ISRCTN17410923 https://doi.org/10.1186/ISRCTN17410923

Lived Experience Narratives in Dementia (LEND) Work Packages 1-3

Submission date
13/11/2025

Recruitment status
Recruiting

Registration date
21/11/2025

Overall study status
Ongoing

Last Edited
04/12/2025

Condition category
Nervous System Diseases

[X] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] Record updated in last year

Plain English summary of protocol

Background and study aims
People living with dementia and their families have powerful stories that show what life with dementia is really like. The LEND Programme (Lived Experience Narratives in Dementia) aims to collect these stories and use them to improve understanding, empathy, and care. The project will bring together stories from people with dementia, carers, charities, and professionals, and use them to create an online learning tool called the Online LEND Intervention. This tool will help users explore real-life experiences and reflect on what they learn.

Who can participate?
People living with dementia, their carers, and members of under-served communities can take part in different parts of the study. Some activities also involve professionals who support people with dementia.

What does the study involve?
The study is divided into three main phases, called work packages (WPs). Here's what participants may be asked to do:

Work Package 1: Developing LEND Theory
This phase explores how stories about dementia are used and what makes them helpful. It includes five activities:
WP1.1 Online survey: Participants answer questions about how they use technology and social media, and what kinds of dementia stories they look for.
WP1.2 Interviews: A researcher talks with participants about how they use and feel about different types of stories, and whether experiences differ for people with dementia and carers.
WP1.3a & WP1.3b Rating stories: Participants rate different types of stories and how they are presented (for example, written, video, or audio).
WP1.4 Focus groups: Participants from under-served communities join group discussions at the Centre for Ethnic Health Research in Leicester. Interpreters will be available for those who need language support.
WP1.5 Discrete Choice Experiment: Participants make choices between different story options to help researchers understand which types are most effective and valuable for care.

Work Package 2: Designing and testing the online tool
This phase creates the Online LEND Intervention. Participants may test early versions of the tool and give feedback on how easy it is to use and what they think of the design.

Work Package 3: Feasibility trial
This phase checks if the online tool works well enough for a larger trial.
WP3.1: Participants complete questionnaires about their quality of life and wellbeing, then are randomly assigned to either use the online tool or not. After six months, they complete the same questionnaires again to see if anything has changed.
WP3.2: Participants who used the tool are invited for an interview to talk about its long-term impact on them and their carers.
What are the possible benefits and risks of participating?
Taking part may help improve dementia care and understanding for others in the future. Some people may find sharing or reading stories emotional, but support will be available. There are no major risks expected.

Where is the study run from?
Nottinghamshire Healthcare NHS Foundation Trust (UK).

When is the study starting and how long is it expected to run for?
December 2025 to December 2027

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

Who is the main contact?
linda.o'raw@nottingham.ac.uk

Contact information

Type(s)
Scientific, Public, Principal investigator

Contact name
Dr Linda O'Raw

ORCID ID
https://orcid.org/0000-0001-5265-2885

Contact details
University of Nottingham, Institute of Mental Health, Innovation Park Jubilee Campus, Triumph Road
Nottinghamshire
United Kingdom
NG7 2TU
+44 7791598280
linda.o'raw@nottingham.ac.uk

Additional identifiers

Integrated Research Application System (IRAS)
351969

Central Portfolio Management System (CPMS)
66864

Study information

Scientific Title
Improving the quality of life for people living with dementia and carers: the design and development of a dementia specific online narrative-based intervention with a feasibility study

Acronym
LEND

Study objectives
Phase 1 – Development (Work Packages 1.1–1.5)
1. To identify, curate, and synthesise existing dementia lived experience narratives from third-sector organisations, research archives, and community sources, ensuring representation across cultural, linguistic, and experiential diversity.
2. To explore stakeholder perceptions—including people living with dementia, carers, professionals, and the public—regarding the authenticity, emotional resonance, and educational potential of dementia narratives.
3. To co-produce a conceptual model that explains how engagement with dementia narratives fosters learning, empathy, and reflective understanding across different audiences.

Phase 2 – Co-production and Prototype Design (Work Package 2.3)
4. To design and co-develop the LEND digital intervention, informed by the conceptual model and stakeholder input, ensuring accessibility, inclusivity, and ethical presentation of dementia narratives.
5. To conduct iterative user testing with people living with dementia, carers, and professionals to assess feasibility, usability, and acceptability of the LEND prototype.

Phase 3 – Evaluation (Work Package 3.1)
6. To evaluate the feasibility and perceived impact of the LEND digital intervention in enhancing empathy, understanding, and reflective learning related to dementia.
7. To identify ethical, cultural, and practical considerations relevant to the collection, curation, and dissemination of lived experience narratives, informing future large-scale implementation.

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 13/10/2025, East Midlands Leicester Central Research Ethics Committee (2 Redman Place, Stratford, London, E20 1JQ, United Kingdom; +44 207 104 8118; leicestercentral.rec@hra.nhs.uk), ref: 25/EM/0199

Primary study design
Interventional

Allocation
Randomized controlled trial

Masking
Blinded (masking used)

Control
Uncontrolled

Assignment
Parallel

Purpose
Device feasibility, Health services research, Supportive care

Study type(s)

Health condition(s) or problem(s) studied
Dementia

Interventions
This study is, in part, an observational, mixed-methods study focused on developing a narrative-based psychosocial intervention for people living with dementia. It does not involve clinical treatments, but, in Work Package (WP) 3, the feasibility study, involve randomisation and allocation to arms. WP1 and WP2 of the study, however, comprises three sequential qualitative and co-production phases:

1. Work Package 1: Sub-work-packages 1.1-1.5
- Explore technology and narrative use and impact by people living with dementia (WP1.1)
- Thematic analysis of anonymised transcripts following interviews with people living with dementia and carers (WP1.2).
- Development of preliminary thematic categories and decision framework for narrative adaptation (WP1.3).
- Exploration of narrative use and impact by ethnic minority focus groups supported by interpreters (via the Centre for Ethnic Health Research, University of Leicester) (WP1.4).
- Economic exploration using the Discrete Choice Experiment (WP1.5)
- Development of LEND Theory
- Duration: ~6 months. No follow-up.

2. Work Package 2: Sub-work-packages 2.1-2.3:
- Thematic and criteria-based outputs derived from third-party narrative analysis, workshops and use of INCRESE-D (WP2.1).
- A collection of third-party narratives that adheres to the themes and criteria set by WP2.1. (WP2.2).
- Co-production of Online LEND Intervention prototype workshops with Lived Experience Advisory Panel (LEAP) members (people with experience of living with dementia, including carers). (WP2.3).
- Refine narrative delivery formats, assess cultural adaptation needs, inclusion and accessibility, and inform prototype features. Utilise a phased production design method (as per protocol). (WP2.3).
- User testing and acceptability evaluation through interviews and focus groups with people

living with dementia and carers. (WP2.3).
- Duration: ~8–10 months.

3. Work Package 3: Sub-work packages 3.1-3.2
- Online recruitment and randomisation methods post baseline validated questionnaire completion (QoL as primary outcome measure). (WP3.1).
- Randomisation into either a TAU arm or Intervention arm, utilising a two-arm clinical trial method. (WP3.1 and WP3.2).
- Duration: WP3.1 ends at 6 months, post following administration of follow up validated questionnaires.
- This involves in WP3.1 are invited to take part in WP3.2, a follow up interview about the long-term impact of using the Online LEND Intervention, post 12 and 18 months.

Intervention Type
Behavioural

Primary outcome(s)
1. Quality of life measured using validated questionnaires and scores (i.e. quality of life) at baseline and six months

Key secondary outcome(s))

Completion date
01/05/2029

Eligibility

Key inclusion criteria
1. Must be an adult over the age of 18 years old
2. Must have a diagnosis of dementia or care for someone living with dementia

Healthy volunteers allowed
Yes

Age group
Mixed

Lower age limit
18 years

Upper age limit
99 years

Sex
All

Total final enrolment
0

Key exclusion criteria

Must be able to consent

Date of first enrolment
01/12/2025

Date of final enrolment
01/12/2027

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Nottinghamshire Healthcare NHS Foundation Trust
The Resource, Trust Hq
Duncan Macmillan House
Porchester Road
Nottingham
England
NG3 6AA

Sponsor information

Organisation
Nottinghamshire Healthcare NHS Foundation Trust

ROR
https://ror.org/04ehjk122

Funder(s)

Funder type

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 datasets generated and/or analysed during the current study will be available upon reasonable request.
Dr Linda O'Raw (Programme Manager)
Linda.oraw@nottingham.ac.uk
Or
Linda.o'raw@nottingham.ac.uk

Type of data: anonymised quantitative data from validated questionnaires and qualitative data from interviews/focus groups, and thematic outputs derived from third-party narrative analysis.
Availability: 12 months following publication of the primary results paper and available for a minimum of 10 years.
Access criteria: requests will be reviewed by the research team and the study sponsor to ensure compliance with GDPR, consent form terms, and ethical restrictions.
Mechanism: secure data transfer under data-sharing agreement.
Consent/anonymisation: consent will explicitly cover data sharing; all datasets will be anonymised prior to sharing.
Restrictions: Individual agreements are reached with all third-party digital narratives, which are considered donations.

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Study website			14/11/2025	No	No