Members Update

April 2023

Job opportunity: Project Manager position for NHMRC study on clinical trial of a digital health intervention to improve the wellbeing of patients with advanced cancer and their family carers.

The University of Melbourne is seeking a Research Fellow for the role of Project Manager for a National Health and Medical Research Council (NHMRC) project entitled "Improving the wellbeing of people with advanced cancer and their family carers: An effectiveness-implementation trial of an Australian dyadic digital health intervention (FOCUSau)." The Project Manager will manage and oversee the day-to-day operational requirements of the FOCUSau project and, in collaboration with the study leaders and the broader team, contribute to governance, data collection, analysis, and reporting of the research.

For further information, position description and how to apply please go to the link:
https://jobs.unimelb.edu.au/en/job/912515/research-fellow-in-digital-health-intervention

Please circulate this opportunity to your colleagues and networks.

Invitation to participate in a Delphi study on determining guiding principles and strategies for an optimal model of palliative care for people with intellectual disability in Australia.

You are invited to participate in a project that aims to identify and reach consensus on guiding principles and strategies for an optimal model of palliative care for people with intellectual disability in Australia. This is important because people with intellectual disability often find it hard to access palliative care that is tailored to their needs.

We are seeking people with expertise in the area of palliative care for people with intellectual disability. This might include clinical experience, involvement in policy and service design, and conducting research and advocacy on palliative care for people with intellectual disability. Participants may include clinical professionals, policy makers, academics, community support staff, health service managers, and professional advocates for people with intellectual disability. Participation will involve engaging in up to four rounds of an anonymous Delphi consultation. Each round will require a participant to complete an on-line survey that will take no longer than 20 minutes to complete. Each round of the survey will run for two weeks, with a two-week time frame between rounds.

If you are interested in participating in this consultation, please read the participant information sheet (attached below) and then complete an on-line registration form at: https://unsw.au1.qualtrics.com/jfe/form/SV_2g9xfyBFZWsuhf0 by **COB April 27, 2023**. Alternatively, you can send an email to a.hagos@unsw.edu.au to request a paper copy of the form to be returned via post to UNSW Sydney.

This project is being undertaken by the Department of Developmental Disability Neuropsychiatry, UNSW Sydney and has received approval from the UNSW Sydney Human Ethics Advisory Panel HREAP ref no HC230054.

For any inquiries / further information regarding the project, please contact the Project Officer, Amanuel Hagos, at a.hagos@unsw.edu.au.

Participant Information Sheet for Online Survey (Delphi Study)

Improving palliative care for people with Intellectual Disability

Professor Julian Trollor, Dr Janelle Weise, Dr Rachael Cvejic, Dr Preeyaporn Srasuebkul, Dr Simone Reppermund, Professor Meera Agar, Professor David Currow, Dr Rebecca Strutt, Professor Claire Vajdic, Tracey Szanto, Janeane Harlum, Maria Heaton, Vanessa Evans, Amanuel Hagos, and Olivia Burton.

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

Title	Determining guiding principles and strategies for an optimal model of palliative care for people with intellectual disability in Australia.
Short Title	Palliative care for people with intellectual disability.
Protocol Number	HC230054
Study 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.

Part 1 What does my participation involve?

1. Introduction

You are invited to take part in this research study, which is called determining guiding principles and strategies for an optimal model of palliative care for people with intellectual disability in Australia. You have been invited because you have been identified as having a specialised interest in this area.

This Participant Information Sheet tells you about the research study and its purpose. 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 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 the research study, by submitting this online survey you are telling us that you:

• Understand what you have read
• Consent to take part in the research described.

You will be given a copy of this Participant Information Sheet to keep.

2. What is the purpose of this research?

The research study aims to reach consensus on the guiding principles and strategies for an optimal model of palliative care for people with intellectual disability in Australia. The subsequent care model will be pilot tested in 2023 in South West Sydney Local Health District, New South Wales, Australia.

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 read this information carefully and complete up to four rounds of an anonymous 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, Amanuel Kidane Hagos on (02) 9348 0111 or IDPalliativeCare@unsw.edu.au, to request this or to ask about other options.

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 generate your personal code and start the online survey. If the screening questionnaire shows that you cannot be in the research study, the research coordinator will discuss other options with you.

You will be involved in a maximum of four rounds and each round will require you to complete an online survey which will take no longer than 20 minutes to complete. You do not have to complete the survey all at once and can return to it as many times as needed. The aim of having multiple rounds of consultation is that group consensus will be reached. In each round you will be asked to rate and comment on proposed content. You will be provided with written feedback after each consultation round.

Any information obtained in connection with this research will remain confidential. This research study has been also 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 study and participants will also not receive any financial benefits to their participation in the study.

4. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that you are eligible to take part. The research study is looking recruit people who meet the following inclusion criteria:

- Are 18 years of age or older, and

- Self-identify as having expertise in the area of palliative care to people with intellectual disability. This might include clinical experience, involvement in policy and service design, and conducting research and advocacy on palliative care for people with intellectual disability. Participants may include clinical professionals, policy makers, academics, community support staff, health service managers, and professional advocates for people with intellectual disability.

Exclusion criteria: under the age of 18 years

5. Other relevant information about the research study

The research team 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 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.

6. Do I have to take part in this research study?

Participation in any research study is voluntary. If you do not wish to take part, you do not have to. If you decide to leave the research study, 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 unless you provide us your email address or unique survey code.

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.

7. 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 study 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 is no clear direct benefit to you personally, but the research study will give you an opportunity to provide insights into your experience, and to use your expertise to facilitate change in this area of need.

8. What are the possible risks and disadvantages of taking part?

We do not expect this survey to cause any harm or discomfort. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately.

9. What if I withdraw from this research study?

You may withdraw from this research study at any time. You can do this by submitting the withdrawal of participation form. This form can be found on the last page of this information statement.

To complete this form, you will need to provide the research team with your email address (if you have only completed the eligibility survey) or the participant code that you generated. The researchers will then be able to destroy any information that has already been collected and no additional information will be collected from you. Please note that once you submit the survey, we will not be able to delete your responses without your participant code as the survey is completely anonymous.

10. Could this research study be stopped unexpectedly?

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

11. What happens when the research study ends?

The research team intend to publish and report the results of the research study in a variety of ways. This includes submitting reports to the funding body, publications in peer reviewed journals, sharing project summaries with key parties (e.g., New South Wales Ministry of Health), sharing plain English and easy read summaries with people with intellectual disability, their support networks and healthcare professionals, and presentations at relevant conferences. All information published or shared with key parties 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. 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 study being conducted?

12. What will happen to information about me?

By submitting the survey, you consent to the research team collecting and using personal information about you to administer the study. The personal information that the research team collects, including your email address will only be used to indicate your participation in the study and cannot be linked to the survey data. This information will only be disclosed to a third party with your permission, except as required by law.

Any information obtained in connection with this research study that can identify you will remain confidential. All information in the survey is anonymous and is not identifiable.

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, Room 241, Level 2, Biolink Building E25, UNSW Sydney 2052. Access to this data is restricted to research team members.

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 study will be published and/or presented in a variety of forums and accessible formats. 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.

13. Compensation

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

14. Who is organising and funding the research?

This research study is being conducted by Professor Julian Trollor, Dr Janelle Weise, Dr Rachael Cvejic, Dr Preeyaporn Srasuebkul, Dr Simone Reppermund, Professor Meera Agar, Professor David Currow, Dr Rebecca Strutt, Professor Claire Vajdic, Tracey Szanto, Janeane Harlum, Maria Heaton, Vanessa Evans, Amanuel Hagos and Olivia Burton.

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

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, Activity ID 4-E10LKYG).

15. Who has reviewed the research study?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Advisory Panel HREAP.

This study 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.

16. 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 study or if you have any problems which may be related to your involvement in the study, you can contact the following people:

Dr Rachael Cvejic
Research Fellow
r.cvejic@unsw.edu.au

Amanuel Kidane Hagos
Project Officer
a.hagos@unsw.edu.au

17. What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	

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.

If you have completed only the eligibility screening questionnaire please provide us with the following details so that we can destroy your personal information.

Participant email address	
Date	

OR

If you have participated in the Delphi please provide us with the following details so that we can destroy your responses.

Participant code	
Date	

A copy of this form should be forwarded to:

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