

# TOOLBOX OF RESEARCH PRINCIPLES



## IN AN ABORIGINAL CONTEXT

**ETHICS • RESPECT • FAIRNESS • RECIPROCITY • COLLABORATION • CULTURE**

## 2021 Edition

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# 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 (OCAPT). 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.



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

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“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-

tened 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> <ul style="list-style-type: none"> <li>- Identify research focus</li> <li>- Examine assumptions</li> <li>- Establish research questions beneficial to all parties</li> </ul>         | <ul style="list-style-type: none"> <li>- Formulate research questions within local context of TEK/LEK and research goals</li> </ul>                                                                                                                                                    | <ul style="list-style-type: none"> <li>- Situate local context into scholarly framework to shape research focus</li> </ul>                                                                                                                           | <ul style="list-style-type: none"> <li>- Share understandings and qualify assumptions about the study system from all perspectives</li> <li>- State research objectives transparently</li> <li>- Examine potential benefits and costs of the research</li> </ul>                                                                                                                                                                                                                    |
| <b>Design</b> <ul style="list-style-type: none"> <li>- Select appropriate scope and methods</li> <li>- Organize local logistics</li> <li>- Craft data sharing agreements</li> </ul>                    | <ul style="list-style-type: none"> <li>- Ensure methodology respects local protocols</li> <li>- Provide clear expectations on research goals and data sharing agreements</li> <li>- Suggest if current project can build from/contribute to other local research</li> </ul>            | <ul style="list-style-type: none"> <li>- Provide design expertise in scientific methods</li> <li>- Contribute to shared vision for project goals and data sharing agreements</li> </ul>                                                              | <ul style="list-style-type: none"> <li>- 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</li> <li>- Ensure academic rigour is adequately maintained, but is dynamic if required to embrace changing research goals or local operations</li> <li>- State potential applications, protections, and storage of data in a transparent manner</li> </ul> |
| <b>Implementation</b> <ul style="list-style-type: none"> <li>- Assemble research team</li> <li>- Engage in collaborative fieldwork</li> <li>- Consult frequently on progress and challenges</li> </ul> | <ul style="list-style-type: none"> <li>- Ensure logistically safe and culturally respectful research operations</li> <li>- Contribute local experts on research teams</li> <li>- Share local knowledge</li> <li>- Provide feedback on research process</li> </ul>                      | <ul style="list-style-type: none"> <li>- Share technical expertise</li> <li>- Respect local protocols</li> <li>- Consult regarding project progress with community</li> <li>- Provide feedback on process</li> </ul>                                 | <ul style="list-style-type: none"> <li>- Share capacity and respect among team members</li> <li>- Provide support for the integration among various assumptions, goals, and relationships to place</li> <li>- Create space for collaborators and community members to engage with the research process</li> </ul>                                                                                                                                                                   |
| <b>Knowledge dissemination</b> <ul style="list-style-type: none"> <li>- Respect both access to and confidentiality of knowledge</li> <li>- Communicate research outcomes</li> </ul>                    | <ul style="list-style-type: none"> <li>- Respect data sharing protocols</li> <li>- Make knowledge accessible to the community</li> <li>- Use information for resource management decisions, as appropriate</li> <li>- Participate in scholarly publications, if appropriate</li> </ul> | <ul style="list-style-type: none"> <li>- Respect data sharing protocols</li> <li>- Make knowledge accessible to the community</li> <li>- Craft academic publications</li> <li>- Offer information for resource management, if appropriate</li> </ul> | <ul style="list-style-type: none"> <li>- Manage and distribute information at community and academic levels, as per previously agreed upon data protocols</li> <li>- Collaborate on authorship of reports and /or scholarly publications</li> <li>- Extend research findings beyond collaborators into the community</li> <li>- Solicit process feedback, for ongoing activities and future collaborations</li> </ul>                                                               |



### 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

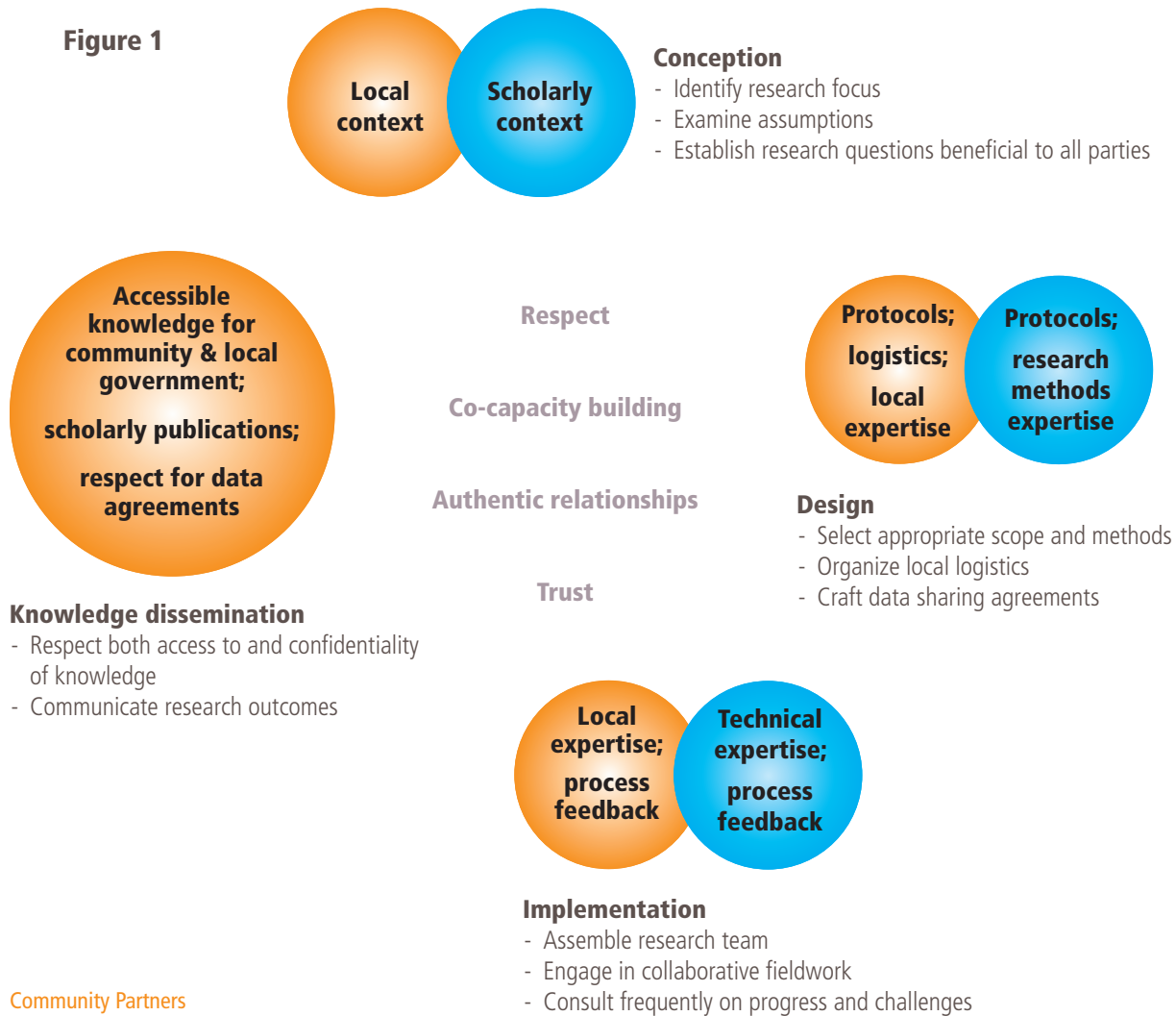
research outcomes. For scholarly publications, this inclusion is expected if community contributions are consistent with typical publishing expectations [20]. Communicating research outcomes involves careful consideration of authorship ethics through respect for data protocols and acknowledgement of 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 Wuikinuxv 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**



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 Corntassel for sharing with us the elegant and powerful concept of 'de-centering the university' from community-based research.

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## EXPANDING THE TOOLBOX: EPISTEMOLOGICAL STRETCHING AND ETHICAL ENGAGEMENT

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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?

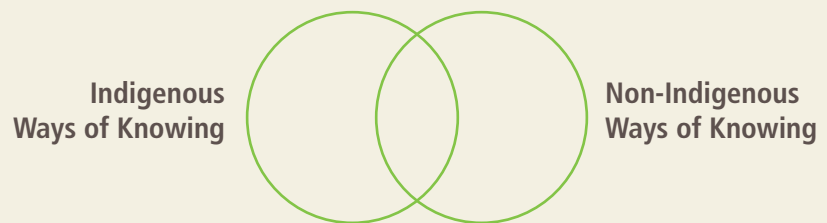
1. Land and Meyer (2006) call these ‘threshold concepts’ gateways “that lead to previously inaccessible, and initially perhaps ‘troublesome,’ ways of thinking about something” (n.p.).

### Activity 2 (45 minutes) :

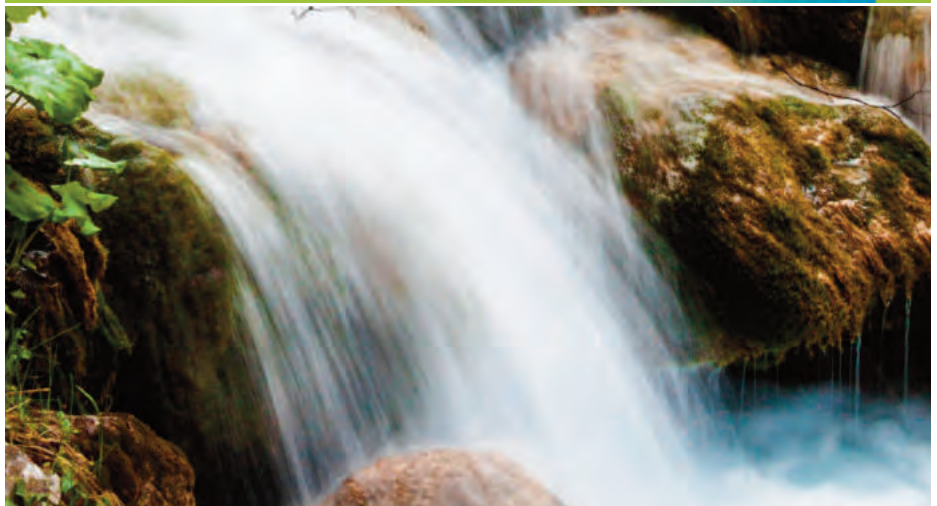
This activity challenges the conception that Indigenous and non-Indigenous ways of knowing may not, as is often assumed, be incommensurable.

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                                                                        |
|-------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------|
| <b>Example 1:</b><br><br>Animals cannot communicate with humans; they do not have agency. | Animals have nothing to contribute to resource management decisions; those who think otherwise are deluded. | Science is the only way to know about animals. This includes measurement, observation and theory. We will only use this kind of knowledge. | 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. | Animals have the ability to contribute and should be asked to do so.                                  |
| <b>Example 2:</b><br><br>Trees cannot communicate with humans.                            | Trees do not have a spirit.                                                                                 | No one listens to trees.                                                                                                                   | I received wisdom from a tree.                                                                                                                                                           | Trees are wise; Trees have a spirit; Spending quiet time with trees can provide knowledge and wisdom. |
| <b>Additional local examples</b>                                                          |                                                                                                             |                                                                                                                                            |                                                                                                                                                                                          |                                                                                                       |

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)

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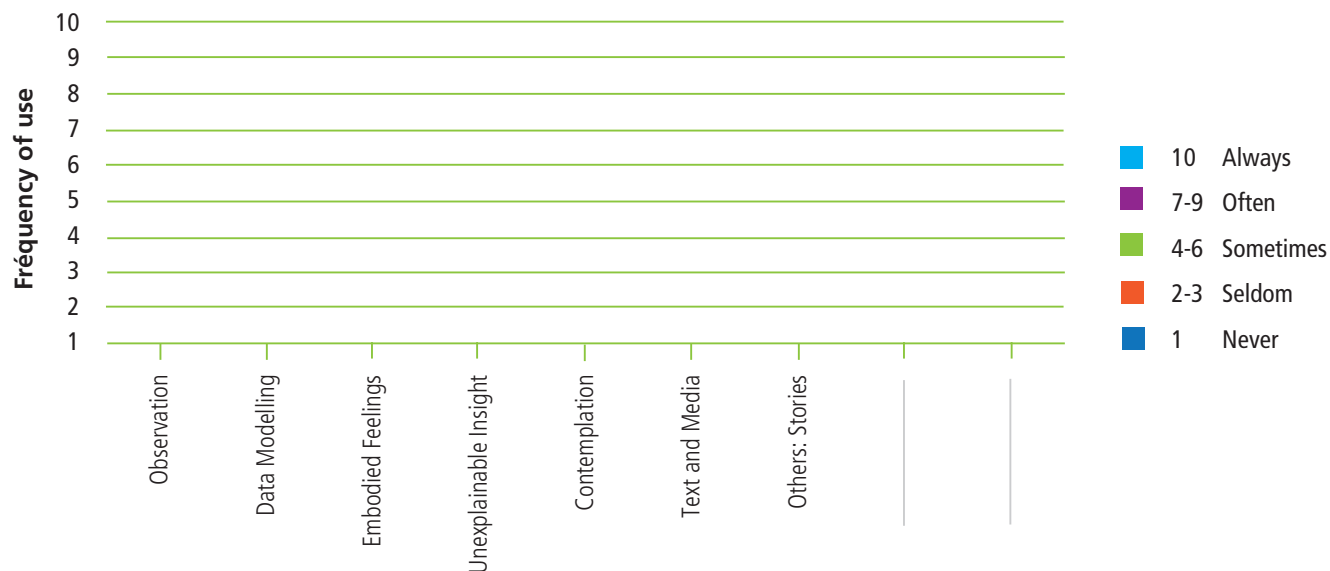
Canada

## 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.

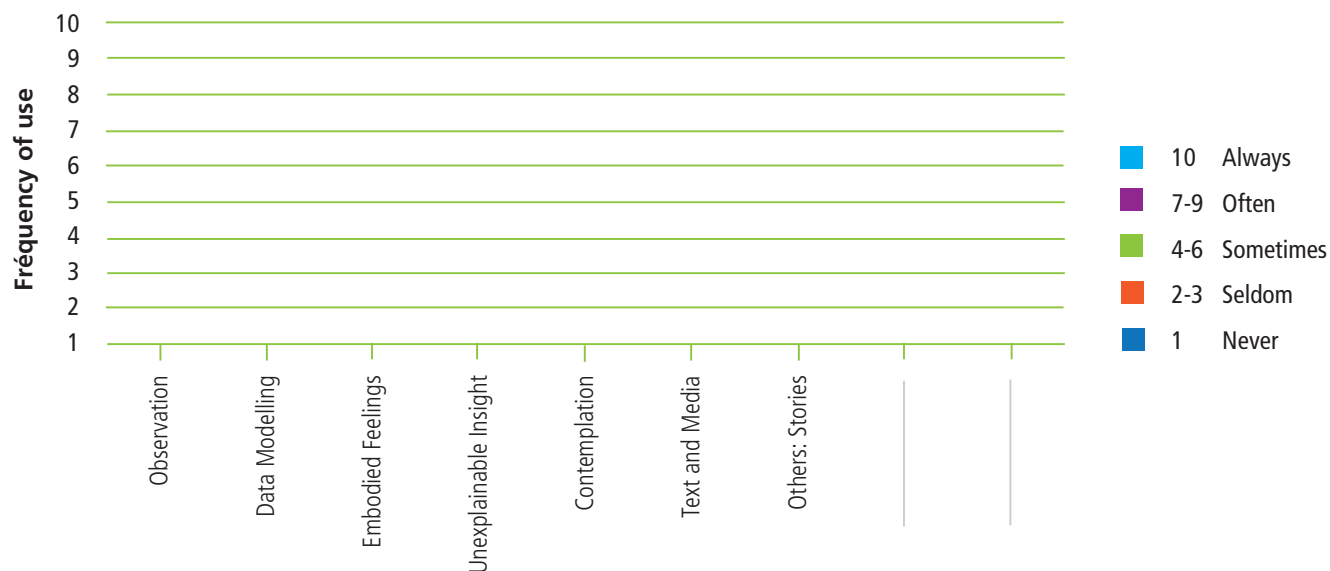
In my professional work, I come to know things through



### 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

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## 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 provided

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.





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# Way of being

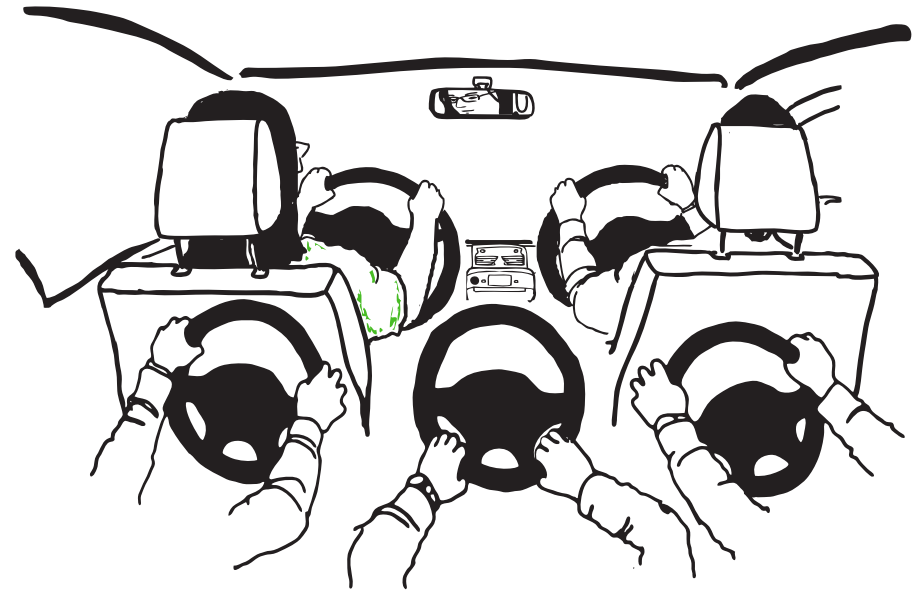
## To promote a shared process

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.

### **Togetherness:** aiming for consensus

"Togetherness" 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.

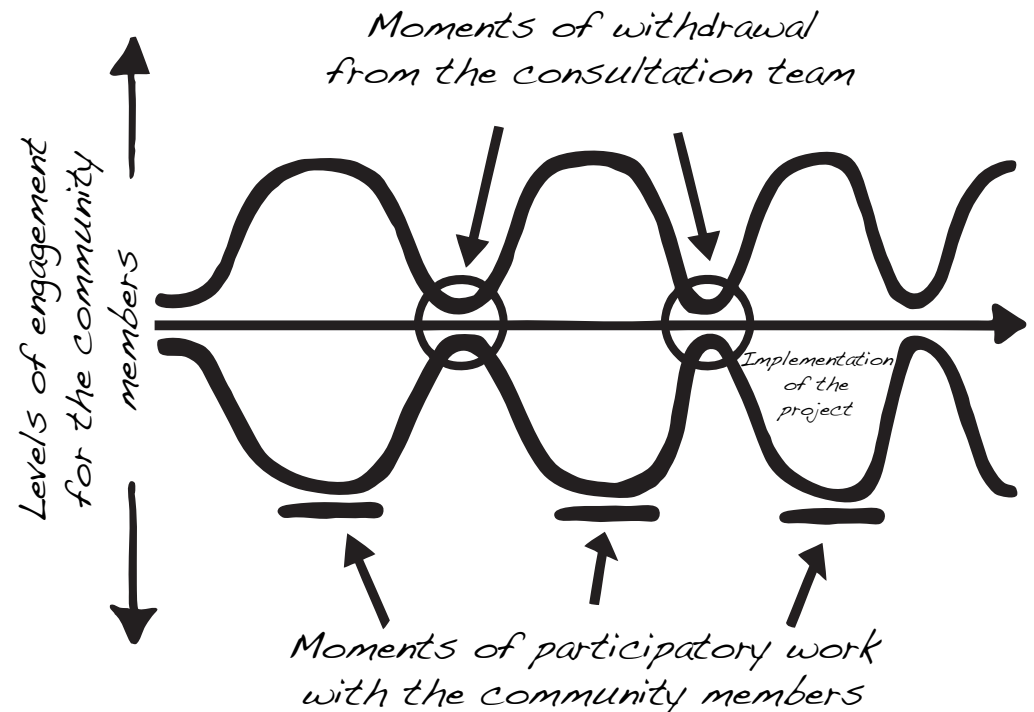


**The pleasure of gathering around shared passions.** In the same spirit of togetherness, a contemporary artist and designer participates in the activities of the community with whom she collaborated on a project. On a regular basis, the women of the *Cercle des fermières* (farmers' circle) gather at 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.

"Togetherness" 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.

## Spirit of the collaboration: responsibility in terms of representation

The consultation processes therefore seek to ensure that a community is involved as much as possible through participatory activities. It is therefore important to involve the people, regardless of whether or not they were identified, who were designated as representatives by their communities and who have received trust and inherent responsibility from their fellow citizens. By force of circumstance, participants must not lose sight of the fact that they are speaking on behalf of their community and that they are responsible for representing it in its entirety, rather than just their own personal interests. They should consider it an honour and take their participation seriously.

## Consent and commitment

In a participatory dynamic, it is very important to apply a protocol by formalizing the commitments of each and everyone in order to protect the participants as well as the team leading the project. Regardless of whether it is for the opinions expressed by any person in connection with a discussion, the images that this person captures by camera or video camera or the ideas expressed by a participant, it is important to establish an agreement concerning respect for the images and intellectual property of those involved. It is therefore important, according to the circumstances of the project and stakeholders, to present to them and have them sign certain documents ranging from notarized contracts (between partners) to informed consent forms (for the participants) in addition to ethical certificates and other such documents. These will endorse the potential uses for the material in question. Through this agreement, the participant authorizes the use of his/her contribution for specific purposes and, in return, the consultation team ensures that these uses are limited to those specified in the agreement. Two forms must be signed: one copy for the participant and a second copy for the consultation team.

Some may perceive the informed consent forms as obstacles to establishing good interpersonal relationships between the participants and the consultation team. Now certainly, these documents can be intimidating and seem to unnecessarily complicate the implementation of the project; it may be wise not to impose them immediately in order to prioritize making contacts and establish a trusting relationship between the parties involved. However, these documents should be seen as a sign of mutual respect, based on an agreement in which the engagement of others is not taken for granted. In the field of research, they are mandatory. Therefore, the importance of these documents must not be underestimated. It is recommended to introduce them tactfully as soon as the activity begins, to present them within a certain perspective and to wait until the end of the meeting to fill them out.



**Respect for the governance structures and authority figures.** While planning a consultation process within the Guarani Nation in Brazil, it was first necessary to meet the *caciques* (chiefs) of the participating communities. The nature of the inventory and cultural transmission project was defined by them. They are also the ones who appointed those who could participate. It was important for these *caciques* to be aware of the activities taking place so that they could have the opportunity to oversee the process and participate. Respect for their authority ensured a better implementation of the project.



**Beyond governance and its delegation, knowing how to recognize and foster the participation of valuable collaborators.** It is just as important to respect the levels of authority within a community as it is to be able to identify those who could facilitate the community process. After the consultation team had arrived in the community, the delegated representatives introduced certain people to them who would greatly facilitate the process. Their extensive knowledge of the community as well as their leadership qualities ensured a better local footing for the team.

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

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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                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | References                                       |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------|
| <p><b>1. I didn't really understand what the research project is about. What can I do?</b></p> <p>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.</p> <p>Researchers often use words that are specialized or complicated, but they must inform you using language that everyone can understand.</p> <p>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.</p> <p>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.</p> | <p><b>Chapter 3</b>, Art. 3.2, TCPS2</p>         |
| <p><b>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?</b></p> <p>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.</p> <p>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.</p>                                                                                                                                                                                                                                                                                                                                                                       | <p><b>Chapter 3</b>, Art. 3.1 and 3.3, TCPS2</p> |
| <p><b>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?</b></p> <p>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.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | <p><b>Chapter 9</b>, Art. 9.13, TCPS2</p>        |



## 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

## References

### **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.

**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

### 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.

## References

**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

## Question

## References

### 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 OCAP™ 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™

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

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# THE NUNATUKAVUT MODEL OF RESEARCH OVERSIGHT: INNOVATION THROUGH COLLABORATION

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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**

1. Engager une discussion préliminaire avec les leaders de la communauté (par téléphone ou par courriel)
  - obtenir une lettre de soutien conditionnelle de la communauté, si exigée aux fins de financement ou de la demande du CÉR
- 2a. Présenter une demande au CCR autochtone aux fins d'examen
- 2b. Présenter une demande au CÉR aux fins d'examen
3. Une fois l'approbation de la communauté et l'approbation du CÉR obtenues, demander la permission d'accéder aux établissements (p. ex. : régies de la santé, commissions scolaires) ou aux terres (p. ex. : permis de recherche archéologique)
4. Recueillir les données
  - assurer une communication continue; obtenir l'approbation des modifications auprès du CÉR et du CCR
5. Diffusion de l'information, notamment à la communauté, conformément aux modalités de la demande

### 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.

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

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*“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.





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

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## 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: Ilnu 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 (Ilnu 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 Mashteuiatsh 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 Tetauan 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 Tetauan 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. Tetauan CURA: <http://www.tetauan.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 Tetuan 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 weaken-

ing 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



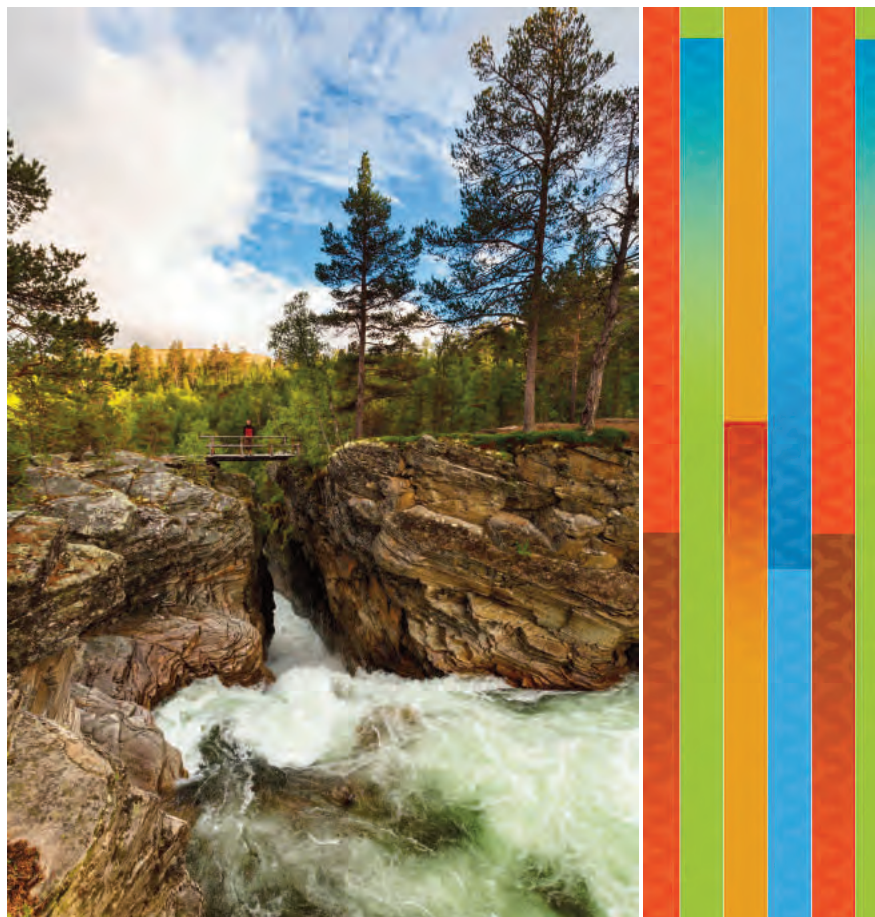


summers of 2011 and 2012; and the data analysis occurred in the fall of 2012 and winter of 2013 and continued with the designing of the panels from March to October 2013, culminating with the presentation of the exhibition *Tshishipiminu : occupation ilnu de la rivière Péribonka et développement hydroélectrique* (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 Mashteuiatsh 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 Mash-teuiatsh, 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 hydro-electric 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.

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

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## 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 Ah-taawin 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

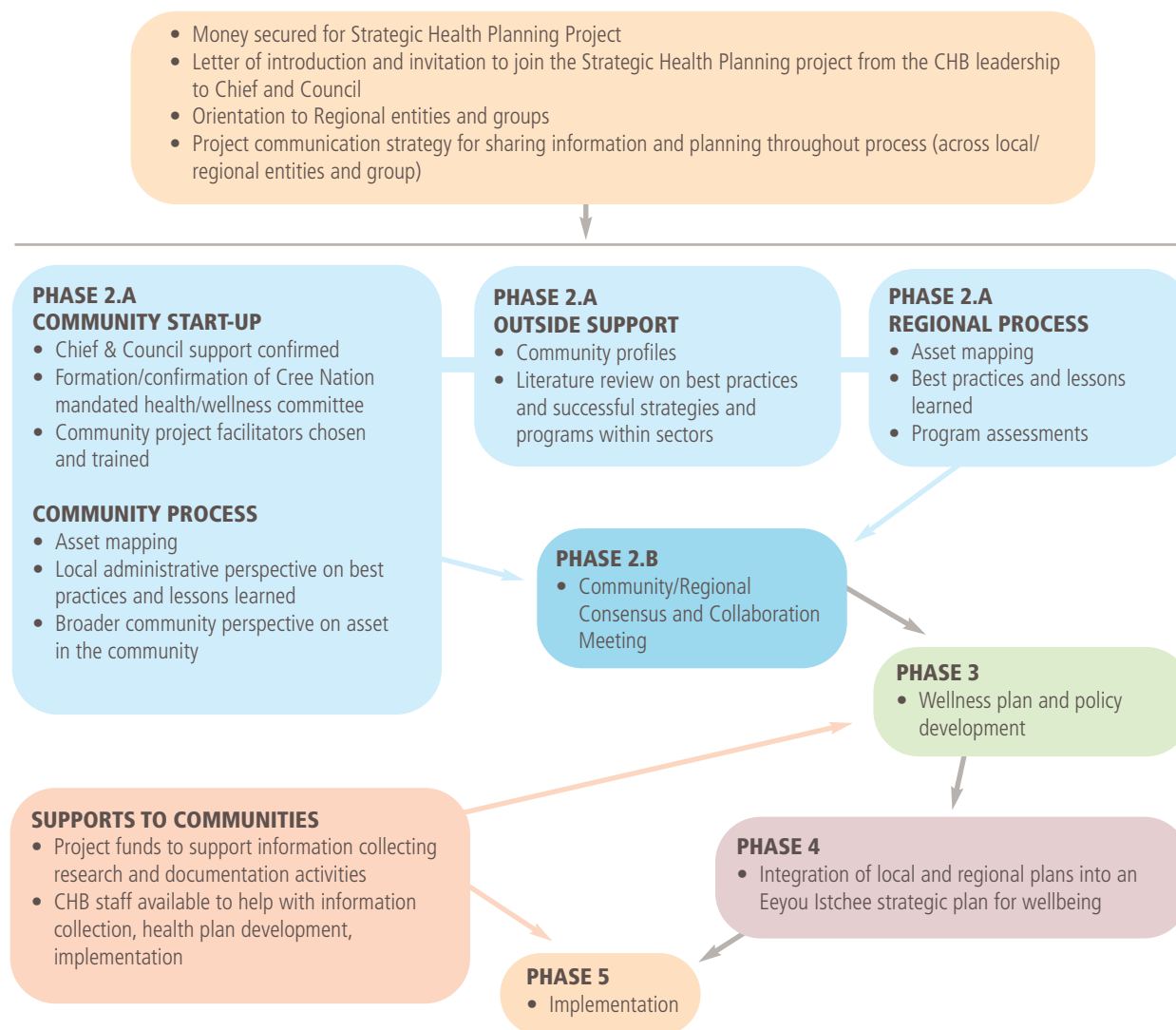
The first question that arises is whether there are enough similarities between public consultations and research to apply research ethics principles. Can we consider public consultations as research? It is difficult to really debate the question without delving deeply into the complex relationship between 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 nonexistent. 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 IYYUU 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 denominated. 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.

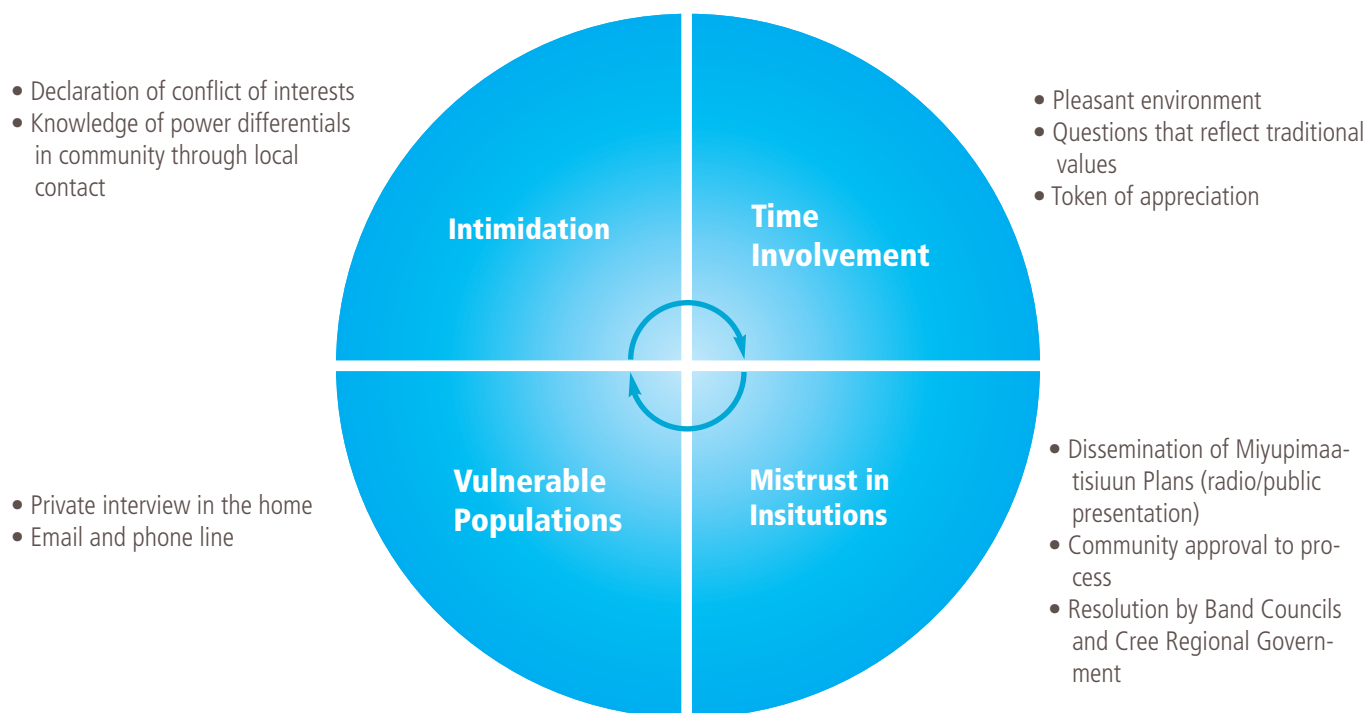
**Intimidation:** The highest risk situation is the risk of intimidation. This can translate into the perceived inability to speak openly due to power differentials related to clan membership, age, social or political standing, gender or disability. We can imagine a scenario where someone may bring up 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 (Shipley & Utz, 2012). Numerous authors advocate a better way of evaluating both the process and outcome of public consultation in healthcare. But as Shipley 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.



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# A CHECKLIST OF SKILLS, KNOWLEDGE AND CONSIDERATIONS FOR UNIVERSITY-BASED RESEARCHERS AND INDIGENOUS COMMUNITIES

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## 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?
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**Thoughts, questions, concerns:**

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## 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?
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### Thoughts, questions, concerns:

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## 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?
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Thoughts, questions, concerns:

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**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

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- ☐ \_\_\_\_\_
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**Thoughts, questions, concerns:**

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## 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
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### Thoughts, questions, concerns:

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**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

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**Thoughts, questions, concerns:**

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## 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?)
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### Thoughts, questions, concerns:

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## 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?
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### Thoughts, questions, concerns:

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## 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?
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**Thoughts, questions, concerns:**

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## 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?

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### Thoughts, questions, concerns:

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## 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?
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### Thoughts, questions, concerns:

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### 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
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#### Thoughts, questions, concerns:

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## 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

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### Thoughts, questions, concerns:

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## 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?)
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### Thoughts, questions, concerns:

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## 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?
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### Thoughts, questions, concerns:

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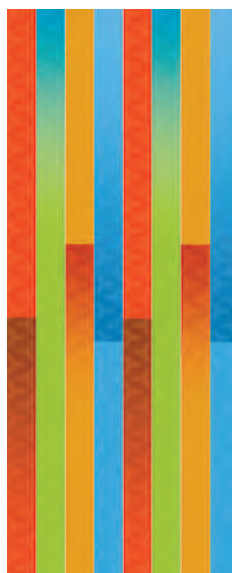
It is our hope that the above checklist of skills, knowledge and considerations for university-based researchers and Indigenous communities is used as a tool by partners engaged in collaborative community-based research. To create this checklist, we have drawn on our collective experience as university-based 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://ofic.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

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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.**

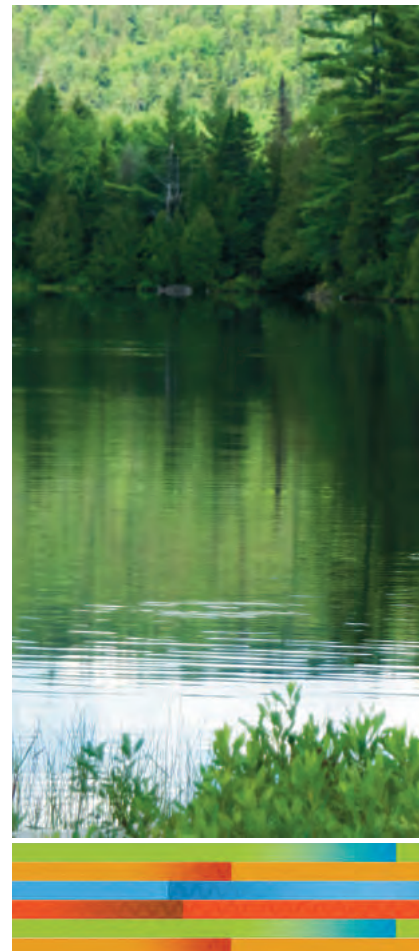
Before undertaking research with an Indigenous community—or for that matter, with anyone—it is always good to ask yourself, “Who does this benefit?” If the research does not benefit the community, but perhaps only uses them to achieve some other end, then the project should be reconsidered. Whether the 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.nptao.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/%7Ehcpo-p/hcpo>. 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."

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# KAPATAKANA/PORTAGE TRAILS

COLLABORATION: NEGOTIATING THE PASSAGE FROM INTENT TO ACTUALIZATION



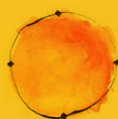
## **Mamu minu-tutamutau**

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?

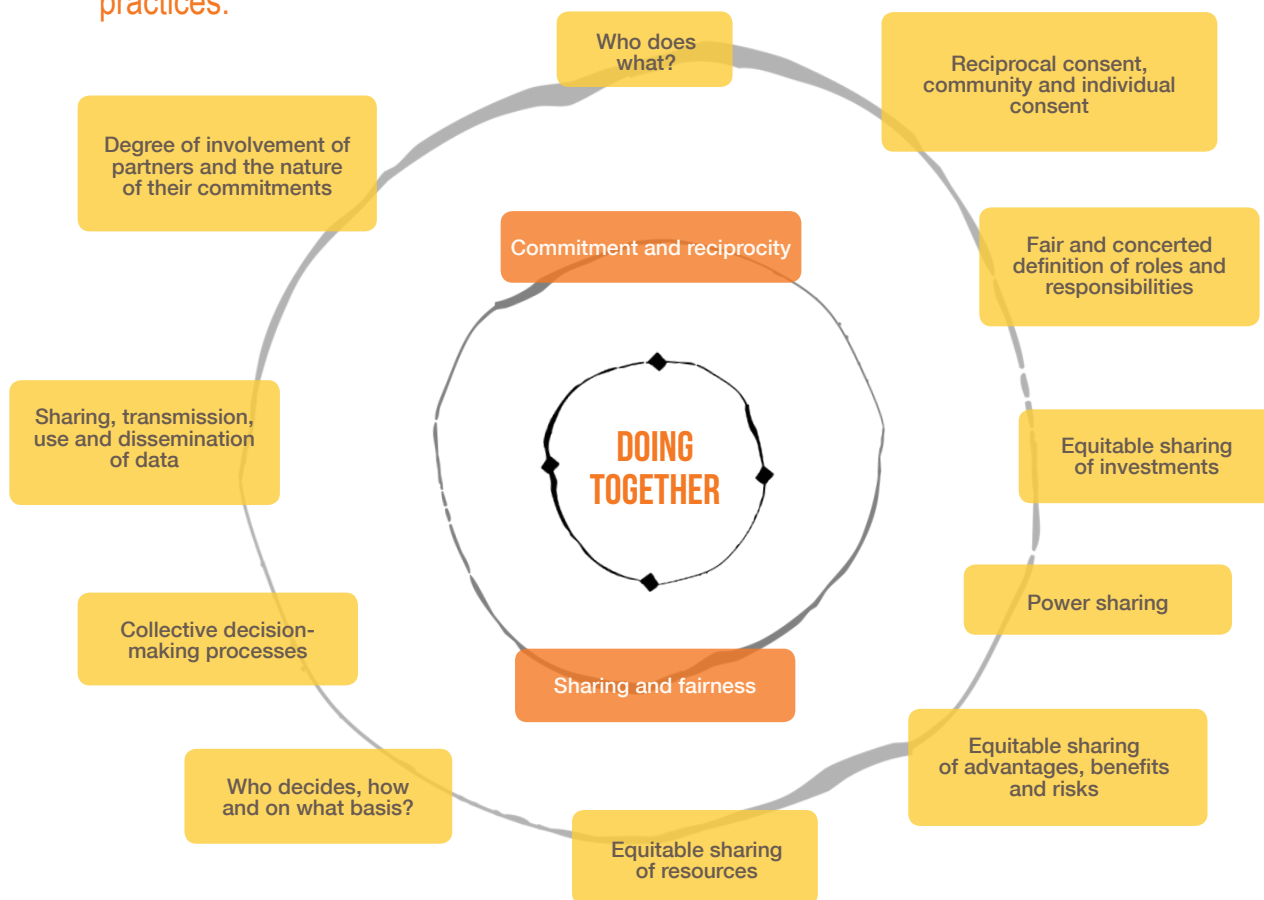
What is collaboration from the perspective of the various partners collaborating on a research project in Aboriginal communities?

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?

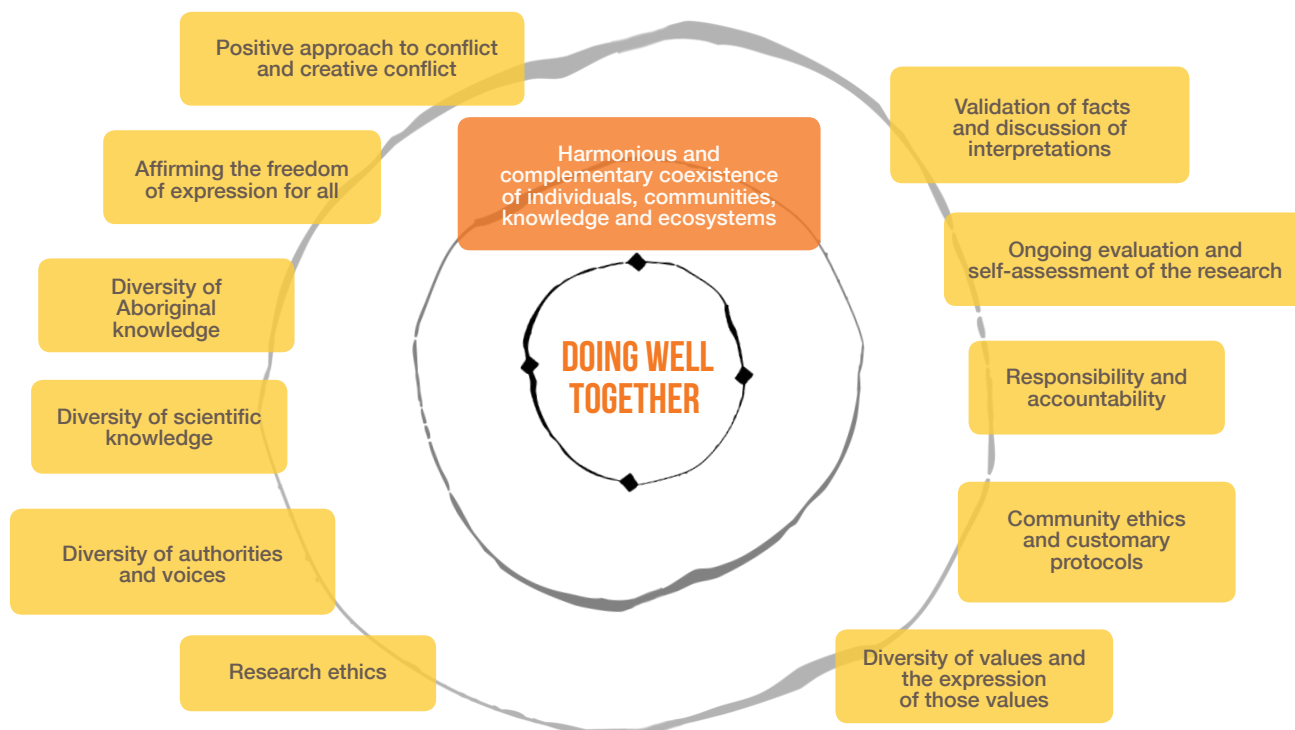
And they will Do well together according to what perspectives and criteria?

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

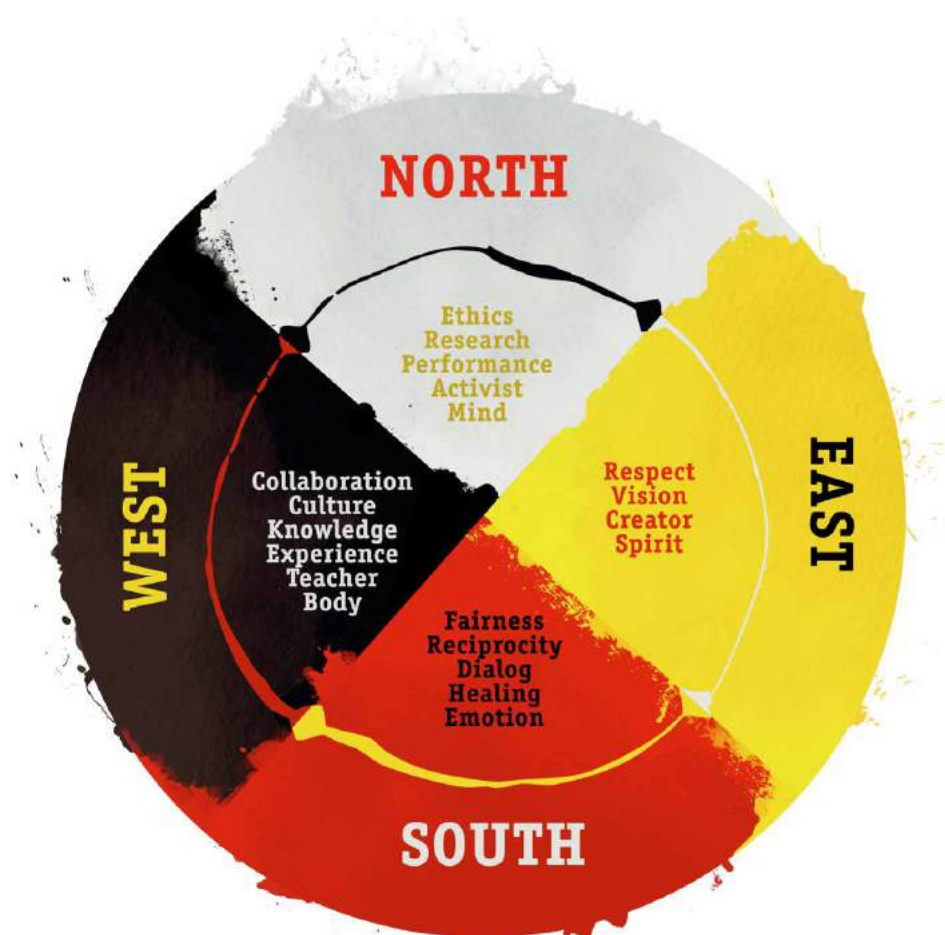
The collaboration agreement identifies:

- ◆ 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).



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**

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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/>

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Photo : Fatou Diop



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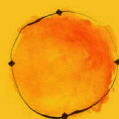
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# KAPATAKANA/PORTAGE TRAILS

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.

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# 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

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## 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, Apparicio 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](http://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](http://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 Bras-sard 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](http://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

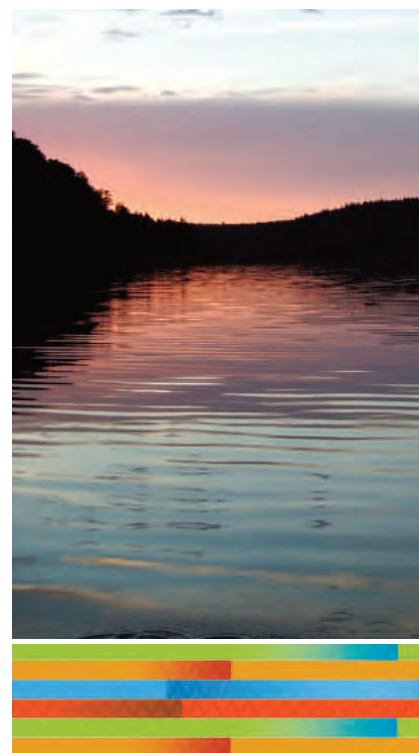
relating to the Aboriginal population in Québec cities; and, in the case of the Minowé Clinic, we took every opportunity to promote this innovative project in order to raise awareness and ultimately affect policy regarding cultural safety in regards to health and social services targeted to Aboriginal 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.



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# MIYUPIMAATISIIUN IN EEYOU ISTCHEE: INDIGENOUS HEALING AND COMMUNITY ENGAGEMENT IN HEALTH AND SOCIAL SERVICES DELIVERY<sup>1</sup>

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## 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-siun 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

## Miyupimaatisiun Committee's Role & Community Relationship

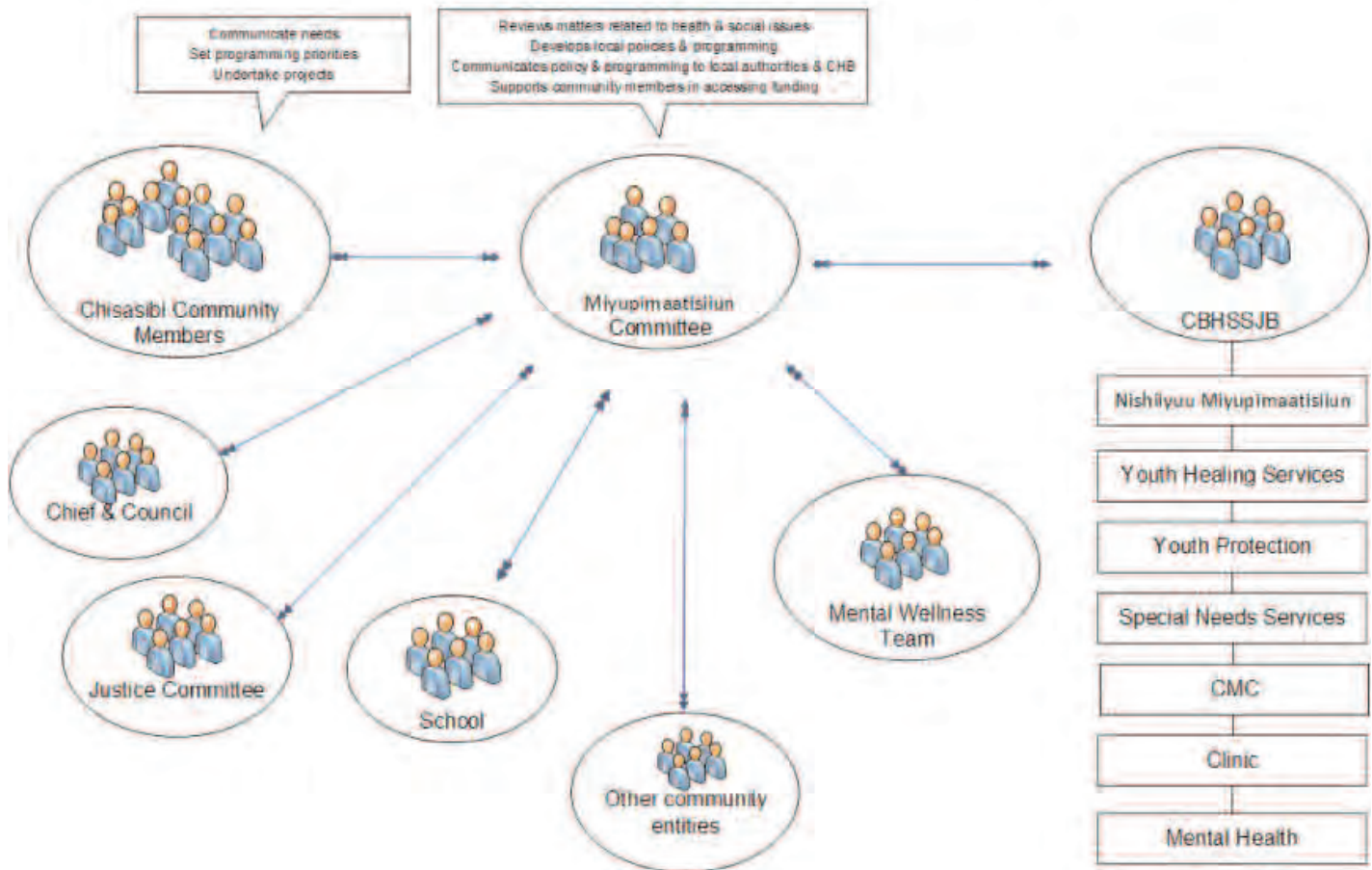


Figure 1. Chisasibi Miyupimaatisiun Committee as envisioned by Cree Nation of Chisasibi

\*CMC – Community Miyupimaatisiun 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 Miyupimaatisiun 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 Miyupimaatisiun 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 Miyupimaatisiun 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 Miyupimaatisiun 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 Nishiiyuu (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 Nishiiyuu 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 Nishiiyuu 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 care-giving 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         |





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## COMMUNITY FILMMAKING AND TERRITORIAL RESEARCH: DEVELOPING NEW RESEARCH METHODS FROM A MAPUCHE PERSPECTIVE

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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://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 *ngvlamtun* (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 of 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 Paineñil:** 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





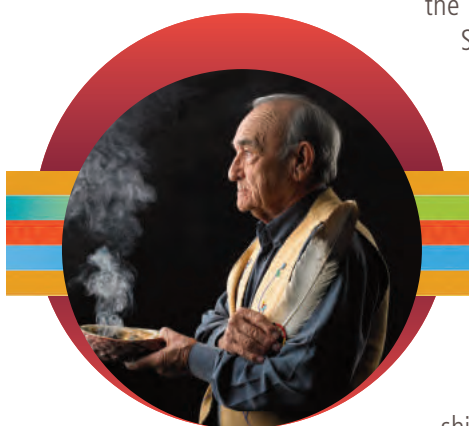
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# DOCUMENTING KNOWLEDGE ON THE TERRITORY FOR TRANSMISSION PURPOSES: MECHANISMS FOR COLLABORATION AND RESEARCH ETHICS AMONG THE PEKUAKAMIULNUATSH

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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 *Nitasinan*<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: *Nitasinan* 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 Mash-teuiatsh 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 Tetauan 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>.

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### 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

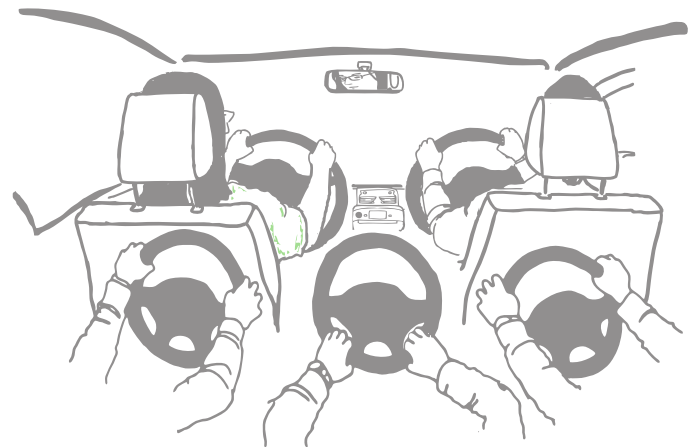
Consensus building and empowerment are closely interlinked. The first process means working collaboratively. The second one means making an individual, group, or organization self-reliant. Consensus building and empowerment are conducive to more equal relationships. Decisions are made bottom-up by members of the community, and not top-down by higher authorities.

## Consensus building: its principles and implications.

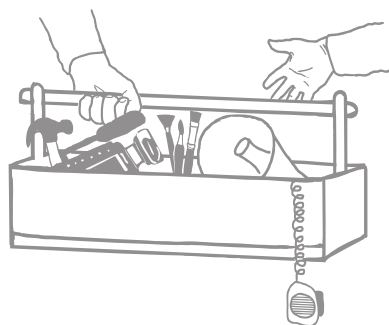
### An ongoing conversation.

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

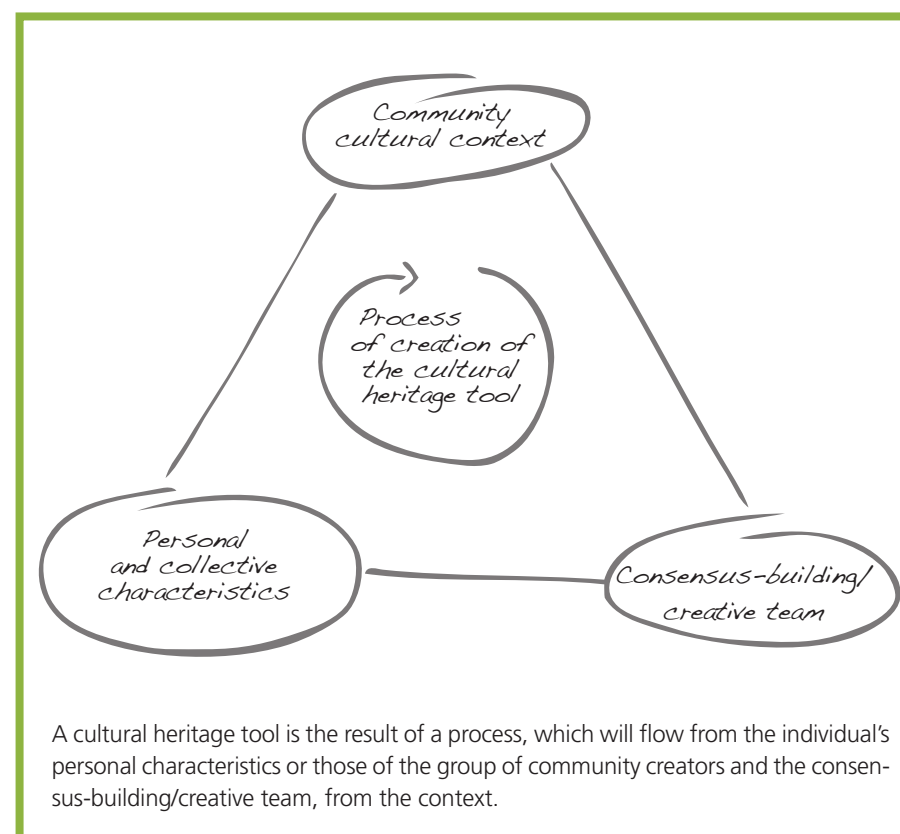
Too often, "creation" is reduced to a flash of genius or an illumination—like a lightbulb suddenly turning on above a cartoon character, without that character knowing exactly why. This capacity to find new ways to solve a problem or to generate new possible solutions is said to be exclusive to artists 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.

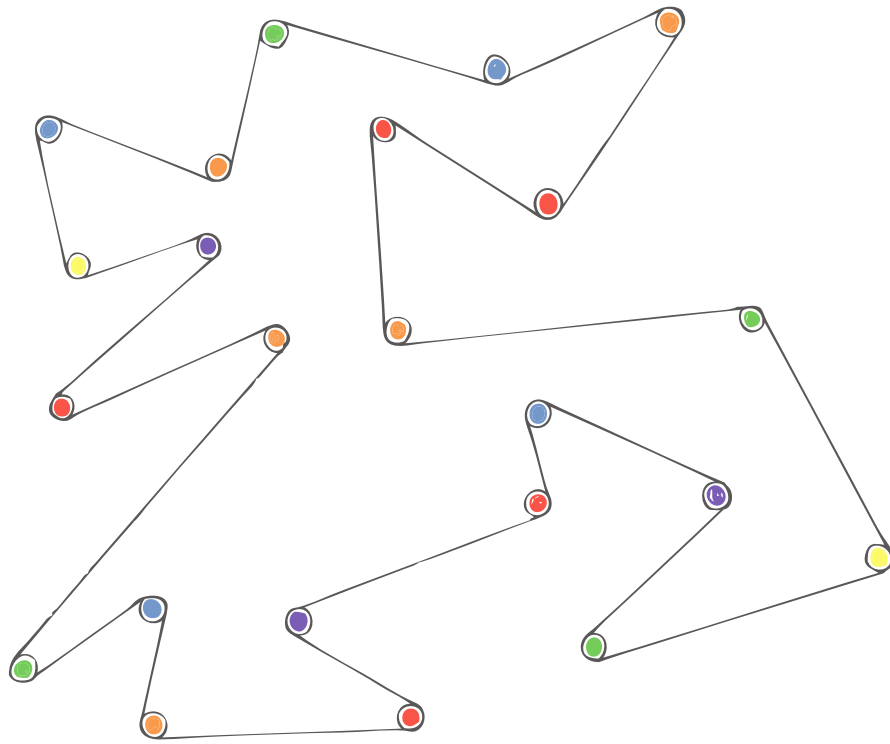
**Getting together around shared interests.** A designer takes part in the activities of Le Cercle des Fermières de Saint-Fulgence, a community with which she has collaborated for an innovative project in product design. All members of the group regularly come together around a snack to talk about their 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.**

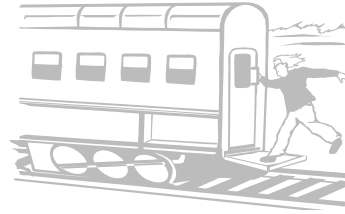
Shooting a short film with a Guarani community in Brazil requires many community resources. All of the work has to be done on site, in places that hold meaning for the community. The focus is on the village elder and cacique, since the project revolves around the goal of passing on his knowledge and 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

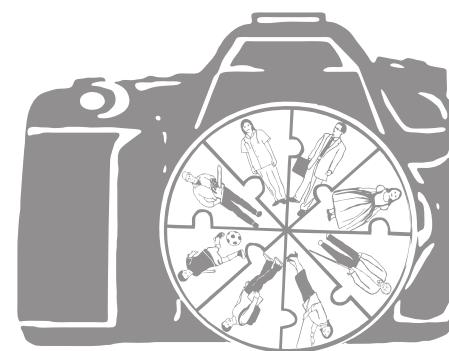
Representativeness is a necessary condition for consensus building. It enables a small group of individuals to reflect the whole community.

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)
- make sure a diversity of viewpoints is gathered (see p. 101)
- carry out activities for each generation (youth, adults, elders), and intergenerational activities
- 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.

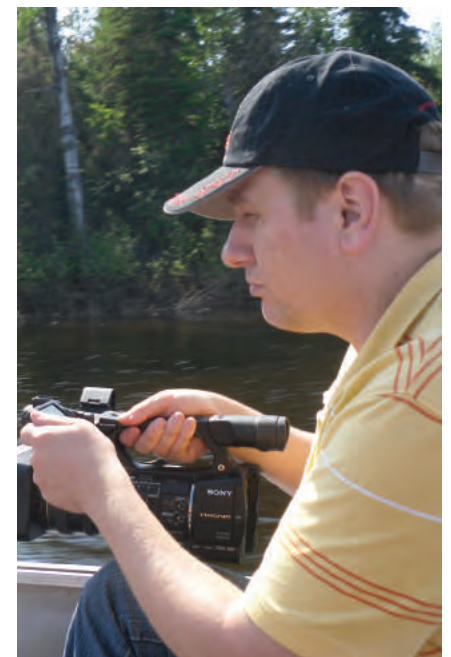
Interaction between generations is nonetheless desired. It makes possible an encounter of ideas, thus contributing to dialogue. Here, a mother and daughter tell how they took part in a program to heal the wounds caused by boarding schools, the wounds having been passed down from generation to generation.



## 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

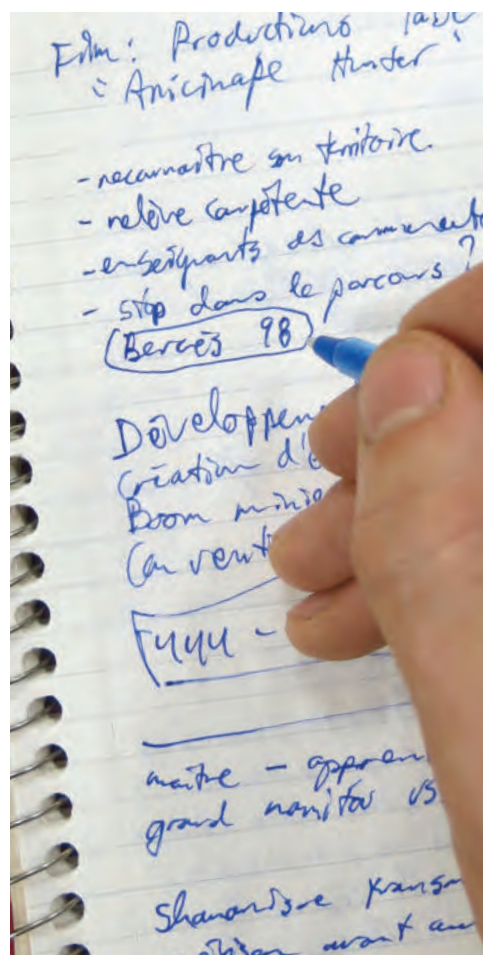
Although the consensus-building/creative team clearly has to collaborate with many people throughout the project, it doesn't have to do so continually. Sometimes, especially when you're reviewing the completed work before going to the next stage, the time for being open towards others, which is associated 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

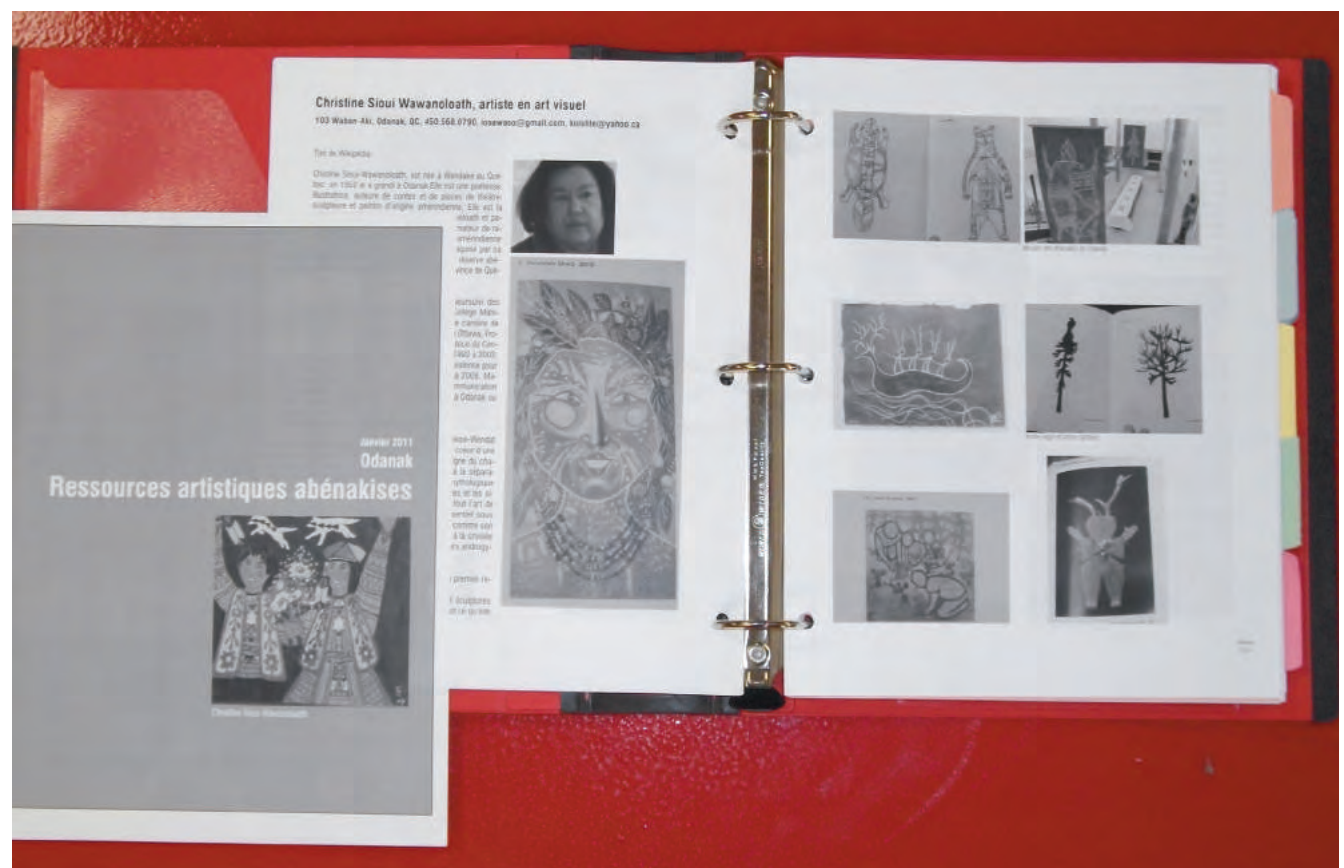
You have to keep in mind all of the community's driving forces, skills, expertise, and resources. The consensus-building/creative team should recognize these resources in order to promote and use them for the project effort. Through a succession of encounters, interviews, and activities, you should identify 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.







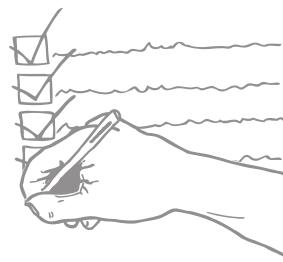


## Going back constantly to the initial project goals

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.

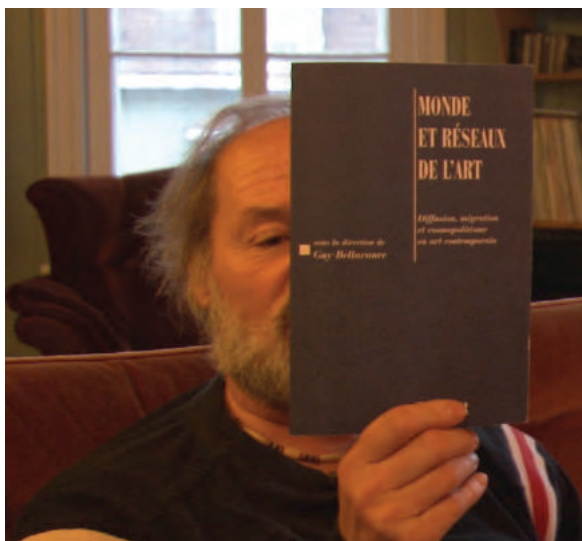
The consensus-building/creative team has a mandate to see to it that the goals are respected throughout the project, since not all of the stakeholders may be present at each stage. In some ways, the consensus-building/creative team acts as a guardian of their respective goals. As the project moves forward, 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.

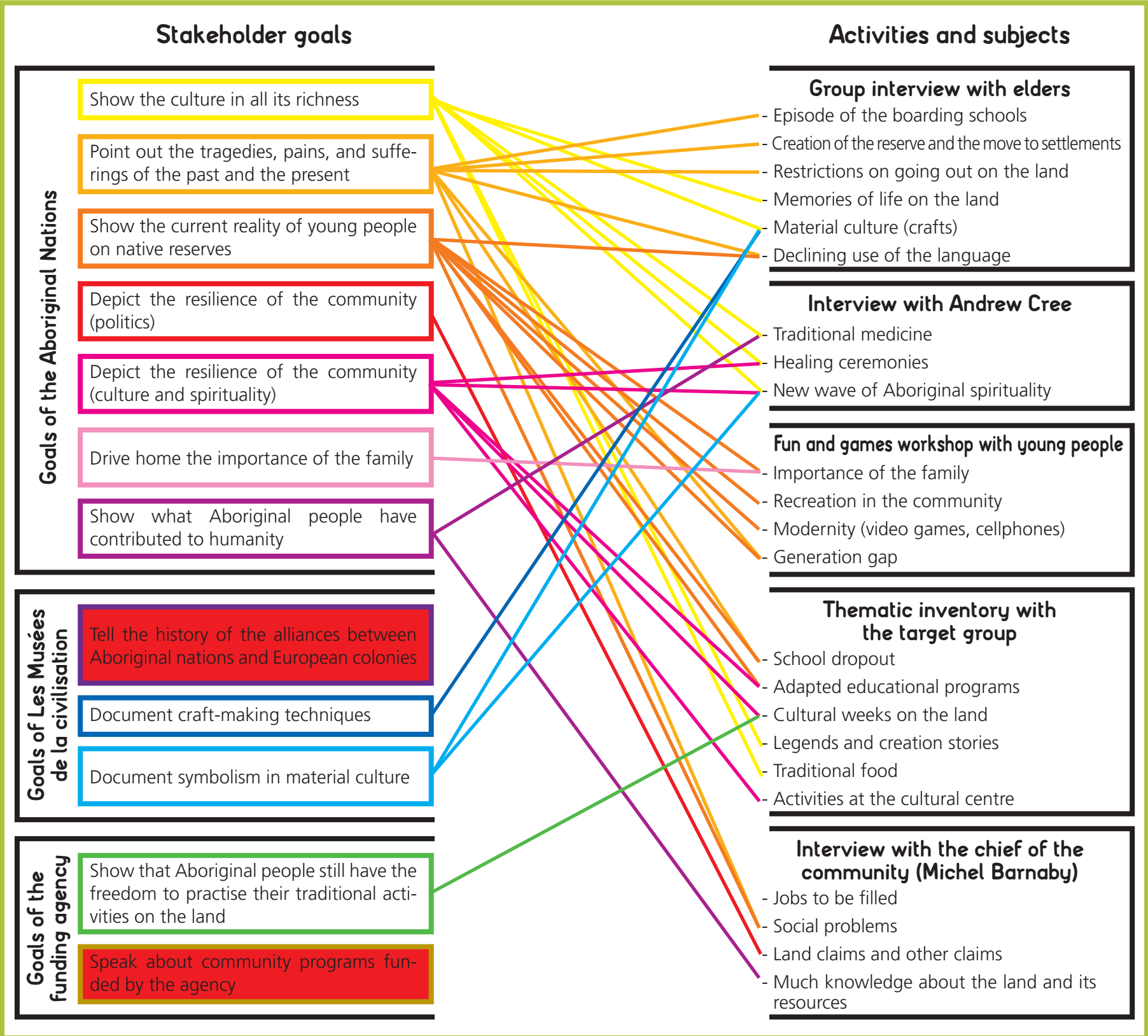
To make these verifications easier, draw up a chart listing all of the goals of each stakeholder and presenting the different themes agreed upon. If you find it difficult to achieve one goal, you may think up other ways of reaching it. If you have to seek out the voice of each generation, and if your 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).

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Back picture of the publication: detail of the exhibition *Because Urbanity is Also Anicinabe*, at Centre d'exposition de Val d'Or.

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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.

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Université   
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## 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.



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Études amérindiennes



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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*)



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# INTRODUCTION

## CO-CREATION OF KNOWLEDGE: A PROCESS OF COMING TO KNOW AND NEGOTIATION OF MEANING

**IOANA RADU**, Research Associate, Institut national de la recherche scientifique/DIALOG Network  
**SUZY BASILE**, Professor and Canada Research Chair in Indigenous Women Issues, UQAT

The 4<sup>th</sup> Seminar on research ethics with Indigenous people, which took place on November 22 and 23, 2018 at the First Peoples Pavilion, Université du Québec en Abitibi-Témiscamingue (UQAT), explored aspects of knowledge coproduction. Placing knowledge, and not necessarily research, at the heart of the conversation enables an epistemic shift that forces us to actively engage and acknowledge that the encounter with Indigenous peoples is an encounter of knowledge systems. Indigenous knowledges are not random data points or disparate information waiting to be scooped up and interpreted by researchers. Indigenous knowledge systems have their own institutions, specialized knowledge holders and knowledge stewards, modes of creation, transmission, and communication that are proper to each Nation and community. They are worldviews, in constant transformation and regeneration, reflective of lived experience, social relations, historicity and culture acquired through intergenerational listening and doing, through storytelling, song and dance, living on the land, and ceremony.

This shift reflects more than a decade of sustained conversations that the Seminar has made possible since 2009 (and remains to this date a unique initiative in the academic world in Quebec), as well as a broader evolution of academic and community engagements in doing research by and with Indigenous peoples. As Crépeau and Grégoire show in this 4<sup>th</sup> edition, UQAT's geographical and epistemological location at the confluence of Indigenous communities and nations in the region has long guided its institutional development as a hub for teaching, learning, and doing research with Indigenous peoples. Indeed, the first Seminar lay the foundation for these continued conversations by listening to the experiences of Indigenous participants and Indigenous research partners, and co-identifying principles that maximize research benefits for them (Asselin & Basile, 2012). The publication of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans in 2010, was an opportunity to explore the operationalization of research in Indigenous communities; thus the 2<sup>nd</sup> edition of the Seminar provided guidelines in strengthening Indigenous participation in academic structures. Finally, the 3<sup>rd</sup> edition, pushed participants to consider and discuss concrete ways of decolonizing research by creating lasting relationships and ethical spaces (Asselin & Basile, 2018).

Thus, the process of knowledge co-creation brings us closer to understanding how these ethical spaces and lasting relationships help research partners and participants negotiate meaning together. From the initial research team meetings that are designed to create a respectful and safe space so that relations can begin to emerge, meaning is negotiated at the confluence of knowledge systems, through the reciprocity of sharing and valuing the many ways in which experiences, knowledges, histories, and stories come together in the research process. Knowledge co-creation is a process of coming to know, a journey of personal transformation for each individual, a convergence of many types of knowledges and skills, and the creation of something new that is anchored in Indigenous spatial and temporal knowledges by having Indigenous knowledge holders guide the whole process. Indeed, knowledge co-creation is a process of embodied self-determination, as conceptualized by Linda Smith (1999). By centering self-determination, we recognize research as being an intervention in the life of others. Self-determination, as the contributors to this edition make clear, is directed at changing institutions and processes which interact with Indigenous Peoples, and not at changing Indigenous Peoples to fit or submit to external structures. And since knowledge is both socially constructed and context dependent, a conversation about knowledge is bundled with a conversation about power. Positionality therefore

becomes foundational to building respectful relationships. As this collection makes evident, whether in long term relations or those engaged with emerging collaborations, situating ourselves within the multiple social relations is conducive to building ethical spaces and relationships. It is how we come to know each other. As Julie Bull insists, "scholarship begins with the self", and that self is evident in the ways in which her Indigenous participants' experiences as members of academic Research Ethics Boards (REB) pointed to the responsibilities "to challenge colonial structures by thinking and acting outside the systemic boxes that have put us here".

Learning to acknowledge positionality is also how settler scholars learn to transform their own understanding of their role and place in the research process. Often this transformation progresses from a role of ally in which we labour to unlearn oppression, to that of an accomplice that is actively disobeying the rules of settler colonialism. Cecil Chabot, a former settler-resident of majority-Cree municipality of Moosonee and a founding board member of the Moose River Heritage and Hospitality Association, advocates for the inclusion of reciprocity as a fourth primary assessment criteria for all Tri-Council-funded research. Inspired in part by his experience of living, learning, and working in Moose Factory, as well as by the concept of *Wihitiko*, Dr. Chabot expounds on Cree ethical ideals as a labouring process of self-education, effort and constant adjustment that mediates power imbalances, and which cultivate an ethic of reciprocity. David Denton, an archeologist who has been working with the Cree Nation Government for several decades, responds, via an open letter, to some of the critiques voiced during the 4<sup>th</sup> Seminar relative to how archaeology (and by extension research in general) has long been a tool for colonization. He shows how the discipline has evolved over time to be more respectful to Indigenous heritage, not least because Indigenous peoples themselves have demanded increased protections, while also bringing attention to the limitation of state-sponsored laws. Indeed, for Mr. Denton archeology “should help promote miyupimaatisiun [wellbeing] as part of community healing and strengthening connections to the land.”

In other words, we decenter settler colonialism by making sure that research promotes Indigenous visions of being in the world in their own terms and upholds shared responsibilities for maintaining ethical spaces. It is this shift that will ultimately re-center Indigenous knowledge as a fundamental component of the research relationship; a relationship that, if guided by reciprocity and respect, enables a truly dialogical process. In this new geography of knowledge, we take turns being learners and teachers and thus shape both the content and the process of research<sup>1</sup>. Vincent Gautier-Doucet and George Lameboy, point towards this shift through the creation of the Chisasibi Eeyou Resource and Research Institute, a local institution that works closely with land users and trappers in Eeyou Istchee to further the work of the Migratory Bird Habitat Task Force. The Institute aims to both train a new generation of young Crees in fieldwork, and to monitor incoming research to ensure that land users' priorities and knowledge are upheld. For their part, Mayappo & al. reflects on the challenges of doing cross-cultural hydrogeology in ᐃᐱᐱᐁ ᐅᐱᐱᐁ ᐃᐱᐱᐁ (Cree Nation of Eastmain) and provide seven lessons they learned as they attempted to reconcile Cree and Western sciences. In their case, ᐱᐱᐱᐱᐱᐱᐱᐱᐱᐱ (Cree language) becomes a central element in creating ethical working relationships by building a common vocabulary, as well as a vehicle by which Cree science informs conservation measures of essential groundwater resources. Moreover, the project ensures intergenerational knowledge transmission through the establishment of the 15-credit undergraduate microprogram in Applied Hydrogeology at UQAT.

These examples show that self-determination and co-creation are concerned with making knowledges for wellbeing and recognizing Indigenous people as 'rights holders and not mere stakeholders', as Julie Bull insists. Whether we learn to tell community stories through data by defining the indicators and variables that are in line with local understandings, or ensure cultural continuity through intergenerational knowledge transmission, the long-term goal of doing research with and for Indigenous peoples is social restoration and transformation. These transformations are not new, communities have always strived towards liberation

1 In order to illustrate the necessary decompartmentalization of these practices, the “Bar des sciences”, a scientific program broadcast on CBC (Canadian broadcasting corporation/Radio-Canada), came to UQAT during the seminar in order to record a program on indigenous knowledge.



Indeed, as Nancy Crépeau and Pascal Grégoire show, universities have a responsibility to ensure that research projects emanating from their institutions are socially acceptable, protect Indigenous participants, and promote community priorities and perspectives. This institutional due diligence not only mitigates precarious community research infrastructures, but also adds an educational mission to university REB. In presenting the evolution of the Ethics Committee for Research Involving Humans at UQAT (CER-UQAT) and the addition of two Indigenous representatives on the committee, the authors show how universities can contribute to decolonizing research by promoting respect, wellbeing and justice in research. Notwithstanding the existing ethics protocols, the educational mission of REBs specifically points towards building capacity, and more specifically a cultural scaffolding, for the future generations of researchers, be they Indigenous or non-Indigenous. As such these institutional transformations are not only directed at undoing past and contemporary oppression, but more so in reflecting on Indigenous futurities (Hunt, 2018; Recollet, 2016; Tuck & Gaztambide-Fernández, 2013). They have helped create spaces, ideas, and the vocabulary for how we might imagine new forms of self-determination, new kinds of relationships, and new epistemologies and methodologies. They have also strived to anticipate the potential impact of emerging technologies in a globalized world. The First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) has long been engaged in establishing an online infrastructure for data management and governance, as well as bringing together communities in reflecting on what and how Indigenous knowledge could be shared with the world. In their article, Gros-Louis McHugh & al., tackle the potential pitfalls and opportunities of open data and how the move to making knowledge accessible can still respect the First Nations principles of ownership, control, access, and possession (OCAP®). Based on their experiences in developing online data management tools, such as I-Zoom and PRISME, the authors propose the establishment of a regional strategy for information governance that will provide local communities with tools for managing and governing their own informational patrimony.

Thus, on one hand, emerging local institutions like the Chisasibi Eeyou Resource and Research Institute, are increasingly bringing new generations in learning, protecting and sharing Indigenous knowledge. On the other hand, elders, knowledge holders, and community members are tackling ways in which modernity can have a role in intergenerational knowledge transmission, how to negotiate differential knowledge sharing, and going public and making Indigenous knowledge open to the world. Appropriating new technologies while keeping their application within the bounds of Indigenous values and Indigenous priorities is possible and desirable. By engaging in this process of knowledge co-creation, a process of coming to know and negotiation of meaning, new vocabularies emerge that reconnect people to land and to each other. The 4<sup>th</sup> Seminar on research ethics with Indigenous people has shown the undeniable potential of doing research with Indigenous people in a good way, by sitting in community spaces and becoming comfortable with being uncomfortable. Also, the 4<sup>th</sup> seminar was an opportunity to present the process of creation of the Research Laboratory on Indigenous Women Issues-Mikwatisiw, of which the two authors of this text are respectively collaborator and director. This research laboratory, headed by an Indigenous professor, is the first in Quebec to

date to be entirely dedicated to conducting research with Indigenous women. To paraphrase Mi'kmaq education scholar Marie Battiste, 'every research project is either a site of reproduction of settler-colonialism or a site of change and decolonization' and to become a site of decolonization we need to build, not only working relationships but true human connection.

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## 'HAVE YOU DUG UP MY GRANDFATHER YET?' ARCHAEOLOGICAL ETHICS AND COMMUNITY CONCERNS IN EYYOU ISTCHEE AND QUÉBEC

DAVID DENTON

June, 2020

### INTRODUCTION

The title of this paper stems from a question put to me recently by a respected Cree Elder. "Have you dug up my grandfather yet?" he asked. The Elder speaks fluent English, is a community leader, participates in negotiations and sits on various committees and boards, but still maintains close relations to the land, to traditional culture and to his language. I found his reference to his grandfather poignantly personal and deeply unsettling. My first reaction was to ask him to sit down at that moment so I could hear his thoughts in detail, and tell him more about the goals and methods of archaeology as practiced in Eeyou Istchee, of the role of the elders and community involvement in our projects. But the context was not right, and surely this, like all the rest of the "diggin' up bones" remarks, was a joke... right?

"What are you up to David? Still digging up bones?" I am often greeted in this manner by Cree colleagues, acquaintances and some friends. Sometimes they break into a chorus of Randy Travis's popular country hit. This is good-natured teasing of the type that Crees love to dish out, in this case playing with popular, tomb-plundering, perceptions of archaeology inspired by Raiders of the Lost Ark.

In this spirit, I summoned a cheerful outlook and informed the Elder that I may well have dug up his grandfather the preceding week! Feeling uneasy about this awkward and perhaps hurtful response, I said my goodbyes and walked away with a heavy heart. This incident was still fresh in my mind when, not long after, Suzy Basile invited me to present at UQAT's 4<sup>th</sup> Research Ethics Seminar on the subject of archaeology and research ethics.

Comments by Indigenous peoples, even those made in a friendly and joking manner, reflect an underlying uneasiness about the discipline. This was emphasized in the comments following the session on archaeology and history at the Research Ethics Seminar. Jimmy Papatie, Director of Natural Resources at Kitcisakik, spoke of archaeologists coming to the territory and leaving with artifacts, never to be seen again. "What use is archaeology if it only serves to make us more invisible?" he asked. Anishnabwe Elders are aware of important sites, including rock paintings and places where arrowheads lie, but as Jimmy Papatie asks, "Why give them [to the archaeologists] and then be treated like this?" Finally, he addressed the sensitive issues surrounding burials, particularly the perception that archaeologists violate Anishnabwe ancestors lying in the ground. He referred to the brutal moving of a cemetery when the Dozois Reservoir

was created and the long battle led by the Algonquin to repatriate ancestral remains found at Parliament Hill in Ottawa. For Mr. Papatie, archaeology is a science that supports the political interests of the state and corporations, and, for the Algonquin, serves only to disrupt the spiritual link with the ancestors<sup>1</sup>.

My presentation at the seminar, and now this paper, are my responses to the Cree Elder and to Jimmy Papatie, about archaeology, as looked at in the context of community concerns and the current reflection on ethics. The remainder of this paper, is presented in the form of a letter to these two.

**WAACHIYAA  
CHISHAAYIYIU<sup>2</sup>,  
KWEI MR. PAPATIE!**

Both of you have some serious concerns about archaeology and I would like to try to address some of these as best I can. I am writing these as an archaeologist who worked for a Cree organization (Cree Nation Government) for several decades. In my remarks, I will include some information on the administrative and legal context of archaeology, as it is practiced in Québec, as that has a bearing on research ethics and how archaeologists interact with Indigenous people and their heritage.

1 See Radio-Canada (2018) for additional comments on archaeology by M. Papatie.

2 Meaning 'old' or 'great' man, Chishaayiyiu is a term of respect for male Cree elders in the northern dialect.

## ARCHAEOLOGY HAS CHANGED (SOMEWHAT)

You should know that archaeology has already undergone some major changes relating to its relations with Indigenous people. I say “somewhat” because there is still much more change required, both of the discipline and of the administrative and legal context in which it is practiced.

### Working with communities

Many archaeologists are now working very closely with Indigenous people and this is having a profound impact on how archaeology is practiced, decolonizing the discipline in many ways. Research questions, methodologies, assumptions about the past and how we talk about it, data ownership, public outreach and many aspects of relations between archaeologists and communities, have been changing. Terms such as “community-based archaeology” or “community-oriented archaeology” and “collaborative archaeology” have been coined to reflect these approaches within the discipline<sup>3</sup>.

These changes have been gradual over several decades. They have been spurred on by Indigenous resistance movements and a strong Indigenous critique of archaeology and anthropology. At the same time, many archaeologists have been doing some serious soul-searching, but examining their ethical responsibilities to the Indigenous descendant communities, whose past they are researching.



The degree of power and authority wielded by Indigenous groups in collaborative relationships with archaeologists varies a great deal. Until recently, the power relationship between archaeologists and Indigenous people was completely unbalanced: non-Indigenous (for the most part) archaeologists have had exclusive power to control and research Indigenous archaeological heritage objects and sites, and exclusive authority to evaluate and interpret the ancient histories of Indigenous Peoples. Thankfully, this situation is changing, and the place on a continuum of power and control is shifting in favour of Indigenous people. The term “Indigenous archaeology” has been applied in cases where Indigenous people have full control of the research.

In Québec, there are increasing numbers of “collaborative” projects between First Nations and academic or independent researchers, some tending toward “Indigenous archaeology” in terms of the power of local First Nations to set the research agenda and other conditions. Some recent examples include a long-term collaboration between the Innu community of Ekuanitshit and an independent archaeologist to jointly explore local ancient Innu history. Another example,

the Tiohtià:ke project, is a recent and on-going collaboration between the Mohawks of Kahnawake and the Université de Montréal, the goal of which is to rewrite the history of Montreal using Indigenous oral tradition and archaeology. There is also a long and dynamic collaboration between the Huron-Wendat and Ontario-based archaeologists focused on protecting Huron-Wendat heritage in their Ontario homeland, including repatriation and reburial of Wendat ancestors, and more recently with researchers from Université Laval. Moreover, Indigenous organizations in Québec are establishing long-term archaeology programs and hiring archaeologists to work for them on a full-time—or project-by-project—basis. Québec Indigenous groups were at the forefront in this, with Cree and Inuit establishing archaeology programs in the 1980s that continue to this day. Now, the Waban-Aki Nation, which has hired a full-time archaeologist, has developed an active archaeology program as part of its Ndakinna Office, and carries out multi-disciplinary projects relating to land-management and “territorial assertion” (affirmation territoriale). The Huron-Wendat have also been carrying out archaeological projects in their historic territories in Québec. A non-profit organisation known as Archéo-Mamu has been cre-

3 For a few recent discussions, see Chalifoux and Gates St-Pierre (2017), Wylie (2019), Gates St-Pierre (2019), Lyons and Blair (2018) and Cook (2020), Mrozowski and Rae Gould (2019).



ated by Innu and non-Indigenous community representatives from Québec's North Shore to carry out archaeological projects. Finally, a very recent project involves a collaboration between Corporation Archéo-08 and the Anishnabe Nation of Lac Simon<sup>4</sup>.

There has been a spirited criticism of community-based and collaborative archaeology by a small number of non-Indigenous archaeologists. It has been suggested that this approach, on the part of archaeologists, is self-serving, masking and allowing archaeologists to avoid confronting the real problems related to modern capitalism and Indigenous rights, including the destruction of Indigenous heritage. This mirrors your own critique, Mr. Papatie, about archaeology being a science that supports the political interests of the state and corporations. However, this critique ignores the fact that many Indigenous groups use archaeology strategically to further the goals of their communities and nations. It also ignores the real, activist engagement of many archaeologists in support of Indigenous struggles. Many of the archaeologists who work in this context are also animated by concerns of social justice, reconciliation and "social and cultural humility," that is, a recognition that they have as much to learn as to teach, and that archaeological interpretations can be greatly enriched through oral tradition and by being anchored in an Indigenous cultural context<sup>5</sup>.

An on-going criticism of archaeology by Indigenous people is that it presents an external view of the Indigenous past that is completely based on a western, scientific perspective, and ignores Indigenous perspectives. This is a valid criticism, but the situation is changing: Traditional Ecological Knowledge (TEK), oral histories, mythologies (or sacred stories) and local Indigenous toponymy—all reflect Indigenous ways of seeing the environment and understanding the world and are increasingly a part of an archaeological research agenda, one that is largely set by Indigenous communities and governing bodies. There are ongoing discussions about how traditional knowledge is used in archaeology, including whether it is possible or desirable to create a single historical narrative integrating and reconciling oral tradition and archaeological findings, whether these should be seen as a "conversation" or "dialogue," or whether the two can be "braided" together in completely original ways. In general, the more serious consideration of traditional knowledge has opened up new realms of interpretation, and enriched the discipline in many ways<sup>6</sup>.

A few academics argue that within archaeology as a discipline, woven into its fabric, is a Western ontology, or way of seeing the world, that cannot be adapted, adjusted or Indigenous. The only ethical stance in carrying out an archaeology of "the other" (read Indigenous people)—the only way to decolonize it—is to "undiscipline" it, to completely dismantle the discipline's

ways of knowing, its language and its methods, and to rebuild it from the ground up, in partnership with Indigenous thinkers<sup>7</sup>. While there is certainly some truth to this view, and it is one that some Indigenous thinkers might agree with, I am not convinced that this needs to be an all or nothing exercise. In fact, there may be some elements of the discipline that Indigenous groups would choose to retain.

Clearly, the way archaeologists talk about the history of Indigenous People needs to be reviewed in collaboration with Indigenous partners. From terms like "prehistoric" and "historic"—referring to pre- and post-European contact periods—to others like "Woodland," "Archaic," and "PaleoIndian," many of these terms are simply off-putting to Indigenous peoples. They have the effect cutting them off from their heritage, dispossessing and alienating them from their ancient past<sup>8</sup>. In some collaborative projects, the term "artifact" is avoided in favour of terms like "belongings," which emphasizes the link between the community or group and the cultural materials. Some groups are proposing new terms and frameworks for their ancient history. For example, in an on-the-land educational program with an archaeological component, carried out by the Tshikapisk Foundation and involving Innu and university researchers working in northern Labrador, the term "Tshiash Innu" (Innu from very long ago) was proposed for the oldest archaeological period, usually referred to by archaeologists as the "Maritime Archaic"<sup>9</sup>.

4 For some recent collaborations in Québec, see Ouellet (2018), Gates St-Pierre (2019), Warrick (2018), Treyvaud, O'Bomsawin, and Bernard (2018), Desrosiers and Rahm (2015), Richard, Lesage, and Plourde (2018).

5 See Wylie (2019) for discussion.

6 See Atalay (2019).

7 For example, see Haber (2015).

8 On the other hand, as pointed out by an anonymous reviewer, some Indigenous people are quite comfortable with terms such as "prehistoric" and "historic," recognizing that "prehistory" does not mean "without history."

9 See Arbour et al. (2018).

The gradual Indigenizing of archaeology is coming about not just through partnerships and collaboration, but through the participation of increasing numbers of Indigenous archaeologists, many researching the history of their own tribal group or nation from a completely different perspective, and focusing on problems that outside archaeologists ignored<sup>10</sup>. Although there are no practicing Indigenous archaeologists in Québec, one of the first anywhere was an Inuk from Nunavik, the late Daniel Weetaluktuk<sup>11</sup>, whose legacy is one of intellectual curiosity about his heritage and a critique of how archaeology was carried out at the time on Inuit lands. Although not an archaeologist, the Huron-Wendat historian, Georges Sioui, contributed a local Indigenous perspective on Wendat history, and another Huron-Wendat, Louis Lesage, is an active contributor to archaeological debates concerning Wendat history, as is Christine Zachary-Diom, an anthropologist and former Chief from Kahnawake, with respect to the Mohawk. There are several practicing Indigenous archaeologists elsewhere in Canada, including some occupying academic positions and others working for Indigenous organizations or working in contract archaeology.

### Contract archaeology

It is important to understand that most archaeology in Québec is carried out by consulting archaeologists or firms under contract to either a developer, a state corporation or agency such as Hydro-Québec or SÉPAQ, a government department such as Transport Québec,

or a municipal government or regional county municipality (municipalité régionale de comté, or MRC). Contract archaeology, sometimes referred to as Cultural Resource Management (CRM)<sup>12</sup>, is often part of government land-planning exercises, or is initiated by the impact assessment process under the Environmental Quality Act. Most contract archaeology in Québec is funded, directly or indirectly, by the state, and it is the way a large proportion of archaeologists in Québec makes their living.

The contract archaeology “industry” has also been criticized by several commentators, arguing it essentially serves the interests of neoliberal capitalism at the expense of other social values. According to this view, the primary function of this kind of archaeology is to “clear the landscape” of Indigenous heritage sites in order to permit the extraction of resources and development. In this view, archaeologists are complicit and profit from the destruction of Indigenous heritage. The laws that govern archaeology create a structure in which professionals (usually non-Indigenous) manage and research Indigenous heritage, a context that further alienates Indigenous peoples from their past and from their heritage, exacerbating the cultural dislocation caused by decades of colonialism. Again, this sounds very much like your critique of archaeology, Mr. Papatie<sup>13</sup>.

I would argue that the broader problem is not archaeology but development in a neocolonial context, where Indigenous

peoples have little say and often few benefits from the exploitation of their lands and resources. While there are certainly more constraints in contract archaeology, partnerships and strategic alignments between consulting archaeologists and Indigenous communities are still possible in this context. Such partnerships have been created in several parts of Canada. Indigenous communities have also developed a variety of tactics to Indigenize contract archaeology, to broaden the scope of work carried out in favour of community interests, and, in general, to maximize benefits stemming from the legal and regulatory obligations of developers or government agencies. Some Indigenous groups hire archaeologists to carry out projects required by laws and regulations relating to the environment and land use planning, and others have established research programs funded through contract work<sup>14</sup>.

Chishaayiyiu, in Eeyou Istchee, contract archaeology resulted in the archaeological recording of thousands of sites between the 1970s and the 1990s in the context of hydroelectric development of the *Complexe La Grande*. Some of these were excavated, and the artifacts removed to the *Laboratoire et réserve d'archéologie* in the City of Québec. The sites now lie under the reservoirs that dot parts of Eeyou Istchee. In the 2000s, based on a critique of salvage archaeology programs associated with earlier hydroelectric development, Crees negotiated and carried out a broad, community-based, heritage program in the areas affected

<sup>10</sup> See, for example, Nicholas (2010).

<sup>11</sup> Sadly, Daniel Weetaluktuk died away in a tragic accident in 1982.

<sup>12</sup> Other common terms are Archaeological Resource Management (ARM), Heritage Resource Management (HRM) or, in French, *archéologie préventive* (preventive archaeology).

<sup>13</sup> See, for example, Hutchings and La Salle (2017), Hutchings (2015), Warrick (2018).

<sup>14</sup> See for example, Connaughton, Leon, and Herbert (2014), Martindale et al. (2016), Ferris and Welch (2015), Klassen (2013).

by development on the Eastmain and Rupert Rivers<sup>15</sup>. Youth, land-users and elders participated in on-the-land research and commemorative activities, creating an archive of the stories and knowledge, passing that knowledge on through educational activities and remembering those buried in the flooded areas. Although there were definite problems reconciling large-scale mitigation work (excavations) with other objectives, the program as a whole shows it is possible to do archaeology that is culturally relevant and benefits the communities in the context of a large development project<sup>16</sup>.

The archaeology unit of the Cree Nation Government carried out collaborative projects with the Cree communities for many years, often supporting their efforts to protect, explore and promote local heritage. This includes projects oriented towards protecting or mitigating the effects of—local Cree—development on Category 1-A lands<sup>17</sup>.

### Burials

You are both very concerned about burials. Nowadays, it is difficult to understand why anthropologists and archaeologists in the 19<sup>th</sup>—and much of the 20<sup>th</sup>—centuries felt they had the right to excavate and remove thousands of “Indian” skeletons from their resting places to museums. Since the late 1980s, American Indian activism focused on the protection of burial sites and the repatriation of skeletal remains and burial belongings, and this ultimately led to the 1990 adoption of the Native American Graves Protection

and Repatriation Act (NAGPRA) in the United States<sup>18</sup>. In Canada, the protest surrounding *The Spirit Sings* exhibition in 1988 led to the creation of a joint task force created by the Assembly of First Nations and the Canadian Museum Association that examined a wide range of issues, including involvement of Indigenous people in the interpretation of their culture and history, access to museum collections and repatriation of artifacts and human remains. The result was not a law, as in the United States, but a series of recommendations whose ongoing implementation has improved many aspects of the relations between Indigenous People and museums in Canada. The same event also led the Canadian Archaeological Association to examine its ethics with respect to Indigenous People, which I will discuss further below. The broader political context in Canada with respect to Indigenous burials includes some dramatic events, including the “Oka Crisis” in 1990 and the “Ipperwash Crisis” in 1995, both illustrating Indigenous resistance, at least partly centred on the issue of protecting burial sites.

In Eeyou Istchee, there have been no archaeological excavation of burials, except in a few instances when requested by local Eeyou / Eenou communities or organizations. Yet, in the 1990s, fear that burials would be disturbed by archaeologists—perhaps inadvertently—was a major concern expressed by Cree Elders at a workshop held in Chisasibi in 1995<sup>19</sup>.

Given the intense politics and ongoing sensitivity surrounding this issue, it is highly unlikely that the excavation of an Indigenous burial would be approved by authorities at the Ministère de la Culture et des Communications du Québec (MCCQ) without the authorization of the local community. In fact, archaeological excavations have been shut down by MCCQ in instances where Indigenous burials were unexpectedly encountered. The repatriation of remains may be a slow and difficult process, as you indicate, Mr. Papatie, but there is a recent positive development in Montreal, where human remains from archaeological excavations in the possession of the Ville de Montréal will be transferred to the Kanewake Mohawks for reburial. Likewise, those in possession of the Université de Montréal are in the process of being returned to the First Nations concerned.

On the other hand, Québec’s lack of a legislative framework to recognize burials outside of consecrated cemeteries is worrisome. It means that many, or most, Indigenous burials have no legal protection. Some Indigenous burials are listed on the official Québec register of archaeological sites (*Inventaire des sites archéologique du Québec*, or ISAQ), in cases where they have been reported by an archaeologist. While, in the short-term, this may actually confer a degree of protection from disturbance from development, you, and other Indigenous people, might well be concerned to know that official government registers identify your ancestors’ graves as archaeological sites.

15 The Archaeology and Cultural Heritage program was funded through the Nadoshtin and Boumhounan Agreements as part of the 2002 Paix des Braves (Agreement concerning a New Relationship between the gouvernement du Québec and the Crees of Québec).

16 See Denton and Izaguirre (2018).

17 Responsibility for the Cree archaeology program has recently been transferred from the Cree Nation Government to Aanishchaaukamikw Cree Cultural Institute.

18 See Mihesuah (2000); Echo-Hawk and Echo-Hawk (1994), Hill and Nicks (1992).

19 See Cree Regional Authority (1995).

By way of comparison, in Ontario, while there are important shortcomings to the legislation, clear measures are provided for Indigenous involvement in the disposition of their ancestors' remains. Here the removal and study of the remains without consent is forbidden.

I am not sure if any of this reassures either of you. The situation has changed a great deal since the days when archaeologists freely excavated Indigenous burials without consultation or consent. On the other hand, the Québec legal and regulatory context for dealing with First Nations and Inuit burials outside of consecrated cemeteries does not instil much confidence, and should be reviewed and revised in consultation with Indigenous communities and organizations.

## CONTEXT OF "RESEARCH ETHICS" FOR ARCHAEOLOGISTS

Archaeology takes place in a broader context that deals with various aspects of how the professional is practiced, and sets rules and constraints. The codes of ethics of our professional organizations are a part of this context, but even more important is the government management of the discipline. What follows is not to reassure you about the "ethics" of archaeological practice in relation to Indigenous people but to set it in a broader context. In fact, you may find parts of this process inadequate and in need of change.

### Professional organizations

There are two principal professional organizations for archaeologists in Québec: the *Association des archéologues du Québec* (Association of Québec Archaeologists) and the Canadian Archaeological Association. The CAA officially adopted its *Statement of Principles for Ethical Conduct Pertaining to Aboriginal Peoples* in 1996, following extensive consultations with Indigenous people throughout Canada. The AAQ's code of ethics is called *Code d'éthique et des normes professionnelles*. The AAQ collaborated with the CAA in the consultations with Indigenous people. In Québec, most practicing archaeologists belong to the AAQ, though membership is not obligatory, and some belong to the CAA<sup>20</sup>.

The concerns of Indigenous people expressed at the consultation meetings in the 1990s were essentially the same ones that continue to be expressed by Mr. Papatie and others: fears that burial sites, or other sacred areas, might be disrupted and concerns of researchers arriving on their lands, removing their cultural heritage without consultation, and returning nothing to the community. As today, these issues were bound up with broader struggles for Indigenous lands and title and for self-government, and the struggle to maintain authority in the presentation of Indigenous culture and history. For their part, archaeologists sought to correct stereotypes relating of archaeologists as "bone diggers" and to present accurate information of what they actually do. Consulting archaeologists

expressed frustration at being held ethically responsible when it is their clients and government that set the ground rules for their work.

The AAQ statement of ethics is embedded in a code that presents the professional norms an archaeologist must follow, and sets out the archaeologist's "responsibilities toward [his or her] own community and to the communities in the territory where [he or she] works." It states that the archaeologist "must be attentive to, and respect, the legitimate concerns of the groups whose culture history is being researched," and must "present archaeology, and the results of [his or her] research to the community" (my translation). It is not clear who defines what concerns are "legitimate" nor how it is determined how the modern community concerned would be identified, and, of course, it makes no explicit mention of First Nations or Inuit peoples. However, the AAQ code of ethics is presently being revised to address these issues in more detail and directly.

The CAA's *Statement of Principles* recognizes the "role" and "fundamental interest" of Aboriginal Peoples with respect to the "archaeological record" and to "their heritage," and pledges that members will "negotiate protocols" relating to archaeological activities. It encourages partnerships "based on respect and mutual sharing of knowledge and expertise," and supports training and "recruitment" of Aboriginal people as archaeologists. It recognizes the "spiritual bond" with

20 See Association des Archéologues du Québec (n.d.), Canadian Archaeological Association (n.d.), Denton and Duguay (1993).



particular places and sites, acknowledges the “cultural significance of human remains and associated objects to Aboriginal people” and undertakes to “respect protocols” relating to “human remains and associated objects.” Finally, the statement pledges members to “respect the cultural significance of oral history and traditional knowledge” in archaeological interpretation, and to “communicate results of investigations to Aboriginal communities in a timely and accessible manner.” The clearest part of this statement relates to negotiating and respecting protocols, though what is not clear is how negotiations would be triggered.

It is not clear the extent to which either statement has significance—beyond a show of good intentions—for how archaeology is actually carried out, and for the power of Indigenous groups to negotiate and control research on their heritage. If a complaint were made by an Indigenous group to one of these organizations concerning the activities of a member, the organization could be forced to study the issue, and, in theory, it could lead to the expulsion of the member.

There is a further context of professional ethics that should be mentioned, although it is not stated in either of the ethical statements cited above. It is a

position that would certainly be rejected in by many Indigenous people, who have seen their history objectified, their connections with their past and traditions threatened by intergenerational trauma, the social and cultural fabric of their communities weakened, and who in no way feel that the state represents them. However, I want to mention it because, for many archaeologists, it may be stronger than ethics, more like a belief, or a set of beliefs or values. It is the principal upon which heritage legislation is predicated. In this view, archaeological remains are seen as an important part of mankind’s—or viewed more locally—Québec’s heritage, and represent a non-renewable resource, which, once destroyed, is gone forever. Material remains from the past—often called “the archaeological record,” by archaeologists—are part of the common good; they testify to the history of cultures and peoples, and need, as much as possible, to be preserved. It is the responsibility of the state—the province of Québec, in this case—to preserve this resource and to dictate that only trained and licenced professionals should be permitted to remove sites by excavation. Further, the state has a responsibility to preserve artifacts and the full record of archaeological interventions, and to provide access to researchers and others seek-

ing to study it, or for use in exhibitions or publications. Disturbance of sites or the removal of artifacts by an individual (for example, a collector), solely for personal gain or pleasure, removes these materials from the common good. In this context, ownership of artifacts by the state is generally considered a good thing by many, or most, archaeologists. However, contrary to Ontario, where the provincial government is the legal owner of each and every archaeological collection found in the province, whether on public or private land, in Quebec the provincial government is the legal owner of the collections found on provincial public lands only.

Some anthropological and archaeological organizations (American Anthropological Association and the World Archaeological Congress) have been much clearer in their codes of ethics that the primary ethical focus of their members should be towards the Indigenous people whose heritage is concerned. However, in general, when archaeologists are asked to consider their ethics in relation to specific social or cultural communities, there may well be a collision between these and the broader valorization of heritage as a common good, referred to above. In cases where there is a collision, archaeologists may have to choose between the two.



## Ethical review boards

The Social Sciences and Humanities Research Council (SSHRC) and Fonds de recherche du Québec – Société et culture (FRQSC) requires formal ethical reviews for research involving “human participants.” Unfortunately, archaeological research is generally exempt because it is considered not to involve human participants.

Chapter 9 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS-2), which sets requirements for “community engagement” applies to research conducted on “lands governed by a self-government agreement or an Inuit or First Nations claim agreement” but not to unceded Indigenous lands<sup>21</sup>. Thus, research in Eeyou Istchee and Nunavik, or on reserve lands would be covered by the ethical review board process, but not research on unceded Algonquin lands, for example. Chapter 9 would also require community engagement where input is sought from “participants regarding a community’s cultural heritage, artefacts, traditional knowledge or unique characteristics” and for “interpretation of research results that will refer to Aboriginal communities, peoples, language, history or culture.” The latter criterion is so broad that most archaeological research on Indigenous archaeological sites could be included. But since, in practice, student and professor archaeological projects are not subject to ethical review triggered by SSHRC rules, I am left wondering whether this criterion is ever applied.

It has been argued that all archaeology projects relating to First Nations and Inuit heritage should systematically be included in ethical reviews for research involving human “subjects” or “participants.”

## Government

In Québec, it is the Ministère de la Culture et des Communications that has the role of managing archaeological research through the Cultural Heritage Act and associated regulations. The government establishes the professional standards for archaeological activities through a permitting system. The Cultural Heritage Act requires that any person carrying out excavations or surveys to find archaeological property or sites obtain an archaeological research permit from the Minister. As mentioned above, heritage legislation and accompanying regulation of archaeology by the state is predicated on the notion of heritage as a common good.

While the archaeological permit application requires written consent of the property owner on which the archaeological intervention is to take place, the process does not require archaeologists to consult with nearby communities on unceded traditional lands nor on Category II or III lands defined by the James Bay and Northern Québec Agreement<sup>22</sup>.

In general terms, there are no obligations for individual archaeologists to consult with First Nations or Inuit communities or governments concerning projects to take place on traditional unceded lands, or, in the case of treaty lands defined by the James Bay and

Northern Québec Agreement, on Category 2 and 3 lands. Instead, the Ministère de la Culture et des Communications undertakes consultations with First Nations and Inuit communities, at its discretion, as part of the archaeological permitting procedures, following an interministerial policy established in 2008. Obligations to consult stem from several Supreme Court decisions. Although information concerning these consultations is not normally released, we know, for example, that in 2016, 40 “information letters” were delivered to Indigenous communities out of a total of 184 permits delivered<sup>23</sup>.

Some Indigenous commentators have contrasted this situation with Ontario’s guidelines requiring archaeologists to consult with Indigenous communities at different stages of archaeological fieldwork. While the Ontario process is still limited in its application it is an important step in engaging Indigenous communities in decisions that affect the fate of their heritage<sup>24</sup>.

In British Columbia, Yukon, the Northwest Territories and Labrador a series of contemporary treaties with Indigenous groups have shifted authority for heritage and archaeological management to Indigenous groups, creating a patchwork of heritage regimes<sup>25</sup>. Although mostly unimplemented so far, they potentially allow the creation of Indigenous regulatory bodies with powers similar to provincial government ministries with respect to managing archaeology. While such issues were not contemplated when the James Bay and Northern

21 TCPS2 (2018), p. 114.

22 As a rule, the Québec permitting process is not applied on Federal reserve lands or Category 1-A lands defined by the James Bay and Northern Québec Agreement.

23 Gouvernement du Québec (2008), Desrosiers (2017).

24 See Richard, Lesage, and Plourde (2018).

25 See Dent (2017).

Québec Agreement was negotiated, recent agreements between the Cree and the Federal government recognize Cree powers with respect to archaeology and heritage on Category 1-A lands<sup>26</sup>, and within the Eeyou Marine Region<sup>27</sup>.

A very contentious issue with Indigenous people in Québec is the ownership of artifacts. Québec asserts ownership of all artifacts and archaeological sites on Crown lands based on its bare ownership of these lands. However, on most privately owned land, the property owner would be considered the owner of these cultural materials. One of the most frequently asked questions to archaeologists by Indigenous people is what happens to the artifacts? Materials found on Crown lands are normally housed at the government *Laboratoire et réserve d'archéologie* in Quebec City.

Many Indigenous people feel strong resentment that artifacts found on their traditional lands are considered the property of the state. Indigenous groups seeking greater access and control of artifacts on Crown lands, could negotiate an agreement with the government of Québec. In this respect, Article 78 of the Cultural Heritage Act holds out a possible option, as the Minister may enter into agreements with "a Native community represented by its band council, in order to develop knowledge of cultural heritage and protect, transmit or enhance that heritage."

However, I have to admit, Chishaayiyiu and Mr. Papatie, that the legal framework in Québec relating to artifacts raises questions in my mind. While you and your communities have no legal rights to these elements of your their heritage found on Crown lands, why is it that owners of private property—including both individuals and corporations—upon which artifacts are found, have full rights to own and dispose of these materials as they wish, and indeed, they can lawfully sell them? While this situation would appear unjust and ethically questionable, it is, once more, beyond the control of individual archaeologists.

#### UNDRIP and the TRC

Canada has finally lent its support to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Article 11 of this declaration refers to the right to "maintain, protect and develop the past, present and future manifestations of their cultures, such as archaeological and historical sites...." Although a proposed Federal bill to implement this declaration did not receive Parliamentary assent, British Columbia has recently passed legislation requiring the government to align its laws with the declaration. While it remains to be seen what changes might be required in British Columbia heritage legislation—and perhaps, one day, in Federal legislation—UNRIP, including Article 11, already has a certain moral weight and now forms part of the ethical and administrative landscape for archaeologists and Indigenous peoples in Canada. The Truth and Reconciliation

Commission of Canada was established to "redress the legacy of residential schools and to advance the process of Canadian reconciliation." While not specifically mentioning archaeology, the commission's recommendations are very much a part of the ethical backdrop for archaeological practice today, with "Calls to Action" concerning commemoration of Aboriginal history, the inclusion of traditional knowledge in education, reviews of museum policy and funding of research on Indigenous issues<sup>28</sup>.

## SUMMARY AND CONCLUSIONS

Several of the presentations at the 4<sup>th</sup> *Seminar on the Ethics of Research with Indigenous Peoples* dealt with research protocols negotiated by Indigenous communities with outside researchers in order to ensure that research meets the needs of the communities. In the case of archaeology, unless the research is being carried out on reserve or treaty land, archaeologists receiving government grants are generally exempt from formal ethical reviews which could trigger this kind of engagement with Indigenous communities, and lead to the negotiation of a formal research protocol. Despite this fact, in Québec, it is becoming more common for archaeological researchers to voluntarily negotiate protocols with local Indigenous communities and governing bodies with whom they often have long-term relationships.

26 Agreement on Cree Nation Governance Between the Crees of Eeyou Istchee and the Government Of Canada (2017).

27 Agreement Between the Crees of Eeyou Istchee and Her Majesty The Queen in Right of Canada Concerning the Eeyou Marine Region (2010).

28 United Nations (2007), TRC (2015).

Government plays a fundamental role with respect to archaeological research, and this touches on some ethical issues related to Indigenous communities. The Québec government manages most aspects of archaeology, including determining who can do it and what qualifications they require. It asserts ownership of artifacts and looks after artifacts in a specialized storage facility. As part of the archaeological permitting process, the Ministère de la Culture et des Communications contacts local Indigenous communities, informing them that an archaeological project will take place that might concern them. The details of this process and the possibility that it could lead to serious consultations are, for now, obscure. While the process in neighbouring Ontario is far from perfect, the obligations placed on archaeologists to consult with local Indigenous communities mean that there is more direct contact and greater opportunity for communities to negotiate, according to their needs and aspirations.

Archaeologists belong to professional organizations with codes of ethics that express, to differing degrees, an ethical responsibility toward the present-day Indigenous communities whose heritage is being researched. In some cases, these ethical principals may run counter to other values concerning "archaeological record," who owns it, who has the right to manage it and to interpret it. Archaeologists have long reserved this as their exclusive domain. No more.

Many indigenous groups around the world have chosen to engage with archaeology, embarking on a wide range of collaborations and partnerships with researchers, setting research agendas and conditions and participating fully in the creation of histories that reflect the needs, interests and cultural values of the communities. Québec First Nations and Inuit were amongst the first to hire archaeologists to carry out community-based research. Much more recently, there has been a surge in collaborative projects and of other nations acquiring the services of archaeologists.

While there are Indigenous archaeologists in many parts of the world and several in other parts of Canada, there are no practicing archaeologists yet in Québec. Elsewhere in Canada, the involvement of Indigenous researchers has accelerated the Indigenization of the discipline as these researchers explore home-grown research problems. Measures like increasing the number of training programs geared for Indigenous researchers, offering positions for interns, and, possibly, re-examining the academic requirements for obtaining permits, should be applied and may, in the not-too-distant future, bear fruit.

Archaeology clearly is rooted in a Western way of looking at the world and thinking about time and the land. While some commentators think that this is too deeply rooted to change, I believe that we have only begun to explore how malleable archaeology might be, adopting changes in method, in terminology and the way we talk about the past, to better reflect local cultural contexts.

One big area of concern, is contract archaeology, where there is often less scope, financially and administratively, to change projects to meet community concerns. However, even here, some communities may be able to press for broader, heritage projects that better reflect a range of community interests, and to exert more community control. Communities have sometimes been able to use requirements to do archaeological impact assessment and mitigation in a strategic manner, to assert broader, territorial interests. A review of the government consultation process, carried out with Indigenous organizations, should be carried out.

In all of the archaeology carried out in Québec, there are some overarching aspects of government control that go beyond the purview of individual archaeologists, including a restrictive permitting system, Crown ownership of artifacts and management of cultural heritage by government. In cases of recent land claims in Canada, agreements include sections which give increased control of heritage to the First Nation or Inuit group concerned. Short of rewriting the Cultural Heritage Act, and, in the absence of new land claims in Québec, there are still some options for the delegation of provincial powers through article 78 of the Cultural Heritage Act.

Chishaayiyiu and Mr. Papatie, my goal in addressing these issues to you both is not to convince you that archaeology is "good" nor to recommend that Indigenous groups get involved with it. My principal objective is to say ar-



chaeology is not as “bad” as it has appeared in the past. It has changed a great deal over the years, largely in response to the various concerns expressed by you and your communities. I would also say that archaeology could be useful to your communities.

Mr. Papatie, you ask why should you show archaeologists the things you know about the land, to show them where things are from long ago that your people left, only for these belongings to be removed. I agree with you, it is a big risk to take. However, it is one that many Aboriginal groups are now taking, often ensuring that there are written agreements in place that set the terms of community involvement and the expectations and responsibilities of both parties. Other communities are developing long-term relationships with archaeologists based on trust and friendship. I ask you, might it not be useful for the community to assemble knowledge of places of historical interest to Anishnabwe Elders, including gathering sites, meeting places and sites where people lived to fish sturgeon in the spring, places where important historic events took place, or places where Anishnabwe people have found or observed old things? Even without digging, archaeology can be a useful tool for working with elders “in the bush” to document such important places. Involving youth in this work would train them and help pass on knowledge. The finding of physical evidence (ancient “belongings”) from these places might also be useful, one day, in supporting your interests in ensuring the long-term protection of these places on Anishnabwe lands.

Chishaayiyiu, I return to the question of your grandfather. I hope you are somewhat reassured that no archaeologist would be permitted to excavate an Indigenous burial site or cemetery, without permission from the descendant group or nearby community. This does not stem from any protection in law, but from an awareness of how sensitive this issue is for First Nations and Inuit, on the part of archaeologists and government heritage managers. It is less reassuring to know that there is no legal protection from the effects of development for unconsecrated graves and cemeteries and no clear measure to consult with Indigenous groups when skeletal remains are inadvertently uncovered. This is another area of government oversight that should be reviewed, in consultation with Indigenous groups.

Chishaayiyiu, I draw a final lesson in ethics from the Cree concept of *miyupimaatisiun*, usually translated as “being alive well.” This concept has come to include cultural and social health coming, among other things, from strong connections to the land and to Cree traditions. When working with Cree Elders, I have often been taken to locations of special interest to them and asked to document features that are culturally and, in some cases, spiritually, important. Ethically, archaeology carried out in the Cree context, should help promote *miyupimaatisiun* as part of community healing and strengthening connections to the land, wherever possible. In other areas, with other Indigenous groups, perhaps there are similar ways archaeology can con-

tribute to community health, healing and transmission of knowledge.

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## GOVERNANCE BY AND FOR QUÉBEC FIRST NATIONS: NUMEROUS ISSUES INCLUDING THAT OF OPEN DATA.

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### BACKGROUND

For thousands of years, First Nations have held learning and knowledge they would like to preserve, protect, organize, and transfer according to their respective values, worldviews, and cultures. This learning and knowledge, connected to tradition, culture, and territory, provide a foundation for their decision-making. Over the last decades, Québec First Nations acquired other types of learning and knowledge: new information accessed through research, population surveys, and various information management systems are now a part of the information assets within communities and organizations.

Although the growing tendency is to have free and quick access to all types of data, such as the open data movement advocates, many structural and legislative obstacles prevent First Nations from gaining access to much information about themselves and owned by third parties. Therefore, in the interests of affirmation and self determination, a renewed and strengthened concept of information governance by and for First Nations is currently being

developed. First Nations wish to define the position to adopt regarding collection, acquisition, conservation, protection, use, management, and sharing of information about them. They would also like to improve the mechanisms meant to provide a framework for their information assets, both locally and regionally. Such regaining of control of information about them and decolonization process are a continuation of the reappropriation of information assets governance in a contemporary context.

But how can such parameters be established for First Nations when the open data approach is globally prevalent? Are the principles of ownership, control, access, and possession (OCAP®) in opposition to open data? This paper proposes initial thoughts on the application of open data within the context of First Nations information governance.

### A STRENGTHENED AND RENEWED CONCEPT FOR INFORMATION GOVERNANCE

On the area of health and social services, information governance is currently imposed by governments according to an approach based on accountability and policies determined by authorities external to First Nations. This governance results from a western vision,

maintaining First Nations within a context of colonization. In accordance with the needs expressed by the communities and organizations, the governance process in Québec First Nations<sup>1</sup> health and social services favour an effective governance approach<sup>2</sup> whose purpose is First Nations wellness. Through this process, information governance by and for First Nations will enable measuring the results obtained and the improvement of the programs and services offered. In order to do so, First Nations will have to: have all the necessary information for informed decision-making; be able to focus on various sources of information, including management information systems, research, population surveys, administrative databases, knowledge keepers within our communities, and all other sources of information held by First Nations communities and organizations; and obtain counsel and support for capacity building, to interpret and use this information for planning, management, and decision making processes.

1 For further information, visit the FNQLHSSC website at the following address: <https://gouvernance.cssspnql.com/en/>.

2 When we discuss effective governance oriented toward the achievement of objectives, we concentrate more on how to coordinate actions to reach a goal. The quality of the results depends on the coordination of all stakeholders to ensure a common goal, namely the improvement of well-being for First Nations. To produce long-term effects, effective governance must implement mechanisms which foster collective learning. (FNQLHSSC, 2019b)

Québec First Nations have collectively developed a vision of information governance that is distinctive and reflects their values:

In harmony with their right to self-determination and information sovereignty, First Nations organize, structure, control, and manage their information assets according to their values, worldview, and practices, enabling them to make informed decisions and orient their actions to effectively serve their populations (FNQLHSSC, 2019a: 3).

Information governance refers to the structure, processes, and protocols through which First Nations are an integral part of decision-making about collection, use, sharing, and management of their information. Information assets take the past into account to explain the current context, while looking to the future.

In this context, First Nations will fully benefit from the sharing of expertise and knowledge and will have access to a wide range of information to achieve their mandates. They will be supported by this information to implement the effective governance model in health and social services. The creation of a network between Québec First Nations communities and organizations, and in the different regions of Canada will foster sharing of good practices and therefore the continued improvement of processes and methods. Furthermore, such sharing will establish regional and national profiles for First Nations based on culturally validated data.

## HISTORY

Throughout the centuries, each nation, even each First Nations family, developed their own cultural heritage, intangible or tangible, which was handed down from one generation to the next. Whereas the intangible heritage referred to oral traditions (including language), social practices, rituals, as well as knowledge and practices related to the land and the universe,<sup>3</sup> the tangible heritage rather refers to occupied sites, artwork, and objects crafted for activities of daily life.

Customary practices, often through oral tradition, regulated the way this heritage was transmitted and used. For First Nations, the purpose of oral transmission of stories is broader than the role of written history in western societies. (RCAP, Volume 1, 1996: 42). For example, there are often references to precise locations, families, and communities in stories about the creation cycle. Story-telling is also a teaching tool to which the notion of responsibility is closely related. Hence, for the Mohawks, the concept of “ongwehonwe” refers to those who currently live on this earth and carry on their shoulders the responsibility of the nation, spirituality, and the relationship with the Creator (RCAP, Volume 1, 1996: 592).

Until the 1800s, Canada’s First Nations maintained their autonomy as well as relationships with non-Indigenous people based on mutual respect for social, cultural, and political differences (RCAP, Volume 1, 1996: 86). However, major changes took place with the Constitution Act of 1867 and the introduction of an assimilation policy. The pro-

cess of dispossession for First Nations begins. Not only does this have to do with the loss of much knowledge, but also the loss of control over what was left of that knowledge and its transmission being cut off. This dispossession has produced lingering effects, including a feeling of helplessness for First Nations (RCAP, Volume 1, 1996: 817).

On a global scale, the 1970’s mark an important step regarding the recognition of the rights of Indigenous peoples. In 1972, the United Nations Educational, Scientific, and Cultural Organization (UNESCO) held a General Conference under the same name during which the Convention Concerning the Protection of the World Cultural and Natural Heritage is adopted. It is noted that:

“[...]the cultural heritage and the natural heritage are increasingly threatened with destruction not only by the traditional causes of decay, but also by changing social and economic conditions which aggravate the situation with even more formidable phenomena of damage or destruction”, and that: “[...] deterioration or disappearance of any item of the cultural or natural heritage constitutes a harmful impoverishment of the heritage of all the nations of the world (UNESCO, 1972: 1).

Other international papers were then developed in which the rights of Indigenous peoples are recognized, such as the Convention on Biological Diversity (United Nations, 1992). Furthermore, with the United Nations Declaration on the Rights of Indigenous Peoples at the beginning of the 2000s, this aspect was recognized and confirmed. Among others, Article 31.1 provides that:

“Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.” (United Nations, 2007: 12).

“Oral societies depend on cultural memory. Each person carries his or her personal story but also those of parents and grandparents. Elders link the coming generations with the teachings of past generations. The cultural teachings are the foundation of Aboriginal peoples’ identity. If the culture is allowed to die, the identity of the people is buried with it.” (RCAP, Volume 4, 1996: 110).

In 2010, Canada commits to supporting the principles outlined in the United Nations Declaration on the Rights of Indigenous Peoples. In 2015, in his mandate letters, the Prime Minister asks the minister of Indigenous and Northern Affairs Canada, as well as other ministers, to implement the Declaration. A year later, the minister of Indigenous and Northern Affairs Canada announces that Canada now fully endorses it without reserve (Government of Canada<sup>4</sup>).

In 2019, more than ten years after the United Nations Declaration on the Rights of Indigenous Peoples, the Public Inquiry Commission on relations between Indigenous Peoples and certain public services in Québec (CERP, 2019) deems necessary to implement these second and third Calls for action:

#### **Call for action #2**

Adopt a motion to recognize and implement the United Nations Declaration on the Rights of Indigenous Peoples in Québec.

#### **Call for action #3**

Working with Indigenous authorities, draft and enact legislation guaranteeing that the provisions of the United Nations Declaration on the Rights of Indigenous Peoples will be considered in the body of legislation under its jurisdiction. (CERP, 20109: 473).

Again in 2019, the National Inquiry into Missing and Murdered Indigenous Women and Girls (NIMMIWG) mentions that cultural rights are inseparable from human rights, and within the

context of international rights, they are defined as having the right to access and participate in culture to their full enjoyment. (NIMMIWG, 2019).

This brief history highlights the structural stumbling blocks between which First Nations must navigate to develop mechanisms allowing them access to a full governance of their own information. The next section presents achievements and objectives in this regard.

## **CURRENT STATE OF FIRST NATIONS INFORMATION GOVERNANCE IN QUÉBEC**

In the past, research or any other activity involving collecting of information about Indigenous peoples was often carried out with no ethical framework and no benefits for the populations themselves as objects of those activities. From an Indigenous perspective, these activities were considered as instruments of oppression and colonization (Durst, 2004). When we speak of this period, the term “colonial research” is widely used (Smith, 1999).

In Canada and in Québec, since the end of the 1990s, many tools were designed to decolonize research and establish a framework for such practices concerning First Nations or on their lands. Some of these tools were created by First Nations in response to the guidelines developed by the various levels of government.

4 Excerpt from website: <https://www.justice.gc.ca/eng/declaration/index.html> (consulté le 17 février 2020).

In 1998, the creation of the principles of property, control, access, and possession (OCAP®) of data by the First Nations and Inuit Regional Health Survey National Steering Committee initiated a change of paradigm: research involving First Nations in Canada would now be done by and for First Nations. The OCAP® principles are a statement of self-determination applied to information governance.

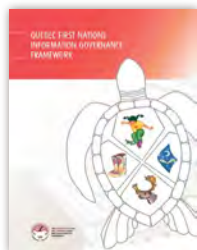
In the aftermath of the decolonization of research, the First Nations of Québec and Labrador Health and Social Services Commission (FNQLHSSC), with its partners and the support of First Nations communities, developed tools to regulate research activities taking place on their lands and aimed at their populations. The following documents are essential references:



◀ *Consultations Protocol of First Nations of Quebec and Labrador* (AFNQL, 2005b and 2014);



◀ *Guidelines for Research with Aboriginal Woman* (QNW, 2012);



◀ *Quebec First Nations Information Governance Framework* (FNQLHSSC, 2019).

▶ *First Nations in Quebec and Labrador's Research Protocol* (AFNQL, 2005b and 2014);



▶ *Toolbox of research principles in an Aboriginal context: ethics, respect, fairness, reciprocity, collaboration, and culture* (FNQLHSSC et al., 2015 and 2018);





The creation of these tools came after that of the OCAP® principles, demonstrating the willingness of First Nations to apply self-determination to information governance.

In parallel, other initiatives at the federal and provincial scales led to the development of guidelines for research involving First Nations and the Inuit; at the current time, these documents are still considered to be references:

- *Ethical Principles for the Conduct of Research in the North* (ACUNS, 2007);
- *Guidelines for Health Research Involving Aboriginal People* (CIHR, 2010);
- *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS, 2010, 2015, and 2018).

These documents are tools developed by regional organizations to support communities and nations in the eventual development of their own reference documents to regulate management of their information assets. They should, among others, ask themselves the following questions: Which information will be made public and which information will be restricted? In which format will data be made public? For how much time will this information be available? How can we ensure that public information is used and interpreted properly, and in consideration of the contextual factors specific to First Nations? Should provisions be established in case of inadequate use of these data?

## OPEN DATA

The International Open Data Charter defines open data as being “[...] digital data that is made available with the technical and legal characteristics necessary for it to be freely used, reused, and redistributed by anyone, anytime, anywhere<sup>5</sup>”. Open data is data that is structured and machine-readable, freely shared, used and built on without restrictions (NordOuvvert, 2017<sup>6</sup>). Following are the six principles that govern access, distribution, and use of open data:

1. Open By Default
2. Timely and Comprehensive
3. Accessible and Usable
4. Comparable and Interoperable
5. For Improved Governance and Citizen Engagement
6. For Inclusive Development and Innovation

Since 2009, the governments of the United States, the United Kingdom, Canada, and New Zealand began to provide the general public with access to certain data. In 2011, the Government of Canada launched its open data portal, Open Government, whose second generation has been available since 2013. This portal gathers more than 80,000 data on a multitude of topics such as agriculture, health, employment, the environment, and transportation. Much of these data concern First Nations. For example, there is data on infrastructure investments or on information about the quality of drinking water in communities.

The major research funding organizations in Canada also came on board and have established the Tri-Agency Open Access Policy on Publications. All researchers supported by the National Sciences and Engineering Research Council of Canada (NSERC), the Canadian Institutes of Health Research (CIHR), or the Social Sciences and Humanities Research Council (SSHRC) must comply with this policy. To foster knowledge sharing and mobilization, research results, that is “research publications and data, to the widest possible audience, and at the earliest possible opportunity.”<sup>7</sup>

Therefore, this new paradigm inevitably leads to asserting the position of First Nations within the movement, especially as regards the application of the OCAP® principles for studies conducted with First Nations on their territory.

The tools developed by First Nations and the principles conveyed are not in contradiction with or in opposition to the open data approach. The desire to regain control of information that concerns them does not imply that they are not willing to share or provide access to their information. They rather claim the authority to use the information in the interest of their nations and organizations and hold the responsibility of establishing the parameters for the management and sharing of these data.

5 Excerpt from website: <https://www.justice.gc.ca/eng/declaration/index.html> (consulted February 17, 2020).

6 Presentation by NordOuvvert on open data at the FNQLHSSC 2017 pre-annual general meeting.

7 Excerpt from the Government of Canada website: [http://www.science.gc.ca/eic/site/063.nsf/eng/h\\_F6765465.html](http://www.science.gc.ca/eic/site/063.nsf/eng/h_F6765465.html) (consulted June 10, 2020).

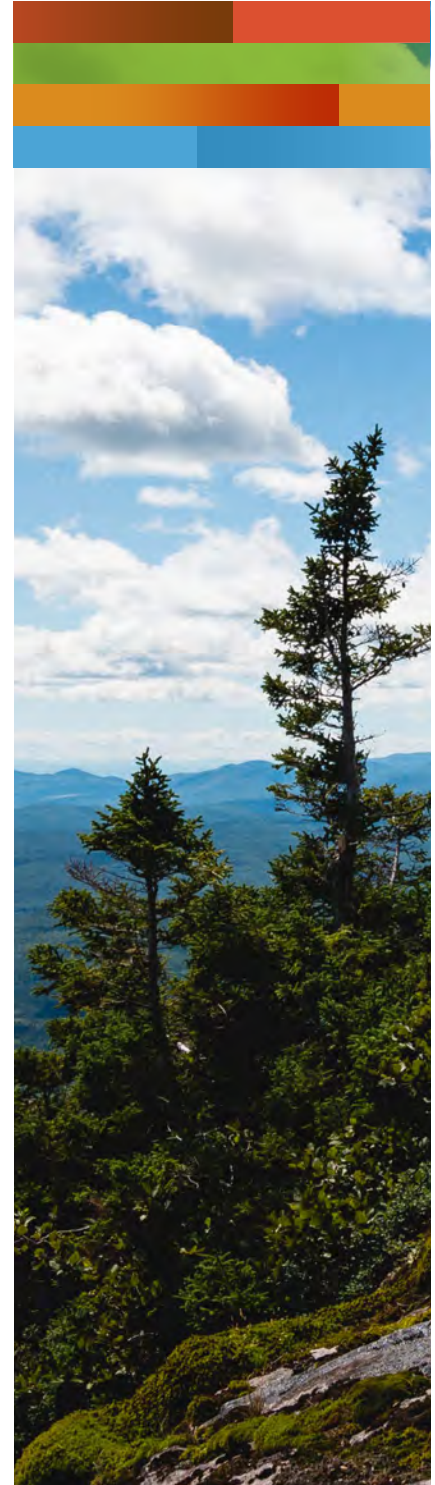
## USES OF OPEN DATA

According to NordOuvr (2017), open data is useful in many ways. Among others, it provides access to public data and information, maximizes the reuse of data, and facilitates informed decision-making. The cost of making them available is almost nil. It would even be cost-saving. In terms of use, open data encourages civic responsibility and social innovation, while resulting in a decrease of requests for access to information and maximizing the sharing of complementary data. Finally, open data benefit program development, analysis, and evaluation.

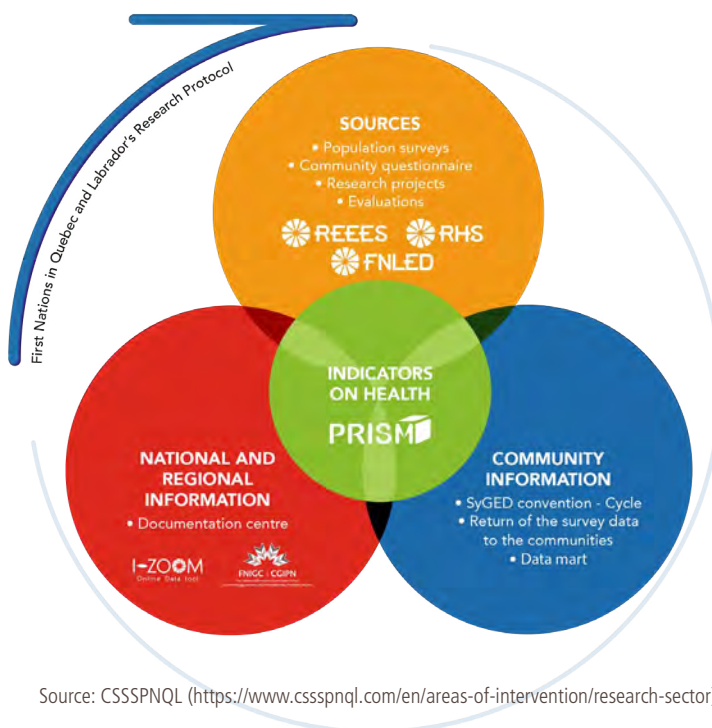
## ISSUES RELATED TO OPEN DATA

Research raises certain issues about open data such as the absence of raw data directories. Therefore, there is no common directory for open data but rather many portals on municipal, provincial, and federal scales. Another issue concerns the fact that data are not standardized. The formats for databases are numerous and little is known about updates. There are also risks related to privacy protection and reidentification. This is a fundamental issue for First Nations since the possibility of identifying individuals by deduction is very real when small populations or sub-groups of a population are targeted. Furthermore, the protection of personal and collective data is a current issue. Finally, the absence of local and regional resources in support of open data exploitation must be pointed out.

Other issues are specific to the contexts and realities of First Nations, especially as regards data sovereignty, the application of the OCAP® principles, and community support for the management of the information assets



## REGIONAL INFORMATION GOVERNANCE AND MANAGEMENT FRAMEWORK



Source: CSSSPNQL (<https://www.cssspnql.com/en/areas-of-intervention/research-sector>)

## DATA DISTRIBUTION BY THE FNQLHSSC

To support access to data and their use by Québec First Nations communities and organizations, the FNQLHSSC has developed various digital tools over the years. Access to these data is determined according to the sensitivity level of the information, some of these being open to the public at large, whereas others are accessible solely to designated individuals in the concerned community. The regional tools we created are the following:

- **I-Zoom** is an interactive tool for the public at large which allows its users to create diagrams and tables based on the information in the FNQLHSSC's data warehouse. All data produced are aggregated on a regional scale and weighted to be representative of First Nations communities across Québec;
- **PRISM** is an evolutionary information platform providing workers with statistical data on the health and well-being of First Nations and communities. Indicators document health and its determinants spanning nine themes: Population profile, Culture and territory, Education, Employment, occupation, and income, Health and wellness, Health services and social services, Lifestyles and behaviours, Physical environment and infrastructures, as well as Community life.
- The **publications resulting from various research studies**, evaluations, and population surveys, as well as different documentation published by the FNQLHSSC or other organizations, can be accessed through the Documentation Centre of our website.

Furthermore, the FNQLHSSC has a secure website for communities to access their respective data (frequency tables/aggregated results). Finally, a process was implemented for the gathering of data associated with various population surveys conducted by the FNQLHSSC; this service is exclusive to First Nations communities.



## CONCLUSION

DAs part of the Québec First Nations Health and Social Services Governance Process, First Nations must determine what data about them should be open, to establish a beneficial sharing of information and responsibility at both the community and regional levels. These orientations must be part of a more extensive reflection concerning information governance, notwithstanding the area of application. To this end, the FNQLHSSC would like to coconstruct a regional strategy for information governance with Québec First Nations. Thus, the nations will be able to implement their own structure to manage their information assets and define accessibility for certain information, if desired, according the parameters they themselves will have defined.

Awareness, learning, and knowledge are essential to better protect information assets, which are in constant evolution. Technological advances will help to establish new foundations midway between tradition and modernity. These movements shall also contribute to redefining our governance.





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# CHALLENGES IN RESEARCH COORDINATION: THE EXPERIENCES OF THE PEKUAKAMIULNUATSH FIRST NATION.

HÉLÈNE BOIVIN,  
Pekuakamiulnuatsh Takuhikan

## 1. INTRODUCTION

This article follows a presentation made at the **4<sup>th</sup> Seminar on the Ethics of Research with Indigenous Peoples**, held at the Université de Québec en Abitibi-Témiscamingue in Val-d'Or in November 2018, by the Coordinator of the Coordination Committee for research projects for Pekuakamiulnuatsh Takuhikan, the transition government of the Pekuakamiulnuatsh First Nation.

It aims to provide an account of the experience and the challenges inherent in coordinating research projects in an Indigenous community, as well as some tools developed using resources from the Pekuakamiulnuatsh Takuhikan.

## 2. INTRODUCTION TO THE PEKUAK- AMIULNUATSH FIRST NATION

The Pekuakamiulnuatsh have lived on a vast territory extending beyond the Pekuakami watershed (figure 1) for millennia. Prior to the arrival of Europeans, they traded with other Indigenous nations to the north and south, and to the east and west. Today, elements of oral tradition bear witness to the undeniable historical presence of the Pekuakamiulnuatsh on Nitassinan

("our land"), if by nothing else than the innumerable names for geographic locations.

Before being declared reserve land in 1856 by the Indian Act of 1850, Mash-teuiatsh—which means "place where there is a point"—had always been a place for special gatherings. Mash-teuiatsh was a unique meeting place on the banks of the Pekuakami where all could meet and share, as much from a cultural and social perspective as a commercial one.

Traditionally, the Innuatsh identified one another by referring to the land where they lived with their families. This is the origin of the name Pekuakamiulnuatsh (Innuatsh of Pekuakami) that identifies us to this day.

Initially called Ouiatchouan, the community has used the name Mash-teuiatsh since 1985. The popular name of Pointe-Bleue ("Blue Point") has long been used to describe the inhabited reserve land.

Located between the municipalities of Roberval and Saint-Prime, the community occupies an area of 16.05km<sup>2</sup> (figure 2). In February 2019 the community totaled 6,803 members, of whom 2,099 were residents and 4,704 non-residents. The majority of members of the Pekuakamiulnuatsh First Nation

are located in the Saguenay–Lac-Saint-Jean region, primarily in the community of Mashteuiatsh.

**Figure 1. Nitassinan of the  
Pekuakamiulnuatsh First Nation**



Source: Pekuakamiulnuatsh Takuhikan – Office of Land Rights and Protection



**Figure 2. Location of the Community of Mashteuiatsh**

Source: Pekuakamiulnuatsh Takuhikan - Office of Land Rights and Protection

### 3. POLITICAL AND ADMINISTRATIVE STRUCTURE OF PEKUAKAMIULNUATSH TAKUHIKAN

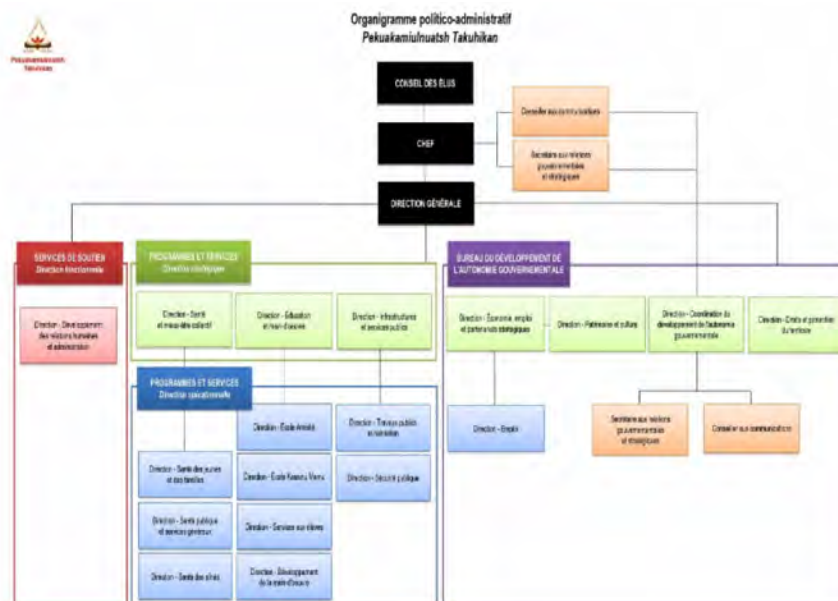
The political structure consists of a council of elected officials, made up of a chief and six councillors. Terms on the council are for four years. Each councillor, as well as the chief, has their own specific responsibilities.

The administrative structure of Pekuakamiulnuatsh Takuhikan includes more than 350 employees, working in such varied departments, as:

- Self-governance (Heritage and Culture, Land Rights and Protection, Economic and Business Affairs, and Strategic and Governmental Affairs);
- Programs and services (Health and Community Well-being, Infrastructure and Public Safety, and Education and Labour);
- Support services (Communications, Human Resources, and Finances).

In 2019 the operating budget was \$58 million, of which \$37 million came from the federal government, not including the budgets of subsidiary companies which totalled \$134 million.

**Figure 3. Organigram of Pekuakamiulnuatsh Takuhikan**



Source: Pekuakamiulnuatsh Takuhikan – Office of the Executive Director

### 3.1 ECONOMIC OVERVIEW

For many years, Pekuakamiulnuatsh Takuhikan has worked toward community development by taking an assertive approach to political, cultural, social and economic autonomy. The Pekuakamiulnuatsh First Nation is resolutely committed to affirming and preserving their ancestral rights, including the title of Ilnu, promoting the interests and aspirations of its people and exercising its inherent right to self-governance.

The economic development model in Mashteuiatsh is mixed, meaning that it depends on community development, private companies and collectives.

The primary activity sectors are:

- Arts and Cultural Expression;
- Forestry;
- Energy;
- Tourism;
- Shops and services;
- Mines.

Despite this level of autonomy and development, the Pekuakamiulnuatsh First Nation lags behind its neighbours in development indicators<sup>1</sup>. Given these conditions, jobs and training remain critical issues for the Pekuakamiulnuatsh First Nation.

## 4. HISTORY AND EXPERIENCE OF PEKUAKAMIULNUATSH TAKUHIKAN IN RESEARCH COORDINATION

### 4.1 THE ILNU HERITAGE COMMITTEE

Our experience with research coordination began with the Ilnu Heritage Committee's creation in 2009 in response to a request from Parks Canada to identify historical sites, events and persons from our First Nation to be commemorated. The committee's mandate was to analyze requests related to the conservation, development and promotion of Pekuakamiulnuatsh cultural heritage.

Recommendations were made to the Office of Heritage, Culture and Land Services, which was responsible for overseeing the work. The committee's representatives included community members, representatives from local organizations, and from various sectors within Pekuakamiulnuatsh Takuhikan.

Gradually, as more university research projects were submitted to the committee, a system for oversight was developed. At that point, the only tool that the committee had for oversight of research projects was the 2005<sup>2</sup> Assembly of First Nation of Quebec and Labrador (AFNQL) protocol, which representatives from the Pekuakamiulnuatsh First Nation had participated in developing. The AFNQL protocol was updated in 2014<sup>3</sup>. While efficient and clearly articulated, the protocol did not respond to all of

the committee's needs, especially to the following question: how to concretely coordinate research projects in an organization like a band council<sup>4</sup> that has neither a dedicated research office nor significant expertise in the field?

The Ilnu Heritage Committee carried out its work over a period of two years, until the departure of the Coordinator and structural changes led to its abolition. However, the end of the Ilnu Heritage Committee's operations did not prevent future partnerships in research projects. For more than a year, the organization managed research requests to the best of its abilities with help from the Historical and Archeological Society of Mashteuiatsh. University researchers generally contacted these institutions when seeking to carry out research projects in partnership with the Mashteuiatsh community.

### 4.2 WORKING GROUP

The need for research coordination was addressed when the Office for Coordination and Self-Governance was created as part of a restructuring process in 2014. A working group was created to present an overview of the situation and its recommendations to the Pekuakamiulnuatsh Takuhikan councillors.

This working group acted as the coordination committee for research projects until it submitted its report in July 2016. Based on the conclusions of the working group's report, the council of elected officials of Pekuakamiulnuatsh Takuhikan officially recommended the creation of a research coordination

<sup>1</sup> According to an internal study ordered as part of the land claim process

<sup>2</sup> AFNQL (2005). First Nations in Quebec and Labrador Research Protocol. Assembly of First Nations of Quebec and Labrador. Wendake.

<sup>3</sup> AFNQL (2014). First Nations in Quebec and Labrador Research Protocol. Assembly of First Nations of Quebec and Labrador. Wendake.

<sup>4</sup> Pekuakamiulnuatsh Takuhikan is a government in waiting and no longer uses the term "band council."



committee duly mandated to provide guidance and oversight to research carried out in partnership with the Pekuakamiulnuatsh First Nation.

Here are some highlights from the working group's report, presented in July 2016.

### 4.3 PROBLEMS IDENTIFIED IN THE WORKING GROUP'S REPORT

- The dissolution of the Ilnu Heritage Committee left a void;
- Multiple research requests submitted via different avenues: some research projects are submitted directly to the chief and others to individuals within the organization;
- Some projects take place without the community's knowledge or oversight;
- No process exists for accepting or coordinating research projects;
- Some projects request sensitive data that the community does not wish to divulge;
- Some administrative bodies have neither the time nor the appropriate resources to accompany research organizers, contributing to a dynamic of permissiveness and absent or inadequate oversight. Under those conditions, there was no follow-up on research results or conclusions;

- Some universities sent students to carry out research projects without informing or involving the community;
- There was a need to catalogue all ongoing projects (organization and community) and keep a register of completed projects and existing data;
- Over just a few years, multiple projects were submitted. We had to choose which projects interested us. Selection criteria had to be developed and research subjects that are relevant and useful to the community had to be determined;
- The council of elected officials was not always asked permission for projects. The acceptance process had to be confirmed (role of the council: information, approval or final decision); what elements allow us to accept or refuse a project? Which reasons are valid?
- There is an absence of accountability to the community. Results must be shared with the community.

### 4.4 SOLUTIONS IDENTIFIED IN THE WORKING GROUP'S REPORT

The working group recommended creating a Research Coordination Committee made up of representatives from Pekuakamiulnuatsh Takuhikan and the Historical and Archeological Society of Mashteuiatsh.

Documents were also developed to respond to issues raised in the report:

- A research protocol for the Pekuakamiulnuatsh First Nation, (attached to this article) strongly influenced by the AFNQL research protocol but adapted to the context and needs of Pekuakamiulnuatsh Takuhikan and the Historical and Archeological Society of Mashteuiatsh;
- A system for processing and organizing research projects in partnership with Mashteuiatsh, which was revised and simplified in 2018;
- A template for resolutions of the Pekuakamiulnuatsh First Nation;
- A research agreement template<sup>5</sup>;
- A list of completed and ongoing research projects;
- A summary sheet for archival and consulting purposes.

## 5. EXPERIENCE OF THE RESEARCH COORDINATION COMMITTEE SINCE ITS CREATION

In Mashteuiatsh, as in many other Indigenous communities, there is no service or office responsible for research and development. Some services or offices, like educational services, carry out research and development, such as when developing educational material.

Culture, land and language are the most in-demand subjects, followed by education and health.

On average, the Pekuakamiulnuatsh First Nation receives twenty research requests each year, most from master's or PhD students. These requests come in from universities throughout Quebec and, increasingly, from abroad. Very few are submitted by community members. As a result, the committee decided to give priority to requests made by students from the community as part of their master's, PhD or internship program. An inventory of research projects was completed in 2015 in partnership with INRS. In total, 75 projects were inventoried in the period from 2009 to 2015.

The First Nation receives a significant volume of requests relative to its capacity, especially when considering that accepting a project means investing time and resources throughout its entire duration. Moreover, as previously mentioned, research and development are not priorities for the organization: its mission from the start has been to

provide programs and services to band members.

Here are some of the elements involved in research oversight and coordination:

- Presenting the project to the Research Coordination Committee;
- Identifying the administrative body responsible for the project;
- Meetings or discussions with the stakeholders involved to agree on project objectives and orientations;
- Negotiating the research agreement and follow-up procedures;
- Preparing funding requests, as needed;
- Budget follow-ups;
- Developing and presenting the introductory file to the council of elected officials for approval;
- Follow-up meetings over the course of the project (average of 4 per year);
- Editing and verifying texts for post-doctoral, doctoral, or master's theses, or others;
- Presenting research results to community members and bodies;
- Participating in doctoral or post-doctoral defenses;
- Organizing and participating in

activities in the academic and community spheres;

- Organizing interviews;
- Hosting researchers in the community.

Research involves a number of elements that require special attention, such as:

- Access to and archiving of data;
- Sensitive data;
- Intellectual property;
- Cultural appropriation;
- Benefits of research for the community or communities;
- Knowledge sharing and transfer;
- Funding.

### 5.1 ACCESS TO AND ARCHIVING OF DATA

Archives for an organization like the Pekuakamiulnuatsh involve some restrictions on access and duration of archiving. Outside parties do not have access to organizational documents and files are considered inactive after ten years. To address these problems, the Research Coordination Committee requested that a copy of data, reports, theses or other documents be submitted to the Historical and Archeological Society of Mashteuiatsh. This facilitates access for community members, the public, and researchers over the long term.

We have also developed a summary card that the researcher can fill out upon the completion of their project so that the Research Coordination Committee can update the list of completed projects carried out in the community. This card also allows individuals to quickly determine whether a given research topic has already been investigated. It was developed based on a template created and used by the Institut national de recherche scientifique and is included in the protocol.

An access procedure was developed by the Innu Heritage Committee. In short, it involves making a written request to the Research Coordination Committee, which can then accept or deny the request.

Despite certain beliefs to the contrary, access to information laws apply to Indigenous communities in both Quebec and the rest of Canada. Thankfully, the committee has not had any access requests that require an arbitration process, although some requests have been denied, specifically those requesting access to research on land use and occupation carried out in the 1980's to support the large-scale land negotiations (land claims) of the Pekuakamiulnuatsh First Nation.

## 5.2 SENSITIVE DATA

The committee established a definition for sensitive data in collaboration with the Historical and Archeological Society of Mashteuiatsh and developed the access procedure described above.

(translated from the original French) *"Sensitive data: data that, if divulged, could interfere with the rights, interests and integrity of the Pekuakamiulnuatsh people, or the political and administrative organization of Pekuakamiulnuatsh Takuhikan, such as:*

- *Internal or external studies that could be used in legal contexts;*
- *Recipes for traditional medicines;*
- *Traditional crafting techniques;*
- *Personal information."*

## 5.3 INTELLECTUAL PROPERTY

Intellectual property is a very complicated issue. For the moment, the committee has made use of an existing definition proposed by the forestry research chair of Université Laval. A clause (23) specifically addressing this question is included in the collaborative agreement attached to this article.

(translated from the original French)  
Definition<sup>6</sup>

Intellectual Property: In general, intellectual property includes all rights that derive from intellectual activity in the industrial, scientific, literary and artistic domains. Recognized intellectual property rights in Canada include patents, trademarks and copyrights. Intellectual property is generated in all research projects, e.g., written reports or publications."

## 5.4 CULTURAL APPROPRIATION

The signing of an agreement between the parties and the clause on intellectual property are both important steps to preventing cultural appropriation. We refer here to the broad but controversial definition of cultural appropriation as the use of elements from one culture by another. More concretely, we want to avoid being relegated solely to the role of subjects in a study. We wish to play an active role in research. Over the course of its experience in coordinating research projects, the Pekuakamiulnuatsh First Nation has had one case of cultural appropriation. The research topic was embroidery motifs used by our First Nation. The research was completed, but the researcher did not provide any further communication with the community and contact was cut off.

## 5.5 BENEFITS OF RESEARCH FOR COMMUNITIES

The committee made several suggestions to increase the benefits of research for the community, including:

- Projects that respond to the community's needs;
- Funding agreements managed by the community with a percentage for coordination;
- Involvement of students from the community in projects;
- Involvement of community members in projects;

- Organization of activities related to the research with schools, museums or other organizations;
- Co-authoring articles.

### 5.6 KNOWLEDGE SHARING AND TRANSFER

Knowledge sharing and transfer requires the involvement of students from the community and other community members in research projects throughout their duration, whenever possible. For example, in one project, a student was asked to transcribe historical documents. In another, youth from

the community were invited via the community's high school to present on the connections between certain artifacts identified in repatriation research and objects used in modern times as part of traditional activities and crafts. In another, the resulting thesis was submitted with a co-research credit given to the individual responsible for coordinating the project.

In general, knowledge sharing and transfer in communities takes place through the organization of exhibitions, the production of publicly accessible collections and by presenting

research results to the population.

### 5.7 FUNDING

Research coordination involves investing time and resources that do not fall under the normal budgets or priorities of the organizations involved. At present, Pekuakamiulnuatsh Takuhikan has no dedicated organizational budget for research. Research coordination is added to the tasks for the organization's staff under the catch-all of "other related tasks". However, more and more funding requests are made jointly with researchers and universities, as recommended, whenever it's possible.

## 6. CONCLUSION

The coordination of research projects presents the committee with certain challenges in terms of resources and expertise. Mash-teuiatsh has nearly reached its limit in terms of research coordination. Requests continue to increase, while resources for project oversight have diminished or stagnated.

The role of the committee has also changed. At first, the committee was responsible for all project coordination. Now it occupies more of a support role for different administrative bodies of the organization, which organize and ensure coordination of projects from start to finish.

From our experience, the work would ideally be mandated to an independent structure focused solely on research. This would allow the community to be more active in the field and foster improved project coordination, increased control over and access to data and the development of a local database.

The likely outcome in the near future is a partnership with universities on a long-term basis. This seems like the best option to respond to the community's current needs. The goal of these partnerships would be for both parties to build skills in the spirit of sharing resources. For communities, a need is seen to train Indigenous individuals in multiple domains, such as implementing a legal system based on cultural tradition, governance, land management, valorization of heritage, repatriation of artifacts, etc. For universities, a continual need is seen to train researchers in the issues and experiences of the First Nations.



## APPENDIX 1

### COLLABORATIVE RESEARCH AGREEMENT



#### As part of the research project:

PROJECT TITLE

BETWEEN:

Researcher:

Role:

Organization:

Address:

Telephone:

Email:

AND:

Organizer:

Contact person:

Role:

Organization:

Address:

Telephone:

Email:

AND

Organization in Question:

Contact person:

Role:

Organization:

Address:

Telephone:

Email:



## 1. Research Topic

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## 2. Description and Scope of the Project

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## 3. Objectives

### 3.1 Research Objectives of Pekuakamiulnuatsh Takuhikan

- Increase local expertise in research;
- Build contacts within the field of research;
- Respond to administrative, collective, community, development, political, economic, social and cultural needs;
- Encourage community youth to do research and get involved;
- Preserve and make accessible research documents or any other work, written or otherwise, in the community.

### 3.2 Objectives of the Organization in Question

## 4. Study Duration

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## 5. Period of Data Collection

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## 6. Research Objectives

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## 7. Modifications to Research Project and Consent

If the researcher wants to modify the research project, the organizer must first provide their consent.



## 8. Collaborative Approach

- 8.1 The parties agree to fully collaborate throughout the study by maintaining regular communication.
- 8.2 The organizer will be informed and involved in any communications to the population as part of the research for the entire duration of the study.
- 8.3 The researcher, in collaboration with the organizer, will jointly evaluate the benefits of the research and will oversee the required follow-up with the Research Oversight Committee and with Katakuhimatsheta, as needed.
- 8.4 The researcher agrees to provide the organizer with an action plan and timeline for the research before beginning any work.

## 9. Presentation of the Project

- 9.1 The research project must be presented to the research committee of Pekuakamiulnuatsh Takuhikan so that it may fulfil its role and responsibilities.
- 9.2 Once authorizations with all related parties have been obtained, meaning the organizer, the Coordination Committee for Research on the Pekuakamiulnuatsh and Katakuhimatsheta, the research project will be examined by the ethics board of the university involved for ethical approval, if needed.

## 10. Funding Sources

Indicate here if no funding.

If funding has been or will be sought, ensure that the request includes a to-be-determined amount to be disbursed to the First Nation for research coordination.

Other forms of support.

The parties agree that the organizer can provide the following to the researcher when possible and depending on availability:

- A workspace for visits to the community as part of the research;
- A contact person within the community to accompany the researcher.

## 11. Expected Benefits and Risks

11.1 The researcher can expect the following benefits from the research:

- Understanding of the community;
- Development of a long-term relationship with the community;
- Successful completion of the study and related activity;
- Publication of the results for scientific purposes only.

11.2 The community can expect the following benefits from the research:

- Knowledge sharing and development;
- Article publication;
- Program;
- Training;
- Exposition(s);
- In-depth data;



- Ideas for future research;
- Funding;
- Other.

Risks for research participants primarily involve the confidentiality of data. Specific measures will be taken by the researcher to protect confidentiality. They are listed in section 11 of this document.

## 12. Research Methodology

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## 13. Data Collection

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## 14. Participant Recruitment

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## 15. Participant Consent

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## 16. Participant Confidentiality

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## 17. Data Confidentiality

From the time of signing this agreement to after the research project has concluded, the researcher agrees to ensure the protection of all information and data in their possession and not to divulge any confidential or personal data obtained during the development or implementation of the study. In accordance with the present agreement, the research must put the following protective measures in place:

- Encoding material and data;
- Encrypting digital material and data to be stored on the researcher's computer under dual-password protection;
- Storing all research material and data in a locked area;
- Storing the "code key" in a separate, locked area from the material and data;
- Storing consent forms in a separate, locked area from the code key and the data.





## **18. Data Preservation**

18.1 With participant consent, all data, whether digital or on paper, will be returned to the community. Access to the data will be limited in accordance with participant consent.

18.2 The community will provide researchers with access to the data if any complementary studies should follow.

## **19. Validation of Preliminary Results**

Verification or validation of preliminary results with the participating community will be done in the following manner:

- The researcher agrees to provide the organizer with updates on research progress via a summary report at the halfway point or as requested;
- The summary report must also be presented to the Research Coordination Committee.

## **20. Presentation of Research Results**

Prior to being made public, research results must be presented in the following order:

1. Interviewed participants
2. Organizer
3. Research Coordination Committee
4. Community
5. Others, as determined and evaluated by the organizer.

## **21. Disclosure and Communication of Results**

Research results will be presented to the public according to the means agreed to by the parties:

Examples

- Participating in doctoral defense whenever possible;
- Publishing doctoral thesis (or other) with the community's approval;
- Publishing academic articles or conference proceedings;
- Presenting at academic conferences;
- Other.

## **22. Use of Research Results**

22.1 Any use of research results must have the express approval of the organizer.

22.2 If results are monetized, an agreement must be made between the parties.

## **23. Intellectual Property Rights**

23.1 Each party maintains ownership over all intellectual property rights that they had prior to the start of the research project;

23.2 The Pekuakamiulnuatsh First Nation maintains full ownership over their traditional and cultural knowledge;

23.3 Notwithstanding the intellectual property rights of each party, the researcher holds copyright over any text they produce as part of the research project;



23.4 Pekuakamiulnuatsh Takuhikan recognizes and accepts the institution's educational, training and research roles. Out of respect for this mission and provided that it puts adequate protective measures in place, the institution may use research results for teaching or research purposes, as well as in general publications for transmitting knowledge, including essays, master's or doctoral theses, and journal articles, provided that it has taken adequate measures to ensure the anonymity of participants and protection of confidential data.

## 24. Review of Publications

Prior to being published, all articles presenting research results must be reviewed and edited by the organizer or another resource person selected by the organizer. They will consult with the community as needed and present their comments to the researcher, in particular as relates to confidential information that cannot be published or interpretations that are more appropriate to the local culture.

The researcher will make an effort to modify the publication based on these comments, as needed. The community can also require that its name not be divulged in the publication if it considers that doing so would harm its members' reputation or if it has not given its approval for publication. The researcher agrees to adapt their publications based on comments from the community. Pekuakamiulnuatsh Takuhikan reserves the right to require that its name, the name of the Pekuakamiulnuatsh First Nation or any other information allowing for the First Nation, its representatives or its members to be identified or which harms their reputation, be withheld.

## 25. Conflict Resolution

If a conflict arises related to the research, all parties agree to attempt to resolve it in good faith by use of a previously designated mediator prior to attempting other procedures for conflict resolution, litigation or arbitration.

## 26. Duration and Cancellation of the Research Agreement

This agreement comes into effect starting from the date of research authorization \_\_\_\_\_ and expires on \_\_\_\_\_.

The parties may agree in writing to prolong the agreement for a specific duration. Any party can also end the agreement by means of a written notice presenting the reasons for their withdrawal.

Upon the expiry of the agreement, certain sections continue to apply, in particular the sections covering confidentiality, data and intellectual property rights.

Upon the expiry of the agreement, either at its prescribed end date or following its cancellation, the researcher must provide Pekuakamiulnuatsh Takuhikan with all documents, originals or copies, regardless of their presumed relevance.

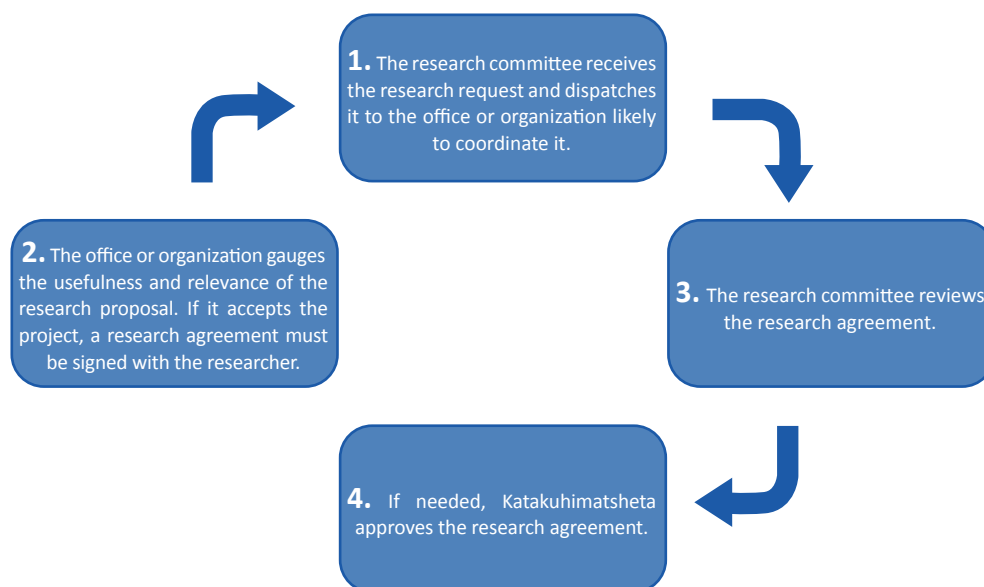
Pekuakamiulnuatsh Organizer \_\_\_\_\_ Date \_\_\_\_\_

Researcher \_\_\_\_\_ Date \_\_\_\_\_



## PROCESS FOR TREATING RESEARCH REQUESTS

Appendix 1



### 1. ROLES AND RESPONSIBILITIES OF THE RESEARCH COORDINATION COMMITTEE

In general, the role and responsibilities of the Research Coordination Committee are to:

- Support, coordinate and guide researchers, the administrative bodies of Pekuakamiulnuatsh Takuhikan and other organizations of the Pekuakamiulnuatsh First Nation in research matters;
- Ensure oversight of requests for and work related to research in the community;
- Protect the Pekuakamiulnuatsh First Nation's knowledge and skills;
- Establish a system by which any data collected and reports are transferred and made available to the community;
- Contribute to knowledge acquisition and transfer.

More specifically,

- Receive research requests and dispatch them to the administrative body or organization likely to coordinate the project, such as the SHAM, SDEI or other;
- Accompany the assigned administrative unit in analyzing the request and determining its adherence to the local protocol;
- Familiarize administrative units with the reference guide for research projects involving the Pekuakamiulnuatsh as well as on the local protocol and project archiving, and share this information with the population and organizations;
- Update the list of research projects carried out in the community;
- Verify research agreements;
- Report on committee activities or any other relevant information to Katakuhimatsheta;
- Compile a list and category code of final research reports according to the organization's archiving procedure.



## **2. ROLES AND RESPONSIBILITIES OF ADMINISTRATIVE BODIES AND/OR OTHER ORGANIZERS;**

- Determine the usefulness and relevance of research proposals;
- Oversee the study's production and follow-up in collaboration with the researcher;
- Regularly report to the coordination committee on the ongoing project and its progress;
- Establish a collaborative research agreement in accordance with the local protocol;
- Submit the signed research agreement to the Office of Human Resources and Administrative Development;
- Provide the category code of the final research report and a copy of the report to the SHAM;
- Ensure research benefits for the community;
- If possible, participate in the thesis defense
- Provide information to various bodies and the population.

## **3. ROLES AND RESPONSIBILITIES OF KATAKUHIMATSHETA**

- If needed, approve the research agreement;
- Provide a mandate to the Research Coordination Committee.

## **4. ROLES AND RESPONSIBILITIES OF THE RESEARCHER**

- Respect the local protocol;
- Ensure that the research supervisor is present throughout the study's progress and at the research oversight committee;
- Carry out their activities with integrity, objectivity, good faith, good judgement, and professionalism, adapting their work when needed to the reality and needs of the office with which they are working;
- Agree on a plan with the organizer, meet deadlines and inform them of delays;
- Provide updates on research progress;
- Convey relevant information;
- Inform the relevant parties in case of conflicts;
- Ensure that their knowledge is transmitted and ensure the circulation of data (depending on the level of sensitivity and any related provisions in the agreement);
- Fill out the summary sheet.





## SUMMARY SHEET

Author:

Title:

Year:

Document type:

University:

### Research objectives

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### Methodology

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#### 1. Research method

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#### 2. Ethical challenges inherent to Indigenous contexts

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### 3. Methodological design

Sampling

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Data collection methods

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Data analysis and processing methods

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Data validation

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Results linked to initial objectives

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## THE ETHICAL EVALUATION OF RESEARCH WITH INDIGENOUS PEOPLES AT UQAT

NANCY CRÉPEAU AND  
PASCAL GRÉGOIRE

In the early 1970s, at the heels of the Parent Report, the Université du Québec (UQ) network was born. At its start, it was composed of the Université du Québec à Montréal (UQAM), the Université du Québec à Trois-Rivières (UQTR), the Université du Québec à Chicoutimi (UQAC), and the Université du Québec à Rimouski (UQAR). Northwestern Québec, for its part, had to wait until 1983 to have its own university, the Université du Québec en Abitibi-Témiscamingue (UQAT). Prior to that year, the people of Abitibi-Témiscamingue had access to a center for university services, which was annexed first to UQTR, then to the former Université du Québec à Hull (UQAH) (now the Université du Québec en Outaouais (UQO), and then finally to the head offices of the Université du Québec.

The name of this youngest addition to the UQ network speaks to its importance in the region: it is not the university of a city, but of an enormous region covering 65,000 km<sup>2</sup>. UQAT, which borrows its name in part from the Anicinabemowin<sup>1</sup>, extends its reach from "where the waters divide" (*Abitibi*) all the way to the "deep lake" (*Témiscamingue*).

However, the Indigenous influence at UQAT goes beyond a surface level, profoundly marking its development. In 1990, seven years after its incorporation, UQAT founded the Unit for Research, Training and Development of Education in Indigenous Contexts (URTDEIC), within the Educational Sciences Teaching and Research Unit (TRU). Still active and thriving to this day, the URTDEIC trains Indigenous teachers in ways that respect the cultures of the First Peoples. Later, the Indigenous Programs Development and Training Unit (IPDTU), was founded to create multi-disciplinary programs to study Indigenous issues. In 2009, the Val-d'Or campus of UQAT inaugurated the First Peoples Pavilion (Paul, Crépeau, Legault and Maheux, 2013). Then, in 2016, UQAT created its School of Indigenous Studies (SIS)<sup>2</sup>, the equivalent of a TRU.

The creation of the URTDEIC and the SIS stimulated an outpouring of research on the experience of Indigenous Peoples. This emerging research at UQAT, in addition to work being done at other Quebec universities, cast light on a number of serious ethical questions: how to evaluate the ethical acceptability of research in an Indigenous context? How to ensure that Indigenous participants in particular are

adequately protected? How to decolonize research so it can be carried out in a true spirit of collaboration between equals?

As a summary of the conference, this article addresses two questions. First, it examines how fundamental ethical principles, addressed in the *Tri-Council Policy Statement* (TCPS2, 2018) and the *First Nations of Quebec and Labrador Research Protocol* (AFNQL, 2014), are applied by UQAT's Human Research Ethics Board (REB). While there could be interest in studying and comparing the approaches of other human research ethics boards with those of the REB at UQAT, we chose to focus solely on UQAT's REB. The second goal of this paper is strictly pragmatic: we wanted to show how Indigenous individuals and issues are taken into consideration by the UQAT REB. These two aspects are respectively addressed in the first and second halves of this article.

### 1. INDIGENOUS PEOPLES AND RESEARCH ETHICS

The UQAT REB uses existing ethical and legislative frameworks to evaluate the ethical acceptability of research projects on Indigenous issues. In this section, we first present these frameworks (section 2.1.) and then examine

1 The Algonquin language.

2 The predecessor of the SIS, the Indigenous Programs Development and Training Unit (IPDTU), was created in 2007 as part of a strategy for approaching teaching and research among Indigenous Peoples (UQAT, 2007).

the ways they highlight certain ethical issues for research in Indigenous contexts (section 2.2.). Lastly, in light of this analysis, we propose certain ideas for decolonizing research (section 2.3) that can also guide the ethical evaluation of projects.

### 1.1. RESOURCES USED IN ETHICAL EVALUATIONS OF RESEARCH PROJECTS

In Canada and Quebec, major advances in the ethics of research in Indigenous contexts have generated a considerable number of protocols and guidelines—laying significant groundwork for scientific research on these questions. These resources aim to provide a framework for research and to encourage equitable practices. At the UQAT REB, as is no doubt the case in other REBs, multiple frameworks are used by members to evaluate research projects involving Indigenous Peoples. Researchers are also strongly encouraged to implement existing protocols or guidelines, which will be briefly described in the following paragraphs: the *Tri-Council Policy Statement* (TCPS2), the *First Nations in Quebec and Labrador Research Protocol*, the *Guidelines for Research with Aboriginal Women* and the *Toolbox of Research Principles in an Indigenous Context*.

Chapter 9 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (2018) focuses on “*Research Involving the First Nations, Inuit and Métis Peoples of Canada*”. Four editions of the TCPS2 have been published: 1998, 2010,

2014 and 2018. It’s also worth remembering that the first steps in research ethics regarding Indigenous Peoples in this country were only made following the 1996 report of the Royal Commission on Aboriginal Peoples. The ninth chapter of the TCPS2 aims to set guidelines for ethical conduct in research with Indigenous Peoples, in a spirit of respect for communities’ traditions and customs and of dialogue between researchers and participants, without trying to replace the ethical principles and protocols developed by Indigenous groups. The TCPS emphasizes the importance of respect for local Indigenous research protocols and an application of the principles of ownership, control, access and possession for research data (OCAP<sup>®3</sup>), allowing communities to protect traditional knowledge (APN, 2007). It also accounts for the different experiences of Indigenous individuals in urban contexts (CIHR, NSERCC and SSHRC, 2018).

The *First Nations in Quebec and Labrador Research Protocol*<sup>4</sup> (AFNQL, 2014), the first version of which was published in 2005, is a tool developed for the managers of First Nations communities and regional organizations, allowing them to provide guidelines for research taking place on their territory or with their people and even to “evaluate the feasibility and acceptability of a research project” (AFNQL, 2014, p. vi). It also seeks to raise awareness among First Nations communities and bodies about the importance of ethically responsible research and of creating an ethical space that respects: (a) the

fundamental values of First Nations in order to guide the research process (respect, fairness and reciprocity); and (b) basic research principles that consider the worldview and culture of First Nations. This document is indirectly intended for the scientific community, inviting them to include it among the other documents used by their research institutions. While the protocol uses the term “community,” it does not solely refer to band councils; it can also include other entities, depending on the context of the research.

The *Guidelines for Research with Aboriginal Women* (QNW, 2012) document was developed for use by Indigenous women as well as members and staff at Quebec Native Women. It is also intended for decision-makers or managers within Indigenous communities or in urban contexts, as well as researchers who want to develop a project involving Indigenous women. Its purpose is to accompany women in managing research project proposals and to help them make informed decisions on whether to participate in these projects. The document provides a brief summary of the context of research with Indigenous women, lists the baseline principles that researchers must take into account to respect the specific knowledge held by Indigenous women—which is essential for a holistic vision of the world and the research—and provide for their participation from the earliest steps of a research project (Ibid). These guidelines are currently being revised.

3 This collection of principles revolves around the question of ownership, control, access and possession of (OCAP<sup>®</sup>) research processes that affect participating communities, as well as research data (TCPS2, 2018). It represents guidelines intended to protect the ownership and jurisdiction of First Nations over their own data and knowledge. This data does not only include factual information, but also culture, identity, traditions and the self-determination of Indigenous Peoples (FNIGC, 2014).

4 This document is available on UQAT’s website at the following link: <https://www.uqat.ca/recherche/ethique/etres-humains/>



These three resources are crucial tools for the ethical evaluation of research with Indigenous Peoples in Quebec. However, they are not replacements for existing policies within First Nations communities. Researchers must acknowledge that “First Nations must provide governance in terms of information management and collective knowledge, which means that they must protect and preserve their informational heritage” (AFNQL, 2014, p. iii). For this reason, we suggest referring to another tool available online: the *Toolbox of Research Principles in an Indigenous Context: Ethics, Respect, Fairness and Reciprocity, Collaboration and Culture* (2015, 2018). From its first edition in 2015, the toolbox was designed to evolve according to the needs of the communities involved in issues around research ethics. It includes useful documents (e.g., procedures, guidelines and initiatives developed in Canada and around the world) and tools to support decision-making and discussions on these issues among community stakeholders. This long-term and unique project serves to document lived experiences and suggest resources to facilitate dialogue between researchers and communities (FNQLHSSC, UQO, UQAT and DIALOG Network, 2018).

To conclude this point, research ethics boards can recommend trainings or tools on the subject of research ethics as part of their educational role, as will be discussed later on. To that end, a group composed of REB members and UQAT staff collaborated on the development of a checklist to facili-

tate the analysis of research projects (whether directed by professors, graduate students, members of the UQAT community, or otherwise), particularly for Indigenous students who make use of UQAT’s different centers and campuses. In this way, staff members who provide information to students about these research projects can refer to this internal document to ensure that the methodology is in accordance with existing protocols. Guidance is provided for essential elements to be considered.

## 1.2. ETHICAL ISSUES AND STEPS TOWARDS DECOLONIZING RESEARCH

Due to its geographic location, UQAT has special ties to First Nations communities; due to its history, it has also established close relationships with many Inuit communities. As a result of these ties, the UQAT REB is often asked to evaluate projects involving Indigenous communities. Over the course of its activities, the work of its members has revolved around certain issues concerning the three base principles of the TCPS2: respect for persons, concern for welfare and justice. While morally unacceptable situations are no longer the norm in research, human research ethics boards must still ensure that participants are protected.

### 1.2.1. Respect for Persons

As stated in the TCPS2 (2018), “an important mechanism for respecting participants’ autonomy in research is the requirement to seek their free, informed and ongoing consent.” (p. 6). For Indigenous Peoples, the requirement of respect for persons has an even wider scope: it also includes the interconnection between humans and the natural world and includes obligations to maintain one’s cultural identity and the knowledge received from ancestors (Asselin and Basile, 2012, p. 335).



This obligation is therefore of particular concern to UQAT's REB from the very first moment it begins evaluating a research project involving Indigenous individuals. Ensuring participants can understand all of the information provided by the researchers, without the slightest ambiguity, is a major issue. Ensuring this level of clarity is the first measure to implement in order to reduce the chance of misunderstandings or even deception.

A major factor that can act as a barrier to understanding is, without a doubt, the multilingual context of many communities where traditional languages, English and French are used and understood to varying degrees. Human research ethics boards must ensure that the language of communication does not create a barrier to understanding the research and securing the participant's consent. The expertise of Indigenous REB members is crucial in these cases because they, more than any other member, understand the particular context of communities involved in the research.

That being said, factors other than language can occlude understanding information about the research and participant consent. As soon as a participant's autonomy is "impaired or diminished" (CIHR, NSERCC and SSHRC, 2018, p. 6), the UQAT REB must ensure that specific precautions are taken. This could be the case for research carried out with marginalized Indigenous participants, due to the vulnerable situations they are experien-

cing (e.g., homelessness) or higher-risk activities they are involved in (e.g., sex work). Human research ethics boards can suggest to the research team that they collaborate with community organizations that work with Indigenous individuals to provide information to potential participants. After being informed of the existence, objectives and methodology of the project, these organizations can serve as a resource to help marginalized Indigenous individuals in need of support consider their participation. If this collaboration is established early on in the research project, it can help increase the cohesion of researchers, on the one hand, and community workers on the other.

This is why researchers should *familiarize themselves with the environment where they wish to study* before even beginning the process of developing a project related to Indigenous issues. This includes: 1) the social, political, cultural, linguistic and institutional context of the research; 2) research priorities and needs within the community or communities; and 3) the different existing research protocols, so researchers can determine how best to integrate them into their process (INQ, 2017). Papatie and Brazeau (2012) point out that communities have devoted a considerable amount of time to educating researchers (e.g., on the role of elders in Indigenous society, the relationship to land, culture, etc.) and believe that researchers should be more prepared when entering Indigenous communities. Elsewhere, Asselin and Basile (2012) summarized the discourse that

emerged from the *Second Seminar on the Ethics of Research with Indigenous Peoples*, held at UQAT in 2011, regarding best practices for recruitment and consent of Indigenous participants in research, for developing agreement protocols between the concerned parties and for recognizing the contributions made by participants.

The first meeting with the community must be well planned in advance by the researchers (INQ, 2017) in order to develop a relationship of trust. From the start, research objectives must be clearly explained in layman's terms so that community managers can make an informed decision about whether or not to participate in a study. At a seminar on research, ethics and Indigenous communities organized by UQAT, some community managers reported that research projects don't always provide enough specifics on their methodology and that predetermined timelines are not always realistic (Basile, Champagne, and Crépeau, 2009; Papatie and Brazeau, 2012). The research strategy must be flexible enough that researchers can take the time to converse with people, get to know them and adapt their approach as needed (da Silveira, Jacob, Pellerin and Paul, 2018; Kovach, 2010; Lachapelle, Maltais-Thériault and Puana, 2018; Wilson, 2008).

### 1.2.2. Concern for Welfare

Researchers concerned for the welfare of their participants must take a multitude of factors into account when planning their interactions: "physical, mental and spiritual health, as well

as their physical, economic and social circumstances. Thus, determinants of welfare can include housing, employment, security, family life, community membership and social participation.” (CIHR, NSERCC and SSHRC, 2018, p.7). For example, when we know that Indigenous households tend to be overcrowded (Statistics Canada, 2017), it could be inappropriate, even thoughtless, to suggest that a participant take part in a remote interview from their home. Studies taking place in Indigenous communities, more than those situated elsewhere, must account for traditional knowledge<sup>5</sup>. The research team must be aware of the people involved in their research and ensure that they are treated with respect and fairly portrayed.

Questions of confidentiality and protection of personal data are another subject of interest for human research ethics boards, especially when participants are part of a marginalized minority group. This marginalization can manifest as part of a larger context of extreme tensions—one must only think of the social crisis in Val-d’Or in 2015. Protecting participants is more crucial than ever in this context. For example, if a research project exposes some illicit activity by Indigenous individuals, they are more likely to suffer reprisals than non-Indigenous individuals. Because they may already be victims of racial profiling, they may also be subject to more active police surveillance (Public Inquiry Commission on relations between Indigenous Peoples and certain public services in Québec: listening,

reconciliation and progress., 2019; Ontario Human Rights Commission, n.d.). Whenever necessary, human research ethics boards should suggest giving an active role to community organizations that work with Indigenous individuals to help provide information to potential participants.

Lastly, concern for welfare also includes positive elements, like the possibility of accessing benefits from research. Ethics boards are also responsible for analyzing plans for the communication of research findings. These must be presented to the Indigenous communities involved, so that their fairness can be evaluated by community members. Indigenous communities consider research to be of great value and use. It should lead to clear benefits, such as developing individual skills and the transfer of knowledge, with the goal of having communities appropriate and apply the research findings (Asselin and Basile, 2018). This work should be done in a dynamic of reciprocity, a fundamental value for many Indigenous cultures. For example, offering something in exchange for the effort required to mobilize community members to help carry out a research project (*Ibid*).

### 1.2.3. Justice

Recent scientific research is often on Indigenous communities, without involving them as partners at every step of data collection. This method does not consider the fundamental power imbalance between researchers, coming from a dominant cultural group, and Indigenous participants, as members of

a minority group.

This inequality can run counter to First Nations’ right to self-governance: by failing to return data or to consider community values, researchers have been able to hoard traditional knowledge that is the rightful property of Indigenous Peoples. In a context of structural inequality, specific measures must be taken to ensure fair and equitable treatment. As the TCPS2 reminds us, “treating people fairly and equitably does not always mean treating people in the same way.” (CIHR, NSERCC and SSHRC, 2018, p. 8)

As a result, human research ethics boards must carefully consider the degree to which the principles of ownership, control, access and possession (OCAP®) are respected regarding research data. These principles, recognized by both the TCPS 2 (CIHR, NSERCC and SSHRC, 2018) and by the *First Nations in Quebec and Labrador Research Protocol*, work toward restricting the ability of a majority group to build intellectual equity at the expense of minority communities, who are then deprived of that equity. It also seeks to attribute certain rights to communities that are not specifically recognized in studies carried out in majority contexts: for example, we can mention the data-validation procedures carried out with Indigenous communities.

This validation procedure seeks to ensure the fairness of findings, especially if the data have been translated into an Indigenous language, and should be carried out before analyzing results and

5 UNESCO (2007) defines traditional knowledge as: “Knowledge, innovations and practices of indigenous and local communities across the world. Developed from experience gained over the centuries and adapted to the local culture and environment, traditional knowledge is transmitted orally from generation to generation. It tends to be collectively owned and takes the form of stories, songs, folklore, proverbs, cultural values, beliefs, rituals, community laws, local language and agricultural practices, including the development of plant species and animal breeds.” (<http://uis.unesco.org/en/glossary-term/traditional-knowledge>)

before publication. If needed, Indigenous partners can ask to review the researchers' analysis and interpretations. Lastly, it's crucial to have a communication strategy for sharing research findings using clear and accessible language so that communities can see the benefits of the research and make use of them in their environment (INQ, 2017).

### 1.3. DECOLONIZING RESEARCH IN INDIGENOUS CONTEXTS

Research involving Indigenous Peoples has undergone a major evolution over the past few decades. Communities have taken ownership of research projects and their protocols foster the creation of an ethical environment and a relationship of trust between researchers and participants (Kovach, 2019; Potts and Brown, 2015; Smith, 1999). The emergence of these changes has helped Indigenous Peoples move from being the *subjects* of research to *stakeholders* in it. These new practices have had an impact on reinforcing local autonomy in communities because they give communities decision-making powers over the research process based on their own priorities (Lévesque, Cloutier and Salée, 2013).

Considering the spike in interest for Indigenous issues among researchers and graduate students, universities in Quebec, and in Canada more broadly, should follow UQAT's example and reserve a seat on their human research ethics boards for an Indigenous representative. However, our opinion re-

mains that this practice alone cannot contribute to decolonizing understandings of and research with Indigenous communities and that this work should be done upstream of ethics boards.

A review of the literature reveals a number of elements related to decolonizing research in Indigenous contexts. According to many authors, decolonization requires researchers to shift the focus of their attention away from the research objectives and toward the community's concerns by adopting Indigenous perspectives, knowledge and methodologies (Asselin and Basile, 2018; Kovach, 2019; Potts and Brown, 2015; Prior, 2007; Wilson, 2008). The following questions have been suggested as a way to guide researchers in their considerations:

- What culturally appropriate practices will ensure that my research unfolds smoothly?
- How will the methods used in my research contribute to establishing a relationship of mutual respect with participants and Indigenous communities?
- Will teaching and sharing take place in a reciprocal manner in this relationship?
- How will my practices as a researcher contribute to deconstructing colonialist structures and power dynamics?
- How will my practices be accountable to Indigenous bodies involved in the research?

As Kermoal (2018) brings up, respect for traditional Indigenous knowledge

does not only apply as part of a "special" educational project intended for an Indigenous audience. As institutions, universities have a larger scope of responsibility in the reconciliation process between Canadians and Indigenous communities. Because research contributed to the marginalization and dehumanization of Indigenous Peoples (Smith, 1999), decolonizing knowledge involves creating more space for Indigenous epistemologies by integrating them into the curriculums of graduate research programs. This approach will allow students to understand the impacts of past colonialist research on Indigenous "subjects" as well as the relationship these Peoples had with research. We need only cite a few examples of research funded by the Canadian government to support this claim, such as the experimental study carried out in the 1960s on three twelve-year-old Inuit children with the goal of determining whether they were as intelligent as "children from the South" who had been educated according to Euro-Canadian norms (Greenwald, 2009). Another example is the experimental study carried out in the 1940s, this time in the field of health, in which nutritional specialists used underfed Indigenous children in Manitoba residential schools to explore the health effects of malnutrition (McGregor, 2018; Mosby and Galloway, 2017). These children were seen as tools, and residential schools as laboratories to be exploited by researchers. These practices must be recognized and remembered in order to understand how the colonialist ideology that guided Canadian policy



at that time influenced the suffering inflicted on Indigenous Peoples in the name of research. In short, these historical elements can raise awareness among stakeholders in the research process about the importance of developing ethical strategies and help them understand research as a process that can help us move towards reconciliation.

## 2. UQAT AND THE ETHICS OF RESEARCH INVOLVING INDIGENOUS ISSUES

As we saw in the previous section, the ethical evaluation of research projects involving Indigenous participants must be guided by principles beyond those listed in the TCPS2. In this section, we explore how the UQAT REB implemented practices to accomplish this goal. We begin by presenting the purpose and structure of the UQAT REB (section 2.1) before moving on to explore the history of including Indigenous representatives on the board (section 2.2.). Lastly, we provide a general overview of the research projects examined by the UQAT REB involving Indigenous Peoples.

### 2.1. THE UQAT REB: MANDATE, ROLE AND STRUCTURE

The UQAT REB is overseen by the Vice-Rector for Teaching, Research and Creation (VRTRC). As described in the *Institutional policy for research ethics*<sup>6</sup>, the UQAT REB is responsible for the ethical evaluation of all research pro-

jects organized by the university's researchers, as well as by any researcher wishing to collect scientific data from UQAT students, teachers or staff. It goes without saying that UQAT's REB must evaluate projects from all researchers, whether they are students or professors.

At its core, the UQAT REB seeks to analyze the degree to which a collection of principles or moral imperatives linked to conducting a research study are respected (UQAT, 2015, p. 1). Specifically, it considers respect for persons, concern for welfare and justice. To do so, three frameworks guide the board's analyses and decisions: first, the Civil Code of Quebec, specifically section 21<sup>7</sup>; secondly, the *Tri-Council Policy Statement* (TCPS2), developed by the Secretariat on Responsible Conduct of Research (2018); thirdly, the *First Nations in Quebec and Labrador Research Protocol* (AFNQL, 2014).

Alongside its work evaluating the ethics of research projects carried out at the University, the UQAT REB also has an educational role within the university community. This role can take many forms, including responding to questions from researchers or offering training sessions or materials<sup>8</sup> related to research ethics.

The UQAT REB has fifteen members, both men and women, in accordance with the recommended composition laid out in article 6.4 of the TCPS2 (2018). As such, the board includes seven professor members and three

students from the RTU, all from the schools or institutes of UQAT. In addition to these members, the UQAT REB includes one person specializing in ethics, one person with legal expertise and one person representing socio-economic diversity.

However, what sets the UQAT REB apart, and has for more than a decade, is the inclusion of two members selected by Indigenous communities. These members don't just evaluate research projects taking place in an Indigenous context: as full-fledged members, they participate in the evaluation of every research project submitted to the REB. The board chose this approach to avoid tokenizing its Indigenous members by relegating them only considering issues related to First Peoples. While their presence on the board is largely taken for granted today, this hasn't always been the case. In fact, their full inclusion was the result of a series of discussions within the board.

### 2.2. THE PRESENCE OF INDIGENOUS REPRESENTATIVES ON THE UQAT REB: A HISTORY

An Indigenous professor first joined the UQAT REB in 2007, participating actively in the evaluation of research projects involving Indigenous issues. While his contributions to the board are undeniable, there wasn't yet a permanent, reserved seat on the board for an Indigenous representative. This was for two reasons: First, as we'll see a bit later, the marked increase in research projects on Indigenous issues at UQAT

6 The policy is available online at the UQAT REB website at the following link (in French): <https://www.uqat.ca/recherche/ethique/etres-humains/doc/politique-ethique-recherche-etres-humains-juin-2015.pdf>

7 Article 21 of the Civil Code of Quebec (para. 6) states that "Consent to research that could interfere with the integrity of a person of full age incapable of giving consent may be given by the mandatary, tutor or curator. However, where such a person of full age is not so represented and the research involves only minimal risk, consent may be given by the person qualified to consent to any care required by the state of health of the person of full age." In practice, REBs require parental consent in any project involving minors under the age of 14.

8 In line with this, a practical tool is presented further on for analyzing research projects led by researchers from other universities that recruit Indigenous students at UQAT.

didn't really begin until around 2006-2007. Second, the way that Indigenous issues were handled by human research ethics boards in 2007 was quite different from today's approach. At that time, chapter 9 of the TCPS2 (Research Involving the First Nations, Inuit and Métis Peoples of Canada) *hadn't even been developed*; only one chapter began to address that question (at that time, chapter 6).

Two years after this professor joined UQAT's REB, the *First Seminar on the Ethics of Research with Indigenous Peoples* was held. In that same year, the First Peoples Pavilion was inaugurated at UQAT's Val-d'or campus (Basile, Champagne, and Crépeau, 2009). The first edition of this ethics seminar, held on May 27 and 28, 2009, welcomed 37 participants and featured discussions on the expectations that local Indigenous communities and organizations had for researchers studying First Peoples, among other topics.

Sioui (2011) notes that many ethical problems were raised at that first seminar, bringing to light some specific sources of unease: Indigenous communities were literally under siege by research teams from multiple Quebec universities; approaches to research, often approved in advance by funding partners, left very little room for dialogue with First Peoples; the sometimes redundant research often focused on trauma experienced by Indigenous communities, without consistently referring to prior research on the subject carried out within communities; researchers

neglected other, more compelling elements such as questions of identity, culture, land, environment, education and health; research studies had a tendency to compare communities against one another in a detached way; and, finally, research was often carried out at breakneck speeds, pushed by timelines developed for funding partners rooted in an unforgiving standard of productivity. This expeditiousness runs counter to the culture of openness and exchange valued by Indigenous traditions.

To sum up the problem: institutions carry out research *on* Indigenous communities, not *with* Indigenous communities. However, as Sioui notes (Sioui, 2011), scientific research has a tremendous potential for First Peoples and offers compelling work opportunities to community members who may not have a formal educational background. Due to the problems mentioned earlier in the text, communities are all too often unable to benefit significantly from research. This brings us to another major ethical dilemma: how can community leaders evaluate the ethics of research proposals if they lack the expertise to judge their relevance or quality? One realistic way REBs can support communities would be to develop short training programs, perhaps in the form of a series of videos or written reference guides, that highlight the important elements for consideration when a researcher wishes to carry out a project in the community.

All of these problems, including the challenges involved in consolidating

the next generation of Indigenous scientists, demonstrate the important role that UQAT's REB can play. Sioui (2011, p. 25) insists on the board's educational mission, which must be kept at the forefront through a number of means.

(paraphrased from the original French) *Of course, we understand that the ethics board, the university's REB, must play an educational role, because one of the mandates of a REB is to train people. We're not here to judge research projects or throw them in the dustbin; we're here to train people. The question of how we can play this educational role has come up in the past, and we considered—more in the second day [of the first seminar]—that it would be important to have one or two members of the university's Human Research Ethics Board who came from [Indigenous] communities.*

This proposal was well received by the first seminar's attendees, and later within the various institutional bodies at UQAT. As a result, two seats for Indigenous representatives were added to the UQAT REB in the 2009-2010 school year<sup>9</sup>: one for a permanent Indigenous representative and the other for an alternate Indigenous representative. Following a public call for candidates and consultation with Indigenous communities, the two seats were filled.

The role of social circumstances in the creation of these two seats should not be ignored. Following a country-wide

9 The Policy on ethical conduct for research involving humans at UQAT was changed at this time to amend the composition of the UQAT - REB (UQAT, 2009).

consultation of Indigenous groups and communities, a new edition of the TCPS2 was published in 2010, including a more detailed chapter on research involving Indigenous people. It was widely discussed at the *Second Seminar on Research in Indigenous Contexts*, held at UQAT on September 20, 2011, on the topic of dialogue between Indigenous communities and researchers.

On the heels of these discussions, UQAT made significant updates to its institutional policy on ethical conduct for research involving humans. In so doing, UQAT's intentions were to set itself apart within the UQ network by continuing to carry out research that is responsive to the needs of these communities, with the approval of Indigenous communities that are involved (UQAT, 2015). The purpose of the modifications was to ensure that research projects involving Indigenous Peoples were subject to particular scrutiny (UQAT, 2015). While the role of the Indigenous representatives within UQAT's REB had already been officially recognized by the university, UQAT's policy updates confirmed its position.

UQAT's institutional policy on ethical conduct for research involving humans also provided guidelines for nominating Indigenous representatives. Candidates responding to an open call must have the support of an Indigenous community in order to fill one of the two reserved seats. All other elements of the recruitment process follow UQAT's REB standard policies.

The two Indigenous seats were filled for the first time from 2011-2013. The terms of these two first representatives were renewed once; both remained at the UQAT's REB until 2016. Two new members replaced them at that time and remain there today. The evolution of this Indigenous presence at the UQAT REB occurred alongside the emergence of prolific research on Indigenous issues. The next section will provide an overview of this research using the available data.

### 2.3. EVALUATION OF RESEARCH PROJECTS INVOLVING INDIGENOUS PEOPLES AT THE UQAT REB

As was addressed in the first part of this article, the UQAT's REB process for studying projects involving Indigenous Peoples includes ensuring the research team has devoted sufficient consideration to the reality of Indigenous communities. In general, six recurring questions guide its interactions:

- Verification that the OCAP<sup>®10</sup> principles are respected;
- Indigenous communities and individuals can benefit from the research or its findings;
- Consultation or active participation of Indigenous communities, community organizations or Indigenous groups affected by the project. A letter attesting the community's support for the research is required in cases where the project is taking place on Indigenous land or under the community's authority or supervision;
- Consideration for the particular linguistic context of Indigenous communities where the research will take place;
- In cases where research will involve the participation of especially vulnerable Indigenous individuals or individuals who are taking part in potentially illegal activities:
  - evaluation of ability to provide consent;
  - implementation of enhanced measures to protect participant anonymity;
  - implementation of enhanced measures to shield data from any future legal proceedings<sup>11</sup>;
  - implementation of measures to ensure that participants have adequate and appropriate support resources following their involvement in the study;
- Overall, the presence of practices that seek to decolonize research (e.g., results validation, knowledge transfer, training and skills development, etc.).

10 Respect for the principles of OCAP<sup>®</sup> must be in accordance with laws on privacy and data confidentiality, as specified in chapter 5 of the TCPS. Researchers who wish to share personal data with community partners must first obtain the consent of the participant in question.

11 This is in reference to the Maillé affair (2015). After researcher Marie-Ève Maillé refused to share sensitive research data with a private company, the company pursued legal action and obtained a court order requiring the researcher to provide access to her data, including confidential information. At first, UQAM refused to support her, but it capitulated following the media attention created by the court order. The matter was ultimately ruled in favour of the researcher. Given this dangerous precedent, the UQAT REB works to ensure that data gathered in the context of very sensitive research cannot be used to identify participants in any manner, even if seized by a third party.

Over the last fifteen years, the volume of studies involving Indigenous communities has grown considerably. These studies have been carried out both by professors working within different RTUs as well as by UQAT graduate students (2019). The table below provides an overview of the number of research projects evaluated, sorted by field of study.

Looking at the data collected by the *Vice-rectorat à l'enseignement, à la recherche et à la création (VRERC)* over the years, we note that the first research project involving Indigenous

issues that was evaluated by the UQAT REB was in the field of Applied Sciences (Forestry) in 2004-2005<sup>12</sup>. Bear in mind that this research approach was studied by the UQAT's REB due to its social composition<sup>13</sup>.

Over the past fifteen years, the number of research projects on Indigenous issues at UQAT has evolved. In total, 407 research projects involving human beings were carried out at UQAT since the 2004-2005 school year. Among that number, 72 were linked to Indigenous issues, for a ratio of nearly 18%. Overall, most of these studies

are in the fields of Human and Social Development (HSD), Indigenous Studies and Education. Fully half of the 72 studies were in the field of HSD. The School of Indigenous Studies (SIS)<sup>14</sup> has conducted 13 research studies since its creation (Université du Québec, 2016). It is worth noting that the three HSD research studies conducted in the 2015-2016 school year were carried out by professors in the Indigenous Training and Program Development Unit, the administrative and academic body that preceded the SIS. 13 research projects were carried out in Education Sciences. These data present an overview of the research related to Indigenous issues that were evaluated by the UQAT REB. However, we are conscious that these findings may not be exhaustive: studies may well have included Indigenous participants without the research focus being on an Indigenous issue. The data presented above doesn't include such projects.

| Academic year | Education | Human and social development | Forestry | Health   | Management | School of Indigenous Studies | Indigenous Research Projects | TOTAL      |
|---------------|-----------|------------------------------|----------|----------|------------|------------------------------|------------------------------|------------|
| 2004-2005     |           | 1                            |          |          |            | 1                            |                              | 12         |
| 2005-2006     | 3         |                              |          |          |            | 3                            |                              | 16         |
| 2006-2007     | 5         | 1                            |          |          |            | 6                            |                              | 32         |
| 2007-2008     | 4         |                              |          |          |            | 4                            |                              | 20         |
| 2008-2009     | 2         | 1                            | 1        |          |            | 4                            |                              | 34         |
| 2009-2010     | 1         | 5                            | 2        |          | 1          | 9                            |                              | 22         |
| 2010-2011     | 2         | 4                            | 1        |          |            | 7                            |                              | 23         |
| 2011-2012     | 4         | 4                            |          | 1        |            | 9                            |                              | 33         |
| 2012-2013     | 2         | 3                            |          |          |            | 5                            |                              | 31         |
| 2013-2014     |           | 1                            |          |          |            | 1                            |                              | 25         |
| 2014-2015     |           |                              | 1        |          | 1          | 2                            |                              | 19         |
| 2015-2016     | 1         | 3                            |          |          |            | 4                            |                              | 27         |
| 2016-2017     | 1         | 1                            |          |          | 7          | 9                            |                              | 41         |
| 2017-2018     |           | 1                            |          |          | 4          | 5                            |                              | 37         |
| 2018-2019     |           | 1                            |          |          | 2          | 3                            |                              | 35         |
| <b>Total</b>  | <b>13</b> | <b>36</b>                    | <b>7</b> | <b>1</b> | <b>2</b>   | <b>13</b>                    | <b>72</b>                    | <b>407</b> |

**Table I**  
**Overview of Research on Indigenous Issues Evaluated by the UQAT REB**

<sup>12</sup> The 2004-2005 school year was our starting point, as the first year in which a research project on Indigenous issues was entered into the VRERC's database.

<sup>13</sup> In general, research projects on groundwater, forestry or mining (to give just a few examples) are not studied by the UQAT REB, even if they take place on Indigenous land, because data collection is not carried out with human participants.

<sup>14</sup> The mission of the School of Indigenous Studies (SIS) is to develop university programs that respect the worldview of Indigenous Peoples, as well as teaching at every level of study and carrying out research in partnership with the communities.



### 3. CONCLUSION

This article began by presenting an overview of the ethical issues that members of human research ethics boards should concern themselves with when analyzing studies that take place in Indigenous contexts. We then demonstrated how this work is structured within the UQAT REB. After presenting its structure, we retraced the historical presence of Indigenous representatives on the board, and then presented a summary of research on Indigenous issues. We recognize that there is sufficient documentation proposing action plans to decolonize research, motivating us to insist that these resources be made available to communities and researchers. While certain methodologies can be presented as ethical cure-alls for working with marginalized populations, such as collaborative research or research-action, Bousquet (2019) highlights the limitations of these approaches, whose expected effects are sometimes overestimated by other members of research teams or Indigenous partners. This is why it is so important to consult with communities before developing a research project of this nature to ensure that partners are aware of the implications and that the project addresses real needs. Researchers must be aware that many communities already lack resources and staff to meet their needs, leaving them overburdened (Bousquet, 2019).

To conclude: universities have a crucial role to play in training the next generation of researchers to conduct research with Indigenous peoples, regardless of their chosen field of study. These academics must be called on to recognize and reconsider the fact that Indigenous issues are, in fact, Canadian issues, because they are part of a colonialist historical context (Beauclair, 2015; Johnston, McGregor and Restoule, 2018; McGregor, 2018). This means that researchers must develop a critical posture toward research "on Indigenous subjects" from past decades, many of which are based on ethnocentric interpretations. It must be noted how this research, which often serves as a reference point for advances made in a given field, failed to consider the perspective of those being studied. It is our opinion that future research should contribute to rebuilding an equitable relationship between the two parties.



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# LESSONS IN IMPLEMENTING “ETHICS IN RESEARCH”: LOCAL INVOLVEMENT IN A COMMUNITY-BASED RESEARCH SETTING

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## ABSTRACT

This paper aims to inform about efforts being carried out in the Cree Nation of Chisasibi to create a community-based/community-driven research centre and to implement research projects and programs that reflect community concerns and interests. We discuss how a community of 4,600 people in Eeyou Istchee/James bay (Quebec, Canada) collectively decided to implement grassroots research for their own benefit. We also discuss how the involvement of other research partners is negotiated and operationalized. In the context of research in a small community, the concept of Ethics can be envisioned from a broad range of points of view ranging from the perspective of a university ethics review board to that of a traditional hunting unit. We argue that ethical research may imply the reliance on community-based research strategies from its beginning to its end. In studies where community members are themselves the “subjects” of research as well as when it concerns their ancestral lands. The Chisasibi Eeyou Resource and Research Institute proposes a model and examples to conducting what is envisioned as both community-based/community-driven research and ethical research.

## THE CREE NATION OF CHISASIBI (OR THE PEOPLE OF THE GREAT RIVER)

The Cree Nation of Chisasibi is a community of around 4,500 Cree<sup>1</sup> and 100 Inuit residents located in eastern James Bay/Eeyou Istchee. Chisasibi is one of the five coastal communities of eastern James Bay and one of the ten Cree communities in Quebec. The traditional territory of the Chisasibi Iiyiyiuch (Chisasibi Crees) covers an area of 82,000 square kilometers dominated by lichen woodland from the eastern coast of James Bay to the center of Quebec. This territory also connects the James Bay to the Hudson Bay in the north. It is the traditional land of Cree and Inuit families since time immemorial. The youth of Chisasibi (under 30 years old) represent 50% of the total population and their proportion is called to grow in the next decade.

<sup>1</sup> Aboriginal population in Quebec 2015, <https://www.autochtones.gouv.qc.ca/nations/population.asp>

## INTRODUCTION

The desire to empower the community of the Cree Nation of Chisasibi toward scientific research was first expressed with the publication of the Migratory Bird Habitat Task Force report in March 2016. The task force was initially created to identify gaps in knowledge between scientific literature and Cree Traditional Ecological Knowledge (TEK) in regard to the disappearance of ecosystems important to migratory waterfowl in James Bay, specifically that of the eelgrass meadows (*Zostera marina*). One of the report's recommendations was for research to accommodate multiple world views through the creation of a community-based research centre. Thus, since 2016, the Chisasibi Eeyou Resource and Research Institute (CERRI) has constituted a small research team carrying out research in the Chisasibi territory and addressing the concerns and interests of community members and active land-users with the help of environmental and social sciences. The issue of the reduction of migratory waterfowl habitats along the James Bay coast, including the loss of eelgrass, remains central to many of CERRI's projects and has steered the composition of the research team. The organisation is overseen by a Board of Directors composed of community members and now has three full-time employees: an anthropologist, a marine biologist and a research assistant. The goal of this paper is to share how our organisation has developed its own way of integrating local ways of doing and local ways of knowing into scientific research and the results that have

come from this combination. The centre has been inspired, developed and built around best practices in research with indigenous communities, community members' own experiences with research on their territory and the specific needs and ambitions of the Cree Nation of Chisasibi. Accordingly, three main components constitute CERRI's community-based approach and will be discussed in detail throughout the text: youth involvement and the engagement of Cree traditional land tenure; the development of a local *culture of research*; and the permanency of the research team in Chisasibi.

This paper provides an overview of community-based research carried out at CERRI over the last four years and highlights how past and present challenges have been overcome in order to conduct ethical research throughout the implementation of the centre. In addition, we discuss how a culture of research specific to the community's needs, interests and organization is created through the participatory research approach. The article is divided into five sections: a description of CERRI's roles in the Cree Nation of Chisasibi, an overview of how participatory research is implemented, an examination of the way Traditional Knowledge (TK) and Western scientific methodologies complement each other in CERRI's projects, an introduction to the CERRI Code of ethics and, finally, a summary of the challenges faced by CERRI. We posit that ethics in research is closely connected to cultural context and world view. We argue that the community-based

and participatory research model developed by our team in Chisasibi supports a relationship between the researchers and community members, in turn allowing the research carried out in Chisasibi to be deemed ethical.

## HOW CERRI CAME TO BE

Following the recommendations of the 2016 Migratory Birds Habitat Task Force report (Migratory Birds Habitat Task Force, 2016), CERRI was developed as a community-based centre to allow research to be conducted within the Chisasibi community. The objectives of the research centre prioritized the protection and preservation of knowledge critical to the pursuit of Cree traditional activities and land use. The report also recommended that TEK provided by Cree hunters and trappers be documented through a community-based approach that would allow the data collected and the information created to be managed and controlled by the Cree, "...information should be shared with the other coastal and inland Cree communities and researchers as required and requested," (p. 39). In addition, it was acknowledged that CERRI would implement research projects that would meaningfully involve members of the community at every step of the research process and that the centre would train younger generations to conduct field research and laboratory analysis.

CERRI's founding was closely linked to a collective determination to conduct research in which Chisasibi liiyiuch

could see themselves and which could empower individuals toward studying and engaging in the Cree way of life<sup>2</sup> and identity. Central to this goal was the desire to see Cree TK and TEK<sup>3</sup> being used to write the initial research guidelines of each project. Accordingly, the research design process employed at CERRI involves a set of steps to ensure the centre's overarching goals are met. The first step in any of the centre's projects is the consultation of TK/TEK<sup>3</sup> holders. The knowledge they provide along with the collective priorities of the consultees establishes the initial project guidelines and steers its design (Figure 1). Additionally, areas of interest to community members are continuously discussed and compiled in an ever-growing list of research topics at CERRI. These topics are reviewed at the outset of a given study in order to determine whether the study can be adapted to examine certain recurring themes pulled from this bank of inquiries. The CERRI research team then seeks out research partners and collaborators. The spirit behind these partnerships is one of co-creation of knowledge between two different knowledge systems (Western Science and Cree Traditional Knowledge) existing as equals and being utilized in a complementary fashion (see Tengö, et al., 2014). Projects are developed with different partners under the premise that research should have positive impacts on the community not only

through its results, but through the way in which it is conducted, "...the process of research [is] as important to the project as its outcomes," (Jacklin & Kinoshameg, 2008, p. 55). Collaborators are thus asked to leave some expertise with the community in the form of various types of legacies that can be appropriated by the youth and their families. We offer strategies to reach this objective through culturally meaningful research logistics, relevant research topics and local youth involvement. This can include the production of pamphlets on research results or the creation of short subject-specific teaching curriculae which can be taught in local schools and which make clear the link between research subjects and the Cree way of life. Such subjects include hunting and fishing activities, travelling on the ice or the sea, wildlife behaviour, bush-food quality, water quality, etc. The intention has been to make explicit the link between activities that are familiar to the youth and their families and the objectives and results of research projects. An example of this, as a result of one of CERRI's ongoing studies, was to explain to high school students the links between ecosystem productivity, the sugar content in plants and the taste and quality of the waterfowl they hunt.

- 2 The literature on the Cree way of life (specifically the Eastern James Bay Crees of Quebec) is extremely vast and dates back to the beginning of the century with the immense contribution of Franck Speck's fieldwork, among others, and that which was carried out between the 1950s and 1980s (Leacock, 1954; Feit, 1973; Berkes, et al., 1978). The papers in *Anthropologica* Vol. 28 (1986) "Who Owns the Beaver? Northern Algonquian Land Tenure Reconsidered" also contributed to the study of the Cree way of life in Eastern James Bay. In the context of the present paper, however, this term is used in the way that it is used by Chisasibi Iiyiyiuch, to refer to their collective traditional way of life or Iiyiyiu Pimatseewin rather than how this way of life has been described by scientists.
- 3 Similarly to the use of "Cree way of life", the use of the terms TK and TEK are quite vast and are usually employed in the way they are used by community members to differentiate scientific knowledge from Cree knowledge. Therefore, in the context of this paper, *Traditional Knowledge* designates the collective knowledge of the Cree concerning their way of life and their history, while *Traditional Ecological Knowledge* refers to the collective knowledge specific to natural ecosystems, wildlife and their dynamics.

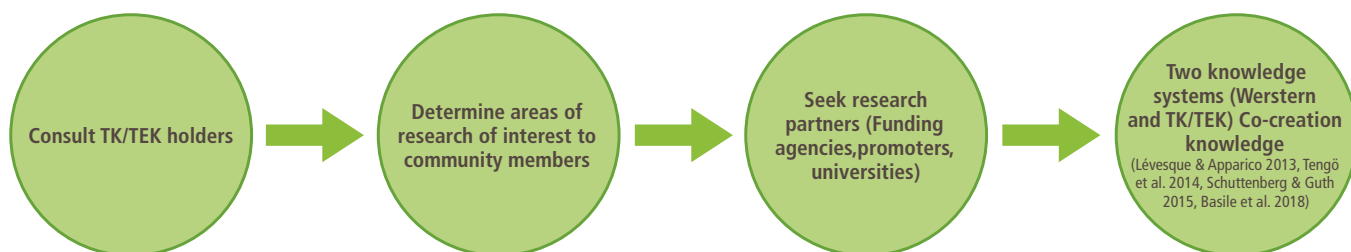


Figure 1. Co-creation of knowledge process in community-based research.

## CERRI'S VARIED ROLES

### RESEARCH INITIATOR AND RESEARCH SUPPORT

CERRI's primary role is that of research support and a research initiator for the community. This means that it welcomes collaboration with outside organizations when it is meaningful to the community and, that it conducts its own research projects. At the moment these projects include topics in anthropology, archaeology and coastal ecology. Research facilities include a laboratory and an office space in the community as well as a land-based education camp and field laboratory on the James Bay coast. Each field intervention is an opportunity to hire young community members and have them experience the practice of research firsthand. These youth are recruited among the families of each Chisasibi trapline<sup>4</sup>. As a result, in addition to obtaining meaningful personal experiences of science in the field, the youth become the resource people for the project among their trapline peers and their families. Interactions around research projects promote horizontal knowledge transmission between community members and researchers as well as between the researchers themselves and their co-researchers (usually youth trainees). Further, these interactions allow for ver-

tical knowledge transmission between different generations of land-users.

### SAFE DATA REPOSITORY

The second role played by CERRI is that of a safe repository for data collected in the community and for research results obtained through different projects. Information collected by researchers is stored electronically or filed in a locked room<sup>5</sup>. Access to data is approved by the CERRI board or in some cases by the original source that shared it. Access control becomes fundamental when the data consist of TK and TEK collected through interviews. Researchers are often asked by interviewees to maintain confidentiality regarding certain pieces of oral history, toponymic information, family history, etc. Access control ensures a physical location to safeguard this information. CERRI has designed a data management system that can tag each data entry with the knowledge sharer's identity or an anonymous source number. This allows interviewees to remain the owners of the data indefinitely and they may ask to have it deleted from the CERRI database at any time. This system is meant to allow for the development of a trusting relationship between informants and researchers while simultaneously reinforcing researchers' respect of the informants' knowledge. This realization about the importance of trust

in community-based research caused the founders of the research centre to imagine a location where community members could bring their questions as well as their personal or collective knowledge and where, in return, training would be offered in order to increase local research capacity. The outcome of these efforts slowly become tangible as the family members of traplines where research was being conducted began to feel comfortable enough to pay frequent visits to the research centre offices and address new concerns with the researchers. An increasing number of trapline leaders - *kiniwaapimaakin* (Tallyman) and *paaschichaauchimaau* (Goose Boss) – have also consulted the research centre to initiate new research on their traplines and to write research proposals and grant requests. Slowly but surely, a culture of research is being developed around the research centre and ideally, in time, the community will fully appropriate CERRI as its own. A healthy culture of research should reflect the intentions, concerns and motivations of the Chisasibi liyiyiuch as well as their collective world views and ways of knowing (Ormiston, 2010). This is the standard by which CERRI judges its own success and is what differentiates its approach from that of the helicopter research model (see Robertson, et al., 2004)<sup>6</sup>.

4 Traplines refer to territorial divisions registered in the 1930s and 1940s across Eeyou Istchee for the purpose of managing fur resources. However, the reality of Cree territorial occupation is far more complex than has been traditionally acknowledge. This is notably represented in the goose hunting territories that can exist within or between traplines. Leadership roles in the traplines are normally designated in agreement between the head of each of the families. The Chisasibi territory is divided into 40 traplines (10 coastal traplines and 30 inland traplines). These have usually been occupied by the same families since time immemorial.

5 A well-documented example of a similar repository is the Aboriginal & Torres Strait Islander Data Archive (<https://www.atsida.edu.au/>).

6 Robertson describes the helicopter researcher as one that will, "...[drop] in for the study period and [exit] quickly afterward, leaving behind little or no work product that is directly useful to the community," (Robertson, et al., 2004, p. 507 ).



## REVIEWER OF OUTSIDE ORGANIZATIONS' RESEARCH

The third role of CERRI is to assist local leadership in evaluating research projects originating outside the community. With few exceptions since the 1970s, research in Chisasibi has typically been initiated and conducted by outsiders, including consultants employed by Hydro-Québec and the Société d'Énergie de la Baie James (SEBJ) as well as southern universities. Some of these researchers have long-standing relationships with community members through which they operationalize their research projects without always informing local leadership (e.g. the Band Council) of their presence. Others will simply show up in the community and in the best cases, ask for a support letter from the Chief and Council which is frequently reused later on for different projects without updating local leadership on new projects. CERRI works to actively abandon the helicopter researcher model of scientific work in northern and First Nation communities by establishing two committees to evaluate research projects in the community and to advise the chief and council about these projects. The first committee is composed of trusted members of the scientific community and it evaluates the quality of research projects and provides expertise and suggestions. The second committee is composed of community members and it presents an opinion to Chief and Council. The second committee's role is fundamental in determining if a proposed study reflects local concerns

and interests as well as the types of potential impacts (positive or negative) on the community and on participating individuals. Research objectives and research protocols are evaluated for their emancipatory and empowerment potential (Khanlou & Peter, 2005). This may take different meanings that in turn may evolve with time. In essence, projects should be evaluated for their capacity to answer to the collective interests and common needs that exist in the community. Project designs and objectives should support community members in achieving their collective goals and be aligned with their ambitions. These reviews also provide an opportunity to create synergy between different projects. Taken together, these varied roles allow CERRI to address local needs through scientific expertise and to increase the meaningfulness and fitness of studies carried out in Chisasibi.

## PARTICIPATIVE RESEARCH AND RECRUITMENT STRATEGIES

Another differentiating approach taken by CERRI is its strategy for recruiting community partners. Empowering community members through research is one of the centre's main objectives and is at the core of its vision. The research centre must operationalize research projects in such a way that they can easily be appropriated by the participants. This is achieved by designing research with the trapline leadership from the beginning. Traplines in Chisasibi, as elsewhere in Eeyou Istchee<sup>7</sup>, represent

traditional social units<sup>8</sup> composed of one or many families/clans that organize land-use activities and occupancy within known territorial boundaries. The involvement at the trapline level encourages retention of participants through a system that speaks to their identity. By doing it this way CERRI ensures:

- that studies reflect concerns at a local level (usually at the trapline level).
- that any expenses directly benefit trapline members.
- that all trapline members are kept abreast of research developments.
- that any training or field experience in a trapline is given to participants that will continuously use it and occupy the land (e.g. field assistants).
- that place-based (local) knowledge (Peloquin & Berkes, 2009), Traditional Knowledge, and Traditional Ecological Knowledge (see Dudgeon & Berkes, 2003) are included from the beginning and throughout the research.

The use of such a system is reflected in the scale of the studies conducted so far. Time and effort are concentrated on single traplines to access deeper knowledge and, hopefully, to explore research topics holistically. In this context, "holistic" refers to the melding of the western scientific perspective and the Cree perspective. Both sets of information complement each other to create an objective picture that accommodates both world views. Studies at the trapline level allow information from a greater number of sources with varying degrees of knowledge of a single area

<sup>7</sup> Eeyou Istchee refers to the Cree territory. In the context of this paper, it is used to refer to the territory of the Eastern James Bay Cree.

<sup>8</sup> The ancientness and significance of Algonquian territorial organization as it exists today has been the focus of continued interest by scholars since the 1950s (Leacock, 1954). Cree land tenure was the subject of a series of publications in *Anthropologica* entitled "Who Owns the Beaver? Northern Algonquian Land Tenure Reconsidered" in 1986. Recently, a follow-up series revisiting the subject 30+ years later was published in the same journal (*Anthropologica*, 2018).

(e.g. one trapline). In past projects in Chisasibi, studies touching on subjects related directly or indirectly to TEK have generally been conducted at larger scales and have only used one or two sources per trapline, typically the Tallymen. Although, as a general tendency, information stemming from TK and TEK provide CERRI research projects with the initial hypotheses and working premises, most of the community-based research happens inductively rather than deductively. The proximity of researchers to the areas of study allows for additional time spent with participants and permits easy access to locations mentioned in interviews.

Further, embracing a holistic approach to research and having readily available researchers in the community has allowed CERRI to easily diversify research avenues when new ideas emerge or different worldviews unveil interconnectedness as a result of newly shared knowledge. This has been a common occurrence during field sam-

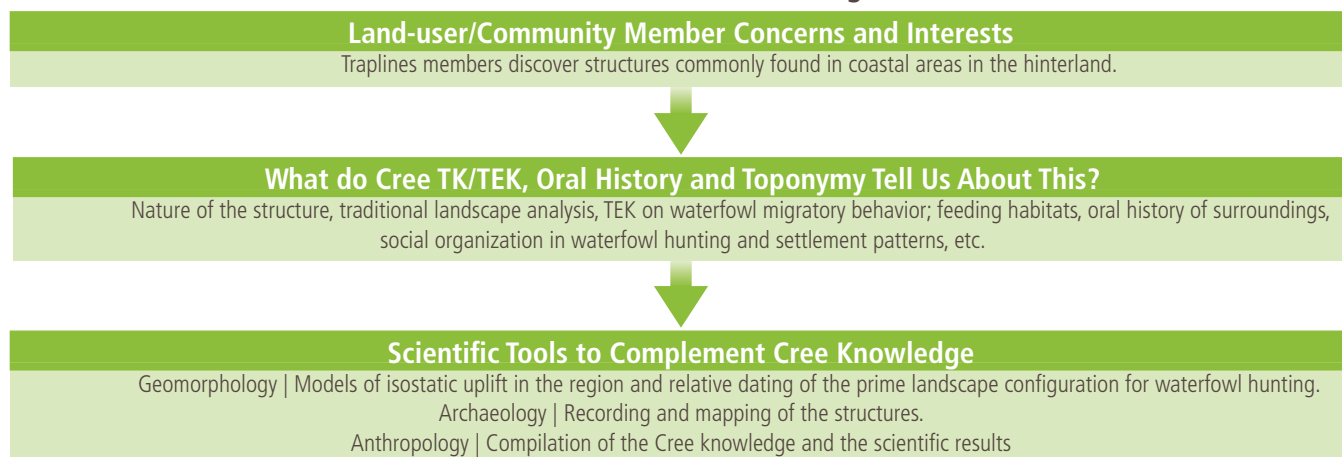
pling and has allowed for the expansion of sampling grids in areas where ecosystem interconnectivity was not initially acknowledged. This knowledge transmission, embedded in a necessarily trusting relationship between researchers and knowledge bearers, allows for Cree traditional environmental indicators to open vast new ways of understanding ecology, climate, wildlife, management and more<sup>9</sup>.

## DEVELOPING A HOLISTIC APPROACH

The community-based approach relies on addressing local concerns and interests in order to combine Cree knowledge with western scientific methodologies. As stated at the beginning of this text, the issue of changing ecosystems and their influence on coastal and near-coastal waterfowl habitats has been central to CERRI's projects. One project in particular exemplifies how the relationship between researchers and the land-users of one trapline

can create opportunities to connect local concerns with research projects. In the case of this project, CERRI was able to combine research into marine ecosystems with the exploration of an archaeological site. Figure 2 exemplifies how the investigation of newly discovered archaeological features related to waterfowl hunting on one of the coastal traplines. In this case, the melding of the two knowledge systems allowed researchers to position the site in the broader region and surrounding landscape, thus offering a relative date of occupation based on isostatic uplift rates and creating a paleoclimatic illustration of waterfowl feeding and staging areas at the scale of the trapline. This project also connected TEK of the landscape and coastal ecosystems, of migratory waterfowl behavior, and of historical hunting practices with geomorphological theory in order to create a datable understanding of settlement strategies and how they have adapted to changing coastal landscapes. This project allowed the connection of

**Figure 2. Steps in the co-creation of knowledge in the context of an archaeological investigation into an ancient waterfowl hunting site.**



<sup>9</sup> Examples of how new measurable indicators or monitoring programs are created using both TK and local knowledge exist in the literature, notably on the timing and monitoring of climate change (see Laidler, 2006), wildlife monitoring (see Gagnon & Berteaux, 2009; Moller, et al., 2004), environmental management methods (see Berkes, et al., 2000; Bronzidio, 2008; Gadgil, et al., 2003) and ecological restoration (see Uprety, et al., 2012).



**Figure 3. CERRI biologist and Chisasibi trapper sampling in the near-coastal area.**

### YOUTH INVOLVEMENT AND TRAPLINE IDENTITY

The operationalization of this project, like others undertaken since 2016, was an opportunity for three youths from the trapline's families to participate in two field visits where they learned skills related to field recording techniques, geomorphology and landscape analysis, as well as the use of scientific tools (see Figure 3). Because of the presence of an elder, it was also an occasion for them to witness firsthand how Cree knowledge about landscape analysis and wildlife behaviour can be intertwined with scientific methodologies to provide new understandings of questions of interest to both the land-users and the research team (e.g. changes in the ecosystems induced by isostatic uplift). Returning to their families and their peers, these youth had become experts in the project and could discuss related topics in depth including their ancestral lands and their trapline history (see Figure 4). Youth involvement in

the context of CERRI's project has been organized to call upon youths' sense of belonging and family/clan identity, something that funding corporations have typically overlooked in participatory research in Chisasibi. Considering the important proportion of individuals under 30 years old in Chisasibi (around 50%), building scientific capacity locally necessarily involves engaging the younger generation of the community and empowering them toward the research that happens on their territory.

### KNOWLEDGE GAPS AND SHIFTING BASELINES

Projects undertaken by CERRI address knowledge gaps within the community: both between generations and between Crees that have experienced the traditional way of life at different intensities. Generally speaking, what cultural ecologists have called the Shifting Baseline Syndrome<sup>10</sup> (Bender, et al., 2013; Pauly, 1995; Saenz-Arroyo, et al., 2005) is well acknowledged by community members and both the objectives and designs of projects allow CERRI to tackle it. In the centre's case, this is notably present in questions that touch on migratory waterfowl harvesting. For example, the changing coastal ecology of the James Bay and its impact on Cree harvest levels are understood very differently depending on hunters' generations and levels of experience because of the fact that, "... [as] one generation replaces another, peoples' perception of what is natural changes even to the extent that they no longer believe historical anecdotes of past abundance or size of species,"

<sup>10</sup> In an article on fisheries, Pauly describes the Shifting Baseline Syndrome as arising, "...because each generation of fisheries scientists accepts as a baseline the stock size and species composition that occurred at the beginning of their careers, and uses this to evaluate changes. When the next generation starts its career, the stocks have further declined, but it is the stocks at that time that serve as a new baseline," (1995, p.430). In the case of Cree hunters, for example, the baseline imagined by younger hunters will have shifted from the older hunters' experiences in numbers of Canada geese (*Branta canadensis*) that used to migrate along the James Bay coast.



(Saenz-Arroyo, et al., 2005, p.1957). Documenting TK, TEK, and place-based oral history from the more experienced land-users to create environmental baselines and culturally relevant measurable indicators of ecosystem change helps to address this gap. This is even more relevant when one considers the unique legislation surrounding Cree harvesting, particularly the levels of harvest guaranteed to Cree beneficiaries by the James Bay and Northern Quebec agreement (Hydro-Québec and Québec, 1998)<sup>11</sup>. These baselines and the documentation of change are vital for the protection of these rights, "...[such] rapid shifts in perception of what is natural help explain why society is tolerant of the creeping loss of biodiversity," (Saenz-Arroyo, et al. 2005, p. 1957). Involving youth in this process educates and empowers them in promoting conservation from a place

of knowledge and gives them tools to set appropriate targets for restoration.

## CODE OF ETHICS IN RESEARCH AND COLLABORATION (CERC)

The key principles for the implementation of projects by CERRI's research team as well as the development of collaborations with outside organizations were included in the Code of Ethics in Research and Collaborations (CERC) in the early days of the centre. The primary objective of the CERC is to elicit community involvement and engagement as the main parameters of the evaluation of a research project and, even more importantly, to propose specific ways of implementing it in Chisasibi.

## GUIDING PRINCIPLES

CERRI's code of ethics includes topics similar to those found in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (CIHR, NSERC and SSHRC, 2018) (TCPS2) or other ethical guidelines typically used by ethics boards at universities. These include security and well-being of the informants, confidentiality, justice, informed consent, etc. (see Khanlou & Peter, 2005). The TCPS2 aims to cover all research across Canada and includes a section on research with indigenous peoples that states that its existence is "[...] is not intended to override or replace guidance offered by Indigenous people themselves" (2018:107). It is meant to offer an initial framework for ethics in research in the absence of better knowledge but does not have the pretention to take into account the extreme variability of local ethical considerations across the country. The CERC aims to address these considerations in Chisasibi. The CERC's originality comes from the inclusion of specific strategies to respond to community requests for studies carried out by CERRI scientists or external collaborators such as universities, research centres, consultants, or funding agencies. By compiling an on-going list of concerns stemming from community members and land-users who occupy a vast and diverse territory as well as through its permanent presence in the community, CERRI is in a unique position to address specific needs and interests. These needs and interests go beyond the scope of the traditional use of a one-time consultation when en-

**Figure 4. Youth participant and Elder participating to a project on ancient waterfowl hunting blind on a Chisasibi trapline**



<sup>11</sup> The James Bay and Northern Quebec agreement is a land claim settlement that was negotiated between the Nunavik Inuit, the Eastern James Bay Crees and the Province of Quebec in the midst of hydroelectric development that began in James Bay in the 1970s (Hydro-Québec and Québec, 1998).



gaging in discussion with potential collaborators. In that respect, the guiding principles include statements surrounding mutual listening and the need for relevant research projects. Community members are therefore seen, not as research subjects, but as equal collaborators that can contribute to research objectives and design; a standard increasingly adopted by researchers working with indigenous communities, but which remains far from ubiquitous. The CERC is a living document that is called to evolve and we acknowledge that efforts are continuously required to better portray local conceptions of what is ethical research.

### RESEARCH VALIDATION, USE AND OWNERSHIP

In order to avoid the misuse of information, the CERC requires that research projects include a process through which sources can validate the interpretation of data gathered. Misinterpretation and subsequent misrepresentation of opinions and knowledge can easily happen, especially at the confluence of knowledge systems and linguistic differences. The validation employed by CERRI may take various shapes, with the most common form being validation interviews summarizing data collected through interviews and following researchers' interpretation. This ensures that the interviewee may point out misinterpretations of the knowledge communicated on the part of researchers.

A statement on the ownership and use of information by the researcher is also required. In cases where TK and TEK are

concerned, the guiding principle is that the knowledge holder(s) should retain control of the use of the information after it is shared. This implies that they may have a say in its use in any future publications or grant requests. CERRI may play a role in maintaining this connection between the informant and the researcher over time.

### RELEVANCE OF RESEARCH OBJECTIVES

We argue that the principles that justify fundamental research do not apply unilaterally to research in Chisasibi, "Science, in the hands of the dominant culture, claims to be neutral but can be used by researchers in ways that are not always acceptable to indigenous peoples," (Chennells, 2015). This can be negotiated through the co-design of research but also through the relevance of research topics. These topics might come as requests from community leadership or be determined through community consultation or discussed with community organizations such as CERRI. When done in the early stages of project design it is unlikely that any willing researcher would be incapable of including community concerns and interests in their project.

### DISSEMINATION OF RESULTS

Community presentations, pamphlets and solution-oriented reports are some of the means that are offered to external researchers by which to share the results of their studies. These are critical in dismantling the helicopter researcher model in that they ensure the long-lasting nature of the relationship

between scientists and the community. They also allow for the measure of outputs and the impacts of research. Including community co-researchers as coauthors in publications in scientific journals is another way to pay tribute to their knowledge and establish this relationship, "...by placing value on local knowledge, academic researchers become open to other ways of knowing, other ways of doing, and as a result are involved in the production of knowledge that is unique..." (Jacklin & Kinoshameg, 2008, p. 62). This implies that researchers will communicate results and outcomes in terms and ways that will be understood and to which community members will relate.

### LOCAL INVOLVEMENT

The most difficult element to include in external project designs, and one which is a great barometer to evaluate researchers' willingness to work with community members, is the involvement of locals, ideally youth. The hiring and training of community co-researchers represents time and effort for researchers and differs from the model with which many researchers have traditionally worked (Fisher & Thomas, 2003). As a result, this is one of the most important components in making any project truly community based. Involving locals allows for continuous input from the community into the research proceedings as it creates a daily link with the researcher as well as a legacy in skill and capacity that is transmitted to the community. CERRI's trapline-based approach makes the recruitment of participants both easier and more meaningful.

## CHALLENGES TO IMPLEMENTATION

Many challenges experienced by the community as a whole, and some witnessed directly by CERRI, led to the centre's creation. These have also influenced the way the organization operationalizes research. These challenges include the ways in which some research projects have been conducted in the past, the reactions of community members to the behaviours or attitudes of some researchers, and the negotiation of ownership of raw data and research results between collaborators (academics and funding agencies) and Chisasibi knowledge holders. These problematic issues have had a major influence on the way research is conducted at CERRI and they are, accordingly, each addressed by the centre.

## TERRITORIALITY AMONG RESEARCHERS

In the past and even since the creation of CERRI, the community of Chisasibi has dealt with a culture of territoriality among some southern researchers when it comes to projects related to certain scientific fields in James Bay and with the Eastern James Bay Cree. This unfortunate research culture has ranged from unspoken agreements between academics about who could work in the region to active intimidation of scholars unaware of the "system" in place and how it functioned. Building upon their personal relationships in Cree communities, researchers have been able to limit other interested scholars' access to Cree communities. This situation had become such that scholars directly invited by Cree com-

munities were reportedly bullied into refusing any involvement. On occasion, established scholars have even refused to involve their graduate students in projects for fear of negative impacts on their budding careers.

This unfortunate situation came as a surprise to many in the Cree community, notably to Chisasibi leadership, as they had been kept in the dark about this unspoken system's existence. This behaviour by researchers is even more deplorable when we consider that these types of behaviour toward First Nations have been widely condemned by academics (see Jacklin & Kinoshameg, 2008; Scott & Receveur, 2005). The discovery of these behaviours among researchers understandably led some in Chisasibi to unilaterally reject collaboration with research teams and has thus strongly hindered local research. One can argue that these power dynamics amongst outside researchers are infantilizing towards the local community. Especially considering that they involve withholding the control of studies from concerned local individuals and leaving them in a passive position regarding research that directly affects them. Hopefully, this state of affairs has in fact changed since being brought to light and is now relegated to the past, but it is fundamental to understanding the measures taken by Chisasibi to support its self-determination in conducting research on its territory and with its people, of which CERRI forms a part. Overcoming wariness to research in this context is a long and frustrating process for all parties, but these challenges should not be seen as an

impediment to developing meaningful, constructive and trusting relationships between researchers and community members.

## RESISTANCE TO RESEARCH

Reversing this trend and building a healthy research culture in the community has been an ongoing challenge and is what led CERRI to propose its code of ethics. Without engaging in any coercive measures, CERRI proposed guidelines for community-based and community-driven research, a best-practice guide of sorts, part of which is discussed in this text. The centre's implementation has also helped to guide researchers toward a single entity that serves as a scientific hub that can report to community leadership on outside research whenever requested.

The centre's presence in the community places researchers in the role of an ally<sup>12</sup>. This entails that researchers might play a, "...supportive rather than a leading role in projects and publications," (Hyett, et al., 2018 620). The resistance and wariness toward research are mitigated through allyship and mutual listening. Hyett, et al., (2018) explain that in order for this mutual relationship to be meaningful and exist in the long term, researchers must have, "...a will to make mistakes and be uncomfortable," (p. 619), review their own paradigms, and transcend their worldviews before experiencing research through indigenous methodologies.

In addition to their empirical value, indigenous methodologies are about "restoring power and control," (Hyett,

12 See "Indigenous Allyship: An Overview" (Smith, et al., 2015) for a guide to the role of Indigenous Ally.

et al., 2018, p. 619) and indigenizing the research process. This also means restoring world views that indigenous community members have themselves rejected to the benefit of western perspectives on science. Indigenizing research, in the context of Chisasibi and in the experience of CERRI, has also meant dealing with one form or another of internalized colonialism: a clash between the perspectives of traditional land-users and modern governance. In the midst of colonization and the decrease in land occupancy for some, indigenizing research thus becomes an attempt to reverse the trend in the loss of Traditional Knowledge as well as in the loss of trust in Traditional Knowledge.

### DATA OWNERSHIP AND INTELLECTUAL PROPERTY

Another issue that has represented a challenge to the development of a healthy culture of research has been the question of research ownership. In recent decades, scholars working in social sciences and conducting interviews have asked participants to sign consent forms for the use of their information. Despite this, a sentiment of wariness concerning the subsequent use of the information, particularly when it concerns TK and TEK, is strongly felt among community members interviewed. It has been the opinion of some community members that scholars make their careers and the careers of their graduate students by using Cree TK without it positively impacting the initial sharers of the information. This lack of control over the use of TK and TEK once it is shared with researchers as well as its misuse—notably when researchers do not grasp its full meaning or context—has been a fre-

quently discussed topic with community members as well as in the scientific literature (Brush, 1996; Clapperton, 2016; Riley, 2005; Wenzel, 1999).

The complexity of this topic may stem from the nature of TK or TEK itself. Traditionally these types of knowledge have been documented following an extractivist approach. However, with the increase in awareness of scientific research in Chisasibi, concerns regarding “intellectual property” have been brought forward by participants, which at times has caused frustration on the part of investigators and research promoters. The idea that TK/TEK is deemed worthy of being protected as “intellectual property” in the cultural context in which it is shared, in the same way a patent would be in the western world, is sometimes met with disbelief and misunderstanding. Indeed, the absence of intellectual property protective measures related to TK and TEK is widespread in research with indigenous people (Brush, 1996) but we have attempted to mitigate this lack through the design of our database and the written agreements we make with interviewees concerning the control of their data and their ability to withdraw it. This is also negotiated with funding agencies that may require the sharing of the raw data which can contain culturally sensitive or secret knowledge. These experiences have helped to structure the way CERRI is organized and how studies are built. Much resistance has come from individuals and organizations accustomed to conducting research in Chisasibi in their own way. For example, researchers often resist the involvement of youth in their re-

search projects because of the coordination challenges it presents and the short timeframes of their studies. We believe that this is mainly due to a lack of knowledge about how to meaningfully engage the community rather than a deliberate rejection of their participation. Another example of this can be seen in the integration of TK/TEK into research projects.

Many studies originate from community concerns related to environmental issues that touch them directly, which are relayed to local and then regional leadership. Despite this, research often begins without first acknowledging community members’ specific issues and thus produces results that are not always relevant to the initial concerns. A specific example of this can be seen on the subject of the disappearance of coastal marine habitat. In this case, ecologists and biologists concentrated on the presence, absence and density of the flora rather than on its nutritional value and its qualities to attract harvested wildlife, which was much more relevant to hunters’ concerns regarding this particular plant. Nonetheless, currently things are evolving toward a healthier relationship between the community as a whole and researchers. New research partnerships have been built on the ideals of mutual respect, equality and sharing the benefits of research. It is our hope that CERRI will play an increasingly large role in establishing meaningful communication and collaboration between research teams and community members by negotiating each side’s priorities.

## CONCLUSION

Three elements of CERRI's approach in Chisasibi have been identified as pillars to adequately support the community-based approach. First, its insight into youth involvement through the engagement of trapline identity and the efforts in capacity development in fields of interest at the trapline, clan or family level. Second, the development of a culture of participatory research and a relationship of trust between the CERRI research team and land-users/community members. Third, the proximity and permanence of CERRI in Chisasibi, which allows the local research team to precisely define and adapt research objectives as they are meaningful to Chisasibi liiyiuch and to obtain constant feedback on all endeavours. The sense of accountability the research team feels to the community is also heightened through this.

The Code of Ethics in Research and Collaboration is also a valuable tool for Chisasibi to be able to define the research carried out as "community-based and participatory". It provides guidelines and strategies for what is considered *ethical* in the context of research in the community. In return, it allows researchers to produce what is locally considered as valuable, ethical and meaningful new knowledge. As for the willingness and sincerity of the researchers' approach, this should naturally come to be as the result of the development of a relationship with the community, "...researchers have adopted PAR [participatory action research] protocols to make research more democratic; however, Indigenous people have argued that PAR still does not prevent outsiders from adopting colonial attitudes towards research..." (Smith, 1999, as cited in Jacklin & Kinoshameg, 2008, p. 55). CERRI's own projects carry the values that we wish to see in the projects of external researchers supported by universities, funding agencies, project promoters, etc. Our work model places the scientist in the role of a student, with all the modesty that entails, and encourages them to take the time to listen and understand the Cree perspective on the object of the study. Throughout this process, holistic understanding is promoted, and knowledge systems are permitted to truly interact and create original and meaningful knowledge.

This paper is more a discussion of one community's experience and perspective on research than it is a discussion of ethics in a broad sense, nonetheless it is written in the hope that it can be included in the continued application of ethical considerations when working with indigenous communities. It is an advocacy for a tailor-made approach for working in Chisasibi, an approach that might not be valid or meaningful in another indigenous community. In line with that, the ethical guidelines of the CERC are understandably designed to evolve as new types of research projects are initiated and new partnerships are established. It is our belief that with further understanding from funding agencies and research promoters about the added value of community-based and participatory research, southern institutions and indigenous communities will come to work hand in hand to conduct better studies and strategize around the meaningfulness of the way research projects are designed and carried out. Research ethics are strongly related to cultural context and it is through mediation and the establishment of sincere relationships between the two world views, and everything that entails, that scientific work can be deemed, first, community-based and second, ethical (Khanlou & Peter, 2005). It is because of this that we argue that the community-based and participatory research model adequately supports this relationship.



## THE ROAD AHEAD

In the future, CERRI will continue to pursue research topics relevant to the land-users of Chisasibi. As community interest in CERRI's work increases, so too does the number of research questions provided to the centre and the level of local involvement. With the appropriate support of a locally based scientific team, a scientific advisory committee and a team of community co-researchers, we hope to increase the scope and the scale of our work. Efforts are notably being made toward developing training workshops with coastal trapline users to implement a participatory environmental program on fish and bird habitats along the coastline with the guidance of knowledgeable land-users and elders.

One of our main priorities is making the research results from these initiatives available to community leadership as well as to traditional leadership (trapline leaders and families/clans) as support for their own resource management strategies, in connection with the pursuit of the Cree way of life. General interest for these types of initiatives has been heightened during the last decade and even more so recently as funding agencies and academic institutions are increasingly recognizing the viability and merit of these sorts of initiatives (Ferreira & Gendron, 2011).

Indigenous guardianship programs being implemented in many First Nation and Inuit communities in Canada are a great example of this and have drawn some support from the Canadian gov-

ernment<sup>13</sup>. Indigenous Protected Areas have also been recently introduced at the federal level and communities are developing support for independent resource management<sup>14</sup>. Maintaining community involvement requires steady resources and is an ongoing challenge we face. We trust that building a strong framework for participatory monitoring in Chisasibi will generate increasing interest from funders and research partners outside of the community that will see this framework as a tool for building meaningful connections and producing quality research results. We hope that in time CERRI will serve as an example for neighboring communities and other indigenous groups to empower themselves toward the research conducted on their respective territories.

Opportunities for project development, sharing of resources and meaningful collaborations are sought at every level to position CERRI as a strong resource for the community. The strengthening of the trust from community members toward the researchers and community co-researchers as well as the development of a *culture of research* in the community are still imperative to CERRI and their continued presence will be the decisive factor in the measure of the centre's success.

13 Indigenous Guardianship Pilot Program. <https://www.canada.ca/en/environment-climate-change/services/environmental-funding/indigenous-guardians-pilot-program.html>.  
See also <https://www.ilinationhood.ca/guardians>.

14 See <https://www.canada.ca/en/environment-climate-change/news/2018/10/first-new-indigenous-protected-area-in-canada-edehzhie-protected-area.html>

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## INTRODUCTION

This new section of the Toolbox of Research Principles in an Indigenous Context : Ethics, Respect, Fairness, Reciprocity, Collaboration and Culture offers a series of interviews relating to concrete experiences of knowledge cocreation and mobilization. These examples result from the joint work of teams from different Quebec universities bringing together researchers on the one hand and Indigenous stakeholders/collaborators on the other. The objective is to retrace the stages of the trajectories pursued by these teams in their efforts to create conditions conducive to sharing and reciprocity in terms of Indigenous research.



## THE CONTAMINATED RABBIT: A RESEARCH PROJECT STEMMING FROM THE CONCERNS OF 4 ANISHNAABEG COMMUNITIES

### INTERVIEW WITH HUGO ASSELIN ON AUGUST 27, 2018

Hugo Asselin is professor at UQAT since 2007. He held the Canada Research Chair in Aboriginal Forestry from 2008 to 2018. He is Director of the School of Indigenous Studies since 2016 and holds the Desjardins Chair in Development of Small Communities. Over the years, Hugo Asselin has supervised the research projects of more than 45 students, several of which having been initiated at the request of Indigenous communities. Here is the story of a few examples of current collaborations in research training...

*Several of the projects I work on stem from the communities. It does not mean that I never submit ideas, but if what I suggest does not raise interest, it stops there. (Hugo Asselin)*

### THE STARTING POINT

A few years ago, four Anishnaabeg (Algonquin) communities met together to submit a grant application within the framework of a program administered by Health Canada to conduct research on the presence of environmental contaminants in game hunted on the Nitakinan (traditional territory), at the heart of which the Horne smelter is established. To be eligible for this grant, the application had to be submitted by Indigenous communities. After a few refusals, the communities came to the conclusion that not having a collaboration with a recognized researcher from the scientific field was detrimental. They thus approached Hugo Asselin to ask for his support in the process. Professor Asselin agreed to help with the project

which he considered very relevant and scientifically sound. His contribution was to make sure the text was worded to meet the expectations of the evaluation committee, using a vocabulary with which they were familiar.

*According to the steps in the process, following initial evaluation of the project, an interview was required with an ethics committee in Ottawa. The communities asked me to play this role. After bombarding me with questions, the committee expressed some hesitations in funding the project because they were concerned that an eventual discovery of high levels of contaminants in game would create a climate of fear within the communities. I replied that the fear already existed, that it was precisely this fear that motivated the community to do research. There is nothing more fearful than not knowing. (Hugo Asselin)*

Without precise information about the presence or absence of contaminants in the meat they ate, hunters and trappers were faced with a dilemma: continue hunting with a potential risk to their health or cease to eat game and therefore cut off a significant link to the land, which has its advantages from a cultural as well as a nutritional perspective.

*Concretely, the need was articulated by Anishnaabeg hunters and trappers who were worried: Is the game we eat contaminated and, if so, are the quantities we consume harmful? These questions came, in part, from wide dissemination of recommendations from the Public Health Department, who advised against eating moose offal because of the cadmium levels it may contain. (Hugo Asselin)*

Having convinced the ethics review board of the relevance of the project to the communities, the application was finally funded. To see the project through to completion, they hired Serge

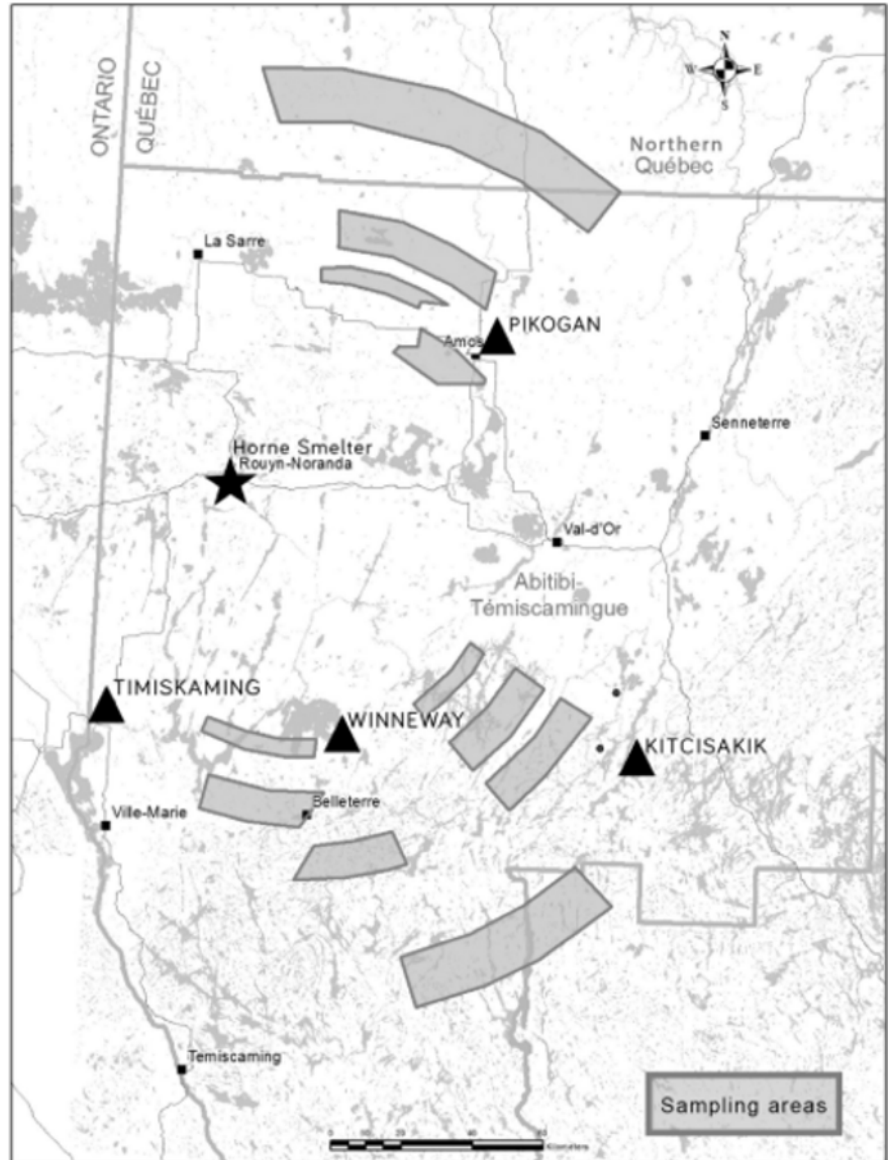


Bordeleau who was well known within the Anishnaabeg communities as a research professional. During preparatory conversations, Hugo suggested Serge could kill two birds with one stone by completing the research as a master's student in Biology. With two Bachelor's degrees (one in Biology and the other in Cinema), the proposal made a great deal of sense; the communities would benefit from more robust results because of the University's support and more qualified staff, and Serge himself would have one more diploma to his credit in the end.

## RESEARCH PROCESS: LESS INTRUSION, MORE COMMUNICATION

The grant was managed by Timiskaming First Nation on behalf of the four communities. After having weighed the possible options, the research team decided to work with rabbit (snowshoe hare) rather than moose, since the latter option involved more challenges for sample collection.

*We hired trappers in the four communities and asked them to trap rabbit for us. The idea was to collect rabbits at different distances from the Horne smelter and at different angles with respect to dominant winds. According to the protocol, the trappers were to take samples of flesh and liver and send them to us for contaminant analysis.*



Source: Bordeleau, S., Asselin, H., Mazerolle, M.J. & L. Imbeau. 2016. "Is it still safe to eat traditional food?" Addressing traditional food safety concerns in aboriginal communities. *Science of the Total Environment*. Vol 565: 531.

Having decided to proceed in the least intrusive way possible, interviews were conducted by Serge with the help of Amandine Jean, to estimate the quantities of rabbits consumed in the communities. For example, to the question: "How often do you eat rabbit?", possible answers included "every day, every week, once a month..." and the participants provided an answer for themselves and for each member of the household. Using photographs, the participants were also asked to estimate the

quantities consumed (ex., leg, offal, saddle, or whole rabbit). Other questions about tobacco use were also asked, since tobacco interacts with certain contaminants such as arsenic.



Source: Image from the video produced by Serge Bordeleau. *Le lièvre contaminé*. <https://www.youtube.com/watch?v=-5VXgF2i508>. A more extended version entitled *Le chasseur contaminé* is also available at the following address: <https://vimeo.com/128494808>

During the interviews, someone from the community always accompanied Serge and Amandine because some respondents spoke only Anishnaabemowin, and also to gain participants' trust and reassure them on the community's support for the project. During all these stages, Professor Asselin's role was to ensure the data were rigorous, so it could be used by the communities. In the event that the conclusion would have been that the rabbits were indeed contaminated, the results had to be sufficiently robust for the communities to rely on them to work with the government, so that actions could be taken.

During the project, Serge found that the presence of a researcher in the four communities to measure contamination raised some questions.

*Serge decided to put on his filmmaker's hat and he produced an animated short film to explain to people what contamination is, how it works, and how it is measured. The video was circulated within the communities so the topic could be better understood and it was very well received, especially with the youth. The short film even won an award at the Université du Québec student video contest! (Hugo Asselin)*



Source: Image from the video produced by Serge Bordeleau. *Le lièvre contaminé*. <https://www.youtube.com/watch?v=-5VXgF2i508>

When data collection was finalized, Serge did the calculations to determine the levels of contaminants in the rabbits from each collection area and estimated the potential levels of contaminants in Anishnaabeg people themselves, based on eating habits consigned qualitatively. The goal was to determine if the estimated levels exceeded the thresholds deemed acceptable by Health Canada and other health agencies.

"The best we can tell Indigenous people is to eat some, "but not too much". At the same time, we know that for the last 50 years, Indigenous people's health has deteriorated. There is an unprecedented diabetes and obesity epidemic for the exact reason that they abandoned traditional food. This good, lean meat, full of minerals, was replaced by sweet and salty processed food from the convenience store or the closest fast food outlet. " Translated excerpt from the video *Le lièvre contaminé contaminé*



## RESULTS, ON SEVERAL SCALES

In the end, Serge demonstrated that the quantity of rabbits consumed was not harmful to the health of the Anishnaabeg. But over and above the beneficial character of the production of reassuring results, that fact that the Indigenous communities found answers to questions they themselves were asking, and that they were in control of the research process from beginning to end, provided them with a very rewarding experience.

*The trappers hired by the communities, as well as the translators, the people Serge and Amandine met with, the representatives of the band councils who made decisions, all found satisfaction in the process. And we too, as scientific collaborators, learned from this experience, especially regarding the issue of communication. Other researchers might have been deterred because of what they would perceive as a "loss of scientific autonomy" or a risk that the project could be stopped without them having a word to say. But then, if a community decides to put an end to a research project, it must be because something was amiss in the way the work was being done. In such a case, it is the responsibility of researchers to self-evaluate their practices. (Hugo Asselin)*

As for Serge, he presented his results at multiple conferences in Abitibi-Témiscamingue and elsewhere. One of his take-home messages was that the recommendations of the Public Health Department for the consumption of game should be nuanced to account for the realities in the field, the cultural context and in particular, the impact of such recommendations on the health of Indigenous communities, often very different from that of recreational hunters. For now, it is impossible to know if these findings were taken into account by the official agencies. However, the interest of many communities seems to have been sparked. As Professor Asselin mentions, increasing research involving environmental contamination in Québec First Nations is ongoing or upcoming whereas only a few years ago, such work existed only within Inuit communities. Let us hope that this future research will also conclude that the benefits of eating traditional food overcome the health risks for Indigenous people in Québec...

## UPCOMING RESEARCH!

A new Cree student at UQAT, Éliane Grant, recently began a master's project in Eeyou Istchee (Cree territory) integrating traditional ecological knowledge (TEK) on moose health to analyses of cortisol levels (the "stress hormone") in moose hair. This research is cosupervised by Nicole Fenton and Hugo Asselin and is part of a larger project aiming to evaluate the impacts of mining development on biodiversity in Cree territory.

To find out more about Éliane and her research project, consult Sophie-Anne Miller's news story at:  
<https://ici.radio-canada.ca/espaces-autochtones/1105870/eliane-grant-biologiste-nation-crie-pont-entre-communautes-autochtones-compagnies-minieres-waswanipi-nemaska-lithium>

## COMMEMORATING FLOODED CULTURAL SPACES: RESEARCH AS A LEVERAGE FOR COMMUNITY ACTION

INTERVIEW WITH JUSTINE GAGNON, DOCTORAL STUDENT IN GEOGRAPHY AT  
UNIVERSITÉ LAVAL, AND ADÉLARD BENJAMIN, PROJECT MANAGER FOR THE  
TERRITORY AND RESOURCES SECTOR, CONDUCTED ON AUGUST 29, 2018

### GENESIS OF THE PROJECT “NITSHISSITUTEN: MEMORY AND CULTURAL CONTINUITY OF PESSAMIULNUAT IN FLOODED TERRITORIES”

In 2013, Justine Gagnon had finished her doctoral studies and was working with her director, Caroline Desbiens, on the completion of the project Tshishipiminu: Innu occupation of the Peribonka River and hydroelectric development, a research partnership between Université Laval and Pekuakamiulnuatsh Takuhikan. One of Justine's tasks was to present the traveling exhibit produced within the framework of this research partnership in other Innu communities. At that time, Justine's doctoral project was not yet defined but she was toying with the idea of developing a research project like the one in which she was collaborating with Professor Desbiens, to be led this time by the Pessamit community.

During the traveling exhibit in Pessamit, Justine met Éric Canapé, counselor for the Pessamit Band Council and in charge of the Territory and Resources

sector. During this first contact, Éric Canapé demonstrated an interest in Justine's ideas; he invited her to develop her doctoral project and submit it formally to the Council. Shortly afterwards, Justine was in Pessamit to present the traveling exhibit. She therefore took the opportunity to meet with the Band Council and share her intention of collaborating with the community.

*I made the proposal to document cultural spaces that had been flooded with the construction of the dams. Initially, I had planned to consider only the dam on the Manicouagan River. To this, the community replied that it would be more interesting to document the cultural spaces of the three rivers harnessed on Nitassinan : the Betsiamites and aux Outardes Rivers, as well as the Manicouagan River. They were interested in the elders' knowledge of the whole hydrographic network. After the presentation, a resolution was adopted by the Council stipulating that the community accepts the collaboration. (Justine Gagnon)*

This resolution marks the beginning of an evolving collaboration, entrenched in research as well as in showcasing

Innu cultural heritage and knowledge. This was part of the development of a series of research collaborations initiated by the team of the Territory and Resources sector during the 2000's, with the notable participation of Adélar Benjamin, who exercised the functions of counsellor for the Band Council from 2000 to 2014.

*Parallel to and in support of the political representation work, the Territory and Resources sector had begun collaboration initiatives with the universities, more particularly with Université Laval's Chair of Aboriginal Forestry... The goal of research collaborations was to integrate into our practices the tools of non-Indigenous society for the development of the territory, the Nitassinan. Furthermore, we continued our community consultations work with elders to know their visions, aspirations, and concerns relative to territorial development. "Two visions" now available to us, so to speak, we hoped to make progress in the recognition of our prerogatives and the relevance of our perspectives, especially for resource development to be sustainable. (Adélar Benjamin)*

## COLLECTION: AN OPPORTUNITY TO LEARN FOR EVERYONE

During the summer of 2015, Justine returned to Pessamit with the objective of conducting a first series of interviews. Meanwhile, another research piloted by the Mamuitun Tribal Council (MTC) in partnership with the Emergency Architects is ongoing in the community. The Kushpita project, initiated by Robin St-Onge and Cimon Picard, both employees of the MTC, also involved data collection in the form of interviews with elders. In this context, Éric Canapé suggested to Justine and the MTC team to do their interviews together, to avoid overly soliciting the elders.

*Plans had not been made this way, but we chose to follow his suggestion and optimize the time dedicated by the elders to these discussions. Finally, this worked well; our questions were often similar. It was an interesting experience; many ideas were shared around the room! (Justine Gagnon)*

Following an initial processing of collected data, Justine was back the following year in 2015 to conduct a new series of interviews with five key informants recognized as knowledge-keepers in the community. At this time, it was to go more in-depth for the themes discussed the year before but this time with the availability of a new tool to propel the research into fertile ground: aerial photos of the rivers taken before the construction of dams. True, during the first phase, the discussions were based on maps produced after the construction of the dams and where it was



Interview held in collaboration with the members of the Innu Council, members of the Mamuitun Tribal Council and the Emergency Architects (photo taken by a member of the Emergency Architects, summer 2015)

impossible to see what the elders were talking about. With the photos, the islands and portages they talk about are easily identifiable.

*During a first interview, when the elders say: "There was an island here", or here "there was a portage", it wasn't easy to see the exact location or the scope of what they were talking about. (Justine Gagnon)*

Much like a window on the past, these photos really stimulated the discussions from both sides. Justine's collaborators who were doing the interviews in Innu, including Adélard and Sébastien Picard, felt particularly privileged in having access to all this knowledge provided by the elders.

*For us, it was quite interesting because we learned things that we had never heard of about the rivers, sites, and portages. It was unbelievable since we could have access to stories that the parents and grandparents of bearers of knowledge told them about events or spaces on the territory, and that our parents didn't tell us. (Adélard Benjamin)*

One of these stories that generated a lot of interest is that of an Innu fort built on one of these islands on the Pipmuakan (which became the Pipmuacan reservoir on the Betsiamites River), that more particularly served as a protection against the Iroquoians. According to the elders' stories, in this Innu fort there were many artifacts that were unfortunately submerged forever. Even though it is impossible to have access to these to learn more about the defence modes of the Innu ancestors in a war situation, the discovery of this segment of their history was a revelation for Adélard and Sébastien.



*For us, to hear all this segment of our history was a surprising discovery. With by brothers and friends, we still talk about it today; it's a source of pride. Without a doubt, our ancestors were peaceful, but they defended themselves and they had knowledge about that.*  
(Adéland Benjamin)

For Justine who attended these discussions, the experience was formative. To see how these links were created around the elders' stories, even without being able to understand them, was fascinating and encouraged her even further in her desire to do more than a doctoral thesis with the stories compiled.

## REWRITE THE HISTORY OF THE NITASSINAN HYDROGRAPHIC NETWORK FROM THE INNU PERSPECTIVE: THE UAMASHTAKAN PROJECT

As the consultations and meetings progressed in the community and with the elders, the research collaborators realized that it was necessary to develop a product, an initiative to multiply the concrete spin-offs resulting from the update of elders' knowledge. This is how the Uamashtakan project emerged, a project to showcase the cultural heritage of the Manicouagan River.

*With the collaboration of designer Géraldine Laurendeau, Adéland Benjamin, Sébastien Picard, Éric Canapé, and others that have become involved since, we developed a project for a lookout point that would be built close to the Manic-5 dam. This name was chosen for the project because there was a waterfall before the construction of the dam. Around this area was one of the longest portages of the Manicouagan River; Uamashtakan means "to make a long contour". Though the waterfall no longer exists, a portion of this portage is visible in the forest on the other side of the river. Two burial places are still there. Practically, the lookout would point to the landscape where the past portage started and tell the river's story from the Innu perspective, thus facilitating the transfer of the knowledge shared by the elders.* (Justine Gagnon)

Portion of the Uamashtakan portage site (Photo taken by Justine Gagnon, spring 2016).



◀ Burial place on the Uamashtakan portage site (Photo taken by Justine Gagnon, spring 2016).

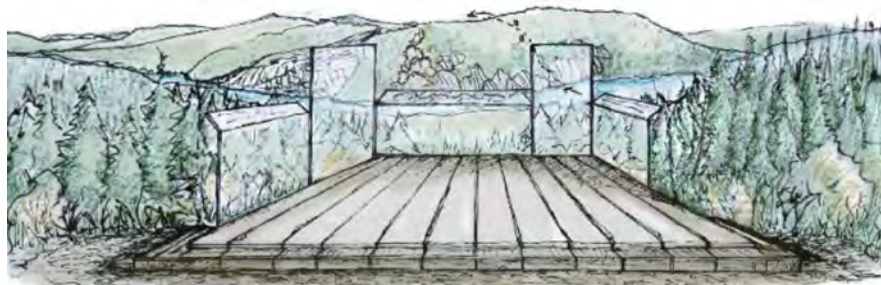
Panoramic view at the future lookout (Photo taken by Géraldine Laurendeau, spring 2016). ▼



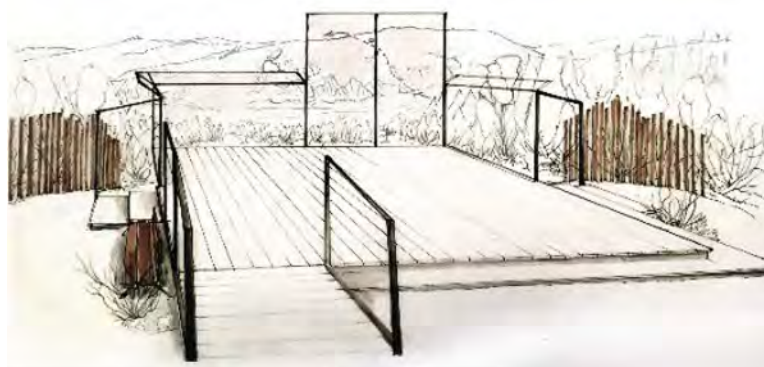


At the current time, the collaborators are actively seeking funding to achieve this project. During a preliminary phase, an exhibition aiming to present the Uamashtakan project to the people of the community was presented at the community centre thanks to the contribution of the DIALOG Network. According to the book of comments at the event, the whole community supports its achievement.

*A project such as the Uamashtakan allows the youth to learn and know about segments of their own history, as well as that of their families and communities. They therefore become conscious of all the changes that took place on their territory during the last 60 years. For the elders who recall times before the dams, this is a unique opportunity to share the knowledge that they alone possess. In general, people are surprised by the results of the research since it was unthinkable to have access to tools such as maps of the flooded areas. It's as if the collaboration work with Justin contributed to connect us with our past. (Adélard Benjamin)*



Drawing of the future lookout, by Géraldine Laurendeau (2016)



Drawing of the future lookout, by Géraldine Laurendeau (2016)

Ideally, this lookout would constitute an experience that would be repeated for each of the three rivers. This would result in a type of network of lookouts aiming to showcase Innu knowledge and heritage related to the Nitassinan rivers, thus rewriting the history of the territory.

*with the territory, without so much as remotely considering our advice and perspectives. The Uamashtakan project is one way among others to assert who we are. We were here before the dams and before colonization. And we are still her. (Adélard Benjamin)*

*These three large rivers were utilized by our parents, our ancestors. For us, these rivers, we often repeat it, were utilized as highways. At one point, in the history of the Province of Québec, the Quiet Revolution took place, bringing in its wake dams on our rivers - highways - sometimes completely taking away from us our connections*

Since she documents the Innu stories related to the flooded territories, the collaboration between the Pessamit community and Justine encouraged not only the transfer of ancestral knowledge, but also the work for the defence and exercise of the community's rights on Nitassinan.

## LONG-TERM SPIN-OFFS OF RESEARCH COLLABORATIONS: THE PROLIFERATION OF CAPACITIES TO ACT FOR THE COMMUNITY'S BENEFIT

Bringing together many people from distinct horizons for a project, when done in a spirit of reciprocity, can constitute an opportunity for collaborators to foresee new potentialities to meet emerging needs, and even engaging in new training programs to better serve the present and the future of the community. Justine and Adélaré illustrate this point in the following words:

*The Uamashtakan project has sown a seed. The teachings and skills acquired throughout the experience are now led by the members of the community. These members will mobilize them to create something else. For example, a new project for a boardwalk telling the story of the mouth of the Pessamit River is currently underway. When we observe the route undertaken and the objectives of this new project, we see similarities with the project. The same willingness to share the stories about the territory is present. The Uamashtakan project experience could also encourage people to be trained in different specialties related to the enhancement of the heritage. We hope that one day an Innu will become an archeologist. The conditions for our wishes to come true are coming together, progressively...*

# SOCIAL PARTICIPATION OF ELDERS AND INTERGENERATIONAL SOLIDARITIES OR HOW TO INFORM THE DIRECT CONTRIBUTION OF ELDERS TO THE WELL-BEING OF THE INDIGENOUS COMMUNITIES OF QUÉBEC

INTERVIEW WITH CHANTAL VISCOGLIOSI, PROFESSOR, ÉCOLE DE RÉADAPTATION,  
UNIVERSITÉ DE SHERBROOKE  
CONDUCTED BY JULIE CUNNINGHAM, POSTDOCTORAL FELLOW AT THE INRS,  
SEPTEMBER 19, 2018

## CONNECTING OCCUPATIONAL THERAPY AND WORKING WITH INDIGENOUS ELDERS AS A STARTING POINT FOR THE RESEARCH PROJECT

As a trained occupational therapist, Chantal Viscogliosi found herself in the field of Indigenous studies as she was preparing to pursue a postdoctoral degree. During a discussion with a colleague, she hears of the existence of the École d'études autochtones à l'Université du Québec en Abitibi-Témiscamingue (UQAT). Shortly thereafter, she decides to contact the director of the school to present her intention of undertaking a postdoctoral degree under his supervision. While reading publications on Indigenous realities, Chantal reflects on the definition from an original - and useful! - perspective that would combine occupational therapy with her interest in working with elders to orient her research project.

Of course, based on a strong experience established over several years with this clientele, she had developed a professional practice anchored in the development of strategies focussed on the use of preserved capacities.

*For me, it was obvious that I had to work with elders because I had always done that, and I have much in common with people in this age group. I enjoy discussing with elders. I enjoy intervening with them and working from their strengths. With the reading I had done and having had discussions with people around me, suddenly, something flashed in my mind that seemed to me an interesting way of orienting my postdoctoral degree project.*

*My idea was: rather than approaching the realities of Indigenous elders as services recipients, it would be to see how their specific contributions are able to respond to the different challenges experienced in their respective communities.*

## A FUNDING OPPORTUNITY AND TIME CONSTRAINTS: THE UNCERTAINTIES OF RESEARCH PARTNERSHIPS

Shortly after having been admitted for the postdoctoral degree, Chantal and her director see that the SSHRC had launched a call for proposals for projects pertaining to synthesis of knowledge. The parameters of the project are truly relevant to the context of the research project in development and very quickly, it is agreed to apply. However, with the preoccupation of wanting to avoid unnecessary disruption in the Indigenous communities, Chantal and the co-researchers decide to first of all target Indigenous organizations such as the FNQLHSSC and the Cree Board of Health and Social Services of James Bay, to request their advice about the initial research question and invite them to collaborate.

*I had written a paragraph that I forwarded to potential partners. The objective was to determine with them if the project corresponded to their priorities or if they would like to articulate the question differently. The comments received after my contacting them proposed relatively minor changes. The original idea therefore somewhat remained the same. People found it interesting to use the strengths of the elders as a foundation. Therefore, they agreed to collaborate with us.*

As a second step, the idea was to begin consultation procedures with a diversity of Indigenous communities, that is, without the time constraint due to the deadline imposed by the SSHRC and ideally after having obtained the confirmation of funding acquisition.

A few weeks later, Chantal receives confirmation that the application was accepted. A new round of discussions begins with new Indigenous representative authorities; the Conseil de la nation huronne-wendat (Wendake), the Conseil des Abénakis d'Odanak, the Mohawk Council of Kanesatake, the Conseil des Atikamekw de Manawan, the Conseil de bande de Uashat mak Mani-Utenam, the Cree Nation of Chisasibi, the Conseil de la Première Nation Abitibiwinini de Pikogan, and the Inuit village of Kuujuaq were all contacted and invited to collaborate. The paragraph previously summarizing the objectives of the project is then forwarded to them while specifying that the research question could be refined and

revised to better harmonize with the realities of each community. In general, Chantal's invitation was transferred to those in charge of issues pertaining to elders, and whom she would contact afterwards to discuss the project verbally more fully, discuss the research question proposed on the contribution of Indigenous elders to well-being, discuss the partnership considered for the synthesis of knowledge, and answer their questions. Chantal proposed to the participating communities a methodology honouring Indigenous sources and oral tradition. In fact, she proposed the inclusion of written, audio, and video documents suggested by the elders of the different Indigenous nations in Québec. Furthermore, because oral tradition is especially important among First Nations peoples, the intention of collaborating with the communities provided the elders with the opportunity to share experiences that are not necessarily included in the written, audio, and video documents.

In all participating communities, this proposal was enthusiastically welcomed by the elders, who were very generous at the perspective of sharing their knowledge of existing resources describing the contribution of Indigenous elders to well-being, as well as narrate experiences they had heard on the same topic.

After discussing with the elder representatives in each community about her desire to offer as a gift, a summary of the Indigenous elders' contribution to well-being according to scientific

literature as well as the secondary analysis of the data from the Aboriginal Peoples Survey (APS, 2012), as an introduction to the thematic coffee meetings and due to the interest generated by this proposal, Chantal begins these research and analyses. With the APS (2012) data, she analyses the relations between variables for population well-being and spending time with an elder or while benefitting from the support of an elder.

When interlocutors confirmed their interest in participating in the project, a date was set for Chantal's arrival. During her visit, Chantal was to facilitate the coffee meetings and set up individual meetings, depending on preferences in each community.

*Some places considered the coffee meeting formula more interesting for sharing and mentioned that group discussions are stimulating and allow for new ideas to come forth. In other communities, after the coffee meetings, some participants wished to continue individually to further develop certain aspects of the elders' contributions. I adapted to the preference of each community.*

Overall, initial contact and subsequent discussions took place between December 2016 and August 2017. The summer period was intensive since the final report was to be submitted September 11, 2017. This was quite a feat which, in hindsight, leaves the researcher happy with the work accomplished,



but wishing the pace for the work had been less intensive to allow for meetings within the communities for which the procedure for the establishment for partnerships requires more time.

*It was necessary to work extremely quickly to respect the requirements of the funding. I really did all I could, considering the circumstances, to avoid putting pressure on the communities. But despite this, I would have preferred to have more time to solicit retroaction, integrate more perspectives...*



Source: CBHSSJB, 2018.

## COFFEE MEETINGS: A FERTILE GROUND FOR THE CIRCULATION OF IDEAS

As agreed with the communities, the coffee meetings organized in each community, except for Pikogan and Kuujuaq, were an opportunity for Chantal to explain her procedure and the objectives of the research, and to solicit from the participants a sharing of knowledge and experiences. After sharing the summary of what was found in scientific literature on the contribution of Indigenous elders to well-being, in turn, the elders shared knowledge and experiences, and proposed written, video, or audio Indigenous sources discussing the contributions of elders to well-being in their communities. The information that emerged from this co-development with the elders was included in the synthesis of knowledge produced subsequently. The elders were also encouraged to share their knowledge about projects pertaining to aspects of elder participation in the community which, this time, had not yet been documented to date.

*Seeing the elders' desire that these experiences undocumented in writing be included in the synthesis of knowledge, in respect of oral tradition, I included them, obviously without the claim that the synthesis is exhaustive in this area. When I came back home, I relaunched the search in the search engines to see if there was any documentation on the subject. And in some cases, my search was fruitful!*

Those people who participated in the coffee meetings were elders for the majority, but there were also a few political representatives and youth in certain cases.

*Through this co-development, I wished to collect a diversity of viewpoints. The small poster announcing the coffee meetings specified that everyone was welcome, but in the end, the elders were the ones who felt concerned the most. They wanted to have their strengths documented. But they also expressed the concern that I come back and for the research to be useful. Yes, this was a very important concern and I have never forgotten it. Upon completion of the synthesis of knowledge, I sent an invitation out to everyone to go back and share the results and consider avenues for action. This is how, during a coffee meeting on the sharing of the results, the idea of the creation of a toolkit on the contribution of Indigenous elders to well-being was proposed by an elder. The elders proposed the production of audio and written versions in French and in English, a Cree version and a drawn version. The latter could subsequently be used for intergenerational activities with children.*



## TREATMENT AND ANALYSIS OF DATA: AN EPISTEMOLOGICAL ISSUE

To proceed with the codification of the different types of actions by elders and the benefits generated by these actions, the team's researchers, including an Indigenous researcher, were inspired by the categories of the WHO's International Classification of Functioning, Disability and Health (2001). Very quickly, the team agreed to modify some categories that were insufficient to describe the contributions of the Indigenous elders.

*Hunting, for example, is considered a leisure activity according to this classification. But for Indigenous elders, hunting is not a leisure activity! Hunting is grounded in a relationship to a very specific territory according to their worldview... It is therefore insulting for most of them to be told that the hunting they practice corresponds to a "leisure activity"... It is the same thing with traditional crafts activities. It was therefore necessary to modify and enhance categorization to account for these cultural differences as to the meaning of certain practices within the Indigenous context. Would it be necessary to develop a completely new one entirely based on an array of Indigenous perspectives? Probably. This constitutes a limit to our research, and we are truly clear on that subject.*

## CREE ELDERS OF CHISASIBI DURING A CULTURAL DAY WHERE THEY SHARE THEIR KNOW-HOW. SOURCE: CBHSSJB, 2018.

Other discussions also touched on the way history is treated, whether oral or in the documentation produced by Indigenous organizations in the synthesis of knowledge. Substantially, where in selected scientific literature the actions are documented apart from the benefits, in the Indigenous sources, the benefits were not often explicitly mentioned. These discussions allowed for the enhancement of the synthesis of knowledge by the promotion of Indigenous knowledge.

*During the coffee meetings, the elders mentioned that, in the Indigenous worldview, the learning process, the experience related to the action, is at least as important as the results, if not more. Therefore, rather than prioritizing respect for a scientific methodology, we respected this epistemology. We therefore included the documentation though it did not comply with the predetermined inclusion criteria, that is, explicitly mention the benefits. Thus, contrary to scientific literature, for Indigenous sources, we have included the literature mentioning actions of elders without necessarily always explicitly describing their benefits if they weren't reported by the elders.*

The co-development of the synthesis of knowledge was achieved thanks to the contributions of multiple partners, including communities of eight different Indigenous nations (Anicinapek, Atikamekw, Abenakis, Huron-Wendat, Mohawk, Cree, Innu, Inuit). Other organizations also contributed to the development of the synthesis of knowledge, including the First Nations of Québec and Labrador Health and Social Services Commission (FNQLHSSC), the Val-d'Or and Sept-Iles Native Friendship Centres, the International Network on the Disability Creation Process (INDCP), the Canadian Medical Association, the Cree Board of Health and Social Services of James Bay, the Coalition pour le maintien à domicile, the Fédération des centres d'action bénévole du Québec, the Community Health Representative at the Temiskaming First Nation Centre, the Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG), the Institut du vieillissement et de la participation sociale.

## THE TOOLKIT AND ITS DIVERSE VERSIONS: KNOWLEDGE MOBILIZATION TOOLS REQUESTED BY THE COMMUNITY

Following a first year of meetings and discussions, the second phase of the project consisted of the production of various tools for the mobilization of knowledge, in keeping with the requests expressed by the communities. Two scientific articles and three articles in mainstream newspapers were written, one participation in Chisasibi's





*any actions that inspired them to respond to the challenges in their communities. This was also for the participants to reflect more globally on obstacles to be considered and winning strategies for intergenerational solidarities.*

The two-hour workshop was a huge success. The general conclusion of the workshop and that emerged from the ensuing plenary session was that this type of collective reflection concerning the contribution of elders to well-being was also relevant and inspiring for non-Indigenous communities.

*People said that there is definitely a deficit of intergenerational solidarity in communities. And that to approach the question from the perspective of elders' contribution was very fertile ground to discuss collective well-being. Many people said that the ideas presented in the excerpts from the toolkit would be engaged to initiate reflection in their respective work circles.*

**THESE CONCLUSIONS  
WERE THE OBJECT OF  
AN ARTICLE IN THE  
PERIODICAL VIE ET  
VIEILLISSEMENT,  
FALL 2018.**

An unexpected result through the realization of the activity was the proposal to hold a forum bringing together all the participants of the Indigenous communities of Québec.

*A representative from the Secrétariat aux affaires autochtones (SAA) felt that the format would be worth repeating on a larger scale such as a provincial forum.*

*A few weeks later, a funding opportunity was launched. With the same team, joined by two Indigenous elders and a researcher in knowledge transfer, we presented a proposal for a competition posted by the Social Sciences and Humanities Research Council of Canada (SSHRC) to this effect. The funding mainly covered residency expenses for people coming to the communities. For this new process, we proceeded with the same exercise as at the beginning of the research project. The communities were contacted again with a formal proposal and invited to articulate their ideas to enhance the content of the proposal. This time, the answers led to adjustments in both substance and form. It was interesting to build on this request as a group!*

Approximately 60 participants from eight nations met in Montréal. Even though, at the start, the research team thought that it would be easier to hold an event further north, after consultation with representatives from different Indigenous nations, Montréal was chosen as a gathering place for the forum. This forum was a space for reflection on how to encourage transmission of knowledge through intergenerational solidarities, as well as research perspectives to be prioritized within the perspective of enhancing the

transmission of Indigenous knowledge through intergenerational solidarities. It goes without saying that this forum was made possible thanks to many collaborators including Matthieu Fannière, Jimmy Fireman, Naomi Georges, Raymond Gros-Louis, Irene House Bearskin, Matthieu-Joffre Lainé, Julie Martel, Gaëlle Mollen, Nicole O'Bomsawin, Angela Phenix, Audrey Pinsonneault, and Sarah Vassigh.

*How should the utilization of Indigenous knowledge transferred orally be considered when research is conducted and in the development of strategies for the involvement of elders? This is one example of a question that was discussed during the forum. Enter into dialogue about the aspects of the transmission of non written knowledge, also reflect on research epistemology. These are other aspects that were discussed. A position statement was developed based on key elements that emerged in the discussions at this intergenerational forum held on February 6 and 7, 2019. It was submitted to the SSHRC and discussed at the national gathering in Ottawa, by an elder and an Indigenous youth, as well as Chantal.*



Collectively, the actors involved in the forum provided clear recommendations for future research projects. More specifically, this involves showcasing the transmission of Indigenous knowledge, then applying it in projects to encourage autonomy and active community engagement at all phases, ensuring the perpetuation of concrete results of the projects, as well as creating lasting intergenerational relationships.

If what is past is prologue, many unexpected and inspiring results from this forum can be expected!



## USING RESEARCH TO HELP CREATE AN INDIGENOUS YOUTH PROTECTION GOVERNANCE MODEL IN UASHAT MAK MANI-UTENAM

INTERVIEW WITH CHRISTIANE GUAY, PROFESSOR OF SOCIAL WORK  
AT THE UNIVERSITÉ DU QUÉBEC EN OUTAOUAIS  
AND NADINE VOLLANT, DIRECTOR OF SOCIAL SERVICES,  
UAUITSHITUN SANTÉ ET SERVICES SOCIAUX D'UASHAT MAK MANI-UTENAM.

CONDUCTED BY JULIE CUNNINGHAM, POSTDOCTORAL FELLOW  
FOR THE DIALOG NETWORK, OCTOBER 11, 2018

### THE ENCOUNTER

In 2006, after having worked five years as Director of professional services - Social for the Cree Board of Health and Social Services of James Bay, Christiane Guay decides to go back to school for doctoral studies in applied social sciences at UQO.

After making contact with the coordinator of Uauitshitun Social Services, Uashat mak Mani-Utenam Health and Social Services Centre, Christiane begins her field research in the summer of 2009. During this trip, she meets Nadine Vollant for the first time. Nadine, who has been working in the field of youth protection since 1995, has recently become clinical supervisor for Uauitshitun. For both women, it is clear that they wanted to collaborate since this first discussion.

*The connection naturally happened. I felt Christiane had sensitivity, a commitment to the cause, and was able to listen. A willingness to learn to listen and understand. I could feel that with her. During my story, I was quite generous because of this trust inspired by Christiane. I shared information that I don't easily provide... (Nadine Vollant)*

*Something clicked. During our meeting that lasted two-and-a-half hours, Nadine spoke to me about one of her dreams: that one day, the community would have governance over youth protection. To contribute to the accomplishment of this dream undeniably guided my work as a researcher. (CG)*

### THE FINDING THAT SPARKED THIS COLLABORATION: THE SERIOUS INADEQUACY OF YOUTH PROTECTION SERVICES FOR FIRST NATIONS

For Nadine, the interview with Christiane brought her to put a name on certain aspects and questions she had had for many years in her daily practice: the interventions prescribed by the youth protection system do not meet the needs of the children and families of her community.

*I was concerned because, from a human point of view, I could very well see that our interventions were harmful to the families. My indignation was confirmed by my readings in that area. Authors such as Cindy Blackstock contributed to the construction of my thinking regarding what was amiss with youth protection here. (NV)*

She recalls that this finding became more obvious in the aftermath of the work done with the legislative reform of the Youth Protection Act (YPA) which led to the adoption of amendments to the YPA in the fall of 2007. Moreover, most First Nations organizations anticipated that the prescribed changes would not be to the advantage of First Nations families.

*During the course of my reading, I came upon the Dumais Report [The Protection of Children, a Better Sharing of the Responsibility], published in February 2004. The Dumais Report is the expert report providing direction for the legislative amendments of 2007. In this report, among other elements, much attention is on the importance of the bonding in children's development. To protect this bond, recommendations were made for the implementation of measures such as the maximum placement period. Upon reading it, it seemed obvious to me that the implementation of such recommendations would create problems for First Nations after. I therefore called the AFNQL to tell them that, as a worker in the field, I felt that the recommendations would affect us negatively and something had to be done. Why? Because as a field worker, we saw that parents needed time to recover and granting priority to children's life plans would entail numerous placements until the children reach the age of majority which, in many cases, is undesirable, for both children and parents. I am able to understand since my mother attended residential schools. Therefore, I quite understand the situation in which our children and our children's children find themselves, having inherited all of this. (NV)*

### Section 91.1, YPA

91.1. If the tribunal orders that a child be entrusted to an alternative living environment under subparagraph e, e.1 or j of the first paragraph of section 91, the total period for which the child is so entrusted may not exceed, depending on the child's age at the time the order is made,

12 months if the child is under two years of age;

18 months if the child is two to five years of age;

24 months if the child is six years of age or over.

[Duration of other measures.] To determine how long the child is to be entrusted, the tribunal must, if it concerns the same situation, take into account the duration of any measure entrusting the child to an alternative living environment included in an agreement on the voluntary measures referred to in subparagraph e, e.1 or j of the first paragraph of section 54. It must also take into account the duration of any measure entrusting the child to an alternative living environment it previously ordered under the first paragraph. It may also take into account any prior period when the child was entrusted to an alternative living environment under this Act.

[Continuity of care.] If the security or development of the child is still in danger at the expiry of the periods specified in the first paragraph, the tribunal must make an order aimed at ensuring continuity of care, stable relationships and stable living conditions corresponding to the child's needs and age on a permanent basis.

[Return to family on the short term.] However, the tribunal may disregard the periods specified in the first paragraph if it is expected that the child will be returned to his family in the short term, if the interest of the child requires it or for serious reasons, such as failure to provide the services agreed upon.

[Continuity of care.] At any time during a period specified in the first paragraph, if the security or development of the child is still in danger, the tribunal may make an order aimed at ensuring continuity of care, stable relationships and stable living conditions corresponding to the child's needs and age on a permanent basis.



As the preceding text box indicates, for each age group, an upper limit is set for the duration of placement. When this period has expired and the parents have still not complied with the requirements imposed on them, the Director of Youth Protection must refer the case to the court in order to determine the appropriate life plan for the child in placement. In these situations, life plans include placement with a significant person, placement in a foster family, an institution, tutorship, adoption, and the youth's autonomy.

*I was disturbed by the establishment of this regime. I knew that if this model was applied, many parents whom I was monitoring were at risk of forever losing custody of their children. Previously, the process allowed for greater flexibility for parents and the possibility of returning to one's family was very real. When Christiane came to Uashat mak Mani-Utenam, we were starting to see the scope of the effects brought on by this change. (NV)*

Nadine was also especially outraged with the conditions imposed by the State for allowing First Nations communities to avail themselves of Section 37.5 of the Youth Protection Act, which allows for the implementation of a specific child protection regime within First Nations communities. The first condition to invoke Section 37.5 is that the community provide front-line services. At the time, most First Nations communities in Québec did not have such services because the federal programs did not fund them.

*The imposition of such a criterion was unfair to the extent where, in Québec the front line has been in existence for years. So, they did what they usually do, that is, impose criteria that make absolutely no sense to the communities. In reality, for the communities, the first contact for front-line services was youth protection. In other words, for a large number of communities, there is no social services infrastructure specific to First Nations children apart from youth protection. In fact, this was demonstrated by a report produced by the Commission des droits de la personne et de la jeunesse on the services infrastructure in Pikogan during the hearings of the Viens Commission. For example, the report specifies that to have access to a psychologist, one had to report their child to the DYP, which is nothing more and nothing less than an aberration. (CG)*



Nadine Vollant, at the Commission Viens. Source: Radio-Canada/ Émilie Rivard-Boudreau. Online: <https://ici.radio-canada.ca/nouvelle/1062688/un-juriste-innu-propose-la-mise-en-place-dun-systeme-juridique-autochtone-au-quebec>

Nadine recalls that when Christiane came to Uashat mak Mani-Utenam for her doctoral field work in 2009, Nadine herself was still in a learning situation with respect to her practice, and therefore had not yet developed the critical approach she has today.

*In all humility, I recognize that I was "a good little Indian". I did the things I was told to do. I wanted to become an expert in my practice. I wanted to know the legislative framework in all its details; for me, it was the only way of being able to change things. There are very few First Nations experts in the area of youth protection. And for an Indigenous person, it is even more challenging to work in youth protection because we interact with the families daily. Not all workers are able to live well in these conditions. Few workers stay long enough to become experts in this area. It is a challenge, and even more so with the reference framework that became extremely complex over the past 20 years. It has grown from 250 pages in the 1990's, to 950 today, including the regulations. It is*



*difficult to master, to say the least. Right now, I feel like I'm between a rock and a hard place. My authority is conferred upon me by the DYP. It is quite an exercise to have to vindicate substantive changes within the system that hires you. (NV)*

For Nadine, becoming an expert in her practice was both the best way to support her community as best she could in a system that did not meet their needs, as well as one of the milestones that would help her fulfil her dream.

*This is what I have consistently tried to do over the last ten years. But then again, you need credibility, structured thinking skills, and a good understanding of the practice. Because it goes without saying that our families criticize the framework but unfortunately, they don't have the knowledge of it to be credible. Sometimes they don't understand they are being wronged. (NV)*

This is therefore the context in which the research partnership with Christiane fits in.

## AFTER THE DOCTORATE, THREE RESEARCH PROJECTS

The year following Christiane's field work, all her energy is dedicated to writing. Eventually, the discussion arose about the project of establishing governance of youth protection in the community.

*One of the elements that had come out of my thesis is that non-Indigenous people showed a lack of knowledge of Innu (and Indigenous in general) intervention methods and cultural practices, as well as mistrust. It seemed to us that a first step within this context was to showcase and raise awareness about certain cultural practices. (CG)*

Christiane became professor of social work at the Université du Québec en Outaouais in 2010 and, in collaboration with Sébastien Grammond, law professor at the University of Ottawa, applied for a SSHRC grant to conduct research on Innu educational practices.

*The first research project following Christiane's thesis was borne out of these concerns [...]. The idea was to document and showcase how Innu parents care for their children. We had to be able to have our parents' practices acknowledged because they were deemed by intervenors to be bad parents. But they have a different way of educating their children. But that, we had to prove. (NV)*

Parallel to this, they also filed an application with the FRQSC. This time, the purpose was to develop another aspect of the thesis: territory as a way of healing and intervening. The idea was to study current initiatives and practices, always from a biographical approach. The results for both applications were positive. The following year, the recipient of the grant from the major research partnership État et cultures juridiques autoch-

tones : un droit en quête de légitimité approached Christiane and Sébastien Grammond, asking them to lead another project on customary adoption, a little known practice at the time.

*This practice had not been formally identified at the start as a research topic but emerged over time and with financing opportunities. (CG)*

## DOING RESEARCH TOGETHER: REVIEW OF METHODOLOGICAL AND ETHICAL PROCESSES

From the beginning of the work on educational practices, the research activities were led by a research committee. Today, this committee is composed of Nadine, the social services coordinator, an Innu collaborator, researchers involved in specific projects, a professional and a research assistant.

During the first three years of the projects, the partnership evolved without Nadine's participation who, during this period, was on maternity leave. Marie-Andrée Michel then played an important role in the different projects. She organizes the research fields; she is there to establish contacts, coordinate the validation processes for the stories. Distance and travel expenses meant that research partners had to take advantage of the new technologies to ensure dialogue and continuous transfer of information.

*Sept-Îles is quite far from Gatineau... 4 to 5 hours by plane or 13 hours on the road. So, I don't go to the community regularly. I went to the community for large data collections, that is, about twice a year, accompanied by students. And we must remember that there was a lot of material to be written due to the simultaneous deployment of the three projects. But we maintained regular contact by videoconference. (CG)*

In compliance with the guidelines provided by the community, expressed very clearly by the political representatives, the ethics for this research is based on the principle of reciprocity.

*The only criteria that we have in the community is simple: if we give, we need to know why and that it gives us something back. Research must make sense for us and allow us to benefit from it. In general, First Nations people are generous people. But it is important to ensure that people not abuse of this generosity and that reciprocity is at the core of the discussions. It is very much within this spirit that the research partnership was built. (NV)*

Over time, it became obvious that the research partnership supported the interests of the community and there would be something back in return for the data collected. The relationship resulted in the creation of written materials allowing the community to be understood and deemed credible.

*In the eyes of our interlocutors, what is not written doesn't exist. In other words, though our knowledge is one of the richest in the world, if it is transmitted orally, it does not have the required credibility. Let us put our knowledge to writing to make it understandable and therefore be able to practice it and transfer it. This is the reflection we developed with Christiane and she has always supported us toward this objective. What I retain is that the research was designed based on our concerns, which was not always the case with other people who came in our community to do research. With the experience we have on hand right now with respect to research collaboration, a bond was created between research and the community, which facilitated knowledge sharing; knowledge must flow between both sides. I understand the necessity of protecting knowledge, but I don't know if this posture is beneficial in the long term. We are able to document our knowledge, and have it recognized; why deprive ourselves of the benefits this recognition could bring? (NV)*



In 2018, all the projects were officially finalized. Most of the articles and reports published in relation to these are available online.

#### FOR MORE INFORMATION

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- Grammond, S., and C. Guay (2018). L'interaction entre droit innu et droit québécois de l'adoption, dans G. Otis (dir), *Revue générale de droit*, 48(1).
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- Grammond, S., and C. Guay (2016). Comprendre la normativité innue en matière d'« adoption » et de garde coutumière. *McGill Law Journal*, 61(4), 885-906.
- Guay, C. (2015). Les familles autochtones : des réalités sociohistoriques et contemporaines aux pratiques éducatives singulières. *Intervention*, (141), 12-27. [https://revueintervention.org/wp-content/uploads/2020/05/intervention\\_141\\_2.\\_familles\\_autochtones\\_des\\_realites\\_sociohistoriques\\_c\\_guay.pdf](https://revueintervention.org/wp-content/uploads/2020/05/intervention_141_2._familles_autochtones_des_realites_sociohistoriques_c_guay.pdf)

In addition to the research projects, the partners contributed to the recent reforms of child protection legislation and the amendments to the Civil Code regarding adoption, based on the vision and values of community members. For Nadine, it is obvious that if the argument for these changes was solid, it is because it was based on the studies and the development of parenting practices and customary guardianship, and on listening carefully to local perspectives.

*This is the documentation that allowed our community to be at the forefront of these issues; without it, we would probably not have been able to play the role that we did. The fundamental quality of the researchers collaborating with us is to have a good listening ear. One of our political representatives who is quite qualified to understand the issues read one of the papers produced by the researchers. Her reaction was to say, "My goodness! This is us!" For her, it was absolutely amazing to recognize herself. To read something that represents us, our vision, our culture, our values, our realities. Amazed to see that we can use written words to describe a practice that, for them, can only be experienced. For them, they experience it. (NV)*

Ultimately, the amendments to the Civil Code concerning adoption led to the implementation of a committee whose mandate was to provide the Uashat mak Mani-utenam community with a policy on customary adoption in order to establish a competent authority.

*The working group's functioning was simple: Sébastien and I wrote the policy; we then submitted the document to the committee members who read it and proposed changes. And this is how the policy was built, with many discussions back and forth. I remember what an elder said during one of these meetings: "How do you manage to so faithfully describe the practice?" I replied: "I've been listening to you for many years." From the beginning, my work has been based on biographical stories. The research methods I use allow for the precise understanding of the meaning of the words and practices. It is not something innate. Years of listening have enabled this. What also helped us as non-Indigenous researchers was to work on three projects at the same time. People don't shorten their stories. Life does not follow categories. Therefore, each discussion is a source of information helping to understand relevant elements. (CG)*

## MOVING TOWARD GOVERNANCE OF YOUTH PROTECTION

In 2016, Christiane is again approached to develop a new research project within the framework of another major partnership entitled *Accès au droit et à la justice (ADAJ)*. Because of this proposal, Christiane approaches Nadine with the idea that this opportunity could lead to phase 2 of their research collaboration, that is, a project for the implementation of an Innu youth protection regime in the Uashat mak Mani-Utenam community.

*Over the past two years, we completed the reports, we worked on a family policy for which work is still ongoing, and we will now work with the support committee on the development of the youth protection governance project. The data collected in the preceding projects; the practices documented and showcased, the principles and values at the core of these will be the foundations of this governance model. (CG)*

Furthermore, another research project undertaken in 2018 will contribute to the work on the governance project. This time, the research partnership will study the trajectories of Innu youth in youth protection (a potential sample of about 300 youth) by engaging in a mixed research method that is both quantitative and qualitative.



*This project is the result of a specific request from Nadine. The idea was to study and eventually demonstrate that, despite placements, the delays imposed and the obligation to place youth in permanent life plans, many of them run away and end up going back to their community on their own or after a judicial decision toward the age of 15. Successfully demonstrating a convergence of trajectories based on an adequate sampling would be a strong argument for allowing the community to develop alternative proposals to what is imposed by the YPA and have those accepted. (CG)*

Moreover, this research project is compatible with the orientations of the amendments to the YPA (Bill 99), adopted on October 4, 2017 (see text-box for more details). In the aftermath of the consultations to prepare for the adoption of these amendments, Uashatmak Mani-Utenam social services developed an “identity” program for children in foster care. Anchored in the perspectives shared by the youth, this program encourages the transfer of Indigenous knowledge through practices at the heart of the community’s culture.

*Youth tell us they want to learn the language, know the culture, beading, the ceremonies, the practises on the land. We were so concerned about the behavioural or learning difficulties of youth that we completely missed a fundamental need they express: to experience their culture. We are currently in an experimental phase of this program. And the culture and knowledge transfer, we are not the experts for this, the members are. We must therefore work closely with the bearers of culture to define objectives and means of reaching out to them in a way that is relevant to them. (NV)*

Since the second phase of the research partnership was launched, the directors of the project communicate even more regularly than before. In fact, they work actively in the development of a work plan to be submitted to the new committee members during the month of November 2018.

*The support committee we are about to launch will include parents, youth, representatives from the school sector, elected officials*

*in charge of the social services and elders portfolio. Representativity will be extended if we compare the composition of this new committee with that of our former working committees. (CG)*

*It is very important for those who have less knowledge of the practice, such as professionals, elders, members of the community and those involved in our work because of their legal training, to know what we have achieved and understand the direction we are taking. We always present the process, the stages we are at. This allows us to clearly explain what each meeting will be about, what themes will be discussed with them, etc. Then, the meetings are more of a discussion forum where people express themselves. This is the way we work as a committee. (NV)*

Bill 99 was adopted on October 3, 2017. From the First Nations’ perspectives, two additions seem to be favorable. Section 3 now specifies that in the case of a child who is a member of a First Nations community, the preservation of their cultural identity is considered when determining the child’s best interest. As for Section 4, it specifies that a decision made for a child who is a member of a First Nations community must tend to entrust this child to a substitute environment able to preserve their cultural identity.

## TRAINING FOR WORKERS ON CULTURAL SAFETY CURRENTLY UNDER DEVELOPMENT

To better meet the needs on the field, Nadine and her team are currently developing training on cultural safety.

*Very few training sessions are currently offered in the communities. It is utopian to think that a one-day training session dedicated to both the historical aspect and the alternatives for intervention would have concrete impacts in the workers' practices. From my perspective, training offered in two phases is required to better equip practitioners: therefore, one in health, another in social services, and finally, one in youth protection. (NV)*

Moreover, this training will include two other experiential days during which culture will be at the core of the teaching.

*This could be in the form of meal preparation, ceremonies. The idea is that people absorb tangible experiences and develop human relations. That they realize the wealth of knowledge First Nations Peoples possess. That they learn how things were done in the past at Uashat mak Mani-Utenam. That they learn our local history. (NV)*

It also means being informed by the work of the Truth and Reconciliation Commission.

*The TRC, even if it was deployed nationally, is very little known. I read the report. From my perspective, it is impossible to remain indifferent in reading these stories. These stories must be made known and they will be within the framework of training on cultural safety that we are currently constructing. (NV)*

For those in charge of the social services portfolio, skills development in cultural safety for the practitioners is a huge challenge.

*There is no mistaking it: interventions without sensitivity and knowledge of context are dangerous for our families. It is absolutely fundamental that workers be able to decode the messages. And the role of First Nations managers in the current context is to tell workers to review their interpretations and validate with the families rather than infer things according to irrelevant models. Training therefore aims at increasing the number of people capable of understanding parents and families to eliminate any aberrations. (NV)*

When all the research projects will have been finalized, an enhancement phase for this training is planned accounting for the results obtained.

## IN CONCLUSION...

At the core of the research partnership reside very clear purposes: change the way things are done at all levels and be heard with the interlocutors who understand the world on the basis of principles and values that are very different from those of the Innu and the First Nations in general.

*The research permitted us to document the aspects more globally and proceed to the practise of integrating all this knowledge into a system. Despite this openness provided for by the law (Section 37.5), the fact remains that we are not masters in our own home. This flexibility provided by the State is very compartmentalized; I know this, I experience it every day. From my perspective, all the research done in my community has the potential of enhancing current and future initiatives of First Nations in youth protection. One day we will write a book on youth protection in a First Nations context. (NV)*

(French only)

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### NADINE VOLLANT

is one of the recipients of the Hommage award for the 40<sup>th</sup> anniversary of the Charter of Human Rights and Freedoms - an honour received in 2015.  
[http://40ansdelacharte.org/ambassadeur-fr-79-Nadine\\_Vollant](http://40ansdelacharte.org/ambassadeur-fr-79-Nadine_Vollant) (French only)

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In 2017, **CHRISTIANE GUAY** and **SÉBASTIEN GRAMMOND** are the recipients of the Rights and Freedoms award granted by the Commission des droits de la personne et des droits de la jeunesse, for their contribution "to the development of knowledge of First Nations governance in youth protection, an area that is still not well documented among French-speaking First Nations since close to ten years."  
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