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Access to personalised dementia care planning in primary care: a mixed methods evaluation of the PriDem intervention

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ABSTRACT

Objectives Provision of personalised care planning is a national priority for people with dementia. Research suggests a lack of quality and consistency of care plans and reviews. The PriDem model of care was developed to deliver feasible and acceptable primary care-based postdiagnostic dementia care. We aimed to increase the adoption of personalised care planning for people with dementia, exploring implementation facilitators and barriers.

Design Mixed-method feasibility and implementation study.

Setting Seven general practices from four primary care networks (PCNs) in the Northeast and Southeast of England.

Participants A medical records audit collected data on 179 community-dwelling people with dementia preintervention, and 215 during the intervention year. The qualitative study recruited 26 health and social care professionals, 14 people with dementia and 16 carers linked to participating practices.

Intervention Clinical dementia leads (CDL) delivered a 12-month, systems-level intervention in participating PCNs, to develop care systems, build staff capacity and capability, and deliver tailored care and support to people with dementia and their carers.

Primary and secondary outcome measures Adoption of personalised care planning was assessed through a preintervention and postintervention audit of medical records. Implementation barriers and facilitators were explored through semistructured qualitative interviews and non-participant observation, analysed using codebook thematic analysis informed by Normalisation Process Theory.

Results The proportion of personalised care plans increased from 37.4% (95% CI 30.3% to 44.5%) preintervention to 64.7% (95% CI 58.3% to 71.0%) in the intervention year. Qualitative findings suggest that the flexible nature of the PriDem intervention enabled staff to overcome contextual barriers through harnessing the skills of the wider multidisciplinary team, delivering increasingly holistic care to patients.

Conclusions Meaningful personalised care planning can be achieved through a team-based approach. Although improved guidelines for care planning are required, commissioners should consider the benefits of a CDL-led approach.

Trial registration number ISRCTN11677384.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Mixed methods approach, including an audit of medical records and large body of qualitative data from a range of sources (interviews with health and social care professionals, people with dementia, carers; observations).
- ⇒ Support received from the National Health Service Confidentiality Advisory Group, enabling preconsent access to patient data to facilitate an audit of medical records.
- ⇒ This was a non-randomised feasibility study, limited in scale.
- ⇒ The study was limited in duration, allowing for minimal collection of longer term follow-up data relating to sustainability.

INTRODUCTION

Dementia is a syndrome affecting cognitive functioning, changes in emotion, behaviour or comprehension and difficulty in performing activities of daily living (ADLs).[1] There are over 900 000 people living with dementia in England and Wales; with increased incidence and population ageing, this figure is projected to increase to 1.7 million by 2040.[2] As a global public health issue, significant increases are anticipated worldwide.[3] Over the same period, annual costs associated with dementia care provision are anticipated to rise from £34.7 billion to £94.1 billion in the UK.[4] Following diagnosis, care for people with dementia and their families is often inadequate and poorly integrated.[5 6] Around half of people with dementia and two-thirds of unpaid carers report receiving insufficient support.[7 8] The World Alzheimer Report 2016 recommended a primary care-led approach to care[9] whereby primary care takes lead responsibility for postdiagnostic care coordination, facilitating specialist care input when required. Such an approach would entail upskilling and supporting a largely non-specialist primary care workforce, to improve capacity and capability for this role.[10] Central to a primary care-led model is the delivery of appropriate dementia care planning, identified as the best means of providing person-centred care.[11] The World Alzheimer's Report 2022[11] (p27) recommends that person-centred care should become the norm and that 'people with dementia should have access to personalised care plans that enable them, along with their carers, to make informed choices, plan for the future, and participate in shared decision-making about the care they receive.' Establishing person-centred care plans has been identified as an area of global consensus within national dementia care guidelines.[12]

Distinct from advance care planning (ACP), which considers preferences and plans for future care including end-of-life,[13] a personalised care plan should consider management of both current and future health and wellbeing, including 'what matters to the person, what care and support the person is having, contingency plans for the future, and arrangements for review'.[14]

While there is evidence on implementing novel interventions to enhance personalised care in general,[15] approaches to elements of personalised care planning, such as ACP,[16] and facilitating care planning remotely,[17] research is lacking on approaches to effective methods of delivering personalised care planning in the broader sense. Evidence for the benefits of care planning for dementia is also mixed. A recent scoping review of care planning for community-dwelling people with dementia revealed limited evidence for improved patient or carer outcomes from intervention studies; however, the benefits of care planning alongside case management were highlighted.[18] This review recommended future studies examine the role of multidisciplinary involvement in care planning.

National Health Service (NHS) England have named personalised care and support planning a national priority for people with dementia.[14] Care plans should be reviewed at least annually, with frequency dictated by individual need,[14] in collaboration with the individual and their family or carers as appropriate.[19] NHS Quality and Outcomes Framework (QOF), a voluntary incentive programme for general practices in England, includes the percentage of patients with dementia whose care plan has been reviewed in the preceding 12 months.[20] This indicator measures care plan completion, but not quality or content. Despite the emphasis on care planning, the suggested content of care plans and annual reviews are not well defined, with research suggesting that the quality of reviews is lacking.[18]

The PriDem programme of research aimed to develop a feasible and acceptable evidence-based model of primary care-led postdiagnostic dementia care. Following extensive stakeholder engagement,[21] a manualised intervention was developed to deliver comprehensive systems-level change.[22] This would place a clinical dementia lead (CDL; specialist nurse or allied health professional) within primary care networks (PCNs; groups of local general practices and other health and social care organisations working together to deliver integrated services) to facilitate change through three interlinking intervention strands; for details, see Bamford *et al* (2023).[22]

1. *Developing systems* for delivery of evidence-based, postdiagnostic support: (eg, CDLs working closely with general practice staff to review referral and transition processes and develop a map of local dementia services to facilitate timely and tailored referrals).
2. *Delivering tailored care and support* to people with dementia and their carers, through optimising annual dementia reviews and personalised dementia care planning, and providing complex case management (eg, CDLs providing advice and direct management of people with more complex needs; working with general practice teams to strengthen processes for annual dementia reviews and personalised dementia care planning, and working with practices to develop resources required for these tasks).
3. *Building capacity and capability* by supporting nonspecialists to deliver multidisciplinary postdiagnostic dementia care and upskilling staff (eg, CDLs building practice-based dementia teams, and providing formal and informal training, including joint patient visits).

A PriDem CDL training package was developed, and clinical supervision provided. CDLs would work with general practice staff to provide expert knowledge and individualised support, as well as bespoke, adaptable resources and training to facilitate enhanced care planning and dementia reviews. We aimed to minimise differences in intervention delivery between the two CDLs by implementing the same training programme, intervention manual and model of regular joint supervision with the same supervisor across the two regions.

Aims

The primary aim was to examine whether implementation of the PriDem intervention in practice led to increased adoption of personalised care planning for patients with dementia. We also examined barriers and facilitators to implementing changes in care planning.

METHODS

Study design

A mixed-method feasibility and implementation study took place between February 2022 and June 2023. This included a quantitative audit of electronic medical records of people with dementia and a qualitative study of healthcare practitioner, patient with dementia and carer experiences of the intervention, examining implementation barriers and facilitators. The protocol for the wider study has been published[21] and the online supplemental file 1 shows the original protocol. The Standards for Quality Improvement Reporting Excellence checklist was used to guide reporting.[23]

Patient and public involvement

A dedicated group of people with dementia, carers and health and social care professionals worked with researchers to shape the research processes, develop the NHS CAG application and determine how to operationalise the concept of personalised care planning.

Setting

Seven general practices from four PCNs in England participated in the study. PCNs were targeted via the research teams' existing connections and chosen for their demographic differences (in terms of urban/rural spread, ethnicity and socioeconomic factors), practicalities of CDLs travelling between general practices, and to ensure adequate numbers of patients on primary care dementia registers. Four practices from three PCNs were located in the Northeast of England, with three practices located within one PCN in the Southeast of England. Two CDLs led the intervention in practices over 12 months; one in each region. Recruited practices represented urban and suburban locations, including a range of social deprivation.

Care plan audit

Sample

Patients were eligible for inclusion in the audit if, at the beginning of the audit year, they had a diagnosis of dementia recorded in their medical records, were living at home (including supported living accommodation) and were registered with a participating general practice. Those who were diagnosed during the audit year or living in a care home were excluded, as were patients under 18 years. Confidentiality Advisory Group support meant that informed consent was not required for this element of the study. This avoided the sample being skewed in favour of those with mild dementia (ie, those with capacity to give informed consent).

To avoid the wide-ranging disruptions to healthcare services experienced during the COVID-19 pandemic, including suspension of the QOF incentive programme, the preintervention audit covered the period from April 2018 to March 2019. The intervention year audit covered the period from April 2022 to March 2023. Samples for the two audit years were independent; individual patients were not followed up over time.

At each time point, a stratified sample of 215 patients was planned, to include a proportionate number of patients on practice dementia registers from each participating practice. Patients were randomly selected and screened for eligibility. The sample size of 215 was determined as sufficient to detect an increase of at least 0.1 in the proportion of personalised care plans, using a one-sided, one sample Z test with a power of 90% and a 5% significance level, assuming that the preintervention proportion of personalised care plans was 0.4.

Box 1 Care plan audit assessment criteria; markers of personalisation and domains of care

Markers of care plan personalisation

⇒ Outcomes, identified needs or goals were recorded
⇒ Evidence that outcomes were agreed with the person with dementia and/or their carer
⇒ Presence of a plan (actions) for how outcomes will be achieved
⇒ Presence of a clear date for when the care plan will be reviewed
⇒ Person with dementia and/or their carer attended the care planning meeting
⇒ Person with dementia and/or their carer were invited to consider their priorities
⇒ Person with dementia and/or their carer were sent information on care planning in advance of the meeting
⇒ Person with dementia and/or carer was provided with a copy of the care plan

Domains of care

⇒ Services currently involved
⇒ Information needs
⇒ Social and personal history
⇒ Home environment and activities of daily living
⇒ Activities and interests
⇒ Discussion of dementia diagnosis
⇒ Cognitive, behavioural and emotional changes
⇒ Planning for contingencies and changes, including advance care planning
⇒ Progression and end-of-life care
⇒ Safeguarding and advocacy
⇒ Physical health check
⇒ Medication review

Data collection

Adoption of personalised care planning was assessed through a preintervention and postintervention audit of electronic medical care records at participating practices. A case report form was developed by the research team and wider advisory group, capturing key patient demographic details (eg, sex, ethnic group, dementia diagnosis), whether a care plan was completed during the given 12-month period, degree of personalisation and domains of care covered.

Personalised care plans

Members of our patient and public involvement group, the *Dementia Care Community* (DCC), worked with the study team and programme management board to operationalise 'personalisation', based on criteria outlined by NHS England.[14] Views on what constituted adequate personalisation were heterogeneous and deemed to be dependent on the needs and values of the individual person with dementia. Each proposed facet of personalisation (see box 1) was considered necessary and valuable, but there was consensus that the minimum requirement for a care plan to be judged as personalised was the presence of the person with dementia and/or their carer for its formulation. As such, a care plan was assessed to be personalised where there was evidence that one or both of these individuals was present for the consultation in which the plan was developed. Presence or absence of each marker of personalisation was also recorded on a case report form codeveloped with the wider PriDem research team and DCC, as well as the individual domains of care covered within completed care plans (box 1).

These data were collected by researchers in both sites, guided by a data collection codebook developed by the research team. As this was a feasibility study with no control sites, researchers were not blind to the intervention. All markers of personalisation were recorded present if evidence for their presence was identified in the patient's free text care notes or a care plan document. In the case of the person with dementia and/or their carer being sent information on care planning in advance of the meeting, attachments and letters were also searched for evidence.

Analysis

Based on a pilot audit by clinical members of the research team, it was hypothesised that the proportion of people with a personalised care plan was 0.4 (40%). One of our aims was to investigate if this proportion increased post intervention. To assess this, we carried out a one-sample Z-test of the null hypothesis that the proportion of people with a personalised care plan is 0.4 against a one-sided alternative that this proportion is >0.4, for each audit year, using a 5% significance level.

Secondary outcomes and demographic data were analysed using appropriate summary statistics (eg, means and ranges for continuous data and counts/percentages for categorical data). Summaries of care plan personalisation measures included estimated 95% CIs to allow exploratory comparisons of preintervention and postintervention data.

Qualitative study

Participants

Researchers and CDLs worked together to identify opportunities for observations, and suitable professionals for interview. These were individuals linked to study sites who had been involved with the intervention. We aimed to interview up to 28 professionals, including general practice staff (eg, general practitioners (GPs), practice managers, care coordinators), external staff (eg, dementia advisors) as well as commissioners of local dementia services. CDLs and their clinical supervisor were also invited to participate in interviews. People with dementia and carers were recruited to the qualitative study from within the broader feasibility and implementation study. People with dementia were eligible for the qualitative study where they had capacity to consent to their participation. We aimed to interview up to 20 people with dementia and up to 20 carers. This sample size would allow for collection of enough rich data, across a diverse sample, with sufficient 'information power'[24] to address the research aims. Informed consent was taken for all study participants.

Data collection

Individual or small group semistructured interviews were conducted face-to-face or online via videoconferencing software, using a topic guide. Topic guides were developed to address the overall PriDem project aims, including questions on implementation. Questions and prompts explored experiences of care planning for people with dementia and carers, as well as perspectives on barriers, facilitators and impact of implementing new systems for annual dementia reviews and care planning. Topic guides were iteratively revised to include areas of importance that emerged during previous interviews. Interviews were audio recorded and transcribed verbatim.

Researchers undertook non-participant observations of non-clinical intervention activities carried out by CDLs, including multidisciplinary team (MDT) meetings, training sessions and practice team planning for dementia annual review clinics. Observations took place in-person or online, with researchers producing detailed fieldnotes.

Analysis

Data were analysed using a codebook approach to thematic analysis,[25] used to consider the facilitators, barriers and impact of implementing changes to care planning, and to contextualise the quantitative results. NVivo V.12[26] was used to organise and code data. Following familiarisation with data, transcripts were coded inductively, line by line. After team discussion of early codes, an initial codebook was developed by ES and KF, which was applied across a subset of the data. Coding of data was checked by SG, who reviewed a selection of the codes to check for consistency of analytic process, aiming for a 'stable perspective' in codebook application between coders.[27] As new data were coded, similar codes were combined, new codes formulated and redundant codes abandoned to create the final codebook, which was applied across the dataset. Themes were developed by ES and KF, in discussion with the wider research team, through the grouping of codes according to patterns of meaning. Normalisation Process Theory (NPT)[28] was used as an additional lens through which to view the findings. NPT offers a framework with which to examine the work undertaken, both individually and collectively, to implement an intervention, considering the *contexts*, *mechanisms* and *outcomes* at play. NPT does not focus on the role of patients in implementation; as such, NPT was not considered in relation to interview data from people with dementia and carers.

Findings

Care plan audit sample demographics

For the preintervention year, a sample of 179 patients was achieved. At four out of the seven practices, the target

Table 1 Care plan audit sample demographics

	Preintervention year (2018–2019) n=*179*	**Intervention year (2022–2023) n=*215***
Age (years), mean (IQR) (range)	82.5 (78–88) (57–99) Missing: 1	83.1 (78–89) (53–103) Missing: 0
Sex, n (%)		
Male	75 (41.9%)	98 (45.6%)
Female	104 (58.1%)	117 (54.4%)
Ethnicity, n (%)		
White	141 (78.8%)	168 (78.1%)
South Asian/East Asian/Asian British	9 (5.0%)	16 (7.5%)
Mixed/multiple ethnic	8 (4.45%)	17 (7.9%)
Black/African/Caribbean	3 (1.7%)	5 (2.3%)
Other ethnic group	3 (1.7%)	2 (0.9%)
Ethnicity not recorded	15 (8.4%)	7 (3.3%)
Dementia type, n (%)		
Alzheimer's	122 (68.2%)	133 (61.9%)
Vascular	23 (12.9%)	21 (9.8%)
Mixed	18 (10.1%)	27 (12.6%)
Lewy body	4 (2.2%)	9 (4.2%)
Other	4 (2.2%)	13 (6.1%)
Unknown	8 (4.5%)	12 (5.6%)
Years on practice dementia register (years), mean (IQR) (range)	2.4 (0.6–3.2) (0.008–16.6); missing/unknown: 18	2.4 (0.6–3.5) (0.003–15.3); missing/unknown: 18
Index of Multiple Deprivation quintile		
1	29 (16.2%)	45 (20.9%)
2	15 (8.4%)	16 (7.5%)
3	33 (18.4%)	43 (20.0%)
4	49 (27.4%)	45 (20.9%)
5	51 (28.5%)	65 (30.2%)
Missing/unknown	2 (1.1%)	1 (0.5%)

sample was not feasible due to a high number of ineligible patients; particularly those who had been living in a care home or registered at a different practice at the beginning of the audit year. As such, practices with higher numbers of eligible patients were oversampled until all eligible patients had been included. The recruitment target of 215 was achieved for the intervention year audit. Samples were similar with respect to a range of sociodemographic characteristics; predominantly white and female, with a diagnosis of Alzheimer's disease (table 1). Samples from both audit years had been on their practice dementia register for an average of 2.4 years, with no significant difference in terms of relative deprivation.

Care plan audit results

While 37.4% (95% CI 30.3% to 44.5%, p =0.759) of patients had a personalised care plan in place during the preintervention audit year, this increased substantially to 64.7% (95% CI 58.3% to 71.0%, p <0.0001) in the intervention year. Therefore, there is evidence to suggest that the proportion has significantly increased, post intervention. Those without any form of care plan (whether personalised or non-personalised) reduced from 45.8% (95% CI 38.5% to 53.1%) preintervention to 22.3% (95% CI 16.8% to 27.9%) of patients.

Each of the markers of personalisation (see box 1) improved (table 2) in the intervention year. Marked improvements were observed in several areas, including recording of goals, agreement of outcomes and evidence of a plan for achieving outcomes.

Domains of care that were previously well represented, such as physical health checks and medication reviews, were maintained, with improvements in psychological (cognitive, behavioural and emotional changes) and social aspects of care being addressed(eg, home environment and ADLs; activities and interests) (table 3). While there were improvements in the proportion of patients for whom plans for contingencies and changes (including

Table 2 Evidence of personalisation within completed care plans

	Evidence of personalisation within completed care plans, n (%) (95% CI)	
	Preintervention year (2018–2019) n=*97*	Intervention year (2022–2023) n=*167*
Outcomes, identified needs or goals recorded	32 (33.0%) (23.6% to 42.3%)	109 (65.3%) (58.0% to 72.5%)
Outcomes agreed with person with dementia and/or carer	10 (10.3%) (4.3% to 16.4%)	64 (38.3%) (30.9% to 45.7%)
Evidence of a plan (actions) for achieving outcomes	21 (21.7%) (13.5% to 29.8%)	79 (47.3%) (39.7% to 54.9%)
Clear date for care plan review	6 (6.2%) (1.4% to 11.0%)	25 (15.0%) (9.6% to 20.4%)
Person with dementia and/or carer invited to consider priorities	3 (3.1%) (0 to 6.5%)	36 (21.6%) (15.3% to 27.8%)
Person with dementia and/or carer sent information on care planning in advance	0 (0.0%)	22 (13.2%) (8.0% to 18.3%)
Person with dementia and/or carer provided with a copy of the care plan	1 (1.0%) (0 to 3.0%)	6 (3.6%) (0.8% to 6.4%)

ACP) were included, the proportion with an active end-of-life care plan in place remained the same.

Qualitative study participant demographics

26 professionals participated in 28 interviews, with interviews lasting an average of 34 min (range 19–80 min). 22 participants took part in a single interview; 4 also took part in a follow-up interview. Two of the interviews involved small groups of two participants.

14 people with dementia and 16 carers participated in 21 interviews, of which 9 interviews were dyadic. Interviews with people with dementia and carers lasted an average of 34 min (range 18–67 min).

Participant demographics for interview participants are presented in table 4.

Fourteen non-participant observations were conducted; demographic data were not collected for those who participated in observations.

Table 3 Domains of care addressed within care plans

	Domains of care within completed care plans, n (%)	
	Preintervention (n=97)	Intervention (n=167)
Services currently involved	30 (30.9%)	87 (52.1%)
Information needs	2 (2.1%)	47 (28.1%)
Social and personal history	31 (32.0%)	84 (50.3%)
Home environment and activities of daily living	29 (29.9%)	103 (61.7%)
Activities and interests	6 (6.2%)	67 (40.1%)
Discussion of dementia diagnosis	5 (5.2%)	38 (22.8%)
Cognitive, behavioural and emotional changes	39 (40.2%)	105 (62.9%)
Planning for contingencies and changes	25 (25.8%)	75 (44.9%)
Progression and end-of-life care	5 (5.2%)	9 (5.4%)
Safeguarding and advocacy	3 (3.1%)	25 (15.0%)
Physical health check	62 (63.9%)	133 (79.6%)
Medication review	55 (56.7%)	97 (58.1%)

Qualitative study findings

Findings are presented under four main theme headings: systemic barriers, innovative approaches, use of care planning resources and experiences of care planning.

Systemic barriers

A key, early component of the intervention involved CDLs engaging staff in reflective practice regarding their annual dementia reviews. Practice was highly variable between individual clinicians and GP practices; as evidenced through the audit, care plans were not routinely reviewed. Some GP practices signalled a reluctance to change what they viewed as acceptable practice, even when this was identified as lacking in quality:

> …it was a real struggle to get them to buy into why a dementia review was really important and why it was necessary, and the benefits to patients and families. They really couldn't understand why we would be bringing people in if they hadn't got something wrong, they hadn't got an issue. PROF-04 (CDL)
>
> I think [the CDL] wanted to kind of bring various different layers in, and [the GPs] felt that that wasn't—they didn't have that much time and resource to give to that cohort of patients and they felt […] that it was very appropriate what we did, they felt like the patient/carer or anyone else would tap into the service if they needed anything. PROF-19 (Practice Manager)

Through NPT, we can see that some professionals struggled with *negotiating capacity*, fitting the intervention within existing ways of working given the existing contextual constraints.

Patients and carers interviewed were naïve to their entitlement to an annual dementia review or care plan. For those benefitting from a care planning meeting through the intervention, this represented a new opportunity:

> I had a phone call recently, a month or so back from the GP to say he was due for his annual dementia review. We've never had one before [laughs]. So, erm, that's something new. C-08 (carer)

Among many professionals, there was consensus that due to the complex needs of people with dementia, existing structures for formulating and reviewing care

Table 4 Qualitative study participant demographics

	Professionals (n=26)	People with dementia (n=14)	Carers (n=16)
Age			
25–35	7		
36–45	4		
46–55	10		3
56–65	3		3
66–75		4	3
76–85		9	5
86–95		1	2
Missing	2		
Sex, n (%)			
Male	3	10	1
Female	21	4	15
Missing	2		
Ethnicity, n (%)			
White	18	12	12
South Asian/East Asian/ Asian British	4		1
Black/African/ Caribbean	2	1	1
Other ethnic group		1	2
Missing	2		
Professional role			
GP	9		
Social prescriber	4		
Practice manager	2		
Care coordinator	2		
Third sector	2		
Commissioner	2		
CDL	2		
CDL clinical supervisor	1		
Dementia advisor	1		
Operations manager	1		
Dementia type, n (%)			
Alzheimer's		10	
Mixed		3	
Lewy body		1	
Marital status			
Married		8	12
Widowed		3	
Divorced		2	2
Separated			2
Single		1	
Living status			
With spouse		8	
Alone		4	
With other family		2	
Relationship to person with dementia			
Spouse			11
Sibling			2
Son/daughter			2
Friend			1

CDL, clinical dementia lead; GP, general practitioner.

plans were inadequate—particularly within the confines of a standard, 10 minute consultation:

> I think that patients with dementia are very complex and they have a lot of other problems in addition to their dementia that they… they affect each other. So, for these kinds of patients the 10-minute model doesn't really work for them in achieving anything… PROF-16 (GP trainee)

Innovative approaches

Throughout the course of the intervention, practices worked to develop their own processes around care planning. The flexible nature of the intervention meant that practices could innovate solutions to fit their context, best using available staff to improve care provision.

In two practices, an MDT approach was adopted, through the running of dementia review 'one-stop-shops'. This involved different members of the team taking responsibility for planning and execution of the review, demonstrating *collective action*. People with dementia and carers were invited to attend an extended clinic, where they would meet with the GP and CDL, as well as other members of staff (eg, dementia advisor, social prescriber). Tasks were organised so that each staff member would have responsibility for specific care domains, leading to *relational restructuring*:

> …we discussed it within the clinical teams, to decide who we felt was best placed to pick up different aspects of the review, so it wasn't just one clinician doing the whole review. And we developed a model there, in one practice, where a social prescriber became involved in the reviews, and they would pick up some aspects of the review. PROF-01 (CDL)

Initially, offering such comprehensive reviews was a time-consuming process, burdensome for both staff and patients. Running a series of clinics over the course of the intervention allowed practices to identify areas for improvement and opportunities to streamline the process:

> I think initially when we started it was very, very long, and if you can bear in mind that their time awareness

> is completely different to our own, so I think for some of them maybe it was a slightly longer day than they were expecting. By the end of the process I think we cut it down by at least half and that worked, but I think there was a learning process […] so did we learn a lot? Yes we did. Will we be doing it again? Yes we will. PROF-10 (Care Coordinator)

For many practices, lack of time and resources (financial or staffing) were significant barriers to enacting change. Some practices used alternative staff in the process, either to support GPs or take on primary responsibility for care planning. In some cases, the CDL or other staff were seen as additional resources to be used for care planning, to ease capacity or free up time for GPs, suggesting problems with *coherence*:

> And so yeah, that's the way it's working now. And I think it definitely has relieved pressure from the GPs especially because they're not feeling like they're rushed to have to do anything when they see patients because [the CDL] and the team are already involved or they can ask [the CDL] to review the patient. PROF-25 (Administrative staff)

Involving the MDT often led to a more holistic approach to care planning. Staff reported addressing numerous domains of care that historically may have been overlooked.

> So, we got all their physical QOFs done, not just their dementia review. But like their COPD review, their asthma review, because that for people with dementia their physical needs get really neglected, everything gets overshadowed, oh, it's just dementia. And they often have many physical needs that just get ignored. So, it was really good to get that physical, mental health, as well as their social needs by using an MDT approach with the social prescriber, the dementia advisor. PROF-01 (CDL)

This is reflected in the care plan audit findings, where the proportion of reviews including physical health checks increased, as did those where social needs (eg, activities and interests) and mental health issues (eg, cognitive, behavioural and emotional changes) were discussed.

Use of care planning resources

All practices were given access to evidence-based bespoke resources, developed by the PriDem research team. These included annual review and care planning templates, as well as resources to support people with dementia and carers. Some practices adopted or adapted resources to facilitate care planning. In some locations, people with dementia were sent information in advance of the review to let them know what to expect, and a tool to help them consider their priorities; two of the identified markers of care plan personalisation (box 1)—although this was not routinely practised. Some practices appeared to view such resources as an additional barrier, due to their comprehensive nature, or chose to adapt existing templates:

> …the [annual review] document, the feedback was, it's too dense for [practice staff] to do. They don't have time. They can't focus on looking at such a big document. PROF-01 (CDL)
>
> Trainee [GP] asked for PriDem template to have a play with—CDL explained at the other surgery the GP created a 'hybrid' with combined elements of the PriDem cover sheet and the 'what could make a difference' document. Explained this gives the patient ideas of what they can ask about; everything is in one place and it gives them 'permission' to ask about any area. Observation fieldnotes

Experiences of care planning

In some sites, specific patient groups were less likely to directly benefit from new approaches to care planning—particularly those who were housebound, who would be unable to attend for face-to-face appointments and as such were often excluded from care planning clinics. While some patients and carers reported positive outcomes from care planning meetings—for example, information provision, practical support or referral to relevant services—a minority of carers reported a lack of follow-up:

> I said to them I think that I need help in knowing what I can claim for, what I can't claim for. What help my mum can get, and that was it, and they took my details and said somebody would call me and nobody's called me. C-05 (carer)

Overall, participants felt that patients and carers benefited from an enhanced care planning process—particularly in the context of reduced services during the pandemic. For professionals, this understanding of potential benefits demonstrated *internalisation* of the intervention aims:

> D-02: It was very enterprising I thought.
>
> C-02: And the staff were wonderful.
>
> D-02: Because it was pretty different from anything I'd ever had at [GP practice] before […] I went away very, very well satisfied.
>
> D-02 and C-02 (person with dementia and carer)

> Do you know it's a softer thing, it's like a lot of patients have felt a bit neglected and lost to general practice in the last two years, and these are our most vulnerable patients but they're also the ones that we find most difficult to access because they're not the loud ones that get the emergency appointments, they're the ones that just, you know, things get worse and worse and they have crisis, and so actually proactively reaching them and offering them such a comprehensive

review I think has regained some of their trust in us. And so I think that's been the overriding real benefit. PROF-09 (GP)

DISCUSSION

The PriDem model of care aimed to improve the proportion and quality of personalised care plans for people with dementia and their carers. Results of the care plan audit demonstrate that even through a short-term, systems-level intervention, meaningful change can be made to practice. Findings suggest that in many practices, a shift towards holistic, personalised care planning was feasible, with increased attention paid to non-medical domains of care. Previous research has identified GP capacity as a barrier to delivering high-quality dementia reviews and care planning, which could be overcome by embedding clinical dementia expertise within primary care.[10] The current study has realised this approach, with CDLs leading primary care teams in using the diverse skillsets of available staff, fostering an MDT approach, rather than relying solely on the limited capacity of GPs. Practices were able to negotiate capacity,[28] integrating a new approach to care planning within existing ways of working. They did this through relational restructuring,[28] or changing how teams usually operated, and iteratively refining a new approach and resources over time to suit their local needs.

Although there were improvements in many areas of care planning, some areas saw no change. Discussion of medication preintervention was relatively well represented at over half of care plans, and this was maintained post intervention. However, NHS England[14] recommend medication review as core to care planning to minimise polypharmacy. The proportion of patients with an active end-of-life care plan was very low and remained so post intervention. Future research is needed to explore reasons for the lack of evidenced improvement in these domains and potential workforce training and resource needs. Within the flexibility of the PriDem intervention, participating practices were enabled and encouraged to innovate their own novel approaches to care planning, supported by a CDL and bespoke resources. Staff reflected enthusiastically on changes made, iterating approaches to encourage sustainability. Changes were not universal: in some practices, a reliance on the CDL as a substitute for other clinicians raises questions about how changes can be sustained following the conclusion of the intervention. Benefits were also not universal, with housebound patients on occasion systematically excluded from reviews, and some evidence that support needs were identified but not always followed up.

Our findings raise questions about the usefulness of the current system for assessing and rewarding quality care within England. QOF guidelines stipulate that people with dementia should be invited to attend an annual review of their care plan.[20] The results of our audit and qualitative findings suggest that a minority of patients experienced face-to-face care planning prior to the pandemic. Fewer patients in our geographical areas attended a review than has been previously reported.[18] The qualitative findings showed that care planning had historically been regarded as a tick-box exercise, completed primarily for fulfilment of QOF. Many participants considered the 10-minute consultation model a key barrier to implementation of care planning, despite QOF recommendations that up to 30 minutes be allocated for this task.[20] In common with previous research,[29] we found that participating patients and carers were unaware of their entitlement to care planning but valued the opportunity to engage in a proactive and holistic discussion about their care when this was offered. Our findings align with recent suggestions that the QOF dementia review system is not meeting the needs of people with dementia and carers, and that financial reimbursement should be based on quality rather than purely quantity indicators.[29] NHS England has published guidelines for the provision of personalised care planning[14]; however, the audit results suggest that even with a successfully implemented intervention these criteria may not be met. Post intervention, some items were only recorded in the minority of cases—for example, people with dementia and carers being provided with information on care planning in advance of the consultation or being given a copy of their care plan. Within our qualitative data, however, we can see that patients from some practices were provided with such information during the intervention period, which may reflect recording issues rather than clinical practice. Practices would benefit from integrated systems whereby documentation is embedded in existing electronic systems, facilitating sharing information with patients.

Strengths and limitation

This study benefited from the inclusion of a large body of qualitative data, from multiple stakeholders. Observations enabled researchers to gain insight into how the intervention was delivered in practice, including how activities around care planning were organised. The study was strengthened by the inclusion of a wide range of professionals in interviews, including those less well represented in primary care research (eg, care coordinators, dementia advisors), as well as the voices of people with dementia and carers. It is possible that the views expressed were not fully representative; some professionals, patients and carers declined to participate or did not respond to requests. These individuals' views may have differed from those of the recruited participants; however, reflections were not universally positive, suggesting a range of views were captured. For the qualitative study, we achieved 70% of our target number of people with dementia, and 80% target of carers. The sample for the wider feasibility study was weighted towards those with moderate-to-advanced cognitive impairment, limiting the proportion eligible for interview. In order to address the gender imbalance and lack of ethnic diversity inherent in the sample, future research may benefit from oversampling under-represented populations.

Qualitative analysis was strengthened by the involvement of multiple members of the research team, from both clinical and non-clinical backgrounds. Analysis was led by researchers from one region, who had greater insight into data collected locally; as such, it is possible that insider knowledge impacted on the analysis. Cross-site analysis meetings took place throughout the process, however, to ensure a balanced perspective.

Although views on sustainability were frequently mentioned in interviews with professionals, due to the short-term nature of the study it was only possible to interview one individual after the intervention closed. Although this interview provided valuable insights into changes sustained over time, the study would have benefited from an extended follow-up period to gather a range of perspectives.

Our intention was to audit the medical records of 215 patients at both timepoints. Due to the high proportion of ineligible patients, our target of 215 for the preintervention audit was not achieved. Instead of a stratified sampling strategy, all eligible patients were included. This may impact generalisability of the audit, with a higher proportion of patients being sampled in the Southeast than the Northeast region and differences in sampling proportions between practices. However, this exploratory/feasibility study was not powered to investigate differences at practice or regional level. A future, larger definitive study should be designed to investigate this.

A further limitation is the pre–post design of the care plan audit. Due to the current focus on care planning within the NHS, with the aim to ensure 2.4 million people are given personalised care by 2024,[30] it is possible that similar increases in personalised care plans would have been seen in other chronic conditions. However, the qualitative data suggest that the systems-level intervention and practice-based innovations were specific to the intervention.

This being a feasibility study, by definition the intervention was delivered in a small number of practices, in two geographical regions. Future research would benefit from examining the impact of such an intervention in different locations, for example, rural practices or areas of greater deprivation.

CONCLUSIONS

The findings of the PriDem study demonstrate that meaningful personalised care planning can be achieved through a team-based approach. Although many professionals considered changes to be sustainable, due to the length of the study it was not possible to gather extensive data on whether changes had in fact been sustained. However, poststudy contact with CDLs and participating general practices indicates that 'one stop shop' dementia review clinics continued beyond the lifetime of the project and were embedded within a local dementia strategy. Future studies would benefit from the collection of longer follow-up data. The results of the audit raise questions about the suitability of financially incentivising GPs to record completion of annual reviews without consideration of quality, highlighting the need for improved guidelines to encourage a move away from care planning as a tick-box exercise. Others have called for quality-based incentivisation but have cautioned that quality indicators should recognise the importance of tailored care planning. Not all care domains will be relevant to all patients and carers.[29] Commissioners of dementia services should consider the benefits of a CDL-led approach, which can result in people with dementia and carers benefiting from increasingly holistic, patient-centred care. This paper has reported on PriDem process evaluation findings specific to personalised care planning. Further findings relating to intervention implementation barriers and facilitators will be published elsewhere.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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use data will be submitted on a standard form and reviewed by a committee prior to data-sharing agreements being developed.

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REFERENCES

1 NHS. About dementia: dementia guide 2020. 2020. Available: https://www.nhs.uk/conditions/dementia/about
2 Chen Y, Bandosz P, Stoye G, *et al*. Dementia incidence trend in England and Wales, 2002–19, and projection for dementia burden to 2040: analysis of data from the English longitudinal study of ageing. *Lancet Public Health* 2023;8:e859–67.
3 Nichols E, Steinmetz JD, Vollset SE, *et al*. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the global burden of disease study 2019. *Lancet Public Health* 2022;7:e105–25.
4 Wittenberg R, Hu B, Barraza-Araiza L, *et al*. *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040*. London: London School of Economics, 2019:2019–11.
5 Bourne J. Improving services and support for people with dementia. National Audit Office; 2007.
6 Morse A. *Improving dementia services in England—an interim report*. London: National Audit Office, 2010.
7 Kane M, Terry G. *Dementia 2015: aiming higher to transform lives*. London: Alzheimer's Society, 2015.
8 Arblaster K, Brennan S. Left to cope alone: the unmet support needs after a dementia diagnosis. Alzheimer's Society; 2022. Available: https://www.alzheimers.org.uk/sites/default/files/2022-07/left-to-cope-alone-after-diagnosis-report.pdf
9 Prince M, Comas-Herrera A, Knapp M, *et al*. *World Alzheimer report 2016-Improving healthcare for people living with dementia: coverage, quality and costs now and in the future*. London: Alzheimer's Disease International, 2016.
10 Frost R, Rait G, Aw S, *et al*. Implementing post diagnostic dementia care in primary care: a mixed-methods systematic review. *Aging Ment Health* 2021;25:1381–94.
11 Gauthier S, Webster C, Servaes S, *et al*. *World Alzheimer report 2022: life after diagnosis: navigating treatment, care and support*. London, England: Alzheimer's Disease International, 2022.
12 Vinay R, Biller-Andorno N. A critical analysis of national dementia care guidances. *Health Policy* 2023;130.
13 NHS England. Universal principles for advance care planning (ACP). 2022. Available: https://www.england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning.pdf
14 NHS England. Dementia: good care planning – information for primary care and commissioners. 2017. Available: https://www.england.nhs.uk/publication/dementia-good-care-planning-information-for-primary-care-and-commissioners
15 Goodall G, Taraldsen K, Granbo R, *et al*. Towards personalized dementia care through meaningful activities supported by technology: a multisite qualitative study with care professionals. *BMC Geriatr* 2021;21.
16 Bryant J, Mansfield E, Cameron E, *et al*. Experiences and preferences for advance care planning following a diagnosis of dementia: findings from a cross-sectional survey of carers. *PLoS ONE* 2023;18.
17 Wheat H, Griffiths S, Gude A, *et al*. Practitioners' ability to remotely develop understanding for personalised care and support planning: a thematic analysis of multiple data sources from the feasibility phase of the dementia personalised care team (D-PACT) intervention. *Dementia (Lond)* 2023;22:1461–86.
18 Low L-F, Duckworth TJ, King L, *et al*. Care planning for community-dwelling people with dementia: a systematic scoping review. *Health Soc Care Community* 2023;2023:1–23.
19 National Institute for Health and Care Excellence. Dementia: assessment, management, and support for people living with dementia and their carers. NICE guideline [NG97]; 2018. Available: https://www.nice.org.uk/guidance/ng97
20 NHS England. Quality and outcomes framework guidance for. 2023. Available: https://www.england.nhs.uk/wp-content/uploads/2023/03/PRN00289-quality-and-outcomes-framework-guidance-for-2023-24.pdf
21 Griffiths S, Spencer E, Wilcock J, *et al*. Protocol for the feasibility and implementation study of a model of best practice in primary care led Postdiagnostic dementia care: PriDem. *BMJ Open* 2023;13.
22 Bamford C, Wilcock J, Brunskill G, *et al*. Improving primary care based post-diagnostic support for people living with dementia and carers: developing a complex intervention using the theory of change. *PLoS ONE* 2023;18.
23 Ogrinc G, Davies L, Goodman D, *et al*. SQUIRE 2.0 (Standards for quality improvement reporting excellence).
24 Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res* 2016;26:1753–60.
25 Braun V, Clarke V. Conceptual and design thinking for thematic analysis. *Qual Psychol* 2022;9:3–26.
26 QSR International. Qualitative data analysis software: NVivo (version 12). 2017. Available: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home
27 Levitt HM, Bamberg M, Creswell JW, *et al*. Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: the APA Publications and Communications Board task force report. *Am Psychol* 2018;73:26–46.
28 May CR, Albers B, Bracher M, *et al*. Translational framework for implementation evaluation and research: a normalisation process theory coding manual for qualitative research and instrument development. *Impl Sci* 2022;17.
29 Wheatley A, Brunskill G, Dow J, *et al*. The primary care annual dementia review: a qualitative study of the views and experiences of service users and providers.medRxiv. 2022.
30 NHS. The NHS long term plan 2019. 2019. Available: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan