-collaborative-research-with-participants/> Consulted 2013-10-10.

LÉVESQUE CAROLE 2003. "La présence des Autochtones dans les villes du Québec : mouvements pluriels, enjeux diversifiés," in D. Newhouse et E. Peters (sous la direction de) : *Des gens d'ici. Les Autochtones en milieu urbain*, Programme de Recherche sur les politiques, Ottawa : 25-37.

LÉVESQUE CAROLE 2009. "La recherche relative aux peuples autochtones à l'heure de la société du savoir et de la mobilisation des connaissances," in N. Gagné, T. Martin et M. Salaün, (sous la direction de.) : *Autochtonie. Vues de France et du Québec* : 455-470. Québec: Les Presses de l'Université Laval/IQRC avec la collaboration de DIALOG.

LÉVESQUE CAROLE. 2012. La coproduction des connaissances en sciences sociales," in Miriam Fahmy (sous la direction de), *L'État du Québec 2012* :290-296. Montréal : Boréal.

LÉVESQUE CAROLE, CLOUTIER ÉDITH, SALÉE DANIEL, DUGRÉ SUZANNE and JULIE CUNNINGHAM. 2009a. *Les Autochtones et la ville au Québec : perspectives scientifiques et défis sociétaux*. Cahier ODENA no. 2009-01. Alliance de recherche ODENA, Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG) et Regroupement des centres d'amitié autochtones du Québec, Montréal.

LÉVESQUE CAROLE, CLOUTIER ÉDITH, SALÉE DANIEL, DUGRÉ SUZANNE and JULIE CUNNINGHAM. 2009b. *Aboriginal people in Québec Cities: Scientific Perspectives and Societal Challenges*. Cahier ODENA no. 2009-02. Alliance de recherche ODENA, Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG) et Regroupement des centres d'amitié autochtones du Québec, Montréal.

LÉVESQUE CAROLE and ÉDITH CLOUTIER. "Une société civile autochtone au Québec," in C. Lévesque, N. Kermoal and D. Salée (dir.) : *L'activisme autochtone : hier et aujourd'hui*. Cahier DIALOG no. 2011-01, Actes de colloque. Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG) et Institut national de la recherche scientifique, Montréal : 16-19.

LÉVESQUE CAROLE, APPARICIO PHILIPPE, GAGNON MARTIN, GUTH KATHARINA, CLOUTIER ÉDITH and JOSÉE GOULET. 2011. *Cartographie sociale et économique de la population autochtone des villes du Québec*. La ville de Val-d'Or et la zone d'influence territoriale du Centre d'amitié autochtone de Val-d'Or. Cahier ODENA no. 2011-01. Alliance de recherche ODENA, Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG) et Regroupement des centres d'amitié autochtones du Québec, Montréal.

LÉVESQUE CAROLE, APPARICIO PHILIPPE and ÉDITH CLOUTIER. 2013. "Favoriser la coconstruction des connaissances en contexte autochtone: enjeux et défis méthodologiques," in C. Lévesque et al., *La coconstruction des connaissances en contexte autochtone: cinq études de cas* : 47-52. Cahier DIALOG no. 2013-03. Actes de colloque. Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG) et Institut national de la recherche scientifique, Montréal.

LÉVESQUE CAROLE and ÉDITH CLOUTIER. 2013. "Les Premiers Peuples dans l'espace urbain au Québec : trajectoires plurielles," in A. Beaulieu, M. Papillon et S. Gervais (sous la direction de) : *Les Autochtones et le Québec* : 281-296. Montréal : Les Presses de l'Université de Montréal.

LÉVESQUE CAROLE and IOANA RADU. 2014. *La Clinique Minowé. Portrait statistique des interventions, 2011 à 2013. Résultats préliminaires*. Document de travail. Institut national de la recherche scientifique et Centre d'amitié autochtone de Val-d'Or, Val-d'Or et Montréal.

LÉVESQUE CAROLE, RADU IOANA and MÉLISSA SOKOLOFF. 2014. *Dossier documentaire. Le concept de sécurisation culturelle : origine, portée et application*. Institut national de la recherche scientifique et Centre d'amitié autochtone de Val-d'Or, Val-d'Or et Montréal.

LÉVESQUE CAROLE and IOANA RADU. 2014. *Modèles et approches autochtones en matière de santé et services sociaux. Recueil d'études de cas internationales*. Institut national de la recherche scientifique et Centre d'amitié autochtone de Val-d'Or, Val-d'Or et Montréal.

MARTIN THIBAUT and ÉRIC DIOTTE. 2010. "Politiques publiques et santé des Autochtones résidant en milieu urbain : l'autonomie gouvernementale une condition de la redéfinition d'un partenariat équitable entre l'État et les Autochtones," in J. P. White et J. Bruhn (dir.), *Aboriginal policy research. Exploring the urban landscape* : 107-134. Toronto : Thompson Educational Publishing.

MARTIN THIBAUT and ÉRIC DIOTTE. 2011. "Politiques publiques et santé des Autochtones résidant en milieu urbain," *Développement social* 11 (3): 15-17.

MACDONALD DAVID and DANIEL WILSON. 2013. *Poverty or Prosperity. Indigenous Children in Canada*. Ottawa: Canadian Centre for Policy Alternatives and Save the Children Canada.

MONTPETIT CHRISTIANE 1989. *Trajectoires de vie de migrants autochtones en milieu urbain*, Mémoire de maîtrise (anthropologie), Université de Montréal, Montréal

OUELLETTE ANDRÉ and ÉDITH CLOUTIER. 2010. *Vers un modèle de services de santé et de services sociaux en milieu urbain pour les Autochtones de la Vallée-de-l'Or : La Clinique MINOWÉ, une ressource intégrée au réseau local de la Vallée-de-l'Or*. Une initiative conjointe du Centre de santé et des services sociaux de la Vallée-de-l'Or, du Centre de jeunesse de l'Abitibi-Témiscamingue et du Centre d'amitié autochtone de Val-d'Or.

RAMSDEN IRIHAPETI. 2002. *Cultural safety and nursing education in Aotearoa and Te Waipounamu*. Victoria University of Wellington, New Zealand.

SMITHERS GRAEME CINDY. 2013. "Indigenous Health Research and the Non-Indigenous Researcher: A Proposed Framework for the Autoethnographic Methodological Approach," *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 11 (3): 513-520.

SMYLIE JANET and PAUL ADOMAKO. 2009. *Indigenous Children's Report: Health Assessment in Action*. Keenan Research Centre, Health Canada. Online: [http://www.stmichaelshospital.com/pdf/crich/ichr\\_report.pdf](http://www.stmichaelshospital.com/pdf/crich/ichr_report.pdf).

TODOROV TZVERAN. 2008. *La peur des barbares. Au-delà du choc des civilisations*. Paris : Robert Laffont.

# MIYUPIMAATISIIUN IN EEYOU ISTCHEE: INDIGENOUS HEALING AND COMMUNITY ENGAGEMENT IN HEALTH AND SOCIAL SERVICES DELIVERY<sup>1</sup>

## IOANA RADU

PhD Candidate, Concordia University /  
DIALOG (Research and Knowledge  
Network Relating to Aboriginal Peoples),  
Montreal, Canada (oanarw@gmail.com)

## LARRY HOUSE

Coordinator Chisasibi Mental Wellness  
Team, Cree Nation of Chisasibi, Canada  
(houselawm@gmail.com)

## INTRODUCTION

Research shows that culture and language are among the most important determinants of Indigenous health because they influence the accessibility to the health care system and health information; increase compliance with treatment; strengthen the delivery of preventative programs and services; and can improve lifestyle choices (NAHO, 2008; Czyzewski, 2011; Health Canada, 2009; NWAC, 2007; Reading & Wien, 2009; Robins & Dewar, 2011). Indigenous-based approaches to healing and wellness have received increased recognition and acceptance by the mainstream Canadian health community, and both the federal and provincial governments have acknowledged the need to provide culturally safe health and social services (NAHO, 2008; Martin-Hill, 2003).

The Cree Nation of James Bay in northern Quebec was the first, and is still the only, First nation<sup>2</sup> in Canada to take full control of health and social services on a regional scale subsequent to the signing of the James Bay and Northern Quebec Agreement (JBNQA) in 1975

(CBHSSJB, 2004: 41; Torrie et al., 2005: 238). Specifically, the Cree Board of Health and Social Services of James Bay (CBHSSJB) has a dual function - that of a regional health council<sup>3</sup> and that of a *Établissement de santé et de services sociaux* which "maintains a public establishment belonging to the classes of a hospital centre, a local community service centre, a social service centre and a reception centre" (CBHSSJB, 2004). Its uniqueness<sup>4</sup> rests on the fact that the CBHSSJB is an Intergovernmental Health Authority co-funded by the federal and provincial governments to serve the particular health care needs of the Cree population, self-administers the health and social services in its territory (region 18), and is linked with the provincial health care system (NCCAH, 2011). Today, the Cree receive health and social services through a community-responsive system marked by complex bureaucratic and fiscal arrangements between the federal, provincial and Cree jurisdictions. In 2005, the CBHSSJB began a process of integrating Indigenous approaches to health and wellness by creating local Miyupimaati-siiun Committees in order to engage



1. A preliminary version of this paper was presented at the 5th biennial International Indigenous Development Conference - Nga Pae o te Maramatanga (Indigenous Centre of Research Excellence) June 27-30, 2012, Auckland, New Zealand.
2. For a summary of Aboriginal health systems and legislation in Canada see NCCAH, 2011
3. as per the *Act respecting health services and social services, R.S.Q., c. S-4.2* and *Act respecting health services and social services for Cree Native persons, R.S.Q., c. S-5*
4. Although the JBNQA also created the Nunavik Regional Board of Health and Social Services, according to the sources consulted its mandate is only designated by the *Act respecting health services and social services, R.S.Q., c. S -4.2*, therefore it functions as a regional health board but not as a public health and social service establishment

community members in the management and delivery of health and social services. The Cree Nation of Chisasibi took an active role in this process by developing a series of measures aimed at mobilizing community participation in defining a local vision and principles for integrated health and social services through a community driven research project that was initiated by the Chisasibi Miyupimaatisiun Committee.

In order to better understand the current efforts of the community of Chisasibi in implementing Eeyou (referring to a Cree person) healing practices, we will focus on how the research partnership developed and evolved over the past five years, and reflect on some key elements for community-university research partnerships. We begin with a brief context on community engagement in service delivery in Eeyou Istchee and follow with a narrative of our collaboration. We will close with our reflections on the achievements and challenges that we believe illustrate how community driven research can foster agency and empowerment by forging local participation in knowledge creation and mobilization.

### CREE CONTROL OVER HEALTH AND SOCIAL SERVICES

In 1975, the James Bay and Northern Quebec Agreement (JBNQA) legislated Cree control over the management and delivery of health and social services through:

- the creation of a Cree Board operating under provincial jurisdiction
- the transfer of fiscal responsibility to

the province

- the transfer of federal health infrastructure to the province and later to the Cree

Section 14, Chapter S-5 of the JBNQA formally recognized Cree values and traditions in regard to the development and delivery of health and social services. In 1978, the Cree Board of Health and Social Services of James Bay (CBHSSJB) was created to manage and administer health and social services for the Cree and non-Cree populations in the James Bay region. Finally, in 2002, *An Act respecting health services and social services for Cree Native persons* (R.S.Q. c. S-5) reiterated the province's responsibility for encouraging the Cree population "to participate in the founding, administration and development of institutions" and for providing appropriate services by taking into account the linguistic and socio-cultural characteristics of the region (Government of Quebec, 2012).

Despite the legislative authority recognized by Section 14, community-responsive service development and delivery reflective of Cree ethos have only recently been implemented following the signing of the Strategic Regional Plan (SRP) in 2004 (Torrie et al., 2005). This implementation gap was due to the failure of both governments to properly and fully implement Section 14. The SRP states that "all services should be provided in accordance with the cultural values and realities of the Crees" and calls for the integration of "traditional approaches to medicine and social services" (CBHSSJB, 2004: 8-9).

Among the measures outlined, the CBHSSJB has initiated a process to determine the future directions and integration of culturally-based "Cree Helping Methods" within the current health system (CBHSSJB, 2004: 29). The local Miyupimaatisiun Committees have been mandated to assist local band councils and to act as liaisons between community members and the CBHSSJB (CNC, 2009).

### CHISASIBI MIYUPIMAATISIUN COMMITTEE: LOCAL ENGAGEMENT IN SERVICE DELIVERY

The existence of Community health committees in Aboriginal milieus were initially envisioned in the federal Indian Health Policy (1978), but they were never formed in the Cree territory except on an ad hoc basis and never as permanently functioning organizations (Torrie et al., 2005). The situation began to change with the creation of the Miyupimaatisiun Committees in 2005. These committees are composed of local institutional representatives, at least one Elder and one youth member, and other community members appointed by the band council. They are responsible for reviewing matters related to community wellness and for assisting "the Council in implementing effective policies and strategies to promote the health and social welfare of the residents" (CNC, 2009: 3). In essence, the Committees serve as an interface between community members, the band council, and the CBHSSJB. Their mandate can nonetheless vary, depending on the community context. At the time of writing this

## Miyupimaatsiun Committee's Role & Community Relationship

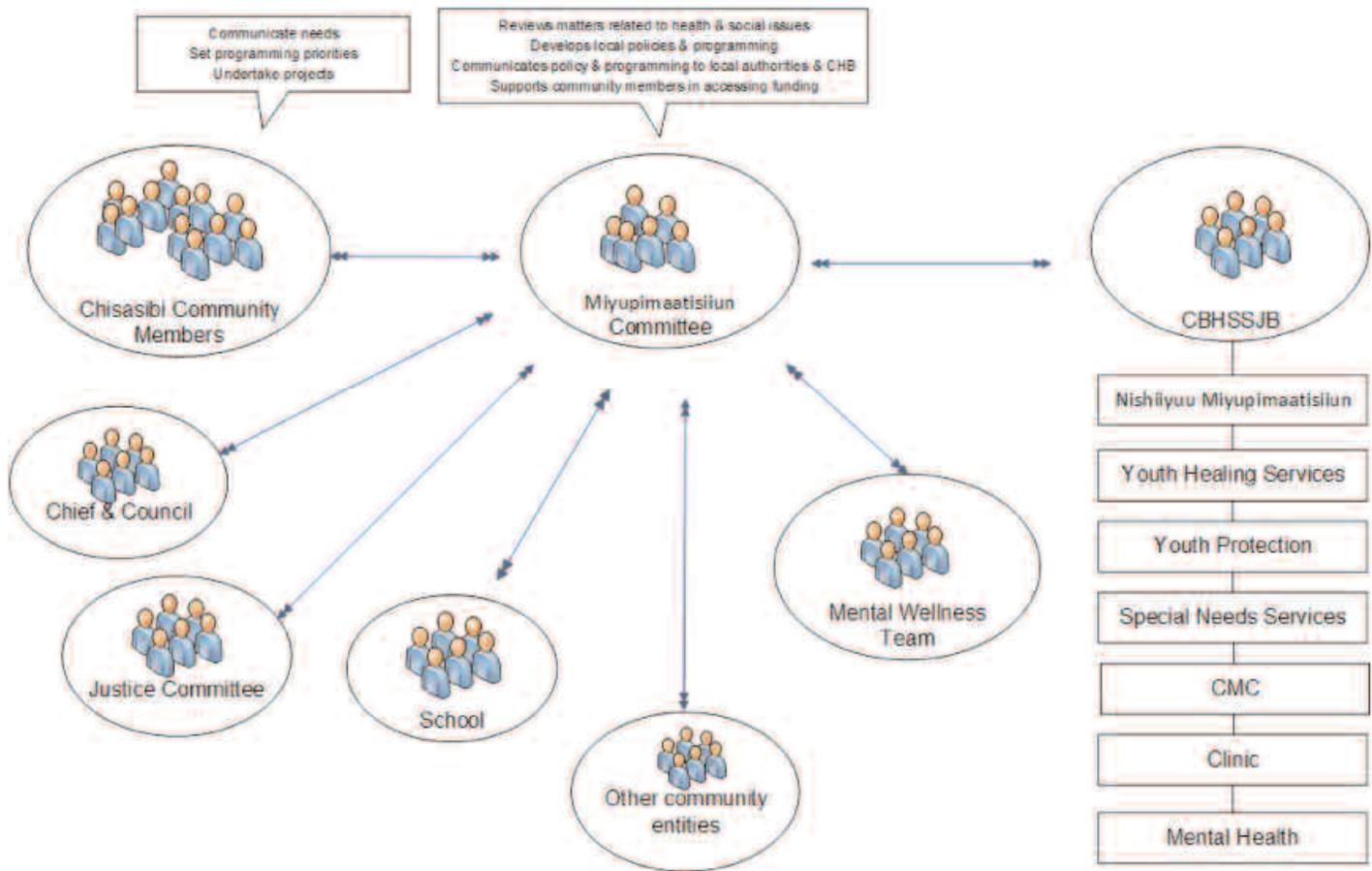


Figure 1. Chisasibi Miyupimaatsiun Committee as envisioned by Cree Nation of Chisasibi

\*CMC – Community Miyupimaatsiun Centre (community clinic or equivalent of CSSS)

article, the authors are aware of only the community of Chisasibi and of Nemaska (out of ten Cree communities) having enacted a by-law to establish a local health committee in 2009 and 2012 respectively.

In the case of Chisasibi, the Miyupimaatsiun Committee is primarily concerned with mobilizing community

participation in defining a local vision and principles for integrated health and social services and with increasing the appropriation of service delivery by community members in a way that directly meets local needs and a long-term vision of care and wellbeing. This orientation, developed at a Special General Assembly in 2009, was in response to the failure to properly communicate the

SRP to the community, resulting in the disengagement of community members from the process. The Committee secured funding for two community-wide symposiums at which the SRP could be formally presented. More importantly, the symposiums sought to create a space for dialogue between community members and local service providers in order to:

- determine community needs and priorities in terms of health and wellness,
- suggest how the gap in service provision could be bridged, and
- establish guidelines for the development of a long-term vision for a local wellness plan.

### DOING RESEARCH WITH AND FOR COMMUNITIES: WHERE DO WE START?

Indigenous scholar Shawn Wilson (2008) maintains that research is a space for building relationships, and together with the community, to cocreate the tools necessary to ensure that these relationships are sustainable in the future. This 'conversation-in-relation', a foundational concept in Indigenous Studies, has guided our research approach from the onset, but as we will explain below, theory was not the starting point of this collaboration and the research framework and ethical principles were formally established later on. The shared values that nevertheless underlined our collaboration were that any research project needs to have a relevant and practical application for the community; that the research process is co-determined by the community and the researcher in the spirit of reciprocity and respect; that all local knowledges (community narratives, personal stories, spiritual expressions, etc.) are fully recognized and valued both as theory and praxis; and finally, that the aims are to foster community agency and empowerment, in this case to develop an integrated model of well-being and living a good life. There was also an element of serendipity in how

this collaboration was born. Our personal and professional experiences greatly helped us put in practice these shared values and build a strong and fruitful relationship.

**Larry:** *It's been 20 years that personally, I have been initiating projects, bringing facilitators and cultural resource people in the community so that people can gain a deeper understanding of the ceremonies and practices that we have. For myself, it was never really a quest for these things, it was more a quest for personal healing but I ended up with certain gifts. I personally experienced family violence and abuse and, as with many other individuals, I abused alcohol and drugs. I was very fortunate that when I ended up in a juvenile detention centre in Montreal I managed to negotiate what would be the first formal bush placement in Eeyou Istchee. I thought I did that just to avoid the penal system but what I got out of there was more than just that, what I got out of there was a deeper understanding of who I am. And it is true, connecting with the elders and gaining a deeper understanding of our cosmology, our world view, has helped me do the work I choose to do, which is addressing or attempting to change the perceptions in the community about why things are the way they are. If you look at Native people in general, health wise, I think it needs to be relearned. I mean, statistically we are in the negative side. Like diabetes, obesity, violence, abuse... there is something there that needs to be understood.*

*There are many ways to understand illness or disease. But the most important thing to establish that foundation is a positive cultural identity. Because it has been such where people have always been dominated or colonized, thinking that their cultures are subservient or less than. It is through that ignorance that this continues. So it is the understanding at that level that needs to happen. Also, it has always been the case where external authorities determine what is good for us. And what we are doing today is trying to build it from the ground up and have some sort of engagement where we take ownership of any programs or any initiatives that we do. It would work better that way because we know what the realities are in our communities. Having worked for Anishnawbe Health in Toronto I know that integrating culturally safe health and social services is feasible and beneficial for individuals and their family. We have these institutions that are charged with the responsibility for the wellness in our communities, so why not? Why not integrate our ceremonies in there if they are perceived to be helpful, beneficial, or done in a way that helps individuals take responsibility for their lives... why not? Personally I don't think that we can work in isolation of the institutions that we have to address the state of our communities. I think the resources are there and is just a matter of creating that collaboration. We just have to create the safety and the opportunity necessary so that the community can take action. So, in 2009, when I was elected Community Health Representative in Chisasibi for the Health Board I*

took the Strategic Plan and tried to understand what the mandate was in terms of implementing Cree approaches to wellness. At the same time the Band passed the Miyupimaatisiun Committee by-law and funds were available to engage community members in defining a local vision and mandate for wellness.

**Ioana:** My initial intention for my PhD research was to explore socio-cultural constructions of resource development of Cree youth and their role in the decision-making process related to resource development. This interest stemmed from my work with the Cree Nation of Nemaska in the environmental impact assessment process for the Rupert River diversion project (2005-2006) where I began to better understand the social impact of hydroelectric development on everyday life in the Cree Nation. My attempts at mobilizing community youth and local institutions around the research topic proved to be a total failure. In 2009 I met with members of the Nemaska Youth Council to discuss my research in the community. Although some interest was shown and I had prepared some specific questions, the conversation instead focused on 'catching up' on community life and my own experiences since I moved back to the city (I had lived in Nemaska for two years prior to returning to do the PhD). Nothing specific came out of that meeting and I was certain that the topic did not resonate with their priorities and concerns at the time.

*In October of the same year, I met with the Chisasibi Chief to discuss my research interests there, hoping to get a better idea on what the community might need in terms of research. All the topics I enumerated were satisfactory, I was given a letter of consent to conduct research in the community, and was told to stop by once I have 'made up my mind'. This was quite a surprise since I had been spending a lot of time reading literature on knowledge mobilization, decolonizing research methodologies and participatory action research, all of which call for researchers to co-develop their research topics with the community. But co-creation is not as obvious as I had thought.*

*While I put my own research on hold hoping to better gauge local needs, in January 2010 I was asked to facilitate a community consultation on health and social services in Nemaska. Although I didn't know much about how the health and social service system functions in Eeyou Istchee, together with the local Cree Health Board representative, we organized a three-day meeting with a one day pre-meeting and a one day post-meeting consultations. All sessions were audio recorded and it was recommended that they be made available to the local radio to be played at a relevant time (either lunch or in the evening) so that the community members that were not present can familiarize with the issues discussed. I also drafted a report that was eventually presented at the Cree Health Board meeting. In October 2010, I was asked to repeat the activity in Chisasibi. I gladly accepted since I*

*wanted to spend more time there for my own research needs (building closer relationships with community youth). This exercise turned into a long-term relationship with the local Miyupimaatisiun Committee which in the end helped frame my research in terms of the community needs. Practically, for me, this has meant that even though my initial intention was to only conduct life-story interviews with the youth, my methodology was flexible and inclusive, and eventually changed to accommodate the research needs as the project evolved over the past five years.*

## MOBILIZING COMMUNITY PARTICIPATION THROUGH RESEARCH PARTNERSHIPS

The Miyupimaatisiun Committee received a mandate from the community to expand Eeyou healing programming in Chisasibi (CMC, 2010). Between 2009 and 2010, it facilitated a nine-month Transfer of Traditional Knowledge project intended to increase community participation in traditional activities such as sweats, Sundance, traditional harvesting, food preparation, and counselling. Eeyou healing services were also made available. Within a three-month period, there were over 400 interventions (out of a total population of 3,015 people aged 15 years or older), which indicates that Eeyou healing can have a role in existing services (CMC, 2012; Statistics Canada, 2012). Healers are now being used by the CBHSSJB Mental Health Department and the Residential Schools Counselling Services.

While counselling services have continued, the questions raised during the symposiums indicated the need for a community roundtable on Indigenous healing. Along the way certain tensions arose between the Committee (and more specifically its focus on Eeyou healing implementation) and its institutional partners in the community. We therefore saw a need to draft a short literature review on how Aboriginal healing is conceptualized and implemented elsewhere in Canada. Similar to the experience of Aboriginal nations throughout Canada, Chisasibi community members wanted an open forum in which issues of transparency, appropriation, and ethics could be discussed. Based on the literature review two roundtables were held in early 2012.

The first focused on specific aspects of Eeyou healing and how it can address the root causes of illness and psychosocial issues in the community. The second discussed concrete steps that the community can take for the implementation of Eeyou healing services. The consensus emerged that although Eeyou healing may not be relevant to all community members, it *does* respond to the needs of a considerable portion of the Chisasibi population. It was underlined that the perspective should not be presented as an “either/or” issue but simply as diversifying health and social services in order to respond to as many needs as possible. The long-term goal, when using either clinical approaches or Eeyou healing, is to help individuals achieve balance in their lives. The community identified three major aspects for

implementation: broad community activities focused on awareness; inter-agency coordination; and strategic management (CMC, 2012).

### BUILDING SOCIAL CAPITAL AND COMMUNITY AWARENESS

To increase community awareness of Eeyou healing, the Miyupimaatsiun Committee suggested that an on-the-land program be ethnographically documented and its results presented to the community, preferably in a video format. In April 2013, we put together a film crew and documented a two-week land-based healing program developed by Eddie Pash, a Chisasibi elder. In addition to the filming, we took the opportunity to work with Eddie and develop a program curriculum to be presented to the Cree Board of Health and Social Services of James Bay as well as to the courts as a justice diversion measure. The document now serves as a model for other Cree communities and the Chisasibi program is the first bush healing pilot program to operate in Eeyou Istchee. A 30 minute documentary was also produced and released earlier in 2014 and was presented at the *Healing Together with Land and Culture: Gathering of Wisdom Conference* in Whitehorse and at the National Native Addictions Partnership Foundation (NNAPF) national conference Honouring Our Strengths (HOS, 2014). These two conferences helped the Committee validate the process undertaken in Chisasibi and its relevance for other Aboriginal communities in Canada. The workshop conducted at the HOS 2014

was ranked first and is now in the process of being developed as a toolkit in collaboration with the NNAPF.

We also approached the Nishiiyuu Miyupimaatsiun Department (see Figure 1) which is mandated to provide integration for traditional approaches to medicine and social services within the CBHSSJB. We were therefore invited to participate in the Department consultation activities as representatives of Chisasibi and attended various meetings with the Council of Chishaayiyuu (Elders’ Council). This included presenting a draft of the documentary for comments to the elders and collaborating with the department in the final edits of the land-based healing curriculum.

A second major achievement for this research collaboration was securing external funding from Health Canada to develop a multidisciplinary intervention team in Chisasibi. The planning processes as well as other culturally relevant activities undertaken in Chisasibi between 2010 and 2014 were made possible by the CBHSSJB Community Initiatives Fund, which ended in 2014. The Miyupimaatsiun Committee nevertheless believed that the programming developed over the past five years responded to the community needs and closed some of the gaps in service provision in terms of health and wellness.



We therefore submitted a proposal for a Mental Wellness Team program with Health Canada in September 2013. The proposal was accepted and in November we received confirmation that Chisasibi secured \$250,000 over the next three years (2013-2016). The first instalment of the funding envelope served to begin training for Community Addictions Workers in collaboration with Nechi Institute (an Aboriginal organization that teaches culturally safe intervention methods). It has also allowed the community to establish a full-time administrative team that is now greatly facilitating the Committee's work and strengthening institutional collaboration.

Finally, the Cree Nation of Chisasibi is currently developing a community vision and principles for integrated health and social services. The aim of the Community Nishiyuu (contemporary Cree) Model is to establish an institutional structure, standard practices, and programming for Eeyou healing. In the short term, the project outcome includes the completion of a Strategic Health Plan (2014-2017) for the Miyupimaatisiun Committee. It is hoped that this process will have a Nation-wide impact as the CBHSSJB is negotiating a new Strategic Plan with the Quebec Ministry of Health and Social Services. Part of the negotiations includes the development of Nishiyuu Miyupimaatisiun (previously, Cree Helping Methods) programming to be submitted for consideration to the Ministry. Recent developments are very promising, as the community of Chisasibi was invited to participate in the negotiations.

## ETHICS CHALLENGES

Because we had to function within the CBHSSJB institutional arrangement as well as that of the university, we faced some challenges in terms of research ethics. First, some community research partners found the formal university ethics review redundant and an administrative barrier to local activities, since our collaboration was already three years into the process. From their perspective our relationship was already based on trust and reciprocity and a signed research agreement was not needed to validate this. Second, since the land-based program is not regularly held as is dependent on CBHSSJB funding schedule, it did not align well with the university ethics approval process. Third, although the Nishiyuu Miyupimaatisiun Department was given a formal research agreement to sign, given the hectic schedule of the Director we did not receive a copy in time to submit to the university. Nevertheless, these challenges helped us to continuously reflect on the ethical implication of doing research in the community. In conducting interviews with the youth we realized that sometimes the formal approach to signing a consent form at the onset can be intimidating and that it can be done during or after the interview.

Although this seems counterintuitive from a formal ethics process, in our case, some youth we interviewed had prior negative experiences with social services which included complicated release of information procedures that created insecurities to sharing personal experiences. By initially approaching interviews on a more informal basis and

over the course of a couple of days, we were able to establish an environment of trust and allowed the youth to better understand and trust the formal ethical process that framed the research in which they participated. It also enabled us to respect the institutional ethics requirements while honouring individual experiences and needs of the participants. In addition, although research agreements are key to clarifying knowledge ownership, consent and benefits, communities can still exercise control over all research conducted within their territories through a close collaboration with the researchers before and after such agreements are signed. Indeed, ethics engagements do not expire once the data has been collected, they constitute a foundational element of research that extends to data analysis and the knowledge mobilization process that follows the formal 'end' of field activities. Finally, this experience has better prepared us to negotiate administrative burdens in a way that respects both the individual research participants and the institutional partners.

### **"IF RESEARCH HASN'T CHANGED YOU AS A PERSON, THEN YOU HAVEN'T DONE IT RIGHT"<sup>5</sup>**

For the Cree Nation, exercising jurisdiction over the social welfare and health of its members is an expression of self-governance and empowerment. This responds to the vision of a Cree society where "individuals are well balanced emotionally, spiritually, mentally and physically," where "families live in harmony and contribute to healthy communities," and where "communities are

5. Wilson, 2008: 135.

supportive, responsible and accountable” (CBHSSJB, 2004: 8). Incorporating Cree values and practices into service provision means moving beyond the Western medical model in order to base programming on Cree healing and caregiving practices.

Our experiences have shown that a successful implementation rests on a variety of factors. Firstly, an inclusive and respectful dialogue between community members, service providers and management is essential because it creates the appropriate conditions for defining a collective vision of care and wellbeing. Secondly, mediating institutions, such as the Miyupimaatisiun Committees, ensure that community needs and worldviews are incorporated into the development of health and social policy and programming. Thirdly, the success of local initiatives depends on their integration into regional institutional and financial arrangements as well as into the broader policy context. Fourthly, even though the institutionalization of Indigenous healing is still a matter of debate within Aboriginal nations, a structured approach with validated ethical and cultural protocols is central to building trust in the healing practice itself and to strengthen individual relationships between community members and healers.

Finally, in order to be successful, local initiatives need a dedicated group of individuals whose particular skills and knowledge can facilitate an equitable dialogue, initiate collective reflection, and maintain transparent and respectful communication. The role of research

and community-university partnerships in this types of processes is key in terms of mobilizing knowledge locally and nationally. Indeed, a true partnership cannot be limited to consent forms and community research agreements. In fact, community research partnerships can only be built in time and through an open and reflexive dialogue around the kitchen table, in community halls, and during long-distance travels. From the perspective of the researcher, sharing authority over the research process may sometimes be a daunting task, as often, this type of close relationship can open the door to many tensions that exist in the community. Finding dedicated community research partners and embedding the research process within existing community institutional arrangements is not easy and sometimes not achievable, nonetheless, we believe it should be a principal goal of community-university partnerships.

## CONCLUSION

Ideally, doing research with Aboriginal communities means co-developing the overall research objectives before the actual research activity (fieldwork) starts. This includes negotiating the role of the researcher according to what the community needs and less to what his

or her initial research objectives may be. It also means that the methodology must remain flexible and inclusive, open and receptive to the inevitable changes that take place *during* the research process. Both the researcher and the research partners must be ready to face a steep learning curve both in respects to theory and to practice. In this instance, the researcher had very limited knowledge of cultural safety theory and practice, but under Larry’s guidance, who is both a Sundance Chief and a community addictions professional, the learning curve was well mediated. In addition, only by spending extended periods of time both on the land and in the community, taking part in day-to-day activities, sharing personal stories and family moments, through experiential learning and building close relationships with community members, a mutual understanding of wellness and care was possible. Conversely, institutional ethics policies can sometimes seem redundant and paternalistic from the perspective of the community, as it happened to us, but retrospectively it has forced us to take the time and reflect on the potential transformations and outcomes of the research project for the community. Indeed, this experience has kept us in constant self-reflexive dialog that in the



end has shaped not only the resultant knowledge but a growing awareness of the transformations that we have experienced as individuals embedded within a research collaboration.

Aboriginal healing is neither monolithic nor static but a contemporary expression of knowledge systems and values reflecting the rich cultural diversity of Canada's First Nations, Métis and Inuit communities (NAHO, 2008). Aboriginal healing encompasses a variety of beliefs and practices that are not uniformly acknowledged or used across the country. Indeed, each practitioner makes use of various treatment methods that best respond to his or her client's needs (herbal remedies, sweats, ceremonies, etc.) and operates within specialized fields of practice (involving spiritualists, midwives, healers, medicine women/men, or herbalists). These practices are nonetheless interrelated, as each practitioner can hold a wide range of specialized knowledges while reflecting particular conceptions of identity, place and health (Martin-Hill, 2003; NAHO, 2008).

Not only is healing as a concept both diverse and multiple but the role and characteristics of Indigenous practitioners also raise issues of authenticity and authority as well as of exploitation and appropriation (Martin-Hill, 2003; NAHO, 2008). These contemporary realities can challenge cultural principles and values as service users' needs and circumstances evolve. Thus, community participation in the development and implementation of Indigenous healing is central not only to a culturally appro-

priate service delivery but also, and especially, to building a collective conception of care and wellness that is in keeping with local knowledge and worldviews. Because Indigenous communities and their client base are heterogeneous, local community members require the appropriate conditions in which this negotiation can take place.

Our experiences illustrate that respect, reciprocity and accountability are the main determinants of an equitable dialogue that is in line with the broader process of decolonization and self-determination. We also hope that the

personal stories we shared have shown how autonomy and wellness are intricately linked and how healing functions as a decolonizing force. In essence, it reflects the political agency in which uncertainties, conflicts, apprehensions, and compromises are continually renegotiated in Indigenous communities. They have also validated the approach of doing research with and for communities - to take a strength based perspective in which the everyday acts of resistance are celebrated. And finally, to honour the relationships with the community as a valid academic and political endeavour.

## GLOSSARY

Miyupimaatisiun	Being alive well
Eeyou	A Cree person; also, a human being
Eeyou Istchee	Land of the Cree people
Nishiiyuu	Future generations of Cree



## BIBLIOGRAPHY

- ADELSON, N. 2000. *'Being Alive Well': Health and Politics of Cree Well-Being*. Toronto: University of Toronto Press.
- BALL, J. 2009. *Cultural safety in health care for Aboriginal Peoples*. Presentation to the British Columbia Public Health Services Authority and Vancouver Coastal Health Authority. Fall, Vancouver. Retrieved April 7, 2014, from <http://www.ecdip.org/culturalsafety>
- CHISASIBI MIYUPIMAATISIUN COMMITTEE (CMC). 2010. *Chisasibi Symposium on Health and Social Issues*, Final Report.
- CHISASIBI MIYUPIMAATISIUN COMMITTEE (CMC). 2012. *Roundtable on Eeyou Healing*, Final Report, February 7-9, 2012.
- CREE BOARD OF HEALTH AND SOCIAL SERVICES OF JAMES BAY (CBHSSJB). 2004. *Strategic Regional Plan to Improve Health and Social Services: Miyupimaatsiun Building a Strong and Healthy Cree Nation*. Retrieved April 7, 2014, from <http://www.creehealth.org/sites/default/files/CBHSSJB%20Strategic%20Regional%20Plan%202004-2014.pdf>
- CREE NATION OF CHISASIBI (CNC). 2009. BY-LAW NO. 2009-001 Respecting the Establishment of the Miyupimaatsiun Committee, a Committee on Health and Social Issues.
- CZYZEWSKI, K. 2011. Colonialism as a Broader Social Determinant of Health. *The International Indigenous Policy Journal*, 2(1). Retrieved January 20, 2012 from <http://ir.lib.uwo.ca/iipj/vol2/iss1/5>
- GOVERNMENT OF QUEBEC. 2012. *An Act respecting health services and social services for Cree Native persons*. Retrieved May 5, 2012, from [http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/S\\_5/S5\\_A.html](http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/S_5/S5_A.html)
- HEALTH CANADA. 2009. A Statistical Profile on the Health of First Nations in Canada: Determinants of Health, 1999 to 2003. HC Pub.: 3555, Cat: H34-193/1-2008E-PDF. Retrieved April 10, 2014 from <http://www.hc-sc.gc.ca/fniah-spnia/pubs/aborig-autoch/2009-stats-profil/index-eng.php#culture>
- JAMES BAY ADVISORY COMMITTEE ON THE ENVIRONMENT. 2011. *Territory covered by the environmental and social protection regime*. Retrieved May 10, 2012, from <http://www.ccebj-bace.ca/english/about-us/territory.html>
- MARTIN-HILL, D. 2003. *Traditional Medicine in Contemporary Contexts: Protecting and Respecting Indigenous Knowledge and Medicine*. Ottawa: National Aboriginal Health Organization. Retrieved January 20, 2012, from [http://www.naho.ca/documents/naho/english/pdf/research\\_tradition.pdf](http://www.naho.ca/documents/naho/english/pdf/research_tradition.pdf)
- NATIONAL ABORIGINAL HEALTH ORGANIZATION (NAHO). 2008. *An Overview Of Traditional Knowledge And Medicine And Public Health In Canada*. Retrieved January 20, 2012, from <http://www.naho.ca/documents/naho/publications/tkOverviewPublicHealth.pdf>
- NATIONAL COLLABORATING CENTRE FOR ABORIGINAL HEALTH (NCCAHA). 2011. *Looking for Aboriginal Health in Legislation and Policies, 1970 to 2008. The Policy Synthesis Project*. Retrieved September 17, 2014 from <http://www.nccah-ccnsa.ca/en/publications.aspx?sortcode=2.8.10&publication=28>
- NATIVE WOMEN'S ASSOCIATION OF CANADA (NWAC). 2007. *Social Determinants of Health and Canada's Aboriginal Women*. Retrieved April 7, 2014 from [http://www.nwac.ca/files/reports/NWAC\\_WHO-CSDH\\_Submission2007-06-04.pdf](http://www.nwac.ca/files/reports/NWAC_WHO-CSDH_Submission2007-06-04.pdf)
- READING, C.L. & F. WIEN. 2009. *Health Inequalities and Social Determinants of Health of Aboriginal Peoples' Health*. National Collaboration Centre for Aboriginal Health. Retrieved January 20, 2012, from [http://www.nccah-ccnsa.ca/docs/social%20determinates/nccah-loppie-wien\\_report.pdf](http://www.nccah-ccnsa.ca/docs/social%20determinates/nccah-loppie-wien_report.pdf)
- ROBBINS, J. A. & DEWAR, J. 2011. Traditional Indigenous Approaches to Healing and the modern welfare of Traditional Knowledge, Spirituality and Lands: A critical reflection on practices and policies taken from the Canadian Indigenous Example. *The International Indigenous Policy Journal*, 2(4). Retrieved 20 January, 2012, from <http://ir.lib.uwo.ca/iipj/vol2/iss4/2>

STATISTICS CANADA. 2012. *Census Profile*. 2011 Census. Statistics Canada Catalogue No. 98-316-XWE. Ottawa. Released May 29, 2012. Retrieved May 10, 2012, from <http://www12.statcan.gc.ca/census-re-censement/2011/dp-pd/prof/index.cfm?Lang=E>

TORRIE J., BOBET E., KISHCHUK N. & A. WEBSTER. 2005. *The Evolution of Health Status and Health Determinants in the Cree Region (Eeyou Istchee): East-main-1-A Powerhouse and Rupert Diversion Sectoral Report*. Volume II: Detailed Analysis. Chisasibi: Cree Board of Health and Social Services of James Bay. Retrieved March 12, 2012, from <http://www.gcc.ca/pdf/QUE000000012.pdf>

WILSON, S. 2008. *Research is Ceremony: Indigenous Research Methods*. Winnipeg: Fernwood Publishers.

WALDRAM, J.B. (Ed). 2008. *Aboriginal Healing in Canada: Studies in Therapeutic Meaning and Practice*. Ottawa: National Network for Aboriginal Mental Health Research and Aboriginal Healing Foundation. Retrieved January 20, 2012, from <http://www.ahf.ca/downloads/aboriginal-healing-in-canada.pdf>

## COMMUNITY FILMMAKING AND TERRITORIAL RESEARCH: DEVELOPING NEW RESEARCH METHODS FROM A MAPUCHE PERSPECTIVE

JUAN RAIN,  
ROBERTO CONTRERAS,  
FRESIA PAINEFIL,  
GERARDO BERROCAL,  
ARIELLA ORBACH,  
THORA HERRMANN ET  
MANON BARBEAU

Indigenous researchers worldwide are increasingly using Indigenous research methods and methodologies to decolonize research on Indigenous histories, realities and worldviews. We wish to contribute to this discussion by sharing an emerging research initiative led by Mapuche communities of the Lake Budi traditional territory in Chile, with the collaboration of a Canadian team.

The Mapuche nation (“people of the land”) is one of the First Peoples of what are today the States of Chile and Argentina. The ancestral Mapuche territory, Wallmapu, extended from the Pacific to the Atlantic coasts of the central and southern parts of both countries. In Chile, after centuries of successful resistance to Spanish invaders, the Mapuche were militarily conquered by the newly independent Chilean State in a violent campaign known as the Pacification of Araucanía, lasting from 1861 to 1883. As a result of this conquest, Mapuche society was torn from its traditional relation to the land as families were forced into *reducciones* (reserves), reducing Mapuche territory from 10 million to 500,000 hectares. Today, as part of a process of

evolving within and resisting colonialism, the Mapuche are reclaiming traditional ways of organizing and relating with their Indigenous territory.

This article shares the voices of four members of the Mapuche research team and three members of the Canadian team. It is co-written to mirror the reflective process of our collaboration and reaffirm the central role that Indigenous knowledge, expertise and analysis should have in an ethical and respectful research partnership.

**Roberto Contreras:** The Indigenous Other has long been a subject of research. Dominant society has always been fascinated by the distinct lifeways and worldviews of Indigenous cultures. These cultures were always observed from a Western point of view, a gaze often only able to grasp a small fraction of Indigenous knowledge and often guilty of distorting or creating crude reproductions of Indigenous peoples' realities – peoples whose cultures pre-date the creation of nation-states and who, still today, resist disappearing into “civilization” and “globalization,” with their tendency to standardize criteria and models for living a good life.



*How could they understand our way of seeing the world, those who still haven't experienced how the earth expresses her sorrow, those who still haven't listened to the birds' sad song and to the slow death of the native forest? The invader drove pain deep into my people, and we withdrew our green attack.*

– Oral testimony of a Mapuche woman, 1998

This model has been applied to First Peoples across the world, including the Mapuche who have survived with a history of over 450 years of resistance, first to the Spanish crown and later to the Chilean state. The unilateral gaze of Western academia has not contributed to our wellbeing, it has damaged our worldview. Many are the publications that have categorized the Mapuche as pagan beings or beings lacking spirituality; these conclusions set the stage for processes of forced evangelization and the loss of knowledge, culture and language.

To resist this ideological process, over the last two decades we have begun re-writing Mapuche history from our own perspective. A new generation of Mapuche historians has initiated a process of historical research grounded in our own sources of knowledge: the survivors of the “genocide” of our people, or what the Chilean state refers to as the “Pacification of Araucanía.” This new way of looking at our history requires new models for relating to, and structuring, information; models that are more

in tune with our ethics and values; models that grant our political and cultural authorities, our Elders who still hold empirical knowledge of their territory, the honour they deserve; models that respect these knowledge holders' rhythms, the oral nature of their narrative, and most of all, their way of understanding the world.

### RECREATING KNOWLEDGE AND RECONSTRUCTING TERRITORY: A MAPUCHE APPROACH TO AUDIOVISUAL COMMUNICATION AND RESEARCH

**Juan Rain:** The *aylla rewe* Budi is one of the territories that make up Lafkenmapu, the territorial space of the Mapuche Lafkenche, or “people who co-exist with the ocean.” The Budi territory is defined by the Trairaico (Imperial) River to the north and the Toltén River to the south. A *rewe* is a territorial space that has its own political and religious authorities. It can also be referred to as a *lofmapu*, or community space defined by natural barriers and how the space is used by its human residents. The *lofmapu* is, in turn, made up of the distinct *lofche*, or families, that reside within its boundaries. An *aylla rewe* is the political structure of a territorial space made up of nine (“aylla”) *rewe*. This structure allows the nine *lof* or *rewe* of a particular territorial space to develop together along the same path, bound by family ties and shared spiritual, organizational and communicative characteristics.

The subjugation of the Mapuche people by the Chilean and Argentinian states caused a social, political and cultural break from this way of organizing space, through the imposition of a new way of administering Mapuche territory. To this day, the Mapuche way of understanding and organizing territory is both unacknowledged and outright rejected. For this reason, we reclaim this territorial space and it is here that we focus our work to restructure the social, political, cultural and spiritual fabric of the territory.

We believe that this restructuring must ground itself in Mapuche principles and perspectives of knowledge. Ancestrally, the Mapuche understood life and space from their own worldview, one that emerges from *kimvn* and *rakizuam* (Mapuche knowledge and wisdom). For this reason, we value the tools that our knowledge provides us: the Mapuche language and its protocols; the spaces, such as the *ruka* (traditional house or living space), that invite us to gather and share experiences and knowledge through *ngvlam* (advice) and *nvtram* (narrative); and our own political structure and the role of our Elders and authorities<sup>1</sup> in passing on knowledge and in exercising our justice, or the process of resolving problems, identifying needs, re-establishing order and consolidating spaces and their organization through conversation and dialogue, *ngvlam* and *nvtram*, to reach consensus.

1. The Mapuche concept of traditional authorities or ancestral authorities refers to individuals who hold political, cultural and spiritual responsibilities, and who are considered guides or experts in their area. For example, a *logko* (chief) is a political guide; a *machi* (healer) is an expert in health and medicine.

There are many ways through which Mapuche knowledge is passed on. Orality is central to sharing knowledge through the stories and narratives of the Elders, advice given to children as part of their education, and the *tragun* (gathering) which is a political event where Mapuche authorities seal agreements through the spoken word. We believe that today, it has become necessary to design strategies for integrating new communication tools and technologies – audiovisual, radio, written – that will allow us to develop a way of communicating that incorporates the codes of our orality and reflects our Mapuche worldview. In this way, we hope to practise a Mapuche way of communicating, exercising the right to territorial control through communication and creating our own media.

In 2003, we initiated a training process, integrating new technologies and creating teams of communicators to accompany these territorial processes through communication. This training is grounded in the Mapuche way of communicating and sharing knowledge, which involves the participation of the *lofche*: the families of a community and in particular, the Elders who are the holders of Mapuche knowledge. This responds to the Mapuche way of training, educating and passing on knowledge.

**The Mapuche School of Filmmaking and Communication** is one of the training and self-training exercises that reflects this process. This “school” is

made up of two major fields of activity, Mapuche filmmaking and Mapuche communication. Here, we focus on the filmmaking field, which includes an annual filmmaking production workshop carried out in collaboration with Mapuche and Canadian organizations.<sup>2</sup> Initiated in 2011, this workshop provides young communicators in our territory with technical skills in digital filmmaking (short film). Youths learn to appropriate audiovisual technologies and techniques as tools for social and cultural research. Over the course of a one-month production process, they create short films that address topics of importance to the territory. The youths are responsible for script development, interviewing, shooting, sound recording and editing. This process is overseen by a Mapuche filmmaker who ensures cultural appropriation of the audiovisual tool and a filmmaking instructor sent by the Québec organization, Wapikoni Mobile. The instructor acts as a guide and technician, allowing the youths to “learn by doing.” The field team also includes two local coordinators who ensure the participation and support of the traditional authorities and *lofche*, and two logistical coordinators, one local and one Canadian.

Audiovisual production is collective, responding to the Mapuche way of handling knowledge. The youths work in groups, at times quite large (ten people), making decisions by consensus and sharing the roles of director, cameraperson, sound recorder, interviewer, editor, etc.

At the end of the month's work, each team presents a finished short film to the community at a large community event. Since 2011, 26 youths from the territory have participated, aged 9 to 23. These filmmaker-researchers have created six short films dealing with subjects as diverse as Mapuche medicine, ideological colonization, youth identity and territorial recovery.<sup>3</sup>

Filmmaking techniques are incorporated into the Mapuche way of understanding communication; the training process involves creating opportunities for reflection by our youths throughout the year, using our own spaces such as the *ruka* and sacred spaces. It is these reflections that are then embodied in the audiovisual products. Therefore, it is the Mapuche way of communicating that provides the foundation and ingredients for developing audiovisual content. Through this exercise, we aim to incorporate new technological tools to construct a distinctly Mapuche way of making films and other audiovisual creations.

**Ariella Orbach:** Our text is accompanied by two short films created by Mapuche youths. In *Kimeltuwn Mapuche Ñymican* (“Teaching Mapuche Weaving”), an Elder reflects on how weaving, an art practised by many Mapuche women, connects her to the land and to the next generations of Mapuche. Mixing documentary evidence with fiction, the film shows how many members of the community came together to

2. Mapuche collaborating organizations are Lafken Ñy Zugvn, the lof Malalhue Chanko and Llaguepulli, and Adkimvn; Canadian collaborating organizations are Wapikoni Mobile and Strategic Video Initiative, both from Montréal.

3. The short films created by youths from the aylla rewe Budi are: *Kimeltuwn Mapuche Ñymican* (2011); *¡Inciñ Getuai Taiñ Mapu!* (2012); *Nutuallin Taiñ Mapuche Ñen* (2012); *Petu Weicalejiñ Mojeleal ta Inciñ ka Taiñ Mapu* (2013); *Ixofil Lawen* (2013); and *Fei Lagenmi Ixofil Mogen* (2014). They can be viewed at: [youtube.com/user/escuelacinemapuche](https://www.youtube.com/user/escuelacinemapuche)



creatively re-enact the weaving process. *Ixofil Lawen* ("Everything is Medicine") is a good example of the application of Mapuche communication codes and protocols to filmmaking. It records a conversation (*nvtram*) between a healer and an Elder and chief as they reflect on the importance of traditional medicine in maintaining social and ecological equilibrium. These films are concrete examples of how audiovisual production can maintain knowledge-sharing protocols and value Elders and cultural authorities as knowledge communicators. The films stand alone as research products that reflect both the young filmmakers' curiosity about their culture and history, and broader community knowledge-sharing priorities. This creative engagement of the young generation is part of a larger research process underway in the territory.

**Gerardo Berrocal:** A research methodology is being developed in the *aylla rewe* Budi that seeks primarily to collect traditional knowledge and historical memories of the old territory using information and communication technologies (ICTs). These tools allow us to develop written, visual and audiovisual research products that contribute practically to local processes.<sup>4</sup>

Research work is being carried out alongside an audiovisual production process. While we collect knowledge and reflections about the territory, we simultaneously record the process using technological tools. Once this "collection" stage has been completed, we can begin analyzing, categorizing and structuring the information gathered through

a post-production (editing) process. This concludes with the creation of practical research products that allow local dissemination of results through public screenings.

The production process differs from conventional research or audiovisual work – that is why we speak of our own methodology – and is carried out according to our own ways of communicating. For example, we do not conduct informative interviews (as in journalistic practice), nor do we conduct semi-structured interviews or cite "sources" (as in an anthropological or sociological practice). Rather, we obtain stories or narratives from *nvtramkawvn* (conversation) or *ngvlamtuwvn* (knowledge sharing). For this reason, we have integrated the concepts of *nvtramkawvn dungun* (conversational narrative) and *ngvlamtuwvn dungun* (knowledge sharing narrative) into our research methodology. This is because orality is an essential characteristic of Mapuche communication, as is the Mapuche language (Mapuzungun) through which these narratives are generally shared.

Another important aspect is the content of these narratives, not obtained according to a pre-defined interview guide or script, or by directing questions toward a topic. A narrative is shared according to the vision and priorities of the person who is sharing it. This assumes that the teller of a narrative is the one who holds knowledge about the topic being researched; therefore it is he or she who has the authority when sharing this information and knowledge.

As noted previously, we do not seek to incorporate the common standards of audiovisual production into our documentaries. Rather, we look for images that reflect everyday Mapuche life in the *lof* and, in this way, prioritize content over "cinematographic language" or "aesthetics" in the final product.

Our current research process involves the development of several products: a sociocultural map that reflects how the old territory is seen in traditional Mapuche knowledge; a documentary that compiles narratives of historical memory about the territory and its importance and use; a visual document that summarizes research findings; and, a report containing historical information compiled from "official" archives about the territory.

The knowledge expressed through narratives, in the *aylla rewe* Budi, is related to the importance and ancestral use of the territory. Through these stories, we obtained information on the original names of each territorial space (toponyms), and why these names were chosen. We also learned about the practical, cultural and spiritual uses of these territorial spaces, like an *eltvn* (Mapuche cemetery) over which the Catholic church built its parish buildings after the "Pacification of Araucanía."

The recorded images reflect everyday situations that mark life in the communities of the *aylla rewe* Budi. The surroundings, elements of nature or landscape, ceremonies, cultural activities, family activities, agricultural work,

4. The research work currently in progress (2012-2014) is being carried out in the field by a team of Mapuche researchers from the *lof* Malalhue Chanko and Llaguepulli and the communication group *Adkimvn*, with the collaboration and support of the Canadian team, researchers Thora Herrmann (University of Montréal) and Ariella Orbach.

the fight for territorial and collective rights, conversations and, of course, the unique way that the Mapuche people perceive the world and understand their existence on Earth. These are all elements emerging from the research and production – i.e., communication – process.

This is how we hope to practically and concretely support the Mapuche people's political process through communication: by collaborating in a process that reverses colonization by reconstructing territory, recovering organizational structures, revalidating culture and spirituality and, as a result, reinforcing Mapuche autonomy and self-determination.

**Juan:** It is important to highlight that despite the negation and subjugation of the Mapuche people by the Chilean State, our culture remains alive as does our political structure, the *rewe* and *aylla rewe*. This is why we consider it necessary to reflect on our worldview and the importance that territory holds for us, with its spaces, organization and authorities, and the importance of our language. Through research, we hope to learn from those who have knowledge about the old territory: the Elders. They are the ones who determine how to develop a research process, identifying the priorities and topics of importance to discuss and research through *ngvlamtuwun* (conversation and stories). With the participation of the *lofche*, in the *ruka*, around the fire, the Elders and authorities share knowledge that defines the content of the research and the form in which the message will be presented. This context allows us to showcase our way of communicating.

We are very interested in how we can collect, structure, document and disseminate knowledge from the Mapuche point of view and, thereby, validate our traditional authorities and their protocols. At the same time, it is crucial that the knowledge collected through research be disseminated in a form that is understandable to us, the Mapuche, and that we feel identified in the way that the information is shared. Documentary filmmaking is a genre that allows us to preserve the way in which the Elders and authorities pass on knowledge through the spoken word and by sharing lived experience. That is why we focus on a process of creating films that is based in Mapuche protocol: first, we identify the people who are able to speak from knowledge; then, they choose the topics of importance, monitor the research process and validate each decision. It is the person who gives their knowledge who, making use of the *ruka*, chooses and prepares a space where the knowledge sharing will take place, through *ngvlam* and *nvtram*. The knowledge is then placed under the responsibility of the research team tasked with the technical role of capturing and documenting it.

This production process is the framework that defines the research work carried out by the young filmmaker-researchers of the Mapuche School of Filmmaking and Communication (through the filmmaking production workshop) and by the research team responsible for the territorial research process.



## RESEARCH PRINCIPLES AND PROTOCOLS FROM A MAPUCHE ETHIC

**Roberto:** The contribution made by the audiovisual research process taking place in the Lake Budi territory is extremely significant, because it is with these technologies that we are able to structure and organize Mapuche knowledge directly from its source. The researchers are members of the community and were given permission by the territory and traditional authorities to carry out their activities. This context enables the creation of diverse audiovisual archives, two of which are shared in this toolkit and illustrate the principles of ethical research from an Indigenous perspective.

Permission to carry out their work was granted to the community researchers because the community validated this new way of doing research: action-research designed in accordance with Mapuche culture and grounded in the following ethical principles.

**Temporal and spatial notions:** the Mapuche way of researching must be carried out according to specific temporal and spatial protocols. Prior to interviewing a Mapuche authority, cultural knowledge holder (kimce), or other community member, the researchers must visit him or her in the morning (at sunrise), when nature's energies are strongest. The researchers must also follow the pentukun, or formal greeting procedure required by Mapuche protocol. It involves inquiring about well-

being, from the personal to the communal (personal health, family health, community health). All these elements are spoken in the Mapuche language, Mapuzungun. The objective of this first visit is to inform the person about the reasons for the research work and to request the necessary authorizations to carry out the work. If these are granted, a date is fixed for an interview.

Whenever possible, this process should take place in a *ruka* or Mapuche house built according to Mapuche cultural criteria, with its door facing the rising sun (puel mapu or east).

**Cooperation and reciprocity:** In our research model, cooperation is reflected in the concept of action-research. Much of what is or can be researched forms part of a body of empirical knowledge and, as such, is passed on from generation to generation. Learning from another is a process that helps renew and reproduce knowledge, and is fundamental to the development of future generations. Introducing a research activity into these learning interactions should be carried out in a context of respect and emotional attachment to the work being researched. Any other way, the researchers risk interrupting not only the technical processes of the work, but also the spiritual rituals that are carried out whenever a Mapuche needs some material found in nature, a process that requires specific ceremonies to ask permission to extract and use the resource.

Cooperation by researchers in the work being researched can be seen in the

short documentary Kimeltuwn Mapuche Ñymican. For the production of this film, the young filmmaker-researchers took part in the work that they documented, participating with the papay (Elder) in the process of recreating the traditional art of weaving. This type of interaction makes research less invasive than in the Western model that positions the researcher as a passive observer who does not help out. When one does not help out in a process, one risks disturbing or getting in the way of the actions that are being carried out.

Research is not just about capturing images or stories! In the Indigenous world, research goes beyond the concrete: it requires an understanding of both the spiritual and the empirical. This re-articulates and validates a way of living and thinking that responds to cultural parameters.

**Respecting Elders:** This element is shared by all First Peoples of the world. In the Mapuche context, respect for Elders as sources of knowledge and their approval and support of the research are fundamental. With our Elders, the collective memory of a society undergoing a process of adaptation remains alive. They are responsible for passing on knowledge, oral tradition, history and custom. For this reason, community researchers validate and strengthen their bond with the Elders.

This is seen clearly in the short documentary Ixofil Lawen, in which the knowledge of the logko (chief) of Malalhue, who is an Elder, is validated. He was interviewed on numerous occa-

sions, in accordance with Mapuche temporal and spatial protocols. These protocols are also at work in the documentary *Kimeltuwn Mapuche Ñymican*, where the process of researching weaving work involves respecting the rhythms of this long and complex task. By accompanying all the stages of processing the wool – shearing, washing, combing, spinning, dying – the young filmmaker-researchers respect the way that the work is carried out at each stage and validate the technical, cultural and spiritual knowledge required of the person who does the work.

## RESPECTFUL COLLABORATIONS: REFLECTIONS BY NON-INDIGENOUS TEAM MEMBERS

### CHANGING ROLES, SHIFTING RESEARCH

**Ariella:** Respectful collaboration on Indigenous research projects begins with two acknowledgements. The first is that research, or the act of producing and sharing knowledge, is not the sole domain of academics and university educated “experts.” It is a natural process that all human beings undertake when they strive to understand the world around them and search (and re-search) for solutions to the diverse issues that they and their communities face. This requires setting aside the categorization of research as an essentially (Western) scientific activity and consequently, opening space for considering Indigenous

research methods and methodologies as equally valid to those offered by Western science.

The second acknowledgment is that those best placed to understand a particular situation are precisely the individuals who live that situation, since they are more likely to understand the contextual dimensions (cultural, political, historical, spiritual) of the situation with which they are faced. They are also the ones who have, to some degree, already engaged individually and collectively in searching (and re-searching) for solutions to the situation. This acknowledgement is congruent with a protocol common to both the Mapuche and First Nations: “You cannot speak about or represent something that is not yours” (Absolon and Willett 2005: 110). In this way, we are brought to consider our Indigenous partners as experts in their field, and ourselves as collaborators who support them by contributing our own expertise: disciplinary, research project management, proposal development, or otherwise.

These two acknowledgements require that the non-Indigenous collaborator approach her work with humility. It is this very humility that creates the conditions through which respectful collaboration can emerge. Just as our Mapuche partners have a specific ethical framework and protocols for carrying out research, so do we as non-Indigenous team members. This ethical framework responds to Indigenous research principles, and more specifically, the Mapuche principles outlined earlier.

**Thora Herrmann:** Respectful ethical research collaboration with Indigenous communities must be built before the start of the project and maintained during all phases the project through meaningful partnership and reciprocity between researchers and communities. It must acknowledge that there is no clear distinction between researchers and Indigenous people. Indigenous people are also researchers. Thus, all participants must be regarded as equal at every stage in a research process.

Over a year, prior to beginning our project, we held regular live and virtual meetings (via Skype) with our Mapuche partners to discuss and re-discuss project aims, objectives and outcomes and clearly define all details regarding activities, methodology, data ownership and management, and risks of the project. We took time to get to know one another. This long process contributed significantly to shaping the leadership roles in our research process and the responsibility structure of our project. It addressed the power relations/practices and rights within the research process. It also tackled the key concern of whose “reality” might gain dominance and legitimacy during the course of the project (Lloyd et al. 2012). As research questions emerged from the Mapuche communities and not from a university laboratory or cultural organization, the results and their interpretation far exceed an outsider’s perspective of looking in to, and taking account of, community knowledge and experience.

We also discussed the title of our project, and decided not to choose an “academic” project name. Rather, we choose a project name in Mapuzungun that expresses the Mapuche understanding of the project’s focus and guiding concept in the title: “Nvtramkaiñ Kom Taiñ Itrofil Mongen” or “Let us talk about all living beings in our lands” (in the Mapuche philosophy, Itrofil Mongen means the diversity and physical/spiritual inter-relation of all life forms).

## FORGING TRUST, BUILDING BRIDGES

**Ariella:** Honouring and cultivating human relationships is central to any collaborative undertaking. In order to be able to walk a path together, we must first come to know one another, share moments – not only of work – but of laughter and entertainment, develop friendships, participate in ceremonies, get to know one another’s families. Given that we are collaborating in Mapuche territory and not vice-versa, it is essential that this process of getting to know one another follow the temporal and spatial protocols of Mapuche culture. In this sense, a long, informal conversation while drinking mate in a *ruka* is just as crucial a part of research as a more structured interview with notepad (or video camera) in hand. In fact, the former tends to prove far more enlightening. This approach of nurturing human relationships and open communication with a vision of long-term collaboration can be summed up nicely with the words of de Lange and Mitchell: “[we choose] to work deeper rather than wider” (2012: 324).

**Thora:** Respectful Indigenous-academic research is essentially about building a relationship over time. I find it very valuable that with this project, we learned how to be co-producers of knowledge, co-writers – how to not just listen – but to incorporate community views into interpretations of our results. A key aspect that I like to highlight is that speed, language and style of communication have emerged as deeply important in our collaboration. We rooted our research in Mapuche ways of knowing, communicating and understanding through storytelling and conversations with Elders.

Most of our project meetings and work were not held in an “office” but in the field. Having all participants – Mapuche youth from the two communities, Canadian partners, scientists and Elders – in the field fosters connection in a supportive environment. It underlines pride for Mapuche culture and identity, as well as inspiring youths’ curiosity in cinematographic art and communication technology to address bio-cultural diversity issues. Through this, a bridge can be built between Indigenous knowledge and science.

The Mapuche School of Filmmaking and Communication and the research on the geographical, social and cultural elements of the Lake Budi territory provided an opportunity for Elders, youths and researchers to connect and open a dialogue on culturally appropriate ways of communicating research. It also provided a platform for Elders and youths to express their feelings, views and raise concerns regarding traditional knowledge, identity, nature, wellbeing and re-

search in their communities. This dialogue assembled and sorted information that came from both Indigenous and Western knowledge, and was grounded in the experiences of the people involved. Youth participants learned how technology (ICT, GIS, and mapping technology), Indigenous and Western science can be complementary. Both types of knowledge are valuable in understanding the Lake Budi territory and the complex changes that are occurring. Several of us felt that the youths, Elders and researchers should devote more attention to each other, and community filmmaking provided such a venue for co-creating, sharing and transferring knowledge in a dynamic manner, a manner appropriate to Indigenous Peoples.

## DECOLONIZING KNOWLEDGE, DEMOCRATIZING COMMUNICATION

**Ariella:** A key principle for collaborating on Indigenous research is to avoid knowledge extraction. The aversion of Indigenous communities to participating in research due to prior negative experiences is well documented by Indigenous scholars. A first and essential step to avoid extractive research is to define and develop a research project based on community priorities, rather than the priorities or interests of non-Indigenous researchers.

The extraction of Indigenous knowledge can also take place in later stages of the research, such as the case discussed by Nêhiyaw/Saulteaux scholar Margaret

Kovach in her exploration of story as methodology. Discussing the holistic nature of Indigenous stories – which goes well beyond simply what is said – she addresses the complexities of transforming oral narrative into text. She cites Cree scholar Winona Stevenson who cautions that frequently, Indigenous stories shared in the context of research are subsequently broken apart into useful parts (“facts” that directly address a research question) and “superfluous” parts, which are put aside. The result: “bits are extracted to meet empirical academic needs, and the story dies” (Stevenson 2000, cited in Kovach 2009: 101).

Avoiding this type of knowledge extraction that corresponds to the limitations of knowledge sharing through traditional (textual) means such as journal/article publication, requires a rethinking of how research is communicated, and of who does the communicating. In our work with the Mapuche team, we applied the principle of self-representation as a path to avoid knowledge extraction. This simply means that we respected the ability, and the right, of our Indigenous partners to speak for themselves and not to be spoken about by us. We applied this principle by emphasizing audiovisual production as the primary platform for research communication, as this form has proven the most appropriate for respecting oral culture and the ways that knowledge is shared by Mapuche Elders and traditional authorities.

**Thora:** Repeatedly, throughout our project, we also used film to record the process of the Mapuche School of Filmmaking and Communication, and to record our own reflections about our roles and the project process as we lived and saw it developing (recorded interviews with each project member). I found this an enriching experience since it blurs and distorts boundaries between researchers and researched: each of us – Mapuche partners, and Canadian partners including myself – become at once researchers and researched, observers and observed, filmmakers and filmed. This denotes a disruption of conventional power dynamics in the research relationship. Consequently, as also stated by Kindon (2003), this way of exploring enables a clearer recognition of the roles of every project participant in the politics of knowledge production associated with the project; it reduces the distance between project partners, and contributes to a deeper level of trust and understanding within our research collaboration itself. In our project, we aimed to build an evidence-based argument that decolonization of the politics of knowledge is critical to improving capacity-building outcomes through Indigenous informed action research.

In our project, we placed the Mapuche communities at the centre of knowledge production for, with and by each other (e.g., refer to the credits of the two short films). This has key implications for the democratizing and power dispersing potential of community filmmaking. Community filmmaking, if used within

carefully negotiated collaborations, has the potential to disrupt the maintenance of Western knowledge production which problematizes Indigenous Peoples and labels them as the “Other” (the consequences of such practice are silencing of Indigenous voices and production of void data that fosters marginalization). We found that the democratizing potential of community filmmaking (Pink 2001) can open up new spaces for Indigenous youths to be creators and disseminators of knowledge, encouraging them to find their voices as future leaders of their communities. As an academic scientist, one of the critical experiences that I faced in our project was that by recognizing research as a set of local collective analyses and the shared resolution of problems, it becomes possible to “de-centre” science and develop a new framework within which all knowledge systems are set on an equal footing. The co-production of locally embedded audiovisual texts, such as this one, and action-oriented academic papers which focus on research praxis, enabled us to explore the production of a “new politics of knowledge” together. For such a transformation process to become real, a strong commitment, high level of engagement and active work participation are required from all project members involved.

**Ariella:** By co-creating the written products – such as this article – arising from our research, we applied our collaborative research principles not only to research design and implementation, but to the act of sharing the research

with the world. This can take more effort than audiovisual production, as writing is not a skill that comes naturally to all community researchers. Collaboratively authoring an article across two or even three languages is a much longer and more complex process than sitting down to write one's own. However, we see co-authoring as a capacity-building exercise that enhances our partners' ability to access means through which to tell their stories and share their knowledge, and that enhances our ability to design and carry out ethical research.

If as non-Indigenous researchers, we use our work to create space instead of taking space (Kovach 2005), then research itself can become a powerful decolonizing project that supports and validates Indigenous knowledge.

**Thora:** Taking time for ongoing reflection and critical analysis, including the knowledge produced, power relations and how the project is, or is not, adhering to its principles, is crucial to developing a truly horizontal partnership with community partners and, in turn, garnering social justice outcomes!

## LEARNING WITH FIRST NATIONS AND IN THE GLOBAL SOUTH

**Manon Barbeau:** Wapikoni Mobile is an organization involving travelling studios dedicated to cultural mediation, training, and audiovisual and musical creation. Wapikoni will celebrate ten years of existence in 2014. Wapikoni is active mainly in First Nations communities in Quebec, having initiated some 3,000 First Nations youths from 25 communities and nine different nations in the art of audiovisual production.<sup>5</sup> Wapikoni Mobile is motivated by a desire to project the voices of young Aboriginals in Quebec who experience isolation and exclusion as a result of the creation of reserves in 1851. Wapikoni Mobile proposes an option to mitigate distress by making technological tools

available to youths, tools that allow them to speak out and express their concerns and dreams through filmmaking.

Oral tradition has passed on to the young generation the art of storytelling and an emphasis on image. The natural interest of these young people for the camera and contemporary media has contributed to Wapikoni's success. Since 2011, Wapikoni has collaborated in offering this training to a number of communities in Latin America, Bolivia, Peru, Chile and Panama. These communities possess the same cultural and spiritual wealth as communities in Quebec, and have many points in common with First Nations regarding environmental and territorial concerns. However, their daily realities are very distinct.

In Quebec, the audiovisual creative process undertaken by participants is more individual. Collective script development is rare. A short film is born from an individual's intimate concern about his or her community, or a topic that is important personally, in his or her own life. The individual establishes a production team to help achieve his or her idea, resulting in the creation of a film. Short films created in this manner are then presented to the community.

Above all, Latin American Indigenous communities privilege a collective approach, consultation, group work, process and consensus. Wapikoni Mobile has had to adapt to new expectations



5. Wapikoni Mobile arrives in a community at the invitation of the Chief and Band Council. Over 600 short films have been created over the past ten years by the young participants in collaboration with filmmaking instructors who act as their mentors.

and other ways of working, while maintaining our practical approach of “learning by doing” or “learning by creating.” Our challenge has been to transfer skills within a context of respect for a partner’s identity and processes that are important to their people, while enabling the creation of finished short films – a source of personal and collective validation – that can be shared within the community, but also beyond it. Spreading Indigenous messages through the dissemination of the films is a key element of Wapikoni philosophy because it allows these messages, put into images, to cross borders. It allows the struggles of one community to become known to others and brings people together, so that one day, the fight for identity and territory can become collective.

Wapikoni’s team has had to reflect on many questions over the years: how can we respectfully unite a pedagogical and artistic approach developed in the North with the distinct social reality of Indigenous communities in the South, with their own protocols and communication needs?

Happily, the environmental, social and human ideals of Wapikoni are shared by the communities that we have visited in the South. The issues and questions that arise over the course of a training process can be destabilizing, but they are infinitely beneficial. They allow us to move forward. For example, we have been immersed in the Mapuche culture, in its way of relating to others, to Elders, in its worldview. This has been genuinely enriching.

Together we have established exchanges between Mapuche and Atikamekw communities, and between Anishnabe and Kuna communities. These exchanges will continue, as they can only contribute to this reciprocal enrichment. These bridges connecting First Peoples through artistic creation are in the process of making one of our long-held dreams become reality: that Indigenous peoples of the planet unite to speak with one voice and make themselves heard.

First Nations communities in Quebec have been traumatized by their painful history. They are emerging from an intense phase of self-destruction. Their Mapuche brothers and sisters provide them with models of resistance and courage.

Regardless of whether the short films created during the workshops result from individual or collective concerns, they reflect issues and struggles that are shared by peoples of the North and the South: defending Mother Earth, protecting territory, preserving language, culture and ancestral values – values essential for the survival of humankind today.

Wapikoni Mobile has learned much from our contact with the communities that have honoured us with their invitation to collaborate. We have not finished reflecting and learning. By encountering others, we exchange what we can each contribute for a common good.

In the perspective of enabling these encounters, an International Network of Indigenous Audiovisual Creation was launched in July 2014. Through such a network, we can strengthen our ties, create the foundation for long-term exchange, develop ways to co-create and evolve together toward new forms of audiovisual creation... building bridges between Self and Other.

## COOPERATION, EXCHANGE AND ADAPTATION: REFLECTIONS BY INDIGENOUS TEAM MEMBERS

**Fresia Painefil:** We aim to counteract the communicational model imposed by the Chilean state with a way of communicating that is grounded in our culture and social base. Faced with a model that manipulates information to categorize Mapuche demands for our rights as vandalism or acts of terrorism, we have begun the exceedingly important process of appropriating technological tools with the help of other First Peoples in order to answer back. This exercise requires the support of institutions that are sensitive to, and able to understand, the context in which First Peoples are struggling today.

For over a decade, our territory has been undergoing a communicational process that has new generations of Mapuche as its protagonists. They have received

continuous capacity-building in the use of audiovisual tools. This process has produced important changes in the way that technology is understood within the communities.

We are forced to acknowledge that this work would not have been funded with Chilean resources because the state has imposed a significant communication barrier between Mapuche communities and the rest of Chilean society. Hence, cooperation with international entities has been extremely important in allowing us to develop these activities. For the communities of the Budi territory, this means:

**Cooperation:** Our logic sees cooperation as always being mutual. A community that receives support and resources grows, but so does the institution that provides that support, because it has the opportunity to come to know firsthand a culture that is still alive, recreating and reproducing its worldview in spite of a history of intervention.

Historically, the management of resources from within our communities has been a complicated matter, because many developed countries do not invest in Chile: it is considered already to be developed. We believe that a developed country, in the true sense of the term, would not treat its Indigenous peoples the way it treats us.

**Exchange:** With the support of Wapikoni Mobile, we have begun a new project of exchange with Manawan, a community of the Atikamekw Nation.

This has opened up relations of friendship and cooperation between two First Peoples. This exchange, facilitated by Wapikoni Mobile acting as a bridge between our peoples, opens the door to a world of possibilities to understand the new communicational challenges and opportunities that peoples across the world must face.

**Gerardo:** The need for a distinctly Mapuche methodology to guide the incorporation and appropriation of technological tools arose in the 1990s, when Mapuche organizations brought forth a proposal for territorial recovery and reconstruction, cultural and spiritual reaffirmation as part of a larger political process and, ultimately, autonomy and self-determination.

Since the 1990s, distinct territories have begun to focus on communication by reinforcing Mapuche ways of communicating and strengthening Mapuche knowledge, philosophy and organizational structures. Communication work is seen as part of this political process. This approach led some of us to create a communication group called Adkimvn,<sup>6</sup> with the vision of developing a proposal for communicating that has the Mapuche worldview as its foundation.

This proposal consists primarily of developing training activities in filmmaking and communication, creating audiovisual products using documentaries as the main tool, supporting communities by producing reports and videos about their activities, and organizing scree-

nings and the dissemination of Indigenous films. It is in the context of this communication work that we began developing a research methodology that seeks to establish a model for carrying out research that corresponds to Mapuche ways of sharing knowledge and is respectful of Mapuche cultural protocols.

We see this methodology as a work in progress and a continuous learning experience. As such, the work respects the internal dynamics of each territory, understanding that such diversity exists and that each *lof* exercises autonomy by engaging in its own processes. For this reason, in each territory we must shape or adapt what we have learned from our own practice – that is, the process of building and learning as we go – to the particular local processes of the territory where we wish to collaborate.

It is in this way that I began working in the Mapuche Lafkenche territory of the *aylla rewe* Budi, where for over ten years I have been supporting the communication process that has emerged in the context of a politico-cultural process led by the Mapuche Lafkenche communities and their traditional authorities.

In recent years, we have begun to research the concept of *aylla rewe* in the Budi territory, its structure, toponyms, use and importance as an ancestral Lafkenche territory. Adkimvn's role in this collaboration has been to support the development and consolidation of a methodology that is adapted to the local process and applied in response to the

6. *Adkimvn* can be translated as "the essence of ancestral Mapuche knowledge."

different practical actions that the communities of the *aylla rewe* are carrying out, particularly the two communities of Llaguepulli and Malalhue Chanko.

## LOOKING FORWARD

**Fresia:** We are working to create a new way of capturing knowledge that is grounded in our culture. For the first time in the history of the *aylla rewe* Budi, we are the ones doing the research on our knowledge, with technological tools in Mapuche hands. The process of appropriating these technological elements brings with it great responsibility and awareness. Many of the recordings will need to be cared for as treasures that will increase in value over time, as some of the knowledge holders are already advanced in age and will be able to continue speaking through the stories they share. This is yet another reason why action-research validates and situates the communication process that we are undertaking in the territory as a new way of rescuing and recreating knowledge – from its origin, from its most intimate awareness. This is the knowledge that our young communicators are sharing with their cameras.

In these times, as Indigenous peoples, it has become very necessary to have a clear plan to counteract the communication invasion; to have our own media that take into account our needs, assertions and struggles at all levels – cultural, linguistic, social, political. These are our only hope of not disappearing as a culture.

**Roberto:** Creating this new research model allows us to interpret the Mapuche world as we perceive it, bringing to the forefront the values particular to our people and our ways of talking about life:

*From knowledge, from collective memory, from that which is ethical, that which still remains, that which must be re-organized and oriented, to be able to resist ideological invasion, colonization, uniform globalization, dictatorial globalization killer of diversity, of lifeways, it is our memory and heart that are the sources of all hope to be able to leave our children a better*

*world in which to live and spend their terrestrial time, where their energy and conscience will be vital to ensure continued existence as a distinct people, to shake off the intolerance, discrimination, genocide, forced evangelization from which we still have not risen; on that day, Arauco will come: he will return to deploy his green attack, the ixofil mogen will be born, the diversity of memories, of energies, once again the Mapuche will believe in his newen, in her mapu, in her feyentun, from this foundation the new children of the land will plant their resistance.*

– Roberto Contreras, March 2014

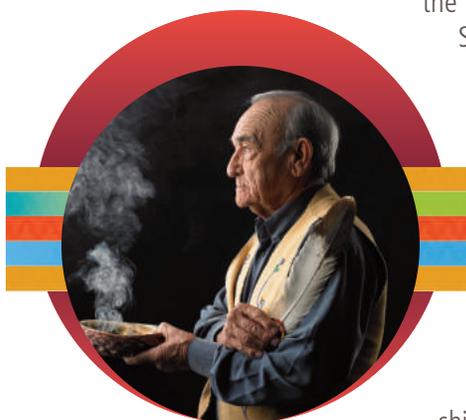


## REFERENCES:

- ABSOLON, K. and C. WILLETT. 2005. "Putting ourselves forward: location in Aboriginal research." In *Research as resistance: critical, Indigenous, and anti-oppressive approaches*, eds. L. Brown and S. Strega, Toronto: Canadian Scholars' Press.
- DE LANGE, N. and C. MITCHELL. 2012. "Building sustainability into work with participatory video." In *Handbook of participatory video*, eds. E-J Milne, C. Mitchell and N. de Lange, Lanham, MD: AltaMira Press.
- KINDON S (2003) Participatory video in geographic research: a feminist practice of looking? *Area* 35: 2
- KOVACH, M. 2005. "Emerging from the margins: Indigenous methodologies." In *Research as resistance: critical, Indigenous, and anti-oppressive approaches*, eds. L. Brown and S. Strega, Toronto: Canadian Scholars' Press.
- KOVACH, M. 2009. *Indigenous methodologies: characteristics, conversations, and contexts*. Toronto: University of Toronto Press.
- LLOYD K, WRIGHT S, SUCHET-PEARSON S, BURARRWANGA L, and BAWAKA COUNTRY (2012) Reframing Development through Collaboration: Towards a Relational Ontology of Connection in Bawaka, North East Arnhem Land. *Third World Quarterly* 33: 1075–94.
- PINK S. (2001) More visualising, more methodologies: on video, reflexivity and qualitative research. *The Sociological Review* 49: 586–99.

# DOCUMENTING KNOWLEDGE ON THE TERRITORY FOR TRANSMISSION PURPOSES: MECHANISMS FOR COLLABORATION AND RESEARCH ETHICS AMONG THE PEKUAKAMIULNUATSH

**ŞÜKRAN TIPI**, M.A.,  
consultant for Mashteuiatsh First Nation  
PhD student in the Department of  
Anthropology, Université Laval  
July 2014



This contribution aims to share the synergic experiences in terms of collaborative and multidisciplinary research, such as the Pekuakamiulnuatsh First Nation (Innuatsh<sup>1</sup> of Lac-Saint-Jean, Mashteuiatsh) actively implements them, while developing and applying ethical rules that ensure lasting respect for the traditional values associated with its culture. First of all, a multidisciplinary research initiative that is still ongoing in the community will be described in connection with its operation and the challenges encountered.

Secondly, the establishment of a committee designed to oversee the collaborative and ethical mechanisms in the area of research will be outlined and followed by an overview of the perspectives that the Pekuakamiulnuatsh consider in terms of the creation of research partnerships and alliances in the future.

## RECONSTITUTING THEIR OWN HISTORY

Like all First Nations in Canada, the Pekuakamiulnuatsh First Nation is faced with many challenges related to progressively taking control over the files that concern them in areas such as politics or the co-management of natural resources, for example. Certainly, the government authorities are under a legal obligation to consult with First Nations according to section 35 of The Constitution Act of 1982,<sup>2</sup> but it is clear that the consultation mechanisms in place are not adapted to the needs expressed locally and that the processes are not yet engaged often enough upstream of the development projects, despite existing tools such as the Consultations Protocol of First Nations of Quebec and Labrador (2005), which provides relevant recommendations associated with ongoing negotiations on Aboriginal rights. During these consultations, the first occupants of the land are asked to provide accurate information regarding their occupation in a specific area and to provide proof of their presence often going so far as documenting their presence prior to the

1. Without going into linguistic details, note that the Innu language, which is referred to as *innu-aimun* by its speakers, has certain dialectal differences, one of which consists of using the phoneme *l* instead of *n* in certain contexts: the communities of Mashteuiatsh and Pessamit.
2. Accessible online : <http://laws-lois.justice.gc.ca/fra/const/page-16.html#docCont>.

conquest or before the period known as contact. Also, since the response times associated with these consultation processes are generally very short, the contact persons that are sought out in the Aboriginal communities are always in a position where they have to react rather than having the opportunity to actively participate as a concerned party.

It was at the end of 2008, within this political context, that the leaders of the various sectors concerned at the *Conseil des Montagnais* (today known as the *Pekuakamiulnuatsh Takuhikan*)<sup>3</sup> set up a research project on the history related to the occupation and use of the land, a project that is still in progress and for which the name Peshunakun was chosen since it means "it is coming, visibly approaching, something is coming soon" (unofficial translation) (Drapeau 1991: 511). Based on an interdisciplinary perspective that was defined at the outset, this major research project's approach is in line with the overall objective of the Pekuakamiulnuatsh which is to reconstitute the history of their ancestral lands based on different components associated with many disciplines: history, geography and geomatics, linguistics, genealogy and archaeology. The working group that was formed accordingly is composed of Innu researchers and interviewer-surveyors, a geomatician-cartographer from the community and an archivist specialising in Innu heritage representing the *Société d'histoire et d'archéologie de Mashteuiatsh* (SHAM) which is the

main partner of the Peshunakun project. Two other human resources complete the team: a linguist and an anthropologist assuming the direction of the research associated with this major project. These team members are supported by an Innu coordinator and various specialised language resources who provide advice and support for the validation of the data collected in *neh-lueun*.<sup>4</sup>

In terms of methodology, the first step consisted of taking stock of the work and studies that were carried out internally by the Pekuakamiulnuatsh Takuhikan organisation, as well as the publications stemming from the academic world that may contain information on the use and occupation of the land from a historical perspective. The second step summarises the research itself: all inventoried works (ethnohistorical studies, surveyor and explorer reports, relationships with the missionaries, etc.) were analysed to extract, in a systematic fashion and according to a precise methodology, various types of information: the names of Innu families, cultural sites, burial sites, travel routes, camp sites, staging areas and toponyms designating places in the Innu language. Meanwhile, various regional and national archive centres (e.g. archives of the colonies, Hudson's Bay Company) were contacted in order to consult old maps and other relevant historical documents regarding the occupation and use of the ancestral territories of the Pekuakamiulnuatsh.

In addition to the literature review, a consultation process was established during which approximately a hundred people testified regarding how their families and ancestors roamed the *Nitassinan*<sup>5</sup> by mentioning sites, hunting routes as well as toponyms (names of places). Considered to be testimonies to the linguistic heritage of the Pekuakamiulnuatsh, the toponyms collected from the documentary research or the interviews conducted were processed in the context of a two phase validation process. On the one hand, with the help of human resources who are assigned to language preservation, translation and the monitoring of the standardisation process for the Nehlueun written language, a committee of three to five Elders was established to validate the linguistic roots and the different meanings of the toponyms from an oral tradition perspective. In order to get better prepared and knowing that the oral testimonies still do not hold the desired weight in the context of the litigations before the Court,<sup>6</sup> the committee validation process, which will actually be ongoing for as long as the project continues, was supplemented with a diachronic linguistic documentation process. Using five Innu language dictionaries, starting from the first dictionary that was compiled by the Jesuit missionary Antoine Silvy in 1678, the verbal or nominal roots of toponyms were documented through time while ending with its current standardised form as it appears in the dictionary representing the North Shore Innu standardised spelling by Lynn Drapeau (1991).

3. Accessible online: <http://www.mashteuiatsh.ca/>.

4. In the dialect of Mashteuiatsh which is in the process of being standardised in order to achieve standardised spelling, *neh-lueun* means "our language".

5. Designation of the ancestral land in the Innu language: *Nitassinan* literally means "our land".

6. Recommended references for more information on the subject: J. CRUIKSHANK, *Invention of Anthropology in British Columbia's Supreme Court: Oral Tradition as Evidence in Delgamuukw v. B.C.*, BC Studies #95, Anthropology and History in the Courts, Autumn 1992, p. 25-42.

This approach illustrates the research ethics that permanently underlie the work related to the Peshunakun project, which consists of striking a balance between validation through oral tradition and consolidation through written tradition in order to demonstrate the continuity of the Innu presence in terms of the use and occupation of the land by the Pekuakamiulnuatsh from an ethnohistorical, cultural and linguistic perspective.

## TAKING RESPONSIBILITY FOR COLLABORATIVE AND ETHICAL RESEARCH MECHANISMS

The work of the research team of the Peshunakun project began in 2009 and continues to this day without having lost any of its relevance from a political point of view or even a heritage point of view. It was at the end of a phase of the work, during a first presentation of the results to the public and the elected leaders of the *Montagnais* Council, that the scope of the process that was undertaken as well as the associated ethical issues became evident. These issues, which continue to be present, appear at many levels. It was noted that many research projects that were conducted by academic researchers or students in the community of Mashteuiatsh did not feature informed consent by all the authorities concerned or a validation process or an adequate return of the data to the Pekuakamiulnuatsh. With respect to the information collected in the context of the Peshunakun project, the stakeholders are faced with issues related to the

protection of the personal information of the individuals concerned, access to the research results for external researchers, intellectual property and the protection and recognition of the cultural and linguistic heritage of the Pekuakamiulnuatsh.

In a context of cultural affirmation and with a focus on self-determination, the Pekuakamiulnuatsh Takuhikan authorised, by way of resolution on January 19, 2010, its heritage, culture and land sector to establish the Innu heritage committee (*Pekuakamiulnuatsh u uelutshiunau*) with the primary mission to analyse and follow-up on the various research applications received, both internally and externally, with the objective of preserving, promoting and disseminating the heritage of the Pekuakamiulnuatsh. In order to ensure the broadest possible representation of the various sectors of the Council, the community organisations and the population, the committee is composed of one representative of the *Société d'histoire et d'archéologie de Mashteuiatsh* (history and archeology), one representative of the *Secteur des travaux publics et habitation* (public works and housing), one representative of the *Secrétariat aux affaires gouvernementales et stratégiques* (strategic and government affairs), one representative of the *Service patrimoine, culture et territoire* (heritage, culture and land) and one representative of the community. One of the first steps taken by the members of this committee was to define the Innu heritage and its various components in order to establish a common basis for discussion related to processing the

applications received regarding heritage-related issues or in the context of the anticipated research projects while relying on the guidelines of the *Politique d'affirmation culturelle des Pekuakamiulnuatsh* (cultural affirmation policy) (2005):

The heritage that was passed down is still alive, but it may be lost if no action is put forward to ensure its protection and preservation. All necessary steps must be taken in order prevent the alteration of this heritage (unofficial translation) (*Conseil des Montagnais*, 2005: 26).

Inspired by definitions that were formulated by various national and international bodies (such as UNESCO, the Council of Europe and the *Conseil du patrimoine de Montréal*), the Innu heritage is thus divided into its different components: the intangible cultural heritage (practices, representations, expressions, knowledge, skills, language and toponymy), material heritage (material culture and built heritage) and natural heritage (natural sites or areas on the Nitassinan) of the Pekuakamiulnuatsh. This definition allows for a holistic view of the world by linking the intangible, material and natural dimensions that are all inextricably interconnected and rooted in the ancestral land, the Nitassinan.

Based on these guidelines, the heritage, culture and land sector of the Pekuakamiulnuatsh Takuhikan was able to conduct a major research project on the Innu heritage in 2012-2013 in partnership with The Native Museum of Mashteuiatsh, through which the project was



able to benefit from a grant from the Department of Canadian Heritage. The initiative's objectives were threefold: the first consisted of determining the distinctive characteristics of the culture and language of the Pekuakamiulnuatsh, the second consisted of developing the means to preserve them and the third consisted of ensuring the transmission, promotion and dissemination within the community and among the non-Aboriginal populations in order to raise awareness regarding Ilnu know-how and life skills. The project was therefore divided into two phases: the first, named *Pekuakamiulnuatsh u uelutshiunau*, involves the gathering of knowledge and expertise from the bearers of the culture and language, and the second, named *Ashu peshtenitau ilnu aitun*, involves the integration of the visual, aural and pictorial documentation into the digital database of The Native Museum of Mashteuiatsh. This major initiative therefore united the responsibility of the heritage, culture and land sector to preserve the Ilnu cultural wealth and ensure the transmission and acquisition of knowledge in relation to the mission of its main partner, The Native Museum, which seeks to preserve, enhance, transmit and promote Ilnu culture through facilitation, exhibition, research, dissemination, interpretation and educational activities. Today, the tools developed in the context of the research project on the Ilnu heritage, such as the Ilnu Aitun journals and informative videos that allow for holding culture and language transmission workshops, are used to support the activities and workshops

that are continuously organised on the Uashassitsh site, which was once a gathering place for the ancestors of the Pekuakamiulnuatsh and is today dedicated to the transmission of the Ilnu culture by the bearers of knowledge among Aboriginal youth or any interested non-Aboriginal visitors.

In order to position the vision of the Ilnu heritage and its components outside the community as well, the Ilnu heritage committee determined that it was necessary to reach out to the various stakeholders from different backgrounds who work in the field of research or heritage protection. At the regional level, the process of coming together with the MCCQ (*Ministère de la Culture et des Communications du Québec*) was taking place in connection with the consultations being held as part of Bill 82 on the Cultural Heritage Act with the achieved objective to establish a table for exchanges and discussions with the department. Furthermore, the community was able to participate in the VVAP (*Entente villes et villages d'art et de patrimoine*)<sup>7</sup> agreement of the MCCQ which allows for sharing the cost of hiring a cultural development agent in order to structure the local cultural development to the benefit of the local community. The agent delegated by Mashteuiatsh participates in the meetings of the Ilnu heritage committee, which ensures a direct connection to the information regarding the current files in the area of culture and heritage. With respect to the provincial government, the committee was able to oversee a

more in-depth process with the *Commission de toponymie du Québec*.<sup>8</sup> Since 2008, various meetings have taken place focused on achieving progressive recognition for Ilnu toponymy as well as the signing of a mutual data sharing agreement for research that is conducted on the toponymy of the Nitassinan of the Pekuakamiulnuatsh. At a secondary level, this process involves requesting the appointment of an Aboriginal commissioner for the seat established for this purpose at the *Commission de toponymie du Québec*.

As for the requests from universities, since its creation, the Ilnu heritage committee has become the authority towards which all research projects converge that require the collection of data from the community. Henceforth, in the medium-term, it aims to develop and implement its own research protocol for the Pekuakamiulnuatsh. This involves a heavy workload for the committee as well as great responsibility while requiring diverse expertise from its members. At the same time, this provides an opportunity to direct and supervise the methods of collecting data from the members of the community in order to ensure that these steps are taken with the informed consent of all stakeholders and in accordance with the values of the Pekuakamiulnuatsh and their vision regarding the research topic in question. The First Nations of Quebec and Labrador Research Protocol (2005: 7) constitutes one of the theoretical tools that guide the Ilnu heritage committee in its reflections, particularly in

7. Accessible online: <https://www.mcc.gouv.qc.ca/index.php?id=2403>.

8. Accessible online: <http://www.toponymie.gouv.qc.ca/ct/accueil.aspx>.

terms of defining the foundations of a shared authority between the community and the researcher based on the fundamental guiding principles of power, fairness and respect.

## BEING PROACTIVE IN THE DEVELOPMENT OF PROJECTS AND PARTNERSHIPS

The systematic supervision work for external research projects also opens the door to lasting alliances with university departments and researchers. Since 2011, the community of Mashteuiatsh has been part of the CURA<sup>9</sup> Tetauan, a partnership of researchers from *Université Laval* (in architecture, anthropology and geography) and representatives from seven Innu communities in Quebec. This research alliance has the objective to develop a participatory approach to architecture and sustainable development based on the construction and representation of the cultural landscapes of the Innu communities of Quebec, while relying on a participatory management structure for different projects that revolve around three research focus areas: 1) cultural landscapes and representations; 2) sustainable environments and collaborative habitat; 3) governance, action and decision support.<sup>10</sup> It is jointly directed by two co-directors: a researcher from the *Université Laval* (architecture school) and a representative of the Innu communities who is the representative for the community of Mashteuiatsh as well as a member of the Innu heritage com-

munity. Several participatory research projects took place and are still taking place in Mashteuiatsh under the CURA Tetauan which oversees them from the beginning to the dissemination of the final results.

The latest research project to be monitored by the committee is a doctoral research project with the working title *LANGUE ET SAVOIRS EN TERRITOIRE ILNU* (unofficial translation: Language and knowledge on Innu territory), which is a study on the geographic knowledge of the Pekuakamiulnuatsh as an expression of ancestral and modern territoriality and for which the idea emerged during work on the Peshunakun project that the PhD student has been involved in since its inception as a linguist. During the work surrounding the validation of the information collected from the Elders, the resource people involved in this process have noted that, beyond the cited traditional activities and toponyms naming visited sites, the testimonies from those interviewed do not only reflect the life skills of the Pekuakamiulnuatsh and their ancestors, but also certain values related to the occupation and use of the land. These values, which are more abstract, seem to revolve around the quantifiable information received through interviews conducted as part of projects such as Peshunakun and it could be interesting to identify the spiritual, cultural, historical and political dimensions according to those involved. This doctoral research project therefore hopes to explore the life skills of the Pekuakamiulnuatsh from an intergenerational perspective so that

a profile of Innu territoriality, which is both modern and ancient, can be completed, while taking into consideration the existing connections to the land that have changed over time. The results of this research can eventually be used as a tool in the affirmation of an identity and a distinct culture within an approach for the safekeeping of the Innu heritage. After internal discussions, the student presented a first draft of the project to the Innu heritage committee in September 2012 after obtaining approval from the heritage, culture and land sector of the Pekuakamiulnuatsh Takuhikan (formerly the Conseil des Montagnais du Lac-Saint-Jean). This approval by the director of the sector at the time first of all confirmed that the proposed research was “in line with the



9. CURA: Community-University Research Alliances.  
10. Accessible online: <http://www.tetauan.org/>.

interests of our First Nation within existing mandates related to heritage, land and traditional knowledge in connection with the culture and more specifically the language" (unofficial translation).<sup>11</sup> The integration dimension of the participatory nature of this research in an Aboriginal setting was consolidated through the acceptance of the project within the research focus area "cultural landscapes and representations" of the CURA Tetawan and the allocation of a dissemination grant. Currently, the research is in the preparatory stage of the data collection process and has received financial support from the Social Sciences and Humanities Research Council (SSHRC) since May 2013. At this stage, various meetings help to clarify the methods that will lead to the joint development of a survey questionnaire, while taking into consideration the needs and interests of the various sectors within the organisation and targeting all those who could contribute to making the results of the upcoming survey more representative. The goal of this methodology for participatory action research is to define with the key stakeholders what the main objective is for the community that is engaged in the research, beyond the PhD student's anthropological interests, and while respecting the fact that the First Nation must always "appear as the primary client of the research" (unofficial translation) (AFNQL 2005: 5). For the time being, the Ilnu heritage committee seems to be in agreement in terms of

advocating an objective of transmission, from a perspective of a more diversified use of the data and in order to preserve and transmit the language, culture and values of the Pekuakamiulnuatsh among the elementary and high schools of the community. The steps of the anticipated intergenerational survey in the context of the proposed doctoral research as well as the validation, analysis and dissemination of the data will be guided by the First Nations principles of OCAP<sup>TM12</sup> (ownership, control, access and possession of the information) and based on respect for local needs and priorities in a spirit of reciprocity and continuous dialogue between the research partners.

In conclusion and in terms of the examples of initiatives that are presented in this paper, the ethical research mechanisms that are at work or in develop-

ment in the community of Mashteuiatsh can be summarized by a desire to ensure management and control upstream of the research initiatives in order to "help communities to create a better framework for research activities, gain a better understanding of the research issues that involve them, fully participate in all stages of the research, and above all take full control over the research process" (QNW, 2012: 7). From decolonizing perspective on research, the community of Mashteuiatsh therefore plays an active role as a partner by overseeing the various research and development projects as well as through its contributions to the emergence of new research projects and the creation of alliances and joint partnerships.



11. Approval letter dated January 30, 2012; heritage, culture and land sector.

12. Accessible online: <http://fnigc.ca/ocap.html>.

## REFERENCES

ASSEMBLY OF FIRST NATIONS OF QUEBEC AND LABRADOR (2005). *First Nations of Quebec and Labrador Research Protocol*, Wendake, AFNQL (version révisée accessible depuis novembre 2014 : <http://www.apnql-afnql.com/fr/publications/pdf/Protocole-de-recherche-des-Premieres-Nations-au-Quebec-Labrador-2014.pdf>).

CONSEIL DES MONTAGNAIS DU LAC-SAINT-JEAN (2005). *Politique d'affirmation culturelle des Pekuakamiulnuatsh*, Commission consultative sur la culture, Mashteuiatsh, Conseil des Montagnais du Lac-Saint-Jean.

DRAPEAU, Lynn (1991). *Dictionnaire montagnais-français*, Quebec, Presses de l'Université du Québec.

QUEBEC NATIVE WOMEN INC. (2012). *Guidelines for Research with Aboriginal Women*, Kahnawake, Quebec, FAQ/QNW.

SILVY, Antoine (ca 1678-1684). *Dictionnaire montagnais-français*; transcription (1974), Lorenzo ANGERS, David E. COOTER and Gérard E. McNULTY, Montreal, Presses de l'Université du Québec.

## TABLE OF CONTENTS - EDITION 2018

### ISSUES OF RESEARCH ETHICS – ARTICLES AND CONTRIBUTIONS:



#### THE LITTLE GUIDEBOOK ON THE EXTENSIVE CONSULTATION CULTURAL CREATION AND TRANSMISSION BY AND WITH COMMUNITIES

Under the direction of Élisabeth Kaine with Denis Bellemare, Olivier Bergeron-Martel and Pierre DeConinck

# THE LITTLE GUIDEBOOK ON THE EXTENSIVE CONSULTATION

## Cultural Creation and Transmission by and with Communities

Under the direction of Élisabeth Kaine with Denis Bellemare, Olivier Bergeron-Martel and Pierre DeConinck  
(in alphabetical order)

La Boîte  
Rouge  
V I F



# Introduction

Key principles of consensus-building:  
how to work together.

The following pages are drawn from a publication entitled *"The Little Guidebook on the Extensive Consultation: Cultural Creation and Transmission by and with Communities"*, produced by La Boîte Rouge VIF and its research section *Design et culture matérielle (DCM)*.

Consensus-building is an approach to decision-making and action in which a group takes account of and negotiates the views of all its members to achieve a consensus. It is an approach that requires all stakeholders of a given project to adopt certain postures and attitudes toward others, including openness, listening, respect and dialogue. These ways of "being" and "acting" make for a better climate and a better flow of consensus-building processes.

The DCM is a multidisciplinary group of researchers from Université du Québec à Chicoutimi and Université de Montréal. Over the past 20 years, thanks to Community-University Research Alliances, the group has had the opportunity to work with a number of Indigenous communities in Quebec and Brazil in the context of cultural inventorying, promotion and transmission projects. The *"Little Guidebook on the Extensive Consultation"* provides helpful tools for anyone wishing to undertake a cultural development project based on a consensus-building/creation approach. As such, it helps implement a collaborative ethics in terms of relational modes, reflexes to develop, and methodologies to apply.

## 1

# Getting the project started

## Vision, values, goals, and planning through consensus building

Your community has a project and the goal is to create a tool to pass on its cultural heritage. The starting point may be a desire or aspiration, or a need to solve a problem in the community. The initiative may come from one person or from a group of people (citizens, community group, or municipal councillors). Even if the initiative comes from only one person, you must also mobilize various members of the community and seek their collaboration in a spirit of jointly defining and creating the project. For this reason, in all cases, you need from the outset to paint a picture of the current situation and agree on the ideal the project will aim for and on its parameters: Why this project? Who should be mobilized and when? What do we hope to obtain? Who's in charge?

When talking about work processes, people often use the metaphor of a house being built. There's no point in erecting the structure if it doesn't sit on solid foundations. First, the main aspects of consensus building will be presented here to put the project on a solid basis. All project partners should know their responsibilities and the constraints and limitations they face, and they should know as soon as possible.

All projects emerge from a specific context. Analysis of this context will help develop a program that will put things in order, both for the project and for the community.

Finally, beyond "what to do," there is "how to do": reflexes; qualities for relating to others; and the role of the "consensus-building/creative team" in bringing together community members and partners. As much for human qualities as for legal requirements, this section of the guide will explain how to behave with other project participants. In the dynamics of collaborative work, all partners should agree on the mental outlooks, attitudes, behaviours, and rules of conduct to be adopted as early as the project planning stage.



There is no one reason for the project concept. Nor is there one way of implementing it. Quite the reverse! Keep in mind the broad range of possibilities. It all comes down to adapting the concept to the context. You need to be attentive to this context to discover the possibilities.

**Encountering all of the partners to bring together each partner's goals and concerns through constructive dialogue.** In 2010, Les Musées de la civilisation de Québec wished to renew and update its permanent exhibit about Quebec's First Nations and Inuit through a collaborative dynamic with the Aboriginal Nations. La BRv, which had expertise in building consensus and creating tools with Aboriginal communities to pass on their cultural heritage, was the major partner of Les Musées de la civilisation for this project. Forming the consultative assembly "Mamo," which means "together" in several Aboriginal languages, was the first action by Les Musées de la civilisation and la BRv. This assembly is composed of each nation's representatives, who are mandated by a decision-making body (band council, cultural institute, or tribal council), and representatives from Aboriginal interest groups. At the first meeting, and at the request of Les Musées de la civilisation, the assembly defined the main themes to be discussed, as well as the logistical, ethical, and methodological issues raised by planned visits to the communities for consensus building.



For two days the consultative assembly Mamo has come together to define the project's goals and parameters. Recommendations are made to adapt the consensus-building program to the realities of Aboriginal communities.



To mark the beginning of this long process, the chief of protocol invites the projects' partners to take part in the Aboriginal sage-smudging ritual, in a spirit of mutual respect.



Members of First Nations, the director of la BRv, and the director of Les Musées de la civilisation de Québec sit at the same table, as equals, to define together the basis of the joint project.

# 1.1 Building consensus and bringing project participants together

On a level playing field with everyone sharing their skills

## The right approach

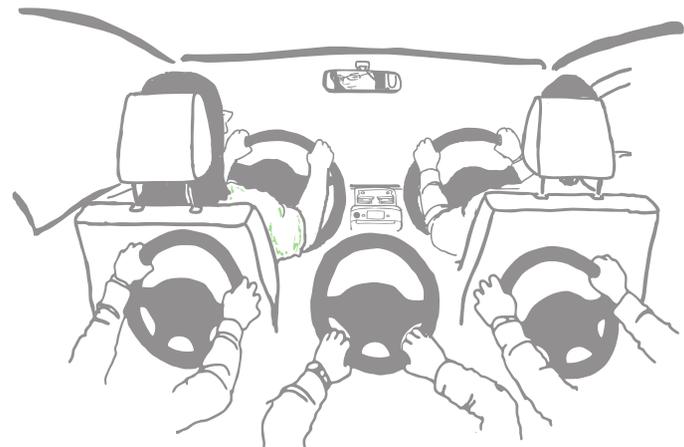
Consensus building and empowerment are closely interlinked. The first process means working collaboratively. The second one means making an individual, group, or organization self-reliant. Consensus building and empowerment are conducive to more equal relationships. Decisions are made bottom-up by members of the community, and not top-down by higher authorities.

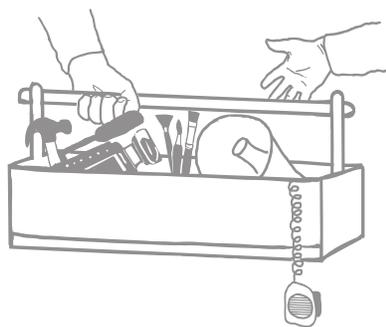
## Consensus building: its principles and implications.

### An ongoing conversation.

To form a vision, to set goals, and to take actions in an atmosphere of collegiality, you need to build consensus through dialogue and conversation to create equal relationships among project participants. This means recognizing the legitimacy of each member's participation and identity. Through such dialogue, you can identify questions and collectively find answers that everyone will accept and defend. Remain open-minded about the other person's position in order to understand what he/she thinks and what lies behind those thoughts. The general goal of consensus building is to make decisions while considering everyone's needs and interests. This dynamic is called a "participatory" or "collaborative" approach.

Because so many people will be taking part in building consensus, it will be that much harder to manage and organize the process. You'll have to be very adaptable. Having the right intentions won't be enough. From the outset, you'll have to measure what these intentions concretely mean in real-life actions. Building consensus for a project will require more resources, more time, more money, and more work. The challenge will be worth the trouble, however—the willingness to work together will be shared by all stakeholders. Our years of experience working collaboratively have shown that this approach is possible for everyone and results in high-quality projects that are firmly grounded in the community setting.





## Empowerment

Empowerment is both a process—making an individual, group, or organization self-reliant for a project—and the result of this process. Empowering an individual is often described by the following metaphor: instead of giving a fish to keep a person fed over the short term, you should give a fishing rod to provide that person with enough food over the long term. The first strategy keeps one in a state of dependence. The second strategy fosters self-reliance and teaches one how to meet one's own needs. This is the spirit of empowerment.

In a community project, the goal of empowerment isn't to make you withdraw into your own cocoon as a result of feeling self-reliant and independent. The goal is rather to learn how to affirm yourself and to become aware of who you are and of what you wish for the future of your community. Individuals and communities can be empowered by giving them the right tools: education, training, and inclusion. Empowerment, however, cannot be decreed or granted. Individuals can gain it through a project or initiative that is social and cultural in scope.

## Creation

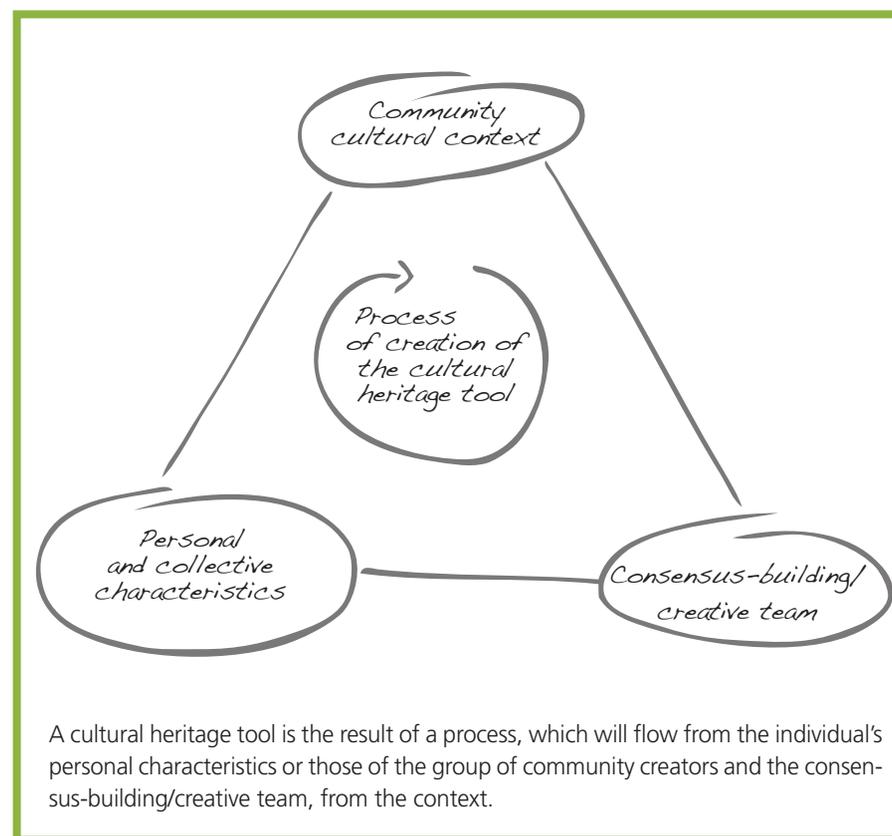
Too often, "creation" is reduced to a flash of genius or an illumination—like a lightbulb suddenly turning on above a cartoon character, without that character knowing exactly why. This capacity to find new ways to solve a problem or to generate new possible solutions is said to be exclusive to artists and artisans, who are gifted with an innate talent. Clearly, each of us doesn't have the same talents as an internationally renowned painter or sculptor, but at some level we can all take part in a process of creation.

Indeed, creation is not only the result (the work of art) or the moment when an idea comes (inspiration). It's much more than that! The creative process can be initiated either by recognition of a need or by an inner prompting, a desire that pushes you to act and do something ... There then generally follows a period of elaboration, exploration, or development, which may be expressed as formal research—drawing blueprints or sketches, creating objects of clay, glass, or ceramic, making mock-ups—or you may use your senses to gather information to satisfy this need, desire, or impetus. Finally, the solutions will be analyzed and verified to see how well they help meet this need or desire, and the solution that best matches the community's expectations and aspirations will be the one

to be implemented. Otherwise, the search for solutions, however creative, may prove to be an inappropriate exercise for the project. Moreover, the spirit of creativity isn't expressed only at the time of the result but also at all stages of the consensus-building process, notably when you have to respond quickly to unforeseen events of any kind and scope that may happen with a community project.

Creation should be omnipresent, whatever its form or degree of intensity, when you're working jointly to take inventory of a cultural heritage and pass it on. Participants can each make their own contribution in their own way and in line with their own capacities. What matters is that all of the participants feel comfortable with the roles and responsibilities they and the team have agreed upon for the current project, knowing that as empowered individuals they don't have to continue in this position in a later project.

On top of the effect of "genius," "chance," or "predestination," a collaborative project also requires a knack for observation, memory, attentiveness to what the other participants say and think, judgement, and logical reasoning, while drawing on your life experience—which essentially defines who you are. Each community member shares in the cultural heritage and has a potential for creativity that may be put to use for his/her relatively narrow field of expertise or for a broader project. You'll have to tap into this natural creative ability and channel it into the dynamic of passing on a cultural heritage.





*"For me, the work of creation will seek out our emotions and the links between these emotions. We rediscover things that have always been precious to us. That makes us look for those things, and that's good."* - Lise Bibeau, Odanak



**Democratizing skills.** Young creators, artisans, and other cultural stakeholders are initiated into several drawing skills: use of cameras and video cameras; processing of digital images; and principles of exhibit design. Don't underestimate the participants' capacities to learn to apply what they may never have experienced before. Training is the basis of empowerment. (For more information about training, go to p. 163.)

In consensus-building/creation projects for cultural transmission, three major components work together synergistically: a community, partners, and the consensus-building/creative team.

## A community

A “community<sup>2</sup>” is composed of a group of people who share the same culture and even some interests and activities. Such people are interlinked within an organizational structure and share a common heritage (history, memory, archives, and achievements). Several communities may share certain cultural traits, while differing from each other in other ways. For example, the village of Manawan, in Quebec’s Mauricie region, is an Aboriginal community of the Nehirowisiw (Atikamek) nation. Its members share several cultural traits with two other communities of the same nation: Obedjiwan and Wemotaci. Together, they can be considered to be the greater Nehirowisiw (Atikamek) community. Yet they form three different villages, with different issues. It would thus be more accurate to speak of three Nehirowisiwok (Atikamek) communities.

The size of a community may range from a simple group as small as a committee to a population as large as all the inhabitants of the world, according to the defining criteria. A cultural development project may therefore cause a more or less large community to get involved in the project, just as it may invite a multitude of communities to take part. This is why we should define from the outset the scope of the project, to ensure that the participants are representative of their community or communities.

## Partners

The project proponent or the consensus-building/creative team should first create a solid network of partners. The “partners” are generally individuals or organizations that team up together and invest (time, money, expertise) in carrying out the project (its conduct). For example, a partner may be an elected official (chief, councillor, MNA or MP), a head of an institution (cultural centre director, school principal, development officer), or an expert who will act as a consultant or counsellor (anthropologist, historian, teacher). Partners will each have decision-making roles in developing the project through the knowledge and experience they’ve gained.

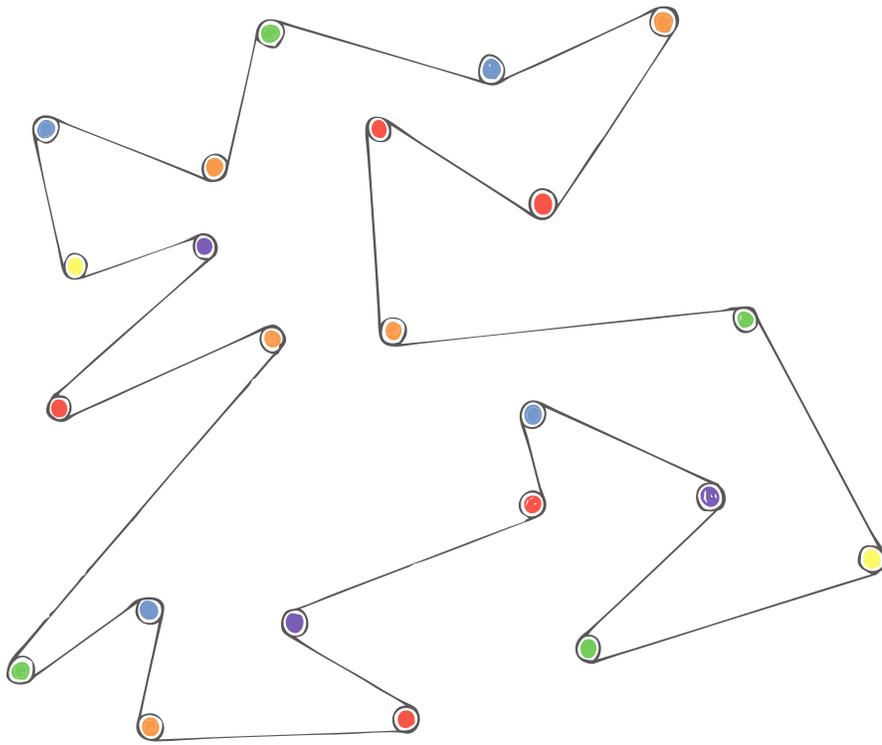
**Getting together around shared interests.** A designer takes part in the activities of Le Cercle des Fermières de Saint-Fulgence, a community with which she has collaborated for an innovative project in product design. All members of the group regularly come together around a snack to talk about their handicrafts.



**Forging and strengthening links between stakeholders.** Being together in a project also means learning to know and appreciate one another through a shared activity. Here, the consensus-building/creative team and creators from several Aboriginal nations meet for a meal. The consensus-building/creative team wishes to create a dynamic that will be conducive to talking and exchanging views. The seating arrangement ensures interaction between the consensus-building/creative team and the participants.



2. The “community of practice” as defined in Wenger E, *Communities of Practice: Learning, Meaning, and Identity*, Cambridge University Press, 1998.



## Questions for the consensus-building/ creative team

As a matter of principle:

- Who should you mobilize for the project ... once the problem to be solved by the project has been spelled out? ...once you've begun looking for solutions that are doable and acceptable in theory? ... once you've begun implementing the solutions that the stakeholders and/or the community have chosen and agreed to?
- What are their respective areas of expertise? Are their areas of expertise complementary or redundant? At what stages of the project should they intervene?
- How do you think other people should be brought into the project? By what means are you going to motivate them to participate? What will be the roles and responsibilities of stakeholders, consultants, or community members?
- How are you going to look for information?
- How are you going to decide together?
- What are the main project goals?
- What strengths, means, and resources are present in the community?
- How will you find the resources you need for the project?

Justify each answer.

## The consensus-building/creative team

When several partners and participants take part in the same project, this participation requires a common meeting place to ensure, as consistently as possible, that the project is successfully carried out and completed. This role is generally played by the consensus-building/creative team or, if the project is small-scale, by one person—the “project leader.” They will help community participants take part throughout all stages of the project.

In some projects, the consensus-building/creative team is created within the community. For example, three members of the community of Ekuanitshit had the idea to create a cultural centre, and they wanted the members of their community to be the ones to determine which contents of their culture would be passed on. This internal team then looked for funding and hired an external firm that specialized in consensus-building/creation. Together, they became a consensus-building/creative team.

Another example is la BRv, whose mission as a research agency is to work with Aboriginal communities to identify and pass on their cultural heritage. To fulfil this assignment, we ask the members of the community to get involved in this kind of project. The initiative is external to the community, and it's all the more important to work collaboratively. Both examples show the many possibilities for such projects where consensus has to be built, creation encouraged, and cultural heritage passed on.

This guide is aimed especially at consensus-building/creative teams. It offers them tools for successful consensus-building. Team members may be more or less experienced, and it's strongly recommended that the same individuals form the team from the beginning to the end of the project. Each new team member must make a lot of effort to adapt, thus preserving the team's cohesion. In addition, community partners are often destabilized by the departure of a team member they had trusted.

### Two scenarios (in relation to the questions on the opposite page)

1. Les Musées de la civilisation is redesigning an exhibit about the First Nations and the Inuit, in collaboration with the latter. The museum (project proponent) enters into partnerships with la BRv, a consensus building /creation agency, and the Aboriginal Nations. Together, all three partners will ask themselves these questions, answer them, and thus determine the project parameters.

2. A community organization (ZIP Saguenay) organizes a series of public meetings, with the help of a consensus-building firm (Chaire en Éco-Conseil of Université du Québec à Chicoutimi), to learn what the population wishes to do with a post-industrial site. Following the meetings, some citizens mobilize to form a committee: Le Comité pour l'Avenir du Site de la « Consol ». The committee decides to follow up on the meetings by pushing for and defending what the public wants for the site. Committee members have to ask themselves these questions, bring together partners, and find sources of funding for the project the public wants.

# 1.8 Developing reflexes

Attentiveness, reliability, respect, diplomacy

Once the project has been defined and planned, and once the program of consensus-building activities completed, you can begin implementing the project in the field. For this, you'll need special abilities and reflexes that can fit the consensus-building/creative team into the context of a participatory project and the realities of the community. With these collaborative abilities and reflexes, the team will become immersed in the culture of the community and adopt an approach based on openness, equality, adaptation, attentiveness, respect, politeness, diplomacy, keen interest in other cultures, and willingness to be together in a unifying project. When the team applies these abilities and reflexes to the specificities of the project context, it will become possible to develop activities that are suitable for the community.



Video recorders, cameras, or other recording equipment can be used to document the activities, thus providing a record of any event. Such documentation will require informed consent from the participants. Never take their approval for granted. Each member of the consensus-building/creative team should always bring informed consent forms, which should be signed before an activity begins. (refer to Appendix III, form example p.260).



**A reflex you should develop: working in the community and using its resources with a view to training and upgrading.**

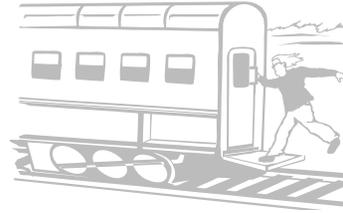
Shooting a short film with a Guarani community in Brazil requires many community resources. All of the work has to be done on site, in places that hold meaning for the community. The focus is on the village elder and cacique, since the project revolves around the goal of passing on his knowledge and experiences. The children and young people, who will receive this knowledge, also take part in the filmmaking according to the “tool” used for this purpose. Musicians likewise take part. Others will become technicians: a cameraman and an audio engineer.

The project involves training and then practising the newly learned skills. Thus, the aim isn't simply to carry out a project with the community but also to enable community members to develop tools on their own and become more self-reliant in developing their local culture.



## Make use of opportunities that come up

The program of consensus-building activities will take place in a limited lapse of time. Many people will be met, and a lot of subjects discussed, with community life going on in the background. Although the activity schedule should be clearly laid out, it should allow some leeway so that the consensus-building/creative team can make use of any opportunities that may come up. Encourage people to participate and don't hold back any initiative from the community, as long as this initiative complies with the project vision that has been agreed upon with the stakeholders.



It's better to have too much information than not enough! It's better to keep the video recorder turned on. Often, fleeting magical moments will be recorded. Let serendipity play its part. All of the material will be archived and classified by medium (photo, video, audio recording) and by community.

**Know how to recognize and seize opportunities that come up.** While visiting the Innu community of Matimekush, the consensus-building/creative team learned that a community caribou hunt was going on at the same time. The team used this opportunity to document the activity, which had been carried out to preserve this tradition in the contemporary way of life. The hunt lasts for about a week each year. It's a must-see. For an exhibit about Quebec's First Nations, these images were used to make a video portrait of the Innu nation and thus show some of its cultural characteristics: hunting as a team and distributing meat to the neediest families of the communities.



## Putting together a collective memory

The consensus-building/creative team creates and galvanizes relations among community members. It has a responsibility to put together a collective memory with respect to identified orientations (see p. 98), and to point to or initiate strategies for passing on this memory. This memory is already present in the community and is stored in each member's head and heart. From one encounter to the next, verbal accounts are gathered fragment by fragment. The picture becomes clearer and comes into focus through the process. The consensus-building/creative team should keep its eyes and minds open in order to recognize elements of this memory. Conversation, questioning, and creation of trusting relationships are reflexes and methods to bring out this cultural heritage.



### Archiving the knowledge.

While we were preparing an exhibit in a community, several of its members mentioned the importance of including traditional legends. We were referred to an elderly woman from the community who knew the legends. The consensus-building/creative team met her to document this important cultural element to be passed on.



### Being available to make it easier to pass on culture.

The consensus-building/creative team will gain from being in a community for several days. From one encounter or activity to the next, community members will become aware of the dynamic of our work, and of the opportunities and advantages available to them. After several days in a community, the consensus-building/creative team received a special request from an elder. He had just trapped a beaver and was planning to show his daughter how to prepare the hide and the meat. He knew how popular the audiovisual medium was among young people and asked us to film him at work.



## The whole and its parts. Equality and diversity

Representativeness is a necessary condition for consensus building. It enables a small group of individuals to reflect the whole community.

Most of the time, it is not possible to get the whole community involved to carry out the participatory cultural inventory. When selecting participants and forming work groups, you need to ensure that they are representative of the community. The inventory will depend on the amount of resources available (time, money) and on community willingness. You can for example determine beforehand that eight properly targeted interviews will be enough.

Each member of a community is a carrier of the culture. The overall portrait will come together to the extent that each new viewpoint is added to the others. With more and more viewpoints, you'll have a more complete and richer vision. For this reason, you should form representative groups (by gender, by age, by family, by occupation) and make them work together. Although it's sometimes better to work in separate generational groups for some activities (teens, young people from 18 to 35 years old, adults, elders), it's also important to bring people together from different walks of life and generations around the same table.

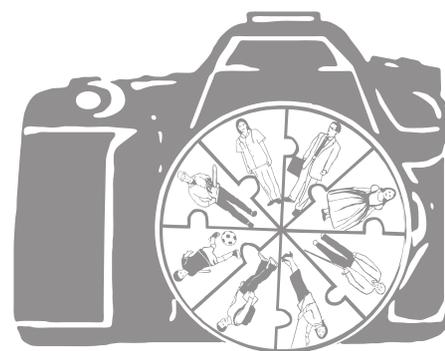


**Speaking with many voices.** Huron-Wendat nation representatives choose by consensus the objects of the collection that, according to them, should be presented in the future exhibit of Les Musées de la civilisation de Québec, and explain why. Community members have different kinds of expertise and express different viewpoints that will enrich the descriptions that accompany the objects. As with all of the other exhibit items, these descriptions will be written by a professional writer and then validated by the community.



## Bring together different kinds of expertise for a more comprehensive vision.

Young people from the Kanien'kehá:ka (Mohawk) community of Akwesasne have come together to make an overall portrait of the cultural dynamism of their community. Different facets of community life are discussed by an administrative officer of the band council, an environmental specialist, a medical student, a youth liaison officer from the justice program, an Aboriginal rights researcher, and an archivist.



In sum, to make sure the community is well represented in the project:

- the cultural delegate (or the political decision-making body) should target those who carry the culture, who in turn may refer you to other community members for their special, known expertise (snowball effect)
- carry out activities for each generation (youth, adults, elders), and intergenerational activities
- make sure a diversity of viewpoints is gathered (see p. 101)
- form a community steering committee to help validate the results of different project stages with the community

**Specific features of gender relations.** In Guarani nation communities in Brazil, project involvement by women shouldn't be taken for granted. Traditionally, the men were the ones who made decisions about projects that might impact the future of their community, while women took care of the children and made handicrafts. Farming was done by both sexes. Women, however, accounted for a very large portion of the culture. So we had to find a way to get around this sociocultural reality and get them to meet each other and take part together in the project. Some activities were held with men and women separately and then, with greater trust developing, the men and the women worked together.



### Ensure participation by young people and elders alike in Aboriginal communities.

Within a community, some sociocultural peculiarities are present in relations between generations. Thus, in Aboriginal communities, a traditional sign of respect is for young people to let elders speak on everyone's behalf. In such a case, how does one get young people to speak up? By playing with and using new technologies, it's possible to get them interested in taking part and giving their side of things.

Among elders, in a climate of respect for their habits and customs, it's by sharing a meal that the encounter and discussion will take place.

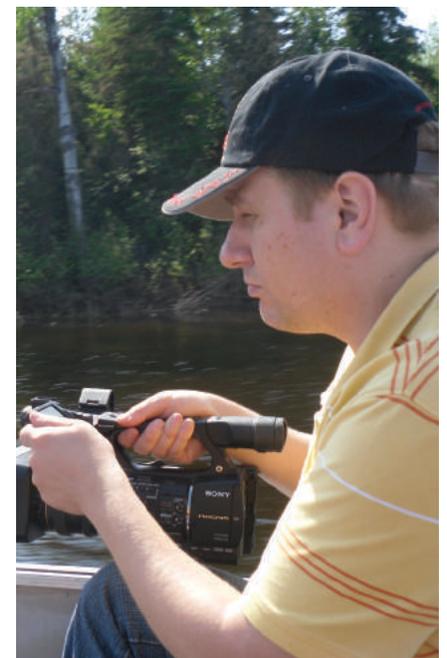
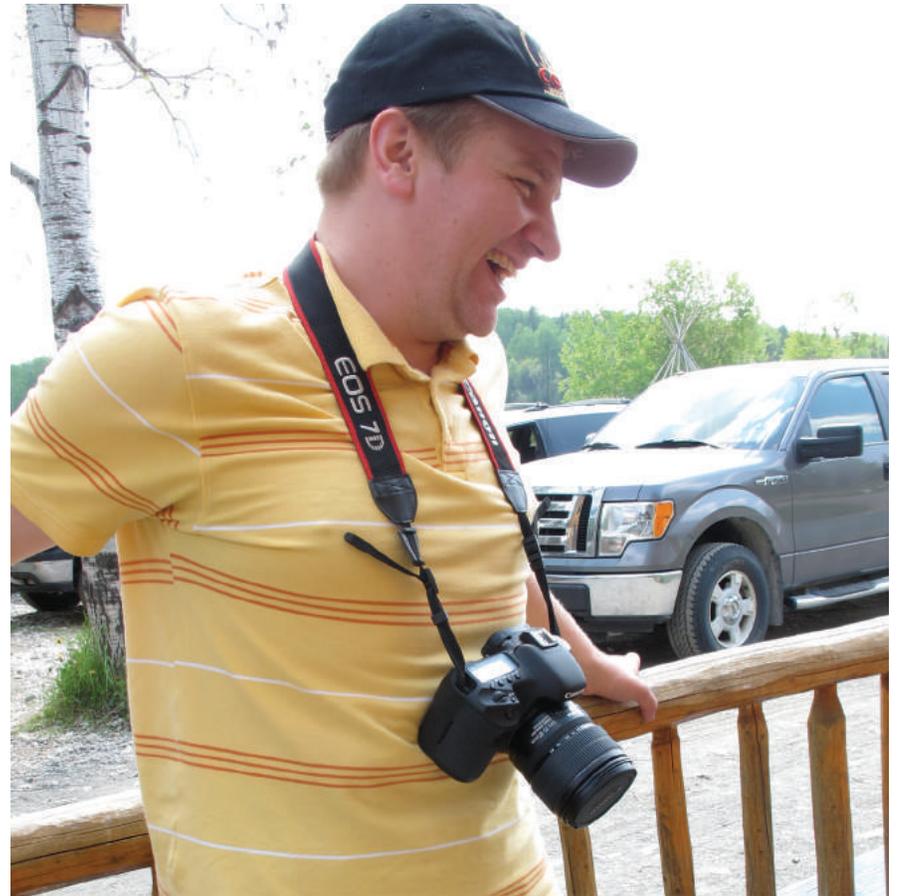
Interaction between generations is nonetheless desired. It makes possible an encounter of ideas, thus contributing to dialogue. Here, a mother and daughter tell how they took part in a program to heal the wounds caused by boarding schools, the wounds having been passed down from generation to generation.



## Document the activities and their results

Documenting is key to a project whose purpose is to inventory culture and pass it on, this documentation being central to the cultural content you wish to pass on. Many people will speak up throughout the encounters and activities. These are unique opportunities for you to seize. Take notes, record conversations, take pictures, and film activities—these are reflexes for you to develop.

The aim is to keep a record of the encounters and archive them so that you and others may know their value and impact. An interview may go unrecorded, and you may leave out much of the content as you scribble the words down on paper. Documenting correctly means respecting and valuing the verbal accounts you gather.



**A visible presence and a transparent activity.** When documenting consensus-building activities, a filmmaker should try to be easy to recognize in the community, such as by meeting people. He/she should also be able to mention the name of a person respected in the community who is taking part in the project. The filmmaker thus shows people that he/she is working for them.

**Promoting skills through an intergenerational encounter.** Quite often, the generations live in very different worlds. Each of them develops its own skills. By having the generations come together in the same activity, you can promote the skills of each generation, thus creating an extremely enriching experience that brings individuals together. Here, a young woman of the Eeyou (Cree) nation uses a camera to document the know-how of an elder of her nation. This elderly woman demonstrates a technique of weaving a child's coat with strips of hare skin.



Don't hide your efforts to record what happens. Be transparent when using recording equipment and taking notes. The participants need to know when you're documenting the activity, and why.



**Documenting a culture.** When you enter a culture different from your own, you have an opportunity to understand its specific features. The consensus-building/creative team will gain from using these trips to amass extensive and diverse visual documentation about the land and the people who inhabit it.





**Beyond the contents, the method: keep a record of “how to work together.”**

Also relevant is documentation about how the partnership with the community plays out. Here, a group of employees from Les Musées de la civilisation and members of la BRv can be seen working with representatives of Aboriginal nations to set up an exhibit. On the table: creative materials, blueprints, and a mock-up being prepared. In the background: reference pictures. All of this material will be preserved in photographs, thus providing a new page of the community's history.

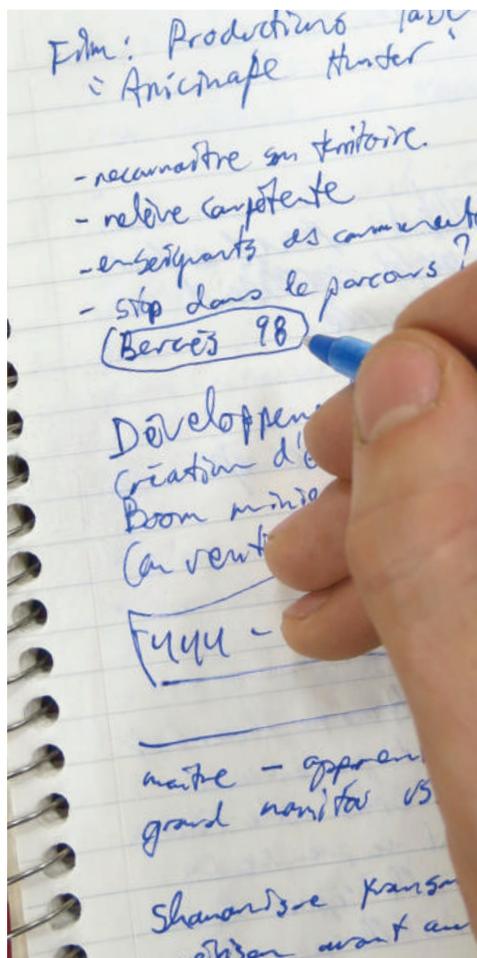
**Set aside time to be by yourselves**

Although the consensus-building/creative team clearly has to collaborate with many people throughout the project, it doesn't have to do so continually. Sometimes, especially when you're reviewing the completed work before going to the next stage, the time for being open towards others, which is associated with all collaborative processes, should give way to an interlude when you can be by yourselves. The consensus-building/creative team will nonetheless make up for this temporary solitude with a rigorous process of validation with community members throughout the progress of its work. During such times, it will continue its mission of being representative and constantly see to it that its work is in line with each stakeholder's goals.



**Time-out for the consensus-building/creative team to measure achievement of project goals.**

Halfway through a major exhibit project, the members of the consensus-building/creative team pulled back to be among themselves. Sometimes, the team has to do this to make a progress report, and thus make further progress possible. Tough questions have to be asked: Is the project moving forward in the way everyone had agreed upon initially? Are the means to this end appropriate? Should certain readjustments be made? If so, what sort of readjustments? (see table on p. 223 for more questions of this sort). Here, the team is trying to produce summaries of the material gathered from each of the nations and make sure that all of the subjects to be covered have in fact been fully documented. Following this progress report, a series of consensus-building activities has been planned to deal with any shortcomings that have come to notice.



**The logbook: a faithful ally whose memory is unlimited.** The members of the consensus-building/creative team should have their logbooks in hand, in all circumstances! The situation won't always let you fully document an event with recording equipment. Always write down what people tell you spontaneously!



*Innu nation - community of Uashat - February 2 to 8, 2011*

*Alexandre André:*

- He should send us a copy of a map of his family's hunting ground, which his grandfather drew in the 1930s.*
- Send him a copy of the video of boarding the train in Schefferville; the people who appear in the video have consented.*

*Jocelyne Mollen:*

- Get back in touch with her in September to tell her about the results of her fieldwork among the elders of her community.*

**Reliability: honouring our commitments.** During collaborative activities, the members of the consensus-building/creative team have to deal with many questions and requests, and they shouldn't rely solely on memory. A logbook can keep a record of all commitments made to or by participants. Each relationship has to be preserved, and each commitment has to be honoured. A relationship of trust will grow progressively if there is mutual recognition and respect.

## Putting together a directory of resource people

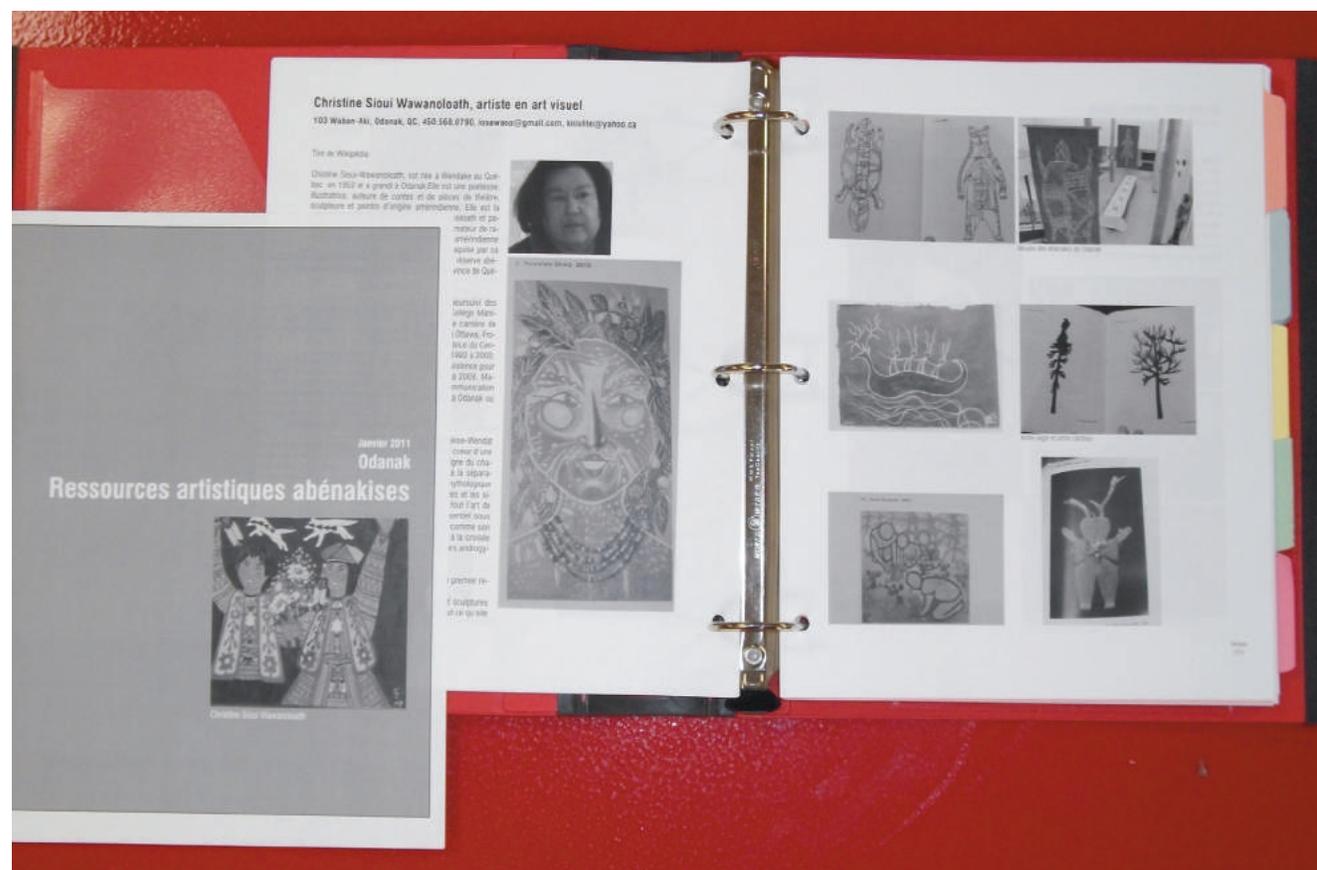
You have to keep in mind all of the community's driving forces, skills, expertise, and resources. The consensus-building/creative team should recognize these resources in order to promote and use them for the project effort. Through a succession of encounters, interviews, and activities, you should identify people in the community with special skills and talents. When the time comes to carry out the project, this directory will be one of the foundations for working collaboratively with members of the community.



### Documenting community resources

**(expertise, skills).** When putting together a directory of resource people, you'll encounter members of a community to document their specialties. Here (above), a craftswoman shows her work during a visit to her basket-weaving workshop in a Kanien'kehá:ka (Mohawk) community. Following the visit, a fact sheet is created with her name and contact information, several photos, and a short biography and description of her skills. On the right, a Waban-Aki (Abenaki) artist's fact sheet can be seen.

Communities seldom know all of the human resources they have. Copies of the directory of resource people and skills should be given to them. It's a useful tool for future projects.



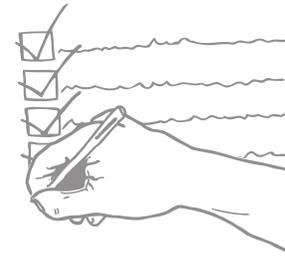


## Going back constantly to the initial project goals

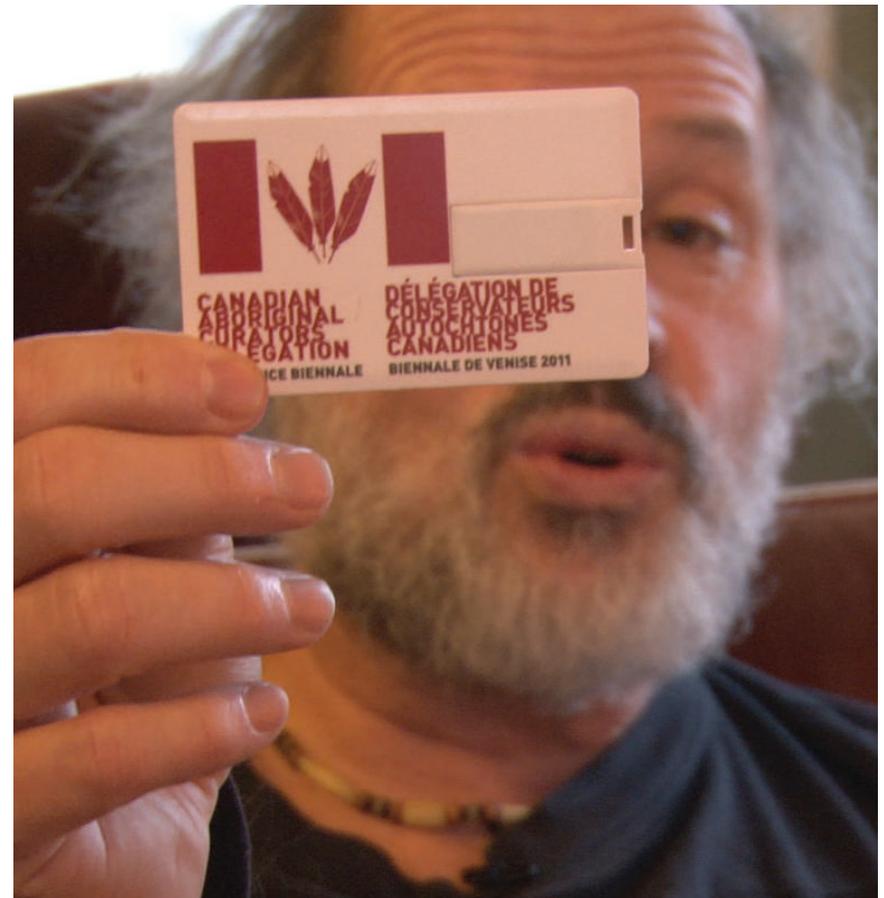
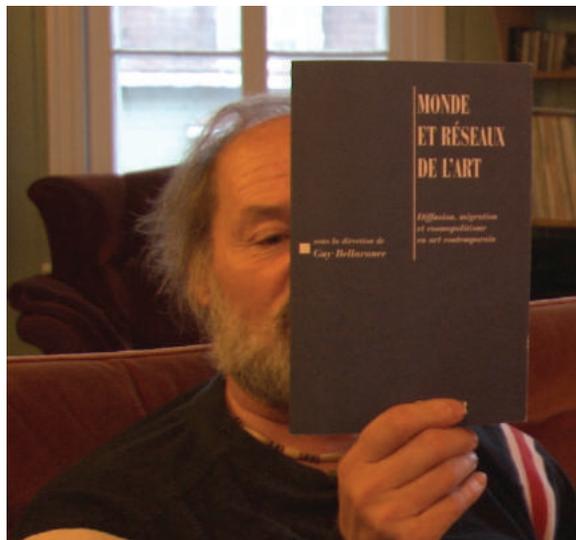
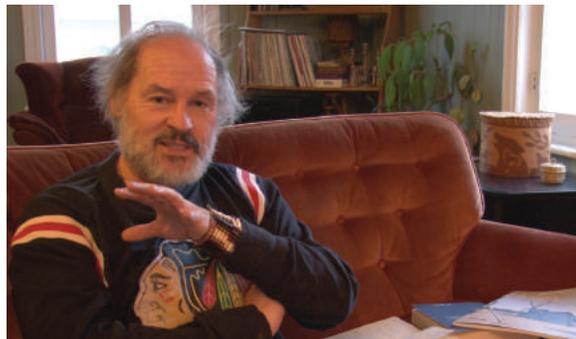
One of the major principles of consensus building is to consider each project stakeholder's aspirations and concerns. When the project is first being put forward, everyone is asked to speak up. This is why the goals will be prepared collectively (refer to definition of project frameworks on p. 71). Ideally, consensus building will seek to fulfil all goals that are put forward.

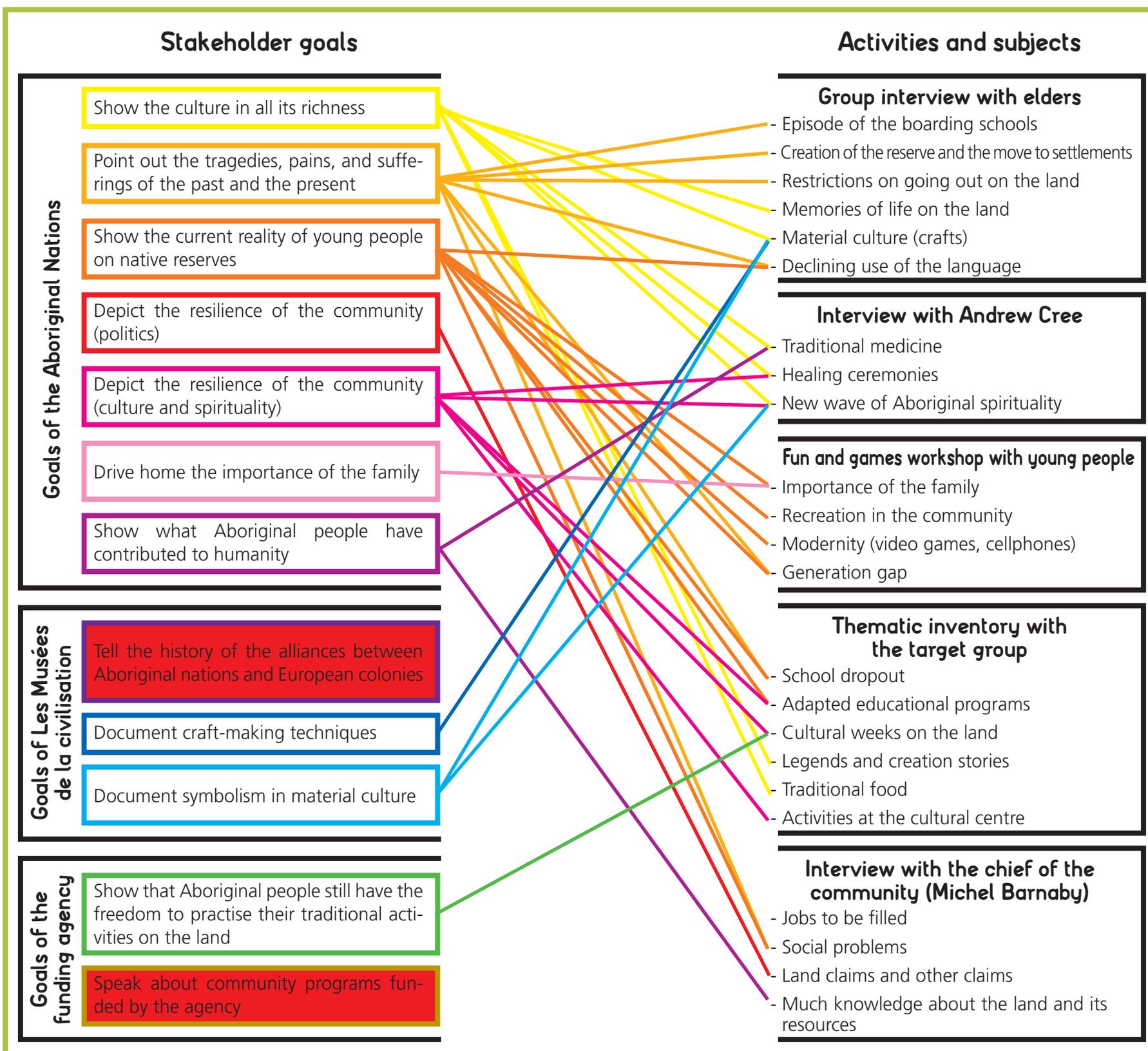
The consensus-building/creative team has a mandate to see to it that the goals are respected throughout the project, since not all of the stakeholders may be present at each stage. In some ways, the consensus-building/creative team acts as a guardian of their respective goals. As the project moves forward, whenever one stage leads to the next, you'll have to look at the goals and make sure they've been achieved. Some goals may change along the way, as knowledge accumulates from one encounter to the next and from one activity to the next. To the extent that the mission and vision of consensus building are respected, it may be acceptable to modify one or more of the initial goals, without compromising the general spirit of the project.

To make these verifications easier, draw up a chart listing all of the goals of each stakeholder and presenting the different themes agreed upon. If you find it difficult to achieve one goal, you may think up other ways of reaching it. If you have to seek out the voice of each generation, and if your approach to young people is proving difficult, you should explore alternatives (refer to p. 83 for more information on this specific example).



**Document a specific subject to make the schedule of activities complete.** For the project to redesign the permanent exhibit of Les Musées de la civilisation, museum management had clearly set itself a goal to deal with issues that are shared by Quebec's Aboriginal peoples with native peoples elsewhere in the world. At the end of the consensus-building visits, one subject remained relatively absent from what people in the communities had been talking about. We then conducted an interview with an aboriginal sociologist of art.





**Make sure project goals are being achieved.** You should often refer to the goals expressed by each project stakeholder to measure how much they have been achieved. Here, a table has been prepared following a series of activities to inventory the cultural heritage to be passed on. This table shows whether all of the cultural content goals have been achieved. Here, by comparing goals with different subjects during the activities, we see that two goals (red boxes) haven't yet been achieved. Other activities will be needed to document these subjects.

# Conclusion

The excerpts presented here address the key foundations, values and principles to be aware of and keep in mind throughout any research project in an Indigenous context in order to promote and facilitate collaboration between all stakeholders.

*"The Little Guidebook on the Extensive Consultation: Cultural Creation and Transmission by and with Communities"* shares and makes accessible a wealth of tools that should be helpful to collaborative research contexts and the production of cultural transmission mechanisms, specifically:

The major steps of a collaborative initiative;

- Advice for acting responsibly;
- Participatory inventory activities connected with a community's cultural heritage;
- Arrangements and principles for co-creation workshops; and
- Practical and instructional exercises for key moments in the process.

The publication can be obtained in print or digital format at:

French edition: <https://www.pulaval.com/produit/le-petit-guide-de-la-grande-concertation-la-transmission-culturelle-par-et-pour-les-communautes>

English edition: <https://www.pulaval.com/produit/the-little-guidebook-on-the-extensive-consultation-cultural-creation-and-transmission-by-and-with-communities>

## Appendix V

# Biographical note about the authors



**Élisabeth KAINE** has been working as an art professor at Université du Québec à Chicoutimi since 1989. Her fields of intervention in the design practice are numerous: furniture, exhibition design, publishing. She has been recipient of grants from the Conseil des arts et des lettres du Québec and from the Canada Council for the Arts for several artistic projects. From 2003 to 2015, she led two Community-University Research Alliances (CURA-SSHRC) projects entitled “La création et la concertation comme leviers de développement des individus et des communautés autochtones” (creation and consensus building as levers in Aboriginal community and individual development). Since 2001, she has been leading La Boîte Rouge vif, an organization that she co-founded. Élisabeth is from Wendake. She has devoted her career to the development of tools and ways to ease cultural transmission in order to valorize Aboriginal cultures.



**Olivier BERGERON-MARTEL** has completed a bachelor's degree of arts and science of animation at Université Laval and a Master of Arts with a concentration in “teaching and transmission” at Université du Québec à Chicoutimi. He has experimented with consensus building and collaborative design processes, which aim to use the possibilities of artistic creation, in order to pass on specific contents (messages, values, principles, desires, ambitions, etc.). He is particularly interested in mechanisms that encourage the empowerment of community groups, as well as in the importance of the cultural sphere in the development of individuals and communities. He has been working for La Boîte Rouge vif since 2010, and has been taking part in many of their cultural transmission projects, including exhibitions, publications, and websites.



**Denis BELLEMARE** is a Doctor in film studies at Université du Québec à Chicoutimi. He specializes in individual or collective identity questions in terms of perceptions and projections of the world. He studies analogies between cinema and ethnology: both question the reality. He has led many major film productions, including C'est notre histoire; Premières Nations et Inuit du XX<sup>e</sup> siècle of the Musées de la Civilisation. He is leading a cultural transmission research project with Guarani communities in Brazil. He is also in charge of film and media production as a way to construct an image and an identity workshops.



**Pierre DE CONINCK** is a professor at the École de design industriel de l'Université de Montréal, engineer-designer, Doctor in planning and specialist in complex systemic analysis. He has expertise in sustainable design and manufacture of products (industrial design), as well as in the development of participatory approaches for the integration of citizens in the decision-making and in the design (focus groups/informed consensus conference) for the local social development (stakeholders, community development, and design).

## CREDITS

WRITERS: Under the direction of Élisabeth Kaine, with Olivier Bergeron-Martel, Denis Bellemare, and Pierre DeConinck (in alphabetical order).

CONTENTS COLLABORATORS: François-Mathieu Hotte, Carl Morasse, Claudia Néron, and Jean-François Vachon. Diane Laurier and Anne Marchand for the Appendix I *Cultural transmission through visual arts, object design, and filmmaking*.

PROJECT MANAGER: Olivier Bergeron-Martel.

GRAPHIC DESIGNER : Renata Marques Leitao

ART DIRECTORS: Olivier Bergeron-Martel and Élisabeth Kaine.

RESEARCHERS (PHOTOGRAPHS): Olivier Bergeron-Martel, assisted by François-Mathieu Hotte, Carl Morasse, Claudia Néron, and Jean-François Vachon.

ILLUSTRATORS: Olivier Bergeron-Martel and Jérémie Fortin (under the responsibility of Claudia Néron).

COMPUTER GRAPHICS TECHNICIANS: Olivier Bergeron-Martel, Justine Bourdages, Marielle Couture (Oh! Lala Productions), Émili Dufour (Centre Sagamie, art actuel), Renata Marques Leitao and Annie Perron.

ADVISORS: Yvon Dubé (Coopérative des arts nehirowisiw) and Anne Marchand (Université de Montréal).

CONTENTS REVISER: Michel Séguin PhD, Environmental consultant, Commissioner at the Office de consultation publique de Montréal.

REVISERS: Peter Frost (English), Mélanie Dutil (English graphic layout).

TRANSLATORS: Peter Frost and Maude Cournoyer.

PRINTING: Marquis Imprimeur (Montmagny).

PHOTOGRAPHS: La Boîte Rouge vif's team (Waubnasse Bobiwash-Simon, Mendy Bossum-Launière, Maxime Girard, François-Mathieu Hotte, Élisabeth Kaine, Carl Morasse, Claudia Néron, and Jean-François Vachon), Design et culture matérielle's team (Catherine Bouchard, Diane Laurier, Anne Marchand, Renata Marques Leitao and Cedric Sportes), Mathilde Dherissard (p. 115), Francis Fecteau McClure (p. 69), and Laurent Jérôme (pp. 69, 80, 115, 121, 246, 247).

Back picture of the publication: detail of the exhibition *Because Urbanity is Also Anicinabe*, at Centre d'exposition de Val d'Or.

## Financial partners

Ministère de l'Économie, de la Science et de l'Innovation (MÉSI), Programme de soutien à la valorisation et au transfert (PSVT) - volet 2 : Soutien aux projets structurants

Social Sciences and Humanities Research Council (SSHRC), under the programs of Community-University Research Alliances (CURA), and Aboriginal Research

Université du Québec à Chicoutimi (UQAC)

Société de développement des entreprises culturelles (SODEC)

Université de Montréal

Ministère des Relations Internationales et de la Francophonie du Québec

Canadian International Development Agency (CIDA)

A production of La Boîte Rouge vif

In this publication, the spelling and the agreement of the ethnonyms are made according to opinions collected by La Boîte Rouge vif from many linguists and translators from aboriginal nations in Québec and in Brazil.

Every effort has been made to find the owners of the photographs' copyrights. However, should corrections be necessary, it will be a pleasure for us to rectify the situation.

**SODEC**  
Québec 

**Économie, Science  
et Innovation**  
Québec 

**UQAC**  
Université du Québec  
à Chicoutimi

Université   
de Montréal

Financé par le gouvernement du Canada  
Funded by the Government of Canada

**Canada** 

## THE LITTLE GUIDEBOOK ON THE EXTENSIVE CONSULTATION

### Cultural Creation and Transmission by and with Communities

Too often, even today, when they are implementing a project, decision-makers or groups in position of power do not believe it is necessary to seek collaboration from the members of a community; and yet, they are the ones who will have to live with the impacts of the project. As a result, after a few information sessions, the community is faced with a done deal, and has to live with decisions that have been made by others, without having the chance to give its opinion.

The Little Guidebook on the Extensive Consultation; Creation and Cultural Transmission by and with the Communities, native and non-native, aims to help reversing the trend by proposing cultural projects' models arising from a real consensus-building approach. It is a "toolbox" to ease the convergence of the driving forces of a community within a common approach, and through a process that springs from the desire of realizing a cultural project. It provides

support to project officers, workshop leaders, partners or decision-makers for the various aspects entailed in making a cultural project. It offers principles, thoughts, and tools to facilitate the population's participation to its own cultural development. The approach of this guide focuses on art creation, design, video, and museography. Many work methodologies are explained. They enable carriers of culture to express themselves, and to formulate the message and the heritage that they want to pass on by themselves.

The principles, thoughts, and tools provided in this guide are based on experience gained over the last 25 years by La Boîte Rouge vif. Since 1991, it works in cultural and mediation transmission through consensus building and creation. Its mission is to develop innovative individual and community development strategies while respecting diversity.



Presses de  
l'Université Laval



ISBN 978-2-7637-3297-8



Études amérindiennes

## TABLE OF CONTENTS

### EXISTING AND EMERGING INITIATIVES / VIDEOS

#### INSPQ:

 Qanuippitaa 2004 – La vidéo (*French*)

 Qanuippitaa 2004 – La vidéo (*English Subtitles*)

 Qanuippitaa 2004 – La vidéo (*Inuktitut*)

 Qanuippitaa – Nunavik Health Survey (*English*)

 Qanuippitaa – Nunavik Health Survey (*Inuktitut*)

 Kimeltuwn Mapuche Ñymican. Enseignement du tissage des Mapuches.  
Escuela de Cine y de Comunicación Mapuche (en anglais : Mapuche School of Filmmaking  
and Communication). 2011. (*French Subtitles*)

 Kimeltuwn Mapuche Ñymican. Enseignement du tissage des Mapuches.  
Escuela de Cine y de Comunicación Mapuche (en anglais : Mapuche School of Filmmaking  
and Communication). 2011. (*English Subtitles*)

 Ixofil Lawen. La médecine englobe tout. Escuela de Cine y de Comunicación Mapuche  
(en anglais : Mapuche School of Filmmaking and Communication). 2013. (*French Subtitles*)

 Ixofil Lawen. La médecine englobe tout. Escuela de Cine y de Comunicación Mapuche  
(en anglais : Mapuche School of Filmmaking and Communication). 2013. (*English Subtitles*)