

# **Dementia post-diagnostic support in UK rural communities: experiences of people living with dementia, informal caregivers, and healthcare professionals. A systematic review protocol.**

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## **Abstract**

People living with dementia in rural areas experience numerous barriers to accessing post-diagnostic support. The aim of this systematic review is to identify and describe the experiences, barriers and provision of post-diagnostic support in UK rural areas; from the perspective of people living with dementia, healthcare professionals and informal caregivers. Systematic searches will be conducted in the following databases; SCOPUS, PubMed, PsychINFO and CINAHL Plus. Systematic review tool Rayyan.ai will be used to screen titles and abstracts, prior to full-text review. Following data extraction, The Critical Appraisal Skills Programme (CASP) will be used to appraise the quality of studies and assess risk of bias. The data will be deductively analysed through the lens of the Candidacy Framework's 6 dimensions, with a secondary inductive analysis capturing any themes that fall outside of the framework. Understanding the rural barriers and experiences of post-diagnostic support will allow researchers and stakeholders to develop and optimise specially tailored dementia interventions in line with the needs of people residing in UK rural communities.

## **Background**

Dementia is a term used to describe a progressive decline in cognitive abilities, including memory loss, reasoning, judgement, and changes in behaviour and mood sufficiently severe to affect social or occupational function [1]. Worldwide, approximately 50 million people were living with dementia in 2015, which is projected to increase to 152.8 million by 2050 [3]. Rural areas are aging faster than urban areas [4], thus more people are at risk for dementia. Yet, rural areas are characterised by their limited access to appropriate post-diagnostic support [5].

## **Rationale**

The purpose of this systematic review is to identify and describe the existing evidence which highlights the experiences of dementia post-diagnostic support in UK rural areas, from the perspectives of people living with dementia, health care professionals, informal caregivers. We will apply existing evidence to the Candidacy Framework [6]. The framework conceptualises access to healthcare as a multifaceted and iterative process of negotiation between individuals, providers, and institutions. The framework comprises of six domains that represent distinct but overlapping dimensions of candidacy. The domains broadly link to key stages in a patient's health care trajectory, from the first recognition that symptoms require medical care, through to the offer and acceptance of post-diagnostic care [6]. The framework has previously been used to examine the healthcare experiences of older adults with dementia, [7,8] therefore is deemed an appropriate framework for examining experiences of post-diagnostic support. A systematic review will provide policy makers and stakeholders the information

required to both develop specialist interventions and improve accessibility to formal service provision in UK rural communities.

## **Aims**

The main aim of this systematic review is to identify the existing evidence within qualitative literature that explores the experiences of post-diagnostic support in UK rural communities. The review will explore the experiences of people living with dementia, informal carers, and healthcare professionals through the lens of the Candidacy Framework [6]. The aim is a full circle approach, to capture the experiences of receiving, delivering, and accessing dementia care provision in rural areas of the UK.

## **Objectives**

To identify the experiences, barriers, and provision of post-diagnostic support for those living with dementia in UK rural communities, from the perspective of people with dementia, informal caregivers, and paid healthcare professionals.

## **Methods**

The systematic review will follow the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [9].

## **Formulating a research question**

The proposed question is 'What are the experiences of people living with dementia, paid healthcare professionals and informal caregivers on post-diagnostic support within rural UK communities?' The SPIDER tool [10] was used to support the formulation of the research question. The question has been agreed by DB, NF and BH to fulfil the systematic reviews aims and objectives.

## **Eligibility**

Eligibility criteria for the systematic search strategy were developed using the SPIDER tool [10], a widely adopted instrument for defining search terms for qualitative and mixed methods studies. The components of the SPIDER tool comprise: sample (S), phenomenon of interest (Pi), design (D), evaluation (E) and research type (R).

- **Sample:** people with dementia and informal caregivers living in rural communities, or healthcare professionals that provide care for these communities.
- **Phenomenon of interest:** post-diagnostic support
- **Design:** interview, focus group, observation, case studies
- **Evaluation:** experiences of post-diagnostic support
- **Research type:** qualitative, mixed methods

The following criteria will be applied to determine whether literature is included or excluded in this systematic review. Several terms will be broadly defined to capture as many pertinent studies as possible.

## **Inclusion criteria**

The following inclusion criteria will be utilised; a) Papers written in the English language; b) UK based samples; c) studies that describe the sample as being derived from (person with dementia or informal caregiver) or serving (healthcare professional) 'Rural' or 'Remote' communities; d) Participants composed of people with 'dementia', self-reported or clinically diagnosed (e.g., Alzheimer's disease, Vascular dementia), and/or an informal caregiver for someone with dementia, and/or paid healthcare professionals involved in the care of people with dementia; e) qualitative or mixed methods design; f) peer-reviewed articles and grey literature; g) studies that explore experiences of post-diagnostic dementia support from the perspective of the person with dementia, informal caregiver or paid healthcare professional noted in the results section of the paper.

Studies that include a mixture of eligible participants (e.g., rural/non-rural, UK residing/non-UK residing) will be included so long as the findings are reported separately sufficient for extraction.

### **Exclusion criteria**

The following exclusion criteria will be utilised; a) studies that report exclusively on diagnostic or pre-diagnostic experiences; and b) editorials, opinion pieces, reviews.

### **Search strategies**

The following databases will be utilised: SCOPUS, PubMed, PsychINFO and CINAHL Plus.

Three main search strategies have been identified for this review, namely, Dementia, Rurality and UK as shown in table 1. Search terms were developed following a search of previous literature to identify specific terms relevant to these concepts. A variation of MeSH terms and synonyms were used to create the search strategy [11]. Boolean operators; 'AND' and 'OR' were used to search for relevant literature in the databases. All advance search strategies and Boolean strings, and date of searches were saved for replicability and ability to update the search strategy if required. All searches were performed in the English language.

Table 1 – Example search strategy terms

<b>Search component</b>	<b>Search strategy</b>
Dementia	Dementia OR Alzheimer* OR neurodegenerative OR cognit*
Rurality	Rurality OR rural OR remote OR countryside OR farming
UK	UK OR "United Kingdom" OR England Or Scotland OR Wales OR "Great Britain"

We will hand search citations of potentially relevant studies and employ lateral search techniques to identify additional studies.

### **Study records**

### **Data Management:**

All articles identified will be exported into the systematic review programme Rayyan.ai [12]. Duplicates will be removed by automatic de-duplication and then manually searching for duplicates. An Excel spreadsheet will then be used to manage the data extracted.

### Selection of studies:

Two reviewers will independently screen titles and abstracts against the inclusion/exclusion criteria. If either reviewer deems the article as relevant based on the title and abstract, it will be brought forward for full-text screening. Full manuscripts that meet the inclusion criteria will then be reviewed independently and in duplicate. Any disagreements between independent researchers will be reviewed and discussed with a third reviewer. Agreement statistics will be reported.

The PRISMA study flow chart (as shown in figure 1.) will be used for the transparency of the selection and screening process.

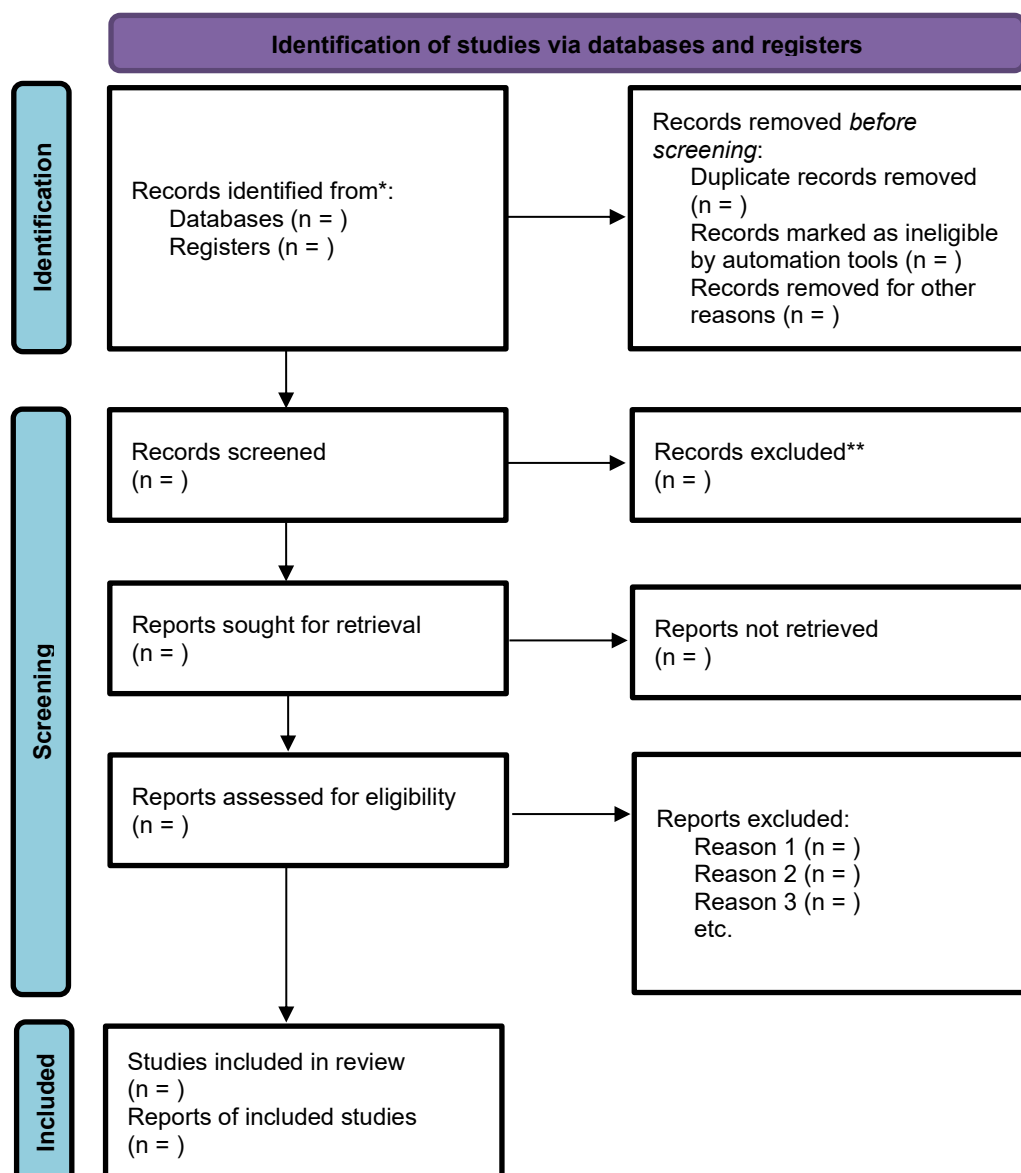


Figure 1. PRISMA study flow chart for systematic reviews [9]

### Data items and collection process

Data will be independently extracted by DB for the studies that are identified as eligible as per the inclusion/exclusion criteria. Full text data will be inputted into a pre-designed form (See table 2.) Data extraction will consist of descriptive information such as study, methodology, sample and demographic information. Research quotes pertaining to themes (or accompanying narrative) and direct participant quotes related to experiences of post-diagnostic support will be extracted from the results section.

Table 2. Characteristics from included studies.

Characteristics	Description
Author	
Year of publication	
Country of study	
Definition of rurality, if provided	
Indicators of sample rurality, if provided (e.g., average distance from nearest city)	
Ethnicity of sample	
Age	Range:              Mean:              SD:              Median:
Sample size	
Deductive themes:	Researcher reported theme      Participant quotes
<i>Identification</i>	
<i>Navigation</i>	
<i>Permeability of Services</i>	
<i>Appearance and Adjudications</i>	
<i>Resistance</i>	
<i>Operating Conditions</i>	
Inductive themes	

### Outcome prioritisation

The primary outcomes of this study will be experiences of rural post-diagnostic support from the perspective of people living with dementia, informal carers, and paid healthcare professionals. There are no secondary outcomes.

### **Risk of bias in individual studies**

The Critical Appraisal Skills Programme (CASP) tool will be used to appraise the quality of studies and assess risk of bias in this review. The CASP tool is a generic tool for assessing the strengths and limitations of any qualitative research methodology [13]. The CASP tool was devised for health-related research, therefore this is an appropriate tool for the context of this review. The tool comprises of 10 questions that focus on each methodological aspect of qualitative studies. The reviewers will rate the questions on a scale of 'yes', 'no' or 'cant tell'. DB and a second reviewer will independently score eligible studies using the CASP checklist. Both reviewers will then meet to resolve any disagreements and consolidate the final decisions. Risk of bias will be narratively described and used to contextualise results. Studies will not be excluded based on an high risk of bias.

### **Data synthesis**

We will use a framework synthesis approach to the data [14]. The data will be synthesised through the lens of the Candidacy Framework's six dimensions; identification, navigation, permeability of services, appearances, and adjudications, offers and resistance and operating conditions [6]. As such, the data will be deductively split into the six dimensions. A secondary inductive thematic analysis will be conducted to capture any additional themes that may fall outside of the Candidacy Framework's dimensions.

### **Confidence in cumulative evidence**

The GRADE-CERQual will be used to assess the confidence of evidence for each finding [15].

### **Discussion**

This systematic review will aim to provide an insight into the current level of post-diagnostic support available in rural areas and the experiences of people living with a diagnosis of dementia, informal caregivers, and healthcare professionals. Understanding more about the rural barriers and facilitators to delivering, accessing, and engaging in post-diagnostic support, will support researchers to develop and optimise post-diagnostic interventions specially tailored to the needs of people living in rural communities with dementia.

### **Author contributions**

DB formulated and prepared the draft protocol under the supervision of NF and BH. Both NF and BH contributed to the development of the design and planned output of the research. DB prepared the manuscript and NF and BH reviewed it. All authors read and approved the final manuscript.

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