**PARTICIPANT INFORMATION STATEMENT**

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

You are invited to take part in this research study. The research study aims capture teachers’ and School Learning Support Officers’ perspectives, practices and resourcing needs for teaching genetic literacy to students with intellectual disability.

It is hoped that by comprehensively understanding these perspectives and needs, strategies and resources can be identified to better support schools and teachers in teaching genetic literacy to students with intellectual disability.

This forms part of broader research 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.

1. **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, Arts, Design, and Architecture, UNSW, and Disability Innovation Institute, UNSW

Professor Jackie Leach Scully Disability Innovation Institute, UNSW

Ms Julie Loblinzk School of Education, Arts, Design, and Architecture, UNSW

Ms Jackie Boyle Genetics of Learning Disability (GOLD) Service, Hunter Genetics, Hunter New England Local Health District

Ms Karen-Maia Jackaman School of Education, Arts, Design, and Architecture, UNSW

Ms Bronwyn Terrill St Vincent’s Clinical School, UNSW Sydney

1. **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:

* 1. High school teachers who have taught science to students with intellectual disability within the last ten years
	2. School Learning Support Officers who have supported science teachers to teach science to students with intellectual disability within the last ten years
	3. Learning and support teachers who have supported science teachers to teach science to students with intellectual disability within the last ten years
	4. Teachers currently working in mainstream NSW schools, including support units within mainstream schools.

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

1. High school teachers who have not taught students with intellectual disability
2. Primary school teachers
3. Teachers in Schools for Specific Purposes (SSPs)
4. Teachers not currently working in NSW schools
5. **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.
1. **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:** Participants that meet the inclusion criteria will be offered the opportunity of an interview, and asked questions about their opinions and experiences about teaching genetic literacy to students with intellectual disability. Participants 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 1 hour. With permission, the research team will audio and video record the interview for transcription purposes. If participants do not wish to be recorded but would still like to participate, they can advise the research team and written notes will be taken.

**Additional Costs and Reimbursement:** There are no costs associated with participating in this research project, nor will staff be paid. However, the school will receive a voucher for $20 which can be offered as a student prize at the end of the year.

1. **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 participants for this research project for:

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

The information about participants will be stored in a:

* Re-identifiable format where any identifiers such as their name, age and gender will be replaced with a unique code.
* Information collected from participants in an electronic format stored on a UNSW password protected OneDrive only accessible to the approved research investigators.
* 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 participants provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). Further information on how the University protects personal information is available in the [**UNSW Privacy Management Plan**](https://www.legal.unsw.edu.au/compliance/privacyhome.html).

1. **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 or your school.

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.

1. **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 any of the organisations involved in this research. 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.

1. **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**

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| --- | --- |
| **Position** | UNSW Human Research Ethics Coordinator |
| **Telephone** | + 61 2 9385 6222 |
| **Email** | humanethics@unsw.edu.au  |
| **HC Reference Number** | [INSERT HC reference number] |

1. **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**

|  |  |
| --- | --- |
| **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**

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

**This information sheet is for you to keep.**

**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/video record the interviews/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 GeneEQUAL 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 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. 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.

* 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 Signature**

|  |  |
| --- | --- |
| Name of Participant (please print) |  |
| Signature of Research Participant  |  |
| 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 93825583 |
| Position | Coordinating Chief investigator, Clinical Lecturer and Clinical Geneticist |