

ONLINE PARTICIPANT INFORMATION STATEMENT

Supporting people with intellectual disability living with dementia: Experiences of health, disability, and aged care workers
Dr Rachael Cvejic

1. What is the research study about?

You are invited to take part in this research study. The research study aims to explore the experiences of professionals across health, disability and aged care sectors when supporting people with intellectual disability experiencing changes in behaviour in the context of dementia. This research is important because the Australian population of people with intellectual disability is ageing, and people with intellectual disability are more likely to develop dementia, often at younger ages, than people without intellectual disability. You have been invited because you may support people with intellectual disability living with dementia as part of your professional role.

2. Who is conducting this research?

The study is being carried out by the following researchers: Dr Rachael Cvejic, Associate Professor Simone Reppermund, Professor Julian Trollor, Dr Tom Morris, and Ms Amelia Law, Faculty of Medicine and Health, UNSW Sydney.

Research Funder: This research is being funded by the Dementia Australia Research Foundation and the Bartle Pathway to Care.

3. Inclusion/Exclusion Criteria

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

- Being aged 18 years and older
- Having experience providing care to or supporting people with intellectual disability living with dementia while working in a paid role within the Australian health, disability or aged care sectors.

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

Participation in any research study is voluntary. If you do not want to take part, you do not have to.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Complete the online survey.

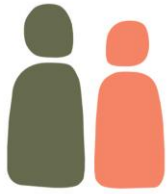
5. What does participation in this research require, and are there any risks involved?

If you decide to take part in the research study, we will ask you to complete an online survey. The survey will ask you questions about your role, your experiences and confidence related to supporting people with intellectual disability living with dementia, and your preferences for training in this area. It should take approximately 25 minutes to complete. Participants are not provided with reimbursement or incentive to take part in this project.

Some of the questions in the survey ask about your confidence supporting people with intellectual disability living with dementia who are experiencing specific mental health and behavioural changes. Some people might find mental health to be a sensitive topic. If you are not comfortable answering questions you can skip them or exit the survey. The survey also includes information about organisations that you can contact if you need of further support.

6. What are the possible benefits to participation?

We hope to use information we get from this research study to bring benefit to others; findings of the study will be used to develop strategies and recommendations for supporting people with intellectual disability living with dementia.



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7. What will happen to information about me?

Submission of the online questionnaire is an indication of your consent. By clicking the 'I agree to participate' button you are providing your permission for the research team to collect and use information about you for the research study.

The research team will store the data collected from you for this research project for a minimum of 5 years after the publication of the research results. The information about you will be stored in a non-identifiable format where your identity will be unknown.

8. How and when will I find out what the results of the research study are?

The research team intend to publish and/ report the results of the research. All Information will be published in a way that will not identify you. A copy of the results will be uploaded to the [project webpage](#) when the project has been completed.

9. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do this by closing the survey, however, we will not be able to withdraw your responses as the questionnaire is anonymous.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact

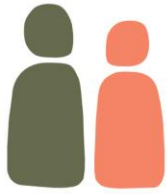
Name	Dr Rachael Cvejic
Position	Senior Research Fellow
Telephone	(02) 9065 1625
Email	r.cvejic@unsw.edu.au

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
Project Id	iRECS7715



National Centre
of Excellence in
**Intellectual
Disability Health**



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Consent Form – Participant providing own consent

Declaration by the participant

By checking the I agree/start questionnaire option below:

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet, or it has been provided to me in a language that I understand;
- I provide my consent for the information collected about me to be used for the purpose of this research study only.
- I understand that if necessary, I can ask questions and the research team will respond to my questions.
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I can download a copy of this consent form from <https://nceidh.org.au/our-work/projects/responsive-behaviours-intellectual-disability-dementia#PISCFP>.

[I agree, start questionnaire](#)