

# The GeneEQUAL Toolkit

## Easy Read Final Report

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This booklet is about the GeneEQUAL Toolkit and



- what people with intellectual disability
- health care workers think about it



This booklet is also about what people say

- GeneEQUAL should work on next

## What is GeneEQUAL?

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Our GeneEQUAL team are



- self-advocates
- researchers
- health care workers
- teachers



You can read more about GeneEQUAL

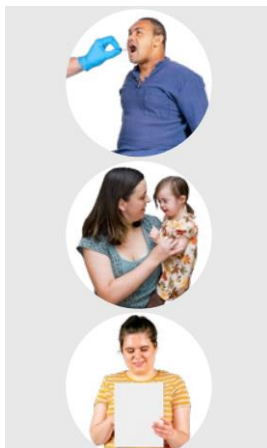
- on our website
- <https://geneequal.com/>

GeneEQUAL team talked to



- people with intellectual disability
- health care workers

about genetic health care



**Genetic health care** is for people who

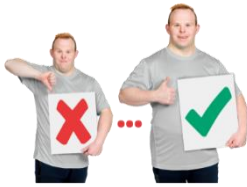
- have a **genetic condition**
- might have a genetic condition
- want to know more about genetic conditions and tests



## A genetic condition can mean

- our health is different
- we learn in a different way to others

## GeneEQUAL asked people



- what is good
- what is bad

## about genetic health care



## People with intellectual disability told us

- what needs to be better about genetic health care



## We wrote these recommendations

- in a report for NSW Health



## You can read the report on our website

<https://geneequal.com/genetic-resources/report-of-the-geneequal-study/>



## These are the top 3 GeneEQUAL recommendations

### Recommendation number 1

People with intellectual disability and researchers need to make together



- videos
- Easy Read information
- websites



### Recommendation number 2

People need information to help make choices

- about genetic test and health care



The information can help people know

- what a genetic test is
- how a test can be helpful
- any risks of the test

### Recommendation 3



Health care workers need more teaching

Teaching needs to be about how to



- do good genetic health care
- talk to people with intellectual disability 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 genetic testing
- support people after a genetic test



## NSW Health



- listened to our recommendations
- gave us money to make the GeneEQUAL Toolkit together

## We made the GeneEQUAL Toolkit to help

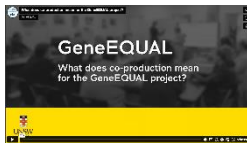


- health care workers give good genetic health care

## The Toolkit has



- information
- videos
- Easy Read booklets



for health care workers



The Toolkit was **co-produced**

This means that it was made together by

- people with intellectual disability
- health care workers
- the GeneEQUAL team



We had 4 co-production workshops



- 3 at Self Advocacy Sydney
- 1 at Wagga Wagga

## What do people with intellectual disability think about the Toolkit?



People liked the Toolkit videos

They said the first video



- was similar to their experience
- showed how health care can be bad



They said the second video

- showed what 'good' health care can be
- helps them speak up for better health care.



People liked the Easy Read booklets because

- the language was simple
- there were pictures
- it was clear



People liked the information about

- how to make a complaint

when health care is bad



People think the Toolkit will help many people

They said it would help

- people with intellectual disability
- family members
- support people
- health care workers







It helps people with intellectual disability

- know how to get health care
- make complaints
- feel empowered



It helps support people and family members

- understand
- get better health care for

the person with intellectual disability



People said the Toolkit should be

- taught to all health care workers

to make health care better



People said the Toolkit would help

- GPs
- nurses
- specialists such as mental health doctors
- training nurses and doctors





People had ideas for more things

People wanted booklets and videos about

- medications
- referrals
- how to speak up



People said the Toolkit should be

- in every doctor's office
- written in other languages



People also liked the **co-production** we did because

- they learn about their health
- it helps them access health care
- we work together to make things better
- all of us are important



People said co-production could be better if

- we give more information in Easy Read about where they can get support



Lots of people said they want to

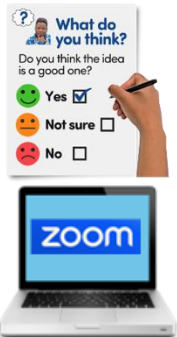
- keep working together
- join more co-production workshops with GeneEQUAL

## What do health care workers think about the Toolkit?



We asked what health care workers think about

- the Toolkit and how to make the Toolkit better



We asked health care workers to

- do a survey online and/or speak to us on Zoom

to tell us what they thought



We counted how many people

- looked at the information
- looked at the Easy Read booklets
- watched the videos



## What we found in the survey?



69 health care workers took part in the survey



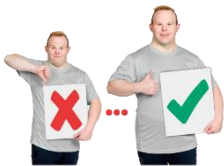
Health care workers looked at the

- information online
- the videos
- the Easy Read booklets



They said they wanted to use the

- information in the Toolkit and Easy Read booklets



to make health care better



The Toolkit helped health care workers

- feel more confident to give good health care

## What we found when we counted how many people looked at the website?



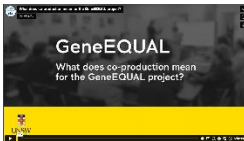
Over 2,700 people looked at the GeneEQUAL Toolkit



These people were from 43 countries



The Easy Read booklets were the most popular bit



The next most population bit was the GeneEQUAL videos

## What we found when we talked to health care workers?



14 health care workers spoke to us



Health care workers told us that they want to

- give good health care to people with intellectual disability



But health care workers

- can find it hard
- were never taught how

to give good health care to people with intellectual disability



Most health care workers said that they liked the Toolkit



They liked that the Toolkit had

- videos
- information to read
- Easy Read booklets
- was co-produced



The Toolkit helped them think about

- how they could give better health care



For example they could



- make longer appointment times
- use the Easy Read booklets
- be aware that people often have trauma



Health care workers said that they wanted

- more time to look at the Toolkit
- workshops to learn how to use the Toolkit





They thought that more

- health care workers
- people with intellectual disability

need to know about the Toolkit



They had ideas to make the Toolkit better



They said GeneEQUAL could make co-produced resources about

- genetic research
- pregnancy and genetic health care
- how to make health care choices
- health care rights
- support after a genetic diagnosis





They wanted printed copies of the booklets for health clinics

## Overall



People with intellectual disability and health care workers thought

- that the Toolkit was good and useful



Lots of people from around the world

- have seen the Toolkit



People with intellectual disability liked

- the co-production workshops

Health care workers also liked

- that the Toolkit was co-produced



People think the Toolkit can help health care workers

- give better health care



People had lots of ideas for things

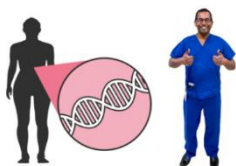
- GeneEQUAL can work on next!



People want the GeneEQUAL team to make

1. more resources to help people make choices about genetic tests

2. more information about



- genetic research
- support after a diagnosis
- genetic health care when planning a baby



3. information about genetic health care in more languages

4. information for **people with high support needs**

## People with high support needs often



- use other than verbal communication
- have complex health care needs
- have more disabilities



## 5. information for families and support people



## People think all health care workers need teaching how

- to do good health care with people with intellectual disability



## People want information



- on websites AND
- in printed booklets and posters



## If you have any questions about this report you can

- email us at [geneequal@unsw.edu.au](mailto:geneequal@unsw.edu.au)
- send us a letter to



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The pictures in this report were from



1. the GeneEQUAL team
2. the paid database Photosymbols  
<https://www.photosymbols.com>



The name of this report is

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