Consumer and clinician questions about quality use of medicines in people living with dementia: what are the priorities for future research?



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Stakeholder Steering Group: Ann Pietsch, consumer representative; Timothy Pietsch, consumer representative; Craig Whitehead, Geriatrician; Stephanie Daly, GP; Josephine To, Pharmacist; Marie Wittwer, Director of Care and Manager Residential Facilities; Judy Deimel, Nurse Practitioner; Lenore de la Perrelle, Social Worker



What is Quality Use of Medicines?

Using medicines safely and effectively, and selecting the best treatment for the individual (including not using medicines) to obtain optimal health outcomes

What are the challenges to achieving quality use of medicines in people living with dementia?

Exclusion of people living with dementia in drug trials = unknown benefits and harms

Polypharmacy, multimorbidity, and underuse of medicines are common

Issues with communication between healthcare professionals and at transitions of care

Continually changing goals of care which changes the benefit:risk ratio

Why ask consumers and clinicians?

- To ensure that research answers the questions that are encountered in practice.
- To efficiently use research funding.
- Reduce the evidence to practice gap (approx. 15 years for research evidence to be translated into practice).
 - Makes sure that research is answering the 'right' questions
 - Realigns healthcare research with the needs of those impacted by the issues being researched → improved research adoption

Aim

To identify the top 10 unanswered questions in the field of quality use of medicines in people with dementia according to Australians living with dementia, their carers, family and friends and health care providers.

Purpose: To inform health research funders, advocacy groups and policy makers about the unanswered questions, with the aim of directing future research funding, research efforts, and policy and practice change.

Methods

Following the James Lind Alliance (JLA) method to identify and prioritise the Top 10 unanswered questions.



- JLA is a non-profit making initiative.
- Brings people with experience of the condition, carers and clinicians together in Priority Setting Partnerships (PSPs).

Steps completed:

Create a Steering Group and recruit Partner **Organisations** Gather evidence uncertainties (survey) Summarise the responses gathered **Future steps: Evidence checking** Interim priority setting (survey) Workshop Publish and promote the Top 10 research priorities

Results

What questions and/or concerns have you had about medicine use in people living with dementia?

151 Consumer Responses People living with dementia (14) Carers (38) Family, friend or other (103)

8 Key Informant Interviews

6

77 Clinician Responses GPs (6) Geriatricians (8) Other specialists (6) Pharmacist (11) Nurse (29) Assistant in nursing/care worker (4) Allied Health and other

(13)

Themes (number of questions in theme)

Awareness and education (3)

Changed behaviours (3)

Healthcare system and person-centred care (7)

Residential aged care facilities (2)

Medication management (6)

Polypharmacy, multimorbidity and deprescribing (8)

Treatment of dementia (9)

Specific co-morbidities (11)

Adverse drug reactions and harms (12)

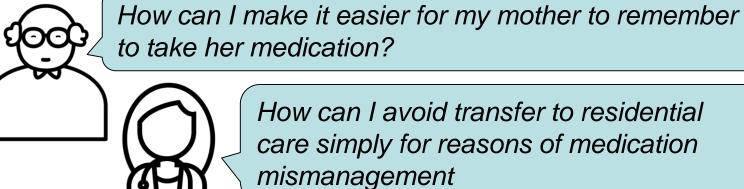
Monitoring for harms and benefits (1)

Pharmacokinetic and pharmacodynamic changes (1)

Influences on prescribing (2)

COVID-19 and lockdown restrictions (2)

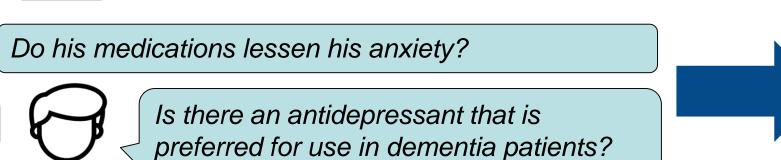
Example quotes and summary questions:

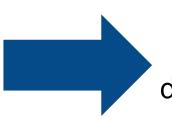




Summary question:

How can people living with dementia and their carers be supported to manage medicines safely at home? (Medication management theme)





Summary question:

When, how and in who should medicines be used to treat depression and anxiety in people living with dementia? (Specific co-morbidities theme)

Partner organisations: Leading Age Services Australia, Australian Association of Consultant Pharmacy, Consumers Health Forum of Australia, Speech Pathology Australia, The Society of Hospital Pharmacists of Australia, Australian College of Nurse Practitioners, Australian Association of Gerontology, Australian Nursing and Midwifery Federation, National Aboriginal and Torres Strait Islander Health Worker Association

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