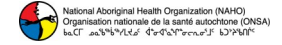




# Research and Research Ethics FACT SHEET SERIES

Fact Sheet #5 – March 2009



## Privacy and Confidentiality in Research

Researchers studying health and other issues need to get information from many individuals about personal things. To do so, researchers might ask very personal questions, or even ask for hair, blood or other samples. All of this is private information. It is a person's own choice to take part in health research and share their private information with the researchers.

### Laws in Canada Protect People's Right to Privacy

Community members might wish to provide all kinds of information to a researcher because, for example, their child or a member of the community has a serious disease and they would like to help in finding a cure.

*Researchers must get informed consent from people to take part in a health, social or environmental research project (see Fact Sheet #2).*

Here are some things Inuit should know and discuss with the researcher **before** agreeing to take part in research:

- ◆ Who else will see the private information, for instance, other members of the research team or their supervisors?
- ◆ How does the researcher make sure that other people cannot see any private information? For example, are questionnaires and copies stored in a locked cabinet, or are computer files that contain personal information protected with a password or locked otherwise?
- ◆ When the project is finished, the researcher will make a report about what they learned. If participants chose not to be identified, researchers must make sure that no one could recognize the person or their private information in the report.
- ◆ In research involving traditional knowledge, it is common for people to require that their name appear next to the knowledge that they shared. This is an individual decision that should be discussed with the researcher.



## Secondary Use

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Sometimes researchers use the same information to answer a different research question later on. This is called ‘**secondary use**’ and it should be addressed in the ‘informed consent form’ of the research agreement. The agreement should clearly state whether the participant agreed to secondary use of their information or not.

## Accidental Disclosure

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Disclosing an individual’s identity can happen by accident but needs to be prevented by the research team. In research projects, for example, that are searching for ‘numbers’ on something, it could happen that a number will tell which person the result is referring to. This can happen in particular when working with small communities. In cases such as this, the researcher will need to publish information about groups of people and, for example, refer to the group of people 15 years of age and older.

*Taking part in research can be a great experience. The results can help us and our communities. To make sure research and research results work for us, we stay informed about research trends, ethics and participation.*

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.

## Privacy and Confidentiality

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A few more things to be aware of:

1. When a researcher publishes a report, it enters the public world and anyone can read it. There is no way for the researcher to control how other people choose to use the results. Someone could use the results to write a different explanation. This is not something the researcher can control.
2. A researcher might get information that could be about a crime or a threat to peoples’ safety (for instance, a contagious disease). In that case, there are laws that force the researcher to report those things to the police or social services.

Fact Sheet #5: “Privacy and Confidentiality in Research” can be retrieved from [www.naho.ca/inuit/e/ethics](http://www.naho.ca/inuit/e/ethics).

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