

Participant Information Sheet – Version 4 (22/04/24)

Thank you for considering to take part in this study. Before you decide to complete the study, it is important for you to understand why the research is being conducted and what participation will involve. Please take some time to read the following information carefully and raise any questions you may have with our researchers (Ellis Blyth: e.blyth@uea.ac.uk or Dr. Jinnie Ooi: jinnie.ooi@uea.ac.uk).

(1) What is this study about?

Anxiety and depression after stroke have been found to be linked with a number of common difficulties that occur as a result of a stroke (e.g. fatigue, changes in physical ability, changes in thinking ability). A talking therapy called Acceptance and Commitment therapy has recently been included in guidelines to support people after a stroke. Acceptance and Commitment therapy focuses on increasing our 'psychological flexibility' – this is the name given to a set of skills that help us to not get hooked on difficult thoughts and feelings, and to live a fulfilling life alongside them. This study will explore how psychological flexibility is linked with anxiety and depression after stroke and whether it changes the relationship between these mental health difficulties and other common experiences after stroke.

(2) Why have I been invited?

You have been invited to take part as a survivor of stroke.

To take part:

- You must be 18 years old or older,
- There must have been at least six months since your stroke,
- You must be able to speak English,
- You must be able to provide your own answers. If you need practical help to fill in the questionnaire, then this is encouraged.

You will not be able to take part if:

- Your stroke was a spinal stroke, a 'mini-stroke' (transient ischaemic attack), or a sub-arachnoid haemorrhage.

- You have experienced a brain injury prior to your stroke.

(3) What will the study involve for me?

You will be asked to complete a questionnaire with 6 parts. It will take no longer than 30 minutes to complete. You can stop and come back later by clicking “finish later” at the bottom of the web page and following the instructions.

This information is designed to provide you with information to help you decide if you wish to take part in the research or not. You are not required to take part if you do not want to.

If you decide to take part, you can withdraw from the study at any time prior to submitting your data, by exiting the questionnaire and your answers will not be recorded or included in the study.

(4) Are there any risks and/or disadvantages with participating in this study?

Completing a long questionnaire may leave you feeling tired or fatigued. Please take breaks when you feel it is necessary.

Answering questions about mood or the potential consequences of stroke may be difficult for some people. Most questions will be multiple choice and you will not be asked to describe any details regarding your mood or potential consequences of your stroke. Details about national support that is available for mental health or stroke are available at the end of the questionnaire for the United Kingdom, United States of America, and Australia.

(5) Are there any benefits associated with being in the study?

There is no direct personal benefit to completing this study. This study gives you the opportunity to be part of developing our understanding of anxiety and depression after stroke and how it may link with psychological flexibility.

(6) What will happen to information about me that is collected during the study?

Only non-identifiable information will be recorded, so you will be completely anonymous throughout. Once you have clicked “submit”, it will not be possible to delete your data. The information collected will be kept strictly confidential on a secure university storage system. After the study, data will be stored securely for a minimum 10 years within a secure university storage system, complying with the University of East Anglia Research Data Management Policy (2022). Your anonymous data may also be used in future research.

(7) Will I be told the results of the study?

The results of the study will be written up into a doctoral thesis in 2025, presented at stroke conferences and submitted to a relevant journal. A lay summary of the results will be shared with stroke organisations that have promoted the research.

(8) What if I would like further information, a complaint or concerns about the study?

If you require more information about this research study, please do contact me at e.blyth@uea.ac.uk.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact Professor Sian Coker (Deputy Head of Department of Clinical Psychology and Psychological Therapies) via email at s.coker@uea.ac.uk.

(9) Who is running the study?

This research is being conducted by Ellis Blyth, Postgraduate Researcher in the Doctorate in Clinical Psychology Programme (ClinPsyD) at Norwich Medical School, UEA. The research is carried out under the supervision of Dr Jinnie Ooi and Dr Joshua Blake. The research has been reviewed by the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee.