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Title

Medicines optimisation at care transitions for people living with Dementia: A best fit framework synthesis of patient, carer and healthcare professional perspectives

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Introduction

Initial topic suggestion
A James Lind Alliance (JLA) Priority Setting Partnership (PSP) exercise conducted in Australia on the topic "Quality Use of Medicines in People Living with Dementia" resulted in a top 10 priorities for research around quality use of medicines in people living with dementia. In addition to these top ten there were six additional priorities identified. Full details of the PSP method and findings are available on the JLA website: https://www.jla.nihr.ac.uk/priority-setting-partnerships/quality-use-of-medicines-in-people-living-with-dementia-Australia/

This research question was supplied to the EnSygN group via the National Institute of Health and Care Research Evidence Synthesis Programme (NIHR-ESP) through their working relationship with JLA as a stakeholder with the specific question being: "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 (PLWD)?"

EnSygN scoping
The EnSygN team undertook a scoping review to provide NIHR and JLA with evidence on the size and scope of the evidence base in relation to the research question. Through a scoping search of evidence (reviews and primary studies), the aim was to determine

- Whether there is evidence of interventions to answer the research question?
- What other evidence there is to answer the research question
- Whether an evidence synthesis would be useful and/or feasible?
- Implications of the current evidence base on the scope of a potential review question?
- Whether the suggested question, which originated from Australia, has UK applicability and potential international application?

Findings of EnSygN scoping
Scoping the evidence base found limited intervention evidence directly within the scope of the research question. Intervention evidence identified tends to date from pre-2019, which may reflect the Covid pandemic or time lags in publication. More substantive evidence exists for the views of healthcare professionals and family carers about transitions of care for PLWD, with observational evidence examining transitions and issues that occur with medicines. Evidence tends to originate from Australia and the USA, with some evidence from the UK but little from European countries. The complexity and variability of settings for transitions of care means that the potential to draw inference from one setting to another would limit the generalisability of evidence from a review of interventions.

Suggested approach
Qualitative evidence synthesis of the views of patients, carers and healthcare professionals around factors that facilitate or impede medicines optimisation at

transitions of care - this will allow a deeper understanding of how medicines optimisation work at transitions of care and allow policy makers and practitioners a greater understanding of how models of care or specific interventions could facilitate this.

Terminology and definitions

People living with dementia (PLWD) - we are using the same terminology of PLWD as used by the JLA PSP team in Australia, to highlight that person centred care is appropriate and necessary for patients with dementia and to highlight that people are individuals beyond their diagnosis. The focus of this review is on people living with a dementia diagnosis, so patients with mild and more severe cognitive impairment, which may be undiagnosed dementia will not be included in the review inclusion criteria. We will use the definition of dementia in the NICE Clinical Knowlege Summary (https://cks.nice.org.uk/topics/dementia/) of 'a progressive, irreversible clinical syndrome with a range of cognitive and behavioural symptoms including memory loss, problems with reasoning and communication, change in personality, and reduction in the person's ability to carry out daily activities'.

Carers - For the purpose of this review we are defining carers in two groups

- Someone who provides unpaid care for a PLWD. This could be a friend, family member, neighbour etc. This also needs to include people who may not define themselves as a carer but still deliver care to a PLWD.
- Paid carers who are not always healthcare professionals.

Healthcare professionals- in order to have a clear definition of Healthcare Professionals we are using the definition by the UK Care Quality Commission - 'A healthcare professional is a person registered with any of the following professional bodies, who is permitted by that body to provide or supervise the provision of the regulated activity: Health and Care Professions Council, Nursing and Midwifery Council, General Medical Council, General Dental Council, General Pharmaceutical Council, General Osteopathic Council, General Optical Council, General Chiropractic Council, Social Work England'. For the purposes of this review on transitions, it can be expected that the review will include evidence relating to healthcare professionals working in primary and community care, secondary care, care/nursing homes and social care settings - for example with homeless PLWD.

Medicines optimisation is a patient centered approach to ensuring that patients get the right medication. Medicines optimisation is particularly important for PLWD, who tend to be older, with co-morbidities and potentially using multiple medications. There are a number of definitions and we are using the definition by NHS England "ensuring people get the right choice of medicines, at the right time, and are engaged in the process by their clinical team" which includes the following objectives - to improve patient outcomes, to take medicines correctly, to avoid taking unnecessary medicines, to reduce wastage of medicines and improve medicines safety.

Transitions of care - these can occur at the following intersections, however this list will not be exhaustive and the transition is not always a clear transition from one location to another (Home to Care Home, Home to Hospital, Care Home to Hospital, Care Home to Home, Hospital to Care Home, Hospital to Home).

Research questions

1. What are the views of patients and carers about the factors that influence medicines optimisation at transitions of care for PLWD?
2. What are the views of healthcare professionals about the factors that influence medicines optimisation at transitions of care for PLWD?
3. What is the perceived impact on PLWD, healthcare professionals and carers when medicines are not managed/optimised at transitions of care?
4. Is there evidence relating to communication as a factor that impacts on medicines optimisation at transitions of care?
5. Can we map evidence on factors that influence medications optimisation onto existing frameworks of transitions of care?

Methods

We will carry out a qualitative evidence synthesis of available literature on the views and perspectives of patients, carers and healthcare professionals on medicines optimisation at transitions of care for PLWD. We will include studies which meet the inclusion criteria below.

Inclusion criteria		
	Include	Exclude
Date	2015 -2025	Pre 2015
Population	People diagnosed with dementia. Diagnosis of dementia is often nonspecific so we will use the populations as identified by study authors and in addition use the definitions used by NICE to determine whether a population is 'diagnosed'.	Patients without dementia including patients with other cognitive impairments including mild cognitive impairment and suspected dementia. Carers (professional and family/long term) of the above patients
	Designated (non healthcare-professional) carers of PLWD (may be family or paid carers)	
	Professionals with a care	

Inclusion criteria		
	Include	Exclude
	responsibility for PLWD in the following settings: Primary care Secondary care Social care Care/Nursing homes Homeless	
Setting	Reporting on PLWD who are experiencing an external transition of care (Home to Care Home, Home to Hospital, Care Home to Hospital, Care Home to Home, Hospital to Care Home, Hospital to Home)	Evidence about transitions within the same (internal) care setting, even if they are between different clinicians (in line with the scope defined by the James Lind Alliance PSP)
Medicine	We will use the Medicines and Healthcare products Regulatory Authority definition of a medicine. “A medicine helps to treat or prevent disease, and can be made up of synthetic (pharmaceutically prepared), herbal or homeopathic active ingredients…in a variety of types or formats, some are only available on prescription from your GP or other healthcare professional…some are available from a pharmacy where a pharmacist is present…and others can be purchased from supermarkets or other retail premises.	Any ‘non’ medicines which fall outside the scope of the MHRA definition. In cases of uncertainty we will refer to our PPI group, experts by professional role and colleagues involved in the JLA PSP.
Views	Lived experiences and perceptions related to medicine taking - administration, management, optimisation and communication about medicines.. Relating to prescribed and non-prescribed medication. Views can be related to patient clinical outcomes, patient	Not related to medication management

Inclusion criteria		
	Include	Exclude
	centred outcomes, economic outcomes although all views relating to medicines taking will be included.	
Study type	Peer reviewed journal articles and peer reviewed reports of qualitative evidence in the form of interviews, free text data from questionnaires, focus groups, other qualitative sources and qualitative evidence from mixed methods sources.	Articles with no full text available. Conference abstracts, case reports, and theses. Website pages where there is no associated report. Articles which are discussions, commentaries or provide discursive information rather than data, protocols for studies. Systematic reviews will not be included. Where systematic reviews are identified these will be used as a source for the identification of primary studies and emergent themes relating to the topic - the reviews will not be used as a source of evidence in themselves.
Other	English Language	
Setting	To ensure inclusion of settings with similar primary and secondary care systems as the UK and Australia, we plan to include studies undertaken in Organisation for Economic Cooperation and Development (OECD) countries. Depending upon the volume of evidence identified, it may be useful to undertake subgroup synthesis e.g. US vs Non US/'Western" OECD countries vs Non Western OECD countries.	

Search approach

A comprehensive search will be conducted to identify relevant peer-reviewed and grey literature pertaining to care transitions in care for people with dementia. The search

will encompass the period between 2015 and 2025 (current), which reflects the last decade of research and practice and changes in practice such as the move from paper records to electronic health records. This timeframe was chosen in order to capture the recent advancements in dementia care, including models of patient centred care and responses to the increasing prevalence of dementia among older adults (Alzheimers Society, 2014)

We will search the following databases: MEDLINE, Embase, PsycInfo, CINAHL, Cochrane Library, Social Science Citation Index (SSCI). Grey literature will be identified through searches of Google Scholar, relevant organisational websites (e.g. Alzheimer's Association, World Health Organization), and policy document repositories (e.g., BASE).

An example search strategy for MEDLINE (via Ovid) is presented below. The search strategy will utilise a combination of controlled vocabulary and keyword combination related to the concepts of ‘care transition’ and ‘dementia’. The search strategy will be iteratively refined based on initial search results and feedback. All search results will be imported into the EndNote reference management software for deduplication.

Ovid MEDLINE(R) ALL <1946 to March 04, 2025>

1	Dementia/	66904
2	Delirium, Dementia, Amnestic, Cognitive Disorders/	9986
3	dement*.tw,kw.	165397
4	alzheimer*.tw,kw.	214145
5	(lewy* adj2 bod*).tw,kw.	12882
6	"benign senescent forgetfulness".tw,kf.	18
7	((people or person*) adj1 living adj2 dementia).ti,ab,tw,kw,kf.	2816
8	or/1-7	338130
9	"Continuity of Patient Care"/	21257
10	(transition adj3 care).ti,ab,tw,kw.	5319
11	(transition adj3 treatment).ti,ab,tw,kw.	1187
12	(transition adj3 patient adj2 journey).ti,ab,tw,kw.	1
13	or/9-12	27118
14	8 and 13	290
15	limit 14 to yr="2014 -Current"	173

In addition to formal screening, we will also scrutinise the reference lists of studies meeting our inclusion criteria, and carry out citation searching on included studies. We will use all systematic reviews which meet our inclusion criteria to identify their included studies for review as per our inclusion/exclusion criteria.

In addition to the search for evidence relating directly to the topic, we will undertake a parallel search process for models/frameworks/theories to scaffold the framework synthesis. This will be undertaken in accordance with the guidance from the Cochrane-Campbell Handbook for Qualitative Evidence Synthesis (Cochrane-Campbell 2021).

Screening and selection

Following deduplication, unique records identified through searches will be screened for inclusion against the previously listed inclusion and exclusion criteria at title and abstract level.
An initial set of 100 references will be used as a pilot set and independently screened by two reviewers to ensure consistency in the application of these criteria. The reviewers will then convene to discuss any discrepancies in the application of these criteria.
The remaining (non-pilot) reference screening will be undertaken by two reviewers independently and any discrepancies discussed and if needed, referred to a third reviewer.
All references screened for inclusion at title and abstract stage will be screened at full text. At this stage, references that will be included in the review will be categorised as follows:
(1) patient/carer views (2) healthcare professional views (3) views from both groups.
As this is a qualitative evidence synthesis, it may be appropriate to sample studies for inclusion,rather than include all eligible studies - this will be undertaken in accordance with the Cochrane-Campbell Handbook for Qualitative Evidence Synthesis (2023).

Extraction

. We will extract study characteristics data from included studies into Covidence using the following fields. Covidence is a web-based collaboration software platform that streamlines the production of systematic and other literature reviews:

- Title, Author, Year and Country
- Population included (number, age, gender, ethnicity)
- Population of patients (if not the study population) (number, age, gender, ethnicity, diagnosis, co-morbidities, medication)
- Recruitment methods as linked to the study design
- Study design - Data collection
- Study design - Data analysis
- Reviewer conclusions

We will then use NVivo to code the following fields in line with Houghton et al (2016):

- Main findings - themes presented etc
- Frameworks or theories used (where appropriate)
- Limitations/applicability to a UK context
- Author conclusions

Both the Covidence and NVivo coding will be tested and refined with a set of three papers, reflecting different study types. Each of the three reviewers (two main reviewers (BK and ABa) and LP will extract data and code independently. The three reviewers will then meet to review the process with any inconsistencies highlighted.Any changes required will be made via discussion and consensus.

Following this, BK and ABa will each extract and code a subset of the papers. LP or LL will extract and code a sample of 10% of these papers and will meet with each reviewer to discuss discrepancies and inconsistencies and resolve via discussion and consensus with reference to our QES topic expert (ABo).

Synthesis

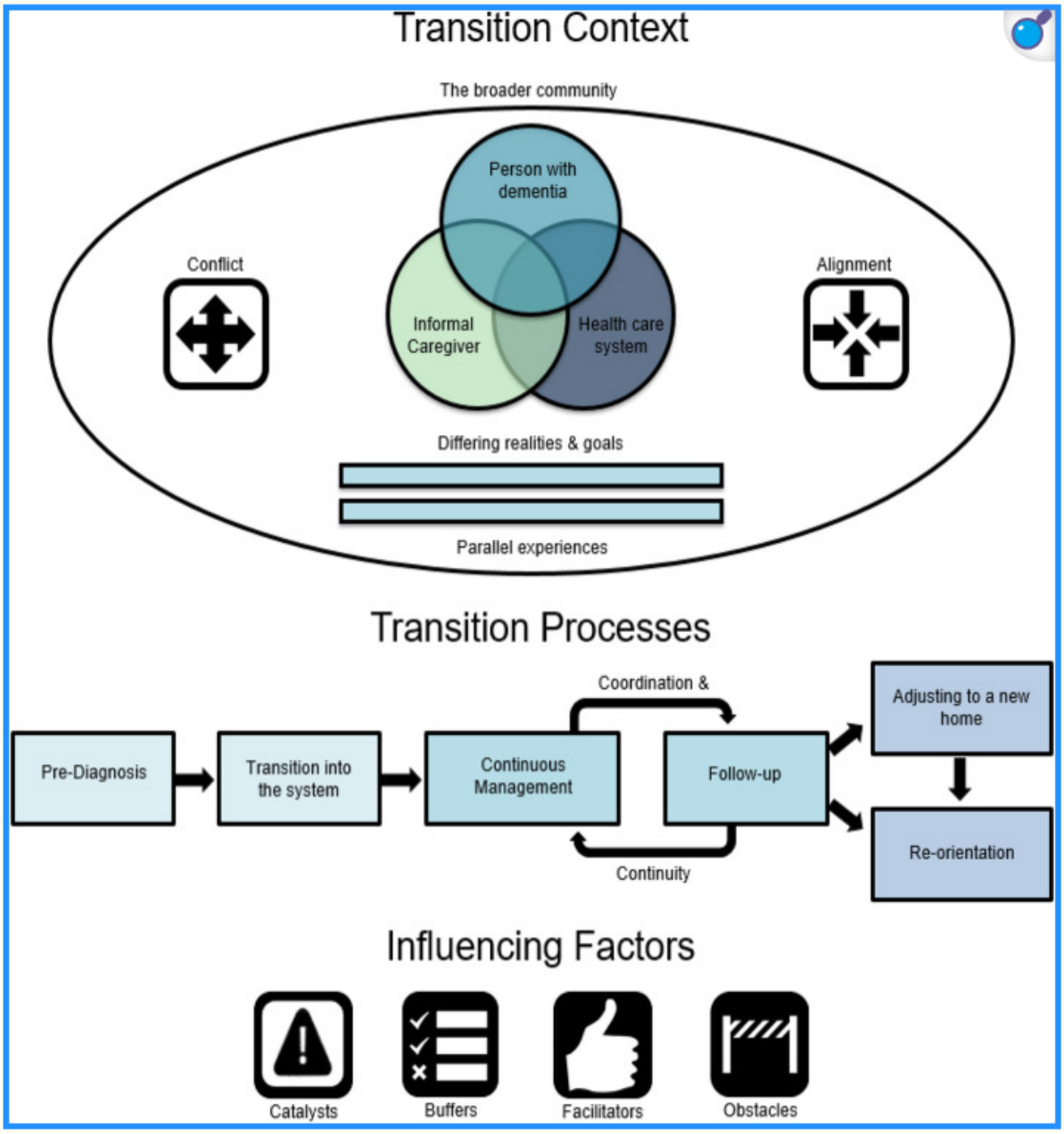
To synthesise the data extracted from the included studies, we will utilise a framework synthesis approach - best fit framework synthesis (Carroll et al 2013). This will ensure a rich exploration of the views of the different stakeholder groups.

The benefits of using a framework for the synthesis of this data are that it will allow rapid and consistent data extraction and synthesis which will underline the methodological strength of this approach (Brunton et al 2020).

The initial framework will be presented in the final outputs, alongside any modifications made through the synthesis process to allow the readers to understand how and why amendments were made.

The framework to be utilised will be identified from systematic searches conducted by the EnSygN team in line with the approach of Booth and Carroll (2015)- initial identified candidates have included the theoretical framework from the MEMORABLE realist synthesis, the Transitional Care Model (Hirschman et al 2015) and the transitions framework pictured below (Ashbourne et al 2021).

Using the Ashbourne framework as an example, we would extract data on views for each link (i.e. arrow) of the flowchart below (excluding the pre-diagnosis to transition into the system as it is outside the scope of this review) and then within each transition element we would identify and use a medication management framework e.g. the NICE 6 rights of medicines administration to identify medication specific views. We have used this meta-framework approach (merging two frameworks that operate at different levels) in other reviews. The benefits of this approach are that this would provide a pathway for the presentation of the review and within each identified transition process the synthesis would be structured in a standardised way.


Transition Context
The broader community
Person with dementia
Informal Caregiver
Health care system
Conflict
Alignment
Differing realities & goals
Parallel experiences
Transition Processes
Pre-Diagnosis
Transition into the system
Continuous Management
Coordination &
Follow-up
Continuity
Adjusting to a new home
Re-orientation
Influencing Factors
Catalysts
Buffers
Facilitators
Obstacles

Quality Assessment

We will use the CochrAne qualitative Methodological LimitatiOns Tool (CAMELOT), a new domain based tool for assessing methodological limitations in primary qualitative studies (Munthe-Kaas et al 2024). For each paper an independent assessment will be made by one reviewer with a 10% subset independently undertaken by a second reviewer to check.
GRADE-CERQual assessments (Lewin et al 2018) will be applied to key findings derived from the framework, with confidence ratings and explanations presented alongside each major finding and a summary of Qualitative Findings and Evidence Profile tables will be generated using the interactive summary of qualitative findings (iSoQ) tool. .

Stakeholder approach

Stakeholders by experience - PPI

We will establish a lived experience patient and public advisory group specific to this topic consisting of people who have experienced issues related to medicines when someone with dementia has moved between care settings e.g. from hospital to a care home. We will advertise the opportunity for people to join this group. We have co-developed a recruitment advert with our PPI strategy group and this is ready to be cascaded to other PPI groups/organisations and advertised on national forums. We will also advertise to existing PPI groups and organisations that we are aware of that have been suggested by our PPI strategy group, such as the Dementia Research Advisory Group South Yorkshire (DRAiSY) https://draisy.sites.sheffield.ac.uk/ We will also advertise this using our links with Dementia UK. . We will select to recruit a diverse range of people in terms of age, gender, location, background and experiences (ideally positive and negative experiences). We will aim for 8-10 group members. It is anticipated that the group will meet online at four points during the review. They will contribute to discussions to define the parameters and inform understanding of the topic, support the identification and selection of a theoretical framework and support the analysis of findings to assist with interpretation, and the identification of key messages and developing outputs. They will also be given the opportunity to contribute to dissemination of the review findings to the public. Our public co-applicant will assist with the recruitment process, using a role descriptor, and offer mentoring if required. We will offer training in the form of a video session and reimburse people for their time, including for attending meetings and commenting on drafts. In addition, our PPI Strategy Group has already contributed to discussions regarding the scope of the work and to the development of the advertisement to recruit the lived experience PPI members. We will report how PPI was embedded in the review and the impact PPI has on the review using the GRIPP2 Framework (Stanizewska et al 2017) and we will also feedback to PPI contributors throughout the review process using a 'you said, we did' approach (Bevan et al 2024).

Stakeholders by professional role

As well as working closely with colleagues from the JLA PSP setting exercise in Australia who are academics and practitioners, we will also consult stakeholders by professional role in the course of this review. These will include academics who we plan to approach (e.g. Ian Maidment, Hadar Zaman and Judy Mullan - members of MEMORABLE team). We will also use our clinical contacts within the School of Medicine and Population Health at the University of Sheffield to identify healthcare professionals who work with PLWD if needed.We have established collaborations with clinicians (doctors, nurses and AHPs) who can provide specific tailored feedback as needed.

EDI approach

In the development of this topic, the JLA identified implications for EDI relating to unequal experiences of different populations within the healthcare system and in particular language or cultural barriers, particularly when considering the interplay between family and professional carers. Additionally people from a culturally and linguistically diverse background and people who are multimorbid, such as people living with dementia, may specifically experience negative health consequences from suboptimal medicines optimisation.

We take EDI considerations seriously and have developed an internal tool SEEDI (Sheffield EnSyN Equality, Diversity and Inclusion), which we will test on this review. The tool incorporates elements of the PRO-EDI tool and considers the impact of research team composition, methods and results via an equity lens. We will be cognisant of the differential experiences and involvement of minoritised groups in the research, in particular racialised minorities, older people, people with comorbid disabilities and diagnoses alongside their dementia. The findings of the SEEDI tool will be included in review outputs and we will complete a PRO EDI participant characteristics table to ensure equity considerations about the participants (or their family members/people they are caring for) and their representativeness.

Reflexivity

In addition to considering EDI implications relating to the research team, we also need to consider reflexivity and the impact that the review team may have on the review and how their views and beliefs can shape the scope, methods and interpretation of the review. Remaining aware of this will ensure that we can (a) be clear of these factors on the findings of the review to review consumers and (b) consider whether any amendments to the findings of the review. It will also be important to consider the impact of the review on the review authors. Reflexivity will be an agenda item for our regular team meetings and prior views of the research team will be explored in early project meetings where we will consider experiences, beliefs and expectations of findings to aid transparency. .

Outputs

We anticipate that the findings of the review will be reported in two journal articles and where appropriate we will use peer reviewed reporting guidelines, Decisions about the type and format of articles will be made by the research team and we will seek advice and recommendations from the stakeholders involved in the review to ensure that these are useful. For the JLA PSP, we will also include a brief cover document with these articles. We will also work with our PPI group to develop public facing outputs and also evidence briefings for professional stakeholders as well as conference presentations at topic and methodological conferences. The JLA have indicated that they will use the findings of the review to consider the feasibility of a grant application to explore the development of an intervention based on the findings of this review.

Timeline

The timeline for the review including activities already completed is below

Activities completed	
Initial topic received by EnSygN	End of September 2024
Scoping review	November and December 2024
Meeting - EnSygN, NIHR and JLA PSP	January 2025
Confirmation of topic and protocol development	February 2025
NIHR, ESG and JLA review of protocol	March 2025
Protocol sign off	End of May 2025

Review timeline			
Month	Internal task(s)	Milestone	External meetings
March and April 2025	Protocol development and approval	Signoff of protocol via NIHR and James Lind Alliance PSP	
May 2025	Searching and study selection	Library of deduplicated references for screening	PPI
June 2025	Screening and study selection	Title and abstract screen completed	
July 2025	Screening and study selection Data extraction	Full text screen completed	PPI
August 2025	Data extraction	Trial extraction process Extraction agreed and started	
September 2025	Data extraction		
October	Data extraction	Extraction completed	PPI

Review timeline			
2025	Synthesis	Synthesis starts	
November 2025	Synthesis		
December 2025	Synthesis Writing Update search		PPI
December 2025	Writing	Submission of journal articles to target journals. Development and delivery of covering note to JLA Development of patient and professional focused materials.	

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