

NEGOTIATING RESEARCH RELATIONSHIPS; A GUIDE FOR COMMUNITIES



The following is a reprint of a pamphlet produced by the Nunavut Research Institute and the Inuit Tapiriit Kanatami (formerly the Inuit Tapirisat of Canada). Although it was produced for the benefit of the Inuit, its guidelines apply equally well to First Nations and Métis Settlements. We include it here as a resource for all Aboriginal and indigenous communities who are, have been, or will be involved in research.

WHAT IS THIS GUIDE ABOUT AND HOW IS IT USEFUL?

This guide is about research relationships. It looks at ways you and your community can decide how research is done in your area, and how you can be involved. This guide will explain your legal rights when it comes to research, and suggest ways you can work with researchers to make sure your individual rights are protected and that you and your community's concerns are respected by researchers. The guide will help you to:

- ◇ Understand what research is.
- ◇ Understand what your rights are when someone wants to involve you in research.
- ◇ Learn the rules and ethics researchers should follow.
- ◇ Get ideas on how you can participate in and influence research.
- ◇ Work with your community to set up research contracts outlining how research should be done.

WHY WE PREPARED THIS GUIDE

We wrote this guide because Inuit have the right to set priorities for research and to influence how research gets done; and because research has the potential to be very valuable both to researchers and the communities involved. Unfortunately, northern research has not always been helpful to everyone it affects. Researchers from the south have been coming to Inuit communities for many years to study all kinds of things about Inuit life, culture and the environment. People in the communities have told us that they aren't always sure about what researchers do, why they do it and how their research benefits the community. Many Inuit feel they have not been involved enough in the research process. Because of this, there sometimes develops a mistrust of research, and local people may even become angry with researchers who intrude into their daily lives. On the other hand, efforts to make researchers more responsible to the communities and people who are being researched have resulted in guidelines for ethical research. Many Canadian universities and government agencies involved in research now use these guidelines. There are also things that individuals and organizations in the North can do to make sure that what gets researched and how research gets done is acceptable and helpful to Inuit communities. We hope that this guide will help individuals in remote communities understand research, how it is done and

why it might be relevant or not relevant for your community,

WHAT IS RESEARCH?

In this guide we are most concerned with research involving people directly. We are also interested in research on animals. There is no single definition of research, but it can be thought of as any planned and organized activity to produce knowledge about events or processes. Research means searching for information — usually, but not always, in one of the following ways:

- ◇ Observation of behaviour or activities of people and/or wildlife.
- ◇ Asking people questions in an interview.
- ◇ Taking blood or any other sample from your body, when it is not for medical purposes.
- ◇ Using non-public records which contain personal information about people.
- ◇ Observing or counting wildlife for scientific purposes.
- ◇ Capturing, then releasing, “tagging,” collaring, or killing animals and fish for scientific purposes.
- ◇ Collecting plants, ice, soil, water samples, artifacts, or fossils.

WHO DOES RESEARCH?

Sometimes researchers are easy to identify because they come from outside your community, and other times they may be members of the community. In the past, most “researchers” came from universities in Canada, from other countries or from government agencies. With the arrival of mining, oil and gas, and hydroelectric companies, many researchers have come to do exploration and environmental impact studies. Researchers may also be medical personnel from health agencies or community health centres taking samples for health and environmental studies. In more recent times, as land claims organizations have been set up, researchers are also people from the community working on traditional knowledge studies and other research.

WHAT ARE YOUR RIGHTS WHEN IT COMES TO RESEARCH?

There are laws both in Canada and internationally, that protect your right to privacy and confidentiality. These laws include the federal Privacy Act, and the Quebec Act Respecting Health and Social Services. You have the right not

to answer a researcher's questions even if your community has approved the research project. A researcher must get informed consent from you before they ask you any questions:

- ◇ The researchers must say whom the research is for, why, how and by whom it is being done, how it will affect the community, who is paying for the research, and who is in charge of it.
- ◇ You must agree to participate in the research before the researcher can begin.
- ◇ The researcher should not pressure you or your community in any way to get information.
- ◇ You can stop participating at any time if you do not feel comfortable with the way the research is going.

You also have rights to have your identity protected. These include:

- ◇ Researchers must not link your name to any information you give unless you agree to it.
- ◇ Anyone from outside the research team who will be allowed to see or work with the information should be identified to you.
- ◇ Personal information should be kept in a secure place where no one can copy it, give it out, or steal it.

Land Claim Agreements make provisions for Canadian Inuit to be in control of research as large areas of and are now owned by Inuit, and access to these lands is managed by Inuit organizations. For example, southern researchers must now have permission from the appropriate regional Inuit Association to work on Inuit Owned Lands in Nunavut.

WHAT ARE RESEARCHERS SUPPOSED TO DO BEFORE, DURING AND AFTER THE RESEARCH?

Researchers must follow certain guidelines and professional codes of conduct when they are doing research. These are not laws, but researchers must follow guidelines if their projects are to be approved by the agencies that fund them, and by the agencies who issue their research licenses or permits. Here are some things researchers are asked to do:

- ◇ Apply for approval from permit agency and community, and offer a full explanation of their research plan.
- ◇ Inform and get permission from individuals who are to be involved in a research project.

- ◇ Offer and guarantee confidentiality.
- ◇ Share with the communities information about the purpose of their research, its methods, and findings throughout the life of the project.
- ◇ Make serious efforts to incorporate traditional knowledge, whenever relevant, throughout their project.
- ◇ Avoid disrupting family and community life.
- ◇ Provide information on their research in the local language and/or dialects.
- ◇ State how consent was given in any document that is published from their work.
- ◇ Whenever possible, provide training to community members.

WHAT IS A NEGOTIATED RESEARCH RELATIONSHIP?

It is not only the researcher's responsibility to make sure that their work is acceptable to the community — you and your community can help make research responsible and useful by negotiating a research relationship. A negotiated research relationship is like a business contract where you and the other person discuss and agree on each other's duties and responsibilities. The researcher often must rely on you for information, so you have the right and responsibility to establish the conditions on what gets researched and how. Research can be very useful to the community, and there are often opportunities for training and employment, particularly in larger research projects. The important thing is that both your community and the researcher come to an agreement that is clear and understandable to both of you; one that does not put too heavy a burden on either of you. Here are some suggestions for negotiating a research relationship agreement:

- ◇ Your community might want to set up a special contact and advisory group to review research applications and give researchers guidance during their projects.
- ◇ Your community should decide what is required to get informed consent from individuals participating in research projects — what kinds of information should the researcher be allowed to ask for, and what form should consent take (oral, written).
- ◇ You should be aware of the requirements for confidentiality, like taking names off any confidential data or interview results.
- ◇ You should decide on how to suspend (put on hold) research if your

community has concerns part way through the project.

- ◇ Make sure there is clear understanding and agreement on the control of data and research result, their storage and release, who has access, how and to whom research data gets distributed.
- ◇ Communication — researchers are not always fluent in the language of the people they study so they may need to be assisted. Hiring local communicators may help improve the situation.
- ◇ Translation — agree with the researcher on what information about their project should be translated, in what format, and how translation costs should be paid for.
- ◇ Involvement of community members — how can this best be achieved? Your community and the researcher should discuss hiring and training requirements.

RESEARCH AS A PARTNERSHIP

When communities and researchers are partners in planning and conducted research projects, there can be great benefits for everyone involved. Negotiating research relationships is one way to set up such partnerships, and this guide has offered some ideas for how to begin the process. We hope this guide has explained your legal rights and responsibilities and researchers' responsibilities when it comes to research. For more information on anything mentioned in this guide, please contact the Inuit Tapirisat of Canada at (613) 238-8181 or the Nunavut Research Institute at (867) 979-6734.

A SAMPLE NEGOTIATED RESEARCH RELATIONSHIP

Pauktuutit Inuit Women's Association/Inuit Tapiriit Kanatami

Inuit Tobacco Control Research Agenda

April 12/02 — DRAFT

submitted to the Canadian Tobacco Control Research Summit

Context for the *Inuit Tobacco Control Research Agenda*

Pauktuutit Inuit Women's Association has been addressing tobacco issues in Inuit communities in Arctic Canada since 1994. Initial research and consultation indicated that communities needed multi-media resource materials to address their alarming smoking rates. The 1991 Aboriginal Peoples Survey showed that 72 per cent of Inuit aged 15 and over were regular smokers. Today, the rates remain between 60 and 80 percent depending on the statistic and the age group studied. Progress has however been made. As a result of more information available and more public discussion, growing numbers of homes are becoming smoke-free, there are numerous stories of people quitting and due to Pauktuutit's efforts, most of the 53 Inuit communities have at least one person trained and resourced with basic prevention and cessation information in Inuktitut and English. In addition, regional health authorities are now making tobacco use reduction a fiscal priority and media regularly give coverage to tobacco related issues.

In March 2002, Pauktuutit and the Inuit Tapiriit Kanatami (ITK — the National Voice of Inuit in Canada) were invited to participate at the Canadian Tobacco Control Research Summit, April 19-21, 2002, to assist in setting research priorities for the next 10 years. In preparation, participants were asked to answer the following question:

In an ideal world not constrained by existing barriers, resources and systems, what research strategies, approaches or tactics could lead to new knowledge that would have a significant impact on tobacco use, nicotine addiction and related problems?

In order to provide an answer, Pauktuutit sought advice from various sources addressing tobacco issues in Inuit communities. These included a community health worker/trainer, a public health physician, nurses, a tobacco cessation counselor/trainer, a government administrator, NGO health staff and a youth coordinator. The ITK and Nunavut Research Institute docu-

ment, *Negotiating Research Relationships: A Guide for Communities*, provided a foundation for the ideas contained in the draft Inuit Tobacco Control Research Agenda. It remains a draft as it is not an official document, but it contains the ideas of those working closely with the issues. Developing the research ideas depends on the will and support of governments and research funding agencies. Barriers to implementation include the lack of capacity and financial resources for NGOs and others to develop research applications.

For more info contact:

Catherine Carry, Special Projects Coordinator

Pauktuutit Inuit Women's Association

131 Bank Street, 3rd Floor

Ottawa ON K1P 5N7

Tel.: 1(613)238-3977

Fax: 1(613)238-1787

Email: famviol@pauktuutit.on.ca

PRINCIPLE

- ◇ Any research in Inuit communities must be conducted according to the Inuit Tapiriit Kanatami's published research protocol and according to the principles of OCAP-ownership, control, access and possession.
- ◇ In other words, Inuit must be involved in developing the research agenda, the research plan, and the research tools, and in the collection, interpretation, analysis and reporting of the results such as described in participatory action research approaches. This will ensure relevance to the community whether at the local, regional, or national levels and promote the development or enhancement of research capacity within the Inuit population.

POTENTIAL RESEARCH QUESTIONS

- ◇ Do health care providers in Inuit communities ask about their patients' tobacco use or not? If not, why not? If yes, do they chart the answer and how do they follow up?
- ◇ How many homes in Inuit communities are smoke-free? Conduct a survey on the number of smoke-free homes in Inuit communities and promote the outcomes. Ask the adults in the homes that are not smoke-free why they are not.

- ◇ Why don't 28% of the adult Inuit population smoke? Ask those who have quit or have never smoked (or used tobacco products) why they don't smoke and how they manage to remain non-smokers.
- ◇ Do the smoking rates of Inuit drop with community and regional level interventions? Conduct periodic (4-5 years) prevalence surveys in each region to see if there is a change in the rates.
- ◇ What childhood interventions could prevent the development of addictions including tobacco use among Inuit children? Conduct a longitudinal study of older Inuit children regarding the development of addiction patterns (incorporating tobacco use) and the potential for and form of strategic interventions.
- ◇ What interventions would help pregnant Inuit mothers to stop smoking?
- ◇ What are the rates of second-hand smoke related medevacs of infants and children and lung-related problems in youth in each Inuit community? Compile and disseminate the statistics to the public.
- ◇ What are the levels of tobacco sales in Inuit communities? (GN is doing some of this.) Compile and disseminate the statistics to the public.
- ◇ How can Inuit communities bring about the kind of radical social/community change that we know is needed to build healthy communities – communities that will not be so dependent on harmful substances and practices? Develop participatory action research activities to answer this question.

DISSEMINATION

- ◇ Disseminate relevant and sound research findings and best practices from other settings/cultures/countries that could guide implementation priorities in the Inuit population.
- ◇ Develop plain language versions and translations into Inuktitut of relevant findings.