



**GeneEQUAL: New South Wales Genomic  
Health Care Inclusive of People with  
Intellectual Disability.  
Easy Read Report.**

**GeneEQUAL** is a research project to help people with **intellectual disability** get better health care.



Picture prepared by Russell Wheatley, Self-Advocacy Sydney

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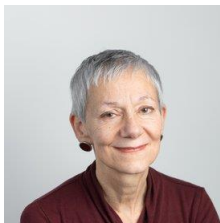
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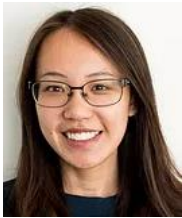


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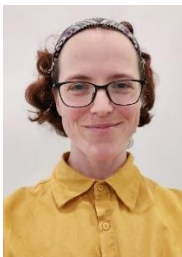


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### **The full name of this report**

Strnadová, I., Scully, J.L., Loblinzk, J., Boyle, J., Danker, J., Tso, M., Dunn, M., Classen, S.A., & Palmer, E.E., (2022). *GeneEQUAL: New South Wales Genomic Health Care Inclusive of People with Intellectual Disability. Easy Read Report.* UNSW Sydney.

### **Copyright and disclaimer**

Copyright in this report and all the information it contains vests in the NSW Ministry of Health, Australia.

## Funding



The GeneEQUAL study was paid for by the NSW Ministry of Health

## Words we use in this report



People use different words

- when they talk about disability



Some people like to use **people-first language**

That means that

- a person comes first
- and disability second

For example, a person with intellectual disability.



In this report we use **people-first language**

This is very common in Australia

Other people like **identity-first language**

That means that they

- put their disability first

For example an autistic person





In this report we say **genomic** health care

Genomic is a new word



Sometimes people say **genetic** instead or genomic

Both genetic and genomic mean to do with our **genetic instructions**

They are really the same thing

You can read more about all these words



- in our **list of hard words**
- it is at the end of this report



The list of hard words is also on our website [www.GeneEQUAL.com](http://www.GeneEQUAL.com)

## What is GeneEQUAL project about?



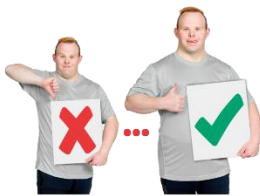
This is the Easy Read Report from the GeneEQUAL study



This is a summary with

- results
- **recommendations**

from a longer report



Recommendations means

- saying what needs to change



GeneEQUAL wants to make **genomic health care** better

We talked to people with intellectual disability



We asked them about genomic health care

- what works well
- what can be better



We asked them what needs to change

Then we wrote this report





## Genomic health care is

talking about why people have a

- health condition
- learning difficulty



Genetic tests may find out

- if their children could have the same condition



Genomic health care helps people

- decide if they want a **genomic test**
- understand more about their conditions
- get the right health checks
- get support
- make plans about having a family
- make decisions about research



A genomic test is a

- blood test
- spit test



to find out if a person has a genetic condition



We talked to people who

- have learning and intellectual disability
- live in NSW
- had a genetic test or talked to a genomic health care team



We talked to

- 19 people with learning and intellectual disability
- 9 support people, like parents, grandparents, and partners



We talked about what we found out

- in a focus group
- with people with intellectual disability



We also had 3 online **advisory workshops** with

- organisations of people with intellectual disability
- health care workers
- people from support groups for people with genetic or rare conditions
- people working for the NSW Ministry of Health
- people doing genomics or rare disease research

## What people told us

# 1



### The first thing we found

Access to genomic health care is not equal



People with intellectual disability

- often do not know about genomic health care
- do not know why it may help them



Other people decide

- when people with intellectual disability go to genomic health teams
- other people decide



These people are

- parents
- family members
- doctors



People talked about what is good about genomic testing, such as

- getting better support

- helping them plan families



When people saw genomic health care teams, they often **did not**

- feel included
- have choices about genomic tests

They often do not have **informed consent**



This can make them feel

- unimportant
- sad

Informed consent means understanding

- what a genomic test is
- what it can find out
- how it can help
- any risks of the test



Informed consent helps you decide

- if you want a genomic test

# 2



## The second thing we found

People have different experiences with genomic health care

Some people felt

- cared for
- supported

Some people said that health care workers do not

- explain things well
- stop and listen
- talk slowly
- check understanding
- use pictures
- use easy read
- give people choices
- use language that makes people feel respected



Richard told us that health care staff

- do not treat you like a person
- they treat you like an 'it'



Not everyone gets good genomic health care



People were not happy with

- high costs
- long wait times
- long distances to travel
- difficulty getting referrals from their GP
- poor communication
- not enough support and information
- blood tests

# 3



## The third thing we found

People need support after a genomic test

Sometimes getting the results of a genomics test

- is confusing
- takes a long time
- does not give people an answer



Genetic condition names can be

- a mix of letters and numbers
- upsetting for many people
- hard to remember



People felt many emotions after a genomic diagnosis

- shocked
- sad
- depressed
- relief
- okay
- guilty
- angry





After a genomic diagnosis

People do not know how to get

- the right health checks
- support from the NDIS
- psychological supports and counselling



Many people want special support from a

- psychologist
- support group



People want to meet other people with the same condition



Doctors often do not ask them if they want

- support
- to meet other people with the same condition



This means it can be hard to

- get support
- meet people with the same condition





Not enough support makes people feel

- alone
- scared
- confused

# 4

## The fourth thing we found

Health care workers need to know more about

- the life experiences of people with intellectual disability

So they can give great genomic health care

Many people with intellectual disability experience

- bullying
- sexual abuse
- physical abuse
- abuse about money



Seeing a new health service team can be scary



People with intellectual disability

- have heard bad things about themselves over their life



This can mean some people start to believe the bad things

This is wrong

What people say has a BIG IMPACT

Words matter



Genomic health teams can use words that

- make people feel sad

Here are some of these words

- problem
- missing
- disorder
- faulty
- not normal





Genomics health care teams often talk about

- pregnancy
- planning families



People have different thoughts about having children

- many love being parents
- others want to be parents
- some are not sure
- others do not want to be parents



Deciding to have a family or not is

- an important personal choice!



Self-advocacy matters!

When people can self-advocate

- they can speak up for themselves!



Others can also advocate

It can help to

- take a support person to health care appointments

# 5

## The fifth thing we found

People with intellectual disability recommend making genomic health care



- respectful
- accessible
- inclusive



People asked for information about genomics terms

- in different ways like Easy Read and videos



People want genomics health care workers to get

- training
- support



Health care professionals need to

- learn how to communicate better



In a way that is

- respectful
- accessible
- inclusive



People want choices about their genetics appointments

- face-to-face
- telehealth
- who comes with them
- what is talked about



People want to choose if they have a

- blood test
- spit test



## What do we recommend?

# 1



### Recommendation number 1

Together

- people with intellectual disability
- health experts
- education experts



Need to make

- Easy Read information
- videos
- websites



That explain all about genomic health care

- what it is
- how it can help people
- what are the risks
- what are the costs

# 2

## Recommendation number 2

There are consent forms

The forms say



- what a genomic test is
- what a test can find out
- how a test can be helpful
- any risks of the test



The consent forms are not accessible

They are not in Easy Read

We recommend making Easy Read information

- to help explain the consent forms



This will help people choose

- they want a genomic test
- or not

Choice is important!

# 3

## Recommendation 3



Health care workers need more teaching about

- good genomic health care
- how to communicate with respect



Health care workers need to know how to make people feel

- safe
- respected
- included



Health care workers need teaching about how to

- give choices to people with intellectual disability
- help people get ready for genomic testing
- support people after a genomic test

# 4

## Recommendation 4



We need a guide on how to

- give good genomic health care

The guide needs to tell health workers how to



- do good genomic health care
- use Easy Read information
- check people feel safe
- check people understand
- check if people have questions
- check if people need more support



The guide will say how health care workers

- must give people choices
- must treat people with respect



The guide will tell health care workers that

- they need to choose the right words



Health care workers need to

- use positive and helpful words

They must not use words that make people feel



- less
- sad
- treated like a child



Health care workers must be

- partners with their patients

# 5

## Recommendation 5

### Easy Read **Communications Folders**

- about genomic conditions

need to be made



A communications folder helps people know

- more about their genetic condition
- what health checks are needed
- what support groups there are
- how to get NDIS funding
- how to get support and better care



This can help share important information with

- health care workers
- families
- therapists
- NDIS workers
- schools
- workplaces





## What do you think?

We want to hear from you

If you have anything you want to say

- about our report



Have we missed anything?

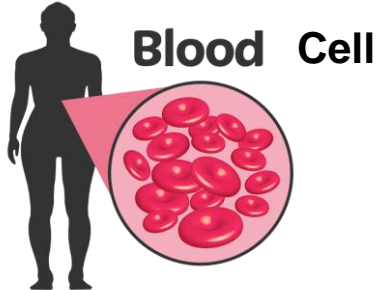


You can email the GeneEQUAL team at

- [geneequal@gmail.com](mailto:geneequal@gmail.com)

# List of Hard Words

## Cells



### Blood Cell

- Our bodies are made up of tiny cells
- Cells in blood and spit are used in genetic testing



- **Cells** are so tiny
- We need a microscope to see cells



## Genes

- Are little 'instructions' inside our cells
- We have many genes

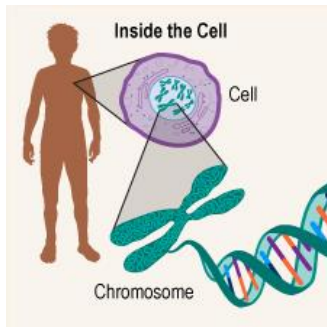


## Genes carry instructions important for

- how healthy you are
- how you learn
- what you look like:
  - ✓ curly or straight hair



- ✓ long or short legs



## Chromosomes

- Your genes are carried on **chromosomes**
- People have 23 pairs of chromosomes.



Our **genes** are passed down from:

- ✓ our mum
- ✓ our dad



Changes in genes can cause

- intellectual disability
- health conditions like walking problems

A **genetic condition** is

- a health or
- learning condition
- caused by a gene change





Many people with intellectual disability have

- a genetic condition



A **syndrome** is when a person has

- a health problem and
- intellectual disability
- together



**Genomic health care** is health care for people who

- know they have a genetic condition
- are not sure if they have a genetic condition
- want to know more about genetics



A **genetic test** is done on

- blood or
- spit

It can help find out if a person has a genetic condition



## Genetic counselling means

Talking about

- why people have health or learning difficulty
- if their children could have the same condition



Helping people:

- decide if they want a test
- understand more about their conditions



Research means

- finding out what people think about things
- using that information to help others



Findings

- what researchers found out by talking to people



**Co-production** means the research that

- academic researchers
- people with disability

do together



**Easy Read** is

- easy to read
- easy to understand
- uses pictures with words to explain things

This list was written by the GeneEQUAL team.

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