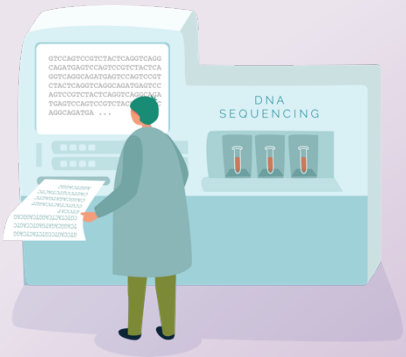
Why share your genomic information?

Australian Genomics



When you have a genomic test, it reads the billions of chemical letters that make up your genetic instructions. This generates **a lot of data**.

When your test is completed, your doctor will discuss the results with you. Your genomic data is then stored **securely** in a database. Because your genomic data is unique to you, it is personal information and is protected by **Australian privacy laws**.

Data sharing is where some or all of your genomic information is shared with other doctors or researchers. There are two types of data sharing:

1. **Anonymous data sharing** allows your genomic data to be shared with the personal information (such as your name and address) removed. This data sharing helps to advance scientific knowledge. For example, sharing gene variant information to help improve our understanding of genomics by comparing your results to those of other people.
2. Data can also be shared with researchers that are **looking into your condition or a related condition**. It is your choice whether your data is shared of this type of research. You will be asked to make your choice about sharing your data when you discuss the genomic test with your doctor. The following information in this fact sheet explains this type of sharing.

Why are you asked to share your genomic data?

Sharing genomic data can help doctors better understand the differences between people's genomes (called **variants**):

1. By comparing genomic information from lots of people, like you, doctors can work out **which variants are found in the general community**. By knowing a lot about common variants, it is easier for doctors to find out which variants are unusual and may be linked with a genetic condition.
2. Studying genomic variant data increases our knowledge of what these changes do to a person, and how. If doctors have a greater **understanding about what the variant does**, it helps them to interpret the genomic data, and help you, and other patients.
3. If you are found to have a rare variant, doctors may need to share data internationally to **find other people with the same variant**. By studying the data of people with the same variant, doctors can gather more evidence about a variant – and build a stronger case about what this variant means for you, and your condition.
4. Genomic information is very complex and scientists and doctors are still learning about **how genetic variants affect health and disease**. Data sharing helps drive scientific knowledge – which will ultimately improve the quality of care you and others receive.

For more information, visit *genomicsinfo.org.au*

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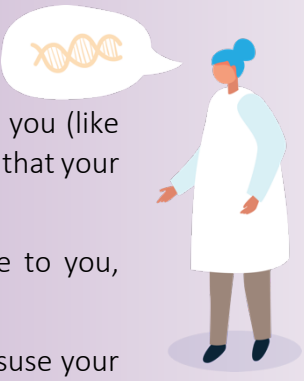
Data sharing is important – to help scientists and doctors, to help you, and to help others.



But what might be the risks in sharing your data?

Your genomic data is stored in a **secure database**. The information that could identify you (like your name, address, date of birth) is never placed in this database, to reduce the chance that your identity is linked to your genomic data.

However, there is a very small risk that because your genetic information is unique to you, someone could trace it back to you.

It is possible that someone with access to your genomic data could identify you, or misuse your data. The systems that hold your genomic data could also be subject to cyber-attack.

So, how do we manage and minimise these risks?

Australia's strong privacy laws protect your personal information. All researchers and medical professionals have a duty to protect your privacy by keeping your information confidential and safe. The penalties for breaching your privacy are severe (for more information, click here (oaic.gov.au/privacy-law/privacy-act)).

Access to your data is limited to specific health professionals involved in your care. If a scientist wants to look at genomic data in a database they must submit their research proposal for review by a Human Research Ethics Committee. These Committees ensure that the researcher has appropriate qualifications, that they adhere to research standards and the research being done is ethical, legal and being conducted with respect for you and your choices.

Medical and research regulations ensure that the databases containing your genomic information are secure and use up-to-date software systems and firewalls to minimise the risk of cyber-attacks.

Remember, scientists and doctors study genomic data to find changes or patterns that may help understand the cause of a disease. **They are not looking at the data to identify you.**

By sharing your data, you are helping doctors find answers for you, and for other people. Though we might not find all the answers now, we are confident we will find more answers in the future.

Genomics provides doctors with **new opportunities to understand the causes of your condition**, and how to manage it. However, this opportunity comes with the responsibility to ensure everything is done to protect your privacy.

Responsible, secure and ethical data sharing is essential to help you, and to help others.

Most importantly: the decision to share genomic data is yours.