



## PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

### Primary Care Insights to Inform Improvements in Dementia Care in South Eastern Sydney

Chief Investigator Dr Stephanie Ward

#### 1. What is the research study about?

You are invited to take part in this research study. The research study aims to understand the experiences of primary care providers in diagnosing and managing dementia, and to explore their perspectives on existing and proposed models of care. The overall goal is to use these insights to inform improvement.

#### 2. Who is conducting this research?

The study is being carried out by the following researchers: Stephanie Ward, Peter Gonski, Anna Kersch, Holly Locke-Sodhi, and Patrick Bolton.

**Research Funder:** This research is being funded by South Eastern Sydney Local Health District (SESLHD).

#### 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 to recruit people who meet the following criteria:

- General practitioner or practice nurse
- Currently working within the South Eastern suburbs of Sydney)
- Aged 18 years or older
- Able to provide informed consent
- Able to participate in a face-to-face focus group conducted in English

Participants meeting the following criteria will be excluded from the study:

- Participants that do not meet the above inclusion criteria.

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

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage prior to commencement of the focus group session.

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 to participate you will be asked to complete the following research procedures.  
Optional Questionnaire: complete a questionnaire on simple demographical information (non-identifiable)

Focus Group: All focus group sessions will take place online and will take approximately 60 minutes. During the focus group, you will be asked about your experiences with diagnosing and managing dementia, as well as your views on current and proposed models of care. The research team will audio record the interview. If you decide to participate in the focus group, your comments along with other participants will be recorded during the group discussions. Because of the way in which the focus group discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses once focus group sessions have begun. If applicable, you will be



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asked to complete a follow up focus group, the research team will contact you via email to organise the time. 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 be paid.

**Risks :** While we don't expect the focus group to be more than an inconvenience, if you feel uncomfortable addressing certain questions or topics (i.e. discussing professional challenges or systemic barriers) please do not hesitate to inform us. If you do not wish to answer a question or contribute to a discussion point, you may skip it and wait for the next question, or you may stop immediately.

**Confidentiality in Group Settings:** There is a small risk of loss of confidentiality within the group setting. You will be sharing your views in front of others, and although all participants will be asked to respect each other's privacy and not repeat what is shared outside of the group, this cannot be guaranteed. All data will be de-identified during reporting to protect your confidentiality.

#### 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 for this research project for:

- A minimum of 7 years after the completion of the research.

Audio recordings may contain identifiable information. These recordings will be stored on a UNSW password protected OneDrive only accessible to approved research investigators. The recording may be made available to a transcription service (Microsoft Teams). Identifying information will be removed from the transcripts.

To participate, you must provide your consent for the research team to share or re-use the information collected from you in any future research.

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](#).

#### 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.

You will be invited to attend an optional follow-up 'member-checking' session (e.g., via Microsoft Teams) where preliminary findings will be presented and you will have the opportunity to provide feedback or clarification. The 'member-checking' session will not be recorded; however, relevant comments or clarifications may be noted and incorporated into the final analysis and write-up of results.



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If you 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 to participate, you 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. However, given the nature of focus group sessions, responses cannot be withdrawn once session begins as this has an impact on the rest of the focus group participant responses. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW, South Eastern Sydney Local Health District (SESLHD) or the Central and Eastern Sydney Public Health Network (CESPHN). If you decide to leave the research study, the researchers will not collect additional information from you.

#### 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

<b>Position</b>	UNSW Human Research Ethics Coordinator
<b>Telephone</b>	+61 2 9385 6222
<b>Email</b>	<a href="mailto:humanethics@unsw.edu.au">humanethics@unsw.edu.au</a>
<b>Project ID</b>	9085

#### 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 Details

<b>Name</b>	Dr Stephanie Ward
<b>Position</b>	Conjoint Associate Professor and Geriatrician
<b>Telephone</b>	02 9382 4252
<b>Email</b>	<a href="mailto:Stephanie.ward@unsw.edu.au">Stephanie.ward@unsw.edu.au</a>

##### Chief Investigator

<b>Name</b>	Dr Stephanie Ward
<b>Position</b>	Conjoint Associate Professor and Geriatrician
<b>Telephone</b>	02 9382 4252
<b>Email</b>	<a href="mailto:stephanie.ward@unsw.edu.au">stephanie.ward@unsw.edu.au</a>



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**Consent Form – Participant providing own consent**

**Declaration by the participant**

- I understand I am being asked to provide consent 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 and transcribe the focus groups; I agree to be recorded for this purpose.
- I provide my consent for the information collected about me to be used for the purpose of this research study and future research, and to be made available to other researchers as described at section 6 of this document.
- 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. I understand my responses will not be removed from the study if withdrawal occurs after a focus session has begun.
- I understand withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I would like to receive a copy of the study results via email, I have provided my details below and ask that they be used for this purpose only.

Name: \_\_\_\_\_

Email Address: \_\_\_\_\_

- I understand that I will be given a signed copy of this document to keep.

**Participant 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.**



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## Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, South Eastern Sydney Local Health District (SESLHD) or the Central and Eastern Sydney Public Health Network (CESPHN)

- I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn where possible (i.e. prior to commencement of focus group session).
- I am withdrawing my 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 and/or not linked to my identity 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 Stephanie Ward
Email:	<a href="mailto:stephanie.ward@unsw.edu.au">stephanie.ward@unsw.edu.au</a>
Phone:	02 9382 4252
Postal Address:	Department of Geriatric Medicine, Edmund Blackett Bldg, South wing, Ground floor, Barker St, Randwick, NSW 2031