

Fact Sheet #6 - March 2009



# Using Human Samples in Health Research

For some types of health research, a researcher needs to get information from a sample of body tissue—material that makes up parts of our body. A tissue sample can be something like hair or blood or a little bit of dead skin scraped off of our arm or the inside of our mouth. Samples can also come from muscles, the uterus or the stomach, for example, if surgery is performed.

Health research that examines samples from people's bodies can be very valuable.

A lot of knowledge that doctors and nurses use to understand and treat sicknesses comes from health research that used these kinds of samples.

Many medical tests do take samples such as blood, but there are also very specialized fields of research that work mainly with human biological samples. These areas of research are, for example, molecular biology, genetics and pathology. In all areas, the goal is a better understanding of diseases and ways to prevent and treat them.

# How do Researchers Study Body Samples?

The researcher usually takes samples to a laboratory which is a specially-equipped room for doing tests. The researcher will do tests and examine the samples to find the information needed for the health research project.

## What Is Done With Body Samples?

It is a choice to take part in health research and give a sample from our body. Researchers must have an



'informed consent' (Fact Sheet #2 in this series) signed by the research participant to take part in a health research project and take a sample from their body.

Here are some things to know about taking body samples:

Samples can be stored for a long time and can be tested again for different reasons later on.

- Researchers work together and share a lot of information. This is a good thing since combining information is a powerful way to build knowledge.
- If a sample from a participant's body is labeled so no one knows which person it is coming from, a researcher could use it for a different study or share it with another researcher without asking your permission. This is called 'secondary use' of samples.

#### It is Good to be Informed

There are some things a research participant might like to know to have a clear idea of the research project being done. Here are things a research participant can ask the researcher:



- How does the taking of the sample affect my body?
- How are body samples being used?
- Who will have access to the samples?
- ▶ How and where will the samples be stored?
- What happens to the samples when the research is finished?

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

### **Rules for Researchers**

Researchers discuss on an ongoing basis what safeguards are appropriate for human research and how to protect the individual. From these discussions, many rules and procedures have been set for research projects.

Researchers in universities have to submit their research projects for approval from at least one ethical review board before they are allowed to develop the research plan further. The taking and storing of human biological samples for research is regulated by national laws and regulations.

The moment a person makes a choice about participating in clinical research is when the 'informed consent' form is signed. This is the current practice. However, there are researchers who prefer that any research involving the storage of human biological samples needs to be discussed with the research participants. These discussions might take place through meetings, e-mail alerts or letters.



Taking part in research can be a great experience. The results can help us and our communities.

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 #6: "Using Human Samples in Health Research" can be retrieved from www.naho.ca/inuit/e/ethics.

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