**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM FOR SIBLINGS AGED 18 YEARS OR OLDER**
**GeneEQUAL NSW Health Genomics Education Inclusive of People with Intellectual Disability**
Chief Investigator: Dr Elizabeth Emma Palmer

# PARTICIPANT INFORMATION STATEMENT

## 1. What is the research study about?

This research study aims to learn more about the siblings of students with intellectual disability's perspectives of and experiences with health and genetics education. We hope to learn from this the barriers and enablers to effective and accessible school-based education for high school students with intellectual disability. You have been approached with this letter because you are a sibling of a student with intellectual disability who is currently attending or previously attended an Australian high school.

This research forms part of broader research program which aims to understand the opinions and experiences of people with intellectual disability about genetic counselling and/or testing. This is to help us provide guidance to NSW Health, doctors, and genetic counsellors in how the model of care can be improved for people with intellectual disability.

## 2. Who is conducting this research?

The study is being carried out by the following researchers:

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| Dr Elizabeth Emma Palmer | School of Women's and Children's Health, UNSW |
| Professor Iva Strnadová | School of Education, Faculty of Arts, Design, and Architecture, UNSW, and Disability Innovation Institute, UNSW |
| Bronwyn Terrill | Garvan Institute of Medical Research, UNSW |
| Jackie Leach Scully | Disability Innovation Institute, UNSW |
| Julie Loblinzk OAM | School of Education, Faculty of Arts, Design, and Architecture, UNSW |
| Ms Chia Roung Chen | School of Education, Arts, Design, and Architecture, UNSW |
| Ms Jennifer Hansen | School of Education, Arts, Design, and Architecture, UNSW |
| Ms Kaitlyn Delaney | School of Education, Arts, Design, and Architecture, UNSW |

## 3. Inclusion/Exclusion Criteria

The research study is looking for participants that meet the following criteria:
1. Young people with a sibling with intellectual disability.
2. People aged 13-29.
3. Young people have attended or are currently attending high school in Australia for at least one full school year.
4. Young people who are engaging or have engaged with a curriculum utilised by an Australian state and/or territory.

Exclusion criteria for those who are not eligible to participate in the study are:
1. Young people who do not have a sibling with intellectual disability.
2. People who are younger than the age of 13 and older than the age of 29.
3. Young people who attended or are currently attending all their high schooling in a country other than Australia.
4. Young people who are attending or have attended high school in Australia for less than one full school year.
5. Young people who are engaging or have engaged with a curriculum that is not utilised by an Australian state and/or territory.

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

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

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

- Read the provided information carefully (ask questions if necessary);
- Sign and return the consent form if you choose to take part in the study;
- Retain a copy of this form for your records.

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

If you consent to take part in the research study, you will be invited to participate in a 30 to 60-minute interview regarding your perceptions and experiences with education on genomics (and more broadly) health literacy for the siblings of students with intellectual disability. You can choose to participate face-to-face, online (via video-conferencing using a platform of your choice), or via phone. With your permission, the research team will record the interview in audio format to ensure accurate data collection and for transcription purposes. If you wish to participate but do not want to be recorded, you will need to discuss alternative options for your involvement with the research team.

You may experience the following discomforts:

1. Discomfort being asked to think about your experiences and perceptions of the genetics and (more broadly) health education provided to you.
2. Discomfort being asked to think about your wellbeing and experiences as a sibling of a student with intellectual disability
3. Discomfort being asked to think about other genetic conditions within the family.

To minimise the risk of these discomforts, the researchers will:

1. Skip questions you do not want to answer and go to the next question.
2. Discontinue the interview at any sign of distress.
3. Provide you with emergency contact numbers and helpline details for Lifeline (13 11 14), Mental Health Access Line (1800 011 511) and People with Disability Australia [(02) 9370 3100].
4. The lead investigator will follow up with you on the same day to see whether you are feeling better and whether any further assistance is required.
5. If further assistance is required then the lead investigator (who is a registered doctor), will be able to arrange for counselling or other appropriate support in coordination with your GP.

We don’t expect the questions to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance.

**Additional Costs and Reimbursement:** Participants will receive a $40.00 AUD EFTPOS voucher which can be used at retailers which accept EFTPOS.

## 6. What are the possible benefits to participation?

We hope to use information obtained from this research study to benefit high school students with intellectual disability. Specifically, the findings will be used to develop the optimal way to support and deliver health and genetics education to students with intellectual disability and to create resources for delivering respectful, accessible, and inclusive education in genomic content. Our aim is to ultimately bridge the fields of health and education to support public genomic health literacy and enable benefits for all Australian citizens, including people with intellectual disability across the lifespan.

## 7. 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. We will keep the data for a minimum of 7 years in a de-identified format on ResData, a university data storage system (see below). Your details will be stored separately so that we can identify which information belongs to you. The information about you will only be used for the purpose of this study.

Researchers at UNSW are required to store any aggregated data in the UNSW data repository, this is a system called ResData. Once the aggregated data is deposited into this repository it will be retained in this system permanently. It will, however, be retained in a format where your identity will not be known.

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 compliant 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**.

## 8. 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 study in a variety of ways. All information published will be done 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 adding your email or postal address within the consent form. We will only use these details to send you the results of the research.

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

If you consent to participate, you may withdraw at any time. You can do so by completing the "Withdrawal of Consent Form," provided at the end of this document. Alternatively, you can contact the research team and inform them that you no longer wish to participate. Your decision not to participate in the study will not affect your relationship with UNSW Sydney.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

The research team will destroy any information about you that was collected during your participation in the study.

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.

### 10. What should I do if I have further questions about my participation 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 involvement in the study, you can contact the following member/s of the research team:

**Research Team Contact Details**

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|---|---|
| **Name** | Professor Iva Strnadová |
| **Position** | Chief Investigator, Professor in Special Education and Disability Studies |
| **Telephone** | 0426 959 172 |
| **Email** | i.strnadova@unsw.edu.au |

### Chief Investigator

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|---|---|
| **Name** | Dr Elizabeth Emma Palmer |
| **Position** | Coordinating Chief investigator, Clinical Lecturer and Clinical Geneticist |
| **Telephone** | 02 93825583 |
| **Email** | Elizabeth.palmer@unsw.edu.au |

### 11. Support Services Contact Details

If at any stage during the project you or your child becomes distressed or require additional support from someone not involved in the research please call:

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|---|---|
| **Organisation** | Mental Health Access Line |
| **Description** | This is a free service which will help you to find assistance near you. |
| **Telephone** | 1800 011 511 |

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| **Organisation** | Lifeline |
| **Description** | This is a telephone counselling service. |
| **Telephone** | 13 11 14 |

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

If you have any complaints about any aspect of the project, the way it is being conducted, then you may contact:

**Complaints Contact**

| | |
|---|---|
| **Position** | Human Research Ethics Coordinator |
| **Telephone** | + 61 2 9385 6222 |
| **Email** | humanethics@unsw.edu.au |
| **HC Reference Number** | HC210342 |

# Consent Form – Participant Consent

**Declaration by the participant**

- ☐ I understand that I am being asked to provide consent to participate in this research project;
- ☐ I have read the Participant Information Sheet or someone has read it to me in a language that I understand;
- ☐ I understand the aim of this research and have been given a description of the study tasks and I understand what I will be asked to do;
- ☐ I understand that the research team will audio record me during the interviews; I provide my consent for this to happen.
- ☐ 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 project and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- ☐ I understand that I will be given a signed copy of this document to keep;
- ☐ 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 Researcher (please print) | |
| Signature of Researcher | |
| 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.**

## 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. In withdrawing my consent, I would like any information collected from me that has been provided for the purpose of this research project withdrawn. In case that I took part in a focus group instead of an interview, I understand that the information collected about me during my participation in the focus group cannot be withdrawn given the nature of the focus group.

**Participant Signature**

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

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

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|---|---|
| CI Name: | Professor Iva Strnadová |
| Email: | i.strnadova@unsw.edu.au |
| Phone: | 0426 959 172 |
| Postal Address: | *UNSW School of Education, Morven Brown G23* |