

**Top 10 unanswered questions
about medicines in people living
with dementia.**

**As determined by people living
with dementia, their carers,
family and friends, and
healthcare professionals.**



What?

This project aimed to identify the Top 10 unanswered quality use of medicines questions for people living with dementia. These questions were generated and prioritised by Australians living with dementia, their carers, family and friends, and health care professionals.

Why?

Quality use of medicines means using medicines safely and effectively to get the best possible health outcomes. It also means only using medicines when they are needed.

People living with dementia are diverse. They often have multiple other medical conditions and come from all socio-cultural backgrounds. There are many potential areas of research that could improve quality use of medicines for people living with dementia.

In the past, health research questions have been led by drug companies or researchers, with little involvement of consumers and healthcare professionals. We aimed to determine which questions are important to people living with dementia and their care team, to prioritise research in these areas and ensure that outcomes of research are directly relevant to the care of people living with dementia. This will lead to improving how medicines are used, which in turn will improve health outcomes in people living with dementia.

How?

We used the James Lind Alliance (JLA) Priority Setting Partnership (PSP) method of bringing together consumers and healthcare professionals, on an equal basis, to identify and prioritise evidence uncertainties for research to address.

This method aims to ensure that research is directed to clinical practice questions that are the most important, relevant and beneficial to the end users. The process involved multiple steps, shown on the next page.

As a person living with dementia, being involved was not only very interesting and rewarding for me, but I also felt respected and valued. There was a commitment from the Steering Group members to value advocates' and consumers' input and this developed into a worthwhile and meaningful research project that will have benefits to people living with dementia as well as to the body of dementia knowledge especially in relation to medication usage.

–

Ann Pietsch
Steering Group member

Our process

1. Form the Priority Setting Partnership

Included a Research Team, Stakeholder Steering Group, Partner Organisations and a JLA advisor.

- 12 x Research Team members (representing pharmacy, medicine, nursing and a consumer representative)
- 9 x Steering Group members (3 consumers and 6 healthcare professionals)
- 10 x Partner Organisations (including professional and consumer advocacy organisations)
- 1 x JLA advisor

2. Gather evidence uncertainties

First national survey which asked 'What questions do you have about medicine use in people living with dementia?'

- Survey responses from: 151 consumers and 77 healthcare professionals.
- We also interviewed 8 Key Informants and reviewed 4 existing documents.
 - 545 questions submitted

We grouped and summarised the responses gathered.

- 68 summary questions

3. Evidence checking

We looked into what research and guidelines existed to determine whether there is an 'answer' to the questions – that is, had high quality research already been done?

- 68 summary questions were individually checked by the Research Team
 - 67 unanswered questions

4. Interim priority setting

Second national survey where consumers and healthcare professionals were asked to pick the 10 questions that were most important to them from the unanswered questions.

- Survey responses from: 171 consumers, 67 healthcare professionals.
 - Top 16 unanswered questions

5. Final workshop

We conducted a virtual workshop with consumers, healthcare professionals and facilitators to determine and rank the top 10 unanswered questions.

- 17 consumers and healthcare professionals worked together with 4 facilitators to determine the:
 - Top 10 unanswered questions ranked

Consumer and healthcare professional **Top 10** unanswered questions about quality use of medicines in people living with dementia: priorities for research

1

How can **shared decision making** about medicines be achieved between healthcare professionals and people living with dementia and their carers?

2

What are effective ways to ensure that **healthcare professionals have the necessary knowledge and skills** to achieve safe, effective and appropriate medicine use in people living with dementia?

3

How can **communication between healthcare professionals** about medicines be optimised, especially at transitions of care, to achieve multi-disciplinary care for people living with dementia?

4

Which medicines are **potentially harmful or unnecessary** in people living with dementia and should be stopped? And how can **deprescribing** (cessation of harmful and/or unnecessary medicines) be achieved in people living with dementia?

5

When, how and in who should medicines be used to manage **pain** in people living with dementia?



6

How can people living with dementia and their carers be supported to **manage medicines safely at home**?

7

When and how should medicines be used to treat **changed behaviours** (previously referred to as behavioural and psychological symptoms of dementia)? Including for different types of dementia. And how to safely and effectively reduce the use of antipsychotics (for changed behaviours) in people living with dementia?

8

How can **residential aged care facilities best achieve safe, effective and appropriate** medicine use in residents with dementia?

9

When, how and in who should medicines be used to treat **depression and anxiety** in people living with dementia?

10

What is the **optimal model for medicine reviews** to achieve safe, effective and appropriate medicine use in people living with dementia? Including who should be involved, how often should reviews be conducted, and what follow-up is needed.

What's next?

Our overall goal is to have research funding and research efforts in Australia directed towards these Top 10 questions.

This will ensure that outcomes of research are directly relevant to the care of people living with dementia.

We cannot do this alone. See FAQs for how you can help us. →

FAQs

What should I do with this information? Are you a:

Researcher?

Consider how your research interests and expertise align with these consumer and healthcare professional priorities and whether there are any opportunities for you to start researching one of the Top 10. You may have students who need project ideas, or there may be funding opportunities you could apply for. Contact us for more information about the Top 10. You can use our findings to support your justification of why this research is important.

If your research interests aren't in the Top 10 – contact us! So many interesting and important questions were identified through our work and they could not all be included in the Top 10. We would love to share our findings about other questions with you.

Professional or consumer advocacy organisation?

Promote the Top 10 to your members! If you also fund research, see below. Contact us if you have other ideas of how we can direct research efforts to these Top 10 priorities.

Research Funder?

Consider a special grant call, or dedicating a portion of a health grant for research that addresses one or more of the Top 10 priorities. You can decide which questions align best with the values and priorities of your organisation.

Policy makers?

Share our findings with other stakeholders such as research funders. Contact us if you have other ideas of how to direct research efforts to these Top 10 priorities.

Healthcare professional, person living with dementia, carer and/or other interested members of the public?

Share this with anyone you think may be able to influence future research. For example, if you are involved with a professional or consumer association – send this summary to them and let them know you are interested in this work.

Why should I as a researcher/funder/policy maker/stakeholder direct my efforts to these Top 10?

Because these are the questions that are considered most important to consumers and healthcare professionals in Australia. The views of people who live with medical conditions and those who treat and care for them provide important insights into what research is most needed. Getting their perspectives helps to make sure that the right research is being done and makes the best use of valuable research funding. This means that if these questions are answered, it can have a direct impact on improving care and the lives of people living with dementia.

We know that when research aligns with consumer and healthcare professional priorities, they have better success at recruiting participants, and the results are likely to be translated into practice quickly. This means that research can start having an impact on real people sooner.

Do I need to ask permission to do/fund research in these areas?

Absolutely not! But we would really appreciate it if you let us know. We have much more information from our study that we would love to share with you which may help your work.

What if I have other questions or want more information?

Contact us.

Email Priorities.Dementia@unisa.edu.au

More information can be found here

www.unisa.edu.au/research/qumprc/our-research/optimising-medicine-use/#QUMDementia

More information about our methods and findings can be found here

www.jla.nihr.ac.uk/priority-setting-partnerships/Quality-Use-of-Medicines-in-People-Living-with-Dementia-Australia/

More information about the James Lind Alliance can be found here

www.jla.nihr.ac.uk/

Appropriate use of medicines in people living with dementia is a subject close to my heart. It was a big part of how my wife was mistreated. This experience gave me the incentive to want to be involved with this Priority Setting Partnership. It was really rewarding to have my input respected. And the end result was fantastic and will hopefully lead to good research that begins to address some of the problems in this area.

—
Ron Sinclair
Steering Group member



Who?

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This work would not have been possible without our Research Team, Stakeholder Steering Group, Partner Organisations and JLA advisor.

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National Association of Aboriginal and Torres Strait Islander Health Workers and Practitioners

Speech Pathology Australia

The Society of Hospital Pharmacists of Australia

