PROTOCOL (STUDY PROPOSAL)

Study 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

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Brief summary

The Adult Social Care Outcomes Toolkit (ASCOT) is used in many countries worldwide 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 (ASCOT-ER). 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. Many 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 the ASCOT for older people using social care. The aim is to make it easier for them to complete the questionnaire themselves so that they can tell care providers, policymakers, and researchers how they feel.

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 around three times to get it right, with up to ten older people each time. Altogether, we will meet with the working group 5-6 times, and we will test the new version with up to 30 older people over different sets of interviews.

Our working group will be made up of older people with lived experience. Working group members will be involved in all decisions and invited to participate in presentations, blogs,

and a training video. The video will teach care providers and others how best to help older people complete the new measure.

Background and Rationale

In 2018-19 over half a million older adults (65+) received publicly funded social care in England (1) and many other older adults funded their own care. The number of older people using social care services is likely to be around 865,000. By 2035, the number of over 85s with low dependency is projected to increase by 149%; those with high dependency will nearly double (2). It is vital to have an inclusive approach to measuring the impact of social care on people’s lives, as a means of improving the equity and quality of services (3). However, evidence demonstrates that older people living in the community with conditions such as cognitive impairment, dementia or even age-related decline may lack suitable tools to enable them to do this (4).

Measuring the outcomes of social care

The Adult Social Care Outcomes Toolkit (ASCOT) measures the impact of social care on users’ social care-related quality of life (SCRQoL). There are eight domains, which were developed and tested with older social care users who can self-report (5). The domains cover both the ‘basic’ (Accommodation, Personal Cleanliness, Safety and Food and Drink) and ‘higher order’ (Control over Daily Life, Social Participation, Occupation and Dignity) aspects of quality of life that can be impacted by social care services/interventions. ASCOT was developed for, and has been applied, across adult social care and comes in different methods of completion. The suite of tools has been shown to be valid and reliable with different client groups, including older people receiving home care (6-8).

The ASCOT has been widely used in research and evaluation studies to increase the evidence base for social care (9-12). It is also included in the annual Adult Social Care Survey (ASCS), which is sent to a sample of social care users in England (13). The ASCS is important because 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) (14). However, some social care users, such as those with intellectual disabilities, cognitive impairment and short-term memory problems, find conventional methods of data collection (e.g. questionnaires and structured interviews) inaccessible (15). They are at risk of exclusion because the mode of data collection does not meet their needs.

Those often excluded include a large group of people who, although having the capacity to consent, are not able to respond to standard questionnaires and surveys. Independent research funded by the NIHR on behalf of the Department of Health and Social Care recently explored this issue of nationally held data on the experiences and outcomes of people using social care (4). The report found that the two main causes of people being under-represented in the national Adult Social Care Surveys were: (1) sampling issues (e.g., self-funders cannot be identified through current systems) and (2) nonresponse (e.g., refusing or being unable to complete the survey). In relation to the latter, the research found that the oldest service users and older people with cognitive decline faced particular barriers to participation (4). This is in line with previous research which found that people with moderate dementia or cognitive decline required support to self-respond (16), such as simplified language and/or the assistance of a carer/interviewer (17). Aznar et al (4) note that the current format of the ASCS means they often have to rely on support to complete the questionnaire, which might lead to bias (e.g. if the person helping them influences their responses) or nonresponse (if they do not have anyone willing and able to help).

Tools designed to measure user experience and outcomes need to be administered flexibly, using adapted methods, to maximise participation (18). Other aids, including pictures, may facilitate understanding and help with focus. This reflects our own experience of administering the ASCOT through surveys and interviews with older social care users. To address these barriers, Aznar et al (4) recommend developing an easy read version of the survey for older adults and exploring more supportive methods of data collection, such as interviews and even qualitative or mixed-methods. Acknowledging that even with such adaptations and support, some people will still be unable to self-report, the research also recommends the use of a 'formally designed and tested proxy version (4). For the ASCOT component of the national surveys, some of this work has already been undertaken and could be drawn upon to increase participation and representativeness. Although enabling self-report is our preferred option, proxy-report is preferable to not considering the person's experience altogether (19).

An ASCOT easy read (ASCOT-ER), using simplified language and images to support understanding, has also already been developed and tested (20) and could be used in national surveys to improve representativeness (4). However, the tool was developed and tested with adults with intellectual disabilities and autism (download the tool here: https://www.pssru.ac.uk/ascot/wp-content/uploads/2021/05/ASCOT-Easy-Read-Tool.pdf) (20) and not with older adults. As the report on the surveys points out, there is scope to adapt and test this easy read format, with older adults who need help to self-complete (4).

Adapting the ASCOT-ER for older adults who struggle to self-complete.

Qualitative work in Australia explored the feasibility of using the ASCOT-ER tool for older adults receiving care in their own homes (21). The study found that when administered as part of a supported interview methodology, it was more inclusive than the standard measure, enabling a greater number of older people to give their own perspectives. The mode of completion was found to be as important as ease of reading, indicating further work should test the measure and its mode of administration in this population, as well as adapting the tool itself (21).

There are several reasons why it is important not to assume that 'one size fits all with easy read adaptions. Firstly, clinical practice indicates that a different type of 'easy read' adaption might be required. Furthermore, consultations with users and carers undertaken as part of the development of the project emphasised the need to codesign new pictures. We also need to test whether the wording itself, which was simplified for people with different needs, works well for this population.

Secondly, ASCOT is a patient-reported outcome measure (PROM) and as such should adhere to international quality standards relating to its development and testing. These standards, known as COSMIN standards (Consensus-based Standards for the selection of health Measurement INstruments) recommend that research establish the relevance, comprehensiveness and comprehensibility of measures when used with new populations (22). They define this type of study as a content validity study.

We are, therefore, undertaking a content validity study of the ASCOT-ER with older social care users who struggle to self-report using the original questionnaire. We will also explore other adaptations to improve it for this population (e.g., simplified layout). This study contributes to a wider programme of work by this team to provide policymakers, care providers and researchers with a comprehensive suite of tools for measuring the social care outcomes of older adults with a whole range of abilities and needs. This will fill an important methodological gap and inform evidence-based interventions.

Research question and aims

The aim is to adapt and assess the content validity of the ASCOT-ER for older people. The main research questions are:

a. When adapted for older people, is the ASCOT-ER relevant, comprehensive, and comprehensible to older social care users?
b. What additional support (e.g., assisted interview) do people need to complete it?

This study aims to:

a) Adapt the simplified wording, layout and images of the ASCOT-ER using the COSMIN criteria for content validity of making it comprehensible, comprehensive, and relevant to this population.
b) Establish the content validity of the ASCOT-ER with older social care users. This will be assessed by its comprehensibility, comprehensiveness, and relevance.
c) Explore whether people need additional support and what types of support are needed (e.g., a supported interview) to be able to understand and self-report.

Study design

We are using a qualitative design involving older social care users as research participants (cognitive interviews) and as research advisors (co-production working group).

Cognitive interviews

There will be three rounds of cognitive interviews with older social care users, and we propose 7 to 10 interviews for each round of interviews. This is based on previous experience of developing ASCOT and adapted versions with diverse samples of social care service users and/or carers.

Cognitive interviews are routinely undertaken as part of questionnaire design, refinement, and testing to ensure that respondents understand the questions and response options, interpret them as intended, are able to weigh up the different response options and provide a response. When adaptations occur, it is essential to repeat this process with the target population to ensure meanings and interpretations remain conceptually the same as the original measure and in comparison, to other user groups/populations. Where requested/needed, informal carers will be welcome to sit in on the interview, but the focus is on the person's answers and the carer is only there to support them.

Co-production working group

A co-production working group of 6-8 older social care users and their informal carers has been established, recruited through 'Forget-me-nots' (a dementia inclusion and empowerment group) and other social care user groups we are connected to. The purpose of the working group is to evaluate the comprehensiveness, relevance and comprehensibility of the ASCOT-ER images, wording, and layout, as well as the concepts covered by the measure. The questionnaire is then being revised as necessary, and the working group are then asked at the next meeting to provide feedback on the changes. As needed, we will work with a provider of illustrations and graphic artists to revise and amend illustrations iteratively.

The co-production working group will have met three times before the cognitive interview rounds begin, to make recommendations about changes that should be made to the ASCOT-ER, with revisions made between each working group.

The working group will then also meet between rounds 1 and 2, rounds 2 and 3 of cognitive interviews, and after the third round. The findings from the previous round of cognitive interviews will be presented at each meeting for the group to discuss and recommend further changes.

At each working group, the discussions are being audio-recorded and additional notes are taken. Following the approach used successfully in previous research (20), recordings will be transcribed verbatim and thematically analysed to check for misunderstandings, inconsistent interpretations, feedback on images and understanding of the concepts covered by each question. These findings will inform the adaptation/revision of the measure and reporting afterwards.

Sampling

The population of interest is older social care users, aged 65+, who cannot complete the original (un-adapted) ASCOT questionnaire and are at risk of exclusion (e.g., those with cognitive impairment/decline or other communication support needs). We will focus on those living in ordinary housing or assisted living.

We will recruit 30 older social care users who meet this criterion, and who are living across the South East of England and London.

Recruitment

There are three routes for how potential participants across Kent, Medway, Surrey and Sussex, North Thames, South London, and the North East will be approached.

Firstly, through the DETERMIND study that the ASCOT-ER study is linked to. 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. The DETERMIND study has a box on their participant consent forms for participants to agree to be contacted about participating in linked studies in the future. They also collect data on social care use at each study visit, and the researchers collecting the data will know which participants may benefit from easy-read versions of questionnaires. The DETERMIND study will help us recruit participants for the ASCOT-ER cognitive interviews by the following process:

1. The ASCOT-ER team ask the DETERMIND team Programme Leader (Dr Ben Hicks; Brighton and Sussex Medical School, University of Sussex) for participants with particular characteristics (e.g. they have answered yes to receiving social care in the service use questions and have the capacity to consent).

2. The DETERMIND Programme Leader will send us a pseudonymised list of potential participants who have agreed to take part in linked studies on their consent form, with some basic demographic characteristics provided (including whether the person self-funds or receives publicly funded social care).

3. The ASCOT-ER team will tell the DETERMIND Programme Leader who we want to approach from this list.

4. The DETERMIND Programme Leader will collate the contact details of these participants from the various DETERMIND researchers who hold these details.

5. The potential participant list, and their contact details, will be sent in a password protected file transfer by the DETERMIND Programme Leader to the ASCOT-ER team.

6. Researchers from the ASCOT-ER team will send the potential participants an invitation letter (approved by the DETERMIND study) and the ASCOT-ER information sheet. After one week, the ASCOT-ER team will try to contact potential participants to see if they are interested in participating. At this stage, an eligibility check will also be undertaken.

When the researcher contacts or is contacted by a potential participant, the researcher will conduct an eligibility check with them over the telephone before they arrange the interview. In this they will check that the person receives social care and whether the need support to fill our paperwork/answer questionnaires, and thus needs an easy read format of the ASCOT.

“Thank you for your interest in this study. I just need to check that you eligible to take part by asking you a few questions:

(1) Do you currently receive social care? [Prompt if needed: “for example, do you have support from care workers with washing, dressing, meals or keeping your house clean? You might call know it as home care”]

IF YES, ASK Q2

IF NO, double check and then explain they are not eligible: So just to confirm, you do not currently receive any help or support at home? I’m very sorry but to take part if the research you do need to be using social care services and support. Thank you for your interest in the study and hopefully there will be other opportunities to take part in other work in the future.”

IF CONFUSED (may indicate lack of capacity): That’s okay, don’t worry. We are really grateful for your interest in the study. However, on this occasion we won’t be able to include you in the study. Hopefully there will be other opportunities to be involved in research in the future and thank you again for getting in touch.

(2) "Do you normally need some help to fill out paperwork/ answer a questionnaire? By help, we mean help to read or understand the question, to think about the answer, or to write the answer."

IF YES: arrange the interview

IF NO, check and then explain they are not eligible: So just to confirm, you are able to manage your paperwork at home or fill out forms and things without any help? I’m very sorry but we are looking for people who find that kind of thing difficult for this study, so on this occasion you are not eligible to take part. Thank you for your interest in the study and hopefully there will be other opportunities to take part in other work in the future.”

To be eligible, the person must answer yes to both questions.

Secondly, through local care/third sector organisations (like Age UK), local authorities (up to three in South East England and London), and the six Forget-me-Not groups (dementia inclusion and empowerment groups) run across Kent and Medway. Printed or electronic copies of the study pack will be shared with these organisations, who will be asked to pass these on to eligible potential participants (i.e. aged 65 years or over, receiving community-based social care (e.g. home care, day centre, personal budget), living in their own or another person's home.). Again, the information pack will invite anyone who wishes to participate, or to find out more, to directly contact the research team. For interested participants, the same eligibility check described above will take place over the telephone.

Thirdly, we will use Join Dementia Research (JDR) (23), an online self-registration service that enables volunteers with memory problems or dementia, carers of those with memory problems or dementia and healthy volunteers to register their interest in taking part in research. JDR allows researchers to set criteria to search for potential participants, which here will be geographical (Kent, Medway, Surrey and Sussex, North Thames and South London) and people with memory problems or dementia who are representing themselves on JDR, not represented by a family carer.

The researcher can then contact potential participants, in line with their preferred method of contact, to further discuss potential inclusion. If their preferred method of contact is by email or post, then potential participants will be sent a letter of invitation and information sheet. They will be invited to contact the research team directly if they wish to participate or find out more. The researcher will discuss the study with them, and if they are interested conduct the eligibility check over the phone (same as described above). If the potential participants preferred contact method is by telephone only, the researcher will give them a telephone call to discuss the study and if they are interested send the information sheet by email or post, and arrange to call them back once they have had time to read over it and conduct the eligibility check over the phone (as described above).

Data collection

Altogether, up to 30 semi-structured qualitative interviews, using cognitive interview methodology will be completed by the researchers.

At the start of the interview, the service user will be asked to complete some brief background questions (e.g., age, use of services) and the Mini-Cog, which is a short 3-question assessment of cognition validated with older adults. This assessment will be used to help us interpret and contextualise the rest of the interview, as we know that previous research has found that cognitive decline is a risk factor in being excluded from social care surveys. Informal carers can be present if requested by the participant and will be permitted to help provide information on the background questions, such as service receipt if required (and with permission of the participant). However, the Mini-Cog and the cognitive interviews must be completed by the participant, as it is their cognition and understanding that we are interested in measuring in this study.

Participants will be asked to complete a characteristics questionnaire, including demographic information, what social care services they use and who pays or funds those social care services.

Interviews will act both as a way of collecting data about the experience of completing the ASCOT-ER and providing support and assistance to those who need it to ensure their participation in the study is manageable. Participants will be given the opportunity to complete the ASCOT-ER as a self-completion questionnaire. The ‘think aloud’ method with follow-up probing questions will be used to assess comprehension, judgement (weighing up of response options) and response to each item. The researcher will make notes (e.g., whether the participant skipped any questions or had difficulty understanding). 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 that might feed into our findings?

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. This interviewing method was used successfully in previous research we have undertaken and will be used to focus and orient the person to ASCOT domains and questions, as well as support comprehension. If the person still struggles to self-report, the interviewer will sensitively close the interview, rather than continuing and causing any distress. This process will enable us to explore mode of administration and will inform guidance on the use of the adapted measure in practice. Interviews will be audio-recorded and transcribed verbatim. Transcripts and field notes will be saved in NViVo.

Data synthesis and analysis

Interviews will be audio-recorded and transcribed verbatim. Transcripts and field notes will be saved in NViVo.

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).

Dissemination

The project benefits from being situated within a wider programme of work to develop and support the ASCOT in research, policy, and practice. This gives us a direct pathway to impact. ASCOT has been used in eight countries outside of the UK with ‘in-country’ ASCOT teams in three to support international impact (e.g. in Austria: https://www.wu.ac.at/altersoekonomie/ascot). There is international reach and significance for this adapted measure. This adapted tool will be made available on the ASCOT website with all the others (see https://www.pssru.ac.uk/ascot/tools/). In England, we have strong links to the Social Services User Survey Group (SSUSG), which is the oversight steering group for the national social care user surveys (including the Adult Social Care Survey) and whose membership includes local authority representatives, academic researchers, NHS Digital, DHSC and CQC, and will be well positioned to advocate for this measure in the annual user survey, if appropriate.

We cannot include the psychometric testing of the adapted ASCOT-ER in this application because there are too many unknowns that have implications for the methodology of the final stage (e.g., whether this population will require interview methods, or whether we might be able to send the adapted measure as a questionnaire).

However, a key output from this study will be a beta version of the adapted ASCOT-ER that can be used by social care providers/organisations while we apply for further money to undertake the final stage of the work. By enabling providers and social care organisations to use the tool early on, we can identify implementation issues and use this learning to inform a future funding application to pilot the measure in this population, with social care providers as co-applicants or collaborators.

To support immediate use of the beta version with a diverse stakeholder audience we will produce:

- A training video showcasing how to administer ASCOT-ER, involving an actual service user. The training video will feature advice from researchers and content from the service user on their experience with ASCOT-ER and what they found helpful/what good administration looks like from a service user standpoint. The video will be featured on the ASCOT website along with the tool (https://www.pssru.ac.uk/ascot/tools/).
- A set of 'testimonial' style short videos will also be filmed (in person or via a videoconference platform depending on pandemic safety). The testimonials will feature social care services users talking about their involvement in co-producing the beta version of ASCOT-ER and their perceived usefulness and efficacy of the tool. The testimonial videos will be used on the ASCOT website and digital advertising of the ASCOT-ER version for older social care users.
- One-page easy read infographic summaries about ASCOT-ER will also be co-designed with the help of the service users involved in the project. Separate summaries will focus on different audiences – service users themselves, informal caregivers, paid care staff, social care managers, commissioners, local authority departments involved in social care, and social care researchers. It is paramount for this project that ASCOT-ER is presented to stakeholder groups in a way that is most relevant to each group.

Dissemination will also include two peer-reviewed publications. We will also produce a lay English summary of the project (in addition to the ASCOT-ER-specific one-page summaries for service user and caregiver audiences).

We will present the work at appropriate social care and public health conferences/ seminars, and produce a blog of the work and use social media to improve wider awareness. Webinars may also be a particularly appropriate platform for widespread dissemination, and we shall endeavour to include working-group members as co-presenters in any webinars.

Patient and public involvement

Social care users and their carers are involved in the study in two ways: co-production and project management/oversight. All service users and carers will be supported to meaningfully participate. People will be offered training and support by the University of Kent.

1. Co-production: 6-8 older social care users and their carers have been recruited to a co-production working group through 'Forget-me-nots' (a dementia inclusion and empowerment group) and other social care user groups we are connected to. Members of the working group will also be offered opportunities to be involved in dissemination through videos, co-presenting at webinars and co-authoring outputs relating to their experiences and contributions, such as blogs. People will be paid for their time and travel in all these activities at INVOLVE rates.

2. Study management and oversight: two users/carers will be recruited to the study steering committee and will be paid for their time at INVOLVE rates.

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