

# Key support person Information and Consent Form

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| **Project Number:** | 103930 |
| **Short Name of Project:** | **Exploring mental health with people with communication needs** |
| **Full Name of Project:** | **What does “mental health” mean to young people with complex communication needs, and how do they share their mental health experiences with the people around them: a qualitative study.** |
| **Principal Researchers:** | Prof Christine Imms, Director Healthy Trajectories, Melbourne Children’s Campus (Christine.Imms@unimelb.edu.au) Ms Jacinta Pennacchia, PhD candidate, Murdoch Children’s Research Institute and University of Melbourne (Jacinta.Pennacchia@mcri.edu.au)  |
| **Version Number:** | [3] | **Version Date:** | [18/12/2023] |

## Why am I receiving this letter?

This project is for key informal support people of 10-24-year-olds with complex communication needs living in Australia. Complex communication needs means not using speech to communicate. Informal support people are family members or close friends who know the person well and are not paid to provide support.

You are receiving this letter because you have expressed interest in taking part in an interview about mental health for people with communication needs. This letter gives you more information about the interview. Taking part in the interview is up to you. You can say no if you want to.

## What do I need to do in this research project?

We would like to know what good wellbeing means to young people with disabilities, and how you and young people with disabilities communicate about mental health. Examples of questions we might ask are: “How do communication devices affect how you communicate with your child about how they are feeling?” and “Have you ever tried finding help for your child’s wellbeing?”. We will do this by conducting an interview. The interviews will be on Zoom and go for approximately one hour. Part of this study involves interviewing young people directly, but we also want to hear from you as a key support person, as we believe key support people will also share insightful experiences.

## What are the risks of the research project?

There is a small chance that you might become upset during the interview because we will be talking about mental health. If this happens, you can take a break from the interview. You may also decide to withdraw from the project. We have tried to make sure that the interview is sensitive and appropriate. However, if you don’t want to answer some questions, you do not have to.

## What are the benefits of the research project?

We are doing this study for research purposes. Our aim is to learn more about mental health in young people with complex communication needs, rather than to provide counselling to you. This means that the study will not directly benefit you, or the young person you support, but outcomes of this study are expected to benefit young people with disability in the longer term.

## Who is involved in this project?

Jacinta Pennacchia will use the project results as part of completing a Doctor of Philosophy (PhD). She is a speech pathologist and researcher. Her PhD is supported by the Swedish Research Foundation Grant for the CHILD research group and the Centre of Research Excellence: CP-ACHIEVE by the NHMRC (GNT1171758). This study is also supported by the Speech Pathology Australia New Researcher Grant. Other people involved in this project are her supervisors: Prof Christine Imms, Prof Dave Coghill, and Prof Mats Granlund, and consumer advisors: Shirley Wong, Greg Bonyhady, and Chris Pacheco. A research assistant may also be involved in this project.

## How will you store, use, and share my information?

By consenting to participate, you are consenting to the researchers collecting information for this project using an interview. Information about you will be stored securely on the University of Melbourne REDCap server.

Interviews will be recorded via Zoom. We will immediately download the recording and store it securely under password protection on the University of Melbourne server. It will then be deleted from Zoom. After the interview, someone in the research team will transcribe the recording. This means we will make a full written copy of the recording. After we have transcribed the recording, it will be permanently deleted. You will not be named or identifiable in the transcripts. Transcripts will be saved and stored securely under password protection on the University of Melbourne server.

Authorised representatives from the University of Melbourne, the RCH Human Research Ethics Committee, Research Governance Office and regulatory agencies may inspect documents and records with your identifiable information. We will not share your identifiable information with anyone else except as required by law. You have the right to access and correct the information we collect and store about you. This is in line with relevant privacy laws. Please contact us if you would like to access this information.

We will store deidentified data for an indefinite period. We will use a special ID number so your name will not be attached to the data. We will use these deidentified data in future ethically approved research. We may need to move your deidentified data to other locations. This includes overseas. We will make sure that we only send data to secure and ethically approved locations. However, any deidentified data that we send overseas are not protected by Australian laws and regulations. We will not contact you to use the data in future research. You can only take part in this project if you consent to us sharing your deidentified data. By signing this consent form, you agree to let us do this.

## Can I withdraw from the project?

You can withdraw from the project at any time. You just need to tell us. You do not need to tell us why you are withdrawing from the research project. If you leave the project, we will continue to use the information we have already collected about you. If you do not want us to use this information, you can tell us. If we have not already begun analysing the data, we will stop using your information and securely destroy the information.

## Will I find out the results of the project?

At the end of the research project, we may present the results at conferences and publish the results in scientific journals. We will do this in a way that protects your privacy. At the end of the project, we will send you a final letter. This letter will explain what we found out in this project – in other words, our project results. The letter will not have any specific information about you.

## What about future research opportunities?

We would like to send you information about future research projects that may be of interest. If you agree to this, we will send you information about these new projects. You can then decide if you want to take part in these projects. You can say no to these projects if you want to. You might agree for us to send you information about new research projects and then change your mind later. This is perfectly ok. If you want us to stop sending you information about new research projects, just let us know.

## What is the next step?

If you choose to be part of this study, the next step is for you to sign the consent form and schedule a time with the researcher to complete the interview. If you have any questions about the project, you can contact Jacinta Pennacchia on 0409 846 211. You can also email her at Jacinta.Pennacchia@mcri.edu.au.

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| You can contact the Director of Research Operations at The Royal Children’s Hospital if you:* have any concerns or complaints about the project
* are worried about your rights as a research participant
* would like to speak to someone independent of the project.

The Director can be contacted by telephone on (03) 9345 5044. |

**Consent Form**

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* I have read this information statement and I understand its contents.
* I understand what I have to do to be involved in this project.
* I understand the risks I could face because of my involvement in this project.
* I have had an opportunity to ask questions about the project and I am satisfied with the answers I have received.
* I understand that this project has been approved by The Royal Children’s Hospital Melbourne Human Research Ethics Committee. I understand that the project is required to be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
* I understand I will receive a copy of this Information Statement and Consent Form.

**Consent**

I voluntarily consent to take part in this research project.

**Optional consents**

|  |  |  |
| --- | --- | --- |
| **Optional consent: [contact about future projects]**I consent to be contacted about future research projects related to mental health and young people with complex communication needs. | [ ]  I consent | [ ]  I **do not** consent  |

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| --- | --- | --- | --- | --- |
| Participant Name |  | Participant Signature |  | Date |

**Declaration by researcher:** I have explained the project to the participant who has signed above. I believe that they understand the purpose, extent and possible risks of their involvement in this project.

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| Research Team Member Name |  | Research Team Member Signature |  | Date |

Note: All parties signing the Consent Form must date their own signature.