**Health/Social Science Research** -*Adult providing own consent*

*MASTER South Eastern Sydney Local Health District*

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| **Title** | Implementing a tailored model of palliative care for people with intellectual disability |
| **Short Title** | Tailored palliative care for people with intellectual disability |
| **Protocol Number** | 2023/ETH01786 V2.0 |
| **Project Sponsor** | Australian Government, Department of Health and Aged Care (Public Health and Chronic Disease Grant Program, National Palliative Care Projects). |
| **Coordinating Principal Investigator/ Principal Investigator** | Professor Julian Trollor |
| **Location** | South Eastern Sydney Local Health District |

**Part 1**  **What does my participation involve?**

**1 Introduction**

You are invited to take part in this research project, which is called implementing a tailored model of palliative care for people with intellectual disability. Palliative care is help for people who have an illness or a condition that they will die from. You have been invited because we would like to learn from your experiences as a person with intellectual disability who is accessing palliative care, to trial and provide feedback on new information resources on palliative care. Your feedback will help shape these resources to support other people with intellectual disability and their supporters, and palliative care health workers.

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, friend or support person.

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 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 test new information resources to help people with intellectual disability, their supporter/s and health workers have a better experience in palliative care.

The resources aim to:

a. Increase awareness of health rights when accessing palliative care among people with intellectual disability and their supporters

b. Increase understanding of palliative care among people with intellectual disability and their supporters

c. Improve identification of personal preferences and questions about palliative care for the person with intellectual disability and their supporters

d. Increase awareness of local palliative care services and supports among people with intellectual disability and their supporters

e. Improve identification and engagement of key team members (including supporters and health professionals) working with the person with intellectual disability.

We will interview people with intellectual disability, their supporter/s, and palliative care health professionals after they use the resources to understand their experiences of the resources.

This is important because research tells us that people with intellectual disability find it hard to access palliative care that meets their needs.

It is expected that your experiences will help to develop a national Toolkit on tailoring palliative care for people with intellectual disability. The Toolkit will be launched in 2024.

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 and Aged Care (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 attend two interviews. The interviews will be one month apart. Please contact our Program Manager, Olivia Burton on 02 9348 1732 or [IDPalliativeCare@unsw.edu.au](mailto:IDPalliativeCare@unsw.edu.au), if you would like to take part.

If you would like to take part, we will first do a screening questionnaire to determine if you meet the requirements for being in the study. Completing the screening questionnaire will take approximately five minutes over the phone with us. 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, you will not be able to take part.

If you choose to be part of the study and can take part, we will ask you to come to two interviews. The first interview will take about 90 minutes. In this interview, we will start with demographics and health questions, followed by questions about the resource topics such as palliative care and health rights. We will also go through the resources with you.

After the first interview, we will invite you to a second interview. The second interview will be about one month after the first interview. The second interview will take about 90 minutes. In the second interview we will ask you questions about the resource topics, what you think about the resources, and any experiences you may have had using the resources.

You can ask a support person to come with you for the interviews if you would like them to. We can also arrange for interviews to take place over shorter sessions if you would prefer. The research team will try their best to adjust the format, time and location of meetings and interviews. For example, this might be face to face at South Eastern Sydney Local Health District, at your home, over the phone, or online (for example through Zoom).

There are no costs associated with this research project. You will be given a $100 gift card for your participation in each interview.

We will take notes during the interviews. We will also ask your permission to record what you say in the interviews. We may also ask to take photos of communication tools or aids. Any information obtained in connection with this research project will remain confidential. This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way.

**4 Other relevant information about the research project**

This project regularly seeks 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 professionals. We would 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. We would not share any personal information that would identify you (e.g., your name). An option is included on the Participant Consent Form asking if you would be happy for us to share 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.

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 routine care, 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 your understanding and experiences of palliative care as the resources have been designed with the aim of improving palliative care for people with intellectual disability. Another benefit may include improvement in the standard of palliative care services for people with intellectual disability. This may or may not directly or indirectly affect the quality of palliative and end of life care that people with intellectual disability, like yourself, are able to access.

**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 Program Manager, Olivia Burton, on 02 9348 1732 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:

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| **Name/Organisation** | Beyond Blue |
| **Telephone** | 1300 224 636 |
| **Email** | [www.beyondblue.org.au](http://www.beyondblue.org.au) |

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| **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 any further information from you. If you no longer wish to have your data stored or do not wish to be contacted about the research, you can ask for your information to be removed by completing the withdrawal of consent form below or by phoning our Program Manager, Olivia Burton on 02 9348 1732 or [IDPalliativeCare@unsw.edu.au](mailto: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.

**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 provided in plain English and Easy Read formats. 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 signing the Consent Form below, you consent to the research team collecting and using personal information about you 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 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 UNSW Sydney, UNSW Medicine & Health, Discipline of Psychiatry & Mental Health, Room 241, Level 2, Biolink Building E25, UNSW SYDNEY NSW 2052.

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 to the transcription service 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 Professor Julian Trollor, Dr Rachael Cvejic, Dr Janelle Weise, Ms Olivia Burton, Mr Amanuel Hagos, Dr Preeyaporn Srasuebkul and Associate Professor Simone Reppermund from the Department of Developmental Disability Neuropsychiatry, UNSW Sydney, as well as Professor Meera Agar, Professor David Currow, Dr Rebecca Strutt, Professor Claire Vajdic, Associate Professor Richard Chye, Ms Tracey Szanto, Ms Vanessa Evans, Ms Maria Heaton, and Ms Janeane Harlum. This research is being funded by the Australian Government, Department of Health and Aged Care (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 your question. If you want any further information about this project or if you have any problems which may be related to your involvement in the project, you can contact the following people:

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| **Ms Olivia Burton**  Program Manager  [o.burton@unsw.edu.au](mailto:o.burton@unsw.edu.au) | **Dr Rachael Cvejic**  Senior Research Fellow  [r.cvejic@unsw.edu.au](mailto:r.cvejic@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 2023/ETH01786.

The conduct of this study at this site has been authorised by SESLHD. Any person with concerns or complaints about the conduct of this study should contact the SESLHD Research Ethics and Governance Office on (02) 8797 7605 and leave a message with your contact details, or email [SESLHD-RSO@health.nsw.gov.au](mailto:SESLHD-RSO@health.nsw.gov.au) and quote 2023/STE03495.

**Thank you for taking the time to consider this study.**

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

**Declaration by the participant**

* 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 names 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 interview/meeting or take pictures of communication aids if neccessary; I agree for myself to be recorded for this purpose.

**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**

**Participant Signature**

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| Name of Participant  (please print): |  |
| Signature of Research Participant: |  |
| Date: |  |

**Declaration by researcher\***

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

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| 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 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 named research members.

**Participant Signature**

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| Name of Participant  (please print): |  |
| Signature of Research Participant: |  |
| Date: |  |

**The Withdrawal of Participation Form should be forwarded to:**

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| Chief Investigator Name: | Professor Julian Trollor |
| Email: | j.trollor@unsw.edu.au |
| Postal Address: | Room 241, Level 2, Biolink Building E25  UNSW SYDNEY NSW 2052 AUSTRALIA |