

Allied Health Reports

Participant Information: people in support networks

This information will help you to decide if you want to join this research.

Who is doing this research?

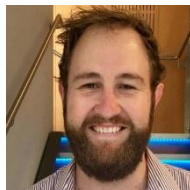


Harmony Turnbull is a research student at the University of Technology Sydney (UTS) and a speech pathologist with a lot of experience talking to people with disability of all ages.

Harmony's research supervisors are:



Professor
Bronwyn
Hemsley, UTS



Dr Ian Skinner,
Charles Sturt
University



Dr Leigha Dark,
Scope Australia



Dr Phillippa
Carnemolla,
UTS

What is the research about?

This research is about the written reports that allied health professionals give to people with communication disability. People with communication disability have a right to access and understand what is written about them in allied health reports. 'Access' is about being able to read and understand what is written in the reports.

We want to know:

- What do people think about written allied health reports?
- How accessible are allied health reports?

Why have I received this information?

We want to talk to people who are in the support networks who have read at least one allied health report about or for a person with a communication disability caused by a lifelong disability. A lifelong disability starts at birth or before the age of 18 years. This includes Cerebral Palsy, Down Syndrome, Intellectual Disability, Autism and other disabilities.

Some of the allied health professionals are dietitians, occupational therapists, physiotherapists, psychologists, speech pathologists, and others.

Do I have to say yes?

You don't have to say yes. You can say yes or no to joining this research.

It is your choice to join this research or not. Your consent is voluntary.

What will happen if I say yes?

1. Harmony will make sure you understand all of the information about the research before you give your consent.
2. Harmony will invite you to have an interview for about 30 minutes:
 - This can be through Zoom or a place that is confidential and convenient,
 - Harmony will talk with you about any allied health reports you have read that are about or for a person with lifelong communication disability,
 - Harmony will record the interview using an audio and a video recorder. She will use the recordings to study what you said in the interview.

3. After the interview, Harmony will:

- Type everything from the audio and video recordings into a transcript,
- Summarise what you said in the interview,
- Offer to meet you a 2nd time for about 15 minutes.

4. At the 2nd interview, Harmony will:

- Tell you a summary of what you said in your interview,
- Check whether you want to add or change anything in the summary of what you said in the interview,
- Record the visit using an audio and video recorder.

What will happen if I say no, or change my mind?

If you say no to joining this research, we will delete any information we have about you. It is your choice to join this research or not. If you say yes, you can also change your mind about joining this research. No one will be upset if you change your mind and want to leave the research. You can leave the research at any time before we publish the results. If you want to leave the research, we will delete the information about you and anything you told us.

Will my information be safe if I say yes?

We will keep your private information safe by doing these things:

- Save audio and video files on a computer that can only be unlocked with a password by the researchers,

- Your interview will not be anonymous, because the researchers know who you are. After the interview we will remove your name and the names of any people, businesses or places when we type what you say in the interview.

We aim to share and publish the results of this research in:

- Research articles,
- Harmony's PhD thesis,
- Podcasts (audio recordings on public websites),
- Workshops for allied health professionals and their employers.

We will share quotes of what you said in the interviews. We **won't** include your name with those quotes.

We will store all your information safely to use in future research that follows-on from this research. We will keep your information safe for 5 years after the last publication, and then we will delete it.

Are there any risks?

There are no major risks if you join this research.

- There is a small risk that you might feel uncomfortable, emotional or tired during the interview. If this happens, Harmony talk with you about what you want to do.

- There is a small risk that other people will recognise you in articles about the research, including your allied health professionals.
 - Only the researchers will hear and read your personal information.
 - We will be careful to remove information about you and other people, businesses or places from the quotes that we use when we share the research results.
 - We **won't** include your name with those quotes.
 - We **won't** share your whole interview in any one article or workshop.

Where can I find more information?

You can watch a video of Harmony talking about this research:

<https://youtu.be/37ytxATqSMg>

You can phone or email Harmony to talk and ask questions about this information:

Phone: 0430 875155

Email: Harmony.M.Turnbull@student.uts.edu.au

What can I do if I have concerns or complaints?

You can talk people at the University of Technology Sydney (UTS) Ethics office.

Tell them this reference number: ETH21-5715. It will be confidential.

Phone: 02 9514 2478

Email: Research.Ethics@uts.edu.au