National Centre of Excellence in Intellectual Disability Health

UNSW SYDNEY

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM – Guardian

Guardians of people with intellectual disability living with dementia

Living with dementia: Experiences of people with intellectual disability and their supporters

Dr Rachael Cvejic

1. **What is the research study about?**
   You and the person you support are invited to take part in this research study. The research study aims to understand the experiences and perspectives of people with intellectual disability living with dementia and unpaid supporters of people with intellectual disability living with dementia. This research is important because people with intellectual disability are more likely to develop dementia, often at younger ages, than people without intellectual disability. This information sheet and consent form is for guardians of people with intellectual disability living with dementia.

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 Dr Janelle Weise at the 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 allow the person you support to participate in this research study, we need to ensure that it is ok for the person you support to take part. The research study is looking for people who meet the following criteria:
   - Aged 18 years or older
   - Live in Australia
   - Have an intellectual disability
   - Have a diagnosis of dementia

   People who meet the following criteria will be excluded from the study:
   - Participants that do not meet the above criteria.

   If you are answering interview questions on behalf of a person with intellectual disability that you support (i.e., as a proxy), we need to ensure that is ok for you to take part. A person acting as a proxy must meet the following criteria:
   - Is a guardian or authorised decision maker of a person with intellectual disability living with dementia

   Exclusion criteria for people who are not eligible to participate as a proxy in the study include:
   - People who do not meet the above criteria

4. **Do I have to take part in this research study?**
   Participation in this research study is voluntary. If you do not want the person you support to take part, they do not have to. If you agree for the person you support to take part and later change your mind, you are free to withdraw the person you support from the study at any stage.

   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);
   - Sign and return the consent form if you decide to participate in the study;
   - Take a copy of this form with you to keep.

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

If you agree for the person you support to participate, you and/or the person you support will be asked to complete the following research procedures.

Screening: A screening interview asking about the study inclusion criteria; this will determine if you and/or the person you support are eligible to take part. Completing the screening measures will take approximately five minutes. The screening questions will be administered to you in a telephone interview. If the screening interview shows that you and/or the person you support meet the criteria for inclusion, then you will be able to start the research project and the research team will organise a day and time convenient you and/or the person you support to participate in the research. If the screening questionnaire shows that you cannot be in the research project, the research team will tell you during the screening phone call will destroy any information that has been collected about you and the person you support.

Interview: An interview (face to face, online video, or telephone, depending on your location and preference), and you and/or the person you support will be asked questions about their experience as a person with intellectual disability living with dementia. The interview will take place at any of the following locations: i) the UNSW Health Translation Hub, Randwick NSW; ii) your home (depending on your location); iii) online over Teams or Zoom and will take approximately 60 minutes. With your permission the research team would like to audio record the interview. If you do not wish to be recorded but you would like to participate you advise the research team and written notes will be taken. The research team will contact you via your preferred contact method within one month to provide a summary of your interview to review and will ask for your feedback on the summary. You can provide your feedback by phone, email, or video call. You will receive an initial reminder and one follow up reminder.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project, nor will you or the person you support be paid. However, people who complete the interview (i.e., you and/or the person you support) will receive a $100 pre-paid gift card to reimburse for any reasonable travel, parking, meals and other expenses while completing the interview.

Psychological Distress: You and/or the person you support may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Alternatively, a number of free contactable support services are included at section 9. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

6. What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information about you for the research study.

The research team will store the data collected from you or the person you support for this research project for a minimum of 5 years after the publication of the research results.

The information about you or the person you support will be stored in a re-identifiable format where any identifiers such as your name, address, date of birth will be replaced with a unique code.

Your information will only be shared for the purposes of this research in a format that will not identify you or the person you support.

Information collected from you in an electronic format stored on a UNSW password protected OneDrive only accessible to the approved research investigators.

Audio recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators. Audio recordings will be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed.

The information you or the person you support provides 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**.

7. **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.

If you or the person you support would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

8. **What if I want to withdraw from the research study?**
If you do consent for the person you support to participate, you or the person you support may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

9. 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	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	10651

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 or the person you support's involvement in the study, you can contact the following member/s of the research team:

Chief Investigator

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

Support Services Contact Details

If at any stage during the study, you or the person you support becomes distressed or require additional support from someone not involved in the research please call:

For support and information about mental health

Name/Organisation	Beyond Blue
Telephone	1300 22 4636
Website	https://www.beyondblue.org.au/about/contact-us

For support and information about dementia

Name/Organisation	National Dementia Helpline
Telephone	1800 100 500
Website	https://www.dementia.org.au/get-support/national-dementia-helpline

Consent Form – Participant providing own consent

Declaration by the participant

- ☐ I understand I am being asked to provide consent for the person that I support to participate in this research study;
- ☐ I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- ☐ I understand the purposes, study tasks and risks of the research described in the study;
- ☐ Recordings: I understand that the research team will audio record the interviews; I agree to be recorded for this purpose.
- ☐ I provide my consent for the information collected about the person I support to be used for the purpose of this research study only.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ 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 will be given a signed copy of this document to keep.
- ☐ I understand that the results of the research will be made available on the National Centre of Excellence in Intellectual Disability Health website.
- ☐ I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: _____

Address: _____

Email Address: _____

Parent/Guardian Signature

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

Declaration by Researcher*

- ☐ I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

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 study. Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent for the person I support to participate in this research study described above and understand that such withdrawal **WILL NOT** affect mine or the person I support's relationship with The University of New South Wales.

- ☐ I am withdrawing the person I support's consent and I would like any identifiable information collected about me or the person I support which I have provided for the purpose of this research study withdrawn.
- ☐ I am withdrawing the person I support's consent to participate in further components of this research and provide my permission for the research team to retain and/or use information collected about me which I have provided for the purpose of this research.
- ☐ I am withdrawing my consent and I understand that any information already published cannot be withdrawn from the research.

Participant Name

Name of Participant (please type)	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Dr Rachael Cvejic
Email:	r.cvejic@unsw.edu.au
Phone:	(02) 9065 1625
Postal Address:	National Centre of Excellence in Intellectual Disability Health UNSW Health Translation Hub 55 Botany Street, Level 6 North Randwick NSW 2031