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

*MASTER South Western Sydney Local Health District*

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| **Title** | Implementing a tailored palliative care model for people with intellectual disability |
| **Short Title** | 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 Western 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. We invite you as a health professional involved in the provision of palliative care to participate in trialling and providing feedback on new information resources for people with intellectual disability, their supporters and health professionals. Your feedback will help improve these resources and understand their potential to improve palliative care for people with intellectual disability.

This Participant Information Sheet/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 colleague.

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?**

The aim of this research is to trial the implementation and effectiveness of new information resources to improve palliative care for people with intellectual disability.

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 undertake a preliminary evaluation of these resources based on interviews with people with intellectual disability, their supporter/s, and palliative care health professionals.

This study is important because research has shown that people with intellectual disability find it hard to access palliative care and to have their palliative care needs met.

It is expected that your experiences will feed into 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 an initial training session to be provided with information resources and asked to complete a short online feedback survey. You will then be asked at month three and six of the study to participate in follow-up interviews to provide more in-depth feedback about the resources. 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.

The first part of this process will determine if you are eligible to take part. 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 be unable to take part. If you choose to be part of the study and can take part, we will schedule an initial training session with you and ask you for some basic demographic information (e.g., your age, gender, professional background and experiences working with people with intellectual disability). The training session will take a maximum of 1 hour. This can be completed with other health professional participants from your district or individually, depending on your preference and availability.

At the end of this training session, you will be provided with a link to a short online anonymous survey to feedback on the provided resources and training. The online survey should take about five minutes and can be completed within the training session or in your own time.

The follow-up interviews will take a maximum of 30 minutes each and will ask you: i) your feedback on the study; ii) your feedback on the resources; iii.) your experiences using the resources with people with intellectual disability and their supporters.

Training and interviews will be offered virtually or face-to-face at the study site at which you are working or at the University of New South Wales.

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.

There are no costs associated with this research project. Health professionals will not be provided any reimbursement for participating in this research project.

**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 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 Project Advisory Group.

**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 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 provision of quality palliative care to everyone. This may or may not directly or indirectly affect your role and the quality of palliative care and 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 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 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 Program Manager, Olivia Burton on 02 9348 1732 and letting them know. Please note, your data would not be able to be removed from data analysis or publications already developed.

Please note, if you decide to withdraw part way through a group interview, we will not be able to remove your comments from the recording. However, we will delete what you say from the audio transcriptions and will not use your 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.

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 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 Department of Developmental Disability Neuropsychiatry, UNSW Sydney, UNSW Medicine & Health, Discipline of Psychiatry & Mental Health, Room 241, Level 2, Biolink Building E25, UNSW SYDNEY NSW 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 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 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:

**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 South Western Sydney Local Health District (site) has been authorised by the South Western Sydney Local Health District. Any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer on (02) 8738 8304, email: [SWSLHD-Ethics@health.nsw.gov.au](mailto:SWSLHD-Ethics@health.nsw.gov.au) and quote project number 2023/STE03494.

**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 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; 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 project advisory group

**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 names 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 |