

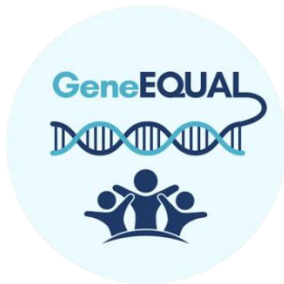
## Easy Read Version

### Genetic health care

- **what people with intellectual disability think about it**



This report was written by the GeneEQUAL team



- people with intellectual disability
- researchers
- health care workers
- teachers of students with disability



People with intellectual disability are not asked

- about their experience with genetic health care

Their ideas are not included in



- medical journals
- planning better health care



The GeneEQUAL team want to change this

That is why we asked

- 18 adults with intellectual disability
- 8 support people



about their experience with genetic health care

They told us what was



- good and not good
- how to make genetic health care better



We shared what people told us with

- a group of people with intellectual disability from Self Advocacy Sydney
- health care workers and experts in disability





These are the things we found



People with intellectual disability

- do not have equal access to genetic health care
- are often not supported to make their own choices



Some people with intellectual disability

- had good genetic health care



Many people with intellectual disability

- had bad experiences with genetic health care

Some people felt



- scared
- not included
- rushed

Some people



- were not supported to make decisions

After getting genetic test results some people felt



- angry
- sad
- not supported

They said they want



- counselling
- peer support
- information on their condition



Many people with intellectual disability have

- bad things happen to them in their life

They often experience



- bullying
- sexual abuse
- physical abuse
- financial abuse

Genetic appointments can

- be another bad experience



feel scary

Words used in genetics can make people feel



- sad
- bad about themselves

like they have something wrong with them

Some people talked about the importance of



- speaking up for yourself
- knowing your rights

They also said it was important to



- be able to choose a support person
- if you want one

People also talked about family planning



- some people want to have children
- others decided not to have children
- some were stopped from having children by their family



To know if their baby has same genetic condition

- some people want genetic testing
- others do not want genetic testing

People told us



- how to make genetic health care better

We need to teach health care workers to



- explain things clearly
- stop and listen

talk slowly

Health care workers should use



- pictures
- Easy Read
- videos



Health care workers should

- give people choices
- support people to make their own decisions
- show respect
- offer longer appointments

People also suggested we should make



- Easy Read information and video resources
- to help people understand genetics
- so they can make their own choices

These should be made in **co-production**

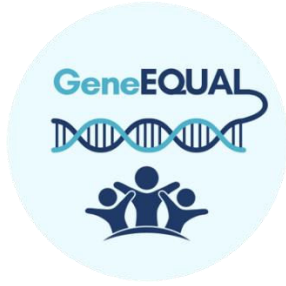


**Co-production** means

- people with intellectual disability and health care workers
- make the resources together



## More information



The GeneEQUAL team made this booklet



It was made with Photosymbols

This booklet is

- an Easy Read summary

about some of our research



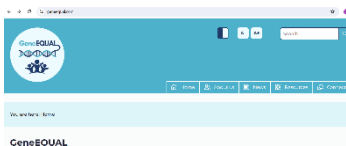
The full article is called

**“I am not a number!” Opinions and preferences of people with intellectual disability about genetic healthcare.**



The GeneEQUAL website has

- the full article





We made GeneEQUAL Toolkit to give health care workers

- tips and
- Easy Read booklets
- Videos



The GeneEQUAL toolkit wants to help people get

- inclusive
- person-centered
- and respectful genetic health care



Go to  
[www.geneequal.com](http://www.geneequal.com)  
or scan the QR code

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