

<Insert Site Logo>



<Participant First Name> <Participant Surname>
<Participant Street Address 1>
<Suburb> <State> <Post Code>

<Date>

Dear <Participant First Name>,

You are receiving this letter because you recently attended <Site Name>, and that clinic is participating in the Australian Dementia Network (ADNeT) Registry. This registry has been established to improve clinical care for people with dementia and mild cognitive impairment.

Your participation in the registry helps us understand what is working well and what needs to be changed to provide the best quality of clinical care and services in Australia for people with dementia and mild cognitive impairment. We have enclosed a Participant Information Sheet which describes what participation involves and how your privacy is protected.

Participation in the ADNeT Registry is voluntary. You do not need to do anything to be included in the registry. If you do not wish to participate, the accompanying Participant Information Sheet provides information on how to withdraw from the registry.

Your decision about participating in the ADNeT Registry will not change the clinical care you receive.

Please feel free to contact us on **1800 314 421** if you have any questions.

We value your involvement and support in this important initiative.

Yours sincerely,

A handwritten signature in cursive script, appearing to read "Susannah Ahern".

Professor Susannah Ahern
Australian Dementia Network Registry
Monash University

Participant Information Sheet

1. What is the Australian Dementia Network (ADNeT) Registry?

The Australian Dementia Network (ADNeT) Registry has been established to improve clinical care for people with dementia and mild cognitive impairment. We gather and analyse health and care information from people like yourself. This information will help us better understand your experience of diagnosis and clinical care. We use this information to see what is working well and what needs to be changed to provide the best quality of clinical care and services.

2. Why have I received this information?

You are being invited to be on the ADNeT Registry because you recently attended <Site Name>, and that clinic is participating in this registry.

3. What does participation involve?

You do not need to do anything to be included in the ADNeT Registry.

<Site Name> confidentially shares information that is gathered as part of your routine care with the registry, using a secure system and practices that comply with Australian privacy legislation and guidelines. This information includes your name, date of birth and contact details, as well as health information such as your diagnosis, medical history and medications. If you attend another participating clinic, your visit information may be added to the registry.

You and your care partner may be invited to complete short surveys, to help us understand your well-being and your experience of clinical care. **Participation in these surveys is voluntary.** You can call us on **1800 314 421** if you do not want to receive any surveys.

(Only for those indicated yes for research participation) [If you have expressed interest in participating in research studies, you may be invited as opportunities arise in the future. All research studies will be reviewed and approved by the ADNeT Registry Steering Committee.]

4. How is registry data used and how is my privacy protected?

We care about your privacy. All information collected is stored securely and treated confidentially. Your privacy is protected by our compliance with Australian privacy legislation and guidelines.

Participating clinics can access the data that they provide to the registry.

To help the registry better understand long-term health outcomes and service use, we will use a secure system to link your registry information to data routinely collected by various government bodies in relation to your health and use of government health and related services, such as Medicare, hospital and aged care

information. Any linked data will be stored in an anonymised form within a secure environment.

Only anonymised data is used to produce reports, papers and presentations for participating clinics, government, industry and researchers. This is how the quality of clinical care and health outcomes will be improved. **You will never be identified in any report, paper, or presentation.**

5. What do I need to do?

Your participation in the ADNeT Registry is voluntary.

You do not need to do anything to be included in the registry.

If you do not wish to participate, please contact us within four weeks from the date on the invitation letter by:

- free call **1800 314 421**, citing your Participant ID <Participant ID>,
- email: adnet.registry@monash.edu, citing your Participant ID <Participant ID>, or
- complete the attached Withdrawal Request Form and return using the reply-paid envelope.

You can change your mind later about participating. Contact us at any time if you wish to withdraw from the registry.

Your decision about participating in the ADNeT Registry will not change the clinical care you receive.

6. Contact information

For information about the ADNeT Registry, please contact us by:

- free call **1800 314 421**, or
- email: adnet.registry@monash.edu.

For information about memory or thinking problems or services available, contact the **National Dementia Helpline (1800 100 500)**.

7. Governance

The ADNeT Registry has been approved by the Alfred Hospital Ethics Committee. If you have any complaints about the registry, please contact the Complaints Officer at the Office of Ethics & Research Governance, Alfred Health on (03) 9076 3619 or email research@alfred.org.au and quote the following reference number: 44037. <If required by local governance office>. Alternatively, please contact <complaint contact details provided by local governance office>.

The Monash University Research Data Protection and Privacy Collection Statement provides more information about how Monash University collects and handles your personal information. You are welcome to access that statement via www.monash.edu.

Australian Dementia Network (ADNeT) Registry Withdrawal Request Form

If you **do not wish** to be included in the ADNeT Registry, please complete this Withdrawal Form and return it using the pre-paid envelope that has come with the form.

Participant First name

Participant Surname

Participant Date of Birth

Date

Month

Year

Please provide reason/s for withdrawing from the registry below if you are happy to share this information with us.

If you are a family member or friend completing this form **on behalf of the participant**, please provide your details below.

First name

Surname

Your relationship to the participant
