

“All doctors should be trained in that”

The co-production of the GeneEQUAL Toolkit

This booklet is about the **GeneEQUAL** Toolkit



- how we made it
- what people with intellectual disability and
- health care workers think about it

What is GeneEQUAL?

Our **GeneEQUAL** team are

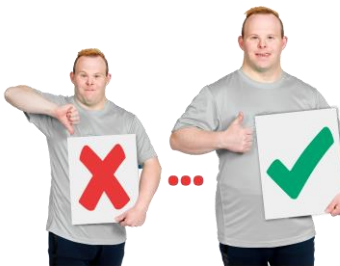


- self-advocates
- researchers
- health care workers
- teachers



You can read more about GeneEQUAL

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



GeneEQUAL wants to make health care and education better

- for people with intellectual disability



People with intellectual disability often get health care which

- is not good quality and is not safe

This is wrong



GeneEQUAL thinks that if we work together

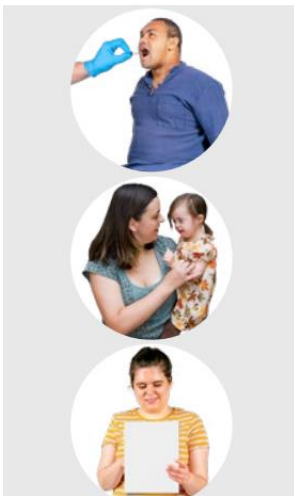
- we can make health care better

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



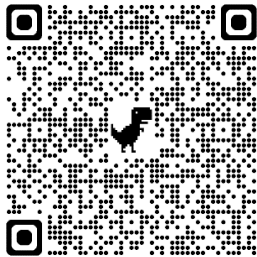
GeneEQUAL asked people what is good and bad

- 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 New South Wales (NSW) Health
- and an article



Below are the top 3 recommendations people made



Recommendation number 1

Inclusive research teams need to make together

- videos
- Easy Read information
- websites



Recommendation number 2

People need accessible information to help make choices

- about genetic tests and health care



The accessible 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 to learn 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 to learn 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

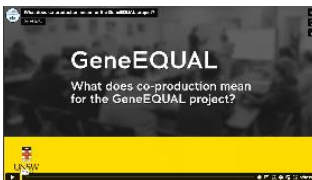


- health care workers give good genetic health care

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 Sydney
- 1 at Wagga Wagga

How we found out what people think about the Toolkit



We asked people with intellectual disability and health care workers

- what they think about the Toolkit
- how to make the Toolkit better



We asked health care workers about their thoughts

- in an online survey and interviews



We asked people with intellectual disability about their thoughts

- in a co-production workshop



We counted how many people

- looked at the information on our website
- looked at the Easy Read booklets
- watched the videos

How many people looked at the website



Over 5,700 people looked at the GeneEQUAL website



These people were from 53 countries



The Easy Read booklets were the most popular



The next most popular were the GeneEQUAL videos

What we found in the survey



74 health care workers took part in the survey



Health care workers looked at the

- information on our website
- videos
- Easy Read booklets



They said they wanted to use the information

- in the Toolkit

to make health care better



The Toolkit helped health care workers

- feel more confident to give good health care

What people with intellectual disability and health care workers told us



We spoke to 21 health care workers



We had a focus group

- with 15 people with intellectual disability



The GeneEQUAL team talked about what people said

We wrote down what topics people talked about

We ended up with 3 main topics people talked about



Topic 1 Health care for people with intellectual disability

People with intellectual disability and health care workers agreed



- health care needs to be inclusive



Both groups also talked about

- many barriers to inclusive health care



For example, health care workers were never taught how

- to give good health care to people with intellectual disability



Topic 2 Feedback on the Toolkit



Both groups liked that the Toolkit

- had “good” and “bad” practice videos
- had Easy Read booklets
- was co-produced



People with intellectual disability said the first video

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



Some health care workers were shocked to hear how

- bad health care is for people with intellectual disability



But people with intellectual disability thought

- the videos were like their experiences



They said the second video

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



People with intellectual disability liked Easy Read booklets because

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



They liked the information about

- how to make a complaint when health care is bad



Both groups had ideas how 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



People with intellectual disability said to make health care better

- the Toolkit needs to be taught to all health care workers



Topic 3 Co-production in health care is important

People with intellectual disability liked the co-production because



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



Both groups said they want to

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

Finally...

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



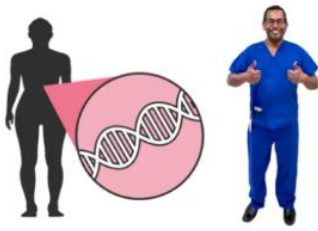
People had lots of ideas for things

- GeneEQUAL can work on next!



People want the GeneEQUAL team to make

1. resources to help people make choices about genetic tests



2. resources about topics like

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



3. resources about genetic health care in more languages



4. resources for children and young people



5. resources accessible to **people with high support needs**

People with high support needs often

- use different ways to communicate
- have complex health care needs
- have more disabilities



6. resources for families and support people



People think all health care workers need to learn

- how to do good health care
- with people with intellectual disability



People want information

- on websites and in printed booklets



If you have any questions you can mail us at geneequal@unsw.edu.au

The pictures in this report were from the



1. GeneEQUAL team

2. paid database Photosymbols

<https://www.photosymbols.com>



The name of this publication is

“All doctors should be trained in that”: The co-production and mixed-methods evaluation of an educational toolkit to enable safe, high-quality genetic healthcare for people with intellectual disability.