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Participant Information Sheet

Project Title: Brain Station: a pre-post study of a co-designed brain health campaign for culturally and linguistically diverse communities

Project Summary:

You are invited to participate in a research study being conducted by Associate Professor Joyce Siette from the MARCS Institute at Western Sydney University. This research aims to evaluate a co-designed, culturally informed dementia risk reduction public health campaign "Brain Station" for ethnic communities. Specifically, Brain Station has been designed with and for Arabic, Chinese and Vietnamese communities. We are interested in the campaign's effect on modifiable dementia risk, awareness, and motivation in culturally diverse adults and older adults now and in 3 months' time.

How is the study being paid for?

This study is being funded by the National Health and Medical Research Council.

What will I be asked to do?

The Brain Station campaign involves an interactive installation that will be set up in a local shopping centre. If you decide to participate in the Brain Station campaign you will be asked to:

- Complete a 5-minute survey asking about your brain health. Question topics include your typical lifestyle behaviours and any pre-existing chronic conditions as well as dementia awareness and motivation levels.
- Undertake the activities in the Brain Station box over the following 12 weeks.
- Complete the same 5-minute survey at follow-up which will happen 112 weeks after visiting Brain Station in a link via email.
- Provide consent to be contacted for a 30-minute evaluation interview after completing the follow-up survey [optional].

How much of my time will I need to give?

- ~ 10 minutes for completing both baseline and follow-up surveys
- ~ 30 minutes for evaluation interview [optional]
- Whilst daily or weekly engagement with at least one item or resource in the Brain Station box is recommended across 12 weeks, this component of the intervention is self-directed. Therefore, you can decide how much time you dedicate to the intervention.

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

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Participants will be paid $10 upon completing the follow-up survey and $20 for completing the evaluation interview. The Brain Station box and its resources and items have an estimated value of $20.

Your participation in this study is invaluable as you contribute much-needed data on a culturally relevant, acceptable, and useful campaign for assessing dementia awareness, dementia risk, and motivation. Participation in this campaign and intervention may also inspire positive changes in your own behaviours and those of the broader community, leading to a healthier lifestyle for culturally diverse adults.

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 survey and results of your brain health profile may cause some discomfort or concern. Additionally, the evaluation interview may address your experience as a caregiver or working with someone with dementia. If you find any aspect of this study stressful for upsetting, you have the option to answer only the questions you are comfortable with or 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.

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. Your personal details (e.g., name) will be assigned a randomly generated ID which we will use for data collection and research purposes. Your personal and data will be disposed of 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

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online survey and stop participating in the interview at any given time. If you do choose to withdraw from participating in the surveys and/or 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, directing them to the website [insert hyperlink when website created] and/or providing the Chief Investigator's contact details.

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

What if I require further information?

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

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

You can also speak to one of our staff members at the Brain Station installation.

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 email the Ethics Committee through Research Services: 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 H16928.

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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 increasing dementia awareness, improving dementia risk and 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

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