



First Nations of Quebec and Labrador Research Protocol

June 2005



Assembly of the First Nations
of Quebec and Labrador

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- First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC);
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Note: This document is a shortened version of the First Nations of Quebec and Labrador Research Protocol, June 2005. The reader can access the complete version of the document on the following websites:

www.cssspnql.com
www.iddpnql.ca
www.cdrhpnq.qc.ca



Foreword by the Regional Chief of the AFNQL, Ghislain Picard

In order to express its position regarding research carried out among First Nations, the Assembly of First Nations of Quebec and Labrador (AFNQL) undertook the development of a research protocol so as to offer their communities a reference guide that would enable them to better monitor the various activities and numerous demands related to the research carried out in their territories. This document is intended to be first and foremost a reflection tool that gathers together the elements or criteria essential to the development of a research policy.

The principles stated in this protocol aim at fostering a spirit of cooperation and mutual respect between researchers and First Nations as well as ensuring adequate running of research in an Aboriginal environment and promoting all facets of Aboriginal science.

The development of this protocol is certainly not aimed at hindering sensitive research work or any form of investigative work likely to lead to undesirable conclusions, but rather to promote a precise and well-informed ethical form of research, whose whole process respects the will of the First Nations involved. The requirements expressed in this document will inform First Nations on research procedure and help them better identify their needs, limits and involvement, define research policies and establish means through which communities will manage said policies. The development of proper research principles and practices aims at guarantying good research processes in First Nation communities.

The partnership research implies must be built on the improvement of relations between communities, scientists and researchers as well as on their cooperation in a work context focussed on trust, respect, cooperation and mutual understanding. In order to ensure an equitable partnership, First Nations need to develop their own research protocol with a full understanding of the preferred method as well as of the positive and negative possible consequences that the process and results of the research could entail.



The AFNQL maintains its commitment towards the advancement of science and foster the development of tools that support communities towards achieving their autonomy.

We want to thank all the people who contributed to the development of this research protocol.

Ghislain Picard
Regional Chief of the AFNQL

Introduction

While in the past communities mostly limited themselves to providing knowledge as study subjects, now they can and must get directly involved in the research process, from its design up to the dissemination of the results. An Aboriginal community or a First Nation should thus:

- Establish research partnerships;
- Identify its research interests and needs;
- Participate actively in the development of research goals and objectives;
- Develop the methodology jointly with the researcher(s);
- Claim the status of main client of the research;
- Be the first ones to use the results;
- Endorse the role of funding party;
- Assume the granting of research permits;
- Co-realize and co-manage research projects in its territory.

This protocol must routinely be applied to research, surveys, questionnaires and discussion groups carried out among First Nation individual(s) or community(ies).

Goals of the protocol:

- Establish a framework of reflection, guidelines and procedures to guide the First Nations willing to develop or perfect their own code of ethics and good practices with regard to research;
- Ensure respect of the culture, language, values, knowledge and standards of each First Nation;
- Contribute to the on-going improvement of communication between developers and First Nations who are research components;
- Contribute to a better understanding of research and the issues it holds for First Nations.

Objectives of the protocol:

- Develop a guide that can answer the concerns, questionings and meet the expectations of the community regarding research;
- Propose tools that can actualize and bring into realization the content of the protocol: research permit, consent form, etc.

1. Fundamental guidelines

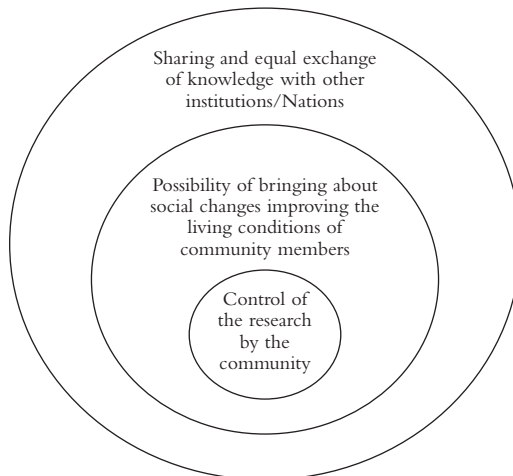
The following three elements foster and maintain good understanding between the community and the researcher.

- **Power:** it is a question of transferring power, of sharing it. Each participant must feel that his needs are being heard, that he/she is respected, and so are his/her ideas. This delegation of power also requires the sharing of power between the community and the researcher;

- **Equity:** the financial aspect or the money only represent one facet of equity; a community's and a researcher's knowledge, networks, personal, political and social powers constitute other

facets where we must try to reach a level of equity profitable for both parties. It is also important to review the terms of this equity throughout the duration of the agreement and according to the evolution of the research process;

- **Respect:** the result will be an understanding of the social, political and cultural structures of the other party. Communication must work both ways. Definitions, postulates and other suppositions must be clarified and questioned by both parties. Customs, traditions, habits, rules and regulations of the community must be respected. The culture, language, jurisdictions as well as the community's formal and informal standards must also be respected and used as much as possible.





2. OCAP principles and intellectual property¹

These principles embody the expression of self-determination in the realm of research, a political answer to a tenacious colonial trend with regard to research and information management. The main notions these principles transmit are:

- **Ownership:** collective ownership of information by a group;
- **Control** of research and information by First Nations;
- **Access** to data and its management;
- **Possession:** physical possession of data.

The advantages of OCAP principles are numerous: rebuilding of trust, improvement of research quality and relevance, decreased bias, efficient capacity building and learning community-based self-determination to get things rolling.

- **Ownership:** This principle expresses the idea that a community or group own information collectively in the same way individuals own their personal information.

From the very first consultations steps, who will own the results must be clearly identified; if this ownership is to be shared, the modalities must seem equitable to all partners and they must be clearly established before the gathering of data.

- **Control:** This principle advocates that First Nation members, their communities, and the groups that represent them are entitled to wish to obtain control over all aspects of research management and of the information having impacts on them.

First Nations' inherent right to autonomy implies that they have authority in the management of their business, territories and resources, consequently, a right of control and decision-making over all steps of proposed research projects, of the methodology, of the elaboration of interview grids to the dissemination of results.

1 Schnarch, B., January 2004, "Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research", *Journal of Aboriginal Health*, vol.1, no 1, p. 80-95.

- **Access:** Wherever they are kept, First Nation members must have access to the information and data that concern themselves and their communities.

This principle also refers to the right of Aboriginal communities and organizations to manage said information and make decisions with regard to their access.

- **Possession:** Even if possession is not a condition of ownership of data per se it nevertheless constitutes a mechanism through which ownership can be asserted and protected.

Make copies of the data available to the community or at a location it has determined.



3. Fundamental aspects to be considered during the first meetings

Researchers must work with the members of the community right from the very first planning steps of their research propositions. They must also give the members of the community enough time so they can review and understand perfectly all aspects of the study, ask questions and solve problems if need be.

Initial contact should be made through a letter of intent setting out the ideas, objectives and goals of the research, letter that will be sent to the authorities of the First Nations involved.

- Presentation of the project, of the objectives of the research, of the methodology proposed and of the results expected;
- Presentation of research expectations towards the host community;
- Setting up of participation modalities of the community.

The following elements, among others, will be discussed right from the very first meetings:

- Modalities related to data collection;
- Commitment and training of co-researchers by integrating into the project a component aiming at building First Nation capacity. It is of the utmost importance to foster the acquisition of research know-how within the communities while ensuring knowledge transfer;
- Information mechanisms during the course of the research;
- Research follow-up mechanisms;
- Intellectual property, confidentiality and access to research products

People responsible for the research must state clearly the way they intend to ensure the confidentiality of the data gathered from individuals or groups in the community, documents as supporting evidence (approach, method and consent forms).



4. Consultations

It is of the utmost importance to hold, at every step of the research, appropriate consultations among the First Nation involved. First Nation members must participate fully, right from the very beginning to the establishment of the criteria and consultations methodology to be adopted. They must also get actively involved in each step of the consultative process. The latter will contribute to:

- Avoid the impacts of dual consultations; those responsible for the research thus make sure that their questions will take into consideration prior results, the approaches and methodologies used to produce them as well as their forces and their weaknesses;
- Prevent potential obstacles by identifying the problems likely to occur in the course of the research and that might adversely affect the community.
- The people who wish additional information on the consultation process can refer to the *First Nations of Quebec and Labrador Consultations Protocol, June 2005*, which is now available.

The negotiation of the community's agreement to a research does not constitute a sole, static event; it inserts itself in the whole cycle of the survey, where each step must be discussed, understood and realized jointly with all the partners. The investigation cycle thus comprises, in community-based research, a learning process from beginning to end.



5. Informed consent and confidentiality

- Informed consent is an *imperative* prerequisite to the launching of a project. The authorities of the community must give their authorization so that the project may begin;
- No research activity involving individuals or their entourage should start before having obtained the informed consent of those who participate in it.

The objective of informed consent is to ensure that the participants in the research project fully understand what their commitment and their participation involve.

In the process of obtaining consent, researchers must clearly identify the objectives of the research, the methodology chosen, the funding sources as well as the eventual positive and negative impacts that the research can cause to the persons involved, the community and its environment. Generally speaking, a letter of information written in a simple, direct and understandable language, in an Aboriginal language if need be, should be enclosed with the consent form and include this essential information.

Please note that you must obtain authorization and consent to make audio-video recordings, to take photos, physiological measures or to take blood, skin or hair samples.

Any person or any First Nation has the right to say « No » to a request to participate in a research project or to withdraw from it at any time.



6. Consent form

- Consent forms must be written in an understandable style, simple and direct, and in the language the subjects speak at home;
- Parents must authorize and approve, signature as supporting evidence, the participation of their children under 18 in a study.

Researchers must make sure respondents still agree to the publication of the information they have given; indeed, according to the nature of said information, they can and do have the right to withdraw their consent, or to require that their names appear if they have been quoted or if they want to appear on the list of informants.

Let us point out that an individual may refuse to sign a document, and give his consent orally. Even if the latter remains more difficult to prove or to verify than a written consent, it is as valid and as legal and is recognized legally.

7. Aboriginal knowledge

- First Nations have their own ways of generating knowledge and handing it down, separate from western scientific methods. They deserve respect and recognition of their intrinsic value for research in an Aboriginal environment;
- Researchers must not only recognize the objective value of Aboriginal knowledge but also understand them and document them so as to make possible a harmonious and complementary cohabitation of the systems of knowledge;
- The communities must define the parameters that can enable them to protect their knowledge while ensuring the recognition of their contribution to the advancement of knowledge.



8. Research steps, methods and approaches

The conventional research procedure consists in a series of successive steps that go from the design of the project and of its problematics to the production and dissemination of the results. Generally speaking, the main steps can be read as follows:

1. Design of the project

- a) Content and problematics
- b) Research questions
- c) Approach and Methodology
- d) Funding



2. Data gathering in and outside the community

- a) One-on-one or group interviews
- b) Discussion workshops
- c) Drawing of samples from humans, animals and/or plants
- d) Biophysical inventories
- e) Other types of data



3. Production of reports

- a) Data processing and analysis
- b) Validation of data gathered among participants and/or local and regional institutions
- c) Drafting of main reports (first transmitted to the community)



4. Dissemination of results

- a) Dissemination of the report (public or restricted)
- b) Publication of articles (scientific and popularized)
- c) Oral and written dissemination of results (lectures, workshops, training programs and others)

The following elements are principles to be kept in mind throughout the research in an Aboriginal environment, whether the community is a partner in the project, a data source or an organization ensuring part or all the funding.



9. Responsibility

Researchers involved in a research project or program in an Aboriginal environment are the first people responsible of the research, thus accountable to the community and particularly to the direct participants and to the official authorities. All decision-related research, including decisions made by co-researchers, come under the responsibility of the persons responsible and must be discussed with the First Nation involved.

10. Data processing, analysis and validation


It is essential that the community, its representatives and/or its respondents proceed to a validation of the data, especially when it is obtained through interviews.

Beyond respect and equity, this exercise may prove to be essential to guarantee the validity of the results and of the cultural context, as much for the participants as for the researchers.

Participants must pay attention to the words used in reports and point out which statements they find incoherent, prejudicial or expressing half-truths.

First to receive the results of the research, the community will also be the first to make suggestions and give its reactions, thus helping to avoid mistakes and misunderstandings. Consensus on observations, comments or conclusions by several individuals also legitimizes the interpretations and analyses.

Research data, reports and results, their summaries and potential articles must be entirely available to First Nations in the language of their choice, and this must be done before they are distributed or communicated to the scientific community, governmental authorities or to the general public.



11. Right of opposition and inclusion of divergent views

A community can dissociate itself from the interpretation of the data and results of a research in which it is involved. It can also refuse to participate in a research in progress if it thinks that the terms of the agreement are not respected or that it will provoke unacceptable perturbations within the community. If no agreement can be entered, the community could wish that the diverging viewpoints be included in the report².

12. Translation and interpretation

Projects must often seek the services of community members to act as interpreters or translators. Right from the planning stage of the project, the selection of qualified resource persons to fulfill these duties must be discussed. It remains wise and prudent to make provisions for substitutes or replacements. In the case of interviews, in order to ensure that the interpretation and the translation of the questions are the same for each respondent concerned, a version of the questionnaire must be elaborated in the required language; uniformity and homogeneity prove to be essential in research.

13. Management of time-research

Communities do not have to follow a schedule coming from outside. Right from the first joint planning sessions, the cultural schedule of the community must be respected by establishing jointly with the researchers a time frame and a work rhythm for the steps of the research that respect the community's requirements, capacities and needs.

14. Assessment

Assessment of the research, analysis of its process, come back on the difficulties, good moves and successful ones will contribute to lead to the planning and management of future projects, adjust research policies, and judge the relevance of the creation/abolition of research advisory and to ensure participation in and control of the research, etc.

² CRSNG/NSERC, 1998, "Tri-Council Policy Statement", *Ethical Conduct for Research Involving Humans*, chap. 6.



CONCLUSION

This document can be summarized in a few essential points to be considered in the framework of research in an Aboriginal environment:


- Participatory approach;
- Respect;
- Consultations;
- Informed consent;
- Protection and respect of Aboriginal knowledge;
- Reciprocity and sharing of costs and benefits;
- Responsibility;
- Right to information;
- Access to results of the research.

OCAP principles – **O**wnership, **C**ontrol, **A**ccess and **P**ossession – also constitute a fair summary of the ideal practices and standards to respect in a context of community-based research among First Nations for they include all the above-mentioned.



GLOSSARY

- *Aboriginal knowledge*: Concerns the relationship between a people or a particular community and its ancestral territory; it comprises its history, its knowledge and its experiences.
- *Funding party*: Organization or individual who funds research activities.
- *Informant*: Person who gives information or who helps the researcher to understand facts, gestures or actions. To differentiate from translator (who most of the time translate recorded interviews that he didn't even participated in) or interpreter (most of the time a research assistant who helps the researcher by summarizing what's being said during interviews, meetings, social or cultural events, etc.).
- *Intellectual property*: Ideas, knowledge or creative manifestations of the human spirit that acquire commercial value and receive or require the legal protection of a property right.
- *Methodology*: Privileged research procedures (e.g.: questionnaire, interview, validation). Systematic study, through observation, of scientific practice, of the principles it is based on and of the research methods it uses.
- *Postulate*: Improvable principle, which seems legitimate, beyond question, and that each and everyone accepts.
- *Research partnership*: Dynamic process, partnership consists in an informed, flexible and negotiated distribution or decision between all partners that require constant and ongoing cooperation and consultation; it allows individuals to push back the borders of knowledge and resources, thus strengthening research.



APPENDIX 1 : Consent form (for a person of full age)

Title and description of the research project

Team: The survey is a joint initiative of the following organizations:

(if there are more than one), including the name of the funding sources of the research project, the name of the organization or the name of the person involved.

Objective of the study: In a few points, description of the “goal” of the study and why it should be carried out.

Duration of the study and method used: The participant will have to take part in (number of sessions) of (length of sessions) during which he /she will have to answer to the following material: questionnaire, directed or semi-directed interview, etc. The sessions anticipated (date and time of sessions).

Advantages/Disadvantages: Enumeration of the middle and long run advantages and disadvantages for the community as well as the complete explanation of the use of this study for the community.

Protection of personal information: The data obtained from the study will be strictly used for the purposes of said research. Mention how the information gathered will be used. The names of the participants will not appear in any report, except if they want it to. Moreover, confidentiality of the answers must be ensured according to the mandate of the research team; the answers will not be made public under any consideration.

Duration of the conservation of personal information: The data gathered will be kept for X days/weeks/months/years then destroyed (means of destruction).

Language used: The language used during the research proceedings must be left to the participant. If the occasion arises, translation services will be paid by the researcher.

Right to refuse or withdraw: The participant will be able to withdraw from the research project at any time, without having to give a reason and will not suffer any kind of prejudice.

Initials _____



All questions concerning the project can be addressed to researcher

(how and where to get in touch with the researcher and his/her director if need be).

I undersigned _____

(*name in block letters*) _____,

freely consent to participate in the research project entitled: « title of the research project ».

I sign two copies of this form and keep one.

Signature of the participant

Date

Signature of the researcher

Date

Note: For research made with an UNDERAGE person or a person of FULL AGE but UNFIT, a specific form must be filled.