

# STUDY REPORT

PriDem evaluation study:  
best practice in primary care  
led dementia support



**PriDem**  
tailored, local, timely dementia support



The PriDem Evaluation was led by University College London (UCL) The PriDem programme was funded by Alzheimer's Society and the Sowerby Foundation and led by Newcastle University.



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# 1. Executive summary

## 1.1 Background

Over 900,000 people in the UK have dementia, but many do not receive the care they need after diagnosis. To address this, the PriDem intervention, a primary care led approach to post-diagnostic dementia care, was developed by researchers, NHS professionals, people with dementia and carers. The intervention involves a Clinical Dementia Lead (or CDL) with expertise in dementia care working with GP practice teams to deliver three key intervention strands:

- Developing and strengthening care systems.
- Delivering care and support that is tailored to the needs and priorities of individuals.
- Building staff knowledge and confidence through training.

Evidence based PriDem adaptable templates support activities such as dementia reviews and care planning.



We worked with 7 GP practices over 12 months



**Over 900,000** people in the UK live with dementia



## 1.2 The evaluation study

To test the PriDem approach, two CDLs worked with 7 GP practices in the Southeast and Northeast of England for 12 months. We looked at whether the approach could improve access to personalised care planning, whether the intervention was feasible and acceptable and what the implementation challenges might be. To do this we:

- Carried out a case notes audit of the presence/absence of a personalised care plan for people on the dementia registers of the 7 practices, comparing pre-Covid 2018-19 (pre-intervention) to 2022-23 (post-intervention).
- Completed health related quality of life questionnaires with people with dementia and carers registered with the 7 practices.
- Collected qualitative data, exploring how people with dementia, carers and professionals experienced the intervention.



### 1.3 Findings

Supported by the CDLs, practice teams innovated in various ways, for instance adapting approaches to delivering annual dementia reviews and care planning. CDLs delivered formal and informal dementia training to a range of staff groups. The North East and South East CDL developed a comprehensive mapping document outlining local and national services and referral systems to support practice staff in making timely and tailored referrals.

Post-intervention, the proportion of patients with personalised care plans increased significantly from 37.4% to 64.7%. Within completed care plans, there were observed changes in the areas of care and support covered, suggesting a move towards more holistic care planning for example pre-intervention, only 30% of care plans addressed home environment and activities of daily living, whereas post intervention this rose to 62%.

There were no marked changes in the results of patient and carer questionnaires. Our qualitative findings showed how pressures experienced in primary can be a barrier to implementation, but that motivated staff champions can help drive change. Due to staffing challenges, in some practices the CDL was seen less as a supporter and influencer for change, and more of an extra clinician, which was not conducive to sustainable change. Overall, those interviewed felt the intervention led to positive outcomes for patients, professionals and practices. Highly engaged practices viewed change as meaningful and sustainable.



A map of local and national dementia services supported practice staff with making appropriate, timely referrals



Personalised care plans increased from **37.4%** to **64.7%**

### Conclusions and recommendations

The PriDem approach to post diagnostic care is feasible and acceptable and can lead to meaningful and long-lasting improvements in dementia care and support. Future commissioning of such an approach should consider funding to support already stretched services, identifying and supporting motivated and engaged staff who can champion the approach, use of PriDem adaptable templates, and ensuring staff understand the aims of this model. A larger scale implementation study would inform future NICE dementia guidelines, commissioning decisions and NHS England recommendations for personalised dementia care planning. Future research should focus on the sustainability of the intervention.

# 2. Background to the evaluation study

## 2.1 The challenge

Receiving a diagnosis of dementia can have a significant psychological and emotional impact. Navigating a dementia diagnosis requires ongoing support that focuses on what matters to people with dementia and their families. However, people with dementia often receive inadequate care and support after their diagnosis. Surveys show:

- Around three in five people affected by dementia feel they do not receive enough support after diagnosis [1].

3 in 5

- 53% of people with dementia said they recently felt anxious or depressed [2].

53%

- 93% of informal carers stated they felt stress either often, all of the time or some of the time [3].

93%

Currently, people with dementia are diagnosed through secondary care specialists like psychiatrists and neurologists. These services are often oversubscribed, face increasing demand and provide little follow up. Ongoing care is provided by primary care such as GPs, but these services are under-resourced and may lack specialist knowledge. Care is often poorly integrated across health and social care services and the quality of care varies significantly between different areas.

## 2.2 A potential solution – The PriDem approach

There is a clear and urgent need for change in how we support people with dementia and their carers. There remains a lack of clarity on what

good post-diagnostic support for people with dementia is.

Research suggests that this can be achieved through using existing resources more efficiently and effectively. A task-shifted and task-shared approach is recommended [4]. This is where primary care, for example general practices, lead on coordinating post-diagnostic support. In practice, this means that primary care, such as GPs, lead on coordinating post-diagnostic care for most people with dementia, referring patients to secondary care specialist services, such as mental health services, when more help is needed. This results in more personalised and timely care and could be up to 40% cheaper than specialist care [5].

The PriDem research programme aimed to address this need for change by improving post-diagnostic support of people with dementia and their carers. A new intervention was co-created with the Dementia Care Community, a dedicated group of people with dementia, their families and carers and health and social care professionals. The Dementia Care Community worked with researchers to design the PriDem intervention, ensuring it was designed with people affected by dementia in mind and included solutions to meet their needs.

## 2.3 How the PriDem intervention was developed

The first stage of the PriDem project, led by UCL, examined research on existing primary care-based models of dementia care and identified factors that can facilitate their success [6-9]. This evidence review showed primary care-based, case management models to be the most successful. For example, when post-diagnostic support is led by a case manager, such as a dementia nurse specialist, this is

associated with positive outcomes such as reduced carer stress and the potential for reduced care costs (8).

Such primary care-based approaches work best if there is: dementia expertise based in primary care to support dementia care capacity building, sufficient resources and funding, and healthcare provider engagement and leadership present (6, 7).

The next stages of the research project, led by Newcastle University, sought the views of people with dementia, their families and healthcare professionals on the current provision of post-diagnostic dementia support with a focus on identifying and evaluating case studies of good practice, where dementia care was led by, or heavily influenced by primary care [4, 10-12]. Six case studies of different models including GPs with special interest, Admiral nurses in primary care, dementia advisor models and shared care memory clinics, were studied. These findings presented a picture of what healthcare providers and, crucially, what people with dementia and their carers, think post-diagnostic support should look like. This research showed a wide geographical, postcode lottery of service provision and no one perfect model of care. However, it highlighted several

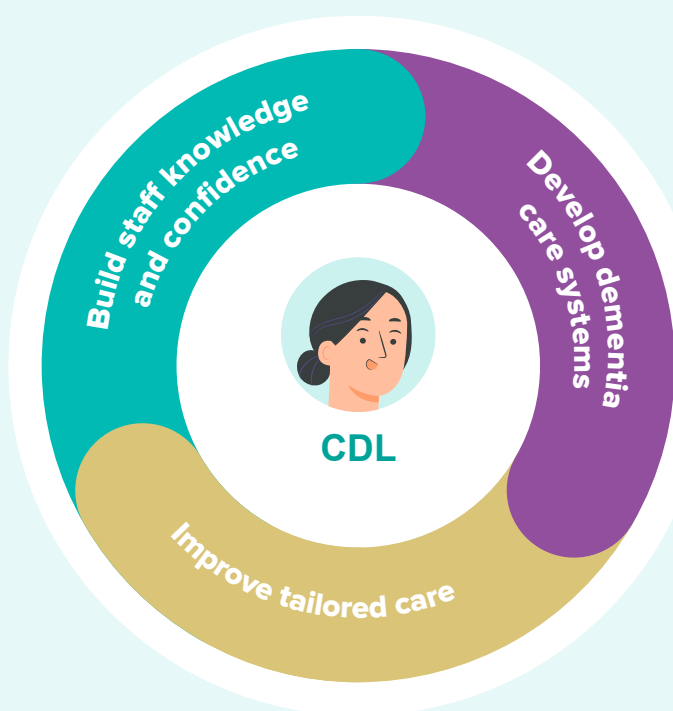
components of good post-diagnostic care [13] which related to the five key themes of:

- Timely identification and management of needs
- Understanding and managing dementia
- Emotional and psychological wellbeing
- Practical support
- Integrated support

As a whole, this research indicated that future post-diagnostic support should focus on three key strands (Figure 1):

1. Developing and strengthening care systems.
2. Delivering care and support that is tailored to the needs and priorities of individuals.
3. Building staff knowledge and confidence, by providing formal and informal dementia awareness raising and training.

The PriDem intervention was developed based on this evidence [14]. The three strands of the intervention are implemented by **Clinical Dementia Leads** (CDLs) working closely with staff in primary care. This kind of lead clinician model is one that has been successfully implemented for the management of other long-term conditions such as cancer and diabetes.



*Figure One:  
The three strands of the  
PriDem intervention*

# 3. The evaluation study

The 15-months evaluation study led by UCL took place between March 2022 and June 2023. We tested the PriDem intervention in practice (i.e., in ‘the real world’). Our main aims were to:

- Improve access to personalised care planning for people with dementia and carers
- Understand how feasible and acceptable the intervention was
- Identify challenges and facilitators to implementing the intervention in real life

## 3.1 Approvals

Approval was obtained from Wales REC4 NHS ethics committee on 20/08/2021, IRAS ID 294881. NHS Confidentiality Advisory Group (CAG) support was also obtained on 23/12/2021, allowing researchers access to electronic care notes of patients for the specific purposes of the study: CAG reference 21/CAG/0182.

## 3.2 Patient and Public Involvement and Engagement

The PriDem ‘Dementia Care Community,’ a dedicated group of people with dementia, carers and health and social care professionals, advised on research design. This included advising on the accessibility of research materials and making sure that the participant involvement was appropriate and not burdensome.

## 3.3 Recruitment and intervention delivery

We recruited seven GP practices in the Northeast (NE) and Southeast (SE) of England. The PriDem intervention was delivered by two Clinical Dementia Leads (CDLs), one in each region. This role was advertised as open to a wide clinical group (e.g., nurses, speech and language therapists, and occupational

therapists). Both CDLs appointed had a nursing background. An evidence-based manual was developed to guide their practice and they received training and regular supervision, from the research team and a clinical supervisor with expertise in dementia care. The CDLs worked with GP practice staff to implement the three strands of the intervention.

We recruited 60 people with dementia and 51 carers across the GP practices and conducted health related quality of life questionnaires with them at the start of the intervention, at 4 months and at 9 months.

The people with dementia recruited included typically underrepresented populations within dementia.

- 44.8% of people with dementia recruited did so via consultee declaration, demonstrating potential to involve people with more advanced dementia in research.

44.8%

- 25.9% of our participants with dementia lived alone and 15.5% did not have a carer participating alongside them.

25.9%

15.5%

- 10.4% of the people with dementia were from non-white ethnic backgrounds.

10.4%

- 22.4% of the carers were from non-white ethnic backgrounds.

22.4%

- 17.3% of the people with dementia were living in areas of high social deprivation (Index of Multiple Deprivation rankings 1 and 2).

17.3%



## 3.4 Intervention highlights

With support from CDLs, practices innovated by

- Setting up information stands in waiting areas signposting to local and national sources of support
- Becoming more dementia inclusive as a practice (including obtaining accreditation)
- Adding care alerts to electronic notes so that staff accessing the notes know immediately that the person has dementia and might benefit from extra support.
- Adapting approaches to delivering annual dementia reviews and care planning (see 2.5).
- CDLs delivering formal and informal training and awareness to a range of staff groups across the seven practices e.g., receptionists, care coordinators, social prescribers and GPs. Sometimes this involved the CDL doing joint visits with other professionals so that learning could happen through discussion of a person's unique situation and care plan.
- CDLs developing resources to increase staff awareness of dementia services.
  - In the South East the CDL developed a comprehensive mapping document outlining local and national services and referral systems, across all sectors, to support practice staff in making timely and tailored referrals to sources of support. This has since been embedded into the professionals' website for the relevant NHS Integrated Care System.
  - In the NE, the CDL contributed to an existing community website, ensuring that information on local dementia services was up-to-date, and provided additional educational content for the website e.g., on delirium.

## 3.5 Care planning

Part of the intervention involved working with GP practice teams to improve Quality Outcomes Framework (QOF) annual dementia review and care planning systems. The QOF is a voluntary incentive programme for GP practices in England: the key indicator of quality care for people with dementia is the percentage of patients with dementia who have had an annual review of their care plan each year [15].

The research team developed evidence-based resources to support annual reviews, which practice staff adapted based on their local needs. Staff were also upskilled in their awareness of local care and support services and referral systems.

In both regions, the intervention led to greater involvement of the wider team (e.g., practice nurses, dementia advisors and social prescribers) and staff from Age UK, to support GPs, for example through 'One Stop Shop Dementia Review Clinics.' This was where several people with dementia and carers attended on the same day and had opportunities to meet with these different practitioners, who worked with them and each other towards achieving personalised care planning. Practices carried out evaluations of these events and they were well received by patients, carers and staff. Feedback led to them adapting and streamlining the process over time, ensuring greater sustainability. One of the SE practices achieved a regional award for primary care service delivery, recognising the changes made in the way they care for patients with dementia.

In order to assess adoption of personalised care planning by participating practices, we carried out an audit of electronic care records to assess the presence/absence, and quality of dementia care plans. To avoid care disruptions related to Covid-19, pre-intervention QOF year 2018-2019 was compared with the intervention year 2022-2023. Individual patients were not followed up. Registered patients with a dementia diagnosis living at home at the beginning of the relevant audit period were eligible.



# 4. Evaluation findings

## 4.1 Care planning

We found that post-intervention, the proportion of patients with care plans (whether personalised or not) increased, and the proportion of **personalised care plans increased significantly from 37.4% to 64.7%** (see Figure One).

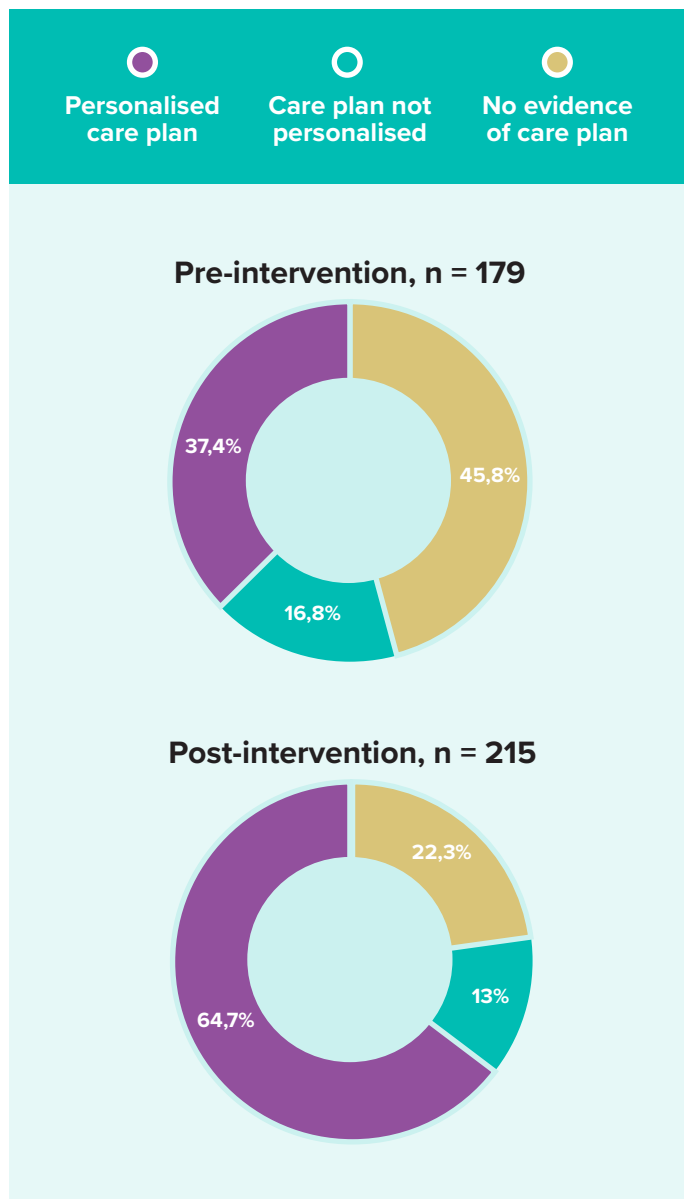


Figure One: Changes in proportions of patients with care plans

Within completed care plans, there were marked changes in indicators of personalisation (informed by NHS England) (see Figure Two). For example, recording of outcomes or goals and planned actions increased and evidence of outcomes being agreed with the person with dementia/carer more than tripled. There was evidence of information on care planning starting to be provided in advance of the meeting. However, at both time points there was little evidence of care plans being shared with patients and carers, although this could be due to under-reporting in the medical notes.

Areas represented	Pre-intervention	Post-intervention
Outcomes/goals recorded	33%	65%
Outcomes agreed	10%	38%
Planned actions recorded	22%	47%
Review date recorded	6%	15%
Person with dementia's priorities considered	3%	22%
Information provided	0%	13%
Copy of care plan provided	1%	4%

Figure Two: Changes in proportions of care plans with indicators of personalisation

Within completed care plans, there were observed changes in the areas of care and support covered, suggesting a move towards more holistic care planning. We assessed 12 areas (Figure three). The majority saw large increases in representation. For example, pre-intervention, only 2% of care plans addressed the activities and interests of the person with dementia, whereas post-intervention, 40% of care plans covered this area. Pre-intervention, 5% of care plans indicated that the person had

been given an opportunity to discuss their diagnosis (e.g., asking questions about it and having it explained) which rose to 23% post-diagnosis. On the other hand, medication reviews had been well represented pre-intervention and saw little change. Representation of dementia progression and end of life care was poorly represented, with no change post-intervention. This may reflect a focus on care planning with those who do not have advanced dementia.

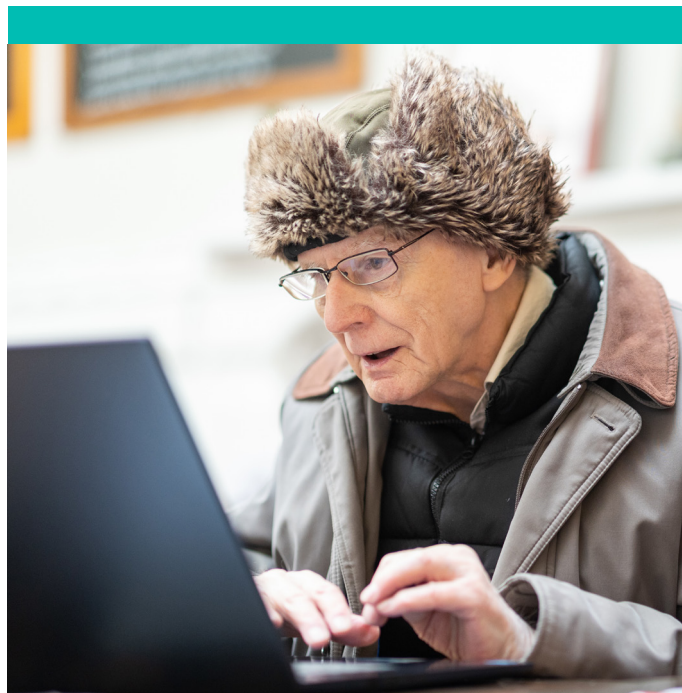
Areas represented	Pre-intervention	Post-intervention
Services currently involved	31%	52%
Information needs	2%	28%
Social and personal history	32%	50%
Home environment and activities of daily living	30%	62%
Activities and interests	6%	40%
The dementia diagnosis	5%	23%
Cognitive, emotional and behavioural changes	40%	63%
Planning for contingencies and changes	26%	45%
Progression and end of life care	5%	5%
Safeguarding and advocacy	3%	15%
Physical health	64%	80%
Medication	57%	58%

**Figure Three: Changes in proportions of care plans representing 12 areas of care and support**

## 4.2 Health related quality of life questionnaires

The results of patient and carer questionnaires remained relatively consistent from baseline to 9 months with no marked changes. This was a small sample but may indicate that the short-term nature of the intervention had not had time to create the kinds of 'trickle down' effects for people with dementia and carers that can be measured using standardised questionnaires.

The qualitative analysis provided a more nuanced picture (see 3.3.2.). Researchers learned a great deal from this element of the study, regarding which questionnaires were acceptable to people with dementia and carers, and which we would not use in a future study. We also developed strategies to support future inclusion of people with dementia and carers in research, such as creating written cues to support people to respond to multiple choice questionnaires. We also found that the amount of researcher time and training needed to build trusting relationships and collect data in a compassionate way should not be underestimated. This is intensive and skilled work.



## 4.3 Qualitative element of the evaluation

The qualitative element of the study explored in depth the acceptability and feasibility of the

### 4.3.1 How we gathered and analysed data

- 28 semi structured interviews with 26 practitioners
  - CDLs: 4 interviews from 2 participants
  - Clinical supervisor: 2 interviews from 1 participant
  - GP practice staff: 16 interviews from 17 participants
  - Other professionals: 4 interviews from 4 participants
  - Commissioners: 2 interviews from 2 participants
- Observations of the CDL in meetings or delivering training: n=14
- Intervention supervision notes: n=13
- Researcher reflections: n=6
- 14 people with dementia and 16 carers participated in a total of 21 interviews, of which nine interviews were dyadic (i.e., involving the person with dementia and their nominated carer).

Data was analysed using thematic analysis and informed by 'Normalisation Process Theory' [16]; a theory about how new interventions are translated into everyday working practices.

### 4.3.2 Qualitative findings

#### 1. The rocky ground of primary care

The primary care context played a key role in the implementation of the PriDem intervention, with change being challenging for many practices in the context of a stretched service. For patients and carers, these challenges were apparent through a lack of continuity of care and difficulty in accessing services. Capacity, finance, and staffing all acted as drains on the system, with this rocky ground frequently cited as a barrier to implementation.

#### 2. The power of people

Individuals were highly influential in the delivery of the intervention, whether that be through facilitating its success, or in some cases, inhibiting it. Personal motivation and investment, level of autonomy and organisational hierarchy can all play a part, acting as facilitators or barriers to implementation.

#### 3. Tension between adaptability and fidelity

Although adaptability was a key benefit of the intervention, attractive to CDLs and staff teams alike, there was a risk of boundaries being stretched past the point of fidelity to the original aims of the intervention.



#### 4. Challenging the status quo: reimagining care planning

Provision of personalised care planning was a key intended outcome of the intervention. Attitudes to care planning were diverse, with variable motivation to promote change. Within the context of the intervention, practices innovated their own approaches to care planning and dementia annual reviews, harnessing the skills of the wider multidisciplinary team (MDT) in order to free up clinical staff capacity or to provide holistic care.

#### 5. One size doesn't fit all

Current care provision is rarely tailored to the needs of the individual. Personalisation, however, is identified as a key priority; both people with dementia and their carers would benefit from a service that is receptive to their circumstances and changing needs.

#### 6. Positive effects on people and systems: towards sustainability

The intervention led to positive outcomes for patients, professionals and practices. Highly engaged practices viewed change as meaningful and sustainable.

# 5. Conclusions and recommendations

Findings indicate that this model of post diagnostic care is feasible and acceptable. A CDL supporting GP practice teams, can lead to meaningful and long-lasting improvements in dementia care and support such as improving the consistency and quality of annual dementia reviews.

Key implementation lessons have been learnt and are relevant to commissioners embarking on system level changes in primary care. When introducing this approach in the future, the following should be considered:

- Funding to support already stretched services.
- Identifying and supporting motivated and engaged staff who can champion the approach, work closely with the CDL, and bring others on board.

- Use of adaptable evidence based PriDem templates for dementia reviews, care planning and mapping local services.
- Making sure that all key stakeholders understand the aims of the approach prior to implementation, so that the CDL does not simply become 'an extra pair of hands.'

The intervention would benefit from a large-scale implementation study to inform future NICE dementia guidelines, commissioning decisions and NHS England recommendations for personalised dementia care planning . Future research should focus on the sustainability of the intervention.



# 6. How has this evaluation work been shared?



## Journal papers:

- **Published July 2023.** Griffiths, S., Spencer, E., Wilcock, J., Bamford, C., Wheatley, A., Brunskill, G., D'Andrea, F., Walters, K.R., Lago, N., O'Keeffe, A. and Hunter, R., Tuijth, R., Harrison Denning, K., Banerjee, S., Manthorpe, J., Allan, L., Robinson, L. and Rait, G. 2023. **Protocol for the feasibility and implementation study of a model of best practice in primary care led post diagnostic dementia care: PriDem.** *BMJ open*, 13(8). <https://bmjopen.bmj.com/content/13/8/e070868>

Other papers are in production.



## Conference presentations and posters:

- **Presentation.** Griffiths, S. on behalf of the PriDem research team. **PriDem project - Primary care-led post diagnostic Dementia Care: developing evidence-based, person-centred sustainable models for future care** Luton and Bedfordshire Memory Services Conference (June 2022)
- **Poster.** Griffiths, S., Moran Spencer, E., Walters, K., Wilcock, J., Bamford, C., Brunskill, G., Wheatley, A., Robinson, L., and Rait, G. **Testing an evidence-based post-diagnostic dementia care model in primary care: preliminary findings from the PriDem feasibility and implementation study.** *Alzheimer's Disease international*. (June 2022).
- **Presentation.** Griffiths, S., Moran Spencer, E., D'Andrea, F., Walters, K., Wilcock, J., Brunskill, G., Wheatley, A., Robinson, L., and Rait, G. **Including people living with dementia in research and making it a positive experience: lessons from the PriDem feasibility and implementation study.** Alzheimer's Europe Conference (October 2022).
- **Presentation.** Spencer, E., Griffiths, S., Wilcock, J., Poole, M., O'Keeffe, A., Flanagan, K., Walters, K., Robinson, L., and Rait, G. **Improving access to personalised care planning for people living with dementia: Findings from the PriDem feasibility and implementation study.** Society for Academic Primary Care (July 2023).
- **Presentation.** Griffiths, S. on behalf of the PriDem research team. **Improving access to personalised care planning for people living with dementia.** Public Policy Exchange Webinar (September 2023).
- **Poster.** Spencer, E., Flanagan, K., Wilcock, J., Poole, M., Walters, K., Robinson, L., Rait, G. and Griffiths, S. **Improving post-diagnostic support for people living with dementia workforce experiences of the PriDem intervention.** Alzheimer's Europe Conference (October 2023).
- **Presentation.** Spencer, E., Griffiths, S., Wilcock, J., Poole, M., O'Keeffe, A., Flanagan, K., Walters, K., Robinson, L., and Rait, G. **Improving provision of annual reviews and care planning for people living with dementia: Learning from the PriDem implementation study.** Alzheimer's Europe Conference (October 2023).
- **Presentation.** Griffiths, S., Spencer, E., Wilcock, J., Poole, M., O'Keeffe, A., Hunter, R., Flanagan, K., D'Andrea, F., Walters, K., Robinson, L., and Rait, G. **Inclusion of people living with dementia in research: findings from the PriDem feasibility study.** Alzheimer's Europe Conference (October 2023).

### Knowledge Exchange:

- Published and circulated nine study newsletters for participants and other interested professionals, patients and carers. Also shared via X: @PriDemProject
- Blog '**How to include people living with dementia in research.**' published via NIHR Dementia Researcher and international Longevity Centre (May 2023) <https://www.dementiaresearcher.nihr.ac.uk/how-to-include-people-living-with-dementia-in-research/>
- Short, animated videos illustrating key findings have been shared on social media.
- This study report for health and social care professionals and commissioners.



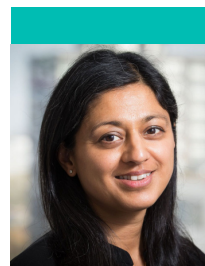
## 7. What next?

### Future work will include:

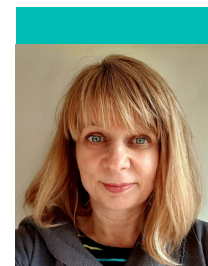
- Seeking funding for a large-scale implementation study, rolling out the intervention across further sites within the UK.
- Exploring routes to sharing the PriDem dementia review, care planning and service mapping templates.

## 8. Authors

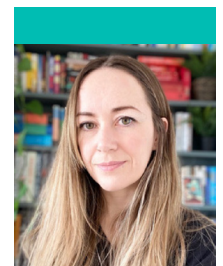
- **The PriDem evaluation was led at UCL by Greta Rait, Sarah Griffiths and Emily Spencer.**
- **Supporting UCL staff:** Kate Walters, Jane Wilcock, Aidan O’Keeffe, Martin Wiegand, Federica D’Andrea, Katie Flanagan, Lewis Benjamin.
- **Supporting Newcastle staff:** Louise Robinson (PriDem programme lead), Claire Bamford, Alison Wheatley, Greta Brunskill, Marie Poole, Alex Hagan and Manjot Brar.



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