The Queensland Pancreatic Cancer Study

A research study looking at the causes of pancreatic cancer.

An information brochure
We are conducting a medical research study to look at the causes of pancreatic cancer.

For this study we need to talk to people who have been diagnosed with pancreatic cancer and also people who have not had pancreatic cancer.

You have been invited to take part in this study. This brochure will tell you in more detail what the study is all about. Before you decide to take part in the study we want you to have all the facts. Please read this brochure carefully and discuss any questions you have with your research nurse.

If you agree to take part in the study we will ask you to fill out some questionnaires. You will also be asked if you will donate a small sample of blood.
Who is conducting the study?

The study is being conducted by scientists at the Queensland Institute of Medical Research (QIMR), together with doctors at some of the major hospitals in Queensland. The study has been approved by the QIMR Scientific Committee as well as the Research Ethics Committees of QIMR, the University of Queensland (UQ) and participating hospitals throughout Queensland. These approvals are in accordance with the guidelines of the National Health and Medical Research Council of Australia. Details of these guidelines can be found at: http://www.nhmrc.gov.au/ethics/human/index.htm

Why do you want me to take part?

Every year in Queensland about 350 people are diagnosed with pancreatic cancer. We are doing this state-wide study to try to find out what causes this condition. If we can find the causes we can then try to prevent it from occurring in future generations of Australians. This study will look at both genes and environmental factors that might influence whether or not a person gets pancreatic cancer.
What will being in the study mean for me?

Being in the study will involve the following steps:

(1) One of our research nurses will visit or phone you to ask you some questions about your general health, lifestyle and well-being. This should take between 30 and 60 minutes. At that appointment our research nurse will leave you a questionnaire about your diet for you to post back to us. We may ask your permission to tape the interview for quality control purposes.

(2) If you agree, we would also like to collect a small blood sample. If you are unable to give blood, we can collect a sample of your saliva instead, although this does restrict the type of tests we are able to do.

There will be no direct benefit to you from taking part in the study. However you will be helping in the fight against cancer. The results of the study will help to find the causes of pancreatic cancer so that we can try to find ways to prevent it occurring in the future.

There will be no cost to you, and if you do not want to take part, this will not affect your future medical care in any way. You can choose to withdraw from the study at any time.

All people who take part in the study will be entered into a draw to win a hamper valued at approximately $150.
If I give a blood or saliva sample, what will it be used for?

We will ask your consent to collect a small amount of blood from a vein in your arm (30ml or about 6 teaspoons). A trained research nurse will take the sample when she visits you to do your interview. Alternatively you could have the sample taken by your general practitioner or local pathology laboratory. If you are unable to give blood, we will ask you to spit into a small tube instead. We will use your blood or saliva sample to do biochemical and genetic tests (see section on ‘Genetic Research on page 9) to look for factors that may make someone more or less likely to get cancer or that affect how a cancer responds to treatment. We may also use your blood to make long-lived cell lines and will keep some of your sample indefinitely for future research studies (see the section on ‘Future Research’ page 8). For example, a number of blood tests are currently done to detect certain types of cancer and it is important to have blood samples from people with and without cancer to evaluate these tests.

We will do a blood test to look for antibodies to a bacterium commonly found in the stomach called *Helicobacter pylori*. This bacterium may increase the risk of pancreatic cancer in a small number of people who are infected, although this has not yet been proven.
How is my privacy protected?

When you complete a questionnaire or donate a sample of blood to this study we will make every effort to protect your privacy. All your questionnaires and samples will be stored securely in such a way that they cannot immediately be identified as having come from you. They will be labelled with a unique number so that they do not get confused with questionnaires or samples from someone else. Any identifying information (your full name, address etc) will be stored separately from the samples and information you provide. Access to this identifying information is restricted to a small number of senior members of the study team. We will keep your identifying information for a period of 7 years. No information that could be used to identify you or your family will be included in any report or publication.

If you consent to your interview being taped for quality control purposes:
- The tape recording will not include your name or address;
- It will only be listened to by a senior member of the research team;
- The tape will be destroyed after it has been listened to.
Can I withdraw from the study?

You may withdraw from the study at any time and this will in no way affect your medical treatment in the future. If you decide now that your blood can be kept for research, you can still change your mind later. Just contact us and let us know that you do not want us to use your sample. Any blood (or any products derived from it) that is left in the bank will then be destroyed.

Will I find out the results of research using my samples?

The results of research done with your blood are not likely to be available in the immediate future. This is because research can take a long time and must use samples from many people before the results are known. For this reason we will not be able to give you individual results from your samples.

Everyone who takes part in the study will be sent an information update to let you know in general how the study is going. You are also welcome to contact the Study Team at any time if you have any questions about the study.
Future research using your samples

After we have finished this particular study we will keep the information and remaining samples that you give us indefinitely. In the future we may match your personal data against various registers maintained by the Australian Institute of Health and Welfare and we will use your samples for future biochemical and genetic studies of cancer. We may also contact you again to ask you to take part in a follow-up study but you will be under no obligation to do so. Any extra studies that use your samples will have to be approved by the Scientific and Ethics Committees at the QIMR, UQ and the institution carrying out the study before your information and material can be used. Any information or material given to researchers will be identified by a code only so as to protect your privacy. You will not receive any notice of future uses of your information or samples.

There is a chance that information derived from the samples that you are donating under this study may, in the future, have some commercial value, for example if they lead to the development of a commercial product. You will not be compensated for your participation in the study or for any future value that the sample you have given may be found to have. However, it is our intention that if money is generated as a result of research using your samples then some will be put into a special fund to be used for cancer control in the future.
Questions about genetic research

People respond differently to things they come into contact with such as smoke, alcohol, foods and medications. We think that the reason people respond differently is partly due to their genes. Some genes may make people more or less likely to become ill when they come into contact with particular factors. We are trying to find out which genes these are, in the hope that this will lead to new treatments that act in the same way as the ‘good’ genes. We would greatly appreciate your participation in the genetic part of the study. However this decision is entirely your own and you do not have to give us any explanation if you do not want to take part.

How will you get a sample of my DNA?

DNA is the genetic molecule of life and it carries the hereditary information that underlies the physical and behavioural characteristics of all living things. DNA makes up genes, and genes are arranged into larger structures called chromosomes.

There are two common ways of obtaining a sample of DNA – either from a blood sample, or by getting some cheek cells from saliva. When your sample arrives at our laboratory, we extract DNA from it. Scientists use centrifuges and chemicals to purify the cells and to extract purified DNA from these cells. The purified DNA will then be screened to look for genes which are thought to be related to your response to particular factors.
Will I find out my genetic results?

No, you will not find out your genetic results. This is because the genetic research that we carry out is not the same as a genetic test. We will not be examining genes that are known to cause cancer. Rather we will be comparing some genes in people who have pancreatic cancer with people who don’t, and these results might help us to better understand the way our genes affect our response to other things we are exposed to. Our results will not tell us anything certain about your risk of getting cancer.

In addition, the QIMR laboratory where we perform the research is not an accredited genetic testing site. The research and tests we carry out are for purely scientific purposes and cannot be interpreted in the same way as an official genetic test.

What are the risks of genetic research?

When a blood sample is taken there is a chance that you might experience slight bleeding, minor bruising or pain. All blood samples will be taken by trained personnel who are qualified to manage any such problems.

Currently in Australia, having taken part in genetic research does not affect your ability to obtain private health or life insurance. You can lawfully answer ‘no’ to any person, or on any form, that asks if you have had a genetic test.

We will not pass on information about your participation or results to anyone, including your family, without your written permission unless we are legally obliged to do so.
What if I have more questions or a complaint?

This study has been cleared by one of the human ethics committees of the University of Queensland in accordance with the National Health and Medical Research Council’s guidelines. You are of course, free to discuss your participation in this study with project staff:

Dr. Rachel Neale  
Principal Investigator – Queensland Pancreatic Cancer Study  
Queensland Institute of Medical Research  
Ph: 3845 3598  
Email: rachel.neale@qimr.edu.au

If you would like to speak to an officer of the Queensland Institute of Medical Research not involved in the study, you may contact the Ethics Officer on 3362 0259.

If you have a complaint or would like to speak to someone else who is not involved in the study, you can also contact the following:

Australian Institute of Health and Welfare  
Executive Unit  
GPO Box 570  
Canberra ACT 2601  
Ph: (02) 6244 1123
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