



The role of primary care

PriDem project - Primary care-led post diagnostic Dementia Care: developing evidence-based, person centred sustainable models for future care

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PriDem Core Team



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Outline

- Background to PriDem programme
- PriDem intervention development phase
- Current Workstream 4: Feasibility and implementation study
- Challenges of embedding the intervention in primary care
- Learning from recruitment phase
- Next steps PriDem
- 'Forward with Dementia'

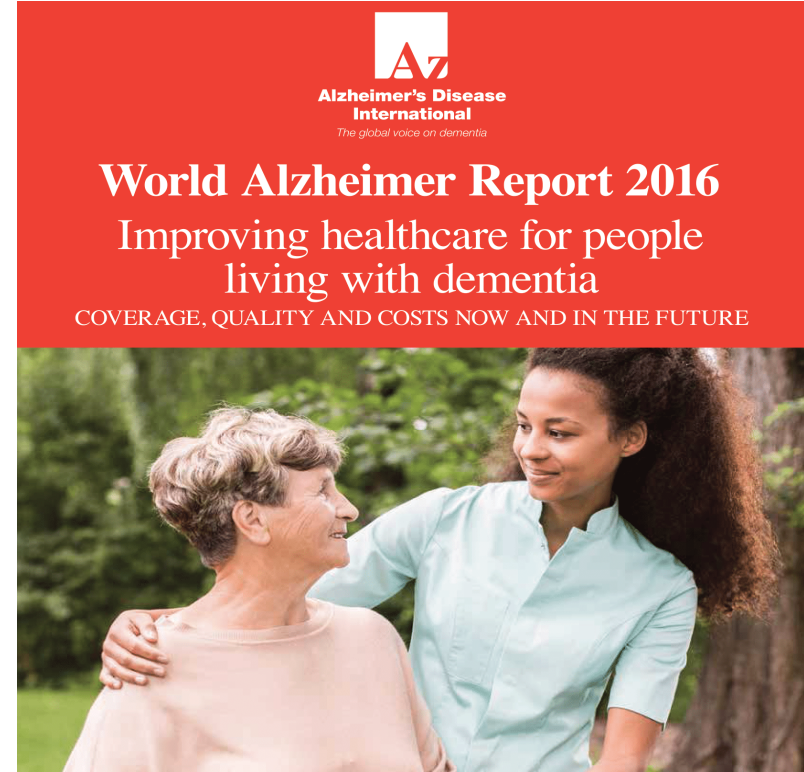
Dementia care: policy shift to primary care

World Alzheimer's Report 2011 Role of primary care underused

World Alzheimer's Report 2016 Current model unsustainable/ inequitable

NICE Dementia guidance 2018 Primary care shift

World Alzheimer's Report 2022 ?



PriDem programme: 2018-2023

- Evidence based, person-centred primary care led
- Acceptable and feasible
- Sustainable
- Post-diagnostic care: *'holistic, integrated continuing care in the context of declining function and increasing needs of family carers'*

Team: Newcastle, UCL, Manchester & Brighton Universities, LSE, Dementia UK



PriDem Six Workstreams

1. *Global evidence synthesis + national mapping*
2. *National practice: qualitative studies*
3. *'Good practice' model development*
4. **Testing in 'real world' settings**
5. *Economic evaluation*
6. *Translation into policy and practice*

← **'Dementia Care Community' (PPPI)** →

Meaningfully engaging stakeholders



Developing and
evaluating
complex
interventions

Evidence synthesis (3 reviews)

Most promising model:

- PCP case management
- Specialist lead situated in primary care
- Dementia expertise available - users AND providers
- Patient/carer self management
- Care network/ good links social care +community services
- Structured, formal collaborations
e.g. shared care pathway, shared care plan

Research

Rachael Frost, Kate Walters, Su Aw, Greta Brunskill, Jane Wilcock, Louise Robinson, Martin Knapp, Karen Harrison Denning, Louise Allan, Jill Manthorpe and Greta Rait, on behalf of the PriDem Study project team

Effectiveness of different post-diagnostic dementia care models delivered by primary care: a systematic review

a systematic review



Aging & Mental Health

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/camh20>

Implementing post diagnostic dementia care in primary care: a mixed-methods systematic review

Rachael Frost , Greta Rait , Su Aw , Greta Brunskill , Jane Wilcock , Louise Robinson , Martin Knapp , Nicole Hogan , Karen Harrison Denning , Louise Allan , Jill Manthorpe , Kate Walters & on behalf of the PriDem team

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REVIEW ARTICLE

Health and Social Care in the community WILEY

What works in managing complex conditions in older people in primary and community care? A state-of-the-art review

Rachael Frost PhD¹ | Greta Rait MD¹ | Alison Wheatley PhD² | Jane Wilcock MSc¹ | Louise Robinson MD² | Karen Harrison Denning PhD³ | Louise Allan PhD⁴ | Sube Banerjee MD⁵ | Jill Manthorpe MA⁶ | Kate Walters PhD¹ on behalf of the PriDem Study project team

BUT...reality of national practice

Survey and qualitative interviews/focus groups

- **HUGE variation in provision**
- Focus on information provision
- Limited provision of specific 'minority subgroup' support
- **50% of services planned to change** in next 5 years
- Funding sources: major challenge to sustainability
- Lack of integration e.g. lack of shared care pathways; data sharing
- Primary care concerns: lack of capacity, skills and willingness

Overall picture: INEQUALITY, INSTABILITY, FRAGMENTATION AND FRAGILITY

Good practice: Six case studies

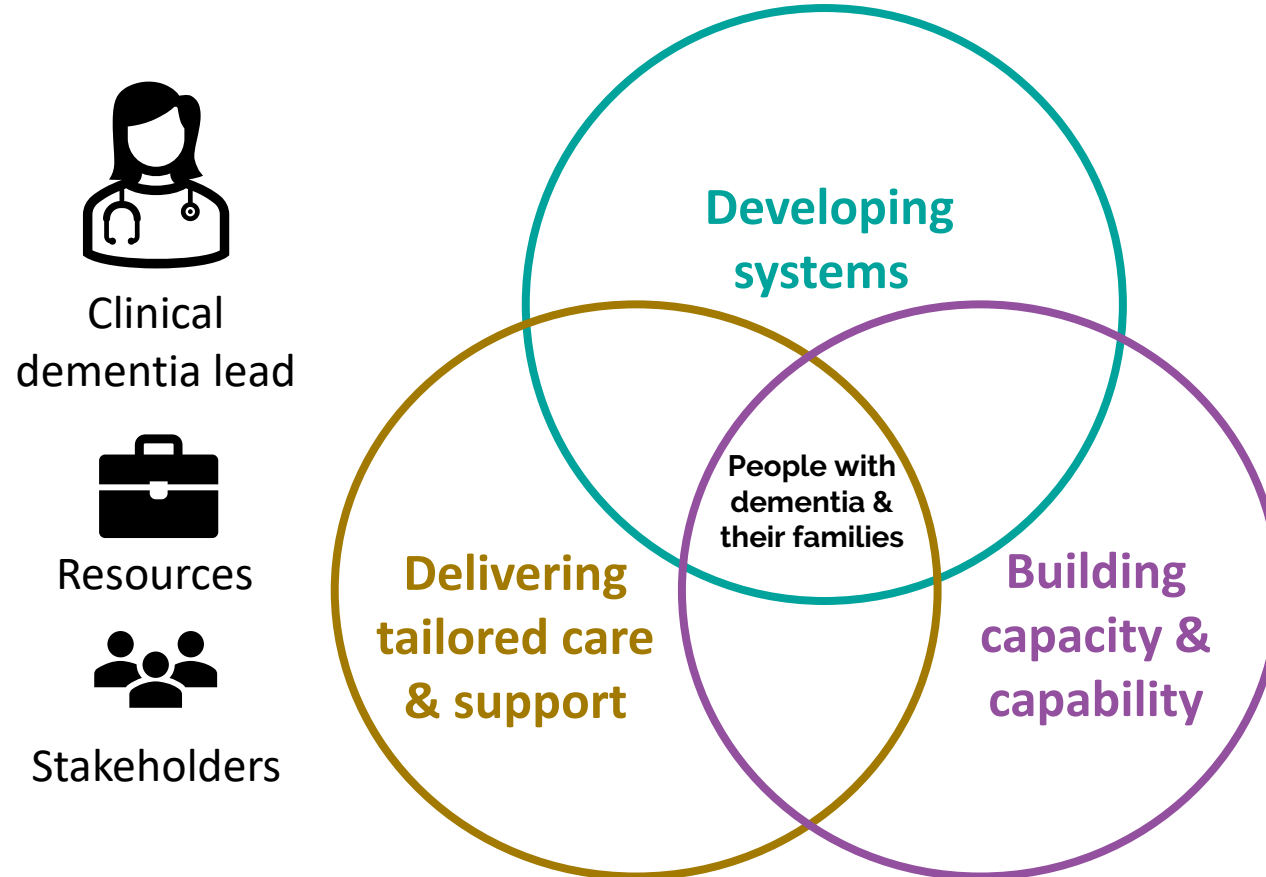
Core components

- Point of contact for PLWD/carer/providers
- Services joined up
- Support for non-specialists
- Ongoing, holistic review and care planning



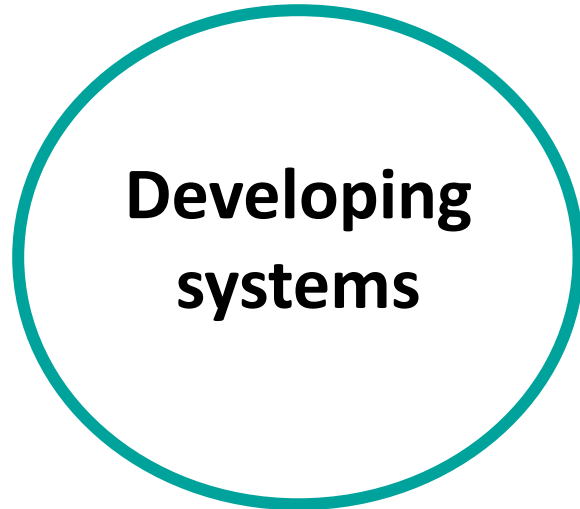
[Implementing post-diagnostic support for people living with dementia in England: a qualitative study of barriers and strategies used to address these in practice](#)

WS3: The PriDem intervention





Clinical dementia
lead



Resources

- **Baseline mapping:** local services against PriDem components of care & NICE recommendations
- Review transitions & information sharing
- Create a **local integrated dementia care pathway**
- Identify **named point of contact**



- Improved understanding of local services & how to access them
- Overview for commissioners, highlighting gaps & duplication
- Shared understanding of post-diagnostic support in dementia



Clinical dementia
lead



Resources

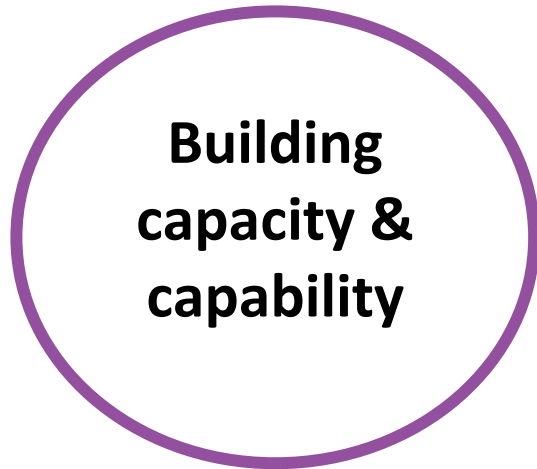
- Develop **formal, holistic review & care planning**
- People with **non-complex needs managed by generalists + support**
- Support management of people + complex needs



- Tailored assessment, information provision & management
- Improved consistency & quality of reviews
- Ensure timely access to appropriate interventions



Clinical dementia
lead



Resources

- Develop a **GP practice dementia team**
- **Improve access to specialist advice**
- Upskill generalist staff
 - Mentoring/Formal training
 - MDT meetings



- Increased awareness/understanding of dementia
- Improved skills of generalist staff
- Increased self-efficacy & confidence of staff
- Tiered system within the practice

WS4: feasibility/implementation study taking place in...



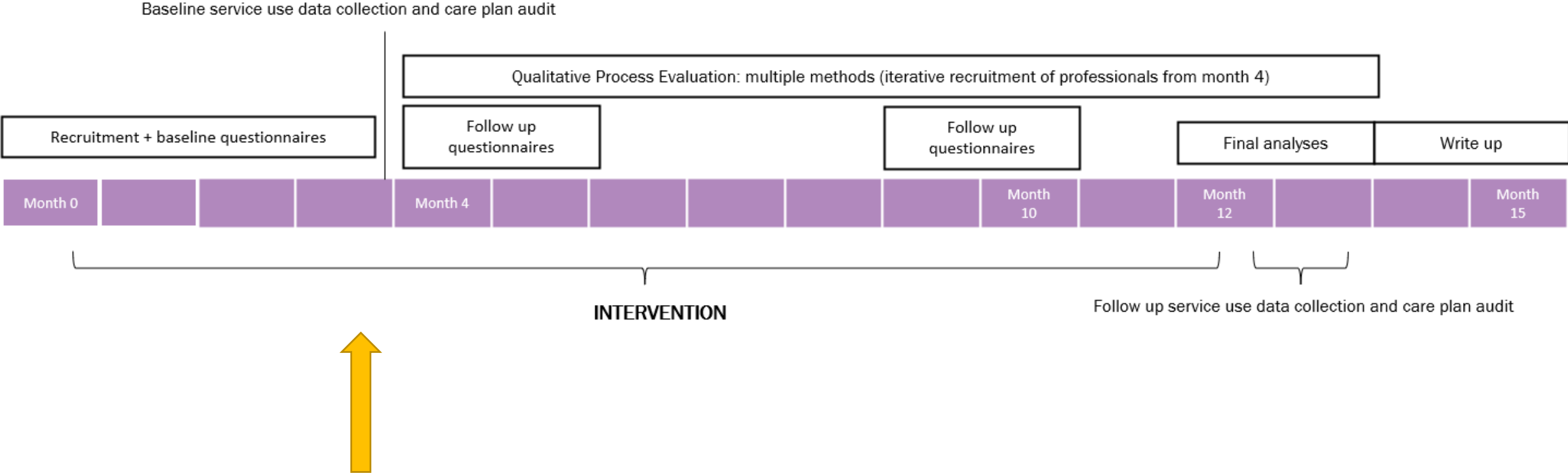
Barnet: three GP practices, one PCN



Newcastle: Four GP practices, three PCNs

NB target was 16-20 GP practices overall

Timeline



What are we researching?

- Barriers and facilitators to implementing this approach over 12 months
- Early signs of impact for patients, carers and professionals (target recruitment is 80 PLWD across participating practices in the SE and NE)

How?

- Interviews
- QoL outcome measures with people living with dementia and carers
- Care plan audit: consistency and quality of care plans

Primary care challenges

Solutions

FOR STUDY SET-UP

Enthusiasm about the research BUT...
concerns about capacity to take part

- Building relationships over time
- Reducing burden on practices e.g., **NHS Confidentiality Advisory Group approval**
- Highlighting benefits e.g., *'The CDL will provide mentorship alongside informal/formal bespoke training'*

OUTCOME: 5 months from initial meetings to first GP practice recruited

FOR THE INTERVENTION

Embedding CDLs into practices

Wanting someone to manage the caseload

- Planting the seed
- Working with enthusiastic staff to make small changes
- Clinical skills as a hook
- Doing some of the work and sharing outcomes with GPs

OUTCOME: 3-4 months in, SE and CDLs are starting to change minds and make an impact.

Insights from recruitment

- People really want to talk
- High level of unmet need
- Lack of peer support
- PLWD in denial – challenge of engagement/problem for carers
- Cynicism that research can improve things
- Loneliness

Intervention highlights so far

- Mapping services in Newcastle and Barnet
- Improving referral routes
- Evaluating dementia review and care planning processes
- One stop shop dementia reviews
- EMIS alerts
- Drop in sessions for patients, carers and staff (advice on cases)
- Identifying staff training needs and tailoring training accordingly
- Exploring support for those who are housebound

PriDem next steps

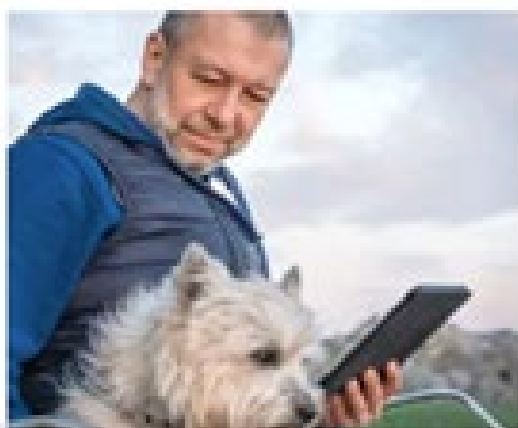
- Interviews with CDLs, supervisor, PLWD, carers
- Observations of the intervention in practice
- Ongoing intervention supervision reflective notes
- Care plan audit baseline data
- Ongoing dissemination

Alzheimer's Europe conference 2022, abstracts accepted:

- 1. Including people living with dementia in research and making it a positive experience*
- 2. PriDem intervention: the experiences of people living with dementia and their carers*

Liverpool dementia and ageing forum, abstract submitted:

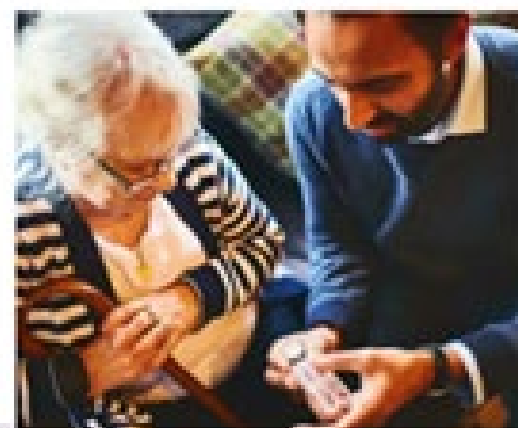
'Post-pandemic, primary care led dementia support: Preferences and values of people living with dementia and carers in the PriDem Study'



For people with dementia



For carers



For healthcare professionals



Following a dementia diagnosis, it's only natural to ask questions

Your diagnosis is the first step in moving forward with dementia. Many people with dementia live full and meaningful lives after diagnosis.

On this website, people with dementia have shared their good and bad experiences, so you can learn from them and find useful strategies. This, combined with evidence based research, will help you choose your own path forward with dementia.

www.arrivabus.co.uk
for up to date timetable & ticket info

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Forward with dementia
A guide to living with dementia

Find your way forward with dementia...

For stories, practical suggestions, planning tools and answers. For free, for you and on any device.

forwardwithdementia.org/support



JOURNEYS HAVE MULTIPLE TOUCHPOINTS

Forward with dementia

A guide to living with dementia

Find your way forward with dementia...

For people recently diagnosed with dementia and those who care about them.

For stories, practical suggestions, planning tools and answers.

For free, for you and on any device.

forwardwithdementia.org/support



A diagnosis of dementia can be overwhelming.

We guide you through

- What happens next
- How to make plans
- Where to get support

Find your way forward with dementia

Find practical suggestions, planning tools and answers written by and for people living with dementia, their care partners and healthcare professionals all in one place on this new easy to use UK website.

Build your own dementia guide

Choose the articles and get a personalised guide.

Find your way forwardwithdementia.org/support

Forward with Dementia is a website and personalised guide to help people with dementia, their families, and carers who access the right information and support on the right time.

All the practical articles and tools have been written in partnership with people living with dementia, carers and healthcare professionals in the UK.

forwardwithdementia.org/support

Print your phone camera here for more information.

Forward with dementia

A guide to living with dementia

Dementia. Now what?

A diagnosis can trigger a whole world of questions...

Find stories, practical suggestions, planning tools and answers for you, for free and available on any device.

forwardwithdementia.org/support

Website: <https://www.forwardwithdementia.org/en>

Email: forwardwithdementia@ucl.ac.uk

Twitter: @ForwardDementia

Instagram: https://www.instagram.com/forwardwithdementia_gb/

Facebook: <https://www.facebook.com/ForwardDementiaGB>

You Tube: Forward with dementia International

PriDem publications

1. Frost R, Walters K, Aw S, Brunskill G, Wilcock J, Robinson L, Knapp M, Harrison-Dening K, Allan L, Manthorpe J, Rait G and on behalf of the PriDem Study project team. Effectiveness of different post-diagnostic dementia care models delivered by primary care: a systematic review *British Journal of General Practice* 2020; 79 (695): e343-e441. DOI: <https://bjgp.org/content/early/2020/05/18/bjgp20X710165>
2. Frost R, Walters K, Wilcock J, Robinson L, Harrison-Dening K, Knapp M, Allan L, Rait G. Mapping post diagnostic dementia care in England: an e-survey. *Journal of Integrated Care* June 2020 ISSN: 1476-9018 <https://www.emerald.com/insight/content/doi/10.1108/JICA-02-2020-0005/full/html?skipTracking=true>
3. Frost R, Rait G, Wheatley A, Wilcock J, Robinson L, Harrison-Dening K, Allan L, Banerjee S, Manthorpe J, Walters K on behalf of the PriDem Study project team. What works in managing complex conditions in older people in primary and community care? A state-of-the-art review. *Health and Social Care* June 2020;28:1915-1927 DOI: 10.1111/hsc13085
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7. Booi L, Wheatley A, Brunskill G, Banerjee S, Manthorpe J, Robinson L, Bamford C. Outcomes valued by people living with dementia and their care partners: protocol for a qualitative systematic review and synthesis. *BMJ Open* 2021; 11:e050909 DOI:10.1136/bmjopen-2021-050909
8. Brunskill G, Wheatley A, Bamford C, Booi L, Costello J, Herbert J, Tucker S, Robinson L, on behalf of the PriDem study project team. How do we meaningfully engage stakeholders in developing a best practice approach to post-diagnostic dementia support? Accepted for publication in *Journal of Dementia Care*
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11. Tuijt, R., Rees, J., Frost, R., Wilcock, J., Manthorpe, J., Rait, G., Walters, K. Exploring how triads of people living with dementia, carers and health care professionals function in dementia health care: A systematic qualitative review and thematic synthesis. *Dementia* 2020 20;3 1080-1104 <https://doi.org/10.1177/1471301220915068>
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13. Tuijt R, Frost R, Wilcock J, Robinson L, Manthorpe J, Rait G, Walters K Life under lockdown and social restrictions - the experiences of people living with dementia and their carers during the COVID-19 pandemic in England *BMC Geriatrics* 2021, 301 <https://bmgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02257-z>