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Social care for people living with young onset dementia: the DYNAMIC study

Submission date 06/12/2023	**Recruitment status** No longer recruiting	☐ Prospectively registered ☒ Protocol
Registration date 12/12/2023	**Overall study status** Ongoing	☐ Statistical analysis plan ☐ Results
Last Edited 01/07/2024	**Condition category** Mental and Behavioural Disorders	☐ Individual participant data ☐ Record updated in last year

Plain English summary of protocol

Background and study aims
The aim of this study is to identify, prioritise and produce recommendations and resources to address improvements in social care for people with young onset dementia (dementia that starts under the age of 65 years) and their families.
Social care for people with young onset dementia is seldom well addressed. Social care needs are very different from those of older people and young onset dementia also impacts families, including children/young people. Little research has been carried out in this area, with only six UK studies located in a 2018 review. The largest UK study of support for people with young onset dementia to date, the Angela project, found that social care is central to quality of life in young onset dementia. The researchers want to build on this by focusing on social care practice and how this can be improved.

Who can participate?
1. People living with or family members/friends/neighbours supporting someone with young onset dementia in England will be eligible to take part in a face-to-face or online interview. The researchers will select from those who express an interest to make sure we hear diverse stories from a wide range of people.
2. Staff with a role in social care will be able to take part in the online survey from anywhere in England.
3. Up to 20 diverse stakeholders will be invited to take part in setting priorities and in the development of the resources and recommendations.

What does the study involve?
People living with Young Onset Dementia or supporting someone with young onset dementia will take part in a one-to-one, 30-60 minute interview with a researcher about their situation and experiences of social care and to find out about their social care needs and support they would prefer.
Staff involved in social care for people with Young Onset Dementia will be invited to complete a 10-minute online survey to find out about their awareness, knowledge and practice.
Stakeholders involved in setting priorities and in producing recommendations and resources will be asked to attend a 90-minute online workshop and give a further 90 minutes to assist with feedback on materials. The stakeholders will be asked to agree on priority improvements.

Finally, the researchers will produce recommendations and resources that address these priority issues. These will be informed by talking with 10-12 professionals who work in existing pockets of excellence and by searching online for evidence about good practice in the relevant areas.

What are the possible benefits and risks of taking part?
People with dementia and carers may find it hard to make time for interviews. Staff are likely to be pressured at work and have little time for research. There is some risk of distress to people with young onset dementia and main supporters from discussing their experiences or situation. There is some risk that those taking part may disclose information which the researcher feels poses a serious risk to the participant or others. In this event, the researcher will discuss this with the research team and the team will contact the Local Authority Adult Safeguarding Team, if appropriate.
People with young onset dementia and supporters often report that it is beneficial for them to talk out loud about their experiences to someone who is attentively listening and interested. In addition, those taking part may gain satisfaction from contributing to a project that is about producing recommendations and resources to improve future social care for people with YOD and their families.

Where is the study run from?
University of Bradford (UK)

When is the study starting and how long will it run for?
DYNAMIC started on 17/4/2023 and will run until 17/10/2025.

Who is funding the study?
1. National Institute for Health and Care Research (NIHR) (UK)
2. University of York (UK)
3. Dementia UK (UK)

Who is the main contact?
1. Prof. Jan Oyebode, j.oyebode@bradford.ac.uk
2. Dr Catherine Quinn, c.quinn1@bradford.ac.uk

Study website
https://www.bradford.ac.uk/dementia/research/current-projects/dynamic/

Contact information

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Additional identifiers

EudraCT/CTIS number
Nil known

IRAS number
329325

ClinicalTrials.gov number
Nil known

Secondary identifying numbers
IRAS 329325

Study information

Scientific Title
Social care planning and provision for people with young onset dementia and their families: current practice and resources for improvement

Acronym
DYNAMIC

Study objectives

Research has established the high level and breadth of social care needs in young onset dementia (YOD), the lack of social care for YOD and the deleterious consequences of living with unmet social care needs for the person, main supporter and children/young people. Consultation work with a range of stakeholders has indicated that no-one seems to have a clear picture of current social care for YOD. This project aims to address this gap by exploring the social care experiences of people living with YOD and their families and finding out about current practice in social care provision. Based on these findings, a co-production approach with key stakeholders will be used to establish priorities for improvement, and produce 2-3 evidence-based recommendations and resources for improvement.

Ethics approval required

Ethics approval required

Ethics approval(s)

1. Approved 20/09/2023, Social Care REC Health Research Authority (2nd Floor, 2 Redman Place, Stratford, London, E20 1JQ, United Kingdom; +44 (0)207 104 8070; socialcare.rec@hra.nhs.uk), ref: 23/IEC08/0034

2. Approved 01/08/2023, University of Bradford Research Ethics Panel (Research & Innovation Services (RAIS), F.24 Richmond Building, Richmond Road, Bradford, BD7 1DP, United Kingdom; +44 (0)1274 236554; nhs-ethics@bradford.ac.uk), ref: IRAS208

The researchers have received approval from the University of Bradford and the HRA Social Care REC for work packages 1 & 2 of the study. If required, they plan to submit a further application for ethical approval of work package 3 in a time-appropriate manner.

Study design

Mixed methods single-centre observational study

Primary study design

Observational

Secondary study design

Cross sectional study

Study setting(s)

Care home, Community, Home

Study type(s)

Other, Quality of life

Participant information sheet

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

Health condition(s) or problem(s) studied

Social care for people living with young onset dementia and their families

Interventions

The DYNAMIC study involves three work packages. The first two will run in parallel over 15-16 months and be followed by the third over the subsequent 15 months.

In work package 1, the project will gather accounts, using in-depth qualitative interviews, from 25 people with young onset dementia and/or their family/friend carers to find out about social care needs, experiences and support they would prefer. Data will be subject to inductive thematic analysis.

In work package 2, a national 10-minute survey of staff with a role in social care will be conducted, to find out about their awareness, knowledge and practice of social care for people with young onset dementia and their families. This will be subject to descriptive data analysis and content analysis.

In work package 3, the findings to date will be presented to ‘stakeholders’ via a workshop to agree on priority improvements. A search for good practices in these priority areas will then be completed by looking at published evidence and interviewing professionals. Work will then be undertaken using co-production to produce recommendations and/or resources to improve social care in 2-3 of the priority areas.

Intervention Type
Other

Primary outcome measure
Experiences of social care for young onset dementia and areas for improvement established through thematic analysis and descriptive data measured by interview at a single time point

Secondary outcome measures
There are no secondary outcome measures

Overall study start date
17/04/2023

Completion date
17/10/2025

Eligibility

Key inclusion criteria
Work package 1 participants will be people with YOD and main supporters:
1. Living in England.
2. Diagnosed with YOD or a relative, friend or neighbour of someone diagnosed with YOD
3. Living alone or with others

Work package 2 participants will be staff with a role in or awareness of adult/older adult social care planning, provision, management or commissioning, including but not limited to:
1. Local authority social workers
2. Local authority community OTs
3. Local authority social services commissioners, managers and coordinators
4. Social prescribers from third sector and primary care organisations
5. Staff from third-sector organisations that provide community and/or residential services, e.g., dementia navigators or link workers, Young Onset Dementia Advisors, support group facilitators

6. Staff from private providers e.g. home carers, personal assistants, care home staff and managers

Participant type(s)
Patient, Carer, Other

Age group
Adult

Lower age limit
18 Years

Upper age limit
100 Years

Sex
Both

Target number of participants
50 for work package 1. Not defined for work package 2.

Total final enrolment
173

Key exclusion criteria
People with young onset dementia will be excluded if:
1. They are diagnosed with dementia caused by HIV, traumatic brain injury, Down's syndrome, Huntington's chorea or alcohol-related dementia
2. They are unable to communicate or lack capacity to consentto take part

Date of first enrolment
03/11/2023

Date of final enrolment
30/06/2024

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
University of Bradford
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Sponsor information

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Sponsor type
University/education

Website
https://www.bradford.ac.uk/dementia/research/current-projects/dynamic/

ROR
https://ror.org/00vs8d940

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care Research NIHR204266

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype

National government

Location
United Kingdom

Funder Name
University of Bradford

Alternative Name(s)

Funding Body Type
Private sector organisation

Funding Body Subtype
Universities (academic only)

Location
United Kingdom

Funder Name
Dementia UK

Results and Publications

Publication and dissemination plan
We will publicise ongoing and final findings using different types of written and spoken communications. We want to convey our recommendations in interesting, accessible ways to people in practice and policy and those with young onset dementia. Links, summaries and resources will be available through the Young Dementia Network website and other networks (e.g. Association of Directors of Social Services).

We have consulted people directly affected by young onset dementia about this proposal. A person with young onset dementia and a family /friend carer will be part of the project team and will be funded to spend half a day every month to contribute to all aspects of the study. Another person with young onset dementia and a carer are part of the steering group. We will make every effort to ensure diversity, for example, through our close contacts with BAME communities. All will be supported by a member of the research team, who will lead on public involvement.

Outputs will be targeted to four key audiences:
1. Social care practitioners, who can use the findings to improve their practice.
2. Social care trainers, managers, commissioners and policy-makers, who can influence standards, training and provision.
3. Academics who can take forward further YOD research or apply our methodology to equivalent areas in other fields.

4. The public, including people affected by YOD, who will be empowered to advocate for their own care or place pressure for social care improvements.

Outputs will comprise:
1. Resources: At least two useful, tangible resources (e.g. YouTube video, Good Practice Handbook) for practitioners
2. Recommendations: A policy briefing for politicians and policymakers
3. Training/education: Curriculum outlines for social care professionals
4. Academic papers in high-impact journals
5. Conference presentations
6. A blog
7. Accessible summaries

Intention to publish date

30/10/2025

Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study will be stored in a publicly available repository. Anonymised research data will be archived after the end of the study using facilities provided by the UK Data Archive (https://www.data-archive.ac.uk/). Participants will be asked to consent for their data to be archived.

IPD sharing plan summary

Stored in publicly available repository

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article		05/02/2024	06/02/2024	Yes	No