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## **Participant Information Sheet (General)**

**Project Title:** The what, how and why of complementary medicine use by Australians living with dementia.

**Project Summary:** You are invited to participate in a research study being conducted by Dr Genevieve Steiner, NHMRC-ARC Dementia Research Development Fellow, at the National Institute of Complementary Medicine (NICM), Western Sydney University.

This project aims to increase our knowledge of the complementary therapies that people living with dementia use, and the reasons for use, and the impact of these choices on quality of life. An understanding of the nature of complementary medicine use will help to prevent potential herb-drug interactions, encourage communication to medical practitioners, enabling the dissemination of evidence on the efficacy and safety of complementary therapies. We would like 30 people living with dementia to participate in this research project.

### **How is the study being paid for?**

The study is being sponsored by the National Institute of Complementary Medicine (NICM) and School of Science and Health at Western Sydney University.

### **What will I be asked to do?**

If you decide to participate in this project, you will complete a brief screening interview over the telephone (TICS-M) that involves some questions to determine your level of mental functioning. If you are eligible to participate, you will then be asked to complete a Participant Consent Form, provide some demographic information (e.g., age, gender, date of birth, diagnosis of dementia, and current medication use), and then answer a series of open-ended questions about your use of complementary therapies and your engagement with health and medical services. We will provide you with the questions at least a week in advance to give you time to prepare your answer and to help you decide whether you would like to participate in a group or by yourself. You can either participate in a focus group of around 6 people, or have an individual interview. The focus groups and interviews can either be done face-to-face, over the phone, or on the internet (via Zoom or Skype). You are also welcome to bring a close family member or friend (e.g., spouse, sibling, child over 18 years old) who does not necessarily need to be your carer if you would like their support. We will provide them with a consent form as well. If you do not wish to participate in a focus group with other people (either people with dementia and/or their close family member/friend), then an interview or an alternative focus group can be organised.

### **How much of my time will I need to give?**

It is expected that the focus group or interview will take around 1-1.5 hours of your time.

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

Although you will not receive any direct personal benefits for participating in the study, this research project has the potential to increase our understanding of the reasons that people living with dementia use complementary medicines, and the impact that this has on their lives. This work may lead to new knowledge which could assist in the development of health literacy information on complementary therapies for dementia. If you attend a face-to-face focus group, refreshments will be provided. All participants will go into a prize draw to win a \$150 Coles voucher.

**Will the study involve any discomfort or risk for me? If so, what will you do to rectify it?**

There is a risk that you might experience some discomfort if you have had a bad experience with complementary therapies, however you will be reminded participation is voluntary and that you can withdraw at any time. A list of appropriate counselling services will be provided should this occur. These will be freely available counselling services outside of the university and research team. Contact information for these services are detailed below:

Alzheimer's Australia National Dementia Help Line: 1800 100 500

Beyond Blue: 1300 22 4636

Lifeline: 13 11 14

**How do you intend to publish the results?**

Please be assured that only the researchers will have access to the raw data you provide. All aspects of the study, including results, will be confidential and only the researchers will have access to information on participants. The data collected from you and other participants will be stored with a participant code and there will be no identifiable information recorded, apart from age and sex, to ensure your confidentiality is maintained.

The findings of the research will be published in academic journals and/or discussed/ displayed in conference presentations, and presented in an annual report to the School of Science and Health. In any case, only group information and trends will be presented. No reference will ever be made to individual results, or individual participants.

\*Please note that the minimum retention period for data collection is five years post publication.

**Can I withdraw from the study?**

Participation is entirely voluntary and you are not obliged to be involved. If you do participate, you can withdraw at any time without giving a reason.

If you do choose to withdraw, any information that you have supplied will be de-identified and used in analyses.

**Can I tell other people about the study?**

Yes, you can tell other people about the study by providing them with the chief investigator's contact details. They can contact the chief investigator to discuss their participation in the research project and obtain an information sheet.

**Data storage**

There are a number of government initiatives in place to centrally store research data and to make it available for further research. For more information, see <http://www.andcs.org.au/> and <http://www.rdsi.uq.edu.au/about>. Regardless of whether the information you supply or about you is stored centrally or not, it will be stored securely and it will be de-identified before it is made available to any other researcher.

**What if I require further information?**

Please contact Ms Camilla Townsend should you wish to discuss the research further before deciding whether or not to participate.

Ms Camilla Townsend Phone: (02) 0413 061 192 Email: [ct937@uowmail.edu.au](mailto:ct937@uowmail.edu.au)

**What if I have a complaint?**

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is: H11733

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Research, Engagement, Development and Innovation office on Tel +61 2 4736 0229 Fax +61 2 4736 0905 or email [humanethics@westernsydney.edu.au](mailto: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.

Participant Information Sheet and Consent Form Version [1] [August 24, 2016]