

What questions and concerns do you have about medicine use in people living with dementia?

About this study

You have been invited to participate because you are a person living with dementia, or a carer, family member, friend or advocate of a person living with dementia. To decide what future research needs to be done we want to know what questions and concerns you have about medicine use in people living with dementia.

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

Participation in this study will involve filling in an anonymous questionnaire. It will take you about 10 minutes.

By completing and submitting this questionnaire online [returning to researchers using the reply-paid envelope] you are providing consent to the research team to use your anonymous responses.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the University of South Australia (HREC #202847).

The study is being conducted by researchers from:

- The University of South Australia, the University of Sydney, Monash University and the University of New South Wales.

And in partnership with the James Lind Alliance.

Click here to see the full Participant Information Sheet *[or See attached Participant Information Sheet for more details]*.

The following questions are about your eligibility for the study.

Are you at least 18 years old? Yes No

Are you Australian OR living and/or working in Australia? Yes No

If you answered 'Yes' to BOTH questions, please click the Next Page button below *[or continue filling out the questionnaire]*.

Phase 1: Evidence uncertainty questionnaire. Consumer version.

Tell us your questions and/or concerns!

It is important that medicines are used safely and effectively to get the best possible health and well-being outcomes. We are interested in your view about all the possible medicines that a person with dementia may take. This may include medicines for memory loss and other related symptoms, medicines for other medical conditions, prescription, over the counter, herbal and complementary medicines.

You may have questions or concerns about the possible benefits and harms of specific medicines (or combinations of medicines). You may also have questions or concerns about what you or healthcare professionals can do to make sure that medicines are being used safely and effectively.

Some examples may be:

- Could any of my medicines be affecting my memory?
- How can I help my loved one manage their medicines at home?

We are **not** looking for questions about the development or discovery of new medicines to treat or prevent dementia. (These types of questions are also important, but they are not the focus of this study.)

Feel free to complete the questionnaire alone or discuss it with others. You can ask a friend, family or an advocate to help you fill it out. You can write specific questions or concerns, something that happened to you or someone you know or a general theme/topic that you think is important. Write as much or as little as you like.

Please list **UP TO THREE** questions and/or concerns about medicine use in people living with dementia **that are the most important to you.**

1. _____

2. _____

3. _____

Phase 1: Evidence uncertainty questionnaire. Consumer version.

Please tell us a little about yourself. We will only use this information to make sure we are reaching a wide range of people.

1. Which of the following best describes you? (You can pick more than one option)

- Person living with dementia
- Family or friend of a person living with dementia
- Carer of a person living with dementia
- Prefer not to say
- Other: please specify _____

2. Your Gender

- Female
- Male
- Other
- Prefer not to say

3. Your Age

- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80+
- Prefer not to say

4. Where do you live?

- ACT
- NSW
- NT
- QLD
- SA
- TAS
- VIC
- WA
- Prefer not to say

5. In which country were you born?

- Australia
- Other, please specify: _____
- Prefer not to say

6. Are you of Aboriginal or Torres Strait Islander origin? *For persons of both Aboriginal and Torres Strait Islander origin, mark both 'Yes' boxes.*

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander
- Prefer not to say

7. Approximately how many different medicines do you (or the person you care for) take?

Please include all prescription and non-prescription medicines (e.g. vitamins and herbal medicines) including creams, inhalers and other non-oral medicines.

- 0 (none)
- 1-4
- 5-9
- More than 10
- I don't know
- Prefer not to say

Phase 1: Evidence uncertainty questionnaire. Consumer version.

8. How did you hear about this survey?

- Word of mouth
- Newsletter
- StepUp for Dementia Research registry
- Other:

Using your answers, we will make a long list of questions. **Would you like to help us decide the most important questions about medicine use in people living with dementia?**

If yes, please provide your name and email or postal address. We will only use your details to contact you about the next stages of this research project. Your details will be kept confidential and will not be shared with any other parties or used for any purposes other than stated here. Even if you say yes, you can decide whether or not you want to participate in future activities when we send you information about the next stages of this research project.

We'll keep your name and address separate from your answers, so this survey won't be linked to you.

THIS IS OPTIONAL. You do not have to provide this information if you do not want to.

Name: _____

Method of contact (email or postal address): _____

We would like as many people as possible to complete this questionnaire so please pass it onto your friends, family and healthcare professionals! Click [or Go to] this {link} for more information.