

# Supplementary Material

## Consumer and Healthcare Professional Led Priority Setting for Quality Use of Medicines in People with Dementia: Gathering Unanswered Research Questions

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## Supplementary file 1: Consumer survey

### **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]*.

**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. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**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

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.**

## Supplementary file 2: Healthcare professional survey

### What questions do you have about medicines use in people living with dementia?

#### About this study

You have been invited to participate because you are a healthcare professional (or healthcare professional in training) and/or staff member of a healthcare organisation that provides care to people living with dementia. To decide what future research needs to be done we want to know what questions you have about medicine use in people living with dementia.

***If you have had any experience providing or facilitating care for people with dementia we would like you to take part in this research.***

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 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.

See attached Participant Information Sheet for more details.

#### The following questions about your eligibility for the study.

Are you at least 18 years old?  Yes  No

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

Are you a healthcare professional, healthcare professional in training (e.g. student) OR employed by a healthcare organisation to provide or administer care?  Yes  No

*If you have had any experience providing or facilitating care for people with dementia we would like you to take part. This includes clinical and administrative roles. You also do not need to be specialised in the area of dementia, nor primarily work in this field.*

If you answered 'Yes' to all three questions, please continue filling out the questionnaire.

## Tell us your questions!

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

### You may have questions about:

- the benefits and harms of specific medicines (or combinations of medicines) in specific scenarios or populations. For example, what medicines (or combinations of medicines) can worsen cognition in people with dementia?
- how to make sure medicines are being used safely and effectively, and only when needed. For example, what is the best way to help people manage their medicines at home?

We are **not** looking for questions about the development or discovery of new medicines to treat or prevent dementia. We are also not looking for questions about non-medicine care of people with dementia (unless it is related to use of medicines, for example, how we can reduce harmful medicine use). (These types of questions are also important, but they are not the focus of this study.)

Please list UP TO THREE questions **that are the most important to you**. You can write specific questions, an example scenario or a general theme/topic that you think is important. Write as much or as little as you like.

1. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**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. What is your profession (current or past relevant to this research)?

*Please tick all that apply (you can pick more than one). If you are currently in training (e.g. student) please tick BOTH the profession that you are training to be and the 'student' category.*

- GP
- Geriatrician
- Neurologist
- Other medical specialist: please specify \_\_\_\_\_
- Pharmacist
- Nurse practitioner
- Registered nurse
- Endorsed enrolled nurse
- Enrolled nurse
- Assistant in nursing
- Personal care assistant, aged care worker or trained carer
- Aboriginal and Torres Strait Islander health practitioner
- Dentist
- Dietician
- Exercise physiologist
- Medical radiation practitioner
- Occupational therapist
- Optometrist
- Physiotherapist
- Podiatrist
- Psychologist
- Social worker
- Speech pathologist
- Student/trainee/intern (please also select the profession that you are training to become)
- Other clinical role: please specify \_\_\_\_\_
- Other non-clinical role, e.g. administrative, support: please specify \_\_\_\_\_
- Other: please specify \_\_\_\_\_
- Prefer not to say

2. Where do you work (or most recent work situation if no longer working)?

*Please tick all that apply (you can pick more than one)*

- Primary care/ community
- Hospital
- Residential Aged Care Facility
- Outpatient clinics
- Other: please specify \_\_\_\_\_
- Prefer not to say

3. Primary location of practice (or most recent work situation if no longer working).

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



4. How long have you worked in your current profession?

- Less than 1 year                       11 – 20 years  
 1 – 5 years                               More than 20 years  
 6 – 10 years                               Prefer not to say

5. What is your experience in providing care for people with dementia? Please think about the proportion of people that you provide care for (either directly or indirectly).

*If you have had significant changes in the type of people you care for, please consider the population that you currently or mostly recently cared for (if you no longer care for people living with dementia).*

- A small to moderate proportion of the people that I care for are living with dementia (e.g. <50%)  
 Most but not all of the people I care for are living with dementia (e.g. >50%)  
 All of the people that I care for are living with dementia  
 Prefer not to say

6. Your Gender

- Female                                       Other  
 Male                                          Prefer not to say

7. Your Age

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

8. In which country were you born?

- Australia  
 Other, please specify: \_\_\_\_\_  
 Prefer not to say

9. 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

Using your answers, we will make a long list of questions. **Would you like to help us decide the most important questions about medicines 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.**

## Supplementary file 3: Key Informant Interview guide

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

Questionnaire for administration by a member of the research team over the phone or videoconference with key informants. Participant information sheet (PIS) will be provided to key informant(s) prior to the questionnaire with verbal information in accordance with the contents of the PIS and ability to clarify any questions prior to providing answers.

#### **Details about the key stakeholder:**

Details about the group that this key stakeholder represents:

*As relevant include details of organisation, consumer vs clinician, gender, age bracket, state, country of birth, Aboriginal or Torres Strait Islander origin. If representing clinicians, also include place/setting of work, and experience caring for people living with dementia.*

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## Supplementary file 4: Evidence checking results

Theme	Research Question (pre-evidence checking)	Q #	Assessment	Summary	Relevant reference(s)*
<b>Awareness and Education</b>	How can healthcare professionals best educate people living with dementia and their carers about their medicines?	1	Unanswered	There is limited evidence addressing this question. A recent systematic review (Sawan et al.) found that there is limited evidence examining the effectiveness of interventions to educate caregivers on medication management for people living with dementia at hospital discharge. Education interventions involving the person living with dementia and their carer to improve the appropriate use of medications are sparse (Allred et al.)	Sawan et al Interventions at Hospital Discharge to Guide Caregivers in Medication Management for People Living with Dementia: a Systematic Review. J Gen Intern Med. 2021 Feb 3; Allred DP et al. Interventions to optimise prescribing for older people in care homes. Cochrane Database Syst Rev. 2016; 2:CD009095.
<b>Awareness and Education</b>	How can medicine literacy be optimised in all people living with dementia and their carers?	2	Unanswered	The limited evidence on this topic is focused on improving medication adherence in this population, and most are of low/moderate quality. There is no evidence that specifically addresses how to improve health literacy (reading medication labels, managing complex regimes, decisions in case of missed doses) in this population.	Aston L et al. Exploring the evidence base for how people with dementia and their informal carers manage their medication in the community: a mixed studies review. BMC geriatr. 2017 2017;17(1):242.
<b>Awareness and Education</b>	What knowledge and skills do healthcare professionals need to achieve safe, effective and appropriate medicine use in people living with dementia and also to support person- and relationship-centred care? What are effective ways of providing them with these skills and knowledge?	3	Partially answered	How to achieve person-centred care and what skills/knowledge are needed to achieve person centred care are answered through SRs. The concept of relationship centred care is unanswered (no SRs/guidelines). What skills/knowledge are required to achieve appropriate medication use is mostly answered (multiple guides/professional documents exist). How to ensure that healthcare professionals have the skills and knowledge is still unknown (no SRs or guidelines).	Rossiter C et al. 2020. The impact of person-centred care on patient safety: An umbrella review of systematic reviews. Int J Nurs Stud. 109:103658; Chenoweth et al. 2019. Systematic review and meta-analysis of organisational interventions for promoting person-centred care for people with dementia. PLOS 1, 14(2): e0212686. Shafiee Hanjani et al. 2019. Interventions to Optimise Prescribing in Older People with Dementia: A Systematic Review. Drugs Aging. 36(3):247-267
<b>Behavioural and psychological symptoms of dementia/Changed behaviours</b>	When and how should medicines be used to treat changed behaviours (previously referred to as behavioural and psychological symptoms of dementia)? Does this recommendation vary by type and stage of dementia or setting of care?	4	Unanswered	Cochrane Review (2011) antidepressants for agitation and psychosis in dementia - concluded more research is needed (no updated reviews). Cochrane review of pharmacological interventions for apathy (2018) - concluded more research is needed. CDPC Dementia Guideline (2016) - several recommendations around antipsychotics, EBR Moderate and PP, other drugs for changed behaviours had variable but generally were PP. NICE Dementia guideline (2020) has several recommendations about antipsychotics, moderate to high quality evidence. But there was insufficient research for other medications and managing all possible symptoms of behavioural change, and in the different types of dementia. (No change to wording of question as it would not be possible to remove the answered element without making the question too lengthy.)	Seitz DP et al. Antidepressants for agitation and psychosis in dementia. Cochrane Database of Systematic Reviews 2011, Issue 2. Art. No.: CD008191. Ruthirakuhan et al. Pharmacological interventions for apathy in Alzheimer's disease. Cochrane Database of Systematic Reviews 2018, Issue 5. Art. No.: CD012197. Assessment, management and support for people living with dementia and their carers NICE Guideline 97, June 2018 Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney. Guideline Adaptation Committee; 2016, CDPC

<p><b>Behavioural and psychological symptoms of dementia/Changed behaviours</b></p>	<p>What is the most effective and safe way to reduce the use of antipsychotics (when used as chemical restraints) in people living with dementia?</p>	<p>5</p>	<p>Unanswered</p>	<p>There is a Cochrane review on Withdrawal versus continuation of long-term antipsychotic drug use for behavioural and psychological symptoms in older people with dementia that found 11 studies with mostly low quality evidence and the reviewers suggested that further evidence of benefits and harms associated with withdrawal of antipsychotic is required in people with dementia and mild and severe neuropsychiatric symptoms. NICE key therapeutic topic KTT7 discusses the issues around antipsychotic use but not definitive information on the most effective strategies to reduce use. Deprescribing algorithms, tools and guidelines exist e.g 2018 Clinical practice guidelines for deprescribing antipsychotics, but states there are still some gaps in knowledge e.g. What are patients' values and preferences regarding the use or deprescribing of antipsychotics for treating BPSD? What is the most effective strategy for tapering or stopping antipsychotics?</p>	<p>Van Leeuwen et al. "Withdrawal versus continuation of long-term antipsychotic drug use for behavioural and psychological symptoms in older people with dementia." Cochrane Database of Systematic Reviews 3 (2018) NICE Key therapeutic topic KTT7, 2019, Antipsychotics in people living with dementia. Bjerre, et al. "Deprescribing antipsychotics for behavioural and psychological symptoms of dementia and insomnia: evidence-based clinical practice guideline." Canadian Family Physician 64.1 (2018): 17-27. Westaway K, et al. 2020. The extent of antipsychotic use in Australian residential aged care facilities and interventions shown to be effective in reducing antipsychotic use: A literature review. Dementia (London). 19(4):1189-1202.</p>
<p><b>Behavioural and psychological symptoms of dementia/Changed behaviours</b></p>	<p>Do certain medicines increase the risk of changed behaviours (previously referred to as behavioural and psychological symptoms of dementia) in people living with dementia?</p>	<p>6</p>	<p>Unanswered</p>	<p>No guidelines or SRs on this question. The CDPC dementia guidelines recommend to review medication at diagnosis to identify those that may be adversely affecting cognitive functioning, and also to consider if a person experiencing changed behaviours are experiencing medication adverse effects, but doesn't specifically discuss the evidence on this issue.</p>	<p>None relevant</p>
<p><b>Healthcare system and person-centred care</b></p>	<p>How can healthcare professionals ensure that informed consent, from the person living with dementia, their substitute decision-maker or carer, is obtained for medicine use?</p>	<p>7</p>	<p>Unanswered</p>	<p>No guidelines or SRs on this question. Current guideline (CDPC) states that 'Valid informed consent should always be sought from the person with dementia for decisions regarding financial affairs, health care and living arrangements.' There are limited studies how health care professionals can ensure that informed consent, from the person living with dementia, their substitute decision-maker or carer, is obtained for medicine use. There is only one tool (The Structured Interview for Competency and Incompetency Assessment Testing and Ranking Inventory) that specifically measures patient capacity to give informed consent for medications.</p>	<p>Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney. Guideline Adaptation Committee; 2016, CDPC; Amaral AS, et al. Decision-Making Capacity in Healthcare: Instruments Review and Reflections About its Assessment in the Elderly with Cognitive Impairment and Dementia. Psychiatr Q. 2021 Jan 2.</p>
<p><b>Healthcare system and person-centred care</b></p>	<p>How can shared decision making about medicines be achieved between healthcare professionals and people living with dementia and their carers and family?</p>	<p>8</p>	<p>Unanswered</p>	<p>While there are a studies that have tested interventions to elicit the preferences of older adults living with dementia with respect to polypharmacy, there are no studies that have tested shared decision making about medications with people living with dementia and their carers. Studies that have tested interventions for increasing the use of shared decision making about medications by healthcare professional haven't been conducted in people without dementia. Reviews conclude further research is required.</p>	<p>Mangin D, et al. Making patient values visible in healthcare: a systematic review of tools to assess patient treatment priorities and preferences in the context of multimorbidity. BMJ Open. 2016 Jun 10;6(6):e010903. Légaré F, et al. Interventions for increasing the use of shared decision making by healthcare professionals. Cochrane Database of Systematic Reviews. 2018(7).</p>

<b>Healthcare system and person-centred care</b>	How can advanced care plans be used to inform use of medicines when the individual no longer has the capacity to express their wishes?	9	Unanswered	No guidelines or SRs on the question. There are limited number of studies describing available decision aids in advanced care planning for medicines use involving substitute decision makers, but there are no studies demonstrating their effectiveness.	Cardona-Morrell M, et al. A systematic review of effectiveness of decision aids to assist older patients at the end of life. <i>Patient Educ Couns.</i> 2017 Mar;100(3):425-35.
<b>Healthcare system and person-centred care</b>	What role do different healthcare professionals play in achieving safe, effective and appropriate medicine use in people living with dementia? And how can access to relevant healthcare professionals be achieved?	10	Unanswered	There are some studies that have investigated the impact of multidisciplinary interventions in older people with dementia and have shown positive effects on medication appropriateness and medication withdrawal. However, the impact of these interventions in people with dementia on clinical outcomes is limited, more research is needed. No guidelines or SRs on the other aspects of the question.	McDerby N, et al. Pharmacist-led medication reviews in aged care residents with dementia: A systematic review. <i>Australas J Ageing.</i> 2020 Dec;39(4):e478-e89; McGrattan M, et al. Interventions to Improve Medicines Management for People with Dementia: A Systematic Review. <i>Drugs Aging.</i> 2017 Dec;34(12):907-16; Shafiee Hanjani L, et al. Interventions to Optimise Prescribing in Older People with Dementia: A Systematic Review. <i>Drugs Aging.</i> 2019 2019/03/01;36(3):247-67; Rankin A, et al. Interventions to improve the appropriate use of polypharmacy for older people. <i>Cochrane Database of Systematic Reviews.</i> 2018(9).
<b>Healthcare system and person-centred care</b>	How can communication between healthcare professionals be optimised, especially at transitions of care, to achieve multi-disciplinary care for people living with dementia?	11	Unanswered	No guidelines or SRs on the question as a whole. Some research into interventions at hospital discharge: the evidence is limited comprising of several non-randomized control trials and mixed methods study that were judged as having unclear quality. Only one study reported on clinical outcomes of a post-discharge multidisciplinary team intervention involving communication with the primary care physician.	Sawan et. al Interventions at Hospital Discharge to Guide Caregivers in Medication Management for People Living with Dementia: a Systematic Review. <i>J Gen Intern Med.</i> 2021 Feb 3.
<b>Healthcare system and person-centred care</b>	How could telehealth be used to achieve safe, effective and appropriate medicine use in people living with dementia, particularly for those living in rural and remote communities?	12	Unanswered	No guidelines or SRs.	None
<b>Healthcare system and person-centred care</b>	How can the process of drug approval be improved to ensure that the results are relevant to people living with dementia?	13	Unanswered	No guidelines or SRs.	None
<b>Residential Aged Care Facilities</b>	How can residential aged care facilities best support safe, effective and appropriate medicine use in residents with dementia?	14	Unanswered	Cochrane review (Feb 2016) of "interventions to optimise prescribing in care homes" identified only 12 studies and the authors could not draw robust conclusions from the evidence due to variability between studies. In Australia we have the Guiding Principles for medication management in RACFs but these are broad, not specific to people with dementia and the quality standards do not cover medication use in detail (and are not specific to dementia). Relevant NICE entries are: "Managing medicines in care homes" [SC1] and "Medicines management in care homes" [QS85], which provide recommendations about supporting residents to make decisions, sharing information	Allred, et al. "Interventions to optimise prescribing for older people in care homes." <i>Cochrane Database of Systematic Reviews</i> 2 (2016); NICE Social care guideline (SC1), 2014, Managing medicines in care homes; NICE Quality standard (QS85), 2015, Medicines management in care homes; McGrattan, et al. "Interventions to improve medicines management for people with dementia: a systematic review." <i>Drugs &amp; Aging</i> 34.12 (2017): 907-916.

				about medicines at transitions of care, keeping up to date records, identifying medication-related problems, keeping an accurate list/reconciliation, prescribing/ordering/dispensing/admin, and training recommendations. These are comprehensive but not dementia-specific. A systematic review by McGratten et al (2017) focusing on RCTs of interventions to improve medicines management for people with dementia (in care homes or living in their own homes) identified only 3 studies of which two studies focused on psychotropic medicines.	
<b>Residential Aged Care Facilities</b>	What knowledge and skills do healthcare workers in residential aged care need to support safe, effective and appropriate medicine use in people living with dementia? What are effective ways of providing them with these skills and knowledge?	15	Partially answered	There is evidence on what knowledge and skills healthcare workers in residential aged care need to support medication use, but not on how to effectively provide them with these skills. In the NICE 2018 'Dementia: assessment, management and support for people living with dementia and their carers' guideline NG97; in the recommendations for research section it recommends more research into staff training and the most cost effective approach to deliver that training. "Robust evidence demonstrates the effectiveness of intensive training for staff heavily involved in providing care and support for people living with dementia. However, it is not clear if it is effective to provide basic training to all staff who come into contact with people living with dementia, or how this training should be provided." On page 66, the CDPC guidelines have identified recommendations that should be prioritised for research translation: These include recommendations 59 and 60 which focus on training for staff and students, recommendation 78 which focuses on behavioural and psychological symptoms of dementia. On page 33, the evidence for staff training interventions in RACFs is reviewed - quality of evidence low to moderate - not medicines specific.	NICE 2018 'Dementia: assessment, management and support for people living with dementia and their carers' guideline NG97; Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney. CPDC.
<b>Medicine management</b>	What is the prevalence of non-adherence in people living with dementia? How can healthcare professionals and carers assess whether the person living with dementia is able to self-manage their medicines at home?	16	Unanswered	Further research is needed on the prevalence of non-adherence and how to assess adherence.	El-Saifi N, et al. 2018. Medication Adherence in Older Patients With Dementia: A Systematic Literature Review. J Pharm Pract. 31(3):322-334.
<b>Medicine management</b>	How can people living with dementia and their carers be supported to manage medicines safely at home?	17	Unanswered	3 relevant SRs identified, they conclude that there is evidence that e-learning on medicine use and telehealth is helpful for the person with dementia and their carers, but all studies recommend that further research is required to identify other approaches that can help the person to self-manage medication compliance and safety and on the development and	El-Saifi N, et al. 2018. Medication Adherence in Older Patients With Dementia: A Systematic Literature Review. J Pharm Pract. 31(3):322-334. Klimova B et al. 2019. E-learning as valuable caregivers' support for people with dementia - A systematic review. BMC Health Serv Res. 19(1):781.



				implementation of interventions to help older patients with dementia and their caregivers make better use of medications.	Lim, RH., Sharmeen, T. 2018. Medicines management issues in dementia and coping strategies used by people living with dementia and family carers: A systematic review. <i>Int. J Geriatric Psychiatry</i> . 33:1652-1581.
<b>Medicine management</b>	What is the best way to support safe and effective medicine management and administration when the person living with dementia is resistant to taking their medicines?	18	Unanswered	SR on strategies and interventions to reduce or manage refusals (including medication) concluded that more research is needed. SR only identified 2 studies that specifically focused on Medication administration.	Backhouse T, et al. Strategies and interventions to reduce or manage refusals in personal care in dementia: A systematic review. <i>Int J Nurs Stud</i> . 2020 Sep;109:103640.
<b>Medicine management</b>	What are the consequences of non-adherence, such as taking more or less than prescribed?	19	Unanswered	No guidelines or SRs.	None
<b>Medicine management</b>	What is the best time of day for people living with dementia to take their medicines?	20	Unanswered	No guidelines or SRs.	None
<b>Medicine management</b>	Can alternative delivery methods or routes of administration be used to facilitate use of medicines in people living with dementia (e.g. patches, crushed medicines)?	21	Unanswered	No guidelines or SRs.	None
<b>Polypharmacy, complexity, multimorbidity and deprescribing</b>	What is the impact of polypharmacy (use of multiple medicines) on people living with dementia? What are effective ways to reduce polypharmacy, simplify medicine use, and reduce the cost for people living with dementia?	22	Unanswered	Guidelines for dementia exist but do not contain evidence-based recommendations about management of polypharmacy. Several SRs have been conducted on the management of polypharmacy but with limited/no inclusion/focus on people with dementia. One SR on the impact of polypharmacy in people with dementia on hospitalisation, but only 1 study informed the impact of polypharmacy. Overall, insufficient evidence on both the impact of polypharmacy in people with dementia and how to reduce polypharmacy and associated burden.	Rankin A, at al. Interventions to improve the appropriate use of polypharmacy for older people. <i>Cochrane Database of Systematic Reviews</i> 2018, Issue 9. Art. No.: CD008165. NICE Guideline NG71 (Parkinson's disease in adults), 2017; NICE Multimorbidity and polypharmacy, Key therapeutic topic 2017; NG97 (Dementia: assessment, management and support for people living with dementia and their carers), 2018; Leelakanok N, D'Cunha RR. Association between polypharmacy and dementia - A systematic review and metaanalysis. <i>Aging Ment Health</i> . 2019 Aug;23(8):932-941; Shepherd H, et al. Hospitalisation rates and predictors in people with dementia: a systematic review and meta-analysis. <i>BMC Med</i> . 2019 Jul 15;17(1):130; Anderson LJ, et al. A systematic overview of systematic reviews evaluating interventions addressing polypharmacy. <i>Am J Health Syst Pharm</i> . 2019 Oct 15;76(21):1777-1787;
<b>Polypharmacy, complexity, multimorbidity and deprescribing</b>	What medicines are commonly used in people living with dementia?	23	Unanswered	Multiple studies have examined medication use in people with dementia in different settings. Systematic review by Hukins et al (2019) of potentially inappropriate prescribing in older people with dementia identified 26 papers. The CDPC dementia guidelines suggests there is a need for more research into: "The characteristics and needs of specific groups of people with dementia: including Indigenous Australians; people from CALD	Hukins, et al "Identifying potentially inappropriate prescribing in older people with dementia: a systematic review." <i>European journal of clinical pharmacology</i> 75.4 (2019): 467-481.

				backgrounds; people in rural and remote areas; gay, lesbian and bisexual people; people from low socioeconomic backgrounds." But no SRs on medicine use as a whole.	
<b>Polypharmacy, complexity, multimorbidity and deprescribing</b>	How can 'prescribing cascades' (the starting of one drug to treat the side effect of another) in people living with dementia be prevented and reversed?	24	Unanswered	Not much literature in dementia specifically. Small number of recent pharmacoepidemiology studies have examined an example of a specific prescribing cascade in people with dementia. A recent scoping review of 58 studies examining prescribing cascades by Brath et al. categorized 29 papers as preventing, 20 as detecting, and 9 as reversing prescribing cascades in the general population; Brath et al did not mention dementia specifically.	Brath, et al. "What is known about preventing, detecting, and reversing prescribing cascades: a scoping review." <i>Journal of the American Geriatrics Society</i> 66.11 (2018): 2079-2085;
<b>Polypharmacy, complexity, multimorbidity and deprescribing</b>	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 they be conducted, and what follow-up is needed?	25	Unanswered	Some guidelines and SRs exist but conclude further research is needed. CDPC dementia guideline recommends a review of medications at diagnosis. Two recent systematic reviews found few studies examining interventions to optimise prescribing/medicines management in people with dementia. A review of Australian studies (Chen et al) identified approx. 15 studies examining the structure, process and outcomes of RMMRs in Australian RACFs. NICE guidance NG5: Medicines optimisation (Mar 2015): Research recommendations include the need to further understand the types of medication review undertaken, type of health professional, frequency, clinical outcomes and cost effectiveness of these medication reviews. There is a quality standard QS120 on medicines optimisation but doesn't mention dementia specifically.	McGrattan, et al. "Interventions to improve medicines management for people with dementia: a systematic review." <i>Drugs &amp; Aging</i> 34.12 (2017): 907-916; Shafiee Hanjani, et al. "Interventions to optimise prescribing in older people with dementia: a systematic review." <i>Drugs &amp; aging</i> 36.3 (2019): 247-267; Chen, et al. "Process, impact and outcomes of medication review in Australian residential aged care facilities: A systematic review." <i>Australasian journal on ageing</i> 38 (2019): 9-25.
<b>Polypharmacy, complexity, multimorbidity and deprescribing</b>	How can deprescribing (cessation of harmful and/or unnecessary medicines) be achieved in people living with dementia? And what are the benefits and risks of deprescribing?	26	Unanswered	No guidelines or SRs identified that specifically focused on achieving or benefits and harms of deprescribing (not restricted to a single medication class) in people with dementia (or that included a sub-group analysis of people with dementia). Evidence-based guidelines do exist for some specific drug classes, but these highlight that further research is needed.	Bjerre LM, et al. Deprescribing antipsychotics for behavioural and psychological symptoms of dementia and insomnia: Evidence-based clinical practice guideline. <i>Can Fam Physician</i> . 2018 Jan;64(1):17-27. Renn BN, et al. A Systematic Review of Practice Guidelines and Recommendations for Discontinuation of Cholinesterase Inhibitors in Dementia. <i>Am J Geriatr Psychiatry</i> . 2018 Feb;26(2):134-147. Reeve E, et al. Deprescribing cholinesterase inhibitors and memantine in dementia: guideline summary. <i>Med J Aust</i> . 2019 Mar;210(4):174-179.
<b>Polypharmacy, complexity, multimorbidity and deprescribing</b>	Which medicines are potentially harmful or unnecessary in people living with dementia and should be stopped?	27	Unanswered	There are a number of tools that identify PIMs in people with dementia. However, further tools to identify PIMs which are evidence-based and account for individual clinical context and give guidance on whether they should be stopped are needed.	Hukins D, et al. Identifying potentially inappropriate prescribing in older people with dementia: a systematic review. <i>European Journal of Clinical Pharmacology</i> . 2019;75(4):467-81; Disalvo D, et al. Systems to identify potentially inappropriate prescribing in people with advanced dementia: a systematic review. <i>BMC geriatr</i> . 2016;16:114-; Masnoon N, et al. Tools for Assessment of the Appropriateness of Prescribing and Association with Patient-Related Outcomes: A Systematic Review. <i>Drugs Aging</i> . 2018 2018/01/01;35(1):43-60.

<b>Polypharmacy, complexity, multimorbidity and deprescribing</b>	What impact does one or more other medical conditions have on the safety and efficacy of medicines in people living with dementia? What guidance is available to guide healthcare professionals to care for people with multiple health conditions including different types of dementia?	28	Unanswered	In the NICE 2018 'Dementia: assessment, management and support for people living with dementia and their carers' guideline NG97; there is a short section (1.8) on assessing and managing other long term conditions in people with dementia. But only includes 11 statements pointing to other NICE guidelines on pain, falls, diabetes, incontinence and sensory impairment. There is a NICE NG56 guideline on multimorbidity clinical assessment and management (but it doesn't mention dementia specifically) which states a research priority is generating info on the clinical and cost effectiveness impacts of stopping preventive meds in ppl with multimorbidity who may not benefit from continuation.	NICE 2018 'Dementia: assessment, management and support for people living with dementia and their carers' guideline NG97
<b>Polypharmacy, complexity, multimorbidity and deprescribing</b>	What are the best tools, guidelines and resources for healthcare professionals to inform safe, effective and appropriate medicine use in people living with dementia?	29	Unanswered	While there are several guidelines to support health professionals ensure the safe use of specific medicines in people living with dementia, it is important to note that the level of evidence to inform guideline recommendations is low- or very low quality evidence. Several tools for healthcare professionals to identify PIMs are available, however limited implementation research has been conducted.	Reeve E, et al. Evidence-based Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine. Sydney: The University of Sydney; 2018; Bjerre LM, et al. Deprescribing antipsychotics for behavioural and psychological symptoms of dementia and insomnia: Evidence-based clinical practice guideline. Can Fam Physician, 64(1), 17-27 (2018); Reeve E. Deprescribing tools: a review of the types of tools available to aid deprescribing in clinical practice. Journal of Pharmacy Practice and Research. 2020 2020;02/01;50(1):98-107.
<b>Treatment of dementia</b>	What are the short-term and long-term benefits and harms of cholinesterase inhibitors and memantine (medicines used to treat the symptoms of dementia)? When and how should these medicines be used and for what types and stages of dementia?	30	Partially answered	Guidelines are quite broad with good evidence on short-term benefits and harms. Lack of evidence on long-term benefits and harms and benefits in relation to patient-important outcomes.	NG97 (Dementia: assessment, management and support for people living with dementia and their carers), 2018; Reeve E, et al. Evidence-based Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine. Sydney: The University of Sydney; 2018; Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney. Guideline Adaptation Committee; 2016, CDPC
<b>Treatment of dementia</b>	Who is most likely to benefit from medicines for dementia? Who is most likely to experience harm? Can this be predicted?	31	Unanswered	No guidelines or SRs have investigated predicting benefit or harm from use of antidementia medications in different types of people (except for a single SR on the effect of APOE). There have been a few single studies on factors including APOE4/genetics, sex, thyroxine levels, anticholinergic burden etc. Further research required.	Cheng, Ying-Chih, et al. "Effect of apolipoprotein E ε4 carrier status on cognitive response to acetylcholinesterase inhibitors in patients with Alzheimer's disease: a systematic review and meta-analysis." Dementia and Geriatric Cognitive Disorders 45.5-6 (2018): 335-352.
<b>Treatment of dementia</b>	What is the prevalence of under-prescribing of medicines in people living with dementia and how can this be improved?	32	Unanswered	No guidelines or SRs although there are individual studies regarding under-prescribing of antidementia drugs and drugs for comorbidities e.g. oral anticoagulants, analgesics etc.	None
<b>Treatment of dementia</b>	Do any complementary, alternative or herbal medicines or dietary supplements have a benefit in treating dementia?	33	Unanswered	SR concluded that the evidence on vitamin and mineral supplements as treatments for dementia/MCI is very limited. CDPC guideline recommends against the use of nutritional drink due to insufficient evidence. Further research required.	McCleery, et al. "Vitamin and mineral supplementation for preventing dementia or delaying cognitive decline in people with mild cognitive impairment." Cochrane Database of Systematic Reviews 11 (2018);

					Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney. Guideline Adaptation Committee; 2016, CDPC
<b>Treatment of dementia</b>	Does medical cannabis have a benefit in treating dementia?	34	Unanswered	Recent SR conducted on this topic concluded that further studies are needed to answer this question.	Charernboon T et al. Effectiveness of Cannabinoids for Treatment of Dementia: A Systematic Review of Randomized Controlled Trials. Clin Gerontol. 2021 Jan-Feb;44(1):16-24.
<b>Treatment of dementia</b>	Do any medicines registered for purposes other than dementia have a benefit in treating or preventing dementia?	35	Unanswered	Evidence does not support use of the studied pharmacologic treatments for cognitive protection in persons with normal cognition or MCI. However, limited by High attrition, short follow-up, inconsistent cognitive outcomes, and possible selective reporting and publication. Further research needed.	Fink, et al. "Pharmacologic interventions to prevent cognitive decline, mild cognitive impairment, and clinical Alzheimer-type dementia: a systematic review." Annals of internal medicine 168.1 (2018): 39-51.
<b>Treatment of dementia</b>	Should medicines be used for reduction of risk factors (such as reducing cardiovascular risk) to prevent or treat dementia?	36	Unanswered	Current evidence indicates that antihypertensives and statins might reduce the incidence of dementia and AD. Further trials to determine the effect of vascular risk reduction on AD are needed.	Larsson, et al. "Does treating vascular risk factors prevent dementia and Alzheimer's disease? A systematic review and meta-analysis." Journal of Alzheimer's disease 64.2 (2018): 657-668.
<b>Treatment of dementia</b>	Are there any drug interactions between the medicines used to treat the symptoms of dementia and the other medicines that people living with dementia take (including non-prescription and herbal medicines)?	37	Partially answered	It is known that drug-drug interactions can occur with cholinesterase inhibitors and memantine and other drugs through pharmacokinetic and pharmacodynamic mechanisms. However, guidelines and reviews highlighted that the clinical significance of these theoretical drug-drug interactions are mostly unknown.	NG97 (Dementia: assessment, management and support for people living with dementia and their carers), 2018; Reeve E, et al. Evidence-based Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine. Sydney: The University of Sydney; 2018.; Caraci, et al. "Clinically relevant drug interactions with anti-Alzheimer's drugs." CNS & Neurological Disorders-Drug Targets 16.4 (2017): 501-513.; Mehrpouya, et al. "Potential drug interactions with cholinesterase inhibitors in Alzheimer patients: a guideline for neurologists." J App Pharm Sci 7 (2017): 223-6.; Auxtero, et al. "Potential Herb-Drug Interactions in the Management of Age-Related Cognitive Dysfunction. Pharmaceutics 2021, 13, 124." (2021).
<b>Treatment of dementia</b>	When should medicines which are used to treat the symptoms of dementia be stopped? How should these medicines be stopped?	38	Unanswered	There is a recent Cochrane Review on the outcomes of discontinuation of these medications and a guideline with NHMRC approved recommendations on this question. While there is some evidence to guide this, both of these sources conclude that more research is needed.	Parsons C, et al. Withdrawal or continuation of cholinesterase inhibitors or memantine or both, in people with dementia. Cochrane Database of Systematic Reviews 2021, Issue 1. Art. No.: CD009081. Reeve E, et al. Evidence-based Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine: Recommendations. Sydney: The University of Sydney; 2018
<b>Specific co-morbidities in people living with dementia</b>	When, how and in who should medicines be used to treat delirium in people living with dementia?	39	Unanswered	There is a guideline for treatment of delirium (not dementia specific), evidence suggests that no medicines are really helpful in delirium. Need for further research specifically in people with dementia.	NICE Guideline (CG103), Delirium: prevention, diagnosis and management, March 2019
<b>Specific co-morbidities in people living with dementia</b>	When, how and in who should medicines be used to treat depression and anxiety in people living with dementia?	40	Unanswered	There was insufficient evidence to draw conclusions about individual antidepressant drugs or about subtypes of dementia or depression.	Dudas R, et al. Antidepressants for treating depression in dementia. Cochrane Database Syst Rev. 2018 Aug 31;8(8):CD003944

					Orgeta V, et al. Efficacy of Antidepressants for Depression in Alzheimer's Disease: Systematic Review and Meta-Analysis. <i>J Alzheimers Dis.</i> 2017;58(3):725-733.
<b>Specific co-morbidities in people living with dementia</b>	When, how and in who should medicines be used to provide comfort in people living with dementia at end of life?	41	Unanswered	SR recommend that further research is required.	Miranda et al. Palliative care for people with dementia living at home: A systematic review of interventions. <i>Palliative Medicine.</i> 2019;33(7):726-742
<b>Specific co-morbidities in people living with dementia</b>	When, how and in who should medicines be used to treat severe mental health conditions in people living with dementia?	42	Unanswered	No guidelines or SRs.	None
<b>Specific co-morbidities in people living with dementia</b>	Are there any special considerations when using medicines to manage heart conditions and diabetes in people living with dementia?	43	Unanswered	No guidelines or SRs.	None
<b>Specific co-morbidities in people living with dementia</b>	When, how and in who should medicines be used to treat insomnia in people living with dementia?	44	Unanswered	SR discovered a distinct lack of evidence to guide decisions about drug treatment of sleep problems in dementia. In particular, it found no RCTs of many widely prescribed drugs, including the benzodiazepine and non-benzodiazepine hypnotics, although there is considerable uncertainty about the balance of benefits and risks for these common treatments. It found no evidence for beneficial effects of melatonin (up to 10 mg) or a melatonin receptor agonist. There was evidence of some beneficial effects on sleep outcomes from trazodone and orexin antagonists and no evidence of harmful effects in these small trials, although larger trials in a broader range of participants are needed to allow more definitive conclusions to be reached. Systematic assessment of adverse effects in future trials is essential.	McCleery, et al. "Pharmacotherapies for sleep disturbances in dementia." <i>Cochrane Database of Systematic Reviews</i> 11 (2020).
<b>Specific co-morbidities in people living with dementia</b>	When, how and in who should medicines be used to manage pain in people living with dementia?	45	Unanswered	No guidelines or SRs.	None
<b>Specific co-morbidities in people living with dementia</b>	Are there any special considerations when treating Parkinson's Disease in people living with dementia?	46	Unanswered	No guidelines or SRs.	None
<b>Specific co-morbidities in people living with dementia</b>	Are there any special considerations when treating epilepsy in people living with dementia?	47	Unanswered	SR identified that further research is required.	Liu et al. Treatment of epilepsy for people with Alzheimer's disease. <i>Cochrane Database Syst Rev.</i> 2018 Dec 20;12(12):CD011922.
<b>Specific co-morbidities in</b>	Are there any special considerations when prescribing	48	Unanswered	Future studies are needed to evaluate the benefits and harms of using antibiotics for patients during end-of-life care in this	Marra et al;. (2020). Antibiotic Use at the End-of-Life in Patients with Advanced Dementia: A Systematic Literature Review. <i>Infection Control &amp; Hospital Epidemiology</i> , 41(S1), S120-S120.

<b>people living with dementia</b>	antibiotics to people living with dementia?			patient population. High levels of antibiotic use in people with dementia. No guidelines found.	van der Maaden et al. Antibiotic Use and Associated Factors in Patients with Dementia: A Systematic Review. <i>Drugs Aging</i> 32, 43–56 (2015).
<b>Specific co-morbidities in people living with dementia</b>	Are there any special considerations when treating skin conditions in people living with dementia?	49	Unanswered	Significant further research is needed to inform future guidelines on dementia-specific prevention and management of wounds, and on translating the dementia-specific prevention and wound management guidelines into practice. Research is also needed on identifying barriers and enablers of maintaining skin integrity to improve quality of life at different points in the dementia trajectory and in different settings.	Parker et al. Exploring the prevalence and management of wounds for people with dementia in long-term care. <i>Int Wound J.</i> 2020; 17: 650– 659.
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines have anticholinergic effects? What harm do these medicines have in people living with dementia, and how can this best be measured and identified?	50	Unanswered	Guideline recommends against using antidepressants with anticholinergic effects due to impact on cognition. There are several systematic reviews but none of them agree as to which medicines are actually anticholinergic.	Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney. Guideline Adaptation Committee; 2016, CDPC
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines cause drowsiness in people living with dementia? What are the harms of use of these medicines (such as benzodiazepines) in people living with dementia?	51	Unanswered	No guidelines or SRs specifically in people living with dementia.	None
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines can cause delirium in people living with dementia?	52	Unanswered	No guidelines or SRs specifically in people living with dementia.	None
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines impair function and activities of daily living in people living with dementia?	53	Unanswered	No guidelines or SRs.	None
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Can any medicines cause dementia?	54	Unanswered	No guidelines or SRs. There are many observational studies showing an association between some medicines (anticholinergics, PPIs, benzos) and incident dementia BUT a lot of them are confounded (eg the medicines are more likely to have been used to treat symptoms of undiagnosed dementia)	None
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines worsen memory and thinking in people living with dementia or speed up decline of dementia?	55	Unanswered	There is evidence to show which medications are associated with worsening cognition in people with dementia - but whether these drugs actually CAUSE the worsening cognition is unanswered part. SR identified limitations of existing research.	Pieper et al. "Anticholinergic drugs and incident dementia, mild cognitive impairment and cognitive decline: a meta-analysis." <i>Age and ageing</i> 49.6 (2020): 939-947.
<b>Specific adverse drug reactions and harms in people</b>	Can any medicines alter mood or personality in people living with dementia?	56	Unanswered	No guidelines or SRs.	None

<b>living with dementia</b>					
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines increase the risk of falls in people living with dementia?	57	Unanswered	We know which medicines increase falls risk in the general population BUT no systematic reviews specifically in people with dementia.	de Vries et al. "Fall-risk-increasing drugs: a systematic review and meta-analysis: I. Cardiovascular drugs." Journal of the American Medical Directors Association 19.4 (2018): 371-e1; Seppala et al. "Fall-risk-increasing drugs: a systematic review and meta-analysis: II. Psychotropics." Journal of the American Medical Directors Association 19.4 (2018): 371-e11; Seppala et al. "Fall-risk-increasing drugs: a systematic review and meta-analysis: III. Others." Journal of the American Medical Directors Association 19.4 (2018): 372-e1.
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines and combinations of medicines cause QT prolongation (changes in the rhythm of the heart which can lead to serious heart problems) in people living with dementia?	58	Unanswered	No guidelines or SRs.	None
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines cause urinary incontinence in people living with dementia?	59	Unanswered	No guidelines or SRs.	None
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Which medicines can harm the kidneys in people living with dementia?	60	Unanswered	No guidelines or SRs.	None
<b>Specific adverse drug reactions and harms in people living with dementia</b>	Can medicines mask (hide) symptoms of dementia or other relevant symptoms or conditions?	61	Unanswered	No guidelines or SRs.	None
<b>Monitoring for harms and benefits</b>	What is the best way to monitor for benefits (or lack of benefits) and harms (side effects and other risks) of medicines in people living with dementia?	62	Unanswered	No guidelines or SRs.	None
<b>Pharmacokinetic and pharmacodynamic changes</b>	Should doses of specific medicines be changed in people living with dementia to prevent side effects?	63	Unanswered	No guidelines or SRs. 2021 Narrative review reported that there is still much unknown about pharmacokinetic and pharmacodynamic changes in dementia and the clinical importance of these.	Maher et al. "Alterations in drug disposition in older adults: a focus on geriatric syndromes." Expert Opinion on Drug Metabolism & Toxicology 17.1 (2021): 41-52.
<b>Influences on prescribing</b>	What influences the prescribing of medicines in people living with dementia?	64	Unanswered	No guideline or SRs	None

<b>Influences on prescribing</b>	What influence does the media have on use of medicines in people with dementia?	64	Unanswered	No guidelines or SRs.	None
<b>COVID and restrictions</b>	What is the impact of 'locking down' care facilities in response to COVID-19 and other infectious diseases on medicine management?	66	Unanswered	No guidelines or SRs. Single observational study found increased proportion of people with dementia receiving antipsychotic prescriptions during COVID pandemic.	Harrison et al. "Associations between COVID-19 and 30-day thromboembolic events and mortality in people with dementia receiving antipsychotic medications." <i>Pharmacological research</i> 167 (2021): 105534.
<b>COVID and restrictions</b>	What is known about COVID-19 in people with dementia in regard to susceptibility, risk of harms and how to treat?	67	Unanswered	SR and meta-analysis of dementia as a mortality predictor among older adults with COVID-19, (15 studies) found that older adults with dementia with COVID-19 infection have a higher risk of mortality (sufficient quality of evidence). However other risks of harm as well as susceptibility and how to treat are unanswered.	Saragih et al. "Dementia as a mortality predictor among older adults with COVID-19: A systematic review and meta-analysis of observational study." <i>Geriatric Nursing</i> 42.5 (2021): 1230-1239.
<b>COVID and restrictions</b>	What vaccines (such as the flu vaccine) should people living with dementia regularly receive?	68	Unanswered	No guidelines or SRs.	None

\*This is not a complete list of all references reviewed when determining whether the question was answered and writing the summary. Instead it is only the most recent and relevant guidelines and systematic reviews for the question.

Guideline = evidence-based clinical practice guideline unless otherwise specified; SR = Systematic Review



## Supplementary file 5: Questions altered after the evidence checking process

Theme	Original summary question	Question number ID	Evidence finding	Unanswered summary question
<b>Awareness and Education</b>	<p>What knowledge and skills do healthcare professionals need to achieve safe, effective and appropriate medicine use in people living with dementia and also to support person- and relationship-centred care?</p> <p>What are effective ways of providing them with these skills and knowledge?</p>	3	<p>How to achieve person-centred care (in general), including skills needed was determined to be answered through systematic reviews.[1-14] Some evidence on what knowledge and skills are needed to achieve appropriate medication use [15-17], but mostly in relation to antipsychotics for changed behaviours [18], but significant uncertainty in how to ensure healthcare professionals have these skills [19]. The concept of relationship centred care is relatively new and not fully established separately to person-centred care.</p> <p><b>Change:</b> Refocused question on to how to achieve the necessary knowledge and skills. Removed reference to 'relationship-centred care' (in checking quotes which informed this question there was no mention of relationship centred care).</p>	<p>What are effective ways to ensure that healthcare professionals have the necessary knowledge and skills to achieve safe effective and appropriate medication use in people living with dementia?</p>
<b>Residential Aged Care Facilities</b>	<p>What knowledge and skills do healthcare workers in residential aged care need to support safe, effective and appropriate medicine use in people living with dementia?</p> <p>What are effective ways of providing them with these skills and knowledge?</p>	15	<p>Guidelines exist on what knowledge and skills are needed to support safe, effective and appropriate use in people living with dementia in residential aged care facilities [15, 16]. Guidelines recommend more research into staff training (in general, not medication specific) and the most cost effective approach to deliver the training [14, 19]. On review of quotes, the focus was on achieving the knowledge and skills.</p> <p><b>Change:</b> Refocused question on to how to achieve the necessary knowledge and skills.</p>	<p>What are effective ways to ensure that healthcare workers in residential aged care have the necessary knowledge and skills to achieve safe, effective and appropriate medicine use in people living with dementia?</p>

<b>Polypharmacy, complexity and deprescribing</b>	What medicines are commonly used in people living with dementia?	23	Several prevalence studies exist (in various settings and countries); however, there is a lack of evidence in certain populations (such as those living in rural and remote areas).[14, 20] While determined to be 'unanswered', evidence checker highlighted that this question isn't in keeping with the other questions that are outcome/clinical practice focused. <b>Change:</b> Question removed.	None
<b>Treatment of dementia</b>	What are the short-term and long-term benefits and harms of cholinesterase inhibitors and memantine (medicines used to treat the symptoms of dementia)? When and how should these medicines be used and for what types and stages of dementia?	30	Guidelines <sup>1</sup> recommend initiation of cholinesterase inhibitors/memantine in patients who fulfil specific criteria (such as type of dementia) based on evidence of the benefits and harms of these medications; however, the evidence is mostly limited to short-term ( $\leq 6$ months) use with uncertainty remaining for long-term use ( $> 12$ months). While there is evidence for the most common types of dementia, uncertainty remains for the rare types of dementia. [14, 19, 21] <b>Change:</b> Removed "short term" to focus on the long-term benefits and harms.	What are the long-term benefits and harms of cholinesterase inhibitors and memantine (medicines used to treat the symptoms of dementia)? When and how should these medicines be used and for what types and stages of dementia?
<b>Treatment of dementia</b>	Are there any drug interactions between the medicines used to treat the symptoms of dementia and the other medicines that people living with dementia take (including non-prescription and herbal medicines)?	37	It is known that drug-drug interactions can occur with cholinesterase inhibitors and memantine and other drugs through pharmacokinetic and pharmacodynamic mechanisms. However, guidelines and reviews highlighted that the clinical significance of these theoretical drug-drug interactions are mostly unknown.[19, 21-24] <b>Change:</b> 'clinically important' added to the summary question.	Are there any clinically important drug interactions between the medicines used to treat the symptoms of dementia and the other medicines that people living with dementia take (including non-prescription and herbal medicines)?

<sup>1</sup> Guidelines considered were those that followed a robust methodology for guideline development, including conducting systematic review(s)

[1] Rossiter C, Levett-Jones T, Pich J (2020) The impact of person-centred care on patient safety: An umbrella review of systematic reviews. *Int J Nurs Stud* **109**, 103658.

- [2] Chenoweth L, Stein-Parbury J, Lapkin S, Wang A, Liu Z, Williams A (2019) Effects of person-centered care at the organisational-level for people with dementia. A systematic review. *PLoS One* **14**, e0212686.
- [3] Kim SK, Park M (2017) Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* **12**, 381.
- [4] Nguyen H, Terry D, Phan H, Vickers J, McInerney F (2019) Communication training and its effects on carer and care-receiver outcomes in dementia settings: A systematic review. *J Clin Nurs* **28**, 1050-1069.
- [5] Feast AR, White N, Candy B, Kupeli N, Sampson EL (2020) The effectiveness of interventions to improve the care and management of people with dementia in general hospitals: A systematic review. *Int J Geriatr Psychiatry* **35**, 463-488.
- [6] Blake D, Berry K, Brown LJE (2020) A systematic review of the impact of person-centred care interventions on the behaviour of staff working in dementia care. *J Adv Nurs* **76**, 426-444.
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