

Online DNA testing



Online DNA tests (also known as personal genomic tests or direct-to-consumer tests) offer people information about their genetic make-up.

Around 3000 Australians told Genioz researchers their views about online DNA testing through focus groups, surveys and workshops. In our workshops, Australians told us that the most important things to consider when ordering an online DNA test are:

- ✓ The **accuracy of the test results**; and
- ✓ **Who could have access** to their genetic information.

Other things that Australians thought were important include:

- ✓ **Whether the laboratory meets standards**;
- ✓ The **type of test** (which parts and how much of the DNA is actually tested and the type of analysis that will be done); and
- ✓ **How the results are returned**.

Making sense of online DNA testing: Key Points

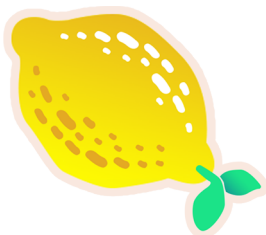


There are different types of DNA tests

- ✓ Not all tests read and analyse the same parts of your DNA.
- ✓ A DNA test is not a general health checkup. It cannot tell you everything about your health and may not be able to tell you about a specific disease or condition.

Different companies can come up with different results from the same DNA.

- ✓ Your DNA results are based on how the company makes sense of differences between your DNA and DNA from other people.
- ✓ Companies often use different evidence and approaches to understand your DNA information.



The marketing approaches for these tests vary.

- ✓ Advertising for online DNA tests can be very emotive.
- ✓ Some of the claims made by these companies overestimate the actions you can take based on the results.

These resources were developed as part of the Genomics: National Insights of Australians (Genioz) Study by researchers investigating the Australian public's expectations of personal genomics.

It can be difficult to find answers to your questions on company websites.

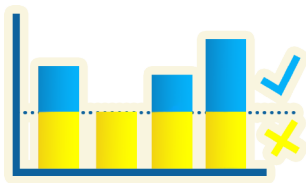


Some laboratories are in Australia, but many are located in other countries, which may have different legal regulations.

- ✓ Online access to testing laboratories all over the world makes this area hard to regulate.

Some of the DNA tests you can buy are not supported by strong scientific evidence.

- ✓ Scientists and doctors don't know everything about DNA.
- ✓ Scientific evidence that links DNA variations with different traits or diseases is not complete and can change rapidly.



There are quality standards for conducting DNA tests in Australia.

- ✓ Not all online DNA testing companies and laboratories meet these standards.
- ✓ It may be difficult to work out whether a DNA testing lab meets national or international standards.

Your doctor or other health professionals may find it hard to help you make sense of your results.

- ✓ There are online forums and other ways to seek information, but these may not be reliable.



Your results from a DNA test, and the testing company's terms and conditions, may have a bearing on your family members.

- ✓ DNA is shared between family members.
- ✓ Your DNA results may identify conditions or characteristics that can also affect other family members. If you agree that your DNA information can be used or sold, you are also indirectly sharing or selling your family's data.

Making sense of online DNA testing: Possible Implications



Depending on what you agree to, your data may be sold to other companies or shared for research.

- ✓ Companies have different terms and conditions that outline what they can or will do with your DNA data.
- ✓ If you agree to share your DNA data, it may improve the overall accuracy of tests or contribute to research.
- ✓ Some companies make money by selling cheap DNA tests so that they can use or sell their customers' data.

Your DNA results may affect your ability to obtain insurance that is 'risk-rated', such as life insurance.

- ✓ If your insurance provider asks, you may need to disclose that you have had a DNA test and any findings from it.
- ✓ In Australia, your health insurance premiums will not be affected because your premium is 'community-rated' and is unaffected by individual DNA test results.



Your DNA results may change the way you think about yourself or others.

Are you thinking about taking a DNA test online?

Here are our TOP10 things to consider:

1. Why do you want the test?
2. Will it give you the information you seek?
3. What would you do with the results?
4. Who are you willing to share this information with?
5. Who will you go to for more information (if you need it)?
6. Have you talked to your family about taking the test?
7. How would you cope with an unexpected result?
8. How will you feel if the test doesn't tell you anything new?
9. How will you choose a testing provider?
10. Are you comfortable with the test's terms and conditions?
(If not, do other people or companies offer the test?)



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