**PARTICIPANT INFORMATION STATEMENT**

**Family carers – Study 1 Workshops**

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| --- | --- |
| **HREC Project Number:** |  |
| **Project Title:** | Draw-Care: Using animation and digital technologies to support Culturally and Linguistically Diverse (CALD) family carers and people living with dementia |
| **Chief Investigator:** | Professor Bianca Brijnath  Senior Research Fellow in the School of Occupational Therapy and Social Work, Curtin University  Divisional Director of Social Gerontology, the National Ageing Research Institute |
| **Co-Investigator:** | A/Prof Tuan Nguyen; Dr. Josefine Antoniades; Prof. Mathew Varghese; Prof. Santosh Loganathan; Dr. Joanne Enticott; Ms. Danijela Hlis; A/Prof. Duncan Mortimer; Prof. Nilmini Wickramasinghe; Dr. Andrew Simon Gilbert; Prof. Briony Dow; Prof. Claudia Cooper; Prof. Lily Dongxia Xiao; Dr. Antonia Thodis; Dr. Thu Ha Dang. |
| **Version Number:** | 2.0 |
| **Version Date:** | 6 December 2021 |

Please read this information carefully. Ask questions about anything you don’t understand or want to know more about.

Participation in this research is voluntary. If you don’t wish to take part, you don’t have to.

You may want to talk to a relative, friend or colleague before deciding whether you take part in this project.

**You can keep this information sheet.**

# **What is the Project about?**

You are invited to take part in the *Draw-Care* study, which aims to develop digital resources to improve the lives of people living with dementia and their family carers who are from a migrant background.

This study is funded by the Medical Research Future Fund (MRFF), Department of Mental Health and Substance Use, World Health Organization (WHO), Dementia Australia, and Federation of Ethnic Communities Council of Australia (FECCA). However, these organizations are not directly involved in the collection of study data, nor will they influence interpretation of the study findings.

# **Who is doing the Research?**

The project is being conducted by the National Ageing Research Institute (NARI); Monash University; Swinburne University of Technology (SUT).

# **What does my participation involve?**

You are invited to participate in up to six online co-design workshops. You do not need to participate in all six workshops; you can participate in as many workshops as you like.

The workshops will be spread over a 2-week period. Family carers, clinicians, and service providers working with people with dementia will participate. Each workshop will be approximately 2 hours long, and they will be held online over video conferencing platform, such as MS Teams.

During each workshop, participants will design an animation on one of the following topics:

* Reaching out for support
* Taking care of yourself
* Ensuring continuity of care
* Responding to change
* Being flexible
* Communicating effectively

Participants will be video-recorded. We will use these recordings to aid development of the animations, and they will not be made publicly available.

Once the digital resources are developed, you will be asked to view them and complete a short survey about their believability and trustworthiness.

# **Can I participate?**

You can take part in this study if you are:

* Aged 18 and over.
* Caring for a person with dementia at home
* Able to speak one of the following languages: Arabic, Cantonese, Greek, Hindi, Italian, Mandarin, Spanish, Tamil, or Vietnamese.
* Able to communicate in English.
* Able to provide consent.
* Able to access an internet connection, and have either a computer, laptop, tablet and/or smart phone.

# **What do I have to do?**

If you agree to participate, please sign the consent form at the end of this form and return it to the research team (EMAIL)

A member of the research team will then contact you to make a time for the interview. The person who contacts you will be fluent in English.

# **Do I have to take part in this research project?**

If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you can withdraw from the study.

Your decision will not affect any future relationship with the researchers, or any other individuals or organisations involved in the project.

# **What are the possible benefits of taking part?**

This study may or may not help improve your care of a person with dementia. By participating in this study, you are helping us to test the efficacy of our resources and make improvements to it.

# **What are the possible risks of taking part?**

Other than a time commitment of two to three hours of your time, we do not anticipate that there are any risks associated with participation in this study.

# **Can I withdraw from this research project?**

To withdraw your interview data, please notify us (EMAIL). We will ask you to sign a withdrawal of consent form, which is located at the end of this document. Please note that you will only be able to withdraw data prior to analyses of your data.

# **What happens when the research project ends?**

At the end of the research project, the resources will be made publicly available for free on the NARI website and on the Moving Pictures website. The research team will also produce reports and publications about the project. At your request, the researchers will also provide you with a one-page summary of the main results.

# **What will happen to information about me?**

Any identifiable information about you will remain confidential, except as required by law. The information will be held at Curtin University and the National Ageing Research Institute in locked filing cabinets and password protected electronic files. Only the research team will have access to these files. All data will be destroyed 25 years after the last publication of the project. De-identified data will be aggregated. This means it cannot be traced back to you. It will be analysed for group patterns. Overall, only group data and anonymous data will be presented in publications and presentations.

Whilst all care will be taken to maintain privacy and confidentiality of any information shared at a focus group or group discussion, you should be aware that you may feel embarrassed or upset if one of the group members repeats things said in a confidential group meeting.

# **Compensation**

There are no costs to you associated with participating in this research study, nor will the Draw-Care project compensate you for your participation. If you suffer any injuries or complications as a result of this research project, you should contact the research team as soon as possible. They will help you find appropriate treatment. If you are eligible for Medicare, you can receive medical treatment, free of charge, as a public patient in any Australian public hospital. If you are not eligible, we will find an alternative in your relevant state or territory.

# **Complaints**

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2020-XXXX). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

# **Further information**

Project manager: Dr. Antonia Thodis (Phone: +61 3 8387 2361; email: [T.Thodis@nari.edu.au](mailto:T.Thodis@nari.edu.au))

Project lead investigator: Professor Bianca Brijnath (email: [B.Brijnath@nari.edu.au](mailto:B.Brijnath@nari.edu.au)).

**CONSENT FORM**

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| --- | --- |
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* I have read the information statement version listed above and I understand its contents.
* I believe I understand the purpose, extent and possible risks of my involvement in this project.
* I voluntarily consent to take part in this research project.
* I have had an opportunity to ask questions and I am satisfied with the answers I have received.
* I understand that this project has been approved by Curtin University Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
* I understand I will receive a copy of this Information Statement and Consent Form.

|  |  |
| --- | --- |
| Participant Name |  |
| Participant Signature |  |
| Date |  |

|  |  |
| --- | --- |
| Witness Name  (if relevant) |  |
| Witness Signature |  |
| Date |  |

\* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older.

Optional

|  |  |  |
| --- | --- | --- |
| I do | I do not | consent to continuing electronic storage of my contact details and would like to be contacted about similar research in the future. |

|  |  |  |
| --- | --- | --- |
| I do | I do not | consent to the continuing electronic storage of my information for use in other research that is closely related to this research project. |

|  |  |  |
| --- | --- | --- |
| I do | I do not | consent to receive the NARI electronic newsletter (monthly), and consent to my email being added to the electronic mailing list. |

Declaration by researcher: I have supplied an Information Letter and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

|  |  |
| --- | --- |
| Researcher Name |  |
| Researcher Signature |  |
| Date |  |

*Note: All parties signing the Consent Form must date their own signature.*

**Withdrawal of consent**

|  |  |
| --- | --- |
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## Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my relationships with the researchers, NARI, or any individuals and/or organsations involved in the project. I understand that only data which has not been analysed or incorporated in the production of Draw-Care or written form may be withdrawn.

|  |  |
| --- | --- |
| Participant Name |  |
| Participant Signature |  |
| Date |  |