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Adapting the Easy Read Adult Social Care Outcomes Toolkit (ASCOT-ER) for older social care users who need additional support to self-report

Submission date
09/12/2022

Recruitment status
No longer recruiting

Registration date
19/12/2022

Overall study status
Completed

Last Edited
28/01/2025

Condition category
Other

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
The Adult Social Care Outcomes Toolkit (ASCOT) is used in lots of countries around the world to measure how social care affects people's lives. In the past, we worked with adults with learning disabilities and added pictures and simplified the words to help them understand. We called this the ASCOT-Easy Read. Lots of people want to use the ASCOT- Easy Read with older people but first older people need to help us make some changes.
This study aims to produce a new 'easy to read' version of a widely used measure of quality of life called the ASCOT. Some older people using social care (age 65+) find it difficult to complete the ASCOT because of memory problems or very old age. This means their voices are not being heard. The aim is to make it easier for them to complete the questionnaire themselves, so that they can tell care providers, policy makers and researchers how they feel.

Who can participate?
People aged 65 years and over who are using adult social care services and need help completing paperwork or questionnaires are eligible to take part.

What does the study involve?
We will work with a group of older people and their carers to adapt the ASCOT-Easy Read for this age group. Then we will test this new version with people who find questionnaires difficult to complete. We expect to have to repeat this process a few times to get it right. Altogether, we will meet with the working group 5-6 times and will test the new version with up to 30 older people.

What are the possible benefits and risks of participating?
Everyone who takes part will be thanked for their time with a £20 high street voucher.
There is a small risk that participants might become upset when talking about their experiences

during the interview. If this happens the researcher will offer the participant the opportunity to pause and have a break, offer to talk about something else, or stop the interview. The researcher will also offer to contact someone who can provide the person with support.

Where is the study run from?
The University of Kent, Canterbury, UK.

When is the study starting and how long is it expected to run for?
May 2022 to April 2024

Who is funding the study?
This project is funded by the National Institute for Health and Care Research (NIHR) under its Research for Social Care (RfSC) Programme (Grant Reference Number NIHR202974). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Who is the main contact?
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Contact information

Type(s)
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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
316222

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number

NIHR202974, IRAS 316222

Study information

Scientific Title
Adapting the Easy Read Adult Social Care Outcomes Toolkit (ASCOT-ER) for older social care users who need additional support to self-report: a content validity study

Acronym
ASCOT-ER Study

Study objectives
The Adult Social Care Outcomes Toolkit (ASCOT) measures the impact of social care on users' social care-related quality of life (SCRQoL). It is used to gather the views and experiences of people using services and inform indicators in the national Adult Social Care Outcomes Framework (ASCOF) in England. Recent research has shown that the oldest social care users and those with cognitive decline are under-represented in national surveys.
Easy to read adaptations, using simplified text and pictures to support understanding, are one way to support people to continue to give their views for longer. An ASCOT-Easy Read (ASCOT-ER) has already been codeveloped and tested with adults with intellectual disabilities and autism but consultation with older people and their carers indicates it requires adaptation for use with older adults.

This study aims to adapt the ASCOT-ER for older people. The objective is to make it easier for older social care users to complete the questionnaire themselves, so that they can tell care providers, policy makers and researchers how they feel about their own SCRQoL.

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 14/12/2022, Coventry and Warwick Research Ethics Committee (The Old Chapel, Royal Standard Place, Nottingham, NG1 6FS, UK; +44 207 104 8009; coventryandwarwick.rec@hra.nhs.uk), 22/WM/0234

Study design
Content validity

Primary study design
Observational

Study type(s)
Quality of life

Health condition(s) or problem(s) studied
Social Care

Interventions
A co-production working group of 6-8 older social care users and their informal carers has been established to evaluate the comprehensiveness, relevance and comprehensibility of the ASCOT-

ER images, wording and layout. Altogether, the working group will meet 5-6 times over 24 months and will be involved in all decision making. Members will be paid for their time at NIHR rates.

Changes made by the working group will be iteratively tested using cognitive interviewing techniques (think aloud) with up to 30 older social care users who struggle to self-complete conventional surveys.

The primary method of recrutiment for the cognitive interviews will be through the DETERMIND study. The DETERMIND study (REC 19/LO/0528; IRAS 261263; https://determind.org.uk/) is led by Brighton and Sussex Medical School, Newcastle University and King's College, London. It is aiming to recruit 900+ people living with dementia within 6 months of their dementia diagnosis, and then to follow them up with yearly visits collecting data for 3 years. Part of the study's remit is to support the recruitment of other linked studies, of which the ASCOT-ER study is now a linked study. Participants will also be recruited via Local Authorities with Social Services Responsibilities and memory clinics.

Intervention Type
Behavioural

Primary outcome(s)
Cognitive interviews using a 'think aloud' method, with probing questions to assess comprehension, judgement (weighing up of response options) and response to each item, will be used to explore participants' understanding of the newly adapted Adult Social Care Outcomes Toolkit (ASCOT) Easy Read questionnaire. The interviews will also explore the questionnaire layout, format and images. This will include making a note of issues relating to physical and sensory age-related decline (e.g. is the text big enough for people to read with their glasses on? Were there any barriers relating to holding a pen and making a mark in a box?). If the person is unable to self-complete (e.g. they repeatedly lose their place, do not understand how to respond, show signs of distress or ask for help/clarification on the same point more than once), the researcher will stop the cognitive interview and will instead administer the ASCOT-ER as a supported interview, using a staggered-reveal approach.

Following the approach used in our previous research to develop and test the ASCOT-ER with adults with intellectual disabilities and autism, the analysis will be led by three main questions:
a. Can participants understand the questions and response options?
b. Are they able to answer the questions based on their own experiences?
c. Do the pictures help people answer the questions?
We will use framework analysis with the lenses of comprehension, interpretation, judgement, response, relevance and comprehensiveness to answer these questions. Participants will be classified as being 'independent' or 'assisted' in the response process with further classification as to whether the assistance was required to 'manage' the demands of the process (e.g. holding a pen, maintaining focus on topic) or related to 'comprehensibility' (e.g. ability to make sense of the domain through the text explanation or the pictorial).

Key secondary outcome(s))
There are no secondary outcome measures

Completion date
30/04/2024

Eligibility

Key inclusion criteria
1. Aged 65 years or over
2. Receiving community-based social care (e.g. home care, day centre, personal budget)
3. Living in their own or another person's home
4. Needs help with questionnaires and paperwork (ie: stand to benefit from an Easy Read format)
5. Has capacity to consent

Participant type(s)
Other

Healthy volunteers allowed
No

Age group
Senior

Lower age limit
65 years

Sex
All

Total final enrolment
25

Key exclusion criteria
1. Under 65 years
2. Live in a care home
3. Not receiving social care
4. Able to complete a questionnaire without help
5. Lacks capacity to consent

Date of first enrolment
09/01/2023

Date of final enrolment
30/09/2023

Locations

Countries of recruitment
United Kingdom

England

Study participating centre

University of Kent
The Registry
Canterbury
United Kingdom
CT2 7NZ

Sponsor information

Organisation
University of Kent

ROR
https://ror.org/00xkeyj56

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 datasets generated and/or analysed during the current study are not expected to be made available due to the fact they are qualitative data and will be difficult to fully anonymise.

IPD sharing plan summary

Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		26/09/2024	27/01/2025	Yes	No
HRA research summary			26/07/2023	No	No
Protocol file	version 1.1	23/11/2022	16/12/2022	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes