ISRCTN62456025 https://doi.org/10.1186/ISRCTN62456025

Co-creating a virtual community to support family carers for people with dementia

Submission date 17/02/2025	**Recruitment status** No longer recruiting	☒ Prospectively registered ☐ Protocol
Registration date 19/02/2025	**Overall study status** Completed	☐ Statistical analysis plan ☐ Results
Last Edited 18/02/2025	**Condition category** Nervous System Diseases	☐ Individual participant data ☒ Record updated in last year

Plain English summary of protocol

Background and study aims
Dementia affects the mind, memory and decision-making which can impact everyday activities, cause dependency and require high levels of care, often offered by family members. As technology advances and information becomes more accessible, the healthcare professional's ability to signpost people to reliable online health information becomes increasingly important. Previous research found that most people used online health forums to seek support from people who shared similar experiences. That study found that a skilled moderator proved beneficial and ensured the safety and accuracy of the information provided. This project aims to co-design an online community with family carers and experts for people with dementia. This will involve creating an online platform for family carers to connect, gain and share information and intends to bring a community of carers with shared experiences together in a safe and supportive environment. To ensure the safety and accuracy of information being shared, this virtual community would be monitored by a trained healthcare professional.

Who can participate?
Adult family carers for people with dementia eligibility and registered healthcare professionals who have experience working with family carers for people with dementia

What does the study involve?
Co-design workshops will be held with family carers and healthcare professionals. This will be evaluated by user testing. A group of family carers will be set up to understand what the needs of family carers for people with dementia are, and how these needs can be met through the platform. Patient and public involvement will be embedded throughout this project.

What are the possible benefits and risks of participating?
This online platform can provide access to a support hub and help address difficulties and social isolation. Primary practitioner appointments can be typically short, and this virtual platform can become a valuable resource that addresses the needs of family carers of people with dementia and provides a resource that healthcare professionals can signpost to family carers for extra support.

No direct risks are expected from participating in this study. Participants can discuss any questions or concerns privately with the research team after the co-design workshops. There may be parts of the discussions that are sensitive and if any participant feels affected by this, the research team will be available before and after the workshops.

Where is the study run from?
Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College London, UK

When is the study starting and how long is it expected to run for?
October 2024 to December 2025

Who is funding the study?
National Institute for Health and Care Research (NIHR), UK

Who is the main contact?
Dr Annabel Farnood, annabel.farnood@kcl.ac.uk

Contact information

Type(s)
Public, Scientific, Principal investigator

Contact name
Dr Annabel Farnood

Contact details
Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation
Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care
King's College London
Bessemer Road
London
United Kingdom
SE5 9PJ
+44 20 7848 2922
annabel.farnood@kcl.ac.uk

Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
Nil known

Study information

Scientific Title

Co-creating a virtual community to support family carers for people with dementia

Acronym
VC Dementia

Study objectives
This project will co-design a virtual platform for family carers for people with dementia.

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 01/10/2024, King's College London University Ethics (5-11 Lavington Street, London, SE1 0NZ, United Kingdom; -; rec@kcl.ac.uk), ref: LRM-24/25-45494

Study design
Co-design workshops and a user-testing workshop will be held with family carers and healthcare professionals to co-design and develop a prototype of the platform.

Primary study design
Observational

Study type(s)
Other

Health condition(s) or problem(s) studied
Family carers for people with dementia

Interventions
Four co-design workshops including family carers for people with dementia and healthcare professionals will be conducted and user-testing of the final prototype platform. Workshops will include one in-person workshop in London, one in-person workshop outside of London, and one online workshop. Finally, there will be a user-testing workshop to understand the functionality and feasibility of the prototype. The workshops will include both family carers and healthcare professionals to encourage discussion from dual perspectives and use smaller breakout groups for discussion within the respective group. The co-design workshops will explore priorities for a supportive online community, what the information needs of family carers for people with dementia are, and the role of a moderator. The workshops will last up to 60-90 minutes and participants will be invited to participate in the online and user-testing workshop once the initial workshop is complete. Participation is voluntary.

Intervention Type
Other

Primary outcome(s)
The following variables will be assessed through the development of this platform using co-design workshops with family carers and healthcare professionals from 3 months onwards of the project:
1. Supporting the needs and priorities of family carers
2. Perceived sense of community and social inclusion
3. Gaps in knowledge and information during healthcare appointments

4. Accuracy, accessibility, and enabling nature of information shared
5. User satisfaction and acceptability of the platform

Key secondary outcome(s))

There are no secondary outcome measures

Completion date

31/12/2025

Eligibility

Key inclusion criteria

Family carers for people with dementia eligibility:
1. Adults over the age of 18 years old
2. Must be a current or bereaved carer (family or close friend) for a person with dementia

Healthcare professionals' eligibility:
1. Experience working with family carers for people with dementia
2. Registered healthcare qualification, e.g., adult nursing, mental health nursing, medical doctor (geriatrician, Old Age Psychiatrist)

Participant type(s)

Health professional, Carer

Healthy volunteers allowed

No

Age group

Adult

Lower age limit

18 years

Sex

All

Key exclusion criteria

Participants will be not eligible for this study if they are under the age of 18 and a family carer for any other condition that is not dementia or a professional carer.

Healthcare professionals will not be eligible if they have no experience working with family carers for people with dementia and do not have a fully registered healthcare qualification.

Date of first enrolment

20/02/2025

Date of final enrolment

11/07/2025

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
King's College London
Bessemer Road
London
United Kingdom
SE5 9PJ

Sponsor information

Organisation
King's College London

ROR
https://ror.org/0220mzb33

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care Research

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

Results and Publications

Individual participant data (IPD) sharing plan

The data sharing plans for the current study are unknown and will be made available at a later date

IPD sharing plan summary

Data sharing statement to be made available at a later date

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes