

# Availability and accessibility of dementia services to migrants, refugees and asylum seekers, and their carers, in the UK: a scoping review.

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## Abstract

**Background:** Dementia is the leading cause of disability in later life, with the WHO estimating that 10 million people develop the condition worldwide every year. In the UK, diagnosis of dementia is on the rise, and developing services to support people living with dementia and their carers has been identified as a priority by the government. However, it has been well documented that accessibility of health services in general, and dementia services in particular, is far from equitable, with people from ethnic minority groups often excluded from the available provision. With ever increasing rates of immigration to the UK, these disparities are likely to be disproportionately impacting migrant, refugee and asylum seeking communities.

**Methods:** This study will be a mixed-methods scoping review. Papers will be identified through systematic database searches on SCOPUS, PubMed, PsycInfo, CINAHL and ASSIA, as well as supplementary hand searches for grey literature. Thematic analysis will be used to analyse extracted data.

**Objectives:** The primary aim is to identify what services are available to migrants, refugees and asylum seekers living with dementia, and their carers, in the UK, and understand the enablers and barriers to accessing these services. In addition, this research will map out the available evidence in order to identify gaps in the existing literature and propose areas for further research.

## Keywords

Dementia; migrant; refugee; asylum seeker; carer; service; support; treatment

## Introduction

Dementia is a growing global health concern. The World Health Organization (WHO) estimates that around 10 million people worldwide are newly diagnosed with the condition annually, and due to its degenerative nature, it is a major cause of death as well as disability in older age (WHO, 2021). Despite ongoing efforts, there remains no cure for dementia, and medication to halt or slow down the progression is limited. Nevertheless, there are various medical and non-medical treatments available aimed at alleviating symptoms and improving quality of life (Alzheimer's Society, 2022a). In the UK, the Living Well with Dementia (LWWD) strategy set out the government's priorities for improving the diagnosis, treatment and quality of life for all residents living with dementia, including addressing associate health inequalities (DOH, 2009). At the same time, international migration is on the rise and set to remain so in coming years, impacted by socio-economic, environmental and political events around the globe (McAuliffe and Khadria, 2019). The UK holds some particular attraction for migrants due to its relative political and economic stability, perceived work and educational opportunities, and established diverse ethnic communities, in part due to the impact of colonialism (Czaika and de Haas, 2017). As a result, substantial net migration into the UK is recorded every year, predominantly of older people and working age adults, who will have a higher risk of developing dementia as they age (Prince et al., 2014). And while existing inequalities among ethnic minority groups in accessing UK healthcare services in general (Ajayi, 2021), and mental health (Memon et al., 2016) and dementia care (National Institute for Health Research, 2020) in particular, are well documented, these are likely to be further exacerbated in migrant, refugee and asylum seeker communities due additional barriers and challenges associated with the geographic transition. In addition, there are studies suggesting a link between migration and reduced cognitive function (Adelman et al., 2011; Livingston et al., 2001). Despite this, the current UK dementia strategy (including its supplementary documentation on equality) does not refer to migrants, refugees or asylum seekers specifically, suggesting that the particular needs of these communities are not being considered as a priority. This project aims to conduct a comprehensive review of the existing literature in order to identify what dementia services are available to migrant, refugee and asylum seeking populations in the UK, and explore the enablers and barrier to accessing the available services. In addition, it will aim to map out the available evidence in order to identify gaps and proposed areas for further research.

## Review question

What dementia services are available to migrants, refugees and asylum seekers, and their carers, in the UK, and what are the enablers and barriers to accessing these services?

## Eligibility criteria

### Participants

Migrants, refugees, asylum seekers and stateless persons aged 18 or over who are residing in the UK and are living with any type of dementia.

Informal (family, friends, neighbours, etc.) carers of above.

### Concept

Services available to above to include medical treatment, nursing care, psychological intervention and social care and support.

### Context

Any part of the United Kingdom, to include England, Wales, Scotland and Northern Ireland.

### Types of Sources

This project will be a mixed-methods scoping review. It will examine peer-reviewed literature (primary research, secondary analysis and systematic reviews) relating to dementia service either specifically for or available to migrants, refugees, asylum seekers and/or stateless persons in the UK, and their carers.

In addition, it will consider grey literature sources such as government and NGO reports, conference reports and abstracts, and any other relevant unpublished literature.

## Methods

This review will be structured using the framework developed by Arksey and O'Malley (2005), and refined by Levac et al. (2010), Colquhoun et al. (2014), and Peters et al. (2020).

### Search strategy

This search strategy strives to identify all the literature available, both peer-reviewed and grey, that is relevant to the research question.

The search terms and synonyms were developed following the PICOT framework (Appendix 1). Following an initial limited search on SCOPUS, additional keywords and terms were extracted from relevant papers, and incorporated into a pilot search strategy used on SCOPUS and PubMed (Appendix 2).

The final search strategy will be used to search five electronic databases to enable the identification of all relevant peer-reviewed articles from a variety of disciplines, corresponding with the types of services the review aims to cover:

- SCOPUS – a comprehensive database with varied content base;
- PubMed – for medicine based perspective;
- PsycInfo – for psychology based perspective;
- CINAHL – for nursing based perspective;
- ASSIA – for social care based perspective.

In addition, the reference lists of all papers identified as relevant will be searched for additional resources (Peters et al., 2020), and Connected Papers (<https://www.connectedpapers.com/>) will be used to support identifying further relevant publications.

Finally, a hand search will be undertaken of relevant stakeholders, such as governmental websites and NGOs, as well as Google searches using the identified search terms to retrieve any relevant unpublished literature.

Only studies available in English will be included. However, this is felt to be appropriate as this project only considers services in the context on the UK. Studies can be published at any time.

### Study/Source of Evidence selection

Once the searches are completed, the Zotero software will be used for the extraction and management of the identified literature. Following adjustments for duplication, the titles and abstracts (or titles only, for grey literature) of all identified papers will be screened. Subsequently, the full text of the remaining articles will be reviewed against the inclusion and exclusion criteria (Appendix 3) to identify literature to be retained for analysis. Although it is recommended that this process is conducted by two or more researchers (Peters et al., 2020), this will not be possible as this project is being undertaken by a single researcher. The study selection process will be thoroughly documented, including the production of a flowchart utilizing the PRISMA Statement 2020 (Page et al., 2021; Peters et al., 2020), to ensure rigour and transparency of process (Colquhoun et al., 2014; Munn et al., 2018).

### Data Extraction

A data extraction tool will be developed for this project. A draft of the data extraction table is attached (Appendix 4). This tool will be adjusted through the extraction process to ensure all the relevant data is captured. Any changes to the tool will be documented.

Although quality assessment is not considered to be an essential component of a scoping review, it was decided to undertake this during this project. To balance the need for comprehensive overview of the topic with minimizing the impact of poor quality data on the findings of this research, it was decided to include all relevant literature in the analysis, but undertake a quality assessment for all literature included, to be used when discussing the results and drawing conclusions. As this review will be used to evaluate published papers (CASP, 2021), while grey literature will be evaluated using the AACODS checklist (Tyndall, 2010).

### Data Analysis and Presentation

The extracted data will be grouped categorically, and thematic analysis will be used to draw out recurrent issues from the literature. The findings of this analysis will be presented descriptively, utilising tables and charts. Data mapping will be completed with the aim of identifying gaps in the existing literature and making recommendation as to further research needs.

## Ethical Considerations

This project will not involve the collection of primary data or secondary analysis of primary data, and therefore, ethics approval will not be required. Due to the nature of a scoping reviews and the need to access the full breadth of the relevant literature (including grey literature), it may not be possible to verify the ethical considerations and/or approval for all the literature included. However, where possible (e.g. peer-reviewed articles), efforts will be made to ensure ethical practices were followed, for example by checking that studies were approved by an ethics board.

At the reporting stage, ethical practices will be employed with regards to citation of any non-original ideas and clear referencing.

### Risk of bias

There are several areas where risk of bias may arise during this project. Due to the nature of a Masters dissertation, literature selection and analysis will be done by a single researcher, despite the recommendation for scoping reviews to be complete by a team of two or more researchers from different disciplines to improve result validity (Peters et al., 2020). This will be somewhat mitigated by a robust research protocol, inclusion of data from diverse sources and disciplines, and input from project supervisor. However, risk of unintentional bias will be impossible to eliminate. Time and human resource limitations may also impact on the ability to obtain and process data from every conceivable source.

Literature included in scoping reviews is commonly not quality assessed which may introduce poor quality data into the review, compromising the results. To mitigate this, a quality assessment has been introduced into this review process. Although this will not lead to the exclusion of literature from the review, it will enable the discussion of the implications of any poor quality literature identified on the research findings.

Language limitation may introduce a selection bias, as only literature available in English will be considered. However, as the context of this project is UK based, it is felt that the majority of the relevant literature will be available in English.

### Funding

No funding has been sought for this project.

### Conflicts of interest

There is no conflict of interest in this project.

## Acknowledgements

This review is being undertaken as the dissertation component toward MSc Global Health award for Bella Tomsett.

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## Timescales

Task	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept
Submit research proposal	25/01								
Refine search strategy									
Register research protocol									
Complete searches									
Title and abstract review									
Full-text review									
Data extraction									
Data analysis									
Write dissertation									
Submit dissertation									01/09

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## Appendices

### Appendix 1: PICOT search terms

	<b>Population</b>	<b>Issue</b>	<b>Context</b>	<b>Outcome</b>
<b>PICO term</b>	Migrant	Dementia	United Kingdom	Service
<b>Alternative terms</b>	Immigrant Refugee Asylum seeker Stateless person Displaced person	Alzheimer's Vascular dementia Frontotemporal dementia Lewy body Cognitive impairment Parkinson's with dementia	UK Great Britain England Wales Scotland Northern Ireland Europe European Union EU	Treatment Assessment Screen Test Care Support Intervention Provision Medication Drugs Therapy

## Appendix 2: Search strategy

### SCOPUS

TITLE-ABS-KEY(((migrant) OR(immigrant) OR(refugee) OR("asylum seeker") OR("stateless person") OR("displaced person")) AND((dementia) OR(Alzheimer's) OR("vascular dementia") OR("frontotemporal dementia") OR("Lewy body") OR("cognitive impairment") OR("Parkinson's with dementia"))) AND(("United Kingdom") OR({UK}) OR("Great Britain") OR(England) OR(Wales) OR(Scotland) OR("Northern Ireland") OR(Europe) OR({EU}) OR("European Union")) AND((service) OR(treatment) OR(assessment) OR(screen) OR(test) OR(care) OR(support) OR(intervention) OR(provision) OR(medication) OR(drug) OR(therapy)))

### PubMed

((migrant\*[Title/Abstract]) OR (immigrant\*[Title/Abstract]) OR (refugee\*[Title/Abstract]) OR (asylum seeker\*[Title/Abstract]) OR (stateless person\*[Title/Abstract]) OR (displaced person\*[Title/Abstract])) AND ((dementia[Title/Abstract]) OR (Alzheimer's[Title/Abstract]) OR (vascular dementia[Title/Abstract]) OR (frontotemporal dementia [Title/Abstract]) OR (Lewy body[Title/Abstract]) OR (cognitive impairment[Title/Abstract]) OR (Parkinson's with dementia[Title/Abstract])) AND ((United Kingdom[Title/Abstract]) OR ("UK"[Title/Abstract]) OR (Great Britain[Title/abstract]) OR (England[Title/Abstract]) OR (Wales[Title/Abstract]) OR (Scotland[Title/Abstract]) OR (Northern Ireland[Title/Abstract]) OR (Europe[Title/Abstract]) OR (European Union[Title/Abstract]) OR ("EU"[Title/Abstract])) AND ((service\*[Title/Abstract]) OR (treat\*[Title/Abstract]) OR (assess\*[Title/Abstract]) OR (screen\*[Title/Abstract]) OR (test\*[Title/Abstract]) OR (care\*[Title/Abstract]) OR (support\*[Title/Abstract]) OR (intervention\*[Title/Abstract]) OR (provision\*[Title/Abstract]) OR (medicat\*[Title/Abstract]) OR (drug\*[Title/Abstract]) OR (therap\*[Title/Abstract]))))

## Appendix 3 : Inclusion/exclusion criteria

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<ul style="list-style-type: none"> <li>• Any sources (peer reviewed and grey literature) relating to formal service and/or support specifically for or available to migrants, refugees, asylum seekers and/or stateless persons living with dementia, and/or their carers.</li> <li>• Any sources (peer reviewed and grey literature) discussing barriers and/or enablers to migrants, refugees, asylum seekers and/or stateless persons living with dementia, and/or their carers, accessing formal services and/or support.</li> <li>• Carers = informal caregivers (eg. family, friends, neighbours, etc.).</li> <li>• Services = prevention, information/advice, diagnosis, medical treatment, community nurse input, social care, psychological support, community engagement, occupation/activity, carer support, residential homes, end of life care.</li> <li>• Adult population = participants age <math>\geq 18</math>.</li> <li>• Explicitly examining any part of the UK.</li> <li>• Published or available in English.</li> <li>• Any publication year.</li> </ul>	<ul style="list-style-type: none"> <li>• Sources not referring to dementia AND migrants, refugees, asylum seekers and/or stateless persons.</li> <li>• Sources only discussing mental health or neurodegenerative conditions other than dementia.</li> <li>• Studies with all participants aged <math>\leq 18</math>.</li> <li>• Sources only considering populations outside UK.</li> <li>• Grey literature replicating information from published studies already included in review.</li> <li>• Sources which are not available in English.</li> </ul>

