

Participant Information Sheet and Consent Form for Interview/Focus Group
For someone supporting a person with intellectual disability
 Improving palliative care for people with Intellectual Disability
 Professor Julian Trollor, Dr Janelle Weise & Dr Rachael Cvejic

Health/Social Science Research - Adult providing own consent

MASTER University of New South Wales (UNSW)

Title	Improving palliative care for people with intellectual disability
Short Title	Palliative care for people with ID
Protocol Number	2021/ETH11030 V2.0
Project Sponsor	Australian Government, Department of Health (Public Health and Chronic Disease Grant Program, National Palliative Care Projects).
Coordinating Principal Investigator/ Principal Investigator	Professor Julian Trollor
Location	UNSW Sydney

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called “Improving palliative care for people with intellectual disability”. You have been invited to provide support for a research participant.

This Participant Information Sheet and Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether to take part, you might want to talk about it with a relative or friend.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

If you decide you want to take part as a person providing support in this project, you will need to read and sign the Consent Form below. You will be given a copy of this Participant Information Sheet to keep.

2 What is the purpose of this research?

This research aims to design, implement, and evaluate a new palliative care service for people with intellectual disability. This is important because people with intellectual disability often find it hard to access palliative care that is tailored to their needs.

To do this we are first speaking to people with intellectual disability, their support networks, and health professionals to find out about access to palliative care for people with intellectual disability. We want to know:

1. What makes good palliative care for people with intellectual disability? and
2. How could palliative care services best operate to meet the end of life needs of people with intellectual disability?

The data will be used to help us to design a new model of palliative care. This new model of palliative care will be piloted in 2022 in South Western Sydney Local Health District.

This research has been initiated by a team led by Professor Julian Trollor from the Department of Development Disability Neuropsychiatry, UNSW Sydney with funding from the Australian Government, Department of Health (Public Health and Chronic Disease Grant Program, National Palliative Care Projects).

3 What does participation in this research involve?

3DN are conducting interviews and focus groups with people with intellectual disability. Some people with intellectual disability may wish to have a support person attend the interview with them.

As a support person your role is to sit in on the interview or focus group with the person with intellectual disability and help them to communicate in the best way possible with the researcher. Your role as a support person in this research is to:

- Facilitate and interpret the person's speech or communication
- Rephrase questions in words or ways that the person will understand
- Give an example that might help the person understand better
- Alert the researcher to subtle signs of the person being upset or distressed
- Provide moral support and motivation

Your role as a support person is not to answer the questions for the person with intellectual disability. Your role is to help the person with intellectual disability answer themselves.

3DN are also interested in the experiences of family members, friends, and support people (both paid and un-paid) of people with intellectual disability during the end of their life. If you are interested in participating in the research project yourself, there is the option to separately complete a survey or participate in an interview or focus group. If you would like more information on this, please contact our Project Officer, Sara Elsie Walker, on (02) 9065 7786 or IDPalliativeCare@unsw.edu.au.

Your responsibilities as a support person are:

- To help the person with intellectual disability communicate in the best way possible

- To assist in ways that are reflective of the person's opinion
- To be discrete about the information you hear from the person during the interview and to respect the person's confidentiality.

The interview/focus group will take a maximum of 2 hours and will ask the person with intellectual disability i) demographic questions (e.g., about their age and gender), ii) about current palliative care services and their ability to meet the needs of people with intellectual disability, and iii) how best a palliative care service for people with intellectual disability could operate.

Any information obtained in connection with this research project will remain confidential.

We would like to take notes during the interview and seek your permission to record what you say to make our notes better.

Please note that if the person being interviewed consents to the audio recording but you do not, the interview will still be recorded. However, we will not use your personal input in the data analysis.

If the person you support uses communication aids, we may also want to take pictures of these aids.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way.

There are no costs associated with participating in this research project, nor will you receive any payment in your role as a support person.

4 Other relevant information about the research project

This project will regularly seek input from an advisory group that is made up of people with intellectual disability, people who support a person/people with intellectual disability and healthcare and disability professionals. We would also like to share de-identified feedback from participants with our research advisors to ensure we understand and appropriately manage any participant feedback that we receive. An option is included on the Participant Consent Form asking if you would be happy for us to share any feedback you give us with our research advisory network.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish 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 project at any stage by signing and returning the Withdrawal of Participation Form provided below.

If you do decide to take part, you will be given a Participant Consent Form to sign and you will be given a copy of this Participant Information Sheet to keep.

Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with professional staff or your relationship with UNSW, Sydney.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, a possible benefit may include improvement in the standard of palliative care services for people with intellectual disability. We hope that this project will enable the Australian Government to fulfil their commitment to the National Palliative Care Strategy, which includes assuring that evidence-based and quality palliative care is available to everyone. This may or may not directly or indirectly affect the quality of palliative care possibly experienced by the person/people with intellectual disability that you would be supporting in this research project.

There will be no clear benefit to you personally from your participation in this research.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may tell us you wish to skip it and go to the next question, or you may stop immediately.

If you become upset or distressed because of your participation in the research project, the research team will be able to recommend counselling or other appropriate support. E.g., we can assist you in contacting your General Practitioner to discuss the possibility of sessions with a psychologist. Please contact our Project Officer, Sara Elsie Walker, on (02) 9065 7786 or IDPalliativeCare@unsw.edu.au, who can help to arrange this support.

Alternatively, you can contact several free services directly, including:

Name/Organisation Beyond Blue
Telephone 1300 224 636
Email www.beyondblue.org.au

Name/Organisation Lifeline Australia
Telephone 13 11 14
Email <https://www.lifeline.org.au/>

8 What if I withdraw from this research project?

If you decide to leave the research project, the researchers will not collect additional information from you. If you no longer wish to have your data stored or do not wish to be contacted for research purposes you can withdraw your information by completing the withdrawal of consent form below or by phoning our Project Officer, Sara Elsie Walker, on (02) 9065 7786 or IDPalliativeCare@unsw.edu.au, and letting them know. Please note, your data would not be able to be removed from any data analysis or publications already developed.

Please note, if you decide to withdraw part way through an interview or focus group, we will not be able to remove your comments from the recording. However, we will not use your personal input in the data analysis.

9 Could this research project be stopped unexpectedly?

There are no foreseeable reasons as to why this project will be stopped unexpectedly.

10 What happens when the research project ends?

The research team intend to publish and report the results of the research project in a variety of ways. All information published will be done in a way that will not identify you or the person you are supporting.

You/the person you are supporting have a right to receive feedback about the overall results of this study. You/they can tell us that you wish to receive feedback by emailing IDPalliativeCare@unsw.edu.au. This feedback will be in the form of a one-page lay summary. You/they will receive this feedback after the study is finished.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the Consent Form below, you consent to the research team collecting and using personal information about you and the person you're supporting for the research project. Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

Any information obtained in connection with this research project that can identify you will remain confidential.

Electronic data collected from you and/or the person you are supporting will be stored on UNSW servers that require UNSW staff authorisation and a password to gain access. Individual logins must be used to access files. Access levels are set by UNSW IT. Data will be stored in adherence to UNSW IT Security Standards and Guidelines Policy.

Hard copies of data collected from you and/or the person you are supporting will be stored in a locked cabinet at the Department of Developmental Disability Neuropsychiatry, UNSW Sydney, 34 Botany Street, UNSW Sydney, Sydney 2052. Access to this data is restricted to research team members.

Audio or video recordings of you and/or the person you are supporting will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators. It will be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed.

Data will be retained for 5 years post publication of resulting manuscripts. After this time, electronic data will be permanently deleted from all storage devices and paper-based data will be shredded.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that neither you, nor the person you support, can be identified.

In accordance with relevant Australian and/or NSW privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Compensation

If you suffer any distress or psychological injury because of participation in this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

13 Who is organising and funding the research?

This research project is being conducted by Dr Julian Trollor, Dr Janelle Weise, Dr Rachael Cvejic, Dr Preeyaporn Srasuebkul, and Dr Simone Reppermund from the Department of Developmental Disability Neuropsychiatry, UNSW Sydney, as well as Professor Meera Agar, Professor David Currow, Dr Rebecca Strutt, Associate Professor Claire Vajidic, Associate Professor Richard Chye, Tracey Szanto, Janeane Harlum, and Professor Irene Tuffrey-Wijne. This research is being funded by the Australian Government, Department of Health (Public Health and Chronic Disease Grant Program, National Palliative Care Projects).

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of NSW Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you or the person you support have any problems which may be related to your/their involvement in the project, you/they can contact the following people:

Dr Janelle Weise

Lecturer

j.weise@unsw.edu.au

Dr Rachael Cvejic

Lecturer

r.cvejic@unsw.edu.au

Sara Elsie Walker

Project Officer

sara.walker@unsw.edu.au

16 Complaints of contact person

This study has been approved by the South Western Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Research and Ethics Office, Locked Bag 7103, LIVERPOOL BC NSW 1871 on 02 8738 8304 / fax 02 8738 8310 / email SWSLHD-ethics@health.nsw.gov.au, website: <https://www.swslhd.health.nsw.gov.au/ethics/information.html> and quote [2021/ETH11030].

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.

Declaration by the person providing support

- I understand I am being asked to provide consent to participate as a support person in this research project.
- I have read the Participant Information Sheet or someone has read it to me in a language I understand;
- I understand the purposes, study tasks and risks of the research as described in the Participant Information Sheet;
- I have had the opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to participate in this research project 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 the named research members;
- I understand that I will be given a copy of the Participant Information Sheet to keep
- I understand that the research team will audio/video record the interviews/focus groups or take pictures of communication aids if necessary; I agree for myself to be recorded for this purpose.
- I agree not to disclose any information discussed during the interviews/focus groups and to maintain confidentiality.

I provide my consent for the information collected about the person I support/myself to be used for the purpose of this research project only.

Sharing de-identified participant feedback with a research advisory network (please circle one option)

- I have read the participant information sheet and consent to sharing of any feedback I give in a de-identified format to a network of research advisors.

YES / NO

Support Person Signature

Name of Support Person (please print):	
Signature of Support Person:	
Date:	

Declaration by researcher*

I have given a verbal explanation of the research project, the project activities and the risks and I believe that the support person has understood the explanation.

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 project.

Note: all parties signing the consent section must date their own signature.

Withdrawal of Participation Form

I wish to **WITHDRAW** my consent to participate as a support person in the research project described in the Participant information Sheet and understand that such withdrawal **WILL NOT** affect my relationship with any of the named organisations and/or the names research members.

Support Person Signature

Name of Support Person (please print):	
Signature of Support Person:	
Date:	

The Withdrawal of Participation Form should be forwarded to:

Chief Investigator Name:	Professor Julian Trollor
Email:	j.trollor@unsw.edu.au
Postal Address:	34 Botany St, Randwick, NSW, 2031