

Participant Information Sheet – English-speaking

Project Title: Brain Health, Your Way: Co-design and usability testing of a dementia risk reduction in culturally and linguistically diverse communities

Project Summary:

You are invited to participate in a research study being conducted by Dr Joyce Siette, Research Theme Fellow at Western Sydney University. This study aims to co-design culturally relevant resources and materials to inform a dementia awareness and risk reduction campaign for Australia's multicultural communities.

How is the study being paid for?

This study is being funded by the National Health and Medical Research Council and the Foundation for Australia-China Relations.

What will I be asked to do?

You will be asked to participate in up to 3 workshops/focus groups (~2hrs each) and/or 1 usability testing interview (~1hr). You will be asked to indicate your preference during the consent process by ticking the box next to which workshop/focus group/s and/or usability interview you would like to participate in. Researchers will then randomly assign you to each focus group you indicate a preference towards. The workshops/focus groups will occur face-to-face or online, depending on your preference. Each workshop/ focus group will focus on a specific topic to identify components that support behaviour change for culturally diverse adults.

After each workshop/focus group you will also participate in a brief survey (~2 min) to share your engagement experience. Campaign materials will also be developed and your feedback sought (approximately 1 hour, face to face).

How much of my time will I need to give?

This will depend on how many workshops/focus groups you attend and whether you decide to participate in a usability interview. Each workshop/focus group will take up to 2 hours and usability interviews will take up to 1 hr.

What benefits will I, and/or the broader community, receive for participating?

Participants will be paid \$30 upon completion of each workshop/focus group and/or usability interview.

Your participation in this study is invaluable as you contribute crucial data on culturally relevant, acceptable, and useful resources for developing a campaign supporting brain health and raising dementia awareness among culturally diverse adults.

You may also gain insights and ideas that could potentially inspire positive changes in your own

behaviours, leading to a healthier lifestyle for your brain.

Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?

We do not anticipate that this study will cause any discomfort or distress. However, as everyone's experiences vary, some questions during the workshops/focus groups, interviews, or surveys may address your experience as a caregiver or working with someone with dementia. If you find any aspect of this study stressful or upsetting, you have the option to stop at any time.

We recommend reaching out to your GP for support. Additionally, there are helplines and resources available for you to contact: *Lifeline: 13 11 14*

NSW Mental Health Line: 1800 011 511

National dementia Helpline: 1800 100 500.

If necessary, the research team can arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team.

How do you intend to publish or disseminate the results?

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified (e.g., in aggregate, overall findings), except with your permission. Participants will not be needed to provide any personal details, for instance, their name or address, so that we can ensure your confidentiality.

Will the data and information that I have provided be disposed of?

Please be assured that only the researchers will have access to the raw data you provide. However, your data may be used in other related projects for an extended period of time. We anticipate these projects to be similar in nature and to answer additional research questions that are yet to arise (e.g., cultural appropriateness, feasibility and acceptability of dementia awareness campaign). We propose that the data will be used for an additional five years. Following this period, the data and information you have provided will be securely disposed of.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. You are able to exit the online survey and stop participating in the workshop/focus group and usability interview at any given time.

If you do choose to withdraw from participating in the workshop/focus group, information that you have provided cannot be deleted because it is a focus group participation.

If you do choose to withdraw from participating in the usability interview your data will be deleted.

Can I tell other people about the study?

Yes, you can tell other people about the study by providing them with the flyer and/or the Chief Investigator's contact details.

- Dr Joyce Siette, Chief Investigator, MARCS Institute for Brain, Behaviour and Development; joyce.siette@westernsydney.edu.au

What if I require further information?

Please contact **Dr Joyce Siette** should you wish to discuss the research further before deciding whether to participate.

- Dr Joyce Siette, Chief Investigator, MARCS Institute for Brain, Behaviour and Development; joyce.siette@westernsydney.edu.au

Privacy Notice

Western Sydney University staff and students conduct research that may require the collection of personal and/or health information from research participants.

The University's Privacy Policy and Privacy Management Plan set out how the University collects, holds, uses and discloses personal or health information. Further details about the use and disclosure of this information can be found on the [Privacy at Western Sydney webpage](#).

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s. This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H 15878

Explanation of Consent

What will happen to my information if I agree to it being used in other projects?

Thank you for considering being a participant in a university research project. The researchers are asking that you agree to supply your information (data) for use in this project and to also

agree to allow the data to potentially be used in future research projects.

This request is in line with current University and government policy that encourages the re-use of data once it has been collected. Collecting information for research can be an inconvenience or burden for participants and has significant costs associated with it. Sharing your data with other researchers gives potential for others to reflect on the data and its findings, to re-use it with new insight, and increase understanding in this research area.

You have been asked to agree to Extended consent.

What does this mean?

When you agree to extended consent, it means that you agree that your data, as part of a larger dataset (the information collected for this project) can be re-used in projects that are

- an extension of this project
- closely related to this project
- in the same general area of this research.

The researchers will allow this data to be used by the research team in addressing similar topic areas (e.g., cultural appropriateness, feasibility and acceptability of dementia awareness campaign) to expand our understanding of motivating behaviour change amongst culturally diverse groups through public health campaigns.

To enable this re-use, your data will be held at the University in its data repository and managed under a Data Management Plan. The stored data available for re-use *will not* have information in it that makes you identifiable. The re-use of the data will only be allowed after an ethics committee has agreed that the new use of the data meets the requirements of ethics review.

The researchers want to keep the data for *five years* for possible re-use. After this time the data will be securely destroyed.

You are welcome to discuss these issues further with the researchers before deciding if you agree. You can also find more information about the re-use of data in research in the National Statement on Ethical Conduct in Human Research – see Sections 2.2.14 - 2.2.18.

<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>