



Sep 08, 2023

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

DOI

<https://dx.doi.org/10.17504/protocols.io.81wgbxrdylpk/v1>

Dannielle Bilkey¹, Nicolas Farina², Ben Hicks³

¹Cornwall Partnership NHS Foundation Trust; ²University of Plymouth;

³Brighton and Sussex Medical School, Centre for Dementia Studies



Dannielle Bilkey

Create & collaborate more with a free account

Edit and publish protocols, collaborate in communities, share insights through comments, and track progress with run records.

Create free account

OPEN  ACCESS



DOI: <https://dx.doi.org/10.17504/protocols.io.81wgbxrdylpk/v1>

Protocol Citation: Dannielle Bilkey, Nicolas Farina, Ben Hicks 2023. Dementia post-diagnostic support in UK rural communities: experiences of people living with dementia, informal caregivers, and healthcare professionals. A systematic review protocol..

protocols.io <https://dx.doi.org/10.17504/protocols.io.81wgbxrdylpk/v1>

License: This is an open access protocol distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited

Protocol status: Working

We use this protocol and it's working

Created: September 08, 2023

Last Modified: September 08, 2023

Protocol Integer ID: 87557

Keywords: dementia in rural area, dementia interventions in line, tailored dementia intervention, dementia, uk rural community, uk rural area, aim of this systematic review, informal caregiver, systematic review, critical appraisal skills programme, systematic review protocol, rural community, rural barrier, rural area, experiences of people

Funders Acknowledgements:

National Institute for Health Research, Clinical research Network, SW Peninsula

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.

Attachments



[Systematic review pr...](#)

322KB

Protocol references

1. Knowles S, Combs R, Kirk S, Griffiths M, Patel N, Sanders C. Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health & Social Care in the Community*. 2015 Feb 23;24(2):203–13.
2. Szymczynska P, Innes A, Mason A, Stark C. A Review of Diagnostic Process and Postdiagnostic Support for People with Dementia in Rural Areas. *Journal of Primary Care & Community Health*. 2011 May 4;2(4):262–76.
3. GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health* [Internet]. 2022 Jan;7(2). Available from: [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(21\)00249-8/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(21)00249-8/fulltext)
4. Anthea I, Debra M. Remote and Rural Dementia Care: Policy, Research and Practice [Internet]. Google Books. Policy Press; 2020 [cited 2023 Sep 7]. Available from: https://books.google.co.uk/books?hl=en&lr=&id=WbXjDwAAQBAJ&oi=fnd&pg=PP1&dq=rural+dementia+care+uk&ots=BYQdYxP_uf&sig=cOKU0TKUPj6jHGkcGEWMT45LF20&redir_esc=y#v=onepage&q=rural%20dementia%20care%20uk&f=false
5. Innes A, Morgan D, Kostineuk J. Dementia Care in Rural and Remote settings: a Systematic Review of informal/family Caregiving. *Maturitas*. 2011 Jan;68(1):34–46.
6. Novek S, Menec VH. Age, Dementia, and Diagnostic Candidacy: Examining the Diagnosis of Young Onset Dementia Using the Candidacy Framework. *Qualitative Health Research*. 2020 Nov 19;31(3):498–511.
7. Koehn S, Badger M, Cohen C, McCleary L, Drummond N. Negotiating access to a diagnosis of dementia: Implications for policies in health and social care. *Dementia*. 2016 Jul 26;15(6):1436–56.

8. De Poli C, Oyebode J, Airoidi M, Glover R. A need-based, multi-level, cross-sectoral framework to explain variations in satisfaction of care needs among people living with dementia. *BMC Health Services Research*. 2020 Jul 15;20(1).

9. Page M, McKenzie J, Bossuyt P, Boutron I, Hoffmann T, Mulrow C. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews [Internet]. *prisma-statement.org*. 2021 [cited 2023 Jul 20]. Available from: <http://prisma-statement.org/prismastatement/flowdiagram.aspx>

10. Cooke A, Smith D, Booth A. Beyond PICO: the SPIDER Tool for Qualitative Evidence Synthesis. *Qualitative Health Research*. 2012 Jul 24;22(10):1435–43.

11. National Library of Medicine. Home - MeSH - NCBI [Internet]. *www.ncbi.nlm.nih.gov*. [cited 2023 Aug 23]. Available from: <https://www.ncbi.nlm.nih.gov/mesh/>

12. CASP. Critical Appraisal Skills Programme (CASP) part of OAP Ltd *www.casp-uk.net* [Internet]. 2018. Available from: https://casp-uk.net/images/checklist/documents/CASP-Systematic-Review-Checklist/CASP-Systematic-Review-Checklist_2018.pdf

13. Rayyan – Intelligent Systematic Review [Internet]. *www.rayyan.ai*. Available from: <https://www.rayyan.ai/>

14. Barnett-Page E, Thomas J. Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*. 2009;9(1).

15. Lewin S, Booth A, Glenton C, Munthe-Kaas H, Rashidian A, Wainwright M, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. *Implementation Science*

[Internet]. 2018 Jan;13(S1). Available from:

<https://implementationscience.biomedcentral.com/articles/10.1186/s13012-017-0688-3>