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Development and evaluation of personalised post-diagnostic dementia support based in primary care: the D-PACT research programme

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Extended Research Article

Development and evaluation of personalised post-diagnostic dementia support based in primary care: the D-PACT research programme

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Abstract

Background: Dementia affects nearly 1 million people in the United Kingdom and their unpaid carers physically, psychologically, socially and economically, highlighting that both need support. Post-diagnostic support is recognised as inadequate globally. In England, it is fragmented or absent apart from primary care – leaving many feeling unsupported as the condition progresses. The Dementia PersonAlised Care Team research programme began in 2018 to address evidence gaps on the effectiveness of dementia support roles and what constitutes 'good' support.

Objective: Dementia PersonAlised Care Team aimed to develop and evaluate an intervention comprising dementia support workers based in primary care, supporting people with moderate to severe dementia and their carers. Phase 1 focused on intervention development and feasibility testing. Phase 2 evaluated the dementia support workers' value and impact. Our Peer Research Group contributed to the design, analysis and interpretation of data in both phases.

Design and methods: Phase 1 employed a realist approach to develop theory, the intervention and practitioner support package. This was informed by literature, consulting experts by experience, academics and practitioners and a formative evaluation. A pilot cluster randomised controlled trial tested the feasibility of recruitment, outcome measures and eligibility criteria.

Phase 2 included a realist longitudinal mixed-methods evaluation to determine what worked, for whom and in what circumstances. High-volume qualitative data included realist interviews with participants with dementia and carers at two time points, interviews with dementia support workers and general practitioner staff/other practitioners, observations, dementia support worker case notes and reflections, and medical records. Quantitative measures of health- and quality of life-related outcomes, experience of care, carer well-being and support, and resource use were collected at three time points. A mixed-methods integration was conducted following separate qualitative, quantitative and economic analyses.

Setting and participants: Phase 1 recruited participants with dementia (some without capacity) and their carers (if present) from general practitioner practices in rural Devon and Greater Manchester. In phase 2, participants were recruited from practices in rural and coastal areas in Devon (high deprivation) and urban Greater Manchester (including areas with higher representation of South Asian communities).

Intervention: The Dementia PersonAlised Care Team intervention, developed in phase 1, delivers personalised, proactive and integrated dementia care via trained dementia support workers embedded in primary care. Drawing on coaching principles, dementia support workers empower decision-making and address psychosocial, health and practical needs through flexible, ongoing support. Support is tailored to individuals' *and* carers' needs. Consented participants were offered 12 months of support, which is flexibly stepped up or down based on need.

Findings: In phase 1, the Dementia PersonAlised Care Team intervention was tested in 10 general practitioner practices. COVID-19 necessitated switching to remote intervention delivery, recruitment and data collection. Intervention and recruitment strategy (including capacity assessment) were acceptable. However, only 51% (56/110) of the recruitment target was met, making a fully powered cluster randomised controlled trial unfeasible within the funding envelope. A mixed-methods longitudinal realist approach was therefore adopted for the evaluation (phase 2).

In phase 2, 126 PwD and 121 carers were recruited from 13 practices – reaching 70% (126/180) of the recruitment target. Retention in the intervention was high (79%). However, participation in follow-up data collection was poor for all quantitative measures, for example, only 22% (28/126) of participants completed the Engagement and Independence in Dementia Questionnaire at 9–12 months.

The longitudinal realist analysis identified four areas of positive impact linked to dementia support worker actions: living well, proactive care, reactive care and care transitions. Participants spoke about improved social engagement, medication management and holistic care outcomes despite the inevitable functional decline. Supervision and peer support for dementia support workers, along with joint work with practice teams, were key to delivering this care.

Quantitative data showed either stable or declining trends except for carer perceptions of support, which improved over time. Realist-informed economic analysis identified 23 cases where dementia support workers likely prevented high-cost care escalation through early intervention, access to general practitioner records and ability to prompt general

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practitioners' care. Resource use shifted towards increased primary/community care and reduced secondary care costs. At a caseload of 53 dyads at any one time, mean annual cost per dyad was estimated at £1222.48.

Limitations: Low data completion rates, individual variability and the non-randomised design significantly limited utility of quantitative findings.

Conclusions: This work demonstrated how gaps in post-diagnostic support for people with dementia and carers can be addressed through tailored, proactive support and dementia support workers being fully embedded in primary care. A comprehensive training and ongoing support package is essential for enabling dementia support workers to carry out their role.

Future work: Further implementation research is needed to test delivery in changing National Health Service contexts, including whether different roles can deliver personalised dementia support.

Study registration: This study is registered as ISRCTN90828574.

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List of supplementary material

Report Supplementary Material 1 Approaching and recruiting South Asians living with dementia and their carers into the Dementia PersonAlised Care Team (D-PACT) study

Report Supplementary Material 2 Extraction of data from electronic healthcare records: Summary of development and implementation

Report Supplementary Material 3 Developing a Talking Mat to facilitate engagement in a realist dementia evaluation

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Supplementary material has been provided by the authors to support the article and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

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List of abbreviations

CA	conversation analysis
CCMO	Context Component Mechanism Outcome
CMHT	Community Mental Health Teams
CMO	Contect Mechanism Outcome
cRCT	cluster randomised controlled trial
DEMQOL	Dementia Quality Of Life Questionnaire
D-PACT	Dementia PersonAlised Care Team
DSW	dementia support worker
EID-Q	Engagement and Independence in Dementia Questionnaire
EQ-5D-5L	EuroQol-5 Dimensions, five-level version
ERG	Expert Reference Group
FTE	full-time equivalent
GP	general practitioner
HE	health economic(s)
IMD	Index of Multiple Deprivation
IPT	initial programme theory
mCWS	modified Carer Wellbeing and Support
MoCA	Montreal Cognitive Assessment
NW	Northwest
PERCCI	Person-centred Community Care Inventory
PRG	Peer Research Group
PSYCHLOPS	Psychological Outcome Profiles
PwD	people with dementia
QOF	Quality and Outcomes Framework
QoL	quality of life
REC	Research Ethics Committee
SIV	site initiation visit
SW	Southwest (England)
WP	work package

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Plain language summary

Support for people with dementia after diagnosis remains very limited and uneven nationally. The Dementia PersonAlised Care Team study examined how a dementia support worker based in general practitioner surgeries can best support people with dementia and their carers, and the value of such support.

In phase 1, we consulted people with dementia, carers and experts, and examined the literature. We developed a dementia support worker role and training package, and worked out how to recruit and collect data from people with dementia, who may have lost capacity. In phase 2, we recruited people with dementia and their carers from general practitioner practices in Southwest and Northwest England. Practices were in rural, coastal, urban areas, some with higher deprivation levels or South Asian communities. One hundred and twenty-six people with dementia and 121 carers from 13 general practitioner practices participated. Participants received 12 months' dementia support worker support. Multiple types of qualitative and quantitative data allowed us to examine value in different ways and how Dementia PersonAlised Care Team worked.

Eighty per cent of participants stayed engaged with the support. Qualitative data showed how positive outcomes were associated with dementia support worker actions in four areas: living well, proactive care, timely reactive care, and care transitions. Additionally, there was some evidence that dementia support workers help avoid expensive negative outcomes. How dementia support workers were supported was also crucial.

Quantitative data were hard to interpret due to low completion rates (22%) and a lack of controls. Only carers' feelings of support improved over time, while other measures remained unchanged or declined slightly. The cost to support a person with dementia and their carer was £1222 per year.

The study highlighted how positive outcomes are possible for many and how they came about. It demonstrated how the dementia support worker model can integrate with primary care to deliver support and provided guidance for organisations to start delivering dementia support worker care.

Scientific summary

Background

Dementia currently affects almost 1 million people in the UK. The condition has physical, psychological, social and economic impacts that extend to unpaid carers, who may experience the emotional, physical and financial strain of caring. Support for both is, therefore, important.

Unfortunately, post-diagnostic support remains inadequate globally and in England, or absent except for primary care. Many feel unsupported especially once beyond diagnosis and as the disease progresses.

When the Dementia PersonAlised Care Team (D-PACT) research programme launched in 2018, evidence on the effectiveness of dementia support roles – variously known as dementia support workers (DSWs), advisors or care navigators – was limited and varied in models. Nor was it known what counts as 'good' post-diagnostic support. Although recent studies have begun addressing these gaps, questions remain.

Aims and objectives

The D-PACT study was funded by the National Institute for Health and Care Research (NIHR; PGfAR RP-PG-0217-20004; 2018–24) to develop and evaluate a personalised post-diagnostic support intervention delivered by DSWs based in primary care. Intended for people with moderate to severe dementia – who often miss out on care – and their unpaid carers, the intervention also aimed to respond to calls for a lead health or social care professional to act as a single point of contact as well as recommendations for a task-shifted approach to dementia care where primary care's role is expanded. To achieve its aim, the programme carried out two phases of work.

Phase 1 had two work packages (WPs). WP1 aimed to develop and iteratively test the programme theory (an explanation of how the D-PACT intervention could have its intended effects). An 'intervention delivery platform', that is a manual, training and supervision guide, was also developed. WP2 tested the feasibility of a cluster randomised controlled trial (cRCT); it demonstrated that the intervention was acceptable but that a RCT design was not feasible for the phase 2 evaluation.

Phase 2 aimed to: (1) test and refine the D-PACT programme theory, (2) assess the intervention's value (importance, usefulness) and impact (effects, positive or negative) in a range of settings (rural, urban, coastal, high deprivation, South Asian communities) and (3) advance methodology for community-based dementia studies, focusing on inclusive recruitment and meaningful outcome measurement for individuals with variable capacity, building on phase 1.

Public and patient partners ['Peer Research Group' (PRG)] and a professional reference group ('Expert Reference Group') contributed to both phases.

Methods

Phase 1 (work package 1 and work package 2)

A realist-informed approach to theory building was employed in WP1. A prospective phase *developed* initial programme theories (IPTs) and the intervention delivery platform. We:

- consulted stakeholders comprising people with dementia (PwD), academics and practitioners
- conducted a pragmatic review of existing literature and existing primary care interventions
- identified key principles underpinning personalised care (to form domain headings for IPTs and ensure the intervention was guided by these principles).

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In the feasibility study:

- IPTs were *elaborated*.
- The prototype intervention was tested via a realist-informed formative process evaluation that took place in general practitioner (GP) practices in Southwest (SW) (Devon) and Northwest (NW) (Greater Manchester) England, allocated to intervention or treatment as usual at a ratio of 3 : 1.
- Theory and intervention were refined based on qualitative data (semistructured realist interviews and observations) with those receiving the intervention (PwD and their carers) and those providing the intervention (DSWs and their supervisors).
- In both the prospective and feasibility phase, an 'if-then' heuristic was used to guide theory development. However, as discussed later (*Phase 1: initial programme theory development*), a decision was made to switch to using a Context-(intervention) Component-Mechanism-Outcome heuristic to configure programme theories.

In WP2, trial methodology was developed by testing outcome measures, recruitment and eligibility criteria in recruited GP practices. Candidate primary [Dementia Quality Of Life Questionnaire (DEMQOL)] and secondary outcome measures [Psychological Outcome Profiles (PSYCHLOPS); Engagement and Independence in Dementia Questionnaire (EID-Q); modified Carer Wellbeing and Support (mCWS)] were selected on the basis of literature and consultation with the PRG. A pilot cRCT trial tested the feasibility of GP practice and participant eligibility criteria, recruitment, randomisation and retention.

Phase 2

We conducted a longitudinal mixed-methods realist evaluation, using high-volume qualitative data from multiple sources, quantitative outcome and experience measures and resource use data collected at regular time points over the intervention period.

People with a diagnosis of dementia and unpaid carers, as well as DSWs, their supervisors and staff from participating surgeries and the community were recruited. A minimum target of 90 (maximum 180) PwD and 80–160 carers (to account for PwD without carers) was set.

Qualitative data comprised: realist interviews with individuals, carers (at two time points – 3–4 months and 9–12 months) and DSWs, DSW case notes, reflective logs, researcher observations and extraction of electronic health records. Quantitative measures for PwD included were the EID-Q and the Person-centred Community Care Inventory (PERCCI); carer support and well-being were assessed using the mCWS. In addition to resource use and EuroQol-5 Dimensions, five-level version (EQ-5D-5L), timesheets that recorded time on all activities were completed by DSWs. Quantitative measures, resource use and EQ-5D-5L were recorded at baseline [time (T) 0], 4–6 months (T1) and 9–12 months (T2). Three analyses were conducted:

- Case study analysis of longitudinal high-volume multiple qualitative data.
- Statistical analysis of quantitative outcome and experience measures collected at three time points.
- An exploratory realist-informed economic analysis, combining conventional health economics (HE) tools, cost the delivery of the intervention with realist approaches to understand the impact of the DSW on relatively low frequency but high-cost events like unplanned hospital admissions, respectively.

Data were then integrated into a joint display matrix.

Results

Phase 1 work package 1

The D-PACT intervention, and related theory as to how it is intended to work and be supported, was the key output. DSWs, based in primary care, provide personalised and integrated support to PwD and their carers. Support in the D-PACT model is ongoing (i.e. people are not discharged); frequency and intensity depend on need. DSWs are trained to use a coaching-inspired approach to empower individuals in decisions about their health and care, as well as support

in a range of areas depending on what matters to the PwD and carer. This includes psychosocial well-being, physical health, future planning, practical help, signposting to support elsewhere and joint work with primary care staff. DSWs are supported in turn via supervision, peer support and refresher training.

Key learning from WP1 included:

- The intervention was highly acceptable to participants.
- The D-PACT model was more easily articulated as two tiers:
  - Delivery tier: theories explained how outcomes (e.g. engagement, shared understanding) were generated for PwD and carers within specific contexts.
  - Facilitation tier: theories explained how outcomes (e.g. readiness for the role) for the DSW were generated through training and supervision.
- Identified gaps in theory for phase 2, for example, theory relating to collaborative working within primary care, support with transition points, and how varying levels of readiness among participants affect outcomes and intervention delivery.
- Some outcomes may be observed only over time, after DSWs themselves had received sufficient ongoing support and developed confidence to deliver the intervention as intended.
- *Remote* delivery of the intervention, necessitated by COVID-19 lockdowns, could influence which mechanisms were triggered and needed to be addressed through training.

Phase 1 work package 2

Participant retention and measures:

- By 12 months, 60.7% (34/56) of participants with dementia and 35.7% (20/56) of carers were lost to follow-up. Completion rates across measures were also low at follow-up: 10.7% (27/56) for PSYCHLOPS, 23.2% (13/56) for EID-Q and 28.6% (16/56) for DEMQOL. Carer completion rate of the mCWS was 42.9% (24/56).
- The EID-Q was selected for phase 2 because it mapped most closely onto programme theory outcomes. A measure for experience of care, the PERCCI, was added. The mCWS was retained in phase 2. The Montreal Cognitive Assessment (MoCA) was included to measure cognitive status of participants with dementia at baseline.

Recruitment and eligibility

- A four-step approach to recruitment was developed (letters, phone call and visit) along with detailed procedures for consent with varied capacity, in person and remotely.
- Recruitment occurred during two active periods due to COVID-19: in-person (September 2019–March 2020) and remote (September 2020–March 2021). Ten out of 33 (30.3%) GP practices approached participated, with recruitment rates of 50% in the SW and 24% in the NW.
- Eligibility criteria for moderate to severe dementia were based on Addenbrooke's cognitive examination III (> 85) or the modified Telephone Interview of Cognitive Status (> 29). This criterion was removed in phase 2. Ultimately, 56 individuals (13% of 421 approached) with dementia and their carers were enrolled, meeting 50.9% of the recruitment target.

Phase 2

Recruitment, participants and retention

Seventy per cent of the recruitment target was achieved: 126 participants with dementia (14.7% of those approached) and 121 carers were recruited from 13 GP surgeries (6 in Southwest Devon and 7 in Greater Manchester). Sixty-one per cent of participants with dementia were female, 5% were South Asian. Mean age was 68 years [standard deviation (SD) = 13]. Severe cognitive impairment was indicated by a mean MoCA score of 4 (SD = 3). Intervention engagement remained strong at 79.3%. However, data completion rates were low: 53.9% of participants and 57% of carers contributed at T1, and 23% (both groups) at T2. Not all returned usable questionnaires, further reducing sample size to be analysed.

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Realist case study findings (qualitative)

This analysis revealed that DSWs delivered holistic and personalised support to both PwD (including those with other long-term conditions) and carers. A broad range of care and support needs were addressed. Achieved outcomes linked to DSW actions were seen across the four care domains, and included support to live well, improved physical and mental health, planning for the future and easing transitions in care. Mechanisms that led to ongoing disclosure, engagement and enactment of agreed actions (immediate outcomes) were triggered by early relationship-building by DSWs. These immediate outcomes created the context that facilitated DSWs' delivery of personalised care. In order for the intended outcomes from personalised care to be realised, people needed to feel more ready to take next steps towards increasing their independence, health and quality of life.

Challenges to achieving outcomes included limited community resources, insufficient buy-in from professionals and delays in accessing patient records. Some gaps were identified in the practitioner support package, such as vague role explanations, which sometimes delayed participants' engagement. Insufficient DSW hours for those on part-time contracts [0.4 full-time equivalent (FTE) or lower] also affected delivery for a small number of cases. Over time, DSWs developed professional autonomy through supervision, training and collaboration with other professionals, enabling them to adapt and personalise care more effectively. The findings highlighted the importance of refining the support package and promoting professional collaboration to ensure consistent delivery of personalised care.

Statistical analysis findings (quantitative measures)

Median scores for EID-Q, PERCCI and mCWS measures were reported across time points. Median EID-Q scores declined from 73 (51–90) at T0 (*N* = 97/126; 76.9%) to 60 (44–78) at T1 (*N* = 51; 40.5%), before rising slightly to 67 (37–79) at T2 (*N* = 28; 22.2%). PERCCI scores for care experience remained stable. mCWS well-being scores for carers showed little change but declined at T2, while mCWS support scores improved. Findings should be interpreted cautiously due to the non-randomised design and data limitations.

Health economics

Six DSWs, equivalent to 3.1 FTEs, delivered the intervention with 1446 direct participant contact events over 12 months, averaging 11.5 events per dyad/PwD. Mean contact duration was 45.47 minutes, though support varied greatly, with 15% receiving under 1 hour annually and 9% exceeding 15 hours. DSWs also performed related activities like liaising with GPs, training and updating files. On average, DSWs spent 31.3 hours on each dyad/individual per year. Assuming 44 working weeks per year and a 37.5-hour week, we estimate a full-time DSW could support an average of 52.7 dyads/individuals at any one time per year at an estimated cost of £1222.48.

An exploratory realist-informed economic analysis of qualitative data identified 24 cases where DSW actions (e.g. flagging an emerging infection, risk of falling or urgent need for medication review to the GP) helped mitigate high-cost events like unplanned hospital admissions. Access to GP records, ability to task GPs digitally and an ongoing relationship where trust/knowledge had been built with dyads were critical in achieving this outcome. Four instances of unprevented escalation highlighted challenges like stretched services, delayed DSW action due to uncertainty about solutions and dyads who were difficult to contact. These findings suggest DSWs may reduce high-cost inappropriate care in some cases, supporting the role of personalised, proactive intervention.

Discussion

Synthesis

Qualitative and quantitative (including HEs) findings were examined in a joint matrix display. This revealed some discrepancies between quantitative and qualitative findings. EID-Q scores declined, while qualitative interviews suggested improvements in social engagement, medication management and other care aspects. Similarly, PERCCI scores on experience of care remained relatively stable but did not reflect the enhanced care described in interviews. mCWS measures of well-being showed an initial increase then decline, but did not capture the subjective experience reported in qualitative interviews. Only the mCWS measure of perception of support, which increased over time, was consistent with qualitative data. Overall, despite increasing needs as indicated by the EQ-5D-5L, DSWs might have helped mitigate or delay deterioration.

Strengths

Dementia PersonAlised Care Team is the first study to conduct a realist evaluation using high-volume longitudinal data. This enabled case-by-case analyses assessment of the impact of the intervention. It also supported further elaboration of an evidence-based model detailing how to achieve personalised dementia care based in primary care. Other methodological contributions include innovations around GP practice recruitment that drew on embedded researcher models and digital capabilities in order to reduce administrative burden and encourage participation.

Limitations

The key limitation was the poor completion rates at follow-up and non-randomised design, making interpretation of quantitative analyses problematic. Despite concerted efforts to recruit GP practices in a range of settings, the participant group was not as diverse as we had hoped.

Conclusion

The D-PACT programme theory outlines personalised support strategies for PwD and their carers, demonstrating impact in living well, addressing health needs via proactive and timely reactive care, future planning, and care transitions. Its manual, support package and detailed evaluation serve as key resources for providing dementia support in primary care.

Study registration

This study is registered as ISRCTN90828574.

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Synopsis

Preamble

There are currently just under 1 million people living with a dementia diagnosis in the UK[1] and 55 million worldwide.[2] This number continues to grow; in the UK, it is estimated that by 2040 there will be 1.4 million with a diagnosis of dementia.[1] Dementia affects individuals physically, psychologically, socially and economically.[3] Its impact extends to family and friend carers (henceforth 'carers') who may experience lost wages, health and social care costs or emotional and physical strain.[4] Sometimes considered the 'invisible second patients',[5] carers account for 50% of total dementia-related costs.[6] Providing support to *both* the people with dementia (PwD) and their carer is therefore paramount.

When the Dementia PersonAlised Care Team (D-PACT) study began in late 2018, standards of dementia care and access to it varied greatly across the country, despite efforts following the Prime Minister's Challenge launched in 2012. Sadly, this situation persists: almost half (45%) of PwD in lower-income countries and 37% in high-income countries still lack support.[7] Post-diagnostic services in England and Wales are still insufficient,[8,9] fragmented and unco-ordinated.[10] There are cross- and within-regional differences in type and availability of services,[10] but also barriers[11] to, and inequalities[12] in, accessing available support. People feel unsupported especially once diagnosis is complete[13] and as the disease progresses.[11]

Lack of timely, appropriate and tailored post-diagnostic support can result in a poor quality of life (QoL), increasing demands on the health and social care system.[13] Knowing what is 'good' and 'appropriate', however, is a key step to providing it,[11] and at the time of D-PACT's inception, there was limited evidence on this.[14] There was also little clarity on what the role should entail. While various dementia support roles existed, for example, dementia support workers (DSWs), dementia advisors or dementia care navigators,[15] these adopted different models and were either non-clinical[15] or clinical.[16] Additionally, evidence on their effectiveness and cost-effectiveness was lacking, leading to uneven commissioning.

Despite emerging evidence from more recent studies,[11,15–24] many questions remain. Available evidence on the impact of dementia care navigators (or similar non-clinical roles) on PwD and their carers is limited and mixed.[15] It is similarly unclear how to ensure the support reaches those who need it most or who are 'left to cope alone',[13] help these individuals engage with proactive care, and stay well at home for longer.

Funded by the National Institute for Health and Care Research (NIHR), D-PACT developed (phase 1) and evaluated (phase 2) a model of post-diagnostic support based in primary care (2018–24). This support, delivered by a non-clinical DSW, is aimed at those with moderate to severe dementia and their carers. The former are often at risk of missing out on care because they are no longer receiving the brief support provided to newly diagnosed individuals, nor so advanced that they qualify for more intensive services provided by community mental health or palliative care teams. A training package for the DSW was developed, to enable the DSW to act as a single point of contact[25] and provide a range of support tailored to the PwD and carer's needs. Having DSWs integrated into primary care would maximise this setting's potential to address physical health care as well as social and emotional needs.[26] It also aligns with a task-shifted, task-shared approach, where primary and community-based post-diagnostic support is expanded so that secondary care can focus on diagnosis and managing complex cases.[27] The D-PACT team also worked through challenges associated with dementia studies like recruiting[28,29] and collecting meaningful data from people with moderate to severe dementia who may have lost capacity to consent to research and are often excluded from research.[30,31]

This report presents our findings, including what worked, for whom and in what circumstances. Phase 1 [and its two work packages (WPs); *Development of the Dementia PersonAlised Care Team theory and intervention (phase 1, work package 1)* and *Development of the Dementia PersonAlised Care Team trial methods (phase 1, work package 2)*] and phase 2 (see *Realist evaluation of Dementia PersonAlised Care Team (phase 2, work package 3)*) are described separately to support readability but are discussed together in *Discussion*. The worldwide interruption caused by COVID-19 during the programme's lifetime provided opportunities for learning that we also share.

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Research pathway diagram

Phase 1 (November 2018–October 2021) included a 6 months' pause triggered by the 2020 pandemic and first national lockdown. Phase 2 (November 2021–January 2024) coincided with two further lockdowns.

Phase 1: intervention development (work package 1) and trial methodology (work package 2)

Initial programme theories (IPTs), explaining how something should create a desired outcome, were developed and elaborated, alongside deciding on evaluation methods. Multiple sources of data and stakeholder engagement (*Box 1*) were used to develop the D-PACT intervention, which aimed to provide personalised, ongoing support for PwD and carers, provided by a DSW based in primary care.

BOX 1 Sources that informed the development of the D-PACT intervention

- Pragmatic review of literature and similar interventions[32] developed within the Community and Primary Care Research Group, University of Plymouth.
- Identified key principles underlying personalised care.
- Stakeholder (people with lived experience of dementia, academics and practitioners) engagement.[32]
- Qualitative data from participants allocated to intervention or treatment as usual at a 3 : 1 ratio.[1,32,33]

Trial methods were developed in parallel, involving:

- selection of outcome measures
- a feasibility trial to test general practitioner (GP) and participant recruitment procedures and eligibility criteria.

Phase 2: realist evaluation (work package 3)

A longitudinal mixed-methods realist evaluation tested and refined IPTs. A range of methods for recruitment, data collection and analysis were developed and implemented. High-volume (> 100 participants), multiple and rich sources of qualitative data and quantitative data were collected at specific time points, followed by a synthesis of mixed-methods data. Three separate analyses were applied: a realist case study analysis, a statistical analysis and a health economic (HE) analysis, including conventional HE and realist methods.

A Peer Research Group (PRG) and Expert Reference Group (ERG) provided input throughout both phases. The PRG comprised PwD and former or current carers, while professionals with relevant experience formed the ERG.

Alterations to the programme

Four workstreams were originally intended, that is, WP1 (intervention theory development) and WP2 (trial methods development) in phase 1, and WP3 [fully powered cluster randomised controlled trial (cRCT) with a HE component] and WP4 (implementation study observing DSWs operating outside the trial) in phase 2. Phase 1 took longer due to the COVID-19-related pause. COVID-19 also increased pressure on primary care, which added delays to recruitment progress. Phase 1 showed that a fully powered cRCT was not feasible. A change in phase 2's design was approved by the funder following the mid-programme checkpoint report. A mixed-methods realist approach, using a non-randomised before/after design, was chosen. This was considered the best approach after it was shown in phase 1 that it was too expensive to conduct a fully powered RCT within the funding envelope. Furthermore, the strict protocolised approach to recruitment and data collection required by a RCT was unsuitable for people with moderate to severe dementia. WP3 and WP4 were replaced with a longitudinal mixed-methods realist evaluation (new WP3, *Figure 1*). Four analyses were originally proposed for phase 2.[34] Three of the analyses are listed above; the fourth intended analysis was a conversation analysis (CA) of recorded interactions. However, this was not conducted because of the truncated phase 2 duration (2 years and 3 months instead of 3 years) and changes in experienced staff. Hannah Wheat (the CA lead) therefore had to focus on the main analysis. It has now been agreed the CA studies of the recorded DSW support meetings will be undertaken as part of Hannah Wheat's NIHR DEM-COMM fellowship.

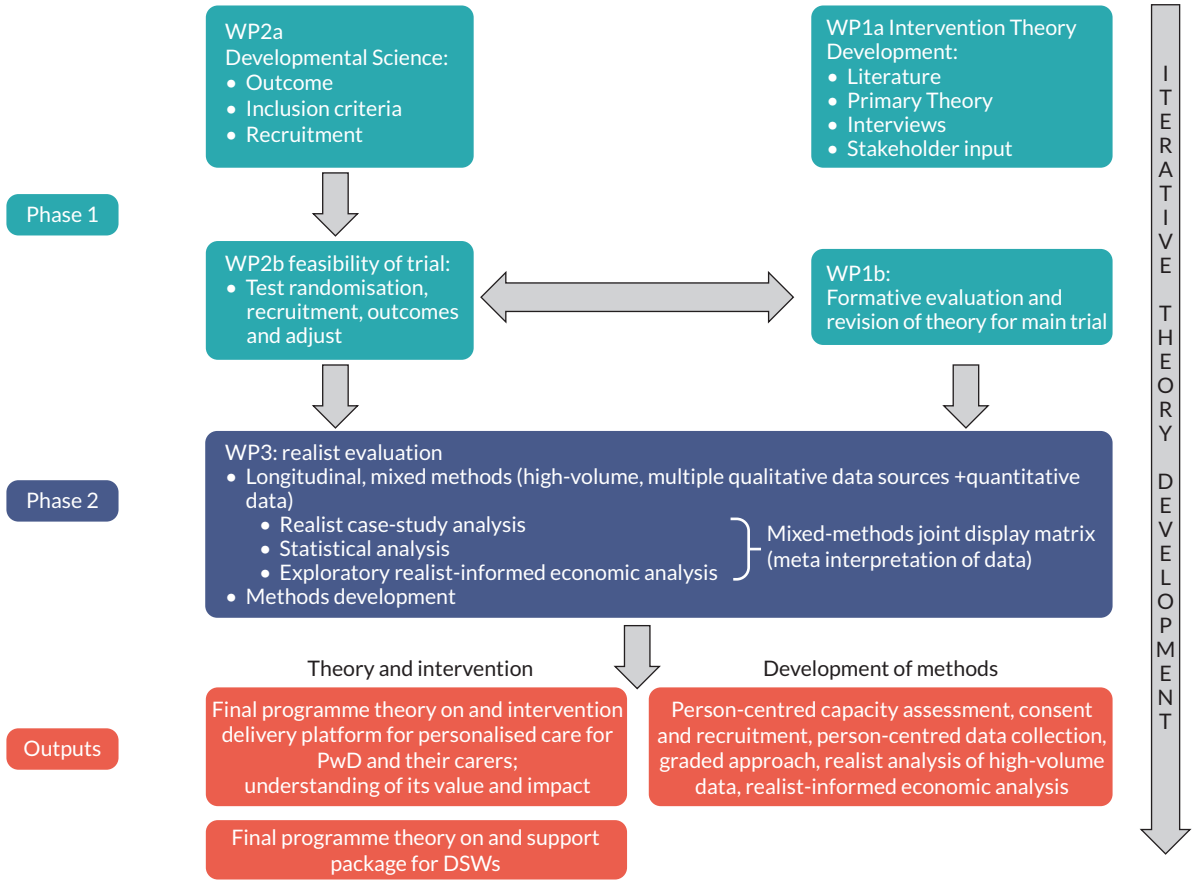

FIGURE 1 Amended D-PACT programme.

Development of the Dementia PersonAlised Care Team theory and intervention (phase 1, work package 1)

Intervention theory development, an explanation of how the D-PACT intervention could produce its intended effects, was central to the programme. Articles detailing the process of developing initial and elaborated programme theory have been published.[2,34–37]

Background

Realist evaluations start with the development of initial hypothetical theories (explanations) of how an existing or new intervention/programme may generate change (outcomes) for intended recipients.[38]

These IPTs can be presented as written statements and/or as a logic model. Theories are configured using a realist heuristic [Context–Mechanism–Outcome (CMO)] that ensures focus is placed not only on whether an intervention worked but also on how it worked, in which contexts and for whom.[38,39]

Through application of the CMO heuristic, IPTs consider:

- What changes in reasoning or behaviour (mechanism responses) the intervention (mechanism-resource) needs to trigger for outcomes to be realised, thus depicting possible causal links.
- How various contexts may influence how the intervention is delivered and to what extent outcome-generating mechanisms are triggered.[40,41]

These theories are iteratively elaborated, refined and consolidated through data collection and analysis during an evaluation. The design of the evaluation is informed by IPTs as it is essential that sufficient data are collected to enable

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the impact of various contexts to be studied and for all parts of causal chain depicted in IPTs to be observed.[40,41] Further stakeholder engagement and reviews of existing middle range theories can also contribute to theory development.

During phase 1, intervention development happened alongside its testing and evaluation. Consequently, the realist IPTs also provided a framework to inform the intervention design.

Methods

Phase 1: initial programme theory development

Box 1 summarises the principles and strands of work undertaken to develop programme IPTs.

Because designing the prototype intervention happened alongside IPT development, we used an 'if-then' formulation for IPT development, rather than the realist CMO heuristic.[42] The if–then configuration enabled us to focus specifically on what the intervention needed to do (the 'if –' or mechanism-resource) for a change to occur (the 'then –' or mechanism-response) for intended outcomes to be achieved. This more succinct configuration also supported stakeholder engagement better.

Broad contextual factors (e.g. stressful and traumatic diagnosis pathways, people living with dementia feeling overwhelmed by information and comorbidities making care needs more complex) affecting the lives of people living with dementia were also noted. These insights provided further rationale for the inclusion of specific intervention components within the D-PACT model. Contextual factors influencing delivery of, and responses to, the intervention, were not articulated in the IPT at this stage, but became a focus during subsequent evaluation (see *Feasibility phase: initial programme theory elaboration methods*). IPT development was tracked through analysis meeting notes and documents detailing the reasoning behind changes made to the IPTs.

Feasibility phase: initial programme theory elaboration methods

Initial programme theories were used to develop a prototype intervention model and a practitioner support package, which initially took the form of a practitioner manual and in-person training days. Band 4 staff from within the NHS were seconded from a range of settings (e.g. hospital wards, primary care) using bespoke job descriptions informed by IPTs, to receive the practitioner support package and take on the DSW role. Trained DSWs then delivered the prototype intervention to people living with dementia and carers (if available) recruited from GP surgeries GP surgery selection was informed by a desire to observe how various contexts may influence intervention delivery and responses to the intervention.

Prototype intervention delivery and data collection occurred during the COVID-19 lockdown periods. The research team rapidly adapted the intervention and recruitment/data collection processes. Consequently, the feasibility phase was also able to study the impact of various pandemic-related contextual factors on the intervention delivery/response.[43]

A range of qualitative data were collected and analysed for theory elaboration and refinement. This work was complemented by further stakeholder engagement (lay and professional) and additional existing evidence-informed theories.

We used IPTs to develop a coding framework to map data to existing theory and examine whether data insights challenged, corroborated or suggested refinements/expansion to existing theory. The framework also enabled new theory to be captured. While the 'if-then' format was maintained within the coding framework, contextual insights were also coded and considered when IPTs were elaborated.

Results: how feasibility work informed next steps for theory development

The analysis identified further aspects of care the intervention could provide to achieve important outcomes. For example, support with transition points in care (e.g. into care homes, hospital admission/discharge, care from another team e.g. safeguarding) was built into the programme theory.

The IPT proposed that DSWs gave PwD and carers the opportunity to take a lead in identifying ideas for required support. However, feasibility findings suggested this was often not an option that people living with dementia could, or wanted, to take. It was clear that further theory needed to unpack how various stages of readiness in the people supported (influenced by various factors, e.g. their current emotional state, level of information about what support was available) needed to be considered during intervention delivery.

A decision was made to split the elaborated theory into two tiers. Theories in tier one (the delivery tier) provided an explanation of how change (outcomes) would be generated for PwD and carers, through their responses to the intervention, when delivered in certain contexts. Tier two (facilitation) theories provided an explanation of how the practitioner support package would generate change in how DSWs delivered the intervention through their responses to the support offers, in certain contexts.

This process resulted in multiple theories (37 in the delivery tier, 48 in the facilitation tier). Theories were grouped based on the types of immediate changes (outcomes) we hoped would be achieved, for example, engagement and disclosure and shared understanding (delivery tier) and readiness to deliver the DSW role (facilitation tier).

This comprehensive elaborated theory was used to design the practitioner support package. To do this, we cross-checked whether the manual and training days covered the breadth of practitioner actions (mechanism-resources) within the elaborated theory. Adaptations included new support offers, for example, an online training course, and further guidance for supervisors as well as DSWs.

Preparations were also made for the phase 2 evaluation. Insights into how various contextual factors could influence the delivery of support by DSWs and how people responded to it was limited in the elaborated theory (provisional or hypothetical) due to limited diversity (e.g. ethnicity, socioeconomic background) in feasibility participants. To develop these contextual insights, programme theories were reconfigured, using a Context-Component-Mechanism-Outcome (CCMO) heuristic to enable focus on specific intervention components, simplify coding of mechanisms and provide an expanded set of causal explanations of how responses to the D-PACT intervention generated change. Outcomes were split into immediate (proximal) and medium-long-term (distal) types. A more detailed explanation for our heuristic choice has been published.[34]

Dementia support workers' and researchers' limited engagement with GP surgeries during the feasibility study resulted in gaps in theory relating to collaborative working within primary care. We, therefore, made data collection and theory development on this aspect of the model a priority for phase 2.

Development of the Dementia PersonAlised Care Team trial methods (phase 1, work package 2)

This work is published,[30,32,35,36] or in preparation.

Recruiting PwD from primary care into trials is known to be challenging.[28] Apart from barriers related to the condition (e.g. progressive decline), those related to the nature of the research exist.[44] Less than one-third of primary care-based studies reach their recruitment targets.[28,45] Furthermore, certain groups may not be coded for dementia in primary care records. Low retention is reported to affect 2/3 of Alzheimer's disease trials,[46] with those with a longer follow-up period possibly being affected more.[47]

There is also a question of what outcome measures should be used in evaluations of non-pharmacological interventions. In a systematic review of outcome measurement instruments used in dementia research, none of the 346 identified instruments had sufficient face validity for the 13 core outcomes previously identified to matter to PwD living at home.[48,49]

Work package 2, therefore, examined: outcomes selection and acceptability to participants, development and testing of a person-centred recruitment strategy and eligibility criteria.

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Methods

Selection of outcomes

Initial candidate measures were selected based on an iterative analysis of relevant literature, examination of psychometric properties of potential measures, PRG consultation and comparison with the emerging intervention theory. Identified key domains were psychosocial well-being, receipt of physical care and social functioning. The Dementia Quality Of Life Questionnaire (DEMQOL)[50] and Bristol Activities of Daily Living Scale[51] were identified as potential primary outcomes.

Candidates for secondary outcomes included: Neuropsychiatric Inventory,[52] Engagement and Independence in Dementia Questionnaire (EID-Q),[53] Psychological Outcome Profiles (PSYCHLOPS),[54] and modified Carer Wellbeing and Support (mCWS)[55] for carers. The Clinical Dementia Rating,[56] completed by the researcher, was included as a measure of dementia severity to enable description of the cohort rather than as an outcome. HE measures included the EuroQol-5 Dimensions, five-level version (EQ-5D-5L)[57] and the Resource Utilisation in Dementia.[58] GP electronic health records were to be analysed for instances where physical health care was received (the analysis of GP records expanded beyond this in the amended phase 2).

General practitioner practice recruitment

Practices in Southwest (SW) and Northwest (NW) England were approached until the target of four practices in each region was reached. Initial approach was followed by further information and a visit with practice representatives. The first recruited practice in each region was allocated to the intervention to enable early learning about the DSW role within primary care and iteratively inform the participant recruitment process. The remaining three practices in each region were randomly allocated to intervention or treatment as usual, at a ratio of 2 : 1. The recruiting team was blinded to the allocation of these remaining practices.

Participant recruitment

Dementia PersonAlised Care Team aimed to include people with moderate to severe dementia, some of whom may have lost capacity to consent to research.[30] A process for researchers to assess capacity for consent was developed and built into the recruitment strategy.[35] Consideration of the study protocol by a NHS Research Ethics Committee (REC) resulted in a decision to not allow the recruitment of people without capacity. This clearly would have limited the usefulness of the feasibility study and data. The team, therefore, resubmitted the application for review by a different REC, who agreed that approaching and recruiting PwD without capacity was ethical and appropriate for this study.

Patients with a pre-defined SNOMED-CT (Systematised Nomenclature of Medicine Clinical Terms) code for dementia were identified from GP records. Inclusion criteria were developed to include those not already receiving substantial support, who would likely benefit from the intervention.

Patients were excluded if they were or had:

- resident outside the local authority boundary to be served
- currently undergoing emergency treatment or care
- within a care home setting
- receiving substantial support from Community Mental Health Teams (CMHT), defined as input within the last 4 months and not due to be discharged within the next 2 months
- presenting as high risk and, after referral, were taken on by CMHT
- open safeguarding referrals and ongoing planned CMHT care
- a long-standing history of mental health difficulties and were currently receiving care from other mental health teams
- diagnosed with an end-stage physical health problem (e.g. cancer, severe heart failure) with substantive multidisciplinary palliative care.

In phase 1, consented participants also needed to score > 85 on the Addenbrooke's cognitive examination III[59] (when recruitment was in person), or > 29 on the modified Telephone Interview of Cognitive Status[60] (when recruitment

became remote). Only two people were excluded based on this criterion, but it was clear that both had unmet needs that may have benefited from DSW support. This criterion was removed in phase 2 (evaluation).

Eligible patients were approached according to our study-specific recruitment pathway[35] (*Figure 2*). This comprised four successive approaches, with each subsequent approach applied to those who had not responded in the previous approach. Positive responders to any approach were contacted by a trained researcher and went on to be consented if they agreed. Contact ceased for those declining. The first two approaches were by letter from their GP surgery, the third a phone call checking on the welfare of the person before offering the opportunity to learn more about the study, if appropriate. The fourth and final planned approach to any remaining non-responders was a home welfare visit to ensure that a non-response was not an indication of unmet needs. Care was taken at every stage to avoid inadvertently asserting pressure on patients. This recruitment pathway was amended for remote working during the COVID-19 pandemic.[32,61]

The phase 1 objective was to achieve a 30% recruitment rate and a total of 110 recruited participants with dementia. Proportion recruited from patients approached, before and during COVID-19, as well as outcome measure completion were calculated. Brief qualitative interviews with a subset of willing participants on the consent and baseline process, respectively, were conducted.

Results

General practitioner practice recruitment

Practice recruitment began in August 2019, reaching the target of four practices per region by January 2020 (pre-COVID lockdown). Thirteen practices were approached (n = 8 in the SW, n = 5 in the NW). Practice recruitment rates were 50% (n = 4) in the SW and 80% (n = 4) in the NW, with an overall rate of 61.5%.

Participant approach and consent were ongoing when all clinical trials were paused temporarily in March 2020; the first national lockdown followed shortly. Our study was allowed to resume in September 2020. However, access issues to staff teams and lists of patients to be approached arose in one SW and two NW practices; these practices subsequently

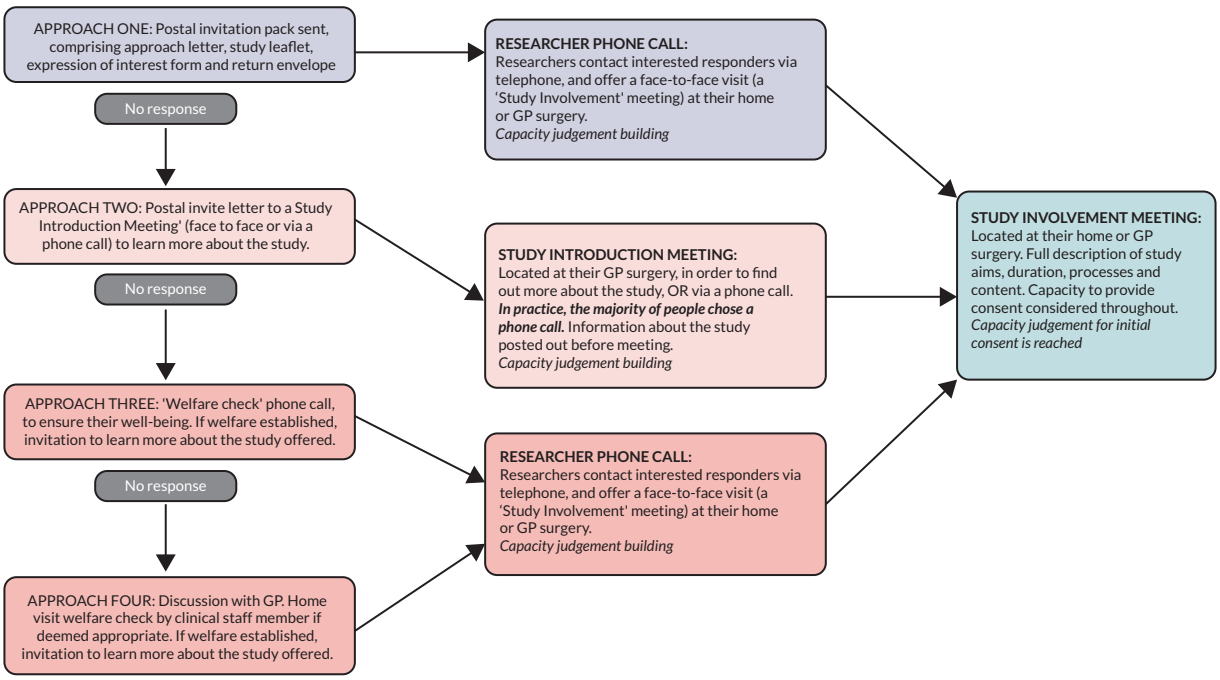

FIGURE 2 Four-stage recruitment pathway. Reproduced with permission from Griffiths *et al.*[35] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The figure includes minor additions and formatting changes to the original text.

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withdrew from the study. The SW practice was not replaced because there were enough patients with a dementia code to approach in the remaining SW practices. Two additional NW practices were recruited in October 2020 but withdrew before participant recruitment began, citing COVID-19 research and lockdown two (November 2020) as contributing factors. Two further NW practices were recruited in December 2020, both allocated to the intervention. Recruitment rate was 20% (4/20 practices approached) in this second GP recruitment round in the NW, contrasting with the previous 80%. Overall, GP recruitment rate across both recruitment periods was 36% (10/33).

Compared to the NW, GP practices in the SW were generally larger, with a slightly higher proportion of dementia patients. Median Index of Multiple Deprivation (IMD) decile was 4.5 (4.0–5.8) for the four SW practices and 5.5 (1.5–8.8) for the six NW practices (based on practice postcodes). IMD ranges (https://imd-by-postcode.opendatacommunities.org/imd/2019) from 1 to 10 (1 being bottom 10%). The wider range among NW practices indicates more diversity in terms of IMD.

Researchers remained blind to allocation until at least post-baseline data collection; unblinding often occurred at follow-up based on participant responses. This became less of a problem because of the change from a cRCT design to a before/after realist evaluation phase 2.

Participant recruitment

Seven hundred and ninety-nine patients with a SNOMED-CT code for dementia were identified from records, out of which 507 met initial inclusion criteria. After further exclusions, 421 patients were approached, of whom 56 (13.3%) were enrolled, along with their carers. Just over half (50.9%) of the recruitment target was achieved. Yield at approaches 1, 2 and 3 (combined with approach 4) is shown in *Figure 3*. Approach 4 (home welfare visit) was undertaken at only one SW GP practice because this was the only practice to have reached approach 4 when the first COVID lockdown was enforced; one participant was recruited from the three who received approach 4. Approach 4 (in-person) did not happen during COVID-19.

Part of phase 1 recruitment took place before the COVID pandemic (in-person; September 2019–March 2020) and during (remote; September 2020–March 2021). We compared recruitment data during both recruitment periods. Twenty-two PwD were consented in person out of 223 approached (9.9%). In comparison, 34 participants were consented remotely. Nineteen of those consented remotely were approached during the remote recruitment phase, while 15 had been approached prior to the first lockdown but consented remotely once recruitment resumed. Remote recruitment rate was 9.6% out of those approached remotely (19/198). Qualitative interviews with a subset of participants about remote recruitment procedures (N = 13) suggest that these were acceptable to participants. The conclusion that remote recruitment did not impact negatively on recruitment rate led us to offer both options to participants in phase 2 of the study.[32]

Thirty-four (60.7%) PwD and 20 carers (35.7%) were lost to follow-up by 12 months. The most frequent reasons among PwD were: death (n = 8), 'unable to contact' (n = 7), becoming ineligible by moving into a care home, and so on (n = 7), measures being 'too much' or the person feeling too anxious (n = 5).

Outcomes

Full results on outcomes are published by Musicha *et al.*[36]

We found low completion rates for outcome measures. For example, completion rate for PSYCHLOPS and EID-Q (follow-up) was 10.7% (6/56) and 23.2% (13/56), respectively. Questionnaire scoring contributed to low completion rates. For example, in the PSYCHLOPS, participants were asked about two problems, but if they reported only one problem or no problems, a total score was not calculable and was therefore reported as missing. Researchers also reported that some questions were difficult to ask, for example, bereavement made some researchers uncomfortable about asking CWS questions related to the carer's role, particularly as they referred to a specific time frame. Participants also struggled to complete HE questionnaires.

Qualitative interviews with participants and carers (n = 19) about collection of baseline measures revealed that they did not find personal questions intrusive. Some participants with dementia reported that questions were 'fairly easy' or

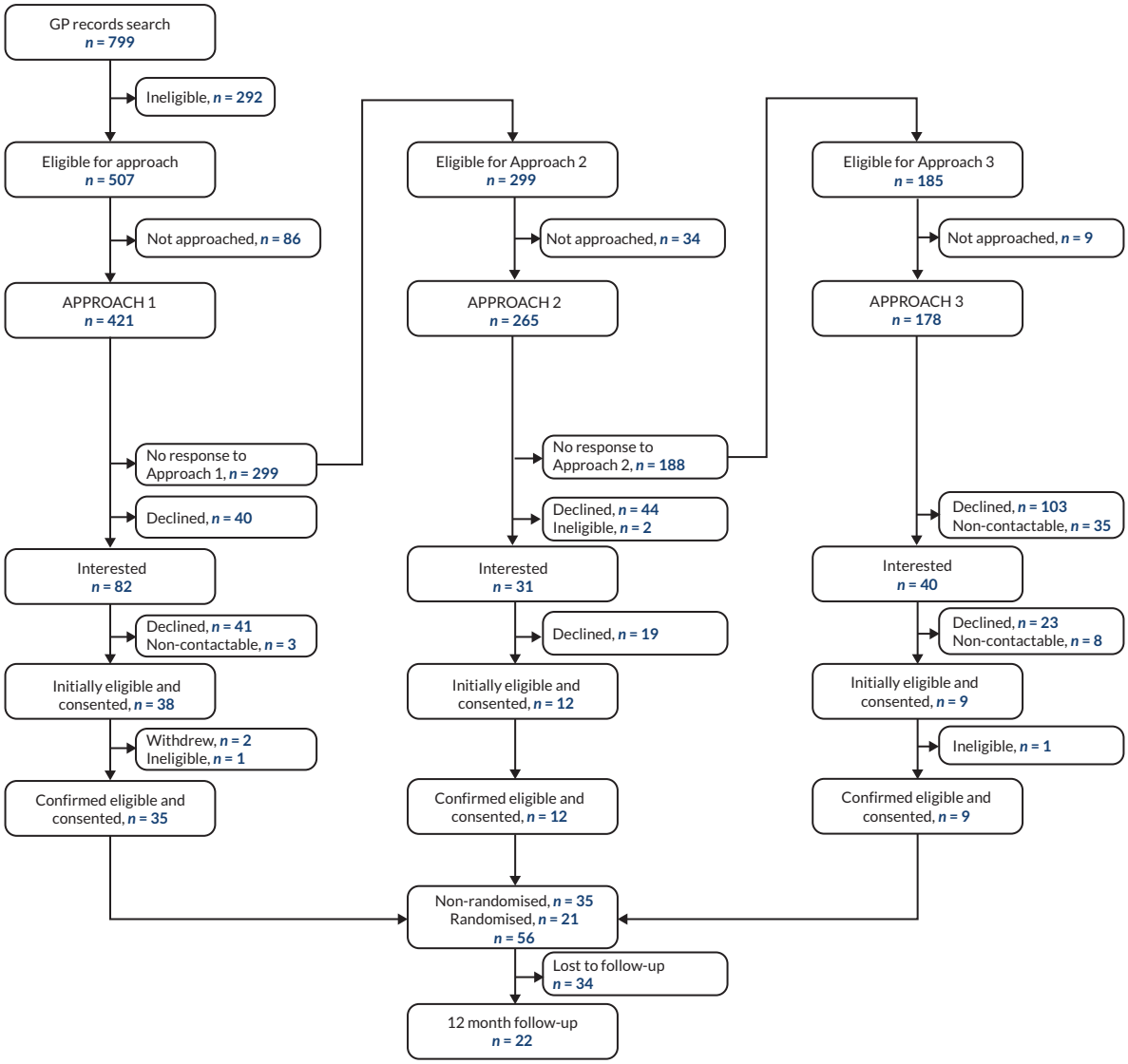

FIGURE 3 Consolidated Standards of Reporting Trial (CONSORT) figure. Reproduced with permission from Oh *et al.*[32] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The figure includes minor additions and formatting changes to the original text.

'fine', although one worried about getting the answers right. Critical feedback tended to be related to: concentration levels (in some participants with dementia) being hard to maintain if measures were too long; the wording and response options used to answer questions being too lengthy in some measures; and the perceived applicability of items within the measures (e.g. time taken to complete caring tasks questions – irrelevant and difficult to quantify).

Phase 1 learning influenced phase 2 in several ways. Firstly, we ensured researchers were better prepared for these challenges, asked them to document their experiences while administering the measures and introduced regular team debriefs. Next, we reduced the number of questionnaires, thereby reducing participant burden. Outcome selection was partly informed by a mapping exercise, which showed the DEMQOL and EID-Q corresponded to our D-PACT intended outcomes (based on our theory building) moderately well, particularly in combination with the mCWS. Resource use questions tapped into intended outcomes not covered by the three. We selected the EID-Q partly because DEMQOL use is problematic when working with a mix of participants with and without capacity to consent: domains for the DEMQOL-Proxy questionnaire differ from DEMQOL, meaning we would have had to rely on proxy responses even for participants with capacity. The EID-Q not only mapped onto many of D-PACT's intended outcomes; it was also

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identified as the measure that best covered the 13 core outcomes previously reported to be those that mattered to PwD living at home.[48] The EID-Q does not have a proxy version, but we worked with the measure developer to create detailed instructions on how to use the EID-Q in a proxy situation, drawing on our experience in administering proxy questionnaires in a person-centred manner and taking a staged (graded) approach. A few intended outcomes were covered less well or not at all, for example, 'good death'. To remedy this, additional questions were piloted alongside and in the same format as the EID-Q in phase 2. We also included a patient-reported experience measure (PREM). The Person-centred Community Care Inventory (PERCCI)[62] was selected after consultation with our PRG group, the mapping exercise and testing two candidate PREMs on volunteers. The mCWS was retained as a measure of well-being and support for carers, along with resource use questions. Finally, the high rates of non-completion underlined the importance of having other sources of (qualitative) data to enable triangulation.

Summary

Phase 1 demonstrated that while the intervention and recruitment strategy were acceptable to participants, recruitment and retention performance indicated the need for a substantial and costly extension in order to progress to the definitive cRCT. The NIHR funder's mid-programme review concluded that a full-scale cRCT trial was not viable due to the difficulties and projected high cost of recruitment in primary care. Instead, a longitudinal non-randomised mixed-methods realist study design was approved. Additionally, we were encouraged to increase efforts to include underserved groups to gain further learning on issues related to inclusion, access and delivering support.

To counter some of the challenges faced during phase 1, we introduced a range of measures for phase 2: a more streamlined GP recruitment process, the offer of in-person or remote consent and data collection, a focus on high-volume qualitative data collected longitudinally and a much smaller number of quantitative measures, collected in a person-centred way and with the intention to maximise opportunities to maintain/capture the PwD's voice [e.g. the graded approach, allowing carers and researchers to support those with reduced capacity to respond; see *Realist evaluation of Dementia PersonAlised Care Team (phase 2, work package 3)*]. We also introduced a midpoint follow-up in the hope of achieving better completion rates with questionnaires. Due to anticipated limitations related to a lack of randomisation, we introduced a priori predictions on the expected direction of change in each measure [see *Realist evaluation of Dementia PersonAlised Care Team (phase 2, work package 3)*].

Realist evaluation of Dementia PersonAlised Care Team (phase 2, work package 3)

The protocol and reports have been published.[34,63,64] Key papers in preparation are cited as supplementary material (*Report Supplementary Materials 1–3*) and In preparation where relevant.

The specific aims of phase 2 were to (1) test and further refine the D-PACT programme theory in a range of settings that included rural (SW), urban (NW) and coastal areas (SW), some with high socioeconomic deprivation and some with a higher representation of South Asian communities; (2) examine the potential value and impact of the intervention; and (3) contribute to methodological development of community-based dementia studies.

Methods

Design

A longitudinal mixed-methods non-randomised design was employed.[34] All consented participants received the intervention for 12 months. Qualitative data, quantitative outcome and experience measures, as well as resource use data, were collected regularly during the intervention. Due to delayed recruitment in the NW, the data collection period ended before most NW participants had reached the second follow-up at 9–12 months. A realist case study analysis, statistical analysis and realist-informed economic analysis were conducted. Mixed-methods findings were then synthesised in a joint display matrix to gain further insights and identify areas for future research.

General practitioner practice recruitment

Researchers, working with their local (then) Clinical Research Networks (CRNs), identified GP practices within primary care networks in the settings of interest. Estimated size of registered dementia population,[65] deprivation score and level

of research activeness were considered. The latter was not a criterion for inclusion but used to tailor communication. GP practices were contacted electronically with an invitation letter, followed by a telephone call from a researcher in the SW and NW, respectively. A brief online meeting to address questions was offered to practices interested to take part, attended by a nominated GP and practice manager. Some practices chose to proceed directly to set up meetings, which could be two shorter meetings or a longer one depending on preference. An information pack, sent before the meeting, contained: further details on D-PACT, including how DSWs would work within the practice, the four-stage recruitment pathway, the two recruitment phases (see *Participants*), and the embedded researcher model designed to minimise the practice's administrative load. We found in phase 1 that delays in setting practices up for recruitment were partly due to practices not fully understanding D-PACT's approach to recruitment. This induction was crucial to help practices understand this and reassure that all processes (including data handling) were secure and adhered to Health Research Authority and CRN guidance. Induction, attended by the practice manager and information technology lead, introduced the study and intervention briefly, what to expect, patient approach and instructions to set up permissions around data access. A support pack was provided, containing templates of relevant agreements (e.g. honorary contracts) and helpful information (payment schedules, recruitment pathway, brief explanations of data flow and measures to protect data). A secure Microsoft Teams (Microsoft Corporation, Redmond, WA, USA) channel set up by each practice, honorary contracts and confidentiality agreements facilitated the researcher, working as an extended primary care team member, to support with screening and approach. Once all processes and documentation were in place, a 30-minute virtual site initiation visit (SIV) was held, covering aspects such as safety monitoring, audit processes and confirmation all set-up processes were completed. Participant recruitment commenced following the local trust confirming the practice's capacity and capability to begin.

Participants

Participants with dementia, with or without a carer, who met study criteria [see *Development of the Dementia PersonAlised Care Team trial methods (phase 1, work package 2)*] were eligible for this study. Carers of recruited participants were eligible and could be a partner/spouse, family member or friend.

Dementia support workers and their supervisors, staff from participating surgeries and the community were also participants.

All patients and practitioners/professionals were taken through an informed consent process.

The minimum recruitment target was 90 participants with dementia (maximum 180) and 80 carers (maximum 160) across both sites. Rather than a formal power calculation, the minimum target was based on an estimation of the number to ensure rigour in this realist mixed-methods evaluation,[40] account for attrition and fulfil requirements around a caseload of 45–55 patients per DSW.

Potential participants were offered in-person or remote consent. In phase 2, another route to recruitment, termed 'responsive recruitment', was added to increase patient chances to participate. The responsive phase took place after the final approach in proactive recruitment was completed. Potential participants could approach the research team directly or be 'referred' by a member of the patient's care team. Those who could potentially be recruited this way included: (1) patients who had previously declined or remained uncontactable during the four approaches in the proactive recruitment phase, (2) those referred by GPs or colleagues in secondary or social care (e.g. community mental health team; memory services; adult social care) to the study (Oh *et al.*, In preparation).

Data collection

Detailed accounts of data collection are reported elsewhere.[33,34]

Qualitative realist interviews focus on theory refinement, through causal process-oriented questions, rather than experiences/perceptions of a specific phenomenon taken in other qualitative approaches.[40] These were conducted with participants with dementia and carer dyads or participants with dementia without a carer at 3–4 months and 9–12 months after the intervention started. DSW (two time points) and other practitioner interviews were also held. DSWs maintained case notes and reflective logs. Other qualitative data included researcher observations, recordings of DSW-participant and DSW-supervisor sessions and electronic health records (*Tables 1* and *2*).

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TABLE 1 Data analysed for the delivery tier

Type of data	Amount of data collected	
Realist interviews with PwD and unpaid carers	T1: 82 interviews	T2: 30 interviews (24 participants gave both T1 and T2 interviews)
Realist interviews with DSWs	T1: *n* = 7	T2: *n* = 6
Recordings of support meetings	34 collected from 18 cases	
Patient medical records	103 records (covering intervention period of up to 12 months)	
DSW case notes	Varied number completed for 125 cases during intervention delivery	
DSW time sheets	Completed for 125 cases during intervention delivery	

TABLE 2 Data analysed for the facilitation tier

Type of data	Amount of data collected	
Realist interviews with DSWs and supervisors	T1 Seven DSWs, five supervisors	T2 Six DSWs,[a] four supervisors[b]
Realist interviews with other practitioners	Two practitioners (admiral nurse and a carer support worker in the SW)	
Video stimulated recall (VSR) interviews	Three DSWs and two Supervisors (SW and NW)	
Exit interviews	12 in total from 4 DSWs (from SW and NW)	
Recordings of supervision sessions	14 (collected from 5 supervisors and 7 DSWs)	
Observation notes of supervisors' support sessions (meta supervision)	*n* = 7	
Field notes from observing DSWs in practice	*n* = 16, collected from 7 DSWs at different time points	
Reflections	*n* = 25, collected from 4 DSWs and one supervisor (SW and NW) at different time points.	
Researcher notes on meetings with DSWs	*n* = 18, collected from 7 DSWs at different time points.	
Feedback sessions with DSWs and supervisors	One with DSWs from all sites and one with supervisors from all sites	One with DSWs from all sites
Feedback sessions with GP surgeries		18 in total

a Due to one DSW in the SW leaving for maternity leave and another reducing their hours due to new training commitments for other role, two new DSWs were employed to cover these hours, making the total number of DSWs who took part in the study seven.
b Two supervisors left the role during the study for new roles, resulting in two new supervisors; total number of supervisors who took part was five.

Quantitative measures, collected at baseline [time (T) 0], 4–6 months (T1) and 9–12 months (T2), comprised:

- positive outcomes (engagement and independence) for the PwD, (EID-Q)[53]
- experience of care by the PwD (PERCCI)[62]
- carer well-being and support (modified CWS)[55]
- resource use questions, using an adapted version of the Client Service Receipt Inventory[66] and health-related quality of life (EQ-5D-5L).[67]

Additionally, DSWs completed timesheets recording all activities and duration.

A 'graded' approach to collecting measures from participants with dementia was tested. Responses from participants with dementia who were able to respond to questions with some support were recorded. This approach enabled more

participants with dementia to take part, resulting in three levels of response (recorded on case report forms): fully self-reported, self-reported with support, and responses by proxy (usually the carer).

Intervention

The D-PACT model provides ongoing, flexible, personalised and integrated support for PwD and their carers, if available. Support is delivered by trained DSWs, already experienced in dementia care, embedded in primary care and supported by colleagues in primary/secondary care. Frequency and medium of meetings are driven by the PwD and cover a range of needs, depending on what matters to the PwD and carer: psychosocial well-being, physical health, future planning, practical help or signposting. Care is both responsive and proactive. DSWs take a coaching-inspired approach, supporting the person/dyad to make decisions regarding their health and care. Although the support is designed to be ongoing, for this study all consented participants were offered the intervention for 12 months.[34]

Analyses

The protocol paper describes planned analyses.[34]

Realist case study analysis

Delivery tier: to refine understanding of if, how, when, and for whom intervention components trigger mechanisms and outcomes for PwD and carers.[34]

The analysis aimed to achieve three interconnected objectives:

- Describe how D-PACT was delivered in practice during phase 2, including whether significant deviations for the intended model occurred.
- Describe the impact of the intervention, including any outcomes established as important for PwD care (improved QoL, health and independence).
- Further refine and consolidate D-PACT programme theory.

The results address these objectives together rather than separately (see *Baseline characteristics*).

Within this high-volume, longitudinal study, the unit of analysis was all individuals with dementia or dementia–carer dyads that took part in the evaluation. The elaborated programme theory from phase 1 guided qualitative data coding in NVivo (version 12) (QSR International, Warrington, UK); *Table 1*.

Phase 2 continued development of *if–then* theories while also examining when and for whom changes occurred at both individual and aggregate levels. To achieve this, data coded to the programme theory were organised chronologically for individual cases. Due to NVivo's limitations (e.g. handling high-volume cases and chronological data review), Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA) was used.

Excel rows containing data relating to the same event were consolidated to complete as much of each CCMO as possible; evidence strength was also reviewed according to pre-set criteria. Analysts then reviewed what happened within cases and across aggregated cases – enabling identification of demi-regularities across cases.

Context–Component–Mechanism–Outcomes were then grouped by type of care (*living well support*, *enhanced reactive care*, *proactive care and transitions in care*). In addition, a subgroup of CCMOs, where the outcome was unintended, was created. This enabled exploration of how specific contexts influenced intervention delivery and response at both case and cohort levels. The analysts continuously cross-checked the initial spreadsheet and raw data to resolve inconsistencies and fill gaps. Analysts met regularly to review coding accuracy, resolve uncertainties and assess whether mapped data corroborated, challenged or extended existing programme theories.

During these discussions and individual analysis, CCMO chains were created showing that relationship-building CCMOs often led to personalised care, which improved QoL, health, well-being and independence (i.e. through extended 'ripple effects' relationship-building became the new context for personalised care[68]). As this sequential process was not captured in the initial existing programme theories or the logic model, the Excel structure was adjusted to support

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mapping of linked rather than isolated CCMOs. The identification of care domains (support with living well, enhanced reactive care, proactive care and support with care transitions) that effectively grouped evidenced outcomes and DSW practices was also established during these meetings.

Facilitation tier: to refine understanding of if, how, when, and for whom support offers trigger mechanisms and outcomes for DSWs – enhancing the delivery of the D-PACT intervention.[34]

This analysis was conducted to refine the programme theory explaining how the practitioner support package led to changes for DSWs that supported the delivery of the D-PACT intervention (see also *Table 2*).

Statistical analysis

Analysis details appear in Musicha *et al.*[64]

Proportion of participants recruited from those approached were recorded, and demographics summarised. To understand the impact of the graded approach to data collection, an independent samples *t*-test was performed to compare independent completers, completers with some support, and proxy responses.

Given the before/after design, quantitative analyses were exploratory. Analyses involving the EID-Q and mCWS were based on data where mean imputation had been performed to replace missing values where appropriate. Analyses of the PERCCI were based on latent scores derived from fitting the Rasch/partial credit model[69,70] to data from all PwD who had responded to at least one of the 12 items.[64]

Participant performance on outcome and experience measures was assessed at each time point using descriptive statistics {numbers [percentages], means [standard deviations (SDs)] and medians [interquartile ranges (IQR)] as appropriate}. Median (IQR) change in score, for participants who had data at more than one time point, was also analysed. STATA (Release 19: StataCorp LP, College Station, TX, USA) and R (The R Foundation for Statistical Computing, Vienna, Austria) software were used to analyse outcome/experience measures data.

Median change in scores were compared to 'a-priori predictions'. These were predictions declared a priori about the expected direction in score trajectory for the EID-Q, PERCCI and mCWS, respectively; this was to support interpretation given lack of a randomised control group. Predictions with and without an intervention were informed by published studies.[71–79]

Health economic analyses

The first substudy examined cost of intervention delivery and resource use. Conventional HE analyses were applied to resource use and DSW timesheet data.[63] The second substudy examined[34] the impact of a DSW on relatively low frequency but high-cost health and social care utilisation events like moves to hospital or care home[34] using an exploratory realist-informed mixed-methods economic analysis[80–82] to test a cost-sensitive IPT that personalised, continuous and proactive care delivered by the DSW (planned low-level care) may reduce high-level care (unplanned and expensive). We were particularly interested in unplanned or unwanted changes in care (e.g. acute admissions, safeguarding or nursing home care). These are high cost and can distort traditional cost-effectiveness analyses, providing a rationale for this supplementary substudy. Qualitative data coded to an 'averted crisis' node were reviewed by two independent researchers for evidence of when a crisis was averted or not. Only examples with unanimous agreement were analysed.

Results

General practitioner practice recruitment

General practitioner practice approaches began in October 2021. Six practices in the SW were enrolled into the study between December 2021 and August 2022. Although approaches in the NW began in October 2021, the seven NW practices were enrolled between June and December 2022. Reasons for this included practice managers feeling anxious about who would have access to their systems, delays with issuing a letter of access which in turn delayed screening and slow communication with practice managers to grant access to necessary systems and conduct primary and secondary screening checks.

TABLE 3 Time between key points in the GP recruitment process

Average time between date of:		SW (mean number of weeks)	NW	SW + NW
Approached	Induction	7.9[a]	19.0[b]	14.8[a,b]
Induction	SIV	5	26.7	16.7
SIV	Site opening	4.2	1.7	2.8
Approached	Site opening	20.2[a]	43.8[b]	33.1[a,b]

a Excludes one SW practice which was approached during phase 1 and put on hold. With this practice, mean number of weeks between approach and induction = 10.6 weeks.
b Excludes one NW practice, which was also approached initially to help with NW GP practice recruitment, but later decided to join the study. With this practice included, mean number of weeks between approach and induction = 20.1 weeks.

Proportion recruited in the SW was 66.7% (6/9 approached) and 33.3% (7/21) in the NW. Overall, GP recruitment rate was 43.3%. Average number of weeks from induction date to the site opening in the SW was 9.2 weeks and 28.3 weeks in the NW (*Table 3*).

Participant recruitment

Participants were recruited from participating GP practices.[36] Approximately, 48% of patients identified from Quality and Outcomes Framework (QOF)[65] registers met eligibility criteria; 853 were approached, offered the intervention and an opportunity to join the study. About 126 (14.8%) participants with dementia consented to the study, meeting 70% of the maximum recruitment target. Six (3%) of the participants were recruited via the responsive route (*Figure 4*). One hundred and twenty-one carers were consented to the study.

One hundred and nineteen of the participants with dementia were recruited with a carer ('dyad'), and seven participants with dementia were recruited without. Two carers were recruited without the person they were caring for because these individuals expressed dissent but were happy for their carers to participate.

Baseline characteristics

There were more female participants with dementia than male (*n* = 77/126; 61%) and the majority of participants were White (*n* = 116/124; 94%), followed by Asian (*n* = 7; 6%). Participants (*n* = 98) had a mean age of 68 (SD = 13) years. More than half of the participants were married (*n* = 77/122; 63%) and a quarter (*n* = 31/122; 25%) were widowed. Spouses made up the largest group of carers (*n* = 74/123; 60%) followed by relatives (*N* = 41/123; 34%). Current income (*n* = 35) and former income (*n* = 27) were collected, but only some participants were willing to provide this information: 68.6% (24/35) and 66.6% (18/27) were earning below £24,999 currently and previously, respectively. Median IMD was 7 (*n* = 30; IQR 5–8, range 2–10).

Median Montreal Cognitive Assessment[83] score participants with dementia (*n* = 79) was 4 (2–7) (scores < 10 indicate severe cognitive impairment).

Carer age income and ethnicity more or less mirrored those of the participants with dementia, but there was a higher proportion of female carers (64% vs. 36% male). Further details in Oh *et al*. In preparation.

DSWs (*n* = 7), supervisors (*n* = 4), a carer support worker (*n* = 1), admiral nurse (*n* = 1) and GP surgery staff (*n* = 18) were also consented as participants (see *Table 2*).

Realist case study results

Specific examples of practical and observable outcomes, relating to these broader concepts, and how the intervention led to them, were evidenced. These outcomes occurred for both PwD and carers, and related to a wide array of care and support needs (associated with living well; maintaining/improving physical and mental health; ensuring care

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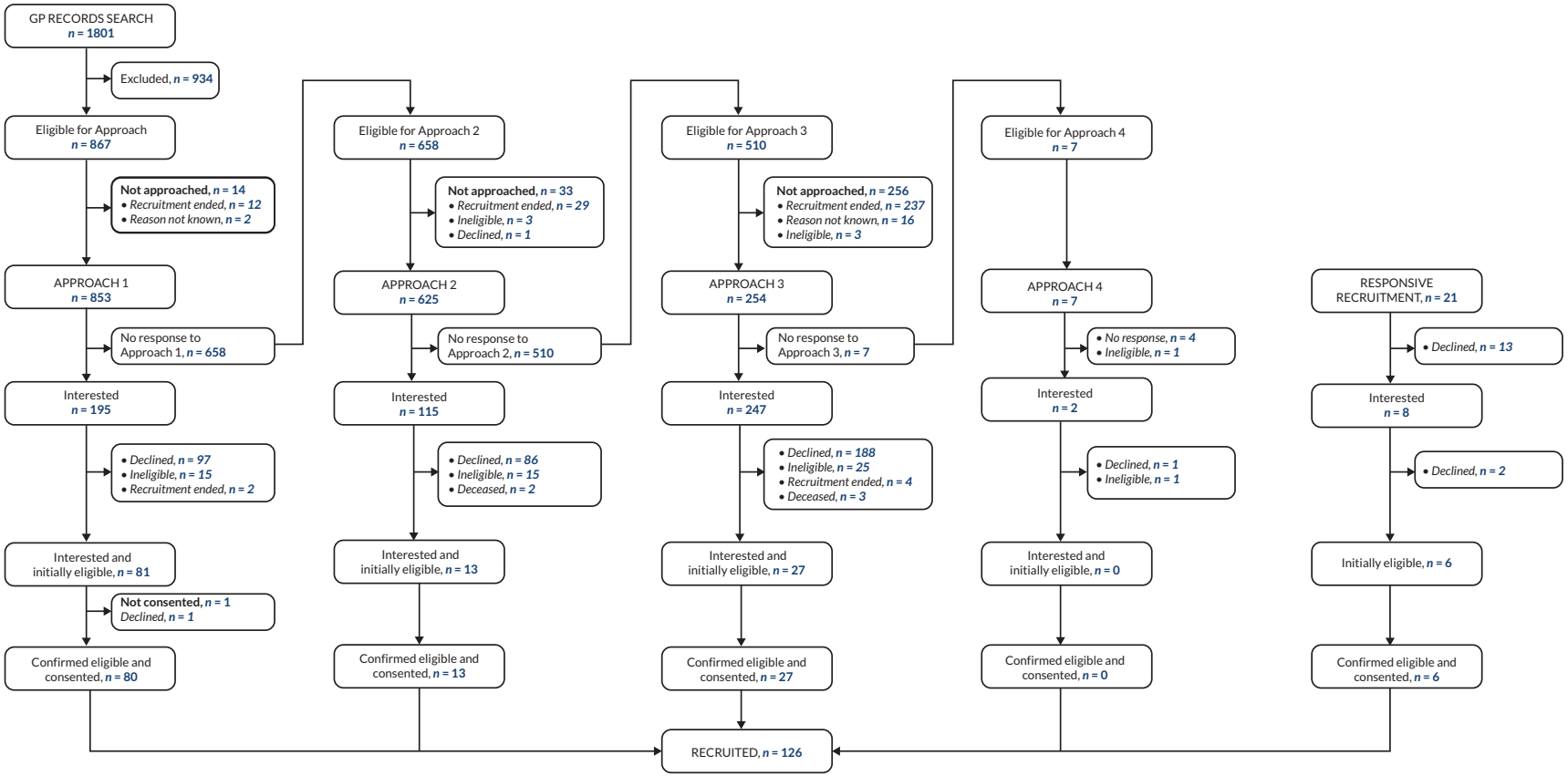

FIGURE 4 Participant flow diagram depicting multistage approach of patients.

preferences were addressed in the future and transitions in care were eased) not just for dementia but also other long-term conditions – evidencing that DSWs provided holistic and comprehensive care (*Box 2*).

BOX 2 Extent to which the range of positive outcomes were generated by D-PACT

Associated outcomes for support with living well: maintained improvement (during support) to mood/emotional well-being (*n* = 19 carers, 3 PwD); new self-management strategies employed = not related to medication (*n* = 14 instances, in 14 cases); care package increased (*n* = 5 cases); financial aid increased (*n* = 3 cases, still in progress at time of data collection ending = 1 case); increased social engagement (*n* = 8 for PwD, *n* = 4 carers, and *n* = 2 for both PwD and carers together); support with managing medication for dementia and other long-term conditions (*n* = 11 cases); new form of care provided by a care professional (*n* = 15 cases) and improve choice and control over care (*n* = 17 cases).

Associated outcomes for reactive care (for new/altered symptoms/situation or unaddressed/unsuccessfully treated symptoms): new or altered medication for dementia or other long-term condition (*n* = 20 cases); referral or actual contact with (non GP) practitioner (*n* = 18 cases); treatment prioritised for patient due to high-risk situation/condition (*n* = 8 cases); further tests and investigations (*n* = 6 cases); dementia or other long-term condition review (*n* = 14 cases).

Associated outcomes for proactive care: some form of plan to manage future care situations put in place (*n* = 27 instances in 19 cases); dementia review conducted – not in response to symptom change/unaddressed symptoms (*n* = 2 cases).

Associated outcomes for support with transitions in care: increased support with hospital admissions/discharge (*n* = 6 cases); support with care home transition (*n* = 1 case); enhanced end-of-life support (*n* = 2 cases).

This phase also further refined and consolidated the IPT (see *Appendix 1* and *Appendix 2*). Many phase 1-elaborated programme theories were corroborated. The analysis described how early relationship-building practices by DSWs triggered mechanism responses that led to ongoing disclosure, engagement and the enactment of agreed actions by people supported (immediate outcomes). It showed that for most people these intermediate outcomes created the necessary context for DSWs to deliver personalised care offers and practices.

To facilitate this process across diverse support needs and situations, DSWs needed to build relationships through sustained care, allocating sufficient time to each case, and possessing the knowledge and skills to deliver primary care-based, person-centred, personalised support.

The evaluation analysis also refined understanding of what mechanisms needed to be triggered, within certain contexts, by personalised DSW support actions for their intended outcomes to be realised. Often, people needed to feel more ready or motivated to take next steps towards improving their independence, health and QoL. This enhanced readiness or motivation resulted from increased knowledge; hope things could change, and reassurance that they would continue to be supported while actions were undertaken.

Greater clarity on what specific DSW practices (intervention components) led to specific types of care outcomes was also achieved through the analysis, these are grouped by care domain (see *Appendix 3*).

Missing from phase 1-elaborated IPTs, but evidenced in this analysis, was the need for practitioners/professionals (GPs and practice nurses) to also undergo changes in their reasoning for key care processes (e.g. treatment changes, annual reviews) to be realised. To have a better understanding of their patients' needs and be prompted to act DSWs informed and tasked GPs through access and use of patient medical records, and through in-person interactions and collaborations.

Outcomes were sometimes not realised, despite DSWs' model fidelity, for a range of contextual reasons, including: limited resource within community/other service providers; lack of buy-in from other professionals; halted/delayed access to patient medical records.

For eight individuals/dyads, there was evidence that DSWs did not deliver D-PACT as intended (e.g. did not listen to what mattered; untailored information; irregular contact; did not follow-up on agreed actions; not acting as a single point of contact), resulting in dissatisfaction and/or inaction. Insufficient DSW contracted hours appeared to be a contributing factor. In all other cases, specific absences were not found and at least one D-PACT component was evidenced, (*n* = 76 cases), that is delivery was broadly found to be in line with the D-PACT model.

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In seven cases, people supported were insufficiently clear about the DSW's role when support first started, resulting in some cases of delayed disclosure. Lack of clarity seemed to stem from the nature of the practitioner support package rather than a lack of fidelity to the model – resources helping DSWs to describe their role to those supported had been kept deliberately non-prescriptive to encourage individualised care and not overwhelm people receiving support. Such insights suggest the need for further DSW support package refinements (e.g. codevelopment of vignettes to explain D-PACT role/possible impact). This finding highlights a possible challenge when practitioners place too much onus on patients to determine how their support should be used that is apply personalised care too liberally.

Dementia support worker

Some D-PACT outcomes appeared to be better realised over time, with experience – once DSWs' professional autonomy to adapt/personalise care developed (see *Appendix 2* for all refined and consolidated theory on D-PACT DSW workforce). When DSWs (seconded, band 4 NHS staff) first started, their professional autonomy was impeded by limited experience/training/confidence with adopting D-PACT approaches and misaligned beliefs about care delivery. The evaluation showed that sustained DSW workforce support beyond initial training was essential. When supervision, peer support, video/audio-assisted reflection, and training/permission to read–write in GP records were experienced as autonomy-supportive, competence-building, and relationship-enhancing, DSWs' motivation, confidence and collaboration grew, strengthening personalised care. When DSWs saw GPs act on their record entries and involve them in care planning, they developed a stronger sense of legitimacy and belonging, needed less scheduled supervision, and exercised more professional autonomy. Mechanisms also needed to 'fire' in other agents [e.g. GPs, Voluntary, Community and Social Enterprise (VSCE) leaders and PwD and carers]. Findings highlighted that clear, case-based role explanations, and timely patient medical record entries, helped PwD, unpaid carers and GP teams understand how to use the DSW, prompting timely actions and richer two-way planning.

Impact was greater where DSWs were fully embedded in practices and had a surgery-based champion, such as a practice-based manager. While having a clinical supervisor was essential, having the addition of the practice-based manager in the NW (extended practitioner support offer component) did notably enhance the realisation of outcomes associated with having primary care-embedded DSWs (e.g. evidence of DSWs engaging in annual care plan reviews, more actively supporting referrals and taking on more primary care-based tasks within these surgeries). Practice managers were able to motivate other colleagues to engage with the DSWs and provide DSWs with a better understanding of how to navigate the surgery systems and resources (mechanism responses). However, the triggering of such responses was also enhanced by DSWs' existing connection/experience of working in those surgeries (contextual factor).

Having both a practice-based and (secondary care-based) clinical supervisor with experience of working within the South Asian community (practitioner support offer component/mechanism/resource), and multilingual DSWs with shared cultural backgrounds as people from this community (context), did observably enhance the delivery and response (i.e. triggering relationship-building mechanism responses) to the D-PACT model in the small number of cases of patients from this group. This support was viewed as essential to DSWs working with this group, to navigate additional barriers to care.

Across site findings, it was clear that access/skills to use medical records were a linchpin in the causal chain (training → confident updates/tasking → GP action → feedback loops reinforcing DSW autonomy and team integration). Organisational and geographical conditions shaped uptake: proactive and engaged GP surgeries, with identified DSW champions enhanced the effects of the DSWs embedding into primary care, while caseloads, geography and variable supervisor engagement could dampen effects – underscoring the need to embed supports as routine practice, not add-ons.

Quantitative findings

Retention and data completion rates

One hundred and fourteen participants with dementia (of 126, or 90.5%) were still enrolled in the study at T1, that is, 4–6 months following baseline.[36] At T2 (9–12 months following baseline), 107 (84.9%) remained. Main reasons for withdrawal were either death or becoming ineligible for the study, for example, moving into a care home. One hundred and ten of 121 carers (90.9%) were still enrolled at T1, 107 (88.4%) at T2 (two of whom were caring for the two participants with dementia who had died by T2).

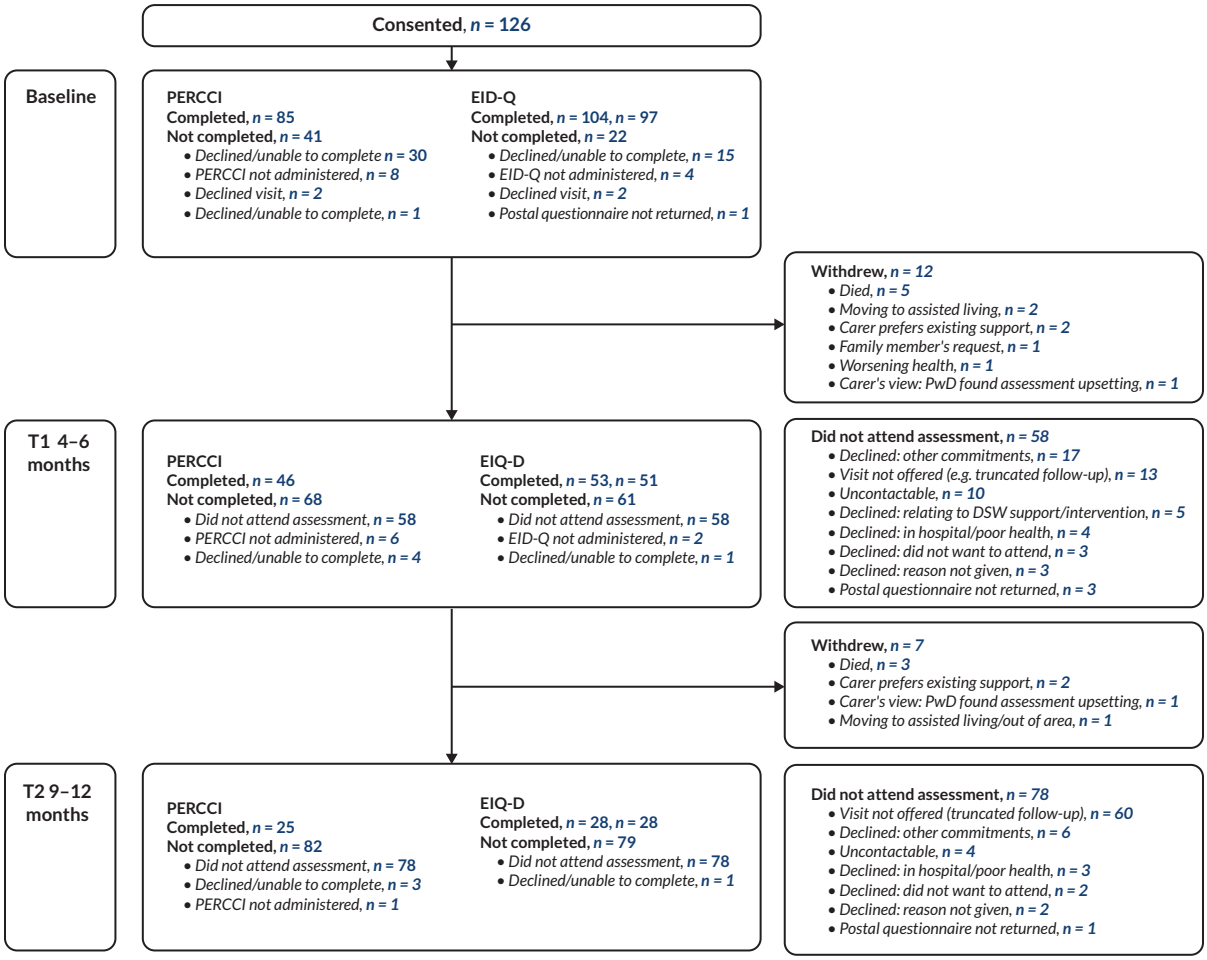

FIGURE 5 Data completion for participants with dementia.

As shown in *Figure 5*, data completion rates were low at all three time points in all scales/measures. Less than half of consented participants completed the EID-Q (42%) or PERCCI (36.5%) at T1, and by T2, under a quarter of the original number completed the EID-Q (22.2%) and PERCCI (19.8%). Reasons for non-completion at follow-up are shown in *Figure 5*. At T1, the main reason for low completion was due to a large proportion of participants with dementia declining to take part for various reasons (n = 32/58; 55.1%) or being uncontactable (n = 10; 17.2%). A further 13 (22.4%) participants were not offered T1 data collection, due to a truncated follow-up period for some. Others were missed due to an error in communication related to staff changeover. At T2, the main reason was a T2 visit not being offered was because of a truncated follow-up (n = 60/78; 76.9%).

A similar picture in data completion emerged for carers (*Figure 6*). At T1, only 58 (47.9%) carers completed the mCWS well-being; and 56 (46.3%) completed the mCWS support. At T2, this fell to 27 (22.3% completion rate) for both.

Challenges with data collection contrasted with engagement in the intervention; 100 (79%) of the 126 consented participants were still engaged with the intervention between 9 months and 12 months (T2). This contrasts with data collection rates at T2, where under a quarter of the 126 consented participants with dementia completed questionnaires and a similar proportion of realist interviews (n = 30; 23.8%).

Graded approach to collecting outcome measures

The impact of a graded approach while responding to the EID-Q was conducted. The graded approach analysis was conducted only on baseline data, and where level of support received was indicated. After imputation (mean imputation at 10% level, for participants with 3 or fewer missing items), 89 participants had sufficient data *and* level of support indicated (this was missing in the remaining questionnaires). Of the 89 participants, 41 (46%) were able to complete the EID-Q independently, 23 (25.8%) required some support and 25 (28%) required a proxy.

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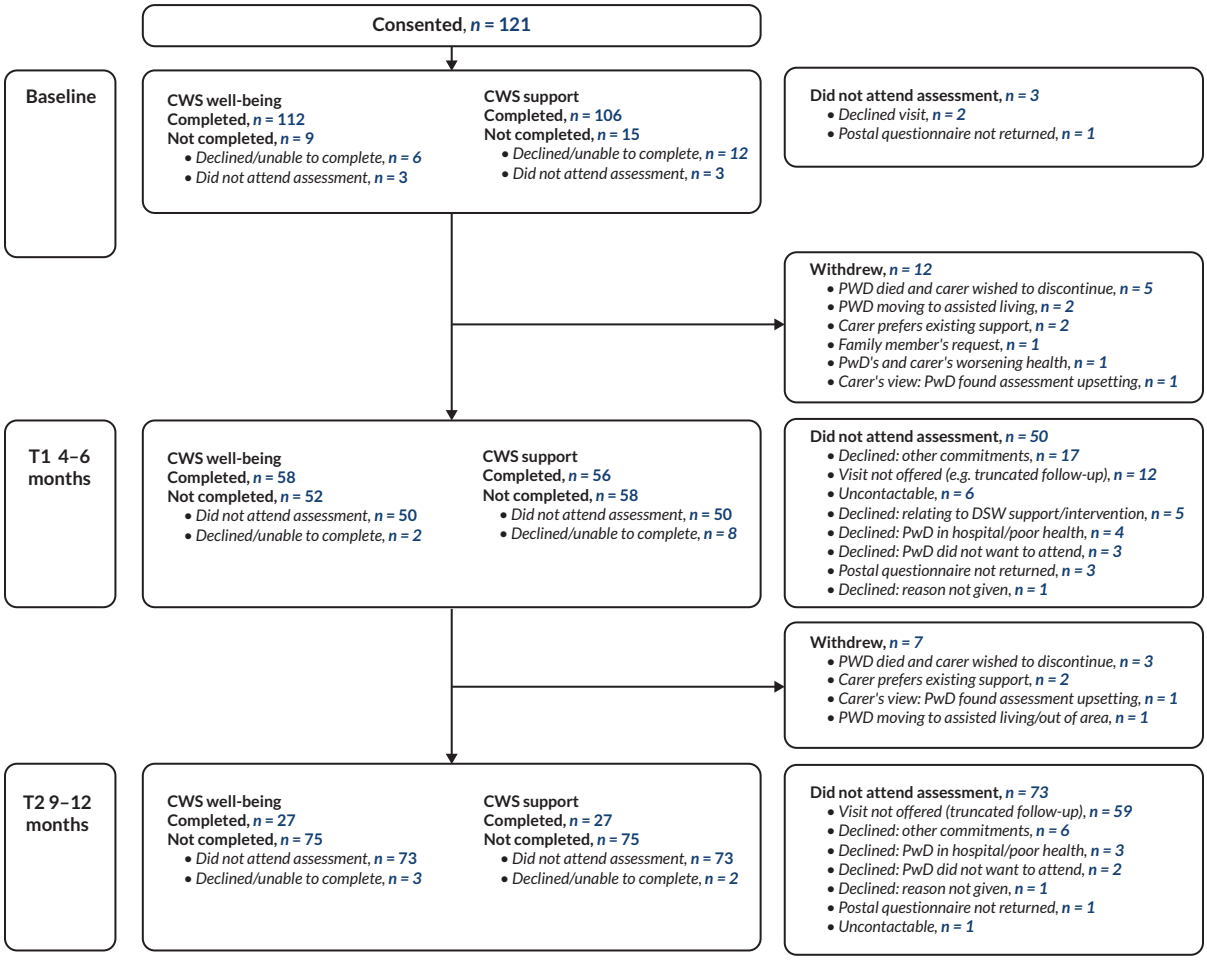

FIGURE 6 Data completion for carers.

There were two main findings. A one-way ANOVA showed there was no statistically significant difference between average EID-Q scores when completed with some support versus independent completion (M = 73.17; M = 79.68, respectively), but this was not statistically significant. However, mean score (M = 47.36) for proxy completion differed significantly ($p < 0.001$).

Outcome and experience measures at three time points

Median EID-Q (independence and engagement for PwD) score at T0 was 73 (51–90) (*N* = 97/126; 76.9%), 60 (44–78) (*N* = 51; 40.5%) at T1 and 67 (37–79) (*N* = 28; 22.2%) at T2.

Estimated median PERCCI (experience of care for PwD) latent scores at T0, T1 and T2 stayed relatively steady at −0.04 (−0.46–0.61) (*N* = 85; 67%), −0.05 (−0.55–0.86) (*N* = 46; 36.5%) and −0.09 (−0.69–0.55) (*N* = 25; 19.%), respectively.

Median mCWS (carer) well-being scores at T0, T1 and T2 were 84 (68–103) (*N* = 112; 92.6%), 86 (69–107) (*N* = 58; 47.9%) and 80 (68–99) (*N* = 27; 22.3%), respectively, suggesting little change in scores over time. By contrast, median mCWS (carer) Support scores (i.e. the extent of feeling supported) at the three time points showing an upward trend: 31 (21–40) (*N* = 106; 87.6%), 34 (25–46) (*N* = 56; 46.3%) and 41 (31–47) (*N* = 27; 22.3%).

Change in outcome and experience measures over time

Where participants had completed a measure more than once, changes in score from T0 to T1 or T0 to T2 were calculated by subtracting the T0 score from T1 or T2 scores, respectively. The median change (IQR) score was then calculated.

Table 4 shows a negative median change from T0 to T1 in the EID-Q and the same trend – albeit smaller – at T2 relative to T0.

TABLE 4 Change in PwD and carer outcome measurements over time

	T0		T1		Change in score	
	N	Median (IQR)	*N*	Median (IQR)	Median (IQR)	Range
Change from baseline to first follow-up (4–6 months)						
EID-Q	44	75 (54.5 to 89.4)	44	62.5 (46.9 to 78.5)	−7.8 (−17.4 to 2.5)	(−42.0 to 26.0)
PERCCI	34	−0.05 (−0.41 to 0.61)	34	0.07 (−0.55 to 0.68)	−0.1 (−0.7 to 0.6)	(−1.4 to 2.2)
mCWS (well-being)	55	84.0 (71.0 to 103.0)	55	86.0 (67.0 to 107.0)	0.0 (−10.0 to 14.0)	(−43.0 to 66.3)
mCWS (support)	51	32.0 (20.0 to 42.0)	51	34.0 (26.0 to 46.0)	5.1 (−2.0 to 13.0)	(−29.5 to 37.2)
Change from baseline to end of follow-up (9–12 months)						
EID-Q	27	75 (43 to 87)	27	69 (40.6 to 80.1)	−4.2 (−12.6 to 7.6)	(−64.5 to 31.9)
PERCCI	19	0.02 (−0.37 to 1.05)	19	0.04 (−0.69 to 0.55)	−0.3 (−0.8 to 0.5)	(−1.6 to 1.6)
mCWS (well-being)	27	84.0 (68.0 to 104.0)	27	80.0 (68.1 to 99.0)	−6.0 (−19.0 to 9.0)	(−42.0 to 42.1)
mCWS (support)	26	35.5 (27.0 to 40.0)	26	41.0 (31.0 to 47.0)	3.0 (−1.0 to 13.0)	(−16.0 to 48.0)

There was minimal median change in PERCCI scores, whether comparing T1 or T2 to T0 indicate that experience of care for PwD remained roughly stable

A downward trend was observed in mCWS well-being at T2 relative to T0. However, there was a positive median change in mCWS support scores at both T1 and T2 relative to T0 respectively. How these changes compared to a priori predictions are discussed below (see *Equality, diversity and inclusion*).

Limitations

These data are difficult to interpret because: (1) low numbers of people taking part in data collection at T1 and T2 introduced problems related to small sample sizes as well as the likelihood of bias, and (2) absence of control along with wide ranges and overlapping IQR at three time points make causal attribution unwise. Recordings of some data collection sessions raise the question of whether participants were responding to questions in the way they were instructed, particularly in the PERCCI; for example, PwD or their proxies appeared at times to misinterpret questions like confusing individual people and whole teams leading to non-response.

Health economic analyses

Cost of delivery and wider costs

Tables referred to in this section correspond to tables in the HE report by Morrish *et al.*[63]

Full-time and part-time DSWs, equivalent to 3.1 full-time equivalent (FTE) DSWs, delivered the intervention. Between them, the DSWs supported 119 dyads, 7 PwD without carers and the 2 carers whose spouses/relatives with dementia who showed dissent during consent. DSWs maintained timesheets, recording number and duration of activities.

In total, there were 1446 direct participant contact events over the 12 months for all participants. With the offer of ongoing support, delivered with variable intensity depending on the needs of the PwD or dyad, mean number of contact events was 11.5 times per dyad/individual over the year. Mean time spent per contact event was 45.47 minutes. High and low users of support were noted: 19 (15% of those consented) received less than 1 hour of support over the intervention period; 14 (11%) received 1–2 hours, while 11 (9%) received 15–20 hours and 6 (5%) more than 20 hours' support over the year.

Direct contact events occupied 27.3% of the DSW's time. Other activities included file updating, liaising with the GP, GP surgery, family or other services and professionals, attending training or supervision, travel and miscellaneous activities related to intervention delivery (table 5 in Morrish *et al.*[63]). After direct contact, travel to participant homes took up the next largest proportion of DSW time (17.9%). Total time spent on all activities (direct contact + related

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activities) was 240,644.5 minutes (4010.7 hours), an average of 49.05 minutes per activity (see table 5 in Morrish *et al.*[63]).

The formal HE analysis examined the intervention cost (see table 6 in Morrish *et al.*[63]), which included training costs, DSW time to deliver support, DSW supervision and support to supervisors. Intervention cost per dyad or PwD was £1222.48 (note the formal HE analysis did not include the two carers, so *n* = 126). Mean cost per part-time DSW (*n* = 6) was £25,672.51; while 3.1 FTE DSWs cost per FTE was £49,688.73.

Resource use data from participants with dementia (see table 8 in Morrish *et al.*[63]) and carers (see table 10 in Morrish *et al.*[63]) were collected at baseline, T1 and T2. However, as with outcome and experience measures, low completion rates were seen at follow-up so findings over time need to be interpreted with caution. Table 8 in Morrish *et al.*[63] illustrates that the highest service use reported by participants with dementia was for home care workers and mean hours per participant increased over time: baseline = 20 hours (range 0–840); T1 = 48 hours (range 0–540); T2 = 90 hours (range 0–1080). This was followed by day care centres [T1 = 27 hours (range 0–360); T2 = 23 hours (range 0–300)], and respite care/nursing homes [T2 = 20 hours (range 0–336)].

Cost of resource use was calculated using specified unit costs (see table 7 in Morrish *et al.*[63]). Both participant with dementia (see table 8 in Morrish *et al.*[63]) and carer (see table 10 in Morrish *et al.*[63]) reported costs increased at each time point. Mean cost per participant with dementia was £1491.94 at baseline, £3453.77 at T1 and £4184.51 at T2. Home care worker use was a cost driver at all three time points; without these, costs mean cost per participant with dementia was £797.53 at baseline, £2347.85 at T1 and £2108.12 at T2. Findings suggest that costs double between baseline and 4–6 months, with a smaller increased observed between T1 and T2 (although this must be interpreted with caution given low completion rates). Overall, the greatest costs at baseline and T1 arose from secondary care, but from primary and community care at T2.

A supplementary pragmatic analysis (outside of the formal HE analysis) was conducted to estimate DSW caseload. We reported above that total time spent by all 6 DSWs (3.1 FTE) to support 128 cases was 4010.7 hours. One FTE was therefore spending on average 1293.8 hours to support a mean of 41.3 cases per annum, or 29.4 hours per week (37.5 hours week,[84] in a 44-working week year), as some of their time was spent on other work because the number of cases supported in this study was limited by how many participants were recruited. If 29.4 hours were needed per week to support 41.3 cases at any one time, then we estimated that 52.7 cases (dyad or individual) per annum could be supported in a full 37.5-hour week. These estimates take into account the learning curve for DSWs starting their role, as well as first activities with new 'clients' – establishing trust, understanding what matters to them and familiarising dyads to this type of coaching-inspired and ongoing support – taking longer at the start.

Impact of the dementia support worker on changing the trajectory of high-cost/high-level events

The exploratory realist-informed economic analysis[80–82] was conducted alongside the main realist case study analysis. Ninety-nine data sources from 44 cases were coded to the 'averted crisis' node. Following review by 2 independent researchers, 24 cases were identified where the DSW's actions appeared to contribute to reducing the risk of negative events (falls, urinary or chest infections, wrong medication) typically associated with preventable hospitalisations among PwD[85] or limiting further escalation of a 'crisis' situation. In four other cases, high-cost events were *not* averted, either because the intervention did not operate as intended or because contextual factors did not trigger required mechanisms.

The analysis suggested that when DSWs were able to intervene early (context), and when their knowledge, observational skills and relational connection with the dyad were activated (mechanism-resource), the risk of escalation was reduced and high-cost care potentially avoided (outcome). Typical mechanisms included early detection of emerging physical health issues [e.g. infections (*n* = 7), falls risk (*n* = 6), medication issues (*n* = 7)] and responding to warning signs of carer strain (*n* = 2) which may have resulted in breakdown of care.

Examples that illustrate some of these mechanism-resources include the DSW's skill at eliciting relevant health information from a participant who reported 'not feeling too well', which resulted in timely medication adjustment

by the GP for high blood pressure. In another case, the DSW knowing how to check blood pressure triggered the identification of a heart condition that led to a pacemaker fitted. Attentiveness during a routine visit for another case enabled removal of a skin lesion and early attention (fast-track) to suspected skin cancer.

The PwD or carer feeling comfortable about contacting the DSW tended to lead to earlier intervention. A carer reported that being able to call when worried about their spouse's blood pressure enabled the DSW to facilitate a rapid GP response so the person was treated at home, potentially avoiding hospital (which the carer said their spouse found stressful). A person with dementia who called the DSW because of a frightening experience the night before (waking up and not recognising where they were) prompted a visit where the DSW noticed an untreated nail issue. The DSW's referral to the podiatry team led to early treatment but also a note in the person's records from that team that the nails had been at risk of becoming septic and timely treatment likely avoided further complications.

One mechanism consistently seen across all 24 cases was the DSW's access to GP records and ability to prompt primary care action via direct communication or digital tasks, and the triggering of early action (outcome). No resistance from GPs about being asked to respond to DSW requests for action was reported.

However, some contexts meant intended D-PACT outcomes were not always realised. For example, a strained relationship with the carer and difficulties in contacting the carer inhibited timely intervention, leading to hospitalisation following unaddressed deterioration in the PwD. In another case, relationship-building was at a very early stage (first meeting) when two falls happened, suggesting that timing within the support trajectory can constrain early intervention. In another case, although the DSW triggered an urgent referral (via the GP) to occupational therapy following identification of high falls risk, systemic delays in service response led to a preventable fall and head injury.

Although further testing of a cost-sensitive IPT was limited by low follow-up completion rates in resource use questionnaires, an interim refined theory can be proposed: where DSWs are positioned to detect and respond to early signs of crisis (context), and relational and professional mechanisms operate effectively, short-term increases in service use and cost may occur, but these actions may help stabilise the situation and avoid higher downstream secondary care costs (outcome).

Synthesis of mixed-methods data

Qualitative, quantitative and economic findings were brought together in a joint display matrix (see *Table 5*) to gain an overarching view, triangulate different analyses and draw further insights.

Table 5 illustrates what, on the surface, are contradictory findings about well-being and experience of care. Quantitative findings showed a decline in engagement and independence (EID-Q) for PwD. By contrast, interviews highlighted improvement in social engagement and beneficial changes to care. This dissonance may be due to increasing use of proxy reporting over time, lack of controls or bias due to low retention. We speculate that EID-Q scores could have been lower still without D-PACT as QoL declines in PwD. Alternatively, despite the extent and analytic rigour of the realist qualitative study, the attribution of better outcomes to DSW support may be flawed.

A decline in some individual EQ-5D-5L domains (mobility, self-care) is indicative of increasing need; qualitative findings suggest that some needs were being met through the DSW via enhanced care – increased care packages, enhanced comfort for end-of-life, annual reviews taking place, urgent care provided as well as an expanded care team. It is possible that the DSW was mitigating worse outcomes in the face of the inevitable decline in function with dementia. So, while superficially contradictory, for both EID-Q and EQ-5D-5L, the stability or decline was not at odds with our a priori predictions of worsening outcomes due to a progressive condition which would only ever be partly mitigated by D-PACT.

Quantitative measures of experience of care (PERCCI) remained fairly stable (albeit downward trajectory, and with wide variation). This was not reflective of the enhanced care described in the qualitative interviews: increased care packages, enhanced comfort for end-of-life, annual reviews taking place, urgent care supported. It also was not in keeping with our a priori predictions: we had assumed experience of care would improve measurably in a non-randomised study

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TABLE 5 Mixed-methods synthesis of qualitative and quantitative data, with insights

Outcome level	Qualitative findings	Quantitative patterns[a]	Economic/resource use[a]	Insights
PwD – well-being	Increased social engagement; tailored changes to medication dose and prescriptions, plus increased guidance and practical support with self-managing medications (for dementia and other long-term conditions), care packages and financial aid received/enhanced	EID-Q: decline EQ-5D-5L: shows physical decline. VAS[b] remained moderately high	Resource use (combined primary/community, secondary and other care) and costs increased over time	There is inconsistency between quantitative and qualitative data. DSWs may help sustain emotional well-being of PwD even as physical needs grow
PwD – process/experience of care	Expanded care team, improved engagement with GP, urgent care needs addressed, proactive medication reviews and increased annual reviews for dementia and other long-term conditions. Preferences for future care documented	PERCCI: relatively stable	Primary/community care use/costs rose over time; secondary care use/costs increased substantially at T1, slightly decreased at T2	Person-specific positive experience of care captured in qualitative data may be difficult to capture in standard metrics. Alternatively dissonance may reflect low follow-up response rates
Carer – well-being	Carers felt less emotional burden, lighter in mood and the mental toll of caring reduced (due to e.g. their caring efforts validated; better understanding of why things were happening, and so on)	No median change in well-being at T1 vs. T0, decline at T2 vs. T0	Resource use (combined primary/community, secondary and other care) and costs increased from T0 to T1 and then stayed relatively stable with a slight increase at T2	There is a mismatch between subjective experience and standardised measures of well-being – mCWS may not be sensitive to mechanism responses, for example, an emotionally overloaded carer reframing a situation following greater understanding of the PwD's situation. However, the emotional benefit of a DSW described qualitatively may not be sufficient on its own to arrest longer-term health decline for carers
Carer – process/experience of care	Improved logistics (e.g. arrangement of a hospital nearer to home), contingencies plans created for situations where they could not provide care, expanded care and end-of-life support for the PwD	Perception of being supported increased modestly over time, more so at T1vs. T0	Primary/community care use/costs increased then decreased slightly; secondary care use/costs increased slightly, mostly outpatient	Meaningful support reported qualitatively seemed to be reflected in measures.Primary care increase in use at T1 *may* suggest that DSW may be prompting appropriate primary and secondary care referrals
DSW (individual)	Scenario-based training supported DSW learning; peer support faced challenges (e.g. competing schedules, geography), but diversity enriched exchanges; accessible resources aided practice	With the offer of ongoing support, DSWs met with dyads/individuals living alone 11.5 times a year on average; average length of contact was under an hour	Average training cost per DSW = £459.67Cost of a full-time DSW = £49,688.73Estimated caseload per FTE using the D-PACT model of support = 52.7 casesMean cost of delivery per dyad or PwD living alone per annum = £1222.48	Adequate training, peer and supervisor support, and accessible resources supported DSW in their delivery.The cost of personalised, proactive care was about £1200 per dyad per year. The potential savings from reducing unnecessary high-level care may offset these costs but this needs further investigation
DSW (working within the system/implementation)	DSWs require sufficient training (incl. medical record use), and ongoing support, especially in underserved areas. Relationship-building prior to starting in a new area enhances collaboration. Inexperienced DSWs take longer to adapt and need more support early to build confidence			

a There was wide individual variation in quantitative and resource use findings, and small sample at T2. Findings should be interpreted with caution.
b VAS, visual analogue scale; self-reported rating of current health state.

given the general lack of health care for the post-diagnostic phase. Potential reasons for this dissonance include qualitative or quantitative methods used being inadequate or capturing different things. Participant expectations about outcomes versus actual achieved outcomes (potentially more modest than expected) may also have influenced ratings.

The matrix shows a picture of how DSWs can contribute to reactive and proactive care and can integrate within GP settings, but do require ongoing training and supervision. DSWs also need time to 'grow' into the role, which entails significant changes in skills, ways of working and expectations.

Overall, the findings underline the importance of collecting qualitative data alongside quantitative outcome measures, including to assess outcomes in situations with low retention and lack of controls. Also, in studies where the programme theory evolves, broad/high-volume qualitative data can support elaboration and identify outcomes that turn out to be important but are not predicted at the start.

Public and patient involvement

Lived experience and perspectives were interwoven throughout the project to deepen and challenge academic perspectives. The views of our PRG and ERG influenced the funding application, intervention development and delivery, data collection tools refinement, and analysis. There is ongoing involvement in dissemination activities.

In-person ERG meetings were held twice during phase 1, and then switched to online meetings during phase 2 (one each year). ERG members were invited to the dissemination event in July 2024, along with PRG and wider stakeholders in lieu of a third meeting.

Initial PRG meetings (November 2018–9) were with three PwD and seven current and former carers. The PRG functioned primarily as a reference group at this point, providing feedback. Members reviewed study documentation, ethics application, skills and attributes required for DSWs, tools and terminology used, and supported thinking around the PwD–carer dyad.

Meetings moved online in May 2020. Membership reduced to three former care partners due to personal circumstances (deaths and advancing illness), and discomfort with the format. The group provided insights into the lockdown challenges of remote support, remote recruitment and maintaining physical health and well-being. They also advised on terminology, confirming assent, future and advance care planning and outcome measures. The online format facilitated the recruitment of a person with dementia who would otherwise have been unable to attend (due to health and distance).

The PRG helped the team think through the midpoint 'stop and go' report and preparation for the amended phase 2: selection outcome and experience measures, widening the DSW role and the realist evaluation theory.

Phase 2 meetings (2022) continued online. The helped reduce 'overwhelming' study documentation; developed 'responsive recruitment' and contributed to discussions about care planning and end of life. The group also experimented with creative approaches, for example, using poems or music to stimulate discussion or build rapport. The meeting formats and focus of the group continued to be directed by them, such as deciding to extend their involvement to research activities, for example, developing diary writing guidelines; requesting an informal introduction of coanalysis (rather than formal training as recommended by patient and public involvement guidelines) which details the importance of offering choice in the coanalysis process. Tensions in resolving divergent opinions such as the type of pictures to use and the tracking and communication about changes are explored in further a separate paper (in preparation).

In 2023–4, membership declined further (one stepped back; one died), reflecting the challenges of involving PwD and carers in 'academic speed' research.

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We believe that we were successful in our aim to give voice and influence to individuals with lived experience rather than accepting that capacity and mortality challenges of dementia make it 'too difficult' to meaningfully involve them. This is evidenced by their length of involvement and the ongoing willingness to contribute, for example, to ongoing dissemination and to a funding application (submitted September 2024).

Equality, diversity and inclusion

Probably, the most important aspect of D-PACT with respect to equality and inclusion was the focus on a recognised NHS unmet need – post-diagnostic care for dementia. In phase 1, this was the priority; while in phase 2, we focused on inclusion of those from low-income areas, individuals living alone, and from South Asian communities.

General practitioner practices were selected to represent those 'not usually reached by conventional trial recruitment methodology', including those with high proportions of individuals from South Asian communities (NW), and rural and deprived areas in urban coastal communities (SW). Our four-step recruitment approach was designed to ensure everyone had opportunities to participate. To achieve South Asian representation, a range of strategies were used (*Report Supplementary Material 1*). In the NW, researchers worked with advocates in local groups and organisations, through conversations and engagement events, to understand how recruitment might best be approached. We mapped the key languages in communities and in the research team to guide translation and translator decisions. Community advocates also contributed to developing culturally appropriate materials where 'translation' might be about a cultural practice, such as who usually cares for people in the family, rather than a literal translation of a word. A community-based responsive recruitment approach targeted those not reached by the proactive recruitment process.

We found that GP practices with a high representation of South Asian communities actually had disproportionately low number of South Asian patients on their QOF registers for dementia. To increase recruitment we developed a more flexible 'working diagnosis' pathway for those not yet formally diagnosed. Additionally, we worked with Oldham memory service identifying those in South Asian communities wishing to participate but who were not registered with the target GP practices.

Even with these strategies, success was modest. In the SW (where data were available), 40% of participants were living in postcodes with IMD ratings 1–5. Twenty-seven of the 126 participants with dementia recruited reported living alone (seven joined the study without a carer participant, others had carers from outside the household). Seven South Asian participants were recruited overall, all at the NW site mostly from our non-standard recruitment. Six of these participants did not speak English and were supported by translators.

Discussion

Overview of results and interpretation

Phase 1 intervention theory development (WP1) and feasibility testing (WP2) informed the final design of the phase 2 evaluation. WP1 led to a reconfiguration of the IPT into two tiers – delivery and facilitation – highlighting how support for the DSW was integral to delivering person-centred support to PwD and their carers. Recruitment challenges, exacerbated by COVID-19, underscored difficulties particular to recruiting from primary care (exemplified by how much primary care teams' ability to collaborate were impacted by the pandemic). However, this created the opportunity to demonstrate that processes could be adapted for remote working with comparable recruitment rates, showing that flexibility and choice are feasible options can be offered to PwD.[32] WP2 also refined outcome measure selection to better align with intended outcomes.

The findings from the phase 2 longitudinal realist evaluation showed that outcomes for the PwD and carer, respectively, were often achieved across four care domains, that is, living well, appropriate reactive care, proactive care and care transitions. Addressing carer needs can positively impact the person they care for.[86,87] Building relationships of trust was a vital foundation, achieved via DSWs being a single (continuous) point of contact, and time (appropriate caseload)

to know each person so that support could be genuinely personalised – a need identified by other studies.[88,89] Access to records and participants' GPs – enabled by being based in primary care – was crucial for timely action but also encouraged collaboration, resonating with another recent study's findings.[18] Our findings add to other (non-UK) studies adopting a task-shifted approach with non-clinical roles.[15,90]

While the uncontrolled design to some extent preserved ecological validity (it likely increased proportions of those perceiving the need for DSWs to participate), the lack of randomisation limited conclusions that could be drawn from quantitative findings. Low completion rates at follow-up led to progressively smaller numbers for analysis, making interpretation difficult, and arguably inappropriate.

With these caveats in mind, the lack of change or decline in independence and engagement (EID-Q) among PwD were consistent with predictions made prior to data analysis based on wider findings.[71–76] The predicted improvement in experience of care[79] however, was not achieved, with latent PERCCI scores staying relatively level. There was a mixed picture in carer support and well-being scores, with the former showing a decline between the 4–6-month and 9–12-month points but the latter increasing across all time points.

Our mixed-methods synthesis underlined that while there is value in standardised measures, they sometimes do not capture nuances or unexpected or unpredicted outcomes that are surfaced by in-depth qualitative interviews. This could explain why an older review on respite care for carers of PwD found limited evidence of effectiveness from RCTs yet considerable evidence of perceived benefits[91] Qualitative data also helped contextualise quantitative data patterns, which on their own may have led to different decisions about the intervention.

Dementia support worker timesheets demonstrated that offering flexible ongoing support (vs. fixed-frequency meetings) resulted in (on average) the DSW seeing people at a frequency of just under once a month. Estimated annual cost was £1222.48 per dyad/individual. It is possible that relationship continuity[90,92] and increasing DSW experience/confidence could increase efficiency.

Reflections on success and challenges

Intervention development and trial science (phase 1)

A key output from phase 1 was the intervention and support package for practitioners which included a manual and online training resources, available for download.[93,94] Their iterative development was informed by previous studies,[95] people with lived experience, relevant professional or academic backgrounds and observation of the intervention in practice. Learning how to engage stakeholders in the development of realist theory was another output.[37] The intervention was largely delivered during the COVID-19 pandemic. By being required to rapidly innovate, we learnt about the possibilities and limits of forming relationships and gaining trust to deliver personalised support *remotely* to people with a range of needs, including communication challenges.[43]

We also contributed to methods for evaluating interventions for PwD but not under secondary care (where recruitment is more straightforward). As well as iteratively testing measures to select the most appropriate for a population with a progressively worsening dementia, we developed recruitment procedures to include people without capacity to consent,[35] despite objection from the REC;[30] this was later adapted for remote working.[32] Despite showing that both remote and in-person recruitment were feasible for involving a reasonable proportion of PwD only supported in primary care, the cost and complexity per person recruited was very high in researcher time, precluding a randomised study in our case.

Intervention evaluation (phase 2)

Dementia PersonAlised Care Team is the first programme of research to conduct a realist evaluation using high-volume longitudinal qualitative case study data, with a far higher sample (> 100 participants) than usual qualitative and/or realist studies.[34] The methodological innovations demonstrate the value of qualitative data in *unpacking* impact of intervention on proximal and downstream outcomes (e.g. improved QoL). This method may be more appropriate for populations

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where evidencing outcomes quantitatively is more challenging or where the range of possible outcomes is wide and hard to predict. Through analysis of this large amount of data, we could establish patterns (demi-regularities); robustness was achieved via the triangulation of multiple sources of qualitative data over time and data collection strategies closely aligned with the intervention. Importantly, we have moved from recommending non-specific personalised principles to an evidence-based model detailing what personalised dementia care delivered by DSWs based at primary care surgeries *actually* consists of in practice.

Phase 2 continued to contribute to the development of methods for community-based dementia studies. First were the innovations around GP practice recruitment – applying an embedded researcher model, including access to electronic health records to reduce the burden of research on primary care teams and increase participation.[96] Recruitment from a primary care setting is difficult,[28] and by offering more options (remote and in-person recruitment, support during recruitment – not possible in a RCT) and increasing recruitment routes, we exceeded our minimum target and achieved 70% of the maximum target. Second were the steps to include professionals' input,[97] capture the voices of PwD (graded approach to data collection and the use of 'TalkingMats' (Talking Mats Ltd, Stirling, Scotland) to support PwD during interviews). Third was the exploratory use of a realist-informed economic analysis, an emerging science, to examine high-cost low-frequency events which can distort traditional HE analyses.[82]

Difficulties reaching more participants from South Asian (or other ethnic minority) communities limited our ability to answer some aspects of our questions. The complexity of managing this programme and its research, for example, theory changing substantially over the course of the evaluation, presented further challenges for coding and analysis which had the effect of activities exceeding their planned time.

Implications

Implications for practice and policy

Dementia PersonAlised Care Team-trained DSWs have continued delivering post-diagnostic support in Devon and Greater Manchester and are applying their training in their practice. Research findings have informed the development of the Devon Dementia Strategy.

Dementia PersonAlised Care Team has highlighted how DSWs need sufficient support to deliver care and embed themselves within the primary care team. Peer support, built-in supervision from more experienced colleagues (clinical and non-clinical), sufficient initial and top-up training are all essential. Empowering the DSW to grow confidence in taking action, including directing experienced clinicians, requires supervisors be well equipped too. Besides having dementia-specific knowledge our DSWs were able to provide care related to other long-term conditions and signpost to or consult colleagues with expertise so that care remained co-ordinated and holistic. The potential of current primary care roles (e.g. social prescribers) was discussed with practices in this study interested to continue providing this service. For similar patient outcomes to be realised, we recommend upskilling (with dementia-specific knowledge) such roles and a shift in thinking about caseload/time for support. Embedding/access to records is essential.

The time to build trust and maintain contact with people living with dementia and their carers facilitated the early detection of signs for a potential crisis, as did being based in primary care with access to medical records. Most people wanted support at home and the flexible approach allowed sufficient home-based contact even in rural areas with travel demands.

The evaluation design prevented us from conducting a cost-effectiveness study, and we also had reservations about this approach given the progressive nature of dementia and events like hospitalisation potentially distorting the findings. Our exploratory realist-informed economic analysis suggests that there is potential to reduce avoidable hospitalisations (and hence gain savings) among those not already receiving substantial support.

Considerations for future research

Implementation research is now needed to understand how to achieve fidelity to the D-PACT model with sufficient reach to underserved communities – and in a stressed NHS context. This knowledge is essential – but lacking – since many evidence-based models of care do not go beyond formal evaluation.[98]

The methodological challenges and innovations that were part of this programme have raised questions for further study. For example, whether traditional RCTs are suitable for evaluation of very complex interventions for populations with specific needs. The value we saw from collecting high-volume qualitative data but the limits non-randomisation placed on interpretation of quantitative data raise the question of whether realist RCTs[99–101] should be further explored.

Future work should examine the very tricky issue of balancing person-centred data collection methods with enough persistence in obtaining good-quality data. Close communication with researchers across sites during data collection to address challenges early is important, but further work is needed on how team leads and researchers can practically manage this with finite resources.

Conclusions

The D-PACT programme theory details how to deliver personalised support for PwD *as well as* their carers. The multiple case study longitudinal realist evaluation demonstrated improved outcomes in living well, uncovering new and previously unaddressed health needs, planning for the future and supporting with transitions in care. The quantitative analysis which was not randomised and had low follow-up rates was not sufficiently robust to either validate or refute these findings. The manual and support package for the DSW and supervisor, along with the depth of analysis in the evaluation, make up important tools and evidence for those commissioning primary care-based dementia support.

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Patient data statement

This work uses data provided by patients and collected by the NHS as part of their care and support. Using patient data is vital to improve health and care for everyone. There is huge potential to make better use of information from

people's patient records, to understand more about disease, develop new treatments, monitor safety and plan NHS services. Patient data should be kept safe and secure, to protect everyone's privacy, and it is important that there are safeguards to make sure that they are stored and used responsibly. Everyone should be able to find out about how patient data are used. #datasaveslives You can find out more about the background to this citation here: https://understandingpatientdata.org.uk/data-citation

Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved by the South Central – Berkshire Research Ethics Committee REC (reference number 19/SC/0264). Local NHS approvals were obtained before the start of recruitment in each region from date. We had an independent Trial Steering Committee. The trial is registered (ISRCTN90828574).

Information governance statement

University of Plymouth is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under Data Protection legislation (UoP) is the Data Processor; the many general practices and NHS Trusts involved in the study are the Data Controllers, and we process personal data in accordance with their instructions. You can find out more about how we handle personal data, including how to exercise your individual rights, here: www.plymouth.ac.uk/students-and-family/governance/information-governance/information-security. The contact details for UoP's Data Protection Officer is dpo@plymouth.ac.uk.

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Publications

Published

Griffiths S, Manger L, Chapman R, Weston L, Sherriff I, Quinn C, *et al.* Letter on 'Protection by exclusion? The (lack of) inclusion of adults who lack capacity to consent to research in clinical trials in the UK'. *Trials* 2020;**21**:104. https://doi.org/10.1186/s13063-020-4054-4

Griffiths S, Weston L, Morgan-Trimmer S, Wheat H, Gude A, Manger L, *et al.* Engaging stakeholders in realist programme theory building: insights from the prospective phase of a primary care dementia support study. *Int J Qual Method* 2022;**21**. https://doi.org/10.1177/16094069221077521

Griffiths S, Gude A, Greene L, Weston L, Sutcliffe CL, Wheat H, *et al.* 'Do I have the capacity to make capacity judgements?' Researcher reflections from a person-centred dementia support study. *Dementia* 2022;**21**:972–94. https://doi.org/10.1177/14713012211067320

Wheat H, Weston L, Oh TM, Morgan-Trimmer S, Ingram W, Griffiths S, *et al.* Longitudinal realist evaluation of the Dementia PersonAlised Care Team (D-PACT) intervention: protocol. *BJGP Open* 2023;**7**:BJGPO.2023.0019. https://doi.org/10.3399/BJGPO.2023.0019

Wheat H, Griffiths S, Gude A, Weston L, Quinn C, Morgan-Trimmer S, *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* 2023;**22**:1461–86. https://doi.org/10.1177/14713012231185281

Hussain B, Wheat H, Oh TM, Byng R. Engagement with professional stakeholders in healthcare research-the case of the Dementia PersonAlised Care Team (D-PACT) project in the United Kingdom. *Health Expect* 2024;**27**:e70133. https://doi.org/10.1111/hex.70133

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Oh TM, Batool S, Musicha C, Greene L, Wheat H, Smith L, *et al.* Comparing in-person and remote consent of people with dementia into a primary care-based cluster randomised controlled trial: lessons from the Dementia PersonAlised Care Team (D-PACT) feasibility study. *BMC Med Res Methodol* 2025;**25**:247. https://doi.org/10.1186/s12874-025-02685-0

Reports (open-access repositories)

Musicha C, Oh TM, Ukoumunne O, Goldsmith K, Byng R, Creanor S. Dementia Person Aligned Care Team – Dementia Support Study Feasibility Trial (https://pearl.plymouth.ac.uk/cgi/viewcontent.cgi?article=1007&context=foh-datasets).

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Morrish N, Medina-Lara A. Health Economics Report *(persistent identifier for the HE report is as follows:* http://hdl.handle.net/10871/140875).

In preparation

Shafi H, Oh TM, Batool S, Butt, A, Quinn C, Clarkson P, *et al*. Approaching and recruiting South Asians living with dementia and their carers into the Dementia PersonAlised Care Team (D-PACT) project. In preparation (*Report Supplementary Material 1*).

Smith L, Griffiths S, Oh TM, Richards D, Lee T, Warwick B, Wheat H. Developing a Talking Mat to facilitate engagement in a realist dementia evaluation. In preparation (*Report Supplementary Material 3*).

Spicer SG, Wheat H, Oh TM, Shafi H, Hart M, Smith L and Byng R. Using electronic healthcare record data in the evaluation of the Dementia PersonAlised Care Team (D-PACT) intervention. In preparation (*Report Supplementary Material 2*).

Oh TM, Musicha C, Byng R, *et al.* Evaluation of a primary care-based intervention for people with dementia and their informal carers using a realist mixed-methods before-and-after design: quantitative findings from the Dementia PersonAlised Care Team (D-PACT) study. In preparation.

Oh TM, Wheat H, Dalkin S, Bate A, Lee T, Byng R, *et al.* Personalised care for people with dementia and their carers in the D-PACT study – what works, for whom, why and at what cost: an exploratory and preliminary realist-informed economic analysis. In preparation.

Wheat H. (Full author list to be confirmed). Enabling dementia support workers to provide personalised, primary care based support: findings from the Dementia PersonAlised Care Team (D-PACT) project. In preparation.

Wheat H, Shafi H, Griffiths S, *et al*. Empowering dementia support workers to deliver personalised, primary care based support: qualitative findings from the Dementia PersonAlised Care Team (D-PACT) project. *BMC Primary Care* (under peer review).

Wheat H, Griffith S (Full author list to be confirmed). The use of conversation analysis, alongside realist evaluation methodology: experiences from the Dementia PersonAlised Care Team (D-PACT) project. In preparation.

Presentations

Griffiths S, Manger L, Chapman R, Sherriff I, Quinn C, Mann V, *et al. Involving Participants from Underserved Populations with Dementia in Primary Care Research*. Poster presentation at the Society for Academic Primary Care Annual Meeting, July 2019.

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Griffiths S, Manger L, Chapman R, Sherriff I, Quinn C, Mann V, *et al. Involving Participants from Underserved Populations with Dementia in Primary Care Research*. Poster presentation at the 5th International Clinical Trials Methodology Conference, October 2019.

Oh TM. *Dementia Person Aligned Care Team (DPACT) Programme: A Study on Dementia Support*. Oral presentation at the Plymouth International Dementia Conference, November 2019.

Wheat H, Griffiths S. *Dementia Support Workers Transitioning from Providing In-Person to Virtual Support During COVID-19*. Webinar hosted by Empowered Conversations, 9 September 2020.

Griffiths S. *What Does Personalised Care Planning Mean for Care Homes? Personalised Care Planning. Transferable Learning from D-PACT*. Oral presentation at PenARC Seminar, December 2020.

Griffiths S, Weston L. *Engaging People Living with Dementia and Field Experts in Programme Theory Development: A Realist Informed Approach*. Oral presentation at CARES (Centre for Advancement in Realist Evaluation and Synthesis) 2020 Conference (online).

Doran Z, Coombes J. *Application of Feasibility Lessons During COVID-19 Within An Evaluation of A Primary Care Based System of Dementia Care in the Form of A Specially Trained Dementia Support Worker*. Oral presentation at the South West Regional Meeting of the Society for Academic Primary Care, March 2022.

Oh T. *The 'Embedded Researcher' Model: Facilitating Research in Primary Care*. Poster presentation at the South West Society for Academic Primary Care Annual Meeting, March 2023.

Wheat H. *Developing Shared Understanding Remotely: A Thematic Analysis of Multiple Data Sources from the Dementia PersonAlised Care Team*. Oral presentation at Alzheimer's Europe, Bucharest, 2023.

Wheat H. *Delivering Theory- Based Practitioner Training for Personalised Coaching to Support People with Dementia and Carers: Qualitative Reflections from Practitioners and Trainers*. Oral presentation at Alzheimer's Europe, Bucharest, 2023.

Wheat H. *Delivering Primary Care Based, Post Diagnostic Dementia Support: Learning Relating to Best Practice from the Dementia Personalised Care Team Evaluation*. Oral presentation at 'Best Practice London' 28 February 2024.

Oh TM, Wheat H, Richards D. *Post-Diagnostic Support for People with Dementia and Their Carers: The D-PACT Study*. Oral presentation at Devon Dementia Event, 16 January 2024.

Oh T. *Advance Care Planning Support by Dementia Support Workers: What Works, for Whom and in What Circumstances*. Poster presentation at Alzheimer's Disease International (ADI), Krakow, Poland, 24–26 April 2024.

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Wheat H. *Supporting Dementia Support Workers to Adapt to Their Role Within A Primary Care Setting: What Works, for Whom and in What Circumstances*. Poster presentation at Alzheimer's Disease International (ADI), Krakow, Poland, 24–26 April 2024.

Oh T. *Recruiting People Living With Dementia (Including Those Who Lack Capacity to Consent) Remotely Versus In-Person: Learning from the Dementia PersonAlised Care Team (D-PACT) Feasibility Study During COVID-19*. Oral presentation at Alzheimer's Disease International (ADI), Krakow, Poland, 24–26 April 2024.

Wheat H. '*Findings of the Realist Mixed Methods, Longitudinal Evaluation of the D-PACT (Dementia Personalised Care Team), Primary Care Based, Post-Diagnostic, Dementia Care Model*'. Oral presentation at the 34th Alzheimer Europe conference 'New horizons – Innovating for dementia' Geneva, Switzerland, 8–10 October 2024.

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Appendix 1 Refined and consolidated delivery tier programme theories

Delivery tier consolidated theory					
Continual chain/loop of CCMOs					
Relationship-building			**Personalised support**		
Intervention component (mechanism-resource)	**Mechanism responses**	**Evidenced outcomes (and new context)**	**Intervention component (mechanism-resource)**	**Mechanism responses**	**Examples of (evidenced) outcomes**
DSWs take a personalised approach to initial relationship-building	Positive relationship between people supported and DSW forms through changes to their reasoning	Ongoing engagement by people supported In 76/83 case studies for as long as the support was offered, or they remained eligible Ongoing disclosure of support needs during meetings Evidence of at least one support need disclosure in all (83) case studies (typically several disclosures occur over course of support) Proactive contact between scheduled meetings by people supported In 55/83 cases (total occurrences of proactive contacts within an individual case ranged from 1 to 5)	Personalised support on what matters most to people (support needs falls under four types of care and support: support with living well; enhanced reactive care, proactive care and transitions in care)	Living well • Carers feel more able to continue to provide support due to reassurance they are doing the right things, their feelings are normal and someone else knows their situation; their role being acknowledged and praised; and an enhanced understanding on their situation/events and how to manage it, for example, why people they care for may be acting in certain ways and how to manage behaviours that challenge or/and how to manage symptoms of dementia at home, such as hallucinations and incontinence • The dyad (PwD and carer) better understand each other's perspectives and start to think about other ways to address/support what matters to each of them • Individuals/dyad's motivation to apply for/try out new forms of support (e.g. government aid, community groups, tools and interact with other professionals/ practitioners improves (through improved knowledge and confidence they will be supported throughout process) • Other medical professionals awareness for how to support the QoL (e.g. by enhancing their ability to self-manage, enhancing their understanding of their diagnosis, attending to other comorbid conditions) of people supported is improved and they become motivated to act	Improved QoL, well-being and independence (see examples of how this was achieved through personalised care below) Maintained improvement (during support) to mood (n = 19 carers, three PwD). New self-management strategies employed (non-pharmaceutical) (n = 14 instances, in 14 cases). Care package increased (n = 5 cases) Financial aid increased (n = 3 cases), or in process of being applied for (n = 1) Increased social engagement (for PwD, n = 8 PwD cases; n = 4 carer cases; and n = 2 cases for dyads). Support with managing medication for dementia and other long-term conditions (n = 11 cases). New forms of care provided from other professionals (n = 1 case, Physiotherapist, n = 3 cases, Occupational therapist), n = 1 case, bowel and bladder clinic; n = 2 cases, district nurse; n = 2 cases, social prescribers, n = 2 cases, carer support worker, n = 2, carer's organisation, n = 1 and n = 1 case, podiatrist). Improved choice and control over care (over what care and support is accessed/provided (or not), and how it is delivered (n = 17 cases).

continued

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Delivery tier consolidated theory					
Continual chain/loop of CCMOs					
Relationship-building			**Personalised support**		
Intervention component (mechanism-resource)	**Mechanism responses**	**Evidenced outcomes (and new context)**	**Intervention component (mechanism-resource)**	**Mechanism responses**	**Examples of (evidenced) outcomes**
				Reactive care • Enhanced GP (or other professional/ practitioner) understanding of situation or gap in care and motivation to act • People supported feel more ready to seek and engage in support (because, e.g. concerns have been validated, enhanced awareness of need for support; concerns about engaging with others have been addressed)	Likelihood of improved health outcomes being realised increased (see examples of how this was achieved through personalised care below) New or altered drug medication for dementia or other long-term condition (*n* = 21 cases, including one carer case – sometimes multiple changes to medication in one case) Referrals or actual contact with other (non GP) practitioner: *n* = 18 cases (including occupational therapists, physiotherapists, podiatrists, Parkinson's team, pain and incontinence clinics, Speech and language therapy team and district nurse). Four cases involved more than one contact with another practitioner Treatment prioritised for patient due to high-risk situation/condition that the DSW has alerted others to directly or by requesting further investigative action (*n* = 8 cases) Further tests/investigations (*n* = 5 instances, in six cases) Dementia (or other long-term condition) review or medication review conducted *n* = 14 (2 × diabetes, 2 × mental health, 1 × asthma, 5 × dementia, 4 × medication). *Medium-long-term outcomes (resulting from above actions)* Ongoing monitoring (e.g. blood pressure, weight) *n* = 2 cases • Reported improvement to physical health of PwD (*n* = 9 cases) • Reported improvements to mental health/well-being *n* = 4 cases for PwD and one carer).

By…	Types of changes for people supported…	Through…		
• Offering flexible, ongoing support, and providing people supported with control over how often, how (with, without carer) and where (remotely, their home, GP surgery or other location) they met • Sufficiently explaining their role and how they could help support • Proactively addresses support needs people are already aware of, while continuing to take time to get to know them • Providing means for people supported to contact DSW in between scheduled appointments, and reinforcing point that it's okay to make contact when they need to • Adapting approach to building initial relationship if existing crisis (i.e. attends to this immediately) • Proactively arranges appointment for next meeting, making sure it works for people supported	• Believe the DSW's interest in them is genuine • Believe the support will lead to positive change (through enhanced understanding of role and confidence in DSW's ability and motivation to support them on an ongoing basis) • Believe the support was something under their control – would not cause more overwhelm and they would be respected • Feel a connection with the DSW • Feel increasingly comforting interacting with the DSW • Feel listed to and understood by the DSW • Feel reassured, and an enhanced sense of safety that they had someone they could reach out to when needed • Look forward to and enjoyed the interactions with the DSW – made them feel more like a normal person	• Personalised information sharing and suggestions of potential actions/ additional forms of support to help address what matters to them (what they have disclosed) • Socioemotional support (individual and relational), • Practical support (e.g. completing application forms) • Support to get new care and support from others/or improve existing support from others by engaging with other professionals (liaising on their behalf, stepping up care or facilitating direct contact) • Detecting changes (e.g. new/altered symptoms, altered ability to cope), making people supported aware and (with permission) altering others	Proactive care • Peoples' motivation to plan (initially or further) for the future increases (through improved knowledge, reassurances of why they are planning and confidence they will be supported throughout process) • practitioners/professionals (not DSW) who can support future planning become aware of peoples' readiness to plan for the future and are motivated to act • DSWs become aware that people supported are not ready to discuss future plans • Practitioners become aware of need to do outstanding/upcoming dementia review	Increased independence (control over care); QoL; and likelihood of enhanced health outcomes being realised (see examples of how this was achieved through personalised care below) Some form of plan to manage future care situations put in place (*n* = 27 instances, in 19 cases). DSW closes topic of future planning (for now) in response to preferences of people support *n* = 6 cases Dementia review conducted (*n* = 2 cases)
			Transitions in care • People better informed about treatment choices and how to manage situations that arise during transitions in care • Practitioners/professionals become more aware of need to support care transitions/consequences of transitions and are motivated to act • People supported more motivated to act (through improved knowledge, validation of concerns and confidence they will be supported throughout process) • People supported feel reassured that plans will be put into place • People supported feel able to share and process how they are feeling during transition	Increased independence (control over care); QoL; and likelihood of enhanced health outcomes being realised (see examples of how this was achieved through personalised care below) Informed decision regarding treatment made (*n* = 2 cases). Increased support with hospital admission/discharge (*n* = 6 cases). Support with care home transition (*n* = 1 case) Enhanced end-of-life support (physical comfort enhanced, plan for care checked and shared, socioemotional support during end of life and for carer after PwD dies (*n* = 2 cases).

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Unintended outcome: in one case, people supported started to contact the DSW inappropriately. DSW received support during supervision to manage situation.	Unintended outcomes: Frustration and disappointment for PwD and carers due to: a) time and effort spent applying for further support not resulting in further help due to their ineligibility (*n* = 2) and b) after reaching out to other practitioners/professionals, they do not receive a response or there is a lack of capacity to provide support (*n* = 4) Increased burden for carers during period in which they apply for certain support, which is not later outweighed by value of additional support. Deters people from applying for further support (*n* = 2) PwD has increased anxiety from seeing people with advanced dementia at support group DSW supported them to attend (*n* = 1) Related to reactive care: PwD and carers feel disappointed by referrals for care being rejected GP potentially being inappropriately tasked with action (costing them time) Related to Proactive care: Focus on planning for future care leads to carer considering whether the DSW's support may have been more suited from someone else
Contextual factors affecting delivery and response to DSWs' support: *Within support meetings:*	Contextual factors affecting delivery and response to DSWs' support: *Within support meetings:* Whether the DSWs … • Continue to take a personalised approach to relationship-building; • DSW staff turnover (could take time to get used to new DSW, some people chose to end support after original DSW left)
Whether the DSWs … • Had sufficient person-centred coaching-based communication skills to develop relationship. Examples of communications kills/approaches that supported relationship-ship building were: friendly and calm demeanour, checking what name to use for individuals supported; displays of empathy and sympathy; not pushing an agenda or rushing conversation – encouraging conversation on a wide range of subjects, not just dementia; using non-judgemental language; asking relevant questions and supporting reflection; picking up on things of interest to people supported; leaving space for everyone to talk and ensures PwD has a voice/is engaged with; attentive listening; use of communication tools/aids and adapting communication to suit specific needs for example, hearing loss; providing opportunities for, and engaging in presented opportunities for laughter. • Participated in shared activities, for example, sharing tea and cake • Appropriately used self-disclosure (interests, life stories; own personal experience of dementia) • Demonstrated dementia expertise • Had local presence and knowledge • Ethnicity and multilingual abilities aligned with needs/preferences of individuals (e.g. when PwD did not speak English)	Personalise suggestions for possible support and care, ensure everyone's' ideas are taken into consideration and used to inform further ideas/decisions; • have had sufficient training/prior experiences, access to patient medical records, and contact with people supported to detect changes (e.g. new/altered symptoms) and/or transition points in care • are amendable and confident to take on other monitoring tasks, such as checking and feeding back blood pressure results (and whether the surgery supports these additional actions) • Proactively seek opportunities to collaborate with surgery staff this will affect the attention GPs give to DSWs medical record entries. T • Can appropriately determine when to task GPs, via patient medical records (too many tasks may make GPs start to feel overwhelmed

Whether there was …
- The copresence of carer/PwD in support meetings (affected peoples' ability to talk freely, build shared understanding; and extent to which PwD was supported to talk)
- A suitable environment – people felt more at ease due to meeting DSW in their own home, some were unable to get to surgery easily, others preferred meeting at surgery as gave them motivation to get out.

DSW support:

Whether DSWs
- Has sufficient contracted hours and a manageable caseload when taking on new cases
- Had sufficient initial and ongoing training, supervision and peer support
- Geographical distance they had to cover for people within their caseload
- Were embedded within GP surgeries (e.g. whether DSW could gain a historical perspective of peoples' situation through access to their medical records, whether people supported viewed the DSW as part of the surgery depended on the extent to which all surgery staff were aware of the DSW role).
- DSW's knowledge of what support/resources were available in the community
- Took time to self-reflect on how interactions are going

Support provided by practitioners/professionals/groups that DSWs facilitate:

Whether …
- Social groups also encourage choice and control e.g. give people choice over how much they engage
- Community activities align with peoples' preferences;
- Contact can be made (by people supported and DSWs), with other practitioners/professionals who can potentially provide support
- There is capacity for others to provide support
- The eligibility criteria for support that others/government sets allow further support to be provided
- The degree of burden imposed through the process of applying for help outweighs the value of support it may provide
- Practitioners hear the voice of the patient and are sufficiently updated on the patients situation, via the DSW, will inform their motivation to act and their own care delivery e.g. how they approach appointments/reviews; the quality of care others provide is adequate, and whether the DSW will try and rectify inadequate care e.g. by seeking an appointment with different professional/supporting patient feedback/pursuing contact when none has been offered or been delayed

DSW support:

Whether DSWs receive …
- Holistic, multimodal, immediate and ongoing training on all four areas of care, as well as how to delivery person-centred, coaching-based care (a skill that can take time to develop). Ongoing training should be reactive to DSWs' specific training needs. Modes of training should support different learning styles/preferences, staggered learning, and provide a means for trainers to identify gaps in knowledge
- Specific training on how to navigate and use patients medical records by surgery staff and supervisors or peer and have ongoing access to patient medical records and ability to add notes/tasks (supports communication with GPs and other professionals and supports monitoring and detection (see above). Access can be affected by software crashes/hacks and governance concerns
- Peer support from fellow DSWs on knowledge acquisition, reflecting on practice and their own emotional well-being. Having DSWs with a range of backgrounds; sufficient time to meet regularly, and a location to meet at, can facilitate this
- An opportunity (and time) to shadow other DSWs at the start of role commencement and shadow specific activities/interactions undertaken by DSWs or other practitioners in the future. This can help enhance confidence to deliver the role by demystifying the role and expand DSW's interactional tool box of how to address certain situations
- Support from other professionals/practitioners within the community, especially when the DSW is unsure of how to handle a new situation, will be working with the same patients/clients (can help avoid duplication, co-ordinated care, greater reach). The degree of support can be affected by others' understanding of the DSW role, the degree to which they think it's needed in the area/the role overlaps with their own, and their capacity to collaborate
- Sufficient contracted hours, and a manageable caseload. This can affect how quickly and to what degree they respond and follow-up on agreed actions
- Support from a supervisor based within one of their PCN surgeries (practice manager or GP, for example), who champions their work and looks for ways to utilise the DSW in current practices
- Support from a clinical supervisor who can help identify and address risk in the DSW's caseload, and provide input, informed by their access to hospital records and own role within the community, when appropriate (helps inform DSW decision-making/address concerns, especially with support with transitions in care)
- Support from all supervisors in extending their (DSW) professionals/practitioner network, reflecting on practice, developing person-centred coaching skills, taking on challenging aspects of the role, and knowledge acquisition of local and national processes. Supervisors require their own sufficient support (time and supervision) to enact all aspects of this role
- A space within surgeries they work within to help build a sense of belonging to the surgery team and creating opportunities to interact

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People supported: • Prior experiences of care (e.g. clinical, rushed, patronising, not listened to) – was notable when DSWs acted differently to this • Extent of current support they are receiving (e.g. if a lot of existing support people may not feel as much need to engage with DSW regularly or may need further clarity on how DSW's role is different to others). • Their current level of mobility, e.g. affecting their choice of where to meet DSW; • Extent of current overwhelm from information shared on dementia • Current level of need (carer and PwD), that is, less appropriate to spend time relationship-building when people are currently at crisis	*People supported:* To what extent they are … • Ready for certain forms of support (e.g. they may not be aware of the types of support on offer; may feel too overwhelmed to take more on; may not want to think about what lies ahead or feel that its best to react to new situation when they arise, rather than plan ahead) • Are able to access certain materials, for example, their ability to read and write (affecting information access and how DSW provides support) • Have had prior negative experiences of GP surgery they are registered at (affecting motivation to engage with them further) • Believe the DSW is part of the surgery and can inform surgery staff actions • Are mobile (able to attend activities, access services) • realistic of what the DSW support could provide e.g. respite (which may not be something DSWs could secure) • Have concerns about whether there is capacity within health/social care to attend to all their needs (may not relay all needs to DSWs or fully commit to action taking as a result) • Aware of what outcomes have been achieved by the DSW (sometimes the DSW's actions were happening behind the scenes)

Appendix 2 Refined and consolidated facilitation programme theories

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CCMO 1: *explaining how training can improve DSWs' understanding of what areas of support PwD and unpaid carers may need – resulting in their improved delivery of personalised care*				
	C	C	M	O
Status of programme theory and previous elaboration theories drawn upon	**Context affecting delivery and response to support offer**	**Support offer (intervention component or mechanism-resource)**	**Mechanism (change in reasoning)**	**Immediate outcome (change in DSW behaviour)**
Refined and substantiated through evidence Informed by elaborated theory 4	Delivery of training	IF initial training provides information on a range of biopsychosocial support topics for PwD and carers, through various formats, and is delivered in a staggered way (with the order of training informed by DSW needs and what information they will need to know right from the start) And ongoing access to these training resources is provided	THEN DSWs will gradually build understanding (through activation of own learning styles, reinforced learning, increasing congruence between training and practice) of a broad range of biopsychosocial needs that people living with dementia and carers can require support on	THEN DSWs will provide support to PwD and their unpaid carers on a wide range of biopsychosocial support needs

CCMO 2: *explaining how peer support can improve DSWs' understanding of what areas of support PwD and unpaid carers may need – resulting in their improved delivery of personalised care*				
	C	C	M	O
Status of programme theory and previous elaboration theories drawn upon	**Context affecting delivery and response to support offer**	**Support offer (intervention component or mechanism-resource)**	**Mechanism (change in reasoning)**	**Immediate outcome (change in DSW behaviour)**
Refined and substantiated through evidence Informed by elaborated theory 11	DSW capacity to meet up with peers Diversity of DSW background	IF DSWs are provided with guidance on how peer support can support knowledge acquisition (through information sharing and a space to share ideas) of how to support people on a variety of support needs AND are encouraged and supported (by trainers, supervisors, employers) to create opportunities to engage in, and self-manage such support (i.e. the frequency, focus and mode of meetings)	THEN DSWs will learn how to approach support for a variety of biopsychosocial needs in different ways/in different situations THEN DSWs will draw confidence from the confidence of other DSWs to provide support on certain topics	THEN DSWs will provide support to PwD and unpaid carers on a wide range of biopsychosocial support needs THEN DSWs will use a wider variety of approaches to improve/tailor the support they provide to the people they work with UNINTENDED: in a team of DSWs with mixed experience, more experienced DSWs may end up providing most of the support, benefit less from support and feel concern that they are not supporting in the right way (due to lack of supervision experience) or are being overly directive

CCMO 3: ***explaining how core competencies checks and reflective exercises during supervision can enhance DSWs' understanding of what areas of support PwD and unpaid carers may need – resulting in their improved delivery of personalised care***

Status of programme theory and previous elaboration theories drawn upon	C Context affecting delivery and response to support offer	C Support offer (intervention component or mechanism-resource)	M Mechanism (change in reasoning)	O Immediate outcome (change in DSW behaviour)
Refined but requires further evidence to be substantiated Informed by elaborated theory 32	Accessibility of language used (further contextual details to be identified through further testing)	IF a core competencies checklist is used by supervisors to prompt a discussion about what types of biopsychosocial support needs can be linked, how to identify links, and how to relay this to people the DSW supports	THEN DSWs will have a better understanding of how to support people with linked biopsychosocial needs	THEN DSWs will help PwD and carers to recognise connections between their biological, social and psychological needs and support them to use this information to inform decisions about their care

CCMO 4: ***explaining how training resources can enhance DSWs' understanding of how to articulate their role and their approach to care to people supported – resulting in their improved delivery of personalised care***

Status of programme theory and previous elaboration theories drawn upon	C Context affecting delivery and response to support offer	C Support offer (intervention component or mechanism-resource)	M Mechanism (change in reasoning)	O Immediate outcome (change in DSW behaviour)
Refined but requires further evidence to be substantiated Informed by elaborated theory 6	Unknown (due to need to test theory out)	IF a resource is made available to DSWs to share with people supported that uses case study examples to help convey what the DSW's role is, what they can provide support on, and how they will provide support	THEN DSWs will have a better understanding of how to explain their role and their approach to support to people on their caseload	THEN DSWs will accurately and effectively explain their role and approach to care to people they support

CCMO 5: ***explaining how shadowing can enhance DSWs' understanding of how to deliver support in a personalised way – resulting in their improved delivery of personalised care***

Status of programme theory and previous elaboration theories drawn upon	C Context affecting delivery and response to support offer	C Support offer (intervention component or mechanism-resource)	M Mechanism (change in reasoning)	O Immediate outcome (change in DSW behaviour)
Refined and substantiated through evidence Informed by elaboration theory 3	Pre-delivery of training on how to interactionally deliver the role IF DWs have capacity to shadow each other IF DSWs within the team have varying levels of experience (of the role, different settings) If supervision provides an opportunity for shadowing experiences to be discussed and used to inform reflections	IF a DSW is given the opportunity to reflect on their own practice by shadowing other DSWs	THEN DSWs will use the comparative insight to strategise on how they want to deliver the role in various settings THEN the DSW will feel reassured that their own approach to care aligns with the D-PACT model	THEN DSWs will adapt their own interactional approach to care, when in various settings

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CCMO 6: ***explaining how semi-guided, video stimulated reflections can enhance DSWs' understanding of how to deliver support in a personalised way – resulting in their improved delivery of personalised care***

	C	C	M	O
Status of programme theory and previous elaboration theories drawn upon	**Context affecting delivery and response to support offer**	**Support offer (intervention component or mechanism-resource)**	**Mechanism (change in reasoning)**	**Immediate outcome (change in DSW behaviour)**
Refined and substantiated through evidence Informed by new theory developed at the feasibility phase	Pre-delivery of training on how to interactionally deliver the role DSW willingness to self-record their support meetings and patients' preferences for whether meetings are recorded – DSW willingness enhanced when they have ongoing positive relationship with trainer and flexibility in when recordings are done is provided	IF DSWs are provided with opportunities to reflect on their own practice through observation of recorded support meetings with patients	THEN DSWs will have more accurate understanding of how they communicate in practice, and how that influences the trajectory of the interaction, which in turn develops or reinforces a belief in the value of using specific communication practices develops Considers what worked well and less well in that situation and how that knowledge could be applied to future support meetings	THEN DSWs will actively work towards the development of communication skills that enhance their delivery of personalised care

CCMO 7: ***explaining how supervision can enhance DSWs' understanding of how to deliver support in a personalised way – resulting in their improved delivery of personalised care***

	C	C	M	O
Status of programme theory and previous elaboration theories drawn upon	**Context affecting delivery and response to support offer**	**Support offer (intervention component or mechanism-resource)**	**Mechanism (change in reasoning)**	**Immediate outcome (change in DSW behaviour)**
Refined and substantiated through evidence Informed by elaboration theories 13 and 14	At the start, DSWs may be less able/willing to bring forward their own suggestions for reflection – scenario-based reflection, using real-life examples, can help facilitate such discussion in this situation	IF the supervisor encourages the DSW (through coaching-based questions, and scenario-based discussions) to think though how to approach care in specific situations and when appropriate, offers suggestions on how to approach care	THEN the DSW will self-assess whether the approach they are currently taking to care is working well, whether it needs to be modified and whether anything else could be done THEN the DSW will gain a better understanding of how various situations can be approached	THEN the DSW will DSW will increasingly self-adapt their approach to care – tailoring it to certain situations

CCMO 8: ***explaining how supervision can enhance DSWs' understanding of how to manage a caseload in a personalised way – resulting in their improved delivery of personalised care***

Status of programme theory and previous elaboration theories drawn upon	C Context affecting delivery and response to support offer	C Support offer (intervention component or mechanism-resource)	M Mechanism (change in reasoning)	O Immediate outcome (change in DSW behaviour)
Refined and substantiated through evidence Informed by elaborated theory 34	IF the DSWs' caseload has suddenly gone up substantially IF DSWs had part-time hours and other commitments (e.g. college/university courses) IF some case-management strategies (e.g. having a space at the local surgery to meet the people they supported to save on travel time) were not possible for reasons beyond the DSWs' control, for example, availability of space at a surgery, geographical distance they had to cover	IF supervisors suggest specific case-management strategies, prompt DSWs to pose their own ideas for caseload management, and then create an opportunity to review each individual strategy's merits/challenges, before one (or more) is selected to try	THEN DSWs will reflect on what approaches to time management will work for them	THEN DSWs will try out time management strategies

CCMO 9: ***explaining how peer support can develop positive beliefs about competency – resulting in their improved delivery of personalised care***

Status of programme theory and previous elaboration theories drawn upon	C Context affecting delivery and response to support offer	C Support offer (intervention component or mechanism-resource)	M Mechanism (change in reasoning)	O Immediate outcome (change in DSW behaviour)	O Distal outcomes
Refined and substantiated through evidence Informed by elaborated theories 11 and 25	IF DSWs think that fellow DSWs are doing a similar role to them IF DSWs start the role at the same time IF DSWs have capacity to meet with one another	IF DSWs are provided with capacity and space to meet (on their own/in group supervision) to share experiences of, and feelings associated with enacting the role	THEN DSWs will feel part of a team	THEN DSWs will disclose uncertainties and concerns to fellow DSWs	THEN DSWs will view their emotions/experiences as normal (rather than an indication of incompetence) THEN DSWs will continue to feel connected and supported (not lonely)

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CCMO 10: *explaining how training on, and access and use of, patient medical records can improve how DSWs' provide timely updates to other surgery staff on changes in symptoms/situation of people supported – resulting in the improved delivery of primary care-based personalised care*

	C	C	M	O	M	O	O
Status of programme theory and previous elaboration theories drawn upon	**Context affecting delivery and response to support offer**	**Support offer (intervention component or mechanism-resource)**	**Mechanism (change in reasoning for DSW)**	**Immediate outcome (change in DSW behaviour) and new resource for other practitioners**	**Mechanism (change in reasoning for other practitioners)**	**Immediate outcome (change in other practitioner, namely GP, behaviour)**	**Medium-long-term outcome for DSWs**
Refined and consolidated through evidence Informed by elaborated theories 30, 44 and 45	*Referral pathways:* when people were referred to DSW through different means, for example, memory clinic, DSWs may not immediately (or ever) have access to their patient medical records as they are held on a different system *Others' access to records:* other professionals DSWs work with may not have access to patient medical records or choose to share case information differently *DSWs' contact with patients:* DSWs needed to have sufficient face to face contact with the people they support to be able to pick up on changes in their symptom/situation *Additional support*: IF supervisors and fellow DSWs (with experience of using patient medical records) can supplement training provided by GP surgeries with their own support	IF DSWs are given access to patient medical records, and the option to add entries, alongside training and support from their assigned GP practice surgeries on navigating and using patient medical records	THEN DSWs will develop a baseline understanding of the current health status of the people they support THEN DSWs will understand how to update surgery staff on changes to symptom/ situation of people they support	THEN DSWs will identify changes/ or a notable lack of change to the symptom and situation of people they support; update other practitioners on these changes; and in some cases task other practitioners (namely GPs) to act	THEN other practitioners will have a better understanding of the needs and situation of PwD and carers registered at their surgery and will be motivated to act	THEN other practitioners will engage with PwD and carers requiring further care/support and if appropriate offer new/ modified treatment options	THEN DSWs (observing that practitioners/ professionals are acting on their insights) will feel an increased sense of belonging to a team, support, and confidence in their ability to manage, and inform complex care cases, through partnership with other surgery practitioners – enhancing their readiness to collaborate

CCMO 11: ***explaining how access to patient medical records can improve how DSWs' ability to monitor whether annual reviews for dementia and other long-term conditions are being undertaken by surgery staff – resulting in the improved delivery of primary care-based personalised care***

	C	C	M	O	M	O	O
Status of programme theory and previous elaboration theories drawn upon	**Context affecting delivery and response to support offer**	**Support offer (intervention component or mechanism-resource)**	**Mechanism (change in reasoning for DSW)**	**Immediate outcome (change in DSW behaviour) and new resource for other practitioners**	**Mechanism (change in reasoning for other practitioners)**	**Immediate outcome (change in other practitioner, namely GP, behaviour)**	**Medium-long-term outcome for DSWs**
New theory	*The extent to which the DSWs are embedded in the surgery affects the extent to which they are involved in the annual review process* (only occurred at surgeries the DSWs has a prior existing relationship with and a supervisor who was a practice manager at the surgery and championed their involvement in the surgery's provision of dementia care) *The attitude of the surgery toward annual dementia reviews:* some surgeries were proactively trying to improve their dementia review offer and their frequency *Disclosure during reviews:* Patients may forget what they want to discuss when they are having the review (and the DSW is not present to remind them). However, if DSW has taken concise, relevant notes regularly and shared with GP this can help ensure things are not missed	IF DSWs have access to patient medical records they can monitor the occurrence of reviews and progress with agreed referrals	THEN DSWs will become better aware of when a review is due	THEN DSWs will prompt GPs to undertake the review (facilitating arrangement making when helpful to do so), highlighting what may need to be focused on in their patient medical record entries	THEN the professional/ practitioner will become more aware of the need for the review	THEN a review, informed by DSW insights, will be conducted *Other possible immediate outcomes* THEN professionals/ practitioners will involve the DSW in the review process and follow-up actions -making the review process more beneficial because 1) GPs can choose to focus on aspects of care needing to be prioritised during the review and leave outstanding actions/ concerns to be followed up on by the DSW (any causes of concern/outstanding actions not addressed in reviews can still be picked up on) 2) (If present) DSWs can help mediate when PwD and carers may have moments of conflict during the review and support disclosure	THEN the DSWs will become more embedded within the surgery

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CCMO 12: ***explaining how supporting DSWs to understand what type of referrals (or more broadly primary care tasks) fall within their remit and how to enact them can enhance DSWs' ability to enhance the care provided by GP practice surgeries – resulting in the improved delivery of primary care-based personalised care***

	C	C	M	O	O
Status of programme theory and previous elaboration theories drawn upon theories	**Context affecting delivery and response to support offer**	**Support offer (intervention component or mechanism-resource)**	**Mechanism (change in reasoning for DSW)**	**Immediate outcome (change in DSW behaviour) and new resource for other practitioners**	**Medium-long-term outcome for DSWs**
New theory	*Extent of DSW embedding:* DSWs needed to be fully embedded with the primary care surgeries they were assigned to *Prior experiences of working within primary care (especially when past experiences were at assigned surgeries):* sped up understanding and associated DSW behaviour change	IF training includes clear instruction on what types of referrals (primary care tasks) should fall within and outside of the DSW remit, and guidance on how to enact these referrals (primary care tasks) And IF primary care surgeries, adopting the D-PACT model, are required to coagree with DSWs as early as possible (potentially through the development of bespoke job descriptions) what referrals (primary care tasks) they will perform to ensure tailored DSW support is provided And IF supervision provides opportunities for DSWs to reflect on the suitability, impact and training requirements imposed by their requirement to complete certain referrals (primary care tasks) And IF DSWs have access to patient medical records and can make referrals (complete primary care tasks) though that system And IF a practice-based supervisor provides guidance on how referral processes and appointments (primary care tasks) can be made within the surgery, and on what resource/capacity is currently available with the surgery	THEN DSWs will better understand what referrals (primary care tasks) they should undertake, and when and how to undertake them	THEN DSWs can either progress a referral themselves or prompt others to do so	THEN GPs will form more positive beliefs about the benefits of working with the DSWs and relationships/ embedding of the DSW will be enhanced THEN DSWs will gain confidence in their ability to deliver the role and enhance the care of people they support

CCMO 13: ***explaining how DSWs being encouraged to initiate contact with other professionals/practitioners can improve DSWs' understanding of how other practitioners/professionals' roles within the surgery and community – resulting in the improved delivery of primary care-based personalised care***

Status of programme theory and previous elaboration theories drawn upon	C Context affecting delivery and response to support offer	C Support offer (intervention component or mechanism-resource)	M Mechanism (change in reasoning for DSW)	M Mechanism (change in reasoning for other practitioners)	O Immediate outcome (change in behaviour for DSW and other practitioners/ professionals)	O Medium-long-term outcomes
New theory	Other practitioners/ professionals pre-existing beliefs about the suitability of the D-PACT model for their area could delay collaboration (continued reassurances, and existing and/or demonstrated DSW expertise could gradually help forge collaborative relationships) DSW caseload, the geographical distance they covered, and contracted hours in the role, influenced the time available for DSW to undertake such activities outside of support meetings Limited DSW time made building relationships with staff at assigned surgeries unlikely. Non-attendance at surgery meetings (often due to DSWs working part-time) was seen as a barrier to developing relationships Some surgery staff felt the DSWs' personality and communication practices influenced relationship-building. Although such behaviours were often not natural or even comfortable actions for the DSW, they were enacted to make the model work	IF DSWs are encouraged during training and through supervision to reach out to other professionals/ practitioners though various means (e.g. attending community events, arranging meetings) to explain role; learn about their role; explore opportunities for them to shadow them (to learn more about their role) and to support each other's work	THEN DSWs will better understand other roles, how they can work with others, and care pathways in their surgery and area	THEN practitioners/ professionals will gain a better understanding of the D-PACT model and the DSW role and how they can work with them	THEN there will be increased collaboration between DSWs and other practitioners/ professionals	THEN DSWs will gain an enhanced understanding of how to support DSWs will a wide range of support needs though their own and others' care

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Appendix 3 The four care domains of D-PACT care and related DSW activities evidenced within the D-PACT evaluation

Care domains			
Support with living well	Enhanced reactive care	Proactive care	Support with transitions in care
Core components (DSW practices) *Which practices were enacted was informed by individual case situation and preferences of people supported. In some cases, multiple actions are taken. Not all care domains may be relevant to (or desired by) all people supported. However, this can change over time. Activities relating to different care domains may be enacted at varying time points in varying order* (i.e. *support related to specific domain not provided in a linear fashion)*			
Attending to the emotional needs of the individual • Provides opportunity/space to talk through challenging emotions, experiences and concerns • Validates carer's need to look after own needs and existing decisions made about care for PwD/their own care, • Highlights what people supported have done well • Provides tailored information about situations they are experiencing ***Attending to relational challenges for PwD-unpaid carer (dyad)*** • Acts as mediator, supports dyad to coagree actions, making tailored suggestions about possible actions when appropriate • Shares information on behaviours that challenges (causes and how to manage) ***Increasing social activities/contact*** • Gives tailored information on community activities • Makes initial introductions to community group leaders • Pairs people up with other people they support (after gaining permission)	***Acting on new/altered symptoms*** • Seeks guidance from experts to inform next actions • Alerts GPs (or other practitioner) of new/altered symptoms (and any relevant additional contextual details) • Requests GP does a medication review/consider change to medication • Suggests specific explanations for altered/new symptoms and possible treatment options • Supports contact between GP (other practitioner) and person supported by arranging/chasing appointments	***Planning for future care/situations*** • Supports carers to undertake contingency planning by sharing information about templates that can be used, how they can help, and by helping with form completion • Supports people to arrange power of attorney by providing tailored information • Supports people supported to meet with GP to discuss treatment escalation plans by sharing information on process, its benefits and liaising with GPs to get appointments set up • Supports PwD to complete the 'This is me document' by sharing the document, talking through its benefits and helping with completion • Supports carers to get a carer card by alerting them to scheme, getting forms sent out and supporting completion	***Supports with treatment decisions*** • Talks through benefits/disadvantages of certain treatments, providing tailored information and reassurances when helpful/appropriate ***Support with move to care/nursing home*** • Provides opportunity for carer to share concerns and suggestions on how to address them
Supporting adoption of new strategies to support independence • Provides tailored information on resources/tools/processes that support independence and practical support with using them • Supports engagement with other practitioners/professionals who can help support independence by sharing information about their roles and facilitating contact	***Acting on prolonged, untreated, unmonitored symptoms/illnesses*** • Prompts GP (or other practitioner) to do review of dementia or other long-term condition • Supports people to think through what to raise at medical appointments • Alerts GPs (and/or other practitioners) about lack of change in symptoms despite current treatment (and other relevant contextual details) • Facilitates contact with practitioners (e.g. helping arrange appointments, encouraging self-referral) • Suggests further tests are done	**Ensuring others are monitoring needs/care** • Monitors when reviews last done • Prompts dementia (or other long-term condition) review when needed/due • Engages with review process at surgery, for example, by sharing knowledge prior to reviews, working on agreed actions post review	

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Care domains			
Support with living well	Enhanced reactive care	Proactive care	Support with transitions in care
Supporting living at home • Provides a sounding board for decisions about day care for PwD • Supports discussions about respite • Provides tailored information about and practical support with applying for government assistance, for example, needs assessments and financial aid • Liaises with adults social care services and/or domiciliary care services about new/enhanced care packages on peoples' behalf • Provides tailored information and/or engages with others to provide support on self-managing symptoms such as incontinence, reduced eating, hallucinations • Supports self-management of medication by prompting action from GPs, pharmacists and other practitioners ***Support with navigating and accessing care and get outstanding queries addressed*** • Helps overcome barriers to contact (e.g. prior negative experiences of care; service unavailability, e.g. podiatry service stopped at GP surgery; triage system for appointments at surgery limiting access; lack of knowledge on how to contact certain professionals; and professionals not getting back to people supported after initial contact) • Shares information about how the surgery is managing certain aspects of care, for example, COVID injections • Ensures people supported have sufficient knowledge about dementia and their diagnosis to have informed perspective on care • Shares care preferences of people supported with other professionals/practitioners involved in care			***End-of-life care*** • Provides emotional support to PwD • Checks whether previously shared plans should still be enacted/amended • Shares people's plans about end-of-life care with relevant professionals • Encourages people supported to keep vocalising their wishes • Supports carer to process emotions after PwD dies

EME
HSDR
HTA
PGfAR
PHR

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