

**First
Nations
in Quebec
and Labrador's
Research Protocol**

2014



A spiral-bound notebook is shown from a top-down perspective, slightly angled. The notebook's cover is a vibrant orange color, and its pages are white with faint, light-orange horizontal lines. The spiral binding, made of a metallic-looking wire, runs along the right edge of the notebook. The notebook is set against a plain white background.

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Aussi disponible en français. Protocole de recherche des Premières Nations au Québec et au Labrador (2014).

A summary map is also available.

The masculine form is used to simplify reading of the text and is in no way aimed at discriminating against women.

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Illustrations for this document were realized by the artist Tim Whiskeychan

Tim Whiskeychan is a Cree artist from the Waskaganish First Nation. He was born in 1968 in Chibougamau and raised in Chapais by his adoptive parents, Harry and Laura Whiskeychan. Art forms the narrative thread of Tim's life; he has been a self-taught artist since childhood. Tim returned to school from 1996 to 1999 to perfect his technique. He paints in acrylics but also enjoys discovering other media. He has worked as an illustrator and a designer. Tim speaks Cree, English and French fluently, which has allowed him to take his art to many different places and garner broad public acclaim. He was among the artists from 11 Nations selected by the Royal Canadian Mint to create a series of collectors' coins. Tim's coin will be inaugurated on September 14, 2014.

Graphic work and synthesis diagram were realized by La Boîte Rouge vif

La Boîte Rouge vif is a non-profit organization that was incorporated in 1999. It is affiliated with Université du Québec à Chicoutimi and is steered by a board of governors, the majority of whose members are Aboriginal people with backgrounds in the areas of education and culture. All profits generated by the design services offered by this organization are reinvested in research activities concerning the promotion of Aboriginal culture. The mission of La Boîte Rouge vif is to produce and disseminate projects bringing together Aboriginal culture with innovative design projects through numerous video productions, exhibitions and publications that showcase Aboriginal works of art. La Boîte Rouge vif is also recognized for its expertise in mounting exhibitions based on a participatory community methodology.

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DEFINITION OF ACRONYMS

AFNQL: Assembly of First Nations Quebec-Labrador
ACUNS: Association of Canadian Universities for Northern Studies
CCL: Canadian Council on Learning
REB: Research Ethics Board
CCÉR: Comité central d'éthique de la recherche
FNIGC: First Nations Information Governance Centre
SSHRC: Social Sciences and Humanities Research Council
NSERC: Natural Sciences and Engineering Research Council
FNQLHSSC: First Nations of Quebec and Labrador Health and Social Services Commission
TCPS2: 2nd edition of Tri-Council Policy Statement (2010)
QNW: Quebec Native Women
CIHR: Canadian Institutes of Health Research
CIPO: Canadian Intellectual Property Office
WIPO: World Intellectual Property Organization
NAHO: National Aboriginal Health Organization
OCAP™: Ownership, control, access and possession
UQAT: Université du Québec en Abitibi-Témiscamingue



ABSTRACT

The First Nations in Quebec and Labrador's Research Protocol is first and foremost a collective tool for community chiefs and managers who are invited to take part in research projects. This document will be used as a guide by not only First Nations, communities and regional organizations, but also indirectly by the scientific community, in order to establish rules for research activities performed with First Nations or on their territory.

The protocol highlights three fundamental values to implement a collaborative research project between a First Nations community and researchers. These values are: *Respect*, *Equity* and *Reciprocity*. They must coexist and pave the way to any collaboration agreement for research projects, regardless of the discipline. These values have been inherent for First Nations from "yesterday to today".

In the same line, the action principles at the heart of the protocol are the First Nations principles of Ownership, Control, Access and Possession (OCAP™). A new element is the First Nations principles of OCAP™ Certification Application Process. In addition, the protocol addresses the position of First Nations on issues of intellectual property and collective ownership of their knowledge. Lastly, the acknowledgement of their knowledge, their sacred heritage and cultural knowledge are addressed.

Each step of the project – *before*, *during* and *after* the research – is detailed. *Before* corresponds to the research project design, the research agreement and ethical considerations. *During* focuses on research operationalization, which is the methodology and research products, in addition to the dissemination, diffusion and/or publication. *After* refers to the communications parameters and research follow-up.

In addition, to achieve those values, principles and steps in a research project, the protocol provides hands-on tools (agreement templates, forms) for First Nations to adapt, modify or use as they are.

Finally, it is not a substitute for existing tools, policies or guides within First Nations, communities and First Nation organizations. First Nations must provide governance in terms of information management and collective knowledge, which means that they must protect and preserve their information heritage. This protocol is therefore an additional tool which allows actions already underway to be pursued.



FOREWORD

Research activities involving First Nations, directly or indirectly, have been constantly increasing since the first version of the First Nations of Quebec and Labrador's Research Protocol was published in 2005. This document resulted from a need expressed by several First Nations for a tool to manage the research propositions that they received. Many First Nations organizations have since developed similar tools, with the same objective to help First Nations in the research participation efforts about their people or taking place on their territory.

Many Canadian teaching and research institutions have adopted stricter rules in terms of research with First Nations over the past few years. Guidelines were developed to help researchers in their research activities. Also, could the university community question the relevance of a new version of the First Nations' Research Protocol by saying that ethics committees already have policies to guide research on First Nations in Canada? Why "impose" additional rules, principles and steps to researchers? You should find partial answers to those questions in this document.

We are referring, among other things, to social and political affirmation movements of many First Nations which, over the past decades, have been particularly strong in terms of whistleblowing, claims, mobilization and concrete actions. An affirmation movement is also seen in the First Nations research, personal, community and territory data management fields. One of the most significant and sad examples once again confirms the need for such protocol, at least to raise awareness among researchers about a heavy past of unethical research with some First Nations: We are talking about so-called scientific nutrition experiments carried out between 1940 and 1950 with children in "boarding schools".

With this document, we reaffirm the right of First Nations to claim full governance for information about them, and to be fully involved in all research projects, regardless of the discipline, which concerns them directly or indirectly. The Assembly of First Nations of Quebec and Labrador maintains its commitment to advance and develop science and a stringent and ethical research process. It fosters the development of tools supporting First Nations, communities and organizations in their journey towards autonomy.

We wish that this protocol can guide First Nations and researchers in their respective and common work in terms of research, and to develop and share knowledge.

The First Nations in Quebec and Labrador's position regarding research is expressed in the following statement of principles.

Ghislain Picard
AFNQL Chief

STATEMENT OF PRINCIPLES

1. The First Nations in Quebec and Labrador have the right to self-government and self-determination, including the right to manage themselves their communities and traditional territories.
2. The First Nations in Quebec and Labrador have a unique worldview and their own value systems.
3. Customary law and teachings dictate that it is the responsibility of the First Nations in Quebec and Labrador to govern their territories by managing and protecting lands to sustain their traditional and contemporary ways of life.
4. Free, prior and informed consent must be obtained from the First Nations in Quebec and Labrador and from the participants involved in the research.
5. The First Nations in Quebec and Labrador are the guardians, interpreters and collective owners of their cultures and past, present and future knowledge systems.
6. The First Nations in Quebec and Labrador have the right and obligation to exercise control over their cultural heritage and traditional knowledge in order to protect them.
7. The First Nations in Quebec and Labrador advocate for the decolonization of research and they control research activities that affect them. They must approve any data collection related to their population or territories as well as any biological sample collection.
8. All research must respect First Nations in Quebec and Labrador's privacy, dignity, cultures, traditions and rights. If, in the course of a research, a community determines that the research is not acceptable, it may withdraw from the project as it should be indicated in the research agreement.
9. At the community and regional levels, the First Nations in Quebec and Labrador have protocols that must be respected. Traditional keepers such as families or groups of individuals have their own customs regarding the transmission of knowledge and they must also be respected.
10. The First Nations in Quebec and Labrador require the highest standards of research practices to ensure the quality and integrity of data, in accordance with the First Nations principles of OCAP™ (Ownership, Control, Access and Possession).
11. Research projects on the First Nations in Quebec and Labrador must have the intention to meet First Nations' needs and priorities. These projects must benefit the First Nations in terms of local capacity building, project management and ethics oversight.
12. All results of research, studies or surveys about the First Nations in Quebec and Labrador must be validated and returned to them. The co-author rights of First Nations contributors are recognized, where appropriate.



INTRODUCTION

In 2005, the Assembly of First Nations of Quebec and Labrador (AFNQL) developed a protocol for all research, evaluations, surveys, focus groups etc. involving First Nations individuals or led on First Nations territory.¹ It was then agreed that the document would eventually need to be revised. In 2010, the revision started in light of recent experiences and new available information. An electronic survey targeting any individual who has used, recommended or referred to the First Nations of Quebec and Labrador's Research Protocol since 2005, as well as phone consultations with First Nations organizations and band councils have supported the reflection on the shape that the new protocol should take (Basile and Gros-Louis Mchugh, 2013).

This protocol is aimed mainly at First Nations who are asked to participate in research or who wish to do their own research. The scientific community is asked to consider the First Nations' Research Protocol in the same way that they would for the protocols, guidelines and other documents used in research institutions. Many researchers ask communities to participate in their research projects, and it is essential that a tool originating from First Nations be available to provide guidelines to manage those requests. The guidelines can, for instance, help evaluate the feasibility and acceptability of a research project on First Nations territory.² The term "community" does not necessarily and solely refer to band council, but also other bodies such as an entire sector (e.g. health, territory), a group of elders or certain families, based on the context and type of research.

This protocol pursues two main targets:

- Raise awareness among First Nations, communities, First Nation organizations and the scientific community in terms of the importance of ethical research, while considering the current challenge which consists in implementing the protocol;
- Suggest an ethical framework for research which puts its respectful development first in a First Nations context under the following forms:
 - i. Fundamental values which guide the research process with First Nations, like a storyline;
 - ii. Basic research principles among First Nations (culture, vision of the world, good practises, etc.);
 - iii. Unavoidable steps.

A visual tool comes with this document to illustrate the suggested contents. The objectives of the protocol update are to increase its use and truly implement it locally, and increase the attention to ethical research within First Nations.

1 The Assembly of First Nations' Joint Council used the term "First Nations" for the first time in 1980-1981 in the *Declaration of the First Nations*. Symbolically, the term attempts to elevate Aboriginal peoples to a status of "first among equals" in their quest for self-determination and self-government alongside the English and French founding nations in Canada. In that spirit, the term First Nations is preferred to Aboriginal people when referring to the First Nations of Canada and Quebec. (Gadacz, 2011)

2 As defined by the First Nations and including the plant, animal and human worlds, as well as the four dimensions in the medicine wheel.

RESEARCH CONTEXT IN A FIRST NATIONS ENVIRONMENT

“Revitalize our lives through research”
(Words of an elder reported by Marlene Brant Castellano)
(UQAT, 2012, p. 13)



In Quebec and in Canada, scientific research³ led by non-natives in a First Nations environment started at the end of the 19th century, especially in the field of anthropology (Lévesque, 2009). It intensified in the 1970's with the launch of major economic development projects in the North. In Quebec, the James Bay hydroelectric development project is a good example. The First Nations and Inuit, directly affected, claimed their rights, which stimulated the interest of researchers from many universities across the country. Various fields of study starting doing research on First Nations, such as anthropology, geography, sociology and law (Lévesque, 2009).

During all those years, the position of non-native researchers was that of experts in their fields of study. Research projects rarely provided for consultations with the concerned First Nations communities, who had little or no control over the research methods being used or on the interpretation of the results (NAHO⁴, 2007). This observation applies to Quebec First Nations, but also to those in Canada and in the rest of the world. A review of the scientific literature from that time shows that the expression “colonial research”⁵ was often used. Colonial research methods have greatly affected the relationships between the research community and First Nations. Negative research experiences made First Nations suspicious and reluctant to get involved in new research projects. That is why research was often seen as a tool of oppression and colonization by First Nations (Durst, 2004).

3 Among the rigorous criteria often mentioned as essential in any scientific research project are veracity, applicability, constancy and neutrality (Lincoln and Guba, 1985, quoted in Pelletier and Pagé, 2002), which competes with the type of research (as a means of acquiring knowledge) traditionally led among First Nations and based on learning through experience and observation.

4 The document in reference was produced by the National Aboriginal Health Organization (NAHO); however, because of its dissolution, a transfer process has begun and all documents produced by it going to be transferred to the First Nation Information Governance Centre (FNIGC). The process is still open at that day.

5 “Colonial” scientific research methods rely on a domination relationship, where the dominant’s methods and concepts are imposed to the dominated. (Smith, 1999)

Since the 1990's, Aboriginal peoples from Quebec, Canada and throughout the world have been openly criticizing the methods used in research projects about them. They complain about the fact that “[...] research projects are a one-way street and, overall, they are more beneficial to researchers and universities than to the populations who make the effort to participate and give their time” (Gentelet, 2009, p.143). From an international perspective, the draft *Declaration on the rights of indigenous peoples* initiated in 1982 paved the way to a favourable context for emancipation, while in Canada, the Royal Commission on Aboriginal Peoples (1996) plays the same role. During that same period, the university research community also understands the conflicts and historical injustices associated with research in First Nations environments (CIHR, 2007). Granting agencies and universities across the country now promote research in cooperation with First Nations communities (Gagné and Salaün, 2009). The methods used by teams of researchers for research project in First Nations environments are gradually changing. The literature on “research decolonization” refers to this transformation (Smith, 1999).

“[...] the Royal Commission on Aboriginal Peoples (RCAP) and other studies all agree on the fact that a major aspect of the solution to the cost of social problems faced by First Nations is the need to change the research paradigm from outside stakeholders trying to find a solution to the ‘Indian problem’ to First Nations leading research and finding solutions themselves.” (SSHRC, 2003, p. 5)

In this context, the First Nations in Canada have started to establish their own rules, committees and procedures to protect their information, their culture, their traditional knowledge and their rights (NAHO, 2007). At the beginning of the 1990's, the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey of First Nations comprised of members from every region in Canada was formed to recommend fundamental research principles: the First Nations principles of OCAP™, which will be discussed further. A series of publications⁶ proposing guidelines for research projects involving First Nations appeared in the

6 In 1996, the Royal Commission on Aboriginal Peoples (RCAP) published in its report a series of guidelines that were widely used by universities and First Nations to develop protocols; the *Tri-Council Policy Statement: Ethical conduct for Research Involving Humans* (TCPS), published in 1998, and its second edition in 2010 (TCPS2) contain a chapter on research involving First Nations; the Association of Canadian Universities for Northern Studies (ACUNS) published *Ethical Principles for the Conduct of Research in the North* in 2003; the Canadian Institutes of Health Research (CIHR) published guidelines for research involving First Nations in 2005 and in 2007; the Assembly of First Nations of Quebec and Labrador (AFNQL) published a *Research Protocol* for First Nations communities and researchers in 2005. This document in the second edition of the protocol.

second half of the 1990's (Lévesque, 2009). In Quebec, the AFNQL implemented a Research Protocol in 2005. It includes the First Nations principles of OCAP™, put forward in 1998 by the National Steering Committee of The First Nations and Inuit Regional Longitudinal Health Survey during the course of population studies with First Nations. Today, these principles provide for “First Nations sovereignty on a much wider data spectrum than forecasted and guide First Nations processes which apply to all their data” (AFN, 2007, p.4).

Following those changes, First Nations and Inuit communities have written their own guide for research conducted on their territories. For instance, the First Nations of Manitoulin, in Ontario, wrote the *Guidelines for Ethical Aboriginal Research (GEAR)* in 2003, the Onkwata'karitahtshera Research Sub-Committee in Kahnawake⁷ published *Regulations for Research in Kahnawake* for the Onkwata'karitahtshera Health and Social Services Research Council in 2006, and the Nunavut Research Institute, with Inuit Tapiriit Kanatami, published *Negotiating Research Relationships with Inuit Communities: A guide for Researchers* in 2007. In recent years, the Quebec Native Women (QNW) have developed *Lignes directrices en matière de recherche avec les femmes autochtones* (2012) to help First Nations women and organizations to better evaluate the relevance of proposed research projects.

This revised version of the AFNQL's Research Protocol falls into the historical research decolonization context. It wishes to answer the First Nations' needs to make research projects with concern them their own by proposing principles such as reciprocity and putting emphasis on trustworthy relationships within the projects.

⁷ Thanks to Kahnawake's Onkwata'karitahtshera Research Sub-Committee for sharing their document as a reference for the revision of our research protocol.

Did you know that?

For First Nations...

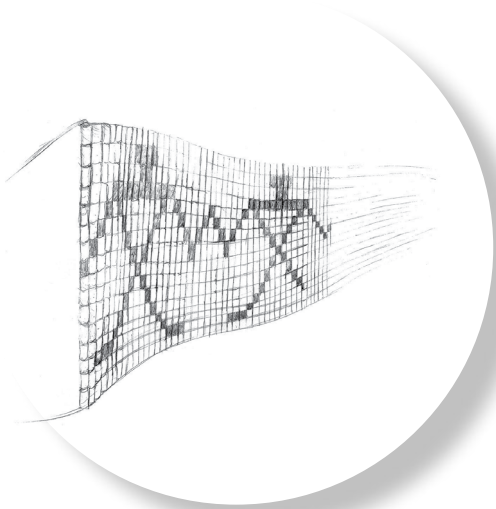
The notion of time is interpreted as a way of life based on activities practised following the seasons and the weather. For instance, travelling, livelihood activities (such as trapping and agriculture) and traditional ceremonies were and still are determined by the weather and the time the year. Those moments vary from one region to another and from one nation to another. For instance, for Atikamekw, there are six seasons separated by climate markers. Some seasonal activities are determined by those markers. For many First Nations, “cultural weeks” are moments in the year, during fall and spring, where you return to the forest for activities such as goose and moose hunting. They are often family gatherings which are held on ancestral territories. These are precious times for First Nations, and researchers should plan their meetings (first meeting to present the research project; data gathering activities, etc.) accordingly.

For the scientific community...

The notion of time is dictated by deadlines imposed by fiscal year and fixed amounts. Research activities must be finalized according to a schedule designed to answer the funder’s needs. Researchers are held accountable for that schedule with very little flexibility. That is why field visits in communities may be few and limited in time.

FUNDAMENTAL VALUES

Taking into account the records for research conducted in a First Nations context, the First Nations' desire to self-govern and have their distinct identity and culture recognized, three fundamental values which help achieve an ethical space for the research protocol are suggested: **respect**, **equity** and **reciprocity**.



These values must inspire and guide the teams of researchers like a thread, and each step of research projects conducted in cooperation with First Nations should abide by these values. But what exactly is included in the notions of *respect*, *equity* and *reciprocity*?

Traditionally, the concept of **respect** is at the heart of relationships between First Nations societies:

“It is the foundation of most of the First Nations teachings on the way to coexist, as shown by the two row wampum doctrine, for instance.” (McCormick, 2009, p. 5)

Therefore, for First Nations, respect is more in the lines of acknowledgement and appreciation of differences, for instance in terms of culture, personality and language (McCormick, 2009). Many languages used by First Nations in Quebec don't actually have a specific word that means “respect” such as it is understood in French or English. Respect is the consideration or importance given to a person or object and the true desire not to affect it in any way (Larousse, 2012). For the protocol, this value is a research principle which applies to individuals, the relationships between them, knowledge, perspectives and conceptions pertaining to every culture. Respect must be mutual and continue throughout the research process. Continued communication based on a trust relationship between researchers and at least one First Nation/community representative, sharing the knowledge between parties or an efficient data interpretation validation mechanism with First Nation/community are all ways through which researchers show respect towards First Nation/community partners for a research project.

Equity is the ability to give everyone what they deserve in reference to the principles of natural justice. In a research project, equity manifests itself in three different ways: 1) acknowledgement of the respective needs of research partners; 2) exercising shared powers between First Nations and the team of researchers; 3) sharing the benefits of research.

Lastly, **reciprocity** is seen as a value characterizing Aboriginal peoples throughout the world (Jimenez Estrada, 2005; Wilson, 2005; Anderson, 2008). For example, “Historically, Aboriginal economies were based primarily on sharing (a familistic, egalitarian pooling of resources) [...] [and] on reciprocity (a calculated, give-and-take exchange)” (Trovato *et al.*, 2011). In the modern world, this value applies to various fields, including research.

There is a reciprocity relationship when the team of researchers and the First Nation community involved give as much as they receive. In that spirit, each party should be able to benefit from research (beyond a strictly financial standpoint). Co-building⁸ or the two-eyed seeing⁹ on knowledge is a concrete example of reciprocity in a research context. In short, reciprocity, just like respect and equity, helps to establish a trust relationship, which is necessary to any relationship with First Nations (Lévesque, 2009).

⁸ In the current context, co-building knowledge manifests itself by researchers sharing their perspectives with the First Nations, in order to develop new knowledge. Refer to the glossary at the end of the protocol for a full definition.

⁹ The concept of two-eyed seeing refers to the differences in conceiving the world between First Nations and non-natives, respecting that difference and sharing in order to generate new knowledge. (Barlett, Marshall and Marshall, 2007).

ACTION PRINCIPLES DICTATED BY VALUES



First Nations have always had protocols for information gathering, usage and transmission. For that reason, families, clans and communities have always owned their narratives, songs, stories, etc. Lastly, protocols were used to dictate the rules in terms of to whom, when and how information could be transmitted (AFN, 2007).

The First Nations principles of *Ownership, Control, Access and Possession* (OCAP™) of information that were created by First Nations in the 1990's are now well known. In Canada, the First Nations principles of OCAP™ principles were integrated in the *CIHR Guidelines* (2007) and in the new version of the *Tri-Council Policy Statement* (2010). More and more researchers use these principles in their research projects. However, they need to understand their reach and the proposed application considerations (FNIGC, 2013).

The First Nations principles of OCAP™ principles are First Nations value statements which pave the way to positive changes in the research and information and knowledge management fields. These principles allow a mutual trust relationship to be established between First Nations, the scientific community, governments and other stakeholders.

While the following description for the First Nations principles of OCAP™ principles is not a true definition, it represents the values and the First Nations' way of seeing the world in terms of authority and collective rights (FNIGC, 2013).

3.1 First Nations Principles of OCAP™

Applying these principles is used to protect the informational and knowledge heritage of First Nations. These principles are about collective ownership of information by a community, a nation or a group. They expand to research, population studies, surveys, documentary monitoring, information management systems and cultural knowledge. They target all aspects of information, including its creation and management. These principles apply to all kinds of research and all research fields which take place on First Nations territories or concern First Nations.

Ownership

The notion of ownership is related to First Nation's relationship with knowledge, data and information associated with its culture. A community or group collectively owns information associated to its culture in the same way that a person owns its personal data. It is not synonym with governance. Governance, which is the administration of information by an institution which is accountable to a group, is a mechanism used to obtain ownership (or respect the principle of ownership) (FNIGC, 2013). For instance, legends and songs are cultural information transmission vehicles and are collectively owned by a First Nations community.

Sections 3.2 and 3.3 provide additional information on ownership.

THE FOLLOWING QUESTIONS TRIGGER A REFLECTION PROCESS ON THE PRINCIPLE OF OWNERSHIP:

- What type of information will be collected and used? What is the target population? What are the data collection methods that will be used?
- How will First Nations individuals be identified in the database (individually, by community, nation, region, geographic zone, etc.)?
- How will First Nations individuals be identified (membership code, self-declaration, band list, Indian Register, etc.)?
- Who will own the information and data used for the project?
- Will everyone who contributed to the project be formally acknowledged in the publications? (FNIGC, 2013)

Control

This principle reflects the aspirations and inherent rights of First Nations members in terms of taking and maintaining control of all aspects of their lives and institutions (research, data and information). It requires First Nations members to have the right to request control, at all steps, of the research and information management process which concerns them, from research initiation to completion. This principle expands to all forms of information management and data collection, as well as data usage, disclosure and destruction (FNIGC, 2013).

THE FOLLOWING QUESTIONS TRIGGER A REFLECTION PROCESS ON THE PRINCIPLE OF CONTROL:

- How will First Nations be able to control or govern their data?
- Is there a memorandum of understanding for First Nations data collection, usage and disclosure?
- What is the decision-making process in terms of data usage, access and disclosure? (FNIGC, 2013)
- What will happen to data at the end of the project?
- Where and how will data be kept?
- Is there a mechanism which allows First Nations to request the destruction or removal or data kept by a third party?

Access

First Nations must have physical access to the data that concerns them and their communities, regardless of where it is stored. This principle also refers to the right of First Nations, communities and First Nation organizations to manage the information that concerns them collectively and to make decisions about it (FNIGC, 2013). Some First Nations have archive where there are standards and access rules for their own population and external researchers.

THE FOLLOWING QUESTIONS TRIGGER A REFLECTION PROCESS ON THE PRINCIPLE OF ACCESS:

- Can the First Nations access the data which concerns them?
- Will the organization managing data access share it with other organizations or individuals who are not part of the research team?
- Will the names of individuals who are part of the research team and who will access, gather or create data be kept in writing?
- Does the participant have liability insurance for information theft, loss, breach of confidentiality, etc.?
- Are there safety procedures for data protection among the First Nations organization concerned? (FNIGC, 2013)

Possession

While possession is not an essential condition to data ownership, it is a mechanism which helps confirm and protect ownership. When data concerning First Nations is kept by a third party, there is often little or no control over data management by the concerned population (FNIGC, 2013). To solve this, upon agreement, it is possible to use a First Nations third-party organization which has the infrastructure and safety standards to keep the data. For instance, data could be kept by an archive centre or a national or regional First Nations organization, such as the First Nations Information Governance Committee (FNIGC) or the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC).

THE FOLLOWING QUESTIONS TRIGGER A REFLECTION PROCESS ON THE PRINCIPLE OF POSSESSION:

- Will the data be kept and controlled by a First Nations organization?
- If the First Nations don't have the data, would it be possible to transfer the responsibility to them later on? (FNIGC, 2013)
- If needed and upon request, can anonymous data be sent back to the community to be used for its own purposes?

Finally, the First Nations principles of OCAP™ are to be owned by all First Nations and communities. They should therefore decide what these principles represent for them and how they wish to use them for research purposes.

Registration process for the First Nations principles of OCAP™

In 2012, the FNIGC started the registration process as a trademark for the First Nations principles of OCAP™ logo. A request for the registration of the First Nations principles of OCAP™ acronym was filed in the fall of 2013. This is to prevent abuse and distortion of the term. In addition, the FNIGC will soon implement an OCAP™ certification mechanism for research projects. The service will be provided by the FNIGC to the scientific community and other organizations wishing to have research projects certified as the First Nations principles of OCAP™ compliant. Those who wish to have their research certified as the First Nations principles of OCAP™ will have to go through this FNIGC process (fees apply), in addition to the usual

process with a Research Ethics Board (REB). Regional First Nation Organizations will also be able to review and make recommendation to the FNIGC for projects to be certified as OCAP™ compliant.

Institutional, educational and bureaucratic considerations associated with the First Nations principles of OCAP™ have been identified for over a decade. For more information on that subject, please refer to the FNIGC work at www.fnigc.ca.

3.2 Acknowledgement of the contribution of First Nations to intellectual property

As a general rule, intellectual property¹⁰ refers to the rights that pertain to intellectual activity in the industrial, scientific, literary and artistic fields.¹¹ The intellectual property rights recognized in Canada include patents, trademarks and copyrights. For research projects, intellectual property is always generated, for instance in written reports or publications.



There are new practices in terms of acknowledgement of the contribution of First Nations to intellectual property generated during research projects (Cuerrier, 2012). While intellectual property is governed by Canadian and international laws, it is possible to decide who is the owner through a contract. Therefore, the question must be addressed upstream of the research project and be explicit in the research agreement (CIHR, 2008). In addition, beyond intellectual property laws and university policy, “[...] local conventions or customs may be acknowledged and even applied” (CAGS, [s.d.], p. 5). Also, intellectual property versus collective property of research products should be clarified between the research project partners and stakeholders.

For example, in arts, intellectual property rights apply to the creation or co-creation of any work, regardless of the medium used (canvas or digital).

10 See glossary for a definition of intellectual property and collective property.

11 Source: CIPO (2013), online: www.cipo.ic.gc.ca

As the First Nations concerned will actively take part in co-building knowledge, their implication should be formally acknowledged. It is therefore recommended that a formal acknowledgement be required by the First Nation community or the local individual(s) concerned. The acknowledgement could take the shape of a co-author status for the community members who played an active role in the publications (Pauktuutit, 2012). Concretely, the co-author status translates itself into the fair sharing or intellectual property between authors, and that one author cannot publish without the other. *Beyond Intellectual Property: Toward Traditional Resource Rights for Indigenous Peoples and Local Communities*, by Posey and Dutfield (1996), is a reference document for intellectual property matters specific to the First Nations context.

3.3 Protection of First Nations knowledge

Research projects are often subjects written about First Nations knowledge. Generally, First Nations transmit knowledge from generation to generation, and it belongs collectively to community members. In some cases, only a select few individuals or groups within the community have the knowledge. Each community has customary law¹² which dictates how knowledge is kept and transmitted from generation to generation. Traditional knowledge does not “belong” to individuals to whom it has been transmitted by the elders. They are however responsible for keeping it and use it for the benefit of their community.

The collective responsibility is explained in Mi'kmaw Ethics Watch's *Research Principles and Protocols*:

“Mi'kmaw knowledge is collectively owned, discovered, used, and taught and so also must be collectively guarded by appropriate delegated or appointed collective(s) who will oversee these guidelines and process research proposals” (Mi'kmaw Ethics Watch, 1999, p. 2).

On an international level, the collective aspect of traditional knowledge and its “intellectual property” considerations are found in Article 31 of the *United Nations Declaration on the Rights of Indigenous Peoples* (2007):

“Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions. [...] They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge and traditional cultural expressions.” (UNO, 2007, p. 12)

¹² Refer to the glossary for a definition of customary law.

NOTES

The World Intellectual Property Organization (WIPO) is currently working on two convention projects, the first one protecting traditional knowledge and the second one traditional cultural expressions. Both texts are only projects and most articles are drafts, as the States have yet to agree on contents. However, both texts refer to the collective aspect of traditional knowledge and traditional cultural expressions.

For more information, refer to the WIPO website: <http://www.wipo.int/portal/en/index.html>

The United Nation's Convention on Biological Diversity includes a paragraph on the protection of traditional knowledge (article 8j), and the Secretariat, located in Montréal (Quebec, Canada), states in its official documents that traditional knowledge is generally owned collectively.

In other parts of the world, several laws rely on the principle of collective ownership. Let's mention for instance Peru's law #27811 (2002), which establishes the protection regime for Aboriginal peoples' collective knowledge in terms of biological diversity, and Panama's law #20 (2000), on the special intellectual property regime governing the collective rights of Aboriginal peoples for the protection of their cultural identity and traditional knowledge. These two laws rely on the principle that Aboriginal knowledge is collectively owned.

Unfortunately, "traditional" First Nations knowledge cannot be fully protected by existing intellectual property systems,¹³ especially in Canada. Since intellectual property laws generally require the creation to be "new" and by an identifiable author or inventor, it creates obstacles for knowledge transmitted from generation to generation within a First Nation community.

Therefore, for a research project, it is especially important to take explicit measures to make sure that traditional knowledge is protected and not used or disclosed without the consent of those who have the knowledge.

¹³ Refer to WIPO (2013): "What is intellectual property?", online: www.wipo.int/about-ip/en/.

4.

COLLABORATIVE RESEARCH

The term “collaborative research” was chosen¹⁴ to stress the importance for First Nations to actively participate in and collaborate to all the steps of the research process in their environment. For instance, the community or the First Nation can be represented by several local individuals who act as community partners, or be represented by a local committee.



No specific research approach is advocated by the protocol. The three values – respect, equity and reciprocity – are more important than they type of approach. In addition, the team of researchers and their partners can determine ways to work in collaboration from the very beginning of the process.

“[...] researchers must offer the option of engagement, a community may choose to engage nominally or not at all. [...] A community may, for example, support a study carried out independent of community influence in order to use scientifically defensible results to validate a negotiating position.” (SSHRC, NSERC and CIHR, 2010, p. 123)

A first meeting between the First Nation community and the team of researchers allows to start a discussion about the research topic and method. It should also be possible to discuss the objective, the ways to process data and the targeted products.

In addition, when a research project is presented to a community or a First Nation, the latter should be allowed to suggest new approaches for methods and concepts to the researchers. These new methods could be more in line with First Nations perspectives, which in turn would make them feel more compelled by the project and its completion. They will influence their participation. Furthermore, knowledge transfer and skills development regarding research methodology in a First Nation is an important aspect for the development of collaborative research.

¹⁴ The term is also used in chapter 9 of TCPS2. According to article 9.13 “Collaborative research should be relevant to community needs and priorities and should benefit the participating community as well as extend the boundaries of societal knowledge.” (SSHRC, NSERC and CIHR, 2010, p. 125)

Dialogue and research agreement

Dialogue, seen here as an exchange, an act of sharing or a way to communicate, is a way for First Nations and the team of researchers to put their perspectives in common. In a research context, the objective of dialogue is to leave room for all mindsets, consider every one of them fairly and allow them to exist (Gentelet, 2009).

The research theme, the way it is addressed, research questions, the respondents, the way the results are processed then presented in a report or an article are examples of subjects that all involved parties should discuss and agree on. The focus agreed on during the dialogue must be included in a written agreement.¹⁵ As mentioned in the *CIHR Guidelines for Health Research Involving Aboriginal People*, “the quality and relevance of a research agreement are directly proportional to the quality of the relationship between the research partners. A respectful relationship is established on the same bases as an efficient research agreement: good communication, honesty, transparency and trust” (CIHR, 2007, p. 27). The research agreement provides protection for all parties; its absence exposes all parties to some rights being denied.¹⁶

NOTES

“A collaborative research agreement consists in a formal summary of the rights, responsibilities and expectations shared by interested parties. It generally contains information on the main researchers and the research project. [...] The collaborative research agreement is usually co-directed by First Nations researchers, ensuring a fair partnership. It should also be written in the First Nations’ preferred language.” (NAHO, 2007, p. 5)

Throughout the research process, both parties must be flexible enough to modify the initial agreement. Mutual agreement must however be reached in order to make any modification.

¹⁵ A collaborative research agreement template is shown in Appendix 1

¹⁶ For example, refer to Nagy, M., 2011: “Access to data and reports after completion of a research project.” *Études/Inuit/Studies*, 35: 1-2.

Right of Examination

First Nations have a right of examination and decision on all the steps of the proposed research.

The right of examination includes:

- research topic;
- consultation process;
- proposed methods;
- approach (selection of participants and meetings);
- data collection material developed for the research;
- research results and products (interpretation and validation);
- anticipated benefits (presentations, publications, etc.) and research follow-up if applicable.

The two-eyed concept is strongly recommended, since it allows for putting many points of view into perspective, improving the quality of decisions and, therefore, the quality of the research results.

Right to Participate

Collaborative research comes with the notion of right to participate in every step of the research for the involved the concern First Nation. The researcher and the First Nation partners must establish a dialogue mechanism between them. This process helps establish a collaborative relationship between all parties (SSHRC, NSERC and CIHR, 2010). It is strongly recommended that the First Nation participation be deeper than the simple approval of the research project by the band council or any other locally-chosen organization. Various degrees of participation are possible. They must be mutually agreed upon, taking into account each party's capacities (i.e.: researcher's budget and human resources availability in the First Nations community).

CONSULTATION

When consultations are made with First Nations, the following must be kept in mind:

“Most traditional Aboriginal philosophies have deep roots in the Earth. Aboriginal languages and cultural practises exemplify this. Traditionally, Aboriginal peoples considered Earth and their lives on Earth as a spider web representing a complex network of interdependence relations (Cohen, 2001). In this delicate web of life, great importance is given to the ‘balance’ principle (Cohen 2001; Kenny, 2002). The elders constantly remind contemporary Aboriginals of the importance of keeping balance in their lives. The definition of ‘balance’ varies greatly based on biogeographic zones, language and culture, which reflect the earth on which one lives. This is why comprehensive consultations and a culture-specific protocol are required for all research projects” [Unofficial translation] (Kenny, 2004, p. 9).

First consultations should be held with the First Nations involved on the research topic even before developing it in details. Normally, when the researcher establishes a contact with the First Nation/community, he can discuss the potential research topic with them. A conversation on the various research aspects between the researcher and the First Nation/community allows for mutual understanding. The consultation determines whether or not the research project answers the First Nations’ needs, if it meets the local protocols as well as the level of implication of the First Nations people at every step. It should also be used to determine the conditions to meet for approval (collective and individual) (Basile, Asselin and Martin, [to be published]; SSHRC, NSERC and CIHR, 2010; Stevenson, 2010). The First Nations involved must take part in the decision-making process for research with concerns them or an element of their community or culture (e.g. fauna resources on ancestral domain) (AFNQL, 2005).

Consultation details must be agreed upon from the start between interested parties. Convocation to consultation activities must be done according to local protocols, by individuals with the necessary authority and involving the First Nations contact person(s) throughout the process (AFNQL, 2005).

Specific consultations must be done with particular groups (elders, women, youth, trappers, healers, entrepreneurs of all ages) (Basile, 2011). Consultation cannot be considered as a data collection step within a research project. Control and final decision must be assumed by the concerned First Nation in order to avoid misrepresentation (Lachapelle and Vollant, 2012).

“Researchers will involve communities to identify elders and other knowledge holders, in order for them to participate in developing and implementing the research project and interpret its results, in a cultural standards and traditional knowledge context.” [Unofficial translation] (SSHRC, NSERC and CIHR, 2010, p. 142)

ACKNOWLEDGEMENT OF FIRST NATIONS KNOWLEDGE

Among the many definitions for “Aboriginal knowledge”, the following is most often quoted and will be used for our purposes:

“Traditional ecological knowledge or TEK is a cumulative body of knowledge, practice, and belief, evolving by adaptive processes and handed down through generations by cultural transmission, about the relationship of living beings (including humans) with one another and with their environment.” (Berkes, 2012, p. 7)

For many Aboriginal peoples, the path to gathering knowledge is more important than knowledge itself (Hatcher *et al.*, [s.d.]). Therefore, “Aboriginal science encompasses a wide array of processes to ‘get to know’ what is coming from human experiences of the natural world” [Unofficial translation] (Hatcher *et al.*, [s.d.] p. 2).



It is understood that each nation, if not each First Nations community, is in the best position to explain what traditional knowledge means to them, the way knowledge is transmitted and who can access it. They must be consulted for any information about that knowledge.

Aboriginal knowledge must be considered as unique and valid, with their own functions and validation process, as well as existing outside the occidental scientific framework (Stevenson, 2010). Although over 200 scientific articles or documents are published annually on Aboriginal knowledge for over 30 years, it is often ranked second, behind so-called “scientific” knowledge, when it comes to defending research results (Cheveau, 2008). While there is an increasing number of First Nations researchers, research is still primarily undertaken and done by non-natives (AFNQL, 2005). It is now well-known that the participation of First Nations contact persons in the research development process and hiring local individuals help taking First Nations knowledge into account. Speaking of which, First Nations researcher Shawn Wilson, who wrote *Research is a Ceremony*, mentions the following: “The foundation of Indigenous research lies within the reality of the lived Indigenous experience. Indigenous researchers ground their research knowingly in the lives of real persons as individuals and social beings, not on the world of ideas” (Wilson, 2008, p. 60).

Did you know that?

For First Nations...

Traditional knowledge is kept collectively and that, for research purposes, it is important to establish standards through formal protocols. For some communities, these standards may not have the subject of internal reflection, and the researcher should systematically study that question.

For the scientific community...

“Researchers who undertake projects that embrace Aboriginal peoples or issues related to them have an obligation to maintain and protect the integrity and context of Aboriginal knowledge gained in the process. Researchers wishing to access Aboriginal knowledge as part of their research must respect any local and other (regional) formal protocols in place.” (Stevenson, 2010, p. 8)

It is not recommended to take First Nations knowledge out of its context and then translate it into so-called scientific language in order to include them in more traditional research results. The knowledge validation methods must be established and acknowledged by First Nations and not rely on methods or criteria from science only (Stevenson, 2010). The scientific doctrine for data verification and knowledge validation can be considered offensive for individuals who hold that knowledge, which has yet been approved for centuries in an adaptive process.

For instance, it is now accepted that First Nations knowledge can actively contribute to Canada’s ecologic restoration efforts, that it can bring essential information to select species and sites, while ensuring significant participation from Aboriginal peoples (Uprety *et al.*, 2012).

Protection measures for Aboriginal knowledge must be implemented (e.g. women knowledge about medicinal plants). While Canada’s legislation in terms of First Nations intellectual property protection is insufficient (e.g. about the use of medicinal plants), some forest certification standards include criteria in that respect (Uprety *et al.*, 2012). Also worthy of acknowledgement is the “world of knowledge” belonging to Aboriginal women, who must receive extra attention due to its unique and invaluable character (Basile, 2011; QNW, 2012). In all research projects involving First Nations, the knowledge of women must be fully acknowledged, just like that of men (Grenier, 1998; Lévesque, Geoffroy and Polèse [in press]).

SHARING BENEFITS



Carrying out research projects brings benefits. They must be recognized from the start for all involved parties (SSHRC, NSERC and CIHR, 2010). The First Nation must be able to measure direct and indirect benefits flowing from its active implication. The research and its results must be beneficial to the entire community (CIHR, 2007).

Benefits can come in many forms, based on individual interests. For instance, research and its results can answer questions from the community. In addition, new knowledge will be beneficial for community decision making (programs, policies, priorities), reinforcing local capacities and advocating claims, etc.

In general, the appreciation of benefits forms the base for a First Nation/ community making the decision to participate in a research project.

Developing local capacities in terms of research

Sharing benefits also translates into developing or reinforcing local capacities, which can happen on an individual or community basis. For instance, on an individual basis, a First Nation/community can require First Nations students to be hired as research assistants or that First Nation/community individuals be trained as research agents, or become co-researchers. First Nation/community representatives can be expected to provide knowledge transfer (related to research) to First Nation/community. It is recommended that researchers allow First Nations/communities to determine their own needs in terms of capacity development or reinforcement by inviting them to discuss these issues. Researchers must also make sure that the necessary budgets are allocated to maximize other activities needed to build a sustainable future (Stevenson and Perreault, 2008). They must have a medium and long-term objective consisting in helping the First Nation/community to develop.

“Research projects will help capacity reinforcement through the improvement of community personnel skills in terms of research methods, project management ethical evaluation and supervision.” [Unofficial translation] (SSHRC, NSERC and CIHR, 2010, p. 141)

Let's study the case of interpreters (who translate from an Aboriginal language to French or English, and vice versa) working on a research project. Their contribution is often essential to the project's intellectual approach, and they should be rightly acknowledged and compensated for their work.

In addition, a First Nations expression can translate into many sentences in French or English. It is therefore fair that the rates for First Nations interpreters is much higher (three to four times) than that of interpreters working from French to English, for example. It is therefore paramount that their participation be fully recognized.

In a research project focusing on specific issues facing a First Nations community, identifying these issues and finding solutions must be done in close collaboration with the community.

Suggested methods:

For individuals:

- Encourage the participation of First Nations co-researchers, recognize their knowledge and listen to them;
- Develop tools to transfer local knowledge;
- Acknowledge the importance of First Nations interpreters and include them in the research teams.

For the community:

- The research team should “make every effort to transfer to Aboriginal peoples and communities relevant skill sets and knowledge that facilitates their empowerment in the research process” (Stevenson, 2010, p. 7).
- Create a local committee or suggest using an existing local committee within the First Nation/community to discuss and validate some research aspects.¹⁷
- Designate one person in the research team who will be in charge of making sure that ethical principles (such as the First Nations principles of OCAP™) are adhered to be all members at all times.

¹⁷ A local committee should consist of community representatives. These individuals are selected based on their knowledge, interest and vision for the future, and they represent various community groups such as women, youths and elders.

ACCOUNTABILITY

Accountability is more than simple responsibility and has legal implications. When a person or organization is accountable, it means that they can bear the legal responsibility of their actions.

In the case of research projects, all participating parties are accountable to other parties. The research team is accountable to the First Nation that it is working with, and the First Nation is accountable to the research team that she accepted to collaborate with.

The specific aspects for which each party is accountable must be mutually agreed upon and ideally written in a research agreement. In that case, the accountability falls on the organizations who sign the agreement.

“Research relations must not be coercive or abusive in nature. They should be developed in the interest of university and Aboriginal communities. Researchers should be aware of their responsibility and increased accountability toward the community when they enter into a research relationship with Aboriginal peoples.” [Unofficial translation] (Stevenson, 2010, p. 8)

SACRED HERITAGE AND CULTURAL KNOWLEDGE

The spiritual beliefs and principles of First Nations are diversified and can vary greatly from one nation or group to another. The same goes for their usage and meaning. There are also common aspects shared by all First Nations. There are strict, if not essential, relations between all forms of life, elements of nature, human beings: they are the foundation of the relationship that First Nations still have with Mother Earth (Deroche, 2008).

In order to emphasize this relationship, First Nations use various objects, often made of natural materials (drums made of animal skin, wood or stone pipe, container made of shell or bark, herbs, plants, etc.) during specific ceremonies or cultural activities. It is important to take into account the distinctions and signification of those objects when developing research projects, holding research activities or other events (Pow-Wow, ceremonies, rituals, etc.) being held in First Nations communities and territories.

Researchers who don't have the necessary knowledge may be a witness of the use of certain objects and purification rites for instance (cedar, sage, tobacco, eagle feather, pipe). It is important, if not essential, that the researcher be informed of the steps to follow (participate or not) and what is allowed (whether or not to touch, record, photograph the objects or rites) (Posey and Dutfield, 1997).



Did you know that?

For First Nations...

The loss of knowledge and sacred ritual objects due to the Canadian government prohibiting their possession or usage is a sensitive issue. These laws have had devastating effects on the preservation of First Nations culture and ceremonial practises. In addition to the systematic looting of sacred objects, their transmission and reproduction were deemed illegal and punishable by law. (Conaty, 2004)

For the scientific community...

The history of First Nations is often misunderstood, as well as the sacred aspect of informal local codes associated to some objects. This misunderstanding is partially explained by the blunders which occurred during some research projects.

Since the early 2000's, a repatriation process for sacred objects, purchased since the XIXth century and kept in Canadian museums (e.g. Glenbow Museum, Canadian Museum of Civilization,¹⁸ Royal Ontario Museum) was undertaken in response to numerous claims from Aboriginal groups (Conaty, 2004; Ficher, 2012). It is strongly recommended that research teams who are interested in those issues to seek information with the appropriate First Nations before starting a research project on such a sensitive issue. Local experiences and protocols vary from one First Nation to the other, and they must be taken into account. Publishing information, images or recordings about sacred objects should first be approved by the appropriate community. The interpretation of their status and usage must satisfy the ones who have the knowledge about those sacred objects. The sacred value of an object does not decrease because of its exhibition in a museum or because it was sold at some point.

¹⁸ The name was recently changed to *Musée canadien de l'histoire / Canadian Museum of History*.

Lastly, Article 12 of the *United Nations Declaration on the Rights of Indigenous Peoples* (2007) states that:

1. Indigenous peoples have the right to manifest, practise, develop and teach their spiritual and religious traditions, customs and ceremonies; the right to maintain, protect and have access in privacy to their religious and cultural sites; the right to the use and control of their ceremonial objects; and the right to the repatriation of their human remains.
2. States shall seek to enable the access and/or repatriation of ceremonial objects and human remains in their possession through fair, transparent and effective mechanisms developed in conjunction with indigenous peoples concerned.

To support First Nations in their respective repatriation measures of sacred objects, a literature review is available on the FNQLHSSC's website.

APPROPRIATE USE OF COLLECTED INFORMATION

Ethical research principles state that prior, free and informed consent (see the section on consent) also applies to the use of collected information. The information and material collected for research must be used in conformance with the initial research agreement. Any secondary use of the information or material collected that is not specified in the initial research agreement requires the negotiation of an additional agreement and “requires an evaluation by a REB (Research Ethics Board)” [Unofficial translation] (SSHRC, NSERC and CIHR, 2009, p. 131).

“The expression ‘secondary use of data’ means using data for a purpose other than research.” [Unofficial translation] (SSHRC, NSERC and CIHR, 1998, p. 3-5)

Take for instance the example of a study made on human tissues to determine their level of contaminant: the collected samples may not be used for other purposes, except if the individual and First Nation/community agree to do so.

Consequently, when a researcher plans to use collected information for a secondary use or transfer them to a third party, he must seek the participants’ approval. When finding the participants proves to be impossible, the collective consent of local authorities could be considered.

“Access to traditional knowledge on plants based on publications to help marketing products is an example of secondary use of data which are identifiable and can be traced back to a specific community, without having an appropriate dialogue with the community. In some fields, such as ethnobotany, a great amount of traditional knowledge was published without the original holder’s consent, and even without them knowing. The researchers will seek advice with individuals familiar with the community’s culture before using the data, in order to determine whether or not using them could cause damage and if the benefits should be shared with the original community.” [Unofficial translation] (SSHRC, NSERC and CIHR, 2010, p. 132)

In some research contexts, it is essential that the research team, First Nation partners and participants discuss possible secondary use of data before starting the project. If it's the case, the agreement between parties must be included in the research agreement.

Material published on the Internet

Obtaining permission (ideally written, in addition to the research agreement) from the individuals concerned is necessary before publishing any material (pictures, videos, publications, etc.) on the Internet. The individuals concerned must have a right of examination on material published online and, on most importantly, be able to express their agreement or disagreement. All parties must also be aware that, once material is published on the Internet, controlling its use or diffusion becomes virtually impossible.

STEPS BEFORE, DURING AND AFTER THE RESEARCH

I. FIRST CONTACTS

Initial contact should be in the form of a letter of intent asking for a meeting with local First Nation authorities, in order to discuss the proposed research's objectives. That first letter must be sent to the appropriate First Nations authorities.¹⁹ The meeting which should take place between the First Nation representatives and the potential researchers will be the occasion to address some fundamental aspects:

- Research needs and priorities identified by the First Nation;
- Presentation of research team expectations towards the hosting First Nation;
- Open discussion on the research project, its sources of financing and any potential conflict;
- Disclosure of the main researcher and contact person's names and contact information, their objectives, the proposed methods, the local protocol and the steps to take;
- Establish participation procedures if the project is deemed acceptable by the First Nation authorities.



Other important elements must be discussed during the initial meetings with interested parties:

- Training and hiring co-researchers, research assistants, research agents, etc.;
- Information publishing mechanisms during the research project;
- Data collection considerations;
- Research follow-up mechanisms;
- Intellectual property, confidentiality and access to data and research products.

¹⁹ Respecting local authority means that the first letter should be sent to the band council, instead of any other individual or organization from the community. However, following the context and the established relationship between the research team and the community, the letter can be sent to another person in charge, such as a manager.

Researchers must clearly state how they will form the research team, how they plan to train local co-researchers and provide confidentiality for data collected from First Nation/community individuals or groups (supporting documents, methods and approaches, draft consent form).

From the first steps of the consultation with First Nations, it is important to decide who will be the owner of the results; if shared ownership is planned, details must be clearly established before collecting any information. The parties should also determine who will pay the costs of report production and translation into the First Nation's language. It is important to clearly identify and agree on the organization(s) that will pay those costs.

II. SOURCES OF FINANCING

Federal and provincial government organizations subsidize the majority of community research project (FNQLHSSC, 2009). They don't always stick to their administrative or monitoring functions and can sometimes act as co-researchers or mediators. It is therefore essential for First Nations to be fully aware of who the project designer is and where the funds are coming from. Donor agencies and sponsors and the roles they wish to play, if applicable, must be clearly mentioned in the research agreement. It is important to make sure that the financing allows for the research to be carried out without influence or control from donor agencies.

While it may seem difficult to finance projects integrating community action and involvement, it may be interesting for First Nations to require from the research team to be a co-manager of the research fund.

NOTES

All of the financing elements should be explained to First Nations managers, in order for the community and researchers to clearly agree on financing limitations, delays and requirements. Here are the elements in question:

- Eligibility conditions;
- Delay between the announcement and presentation of the research project;
- Theme predetermined at the time of announcement;
- Participation of experimented writer for grant application;
- Person in charge or project staff;
- Available funds (CIHR, 2007, p. 34).

III. RESEARCH AGREEMENT

The collaborative research agreement²⁰ can be interesting for First Nations, as it is usually written with research partners. It provides for a true partnership, transparent and fair, at every step of the research (NAHO, 2007).

Regardless of the research agreement model used, it should contain at least the following information:

- Information on the main researchers and the research project (including a summary of the proposed method);
- Sources of financing;
- Roles, rights, expectations and responsibilities of each party;
- First Nations principles of OCAP™.

The research agreement should be written in a mutually agreed on language, which is understood by all parties involved.

NOTES

“Even if trust and verbal agreements are important, it is best to have the necessary documents when working with external researchers, in order to avoid all potential misunderstandings and conflicts.” (NAHO, 2007, p. 5)

A research agreement has a start date and an end date, and they should be specified. If publications or other result publication methods are planned at the end of the agreement, a section must be added. It will clarify that all parties have agreed on the publication of research results at the end of the agreement.

²⁰ A collaborative research agreement template is shown in Appendix 1.

IV. RESEARCH ETHICS BOARD (REB)

Research projects which must be evaluated by a Research Ethics Board (REB) before they begin are the ones involving humans (UQAT, 2010). This committee has the necessary authority to approve or reject a research project. In addition, it must protect all participants.

For example, the establishments associated with the researchers have a Research Ethics Board (REB). If not, they must submit their research project related to health and social services to the *Comité central d'éthique de la recherche* (CCÉR). This committee is under the responsibility of the *ministre de la Santé et des Services sociaux* and is housed at the *Fonds de recherche du Québec – Santé* (FRQ-S).²¹

A REB is an authority created to evaluate whether or not a research project is acceptable. It is composed of individuals with various fields of expertise (traditional ecologic knowledge, empowerment skills, know-how, university and scientific knowledge, local, community and political representatives and any other individual with a relevant expertise for the First Nations context).

The *Tri-Council Policy Statement* (TCPS2) states that REB evaluation is also required when a research project focuses on “biological material, embryos, foetuses, foetal tissue, human reproductive material or human stem cells. It can be material coming from live or dead humans” [Unofficial translation] (SSHRC, NSERC and CIHR, 2010, p. 15). While TCPS2 provides for exemptions, including research relying only on public information and those that produce results which are impossible to associate with individuals or jeopardize privacy, it is recommended to plan specific measures for the Aboriginal context, due to the higher risk of privacy violation (through data association) for individuals participating to a research project. In addition, research projects generating results which could prejudice or modify significantly a community or First Nation’s written history, even the contemporary territory occupation, should be evaluated by a REB.

²¹ For more information, refer to the following website: www.ethique.msss.gouv.qc.ca/site/ccer.phtml.

Nomination procedures must be implemented for the community or First Nations ethics board members. The committee should include ethics experts, legal experts, representatives for elders, women, youths, elected officials, etc. A training session on research ethics with Aboriginal peoples should systematically be provided to all committee members. Some First Nations, communities or organizations have already established a procedure for issuing research ethics certificates (Kanhawake community; Nunavut Inuit, communities in the Manitoulin region, Ontario). This certificate should come before the one issued by the research institution or university to which the researcher belongs.

Did you know that?

For Inuit...

Some communities and nations have developed their own research ethics board. For example, the Nunavut Research Institute is the ethics committee which issues permits for all research carried out in Nunavut. It also acts as a transmission belt between Inuit knowledge holders and researchers. Research projects are evaluated based on various criteria, including respecting the Inuit communities' interests and needs in terms of research. The Inuit know how their institution works and usually verify whether or not researchers have their permit before participating in a research project (van den Scott, 2012). First Nations communities and organizations can use that model to establish a research follow-up committee and a procedure to issue research permits.

For the scientific community...

Obtaining an ethics certificate is mandatory for research with human subjects. To obtain it, researchers must satisfy a series of criteria dictated by their institution, including the demonstration that the risks for humans involved in their project are minimal and that they are participating willingly.

Where required, researchers should always be able to provide the ethics certificate issued by the First Nation or regional First Nations organization, as well as the one issued by their institution. The institution should, in addition, require the ethics certificate (or official letter) issued by the First Nation or regional organization before issuing their own certificate.

The few existing First Nations structures in terms of ethics are considered as a first step towards self-management. They remain pioneers to this day, and their relations with REBs still need to be defined. The existing multi-centre mechanism²² seems to be a measure which could also apply in this context.

NOTES

In the fall of 2011, most Quebec universities have signed an agreement providing for a research project led by researchers from several universities to be evaluated only by the Research Ethics Board (REB) of the main researcher's institution. This agreement is only valid for projects with minimal risks. It applies only to university research project, excluding university medical centre or university institute projects. (CÉR-UQAT, 2012)

²² A multi-centre research project is carried out in several establishments. The multi-centre mechanisms prevents the research project from being evaluated (from an ethics standpoint) by as many REB's as there are establishments working on the project. The main REB can therefore act as the main authority for many establishments. (MSSS, 2012) For more information: www.ethique.msss.gouv.qc.ca/site/fr_mecanismemulticentrique.phtml.

V. INFORMED CONSENT/CONFIDENTIALITY/RIGHT TO REFUSE



Before they begin, all research projects must receive a collective consent from the First Nations or organization rightfully tasked with giving that consent. The consent must be in a written form, after detailed analysis of the research project, submitted in writing to local authorities (letter or agreement protocol). Collective consent may not replace the consent of individuals involved in the research project. Individuals must be informed clearly, fully and in writing of the research topic, goals and objectives, the planned methods, the advantages and disadvantages of participating, the benefits and use of research results.

The consent, both collective and individual, must rely on an informed decision and full understanding of the research goals and details, in addition to being maintained throughout the research project (SSHRC, NSERC and CIHR, 2010). Individual consent must be in writing, except in some specific cases where individuals, often elders, prefer to consent orally. In those cases, recording the consent is advisable. It is strongly recommended to provide the consent form in the language used by participants.

In addition, “respecting the confidentiality of contents and the participants’ anonymity is very important in an Aboriginal context, due to the strong social cohesion (individuals can be easily recognized) and the small number of residents in some communities” [Unofficial translation] (Basile, Asselin and Martin, [to be published]). Specific measures must be discussed between the research team and the First Nation, community or First Nation organization concerned.

“One of the main tools to ensure that the autonomy of participants is respected is the requirement to seek an informed and continued consent. This requirement is evidence of how important it is that participation to research, including individual participation through the use of their data or biological material, be a true choice, which must absolutely be well informed.” [Unofficial translation] (SSHRC, NSERC and CIHR, 2010, p. 9)

Lastly, any organization or individual may opt out, at all times, from a research project, without prejudice or having to justify their decision.

VI. COLLECTION OF INFORMATION

The collection of information can occur on or off the First Nations territory, depending on the type of information wanted. It can focus on material or non-material heritage. It is understood that, even if the collection of information is done based on document sources (e.g. archives), the First Nations concerned should be informed.

The joint preparation of collection of information materials (research protocol, consent form, questionnaire) allows to establish a true partnership between researchers and First Nations communities. Ideally, the development of those tools should not be done in isolation, but rather in interaction with the participants and representatives from the First Nations involved. While it is difficult for the research team to travel and meet with their partners in communities, technology can be used to help with the dialogue. This exercise will help define the values and ethics that will guide the proposed research project and help the knowledge transfer, training future research managers from First Nations and First Nation organizations (Basile, Asselin and Martin, [to be published]).

The information collection process is generally a one-time event and can take different forms: individual or group interviews, sharing circles, stories, discussion workshops, consultations, World Café, observation, etc. (AFNQL, 2005). Some publications from the Sustainable Forest Management Network contain data collection tools and examples of best practices inspired by Aboriginal principles and values (Kopra and Stevenson, 2007; Stevenson, 2010; Wyatt, Fortier, Greskiw *et al.*, 2010).

Did you know that?

For First Nations...

The plant, animal and human worlds are interconnected. Consequently, taking samples from one of these worlds without consent (biological or genetic materials, archives, documents or manuscripts, cultural objects, administrative databases, individual or collective files, information management system, etc.) can be perceived as offensive. For instance, based on the First Nations' conception of "body integrity", all parts or products of the human body are sacred and cannot be separated. (SSHRC, NSERC and CIHR, 2010) Therefore, all human, plant or animal biological materials should be considered as a loan to the research team. (CIHR, 2007)

For the scientific community...

Human, animal or plant biological material can be used for many years and is considered as a resource contributing to the advancement of knowledge. No sacred or inter-relation dimension is associated by researchers, but they must be aware of the known values, beliefs and attitudes of individuals providing the materials. (SSHRC, NSERC and CIHR, 2010, p. 191)

The collection of information can be performed at different moments throughout the research and by various individuals associated to the research time and having signed a confidentiality agreement. In addition, the information collected can be quantitative (access to existing documents or statistics) or qualitative (interviews or discussions).

Respecting local ways and practices in terms of collection of information must be part of the planning process. When possible, these local ways and practices should be preferred to the research teams.

EXAMPLE OF RESPECTFUL PRACTICE:

Contaminants and traditional food among Atikamekw (2004-2010)

Contamination of traditional food is a major concern for Atikamekw. The Atikamekw nation has a well-known environmental knowledge, coming from thousands of years of territory occupation and using resources to survive. That knowledge includes extensive understanding of traditional food. The research project aimed at showing a portrait of contamination and develop, if necessary, solutions to balance the benefits and risks associated to traditional food contamination (fish, game, birds, etc.). Focus groups were organized to make better use of the Atikamekw knowledge and better understand the traditional food contamination problem, as experienced by the Atikamekw in the Manawan, Opitciwan and Wemotaci communities. In order to analyze the contamination of traditional foods more in details, the researchers proceeded with taking 1) hair strands to measure the participant's mercury rate (431 total) and 2) blood samples to measure the exposition to various contaminants as well as the nutritional benefits (199 participants). The analysis results from the hair strands and blood samples were then sent to the participants, and no secondary use of data is provided for by the research protocol signed by the researchers and the Atikamekw nation (de Grosbois, 2012).

VII. FIRST NATIONS METHODS

The methodology refers to the “How is knowledge gained?” theory. In other words, the objective consists in finding things on a given subject and ask “How can I find information on that subject?” [Unofficial translation] (Wilson, Shawn, 2008, p. 35). There is no single and best research methodology (SSHRC, 2010); using a variety of First Nations and occidental principles and methodologies is recommended (Loppie, 2007).



Similarly, Linda Tuhiwai Smith (1999), a Maori academic, published in 1999 the often-quoted *Decolonizing Methodologies, Research and Indigenous Peoples*. She states that respecting Aboriginal research principles means that the researcher must be present in the community or nation where the research is done. Often, the “after research” period is just as important, if not more than the “during the research” period. The chosen methodology must not be imposed by researchers. It must respect the conditions required by the Aboriginal community and integrate the protocols and values of the Aboriginal community or organization involved in the research (Smith, 1999; McDonald, 2004).

Integrative science provides an interesting methodology that should be considered for that purpose. Developed in the 1990’s at the Cape Breton University in Sydney, Nova Scotia, Canada, integrative science brings together Aboriginal and occidental knowledge and scientific methods (Bartlett *et al.*, 2012). The following words, shared by a Mi’kmaq elder, have inspired one of the guiding principles (Trees Holding Hands) for this science:

“Go into the forest, you see the birch, maple, pine. Look underground and all those trees are holding hands. We as people have to do the same. [...] Everything I do, I do with respect. Father used to say, believe in all people. It’s not we and them. It’s us.” (Bartlett *et al.*, 2012, p. 10)

The Two-Eyed Seeing concept, mentioned previously is another integrative science guiding principle.

The use of the “tree of life”, or *Cieba* method, inspired from Mayan cosmology, is recommended. *Cieba* is a model based on bark (research protocol), trunk (theoretical framework and research subject) and branches (various methodological instruments) based on the respect of other Aboriginal concepts, such as the “four direction”, the “circle of life” and the “seven generations” prophecy (Jiménez Estrada, 2005). The meaning of those concepts can vary from one First Nation to another, and it is recommended to verify their application and relevance during preliminary discussions.

As a last example, in Western Canada, the desire to integrate First Nations perspectives to education science has been growing for decades and has led to the creation of the Aboriginal Learning Knowledge Centre. Learning is seen as a multi-dimension and holistic experience. Based on that perspective, learning is a process spreading over an entire lifetime and “[...] includes all other fields which influence the quality of life: environment, health, economy, housing and inter-relations with all forms of life” [Unofficial translation] (CCL, [s.d.]).²³

Therefore, research decolonization continues and more and more methodologies are developed in various fields. Various sources were proposed to First Nations and non-native researchers who wish to integrate First Nations perspectives to their research methodology.

“[...] some Aboriginal academics tend to claim the right to use their own research channels increasingly, as well as their own research methodology, created according to their communities’ values and political and social objectives.” [Unofficial translation] (Gentelet, 2009, p. 150)

²³ Canadian Council on Learning. For more information: www.ccl-cca.ca.

VIII. DATA/INFORMATION ANALYSIS AND INTERPRETATION

The implication of First Nation partners for data analysis and interpretation will prevent erroneous interpretation and potential misunderstandings. The degree of First Nation implication at this step must be determined between partners before beginning research activities, in the research agreement. The agreement must include an analysis plan which allows First Nation partners to understand the methodology used and the way that they can contribute to it (e.g. through the exchange of expertise). Researchers must also make sure that the information is available in a clear and understandable language for First Nation individuals. A verbal and clear presentation by the research team to the community can sometimes be more appropriate than presenting the analysis plan.

To confirm the study's validity, the research team must understand that it is essential that data analysis and interpretation be done in respect of the First Nation's values, its representation of the world, its concepts, etc. The First Nation's participation to data analysis will provide comprehensive contextual information and more significant conclusions, improving the result's cultural validity and the entire research's relevance. Participants should pay attention to the words used, mention what they find incoherent, prejudicial or inaccurate.

It should be noted that, where there are discrepancies in the interpretation of data between the research team and the First Nation, the research team must allow the First Nation to share its views. In case of discrepancy, that point of view should be accurately detailed in the publications. The community can always dissociate itself from the results and ask that this is reflected in potential publications.

EXAMPLE OF RESPECTFUL PRACTICE:

Ontario Rural Woman Abuse Study - *ORWAS*

The research project on women abuse has mobilized the participants for the study conception as well as for data collection, analysis and interpretation. As soon as the preliminary results were available, the participants were allowed to comment. This is a research method used as an empowerment tool (for more information: <http://www.justice.gc.ca/eng/rp-pr/jr/index.html>).

IX. VALIDATION

It is essential to proceed with a validation exercise, especially when information is obtained through interviews and that analysis and interpretation are done in cooperation with First Nation partners. Beyond respect and equity matters, this exercise is necessary to guarantee the results' accuracy, especially if statements were translated from one language to another, as certain concepts in First Nations language may be difficult to translate in French or English (Asselin and Basile, 2012). The validation must be done before interpreting the results. To do that, the research team and their community partners must return on the data collected and the results. If needed, the First Nation partners may request a revised interpretation, analysis or conclusion from the research team.



Did you know that?

For First Nations...

The possibility to validate research results is considered as an added value to the research process. There can be two types of validation: 1) by research participants who will verify, for instance, if their testimonies have been correctly transcribed, analyzed and interpreted and 2) by Aboriginal knowledge, which must be considered as well as scientific knowledge, particularly in an environmental science or climatic change context of research.

For the scientific community...

Research design does not necessarily include a results validation process with research participants. The validation of results with First Nations partners to ensure proper information interpretation can be seen as an additional step. Its integration in the research design requires the main researcher to be open-minded, as it can lead to a different interpretation of the results.

X. RESEARCH PRODUCTS AND RESULTS

As soon as a First Nation is contacted by a researcher with a project, research objectives, data processing and research products can be discussed. Generally, when a researcher contacts a First Nation, he already has a preliminary idea of his research project and can provide answers to those questions. A conversation on the various research aspects between the researcher and the First Nation allows for mutual understanding. In addition, for the community, the way it will benefit from the research results becomes clear (e.g. improving services, access to financing, support to autonomy claims, etc.).

The products (reports, summaries, articles, etc.) must be clear and accessible for First Nations and in the language of their choice, before making it available to the scientific community, government authorities or general population.

Did you know that?

For First Nations...

The priority presentation of research results to the community is seen as a sign of respect. Before any public presentation of research results involving First Nations communities, they should be informed and be able to access research products.

For the scientific community...

Funders have high expectations and can sometimes pressure researchers for them to publish their research results within the prescribed time frame. The priority presentation of research results to the community should be planned from the first discussions and be part of the research team's results diffusion plans.

XI. MONITORING METHODS

Monitoring methods consist in an exchange of information between the parties concerned and a monitoring of activities planned in the research project. In fact, from the request for funding and at the beginning of the research project, the research team should at least plan going back to the community to present their results. Throughout the research, at least one First Nation representative should be chosen to maintain regular contacts with the research team. Regular exchanges between the parties will allow the First Nation/community to be informed of research progress and the steps to come.

The completion of a research project should be seen as step in the development of a mutually-beneficial relationship between First Nations and researchers.

XII. TRANSLATION, LANGUAGE AND COMMUNICATION

Translation and interpretation

The research team must often rely on the skills of First Nation/community individuals to act as interpreters or translators during their research activities. From the start of the project, selecting qualified contacts to accomplish those tasks should be discussed. It is recommended that the research team plans for the time and costs of translating data collection materials, the consent form, collection tools and research results.

Language

The language - written or spoken - used in an academic-type research is often technical and specialized. It can create an obstacle to communication between interested parties. Participants who cannot fully understand the subtleties of the research language will never be able to fully comprehend the process and results. A research project should therefore use a language understood by all the participants.

NOTES

Communications for communities, research summaries and full reports should be provided in the language of the First Nation concerned, to facilitate understanding and access.

Communication of research products

All publications issued from the research project, subject to privacy requirements, should mention the contribution of all individuals involved. Once those requirements are met, some individuals could ask for their name to appear after quoting their statements or on the list of informants.

The diffusion of results through unconventional methods is considered as a key element of community research, easily transforming into action programs, as those research plans enable the participants by given them access to the knowledge and given them control. The First Nation and its respondents' active participation to the various aspects of result publication, combined with community engagement, will likely lead to a greater appropriation (better understanding) of research results and their use.

XIII. DIFFUSION PLAN

In a collaboration perspective, the First Nation/community partners and the research team should agree on a research results diffusion plan.²⁴ The issue of public or restricted diffusion of research products must be determined by both parties. The details (communication language and formats) for communicating results to the participants and the host First Nation must also be discussed.

Designing a diffusion plan clarifies each party's expectations. The diffusion plan must contain the following:

- target audience(s);
- product(s) published (PowerPoint presentation, article, summary, video, etc.);
- method(s) used (official launch, Internet website, magazine, public event, etc.);
- time(s) of diffusion (month and year) for each method;
- available format (paper, CD, USB key, Internet website);
- language(s) used;
- budget (associated with the research report deadlines).

²⁴ A collaborative research agreement template is shown in Appendix 9.

CONCLUSION

Research decolonization through the development of tools by First Nations over the past decades has widely contributed to changing the way research is understood and done with them. Today, the *First Nations in Quebec and Labrador's Research Protocol* provides an ethical process which considers the desires and needs of First Nations. Since that tool was implemented, some research projects have used respectful practices and the voice of First Nations is heard. It also seems that the research projects' interests and their results mutually benefit both the First Nation involved and the scientific community. The First Nations principles of ownership, control, access and possession (OCAP™), developed nearly 20 years ago by National Steering Committee of the First Nations Regional Longitudinal Health Survey and now copyright through the FNIGC, are increasingly acknowledged and are sometimes implemented by the scientific community and government organizations. Finally, collaboration at every step of the research project, the transfer of knowledge gained through research projects and reinforcing local capacities are increasingly encouraged.

The consultations led for the revision of the *First Nations in Quebec and Labrador's Research Protocol* show that, from now on, advocacy efforts on the importance of defining and controlling research parameters should be focused on First Nations. Mobilization will be necessary. Promoting the protocol with First Nations, training First Nations researchers and implementing governance processes in the area of research by the First Nations communities and organizations are promising initiatives from a research decolonization perspective.

Finally, we hope the elements in this protocol will bring the necessary clarifications and solutions in order to effectively conduct research within the First Nations in Quebec and Labrador.

GLOSSARY

Donor agencies: Organization or individual who finances research activities.

Patent: Title of ownership giving its holder protection on an invention for a limited time (generally 20 years). The title describes the invention, which cannot be made, used or sold without the patent holder's authorization.²⁵ Patents protect useful inventions, such as a new type of snowshoes or new medicine created from plants.

Co-building "Co" comes from the Latin prefix *cum*, which means "with", and it is found in many words referring to association, participation and simulation. "Building" is "the act of constructing something, the techniques which allow building" [Unofficial translation] (Larousse, 2013).

Confidentiality: Done or communicated in confidence; contains personal information, which mustn't be unveiled or made public. Guarantee given that the information provided will remain secret and cannot be deducted from published results.

Traditional ecological knowledge: " Cumulative body of knowledge, practices and beliefs, evolving by adaptive processes and handed down through generations by cultural transmission, about the relationships of living beings (including humans) with one another and with their environment" (Berkes, 2012, p.7).

Informed consent: Agreement, assent, authorization given in full knowledge of the stakes, risks, advantages and disadvantages.

Consultation: Act of consulting, take and consider someone for their advice; management mechanism built on the full participation of all the members of a community, included in the decision-making process; focusing on the consideration and interrogation of individual opinions and aspirations.

Request for approval: Document prepared by researchers to receive the authorization to do research.

Data: Information, fundamental element used as a base for reasoning, for research (e.g. number of residents per household).

Aggregated data: "[...] Data collected from two or more sources. Aggregating data means reassembling independent series and present them as a whole. Aggregating data is a process through which information is reassembled and expressed collectively or in summary, for purposes such as statistical analysis" [Unofficial translation] (National Collaborating Centre for Aboriginal Health, 2009-2010, p. 2).²⁶

Raw data: Data which have not been processed, without any modifications: completed questionnaires, audiovisual recordings, databases built from data.

Non-identifying data: Coded data providing anonymity for participants.

²⁵ WIPO's glossary PATENTSCOPE, accessible on line: www.wipo.int/edocs/mdocs/tk/en/wipo_grtkf_ic_25/wipo_grtkf_ic_25_inf_7.pdf.

²⁶ www.nccah.netedit.info/docs/french%20fact%20sheets/1689_NCCAH_fs_disaggregated_FR_V3.pdf.

Disaggregated data: “Data taken from aggregated data and divided or separated in smaller information units. [...] Desaggregating data requires studying a series of data to understand the problems affecting sub-groups of individual results and/or aggregated data results. Collective or aggregated data can be divided or disaggregated, for example, by urban/rural environment, income, socio-economic or ethnic background, language, geographic location, political/administrative unit or age group” [Unofficial translation] (National Collaborating Centre for Aboriginal Health, 2009-2010, p. 2).

Two-eyed seeing: Approach combining the strengths of scientific methods and Aboriginal ways.

Customary law: In an Aboriginal context, customary law comprises a series of customs or beliefs widely accepted or recognized as mandatory rules of conduct for an Aboriginal community.²⁷

Copyright: Copyrights are the rights of on his original intellectual work. These rights include the exclusive rights to reproduce their work. Authors can give their copyright to an individual or a company. Copyrights protect for instance recorded songs or collections of written stories.

Sample: Restricted group representing participants to a research, who sometimes test research methods; small amount which gives an idea of the larger group, of a population, and which allows to qualify it.

Ethics: Moral science; reflection on the character, behaviour, conduct of a society, company, individual taking into account the potential and likely impacts on the life of others, their feelings, their opinions, their integrity.

Focus group/Group interview: Target group formed to ensure their participation to a research (e.g. group of women or trappers); it allows participants to answer freely, discuss, express and exchange ideas, values and opinions.

Consent form: Form which confirms the consent, agreement of an individual to participate in a research.

Accountability: Ability to give someone responsibility.

Methodology: Preferred validation procedures (e.g. questionnaire, interview, validation); systematic study, through observation, of scientific practices, underlying principles and research methods it uses.

Partnership: System fairly associating partners in preparation for a common action.

First Nation: Term used in Canada to designate the territory’s first occupants, formerly known as “Indians,” that excludes Inuit and Metis.

Problematic: Situation on which a question is based and, eventually, a research subject.

27 www.wipo.int/tk/fr/indigenous/customary_law/.

Ownership: “Natural persons or legal persons (companies, etc.) who have the property of something limited in supply. It can be removable or static objects, both on or underground, a part of the terrestrial surface or information (intellectual property).” In addition, “ownership has limitations, dictated by customs or law, in terms of property usage by non-owners. Property rights are normally associated with some obligations” [Unofficial translation] (Posey and Dutfield, 1997, p. 266).

Intellectual property: Any form of knowledge or expression created, in whole or in part, by human intelligence and that can be legally protected. It is the result of a creation act – invention, text, painting, design, song, etc. An invention is a product of the human intelligence which is unique, new and not evident for a specialist in the field of that invention. Individuals or institutions can own the products of their creativity and innovation just as they can for physical objects. There are three main types of intellectual property protected by Canadian laws: patents, copyrights and trademarks.

Collective intellectual property: Expression used in the *United Nations Declaration on the Rights of Indigenous Peoples* (2007) to designate the rights of Aboriginal peoples over their collective knowledge. Collective intellectual is aimed mainly but not exclusively at traditional knowledge.

Protocol: Set of established rules, pre-established steps and procedures.

Research: Body of studies and work led methodically by a specialist in order to advance the knowledge base.

Participatory research: “Research in which research subjects participate actively. This type of research is usually focused on action, i.e. with the intention of implementing measures based on research results. Participants contribute to the research process by helping define the research project, data collection and analysis, realizing the final product and implementing measures based on the results” [Unofficial translation] (SSHRC, NSERC and CIHR, 2010, glossary).

Traditional knowledge: Deep Aboriginal understanding of the complex inter-relations of elements in their environment (biophysical, economic, social, cultural and spiritual); knowledge gained and transmitted over time. It should be noted that this knowledge is dynamic and ever-changing, just like environment.

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APPENDICES

The following appendices are tools which are ready to use or adapt by first nations and first nations organizations who wish to reach a research agreement with a research partner.

Appendices 1 and 2 take the form of a contract. Appendix 1 also applies to general research projects, and appendix 2 when there is only data transfer. Filled according to the instructions, the contracts will create legal obligations between first nations and research partners and must be respected.

In all cases, it is important for first nations and research partners to carefully read the text in the sample contract and modify it to answer their specific needs.

Other appendices are additional tools that can be used as they are or adapted if necessary.

APPENDIX 1: RESEARCH AGREEMENT TEMPLATE²⁸

The parts in italics or in colour are explanation notes which must be deleted when the template is adopted as a research agreement.

Project title: _____

THIS RESEARCH AGREEMENT was signed on *(date)* _____

in *(location)* _____ .

BETWEEN:

Organization: _____

Main researcher(s): _____

Address: _____

Telephone: _____

Email: _____

AND

First Nation/Community: _____

Local organization supporting the project: _____

Contact person: _____

Organization: _____

Address: _____

Telephone: _____

Email: _____

Research team's roles and responsibilities:

The agreement must have been pre-discussed with the First Nation/community and include the known and verbally-agreed upon items.

Roles and responsibilities of the First Nation/community:

Be familiar with all the items and read the document fully before signing it.

²⁸ Adapted from: First Nations Information Governance Centre (2013), *Analyse et modèle d'éthique de recherche*, National Aboriginal Health Organization. (NAHO, 2007)

Sample text:

The main researcher(s), on behalf of their organization, whose names appear above and the _____ First Nation/community/organization have reached an agreement to carry out this collaborative research project, as per the directions and conditions contained in the following document.

1. Objective of the research project

Research team's roles and responsibilities:

Any substantial or significant modifications to the research project must be defined in a new agreement research with the First Nation/community. In that case, the modified research design must be resubmitted to the research ethics committee concerned, and a new certificate will have to be given to the First Nation/community.

Roles and responsibilities of the First Nation/community:

At least one person from the First Nation/community will have to be named as a guardian for this agreement and make sure that the research project is carried out as per the agreement.

Sample text:

As discussed and understood by the _____ First Nation/
community/organization, the general objective of this research program is:

The results cannot be used for purposes other than:

Should the researchers wish to modify the project, they must first obtain the First Nation/
community/organization's consent.

2. Description of the research project

This section features a more detailed description of the research project. Specific objectives and research questions are included as well as the project's social outreach. The commercialization of the research results must also be determined. If it is allowed, commercialization parameters must be defined.

Research team's roles and responsibilities:

Attach a copy of the full research protocol to this document. Any modification to the protocol must receive a new authorization from the First Nation/community.

Roles and responsibilities of the First Nation/community:

Participate in the definition of objectives and research questions. The research protocol and other related documents must be read.

Sample text:

The research project includes the following specific objectives:

It aims at answering the following questions:

It features the following social outreach for the First Nation/community *(is the research subject part of the community's priorities? In what way the community's – or some community members – implication will help strengthen it?) :*

The results of the research project *(select one of two options)*:

1. will be commercialized as follows:

2. will not be commercialized.

The project is described more in details in the attached document **A – Research design**.

3. Sources of financing

The sources of financing and the responsibilities of all partners must be specified, as per the financing conditions. This section is optional.

Research team’s roles and responsibilities:

Any multiple interest between the research team and a source of financing must be declared. To that end, the community can require each researcher to declare their activities or sources of financing which could lead to a potential conflict of interest.

Roles and responsibilities of the First Nation/community:

The First Nation/community should ask for a part of the research project global financing to be reserved for knowledge transfer to the First Nation/community (for instance: having the research team travel to the community at the end of the research project to validate and present the final results).

Sample text:

The research team obtained the financing and the other following forms of support *(indicate each source and the amount awarded for each of them)*:

The above-mentioned sources of financing have imposed on the research team the following deadlines, criteria, communication and/or dissemination, limitations and obligations to report:

It was agreed that the _____ First Nation/community would contribute to the research project by providing the following resources if applicable (e.g. interpreters, liaison officers, etc.):

As per the financing conditions, it was agreed that the _____ First Nation/community would cover the costs if applicable:

4. Expected advantages and risks

This section presents the expected advantages and risks for the research project. It is important to be clear and honest about the expected advantages for the research team and the First Nation/community. The research team could derive a financial gain (by publishing) or indirect financial advantage through professional advancement (for the individual or research centre). The First Nation/community could benefit from the information generated, which would help future requests for funding or improve the program and service offering in the First Nation/community, as well as education and training. The research team and the participants could be paid directly for their participation. The potential risks for the First Nation/community should also be considered, as well as mitigation measures (e.g.: environmental impacts, privacy or collective life violation, negative presentation of the community, other projects disturbed due to research).

Research team's roles and responsibilities:

Make sure that the benefits associated with the research project can also benefit the First Nation/community (or partners), at least through the gain of new knowledge for research design, revision process planning, data collection, analysis, interpretation, etc. The benefits for individuals and/or the First Nation/community must be greater than the potential risks.

Roles and responsibilities of the First Nation/community:

Participate actively in the description of advantages, potential risks and steps to take to mitigate those risks. Make sure that all the possibilities are mentioned by asking all the necessary questions.

4.1 Advantages

The advantages that the research team can benefit from and the advantages for First Nation/community participants associated with the research must be appropriately described. The advantages can be for individuals, particular groups, communities or the First Nation.

Sample text:

The research team could benefit from the following research advantages:

The First Nation/community could experience the following individual or collective advantages:

4.2 Risks

The potential risks for First Nation and/or community participants with the research project must be presented (eg.: physical, social, legal, psychological and economic risks, community stigmatization, dissemination of traditional knowledge without consent, etc.) and clearly defined. The methods used to mitigate those risks as much as possible must be published.

Sample text:

The project poses the following risks for participants (individual) or the First Nation/ community (group):

The following measures will be taken to mitigate those risks:

5. Ethical review

This section focuses on the ethical process which the research project will be submitted to (institutional research ethics committee and/or that of the First Nation/community), and the projected time frame for the process.

Sample text:

The research project will be reviewed by the following research institution ethics committee, approximately during the following month and year:

The research project will be reviewed by the by the following authority from the _____ First Nation/community/organization, approximately during the following month and year:

See the attached document **B – Ethics certificate**.

According to the local policies and practices, the First Nation/community has the authority to deliver a research permit. If applicable, the research permit of the First Nation/community will be delivered to the research team as follows:

6. Research methods

This section briefly describes (details are provided in the full research protocol attached) the target population, the recruiting methods for participants, the mechanisms used to protect the participants’ anonymity and their privacy, the methods to obtain a free and informed consent and the data collection methods used.

6.1 Research method adaptation

Sample text:

The team of researchers is aware that research with a First Nation/community requires some adaptation of the research method and an open mind to interpret the results based on the community’s comments.

All the research team members working on the project agree to sign the document **C – Declarations on confidentiality and conduct of research** attached.

6.2 Research committee

Sample text:

The research team and the First Nation/community agree to fully collaborate during the research project. They will create a research committee, comprising two researchers and two First Nation/community representatives, in order to ensure fluid communications.

The research committee includes *(name individuals, their title and the organization they represent)*:

6.3 Target population and recruitment

This is the place to mention the targeted participants for data collection as well as the methods used to contact them and recruit them as participants.

Sample text:

The following segment of the population is targeted by the research project:

The following methods will be used to recruit participants: *(Is a form of compensation planned to thank them for the time given to the research project?)*

6.4 Anonymity and confidentiality

The procedures used by the research team to preserve the participants' anonymity and the confidentiality of information provided by the participants must be specified.

Sample text:

The following steps will be taken to preserve the participants' anonymity:

The following steps will be taken to preserve the confidentiality of information:

6.5 Consent

The methods to obtain consent (individual and/or collective; minors, disabled or major individuals) must be described in detail²⁹. It is suggested that the consent form be prepared with the First Nation, community or organization concerned.

Sample text:

The consent from parents/guardians for minors will be obtained as follows:

The consent from adults will be obtained as follows:

²⁹ Refer to the consent form template (Appendix 3) in this research protocol to make sure that all items of an informed consent are appropriately covered.

The consent from disabled adults will be obtained as follows:

The consent forms used are found in Appendix D – **Consent forms**.

6.6 Collection of information

In this section, it is important to accurately describe the type of information collected as well as the collection methods:

- *The collection methods (information gathering using databases, environmental samples, surveys, audio/video recordings, interviews or focus groups, sharing circles, testimonies, etc.) receive compensation.*
- *The spectrum or quantity of information collected (eg.: statistical variables, number of interviews/surveys, number of samples) must be specified.*
- *The role of the First Nation/community (interview participants, compensated researchers, on-site stakeholders or guides) during that phase must be specified:*

Sample text:

This agreement applies to all the information collected for the research program from community members or within the community, regardless of its form (tangible, intangible, written, video, recordings, etc.) as well as any compilation of that information.

Information will be gathered through the following methods or processes:

The following quantity of data will be collected for the research project for the following reasons:

7. The First Nations principles of OCAP™ on data and intellectual property rights

The information collected or modulated into data through research distinguish themselves from research results. The First Nation/community concerned and the research team involved must discuss and agree on data ownership for the research project (is one of the parties the sole owner, or do parties share ownership?). The location where data is stored, the access right for and the power to impose conditions to the person in charge of keeping it in order to use it after the research project must also be discussed and agreed on with the First Nation/community/organization.

7.1 The First Nations principles of ownership, control, access and possession (OCAP™)

The methods used in the research project in order to adhere to the First Nations principles of OCAP™ (see section 3.1 of the Research Protocol for a full description) must be specified.

The reasons to access data, the objective behind that access and the type of data available must be indicated in the agreement, as well as the parties concerned. If individual files are shared, federal, provincial and territorial legislation governing the use and right to disseminate personal information should be specified (e.g.: access to information laws, protection of privacy and other First Nation/community protocols, such as a code of ethics for research or the framework for the protection of personal and collective information held by a First Nations community/organization). The partners who agree on the sharing of data access must fully understand the objective and give their formal consent.

The data backup methods must be specified, as well as the procedures to ensure a limited and secure access.

Sample text:

The _____ First Nation/community adopts strict research standards and ensures that the principles of ownership, control, access and possession are adhered to for the information it has. These principles are a form of self-determination applied to research.

The following methods are used to make sure that the First Nations principles of OCAP™ are respected:

a) Data ownership

Individuals own their personal data, while the _____ community (generally represented by the band council) is the owner/in charge of^{f30} all information gathered from the community or First Nation, including aggregated data.

b) Data control

The First Nation/community controls the use of their information/data. The researchers have the right to use data for the research project, as described in the research project found in Appendix A. Any other use requires the consent of the First Nation/community.

c) Data access

The information/data may not be transmitted to a third party, unless the First Nation/community gives its explicit consent. The First Nation/community agrees for the following types of data to be shared (eg.: data extracted from a file, aggregated data, anonymous data) with the following partners:

d) Data possession and protection

Data confidentiality, security and integrity will be protected as follows:

Data is kept in the following location, based on a pre-established agreement:

³⁰ In some cases, the term “owner” can be replaced by “responsible”.

7.2 Data repatriation

As the owner (or co-owner), the First Nation/community must be able to repatriate the information/data gathered for the research project and assume possession. The mechanism must be clearly established within the agreement. In some cases, a band council resolution can be required to clarify the legal and fiduciary obligations of the band council in terms of ownership management in the best interest of the First Nations population concerned. The band council can also name a person in charge among the community as a data keeper. This information must be specified in the resolution.

Sample text:

At the end of the research program, unless a particular agreement is reached with the First Nation/community, data will be transferred to the First Nation/community as follows:

7.3 Secondary use of data

Sample text:

Under no circumstances will the data be used for a secondary purpose. If the research team or the First Nation/community (as co-owners) so wish, they must obtain the free and informed consent of the participants.

7.4 Intellectual property right

This section contains a list of all types of information gathered (personal and/or collective) for the research project and the associated intellectual property rights (see section 3.2 of the Research Protocol for a full description).

Research team's roles and responsibilities:

The data ownership and of intellectual property right issues must be discussed with the First Nation/community. The research team must make sure that all the associated implications are well understood by First Nation/community partners.

Roles and responsibilities of the First Nation/community:

When it comes to the knowledge, data and information about their culture, the First Nation/community must clearly state that it is the sole owner and must assert its rights in terms of intellectual property.

Sample text:

The First Nation/community partners who will collaborate to the various research steps and provide intellectual input will be acknowledged as follows (included as co-authors of the publication if they participate to the writing process):

The participants who so wish will be officially thanked as follows:

8. Data analysis and interpretation

The analysis and interpretation methods leading to results and conclusions must be detailed. The possibility for a First Nation/community to participate in the analysis and/or interpretation of data must be mentioned, as well as the mechanisms used.

Sample text:

Data will be analyzed and interpreted with the following methods:

First Nation/community partners will participate in the analysis/interpretation of data as follows:

9. Validation of preliminary results

The preliminary research results must be submitted to the First Nation/community in an understandable language, for the review and approval of results interpretation. The First Nation/community must make sure that the local context is adequately considered. This section focuses on the method used to validate the preliminary research results with the First Nation/community.

Sample text:

The preliminary results will be verified or validated with the participating First Nation/community as follows:

10. Presentation of research conclusions

The First Nation/community must be the first to access the research conclusions and the first to voice its opinion. The language used for the conclusions must be appropriate and accessible for the First Nation/community. The conclusions cannot be published without the First Nation/community's consent.

Sample text:

The research conclusions are presented to First Nation/community members in a clear, accessible language and format as follows:

The research conclusions will be presented to the public or other audiences in the following form:

11. Dissemination and diffusion of results

There is a difference between the dissemination and the diffusion of results. Research results can be disseminated to specific partners, without being diffused to the general public (for example on the Internet). This section presents all the interested parties (First Nations, communities, universities, funding organizations, professional organizations, departments, etc.) to whom the final results will be disseminated, as well as the methods used. If applicable, the public results diffusion methods are also described (refer to the Research Protocol, section XIII, Diffusion Plan).

Research team's roles and responsibilities:

The First Nation/community must receive prior notice of any participation to public events for the diffusion of results. In addition, all other final documents (articles, PowerPoint presentations, etc.) must be submitted in advance to the First Nation/community, without any time limitation, starting from the day the agreement is signed.

Roles and responsibilities of the First Nation/community:

Make sure that the degree of control of the First Nation/community over the publication and dissemination of the final results of the research is determined in this section.

Sample text:

The final results of the research will be disseminated to the following partners, based on the following methods and order:

Any communication relating to the research topic, including progress reports to the First Nation/community will occur as follows:

For all media communications, during and after the project, the following individual will act as a spokesperson:

The final results of the research will be available in the following language(s):

Other than what the agreement specifies, no research results are to be disseminated or published without the _____ First Nation/community’s consent.

11.1 Revision of publications (optional)

Sample text:

Before being published, all articles unveiling research results must be reviewed by the First Nations members of the research committee. They will consult with the First Nation/community if needed and submit their comments to the researchers, in particular for confidential information that should not be published, or interpretations which are more in line with the local culture, or interpretations who could cause prejudice for the community.

If applicable, the researchers will make efforts to modify their publications based on those comments.

If the interpretation of data differs too much between parties, the researchers will allow the First Nation/community to include a “response” in their publication, to present their own interpretation.

The First Nation/community can also require for their name not to be mentioned in the publication, if it believes it could prejudice its members.

12. Conflict resolution

This section presents the steps to follow to resolve conflicts about the implementation, interpretation or dissemination of the research data/conclusions.

Sample text:

In case of conflict about the research subject, all parties agree to try and find a solution in good faith, with a neutral, pre-determined mediator, before submitting the dispute, use arbitration or any other conflict resolution procedure. The mediator must help the parties involved to find a solution which is acceptable for all.

If the parties are unable to reach an agreement, the research project can be terminated, as per the conditions in section 14 of the agreement.

13. Duration and termination of the research agreement

This section specifies the project duration and the steps to take should either party decide to terminate the research project. If needed, the agreement can be renewed or extended.

Sample text:

This agreement comes into force on _____ and comes to an end on _____.

The parties can jointly agree to extend the agreement, in writing, for a specific duration.

Any party can also terminate the agreement by justifying, in writing, the reasons for termination. Each party must consider the other party's expectations before terminating the agreement.

When the agreement comes to an end, some sections of the agreement remain valid, including the section on the First Nations principles of OCAP™ concerning data and intellectual property rights. It is especially important to mention that, at the end of the agreement, the research team cannot use data, unless there is an agreement with the First Nation/community.

(Research team/Organization) _____
(First Nation/community)

List of appendices which must be attached to the research agreement:

- A – Research design (provided by the research team)
- B – Ethics certificate (provided by the research team)
- C – Declarations of researchers and students on confidentiality and conduct of research
(see template in Appendix 3)
- D – Consent forms (see template in Appendix 4)

APPENDIX 2: DATA SHARING AGREEMENT TEMPLATE³¹

The parts in italics or in colour are explanation notes which must be deleted when the template is adopted as a formal data sharing agreement.

This data sharing agreement was signed on *(date)* _____ in *(location)* _____.

BETWEEN

(First Nation, community or organization),

Represented by _____

AND

_____ (research partner),

Represented by _____.

1. Introduction

Generally, this paragraph presents the context in which the data sharing agreement was developed. The name, title and contact information of the agreement signatories should be displayed in it, as well as their affiliated organization.

Sample text:

The _____ First Nation/community accepts to collaborate with _____ (research partner) to conclude a determining partnership. This partnership is based on *(include historic)* _____.

³¹ Adapted from: First Nations Information Governance Centre (2013), *Analyse et modèle d'éthique de recherche*, National Aboriginal Health Organization (NAHO), 2007.

The _____ First Nation/community consents to sign a data sharing agreement which authorizes _____ (research partner) to use the data _____ (from a file or aggregated data), collected during _____ (name of previous research project), as per the research agreement. The data sharing protocol protects the values, principles and rights of First Nations. It may not be used for other purposes.

2. Definitions

This section includes some useful definitions.

Information sharing: exchanging, collecting, using or disclosing personal information for specific purposes between two organizations such as First Nations, government organizations, teaching institutions, non-profit organization, etc. Sharing information can be done using a chosen method over a determined period.

Data association or profiling: for administrative reasons, electronic use of personal data gathered from various sources, such as personal files, to regroup or compare individual files or identifiable categories of individuals. Data association or profiling allows to create a new personal data file or create a specific population.

Personal data: recorder data or information about an identifiable individual.

Data extracted from a file: information on an individual or group of individuals allowing a person to be identifiable or not.

Aggregated data: group of data gathered from various sources which do not reveal the identity of individuals. They are collective data compiled for statistics or planning (eg.: in the health field, to combine client geographic data from primary health care provider files, in order to generate aggregated files on clients' characteristics).

3. Objectives

This section must include the reasons and objective of the data sharing agreement and the First Nations policies. If individual files are shared, federal, provincial and territorial legislation governing the use and right to disseminate personal information should be specified (e.g.: the laws on freedom of information, protection of privacy, information on health and other community protocols, such as a code of ethics for research or the framework for the protection of personal and collective information). The parties who sign the data sharing agreement must fully understand the protocol's objective and give their formal consent.

Sample text:

The data sharing protocol has the following objectives:

- a) Summarize the conditions and accommodations:
 - i. for data sharing;
 - ii. for data or information collection;
- b) Establish the formal principles and obligations by which all organizations must abide for the collection, storage, use and dissemination of the First Nation members' personal data.
- c) Explain why information or data are shared, at what time, why and who is in charge of gathering and sharing data;
- d) Protect the interest, information and privacy of the First Nation/community and its members;
- e) Maintain adequate standards and prevent misunderstandings about everyone's responsibilities;
- f) Clarify ownership, control, access, intellectual property, aggregated data, privacy, use and dissemination of information issues.

The protocol provides a framework for using data which supports the First Nations principles of OCAP™ principles in terms of research. It also addresses the data capacity and needs of the _____ First Nation/community and _____ (research partner) for using information for planning, advocating rights and establishing focus and priorities within the First Nation/community.

Ownership: the principle focuses on the First Nations' relationship with knowledge, data and information pertaining to their culture. The principle states that a community owns the information which concerns them, just like an individual owns his personal data. It should be distinguished from possession (see Possession).

Control: through this principle, First Nations express their right to maintain and take over the control over all aspects of their lives and institutions, such as research, information and data. The principle of control states that First Nations peoples, communities and representatives have the right to control all aspects of research and information management methods which concern them. For instance, First Nations control all aspects of a research project, from the beginning to the end. The principle spreads to the revision resources and process, the drafting of global plans and data management.

Access: First Nations must have access to the information and data which concerns them or their communities, regardless of where the information is being kept. The principle is also about the right of First Nations organizations and communities to make decisions about and manage the access to information on their community. The principle is implemented through formal and standardized protocols.

Possession: while ownership implies the relationship between people and the information which concerns them, possession is seen more literally. While it is not a condition for ownership as such, data possession is a mechanism allowing to affirm and protect ownership. When a group has data belonging to another group, there is a risk of violation or abuse, especially when there is a lack of trust between the owner and the keeper.

4. Information to be shared

For the protocol, it is important to describe the information to be shared.

Sample text:

Data extracted from First Nation/community files or aggregated data (*Note: detail the information to be shared*) _____ will be shared as per the objectives of this agreement.

5. Use of information or data

The way that shared information or data is shared, as per the protocol, must be clearly indicated in the protocol. What purposes will the information or data be used for? The protocol sometimes indicates that information and data are solely used for the reasons stated and cannot be used for other purposes (disseminated), without prior written consent from the First Nation/community. Research partners may not disseminate data for other reasons, unless all parties concerned have agreed otherwise, and only if disseminating data will not violate provincial, territorial or federal law.

Sample text:

Research partners agree to use data for the following objectives:

Research partners agree to use data only for the mentioned reasons, and not for any other purpose (additional dissemination), without prior written consent from the _____ First Nation/community. Research partners may not disseminate data for other reasons, unless all parties concerned have agreed otherwise, and only if disseminating data will not violate provincial, territorial or federal law.

6. Information sharing mechanism

Information sharing methods must be defined. Among them is electronic transfer on a secure network, or electronic transfer through a password-protected external drive.

Sample text:

Data sharing will be done by electronic transfer on a secure network. Data will be linked.
(Note: this is only an example; the First Nation/community can choose another sharing mechanisms as it sees fit).

7. Data ownership

It is recommended to address the issues of data control and access for all parties in the agreement. They can be designated as data keepers or guardians, as per the conditions included in the research agreement and based on the nature of the project. They have access to either individual files or aggregated data. It is possible to forbid users to use data for commercial or other lucrative purposes, public or private.

Sample text:

The _____ First Nation/community is the owner of data collected on its territory. It is in charge of negotiating and determining responsibility and access to data.

8. Publication and dissemination

Based on the type of information for which it grants the research partners access, the First Nation/community can require their name to be displayed as a co-author or research project partner. It allows the First Nation/community to protect information and maintain certain publishing rights, without impacting with ensures the integrity of research results.

Sample text:

Research partners may not publish or disseminate the data obtained to other institutions or organizations without written consent from the _____ First Nation/community. Any organization or research institution interested by the project must contact the First Nation/community directly.

9. Confidentiality and data security

The person in charge of data must protect and maintain the confidentiality, based on the defined principles and the data protection methods and standards, both stringent and formal. Each person in charge of data concerning identifiable individuals must take all the necessary steps to protect confidentiality and security, as per the personal and collective data protection framework, health information and, if applicable, other legislations such as their institution or protocols of the First Nation/community. If one party deems the security or level of protection as insufficient, the data should be destroyed or their responsibility transferred to someone else. Data integrity and security should be monitored by regulatory measures, such as granting access only to authorized individuals and appropriately managing/securing the access to electronic systems.

Sample text:

Confidentiality

All employees, agents and _____ First Nation/community representatives, as well as the research partners who can access the data must sign a confidentiality agreement (see Appendix 3). The First Nation/community vows to keep a record of the names of all individuals who have signed the agreement, complete with the date.

Data security

The _____ First Nation/community and the research partners must have all the necessary equipment, material and methods to protect the confidentiality of data collected for the survey, including but not limited to:

- A locked storage room and a locked filing cabinet;
- Restricted and controlled access (with key or password) to paper or electronic copies of information or data;
- A firewall or similar software for protecting data saved on a computer directly or indirectly connected to the Internet.

The _____ First Nation/community and the research partners must make sure that information and data are kept by an authorized person at all times. Records should be kept for all employees or agents who can access data as they carry out their duties.

10. Information conservation and destruction

The agreement must specify the time that shared data will be kept and saved for. It must also contain details about the destruction of data when the agreement is cancelled or comes to an end. Data can be returned to the source or destroyed by the recipient, either physically or electronically.

Sample text:

_____ (research partner) agrees to store and save the data as per the agreement’s conditions and details. When the agreement is cancelled or ends, _____ (research partner) agrees to immediately eliminate and destroy permanently all originals and copies (paper or electronic) of data transmitted, as per the applicable legislation and policies (band council’s rules and policies, government laws).

The certificate of destruction of data, copies, backups etc. is found in Appendix **A – Certificate of destruction**.

11. Intellectual property

While this interpretation of intellectual property does not match the opinion of some First Nations, in Canada, if nothing is specified in the agreement, intellectual property is generally awarded to the organization leading the research project. Therefore, before transmitting data to an organization with research projects, it is important to reach an agreement stating that intellectual property (including copyrights) is given to the First Nation concerned. For instance, the agreement can provide a licence to access the information generated by data and its use. It can also indicate that no other title or right is granted. Refer to the First Nations' research protocol, section (3.2 Intellectual Property).

Sample text:

The _____ First Nation/community has all the intellectual property rights (including copyrights) applicable to the transmitted data, as per this agreement. The agreement grants a license only for accessing the information generated by data and their use, and no further title or right.

As for data created during the project, the First Nation/community and the partner are joint owners.

12. Duration and renewal

It is recommended to include a clause indicating the date when the agreement starts (date of signature) and the agreement duration. If necessary, add a renewal, modification or extension clause.

Sample text:

The agreement enters into force at the date when all parties have signed and comes to an end after ____ years.

The agreement can be renewed, modified or extended if all parties express their written consent at least 60 days before the expiration date.

Notwithstanding the above, each party can terminate the agreement, by giving the parties concerned at least a 60-day notice, in the case where a party would fail to meet the obligations mentioned in the agreement.

Data access privileges will be immediately revoked. After the period of notice is over, all data and copies will be taken back and destroyed, as per section 10.

13. End of agreement or revocation of license

A clause detailing the conditions of the agreement end or termination must be included.

Sample text:

When the agreement expires, research partners must, at the First Nation/community's request, transfer to the First Nation/community or immediately destroy all copies and originals (electronic and paper) of raw initial data transmitted by the First Nation/community. In addition, they must abide by all federal and provincial regulations.

Under exceptional circumstances such as bad use or misinterpretation of statistical data, a First Nation/community may also inform the research partner in writing of the inappropriate action and ask for the situation to be addressed within 60 days. If the research partner does not address the inappropriate action before then, the _____ band council can, on behalf of the First Nation/community, revoke the research partner's license to use data. The partner then has 10 days to destroy all copies of data and provide a sworn declaration to the First Nation/community stating that all data was destroyed.

Lastly, for data generated during the agreement and of which the First Nation/community and research partner are joint owners, the research partner must provide a copy to the First Nation/community. The partner and the First Nation/community can keep a copy, but the written consent of both parties is required to use them for other purposes.

14. Authorized signatories

It is important to specify in the agreement the names of authorities for all parties, as well as the names, contact and information and title of authorized signatories. The authorized representatives for each party must sign and date the agreement. The information allows members of the public to communicate with the parties involved.

In witness whereof, the authorized representatives for the parties concerned have signed this agreement:

For the First Nation/community:

Name and title

Date

For the research partner:

Witness

Date

Name and title

Date

Witness

Date

APPENDIX 3: TEMPLATE FOR THE DECLARATION OF CONFIDENTIALITY AND THE CONDUCT OF RESEARCH³²

The parts in italics or in colour are explanation notes which must be deleted when the template is adopted as a formal declaration.

[Project Title]

Note: Generally, the research agreement involves the university to which the main researcher is associated. It is signed by the university's legal representative rather than by the researcher or students. This declaration can be used to impose obligations directly to the individuals involved (researcher, students, partners). It can be used before a research agreement is signed or after. Modify the declaration if needed, and remove the text between parentheses if not applicable. When a research agreement is signed, the main researcher should also commit to respect any signed agreement with his university. This declaration should however be sufficient for students, which wouldn't have to read and sign the full research agreement.

I hereby declare that I am an employee, student, intern, coordinator, researcher or other individual involved in the project aiming at _____.

[I understand that the project is governed by a final research agreement dated _____.] *(Not: include if applicable.)*

The following organizations are involved in the project:

(Insert the names of universities, First Nation, community or organization involved.)

I understand that the First Nation(s)/community(ies) _____ is (are) partner(s) in the research project and that it modifies the usual conduct of research.

Confidentiality: I agree to keep secret all information on a participant and all confidential information that I have been made aware of, both for the duration of the project and after.

(Be more specific if needed: traditional knowledge, sensitive data, personal data, etc.)

³² Developed by Elisabeth Patterson, Esq.

Publications: I consent that the publications that I work on will be reviewed by _____ *(name of the First Nation, community or organization concerned)* and I understand that this process can also delay publishing. In addition, _____ *(name of the First Nation, community or organization concerned)* may require that some confidential information be removed from publications.

Ownership of information/raw data and limited use: I understand that the information transmitted and the raw data belong to the First Nation and/or the individuals interviewed.

I agree to use only the information transferred by:

_____ *(name of the First Nation, community or organization concerned)* for the above-mentioned research project. I also agree not to use this information without _____'s *(name of the First Nation, community or organization concerned)* consent for other projects that I may be working on in the future. I will not commercialize the information belonging to _____ *(name of the First Nation, community or organization concerned)* that was transmitted to me without _____'s *(name of the First Nation, community or organization concerned)* consent.

Limited use of results: *(Note: remove or adjust the paragraph, based on the contents of the agreement).* As _____ *(name of the First Nation, community or organization concerned)* and research organization _____ jointly own the results and intellectual property of the research project, I understand that I cannot use the results or intellectual property that I have generated during the project without their prior consent, even if the results have been published.

I understand that this declaration has legal obligations. Should I fail to respect it, it could cause irreparable damage to the parties involved in the project, and they could seek legal action against me in that situation.

Add only for main researcher: I have read and understood the research agreement and agree to respect the obligations imposed on my research institution as if I were personally liable.

Declaration signed on *(date)* _____ in front of the research team’s designated representative.

For the research team:

Declaration signatory:

Name

Name

Title

Title

Signature

Signature

For the First Nation/community

Name

Title

Signature

Note: Signatories do not have to be physically together when they sign. They can sign and then fax their sent copy to the other party.

Note: A copy of each signed declaration must be sent to

(name of the First Nation, community or organization concerned).

APPENDIX 4: CONSENT FORM TEMPLATE FOR RESEARCH PARTICIPANTS³³

(For adults)

The parts in italics or in colour are explanation notes which must be deleted when the template is adopted as a consent form.

Note: It is recommended that researchers develop (or seek validation of) the consent form with the First Nation(s) and/or the community(ies) involved, to establish an equal relationship within the research agreement which has been previously reached between the parties.

Preamble: Mention that research participants must first read the contents of the form before signing it. Explain the goal and contents of the form. Mention that the research project relies on the principles dictated by existing research protocols, guidelines and rules. Invite participants to contact the main researcher if they have questions about the contents of the form or to have more information on the terminology used.

Research project title and description

Team: The research project is a joint initiative between the following organizations *(if more than one): indicate the name of the research product funders, the name of organizations or individuals involved.*

Source of financing: *Identify the sources of financing for the research project.*

Duration of research project: *Projected duration of the research project.*

Certification obtained: *Name the organizations and institutions that issued a research ethics certificate and the date of issuance.*

Research goals and objectives: *Describe in a few points the research goals and objectives and the reasons motivating it.*

Methodology used: *Description of the various data collection steps.* The participant will have to take part in *(number of sessions)* of *(session duration)* during which he will have to fill the following materials: *questionnaire, directed or semi-directed interview, etc.* The planned sessions are: *(duration, dates and hours)* and will be held: *(based on the participants' preferences).*

Mention the methods used to collect data, video or audio recording, service of an interpreter (based on the language(s) of use) with whom the researcher must conclude

³³ Adapted from: *La Boîte rouge vif.*

a prior confidentiality agreement, pictures, post-interview validation, usage of analysis software, result validation and diffusion (means, tools, languages, time), secondary use of data forbidden, etc.

Advantages/disadvantages: List of medium and long-term advantages and disadvantages for the *First Nation/community, and full explanation of the research project's relevance for the First Nation/community.*

Traditional knowledge processing: *If applicable, state why and how traditional knowledge will be shared by the research participants. Specify the appropriate protection clauses.*

Protection of personal data: Data gained through data collection will be strictly used for this research project. *Mention how personal data will be used.* The name of participants will not be shown on any report. In addition, the research team must protect the confidentiality of answers; under no circumstances should the answers (raw data) be made public. *If personal data/information repatriation in the First Nation/community is possible, specify who (band council or other) will ask for it, where personal data/information will be stored in the First Nation/community and who will be the guardian (person in charge).*

Duration of personal data conservation: The data gathered will be kept *(number of days/weeks/months/years)* then destroyed. *Indicate the data conservation site and conditions.*

Language used: The choice of the language used during the research project must be left to the participant. If applicable, translation services will be provided by the researcher (or based on the terms of the research agreement). It is recommended that this consent form be made available in the language of the First Nations concerned.

Compensation: *Indicate if compensation (indemnity, gifts, others) is provided.*

Commercialisation of results or conflicts of interest: *Indicate if the research results will be commercialized and if there's a risk of conflict of interest.*

Dissemination of results: *Indicate how the results will be disseminated (Internet or other methods) and how/in what form they will be returned to the community (vulgarisation tools, articles, web or radio clips, etc.).*

Liability clause: By accepting to participate to the research, participants do not waive any of their rights and do not release the main researcher or any organization or institution involved of their legal and professional responsibilities.

Right of refusal and right to withdraw: Participation to the research project is voluntary and the participant can withdraw at any time, without providing justification or being prejudiced in any way.

Any questions about the research project can be sent directly to the researcher: *(full contact information of researcher and his director if applicable)*

I, the undersigned, _____ *(print name)* fully consent to participating to the research project titled: *"research project title"*.

I, the undersigned, _____ *(print name)* do not consent in participating to the research project titled: *"research project title"*.

Note: give the participant the option to consent verbally, in which case the statement must be recorded.

I am signing this form in two copies and am keeping one.

Name of participant

Signature of participant

Date

Name of researcher

Date

Signature of researcher

Date

Note: For participants who are MINOR or MAJOR but INCAPABLE, a specific form must be filled.

APPENDIX 5: CONSENT FORM TEMPLATE FOR RESEARCH PARTICIPANTS (ATIKAMEKW LANGUAGE)

(Consent Form for a minor or major incapacitated person)

NASKAMO MASINAHIKAN

(aniki otci aka moci ka tipi asitatisitcik kaie aka ka 18 tato piponesitcik kekotc ka tipi asitatisitc aka aric ka kokwatisitc kekotc aka kecketatcicik kitci masinahotisitcik)

E icinikatek acitc kitciwe e witcikatek kekwan ka otamirotcikatek

Aniki ka mitatcicik otamirowiniw : Anihe ka wi nanto kiskeritcikatek, enko aniki : _____
_____ (kecpin awocamec peikw e tacitcik), aniki ka pakitinakik coriariw, e icinikasotcicik kekotc e icinikasotcicik aniki ka mitatcicik acitc ka atoskectakaniwitcicik, ohweriw ka miwotakaniwonik nanto kiskeritcikesinahikananiw.

Wetci nanto kiskeritcikatek : kata witcikatew acitc kekwan wetci wi nanto kiskeritcikatek nihe. Kaie anahwe ka atoskectakaniwitc kata witcikateriw wetci nataweritak kitci ici otamironaniwonik.

Irikik ke tacikatek e otamironaniwok acitc tan ke totcikatek icikwisk kitci otamirotakaniwok ohwe ka nanto kiskeritcikatek : Aniki ke naskamotcicik kitci witcihiwetcicik patam aspinikotc kata icawok e nakickotatonaniwonik acitc kata naheritamok kitci naskamotcicik kotc ke icinakonik ke ici kokwetcimakaniwitcicik mitowi : kokwetcikemosinahikan acitc kotak masinahikan. Kitci taciketcicik irikik e acterik kitci arimwaniwonik.

Ke ici witcihiwemakak/ aka ke ici witcihiwemakak : Kata witcikatew tan ke ici witcihiwemakak kaie aka ke ici witcihiwemakak kotenaminak otci, acitc tekaci kata tipatcimotakaniwon misuwe tan ke irapatak nihe ka wi nta kiskeritcikatek.

Nama kata pakitinikateriw awik e icinikasotc : Kaskina ke ici tipatcimowananiwok nihe otci ka nta kiskeritcikatek ekoni tepirak ke irapatak nama kotak kekwan. Kata witcikatew tan ke irapatak kaskina ka ki ici pakitinikatek tipatcimowin. Tekaci nama wiew kata ici nokoniw awik e icinikasotc. Acitc kitci wiewakaniwitcicik aniki ke naskamotcicik aka tekaci kitci pakitinikaterik ka ki aitetcicik, ekoni e itacterik kitci ici nosanetatcicik aniki ka nanto kiskeritakik kekwariw : Nama wiew kata masinateriw awik e ki ici naskamotc.

Kecpin wa kiwe nataweritakonokwe tipatcimowin otenaminak wewerita kata witcikatew awin ka nataweritak (okimawok, kotak awik,) tipatcimowiniw tipirawe awik otipatcimitisowin neta kata kanaweritcikateriw otenaminak acitc awin mia ke nakataweritak.

Irikik ke kanaweritcikaterik awik e icinikasotc : kata kanaweritcikateriw kaskina ke ici tipatcimotc awik ni irikik _____ tato kickwa / _____ tato manactakana / _____ tato pisimwa / _____ tato pipona minawatc kata wepinikatewa kekotc kata matcictewehikatewa.

Arimwewin : Anahwe ka ki naheritak kitci naskamotc, wir kata witam kekw arimwewiniw ka wi apatcitatc e naskamotc. Kecpin nehirowimote, patam aniki ka nanto kiskeritakik kekwariw kata nantonewok ke itectamakotcik wirawaw tipirawe kata kicikwewok.

Matci awik kata ki oreritam aka kitci witcihiwetc matci kaie kecpin e ki oreritak kitci witcihiwetc kata ki note ponitaw : anahwe ka witcihiwetc matci nataweritake kitci note ponitac e witcihiwetc, matci kata ki totam nama kaie soka kata witam kekwariw wetci note ponitac. Acitc nama acteriw wiec kitci itakaniwitc, ni e ici oreritak.

Kotc e wi ici kokwetcikemonaniwok anihe otci ka nta kiskeritcikatek matci ki ka masinahamowaw aniki ka mitatcik ohwe ka wi nta kiskeritcikatek. (e ici taciketcik kata masinateriw, kaskina aniki ka otamirotatcik ohweriw)

Nin, _____ ni naheriten kitci witcihiwean ohwe ka wi nta

(aka moci e tipi asitatisitc)

kiskeritcikatek : « e icinikatek nihe ka wi nta kiskeritcikatek ».

Nin, _____ ni naskamon anahwe otci icpimik ka masinasotc e ki (onikihikonan kekotc kotak awik ka tipi asitatisitc.)

naskamotc kitci witcihiwetc _____ ohweriw ka wi nta (e icinikasotc anahwe aka ka tipi asitatisitc)

kiskeritcikaterik. [Kekotc nin ni masinahotison anahwe otci aka ka kokwatisitc, nin e actek e kanawerimak kekotc nin e ki mirikoan tipaskonikewinik itekera kitci naskamoan wir otci. Matci kaie nin e ki mirikoan kitci mitawok kaskina omasinahikana aka kitci wecimakaniwitc anahwe aka ka kokwatisitc.]

Nicw naskamo masinahikan ni masinahotison, peikw ni ka kanaweriten.

Masinahotiso ka witcihiwetc

e tatokonekisitc

Masinahotiso ka nta kiskeritak
kekwariw

e tatokonekisitc

APPENDIX 6: CONSENT FORM TEMPLATE FOR RESEARCH PARTICIPANTS (INNU LANGUAGE)

Eshinakuak mashinaikan, auen ka tapuetak tshetshi uitshiaushit natu-tshissenitakaniti tshakuan (Shash auen ka tatupipuneshit tshetshi aitutatishut)

Ne mashinaikan ka itashteua miam e patshitinikau *kapapeikushteshiti*, aimun an patshitinakanu kie tshika ui itshenakanua apashtakaniti ne mashinaikan tshetshi mishituepanitakanit ne mashinaikan ka tapuetatishunanut.

Kananatuapatitshesht nanatuapatitsheu

Aimun patshitinakanu : Itakanuat anitshenat kananatuapatitsheshiht tshetshi tutahk (kie ma tshetshi shash tapuetakannit) nenu umashinaikanuau tshe tapuetatishuniti auennua anite ka taniti innu-assit kie ma mitshet innu-assia ka takauakaniti. Tshika ui minu-uitshi-atussemitunanu anite tapuetatunanuti ne ka nanatuapatitshenanut tutakanit, miam ishi-tapuetatishutau anitshenat ka katshitaukuht umenu mashinaikannu.

Eshk^u eka tshitshipannanut : Tshetshi uitakannit ne auen tshe uitshiaushit netuapatitshenanunit, eshk^u eka mashinatautishut nenu mashinaikannu tshipa ui pitama tshitapatam^u etashtenit. Tshika ui uitakanu tshakuan uet tutakanit kie tshakuan etashtet ute mashinaikanit. Tshika ui uitakanu ne e nanatuapatitshenanut ashpattshishimuatsheu shash ka-takuanniti mashinaikana ka nashatakaniti takuaikana. Tshika ui itakanu ne auen tshe uitshiaushit tshetshi aimiat nenua utshimaua ka takuaimataminiti nenu ka nanatuapatitshenanunit tshetshi minu-uitamuakanit tshekuannu anite tekuannit mashinaikanit kie ma kutakanu tshekuannu ui natu-tshissenitaki.

Tan eshnikatet kie tshakuan anite uiauitakanit anite ua nanatuapatitshenanut

Auenitshenat anite etaht : Ne netuapatitshenanut, utshenat mamu atusseshtamuat natuenitamuat nenu : **(mitshetitau), uinakanuat anite anitshenat ka patshitinahk shunianu tshetshi tutakannit nenu atusseunnu, tan eshnikatakanit ne atusseutshuap kie auenitshenat anite etaht.**

Tanite uetshipanit ne shuniau tshe apashtakanit : Tshika uitakanu ute tanite uetshipanit ne shuniau tshe apashtakanit.

Tshe ishpish nanatuapatitshenanut : Tan ishpish nuash tshe nanatuapatitshenanut.

Tshe ishi-katshitinakaniti mashinaikana anite atusseutshuapa : Tshe uinekuttsheku-atusseutshuapa kie ma mashinaikanitshuapa ka patshitinahk mashinaikana tshe ishi-nashatakanit

Tshekuan ma uet tutakanit kie tshekuan ua utitaikanit : *Apishish e uitakanit, tshetshi uauitakanit tshekuan ma uet tutakanit kie tshekuan ua utitaikanit anite ka nanatuapatitshenanut kie mak tshekuan uet tutakanit.*

Tshekuan iapashtakanit ne e tutakanit atusseun : *Uauitakanu tan etutakanit tshetshi mamushatinakaniti aimuna. Ne auen ka tapuetak tshetshi uitshiaushit, tshika ui ituteu (tan tatuau tshe itutet), tshe ishpish tat anite (tshe ishpish itatussenanut) anite tshe tat kie tshe ui uitak nenu eshi-natu-tshissenimakanit : kukuetshitshemunnu, kukuetshimakanu tshekuannu kie ma peikussu e tutak umashinaikan ka kukuetshimakanit, mak kutak tshekuan. Tan tatuau tshe uapamakanit (tshe ishpish itatussenanut, tsheku-tshishikua mak tatutipaikana tshe atussenanut mak tanite : (muk^u eshi-minupanikut ne auen ka uitshiaushit). Uitakanua ute tshekuan tshe apashtakan tshetshi utinakanit aimun, ashupanitakaniti kie ma akunitshenanuti, auen ka ashu-uitamatshet apatshiakaniti (muk^u eshinakuak ne aimun iapashtakanit) nenu ne kanatuapatitshesht tshe ui pitama nishtutatishut tshetshi eka tshekuannu uitaminiti, akunikana, tshetshi ashit natu-tshissenitakanit ka ishi-patshitinakanit aimun, e apashtakanit tshetshi natu-tshissenitakanit, tshe tapuetatitshunanut ne aimun ka patshitinakanit kie tshe unuipanitakanit (tshekuan tshe apashtakanit, atusseuakan, aimuna, tan ishpish), eka tapuetakanit tshetshi ait itapashtakanit ne eshi-patshitinakanit, mak kutak tshekuan.*

Tshekuan tshe katshitinakanit/tshekuan tshe unitakanit : *Uauitakanu tshekuan tshe katshitinakanit mak tshekuan tshe unitakanit pessish kie ma nete nikan anite innu-assit mak tshetshi uauitakanit tan eshi-minuat ne e tutakanit atusseun e nanatuapatitshenanut anite innu-assit.*

Tan tshe tutakanniti utshissenitamunuaua shashish ka-takuaniti : *Ishinakuaki tshetshi tutakanit, tshika minuau uitakanit tshekuan ma uet natu-tshissenitakanit aimun ka patshitinakanit nenu eshi-nishtuapatak tshiashi-aitunnu kie tan tshe itapashtat nenu ne kananatuapatitshesht, nenu tshe matinuemakaniht anitshenat ka natu-tshissenimakaniht. Tshika ui uitakanu tan tshe ishi-nakatuenuitakanit ne aimun.*

Akua tshika tutakannu nenu tshekuannu ka patshitinak auen : *Ne aimun tshe katshitinakanit anite ka mamushatinakanit aimun, tshika apashtakanu anite muk^u tshiam ute atusseun etutakanit. Tshika ui uitakanu tan tshe itapashtakanit ne aimun tshe utinakanit. Apu uiesh anite tshika ut uitakanniti utishinikashunuaua auenitshenat. Mak ashit, tshika ui nakatuapatakanu tshetshi eka auen uapatak nenu ka ishi-patshitinakanit aimunnu miam ka ishinakuannit utatusseunuau anitshenat ka nanatuapatitshesht, ne eshi-patshitinakanit aimun (eshi-unuipanit aimun) apu*

tshika uiesh anite nukutakaniti kie uitakaniti. *Ishinakuaki tshetshi tshiuetsishaikanit ne aimun ka mamushatshinakanit/aimun ka utshipanit anite innu-assit, uitamuk^u auen (conseil de bande ou autre) tshe natuenitak nenu tshetshi tshiuetsishaimuakanit, tanite tshe takuaki neni aimuna/aimuna ka utshipanit anite innu-assit, auen nenua tshe kanuenitak (ka takuaimatak).*

Tshe ishpish kanuenitakannit nenu auen ka patshitinak tshekuannu : Nemeni aimuna ka utinakaniti, tshika kanuenitakanua (*tatutshishikua/tatuminashtakana/tatupishimua/tatupipuna*) tshe pikunakaniti. **Uitamuk^u tanite kie tan tshe ishi-kanuenitakaniti neni aimuna.**

Tsheku-aimun tshe apashtakanit : Ne aimun tshe apashtakanit mekuat nanatuapatitshenanuti, tshika ui minakanu tshetshi naushunak ne auen ka uitshiaushit. Ishinakuaki, nemenu tshika tshishikashu nenu ne kanatuapatitshesht (kie ma ka ishi-tapuetatishunanut anite nishtutatunit ka natuapatitshenanut) tshetshi ashushtakaniti mashinaikana. Natuenitakanu tshetshi takuak ume mashinaikan e itashtet miam nenu innuat eshi-aimiht.

Tshe ishi-tshishikatunanut : **Uitamuk^u tshetshi ma takuanikue tshetshi tshishikatunanut (e tshishikuakanit auen, minakanit atamishkatunnu, kie ma kutakanu tshekuannu).**

Tshetshi ataatshenanut ne ka ishi-unuipanit kie ma eka minupaniti anite uiesh : **Uitamuk^u tshetshi ma ne eshi-mishkamashunanut anite ka natuapatitshenanut tshima ataatshenanukue kie ma mauat mak tshima auen uetshit katshitaukut.**

Tshetshi unuipanitakanit ne ka ishi-mishkamashunanut : **Uitamuk^u tan tshe ishi-pimipanitakanit aimun ka mishkamashunanut (e uitakanit anite atusseu-katshitapatakanit kie ma ait) mak tan tshe ishinakuak unuipaniti aimun kie tan tshe ishi-tshiuenakanit ne aimun tshe itishaikanit nete innu-assit (tshekuan tshe apashtakanit tshetshi pimipanitakanit aimun, mashinaikanissa, tshe mashinaitshenanut anite atusseu-katshitapatakanit kie ma kanatutakanit, mak kutak).**

Tan tshe ishi-takaukut nenu atusseunnu tutakaniti : Tapuetaki tshetshi uitshiaushit ume netuapatitshenanunit ne auen ka uitshiaushit apu patshitinak nenua utipenitamuna kie apu itshenamuat nenu eshinakuannit utatusseunnu nenua kananatuapatitsheniti, atusseutshuapa kie mashinaikanitshuapa ka takaukuht.

Tapuetuakanu tshetshi eka ui tutak kie ma tshetshi unuit anite atusseunnu etutakannit : Ne ui uitshiaushinanuti ute netuapatitshenanut, uin nenu auen tapuetam^u, apu ushkuishtuakanit kie tshika tshi itsheteu anite muk^u eshpish ui itshetet, apu kukuetshimakanit tshekuannu kie apu tshekuannu tshika ut tutuakanit.

Kassinu tshekuannu tshika tshi kukuetshimakanu ne auen ka tipenitak umenu netuapatitshenanunit **(tanite epit ne kananatuapatitshesht mak nenua utshimama ashit tshipa tshi natuenitakannu).**

Nin ute meshinatautishuian _____ **(mashinataimuk^u ute tshitishinikashunuau)** nitapueten, eka ushkuishtakauian, tshetshi uitshiaushian ume netuapatitshenanut eshinikatet **« eshinikatakanit ne kananatuapatitshenanut ».**

Nin ute meshinatautishuian _____ **(mashinataimuk^u ute tshitishinikashunuau)** apu tapuetaman tshetshi uitshiaushian ume netuapatitshenanut ka ishinikatet : **« eshinikatakanit ne kananatuapatitshenanut ».**

Aimun patshitinakanu : tshetshi minakanit ne auen ka uitshiaushit tshetshi uitak nenu tiapuetak, ui aimiti. Tshika ui ashupanikanu mishkut.

Nimashinatautishun ume nish^u mashinaikanuiana, peik^u tshe kanuenitaman.

Utishinikashun ne auen ka uitshiaushit

Ute tshe mashinatautishut ne ka uitshiaushit

Tshishik^u etananut

Utishinikashun ne kananatuapatitshesht

Ute tshe mashinatautishut ne kananatuapatitshesht

Tshishik^u etananut

Ui kukuetshimuiekui ume netuapatitshenanut, tshika tshi aimiauau : **(Utishinikashun kie tanite tshe aimiek^u ne auen ka takuaimatak nenu netuapatitshenanunit)**

Aimun patshitinakanu : Ne nanatuapatitshenanuti auen eka ka itatupipuneshit kie ma auen ka itatupipuneshit muk^u eka katshi aitutatishut, kutak mashinaikan tshika ui shakassinitakanu.

APPENDIX 7: DISSEMINATION AND COMMUNICATION PLAN TEMPLATE³⁴

DESCRIPTION		
Project title		
Ethics committee	Submission	<input type="checkbox"/> Yes <input type="checkbox"/> To come
	Approval	<input type="checkbox"/> Yes <input type="checkbox"/> To come <input type="checkbox"/> Ethics certificate attached
Affiliated organization		
Main researcher	Name:	
	Title:	
First Nation or Community representative	Name:	
	Title:	
Project objective		
	Name	Function
Should be CC'D on all correspondence	_____	_____
	_____	_____
	_____	_____
	_____	_____
Other collaborators/ partners	_____	_____
	_____	_____
	_____	_____
	_____	_____

³⁴ Adapted from: FNQLHSSC, internal document [s.d.].

PLANNED PRODUCTS

PRODUCT	DEADLINE	DISSEMINATION	
		Vast public	Restricted
<input type="checkbox"/> Report _____	____ / ____ / ____	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> PowerPoint presentation	____ / ____ / ____	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> CD-ROM	____ / ____ / ____	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Web site	____ / ____ / ____	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Scientific publication (newspaper)	____ / ____ / ____	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Other: _____	____ / ____ / ____	<input type="checkbox"/>	<input type="checkbox"/>
Community dissemination	<input type="checkbox"/> Yes <input type="checkbox"/> No	Deadline: ____ / ____ / ____	
HOW	WHO		

TRANSLATION	
Language(s)	

COMMUNICATION PLAN

	Product	Web site	Other links (specify)
Publication on the internet	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
	_____	_____	_____

First Nation/Community authorities' approval Yes No

Report introduction letter

Design: _____

Signature: _____

Official launch Yes No
 Date ____/____/____

Comments

BUDGET

Global	Translation	Editing/ graphic design	Printing	Launch

SIGNATURES

Main researcher

First Nation or community representative

DISSEMINATION ACTIVITIES PLANNING

Priority	Audience Targeted potential audiences	Activity	Support	Who? Persons in charge/ collaboration	When?
1					
2					
3					
4					
5					

APPENDIX 8: CERTIFICATE OF DESTRUCTION OF PERSONAL AND CONFIDENTIAL INFORMATION

I, the undersigned, _____
First name and last name of the employee

performing my duties with _____

whose main office is located at _____,

solemnly declare that I am duly authorized to certify that that the personal and confidential information submitted by _____ as part of the project awarded to _____, have been destroyed according to the following method or methods:

(Check the appropriate box or boxes).

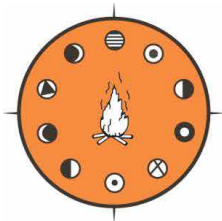
<input type="checkbox"/>	By shredding: information on paper support
<input type="checkbox"/>	By logical destruction and physical deletion using overwrite software: information on computer support
<input type="checkbox"/>	By another method of destruction: specify the support and the method of destruction <div style="border-bottom: 1px solid black; margin-bottom: 5px;"></div> <div style="border-bottom: 1px solid black; margin-bottom: 5px;"></div> <div style="border-bottom: 1px solid black;"></div>

IN WITNESS WHEREOF, I HAVE SIGNED AT _____, THIS _____

DAY OF THE MONTH OF _____ IN THE YEAR OF _____.

Signature of the employee

APPENDIX 9: AFNQL'S RESOLUTION



Assemblée des Premières Nations Québec-Labrador

250, Place Chef Michel Laveau, bureau 201
Wendake (Québec) G0A 4V0
Tél. : 418-842-5020 • Téléc. : 418-842-2660
www.apnql-afnql.com

Assembly of First Nations Quebec-Labrador

250, Place Chef Michel Laveau, Suite 201
Wendake, Quebec G0A 4V0
Tel.: 418-842-5020 • Fax: 418-842-2660
www.apnql-afnql.com

RESOLUTION NO. 09/2014

FIRST NATIONS IN QUEBEC AND LABRADOR'S RESEARCH PROTOCOL (version 2014)

Preamble:

The First Nations in Quebec and Labrador have inherent rights to self-determination, a unique vision of the world, the responsibility to preserve their territory for future generations, as well as the right to exercise their research governance and develop their own research policies.

Therefore, they want to continue the decolonization of research by monitoring research activities taking place amongst their population, by actively participating in research, and by being involved in all decision-making processes with regard to the funding of research activities that affect them.

For these reasons, the First Nations in Quebec and Labrador developed a research protocol to guide their research activities, which does not replace in any way the tools, guidelines and processes already in place in the communities. It is available for the communities and organizations who wish to use it for their own needs.

WHEREAS the First Nations in Quebec and Labrador expressed their position regarding research through the statement of principles included in the First Nations in Quebec and Labrador's Research Protocol (version 2014);

WHEREAS the United Nations Declaration on the Rights of Indigenous Peoples (2007), article 31, stipulates 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, 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";

WHEREAS the First Nations in Quebec, the communities and regional First Nations organizations are regularly asked to participate in various research projects on their territory or with their people;

WHEREAS the First Nations in Quebec, their communities and regional organizations are no longer targeted by research for which they have not given prior consent and in which they have not been involved actively;

WHEREAS the Chiefs of the Assembly of First Nations in Quebec and Labrador (AFNQL) have adopted a resolution (14/2005) recognizing the First Nations in Quebec and Labrador's Research Protocol (2005) as a reference document for communities, AFNQL's commissions and organizations to use as guidance;

WHEREAS the Chiefs of the AFNQL have voted for the revision of the First Nations in Quebec and Labrador's Research Protocol (2005), through a collaboration between the FNQLSDI, the FNQLHSSC and the FNHRDCQ,

THEREFORE BE IT RESOLVED THAT the new version of the First Nations in Quebec and Labrador's Research Protocol 2014 may be used as a reference document for communities, commissions and organizations to use as guidance for their respective governance process in terms of research, information and collective knowledge management and preservation of their information heritage;


FURTHER BE IT RESOLVED THAT the communities demand that any research conducted on their people by any entity be authorized by First Nations local authorities by way of resolution, licence or permit.

FINALLY BE IT RESOLVED THAT the 2014 version of the Research Protocol be adopted by the Chiefs of the AFNQL.

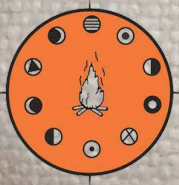
PROPOSED BY: Chief Jean-Charles Piétacho, Ekuanitshit

SECONDED BY: Chief Gilbert Dominique, Mashteuiatsh

ADOPTED BY CONSENSUS ON JUNE 12, 2014 IN QUEBEC CITY



Ghislain Picard
Chief of the AFNQL



Assembly of First Nations Quebec-Labrador
250 Place Chef Michel Laveau, suite 201
Wendake, Quebec G0A 4V0
Phone number: 418-842-5020
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