



May 2022: Issue 5 The Monthly Newsletter GeneEQUAL



We hope you have been safe and well this past month!



GeneEQUAL will make genetic health care better for people with learning and intellectual disabilities.

Where we are up to:



- 17 people with intellectual disability and their 10 support people have been interviewed by Iva and Julie



- We analysed the data from the interviews



- We are preparing a focus group at Self Advocacy Sydney to hear their thoughts on the findings



From the interviews, we found many participants:

- Found out about their diagnosis through a letter
- Internalised language from genetic testing and felt they were not 'normal'
- Had different plans about having children



Participants recommended for health care workers to:

- Give time for people to ask questions
- Use less jargon
- Speak more slowly
- Treat people with greater dignity and respect



We will have another Advisory Workshop on Friday 3rd June.

See you then!