

Background

How did we develop the GeneEQUAL Educational Package?

This package, including

- the **Educational Toolkit**,
- Inclusive, Accessible, and Respectful Best Practice Videos **Video Series**, and
- **Easy Read Booklets**,

is informed by qualitative research through the **GeneEQUAL project**.

The GeneEQUAL project conducted in-depth interviews and focus groups with people with intellectual disability and their support people.



The team was iteratively guided by a multi-disciplinary stakeholder advisory committee, including health professionals and representatives of

- NSW Health,
- Australian Genomics,
- Patient and self-advocacy groups.



A series of recommendations was made for more respectful, inclusive and accessible genetic health care, which was included in a report for NSW Health and an Easy Read report which is available on the GeneEQUAL website. You can read more about the research that informed these videos at our open access publication:



Strnadová, I., Loblinzk, J., Scully, J.L. et al. **“I am not a number!” Opinions and preferences of people with intellectual disability about genetic healthcare.** Eur J Hum Genet (2023).



These recommendations formed three key principles of the **Educational Toolkit**:

- person-centred care,
- trauma-informed care, and
- making reasonable adjustments.



Why are these principles important when providing genetic health care to people with intellectual disability?

People with intellectual disability have negative experiences with genetic testing and receiving a genetic diagnosis. The use of deficit language and experiences of trauma affects the physician-patient relationship.



“Doctors know that people with intellectual disability will not question them... and they abuse it.”
(Mike)

“...they just quickly ... go and do this, let's do it...”
(Lilian)

Making reasonable adjustments can improve the quality of inclusive health care for people with intellectual disability. People with intellectual disability have expressed their frustration with hurried appointments and the use of complicated language.



“...don't just have big words... break the words up for us.”
(Katrina)

Why are these principles important when providing genetic health care to people with intellectual disability?

A genetic diagnosis can significantly impact on people with intellectual disability, and health professionals need to be aware of this and provide post-diagnosis support. A diagnosis can result in feelings of isolation or feeling 'different' and, in some cases, contemplation of suicide.

I feel like I'm not normal now.
(Katrina)

I came to a point when I found out... I had contemplated on suicide.
(Mason)



Information about genomic medicine can be difficult to understand, and people with intellectual disability prefer accessible health information (e.g., Easy Read booklets).



It wasn't Easy Read... it's very hard to read the form...
(Lilian)



What is the relevant legislation, policy, standards, and rights?

The Australian Commission on Safety and Quality in Health Care highlights patients' rights and relevant clinical standards.



Australia's Charter of Healthcare Rights

National Safety & Quality Health Service Standards (Factsheet for Clinicians: Informed consent in health care)



All health professionals are mandated to ensure that their health care is accessible and inclusive. Relevant legislation includes:

NSW Disability Inclusion Act 2014 No 41

"People with disability have the same rights as other members of the community to make decisions that affect their lives (including decisions involving risk) to the full extent of their capacity to do so and to be supported in making those decisions if they want or require support."



This legislation has informed NSW Health Policy, which mandates that NSW health staff and services must make reasonable adjustments to address the needs of people with intellectual disability.



The Toolkit explains what reasonable adjustments are, and some practical resources to help health professionals make reasonable adjustments.



The international Convention on the Rights of Persons with Disabilities (CRPD) to which Australia is a signatory, specifically:



Article 19 – Persons with disabilities have the equal right to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

Article 25 – Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services.

Who is the GeneEQUAL Educational Package for?

The package is for a wide range of health professionals.
We encourage health professionals to:



- Look through the **Educational Toolkit**
- Download and read the **Easy Read booklets**
- Watch the Inclusive, Accessible, and Respectful Best Practice Videos **Video Series**



to learn about how their approach to clinical consultations can be guided by principles of trauma-informed, person-centred care, and the mandatory requirement of all health professionals to make reasonable adjustments.

This will support them to improve the inclusivity and accessibility of discussions about genetics, genetic testing, and genetic test results.



Would you like to learn more about the GeneEQUAL Videos?



These are fictional scenarios based on what people with intellectual disability and their support people told us.

The first videos (take one) in each scenario reflects the poor practice that people with intellectual disability and their carers and support people described in our GeneEQUAL research project. These also resonated with members of our focus groups.

The second videos (take two) in each scenario suggests more positive experiences that GeneEQUAL participants had had and follows recommendations of our participants who told us what would make them feel more respected, included and empowered.

“They [medical professionals] don't treat you like a person. They treat you like an 'it'.” (Richard)

“We had a really good experience the whole way through. Very supportive.” (Teresa, support person).





We recommend that health professionals watch these videos and take some time to reflect on the key learning points.



Inclusive health care has only recently become a topic in clinical curricula, and many of us unconsciously adopt some of the approaches demonstrated in the first video for each scenario. Hopefully, by watching these videos and reflecting on your current clinical practice, you can help think of ways you can continually improve.



These videos were designed to help support the training of health professionals.

However, in co-producing these with people with intellectual disability and their support people, many let us know that they found watching the videos, especially the 'better approaches' both

- Helped them prepare for a conversation about genetics and
- Showed them the type of health care they have the right to receive.

We encourage you to direct people with intellectual disability and their support people to the 'Take 2' versions of these [videos](#), which are also profiled in [our website](#).



What do you think about the GeneEQUAL Educational Package?

We would love to know what health professionals think about this educational package. We invite you to participate in a **brief survey** by clicking on **this link**.



We also have information in Easy Read about the GeneEQUAL project, as well as our resources including Easy Read booklets and best practice video series, on our accessible website www.GeneEQUAL.com. This website is tailored to people with intellectual disability and their support people, and we will be seeking feedback from these groups through qualitative research.



More accessible resources will become available on the [GeneEQUAL website](http://www.GeneEQUAL.com). If you would like to contact the GeneEQUAL team to provide feedback or suggest additional resources, please feel free to contact the team via:

- Email (GeneEQUAL@unsw.edu.au), or
- Phone **+61 (0) 2 9348 1601**, or
- By **sending us a letter**

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