

Exploring the experiences of loneliness to improve social care

Submission date 11/02/2020	Recruitment status No longer recruiting	<input checked="" type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 19/02/2020	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input checked="" type="checkbox"/> Results
Last Edited 16/09/2024	Condition category Mental and Behavioural Disorders	<input type="checkbox"/> Individual participant data

Plain English summary of protocol

Background and study aims

Local authorities need to find new ways of improving service design and quality using social care users' experiences. This study will explore if an approach to service improvement used in healthcare is effective in social care, using loneliness as a focus.

Who can participate?

Adult social care users who self-identify as being lonely and social care staff.

What does the study involve?

There are two stages: 1. DISCOVERY. Interviews with a national sample of 40-50 people exploring their experiences of loneliness and social care, and with 20 social care staff to explore opportunities for service improvement around loneliness. Interviews will be filmed or audio recorded if the person prefers, typed in full and analysed for 'touch points' which show positive care moments or areas where services could be improved. A 'touch points' film will be produced. 2. CO-DESIGN involves separate feedback workshops with staff and social care users followed by a joint meeting where the film is shown to both. Participants work together to agree a list of priorities to put in place for improving services.

What are the possible benefits and risks of participating?

This research will allow us to think about how social care services can be improved and provide a resource for people experiencing loneliness, social care staff and students. It is possible that people taking part in the research interviews may feel some distress. Our researchers are experienced in managing this.

Where is the study run from?

Manchester Metropolitan University (UK)

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

June 2020 to January 2023

Who is funding the study?

National Institute for Health Research (UK)

Who is the main contact?

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Contact information

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Additional identifiers

Clinical Trials Information System (CTIS)

Nil known

Integrated Research Application System (IRAS)

279458

ClinicalTrials.gov (NCT)

Nil known

Protocol serial number

NIHR128616 V3, IRAS 279458

Study information

Scientific Title

Understanding and using people's experiences of social care to guide service improvements: could an effective and efficient co-design approach be translated from health to social care using the exemplar of loneliness?

Study objectives

The study aim is to assess whether an effective and efficient co-design approach 'accelerated experience-based co-design' (AEBCD) can be translated from health to social care using the experience of loneliness as an exemplar.

Ethics approval required

Old ethics approval format

Ethics approval(s)

20/WM/0223

Study design

Qualitative observational study

Primary study design

Observational

Study type(s)

Quality of life

Health condition(s) or problem(s) studied

Social care (loneliness)

Interventions

In-depth interview study involving a national sample of 40-50 social care users who experience loneliness and 20 social care staff who provide support or manage these services with a remit to tackle loneliness from local authorities (LAs), private/voluntary sectors. Data will be analysed thematically using a grounded theory approach.

A catalyst film will be co-produced capturing touch points (good practice points or examples where services could be improved) from the interview data.

One LA will be used as the test site for the AEBCD process which will involve workshops with service users, staff and the identification of service improvement priorities. Evaluation of this approach will adopt methods used successfully in the evaluation of AEBCD in health settings including ethnographic observation, attending planning meetings and co-design groups. Our focus will include the acceptability of the approach to social care staff and what adaptations might be needed for future use in social care.

There are two stages:

1. DISCOVERY. Interviews with a national sample of 40-50 people exploring their experiences of loneliness and social care, and with 20 social care staff to explore opportunities for service improvement around loneliness. Interviews will be filmed or audio recorded if the person prefers, typed in full and analysed for 'touch points' which show positive care moments or areas where services could be improved. A 'touch points' film will be produced.
2. CO-DESIGN involves separate feedback workshops with staff and social care users followed by a joint meeting where the film is shown to both. Participants work together to agree a list of priorities to put in place for improving services.

Interviews will include those who are less often heard in research e.g. learning disabled people and people from black and minority ethnic groups. Doncaster will be the test site for stage 2 because loneliness is a high risk in many parts of the city and tackling it is a priority for the local authority. Given the challenges that social care research faces in engaging practice and the time it can take to build and sustain links with local authorities it is important to have a willing organisation who are interested in research and are committed to the topic area.

Working with social care service improvement colleagues from adult social care and Doncaster residents who experience loneliness, we will use observations and interviews to study how improvements are made over a nine month period. Key questions will include i) whether this approach using a film based on a national interview study of social care users and staff perspectives of loneliness would work in a local setting and ii) whether this quality improvement approach is acceptable, or needs adapting, for wider use in social care.

Intervention Type

Other

Primary outcome(s)

Qualitative methods will be used:

1. To understand how loneliness is i) characterised and experienced by people who are in receipt of social care in England and ii) characterised by social care staff and the voluntary sector
2. To identify how services might be changed to help tackle the problem of loneliness experienced by users of social care
3. To test, with one local authority, whether an approach to service improvement, known to be effective in health care, could be adapted for use in social care

Key secondary outcome(s)

Qualitative methods will be used to disseminate all study outputs and publish resources on a newly established Socialcaretalk.org platform for public, family carers, service users, voluntary organisations, researchers, teachers, policy makers and providers

Completion date

31/01/2023

Eligibility

Key inclusion criteria

DISCOVERY PHASE

1. social care users who self-identify as being lonely
2. social care staff

CO-DESIGN PHASE

3. social care users

4. social care staff

Participant type(s)

Mixed

Healthy volunteers allowed

No

Age group

Adult

Sex

All

Total final enrolment

83

Key exclusion criteria

Does not meet inclusion criteria

Date of first enrolment

01/06/2020

Date of final enrolment

31/10/2022

Locations

Countries of recruitment

United Kingdom

England

Study participating centre

University of Oxford

Nuffield Department of Primary Care Health Sciences

Radcliffe Observatory Quarter

Woodstock Road

Oxford

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Study participating centre

Manchester Metropolitan University

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Sponsor information

Organisation

Manchester Metropolitan University

ROR

<https://ror.org/02hstj355>

Funder(s)

Funder type

Government

Funder Name

National Institute for Health 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 current data sharing plans for this study are unknown and will be 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?
Results article		01/08/2024	16/09/2024	Yes	No
HRA research summary			28/06/2023	No	No
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes