

**Participant Information Sheet for Online Survey  
Support Person**

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)*

<b>Title</b>	Improving palliative care for people with intellectual disability
<b>Short Title</b>	Palliative care for people with ID
<b>Protocol Number</b>	2021/ETH11030 V2.0
<b>Project Sponsor</b>	Australian Government, Department of Health (Public Health and Chronic Disease Grant Program, National Palliative Care Projects).
<b>Coordinating Principal Investigator/ Principal Investigator</b>	Professor Julian Trollor
<b>Location</b>	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 because we would like to learn from your experiences of supporting a person with intellectual disability at the end of their life.

This Participant Information Sheet 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, friend or local health worker.

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 in the research project, by submitting this online survey you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

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 which 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?

Your experiences will be used to help us to design a new model of palliative care. This new model of palliative care will be tested 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?**

If you decide to participate in this study, you will be asked to complete an online survey. You can complete this survey by clicking on the link provided to you in the invitation email. Alternatively, we can send you a paper-based version for completion. Please contact the Project Officer, Sara Elsie Walker on (02) 9065 7786 or [IDPalliativeCare@unsw.edu.au](mailto:IDPalliativeCare@unsw.edu.au), to request this.

The first part of this survey will determine if you are eligible to take part. Completing the screening questionnaire will take approximately one minute. If the screening questionnaire shows that you meet the requirements, then you will be able to start the research project. If the screening questionnaire shows that you cannot be in the research project, the research coordinator will discuss other options with you.

The survey will take no longer than 20 minutes and will ask you i) demographic questions, 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. You do not have to complete the survey all at once and can return to it as many times as needed.

Any information obtained in connection with this research project will remain confidential. You will not be asked for your name or contact details (unless you request a paper-based

copy of the survey or provide your email address in a separate survey form to receive a copy of the study results or enter the prize draw).

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, you can elect at the end of the survey to put your name in the draw to win a \$120 gift voucher.

#### **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 survey 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 leave the research project, the researchers will not collect additional information from you. Please note that once you submit the survey, we will not be able to delete your responses as the survey is completely anonymous.

If you do decide to take part, 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 your support role and the quality of end of life care experienced by the person/people with intellectual disability that you support.

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 GP to discuss the possibility of a Mental Health Care Plan. This will entitle you to 20 Medicare rebated mental health sessions with a Clinical or General

Psychologist. Please contact our Project Officer, Sara Elsie Walker, on (02) 9065 7786 or [IDPalliativeCare@unsw.edu.au](mailto: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](http://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. Please note that once you submit the survey, we will not be able to delete your responses as the survey is completely anonymous.

## **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.

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by emailing [IDPalliativeCare@unsw.edu.au](mailto:IDPalliativeCare@unsw.edu.au). This feedback will be in the form of a one-page lay summary. You 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 submitting the survey, you consent to the research team collecting and using personal information about you for the research project. The personal information that the research team collect, and use is information from the online survey. 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. All information in the survey is anonymous and is not identifiable. If you decide to go in the draw to win the prize your email address will be collected but will not be linked to your survey responses.

Electronic data 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 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 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 you cannot 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 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 South Western Sydney Local Health District, 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 have any problems which may be related to your involvement in the project, you can contact the following people:

### **Dr Janelle Weise**

Lecturer

[j.weise@unsw.edu.au](mailto:j.weise@unsw.edu.au)

### **Dr Rachael Cvejic**

Lecturer

[r.cvejic@unsw.edu.au](mailto:r.cvejic@unsw.edu.au)

### **Sara Elsie Walker**

Project Officer

[sara.walker@unsw.edu.au](mailto: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](mailto: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.**

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