

Experiences of Family and Friends of those affected by PCS/TES/CTE

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

This study is looking to explore how Post-Concussion Syndrome (PCS), Traumatic Encephalopathy Syndrome (TES) and/or Chronic Traumatic Encephalopathy (CTE) manifest in the real-world and what is the impact of this on the family and social context for which the person living with PCS/TES/CTE is situated. This information will be used to develop our scientific knowledge on PCS/TES/CTE, particularly on the impact of the condition on people's lives, including their family members. Furthermore, information gathered from this research will consider how best to support those living with PCS/TES/CTE and their immediate family.

Why have I been invited to participate?

You have been invited to participate in this research as you are:

1. somebody who is currently suffering with PCS (i.e. concussion symptoms for more than 28 days) or possible / probable TES
2. a direct/immediate family member of somebody who is suffering with PCS (i.e. concussion symptoms for more than 28 days) or possible / probable TES
3. a direct/immediate family member of somebody who has been posthumously diagnosed with CTE

Do I have to take part?

It is up to you to decide whether or not to take part in this research project. If you do decide to take part, you will be given this information sheet that will explain how your data will be collected and used and be asked to give your consent. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If, once you have read this information sheet, you would like to participate in this research study, please complete the online consent form ([available here](#)). An online interview will be organised with you at a convenient time and place (this will be using Google Meet, FaceTime, Zoom or WhatsApp). The interview should last no more than one hour and while the interview will be audio-recorded, with your permission, it will remain confidential.

In the interview you will be asked about your experiences, the impact on social and family life and what support would be useful for someone suffering PCS/TES/CTE and their family members. As these interviews are completely voluntary, you are welcome to share as much information as you feel comfortable. If you do not want to answer any questions or share any information, you will not be pressured to do so.

What are the possible disadvantages and risks of taking part?

There are no risks above and beyond everyday life through participating in this research. If the interview causes excess emotion, you may choose to either stop the interview and not return, stop the interview and return, or carry-on. If you feel distressed, we have British Psychological Association qualified psychologists that will be happy to meet with you independently. Simply tell any member of the research team and this will be organised. Additional support is available from the Concussion Legacy Foundation, through the CLF HelpLine (visit: <https://concussionfoundation.org/helpline>).

What are the possible benefits of taking part?

While the research may not benefit you directly, we aim to develop our scientific knowledge on PCS/TES/CTE, particularly on the impact of the disease on people's lives. Furthermore, information gathered from this research will consider how best to support those living with PCS/TES/CTE and their family members.

Will what I say in this study be kept confidential?

All information or data shared in this research project will be confidential (subject to legal limitations). Your de-identified data will be stored securely and will not be shared beyond the research team. All information published following this research will use pseudonyms and will remove any identifiable data. Any third-party data will also be de-identified and replaced with a pseudonym.

Data generated in the course of the research must be kept securely in electronic form for a period of ten years after the completion of this research project.

Can I review the transcripts?

You have the right to review and amend the transcripts of your interview prior to analysis. You have the right to determine that you do not wish, partially or in entirety, for your transcripts to be included in the analysis. To do this, please contact the Principal Researcher, Dr Adam J White.

What should I do if I want to take part?

If you wish to participate in this research project, please complete the online consent form ([available here](#)).

What will happen to the results of the research study?

The results of this study will be disseminated in a range of mediums. This may include research reports, academic journal articles, videos, conference presentations and online blogs. You are welcome to a copy of any research reports, articles or presentations that result from this research project.

Who is organising and funding the research?

This research is being organised by academics from Oxford Brookes University and the University of Winchester. Funding has been provided by Oxford Brookes University and the University of Winchester.

The research team includes: Dr Rachael Bullingham, Dr Matthew Smith, Dr Keith Parry, Dr Jo Batey and Rosie Collins.

Who has reviewed the study?

The ethical aspects of this study have been scrutinised and approved by the University of Winchester Research and Knowledge Exchange Ethics Committee. The Approval number is [RKEEC2001010](#).

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee via email ethics1@winchester.ac.uk. If you have any questions about data collected within this research, you may contact the Data Protection Officer on Joseph.Dilger@winchester.ac.uk.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Contact for Further Information

If you have any further questions or wish to participate, please contact any member of the research team below.

Thank you

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