PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
Exploring the Value of CogDrisk in a Memory Clinic Setting
Chief Investigator: Professor Kaarin Anstey

1. What is the research study about?

You are invited to take part in this research study. The research study aims to explore clinicians' views on the value of implementing a validated, online dementia risk assessment tool (CogDrisk) in memory clinic settings. The study will use focus groups with 4 to 10 clinicians per session to understand their preferences and perspectives regarding using a dementia risk assessment tool, and clinical experiences of practicing preventive health in memory clinics. The focus groups will be conducted by a clinician-researcher and will be audio recorded to assist with accurate data transcribing and analysis. The data will be used to evaluate the level to which the CogDrisk online tool meets identified needs, its useability, barriers, and facilitators to use, as well as areas for further improvement.

2. Who is conducting this research?

The study is being carried out by the following researchers:

- Scientia Professor Kaarin Anstey, Professor in the School of Psychology at the University of New South Wales (UNSW) and Senior Principal Research Scientist at Neuroscience Research Australia (NeuRA)
- Professor Sharon Naismith, School of Psychology at the University of Sydney
- Dr Alex Bahar-Fuchs, School of Psychology at Deakin University
- Professor Nicola Lautenschlager, Academic Unit for Old Age Psychiatry, University of Melbourne
- Dr Terence Chong, Academic Unit for Old Age Psychiatry, University of Melbourne
- Dr Matt Paradise, Centre for Healthy Brain Ageing, UNSW
- Professor Dina LoGiudice, Aged Care Medicine, Royal Melbourne Hospital
- Dr Inga Mehrani, Centre for Healthy Brain Ageing, UNSW
- Ms Alicia Zavarce, Research Assistant, Neuroscience Research Australia (NeuRA)
- Mrs Mollie Cahill, Research Assistant, Neuroscience Research Australia (NeuRA)
- Mrs Katrina Fyfe, Centre for Healthy Brain Ageing

Research Funder: This research is being funded by the Commonwealth Department of Health and Aged 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:

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- Fully registered and currently practicing health professional.
- Currently delivering memory clinic or specialist medical services (diagnostic, assessment, care coordination) for adults aged 40+ years referred due to memory or cognitive concerns.
- Field of practice includes geriatrics, neurology, psychiatry, nursing, psychology, other allied health.
- Based in Australia.
- Proficient in English.
- Have access to the internet.
- Willing to participate in an audio-recorded online focus group

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

- Read the information carefully and ask any questions.
- Digitally sign the consent form.
- Attend an online focus group session.

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

If you consent to take part in this study, you will be contacted by the Research Assistant to complete an online questionnaire and to arrange a focus group.

Focus Group: The focus group will take place online (on Zoom and/or Teams), consist of 4 to 10 participants and will take approximately 1 hour. It will be conducted by a clinician who will ask some structured questions to discuss your thoughts on the following questions/topics:

- Whether clinicians in memory clinics use risk assessment tools and what type.
- What aspects of such tools would make them useful or not.
- What are the barriers and facilitators to using risk assessment tools in the clinic.
- Experiences of practicing preventative health approaches in memory clinics.
- What sort of evidence, training or accessibility needs must be met before using such tools.

With your permission the research team would like to audio record the session. If you decide to participate in the focus group, your comments will be recorded during the session, but all data will be de-identified and collated in the analysis and subsequent reporting of results.

6. Total participation time

Participation in this study will involve 1 hour of your time.

7. Recompense to participants.

You will receive a $50 prepaid gift card as a token of appreciation. This will be emailed to you as an E-gift card.

8. What are the possible benefits to participation?

We cannot promise that you will receive any benefits from this study. Findings from this study will be used to improve the development of the CogDrisk online dementia risk assessment tool and future approaches to implementing it in clinical practice.

9. 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. You will be onboarded and give consent through the UNSW REDCap secure data capture system and your contact details will be stored there, kept separate from any survey or collected data. The audio recordings of the focus groups will

be downloaded and transcribed, and your name will be replaced with a unique code so that the data you provide is not linked to your identity, Data collected from you for this research project will be safely stored at UNSW and NeuRA servers. The de-identified data will be stored for a minimum of 5 years after the publication of the results while any identifiable data will be deleted once the study is completed. Folder access will be restricted to personnel via internal data security systems at NeuRA and will be limited to only named members of the research team on this application.

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

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

If you do consent to participate, you may withdraw at any time. You do not have to give any reason for withdrawing. However, please let the research know by email or a phone call.

Your decision not to participate or to withdraw from the study will not affect your relationship with any of the research team or Neuroscience Research Australia (NeuRA), UNSW Sydney or other institutions and organisations associated with this project. If you decide to leave the research study, the researchers will not collect additional information from you.

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 NeuRA, 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 NeuRA protects personal information is available in the NeuRA Privacy Policy.

12. 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	iRECS7033

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

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

Name	Alicia Zavarce
Position	Research Officer
Email	a.zavarce@neura.edu.au

Chief Investigator

Name	Kaarin Anstey
Position	Scientia Professor
Telephone	+61 02 9339 1019
Email	k.anstey@unsw.edu.au

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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 the focus group; 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 only.
- ☐ 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 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 (where applicable).

Name: _____

Email Address: _____