Access to general research results will be made available through the ICGC website (www.icgc.org). All data will be presented as group data, rather than individual data.

PARTICIPATION IN OTHER RESEARCH STUDIES

If it is found that you have pancreatic cancer, you may be asked to consider taking part in another research study called the Ontario Pancreas Cancer Study. Should you decide to participate, your samples and data may be used for both studies.

ARE THERE ANY RISKS FOR YOU?

The physical examination involves little risk. You may become anxious during the drawing of the blood and you may experience some dizziness and/or discomfort. As well, there may be some pain, bleeding or bruising at the site of the needle puncture.

There is a remote risk that the genetic information generated by ICGC projects could eventually be linked to genetic or medical information in other databases. It is also possible that the security of the computer systems used to store the codes linking your genetic and medical information to you could be breached. If this happens, it is possible you could be identified. This might lead to social risks such as discrimination or loss of privacy. However, we will make every effort to protect the confidentiality of your information and make sure your personal identity does not become known.

When you participate in the ICGC study, you do not waive your legal rights. Researchers have legal and professional responsibilities. Your participation in the study does not change these responsibilities.

WHAT ARE THE BENEFITS?

This study is not treating patients diagnosed with pancreatic cancer. The information gathered from this study may be helpful in the diagnosis and treatment of patients with this disease in the future.

WILL YOU RECEIVE ANY COMPENSATION FOR BEING INVOLVED?

Your participation is voluntary. You will not be paid. If you become ill or are physically injured as a result of participating in this study, medical treatment will be provided.

ICGC members have agreed that they will not patent the primary datasets. It is possible that research conducted with your samples or information in the future may lead to the development of diagnostic tests, drugs or other commercial products. You will not receive any of the profits from such products.

WITHDRAWAL

You may withdraw your consent to have your samples used for research at any time by contacting:

Dr. Patricia Shaw
Director, PMH/UHN Biobank
416-340-4690

If your coded data has been transferred to shared databases, it may not be possible to withdraw it.

WHO WILL OVERSEE THE ETHICAL AND SCIENTIFIC ISSUES?

An International Scientific Steering Committee, made up of international scientists, pathologists, ethicists, laypersons and others will oversee the ICGC's progress and address ethical and scientific issues that arise.

WHAT IF YOU HAVE QUESTIONS OR CONCERNS?

If you have any questions or concerns please contact:

Dr. Patricia Shaw
Director, PMH/UHN Biobank
416-340-4690

Thank you very much for your participation.

International Cancer Genome Consortium

Ontario Institute for Cancer Research
science → discoveries → solutions

University Health Network
Toronto General Hospital Toronto Western Hospital Princess Margaret Hospital

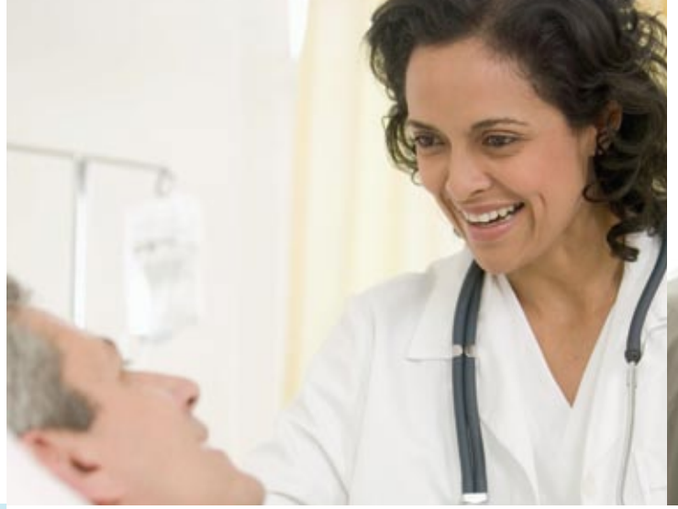
Version Date: June 2, 2010

PANCREATIC RESEARCH STUDY

WHAT IS THE INTERNATIONAL CANCER GENOME CONSORTIUM?

Cancer can result from changes in a person's genetic material (DNA). By studying the genetic changes, researchers can learn what causes cancer. This will lead to new ways to prevent, detect and treat cancer. The International Cancer Genome Consortium (ICGC) was created to coordinate a large number of research projects. The ICGC will develop a comprehensive catalogue of the genetic changes in cancer.

Scientists around the world are participating in the ICGC. They are studying 50 different types of cancer. In Ontario, the Ontario Institute for Cancer Research (OICR) is leading a study on the genetics of pancreatic cancer. OICR will recruit 500 people with pancreatic cancer for this study.



HOW WERE YOU SELECTED?

You are being asked to consider participating in the study. You were chosen because you will be having surgery to remove a tumour which may or may not be cancerous and/or will be having abdominal fluid removed during one of your clinic visits. You will have the procedure(s) at the Toronto General Hospital and/or Princess Margaret Hospital.

WHAT DOES PARTICIPATION INVOLVE?

If you agree to participate and it is confirmed that you have pancreatic cancer, cells from the tumour and/or abdominal fluid that were not needed to confirm the diagnosis will be stored at the Princess Margaret Hospital/University Health Network's Biobank (PMH/UHN Biobank). Some cells may be used to develop a permanent supply of cells (also known as cell lines) that can be grown in specialized laboratories. Some cells may be injected into mice at the Ontario Cancer Institute at Princess Margaret Hospital. Researchers will study the cells grown as cell lines or in mice to learn about the genetic changes in the tumour. Some of these cells will also be stored for future research.

A blood sample (approximately 20 mL or 4 teaspoons) and/or a saliva sample (approximately 2 to 4 mL or 1/2 to 3/4 teaspoons) may also be taken. These samples will be used for genetic and other biological studies in the future by researchers within the ICGC. They may be used for whole genome sequencing, which is an extensive study of your DNA.

The samples are collected for use by Ontario researchers. Some samples may be shared with collaborating researchers in other provinces or countries.

If it is found that you do not have pancreatic cancer, your samples will be used for other research projects. If you do not want your samples being studied in other projects, please inform the PMH/UHN Biobank staff:

Dr. Patricia Shaw
Director, PMH/UHN Biobank
416-340-4690

WHO CAN ACCESS YOUR DATA?

The ICGC was set up to help researchers investigate the genetic changes in cancer. The ICGC supports the sharing of data with the international research community. This may include researchers from academia, charitable organizations and the private sector, such as drug companies. At the same time, the ICGC respects the privacy of those who contribute to ICGC projects and will protect their information and samples. The ICGC policy states that data from participants will be placed into two databases, Open-Access and Controlled-Access.

Your name, address and telephone number will NOT be put into either the open or controlled databases.

Open-Access: Researchers will have access to the information in this publicly accessible database. It will not contain data that can be used to identify an individual.

Controlled-Access: This database will contain your medical information and more detailed analyses of your samples which have been stripped of all personal identifiers such as your name. Information in this database will be available only to researchers who sign agreements that define how your data may be used. They will not be permitted to disclose or transfer data to anyone else. They must use it only for the purposes to which they agreed with the ICGC. Researchers must also agree that they will not attempt to re-identify you from your data.

Individual data will not be offered to third parties such as employers, insurance companies or other family members. It will only be made available to them if required by law or a court order.