Accessible Consent Education:

Terms of Reference and Participant Information Statement

HREC Project Number:	*2025-0135*
Project Title:	Accessible Consent Education for Young People with Disability Aged 12-16 Years of Age: A Participatory Action Research Approach Utilising Design Justice Principles
Chief Investigator:	Dr Jacqueline Hendriks
Student researcher:	Kim Andreassen (PhD Candidate)
Version Number:	1.3
Version Date:	20/02/2026

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number 2025-0135). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

BACKGROUND

A **PhD Candidate** called Kim Andreassen, pronouns are they and them, will do the **research**.

The **research** wants to:

- reduce **violence** towards **people with disability**

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- give **people with disability** choice and control

- teach **consent**.

You are reading this because you or your parent or guardian heard about this research.

You or they may have seen the advertisement or heard about it through someone you know.

You or your parent or guardian contacted us, and that's how we got your personal information.

This form gives you information about the **research**, so that you can decide if you want to be involved. If you decide to get involved, we will ask you to either fill out a **consent** form or tell us that you **consent** when we meet. If you are under 18 or need support in making decisions like this, your parent or guardian will also need to **consent**.

STAKEHOLDER ADVISORY GROUP (SAG) PURPOSE

The Youth Disability Advisory Group (YDAG) assists in the **research** mentioned above.

The YDAG will help direct the **research** to make sure it is safe and comfortable for **people with disability**.

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The YDAG will meet for up to 12 meetings.

The meetings will be on Curtin University campus.

If online meetings are needed, these will be held on Microsoft Teams.

If online meetings are needed, these will be recorded through Microsoft Teams if all YDAG members agree.

The meetings will be 1 hour to 2 hours long.

You can have a support person at the meetings.

The dates, times and location for the meeting will discussed and given to YDAG members before each meeting.

A maximum of 10 members will be in the YDAG at any time.

A minimum of 3 members will be in the YDAG at any time.

If members drop below 3, new members will be invited to the group.

ROLES AND RESPONSIBILITIES OF YDAG MEMBERS

The primary role of YDAG members is to help ensure the **research**, ethics, and resources developed from the **research** are safe for people with disability.

It is estimated that each member of the YDAG will, provide between 12 hours to a maximum of 18 hours of their time.

During these meetings, it is important to ensure a respectful environment by respecting other people's experiences, thoughts, and opinions.

A code of conduct will be made during the first YDAG meeting to ensure everyone feels safe and comfortable.

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Please note that while all input is valued and considered, the Candidate and the supervisory team will be responsible for making the final decisions.

ADMINISTRATIVE DUTIES - CANDIDATE

The **PhD Candidate** will be responsible for duties as follows:

- establish individual meeting times and convene meetings when required
- provide detailed and clear agendas for the YDAG meetings
- take notes of, and record key discussions during the YDAG meetings
- distribute any readings to all members,. If necessary
- ensure that actions are completed within appropriate timeframes
- ensure that the YDAG understand the decisions and actions made
- organise meetings in accordance with individual YDAG schedules
- convene meetings (online or in-person) and provide meeting notes to YDAG members involved no later than one week after receipt of the information
- follow up on action points.

BENEFITS TO SAG MEMBERS

Future benefits of this project includes:

- development of **consent** and teaching approaches for **people with disability** or those with lower English literacy levels;
- understand current gaps in **research** and knowledge related to disability, education, and consent;
- promote an increase in health literacy and sexual safety in **people with disability**;

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- increase understanding of body autonomy, self-determination, choice and control for **people with disability** or those with lower English literacy levels;
- add to our knowledge and understanding of how **people with disability** think about **consent**.

All YDAG members will be offered a $60 gift card per hour of meetings to thank them for their time and travel costs.

POTENTIAL RISKS TO SAG MEMBERS

The **research** team have identified a few risks YDAG members should be aware of:

1. we are aware that the topic of **consent** can be a confronting topic, particularly for **people with disability** who are more likely to have experienced unwanted touch, abuse, and/or lack of body autonomy
2. in person meetings may be hard for YDAG members to get to pending accessibility needs/concerns so please let **researchers** know of any accessibility needs
3. online meetings can increase the chance of distress without appropriate support and will be minimised
4. personality or clashes between Advisory Group members and/or **research** team, with disputes mediated by the code of conduct created

If you decide to participate and you feel uncomfortable at any point during the meetings, you can remove your consent.

If you feel distressed, you can talk to a **trusted person** or contact Lifeline Australia on 13 11 14 for support.

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CONFIDENTIALITY

Each YDAG member has the option for:

- The information collected in this **research** to be identifiable. This means that any information we collect that can identify you will stay on the information we collect and it will be treated as confidential and used only in the project unless otherwise stated. We can let others know this information only if you say so or if the law says we need to. All information will be stored securely in locked cabinets in Building 400 at Curtin University. The following people will have access to the information we collect in this **research**: the **research** team and, in the event of an audit or investigation, staff from the Curtin University Office of **Research** and Development.
- The information collected in this research to be re-identifiable (coded). This means that we will collect data that can identify you, but will then remove identifying information on any data or sample and replace it with a code when we analyse the data. Only the **research** team have access to the code to match your child's name if it is necessary to do so. Any information we collect will be treated as confidential and used only in this project unless otherwise specified. The following people will have access to the information we collect in this **research**: the **research** team and, in the event of an audit or investigation, staff from the Curtin University Office of **Research** and Development.

Electronic data will be password-protected and any hard copy data (including video or audio tapes) will be in locked storage or scanned and destroyed appropriately. The information we collect in this study will be kept under secure conditions at Curtin University for seven years up to 25 years (if you are under 18) after the **research** is published, and then it will be destroyed.

The results of this **research** may be presented at conferences or published in professional journals. Pending your selection above, (identifiable) you will be acknowledged for your contribution by name, or (re-identifiable) you will not be identified in any published or presented results.

BECOMING A SAG MEMBER

Taking part in a **research** project is voluntary.
This means it is your choice to take part or not.
You do not have to agree if you do not want to.
If you decide to take part and then change your mind, that is okay.
You can remove your **consent**.

If you choose to participate or start and then stop the study, it will not affect your relationship with the University, staff or colleagues.

With your permission, if you choose to leave the study, we will use any information collected unless you tell us not to.

CONTACT INFORMATION

Any questions or concerns related to this project can be directed to:

- Principal Investigator: Dr Jacqueline Hendriks, email: jacqui.hendriks@curtin.edu.au
- Student Investigator: Kim Andreassen (they/them), email: kim.andreassen@postgrad.curtin.edu.au;
- Ethics officer on (08) 9266 9223, or the Manager, Research Integrity on (08) 9266 7093 or email: hrec@curtin.edu.au

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If you decide to take part in this **research**, we will ask you to sign the **consent** form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the **consent** indicates that you agree to be in the **research** project and have your health information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the **consent** form to keep.

Established
MARCH 2026.

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Glossary

Advisory Group

The **Advisory Group** is a group of **people with disability** who will help make the **research** safe and comfortable for all people. The advisory group will meet at least five times to help the researcher called Kim Andreassen, pronouns are they and them, and give their thoughts on the **research**.

Consent

Consent means all people feel safe and happy and agree to something they want to happen. This is also called permission. To give **consent** you need to understand what will happen, have your questions answered and be listened to. You need **consent** before and during an activity.

People with Disability

For this **research**, **people with disability** means people who feel they have a disability or are diagnosed with a disability. The **research** will focus on **people with disability** who want or need audio options, less writing or text, more pictures, Easy English writing, and are non-speaking or minimally speaking.

PhD Candidate

A **PhD Candidate** is a person studying at a University. They are doing a **research** degree.

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Research

Research is done to look for new information about a topic. **Research** helps find new ways of thinking and doing.

Trusted Person

A **trusted person** is someone you know well, who is kind and helps you. You can talk to **trusted people** about things that worry you.

Violence

Violence is any action a person does that hurts another person and makes them feel pain. **Violence** can be:

- physical – for example, fighting and hitting
- psychological – for example, bullying
- sexual – for example, sexual assault or rape.