

GENOMIC TESTING

About this information sheet

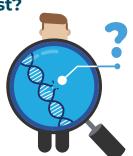
This information aims to help you decide whether to have a genomic test. Your healthcare provider will discuss this information with you, and may ask you to sign a consent form before having the test.

An <u>animated video</u> is also available.



What is a genomic test?

Genes are like instructions telling the body how to function, grow and develop. Some people may have missing information or changes to their genes which can affect how their body works.



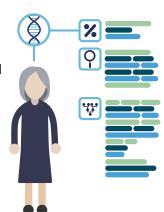
Sometimes doctors need to look at one, a few or many of these genes in what we call a genomic test. The exact type of test will depend on the reason for testing and the gene/s that they are looking at.

Why a Genomic test?

There are many different reasons why your doctor may recommend that you consider a genomic test.

It may be:

- ► To find out what is causing your or your child's / relative's condition.
- ► To help families understand a condition, access support, and plan for the future.
- ► To let families know how likely it is that they will develop a disease, or have a child with or develop a health condition.
- ► To help find the best treatment, screening or therapy for you or your child.



How is a Genomic test done?

It's your choice to have a Genomic test.

If you do, your healthcare provider will discuss the type of test with you.



A sample will be collected from you for testing. This sample can be blood, saliva, hair or tissue.

Your sample is then sent to a laboratory to find out about your genes. They will send this information back to your doctor.

Your healthcare provider will explain your results to you.

What are the possible results of a Genomic test?

The test results might be useful for your or your child's / relative's care.

The test results may not be useful if, for example, nothing is found to explain your symptoms, or if we don't yet understand what the results mean. These results are called 'uncertain findings' and they may become useful when more is known in the future. This may mean you need to have further testing or your genetic information looked at again in the future. This may include testing of your genetic relatives.

There are some instances, the test may show additional findings not related to the reason for testing, called an **incidental or secondary finding**. Your health professional will discuss this with you if this is found.

How is my genomic information protected?

Your results and genomic information from the test will be stored securely using systems that meet Australian and international privacy and security standards and laboratory guidelines.

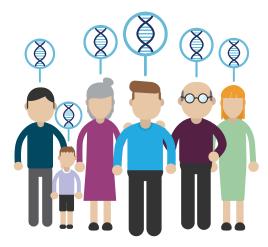


Your genomic information is confidential and will only be shared with your consent, unless required or permitted by law.

Further information on how your information is kept private and secure can be sought from your healthcare provider.

Can my genomic information help others?

Because you share a lot of your genetic information with your relatives, results of one family member can also be important for keeping other family members healthy.



If your information is shared to help with the care of other **family members**, your identity will be protected.

You may also be contacted in the future to ask if you want to participate in ethically approved **research** into a same or related condition. You may decline any such request.

What else do I need to know?

To help you decide whether to have this test, it is important that you are given information specific to your test, and have the opportunity to have all of your questions answered in detail by your healthcare provider.

Some questions you may wish to ask include:

