



Participant Information Sheet for older people with subjective cognitive decline (v2, 25.03.19)

UCL Research Ethics Committee Approval ID Number: 12212/002

YOU WILL BE ABLE TO DOWNLOAD OR REQUEST A COPY OF THIS INFORMATION SHEET TO KEEP.

Title of study: A cross-sectional study of psychological flexibility processes in older people with subjective cognitive decline.

Secondary title: An examination of psychological factors in older people who self-report difficulties with their memory and/or attention.

1. Invitation to participate in a research study

You are being invited to take part in a research study, which Elnaz Gültekin is conducting as part of her MSc course. Before you make a decision, it is important for you to understand why the study is being carried out, and what it will involve. Please take your time to read the following information carefully and decide whether or not you wish to take part. Please discuss it with others if you wish. Please feel free to email us if there is anything that is not clear or if you would like more information. Thank you for reading this.

2. What is the purpose of the research study?

The purpose of this research study is to find out whether there are relationships between SCD, psychological factors, satisfaction with life and mood in older people who experience difficulties with their memory and/or attention, but have been told that there is nothing wrong with their memory and/or attention (also known as subjective cognitive decline). We are finding this out by asking people to complete an online survey which asks questions about their subjective cognitive decline, satisfaction with life and mood.

If we find that there are relationships between SCD, psychological factors, satisfaction with life and mood in older people with subjective cognitive decline then this may suggest that a type of talking therapy called Acceptance and Commitment Therapy might be beneficial for this group of people. No studies have examined whether this newer form of talking therapy that is not currently routinely available in the NHS is beneficial in this population. This study represents the first steps in finding this out.

3. Why have I been chosen?

We are asking 50 people who meet the following criteria to take part in this study:

- Aged 60 years or more;
- Experiencing self-reported difficulties with memory and/or attention, but have been told that there is nothing wrong with their memory and/or attention;
- Sufficient ability to read and understand English to complete some questionnaires about their self-reported difficulties with memory and/or attention and their mood;
- No diagnosis of dementia or mild cognitive impairment by a GP, psychiatrist, psychologist or memory clinic.

You have been approached because you have self-identified that you have been experiencing difficulties with your memory and/or attention, but have been told that there is nothing wrong with your memory and/or attention.

4. Do I have to take part?

It is up to you to decide whether you would like to take part in this study. If you do decide to take part in the study then you can stop it at any time without giving a reason and without it affecting any benefits that you are entitled to. A decision to withdraw from the study at any time or a decision not to take part in the study will not affect your medical care or legal rights.



You will be able to download this information sheet to keep - alternatively you can request a copy from Elnaz Gültekin (elnaz.gultekin.18@ucl.ac.uk). If you decide to withdraw from the study after you have completed the online survey then it will not be possible to withdraw the data you have provided up to that point because all data will be provided anonymously.

5. What will happen to me if I take part?

If you take part in the online survey, you will be asked a series of questions about your self-reported difficulties with memory and/or attention, your mood, your satisfaction with life and various other psychological factors. You will also be asked some basic questions about yourself such as your age, self-identified sex and ethnicity, and education. You will not be asked to provide any identifying information such as your name or contact details.

The online survey will take approximately 30-40 minutes to complete. You can stop the survey at any point, without having to give a reason. If you complete some but not all of the questions in the survey then we would use any information that you provided up to the point that you stopped the survey. If there are particular questions that you would prefer not to answer then you will be able to indicate this in the survey, without having to give a reason. You will only be asked to complete this online survey on one occasion.

6. What are the possible disadvantages and risks of taking part?

The risks of taking part could be that you may feel inconvenienced by taking part in this online survey or you may feel bored, irritated, sad or anxious while completing it. However, you will be free to stop the survey at any time, without it affecting your care or legal rights.

7. What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in this research study, it is hoped that this work will enable us to find better ways of helping older people who are experiencing self-reported difficulties with memory and/or attention.

All participants who complete the online survey will be invited to put their name in a draw for one of ten Love2Shop vouchers worth £50 each. Anybody who would like to be entered into the draw will need to email Elnaz Gültekin (elnaz.gultekin.18@ucl.ac.uk). This means that the responses to the online survey will remain anonymous and not be linked to any email address.

8. What if something goes wrong?

If you have a complaint about this study or are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. If there is a problem or if you have any concerns about the way you have been approached or treated in this survey, then please contact Dr Rebecca Gould, Department of Psychiatry, University College London, Wing A, 6th floor Maple House, 149 Tottenham Court Rd, London W1T 7NF. Tel: 020 7679 9925. Email: r.gould@ucl.ac.uk.

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during this survey, then please contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk.

If something goes wrong or if you are harmed by taking part in this online survey, there are no special compensation arrangements. If you are harmed because of someone's negligence, then you may have grounds



for a legal action for compensation against University College London, but you may have to pay for your legal costs.

9. Will my taking part in this project be kept confidential?

All of the information we collect about you will be anonymised using a unique identification number so that it will not be possible to identify you from any of your information. Your data will be stored using this unique identification number so that you cannot be identified from it. You will not be asked to provide any personal details such as your name or contact details within the online survey. All data will be kept strictly confidential, and will only be seen by members of the research team.

All of the information you provide such as information about yourself and your responses to the questionnaires will be stored in one of two ways so that we can verify the information at a later date, if necessary. All electronic data will be held on a secure database on a password-protected computer and on University College London's password-protected secure electronic network. All electronic data will be stored at University College London for 10 years, and will be destroyed after this. You will not be able to be identified in any ensuing dissertation or publication.

Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

10. What will happen to the results of the research project?

At the end of the study, we will analyse all of your information with other participants' information. Elnaz Gültekin will then present this as part of her MSc dissertation. We will then publish our findings in an academic journal. We will send you a summary of the findings if you request this. You will not be identified in the dissertation or any publication arising from this online survey.

11. Local Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, please click [here](#) or go to:

<https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice>

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:

- i) Questions about yourself such as your age, self-identified sex and ethnicity, and education.
- ii) Questions about your self-reported difficulties with your memory and attention.
- ii) Questions about your psychological well-being (symptoms of depression or anxiety, satisfaction with life).

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest.



The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes.

Your personal data will be processed so long as it is required for the research study and for publication of the research findings. We will undertake to anonymise or pseudonymise the personal data you provide, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

12. Will my data be shared with anybody else?

Your anonymized data, not containing personal identifiers, may be used to support other research in the future, and may be shared with other authenticated researchers from organisations such as universities or NHS Trusts in the UK. Your information will only be used by organisations and researchers in accordance with the UK Policy Framework for Health and Social Care Research.

It will not be possible to identify you from your data, and it will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

13. Who is organising and funding the research?

The research is sponsored by University College London.

14. Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee in order to protect participants' safety, rights, well-being and dignity. This study has been reviewed and been given a favourable opinion by UCL Research Ethics Committee (reference number 12212/002).

15. Who can I contact for further information?

If you have any questions or require any further information about this study then you can contact Elnaz Gültekin (elnaz.gultekin.18@ucl.ac.uk) or Dr Rebecca Gould, who is the supervisor of Elnaz Gültekin (r.gould@ucl.ac.uk, 020 7679 9925). Alternatively, you can write to Dr Rebecca Gould at: Division of Psychiatry, University College London, Wing A, 6th floor Maple House, 149 Tottenham Court Rd, London W1T 7NF.

Thank you for reading this information sheet and for considering taking part in this research study.