Website and Handbook information

Project name:
GeneEQUAL National

This project is about: People with intellectual disability told us...
People with intellectual disability told us they • felt unsafe • did not understand the information • were not listened to • and were not included in decisions about their genomic health care.

What is the project about (3-4 points)? - Why are we doing it? What is the problem?
The main aim of this project is to make genomic health care in Australia better by listening and working together with people with intellectual disability. People with intellectual disability should • feel safe • understand • have a say • and make their own choices in their genomic health care.

What are we trying to change?
We are trying to make genomic health care • respectful • accessible • inclusive for people with intellectual disability.

What are we doing together? (Who are we talking to?)
We are talking to • people with intellectual disability of all support needs   o including people from Aboriginal and Torres Strait Islander communities • their families and support people • and their health care workers They are telling us what they

- think
- feel
- want to know

about genomic health care for people with intellectual disability

They are telling us about their experiences and the things that make genomic healthcare
- hard
- or easy

What are we finding out?

We are learning about what
- works
- does not work
- people want
- needs to be made better

What are we making together?

We are making a plan with people with intellectual disability for good genomic healthcare that treats everyone with respect

The plan includes ways to:
- help health care workers support people to make choices

The plan is to make resources that help
- people with intellectual disability
- families and support people
- health care workers

Handbook Information

Project manager:

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Our team members:

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How long have we been doing this?

We have been doing this since 2023

We are in the 2nd year

The project will finish in 2028

How is this funded?

This is funded by the National Health and Medical Research Council

External team:

Kris Barlow-Stewart
Greg Pratt
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Advisors and partners:
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