

Participant Information Sheet

Hello!

You are being invited to take part in a research study. Before you making a decision on taking part in the study or not, it is very important that you take your time in reading and understanding the following information, where information is provided on why the research is being done and what it will involve.

Study Title:

The barriers to treatment for individuals with Obsessive-compulsive disorder (OCD)

What is the purpose of the study?

Obsessive-compulsive disorder (OCD) is a mental health disorder which is mainly characterized by obsessions and/or compulsions. These obsessions and compulsions are often clustered into various groups, depending on the content and behaviours the person experiences. These obsessions and compulsions can have a big impact on an individual's day to day and life.

Different types of pharmacological and psychological treatment, such as Cognitive-behavioural therapy, are available for those with OCD. However, studies report a big delay from the first appearance of symptoms to seeking treatment (the average is of 10 years!). Various possible causes of this delay have been found; these are considered barriers to treatment. Examples of these barriers are “not knowing where to seek help”, feelings of shame and stigma, and problems with booking appointments and getting to appointments.

The present study aims to explore these barriers to treatment. Furthermore, the study will also investigate the relationship between certain types of obsessions/compulsions and barriers to treatment, alongside taking into consideration how demographic details (such as ethnicity, religion, and economic status) also impact the barriers.

Why have I been approached?

This study has been advertised on various OCD and Anxiety groups and mental health charities, with the aim of reaching individuals who are suffering from OCD to participate in the current study, where the study aims to collect data from approximately 100-200 participants. To take part in the study you need to be above the age of 18, have access to a laptop or computer, be able to read and answer questions in English, be diagnosed or believe to have OCD, and be of any gender. Sensitive topics in relation to OCD symptoms, types of Obsessions and Compulsions, and barriers to treatments are discussed in the questionnaires. Please do not take part in the study if you believe you could find the content of the questionnaires distressing.

Do I have to take part?

Participation in the current study is completely voluntary. Following this information sheet, you will be presented with a consent form; you will only continue to take part in the study if you consent to all the items. You can exit the study at any time by closing the browser; you are also able to skip any question which you are not happy to answer. If you do wish to withdraw from the study, you are able to do so by providing your 6-digit unique code (which you will provide if you consent to take part in the study).

What will happen if I don't want to carry on with the study?

As mentioned, you have a right to change your mind and withdraw from the study at any point without giving any penalties or reasons asked. During the study you can exit the study by closing the web browser. If you wish to withdraw after completing the study, please contact the researcher with your unique participant code. If you wish to withdraw from the study, please do so before the analysis stage of the research report (before March the 14th of 2023). All data collected up to the point of withdrawal will be immediately destroyed.

What will happen to me if I take part?

If you decide to take part in the study you will be asked questions surrounding the obsessions and compulsions you experience, and the severity of these. Following this initial questionnaire, you will be asked 10 questions about your experience accessing or thinking about accessing treatment. Lastly, you will be asked an open question about your experience accessing treatment. **All questionnaires will be provided online, where it is estimated that the study will take no longer than 20 minutes to complete.**

What are the possible disadvantages and risks of taking part?

There are no expected disadvantages or risks of taking part in the current study, however, the questionnaires do involve questions surrounding obsessions and compulsions which some individuals may find distressing or triggering, which is something to consider before taking part in the study; if you believe completing this questionnaire could cause you distress, please do not take part.

If you do decide to take part, and then find any of the items distressing, please feel free to exit the study. If you need support following the study, here is a list of good support groups/research groups and charities which could provide further support and/or resources to get support:

Orchard OCD:

- Website: Orchardocd.org
- Contact email: infor@orchardocd.org

OCD Action:

- Website: ocdaction.org.uk
- Helpline: 0300 636 5478
- Helpline email: support@ocdaction.org.uk

TOP UK

- Website: <https://www.topuk.org/>
- Email: infor@topuk.org
- Telephone: 01225 571740

International OCD foundation

- Website: <https://iocdf.org/>

What are the possible benefits of taking part?

There are no direct benefits of taking part in the study, however, participation in the study could increase your knowledge in the topic area, whilst also contributing to research to understand how the different barriers to treatment affect individuals with OCD.

What if something goes wrong?

If you are unhappy with the conduct of this study please contact my supervisor Jon Rees, or the Chair of the University of Sunderland Research Ethics Group Dr John Fulton. Contact details are included below.

How will my information be kept confidential?

All data will be handled in accordance with the Data Protection Act (2018). Data collected will remain completely anonymous, and no location data will be collected. Data will be stored securely in the qualtrics secure cloud based system and analysed on a password-protected laptop, which will only be shared with the project supervisor. All data will be securely disposed of two years post completion of the study.. Anonymised data or results of the current study may be shared with other researchers and/or may be used for teaching purposes. Data may also be viewed by authorised staff of the University of Sunderland for audit and quality assurance purposes.

What will happen to the results of this study?

Results of the study will form part of the project report and in an academic poster of the research report. If suitable, results may also be published in academic journals and/or presented in academic conferences.

Who is organising and funding the research?

The research is organised by Robyn Jones, who is a Psychology and Counselling student at the University of Sunderland, Faculty of Health Sciences and Wellbeing, School of Psychology.
This project is not externally funded.

Who has reviewed the study?

The study has been reviewed and approved by the University of Sunderland Research Ethics Group's review system.

Further information and contact details

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Dr John Fulton (Chair of the University of Sunderland Research Ethics Group)

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Thank you for taking time to read the information sheet!