



## PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Cohort D: Health Care Professionals  
GeneEQUAL Phase 1: Interviews/ Focus groups  
Chief Investigator Elizabeth Emma Palmer

Dear health care professional,

### **Research Study Title: GeneEQUAL: equitable and accessible genomic healthcare for people with intellectual disability**

Researchers at UNSW are conducting a project about the opinions and experiences of people with intellectual disability about genetic counselling and/ or testing.

The research study is looking recruit people who meet the following criteria:

- Health professionals of any age who have ever worked with children, adolescents and adults with an intellectual disability
- Health professionals currently living in Australia

Participants meeting the following criteria will be excluded from the study:

- Health professionals who have never worked with children, adolescents and adults with an intellectual disability
- Health professionals not currently living in Australia

Participants will be asked to complete the following research activities if they agree to participate:

- A face-to-face, online (for example via platforms such as Zoom or Skype), or phone interview that will take approximately 30 minutes to 1 hour to complete
- And/or participation in a Focus Group (face-to-face or online).

A full description of all research activities, including any risks, harms or discomforts that you may experience while participating in this research is included in the attached Participant Information Statement and Consent Form.

Please contact the following person via email or phone to register your interest in taking part in the research:

<b>Name</b>	Dr Elizabeth Emma Palmer
<b>Position</b>	Coordinating Chief investigator, Clinical Lecturer and Clinical Geneticist
<b>Telephone</b>	(02) 9348 1601
<b>Email</b>	elizabeth.palmer@unsw.edu.au



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### 1. What is the research study about?

You are invited to take part in this GeneEQUAL research study. The overarching aim of GeneEQUAL research program is to develop and evaluate a world-first inclusive, person-centred and respectful model of genomic healthcare for all people with intellectual disability and will take part in three phases.

This GeneEQUAL research study is part of the first phase and aims to identify the barriers and enablers to inclusive, person-centred, and respectful model of genomic healthcare for people with intellectual disability from the perspective of:

- people with intellectual disability of all support needs and inclusive of people of Aboriginal and Torres Strait Islander communities,
- their families, support people and legal guardians, and
- their health professionals.

### 2. Who is conducting this research?

The study is being carried out by the following researchers:

Dr Elizabeth Emma Palmer	School of Women's and Children's Health, UNSW
Professor Iva Strnadová	School of Education, UNSW
Professor Jackie Leach Scully	Disability Innovation Institute, UNSW
Ms Julie Loblinzk OAM	School of Education, UNSW; Self-Advocacy Sydney Inc.
Associate Professor Stephanie Best	Peter MacCallum Cancer Centre
Dr Erin Turbitt	University of Technology Sydney
Professor Julie McGaughran	Genetic Health Queensland
Mr Gregory Pratt	Queensland and Islander Health Council
Dr Helen Mar Fan	Genetic Health Queensland
Dr Elizabeth Evans	NSW Council for Intellectual Disability
Dr Yvette Vella	Northern Sydney Local Health District, NSW Health
Dr Jonathan Rodgers	Genetic Health Queensland
Associate Professor Helen Leonard	Telethon Kids Institute
Mrs Skie Sarfaraz	Self-Advocacy Sydney Inc.
Ms Jackie Boyle	Hunter New England Local Health District, NSW Health
Associate Professor Kristine Barlow Stewart	University of Sydney

**Research Funder:** This research is being funded by the National Health and Medical Research Council.

### 3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

- Health professionals working with children, adolescents and adults with an intellectual disability
- People currently living in Australia

Participants who meet the following criteria will be excluded from the study:

- People who are health professionals who have never worked with children, adolescents and adults with an intellectual disability
- People not currently living in Australia.



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### 4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

### 5. What does participation in this research require, and are there any risks involved?

If you agree to participate you will be asked to complete the following research procedures.

**Interview:** You will be offered the opportunity of an interview, and you will be asked questions about your opinions and experiences about genetic counselling and / or testing. You can choose between taking part face-to-face, online (i.e., video-conferencing, using a platform of your choice), or via phone. The interview will take approximately 30 minutes to one hour. With your permission the research team would like to audio and video record the interview. If you do not wish to be recorded but you would like to participate you advise the research team and written notes will be taken. You may also be asked if you would like to join in a focus group.

**Focus Group:** All focus group sessions will take place either online or face-to-face in a community centre close to where you live and will take approximately 30 minutes to one hour. During the focus group you will be asked questions about your opinions and or experiences with genetic testing and or counselling and/ or with a draft report we will have prepared including recommendations for health providers and government regarding genetic counselling and testing.

With your permission the research team would like to audio and or /video record the interview. If you decide to participate in the focus group, your comments along with other participants will be recorded during the group discussions. Because of the way in which the focus group discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses.

**Additional Costs and Reimbursement:** There are no costs associated with participating in this research project, nor will you be paid.

**Psychological Distress:** You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. As the interviews/focus groups will take place at your local community centre or disability service, if necessary, we will be able to bring in your support worker to provide additional support. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Alternatively, several free contactable support services are included at section 9. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

### 6. What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information about you for the research study.

The research team will store the data collected from you for this research project for:

- A minimum of 7 years after the completion of the research.



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The information about you will be stored in a:

- Re-identifiable format where any identifiers such as their name, address, date of birth will be replaced with a unique code.
- Information collected from your child in an electronic format stored on a UNSW password protected OneDrive only accessible to the approved research investigators.
- Information collected from your child using paper-based measures will be stored in the secure office of the Chief Investigator Professor Iva Strnadová at the School of Education, UNSW, and only the approved research investigators will have access to this information.
- Audio or video recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators which will also be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

### 7. How and when will I find out what the results of the research study are?

The research team intend to publish and/ report the results of the research. All Information will be published in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

### 8. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or the National Health and Medical Research Council. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

### 9. What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

#### Complaints Contact

<b>Position</b>	UNSW Human Research Ethics Coordinator
<b>Telephone</b>	+ 61 2 9385 6222
<b>Email</b>	<a href="mailto:humanethics@unsw.edu.au">humanethics@unsw.edu.au</a>
<b>HC Reference Number</b>	HC230353



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### 10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

#### Research Team Contact Details

<b>Name</b>	Professor Iva Strnadová
<b>Position</b>	Chief Investigator, Professor in Special Education and Disability Studies
<b>Telephone</b>	0426 959 172
<b>Email</b>	i.strnadova@unsw.edu.au

#### Chief Investigator

<b>Name</b>	Dr Elizabeth Emma Palmer
<b>Position</b>	Coordinating Chief investigator, Senior Clinical Lecturer and Clinical Geneticist
<b>Telephone</b>	02 9348 1601
<b>Email</b>	elizabeth.palmer@unsw.edu.au

#### Support Services Contact Details

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

<b>Name/Organisation</b>	Lifeline
<b>Telephone</b>	13 11 14

<b>Name/Organisation</b>	Mental Health Access Line
<b>Telephone</b>	1800 011 511



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### Consent Form – Participant providing own consent

#### Declaration by the participant

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research described in the study;
- Recordings: I understand that the research team will audio and or /video record the interviews and /or focus groups; I agree to be recorded for this purpose.
- I provide my consent for the information collected about me to be used for the purpose of this research study only.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;
- I understand that I will be given a signed copy of this document to keep.
- I understand that the results of the research will be made available on the Disability Innovation Institute, UNSW, website.
- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email Address: \_\_\_\_\_

#### Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

#### Declaration by Researcher\*

- I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

#### Researcher Signature\*

Name of Participant (please print)	
Signature of Research Participant	
Date	

**+An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

**Note: All parties signing the consent section must date their own signature.**



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### Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales.

- I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.
- I am withdrawing my consent to participate in further components of this research and provide my permission for the research team to retain and/or use information collected about me which I have provided for the purpose of this research.
- I am withdrawing my consent and I understand that any information already published and/or not linked to my identity cannot be withdrawn from the research.

#### Participant Name

Name of Participant (please type)	
Date	

#### The section for Withdrawal of Participation should be forwarded to:

CI Name:	Dr Elizabeth Emma Palmer
Email:	elizabeth.palmer@unsw.edu.au
Phone:	02 9348 1601
Postal Address:	Level 9, Bright Alliance Building, School of Paediatrics and Child Health, Cnr of Avoca and High Street, Randwick, NSW 2031, Australia