INFORMATION SHEET

GENOMIC TESTING

ABOUT THIS INFORMATION SHEET

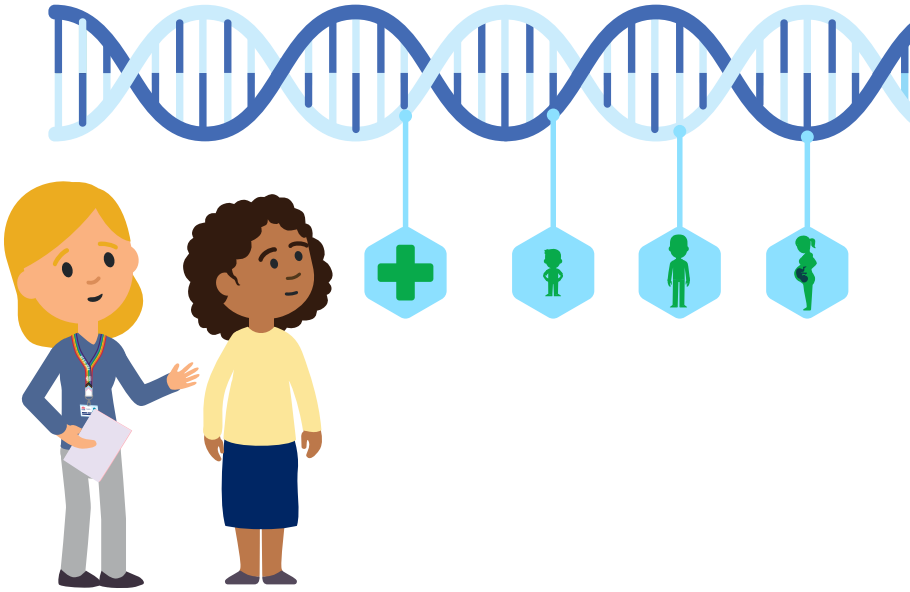
This information sheet will help you make an informed decision about genomic testing. This means giving you the information and time you need to help you make a choice that is right for you. NSW Health are here to help you make an informed decision about genomic testing. If you have any questions, or need more information or support, talk to your healthcare provider.

WHAT IS GENOMIC TESTING?

Genes are like your body's instruction manual, and a huge part of what makes you, you. Genomic information can be used to help find answers to many health conditions relating to children, adults, and even pregnancies.

Your genes are made up of your DNA code. This is what a genomic test will look at. Your DNA is important for how your body is made, and how your body functions. Genomic testing looks for any variations which could have an impact on your health, or the health of your current or future children.

The information from your genomic test can help you and your healthcare providers make more informed decisions about your healthcare.



WHY HAVE A GENOMIC TEST?

Some reasons to think about having a genomic test include:

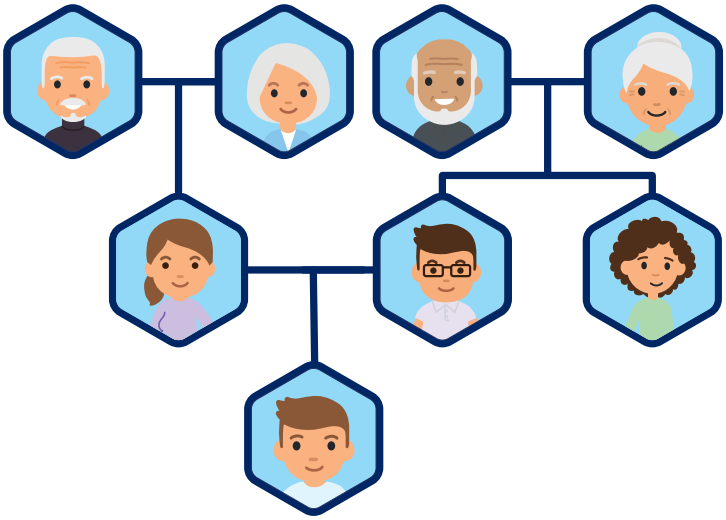
- Finding a genetic diagnosis for you or your child's condition.
- Helping families understand a condition and access the support they need.
- Understanding if there is a health condition that runs in the family that may start in adulthood.
- Guiding the best treatment or support options for a condition.
- Providing families, people who are pregnant or planning a pregnancy, information about genetic conditions.

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.

To do a genomic test, a sample of your saliva or blood is usually taken, sometimes other types of samples are taken. The sample is then sent to a laboratory for testing, and the results are given back to you at a face-to-face appointment, or in a video or phone call appointment.

WHAT ARE THE POSSIBLE RESULTS OF A GENOMIC TEST?



Your healthcare provider may find:

- A genetic mutation, or variant, that explains the condition, or is important for understanding the chance of a condition.
- A variant in your genes we are not sure about. This is called a Variant of Uncertain Significance. This is a common result and might mean something or not. We just cannot say if the variant is the cause of the disease we are looking into. We all have gene variants in our DNA, and not all variants cause disease. We may ask to test other members of your family as this can help us understand your own results further.
- A gene variant not connected to the reason for the test. These types of variants are called incidental or secondary findings. For example, we might find a genetic variant that increases the risk of developing a future condition.
- Rarely results may show unexpected family relationships. They do not occur commonly. Some people ask their clinician not to report this information back to them.

Our understanding of your genomic test findings may improve as we learn more about DNA. We may come back to you in the future to ask if you want your sample re-tested as technology improves.

SHARED **SECURELY** AND **CONFIDENTIALLY**

HOW IS MY GENOMIC INFORMATION PROTECTED?

All genomic testing results are stored securely, meeting the highest NSW and Australian privacy and security standards.

Your results are kept private and will only be shared with your consent, unless there is a rare situation where it is required by law that we share your results.

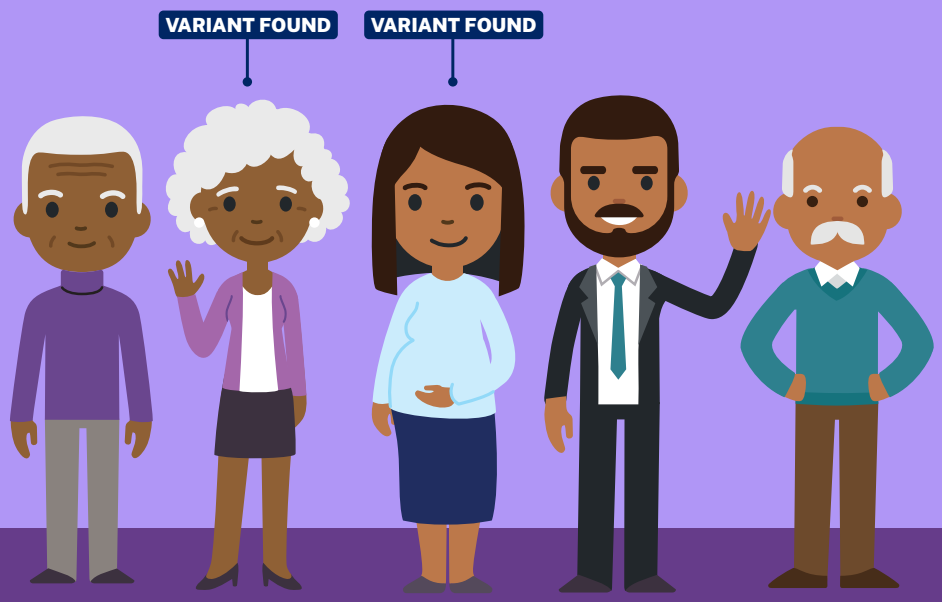
Your healthcare provider may also ask if you are ok that your results are shared with another healthcare provider. For example, to help them provide you or a family member with the best possible care. In these instances, your results will be shared securely and confidentially.

For more information about how we protect confidentiality, refer to the **NSW Health Privacy Leaflet for Patients**

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 results could help other family members, we may suggest that your relatives are given the choice of genomic testing.



WHAT ELSE DO I NEED TO KNOW?

In Australia, genomic testing will not change your ability to obtain health insurance or affect your health insurance premiums.

If you're unsure about how a genomic test result might impact your eligibility for other types of insurance, talk to your healthcare provider.

We need your informed consent before genomic testing can start. Your healthcare provider will ask you to complete a consent form. It is important you understand each point and show this by signing the form.

Remember, it is your choice whether to have a **genomic test** or not.

So if you have any questions, or need more information or support, **make sure to ask your healthcare provider**

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