

Participant Information Form – The Impact of the COVID-19 Pandemic on the Psychosocial Functioning of Individuals with an Acquired Brain Injury, and Their Carers

This research has been approved by the University of Suffolk Research Ethics Committee.

Should you have any concerns about the Ethics of this research, please feel free to contact the Chair of the Ethics Panel, Professor Emma Bond e.bond@uos.ac.uk (01473 338564) or the Research Development Manager, Andreea Tocca a.tocca@uos.ac.uk (01473 338656).

Study Title: The impact of the COVID-19 pandemic on the psychosocial functioning of individuals with an acquired brain injury, and their carers

Research Lead: Emilie Witt

Academic Supervisor (for Student Led Research): Dr Rachael Martin

You are invited to take part in a study exploring the impact of the COVID-19 pandemic on the wellbeing of individuals with an acquired brain injury, and their carers. This research is being conducted as part of the fulfilment for a postgraduate, Master's dissertation, in conjunction with Headway Cambridgeshire.

This Participant Information Form will help you decide if you would like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. I will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. If you agree to take part in this study, you will be asked to sign the Informed Consent Form. You will be given a copy of both the Participant Information Form and the Informed Consent Form to keep. Please make sure you have read and understood all the pages of the Participant Information Form.

1. What is the purpose of the study?

The research aims to be one of the first in-depth studies to explore the impact that the COVID-19 pandemic has had on the mental wellbeing of individuals with a brain injury, and those who care for them. It is hoped that by highlighting the effect that the pandemic has had on people with a brain injury and their carers, and how they have adapted to changes as a result of the pandemic, that this may help inform how best to support these individuals going forward.

2. What will my participation in the study involve?

If you chose to take part in the study, you will be asked to take part in an interview. The interviewer will ask you a set of questions about how the pandemic has affected you, with a particular focus on your mental wellbeing and how you have adjusted to any potential changes in your life as a result of the pandemic. The interview will be recorded on a Dictaphone, so that

the researcher can write this down verbatim at a later date. The interview will last approximately 45 minutes – 1 hour, but you will be able to take breaks if necessary.

3. What are the possible benefits and risks of this study?

By taking part in this research, you are helping to contribute to knowledge about the impact that the COVID-19 pandemic has had on people with a brain injury, and those that care for them; an area of research which is only beginning to be considered. It is hoped that the information you provide will help to inform how best to support those with a brain injury, whose mental wellbeing has been affected as a result of the pandemic.

Whilst the research is not intended to cause harm, reflecting on, and discussing the impact of the pandemic may be distressing for some. In this instance, you are reminded that you may take a break from the interview, and that your participation is completely voluntary, and therefore you are free to withdraw from the study at any point.

4. What if I feel uncomfortable with an aspect of the study?

Participation in this research is completely voluntary, therefore, if you feel uncomfortable at any time, you have the right to withdraw from the study. You do not have to answer any question that you do not wish to answer. It is not compulsory for you to take part, and the research does not form part of the services you receive from Headway Cambridgeshire. As such, not taking part in the study will not have a negative impact on the services that you or your family member receive from Headway Cambridgeshire, now or in the future.

5. What happens if I change my mind?

You have the right to terminate your participation at any point during the interview without providing an explanation for doing so. You also have the right to withdraw any data you provide for the study, within 2 weeks of the interview taking place.

6. Is the information I provide confidential?

The information you provide as part of the interview will be written up for the project, therefore your answers are not confidential. However, you have the right to anonymity. As such, participants will not be referred to by name, but will be given a pseudonym for which their data will be identified. Therefore, only the primary researcher, Emilie Witt, will have means of tracing the pseudonym given to you to your responses. Whilst you will not be named in the write up of the data, you should be mindful that due to the personal nature of the interview, it may be that those familiar with your circumstances may be able to identify you by the answers you provide.

7. How will my data be stored?

The interview will be recorded on a Dictaphone, so that this can be transcribed by the researcher at a later date. The voice recordings will only be heard by the primary researcher and will be deleted as soon as they have been transcribed.

7. What happens after the study?

You will be provided with a debrief sheet, which will provide further information about the study for you to take away. The debrief sheet also includes information about how you can withdraw from the study if you change your mind, as well as providing details of support you can access, should you need to.

Once data has been collected, it will be analysed and reported by the researcher in the form of a postgraduate dissertation. The findings of the research may also be published in academic journals.

8. Who pays for this study?

This study receives no funding from any organisations, as it is being conducted as part of the fulfilment of a postgraduate dissertation.

9. Who do I contact for more information or if I have concerns?

The contact details of the primary researcher, Emilie Witt, and the dissertation supervisor, Dr Rachael Martin, are provided below. You may contact them should you wish to have more information or to express your concerns.

Primary researcher: Emilie Witt – MSc Applications of Psychology Student

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