



Genetic Support Network of Victoria

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Participating in Genetic Research Fact Sheet

There are some issues unique to participating in genetic research, as opposed to other types of research.

1) What is genetic research?

Genetic research involves studying an individual's DNA to gain information about health and disease. There are several different types of genetic research.

Research involving families: this type of research is often used to study common conditions, such as cancer, asthma or Alzheimer's disease. For these types of conditions, we know there are many genes involved, as well as non-genetic factors. However, for many of these complex conditions, the particular genes that are involved are unknown. By studying families who have a strong history of a particular condition, researchers can look at which gene variations family members with the condition have, compared to which gene variations family members without the condition have. This gives scientists a better idea about which genes may be involved in the disease.

Research comparing large groups of people: this is where the genes of two large groups of people are compared, typically a group of people with a condition of interest compared to a group of people who don't have the condition. Every person has many normal variations in their genes. However by doing this type of study, researchers can determine which gene variations are more common in the group of people who have the condition, compared to those who don't. These are also known as *association studies*.

2) Why is genetic research important?

Almost all diseases are influenced by our genetic make-up. While some diseases have a genetic cause, such as cystic fibrosis or thalassemia, other diseases involve the complex interplay of both genetic and non-genetic factors, such as heart disease, arthritis, or asthma. Our genes can also influence our susceptibility to infectious diseases, such as influenza or HIV. Advances in understanding human genetics have come a long way in the past decade. However, there is still a great deal of information that the scientific community has not yet been able to understand. It is important to understand more about which genes are involved in diseases, in order to develop better treatments, diagnostic tests, or even cures.

It is essential to remember that research is designed to benefit the community. The benefits of the research you participate in may not directly benefit you.

3) Will participating affect my insurance?

Health insurance: In Australia, private health insurance premiums are not based on an individual's current or past health. *Your participation in genetic research should not affect your private health insurance.*

Life insurance: In Australia, life insurance products such as cover for death and income protection are risk-related, therefore applicants are required to declare any known genetic information. Your genetic information may affect your premium, or whether you are eligible for cover at all. The current Disability Discrimination Act ensures that genetic information affects your policy only in a way that is fair. You should discuss any possible implications for insurance with the researchers conducting the specific project in which you are planning to participate. *Your participation in genetic research may affect your life insurance.*

4) What are the implications for my family members?

Genetic information is unlike other types of information in that it is both uniquely your own, as well as shared between your whole family. You may find out information about your genetics that may be useful to other family members. On the other hand, you may find out genetic information about yourself that has implications for family members who have expressed the desire not to know. It is important to keep in mind that your decision to participate in research may affect members of your immediate and extended family.

5) What if I am part of a minority group?

It is important that genetic research involves individuals from diverse ethnic backgrounds. Because genes 'flow' through a gene pool of a community, many communities share the same variations in their DNA. Studying individuals from a variety of ethnic background gives the most complete information.

Unfortunately, due to lack of community understanding and awareness about genetics, there can be negative stigma associated with some genetic conditions. If the research in which you are participating involves a minority group (including geographically isolated community, a cultural minority group, or an ethnic minority), it is important to keep in mind the potential for stigmatisation. This is something all researchers should have taken into account also when designing their research, as thoughtful consideration of these kinds of issues is required for ethics approval for the research to be conducted.

6) How is my privacy protected?

As your genetic information is both uniquely your own and also has implications for others, it is important to understand how your information will be kept confidential. Where a participant has given informed consent, the Australian Government Privacy Act allows participant information to be disclosed to relevant people. For example, a genetic researcher could share your information with your GP only if you have given permission for this to happen.

Your genetic information cannot lawfully be shared with another person without your permission. It is important to carefully read the research consent form to see how your information will be protected.

7) What if there are unexpected findings?

When participating in genetic research, the laboratory testing your sample may come across something they weren't looking for. For example, they may want to see what gene A looks like, but notice a change in the neighbouring gene B. This information may be important for your health, for example the change increases your chance of developing a particular condition, perhaps when the condition could be prevented.

Another circumstance that may arise is the laboratory is looking for changes to gene A, and they find a type of change in your gene A about which they are unsure of the significance. This can happen because with 25,000 genes, and many variations that can occur in each, the scientific community cannot yet predict the impact of every change. Some changes to certain genes may increase your chance of developing a disease. There are also some types of changes in those genes that do not affect your chance of developing a disease. And there are some changes for which the effect on your health is not known yet. Research sometimes finds things like this and it can be difficult for the researchers to know what to do with that information.

It is important that you think about what kind of information you would want to know, and what kind of information you wouldn't want to know. Sometimes these kinds of things will be asked in the consent form. If not, you have a right to speak to the researchers about the potential for these sorts of situations.

You may wish to discuss the following with the researchers:

- Will I be told my test result? How will I be told and who will tell me?
- Will I be told about any incidental findings?
- Will I have access to genetic counselling afterwards?
- How will my family members be affected by my test result?
- What will a positive result mean?
- What will a negative result mean?
- How accurate is the testing?
- Will my genetic information be stored? How will it be stored and who will have access to it?

Written by Amy Schneider and Emily Higgs, Master of Genetic Counselling students, reviewed by Dr Jan Hodgson, Research Coordinator and Senior Lecturer, University of Melbourne and Murdoch Childrens Research Institute.

Sources:

<http://www.geneticsawareness.org/geneticresearch>

<http://www.nhmrc.gov.au/your-health/egenetics/ethics-and-legal-issues/genetic-discrimination>

<http://www.privacy.gov.au/law/act/genetic>