



Fact Sheet #3 – March 2009



Individual Informed Consent for Research

Researchers must follow guidelines to make sure their work is honourable and respectful (ethical). One of the most important rules is to make sure research participants have given *'informed consent'* to take part in a research project.

What is Informed Consent?

Informed consent means that people participating in a research study or project have been given all of the information about the risk and benefits of participating before she/he agreed to take part.

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Informed consent is an agreement between each individual participant and a researcher. It says what the participant will do and what the researcher will do. It is usually a written form that is signed but it can also be agreed upon

verbally. Particularly in health research, an informed consent agreement can be several pages long and make up a whole binder.

Only adults can give informed consent. This means research participants must be 19 in Nunavut, Northwest Territories and Nunatsiavut and 18 in Nunavik. Parents and guardians can give informed consent for their children under these ages.

Taking Part in Research is Always a Choice

Before verbally agreeing to or signing an informed consent form, participants can ask all the questions they need to. And, they need to make sure they understand everything that has been explained or written in the consent form.



If there are parts of the consent form that a person understands but does not agree to— they can say so. The participant and researcher can change details in the agreement until both are comfortable with it.

Questions to Ask the Researcher Before Giving Consent

Here are some things Inuit may ask the researcher before giving their informed consent:

- What is the project about?
- Who is the main contact and how can they be reached?
- How will the research help Inuit and their community?
- Why are they being asked to participate?
- How will private information be used?
- How is privacy protected?
- If the research involves taking body samples, how will they be used and will the samples be destroyed or returned after the research is finished?
- Will the researcher tell the participants the results of the research? How? Does the researcher plan to inform the community? How?
- How can people stop being involved in the research study if they change their mind during the project?
- After a person withdraws from a research project, what happens to the information they provided up to that point?
- Who can people contact if they have complaints about the project or the researcher? How?

Taking part in research can be a great experience.



We stay informed about research trends, ethics and participation to make sure research and research results work for us.

Research and research ethics are the key focus of the **Inuit Nipingit – National Inuit Committee on Ethics and Research**. Inuit Nipingit is co-ordinated jointly by Inuit Tuttarvingat of the National Aboriginal Health Organization and Inuit Tapiriit Kanatami.

Fact Sheet #3: “Individual Informed Consent for Research” can be retrieved from www.naho.ca/inuit/e/ethics

March 2009