

Understanding public and private genetic testing for cancer risk

Frequently asked questions



What is genetic testing for cancer risk?

Certain gene faults (also called mutations or variants) increase the risk of cancer in families.

Genetic testing uses a sample of blood (or saliva) to check for faults in one or more genes based on the type of cancer in your family. This may include one or many (20+) genes as part of a gene panel test.

What types of genes can be tested?

- High risk genes – faults in these cause a high risk of certain cancer types
- Moderate risk genes – faults in these genes are common. They cause a small - medium increase in cancer risk
- Genes with uncertain risk - some tests include new genes where not much is known about the cancer risks. If you have a fault in one of these genes, it may be unclear how to manage your cancer risk.

Why doesn't everyone have genetic testing for cancer risk?

Less than 5% of cancers are due to high risk gene faults. For a person without a strong family history, genetic testing is unlikely to clarify their risk of cancer.

High risk gene faults are not common and can be costly to test. Because of this, public genetics services are only able to test the people who are most at risk. This may change in the future as technology improves, costs reduce and testing guidelines change.

What can I do to be proactive about my cancer risk?

- Talk to your relatives and document your family history
- Discuss your family history with your GP or family cancer clinic.
 - Explore whether your family may be eligible for genetic testing
 - Whether you have genetic testing or not, you may need screening tests earlier or more often than the average person
- Maintain a healthy diet and lifestyle - this can prevent one third of all cancers.

When is cancer genetic testing available in public hospitals?

In Australia, public genetics services offer cancer genetic testing if there is a significant chance of finding a fault (usually over 10%). This is based on the number of people in the family with cancer, age, and cancer type. Testing usually begins with a blood sample from someone who has had cancer. If a gene fault is found, relatives can have testing for the family gene fault free of charge (called predictive testing).

I am willing to pay for genetic testing. Are there any tests available for me?

If you or your family are not eligible for public genetic testing, there are private services that offer testing. The cost is around \$400 - \$1000 with no Medicare or insurance rebates.

What are the possible results from genetic testing?

Gene fault found - Your cancer risk will depend on which gene is involved. You will be given advice about cancer screening and/or prevention and what this means for your family.

No gene fault found - Testing cannot rule out a gene fault unless the cause of cancer in your family is already known. Your risk of cancer may still be increased based on your family history.

Uncertain or unexpected findings - Everyone has variations in their genes and some variants in cancer genes are hard to interpret.

It may be unclear if your cancer risk is increased, or the cancer risk for the gene that is tested may not be known.

The more genes tested, the higher the chance of an uncertain result.

What are the limitations of genetic testing for cancer risk?

Current tests cannot detect all gene faults that increase cancer risk. This means genetic testing is usually only useful if a gene fault is found in you or your relative.

The testing options, price and interpretation are changing rapidly. Because of this, testing in the future may give better risk estimates for you and your family.

Can my GP order genetic testing?

Because there are many test options and possible results GP's do not usually order cancer genetic testing.

Your GP can refer you to a local genetics service or family cancer clinic if you have a strong family history of cancer.

Alternatively, a private genetics practice can provide private testing.

What should I ask my doctor before having a genetic test?

- What is my cancer risk based on my family history?
- What is my chance of carrying a high risk gene fault?
- What genes can be tested and what types of cancer do they cause?
- How and when will I receive my results?
- How and where is my sample tested and what happens to it after the test?

Other considerations

- What do my relatives think about genetic testing?
 - How might testing impact my ability or my relatives' ability to get life insurance?
 - Am I prepared to receive an unexpected or uncertain result?
 - Are there some cancer risks that I would not want to know about?
- 

Key points

- Cancer genetic testing is most useful for people with a strong family history of cancer
- There are many test options and possible results from genetic testing
- It is not possible to test for all genes associated with cancer
- The pros and cons of genetic testing should be discussed with a genetics specialist.

Where can I get more information?

Centre for Genetics Education NSW Health

For further information or to find a family cancer clinic visit

www.genetics.edu.au

(02) 9462 9599

Cancer Australia

<https://canceraustralia.gov.au>

National Health and Medical Research Council

<https://www.nhmrc.gov.au/health-topics/genetics-and-genomics>

This information is not a substitute for professional medical advice. Always consult a qualified health professional for personal advice about genetic risk assessment, diagnosis and treatment. Knowledge and research into genetics and genetic conditions can change rapidly. While this information was considered current at the time of publication, knowledge and understanding may have changed since.