

PARTICIPANT INFORMATION SHEET

UNIVERSITY OF EAST LONDON
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INTERNATIONAL ONLINE ‘SURVEY OF PEOPLE WHO HAVE EXPERIENCED ELECTROCONVULSIVE THERAPY (ECT), AND THEIR FAMILY AND FRIENDS’ (SECTAFF)

RESEARCH INTEGRITY

The University adheres to its responsibility to promote and support the highest standard of rigour and integrity in all aspects of research, observing the appropriate ethical, legal and professional frameworks, obligations and standards.

The University is committed to preserving your dignity, rights, safety and wellbeing and as such it is a mandatory requirement of the University that formal ethical approval, from the appropriate Research Ethics Committee, is granted before research with human participants, human data, human material, personal and/or sensitive data, or non-human animal commences.

Ethical approval for this project has been granted by the U.E.L. Ethics and Integrity Subcommittee (EISC).

The purpose of this **Participant Information Sheet** is to provide you with the information that you need to consider in deciding whether to participate in this research project.

PARTICIPANT INFORMATION

You are invited to take part in an online survey. Before you decide whether to participate, please consider the following information.

The Principal Investigator

Dr John Read, Professor of Clinical Psychology at the University of East London in the UK. Professor Read has published many research studies and reviews on ECT.
<https://uel.ac.uk/about-uel/staff/john-read>

Project Title

International online ‘Survey of people who have experienced Electroconvulsive Therapy (ECT), and their family and friends’ (SECTAFF)

Project Description

The purpose is to understand the experience of Electroconvulsive Therapy (ECT), in order to enhance the information given to people being offered ECT and their families. This is your opportunity to share your experiences of this treatment, positive and negative.

The survey is for people around the world who have received ECT at any point in the past. It is also for relatives or friends of people who have received ECT and are aware of how ECT affected that person. You must be aged 18 years or older.

Taking part involves answering an anonymous survey about your experiences with ECT, or the experiences of a loved one. You can complete the survey online. It takes about 30-40 minutes. Not all questions will be relevant to everyone, so the time taken will be different for each person.

It is possible that answering some of the questions may cause some participants some distress. There are questions about how you were feeling before and after ECT, including whether you had any suicidal thoughts or feelings, and questions about childhood abuse. If you think questions like that might be distressing you may not want to take the survey.

Here is a list of international helplines should you take the survey and feel in need of additional emotional support besides your other usual supports and coping strategies:

https://en.wikipedia.org/wiki/List_of_suicide_crisis_lines

And here is a list of helplines in each state of the USA:

<https://warmline.org/warmdir.html#directory>

The survey is anonymous. You will not be asked for any information that could identify you. No one other than the researcher will have access to your completed survey results, and, because the survey is anonymous, there will be no way that anyone, including the researcher, will be able to identify you. We ask that you avoid sharing information that would allow the researcher to identify you. If you do share any information that identifies you, it will be kept confidential. No information that could allow people to identify you or anyone else will be shared in any of the reports written about the research.

Submitting responses to the survey indicates consent to participate in the research project. Once you have submitted responses it will not be possible to automatically withdraw from the research because there will be no way of identifying which survey responses have come from you. If you wish to withdraw your data, for either a complete or incomplete survey, you can email Dr Read at john@uel.ac.uk, up to one month after you responded to the survey, and provide sufficient details of your responses to identify your survey, which will then be deleted.

Confidentiality of the Data

The information you provide is anonymous. The survey does not ask for your name.

The information you provide will be used to help researchers understand the experiences of people who have had ECT. Your data will be combined with the data provided by other participants and used for two purposes:

1. To inform healthcare organisations about the experiences of people who have had ECT and what people should be told when being offered ECT.
2. To produce academic research articles that publicise the results, in order to improve mental health services and foster further research.

The anonymised data may be in the public domain through peer reviewed journals, internal report, conference presentations, books or chapters, the University's research website (ROAR), and blogs.

We may use quotes from your survey responses, or interviews, when we publish the results of the study, but we will ensure we share quotes in a way that stops anyone from identifying you. We will also use the results to create summary sheets to enable people who are not researchers to read and understand the results of the study. No information that could identify you will be included in any of the published articles, summary documents or public presentations about the results.

How Will Your Information Be Stored?

During the study, electronic data will be securely stored by Qualtrics, the web-based survey software that is being used for this survey. For an overview of Qualtrics privacy policy, see <http://www.qualtrics.com/privacy-statement/>

After that, it will be stored, for six years, in a password protected system that only the lead researcher has access to. It will then be deleted.

The data generated will be retained in accordance with the University's Data Protection Policy.

Data Protection statement

In compliance with the General Data Protection Regulation (GDPR) the University's lawful basis for the processing of personal data collected, used and retained for research purposes is the 'public task' condition. Therefore, the University does not rely on consent to process your personal data. However, the University will seek your consent to participate in this research project. Please see the following link for more information: [Data protection – University of East London \(UEL\)](#)

Funding

This project has received no funding from any commercial or other organisation.

Who do I contact for further information or if I have any ethical concerns about this research?

If you have any general inquiries or would like any further information, please contact Professor John Read, john@uel.ac.uk

If you have any concerns regarding the conduct of this research, please contact Catherine Hitchens, Research Integrity and Ethics Manager, Graduate School, EB 1.43, University of East London, Docklands Campus, London E16 2RD (Telephone: 020 8223 6683, Email: researchethics@uel.ac.uk)