QUALITATIVE PAPER

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

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Abstract

Background: inequalities and gaps in post-diagnostic support (PDS) for people with dementia persist despite a policy focus on dementia in England and Wales. Understanding and overcoming the factors contributing to these inequalities is vital to improve care for people living with dementia (PLWD) and their families.
Objective: to explore common barriers to the delivery of PDS in England and Wales and describe successful strategies to address them, drawing on examples from current practice.
Design: qualitative semi-structured interviews, focus groups and observation.
Settings: Phase 1: interviewees were drawn from multiple sectors across England and Wales, including NHS clinical commissioning groups and social care. Phase 2: six case study sites based in different sectors (primary care, secondary mental health and third sector) in England.
Participants: Phase 1: 61 professionals, including commissioners and service managers. Phase 2: 68 professionals, including frontline staff and those working in related services; 17 PLWD; 31 carers.
Results: barriers to implementing PDS in dementia were an unsupportive infrastructure, limited proactive review and limited capacity and capability particularly in primary care. Strategies used successfully in practice to address these challenges included creating opportunities for service development, improving joint working, supporting non-specialists and developing ongoing, holistic review and care planning.
Conclusion: a range of practical strategies have been identified to address many of the common barriers to PDS in dementia. To achieve policy goals of a task-shifted and task-shared approach to PDS, widespread use of these strategies is recommended.

Keywords: dementia, post-diagnostic support, qualitative research, older people

Key Points

- Post-diagnostic support for people with dementia is often fragmented and fragile.
- We explored common barriers to implementing dementia care recommendations in current practice.
- This paper offers examples of solutions used by commissioners and service managers to address these barriers.

Introduction

Providing post-diagnostic support (PDS) and care throughout the illness trajectory is fundamental to the wellbeing of people living with dementia (PLWD) and their families [1]. Understandings of PDS vary, with some professionals interpreting PDS as a single meeting following diagnosis [2]. In this paper, we use the Alzheimer Disease International definition of PDS as 'holistic, integrated continuing care in the context of declining function and increasing needs of family' [1]; such care covers the entire period from the point of diagnosis through to end of life.

In many countries, the growing evidence base to inform PDS is summarised in national dementia guidelines or dementia strategies [e.g. 1, 3, 4–7]. However, inequalities and gaps in provision persist [1, 8]. In England, for example, the percentage of PLWD having their care plan reviewed in the last 12 months ranged from 32 to 93% [9] and the quality of annual dementia reviews by general practitioners (GPs) can be variable [10]. Around one quarter of memory services were unable to provide or offer cognitive stimulation therapy (CST) with a similar proportion unable to provide or offer carer psychoeducation [11], despite these interventions being recommended in national guidelines [3]; reasons given included lack of resources and feeling that interventions were better suited to third sector provision [11]. Understanding the barriers to the delivery of PDS and strategies for addressing these is essential to improve provision to PLWD and their families. Previous research on barriers to PDS has focused predominantly on primary care [12–16]; factors influencing the provision of PDS by other sectors and service providers are less well understood.

In this paper, we examine common barriers to the delivery of PDS for dementia in England and Wales including services from all sectors. We additionally describe a range of practical solutions used successfully by providers to address common barriers.

Methods

The research was conducted in two phases. Initially, we sought examples of good practice through snowball sampling and online searches to identify award-winning services and those included in policy documents. In phase 2, we selected six of these services for more detailed study, focusing on services with strong links with primary care. We included examples of services based in different sectors (primary care, secondary mental health and third sector); staffed by different personnel (specialist nurses, GPs with extra responsibilities, multidisciplinary teams, community psychiatric nurses and dementia navigators) and with diverse approaches to PDS (see Appendix 1, Supplementary data are available in *Age and Ageing* online).

Phase 1 data were collected through telephone interviews and a focus group with service managers and commissioners (details are reported elsewhere [2]). Phase 2 data were collected between July and December 2019 by AW (sociologist), GB (clinical psychologist) and CB (social gerontologist). We used focus groups and semi-structured interviews to capture the views of frontline staff and linked professionals who worked with case study sites either through joint activities, or simply through shared care of PLWD). Semi-structured interviews (either face-to-face or telephone) were used to explore the views and experiences of PLWD and informal carers; most were recruited through the case study sites, but we also included some participants living in North East England and identified through Join Dementia Research (JDR; [17]). Additional data were collected through observation of service delivery and relevant meetings.

Interviews and focus groups were audio-recorded, transcribed and edited to ensure respondent anonymity. Details of observation were recorded in anonymised field notes immediately after the observation period [18]. Analysis drew on varied qualitative traditions and followed standard procedures of rigorous qualitative analysis [19]. Initially, we individually closely read some transcripts, noting preliminary themes and ideas and met to discuss our findings. We iteratively developed our coding frame through constant comparison [20], using group discussions to refine our initial codes and the relationships between them. We then applied the refined coding frame to the full data set using QSR NVivo 12 software. Analytic memos [21] were developed for codes, followed by a final round of group discussions to further sort, refine and integrate the memos and develop the findings for the paper.

Ethical approval was received from NHS Research Ethics Committee Wales 3 (reference 18/WA/0349). Participants in face-to-face interviews and focus groups provided formal written consent. The majority of participants in telephone interviews provided formal written consent via email or post, although we sought verbal consent before the interview for those who had not returned a completed consent form. Prior to observation, professionals provided written consent; PLWD and carers were asked for verbal consent. No personal identifiable information was recorded about PLWD or carers during observation. All participants were allocated a unique identifier, used in all quotations.

Findings

Participants

Phase 1 data comprised telephone interviews with 50 service managers and commissioners and a focus group with 11 health and social care commissioners [2].

Phase 2 data included 10 interviews and 5 focus groups with 42 frontline staff; interviews with 26 linked professionals (including GPs, social prescribers, community matrons and care home staff); interviews with 17 PLWD (of whom 6 were recruited via JDR); interviews with 31 carers (6 JDR) and 36 periods of observation. Observation sessions ranged in length from a single appointment to a full day. We observed initial assessments, reviews, clinic sessions, group

Table 1. Barriers to the delivery of PDS

Challenge/barrier	Illustrative quotation	Strategies
Unsupportive infrastructure		
Fragile services that are not sustained long term [22]	*[. . .] we're really struggling because the money that we've had to support our service is [. . .] rolled out on a yearly basis [. . .] that impacts on continuity then because it creates all kinds of anxieties amongst the staff.* (S019, manager and community dementia team)	1, 2, 3
Fragmented services, with multiple providers from different sectors and poorly managed transitions [16, 22, 25]	*I think that's the absolute bane of everyone's life, the fact that we cannot see the GP record or I can't see if someone's been seen by community speech therapy team* (S613, allied health professional)	4, 5, 6, 7, 8, 9
Lack of explicit care pathways [12, 16, 22]	*The current model we have of the dementia pathway, there has been gaps in the moderate stages, shall we say. Historically, there's a lot of pre-loading of supporting information at pre and post-diagnosis for the first year and then, quite often people are no longer having contact with anybody.* (S058, manager and third sector service)	6, 10
Limited proactive, holistic tailored support		
Variable frequency, quality of review [10]	*Primary care offer annual care reviews, but they vary in that quality, if I'm being perfectly honest about it. [. . .] it's all about numbers, and not quality. Because there isn't a template, and there isn't a way to do it* (S042, GP)	10, 11, 12
Lack of holistic approach to care [10]	*It's not just about medication. It's not about just their comorbidities as well, but we have to look at the socialisation, we have to look at steps that actually promote their wellbeing, as well.* (S057, community dementia practitioner)	10, 11, 12
Limited discussion of progress and anticipation & planning for future needs [15, 22]	*It's like, 'How long are we able to keep my mum in the situation that she is?' [. . .] it would be quite nice to have a little bit of knowledge of. . . And the reassurance of knowing that there are options there, and what they are, if things do go downhill. Rather than facing it, immediately, at the time when it's all happening* (C101, carer)	10, 11, 12
Limited capacity and capability		
Capacity and willingness of primary care to increase their role in post diagnostic dementia support [12, 15, 16, 22]	*I realistically am not sure that they [GPs] have the dedicated time you need to spend with people with dementia.* (S022, manager and memory service)	7, 8, 9, 10
Lack of skills in tailoring care [22]	*When you get offers of help or whatever, it's not, "What do you need?" It's, "This is what we have got. You might be able to find something in that" or whatever. It's not needs led at all. It's not individual planned at all. It's one size fits all, if you are with me, which does not necessarily work* (P202, PLWD)	10
Lack of understanding of dementia [12, 15, 22]	*[. . .] my experience will be that some [GP] practices [. . .] are still stuck in that, 'Actually it's just a normal part of aging, and what's it got to do with me?' kind of thing* (S049, admiral nurse)	7, 10
Limited access to specialist support [22]	*Communication has been a problem with the Memory Service [. . .] trying to get a reply, that has been quite challenging in the past* (S402, practice nurse)	4, 5, 7, 10

interventions, internal team meetings and multidisciplinary team meetings (MDTs) with GP practices.

Case study sites are briefly summarised below (for further details, see Appendix 1, Supplementary data are available in *Age and Ageing* online):

- Specialist dementia nurse in general practice;
- Ongoing review by GPs with extended roles (GPWERs) across an NHS Clinical Commissioning Group;
- Secondary care led step up/down models linked to specific GP practices (two sites);
- Secondary care led enhanced memory assessment service;
- Third sector community-based dementia navigators.[1]

Barriers to the delivery of PDS

Barriers to the delivery of PDS related to limitations around: infrastructure; proactive, holistic tailored support; and capacity and capability. Table 1 illustrates the subthemes

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1 We have used the term 'dementia navigator' throughout for consistency and to facilitate confidentiality, although a variety of terms were used for similar posts in different areas.

Table 2. Numbered list of strategies

#	Strategy
	Creating opportunities for service development
1.	Using funding opportunities creatively
2.	Building on policy initiatives
3.	Developing strategic alliances with key stakeholders
	Facilitating joint working
4.	Developing working relationships across services and sectors
5.	Supporting information sharing
6.	Developing shared pathways
	Supporting non-specialists to deliver dementia care
7.	Providing specialist advice and support
8.	Creating dedicated posts/services
9.	Enhancing step up/down models
10.	Upskilling non-specialists through training and supervision
	Developing ongoing holistic support
11.	Developing holistic review procedures and paperwork
12.	Creating opportunities for additional review

relating to each broad area. Many of these barriers are consistent with those reported in previous studies of diagnosis or management of dementia [12, 15, 16, 22] and are therefore not elaborated here. Instead, we focus on practical strategies used by services to address the barriers. These are indicated by a number in Table 1, which can be cross-referenced against Table 2. The UK policy context also influenced the provision of PDS: a period of policy emphasis on dementia [23] has now shifted to a broader focus on frailty [24], which aims to improve the wellbeing of older people by providing proactive support to older people living with frailty in the community.

Strategies to address barriers to delivery of PDS

Using data collected in both phases of the study, we identified strategies used successfully to address the barriers to the delivery of PDS (Table 2). There is not a simple one-to-one correspondence between barriers and strategies since barriers could be addressed by more than one strategy, and individual strategies could address more than one barrier. Strategies have been grouped into four main themes and are described and illustrated below.

Creating opportunities for service development

Strategies in this section relate to creating opportunities, individually or collectively, to develop existing or new services in ways that enhanced the chances of sustainability.

1. Using funding opportunities creatively
   New or existing sources of funding could be used for service development. For example, one general practice funded an Admiral Nurse post by combining funding allocated for long-term conditions and the annual dementia review (funded under the Quality Outcomes Framework [10]). Another site had developed a comprehensive approach to PDS using the NHS Better Care Fund for joining up health and social care services [26].

2. Building on policy initiatives
   Although recent UK policy shifts led to concerns about sustainability of PDS services for some professionals, others developed explicit links with frailty services and pathways, to ensure continuing emphasis on PLWD:

   'I try to get dementia in the frailty pathway as another way of keeping the eye on dementia as well, to keep it on the agenda. [. . .] we looked at our dementia link nurses, so now within their assessment, they are making sure they also do the frailty assessment as well. So, that can feed back into the frailty pathway electronic record. So, there is a bit more kind of awareness, again, of dementia. (S021, NHS commissioner)'

3. Developing strategic alliances with key stakeholders
   Although commissioners with an interest in dementia facilitated PDS, not all commissioners prioritised dementia. In these circumstances, building strategic alliances across services and sectors could create impetus for change and service development:

   'The Dementia Alliance came into being about four years ago [. . .] for us to meet regularly with the [Mental Health Trust] and [Hospital], with the purpose of developing joint goals around dementia. This was to improve things like support for carers, to improve joined up working and to basically stop silo working. (S058, manager, third sector service).'

   In addition to working collaboratively at a strategic level, other strategies focused on improving joint working within and across sectors.

Facilitating joint working

The fragmented nature of services, with multiple providers and sectors involved in PDS, required explicit attention to joint working. A range of approaches had been successfully implemented to address different aspects of joint working.

4. Developing working relationships across services and sectors

   Investing in building relationships between staff with different roles was central to enhancing joint working. Co-location was a key way of facilitating joint working and increasing understanding of the roles of different workers by encouraging informal discussions and sharing of information:

   '[The dementia navigator] shared the office with a physiotherapist, a district nurse, a social worker and a pharmacy technician. I observed several informal conversations about service users during the day, and everyone said that being co-located was beneficial to their work as they were more easily able to connect, work together and share knowledge/information about service users. (Fieldnotes of observation).'

   However, simply basing external services in GP surgeries did not necessarily enhance integration unless positive efforts were made to use such services effectively. One GP surgery hosted a drop-in session by the local carers' services once a month but found that it was initially underused. By

taking a more proactive approach, in which carers of PLWD registered with the practice were identified and invited to the clinic, uptake of the service improved.

Joint activities with staff from different sectors were another way of developing relationships; one secondary care drop-in clinic, for example, involved third sector agencies. Joint working could increase clarity over role and expertise, and direct access to these agencies additionally had benefits for PLWD and carers by avoiding the need for signposting or referrals and ensuring that the diverse needs of those attending could be addressed by staff with appropriate expertise.

5. Supporting information sharing

Successful strategies often involved improving or working within existing systems. Cross-sector shared record systems worked successfully in some areas, either through a specific project or local arrangements:

> 'I can find out everything I need to know on [local shared record system]. It is absolutely massive; it has made a big change. We're not phoning GPs, waiting four days for a GP to get back to us, because actually we can read it ourselves. (S212, dementia practitioner).'

In addition to accessing PLWD notes, shared information systems could facilitate communication between professionals, for example by allowing tasks to be allocated to dementia navigators without requiring a formal referral. Although shared information systems had significant benefits, most systems had limitations either in terms of the information available or difficulties in accessing the system due to problems with connectivity. There could also be concerns regarding confidentiality, which required formal data sharing agreements and/or third sector workers to have employment contracts with an NHS Trust.

6. Developing shared care pathways

The development and local agreement of formal shared care pathways—written agreements which explicitly set out responsibilities of different professionals relating to specific aspects of patient care—was one way of clarifying expectations and supporting the transfer of responsibility from secondary to primary care. Including a commitment to rapid response times for referrals to specialists for management of complex problems was thought to enhance GP commitment to the pathway, since they could access specialist help when needed:

> 'If there is a problem in the community and they are really struggling because of the dementia [. . .] then they can refer back to us. And we would see people within two weeks, three weeks. That's our agreement with the GPs and it's worked really, really well. It's enabled us to discharge faster, but also, I suppose, the confidence of the GPs, that they can refer back in if they need to. (S036, manager, memory service).'

Explicit pathways could facilitate transitions, for example, by automatically referring PLWD from the memory service to dementia navigators or similar services.

Supporting non-specialists to deliver dementia care

Simply improving joint working or providing shared care pathways were not, however, sufficient to support the task-shifted approach to dementia care advocated in recent policy [1, 2]. Non-specialists additionally needed easy access to specialist advice and training which could be achieved in a number of ways.

7. Providing specialist advice and support

This could be achieved through a central telephone hub, a helpline available at set times each day/week to the local memory clinic, or through MDTs. The following extract from fieldnotes illustrates the added value that shared information systems gave to a central telephone hub:

> 'S212 [dementia practitioner] took a call from a day centre manager regarding concerns about a known PLWD's incontinence as described by her carer on arriving at the centre [. . .] After the call, S212 reflected that by having access to the GP record, she could triangulate and help resolve an issue that was clearly causing the carer lots of concern. (Fieldnotes of observation).'

This information hub was valued by other professionals, but some felt that the service should also be available on evenings and weekends. Other services had negotiated rapid access to memory clinic staff for specialist advice, either through a helpline available at a set time each day or through emails or telephone calls.

Cross-sector MDT meetings were another common strategy for bringing workers from different sectors together to discuss complex service users and share expertise to support decision-making:

> 'Yes, they are useful. Not only for networking, but in terms of knowing our patients more. You do get more of an idea on how everybody works in the community, because I've always worked in [hospital]. (S117, hospital matron)'

8. Creating dedicated posts/services

Many of the case study sites had created new posts such as dementia navigators or social prescribers. These were valued for their detailed local knowledge which could otherwise be difficult to access due to the fragmentation and fragility of services. One site had established assistant psychologist posts to support the delivery of NICE recommended interventions such as CST and carer psychoeducation. In the absence of dedicated posts, these interventions were often reliant on the interest of individual workers who rarely had protected time to develop the service. A dedicated post allowed a number of CST groups to be run concurrently, enabling tailoring and the inclusion of people with more severe dementia:

> 'When I first joined the service, the same activities were used for everyone, regardless of the type of group. I found, within the first maybe month, that seemed a bit- I think people found it a bit condescending. [. . .] we do get referrals for those who might score quite lowly on cognitive testing, or might be veering towards the more severe stages of dementia. [. . .] I'd go to their home to visit them, bring along some materials and just have a look through

what we have available, see if it's something that they could engage with. (S104, assistant psychologist).'

A strategy used by several sites was to introduce linked workers who were allocated to a number of GP practices, typically providing training, support with diagnosis and PDS. The background of linked workers varied; some were clinical (including specialist nurses and OTs) while others, such as dementia navigators, were usually non-clinical. Linked workers had limited availability and lower visibility than staff who were embedded in a single practice, and a recurrent issue raised by sites providing this model of care was the variability in engagement of GP practices.

9. Enhancing step up/down models

'Step up/down' models across sectors were widely available, since primary care staff could refer to specialist secondary mental health teams, dementia navigators could refer to GPs etc. In these situations, a formal referral process was usually required, potentially creating delays. Some sites had introduced tiered support internally, enabling PLWD to seamlessly transfer to more qualified staff as and when needed:

> '[. . .] if that [dementia navigator] [. . .] feels as though the risk and the complexity is getting beyond [them], or it's getting quite complicated, then they would look to step that individual up to the nursing staff [. . .] Then once it's settled back down again to drop back to the [dementia navigator]. (S018, manager, memory service)'

10. Upskilling non-specialists through training and supervision

In addition to ad hoc support relating to individual PLWD through telephone helplines or MDTs, several sites provided more formal training for GPs and other non-specialist staff through annual training days. The turnover of GPs highlighted the importance of regular training opportunities, particularly where they took an enhanced role in diagnosis or management of dementia:

> 'We run training, annual training for GPs to enable them to fulfil their enhanced role because we had to enhance the confidence, experience, skills of the GPs to be able to do the regular diagnostic work. (S208, dementia practitioner).'

The GPs with extra responsibilities who provided enhanced review for PLWD received supervision from an old age psychiatrist to provide oversight of their new role and support the ongoing development of their skills and knowledge. Sites relying on non-registered staff for the provision of PDS often developed a culture of informal support and team building which enabled staff to develop their skills and knowledge.

Developing ongoing holistic support

In England, a key component of PDS is an annual review conducted in primary care as part of the Quality Outcomes Framework [10]. Concerns were frequently expressed during data collection about the quality and consistency of these reviews [2]. A range of strategies were used to enhance both the frequency and quality of reviews.

11. Developing holistic care planning procedures and paperwork

Developing and local care planning tools could help ensure consistency and continued fitness for purpose:

> 'I've redesigned our wellbeing plans, so that they are a lot more holistic and comprehensive. [. . .] We did a bit of an audit on the old one and, unfortunately, lots of people didn't really know of their existence. And, if they did, they didn't really find them very useful, so it was clear we needed a big change. And it's a tricky one, because there are so many audiences, our service-users and families but there are also a number of professionals who would really benefit from having a co-ordinated, one, document, where there is some useful information. (S213, psychologist).'

Robust systems and templates for gathering, recording and sharing information facilitated recall between visits and ease of sharing with other professionals in order to tailor care appropriately. Strategies to facilitate holistic review also included sharing responsibilities between different professionals, for example, by involving a healthcare assistant to complete physical health checks or a social prescriber to focus on activities, friendships and resilience:

> 'We have a [dementia navigator] from the [third sector] sits in a room adjacent to where I do the reviews [. . .] Quite often, when they've finished with me, they [service users] might go in and talk to the [dementia navigator] if there are specific things they might want to find out from them. (S046, GP).'

In another site, regular dementia reviews and long-term condition reviews had been combined to ensure a holistic approach and to improve the PLWD experience and reduce duplication.

Observation highlighted marked variations between staff even within the same service, particularly in the comprehensiveness of initial assessments and reviews, suggesting that supervision is needed to maintain a consistent standard.

12. Creating opportunities for additional review

Many professionals thought that an annual review was not sufficient for PLWD, particularly those in the moderate and advanced stages of the illness. Interviews with many PLWD and carers highlighted their reluctance to seek help which seemed to reflect a lack of awareness that symptoms were related to dementia, low expectations that support would be available, and an unwillingness to 'bother' busy professionals. Proactive and regular reviews were therefore essential to identify problems at an early stage and also ensured that actions from care plans were followed up. Additional formal reviews were an integral part of several case study sites usually with flexibility over the timing to meet individual needs.

Less formal review was provided by some sites through easy-access drop-in clinics for PLWD and carers or outreach visits to third sector clubs or community groups. The latter allowed staff to informally monitor service users in a relaxed environment and was valued by PLWD and carers:

'We used to have [dementia navigators] come along to the sessions once a week. That was marvellous because you could ask them any questions and all that. Though they are at the end of a telephone, you are much more likely to say to someone that's in the room, 'Have you known anything about this?' or, 'Where would I go for that?' (C302, carer).'

Discussion

This paper reports the findings of an extensive qualitative study exploring the provision of PDS for dementia in England and Wales. It augments the existing literature on barriers to PDS by covering a wide range of services and providers and by highlighting strategies to support PDS. Previous reviews have generally focused on barriers to the diagnosis and management of dementia in primary care [12, 22] or the implementation of specific interventions such as case management [13, 16], although one review has considered implementation research in dementia more broadly [15]. Consistent with our findings, these reviews highlight the systemic and structural barriers to post diagnosis support in dementia, including the lack of a coherent pathway and limited knowledge of local services and professional roles [12, 15, 16]. The lack of shared information systems has been identified as a barrier to the successful implementation of some interventions [25], with a broader focus on inter-organisational communication in other studies [16, 27].

The strategies used by service commissioners and providers to overcome common barriers to delivering PDS overlap with facilitators noted in the existing literature. For example, the need for shared care pathways and improved referral processes has been highlighted [28] and has been used to facilitate task-shifting to non-specialists in other long term conditions such as diabetes and stroke [29]. The desire to promote integration is central to many case management interventions, with co-location highlighted as a significant facilitator [16, 25].

Our study adds to the existing literature by providing examples of how strategies have been enacted in practice to address common barriers. Some of these strategies, for example the creation of an advice and support hub for service users and professionals, addressed several challenges. However, there were some challenges for which there were few good strategies. Anticipating and planning for future needs was an ongoing challenge for many of the services in our study as was ensuring consistency of assessment and review. More work is needed to find ways of mitigating these challenges.

There are limitations to our study. Although we secured a wide geographical spread of participants within England and Wales, our original plans to undertake a UK-wide study were hindered by delays in research governance approvals [2]; thus the inclusion of sites in Scotland and Northern Ireland was not possible. In addition, while we aimed to include the views of all stakeholders within the case study sites (i.e. frontline staff, linked professionals, PLWD and their families), we experienced some recruitment difficulties. This partly reflected the time scale, but it was disappointing that some services with very large caseloads proved unable to recruit services users. It is likely that stakeholders who were more positive about each of the services were more likely to participate, potentially giving a skewed view of services and a lack of insight into any negative features or problems. Nonetheless, by including observation, we were able to develop an adequate understanding of how the service was delivered and identify key strengths and limitations of each service.

Conclusions/implications for practice

Despite a strong, ongoing policy focus on improving dementia care in England and Wales, our findings highlight ongoing challenges to the delivery of post-diagnostic care and support for a long-term illness which is one of the most costly in terms of personal, economic and societal burden [30]. Interventions that have evidence of efficacy and are recommended in national policy have not been implemented systematically in the UK. This paper reports successful examples of practical solutions used successfully by service commissioners and providers to promote the delivery of coordinated, integrated PDS for PLWD and their carers. These qualitative data are also informing the development of a primary care-based, complex intervention to improve the equity and quality of post-diagnostic dementia care and support which we intend to implement and evaluate.

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