

# Evaluation of the Dementia-Personalised Care Team intervention for individuals with dementia and carers

<b>Submission date</b> 17/11/2021	<b>Recruitment status</b> No longer recruiting	<input checked="" type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
<b>Registration date</b> 13/12/2021	<b>Overall study status</b> Completed	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
<b>Last Edited</b> 20/01/2025	<b>Condition category</b> Mental and Behavioural Disorders	<input type="checkbox"/> Individual participant data <input checked="" type="checkbox"/> Record updated in last year

## Plain English summary of protocol

### Background and study aims

Dementia is a set of symptoms that includes short-term memory loss, problem-solving difficulties and communication problems. Such symptoms worsen over time. Currently, over 850,000 people in the UK live with dementia. The burden for people diagnosed with dementia and their carers is substantial. People with dementia and their carers often find accessing support services stressful and challenging. Access to a single person, to help with the coordination of care throughout the dementia journey, is strongly desired.

This study aims to find out whether Dementia Support Workers (DSWs), based in GP surgeries, are a good way to support people. In a previous study, the researchers developed and tested an intervention for people with dementia and carers. They now want to understand how D-PACT should be delivered in various settings, including those often overlooked in dementia research, such as South Asian communities, impoverished coastal communities and individuals with no carer at home.

### Who can participate?

Patients who have a diagnosis of dementia. Information will be sent out to potential participants who are identified by the GP practices taking part in the study. A main carer will also be recruited to the study wherever possible.

### What does the study involve?

Participants will receive a dementia support worker for roughly 12 months to identify issues that are personally important to them. The carer is not forgotten; their priorities are taken into account too. The DSW won't tell participants what to do. Instead, the DSW will help participants plan things to improve physical and mental well-being. This might include how to access available services, and 'thinking ahead' to the future. Researchers will invite participants for an interview at several points throughout the study, in order to understand their experiences. Participants will be asked to take part in audio-recorded interviews with a researcher about their experience of D-PACT, and to complete a set of questionnaires when they join and again at 6 and

12 months. Some participants will complete a diary to document their D-PACT experience, and some will be asked for their permission to have some of their sessions with the DSW audio recorded for analysis.

What are the possible benefits and risks of participating?

It is hoped that the study will help lead to a better understanding of how we can improve future support. It is possible that carrying out questionnaires and assessments at the beginning and end of the study might feel challenging or upsetting for some people. Researchers are experienced and sensitive to this and will adapt their process where needed.

Where is the study run from?

The study is run across two UK sites: South West (Devon Partnership Trust) and North West (Pennine Care NHS Foundation Trust). The South West is the lead site.

When is the study starting and how long is it expected to run for?

May 2021 to January 2024

Who is funding the study?

National Institute for Health Research (NIHR) (UK)

Who is the main contact?

Prof. Richard Byng

[richard.bying@plymouth.ac.uk](mailto:richard.bying@plymouth.ac.uk)

## Contact information

### Type(s)

Scientific

### Contact name

Prof Richard Byng

### ORCID ID

<http://orcid.org/0000-0001-7411-9467>

### Contact details

Community and Primary Care Research Group

Faculty of Health

University of Plymouth

Room N14

ITTC Building

Plymouth Science Park

Plymouth

United Kingdom

PL6 8BX

+44 (0)1752 764260

[richard.bying@plymouth.ac.uk](mailto:richard.bying@plymouth.ac.uk)

### Type(s)

Scientific

**Contact name**

Dr Tomasina Oh

**ORCID ID**

<http://orcid.org/0000-0003-4662-3193>

**Contact details**

Community and Primary Care Research Group  
Faculty of Health  
University of Plymouth  
Room N9  
ITTC Building  
Plymouth Science Park  
Plymouth  
United Kingdom  
PL6 8BX  
+44 (0)1752 764287  
[tomasina.oh@plymouth.ac.uk](mailto:tomasina.oh@plymouth.ac.uk)

## Additional identifiers

**EudraCT/CTIS number**

Nil known

**IRAS number**

302690

**ClinicalTrials.gov number**

Nil known

**Secondary identifying numbers**

CPMS 50334, IRAS 302690

## Study information

**Scientific Title**

Realist informed mixed-methods evaluation of the Dementia-Personalised Care Team intervention (D-PACT): a complex intervention for individuals with dementia and carers

**Acronym**

DPACT2

**Study objectives**

The Dementia Personalised Care Team Programme (D-PACT) is a National Institute of Health Research (NIHR) Programme Grant for Applied Research (PGfAR) funded programme that aims to determine the most effective deployment of dementia support personnel in primary care. In the initial feasibility study the intervention theory and inclusive recruitment methods were developed, as well as the selection of outcome measures. The D-PACT2 study aims to achieve an enhanced understanding of the D-PACT intervention delivery by:

1. Understanding how the D-PACT intervention is – and should be – delivered in varied settings

and further refine programme theory

2. Providing evidence about the potential value and impact of the D-PACT intervention

3. Contributing to the methodological development of community-based dementia studies

### **Ethics approval required**

Old ethics approval format

### **Ethics approval(s)**

Approved 05/10/2021, South Central Berkshire Research Ethics Committee (Whitefriars, Level 3, Block B, Lewins Mead, Bristol, BS1 2NT, UK; +44 (0)2071048224; berkshire.rec@hra.nhs.uk), REC ref: 21/SC/0280

### **Study design**

Non-randomized; Both; Design type: Treatment, Process of Care, Education or Self-Management, Dietary, Psychological & Behavioural, Complex Intervention, Physical, Management of Care, Active Monitoring, Qualitative

### **Primary study design**

Interventional

### **Secondary study design**

Non randomised study

### **Study setting(s)**

GP practice

### **Study type(s)**

Treatment

### **Participant information sheet**

Not available in web format, please use the contact details to request a participant information sheet

### **Health condition(s) or problem(s) studied**

Dementia

### **Interventions**

Potential participants will be approached by letter in the first instance. If there is no response to this invitation to take part, further approaches are made, in stages, which include a telephone call and home visit, where applicable. Potential participants who decline participation will be offered a short interview with a researcher to explore their reasons for declining - this is optional. Potential participants who then express an interest in participating to the researcher (as well as those potential participants who have self-referred to the researcher via word of mouth) will be provided with the Participant Information Sheet and Further Information Sheet and offered a meeting with the researcher (Study Involvement Meeting).

A member of the research team who is knowledgeable about the research will discuss the study with the potential participant. If the individual with dementia is eligible and agrees to participate in the study, the researcher and the individual with dementia will complete the approved Informed Consent Form. Similarly, if the carer agrees to participate in the study, the researcher and the carer will complete the approved Informed Consent Form. Should the individual with

dementia lack the capacity to give informed consent, and the designated consultee (usually the carer participant) considers that the individual with dementia would want to take part, the researcher and the consultee will complete the Consultee Declaration Form.

Participants with dementia will be asked to:

1. Complete demographics data collection with the researcher at baseline
2. Complete an assessment of cognition (MoCA) with the researcher at baseline
3. Take part in semi-structured interviews with a researcher at a minimum of one timepoint (but up to three) throughout their participation in the study
4. Keep and share with the researcher a reflective diary (in the form of either photos, texts or audio or written diary). This is optional
5. Have some selected DSW-participant interactions and follow-up feedback calls audio-recorded by the researcher. This is a sub-set of participants
6. Allow certain health care record data to be captured (general practice and Dementia Support Worker records)
7. With the researcher, complete a set of questionnaires at baseline, 4-6 months and 9-12 months, comprised of:
  - 7.1. A measure of experience of care (PERCCI)\*
  - 7.2. Supplementary questions to the PERCCI\*
  - 7.3. A measure of positive outcomes (EID-Q)\*
  - 7.4. Supplementary questions to the EID-Q\*
  - 7.5. A quality of life measure (EQ-5D-5L)\*
  - 7.6. A health and social care resource use survey\*

\*If the individual is unable to self-report, the carer will be asked to act as a proxy for the individual with dementia.

Carer participants will be asked to:

1. Take part in up to three semi-structured interviews with a researcher throughout their participation in the study
2. Keep and share with the researcher a reflective diary with the individual with dementia (in the form of either photos, texts or audio or written diary). This is optional.
3. Have some selected Dementia Support Worker-participant interactions and follow-up feedback calls audio-recorded by the researcher. This is a sub-set of participants.
4. With the researcher, complete a set of questionnaires at baseline, 4-6 months and 9-12 months, comprised of:
  - 4.1. Carer Wellbeing and Support questionnaire
  - 4.2. A health and social care resource use survey
  - 4.3. A measure of experience of care (PERCCI)\*
  - 4.4. Supplementary questions to the PERCCI\*
  - 4.5. A measure of positive outcomes (EID-Q)\*
  - 4.6. Supplementary questions to the EID-Q\*
  - 4.7. A quality of life measure (EQ-5D-5L)\*
  - 4.8. A health and social care resource use survey\*

\*as a proxy for the individual with dementia when a proxy is needed

Participants with dementia and carer participants will be offered the intervention for 12 months.

Dementia Support Workers will be asked to:

1. Keep and share with the researcher a reflective diary (in the form of either photos, texts or audio or written diary). This is optional
2. Take part in semi-structured interviews with a researcher throughout the study
3. Have some sessions with their supervisor audio-recorded by the researcher

4. Have selected DSW-participant interactions and follow-up feedback calls audio-recorded by the researcher
5. Share certain records and notes pertaining to intervention delivery with the researcher
6. Be shadowed by the researcher at GP surgeries, Primary Care Network meetings and multi-disciplinary team meetings relevant to intervention delivery/participants
7. Provide timesheets relevant to the study/intervention delivery to the researcher

GP staff, other practitioners, and team leaders, in other services relevant to the study will be asked to take part in a semi-structured interview with a researcher about their perceptions of, and interactions with, the Dementia Support Workers, participants and the intervention.

## **Intervention Type**

Behavioural

## **Primary outcome measure**

The study will mainly be collecting people with dementia and carers' experiences and perceptions of the support they have received from the D-PACT DSW and what changes it has led to in their lives, collected using realist qualitative interviews at 4-6 months and 9-12 months follow-up.

The study does not have a primary outcome measure, but the following quantitative data will be collected:

1. Engagement and independence measured using the Engagement and Independence in Dementia Questionnaire (EID-Q) at baseline, 4-6 months and 9-12 months
2. Care experience measured using the Person Centred Community Care Inventory (PERCCI) at baseline, 4-6 months and 9-12 months
3. Quality of life for both the individual with dementia and carer measured using the EuroQol (EQ-5D-5L) at baseline, 4-6 months and 9-12 months
4. Carer wellbeing measured using the Carer Wellbeing and Support Questionnaire (CWS) at baseline, 4-6 months and 9-12 months

## **Secondary outcome measures**

There are no secondary outcome measures

## **Overall study start date**

01/05/2021

## **Completion date**

31/01/2024

# **Eligibility**

## **Key inclusion criteria**

1. People with a clinical diagnosis of dementia, and their carers if applicable:
  - 1.1. Dementia is a broad term used to describe a range of neurodegenerative disorders which may include but will not be limited to: Alzheimer's disease (AD); late-onset Alzheimer's disease (LOAD); early onset Alzheimer's disease (EOAD); vascular dementia (VAD); mixed dementia (AD with VAD); dementia with Lewy bodies (LBD); frontotemporal dementia (FTD); Parkinson's disease dementia (PDD)
  - 1.2. Carers in this context are unpaid and are defined as the primary person who feels responsible for and supports the person with dementia

**Participant type(s)**

Mixed

**Age group**

Mixed

**Sex**

Both

**Target number of participants**

Planned Sample Size: 180; UK Sample Size: 180

**Total final enrolment**

247

**Key exclusion criteria**

1. Those who are resident outside the local authority boundary to be served
2. Those currently undergoing emergency treatment or care. (however, a delayed second approach will be attempted, if appropriate, if the person returns home within the timeframe of the research recruitment)
3. Those within care home setting
4. Those receiving substantial support from Community Mental Health Teams (CMHT), defined as input within the last four months and not due to be discharged within the next 2 months
5. Those who present as high risk and, after referral, are taken on by CMHT
6. Those with open safeguarding referrals and ongoing planned CMHT care
7. Those with a longstanding history of mental health difficulties and currently receiving care from other mental health team
8. Diagnosed with an end-stage physical health problem (e.g. cancer, severe heart failure) with substantive multi-disciplinary palliative and/or end-of-life care in place
9. Clinically qualified decision

**Date of first enrolment**

01/01/2022

**Date of final enrolment**

31/07/2022

**Locations****Countries of recruitment**

England

United Kingdom

**Study participating centre**

Wonford House Hospital

Dryden Road

Exeter

United Kingdom  
EX2 5AF

**Study participating centre**  
**Prestwich Hospital**  
Bury New Road  
Prestwich  
Manchester  
United Kingdom  
M25 3BL

**Study participating centre**  
**University of Plymouth**  
Drake Circus  
Plymouth  
United Kingdom  
PL1 4AA

**Study participating centre**  
**University of Manchester**  
Ellen Wilkinson Building  
Manchester  
United Kingdom  
M13 9PL

## **Sponsor information**

**Organisation**  
Devon Partnership NHS Trust

**Sponsor details**  
c/o Ashley Wilkie  
Research and Development  
Exeter  
England  
United Kingdom  
EX2 5AF  
+44 (0)1392674114  
a.wilkie@nhs.net

**Sponsor type**



Hospital/treatment centre

**Website**

<https://www.dpt.nhs.uk/>

**ROR**

<https://ror.org/04fkxrb51>

## Funder(s)

**Funder type**

Government

**Funder Name**

NIHR Central Commissioning Facility (CCF); Grant Codes: RP-PG-0217-20004

## Results and Publications

**Publication and dissemination plan**

The study protocol will be made available. The researchers plan to disseminate the study in high-impact peer-reviewed journals and conferences, as well as the study website. A summary of findings will be sent to each of the study sites, and participants will be given the option of receiving a summary.

**Intention to publish date**

31/12/2025

**Individual participant data (IPD) sharing plan**

After the results of the study have been published, the individual participant-level data that underlie the results will be available on request from the Chief Investigator (CI), Prof. Richard Byng (D-PACT@plymouth.ac.uk) and Sponsor, along with supplementary files as required (e.g. data dictionaries, blank data collection forms, analysis code, etc). Data will be shared with (or access to the data will be provided to) requestors whose proposed use of the data has been approved by the CI and Sponsor, under an appropriate data sharing agreement. It will not be possible to identify participants personally from any information shared.

**IPD sharing plan summary**

Available on request

**Study outputs**

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">HRA research summary</a>			26/07/2023	No	No